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## EFFECTS OF A PARENTAL TRAINING PROGRAM USING GROUP-BASED ACCEPTANCE AND COMMITMENT THERAPY FOR MANAGING CHILDREN WITH ASTHMA: A RANDOMIZED CONTROLLED TRIAL

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Effects of a Parental Training Program using Group-based Acceptance and Commitment Therapy for Managing Children with Asthma: A Randomized Controlled Trial

**Chong Yuen Yu** 

A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy

April 2018

### **CERTIFICATE OF ORIGINALITY**

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<u>CHONG YUEN YU</u> (Name of student)

Abstract of dissertation entitled: "Effects of a Parental Training Program using Group-based Acceptance and Commitment Therapy for Managing Children with Asthma: A Randomized Controlled Trial" submitted by CHONG Yuen-yu for the degree of Doctor of Philosophy at The Hong Kong Polytechnic University

### **Background:**

Efforts to control childhood asthma remains suboptimal. In the Asia-Pacific region, over half of the Asian children with asthma require emergency care services due to asthma exacerbations per year. Childhood asthma also imposes a heavy psychological burden on parents, which can adversely affect the child's health. Effective psychological interventions for these parents, however, are still lacking. Fostering parental psychological flexibility (PF) through Acceptance and Commitment Therapy (ACT) may help parents to accept their psychological difficulties and to improve their childhood asthma management in the service of their personally held values. Positive effects of ACT on the psycho-social outcomes of parents and their children with acquired brain injuries, cerebral palsy, and anorexia nervosa have been shown in a number of interventional studies.

### Aim:

This study aimed to examine the efficacy of a parental training program using groupbased ACT integrated with asthma education, in comparison with an asthma education talk as the usual care, on children's asthma management outcomes and their parents' psychological health outcomes measured at six months postintervention in a randomized controlled trial (RCT) design.

### Methods:

A two-arm RCT was conducted. Between 6<sup>th</sup> January 2016 and 26<sup>th</sup> May 2016, parents with children aged 3 to 12 years who had received a physician's diagnosis of asthma and without significant co-morbidities were consecutively recruited in a public hospital in Hong Kong. Eligible parent-child dyads were randomly assigned either to four weekly sessions of a training program using group-based ACT integrated with asthma education (ACT group) or to an asthma education talk as the usual care plus three weekly telephone follow-ups (Control group).

The goal of ACT was to enhance the PF of the parents in caring for a child with asthma in the following ways: (i) to be aware of the thoughts and feelings of the present moment, (ii) to accept and to adapt flexibly to challenging situations, and (iii) to take actions to achieve valued goals in childhood asthma management. Throughout the four ACT sessions, six ACT therapeutic processes were applied interchangeably, which were contacting with the present moment, defusion, acceptance, self-as-context, values and committed action. An ACT-based Intervention Protocol was employed, which was developed according to the ACT

model of PF by Professor Steven C. Hayes and colleagues (1999), as well as the findings from qualitative interviews of 14 Hong Kong Chinese parents to explore their psychological difficulties in taking care of a child with asthma. This protocol was tested in a pilot study of eleven parents of children with asthma to address their specific needs. The interventionist was the research investigator (Ms. Yuen-yu Chong, Ph.D candidate), who is a registered nurse in Hong Kong and had received ACT skills training, as well as supervisions by Chief Supervisor and a psychologist throughout the study period.

The primary outcome of this study was the frequency of ED visits due to asthma exacerbations in children over a six-month follow-up period, measured at six months post-intervention. The secondary outcomes included the unscheduled health care service utilizations due to asthma exacerbations and asthma symptoms of the children. Other secondary outcomes included the PF, psychological adjustment in raising children with asthma, psychological symptoms in terms of anxiety, depression, and stress, asthma knowledge, asthma management self-efficacy and the quality of life of parents. All the outcomes were assessed by parental reports through validated questionnaires and the data collectors were blinded to the group assignments. Changes in the aforementioned outcomes between groups over time were analyzed using adjusted generalized estimating equations and in accordance with the intention-to-treat principle.

### **Results:**

One hundred and sixty-eight parents (age M = 38.4, 88.1% mothers) and their children with asthma (age M = 6.8) participated in the RCT. Of these, six parent-child dyads were lost to follow-up by the end of the study. At six months post-intervention, when compared with the Control group, children whose parents were in the ACT group had significantly fewer ED visits (adjusted incidence rate ratio (IRR) = 0.20, 95% CI [0.08, 0.53], p = .001) and fewer private practitioners' clinic visits (adjusted IRR = 0.47, 95% CI [0.26, 0.85], p = .012) due to asthma exacerbations over the six-month follow-up period. In addition, these children exhibited fewer days of asthma symptoms during the daytime, fewer nights with disturbed sleep due to asthma symptoms and fewer days of using inhaled bronchodilators to relieve asthma symptoms (all *ps* ranged from <.001 to .001). There were no significant effects on the general outpatient visits (p = .063) and hospital admissions due to child's asthma exacerbations (p = .327).

Significant time-by-group interactions were found in almost all parental psychological health outcomes (all *ps* ranged from <.001 to .025). Parents who were trained with ACT became more psychologically flexible (d = 0.80), reported with less negative emotional experiences such as guilt and worry (d = 0.46), sorrow and anger (d = 0.39), less anxiety (d = 0.47) and stress symptoms (d = 0.35), and attained a better quality of life (d = 0.36) at six months post-intervention when compared with those who attended an asthma education talk only. The time-by-group

interaction effects on the parental asthma knowledge (p = .053) and the parental selfefficacy in preventing asthma exacerbations (p = .168) were non-significant.

### Significance:

This RCT study is one of the first to test an innovative intervention, ACT, for helping parents to manage psychological difficulties aroused when taking care of their children with asthma. The results suggest that fostering the psychological flexibility of parents through ACT combined with asthma education improve their childhood asthma management and their psychological well-being. Given that the ACT intervention was delivered by a trained nurse, via a group-based approach and in brief sessions, it has its practical utility in clinical settings with less resource implications. In addition, this study raises the importance of incorporating an assessment of parental psychological difficulties in routine asthma care, which may help to identify those parents most in need for a psychological intervention like ACT.

To conclude, helping parents to develop an unconditional acceptance of challenges and a consistent commitment to what they truly value may be particularly helpful to improve their management of a child's chronic disease.

#### **Publications arising from the thesis**

#### **Journal publications**

- Chong, Y. Y., Leung, D., & Mak, Y. W (2018). When control exacerbates distress: The experiences of Chinese parents in caring for a child with asthma. *International Journal of Environmental Research and Public Health*, 15(7), 1372. doi: 10.3390/ijerph15071372.
- Chong, Y. Y., Mak, Y. W., Loke, A. L., Leung, S. P., & Lam, S. Y. (2018). Effects of a group-based Acceptance and Commitment Therapy versus asthma education for training parents to manage their children with asthma: A randomized controlled trial. *Hong Kong Journal of Pediatrics*, 23(1), 53-54.
- Chong, Y. Y., Mak, Y. W., & Loke, A. Y. (2017). Psychological flexibility in parents of children with asthma: Analysis using a structural equation model. *Journal of Child* and Family Studies, 26(9), 2610–2622. doi:10.1007/s10826-017-0757-x.

#### **Conference and symposium presentations**

- Chong, Y. Y., Mak, Y. W. & Loke, A. Y. (2018, July). Using group-based Acceptance and Commitment Therapy for improving parental management of childhood asthma in Hong Kong, *How Do We ACT in Asia? - The Contextualization of ACT in Eastern Asian Culture*. Symposium conducted at the Association for Contextual Behavioral Science (ACBS) Annual World Conference 16, Montréal, Canada.
- Chong, Y. Y., Mak, Y. W. & Loke, A. Y. (2018, July). Exploring mediators of change in a parental training program using ACT for improving asthma outcomes in children: An analysis using structural equation model based on a clinical trial data. Paper presented at Association for Contextual Behavioral Science (ACBS) Annual World Conference 16, Montréal, Canada.
- Chong, Y. Y., Mak, Y. W. & Loke, A. Y (2018, July). A randomized controlled trial of group-based Acceptance and Commitment Therapy in parents of children with asthma: Effects on the asthma outcomes of children. Paper presented in the Association for Contextual Behavioral Science (ACBS) Annual World Conference 16, Montréal, Canada.
- Chong, Y. Y., Mak, Y. W., Loke, A. L., Leung, S. P. & Lam, S. Y. (2017, October). Effects on the asthma outcomes of young children: A randomized controlled trial in training parents through a group-based, educational program using Acceptance and Commitment Therapy. Paper presented at the 9<sup>th</sup> Cross-Strait Paediatric Respirology Congress cum 20th HKSPRA Annual Scientific Meeting, Hong Kong.
- Chong, Y. Y., Leung, D., Mak, Y. W. & Lam, S. Y. (2017, October). What do Hong Kong Chinese parents of children with asthma tell us? A qualitative descriptive study.
   Poster presented at the 13<sup>th</sup> Congress of Asian Society for Pediatric Research, Hong Kong.
- Chong, Y. Y., Mak, Y. W. & Loke, A. Y. (2017, June). The efficacy of a group-based Acceptance and Commitment Therapy on the psychological flexibility and the psychological adjustment of parents of children with asthma: A randomized

*controlled trial.* Paper presented at the Association for Contextual Behavioral Science (ACBS) Annual World Conference 15, Seville, Spain.

- Chong, Y. Y., Mak, Y. W. & Loke, A. Y. (2017, June). *The relationships between* psychological flexibility, asthma knowledge, and asthma management self-efficacy among parents of children with asthma and their children's asthma morbidity. Paper presented at the Association for Contextual Behavioral Science (ACBS) Annual World Conference 15, Seville, Spain.
- Chong, Y. Y., Mak, Y. W. & Loke, A. Y. (2016, September). Effects of a parental training program using group-based Acceptance and Commitment Therapy for childhood asthma care: A pilot study. Paper presented at the 9<sup>th</sup> International Council of Nurses (ICN) International Nurse Practitioner/ Advanced Practice Nursing (INP/APN) Network Conference, Hong Kong.
- Chong, Y. Y., Mak, Y. W. & Loke, A. Y. (2015, February). The impact of training parents by Acceptance and Commitment Therapy (ACT) for managing their children with chronic health problems: A literature review. Poster presented at the 18<sup>th</sup> East Asian Forum of Nursing Scholars (EAFONS), Taipei, Taiwan.

### Awards

### Early Career Research Paper Award 2018

Association for Contextual Behavioral Science for recognizing a rising star researcher presenting the doctoral dissertation entitled: Effects of a parental training program using group-based Acceptance and Commitment Therapy for managing children with asthma: A randomized controlled trial at the Association for Contextual Behavioral Science (ACBS) Annual World Conference 16, Montréal, Canada (24-29 July 2018).

#### Pi Iota Chapter Scholarship Award 2018

Honor Society of Nursing, Sigma Theta Tau International for the doctoral dissertation entitled: Effects of a parental training program using group-based Acceptance and Commitment Therapy for managing children with asthma: A randomized controlled trial.

#### Michael J. Asher Student Dissertation Award 2018

Association for Contextual Behavioral Science for her doctoral dissertation entitled: Effects of a parental training program using group-based Acceptance and Commitment Therapy for managing children with asthma: A randomized controlled trial.

### **Student World Conference Scholarship Award 2015**

Association for Contextual Behavioral Science for a paper entitled: Acceptance-based intervention for parents and children with chronic health problems: A systematic review and meta-analysis presented at the Association for Contextual Behavioral Science (ACBS) Annual World Conference 13, Berlin, Germany (14-15 July 2015).

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Before I started my Ph.D study, Dr. Mak shared her stories about the use of ACT in smoking cessation counselling in many occasions. I could not see the merit of this therapy until the moment that I started the qualitative interviews with parents and attended the Association for Contextual Behavioral Science World conferences after her encouragement. I finally realized the connection between the ACT model of psychopathology and an individual's psychological struggle, such as my fusion with my self-evaluation: "*I am a nurse but not a clinical psychologist, how can I put ACT into real practice*?" Throughout the four-year supervision, Dr. Mak has embodied patience, acceptance, improved my competencies in delivering ACT, fostered me to deepen the understanding of ACT and self-understanding when I encountered distress. Her enthusiasm in ACT and in research for improving family health and well-being helps me to realize the true nature of values and committed action as a scholar. Because of her, I started learning to let go of my own self-criticism.

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I am deeply thankful to all parents of this study for the valuable time, experience sharing and active participation in our training program. I am inspired by so many parents who engaged in the sessions. They were honest and brave to share their own insecurities, which allowed me to find my way in delivering ACT and witnessed their openness to what they truly treasure in their parenting life. I have also been deeply supported by my family and my friends throughout the study, their love and support has empowered me to persist through difficult times.

Discomfort often shows up when I deliver ACT and experience ACT, while ACT fosters me to commit to a values-based journey in research and in personal development. I consider ACT as a self-help intervention. I am incredibly grateful that I have this opportunity to learn and to practice ACT: A therapy which allows me to integrate attitudes, compassion and practices for improving one's health and wellbeing.

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### LIST OF ABBREVIATIONS

AAQ-II	Acceptance and Action Questionnaire-II
ACC	Ambulatory Care Centre
ACT	Acceptance and Commitment Therapy
aIRR	Adjusted Incidence Rate Ratio
AKQ	Asthma Knowledge Questionnaire
CBT	Cognitive Behavioral Therapy
CI	Confidence Interval
DASS-21	Depression Anxiety Stress Scales-21
ED	Emergency Department
ES	Effect Size
GEE	Generalized Estimating Equations
GOPC	General Outpatient Clinic
ICS	Inhaled Corticosteroids
IRR	Incidence Rate Ratio
ISAAC	International Study of Asthma and Allergies in Childhood
ITT	Intention-To-Treat
Mdiff	Mean Difference
PACQLQ	Pediatric Asthma Caregiver's Quality of Life Questionnaire
PAMSE	Parent Asthma Management Self-Efficacy
PECI	Parent Experience of Child Illness
PF	Psychological Flexibility
RCT	Randomized Controlled Trial
SEM	Structural Equation Modelling

### LIST OF STATISTICAL ACRONYMS

95% CI	Ninety-five percent confidence interval
d	Cohen's d
df	degree of freedom
g	Hedge's g
М	mean
р	<i>p</i> -value
r	correlation coefficient
SD	standard deviation
SE	standard error
Wald $\chi^2$	Wald Chi-square
α	Cronbach's alpha
β	standardized beta coefficient
$\chi^2$	Chi-square

### **CHAPTER ONE**

### **INTRODUCTION**

### 1.1. Introduction

- 1.2. Definition, risk factors and diagnosis of childhood asthma
- 1.3. Global prevalence of childhood asthma
- 1.4. Burden of childhood asthma
  - 1.4.1. Health burden on children
  - 1.4.2. Psychological burden on parents
  - 1.4.3. Impacts of parental psychological burden on childhood asthma outcomes
- 1.5. Current approaches to asthma management in children
- 1.6. Limitations of the current asthma control strategies in children across the globe
- 1.7. Psychological interventions for parents of children with asthma
- 1.8. Acceptance and Commitment Therapy (ACT): A potential intervention addressing the psychological difficulties encountered by parents of children with asthma
- 1.9. Summary
- 1.10. Organization of the thesis chapters

### **1.1. Introduction**

This chapter presents the background of the study. It begins by presenting an overview of childhood asthma, such as its definition and its prevalence across the globe. The burden of childhood asthma is described in detail, including the health burden on children and the psychological burden on parents. Next, the impacts of parental psychological burden on childhood asthma outcomes are addressed. This chapter summarizes the current approaches to childhood asthma management and the limitations of current asthma control strategies across the globe. Evidence regarding the effects of psychological interventions serving for parents of children with asthma is reviewed, indicating the lack of effective interventions to improve the psychological well-being of parents and the asthma morbidity of their children.

Acceptance and Commitment Therapy (ACT) is introduced in this chapter. In brief, ACT is a mindfulness and values-based cognitive behavioral therapy that targets the psychological flexibility (PF) of an individual, posits that an individual's PF can be fostered by using metaphors, experiential exercises and/or mindfulness exercises, so that he/she can develop acceptance of psychological difficulties, awareness of life values and commitments to take values-driven actions. It is expected that if parents are getting more psychologically flexible after receiving an ACT intervention, they could be more opened up to look for opportunities to improve their asthma self-management skills as a caregiver rather than struggling with their psychological difficulties. This may lead to an eventual improvement of their children's asthma conditions. In this chapter, the philosophical and theoretical roots of ACT, the six therapeutic processes of ACT and the efficacy of ACT in the

health care context are discussed. This chapter ends with presenting the organization of the thesis chapters.

#### 1.2. Definition, risk factors and diagnosis of childhood asthma

Asthma is defined as a chronic inflammatory respiratory disorder, characterized clinically with recurrent symptoms of wheezing, breathlessness, chest tightness and/or cough (Pijnenburg et al., 2015), and physiologically with reversible airflow obstruction (Global Initiative for Asthma, 2016). Asthma often begins early in life, nearly one-third of children suffer from asthma symptoms during the first three years of life (Martinez et al., 1995; Morgan et al., 2005). Genetic predisposition, environmental triggers and exposure to respiratory viral infection can contribute to the development of asthma since childhood (Pijnenburg et al., 2015). Since asthma could have many variable presentations in young children, with the lack of objective lung function measurements and definitive biomarkers, diagnosis of asthma in young children is particularly difficult, and mainly based on physicians' interpretations of caregivers' reports, such as parental reports of a child's history of illness (Bakirtas, 2017; Cave & Atkinson, 2014).

### 1.3. Global prevalence of childhood asthma

Asthma is the most common non-communicable disease affecting 334 million individuals worldwide (Global Initiative for Asthma, 2016). According to the latest epidemiological study conducted by the International Study of Asthma and Allergies in Childhood (ISAAC) involving over 1.2 million schoolchildren and 61 countries worldwide, the lifetime prevalence of asthma in children aged six to seven years, and in children aged thirteen to fourteen years are currently 9.4% and 12.6%, respectively (Lai et al., 2009; Mallol et al., 2013). When compared with the data shown in an earlier ISAAC survey (The International Study of Asthma and Allergies

in Childhood Steering Committee, 1998), for both children's age groups (6-7 years, 13-14 years), their lifetime prevalence of asthma have been increased annually at a rate from 0.18% to 0.28% per year (Pearce et al., 2007). In Hong Kong, the lifetime asthma prevalence in children of two age groups (6-7 years, 13-14 years) are currently 7.9% and 10.2%, respectively (Wong, Leung, & Ko, 2013), these prevalence data remain static over the past ten years (Wong, Leung, et al., 2013), but are higher than that of other urban cities in China, such as Beijing (6.3%) and Guangzhou (6.9%) (Chen, Wong, & Li, 2016).

### 1.4. Burden of childhood asthma

### 1.4.1. Health burden on children

Asthma can bring in a substantial physical health burden to children if it is not well controlled. Children who are diagnosed with severe asthma are at least 10fold risk of suffering persistent asthma by the age of 50 years (Tai et al., 2014), they are also at risk of impaired lung functions and chronic obstructive airway disease in their adult life (Martinez, 2016). In addition, about one in every six children discharged with a primary diagnosis of asthma will be re-hospitalized within one year due to asthma exacerbations (Kenyon et al., 2014), with the readmissions rates ranging between 17% and 30% (Auger, Kahn, Davis, & Simmons, 2015; Bloomberg, Trinkaus, Fisher Jr, Musick, & Strunk, 2003; Kenyon et al., 2014).

The perceived lack of control over the asthma episodes and the frightening asthma symptoms (e.g., difficult to breathe) are often the sources of psychological burden on children (Peters & Fritz, 2010), which can further exacerbate their asthma symptoms (Wright, Rodriguez, & Cohen, 1998). A meta-analysis of 64 studies (publication year ranged from 1989 to 2011) has indicated that, children with asthma have higher tendencies of internalizing problems (e.g., anxiety, depression, and

social withdrawal) than healthy children with a medium effect size (Hedge's g = 0.63, 95% confidence interval (CI) [0.53, 0.72], *p*-value (*p*) <.001) (Pinquart & Shen, 2011). Children with asthma are often experiencing poor health-related quality of life. One meta-analysis of 15 studies (publication year ranged from 1994 to 2013) has shown that, children with asthma report with a lower level of asthma-related quality of life, in terms of physical, psychological and social functioning, when compared with those without asthma (Silva, Carona, Crespo, & Canavarro, 2015).

### 1.4.2. Psychological burden on parents

Asthma in children can impose a substantial caregiving burden on their parents (Celano, 2006; Kaugars, Klinnert, & Bender, 2004). To achieve an optimal control of childhood asthma, parents need to engage in a variety of asthma management activities, including administering asthma medications on a daily basis (Celano, 2006), monitoring asthma symptoms, and coordinating family routines to avoid environmental triggers (Fiese, Winter, Anbar, Howell, & Poltrock, 2008). This could be complex and brings additional burden to their parenting responsibilities (Fiese et al., 2008; Gates & Akabas, 2012; Lee, Parker, DuBose, Gwinn, & Logan, 2006). Notably, for very young children with asthma whose general cognitive competencies are still developing, they may encounter difficulties to describe their physical complaints accurately. As a result, it is the core responsibility of parents to maintain heightened vigilance of the health conditions of their children and to make prompt decisions in different situations, such as whether the child shall stay at home and use inhaled bronchodilators, attend a clinic, or attend an emergency department when asthma symptoms occur.

In addition, studies have shown that owing to the episodic and lifethreatening nature of childhood asthma exacerbations, parents often experience

heavy psychological burden with feelings of fear and worry (Arcoleo, Zayas, Hawthorne, & Begay, 2015; Berg, Anderson, Tichacek, Tomizh, & Rachelefsky, 2007; Shaw & Oneal, 2014), uncertainty and powerlessness prior to the diagnosis of asthma (Finnvold, 2010; Horner, 1997; Trollvik & Severinsson, 2004). Even though the child is confirmed with a diagnosis of asthma and is receiving medical treatment, parents still report ongoing fear and panic once their child's asthma is getting worse, which could develop into life-threatening asthma exacerbations (Arcoleo et al., 2015; Berg et al., 2007; Jan, Sophie Lee, & Cheng, 2014; Jonsson, Egmar, Hallner, & Kull, 2014; Kieckhefer & Ratcliffe, 2000). Furthermore, it is commonly found that parents are worried about the impacts of asthma on their child's learning and future development (Cheng, Chen, Liou, Wang, & Mu, 2010), the side effects of medications (Klok, Brand, Bomhof-Roordink, Duiverman, & Kaptein, 2011), as well as the risk of drug dependence (Klok et al., 2011).

Evidence from reviews has indicated that parents of children with asthma experience more psychological difficulties than their counterparts. For instance, one meta-analysis of 13 studies (publication year ranged from 1992 to 2012) have suggested that parents of children with chronic illness, including those with children suffered from asthma, have significantly greater parenting stress than parents of healthy children ((Cohen's *d*) d = 0.40, 95% CI [0.19, 0.61], p < .001), owing to the greater parental responsibility for the demanding treatment management (Cousino & Hazen, 2013). Another recent meta-analysis identified 25 studies and compared symptoms of anxiety and depression in 4,300 parents of children with asthma with those in 25,064 parents of healthy children. This review has also highlighted the fact that parents of children with asthma exhibit more symptoms of anxiety (d = 0.50, 95% CI [0.22, 0.75], p = .001) and depression (d = 0.44, 95% CI [0.25, 0.64], p

<.001) when compared with parents of healthy children (Easter, Sharpe, & Hunt, 2015).

### 1.4.3. Impacts of parental psychological burden on childhood asthma outcomes

Childhood asthma can impose a substantial psychological burden on parents, while research has also suggested its negative impacts on the outcomes of childhood asthma. A number of studies have indicated that parental anxiety or depressive symptoms are associated with increased asthma disease severity (Lim, Wood, & Miller, 2008; Lim, Wood, Miller, & Simmens, 2011), more frequent physicians' office visits (Ferro, Boyle, Alati, Scott, & Dingle, 2014), ED visits (Bartlett et al., 2001) and hospitalizations (Lange et al., 2011; Weil et al., 1999) due to asthma exacerbations in children. Furthermore, parental stress has been found to be linked with poor control of asthma symptoms in children (Shalowitz, Berry, Quinn, & Wolf, 2001; Sharp et al., 2009).

It has been suggested that the influence of parental psychological burden on childhood asthma morbidity could be attributed to ineffective asthma management behaviors (Celano, 2006; Kaugars et al., 2004; Klinnert, Kaugars, Strand, & Silveira, 2008). For those parents who find it difficult to maintain a healthy emotional balance between the multiple stressors related to childhood asthma care and the available personal resources (such as self-efficacy) (Wallander & Varni, 1998), they tend to manage childhood asthma ineffectively (Celano, 2006; Kaugars et al., 2004; Klinnert et al., 2008). For example, for parents who are constantly worried about their child's health conditions, they may keep their child away from schools and from engaging in physical activities owing to their perceptions of their child's heightened vulnerability due to the illness, but not on the actual severity of the asthma symptoms (Spurrier et al., 2000). Parents with depressive symptoms could be overwhelmed by the

caregiving responsibilities of managing childhood asthma and cope with avoidant strategies, for example, being less observant regarding the assessment of wheezing symptoms, or non-adherence to the lifestyle recommendations related to childhood asthma control (e.g., smoking cessation and allergen avoidance) (Kavanaugh et al., 2006; Leiferman, 2002). These parents also tend to have lower self-efficacy and expectations for achieving an optimal asthma control (Martinez, Perez, Ramirez, Canino, & Rand, 2009; Wolf, Miller, & Chen, 2008), and they are less likely to be adherent to medication (Bartlett et al., 2004; Rand, 2005). In addition, it is commonly observed that parents tend to weight their fears about the potential side effects from inhaled corticosteroids (ICS) (e.g., growth retardation) against fears of acute asthma exacerbations (Klok et al., 2011; Klok, Kaptein, & Brand, 2015; Santer, Ring, Yardley, Geraghty, & Wyke, 2014). Eventually, they carry out trials of withholding the regular use of ICS once their child does not have asthma symptoms (Santer et al., 2014), leading to poor adherence of ICS but over-reliance of using bronchodilators for a quick relief of asthma symptoms (Gustafsson, Watson, Davis, & Rabe, 2006).

### **1.5.** Current approaches to asthma management in children

Asthma remains incurable (World Health Organization, 2017). Hence, the principles of managing asthma are to achieve a good control of asthma symptoms, to maintain normal activity levels and to reduce the future risks of asthma exacerbations (Papadopoulos et al., 2012). International experts recommend that pharmacological treatment and asthma education are integral in the management of asthma in young children (British Thoracic Society/Scottish Intercollegiate Guideline Network, 2016; Global Initiative for Asthma, 2016; National Asthma Education and Prevention Program, 2007). There is a growing interest of research in

exploring other non-pharmacological approaches, such as interventions focusing on improving treatment adherence and home-based environmental intervention (Ritz, Meuret, Trueba, Fritzsche, & von Leupoldt, 2013). The following sections present a summary of current evidence regarding each of the aforementioned approaches.

### **1.5.1.** Pharmacological treatment

Inhaled corticosteroids (ICS), namely the controller medications, are recommended as the first line of preventive treatment of asthma (British Thoracic Society/Scottish Intercollegiate Guideline Network, 2016; Global Initiative for Asthma, 2016; National Asthma Education and Prevention Program, 2007). Inhaled short-acting beta-2-adrenergic agonists, namely the reliever (or rescue) medications, are commonly used for quick relief of asthma symptoms, such as wheezing and shortness of breath (Bateman et al., 2008). Generally, the types or the dosage of controller and reliever medications are selected through a stepwise approach according to the level of asthma control in each child (Papadopoulos et al., 2012). The goal of pharmacological treatment is to use the least possible medication while achieving an optimal asthma control (Papadopoulos et al., 2012). For young children, it is important to ensure whether the caregivers (e.g., parents) perform right inhaler technique when assisting their child to take inhaled medications via spacers or dry powder devices, and whether the parents adhere to the prescribed medication regimen (Bush & Fleming, 2015).

### 1.5.2. Asthma education

Apart from medications, asthma education is the most widely adopted existing practice to help parents for managing childhood asthma in many clinical settings (Bateman et al., 2008; Global Initiative for Asthma, 2016), with a theoretical assumption that improving parental knowledge and asthma management self-

efficacy through education can facilitate a specific parental behavioral change in disease management (e.g., adherence to medical treatment), thereby leading to a better childhood asthma control (Bandura, 1977; Clark, Gong, & Kaciroti, 2014; Clark & Valerio, 2003).

International experts recommend that the content of a structured asthma education program should include the following information: (1) the clinical presentation of childhood asthma (chronic and relapsing), (2) the importance of monitoring asthma symptoms and professional regular review by a consistent clinician, (3) strategies of avoiding identifiable asthma triggers, (4) the use of inhalers for treating asthma, and (5) the use of a written asthma action plan, which guides them what to do in case of worsening asthma symptoms (Bateman et al., 2008; Papadopoulos et al., 2012).

Evidence from a number of meta-analyses of randomized controlled trials (RCTs) has consistently revealed that asthma education programs for parents can improve childhood asthma outcomes (Boyd et al., 2009; Coffman, Cabana, Halpin, & Yelin, 2008; Wolf, Guevara, Grum, Clark, & Cates, 2002). The results of each of the meta-analyses are summarized as below.

An earlier Cochrane systematic review presented an overview of the efficacy of asthma education programs when compared with standardized medical treatments on the health outcomes of children with asthma (Wolf et al., 2002). Thirteen out of 32 reviewed RCTs (publication year ranged from 1980 to 1997) included parents or parent-child dyads as the participants. This review reported that children whose families received asthma education had better lung functions (standardized mean difference (SMD) = 0.50, 95% Confidence Interval (CI): [0.25 to 0.75]), less ED visits (SMD = -0.21, 95% CI [-0.33, -0.09]) and less hospitalizations (SMD = -0.08,

95% CI [-0.21, -0.05]) due to asthma exacerbations at post-intervention than those without receiving asthma education.

One meta-analysis of 37 RCTs (publication year ranged from 1984 to 2007) examined the effects of asthma education programs serving only for parents or parent-child dyads on the health outcomes of children with asthma (Coffman et al., 2008). The results also suggested that offering an additional asthma education in the existing medical service significantly reduced the frequencies of ED visits (SMD = -0.17, 95% CI [-0.31, -0.03]) and hospitalizations (SMD = -0.35, 95% CI [-0.63, -0.08]) due to asthma exacerbations in children at one year after the intervention (Coffman et al., 2008).

A further updated Cochrane systematic review of 38 RCTs (publication year ranged from 1986 to 2007) focused on examining the effects of asthma education programs in families whose children had experienced at least one ED visit due to asthma exacerbation over the past 12 months (Boyd et al., 2009). The comparison conditions consisted of standardized medical treatment of asthma, information leaflets about childhood asthma care and nursing instructions of administering inhalers. Consistent with the findings of the previous reviews (Coffman et al., 2008; Wolf et al., 2002), the results showed that children whose families participated in asthma education programs had a significant reduction of the risk of subsequent emergency admissions due to asthma exacerbations at one year after the intervention (Relative risk (RR) = 0.60, 95% CI [0.47, 0.77]) (Boyd et al., 2009).

In view of the benefits of pediatric asthma education programs on the health outcomes of children, a number of reviews have attempted to evaluate the utility of these programs in different non-clinical settings, such as at home (Welsh, Hasan, & Li, 2011), at school settings (Coffman, Cabana, & Yelin, 2009), and through

computers and internet (Bussey-Smith & Rossen, 2007; McLean et al., 2010). However, the effects of these programs on the health outcomes of children with asthma are yet to be confirmed, due to significant clinical heterogeneity in terms of the age groups of children, the control conditions, the content of the educational components, as well as the poor methodological quality of the included studies (Bussey-Smith & Rossen, 2007; Coffman et al., 2009; McLean et al., 2010; Welsh et al., 2011). One recent Cochrane systematic review compared the effects of enhanced inhaler technique education with general asthma education on the clinical outcomes of adults and children with asthma (Normansell, Kew, & Mathioudakis, 2017). Given that the pooled effect sizes of children's health outcomes in this review were based on a few trials (i.e.,  $\leq 2$  RCTs) (Normansell, Kew, & Mathioudakis, 2017), evidence again remains inconclusive.

### **1.5.3.** Interventions for promoting treatment adherence

Despite its proven efficacy, approximately 30% to 70% of children with asthma do not fully adhere to their prescribed ICS (Klok et al., 2015), which results in poor asthma symptom control (Bårnes & Ulrik, 2015). A recent Cochrane systematic review has explored the effects of interventions targeting at improving adherence to ICS on health outcomes in adults and children with asthma (Normansell, Kew, & Stovold, 2017). A total of 39 RCTs (publication year ranged from 1992 to 2016), of which 18 of them concerned parents and their children, were reviewed. A wide range of educational and behavioral interventions had been tested, such as education focusing on improving adherence to ICS, motivational interviewing, adherence prompting by interactive voice response systems, electronic trackers or cell phone messaging (Normansell, Kew, & Stovold, 2017). This review

found that none of the interventions so far demonstrate clinical benefits in children with asthma (Normansell, Kew, & Stovold, 2017).

#### **1.5.4.** Home-based environmental interventions

Exposure to allergens within the home environment can trigger asthma exacerbations (Papadopoulos et al., 2012). One systematic review identified 20 interventional studies and indicated that home-based environmental interventions, such as home-based asthma education plus environmental remediation to reduce asthma triggers at home, can successfully reduce the number of days with asthma symptoms and the school days missed by children (Crocker et al., 2011). However, questions remain regarding the implementation of this intervention in real-life practice, such as the required intensity of home visits, the applicability in rural populations and the related resource implications (Crocker et al., 2011).

# **1.6.** Limitations of the current asthma control strategies in children across the globe

Despite of the availability of effective medications, evidence-supported asthma education programs (Boyd et al., 2009; Coffman et al., 2008; Wolf et al., 2002) and asthma management practice guidelines (British Thoracic Society/Scottish Intercollegiate Guideline Network, 2016; Global Initiative for Asthma, 2016; National Asthma Education and Prevention Program, 2007), epidemiological studies have clearly indicated that asthma control in young children remains unsatisfactory in real-life practice. A global survey involving Canada, South Africa and four other European countries has shown that high frequencies of asthma-related coughing (92%), sleep disturbance due to asthma symptoms (59%) and restricted physical activities (47%) are reported in children with asthma (Wildhaber, Carroll, & Brand, 2012). The Asthma in Reality in Asia-Pacific (AIRAP) study, which surveyed

children in twelve Asia-Pacific regions, including Hong Kong, Mainland China, Taiwan and Singapore, has found that over half of the Asian children with asthma have asthma symptoms at least one day per week, almost one-third have disrupted sleeps, at least 40% experience restrictions in their normal physical activities and have missed schools due to asthma over the past four weeks (Wong, Kwon, Hong, Hsu, & Gunasekera, 2013).

Another evidence reflecting the current state of poor childhood asthma control across the globe is the heavy use of health care services due to childhood asthma exacerbations in various countries. In United States, asthma exacerbations in children aged less than 18 years account for about 1.6 million emergency department (ED) visits, and 137,000 hospital inpatient discharges per year (Centers for Disease Control and Prevention, 2017). It is estimated that the annual health care expenditure attributable to asthma, including ED, inpatient, and outpatient expenditures, for school-aged children in United States is \$5.92 billion United States Dollars (USD) (in 2015) (Sullivan et al., 2017). In the Asia-Pacific region, over half (51.7%) of the Asian children who have a diagnosis of asthma need unscheduled medical care services (either ED visits or hospitalizations) due to asthma exacerbations per year (Wong, Kwon, et al., 2013). In Hong Kong, the childhood asthma hospitalization rates have been increased annually on average by 4.0% in children aged 1 to 4 years, and by 2.0% in children aged 5 to 14 years, respectively (Chua et al., 2011).

# 1.7. Psychological interventions for parents of children with asthma

Owing to the significant psychological difficulties experienced by parents in managing childhood asthma and their negative impacts on the health outcomes of children, it has been recently suggested that apart from asthma education and pharmacological treatments, psychological interventions, which are specifically

designed to change the cognition and/or behaviors of parents with an intention of improving their child's health outcomes, may be beneficial to the parent-child dyads (Ritz et al., 2013).

One of the most commonly used interventional approaches is cognitive behavioral therapy (Beck, 2011). Cognitive behavioral therapy (CBT) aims to modify unhelpful cognitive processes that generates negative perceptions about the self and others, so that a person (e.g., a parent with a child suffers from asthma) can develop a more positive way of thinking about difficult situations and establish a more helpful behavioral response (Beck, 2011). Examples of interventional strategies could be, for example, cognitive restructuring/relaxation training/thought suppression to alter dysfunctional thoughts related to the child's illness, and maximizing well-adapted behaviors in response to the child's illness (Palermo, Wilson, Peters, Lewandowski, & Somhegyi, 2009; Robins, Smith, Glutting, & Bishop, 2005; Wade, Carey, & Wolfe, 2006). Problem-solving therapy (PST) is a psychotherapy which adopts cognitive behavioral models (Nezu, 2004), aiming at enhancing the competencies of parents in solving problems related to childhood asthma care in a more systematic way. Specific problem-solving skills are taught which include the following sequential steps: defining the problem, setting achievable goals, generating and choosing preferred solutions, implementing preferred solutions and evaluations (Nezu, 2004).

Another psychotherapy that emerges from the perspectives of family systems theory is the family-based psychotherapies, such as family therapy (FT) (Minuchin et al., 1975). Poor childhood asthma control is regarded as the "symptoms" caused by a dysfunctional family system, in which family members within the family system could carry out dysfunctional behaviors (e.g., ineffective asthma management

behaviors) which give rise to the symptoms (Lask & Matthew, 1979). Family therapy serves the whole family as unit of intervention, it aims to alert the family system to its dysfunctional behaviors by helping parents to explore the impacts of the disease on different family members, to resolve familial conflict and to improve family communication in childhood asthma care (Cottrell & Boston, 2002). Different strategies, such as problem-solving skills training, communication skills training, conflict resolution discussions and cognitive restructuring, could be adopted in FT (Gustafsson, Kjellman, & Cederblad, 1986).

Evidence from the meta-analyses of RCTs has shown that there are limited data to demonstrate the beneficial effects of the aforementioned psychological interventions (i.e., CBT, PST and FT) on the psychological health of parents, as well as the physical health of their children with asthma when compared with treatmentas-usual, such as parental asthma educational program available in the naturalistic settings (Eccleston, Fisher, Law, Bartlett, & Palermo, 2015; Yorke, Fleming, & Shuldham, 2005; Yorke & Shuldham, 2005). The results of each of the metaanalyses are summarized as below.

An earlier Cochrane systematic review assessed the efficacy of FT as an adjunct treatment to medication on the health outcomes of children with asthma (Yorke & Shuldham, 2005). Even an updated search was carried out in 2007, only two RCTs which were published in 1979 and 1986 were eligible to be reviewed (Gustafsson et al., 1986; Lask & Matthew, 1979). Owing to the scarcity of trials, selection bias and measurement bias, the review authors found difficult to draw a conclusion about the generalizability of FT to families of children with asthma. Another Cochrane review examined the effectiveness of psychological interventions for children with asthma (Yorke et al., 2005). Twelve RCTs (publication year ranged

from 1972 to 2004) were reviewed, but only one RCT included parents as the participants (Yorke et al., 2005). It was again difficult to make recommendations about the intervention effects of psychotherapies serving for both parents and their children with asthma.

One recent Cochrane review comprehensively examined the efficacy of psychological interventions, including CBT, PST and family-based psychotherapies received by parents of children with chronic health conditions on the following six outcomes: (1) parental psychological health, (2) parenting behavior, (3) family functioning, (4) child's physical health symptoms, (5) child's mental health symptoms, and (6) child's behavioral/disability problems, respectively (Eccleston et al., 2015). A total of 47 RCTs published from 1979 to 2014 were identified and nearly half used CBT (22 trials). Cognitive behavioral therapy (CBT) being delivered to parents was found effective to improve the physical health symptoms of their children with chronic health problems at post-treatment, but the review authors indicated that this finding was based on trials that used CBT in parents of children with chronic pain, diabetes and eczema only, but not asthma (Eccleston et al., 2015). Further, in this review, there were no evidence supporting the significant effects of CBT on other parental and child outcomes, including parental psychological health (Eccleston et al., 2015). Problem-solving therapy (PST) was found effective to improve parental psychological health at post-treatment and at follow-up, as well as parenting behavior at post-treatment (Eccleston et al., 2015). However, the review authors again indicated that these findings were based on trials that predominantly applied PST in parents of children with cancers only (Eccleston et al., 2015), there were no evidence demonstrating significant effects of PST on improving other parental and child outcomes (Eccleston et al., 2015). This review showed that

family-based psychotherapies did not demonstrate significant effects on the six selected parental and child outcomes (Eccleston et al., 2015). More importantly, the review authors found that the overall quality of evidence was rated as "low" to "very low", meaning that future research is very likely to change the estimated treatment effect (Eccleston et al., 2015).

In fact, in the Cochrane review conducted by Eccleston et al. (2015), only five out of 47 included RCTs (10.6% of total) published from 1979 to 2014 were asthma-related in which four used family-based psychotherapies (e.g., FT) (Celano, Holsey, & Kobrynski, 2012; Lask & Matthew, 1979; Naar-King et al., 2014; Ng et al., 2008) and one used PST (Seid, Varni, Gidwani, Gelhard, & Slymen, 2010). The review authors excluded the study conducted by Lask & Mathew (1979) due to lack of extractable quantitative data. For the remaining four RCTs, their pooled effect estimates showed no beneficial effects on the parents' mental health at post-treatment (p = .39), the child's asthma symptoms at post-treatment (p = .13) and at follow-up (p = .58) (Eccleston et al., 2015).

# **1.8.** Acceptance and Commitment Therapy (ACT): A potential intervention addressing the psychological difficulties encountered by parents of children with asthma

As noted earlier, asthma is a chronic and incurable disease. In view of the unpredictability, relapsing and the life-threatening nature of asthma episodes, as well as the demanding care to prevent future asthma exacerbations, emotions (e.g., fear, worry, sadness, uncertainty or self-doubt), memories (e.g., managing a child's acute asthma attack by the parent alone), as well as challenging thoughts (e.g., negative thoughts about medications) experienced by parents when caring for their children with asthma may inherent to many caregiving situations. In fact, the emotional experiences are not necessarily untrue or exaggerated given the challenges these parents encountered. Even the asthma management tasks are performed by these parents in everyday, for example, to assist a young child in using ICS via an aerochamber, may entail thoughts of their child's illness, which could be hardly modified or eliminated. There is a need to look for a psychological intervention to help parents in confronting these intrusive emotional experiences more effectively, so that these experiences could have less impact on their childhood asthma management and thus their children's health outcomes.

Acceptance and Commitment Therapy (ACT) seems applicable to the psychological situations encountered by parents of children with asthma. Acceptance and Commitment Therapy (ACT) is a mindfulness and values-based cognitive behavioral therapy that encourages individuals to better accept their psychological difficulties and work toward their values-based goals (Hayes, Luoma, Bond, Masuda, & Lillis, 2006; Hayes & Wilson, 1994). Instead of attempting to modify beliefs and/or to reduce distress (e.g., helping parents to replace maladaptive

thoughts with more adaptive thoughts) like the cognitive behavioral approaches do, ACT posits that difficult emotional experiences are unavoidable and can be persisted for a long time, while being opened up and experiencing them without defense, and engaging in values-consistent behaviors are likely to achieve better psychological functioning and well-being (Hayes, 2004). The goal of ACT is to foster the psychological flexibility (PF) of an individual: the ability to be fully aware of one's present-moment experience when interacting with the contextual environment, and the ability to engage in behaviors in the service of chosen values even though difficult emotional experiences occur (Hayes et al., 2006).

# 1.8.1. Philosophical and theoretical roots of ACT

Acceptance and Commitment Therapy (ACT) is rooted from a philosophical pragmatism called functional contextualism, which suggests that any behavior is interpreted as closely linked with its current context (Hayes, 2004; Hayes et al., 2006). Further, the *function* of the behavior is the target of understanding and influence during therapy sessions (Hayes, 2004; Hayes et al., 2006). In other words, psychological experiences (e.g., thoughts, feelings and bodily sensations) are not inherently problematic or positive but seen as whether they have *functions* for obtaining a more values-based life.

Consistent with the philosophy of functional contextualism, ACT is built under the theoretical principles of Relational Frame Theory (RFT). Relational Frame Theory (RFT) is a phenomenon that helps to explain that humans have unique qualities in *relational responding* (Blackledge, 2003; Hayes, 2004). The core RFT assumption is that humans have cognitive abilities to relate different stimuli mutually under arbitrary contextual cues (i.e., social constructed definitions and conventions created by language), that means, the ability to abstract the features of stimuli that do

not share similar physical properties (Blackledge, 2003; Hayes, 2004). In addition, based on the RFT principle, making deliberate attempts to avoid or to control negative psychological experiences in fact strengthens the underlying relational frame networks (e.g., trying not to think of a thought will serve as a contextual cue for that thought). Consequently, this suppression/ avoidance leads to further entanglement with these experiences, even when psychological or behavioral harm occur (Blackledge, 2003; Hayes, 2004). This psychological process is named as experiential avoidance (EA).

The principle of RFT may be applicable to parents when caring for a child with asthma, as similar to parents of children with behavioral problems (Coyne & Wilson, 2004). For example, a mother's thought of her young son's recent asthma attack (e.g., "the attack comes again...") could be triggered by any situations that have been *relationally framed* with that particular thought, such as her son's coughing spell, other children's coughing spells or any other cues. If the mother tries to avoid experiencing this painful thought process chronically by restricting her son from enjoying physical activities that may trigger cough, this behavior serves as a contextual cue for her thought about her son's asthma, and further strengthens the relational networks. In fact, this behavior may be maintained not because of the mother's lack of knowledge about appropriate physical exercise to improve the lung functions of her son with asthma, but because such behavior has a *psychological function* for the mother to avoid encountering difficult psychological experiences related to her son's asthma attack. More importantly, this ineffective parental asthma management behavior may bring in negative impacts on the child's health and wellbeing.

An individual with poor psychological flexibility (PF) can be regarded as being excessively entangled in EA process. For example, individuals with poor PF tend to manage their social fears by concealing their ongoing feelings through behavioral avoidance strategies (e.g., avoiding the crowd). This EA process may be useful in short-term, but paradoxically, if continues, the long-term workability of engaging EA could intensify their symptoms of anxiety and result in social anxiety disorders (Kashdan & Rottenberg, 2010). Another example relates to parenting practices. When a child misbehaves, a mother with poor PF might engage in a negative self-evaluation of her competence as a parent and in punitive parenting to control her child's behavior. This is again an EA process which not only exacerbates the mother's stress, but also intensifies the child's behavioral problem if the behavior becomes dominant (Shea & Coyne, 2011).

Putting the concept of PF into the context of parental involvement in managing childhood asthma, when negative emotions arise, such as fear of the recurrence of asthma attacks, parents with poor PF may engage in the EA process, in which they may attempt to alleviate their perceived difficulties by responding with avoidance and carrying out ineffective asthma management behaviors. A mother may suppress her own fear with avoidance, for example, by keeping herself awake all night to monitor her child's breathing, so that she could take immediate action once her child's condition changes and avoid experiencing the "fear" of handling another unpredictable childhood asthma attack. However, this maladaptive behavioral response reflects her narrow and inflexible repertoire that this mother may become insensitive to the context, but only engage in EA chronically. As a result, this may bring negative impacts on her own well-being and make her even more difficult to manage childhood asthma effectively. On the other hand, if the PF

of parents could be improved after receiving an ACT intervention, they may learn acceptance of psychological difficulties, awareness of life values and commitment to take values-driven actions, those very same negative thoughts, feelings and memories may be viewed very differently as normal human experiences, which would impact much less on their childhood asthma management.

# 1.8.2. Six therapeutic processes of ACT

In ACT, there are six therapeutic processes contributing PF. These processes are interrelated simultaneously as a form of hexagon and can be identified as: acceptance, cognitive defusion, contact with the present moment, stay self as context, values and committed action, as shown in the Figure 1.1. The four processes on the left side of the model address the core principles of acceptance and mindfulness, whereas those on the right side primarily address commitment and behavior change processes (see Figure 1.1).

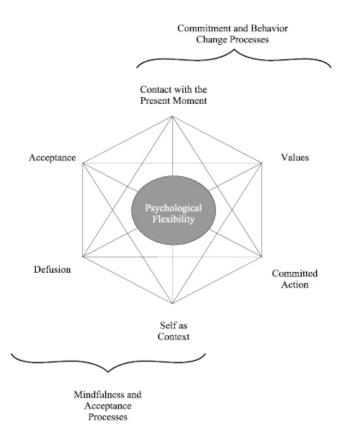


Figure 1.1. ACT model of psychological flexibility (Hayes et al., 2012, pp. 63)

Acceptance refers to the willingness to be opened to varied aspects of emotional experiences non-judgmentally. This is an action, for example, actively being in situations that bring in anxiety in a welcoming manner, rather than tolerance.

**Defusion** refers to the capacity to see thoughts as they are (with a psychological distance) rather than reacting to them as a literal truth. When a client has a strong cognitively fused mind with lots of reasons-giving, his/her behaviors can become inconsistent with values and goals, even the context provides opportunities for committing to values-driven behaviors (Hayes et al., 2006). Defusion helps the client to de-literalize the content of thoughts and to not let these thoughts influence his/her actions.

**Contact with the present moment** refers to the capacity of noticing the here and now experiences, and not being trapped in ruminating about the past or being preoccupied with the future. A person with psychological difficulties commonly fuses with the verbally-constructed past or future, for example, repeatedly thinking about the past failures but not paying attention to what is happening here and now (Luoma, Hayes, & Walser, 2007). Contact with the present moment is a core therapeutic process of ACT (Hayes et al., 2006), which entails three qualities: (1) the ability to regulate attention to the "now"; (2) the ability to fully experiencing what is occurring, and (3) the ability to acknowledge and to describe internal and external events in a non-judgmental manner.

**Self as context** refers to the capacity of developing a sense of self as an observer of the present event independently, without being trapped in the concepts about self, such as negative self-evaluations or categorizations. In ACT, the self is

the place of awareness or perspective taking that allows internal and external events to be experienced from "I/here/now" without being defined by those events.

**Values** refers to ongoing qualities of action that informs a broad sense of chosen life direction, with guidance and meaning of our actions. Values work in ACT can help the client to develop a constructive direction in establishing goals that is in line with his/her desired values with greater flexibility.

**Committed action** refers to the ability to engage in ongoing patterns of actions that are consistent with one's values even in the face of psychological barriers. The goal of ACT is to help the client to engage in behavioral patterns toward the clarified values-based paths, which involves practicing other ACT therapeutic processes, such as acceptance, defusion, being present and self as context.

In ACT, metaphors, experiential exercises and/or mindfulness exercises could be used interchangeably to foster an individual's PF, for example, the use of mindfulness exercises to facilitate present-moment awareness, defusion exercises to change the relationship between thoughts and the individual, or values clarification exercises to identity the personally-held values.

# 1.8.3. Efficacy of ACT in health care context

Psychological flexibility (PF) is the fundamental of psychological health (Kashdan & Rottenberg, 2010). Evidence from reviews of 22 correlational studies has shown that lower level of PF is associated with more depressive symptoms (Ruiz, 2010), more anxiety symptoms (Ruiz, 2010), and poorer quality of life (Hayes et al., 2006), implying that fostering an individual's PF may lead to better psychological well-being. Further, the beneficial effects of ACT in adult population on physical and mental health outcomes have been previously reported in systematic

review (Graham, Gouick, Krahé, & Gillanders, 2016) and meta-analyses of RCTs (A-Tijak et al., 2015; Öst, 2014). The main results of these reviews are discussed as follows.

One meta-analysis reported an overview of the health effects of ACT in adults with somatic problems (e.g., chronic pain, headache, epilepsy, cancer, diabetes, multiple sclerosis and overweight) and psychiatric problems (e.g., depression, anxiety, psychotic symptoms, borderline personality disorders, obsessive and compulsive disorders) (Öst, 2014). Sixty RCTs published from 1986 to 2013 were included, the comparison group was treatment-as-usual (TAU), such as standardized counseling services, psychotherapy services using cognitive behavioral approach, or existing medical treatment offered in the naturalistic settings. Medium effect sizes in favor of ACT were observed when compared with TAU (at posttreatment: Hedge's *g* pooled effect size (*g*) = 0.55, 95% CI [0.28, 0.83], *p* < .001; at follow-up for at least four months, g = 0.48, 95% CI [0.27, 0.69], *p* < .001) (Öst, 2014).

The above meta-analysis was further updated by A-Tijak and colleagues (2015) using stricter selection criteria of the included studies. These criteria were: (1) ACT serving adult patients with a physician-confirmed medical or psychiatric diagnosis only rather than those presented with symptoms, (2) at least 80% of participants in the ACT group received the allocated intervention, and (3) at least ten participants in the ACT group remained at post-treatment for assessments (A-Tijak et al., 2015). Thirty-nine RCTs published from 1989 to 2012 were reviewed. This meta-analysis showed that, ACT performed better than TAU (e.g., medications, psychoeducation, counseling services or case management) in a variety of physical health problems (g = 0.58, 95% CI [0.33, 0.84], p < .001). The improvements

included less pain symptoms and pain-related functional disability in chronic pain patients (Wetherell et al., 2011), reduction of Hemoglobin A1C levels in diabetic patients (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), less seizure frequency and duration in drug refractory epilepsy patients (Lundgren, Dahl, Melin, & Kies, 2006) and less eating disorder behaviors in bariatric surgery patients (Weineland, Hayes, & Dahl, 2012). Further, this meta-analysis also found that ACT worked better than TAU to reduce anxiety and depressive symptoms (g = 0.37, 95% CI [0.04, 0.70], p = .03) and other mental health symptoms (g = 0.92, 95% CI [0.35, 1.48], p= .001) (A-Tijak et al., 2015).

A recent systematic review conducted by Graham and colleagues (2016) explored the application of ACT in long-term conditions. A total of 18 studies published from 2008 to 2014 were reviewed (8 RCTs, 4 single group pretest-posttest design studies and 6 case studies) (Graham et al., 2016). Though the majority of included studies were not RCTs with low methodological quality, this review reported the consistent small-to-medium effects of ACT across diverse conditions at post-intervention, for instance, lifestyle modifications in patients with cardiac problems (within-group comparison: *d* ranged from 0.54 to 1.57) (Goodwin, Forman, Herbert, Butryn, & Ledley, 2012), reduction of distress and improvements of quality of life in cancer patients (within-group comparison: *d* ranged from 0.56 to 1.87) (Feros, Lane, Ciarrochi, & Blackledge, 2013; Hawkes, Pakenham, Chambers, Patrao, & Courneya, 2014; Rost, Wilson, Buchanan, Hildebrandt, & Mutch, 2012).

In general, the benefits of ACT in adult population has been shown in a variety of health outcomes. Evidence regarding the effects of ACT for improving the health outcomes of parents and their children suffering from physical or mental health problems is discussed in Chapter Two.

# 1.9. Summary

It is well recognized that an optimal control of asthma in young children can be achieved if their parents are actively involved in the childhood asthma management. However, caring for a child with asthma can impose a heavy psychological burden on parents, which can adversely affect their psychological health, asthma management behaviors, and their child's health. Current approaches to childhood asthma management mainly focus on pharmacological treatments and asthma education, both are shown to be successful for improving childhood asthma outcomes but do not address parental psychological needs. In addition, there is a lack of effective psychological interventions for improving the psychological well-being of parents, as well as the health outcomes of their children with asthma. The focus of ACT on encouraging individuals to accept psychological difficulties nonjudgmentally in the service of meaningful activities may be efficacious to parents for improving childhood asthma management. In view of the potential utility of ACT in populations with long-term conditions, the study presented in this thesis aimed to examine the efficacy of a parental training program using group-based ACT integrated with asthma education (the ACT group), in comparison to an asthma education talk (the Control group), on the health outcomes of parent-child dyads using a RCT design.

### **1.10.** Organization of the thesis chapters

This thesis is divided into eight chapters. Following this introductory chapter, Chapter Two presents a systematic review of experimental and quasi-experimental studies examining the effects of mindfulness- and acceptance-based interventions (including ACT) for improving the health outcomes of parents and their children with physical or mental health problems. The knowledge gaps about the utility of

ACT in the context of pediatric care are then identified. Chapter Three presents the study methods, including the hypothetical model of the study, the aim and specific objectives of the present study, the study design, sampling, data collection methods and data analyses. Chapter Four presents the process of developing an ACT intervention protocol, including a qualitative descriptive study to explore the psychological difficulties experienced by Hong Kong Chinese parents in caring for a child with asthma. The program goals, the program structure and the content of each of the ACT sessions are also described in detail. Chapter Five delineates the pilot study conducted prior to the commencement of the RCT. The pilot study aimed to validate a self-administered questionnaire for collecting data from parents and to determine the acceptability and feasibility of the group-based ACT intervention in parents of children with asthma.

Chapter Six presents the findings of the RCT study investigating the effects of the ACT group versus the Control group on the health outcomes of children with asthma, the psychological health outcomes and the asthma management outcomes of parents across the six months follow-up period immediately after the intervention. This chapter also incorporates a process evaluation to examine how the RCT was conducted by examining the participation of the parental training program, the completion of the assigned intervention sessions, the lost to follow-up and the fidelity of the group-based ACT intervention. Chapter Seven focuses on discussing the meaning of the intervention effects on the asthma-related health outcomes of children, the psychological health outcomes, the asthma management outcomes of their parents, study strengths and limitation, implications for clinical practice and research and recommendations to health care professionals. The final chapter presents the conclusion of the present study.

# **CHAPTER TWO**

# LITERATURE REVIEW

- 2.1. Introduction
- 2.2. Background of the review
- 2.3. Aim of the present review
- 2.4. Methods
  - 2.4.1. Eligibility criteria for identifying studies for this review
  - 2.4.2. Search methods and identification of studies
  - 2.4.3. Data extraction and data management
  - 2.4.4. Risk of bias assessments
- 2.5. Results
  - 2.5.1. Results of the search
  - 2.5.2. Study characteristics
  - 2.5.3. Risk of bias within studies and across studies
  - 2.5.4. Intervention efficacy on parental health outcomes
  - 2.5.5. Intervention efficacy on child health outcomes
- 2.6. Discussion
  - 2.6.1. Summary of evidence
  - 2.6.2. Quality of the evidence
  - 2.6.3. Limitations of the review
  - 2.6.4. Implications for future research
- 2.7. Summary

### **2.1. Introduction**

This chapter reports a systematic review of experimental and quasiexperimental studies evaluating the efficacy of mindfulness- and acceptance-based interventions (MABIs), including Acceptance and Commitment Therapy (ACT), Mindfulness-based Cognitive Therapy (MBCT) and Mindfulness-based Stress Reduction (MBSR), for improving the health outcomes of parents and their children with physical or mental health problems. The background of the review is addressed, followed by presenting the review objectives, the procedures of searching and identifying relevant studies and extracting data for analysis. Quality of the selected studies is appraised, the effects of MABIs on the parental health outcomes and the child health outcomes are then evaluated. Implications for further studies in investigating the efficacy of MABIs, particularly ACT, in parents for improving the health outcomes of parent-child dyads are addressed at the end of this Chapter.

### 2.2. Background of the review

Asthma is the most common chronic health conditions (CHCs) of childhood (Global Initiative for Asthma, 2016). Similar to other types of CHCs, such as cancers (Gibbins, Steinhardt, & Beinart, 2012), and congenital heart disease (Jackson, Frydenberg, Liang, Higgins, & Murphy, 2015), caring for a child with asthma imposes a heavy psychological burden on parents, possibly due to the threatening symptoms, the demanding care to avoid relapses of symptoms and the degree of the child's functional disability (Cousino & Hazen, 2013; Easter et al., 2015; Kaugars et al., 2004). More importantly, this psychological burden could affect how parents manage childhood asthma effectively and eventually bring negative impacts on their

children's health outcomes (Celano, 2006; Kaugars et al., 2004; Klinnert et al., 2008).

Recently, there is growing evidence showing that acceptance, rather than controlling or fighting against negative psychological experiences, may help to improve the functioning of an individual in managing CHCs, leading to an improvement of health outcomes (Graham et al., 2016). Acceptance refers to the ability of being open and to stay present with experiences (e.g., thoughts, feelings, memories and bodily sensations) (Hayes et al., 2006), it is also closely related to another concept called mindfulness, which has been described being aware of the present-moment experiences non-judgmentally (Kabat-Zinn, 1994).

In literature, interventions that are most well-established and cover the concepts of acceptance and/or mindfulness include Acceptance and Commitment Therapy (ACT) (Hayes et al., 2006), Mindfulness-based Cognitive Therapy (MBCT) (Segal, Williams, & Teasdale, 2002), and Mindfulness-based Stress Reduction (MBSR) (Kabat-Zinn, 1990). As described earlier in Chapter One, ACT focuses on fostering the psychological flexibility of an individual as the goal of treatment by attaining the following six psychological skills: acceptance, defusion, contacting with the present moment, contacting with self-as-context, values clarifications and committed actions (Hayes et al., 2006). The strategies used in ACT to foster psychological flexibility (PF) are mainly using metaphors, experiential exercises and establishing values-based goal setting. Mindfulness exercises are seen as one of the strategies that strengthens the process of present-moment awareness in particular, and less structured when compared with MBSR and MBCT.

MBSR is introduced by Kabat-Zinn (1990), it is a group-based program lasting for eight weeks where participants practice different types of formal

mindfulness exercises, such as sitting meditation, walking meditation and body scan meditation, in session and as homework between sessions. Through practicing mindfulness, participants in the MBSR program can learn to develop non-judgmental awareness to stressors. MBCT is developed by Segal, Williams and Teadale (2002) which has a similar program structure as the MBSR, but additionally incorporates cognitive therapy serving for individuals with recurrent depression. Participants in the MBCT program can learn non-judgmental awareness of and disengagement from depressive cognitive processes.

In recent literature, ACT, MBSR and MBCT are often concurrently reviewed as "mindfulness- and acceptance-based interventions (MABIs)" (Cavanagh, Strauss, Forder, & Jones, 2014; Norton, Abbott, Norberg, & Hunt, 2015; Rudaz, Twohig, Ong, & Levin, 2017; Veehof, Trompetter, Bohlmeijer, & Schreurs, 2016; Vøllestad, Nielsen, & Nielsen, 2012). Despite using different therapeutic techniques, these three interventions conceptually share an emphasis on present-centered and non-evaluative stance of awareness of experiences, instead of avoidance, control or suppression, which can facilitate behavioral changes in the face of distress (Hofmann & Asmundson, 2008; Vøllestad et al., 2012). Putting into the context of parents in taking care of their children with CHCs, MABIs may help parents to develop the capacity of becoming more observant and accepting towards their psychological experiences, as well as the capacity to respond with greater flexibility to events related to the management of their child's health problems. Eventually the psychological health of parents, as well as the health conditions of their children could be improved.

# Prior reviews of mindfulness- and acceptance-based interventions (MABIs) in families and their children

The utility of MABIs in families and their children with CHCs were not evaluated in prior reviews focusing on evaluating the efficacy of psychological interventions in this target population (Clarke & Calam, 2012; Eccleston et al., 2015; Law, Fisher, Fales, Noel, & Eccleston, 2014; Meyler, Guerin, Kiernan, & Breatnach, 2010). It is because in these reviews, the included interventional studies were selected according to different theoretical models, such as the behavioral family systems theoretical model (Eccleston et al., 2015; Law et al., 2014), and the Pediatric Psychosocial Preventive Health Model (Meyler et al., 2010). Hence, the types of psychological interventions being reviewed were confined to cognitive behavioral therapy, problem-solving therapy and systems therapies (such as family therapy, multisystemic therapy and behavioral family systems therapy).

Starting from 2006 onwards, there is a growing body of evidence based on published reviews which separately evaluated the use of ACT (Coyne, McHugh, & Martinez, 2011; Graham et al., 2016; Murrell & Scherbarth, 2006; Swain, Hancock, Dixon, & Bowman, 2015; Wicksell, Kanstrup, Kemani, Holmström, & Olsson, 2015), and mindfulness-based interventions (Cachia, Anderson, & Moore, 2016; Rayan & Ahmad, 2017; Whittingham, 2014), in children and families. The findings of the aforementioned reviews have indicated the efficacy of MABIs in parents of children with neurodevelopmental disorders, such as autism, acquired brain injuries, cerebral palsy and disabilities (Cachia et al., 2016; Graham et al., 2016; Rayan & Ahmad, 2017; Whittingham, 2014; Wicksell et al., 2015). None of these reviews, however, have provided a thorough overview regarding the efficacy of MABIs as a whole in parents of children with CHCs, especially for those parents of children with

physical or mental health problems. Limitations of each of these reviews are summarized as below.

Two previous narrative reviews have been conducted to describe the evidence base of ACT-related work in children, adolescents and families since 1989 to 2009 (Coyne et al., 2011; Murrell & Scherbarth, 2006). During the time of conducting these reviews, ACT-related research was still developing, hence both reviews mainly described the theoretical application of ACT (Coyne et al., 2011), the development of ACT-related processes measures (Coyne et al., 2011), and theoretical papers that hypothetically described the application of ACT but without empirical data support (Murrell & Scherbarth, 2006). In addition, most of the empirical studies under these two reviews were case studies or small-scale pilot studies which focused on the treatment adaptations of ACT in children or adolescents only (Coyne et al., 2011; Murrell & Scherbarth, 2006). Nevertheless, both reviews identified one study in single-group pretest-posttest design, showing that psychological inflexibility and psychological distress of parents of children with autism were reduced after receiving two days of ACT workshop (Blackledge & Hayes, 2006).

After the publications by Coyne et al. (2011) and Murrell et al. (2006), two reviews summarized the effects of ACT for pediatric populations with physical or mental health problems (Swain et al., 2015; Wicksell et al., 2015), another recent systematic review collated all ACT interventions for populations with long-term conditions and evaluated the intervention efficacy (18 studies, publication year ranged from 2006 to 2014) (Graham et al., 2016). These three reviews mainly included studies in one-group pretest-posttest design and RCTs that were published in peer-reviewed journals. Wicksell et al. (2015) and Graham et al. (2016) identified

two randomized waitlist-controlled studies, showing that dysfunctioning parenting style, parental psychological health, child behavioral and emotional problems were improved after parents of children with acquired brain injuries, or cerebral palsy received an ACT-based parenting program, when compared with those in the control conditions receiving rehabilitation services (Brown, Whittingham, Boyd, McKinlay, & Sofronoff, 2014; Brown, Whittingham, Boyd, McKinlay, & Sofronoff, 2015; Whittingham, Sanders, McKinlay, & Boyd, 2014; Whittingham, Sanders, McKinlay, & Boyd, 2016). However, in the review conducted by Wicksell et al. (2015), only studies that used ACT for improving the health outcomes of children and adolescents with physical concerns were selected. The eligibility criteria of the included studies were not clearly stated (e.g., in terms of the types of participants, of whom as the recipient(s) of ACT interventions). Studies that delivered ACT to parents of children with physical health problems for improving parental psychological health, or ACT to parents of children with mental health problems for improving the psychological health of either parents and/or their children, were not covered in this review. For the review conducted by Graham et al. (2016), it focused on the utility of ACT in populations with long-term physical conditions only. Populations with chronic pain problems and mental health problems were excluded by the authors. Hence, this review may not be able to cover the current state of evidence regarding the efficacy of ACT in parents of children with the above health problems.

Evidence from three recent reviews have supported the potential efficacy of interventions using formal mindfulness training (e.g., MBSR, MBCT, or mindfulness-based programs adapted from MBSR or MBCT) for improving the psychological health and parenting behaviors of parents of children with autism, cerebral palsy and disabilities (Cachia et al., 2016; Rayan & Ahmad, 2017;

Whittingham, 2014), mainly based on empirical studies using single-group pretestposttest design. Yet, these reviews did not cover the evaluations of interventions in parents of children with other CHCs.

# 2.3. Aim of the present review

This systematic review aimed to evaluate the efficacy of mindfulness- and acceptance-based interventions (MABIs) that included parents as the participants for improving the health outcomes of parents and their children suffering from physical or mental health problems.

# 2.4. Methods

This review was conducted and reported according to the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) statement (Liberati et al., 2009). The PRISMA statement is a checklist of 27 items which guides authors for a complete and transparent reporting of a systematic review (Liberati et al., 2009). In the following method section, it covers the following areas as guided by the PRISMA statement: eligibility criteria for identifying studies, search methods and identification of studies, data extraction, data management, and the risk of bias assessments.

# 2.4.1. Eligibility criteria for identifying studies for this review

# **Inclusion criteria**

We included empirical studies that were published in peer-reviewed journals and prepared in English. In addition, the studies under this review should fulfill the following eligibility criteria, in terms of types of study design, participants, interventions and outcomes.

**Types of study design.** Experimental studies in either randomized controlled trials (RCTs), such as cluster-RCTs, RCTs with waitlist-controlled group(s), RCTs

in parallel group design; or quasi-experimental studies, such as controlled clinical trials, studies in single-group pretest-posttest design, were included.

**Types of participants.** Participants of the included studies must be either one of the followings: (1) parents of children suffering from a physical or a mental health problem; or (2) parent-child dyads in which the child suffered from a physical or a mental health problem. For both criteria, parents must be the recipients of the intervention.

Parents could be either fathers, mothers, both parents, or caregivers who adopted the responsibility of taking care of their children with physical and mental health conditions.

Children were defined as "child" or "adolescent" under the age of 18 years. According to a representative national survey conducted in United States about children with special care needs (Data Resource Center for Child & Adolescent Health, 2010), the child must have one of the following physical or mental health problems, in which the consequences of such health problem could lead to functional limitations and/or the need for medical or other care services (van der Lee, Mokkink, Grootenhuis, Heymans, & Offringa, 2007): (1) allergies, (2) anxiety problems, (3) arthritis, rheumatologic conditions and joint problems, (4) asthma, (5) blood problems, such as anemia or sickle cell disease, (6) cancers, (7) cystic fibrosis, (8) anxiety, depression and mood disorders, (9) diabetes, (10) epilepsy or seizure disorders, (11) head injuries, concussion or traumatic brain injuries, (12) heart problems, such as congenital heart disease, (13) idiopathic pain conditions, complex regional pain syndrome, migraine or frequent headaches and chronic pain problems, and (14) muscular dystrophy. We took reference from this survey because it comprehensively covered most of the common pediatric physical and mental health

problems in literature; it has also been adopted in a number of systematic reviews investigating the efficacy of psychological interventions in families for managing childhood chronic diseases (Eccleston et al., 2015; Law et al., 2014).

**Types of interventions.** Studies were included if the MABI was delivered to parents, or to the parent-child dyads, with the goal of improving the health conditions of parents and/or their children with physical or mental health problems.

If a comparator was included in the studies, there were no restrictions on the comparison conditions. The comparator could be, for example,

- active alternative treatment, which referred to any kinds of treatment specially designed to compare the effect of ACT. The treatment could be psychotherapies, psychotropic medications or other program-based interventions, or
- (2) treatment-as-usual (TAU), or alternatively named as usual care, which referred to any appropriate medical or psychological care as the standard practice of the study site. Standard care, usual care and no treatment conditions were also included in this category. Waitlist control condition was regarded as TAU, in which the delivery of the intervention to the comparison group would be delayed until the participants in the intervention group had completed the treatment.

**Types of outcomes.** We included studies which reported the health outcome(s) of parents and/or their children with physical or mental health problems at post-intervention and/or at the last follow-up time point at least under one of the following domains:

- (1) parental psychological health.
- (2) child's psychological health,
- (3) child's functioning (i.e., impairments in physical and psychological functioning in everyday social roles due to the physical health symptoms), and/or

(4) child's physical health conditions (e.g., medical symptoms).

# **Exclusion criteria**

We excluded articles that were not prepared in English, studies which were reviews, meta-analyses, study protocols, case studies (e.g., case series studies, case reports), ongoing studies, studies that reported only data for individual participants or qualitative data. We also excluded studies that included children as the only recipients of the MABI, while their parents did not receive the intervention. Given that this review focused on examining the efficacy of MABIs for parents of children with physical or mental health problems, we excluded studies that examined the efficacy of MABIs in parents of children with neurodevelopmental behavioral intellectual disorders, such as attention deficit hyperactivity disorder (ADHD), autism, developmental delay, cerebral palsy and learning disabilities (*Note*. For the evidence of ACT for this population, see the full review conducted by Graham et al. (2016); for the evidence of mindfulness-based interventions, see the full review conducted by Cachia et al. (2016) and Rayan & Ahmad (2017)).

### 2.4.2. Search methods and identification of studies

A systematic search of English language, published peer-reviewed journal publications was undertaken using the following search syntax: ((acceptance and commitment therapy) OR (acceptance-based) OR (acceptance and commitment) OR (mindfulness-based stress reduction) OR (mindfulness-based cognitive therapy) OR (mindfulness-based)) AND (child\* OR infant\* OR adolesc\* OR baby OR babies OR toddler\* OR teenager\* OR youth\* OR pediatric\* OR preschool\*) AND (parent\* OR maternal OR mother\* OR paternal OR father\* OR family OR famil\*). The following Medical Subject Heading (MeSH) terms were also used during the search, including "acceptance and commitment therapy", "mindfulness", "parents", "family",

"fathers", "mothers", "child" and "infant" were used. Six databases were searched from their inception to 31<sup>st</sup> December 2016: The Cochrane Central Register of Controlled Trials via CENTRAL, MEDLINE via Ovid, EMBASE via Elsevier, CINAHL via EBSCOhost, PsycINFO via ProQuest search engines, and SCOPUS via Elsevier. For the exact search strategies for each database, please see Appendix 2.1 at the end of this Chapter. Official websites that specially received literature related to MABIs, including the Association for Contextual Behavioral Science (ACBS) (http://contextualscience.org/publications), the Center for Mindfulness in Medicine, Health Care and Society in the United States

(https://www.umassmed.edu/cfm/research/publications/), the Oxford Mindfulness Center in the United Kingdom (http://oxfordmindfulness.org/about-us/research/), the Center for Mindfulness Studies in Canada

(https://www.mindfulnessstudies.com/mindfulness/evidence/) were also searched to retrieve potential relevant studies. Initial screening on titles and abstracts was conducted. Duplicated studies were removed from the total number of identified records. Abstracts from the remaining records were then screened to retrieve full-text articles for the assessment of eligibility. For each of the identified studies, its reference list was checked, followed by citation search and author search to look for other potential eligible studies. The identified papers were cross-checked later by another independent researcher for eligibility.

# 2.4.3. Data extraction and data management

The following information for each included study was extracted by a researcher according to the predesigned data extraction form: (1) study design; (2) study setting(s), sample size, characteristics of the parents and their children (i.e., mean age and gender distribution of parents and their children, diagnosis of

children); (3) key features of the MABIs (if any), in terms of modality, number of sessions, total number of contact hours, therapist(s) and qualifications, strategies used for fidelity assessment(s), use of process measures (if any), adherence rate (i.e., the percentage of participants who attended all the assigned MABI sessions); (4) key features of the control condition(s) (if any); (5) participation rate (i.e., the percentage of eligible parents/ parent-child dyads who participated in the MABIs) and attrition rate (i.e., the percentage of participants who were lost to follow-up by the end of the study); (6) parent and/child health outcomes that are relevant for this review and the corresponding instrument(s), and (7) outcome data. The above extracted information was checked by another researcher for any discrepancies.

This review included experimental studies with expected heterogeneities in the participants' characteristics (e.g., types of CHCs in children), study design, types of MABIs, types of control conditions, outcome measures and timing of outcome measurements. To avoid an inaccurate summary of treatment effect (Higgins & Green, 2011), we did not perform the meta-analyses by pooling the data statistically. In addition, subgroup analyses were not performed because of these expected variations across each individual study (i.e., these studies could be difficult to combine as a subgroup for further analysis).

Hence, for continuous outcomes, we decided to extract the findings, in terms of effect sizes (ESs), as reported in the publication. If these data were not available, for studies with a control group, we calculated the between-group ESs (*d*) by comparing the means between the experimental group and the control group at post-intervention and at the last follow-up time point (if measured) using the following formula (Cohen, 1988):  $d = M_1 \cdot M_2 / SD_{pooled}$ , where  $M_1$  and  $M_2$  refer to the means of both groups, while the pooled standard deviation (SD<sub>pooled</sub>) was calculated by using

the following formula (Cohen, 1988):  $SD_{pooled} = \sqrt{(SD_1^2 + SD_2^2)/2}$ . For studies in single-group pretest-posttest design, we calculated the within-group ESs (*d*) by comparing the means between pre- and post-intervention, as well as pre- and at the last follow-up time point (if measured) using the formula developed by Morris & DeShon (2002):  $d = (M_1 - M_2/SD_{pretest})/\sqrt{2}(1 - r)$ , where *r* refers to the correlation between pre- and post-treatment measures, taking the potential within-subject correlations across time into consideration. This correlation was often not reported in publications; hence we followed the recommendation by Rosenthal (1993) to take the most conservative estimation of *r* as 0.7. The magnitude of Cohen's *d* can be interpreted as small (0.2), medium (0.5), or large (0.8) (Cohen, 1988). If correlational effect sizes (*r*) were reported in studies using single-group pretest-posttest design, 0.1 indicates a small effect, above 0.3 as a medium effect, and above 0.5 as a large effect, respectively (Cohen, 1988).

In case of dichotomous outcomes and if the study had a control group, risk ratios (RRs) with 95% CIs would be calculated by dividing the risk of events in the experimental group (e.g., the number of participants presented with depressive symptoms divided by the total number of participants) over the risk of events in the control group at post-intervention and at the last follow-up time point (if measured). For studies in single-group pretest-posttest design, the proportion of the participants with events at post-intervention and at the last follow-up time point (if measured) would be calculated.

# 2.4.4. Risk of bias assessments

Risk of bias assessments of the included studies were conducted and counterchecked with another researcher using two instruments: (1) the Quality Assessment Tool for Quantitative Studies developed by the Effective Public Health Practice

Project (EPHPP) (Thomas, Ciliska, Dobbins, & Micucci, 2004), and (2) the Psychotherapy Outcome Study Methodology Rating Form (POMRF) (Öst, 2008).

The EPHPP assessment tool is developed for comprehensively assessing the methodological quality of all types of experimental studies related to health care (Thomas et al., 2004). It covers six domains: (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) data collection methods, (6) and withdrawals and drop-outs. Each domain was rated as "strong", "moderate" or "weak". A global quality rating was then made based on the ratings of all these domains. Studies were considered as "strong" quality if they received no "weak" ratings on any of these domains, "moderate" quality if they received one "weak" rating, and "weak" quality if they received two or more "weak" ratings.

Apart from evaluating study methodology in a general perspective, we also examined the quality of MABIs in detail by using the POMRF. The POMRF has been used in a number of systematic reviews of ACT-related interventional studies (A-Tijak et al., 2015; Graham et al., 2016; Öst, 2008, 2014; Swain et al., 2015; Swain, Hancock, Hainsworth, & Bowman, 2013), psychological treatments in general (Temple, Salmon, Tudur-Smith, Huntley, & Fisher, 2018), and cognitive behavioral interventions (Arnberg & Öst, 2014; Öst, Havnen, Hansen, & Kvale, 2015). The POMRF shows satisfactory inter-rater reliability within the range 0.50– 1.00 with a mean of 0.75 (Öst, 2008, 2014). It comprises 22 indicators that specifically evaluate the methodological quality of psychotherapy outcome studies, for example, clarity of sample description, reliability and validity of outcome measures, use of manualized, replicable, specific treatment programs, therapist training/ experience, checks for treatment adherence and checks for therapist competence, and handling of attrition. Each item was rated as "Poor" (0 points),

"Fair" (1 point) or "Good" (2 points). The overall score ranges from 0 to 44, with higher overall scores indicative of greater methodological rigor.

#### 2.5. Results

# 2.5.1. Results of the search

Electronic searches of databases identified a total of 596 records. Thirty-six additional records were identified through the official websites that specially received literature related to MABIs, author search, reference lists and citation search. After the duplicates were removed, 345 records were screened based on their titles and abstracts, with 329 records being excluded due to the following reasons: non-relevant records (number of studies (n) = 117), not peer-reviewed journal articles (e.g., conference abstracts) (n = 11), non-experimental studies (n = 94), interventions were not delivered to parents of children with physical or mental health problems (n = 107). Sixteen full-text articles were extracted and assessed for eligibility, of which eight were excluded. Of these eight excluded papers, two were case studies (Mehranfar, Younesi, & Banihashem, 2012; Merwin, Zucker, & Timko, 2013). Two studies reported that parents were involved in the assessments only, but not the intervention (Tan & Martin, 2013, 2015). Two studies included parents of offspring, who were in fact young adults, aged 19 to 20 years old (Martin et al., 2016; Wicksell, Melin, & Olsson, 2007). One study reported that 2.9% of the participants were parents of children with anxiety disorders, the rest of the participants did not fulfill the inclusion criteria of this review (e.g., parents of children with autism, ADHD or those with parent-child relational problems) (Meppelink, de Bruin, Wanders-Mulder, Vennik, & Bögels, 2016), while Meppelink et al. (2016) did not report the results of intervention effects for each subgroup of the participants, including those with children suffering from anxiety disorders. The

remaining excluded study was an ongoing trial, full trial data were not available at the time of publication (Swain, Hancock, Hainsworth, & Bowman, 2015). Eight studies were finally included in this review. Figure 2.1 presents the flow chart of study selection.

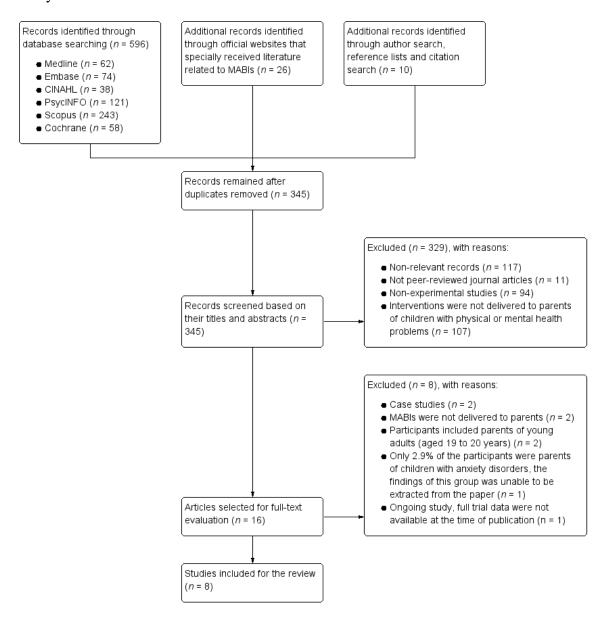


Figure 2.1. Flowchart showing the process of selecting studies

*Note. n* = number of studies; MABIs = mindfulness- and acceptance-based intervention

### 2.5.2. Study characteristics

Table 2.1 displays the characteristics of the included studies (number of the studies (n) = 8). Most of the included studies adopted the single-group pretest-posttest design (n = 5), while the remaining three studies followed a RCT design. Of these trials, one used a three-arm, waitlist control group design by comparing ACT, CBT and a 10-week duration of waitlist control group (Hancock et al., 2016), one examined the use of ACT when compared with a multi-disciplinary treatment (Wicksell, Melin, Lekander, & Olsson, 2009), and another one compared the effects of group-based ACT versus individual-based ACT (Kanstrup et al., 2016). All studies took place in western countries, such as Australia (n = 3), the United States (n = 3) and Sweden (n = 2), and they were mainly conducted in hospital settings (n = 5).

