A RANDOMISED CONTROLLED TRIAL ON CLINICAL EFFECTIVENESS OF MASSAGE THERAPY IN MULTISENSORY ENVIRONMENT FOR RESIDENTS WITH SEVERE AND PROFOUND INTELLECTUAL DISABILITIES (SPID)

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CHAN SAU LAI JENNY

A thesis submitted in partial fulfilment of the requirements

for the degree of Doctor of Philosophy

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CERTIFICATE OF ORIGINALITY

I hereby declare that this thesis is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material which has been accepted for the award of any other degree or diploma, except where due acknowledgment has been made in the text.

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ABSTRACT

Background

Institutional care is the major service provision for people with severe and profound intellectual disabilities due to their high dependence on activities of daily living and physical illness. The daily schedule is usually non-stimulating and monotonous, which can be the contributing factors of their challenging behaviour. The adverse consequences of challenging behaviour can induce physical injury to self, as well as others. As a result, physical isolation and social exclusion are inevitable. Eventually, quality of life of these intellectually disabled persons could be compromised due to markedly reduce access to the community and recreational facilities. Recent literature has suggested that relaxation activities could reduce their challenging behaviour contributed by the counteractive effect of muscle relaxation on psychological distress. Despite having inconclusive evidence, multisensory environment and massage therapy have been increasingly used to manage challenging behaviour.

Aim

The aim of this study was to evaluate the clinical effectiveness of

multisensory environment and massage therapy for residents with severe and profound intellectual disabilities in improving positive behaviour, and reducing the challenging behaviour through observations and non-invasive instrument as measuring tools.

Methods

A randomised controlled trial with mixed methods design was conducted in a long-term care facility in Hong Kong to evaluate the effects of three intervention groups, i.e., multisensory environment, massage therapy and their combined use with a control group of usual care on reducing the challenging behaviour of residents with severe and profound intellectual disabilities. All eligible residents were recruited and then randomly assigned into one of the three treatment groups, or usual care only (n=31-34/group) for 10-week intervention after a one-month washout period. Outcome measures, including frequency and severity of challenging behaviour, adaptive and maladaptive behaviour, alertness level, and physiological data (heart and respiration rates), were assessed at recruitment, and immediately after the 10-week intervention. Carryover effects were also assessed two weeks after the completion of all intervention in the usual care environment.

After completion of the quantitative study, a semi-structured interview was conducted for the primary nurses of the participants in the qualitative study. Their perceptions on the benefits and limitations of the interventions were explored to supplement the quantitative data as all participants were unable to express themselves.

Results

A total of 129 participants (63 male and 66 female) completed the study. There were significant improvements in frequency and severity of challenging behaviour, respiration rate, amount and duration of adaptive behaviour, passive alert and sleepiness in the study groups. The primary outcomes, frequency and severity of challenging behaviour, showed significant change between groups, but unable to identify which group was more remarkable in pairwise comparison, probably due to insufficient sample size and homogeneous of the sample. Participants in the three intervention groups showed persistent reduction of respiration rate than the control group, especially in the multisensory environment and the combined treatment. Participants in massage therapy had significantly greater increases in their amount and duration of adaptive behaviour over 2-week follow-up than those in

multisensory environment, and those in combined treatment; and they also showed greater reduction in sleepiness during and after the intervention. The massage therapy in multisensory environment demonstrated the most relaxed level in passive alert during the intervention, and massage therapy maintained its passive alert level after two week follow up. Overall, the within-group effects on most study outcomes were significant in the study.

The perceptions of the nursing interviewees were very positive to the massage therapy and multisensory environment but commented the insufficient dose and duration of the interventions, especially the massage therapy. Nevertheless, they did not notice the gradual improvement of the participants in the frequency and severity of challenging behaviour.

Conclusion

Generally, the therapeutic effect of massage therapy was more significant than multisensory environment and combined treatment, and able to sustain for 2 weeks. Though massage therapy had greatest magnitude of change in frequency and severity of challenging behaviour than other study groups, the significance level of pairwise contrast test was not substantiated. Hence, there is a need for additional

strategies to enhance longer-term effects of massage therapy and multisensory environment in reducing challenging behaviour in the usual care environment. Brief mental exhaustion could be resulted due to overwhelming of sensory inputs in the multisensory environment; hence, there is a need for manipulation of dose and frequency of the treatment. The findings also indicated that the adaptive behaviour appeared to be associated with the alertness state. More research work is necessary to identify the potential predictive factors in order to improve the primary and secondary outcomes of these treatments for the residents.

LIST OF PRESENTATIONS AND PUBLICATIONS

Conference / forum presentations:

1. Chan, S.L.J. (2014, May). An evaluation of the clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities: A pilot study. Speed oral and poster presented at the *Hospital Authority Convention 2014*, Hong Kong.

2. Chan, S.L.J. (2016, May). A pilot controlled trial on clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities. Paper presented at the *Postgraduate Student Research Forum 2016*, the Hong Kong Polytechnic University, Hong Kong.

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2. Chan, J.S.L. & Chien, W.T. (2017a). A randomised controlled trial on evaluation of the clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities: A pilot study. *Journal of Intellectual Disability Research, 61*(6), 532-548.

3. Chan, J.S.L. & Chien, W.T. (2017b). A randomized controlled trial on clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities. *Neuropsychiatry (London), 7*(4), 321-336.

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TABLE OF CONTENTS

		Page
CERTIFICATE OF ORIGINALITY		i
ABSTRACT		ii
LIST OF PRESENTATIONS AND PUBLICATIONS		vii
ACKNOWLEDGEMENTS		viii
TABLE OF CONTENTS		xi
LIST OF FIGURES		xvii
LIST OF TABLES		xviii
LIST OF ABBREVIATIONS		xx
Chapter 1	**Introduction**	**1**
1.1	Study Background	1
1.1.1	Prevalence and classification of intellectual disability	1
1.1.2	Use of touch as a means of communication	3
1.1.3	Need for long-term residential placement	5
1.1.4	Conceptual framework of challenging behaviour	6
1.1.5	Adverse effects of challenging behaviour	9
1.1.6	Management of challenging behaviour	9
1.2	Research Problem	15
1.3	Aim, Objectives and Hypothesis	17
1.4	Research Significance	20
Chapter 2	**Literature Review**	**22**
2.1	Introduction	22
2.2	Factors Associated with Challenging and Self-Stimulating Behaviour	23
2.2.1	Genetic and biological factors	24
2.2.2	Psychosocial factors	25
2.2.3	Staff attributes	27
2.2.4	Environmental factors	28
2.2.5	Sensory driven	29
2.2.6	Resident-staff interaction patterns	30
2.3	Special Needs of People with Severe and Profound Intellectual Disabilities	32
2.4	Relationship Between Anxiety/Stress and Challenging	34

				Page
	Behaviour in People with Severe and Profound Intellectual Disabilities			
2.5	Interventions for Challenging Behaviour			35
2.6	Use of the Multisensory Environment			37
	2.6.1	Long-term effects		51
	2.6.2	Evaluating the effectiveness of the multisensory environment		53
2.7	Use of Massage Therapy			55
	2.7.1	Mechanisms of massage therapy		63
2.8	Use of Massage Therapy in the Multisensory Environment			65
2.9	Behavioural States of People with Severe and Profound Intellectual Disabilities in Response to Stimuli			69
2.10	Alertness and Behavioural States			73
2.11	Interactions with Environmental Stimuli			77
2.12	Measuring Challenging Behaviour, Levels of Relaxation, Alertness and Adaptive and Maladaptive Behaviour			80
	2.12.1	Evaluating the frequency of challenging behaviour		81
	2.12.2	Evaluating the relaxation effect		82
	2.12.3	Evaluating the frequency of adaptive behaviour		85
2.13	Summary			86
Chapter 3	**Study Methods**			**90**
3.1	Overview of Research Design			90
3.2	Research Setting			93
3.3	Sampling			96
	3.3.1	Study population and sample		96
	3.3.2	Inclusion and exclusion criteria		96
	3.3.3	Primary nurses as informants in semi-structured interviews		98
	3.3.4	Sample size		100
		3.3.4.1	Quantitative approach – randomised controlled trial design	100
		3.3.4.2	Qualitative data	102
	3.3.5	Recruitment and randomisation		103
	3.3.6	Ethical considerations		107
3.4	Interventions			108
	3.4.1	Multisensory environment		110

			Page
	3.4.2	Massage therapy	111
	3.4.3	Massage therapy in the multisensory environment	112
	3.4.4	Control group and post-intervention	113
3.5	Instruments and Outcome Measures		113
	3.5.1	Behaviour Problems Inventory	115
	3.5.2	Alertness Observation Checklist	117
	3.5.3	Behaviour Checklist	119
	3.5.4	Physiological data	120
3.6	Participants' Socio-Demographic and Clinical Data		120
	3.6.1	Semi-structured face-to-face interviews	121
3.7	Data Collection Procedure		123
	3.7.1	Quantitative data	123
	3.7.2	Qualitative data	125
3.8	Methods of Data Analysis		125
	3.8.1	Quantitative data	125
	3.8.2	Qualitative data	127
3.9	Summary of Study Methodology		129
Chapter 4	**Pilot Study**		**131**
4.1	Study Overview		131
4.2	Research Setting		132
4.3	Sampling		132
	4.3.1	Sample size calculation	132
	4.3.2	Recruitment and randomisation	133
4.4	Inclusion and Exclusion Criteria		133
4.5	Interventions		134
4.6	Measures		136
4.7	Data Collection Procedure		139
4.8	Data Analysis		139
4.9	Results		140
	4.9.1	Participants	140
		4.9.1.1 Descriptive data	140
	4.9.2	Results of outcome measures at baseline	141
	4.9.3	Main treatment effects (between-subject tests)	144
		4.9.3.1 Primary outcome	145
		4.9.3.2 Secondary outcomes	147
4.10	Discussion		147

			Page
	4.10.1	Overview	147
	4.10.2	Alertness states	148
	4.10.3	Frequency and severity of challenging behaviour	150
	4.10.4	Relaxation state	151
	4.10.5	Limitations of the pilot study and implications for the main study	152
4.11	Conclusions		154
Chapter 5	**Quantitative Results of the Main Study**		**155**
5.1	Introduction		155
5.2	Results		155
	5.2.1	Sample characteristics	155
	5.2.2	Outcome scores at baseline	159
	5.2.3	Interim progress of the outcome measures	161
	5.2.4	Overall treatment effects	167
	5.2.5	Between-group effects	170
	5.2.6	Within-group effects	181
5.3	Summary of Results		184
Chapter 6	**Qualitative Results of the Main Study**		**188**
6.1	Introduction		188
6.2	Interviewee Characteristics		188
6.3	Main Categories and Sub-categories Identified		189
6.4	Perceived Benefits of the Multisensory Environment and/or Massage Therapy		191
	6.4.1	Providing a place or an activity for relaxation and enjoyment	192
	6.4.2	Appraising massage therapy and the multisensory environment	193
	6.4.3	Offering sensory stimulation to fulfil the needs of those with sensory deficits	199
	6.4.4	Providing physical touch as a form of care and concern	201
6.5	Enhancing Intervention Quality		202
	6.5.1	Increasing intervention doses	202
	6.5.2	Providing a variety of intervention modalities	205
6.6	Possible Factors Contributing to Challenging Behaviour		206

			Page
	6.6.1	Personal factors	207
	6.6.2	External factors	208
		6.6.2.1 Usual care environment	208
		6.6.2.2 Work culture and attitude of direct care staff	210
		6.6.2.3 Support from family members	214
6.7	Managing Challenging Behaviour		215
	6.7.1	Identifying the purposes of challenging behaviour	216
	6.7.2	Improving the physical environment	220
	6.7.3	Engaging in meaningful activities	222
	6.7.4	Implementing person-centred care	224
6.8	Summary of Qualitative and Quantitative Findings		228
	6.8.1	Increasing adaptive behaviour during interventions	228
	6.8.2	Inducing relaxation in the massage therapy and multisensory environment	229
	6.8.3	Inducing sleepiness in the multisensory environment	230
	6.8.4	No significant change in challenging behaviour	230
Chapter 7	**Discussion**		**232**
7.1	Introduction		232
7.2	Treatment Effect on the Primary Outcome		232
	7.2.1	Challenges of managing challenging behaviour	243
7.3	Treatment Effects on Secondary Outcomes		246
	7.3.1	Heart and respiration rates	248
		7.3.1.1 Level of relaxation	249
	7.3.2	Levels of alertness	252
		7.3.2.1 Alertness and responsiveness	257
	7.3.3	Adaptive and maladaptive behaviour	264
		7.3.3.1 Presentation of positive behaviour	267
Chapter 8	**Limitations, Recommendations and Conclusions**		**272**
8.1	Introduction		272
8.2	Major Outcomes and Contributions to Health Service Research		272
8.3	Study Limitations		276
	8.3.1	Generalisability	276
	8.3.2	Inclusion and exclusion criteria	277
	8.3.3	Outcome measurements	278
8.4	Implications		279

			Page
	8.4.1	Implications for clinical practice	279
	8.4.2	Implications for nursing research	280
	8.4.3	Implications for staff development	282
	8.4.4	Implications for policymaking	283
8.5	Recommendations for Future Research		286
8.6	Conclusions		288

APPENDICES

Appendix I	Information Sheet for Nursing Staff	291
Appendix II	Informed Consent Form for Nursing Staff	294
Appendix III	Semi-structured Interview Guide (Investigator-constructed Questions)	296
Appendix IV	給家屬及監護人的資訊	299
Appendix V	同意書 (家長、親屬、監護人代理)	301
Appendix VI	Protocol of Massage Therapy	302
Appendix VII	Enabling Approach: The Roles of an Enabler	305
Appendix VIII	The Behaviour Problem Inventory (BPI-01)	306
Appendix IX	Descriptions of Alertness Observation Checklist (AOC)	309
Appendix X	Alertness Observation Checklist (AOC) Form C – Observation form for “Reactions to stimuli”	310
Appendix XI	Behaviour Checklist (15-minute observations)	311
Appendix XII	Behaviour Checklist (30-minute observations)	312
Appendix XIII	Socio-demographic & Clinical Data Sheet	313
Appendix XIV	Interview Questions for Primary Nurses of the Study Participants	314
Appendix XV	Summary of Remaining Verbatim	316

REFERENCES **328**

LIST OF FIGURES

Figure		Page
Figure 1.1	A conceptual framework explaining why challenging behaviour occurs	8
Figure 1.2	Proactive strategies and interventions for managing challenging behaviour based on the positive behaviour support approach	11
Figure 2.1	Model of descriptions	76
Figure 3.1	Flow diagram of the main study and sampling procedure	106
Figure 4.1	Flow diagram of the pilot study and sampling procedure	135
Figure 5.1	Change in the frequency of challenging behaviour from baseline to carryover	171
Figure 5.2	Change in the severity of challenging behaviour from baseline to carryover	171
Figure 5.3	Change in respiration rate from baseline to carryover	175
Figure 5.4	Change in the amount of adaptive behaviour from baseline to carryover	177
Figure 5.5	Change in the duration of adaptive behaviour from baseline to carryover	177
Figure 5.6	Change in the passive alert state (green 2) on the Alertness Observation Checklist from baseline to carryover	179
Figure 5.7	Change in the sleepy state (red) on the Alertness Observation Checklist from baseline to carryover	179
Figure 5.8	Change in the active alert state (green 1) on the Alertness Observation Checklist from baseline to carryover	183
Figure 5.9	Change in the inactive state (amber) on the Alertness Observation Checklist from baseline to carryover	183

LIST OF TABLES

Table		Page
Table 2.1	The characteristics of the multisensory environment studies for people with severe and profound intellectual disabilities	42
Table 2.2	The characteristics of the massage therapy studies for people with severe and profound intellectual disabilities	58
Table 2.3	The use of massage therapy in the multisensory environment for people with severe and profound intellectual disabilities	66
Table 3.1	Instrument details	114
Table 3.2	The psychometric properties of individual subscales of BPI-01	116
Table 4.1	Participants' demographic and clinical characteristics (N=42)	142
Table 4.2	Baseline assessment of different outcome measures in terms of mean and standard deviation (N=42)	143
Table 4.3	Treatment effects on different outcome measures in terms of mean and standard deviation (N=42) (Final data)	146
Table 4.4	Comparison of treatment effects on the Alertness Observation Checklist using the Mann-Whitney U test	147
Table 5.1	Participants' demographic and clinical characteristics (N=129)	158
Table 5.2	Baseline assessment of different outcome measures (N=129)	160
Table 5.3	Mean scores and standard errors of the outcome measures between baseline and interim measurements (N=129)	164
Table 5.4	Contrast tests of mean scores on significant outcome measures (respiration rate, passive alertness state and inactive state) at the interim measurement	166
Table 5.5	Comparison of mean scores on significant outcome measures within groups between the baseline and interim assessments (N=129)	166

Table		**Page**
Table 5.6	Mean and standard error of primary and secondary outcome measures from baseline to carryover (N=129)	168
Table 5.7a	Contrast tests of significant outcome measures on mean differences and significance levels from immediately after treatment (T_2) to carryover (T_3)	172
Table 5.7b	Contrast tests of significant outcome measures on mean differences and significance levels from immediately after treatment (T_2) to carryover (T_3)	173
Table 5.8	Within-group comparisons of mean scores on outcome measures across three time points (T_0 vs. T_3) (N=129)	181
Table 6.1	Interviewees' demographic characteristics (N=13)	189
Table 6.2	Main categories and subcategories of primary nurses' perceptions of the interventions used and managing challenging behaviour	190

LIST OF ABBREVIATIONS

AAC	Augmentative and Alternative Communication
AB	Adaptive Behaviour
ABA	Applied Behavioural Analysis
ANOVA	Analysis of Variance
AOC	Alertness Observation Checklist
AOL	Alertness Observation List
BC	Behaviour Checklist
BOS	Behaviour Observation Scale
BP	Blood Pressure
BPI-01	Behaviour Problems Inventory
Bpm	*breaths per minute*
bpm	*beats per minute*
BRS	Behavioural Relaxation Scale
CB	Challenging Behaviour
CBS	Challenging Behaviour Scale
CONSORT	Consolidated Standards of Reporting Trials
ECG	Electrocardiogram
EEG	Electroencephalogram
GEE	Generalized Estimating Equations
HA	Hospital Authority
HKSAR	Hong Kong Special Adminstrative Region
HR	Heart Rate
IBM SPSS	International Business Machines Statistical Package for the Social Sciences
ICC	Intra-class Correlation Coefficients
ID	Intellectual Disability
IFA	International Federation of Aromatherapists
IQ	Intelligence Quotient
M	Mean
MB	Maladaptive Behaviour
MSE	Multisensory Environment

MT	Massage Therapy
MT-MSE	Massage Therapy in Multisensory Environment
N	Number
NCR	Non-contingent Reinforcement
NICE	National Institute for Health and Care Excellence
PBS	Positive Behaviour Support
PEG	Percutaneous Endoscopic Gastrostomy
PIMD	Profound Intellectual and Multiple Disabilities
RR	Respiration Rate
SD	Standard Deviation
SIB	Self-injurious Behaviour
SPID	Severe and Profound Intellectual Disabilities
SSB	Stereotypic self-stimulating Behaviour

CHAPTER ONE
INTRODUCTION

1.1 Study Background

1.1.1 Prevalence and classification of intellectual disability

The prevalence of intellectual disability (ID) in the general population varies globally between 1% and 3% (Cooray & Bakala, 2005; Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). People with moderate and severe/profound grades of ID constitute approximately 10% and 5%, respectively, of the total ID population in the United States (American Psychiatric Association, 2013). In Hong Kong, the prevalence of ID is approximately 1-1.3% of the general population, accounting for 67,000-87,000 people (HKSAR Census and Statistics Department, 2014). There is no clear distinction between severe and profound ID, due to conflicting views over the classification and purpose of service provision (Lim, 2007). As a result, people who are unable to take intelligence assessments or are incapable of expressing themselves are eventually categorised as having severe to profound ID. In fact, the primary service provision for those with severe and profound ID is long-term residential care due to their severe cognitive impairments and associated physical disablements (Secretary for Labour and Welfare Bureau, 2016).

The diagnostic criteria of ID comprise three dimensions: (a) mental age or intellectual capacity is significantly lower than ordinary; (b) at least two adaptive functions in the aspects of verbal communication, social and interpersonal skills, and access of community resources and self-initiated activities are markedly disturbed; and (c) onset occurs before 18 years of age (American Psychiatric

Association, 2013). Most often, reliable informants are essential to evaluating the adaptive functioning of an individual with ID, as maladaptive functioning is often the manifestation of ID rather than the acknowledgement of a low intelligence quotient (IQ). Level of IQ is crucial in determining eligibility for access to ID service provisions in Hong Kong. Each level of ID is associated with an IQ range, including profound (IQ below 20), severe (IQ 20-34), moderate (IQ 35-54) and mild (IQ 55-70). Generally, ID includes all people with ID irrespective of their degree of mental incapacity. The term 'severe and profound intellectual disabilities (SPID)' specifically describes people with the lowest mental capacity and diverse physical disablements.

People with SPID are an extremely heterogeneous group in terms of their functional abilities and behavioural patterns, as some residents are able to walk independently, but most are bedridden and wheelchair bound. In Western countries, the classification of profound ID has further developed into a group that includes people with profound intellectual and multiple disabilities (PIMD) for whom the existing standardised assessment tests cannot provide valid estimates of their level of intellectual capacity and/or who exhibit profound neuromotor dysfunction, such as spastic tetraplegia and cerebral palsy (Nakken & Vlaskamp, 2007). They have an overall high risk of developing medical complications, such as seizure disorders, gastro-oesophageal reflux, gastritis, recurrent pulmonary infections, dysphagia and intestinal obstruction. Almost all require regular medications to prevent gastrointestinal bleeding, to control epilepsy and mental health problems and to sedate maladaptive behaviour (International Association for the Scientific Study of Intellectual Disabilities, World Congress, 2004). In Hong Kong, there is no further delineation between SPID and PIMD, as the term SPID

already includes the most fragile people and those who require support in their daily activities. They share the same service provisions and the same medical and financial benefits in Hong Kong.

Some may exhibit severely challenging behaviour with aggression. However, they more often display various forms of self-stimulating behaviour that frequently ignores environmental stimulation if not intervened. In addition, most individuals with SPID have apparently incapable to express or understand verbal language, cannot engage in symbolic or verbal interactions and have nearly zero ability for self-support. Their daily activities are mostly assisted by or dependent on caregivers. Furthermore, visual and/or hearing impairments are not uncommon (Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001).

1.1.2 Use of touch as a means of communication

In a local survey, over 95% of residents with SPID were identified as having a speech defect and communication problems, and approximately 10% of residents could only use single (mostly dichotomous answers) or simple words to communicate (Hospital Authority Mental Handicap Infirmary Service, 2003). Most were entirely unable to articulate clearly, and verbal communication was nearly impossible. In fact, facial expression and body language are the main communication means of residents with SPID who are fixated in a physical perception stage to interact with their surroundings, i.e., they use different sensations to experience their immediate environment (Hulsegge & Verheul, 1987). Another study showed visual and hearing impairments in 51% and 25%, respectively, of people with severe or profound ID below 50 years of age; for those 50 years of age or above, the prevalence of visual and hearing impairments

increased to 53% and 38%, respectively (Evenhuis et al., 2001). From the perspectives of caregivers, physical touch not only is the simplest way to communicate with residents with vision and hearing defects, but also fosters social closeness and affection. People with SPID often have difficulty maintaining a state of optimal alertness, and touch may be the clearest way for them to focus their attention to receive information from persons in their vicinity and to make contact with their immediate environment (Forster & Iacono, 2008). This is supported by a study of Field (2005), who found that increased affectionate touch could encourage children to exhibit more physical contact, sociable and helpful behaviour and less aggression towards their peers.

Touch is a basic human need and plays a very important role in normal human development. In particular, early tactile experiences may strongly contribute to shaping and strengthening the biopsychosocial functioning of an adult (Gallace & Spence, 2010). In an observational study, Gale and Hegarty (2000) noted that people with SPID expressed positive facial responses when therapeutic touch was administered. This form of touch is not contact through procedural care, but purposeful touch to facilitate physical or psychological benefit, such as that frequently performed in massage therapy (MT). It also involves emotional exchange with a reciprocal positive affect between the individual and staff, such as increased smiling and eye contact (Gale & Hegarty, 2000). Touch is perceived as a means of communicating care and attention. It is especially crucial for people with SPID and sensory deficits to relate their existence with their immediate environment. MT is described as a kind of therapeutic touch that facilitates relaxation (Gale & Hegarty, 2000). The indicators of relaxation that follow MT include lower blood pressure, heart and respiration rates and muscle excitability,

which is important in neurological rehabilitation in people with the spasticity (Goldberg, Sullivan, & Seaborne, 1992) that is common among those with SPID.