**Participants.** Altogether the eight included studies enrolled a total of 395 families, of which 47 were family triads (i.e., father, mother and child), 273 were parent-child dyads and 75 were parents only. Among these eight studies, parents who participated in the MABIs were mainly mothers (n = 4). Generally, their mean age ranged from 31 to 48 years old (n = 3). A large variation of their children's age range (i.e., from 2 to 18 years) was noted. Four studies included parents as the participants only, where their children were usually at preschool age (n = 3), the remaining four studies involved parent-child dyads or family triads (n = 4), where the children's age range ranged approximately between 11 and 17 years old.

Parents who participated in the MABIs had children suffering from a range of physical and mental health problems, including chronic pain (Kanstrup et al., 2016; Wallace, Woodford, & Connelly, 2016; Wicksell et al., 2009), cancers and congenital heart disease (Burke et al., 2014; Rayner et al., 2016), diabetes and

asthma (Minor, Carlson, Mackenzie, Zernicke, & Jones, 2006), anorexia nervosa (Timko, Zucker, Herbert, Rodriguez, & Merwin, 2015), and anxiety disorders (Hancock et al., 2016). The health conditions of these children were chronic or difficult to be treated. For example, Burke et al. (2014) and Rayner et al. (2016) reported that the young children in their studies had been diagnosed with pediatric cancers (e.g., leukemia, solid tumors) or congenital heart disease for almost 44 months. Three studies showed that for those children who had chronic pain problems, the time since the diagnosis was confirmed could be up to three years (Kanstrup et al., 2016; Wallace et al., 2016; Wicksell et al., 2009). These children often reported with unsatisfactory effects in previous pain treatments (Kanstrup et al., 2016), and suffered from substantial pain-related functional impairments, such as sleep problems, missing age-appropriate activities, and school absences (Wallace et al., 2016; Wicksell et al., 2009). Furthermore, Timko et al. (2015) reported that approximately one-third of the children who suffered from anorexia nervosa needed hospitalization for medical stabilization prior to the ACT intervention.

In the included studies, parents were excluded from receiving MABIs if they experienced another major trauma two months prior to the child's diagnosis was confirmed (n = 1), or if their children had significant intellectual disabilities or cognitive impairment (n = 4), were at risk of suicide (n = 3) or needed palliative care due to their health problems (n = 1).

**Interventions.** Nearly all the included studies used ACT as their experimental conditions (n = 7), only one study used MBSR (Minor et al., 2006). Most of the MABIs were delivered in groups using face-to-face format (n = 7). Specifically, one study delivered group-based ACT via online video-conferencing to a sample of parents of children with cancers or congenital heart diseases in which

they might find difficult to attend the group therapy sessions regularly (Rayner et al., 2016). Of these eight studies that delivered MABIs to parents, half included children as their participants as well. Parents generally received an average of 7.8 sessions (SD = 5.8, range = 2.20) over an average of 15.8 weeks (SD = 14.6, range = 8.48). Only one study involved parents and their children together in every group therapy sessions (Hancock et al., 2016), while three studies delivered the interventions to the parent-child dyads separately in a parallel format and less than 30% of the MABI sessions were conjoint sessions (Kanstrup et al., 2016; Timko et al., 2015; Wicksell et al., 2009). Generally, each MABI session lasted for one to two hours (n = 7).

Where reported, the MABIs were delivered by trained health care professionals, such as psychologists or clinical psychologists (n = 5), physicians and social workers (n = 2). Three studies reported the strategies of monitoring the fidelity of intervention, for example, assessing the randomly-selected videotaped sessions for treatment adherence and competence using a validated checklist by a blinded evaluator (Hancock et al., 2016), regular meetings with therapists for reviewing videotaped sessions (Timko et al., 2015), and receiving supervisions by ACT experts (Kanstrup et al., 2016). The mean adherence rate of the intervention was 73.3 % (*SD* = 10.9, range = 58.3%-93.7%). Parental psychological flexibility, the process measure of ACT, was assessed in most of the included studies using ACT (n = 5) via the Acceptance and Action Questionnaire-II (AAQ-II) (Bond et al., 2011), the Parental Psychological Flexibility Questionnaire (Burke & Moore, 2015), and the Parent Psychological Flexibility Questionnaire for pediatric chronic pain (McCracken & Gauntlett-Gilbert, 2011), respectively.

**Comparisons.** Three studies compared the ACT condition with at least one control condition(s). Of these, one used 18 weekly sessions of individual-based ACT

as the comparison condition to test the efficacy of a group-based ACT (also 18 weekly sessions) in parents and their children with chronic pain (Kanstrup et al., 2016); while another compared ten weekly sessions of group-based ACT, with ten weekly sessions of group-based CBT, and with a waitlist control group which received the usual care in the study setting (Hancock et al., 2016). One study compared the efficacy of ACT with a multidisciplinary treatment program as the usual care provided by the hospital, which included an escalating dose of amitriptyline, physical training exercises and family-based counseling sessions to discuss the pain-related disability problems (Wicksell et al., 2009).

**Parent health outcomes.** Four studies assessed the effects of MABIs on the psychological health outcomes of parents (Burke et al., 2014; Kanstrup et al., 2016; Minor et al., 2006; Rayner et al., 2016). Parental psychological symptoms in terms of anxiety, depression, and stress were evaluated by three studies using the Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1986), the Depression Anxiety Stress Scales (DASS) (Lovibond & Lovibond, 1995a), and the Symptoms of Stress Inventory (SOSI) (Leckie & Thompson, 1979). Parental distress and parental psychological adjustment to the child's illness were measured by two studies using the Posttraumatic Stress Disorder Checklist-Civilian Version (PCL-C) (Weathers, Litz, Herman, Huska, & Keane, 1993), and the Parent Experience of Child Illness (PECI) (Bonner et al., 2006).

**Child health outcomes.** Three studies assessed the effects of MABIs on the psychological health of children (Hancock et al., 2016; Kanstrup et al., 2016; Wicksell et al., 2009). Depressive symptoms in children were assessed by two studies using the Center for Epidemiological Studies-Depression Scale for Children (CES-DC) (Faulstich, Carey, Ruggiero, Enyart, & Gresham, 1986), and the Child

Depression Inventory (CDI) (Saylor, Finch, Spirito, & Bennett, 1984). Anxiety symptoms in children were assessed by one study using the Multidimensional Anxiety Scale for Children (MASC) (March & Sullivan, 1999).

Three studies evaluated the effects of MABIs on the functioning of children with chronic pain by using a variety of measures (Kanstrup et al., 2016; Wallace et al., 2016; Wicksell et al., 2009), such as the Functional Disability Index (FDI) (Claar & Walker, 2006), the Pain Interference Index (PII) (Holmstrom, Kemani, Kanstrup, & Wicksell, 2015), and the Patient Reported Outcomes Measurement Information System (PROMIS) pain interference scale (Varni et al., 2010).

Three studies investigated the effects of MABIs on the physical health conditions of children who had been diagnosed with chronic pain and anorexia nervosa. Of these, two assessed the intensity of pain symptoms in children with chronic pain by using self-rating scales (Kanstrup et al., 2016; Wicksell et al., 2009). One assessed the child's eating disorder symptoms by conducting a formal Eating Disorder Examination (EDE) with trained assessors (Timko et al., 2015).

**Follow-up period and attrition.** Most of the included studies followed the participants for three to six months after the completion of intervention (n = 6), the mean attrition rate was 28.8% (SD = 18.8, range = 0%-62.5%). Reasons for attrition were mainly logistical or practical (n = 6), such as conflicts with family or work schedule to participate in the remaining therapy sessions or moved away. In the RCT conducted by Hancock et al. (2016), 16 out 62 parent-child dyads (26%) whose children had anxiety disorders and were randomly allocated to the waitlist-control group withdrew from the study during the 10-week waiting period, because they sought treatment elsewhere. In addition, in an open trial conducted by Timko et al. (2015), five out of 47 parent-child dyads (10.6%) whose children suffered from

anorexia nervosa withdrew for clinical reasons, such as requiring a higher level of care and immediate medical treatment during the 24-week intervention period.

## Table 2.1

## *Characteristics of included studies* (n = 8)

		Participant	ts' characteristics			MABI		Control	Health outcom	nes (Instruments)			Study quality <sup>a</sup>
Author (year) Setting(s), Country	Design, sample size (N),	Parents Age: M (SD) Mo: % of mothers	<u>Children</u> Dx: Diagnosis Age: M (SD) M: % of boys	Туре	Modality	hrs per session x no. of sessions, total contact hours over week(s) Ad: Adherence rate	Th: Therapist(s) FC: Fidelity assessment P: Process measures	Type(s), description	Parents	Children	Timing of measures	PR: participation rate AR: attrition rate	EPHPP global rating, POMRF score
Burke (2014)	1 group pre- post design	<b>Age:</b> ≥18 yrs. Details NR	<b>Dx:</b> 69% CHD, 31% cancers	ACT	Group- based	1.5hrsx5 = 7.5 hrs for parents over 8	<b>Th:</b> NR <b>FC:</b> NR <b>P:</b> PPF and	No control group	Distress (PCL-C) Adjustment (PECI)	Not measured	Baseline, post, 6mths post	<b>PR:</b> NR <b>AR:</b> 0/11 =	Weak, 10 out of 44
1 hospital, Australia	11 parents	Mo: NR	Age: 3.7 (2.3) M: 63.6			<b>Ad:</b> 7/11 = 63.6%	MAAS for parents				1	0%	
Hancock (2016)	3-arm RCT 193 parent-	<b>Age:</b> ≥18 yrs. Details NR	<b>Dx:</b> Anxiety disorders	ACT	Group- based	1.5hrsx10 = 10.5 hrs for parent-child dyads over 10	Th: 3 trained CPs FC: Yes P: AFQ-Y for	CBT (Group- based, 10.5 hrs)	Not measured	Anxiety symptoms (MASC)	Baseline, post, 3mths post	<b>PR:</b> 193/230 = 83.9%	Strong, 32 out of 44
1 hospital, Australia	child dyads (68 vs. 63 vs. 62)	Mo: NR	Age: 11.2 (2.8) M: 42%			weeks. <b>Ad:</b> 54/68 = 79.4%	children	WLC (10 weeks of usual care in study setting)				<b>AR:</b> 36/193 = 18.7%	
Kanstrup (2016)	2-arm RCT 48 parent-	<b>Age:</b> 47.3 (4.8)	<b>Dx:</b> Chronic pain <b>Age:</b> 16 (1.6)	ACT	Group- based	2hrsx18 = 36 hrs for children, 2hrsx4 = 8 hrs for parents over	<b>Th:</b> 5 trained psychologists, 2 pain physicians, 1	ACT (Individual- based, 45mins	Anxiety symptoms (HADS-A)	Depressive symptoms (CES- DC)	Baseline, mid-point, post	<b>PR:</b> NR <b>AR:</b> 20/48 =	Weak, 18 out of 44
l pain specialist clinic, Sweden	child dyads (24 vs. 24)	<b>Mo:</b> 86%	<b>M:</b> 20%			18 weeks. Ad: 18/24 =75%	physio. FC: NR P: PPFQ for parents, PIPS for children.	x18 sessions = 13.5 hrs for children, 1.5 hrs x4 sessions = 6 hrs for parents)	Depressive symptoms (HADS-D)	Functional disability (FDI) Pain interference (PII) Intensity of pain symptoms (6-point rating scale)		41.7%	
Minor (2006)	1 group pre- post design	Age: 31-35 (69.8%)	<b>Dx:</b> Mainly diabetes and asthma (% NR)	MBSR	Group- based	2hrsx8 = 16 hrs for parents over 8 weeks.	Th: 1 trained social worker and 1 trained family	No control group	Stress symptoms (SOSI)	Not measured	Baseline, post	<b>PR:</b> NR <b>AR:</b> 10-15%	Weak, 10 out of 44
1 hospital, United States	44 parents	<b>Mo:</b> 86.4%	<b>Age:</b> 3-6 (27.9%), 13-18 (39.5%)			<b>Ad:</b> 75%	physician FC: NR P: NR						
Rayner	1 group pre-	Age: 36-40	M: NR Dx: 66% CHD,	ACT	Group-	5 sessions over 8	Th: 4 trained	No control	Anxiety,	Not measured	Baseline,	PR: NR	Weak,
(2016)	f group pre- post design	Age: 56-40	33% cancers	AU I	based, online	weeks	psychologists FC: NR	group	depressive, stress	not measured	post, 6	<b>AR:</b> 4/12 =	Weak, 14 out of 44
1 hospital, Australia	12 parents	1 <b>v10:</b> 00.0%	Age: 2.6		video- conference	<b>Ad:</b> 7/12 = 58.3%	<b>PC:</b> NR <b>P:</b> PPFQ for parents		symptoms (DASS) Distress (PCL-C)		mths post	<b>AR:</b> 4/12 = 33.3%	44
			<b>M:</b> 50						Adjustment (PECI)				

Timko (2015)	1 group pre- post design	<b>Age:</b> ≥18 yrs. Details NR	Dx: Anorexia nervosa	ACT	Individual- based	1.5 hrsx16 + 1hr x4 = 28 hrs for family triads over 24 weeks	Th: 3 trained CPs FC: NR P: AAQ-II for	No control group	Not measured	Anorectic symptoms (EDE) Body weight (BMI	Baseline, post, 3 mths post	<b>PR:</b> 47/87 = 54.0%	Weak, 21 out of 44
1 academic center and 1 research clinic, United States	47 family triads (both parents and child)	Both father and mother participated in the study	Age: 14.0 (1.6) M: 12.8			<b>Ad:</b> 31/47 = 66%	parents, AFQ-Y for children			percentile)		<b>AR:</b> 16/47 = 34.0%	
Wallace (2016)	1 group pre- post design	<b>Age:</b> ≥18 yrs. Details NR	<b>Dx:</b> Chronic pain <b>Age:</b> 17 (median)	ACT	Group- based	75 minsx8 = 10 hrs for parents over 8 weeks	Th: NR FC: NR P: PPF for parents	No control group	Not measured	Pain interference (PROMIS pain interference)	Baseline, weekly assessment	<b>PR:</b> 8/21 = 38.1%	Weak, 11 out of 44
1 pain specialist clinic, United States	8 parents	<b>Mo:</b> 100%	<b>M:</b> 37.5			<b>Ad:</b> 6/8 = 75%					s, post, 2	<b>AR:</b> 5/8 = 62.5%	
Wicksell (2009)	2-arm RCT 32 parent-	<b>Age:</b> ≥18 yrs. Details NR	<b>Dx:</b> Chronic pain <b>Age:</b> 14.8 (2.4)	ACT	Individual- based	1hrx10 = 10 hrs for children, 1.5 hrsx1-2 = 1.5-3 hrs for	Th: 2 trained psychologists FC: NR	TAU (individual- based MDT +	Not measured	Depressive symptoms (CES- DC)	Baseline, 3.5 mths and 6.8	<b>PR:</b> 32/34= 94.1%	Strong, 21 out of 44
1 hospital, Sweden	child dyads (16 vs. 16)	Mo: NR	M: 21.9			parents over 4 mths	<b>P:</b> NR	amitriptyline, mean contact		Functional disability (FDI)	mths post	<b>AR:</b> 8/32 = 25%	
			d Action Quarti			Ad: 15/16 = 93.7%		hrs = 22.8 hrs)		Pain interference (10-point rating scale) Intensity of pain symptoms (10- point rating scale			

*Note.* AAQ-II = Acceptance and Action Questionnaire-II; ACT = Acceptance and Commitment Therapy; AFQ-Y = Avoidance & Fusion Questionnaire-Youth; BMI = Body Mass Index; CBT = Cognitive Behavioral Therapy; CED-DC = Center for Epidemiological Studies Depression Scale-Children; CHD = congenital heart disease; CP = clinical psychologist; DASS = Depression Anxiety Stress Scale; EDE = Eating Disorder Examination; EPHPP = Effective Public Health Practice Project; FDI = Functional Disability Index; HADS = Hospital Anxiety and Depression Scale; hrs = hours; MAAS = Mindfulness Attention Awareness Scale; MABIs= mindfulness- and acceptance-based interventions; MASC = Multidimensional Anxiety Scale for children; MBSR = mindfulness-based stress reduction; MDT = Multi-disciplinary treatment; mths = months; N = number of samples, NR = not reported; PCL-C = PTSD Checklist-Civilian Version; PECI = Parent Experience of Child Illness; PII = Pain Interference Index; POMRF = Psychotherapy outcome study methodology rating form; PPFQ = Parental Psychological Flexibility Questionnaire; PROMIS pain interference = Patient-Reported Outcomes Measurement Information System pain interference; SD = standard deviation; SOSI = Symptoms of Stress Inventory; yrs = years.

<sup>a</sup>For the details of the methodological quality ratings, please refer to Table 2.2 and Table 2.3.

#### 2.5.3. Risk of bias within studies and across studies

The results of risk of bias assessments of each included study using the Quality Assessment Tool by the EPHPP and the POMRF are shown in Table 2.2 and Table 2.3, respectively. Only two studies were rated as strong quality via the EPHPP assessment tool (Hancock et al., 2016; Wicksell et al., 2009), the remaining six studies were rated as weak quality. One common reason that these studies did not receive a strong overall quality was selection bias (n = 6) (*Note*. According to the EPHPP, selection bias refers to the sample not being representative to the target population). In these studies, participants were either referred from different sources (e.g., clinics, hospitals and schools), clinicians' or psychologists' referrals, or selfreferrals, rather than being randomly selected from a list of individuals of the target population. In addition, the participation rates of these studies were either not reported (Burke et al., 2014; Kanstrup et al., 2016; Minor et al., 2006; Rayner et al., 2016), or less than 60% (Timko et al., 2015; Wallace et al., 2016) (see Table 2.1 for the details of the participation rates). Due to the nature of psychotherapeutic interventions in all types of MABIs, it was impossible to blind therapists or participants. Still, lack of blinding of data collectors and/or outcome assessors were common across studies (n = 6). Nevertheless, all included studies used valid and reliable assessment tools, and the majority reported the follow-up rate of over 60% (n = 7) (see Table 2.1 for the details of the attrition rates).

Study quality rated via the POMRF was also generally low (M = 17.1 out of 44, SD = 7.6, range: 10-32). Nearly two-thirds of the POMRF items (i.e., 13 out of 22 items) were rated from "poor" to "fair", (i.e., the mean score per each POMRF item was <1, out of 2), highlighting that some methodological limitations were common across studies. In particular, almost all the studies did not report: (1) a priori

power calculation (n = 7), (2) assessments of treatment fidelity (n = 7), in terms of the quality checks of the therapists' adherence to the treatment protocol and competence to deliver the intervention, as well as (3) strategies regarding the control of potential concomitant treatments during the course of the study (e.g., medications or other psychotherapies) (n = 7). For the two included RCTs in a non-waitlist control group design (Kanstrup et al., 2016; Wicksell et al., 2009), the control conditions were markedly unequal, in terms of the total number of contact hours, when compared with the experimental conditions (see Table 2.1 for the details of the characteristics of these studies). Consideration of clinical significance was only presented in two studies, which assessed whether ACT in parent-child dyads could effectively lead to remissions in children who had been diagnosed with anxiety disorders (Hancock et al., 2016), and anorexia nervosa (Timko et al., 2015).

On the other hand, almost one-third of the POMRF items (i.e., 6 out of 22 items) attained the average ratings between "fair" and "good" (i.e., the mean score per each POMRF item was >1, out of 2), indicating that there were a few consistent strengths across studies. For instance, many included studies adopted specific outcome measures with good psychometric properties (n = 8), presented with detailed statistical analyses and data (n = 8), and used practicing therapists who were well-trained with ACT as the interventionists of the study (n = 5). In addition, the included studies generally provided fair to good descriptions of the MABIs which were specifically designed for parents or parent-child dyads to manage the child's health problems (n = 8).

## Table 2.2

## Methodological quality of the included studies as assessed by the EPPHP Quality Assessment Tool (n = 8)

	Effective	Public Health Practice I	Project (EPPHP) Quality	Assessment Tool				Risk	ts of bias			
Cor rati	nponents and ngs	Strong	Moderate	Weak	Burke (2014)	Hancock (2016)	Kanstrup (2016)	Minor (2006)	Rayner (2016)	Timko (2015)	Wallace (2016)	Wicksell (2009)
1.	Selection bias	Very likely to be representative of the target population and greater than 80% participation rate	Somewhat likely to be representative of the target population and 60–79% participation rate	All other responses or not stated	Weak	Moderate	Weak	Weak	Weak	Weak	Weak	Moderate
2.	Design	RCT and CCT	Cohort analytic, case-control, cohort (one group pre + post (before and after) or an interrupted time series	All other designs or design not stated	Moderate	Strong	Strong	Moderate	Moderate	Moderate	Moderate	Strong
3.	Confounders	Controlled for at least 80% of confounders	Controlled for 60%– 79% of confounders	Confounders not controlled for, or not stated	Weak	Strong	Strong	Weak	Weak	Strong	Weak	Strong
4.	Blinding	Blinding of outcome assessor and study participants to intervention status and/or research question	Blinding of either outcome assessor or study participants	Outcome assessor and study participants are aware of intervention status and/or research question	Weak	Moderate	Weak	Weak	Weak	Weak	Weak	Moderate
5.	Data collection methods	Tools are valid and reliable	Tools are valid, but reliability not described	No evidence of validity or reliability	Strong	Strong	Strong	Strong	Strong	Strong	Strong	Strong
6.	Withdrawals and dropouts	Follow-up rate of >80% of participants	Follow-up rate of 60%–79% of participants	Follow-up rate of <60% of participants or withdrawals and dropouts not described	Strong	Strong	Moderate	Strong	Moderate	Moderate	Weak	Moderate
				Global quality rating <sup>a</sup>	Weak	Strong	Weak	Weak	Weak	Weak	Weak	Strong

Note. CCT = controlled clinical trial; EPPHP = Effective Public Health Practice Project; n = number of studies; RCT = randomized controlled trial.

<sup>a</sup>Global quality rating of each included study was determined by the ratings of the following six domains in the Effective Public Health Practice Project (EPPHP) Quality Assessment Tool: (1) selection bias, (2) study design, (3) confounders, (4) blinding, (5) data collection methods, (6) and withdrawals and drop-outs. Studies were considered as "strong" quality if they received no "weak" ratings on any of these domains; "moderate" quality if they received one "weak" rating, and "weak" quality if they received two or more "weak" rating.

## Table 2.3

## Methodological quality of the included studies as assessed by the POMRF (n = 8)

	Burke	Hancock	Kanstrup	Minor	Rayner	Timko	Wallace	Wicksell	Mean score per each
	(2014)	(2016)	(2016)	(2006)	(2016)	(2015)	(2016)	(2009)	POMRF item (out of 2)
Clarity of sample description	1	1	2	1	2	1	1	1	1.25
Severity/ chronicity of the disorder	1	1	2	0	1	2	2	2	1.375
Representativeness of the sample	1	1	1	1	1	1	1	1	1
Reliability of the diagnosis in question	na	1	na	na	na	1	na	na	1
(Note: for studies which included parents of children with mental									
health problems only)									
Specificity of outcome measures	1	2	2	1	1	2	1	2	1.5
Reliability and validity of outcome measures	2	2	2	2	2	2	2	2	2
Use of blind evaluators	0	2	0	0	0	0	0	1	0.375
Assessor training	0	2	0	0	0	1	0	1	0.5
Assignment to treatment	0	2	1	0	0	0	0	1	0.5
Design	0	2	2	0	0	0	0	1	0.625
Power analysis	0	1	0	0	0	0	0	0	0.125
Assessment points	1	1	0	0	1	1	1	1	0.75
Manualized, replicable, specific treatment programs	1	2 <sup>a</sup>	1	1	1	2 <sup>b</sup>	1	2 <sup>c</sup>	1.375
Number of therapists	0	1	1	1	1	2	0	1	0.875
Therapist training/ experience	0	2	2	1	2	2	0	2	1.375
Checks for treatment adherence	0	1	0	0	0	0	0	0	0.125
Checks for therapist competence	0	1	0	0	0	0	0	0	0.125
Control of concomitant treatments	0	1	0	0	0	0	0	0	0.125
Handling of attrition	0	2	0	0	0	1	0	1	0.5
Statistical analyses and presentation of results	2	2	2	2	2	2	2	2	2
Clinical significance	0	2	0	0	0	1	0	0	0.375
Equality of therapy hours	na	na	0	na	na	na	na	0	0
( <i>Note</i> : for studies in non-waitlist control designs only)									
Total POMRF score (out of 44) <sup>d</sup>	10	32	18	10	14	21	11	21	17.1, SD = 7.6

*Note. n* = number of studies; na = not applicable; POMRF = Psychotherapy Outcome Study Methodology Rating Form; SD = standard deviation

"This item was rated that based on its study protocol (Swain, Hancock, Dixon, Koo, & Bowman, 2013).

<sup>b</sup>This item was rated that based on its case study (Merwin et al., 2013).

"This item was rated that based on its pilot studies (Wicksell, Dahl, Magnusson, & Olsson, 2005; Wicksell et al., 2007).

<sup>d</sup>Total POMRF score of each included study was the sum of the scores of 22 items in the Psychotherapy Outcome Study Methodology Rating Form (POMRF). Each item scored 0 as poor, 1 as fair, or 2 as good, producing a total score ranging from 0 to 22. Higher scores indicate better methodological quality.

#### **2.5.4.** Intervention efficacy on parental health outcomes

The effect sizes across studies delivered MABIs to parents or parent-child dyads for improving the psychological health of parents, in terms of their psychological symptoms (i.e., symptoms of anxiety, depression and stress), psychological distress and psychological adjustment to the child's illness, are shown in Table 2.4.

#### **Psychological health**

Three weak-quality studies examined the efficacy of MABIs on the psychological symptoms of parents with children who had been diagnosed with the following CHCs, including chronic pain (Kanstrup et al., 2016), congenital heart disease and cancers (Rayner et al., 2016), asthma and diabetes (Minor et al., 2006). Of these, two adopted an ACT intervention (Kanstrup et al., 2016; Rayner et al., 2016) and one used MBSR (Minor et al., 2006). In particular, in a trial conducted by Kanstrup et al. (2016), an ACT-based parental support program (i.e., four sessions for parents, together with 18 sessions for children over 18 weeks) was compared with that of in an individual format, there were no significant between-group differences in any of the parental outcomes (Kanstrup et al., 2016). If concerned the within-group subject effects, similar to Rayner et al. (2016) which also used ACT, both studies yielded non-significant reductions of symptoms of anxiety, depression and stress in parents at post-intervention (d = 0.06) and at follow-up (d = 0.24-0.25) (Kanstrup et al., 2016; Rayner et al., 2016). On the other hand, Minor et al. (2006) evaluated an 8-week of group-based MBSR program. After the program participation, parents reported significantly less stress symptoms with large effect size (d = 0.76) when compared with the baseline.

Two weak-quality studies evaluated ACT on the psychological distress and the psychological adjustment to child's illness among parents of children suffering from congenital heart disease who had life-saving cardiac surgery and cancers (Burke et al., 2014; Rayner et al., 2016). Both studies delivered four weekly sessions of ACT and a fifth delivered one month later in groups but with different modalities, one using face-to-face format (Burke et al., 2014), and another adopted an online video-conferencing approach (Rayner et al., 2016). Following the intervention, the significant improvements of parental psychological distress and psychological adjustment were only found in the study that delivered group-based ACT via a faceto-face format (Burke et al., 2014), with a large effect size (d = 0.92-1.17). At six months post-intervention, the improvements shown in both studies became apparent with medium-to-large effect sizes when compared with the baseline (d = 0.65-1.96) (Burke et al., 2014; Rayner et al., 2016).

## Table 2.4

Effect sizes across studies of mindfulness- and acceptance-based interventions for improving the psychological health outcomes of parents (n = 1)

4)

					Within-group e	effect sizes (d)	Between gro	oup effect sizes (d)
Types of domain	Outcomes	Author (Year)	Types of MABIs	Types of CHCs	Improvement at post vs. pre-test	Improvement at FU vs. pre-test	Improvement at post vs. active control	Improvement at FU vs. active control
Parent	Anxiety	Kanstrup (2016)	ACT	Chronic pain	n.s.		n.s.	
psychological health	symptoms	Rayner (2016)		CHD, cancers	0.06	0.24		
	Depressive	Kanstrup (2016)	ACT	Chronic pain	n.s.		n.s.	
	symptoms	Rayner (2016)		CHD, cancers	0.06	0.25		
	Stress	Minor (2006)	MBSR	Diabetes, asthma	0.76ª			
	symptoms	Rayner (2016)	ACT	CHD, cancers	0.06	0.22		
	Psychological	Burke (2014)	ACT	CHD, cancers	0.92	1.72ª		
	distress	Rayner (2016)			0.23	0.90		
	Psychological	Burke (2014)	ACT	CHD, cancers	1.17 <sup>b</sup>	1.96 <sup>a,b</sup>		
	adjustment	Rayner (2016)			0.16 <sup>b</sup>	0.65 <sup>b</sup>		

*Note.* d = Cohen's d; ACT = Acceptance and Commitment Therapy; CHCs = Chronic health conditions; CHD = congenital heart disease; FU = follow-up; MABIs = mindfulness- and acceptance-based interventions; MBSR = Mindfulness-based Stress Reduction; n = number of studies; n.s = non-significant

<sup>a</sup>Effect size in terms of Cohen's *d* was not reported, hence the effect size was calculated by using the descriptive data reported in the publication. <sup>b</sup>This effect size was the average of the effect sizes measured by all the four subscales of Parent Experience of Child Illness (Bonner et al., 2006).

#### 2.5.5. Intervention efficacy on child health outcomes

The effect sizes across studies delivering MABIs to parents or parent-child dyads for improving the psychological health, functioning and physical health conditions of children are shown in Table 2.5. The health outcomes being assessed by the included studies were psychological symptoms (i.e., symptoms of anxiety and depression), functioning outcomes in terms of functional disability and pain interference, as well as other illness-specific physical health conditions, including the intensity of pain symptoms, anorectic symptoms and body mass index percentile.

## **Psychological health**

Three studies evaluated ACT for improving the psychological health of children diagnosed with anxiety disorders (Hancock et al., 2016), and chronic pain (Kanstrup et al., 2016; Wicksell et al., 2009). Of these, two were strong-quality RCTs and demonstrated significant reductions in the child's anxiety symptoms and depressive symptoms with medium-to-large effect sizes at post-intervention (d = 0.53-0.74) and at follow-up (d = 0.78-0.94), when compared with the baseline (Hancock et al., 2016; Wicksell et al., 2009). Such significant reductions were also observed when ACT was compared with treatment-as-usual at post-intervention (d = 0.53-0.64) (Hancock et al., 2016; Wicksell et al., 2009). Wicksell et al. (2009) further demonstrated that the intervention effect on the child's depressive symptoms in favor of ACT maintained at follow-up (d = 0.54). However, as indicated by Hancock et al. (2016), no statistically significant differences in the child's anxiety symptoms and depressive symptoms over time were found when comparing ACT and CBT, with small effect sizes (d = 0.23-0.37).

#### Functioning

Three studies assessed the effects of ACT for improving the functional disability (Kanstrup et al., 2016; Wicksell et al., 2009), and the pain-related interference of children with chronic pain problems (Kanstrup et al., 2016; Wallace et al., 2016; Wicksell et al., 2009). Of these, two were weak-quality studies (Kanstrup et al., 2016; Wallace et al., 2016). For these two outcomes, all these three studies produced medium-to-large effect sizes at post-intervention (r = 0.35-0.51, d = 0.53-1.01) and at follow-up (d = 0.49-1.46) when compared with the baseline. Only one strong-quality RCT showed that ACT outweighed treatment-as-usual at post-intervention (d = 0.71) and at follow-up (d = 0.47-0.53) with medium effect sizes (Wicksell et al., 2009).

#### **Physical health conditions**

Three studies evaluated whether ACT could improve disease management in children suffering from chronic pain (Kanstrup et al., 2016; Wicksell et al., 2009), or anorexia nervosa (Timko et al., 2015). Of these, two were weak-quality studies (Kanstrup et al., 2016; Timko et al., 2015). With one exception (Kanstrup et al., 2016), two trials observed significant and large improvements in the child's physical health conditions, such as reduction in pain intensity (d = 1.58) (Wicksell et al., 2009), reduction in eating disorder symptoms (d = 0.78) and improvement in body mass index (d = 1.83) at post-intervention when compared to the baseline (Timko et al., 2015). In Wicksell et al. (2009), when compared with treatment-as-usual, which was a multidisciplinary treatment, the reduction in pain intensity maintained at post-intervention (d = 0.54) and at follow-up (d = 0.55).

## Table 2.5

Effect sizes across studies of n	nindfulness- and accept	ance-based interventions	for improving	the health outcomes of	of children $(n = 4)$

					Within group e	effect sizes (d)		Between group	p effect sizes (d)	
Types of domain	Outcomes	Author (Year)	Types of MABIs	Types of CHCs	Improvement at post vs. pre- test	Improvement at FU vs. pre- test	Improvement at post vs. TAU	Improvement at FU vs. TAU	Improvement at post vs. active control	Improvement at FU vs. active control
Child psychological	Anxiety symptoms	Hancock (2016)	ACT	Anxiety disorders	0.53	0.94 <sup>a</sup>	0.53 <sup>a</sup>		-0.37 <sup>a</sup>	-0.23 <sup>a</sup>
health	Depressive symptoms	Kanstrup (2016) Wicksell (2009)	ACT	Chronic pain	$0.37^{\rm b}$ $0.74^{\rm a}$	 0.78ª	 0.64ª	 0.54ª		
Child functioning	Functional disability	Kanstrup (2016) Wicksell (2009)	ACT	Chronic pain	0.35 <sup>b</sup> 0.53 <sup>a</sup>	 0.87ª	 0.18ª	 0.47 <sup>a</sup>		
	Pain-related interference	Kanstrup (2016) Wallace (2016) Wicksell (2009)	ACT	Chronic pain	0.51 <sup>b</sup> 0.62 <sup>a</sup> 1.01 <sup>a</sup>	 0.49 <sup>a</sup> 1.46 <sup>a</sup>	  0.71ª	  0.53ª	 	 
Child physical health conditions	Intensity of pain symptoms	Kanstrup (2016) Wicksell (2009)	ACT	Chronic pain	0.13 <sup>b</sup> 1.58 <sup>a</sup>	 1.58ª	 0.54ª	 0.55ª		
	Anorectic symptoms BMI percentile	Timko (2016) Timko (2016)	ACT	Anorexia nervosa	0.78 1.83 <sup>a</sup>					

*Note.* d = Cohen's d; ACT = Acceptance and Commitment Therapy, BMI = body mass index; CHCs = Chronic health conditions; FU = follow-up; MABIs = mindfulness- and acceptance-based interventions; n.s = non-significant; TAU = treatment-as-usual

<sup>a</sup>Effect size in terms of Cohen's *d* was not reported, hence the effect size was calculated by using the descriptive data reported in the publication.

<sup>b</sup>Correlation coefficient effect size was reported. 0.10 indicate a small effect, above 0.30 a medium effect and above 0.50 a large effect (Cohen, 1988).

#### 2.6. Discussion

#### 2.6.1. Summary of evidence

This systematic review identified a total of eight studies, including three RCTs and five studies in single-group pretest-posttest design, which delivered MABIs to parents or parent-child dyads, aiming at improving the health outcomes of parents and their children with physical or mental health problems. A total of 395 families were included, of which 47 were family triads (both parents and child), 273 were parent-child dyads and 75 were parents only. This review found that almost all studies used ACT, and ACT is the only type of MABI which has been applied across a variety of pediatric conditions, including chronic pain, cancers and congenital heart diseases, anorexia nervosa, and anxiety disorders. In most situations, ACT is delivered by trained health care professionals in small groups using face-to-face format, to parents who are mainly mothers.

The findings of this review support the preliminary efficacy of ACT for improving the health outcomes of parents and children who suffered from various chronic health problems. When compared with baseline, the effect sizes of ACT for psychological distress and psychological adjustment to the child's illness in parents of children with congenital heart disease and cancers at post-intervention were medium-to-large (Burke et al., 2014; Rayner et al., 2016). Similarly, ACT produced medium-to-large within-group effect sizes in many other child's health outcomes, such as: (1) anxiety symptoms of children with anxiety disorders (Hancock et al., 2016); (2) depressive symptoms, functional difficulties and intensity of pain symptoms of children with chronic pain (Kanstrup et al., 2016; Wallace et al., 2016; Wicksell et al., 2009); as well as (3) anorectic symptoms and abnormal body weight of children with anorexia nervosa (Timko et al., 2015). In these parental and child

outcomes, the improvements could be maintained from post-intervention up to six months post-intervention. In addition, ACT was found to be significantly more efficacious than usual care for reducing the anxiety symptoms, depressive symptoms, pain-related interference and pain symptoms of children at post-intervention till six months post-intervention, with medium effect size (Hancock et al., 2016; Wicksell et al., 2009). However, ACT showed no additional benefits on the anxiety and depressive symptoms of parents (Kanstrup et al., 2016), as well as the child's anxiety symptoms (Hancock et al., 2016), when compared with active control.

Previous reviews have indicated the efficacy of MABIs in parents of children with neurodevelopmental disorders, such as autism, acquired brain injuries, cerebral palsy and disabilities (Cachia et al., 2016; Graham et al., 2016; Rayan & Ahmad, 2017; Whittingham, 2014; Wicksell et al., 2015). This present review extends the current understanding of the utility of MABIs in pediatric care, showing that one type of MABIs, ACT, has its potential to improve the health outcomes of parents, as well as their children with a range of physical and mental health problems. This is generally consistent with other meta-analyses of ACT in adults populations (A-Tijak et al., 2015; Öst, 2014; Powers, Vording, & Emmelkamp, 2009), and adults with long-term physical health conditions (Graham et al., 2016). It is bear noting that most of the included studies using ACT were published in 2015 or after (i.e., one year before the systematic search for eligible studies was started in 2016), suggesting a proliferation of ACT-related research for parents in recent years.

#### 2.6.2. Quality of the evidence

Caution is warranted because the evidence of this review is predominantly based on a small number of studies using single group pretest-posttest design with small sample size and poor in methodological quality, such as high risks of selection

bias and detection bias. In addition, the priori power calculation, the fidelity assessments of the interventions, and the strategies to control the potential concomitant treatments throughout the study were inadequately reported. Assessment of publication bias, such as using funnel plots for each outcome, could not be conducted due to a limited number of RCTs. Overall, due to the small number of studies and most of them had methodological limitations, we considered the body of evidence regarding the intervention efficacy as too weak to make any robust conclusions. By comparing the average POMRF rating in this review (M = 17.1), relative to those shown in other ACT-related reviews of experimental or quasiexperimental studies for adults with anxiety disorders (M = 17.29) (Swain, Hancock, Hainsworth, et al., 2013), and long-term conditions (M = 19.33) (Graham et al., 2016), the ratings are relatively close. This suggests that the poor methodological quality of the included studies involving parent samples is also notable in those studies concerning adult populations.

#### 2.6.3. Limitations of the review

Despite the electronic search was large in scale, covered the major databases in the field of psychotherapy and did not set any restrictions about the types of pediatric physical or mental health problems, only eight studies could be identified. There could be a chance that the missing non-English articles could be added and create conflicting evidence, but this chance would be minimal because the empirical studies that had been reviewed by most of the MABIs-related reviews were published in English (e.g., A-Tijak et al., 2015; Graham et al., 2016). Evidence regarding the effects of MABIs on the health outcomes of parent-child dyads remains very limited to a few of pediatric CHCs as identified in this review, the nature of the comparison group (i.e., mainly usual care as the control condition, such

as the health care services provided by the study settings), and a small number of studies (i.e., equal or less than three studies per each outcome) with methodological flaws, including selection bias and detection bias. Further, with such a limited number of RCTs, we were unable to perform meta-analysis by integrating the results from individual studies for a more precise estimation of the effect of MABIs. The inadequate number of studies and the large variations across studies (e.g., types of CHCs, instruments and outcomes) again restricted us to conduct subgroup analyses to assess the heterogeneity of the intervention effects in subgroups of participants, for example, among different types of MABIs (e.g., comparison between ACT and MBSR), different modalities of delivering MABIs (e.g., comparison between group therapy and individual therapy), or different types of recipients of the MABIs (e.g., comparison between parents and parent-child dyads). Hence, we were unable to address whether the effects of MABIs in these subgroup populations could be differed from the findings as shown in this review.

#### 2.6.4. Implications for future research

Mindfulness- and acceptance-based interventions (MABIs), especially ACT, appear promising on improving the health outcomes of parents and their children with physical or mental health problems. However, with such a low number of studies being identified, this review makes clear the limited research in this area. The potential health benefits of MABIs on child's health outcomes as shown in this review are only based on studies examining the intervention effects in parents and their children, who reached the age of adolescence (Hancock et al., 2016; Kanstrup et al., 2016; Timko et al., 2015; Wicksell et al., 2009). The efficacy of MABIs in parents for improving the health outcomes of their children with physical or mental health problems, particular among those parents whose children were young in age

(e.g., less than 12 years old) remains largely unknown. Further, despite an extensive search for peer-reviewed publications, we found only one study, showing that an 8-week sessions of MBSR program could significantly reduce the stress symptoms of parents of children with asthma at post-intervention, but its effects on the child's asthma-related health outcomes were not assessed (Minor et al., 2006). Evidence regarding the efficacy of MABIs on the health outcomes of parents and their children with asthma is extremely scarce. To the best of our knowledge, no studies have examined the efficacy of ACT in parents of children with asthma.

Nevertheless, this review clearly indicated that ACT, as a psychotherapy, has extended its application from parents of children with mental health problems, to those who had children suffering from a variety of physical health problems, such as chronic pain, anorexia nervosa, congenital heart disease and cancers, with positive health outcomes. Indeed, ACT is a trans-diagnostic intervention, aiming at addressing an individual's psychological difficulties that underpins a broad array of maladaptive behaviors and facilitate behavioral changes, rather than treating any single mental or physical health problem (Newby, McKinnon, Kuyken, Gilbody, & Dalgleish, 2015). The broad applicability of ACT in parents and their children with a range of physical and mental health problems reflects the flexibility of the ACT model. More importantly, the favorable health outcomes of parents-child dyads as shown in this review imply the potential health benefits of ACT in parents and their children with other types of physical or mental health problems.

There is an urgent need for RCTs to further establish the efficacy of ACT (and other types of MABIs) in parents of children with CHCs. Future RCTs should adhere to the current standards of methodology and reporting following the Consolidation Standards of Reporting Trials (CONSORT) statement, to minimize the

risks of bias as noted previously. Researchers shall provide sufficient information regarding the quality control of MABIs, such as the assessments of the adherence and competence of the therapists in delivering the interventions. Besides comparing with the usual care, there is a need to extend our understanding regarding the effects of MABIs compared with other alternative treatments, such as cognitive behavioral therapies or other active treatments available in the study settings, which had been addressed only one trial (Hancock et al., 2016).

#### 2.7. Summary

This chapter reports a systematic review of experimental and quasiexperimental studies evaluating the efficacy of mindfulness- and acceptance-based interventions (MABIs), including Acceptance and Commitment Therapy (ACT), Mindfulness-based Cognitive Therapy (MBCT) and Mindfulness-based Stress Reduction (MBSR), on the health outcomes of parents and their children with physical or mental health problems. Studies were searched from inception to December 2016 in six electronic databases: The Cochrane Central Register of Controlled Trials, MEDLINE, EMBASE, CINAHL PsycINFO and SCOPUS. Effect sizes regarding the intervention effects on the outcomes related to parental psychological health, child's psychological health, child's functioning and child's physical health conditions were extracted or calculated if they were not reported. Methodological quality of the selected studies was assessed.

Eight studies, of which three were RCTs and five were studies in singlegroup pretest-posttest design, were identified, with a total of 395 participants. This review found that almost all studies used ACT and applied ACT across a variety of pediatric conditions, including chronic pain, cancers and congenital heart diseases, anorexia nervosa, and anxiety disorders. Generally, evidence of this review indicates

that there is a preliminary efficacy of ACT for improving the psychological distress and adjustment of parents in taking care of their children with chronic health conditions. ACT could also improve the anxiety and depressive symptoms of children with anxiety disorders or chronic pain, the functional disability and the pain symptoms of children with chronic pain, as well as the anorectic symptoms and the body mass index percentile of children suffered from anorexia nervosa. The withingroup effects of all these parental and child health outcomes ranged from medium to large. When compared with treatment-as-usual, children whose parents were involved in the ACT intervention achieved better health outcomes with medium effect sizes, in which the effects could be maintained up to six months after the intervention.

Evidence of this review highlights the broad applicability of ACT and the favorable health outcomes as brought by ACT. However, evidence regarding the health benefits of MABIs (including ACT) in parents and children with physical or mental health problems is limited in quantity and quality, precluding us from drawing any conclusions for the direct application of MABIs in clinical areas. Further, no studies have examined whether delivering MABIs to parents would bring benefits to improve the health outcomes of their young children suffering from physical or mental health problems, such as childhood asthma. Apparently, the findings of this review further support the implementation of a new RCT as proposed in Chapter One: A RCT to determine whether a parental training program integrating ACT with asthma education would be more promising than asthma education alone for improving the health outcomes of young children with asthma, as well as their parents. The study methods of this RCT will be presented in detail in Chapter Three.

## Appendix 2.1. Search strategies for identifying eligible studies in each database

# **Cochrane Central Register of Controlled Trials (CENTRAL), 1968 to January 2016**

'(acceptance and commitment) or (acceptance-based) or (acceptance and commitment therapy) or (mindfulness-based stress reduction) or (mindfulness-based cognitive therapy) or (mindfulness-based) in Title, Abstract, Keywords and (child\* or infant\* or adolesc\* or baby or babies or toddler\* or teen\* or youth\* or pediatric\* or preschool\*) in Title, Abstract, Keywords and (parent\* or father\* or mother\* or famil\* or paternal or maternal) in Title, Abstract, Keywords , Publication Year from 1966 to 2016 in Trials'

Note. 58 records were identified

## MEDLINE via Ovid, 1946 to December week 4 2016

- 1. (acceptance and commitment).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (acceptance based or acceptance-based).mp.
- 2. (acceptance and commitment therapy).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
- 3. acceptance-based.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
- 4. exp Mindfulness/ or mindfulness-based.mp.
- 5. mindfulness-based stress reduction.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
- 6. mindfulness-based cognitive therapy.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
- 7. 1 or 2 or 3 or 4 or 5 or 6
- 8. exp PARENTS/ or parents.mp.
- 9. fathers.mp. or exp FATHERS/
- 10. mothers.mp. or exp MOTHERS/
- 11. families.mp. or exp Family/
- 12. (parent\* or father\* or mother\* or famil\* or paternal or maternal).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
- 13. 8 or 9 or 10 or 11 or 12
- 14. child\*.mp. or exp CHILD, PRESCHOOL/ or exp CHILD/
- 15. exp Adolescent/ or adolescen\*.mp.
- 16. exp INFANT/ or infant\*.mp.

- 17. (child\* or infant\* or adolesc\* or baby or babies or toddler\* or teen\* or youth\* or pediatric\* or preschool\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
- 18. 14 or 15 or 16 or 17
- 19.7 and 13 and 18
- 20. limit 19 to (english language and yr="1860 2016")
- 21. limit 20 to journal article
- 22. limit 21 to ("therapy (maximizes sensitivity)" or "therapy (maximizes specificity)" or "therapy (best balance of sensitivity and specificity)")

Note. 62 records were identified

## EMBASE via Elsevier, 1966 to December week 4 2016

(('acceptance':ti,ab,kw AND 'commitment therapy':ti,ab,kw OR 'acceptance':ti,ab,kw) AND 'commitment':ti,ab,kw OR 'acceptance-based':ti,ab,kw OR 'mindfulness based stress reduction':ti,ab,kw OR 'mindfulness based cognitive therapy':ti,ab,kw OR 'mindfulness based intervention':ti,ab,kw OR 'mindfulness based therapy':ti,ab,kw) AND ('child\*':ti,ab,kw OR 'infant\*':ti,ab,kw OR 'adolesc\*':ti,ab,kw OR 'baby':ti,ab,kw OR 'babies':ti,ab,kw OR 'toddler\*':ti,ab,kw OR 'teenager\*':ti,ab,kw OR 'youth\*':ti,ab,kw OR 'pediatric\*':ti,ab,kw OR 'preschool\*':ti,ab,kw) AND ('parent\*':ti,ab,kw OR 'father\*':ti,ab,kw OR 'mother\*':ti,ab,kw OR 'famil\*':ti,ab,kw OR 'paternal':ti,ab,kw OR 'maternal':ti,ab,kw) AND [1966-2016]/py AND 'article'/it

Note. 74 records were identified

## CINAHL via EBSCOHost, 1966 to December week 4 2016

AB ( ( acceptance AND commitment ) OR ( acceptance-based ) OR (acceptance and commitment therapy) OR ( mindfulness-based stress reduction ) OR ( mindfulness-based cognitive therapy) OR (mindfulness-based) ) AND AB ( child\* or infant\* or adolesc\* or baby or babies or toddler\* or teen\* or youth\* or pediatric\* or preschool\* ) AND AB ( parent\* or father\* or mother\* or famil\* or paternal or maternal )

Limiters - Published Date: 19660101-20161231; English Language; Peer Reviewed; Research Article

Note. 38 records were identified

## PsycINFO via ProQuest, 1806 to December week 4 2016

((acceptance AND commitment therapy) OR (acceptance-based) OR (acceptance AND commitment) OR (mindfulness-based stress reduction) OR (mindfulness-based cognitive therapy) OR (mindfulness-based)) AND (child\* OR infant\* OR adolesc\* OR baby OR babies OR toddler\* OR teen\* OR youth\* OR pediatric\* OR preschool\*) AND (parent\* OR father\* OR mother\* OR famil\* OR paternal OR matern

Additional limits - Date: till 2016; Methodology: Quantitative Study, Treatment Outcome; Peer reviewed journals

Note. 121 records were identified

## Scopus via Elsevier, 1966 to December week 4 2016

(TITLE-ABS-KEY ((acceptance AND commitment) OR (acceptance-based) OR (acceptance AND commitment AND therapy) OR (mindfulness-based AND stress AND reduction) OR (mindfulness-based AND cognitive AND therapy) OR (mindfulness-based)) AND TITLE-ABS-KEY ((child\* OR infant\* OR adolesc\* OR baby OR babies OR toddler\* OR teen\* OR youth\* OR pediatric\* OR preschool\*)) AND TITLE-ABS-KEY ((parent\* OR father\* OR mother\* OR famil\* OR paternal OR maternal))) AND DOCTYPE (ar) AND PUBYEAR > 1959 AND PUBYEAR < 2017 AND (LIMIT-TO (LANGUAGE, "English"))

Note. 243 records were identified

## **CHAPTER THREE**

## **METHODS OF THE STUDY**

- 3.1. Introduction
- 3.2. Operational definitions
- 3.3. Hypothetical model of the study
- 3.4. Study aim and objectives
- 3.5. Study design
- 3.6. Sampling
  - 3.6.1. Study settings
  - 3.6.2. Eligibility criteria for participants
  - 3.6.3. Sampling method
  - 3.6.4. Sample size estimation
- 3.7. Randomization and allocation concealment
- 3.8. Blinding
- 3.9. Treatment conditions
  - 3.9.1. Control group
  - 3.9.2. ACT group
- 3.10. Data collection methods and procedures
- 3.11. Measures
- 3.12. Ethics considerations
- 3.13. Data management
- 3.14. Data analyses
  - 3.14.1. Examining the role of psychological flexibility in parents of children with asthma
  - 3.14.2. Examining the intervention effects between groups over time
  - 3.14.3. Identifying the predictors of participation
  - 3.14.4. Identifying the predictors of non-completion of the assigned intervention
- 3.15. Summary

#### **3.1. Introduction**

This chapter begins by stating the operational definitions of the terminologies used in this study. The hypothetical model of the study is described. The methods of the study are then presented in detail, including the study aim and objectives, study design, sampling strategies, procedures of random assignment and allocation concealment, blinding, data collection methods and procedures, measures, ethics considerations, data management and data analyses strategies.

#### 3.2. Operational definitions

Asthma exacerbation(s). Asthma exacerbation(s) is defined as an acute worsening of respiratory symptoms, either shortness of breath, non-stop coughing, wheezing, chest tightness or difficulty talking, that represent a change from the patient's usual status to a condition that require immediate medical attention (Reddel et al., 2009). Very often, patients attribute a wide range of severity of asthma, including the mild to life-threatening episodes, to the word "asthma attack(s)", instead of "asthma exacerbation(s)" (Vincent, Toelle, Aroni, Jenkins, & Reddel, 2006). As recommended by the asthma management guidelines (Global Initiative for Asthma, 2016), the term "asthma exacerbation(s)" would be used throughout this chapter to standardize the descriptions of the episodes of worsening asthma.

Asthma symptoms. Asthma symptoms refer to either one of the following clinical presentation(s) concerning the patient's respiratory health status: shortness of breath, chronic cough, wheezing or chest tightness, difficulty in performing normal daily activities (Reddel et al., 2009).

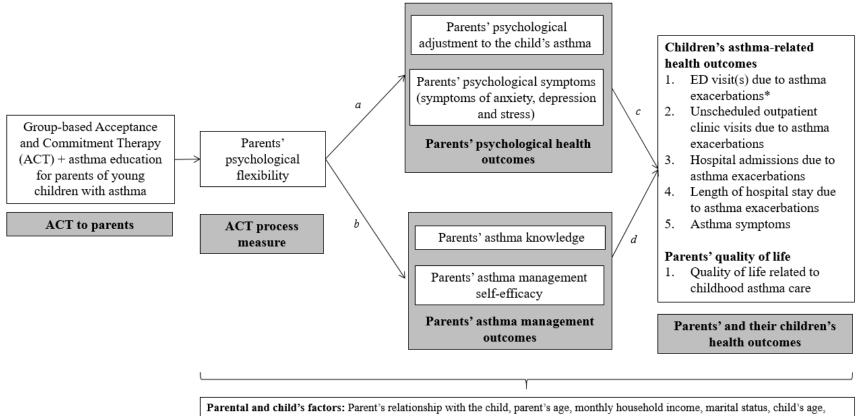
**Parent-child dyad(s).** Parent-child dyad(s) is defined as two individuals, one parent who can be either the father or the mother, and one child as a family unit, which was regarded as a pair.

Incidence rate ratio (IRR). IRR is the incidence rate of outcome of interest for one group divided by the incidence rate for the comparison group (Sedgwick, 2010). In this study, IRR was used to describe the occurrence of asthma-related events in children during a given period in the experimental group (i.e., the ACT group) divided by that of in the comparison group (i.e., the Control group). These events, which would be shown as count data, were: (1) ED visits, unscheduled outpatient visits, hospital admissions and the length of days of hospital stay due to asthma exacerbations in children in the past six months; and (2) days presenting with asthma symptoms, nights awakening due to asthma symptoms, days with activity limitation due to asthma symptoms and days requiring the symptom-relieving medications in children in the past four weeks. For example, in this study, an IRR of 0.5 measured at six months post-intervention for the total number of ED visits due to asthma exacerbations in children in the past six months would indicate that, children whose parents were randomized to the ACT group had 0.5 times as many ED visits due to asthma exacerbations within a six-month period when compared with those in the Control group at six months post-intervention.

#### **3.3. Hypothetical model of the study**

Figure 3.1 shows the hypothetical model of the study. It is expected that if parents receive group-based ACT integrated with asthma education, they become more psychologically flexible towards the psychological difficulties related to childhood asthma care. Their psychological health, as indicated by symptoms of anxiety, depression and stress, as well as their psychological adjustment to their

child's illness, may improve (path a). With greater psychological flexibility, parents may be more willing to strengthen their childhood asthma management in the service of their values even though encountering difficult experiences, as reflected by better asthma knowledge and better asthma management self-efficacy (path b). Improvements in both psychological health and childhood asthma management of parents may contribute to better health outcomes of their children, including less health care service visits due to asthma exacerbations, less asthma symptoms and better quality of life (path c). Likewise, parents may attain a better quality of life as their children's asthma-related health conditions improve (path d). Parental and child's factors, which could potentially influence the causal relationships between the intervention and the outcomes, are also included in this model. They are the socio-demographic factors, such as parents' age, relationship with the child, marital status, educational level and monthly household income, child's age, child's gender (Kaugars et al., 2004), the types of inhaled corticosteroids use (Global Initiative for Asthma, 2016) and the season of enrollment (Teach et al., 2015).



child's gender, types of inhaled corticosteroids use and season of subject enrolment.

Figure 3.1. A hypothetical model of the study

*Note*. ACT = Acceptance and Commitment Therapy, ED = emergency department \*Primary outcome of the study

#### 3.4. Study aim and objectives

This study aimed to examine the efficacy of a parental training program using group-based Acceptance and Commitment Therapy (ACT) integrated with asthma education (the ACT group), in comparison with an asthma education talk as the usual care (the Control group), on children's asthma management outcomes and their parents' psychological health outcomes measured at six months post-intervention in a randomized controlled trial (RCT) design.

The specific objectives of the study were:

- to examine the effects of a parental training program using group-based ACT in addition to asthma education, in comparison with an asthma education talk, on the following child's health outcomes measured at six months post-intervention:
  - a. emergency department (ED) visit(s) due to asthma exacerbations in the past six months (the predefined primary outcome of the study),
  - b. unscheduled outpatient clinic visit(s) in the following health care settings,
     the general outpatient department clinics (GOPCs) and the private
     practitioners' clinics, due to asthma exacerbations in the past six months,
  - c. hospital admission(s) due to asthma exacerbations in the past six months,
  - d. day(s) of hospital stay due to asthma exacerbations in the past six months,
  - e. day(s) per week with asthma symptoms in a four-week recall period,
    including day(s) presenting with asthma symptoms, night(s) awakening
    due to asthma symptoms, day(s) with activity limitation due to asthma
    symptoms and day(s) requiring the symptom-relieving medications,
- to examine the effects of a parental training program using group-based ACT in addition to asthma education, in comparison with an asthma education talk, on the following parental outcomes measured at six months post-intervention:

- a. psychological flexibility (PF),
- b. psychological adjustment to the child's asthma,
- c. psychological symptoms, including anxiety, depression and stress symptoms,
- d. asthma knowledge,
- e. asthma management self-efficacy, and
- f. quality of life.

In this study, we hypothesized that there were no significant differences in the frequencies of ED visits, unscheduled outpatient clinic visits and hospital admissions due to asthma exacerbations measured at six months post-intervention, between the ACT group and the Control group over the past six months. We also hypothesized that there were no significant differences in the average number of days per week with asthma symptoms measured at six months post-intervention, between the ACT group and the Control group over the past six months, in terms of days presenting with asthma symptoms, nights awakening due to asthma symptoms, days with activity limitation due to asthma symptoms and days requiring the symptom-relieving medications. Further, we hypothesized that there were no significant differences in the PF, psychological adjustment, psychological symptoms, asthma knowledge, asthma management self-efficacy and quality of life of the parents measured at six months.

Apart from evaluating the effects of group-based ACT intervention, there is a need to conduct a process evaluation to enhance the understanding on how the intervention had been delivered by the interventionist and had been actually received by the participants in the study settings (Oakley et al., 2006). In addition, knowing

about the factors contributing to the program participation could provide evidence and direction about which population group could be the best targeted in future recruitment. The process evaluation of this RCT study aimed:

- to describe the characteristics of the parent-child dyads whose parents chose and those who chose not to participate in the training program, and to identify the predictors of participation,
- to describe the characteristics of the participants who attended all assigned intervention sessions (i.e., completers) and those who did not attend all the sessions after randomization (i.e., non-completers), and to identify the predictors of non-completion, and
- 3. to describe the characteristics of the participants who were lost to follow-up.
- 3.5. Study design

This was a randomized controlled, parallel-group trial. Parents and their children (i.e., the parent-child dyads) with asthma who were both eligible to the study would have the same chances of being assigned in 1:1 ratio to either a parental training program using group-based ACT for childhood asthma management (ACT group), or an asthma education talk (Control group). The parents in the ACT group received four weekly sessions of group-based ACT plus asthma education, while the parents in the Control group received one session of asthma education talk as the usual care, followed by three weekly sessions of telephone follow-up calls for assessing the asthma conditions of their children. The parent-child dyads were assessed and follow-up up to six months immediately after intervention. The intervention effects between groups across time were then compared and analyzed. Randomized controlled trial (RCT) was chosen as the study design, as this is a golden standard design to offer the best ability to make a causal inference for

assessing the effectiveness of a therapeutic intervention and effectively minimizes bias (Abel & Koch, 1999).

#### 3.6. Sampling

## 3.6.1. Study settings

The present study took place in two pediatric respiratory outpatient clinics, which were an Ambulatory Care Centre (ACC) and a nurse-led asthma clinic, in one public hospital in Hong Kong.

Hong Kong is one of the most densely populated cities in the world (6690 persons per square kilometer) (Census and Statistics Department, 2015), about 11.1% of the total population (804,000) were children aged 15 years or below (Census and Statistics Department, 2015). In Hong Kong, the lifetime asthma prevalence in children aged six to seven years and aged 13 to 14 years were 7.9% and 10.2%, respectively (Chen et al., 2016). The health care system of Hong Kong runs on a dual-track basis incorporating the public and the private sectors (The Government of the Hong Kong Special Administrative Region, 2017). Patients (e.g., children who are diagnosed with asthma and their parents) are not required to register with one general practitioner, who serves as the first contact person for medical services. They can choose to receive care in private clinics and private hospitals through a fee-for-service arrangement, and/or in general outpatient clinics and public hospitals under the Hong Kong Hospital Authority on a subsidized basis (Leung, Wong, Chan, Choi, & Lo, 2005). Charges for the use of ED services and for inpatient stay at a public hospital are 180 Hong Kong Dollars (HKD) per attendance, and 120 HKD (1 United States Dollars (USD) = 7.8 HKD) per day, respectively (Hospital Authority, 2017a).

The study hospital is a major public hospital that is operated under the regulations of the Hospital Authority. It serves Tuen Mun, Yuen Long, and the northwest regions of the New Territories of Hong Kong. In 2016, these districts had a total population of 132,000 children (15.7% of the total population aged under 14 years in Hong Kong) (Census and Statistics Department, 2016a).

The Department of Paediatric and Adolescent Medicine of the study hospital provides outpatients services in the Ambulatory Care Clinic (ACC) and in the nurseled clinic for children aged 18 years below with respiratory health problems. These children are referred either from: the private practitioners' clinics, the general outpatient clinics, or the inpatient hospital wards where the child was previously hospitalized due to an asthma exacerbation and require additional outpatient followups.

The ACC is a specialist outpatient clinic where children (accompanied by their parents) who have been diagnosed with asthma, allergic rhinitis, pneumonia and obstructive sleep apnea, can access medical consultation services provided by pediatricians, and receive education on how to manage their conditions from an Advanced Practice Nurse, who is specialized in pediatric respiratory care. In every month, a total of approximately 380 to 400 children attend the ACC for outpatient care. In general, children who have been diagnosed with asthma need to visit the ACC once in every three to six months for reviewing their health conditions and refilling medications (e.g., inhaled corticosteroids, inhaled bronchodilators).

The nurse-led clinic is another outpatient clinic where parents and their children with asthma, who have repeated asthma exacerbations and/or hospitalization in the past six months, receive additional asthma consultation service by the

Advanced Practice Nurse. A total of 40 to 50 children with asthma attend to this clinic for the above service.

#### 3.6.2. Eligibility criteria for participants

The parent-child dyads were recruited if they fulfilled the following eligibility criteria:

Parents should be between 18 and 65 years old, fathers or mothers in each family who were the primary caregivers responsible for the daily care of their child with asthma (e.g., the same parent who accompanied the child for follow-up appointments at every time), living together with the index child, able to communicate in Cantonese, Hong Kong permanent residents who planned to stay in Hong Kong for at least six months, and accessible by telephone or by mail.

Children should be three to 12 years old and diagnosed of asthma by a physician (International Classification Diseases – 10 codes J45, J46) as documented in the electronic medical records.

Parents and/or their child who were currently participating in another asthma-related intervention study would be excluded.

To increase the homogeneity of the sample, this study had additional exclusion criteria. Children aged two years or below were excluded, because transient asthma symptoms that occur in children at this age range can be due to Respiratory Syncytial Virus (RSV) bronchiolitis or RSV-induced wheeze, a viral infection, rather than asthma (Martinez et al., 1995; Sigurs, Bjarnason, Sigurbergsson, & Kjellman, 2000). In addition, studies have shown that the coexistence of asthma with medical and/or mental morbidities affects the prognosis of asthma in children (Kotey, Ertel, & Whitcomb, 2014; Schieve et al., 2012). The psychological difficulties of those parents rearing a child with asthma together with

additional medical and/or mental co-morbidities can be complex (Koehler, Fagnano, Montes, & Halterman, 2014; Nicholl & Begley, 2012; Woodgate, Edwards, Ripat, Borton, & Rempel, 2015), hence their responses to a specific psychological intervention may vary significantly. In this regard, parents whose children had the following health problems were excluded:

- under the care due to significant mental morbidities, including autism, epilepsy, Attention Deficit Hyperactivity Disorders, Down's syndrome, cerebral palsy, or psychomotor retardation., and/or
- 2. under the care due to significant medical morbidities, including congenital problems, oxygen-dependent conditions, or the presence of tracheotomy.

## 3.6.3. Sampling method

This study employed consecutive sampling method (Portney & Watkins, 2000). The sampling frame was constructed from the list of children who had scheduled appointments for the respiratory health problems in the two clinics. Between January 2016 and May 2016, the research investigator (Ms. Yuen-yu Chong., Ph. D candidate) screened the list every month and identified those children who met the eligibility criteria for the study. For every eligible child who attended the clinics with his/her accompanied parent, the research investigator or the Advanced Practice Nurse further screened the parent for his/her eligibility. All the eligible parents were then invited by the nursing staffs of the clinics to complete a set of self-administered structured questionnaires soliciting their information and their children's clinical information, these parents were further invited by the research investigator to participate in the RCT study with explanations provided. Those parents who agreed to take part in this study provided written consent. The parent-

child dyads were then randomly allocated to either the ACT group or the Control group.

#### **3.6.4.** Sample size estimation

The sample size estimation was based on the primary outcome of this study: the frequency of ED visits due to asthma exacerbations in children in the past six months. Before the estimation, there is a need to pre-specify the magnitude of the minimum expected differences between the two study groups on the primary outcome, namely the minimum expected effect size, so that the effect of the intervention in the present study could be regarded as clinically meaningful and important (Devane, Begley, & Clarke, 2004). The setting of such effect size could be subjective and is based on the clinical experience, or other studies adopting similar study design and interventions (Eng, 2003).

As there have been no studies concerning ACT-related interventions in parents of children with asthma, the RCTs that tested the effectiveness of ACT interventions in parents of children with chronic health problems for improving their children's health outcomes were taken as references to estimate the expected effect size of the present study.

Three RCTs, with a total of 158 participants, reported that among the parents who received the ACT intervention, their children with chronic pain, acquired brain injuries and cerebral palsy had better physical, psychological and functional health outcomes at follow-up (at least three months post-intervention) (Brown et al., 2014; Whittingham et al., 2014 ; Wicksell et al., 2009). These child health outcomes were: behavioral problems (Cohen's d (d) = 0.76 to 1.33), functional disability (d = 0.47 to 0.53), depressive symptoms (d = 0.54) and pain symptoms (d = 0.55) (Brown et al., 2014; Whittingham et al., 2014; Wicksell et al., 2009). In these studies, their

comparison groups were the usual care available in the study settings, such as rehabilitation services, general parenting services, or pain management services offered by a multidisciplinary team (Brown et al., 2014; Whittingham et al., 2014; Wicksell et al., 2009).

The effect size of the aforementioned studies ranged from 0.47 to 1.33. To be conservative, the value of the smallest effect size (Cohen's d = 0.47) was used for sample size estimation. Using G\*Power version 3.1.9.2 statistical software (Faul, Erdfelder, Lang, & Buchner, 2007), considering an effect size of 0.47, two-tailed tests of significance and approximately 10% of attrition, a total of 160 participants, with 80 in each group, were required for a power of 80% and a maximum error of 5% by independent samples *t* test.

## 3.7. Randomization and allocation concealment

Permuted block randomization was employed in this RCT (Altman & Bland, 1999). A block size of six of every consecutively enrolled parent-child dyad was set; this could avoid long strings of assignments to either group while ensuring that the assignment of any parent-child dyad would not be predictable from the preceding assignment.

By using an online, computerized sequence generation randomization tool (www.randomizer.org) (Urbaniak & Plous, 2011), a list of the permuted block sequence of two group labels (1 = ACT group, 2 = Control group) was generated and the list was checked whether the ratio of the two group labels in every block was in 1:1. After that, the group labels (1, 2) were marked on pieces of paper and placed inside sequentially numbered opaque sealed envelopes. The whole randomization procedure was carried out by a nursing student with no other clinical involvement in this study (i.e., the random-list keeper). This random-list keeper was the only person

who knew the sequence of random allocation, hence the sequence was concealed to all the research investigators and other members involved in this study. In addition, the random-list keeper was blinded to the meaning of the group labels (1, 2). The envelopes were only opened by the research investigator after the completion of assessments of the parent-child dyads during the recruitment, and after the parents provided written consent. Each time before the research investigator went to the study hospital for the subject recruitment, the random-list keeper marked down the sequentially numbered envelope(s) being given to the research investigator in the randomization list. At the end of the day of recruitment, the research investigator returned all the opened and unopened envelopes to the random-list keeper. The random-list keeper would check whether the returned envelopes had the same sequential numbers as marked in the randomization list. Hence, there was no chance for the research investigator to reach or to keep the envelopes.

## **3.8. Blinding**

Due to the nature of psychoeducational intervention (ACT and asthma education), it was impossible to blind parents to their group assignment. The research investigator was the interventionist and thus it was also unable to be blinded to the group assignment. The blinding to randomization status was adopted for the following personnel: (1) the health care providers in the clinic of the study hospital, (2) the data collectors, and (3) the research assistant involved in the data entry.

The health care providers in the clinic of the study hospital, who would potentially provide care to the parent-child dyads, were not informed which group that the participants had been assigned. Furthermore, the data collectors of this study included the nursing staffs in the clinic and a research assistant. The nursing staffs were responsible for collecting the completed self-administered questionnaires given

by parents. The research assistant was responsible for collecting the data from parental reports via telephone interviews. All the aforementioned data collectors were concealed from the group assignment. Another research assistant, who was responsible for the data entry, was not aware of the intervention being assigned in the group labels (1 = ACT group, 2 = Control group).

# 3.9. Treatment conditions

After the parents completed the assessments and provided the written consent for participating in the study, the parent-child dyads would be randomly allocated to either the Control group or the ACT group. The assigned intervention sessions were scheduled in accordance with the parents' availability within one month after receiving the consent. In both study groups, three scheduled session timeslots (morning sessions during weekdays, afternoon sessions during weekdays, and morning sessions during weekends) were offered in every month to the parents, so that they could choose their most convenient time for participation. These scheduled sessions were arranged during the children's school time, child care service was provided by the study hospital when the sessions were conducted during weekends.

## 3.9.1. Control group

The parents who were randomly allocated to the Control group received one session of a 2-hour asthma education talk in the first week, plus three telephone follow-up calls (15 minutes per each call) for assessing their children's asthma conditions on a weekly basis, starting from the second to the fourth week.

*Asthma education talk.* The asthma education talk was the usual care provided by the study hospital to the parents of children with asthma. The talk was delivered in one session by an Advanced Practice Nurse of the clinics and lasted for two hours, it served approximately 10 to 15 parents in a meeting room of the ACC in

every month. The content of the talk mapped to an international asthma management guideline named as "Global Strategy for Asthma Management and Prevention 2016 Update" (Global Initiative for Asthma, 2016), which was written by an international workgroup, the Global Initiative for Asthma (GINA), in collaboration with the National Heart, Lung and Blood Institute and the World Health Organization. Since 1995, the GINA guidelines have formed the basis of clinical practice guidelines and education for childhood asthma management in worldwide (Reddel et al., 2015). Asthma education programs which had been reviewed in previous meta-analyses adopted the GINA guidelines as the framework to formulate the content of the intervention, and showed improvements in child's asthma symptoms and reduction in the emergency care visits due to asthma exacerbations (Coffman et al., 2008; Guevara, Wolf, Grum, & Clark, 2003).

As the usual care offered by the study hospital, during the asthma education talk, parents were taught with the following information about childhood asthma management:

- 1. basic pathogenesis of childhood asthma,
- 2. signs and symptoms of asthma,
- 3. identification of asthma triggers at home and at school,
- 4. indications and side-effects of controllers and relievers,
- 5. strategies to achieve an optimal childhood asthma control: symptom monitoring by using a daily asthma diary, allergen avoidance and the use of written asthma action plan, and
- 6. management of childhood asthma exacerbations.

In addition, the nurse demonstrated the procedures of administering medications to young children (e.g., how to use an inhaler together with an aero-

chamber). At the end of the asthma education talk, each parent received one set of handouts including the key information about childhood asthma care (see Appendix 3.1).

*Telephone follow-up calls.* After attending the asthma education talk, in the following three consecutive weeks, the parents in the Control group received three telephone follow-up calls on a weekly basis. Hence, the parents in both groups (the ACT group and the Control group) could receive equal number of attended sessions (four sessions), while this arrangement could approximate the existing practice (asthma education talk) naturalistically available in the study settings (Freedland, Mohr, Davidson, & Schwartz, 2011). The telephone follow-up calls were provided by a registered nurse of the clinics. For each call which lasted around 15 minutes, the parents were invited to report their children's conditions related to asthma in the past week, including asthma symptoms during daytime, asthma symptoms during nighttime, any use of bronchodilator to relieve asthma symptoms and any activity limitation due to asthma symptoms. In case of any queries raised by parents regarding childhood asthma care, a brief nursing advice based on the educational information shown in the handout (see Appendix 3.1) was provided, followed by referring the parent's enquiry to the Advanced Practice Nurse in the Department of Paediatric and Adolescent Medicine of the study hospital for considerations of further actions.

# 3.9.2. ACT group

The parents who were randomly allocated to the ACT group received a training program using group-based ACT plus asthma education for childhood asthma management.

*Training program using group-based ACT plus asthma education.* The training program was conducted in four weekly sessions for four consecutive weeks. Each session lasted for two hours and served a group of six to eight parents. At least two ACT group classes were organized in every month. The parents received a total of six hours of group-based ACT (90 minutes per session), followed by a total of two hours of asthma education (30 minutes per session) in which the content was the same as of that received by the Control group.

Four sessions were decided as the adequate dose of intervention in the present study. One systematic review of 18 experimental studies (publication year ranged from 2006 to 2014) have examined the current state of knowledge of ACT in adult patients for chronic disease self-management, and in parents of children with neurodevelopmental disorders for improving parenting (Graham et al., 2016). This review has found that most of the ACT interventions are brief; ACT interventions, which are delivered no more than five sessions, can demonstrate significant improvements in various health indicators with medium-to-large effect sizes starting from post-intervention up to 12 months post-intervention when compared with usual care (Graham et al., 2016). These indicators include: hemoglobin A1c level in adult patients with type II diabetes (d = 0.61) (Gregg et al., 2007), seizure intensity in adult patients with epilepsy (d = 1.45) (Lundgren et al., 2006), as well as emotional and behavioral problems of children with acquired brain injuries or cerebral palsy (d = 0.48 to 0.67). In addition, this review has indicated that individuals who receive ACT interventions no more than five sessions achieve significant improvements in their PF with medium effect sizes at post-intervention when compared with baseline (d = 0.49 to 0.72) (Burke et al., 2014; Goodwin et al., 2012; Gregg et al., 2007).

Group-based approach was adopted when delivering ACT to the parents. One Cochrane systematic review of 48 RCTs (publication year ranged from 1983 to 2010) has shown that when compared with the control conditions (waitlist, no treatment or usual care), group-based parental training programs underpinned by a cognitive or cognitive-behavioral approach in groups could lead to significant improvements of parental psychological symptoms, including symptoms of anxiety, depression and stress, at post-intervention and at six months post-intervention (Barlow, Smailagic, Huband, Roloff, & Bennett, 2012). Furthermore, as shown in Chapter Two, empirical evidence has revealed that mindfulness- and acceptancebased interventions, such as ACT, are commonly delivered in groups (see Chapter Two Section 2.5.2: Study characteristics). Other therapeutic advantages of a groupbased intervention serving for parents include gaining mutual support and empathy from other parents, reducing the feelings of guilt and social isolation, and enabling them to regain control to cope with the caregiving difficulties (Kane, Wood, & Barlow, 2007). In a group-based ACT session, each member will be somewhere along the continuum of psychological flexibility (PF) at any point of time, hence the therapeutic process of fostering PF would not only be applicable to one group member, but to everyone else in the group sessions (Westrup & Wright, 2017).

During the ACT intervention, multiple activities were carried to foster the parents' PF, so that they could develop acceptance of psychological difficulties and commitment to values-based actions for improving their childhood asthma management. Example activities included: (1) mindfulness exercises, to guide parents to observe their painful thoughts and feelings that they were attempting to avoid when managing asthma; (2) experiential exercises, such as the Tug-of-War with a Monster metaphor, to let parents realize that the cost of struggling with

psychological distress often creates more distress. Parents were facilitated to explore whether their current childhood asthma management strategies were acting towards or away from their parental values, and to establish values-based action plans.

All the sessions were delivered by the trained research investigator (Ms. Yuen-yu Chong, Ph. D candidate) guided by an ACT intervention protocol. After each session, the interventionist conducted a self-evaluation to assess her adherence to the intervention protocol and her competence in delivering all the six ACT therapeutic processes by using a fidelity checklist containing items of rating scales of 1 (*never true*) to 7 (*always true*) (Luoma, Hayes, & Walser, 2007). In addition, throughout the study period, all the ACT sessions were videotaped under the parental consent and the recorded sessions were reviewed by Ms. Chong and an experienced ACT researcher (Chief Supervisor) during weekly meetings for ACT skills supervision and quality monitoring.

The process of developing the ACT intervention protocol, the content of the intervention protocol, the credentials of the interventionist, as well as the fidelity assessments of the ACT intervention are described in detail in Chapter Four. By the end of each session, each parent received a set of intervention materials, including one set of session handouts, its content included both ACT intervention and childhood asthma education, and one homework assignment (see Appendix 4.2 to 4.5 for the details). Before the commencement of RCT, the training program had also been pilot-tested among a sample of parents of children with asthma recruited in the study hospital. Details of this pilot test are described in Chapter Five.

**Treatment adherence.** For each study arm, parents who attended all four assigned intervention sessions would be regarded as adherence to the intervention (i.e., completers). To improve the adherence to subsequent intervention sessions,

weekly reminders of session attendance were sent via text messages to the parents after attending the first session. For parents who did not attend all four sessions (i.e., 0-3 sessions, non-completers), we invited them to state their reason(s) for nonattendance, the data collection were continued as planned with the parents' consent.

## **3.10. Data collection methods and procedures**

The present study had four assessment time points, which were: (1) at baseline, (2) immediately after intervention (3) at three months and (4) at six months post-intervention, respectively. As discussed, blinding to the randomization status of the participants among the data collectors (i.e., the nurses in the clinics and the research assistant) were employed. A six-month follow-up period is the minimal required duration for a follow-up medical consultation (e.g., refilling medication) in children with asthma, this duration is also internationally recommended by the National Institutes of Health Institute and the Agency for Healthcare Research and Quality when conducting prospective asthma-related clinical trials for children (Busse, Morgan, Taggart, & Togias, 2012). In accordance with the intention-to-treat (ITT) principle, all randomized participants should be followed up regardless of the actual intervention that they received (Gupta, 2011; White, Horton, Carpenter, & Pocock, 2011). Hence, in this study, all the randomized parent-child dyads were attempted to be followed up.

For each time point, the data collection methods and procedures are shown as follows.

At baseline. Prior to an invitation for participation of the RCT study, each eligible parent was initially invited to complete a structured questionnaire (see Appendix 3.2). This questionnaire consisted of three parts. Part one included child measures, which were designed to collect information regarding the use of

unscheduled health care services due to asthma exacerbations and the asthma symptoms of the index child. Part two composed of six parental measures, they were psychological flexibility, psychological adjustment to the child's asthma, psychological symptoms (i.e., symptoms of anxiety, depression and stress), asthma knowledge, asthma management self-efficacy and the quality of life of the parent. Part three was used to collect data regarding the sociodemographic characteristics of the parent-child dyads. The data collected from all the eligible parents who completed the questionnaires *and* were consented to participate in the RCT were regarded as the baseline data (i.e., pre-intervention) of this RCT.

At post-intervention. After four weekly sessions of intervention (i.e., one month), parents in both groups were re-assessed by administering the follow-up questionnaires, which included all the six parental measures. Parents in the ACT group completed the questionnaires in the last intervention session by themselves and returned them immediately to the nurses in the clinic. On the other hand, parents in the Control group were assessed through telephone interviews by the research assistant. This research assistant was trained by the research investigator in using the follow-up questionnaires to conduct telephone interviews.

At three months post-intervention. At three months immediately after the intervention, parents in both groups received brief telephone-based assessments by the research assistant. They were asked to report their children's asthma symptoms.

At six months post-intervention. At six months immediately after the intervention, each parent in both groups received a final assessment while accompanying his/her child for follow-up visits in the clinics by completing a follow-up questionnaire. Similar to the questionnaire used at baseline, the follow-up questionnaire composed of child measures (Part one) as well as six parental

measures (Part two). To minimize the risk of lost to follow-up, the date of this sixmonth follow-up assessment was scheduled at the same date of the child's follow-up appointment in the clinic.

For those randomized parents who missed the assigned sessions after the start of the intervention, they would be contacted by the research assistant to complete the follow-up assessments via telephone interviews. The details of establishing the validity and reliability, and the feasibility of implementing the self-administered questionnaire will be presented in Chapter Five.

# 3.11. Measures

## **3.11.1. Child measures**

**Emergency department (ED) visits due to asthma exacerbations.** The frequency (i.e., total number) of ED visits due to asthma exacerbations in children in the past six months was selected as the pre-specified, primary outcome of the study. Asthma-specific ED visits is an objective and internationally recognized marker of asthma severity (Akinbami et al., 2012; Busse et al., 2012); it is also a significant predictor of both subsequent ED visits and hospitalizations (Auger et al., 2015; Tolomeo, Savrin, Heinzer, & Bazzy-Asaad, 2009). In this study, ED visits were referred to the health care service visits due to asthma exacerbations in children in the Accident and Emergency Department of a hospital setting, either public hospitals under the Hong Kong Hospital Authority and/or private hospitals. This outcome measure was assessed at baseline and at six months post-intervention by parental reports in the self-administered questionnaires, using the following question: *"During the past 6 months, how many times did your child visit an emergency room because of his/her asthma attacks?"* 

**Unscheduled outpatient clinic visits due to asthma exacerbations.** The frequency of unscheduled health care service visits, including the general outpatient department clinics (GOPC) of the public hospitals, and the private practitioners' clinics, due to children's asthma exacerbations in the past six months were assessed at baseline and at six months post-intervention by parental reports in the self-administered questionnaires, using the following question: "During the past 6 months, how many times did your child visit the general outpatient clinic because of his/her asthma attacks?" and "During the past 6 months, how many times did your child visit the private of his/her asthma attacks?"

Hospital admissions due to asthma exacerbations. The frequency of hospital admissions due to children's asthma exacerbations in either public hospitals under the Hong Kong Hospital Authority and/or private hospitals in the past six months was assessed at baseline and at six months post-intervention by parental reports in the self-administered questionnaires, using the following question: *"During the past 6 months, how many times has your child been admitted to private or public hospitals because of asthma attacks?"* 

Length of hospital stay due to asthma exacerbations. The total duration (total number of days staying overnight) of all the episodes of hospitalization due to children's asthma exacerbations in either public hospitals under the Hong Kong Hospital Authority and/or private hospitals in the past six months was assessed at baseline and at six months post-intervention by parental reports in the self-administered questionnaires, using the following question: "During the past 6 months, how many days did your child stay in hospital overnight after hospital admissions due to asthma attacks?"

As stated in Section 3.6.1, the health care system of Hong Kong runs on a dual-track basis incorporating the public and the private sectors. Any asthma-related health care service visits in public clinics (e.g., general outpatient clinics) and in public hospitals under the Hong Kong Hospital Authority could be retrieved directly from the electronic patient records (ePR) of the study hospital (i.e., a public hospital). Yet, there could be a chance that parents would send their child to seek medical care in private hospitals/clinics if an asthma exacerbation arrives, while such attendance(s) could only be known by parental proxy reports rather than by reviewing the administrative records in the ePR system. As recommended by the international experts (i.e., American Thoracic Society (ATS) and the European Respiratory Society (ERS), the data for asthma-related health care events in different settings should be collected with the same approach (Akinbami et al., 2012). Hence, in this study, it was decided to use parental reports as the data source. Indeed, unscheduled health care service visits due to asthma exacerbations in children are considered as patient and/or family-initiated visits resulting from worsening asthma symptoms. They are the major asthma-related events that require immediate medical attentions and less subjective to recall bias in parents if the recall period is equal or less than six months (Akinbami et al., 2012; Pless & Pless, 1995; Ungar, Davidson-Grimwood, & Cousins, 2007). In this study, to strengthen the validity of parental reports on the child's asthma-related events, all the question items were retrieved from standardized, international health surveys, such as the National Health Interview Surveys (United States Department of Health and Human Services, 2015) and the Behavioral Risk Factor Surveillance Call-back Surveys (Centers for Disease Control and Prevention, 2009).

Asthma symptoms. Asthma symptoms of children were assessed at baseline, at three months and at six months post-intervention respectively, based on parental reports in the questionnaires. Parents were asked to recall the average number of days per week that their child were presented with asthma symptoms (either chronic coughing, wheezing, shortness of breath or chest tightness) in the past four weeks as follows:

- day(s) presenting with asthma symptoms, via the following question: "During the past 4 weeks, how often did your child had chronic cough, wheezing, shortness of breath or chest tightness during daytime per week?"
- 2. night(s) awakening due to asthma symptoms, via the following question: "During the past 4 weeks, how often did your child had chronic cough, wheezing, shortness of breath or chest tightness causing night awakening during the night per week?"
- 3. day(s) with activity limitation (e.g., the child needs to slow down to take a rest during activity) due to asthma symptoms, via the following question: "During the past 4 weeks, how often did your child had chronic cough, wheezing, shortness of breath or chest tightness, which had to slow down or to discontinue during play or exercise, per week?" and
- 4. day(s) requiring the use of short-acting inhaled bronchodilators to relieve the child's asthma symptoms. via the following question: "During the past 4 weeks, how often did your child had chronic cough, wheezing, shortness of breath or chest tightness, that needed Ventolin (blue inhaler) to relieve asthma symptoms per week?"

To account for seasonal influence, this study followed the recommendations by the international experts to monitor child's asthma symptoms for every three

months (Pijnenburg et al., 2015). Notably, parental proxy reports, rather than children's own self-reports, were regarded as the source of gathering data for child's asthma symptoms. Prior studies have shown that there could be discordance between a parent's and his/her child's report of symptoms, due to differences in their psychological experiences of the illness (Davis, DiSantostefano, & Peden, 2011; Dell, Foty, Becker, Franssen, & Chapman, 2007). Given that this study focused on parents of young children with asthma (i.e., including children who are in preschool age), parental reports can help to overcome the limitations that come with a study involving young children, whose general cognitive competencies are still developing and whose ability to recall their past asthma-related activities might therefore be limited (Bevans, Riley, Moon, & Forrest, 2010). Furthermore, relying on proxy reports by the primary caregivers to evaluate young children with asthma who present with observable symptoms, such as wheezing and coughing, is wellsupported by experts (Barrett, Clark, Demuro, & Esser, 2013). In this study, the question items for assessing the child's asthma symptoms were retrieved from the international asthma management guidelines (Global Initiative for Asthma, 2016).

## 3.11.2. Parent measures

Six parental measures were assessed at baseline, at post-intervention, and at six months post-intervention, based on the parental reports in the questionnaires. Each parental measure is described as follows:

**Psychological flexibility.** The Acceptance and Action Questionnaire-II (AAQ-II) was used to assess the psychological flexibility (PF) of parents (Bond et al., 2011), which was also regarded as the process measure of this study. Parents rated seven statements on a 7-point Likert scale ranging from 1 (*never true*) to 7 (*always true*), for example: "*My painful experiences and memories make it difficult* 

for me to live a life that I would value." A higher total score indicates poor PF (i.e., more psychologically inflexible). The AAQ-II possessed good internal consistencies (mean Cronbach's alpha ( $\alpha$ ) = .84, range  $\alpha$  = .86 to .88) and test-retest reliabilities over a 3-month interval (test-retest reliability coefficient (r) = .81) and 12-month interval (r = .79), respectively (Bond et al., 2011). Its Chinese language version also possessed good internal consistencies ( $\alpha$  = .86 to .88) and test-retest reliability over a 1-month interval (r = .74 to .86) in two Hong Kong community samples (Zhang, Chung, Si, & Liu, 2014).

Psychological adjustment to the child's asthma. The Parent Experience of Child Illness (PECI) was used to capture the psychological adjustment of parents in taking care of a child with asthma (Bonner et al., 2006; Bonner, Hardy, Willard, Hutchinson, & Guill, 2008). The PECI contains 25 statements with three subscales for assessing the illness-specific psychological distress experienced by a parent who has a chronically ill child, including Guilt and Worry (e.g., "I feel guilty because my child became ill while I remained healthy"), Unresolved Sorrow and Anger (e.g., "I am jealous of parents who have healthy children"), and Long-term Uncertainty (e.g., "I worry about whether my child will be able to live independently as an adult"), together with one subscale on perceived Emotional Resources (e.g., "I feel ready to face challenges related to my child's wellbeing in the future"). Parents rated the degree to which each statement applied to them over the past month on a 5-point Likert scale from 0 (*never*) to 4 (*always*). The PECI had adequate internal consistencies ( $\alpha$  in each subscale = .72 to .89) (Bonner et al., 2006) and test-retest reliabilities over a 2-week interval (r in each subscale = .83 to .86) (Bonner et al., 2008). The PECI also possessed strong construct validity. It had significant correlations with other standardized measures of parental adjustment, such as the

Brief Symptom Inventory (BSI), Care-giver Strain Questionnaire (CGSQ) and Global Assessment of Functioning (GAF) (Bonner et al., 2006; Bonner et al., 2008). Its Chinese language version showed its adequate reliability among a sample of Chinese parents with children suffering from chronic disease including asthma ( $\alpha$  of each subscale = .73 to .81) (Wan, 2008).

Psychological symptoms. The Depression Anxiety Stress Scales-21 (DASS-21) (a short form of the original DASS-42 scale) with 21 statements was used to evaluate the states of depression (e.g., "I felt that I had nothing to look forward to"), anxiety (e.g., "I felt I was close to panic") and stress in adults (e.g., "I found myself getting agitated") (Henry & Crawford, 2005). Parents rated the degree to which each statement applied to them in the past week on a 4-point Likert scale from 0 (does not apply to me at all) to 3 (applies to me very much, or most of the time). A higher score on each subscale indicates more severe symptoms of depression, anxiety, or stress. The reliabilities for the depression, anxiety, and stress subscales in the DASS-21 were .82, .88 and .90, respectively (Henry & Crawford, 2005). Its Chinese language version showed good internal consistency among a sample of Hong Kong parents with healthy children ( $\alpha$  of the DASS-21 depression, anxiety and stress were .84, .78 and .84, respectively) (Leung, Sanders, Ip, & Lau, 2006). All the DASS-21 subscale scores were multiplied by two, the DASS manual cut-off scores indicating at least a mild level of psychological symptoms of an individual are 9 for depression; 7 for anxiety and 14 for stress, respectively (Lovibond & Lovibond, 1995b). The mean scores (SD) of doubling the DASS-21 scores from a large, non-clinical adult sample (n = 1794) were 5.66 (7.74) for depression, 3.76 (5.90) for anxiety and 9.46 (8.40) for stress, respectively (Henry & Crawford, 2005).

Asthma knowledge. The Asthma Knowledge Questionnaire (AKQ) was used to assess the knowledge of parents in understanding childhood asthma (Ho et al., 2003). The AKQ has 25 true and false statements concerning children's asthma symptoms, types of asthma triggers, common asthma treatment and preventive strategies, for example "*Smoking in the home can make a child's asthma worse*". Parents decided the right answer of each statement. A higher score indicates better asthma knowledge. The AKQ had adequate internal consistency ( $\alpha = .69$ ) and representativeness to cover the practical aspects of childhood asthma care as recommended by the national experts of the Child Asthma Management Program Executive Committee (Ho et al., 2003). The AKQ was rated a grade 6.7 reading level, which is appropriate to most of the parents in Hong Kong who attain at least primary educational level or above.

Asthma management self-efficacy. The Parent Asthma Management Self-Efficacy (PAMSE) was employed to assess the self-efficacy of parents in managing their children's asthma (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999). The PAMSE consists of 13 questions with two subscales in assessing the self-efficacy of parents in preventing (e.g., *"How sure you can use the medication correctly?"*) and in managing childhood asthma exacerbations (e.g., *"How sure you know when to take your child to the AED during a serious breathing problem?"*). Parents rated the strength of beliefs in a variety of situations related to childhood asthma management in a 5-point rating scale from 1 (*not at sure*) to 5 (*completely sure*). A higher score indicates better self-efficacy. The PAMSE had satisfactory internal consistency ( $\alpha$  of each subscale = .77 to .82) and strong construct validity with the self-efficacy of children in managing asthma (r = .36) (Bursch et al., 1999).

**Quality of life.** The Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) was used to measure the well-being of parents in caring for their children with asthma (Juniper et al., 1996). The PACQLQ has 13 questions with two subscales in assessing the emotional function (e.g., *"How often did you feel helpless or frightened when your child experienced cough, wheeze, or breathlessness?"*) and the activity limitation (e.g., *"How often did you have sleepless nights because of your child's asthma?"*) of parents. Parents recalled their experiences during the previous week and scored on a 7- point Likert scale from 1 (*severe impairment*) to 7 (*no impairment*). A higher score indicates a better quality of life. The PACQLQ had stable reliabilities within the intervals of four weeks (intraclass correlation coefficient (ICC) = .80 to .85), its established minimal clinically importance difference score was 0.5 (Quittner, Modi, & Cruz, 2008). Measuring the quality of life of parents via the PACQLQ has been shown to reflect the current asthma control of their children (Stelmach et al., 2012). The Chinese language version of the PACQLQ is also available (Juniper et al., 1996).

## 3.11.3. Sociodemographic information

Apart from assessing outcomes, it is important to obtain information about the characteristics of participants at baseline for assessing the comparability of study groups, and evaluating the applicability and generalizability of the trial results (Moher et al., 2010). Prior to the randomization, the parents reported the following information regarding their index child's demographics and clinical characteristics in the questionnaire, such as age, gender, age of diagnosis as asthma, the current treatment regimen of asthma, history of allergic rhinitis and history of eczema. Furthermore, the parents reported their socio-demographic characteristics, including age, relationship with the index child, level of educational attainment, monthly

household income, occupation, personal history and family members' history of asthma and parents' smoking status.

#### **3.12. Ethics considerations**

This study received ethical approvals from the study hospital's ethics review board (reference number: NTWC/CREC/15042) and the university (reference number: HSEARS20150109001) (see Appendix 3.3). This study was also registered with the U.S. National Institutes of Health (NCT02405962) (see Appendix 3.4). Several steps were taken to ensure that the ethics issues in conducting the study were well-addressed. These steps included consenting, anonymity and data confidentiality, and estimating the potential risks and benefits of participating in the study.

**Consenting.** Verbal consent was obtained from all the eligible parents who agreed to complete the structured questionnaires (see Appendix 3.2)

For those eligible parents who agreed to take part in the RCT study, further explanations were given on the details of the study as described in the Information Sheet (see Appendix 3.5), with written consent obtained (see Appendix 3.6 for the Consent Form). These parents were informed by the research investigator that: (1) they could have an equal chance of being randomly allocated to any one of the two groups; (2) the parents could be possibly being videotaped when participating in the intervention sessions, and the videos would only be viewed by the research team members for the fidelity assessment; (3) their participation would not affect the pediatric care services that their children would receive. They were reminded of their voluntary participation and of their right to withdraw from the study at any time without any negative consequences. Prior to the start of the intervention session, the research investigator, who was also the interventionist, had to ensure that all the participants agreed in video-recording.

Anonymity and data confidentiality. To avoid the loss of anonymity of the participants in the intervention sessions, the video camera was placed at the back of the participants; this also helped to avoid affecting how they behaved during the intervention.

After the data collection, data in hard copies with identifiable information were kept in a locked cabinet, which could be accessed by the research investigator and a research assistant who was involved in data entry. All personal data (including the electronic video records) were stored in password-protected files and encrypted. No data were stored on personally-owned personal computers. Each participant was assigned to a unique identification (ID) code, which was used instead of the name of the participants, the ID codes and the names of the participants were stored separately.

Estimated risks and benefits. In this study, parents in the ACT group were asked to revisit their experiences in caring for their children with asthma; hence there could be a chance that parents could expose a certain degree of psychological discomfort. Previous studies using ACT in supporting parents for managing their children's health problems did not report study-related adverse events (Blackledge & Hayes, 2006; Brown et al., 2015; Burke et al., 2014), hence it was expected that the risk for the participants in receiving the group-based ACT intervention would be minimal. Nevertheless, several measures were undertaken to reduce the risk. When conducting the intervention sessions, the research investigator (i.e., the interventionist) would pay special attention to those emotional vulnerable parents and referred these parents (if any) to the pediatric respiratory team for further care and follow-up observations. These parents might also be referred to medical social workers of the study hospital or other relevant professions for further psychological

support. Regular meetings were held among the research team members to review any situations that the participating parents experienced significant psychological distress and required further care.

On the other hand, all the parent-child dyads, either in the ACT group or the Control group, received standard care of childhood asthma management, including (1) asthma education based on the international asthma management guidelines, (2) asthma medications if needed, and (3) regular follow-up visits in the clinics. Parents who were randomly allocated to the ACT group would receive an additional ACT training, which offered them an opportunity to learn to handle their psychological difficulties when taking care of their children with asthma.

## 3.13. Data management

**Data entry and screening.** The data collected from the coded questionnaire items were entered twice by the research investigator and a research assistant independently into the Statistical Package for the Social Sciences (SPSS) software for Windows (Version 23.0; IBM Corp., 2014) database. Any discrepancies of the data entry between the two people were resolved by retrieving the raw data from the questionnaires and corrections were made. Next, to detect potential outliers, each of the variables in the dataset was screened by descriptive statistics, which referred to the frequency distributions for the categorical variables; the maximum values, the minimum values, the values of skewness and kurtosis for the continuous variables, respectively. If any outliers were found (e.g., the skewness value of one continuous variable was  $\pm$  1) (Tabachnick, Fidell, & Osterlind, 2001), manual cross-checking the input data with the raw data was carried out and errors due to data entry were made accordingly.

During the screening, positive skewness was noted in the variables concerning the depressive symptoms (skewness values at baseline = 2.05, at postintervention = 2.05, at six months post-intervention = 1.75) and anxiety symptoms (skewness values at baseline = 1.69, at post-intervention = 2.20, at six months postintervention = 1.52) of the parents. This is an expected finding, because the parents were recruited in a general population (rather than a clinical population) and the majority might attain a low score of psychological symptoms. By using the generalized estimating equations (GEE) models, the statistical method used to estimate the intervention effects in this study, the distribution assumption could be relaxed (Zeger & Liang, 1986). Hence, data transformation or using other methods of data aggregation were not required in this study prior to conducting further data analyses, so as to avoid losing the clarity in interpreting results (Ballinger, 2004).

**Checking for the missingness of the data.** The data analyses of the present study was conducted in an intention-to-treat (ITT) basis, which refers to "analyze as randomized", by including all participants in the groups to which they were randomly assigned regardless of any departure from the assigned groups, such as interventions that they actually received and lost to follow-up (Joseph, Sim, Ogollah, & Lewis, 2015). Adopting the ITT principles in data analyses can preserve the benefits of randomization in RCTs: balancing both known and unknown factors and eliminating selection bias between groups (Hollis & Campbell, 1999). However, during follow-up assessments, if the outcome data are missing, a true ITT analysis can be difficult to achieve which threatens the validity of treatment effect estimates in RCTs.

Missing value analyses were conducted as follows. First, the proportion of missing data for each variable was checked, it is suggested to be less than 5%

(Schafer, 1999). Next, Little's Missing Completely at Random (MCAR) test was used to check whether the missingness in a given variable depended on any other variables as observed or unobserved in the dataset (Little, 1988). If the result of the Little's MCAR test was non-significant, this indicated that the missing data mechanism was under missing completely at random (MCAR) (Little, 1988). Standard GEE models could be employed which allow modeling of incomplete data by making use of all available data (Fitzmaurice, Laird, & Ware, 2011; Joseph et al., 2015), without the need of using simple imputation (e.g., last observation carried forward) and multiple imputation to replace missing data (Bell & Fairclough, 2014). If the result of the Little's MCAR test was significant, this indicated that the missing-data mechanism could be not completely missing at random, then multiple imputation using fully conditional specification with at least five imputations would be performed to replace the missing values (Rezvan, Lee, & Simpson, 2015), followed by using GEE to examine the intervention effect (Paik, 1997).

In this study, no missing data were found for all the study variables measured at baseline, indicating that every parent-child dyad in this RCT provided one full dataset of all variables at one timepoint (at least). For the variables measured during the follow-up period, the proportions of missing data per variable were small, ranging between 0% and 3.6% (<5%). All the variables were analyzed by the Little's MCAR test with non-significant results (Chi-square = 63.61, df = 234, p = 1.00), indicating that the missing data mechanism of the dataset was completely at random (i.e., MCAR). Hence, as explained earlier, the standard GEE models could be used which allow modeling of incomplete data by making use of all available data, including the full set of baseline data from all the participants. As a result, all the

participants in this study being randomized were included in the data analysis, which were in line with the ITT principle (Hollis & Campbell, 1999).

#### 3.14. Data analyses

All data analyses were conducted in two-tailed with a significance level of p <.05. For the variables which presented as continuous or count data, the mean, the standard deviation, the range and the possible range (as provided in the instrument), were reported. For the variables which presented as categorical data, the frequencies and the proportions were reported.

The data analyses served the following purposes: (1) to examine the role of PF in parents of children with asthma, (2) to examine the intervention effects between groups over time, (3) to identify the predictors of participation, and (4) to identify the predictors of non-completion of the assigned intervention sessions.

# **3.14.1.** Examining the role of psychological flexibility in parents of children with asthma

As mentioned earlier, all the eligible parents, regardless of their participation status, were invited to complete a set of self-administered questionnaires soliciting their information and their child's clinical information before randomization (see Section 3.10 - Data collection methods and procedures – At baseline). This cross-sectional data were used to examine the ways in which the PF of parents, their psychological adjustment to their child's illness and their psychological symptoms including anxiety, depression, and stress, related to their child's asthma morbidity by structural equation modeling (SEM) (see Figure 3.2).

Previous research has shown support for an association between the psychological characteristics of parents and the prognosis of their child's asthma (Bartlett et al., 2001; Lange et al., 2011; Otsuki et al., 2010; Weil et al., 1999).

However, other factors beyond mental health problems alone have rarely been postulated. If this SEM analysis demonstrates that poor PF would be associated with poor psychological adjustment to the child's illness and psychological symptoms of parents, as well as poor asthma morbidity of their children, this finding could provide additional empirical evidence to the RCT study, implying that fostering the PF of parents through ACT may potentially improve their own psychological health, and more importantly their children's asthma-related health conditions.

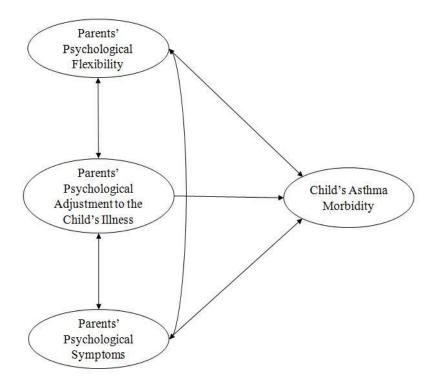


Figure 3.2. A conceptual model for the structural equation modeling analysis

Structural equation modeling (SEM) is an extension of regression analysis which allows researchers to simultaneously instead of separately examine the interrelationships of multiple factors in a model (Nachtigall, Kroehne, Funke, & Steyer, 2003). Latent factors in SEM refer to the hypothetical constructs that cannot be measured directly, but are inferred from a class of indicators that belong to the same dimension (Bollen, 2002). In other words, latent factors such as parents'

psychological adjustment, psychological symptoms, asthma knowledge and asthma management self-efficacy, can be constructed directly by indicators (observed variables); and hence the relationships of these latent factors can be assessed by SEM.

The SPSS Analysis of Moments Structure (AMOS) software version 23.0 (Arbuckle, 2014), based on a maximum likelihood model estimation, was used for SEM. Analyses were conducted in four stages. First, the multivariate outliers were detected by checking the Mahalanobis distance at p = .001 (Osborne & Overbay, 2004). Second, descriptive statistics and Pearson's correlation coefficients (r) were obtained to explore the zero-order correlations among all of the observed variables to be included in the model. Effects sizes for absolute r were interpreted as follows: > .10, small; > .30, medium; > .50, large (Cohen, 1988). Third, a confirmatory factor analysis (CFA) was conducted to examine whether the constructs were measured by the indicators with significant loadings. Finally, a structural model was tested to examine the correlations and the regressive relationships among the latent variables and whether the model had acceptable indices. The criteria for a good model fit were: comparative fit index (CFI)  $\ge$  .95; Tucker-Lewis Index (TLI)  $\ge$  .95; standardized root means square residual (SRMR)  $\le$  .08; and root mean square error approximation (RMSEA)  $\le$  .06 (Hu & Bentler, 1999).

When screening the data, the joint multivariate kurtosis value was found to be 28.70 with a critical ratio of 14.75. In order to address the issue of non-normality to further confirm the SEM model fit, a Bollen-Stine bootstrap test with 2,000 bootstrapped samples was conducted to produce a corrected chi-square *p*-value for the goodness of fit of the null model (a non-significant result indicates a good fit) (Bollen & Stine, 1992). This was followed by a comparison of whether the

parameter estimates calculated by the bootstrap method differed from those of the original maximum-likelihood based model as shown by the bias values (Nevitt & Hancock, 2001).

Attempts to improve the goodness of fit of the SEM model were carried out by adding covariance path(s), if a significant modification index (MI) coincided with a large expected parameter change (EPC) value (Saris, Satorra, & Sörbom, 1987). The above adjustments were made only under conceptual justification (Byrne, 2010). Previous research suggests that parents' relationship with the child (Kaugars et al., 2004), parents' history of asthma diagnosis (Burke, Fesinmeyer, Reed, Hampson, & Carlsten, 2003) and the child's age may affect the interrelationships between the parental psychological factors and children's asthma outcomes (Global Initiative for Asthma, 2016), they were included as control variables, analyzed as correlated with all latent constructs in the SEM model.

## 3.14.2. Examining the intervention effects between groups over time

After analyzing the cross-sectional data via SEM, the following analyses aimed at examining the intervention effects between the ACT group and the Control groups on study outcomes over the six-month follow-up period. As stated earlier (see Section 3.10 Data collection methods and procedures), the data collected from the parents who completed questionnaires and participated in this RCT were used as the baseline data (i.e., at pre-intervention) of this RCT.

To assess the between-group equivalence, the baseline characteristics of the parent-child dyads between the ACT group and the Control group were compared via Chi-square tests (or Fisher's exact tests, as appropriate) for categorical variables, and/or independent sample *t*-tests (or Mann-Whitney U tests, as appropriate) for continuous variables, respectively. Next, generalized estimating equations (GEEs)

were used to examine the changes in the child's asthma-related health outcomes and the parental outcomes between study groups and across all the assessment time points. The SPSS software for Windows, (Version 23.0; IBM Corp., 2014) was used to conduct the above statistical analyses.

**Rationale of using GEEs.** Generalized estimating equation (GEE) has several advantages, including the ability to relax the assumptions of normality and the ability to take into account the dependency of observations by specifying a particular correlation structure (Ballinger, 2004; Bell & Fairclough, 2014; Zeger & Liang, 1986). In addition, GEE is a semiparametric regression-based method which can accommodate all the participants in the analysis without the need of imputing missing values, given that if the missing data are not seriously flawed and at least one observed data are available for each participant (Ballinger, 2004; Bell & Fairclough, 2014; Zeger & Liang, 1986).

Other rationales of using GEEs are listed in here. First, the data regarding the child's health conditions, such as the average number of days that the child has asthma symptoms per week in the past four weeks, the frequency of ED visits due to asthma exacerbations in the past six months, the frequency of using other health care services (e.g., private practitioner's clinic visits, GOPC visits, hospital admissions) due to asthma exacerbations in children in the past six months, all follow the Poisson distributions, because these data are the counts of events that occur randomly in a given interval of time (Cameron & Trivedi, 2013). Further, the distribution of data regarding the psychological symptoms of parents were positively skewed (see Section 3.13 - Data entry and screening for the details). To accommodate various types of outcomes with different distributions, in GEE models, different link functions could be employed to model the relationship between independent

variables and outcomes. For example, a log link function could be served for count data, while an identity link function could be used for continuous data, respectively.

Second, the spacing of assessment time points of the parental variables (at baseline, at post-intervention and at six months post-intervention) were unequal. If using repeated-measures univariate analysis of variance (RM-ANOVA), one of the most common methods for analyzing correlated responses, the outcomes are required to have constant variance across all the assessment time points, as well as constant correlations between any two time points (i.e., assumption of sphericity) (Kwok et al., 2008). However, the assumption of constant correlations between repeated measures in this study may inflate the Type I error, as repeated measures often become less correlated with increasing time from the intervention (Ballinger, 2004). Hence, to accommodate both between-subject covariances, as well as the variations of within-subject covariances between repeated measures, the GEE model is recommended by specifying a correlation structure (Ballinger, 2004).

**Data analysis procedures of using GEEs**. In this study, the first-order autoregressive (AR(1)) working correlation structure was selected for all the GEE analyses, as for longitudinal trials, it is plausible that the correlation between consecutive measurements decrease when the separation between measurement increases across time (Ballinger, 2004; Kwok et al., 2008). The change in each of the outcome measures between groups over time was measured by one GEE model, including the time, the study group, and the time-by-group interaction terms.

As stated in the study objectives (see Section 3.4 for the details), the primary outcome of this study was the frequency of ED visits due to asthma exacerbations in children in the past six months. The secondary outcomes were listed as follows:

- the frequencies of unscheduled outpatient clinic visits in the following health care service settings due to asthma exacerbations, including the GOPCs and the private practitioners' clinics, in the past six months,
- the frequency of hospital admissions due to asthma exacerbations in the past six months,
- the total number of days of hospital stay due to asthma exacerbations in the past six months, and
- 4. the average number of days per week with asthma symptoms in a four-week recall period, including days presenting with asthma symptoms, nights awakening due to asthma symptoms, days with activity limitation due to asthma symptoms and days requiring the symptom-relieving medications.

To assess the changes of the aforementioned child health outcomes (count data) between study groups over time, the GEE models that specified a log-link function and Poisson distribution were used to estimate the incidence rate ratios (IRRs) and 95% CIs. Each model included the time effect, group effect, time-by-group interaction effect and was adjusted for the following covariates: parent's relationship with the child, parent's age, monthly household income, marital status, child's age, child's gender, the types of inhaled corticosteroids use (Global Initiative for Asthma, 2016) and the season of enrollment (Teach et al., 2015).

Other secondary outcomes of this study included the PF, psychological adjustment to child's asthma, psychological symptoms, asthma knowledge, asthma management self-efficacy and quality of life of parents. To assess the changes of the aforementioned outcomes (continuous data) between study groups over time, the GEE models that specified an identity link function and a normal distribution were used. Each model included the time effect, group effect, time-by-group interaction

effect and was adjusted for the following covariates, including parents' age, relationship with the child, marital status, educational level and monthly household income (Kaugars et al., 2004). For each study group, post-hoc comparisons were then carried out to examine changes of the outcomes from baseline to postintervention, from baseline to six months post-intervention (i.e., within-group comparisons), and to examine any significant between-group differences based on the estimated marginal means derived from the GEE models.

## **3.14.3. Identifying the predictors of participation**

As noted earlier (see Section 3.10 - Data collection methods and procedures – At baseline), all the eligible parents, regardless of their participation status, were invited to complete the self-administered questionnaires in soliciting their information and their child's health information prior to the randomization. By using the data obtained from this assessment, the characteristics between the participants (parent-child dyads) and the non-participants were compared by using inferential statistical analyses, including independent sample *t*-tests, Mann-Whitney U tests, Chi-square tests, or Fisher's exact tests, as appropriate. Significant variables, if any, would be entered simultaneously into a logistic regression model. The goodness-of-fit for the model would be assessed by the Hosmer- Lemeshow test, where p > .05 indicates an acceptable fit. The adjusted odds ratios (aORs) and 95% CIs for all significant predictors (if any) would be reported.

# 3.14.4. Identifying the predictors of non-completion

The characteristics between the participants who attended (i.e., completers, 4 sessions) and those who did not attend all the assigned intervention sessions after randomization (i.e., non-completers, 0-3 sessions) were compared by carrying out inferential statistical analyses, including independent sample *t*-tests, Mann-Whitney

U tests, Chi-square tests, or Fisher's exact tests, as appropriate. Significant variables, if any, would be entered simultaneously into a logistic regression model. The goodness-of-fit for the model would be assessed by the Hosmer- Lemeshow test, where p > .05 indicates an acceptable fit. The adjusted odds ratio (aORs) and 95% CIs for all significant predictors (if any) would then be reported.

# 3.15. Summary

This chapter presents the methods of the study. This study aimed to examine the efficacy of a parental training program using group-based ACT in addition to asthma education (ACT Group), in comparison with an asthma education talk (Control Group), on the frequency of emergency department (ED) visits due to asthma exacerbations in children, and other health outcomes of the parent-child dyads over a six-month follow-up period, measured at six months post-intervention.

A two-arm RCT design with repeated measures was adopted. Hong Kong Chinese parents and their children aged 3 to 12 years who had received a physician's diagnosis of asthma and without significant co-morbidities were consecutively recruited in a public hospital in Hong Kong between January and May 2016. Using a permuted block randomization of six, the parent-child dyads were randomly assigned either to the four weekly sessions of group-based ACT plus asthma education (the ACT group), or to an asthma education talk as the usual care provided by the study hospital plus three weekly telephone follow-up calls for assessing the child's asthma conditions (the Control group). The goal of ACT was to enhance the psychological flexibility (PF) of parents, enabling them to: (1) become aware of their thoughts and feelings regarding their child's asthma, (2) accept and adapt flexibly to challenging situations, and (3) take actions to achieve valued goals in childhood asthma management. Throughout the four ACT sessions, six ACT therapeutic processes

were applied interchangeably, which were contacting with the present moment, defusion, acceptance, self-as-context, values and committed action. Metaphors, experiential exercises and brief mindfulness exercises were adopted. The groupbased ACT intervention was delivered by the trained research investigator (Ms. Yuen-yu Chong., Ph. D candidate) according to an ACT intervention protocol. All the ACT sessions were videotaped under the parental consent for fidelity assessments.

The primary outcome of this RCT was the frequencies of visits to EDs due to asthma exacerbations in children in the past six months, measured at six months post-intervention by parental reports. The secondary outcomes concerned the physical health outcomes of children, including unscheduled health care service visits due to asthma exacerbations and asthma symptoms of children, as well as the PF, psychological adjustment to the child's asthma, psychological symptoms (symptoms of anxiety, depression and stress), asthma knowledge, asthma management self-efficacy, and quality of life of their parents. Both children with asthma and their parents were followed-up and assessed from baseline till at six months post-intervention. The effects between the ACT group and the Control group over time on all the study outcomes were examined by adjusted GEE models.

Apart from examining the intervention effect, a process evaluation was conducted, aiming at: (1) identifying the predictors of participation, (2) identifying the predictors of non-completion of the assigned intervention sessions, and (3) describing the characteristics of parent-child dyads who were lost to follow-up.

# **CHAPTER FOUR**

# **INTERVENTION PROTOCOL**

# 4.1. Introduction

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- 4.10. Summary

#### **4.1. Introduction**

This chapter presents the details of an intervention protocol. This protocol serves to guide the interventionist (i.e., the therapist) to deliver a parental training program using group-based Acceptance and Commitment Therapy (ACT) in addition to asthma education to a sample of Hong Kong Chinese parents of children with asthma in the main RCT study.

This chapter starts with a description of the stages of developing the intervention protocol. At the beginning, literature encompassing ACT therapist books and training manuals, experimental studies that applied ACT on parents with positive health outcomes in children diagnosed with a range of chronic health conditions, as well as the international asthma management guidelines were reviewed. A sample of 14 Hong Kong Chinese parents were interviewed to gain a better understanding of their caregiving experiences related to childhood asthma. Data collected through literature reviews and qualitative interviews were used for the initial protocol writing. Next, the protocol was reviewed by a panel of experts, including a psychologist, an ACT researcher (Chief Supervisor), an Advanced Practice Nurse and a pediatrician for feedbacks, its trial version was pilot-tested in a sample of eleven Hong Kong Chinese parents of children with asthma recruited from the study settings of the main RCT study.

This chapter also presents an overview of the parental training program using group-based ACT and asthma education, including the goal, the structure, the key features of the program, and the credentials of the therapist. The ACT components and asthma educational components implemented in each session of the program

were then outlined. A step-by-step guide of how each session had been conducted in the main RCT study is described. The fidelity assessment of the ACT components in the program, as well as the strategies in handling missed sessions and late comers are reported at the end of this Chapter.

# 4.2. Development of the intervention protocol

Using protocols is one of the methodological strategies to enhance the standardization and consistency of delivering a psychotherapeutic intervention (Waltz, Addis, Koerner, & Jacobson, 1993). In this study, the parental training program consists of two important elements: ACT and asthma education. To the best of our knowledge, there are no existing intervention protocols covering both ACT and asthma education for parents of children with asthma. Hence, there is a need to develop a new intervention protocol serving for the target population of this study. The development of the intervention protocol composed of four stages, each stage is described in detail as follows.

# 4.2.1. Literature reviews

Three sources of literature were reviewed for guiding the protocol writing. The first type of sources was the ACT therapist books and training manuals (Harris, 2009; Hayes, Strosahl, & Wilson, 1999; Luoma et al., 2007; Wilson & DuFrene, 2009), as well as the training videos supplemented with client-therapist transcripts drawn from the authors' clinical work, showing the use of ACT in real clients (American Psychological Association, 2009). These literature provided an overview of theory behind ACT and a preliminary understanding about the actual application of ACT in real-life practice.

As shown in the literature review presented in Chapter Two, no studies have examined the efficacy of ACT in parents of children with asthma. Hence, we decided

to search for experimental or quasi-experimental studies that presented positive effects of ACT on the health outcomes of parents and/or their children with chronic health conditions, in which the chronicity of disease and the complexity of care were similar to childhood asthma, as the second type of resources used for developing the intervention protocol. These studies were identified through two sources. First was from the literature review that we conducted earlier, aiming at investigating the efficacy of mindfulness- and acceptance-based interventions, including ACT, on the health outcomes of parents and their children with physical or mental health problems (see Chapter Two Section 2.4.2 Search methods and identification of studies). Second was from other previous reviews that explored the utility of ACT in parents of children with other chronic health conditions, such as children with neurodevelopmental disorders (Graham et al., 2016; Wicksell et al., 2015). For serving the purpose of protocol development, the selected studies should also fulfill the following criteria: (1) ACT should target parents as the participants, (2) positive health outcomes in either parents and/or their children should be presented, and (3) the intervention is explained in sufficient detail for replication.

A total of five studies (with their corresponding intervention protocols) were identified. These studies investigated the utility of ACT in parents of children with a range of chronic health conditions, including anorexia nervosa (Merwin et al., 2013; Timko et al., 2015), acquired brain injuries (Brown et al., 2015; Brown, Whittingham, McKinlay, Boyd, & Sofronoff, 2013), anxiety disorders (Hancock et al., 2016; Swain, Hancock, Dixon, Koo, & Bowman, 2013), chronic pain (Wicksell et al., 2005; Wicksell et al., 2009) and sickle cell disease (Masuda, Cohen, Wicksell, Kemani, & Johnson, 2011). Overall results of these studies have shown positive improvements in the psychological flexibility and the psychological symptoms of

parents (Brown et al., 2015; Masuda et al., 2011; Merwin et al., 2013), and/or the health outcomes of their children (Hancock et al., 2016; Masuda et al., 2011; Merwin et al., 2013; Wicksell et al., 2005). Mindfulness exercises, as well as a few classic ACT metaphors were commonly used across these studies, such as the Two Mountain metaphor (Hayes et al., 1999), the Man in a Hole metaphor (Hayes, 2004), the Tug-of-War with a Monster metaphor (Hayes et al., 1999) and the Passengers on the Bus metaphor (Hayes et al., 1999). These activities were modified to fit into the context of parental management of childhood asthma, so that they could address the parental psychological needs in various situations of asthma care more appropriately.

The third type of resources was an international asthma management guideline named as "Global Strategy for Asthma Management and Prevention 2016 Update" (Global Initiative for Asthma, 2016). This guideline was chosen as it is the basis of education for childhood asthma management in worldwide (Reddel et al., 2015).

# **4.2.2.** Exploring the experiences of Hong Kong Chinese parents in caring for a child with asthma: A qualitative descriptive study

To ensure the activities (e.g., experiential exercises, metaphors, and mindfulness exercises) to be used in the group-based ACT intervention are well fitted into the parents' context, languages and life experiences, we decided to explore the experiences of Hong Kong Chinese parents in caring for a child with asthma through a qualitative descriptive study. As the interviewer (i.e. Ms. Yuen-yu Chong, Ph. D candidate) would be the interventionist to deliver ACT to parents of children with asthma, the interviews served to prepare the interventionist for conducting ACT by gaining a thorough understanding of the psychological difficulties experienced by these parents along with their child's illness trajectory. In addition, this qualitative

study served to address the lack of understanding regarding what Hong Kong Chinese parents exactly experience when taking care for a child with asthma in literature.

# Methods

**Study design and participants.** A qualitative descriptive design was chosen, because this design is appropriate for exploring the experiences of individuals situated in a particular context that have received little attention in the literature (Sandelowski, 2000). Realists recognize that social representations of truth exist and are located in the narratives of an individual's inner experiences (Maxwell & Mittapalli, 2010). A realist approach was adopted to explore how parents experienced events related to childhood asthma care as they occurred.

The study took place at one Ambulatory Care Centre (ACC) under the Department of Paediatric and Adolescent Medicine of a public hospital in Hong Kong. The ACC is a specialist outpatient clinic where children aged 18 years or below who have been diagnosed with respiratory health problems, such as asthma, allergic rhinitis, pneumonia and obstructive sleep apnea, can access medical consultation services provided by pediatricians, and receive education from an Advanced Practice Nurse on how to manage their condition. The majority of children with asthma who are under the care of the ACC had attended the emergency department at least once due to an asthma attack.

Parents were recruited if they were: (1) between 18 and 65 years old, (2) fathers or mothers who were primarily responsible for the daily care of their child with asthma, (3) living together with the index child, (4) able to communicate in Cantonese, and (5) Hong Kong permanent residents. Their children should be three to 12 years of age and possess a physician's diagnosis of asthma (International

Classification Diseases – 10 codes J45, J46) as documented in the electronic medical record. To achieve an in-depth description of a homogenous sample, parental experiences of caring for a "typical" child with asthma were chosen. Thus, parents of a child with asthma who also had mental and/or congenital problems were excluded.

Convenience sampling was employed. First, the Advanced Practice Nurse screened children's records of scheduled appointments for regular medical followups in the ACC of their respiratory health problems. Second, when a child who met the criteria for eligibility was identified, the research investigator (Ms. Yuen-yu Chong, Ph. D candidate, Y.Y.C.) contacted the parent who had accompanied the child and screened the parent for eligibility to participate in this study. Those parents who were eligible were approached, and the written informed consent of those who agreed to take part in this study were obtained.

**Data collection.** The data were collected through individual face-to-face interviews in Cantonese by the research investigator (Y.Y.C.). A semi-structured interview guide containing the following open-ended questions was used:

- "I wish you would share your experiences in taking care of a child with asthma.
   What experiences do you think are most worthy of sharing? Which were the most memorable to you? And how did you feel at the time?"
- 2. "As a parent of a child with asthma, what do you do to take care of your child?"
- "What are the most challenging situations you have faced when taking care of a child with asthma?", and
- 4. "What are the issues of most concern to you when taking care of a child with asthma?"

This interview guide was designed by the research team (Y.Y.C. and the Chief Supervisor, Y.W.M.) and refined after a pilot test involving two parents of

children with asthma. Prompts were used where necessary to encourage more detailed responses, such as, "Can you describe this in a bit more detail?" and "Please tell me more about..."

The research investigator (Y.Y.C.) is a registered nurse with experience in pediatric care and had no affiliation to any of the participants prior to the study. Prior to the interviews, the participants were invited to complete a short survey to retrieve information concerning their socio-demographic characteristics, personal and family history of asthma, and their children's clinical characteristics. Interviews were held in a private room of the ACC at a time that was convenient to the participants. The interviews were audio-recorded with the participants' permission. Field notes were taken to capture non-verbal cues. Each interview lasted between 45 to 75 minutes. Data collection continued until the research team determined that data saturation had been reached after 14 interviews.

**Ethical considerations.** Before the commencement of the study, ethical approvals were obtained from the institutional review boards of the study hospital and the university. The parents were assured that their participation would not affect the health care services that their children received. Informed written consent was obtained from all participants. Child care services were offered at the request of the parents, so that they could focus on participating in the interviews.

**Data management and analysis.** The recorded interviews were transcribed verbatim in Chinese by two trained student assistants. The research investigator (Y.Y.C.) further checked the transcripts against the audio-taped data for accuracy. Conventional content analysis following the paradigm of realism was used to detect the manifest and latent meanings from the data (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). The research investigator (Y.Y.C.) listened to the audio

recordings of the interviews and read the transcripts several times to obtain a general understanding of the parents' experiences. Next, different segments of the text were fractured into meaning units and assigned a code. Codes were chosen to retain the core meaning of the parents' experiences. The codes were then grouped into patterns and labeled under subcategories. The subcategories were grouped into main categories representing the process of the parents' experiences over time. Interpretation followed ideas of metaphorical extraction, which means that the codes, subcategories, and categories were drawn from the direct meaning of the extracted text (denotation) and, more importantly, from the contextual relationship between the text and the context of the whole interview (connotation) (Chenail, 2012). A further comparison of one part of a participant's story was made with parts of the stories of other participants, and each interview with all interviews as a whole (Chenail, 2012).

Rigor was achieved by an audit trail of all analytic decisions. For credibility, the initial codes of the transcripts of the first three interviews (with each interview lasting for 65–75 minutes) were translated from Chinese to English and independently coded by Y.Y.C. and an experienced qualitative researcher who is a native speaker of English (D.L.). The translation was carried out by a bilingual professional and was double-checked by Y.Y.C. and another qualitative researcher (Y.W.M.). To ensure plausibility, Y.W.M. also independently scrutinized the codes and sub-categorizations from all of the translated transcripts. Regular meetings of the entire research team (Y.Y.C., D.L., and Y.W.M.) helped to resolve any differences in coding and to refine the analysis to determine the final categories. Notably, all team members were nurses with clinical expertise in child and adolescent health, and both Y.Y.C. and Y.W.M. are bilingual in English and Chinese. Last, transferability was

attained by comparing the key findings with existing literature about parents of children with asthma and other similar chronic illnesses.

# Results

**Recruitment and the characteristics of the participants.** Between April 2015 and August 2015, 14 out of the 18 parents who were approached, all of them mothers, agreed to take part in interviews. Three fathers refused to participate in the interviews, saying that they were unfamiliar with their child's asthma condition. One mother left during the interview as she was pregnant and feeling unwell. Her data was excluded from the analysis.

The demographic characteristics of the parents and their children are shown in detail in Table 4.1. The mothers ranged in age from 30-54 years; two of them were working mothers, while the rest were housewives. Out of 14 interviewed mothers, five had a history of asthma, one mentioned that both parents (father and mother) had a history of asthma, and one stated that two children in her family had asthma. The children ranged in age from three to 10 years. They had been diagnosed with asthma at preschool age (1-5 years) and the majority (12 out 14 children) needed inhaled corticosteroids (ICS) for at least six months to control their asthma symptoms. At the time of the interviews, eight children presented with asthma

Parent's information							Child's information			
Participant	Relationship with the child, age, marital status	Level of education, occupation	Monthly household income (HKD)	History of asthma	Other family members' history of asthma	Gender, age	Age of asthma diagnosis	Current use of ICS for at least 6 months	Average number of days with asthma symptoms per week in the past 30 days	
01	Mother, 30, married	Secondary, housewife	25000- 50000	No	Child's elder brother and sister	Male, 4	2	No	No symptoms	
02	Mother, 32, married	Secondary, housewife	10000- 25000	No	Father	Male, 6	5	Yes	1 day with symptoms	
03	Mother, 35, married	Secondary, housewife	<10000	No	No	Male, 10	4	Yes	1 day with symptoms	
04	Mother, 38, married	Secondary, housewife	10000- 25000	No	No	Female, 5	2	Yes	5 days and 5 nights with symptoms, 5 days requiring reliever therapy	
05	Mother, 54, married	Primary, housewife	25000- 50000	Yes	No	Female, 4	3	No	No symptoms	
06	Mother, 36, married	Secondary, housewife	10000- 25000	Yes	Father	Female, 3	2	Yes	2 days with symptoms, 2 days requiring reliever therapy	
07	Mother, 36, married	Secondary, housewife	<10000	Yes	No	Female, 6	2	Yes	No symptoms	

# Table 4.1. Characteristics of the parents interviewed and their children

08	Mother, 35, married	Secondary, housewife	10000- 25000	No	No	Female, 8	2	Yes	No symptoms
09	Mother, 36, married	Secondary, housewife	23000 10000- 25000	Yes	No	Male, 5	2	Yes	No symptoms
10	Mother, 36, divorced	Secondary, housewife	<10000	No	Father	Male, 4	1	Yes	4 days and 4 nights with symptoms, 4 days requiring reliever therapy
11	Mother, 45, married	Secondary, housewife	10000- 25000	No	No	Male, 7	1	Yes	2 days with symptoms, 2 days requiring reliever therapy
12	Mother, 38, married	Secondary, manager	25000- 50000	Yes	No	Male, 9	3	Yes	1 day with symptoms, 1 day requiring reliever therapy
13	Mother, 35, married	Secondary, housewife	<10000	No	No	Male, 3	3	Yes	No symptoms
14	Mother, 47, married	Secondary, manager	10000- 25000	Yes	No	Male, 8	3	Yes	2 nights with symptoms, 2 nights requiring reliever therapy

*Note.* HKD = Hong Kong Dollars (1 United States Dollars = 7.8 HKD); ICS = inhaled corticosteroids. Reliever therapy refers to the inhaled short-acting bronchodilators for a quick relief of the child's asthma symptoms.

The mothers' experiences of caring for a child with asthma were organized into five categories: (1) uncertainty and fear about controlling asthma when asthma was diagnosed; (2) the recurrence of asthma, leading to a search for ways to endure the condition; (3) working through the challenges of controlling asthma; (4) ongoing distress as the asthma continued; and (5) learning to manage asthma better after accumulating experience.

In the following sections, symbols and numbers are used to differentiate the participants (M = mother, interview number, personal/family history of asthma, son/daughter, child's age).

# Category one: Uncertainty and fear about controlling asthma when asthma was diagnosed

Subcategory 1: Becoming aware of what asthma looks like when the child is young

When the research investigator invited the mothers to share "their most memorable experience" of caring for their child with asthma, it quickly became clear that they had felt stress at that moment.

The majority of the interviewed mothers shared stories of when they had encountered an asthma attack that caused their child to be unable to breathe. Even when the attack happened from six months up to six years ago, they were all able to recall in vivid detail how it started. In general, the mothers described asthma attacks that began when their child was of preschool age as something that "just happened all of a sudden." The high-pitched wheezes, which they described as "he he" sounds, recurred with no recognizable patterns. This created distress, which intensified when a diagnosis of asthma was not being confirmed (which some parents suspected their child had). Rather, physicians pronounced that the child was suffering from "flu" or

from "bronchial hypersensitivity." Without a confirmed diagnosis, the mothers found it difficult to make sense of what was happening to their child.

Subcategory 2. Becoming aware of and responding to the life-threatening nature of asthma

As long their child was unable to breathe properly, and demonstrated other distinguishable signs, such as a loss of energy or an inability to express words, or made more wheezing sounds, many mothers realized that this scenario was a medical emergency and their child's life was in danger. Fear and frustration were evident as they thought that their child could die in their arms. The following two quotations exemplify how emotionally the mothers reacted:

I was definitely in great fear ... when we [she and the child's father] arrived at the hospital. I did not dare to release my arms. (M6, both parents had asthma, daughter aged 3)

She was just like, losing her breath and saying, 'hah mommy, hah mommy....' You could exactly feel that she ... really didn't have any energy to talk. At that time, I was definitely in a great fear... (M4, no personal/family history of asthma, daughter aged 5)

Category two: The recurrence of the asthma, leading to a search for ways to endure the condition

Subcategory 1. Enduring suffering during acute asthma attacks

All of the interviewed mothers reported that their child had paid at least one visit to the emergency department due to an asthma attack. Five children required hospitalization for three to five days. According to the hospital's policy, only one parent, preferably mothers, was allowed to stay with the child during the hospital admission. Some of the interviewed mothers witnessed the efforts of clinicians to

control the asthma, such as by oral suctioning or administering a bronchodilator. They reported feelings of heartbroken and a sense of helplessness when witnessing their child's struggles. One mother became emotional when she described the scenario:

> I ... was staying outside and watching him, and [the doctors] did the blood taking, when [I was] listening to him and he was shouting: "Mommy! Mommy! Help me! Help me!" I was sitting in a chair and just could not stop crying myself. The tears ... it's a kind of feeling of being stabbed by a knife.... I felt that I was useless, helpless too. (M11, no personal/family history of asthma, son aged 7)

Another mother described the moment when the nurses asked her to assist her young child in receiving the inhalation therapy at the bedside. She closely witnessed how her child struggled:

> I didn't sleep during the [hospital] stay, as for every two hours I needed to give him the inhaler. At that time, he was small – asking him to inhale the medication through the mask was indeed a misery to him. He simply pushed it away ... but he just kept on struggling and moving around.... I had to grab him for the next dose again... (M1, other children had asthma, son aged 4)

Many mothers highlighted the experience of staying overnight in a hospital ward without adequate facilities for rest as "the toughest experience to endure." A few of them perceived that the treatment offered in the hospital, for example inhalation therapy, was something that they could have managed themselves at home. As such, these mothers reported that

they were reluctant to go to the hospital again unless they perceived that their child "was on the verge of death."

#### Subcategory 2. Enduring suffering whenever asthma recurs

Given that asthma attacks in young children could recur unpredictably, the suffering that the mothers endured continued. In general, when the mothers suspected something "different" about the sound of their child's breathing, they took a series of prompt actions, such as closely monitoring their child's breathing, giving their child symptom-relieving medications, and taking him/her to a nearby clinic for immediate medical advice or to a hospital to prevent life-threatening consequences. Their child's repeated coughing and wheezing prompted some mothers to remain awake all night, to monitor their child's breathing and to administer the inhaler in a timely manner. One mother said that she had not been able to sleep well for years due to her son's asthma:

In these three years, when I hear [my child] cough, I will get up at once. I am afraid that he'll have [an attack] again. The last time [he had an attack], I simply watched my child suffering, and with great fear. He just kept on struggling and crying, so that's why I have to take care of him for the whole night, and that's why I cannot sleep well now. Yes, I sleep badly, until now during the night I'll be in great fear... (M10, father had asthma, son aged four)

Subcategory 3. Distress from searching for the reasons for their child's asthma

Searching for the reason for their child's asthma was important, especially for mothers with no family history of asthma. Some of the interviewed mothers did this by comparing their child with his/her siblings or reflecting on whether they had paid

enough attention to their child's early development. For one mother, the lack of an explanation was the source of a great deal of distress:

I was in great psychological distress; [I] wanted to just cry and cry, because why did I give birth to a child to have this [disease]? (M13, no personal or family history of asthma, son aged 3)

# Category three: Working through the challenges of controlling asthma

When the interviews continued with another open-ended question: "As a parent of a child with asthma, what do you do to take care of your child?" many of the interviewed mothers gave detailed accounts of what they had done to control the asthma, which was very demanding.

# Subcategory 1. Staying alert and preventing asthma attacks

All of the interviewed mothers could list several asthma triggers: secondhand smoke, burning incense, fluffy toys, dust, perfume, cold air, and cold food and drinks. Some of the mothers monitored these triggers, and others firmly prevented their children from coming into contact with them. Furthermore, many of the mothers believed that the "blue inhaler" was a life-saving bronchodilator that had to be administered regularly overnight to prevent nocturnal asthma attacks. A few of them were very vigilant about the immediate effect on their child after using the "blue inhaler." One mother shared her strategy:

I won't offer the blue inhaler frequently at one go. First [I'd] try one puff; if he's okay then I'd stop. If he's not that okay, then I'd offer him another puff. I mean I try to avoid giving too much medication to my child. Then, after one to two minutes, I'd ask him whether he felt easier to breathe... (M14, has a personal history of asthma, son aged 8)

#### Subcategory 2. Keep trying different ways to get control of a child's asthma

A few of the mothers explored different kinds of complementary and alternative dietary therapies, such as "boiled crocodile meat soup" (M6, M7, M9, and M14); "boiled gecko soup" (M7); "boiled fritillary bulbs" (M7, M14), and moxibustion therapy (M14) (a non-invasive procedure that involves burning herbal materials on or above the skin at acupoints to alleviate symptoms). All of these soups or herbs were considered effective over the long term at strengthening a child's health to improve his/her asthma. As one mother put it:

It's just like doing homework – you've got to do it every single day; otherwise you can't see the effect on him [the child]. (M11, no personal or family history of asthma, son aged 7)

Subcategory 3. Working through frustration due to the unpredictability of asthma

Despite the strenuous efforts made by the interviewed mothers to control their child's asthma, many expressed disappointments when the asthma recurred after a year had gone by without an attack, when they had come to believe that it had "disappeared." Repeated hospital admissions led the mothers to lose confidence and to feel powerless. One mother said:

In the last year I was thinking it should be alright. But then, all of a sudden, it [the asthma] came again.... There was nothing further that we could do, and she finally needed to take oral steroids for three days.... Okay, my child was finally settled and discharged [from the hospital]. But, then, not less than a week later, [she] wheezed and was admitted again. Then, [she] had the oral steroids again... (M4, no personal or family history of asthma, daughter aged 5)

Another mother reflected that she had "overlooked" the recurrence of asthma:

Asthma is something that I can't control. Why, when he [her child] got an attack, did it come all over again? (M3, no personal/family history of asthma, son aged 10)

Subcategory 4. Conflicts with others surrounding daily asthma care

A few of the interviewed mothers described their concerns as misunderstood by others. This was particularly common, as their children appeared mostly asymptomatic. They often heard others say: "There's no need to be that nervous" or "It's only a cough."

Misunderstandings were more pronounced when they involved family members. For instance, some of the interviewed mothers would be questioned by their spouse for hastily seeking medical advice for their child's flu-like symptoms. Some fathers, who were smokers, might not comply with instructions to keep their child away from tobacco smoke. Furthermore, extended family members were expected to comply with house rules to avoid potential asthma triggers, such as avoiding fried snacks or cold drinks. When these rules were not followed, conflict ensued. One mother stated her resentment in this way:

I told them [the extended family members], please don't let him [her child] have any junk food or soft drinks, okay? But sometimes they just let my child drink and say something like, "Come on, wouldn't it be too harsh for a kid to not enjoy cold drinks?" But I said, "It'll be even harsher for me if you attempt to let the child try it once! (M9, had a personal history of asthma, son aged 5)

Subcategory 5. Searching for the best possible health care service suitable for the family

When a child suffered from an acute asthma attack, most of the mothers immediately sought medical help from the emergency department of a public hospital. However, they stated that this did not guarantee that their child would receive immediate treatment. As one mother recalled:

When the triage nurses spot that your child's oxygen saturation is fine, they obviously won't act fast. (M8, no personal/family history of asthma, daughter aged 8)

On the other hand, some of the mothers appreciated the efficiency and comprehensiveness of the medical investigations provided by private hospitals but were deterred by the cost. Another mother stated:

If it's financially affordable, I'd rather choose a private hospital for my child. (M6, father had a history of asthma, daughter aged 3)

In addition, finding a pediatric respiratory specialist in HK was challenging. One mother recalled that it was "by luck" that she had met a private practitioner who immediately offered inhalation therapy to her child. She further emphasized:

In fact, it is really difficult for the parents. First, I didn't know where I should find [the specialist]; second, who is a good one? (M12, had a personal history of asthma, son aged 9)

Deciding on what was "best" was further complicated by differences in the treatment strategies offered by the public and private sectors. For instance, one mother reported inconsistencies in the method of delivering inhaled bronchodilators

between the private clinic (via nebulizers, which she had been taught to use) and the public hospital (via aero-chambers). She said that a nurse working in a clinic of a public hospital once told her the following:

As you didn't really know how to use it [aero-chamber], this led to the fact that he [the child] couldn't take in all the medication powder.' But that was not the case. (M10, father had asthma, son aged 4)

#### Category four: Ongoing distress as the asthma continues

When the research investigator invited the mothers to share "the issues of most concern to them when taking care of a child with asthma," they raised a number of concerns that brought them worry and stress, as their child's asthma persisted. These concerns were not at the forefront of their thoughts but became prominent as they were revealed.

# Subcategory 1. Worries about the effects on their child's learning and development

Most of the interviewed mothers expressed worry and concern about the potential negative impacts of asthma on their child's learning and development. Specifically, their child's frequent absence from school was felt to threaten the child's academic performance and social interactions with peers. Furthermore, many mothers were worried about the potential detrimental side effects of the chronic use of inhaled corticosteroids on their child's development. These include appetite loss, facial puffiness, and impaired growth (M1, M7, M9, M10, M12). In addition, a few mothers (M10, M11, M13) questioned whether their child would develop resistance to antibiotics.

## Subcategory 2. Helplessness when losing the fight against asthma

Another concern that was worth noticing was the mothers' strong desire to not only control, but to "just get rid of it [the asthma]," given that the asthma symptoms had recurred throughout the years. Those mothers believed that they possessed the gene for asthma, and perceived asthma as "something that you must carry for the rest of your life, carrying over to their child's next generation." One mother said:

If you had this disease, you dare not to try to have your own family, right? (M5, had a personal history of asthma, daughter aged 4)

Some of the mothers described a few critical moments when they encountered feelings of helplessness and a sense of "being trapped," or feeling as if "everything was just simply offensive to me." That moment was the time when the child kept wheezing frequently despite all possible preventive strategies having been tried, and the child was too small to be able to voice his/her complaints. One mother projected her anger onto her child in the following way:

Sometimes [1] would project my negative emotions directly to him [the child] and say, 'Oh! You see, other children are good at all sort of things, but why did this [the asthma] happen to you? (M3, no personal of family history of asthma, son aged 10)

Subcategory 3. Despair related to insufficient support

It was worth noticing that of the 14 interviewed mothers, two recounted feeling a sense of hopelessness and overwhelming distress when living with a child suffering from asthma. Both mothers became emotional and occasionally had to pause during the interview. One of them, who found it difficult to ask for support from others, described her feelings of despair in the following way:

You seem to have no energy every day, but deep in your heart you wish to share everything with others. But you don't know who you can talk to, as once you share you don't know how others would regard you. (M7, had personal history of asthma, daughter aged 6) The lack of spousal support triggered another mother to contemplate

suicide. She recalled:

From the beginning till now, his dad wasn't involved in anything about the care. [He] simply blamed me for not doing well enough. When she [the child] was two to three years old, she just cried for the entire night.... No matter what you did, it just failed. I was not sure what she needed! Every night was the same, and then you ... you definitely had the feeling that [you] wanted to jump from [a] height with the child. (M4, no personal or family history of asthma, daughter aged 5)

# Category five: Learning to manage the asthma better after accumulating experience

# Subcategory 1. Asthma care becomes easier when the asthma improves

Stressful experiences of childhood asthma care were emphasized in most of the interviews. However, some of the mothers who had at least two years of experience in rearing a child with asthma shared positive experiences. These mothers became familiar with the nature of the asthma and learned how to differentiate its symptoms from those of other illnesses. They shared such thoughts as, "I have full confidence now" and "asthma is not a big deal to me." In this regard, their emotional distress and the challenges that they faced in caregiving were mitigated by newly formed positive perceptions that came from learning to manage asthma.

# Subcategory 2. Building support with others

Multiple sources of support within the hospital, including patient support groups and follow-ups by specialist nurses, were highly valued by the majority of the interviewed mothers. When the responsibility for asthma management was eventually shared with their husbands, they expressed relief and were less vigilant about monitoring their children. In addition, peer support helped the mothers to ventilate their emotions and concerns. One mother expressed her appreciation of this mutual support as follows:

I felt glad that I have a friend whose son has asthma, as we're all in the same boat. We chat a lot, and we share [our thoughts and feelings] with each other. It's a very good way, as we are all up against the [same] difficulty. (M12, father had asthma, son age 6) Subcategory 3. Learning to live a normal life

As the children grew older, their asthma symptoms became less severe. The mothers described caring for a child with asthma as being "exactly the same as caring for other ordinary children." One mother with a 10-year-old son remarked:

You need to take a long time to understand ... but once you accept the fact that the child has asthma, face it with an open mind and accept it, you'll feel much happier. (M3, no personal or family history of asthma, son aged 10)

# Discussion

To the best of our knowledge, this is one of the few qualitative studies to uncover the experiences of Hong Kong Chinese mothers in caring for a child with asthma. This study highlights that mothers in Hong Kong experience significant psychological distress along with their care. Consistent with the findings of other

studies conducted in other Western countries, the Hong Kong Chinese mothers in this study endured hardships in handling their child's asthma crises and daily care. They expressed feelings of uncertainty and fear when seeking emergency care services (Finnvold, 2010; Horner, 1997), and worried extensively about the recurrence of asthma attacks (Arcoleo et al., 2015; Sampson et al., 2013). The mothers also worried about the impacts of asthma on their child's learning and future development (Cheng et al., 2010), the side effects of medications (Klok et al., 2011), and the risk of drug dependence (Klok et al., 2011).

Moreover, as reported elsewhere, the mothers in this study mentioned that conflicts with others arose over managing the asthma, such as when family members held different perceptions of how to handle the asthma symptoms, and when there were disagreements over the asthma management routines at home (Chen, Huang, Yeh, & Tsai, 2015; Kaugars et al., 2004). The mothers also stated that a lack of support from their spouse exacerbated their distress, which was similar to the findings in other studies on Hong Kong Chinese families rearing children with chronic and behavioral health problems, such as eczema (Cheung & Lee, 2012), autism (Lam & Mackenzie, 2002), and attention deficit hyperactivity disorder (Ma & Lai, 2014).

However, in contrast with the findings of other studies, the distress of the Hong Kong Chinese mothers in this study was not necessarily resolved with emergency medical care for their child's asthma attacks (Shaw & Oneal, 2014), nor from being involved in treatment decisions (Dickinson & Dignam, 2002). Rather, some mothers felt heartbroken and continued to express some degree of helplessness for much longer periods than others. Notably, although some of the interviewed mothers learned to better manage their child's asthma over time, this process was

marked by a tendency to negatively evaluate their role as parents, the asthma prognosis, the adequacy of family support, and the adequacy of the health care system as a whole. In this study, the mothers' perceptions of guilt seem more pronounced than that of parents of children with asthma in other studies, who similarly perceived an inability to safeguard their child's health (Borhani, Asadi, & Mohsenpour, 2012; Finnvold, 2010; Stepney, Kane, & Bruzzese, 2011).

It is worth noticing that the mothers in the interviews engaged in practicing self-blame and blaming others (and the health care service) if their child's asthma was not well-controlled. The mothers perceived that nobody could fully comprehend what they had gone through, they were distressed by this perceived lack of support from others. Blame can be regarded as a maladaptive emotional control strategy that allows individuals to avoid difficult thoughts and feelings when a stressful event occurs (Karekla & Panayiotou, 2011). As shown in the interviews, the mothers applied various strategies to control asthma, such as searching for the root causes of the asthma; avoiding environmental triggers of the asthma; using a "trial-and-error" approach to finding the most appropriate health care service, similar to the "doctor shopping" found in many countries (Sansone & Sansone, 2012); and maintaining heightened vigilance of their child's health condition. While these control strategies worked in the short term, the mothers often could not fulfill their desire to control the asthma permanently due to its unpredictability and recurrence. Hence, this desire may have exacerbated their psychological distress and created overwhelming crises, which led a few of the interviewed mothers to report a sense of extreme despair with suicidal ideations early in the process of adapting to their child's asthma. In fact, the parents in the interviews might had gone through the process of excessively evaluating unwanted emotional experiences and making deliberate efforts to control

or escape with these experiences, which could lead to greater dysfunction (e.g., managing childhood asthma ineffectively) and increased distress.

This study has several limitations. As no fathers were recruited, the findings cannot represent the experience of Chinese fathers in caring for a child with asthma. The diversity of the sample of participants was limited as the recruitment was conducted in only one study hospital. Furthermore, the mothers who were interviewed had been recruited in an ACC of one public hospital in Hong Kong, so that their child already had at least one experience of being treated by emergency care services due to a life-threatening asthma attack. Hence, the caregiving experience reported by the mothers in this study may not be transferable to other parents of children with less severe asthma. Despite these limitations, this study adds an empathetic and detailed understanding of the experiences of Hong Kong Chinese parents who are caring for a child with asthma.

# Implications for the protocol development

As shown in our qualitative interviews, the significant psychological distress experienced by Hong Kong Chinese mothers in caring for a child with asthma deserves attention. Acceptance and Commitment Therapy (ACT) posits that acceptance of psychological difficulties, awareness of life values and commitment to take value-driven actions are likely to promote better health outcomes (Hayes et al., 2006), in which ACT might be useful to parents struggling with the management of childhood asthma. Indeed, the presenting problems as identified in the parents' interviews could be viewed through the six therapeutic processes of ACT, this could help to design the ACT experiential exercises for the training program to be more relevant to the parents' contexts. Examples of the applications are tabulated as follows:

# Table 4.2

# Presenting problems shared by the parents during qualitative interviews and the

# potential application of the ACT therapeutic processes

Exemplars of presenting problems as identified in the parents' interviews	ACT processes	Purpose	Examples of experiential tasks
Restricting the child's physical activities due to fear of the reoccurrence of asthma exacerbations	Acceptance of painful thoughts, feelings and other emotions related to childhood asthma care	Opening up to difficult thoughts and feelings without struggle to control. This acceptance should not be confused with self-defeat or of toleration of negative experiences.	Drawing out the workability of control strategies (Luoma et al., 2007): To help parents in realizing that their attempts to control or to avoid experiencing fear related to childhood asthma (e.g., restricting their children to participate in physical exercises) are actually counterproductive in a long term. Learning acceptance and dropping the struggle can be a possible alternative.
Feeling frustrated by the comments given by the family members (e.g., husband) regarding her own childhood asthma management strategies and perceived that her husband did not support her	Defusion to create psychological distance from painful thoughts, feelings and other emotions	Seeing thoughts as what they are (products of language and cognition), separated from the own person's thinking	Creating a distance between a thought and a thinker (Luoma et al., 2007). The therapist can try to source from "here and now" by objectifying language as an external object in the therapy room, for example tissue paper in a box. When a parent shares his/her distressing experience, the therapist can label each thought, feeling and emotion as a tissue paper one after the other and place it on the parent's lap. Then, the therapist could say: "Look at the tissue papers which are now resting on your lap, what is your body sensation right now? They are still resting on your lap, but can you still communicate with me and the rest of our group members?"
Struggling with the fears about his/her child's	Contact with the present moment	Noticing here-and- now experiences with a non-	Mindfulness exercise (Hayes et al., 1999): To facilitate parents' increasing awareness of the here-

illness progression and future development Negative evaluation of self	Self as context	judgmental manner Taking an observer's	and-now situations with their emotional experiences (e.g., fear), rather than changing, controlling or avoiding it. A lifetime exercise (Hayes et al., 1999): To invite parents in writing
as being incapable to take care of his/her child		perspective as a sense of self	down their experiences of different moments in their life and help them to take an observer's perspective to watch all of these personal experiences.
Losing hope about the child's prognosis	Values	Knowing what really matters and meaningful	Mindfulness exercise - pick up the most unforgettable person in your life (Hayes et al., 1999): To invite parents in recalling the experience in picking up the most unforgettable person in their life, in which he or she felt intense vitality, and then clarify their own personally held values.
Non-adherence to inhaled corticosteroids	Committed actions	Taking actions that are consistent with personally held values	Setting a values-based action plan (Luoma et al., 2007): To ask parents in writing down workable goals which support their clarified values (e.g., child's vitality living) and to evaluate whether their current asthma management strategies are moving towards or away from their values. Next, the therapist facilitates parents to understand the importance of keeping commitment in the presence of psychological difficulties along their care (e.g., worry about the perceived side effects of medications)

# 4.2.3. Expert consultations

Four experts were consulted to ensure that the components of the intervention protocol were fit into the context of parents of children with asthma. The initial protocol writing regarding the ACT components was supervised by a psychologist who is an expert in facilitating acceptance- and mindfulness-based interventions. All

the ACT intervention materials, such as metaphors and experiential exercises, were prepared by the research investigator in Chinese and reviewed by the psychologist for checking their relevance to Hong Kong Chinese parents of children with asthma, for example, whether the experiential exercises fit into the context of childhood asthma management and could be understood by Hong Kong Chinese parents. The ACT intervention materials were also reviewed by an experienced ACT researcher (Chief Supervisor). Revisions were made according to the recommendations given by these two experts: (1) begin each ACT session with a brief mindfulness exercise to facilitate parents in practicing observing the self in the present state, (2) provide more time for parents to give feedbacks and experientially response to each ACT exercise rather than applying one after the other, (3) assign homework after each session and offer adequate time to review the homework in the next session. In addition, an Advanced Practice Nurse and a pediatrician specialized in pediatric respiratory care of the study hospital were also consulted to review the intervention components related to asthma education. Both experts commented that the overall content of asthma education in the training program is in line with the asthma management guidelines "Global Strategy for Asthma Management and Prevention 2016 Update" (Global Initiative for Asthma, 2016).

# 4.2.4. Pilot-testing

The intervention protocol was then pilot-tested in a sample of parents of children with asthma recruited in the study hospital in a single-group pretest-posttest design (see Chapter Five Section 5.4 for the details).

Between September 2015 and October 2015, a total of eleven Hong Kong parents, who accompanied their children with asthma for respiratory follow-up services, were conveniently recruited by the research investigator in two pediatric

respiratory outpatient clinics, which were the Ambulatory Care Centre (ACC) and a nurse-led asthma clinic, of the study hospital. In line with the structure of the training program as proposed in the main RCT study, these parents received four sessions of a training program using group-based ACT plus asthma education on a weekly basis. Each group-based ACT session lasted for two hours (90 minutes of ACT, followed by 30 minutes of asthma education), served a group of five to six parents, and was led by the research investigator (Ms. Yuen-yu Chong, Ph. D candidate) who had received training in ACT. Parents were invited to complete the self-administered questionnaires during subject recruitment in the clinics, and immediately after the fourth session of group-based ACT training program.

The feasibility of the training program was assessed by six parental measures (as adopted in the main RCT study), which were psychological flexibility (PF), psychological adjustment to the child's asthma, psychological symptoms, asthma knowledge, asthma management self-efficacy and quality of life (see Chapter Three Section 3.11 for the details of the instruments). The acceptability of the training program was assessed by using questions adapted from the Credibility and Expectations Scale (CES) (Devilly & Borkovec, 2000). Further, the session attendance was noted.

At post-test, the parents had significant improvements in their PF, psychological adjustment in terms of emotional resources, as well as asthma knowledge, asthma management self-efficacy and quality of life (all *p*s ranged from <.01 to <.05). Generally, the parents rated 8 out of 10 in all the items of the CES, indicating the acceptability of the program. Based on the experience in carrying out the pilot version of an ACT intervention, a modification was made in the

intervention protocol prior to its use in the main RCT study (see Chapter Five Section 5.4.2—Modification in the intervention protocol).

# **4.3.** Overview of the parental training program using group-based ACT and asthma education

This Section 4.3 presents an overview of the parental training program using group-based ACT for childhood asthma management implemented in the main RCT study.

## 4.3.1. Program goal

The overarching goal of the intervention was to foster the psychological flexibility of parents, enabling them to be fully aware of their own present-moment experiences, and to engage in values-driven behaviors for improving childhood asthma management even in the presence of challenges related to their child's asthma.

## **4.3.2. Program structure**

The training program was structured in four weekly, face-to-face sessions for the consecutive four weeks. Each session lasted for two hours. Six to eight parents were formed in one group with one interventionist (i.e., therapist). Once the group was formed, the same membership would be retained from the beginning to the end of group without the addition of any new members during the therapy session. This is a closed-group format, which allows the therapeutic effect of ACT to progressively emerge as the sessions continue (American Psychological Association, 2017).

Four sessions were decided as the adequate dose of intervention in the present study. As mentioned earlier (see Chapter Three Section 3.9.2 – ACT group for the details), a recent systematic review has reported that, ACT interventions

which delivered no more than five sessions could demonstrate significant improvements with medium-to-large effect sizes on various health indicators at postintervention and at follow-up when compared with the baseline (Graham et al., 2016).

Group-based approach was adopted when delivering ACT to the parents. The positive effects of delivering a group-based parental training program on the psychological health outcomes of parents are well supported by a Cochrane review (Barlow et al., 2012) (see Chapter Three Section 3.9.2 – ACT group for the details). Furthermore, the systematic review as presented in Chapter Two has revealed that mindfulness- and acceptance-based interventions, such as ACT, are commonly delivered in groups (see Chapter Two Section 2.5.2 – Study characteristics).

By participating in the parental training program, parents would receive a total of six hours of group-based ACT (90 minutes per session), and a total of two hours of asthma education (30 minutes per session). After each session, the parents received a handout of ACT and asthma educational materials.

Each session was generally structured as follows:

- 1. orientation of the session and check-in,
- 2. open the session with a brief mindfulness exercise,
- review experiences and reactions since the last session and review homework,
- implement ACT-related exercises (e.g., metaphors, experiential exercises, mindfulness exercises, small group and large group activities),
- 5. assign ACT homework,
- 6. asthma education, and
- 7. round-up the session.

# 4.3.3. Program features

There were several key features in this training program as described below:

ACT metaphors and experiential exercises. One of the distinct features of ACT being different from the rest of psychotherapies is the use of metaphors and experiential exercises interchangeably across the therapy sessions. In the main RCT study, the following metaphors and experiential exercises were used, including the Two Mountain metaphor (Hayes et al., 1999), the Man in a Hole metaphor (Hayes, 2004), the Tug-of-War with a Monster metaphor (Hayes et al., 1999), the Passengers on the Bus metaphor (Hayes et al., 1999), and the Unwelcome Guest in a Child's Birthday Party metaphor (Harris, 2009). For example, parents were invited to physically experience a tug-of-war exercise, so that they could realize that the cost of trying to control distressing emotional experiences (i.e., keep on pulling on the rope) often exacerbates the problem. Metaphors and experiential exercises offer an opportunity to participants to revisit their emotional experiences experientially during the therapy sessions, but in a safer context, so that they could observe the concrete consequence of their actions that may go unnoticed in their real-world environment, through the connection between the metaphors and their real-life situations (Stoddard & Afari, 2014).

**Mindfulness exercises.** Mindfulness is an integral part of this training program, it is not simply "meditating" or "doing an exercise," but it allows parents to cultivate an attitude of openness, acceptance and a commitment to live more consciously. During the therapy sessions, mindfulness exercises were used for guiding the evocation of important memories from parents, for example, a difficult memory in which the parent was managing his/her child's asthma attack during the nighttime; or a memory that was related to an unforgettable person in his/her life.

These exercises allowed parents to observe and to contact varied aspects of internal experiences (e.g., fear related to their child's asthma) non-judgmentally as they occur with acceptance.

Mindfulness helps parents to connect with a combination of ACT therapeutic processes, including acceptance, defusion, present-moment awareness and self-ascontext (Stoddard & Afari, 2014). The most obvious ACT connection to mindfulness is the here-and-now qualities of mindfulness itself, which is **contact the present moment**. The non-judgmental and openness posture of mindfulness captures **acceptance**. In a mindfulness exercise, when coaching parents to develop an accepting and open awareness of thoughts as thoughts, of emotions as emotions, parents are facilitated to notice these psychological experiences as an ongoing process rather than being caught by the contents of consciousness, which addressed **defusion.** When being at the present moment, mindfulness helps the parent to precipitate the experience of a sense of self that is independent of the contents of consciousness, which illustrates the observing self (**self-as-context**).

**Small group and large group activities.** During the therapy sessions, parents were divided into small groups (three to four parents in a group) for ACT-related activities, for example, parents were invited to share their experiences within their small groups after practicing a brief mindfulness exercise. These small group activities create a safe and a normalized context for the parents to mutually share their experiences. Afterwards, the therapist would invite a few members of the small groups to share their experiences back to the entire large group. These large group activities offer a learning opportunity for other parents to practice the self-as-observer and to understand how behavioral flexibility among other parents can be practiced when encountering contingencies.

# **4.3.4.** Credentials of the therapist

The therapist was the research investigator (Ms. Yuen-yu Chong, Ph. D candidate) of the main RCT study. She is a registered nurse with experiences in patient counselling and pediatric care, as well as a professional member of the Association for Contextual Behavioral Science, United States. She had received a total of 132 hours of introductory and intermediate ACT skills training from workshops led by ACT experts worldwide (see Appendix 4.1 for the references about the credentials of the therapist). Further, she had received a total of 48 hours of training (i.e., 2 hours per session on a weekly basis for 6 months) given by a psychologist (Dr. Allen Dorcas) through a guided study subject for group skills and mindfulness skills training. The therapist was qualified by the psychologist as competent enough to deliver ACT.

Prior to the commencement of the pilot test and the main RCT study, the therapist had conducted four weekly sessions of group-based ACT in a sample of four parents of children with asthma recruited from the community, under the on-site supervision by the Chief Supervisor who has extensive experience in ACT.

# 4.3.5. Overview of each group-based ACT session

Table 4.3 displays the session-by-session outline of the group-based ACT intervention.