1.1.3 Need for long-term residential placement

Many people with SPID require long-term residential placement due to the severity of physical and/or mental problems. The conventional medical rehabilitation services for this group of people are focused on care and protection (Secretary for Labour and Welfare Bureau, 2016), which is mainly offered in an in-patient infirmary care setting. Once admitted to such a facility, they may live out the rest of their lives there. Care in the hospital setting is usually highly structured by a set of rigid daily routines. The environment is usually non-stimulating and monotonous (Chan et al., 2010). Details are discussed in Section 2.2.4. This may contribute to the challenging behaviour observed in many SPID residents. The new definition of challenging behaviour addresses the importance of social constructs. It refers to 'culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities' (Emerson & Einfeld, 2011, p. 7).

Challenging behaviour affects social order and may lead one to cause harm to oneself or others. More importantly, such behaviour limits one's access to community facilities and social integration, thus jeopardising one's quality of life (Emerson, 2001).

1.1.4 Conceptual framework of challenging behaviour

The challenging behaviour of ID residents comprises self-injurious behaviour (SIB), stereotypic self-stimulating behaviour (SSB), and destructive or aggressive behaviour. SIB refers to behaviour in which one causes damage to one's own body, such as by biting, eye/anal poking, head banging and slapping (Lambrechts & Maes, 2009; Singh et al., 2004). SSB includes behaviour that appears to be unusual, strange, ritualistic and repetitive and such behaviour has no purposeful function in daily life, for example, body rocking, hand flapping and finger twirling (Durand & Carr, 1987; Shapiro, Parush, Green, & Roth, 1997). Destructive or aggressive behaviour includes violent act and intentional attacks directed towards other individuals or objects, such as kicking, punching, and hitting (Lambrechts & Maes, 2009; Singh et al., 2004).

The causes of challenging behaviour are multifactorial. Hastings and his colleagues (2013) developed a conceptual framework to explain the factors contributing to the recurrence of challenging behaviour and ultimately leading to social exclusion and denial of access to community facilities.

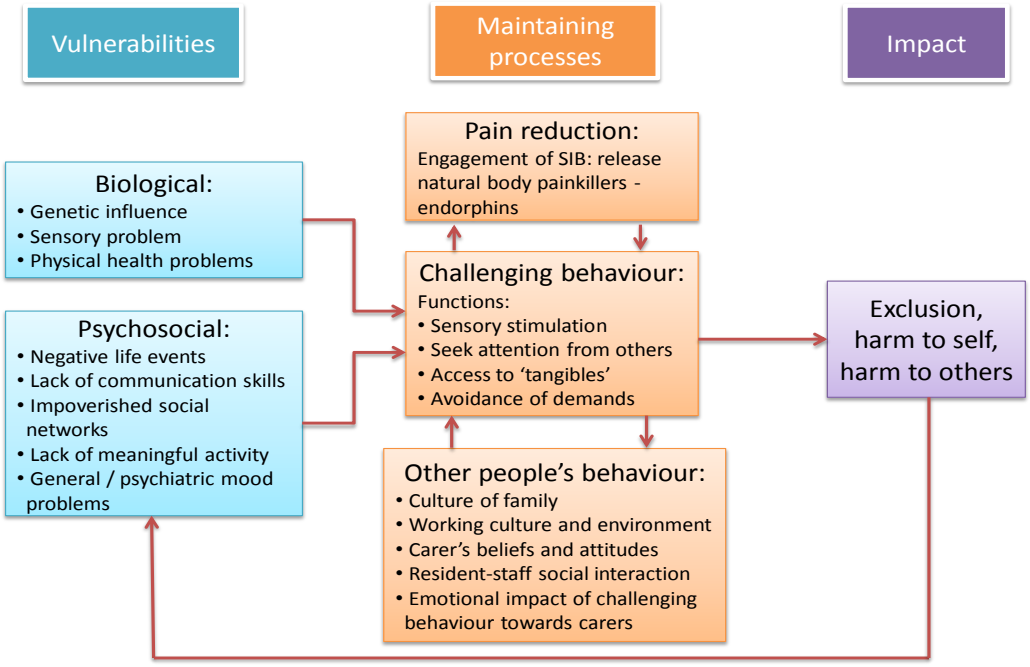
The major contributing factors are vulnerabilities to biological and psychosocial issues. The biological factor includes genetic influences and sensory or physical health problems, especially pain-related issues, which may be the source of SIB. This form of behaviour generates biological painkilling endorphins, leading to a vicious cycle between SIB and endorphins (Hastings et al., 2013). Regarding the psychosocial vulnerabilities, the major components are stressful or negative life events (e.g., traumatic experiences and physical abuse), limited communication skills, a poor social network leading to social isolation and, consequently, no engagement in meaningful activities. Likewise, the absence of

an enriched environment or purposeful activities can make people with challenging behaviour un-stimulated and bored (Hastings et al., 2013).

The literature reveals that mood problems also contribute to challenging behaviour (Hayes, McGuire, O'Neil, Oliver, & Morrison, 2011; Matson, Smiroldo, Hamilton, & Baglio, 1997; Ross & Oliver, 2002). Mood disturbances, such as depression and anxiety disorder, are complex and challenging to diagnose in people with SPID, as they often have difficulty expressing their subjective feelings (Matson et al., 1997; Ross & Oliver, 2002). Other ways to identify depression and anxiety is through vigilant observation of symptoms, such as low affection and loss of interest and pleasure (Ross & Oliver, 2002), and physiological signs, such as trembling, hyperventilation and excessive motor activity. Sometimes these sudden motor or vocal responses may only indicate self-stimulating behaviour (Matson et al., 1997). Anxiety is frequently used to address the tension that accompanies behavioural reactions to such distressing emotions (Cooray & Bakala, 2005). Anxiety is different from anxiety disorder in terms of the intensity and duration of emotion arousal level (American Psychiatric Association, 2013). In a systematic review, Lang and his colleagues (2010) postulated that skin-picking behaviour or SIB might be induced by internal arousal of anxiety in the absence of adaptive environmental coping behaviour. Such challenging behaviour can somewhat reduce the tension of anxiety, leading to a vicious cycle (Lang et al., 2010). However, a few important issues, such as what kinds of environmental stimuli are likely to trigger anxiety, methods to control or remove such stimuli and the skills needed to cope with anxiety, were not addressed in the review. Similarly, the association between depression and manifestations of low mood and SIB was also significant for people with SPID (Hayes et al., 2011; Ross & Oliver, 2002).

Challenging behaviour may generally serve four functions for an individual, including sensory stimulation, attention seeking, access to tangibles (both edible and non-edible) and avoidance of demands. Pain reduction has recently been added as one of the functions that explain engagement in SIB (Hastings et al., 2013). The responses and beliefs of caregivers and involved people towards challenging behaviour have direct influences on its recurrence. For instance, challenging behaviour is likely to recur if a caregiver removes his/her demand once challenging behaviour appears. Such negative reinforcement ultimately connects the staff approach to occurrence of challenging behaviour (Hastings, 1997; Lambrechts & Maes, 2009). The conceptual framework of challenging behaviour is shown in *Figure 1.1* to illustrate the relationship between vulnerabilities and the maintenance process, and ultimately the social impact of challenging behaviour (Hastings et al., 2013).

Figure 1.1. A conceptual framework explaining why challenging behaviour occurs (Hastings et al., 2013)



1.1.5 Adverse effects of challenging behaviour

According to a survey conducted in two districts of England (Emerson et al., 2001), the prevalence of challenging behaviour among people with ID was 10-15%, with 60% of residents living in the community and 40% in long-term stay institutions. More difficult challenging behaviour, such as SIB, is more often exhibited in people with SPID. In fact, SIB is frequently a persistent and problematic feature of people with SPID. Some studies (Hayes et al., 2011; Moss, Emerson, & Kiernan, 2000; Ross & Oliver, 2002) have suggested that SIB is strongly associated with psychiatric disorders, such as depression, anxiety and obsessive-compulsive disorder.

The incidence of challenging behaviour definitely increases the costs of service provisions from the already restrictive resources for treatment and care in terms of manpower, chemical and mechanical sedations and the physical structure of the living environment (Emerson et al., 2000).

Challenging behaviour can induce physical injury to the involved parties, such as people with ID and their care staff. As a result, physical isolation and social exclusion, neglect and abuse from caregivers or increased psychological stress and physical strain among caregivers are ubiquitous. Ultimately, the quality of life of people with ID can be jeopardised due to their markedly reduced access to community facilities (Hastings et al., 2013).

1.1.6 Management of challenging behaviour

The terms that have been used to describe challenging behaviour include ‘behavioural disturbance’, ‘maladaptive behaviour’, ‘aberrant behaviour’,

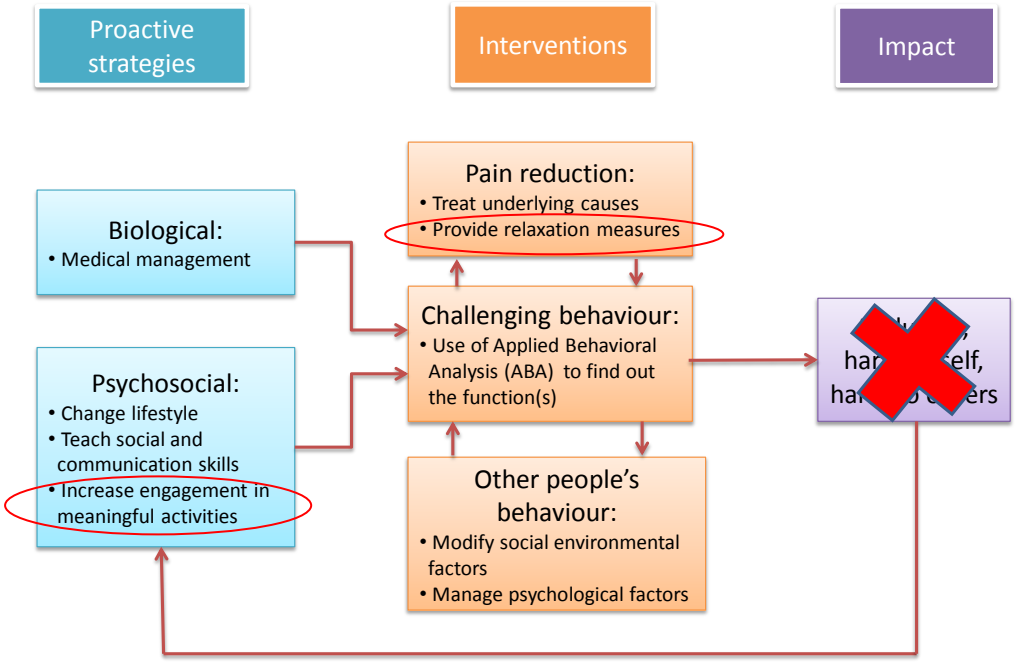
‘behavioural disorder’ and ‘behavioural abnormality’ (Lowe & Felce, 1995; Xeniditis, Russell, & Murphy, 2001). The change in terminology reflects the movement towards the use of more respectful and less problem-oriented approaches. The nature of the challenge is not a one-way direction, but is a shared responsibility between residents and service providers. Interventions for challenging behaviour emphasise the development and improvement of services to meet residents’ health needs (Lowe & Felce, 1995).

Emerson et al. (2000) found that the most common strategies for handling challenging behaviour in residential care settings were physical restraint, sedation and seclusion. All of these strategies are resource-intensive and cause psychological stress for both residents and caregivers. In fact, non-aversive intervention approaches have been suggested to meet residents’ communication needs and possibly minimise the occurrence of challenging behaviour (Emerson et al., 1988; Emerson et al., 2000).

The conceptual framework developed by Hastings et al. (2013) proposes adopting positive behaviour support (PBS), as it comprises multi-level strategies for managing challenging behaviour. Proactive strategies for lessening vulnerabilities include the medical treatment of sensory and physical health problems, lifestyle changes, positive thinking, the use of augmentative and alternative communication (AAC) skills and the provision of enriched environments and active engagement in meaningful activity. Interventions to reduce challenging behaviour include applying relaxation measures to alleviate pain sensation, using applied behavioural analysis (ABA) to identify the functions of such challenging behaviour, changing involved people’s responses to challenging behaviour through training, modifying the work environment and managing psychological stress (Hastings et al., 2013).

The overall interventions for challenging behaviour are depicted in *Figure 1.2*.

Figure 1.2. Proactive strategies and interventions for managing challenging behaviour based on the positive behaviour support approach (Hastings et al., 2013)



In view of active engagement in an enriched environment and the application of relaxation measures, the use of the multisensory environment (MSE) and MT is suggested for managing challenging behaviour in this study. In the 1980s, the MSE was adopted as an important facility for experiencing pleasure and relaxation from idleness. The MSE explores the normalisation principle (Wolfensberger & Tullman, 1982), which upholds that intellectually disabled people living in institutions still have the right to access high-quality activities, as MSE equipment is costly and tailor-made for people with special needs. MSE is an adapted environment that offers various stimulations through light, sound, touch and smell to engage the attention of people with SPID, who are usually passive due

to their poor perceptual process (Munde, 2011; Vlaskamp, de Geeter, Huijsmans, & Smit, 2003). Gustatory stimulation is usually not included in the MSE because SPID residents are prone to develop dysphagia (de Winter, Jansen, & Evenhuis, 2011).

There are many choices to meet specific senses. For instance, projector with colourful effect wheels, mirror ball, bubble tubes, fibre-optic tails, line-lite are commonly used for visual stimulation, while music and interactive sound are usually for auditory stimulation. The basic requirement of a multisensory room is quiet background, so that the sound effect can be more prominent and rigorous. Soft floor, tactile wall, water bed, vibrating chair and cushion are frequently employed for tactile sensation. During the course of MSE session, the enabler facilitates the resident to make frequent use of touch on different sensory equipment to explore the immediate environment. If the resident has limited mobility, water bed or tactile wall is the best choice to maximise the sensation of touch. A subtle body movement on water bed can generate the waving motion for the whole body. The tactile wall composes various textures, e.g., wool, nylon, fabric, metal, wood, leather. The resident can sit or lie on soft floor to touch these materials. Aroma box and wind blower are connected with interactive switch pads to release the smell from the breeze of air when the resident touches on the switch. Lavender pillow and aromatic balls (made of wood or cotton) are also often offered for olfactory stimulation (Hulsegge & Verheul, 1987; Hutchinson & Kewin, 1994). As the MSE are standardized installation and products, most of the above described tools or equipment are available and would be used in the multisensory room of the study setting.

The prevalence of SPID with sensory defects is as high as 30% of this (SPID)

population (Vlaskamp et al., 2003). Individuals with SPID tend to engage in challenging behaviour to satisfy a primary need for stimulation as a result of their failure to seek spontaneous arousal from the immediate environment. Sensory damage is common among people with SPID, especially cerebral visual impairment (Vlaskamp et al., 2003). To compensate for visual and hearing deficits, physical touch becomes more valuable than other sensory stimulations (Hutchinson & Kewin, 1994). MT is perceived as the most pleasurable mode of physical touch and effective for pain relief (Ayer, 1998; Field, 2010).

Some studies have integrated MT into MSE sessions for children with SPID (Ayer, 1998; de Bunsen, 1994). MT involves the 'mechanical manipulation of body tissues with rhythmical pressure and stroking for the purpose of promoting health and well-being' (Harris & Lewis, 1994, p. 16). The use of hand massage is believed to promote relaxation and body awareness, and to relieve pain due to muscle spasm (Goldberg et al., 1992). The relationship between children and caregivers can be substantially enhanced through physical closeness and tenderness during the massage process (Ayer, 1998). As postulated, the enjoyment of MSE is come from free choice and physical touch (Haggar, 1994; Hutchinson & Haggar, 1994; Kewin, 1994).

In a review, Chan et al. (2010) found that positive behaviour increased after MSE sessions. Solomons (2005) also showed the same positive results in children with autism and severe ID after MT. Such positive behaviour includes increased attention and interest to the immediate environment, eye contact and interaction initiatives (Chan et al., 2010; Solomons, 2005).

Despite the popular use of MT and MSE for people with SPID, few studies have evaluated its net effects when it is combined together or with other therapies,

such as music and relaxation exercises. MT claims to enhance relaxation, raise awareness of the environment, reduce challenging behaviour and develop social interaction through a trusting relationship (Maher, 2010; Sanderson & Carter, 1994; Weidner, 2007). However, these positive assertions have come from personal clinical experiences and have not been properly evaluated through systematic evaluations or experimental studies. A more stringent research method, e.g., randomised controlled trial, is lacking to support these positive results. Apart from active engagement in enriched environments, the therapeutic value of both MSE and MT is the relaxation effect, which may reduce the frequency of challenging behaviour. Physiological data, such as heart and respiration rates, are commonly collected to indicate the relaxation outcome of MT and MSE. However, the observed physiological responses have not been conclusive. Some studies have reported the decrease of heart and respiration rates after MT (Croghan, 2009; Hegarty & Gale, 1996). However, it is difficult to determine the validity and reliability of such results, as the significance level of the difference between pre- and post-interventions have not been reported. In fact, some studies have reported no significant relaxation outcome after MSE and MT treatment (Lindsay et al., 1997; Lindsay, Black, Broxholme, Pitcaithly, & Hornsby, 2001), but a significant effect on reducing challenging behaviour after MSE (Lindsay et al., 1997; 2001). The results of these studies make it difficult to draw conclusions on the effects of MSE and/or MT. Details of the individual studies, including its limitations, will be discussed in the sections 2.6 and 2.7 of Chapter Two.

In addition, it is believed that challenging behaviour is likely to exhibit where the usual care environment is lack of meaningful activities and physical contact (Emerson et al., 2000; Field, 2010; Hulsegge & Verheul, 1987; Hutchinson

& Kewin, 1994). Literature showed that people with ID living in hospital-based residential settings had more refractory challenging behaviour than their community partners (Emerson et al., 2001). Due to the movement of deinstitutionalisation, studies of MT and MSE in hospital-based residential care setting for adults with SPID become rare in recent decade. Many related studies in hospital setting were developed from 80's to 90's (Ashby, Lindsay, Pitcaithly, Broxholme, & Geelen, 1995; Hegarty & Gale, 1996; Hulsegge & Verheul, 1987; Hutchinson & Haggar, 1994; Lindsay et al., 1997; 2001; Martin, Gaffan, & Williams, 1998). Recently, MT and MSE studies for people with SPID have been carried out in community-based residential facilities, day centres, and special schools (Cole & Burt, 2011; Munde & Vlaskamp, 2015; Woods, 2014). Yet, none is come from institutional or local residential setting. In a meta-analysis study, no previous studies had adopted randomised controlled trials to investigate the effects of MSE for people with ID (Lotan & Gold, 2009).

To evaluate the effectiveness of MT and MSE, either independently or in combination, on inducing relaxation and reducing challenging behaviour, a more stringent research design such as randomised controlled trial is deemed necessary to fill up the research gap of these two interventions.

1.2 Research Problem

Various reasons may contribute to the occurrence of challenging behaviour, however, it may indicate a desire for social attention or an escape from the demands of learning new skills or the experiences that distress them (González et al., 2009). Whatever the reason, people with SPID are prone to exhibiting challenging behaviour (Emerson et al., 2001). Both MSE and MT are believed to promote a

sense of enjoyment and relief from tension and pressure, with consequent improvement in general behaviour (Croghan, 2009; de Bunsen, 1994; Hutchinson & Haggar, 1994). Such a relaxation effect may bring about a decrease in challenging behaviour and an increase in positive behaviour, such as calm and interactive responses, which can then enhance social acceptance by professional caregivers and community/residence members (Forster & Iacono, 2008). Although there is no precise definition of relaxation, it primarily means 'unspecified states of psychophysical easing of tension or resting' or just 'absence of tension' (Kokoszka, 1992, p. 4). In general, presentation of positive behaviour indicates an increase of adaptive behaviour, the initiation of communicative attempts, rapport building, engagement behaviour and concentration (Chan et al., 2010). Sufficient evidence supporting the postulation that relaxation induced by MSE or MT can reduce the frequency of challenging behaviour is lacking.

Massage is an extension of physical touch. The use of MT in MSE may break down the barriers of vision and hearing loss to maximise sensory responses. Another reason to espouse MT for people with SPID is that a resident's cognitive capacity is not required to understand the process (McEvoy, Perrault, & Graetz, 1987). For people demonstrating challenging behaviour, the specific purpose of MT is to divert their attention to induce pleasure and relaxation (de Bunsen, 1994; McEvoy et al., 1987). In fact, a few studies have shown that MT alone may increase positive or adaptive behaviour (Croghan, 2009; Hegarty & Gale, 1996). Therefore, the research problem is whether MSE and/or MT can produce significant relaxation effects and, subsequently, reduce challenging behaviour and increase adaptive behaviour.

Synonyms for intellectual disability include 'mental handicap', 'mental

retardation', 'mental deficiency', 'developmental disability' and 'learning disability'. To uniform the terminology, 'intellectual disability' is used unless direct quotations from the literature use other terms. As mentioned, people with SPID also include those with PIMD.

1.3 Aims, Objectives and Hypotheses

As the results on the effects of MSE and MT are inconclusive, it is useful to examine whether either intervention or a combination of the two can effectively reduce challenging behaviour in people with SPID. Some of the research (Martin et al., 1998; Withers & Ensum, 1995) has postulated that the effect of MSE on challenging behaviour relies on enabling approach, not the stimulating environment itself. At present, there was no randomised controlled trial only involved adults with SPID, particularly in the hospital-based residential setting or in Hong Kong. Similarly, the combined effect of both MSE and MT on this population has not been evaluated. Clinical effectiveness is an evaluation of an intervention or interventions on patient outcomes. It aims to review factors that may affect the outcome(s) and improve the measuring tool(s) to develop a model of treatment progressively that is different from conventional treatment of a morbid condition (Nasrallah, Targum, Tandon, McCombs & Ross, 2005). In the present study, the morbid condition is the exhibition of challenging behaviour. Therefore, the aim of this study is to evaluate the clinical effectiveness of MSE and MT for residents with SPID in a long-stay residential facility under the Hospital Authority (HA), Hong Kong, and to compare residents' outcomes across four study groups, including those receiving MT in MSE, MSE alone, MT in a usual care environment and usual care with social attention and interaction in reducing challenging

behaviour. Due to the cognitive and physical limitations of people with SPID, only observations and non-invasive instruments are selected as measuring tools. The objectives of this study are as follows:

- To compare the relative behavioural and physiological impacts of the first post-test immediately after interventions with baseline assessment on the participants treated with MT in MSE (MT-MSE) combined, MSE alone, MT alone in the usual care environment and the usual care environment without MSE or MT (control group).
- To compare the relative behavioural and physiological impacts at the second post-test 2 weeks after completion of interventions with the baseline assessment on the participants treated with MT-MSE, MSE alone and MT only and the control group.
- To examine the sustainable effects of the three intervention approaches on the participants at a 2-week follow-up.
- To assess the benefits and limitations of the intervention approaches as perceived by the nursing staff and the changes they suggest in daily clinical practices to improve residents' behaviour.

The primary outcomes of this study are the frequency and severity of challenging behaviour. The secondary outcomes include the physiological state (mainly heart and respiration rates), the alertness state and the maladaptive and adaptive behaviour of the participants. Maladaptive behaviour refers to stereotypic and self-stimulating behaviour, whereas adaptive behaviour refers to the initiation of communication attempts, rapport building and concentration (Chan et al., 2010). All of the outcome measures were administered at baseline (before random assignment to study groups), midway through the interventions,

immediately after the interventions and 2 weeks after the interventions. A pilot study with pre-test and post-test comparison designs was conducted to explore the subject recruitment, data collection and data analysis methods. Hence, comparing the intervention effects of the pilot study was restricted to the baseline assessment and immediately after the interventions. The details of the pilot study are described in Chapter 4.

After completing the quantitative data collection, semi-structured face-to-face interviews were carried out to evaluate the intervention process. The study participants' primary nurses were invited to share their perceptions of the interventions and their experiences managing challenging behaviour.