Table 4.3

# Session-by-session outline of the group-based ACT intervention

Objective of each activity	Activity	Descriptions of each activity	ACT process(es) targeted
	SESSION ONE: V	VELCOME AND INTRODUCTION, CREATIVE HOPELESSNESS	
To let parents familiarize with their roles as the participants in an ACT- based parental training program	Introduction and informed consent	The therapist welcomes the parents, introduces the purpose, the format and the ground rules of participating in an ACT-based parental training program. The therapist reviews standard confidentiality, obtains consent, and emphasizes the commitment to the program.	
To let parents get known to each other, to establish a safe and supportive environment and to form rapport	Rapport building	The therapist invites parents to introduce themselves, including their names, their child's age and the most favorite activity when they are getting along with the child.	
To bring up the importance of taking an observer's perspective on a parent's problem	ACT metaphor illustration: The Two Mountains metaphor (Hayes, Strosahl, & Wilson, 2011)	A photo of a steep mountain taken in a high angle view is used. It is used to illustrate that parents and the therapist are still "climbing their own mountains" even encountering the areas that are steep. Parents are encouraged to remind each other to be aware of places where they "might slip" (i.e., provide an observer's perspective on a parent's problem)	
To allow parents to initially experience a way of practicing observing self in the present state	Brief mindfulness exercise: Noticing five things in a room	Open the session with an eyes-closed exercise where parents are asked to notice five things via focusing one sensation only, such as listening. After the exercise, two to three parents are asked to volunteer to share their experiences of centering themselves being at present	
To guide parents in identifying their struggles in childhood asthma care	Mindfulness exercise to guide parents in exploring	An eyes-closed exercise that parents are guided to revisit a challenging moment when they were with their child with asthma. Example of facilitation could be: " <i>I am going</i> to ask you to look at some of the things that you have experienced during the challenging	Contacting with the

and their strategies to eliminate their struggles	a challenging moment in taking care of their children with asthma	moments about your child with asthma, in your parenting life. You have a strong feeling of reaching the limits already. Try to remember as many details about the situation as you can, picture it as if you are watching a scene in a movie and place yourself in that scene. Where were you and what was happening"	present moment
		Parents are invited to share their experiences within small groups. During the facilitation, the therapist would like to know how the parents perceive their situations, how they respond to these situations and how that then function in their lives.	
		When a parent comes into contact with the pain and vulnerability, the therapist will invite him/her to observe that experience: <i>"What's it like for you when experiencing this, when you have these thoughts? How did you respond when they showed up?"</i> and check for other parents' shared experiences of pain, aiming at normalizing the experience of suffering. The therapist then lists out the strategies that the parents have been using to avoid and/or to control their experiences (i.e., control-based strategies).	
		Once a fairly exhaustive list of strategies has been created, the therapist could facilitate the parents to explore the long-term workability of those strategies.	
To facilitate parents in realizing that the strategies they have been using to eliminate/control unwanted thoughts and feelings in childhood asthma care often exacerbate the problem	ACT metaphor illustration: A Man in a Hole Metaphor (Hayes, Strosahl, et al., 2011; Luoma et al., 2007)	An experiential exercise to let parents physically experience their control-based strategies (shovels) that they have do not create a way out of the hole, but rather make it larger, thus the goal is to drop the shovel.	Acceptance
To let parents start experiencing how to be mindful with their emotional experiences when getting along with	Homework assignment	In the coming week, parents are asked to identify a challenging moment when they are getting along with their child in their parenting lives, practice mindful awareness of their experiences (e.g., thoughts, feelings and emotions) and record these experiences in a mindfulness log exercise.	

their child in their daily life			
To introduce an overview of childhood asthma	Asthma education	Parents receive the following educational information: the prevalence of asthma in children in Hong Kong, the basic etiology of asthma and the types of environmental triggers of asthma	
	SESSION TWO	O: WATCH YOUR THINKING AND EXPLORE ACCEPTANCE	
To allow parents in getting into the practice of being mindful at present state and to get centered	Brief mindfulness exercise: Arm- stretching	An eyes-closed exercise that parents are invited to notice their bodily sensations in detail during arm-stretching. After the exercise, two to three parents are asked to volunteer to share their experiences of centering themselves being at present.	
To facilitate parents in recognizing the literal meaning of their difficult thoughts, feelings and emotions as they are but not being caught up which may affect their childhood asthma care	Homework review	During group sharing, when parents start to verbalize their thoughts and emotions, defusion exercises can be applied. For example, the therapist could help the parents to create a distance between a thought and a thinker (Luoma et al., 2007). The therapist can try to source from "here and now" by objectifying language as an external object in the therapy room, for example tissue paper in a box. When a parent shares his/her experience, the therapist can label each thought, feeling and emotion as a tissue paper one after the other and place on the parent's lap. Then, the therapist could say: "Look at the tissue papers which are now resting on your lap, what is your body sensation right now? They are still resting on your lap, but can you still communicate with me and the rest of our group members?"	Defusion
To reinforce the parents' understanding about the cost of trying to control distressing emotional experiences often exacerbate the problem	ACT metaphor illustration: The Tug-of-War Metaphor (Hayes, Strosahl, et al., 2011)	An experiential exercise to let parents realize that they will soon lose the tug-of-war with their struggles, if they keep on pulling the rope harder (i.e., control-based strategies that had been used for a long time to handle their psychological difficulties related to childhood asthma care). The mission is not to win the tug-of-war, but it is to drop the rope.	Acceptance
		Example of the therapist's facilitation could be: "It seems like you are in a bit of a tug- of-war with a monster. Every time when you hear your child's coughing spell, the monster, we may call it as "the anxiety monster" will comefrom what I understand you have been in this tug-of-war for a very long time, maybe starting from the time that you	

		have queries whether your child is truly diagnosed with asthma or not. I'm wondering if	
		there is anything else you might be able to do that could change this situation"	
To consolidate the	Group activity:	An experiential exercise to let the parents experience that they could still decide the	Defusion,
parents' understanding	Acting out the	direction of the bus (i.e., valued direction) irrespective of the passengers' insistence (i.e.,	Acceptance,
about the cost of	"Passengers on the	painful thoughts, feelings or memories related to their child's asthma), if they are willing	
misapplied control and the benefits of experiential	Bus" metaphor (Hayes, Strosahl, et	to take them along for the ride rather than engaging in efforts to get them off the bus.	
willingness when working	al., 2011; Luoma et	Example of the therapist's facilitation could be: "you're driving along, and the	
towards their values	al., 2007)	passengers start threatening youYou try to calm the passengers down and follow what	
		they said. The problem with this deal is that you are no longer driving, and you must	
		give them a full attention. There are periods of your parenting life where you've really	
		intensely fought inside your mind and you have no connection with your valuesDo you	
		want to be about controlling the passengers on your bus?"	
To let parents to	Homework	In the coming week, parents are asked to identify a challenging moment related to	
experience willingness as	assignment	childhood asthma care when they are getting along with their child, practice mindful	
another option when		awareness of their experiences (e.g., thoughts, feelings and emotions) and record these	
encountering struggles in		experiences in a mindfulness log exercise.	
caring for their child with asthma		Additionally, parents are asked whether they shoese to be willing to stay with the	
astnina		Additionally, parents are asked whether they choose to be willing to stay with the	
		psychological discomfort and to continue to complete their tasks as needed. Parents are asked to describe their experiences of willingness in this homework.	
To teach parents about the	Asthma education	Parents receive the following educational information: asthma signs and symptoms,	
strategies to monitor	Astillia cudcation	symptoms monitoring and strategies of allergen avoidance. The therapist demonstrates	
child's asthma symptoms		the correct skills of using peak flow meters.	
and to prevent asthma		the context skins of using peak now meters.	
attacks			
S	ESSION THREE: BE	HERE AND NOW, YOUR OBSERVING SELF AND CLARIFY VALUES	
To allow parents to get	Brief mindfulness	An eyes-closed exercise that parents are asked to notice their bodily sensations in detail	
into the practice of being	exercise: Mindful	during sitting. After the exercise, two to three parents are asked to volunteer to share	
mindful at present state	sitting	their experiences of centering themselves being at present.	
and to get centered			

To recapture the willingness could be an alternative of control when facing difficult emotional experiences	Homework review	Parents are invited to share their experiences of challenging moments, they are asked to share whether willingness had been practiced. The therapist uses the metaphors that were stated in the previous sessions (e.g., the Man in a Hole Metaphor, the Tug-of-War Metaphor) to validate their experiences.	Acceptance
To let parents experientially practice willingness despite of discomfort	Group activity: The Eyes-On Exercise (Hayes, Strosahl, et al., 2011; Luoma et al., 2007)	Parents are asked to sit opposite their partners, close together, with knees almost touching. The therapist then guides them to make rooms for what arises when encouraging continued engagement in the exercise. Parents typically express how much they wanted to laugh or how uncomfortable they were, while the therapist could point out that for those who struggled and yet continued with exercise, they just demonstrated practicing willingness nicely.	Acceptance
To facilitate parents in developing a sense of self as observer by noticing life experiences among the rest of the parents in different perspectives	Group activity: The storyline exercise (Hayes, Strosahl, et al., 2011)	Parents are asked to plot a graph of their lifetime, indicating their ups and down ever happened in their life, followed by sharing their life experiences. After the small group sharing, the therapist gathers the parents back to a large group and asks them to share their experiences based on the following questions: "What did you notice? Are they any common things between us? Do you feel connected between us?"	Self-as- context
To let parents experience self-as-context and help them in exploring their own personally held values in their life	Mindfulness exercise: Recall your experience with the most unforgettable person in your life	<ul> <li>*An eyes-closed exercise that parents are guided to contact all the thoughts, feelings, and sensations that have shown up when they were getting along with the most unforgettable person in their life. (i.e., to experience self-as-process). Then, parents are guided to imagine what they would say to that person.</li> <li>Example of the therapist's facilitation could be: "<i>Take a moment to notice what you are thinking notice the things that you have not thought of some time ago. Notice the list of emotions that you may have. Given that you are now sitting in this room with a purpose related to your child's health and your parenting life, you have paid a lot of effect on your child and your family, what do you think the advisor will say to you?"</i></li> </ul>	Self-as- context, Contact with the present moment, Values
To facilitate parents in setting realistic goals that are in line with clarified values	Homework assignment	An exercise that invites parents to identify a valued area as the initial focus for commented actions and to develop specific plans to work on the chosen value.	

To teach parents about the	Asthma education	Parents receive education about medications to control the child's asthma. The therapist	
use of asthma medications		demonstrates the correct skills in using inhalers, together with different types of aero-	
		chambers, and the after-care of using aero-chambers.	
	SESSI	ON FOUR: COMMIT YOUR VALUES-BASED ACTION	
To allow parents to get into the practice of being mindful at present state and to get centered	Brief mindfulness exercise: Mindful breathing	An eyes-closed exercise that parents are asked to notice their bodily sensations in detail during breathing. After the exercise, two to three parents are asked to volunteer to share their experiences of centering themselves being at present.	
To facilitate parents in distinguishing between values and goals	ACT metaphor illustration: Two Kids in a Car Heading to an Amusement Park (Harris, 2009).	The therapist illustrates a metaphor, showing that the present-moment experience when heading to an amusement park (i.e. an important destination that the child values) should be embraced, rather than merely achieving the goal one after the other.	Values
To help parents in making short-term and long-term plans for their values- based actions, identifying the potential obstacles and strategies to get back to the values-based directions	Homework review	This is the Stand and Commit exercise (Hayes, Strosahl, et al., 2011). Each parent is asked to stand up, to get connected to other parents and to say what he/she is going to commit in the next day, in the following week and in the following month that are connected with their chosen values (i.e., the tiniest step that is potentially achievable), and their strategies to deal with their psychological barriers.	Values, Committed Action
To teach parents about the management of childhood asthma attacks	Asthma education	To provide education about the management of asthma attack in young children and the use of a written asthma action plan	

*Note.* \* The Bull's eye exercise (Harris, 2009) was used in the pilot study for facilitating parents in clarifying values and setting-up values-based goals. After the pilot study, this exercise was replaced by a mindfulness exercise that parents are guided to revisit the experiences when they were getting along with the most unforgettable person in their life. Then, parents are guided to imagine what they would say to that person. This exercise was derived by the Sweet Spot exercise suggested by Wilson and colleagues (2009), by simply asking what matters the most to the parents (Wilson & DuFrene, 2009). Next, as a homework assignment for preparing the last ACT session, parents are asked to develop specific plans to work on their chosen value. For the rationales of this modification, please see Chapter Five Section 5.4.2: Modification in the intervention protocol for the details.)

The following Section 4.4 to Section 4.7 present the detailed session-by session instructions of how a training program using group-based ACT for childhood asthma management can be implemented in parents of children with asthma. Each section composes of a description of one ACT session, including the following information: (1) session objective(s), (2) session rundown and preparation of materials, (3) content of ACT intervention and asthma education.

To facilitate readers for a better understanding of applying ACT in the context of childhood asthma care, examples of parents-therapist dialogue are illustrated.

# 4.4. Session One: Welcome and introduction, creative hopelessness

# 4.4.1. Session objectives

The objectives of the first ACT session are: (1) to establish rapport between the therapist and the parents, (2) to facilitate parents in realizing that the strategies they have been using to eliminate/control unwanted thoughts and feelings in childhood asthma care often exacerbate the problem, and (3) to provide an overview of asthma in young children.

# 4.4.2. Session rundown and preparation of materials

The rundown of the first session is shown as below:

- Introduction and informed consent
- Rapport building
- ACT metaphor illustration: The Two Mountains Metaphor
- Open the session with a brief mindfulness exercise: Noticing five things in a room
- Mindfulness exercise to guide parents in exploring a challenging moment in taking care of their children with asthma

- ACT metaphor illustration: A Man in a Hole Metaphor
- Homework assignment
- Asthma education

The following materials shall be prepared for the Session One: (1) pens, (2)

flipchart, (3) eye shields, (4) PowerPoint slides, handouts, and homework (see

Appendix 4.2 for the details).

# 4.4.3. Introduction and informed consent

The opening of the first ACT session is to let parents familiarize with their

roles as the participants in an ACT-based parental training program.

Instructions. At the beginning, the therapist welcomes the parents,

introduces the purpose and the features of the program, and the ground rules of

participating in the program.

The following box shows an example of how the purposes of an ACT-based

program can be illustrated:

**Therapist:** "After you participate in the entire program, you should be able to achieve two things that can be very helpful in caring for your child with asthma. Firstly, you will learn how to approach difficult thoughts and feelings differently, so that they become less influential and less impact on you. We can call these skills as acceptance and mindfulness skills.

Secondly, you can get more familiar with your life direction, we can call as values. Values is like a compass in your life and guide you to continue to work on, especially at times when you feel struggled during your parenting journey. You will learn more in the later sessions of the workshop. Just like running for a marathon, doing voluntary service, there must be a drive deepen in your heart of why you would like to participate in unconditionally and take actions. Once you know your direction that keeps you ahead, all along the workshop I will support you in educating some important asthma management skills and hopefully you can acquire these skills and apply them to improve your child's health much better."

The therapist shall highlight the following features of an ACT-based program:

(1) Begin each session with a mindfulness exercise. The purposes of this exercise are to bring the therapist's and parents' attention into the room as a preparation for the session, and to help parents in practicing mindful awareness as a part of the overall treatment intervention.

(2) Group sharing. Parents are encouraged to actively share their experiences in caring for their children with asthma in their small groups (i.e., three to four parents in a group) and in a large group (i.e., include all the parents in the group session).

(3) Metaphors and experiential exercises. The therapist shall emphasize that this training program is different from an education talk which provides information only, several metaphors and experiential exercises would be used throughout the sessions, so as to get parents connected with their actual situations more emotionally evocative and memorable.

(4) Homework assignments. Parents are told that at the end of each session, they will receive a homework assignment to encourage them to apply the strategies that they have learnt. There is no right or wrong answer but a willingness to try is a very good start.

In addition, setting up the stage of commitment to the program is very important before the start of ACT. Ground rules should be written clearly on a flipchart (or a screen) for every parent and the therapist in the group as reference along the group sessions. The therapist shall seek for the agreement from all the parents in the group before the start of the sessions. The ground rules are:

(1) be committed to participate in all sessions and be punctual,

(2) keep everything being discussed, especially the difficult experience of caring for a child with asthma, as confidential,

(3) listen and learn to make rooms for other parents' feelings without judgments, and

(4) be willing to experience with curiosity when participating in group activities and mindfulness exercises. Parents shall be prepared to expect the sense of confusion, upset or disorientation, which can occasionally occur throughout the program.

# 4.4.4. Rapport building

An ice-breaking activity is introduced to let parents get known to each other and to establish a safe and supportive environment.

**Instructions.** This is a warm-up exercise that each parent has a chance to reveal little about themselves and their positive experiences related to their children. The therapist shall firstly introduce himself/ herself briefly, followed by inviting each parent to have a brief self-introduction, for example, his/her name (e.g., how he/she would like to be called throughout the sessions), his/her child's age and the most favorite activity when he/she is getting along with the child. The therapist shall ensure that each parent in the group takes equal amount of time in the introduction.

#### 4.4.5. ACT metaphor illustration—The Two Mountains Metaphor

The Two Mountains Metaphor is illustrated (Hayes, Strosahl, et al., 2011). This metaphor involves seeing one's path up a mountain from the perspective of someone watching from afar on a different mountain. Illustrating this ACT metaphor serves two purposes: (1) to encourage parents gear in an initial discussion about the difficulties in childhood asthma care, (2) to bring up the importance of taking an observer's perspective on a parent's problem throughout the training program.

#### Instructions. The therapist shows a photo of a steep mountain taken in a

high angle view. Parents are invited to discuss the following issues:

(1) any experience in climbing up a mountain,

(2) whether the experience of caring for a child with asthma is similar to the

experience of climbing up a mountain as shown in the picture. If yes, how does the

experience looks like, and

(3) when they are climbing up the mountain, if they come across the areas

that are dangerous and steep, are they able to notice them all? How about another

person who views in another angle, like a higher angle view as shown in the picture,

can he/she be able to see the whole path clearer?

After the discussion, the therapist can illustrate this metaphor in the

following way:

**Therapist:** "Taking care of a child with asthma is like walking along a mountain with steep slopes and there are lots of dangerous places on it. All of us in here, including me, are still climbing our own mountains even encountering the areas that are steep, and we are in different positions of our own mountains. In our group, some of us may have a good view of another parent's path, just the one across the mountain, and have an advantage of being able to see from a different perspective.

> My job, and each one of you in here, is to remind each other to be aware of places where we "might slip" Together in the following sessions, we might be able to figure out a way to climb."

# 4.4.6. Open the session with a brief mindfulness exercise: Noticing five things in a room

# a room

The therapist begins the first ACT session with a brief mindfulness exercise.

The purposes of this exercise are to bring the therapist's and parents' attention "into

the room" as a preparation for the session, and to help parents in practicing mindful

awareness as a part of the overall treatment intervention. This exercise also offers an

opportunity for practicing observing self in the present state.

**Instructions.** Parents are asked to close their eyes and to notice five things that they can hear. After the exercise, two to three parents are asked to volunteer to share their experiences of centering themselves being at present. Parents usually report that they feel relaxed after the exercise, the therapist shall respond by stating that the feeling of relaxation is the by-product, but not the goal of the exercise. The exercise aims to learn awareness.

# 4.4.7. Mindfulness exercise to guide parents in exploring a challenging moment in taking care of their children with asthma

The main purpose of this exercise is to guide parents in identifying their struggles in childhood asthma care and their strategies to eliminate their struggles. In brief, parents are guided to revisit their most challenging experiences in taking care of their children with asthma. Next, the therapist facilitates group sharing, helps the parents to come into contact with all the efforts that they had been made to avoid or to control their emotional experiences, and guides them to assess their experiences of workability. This exercise mainly targets for the process of contacting with the present moment.

**Instructions.** The therapist begins this activity with a mindfulness exercise. The following box shows a dialogue example of illustration. During the facilitation, pause times are required in between for the parents to stay and to reveal their experiences.

**Therapist:** (Seek permission) "We are now going to do a short eyes-closed exercise where we will take a closer look along your caring journey. This is not a relaxation exercise, while it is to make ourselves concentrated. Are you willing to do this?

> (Get centered) "I will now ask you to sit comfortably on your chair. See if you can maintain a position that indicates alertness with a straight back without there being too much tension. Put your feet on the floor and your hands on your thighs. You can close your eyes, or you can

choose to keep your eyes open and instead just focus on a point on the floor if this is more comfortable."

(Noticing physical sensation from outwards) "I would like to invite you to start paying attention to sensations you are feeling right here and now. In this moment, in this room. See if you could notice the points of contact with the chair. The places where your body is touching the chair. Your thighs which are in contact with the seat of the chair. Your feet on the floor. Become curious and see if you can locate the sensations in one part of your body in this moment: Tingling, warmth, cold, pressure, tension? What sort of a sensation is present? Also notice how the sensations change from moment to moment. Do not try to change or to hold onto these sensations."

(Noticing breathing) "Now spend a little time paying attention to the movements and notice your breathing in your body. You might notice the sensations of the air moving out from your nostrils. Notice the feeling of your chest rising and falling. As you do this you might notice your mind drifting away from noticing your breathing – if that happens, acknowledge where your mind took you and gently bring your attention back to your breathing. Continue to notice how you breathe in ... and how you breathe out."

(Exploring struggle) "In a moment I am going to ask you some questions. See if you can let the questions stand without having to force an answer. Simply listen to the questions and perhaps an answer will come, perhaps it won't. But just let it come gently. So, ask yourself the question: What brings you in here today? What is your purpose inside? You don't need to mention it now to me while you just continue to pay attention to your breathing and explore the question. There is no right or wrong answer. And with that purpose, I am going to ask you to look at some of the things that you have felt during the challenging moments about your child with asthma, in your parenting life. Deepen in your heart, you may have a strong feeling of reaching your limits already. Try to remember as many details about the situation as you can, or picture it as if you are watching a scene in a movie and place yourself in that scene. Where were you? What was happening? Was there anything that was ongoing inside you that make you feel worried, scared stressed, or you have a sensation of discomfort...being pulled or pushed? Have a closer look at this place. Take a few deep breaths and really feel the sensation for what it really is".

(Get centered again) "Now take a few moments to sit with your struggles and your purpose in here, start to pay attention to the room again. Notice the sounds you can hear. Notice the way you are sitting and your feet on the floor. Notice that you are sitting in this group and the next person, what he/she is wearing. When you feel ready, open your eyes again"."

After the exercise, parents are divided into groups of three to four. Within the small groups, parents are invited to share their challenging moments when they were taking care of their children with asthma. The therapist shall facilitate the small group discussions based on the following three questions to guide the parents to picture themselves into that scenario: *"What did you see?" "What did you hear?" "What was the first sentence that came into your mind? What was the feeling at that moment?"* During the facilitation, the therapist would like to know how the parents perceive their situations, how they respond to these situations and how that responses functions in their lives. When a parent comes into contact with the pain and vulnerability, the therapist will invite him/her to observe that experience: *"What's it like for you when experiencing this, when you have thoughts? How did you respond when they showed up?"* and check for other parents' shared experiences of pain, aiming at normalizing the experience of suffering.

When the parents are getting back in a large group, three to four parents are invited as volunteers to share their experiences. During the conversation with the invited parent, the therapist writes down the parents' difficult thoughts, feelings and emotions (e.g., *'fear when my child coughs''*) on a whiteboard to create a mental list. Next, the therapist facilitates all the parents in the group to share what has been tried out to fix these psychological difficulties (e.g., coping strategies). Many parents may think that their psychological difficulties in caring for their children with asthma would disappear if the child's asthma symptoms are under control, hence it is expected that the parents would list out all possible strategies to control or to cure their child's asthma, such as seeking medical advice from different doctors, or searching for the best possible medication or food therapy to control the asthma symptoms.

Once a fairly exhaustive list of strategies has been created, the therapist could facilitate the parents to explore the long-term workability of those strategies. Examples of dialogues could be: *"What do you think would happen if you went inside to that particular emotion, for example, fear of your child's asthma, what would be the consequences in long-term?" "Do you think all these strategies listed here are helpful to eliminate your feeling of anxiety related to your child's asthma attack?" or <i>"What could be the cost if engaging in all these strategies as shown in here?"* Further, the therapist shall invite the parents to reflect on the list, ask them what they notice and how they feel about it. If the parents feel confused and not sure what to do next, the therapist could remind them the feeling of "not knowing" allows openness to new possibilities, the entire process could be further explored by introducing a metaphor named "The Man in a Hole Metaphor" (Hayes, Strosahl, et al., 2011; Luoma et al., 2007).

**Notes to the therapist.** There are two issues that are worth noticing for the therapist to facilitate the group discussions more efficiently.

First, some of the parents in the group, particularly those who have extensive years of experiences in caring for their children with asthma, might have an intention to rescue other parents who appear to be struggling with negative thoughts and feelings, even though such struggle is in fact getting touch in a therapeutic point for the therapist to explore the cost of experiential avoidance. Hence, the therapist shall explain to the parents that ACT is an exposure-based therapy, in which its therapeutic approach creates an opportunity for *every* parent to go through his/her individual journey with ongoing self-reflections about their experiences in childhood asthma care. In addition, the therapist shall reassure that all the parents in the group

shall work together to create an open, accepting and safe space for experience sharing.

Second, the therapist shall avoid being caught by the *content* of the parents' strategies to control their child's asthma, but rather looking for the functional category of these strategies contextually. For example, when a mother shares her strategy, such as "seeking medical advices from different doctors to control my child's asthma", the therapist may use other wordings, such as "trying harder", or "getting information from someone else". Hence, parents can realize that whether these strategies are helpful to eliminate or to control their negative thoughts and emotions in a long run.

# 4.4.8. ACT metaphor illustration- A Man in a Hole Metaphor

An ACT metaphor named as "A Man in a Hole Metaphor" is introduced to the group (Hayes, Strosahl, et al., 2011; Luoma et al., 2007). The purpose of illustrating this metaphor is to facilitate parents in realizing that the strategies they have been using to eliminate/control unwanted thoughts and feelings in childhood asthma care often exacerbate the problem. This process of facilitation could be described as "creative hopelessness" (Hayes, Strosahl, et al., 2011), as the parents begin to notice the unworkability of excessive and misapplied control to their internal experiences. This metaphor mainly targets for the process of acceptance.

In this exercise, parents are invited to physically experience their strategies (shovels) that they have been used for a long time do not create a way out of the hole, but rather make it larger, thus the goal is to drop the shovel (Hayes, Strosahl, et al., 2011; Luoma et al., 2007).

**Instructions.** Two to three parents who just shared their psychological difficulties in childhood asthma care in the previous exercise are invited to

experience the metaphor. Each of them is given an eye shield and a ball pen, they are asked to wear the eye shield. An example of illustrating the metaphor is shown in the following box.

**Therapist:** "Maybe it's like this. Suppose you all in here are being blindfolded, you are given a bag of tools (just like the pens you are holding right now) and then placed in a large field. You're told that, this is the life as a parent. Run around and this is how you are supposed to live for a life. And now you ran around. And sometimes, several years ago, you fell into a hole of the feelings of worry, helplessness, and uncertainty and guilty that you've been living with your child, even before your child had been diagnosed with asthma, as probably you've been encountering this feeling before your child's diagnosis of asthma is confirmed. It's a deep enough hole that there's no apparent way out and you wait a while to be rescued." (Parents are asked to sit down, which mimic the situation that they fall into a hole)

> "Nobody comes, and you are still blindfolded. You try to search if anything else can help you and you find several nice shovels. And these ball pens you are now holding are exactly the shovels that you are having right now. Being blindfolded and fell into a deep hole, what do you do?" (Invite parents to respond) "You grasp the handle of the shovel and then you all start digging."

"You dig with big scoops and small scoops and fast scoops and some fancy ones. You also tried different sizes of shovels. These digging methods refer to all the efforts made to control, or to eliminate your psychological difficulties. What happened if we keep on digging? Does the hole get larger and deeper?" (Invite the parents to answer)

"What is coming up right in front of us is, everyone in this room is using his/her own methods of digging and you all have been through a few rounds of it. But still here we are, in the same situation. Asthma is still there, the fear is still there, and we still dig and dig. What shall we do next?" (Invite the parents to answer)

(A few ropes were set aside for the parents who were blindfolded and very often they were still holding their "shovels". The therapist shall facilitate the parents to explore any alternatives in getting a way out of the hole. The metaphor continues to be presented in the following way)

"What if a person offers you a rope? If you don't first <u>let go</u> of digging as the agenda, you'd just try to dig with it and probably you are not aware of that there is a rope that you can reach and get you out from the hole. If you want a shovel, you've got a perfectly good one already."

"If you are honest to yourselves enough, there are two parts of you coming into your mind. One is your mind and another one is yourself. One part of you is expecting that in the remaining three sessions, I am going to teach a new strategy to get your way out from the hole, which means a new strategy to control your child's asthma so as to eliminate your fear, anxiety and sadness. You've been hunting all your life for this "new strategy" but you are going to dig deeper and deeper. However, probably there is another part of you asking: is that the life that you want to be living? Focusing on digging only? What is the way out?"

Note to the therapist. Creative hopelessness is a part of building the path to acceptance. It is important for the therapist to spend more time in this area before moving on to the next session. Further, creative hopelessness aims at pointing out the unworkability and the cost of a change agenda, this process entails exploring the difficult emotions and thoughts that the parents may have been gone through for a long time. It could be an emotionally distressing experience. Worthy to note, this process does not aim for making parents to feel "entirely hopelessness". The therapist shall remain in a compassionate place and from a place of recognition of how hard it has been for the parents in trying out to get rid of their child's asthma. When inviting parents to select the volunteered parent(s) who may have "less" emotional distress (which could be noticed during the experience sharing session). In addition, the therapist shall keep a safe environment and check for other parents' shared experiences of pain, aiming at normalizing the experience of suffering in the caregiving journey.

# 4.4.9. Homework assignment

This homework aims to provide an opportunity to let parents start experiencing how to be mindful with their emotional experiences in their childhood

asthma care, it also helps to prepare some groundwork for the next ACT session when conducting the defusion work.

Parents are asked to identify a challenging moment when they are getting along with their child in their parenting lives, practice mindful awareness of their experiences (e.g., thoughts, feelings and emotions) and record these experiences in a mindfulness log exercise in the coming week. Parents are asked to note down their thoughts, feelings and emotions (as many details as possible); the strategies that they have used to handle these difficult moments; and the long-term consequences if they engage in those strategies. Parents are told to complete the homework and to bring it back for the next session.

# 4.4.10. Asthma education

Parents receive the following educational information, including the prevalence of asthma in children in Hong Kong, the basic etiology of asthma, and the predisposing factors causing asthma (e.g., family history of asthma, family member's smoking history, viral infection, allergens, weather changes and emotional triggers) (see Appendix 3.1 for the detailed information).

# 4.5. Session Two: Watch your thinking and explore acceptance

#### 4.5.1. Session objectives

The objectives of the second ACT session are (1) to increase willingness by helping parents to build acceptance and defusion from language, and (2) to increase knowledge by educating parents about the strategies to monitor their child's asthma symptoms and to prevent asthma attacks.

#### 4.5.2. Session rundown and preparation of materials

The rundown of the second session is shown below:

• Brief mindfulness exercise: Arm-stretching

- Homework review
- ACT metaphor illustration: The Tug-of-War Metaphor
- Group activity: Acting out The Passengers on the Bus Metaphor
- Homework assignment
- Asthma education

The following materials shall be prepared: (1) blank papers, (2) ropes, (3) pens, (4) PowerPoint slides, handouts, and homework (see Appendix 4.3 for the details).

## 4.5.3. Open the session with a brief mindfulness exercise: Mindful stretching

The therapist welcomes the parents to join the Session Two, introduces the session objectives and begins the session by a brief mindfulness exercise. Parents are asked to close their eyes and to notice their bodily sensations during arms stretching. During the facilitation, the therapist guides the parents to pay attention to the details of bodily sensations, for example, the sensation of blood flow when raising their hands, the rubbing sensation between the clothes and the skin, or any pain sensations during arm stretching. The therapist shall provide silent pauses between instructions, from time to time parents should be reminded to gently refocus their attention on sitting. After the exercise, two to three parents are invited to volunteer to share their experiences of centering themselves being at present.

# 4.5.4. Homework review

The therapist shall review the homework assigned in Session One together with parents. The purpose of this homework review is to facilitate parents in recognizing the literal meaning of their difficult thoughts, feelings and emotions as they are but not being caught up which may affect their childhood asthma care. Defusion work begins in here.

**Instructions.** Parents are divided into groups of three to four, they are then invited to share their experiences when they feel stuck in taking care of their children with asthma in the last week, based on their homework as assigned in Session One. When the parents gather back to a large group, three to four parents are invited to share their experiences.

At the beginning, parents may have difficulty to describe their experiences particularly their thoughts, feelings and emotions. Very often their conversations move quickly over into their emotions or evaluation, it seems that parents have hooked thoughts and push them into reaction, and very likely into overt behaviors. When encountering this situation, the therapist shall walk through the thought process together with the parent, and at first, is to let the parent *stay* within their experiences. This begins to facilitate the defusion process by inviting parents in stepping back and observing the content of the mind. For example, the therapist could use the following probing questions, for example: "*Is it okay if we rewind the session to just before you said, just like acting on a television program, and see what triggers you*?" "*I'm going to ask you the very same question again, but this time all I want you to do is pause, notice what thoughts and feelings are showing right in front of you.*"

When parents start to verbalize their thoughts and emotions, at least one of the defusion exercises can be applied:

(1) Create a distance between a thought and a thinker (Luoma et al., 2007). The therapist can try to source from "here and now" by objectifying language as an external object in the therapy room, for example tissue paper in a box. When a parent shares his/her experience, the therapist can label each thought, feeling and emotion as a tissue paper one after the other and place on the parent's lap. Then, the therapist

could say: "Look at the tissue papers which are now resting on your lap, what is your body sensation right now? They are still resting on your lap, but can you still communicate with me and the rest of our group members?"

(2) Teach the limits of language in rediscovering experience (Luoma et al., 2007). This can be demonstrated by asking parents to verbally instruct the therapist to engage in a physical movement, such as walking or using a finger to touch the nose. The therapist shall response to the parent by asking him/her how to do each move as instructed. This exercise can point out the language limits that physical movement is generally learned through experience, not through instructions. Following the exercise, the therapist can suggest something like: "It's a similar case when you are struggling with anxiety and fear of your child's asthma. Your mind keeps telling you how to get rid of them and it does not help you to get out of the situation. What if we learn another way of responding to the situation you are in, something that looks like learning how to walk (or using a finger to touch the nose) than reading a list of instructions of how to walk?"

(3) Undermine the attachment of a programmed thought (Luoma et al., 2007). The therapist asks the parent to remember three numbers (for example, one, two and three). If the parent can remember, he or she is going to have a big prize. The therapist can further carry on the conversation as shown in the following box:

Therapist: "Because you are going to get \$500000 in the next session, so you have to remember that long. Let's practice and if I say what the numbers are, you are going to say?"

Parent: "One, two, three."

Therapist: "Okay and now don't forget them. Suppose we meet one month later in the asthma clinic and I am going to ask you, what are the numbers? And what are you going to say?"

Parent: "Still one, two, three."

Therapist: "How about a few months later?

Parent: ".... Oh of course that would be...one, two, three."

Therapist: "We spent few minutes on something and you carry this thought around your head possibly for the rest of your life. For example, so how about when you hear your child's cough..." (Pauses and directs the parent to answer)

Parent: "He may have another asthma attack."

Therapist: "*And when your child is playing with other children in a park...* (Pauses and directs the parent to answer)

Parent: "Oh he may have an attack!"

Therapist: *"And then when you saw a picture of a soft drink.* (Pauses and directs the parent to answer)

Parent: "Oh another attack may happen ... "

Notes to the therapist. It is necessary to integrate defusion techniques during

group discussions, which allow parents to realize how difficult thoughts and feelings

could have less impacts on them. Examples of the verbal conventions are shown as

below:

Therapist: (Treating the mind as an external object) "Can you notice what your mind is telling you right now?" or "Did you notice that your mind keeps pulling you back to your struggle about your child's asthma attack?"

(Using the language of noticing) "It is worth noticing your thoughts regarding the sides effects of steroids are coming after the other, and then followed by another and with different voices too"

(Physicalizing and using action words) "How would you respond to this feeling, fear, right now? Actively fighting it? Or pushing it away?"

# 4.5.5. ACT metaphor illustration: The Tug-of-War Metaphor

After the defusion work, the therapist could move on to the next exercise by

illustrating an ACT metaphor named as The Tug-of-War Metaphor (Hayes, Strosahl,

et al., 2011). The purpose is to reinforce parents in understanding about the cost of

trying to control distressing emotional experiences often exacerbate their problems.

This exercise mainly targets for acceptance.

Instructions. One parent, who just shared his/her recent difficult experience

in taking care of his/her child with asthma in the previous group sharing session, is

invited to experience the exercise. The therapist holds one end of the rope while the

parent is asked to hold the other end of the rope. Next, the therapist can facilitate the

parent to physically act this metaphor in the following way:

Therapist: "It seems like you are in a bit of a tug-of-war with a monster. Every time when you hear your child's coughing spell, the monster, we may call it as "the anxiety monster" will come. The monster looks very big, ugly and very strong that you try very hard to fight against it. In between you and the monster, it's a very deep hole. If you lose this tug-of-war then you will be pulled by the monster, so you don't want to lose. So, what will you do then?" (Invite the parent to respond when he/she is holding the rope)

Therapist: "If you lose this tug-of-war then you will be pulled by the monster and fall into that deep, bottomless hole. So, you pull, and the monster pulls, back and forth. From what I understand you have been in this tug-of-war situation for a very long time, maybe starting from the time that you had queries whether your child had asthma or not. I'm wondering if there is anything else you might be able to do that could change this situation" (Pause and let the parent answer, see if the parent can detect that dropping the rope is it.). What is your feeling right now when you pull the role? (Guide the parent to notice his/her bodily sensation, for example the cramping sensation over the arms, see whether he/she feels pain or tired when pulling the role.)

Therapist: "In fact, the hardest thing to see is that our job here is not to win the tug-of-war. ..... Our job is to drop the rope. Notice that "the anxiety monster" is still on the other side of the hole, it's still there but notice that once you drop the rope, you are free to move. In fact, you can place your energy and effort in other places...what about other things that you treasure the most in your life?"

# 4.5.6. Group activity: Acting out The Passengers on the Bus Metaphor

By the time after the Tug-of-War Metaphor (Hayes, Strosahl, et al., 2011;

Luoma et al., 2007), parents may start realizing how fighting with their anxiety

related to their child's asthma seems adding to the problem—anxiety plus fighting with anxiety. The therapist could move to another group activity using another metaphor named "The Passengers of the Bus Metaphor" (Hayes, Strosahl, et al., 2011; Luoma et al., 2007), which targets for the processes of acceptance, defusion and values together into a coherent whole.

In this group activity, parents can experience that they could still decide the direction of the bus (i.e., valued direction) irrespective of the passengers' insistence (i.e., painful thoughts, feelings or memories related to their child's asthma), if they are willing to take them along for the ride rather than engaging in efforts to get them off the bus.

**Instructions.** The metaphor is acted as a role play. The therapist is the facilitator of the role play and parents are invited as volunteers as: (1) a driver, (2) a valued station and (3) the passengers of the driver. The opening of this role play can be illustrated as follow: *"Taking care of a young child suffered from asthma could be stressful and sometimes we encounter psychological difficulties. Dealing with barriers and obstacles is a bit like being a driver of a bus and managing the passengers on the bus. And maybe this is what life is like. It's like a life bus"*.

The therapist shall ask a parent, the bus driver, to talk about a recent struggle that he/she has experienced with when taking care of his/her child with asthma. During the sharing, the therapist shall write down each of the parent's thoughts and feelings (e.g., fear, worry, stressed out, self-doubt, self-blaming) in a piece of paper and hand it to each of the parents who acts as a passenger. The passengers are instructed that they can be noisy at times and can even come to the front of the bus and disturb the driver. Further, the therapist would ask the parent who acts as a bus driver about what matters the most to him/her, which gives the parents a direction in

living. The therapist also notes down the values of that parent in a piece of paper and ask the parent, who acts as a valued station, to hold it and stand at one end of the room.

The role-play would have two rounds. The first round is that the driver simply follows what the passengers direct to him/her (e.g., turning left or right, asking the driver to stop). The second round is that the driver just gently looks at each passenger and keeps heading towards the valued direction. Afterwards, the therapist shall ask the parents' thoughts and feelings, including those who were acting the roles as "the bus driver", "the passengers" and "the valued station". The therapist can round up this activity in the following way as shown in the following box:

Therapist: "Suppose you are the driver of a bus. On this bus we've got many passengers. The passengers are your thoughts, emotions, memories, and other experiences related to your child's asthma. It could be related to your fear of childhood asthma attacks, self-doubt about your ability in managing asthma, sadness, or anger related to "why I give birth to a child who needs to suffer a lot?" Some of them are very nice and some of them are scary. What has happened is that in the first round, you're driving along, and the passengers start shouting at you, telling you what you must do, where you have to go, such as "You've got to turn left," "You've got to go right" You try to calm the passengers down and follow what they said.

Therapist: "The problem with this deal is that you are no longer driving, and you have to give them a full attention. There are periods of your parenting life where you've intensely fought inside your mind and you have no connection with your values. Just like in our previous role play, the driver did not have an eye contact with the "valued station". We are getting used to get rid of negative thoughts and feelings. However, if you look back from your experience, can you think of a thought or an emotion that can be eliminated in which you cannot mention now? In your entire parenting life, your passengers in your life bus would just keep on increasing.

> In the second round, I was going to reframe the choice in a different way by acknowledging, rather than reacting towards your thoughts and feelings. Do you want to be about controlling the passengers on your bus?

#### 4.5.7. Homework assignment

This homework aims to let parents experience willingness as another option when facing struggles in caring for their child with asthma.

This is a mindfulness log exercise which is similar to the ones used in Session One. In the coming week, parents are asked to identify a challenging moment related to childhood asthma care when they are getting along with their child, practice mindful awareness of their experiences (e.g., thoughts, feelings and emotions) and record these experiences in a mindfulness log exercise. While for this Session Two homework, parents are asked whether they choose to be willing to stay with the psychological discomfort and continue to complete their tasks as needed. Parents are asked to describe their experiences of willingness in this homework.

# 4.5.8. Asthma education

The therapist presents the following educational information to parents, including the signs and symptoms of childhood asthma, strategies for monitoring asthma symptoms and allergen avoidance. In addition, the therapist demonstrates the correct skills of using peak flow meters (see Appendix 3.1 for the detailed information).

# 4.6. Session Three: Be here and now, your observing self and clarify values

#### 4.6.1. Session objectives

The objectives of the third ACT session are: (1) to let parents experience an observing self, (2) to clarify personally held values, (3) to learn to differentiate between different types and indications of asthma medication, and to acquire correct skills in using inhalers, inhaler devices and the after-care.

#### 4.6.2. Session rundown and preparation of materials

The rundown of the third session is shown below:

- Brief mindfulness exercise: Mindful sitting
- Homework review
- Group activity: The Eyes-On Exercise
- Group activity: The storyline exercise
- Mindfulness exercise: Recall your experience with the most unforgettable person in your life.
- Homework assignment
- Asthma education

The following materials shall be prepared: (1) blank papers, (2) pens, (3) PowerPoint slides, handouts, and homework (see Appendix 4.4 for the details).

#### 4.6.3. Brief mindfulness exercise: Mindful sitting

The therapist welcomes the parents to join the Session Three, introduces the session objectives and begins the session by a brief mindfulness exercise. Parents are asked to close their eyes and notice their bodily sensations during sitting. During the facilitation, the therapist asks the parents to pay attention to the details of bodily sensations, for example, feeling the weight of the body on the chair, the rubbing sensation between the clothes and the skin, or any pain sensations when sitting mindfully. The therapist shall provide silent pauses between instructions, from time to time parents should be reminded to gently refocus their attention on sitting. After the exercise, two to three parents are invited to volunteer to share their experiences of centering themselves being at present.

#### 4.6.4. Homework review

The therapist shall review the homework assigned in Session Two together with the parents. The purpose of this homework review is to recapture that willingness could be an alternative of control when facing difficult emotional

experiences. More importantly, this homework can explore the progress of parents in bringing willingness in their care of a child with asthma. Acceptance work is focused in here.

**Instructions.** Two to three parents are invited to share their experiences when encountering difficult moments in taking care of their child with asthma in the past week, and more importantly, whether (and by how) the willingness has been practiced. The therapist could use the metaphors that stated in previous sessions (e.g., the Man in a Hole Metaphor, the Tug-of-War Metaphor) to validate their experiences.

## 4.6.5. Group activity: The Eyes-On Exercise

The Eyes-On Exercise provides an additional experiential learning opportunity to practice willingness despite of discomfort (Hayes, Strosahl, et al., 2011).

**Instructions.** The therapist divides group members into pairs and asks them to sit opposite to their partners, close together with their knees almost touching. Parents are asked to look their partner in the eyes without speaking or otherwise trying to communicate. The therapist guides the group to make room for what arises while encouraging continued engagement in the exercise; he/she shall also facilitate the parents to just notice the urge of being uncomfortable while still be willing to stay engaged with their partners. The therapist shall allow for a long moment of silence around two to three minutes. After the exercise, the therapist shall ask the parents to relate their experiences. Parents typically express how much they wanted to laugh or how uncomfortable they were, while the therapist could point out that for those who struggled and yet continued with exercise, they just demonstrated practicing willingness nicely.

#### 4.6.6. Group activity: The storyline exercise

After several experiential exercises in the previous ACT sessions which are working on acceptance and defusion, the therapist could proceed to work on another ACT process known as self-as-context. The purpose of the following exercise is to facilitate parents in developing a sense of self as observer by noticing life experiences among the rest of the parents in different perspectives. In brief, parents are asked to plot a graph of their lifetime, indicating ups and downs that had ever happened in their life, followed by sharing their life experiences (Hayes, Strosahl, et al., 2011).

**Instructions.** The therapist divides parents into groups of three or four. Each parent has a piece of blank paper and is asked to plot a graph indicating his/her ups and downs, around five or six major events, that occurred in his/her life. Common examples are marriages, birth of the child, deaths, and moves (to a new home, or to a new working environment). More importantly, parents are also encouraged to recall a sweet moment in time that had great impact, such as "the first time the child is able to walk".

After finish plotting the graph, parents are asked to share their stories within the small group. During the group sharing, one parent would be the case presenter who presents his/her own story for around four to five minutes. The rest of the parents in the group would be the listeners; they listen to the presenter's story without interrupting. After presentation, each listener has one minute of sharing his/her emotion, personal appreciation and any points of connection. Every parent in the group has a chance to be the case presenter. After the small group sharing, the therapist shall gather the parents back to a large group and ask them to share their

experiences based on the following questions: "What did you notice? Are there any commons things between us? Do you feel the connection between us?"

When the parents share their life stories individually within their small groups, their responses usually contain judgments, evaluations, rules, memories or roles that comprise their sense of self and what they might call as their "identity" (the conceptualized self). To highlight the notion of oneself who experiences thoughts and feelings and yet separates from the contents, the therapist could adopt the following ACT metaphor named as "An unwelcomed guest in a birthday party". This metaphor uses an approach similar to that of the Chessboard Metaphor (Hayes, Strosahl, et al., 2011), which fits in the context of parenting. An example of illustration is shown in the following box:

Therapist: "Imagine that this room is full of guests that one mother has invited to join her child's birthday party. Since this party is to celebrate her child becoming one year old, she has spent a lot of time in preparing the party and she is looking forward to a very memorable one. The day arrives, and people begin to show up. The guests enjoy their time so much. Unfortunately, one old man that she didn't know comes in. He has not dressed up properly and seems that he has poor hygiene. He is walking around the room and searching for food. So, what do you think the mother will do?

Parent: "Of course she will just ask the man to get out of the room, as he is disturbing the others."

Therapist: "I see. But he didn't leave. He just sits quietly at the corner of the room, and he is watching the mother, and other guests. But sometimes he walks around, and he is looking for food."

- Parent: "Then she may share some food that has been prepared for her child and the guests and ask him to leave."
- Therapist: "Okay and she did. But the old man is still there, he is sitting over there."
- Parent: "Then she may call the security guard to help her. As she booked the room for the party. She could do that.

Therapist: "I see, and this normally what many of us will do. While she is spending her time struggling about how to send that man away from

her party. She suddenly realizes that the party is over, and she misses something that's very important to her. Probably a precious moment that the mother and her child can have a picture together when they both blow out the candles on a birthday cake. What she discovers about this is that she is not at the party."

- Therapist: "Your thoughts and feelings about your life, including your parenting life with a child diagnosed with asthma, are like the guests in a room, some are negative, and some are positive, too. And there's also a part of you that tend to evaluate your thoughts and feelings. Like that parent, it probably tries to push away the negative thoughts, for example thoughts or experiences about your child's illness and attempts to keep the positive thoughts only. We sometimes may think, to get on with a life, a large part of our actual painful experience must disappear forever. But in that case, we can become absorbed with our internal struggles, disconnected from the outside world and the things in life that matter most to us. Like that parent, what she matters the most is the sweet moment that she can stay with her child to celebrate her child's growth. Just like the sweet moment that you all just shared in the lifetime exercise."
- Therapist: "We can become so absorbed with our internal struggles that we don't "see" the outside world. But there is another part of this metaphor: the room that contains all the guests, the mother and the child, not attempting to control them or to get rid of them. It's the context that contains them and let go. So perhaps you could be in the room that simply contains those experiences. My final question to you is: would you be willing to let the old man wander around your party if the purpose of your party is to serve the ones that you truly treasure the most?"

# 4.6.7. Mindfulness exercise: Recall your experience with the most unforgettable person in your life

To further help the parents in getting contact and experience the sense of self, this final ACT exercise can help parents to experientially increase their awareness of the observer self (Hayes, Strosahl, et al., 2011). This exercise was derived by the Sweet Spot exercise by simply asking what matters the most to the parents (Wilson & DuFrene, 2009), which facilitates parents to identify their personally held values in their life. In brief, this mindfulness exercise is an eyes-closed exercise that parents are guided to contact with all the thoughts, feelings, and sensations that have shown

up when they were getting along with the most unforgettable person in their life. The parents are guided to imagine what they would say to that person. This could be a therapeutic point that the therapist could reveal what he/she treasures the most in his/her life. This self-disclosure allows the therapist to model an accepting stance toward their own psychological difficulties, and to model the ability of carrying out value-consistent behaviors.

**Instructions.** The therapist begins this activity with a mindfulness exercise.

The following box shows a dialogue example of illustration. During the facilitation,

pause times are required in between for the parents to stay and to reveal their

experience.

Therapist: (Seek permission and get centered) "As a parent of a young child with asthma, you probably find it hard to remember the last time you sat back and considered the things that are truly important to you."
"We are now going to do a short eyes-closed exercise. Again, it is not a relaxation exercise; it is an exercise which helps us to concentrate, with some quiet time and to do self-reflection. I will now ask you to sit comfortably on your chair. See if you can maintain a position that indicates alertness with a straight back without there being too much tension. Put your feet on the floor and your hands on your thighs. You can close your eyes, or you can choose to keep your eyes open and instead just focus on a point on the floor if this is more comfortable."
(Noticing physical sensation from outwards) "Now turn your attention to just being in this room. Notice the sound which may arise in the room and outside. Notice how you are sitting on the chair. Focus on the place at which your body comes into contact with the chair. How does it feel? How does it feel to be sitting where you are sitting? Notice the place where your hands are in contact with your thighs. What are the sensations? For any sensations, just notice and acknowledge its presence.
(Think of a person that truly matters) "Think about somebody who's really important in your life. It could be a friend, a family member, or somebody who is still here or who passed away, but somebody who really stands out in some ways as being honorable and respectful. Who comes to your mind? Take a moment to notice that what you are thinking notice that the things you have not thought of some time ago. Notice the list of emotions that you may have. Given that you are now sitting in this room with a purpose related to your child's health

and your parenting life, you have paid a lot of efforts on your child and your family, what do you think the advisor will say to you? Take a moment to take a snapshot of what he/she is going to say."

(Centered again) "Now the scene fades into the background. Turn your attention back to the present, to the room you are sitting in and the sounds around you, your breathing and the chair you are sitting. Think about what your advisor says to you. If you feel ready, you can open your eyes."

After the mindfulness exercise, parents are invited to write down in a piece of paper about: (1) who is the advisor, and (2) what would your advisor say to you? Within the large group, parents are invited to volunteer to share with the group their personal stories of what they truly care about. Very often, parents would share their stories related to their own child suffered from asthma and their families. When parents are asked about the person that they treasure the most, this is what they value most that offer them a direction.

Note to therapist. This is an important exercise in the entire ACT intervention by facilitating parents in exploring their values—what truly matters to them in view of the ultimate purpose of attending the training program for improving childhood asthma care. This exercise serves to link the last ACT session, which focuses on supporting parents in taking specific actions that bring their values to life. This session deserves more time for parents to share their stories.

#### 4.6.8. Homework assignment

This homework aims to facilitate parents in setting realistic goals that are in line with their values. Parents are asked to (1) identify one valued direction, (2) decide a specific plan for actions that are in line with the values, and (3) identify the potential obstacles that could be foreseen when working towards the valued

direction. This exercise prepares the groundwork for the last session: values clarification and goal setting.

#### 4.6.9. Asthma education

The therapist presents the educational information about the medications in managing childhood asthma to parents, including the types of inhaled medication (controllers and relievers), the indications and the potential side effects of using different types of medications. Further, the therapist demonstrates the correct skills of using inhalers, together with different types of aero-chambers, and the after-care of using aero-chambers (see Appendix 3.1 for the detailed information).

# 4.7. Session Four: Commit your values-based action

# 4.7.1. Session objectives

The objectives of the fourth ACT session are to facilitate parents in establishing values-based action plan and to educate parents about the management of childhood asthma attacks.

# 4.7.2. Session rundown and preparation of materials

The rundown of the fourth session is shown below:

- Brief mindfulness exercise: Mindful breathing
- ACT metaphor illustration: Two kids in car heading to an Amusement Park
- Homework review
- Asthma education

The following materials shall be prepared: (1) blank papers, (2) pens, (3)

PowerPoint slides and handouts (see Appendix 4.5 for the details).

#### 4.7.3. Brief mindfulness exercise: Mindful breathing

The therapist welcomes the parents to join the last session of the group-based ACT intervention, introduces the session objectives and begins the session by a brief

mindfulness breathing exercise. Parents are asked to close their eyes and to notice their bodily sensations during breathing. During the facilitation, the therapist asks the parents to pay attention to the details of bodily sensations, for example, noticing the sensation of air moving through their nostrils and filling their chests. The therapist shall provide silent pauses between instructions, from time to time parents should be reminded to gently refocus their attention on breathing. After the exercise, two to three parents are invited to volunteer to share their experiences of centering themselves being at present.

# 4.7.4. ACT metaphor illustration: Two Kids in a Car Heading to an Amusement Park

The last ACT session focuses on values and committed action. The therapist illustrates an ACT metaphor, named as the Two Kids in a Car Heading to an Amusement Park (Harris, 2009), to help parents in making the distinction between goals and values. In brief, the therapist illustrates a metaphor, showing that the present-moment experience when heading to the park (i.e., an important destination that the child values) should be embraced, rather than merely achieving the goal one after the other.

**Instructions.** The therapist illustrates a metaphor describing a road trip with two kids in the back seat of a car, both are anticipating their arrival at an important destination, for example the amusement park, while it takes several hours to get there. The first kid is preoccupied with frustration, thinking about the future at when they can arrive. On the other hand, the second kid is rooted in the present moment, looking around and enjoying the sceneries when heading to the park. Both kids arrived to the destination and had a great time, but one of them had a more rewarding journey due to his values in exploring, travelling and learning about the world

outside the car, rather than focusing on the goal only. The therapist could further explain that values indicate a general direction (a life compass) while goals refer to the objectives that you want to accomplish along the way.

# 4.7.5. Homework review

The purpose of reviewing the homework assigned in Session Three is to facilitate parents in making short-term and long-term action plans for the valuesbased actions. This is the Stand and Commit exercise (Hayes, Strosahl, et al., 2011), it entails having parents to declare their values and intentions about moving forward with their life. In brief, every parent in the group is asked to stand up, to get connected to other parents and to make clear statements regarding what he/she is going to commit in the following week, the following month and the following six months that are connected with their chosen values (i.e., the tiniest step that is potentially achievable), and the potential psychological barriers when working towards the chosen values.

**Instructions.** Parents are divided into group of three. Within in the small group, each parent has a chance to share one value and the action plan. During the group sharing, one parent would be the case presenter who presents his/her plan of actions for around four to five minutes, based on the following questions: (1) What is your value that you wish to work for? (2) What are your planned goals so that you move closer to the target? (3) Any thoughts and feelings related to your child's asthma that may pull you back from acting on your chosen value? The rest of the parents in the group would be the listeners; they listen to the presenter's sharing without interrupting. After presentation, each listener has one minute of sharing his/her personal appreciation. Every parent in the group shall have a chance to be the case presenter.

After the small group sharing, the therapist shall gather the parents back to a large group. Three to four parents are invited to share their homework. They are asked to stand up, to make eye contact with other parents, and to present their work.

The following table shows an example of a mother of a child with asthma who valued parent-child relationship as an important life domain. Here is her identified value, action plan and potential psychological barriers:

Values	Goals	Obstacles
What matters to you?	What are the steps you are going to commit?	Any thoughts and feelings related to your child's illness, which pull you back?
What I matter the most is to develop a companionable relationship with my child when he grows up, so that my child will consider me as a "true friend."	In the next day, I am planning to go jogging with my child. In the following week, I will allow my child to join the sports day at school. In the following month, I will plan to have a trip with my child and my family.	My sticky thoughts are "What if asthma comes again? Will my child be able to manage by himself?" Once these thoughts come, I have hesitation in letting my child to participate in sports. I am afraid of my child's asthma will be triggered during exercise.

When facilitating the group sharing, the therapist could check whether the values-based goals set by the parents possess the following qualities: (1) be specific with small steps and large steps, (2) be meaningful and connected with the chosen value, (3) be realistic and (4) time-framed. Parents shall be encouraged that working on very small goals that are in line with their values is better than "trying to work" by using the following example:

Therapist: "It's important to take action with respect to your values, it is the willingness to jump. I am not saying that you have to jump off a cliff. You can jump off a chair (invite a parent to demonstrate) or jump off

*a piece of paper* (lay a piece of paper on the ground and invite another parent to jump off the piece of paper, using the same motion as jumping off the chair). *But whatever you do is...to jump.*"

Note to therapist. When helping parents to build patterns of committed action for strengthening their asthma management skills or behaviors, parents could be in contact with difficult thoughts and feelings that they were previously avoiding contributing to avoidance behavior that could affect their children's health and wellbeing. This could be the potential obstacles that prevent the parents from moving forward. During the facilitation, the therapist shall often remind the parents to evaluate whether the committed action plan is moving toward or away from their values. Further, the therapist shall highlight that willingness to experience pain is the key. The ACT metaphors that have been adopted in the previous sessions could be recalled in this last session to make the pain-values connection be visualized to the parents. For example, the Man in a Hole metaphor (Session One) or the Tug-of-War metaphor (Session Two) could be used to convey the message that acceptance and willingness are alternatives to struggling with the unworkable change agenda. The Passenger on the Bus Metaphor (Session Two) could be used to objectify the psychological experience as passengers that parents are currently struggling with, the importance of willingness to be in contact with those difficult experience without defense, and the benefits of focusing on a chosen action (the valued direction).

# 4.7.6. Asthma education

The therapist presents the educational information about the management of childhood asthma attacks and the use of asthma action plan (see Appendix 3.1 for the detailed information).

### 4.8. Fidelity assessment

Determining the fidelity of an intervention provides a logical inference about how the outcomes were due to the intervention (Bellg et al., 2004). Mediation analyses of ACT studies have shown that change in psychological flexibility (PF) and its six therapeutic processes mediates clinical outcomes (Hayes et al., 2006; Juarascio et al., 2013; Wicksell, Olsson, & Hayes, 2011). Hence, it is important to assess whether these processes are delivered as intended, so as to provide strong empirical evidence that the proposed ACT intervention in fostering an individual's PF is indeed responsible for the changes in outcomes (Plumb & Vilardaga, 2010).

The fidelity assessment of the ACT was implemented as follows. The therapist completed a behavioral checklist to self-evaluate her competency in delivering the group-based ACT intervention components right after each session. This checklist was originally developed as a consensus measure of assessing the treatment fidelity of ACT by experts in ACT, it was also published in A Practical Guide to Acceptance and Commitment Therapy (Strosahl & Hayes, 2004) and in the official website of the Association for Contextual Behavioral Science (ACBS) (https://contextualscience.org/complete\_the\_act\_core\_competency\_self\_assessment). The checklist contains seven core competency domains, each domain consists of multiple items with a rating scale of 1 (never true) to 7 (always true) in each (Luoma et al., 2007). These domains are: (1) ACT therapeutic stance, (2) developing acceptance and willingness/undermining experiential control, (3) undermining cognitive defusion, (4) getting in contact with the present moment, (5) distinguishing the conceptualized self from self-as-context, (6) defining valued directions and (7) building patterns of committed action (Luoma et al., 2007) (see Appendix 4.6 for the fidelity checklist for each ACT session).

In addition, all the ACT sessions were videotaped for supervision and fidelity purposes after the parents provided their written consent. The videotaped sessions were then independently reviewed by the Chief Supervisor. Weekly meetings were held between the therapist and the supervisor to ensure protocol adherence and competence in delivering ACT. Self-rated competency was agreed by the supervisor. For each ACT session, the therapist made session notes and recorded areas for improvements in delivering ACT. Further, to avoid the ACT skills drift over time, the therapist met the psychologist, who has extensive experience in acceptance and mindfulness-based intervention, in a monthly basis for training the delivery of ACT metaphors and mindfulness exercise. The results of the fidelity assessment are presented in Chapter Six Section 6.7.4.

### 4.9. Troubleshooting-missed sessions and late comers

Ideally, the group session begins when all parents are present and punctual and runs without interruptions until it ends. However, it is difficult to approximate these conditions, as parents might have other unplanned commitments that make them unavailable to attend the sessions. Besides, some parents may feel that the group can still move on in a significant way even with his/her absence. When a parent who missed the previous ACT session rejoins the group, other group members or the therapist can recap what had happened in the last session. However, it might not fit well with the ACT model which focuses on experientially-driven behavioral change.

Hence, when facilitating the ACT sessions, the therapist should share the expectations as a participant in the ACT group before the first ACT session begins, including the commitment to attend every session and the punctuality. In this study, parents were invited to agree to the regulations regarding session attendance: (1)

come to all sessions on time and stay for the entire time, (2) inform the therapist in advance if the parent is going to miss or to be late in the next session. At occasions, a ten-minute window period for late arrivals was provided. In addition, the parents received weekly reminders of session attendance and punctuality via text messages after attending each session. If the parent missed a session, he/she would receive the corresponding ACT session materials via mail within three days, before the next ACT session begins in the coming week. The therapist would contact the parent via telephone and introduced the ACT materials.

# 4.10. Summary

This chapter presents the intervention protocol that guides the interventionist (i.e., therapist) to deliver a training program using group-based ACT for childhood asthma management serving for the parents of children with asthma in the main RCT study. The intervention protocol was developed based on a series of ACT literature; findings of a qualitative interview of fourteen Hong Kong Chinese parents in taking care of a child with asthma; advice from a panel of experts in ACT and pediatric asthma education (a psychologist, an ACT researcher, an Advanced Practice Nurse and a pediatrician); as well as the results of a pilot study testing the feasibility and acceptability of the training program.

The overarching goal of the training program using group-based ACT was to foster the psychological flexibility (PF) of parents, enabling them to be fully aware of their own present-moment experiences, and to engage in behaviors in the service of chosen values even though difficult emotional experiences occur. The training program was structured in four weekly, face-to-face sessions for the consecutive four weeks. Six therapeutic processes of ACT, including acceptance, defusion, self-ascontext, contact with the present moment, values clarification and committed were

applied interchangeably across the ACT sessions by using ACT-specific experiential exercises, metaphors and mindfulness exercises. All the ACT sessions were delivered by a trained research investigator (Ms. Yuen-yu Chong, Ph. D candidate) with fidelity monitoring and ongoing supervisions by an experienced ACT researcher and guided by session-by-session instructions in the intervention protocol.

# **CHAPTER FIVE**

# PILOT STUDY

## 5.1. Introduction

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asthma

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### **5.1. Introduction**

This chapter presents the details of a pilot study, which was divided into two stages. The first stage aimed to validate a self-administered questionnaire for soliciting information from Hong Kong Chinese parents of children with asthma. The second stage aimed to determine the feasibility of subject recruitment, the feasibility and the acceptability of a parental training program using group-based ACT for childhood asthma management in Hong Kong Chinese parents of children with asthma. Findings of each stage of the pilot study are summarized and presented at the end of the chapter.

### 5.2. Purposes of the pilot study

Pilot studies play an important role in guiding the development and refinement of a novel intervention and study procedures (Leon, Davis, & Kraemer, 2011), it also helps to examine whether the proposed approach is feasible to be carried out in the larger scale study (Leon et al., 2011).

A pilot study was conducted prior to the commencement of the main RCT study. The first stage of the pilot study was to test the psychometric properties of the measures used in the questionnaire (see Appendix 3.2), and the feasibility of using the self-administered questionnaire in soliciting information from Hong Kong Chinese parents. This questionnaire was a key data collection tool in the main RCT study. It was designed to collect information concerning the health conditions of children with asthma, the psychological health and the asthma management aspects of their parents. As stated in Chapter Three Section 3.11, the measures adopted in the questionnaire demonstrate adequate psychometric properties in different studies and

population groups. Nevertheless, to further strengthen the validity and reliability of assessments when conducting the main RCT study specifically for Hong Kong Chinese parents of children with asthma, the psychometric properties of the measures adopted in the questionnaire needed to be further examined. Furthermore, the questionnaire would be self-administered by parents. Hence, the feasibility of administering the questionnaire, in terms of its readability and the time required for completion, were also explored.

The second stage of pilot study was to determine the feasibility of subject recruitment, the feasibility and acceptability of a training program using group-based ACT for childhood asthma management in Hong Kong Chinese parents of children with asthma. As noted earlier in Chapter Two, ACT has not been examined in parents of children with asthma, nor in a Hong Kong setting. Hence, the pilot results can inform researchers about the modifications required when planning for the main RCT study.

The following sections describe each stage of the pilot study in detail.

### 5.3. Validation of the self-administered questionnaire

The first stage of the pilot study aimed to validate the self-administered questionnaire and to determine its feasibility for self-completion by parents. Three phases were involved in this stage. The first phase was to translate an instrument, named the Parent Asthma Management Self-Efficacy Scale (PAMSE), from English to Chinese; the second, to establish the content validity of all the items in the questionnaire; and the third, to assess the internal consistency and test-retest reliability of these items. Each phase is described as follows.

### 5.3.1. Phase one: Instrument translation

In the questionnaire, an instrument that was used to assess the asthma management self-efficacy of parents is the 13-item of the Parent Asthma Management Self-Efficacy Scale (PAMSE) (Bursch et al., 1999). No published reports can be found on its translation into Chinese and its psychometric properties in Chinese parents of children with asthma.

The translation of the PAMSE was conducted in the following steps. First, approval of translating the original PAMSE into Chinese was obtained from the original author, Professor Brenda Bursch. Second, the original English version of the PAMSE was forward-translated into Chinese by three independent translators, who were all native Chinese (Cantonese) speakers, bilingual in Chinese and English and attained at least Master's degree in translation (one of them was a health care provider). A panel consisted of these three translators, together with two researchers, critically reviewed the translations and drafted the Chinese version of the PAMSE. Third, another bilingual professional translator, who had no knowledge about the original version of the PAMSE, performed the backward-translation of the draft into English. Finally, the backward-translated English version of the PAMSE was assessed for equivalence with the original English version of the PAMSE by the panel. Discrepancies between the original version, the forward-translated version and the backward-translated version of the PAMSE were discussed to produce a final Chinese version of the PAMSE.

### 5.3.2. Phase two: Content validity

All the items in the questionnaire, including the items of the Chinese version of the PAMSE, were examined by a panel of four experts comprising a respiratory specialist in pediatric asthma, a nurse specialist in pediatric asthma, an academia

with expertise in mental and psychological health, and a statistician with expertise in instrument validation in health psychology. Each panel member received a questionnaire that included all the items and was asked to rate whether each item appeared to be relevant to the intended constructs under study. These constructs included: (1) child's unscheduled health care service visits due to asthma exacerbations, (2) child's asthma symptoms, (3) parents' psychological flexibility, (4) parents' psychological adjustment to the child's asthma, (5) parents' psychological symptoms, (6) parents' asthma knowledge, (7) parents' asthma management self-efficacy and (8) parents' quality of life. The rating of each item was conducted by using a 4-point Likert scale, with 1 indicating "item is not relevant", 2 "item needs major revision to be relevant", 3 "item needs minor revision to be relevant" and 4 "item is relevant". Panel members were also invited to comment on the wording of items, so that the items are understandable among Hong Kong Chinese parents, who mainly attained at least primary school educational level.

The Content Validity Index (CVI) in both item level (I-CVI) and scale level (S-CVI) of all items were reported to indicate the agreement among four experts. For each item, I-CVI was computed based on the number of expert(s) giving a rating of either 3 or 4 divided by the total number of experts. For each measure, its S-CVI was calculated by averaging the I-CVIs for all items on that measure. It is recommended with a panel of five and fewer experts, the S-CVI should achieve at least .9 or higher (Polit & Beck, 2006; Polit, Beck, & Owen, 2007).

### 5.3.3. Phase three: Internal consistency and test-retest reliability

In the final phase, the questionnaire was pilot-tested in two groups of parents of children with asthma. The first group (Sample 1) was used to assess the internal consistency of the items assessing the asthma symptoms of children (4 items), as

well as the following six parent measures: which were psychological flexibility (PF) (7 items), psychological adjustment to the child's asthma (25 items), psychological symptoms including symptoms of depression, anxiety and stress (21 items), asthma knowledge (25 items), asthma management self-efficacy (13 items), and quality of life (13 items). The second group (Sample 2) served the purpose of assessing the test-retest reliability of all the items in the questionnaire. It was decided to use another source of sample to avoid repeated assessments of the parents in Sample 1.

**Participants.** In both groups, parents were recruited if they were between 18 and 65 years old, fathers or mothers in each family who were the primarily caregivers responsible for the daily care of their child with asthma, living together with the index child, and able to communicate in Cantonese. Their children should be aged 3 to 12 years who had been diagnosed with asthma.

**Recruitment and data collection procedures.** A consecutive sample of 49 parents of children with asthma (Sample 1) were recruited in the Ambulatory Care Clinic (ACC) of the study hospital between April 2015 and May 2015. While the parent-child dyads were awaiting for the respiratory outpatient services, they were approached by the research investigator for eligibility screening. Eligible parents were asked to complete the self-administered questionnaire. Ten out of 49 parents were randomly sampled. They were asked to comment on the readability of questionnaire and the difficulties (if any) to comprehend the meaning of items. The average time required to complete one questionnaire was noted.

For assessing the test-retest reliability, another convenience sample of 20 parents of children with asthma (Sample 2), who attended asthma classes organized by the Hong Kong Asthma Society (a patient support group in the community setting), were recruited between July 2015 and August 2015. After the asthma

classes, parents were approached by the research investigator for eligibility screening. Eligible parents were then invited to complete the questionnaire twice within a two-week interval.

Notably, this pilot test did not serve the purpose of developing new instruments, but to check the performance of items in a new population (i.e., Hong Kong Chinese parents of children with asthma), derived from the instruments with well-established psychometric properties. Thus, as a pilot, a small sample size ranging from 10 to 40 can precisely reach the lowest confidence interval of the estimates to fulfill the aim of instrument validation (Hertzog, 2008).

**Data analyses.** The Cronbach's alpha coefficient and corrected item-to-total correction (correction of each item with the summated scale score) of the items assessing the measures regarding the asthma symptoms of children, as well as the parent measures, were calculated to indicate the internal consistency. Minimal acceptable alphas and item-to-total correlations were specified at .70 and .30, respectively (Nunnally & Bernstein, 1994). The 2-week test-retest reliabilities of the items were examined using the intraclass correlation coefficient (ICC). ICCs are designated as follows: .40 or less indicates poor to fair agreement; .41 to .60, moderate agreement; .61 to .80, good agreement; and .81 to 1.00, excellent agreement (Nunnally & Bernstein, 1994). In particular, the test-retest reliability of the Asthma Knowledge Questionnaire (AKQ) was assessed by indicating the proportion of agreement of each item. This is the most appropriate test, as each item was a true and false question (binary outcome) and the small sample size in this pilot test.

**Readability, time required for completion and missing items.** The time required for completing one questionnaire and the percentage of missing items of

each measure were noted and presented with descriptive statistics (e.g., mean, percentage).

## 5.3.4. Results

**Sample characteristics.** Demographically the two samples were comparable as shown in Table 5.1. Both sample 1 (hospital sample) and sample 2 (community sample) had their child (age mean = 6 to 7) who had been diagnosed with asthma approximately at three years old. Both samples had more mothers (83.7% in sample 1, 80.0% in sample 2) than fathers. The majority of parents had educational attainment at secondary school level (79.6% in sample 1, 60.0% in sample 2) and were housewives (44.9% in sample 1, 35.0% in sample 2). The monthly household income ranged from \$10,000 to 19,000 Hong Kong Dollars (HKD) (53.1% in sample 1, 50.0% in sample 2).

# Table 5.1

Characteristics of the parents and their children with asthma in hospital sample and in community sample

	Frequency (%), except for age		
	Sample 1 $(n = 49)$	Sample 2 $(n = 20)$	
	from hospital	from community	
Child's characteristics			
Gender			
Male	31 (63.3)	14 (70.0)	
Female	18 (36.7)	6 (30.0)	
Age (years), M (SD)	7.5 (3.1)	6.7 (3.3)	
Age of diagnosis as asthma (years), M (SD)	4.2 (2.2)	3.9 (2.4)	
Parents' characteristics			
Relationship with child			
Mother	42 (85.7)	17 (85.0)	
Father	7 (14.3)	3 (15.0)	
Age (years), M (SD)	40.7 (8.4)	41.8 (10.7)	
Marital status			
Single	2 (4.1)	2 (10.0)	
Married	45 (91.8)	17 (85.0)	
Divorced/ separated	2 (4.1)	1 (5.0)	
Educational attainment			
Primary education or below	1 (2.0)	1 (5.0)	
Secondary education	39 (79.6)	12 (60.0)	
Tertiary education or above	9 (18.4)	7 (35.0)	
Monthly household income (HKD) <sup>a</sup>			
\$4000 to \$9999	5 (10.2)	3 (15.0)	
\$10000 to \$19999	26 (53.1)	10 (50.0)	
\$20000 to \$29999	6 (12.2)	1 (5.0)	
\$30000 to \$59999	10 (20.4)	4 (20.0)	
\$60000 or above	2 (4.1)	2 (10.0)	
Occupation			
Home-duties	22 (44.9)	7 (35.0)	
Managers and professionals	10 (20.5)	6 (30.0)	
Clerks	3 (6.1)	2 (10.0)	
Services and shop sales workers	4 (8.2)	1 (5.0)	
Unemployed	2 (4.1)	1 (5.0)	
Others <sup>b</sup>	8 (16.2)	3 (15.0)	

*Note.* n = number of samples; M = mean; SD = standard deviation; HKD = Hong Kong Dollars (1 USD = 7.8 HKD)

<sup>a</sup>According to the Quarterly Report on General Household Survey data conducted in Hong Kong on January to March 2016, the median monthly household income for an average household size of 2.9 (a Hong Kong couple with a child) was approximately \$25,000 Hong Kong Dollars (Census and Statistics Department, 2016b).

<sup>b</sup>Others included craft and related workers, and machine operators.

**Content validity.** The results of the Content Validity Index (CVI) in both item levels (I-CVI) and scale levels (S-CVI) are presented in Table 5.2. All four experts commented that the items in the questionnaire were visually relevant to measure the intended constructs under study and readable for Hong Kong Chinese parents. The item-CVIs in all items were 1.00, except for the four items assessing the asthma symptoms of children (I-CVI = .75). One expert commented that the reference time-point in asking parents to recall their child's asthma symptoms in the past month was unclear. A clearer description (e.g., in the past 30 days, which means in the past one month) was added in each of the four items. The overall CVI was .99 (99.1%) and of the items ranged from .75 to 1.00 (75% to 100%). In general, all the items in the questionnaire were considered to demonstrate adequate content validity.

### Table 5.2

<b>a</b>	1. 1.	• 1	C .1	• ,	•	.1	· •	•
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Measures/items (Name of the instrument)	Number	Item-CVI	Scale-CVI
	of items	(range)	
Child measures			
Emergency department (ED) visits due to asthma exacerbations	1	All 1.00	1.00
Unscheduled outpatient visits, hospital admissions and length of hospital stay due to asthma exacerbations	4	All 1.00	1.00
Asthma symptoms	7	.75 to 1.00	.96
Parent measures			
Psychological flexibility (AAQ-II)	7	All 1.00	1.00
Psychological adjustment to the child's asthma (PECI)	25	All 1.00	1.00
Psychological symptoms (DASS-21)	21	All 1.00	1.00
Asthma knowledge (AKQ)	25	All 1.00	1.00
Asthma management self-efficacy (PAMSE)	13	All 1.00	1.00
Quality of life (PACQLQ)	13	All 1.00	1.00
Child's clinical characteristics			
Use of oral and inhaled corticosteroids	6	All 1.00	1.00
Parents' characteristics			
Family history of asthma	2	All 1.00	1.00
Family smoking history	3	All 1.00	1.00
Total items	160	.75 to 1.00	.99

*Note*. AAQ-II = Acceptance and Action Questionnaire-II; AKQ = Asthma Knowledge Questionnaire; CVI = Content Validity Index; DASS-21 = Depression Anxiety and Stress Scales-21; PACQLQ = Pediatric Asthma Caregiver's Quality of Life; PAMSE = Parent Asthma Management Self-Efficacy; PECI = Parent Experience of Child Illness

Internal consistency. The internal consistency using Cronbach's alpha

coefficients of the measure assessing the child's asthma symptoms, as well as the parent measures are presented in Table 5.3. Generally, the Cronbach's alphas of each measure were moderate to high, ranging from .74 to .90. This demonstrated that the items maintained their homogeneity within their measures among the sample of Hong Kong Chinese parents of children with asthma. The corrected item to-total correlations of each measure were also sufficiently higher (range = .59 to .72) than

the accepted cutoff of .30 (Nunnally & Bernstein, 1994), indicating that each item was related to their corresponding measure and should be retained.

Given that this pilot test had 49 samples and most of the calculated overall Cronbach's alphas were above .80, it is estimated that up to a population level, the 95% limits of confidence intervals of the Cronbach's alpha would be ranged from .71 to .87 (Fern & Monroe, 1996; Hertzog, 2008). This demonstrated that the items in the questionnaire can maintain satisfactory internal consistency when applied to a larger sample in the main RCT study.

### Table 5.3

Internal consistency of the child and parent measures in the questionnaire (hospital

sample, n = 49)

Measures (Name of the instrument)	Cronbach's	Corrected Item to-Total
	alpha	Correlation (range)
Child measures		
Asthma symptoms	.81	.7685
Parent measures		
Acceptance and Action Questionnaire (AAQ-I	I)	
Overall	.88	.6580
Parent Experience of Child Illness (PECI)		
Guilt and worry	.86	.6276
Unresolved sorrow and anger	.84	.6676
Long-term uncertainty	.76	.5176
Perceived emotional resources	.74	.5979
Depression Stress Anxiety Scale-21 (DASS-22	1)	
Depression	.84	.7885
Anxiety	.83	.6389
Stress	.82	.7786
Parent Asthma Management Self Efficacy (PA	MSE)	
Overall	.85	.6881
Attack prevention	.83	.6986
Attack management	.86	.5972
Pediatric Asthma Caregiver Quality of Life Qu	uestionnaire (PA	CQLQ)
Overall	.81	.7790
Emotional function	.83	.8092
Activity limitation	.90	.7890

*Note.* AAQ-II = Acceptance and Action Questionnaire-II; AKQ = Asthma Knowledge Questionnaire; DASS-21 = Depression Anxiety and Stress Scales-21; n = number of samples; PACQLQ = Pediatric Asthma Caregiver's Quality of Life; PAMSE = Parent Asthma Management Self-Efficacy; PECI = Parent Experience of Child Illness

**Test-retest reliability.** All the parents in the sample 2 (n = 20) were able to re-contact after two weeks for completing the questionnaires as the retest. The test-retest reliabilities using the intra-class correlations (ICCs) for the child and parent measures, as well as the proportion of agreement of items of the AKQ across two weeks are presented in Table 5.4. The ICC for each measure in the questionnaire ranged from .76 to 1.00, and the mean proportion of agreement for all items in the

AKQ was 81.4%. These data indicated the satisfactory stabilities of the instruments in assessing the child's and parental outcomes over two weeks.

Based on this 20 samples and most of the calculated ICCs were above .80, it is estimated that up to a population level, the 95% limits of confidence intervals of the ICC would be ranged from .55 to .92 (Fern & Monroe, 1996; Hertzog, 2008), which means that moderate agreements of assessing the child's and parental outcomes can still be achieved when applied to a larger sample in the main RCT study.

### Table 5.4

Two-week test-retest reliability of the child and parent measures in the questionnaire

(community sample, n = 20)

Measures (Name of the instrument)		
	ICC	95% CI
Child measures		
Emergency department visits due to asthma	1.00	1.00-1.00
exacerbations		
Outpatient visits, hospital admissions and length of	.90	.8892
hospital stay due to asthma exacerbations		
Days presenting with asthma symptoms	.82	.7089
Nights awakening due to asthma symptoms,	.80	.6985
Days requiring the use of short-acting inhaled	.87	.7789
bronchodilators to relieve the child's asthma symptoms		
Days with activity limitations due to asthma symptoms	1.00	1.00-1.00
Parent measures		
Acceptance and Action Questionnaire (AAQ-II)		
Overall	.94	.8098
Parent Experience of Child Illness (PECI)		
Guilt and worry	.76	.6593
Unresolved sorrow and anger	.85	.7288
Long-term uncertainty	.81	.7187
Perceived emotional resources	.68	.6086
Depression Stress Anxiety Scale-21 (DASS-21)		
Depression	.78	.6690
Anxiety	.79	.6889
Stress	.88	.7492
Asthma knowledge (AKQ)#		
Overall (Mean percentage of agreement (SD))		81.4 (12.1)
Asthma management self-efficacy (PAMSE)		
Attack prevention	.76	.6893
Attack management	.87	.7990
Asthma-related quality of life (PACQLQ)		
Emotional function	.84	0.79-0.90
Activity limitation	.85	0.75-0.90

*Note.* AAQ-II = Acceptance and Action Questionnaire-II; AKQ = Asthma Knowledge Questionnaire; CI = confidence interval; ICC = intraclass correlation coefficient; DASS-21 = Depression Anxiety and Stress Scales-21;*n*= number of samples; PACQLQ = Pediatric Asthma Caregiver's Quality of Life; PAMSE = Parent Asthma Management Self-Efficacy, PECI = Parent Experience of Child Illness.

#Test retest reliability of the AKQ was indicated by the proportion of agreement of each item across two weeks.

**Readability, time required for completion and missing items.** Ten parents in sample 1 (hospital sample) were randomly selected and they were asked to give comments about the readability of the questionnaire. All parents found that the items were readable and had no difficulty to follow the instructions.

Notably, in both instruments, named the Asthma Knowledge Questionnaire (AKQ) and the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ), five parents felt difficult to understand the translated English word "wheeze" into Chinese, which can be "氣喘", "喘鳴", "扯哈聲" and "喘鳴", depending on different Chinese contexts such as in Mainland, Taiwan and Hong Kong. The research team members finally determined to use the word "喘鳴" that is the most ideal wording to describe the wheezing sound when a child suffers from an asthma attack.

The average time needed to complete the entire questionnaire was 32 minutes. All the parents were able to complete it independently. From the on-site clinics observation over four months, the awaiting time for outpatient clinic services in the study hospital was approximately 30 to 60 minutes, while allowed the parents to have enough time for completion. In both samples, no items in the questionnaire had more than 2% of missing values (range from 0% to 1.9%).

### 5.3.5. Implications for the main RCT study

The first stage of the pilot study was to validate a self-administered questionnaire to be used in the main RCT study. The findings of this pilot study indicate that the questionnaire is a valid and reliable data collection tool in soliciting information related to the Hong Kong Chinese parent-child dyads for the main RCT study. The selected items and the instruments in the questionnaire have high content validity (Overall CVI = .99), acceptable internal consistency ( $\alpha$  = .74 to .90) and

moderate level of stability (ICCs = .76 to 1.00) over two weeks. The parents were able to complete the questionnaire by themselves, only a very small proportion of missing data was found (range from 0% to 1.9%), which implies the feasibility of collecting valid data from parents by using the self-administered questionnaires in the study settings.

5.4. Examining the feasibility and acceptability of a training program using group-based ACT for childhood asthma management in parents of children with asthma

The second stage of the pilot study aimed: (1) to determine the feasibility of subject recruitment when conducting the main study, (2) to determine the feasibility and acceptability of a training program using group-based ACT for childhood asthma management in parents of children with asthma, and (3) to identify any modification(s) required in the intervention protocol before implementing in the main RCT study.

### 5.4.1. Methods

To explore the feasibility of recruiting eligible and adequate number of the parent-child dyads in the main study, the research investigator participated in a fourmonth period of clinical attachment in the clinics of the study hospital between May 2015 and August 2015. The purpose of the clinical attachment was to explore the patient referral system in the clinics and the flow of the attendees (children and their parents) when they arrive at the clinics. It was found that out of an average of 380 to 400 children attended the clinics in every month, one-fifth (n = 80) of them were diagnosed with asthma. Furthermore, out of 80 parent-child dyads being consecutively screened and approached by the research investigator in May 2015 (one-month), 36 (45%) were found to be eligible, of which 75% (27 out of 36) of the

parents were willing to be randomized and to participate in the parental training program after an explanation of the purpose of the study according to the Information Sheet. Thus, it was estimated that the recruitment period would last for five to six months to reach the adequate number of participants (estimated sample size = 160 subjects, see Chapter Three Section 3.6.4 for the details).

Next, the feasibility and acceptability of a training program using groupbased ACT for childhood asthma management in parents of children were examined in a single-group pretest-posttest design. Details of this pilot test is described as follows.

**Participants and recruitment.** Convenience sampling was adopted. Between September 2015 and October 2015, parents who accompanied their children diagnosed with asthma for respiratory follow-up visits were recruited by the research investigator in two pediatric respiratory outpatient clinics, which were the Ambulatory Care Centre (ACC) and a nurse-led asthma clinic, of the study hospital. Promotional flyers about a parent training workshop related to childhood asthma care were distributed in the clinics. Those parents who were interested in would be contacted by the research investigator for screening the eligibility. The eligibility criteria were the same as the ones determined in the main RCT study (see Chapter Three Section 3.6.2 for the details). Eligible parents provided written consent for their participation.

**Intervention.** The training program using group-based ACT for childhood asthma management was conducted in a weekly basis over four weeks (i.e., a total of four weekly sessions). Parents received a total of two hours of asthma education (30 minutes per session), plus a total of six hours of group-based ACT (90 minutes per session). Each session included ACT-specific exercises, such as metaphors,

experiential exercises and/or mindfulness exercises, as well as asthma education. The goal of the training program was to encourage parents to accept difficult thoughts and feelings about childhood asthma care in a non-judgmental manner, and to be committed to carrying out effective childhood asthma management strategies connected to their personal values.

Each group-based ACT session served a group of five to six parents and was led by the research investigator who had received training in ACT (see Chapter Four Section 4.3.4 for the details of the credentials of the therapist). Guided by the ACT intervention protocol, the contents of the intervention sessions were generally the same as shown in the main study (see Table 4.3 for the session-by-session outline of the intervention). Each session was videotaped after the informed written consent was obtained from the parents. The videotapes were then reviewed by the research investigator and an experienced ACT researcher (Chief Supervisor) together for weekly supervisions to ensure the ACT skills development and the ACT competence. Any modifications required in the ACT intervention protocol would be noted.

**Data collection methods and procedures.** Data collection took place before and after the training program. Parents were invited to complete the selfadministered questionnaires during subject recruitment in the clinics, and immediately after the fourth session of group-based ACT training program. Parents were asked to return the completed questionnaires to the nurses in the clinics.

**Measures.** The feasibility of the training program using group-based ACT for childhood asthma management was assessed by using the ACT therapy-specific measure, PF via the Acceptance and Action Questionnaire-II (AAQ-II) (Bond et al., 2011), as well as the following parent measures: (1) psychological adjustment to the

child's asthma via the Parent Experience in Chronic Illness (PECI) (Bonner et al., 2006; Bonner et al., 2008), (2) psychological symptoms via the Depression Anxiety Stress Scales-21 (DASS-21) (Henry & Crawford, 2005), (3) asthma knowledge via the Asthma Knowledge Questionnaire (AKQ) (Ho et al., 2003), (4) asthma management self-efficacy via the Parent Asthma Management Self-Efficacy (PAMSE) (Bursch et al., 1999), and (5) quality of life via the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) (Juniper et al., 1996), respectively. The psychometric properties of these measures have been well-established in literature (see Chapter Three Section 3.11) and in the first stage of the pilot study, respectively. These measures would also be adopted in the main study.

In addition, the acceptability of the training program was assessed by using questions adapted from the Credibility and Expectations Scale (CES) (Devilly & Borkovec, 2000). The CES assesses an individual's view of how logical, likely to help, to recommend and to feel satisfied about the program, and whether the program reached his/her own expectation (Devilly & Borkovec, 2000). Immediately after the training program, parents were asked to rate five statements in an 11-point Likert scale ranging from 0 (*not at all*) to 10 (*completely*). Rating of 5 or higher indicates that the training program using group-based ACT approach appears to be acceptable among the parents. The CES has been widely adopted in pilot studies assessing the acceptability of a newly developed ACT intervention (Gaudiano, Nowlan, Brown, Epstein-Lubow, & Miller, 2013; McCracken, Sato, Wainwright, House, & Taylor, 2014; Pincus et al., 2015). Further, the number and the reasons of participants who missed the ACT sessions were noted to indicate the program acceptability.

Statistical analyses. The mean and standard deviation of the abovementioned outcomes were presented. Due to small sample size (n = 11), the data

were non-normally distributed, Wilcoxon signed-rank test was used to determine any significant within-group difference(s) in the parental outcomes. Effect sizes were calculated from Wilcoxon signed-rank test z-scores and the number of total observations (i.e., 11 subjects x 2 time points = 22 observations) by the use of *r* (that is,  $r = z/\sqrt{N}$ , N = total number of observations) (Rosenthal, 1993). Effect sizes for *r* were interpreted as follows: > .10, small; > .30, medium; > .50, large (Cohen, 1988). **5.4.2. Results** 

**Recruitment.** Between September 2015 and October 2015, out of 20 parents approached, eleven parents provided written consent for the participation (participation rate: 11/20 = 55%). Nine parents refused to participate in the training program with the following reasons: (1) no time as occupied by the full-time work or the child's activities (number of samples (n) = 6), (2) not interested in, as their child's asthma were well-controlled (n = 2), and (3) not interested in, as the parent joined in the asthma class which was offered by the study hospital in last year (n = 1). Two ACT classes were successfully organized, of which one class (n = 6) had sessions on every Wednesday morning, and the other one (n = 5) had sessions on every Thursday afternoon.

**Characteristics of the participants and their children.** Table 5.5 shows the characteristics of the participants and their children (n = 11). The majority of participants were mothers (63.6%, age M = 45.6, SD = 10.9), housewives (63.6%) and had educational attainment at secondary school level (72.7%). Approximately one third of them had asthma (36.4%). Around half of the parents participated in the training program whose children were male (54.5%, age M = 6.9, SD = 2.3), and over half of these children did not require the long-term use of inhaled

corticosteroids for asthma control. Approximately one-third of the children had

attended EDs and hospitalized due to asthma exacerbations in the past six months.

# Table 5.5

Descriptive summary of the parents' and their children's characteristics (n = 11)

Parents' characteristics	n (%
Relationship with the child	
Father	2 (18.2
Mother	9 (63.6
Age (years), M (SD)	45.6 (10.9
Marital status	
Married	9 (81.8
Single/ separated/ divorced/ widowed	2 (18.2
Educational attainment	
Primary education or below	1 (9.1
Secondary education	8 (72.7
Tertiary education or above	2 (18.2
Monthly household income (HKD)	
< \$ 10,000	5 (45.5
\$10,000 to \$25,000	1 (9.1
\$25,001 to \$50,000	2 (18.2
>\$50,000	3 (27.3
Employment status	
Home-makers or unemployed	7 (63.6
Full-time employed	2 (18.2
Part-time employed	2 (18.2
Marital status	
Single/ separated/ divorced/ widowed	2 (18.2
Married	9 (81.8
Smoking status	
Both parents are non-smokers	7 (63.6
At least one parent is a current smoker	4 (36.4
History of asthma diagnosis	× ×
Neither parents have a history of asthma	7 (63.6
At least one parent has a history of asthma	4 (36.4
Child's characteristics	× ×
Male	6 (54.5
Age (years), M (SD)	6.9 (2.3
Age of diagnosis as asthma (years), M (SD)	4.1 (2.8
Current use of inhaled corticosteroid	
Yes	4 (36.4
No	7 (63.6
Asthma symptoms in the past 4 weeks, <i>M</i> ( <i>SD</i> )	. (5510
Average days with asthma symptoms/ week	0.6 (1.2
Average nights awakening due to asthma symptoms/ week	0.9 (1.2

Average days the use of short-acting inhaled bronchodilators to relieve asthma/ week	1.1 (2.3)
Average days with activity limitation due to asthma symptoms/ week	0.6 (1.0)
ED visit(s) due to asthma exacerbations in the past 6 months, $M(SD)$	0.3 (0.7)
0 visit	8 (72.7)
1 visit	3 (27.3)
Hospitalization(s) due to asthma exacerbations in the past 6 months, $M$	0.3 (0.7)
( <i>SD</i> )	
0 visit	8 (72.7)
1 visit	3 (27.3)
Total number of unscheduled physician's office visit(s) <sup>a</sup> due to asthma	1.3 (1.8)
exacerbations in the past 6 months, $M(SD)$	
0 visit	0
1 visit	8 (72.7)
2 visits	3 (27.3)

*Note.* ED = emergency department, HKD = Hong Kong Dollars, M = mean, n = number of samples, SD = standard deviation

<sup>a</sup>Unscheduled physician's office visit(s) refers to the sum of unscheduled service attendances due to children's asthma attacks in the General Outpatient Clinics and in the private practitioners' clinics.

### Pre-post differences in the parental outcomes. Table 5.6 presents the

descriptive statistics, the Wilcoxon Signed Rank z-scores and the within-group effect sizes for the parental outcomes. At post-test, the parents attained significantly lower mean AAQ-II score than that of at pre-test (M = 16.27 versus 22.00, p < .05), with a large effect size (r = 0.55), implying that they were more psychologically flexible after participating in the training program using group-based ACT for childhood asthma management. In addition, the parents had a significantly higher mean score of the PECI-emotional resource at post-test than that of at pre-test (M = 2.62 versus 2.05, p < .05), with a medium effect size (r = 0.43), indicating that the parents acquired a better ability to cope with their negative emotions after ACT training. Similarly, the AKQ total score (z = -2.39, p < .05), the PAMSE total score (z = -2.49, p < .05), and the PACQLQ total score (z = -2.70, p < .01) were all significantly improved at post-test when compared with the scores attained at pre-test, with

medium-to-large effect sizes ranging from 0.44 to 0.58, showing that the parents had better asthma knowledge, asthma management self-efficacy and quality of life. There were no significant changes in the psychological symptoms of the parents after the intervention.

Table 5.6

Descriptive statistics, the Wilcoxon Signed Rank z-scores and the effect sizes of the

Measures (Name of	Pretest,	Posttest	Wilcoxon	Effect
instrument)	$M\left(SD\right)$	M(SD)	Signed Rank	size ( <i>r</i> ) <sup>a</sup>
			test statistics	
Psychological flexibility				
Total score (AAQ-II)	22.00 (10.81)	16.27 (8.87)	-2.58*	0.55
Psychological adjustment to t	he child's asthma	(PECI)		
Guilt and worry	1.52 (0.68)	1.43 (0.71)	-1.34	0.29
Unresolved sorrow and	1.33 (0.76)	1.18 (0.85)	-1.13	0.24
anger				
Long-term uncertainty	1.45 (0.95)	1.15 (0.74)	-1.67	0.36
Emotional resources	2.05 (0.94)	2.62 (0.76)	-2.02*	0.43
Psychological symptoms (DA	SS-21)			
Depression	8.18 (8.78)	5.27 (4.84)	-1.07	0.23
Anxiety	6.36 (6.50)	4.36 (5.12)	-1.14	0.24
Stress	12.00 (10.27)	7.64 (4.88)	-1.34	0.29
Asthma Knowledge (AKQ)				
Total score	18.81 (2.23)	21.36 (2.41)	-2.39*	0.51
Asthma management self-effi	cacy (PAMSE)			
Total score	3.46 (0.66)	3.97 (0.67)	-2.49*	0.53
Attack prevention	4.05 (0.71)	4.15 (0.60)	36	0.08
Attack management	2.96 (0.84)	3.81 (0.83)	-2.71**	0.58
Asthma-related quality of life	(PACQLQ)			
Total score	4.55 (1.31)	5.34 (1.12)	-2.70**	0.58
Emotion function	4.54 (1.51)	5.34 (1.12)	-2.59*	0.55
Activity limitation	4.59 (1.13)	5.32 (1.23)	-2.05*	0.44

parental outcome measures (n = 11)

*Note.* AAQ-II = Acceptance and Action Questionnaire-II, AKQ = Asthma Knowledge Questionnaire, DASS-21 = Depression Anxiety and Stress Scales-21, M = mean, PACQLQ = Pediatric Asthma Caregiver's Quality of Life, PAMSE = Parent Asthma Management Self-Efficacy, PECI = Parent Experience of Child Illness, SD = standard deviation. \*p < .05; \*\*p < .01, \*\*\*p < .001

<sup>a</sup>Effect sizes for *r* were interpreted as follows: > .10, small; > .30, medium; > .50, large (Cohen, 1988).

Acceptability. Table 5.7 shows the results from the post-test rating by the parents about the acceptability of the training program using the CES. All CES items yielded very positive responses, with the mean score ranging from 7.44 to 8.22. Parents reported that the training program using group-ACT could help them to manage their child's asthma (M = 8.11, SD = 1.05), and they would recommend this program in their social network (M = 7.44, SD = 1.33).

### Table 5.7

Descriptive statistics of the CES scores at post-test (n = 11)

Credibility and Expectancy Scale Item (score range: 0 to 10)	M	SD
How logical does the childhood asthma workshop offered to you seem?	8.22	1.09
How successfully do you think the childhood asthma workshop can help you to manage asthma?	8.11	1.05
How confident would you be in recommending this childhood asthma workshop to a friend?	7.44	1.33
Does this childhood asthma workshop reach your learning expectation in managing childhood asthma?	7.67	1.32
How satisfied were you with the overall quality of the childhood asthma workshop?	8.00	1.22
Overall	7.89	0.99

*Note.* M = mean, SD = standard deviation

## Session attendance. Nine out of eleven parents attended all four assigned

ACT sessions while the remaining two attended three sessions (missed the third session). The reasons for non-completion were: (1) no time as the parent needed to accompany his/her child for participating in extracurricular activities (n = 1), and (2) no time due to the part-time job (n = 1).

# Modification in the intervention protocol. After the pilot test, one

modification was made in the intervention protocol prior to its use in the main RCT study. In Session Three of the pilot ACT intervention, the Bull's eye exercise

(Harris, 2009) was introduced to the parents as a homework (see Appendix 5.1 for the exercise). This exercise aimed to facilitate parents in clarifying their personal held values in four major life domains: career/learning, leisure, relationship and health, and to help parents in setting values-based goals and action plans. Parents were asked to complete this homework assignment for a review in the fourth week. However, of the eleven parents who participated in the pilot test, six of them did not complete the assignment, which made it difficult for the therapist to apply two therapeutic processes of PF, values clarification and committed action, in the fourth session. The parents reflected that they found it difficult to grasp the meaning of the exercise. There was also inadequate time for the therapist to work through a few examples together with the parents for the values clarification of all four life domains. Hence, to help parents in clarifying these personally held values, it was decided for the use of a mindfulness exercise in which parents are guided to revisit the experiences when they were getting along with the most unforgettable person in their life. Then, parents are guided to imagine what they would say to that person. This exercise was derived by the Sweet Spot exercise as suggested by Wilson and colleagues (2009), by simply asking what matters the most to the parents (Wilson & DuFrene, 2009). Next, as a homework assignment for preparing the last ACT session, parents are asked to develop specific plans to work on the chosen value.

### 5.4.3. Implications for the main RCT study

This pilot test served to determine the feasibility of recruitment, the feasibility and acceptability of using group-based ACT in helping parents to improve their childhood asthma management, and to identify any modification(s) required in the intervention protocol before the commencement of a full-scale RCT. Several implications for the main RCT study are stated in here.

First, it was estimated that approximately a five to six-month period was required to recruit adequate number of participants serving for the main RCT study (estimated sample size = 160 subjects, see Chapter Three Section 3.6.4 for the details). Hence, in the main RCT study, recruitment would be preceded at a rate of 25 to 30 participants per month, which was an acceptable pace for carrying out subject recruitment with less resource implications.

Second, it was noted that nine out 20 parents refused to participate in the group-based ACT training program. The main reason for non-participation was that the timetable of the four ACT sessions (i.e., every Wednesday morning and every Thursday afternoon) conflicted with the work or family schedule (n = 6). To improve the participation rate of the main RCT study, a list of different timeslots of the scheduled sessions would be offered to parents, such as morning sessions during weekdays, afternoon sessions during weekdays, and morning sessions during weekends, so that they could choose their most convenient time to participate in.

Third, the results of the pilot test showed that the PF of parents improved from pre-post with large within-group effect size. This demonstrated that the ACT intervention, as delivered in accordance with the intervention protocol, generally addressed the ACT therapeutic processes effectively. The significant improvements of other parental outcomes at post-test, such as psychological adjustment in terms of emotional resources, asthma knowledge, asthma management self-efficacy and quality of life, could provide the preliminary evidence about the beneficial effects of ACT in parents of children with asthma. Furthermore, this training program using group-based ACT was generally acceptable among the parents, over 80% of the participants attended all assigned ACT sessions and no adverse events were found when implementing the training program. Overall speaking, the findings of this pilot

study indicate that ACT is safe, acceptable and feasible to be carried out when serving for parents who are experiencing psychological difficulties in their childhood asthma management. These findings also imply a need for further studies by using methodologically rigorous design, such as the RCT as proposed in the main study, to confirm the findings.

It is noteworthy to find that there were no significant changes on the psychological symptoms of parents (anxiety, depression and stress symptoms) after the intervention. Though symptom reduction is an important goal in clinical settings, the purpose of ACT is to help parents foster a better psychological flexibility, so that they learn to develop willingness to negative emotional experiences while choosing value-directed behaviors. Solely seeking symptom reduction is in fact working towards in controlling or avoiding symptoms, which may further create more psychological problems (Hayes & Wilson, 1994). Rather, parents who learn ACT may be more opened to difficult thoughts and feelings, so that they may no longer perceive them as "symptoms". In this pilot study, significant improvements of the PF and the psychological adjustment in terms of emotional resources, but a nonsignificant change of the psychological symptoms of parents may reflect that the essence of ACT was delivered. Nevertheless, further studies are needed to examine whether significant changes of parents' psychological symptoms occur after a longer duration of follow-up.

As reported in the Results Section, one modification was made in the intervention protocol. In the last ACT session, a mindfulness exercise would be used to guide parents to revisit the experiences when they were getting along with the most unforgettable person in their life, and to imagine what they would say to that person. This exercise serves for a better facilitation of values clarification and goal

setting. Besides, the research investigator (i.e., therapist) identified several challenges when facilitating the training program using group-based ACT in parents of children with asthma. These challenges deserve attention when conducting the main RCT study and are discussed as follows.

At the first session, the therapist attempted to create the context of creative hopelessness to highlight the long-term unworkability of the previous avoidance coping strategies. However, the therapist observed that some parents were reluctant to disclose their inner psychological experiences about their journey in childhood asthma care. In fact, the parents in Hong Kong have a strong sense of obligation to be good parents and concern whether they are considered as good and competent parents by the others. Negative psychological experiences in the caregiving process may possess feelings of guilt, shame and failures to "control" their children's behaviors, in which parents may find difficult to reveal and to express verbally. For the main RCT study, more time would be given to the parents when participating in the group exercises, so that they could have more time in getting familiarize with one another for a better engagement in ACT-related activities.

In addition, the therapist observed that the parents in the training program commonly engaged in seeking the best possible therapies to help their children to cure asthma, or to get rid of asthma, they might misinterpret acceptance as a means of giving up, particularly in the earlier ACT sessions when working on experiential avoidance. This situation was also seen in case studies of applying ACT in parents of children with other chronic diseases, such as sickle cell disease and anorexia nervosa (Eifert et al., 2009; Masuda et al., 2011). The therapist should be reminded that ACT posits acceptance as the willingness to stay with difficult thoughts and feelings related to childhood asthma, while more importantly is to actively engage to value-

### CHAPTER FIVE PILOT STUDY

driven behaviors related to their child's well-being. Acceptance as an active process should be emphasized throughout the group sessions. Hence, for the main RCT study, more time would be spent on mindfulness exercises, this could allow parents to practice in contacting with the present moment and different emotional experiences.

### 5.5. Summary

This chapter reports the details of the pilot study for supporting the commencement of the main RCT study. The pilot study was divided into two stages. The first stage aimed to validate a self-administered questionnaire for soliciting information from Hong Kong Chinese parents of children with asthma. All the measures included in the questionnaire demonstrated high content validity (Overall CVI = .99), acceptable internal consistency ( $\alpha = .74$  to .90) and moderate level of stability (ICCs = .76 to 1.00) over two weeks. These findings indicate that the questionnaire designed for the main RCT study is a valid and reliable data collection tool in soliciting information from the Hong Kong Chinese parents of children with asthma. In addition, the parents could complete the questionnaires by themselves, only a very small proportion of missing data was found (range from 0% to 1.9%), which implies the feasibility of obtaining valid data from parents by using self-administered questionnaires in the study settings.

The second stage aimed to determine the feasibility of subject recruitment, the feasibility and the acceptability of a parental training program using group-based ACT for childhood asthma management. The feasibility of recruiting eligible and adequate number of participants for the main RCT study were explored by participating in a four-month period of clinical attachment in the clinics of the study hospital. It was estimated that the recruitment period would last for five to six

### CHAPTER FIVE PILOT STUDY

months so as to reach the adequate number of participants. The training program was pilot-tested in a sample of Hong Kong Chinese parents of children with asthma recruited from the clinics of the study hospital using a single-group pretest-posttest design. The feasibility of the training program used group-based ACT approach was demonstrated, as evidenced by significant improvements in the PF, psychological adjustment in terms of emotional resources, as well as asthma knowledge, asthma management self-efficacy and quality of life of parents after their participation when compared with the baseline (all *ps* ranged from <.001 to <.05). The within-group effect sizes (*r*) for all these outcomes were medium-to-large, ranging from 0.43 to 0.58. Furthermore, group-based ACT training program was found to be acceptable among the parents. The next step is to conduct a RCT, with a long-term follow-up to confirm the promising findings as shown in the pilot study, and more importantly to examine whether the health outcomes of children with asthma could be eventually improved after their parents received the ACT training.

# **CHAPTER SIX**

# RESULTS

### 6.1. Introduction

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- 6.3. Examining the role of psychological flexibility in parents of children with asthma: Analysis of a structural equation model
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- 6.7. Process evaluation
  - 6.7.1. Predictors of participation
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  - 6.7.3. Lost to follow-up
  - 6.7.4. Fidelity assessment
- 6.8. Summary

### **6.1. Introduction**

This chapter reports the results of the study. It begins by displaying the results of recruitment and the flow of participants. This chapter includes a structured equation model analysis exploring the relationships between the psychological flexibility (PF), the psychological adjustment to the child's asthma and the psychological symptoms of parents, as well as the asthma symptoms of their children. The results of the analysis support that parental PF may play an influential role in childhood asthma management.

Following the above preliminary analysis, the results of the RCT study are reported in this chapter. The baseline characteristics of parents and their children with asthma between the study groups (i.e., the ACT group and the Control group) are presented and compared for checking the baseline equivalency. The intervention effects between the study groups over six months post-intervention on the following childhood asthma-related health outcomes are reported, which are ED visits, unscheduled outpatient clinic visits, hospital admissions and length of hospital stay due to asthma exacerbations, as well as the asthma symptoms. In addition, the intervention effects on the following six parental outcomes are shown, which are psychological flexibility, psychological adjustment to the child's asthma, psychological symptoms, asthma knowledge, asthma management self-efficacy and quality of life. Finally, this chapter reports the evaluation of how the RCT was implemented, including identifying predictors of participation, predictors of noncompletion of the assigned intervention sessions, describing the characteristics of the

participants who were lost to follow-up, as well as the fidelity assessment of the group-based ACT intervention.

### 6.2. Recruitment and the flow of participants

Figure 6.1 shows the flow of participants as recommended by the CONSORT statement (Moher et al., 2010). Between 6<sup>th</sup> January 2016 and 26<sup>th</sup> May 2016, 1727 children's records were screened for the eligibility for participation. Of the 302 parent-child dyads who were identified as eligible for participation, 168 were enrolled and randomly allocated to either the Control group (n (number of subjects) = 84) or the ACT group (n = 84), they were all included in the final data analysis.

A total of 1425 parents and their children (1031 children, 79 parents and 315 parent-child dyads) were excluded from the study, because either parents and/or their children did not fulfill the eligibility criteria. Of those 1031 excluded children, approximately half of them (558/1031 = 54.1%) were less than three or more than 12 years old, 38.7% of them (399/1031) were not diagnosed with asthma. Of those 79 excluded parents, 35 were non-Hong Kong residents, 29 were aged 65 years or older, who were either grandfathers or grandmothers. Of those 315 parent-child dyads excluded, the majority (n = 233) did not attend the scheduled follow-up appointments in the clinics during the study period. Hence, they could not be reached for assessing their eligibility.

Three hundred and two eligible parent-child dyads were identified as eligible participants. Of these, parents were invited to complete a set of self-administered questionnaires soliciting their information and their child's clinical information in the clinics. They were further invited to participate in the RCT. A total of 134 parents declined participation (i.e., participation rate = 168/302 = 55.6%), around 80% of them (108/134) were unavailable as they were too busy with their full-time

work, part-time work, housework or due to their personal health problems. Twentytwo parents perceived that the asthma condition of their children was well-controlled and hence they refused an additional intervention for childhood asthma management. The remaining four parents had previously participated the asthma education talk offered by the study hospital and hence they were not interested in participating in the intervention study.

One hundred and sixty-eight parent-child dyads were randomly assigned to either one of the study groups. Of these, 74.4% (125/168, 62 in ACT, 63 in Control) attended all four assigned sessions, 7% (12/168, 7 in ACT, 5 in Control) attended 1-3 sessions, and 18.5% (31/168, 15 in ACT, 16 in Control) did not attend any assigned sessions after randomization. The reasons of non-attendance mainly related to the parents' busy schedules, such as no time as occupied by their jobs (12 in ACT, 9 in Control) and commitment to family activities (5 in ACT, 5 in Control), or their personal or child's health problems (3 in ACT, 2 in Control). As planned in this study and in line with the intention-to-treat (ITT) principle, all randomized parentchild dyads were continued to be assessed and followed up (White et al., 2011).

Six out of 168 participants (3.6%, 1 in ACT, 5 in Control) were lost to follow-up at six months post-intervention. The majority defaulted from follow-up at the clinics and were not contactable (1 in ACT, 4 in Control). One mother in the Control group refused to be followed up as her family moved away and her child would have follow-up appointments in another hospital. There were no significant differences in the proportions of lost to follow-up between groups (1/84 = 1.2% in ACT, 5/84 = 6.0% in Control,  $\chi^2 = 2.78$ , p = .096).

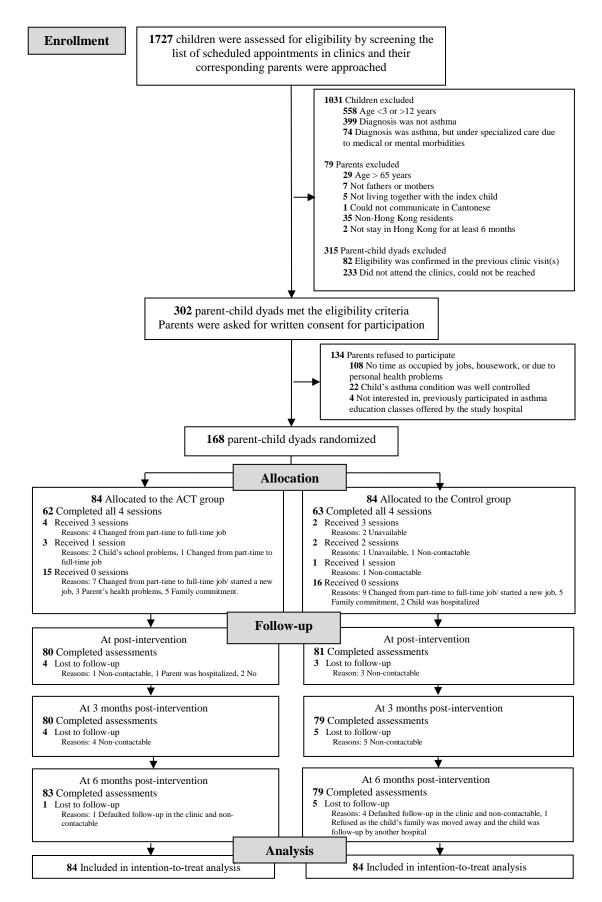


Figure 6.1. The CONSORT diagram indicating the flow of participants. Note. ACT

= Acceptance and Commitment Therapy.

# 6.3. Examining the role of psychological flexibility in parents of children with asthma: Analysis of a structural equation model

This Section 6.3 presents the results to examine the ways in which the PF of parents, their psychological adjustment to their child's illness and their psychological symptoms including anxiety, depression, and stress, related to their child's asthma morbidity by structural equation modeling (SEM), using the cross-sectional data from all the eligible parents (n = 302) who completed the questionnaires prior to the random assignment of the study groups.

Table 6.1 presents the means, standard deviations, actual ranges, possible ranges, and zero-order correlations of the observed variables in the SEM. The mean scores for the Depression Anxiety Stress Scales (DASS)-21 depression (mean (M) = 4.24, standard deviation (SD) = 5.71, range: 0-28), anxiety (M = 4.91, SD = 5.83,range 0-32), and stress (M = 9.19, SD = 8.17; range 0-42) were lower than the DASS-21 clinical cut-off values indicating psychological problems (score = 9 for depression; 7 for anxiety; 14 for stress). In addition, the mean scores for the Parent Experience of Child Illness (PECI) Guilt and Worry (M = 1.50, SD = 0.68), the PECI Unresolved Sorrow and Anger (M = 1.15, SD = 0.63), and the PECI Long-term Uncertainty (M = 1.11, SD = 0.76) revealed that, on average, the parents rated themselves as having "rarely" or "sometimes" experienced emotional distress in caring for their child with asthma. Correlations between the observed variables among two latent variables, including the DASS-21 subscales (Pearson correlation coefficient (r) = .70 to .85, all *p*-values (ps) < .001) and the child's asthma morbidity (r = .55 to .69, all ps < .001) were significant with large effect sizes. Notably, regarding a latent variable concerning the psychological adjustment of parents to their child's illness, three PECI subscales, namely Guilt and Worry, Unresolved

Sorrow and Anger and Long-term Uncertainty were significantly correlated (r = .79 to .85, all ps < .001), while their correlations with the PECI Emotional Resources were relatively weak (r = -.06 to .15).

# Table 6.1

# Means, standard deviations, actual ranges, possible ranges and zero-order correlations of observed variables

Variables					Parents					Children	1
	AAQ-II	PECI-G	PECI-U	PECI-L	PECI-E	DASS21-	DASS21-	DASS21-	Day	Night	Reliever
						D <sup>a</sup>	A <sup>a</sup>	S <sup>a</sup>	sym	sym	use
Parents											
AAQ-II	-										
PECI-G	.62***	-									
PECI-U	.62**	.85***	-								
PECI-L	.60***	.79***	.81***	-							
PECI-E	24**	06	15**	.01	-						
DASS21-D	.51***	.52***	.56***	.51***	20**	-					
DASS21-A	.47***	.55***	.58***	.51***	12*	.85***	-				
DASS21-S	.60***	.60***	.55***	.50***	13*	$.70^{***}$	.71***	-			
Children											
Day sym	.25***	.22***	.20***	.20***	02	.09	.05	.12*	-		
Night sym	.24***	.17**	.13*	.15**	02	.12*	.07	.09	.62***	-	
Reliever use	.24***	.23***	.19**	.18**	.04	.10	.07	.14*	.69***	.55***	-
М	18.91	1.50	1.15	1.11	2.27	4.24	4.91	9.19	1.18	0.95	1.29
SD	8.46	0.68	0.63	0.76	0.89	5.71	5.83	8.17	1.75	1.52	1.88

Actual range	7.0-49.0	0.1-3.8	0.0-3.3	0.0-3.6	0.0-4.0	0.0-28.0	0.0-32.0	0.0-42.0	0.0-7.0	0.0-7.0	0.0-7.0
Possible range	7-49	0-4	0-4	0-4	0-4	0-42	0-42	0-42	0-7	0-7	0-7

Note. N = 302. M = mean; SD = standard deviation; AAQ-II = Acceptance and Action Questionnaire-II; PECI-G = Parent Experience of Chronic Illness-Guiltand Worry; PECI-U = Parent Experience of Chronic Illness-Unresolved Sorrow and Anger; PECI-L = Parent Experience of Chronic Illness-Long-termUncertainty; PECI-E = Parent Experience of Chronic Illness-Emotional Resources; DASS21-D = Depression Anxiety Stress Scales 21-Depression; DASS21-A = Depression Anxiety Stress Scales 21-Anxiety; DASS21-S = Depression Anxiety Stress Scales 21-Stress; Day sym = day symptoms; Night sym = nightsymptoms.

<sup>a</sup>DASS-21 subscales were multiplied by two for comparison with the normative data in the DASS manual and the DASS-related publications (Henry & Crawford, 2005; Lovibond & Lovibond, 1995b).

\**p* < .05, \*\* *p* <.01, \*\*\* *p* <.001

Table 6.2 presents the progression of model modifications and model fit indices. The results of the confirmatory factor analysis indicated an acceptable structural equation model for the proposed latent variables and the indicators, with the exception of RMSEA (see Model 1 in Table 6.2). The modification indices (MIs) suggested that the model fit could be further improved by adding the following two covariance paths between: (1) the parents' PF and the DASS-21-Stress (MI = 26.30, expected parameter change (EPC) = 9.28); (2) the PECI-Guilt and Worry and the DASS-21-Stress (MI = 17.48, EPC = 0.41), respectively. It was determined that the above relationships were justified. Theoretically speaking, parents of children with asthma who are psychologically less flexible may regard their caregiving roles as a huge burden of responsibility. Guilt and worry about their child's future, together with stress, are common psychological experiences that can occur concurrently among parents of children with chronic illnesses (Semple & McCance, 2010; Senger, Ward, Barbosa-Leiker, & Bindler, 2016; Trollvik & Severinsson, 2004). After the inclusion of the covariance paths, the final structural model (see Model 3 in Table 6.2.) was tested and demonstrated a very good fit with the data (Chi-square  $(\gamma^2)$  = 69.43, degree of freedom (df) = 53; comparative fit index (CFI) = .993; Tucker-Lewis Index (TLI) = .988; standardized root means square residual (SRMR) = .028; root mean square error approximation (RMSEA) = .031).

### Table 6.2

Model	Model details and modifications	$\chi^2 (df)$	CFI	TLI	SRMR	RMSEA (90% CI)
1	4 latent constructs: (a) AAQ-	123.20	.971	.952	.034	.061
	II for parents' psychological	(55)				[.047, .077]
	flexibility; (b) PECI					
	subscales for parents'					
	psychological adjustment to					
	the child's illness; (c)					
	DASS21 subscales for					
	parents' psychological					
	symptoms; (d) day					
	symptoms, night symptoms					
	and reliever use for the					
	child's asthma morbidity,					
	and 3 control variables: (a)					
	parents' relationship with the					
	child; (b) parents' history of					
	asthma and (c) the child's					
	age					
2	Covariance between parents'	95.13 (54)	.982	.970	.030	.049
	psychological flexibility and					[.032, .064]
	DASS21-S allowed					
3	Covariance between PECI-G	69.43 (53)	.993	.988	.028	.031
	and DASS21-S allowed					[.000, .050]

# Progression of the model modifications and model fit indices

*Note*.  $\chi^2$  = Chi-square; *df* = degree of freedom; CFI = comparative fit index; TLI = Tucker Lewis Index; SRMR = standardized root means square residuals; RMSEA = root mean square error approximation; CI = confidence interval; AAQ-II = Acceptance and Action Questionnaire-II; PECI = Parent Experience of Chronic Illness; DASS21 = Depression Anxiety Stress Scales 21; DASS21-S = Depression Anxiety Stress Scales 21-Stress; PECI-G = Parent Experience of Chronic Illness-Guilt and Worry.

Figure 6.2 illustrates the standardized path coefficients and correlations of the final structural equation model, controlling for the parents' relationship with the child, the parents' history of asthma, and the child's age. The Bollen-Stine bootstrap test showed a non-significant result (p = .134). There was no substantial discrepancy between the results of the bootstrap analysis and the original maximum likelihood analysis, as shown by the bias values of each parameter estimate ranging from 0.001

to 0.006. These findings offer support for the stability of the model with non-normal data. As hypothesized, poor PF was significantly associated with poor psychological adjustment to the child's illness in parents (r = .67, 95% CI [.61, .73], p = .001). Similarly, the significant associations were found between poor PF and increased psychological symptoms (r = .54, 95% CI [.45, .63], p = .001); and between poor psychological adjustment to the child's illness and increased psychological symptoms in parents (r = .65, 95% CI [.58, .72], p = .001). Overall, three parental psychological constructs (PF, PECI, and DASS-21) explained 15% of the variation in the child's asthma morbidity. Parents' PF was found to be the only latent construct possessing a significant association with the child's asthma morbidity (standardized beta coefficient ( $\beta$ ) = 0.27, 95% CI [0.09, 0.42], p = .002). No significant associations were found in the case of psychological adjustment to the child's illness ( $\beta = 0.14, 95\%$  CI [-0.04, 0.32], p = .120) or in psychological symptoms ( $\beta = -0.13$ , 95% CI [-0.27, 0.04], p = .126), respectively.

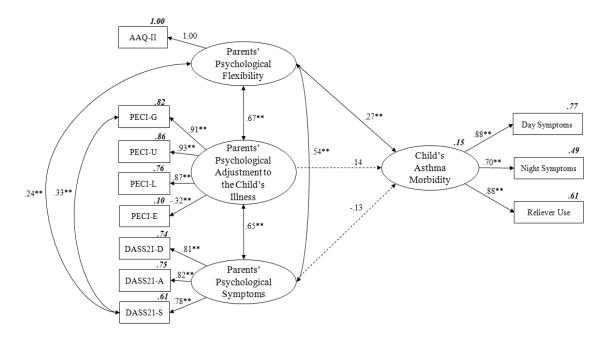


Figure 6.2. The final structural equation model.

*Note.* Latent variables are represented by ellipses and observed variables by squares. Solid lines indicate significant paths, while dashed lines indicate non-significant paths. The bold, italicized values on the top right-hand corner denote the squared multiple correlations. For simplicity, control variables including parents' relationship with the child, parents' history of asthma diagnosis and the child's age are not displayed. The error covariance paths between (1) PECI-G and PECI-E; (2) PECI-U and PECI-E; (3) PECI-L and PECI-E within the latent variable are also not displayed. All coefficients are standardized.

AAQ-II = Acceptance and Action Questionnaire-II; PECI-G = Parent Experience of Chronic Illness-Guilt and Worry; PECI-G = Parent Experience of Chronic Illness-Guilt and Worry; PECI-U = Parent Experience of Chronic Illness-Unresolved Sorrow and Anger; PECI-L = Parent Experience of Chronic Illness-Long-term Uncertainty; PECI-E = Parent Experience of Chronic Illness-Emotional Resources; DASS21-D = Depression Anxiety Stress Scales 21-Depression; DASS21-A = Depression Anxiety Stress Scales 21-Anxiety; DASS21-S = Depression Anxiety Stress Scales 21-Stress.

\**p* < .05, \*\* *p* <.01, \*\*\* *p* <.001

The following Section 6.4 and Section 6.5 present the findings of the RCT study. Section 6.4 reports the characteristics of the parents and their children who participated in the RCT measured at baseline, and the results of testing the baseline homogeneity by assessing the observed differences between the study groups (the ACT group and the Control group) (n = 168). Section 6.5 reports the results of examining the intervention effects of the study groups over six months after the intervention on the health outcomes of children with asthma, the psychological health outcomes, as well as the asthma management outcomes of their parents.

# 6.4. Characteristics of the participants at baseline

### 6.4.1. Parents

Socio-demographics, smoking status and family history of asthma. The socio-demographic characteristics, smoking status and family history of asthma of the parents in the ACT group, the Control group and of all the parents that participated in the RCT (n = 168) are shown in Table 6.3. Most of the parents who participated in this study were mothers (88.1%, age M = 38.4, SD = 5.9), married (86.3%) and full-time parents (55.4%). They had educational attainment at secondary school level (73.2%). Over half of the families (52.4%) had the monthly household income of \$25,001 to \$50,000 Hong Kong Dollars, which were above the median of the monthly household income for an average household size of 2.9 (a Hong Kong couple with a child) (Census and Statistics Department, 2016b). Though the children in this study had asthma, over one-third (38.1%) of their parents were current smokers. Around one-fourth (27.4%) of the parents had their personal history of asthma, 13.7% of the parents reported that other family members, such as other children in their families, had history of asthma. There were no significant

differences in the socio-demographics, smoking status and family history of asthma between the two study groups (all *ps* ranged from .073 to .895).

# Table 6.3

Socio-demographics, smoking status and family history of asthma of the parents by

group assignment (N = 168)

		Total	AC	Гgroup	Contro	l group	$\chi^2$ ( <i>df</i> )/ <i>t</i>	р-
	(N	= 168)	(	<i>n</i> = 84)	(	<i>n</i> = 84)		value
	n	%	n	%	n	%		
Relationship with child								
Father	20	11.9	8	9.5	12	14.3	0.91 (1)	.476
Mother	148	88.1	76	90.5	72	85.7		
Age (years), M (SD),	38.40	) (5.90)	37.74	4 (5.55)	39.07	7 (6.19)	-1.47	.144
[range]		[25-58]		[26-52]		[25-58]		
Educational attainment								
Primary education or below	9	5.4	4	4.8	5	6.0	1.98 (1)	.159ª
Secondary education	123	73.2	58	69.0	65	77.4		
Tertiary education or above	36	21.4	22	26.2	14	16.7		
Monthly household inco	me (HK	٥رلط						
< \$ 10,000	25	14.9	10	11.9	15	17.9	3.20(1)	.073ª
\$10,000 to \$25,000	45	26.8	18	21.4	27	32.1	5.20 (1)	.075
\$25,001 to \$50,000	88	52.4	51	60.7	37	44.0		
>\$50,000	10	6.0	5	6.0	5	6.0		
Occupation <sup>c</sup>	10	0.0	C	010	U	0.0		
Home-duties	93	55.4	49	58.3	44	52.4	5.29 (7)	.625
Managers	13	7.7	6	7.1	7	8.3		
Professionals	8	4.8	2	2.4	6	7.1		
Technicians and	5	3.0	1	1.2	4	4.8		
associate								
professionals								
Clerical support workers	18	10.7	9	10.7	9	10.7		
Service and sales workers	28	16.7	15	17.9	13	15.5		
Plant and machine	1	0.6	1	1.2	0	0.0		
operators and assemblers Elementary occupations	2	1.2	1	1.2	1	1.2		
Marital status Single/ separated/ divorced/ widowed	23	13.7	11	13.1	12	14.3	0.05 (1)	.822

Married	145	86.3	73	86.9	72	85.7		
Living district								
Tuen Mun	76	45.2	40	47.6	36	42.9	2.46 (2)	.482
Yuen Long	51	30.4	26	31.0	25	29.8		
Tin Shui Wai	39	23.2	18	21.4	21	25.0		
Others	2	1.2	0	0.0	2	2.4		
Smoking status								
Both parents are non-	104	61.9	51	60.7	53	63.1	0.10(1)	.751
smokers								
At least one parent is	64	38.1	33	39.3	31	36.9		
a current smoker								
History of asthma diagne	osis							
Neither parents have	99	58.9	51	60.7	48	57.1	0.22 (2)	.895
a history of asthma								
At least one parent	46	27.4	22	26.2	24	28.6		
has a history of								
asthma								
Other family	23	13.7	11	13.1	12	14.3		
members have a								
history of asthma								

*Note.* ACT = Acceptance and Commitment Therapy; N = total number of participants; GOPC = general outpatient clinic; n = number of participants per group;  $\chi^2 =$  Chi-square; t = t-statistics; df = degree of freedom; M = mean; SD = standard deviation; HKD = Hong Kong Dollars (1USD = 7.8HKD)

<sup>a</sup> Linear-by-Linear Association test was used due to ordinal data.

<sup>b</sup> According to the Quarterly Report on General Household Survey data conducted in Hong Kong on January to March 2016, the median monthly household income for an average household size of 2.9 (a Hong Kong couple with a child) was approximately \$25,000 Hong Kong Dollars (Census and Statistics Department, 2016b).

<sup>c</sup> Classification of the types of occupation was based on the International Standard Classification of Occupations 2008 ISCO-08 (International Labor Organization, 2016).

Psychological health. The psychological flexibility (PF), psychological adjustment to the child's illness and psychological symptoms of the parents were assessed via the AAQ-II, PECI and the DASS-21, respectively. The mean scores (and SDs) of the AAQ-II, PECI subscales and the DASS-21 subscales, and the distributions of severity of psychological symptoms indicated by the DASS-21 subscales for the parents in the ACT group, the Control group and for all the parents participated in the RCT (n = 168) are shown in Table 6.4. At baseline, for all the parents, the mean score (SD) for the AAQ-II was 19.88 (8.64). The mean scores for the PECI Guilt and Worry (M = 1.55, SD = 0.67), the PECI Unresolved Sorrow and Anger (M = 1.16, SD = 0.60), and the PECI Long-term Uncertainty (M = 1.13, SD =0.77) revealed that, generally the parents rated themselves as having "rarely" or "sometimes" experienced psychological maladjustment in taking care of their children with asthma. Nevertheless, at least 20% of the parents had at least mild level of psychological symptoms as measured by the DASS-21 subscales, including symptoms of depression (20.2%), anxiety (31.0%) and stress (25.0%), respectively. There were no significant differences in the mean scores of the AAQ-II, the PECI subscales and the DASS-21 subscales between two study groups measured at baseline (all ps ranged from .125 to .396). In addition, no significant differences in the proportions of the level of psychological symptoms (depression, anxiety and stress), as indicated by the DASS-21 subscales, were observed between groups measured at baseline (all *ps* ranged from .354 to .924).

# Table 6.4

Parent	Possible		Total		T group	Contro	ol group	$\chi^2 (df)/$	р
measures	range	(N	7 = 168)		(n = 84)		(n = 84)	t	
		М	SD	М	SD	М	SD		
		[range]	]/ n (%)	[range	]/ n (%)	[range	]/ n (%)		
Psychological f	•								
AAQ-II <sup>a</sup>	7-49	19.88	8.64	20.90	8.14	18.86	9.04	1.54	.125
Derrohala si sala		4 a 41 a a 1. :	[7-49]		[7-49]		[7-49]		
Psychological a PECI- Guilt	0-4	1.55	0.67	ma 1.62	0.67	1.47	0.66	1.42	.157
and Worry	0-4							1.42	.157
•		-	8-3.18]	_	[8-3.18]	-	36-3.09]		
PECI-	0-4	1.16	0.60	1.23	0.64	1.10	0.57	1.46	.147
Unresolved		[0.	13-2.5]	[0	.13-2.5]	[0.1	[3-2.25]		
Sorrow and									
Anger PECI-	0-4	1.13	0.77	1.21	0.79	1.05	0.74	1.39	.166
Long-term	0-4	1.15		1.21		1.05		1.57	.100
Uncertainty			[0-3.2]		[0-3.2]		[0-3.2]		
PECI-	0-4	2.32	0.85	2.21	0.81	2.43	0.88	-1.71	.190
Emotional		0.01	0-4.00]	01	00-3.80]		[0-4]		
Resources		[0.0		[0.0	0 0.00]		[0]]		
Psychological s	symptoms								
DASS21-	0-42	4.70	6.34	5.12	6.84	4.29	5.81	0.85	.396
Depression <sup>c</sup>			[0-38]		[0-38]		[0-26]		
Normal	0-9	134	4 (79.8)	6	7 (79.8)	6	7 (79.8)	0.01	.924 <sup>b</sup>
Mild	10-13		14 (8.3)		8 (9.5)		6 (7.1)	(1)	
Moderate	14-20		14 (8.3)		5 (6.0)		9 (10.7)		
Severe	21-27		5 (3.0)		3 (3.6)		2 (2.4)		
Extremely	≥28		1 (0.6)		1 (1.2)		0 (0.0)		
severe							~ /		
DASS21-	0-42	5.50	6.22	5.93	6.03	5.07	6.42	0.89	.374
Anxiety <sup>c</sup>			[0-32]		[0-28]		[0-32]		
Normal	0-7	110	6 (69.0)	5	6 (66.7)	6	0 (71.4)	0.51	.477 <sup>t</sup>
Mild	8-9		13 (7.7)		8 (9.5)		5 (6.0)	(1)	
Moderate	10-14		8 (16.7)	1	3 (15.5)	1	5 (17.9)		
		20		1	. ,	1			
Severe	15-19		5 (3.0)		3 (3.6)		2 (2.4)		
Extremely severe	≥20		6 (3.6)		4 (4.8)		2 (2.4)		
DASS21-	0-42	9.79	8.49	10.40	8.80	9.17	8.17	0.95	.346
Stress <sup>c</sup>			[0-32]		[0-32]		[0-30]		

Psychological health of the parents by group assignment (N = 168)

Normal	0-14	126 (75.0)	61 (72.6)	65 (77.4)	0.86	.354 <sup>b</sup>
					(1)	
Mild	15-18	13 (7.7)	6 (7.1)	7 (8.3)		
Moderate	19-25	19 (11.3)	11 (13.1)	8 (9.5)		
Severe	26-33	10 (6.0)	6 (7.1)	4 (4.8)		

*Note.* ACT = Acceptance and Commitment Therapy; N = total number of participants; n = number of participants per group;  $\chi^2 =$  Chi-square; t = t-statistics; p = p-value; M = mean; SD = standard deviation; AAQ-II = Acceptance and Action Questionnaire-II; PECI = Parent Experience of Chronic Illness; DASS-21 = Depression Anxiety Stress Scales-21. <sup>a</sup> For the AAQ-II, a higher total score indicates poor psychological flexibility. <sup>b</sup> Linear-by-Linear Association test was used due to ordinal data.

<sup>c</sup> DASS-21 subscales were multiplied by two for comparison with the normative data in the DASS manual and the DASS-related publications (Henry & Crawford, 2005; Lovibond & Lovibond, 1995b).

Asthma management. The asthma knowledge, asthma management selfefficacy and quality of life of the parents were assessed via the AKQ, the PAMSE and the PACQLQ, respectively. Table 6.5 assembles the mean scores (and *SD*s) of the AKQ, the PAMSE and the PACQLQ for the parents in the ACT group, the Control group and for all the parents participated in the RCT (n = 168). For all the parents at baseline, their mean score (*SD*) for the AKQ was 18.3 (2.5), indicating that they had already attained about 70% of correct answers (18/25) in the assessment of their asthma knowledge. The mean scores (*SDs*) for the PAMSE subscales ranged from 3.25 (0.94) to 3.82 (0.75), showing that generally the parents rated themselves as "fairly sure" in preventing and managing childhood asthma attacks. Further, the mean scores (*SD*s) for the PACQLQ subscales ranged from 4.66 (1.27) to 4.72 (1.20), indicating that the parents perceived that the childhood asthma could have impacts on their emotions and their daily activities at "some of the time". There were no significant differences in the mean scores of the AKQ, the PAMSE and the PACQLQ between groups measured at baseline (all *ps* ranged from .144 to 1.00).

# Table 6.5

Parent	Possible		Total	A	CT group	Cont	rol group	t	р
measures	range	(	N = 168)		(n = 84)		(n = 84)		
		М	SD	М	SD	М	SD	-	
			[range]		[range]		[range]		
Asthma knowle	edge								
AKQ	0-25	18.31	2.47	18.31	2.36	18.31	2.59	0.00	1.00
			[12-24]		[12-23]		[12-24]		
Asthma manage	ement self-ef	ficacy							
PAMSE-	1-5	3.82	0.75	3.81	0.81	3.82	0.69	10	.918
Attack			[1.33-5]		[1.33-5]		[2.33-5]		
Prevention									
PAMSE-	1-5	3.25	0.94	3.16	0.89	3.33	0.90	12	.246
Attack			[1.43-5]		[1.43-5]		[1.57-5]		
Management									
PAMSE-	1-5	3.51	0.78	3.46	0.81	3.56	0.74	80	.424
Total score			[1.77-5]		[1.77-5]		[2-5]		
Quality of life									
PACQLQ-	1-7	4.74	1.24	4.60	1.28	4.88	1.19	-1.44	.152
Emotional			[1 70 7]		[0 11 7]				
Function			[1.78-7]		[2.11-7]		[1.78-7]		
PACQLQ-	1-7	4.66	1.27	4.53	1.27	4.79	1.27	-1.34	.183
Activity			[1.25-7]		[1.25-7]		[1.75-7]		
Limitation									
PACQLQ-	1-7	4.72	1.20	4.58	1.21	4.85	1.17	-1.47	.144
Total score			[1.77-7]		[2.08-7]		[2-5]		

As thma management of the parents by group assignment (N = 168)

*Note.* ACT = Acceptance and Commitment Therapy; N = total number of participants; n = number of participants per group; t = t-statistics; p = p-value; M = mean; SD = standard deviation; AKQ = Asthma Knowledge Questionnaire; PAMSE = Parent Asthma Management Self-Efficacy; PACQLQ = Pediatric Asthma Caregiver's Quality of Life Questionnaire

### 6.4.2. Children

**Demographic and clinical characteristics.** The demographic and clinical characteristics of the children in the ACT group, the Control group and for all the children participated in the RCT (n = 168) are shown in Table 6.6. For all the children, approximately 60% of them were boys (age M = 6.81, SD = 2.50), they had been diagnosed with asthma during their preschool age (age M = 3.46, SD = 1.79). Around one-third (35.1%) of them had also been diagnosed with allergic rhinitis, 10.7% also had eczema. Over half of the children needed inhaled corticosteroids as prophylaxis to control their asthma symptoms (52.4%) and had received at least one course of oral prednisolone in the previous year (56.0%). These findings indicate that these children had suffered from at least one episode of acute asthma exacerbation in the past year. Twenty-one children had received an alternative therapy, such as herbal soup (n = 17) and natural moxibustion (n = 4) in the past six months. There were no significant differences for all the demographic and clinical characteristics of the children between the study groups assessed at baseline (all ps ranged from .125 to .874).

# Table 6.6

Demographic and clinical characteristics of the children by group assignment (N =

1	68	)
1	00	,

		Total	ACT	group	Contro	l group	$\chi^2$ ( <i>df</i> )/ <i>t</i>	р
	(N :	= 168)	(1	i = 84)	(	<i>n</i> = 84)	_	
	n	%	п	%	n	%	-	
Gender								
Male	103	61.3	51	60.7	52	61.9	0.03 (1)	.874
Female	65	38.7	33	39.3	32	38.1		
Age (years), $M$ (SD),	6.81	(2.50)	6.67	(2.55)	6.95	5 (2.46)	-0.72	.471
[range]		[3-12]		[3-12]		[3-12]		
Age of diagnosis as asthma	3.46	(1.79)	3.31	(1.70)	3.61	1 (1.88)	-1.10	.273
(years), M (SD), [range]	[0	).5-11]	[(	).5-11]		[0.5-9]		
Concurrently diagnosed with	allergi	c rhiniti	S					
Yes	59	35.1	29	34.5	30	35.7	0.03 (1)	.872
No	109	64.9	55	65.5	54	64.3		
Concurrently diagnosed with	eczem	a						
Yes	18	10.7	10	11.9	8	9.5	0.25 (1)	.618
No	150	89.3	74	88.1	76	90.5		
Current use of oral Monteluk	ast as p	prophyla	axis					
Yes	24	14.3	11	13.1	13	15.5	0.19 (1)	.659
No	144	85.7	73	86.9	71	84.5		
Current use of inhaled cortic	osteroic	l as prop	ohylaxi	is, by typ	pes			
None	80	47.6	47	56.0	33	39.3	5.74 (3)	.125
Beclomethasone	81	48.2	35	41.7	46	54.8		
dipropionate								
Fluticasone propionate	5	3.0	1	1.2	4	4.8		
Fluticasone propionate	2	1.2	1	1.2	1	1.2		
and Salmeterol								
One or more course of oral p	redniso	lone use	ed in th	ne past 1	2 months	5		
Yes	94	56.0	50	59.5	44	52.4	0.87 (1)	.351
No	74	44.0	34	40.5	40	47.6		
Alternative therapy received	in the p	oast 6 m	onths,	by types	a			
Herbal soup	17	81.0	8	80.0	9	81.8	0.01 (1)	.916
Natural moxibustion	4	19.0	2	20.0	2	18.2		

*Note.* ACT = Acceptance and Commitment Therapy; N = total number of participants; n = number of participants per group;  $\chi^2 =$  Chi-square; t = t-statistics; p = p-value; M = mean; SD = standard deviation.

<sup>a</sup>For the child who had received alternative therapy for treating asthma in the past six months (n = 21).

Unscheduled health care service visits due to asthma exacerbations. The unscheduled health care service visits due to asthma exacerbations over the past six months for the children in the ACT group, the Control group and for all the children participated in the trial are presented in Table 6.7. Approximately 40% of the children in this study had visited emergency department at least once during the past six months for treating acute asthma exacerbations (i.e., total number of visits: M = 0.67, SD = 1.01), while approximately one-fourth (24.4%) of the children required hospital admissions (i.e., total number of admissions: M = 0.34, SD = 0.69). If admitted, the majority (53.7%) needed to be hospitalized for approximately three to four days. The proportion of children who attended at least one private practitioner's clinic due to asthma exacerbations (44.6%) was almost the three times of those who attended at least one general outpatient clinic (14.9%). Overall speaking, there were no significant differences in either the means, or the proportions of all the indicators related to the unscheduled health care service visits due to asthma exacerbations in children between groups assessed at baseline (all *ps* ranged from .198 to .967).

### Table 6.7

Unscheduled health care service visits due to asthma exacerbations in children over

the past six months	by group	p assignment ( $N = 168$ )
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		Total		Г group		ol group	$\chi^2 (df)/Z$	р
	(N	<i>l</i> = 168)	(	<i>n</i> = 84)	(	(n = 84)		
	n	%	п	%	n	%		
General outpatient clinic	0.39	9 (1.19)	0.46	5 (1.38)	0.3	1 (0.97)	-1.01	.311ª
visit(s) M (SD), [range]		[0-10]		[0-10]		[0-6]		
None	143	85.1	69	82.1	74	88.1	0.58 (1)	.445 <sup>b</sup>
1-2 visits	15	8.9	10	11.9	5	6.0		
3-4 visits	7	4.2	3	3.6	4	4.8		
$\geq$ 5 visits	3	1.8	2	2.4	1	1.2		
Private practitioner's	1.2	5 (2.46)	1.29	9 (2.32)	1.2	1 (2.59)	-0.04	.967ª
clinic visit(s), M (SD),		[0-20]		[0-15]		[0-20]		
[range]								
None	93	55.4	47	56.0	46	54.8	0.36 (1)	.548 <sup>b</sup>
1-2 visits	48	28.6	22	26.2	26	31.0		
3-4 visits	16	9.5	7	8.3	9	10.7		
$\geq$ 5 visits	11	6.5	8	9.5	3	3.6		
Emergency care visit(s),	0.6	7 (1.07)	0.69	9 (1.08)	0.6	5 (1.07)	-0.47	.640 <sup>a</sup>
<i>M</i> ( <i>SD</i> ), [range]		[0-6]		[0-6]		[0-5]		
None	103	61.3	49	58.3	54	64.3	0.70(1)	.403 <sup>b</sup>
1-2 visits	55	32.7	29	34.5	26	31.0		
3-4 visits	8	4.8	5	6.0	3	3.6		
$\geq$ 5 visits	2	1.2	1	1.2	1	1.2		
Hospital admission(s), M	0.34	4 (0.69)	0.38	8 (0.69)	0.30	0 (0.69)	-1.16	.245ª
(SD), [range]		[0-4]		[0-3]		[0-4]		
None	127	75.6	60	71.4	67	79.8	1.65 (1)	.198 <sup>b</sup>
1-2 visits	38	22.6	22	26.2	16	19.0		
3-4 visits	3	1.8	2	2.4	1	1.2		
Total number of days of	4.0	5 (2.00)	3.79	9 (1.96)	4.4	1 (2.06)	-1.03	.303ª
inpatient hospital stay, M		[1-11]		[1-11]		[2-10]		
( <i>SD</i> ), [range] <sup>c</sup>								
1-2 days	7	17.1	5	20.8	2	11.8	1.09(1)	.296 <sup>b</sup>
3-4 days	22	53.7	13	54.2	9	52.9		
5-6 days	9	22.0	5	20.8	4	23.5		
$\geq$ 7 days	3	7.3	1	4.2	2	11.8		

*Note.* ACT = Acceptance and Commitment Therapy; *N* = total number of participants; *n* = number of participants per group; *Z* = z-value of the Mann-Whitney U test;  $\chi^2$  = Chi-square; *t* = *t*-statistics; *p* = *p*-value; *M* = mean; *SD* = standard deviation.

<sup>a</sup> Mann–Whitney U tests were used due to count data.

<sup>b</sup>Linear-by-Linear Association test was used due to ordinal data.

<sup>c</sup> For the child who was hospitalized due to an asthma exacerbation in the past 6 months only (n = 41).

Asthma symptoms. The asthma symptoms over the past four weeks for the children in the ACT group, the Control group and for all the children participated in the trial are displayed in Table 6.8. On average, the parents reported that their children experienced at least one day per week with asthma symptoms, such as chronic coughing, wheezing, shortness of breath or chest tightness, during the daytime (M = 1.27, SD = 1.82), the nighttime (M = 0.96, SD = 1.52), and required short-acting bronchodilators for symptoms relief (M = 1.33, SD = 1.93). Specifically, around 10% of the children had the above asthma symptoms for three to four days per week. Almost 30% of the children experienced at least one day of activity limitations due to asthma symptoms per week, for instance, they needed to slow down during physical exercises. Overall, there were no significant differences in either the means, or the percentages of all the parameters indicating the child's asthma symptoms between groups assessed at baseline (all *p*s ranged from .160 to .943)

# Table 6.8

As thma symptoms in children over the past four weeks by group assignment (N =

### 168)

		Total	ACT	group	Contro	l group	$\chi^2 (df)/$	p
	(N = 168)		(n = 84)		(n = 84)		Z	Г
	n	%	n	%	n	%		
Daytime symptoms/week, M	1.27	7 (1.82)	1.48	(1.98)	1.05	5 (1.64)	-1.28	.200ª
( <i>SD</i> ), [range]		[0-7]		[0-7]		[0-7]		
None	87	51.8	42	50.0	45	53.6	1.98 (1)	.160 <sup>b</sup>
1-2 days	48	28.6	21	25.0	27	32.1		
3-4 days	20	11.9	12	14.3	8	9.5		
5-6 days	7	4.2	5	6.0	2	2.4		
Every day	6	3.6	4	4.8	2	2.4		
Nighttime awakening due to	0.96	5 (1.52)	0.84	(1.44)	1.07	7 (1.60)	-1.04	.299ª
asthma symptoms/week, M		[0-7]		[0-7]		[0-7]		
( <i>SD</i> ), [range]								
None	99	58.9	53	63.1	46	54.8	1.39 (1)	.238 <sup>b</sup>
1-2 nights	47	28.0	23	27.4	24	28.6		
3-4 nights	16	9.5	5	6.0	11	13.1		
5-6 nights	4	2.4	2	2.4	2	2.4		
Every night	2	1.2	1	1.2	1	1.2		
Days required to use inhaled	1.33	3 (1.93)	1.31	(1.79)	1.35	5 (2.07)	-0.61	.541ª
bronchodilators to relieve		[0-7]		[0-7]		[0-7]		
asthma symptoms/week,								
M(SD), [range]								
None	87	51.8	41	48.8	46	54.8	0.01 (1)	.943 <sup>b</sup>
1-2 days	47	28.0	27	32.1	20	23.8		
3-4 days	19	11.3	10	11.9	9	10.7		
5-6 days	8	4.8	3	3.6	5	6.0		
Every day	7	4.2	3	3.6	4	4.8		
Days with activity limitation	0.61 (1.34)		0.60 (1.40)		0.62 (1.29)		-0.32	.748ª
due to asthma symptoms/	[0-7]		[0-7]		[0-7]			
week, $M$ (SD), [range]								
None	120	71.4	61	72.6	59	70.2	0.01	.923 <sup>b</sup>
1-2 days	36	21.4	17	20.2	19	22.6		
3-4 days	6	3.6	3	3.6	3	3.6		
5-6 days	3	1.8	1	1.2	2	2.4		
Every day	3	1.8	2	2.4	1	1.2		

*Note.* ACT = Acceptance and Commitment Therapy; N = total number of participants; n = number of participants per group;  $\chi^2 =$  Chi-square; Z = z-value of the Mann-Whitney U test; p = p-value; M = mean; SD = standard deviation.

<sup>a</sup> Mann–Whitney U tests were used due to count data.

<sup>b</sup>Linear-by-Linear Association test was used due to ordinal data.

### 6.5. Effects of ACT versus Control on the child health outcomes

This Section 6.5 reports the results of the adjusted GEE analyses for assessing the intervention effects between the ACT group and the Control group on the health outcomes of children with asthma across time.

Emergency department (ED) visits due to asthma exacerbations. The predefined primary outcome of this RCT study was the frequency of emergency department (ED) visits due to asthma exacerbations in children over the six-month period assessed at six months post-intervention. As shown in Table 6.9, significant group (Wald  $\chi^2$  (Wald Chi-square) = 9.27, *p* = .002) and time-by-group interaction effects (Wald  $\chi^2$  = 8.46, *p* = .004) were found on this primary outcome, showing that when compared with the Control group, the children whose parents were allocated to the ACT group had significantly fewer ED visits due to asthma exacerbations at six months post-intervention (adjusted incidence rate ratio (aIRR) = 0.20, 95% CI [0.08, 0.53], *p* =.001).

### Other unscheduled health care service visits due to asthma

**exacerbations.** It can be seen from Table 6.9 that, significant time-by-group interaction effects could be found for the general outpatient clinic (GOPC) visits (Wald  $\chi^2 = 7.11$ , p = .008), the private practitioners' clinic visits due to asthma exacerbations in children (Wald  $\chi^2 = 6.14$ , p = .013), but not for the hospital admissions (p = .310) and the length of days of hospital stay (p = .747).

At six months post-intervention, the intervention effect was in favor of ACT as evident in the frequency of the private practitioners' clinic visits due to children's asthma exacerbations (aIRR = 0.47, 95% CI [0.26, 0.85], p = .012), but not in the frequencies of GOPC visits (p = .063), as well as hospital admissions (p = .327), and the length of days of hospital stay (p = .921) in the past six months.

By the end of the study, a total of seven children (3 in ACT, 4 in Control) were hospitalized due to asthma exacerbations. There was no difference between groups with respect to the total number of days of hospitalization (p = .856).

# Table 6.9

Intervention effects on the child's unscheduled health care service visits due to asthma exacerbations by groups across time using generalized

### estimating equations

Measures	Mear		Tests o	Adjusted IRR at 6MFU <sup>a</sup>						
	Baseline	6MFU	Time effect		Group effect		Time-by-group effect		exp β [95% CI]	р
			Wald $\chi^2$	р	Wald $\chi^2$	р	Wald $\chi^2$	р		
Emergency department visit(s)		24.44	<.001	9.27	.002	8.46	.004	0.20 [0.08, 0.53]	.001	
ACT group	0.69 (0.12)	0.08 (0.04)								
Control group	0.65 (0.12)	0.38 (0.11)								
General outpatient clir	nic visit(s)		18.40	<.001	0.45	.502	7.11	.008	0.31 [0.09, 1.07]	.063
ACT group	0.46 (0.15)	0.05 (0.02)								
Control group	0.31 (0.11)	0.18 (0.06)								
Control group         0.31 (0.11)         0.18 (0.06)           Private practitioners' clinic visit(s)         0.40 (0.09)           ACT group         1.29 (0.25)         0.40 (0.09)		19.00	<.001	2.07	.150	6.14	.013	0.47 [0.26, 0.85]	.012	
ACT group	1.29 (0.25)	0.40 (0.09)								
Control group	1.21 (0.28)	0.85 (0.14)								
Hospital admission(s)			23.09	<.001	0.64	.424	1.03	.310	0.47 [0.10, 2.15]	.327
ACT group	0.38 (0.08)	0.04 (0.02)								
Control group	0.30 (0.08)	0.06 (0.03)								
Total number of day(s) of inpatient hospital stay <sup>b</sup>			1.03	.310	0.25	.617	0.10	.747	0.97 [0.57, 1.67]	.921
ACT group	3.79 (0.39)	3.67 (0.72)								
Control group	4.41 (0.49)	3.75 (0.42)								

*Note.* ACT = Acceptance and Commitment Therapy; GEE = Generalized estimating equation; IRR = Incidence Rate Ratio; SE = standard error; Wald  $\chi^2$  = Wald Chi-square, p = p-value; exp  $\beta$  = exponential beta coefficient; 6MFU = 6 months follow-up after the intervention

<sup>a</sup>Adjusted for parent's relationship with the child, parent's age, monthly household income, marital status, child's age, child's gender, types of inhaled corticosteroids use and season of enrollment.

<sup>b</sup>For those children who had hospitalized due to asthma exacerbations only (n = 7).

Asthma symptoms. Table 6.10 displays the intervention effects on the child's asthma symptoms between groups across time. Significant group effects and time-by-group interaction effects could be found in all the indicators assessing the child's asthma symptoms (all *p*s ranged from <.001 to .001). At six months post-intervention, the children whose parents received ACT had significantly greater reductions in the average number of days per week with asthma symptoms during the daytime (aIRR = 0.25, 95% CI [0.15, 0.43], *p* < .001), nights per week with sleep disturbance due to asthma symptoms (aIRR = 0.30, 95% CI [0.18, 0.50], *p* < .001), days per week with activity limitations due to asthma symptoms (aIRR = 0.20, 95% CI [0.09, 0.47], *p* < .001), and days per week of using inhaled bronchodilators for controlling asthma symptoms (aIRR = 0.36, 95% CI [0.21, 0.65], *p* = .001) in the past four weeks than those in the Control group.

# Table 6.10

# Intervention effects on the child's asthma symptoms by groups across time using generalized estimating equations

Measures	Mean (SE)				Tests	Adjusted IRR at 6MFU <sup>a</sup>					
	Baseline	3MFU	6MFU	Time effect		Group effect		Time-by-group effect		exp β [95% CI]	р
				Wald $\chi^2$	р	Wald $\chi^2$	р	Wald $\chi^2$	р		
Day sympto	ms <sup>b</sup>			0.77	.681	8.81	.005	35.43	<.001	0.25 [0.15, 0.43]	<.001
ACT	1.48	0.84	0.58								
group	(0.21)	(0.17)	(0.15)								
Control	1.05	1.42	2.29								
group	(0.18)	(0.21)	(0.22)								
Night sympt	toms <sup>c</sup>			0.71	.700	16.33	<.001	9.11	.011	0.30 [0.18, 0.50]	<.001
ACT	0.84	0.63	0.55								
group	(0.15)	(0.15)	(0.13)								
Control	1.07	1.23	1.87								
group	(0.17)	(0.19)	(0.23)								
Reliever use	d			6.60	.037	6.71	.010	10.69	.005	0.36 [0.21, 0.65]	.001
ACT	1.31	0.68	0.59								
group	(0.19)	(0.18)	(0.15)								
Control	1.35	1.13	1.62								
group	(0.23)	(0.22)	(0.22)								
Activity lim	itations <sup>e</sup>			10.98	.004	12.15	<.001	13.76	.001	0.20 [0.09, 0.47]	<.001
ACT	0.60	0.12	0.17								
group	(0.15)	(0.05)	(0.07)								
Control	0.62	0.44	0.84								
group	(0.14)	(0.13)	(0.16)								

*Note.* ACT = Acceptance and Commitment Therapy; IRR = Incidence Rate Ratio; n = number of participants per group; Wald  $\chi^2$  = Wald Chi-square, p = p-value; SE = standard error; exp  $\beta$  = exponential beta coefficient; 3MFU = 3 months follow-up after the intervention; 6MFU = 6 months follow-up after the intervention

<sup>a</sup> Adjusted for parent's relationship with the child, parent's age, monthly household income, marital status, child's age, child's gender, types of inhaled corticosteroids use and season of enrollment.

<sup>b</sup> Day symptoms refers to the average number of day(s) with that the child presented with asthma symptoms (either chronic coughing, wheezing, shortness of breath or chest tightness) during daytime per week during the 4-week recall period.

<sup>c</sup>Night symptoms refers to the average number of night(s) that the child was awaken due to asthma symptoms per week during the 4-week recall period.

<sup>d</sup>Reliever use refers to the average number of day(s) that the child required to use inhaled bronchodilator to relieve asthma symptoms per week during the 4-week recall period.

<sup>e</sup> Activity limitations refers to the average number of days that the child needed to slow down his/her activities due to asthma symptoms per week during the 4-week recall period.

### 6.6. Effects of ACT versus Control on the parental outcomes

This Section 6.6 reports the results of the adjusted GEE analyses for assessing the intervention effects between the ACT group and the Control group on the parental outcomes, including psychological health outcomes and asthma management outcomes, across time.

### 6.6.1. Psychological health outcomes

Table 6.11 displays the adjusted GEE analyses for the parental psychological health outcomes, including psychological flexibility (PF), psychological adjustment to the child's illness and the psychological symptoms, between groups across time, while Table 6.12 shows the post-hoc comparisons from the GEE models for these outcomes, including within-group and between-group comparisons.

**Psychological flexibility.** There was a significant time-by-group interaction for the AAQ-II (Wald  $\chi^2 = 39.52$ , p < .001) (see Table 6.11), with the ACT group showing a significant reduction in the psychological *in*flexibility from pre- to postintervention (Mean difference (*M*diff) = -4.76, 95% CI [-6.21, -3.31], p < .001) and even a larger reduction from the pre-intervention to six months post-intervention (*M*diff = -6.24, 95% CI [-8.11, -4.38], p < .001), while the Control group did not demonstrate significant changes across the assessment time points (p at post = .509, at follow-up = .083) (see Table 6.12). The between-group comparisons indicated that when compared with the Control group, the parents in the ACT group had a significantly lower psychological *in*flexibility at post-intervention with a small-tomedium effect size (*M*diff = -3.05, 95% CI [-5.49, -0.62], p = .016, d = 0.41), and at six months post-intervention with a large effect size (*M*diff = -5.51, 95% CI [-7.71, -3.30], p < .001, d = 0.80) (see Table 6.12).

Psychological adjustment to the child's illness. Significant time-by-group interactions could be found in all the PECI subscales (all ps ranged from <.001 to .025) (see Table 6.11). Post-hoc comparisons showed that the interactions occurred because of the significant reductions in the emotional experiences of guilt and worry, unresolved sorrow and anger, and uncertainty, as well as a significant improvement in the perceived emotional recourses from pre- to post-intervention (all *ps* were <.001) and from pre-intervention to six months post-intervention (all *ps* ranged from <.001 to .002) in the ACT group, and lack of changes in the Control group across all the assessment time points (all ps ranged from .200 to .930) (see Table 6.12). The between-group comparisons showed that the parents in the ACT group had significantly less negative emotional experiences in terms of guilt and worry (Mdiff = -0.28, 95% CI [-0.46, -0.11], p = .002, d = 0.46), and unresolved sorrow and anger [Mdiff = -0.22, 95% CI [-0.40, -0.04], p = .017, d = 0.39] when compared with the Control group at six months post-intervention, but not at postintervention (all ps ranged from .125 to .766). There were no significant betweengroup differences for the long-term uncertainty (all ps ranged from .146 to .427), and the perceived emotional experiences (all ps ranged from .097 to .333) across all the assessment time points (see Table 6.12).

**Psychological symptoms.** The time-by-group interactions were significant for the DASS21-Anxiety (Wald  $\chi^2 = 12.29$ , p = .002) and the DASS21-Stress (Wald  $\chi^2 = 12.68$ , p = .002), but not for the DASS21-Depression (Wald  $\chi^2 = 5.80$ , p = .055) (see Table 6.11). Post-hoc comparisons demonstrated significant decreases in symptoms of anxiety from the pre- to post-intervention [*M*diff = -2.66, 95% CI [-3.90, -1.41], p < .001], and from the pre- to six months post-intervention [*M*diff = -2.14, 95% CI [-3.46, -0.83], p = .001] in the ACT group, the Control group also

showed a significant decrease from the pre- to post-intervention (p = .029), but this effect could not be sustained at six months post-intervention (p = .128). Post-hoc comparisons for the symptoms of stress showed significant reductions from the pre-to post-intervention [*M*diff = -2.26, 95% CI [-3.87, -0.66], p = .006] and from the pre-to six months post-intervention [*M*diff = -2.99, 95% CI [-4.63, -1.36], p < .001] in the ACT group, while the Control group did not show significant changes across the study period (all *ps* ranged from .155 to .408) (see Table 6.12). For the between-group comparisons, the parents in the ACT group had less symptoms of anxiety [*M*diff = -2.20, 95% CI [-3.66, -0.73], p = .003, d = 0.47] and stress [*M*diff = -2.50, 95% CI [-4.45, -0.47], p = .016, d = 0.35] at six months post-intervention (all *ps* ranged from .079 to .881). There were no significant differences in the symptoms of depression between groups across the study period (all *ps* ranged from .095 to .868) (see Table 6.12).

# Table 6.11

Intervention effects on the parental psychological health outcomes by group assignment across time using generalized estimating equations

Measures		Mean (SE)			Tests of	of adjusted G	EE mode	el effects <sup>a</sup>	
	Baseline	Post	6MFU	Time e	effect	Group et	ffect	Time-by-gro	oup effect
				Wald $\chi^2$	р	Wald $\chi^2$	р	Wald $\chi^2$	р
Psychological flexibility									
AAQ-II <sup>b</sup>				18.08	<.001	4.37	.036	39.52	<.001
ACT group	20.90 (0.88)	16.13 (0.72)	14.67 (0.72)						
Control group	18.86 (0.98)	19.42 (1.03)	20.40 (0.89)						
Psychological adjustment	t to the child's asth	та							
PECI-Guilt and Worry				25.28	<.001	1.65	.199	18.98	<.001
ACT group	1.62 (0.07)	1.25 (0.07)	1.19 (0.06)						
Control group	1.47 (0.07)	1.42 (0.08)	1.46 (0.07)						
PECI- Unresolved Sorrow	w and Anger			13.08	.001	0.30	.580	12.72	.002
ACT group	1.23 (0.07)	0.98 (0.07)	0.95 (0.05)						
Control group	1.10 (0.06)	1.01 (0.07)	1.16 (0.07)						
PECI-Long-term Uncerta	inty			13.30	.001	0.27	.601	7.37	.025
ACT group	1.21 (0.09)	0.96 (0.07)	0.98 (0.06)						
Control group	1.05 (0.08)	0.88 (0.08)	1.13 (0.08)						
PECI-Emotional Resourc	ces			13.47	.001	0.05	.827	13.08	.001
ACT group	2.21 (0.09)	2.65 (0.07)	2.64 (0.08)						
Control group	2.43 (0.09)	2.50 (0.08)	2.38 (0.10)						
Psychological symptoms									
DASS21-Depression <sup>c</sup>				12.44	.002	0.00	.990	5.80	.055
ACT group	5.11 (0.74)	3.02 (0.46)	2.75 (0.40)						
Control group	4.28 (0.63)	3.14 (0.60)	4.12 (0.58)						

DASS21-Anxiety <sup>c</sup>				23.37	<.001	0.49	.486	12.29	.002
ACT group	5.93 (0.65)	3.23 (0.45)	3.80 (0.42)						
Control group	5.07 (0.70)	3.54 (0.69)	6.10 (0.65)						
DASS21-Stress <sup>c</sup>				3.79	.151	1.52	.218	12.68	.002
ACT group	10.40 (0.95)	8.11 (0.80)	7.41 (0.63)						
Control group	9.17 (0.89)	10.42 (1.07)	9.85 (0.90)						

*Note.* ACT = Acceptance and Commitment Therapy; Wald  $\chi^2$  = Wald Chi-square, p = p-value; GEE = Generalized estimating equation; Post = post-intervention; SE = standard error; 6MFU = 6 months follow-up after the intervention

AAQ-II = Acceptance and Action Questionnaire-II; DASS-21 = Depression Anxiety Stress Scales-21; PECI = Parent Experience of Chronic Illness.

<sup>a</sup> Adjusted for parents' age, relationship with the child, marital status, educational level and monthly household income.

<sup>b</sup> For the AAQ-II, a higher total score indicates poor psychological flexibility.

<sup>c</sup>DASS-21 subscales were multiplied by two for comparison with the normative data in the DASS manual and the DASS-related publications (Henry & Crawford, 2005; Lovibond & Lovibond, 1995b).

# Table 6.12

Post-hoc comparisons from the generalized estimating equations models for the parental psychological health outcomes within groups and

# between groups across time

Measures	Wit	hin-group	comparison		Betw	veen-grou	up comparison	
-	Baseline to Pos	st	Baseline to 6M	FU	Post		6MFU	
	Mdiff [95% CI]	р	Mdiff [95% CI]	р	Mdiff [95% CI]	р	Mdiff [95% CI]^	р
Psychological flex	ibility							
AAQ-II <sup>a</sup>								
ACT group	-4.76 [-6.21, -3.31]	<.001	-6.24 [-8.11, -4.38]	<.001	-3.05 [-5.49, -0.62]	.014	-5.51 [-7.71, -3.30]	<.001
Control group	0.54 [-1.08, 2.17]	.509	1.52 [-0.20, 3.23]	.083				
Effect size <sup>b</sup>					0.41		0.80	
Psychological adj	ustment to the child's a	sthma						
PECI-Guilt and W	orry							
ACT group	-0.36 [-0.49, -0.22]	<.001	-0.43 [-0.57, -0.29]	<.001	-0.16 [-0.37, 0.04]	.125	-0.28 [-0.46, -0.10]	.002
Control group	-0.06 [-0.20, 0.08]	.419	-0.01 [-0.15, 0.14]	.930				
Effect size <sup>b</sup>					0.25		0.46	
PECI- Unresolved	Sorrow and Anger							
ACT group	-0.25 [-0.39, -0.11]	<.001	-0.29 [-0.42, -0.16]	<.001	-0.03 [-0.22, 0.16]	.766	-0.22 [-0.40, -0.04]	.017
Control group	-0.09 [-0.23, 0.05]	.200	0.06 [-0.08, 0.21]	.387				
Effect size <sup>b</sup>					0.05		0.39	
PECI-Long-term U	Jncertainty							
ACT group	-0.25 [-0.38, -0.12]	<.001	-0.24 [-0.39, -0.09]	.002	0.09 [-0.13, 0.30]	.427	-0.15 [-0.34, 0.05]	.146
Control group	-0.17[-0.35, 0.02]	.074	0.08 [-0.10, 0.26]	.393				
Effect size <sup>b</sup>					0.12		0.24	
PECI-Emotional F	Resources							

ACT group	0.43 [0.25, 0.62]	<.001	0.43 [0.24, 0.62]	<.001	0.11 [-0.11, 0.32]	.333	0.22 [-0.04, 0.48]	.097
Control group	0.07 [-0.15, 0.29]	.530	-0.05 [-0.25, 0.15]	.600				
Effect size <sup>b</sup>					0.22		0.32	
Psychological sym	ptoms							
DASS21-Depressi	on <sup>c</sup>							
ACT group	-2.06 [-3.43, -0.69]	.003	-2.38 [-3.89, -0.86]	.002	0.13 [-1.37, 1.62]	.868	-1.18 [-2.57, 0.20]	.095
Control group	-1.15 [-2.30, 0.00]	.050	-0.16 [-1.33, 1.01]	.785				
Effect size <sup>b</sup>					0.03		0.31	
DASS21-Anxiety <sup>c</sup>								
ACT group	-2.66 [-3.90, -1.41]	<.001	-2.14 [-3.46, -0.83]	.001	-0.12 [-1.70, 1.46]	.881	-2.20 [-3.66, -0.73]	.003
Control group	-1.55 [-2.94, -0.16]	.029	1.04 [-0.30, 2.37]	.128				
Effect size <sup>b</sup>					0.06		0.47	
DASS21-Stress <sup>c</sup>								
ACT group	-2.26 [-3.87, -0.66]	.006	-2.99 [-4.63, -1.36]	<.001	-2.33 [-4.92, 0.27]	.079	-2.50 [-4.54, -0.47]	.016
Control group	1.24 [-0.47, 2.95]	.155	0.69 [-0.96, 2.33]	.408				
Effect size <sup>b</sup>					0.27		0.35	

*Note.* ACT = Acceptance and Commitment Therapy; CI = confidence interval; Mdiff = difference of the estimated marginal means; <math>p = p-value; Post = post-intervention; 6MFU = 6 months follow-up after the intervention

AAQ-II = Acceptance and Action Questionnaire-II; DASS-21 = Depression Anxiety Stress Scales-21; PECI = Parent Experience of Chronic Illness.