Given the preliminary research evidence, the effectiveness of MT and MSE in inducing relaxation and reducing challenging behaviour remains inconclusive, but tends to be more favourable for the reduction of challenging behaviour after MT and/or MSE intervention. The hypotheses of this study are as follows:

1. Treatment with MT-MSE, MSE alone and MT alone significantly reduce the frequency and severity of challenging behaviour compared to the control group.
2. Treatment with MT-MSE, MSE alone and MT alone significantly improve the participants' secondary outcomes immediately after intervention compared with the control group:
    a. Stable and normal heart and respiration rates representing low bodily excitement.
    b. Maintaining the alert state, showing awareness of the immediate environment and maintaining social contact.

c. A decrease in maladaptive behaviour and an increase in adaptive behaviour.

3. Treatment with MT-MSE, MSE alone and MT alone have significant carryover effects 2 weeks after the interventions compared with the control group:
   a. Significantly decreased frequency and severity of challenging behaviour.
   b. Significantly decreased heart rate, respiration rate and maladaptive behaviour.
   c. Significantly increased adaptive behaviour and maintenance of the alert state to maintain contact with the immediate environment.
4. Treatment with MT-MSE significantly decreases maladaptive behaviour and increases the alert state (i.e., showing awareness to the immediate environment) more than the two single intervention modes (i.e., MSE alone and MT alone).

1.4 Research Significance

People with SPID frequently engage in challenging behaviour. The disadvantages of challenging behaviour include interference with learning, susceptibility to social isolation and difficulty achieving community integration (Case-Holden & Hupp, 1989; Emerson et al., 2000). Strategies for engaging in adaptive behaviour to reduce challenging behaviour are the major concern in the fields of ID and SPID. Positive interventions are more effective than aversive methods, particularly for sensory-reinforced challenging behaviour (Case-Holden & Hupp, 1989; Lanovaz, Robertson, Soerono, & Watkins, 2013). One of the alternative sensory reinforcers in the ID field is MSE, which provides multidimensional sensory stimulation and is the most accessible leisure activity in different care settings. Both MSE and MT offer additional tactile sensation (Ayer,

1998), especially for those with visual and/or hearing impairments. To improve professional practices, nurses should evaluate the effectiveness of practising interventions, such as MSE and MT, based on research evidence promoting relaxation in the reduction of the intensity of challenging behaviour (Slevin & McClelland, 1999).

Reducing challenging behaviour may also benefit social integration and promote social contact with the immediate environment. These therapeutic effects certainly increase the confidence of nurses in handling people with challenging behaviour.

The positive findings of this study and thus the use of MSE and MT may be generalised to severe disabled patients in different healthcare settings. Alternate sensory reinforcers and complementary therapies may also be tested to enhance the treatment options for managing challenging behaviour.

For health professionals, residents and their caregivers, the greatest concerns are the effectiveness and safety of interventions. Hence, more scientific and objective evidence proving the beneficial assertions of MSE and MT are essential to upholding professional standards and values (Stevensen, 1997).

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The coexistence of ID and challenging behaviour is a complex but common phenomenon among people with more severe ID (Ali, Blickwedel, & Hassiotis, 2014). As mentioned, challenging behaviour adversely affects an individual's quality of life by denying his or her access to community facilities and affecting his or her social contact with community partners (Ali et al., 2014; Emerson, 2001). Challenging behaviour is a socially constructed concept of undesirable behaviour that varies across cultures and settings (Emerson & Einfeld, 2011). The more severe the ID, the higher the incidence of challenging behaviour, with a prevalence of 82% for SIB and SSB and 45% for aggressive behaviour in people with PIMD (Poppes, van der Putten, & Vlaskamp, 2010).

The management of challenging behaviour is particularly important for people with SPID who have difficulty with community integration and who often live in a long-stay hospital (Emerson et al., 2000), where those with visual and/or hearing impairments prevail (Evenhuis et al., 2001). A local institution with visual and auditory defects in over 30% of its residents (Hospital Authority Mental Handicap Infirmary Service, 2003) is perceived as a factor contributing to challenging behaviour.

Restrictive practices, such as physical restraint, sedation and seclusion, are commonly used in institutional settings to control manifestations of challenging behaviour (Emerson et al., 2000). However, these strategies are very stressful for

both residents and staff. Referring to the recent conceptual framework of maintaining challenging behaviour (Hastings et al., 2013), the PBS model has been proposed in Western countries to manage challenging behaviour. Its focus is environmental manipulation, such as through engagement in meaningful activities, and the responses of direct care staff who may trigger and reinforce the occurrence of challenging behaviour (Hastings, 1997).

This chapter reviews the literature on the factors associated with challenging and self-stimulating behaviour, the psychological needs of people with SPID, the relationship between anxiety and challenging behaviour and the current interventions for challenging behaviour. It also discusses the effectiveness of MSE and MT in affecting challenging behaviour, alertness level and behavioural state. The interactions of MSE and/or MT with environmental stimuli and the tools/instruments used to evaluate resident outcomes are also discussed.

2.2 Factors Associated with Challenging and Self-Stimulating Behaviour

The causes and maintenance of challenging behaviour are complex and interwoven with biopsychosocial factors. Six main factors contribute to the occurrence of challenging behaviour in people with SPID, including genetic and biological factors, psychosocial factors, staff attributes, environmental influences, sensory drive and resident-staff interaction patterns (Ali et al., 2014; Lambrechts & Maes, 2009; Xenitidis et al., 2001).

Knowing the causal factors of challenging behaviour facilitates the understanding and manipulation of modifiable factors to minimise its occurrence.

2.2.1 Genetic and biological factors

The genetic and biological factors are mixed with both non-modifiable and modifiable causes. Genetic influences are non-modifiable cause which identifies particular syndromes prone to SIB and abnormal brain structures possibly leading to violent behaviour (Xeniditis et al., 2001). A number of predisposing genetic factors contribute to specific forms of challenging behaviour. For instance, Tourette's, Lesh-Nyhan, Prader-Willi and Cornelia de Lange syndromes are associated with increased SIB (Xenitidis et al., 2001). However, very little research evidence has supported this proposition (Furniss & Biswas, 2012; Lang et al., 2010; Sloneem, Arron, Hall, & Oliver, 2009).

Damage to the frontal lobe can also result in SIB (Kingdon, 2005). Lesions on the prefrontal cortex and the limbic system, involving the amygdala and hippocampal complex, are associated with the frequency of violence (Xenitidis et al., 2001). In short, genetic composition and brain damage play an important role in the manifestations of challenging behaviour. However, studies of these non-modifiable causes have not reached any conclusions (Kingdon, 2005; Xenitidis et al., 2001).

Modifiable biological factors mainly involve neurochemical substances mediating mood arousal (Xenitidis et al., 2001), physical illness and symptoms, such as gastro-oesophageal reflux disorder, constipation, otitis media and dental problems in people with SPID (Ali et al., 2014).

Neurotransmitters, such as β-endorphins, dopamine and serotonin, are believed to mediate the intensity of SIB and aggression. Studies of pharmacological treatments have shown certain progress related to how neurotransmitters mediate human behaviour in clinical trials (Xenitidis et al., 2001).

For instance, serotonin levels can manipulate the impacts of SIB, aggression and anxiety. Increased serotonin levels reduce the intensity of these behavioural and negative emotional states. Children with Down syndrome are less likely to develop SIB due to their relatively low risk of mood disturbance (Furniss & Biswas, 2012). Sleep disturbances are more likely in this population as they progress to the ageing stage, particularly for those over 50 years of age, when clinical diagnoses of anxiety or depression are common (Esbensen, 2016).

Research findings have recently shown that SIB is also associated with sleep disorders and chronic pain conditions. The disturbance of nociception may lead to repeated tissue damage, with the release of natural painkillers (endorphins), which may support the vicious cycle of SIB (Hastings et al., 2013; Symons, 2011). A strong correlation between pain or discomfort and challenging behaviour has been proposed, especially for those with SPID due to their poor capacity to communicate verbally. Hence, annual physical examinations and regular medical check ups are strongly recommended for the early identification of medical and physical diseases. More importantly, studies of differential diagnoses of behavioural patterns of physical deterioration and challenging behaviour are needed to establish evidence-based clinical guidelines for appropriate and prompt treatments (de Winter et al., 2011).

2.2.2 Psychosocial factors

Psychosocial factors include psychological trauma, mental illness, poor communication skills that seriously limit social networks, lack of meaningful activity leading to idleness during the day, suboptimal physical health, neuropsychiatric disorders, such as autism, family discord, economic deprivation,

negative life events, bereavement, and general mood problems (Ali et al., 2014; Hastings et al., 2013). Challenging behaviour is believed to be a form of communication that conveys an individual's message, such as insufficient caregiver support and lack of engagement in activities (Ali et al., 2014). According to a meta-analysis of 22 studies (McClintock, Hall, & Oliver, 2003), the most frequent reported risk factors of challenging behaviour are age, mobility, visual and hearing impairments and the nature of residential settings, whereas the least frequently reported risks are epilepsy, psychiatric diagnosis, race, socioeconomic status and conditions associated with challenging behaviour, such as hyperactivity. Ultimately, only severity of ID, communication skills and autism have shown significant associations with challenging behaviour (McClintock et al., 2003).

As childhood experiences and adverse life events cannot be changed in adulthood, emphasis is put on modifiable factors, particularly interactions with social and physical environments (Xeniditis et al., 2001). Manipulation of reinforcers is needed to eliminate the causes and recurrence of challenging behaviour in SPID residents (Emerson, 2001; Xeniditis et al., 2001). This includes increasing social network connections by encouraging visits from family and volunteers, increasing engagement with structured activities rather than idling in the usual care environment and improving the attitudes of the direct care staff (Hastings et al., 2013).

Residents with SPID are vulnerable to stress and anxiety due to their inability to communicate effectively, lack of choice in daily living, lack of appropriate stimulation and dependence on others for involvement in daily activities (Cooray & Bakala, 2005; Harrison & Ruddle, 1995). Due to their poor information processing skills, passive relaxation programmes appear to be

appropriate for identifying the underlying causes of challenging behaviour, relieving tension and reducing apprehension.

2.2.3 Staff attributes

In day-to-day care, behaviour that includes temper tantrums, making disturbing noises, hyperactivity and disruptiveness may require immediate action from professional caregivers. Direct care staff tend to label overt behaviour as more problematic than forms of behaviour with less impact on the staff and co-residents, such as social withdrawal, self-isolation, non-responsiveness to stimuli and stereotypic and repetitive movements (Lowe & Felce, 1995). Behaviour causing disturbance to the staff or services is more likely to be defined as challenging, regardless of whether the primary reasons can be easily prevented or influenced by other physical and psychological factors, such as physical discomfort and pain (Lowe & Felce, 1995). If residents' basic needs are fulfilled, the frequency of challenging behaviour decreases. Hence, staff attitudes and their care provisions may be important contributing factors to residents' challenging behaviour.

Rose and Rose (2005) found that direct care staff who reported lower levels of psychological well-being provided less physical assistance to and had fewer positive interactions with residents who then presented with more challenging behaviour. Similarly, direct care staff with intense negative emotional reactions to challenging behaviour tend to report more challenging behaviour among their residents (Lambrechts & Maes, 2009).

Staff characteristics, such as staff's age and years of working experience with people with ID, can also be related to label residents' behaviour as challenging.

Lambrechts and Maes (2009) also found that younger staff tended to have more negative feelings towards challenging behaviour than older staff and that experienced staff tended to be less likely to label residents as demonstrating challenging behaviour than new staff. However, fewer complaints about challenging behaviour may also be related to experienced staff having higher levels of competence. They may find various ways to reduce such behaviour, such as by providing more social attention and activities to distract the residents from self-stimulation and/or seeking attention from others.

2.2.4 Environmental factors

Nature and nurture are interwoven in every aspect of human development, including the development of challenging behaviour. In addition to the aforementioned staff attitudes, environmental influences on challenging behaviour can include reinforcement mechanisms, the physical structure of the setting and the caring atmosphere and activities in the setting. All forms of behaviour demonstrated by SPID residents have meanings and purposes. It is important to look for any messages that these residents want to deliver, such as requesting access to preferred objects or activities (Lambrechts, Kuppens, & Maes, 2009). If rejected, challenging behaviour may continue. In a study of the environmental features in relation to stereotypic behaviour (Hall, Thorns, & Oliver, 2003), the frequency with which eight severe to profound ID residents (from 7 to 26 years of age) exhibited stereotypic behaviour was observed for four types of environmental stimulation. Stereotypic behaviour was frequently exhibited in low stimulation environments with minimal physical contact, social interactions and sensory stimulation (Hall et al., 2003).

Nevertheless, aggression is a manifestation of the autonomic fight or flight response to a perceived threat. Environmental manipulation is necessary to minimise provoking stimuli and thereby create a non-threatening atmosphere (Singh et al., 2004). Control of environmental factors, such as manipulating the reinforcement schedule from fixed to variable intervals is perceived to be an effective strategy for reducing aggression and other forms of challenging behaviour in the residents with SPID (Sloneem et al., 2009). Reinforcers can be delivered within a specific period, such as immediately or shortly following desirable behaviour, depending on the strength of association between the behaviour and reinforcer. As people with SPID find it hard to express themselves, staff's attentiveness, caring manner and vigilant observation are useful to identifying the early signs or signals of challenging behaviour. This can subsequently prevent the aggravation of challenging behaviour.

2.2.5 Sensory driven

One of the explanations about the occurrence of SSB and SIB is that they are sensory driven (Shapiro et al., 1997). The adapted sensory environment can modify incoming sensory stimuli and may cause neuronal activity in the nervous system. The eighth cranial nerve (vestibulocochlear) is believed to function as a dual neural pathway for the auditory and vestibular systems. The neuro-physio-behavioural relationship suggests that appropriate sensory stimulation can reduce the frequency of SSB and SIB (Shapiro et al., 1997).

A non-socially mediated reinforcement, which does not involve external incentives, may maintain the manifestation of SIB in some residents (Sandler & McLain, 2007). For instance, lack of visual stimulation may trigger eye-poking

behaviour in a person with SPID to obtain internal visual input. Sandler and McLain (2007) found that a 9-year-old boy reduced his SIB by applying a sensory stimulus (i.e., rotating the child in a suspended swing and using vibration) serving as a non-contingent reinforcement (NCR) in which the reinforcer was occasionally given regardless of whether SIB existed.

The rationale for using NCR is based on the principles of extinction and satiation, which suggest that an individual enjoys 'free' reinforcers without engaging in painful problem behaviour (Holden, 2005). Non-contingent tactile and vestibular reinforcements, such as massage, vibration, rocking and spinning movements, are used to give the resident sufficient sensory inputs to cease their sensory desire for engagement in SIB, such as head banging, hitting and rubbing. Increasing the magnitude of NRC can also fasten the satiation process, as deprivation of sensory inputs is quickly removed, subsequently shortening the SIB intervention period (Holden, 2005; Sandler & McLain, 2007). Hence, the residents' satisfaction with sensory inputs through constant stimulation irrespective of sensory needs may effectively reduce the frequency of their SIB and SSB.

2.2.6 Resident-staff interaction patterns

The interactions between residents with SPID and direct care staff in a usual living environment are often reported to be poor in quality, as indicated by the clinical observations of daily routines and the contents of interactions (Chan & Yau, 2002; McConkey, Morris, & Purcell, 1999). In Chan and Yau's (2002) observational study of staff-resident interactions, routine care procedures, such as physical care and meal serving, the most common interaction mode was neutral with no exchange of emotion or apathetic facial expressions (with the highest

percentage of all observed interaction modes). Positive emotional exchange is rare, especially during rush hours of daily care and particularly due to lack of manpower. The lack of reciprocal interactions between staff and SPID residents may also reduce staff's help to residents. The return or reward of their efforts, such as the physical health improvements of and verbal gratitude from their residents, is minimal or even absent (Rose & Rose, 2005).

The findings of McConkey et al. (1999) indicate that the frontline staff in an institutional setting tend to use directive and instructional content to interact with their residents, rather than engaging in social interactions, such as chats and conversations, even when they are communicating with predominantly non-verbal residents, such as those with SPID. The majority of direct care staff often fail to adjust their language to residents' understanding. Generally, direct care staff do not provide adequate opportunity for effective communication with their residents, and they seldom attempt to understand residents' non-verbal behaviour. Staff perceptions towards their roles in providing care also contribute to ineffective communication, as they may assume themselves to be paid for satisfying residents' physical and personal needs, rather than engaging in conversations. Hence, behavioural control and task completion are their major daily clinical work goals (Lowe & Felce, 1995; McConkey et al., 1999).

The job nature and time spent with residents during the day also influence the identification of challenging behaviour. For instance, managers generally report less challenging behaviour than their frontline staff, as they usually have fewer interactions and physical contact with their residents. Another factor is the context of contact. In a context with special training task engagement, such as training sessions held by occupational therapists, therapists tend to report fewer

behavioural problems and more functional skills than nurses, who often care for residents in an environment without any structured training elements (Lambrechts & Maes, 2009).

2.3 Special Needs of People with Severe and Profound Intellectual Disabilities

In people with SPID, the higher the prevalence of challenging behaviour, the higher the consequence of an out-of-home placement in a residential care setting (Janssen, Schuengel, & Stolk, 2002; Lotan, Gold, & Yalon-Chamovitz, 2009). Moreover, if the challenging behaviour cannot be managed effectively, the potential risks of social isolation and physical injury are high for both caregivers and residents (Emerson et al., 2000). This seriously disrupts community rehabilitation and social relationships in residential care, as caregivers may not bring residents to the community orientation programme and decrease their social contact with other residents to avoid injury.

A form of challenging behaviour, self-stimulating behaviour is habitually displayed among people with SPID because the basic human need of an individual is to process different sensory inputs / stimulations from their immediate environment for motor development and survival through any of the five sensory modalities (Ayer, 1998). Individuals with SPID are frequently passive and unaware of external stimuli due to their severe cognitive deficits. The exhibition of self-stimulating behaviour not only fulfils their sensory needs, but also helps them to escape from task demands or aversive situations (Durand & Carr, 1987). As suggested by Lang et al. (2010), skin picking in people with ID is maintained for sensory stimulation or as a result of socially mediated consequences in which attention from caregivers reinforces this recurring self-inflicting behaviour.

SIB and aggressive behaviour are also associated with affective disorders, whereas screaming is more likely associated with autism-related social impairment (Hemmings, Gravestock, Pickard, & Bouras, 2006). Nevertheless, there has been no concrete evidence to support that these psychiatric symptoms are associated with challenging behaviour in people with SPID (Hemmings et al., 2006). Indeed, many people who exhibit challenging behaviour do not have a mental disorder and many people with mental disorders do not necessarily exhibit challenging behaviour (Xeniditis et al., 2001).

It is worth noting that if the challenging behaviour of these SPID residents can be reduced, the chance of caring in community will probably increase (McEvoy et al., 1987; Smith, Press, Koenig, & Kinnealey, 2005). According to the stress-attachment model (Janssen et al., 2002), physical security and comfort are the bases for building positive social attachments and close interpersonal relationships. The frequency of challenging behaviour lessens if people feel relaxed and supported. Otherwise, stress-related illnesses and maladaptive behaviour may arise.

Most of the literature suggests that any kind of interventions promoting relaxation can have therapeutic value to reduce challenging behaviour for people with SPID (Deakin, 1995; Lindsay & Baty, 1986; Schilling & Poppen, 1983). The assumption is that muscle relaxation neutralises anxiety, SSB (e.g., hand mouthing, finger weaving and arm waving) and challenging behaviour, as relaxation responses cannot coexist in fidgeting and uneasy people and, consequently, replace one's maladaptive behaviour (Chan et al., 2010). Relaxation can alleviate not only physiological arousal, but also psychological stress and anxiety-related behaviour, such as challenging behaviour in residents with SPID.

2.4 Relationship Between Anxiety/Stress and Challenging Behaviour in People with Severe and Profound Intellectual Disabilities

Challenging behaviour has many causes. One possible cause is anxiety disorder. However, as Matson et al. (1997) advised, diagnosing anxiety disorder in people with SPID may be complex and challenging due to their inability to express their subjective feelings. Another way to identify symptoms of anxiety is through vigilant observation of related physiological signs, such as trembling, hyperventilation and excessive motor activity. Sometimes, these sudden motor or vocal responses may simply indicate self-stimulating behaviour, but are not severe enough to diagnose anxiety disorder; thus, pharmacological and psychiatric treatment implications should be made cautiously (Matson et al., 1997).

People with SPID are vulnerable to psychological stress and anxiety in relation to their problems with appraising and processing information, inadequate social support, limited behaviour repertoires and poor coping skills (Cooray & Bakala, 2005). Stress may also arise from their inability to communicate effectively, their lack of choice in their everyday lives or the challenge of new experiences, such as transitioning and learning (Harrison & Ruddle, 1995). In addition, a lack of appropriate stimulation, along with dependence on others to engage in daily activities, can also induce considerable stress in people with SPID. When stress and anxiety cannot be expressed, challenging behaviour may arise (Moss et al., 2000). Although the concepts of stress and anxiety are not the same, they often go together and reinforce each other. Stress intensifies anxiety if not treated and overt behavioural problems under stress, such as restlessness and aggression, may occur due to continuously increasing anxiety.

The prevalence of anxiety disorder among people with ID has been estimated to be as common as in the general population, which is approximately 10.6-16.6% (Cooray & Bakala, 2005; Somers, Goldner, Waraich, & Hsu, 2006). Mental illness in individuals with SPID may manifest as challenging behaviour rather than typical symptoms, such as low mood and interest in the surrounding environment (Ali et al., 2014; Ross & Oliver, 2002). The emotional state presentations in people with SPID are relatively different in people with mild and moderate ID due to their significant communication difficulties and the high prevalence of physical disabilities (Ross & Oliver, 2002). Challenging behaviour may be regarded as an atypical symptom of depression in people with SPID, who exhibit increased maladaptive behaviour and decreased adaptive behaviour (Ross & Oliver, 2002). Hayes et al. (2011) supported that the presence of challenging behaviour was strongly related to mood problems in people with SPID living in an institutional setting, especially low mood. Low mood may also overlap with other symptoms, such as anxiety (Hayes et al., 2011). Hence, the observed behaviour can reflect the level of anxiety experienced by SPID residents and the intensity of their stress. Such challenging behaviour is perceived as a way of signifying high levels of tension or anxiety (Cooray & Bakala, 2005). As such, measuring challenging behaviour is an alternative way to assess one's anxiety level and thus evaluate the intensity of stress experienced by people with SPID.

2.5 Interventions for Challenging Behaviour

According to the literature, challenging behaviour serves four main functions, namely sensory stimulation, attention seeking, access to tangibles and avoidance of demands (Emerson & Einfeld, 2011). Recently, pain reduction is

proposed the fifth function of challenging behaviour because the persistent manifestation of SIB is an attempt to reduce pain by releasing natural painkillers in the body (Hastings et al., 2013). An effective intervention for challenging behaviour has yet to be firmly established. Current conventional interventions for challenging behaviour consist of psychotropic medications, physical restraint, cognitive-behavioural therapy, behaviour modification programmes (Lotan et al., 2009) and psychotherapy with a psychodynamic approach, which is probably confined to individuals with relatively higher cognitive functions (Xeniditis et al., 2001). There are several drawbacks to using these conventional methods of treatment. One study indicated that the routine use of psychotropic drugs, namely haloperidol and risperidone, by adults with ID was not based on evidence for their cost-effectiveness in dealing with challenging behaviour, but to subdue undesirable behaviour through sedation (Romeo, Knapp, Tyrer, Crawford, & Oliver-Africano, 2009). Moreover, it is unethical to use drug treatments for challenging behaviour without clinical indication of agitation and violence (Xenitidis et al., 2001). Physical interventions, such as physical restraint and seclusion, have the potential to become physical abuse as a form of punishment or method of social control, especially when staff are busy or short on manpower. Residential care settings tend to use mechanical or physical restraint, seclusion and sedation to manage challenging behaviour (Emerson et al., 2000). The effectiveness of cognitive-behavioural therapy, psychotherapy and behavioural modification programmes in residents with SPID is limited. Indeed, it is difficult for residents with limited intelligence to use the cognitive process to associate difficult situations and maladaptive behaviour (Xenitidis et al., 2001). Hence, the effectiveness is far from consistent and conclusive, especially in severe cases. All of the available

evidence indicates the need for an effective psychosocial intervention for these residents with maladaptive behaviour.

Recently, a study of 202 participants showed that SIB was associated with aggression and sexually inappropriate behaviour, such as masturbation or public self-exposure (Matson, Cooper, Malone, & Moskow, 2008). Yet, irritability was a predictive indicator of SIB in people with SPID and, thus, regular assessment of irritability level was important in reducing the occurrence of SIB. More fundamental was the intervention to lessen irritability (Matson et al., 2008).

Relaxation is believed to reduce tension, anxiety and the frequency of challenging behaviour, thereby promoting skills learning and/or adaptive behaviour and facilitating community rehabilitation (Chan et al., 2010; Kokoszka, 1992; Slevin & McClelland, 1999). MSE and MT are commonly applied in the field of SPID for relaxation. However, whether these two interventions can lessen challenging behaviour is uncertain due to the insufficient evidence proving its beneficial effects.

2.6 Use of the Multisensory Environment

MSE always includes a harmonious stimulating combination of all senses to fulfil sensory drive needs. Most settings adopt MSE to facilitate recreation and leisure, as limited alternatives, resources and appropriate tailor-made leisure activities are available for people with SPID (Hutchinson & Haggar, 1994). MSE is perceived as a pleasurable, enjoyable and highly humane approach (Lancioni, Cuvo, & O'Reilly, 2002; Slevin & McClelland, 1999). Anecdotal reports of its beneficial effects are most often provided to support the application of MSE. The essence of MSE is to provide a favourable environment for relaxation through free

expression of interest in an unhurried manner. The use of an enabling approach is one of the key elements of MSE, as it provides emotional support (Hutchison & Kewin, 1994). The enabling approach was first introduced in the project of Whittington Hall Hospital in Chesterfield. The initial purpose was to assist SPID residents who felt uneasy and timid to relax for exploration in the newly launched sensory environment (Kewin, 1994). As the concept of the enabling approach was fully supported in the healthcare team of the Whittington Hall Hospital in Chesterfield, it has been well adopted in subsequent studies on MSE for people with ID or other populations, such as the elderly (Pinkney & Barker, 1994).

Enabling is a sensitive and non-directive approach used by staff in MSE, where an enabler establishes a positive relationship through increased personal contact and communication with a resident. A safe and secure atmosphere is created and the resident is encouraged to freely choose his/her favourite sensory equipment. The enabler shares a common positive emotional experience with the resident irrespective of their behaviour and does not make any demand to learn (Hutchinson & Kewin, 1994; Lancioni et al., 2002).

The application of MSE has been adopted by two groups of proponents: one that defines MSE as a place where therapists take charge and use therapeutic measures to ameliorate particular conditions related to their interests, and one group that is keen on the theme of relaxation and leisure, emphasising the nondirective nature of and free choice in MSE (Hutchinson & Haggar, 1994; Pagliano, 1998). These professionals, who include doctors, nurses, teachers and physical and occupational therapists, believe that leisure has its own self-awareness and self-development value (Hogg, Cavet, Lambe, & Smeddle, 2001a). Nevertheless, the transition from recreational purpose to therapeutic effect must still be verified

by scientific and evidence-based studies (Lotan & Gold, 2009).

Hogg et al. (2001a) reviewed 17 studies ranging from 1 to 27 participants per study. Eight studies involved people with SPID (Ashby et al., 1995; de Bunsen, 1994; Hutchinson & Haggar, 1994; Kenyon & Hong, 1998; Lindsay et al., 1997; Long & Haig, 1992; Martin et al., 1998; Withers & Ensum, 1995). Behavioural observations and staff interviews were used to evaluate the outcomes, which mainly contained levels of enjoyment, relaxation, concentration and frequency of challenging behaviour. Very limited information on the reliability of the behavioural observations was presented. The qualitative data were abundant in the staff interviews and targeted in-depth investigation of the perception of enjoyment and relaxation, and effect on challenging behaviour of the MSE users from the staff's perspectives (de Bunsen, 1994; Hutchinson & Haggar, 1994). All except two studies (Martin et al., 1998; Withers & Ensum, 1995) showed positive results. These two studies used quantitative research designs with sophisticated crossover intervention patterns to minimise residual effects to influence the upcoming intervention schedule. Despite the stringent study design, no independent control group was available (Martin et al., 1998).

Another systematic review (Chan et al., 2010) examined 17 studies of the behavioural effects of MSE in adults with ID, involving 381 participants ranging from 11 to 73 years of age. The number of participants in these studies comprised single to 96 participants. The duration of the MSE sessions varied from 10 minutes to 1 hour. The number of MSE sessions per subject also varied from 4 to 36. Both physiological measurements, such as pulse, and behavioural observations, such as the frequency of challenging and stereotypic behaviour, were made. Most of the studies reviewed generally supported the immediate positive

impacts of MSE in promoting communication, concentration, social engagement, relaxation and positive behaviour. Yet, such short-term therapeutic effects on challenging and self-stimulating behaviour could not be carried over from MSE to their usual living environment. However, these concluding remarks were contradicted by a meta-analysis of 13 studies (Lotan & Gold, 2009). Not all of the studies included were focused on challenging behaviour and only for people with SPID. Various research designs were involved, but pre- and post-intervention comparison was most common. Single group with crossover design was generally adopted in the selected articles (Ashby et al., 1995; Kaplan, Clopton, Kaplan, Messbauer, & McPherson, 2006; Shapiro et al., 1997). The participants involved people with moderate to profound ID. The total number of participants ranged from 2 to 54 participants per study, with an average of 9. They ranged from 5 to 65 years of age, with a mean of 33 years of age. Standard deviations were not reported in the review. Only two studies with crossover and experimental designs (Ashby et al., 1995; Cuvo, May, & Post, 2001) were focused on people with SPID. This meta-analysis indicated that individual MSE intervention was only a little better than its group treatment effect, and the individual participants exhibited more adaptive behaviour in areas of concentration, responsiveness and task engagement, such as sandwich making and ball throwing (Kaplan et al., 2006). The meta-analysis also analysed the MSE patterns, showing that the duration of each session varied from 20 to 40 minutes, with an average of 30 minutes per session. The intervention frequency ranged from one to five sessions per week, with an average of two sessions per resident. In addition, the total number of sessions in each programme ranged widely from 2 to 50 sessions, with an average of 20 sessions per resident (Lotan & Gold, 2009). As different severities of ID and age

groups have a variety of intensities of sensory drives, various intervention patterns may be needed to accommodate individual needs and thereby produce optimal effects (Chan et al., 2010; Lotan & Gold, 2009). The characteristics of selected MSE studies for people with SPID are shown in the *Table 2.1*.

Table 2.1. The characteristics of the multisensory environment studies for people with severe and profound intellectual disabilities

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
Ashby et al. (1995)	Convenience sampling Eight subjects (2 male & 6 female) with SPID, aged 23 to 62 (M = 38.9 year-old)	One ward of a hospital	Case study report	MSE: 20 min/session 3 sessions/week Total 20 sessions to each subject	Concentration span: count the number of meaningful movement in a 5-minute simple task Responsiveness: rate on a scale of 0-4 in terms of enjoyment, relaxation and comfort in a video which taken in 1st, 5th, 10th, 15th and 20th session Therapeutic value of the session: rate on a scale of 1-5 on twelve randomly selected recorded sessions	Repeated measures ANOVA Concentration & responsiveness: improvement in 6 out of 8 subjects Therapeutic value: consistently rated at 4, perceived therapeutic to the subjects Overall: Positive effect in using MSE	Not studied
Chan et al. (2005)	Simple random sampling Total 89 subject s with dual diagnosis treatment group: 48 subjects (19 male & 29 female, 22 mild ID, 14 moderate ID & 12 severe ID), aged 11 to 70 Control group: 41 subjects (17 male & 24 female, 22 mild ID, 11 moderate ID,	An intellectual disability unit of a mental hospital	Experimental design	Experimental group (MSE): 1 hour/session 3 sessions/week Control group (standardised activity): 1 hour/session 3 sessions/week Total 36 sessions (12 weeks) to each subject	Level of relaxation (assessed by Behavioural Relaxation Scale, pulse rate, and Snoezelen Dairy Card) conducted immediately before and after each session Frequency of challenging behaviour (assessed by Checklist of Challenging Behaviour & Behaviour Checklist) conducted before, at midpoint of intervention, immediately after intervention, and then 5th	ANOVA & paired t-test Level of relaxation: no significant different in pulse rate, and level of relaxation between experimental and control groups, but significant change within experimental group. Immediate positive mood was seen just after the interventions in the experimental group. Such positive effect was also obtained from the	Frequency of challenging behaviour: 5 weeks & 12 weeks after the intervention Insignificant result

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
	& 8 severe ID), aged 11- over 71				and 12th week after the interventions to explore sustainable effect Semi-structured interviews: all involved registered nurses were invited at the end of the interventions to understand their perceived benefits and difficulties during the period of interventions (no details provided)	semi-structured interviews. Frequency of challenging behaviour: both groups showed reduction of challenging behaviour immediately after the interventions. Overall: time effect in MSE, but no group difference between MSE & control group	
Cuvo et al. (2001)	Purposive sampling Four adults (2 male & 2 female) with SPID and severe stereotypic behaviour	State operated residential home for adults with ID	Case study	Comparison between living room, MSE, and outdoor activity x 3 subjects, one subject stayed in living room as control Experiment 1: MSE session x 45 min from Monday - Friday x 14-18 days Experiment 2: Living room, MSE and outdoor activity (counterbalanced order) x at least	Frequency of stereotypic behaviour and percentage of engagement in meaningful activities Experiment 1: Observe before & after each MSE session x 20 min with 15-second intervals in living room. Observe MSE x 20 min with 15-second intervals from Monday - Friday x 14-18 days Experiment 2: Similar to experiment 1, the observation order: living room → MSE → outdoor activity or living room →	Descriptive statistics Results showed outdoor activities were most effective to reduce stereotypic behaviour and increase percentage of engagement, then MSE, and the least was living room Overall: MSE was better than living room, but less effective than outdoor activity	Not studied

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
				15-20 min x 6 days per week for 2 weeks	outdoor activity → MSE. Observation x 6 days per week for two weeks		
de Bunsen (1994)	Convenience sampling Six pupils with SPID and challenging behaviour	One special school	Case study	MSE: Daily session with massage therapy x 2 weeks	Exhibition of challenging behaviour in MSE and school	Descriptive in nature Reduction of challenging behaviour and increased eye contact in MSE > school (more details are shown in Table 2.3) Overall: MSE was better than classroom	Not studied
Hutchinson & Haggar (1994)	Purposive sampling 15 subjects with SPID	A resource centre of a large institution for people with ID	An exploratory study	MSE: Various patterns of individual subjects, by average 2 hours/week	3 major dimensions: Happiness/sadness, agitation/relaxation, interest/disinterest through 2 descriptive records (Portrait sheet & Snoezelen diary card) and staff interviews	Descriptive in nature One subject dropped out because of personal affairs, remaining subjects showed happiness and relaxed. 12 showed interest to the MSE. 7 ambulant subjects able to demonstrate free choice. 4 subjects were reported generalisation of positive affect and relaxation in ward level Overall: MSE was favourable to positive affect, relaxation and interest	Not studied

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
Kenyon & Hong (1998)	17 subjects (10 male & 7 female) with SPID & at least one of the following conditions: profound physical disability, sensory impairment, & challenging behaviour, aged 18-65	Occupational therapy centre of a hospital for people with disabilities	An exploratory study	MSE session x 14 weeks (no information about the treatment pattern)	1st objective: Behaviour change, choice making and preference in the MSE 2nd objective: Enjoyment and relaxation Through direct observations and interview with nursing staff	Descriptive in nature 1st objective: 87% subjects showed positive behaviour changes, e.g., reduced challenging behaviour, & look calmer in the MSE. 2nd objective: 67% subjects showed relaxed and enjoyed the MSE activity	Not studied
Lindsay et al. (1997)	Convenience sampling Eight subjects (2 male & 6 female) with SPID and challenging behaviour, aged 23 to 62 (M = 38.6 year-old)	One ward of a hospital. Both MSE and activity area were used to administer four interventions one by one.	Crossover design of a single group	Four different interventions in an order as follows: behavioural relaxation therapy, hand massage or aromatherapy, active therapy, and MSE. 20 min/session 3 sessions/week 20 sessions/therapy, total 80 sessions over 27 weeks to each subject	Concentration: four sessions of each therapy were video-taped to evaluate engagement of meaningful movement in an occupational task. Inter-rater reliability r (Spearman's correlation) = 0.96, inter-rater agreement = 93%. Responsiveness: a four-point Likert scale to rate relaxation / enjoyment level. Inter-rater reliability r = 0.82, inter-rater agreement = 86%.	Repeated measures ANOVA Hand massage and active therapy: no significant improvement in concentration and responsiveness. MSE and behavioural relaxation therapy: positive effect on concentration and relaxation. Overall: MSE was favourable in concentration and relaxation	Not studied

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
Lindsay et al. (2001)	Convenience sampling Eight subjects with SPID and challenging behaviour, aged 23 to 62 (M = 38.6 year-old), same sample of Lindsay et al. (1997)	One ward of a hospital. Both MSE and activity area were used (same as Lindsay et al., 1997)	Crossover design of a single group	Same intervention pattern as Lindsay et al. (1997)	Communication: three sessions of each therapy to evaluate through a five-point Likert scale which consisted of five positive variables (e.g., friendly vocalization, soft touch) and five negative variables (e.g., screaming, self-injury) Inter-rater agreement > 95%	Repeated measures ANOVA MSE and behavioural relaxation therapy: increased positive communication and decreased negative communication. Active therapy and hand massage: little or no effect on communication Overall: MSE was favourable in communication	Not studied
Long & Haig (1992)	Convenience sampling 4 residents with SPID (no demographic data provided)	A resource centre of an institution for people with ID	An exploratory case study	No structured intervention provided. Comparative observations were made between MSE and usual care environment. 5-minute interval record x 45 minutes / observation 3 times in usual care environment & 4 times in MSE over a period of 6 months	Behavioural change by recording on an observation chart between MSE and usual care environment. The contents of the observation chart included activity level, challenging behaviour, and emotional status.	Descriptive in nature More interaction with the immediate environment was recorded in MSE than usual care environment. More inactive state was recorded in usual care environment than MSE Overall: MSE showed more awareness to immediate environment	Not studied

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
Martin et al. (1998)	Convenience sampling 27 adults (18 male & 9 female) with SPID aged 22-61, M=38 year-old	Different residential homes and day centres	Counter-balanced crossover design	Split 27 subjects into 2 groups. One group: MSE → control → MSE; another group: control → MSE → control. Each MSE/control intervention: one hour/session & two session/week x 16 weeks, in which 12-min social interaction/session Between each intervention period, 2-4 resting week(s) as intervals to assess carryover effect	Analogue functional assessment at four conditions: Alone, contingent attention, non-contingent attention, and demand to check percentage of challenging behaviour, stereotypic behaviour & task attention for comparison. Functional performance to indicate activity level of positive and negative social behaviour & frequency of challenging behaviour: both were assessed before and after intervention	Descriptive & inferential statistics No improvement on functional performance and challenging behaviour after intervention. For immediate intervention effect, positive MSE effects were expressed by the enablers, yet not significantly different than control sessions. Addressed the importance of environmental variables e.g., reliability, predictability, relaxation and freedom from demand. Overall: MSE had no better effect than control group	>2 weeks and <4 weeks No carryover effect
Shapiro et al. (1997)	Convenience sampling Twenty children (15 male and 5 female), aged 5-10 (M=7.5 year-old) with 8 moderate and 12 severe ID,	An institution for disability	Experimental crossover design	Split into 2 groups and conducted two stages: One group (10 subjects/group): MSE → Playroom in stage I, then Playroom → MSE in the stage II. The other group	Level of stress: absolute change of heart rate by using a Holter to monitor before, during, and after treatment. Frequency of stereotypic and adaptive behaviour: Behaviour Checklist was developed and it was rated by two raters based on four	Inferential statistics No order effect detected between two stages. Heart rate: greater mean absolute change in MSE than playroom. Adaptive behaviour: increased in MSE than	Not studied but 7 days apart between two stages. Assumed that carryover effect might exist within one week

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
	exhibiting stereotypic behaviour Randomly divided into 2 groups with 10 children per group			was reverse order of the first group Each stage: 2 session/week & 20 min / session x 10 days, total 20 days for two stages	videos of each child, two videos in each setting.	playroom. Maladaptive (=stereotypic) behaviour: decreased in MSE than playroom. Overall: MSE had better immediate effect than playroom	
Slevin & McClelland (1999)	Purposive sampling Single subject – 22 year-old man with severe ID, autism, and exhibiting frequent challenging behaviour	Staff-supported residence	Quasi-experimental pretest & posttest design	Daily 20-min MSE session without enabling approach x 12 weeks	Level of relaxation: rated on 5-point scale of Behavioural Relaxation Scale during session and pulse rate before and after session Nursing notes of recording challenging behaviour incidents in usual care environment, and verbal reports of involved care staff	Paired t-test analysis Both Behavioural Relaxation Scale and pulse rate showed significant change to indicate relaxation effect after MSE. Verbal reports supported that the intensity of behavioural outbursts appeared improved, but the number of challenging behaviour incidents showed no significant change. Overall: immediate relaxation effect after MSE was supported, but sustainability of such relaxation in usual care environment did not observe	Not studied

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
Vlaskamp et al. (2003)	Purposive sampling 19 adults (8 male & 11 female) with SPID, aged 18-41, M=28 year-old	15 facilities for people with ID in Netherlands and Belgium	Observational study	At least two 30-min MSE session with 30-second observation intervals (no enabling approach in MSE)	Level of interaction and alertness by using momentary time sampling observations in MSE and usual care environment. Three observations (2x MSE, 1x usual care)/subject, in which only one MSE observation was used to compare with the behavioural pattern of usual care	Descriptive statistics & paired t-test The results showed that similar activity level in alertness and initiation, passivity, and engagement of interaction between MSE and usual care. MSE did not demonstrate superior than usual care. Even the number of direct care staff between MSE & usual care was comparable, about 1:2 up to 1:3 staff-resident ratio. Overall: no treatment effect between MSE & usual care	Not studied
Withers & Ensum (1995)	Convenience sampling Single subject: 17 year-old boy with SPID & severe SIB	A residential home for children	Case study	Use of differential reinforcement of other (DRO) with MSE, and orientation cues x 18 weeks DRO: Rewards with favourite foods & praise if no SIB MSE: at least daily session with a direct care staff	Frequency of SIB, positive behaviour e.g., engaged in constructive activities, no SIB during unstructured time, and negative behaviour e.g., shouting, throwing objects according to staff report	Descriptive statistics The results showed that SIB was abruptly decreased since week 3, and frequency of positive behaviour increased gradually, but the frequency of negative behaviour was swinging and fluctuated throughout the study period. After on-site observation by the authors, the frequency of negative behaviour might be	6-month follow up Effective to reduce SIB with the continuation of treatment package. The psychiatrist started to reduce the

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results	Carryover effect
				Orientation cues: regular routine with cues to indicate next schedule or upcoming activities to provide sense of security and relieve his anxiety Regular staff group meeting: feedback the progress & response his needs timely		distorted because the direct care staff were afraid of fading out the treatment package, hence, the negative behaviour was exaggerated in the report. Frequency of positive behaviour was affected once there was change of routine e.g., school holidays. Hence, orientation cues for upcoming schedule was important for SPID persons to reduce their anxiety-related behaviour problems Overall: treatment package was effective to reduce SIB, not only because of MSE	dosage of anti-psychotic drug

ANOVA: Analysis of Variance; ID=Intellectual Disabilities; M=Mean; min=minutes; MSE=Multisensory Environment; SIB=Self-injurious Behaviour; SPID=Severe and Profound Intellectual Disabilities

2.6.1 Long-term effects

Most studies involving people with SPID (Ashby et al., 1995; Cuvo et al., 2001; de Bunsen, 1994; Hutchinson & Haggar, 1994; Kenyon & Hong, 1998; Lindsay et al., 1997; 2001; Slevin & McClelland, 1999; Vlaskamp et al., 2003) have evaluated the immediate or short-term effects of MSE with the outcomes measured immediately following MSE sessions. Very few studies have examined its long-term or carryover effect, with the longest effects being up to 12 weeks after the MSE intervention (Chan, Chien, & To, 2007). Two studies attempted to estimate the carryover effect of MSE to prevent the residual effect from one intervention on subsequent interventions when they adopted a crossover research design (Martin et al., 1997; Shapiro et al., 1997). The maximum washout period between interventions was 2 weeks (Marin et al., 1998). The findings did not show statistically significant behavioural improvement due to MSE compared with the control group. According to Shapiro et al. (1998), the carryover effect of MSE on participants' daily life may be sustained for a few days after MSE. As the number of days with significant effects has not been clearly addressed, it probably would not be longer than 1 week, as MSE is frequently given on a weekly basis (Lotan & Gold, 2009).

In Singh et al. (2004), both aggressive behaviour and SIB were significantly lower in MSE sessions, which carried over (mainly the lower SIB) to the successive sessions regardless of the training condition that followed (i.e., either daily living activities or vocational skills training). However, the carryover effect lasted approximately 1 hour maximum, as each intervention was stayed apart for only 1 hour.

Only two studies (Chan, To, Chien, & Thompson, 2005; Martin et al., 1998) have evaluated the long-term effect of MSE after the completion of all MSE sessions. Chan et al. (2005) reassessed the effectiveness of MSE after 5 and 12 weeks, whereas Martin et al. (1998) followed up with participants over 4 weeks after the completion of the intervention. However, the results of both studies showed no significant carryover effect, and the researchers believed that the behavioural effect of MSE intervention was only very short term, with any therapeutic effects ceasing shortly after the sessions ended. The perceived positive effect is primarily related to the working relationship between the enabler and individuals with SPID and may be mainly due to increased physical contact and interaction, which can differ significantly from the usual living environment. Such contact and interaction are usually empathetic and can promote emotional exchange (Hogg, Reeves, Roberts, & Mudford, 2001b; Martin et al., 1998). Martin et al. (1998) suggested not using MSE, as it was not justified to spend enormous amounts of money on expensive equipment that produced insignificant long-term effects or effects only sustainable for a few days.

In summary, there is no strong evidence to support the effectiveness of MSE in the literature. In view of inconsistent findings, the carryover effect of MSE for residents with SPID can be examined to identify any residual effects of MSE up to 2 weeks after intervention completion, as suggested by Martin et al. (1998), who showed very minimal carryover effects after 4 weeks. However, Shapiro et al. (1997) reported carryover effects might exist within 1 week post-intervention. Thus, this study evaluates the carryover effects at 2 weeks after intervention completion.

2.6.2 Evaluating the effectiveness of the multisensory environment

Many methodological issues have hampered the positive effects of MSE in other studies. There have been four main weaknesses in research methodology. First, the positive results reported in a few studies have largely been based on qualitative data, such as post-session ratings to estimate the overall effect for participants, diary cards retrospectively completed by care staff to record any behavioural changes and interviews to explore staff's perceptions of interventions (Ayer, 1998; de Bunsen, 1994; Hutchinson & Haggar, 1994). Second, the staff-to-resident ratio in MSE is different from the usual care environment, being especially high in individual intervention sessions, from 1:1 (Slevin & McClelland, 1999) to 1:5 (Chan et al., 2005). Although no study has explicitly mentioned the staff-to-resident ratio in usual care environments, it is unlikely that the ratio is better than the intervention group. If staff facilitation is a crucial component of MSE success, it may not be possible to transfer the therapeutic effect to other clinical areas due to very different levels of staff strength. Third, several studies have involved a relatively small number of MSE sessions or very few participants, minimising the strength of conclusions on its effectiveness with satisfactory standards of intervention integrity and adequate sample size (Kenyon & Hong, 1998; Long & Haig, 1992; Slevin & McClelland, 1999). Fourth, the lack of a standardised assessment tool for challenging behaviour weakens comparisons of studies (Kenyon & Hong, 1998; Martin et al., 1998). The meaning of unstandardised tool is the outcome measure that was designed by the researchers themselves without showing the psychometric properties of the tool e.g., on-task behaviour is the measure of duration engaging in sandwich making, shared attention behaviour is the frequency of eye-contact with the direct care staff within the observed intervals (Kaplan et al., 2006; Solomons,

2005). These, along with the lack of control of confounding variables in study groups, such as co-morbidity of mental and physical illnesses, homogeneity of study groups, work culture, and heterogeneous research designs, are the main barriers to confirming MSE as an effective intervention for reducing challenging behaviour, stereotypic behaviour or SSB in people with SPID (Lotan & Gold, 2009).

In view of most of the studies reviewed, more research is needed to determine whether people with SPID can consistently benefit from the sensory inputs of MSE. Most studies have been explorative in nature, without a control group for comparison (Lotan & Gold, 2009). A well-designed randomised controlled trial with an adequate number of participants, valid outcome measures and an appropriate follow-up period is needed to evaluate the effectiveness of MSE to reduce challenging and other forms of maladaptive behaviour in people with SPID, without which MSE remains a leisure activity rather than a therapy for these residents (Chan et al., 2010).