<sup>^</sup> This mean difference was equivalent to the regression coefficient estimated by the generalized estimating equation model.

<sup>a</sup> For the AAQ-II, a higher total score indicates poor psychological flexibility.

<sup>b</sup>Cohen's *d* effect size was calculated for the between-group effects based on the estimated marginal means and the standard errors measured at postintervention and at 6-month follow-up after the intervention.

<sup>c</sup>DASS-21 subscales were multiplied by two for comparison with the normative data in the DASS manual and the DASS-related publications (Henry & Crawford, 2005; Lovibond & Lovibond, 1995b).

#### 6.6.2. Asthma management outcomes

Table 6.13 presents the adjusted GEE analyses for the parental asthma management outcomes, including asthma knowledge, asthma management self-efficacy and quality of life, between groups across time, while Table 6.14 shows the post-hoc comparisons from the GEE models for these outcomes, including within-group and between-group comparisons.

Asthma knowledge. There was no significant time-by-group interaction for the AKQ (p = .053) (see Table 6.13). The lack of interaction could be related to the significant increases for the parental asthma knowledge from pre- to postintervention in both the ACT group (*M*diff = 2.13, 95% CI [1.46, 2.80], p < .001) and the Control group (*M*diff = 1.02, 95% CI [0.41, 1.64], p = .001), while the increase from pre-intervention to six months post-intervention in the ACT group leveled off (*M*diff = 1.20, 95% CI [0.61, 1.80], p < .001) (see Table 6.14). When compared with the Control group, the ACT group attained significantly better asthma knowledge at post-intervention (*M*diff = 0.86, 95% CI [0.04, 1.66], p = .040, d = 0.43), but not at six months post-intervention (p = .243) (see Table 6.14).

Asthma management self-efficacy. Significant time-by-group interactions could be found for the PAMSE (Wald  $\chi^2 = 7.83$ , p = .020) and one of its subscales, PAMSE-Attack Management (Wald  $\chi^2 = 8.44$ , p = .015), but not for another subscale, PAMSE-Attack Prevention (p = .168) (see Table 6.13). The interactions occurred because of the significant improvements of these outcomes from the pre- to post-intervention (PAMSE total: *M*diff = 0.53, 95% CI [0.35, 0.70], p < .001; PAMSE-Attack Management: *M*diff = 0.68, 95% CI [0.49, 0.87], p < .001), as well as from the pre-intervention to six months post-intervention (PAMSE total: *M*diff = 0.49, 95% CI [0.33, 0.64], p < .001; PAMSE-Attack Management: *M*diff = 0.65, 95%

CI [0.48, 0.83], p < .001) in the ACT group, while the magnitude of these improvements (i.e. mean differences) were larger than those shown in the Control group (see Table 6.14). There were no significant between-group differences for the asthma management self-efficacy of the parents at post-intervention (all ps ranged from .775 to .891), and at six months post-intervention (all ps ranged from .055 to .121) when compared with the Control group (see Table 6.14).

Quality of life. There were significant time-by-group interactions for the PACQLQ and all of its subscales (all ps = .001) (see Table 6.13). The parents in the ACT group achieved significant improvements in their quality of life related to childhood asthma care from the pre- to post-intervention (Mdiff for the PACQLQ and its subscales = 1.08, all ps = <.001), and from the pre-intervention to six months post-intervention (Mdiff for the PACQLQ and its subscales ranged from 1.09 to 1.11, all ps = <.001) in the ACT group, while the magnitude of these improvements (i.e., mean differences) were larger than those in the Control group (see Table 6.14). Notably, in the ACT group, the increases of the PACQLQ and its subscales at each assessment time point when compared with the baseline were all larger than 0.5, which is the minimal clinically importance difference score of the PACQLQ (Quittner et al., 2008), these findings highlighted that the parents in the ACT group perceived the intervention as beneficial to improve their well-being. The betweengroup comparisons showed that the parents in the ACT group had a better quality of life than those in the Control group at post-intervention (Mdiff for the PACQLQ and it subscales ranged from 0.43 to 0.60, all ps ranged from .003 to .017) and at six months post-intervention (Mdiff for the PACQLQ and it subscales ranged from 0.33 to 0.44, all *ps* ranged from .014 to .039).

# Table 6.13

Intervention effects on the parental asthma management outcomes by group assignment across time using generalized estimating equations

Measures		Mean (SE)			Tests	of adjusted G	EE mode	el effects <sup>a</sup>	
	Baseline	Post	6MFU	Time	effect	Group e	ffect	Time-by-group effect	
				Wald $\chi^2$	р	Wald $\chi^2$	р	Wald $\chi^2$	р
Asthma knowledge									
AKQ				46.17	<.001	1.55	.214	5.88	.053
ACT group	18.31 (0.26)	20.45 (0.29)	19.50 (0.27)						
Control group	18.31 (0.28)	19.33 (0.29)	18.81 (0.29)						
Asthma management self-	efficacy								
PAMSE- Attack Preventi	ion			20.47	<.001	0.68	.409	3.57	.168
ACT group	3.81 (0.09)	4.16 (0.08)	4.10 (0.07)						
Control group	3.82 (0.07)	4.10 (0.08)	3.89 (0.07)						
PAMSE- Attack Manager	nent			70.54	<.001	0.01	.940	8.44	.015
ACT group	3.16 (0.11)	3.84 (0.09)	3.81 (0.08)						
Control group	3.33 (0.10)	3.77 (0.08)	3.59 (0.08)						
PAMSE- Total score				59.02	<.001	0.10	.753	7.83	.020
ACT group	3.46 (0.09)	3.99 (0.07)	3.94 (0.07)						
Control group	3.56 (0.08)	3.92 (0.07)	3.72 (0.07)						
Quality of life									
PACQLQ- Emotional Fur	nction			73.74	<.001	1.43	.231	13.26	.001
ACT group	4.60 (0.14)	5.68 (0.11)	5.69 (0.10)						
Control group	4.88 (0.13)	5.25 (0.14)	5.36 (0.12)						
PACQLQ- Activity Limit	ation			54.53	<-001	3.32	.069	13.70	.001
ACT group	4.53 (0.14)	5.61 (0.12)	5.65 (0.11)						
Control group	4.79 (0.14)	5.03 (0.16)	5.23 (0.13)						

PACQLQ- Total score				72.07	<.001	2.09	.148	14.51	.001
ACT group	4.58 (0.13)	5.66 (0.11)	5.67 (0.10)						
Control group	4.85 (0.13)	5.18 (0.14)	5.32 (0.12)						

*Note.* ACT = Acceptance and Commitment Therapy; GEE = Generalized Estimating Equation; SE = standard error; Post = post-intervention; <math>6MFU = 6 months follow-up after the intervention; AKQ = Asthma Knowledge Questionnaire; PAMSE = Parent Asthma Management Self-Efficacy; PACQLQ = Pediatric Asthma Caregiver's Quality of Life Questionnaire.

<sup>a</sup> Adjusted for parents' age, relationship with the child, marital status, educational level and monthly household income.

# Table 6.14

Post-hoc comparisons from the generalized estimating equations model for the parental asthma management outcomes within groups and

# between groups across time

Measures	Wit	hin-group	comparison		Betw	een-grou	p comparison	
-	Baseline to Po	st	Baseline to 6MI	FU	Post		6MFU	
	Mdiff [95% CI]	р	Mdiff [95% CI]	р	Mdiff [95% CI]	р	Mdiff [95% CI]^	р
Asthma knowledge								
AKQ								
ACT group	2.13 [1.46, 2.80]	<.001	1.20 [0.61, 1.80]	<.001	0.86 [0.05, 1.67]	.037	0.46 [-0.32, 1.20]	.243
Control group	1.02 [0.41, 1.64]	.001	0.50 [-0.12, 1.12]	.112				
Effect size <sup>a</sup>					0.43		0.28	
Asthma management	self-efficacy							
PAMSE- Attack Prev	vention							
ACT group	0.34 [0.14, 0.55]	.001	0.29 [0.11, 0.48]	.002	0.03 [-0.18, 0.24]	.775	0.19 [-0.00, 0.39]	.055
Control group	-0.04 [-0.25, 0.17]	.726	0.06 [-0.10, 0.23]	.459				
Effect size <sup>a</sup>					0.08		0.34	
PAMSE- Attack Mar	nagement							
ACT group	0.68 [0.49, 0.87]	<.001	0.65 [0.48, 0.83]	<.001	0.02 [-0.22, 0.26]	.891	0.18 [-0.05, 0.41]	.121
Control group	0.44 [0.24, 0.65]	.001	0.25 [0.05, 0.46]	.015				
Effect size <sup>a</sup>					0.09		0.31	
PAMSE- Total score	;							
ACT group	0.53 [0.35, 0.70]	<.001	0.49 [0.33, 0.64]	<.001	0.03 [-0.17, 0.22]	.797	0.19 [-0.00, 0.38]	.055
Control group	0.37 [0.21, 0.53]	<.001	0.17 [0.00, 0.33]	.048				
Effect size <sup>a</sup>					0.11		0.35	
Quality of life								

PACQLQ-Emotiona	l Function <sup>b</sup>							
ACT group	1.08 [0.81, 1.34]	<.001	1.09 [0.82, 1.34]	<.001	0.43 [0.08, 0.79]	.017	0.33 [0.02, 0.64]	.039
Control group	0.38 [0.08, 0.68]	.014	0.49 [0.22, 0.76]	<.001				
Effect size <sup>a</sup>					0.38		0.34	
PACQLQ- Activity L	Limitation <sup>b</sup>							
ACT group	1.08 [0.76, 1.40]	<.001	1.11 [0.84, 1.39]	<.001	0.60 [0.20, 0.98]	.003	0.44 [0.09, 0.78]	.014
Control group	0.24 [-0.10, 0.59]	.163	0.44 [0.12, 0.76]	.006				
Effect size <sup>a</sup>					0.46		0.39	
PACQLQ-Total score	e <sup>b</sup>							
ACT group	1.08 [0.81, 1.35]	<.001	1.09 [0.84, 1.35]	<.001	0.48 [0.13, 0.84]	.008	0.36 [0.05, 0.67]	.023
Control group	0.34 [0.03, 0.64]	.029	0.48 [0.20, 0.75]	.001				
Effect size <sup>a</sup>					0.43		0.36	

*Note.* ACT = Acceptance and Commitment Therapy; Post = post-intervention; 6MFU = 6 months follow-up after the intervention; AKQ = Asthma Knowledge Questionnaire; PAMSE = Parent Asthma Management Self-Efficacy; PACQLQ = Pediatric Asthma Caregiver's Quality of Life Questionnaire.

<sup>^</sup> This mean difference was equivalent to the regression coefficient estimated by the generalized estimating equation model.

<sup>a</sup> Cohen's *d* effect size was calculated for the between-group effects based on the estimated marginal means and the standard errors measured at postintervention and at 6-month follow-up after the intervention.

<sup>b</sup> The minimal clinically importance difference score of the PACQLQ had was 0.5.

#### 6.7. Process evaluation

As stated in the study objectives (see Chapter Three Section 3.4 for the details), apart from evaluating the intervention effects between groups on child health outcomes and parental outcomes across time, there is a need to conduct a process evaluation to enhance the understanding on how the intervention had been implemented. Four areas were assessed: (1) participation, (2) completion of the assigned sessions, (3) lost to follow-up, and (4) the fidelity of the group-based ACT intervention.

### 6.7.1. Predictors of participation

This section reports the analysis of identifying the predictors of participating in a parental training program using ACT for childhood asthma management in parents and their children with asthma.

Of the 302 parents who completed the questionnaires and were further invited to participate in the study, 134 parents declined participation (i.e., participation rate = 168/302 = 55.6%). Reasons for non-participation were noted previously when illustrating the flow of the participants (see Section 6.2 for the details).

**Differences between participants and non-participants.** Table 6.15 and Table 6.16 summarize the comparisons of the baseline characteristics of parent-child dyads, the baseline scores of all the parent and child measures between the parents who chose to participate (n = 168) and those chose not to participate in a training program for childhood asthma management (n = 134). Participants generally had a higher monthly household income (p = .032), more psychologically inflexible (for the AAQ-II score, M = 19.88, SD = 8.64 versus M = 17.57, SD = 8.40, p = .020) and poorer quality of life (for the PACQLQ total score, M = 4.72, SD = 1.20 versus M = 1000

5.03, SD = 1.18, p = .022) than non-participants. More children whose parents as participants than those whose parents as non-participants needed at least one course of oral prednisolone in the past year (44.0% versus 32.1%, p = .034). In addition, children whose parents as participants attended the EDs more frequently (M = 0.67, SD = 1.08 versus M = 0.22, SD = 0.54, p < .001), and were admitted to hospitals more frequently due to asthma exacerbations in the past six months (M = 0.34, SD =0.69 versus M = 0.13, SD = 0.38, p = .003) than those whose parents as nonparticipants. The two groups did not differ in the rest of parental and child-related variables (all ps ranged from .080 to 1.00).

**Identifying predictors of participation.** The results of the logistic regression are shown in Table 6.17. Four potential variables were analyzed in the logistic regression model using the "ENTER" method, they were parental PF, parental qualify of life, children's ED visits due to asthma exacerbations and their hospital admissions due to asthma exacerbations. The model revealed that only one variable significantly predicted the participation of a parental training program for childhood asthma management. Parents whose children had attended at least one ED visit due to asthma exacerbation in the six-month period was associated with more than three-fold increase in program participation (adjusted OR = 3.36, 95% CI [1.36, 8.26], p = .008).

# Table 6.15

Comparisons of socio-demographics, smoking status and family history of asthma and the baseline scores of all parent measures between participants and non-

*participants* (N = 302)

		cipants $= 168$ )	Non-parti (n	icipants = 134)	$\chi^2 (df)/t$	р
—	п	%	n	%		
Relationship with child						
Father	20	11.9	16	11.9	0.00	1.00
Mother	148	88.1	118	88.1		
Age, Mean (SD)	38.40	) (5.90)	39.28	8 (6.28)	-1.23	.216
Educational attainment						
Primary education or below	9	5.4	11	8.2	1.89	.169ª
Secondary education	123	73.2	101	75.4	(1)	
Tertiary education or above	36	21.4	22	16.4		
Monthly household income (HKD) <sup>b</sup>						
< \$ 10,000	25	14.9	22	16.4	4.61	<b>.032</b> <sup>a</sup>
\$10,000 to \$25,000	45	26.8	58	43.3	(1)	
\$25,001 to \$50,000	88	52.4	47	35.1		
>\$50,000	10	6.0	7	5.2		
Occupation <sup>b</sup>						
Home-duties	93	55.4	69	51.5	6.28	.616
Managers	13	7.7	9	6.7	(8)	
Professionals	8	4.8	10	7.5		
Technicians and associate	5	3.0	1	0.7		
professionals						
Clerical support workers	18	10.7	14	10.4		
Service and sales workers	28	16.7	27	20.1		
Craft and related workers	0	0.0	2	1.5		
Plant and machine operators	1	0.6	1	0.7		
and assemblers						
Elementary occupations	2	1.2	1	0.7		
Marital status						
Single/ separated/ divorced/	23	13.7	18	13.4	0.00	.948
widowed					(1)	
Married	145	86.3	116	86.6	(-)	
Living district	1.0	0010	110	0010		
Tuen Mun	76	45.2	56	41.8	1.91	.591
Yuen Long	51	30.4	38	28.4	(3)	
Tin Shui Wai	39	23.2	36	26.9		
Others	2	1.2	4	3.0		
Smoking status	4	1.4	т	5.0		
Both parents are non-smokers	104	61.9	78	58.2		.514

At least one parent is a current smoker	64	38.1	56	41.8	0.43 (1)	
History of asthma diagnosis						
Neither parents have a history of asthma	99	58.9	73	54.5	0.82 (2)	.662
At least one parent has a history	46	27.4	43	32.1		
of asthma						
Other family members have a	23	13.7	18	13.7		
history of asthma						
	М	SD	М	SD	t	р
Psychological flexibility						
AAQ-II <sup>d</sup>	19.88	8.64	17.57	8.40	2.33	.020
Psychological adjustment to the child	ld's asthma					
PECI- Guilt and Worry	1.54	0.67	1.42	0.67	1.61	.108
PECI- Unresolved Sorrow and	1.16	0.60	1.13	0.61	0.48	.630
Anger						
PECI- Long-term Uncertainty	1.16	0.60	1.13	0.61	0.48	.630
PECI- Emotional Resources	2.32	0.85	2.24	0.93	0.85	.397
Psychological symptoms						
DASS21- Depression <sup>e</sup>	4.70	6.34	4.13	5.87	0.80	.425
DASS21- Anxiety <sup>e</sup>	5.50	6.22	4.57	6.05	1.31	.191
DASS21- Stress <sup>e</sup>	9.79	8.49	8.55	8.05	1.28	.200
Asthma knowledge						
AKQ	18.31	2.47	18.55	2.65	-0.82	.413
Asthma management self-efficacy						
PAMSE- Attack Prevention	3.82	0.75	3.92	0.64	-1.31	.191
PAMSE- Attack Management	3.25	0.94	3.38	0.88	-1.31	.192
PAMSE- Total score	3.51	0.78	3.63	0.70	-1.44	.151
Quality of life						
PACQLQ- Emotional Function	4.74	1.24	5.08	1.17	-2.42	.016
PACQLQ- Activity limitation	4.66	1.27	4.93	1.31	-1.79	.074
PACQLQ- Total score	4.72	1.20	5.03	1.18	-2.30	.022

*Note.* n = number of participants per group;  $\chi^2 =$  Chi-square; t = t-statistics p = p-value; HKD = Hong Kong Dollars; M = mean; N = total number of eligible participants; SD = standard deviation; AAQ-II = Acceptance and Action Questionnaire-II; PECI = Parent Experience of Chronic Illness; DASS-21 = Depression Anxiety Stress Scales-21; AKQ = Asthma Knowledge Questionnaire; PAMSE = Parent Asthma Management Self-Efficacy; PACQLQ = Pediatric Asthma Caregiver's Quality of Life Questionnaire.

<sup>a</sup> Linear-by-Linear Association test was used due to ordinal data.

<sup>b</sup> According to the Quarterly Report on General Household Survey data conducted in Hong Kong on January to March 2016, the median monthly household income for an average household size of 2.9 (a Hong Kong couple with a child) was approximately \$25,000 Hong Kong Dollars (Census and Statistics Department, 2016b).

<sup>c</sup> Classification of the types of occupation was based on the International Standard Classification of Occupations 2008 ISCO-08 (International Labor Organization, 2016).

<sup>d</sup> For the AAQ-II, a higher total score indicates poor psychological flexibility.

<sup>e</sup> DASS-21 subscales were multiplied by two for comparison with the normative data in the DASS manual and the DASS-related publications (Henry & Crawford, 2005; Lovibond & Lovibond, 1995b).

### Table 6.16

Comparisons of demographic and clinical characteristics of the children and the

baseline scores of all child measures between participants and non-participants (N

= 302)

		cipants	Non-part	-	$\chi^2$ (df)/ t	р
	( <i>n</i>	= 168)	( <i>n</i>	<i>i</i> = 134)	_	
	n	%	n	%		
Gender						
Male	103	61.3	86	64.2	0.26(1)	.609
Female	65	38.7	48	35.8		
Age, M (SD)	6.81	(2.50)	7.3	1 (2.58)	-1.70	.090
Age of diagnosis as asthma, $M$ (SD)	3.46	(1.79)	3.4	6 (1.79)	-0.31	.759
Concurrently diagnosed with allergic r	hinitis					
Yes	59	35.1	53	39.6	0.63 (1)	.428
No	109	64.9	81	60.4		
Concurrently diagnosed with eczema						
Yes	18	10.7	11	8.2	0.54 (1)	.463
No	150	89.3	123	91.8		
Current use of oral Montelukast as pro	phylaxis					
Yes	24	14.3	18	13.4	0.05 (1)	.831
No	14	85.7	116	86.8		
Current use of inhaled corticosteroid as	s prophyla	xis, by	types			
None	80	47.6	67	50.0	0.85 (3)	.838
Beclomethasone dipropionate	81	48.2	61	45.5		
Fluticasone propionate	5	3.0	3	2.2		
Fluticasone propionate and	2	1.2	3	2.2		
Salmeterol						
One or more course of oral prednisolo	ne uses in	the prev	vious year			
Yes	74	44.0	43	32.1	4.49(1)	.034
No	94	56.0	91	67.9		
Alternative therapy being received in t	he past 6 r	nonths,	by types <sup>a</sup>			
Herbal soup	17	81.0	11	84.6	2.33 (2)	.312
Natural moxibustion	4	19.0	1	7.7		
Aromatherapy	0	0.0	1	7.7		
15	М	SD	М	SD	U	$p^{t}$
Unscheduled health care service visits						
months						
General outpatient clinic visit(s)	0.39	1.19	0.21	0.63	-0.86	.391
Private practitioner visit(s)	1.25	2.46	0.89	1.59	-1.32	.188
Emergency care visit(s)	0.67	1.08	0.22	0.54	-4.36	<.001
Hospital admission(s)	0.34	0.69	0.13	0.38	-3.02	.003
	1.07	0.02	2.07	1.04	1.02	

Asthma symptoms in the past 30 days

hospital stay<sup>c</sup>

Total number of days of inpatient

4.05

2.00

3.07

1.34

-1.75

.080

Daytime symptoms/week	1.27	1.82	1.09	1.69	-1.16	.236
Nighttime awakening due to	0.96	1.52	1.07	1.75	-0.11	.916
asthma symptoms/week						
Days required to use inhaled	1.33	1.93	1.36	1.99	-0.30	.765
bronchodilators to relieve asthma						
symptoms/week,						
Days with activity limitation due	0.61	1.34	0.54	1.00	-0.06	.955
to asthma symptoms/week						

*Note.* N = total number of participants; n = number of participants per group;  $\chi^2 =$  Chi-

square; t = t-statistics; df = degree of freedom; p = p-value; M = mean; N = total number of

eligible participants; SD = standard deviation; U = Mann–Whitney U test statistics

<sup>a</sup> For the child who received alternative therapy in the past 6 months (n = 34).

<sup>b</sup> Mann–Whitney U tests were used due to count data.

<sup>c</sup> For the child who was hospitalized due to asthma attack in the past 6 months only (n = 56).

### Table 6.17

Independent variables	Crude OR	р	Adjusted OR	р
	[95% CI]		[95% CI] <sup>a</sup>	
Parents' characteristics				
Monthly household income (HKI	D) (ref = < \$ 10,000)			
\$10,000 to \$25,000	0.68 [0.34, 1.37]	.280		
\$25,001 to \$50,000	1.65 [0.84, 3.23]	.146		
>\$50,000	1.26 [0.41, 3.87]	.690		
Psychological inflexibility (mean	AAQ-II score $= 18.86$	ó, ref = le	ss psychological	
inflexible, i.e., values below mea	n) <sup>b</sup>			
More psychologically	1.64 [1.04, 2.60]	.035	1.44 [0.90, 2.33]	.129
inflexible				
Quality of life (mean PACQLQ t	otal score = 4.86, ref =	better qu	ality of life, i.e., val	ues
above mean) <sup>b</sup>				
Poor quality of life	0.65 [0.41, 1.03]	.064		
Child's characteristics				
Use of oral prednisolone in the pr	revious year (ref = no)			
Yes	1.66 [1.04, 2.68]	.035	1.19 [0.71, 2.01]	.505
Emergency care visits due to asth	ma exacerbations in th	ne past 6 i	months (ref = none)	
At least $\geq 1$	3.21 [ 1.85, 5.58]	<.001	3.36 [1.36, 8.26]	.008
Hospital admissions due to asthm	a exacerbations in the	past 6 m	onths (ref = none)	
		.004	0 70 [0 20 2 10]	
At least $\geq 1$	2.56 [ 1.35, 4.87]	.004	0.78 [0.28, 2.18]	.776
At least $\geq 1$ Model summary using "ENTER"		.004	0.78 [0.28, 2.18]	.776
	method	.004	2.39 (5), <i>p</i>	

## Predictors of participation by logistic regression analyses

*Note.* OR = odds ratio; CI = confidence interval; HKD = Hong Kong Dollars; ref = referent; AAQ-II= Acceptance and Action Questionnaire-II; PACQLQ = Pediatric Asthma Caregiver's Quality of Life Questionnaire; p = p-value; df = degree of freedom. <sup>a</sup> Adjusted for all of the significant variables in the univariate analysis.

<sup>b</sup> The mean score of this variable was used to divide the sample into two groups: values

below mean versus values above mean.

#### 6.7.2. Predictors of non-completion

Of those randomized 168 parent-child dyads, 43 parents (43/168 = 25.6%, 22 in ACT, 21 in Control) did not attend all four assigned intervention sessions after randomization. Reasons of non-attendance were stated previously when describing the flow of the participants (see Section 6.2 for the details).

**Differences between completers and non-completers.** Table 6.18 and Table 6.19 display the comparisons of the baseline characteristics of parent-child dyads, the baseline scores of all the parent and child measures between the participants who attended all 4 sessions (i.e., completers, n = 125) and those who attended 0-3 sessions (i.e., non-completers, n = 43). Non-completers were significantly younger (for the parents' age, M = 36.26, SD = 6.31 versus M = 39.14, SD = 5.59, p = .005) and had lower monthly household income (p = .046) than the completers. In addition, among the non-completers, more parents reported that they were either single/ separated/ divorced/ widowed (p = .034); they (or their spouses) were current smokers (p = .016). In addition, children whose parents as noncompleters were admitted to the hospitals due to asthma exacerbations more frequently in the past six months (M = 0.26, SD = 0.55 versus M = 0.58, SD = 0.96, p= .040) than those whose parents as completers. The two groups did not differ in the rest of the parental and child-related variables (all ps ranged from .068 to .974).

**Identifying predictors of non-completion.** The results of the logistic regression are shown in Table 6.20. Three potential variables, including parents' age, marital status and smoking status were analyzed in the logistic regression model using the "ENTER" method. The model revealed that only one variable significantly predicted non-completion. Parents who are young (i.e., mean age < 38) were associated with two-fold increase in missing the assigned intervention sessions

(adjusted OR = 2.59 [1.23, 5.45], *p* = .012).

Table 6.18

Comparisons of socio-demographics, smoking status, family history of asthma and

the baseline scores of all parent measures between completers (n = 125) and non-

*completers* (n = 43)

		npleters	Non-cor	-	$\chi^2$ (df)/ t	p
	(attended all 4		(atter	ided 0-3		
	s	essions)	S	sessions)		
	(1	<i>i</i> = 125)		( <i>n</i> = 43)		
	n	%	n	%		
Relationship with child						
Father	17	13.6	3	7.0	1.34 (1)	.247
Mother	108	86.4	40	93.0		
Age (years), M (SD)	39.1	4 (5.59)	36.2	6 (6.31)	2.83	.005
Educational attainment						
Primary education or below	7	5.6	2	4.7	0.01 (1)	.974ª
Secondary education	91	72.8	32	74.4		
Tertiary education or above	27	21.6	9	20.9		
Monthly household income (HKD) <sup>b</sup>						
< \$ 10,000	16	12.8	9	20.9	3.98 (1)	<b>.046</b> <sup>a</sup>
\$10,000 to \$25,000	31	24.8	14	32.6		
\$25,001 to \$50,000	69	55.2	19	44.2		
>\$50,000	9	7.2	1	2.3		
Occupation <sup>c</sup>						
Home-duties	74	59.2	19	44.2	13.17	.068
Managers	11	8.8	2	4.7	(7)	
Professionals	5	4.0	3	7.0		
Technicians and associate	4	3.2	1	2.3		
professionals						
Clerical support workers	15	12.0	3	7.0		
Service and sales workers	14	11.2	14	32.6		
Plant and machine operators	1	0.8	0	0.0		
and assemblers						
Elementary occupations	1	0.8	1	2.3		
Marital status						
Single/ separated/ divorced/	13	10.4	10	23.3	4.48(1)	.034
widowed						
Married	112	89.6	33	76.7		
Living district						
Tuen Mun	57	45.6	19	44.2	0.84 (4)	.933
Yuen Long	38	30.4	13	30.2	. /	
Tin Shui Wai	28	22.4	11	25.6		
Others	2	1.6	0	0.0		

Smoking status						
Both parents are non-smokers	84	67.2	20	46.5	5.81 (1)	.016
At least one parent is a current	41	32.8	23	53.5		
smoker						
History of asthma diagnosis						
Neither parents have a history	71	56.8	28	65.1	1.26 (2)	.533
of asthma						
At least one parent has a	37	29.6	9	20.9		
history of asthma						
Other family members have a	17	13.6	6	14.0		
history of asthma						
	Mean	SD	Mean	SD	t	p
Psychological flexibility						
AAQ-II <sup>d</sup>	20.01	8.73	19.49	8.42	0.35	.731
Psychological adjustment to the cl	nild's asthm	a				
PECI- Guilt and Worry	1.55	0.69	1.54	0.59	0.09	.929
PECI- Unresolved Sorrow and	1.17	0.62	1.15	0.58	0.13	.897
Anger						
PECI- Long-term Uncertainty	1.15	0.80	1.07	0.67	0.57	.569
PECI- Emotional Resources	2.32	0.86	2.33	0.82	-0.11	.913
Psychological symptoms						
DASS21- Depression <sup>e</sup>	4.74	6.55	4.60	5.77	0.12	.907
DASS21- Anxiety <sup>e</sup>	5.47	6.61	5.58	4.99	-0.10	.921
DASS21- Stress <sup>e</sup>	9.71	8.63	10.00	8.15	-0.19	.849
Asthma knowledge						
AKQ	18.30	2.65	18.33	1.90	-0.06	.954
Asthma management self-efficacy	,					
PAMSE- Attack Prevention	3.85	0.74	3.73	0.77	0.86	.391
PAMSE- Attack Management	3.24	0.97	3.26	0.85	-0.14	.893
PAMSE- Total score	3.52	0.80	3.48	0.73	0.30	.769
Quality of life						
PACQLQ- Emotional	4.72	1.27	4.79	1.15	-0.30	.763
Function						
PACQLQ- Activity limitation	4.65	1.32	4.70	1.15	-0.24	.813
PACQLQ- Total score	4.70	1.23	4.76	1.11	-0.29	.769

*Note.* n = number of participants per group;  $\chi^2 =$  Chi-square; t = t-statistics p = p-value; HKD = Hong Kong Dollars; M = mean; SD = standard deviation; AAQ-II = Acceptance and Action Questionnaire-II; PECI = Parent Experience of Chronic Illness; DASS-21 = Depression Anxiety Stress Scales-21; AKQ = Asthma Knowledge Questionnaire; PAMSE = Parent Asthma Management Self-Efficacy; PACQLQ = Pediatric Asthma Caregiver's Quality of Life Questionnaire.

<sup>a</sup> Linear-by-Linear Association test was used due to ordinal data.

<sup>b</sup> According to the Quarterly Report on General Household Survey data conducted in Hong Kong on January to March 2016, the median monthly household income for an average household size of 2.9 (a Hong Kong couple with a child) was approximately \$25,000 Hong Kong Dollars (Census and Statistics Department, 2016b). <sup>c</sup> Classification of the types of occupation was based on the International Standard Classification of Occupations 2008 ISCO-08 (International Labor Organization, 2016).

<sup>d</sup> For the AAQ-II, a higher total score indicates poor psychological flexibility.

<sup>e</sup>DASS-21 subscales were multiplied by two for comparison with the normative data in the DASS manual and the DASS-related publications (Henry & Crawford, 2005; Lovibond & Lovibond, 1995b).

# Table 6.19

Comparisons of demographic and clinical characteristics of the children and the

baseline scores of all child measures between completers (n = 125) and non-

completers (r	ı =43)
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Hospital admission(s)

	Cor	npleters	Non-cor	npleters	$\chi^2$ ( <i>df</i> )/ <i>t</i>	р
	(attend	led all 4	(atten	ded 0-3		
	S	essions)	S	essions)		
_	(1	<i>i</i> = 125)		( <i>n</i> = 43)		
	n	%	n	%		
Gender						
Male	77	61.6	26	60.5	0.02 (1)	.895
Female	48	38.4	17	39.5		
Age, $M(SD)$	6.8	2 (2.52)	6.7	9 (2.47)	0.07	.947
Age of diagnosis as asthma, M	3.3	7 (1.66)	3.7	2 (2.12)	-1.10	.271
( <i>SD</i> )						
Concurrently diagnosed with allergi	c rhinitis					
Yes	47	37.6	12	27.9	1.32 (1)	.251
No	78	62.4	31	72.1		
Concurrently diagnosed with eczem	a					
Yes	16	12.8	2	4.7	2.22 (1)	.136
No	109	87.2	41	95.3		
Current use of oral Montelukast as p	orophylaxi	S				
Yes	11	13.1	13	15.5	0.19 (1)	.659
No	73	86.9	71	84.5		
Current use of inhaled corticosteroid	l as prophy	ylaxis, by t	ypes			
None	59	47.2	21	48.8	0.79 (3)	.851
Beclomethasone dipropionate	60	48.0	21	48.8		
Fluticasone propionate	4	3.2	1	2.3		
Fluticasone propionate and	2	1.6	0	0.0		
Salmeterol						
One or more course of oral predniso	lone uses	in the past	12 months			
Yes	67	53.6	27	62.8	1.10(1)	.295
No	58	46.4	16	37.2		
Alternative therapy being received in	n the past	6 months,	by types <sup>a</sup>			
Herbal soup	12	75.0	5	100.0	1.54 (1)	.214
Natural moxibustion	4	25.0	0	0.0		
	Mean	SD	Mean	SD	Z	$p^{b}$
Unscheduled health care service visit	its due to a	sthma exa	cerbations	in childre	en in the pas	st six
months						
General outpatient clinic visit(s)	0.33	1.20	0.56	1.16	-1.09	.277
Private practitioner visit(s)	1.37	2.72	0.91	1.43	-1.06	.291
Emergency care visit(s)	0.61	1.08	0.86	1.04	-1.33	.185
	0.04	<b>• • •</b>	0.50	0.0.4		

0.55

0.58

0.96

-2.11

.040

0.26

Total number of days of inpatient hospital stay <sup>c</sup>	3.81	1.89	4.47	2.17	-1.02	.315
Asthma symptoms in the children in	the past for	our weeks				
Daytime symptoms/week	1.34	1.87	1.09	1.70	0.75	.453
Nighttime awakening due to	0.98	1.48	0.88	1.65	0.37	.744
asthma symptoms/week						
Days required to use inhaled	1.27	1.88	1.51	2.10	-0.70	.485
bronchodilators to relieve						
asthma symptoms/week,						
Days with activity limitation due	0.70	1.38	0.37	1.20	1.37	.172
to asthma symptoms/week						

*Note.* n = number of participants per group;  $\chi^2 =$  Chi-square; p = p-value; Z = z-value of the Mann-Whitney U test; M = mean; SD = standard deviation.

<sup>a</sup> For the child who received alternative therapy in the past 6 months (n = 21).

<sup>b</sup> Mann–Whitney U tests were used due to count data.

<sup>c</sup> For the child who was hospitalized due to an asthma exacerbation in the past 6 months only (n = 41).

# Table 6.20

ndependent variables	Crude OR	р	Adjusted OR	р
	[95% CI]		[95% CI] <sup>a</sup>	
Parents' characteristics				
Age (mean age = $38.4$ , ref = older	$;$ i.e., age $\geq$ mean) <sup>b</sup>			
Younger in age	2.81 [1.36, 5.84]	.005	2.59 [1.23, 5.45]	.012
Monthly household income (HKI	D) (ref = $<$ \$ 10,000)			
\$10,000 to \$25,000	0.80 [0.29, 2.25]	.677		
\$25,001 to \$50,000	0.49 [0.19, 1.28]	.145		
>\$50,000	0.20 [0.02, 1.82]	.152		
Marital status (ref = married)				
Single/ separated/ divorced	2.61 [1.05, 6.49]	.039	2.04 [0.76, 5.47]	.156
Smoking status (ref = both parent	s are non-smokers)			
At least one parents is a	2.36 [1.16, 4.77]	.017	1.91 [0.90, 4.05]	.090
current smoker				
Child's characteristics				
Hospital admissions due to asthm	a exacerbations in the p	past 6 m	onths (ref = none)	
At least $\geq 1$	2.04 [0.95, 4.37]	.067		
Model summary using "ENTER"	method			
Hosmer-Lemeshow test chi-squ	are (df)		0.60 (4), p	= .963
Overall rate of correct classification	ation		,	76.8%

# Predictors of non-completion by logistic regression analyses

*Note.* OR = odds ratio; CI = confidence interval; HKD = Hong Kong Dollars; ref = rep = p-value; df = degree of freedom.

<sup>a</sup> Adjusted for all of the significant variables in the univariate analysis.

<sup>b</sup> The mean score of this variable was used to divide the sample into two groups: values below mean versus values above mean.

Session attendance. In the present study, over 80% of the randomized parents (137/168 = 81.5%, 69 in ACT, 68 in Control) attended at least one assigned intervention session (i.e. 1-4 sessions). Of these, there was no significant difference in the number of the attended sessions between the ACT group and the Control group (M = 3.81, SD = 0.65 versus M = 3.85, SD = 0.58, t = -0.39, p = .695).

**Completion of the assigned ACT homework.** Of those parents who were randomly allocated to the ACT group and attended at least one ACT session (n =69), they received three ACT homework assignments starting from the second ACT session, which were named as "A mindfulness log to record your experiences in parenting a child with asthma", "A mindfulness log to explore your willingness to experience your struggles when caring for a child with asthma" and "Your valuesbased action". The completion rates corresponding to the aforementioned assignments were 87% (60/69), 76.8% (53/69) and 88% (61/69), respectively. Generally, approximately 80% of the participants who attended the ACT sessions completed the assigned homework.

### 6.7.3. Lost to follow-up

Of those randomized 168 parent-child dyads, six (6/168 = 3.6%, 1 in ACT, 5 in Control) were lost to follow-up at six months post-intervention. Reasons of lost to follow-up were mentioned previously when describing the flow of the participants of the study (see Section 6.2 for the details).

**Characteristic of the participants who were lost to follow-up.** Since the proportion of the participants who lost to follow-up was less than 5% (6/168 = 3.6%), it was unlikely to influence the validity of the results. Hence, it was decided not to compare the baseline characteristics of the participants who were lost to follow-up and those who remained in this study at six months post-intervention by

conducting inferential statistical analyses. Yet, the characteristics of those parentchild dyads who lost the follow-up were reported as follows.

The parents who dropped out from the study were all mothers (n = 6, age M =36.7, SD = 7.9). Half of them were housewives (n = 3) and all attained secondary school educational level (n = 6). Their monthly household income was mainly less than 25,000 HKD (n = 4). By using the PECI subscales, all the parents rated themselves as "rarely" having negative psychological experiences such as guilt and worry, unresolved sorrow and anger, and long-term uncertainty. Further, as indicated by the DASS-21 subscale scores, they were at normal level of psychological symptoms, including symptoms of depression (range of doubled DASS21-depression score = 0-2), anxiety (range of doubled DASS21-anxiety score = 0-4) and stress (range of doubled DASS21-stress score = 0-10). Their children were mainly boys (*n* = 4), at primary school age (range = 4-9) and had been diagnosed with asthma during their preschool age (range = 1-4). Most of the children required inhaled steroids as the prophylaxis (n = 4). Their asthma symptoms were generally well controlled, at least half of them did not have asthma symptoms during daytime (n = 4) and night time (n = 3), and half of the children did not need to use inhaled bronchodilators for symptom relief (n = 3) in the past four weeks. During the six-month period, two children were hospitalized due to asthma exacerbations for two to four days.

#### **6.7.4.** Fidelity assessment

Forty ACT sessions (i.e., ten ACT group classes in total, each group class had four sessions) were conducted in this RCT and they were all videotaped after obtaining the parental consent. These videotapes were self-rated as planned on a session-by-session basis by the interventionist (i.e., therapist), they were all reviewed by an experienced ACT researcher (see Chapter Four Section 4.8 about the methods

of fidelity assessment). Table 6.21 and Table 6.22 assemble the results of the fidelity assessment regarding the therapeutic stance and competence of the therapist in delivering the group-based ACT intervention. The mean (*SD*) ratings on scale items assessing the therapeutic stance of the therapist in delivering ACT ranged from 3.9 (1.0) to 5.3 (0.7) out of 7, which were mostly rated as "sometimes true" (score 4) to "frequently true" (score 5). These findings indicate that the therapist developed a satisfactory therapeutic relationship with the parents. All the planned ACT-related activities were delivered as stated in the intervention protocol. The mean (*SD*) ratings on scale items assessing the six ACT therapeutic processes delivered by the therapist ranged from 3.8 (0.6) to 6.3 (0.5) out of 7. Most of the items were rated as "sometimes true" (score 4) to "frequently true" (score 5), reflecting that the group-based ACT intervention was delivered in accordance with the intervention protocol and was generally consistent with the ACT model of psychological flexibility.

# Table 6.21

# Fidelity assessment of the therapeutic stance of the therapist in the group-based Acceptance and Commitment Therapy

State	Statement for rating*		nd 1, s	Session 2: your thinki explore acceptance e across all th	ng and	Session 3: here and no your obser self and cla values	ow, ving arify	Session 4: Commit ye values-bas action	our
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
1.	The therapist realizes that he or she is in the same boat as the client and speaks to the client from an equal, vulnerable, genuine, and sharing point of view.	5.2	0.8	5.0	0.8	4.7	0.7	4.6	0.5
2.	The therapist models willingness to hold contradictory or difficult ideas, feelings, and memories without needing to "resolve" them.	4.5	0.5	4.6	0.7	4.8	0.8	4.4	0.5
3.	The therapist takes a compassionate and humanizing stance toward the client's suffering and avoids criticism, judgment or taking a "one up" position.	5.1	0.7	5.1	0.7	5.3	0.7	5.1	0.7
4.	The therapist always brings the issue back to what the client's experience is showing and does not substitute his or her opinions for that genuine experience.	5.3	0.7	5.1	0.9	5.3	0.7	5.3	0.7
5.	The therapist does not argue with, lecture, coerce or even attempt to convince the client of anything.	5	0.7	4.3	1.1	4.7	0.7	4.6	0.5
6.	The therapist does not explain the "meaning" of paradoxes or metaphors to develop "insight"	4	0.7	4.4	0.8	4.5	0.5	4.2	0.4

7.	The therapist is willing to self-disclose about personal issues when it	N/A	N/A	N/A	N/A	5.2	1.1	5.2	1.1
	makes a therapeutic point								
8.	The therapist avoids the use of "canned" ACT interventions. The	4.8	1.0	4.5	0.8	4.8	0.8	4.7	0.5
	therapist strategies are applied flexibly in response to client needs.								
9.	The therapist tailors interventions to fit the client's language and	4.8	0.9	4.8	0.9	4.8	0.9	4.8	0.9
	immediate life experience.								
10.	The therapist sequences and applies specific ACT interventions in	3.9	1.0	4.6	1.1	4	0.9	3.9	0.9
	response to client needs and is ready to change course to fit those								
	needs at any moment.								
Note	$\Delta CT - Acceptance and Commitment Therapy: N/A - not applicable: SD$	– standard	deviation						

*Note*. ACT = Acceptance and Commitment Therapy; N/A = not applicable; SD = standard deviation

\*These statements were retrieved from the Acceptance and Commitment Therapy Core Competency Self-Rating Form (Luoma et al., 2007). Each statement would be rated in a scale of 1 to 7. The interpretation of the scoring item is stated as follows: 1 = never true; 2 = very seldom true; 3 = seldom true; 4 = sometimes true; 5 = frequently true; 6 = almost always true; 7 = always true.

# Table 6.22

# Fidelity assessment of the therapeutic processes of the group-based Acceptance and Commitment Therapy

Session	Activity	ctivity ACT Statement for rating* process(es) targeted		Rating score a all the ACT g (range 1 to 7)	groups
				Mean	SD
Session 1: Welcome and	Mindfulness exercise to guide parents in	Contacting with the	• The therapist can defuse from client content and direct attention to the moment.	6.1	0.6
creative cha hopelessness tak chi AC	exploring a challenging moment in	present moment	• The therapist uses exercises to expand the client's sense of experience as an ongoing process.	6.3	0.5
	taking care of their children with asthma		• The therapist detects client drifting into past and future orientation and comes back to now.	6.2	0.8
	ACT metaphor illustration: A Man in a		• The therapist helps client examine direct experience and detect emotional control strategies	5.4	0.7
	Hole Metaphor		• The therapist helps client make direct contact with the paradoxical effect of emotional control strategies (e.g., using metaphors such as "A Man in a Hole Metaphor).	5.5	0.5
			• The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative.	4.7	0.5
			• The therapist helps client make experiential contact with the cost of being unwilling relative to valued life ends (e.g., listing out the emotional control strategies, cost, short term/long term costs and benefits).	5.5	0.5

Session 2: Watch your	Homework review: A mindfulness log to	Defusion	• The therapist identifies client's emotional, cognitive, behavioral or physical barriers to willingness.	4.1	0.6
thinking and explore	record your experiences in		<ul> <li>The therapist suggests that "attachment" to the literal meaning of these experiences makes willingness difficult to sustain.</li> </ul>	4.2	0.4
acceptance	parenting a child with asthma		• The therapist actively contrasts what the client's "mind" says will work versus what the client's experience says is working.	4.6	0.7
			• The therapist uses various exercises, metaphors and behavioral tasks to reveal the "hidden" properties of language.	5.1	0.6
	ACT metaphor illustration: The Tug-	Acceptance	• The therapist helps client examine direct experience and detect emotional control strategies	4.5	0.7
	of-War metaphor		• The therapist helps client make direct contact with the paradoxical effect of emotional control strategies (e.g., using metaphors such as the tug-of-war metaphor).	4.8	0.8
			• The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative.	4.5	0.7
	Group activity: Acting out the "Passengers on the Bus" metaphor	Defusion	• The therapist uses language tools and/or metaphors (e.g., the passengers on the bus metaphor) and experiential exercises to create a separation between the client and client's conceptualized experience.	5.1	0.6
		Acceptance	• The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative.	4.5	0.7
			• The therapist uses metaphors (e.g., the passenger on the bus metaphor) to help client contact willingness the action in the presence of difficult material.	4.9	0.6

Session 3: Be here and now,	Homework review: A mindfulness log to	Acceptance	• The therapist helps client examine direct experience and detect emotional control strategies.	4.8	0.6
your observing self and clarify values	explore your willingness to experience your		<ul> <li>The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative.</li> </ul>	4.6	0.5
	struggles when caring for a child with asthma		• The therapist helps client make experiential contact with the cost of being unwilling relative to valued life ends (e.g., listing out the emotional control strategies, cost, short term/long term costs and benefits).	3.8	0.6
	Group activity: The storyline exercise	Self-as- context	• The therapist uses metaphors to highlight distinction between products and contents of consciousness versus consciousness (e.g., the unwelcomed guest in the birthday party metaphor).	5.8	0.6
			• The therapist utilizes exercise to help the client make contact with self as context and distinguish this from the self as conceptualized	5.6	0.8
	Mindfulness exercise: Recall your experience	Self-as- context	• The therapist employs mindfulness exercises to help client make contact with self-as-context.	5.5	0.5
	with the most unforgettable person in	Contacting with the	• The therapist can defuse from client content and direct attention to the moment.	5.4	0.5
	your life	present moment	• The therapist uses exercises to expand the client's sense of experience as an ongoing process.	5.6	0.5
		Values	• The therapist helps client clarify valued life directions (e.g., pick up the most unforgettable person in your life).	5.3	0.8
			• The therapist puts his or her own therapy relevant values in the room and models their importance.	4.3	0.8
Session 4: Commit your	ACT metaphor illustration: Two Kids in	Values	• The therapist teaches clients to distinguish between values and goals.	5.4	0.5
			• The therapist helps client clarify valued life directions	5.2	0.8

values-based action	a Car Heading to an Amusement Park				
	Homework review: your values-based	Values	• The therapist helps client "go on record" as wanting to stand for valued life ends.	4.8	0.6
	action		• The therapist distinguishes between outcomes and processes.	4.5	0.7
	Homework review: your values-based action	Committed Action	• The therapist helps client identify valued life goals and build an action plan.	5.0	0.7
			• The therapist encourages client to "have" barriers and make and keep commitments.	4.7	0.7
			• The therapist encourages client to take small steps and to look at the quality of committed action.	4.8	0.6
			• The therapist integrates slips or relapses into the experiential base for future effective action.	4.8	0.6

*Note*. ACT = Acceptance and Commitment Therapy; SD = standard deviation

\*These statements were retrieved from the Acceptance and Commitment Therapy Core Competency Self-Rating Form (Luoma et al., 2007). Each statement would be rated in a scale of 1 to 7. The interpretation of the scoring item is stated as follows: 1 = never true; 2 = very seldom true; 3 = seldom true; 4 = sometimes true; 5 = frequently true; 6 = almost always true; 7 = always true.

#### 6.8. Summary

In summary, this chapter presents: (1) the results of the SEM in examining the role of parental PF in the childhood asthma morbidity, (2) the results of the RCT, that is the intervention effects of the ACT group versus the Control group on the health outcomes of the children with asthma, the psychological health outcomes and the asthma management outcomes of the parents across the six months follow-up period after the intervention, (3) the predictors of participation, as well as (4) the results of evaluating the implementation of the RCT.

The SEM analysis revealed that poor PF was significantly associated with poor psychological adjustment to the child's illness and increased psychological symptoms in parents. Parental PF was found to be the only latent construct possessing a significant association with the child's asthma morbidity ( $\beta = 0.27, 95\%$ CI [0.09, 0.42], p = .002). These results imply that by fostering parents' PF, their psychological well-being, as well as their children's asthma conditions, may improve.

In the RCT, 168 parents (age M = 38.4, 88.1% mothers) and their children with asthma (age M = 6.8) participated in the RCT. The results from the adjusted GEE analyses showed that, when compared with the Control group, the children whose parents were allocated in the ACT group showed significant reductions in the frequencies of the visits to emergency departments (aIRR = 0.20, 95% CI [0.08, 0.53], p = .001) and private practitioners' clinics (aIRR = 0.47, 95% CI [0.26, 0.85], p= .012) due to asthma exacerbations over the six-month follow-up period, at six months post-intervention. In addition, these children exhibited fewer days of asthma symptoms in daytime (aIRR = 0.25, 95% CI [0.15, 0.43], p < .001), fewer nights awakening due to asthma symptoms (aIRR = 0.30, 95% CI [0.18, 0.50], p < .001)

and experienced fewer days of using inhaled bronchodilators to control the symptoms (aIRR = 0.36, 95% CI [0.21, 0.65], p = .001) in the past four weeks, at six months post-intervention. The parents who received the group-based ACT intervention became more psychologically flexible (d = 0.80), had less negative emotional experiences, such as guilt and worry (d = 0.46), sorrow and anger (d =0.39), reported with less anxiety symptoms (d = 0.47), stress symptoms (d = 0.35), and better quality of life (d = 0.36) at six months post-intervention when compared with those who attended an asthma education talk only. There were no significant time-by-group interaction effects on the child's hospital admissions due to asthma exacerbations (p = .327), the parental asthma knowledge (p = .053) and the parental self-efficacy in preventing asthma exacerbations (p = .168), indicating the nonsignificant intervention effects on these variables.

Four areas related to the process of implementing the RCT were evaluated, including the participation of the parental training program, the completion of the assigned intervention sessions, the lost to follow-up and the fidelity of the group-based ACT intervention. The participation rate of the present study was 55.6% (168/ 302). Adjusted logistic regression analysis found that, parents whose children had attended at least one ED visit due to asthma exacerbations in the six-month period were three times more likely to join the training program than those whose children had not experienced ED visits before (adjusted OR = 3.36, 95% CI [1.36, 8.26], *p* = .008). Of those 168 participants, around one-fourth (43/168, 22 in ACT, 21 in Control) did not attend all four assigned sessions. Adjusted logistic regression analysis found that parents who are younger (i.e., mean age < 38) are more likely to miss the assigned intervention sessions (adjusted OR = 2.59 [1.23, 5.45], *p* = .012). A total of six parent-child dyads (3.6%) were lost to follow-up at six months post-

intervention. Reasons regarding the non-participation, the non-completion of the assigned intervention and the lost to follow-up were all noted. Finally, the fidelity assessment of the group-based ACT intervention indicated that the therapist developed a satisfactory relationship with the participants, the intervention also generally adhered to the ACT model of psychological flexibility.

# **CHAPTER SEVEN**

# DISCUSSION

- 7.1. Introduction
- 7.2. Child health outcomes
- 7.3. Parental outcomes
- 7.4. Study strengths
- 7.5. Study limitations
- 7.6. Implications for clinical practice
- 7.7. Implications for future research
- 7.8. Recommendations

#### 7.1. Introduction

This discussion chapter starts with stating the major findings and the novel contributions of the present randomized controlled trial (RCT) study. The meaning of the findings on child health outcomes and parental outcomes are discussed. Further discussion will be made by relating the findings of the present study to those of similar studies, such as studies adopting Acceptance and Commitment Therapy (ACT) in parents of children with chronic diseases and general populations, as well as studies adopting other non-pharmacological interventions that address parental psychological needs for improving the child's asthma-related health outcomes. Methodological strengths of the present study are then presented, followed by study limitations with explanations that may possibility temper the threats to internal and external validity of the findings. Implications of this study to improve clinical practice, including the need to address parental psychological difficulties to childhood asthma care and the role of ACT in strengthening childhood asthma management programs, are stated, followed by a discussion of important areas for future studies to extend the evidence base of ACT. This chapter ends with two specific recommendations that require health care professionals in Hong Kong who are specialized in pediatric asthma to draw immediate attention: (1) parents of children with asthma who are in need for psychological support should be proactively identified, and (2) the development of asthma management programs should move beyond an educational approach towards a psychoeducational approach.

#### 7.2. Child health outcomes

In this RCT, we demonstrated that a parental, psycho-educational program, using four sessions of group-based ACT plus asthma education worked significantly better than parental asthma education alone for improving the health outcomes of young children with asthma. By the end of this study, those children whose parents received the ACT training, their 6-month incidence of ED (emergency department) visits due to asthma exacerbations was only one-fifth of those whose parents attended an asthma education talk, while their 6-month incidence of unscheduled private practitioners' clinic visits were almost half of the aforementioned counterparts. Likewise, children whose parents were trained with ACT achieved better asthma symptom control, as evidenced by more significant reductions on the days with asthma symptoms, nights affected by asthma symptoms, as well as the days requiring medications to control asthma symptoms, up to an average of approximately 0.5 days per week only, when compared with those whose parents received asthma education (approximately 1.6 to 2.3 days per week). No adverse events were reported in children.

In general, the above findings support previous research indicating that the effects of family interventions outweigh asthma education as usual care on the child's asthma-related health outcomes (Duncan et al., 2013; Morawska, Mitchell, Burgess, & Fraser, 2016; Yeh, Ma, Huang, Hsueh, & Chiang, 2016). These interventions have addressed a variety of problems that could be possibly aroused among families in childhood asthma management, such as parent-youth teamwork intervention to improve adherence to inhaled corticosteroids (Duncan et al., 2013), parenting program to improve ineffective parenting practice (Morawska et al., 2016), and family empowerment program to resolve family conflicts related to childhood

asthma care (Yeh et al., 2016). Following the interventions, children have achieved better asthma symptom control, in terms of lower asthma-related functional severity score (Duncan et al., 2013), better lung functions (Yeh et al., 2016) and fewer asthma episodes per week (Morawska et al., 2016), in which the improvements could be sustained from six to twelve months post-intervention (Duncan et al., 2013; Morawska et al., 2016; Yeh et al., 2016). In the present study, we extend previous work on family interventions by targeting at the management of psychological difficulties experienced by parents in caring for their children with asthma, regardless of the exact practical problem that they could possibly encounter when managing asthma along their child's illness trajectory. The positive health outcomes in children as seen in here highlight the merits of addressing the psychological needs of their parents, and reinforce the significance of familial roles in childhood asthma care (Kaugars et al., 2004).

Worthy to note, the psychological impact of parents affecting childhood asthma has been recognized in literature for a long time (Kaugars et al., 2004), but a recent Cochrane Collaboration review has highlighted that research on addressing parental psychological needs is still in its infancy (Eccleston et al., 2015). This review identified 47 RCTs of examining the efficacy of psychological interventions for parents on the health outcomes of children with various types of chronic disease (Eccleston et al., 2015), but only four RCTs concerned parents of children with asthma, of which three used family therapy (Celano et al., 2012; Naar-King et al., 2014; Ng et al., 2008) and one used problem-solving therapy (Seid et al., 2010). Apparently, the present study assists in addressing the paucity of published trials concerning parental psychological needs in childhood asthma care.

More importantly, as only four RCTs could be identified, Ecceleston et al. (2015) has acknowledged that current evidence to support the efficacy of parentfocused psychological interventions for improving child's asthma-related health outcomes remains very limited and inconclusive. According to the Ecceleston et al. (2015), the pooled effect estimates of these four trials on child's asthma symptoms were insignificant (pooled ES = 0.17, p = .13, 337 families). Of these four RCTs, two integrated home-based asthma education programs with problem-solving therapy (Seid et al., 2010), as well as family therapy (Celano et al., 2012), respectively, and assessed their effects on the ED visits due to asthma exacerbations in children in comparison to asthma education. However, none of them yielded significant results at six months and at one-year post-intervention (Celano et al., 2012; Seid et al., 2010). Several plausible reasons have been suggested by the trial authors. For example, Seid et al. (2010) reported that multiple sessions in problemsolving therapy (i.e., eleven weekly sessions) might lead to high attrition and inadequate power to detect group difference. Celano et al. (2012) commented that some planned asthma management modules were not delivered to families as intended due to mismatch with the family-selected goals, which weakened the fidelity of the intervention. The other two trials did not measure any indicators concerning the health care service use related to childhood asthma (Naar-King et al., 2014; Ng et al., 2008).

Perhaps, the present study is one of those few trials to demonstrate the efficacy of parent-focused psychological interventions for improving the health outcomes of children with asthma. Possible reason could be related to the novel therapeutic approach to address parental psychological difficulties by enhancing psychological flexibility (PF) via ACT. To date, psychological interventions serving

for parents of children with chronic diseases (including asthma) are mainly dominated by cognitive behavioral therapy, problem-solving therapy and family therapy (Eccleston et al., 2015). Cognitive behavioral therapy posits that maladaptive appraisal processes related to the illness or symptoms are thought to be the core contributing an individual's psychological difficulties, hence the therapy mainly focuses on cognitive reappraisal (Aldao, Nolen-Hoeksema, & Schweizer, 2010; Dobson, 2010). Problem-solving therapy postulates that increasing an individual's ability of problem-solving skills systematically can change the stressful situation related to the illness (Aldao et al., 2010; Nezu, 2004). Family therapy focuses on identifying dysfunctional familial patterns, resolving familial conflicts and empowering family members to work together in managing the child's problem more effectively (Cottrell & Boston, 2002). In general, these three types of psychological interventions draw on cognitive and behavioral theories (Cottrell & Boston, 2002; Nezu, 2004), share a common approach that targets on the antecedents (i.e., situations or events) which trigger an individual's negative emotional experiences (Aldao et al., 2010; Hofmann & Asmundson, 2008), and adopt reappraisal and problem-solving as the emotion-regulation strategies (Aldao et al., 2010).

Different from the aforementioned psychological interventions, ACT targets on the individual's *response* to negative emotional experiences aroused from those events, such as avoidance, the long-term workability of avoidance towards his/her valued life, and acceptance as a regulatory strategy (Hofmann & Asmundson, 2008). Considering the difficulties in achieving a complete cure of childhood asthma and the unpredictability of asthma crises, the workability of using reappraisal and problem-solving approaches to handle parental psychological difficulties may be

questioned. In the present study, we used ACT, a contextual-driven psychotherapeutic approach that is specifically designed to reduce parental experiential avoidance, and to facilitate parents to develop better psychological flexibility (PF) when encountering a spectrum of challenging situations related to childhood asthma management. In fact, every parent could encounter unique challenges in taking care of his/her own child with asthma along the child's illness trajectory. By using ACT, we facilitated parents into direct experiential contact with their own unwanted experiences related to their child's asthma that they were attempting to avoid, and more importantly the paradoxical effects of avoidance behaviors which could affect their child's health conditions. Throughout the ACT intervention, we fostered the PF of parents by strengthening the acceptance of unwanted emotional experiences, as well as the commitment to values-driven behaviors that are associated to strengthen their childhood asthma management.

The role of parental PF in childhood asthma may be supported by our preliminary analysis, which used a structural equation model (SEM) to explore the associations between three parental psychological constructs (i.e., PF, psychological adjustment to the child's illness, and psychological symptoms) and the child's asthma morbidity (i.e., child's asthma symptoms) (Chong, Mak, & Loke, 2017). Results have indicated that only parents' PF is associated with their child's asthma morbidity. Altogether, our results of the SEM analysis and the RCT contribute new knowledge regarding the current scientific work on psychological interventions for parents of children with asthma: an intervention like ACT targeting at fostering parental PF may bring positive impacts on child's asthma-related health outcomes.

Indeed, in the present study, parents of children with asthma who received the ACT training became more psychologically flexible starting at post-intervention

in comparison with those who received asthma education only (Cohen's *d* effect size (d) = 0.41), effect size of their PF doubled from medium to large at six months postintervention (d = 0.80). On the other hand, the significant reductions on the asthmarelated ED visits, the unscheduled private clinic visits, as well as the asthma symptoms of children whose parents were trained with ACT all occurred at six months post-intervention. Taken these observations together, the changes of parental PF and child's health outcomes that were shown *in sequence* suggests that, fostering parental PF via ACT may initiate and maintain a better parental management of childhood asthma, leading to an eventual improvement of their child's asthma morbidity. Notably, this pattern of changes should merely be seen as indicative only, suggesting the importance for further analyses in exploring the mediating effect of parental PF on the childhood asthma outcomes.

Our findings also contribute to the growing knowledge base regarding the efficacy of ACT in parents for improving their children's health outcomes (Coyne et al., 2011; Graham et al., 2016; Murrell & Scherbarth, 2006; Wicksell et al., 2015). As indicated earlier in Chapter Two, in literature, only two RCTs have shown that when compared with usual care, providing ACT training to parents *and* their children diagnosed with chronic pain or anxiety disorders improve the child's psychological health (i.e., reduction of anxiety and depressive symptoms) (Hancock et al., 2016; Wicksell et al., 2009), the child's pain-related functioning and pain symptoms (Wicksell et al., 2009), with medium effect sizes at post-intervention and at follow-up (see Table 2.5 for the details). If considered studies that solely offering ACT training to parents of children with chronic diseases as similar to our study, again only two RCTs have been published so far demonstrating that a parental training program using ACT is more efficacious than usual care for improving the

health outcomes of their children with neurodevelopmental behavioral intellectual disorders (Brown et al., 2014; Whittingham et al., 2014, 2016). In these two trials, both examined the efficacy of two sessions of group-based ACT plus Stepping Stone Triple-P parenting program in parents of children with cerebral palsy (Whittingham et al., 2014, 2016), and acquired brain injuries (Brown et al., 2014), while the Stepping Stone Triple-P parenting programs have the therapeutic aim of improving the behavioral problems and emotional adjustment of children through developing positive parenting practices (Sanders, Mazzucchelli & Studman, 2009). When compared with usual care (i.e., rehabilitation services), both studies have found that children whose parents received ACT-based parenting program have more significant improvements on their behavioral problems, emotional problems and disability-related functional performance at post-intervention with medium-to-large effect sizes, while such improvements could be maintained up to six months postintervention (Brown et al., 2014; Whittingham et al., 2014, 2016). To the best of our knowledge, the present study is the first RCT to test the effect of ACT in parents of children with asthma, demonstrating that a training program using ACT together with asthma education for parents is effective to improve their childhood asthma management, as indicated by better child health outcomes.

In addition, by referring to the trials conducted by Brown et al. (2014) and Whittingham et al. (2014, 2016), they both offered relatively intense interventions (e.g., 11 weekly sessions). The ACT components, in terms of the number of therapy hours (4 hours in total), were much less than the parenting intervention components (16.5 hours in total) (Brown et al., 2014; Whittingham et al., 2014). In the present study, an innovative feature of our intervention was in brief sessions (4 weekly sessions), but more time was given to parents in practicing ACT (6 hours in total)

than receiving education regarding childhood asthma management (2 hours in total). Yet, the improvements of childhood asthma conditions, in terms of asthma symptoms and asthma-related health care service utilization, could still be maintained from post-intervention up to six months post-intervention. Our findings may support the dissemination of ACT using brief sessions to parents with less resource implications and imply that an ACT-inclusive psychoeducational intervention (e.g., ACT plus asthma education as seen here) for parents, with more ACT components, could also bring benefits to their children's physical health outcomes.

### 7.3. Parental outcomes

#### **Psychological health**

In the present study, at six months post-intervention, parents who were trained with ACT had better psychological adjustments to their child's asthma, in terms of feelings of less guilt and worry, unresolved sorrow and anger, when compared with those who received asthma education only. In addition, these parents had less anxiety and stress symptoms. No adverse events were reported in parents. Overall speaking, our ACT intervention in this study yielded small-to-moderate between-group effect sizes in most of the parental psychological health outcomes (d = 0.35-0.47). This is consistent with existing evidence from meta-analyses of RCTs, suggesting that ACT outperforms treatment-as-usual for improving the psychological health outcomes in adult populations with approximately moderate effects (pooled ES, in terms of Cohen's d or Hedge's g, ranging from 0.36 to 0.55) (A-Tjak et al., 2015; Hacker, Stone, & Macbeth, 2016; Öst, 2014). Another two recent trials have also supported the durable impacts of a group-based parenting program using ACT in comparison to usual care on reducing the anxiety and stress

symptoms of parents who have children with cerebral palsy or acquired brain injuries, with medium effect sizes at post-intervention (d = 0.39-0.56), while the effects could be maintained up to six months post-intervention (Brown et al., 2015; Whittingham, Sanders, McKinlay, & Boyd, 2016). To summarize, there is growing evidence to support the effects of ACT on the psychological health of parents with children diagnosed with various types of chronic diseases. Our findings, derived from a RCT, may further strengthen this evidence with internal validity.

It is worth noticing that from the post-hoc between-group comparisons, the improvements of parental psychological adjustment, anxiety symptoms and stress symptoms occurred at six months after the intervention (at baseline: all ps were nonsignificant: at 6 months: all ps ranged from .003 to .017), later than that of shown in the parental PF (at baseline: p = .014, at 6 months: p < .001). These changes support the premise of ACT model: an individual's acceptance of distressing emotional experiences and reengagement to meaningful life activities may bring in an eventual improvement of his/her own psychological well-being (Kashdan & Rottenberg, 2010), such that reduction in psychological symptoms could be happened as a byproduct of ACT (Hayes et al., 2006). As mentioned earlier, our SEM analysis has acknowledged the significant relationships between parental PF, parental psychological adjustment to the child's asthma and psychological symptoms (Chong et al., 2017). This may contribute a better understanding regarding the possible mechanism of ACT in the present study, in which parents with better PF after receiving ACT would be more capable to adjust to situational changes related to childhood asthma management, leading to improvements of their psychological symptoms.

Interestingly, in the present study, significant intervention effects were found in parent-reported anxiety and stress symptoms, but not for depressive symptoms. Given that the mean score for parental depressive symptoms (M = 4.7) was relatively lower than anxiety symptoms (M = 5.5) and stress symptoms (M = 9.8), this reflects a floor effect where the majority of parents in the ACT group might have less room to further improve their depressive symptoms. Still, we observed that the standard errors (SEs) regarding parental depressive symptoms in the ACT group decreased across time (SE at baseline = 0.74, at post-intervention = 0.46, at six months postintervention = 0.40), highlighting that parents presented with more depressive symptoms might had been benefited significantly after receiving the ACT training. It is possible that the between-group differences could be observed, if we recruit larger samples with greater statistical power.

In literature, by far Whittingham et al. (2016) is the only trial that has shown the benefits of ACT on parental depressive symptoms. In this study, 67 parents of children with cerebral palsy were randomly allocated to either two sessions of groupbased ACT (4 hours in total) plus nine sessions of parenting program (13.5 hours in total), parenting program, or waitlist-control receiving rehabilitation service as usual care (Whittingham et al., 2016). By using the instrument (i.e., DASS) which was the same as our study, the parents in the Whittingham trial had a higher mean depressive score (M = 6.7) than those in our study (M = 4.7) at baseline, and attained more substantial reduction in their depressive symptoms at post-intervention when compared with the waitlist group (Whittingham et al., 2016). This significant result, however, was not supported by another trial, which tested ACT by using the same intervention design as Whittingham et al. (2016), in 59 parents of children with acquired brain injuries (Brown et al., 2015), again with a relatively high mean

depressive score (i.e., the mean score measured by the DASS = 8.6). Such conflicting results have also been reported in several quasi-experimental studies (Blackledge & Hayes, 2006; Kanstrup et al., 2016; Rayner et al., 2016). We suggest the need for further studies to confirm the efficacy of ACT on the depressive symptoms of parents with children diagnosed with chronic diseases like asthma.

## Asthma management

Parents who received ACT reported with better quality of life in taking care of their children with asthma than those who received asthma education only. Smallto-medium effect sizes in favor of ACT were found at post-intervention (d = 0.38-(0.46), and at six months post-intervention (d = 0.34-0.39). In particular, for those parents in the ACT group, the increase of their quality of life sub-scores at both follow-up time points when compared with the baseline data ranged from 1.08 to 1.11, which were larger than the minimal clinically importance difference (MCID) score (i.e., 0.5) (Quittner et al., 2008). In literature, the roles of parents' acceptanceor avoidance-based coping on their quality of life have been examined (Sales, Fivush, & Teague, 2008; Silva, Crespo, Carona, & Canavarro, 2015), but so far psychosocial interventions for improving the quality of life in parents of children with asthma have reached limited success (Clarke & Calam, 2012). The positive effect of ACT on parents' quality of life as shown in our study may be possibly due to the fact that by fostering parental PF via ACT, parents might become less engaged in avoidance-based coping strategies to deal with stressors related to their childhood asthma management. Eventually, they perceived childhood asthma as imposing less impacts on their daily activities and emotions. In the present study, the increase of the quality of life score larger than the MCID score up to six months following the intervention is of clinical significance. This highlights that parents who receive ACT

could have actual and sustainable improvements in their well-being. Further, the improvement of parental quality of life is associated with better childhood asthma control (Cano-Garcinuño et al., 2016; Stelmach et al., 2012).

One shall note that we did not find significant intervention effect on parental asthma knowledge. This may be explained by the ceiling effect that it was difficult to further enhance the high asthma knowledge, with a mean score of 18.31 (possible scores, 0 to 25) measured at baseline. Since the children in this study had been diagnosed with asthma for approximately three years, parents might be quite familiar with the childhood asthma management. The instrument (the AKQ) used in this study focuses on assessing the parents' understanding about the basic facts of asthma, the role of trigger reduction and asthma medications. Knowing these topics is important, but other key asthma educational messages could also be evaluated by focusing on self-management behavioral skills, such as return-demonstration by parents in using inhalers together with spacers. Without an exact measure on the parents' asthma management skills but only their asthma knowledge via the AKQ, the effect of ACT for assisting parents to comprehensively learn more about childhood asthma care might not be clearly confirmed. There is a need to replicate this study by including additional measure(s) assessing the childhood asthma management behaviors among the parents. For instance, if future work targeting on parents of children with asthma who need long-term inhaled corticosteroids, researchers may carry out an assessment of parents' adherence of assisting their children to use inhaled corticosteroids by parental reports, pharmacy refill rates or electronic recordings (Rottier et al., 2015).

Another null finding was that our ACT intervention did not significantly affect the parental self-efficacy in childhood asthma management. In literature, self-

efficacy and PF have been shown to be related (Wei, Tsai, Lannin, Du, & Tucker, 2015; Wicksell, Olsson, & Hayes, 2010), as both constructs refer to an individual's perceived ability to carry out relevant activities in the face of adversity (Bandura, 1977; Kashdan & Rottenberg, 2010). Parental self-efficacy in childhood asthma management refers to the perceived confidence in performing asthma management tasks (e.g., assisting a child to use an inhaler properly) and overcoming barriers (e.g., management of an asthma attack) (Bursch et al., 1999). Parental psychological flexibility in the context of childhood asthma management may refer to the ability to commit to values-driven behaviors while accepting difficult emotional experiences related to childhood asthma non-judgmentally. As a result, it was hypothesized the mechanism by which the parents in the ACT group with higher PF may have better self-efficacy in taking care of their children with asthma. In view of the nonsignificant intervention effect, it may be related to the conceptualization of selfefficacy used by the instrument (PAMSE), which focuses on the prevention and management of childhood asthma attacks only, could not adequately capture the broader sense of the parental self-efficacy in raising their children with asthma. Parental self-efficacy is a multifaceted construct and it could be operationalized in different ways (Jones & Prinz, 2005), such as the general self-efficacy focusing on how competent a parent perceives him/herself in the childhood asthma care, or the task-oriented self-efficacy focusing on how confident a parent feels for a specific asthma management task. Future studies may adopt other instrument(s) measuring multiple aspects of parental self-efficacy in caring for a child with asthma to further explore the intervention effect.

More importantly, parents in both groups received identical content and contact hours of asthma education, hence the significant time effects as seen in

parental asthma knowledge and asthma management self-efficacy imply that asthma education was in fact *effective*, but the additional ACT components, as reflected by improved parental PF, conferred additional benefits on many other parental and child health outcomes.

### 7.4. Study strengths

This study possesses several methodological strengths in the following areas: (1) program design, (2) fidelity monitoring, and (3) attrition.

#### **Program design**

As noted earlier, our ACT training program to parents was offered as four sessions only in weekly basis while its benefits on the health outcomes of parentchild dyads could be seen up to six months post-intervention. This brief intervention may have less resources implications when compared with other asthma management programs to families, which offered frequent home visits (Celano et al., 2012; Kamps et al., 2008; Otsuki et al., 2009), and telephone coaching for 12 months (Garbutt et al., 2010).

Further, in literature, psychotherapies which have been applied to parents of children with asthma are often in multiple sessions (Naar-King et al., 2014; Ng et al., 2008; Seid et al., 2010), and/or in individual basis (Celano et al., 2012; Naar-King et al., 2014; Seid et al., 2010). In the present study, we delivered ACT to parents in brief sessions and in groups, which might reduce the time and travel burden, optimize social support and peer learning among group members, as well as increase group engagement. More importantly, the ACT metaphors and experiential exercises used in this study were selected from classical ACT therapist books and training manuals, modified in accord to the findings of our qualitative interviews, and fit into the parents' language and life experiences when encountering challenging situations

in managing childhood asthma. As a result, parents might be able to handle their emotional experiences associated with their child's asthma more effectively and to better engage in participating the rest of the ACT sessions.

In the present study, 74.4% of randomized parents (125/168, 62 in ACT, 63 in Control) completed all four assigned sessions and were successfully followed up. This rate was close to the mean adherence rate of other ACT-related interventional studies for parents of children with physical and mental health problems as reviewed in Chapter Two (M = 73.3 %) (Burke et al., 2014; Hancock et al., 2016; Kanstrup et al., 2016; Rayer et al., 2016; Timko et al., 2015; Wallace et al., 2016; Wicksell et al., 2009). Further, over 80% of parents who participated in the ACT sessions completed all the assigned ACT homework. Overall, the completion rates of the assigned intervention sessions and the ACT homework as shown in our study reflect that parents of children with asthma can engage in our ACT intervention. This is an important finding for supporting the acceptability of ACT among parents of children with asthma and the dissemination of ACT in pediatic settings.

### **Fidelity monitoring**

We adopted multiple strategies to strengthen the fidelity of the intervention. An ACT-based intervention protocol was specially designed and had been pilottested to demonstrate its potential efficacy and acceptability among Hong Kong Chinese parents of children with asthma, which provided a basis for the interventionist to deliver the intervention with fidelity. The interventionist was a nurse who had received introductory and intermediate skills building in ACT. This echoes the common practice in literature that ACT could be delivered by novicelevel therapists and/or by health care professionals under adequate amount of training and supervisions (Hayes, Boyd, & Sewell, 2011; Kohtala, Lappalainen,

Savonen, Timo, & Tolvanen, 2015; Kohtala, Muotka, & Lappalainen, 2017; McCracken & Gutiérrez-Martínez, 2011). Further, the intervention was monitored throughout the study period by receiving weekly supervisions from supervisor through reviewing videotaped sessions. Treatment fidelity was assessed by using a standardized behavioral checklist (Luoma et al., 2007). We acknowledged that the fidelity assessment was conducted by the interventionist, rather than by blinded evaluators with the inter-rater reliability confirmed as suggested in literature (Öst, 2014; Plumb & Vilardaga, 2010). Still, our fidelity checks may at least add credibility to the study findings, because it is often not reported in many studies examining the efficacy of ACT in parents of children with physical or mental health problems (Burke et al., 2014; Kanstrup et al., 2016; Rayner et al., 2016; Timko et al., 2015; Wallace et al., 2016; Wicksell et al., 2009).

# Attrition

Only a total of six out of 168 parent-child dyads (3.6%) were lost to follow up at six months post-intervention. The overall attrition rate in our study was lower than that of reported in a number of ACT-related studies as reviewed earlier in Chapter Two (Hancock et al., 2016; Kanstrup et al., 2016; Rayner et al., 2016; Timko et al., 2015; Wallace et al., 2016; Wicksell et al., 2009), which varied from 10% to 62.5%. A possible reason could be related to the data collection strategy which minimized the participants' burden. Given that the children and their parents needed to attend the clinics for regular medical consultations and refilling asthma medications in at least every three months, the data collection during the follow-up assessments was incorporated into the children's regular clinic visits in the study hospital, hence it was possible for the research team to trace most of the parent-child

dyads within the six-month follow-up period. The very low attrition as shown in here minimized the risk of attrition bias.

#### 7.5. Study limitations

This study possesses several limitations in the following areas: (1) study design, (2) data collection method, and (3) the generalizability of study results.

# Study design

Same as other psycho-educational interventional studies, double blinding (i.e., blinding of the interventionist and the participants) was difficult to achieve. The extended time devoted to parents who were allocated to the ACT group (8 hours) when compared with the Control group (2 hours and 45 minutes) might contribute to the significant intervention effects. As our study was a superiority trial aiming at determining whether an intervention (ACT plus asthma education) was superior to an existing practice (asthma education as usual care) (Freedland, Mohr, Davidson, & Schwartz, 2011), we used the existing practice as provided by the study hospital as the comparison condition. Nevertheless, we included a process measure, parental PF, to assess whether the ACT model of PF was addressed effectively. When the ACT group compared with the Control group, the between-group effect size of parental PF increased from medium (d = 0.41 at post-intervention) to large (d = 0.80 at six months post-intervention) across time, indicating that the psychotherapy, but not merely clinical attention, made the difference.

We adopted RCT as the golden standard design to determine the cause-andeffect relationship between interventions (the parental training program using groupbased ACT and asthma education as usual care) and a predefined primary outcome (the ED visits due to child's asthma exacerbations in the past six months), but to further strengthen the causal inference of intervention, future RCTs may use a

credible comparison group in which the contextual factors could be addressed but lacking the ACT components only (Safer & Hugo, 2006).

#### **Data collection methods**

This study relied on parental proxy reports to collect data related to the child's health outcomes. One may argue that parent-reported outcomes may be subjected to recall bias and social desirability responses bias. However, as noted earlier in Chapter Three, parents are regarded as accurate proxy reporters of their children's unplanned use of health care services due to asthma exacerbations if the recall period is equal or less than six months (Akinbami et al., 2012; Pless & Pless, 1995; Ungar et al., 2007). More importantly, the public hospitals under the Hong Kong Hospital Authority (HA) account for 81% of inpatient health care services in Hong Kong (Hospital Authority, 2017b). If we solely rely on the data retrieved from the study hospital's electronic Patient Record (ePR) under the HA, those children who had been received care in private sectors would have been missed throughout the study period (Yu et al., 2017), leading to a high risk of attrition bias.

In addition, as over one-third of the children (61/168 = 36.3%) in our study aged five years or below, they might have short attention span and be unable to follow instructions to perform an accurate measurement of lung function test as a verification of the improvement of child's asthma symptoms (Beydon, 2009). The measurement of exhaled nitric oxide (FeNO) in breath has been recently suggested to monitor asthma control in young children even as young as four years of age (Rao & Phipatanakul, 2016). However, this non-invasive measurement is easily confounded by many factors, such as dosage of inhaled corticosteroids, diet (e.g., nitrate rich food, such as lettuce, radishes, caffeine and water) and history of atopy (Abba, 2009). When compared with the spirometric and exhaled FeNO measurements, a

self-report by parents on their child's asthma symptoms and the use of rescue medications may even more closely reflect the actual disease status of a child at the time of data collection (Barrett et al., 2013; Brand, Mäkelä, Szefler, Frischer, & Price, 2015).

Another point worth for discussion is the different data collection methods between groups to assess parental psychological health and asthma management outcomes at post-intervention. Parents in the ACT group were assessed by using self-administered questionnaires (right after the end of the fourth ACT session). As there could be a chance that parents in the Control group refused to return to the clinics to complete questionnaires leading to low response rate, we assessed these parents by using interviewer-administered questionnaires via telephone. Despite of the different modes of administrating questionnaires, we suggest that the impact on study quality would be minimal. As supported in literature (Higgins & Green, 2011), the aforementioned outcomes are regarded as "patient-reported outcomes (PRO)", which refer to the reports coming directly from clients about how they feel or function in relation to a therapy without interpretation by health care professionals or anyone else (Higgins & Green, 2011). One recent meta-analysis published in 2016 identified 56 studies aiming at comparing two or more modes of administration for a health-related PRO measure in adult samples (Rutherford et al., 2016), indicating that there were no significant differences in the mean scores for comparisons between self-completion and assisted completion (ES = 0.04, 95% CI [-0.01, 0.08]). Hence, the evidence provided by this review highlights that a mix of self-completion and assisted completion for PRO measures can generally produce equivalent scores.