The sensory stimulation in MSE is inevitably much richer than that in usual care. The unconditional acceptance of residents' behaviour by nurses conducting MSE sessions can definitely promote their free expression. However, not all MSE study results have revealed an optimal effect in enhancing residents' relaxation and positive behaviour. The prevalence of visual and hearing impairments in some residents may also limit the therapeutic effect of the sensory stimulation provided in MSE. Hence, the alternative or supplemental use of tactile stimulation, such as physical touch and MT, is often reported in residents with partially defective senses. Therefore, it is important to conduct research to examine the therapeutic effect of alternative treatment with tactile stimulation, such as MT in usual care

environments or MSE, as proposed in this study, to bridge the knowledge gap.

2.7 Use of Massage Therapy

Massage therapy (MT) has been commonly used to relax and improve muscle tone, increase blood flow, relieve muscle spasms and improve sense of well-being and mood. A qualitative study investigated the importance of physical touch in the form of MT in promoting general health among hospitalised patients (Smith, Stallings, Mariner, & Burrall, 1999). After four MT sessions, seventy hospitalised patients with cancer in rehabilitation and oncology units completed a questionnaire to evaluate physical outcomes, such as appetite and elimination, levels of relaxation, alertness, interaction and sense of recovery. At the end of the questionnaire, a narrative description of MT was requested. Fourteen healthcare providers (specifically, ten registered nurses, one medical student and three psychiatric fellows) and four massage therapists completed the questionnaires with open-ended questions or interviews to explore the patient benefits of MT. Thematic content analysis revealed that most patients subjectively felt that their general conditions improved after receiving MT, particularly in the areas of relaxation, social interaction, orientation and alertness and mobility. The perceptions of healthcare providers were very positive towards the effect of MT in achieving relaxation, a sense of well-being, positive change of mood and increased mobility and activity level while decreasing signs of discomfort. The massage therapists' expressed similar perspectives as the healthcare providers (Smith et al., 1999).

Evidence of the effect of MT in people with SPID is very limited. Only seven relevant studies (Croghan, 2009; Dossetor, Couryer, & Nicol, 1991; Hegarty

& Gale, 1996; Lindsay et al., 1997; 2001; McEvoy et al., 1987; Solomons, 2005) using objective assessment tools for MT were conducted between 1966 and 2010. The effectiveness of MT can be evaluated in terms of single-dose and multiple-dose values. Single-dose effects are determined when assessments are conducted before and after each intervention, whereas a multiple-dose effect is determined through an assessment conducted after a series of intervention sessions (Moyer, Rounds, & Hannum, 2004). Five studies employed a case study design and two adopted a crossover design, such that all participants received a sequence of different treatment patterns and were evaluated individually (Lindsay et al., 1997; 2001). No experimental study or randomised clinical trial has conducted to demonstrate the effectiveness of MT. Due to paucity of studies and small sample sizes (N=20 in total; number of participants per study ranged from one to eight), the effectiveness of MT is therefore inconclusive.

Nevertheless, narrative descriptions and qualitative exploratory findings are abundant. All studies have involved multiple-dose MT for different kinds of residents. The description of massage intervention has varied from simple depiction, for example only mentioning an oil massage to be applied twice a day (Dossetor et al., 1991), to detailed accounts of massage techniques in the forms of effleurage and petrissage and other bodywork manipulations, such as acupressure stimulation and craniosacral therapy (McEvoy et al., 1987). The maximum duration of each massage session has varied between 10 and 45 minutes, with the shortest treatment period ranging from 3 months (Hegarty & Gale, 1996) to 8 months (Solomons, 2005). One of the studies, MT was conducted in daily schedule and continued for at least 18 months to assess its effectiveness in reducing challenging behaviour (Dossetor et al., 1991). The frequency of MT ranged from

daily to weekly, with an average of twice a week. The most common body part of receiving massage was hands because it was easy accessible (Croghan, 2009; Hegarty & Gale, 1996; Lindsay et al., 1997; 2001; Solomons, 2005), possibly because it is the most convenient site to access and assist residents to experience the pleasant feeling of physical touch (Gale & Hegarty, 2000). The characteristics of the MT studies for people with SPID are summarised in *Table 2.2*.

Pre- and post-treatment assessments are commonly adopted to evaluate physiological and behavioural changes on relaxation level. To monitor the behavioural changes of the residents in all of the identified studies, observations and staff interview were used. Physiological data, namely heart and respiration rates, have been frequently used to evaluate relaxation level (Croghan, 2009; Hegarty & Gale, 1996). Generally, the lower heart and respiration rates than the baseline level after intervention imply the likelihood of relaxation. Qualitative or narrative data often come from formal or informal interviews with the involved caregivers, mainly parents, teachers, nurses and direct care staff to validate the data collected from physiological measures and behavioural observation (Hegarty & Gale, 1996; Solomons, 2005).

Two case studies of two persons with SPID using physiological data to reflect relaxation effects revealed positive results (Croghan, 2009; Hegarty & Gale, 1996). Both pulse and respiration rates of residents with severe challenging behaviour significantly decreased after the intervention compared with the baseline measurement. Yet, the significance level of the results was not reported clearly in these studies.

Table 2.2. The characteristics of the massage therapy studies for people with severe and profound intellectual disabilities

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & Major results
Croghan (2009)	Convenience sampling Single subject: a 13 year-old blind girl with SPID	Hospice setting	Case study report	Hand massage: 10-min / session x 3 sessions	Effect of relaxation by measuring pulse rate that taken 15-min before, during and after each hand massage session Emotional response to hand massage was evaluated by "Affective Communication Assessment" tool which observed before and after each intervention	Descriptive in nature Pulse rate: decreased an average of 7 beats than baseline after hand massage, indicating the likelihood of relaxation The emotional response to hand massage was relaxed and comfortable
Dossetor et al. (1991)	Convenience sampling Single subject: a 14 year-old girl with SPID & Cornelia de Lange syndrome, exhibiting severe SIB for over 10 years	Community residential home	Case study report	Daily body massage after bath, involving trunk & back. 30 min/session, twice per day x 18 months (integrated into treatment plan). In case of bad mood & temper tantrum, extra dose of body massage provided	Frequency of challenging behaviour, including SIB, aggression, temper tantrum. Other observations included bad mood, wound healing, duration of wearing splints and helmet	Descriptive in nature The frequency of self-injurious behaviour was progressively decreased after 3 weeks of intervention. After 3 months, wound healed & no splint for whole day. No medication and free of splint to control SIB at 6 months. Such improvement maintained for a minimum of 18 months
Hegarty & Gale (1996)	Convenience sampling Single subject: a 23 year-old lady with SPID & severe challenging behaviours, including aggression	Female ward of a long-stay hospital	Case study report	Swedish style massage x head, neck, shoulders, hands & forearms with 10-25 min, other therapies included counselling and rapport building to make up 45 min / session in a quiet room of the ward x 12	Relaxation level by monitoring of pulse and respiration rates before, during and after each session Frequency of challenging behaviour by comparing the nursing record: 6-month prior to the intervention, and during the intervention Behavioural change: collected from verbal comments of direct care staff	Descriptive in nature Relaxation level: both pulse and respiration rates were lower than baseline after massage therapy indicating relaxation Frequency of challenging behaviour decreased after intervention as shown in the nursing record. Only 4 incidents

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & Major results
				sessions in weekly basis for 3 months		recorded during the intervention, whereas the subject was not visited on that month From the staff perspective, subject became more sociable, increased self-initiated interaction, and able to tolerate outdoor activities after the interventions
Lindsay et al. (1997)	Convenience sampling Eight subjects (2 male & 6 female) with SPID and challenging behaviour, aged 23 to 62 (M = 38.6 year-old)	One ward of a hospital. Both MSE and activity area were used to administer four interventions one by one	Crossover design of a single group	Four different interventions in an order as follows: behavioural relaxation therapy, hand massage or aromatherapy, active therapy, & MSE 20 min/session 3 sessions/week 20 sessions/therapy, total 80 sessions over 27 weeks to each subject	Concentration: four sessions of each therapy were video-taped to evaluate engagement of meaningful movement in an occupational task. Inter-rater reliability r (Spearman's correlation) = 0.96, inter-rater agreement = 93% Responsiveness: a four-point Likert scale to rate relaxation / enjoyment level. Inter-rater reliability r = 0.82, inter-rater agreement = 86%	Repeated measures ANOVA Hand massage and active therapy: no significant improvement in concentration and responsiveness MSE and behavioural relaxation therapy: positive effect on concentration and relaxation
Lindsay et al. (2001)	Same sample of Lindsay et al. (1997)	Same setting of Lindsay et al. (1997)	Crossover design of a single group	Same intervention pattern as Lindsay et al. (1997)	Communication: three sessions of each therapy to evaluate through a five-point Likert scale which consisted of five positive variables (e.g., friendly vocalization, soft touch) and five negative variables (e.g., screaming, self-injury)	Repeated measures ANOVA Hand massage and active therapy: little or no effect on communication MSE and behavioural relaxation therapy: increased positive communication and decreased negative communication

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & Major results
McEvoy et al. (1987)	Convenience sampling Five subjects (2 male & 3 female) with SPID & challenging behaviour, aged 14 to 24 (M = 19.6 year-old)	Special school	Case study report	Massage therapy: 45 min/session 2-3 sessions/week x 16 weeks. All subjects: On behaviour programme & psychotropic medications throughout the study period	Frequency of challenging behaviour: based on daily observation of behaviour checklist (inter-observer agreement > 83%) and descriptive notes of massage therapist	Descriptive in nature Behaviour change noted in three subjects: increased verbalizations for social communication, decreased challenging behaviour, especially SIB & aggression, increased functional hand use in skill acquisition, & increased on-task behaviour Two subjects dropped out because of strong resistance to physical contact
Solomons (2005)	Convenience sampling Four subjects (3 male & 1 female) with SPID, autistic spectrum disorder, & challenging behaviour, aged 5 to 6 (M = 5.5 year-old)	Aromatherapy room & MSE of a special school	Case study report	Aromatherapy massage (hands and/or feet): 2 sessions/week & max. 10 min/session (depending on child's tolerance) x 8 months MSE session: according to school schedule & no control of the attendance	Frequency of shared attention behaviour (e.g., eye contact, pointing, showing & giving direction of sharing object/activity), challenging behaviour & social interaction: use "early communication assessment" for direct observation during massage therapy & MSE session once a month for consecutive 8 months Semi-structured interviews with school staff and parents at the beginning and the end of the study to assess the frequency of shared attention behaviour at school & home	Descriptive in nature Aromatherapy massage: obtained higher frequency of shared attention behaviour, decreased challenging behaviour and increased tolerance to physical touch and emotional engagement than MSE

ANOVA: Analysis of Variance; ID=Intellectual Disabilities; M=Mean; min=minutes; MSE=Multisensory Environment; SIB=Self-injurious Behaviour; SPID=Severe and Profound Intellectual Disabilities

Based on behavioural observation, most participants reached a state of relaxation and enjoyment during and after MT. For example, the participants took initiative to seek for massage therapy (Dossetor et al., 1991), increased attempts to interact with others, improved social awareness (McEvoy et al., 1987) and looked very relaxed and tranquil during observation (Croghan, 2009). Overall, the relaxation effect has been predominant in most studies. Although it has not yet been explicitly assessed with measurement tools, a decrease in challenging behaviour and an increase in positive behaviour may be behavioural indicators of relaxation.

Several case studies (Dossetor et al., 1991; Hegarty & Gale, 1996; McEvoy et al., 1987) have revealed that the frequency of challenging behaviour among residents with SPID decreases a lot immediately after MT. This result is very obvious in Dossetor et al. (1991), as the frequency of a single subject's SIB progressively reduced after a 3-week massage programme. After 6 months of intervention, the subject was free from her medications and hand splint to control her severe SIB, which had been exhibited for more than 10 years (Dossetor et al., 1991).

In addition, other than reducing challenging behaviour, all ID subjects (three females and two males) in the study of treatment of SIB by McEvoy et al. (1987) also showed an increased number of verbalisations and engaged behaviour following MT. In another case study, the behavioural change of a subject was very remarkable as she became more sociable, interacted with direct care staff, and was able to participate outdoor activities that she had never attempted before the intervention (Hegarty & Gale, 1996).

MT is believed to promote positive emotional exchange and improve physiological data. A study in a hospice care home of England revealed that hand massage could facilitate effective communication between direct care staff and residents. The staff themselves expressed satisfaction to their meaningful action because they helped the terminally-ill residents to experience the pleasure of MT (Croghan, 2009).

Several factors contribute to effective MT, such as frequency and duration of intervention, massage location, intensity of pressure, type of massage techniques and speed of massage movement (Fraser & Ross Kerr, 1993). However, these factors have seldom been examined in the massage studies (Croghan, 2009; Hegarty & Gale, 1996; Solomons, 2005). The difficulty of evaluating the effectiveness of massage techniques across studies is identified (Chan & Tse, 2011).

Apart from physiological data, behavioural observations have been frequently used in outcome measures. A number of reviewed studies did not disclose the results of inter-rater reliability. Only McEvoy et al. (1987) indicated the results. However, this unpublished manuscript contains many confounding variables. For example, change/modification of behavioural programmes and psychotropic drugs were concurrently applied during the study. Hence, the net effect of massage therapy is difficult to evaluate because these variables would affect treatment outcomes.

Complementary therapies, e.g., aromatherapy (Solomons, 2005), bouncing therapy, behavioural relaxation therapy (Lindsay et al., 1997; 2001), counselling (Hegarty & Gale, 1996), and activity in multisensory room (Lindsay et al., 2001) have been simultaneously used as comparable interventions to MT to assess which therapy is the most effective in inducing relaxation. Apart from the findings of

Lindsay et al. (1997; 2001), MT has been found to be the most effective therapy for inducing relaxation. However, according to Lindsay (1997; 2001), multisensory activity is the best choice for relaxation.

Compared with other study populations, such as pain management for cancer patients, MT for people with SPID is not a popular research topic. This may be due to the low cognitive functioning of the research subjects who are unable to give direct verbal feedbacks to the interventions. Even worse, their limited repertoires towards stimulations are subject to interpretation of individual observers. For instance, yelling can mean excitement, but also painful experiences (Chan & Tse, 2011). However, massage has been widely employed in nursing and physiotherapeutic interventions. Most studies of people with SPID (Dossetor et al., 1991; Hegarty & Gale, 1996; McEvoy et al., 1987; Solomons, 2005) have largely depended on qualitative data and reports of staff's views with noticeably positive results and perceived benefits to residents. Without using rigorous scientific methods, such as clinical trials, the effects of MT are difficult to confirm.

2.7.1 Mechanisms of massage therapy

The therapeutic effects of MT have four possible mechanisms, namely biomechanical, physiological, neurological and psychological (Weerapong, Hume, & Kolt, 2005). Biomechanical effects are come from the mechanical pressure against body tissues, thereby increasing muscle compliance and range of joint movement, subsequently stiffness of joint, muscle and body tissue decreased (Weerapong et al., 2005). Both hyperaemia and haemodilution can increase blood flow in skeletal muscle by 35% in response to tapotement (i.e., a vibration technique that involves striking and cupping hand movements on the skin surface),

but effect little change with petrissage (i.e., a forceful technique that involves skin rolling and wringing). Haemodilution decreases the viscosity of serum plasma and the haematocrit, subsequently increasing blood flow to the muscle or skin and hence improving the limb and body functions (Harris & Lewis, 1994).

Relaxation effect can benefit the physiological outcomes and is generally assumed an activation of parasympathetic nervous system, especially vagus nerve to suppress the sympathetic activity on physiological changes. This assumption is validated by lowering of blood pressure, and heart and respiration rates (Field, Diego, & Hernandez-Reif, 2007; Fraser & Ross Kerr, 1993; Moraska, Pollini, Boulanger, Brooks, & Teitlebaum, 2008). Vagus nerve consists of both parasympathetic effect for controlling of heart, lungs, and digestive tract to decrease heart and respiration rates, help with calmness, relaxation and digestion; and sympathetic function for increasing alertness, energy, and physiological variations (Field, 2014). However, if the physiological arousals are remaining low in the baseline measurement before the intervention, it is difficult to identify the physiological changes between pre- and post-treatment comparisons. Specifically, when blood pressure, heart and respiration rates are comparatively stable, it is not easy to recognise significant changes after the intervention.

The neurological effects induced by MT are connected to reflex stimulation, thereby decreasing neuromuscular excitability and pain sensation and reducing muscle tension or spasm by blocking neurotransmitter transmission. Indeed, some neurophysiological changes can change electroencephalogram (EEG) patterns from active state to a resting position (i.e., the beta wave decreases and the alpha and delta waves increase), and enhance the secretion of relaxation hormones, such as endorphins, while decreasing the level of stress hormones, such as cortisol (Field et

al., 2007; Weerapong et al., 2005).

Lastly, the psychological effects of MT may involve building a relationship between the body and mind, thereby promoting relaxation and decreasing anxiety. However, all of these mechanisms are still under experimental study to identify the mechanism that activates when MT is administered (Weerapong et al., 2005). Therefore, it cannot yet be determined whether the mechanisms described previously fully explain the various relaxation and therapeutic effects of MT. Further research is needed to address this important issue.

2.8 Use of Massage Therapy in the Multisensory Environment

To better facilitate resident-staff relationships, three MSE studies have integrated MT to provide tactile sensation (Ayer, 1998; de Bunsen, 1994; Lotan et al., 2009), with emphasis on relaxation and enjoyment, and behaviour management. The details of these three studies are summarised in *Table 2.3*.

In Ayer (1998), hand massage was applied in MSE for children with SPID. Ayer (1998) believed that hand massage could promote relaxation and body awareness, relieve stiffness and pain and improve circulation and manipulation of the hands for skills development, such as sign language. The one-to-one contact in the MSE had increased the level of interaction with the enabler and no challenging behaviour was recorded during the sessions. The reduction of challenging behaviour was believed because of relaxation effect (de Bunsen, 1994). Qualitative data have been collected through questionnaires and interviews from caregivers, teachers, and aromatherapists of schools, homes and a day centre to evaluate the value of MSE in children with SPID (Ayer, 1998; de Bunsen, 1994).

Table 2.3. The use of massage therapy in the multisensory environment for people with severe and profound intellectual disabilities

Author(s)	Sample	Setting	Study design	Intervention pattern	Outcome measure	Analysis & major results
Ayer (1998)	Purposive sampling Carers closely involved in MSE (number of participants not disclosed)	Two special schools and one day centre	Exploratory qualitative study to describe the experiences of the children with SPID in MSE from the carers' perspectives	Involved carers filled up the semi-structured questionnaires that based on their routine observations on 183 children with SPID using the MSE and age range 3-18 years	Extracted contents of the semi-structured questionnaires to present as single case studies	Latent content analysis of the questionnaires The positive experiences of children using MSE
de Bunsen (1994)	Convenience sampling Six pupils with SPID and challenging behaviour, and one control group (no demographic data provided)	One special school	Case study	Intervention group: No MSE x 2 weeks, then daily morning MSE with massage therapy x 2 weeks Control group: no MSE x 4 weeks (no information on duration of each session)	Compare the exhibition of challenging behaviour and relaxation level between MSE and school based on recording sheets, and interviews of involved carers e.g., teachers, therapists	Mainly qualitative data 24-hour and time sampling recording sheets were used to generate pie charts and histograms of individual pupils to reflect weekly behavioural change. MSE showed more reduction of challenging behaviour and increased relaxation than control group in some pupils
Lotan et al. (2009)	Convenience sampling Total ten adults with 7 moderate ID (4 male & 3 female) and 3 severe ID (2 male & 1 female), aged 25 to 74 (M=45 year-old, SD=16.45)	Community home for different ID levels	Case study	MSE: 30 min./session 2 sessions/week Duration, MSE setting and site of massage: depend on individual preferences Washout and re-intervention period: depend on availability of manpower and recurrence of challenging behaviour	Mean frequency of challenging behaviour / week	Pretest & posttest by using two-tailed student t-test Significant reduction of challenging behaviour during interventions x 9 cases

ID=Intellectual Disabilities; M=Mean; min=minutes; MSE=Multisensory Environment; SD=Standard Deviation; SIB=Self-injurious Behaviour; SPID=Severe and Profound Intellectual Disabilities

Another study adopted a case study design to evaluate the effectiveness of MSE on reducing challenging behaviour for 10 adult residents with moderate to severe ID (Lotan et al., 2009). MT or physical touch, e.g., light physical contact on the body surface without rhythmical stroking was provided in the individual sessions. The duration of the programmes and length of individual sessions were various, depending on the availability of caregivers and MSE, and the tolerance of the participants. The use of MSE equipment was also much personalised. Washout period (termination of interventions), either planned or unplanned was introduced between the MSE programmes. Weekly mean frequency of challenging behaviour was used to evaluate the effectiveness. The planned washout period was the result of challenging behaviour extinction and to release the service to other residents. Once the challenging behaviour recurred to baseline level, the programme resumed. Though the study harboured many confounding variables, e.g., diverse duration and length of interventions, the recurrence of challenging behaviour was consistent during washout period (Lotan et al., 2009). It demonstrated that active engagement in MSE with MT or physical touch was able to control the frequency of challenging behaviour. However, no specific outcome measuring tool has been employed to examine the therapeutic effects of MT in MSE, e.g., relaxation response.

In addition to resident-staff relationships, Sanderson and Carter (1994) supported the view that massage diverted the attention of people with SPID from challenging behaviour to pleasurable experiences and the feeling of physical touch. However, these studies (Ayer, 1998; de Bunsen, 1994; Lotan et al., 2009) did not evaluate the differential or standalone effect of MT on resident outcomes. The researchers only explored the therapeutic effects of MSE from staff's perspectives

through diary cards and/or interviews. The direct care staff reported that most residents had positive behavioural outcomes in MSE, where the staff were not required to meet any set objectives of the activity. Hence, they might have been more willing to stay with the residents in MSE, which further conveyed positive results.

Both MSE and MT are frequently applied to people with SPID for relaxation, as these interventions do not require the recipients' cognition to achieve the preferred outcomes (Ashby et al., 1995; Croghan, 2009; Slevin & McClelland, 1999; Solomons, 2005). However, very few studies have preliminarily evaluated the effect of MT used with MSE that is often practised in clinical setting for leisure activity. The relaxation effect is thought to be augmented by tactile stimulation, which may thus compensate for these residents' visual and hearing defects through sensory inputs. Subsequently, the enhanced relaxation effect, along with intense resident-staff interactions, is expected to lessen challenging behaviour. This assumption must be corroborated through controlled trials.

Three studies have compared the relative effectiveness of MT and other behavioural and sensory stimulation therapies for people with SPID. Lindsay et al. (1997; 2001) examined the effects of hand massage, behavioural relaxation training, active therapy (i.e., bouncing castle) and MSE on levels of concentration, responsiveness and communication in adaptive tasks, which could replace self-stimulating behaviour. Only MSE and behavioural relaxation training had significant positive effects on concentration and communication. The results of hand massage only showed a modest effect on relaxation (Lindsay et al., 1997; 2001).

In another study of four children with autism spectrum disorders, the frequency of avoidance behaviour decreased and social engagement simultaneously increased during interactive massage sessions, where reciprocal interaction, either verbal or nonverbal, was encouraged to indicate individual preference of MT (Solomons, 2005). The treatment length of interactive massage depended on individual tolerance to the massage therapy. The maximum duration was 10 minutes. Based on the narrative information of direct care staff and the behavioural observations of a validated communication assessment tool (Coupe O'Kane & Goldbart, 1998), communicative functioning in the areas of eye contact and object of reference, positive behaviour such as vocalisation and physical contact generally increased immediately following MT compared with sensory stimulation sessions (Solomons, 2005).

Considering the inconsistent and preliminary results of these three studies, it is difficult to conclude whether MT, MSE or other sensory stimulations are superior to any others. In addition, MT and MSE have been conducted and evaluated separately. The enhancement effect of MT in MSE is still uncertain, although the practice of MT in MSE is very common in the clinical field for residents with SPID.