#### Generalizability of study results

Caution is warranted because we found no significant differences between groups from baseline till six months post-intervention in some of the child's health outcomes, including the GOPC visits, hospital admissions and the length of hospital stay due to asthma exacerbations, respectively. Possible explanations could be the insufficient statistical power to detect the small effect sizes, or short duration of follow-up period. An extension of measurement period up to 12 months may be able to capture the adverse asthma-related events that may be relatively rare or seasonal (Akinbami et al., 2012). Another plausible explanation could be related to the sample characteristics. At baseline, 75% of the children in our study sample did not require hospital admissions due to asthma exacerbations over the past six months, half of the children (52.4%) had well-controlled asthma and did not require prophylactic inhaled corticosteroids therapy. These findings imply that the children in this study generally had a low asthma severity, thus the non-differential changes between groups might be influenced by the floor effect. Our results may not be generalizable to parents whose children are hospitalized due to asthma and receiving inpatient care.

In Hong Kong, the health care system runs on a dual-track basis. Children diagnosed with asthma can receive asthma-related health care services on a fee-forservice basis in private clinics and hospitals, and/or on a subsidized basis in GOPCs and public hospitals run by the Hong Kong Hospital Authority (Leung et al., 2005). Parents, as the main caregivers of young children with asthma, need to make the decision on which of the abovementioned health care services to choose when their child needs medical care for treating asthma. In the present study, we found that at baseline, the total number of GOPC visits by children's asthma exacerbations over

the six-month period (mean = 0.39 visits) was only around one-third of the total number of the private practitioner's clinic visits (mean = 1.25 visits). This finding further reflects the actual situation in Hong Kong that the general public preference to seek medical advice from the private practitioners, other than the GOPCs, due to greater accessibility to specialists and better perceptions towards the health care services provided by the private sectors (Wong et al., 2010). Hence, it is not surprising to see significant between-group difference in private practitioners' clinic visits, but not in the GOPC visits, across time.

This was a single-center trial which limited the generalizability of our study results. Nevertheless, the trial was conducted in two outpatient asthma clinics of the largest public, acute hospital located in the New Territories West region, Hong Kong. Consecutive sampling was adopted by screening all parent-child dyads who would attend the clinics for follow-up appointments for five months. In view of the fair participation (168/302 eligible parent-child dyads = 55.6%), the baseline characteristics between participants and non-participants were compared for identifying predictors of participation, adjusted logistic regression analysis showed that parents whose children required ED services due to asthma exacerbations over the past six months were three time more likely to participate in our training program (adjusted OR = 3.36, 95% CI [1.36, 8.26], p = .008) than those whose children did not need ED services before. Overall speaking, our findings may be able to generalize to Hong Kong Chinese parents whose children are currently receiving outpatient care due to asthma but experienced an asthma attack before.

In addition, our participants may be able to represent the populations of Hong Kong Chinese families, as well as families living in Asian urban cities, in which mothers play the major role in taking care of a young child with asthma from a

general perspective. The parents who participated in the present study have marked similarities with those of the Hong Kong Chinese parents, who participated in parenting interventions or interventions for enhancing familial relationships (Fabrizio et al., 2015; Fabrizio, Stewart, Ip, & Lam, 2014; Ho et al., 2016; Leung, Tsang, Sin, & Choi, 2015; Li, Chan, Mak, & Lam, 2013), they were all mainly mothers, housewives and reached secondary school educational level. In addition, the characteristics of the children in the present study are comparable to those of a representative sample of 4805 children recruited from 12 Asian urban cities and countries, in terms of daytime asthma symptoms (54.9%), nighttime asthma symptoms causing disrupted sleeps (29.1%), and activity limitations due to asthma symptoms (40.0%) (Wong, Kwon, et al., 2013).

Nevertheless, we suggest that to address the limitation regarding generalizability, there is a need to replicate the study in other geographical contexts with diverse ethnic groups and in different target populations, such as parents whose children are currently hospitalized due to asthma, parents whose children receive care for asthma in an emergency department, or parents with children suffering from poor asthma control (e.g., repeated hospital admissions within one year and/or requiring long-term inhaled corticosteroids). It is expected that these groups of parents may have more psychological burden in managing childhood asthma and response to ACT differently.

# 7.6. Implications for clinical practice

We considered the findings of the present study to possess the following clinical implications: (1) the need to address parental psychological difficulties to childhood asthma care, and (2) the potential application of ACT in strengthening childhood asthma management programs.

# A pressing need to address the parental psychological distress in childhood asthma care

The participants of this study were Hong Kong Chinese parents, who were mainly mothers as the caregivers and from middle-lower socioeconomic group, and their children who had been diagnosed with asthma. At baseline, less than half (40%) of these children visited to the ED at least once for treating acute asthma exacerbations in the past six months. Nevertheless, nearly half (48.2%) still needed inhaled corticosteroids to control asthma symptoms. Children in our sample generally experienced at least one day per week with asthma symptoms, around 40% suffered from disrupted sleep due to night symptoms at least once per week, and 30% experienced activity limitations due to asthma symptoms over the one-month period. Our data indicate that the daily life and functioning of the Hong Kong children with asthma are affected by the disease.

In addition, our data reflect that the parents in this study were in fact quite familiar with the childhood asthma management, as evidenced by an acceptable asthma knowledge score (i.e., the mean score of the AKQ = 18.3 out of 25). They also perceived themselves as "fairly sure" in preventing and managing childhood asthma attacks, as shown by satisfactory scores in asthma management self-efficacy at baseline (i.e., the mean scores of the PAMSE- Attack Management = 3.25 out of 5).

However, we still found that approximately around one-third of the parents had at least mild level of psychological symptoms as measured by the DASS-21 subscales, including symptoms of depression (20.2%), anxiety (31.0%) and stress (25.0%), respectively. In addition, as addressed earlier in Chapter One, the findings from our qualitative interviews suggest that Hong Kong Chinese mothers experience

substantial psychological difficulties in taking care of their children with asthma, such as feelings of uncertainty and fear of asthma crises, extensive worry about their child's future and development, guilt and self-doubt at the perceived incapacity to safeguard their child's health, and practicing self-blame and blaming others (e.g., family members and health care professionals) as long as their child's asthma is not well-controlled.

Health care professionals may naturally appreciate the presence of psychological distress in families raising children with life-threatening illnesses (e.g., cancers, congenital disorders) and physical disabilities. In fact, the findings of the qualitative interviews and the baseline assessment of this study suggest that the Hong Kong Chinese parents still experience a considerable level of psychological distress in taking care of their children with asthma – even they are generally knowledgeable and confident in managing their child's health conditions. More importantly, from our trial results, the positive intervention effects of ACT on the PF, psychological adjustment to the child's illness, anxiety and stress symptoms of the parents, as well as on the asthma outcomes of their children indicate that parental psychological distress plays a key influential role in childhood asthma management. Altogether, the data shown in our qualitative interviews, baseline assessment and trial study imply the pressing needs to identify parents of children with asthma who are at distress, to intervene early, and to improve the health conditions and overall well-being of the parent-child dyads.

# The potential application of ACT in strengthening childhood asthma management programs

We delivered ACT to parents of children with asthma who were recruited from outpatient clinics under the following conditions: (1) integrating ACT into

evidence-based asthma education, (2) delivering ACT by a trained health care professional, and (3) using a group-based, brief interventional approach. Even the parents received only four sessions of group-based ACT integrated with asthma education, the parent-child dyads achieved better health outcomes than those whose received asthma education only, with gains maintained up to six months postintervention. Altogether, our findings support the feasibility and practical utility of disseminating ACT through childhood asthma management programs in clinical areas.

In our analysis of identifying the predictors of participation, parents whose children had visited to the ED at least once due to asthma exacerbations over a sixmonth period was associated with more than three-fold increases in program participation. It is speculated that these parents might have a greater concern of preventing life-threatening asthma exacerbations in the future, and hence they were more eager to participate in interventions that could improve their childhood asthma management. We suggest that future recruiting efforts could focus on this group of parents.

It is bear noting that ACT is not a psychotherapy with a specific set of techniques that could only be used in a treatment context, it could be a training prevention in a non-treatment context, referenced as Acceptance and Commitment training (Biglan, Hayes, & Pistorello, 2008). Helping parents to learn acceptance of difficult emotional experiences early may reduce the functional impacts of such experiences on their psychological well-being and childhood asthma care. An ACT intervention could also be introduced to parents when their child's diagnosis of asthma is disclosed.

#### 7.7. Implications for future research

The findings of the present study identify several understudied and important areas for future research that can contribute to the advancement of ACT application in families of children with chronic diseases, such as childhood asthma. Areas for further exploration include: (1) the role of parental psychological flexibility (PF) in childhood asthma management, (2) assessment of parental PF, (3) parental experiences of participating in a group-based ACT training program, (4) other modalities of disseminating ACT to parents, and last but not the least (5) the feasibility and potential efficacy of ACT in parents of children with other chronic diseases.

# The role of parental psychological flexibility in childhood asthma management

Our results indicated the efficacy of a parental psychoeducational program using group-based ACT integrated with asthma education on the health outcomes of children with asthma. The key focus of the intervention was to foster parental PF, but to further investigate what contributes to the mechanism of change, future analysis/studies can evaluate whether parental PF, in comparison with other potential mediators, such as parental psychological adjustment, or parental self-efficacy in childhood asthma management, mediates the effect of the ACT intervention on childhood asthma outcomes. This evaluation may explain how PF actually functions in ACT for improving the health outcome of parent-child dyads, and enrich the body of knowledge regarding the role of parental PF in pediatric care (Brassell et al., 2016; Chong et al., 2017; Moyer & Sandoz, 2015; Wallace, McCracken, Weiss, & Harbeck-Weber, 2015).

One shall note that in this trial, the between-group ESs of improved parental PF (d = 0.41-0.80) was larger than other parental outcomes (d = 0.35-0.47) across

time, while the SEM analysis assessing the associations between parental PF and child's asthma morbidity, together with other parental psychological constructs (i.e., psychological adjustment to child's illness and psychological symptoms), found that the overall model variance was only 15% (see Figure 6.2). Hence, it is expected that apart from parental psychological factors, other contributing factors might play an influential role of child's asthma morbidity but had not been assessed in our study, for example, parental asthma management behaviors, or child's psychological symptoms/ well-being. Further mechanistic studies in exploring how improved parental PF leads to improved child's health outcomes may consider including more parent/ child measures.

# Assessment of parental psychological flexibility

Another issue that is worth discussion is the use of Acceptance and Action Questionnaire—II (AAQ-II) as the process measure of this study to assess PF. The nine-item AAQ-II used in this study is the most well-known and a very general measure of PF (Bond et al., 2011). Some ACT studies have suggested the use of a context-specific instrument for a more valid measurement of the psychological processes experienced by the clients. These instruments are, for example, the Acceptance and Action Diabetes Questionnaire for diabetic patients (Gregg et al., 2007), the Chronic Pain Acceptance Questionnaire for chronic pain patients (McCracken, Vowles, & Eccleston, 2004), as well as the Parental Psychological Flexibility Questionnaire (Burke & Moore, 2015), and the Parental Acceptance and Action Questionnaire (Cheron, Ehrenreich, & Pincus, 2009) for assessing the PF of parents in the context of parenting. To gain a better understanding the ways in which the association between parental PF and child's asthma-related health outcomes,

future studies could develop and validate a PF measure that is specific in the context of parental management of childhood asthma.

In addition to assess the PF of clients as a whole, there has been an accumulating evidence for assessing the six therapeutic processes of the PF model, and to examine the impacts of these processes on outcomes in efficacy trials (Hoffmann, Halsboe, Eilenberg, Jensen, & Frostholm, 2014; McCracken & Gutiérrez-Martínez, 2011; Villatte et al., 2016). Having a thorough understanding of how the therapeutic processes unfold over time, and what exactly the process(es) that mediate(s) in treatment outcomes could inform the future development of a more flexible, targeted ACT-based intervention, for instance, selecting the most appropriate ACT experiential exercise to address a particular therapeutic process during the therapy, rather than providing a manualized-based ACT intervention. **Parental experiences of participating in a group-based ACT training program** 

There has been a call for qualitative research to explore the participants' experiences in ACT, which can provide a better understanding of how the therapeutic processes of ACT are actually applied to particular populations (Hayes, Long, Levin, & Follette, 2013). Qualitative data from the interviews of participants who suffered from psychosis (Bacon, Farhall, & Fossey, 2014), chronic pain (Clarke, Poulis, Moreton, Walsh, & Lincoln, 2017; McCracken et al., 2014), and of those who were family caregivers of persons with acquired brain injuries (Jonathan, Frances, Jaci, & Richard, 2014), have indicated a mixed picture of experiences.

Clarke et al. (2017) shared some positive experiences as reported by their participants, such as learning to accept limitations and taking values-based actions, gaining better attention to the present moment, and developing a different perspective to view their discomfort or pain. Authors in some studies, however, have

discussed that ACT could be emotionally challenging (Bacon et al., 2014; McCracken et al., 2014; Williams, Vaughan, Huws, & Hastings, 2014). Further, participants may find it confusing and difficult to understand the metaphors and experiential exercises, which creates disconnection with the underlying meaning of PF (Bacon et al., 2014; McCracken et al., 2014). There is also a tension between the participants' expectations of treating discomfort, and the ACT-related strategies that ask participants to accept discomfort non-judgmentally (McCracken et al., 2014).

In our study, though no adverse events were reported, we did not qualitatively explore how parents responded to ACT. There is a need for further studies in understanding parental experience of participating in the group-based ACT training program, or how the ACT-related techniques may facilitate parents to improve their childhood asthma management after the end of the program.

## Other modalities of disseminating ACT to parents

In the present study, we adopted a number of strategies to increase the participation rate and to reduce the possibilities of randomized parents who might miss some of the sessions. First, to avoid stigmatization of a psychotherapy as a barrier to participation (Schomerus et al., 2012), we delivered ACT to parents of children with asthma by integrating ACT with an evidence-based asthma education, and packaged the intervention as a parental training program, rather than a "therapy". This may be more suited to parents in which the majority may not recognize the negative impacts of psychological difficulties that they had been experienced so far on their health, and on their child's health. Second, to ease the travel and time burden, the intervention was designed as brief, parents who were either in the ACT group or the Control group received four weekly sessions. The study venues were two outpatient clinics of a public hospital in Hong Kong, they were easily accessible

by most of the parents who lived nearby while their children need to be followed up regularly in the study hospital. Third, in terms of logistic arrangement, the intervention sessions were arranged during the children's schooldays before the summer holidays began to avoid conflicting with family schedule. Child care services and telephone reminders for session attendance were both offered.

Despite of using the above strategies to disseminate ACT, only half of the eligible parents participated in our study (168/302 = 55.6%). This participation rate of this study was slightly lower than that of other ACT-related studies as reviewed earlier in Chapter Two (Hancock et al., 2016; Timko et al., 2015; Wallace et al., 2016; Wicksell et al., 2009) (i.e., mean = 64.5\%, range from 38.1% to 94.1%, see Table 2.1 for the details). In addition, 31 out of 168 (18.5%) randomized parents (15/84 = 17.9% in ACT, 16/84 = 19% in Control) did not turn up to attend any of the sessions after the start of the trial.

Among those non-participants, 80% (108/134) were unavailable as they were too busy with their full-time work, part-time work, housework or due to their personal health problems. Similarly, the main reason for the parents could not complete the assigned intervention was their unavailability due to unforeseeable circumstances, such as scheduling conflicts or the child's health problems. It seems that, the parent's availability to attend all the face-to-face sessions is a common concern that hinders parents to fully engage in the training programs (Haine-Schlagel & Walsh, 2015; Ingoldsby, 2010). In other trials examining an ACT-based training program for parents of children with acquired brain injuries and cerebral palsy have also noted that the proportion of parents who missed the sessions could be up to 30% (Brown et al., 2015; Whittingham et al., 2014). Future studies may draw attention to examine other modalities of delivering ACT interventions to parents of children with

asthma for fitting parents' busy schedules. The suggested modalities could be, for example, by using mobile apps, internet, or by offering a hybrid combination of faceto-face sessions, plus web-based training sessions (Brown, Glendenning, Hoon, & John, 2016; Plaza, Demarzo, Herrera-Mercadal, & García-Campayo, 2013).

# Feasibility and potential efficacy of ACT in parents of children with other chronic diseases

The positive findings of the present study may enlighten researchers to explore the feasibility, acceptability and the potential efficacy of ACT in parents of children with other physical health problems, such as type I diabetes, congenital disorders, cancers and inflammatory bowel disorders. Like childhood asthma, the chronicity of these diseases and the complexity of demanding care create a substantial psychological burden on parents (Cohen, 1999; Drotar, 1997; Wallander & Varni, 1998), which may affect their psychological well-being and functioning in terms of managing their child's health problems (Cousino & Hazen, 2013; Jackson et al., 2015; Kaugars et al., 2004). ACT may facilitate parents to initiate and to maintain desired behavioral changes that are aligns with their personally held values, leading to improvements in disease management and thus their child's health. To date, for the ACT-related studies that included parents as the participants, they often examined the health benefits of ACT exclusively for either parents (Burke et al., 2014; Rayner et al., 2016) or their children only (Hancock et al., 2016; Timko et al., 2015; Wallace et al., 2016; Wicksell et al., 2009). Similar to our study, assessing the health outcomes of both parents and their children may help to gain a better understanding about the impacts of parental psychological health on child's health after the ACT intervention.

#### 7.8. Recommendations

This is the first report of a RCT using ACT for parental management of childhood asthma. We demonstrated that a 4-session of parental training program using group-based ACT integrated with asthma education was more effective than an asthma education talk for improving childhood asthma morbidity. Our findings should not be interpreted as evidence to confirm a *direct* implementation of our training program to parents of children with asthma, unless a stronger evidence base is established across different demographic groups and settings. We would like to conclude this chapter by the following recommendations that require health care professionals in Hong Kong who are specialized in pediatric asthma to pay immediate attention:

# Parents of children with asthma who are in need for psychological support should be proactively identified

Parents, especially mothers, with mental health issues often do not seek care on their own (Freed, Chan, Boger, & Tompson, 2012), but they often pay regular visits to health clinics when their young children require regular immunization, or their children's asthma are not yet well-controlled. Hence, pediatric health clinics could be an important venue to identify parents who are in need for psychological support. Health care professionals are in a unique position in identifying and responding parents who need psychological support, as they are the first personnel with whom parents could contact when they encounter asthma crises in their children. It remains a common practice that health care professionals use observation (Gupta & Ford-Jones, 2014), or ask informal questions if they suspect a parent has mental health issues (Kerker et al., 2016). Including an assessment of the parents' psychological health status via the DASS-21 (Ng et al., 2007), or other brief

screening tools, such as the Patient Health Questionnaire-4 items (PHQ-4) (Kroenke, Spitzer, Williams, & Löwe, 2009), as part of routine care is highly recommended, which can proactively detect those parents who need assistance for further formal evaluations and interventions. The feasibility and acceptability of mental health screening among mothers during regular child's clinic visits have been empirically supported in literature (Freed et al., 2012; Gupta & Ford-Jones, 2014).

# The development of asthma management programs in Hong Kong should move beyond educational approach to psychoeducational approach

To the best of our knowledge, only two interventional studies had been conducted in Hong Kong focusing on childhood asthma management (Hui et al., 2002; Ng et al., 2008). Between 1996 and 1998, Hui et al. (2002) investigated the effects of an outpatient, clinic-based asthma management program on the health outcomes of young children with asthma using a single group pretest-posttest design with repeated measures. In this study, 106 parents of young children with asthma received one session (two hours) of group-based, interactive asthma education (i.e., a video display summarizing the key issues of childhood asthma management), followed by a question-and-answer session (30 minutes) led by a pediatric nurse. At 12 months follow-up post-intervention, parents reported that their children had significant reductions of the utilization of health care services due to asthma exacerbations when compared with the baseline (Hui et al., 2002). In 2004, Ng et al. (2008) conducted a randomized waitlist-controlled trial to examine the effects of a psychoeducational program incorporating family therapy into asthma education on the health outcomes of parent-child dyads. A total of eleven weekly sessions were given to 46 parents and their school-aged children separately. At three months after the intervention, children had a significant improvement of their asthma symptom

control, while their parents had better psychological adjustment to their child's asthma and self-efficacy in managing asthma (Ng et al., 2008), however the utilization of health care services was not assessed.

Our study was conducted almost ten years after Ng and colleagues (2008), implying that addressing parental psychological needs could be a neglected area in childhood asthma management programs in Hong Kong. Asthma management by doctors in Hong Kong to date is currently in line with the recommendations by the Global Initiate for Asthma (GINA) guideline, which mainly focuses on providing medications, teaching the patient (and his/her caregivers) about symptom monitoring and the use of inhalers, and offering a written asthma action plan to guide the management of worsening asthma symptoms (Ko, Chan, & Chan, 2010). The positive outcomes of parental psychological well-being and childhood asthma outcomes as seen in our study send us a clear message: Asthma management programs in Hong Kong should move beyond childhood asthma control to put more efforts in psychologically supporting their parents along the caring journey.

Childhood asthma control remains unsatisfactory worldwide. Evidence from literature has indicated that parents experience substantial psychological burden in childhood asthma care. This could affect their asthma management behaviors and their children's health conditions, including poor asthma symptom control, more frequent ED (emergency department) visits and hospitalization due to asthma exacerbations. The present Ph. D study demonstrates the efficacy of a parental training program using group-based Acceptance and Commitment Therapy (ACT) combined with asthma education on the children's health outcomes and their parents' psychological health outcomes at six months following the intervention by using a two-arm randomized controlled trial (RCT) design.

In the present study, we offered a novel approach to empower parents in managing their own psychological difficulties by enhancing their psychological flexibility (PF) through four weekly sessions of group-based ACT program. Desired effects on reducing their children's asthma symptoms and ED visits due to asthma exacerbations were sustained up to six months post-intervention. The study highlights the merits of addressing parental psychological needs, leading to an eventful improvement of children's health conditions.

The rationales of using ACT for improving an individual's health outcomes are theoretically supported by the ACT model of PF, as developed by Professor Steven C. Hayes and his colleagues (1999). In the present study, the group-based ACT intervention was informed by qualitative and quantitative evidence. Qualitative evidence was based on individual interviews of a sample of 14 Hong Kong Chinese parents, highlighting that parents experience significant psychological difficulties along the child's illness trajectory. These psychological difficulties could be feelings

of uncertainty, fear of asthma crises, guilt and self-doubt at the perceived incapacity to safeguard their child's health. Quantitative evidence was derived from: (1) Cochrane systematic reviews which showed the limited effects of interventions to address parental psychological needs, (2) systematic reviews that highlighted the efficacy of ACT in health care context, as well as (3) a systematic review of ACTrelated studies in parents and children with chronic diseases as reported in this thesis. This review identified the promising results of ACT on the parental psychological health and child's health outcomes across a range of chronic diseases, including chronic pain, cancers, congenital heart diseases, anorexia nervosa, and anxiety disorders. However, only eight studies, of which the majority were quasiexperimental studies, could be found, which makes clear the limited research of ACT in pediatric care. Further, no studies examined the effects of ACT in the context of childhood asthma.

Prior to the commencement of the RCT, a pilot study was conducted to test the feasibility and potential efficacy of group-based ACT training program on 11 Hong Kong Chinese parents of children with asthma. The program was found to be acceptable among parents, with a medium within-group effect size in reducing parental psychological inflexibility. The strategies of subject recruitment and data collection methods were also found to be feasible for implementation in the RCT. Furthermore, a structural equation model analysis was conducted by using the data collected from a cross-sectional survey involving all the parents who were eligible to participate in the RCT. This model found that when considering other parental psychological factors, including psychological adjustment to their child's illness and psychological symptoms (anxiety, depression, and stress), parental PF is the only latent construct possessing a significant association with the child's asthma

morbidity. Altogether, these preliminary analyses imply the significant role of parental PF on child's health outcomes and the potential efficacy of ACT in parents of children with asthma.

After a series of groundwork, a two-arm RCT was conducted. Parents and their children aged 3-12 years were consecutively recruited in a public hospital in Hong Kong from January to May 2016. The parents were randomly assigned either to four weekly, face-to-face sessions of a training program using group-based ACT combined with asthma education, or to one session of asthma education talk as usual care plus three weekly telephone follow-up calls for evaluating child's asthma symptoms.

The goal of ACT in the present study was to enhance the PF of the parents in caring for a child with asthma in the following ways: (1) to be aware of the thoughts and feelings of the present moment, (2) to accept and adapt flexibly to challenging situations, and (3) to take actions to achieve valued goals in childhood asthma management. Six ACT therapeutic processes were applied interchangeably, which were contacting with the present moment, defusion, acceptance, self-as-context, values and committed action, throughout the four ACT sessions. Example activities included: (1) mindfulness exercises to guide parents to observe their painful thoughts and feelings that they were attempting to avoid when managing childhood asthma attacks; (2) experiential exercises, such the Tug-of-War with a Monster metaphor, to let parents realize the paradoxical effects of controlling difficult thoughts and feelings by asking them to keep on pulling on the rope, often exacerbate the problem, and contribute to avoidance behaviors that affect their childhood asthma management. In addition, we facilitated parents to contact with their values by using mindfulness exercises, which guided them to experientially contact what matters

most as a parent. Further, we invited parents to check whether their current childhood asthma management strategies or behaviors were moving towards or away from their own parental values. We finally assisted parents to establish action plans for improving their child's asthma-related health and well-being that were linked to their values. By the end of each ACT session, parents received asthma education in which the content was identical as those who attended the asthma education talk in the Control group, they also received a handout of ACT and asthma educational materials.

The ACT intervention was delivered according to an ACT-based intervention protocol that was designed to fit into the context of parents in childhood asthma care. The interventionist was the research investigator (Ms. Yuen-yu Chong, Ph. D Candidate), who is a registered nurse in Hong Kong and had received introductory and intermediate skills building in ACT, as well as weekly supervisions by a psychologist who is expertise in acceptance- and mindfulness-based interventions throughout the study period. To monitor the quality of the ACT intervention, all the ACT sessions were videotaped and reviewed together with an experienced ACT researcher during weekly meetings for debriefing and skills supervision. The fidelity of the intervention was assessed by the research investigator using a standardized behavioral checklist.

The primary outcome of this RCT was the frequency of visits to emergency departments (EDs) due to asthma exacerbations in children over a six-month followup period, measured at six months post-intervention. The secondary outcomes concerned the asthma-related health conditions in children, including unscheduled health care service visits due to asthma exacerbations and the asthma symptoms of children, as well as the PF, psychological adjustment to the child's asthma,

psychological symptoms (symptoms of anxiety, depression and stress), asthma knowledge, asthma management self-efficacy, and quality of life of their parents. Both children with asthma and their parents were followed-up and assessed till at six months post-intervention. All the outcomes were assessed by parental reports in the self-administered questionnaires and the data collectors were blinded to the group assignments. Changes in the aforementioned outcomes between groups over time were analyzed using generalized estimating equations, adjusted with parental sociodemographics, child's demographics, corticosteroid use and season of enrollment, and in accordance with the intention-to-treat principle.

A total of 168 parents, who were mainly mothers, and their young children with asthma participated in this RCT. At six months post-intervention, children whose parents were trained with ACT had significantly fewer ED visits and private practitioner's clinics due to asthma exacerbations over the six-month follow-up period than those whose parents received asthma education only. These children also exhibited fewer daytime asthma symptoms and nocturnal asthma symptoms, experienced fewer days with activity limitations due to asthma symptoms and required to use inhaled bronchodilators less frequently to control their asthma symptoms. Likewise, at six months post-intervention, the parents who were trained with ACT became more psychologically flexible, reported with less negative emotional experiences such as guilt and worry, sorrow and anger, less anxiety and stress symptoms and attained a better quality of life at six months post-intervention when compared with those who attended an asthma educational talk only. Yet, the intervention effects in favor of ACT could not be held for some child's health outcomes, including the general outpatient clinic visits, hospital admissions and the length of hospital stay due to asthma exacerbations. No significant effects were also

found in the parental asthma knowledge and the parental self-efficacy in preventing asthma exacerbations.

In overall, the results of this RCT provide strong empirical evidence that ACT could be one of the viable strategies for helping parents to manage their psychological difficulties aroused when taking care of their children with asthma, as well as improving childhood asthma control. The ACT intervention was delivered by a trained nurse, via a group-based approach and in brief sessions (i.e., four weekly sessions, each session lasted for two hours), while the positive health outcomes of parent-child dyads could be maintained up to six months after intervention In addition, on average, the parents received 3.8 out of 4 assigned sessions, very low attrition (6/168 = 3.6%) was noted. To summarize, these favorable findings reflect the acceptability of the ACT in parents of children with asthma and the potential dissemination of ACT in clinical settings with low resource implications.

This RCT addresses several gaps of knowledge in literature regarding: (1) the lack of effective interventions targeting at the management of parental psychological difficulties in childhood asthma care, for an ultimate purpose of improving child health outcomes; (2) the lack of studies using a methodologically rigorous design, a RCT, to investigate the efficacy of ACT being delivered to parents on the health outcomes of both parents and their young children, and (3) the flexibility of delivering ACT by using a relatively brief intervention (four weekly sessions) via a trained health care professional. Perhaps, this RCT is one of the first studies demonstrating that delivering ACT to parents could bring health benefits to their children with asthma. The psychological well-being of parents could also be improved. Further, the findings of this RCT raise the importance of incorporating an assessment of parental psychological difficulties in routine asthma care, which may

help to identify those parents the most in need for a psychological intervention like ACT. Future studies may explore the potential mechanism of change processes, the experience of parents in participating in a training program using an ACT approach, as well as the feasibility and potential efficacy of ACT in parents of children suffering from other chronic diseases, such as cancers, inflammatory bowel disorders or type 1 diabetes. We strongly recommend that for the future development of childhood asthma management programs in Hong Kong, addressing parental psychological needs should be taken into consideration.

In conclusion, the present study demonstrates that integrating Acceptance and Commitment Therapy (ACT) into parental asthma education is effective at improving the asthma conditions of children and the psychological well-being of their parents. By facilitating parents to develop an openness to adversity along the child's illness trajectory and a consistent commitment of what they truly value, their own well-being, their children's health conditions and well-being may be eventually improved.

# Appendices

# Appendix 3.1. Key contents of asthma education to parents

*Note.* Appendix 3.1 presents the educational information for childhood asthma management delivered to all the parents participated in the study. Specifically, the parents in the Control group received the information in one session of asthma education talk, while the parents in the ACT group received them separately as four sessions listed as follows:

# ACT Session 1

- (1) Prevalence of asthma in children in Hong Kong
- (2) Basic etiology of asthma
- (3) Types of triggers of asthma

# ACT Session 2

- (1) Asthma signs and symptoms
- (2) Strategies for monitoring asthma symptoms
- (3) Correct skills of using peak flow meters
- (4) Allergen avoidance

# ACT Session 3

- (1) Types of asthma medications
- (2) Corrects skills in using aero chambers
- (3) Aftercare of using aero-chambers

# ACT Session 4

- (1) Management of asthma attacks
- (2) Use of an asthma action plan

The content of the asthma education mapped to an international asthma management guideline named as "Global Strategy for Asthma Management and Prevention 2016 Update" (Global Initiative for Asthma, 2016), which was written by an international workgroup, the Global Initiative for Asthma (GINA), in collaboration with the National Heart, Lung and Blood Institute and the World Health Organization.

#### For ACT Session 1)

#### (1) Prevalence of asthma in children in Hong Kong

Asthma is a chronic inflammatory disease affecting children's airways—the small tubes that carry air in and out of lungs. Asthma can be happened in any age, but it often occurs when a child is at preschooler age. In Hong Kong, it is estimated that around 10% of children have experienced asthma symptoms, such as wheezing and chronic cough. In worldwide, the prevalence of asthma among children is increasing.

#### (2) Basic etiology of asthma

When a child is diagnosed with asthma, the airways will become very sensitive and if something irritates the airway, an asthma episode may begin suddenly, or may have a slow onset of gradual worsening of symptoms. This episode can be last for a few minutes to several days, related to a hyper-responsiveness of the airway.

During an asthma attack, there are three distinct features that are happening in a child's airway:

- Swollen: Lining around the airways becomes inflamed and swelled;
- Squeezed: The muscles around the walls of the airways are tightened and the airways become narrower
- Increased mucus secretion: the airways make more mucus

All these three reactions cause the airways to become narrower and irritated - making it difficult to breath and leading to symptoms of asthma.

#### (3) Types of triggers of asthma

Recent research has shown that family history of asthma, smoking history of parents and the child's history of allergic rhinitis or eczema may cause asthma. However, it can be difficult to identify exactly what triggers your child's asthma. Nevertheless, the link could be obvious, and it quite depends on your observation when you are getting along with your child. For example, when your child's symptoms start within minutes of coming into contact with tobacco smoke, then probably it is one of the source of asthma triggers. If you wish to confirm your child's allergy, he/she may need an allergy test.

The following are the common triggers among children that might result with asthma:

- Tobacco smoke, including first handed, seconded and third handed smoke. This
  is the most common asthma triggers in Hong Kong.
- House mites. Research evidence found that the relationship of asthma symptoms
  occurrence and exposure to house mites is the strongest. In fact, many people
  with asthma are sensitive to the droppings of house-dust mites. These are tiny
  creatures that live in the dust that builds up around the house, in bedding, soft
  furnishings and soft toys. They live and multiply easily in warm, humid places.
  In particular, asthma symptoms in some children could become particularly
  obvious during spring due to the warm and damp weather.
- Mold and fungi are also common in Hong Kong, in particular if your house is near the seashore. In spring time, the humid weather allows mold and fungi to

### **APPENDICES**

- grow quickly too.
- Outdoor pollutants.
- Indoor chemicals, such as paint or perfume.
- Pet dander and cockroaches
- Food, such as eggs, peanuts, shellfish and cow's milk.
- Viral infection. In Hong Kong, viral-induced wheezing is another common trigger of asthma, in particular if your child age is 5 years old or below. This wheeze could be named as preschool wheeze and it is induced by viral infection. Since viral-induced wheeze and asthma have very similar signs and symptoms, it is difficult for doctors to confirm whether your child diagnosed with asthma at age 5 or below. Furthermore, wheeze and asthma attack, very often, will be triggered if your child is exposed to a certain allergen in combination with viral infection.
- Exercise-induced asthma. During physical exercise, your child will breathe faster, deeper and more through his/her mouth. It is a very common body response in particular your child in young age. That means the air that enters our lungs is colder and drier than usual. When your child has asthma, the membranes lining over the airways would be very sensitive, tend to react very strongly and even restricted. Exercise-induced asthma attacks usually start about five to ten minutes after the physical activity is stopped. Hence, doctors and nurses advise your child to take medication (that is the inhal ed bronchodilators) 10 to 15 minutes before exercise.

### (For ACT Session 2)

#### (1) Asthma signs and symptoms

For children, the signs and symptoms of asthma are easily mixed up with respiratory symptoms, such as acute bronchitis, both have cough and wheeze. There are still some distinguished features of asthma symptoms:

- More than one type of symptoms (tight chest, cough, wheeze). Wheezing sound can be heard over the child's chest. If wheeze is present, that means asthma is still in active stage. However, if you cannot hear the wheezing sound but you found that your child has difficulty in breathing, lips and fingers become blue, probably asthma is getting more severe and your child requires emergency service at once.
- Symptoms are often getting worse at night or in the early morning, your child may have difficulty to sleep well. Thus, your child, in particular the younger ones, may easily get irritated and cried with reasons unknown. For children in schooldays, they usually have difficulty to concentrate, they also feel tired easily.
- Symptoms occur variably over time and vary in intensity.
- Symptoms are triggered by viral infections (colds), exercise, allergen exposure, changes in weather, laughter, or irritants such as car exhaust fumes, smoke or strong smells
- For young children (at birth till 3 to 4 years old), there will be sign of in-sucking chest, flaring nostril.
- · Increase frequency of reliever medication use; drop in peak flow meter reading
- Behavioral change (e.g., anxiety, irritability)

#### (2) Strategies for monitoring asthma symptoms

Parents can make use of asthma diary and peak flow meter for monitoring their child's asthma symptoms:

#### Asthma diary

Asthma diary is a calendar to record your child's asthma symptoms. This helps you and your doctor see the patterns in your child's asthma symptoms (e.g., any flare-ups in a particular period), to help your child's doctor adjust your child's asthma medicine and to gain better control of asthma symptoms. It is advisable to keep recording child's asthma symptoms as a routine, so that the health care professionals can check how well your child' asthma is under control, or changes over the seasons. Each day, you can record the following information in your child's asthma diary:

- Your child's peak flow readings, if appropriate for your child's age (e.g., age six or above) and your child can grasp the techniques of using the inhalers
- Your child's asthma symptoms, if any (e.g., chronic cough, wheezes, disturbed sleeps due to asthma symptoms)
- How many doses of reliever medicine your child takes (e.g., number of inhaler puffs received per day)
- Any activities or exposure to things that may have triggered asthma symptoms (e.g., physical exercises during school days)
- Any activities that have been affected by asthma, such as doctor's appointments, missed school days or hospitalization

We strong recommended parents to bring along with their child's asthma diary to each clinic visit. This is very helpful for the doctors to revise the progress of your child's asthma symptom control and adjust the medication accordingly.

#### Peak flow meter

Peak flow meter is a handheld device that measures how well air is entering into your child's lungs. It is a device applicable for children aged 6 or above. Measuring peak flow regularly can help you to:

- Tell if your child is having difficulty with their asthma
- See if your child's medicines are working well
- See if your child is getting better after an asthma episode

Peak flow is predicted based on average readings for your child's height. In normal circumstances, the predicted value of peak flow increases as your child grows. It is recommended that, at least two weeks of monitoring asthma symptoms via peal flow meter is required to see the response to asthma treatment. If there is excessive variation on the peak flow monitoring throughout weeks, your child's asthma is still not yet well-controlled.

## (3) Correct skills of using peak flow meters

- Here are the steps of using peak flow meters:
- 1. Attach the mouthpiece to the peak flow meter if there is one.
- 2. Put the marker at the bottom of the scale.

### **APPENDICES**

- 1. Hold the peak flow meter upright.
- 2. Do not block the opening with your fingers.
- 3. Ask your child to stand up and breathe in as deeply as he/she can.
- 4. Your child should put the mouthpiece into his mouth and close his lips tightly around the mouthpiece (not biting the mouthpiece)
- Ask your child to blow out as hard and as fast as he/she can. The marker will shift up the scale to the number that is the peak flow measurement.
- 6. Write down the measurement. Put the marker back down to the bottom of the scale.
- 7. Repeat steps 2 to 8 for two more times.
- In your child's asthma diary, write down the date, the time, and the highest reading out of the 3 measurements.

If your child's meter has a separate mouthpiece, you should clean it once a week. Wash it with warm water and let it air dry thoroughly.

#### (4) Allergen avoidance

Identifying and avoiding the allergen causing asthma symptoms is a vital part of childhood asthma management. Once the causes are correctly identified, the following practical advice on avoiding or minimizing the exposure to allergens should help. If the allergen is difficult to be identified, the doctor will consider your child's medical history together with the results of your child's allergy tests (e.g., skin prick test) in order to give you advice for allergen avoidance measures that you have to consider.

#### Tobacco smoke

Secondhand smoke, as well as "Third-hand Smoke" (the chemical residual of tobacco smoke contamination that clings to clothing, wall, furniture and any other materials after the cigarette is extinguished) and the key allergens to trigger asthma. Tobacco toxins can stick on the surface of objects for weeks and even months after nicotine vapor has been absorbed. Ventilating a room by using fans or opening windows would not help to reduce the third-hand smoke. More importantly, there is no safe level of exposure to tobacco smoke. We strongly advise parents of children with asthma to quit smoking and to establish a complete smoke-free environment.

#### House dust mites

House dust mites are microscopic creatures which live off dead skin cells found in house dust, they are very difficult to remove completely from the home since they move down into the lower parts of carpets and cling onto material fibers. Typical cleaning methods cannot remove all house dust mites, and allergy symptoms are actually caused by the mites' digestive enzyme mainly found in its excreta. Hence, we recommend the following advice:

- Damp dust hard surfaces (including mop flooring) weekly.
- Vacuum floor weekly but be aware that vacuuming increases the amount of house dust mite allergen in the air. So, if possible, ask someone else to do the vacuuming and wait for 2 hours before re-entering the room.
- Cover mattresses, pillows and quilts with dust mite resistant covers. Wash bedding and pillow cases at least weekly, in hot water (more than 60°C). This will kill dust mites and wash away the allergen they produce.

- Consider replacing carpets with hard floors, such as wood and tiles, where
  practical and financially affordable. Carpets can contain large amounts of house
  dust mite and animal allergens which cannot be removed completely by
  vacuuming.
- Avoid excessive humidity in the home. Use a dehumidifier or air conditioner in the summer to keep relative humidity below 50%.
- De-clutter: remove books, mobiles, toys from bedroom. Keep storage closets closed and containers.

#### Mold

Molds commonly form in the rooms where moisture is created, such as the bathroom and kitchen. It is also very common if your living area is near to the seashore. Like the house dust mite allergy, mold allergy may cause symptoms such as breathing problems, a constantly runny nose and sneezing. These rhinitis symptoms can lead to more serious health problems such as asthma. For cleansing, we recommend the following:

- Removing visible mold by cleaning with bleach
- Ensuring adequate ventilation in your home to keep the room humidity less than 50%, in particular the bathroom areas
- Removing indoor pot plants (which promote mold growth)
- Drying or removing wet carpets

#### (For ACT Session 3)

#### (1) Types of asthm a medications

Medications that used for controlling asthma are often in inhaled format. There are two main types of asthma medicines: controllers and relievers. Your child may need to take both types of medicine at different times.

Reliever medicines are used for quick relief during an asthma episode or when your child is having asthma symptoms. In medical terms, we called them as short-term acting bronchodilators. They are also called as "blue inhalers" containing Albuterol (Ventolin). They act quickly to loosen the airways, to relieve wheezing and coughing, and to help your child to breathe. However, if your child is having a severe asthma episode, she may need to another type of asthma medicine named as corticosteroid (a white rounded shape pill) in oral format.

Controller medicines are used over the long term to help control the chronic inflammation and tightening of your child's airways. In medical terms, we called them as steroid, they are also called as "brown inhalers" containing Becotide/ beclomethasone. Your child will usually take a controller medicine every day, even if he/she is feeling well. Very often your child may need to use these medications for several months before they gain the maximum benefit. Controllers are usually inhalers containing corticosteroids in a very low dose without serious side effects. When side effects occur, they generally include mouth and/or throat irritation and oral yeast infections. It is highly recommended that when your child is using inhaled corticosteroids, please use an aero-chamber and rinse the mouth with water after each use to reduce the amount of drug that can be swallowed and absorbed into your child's body. Aero-chambers assist with taking asthma medication that are manufactured as inhalers. They are usually plastic, or polycarbonate and cylinder shaped; at one end, an inhaler is inserted, and the other end goes in your child's mouth. An aero-chamber helps your child to take medication by reducing the amount of medicine (i.e., medication powder) to be absorbed by your child's mouth and allowing more to go down into the bronchi of the lungs.

If your child is now using inhalers as asthma treatment, it is highly recommended that young children especially aged 6 or below need to use the inhalers with an aerochamber and a mask, while for those aged 6 or above, they can use their inhalers with aero-chambers only. For a face mask is used, it must be fitted tightly around the child's mouth and nose, otherwise the amount of drug inhaled is reduced. The majority of children has difficulty in coordinating the start of their breath in with pressing the puffs, thus using inhalers via an aero-chamber with a mask, will bring the most beneficial effect of medications to your child.

We strongly recommend that parents need to adhere to the medication regimen of using inhaled corticosteroids as suggested by the physician, but not to adjust by their own. Different from reliever medicines, the effect of improving your child's asthma symptoms cannot be readily seen until your child achieve full adherence of inhaled corticosteroids as prescribed for months.

Another important point is to check whether the medication is expired or not. You may have some stocks of Ventolin at home as distributed during the last regular clinic visit. Hence, when you need to use Ventolin immediately for your child, you can ensure that the medication could maximize its therapeutic effect.

#### (2) Corrects skills in using aero chambers

For young children, it is highly recommended that an aero-chamber and a mask are recommended to be used together with the inhaler. The following are the steps required:

- Remove the caps from the inhaler and aero-chamber chamber (add aerochamber device if needed).
- 2. Shake the canister well.
- 3. Insert the inhaler into the back end of the aero-chamber chamber.
- If there is an aero-chamber device such as a mask, place it over your child's nose and mouth, making sure there is a good seal.
- Press down firmly on the canister to release one puff of the medication into the aero-chamber chamber.
- 6. Hold the mask firmly in place while your child takes at least ten breaths.
- Repeat steps 2 through 6 for each puff of medication ordered.
- 8. When treatment is complete, remove the inhaler from the space chamber.
- If using this device with an inhaler that contains a steroid (i.e. controller), rinse your child's mouth with water.

#### (3) Aftercare of using aero-chambers

The following is the list of steps on cleaning the aero-chambers:

### **APPENDICES**

- Remove the MDI (metered dose inhaler) adapter at the back of the aero-chamber and the facial mask.
- Put all the parts (facial mask with aero-chamber, MDI adapter) into a basin of warm water and add 1-2 drops of dish washing detergent, then soak for 15 minutes (*Note*. Do not rinse, brush or rub the aero-chamber)
- Take all the parts of aero-chambers and lightly shake away excess soapy water droplets.
- Place on a clean surface to air dry. (Note. Do not dry or rub the inside of aerochamber with a cloth or tissue paper)
- 5. Caution must be taken to avoid damaging the one-way diaphragm valve
- 6. Ensure to clean the aero-chamber monthly or when necessary.

Static electricity accumulates on many polycarbonate and plastic aero-chambers, attracting drug particles. Hence, if we clean the aero-chamber simply by rubbing/ rinsing, the aero-chamber could be charged, and the drug delivered would be less as expected. A simple way of reducing any charge on an aero-chamber is to soak it with detergent and leave it until dry.

#### (For ACT Session 4)

#### (1) Management of asthma attacks

The following are the signs and symptoms of worsening asthma signs and symptoms:

- Increased in cough, wheeze, pressing chest, shortness of breath, in-sucking chest, your child is getting anxious and irritated easily
- · Disrupted sleeps due to cough, wheeze, shortness of breath and pressing chest
- Cough, wheeze, shortness of breath and pressing chest results in intolerance to
  physical exercise
- Personal peak flow meter is less than 80% of the personal best predicted value
- Increasing the use of short-acting bronchodilator in which its effect cannot be sustained over 4 hours. It is highly recommended to seek doctor's advice for treatment, if you found your child needs the reliever medication more than three times or above per week

Home treatment steps to stop an asthma attack generally include taking Albuterol (Ventolin) with 2 consecutive puffs in every 15 minutes for 30 minutes (i.e., a total of 4 puffs in 30 minutes). If the situation gets worse, please call for emergency service. If you use a peak flow meter to monitor your child's asthma, peak expiratory flow readings ranging from 50 to 79 percent of the personal best are a sign that you need to use salbuterol inhaler medication for rescue. Routinely checking your child's peak flow is recommended because your child's lung function may decrease before you notice any other signs or symptoms of worsening asthma.

#### (2) Use of an asthma action plan

Personal written asthma action plans show parents of children diagnosed with asthma in how to make short-term changes to their prescribed treatment in response to changes in their symptoms and/or peak expiratory flow. They also describe how and when to access medical care.

Asthma action plan usually includes both a step up in inhaled corticosteroids, the addition of oral corticosteroids (if required), and for peak expiratory flow-based plan, when their child (in particular aged 6 or above) is based on personal best peak flow meter reading. The goal of an asthma action plan is to reduce or to prevent flare-ups and emergency department visits through day-to-day management. Having a written step-by-step plan in place provides clear instructions so you and your child can:

- identify early symptoms of a flare-up and treat them to prevent the flare-up from getting worse to become a life-threatening asthma attack
- know how to manage an asthma attack
- know when to seek emergency care

Asthma action plans should be updated regularly by your child's doctor in conjunction with an asthma review during regular clinic visits in every three to six months. For those children with more severe asthma such as a recent history of hospitalization within 1 year, more frequent reviews might be needed.

There are altogether three colored zone of asthma action plan:

#### The Green Zone

This is a safe zone for your child. You'll know he/she's in the green zone when he/she:

- Is breathing easy
- Isn't coughing or wheezing
- Can do his/her regular activities (e.g., playing without wheeze)
- Sleeps throughout the night
- Uses short-acting bronchodilator less than three times per week
- 80% or above of the personal best peak flow

If you can say "yes" to at least four of the above items, your child is doing well and please keep up his/her medication especially the controllers. Please make sure you follow the instructions for the dose and when to take it.

#### The Yellow Zone

You can think of this category as a warning sign that you need to take caution. You'll know your child belongs there when he/she:

- Coughs and wheezes
- Has some trouble in breathing properly
- Feels fatigue after physical exercise (e.g., your child's presentation is abnormal when compared with normal days)
- Has a tight feeling in his/her chest
- · Has disturbed sleep due to the difficulty in breathing
- Use short-acting bronchodilator more than three times per week

If he/she has some or all of those, parents should check whether the child is on regular treatment (e.g., inhaled corticosteroids). If not, we advise the child to see the doctor for a consultation within 24 hours.

### The Red Zone

This zone means danger. Use Ventolin and call for emergency service (999) if your child presents with the following signs and symptoms:

- Has trouble in breathing: hard and fast.
- Has his/her nostrils widely opened for breathing
- Has difficult to speak/ in-sucking chest
- Is un conscious

## Appendix 3.2. Baseline Questionnaire (Chinese Version and English Version)







### 家長心理靈活程度及護理兒童哮喘認識

#### 基線評估

親愛的家長:

誠邀閣下參加由香港理工大學護理學院麥艷華博士負責監督,香港理工大學護理學院 博士研究生及註冊護士莊婉瑜女士負責執行,聯同屯門醫院兒童及青少年科副部門主 管林樹仁醫生及其團隊合作的上述項目。

我們現藉着問卷了解家長對兒童哮喘的認識和心理靈活程度,所得資料將有助我們將 來制定適切的護理本港兒童哮喘計劃。參加這項評估與否,純屬自願。你可以選擇不 參加,參加與否將不會影響閣下及 貴子女所獲取的標準醫療及護理,所有參加者的資 料是絶對保密,參加者的個人身份,絕對不會在任何研究報告或其他相關文件發表。

### 完成問卷後,請將問卷交回\_\_\_號房內核對。

如對計劃有其他查詢,請與計劃研究負責人:

香港理工大學護理學院博士研究生 莊婉瑜 (電話:2766-6384),或 香港理工大學護理學院助理教授麥艷華博士 (電話:2766-6421)聯絡。

謝謝閣下的參與。

屯門醫院兒童及青少年科 副部門主管 林樹仁醫生 香港理工大學護理學院助理教授 麥艷華博士 屯門醫院兒童及青少年科資深護師 深瑞平女士 香港理工大學護理學院博士研究生及註冊護士 莊婉瑜女士 香港理工大學護理學院 袁楨德教授

謹啟

	For office use only
Next FU	
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Remark	

ACT\_asthma\_baseline

	THE HONG KONG POLYTECHNIC UNIVERSITY 香港理工大學	Rided of Participant		B 醫院 HOSPITAL
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	AI 孩	子性別: 🏼	男 □²女	
	A2孩	子年齡:	歲	
	A3你的孩子第一次經醫生診斷為「哮喘」是	多少歲?	歲	
	44 上次哮喘發	作日期 :	年月	
B1	在過往十四日內 (兩星期內),有多少日出現持	寺續咳嗽、靠	低喘、或呼吸困難的情況?	日間:日 BI-1 夜晚:晚 BI-2
B2	在過往三十日內(一個月內),你的孩子有多行在 但 <u>間</u> 出現持續咳嗽、氣喘、或呼吸困難的情況?	常在出現以一	下情况?	平均每星期日
В3	在 <u>晚上</u> 因為持續咳嗽、氣喘、或呼吸困難而醒來?			平均每星期晚
B4	<b>因為出現</b> 持續咳嗽、氣喘、或呼吸困難的情況,而用	目喘樂寧 (Ve	ntolin®,藍色噴霧劑)?	平均每星期次
В5	在 <b>玩耍、運動時曾出現</b> 持續咳嗽、氣喘、或呼吸困難	准的情况?		平均每星期日
B6	有多常哮喘病發?			平均每星期日 B6-1 或每月一次 B6-2
B7	<b>過往的六個月內(半年內)</b> ,你的孩子有沒有 公立普通科門診	<b>5哮喘病</b> ● <sup>®</sup> 没有	而使用以下醫療服務?	□有,一共次
B8	私家診所、私家兒科專科門診	□⁰沒有		□有,一共次
В9	急症室	□⁰沒有		□有,一共次
B10	公立、私家醫院留醫	□⁰沒有	住院日期:年月 BIO 住院日期:年月 BIO 如有其他,請記	-1 留院日數: 日 B10-2
B11	接受其他治療 (例如中醫)	□⁰沒有	請註明	□有,一共次 :B11-1
B12	過往的六個月內(半年內),你的孩子有沒有 因哮喘病發而缺課?	□⁰沒有		□有,一共日

	THE HONG KONG POLYTECHNIC UNIVERSITY 香港理工大學第二部分:用藥	、哮喘日常	>		UEN MUN H	B 醫院 HOSPITAL
	請	於適當方格四	为填上√號			
C1	你的孩子 <b>於一年內</b> 有沒有服用過口服	類固醇?			1 從來沒有	<b>□</b> <sup>2</sup> 有
C2a C2b C2c C2d C2d	舒悅泰 (Seretide <sup>®</sup> ,紫色吸入器) 善古靈 (Singular <sup>®</sup> ,青蛙仔) 輔舒酮 (Flixotide <sup>®</sup> ,橙色吸入器)	啡色、紅色	噴霧劑)		] <sup>1</sup> 沒有 ] <sup>1</sup> 沒有 ] <sup>1</sup> 沒有 ] <sup>1</sup> 沒有 ] <sup>1</sup> 沒有	□ <sup>2</sup> 有 □ <sup>2</sup> 有 □ <sup>2</sup> 有 □ <sup>2</sup> 有
D1 D2	你有沒有哮喘病歷? 孩子的其他家人有沒有哮喘病歷?	□ <sup>1</sup> 沒有 □ <sup>1</sup> 沒有		□²有 □²有,	請註明關係 D2	
	以下是各種 <u>日常哮喘護理的事項</u> 。 在每一項中,請選出那位家庭成員為孩子 <u>最</u>	主要照顧者		項)		者(請註明的關係)
D3a D3b D3c D3d D3e	檢查和補充藥物 監測哮喘症狀 家居清潔 通知校方有關孩子患有哮喘 陪同看醫生	孩子 □ <sup>1</sup> □ <sup>1</sup> □ <sup>1</sup>	父親 □ <sup>2</sup> □ <sup>2</sup> □ <sup>2</sup> □ <sup>2</sup>	母親 □³ □³ □³ □³	□ <sup>4</sup> □ <sup>4</sup> □ <sup>4</sup>	D3-1
E1	請問你現在有沒有吸煙? □ <sup>1</sup> 有,每日吸煙(即每日起碼1枝,每星期至 □ <sup>2</sup> 有,間中吸煙(有時全日不吸煙,即每星 □ <sup>3</sup> 沒有,已經完全戒煙。我戒了*年 □ <sup>4</sup> 我從來沒有吸煙	期吸少過7		<b>·</b> 適用者	DEI-1	
E2	E2 請問你的配偶現在的吸煙習慣怎樣? □'有,每日吸煙(即每日起碼1枝,每星期至少7枝) □'有,間中吸煙(有時全日不吸煙,即每星期吸少過7枝) □'沒有,已經完全戒煙。戒了*年/月/日(** 請删去不適用者) E2-1 □'從來沒有吸煙					
E3	在與(孩子)同住的人中,除了父母外,有沒有 □'沒有 □'有,一共人 E-1	与其他吸煙者	者?			
E4	以下那一句句子最能表達你家中是否採納「 □ <sup>1</sup> 任何人都不可以在家中吸煙 □ <sup>2</sup> 在家中,某些地方或某些時間下,例如: □ <sup>3</sup> 在家中,任何地方,任何時間或任何情況	有探訪者们	[客,是容]	許吸煙的		
	ACT asthma baseline					Page 3

	THE HONG KONG       电 門 醫         POLYTECHNIC UNIVERSITY       正 門 醫         香港理工大學       第三部分: 關於您對兒童哮喘的認識	B 院 PITAL	
	請於適當方格內填上√號		
F1	是非題	是1	否』
F1 F2	咳嗽不是哮喘的症状。		
F2 F3			
F3	在家裡吸煙可以使孩子的哮喘惡化。		
F4	當吸入了油漆,汽油,煙霧或污染物後,哮喘都可能發生。		
	醫生只能做到以防哮喘發作。		
F6 F7	當孩子開始哮喘發作時,你可能會注意到胸口有壓迫感,然後有喘鳴。		
F7	最高流速計(吹氣測試)是用來確保你孩子的鼻竇暢通。		
F8	如果哮喘症狀,如胸悶和喘鳴不在這數年間發生了,那麼孩子的哮喘已痊癒了。		
F9 F10	哮喘是一種情緒或心理病。		
	大多數哮喘兒童發作時一定要到醫院。		
F11	對一些人來說,當他們長大後,哮喘會變得沒有那麼嚴重。		
F12	醫生真的不確實知道為什麼有些人患有哮喘,但他們知道有什麼可以引致病發。		
F13	若給予適當治療,大多數哮喘兒童都能過正常生活,而且活動沒有任何限制。		
F14	憤怒、哭、或笑可以引起哮喘發作。		
F15	如果你四十歲時都沒有哮喘,你永遠都不會患上。		
F16	哮喘兒童不宜做運動,因為他們要跑很多。		
F17	在年幼的孩子,哮喘有時會因病毒性呼吸道疾病引起。		
F18	致敏原是哮喘病人缺乏的一種抗體。		
F19	如果沒有注意到在孩子的呼吸變化,哮喘有可能會變差。		
F20	在寒冷的天氣運動,可以引起哮喘發作。		
F21	魚和鳥類都適宜給予哮喘兒童飼養。		
F22	即時氣管舒緩藥物 (喘樂寧 ,Ventolin® ,藍色噴霧劑)是幫助肺部消炎。		
F23	有些哮喘藥物,除非你孩子每天都用,否則是不會發揮作用。		
F24	在使用大部份哮喘藥物前,都不需要搖動吸入器。		
F25	相比 10 年前,越來越少人患有哮喘。		







### 第四部分:哮喘病童照顧者生活質素

### 我們希望利用這份問卷來了解你在**過去一星期**的狀況。

我們想知道你孩子的哮喘如何妨礙你的日常活動,以及對此你的感受。 請回答每題問題,並圈選適當的數字,每題只可圈選一個數字。

我們	希望知道你在過去一星期的經歷:	不停有	大多時	經常	有時	間中	幾乎沒有	完全沒有
Gl	當孩子咳嗽、喘鳴或呼吸困難時,你有多經常感到無助或驚慌?	1	2	3	4	5	6	7
G2	你的家庭有多經常因你孩子的哮喘而需要更改活動計劃?	1	2	3	4	5	6	7
G3	當孩子因哮喘變得煩躁時,你有多經常因而感到有挫敗感或不耐煩?	1	2	3	4	5	6	7
G4	你有多經常因孩子的哮喘而妨礙你的工作或家務?	1	2	3	4	5	6	7
G5	你有多經常因孩子的咳嗽、喘鳴或呼吸困難而感到不安 ?	1	2	3	4	5	6	7
G6	你有多經常因孩子的哮喘而不能入睡?	1	2	3	4	5	6	7
G7	當孩子的哮喘影響了家庭關係時,你有多經常因而感到困擾?	1	2	3	4	5	6	7
G8	你有多經常因孩子的哮喘而在晚間醒來?	1	2	3	4	5	6	7
G9	你有多經常因孩子患上哮喘而感到憂愁?	1	2	3	4	5	6	7
我們	希望知道你在過去一星期有多擔心:	極擔心	十分擔心	幾擔心	有些擔心	少許擔心	幾乎不擔心	不擔心
G10	你對你孩子日常活動的表現有多擔心?	1	2	3	4	5	6	7
G11	你對你孩子所服用的哮喘藥物及其副作用有多擔心?	1	2	3	4	5	6	7
G12	你有多擔心自己會過分保護孩子?	1	2	3	4	5	6	7
G13	你對你孩子能否過正常生活有多擔心?	1	2	3	4	5	6	7

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### 第五部分:家長處理哮喘自我效能感

以下問題是關於你是如何確定你可以做一些事情來幫助你孩子的哮喘。 答案沒有對錯之分。

這不是一個測試。**請圈出一個答案最適用於你**。如不適用,請圈 "8"

H1	你有多少肯定孩子有服用藥物嗎?	不肯 定 1	少許 肯定 2	頗為 肯定 3	相當 肯定 4	完全 肯定 5
H2	你有多少肯定自己能準確使用藥物嗎?	1	2	3	4	5
H3	你有多少肯定會陪伴孩子覆診嗎?	1	2	3	4	5
H4	你有多少肯定能依據指示,協助孩子服用藥物嗎?	1	2	3	4	5
H5	你有多少肯定能為孩子避免接觸致敏原嗎?	1	2	3	4	5
H6	你有多少肯定能為孩子預防嚴重的呼吸問題嗎?	1	2	3	4	5
H7	如孩子有嚴重的呼吸問題,你有多少肯定能隨身帶備 舒緩藥物嗎((喘樂寧, Ventolin®, 藍色噴霧劑)?	1	2	3	4	5
H8	你有多少肯定你能在家控制孩子的嚴重呼吸問題,而 不用到急症室處理?	1	2	3	4	5
H9	當你的孩子出現喘鳴或咳嗽時,你有多少肯定能避免 哮喘惡化嗎?	1	2	3	4	5
H10	當孩子出現嚴重呼吸問題時,你有多少肯定能幫助孩 子保持冷靜嗎?	1	2	3	4	5
H11	當孩子出現嚴重呼吸問題時,你有多少肯定能知道使 用何種藥物嗎?	1	2	3	4	5
H12	你有多少肯定在家中能夠控制孩子的呼吸問題嗎?	1	2	3	4	5
H13	當孩子出現嚴重呼吸問題時,你有多少肯定什麼時候 送孩子到急症室嗎?	1	2	3	4	5

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### 第六部分:家長心理靈活性

以下有一系列的句子,請在右方寫上一數字,最適用描述於你。 請根據以下的尺道作出選擇。

1 從來不	適用	2 極少適用	3 很少適用	4 有時適用	5 經常適用	<b>6</b> 幾乎 總是適用	7 總是適用
11	痛苦	的經驗和記憶	讓我很難去這	過一種我覺得	有價值的生活	<u> </u>	<u></u>
12	我自	己的感覺讓我	、感到害怕。				
13	我擔	心無法控制自	1己的憂慮和關	或受。			
I4	痛苦	的記憶阻礙我	擁有充實的生	<b>主活。</b>			
15	情緒	給我的生活帶	來問題。				·
16	好像	大多數人都能	夠比我更好均	也處理自己的	生活。		
I7	憂慮	阻礙我的成功	J °				

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# 第七部分:家長照顧病童經驗

以下問題都是有關您照顧孩子患有哮喘的想法和感受。

請小心閱讀以下每一個句子,並在其右方圈上一數字最適用形容您過往一個月的想法和感受。

		從未	很少	有時	經常	總是
J1	想到假如我的孩子沒有得病會是什麼樣子時,我感覺痛苦。	0	1	2	3	4
J2	我能平靜面對生活中發生的任何情況。	0	1	2	3	4
J3	自己健康而孩子生病使我感到内疚。	0	1	2	3	4
J4	擔心孩子的未來。	0	1	2	3	4
J5	我已經準備好面對與孩子健康相關的各種困難。	0	1	2	3	4
J6	孩子患病自己或許負有一定責任的想法讓我焦慮不安。	0	1	2	3	4
<b>J</b> 7	隨時擔心情況會變得更糟。	0	1	2	3	4
<b>J</b> 8	擔心我的孩子長大後能否獨立生活。	0	1	2	3	4
J9	我後悔所做的關於孩子疾病的某些決定。	0	1	2	3	4
J10	想著會不會失去孩子。	0	1	2	3	4
J11	我知道有效處理自己的悲傷和失落的方法。	0	1	2	3	4
J12	想到孩子的疾病時我有憤怒感。	0	1	2	3	4
J13	害怕其他家人會得到這種病。	0	1	2	3	4
J14	無論發生什麼事,我相信自己能處理未來。	0	1	2	3	4
J15	我發現很難與那些不理解父母對孩子的重要性的人交流。	0	1	2	3	4
J16	孩子盡情玩耍時,我擔心她/他會受傷。	0	1	2	3	4
J17	我無法像孩子生病以前那麼開心和滿足。	0	1	2	3	4
J18	我不確定自己寄予孩子的期望和夢想能否實現。	0	1	2	3	4
J19	我羡慕那些擁有健康孩子的父母。	0	1	2	3	4
J20	擔心孩子的疾病會惡化/復發。	0	1	2	3	4
J21	看到那些每天活潑好動的健康孩子,我感到悲傷。	0	1	2	3	4
J22	我擔心若孩子不是由我去照顧,會有不好的事情發生。	0	1	2	3	4
J23	當我需要的時候我可以獲得幫助和支持。	0	1	2	3	4
J24	夜裡我會醒來察看孩子的情況。	0	1	2	3	4
J25	和孩子分開時,經常想他/她好不好。	0	1	2	3	4

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### 第八部分:情緒自評量表

填表說明:

請小心閱讀以下每一個句子,並在其右方圈上一數字,表示**過往一個星期**如何適用於你。答案並無對 錯之分。請不要花太多時間在某一句子上。

		不適用	間中適用	經常適用	常常適用
K1	我覺得很難讓自己安靜下來	0	1	2	3
K2	我感到口乾	0	1	2	3
K3	我好像不能再有任何愉快、舒暢的感覺	0	1	2	3
K4	我感到呼吸困難(例如不是做運動時也感到氣促或透不過氣來)	0	1	2	3
K5	我感到很難自動去開始工作	0	1	2	3
K6	我對事情往往作出過敏反應	0	1	2	3
K7	我感到顫抖(例如手震)	0	1	2	3
K8	我覺得自己消耗很多精神	0	1	2	3
K9	我憂慮一些令自己恐慌或出醜的場合	0	1	2	3
K10	我覺得自己對將來沒有甚麼可盼望	0	1	2	3
K11	我感到忐忑不安	0	1	2	3
K12	我感到很難放鬆自己	0	1	2	3
K13	我感到憂鬱沮喪	0	1	2	3
K14	我無法容忍任何阻礙我繼續工作的事情	0	1	2	3
K15	我感到快要恐慌了	0	1	2	3
K16	我對任何事也不能熱衷	0	1	2	3
K17	我覺得自己不怎麼配做人	0	1	2	3
K18	我發覺自己很容易被觸怒	0	1	2	3
K19	我察覺自己在沒有明顯的體力勞動時,也感到心律不正常	0	1	2	3
K20	我無緣無故地感到害怕	0	1	2	3
K21	我感到生命毫無意義	0	1	2	3

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R	THE HONG KONG POLYTECHNIC UNIVERS 香港理工大學	ⅢY 第九部分:關於您的個人 請於適當方格內填上√景			明 醫 院 NUN HOSPITAL
Ll	你與孩子的關係:				
	□└父親	□²母親	□³享	其他	L1-1
L2/ S1	你的年齡:				
L3	婚姻狀況				
	□'單身	□2已婚	□3离	惟婚/分居	□4喪偶
L4	教育程度:				
	□'從未接受過正規教育	□²小學	<b>□</b> ³ q	中學	□ 4 大專或以上
L5	每月家庭收入 (HKD\$):				
	□1 4000 以下	<b>4000-9999</b>	$\square^3 1$	0000-19999	<b>□</b> <sup>4</sup> 20000-29999
	<b>□</b> <sup>s</sup> 30000-59999	□ 60000 或以上	<b>口</b> 7約	宗合社會保障	重援助(綜援)
L6	您現在的職業:				
	□家庭主婦	□²經理/管理人員	<b>口</b> 3 裏	專業人士	□ 工藝及有關人士
	■文員	□°機械操作員	□7用	服務及銷售	□°待業
	□ 學生(全日制)	□¹⁰其地,			
L7	您現在住在的地區	請註明:	L6-1		
	□'屯門 □²元朗	□ 3天水圍	<b>口</b> 4 其	<b>共</b> 地,請註明	:L7-1
s3 你本 s4 你是	本人是否孩子的主要照顧者? 本人是否與就診兒童同住? 是否能操廣東話溝通? 售居民,並計劃留港至少六6		1	□ <sup>2</sup> 主要則 □ <sup>2</sup> □ <sup>2</sup> □ <sup>2</sup>	否 照顧者是
小朋友	友姓名:			For non p	articipants only, reasons:
家長姓聯絡電	铭:(手 話:(手	提) _(在家)		□ Well-con	class before:
方便聯 的時間		_*早上/下午/晚上 (請圈出適 _*早上/下午/晚上	[用]	Preference of	date/ time (please circle):
H 2H 3 1E	aj · (2)	***非常感謝閣下參與	***	Mon/Tue/W AM/PM	/ed/Thu/Fri/Sat/Sun

# Appendix 3.2. Baseline Questionnaire (Chinese Version and English Version)

	THE HONG KONG POLYTECHNIC UNIVERSITY 香港理工大學	Net of the second secon	ACT05 B 电門醫院 TUEN MUN HOSPITAL
	Part 1: Your i	ndex child's i	nformation
	Please tick the box 🗹	or fill in the bla	nks as appropriate
	AI YC	our child's gen	der: $\Box^1$ Male $\Box^2$ Female
	A2	2 Your child's a	age:
	A3 What was the age when your child first diagno	osed with asthi	ma? years old
	A4 Latest date	of asthma atta	ack: : yymmdd
B1	<b>During the past 14 days (2 weeks),</b> how n did your child have chronic cough, wheeze, short tightness?		
	During the past 30 days (4 weeks), how o	often did your o	child have the following conditions?
B2 B3	Had a chronic cough, wheezing, shortness of breaduring the <u>day</u> Had a chronic cough, wheezing, shortness of bread		
B4	causing night awakening during <u>night</u> Had a chronic cough, wheezing, shortness of brea	ath and chest ti	
B5	needed Ventolin (blue inhaler) to relieve asthma Had chronic cough, wheezing, shortness of breath had to slow down or discontinue during play or	h or chest tight	ness, which day(s) per week
B6	Had an asthma attack		day(s) per week
	<b>During the past 6 months</b> , how many times because of his/her asthma attacks?	did your child	d visit the following healthcare services
B7	General Outpatient Clinics (GOPCs)	$\Box^1$ No	$\Box^2$ Yes,time(s)
B8	Private practitioners' clinics	$\Box^1$ No	$\Box^2$ Yes,time(s)
B9	Emergency department(s)	$\Box^1$ No	$\Box^2$ Yes,time(s)
B10	Public and/or private hospital admission	□ <sup>1</sup> No	□ <sup>2</sup> Yes,time(s) date of hospitalization:B10-1 length of hospital stays:B10-2 (i.e., stay in hospital overnight after hospital admissions)
B11	Other alternative treatment, such as Traditional Chinese Medicine consultation	$\square^1$ No	$\square^2$ No/ Yes,time(s) Please specify:B11-1
B12	<b>During the past 6 months</b> , did you child miss school day(s) due to asthma attacks?	$\Box^1$ No	$\Box^2$ Yes, <u>day(s)</u>





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#### Part 2: Child medication history, family asthma management and smoking history

#### Please tick the box 🗹 as appropriate

Cl	Have your child had oral steroid within one year?	$\square^1$ Never	$\square^2$ Yes
	Is your child currently having the following r	nedication?	
C2a	Becotide/ Becloforte	$\square^1$ No	$\square^2$ Yes
C2b	Seretide	$\square^1$ No	$\square^2$ Yes
C2c	Singulair	$\square^1$ No	$\square^2$ Yes
C2d	Flixotide	$\square^1$ No	$\square^2$ Yes
C2e	Pulmicort	$\square^1$ No	$\square^2$ Yes
D1	Do you have history of asthma?	$\square^1$ No	$\square^2$ Yes
D2	Do your family members have history of asthma?	$\square^1$ No	$\square^2$ Yes , Please state the relationship: $\square^{2-1}$

Below are different tasks that related to asthma management for your child. For each task, please rate who takes the most of the responsibility below:

		Child	Father	Mother	please specify	D3-1
D3a	Follow the regimen and refill medication		$\square^2$			05-1
D3b	Symptom monitoring: (e.g. asthma diary)		$\square^2$	$\square^3$		
D3c	Avoid environmental triggers at home (e.g.		$\square^2$	$\square^3$	$\square^4$	
	home cleansing)					
D3d	Telling teachers about child's asthma			$\square^3$	$\square^4$	
D3e	Visiting the doctor		$\square^2$		$\square^4$	

E1 Are you a smoker?

 $\square^1$  I am a current smoker. (at least one cigarette per day/ 7 per a week)

 $\square^2$  I smoke occasionally. (sometimes do not smoke in a day, meaning less than 7 cigarettes per week)

□<sup>3</sup> I have stopped. How long have you stopped ? \_\_\_\_\_ \*year/months/days (Please circle as appropriate) E1-1

<sup>4</sup> I am a non-smoker.

E2 Does your wife/husband smoke?

 $\Box$ <sup>1</sup> He/she is a current smoker. (at least one cigarette per day/ 7 per a week)

 $\square^2$  He/ she smoke occasionally. (sometimes do not smoke in a day, meaning less than 7 cigarettes per week)

 $\square$ <sup>3</sup> He/she has stopped. How long have you stopped ? \_\_\_\_\_ \*year/months/days (Please circle as appropriate) E2-1  $\square$ <sup>4</sup> He/ she is a non-smoker

# E3 Are there any other smokers who <u>live with</u> your child (not counting child's parent)? $\Box^1$ None

E4 Which of the following sentence is the best to describe your usual smoke-free practice at home?

 $\square^2$  At some place or at some time, for example when visitors come, smoking is allowed at home

 $\square$ <sup>3</sup> Smoking is allowed at any time and in any place at home

<sup>□&</sup>lt;sup>2</sup> Yes, \_\_\_\_\_ people E3-1



### Part 3: About your asthma knowledge

#### Please tick the box $\blacksquare$ as appropriate

F1	True and False Coughing is not a symptom of asthma	True1	False <sub>2</sub>
F2	Asthma is due to inflammation in the lungs		
F3	Smoking in the home can make a child's asthma worse		
F4	Asthma attacks can happen when you breathe things like paint fumes, gasoline, smoke or		
F5	pollution. Keeping an asthma attack from happening is something only a doctor can do.		
F6	If you start to have an asthma attack, you might notice a tight feeling in your chest before wheezing starts.		
F7	A peak flowmeter is used to make sure your sinuses are open.		
F8	If asthma symptoms such as tightness and wheezing do not occur for several years, a child has outgrown his/her asthma.		
F9	Asthma is an emotional or psychological disease.		
F10	Most children with asthma have to go to the hospital for asthma attacks		
F11	For some people, asthma becomes less severe as they get older.		
F12	Doctors are not really sure why some people have asthma, but they know what can start an attack		
F13	With appropriate treatment, most children with asthma should lead a normal life with no restrictions on activities.		
F14	Anger, crying, or laughing can start an asthma attack.		
F15	If you don't have asthma by the time you are 40 years old, you will never get it.		
F16	Children with asthma should not play sports in which they have to run a lot.		
F17	In young children, asthma sometimes starts after a viral respiratory illness.		
F18	An allergen is the antibody missing people with asthma.		
F19	It is possible for your asthma to be worse without noticing a change in your breathing.		
F20	Exercising in cold weather can start an asthma attack.		
F21	Fish and birds are both good pets for a child with asthma.		
F22	A rescue inhaler (i.e. bronchodilator) is taken to reduce inflammation in the lungs.		
F23	Some asthma medications don't work unless you take them every day.		
F24	You don't need to shake most asthma medication inhalers before using them.		
F25	Fever people have asthma today than 10 years ago.		

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B







### Part 4: Pediatric Asthma Caregiver Quality of Life

These questions are designed to find out how you have been during the **past week.** Please read the statement and circle the number that is appropriate

		All the time	Most of the time	Quite often	Some of the time	Once in a while	Hardly any of the time	None of the time
G1	How often did you feel helpless or frightened when your child experienced cough, wheeze or breathlessness?	1	2	3	4	5	6	7
G2	How often did your family need to change plans because of your child's asthma?	1	2	3	4	5	6	7
G3	How often did you feel frustrated or impatient because your child was irritable due to asthma?	1	2	3	4	5	6	7
G4	How often did your child's asthma interfere with your job or work around the house?	1	2	3	4	5	6	7
G5	How often did you feel upset because of your child's cough, wheeze, or breathlessness?	1	2	3	4	5	6	7
G6	How often did you have sleepless nights because of your child's asthma?	1	2	3	4	5	6	7
G7	How often were you bothered because your child's asthma interfered with family relationships?	1	2	3	4	5	6	7
G8	How often were you awakened during the night because of your child's asthma?	1	2	3	4	5	6	7
G9	How often did you feel angry that your child has asthma?	1	2	3	4	5	6	7
		Very, very worried	Very worried	Fairly worried	Somewhat worried	A little worried	Hardly worried	Not worried
G10	How worried or concerned were you about your child's performance of normal daily activities?	1	2	3	4	5	6	7
G11	How worried or concerned were you about your child's asthma medications and side effects?	1	2	3	4	5	6	7
G12	How worried or concerned were you about being overprotective of your child?	1	2	3	4	5	6	7
G13	How worried or concerned were you about your child being able to lead a normal life?	1	2	3	4	5	6	7



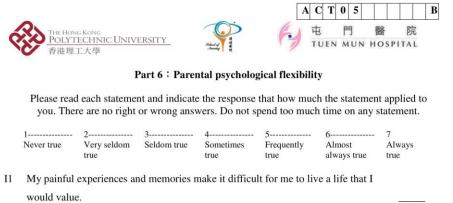




#### Part 5. Parent asthma management self-efficacy

The questions are about how sure you are that you can do things to help your child's asthma. There are no right or wrong answers. Please circle the answer that is most true for you. If the answer doesn't make sense for you, please circle "8, does not apply"

		Not at all sure	A little bit sure	Fairly sure	Quite sure	Completely sure
H1	How sure you can get your child to take his/her medications?	1	2	3	4	5
H2	How sure you can use the medication correctly?	1	2	3	4	5
H3	How sure you can get your child to a doctor's appointment?	1	2	3	4	5
H4	How sure you can follow the direction for giving medication to your child?	1	2	3	4	5
Н5	How sure you can avoid things he/she is allergic to?	1	2	3	4	5
H6	How sure you can help your child to prevent a serious breathing problem?	1	2	3	4	5
H7	How sure you can have inhalers with you if your child has a serious breathing problem?	1	2	3	4	5
H8	How sure you can control a serious breathing problem at home, rather than take your child to AED?	1	2	3	4	5
H9	How sure you can keep the asthma from getting worse if your child starts to wheeze or cough?	1	2	3	4	5
H10	How sure you can help you child stay calm during a serious breathing problem?	1	2	3	4	5
H11	How sure you would know which medications to use when you child is having a serious breathing problem?	1	2	3	4	5
H12	How sure you know your child's breathing problem can be controlled at home?	1	2	3	4	5
H13	How sure you know when to take your child to the AED during a serious breathing problem?	1	2	3	4	5



I2 I'm afraid of my feelings.

13	I worry about not being able to control my worries and feelings.	
I4	My painful memories prevent me from having a fulfilling life.	
15	Emotions cause problems in my life.	
I6	It seems like most people are handling their lives better than I am .	
I7	Worries get in the way of my success.	



Please read each statement and circle the response which indicates how much the statement applied to you over the **past month.** There are no right or wrong answers. Do not spend too much time on any statement.

		Never	Rarely	Sometimes	Often	Always
J1	It is painful for me to think about what my child might have been like had s/her never gotten sick.	0	1	2	3	4
J2	I am at peace with the circumstances of my life.	0	1	2	3	4
J3	I feel guilty because my child became ill while I remained healthy.	0	1	2	3	4
J4	I worry about my child's future.	0	1	2	3	4
J5	I feel ready to face challenges related to my child's wellbeing in the future.	0	1	2	3	4
J6	I worry that I may be responsible for my child's illness in some way.	0	1	2	3	4
J7	I worry that at any minute, things might take a turn for the worse.	0	1	2	3	4
<b>J</b> 8	I worry about whether my child will be able to live independently as an adult.	0	1	2	3	4
J9	I have regrets about decisions I have made concerning my child's illness.	0	1	2	3	4
J10	I think about whether or not my child will die.	0	1	2	3	4
J11	I am aware of the specific ways I react to sadness and loss.	0	1	2	3	4
J12	I experience angry feelings when I think about my child's illness.	0	1	2	3	4
J13	I am afraid of this diagnosis occurring in another member of my immediate	0	1	2	3	4
J14	family. I trust myself to manage the future, whatever happens	0	1	2	3	4
J15	I find it hard to socialize with people who don't understand what being a	0	1	2	3	4
J16	parent to my child means. When my child is playing actively, I find myself worried that s/he will get hurt.	0	1	2	3	4
J17	I believe I will never be as completely happy or satisfied with my life as I was before my child became ill.	0	1	2	3	4
J18	My hopes and dreams for my child's future are uncertain.	0	1	2	3	4
J19	I am jealous of parents who have healthy children.	0	1	2	3	4
J20	I worry that my child's illness will worsen/return	0	1	2	3	4
J21	Seeing health children doing everyday activities makes me feel sad.	0	1	2	3	4
J22	I worry about something bad happening to my child when s/he is out of my	0	1	2	3	4
J23	care. I can get help and support when I need it.	0	1	2	3	4
J24	I wake up during the night and check on my child.	0	1	2	3	4
J25	When I am not with my child, I find myself thinking about whether or not s/he is okay.	0	1	2	3	4

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B





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### Part 8. Parent's psychological status

Please read each statement and circle the response which indicates how much the statement applied to you over **the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

		Never	Some times	Often	Always
K1	I found it hard to wind down.	0	1	2	3
К2	I was aware of dryness of my mouth.	0	1	2	3
K3	I couldn't seem to experience any positive feeling at all.	0	1	2	3
K4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion).	0	1	2	3
K5	I found it difficult to work up the initiative to do things.	0	1	2	3
K6	I tended to over-react to situations	0	1	2	3
K7	I experienced trembling (eg, in the hands).	0	1	2	3
K8	I felt that I was using a lot of nervous energy.	0	1	2	3
K9	I was worried about situations in which I might panic and make a fool of myself.	0	1	2	3
K10	I felt that I had nothing to look forward to.	0	1	2	3
K11	I found myself getting agitated.	0	1	2	3
K12	I found it difficult to relax.	0	1	2	3
K13	I felt down-hearted and blue.	0	1	2	3
K14	I was intolerant of anything that kept me from getting on with what I was doing.	0	1	2	3
K15	I felt I was close to panic	0	1	2	3
K16	I was unable to become enthusiastic about anything.	0	1	2	3
K17	I felt I wasn't worth much as a person.	0	1	2	3
K18	I felt that I was rather touchy.	0	1	2	3
K19	I was aware of the action of my heart in the absence of physical exertion (e.g., sense of heart rate increase, heart missing a beat)	0	1	2	3
K20	I felt scared without any good reason	0	1	2	3
K21	I felt that life was meaningless.	0	1	2	3

(A)	THE HONG KONG POLYTECHNIC UN 香港理工大學	IVERSITY		CT05 B 电門醫院 TUEN MUN HOSPITAL	
			sonal information x ☑ as appropriate		
LI	Your relationship with c	hild:			
	$\square^1$ Mother	□ <sup>2</sup> Father	□ <sup>3</sup> Others	L1-3-1	
L2/S1	Your age:				
L3	Marital status				
	$\Box^1$ Single	□ <sup>2</sup> Married	<sup>3</sup> Divorced	/ $\square^4$ Widowed	
L4	Educational level:		separated		
L5	<sup>1</sup> No formal education Monthly household inco	□ <sup>2</sup> Primary ome (HKD\$):	$\square^3$ Secondar	y □ <sup>4</sup> Tertiary level or above	
	□ <sup>1</sup> Under 4000	□ <sup>2</sup> 4000-9999	□ <sup>3</sup> 10000-19	9999 <b>□</b> <sup>4</sup> 20000-29999	
	□ <sup>5</sup> 30000-59999	$\square^6$ 60000 or above	□ <sup>7</sup> Compreh	ensive Social Service Assistance	
L6	Current occupation:				
	□ <sup>1</sup> Housewife	□ <sup>2</sup> Manager /administrators	<sup>3</sup> Professional	s □ <sup>4</sup> Craft & related workers	
	□ <sup>5</sup> Clerk	□ <sup>6</sup> Machine operators	□ <sup>7</sup> Services and	d shop $\square^8$ Unemployed	
	□ <sup>9</sup> Students (full time)	<sup>10</sup> Others:	sales workers L6-10-1		
L7	District where you are n	ow living in:			
	□ <sup>1</sup> Tuen Mun □	<sup>2</sup> Yuen Long <sup>3</sup> Tin	n Shui Wai □ <sup>4</sup> Ot Pleas	thers. e specify: L7-4-1	
s2Are you t	he main caregiver of the i	Yes	No □²The main		
s3 Are you living with the index child? s4 Hong Kong resident and plan to stay in Hong s5 Please provide your contact number Phone:(mobile);(Home)					
Your avail contact tin			AM/PM AM/PM	Mon/Tue/Wed/Thu/Fri/Sat/Sun AM/PM	

\*\*\*End of questionnaire. Thank you very much for your time\*\*\*

#### Appendix 3.3. Ethical approvals from the study hospital's ethics review board

and the university



Email hsenid@ Date 29-Jan-2015

Application for Ethical Review for Teaching/Research Involving Human Subjects

I write to inform you that approval has been given to your application for human subjects ethics review of the following project for a period from 26-Jan-2015 to 31-Jan-2017:

Project Title:	Effects of a parental training program using group-based acceptance and commitment therapy for managing children with asthma: a randomized controlled trial
Department:	School of Nursing
Principal Investigator:	Mak Yim Wah
<b>Reference Number:</b>	HSEARS20150109001

Please note that you will be held responsible for the ethical approval granted for the project and the ethical conduct of the personnel involved in the project. In the case of the Co-PI, if any, has also obtained ethical approval for the project, the Co-PI will also assume the responsibility in respect of the ethical approval (in relation to the areas of expertise of respective Co-PI in accordance with the stipulations given by the approving authority).

You are responsible for informing the Departmental Research Committee in advance of any changes in the proposal or procedures which may affect the validity of this ethical approval.

You will receive separate email notification should you be required to obtain fresh approval.

KWONG Wai Yung

Delegate

Departmental Research Committee

//	TUEN MUN HOSPITAL	勝調辦事處Cluster Office           第二時日本         (5.5)           第二時日本         (6.5)           第二時日本         (6.5)           2415年日本         (6.5)           2455191         (6.5)	
	NTV	V Cluster Clinical & Research Ethics Committee 新界西醫院聯網臨床及研究倫理委員會	
		Confidential	
Our R	ef.: (7)	in NTWC/CREC/15042	
		28 April 2015	
PhD s Schoo	onnie CHONG Yu tudent I of Nursing ong Kong Polytee		
Dear M	As CHONG		
		Application for Ethics Approval <u>Clinical Research Study</u>	
Study Title: Principal Investigator:		Effects of a parental training program using group-based acceptance and commitment therapy for managing children with asthma: a randomized controlled trial Lead PI - Ms Connie CHONG Yuen-yu, PhD student, School of Nursing, The Hong Kong Polytechnic University	
Study Site(s) :		Tuen Mun Hospital	
	I am pleased to red your applicati	supersede the one ref: (6) in NTWC/CREC/15042 dated 24 April 2015. inform you that the NTW Cluster Clinical & Research Ethics Committee has on and approval was given to you on 24 April 2015 for conducting the above h the following documents submitted:	
2 Research Protoc		ch Ethics Review Application Form;	
		col, Appendix 2.1;	
		(English & Chinese), Appendix 2.2;	
		eet (RCT) (Chinese), Appendix 3.1;	
5	Consent Form (	RCT) (Chinese), Appendix 3.2;	
		Our Ref: (7) in NTWC/CREC/15042 Pag	
		retary of NTW Cluster Clinical & Research Ethics Committee	

HA II IO/NTWO

1	ビージョン 2017年 Class set = Notice Class
6	Information Sheet (Pilot) (Chinese), Appendix 3.3;
7	Consent Form (Pilot) (Chinese), Appendix 3.4;
8	Questionnaire (Chinese), Appendix 4.1;
9	Nursing assessment, Appendix 4.2;
<ul> <li>10 Investigators' Curriculum Vitae:</li> <li>- Dr LAM Shu-yan (Local PI),</li> <li>- Ms Connie CHONG Yuen-yu (Lead PI),</li> <li>- Dr MAK Yim-wah,</li> <li>- Ms LEUNG Sui-ping,</li> <li>- Professor Alice Yuen LOKE;</li> </ul>	
11	Copy of approval letter granted by Departmental Research Committee, The Hong Kong Polytechnic University.
	Please note that you are required to adhere to the following conditions:
	<ol> <li>Do not deviate from, or make changes to the study protocol without prior written approval of the NTWC-C&amp;REC, except when it is necessary to eliminate immediate hazards to research subjects or when the change involves only logistical or administrative issues.</li> </ol>
	<ol> <li>Report the followings to NTWC-C&amp;REC: (i) study protocol or consent document change (use 'NTWC CREC001F7'), (ii) serious adverse event (use 'NTWC CREC001F8'), (iii) new information that may be relevant to a subject's willingness to continue participation in the research.</li> </ol>
	<ol> <li>Report research progress [use "NTWC CREC001F9a"] to NTWC C&amp;REC at 12-monthly intervals until study closure. Submit a final report [use "NTWC CREC001F9b"] to the NTWC C&amp;REC upon research completion.</li> </ol>
	(Forms down-loadable from http://ntwc.home/ccrec/)
	The NTW Cluster Clinical & Research Ethics Committee serves to ensure that research

Yours sincerely

(Sónnia<sup>†</sup>WONG) Secretary NTW Cluster Clinical & Research Ethics Committee

cc Dr N S KWONG, COS(PAED&AM), TMH/POH Dr S Y LAM, Deputy COS (PAED&AM), TMH/POH (Local PI)

Our Ref. (7) in NTWC/CREC/15042 Page 2 of 2

国民攜手 Media Frank Reality 保健容康

Secretary of NTW Cluster Clinical & Research Ethics Committee 57F, Rehabilitation Block, Tuen Mun Hespital, Tuen Mun, N.T. Tel. No.: 2468 6118

# Appendix 3.4. Proof of clinical trial registration

# Clinical Trials. gov PRS Protocol Registration and Results System

ClinicalTrials.gov Protocol Registration and Results System (PRS) Receipt Release Date: 04/05/2016		
	ClinicalTrials.gov ID. NCT02405962	
Study Identification		
Unique Protocol ID:	HSEARS20150109001	
Brief Title:	Training Parents by Acceptance and Commitment Therapy for Managing Childhood Asthma Caro	
Official Title:	Effects of a Parental Training Program Using Group-based Acceptance and Commitment Therapy for Managing Children With Asthma: a Randomized Controlled Trial	
Secondary IDs:		
Study Status		
Record Verification:	April 2016	
Overall Status:	Recruiting	
Study Start:	January 2015	
Primary Completion:	January 2017 [Anticipated]	
Study Completion:	May 2017 [Anticipated]	
Sponsor/Collaborators		
Sponsor:	The Hong Kong Polytechnic University	
Responsible Party:	Principal Investigator Investigator: Dr. Yim Wah Mak (ymak) Official Title: Assistant Professor Affiliation: The Hong Kong Polytechnic University	
Collaborators:	Hospital Authority, Hong Kong	
Oversight		
FDA Regulated?:	No	
IND/IDE Protocol?:	No	
Review Board:	Approval Status: Approved Approval Number: HSEARS20150109001 Board Name: Human Subjects Ethics Sub-committee Board Affiliation: The Hong Kong Polytechnic University Phone: 852-2766-6378 Email: chorrie.mok@	
Data Monitoring?:	Yes	

Plan to Share Data?:

Page 1 of 5

Oversight Autho	rities: Hong Kong: The Hong Kong Polytechnic University
Study Description	
Brief Sum	mary: The purpose of this study is to examine whether a parental training program using group-based Acceptance and Commitment Therapy for childhood asthma care, is effective in reducing the number of children's unplanned health care services utilization and asthmatic symptoms.
Detailed Descri	iption: One-tenth of children in worldwide are diagnosed with asthma and it is the leading cause for unplanned health care services utilization. Parents, as the primary caregivers, experience different level of psychological distress in taking care of their children with asthma. Some of them responded with avoidance-based coping, which results in poor asthma symptom management and monitoring. Acceptance and Commitment Therapy (ACT) is a contextual focused, behavioral therapy aiming at improving psychological flexibility, so that a person can be more opened up to engaging in value-driven behavior modification, thus attaining an optimal disease control. The benefits of ACT have been demonstrated on both parents and their children with chronic health conditions such as developmental disabilities, acquired brain injuries, chronic pain, cancer and mental disorders. To date, no ACT intervention has been conducted on examining its effects on training parents in managing their children with asthmatic conditions.
	This is the first study aims to examine the effects of a parental training program using group-based Acceptance and Commitment Therapy (ACT) in reducing the number of unplanned health care services utilization and asthmatic symptoms, among children with asthma. Parents of children diagnosed with asthma will either receive one session of pediatric asthma educational talk as usual practice in the study hospital, or in addition, four sessions of group-based ACT integrated with asthma education.
	If the group-based ACT is effective in reducing children's asthmatic symptoms and overall unplanned asthma-related health services utilization, it could lead to substantial health benefits on children with asthma and on parents with a reduction in psychological distress. In addition to cutting medical expenses, it could also contribute to the community health through the reduction in mortality and morbidity due to asthmatic attack. Furthermore, information collected from this proposed study will open up an opportunity for exploring the potential of ACT-based intervention in managing other childhood chronic diseases.
Conditions	
Condi	itions: Childhood Asthma
Кеуи	vords: Acceptance and Commitment Therapy Childhood asthma Randomized controlled trial Training parents
Study Design	
Study	Type: Interventional
Primary Pur	pose: Treatment
Study P	hase: N/A
	/lodel: Parallel Assignment
	-

- Page 2 of 5 -

#### Allocation: Randomized

Endpoint Classification: Efficacy Study

Enrollment: 120 [Anticipated]

Arms and Interventions

Arms	Assigned Interventions
Placebo Comparator: An educational talk (Usual care group) Parents of children with asthma, will receive one session of asthma educational talk as an usual care, plus three weekly sessions of assessment only by telephone.	Behavioral: An educational talk One session of educational talk about pediatric asthma care, as usual practice.
Experimental: ACT group In addition to asthma educational talk as usual care, parents of children with asthma will receive four sessions of group-based ACT integrated with asthma education.	Behavioral: ACT Four sessions of group-based ACT integrated with asthma education. Each session will compose of pediatric asthma education based on guidelines of Global Strategy for Asthma Management and Prevention Revised 2011, plus group-based Acceptance and Commitment Therapy (ACT). Parents will learn to (1) increase acceptance of subjective experiences, (2) learn mindfulness of the present rather than an over-attachment to the past or future; (3) clarify personally held values and (4) move on in an effort to promote asthma care and parenting.

#### Outcome Measures

Primary Outcome Measure:

1. Children's total number of hospital emergency care service attendance(s) due to asthma attack, based on parent's report

[Time Frame: At 6 months since the initial of intervention] [Safety Issue: No]

Secondary Outcome Measure:

- 2. Children's unplanned asthma-related health care service utilization due to asthma attack, based on parent's report [Time Frame: At 6 months since the initial of intervention] [Safety Issue: No]
  - The number of general practitioner's care service attendance;
  - · The number of private pediatrician's care service attendance;
  - . The number of hospital admission(s);
  - . The length of hospital stay

3. Children's average number of day(s)/night (s) per week with asthma symptoms and attacks, based on parent's report and child's health assessment

- [Time Frame: At 6 months since the initial of intervention] [Safety Issue: No]
  - . Day(s) with symptoms such as chronic cough, wheezing, shortness of breath or chest tightness at daytime;
  - · Night(s) with disturbed sleep due to asthma symptoms;
  - · Day(s) in which the child has to slow down or discontinue play activities due to asthma attack;
  - · Day(s) in using reliever medications due to symptoms occurrence;
  - · Day(s) with asthma attack.
- 4. Parent's psychological flexibility

[Time Frame: At 1 month and at 6 months since the initial of intervention] [Safety Issue: No]

Chinese version of Acceptance and Action Questionnaire-II (AAQ-II) will be used to assess the psychological flexibility of the parents. It is a 7-statement measuring psychological flexibility in a one-dimensional manner. (Cronbach's alpha =0.86-0.88).

5. Parent's perceived psychological difficulties

- Pane 3 of 5 -

[Time Frame: At 1 month and at 6 months since the initial of intervention] [Safety Issue: No] Parent Experience of Child Illness (PECI) will be used to assess the perceived psychological difficulties of the parents. It is a 25-statement in a 5-point Likert scale measuring four constructs of pediatric chronic disease-specific distress experienced by parents, including guilt and worry, unresolved sorrow and anger, long-term uncertainty and perceived emotional resources (Cronbach's alpha =0.72-0.89).

6. Parent's quality of life

[Time Frame: At 1 month and at 6 months since the initial of intervention] [Safety Issue: No] Chinese version of Pediatric Asthma Caregiver's Quality of Life (PACQLQ) will be used to assess the quality of life of the parents. It is a 13-question, 7-point Likert scale measuring parental psychosocial well-being in terms of emotional function (intraclass correlation coefficient (ICC)=0.80) and activity limitation (ICC=0.84).

7. Parent's knowledge in asthma management

[Time Frame: At 1 month and at 6 months since the initial of intervention] [Safety Issue: No] Asthma Knowledge Questionnaire (AKQ) will be used to assess the knowledge level among parents in pediatric asthma management. It composes of 25 true and false statements to measure parental asthma knowledge, including symptoms, triggers, treatment and prevention (Cronbach's alpha =0.69).

8. Parent's self-efficacy

[Time Frame: At 1 month and at 6 months since the initial of intervention] [Safety Issue: No] Parental Asthma Management Self-Efficacy Scale (PAMSE) will be used to assess the self-efficacy of parents in childhood asthma care. It consists of 13-item, 5-point rating scale measuring attack prevention and attack management self-efficacy (Cronbach's alpha =0.87).

#### Eligibility

Minimum Age:	3 Years
Maximum Age:	12 Years
Gender:	Both
Accepts Healthy Volunteers?:	No
Criteria:	Inclusion Criteria for parents:
	<ul> <li>Aged 18 or above</li> <li>As the primary caregiver of the child, as any adult who is responsible for the role of parenting the child, this could be biological parent, guardian or other adult family member</li> <li>Living together with the index child</li> <li>Able to communicate in Cantonese</li> <li>Hong Kong resident who plans to stay in Hong Kong for at least 6 months</li> <li>Accessible by telephone and by mail</li> </ul>
	Inclusion Criteria for children:
	<ul> <li>3 to 12 years old with a physician's diagnosis of asthma</li> </ul>
	Exclusion criteria for parents:
	<ul> <li>Enrolled in another asthma research intervention study</li> </ul>
	Exclusion criteria for children:
	<ul> <li>Enrolled in another asthma research intervention study</li> <li>Two years old or under presented with acute wheezing attack. As symptoms at this age can be due to bronchiolitis, a viral infection, rather than asthma</li> <li>Have (1) other chronic pulmonary disease, such as cystic fibrosis (CF), bronchopulmonary dysplasia (BPD), oxygen dependent conditions, or presence of tracheotomy; (2) other significant medical and mental morbidities, such as congenital malformation, Down's syndrome, carebral palsy and psychomotor retardation. Both may hinder the control of asthma.</li> </ul>

<sup>-</sup> Page 4 of 5 -

Contacts/Locations	
	Yim Wah Mak, PhD
Central Contact	Telephone: 852-2766-6421
	Email: yw.mak@
Central Contact Backup:	Yuen Yu Chong, MN, MSc(EPB)
	Telephone: 852-2766-6384
	Email: connie.yy.chong@c
Study Officials:	Yim Wah Mak, PhD
	Study Principal Investigator
	School of Nursing, The Hong Kong Polylechnic University
Locations:	Hong Kong
	School of Nursing, The Hong Kong Polytechnic University
	[Recruiting]
	Hung Horn, Kowloon, Hong Kong
	Contact: Yuen Yu Chong, MN, MSc(EPB) 852-2766-6384
	connie.yy.chong@ Contact: Yim Wah Mak, PhD 852-2766-6421 ww.mak@
	Principal Investigator: Yim Wah Mak, PhD
	Sub-Investigator: Yuen Yu Chong, MN, MSo(EPB)
	Sub-Investigator: Yuen Jean Tak Alice Loke, PhD
	Ambulatory Care Clinic, Department of Paediatrics and Adolescent Medicine, Tuen Mun Hospital
	[Not yet recruiting]
	New Territories, Hong Kong
	Contact: Yuen Yu Chong, MN, MSc(EPB) 852-2766-6384
	connie.yy.chong@c
	Principal Investigator: Yim Wah Mak, PhD
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	Sub-Investigator: Shu Yan Lam, FHKCP Sub-Investigator: Sui Ping Leung, MN
	Pediatric asthma nurse-led clinic, Department of Paediatrics and Adolescent Medicine, Tuen Mun Hospital
	[Not yet recruiting]
	New Territories, Hong Kong
	Contact: Chong Yuen Yu, MN, MSc(EPB) 852-2766-6384
· · · · · · · · · · · · · · · · · · ·	connie.yy.chong@i
	Principal Investigator: Yim Wah Mak, PhD
	Sub-Investigator: Yuen Yu Chong, MN, MSc(EPB)
	Sub-Investigator: Shu Yan Lam, FHKCP Sub-Investigator: Sui Ping Leung, MN
	and arready out and monthly had
References	
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Citations:	
Links:	
Study Data/Documents:	
U.S. National Ubrary of Med	icine   U.S. National Institutes of Health   U.S. Department of Health & Human Services

- Page 5 of 5 -

#### **Appendix 3.5. Information Sheet (Chinese Version)**





屯 門 醫 院 TUEN MUN HOSPITAL

有關資料

#### 探討家長參與護理兒童哮喘計劃的成效

誠邀閣下参加由香港理工大學護理學院麥艷華博士負責監督,香港理工大學護理學院博士研究生及註冊護士莊婉瑜女士 負責執行,聯同屯門醫院兒童及青少年科副部門主管林樹仁醫生及其團隊合作的上述研究項目。

哮喘是兒童最常見的慢性疾病,急性發作危機往往是家長害怕、擔心和不確定感的來源,故照顧哮喘兒童寶為父母的一 大挑戰。本研究旨在了解並協助家長學習預防及處理哮喘發作護理技巧,以達到控制兒童哮喘的狀態及減少急性發作。

若閣下參與這個研究計劃,將被隨機分配到研究的兩個不同組別,接受由註冊護士在屯門醫院執行一共四節的兒童哮喘 學習工作坊,或兒童哮喘護理講座及三次電話跟進訪問。工作坊將以小組形式舉行,每星期一次,每次約2小時:哮喘 護理講座為1節約2小時;而電話訪問需時約15至30分鐘,評估 貴子女哮喘狀況。

為評估計劃成效,我們會在計劃開始前、開始後第一個月及第六個月需要你填寫或回答一份問卷,問卷內容主要包括 貴子女哮喘狀況,以及你照顧哮喘兒童絕驗及心理狀況。此外,我們並邀請閣下和 貴子女在計劃開始前,接受由註冊 護士執行的綜合護理評估,包括兒童身高體重檢查、最高流速測試、哮喘控制指數測試、兒童用藥技巧、以及家長護理 兒童哮喘技巧。在計劃開始後第三個月,我們會以電話訪問跟進 貴子女健康狀況以及你對護理兒童哮喘的需要;而在 第六個月我們會為閣下和 貴子女重複執行綜合護理評估。

本項研究不會引起任何不適的感覺。部份家長會被隨機抽樣,在計劃進行期間,該話內容可能會被錄音以評估計劃進行 的質素及改善本研究。您的參與有助我們了解香港家長在照顧兒童哮喘治療的需要,有助制定更適切的兒科哮喘控制對 策。

此項研究全屬自顯性質。關下享有充分的權利在研究開始之前或之後決定退出這項研究,此舉亦不會影響關下及 貴子 女所獲取的標準醫療及護理。此計劃所得資料,只有研究小組有權閱覽,所有參加者的資料絶對保密。參加者的個人身 份,絕對不會在任何研究報告或其他相關文件發表。

如關下對研究項目有任何不滿,可隨時親身或以書面與與香港理工大學人類實驗對象操守小組委員會秘書莫小姐聯絡 (地址:香港理工大學研究事務處轉交)。

如果 関下 想獲 得 更 多 有 關 這 項 研 究 的 資 料, 請 與 香 港 理 工 大 學 護 理 學 院 博 士 研 究 生 莊 婉 瑜 (電 郵: connic yy.chong@, , 電話: 2766-6384, 或 要 艷 華 博士 (電郵: yw.mak@ 電話: 2766-6421) 聯絡。

謝謝閣下有興趣參與這項研究。

麥艷華博士

莊婉瑜女士

林樹仁醫生

主要研究員 香港理工大學護理學院 助理教授

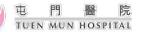
香港理工大學護理學院 博士研究生及註冊護士 屯門醫院兒童及青少年科 副部門主管

Hung Hom Kowloon Hong Kong  $\frac{1}{2}$  (a)  $\frac{1}{2}$  (c)  $\frac$ 

## Appendix 3.6. Consent Form (Chinese Version)







#### 參與研究同意書

#### 探討家長參與護理兒童哮喘計劃的成效

本人,\_\_\_\_\_(姓名)同意参加由香港理工大學護理學院麥艷華博士負責監督,香港理工大學護理學院博士研究生及註冊護士莊婉瑜女士負責執行,在屯門醫院進行的研究項目。

本人清楚明白此計劃所得的資料,有機會被用於日後的學術研究及發表;然而本人的個人資料會 絕對保密,完全保留私隱權利。

同意參與該項研究,您明確作出以下授權:

 為了監督該項研究,授權主要研究者及其研究團隊和新界西醫院聯網臨床及研究倫理委員 會根據本項研究和本知情同意書規定的方式獲得、使用並保留您的個人資料。

本人知道有權就此計劃的任何部分提出疑問,並有權隨時終止參與,而不會影響本人及其子女現 在或將來會接受的福利和治療。研究人員已清楚向本人解釋附上的計劃詳情,明白當中涉及的一 切利益及風險。

本人是自願參與這項研究。

参加者姓名	参加者簽署	日期
研究員姓名	研究員簽署	日期
見證人姓名	見證人簽署	日期

Hung Hom Kowloon Hong Kong 香港 九龍 紅頭 Tel 電話 (852) 2766 5111 Fax 侍真 (852) 2784 3374 Email 電郵 <u>polyu@polyu.edu.hk</u> Website 期壯 www.polyu.edu.hk

#### Appendix 4.1. Credentials of the therapist



19 JULY, 2015

This is to certify that:

## YUEN YU, CONNIE CHONG

participated in a continuing education activity

TITLE: ACBS World Conference 13

DATE(S): 16-19 July, 2015

LOCATION: Estrel Berlin, Berlin, Germany

Founded in 2005 (incorporated in 2006), the Association for Contextual Behavioral Science (ACBS) is dedicated to the advancement of functional contextual cognitive and behavioral science and practice so as to alleviate human suffering and advance human well being. Emily Rodrigues Executive Director Association for Contextual Behavioral Science contextualscience.org



15 JULY, 2015

This is to certify that:

#### YUEN YU, CONNIE CHONG

participated in a continuing education activity

TITLE: ACT II: Skill-Building in Acceptance and Commitment Therapy - Steven C. Hayes, Ph.D.

DATE(S): 14 & 15 July, 2015

LOCATION: Estrel Berlin, Berlin, Germany

Founded in 2005 (incorporated in 2006), the Association for Contextual Behavioral Science (ACBS) is dedicated to the advancement of functional contextual cognitive and behavioral science and practice so as to alleviate human suffering and advance human well being.

Emily Rodrigues Executive Director Association for Contextual Behavioral Science contextualscience.org

CERTIF b Day Training Works Prof. Wong Wing-Sze, Director.
---------------------------------------------------------------------



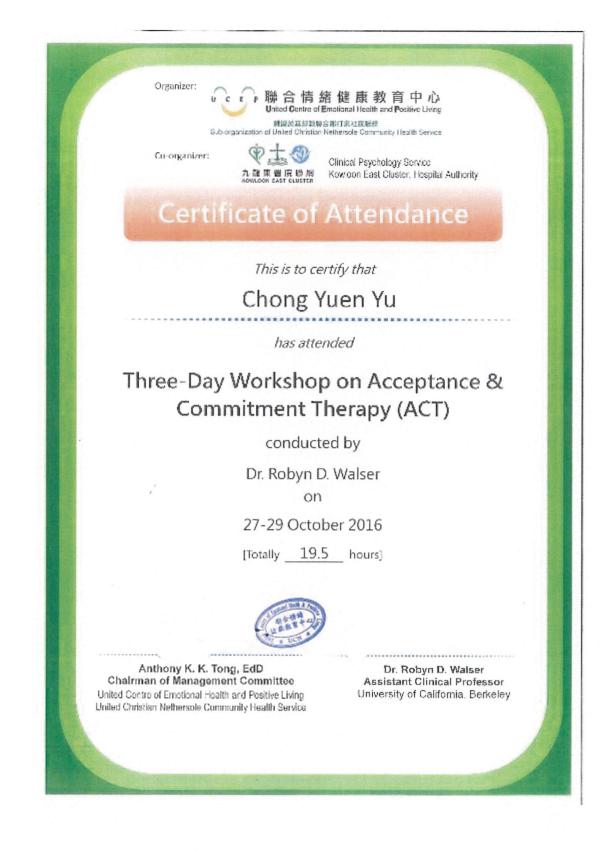
Professor Steven C. Hayes on 10-12 December 2015

[Totally \_\_\_\_\_\_ hours]

Anthony K. K. Tong, EdD Chairman of Management Committee United Centre of Emotional Health and Positive Living United Christian Nethersole Community Health Service Steven C. Hayes, PhD Foundation Professor Department of Psychology University of Nevada, Reno, USA

Supporting Agency: Social Work & Social Monte &

and the second second





# **Certificate of Attendance**

This is to certify that

Chong Yuen Yu

has attended

# Two-Day Advanced Training in Acceptance & Commitment Therapy (ACT)

conducted by

Dr. Robyn D. Walser on

16-17 October 2017

[Totally 13 hours]

Anthony K. K. Tong, EdD Chairman of Advisory Committee United Centre of Emotional Health and Positive Living United Christian Nethersole Community Health Service Dr. Robyn D. Walser Assistant Clinical Professor University of California, Berkeley ACBS P.O. Box 655 Jenison, MI 49429 USA

June 25, 2017 This is to certify that: Chong Yuen Yu



participated in a continuing education activity

#### ACBS World Conference 15 - Seville, Spain

Date(s): June 22-25, 2017 Contact Hours: 15

Sincerely, Emily N. Rodrigues, M.A.

Executive Director Association for Contextual Behavioral Science

Founded in 2005 (incorporated in 2006), the Association for Contextual Behavioral Science (ACBS) is dedicated to the advancement of functional contextual cognitive and behavioral science and practice so as to alleviate human suffering and advance human well being.

> ACBS P.O. Box 655 Jenison, MI 49429 USA

June 21, 2017 This is to certify that: Chong Yuen Yu

participated in a continuing education activity Process-based ACT: An intermediate ACT II Workshop - Steven C. Hayes, Ph.D.

Date(s): June 20-21, 2017 Seville, Spain Contact Hours: 13

Sincerely, Emily N. Rodrigues, M.A. Executive Director Association for Contextual Behavioral Science

Founded in 2005 (incorporated in 2006), the Association for Contextual Behavioral Science (ACBS) is dedicated to the advancement of functional contextual cognitive and behavioral science and practice so as to alleviate human suffering and advance human well being.



## Appendix 4.2. ACT interventional materials for Session One

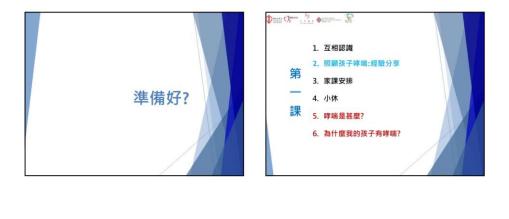
## **PowerPoint Slides (Session One)**



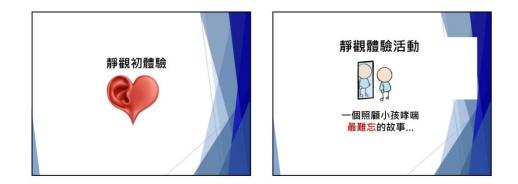




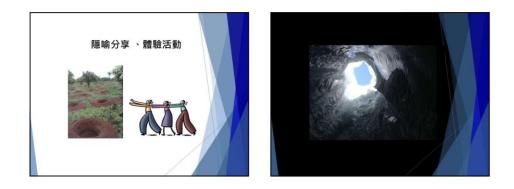


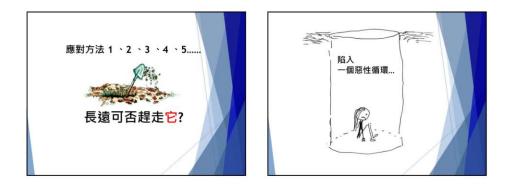




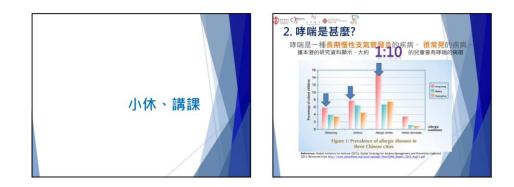


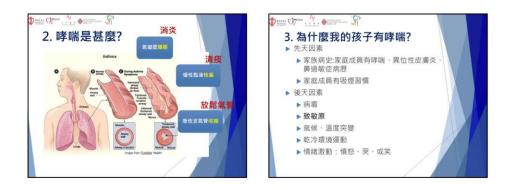












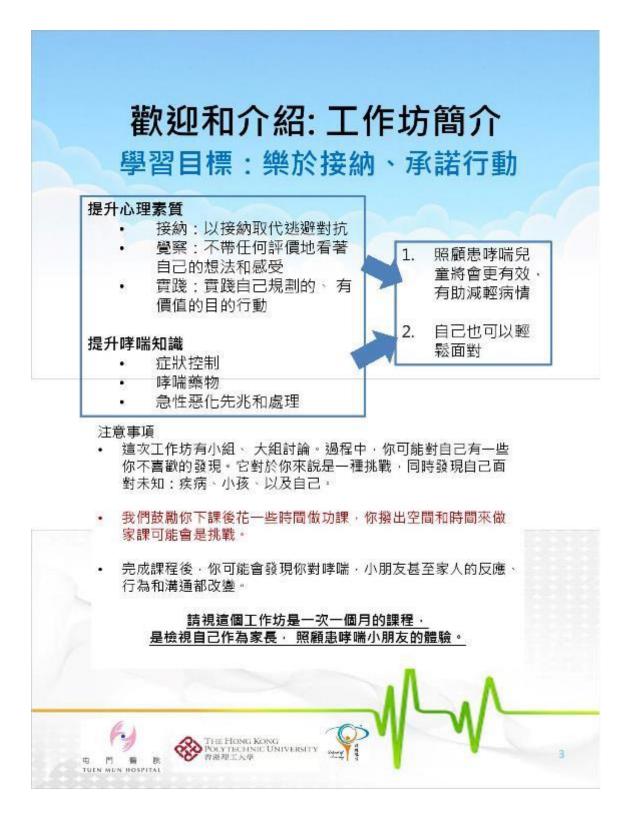




## Handouts (Session One)













E

电 門 醫 胞 TUEN MUN HOSPITAL



- 情緒激動:憤怒、哭、或笑可以引起哮喘發作

The Hong Kong Polytechnic University

## 請注意

在五歲以下兒童診斷哮喘有其困難性。因為在這個年齡群發生的 咳嗽喘鳴並不全都是哮喘,尤其是小於三歲的孩童。在這段時期 的喘鳴經常跟以下有關:

 上呼吸道感染和其他致敏原: 多觸發性哮鳴 (multiple trigger wheeze)

 病毒性呼吸道感染 (viral-induced wheeze) · 例如呼吸合胞 病毒 (RSV)

# Homework assignment (Session One)

家長姓名:\_\_\_\_\_\_ 小朋友姓名:\_\_\_\_\_\_

#### 護理兒童哮喘計劃

#### 家長工作坊: 第一節

## 家課:照顧孩子覺察日記

在這一星期內日常生活中,請你您在照顧小孩覺得挑戰的事情,尤其是您的想法和感受。

例如是:小孩回校上課時不肯/忘記用藥,到公園玩時有病徵,睡覺時有病徵,花費功夫避開 致敏源 (煙, 龐物)而,小孩有情緒時,你有情緒時等

日期	前因	行為	後果
	發生了什麼事?		之後發生了什麼?
例子:			
	情況 (你見到什麼?)	<b>(</b> 你的想法和感受出現	你的想法和感受有沒有離開
	晚上,女兒又喘氣了。	後,你如何應對?)	過?仍然存在,還是越來越
		<i>幫我女兒用藥,用藍色氣</i>	差?
	<u>想法</u> (你腦海第一時間,想了什	管擴張劑先。	一直存在,天氣一轉就有。
	麼說話?)		
	「點解又喘氣呢? 我希望幫到佢	我會處理女兒喘氣先。我	
	改善。」	經常想: 我什麼都幫唔到	如果長此下去,會有什麼影
		<i>佢,我會擔心藥物副作</i>	響?
	感受	用,為什麼病情一直方好	<i>過份擔心,好想有人幫助我</i>
	身心都覺得好無助,好似方其他	轉?	女兒
	藥物或醫生能助我女兒改善病		
	情。		
	身體感覺		
	心跳快		

1

<u>情況</u> (你見到什麼?) <u>想法</u> (你腦海第一時間想了什麼說 話?) <u>感受</u>	(你的想法和感受 出現後,你做了些 什麼?)	你的想法和感受有沒有離開過?仍 然存在,還是越來越差? 如果長此下去,會有什麼影響?
 <u>身體感覺</u> 情況 (你見到什麼?)	(你的想法和感受 出租後,你做了些	你的想法和感受有沒有離開過?仍 然存在,還是越來越差?
<u>想法</u> (你腦海第一時間想了什麼說 話 <b>? )</b>	山戎復,亦咸了≦ 什麼?)	<u>灬仔忙,遂定陞术陞左!</u>
感受		如果長此下去,會有什麼影響?
身體感覺		
<u>情況 (</u> 你見到什麼 <b>?)</b>	(你的想法和感受 出現後,你做了些 什麼?)	你的想法和感受有沒有離開過?仍 然存在,還是越來越差?
<u>想法 (</u> 你腦海第一時間想了什麼說 話?)		
感受		如果長此下去,會有什麼影響?
身體感覺		

# Appendix 4.3. ACT interventional materials for Session Two

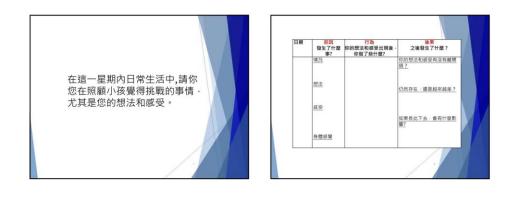
**PowerPoint Slides (Session Two)** 





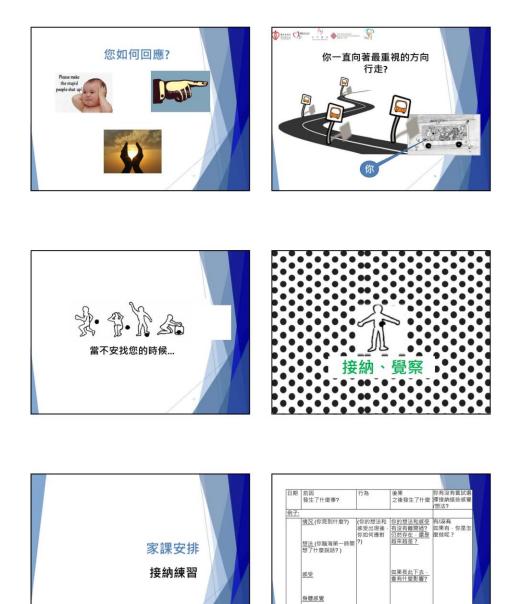






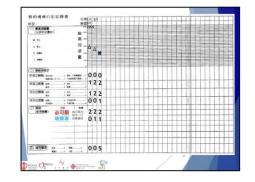




















#### Handouts (Session Two)



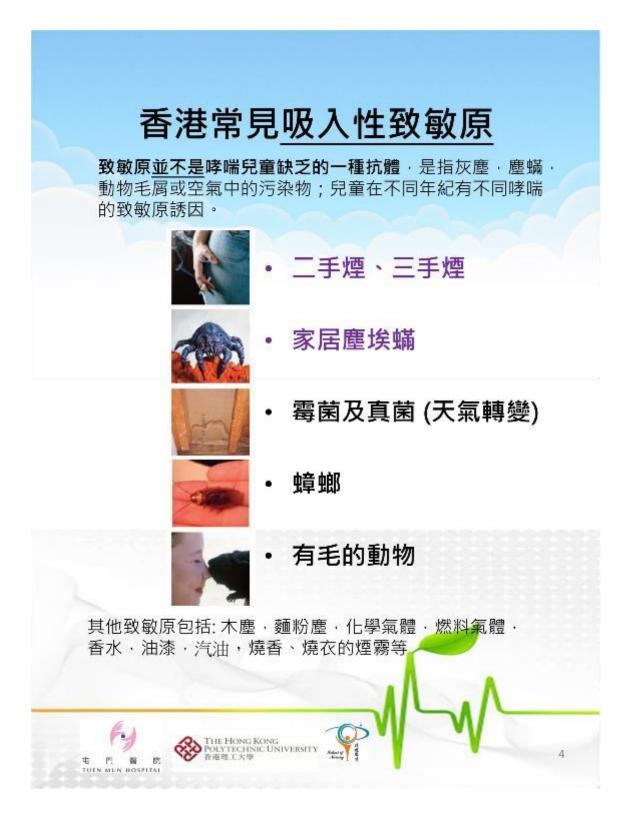
**o**)

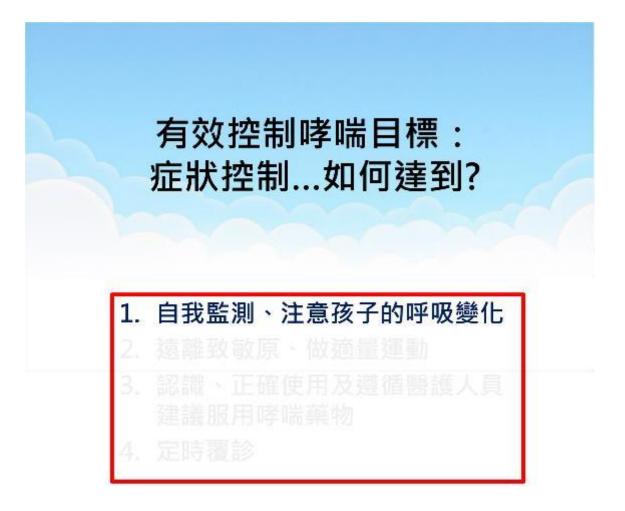


一 位家長的心聲說:「小朋友哮喘就好似佢人生一個污點,抹極 都係度。」其實,倒不如說:「小朋友哮喘所帶俾你既情緒同感覺 就好似你作為父母的人生一個污點,抹極都係度。」

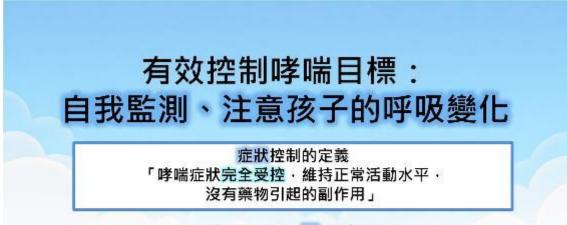












如果你的孩子是五歲或以下...

徵狀	完全受控	部份受控	不受控
(過去4星期)	符合以下所有情況	符合以下1或2項情況	符合以下3項或以上情況
日間病癥	沒有/每星期一次	每星期间	雨次或以上
日常活動受阻	沒有	有	
夜間病癥	沒有	有	
使用氣管舒張劑	沒有 / 每星期一次或 以下	或 每星期次兩次或以上	

#### 如果你的孩子是六歲或以上...



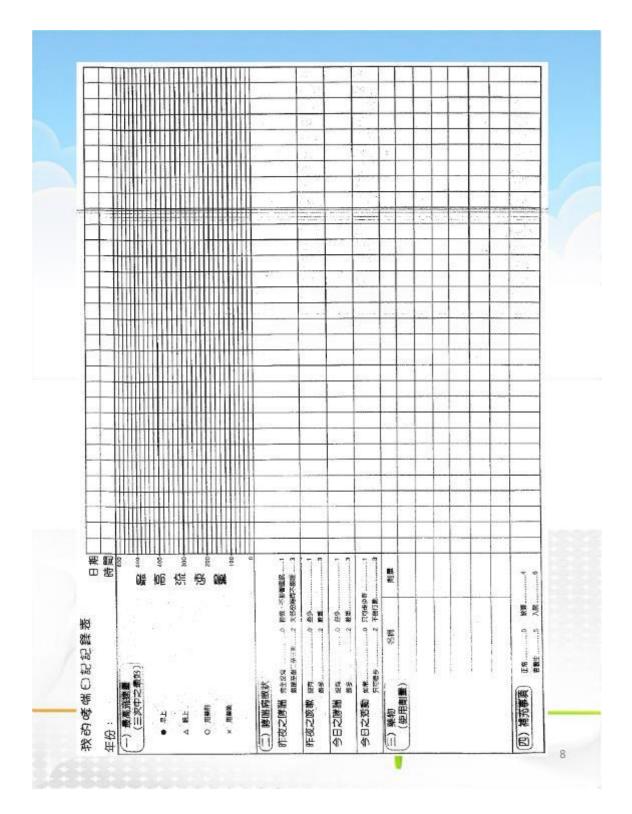


- 幫助判斷哮喘是否控制得宜,監察小孩對治療的反應
- 幫助及早發現哮喘的惡化情況

#### 注意:

 每次覆診時,請帶上你孩子的哮喘日記,你和你的醫 生可以重溫哮喘日記,以了解對你的孩子的哮喘控制 的結果。





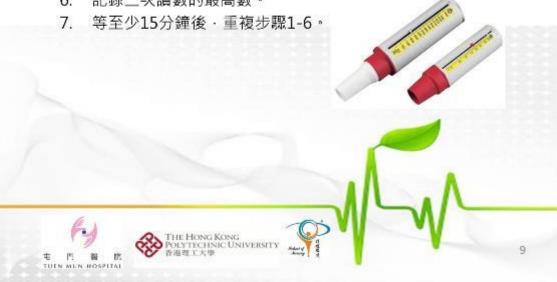
# 如何使用最高流速計

#### 注意事項:

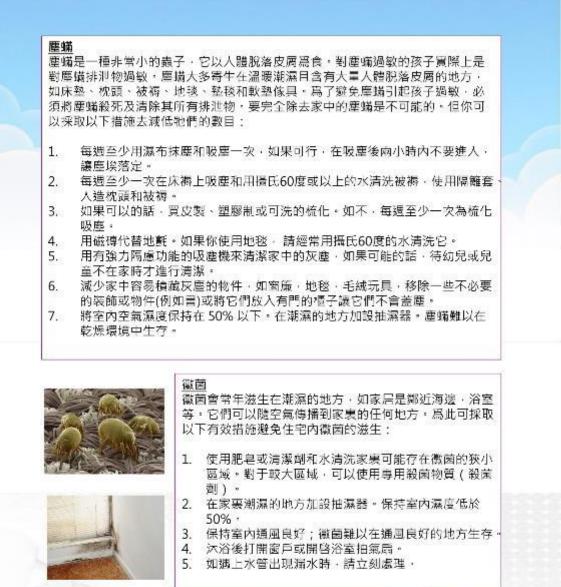
- · 只限六歲或以上兒童使用
- 應在服藥之前,早晚,每天同樣時間測試。
- 每次都應作最大努力以得可靠結果。

#### 步驟:

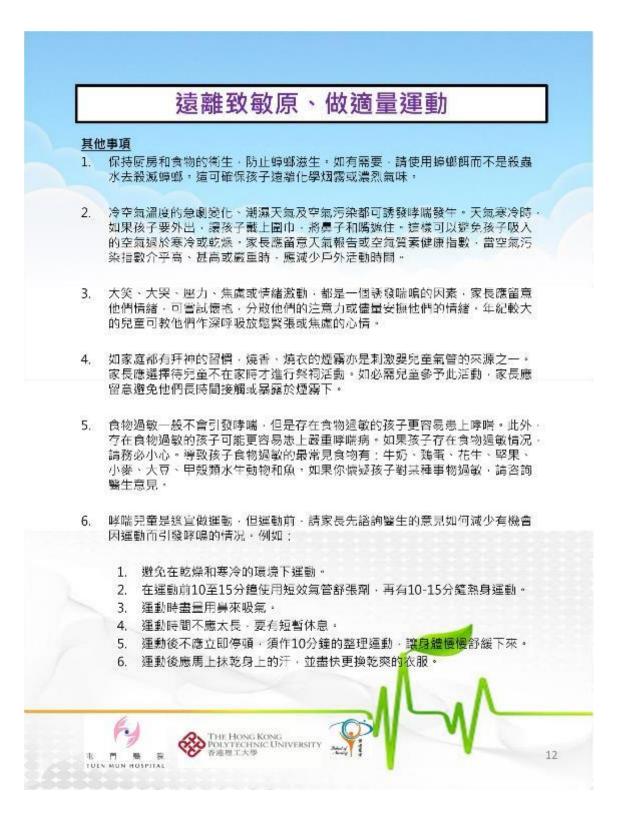
- 1. 把指標移到量尺底部
- 2. 用手指輕握量表,避開指標的移動。
- 盡可能作一次深呼吸,用嘴唇緊緊封住吹口。盡可能用 力氣和快速地吹,讓量表保持水平狀態。
- 4. 注意量尺的讀數。
- 5. 把指標退回量尺底部。重複一次。
- 6. 記錄三次讀數的最高數。











Homework assignment (Session Two)

家長姓名:\_\_\_\_\_\_ 小朋友姓名:\_\_\_\_\_\_

#### 護理兒童哮喘計劃

家長工作坊: 第二節.

#### 家課:接納照顧孩子的挑戰

在這一星期內,日常生活中,請你您在照顧小孩覺得挑戰的事情,尤其是您的想法和感受。

例如是:小孩回校上課時不肯/忘記用藥,到公園玩時有病徵,睡覺時有病徵,花費功夫避開 致敏源 (煙, 寵物)而,小孩有情緒時,你有情緒時等。如果嘗試選擇接納,會有什麼不同?

日期	前因	行為	後果	你有沒有嘗試選擇接
	發生了什麼事?		之後發生了什麼?	納這些感覺/想法?
例子:				
	情況 (你見到什麼?)	(你的想法和感受出	你的想法和感受有沒	有/沒有
	晚上,女兒又喘氣了。	現後 · 你如何應對?)	有離開過?仍然存	
		幫我女兒用藥·用藍	在·還是越來越差?	
	想法 (你腦海第一時間·	色氣管擴張劑先。	一直存在·天氣一轉就	如果有·你是怎麼做
	想了什麼說話?)		有。	呢?
	「點解又喘氣呢?我希望	我會處理女兒喘氣		
	幫到佢改善。」	先。我經常想: 我什		我知道無助、擔心的
		麼都幫唔到佢·我會	如果長此下去·會有什	感覺又來了。我有嘗
	感受	擔心藥物副作用·為	麼影響?	試深呼吸·然後仔細
	身心都覺得好無助·好似	什麼病情一直方好	過份擔心·好想有人幫	觀察當下女兒喘氣的
	方其他藥物或醫生能助我	轉?	助我女兒	情况, 幫我女兒用
	女兒改善病情。			<i>藥 · 用藍色氣管擴張</i>
				劑先。
	身體感覺			
	心跳快			

1

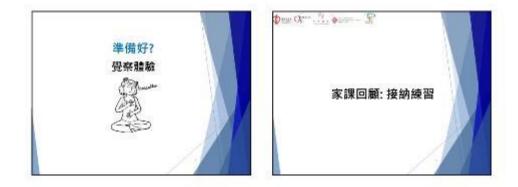
日期	前因	行為	後果	你有沒有嘗試選擇接納
니까	發生了什麼事?	שאי ב ו	这 <sup>条</sup> 之後發生了什麼?	這些感覺/想法?
	情況 (你見到什麼?)	(你的想法和感受	你的想法和感受有沒有離開	
			過? 仍然存在,還是越來越	
		出號後·亦做了重 什麼?)	差?	
	想法 (你腦海第一時間想了	11/24:)	<u> 左:</u>	如果有·你是怎麼做
	什麼說話?)			呢?
	11/34, p/L pD : )			₩C :
	感受		如果長此下去・會有什麼影	
			響?	
			<u> </u>	
	身體感覺			
	2腔感見			
<u> </u>	情況 (你見到什麼?)	(你的想法和感受		<u></u> 右心右
			過?仍然存在·還是越來越	7月/汉方
		山現後・小岡丁型 什麼?)	差?	
	想法 (你腦海第一時間想了	11/22:)	<u>左(</u>	如果有·你是怎麼做
	<u>湿法</u> (小脑海第一时间湿了 什麼說話?)			如未有,你定怎麼做 呢?
	11/22 武 前()			₩Б :
			和田巨山丁十 金方仙庭影	
	<u>感受</u>		如果長此下去·會有什麼影	
			響?	
	白血素式問			
	身體感覺			
			你的相计和成立方法主动的	
	情況 (你見到什麼?)	(你的想法和感受 出現後、你做了些	你的想法和感受有沒有離開	7月/ 汉 7月
			過?仍然存在 · 還是越來越	
	相计 化应燃发体 时期中了	什麼?)	差?	加用方 你自定庭世
	想法 (你腦海第一時間想了			如果有 · 你是怎麼做 呢 ?
	什麼說話?)			ΨԵ 1
	感受			
			如果長此下去,會有什麼影	
			響?	
	身體感覺			

#### Appendix 4.4. ACT interventional materials for Session Three

#### **PowerPoint Slides (Session Three)**

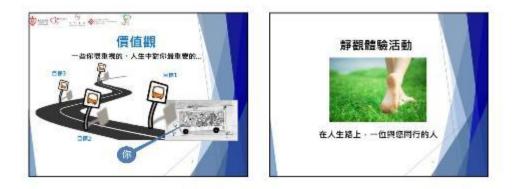


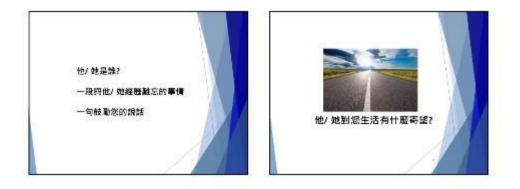


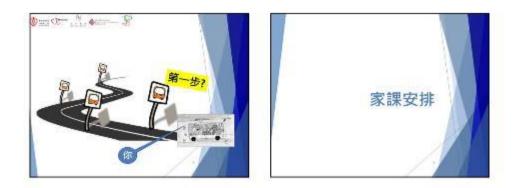


183	東因 日中7年出進7	行為	祝年 之後後年7日夜	使有效有量试剂 增加於注意服果 均均33	接納體驗活動
	歴史 に 東京 市 東京 市 東京 市 市 東京 一 小 町 市 市 市 市 市 市 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 町 一 小 二 一 小 二 一 小 二 一 小 二 一 一 小 二 一 一 小 二 一 一 二 一 一 一 一 一 一 一 一 一 一 一 二 一 一 一 一 一 一 一 一 一 一 一 一 一	(年19月1日年 第三日1日 第三日日第十 7)	体的相应在接受 <u>通过通知度适</u> 。 (約約47 法) 起来后差了 正来后差了 二 二 二 二 二 一 二 一 二 一 二 二 一 二 二 一 二 二 一 二 二 一 二 二 一 二 二 一 二 二 一 二 二 一 二 二 二 二 二 二 二 二 二 二 二 二 二 二 二 二 二 二 二 二	404 247 - 923 247 -	
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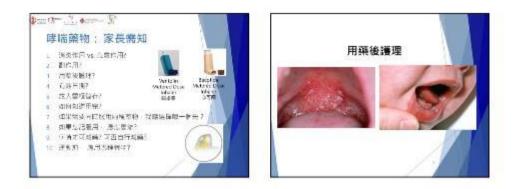
















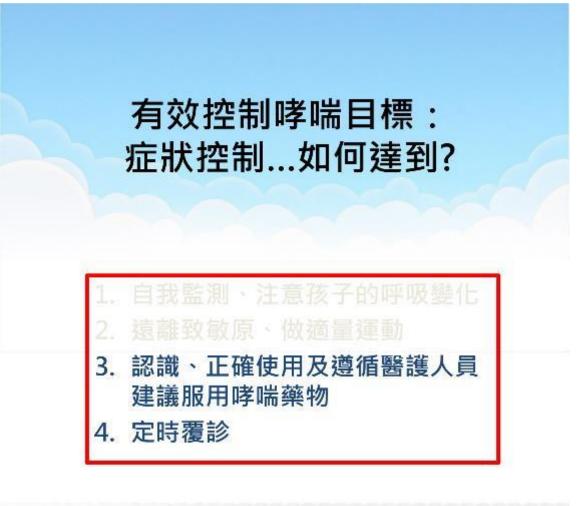
#### Handouts (Session Three)



## 如何更有效回應情緒和壓力? 覺察當下

- 家長們有情緒問題往往並非是遇到不幸的事情,而是他們面對事情的態度, 覺察當下是全神貫注地留意當下眼前的事情,只留意當下身、心的每一刻反應,注意思想和感受,不加上任何個人意見或批評。有時不經意把自己等同 了情緒。例如他們抑鬱時,把自己和抑鬱混為一體,或把自己困在抑鬱裡, 走不出來,因此自我就停留在抑鬱的情緒裡,幾乎將「我」等同「抑鬱」, 擔心內疚等各樣負面情緒。
- 其實不快的情緒有如烏雲飄來,把太陽遮擋,但過一會兒,烏雲會飄走,太 陽便會再次照耀大地,當然,烏雲也會有再來的時候,但因為我們知道它是 會飄走的,所以仍能保持平常心,







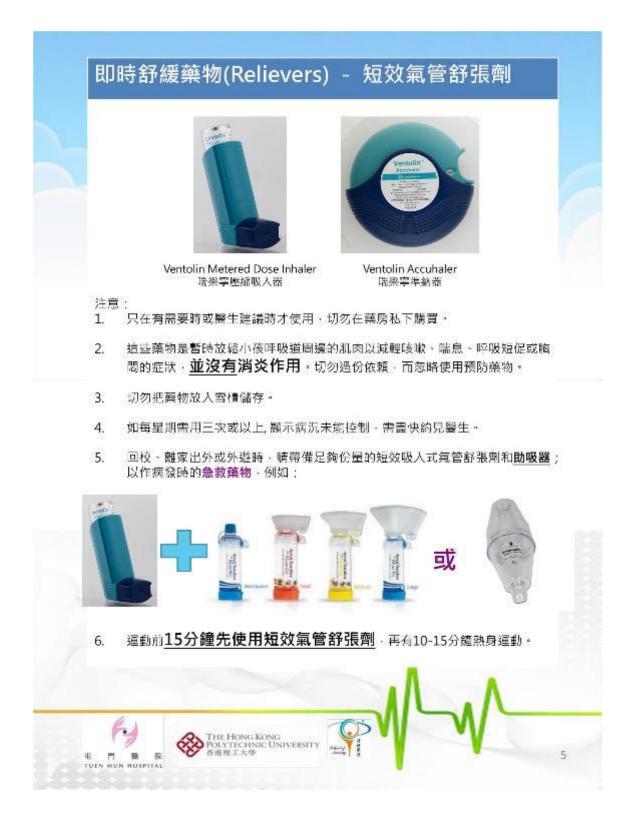
# 有效控制哮喘目標:要點3

## 認識、正確使用及遵循醫護人員建議服用 哮喘藥物

哮喘藥物共分為兩大類:

- 1. 即時舒緩藥物(Relievers) 短效氣管舒張劑
- 2. 長期預防藥物 (Controllers) 吸入式類固醇、吸入式混合型藥物和 口服長期預防藥物

	井方	吸入式類固醇	
顏色	藍色	啡/ 紅/ 橙色	
用途	即時舒緩藥物: 哮喘病發時或運動前使用	長期預防藥物: 每日長期及按時使用,沒有病徵的日子, 亦應繼續用藥,否則是不會發揮作用	
作用	<ol> <li>迅速舒缓收紧的氣管肌肉</li> <li>氣管擴張</li> <li>改善氣喘、連續咳嗽及胸口發悶</li> <li>每星期需用三次或以上, 顯示病況未能控制、需盡快約見醫生</li> </ol>	<ol> <li>定期使用可减少支氣管的發炎及腫脹</li> <li>減低支氣管的過敏反應</li> <li>預防哮喘發作</li> <li>有別於用作殺細菌的消炎藥[抗生素</li> </ol>	
副作用	極少,但若劑量很高的話會短 暫使心跳加速、肌肉輕微抖震, 又有點過度活躍,但這些情況 通常是因為氣管擴張劑的劑量 很高	少許機會出現舌痛、喉痛、聲音沙啞,以 及口腔感染(即鵝口瘡),要防止這些副 作用,你應確保子女在使用長期預防藥物 吸入器後 <mark>漱口刷</mark> 牙	
	若 <b>同時</b> 使用哮喘藥物,外 等五分鐘再服		







Reference: Global Initiative for Asthma (2015). Global Strategy for Asthma Manag http://www.pinasthma.org/local/colocads/files/GINA\_Report\_2015\_Auri1.odf

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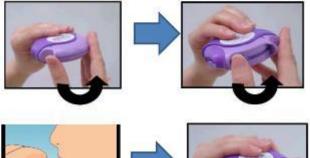






#### 如何使用準納器

- 用一隻手握住準納器的外殼,用另一隻手的大姆指把手掣推開,打 開吸嘴。
- 手握準納器·把吸嘴口向着小孩自己·推開釋藥扳機·直至聽到卡 嗒響聲。這步驟準備藥粉以供吸入·並把劑量計算器推動。
- 緩緩呼氣,橫向握着準納吸入器,將吸嘴含於唇間,迅速地深長吸氣。
- 4. 把準納器移離口部,忍氣約10秒,再慢慢地呼氣。
- 5. 用完儀器請封蓋·把手掣往自己方向推至盡頭,即可關閉吸入器。
- 6. 如需服用第二劑量,請重複步驟1至5。







#### 都保吸入器注意事項:

- 如想知道你的孩子的準納器吸入裝置中還剩餘多少藥,請經常觀察 準納器吸入裝置一側的劑量記數器。計數器開始於60劑。每用一個 劑量的藥物,計數器會減去1個劑量。當劑量跌至0至5時,全以紅 色顯示,提示只剩下數次劑量。
- 2. 使用完畢後務必漱口。
- 3. 保持吸入器的乾燥。
- 4. 不要對著吸入器吹氣。
- 5. 只有當小孩要吸入藥品時,才推動釋藥扳機。

Reference: Global Initiati-	ve for Asthma (2015). Instructions for inha	aler and spacer use. Retrieved from	٨
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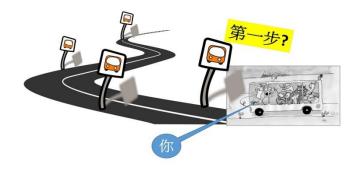
### Homework assignment (Session Three)

家長姓名:\_\_\_\_\_\_ 小朋友姓名:\_\_\_\_\_\_

1

2

護理兒童哮喘計劃 哮喘工作坊:第三節 家課:你對自己價值觀的了解

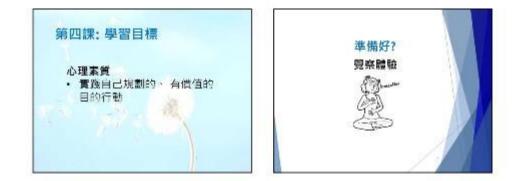


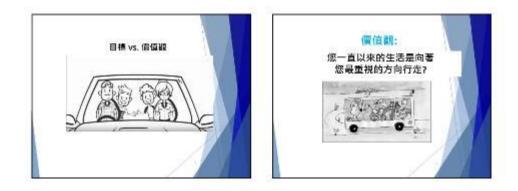
您人生最重視的方向	您的第一步 (有什麼可以做得更好?)	障礙您的想法.感受 (人生巴士麻煩的乘容)
我最重視的是:	明天 · 我會做:	1: 2: 3: 4: 5:

#### Appendix 4.5. ACT interventional materials for Session Four

#### **PowerPoint Slides (Session Four)**

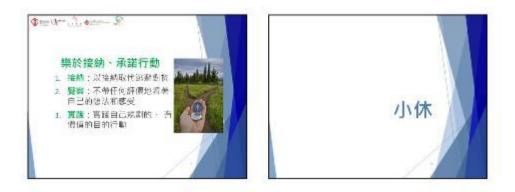




















#### Handouts (Session Four)

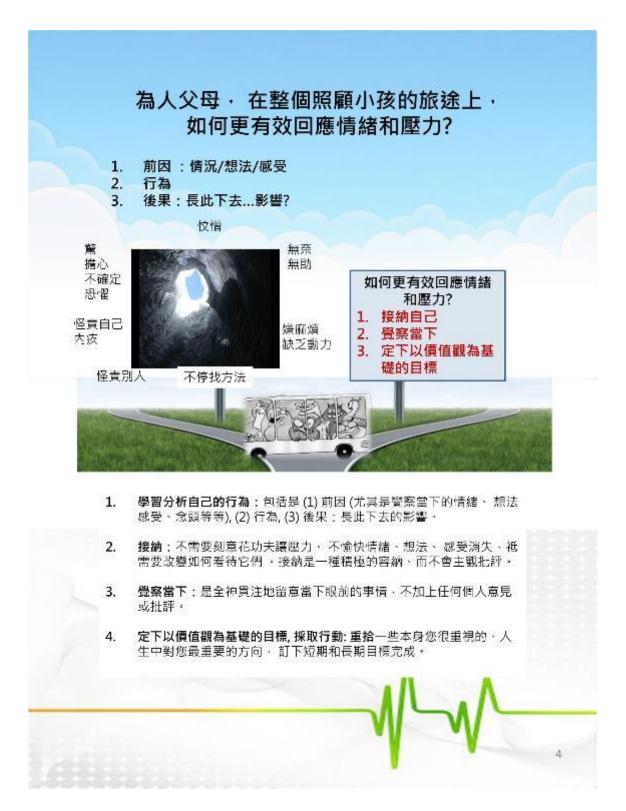


# 如何更有效回應情緒和壓力? 你對自己價值觀的了解

 價值觀指是指向未來的,嚮往的和所選擇的生活方向。按照自己 的價值觀選擇生活方式,可以使生活充滿活力。小孩患上哮喘後, 少不免在父母生涯中帶了些起伏。有如第三課所提及,家長們有 情緒問題往往並非是遇到這件事情的本身,而是他們面對事情的 態度。父母會不知不覺間困在不愉快的記憶、想法、情緒和感受 中,和它們糾纏,而將一些本身很重視的、人生中對你最重要的 東西忘記。有如駕駛著您的人生巴士,您對不安、煩燥的乘容給 予的反應越多,您根本沒有專注您的軚盤,您只會越來越喪失方 向。

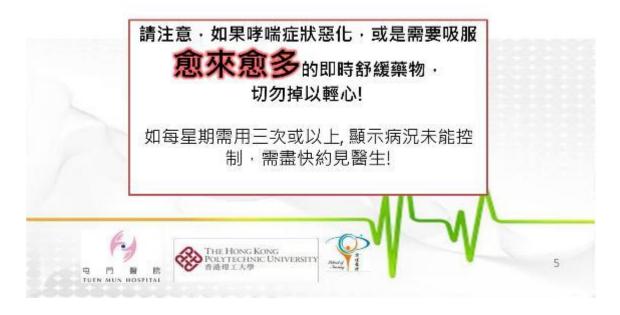
 家課內「你對自己價值觀的了解」是一個了解您自己,作為爸爸、媽媽、照顧者的角色中,是否過著有價值的生活。當您明白您的價值觀是什麼,就算面對著巨大的不幸、將來的挑戰, 選擇您所重視的並朝著這個方向努力,也可以令您的生活更富有和充滿意義。





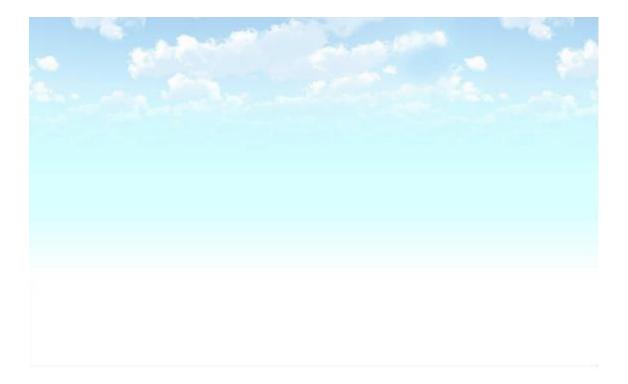
# 哮喘急性惡化的先兆 和處理

- 開始出現或增加咳嗽、喘鳴、胸口有壓迫感或呼吸急 促等症狀;胸骨上方或肋骨下方凹陷;通常焦躁不安
- 半夜因為咳嗽、喘鳴、胸口有壓迫感或呼吸急促而影響睡眠;
- 運動或爬樓梯後會有咳嗽、喘鳴、胸口有壓迫感或呼吸急促等症狀;
- 4. <u>短效氣管舒張劑的使用頻率增加</u>· 無法維持四個小時 以上;
- 5. 最高流速率遠低於預測參考值或個人最佳值的80%。



2	
	你需要什麼?
哮	
1.	保持冷靜·安撫孩子·不要獨自離開·坐起。
2.	搖動吸入器,立即使用有面罩的、助吸器及吸服即時舒緩藥物(喘樂寧,Ventolin®,藍色噴霧劑)。
3.	<ul> <li>2次劑量、15分鐘再2次,一共4劑,可迅速紓解氣喘</li> <li>如果症狀有所改善,無須打999,你仍必需要在24 小時內送孩子去看醫生或哮喘專科護士,在24小時 內每四小時吸一口,密切觀察。</li> </ul>
	<ul> <li>如沒有改善,請打999求助(必須清楚說明小朋友現 在哮喘病發),立即到急症室。</li> </ul>







# Appendix 4.6. Fidelity checklist for each ACT session

# ACT FIDELITY CHECKLIST (ACT GROUP CLASS \_\_\_\_\_)

Date of therapy session:

Date of assessment:

Assessor:

# Part A. Therapeutic stance

Instruction: Below are listed a number of statements. Please rate how true each statement is when Therapist is using ACT, by filling in the number in the spaces provided. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

	Session	1	2	3	4
1.	Therapist realizes that he or she is in the same soup as the client and speaks to the client from an equal, vulnerable, genuine, and sharing point of view. (ACT CCR item 1)				
2.	Therapist models willingness to hold contradictory or difficult ideas, feelings, memories, and the like without needing to "resolve" them. (ACT CCR item 2)				
3.	Therapist takes a compassionate and humanizing stance toward the client's suffering and avoids criticism, judgment or taking a "one up" position. (ACT CCR item 3)				
4.	Therapist always brings the issue back to what the client's experience is showing and does not substitute his or her opinions for that genuine experience. (ACT CCR item 4)				
5.	Therapist does not argue with, lecture, coerce or even attempt to convince the client of anything. If you find yourself attempting to change a client's				

mind, stop. You are not doing ACT. (AC item 5)	CT CCR
6. Therapist does not explain the "meaning paradoxes or metaphors to develop "insi CCR item 6)	
<ol> <li>Therapist is willing to self-disclose about issues when it makes a therapeutic point CCR item 7)</li> </ol>	1
8. Therapist avoids the use of "canned" AC interventions. Interventions are response particular client we are treating. (ACT C	s to the
9. Therapist tailors interventions to fit the c language and immediate life experience item 9)	
10. Therapist sequences and applies specific interventions in response to client needs, ready to change course to fit those needs moment (ACT CCR item 1)	and is

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# Part B1. Core competence assessment: Session 1

Date of therapy session: \_\_\_\_\_

Date of assessment:

Assessor: \_\_\_\_\_

Below are listed a number of statements. Please rate how true each statement is when

Therapist is using ACT, by filling in the number in the spaces provided. Use the

scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

Activity	ACT process(es) targeted	Statement for rating	Video record time	Score
Mindfulness exercise to guide parents in exploring a	Contacting with the present moment	• The therapist can defuse from client content and direct attention to the moment (ACT CCR item 36)		
challenging moment in taking care of their children with asthma		<ul> <li>The therapist uses exercises to expand the client's sense of experience as an ongoing process (ACT CCR item 38)</li> <li>The therapist detects client drifting into past and future orientation and comes back to now. (ACT CCR item 41)</li> </ul>		
ACT metaphor illustration: A Man in a Hole Metaphor	Acceptance	<ul> <li>The therapist helps client examine direct experience and detect emotional control strategies (ACT CCR item 14)</li> <li>The therapist helps client make direct contact with the</li> </ul>		
		paradoxical effect of emotional control strategies (e.g., using metaphors such as "A Man in a		

Hole Metaphor) (ACT CCR item 15)	
• The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative (ACT CCR 17)	
• The therapist helps client make experiential contact with the cost of being unwilling relative to valued life ends (e.g., listing out the emotional control strategies, cost, short term/long term costs and benefits). (ACT CCR item 20)	

Comments:\_\_\_\_\_

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# Part B2. Core competence assessment: Session 2

Date of therapy session: \_\_\_\_\_

Date of assessment: \_\_\_\_\_

Assessor: \_\_\_\_\_

Below are listed a number of statements. Please rate how true each statement is when

Therapist is using ACT, by filling in the number in the spaces provided. Use the

scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

Activity	ACT process(es) targeted	Statement for rating	Video record time	Score
Homework review: A mindfulness log to record your experiences in parenting a child with asthma	Defusion	<ul> <li>The therapist identifies client's emotional, cognitive, behavioral or physical barriers to willingness. (ACT CCR item 26)</li> <li>The therapist suggests that "attachment" to the literal meaning of these experiences makes willingness difficult to sustain. (ACT CCR item 27)</li> </ul>		
		• The therapist actively contrasts what the client's "mind" says will work versus what the client's experience says is working. (ACT CCR item 28)		
		• The therapist uses various exercises, metaphors and behavioral tasks to reveal the "hidden" properties of language. (ACT CCR item 32)		
ACT metaphor	Acceptance	• The therapist helps client examine direct experience and detect		

illustration: The Tug-of- War Metaphor		<ul> <li>emotional control strategies. (ACT CCR item 14)</li> <li>The therapist helps client make direct contact with the paradoxical effect of emotional control strategies (e.g., using metaphors such as The Tug-of-War Metaphor). (ACT CCR item 15)</li> </ul>	
		• The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative. (ACT CCR item 17)	
Group activity: Acting out the "Passengers on the Bus" Metaphor	Defusion	• The therapist uses language tools and/or metaphors (e.g., the Passengers on the Bus metaphor) and experiential exercises to create a separation between the client and client's conceptualized experience. (ACT CCR item 29)	
	Acceptance	<ul> <li>The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative. (ACT CCR item 17)</li> <li>The therapist uses metaphors (e.g., the Passenger on the Bus metaphor) to help client contact willingness the action in the presence of difficult material. (ACT CCR item 22)</li> </ul>	

# Comments:\_\_\_\_\_

*Note*. ACT = Acceptance and Commitment Therapy. CCR = Core competency rating. The above statements were retrieved from the Acceptance and Commitment Therapy Core Competency Self-Rating Form (Luoma et al., 2007). The item number indicates the ones stated in the Core Competency Self-Rating Form.

#### Part B3. Core competence assessment: Session 3

Date of therapy session:

Date of assessment: \_\_\_\_\_

Assessor: \_\_\_\_\_

Below are listed a number of statements. Please rate how true each statement is when

Therapist is using ACT, by filling in the number in the spaces provided. Use the

scale below to make your choice.

1	2	3	4	5	6	7
nev tru	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

Activity	ACT process(es) targeted	Statement for rating	Video record time	Score
Homework review: A mindfulness log to explore your willingness to experience your struggles when caring for a child with asthma	Acceptance	<ul> <li>The therapist helps client examine direct experience and detect emotional control strategies. (ACT CCR item 14)</li> <li>The therapist actively encourages client to experiment with stopping the struggle for emotional control and suggests willingness as an alternative. (ACT CCR item 17)</li> </ul>		
		• The therapist helps client make experiential contact with the cost of being unwilling relative to valued life ends (e.g., listing out the emotional control strategies, cost, short term/long term costs and benefits). (ACT CCR item 20)		

Group activity:	Acceptance	The therapist uses exercise
The Eyes On exercise		(e.g., the Eyes On exercise) to help client contact willingness the action in the presence of difficult material. (ACT CCR item 22)
Group activity: The storyline exercise	Self-as- context	<ul> <li>The therapist uses metaphors to highlight distinction between products and contents of consciousness versus consciousness (e.g., the unwelcomed guest in the birthday party metaphor) (ACT CCR item 45).</li> <li>The therapist utilizes exercise to help the client make contact with self as context and distinguish this from the self as</li> </ul>
		conceptualized (ACT CCR item 46)
Mindfulness exercise: Recall your experience with the most unforgettable	Self-as- context	The therapist employs mindfulness exercises to help client make contact with self-as-context. (ACT CCR item 44)
person in your life	Contacting with the present moment	The therapist can defuse from client content and direct attention to the moment. (ACT CCR item 36)
		The therapist uses exercises to expand the client's sense of experience as an ongoing process. (ACT CCR item 38)
	Values	The therapist helps client clarify valued life directions (e.g., pick up the most unforgettable person in your life). (ACT CCR item 49)
		The therapist puts his or her own therapy relevant values in the room and models their importance. (ACT CCR item 51)

Comments:\_\_\_\_\_

*Note*. ACT = Acceptance and Commitment Therapy. CCR = Core competency rating. The above statements were retrieved from the Acceptance and Commitment Therapy Core Competency Self-Rating Form (Luoma et al., 2007). The item number indicates the ones stated in the Core Competency Self-Rating Form.

#### Part B4. Core competence assessment: Session 4

Date of therapy session: \_\_\_\_\_

Date of assessment: \_\_\_\_\_

Assessor: \_\_\_\_\_

Below are listed a number of statements. Please rate how true each statement is when

Therapist is using ACT, by filling in the number in the spaces provided. Use the

scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

Activity	ACT process(es) targeted	Statement for rating	Video record time	Score
ACT metaphor illustration: Two Kids in a	Values	<ul> <li>The therapist teaches clients to distinguish between values and goals. (ACT CCR item 52)</li> <li>The therapist halos client</li> </ul>		
Car Heading to an Amusement Park		• The therapist helps client clarify valued life directions (ACT CCR item 52)		
Homework review: your values-based action	Values	• The therapist helps client "go on record" as wanting to stand for valued life ends. (ACT CCR item 50)		
		• The therapist distinguishes between outcomes and processes. (ACT CCR item 53)		
	Committed Action	• The therapist helps client identify valued life goals and build an action plan. (ACT CCR item 55)		
		• The therapist encourages client to "have" barriers and make		

and keep commitments. (ACT CCR item 56)	
• The therapist encourages client to take small steps and to look at the quality of committed action. (ACT CCR item 58)	
• The therapist integrates slips or relapses into the experiential base for future effective action. (ACT CCR item 60)	

Comments:\_\_\_\_\_

*Note.* ACT = Acceptance and Commitment Therapy. CCR = Core competency rating. The above statements were retrieved from the Acceptance and Commitment Therapy Core Competency Self-Rating Form (Luoma et al., 2007). The item number indicates the ones stated in the Core Competency Self-Rating Form.

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Luoma, J. B., Hayes, S. C., & Walser, R. D. (2007). *Learning ACT: an Acceptance and Commitment Therapy skills-Training Manual for therapists*. Oakland: New Harbinger.

#### Appendix 5.1 The Bull's eye exercise

Note. This ACT was used in the pilot intervention, but it was excluded in the main RCT study. Please refer to Chapter Five Section 5.4 for the details.

<u>Part 1: Find your values</u> 第一部分:找出你的價值觀

Instruction: There are 4 important domains of life as a person: career/self-learning, leisure, relationships, personal health. Please write down your values in the four domains of life listed below. What's important? What do you care about? And what you would like to work towards?

指示: 在以下四個範疇中, 你的人生目標是怎樣? 你希望透過這些範疇中展現你 是什麼的人?

Career/ self-learning: _	
事業/學習:	

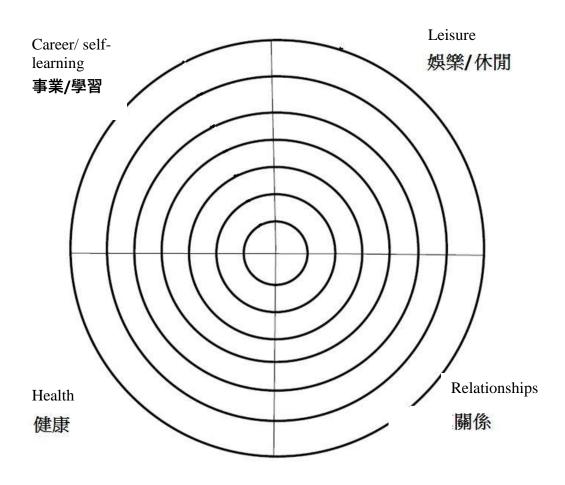
Relationships: _	
關係:	

Health:	
健康:	 _

Leisure:	
娛樂/休閒:	

Read through your values, then mark an X in each area of the dart board, to represent where you stand today. An X in the Bull's eye means you are living fully by your values in that area of life. An X far from Bull's eye means that you are way off the mark in terms of living by your values.

請閱讀你寫的價值觀,然後在飛鏢板的每個區域標記一個 X,以表示今天你站在哪裡。如果你標記 X 在中心點,這意味著你完全按照你的價值觀生活。如果你標記 X 是遠離中心,這意味著你沒有按照你的價值觀生活。



<u>Part 2: Action plan</u> 第二部分:行動計劃

What could you do to move closer to your values? Brainstorm and write down any tiny steps you could easily make in your everyday life? What would be the smallest step you could make closer to your values?

你能做些什麼來接近你的價值觀?請想一想並寫下你在日常生活中可以輕鬆做 到的任何微小步驟?你最接近你的價值觀最小的一步是什麼?

For example, in the life domain about RELATIONSHIP, you value about of "Developing a companionable relationship with my child when he/she grows up, so that my child will consider me as a true friend"

例如,關於「關係」的領域中,你重視「與我的孩子建立同伴關係,希望將來我的孩子會視我為一個真正的朋友。」

If you choose to commit to working on this value, one of the smallest and achievable goals could be: *"To allow my child enjoy jogging with his friends next week (less restriction to physical exercise that my child loves to)* 

如果你選擇致力於實現這一價值,則其中一個最小且可實現的目標可能是: 「允許我的孩子下週與他的朋友一起享受慢跑。」(較少限制我的孩子參與體 育運動)

Career/ self-learning: \_\_\_\_\_\_ 事業/學習:\_\_\_\_\_

Relationships:	
關係:	

Health:	 _
健康:	 

Leisure:	
娛樂/ 休閒 :	

<u>Part 3. Identify your obstacles</u> <u>第三部分:找出你的障礙</u>

What are the obstacles between you want to act on and the life you want to live? In each life domain, pick up an event that's difficult to you.

你想要採取行動和你想要的生活之間有什麼障礙? 在每個生活領域,拿起一件難以對付的事件。

For example, one of the smallest and achievable goals could be: "To allow my child enjoy jogging with his friends next week", but your immediate thought could be: "My child always begs for outdoor activities with his friend. I was thinking what if my child forgot to bring his inhaler? Can he manage his asthma well?" "I feel worried about that. I am not sure whether he can take care of himself" 例如,其中一個最小且可實現的目標可能是:「允許我的孩子下週與他的朋友 一起享受慢跑。」但即時障礙您的想法可能是:「我的孩子總是乞求和他的朋 友去外面玩。我在想,如果我的孩子忘了帶他的吸入器怎麼辦?他能治好他 的哮喘嗎?我很擔心。我不知道他能否照顧自己...」

Please fill in a score, from 0 to 10, to indicate how powerful the obstacle is. 請填寫從 0 到 10 的分數,以表明障礙的強大程度。

Career/ self-learning:	[]
事業/學習:	[]
Relationships:	[]

關係:	[ ]
Health:	
Leisure: 娛樂/ 休閒 :	

# Part 4. Strategies to get back your valued-based direction

第四部分:讓自己回到以價值為本的策略

From time to time, if we have difficult thoughts and feelings in fulfilling the above life domains, you may feel struggled. We are easily getting away from our values and begin to "dig" and to avoid. What are your plans to tackle and to keep you on track?

有時候,如果我們在實現上述生活領域遇到困難的想法和感覺,你可能會感到 掙扎。我們處理事情時很容易擺脫我們的價值觀,開始逃避不安的感覺。你 有什麼方法應對?

Career/ self-learning: 事業/學習 :	
Relationships: 關係 :	
Health:	
Leisure: 娛樂/ 休閒 :	

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