2.9 Behavioural States of People with Severe and Profound Intellectual Disabilities in Response to Stimuli

People with SPID are often unable to communicate verbally or symbolically. They appear passive and seldom take initiative to interact with their immediate environment (Nakken & Vlaskamp, 2007). Hence, observational studies on the behavioural states of people with SPID are very popular in special education, because teachers want to determine the 'right' time to provide classroom education

programmes for these students (Guess et al., 1988; Guess et al., 1990; Guess et al., 1993; Guess & Siegel-Causey, 1995; Munde, Vlaskamp, Ruijssenaars, & Nakken, 2011; Vlaskamp, Fonteine, Tadema, & Munde, 2009). As stated by Helm and Simeonsson (1989), a behavioural state is an expression of the maturity, status and organisation of the central nervous system of children with the capacity to respond to the environment and stimulation. A behavioural state has also been described as a measure of individual functioning level of engagement at any given time (Munde, Vlaskamp, Ruijssenaars, & Nakken, 2009a).

Guess et al. (1988) developed the Biobehavioural Observational Scale to observe the responsiveness of behavioural state of children with SPID to stimulus presentation in a study. As this group of people is susceptible to physical health problems and neurological disorders, such as epilepsy, they are often heavily medicated to control symptoms of physical illness and seizure attacks. The Scale consists of six behaviour patterns, namely asleep with eye closed without movement; awake/agitated with eyes open, crying and fidgeting; awake/inactive with eyes contact but no apparent physical movement; self-directed with some sensory orientation toward self; visually attentive with visual scanning or gazing to external stimuli; and active reaching with intention for reaching and grasping objects (Guess et al., 1988). It was observed that the participants spent considerable time fallen asleep, drowsy or daze, requiring intervention to activate their alertness and responsiveness to the environment. Some participants showed excessive self-stimulating or crying/agitated behaviour (Guess et al., 1988).

A follow-up study (Guess et al., 1993) attempted to construct an association between behavioural state and environmental variables in a similar cluster of students with longer classroom observation periods. They concluded that it was

impossible to link specific time duration with a particular behavioural state, but it was likely to predict one particular behavioural state that would follow another state. For instance, the major behavioural state was awake-inactive-alert, and this state was relatively readiness to shift between daze and alert, depending on the connectivity to environmental variables. The change from one state to another state could be happened within a comparatively short period. Their findings showed that lack of change in body position and location probably limited the students' interactions with the environment and more than half of the observed durations involved no interactions at all between the students and teachers/paid staff. The optimal behavioural state, awake-active-alert, was typically associated with environmental variables in adult interaction, self-help activities and materials present. Deep sleep was frequently associated with no interactions and students were placed in the prone or side-lying position. Generally, the behavioural states were closely related to certain environmental variables, such as body position, existence of social interaction and availability of materials (Guess et al., 1993). A study showed that enrichment of sensory environment did not automatically induce changes in alertness and interaction levels of children with SPID. Only vigilant observations could identify the subtle changes of their social and emotional responses to external stimuli (Tunson & Candler, 2010).

In another observational study (Guess & Siegel-Causey, 1995), 5-hour subject observations were conducted. For the 66 subjects between 2 and 21 years of age, some behavioural states were found relatively stable and not easy to change. For instance, deep sleep was a strong state that was resistant to perturbations by environmental stimuli, such as body movement, light and noise. Although this stable behavioural state might temporarily shift to another behavioural state during

a given perturbation, it was likely to return to original state when the perturbation stopped. This reversal pattern is described as the 'butterfly effect'. The study reconfirmed that some behavioural states were more readily to shift permanently into other behavioural states, even though the perturbation has ceased, such as the awake-inactive-alert state (Guess & Siegel-Causey, 1995).

In the absence of environmental stimuli, most observed behavioural states have not been at the right moment for learning (i.e., in the states of asleep, drowsy, dazed, self-stimulating or crying/agitation during the day). It has been speculated that reduced environmental stimulation may lead to increasing stereotypic behaviour to compensate for the need for sensory stimulation (Guess et al., 1990; Guess & Siegel-Causey, 1995). Behavioural states not only provide information on alertness and responsiveness to environmental stimuli, but also reflect the outcomes of interactions between physiological (such as mental state and physical health), developmental (such as cognitive process) and environmental variables (such as living condition) (Guess et al., 1990).

Currently, the elements that precisely promote the optimal behavioural state (i.e., the awake-active-alert state) and facilitate the switch from undesirable states to the favourable state are still uncertain, although it has been perceived that stimulating and engaging environments may promote alertness and responsiveness in people with SPID. The ultimate goal of these studies not only enhances their learning opportunity but also improve their quality of life (Guess & Siegel-Causey, 1995).

2.10 Alertness and Behavioural States

The focus of studies of people with SPID has evolved from behavioural states to alertness and responsiveness towards external stimuli to facilitate learning and training (Green, Gardener, Canipe, & Reid, 1994; Munde & Vlaskamp, 2015; Munde et al., 2009a; Munde, Vlaskamp, Ruijssenaars & Nakken, 2009b; Vos et al., 2013). People with SPID frequently lack alertness for skill acquisition training. Some trainers have suggested withholding training until they can maintain their alertness and responsiveness in the training programme (Munde et al., 2009a; 2009b). In Green et al. (1994), alertness was divided into three categories, namely asleep, drowsy and awake, with awake divided into five subcategories, namely nonalert-nonactive, alert-nonactive, alert-active, agitated and alert-active-nonpurposeful (Green et al., 1994). Three sets of behaviour were recorded in the observations: position and/or movement of the eyes, gross body movement and vocalisation (Green et al., 1994). Medication change was not perceived as a confounding variable due to the study's randomness design (Green et al., 1994). Nonalertness before training was common, but did not relate to the performance of the participants during the training session (Green et al., 1994). Rather, alertness and responsiveness increased during training regardless of the alertness level before the training (Green et al., 1994). Thus, it was not justified to withhold training just because of nonalertness before the training programme (Green et al., 1994). The findings reflected that the change of alertness state in response to external stimuli was rapid and unpredictable of the shifting directions.

A literature review (Munde et al., 2009a) conducted on alertness in people with SPID yielded 42 relevant articles, including 34 empirical studies, 5 literature reviews and 3 commentary articles on earlier studies. Of the 34 empirical studies,

one used interviews with teachers and students' daily schedules. Thirty-three studies used observation to collect data. Twenty-two of the observational studies observed participants in naturalistic settings, six studies observed participants in experimental settings and five studies used videotaping. The methods of observation included interval and continuous scoring with intervals ranging from 3 seconds to 5 minutes, momentary time-sampling and post-intervention observation. The observation duration ranged from 3 minutes to 5 hours. As people with SPID rapidly shift between levels of alertness, the continuous rating observation was better adopted (Arthur, 2004; Guess et al., 1993).

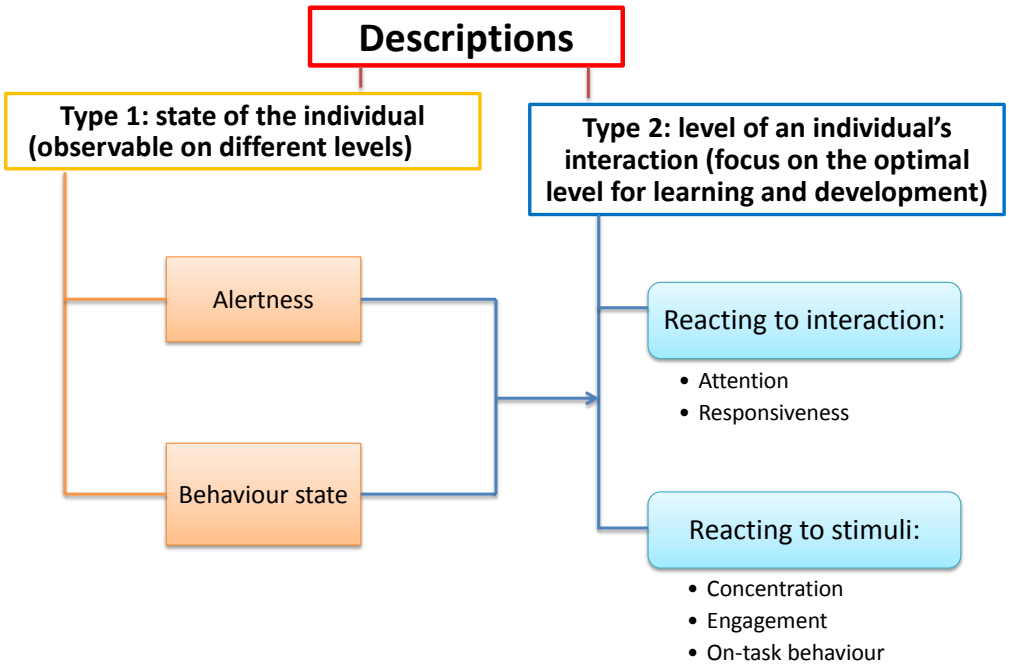
A study was conducted to compare the alertness level among MSE, usual care environment, and outdoor activities, the highest alertness level was identified in active physical involvement, i.e., outdoor activities, then MSE, and least alertness in usual care environment (Cuvo et al., 2001). The findings were consistent with another study to support that SPID residents preferred mobility task rather than sedentary task because mobility task could actively draw their interest and alertness (Lancioni, O'Reilly, Campodonico, & Mantini, 1998). Since the study only involved 3 subjects, the physical limitations of SPID residents make the possible choices of activities with active physical involvement challenging. Hence, studies on level of alertness for people with SPID often employ MSE which is more readiness in most facilities (Munde, 2011; Munde & Vlaskamp, 2015).

The terms 'alertness' and 'responsiveness' are frequently used together to show their interrelationship and the involvement of environmental factors (Munde et al., 2009a). Alertness focuses on reaching the optimal level of learning and personal development in interactions between an individual and the environment, which is similar to the observation of a behavioural state (Munde et al., 2009a;

Vlaskamp et al., 2003). After reviewing the literature (Foreman, Arthur-Kelly, Pascoe, & King, 2004; Guess et al., 1993), Munde et al. (2009a) divided the descriptions of alertness into two foci. Alertness is a state of an individual, which becomes manifest and observable in the individual's behaviour; alertness can also be the level of an individual's interaction and engagement with the environment (Munde et al., 2009a, p. 475). Other terms that are frequently used to describe the interaction between an individual and the environment include 'attention', which is used to determine the inclination of an individual towards objects or people (Munde et al., 2009a); 'responsiveness', which is used to describe the reaction of an individual to environmental interaction (Ashby et al., 1995); 'engagement', which involves physical touch and visual focus on external stimuli or materials (Cuvo et al., 2001); and 'on-task behaviour', where an individual is assigned to work on a task or a series of tasks and then evaluated on his or her 'concentration' on the task, in terms of duration or amount of meaningful movements (Ashby et al., 1995; Lindsay et al., 1997). Munde et al. (2009a) eventually conceptualised these descriptive terms into a model of descriptions, as shown in *Figure 2.1*.

Arthur (2004) also echoed the findings of previous studies (Guess et al., 1993; Guess & Siegel-Causey, 1995), such that the shift between awake-active-alert and awake-inactive-alert states was frequently followed by a return to the original state (i.e., baseline). In fact, alertness to environmental conditions can have a considerable effect on the internal state of individuals with SPID. Evidence has shown that environmental interactions, such as social interaction with teachers, direct care staff or parents, consistently uplifts the alertness level to the awake-active-alert state, instead of stereotypic behaviour (Arthur, 2004; Guess & Siegel-Causey, 1995).

Figure 2.1. Model of descriptions (Adapted from Munde et al., 2009a, p. 476)



Once activities or environmental interactions are provided, the frequency of awake-inactive-alert, dazed, self-stimulation and/or crying/agitation is reduced (Arthur, 2004). However, most often, people with SPID are left alone and no activity is offered in the usual care setting, which contributes to a low alertness level. Vlaskamp and Nakken (1999) reported that up to 40% of planned activities were not carried out in long-term residential care facilities due to staff shortage or cancellation. Like other people, people with SPID have the right to enjoy pleasurable activities for stimulation and relaxation. Clear objectives and evaluation criteria for planned activities should be enforced for staff to follow and evaluate the activity. In fact, task engagement with frequent prompting can divert self-stimulating behaviour to the awake-active-alert level (Vlaskamp & Nakken, 1999).

After reviewing 34 quantitative studies, Munde et al. (2009a) did not find any general principles on the elevation of alertness level for people with SPID. Hence, Munde et al. (2009b) attempted to use the concept mapping method to establish a clear description of alertness level and to identify environmental conditions that affected one's alertness level. All of the participants were experts in working with people with SPID (Munde et al., 2009b). The key descriptions of alertness involved the relationship of alertness to other functions and alertness as an observable reaction to stimuli (Munde et al., 2009b). The environmental conditions addressed physical and social interactions, stimulation and activities, communication, individual differences and the use of MSE (Munde et al., 2009b).

Various outcome measures exist when MSE is used as an environmental stimulus, such as engagement, concentration, responsiveness, enjoyment, and more importantly, comfort and relaxation (Ashby et al., 1995; Hutchinson & Haggar, 1994). Since alertness and behavioural states were first described (Green et al., 1994; Guess et al., 1993), MSE has been widely used to evaluate the alertness levels of people with SPID (Munde & Vlaskamp, 2015; Munde, Vlaskamp, Maes, & Ruijssenaars, 2012; Munde et al., 2011; Vlaskamp et al., 2003).

2.11 Interactions with Environmental Stimuli

Direct care staff often face the problem of interpreting the emotional expressions of people with SPID, and they also wonder what environmental conditions may affect their alertness levels (Munde et al., 2009b). It is difficult to interpret the communicative signals of people with SPID, as one signal may have several meanings. Their expressions of alertness may be different from conventional reactions to environmental stimuli. Studies (Arthur, 2004; Guess et

al., 1990; 1993) have supported that external stimulation and social interaction have greater impacts on alertness level than an individual's internal conditions. The initiation of interaction has shown different alertness level outcomes (Munde & Vlaskamp, 2015). As mentioned, alertness is an individual's interaction and engagement with the environment. It is closely related to other functions and is reflected by an individual's behaviour (Munde et al., 2009a). It is believed that alertness is an important precondition for learning and development in people with SPID, especially those with multiple disabilities (Green et al., 1994; Guess et al., 1990; Munde et al., 2011). Due to their concomitant physical disabilities, the signals of alertness may be very subtle, such as fleeting sounds, change of facial expressions or muscle tension. These signals may easily go unnoticed by the direct care staff. One signal may have different meanings in different situations, creating difficulty. The rapid and irregular shifting between awake-inactive-alert and awake-active-alert states further complicates behavioural state observations (Guess & Siegel-Causey, 1995; Mudford, Hogg, & Roberts, 1997; Munde et al., 2012). In Arthur (2004), active choice making and active control were associated with higher levels of alertness.

As people with SPID have physical limitations, they are expected to initiate interactions infrequently and mostly present responding behaviour. Initiation is defined as introducing or starting an interaction or activity. A study of 24 subjects with SPID examined the relationship between initiating interaction and changes in alertness level (Munde & Vlaskamp, 2015). It used MSE as an environmental stimulus to test the initiation of an interaction whether by direct care staff or the individual with SPID in correspondence with different alertness levels. The Alertness Observation List (AOL) was used for observation scoring. The AOL

categorises alertness into four levels, namely alert (subdivided into active alert and passive alert), inactive alert or withdrawn, asleep and agitated. Continuous observations were videotaped for the first 5 minutes after the start of the activity (Munde & Vlaskamp, 2015).

When the subjects were in active alert state before the initiation of the activity, self-initiated activity increased. When the direct care staff initiated the activity, the subjects showed high passive alert and asleep state levels. When the subjects initiated the activity, they frequently demonstrated active alert and no asleep state levels. Direct care staff usually activated the subjects' vestibular and auditory stimulations, whereas the subjects initiated more visual and tactile movements towards external stimuli. No agitated behaviour was observed in any of the situations (Munde & Vlaskamp, 2015). The rapid shifting between alertness and nonalertness or vice versa was described as waves (Munde et al., 2012). This caused direct care staff to terminate the activity earlier than planned, as they misinterpreted the shift from alertness to nonalertness in a one-way direction and hence stopped the activity at the nonalertness state (Munde & Vlaskamp, 2015). Staff training is always an important agenda in quality of care. Hastings (1997) addressed the mismatch between the beliefs of direct care staff and clinical professionals about handling challenging behaviour. These barriers included the staff not accepting or agreeing with the results of ABA, causing them to fail or refuse to implement behavioural programmes. The congruence between staff beliefs about and interventions for challenging behaviour is pivotal to compliance with planned interventions, which are usually beneficial to the development and maintenance of adaptive behaviour (Hastings, 1997; 2013).

Vos et al. (2013) hypothesised that people with SPID are unable to control

the presentation of positive and negative stimuli in their immediate environments, hence, they manipulate their attention to regulate their emotions. Emotion is reflected by heart rate and alertness level or intensity of attention (i.e., a lower heart rate is associated with high alertness or a high attention level). However, Vos et al. (2013) found a positive relationship between heart rate and alertness level. Nevertheless, the results supported that people with SPID direct their attention away from negative stimuli rather than from positive stimuli to regulate their emotions (Vos et al., 2013). As visual impairment among people with SPID is common, in addition to short attention spans, the effectiveness of manipulating emotion through attention deployment is uncertain. It is a natural inborn reflex to avoid unpleasant stimuli. However, negative and positive stimuli, which were selected by the direct care staff in Vos et al. (2013), are rather subjective from person to person. Hence, negative and positive stimuli may differ between the general population and people with SPID.

2.12 Measuring Challenging Behaviour, Levels of Relaxation, Alertness and Adaptive and Maladaptive Behaviour

As people with SPID have communication problems, most of them are unable to express themselves verbally and some are even speechless. Hence, assessing particular interventions is often restricted to informant-based scales, which collect information from direct caregivers, direct behavioural observations and objective biological/physiological measures. The following paragraphs discuss the most appropriate tools for assessing specific outcomes in people with SPID.

2.12.1 Evaluating the frequency of challenging behaviour

Three instruments are commonly used to assess challenging behaviour in Hong Kong. Two have been translated into Chinese versions.

The Challenging Behaviour Scale (CBS) is a measurement tool for assessing the frequency and severity of challenging behaviour in older people living in care homes (Moniz-Cook, Woods, Gardiner, Silver, & Agar, 2001). The tool was translated into a Chinese version in 2006 (Lam, Chan, Mok, Li, & Lam, 2006) with intraclass correlation coefficients (ICCs) for test-retest reliability ranging from 0.96 to 0.98 and inter-rater reliability ranging from 0.79 to 0.85. The explicit forms of behaviour largely involve aggression and disruptive behaviour, such as setting fire, spitting and faecal smearing. In view of the contents, the CBS is more relevant to demented people.

The Aberrant Behaviour Checklist consists of 58 items organised under 5 categories, namely irritability, lethargy, stereotypy, noncompliance and inappropriate speech. Aman, Singh, Stewart, and Field (1985) used the checklist to assess drug and treatment effects on people with SPID. However, the authors excluded residents who were nonambulant and blind from the study, as these residents were incapable of engaging in many of the forms of problematic behaviour included in the checklist (Aman et al., 1985). The checklist has since been used to assess the frequency of challenging behaviour and has been translated into Chinese (Lee, 2000). Subjects assessed with the checklist have only been ambulant and have mainly had moderate grade ID.

The Behaviour Problems Inventory (BPI-01) is a 49-item scale used to rate the frequency and severity of challenging behaviour (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). It is tailor-made for people with ID of all age ranges

and levels of functioning. In fact, the BPI-01 has been frequently used in people with profound ID who live in residential settings (González et al., 2009; Rojahn et al., 2001). The inventory has been developed and improved over time from a single behaviour subscale to its current multidimensional format. It involves three dimensions of challenging behaviour: SIB, SSB and aggressive/destructive behaviour. The BPI-01 can be rated by the informant (i.e., assessed by a caregiver) or through a semi-structured interview. The informant should be acquainted with the resident with SPID and thoroughly and accurately understand their behaviour. The ICCs of the BPI-01 indicate that its inter-observer agreement and internal consistency are good (0.91 and 0.83, respectively).

By comparing the instruments' contents, study population applications and relevance of collected data to the study objectives, the BPI-01 is found to be most appropriate for the target population. Hence, it is selected to evaluate challenging behaviour in this study.

2.12.2 Evaluating the relaxation effect

Due to their cognitive and communication deficits, not all self-report measures are feasible for people with SPID. Therefore, observational measures of behavioural manifestations and physiological changes are valuable for evaluating the relaxation effect in people without communication abilities.

The Behavioural Relaxation Scale (BRS; Schilling & Poppen, 1983) is frequently adopted for people with mild to severe ID and normal physiques to compare the effectiveness of different relaxation therapies by means of physical posture during relaxation (Chan et al., 2007; Lindsay et al., 1989; Martin et al., 1998). However, as deformity and contracture are common among people with

SPID, this assessment tool may not be appropriate for this group of residents.

Another observation tool, the Behaviour Observation Scale (BOS; Platania-Solazzo et al., 1992), has been extensively applied in MT studies (Field, 2000; 2006). This scale consists of seven areas for evaluating the relaxation effect of MT and emphasises affect and activity levels during relaxation. As the BOS only compares changes just before and after each treatment session, the moment that captures data may miss significant changes, as the attention spans of people with SPID are very brief.

The Alertness Observation Checklist (AOC) or the AOL (Vlaskamp et al., 2009) is specifically designed for people with SPID to detect their optimal alertness state or the 'right moment'. That is, the most appropriate time for interaction and learning. The right moment is described as when a resident pays attention to their immediate environment or shows awareness of an external stimulus.

The AOC is an interval-scoring checklist that has been validated and used in clinical settings since 2009. Most often, the AOC has been applied in MSE to determine the frequency of alertness (Vlaskamp et al., 2009). Apart from detecting the waking moment, it is able to assess a resident's reactions to stimuli or treatments (Vlaskamp et al., 2009). Although the AOC does not exactly examine the level of relaxation, it can provide a continuous observation of behavioural reactions before and after an intervention. Hence, the responsiveness to external stimuli can be evaluated.

The physiological data indicating relaxation level that are frequently adopted are heart rate and respiration rate (Croghan, 2009; Hegarty & Gale, 1996). In a meta-analysis of the effect of massage on the relaxation levels of different groups of residents, such as subjects with cardiovascular diseases, both heart and

respiration rates decreased gradually during 3 minutes of MT and remained much lower than the baseline level during the massage period. Although the subjects of the studies in the meta-analysis did not involve ID or SPID residents, the results indicated that a reduction in heart rate was correlated with a 10-minute MT session, whereas respiration rate achieved its maximum reduction at approximately 7 minutes of MT (Labyak & Metzger, 1997). Such positive effects of physiological relaxation correspond to individual self-reports of experiencing comfort and relaxation regardless of the length of the MT. On the contrary, blood pressure has not been consistently reduced in MT (Labyak & Metzger, 1997).

Nevertheless, studies involving people with ID have shown that the reduction of heart rate after either MT or MSE is inconsistent (Croghan, 2009; Hegarty & Gale, 1996; Shapiro et al., 1997; Slevin & McClelland, 1999). If heart rate is an objective indicator of relaxation, further studies are required to confirm which therapy is better for people with SPID, as most of them are unable to express themselves.

The stress hormone cortisol has been used to indirectly reflect the level of relaxation, with lower levels of cortisol than the baseline reading indicating relaxation (Platania-Solazzo et al., 1992). With the invention of new immunoassay methods, salivary cortisol levels have been found to be comparable with serum cortisol levels (Hanrahan, McCarthy, Kleiber, Lutgendorf, & Tsalikian, 2006). The advantages of using salivary samples are that they are non-invasive and painless compared with taking blood samples via venous puncture. However, the salivary cortisol level is easily affected by various factors, such as psychotropic medications (Granger, Hibel, Fortunato, & Kapelewski, 2009), which are commonly used by people with ID to control their challenging behaviour and

mental illnesses. More importantly, no local government laboratory analyses the salivary cortisol level. Hence, the use of the salivary cortisol level as an outcome measure is not popular in Hong Kong.

2.12.3 Evaluating the frequency of adaptive behaviour

Adaptive behaviour can be assessed using the Behaviour Checklist (BC), which was developed by Shapiro et al. (1997). The BC consists of 22 items, 16 items of which are for self-stimulating behaviour and 6 items of which are for adaptive behaviour. As the BC is tailor-made for MSE activity (e.g., one of the assessment items is 'looks in mirror'), it may affect the rating of the checklist if interventions do not involve MSE (e.g., MT and usual care environment where mirror may not be available). Hence, the item 'looks in mirror' can be interpreted as looking at an item of interest, rather than restricted to a mirror. Generally, the BC is easy to administer.

As mentioned earlier, the AOC (Vlaskamp et al., 2009) is designed to identify the optimal alertness state or the right moment for interaction and learning. Behaviour during the right moment is described as directing eyes towards the stimulating source, attempting interaction and being 'focused on the surroundings…focused on other people' (Vlaskamp et al., 2009, p. 2) in a manner comparable with adaptive behaviour. Hence, the AOC was used to correlate the assessment of adaptive behaviour with different interventions by looking at the frequency of the 'active, focused on the surroundings' category. Increased frequency of the active category indicates increased frequency of adaptive behaviour towards the immediate environment.

2.13 Summary

The aetiology of challenging behaviour involves various biopsychosocial dimensions. Many genetic and biological factors are non-modifiable, as they involve hereditary and anatomical structures of the brain. However, some of them are modifiable, especially the causative factors of physical or medical problems. For psychosocial factors, social and environmental interactions are modifiable, such as by increasing social network contacts, engaging in meaningful activities and reducing changes in staff. Challenging behaviour is expected to decrease through the use of appropriate reinforcers, which can break the causal and/or maintenance factors. People with SPID are most vulnerable to psychological stress due to their communication and cognition problems, which may lead to anxiety and challenging behaviour. Passive relaxation programmes may be able to reduce challenging behaviour to increase quality of life in long-term residential care facilities.

Currently, MSE is almost a standard leisure activity for people with ID and SPID in residential care settings. MSE is believed to promote enjoyment, relieve tension and pressure and consequently improve general behaviour in usual care environments in areas of socialisation and responsiveness. This approach is also well accepted by the professional and non-professional caregivers of people with SPID, as it is difficult to tailor other appropriate recreation and leisure activities to these severely disabled residents. In addition, MSE is perceived to offer a highly pleasurable and humane environment.

According to the literature review of MSE intervention (de Bunsen, 1994; Long & Haig, 1992; Slevin & McClelland, 1999), 1:1 staff-to-resident ratio is likely to yield positive results as compared with higher staff-to-resident ratio e.g., 1:5 ratio in Chan's study (2005). Apart from staff-resident ratio, active engagement with

the resident is also important to promote the effectiveness of MSE. For instance, the staff-to-resident ratio of Vlaskamp's study (2003) was similar between MSE and usual care environment with 1:2-3, but involved staff deliberately provided no interaction with the subjects, i.e., sat aside and observed. Hence, no treatment effect detected in the study (Vlaskamp et al., 2003). In contrast, the robustness of individual MSE intervention with adopting enabling approach can lengthen the positive affect of some subjects in the usual care environment after completion of intervention (Hutchinson & Haggar, 1994).

The range of treatment sessions varies from daily to twice per week, and time ranges from 20 minutes to one hour per session. In view of low cognitive processing, mental exhaustion is common. Hence, the number of sessions may need to address individual tolerance to maximise the sensory threshold. That may be why unique MSE treatment regime with stringent research methods occasionally yielded non-significant results (Chan et al., 2005; Martin et al., 1998), unless other supportive treatment measures are concurrently provided e.g., social attention and interaction, tangible rewards, fixed daily schedule (Cuvo et al., 2001; Withers & Ensum, 1995).

Non-routine activities are particularly important for people requiring long-term institutional care rather than idling in the usual care environment. If the therapeutic value of MSE is not evaluated, its use would be perceived as optional, although it is the only available leisure activity for people with SPID (Vlaskamp & Nakken, 1999).

Despite some objections from the inventors of MSE (Hulsegge & Verheul, 1987), many researchers are interested in investigating the effects of concentration, communication and environmental alertness to facilitate skills learning and

development, such as self-help and social skills (Ashby et al., 1995; Cuvo et al., 2001; Lindsay et al., 1997; 2001; Munde et al., 2012; 2015; Vlaskamp et al., 2003), and reduction of challenging behaviour (Chan et al., 2005; Martin et al., 1998; Shapiro et al., 1997; Smith et al., 2005). Studies of the relaxation and enjoyment effects of MSE have always yielded positive results, with results primarily based on staff perspectives or feedback (Ayer, 1998; de Bunsen, 1994; Hutchinson & Haggar, 1994). Immediate positive effects after intervention sessions have often been reported (Ashby et al., 1995; Cuvo et al., 2001; Kenyon & Hong, 1998; Shapiro et al., 1997). However, whether carryover effects (e.g., at 2 weeks) exist in daily living is uncertain (Chan et al., 2005; Martin et al., 1998).

However, only two studies (Chan et al., 2005; Martin et al., 1998) have evaluated the long-term effect of MSE from 4 weeks or longer for residents with ID. The longest was 12 weeks (Chan et al., 2005), although the results showed no carryover effect. Therefore, it is assumed that the behavioural effects of MSE intervention are relatively short term, as most therapeutic effects have ceased within a few days of sessions ending. In view of such results, this study evaluates carryover effects at 2 weeks after the completion of interventions.

Of the concluding remarks of most studies, one unbeatable attribute of MSE is the use of the enabling approach, which supports the establishment of good interpersonal relationships (Hogg et al., 2001b). However, not many studies have achieved positive results with the enabling effect (Chan et al., 2005; Martin et al., 1998). Strong evidence that MSE reduces problem behaviour is currently lacking. The methodological faults of previous studies, such as small sample sizes and a lack of control of confounding variables (Hogg et al., 2001a), make their findings on the therapeutic effect of this intervention on residents with SPID more inconclusive.

MT, another commonly used intervention, is frequently integrated into MSE for tactile sensation, as the prevalence of visual and hearing impairments in SPID are significant (Hospital Authority Mental Handicap Infirmary Service, 2003). MT can provide an alternative sensory input to compensate for the impacts of visual and hearing defects. However, the recent literature on MT for people with SPID is very limited, with only seven non-experimental studies with very small sample sizes available. Most of these studies adopted case study designs with predominantly positive results on challenging behaviour reduction, except for two studies that used crossover research designs (Lindsay et al., 1997; 2001). As all of the positive results have been based on qualitative data and staff reporting, the effectiveness of MT has not been well documented or evidenced.

The use of MT in MSE is not uncommon (Ayer, 1998; Hutchinson & Haggar, 1994), but the evaluation has often focused on qualitative feedback. Few quantitative studies have evaluated the combined effect of MT and MSE, whereas both MSE and MT are perceived to have potential enjoyment and sensory stimulation effects, especially in people with SPID. These activities do not require cognition to be beneficial. It has been postulated that the combination of MT and MSE is much more effective if adequate resident-staff interactions are available. Through physical touch and attention, the residents' awareness of their immediate environments can be enhanced and, as a result, challenging and self-stimulating behaviour can be reduced. However, the net effects of MT and/or MSE have seldom been fully investigated. Therefore, this study conducts more rigorous research using a randomised clinical trial, which is needed to examine and confirm the effectiveness of these single or combined interventions in reducing anxiety and challenging behaviour in residents with SPID.

CHAPTER THREE

STUDY METHODS

3.1 Overview of Research Design

A mixed research methods design was adopted. It included both quantitative and qualitative approaches seldom used in other studies. Compared with the quantitative approach, the qualitative approach looks into the process and captures the meanings of a phenomenon (Field & Morse, 1985). Miles and Huberman (1994) described all qualitative approaches as trying to make sense of an event. The perceptions of primary nurses of various types of interventions used to manage challenging behaviour in their SPID residents were explored via semi-structured face-to-face interviews. As the residents could not respond to questions or interviews, the benefits and limitations perceived by their primary nurses would be useful to understand the therapeutic values and areas for improvement of the interventions used.

In the quantitative part, a randomised controlled trial was conducted and compared across three intervention groups and one control group on the outcome improvements of SPID participants over time, which included their frequency and severity of challenging behaviour (primary outcomes measured using the BPI-01), physiological state (i.e., heart and respiration rates), maladaptive and adaptive behaviour (measured using the BC) and alertness level (measured using the AOC). The durations of the study (measurements) and interventions undertaken for each participant were 12 and 10 weeks, respectively. These behavioural and physiological outcomes were measured at recruitment before the group assignment

(T_0), at the midterm of the interventions to check progress (i.e., at the fifth week or tenth session of the intervention, T_1) and at two post-tests (i.e., T_2, immediately after completion of the intervention at week 10, and T_3, 2 weeks post-intervention at week 12). No intervention was provided to the four study groups between weeks 10 and 12 when investigating any sustainable treatment effect from these interventions at the 2-week follow-up. The aim of the midterm assessment was to check the progress of the intervention to serve two purposes based on the results of the pilot study:

1. Assess physical tolerance and possibility of physical deterioration, and terminate the intervention promptly if necessary
2. Provide preliminary intervention data to impute missing data if drop out after the midterm assessment

As the recruited participants might have received MT and MSE before the study, they were required to undergo a 1-month washout period to minimise the residual effects of the two interventions and thus avoid contamination of the intervention effects during the study. The recommended 1-month washout period and 2-week study follow-up were based on findings in the literature (Chan et al., 2007; Martin et al., 1998; Moyer et al., 2004; Shapiro et al., 1998) in which non-significant carryover effects followed the interventions (i.e., carryover effects were only found at 1-2 weeks post-intervention).

The reason for examining the carryover effect over 2 weeks was to estimate the period for sustainable effect to maximise clinical resources to cater more residents in the use of the treatment facility in the residential care setting. The MSE service is generally established for all residents. The longer the carryover

cycle yielded, the more the suitable residents could be engaged. As comparing with previous studies, 2-week carryover effect is a starting point to explore any strategies to enhance the carryover effect, hence, more residents can be benefit for the interventions. To optimise the treatment schedule over time while considering the duration of sustainable carryover effects of the intervention used, future studies should explore the ceiling of sensory threshold to optimise the sensory stimulation without the residue mental exhaustion. For those restless and resistant to stay in confined area, the use of sensory mobile cart in the usual care environment may be plausible to satisfy their sensory needs.

The three intervention groups (in addition to routine care) included MT combined with or applied in an MSE, MSE only and MT only. The usual care group in which the participants received routine residential care only served as the control. In the control group, the staff attention and interactions were similar to those in the intervention group. After the baseline assessment, the participants were assigned randomly to one of the four study groups and underwent one of the interventions, which were given twice per week for 10 consecutive weeks. After completion of the interventions, all of the participants in the four groups stayed in their usual care environments during the subsequent 2 weeks and undertook the follow-up measurements immediately and at 2 weeks post-intervention (i.e., T_2 at week 10 and T_3 at week 12). The relative/comparative effects of the three interventions and usual care only on the study outcomes were evaluated using several outcome measures as described in Section 2.12. The details of the instruments used are described in Section 3.5.

3.2 Research Setting

As indicated in the literature, an increasing amount of challenging behaviour was found among those with more severe forms of ID (Emerson et al., 2001; Emerson & Einfeld, 2011). The study venue was the largest specialty care institution solely for adults with SPID in Hong Kong, which provided long-term residential services with specialised care and was thus the most appropriate setting for this study. It provided 500 beds for comprehensive infirmary and rehabilitative care for the whole territory under the HA governance. In addition to SPID, most of the residents suffered from physical and/or multiple impairments. The admission criteria were formulated by the HA and Social Welfare Department in 1988. All of the applicants had to apply through the HA's infirmary care central waiting list, with a comprehensive pre-admission assessment for each applicant. Applicants had to be at least 16 years of age. The average waiting time for admission was approximately 2 years. Thus, all new applicants had reached 18 years of age or above upon admission. The admission criteria for residents included diagnosis with SPID according to the criteria of the Diagnostic and Statistical Manual (American Psychiatric Association, 2013) and at least one of the following physical conditions or diagnoses:

- Having more than two kinds of physical disablement
- Being bed-ridden
- Suffering from refractory epilepsy not well controlled by treatment
- Requiring special feeding, such as tube feeding or percutaneous endoscopic gastrostomy (PEG)
- Suffering from severe behavioural problems, particularly of a violent nature
- Being in poor physical condition and requiring constant observation and

nursing care

The research setting had 10 units for inpatient or residential care services and 1 activity centre. Each of the 10 units served 50 residents, and 2 of the units provided special care for residents with severe challenging and disruptive behaviour (i.e., 1 for males and 1 for females). A primary nursing care system had been implemented for more than 10 years, in which each resident would be assigned to one primary nurse who was responsible for devising individualised care plans and liaising with the multidisciplinary team to plan and implement treatment and care regimes immediately after admission. The primary nurse was the contact point for residents, their relatives and health professionals. Therefore, each primary nurse was required to take care of five to six residents and to monitor their treatment regimens. They were also the most familiar with the residents under their care.

The activity centre was responsible for planning and conducting various recreational and training activities for the institution's residents. The activity centre's nursing and support staff were trained to actively engage with residents while they attended their assigned clinical activities/interventions, such as MSE, toy sessions, music and dance movement and crafts. They were also given self-help skills training.

Apart from the medical and nursing staff, the supporting staff constituted two thirds of the total frontline workforce. The supporting staff usually helped monitor the residents' physiological data, such as their blood pressure, heart rate and body temperature, and recorded their intake and output in daily care. All of the supporting staff were also required to provide basic care, such as bathing, feeding and diaper changing. The nursing staff were responsible for more complex and advanced care, such as behavioural training, wound management,

nasogastric or PEG feeding, psychotherapeutic interventions and overall supervision of residents' daily care provided by the supporting staff. During the day, two to three nursing staff and five to six supporting staff worked together in each duty shift. Each supporting staff was assigned a posting or clinical duty to take care of the residents' daily activities and look after their daily functioning. All of the frontline nursing staff were accountable for the clinical care of all of the residents during duty hours. They were also responsible for supervising the performance of the supporting staff.

The activity centre contained two multisensory stimulation rooms for the residents, one of which was used in the study. The environment was designed to keep people calm and relaxed in an optimally stimulating setting. The equipment for stimulation mainly included spot lights, a rotating effect wheel with a projector showing different colourful patterns on the wall, a revolving mirror ball, fibre-optic tails, vibrant and non-vibrant bean bags, a rocking chair and bean beds. The surface area of the room was approximately 350 square feet. One psychiatric nurse, along with at least three supporting staff, looked after a maximum of ten residents throughout each MSE session to provide the best therapeutic care to each of the users. The staff-to-resident ratio was kept at approximately 1:2. The residents who were assessed and found suitable to attend the MSE were scheduled leisure time once or twice per month, spending approximately 30 minutes per session.

3.3 Sampling

3.3.1 Study population and sample

As the primary objectives and outcomes of the study focused on the frequency and severity of challenging behaviour, only those residents who had exhibited at least one type of challenging behaviour over the previous 2 months were recruited. A prevalence survey on challenging behaviour was conducted in the research setting in 2011, the results showed that approximately 69% of the residents exhibited at least one kind of challenging behaviour (Lee & Tso, 2011). The number of residents exhibiting challenging behaviour in the study institution was monitored by a monthly survey. Approximately 300 residents were reported to exhibit challenging behaviour in the 10 units, accounting for 60% of the resident population. However, the clinical staff of individual units confirmed the actual number of eligible subjects. Eligibility to participate in the study was based on inclusion and exclusion criteria, which are stipulated in Section 3.3.2. To minimise the confounding effects or influences of different nature and environment of the residential units on the intervention groups, similar numbers of residents were randomly recruited from each unit and assigned to each of the four study groups.

3.3.2 Inclusion and exclusion criteria

The residents in the 10 clinical units under study varied from ambulant to poor mobility and even bedridden. The inclusion criteria included the following:

- Exhibiting at least one type of challenging behaviour which was based on monthly return of the clinical data from individual wards, and confirmed with clinical assessors.
- Admitted for at least 3 months to provide sufficient time for the caregivers

to become familiar with their usual behavioural patterns to avoid misinterpretations of their behaviour. For instance, some residents might have shown restlessness and irritability if suffering from constipation or having to adapt to a new residential environment.

- Receiving infirmary care for long-term service instead of short-term care for urgent placement where residents were frequently discharged in 3 months.
- Requiring regular assistance and nursing care in daily living activities.
- Being 18-64 years of age, due to the skin texture and sensitivity of mechanoreceptors to external pressure declining along with age (Gescheider, Bolanowski, Hall, Hoffman, & Verrillo, 1994), especially the nerve endings over the palms (Humes, Busey, Craig, & Kewley-Port, 2009).

In addition to the requirement of less than 3 months of hospitalisation, the following residents were excluded from the study:

- Residents who were seriously ill or completely bedridden and not allowed to participate in outside activities or to transfer out of bed due to physical fragility.
- Residents with infectious diseases, such as methicillin-resistant staphylococcus aureus, to prevent cross-infection.
- Residents who had been frequently discharged to general hospitals for the management of acute medical conditions in the previous 3 months, which indicated unstable physical conditions for study participation.
- Residents who had frequent home or day leave or regular attendance at non-HA day centres, as such residents might have received excessive stimuli from external environment.

- Residents who were restless and resistant to staying in MSE. (Four references were taken into consideration, including: 1. 2011 BPI-01 record with hourly frequency and severe severity of challenging behaviour; 2. challenging behaviour incidents in the past 3 months in the report book or medical record file; 3. record of absence in MSE session in the past 3 months because of challenging behaviour; and 4. feedback from training staff who organised MSE and training activities for all residents)
- Residents whose case medical doctor instructed suspension from MT.
- Residents who had pressure ulcers, severe contractures and deformities in both the hands and feet, as such conditions could affect the application of MT.

3.3.3 Primary nurses as informants in semi-structured interviews

Qualitative face-to-face interviews with individual primary nurses were conducted to evaluate the perceived benefits and weaknesses of the interventions (MT and/or MSE) and the potential improvements as perceived solely from the staff, due to the impracticality of interviewing the participants with SPID. As suggested by Morse (2011), several factors were used to determine the sample size for the qualitative interviews. The fundamental factor was the quality of the interviewees, which affected data quality and the usefulness of the obtained information. If the interviewees with rich experience on the topic were willing to share their experiences with the interviewer and were able to articulate themselves fluently, fewer interviewees would be required to reach data saturation. The initial intention was to use purposive sampling (Streubert & Carpenter, 2011), which could facilitate the inclusion of the key informants to maximise the amount of rich

and in-depth qualitative data obtained. However, the low response rate of the primary nurses led to the use of convenience sampling instead. The possible reasons of the low response rate might be primary nurses:

- not willing to use their personal time to conduct the interview
- avoiding embarrassment if negative comment given despite an external interviewer was recruited to conduct the interview and such arrangement had mentioned in the briefing sessions
- not knowing a supermarket coupon as a token of appreciation after the interview as it did not disclose in the briefing sessions
- too many personal engagements as the interviews to be conducted around Christmas festival. In fact, two primary nurses withdrew their consent due to personal engagement
- too late to sign the consent form, and unable to arrange the observations in the intervention sessions. At least two primary nurses were rejected.

Four briefing sessions were held for the frontline nursing staff from October 2012 to January 2013 to explain the study's purpose and procedure. They were informed of the use of semi-structured interviews. They were asked to be the informal observers in the units to assess the participants' behaviour.

As the SPID participants could not express their own opinions about the interventions, only the primary nurses of the residents who were assigned to one of the three intervention groups were invited to participate. An information sheet (Appendix I) describing the purpose and main procedure of the study and its significance to service was distributed to the primary nurses. The identity codes of the participants were also marked on the information sheet for data collection and

management. The latter part of the information sheet described the purpose of the face-to-face interviews and invited the primary nurses to participate in the semi-structured interviews. During the intervention period, it was arranged for those who agreed to participate in the interviews to attend the intervention sessions in which their residents (i.e., the participants) took part so that they could fully understand the interventions used and the performance of the residents during the interventions. In the interviews, they were encouraged to share their experiences and opinions about the interventions and to describe any changes in their residents' behaviour that they observed in between the intervention sessions. Critiques on the perceived benefits and strengths and weaknesses of the interventions were probed. Written consent (see consent form in Appendix II) to the interview and its audio recording was obtained from each primary nurse before the interview. The interviews were conducted from November to December 2013 after the interventions in the main study were completed.

3.3.4 Sample size

3.3.4.1 Quantitative approach – randomised controlled trial design

Very few relevant randomised controlled trials have been conducted on similar study outcomes, especially the behavioural measures. The most relevant clinical trial was that of Chan et al. (2005), who evaluated the effect of MSE in reducing challenging behaviour in ID patients residing in a mental hospital in Hong Kong, with more than 4 weeks of post-intervention follow-up. The main outcome measures included heart rate and the BC. However, both outcomes were statistically insignificant and the calculated effect size was very small (Cohen's d ranged from 0.07 to 0.17) (Cohen, 1992), requiring approximately 300 subjects per

group. This estimated sample size was not applicable to the research setting as the maximum target population was only 500, approximately 300 of whom were reported to exhibit challenging behaviour. The results of the pilot study mentioned in Chapter 4 were based on a very small sample of approximately 10-12 people in each group and were found to be non-significant. Therefore, they were not used for sample size estimation in the main study.

Due to the lack of appropriate reference studies, the sample size was calculated according to Cohen's conventional effect or sample size estimation in social and behavioural science research (Portney & Watkins, 2009). With repeated-measures ANOVA tests used for within and between comparisons of four groups (especially between the three intervention groups), it was estimated that 45 participants were required in each study group to achieve a low medium Cohen's f effect size (0.25) at α=0.05 and a study power of 0.80. The possible reasons for dropout were mortality and being discharged to a general hospital for acute medical management. The attrition rate was estimated to be approximately 10%. To account for this potential attrition rate, five participants were added to the forty-five participants in each group calculated above to maintain the level of significance and statistical power. Thus, each study group was expected to have 50 participants for a total of 200 residents with SPID to be randomly recruited to the main study.

The main study was conducted from August to December 2013. Of 493 residents, 289 were rated as demonstrating challenging behaviour in the previous 2 months, yielding a prevalence rate of 58.62% (i.e., similar to that of the pilot study). To avoid contraindication and confounding effects, all of the participants in the pilot study were excluded from the main study. After considering the inclusion and exclusion criteria, 103 residents were excluded. The remaining 186 residents were

invited to participate in the main study. With the experience of the pilot study, the response time for obtaining written proxy consent from the potential participants' guardians/next-of-kin was reduced to 2 weeks. Finally, 131 proxy consents were received, 23 relatives agreed to participate but did not return written proxy consents, 19 relatives declined participation, 9 relatives could not be reached and 4 residents were transferred to other units after invitation. Thus, a total of 55 invited residents were unable to participate. The response rate was 70.43%.

3.3.4.2 Qualitative data

Ninety-nine frontline nursing staff were in the workforce at the time of main study. Sixty-eight primary nurses were involved in the care planning of the one hundred and thirty-one recruited participants. Four of these nurses had already been invited to be the clinical raters of an assessment tool (BPI-01). Thus, 64 primary nurses were invited for the face-to-face interviews. Only 15 nursing staff agreed and signed the consent form to participate in the study, yielding a response rate of 23.44%. However, two withdrew due to personal engagements. Ultimately, 13 nursing staff were successfully interviewed.

Given the low response rate, all of the available informants (nurses) were interviewed without any further consideration of their service experiences or personal attributes. An interview guide (Appendix III) was devised to cover the possible common factors of challenging behaviour and the strategies that nurses could use to manage the challenging behaviour of their SPID residents in practice. Their perceptions of the interventions used were also discussed in the interviews. Each interview was expected to be 30-45 minutes in duration.

3.3.5 Recruitment and randomisation

Before recruitment started, six briefing sessions were conducted to inform the participating residents' family members/guardians about the study. Four briefing sessions were conducted for the nursing staff. All of the briefing sessions took place from October 2012 to February 2013. Subject recruitment began in August 2013. A few family members signed the proxy consents during their visits to the residents. Most of them preferred to receive an invitation letter for study participation by mail. Blank stamped envelopes with printed return addresses enclosed with the invitation letters were sent to the guardians/next-of-kin to facilitate the return of their proxy consents.

Given the results of the pilot study, a 2-week response time was allowed when recruiting subjects (residents with SPID) for the main study. A reminder was sent to them by the end of the first week to enhance the responses from the guardians. After confirming the mailing addresses with the guardians, a second letter was sent if they had not received the first one. The response rate for the main study was 70.43%. The subject recruitment period and data collection procedure were shorter than those of the pilot study.

Only 186 of 493 residents met the inclusion criteria and were invited to participate in the main study, which was below the planned sample size of 200 residents for the 4 intervention groups (Section 3.3.4.1). Thus, there was no random selection of the sample in this study. The relatives of all 186 eligible residents were invited to provide proxy consent. Ultimately, 131 proxy consents were obtained.

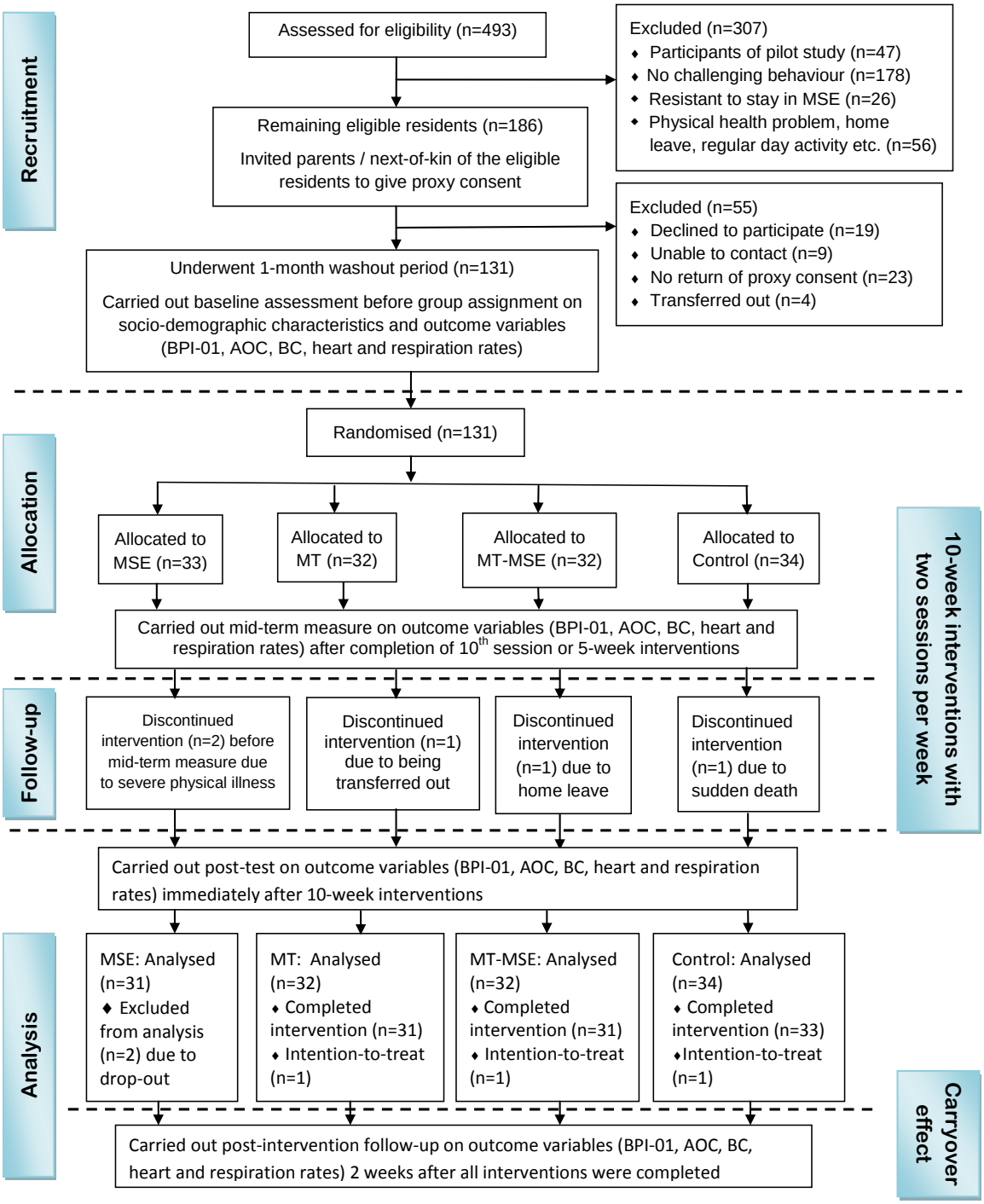
All of the participants went through a 1-month washout period to eliminate any residual effects of MSE and/or MT experienced before recruitment. After the washout, all of them completed a baseline measurement of their demographic and clinical characteristics and outcome measures. The participants were then assigned identity codes to uphold their anonymity in the group assignments. A clinical staff, who was blind and concealed to the participant lists of each unit, was invited to draw cards from a large envelope where each card marking with four numbers in random order in blocks (e.g., 1234, 3241, 2341 and so on with a total of 24 combinations, where 1=MSE alone, 2=MT alone, 3=MT-MSE and 4=usual care), so that participants were randomly and evenly assigned to each of the four study groups after this random assignment. Blocked randomization offers a simple means to achieve balance between study groups and to reduce the selection bias and confounding variables between ward natures and staff culture of individual units.

Overall, 131 residents participated in the study. Five of the participants discontinued the assigned interventions, as two MSE participants dropped out after the first two sessions due to severe physical illness; two participants dropped out at T_1, as one was transferred to another clinical unit and the other died suddenly; and one dropped out after completing the interventions and the first post-test (T_2), and then had a long period of home leave and thus was unable to complete the second post-test (T_3).

One of the characteristics of randomised control trial is to apply intention-to-treat principle in data analysis to provide an unbiased comparison of treatment effects (Montori & Guyatt, 2001). Since three drop-out participants had been assessed the treatment progress in the midterm, the missing data of these three participants were imputed by multiple imputation which is a highly efficient

approach for modelling of missing information (Molenberghs & Kenward, 2007). Finally, data for 129 participants were analysed, including 126 full datasets and 3 partially completed datasets. The overall attrition rate was 3.8%. Details of the sampling and study procedures according to the latest CONSORT statement (Schulz, Altman, & Moher, 2010) are presented in *Figure 3.1*.

Figure 3.1. Flow diagram of the main study and sampling procedure



BPI-01: Behaviour Problem Inventory; AOC: Alertness Observation Checklist; BC: Behaviour Checklist; MSE: Multisensory environment; MT: Massage therapy; MT-MSE: Massage therapy in multisensory environment

3.3.6 Ethical considerations

The research proposal was submitted to the Human Subjects Research Ethics Committee of The Hong Kong Polytechnic University, and approval was obtained in August 2012. Ethics approval from the Cluster Clinical Research Ethics Committee of Hospital Authority, Hong Kong, was received in December 2012. Six and four briefing sessions were conducted for relatives and nursing staff from October 2012 to February 2013, respectively. The purpose of the briefing sessions was to introduce the study and its procedure, answer questions and address any concerns about the study. A written information sheet of the study (Appendix IV) was distributed to the attendees to explain and facilitate their understanding of the purpose and procedure of the study.

Proxy consent forms (Appendix V) and written information sheets were sent to the potential participants' guardians or parents, in which the purpose of the study and their right to withdraw at any time during the study were described. The interventions caused no harm to the participants, even if no significant benefits were identified. The instruments selected and used were non-invasive and harmless to the participants. If challenging behaviour, especially self-harm and violence, increased dramatically during the study process, the researcher or primary nurse would conduct an urgent medical consultation. Those with acute medical illness who were transferred to general hospitals and those who were dead or discharged during the study period were treated as having withdrawn from the study.

The anonymity and confidentiality of the participants' data were strictly assured and the personal identities of the individual participants were not disclosed. Guardians or close relatives were reassured that they were free to refuse their relatives' (i.e., the residents') participation in the study or to withdraw from the

study at any time, and that such refusal or withdrawal would not affect the treatment of their relatives with SPID. Since all MSE and MT sessions were withheld for the participants of the control group during the study period, 20 MSE sessions would be provided to them after the study. This compensation arrangement had been written on the ethical application and mentioned in the briefing sessions to relatives and guardians. Approval was obtained from the hospital management level and the Cluster Ethical Committee.

An information sheet for the nursing staff was distributed to the participants' primary nurses. The information sheet included a consent form for participating in the semi-structured face-to-face interviews and for the tape recording of the interviews. Once this consent form was signed, arrangements were made for the primary nurses to observe their residents while they attended their assigned interventions. All of the interview audio recordings were discarded after data analysis. All of the collected data were used for research purposes only. Their willingness to be interviewed or their withdrawal from the study did not affect the primary nurses' job performance appraisal or terms of employment.

3.4 Interventions

To promote physical touch and resident-staff interactions, manual MT was adopted in the study. Unlike developed Western countries, there is no registration system or legally recognised body for therapists who practise complementary and alternative medicine in Hong Kong. Hence, all qualified massage therapists obtain their qualifications from internationally recognised organisations and associations, such as the International Federation of Aromatherapists (IFA) in the United Kingdom.

A qualified massage therapist provided MT training to the nursing staff, which involved background information on and technical skills of MT. The training contents and monitoring schedule are detailed in Section 3.4.2. A MT practice protocol is shown in Appendix VI. Three nursing staff from the training centre assisted in the MT sessions in the main study. They had learned and practised MT for more than 1 year. To ensure the reinforcement of and compliance with the MT practice protocol, a return demonstration was required to meet the required international standard for MT (by the IFA), as assessed by the qualified massage therapist before the intervention began.

All of the trained massage therapists were required to act as enablers in both the MT-MSE and MT groups. For the MSE and control groups, the direct care staff of the training centre acted as enablers, who accompanied the residents during their stay in the designated intervention sessions without making any negative or judgmental comments about the participants' behaviour. During their stay in MSE, the enablers were also required to allow the participants to use and play with sensory equipment freely. The roles of an enabler during interventions are presented in more detail in Appendix VII.

To ensure treatment fidelity and compliance with intervention protocols (Spillane et al., 2007) especially in the beginning of the study, the researcher visited the participants in the first two sessions and then on a regular basis to observe the implementation of the interventions and the performance of the enablers and massage therapists, which was rated on a checklist with the same protocol contents (i.e., >90% adherence to the protocol was required). Surprise checks were conducted in subsequent sessions to ensure the compliance of the treatment protocols.

Three intervention groups or programmes were administered in the study and included MT delivered in the multisensory environment (MT-MSE), MSE only and MT alone. The fourth study group was a control group. The control group participants stayed in their usual care environment and received social attention from and interacted with the enabler for similar time durations to the three intervention groups. As a general principle, the attending medical officer had to authorise the application of MT to assure the residents' suitability for receiving such complementary and alternative therapy in the institutional care setting. The therapy was not given without the doctor's approval.

3.4.1 Multisensory environment

The most common MSE intervention protocol adopted was a 30-minute stay in MSE twice per week for 20 sessions over 10 consecutive weeks, according to a systematic review comprising 20 MSE-related studies for people with ID (Chan et al., 2010; Lotan & Gold, 2009). As the use of MSE as a leisure activity is common in the research setting, the standard preparation of an MSE session had already been established before the research study, such as dim light, operation of the equipment and room temperature setting. During their stay in the MSE, the participants were accompanied by activity centre staff who acted as enablers to facilitate the interaction with different kinds of sensory equipment based on their individual needs and/or preferences. For instance, waterbeds were used for residents with pressure ulcers. All of the participants were encouraged to choose their preferred equipment to meet the basic principle of entertaining their free choices in the MSE. In reality, many of the participants were unable to explicitly indicate their preferences. Thus, choices were made by the direct care staff as

needed. Facial expressions were often the best indicators of their acceptance of or satisfaction with the designated equipment (Nakken & Vlaskamp, 2007).

During the intervention sessions, the direct care staff involved nursing staff and supporting staff of the training centre. Only nursing staff were responsible to identify the best choice of MSE equipment for individual residents. All of the nursing staff had attained the specialty training in ID nursing.

3.4.2 Massage therapy

Participants in the MT group received 15-minute hand or foot massages twice per week for a consecutive 10-week period. Three nursing staff from all of the training units under study performed MT. A qualified massage therapist trained them on massage techniques. As they had experience working with people with ID, and advanced (trained) communication skills with the participants with SPID. In addition to massage skills, the training contents involved preparing the participants, such as by cleaning the area to be massaged with a wet cloth to remove skin debris before applying massage oil and supporting the body part to be massaged with soft padding. The massage protocol was adopted from a massage guideline for people with ID (Sanderson, Harrison, & Price, 1991). The validity of the massage protocol was confirmed by two training organisations: a local institute (International Cosmetology & Health Training Institute of Hong Kong) and the IFA in the United Kingdom. The local and overseas expert panels reiterated a caring staff attitude towards the participants and preparation of the environment to promote a therapeutic atmosphere, such as dim light and good ventilation.

Apart from regular inspection to ensure treatment fidelity and integrity, especially in the first several sessions, surprise checks were conducted to minimise

deviation from the massage protocol. The three trained nurses were required to act as enablers for the MT-MSE and MT groups to promote resident-staff interactions.

The MT schedule was synthesised from two meta-analyses of fifty-six articles (Moraska et al., 2008; Moyer et al., 2004) in terms of the minutes per session, the number of sessions per participant and the length of the intervention period. The most common schedule was 15 minutes per session and twice per week; the massage programme was carried out for 10 weeks to evaluate the intervention effect (Moraska et al., 2008; Moyer et al., 2004). An interim assessment was carried out at the midterm of intervention at the end of the 10th session (i.e., at week 5) to check the progress of the treatment effect.

The choice of body part for MT depended on the resident's preference if able to indicate, such as by stretching the hand or foot while being approached for massage, or was determined by ease of access if the resident was unable to express their preference. For instance, the hand is easier to access for massage than the foot. If severe contracture or deformity on both hands was found, a foot massage was the only option. Only vegetable oil without aromatic scent was used as the lubricant for MT, as aromatherapy proposes that each aromatic scent has specific healing properties.

3.4.3 Massage therapy in the multisensory environment

The participants in the MT-MSE group received both 30-minute MSE and 15-minute MT sessions twice a week for 10 consecutive weeks. During the 30-minute stay in MSE, a 15-minute MT treatment was applied in the first 15 minutes and then the participant focused on the MSE activities in the last 15 minutes. The participants were accompanied by enablers throughout their

sessions.

3.4.4 Control group and post-intervention

The participants in the control group stayed in their usual care environments and followed their usual daily schedule without the involvement of MT or MSE activities throughout the 10-week intervention period. To match the enabler effect to the other study groups, attention from and social interaction with the direct care staff were arranged individually twice per week during 15-minute sessions. The residents mostly spent their free time watching television or listening to music. After the 10-week intervention, all of the participants across the four study groups received routine care in their residential units from weeks 11 to 12 and received follow-up measurements at the end of week 12.

3.5 Instruments and Outcome Measures

All of the selected outcome instruments were well validated, observationally or objectively measured and non-invasive. The behavioural observation instruments included the BPI-01, AOC and BC. A physiologic monitor was used to record heart and respiration rates. The outcomes and physiological signs were assessed at recruitment, immediately after completion of 10 sessions and 2 weeks after completion of the interventions. In addition, a demographic data sheet was developed to record personal profiles and clinical characteristics. The important characteristics (e.g., psychometric properties) of the four instruments used for behavioural outcome measurements are summarised in *Table 3.1*.

Table 3.1. Instrument details

Instrument	BPI-01 (Behaviour Problems Inventory)	AOC (Alertness Observation Checklist)	BC (Behaviour Checklist)	Nellcor UP-7000 Physiologic monitor
Purpose	Assess frequency and severity of challenging behaviour	Identify four levels of alertness	Observe amount and duration of maladaptive and adaptive behaviour	Monitor HR and RR
Outcome	Overall frequency/severity score=0-208/0-156 SIB=0-60/0-45 SSB=0-100/0-75 Aggression=0-48/0-36	Different colours to reflect individual alertness states: Green: active alert and passive alert Orange: inactive and withdrawn Red: sleepy or drowsy Blue: agitated and discontented	Duration of exhibited behaviour (minutes)=0-30 Amount of behaviour=0-22	HR=30-240 bpm RR=0-120 Bpm
Items	49 items with three subscales SIB (14) SSB (24) Aggressive behaviour (11)	Five levels with four colours, where green represents the active alert state with body movements and the passive alert state without body movements.	22 items: Maladaptive behaviour (=SSB) (16) Adaptive behaviour (6)	-
Test-retest reliability	ICC=0.76	Pearson's r=0.87	-	-
Inter-rater reliability	ICC=0.91	Pearson's r=0.81	Pearson's r=0.95	-
Internal consistency	Cronbach's alpha=0.83	-	-	Error: HR: ±2 bpm RR: ±3 Bpm

bpm=beats per minute, Bpm=breaths per minute, HR=Heart Rate, ICC=Intra-class Correlation Coefficient, RR=Respiration Rate, SIB=Self-injurious Behaviour, SSB=Self-stimulating Stereotypic Behaviour

3.5.1 Behaviour Problems Inventory

The BPI-01 was designed for studying the prevalence of behavioural problems of people with ID, and for repeated measurements of treatment outcomes in terms of the observed forms of problem behaviour included in the scale (Rojahn et al., 2001). The BPI-01 (Appendix VIII) consists of 49 items with three subscales, including 14 items of SIB, 24 items of SSB and 11 items of aggressive/destructive behaviour. SIB is defined as 'behaviour which can cause damage to the subject's own body and occur repeatedly and in an essentially unvarying manner' (Rojahn et al., 2001, p. 580). SSB is defined as 'peculiar or inappropriate voluntary acts which occur habitually and repetitively. Aggressive or destructive behaviour are abusive, deliberate attacks against other individuals or objects' (Rojahn et al., 2001, p. 580). The BPI-01 has been widely used in people with profound ID living in a residential setting (González et al., 2009; Rojahn et al., 2001). This instrument was used to evaluate the frequency and severity of challenging behaviour and to summarise the scores on the three subscales during the previous 2 months. To unify the assessment period in the study, the assessors were required to rate the behaviour that existed during the previous 2 weeks.

Each item of the scale assesses both the frequency and severity of each kind of behaviour. The frequency scale is a 5-point rating scale (where 0=never, 1=monthly, 2=weekly, 3=daily and 4=hourly). The severity scale is a 4-point Likert scale (where 0=no problem, 1=a slight problem, 2=a moderate problem and 3=a severe problem). If a resident does not exhibit a form of behaviour listed in an item, that item would be rated as 'never' and 'no problem'. Forms of behaviour not mentioned in the scale but that are dominant and difficult to manage could be categorised as 'others'. The total score of the frequency scale ranged from 0 to

208, whereas that of severity scale ranged from 0 to 156.

According to Rojahn et al. (2001), the ICCs indicated that the inter-observer agreement of the BPI-01 was satisfactory (i.e., 0.96 for the SIB subscale, 0.9 for the SSB subscale, 0.59 for the aggression/destruction subscale and 0.91 for the overall scale). The internal consistency of the BPI-01 was also satisfactory, with a Cronbach's alpha value of 0.83. Its test re-test reliability was 0.76. The internal consistency, inter-rater and test-retest of individual subscales of BPI-01 are shown at *Table 3.2*.

Table 3.2. The psychometric properties of individual subscales of Behaviour Problems Inventory (BPI-01)

Scale	Internal consistency (n=100)		Inter-rater (n=100)		Test-retest (n=80)	
	Frequency	Severity	Frequency	Severity	Frequency	Severity
Self-injurious behaviour	0.48	0.47	0.67	0.63	0.65	0.70
Stereotyped behaviour	0.68	0.65	0.41	0.50	0.45	0.28
Aggression/destruction	0.86	0.87	0.80	0.77	0.66	0.67
	0.67	0.66	0.63	0.63	0.59	0.55

A local survey was conducted to identify the prevalence of challenging behaviour using the BPI-01 (Lee & Tso, 2011). The results revealed that the stereotyped behaviour subscale was more dominant than other subscales, accounting for 44.3% of all of the challenging behaviour in the sample. The least frequent behaviour was aggression, which was detected in 24.9% of 302 subjects with a response rate of 82.3%. The internal consistency and inter-rater reliability of the three subscales were 0.53 and 0.50 for SIB, 0.86 and 0.85 for SSB and 0.80 and 0.79 for aggression, respectively. The results were quite different from the original work of Rojahn et al. (2001). Compared with SIB and aggression, the SSB subscale was found to be relatively stable across different settings. In fact, the items of the SSB subscales covered all of the items of maladaptive behaviour in

the BC. The BPI-01 was used to evaluate the sustainable effect in the usual care environment after the intervention, whereas the BC evaluated the immediate effect of the intervention.

The BPI-01 could be completed by the caregiver directly or through a semi-structured interview with the caregiver (i.e., informant) to obtain the information. Nevertheless, the rater or informant of the BPI-01 had to be familiar with the person to be rated, especially the meaning of the behaviour they exhibited. One frontline nurse from each unit was invited to complete the BPI-01 for the participants of that unit. All of the invited raters had worked on the unit for more than 2 years. They were required to rate the frequency and severity of challenging behaviour presented by the participants for the previous 2 weeks. They were blind to the group assignments.

3.5.2 Alertness Observation Checklist

The AOC (Vlaskamp et al., 2009) was designed to detect the optimal alertness state or the right moment for interaction and to identify where a resident's attention to their immediate environment was strong. The AOC is an interval-scoring checklist consisting of four forms. Forms A and B are used to identify the alert moments in a day and Form D is for the assessor to record the alertness profile of the observed person. Only Form C is used to identify the influence of various stimuli (visual, tactile and auditory) on alertness to assess the effect of the interventions on the participant's alertness level. As suggested by the original authors of the AOC (Vlaskamp et al., 2009), observation started at 15 minutes with 5-minute recording intervals before the intervention, followed by 20-second recording intervals during the intervention to capture the subtle or rapid

changes of residents' responses. After the intervention, observation continued for 15 minutes with 5-minute recording intervals to determine any sustained reaction in the resident. A total of 51 observation intervals was yielded for the 15-minute interventions and 96 observation intervals for the 30-minute interventions (i.e., MSE only). The net observations for 15- and 30-minute interventions were 45 and 90, respectively. To align the analysis of observation data across the four study groups, the 15-minute observation records were used.

As discovered in the pilot study, the updated version of the AOC has maintained four alertness state levels, but has separated the green active state into two categories: the active alert state (G1), where body movement is observed, and the passive alert state (G2), where no body movement is observed but the person is still in contact with the immediate environment (Munde et al., 2012). The other levels of alertness include amber for inactive and withdrawn, red for sleepy or drowsy and blue for agitated and discontented. The descriptions of the four alertness levels of the AOC are provided in Appendix IX. The interval records were then changed into the frequency and percentage of each particular colour coding, and comparisons were made based on different colours. For instance, the number of amber colours in the four study groups was compared to indicate which group had the highest level of residents demonstrating the inactive and withdrawn state. The inter-observer reliability was r=0.81 and the intra-observer reliability was reported as r=0.87 by Vlaskamp et al. (2009), whose observations were conducted in both the classroom and multisensory room. The new AOC form is shown in Appendix X.

3.5.3 Behaviour Checklist

The BC was developed by Shapiro et al. (1997) to assess the behavioural reactions towards MSE and the relevant psychological interventions, such as social interaction. The checklist consists of 22 items, 16 of which are for SSB and 6 of which are for adaptive behaviour. The inter-rater reliability was high (Pearson's r=0.95) when used in people with ID (Shapiro et al., 1997). The observations of SSB and adaptive behaviour are based on 1-minute intervals to assess the amount of behavioural forms exhibited during the interventions. Hence, the maximum durations of presented behaviour were 15 or 30 minutes, depending on the type of intervention. The range of exhibited behaviour was between 0 and 22, and the maximum number shown in the observations depended on the amount of major behaviour exhibited, as each dominantly presented form of behaviour was counted during the 1-minute observation intervals. To avoid term confusion on the SSB of the BPI-01, the SSB of the BC was renamed as maladaptive behaviour.

To maximise the consistency of the observations made, the AOC raters were required to rate the maladaptive and adaptive behaviour of the BC simultaneously such that every three observations (20-second interval) of the AOC constituted one observation record (1-minute interval) of the BC during the intervention. For the convenience of charting, two forms were devised for 15- and 30-minute observations, as shown in Appendices XI and XII, respectively. Similar to the AOC, the 30-minute observation data were converted into 15-minute records by dividing them by 2 to align the analysis across the four study groups.

3.5.4 Physiological data

Heart rate and respiration rate are physiological data frequently adopted to indicate relaxation level (Croghan, 2009; Hegarty & Gale, 1996). It has been hypothesised that relaxation is a state of parasympathetic activation by the vagus nerve and suppression of nervous system activity (Fraser & Ross Kerr, 1993; Moraska et al., 2008). The Nellcor UP-7000 physiologic monitor was used to record both heart and respiration rates. It has five functions, namely simple electrocardiogram (ECG), blood pressure, heart oximeter, respiration rate and body temperature. The default range for heart rate was 30-240 beats per minute (bpm) with a 2-bpm error, and the default range for respiration rate was 0-120 breaths per minute (Bpm) with a 3-Bpm error. If MT and/or MSE could have a relaxation effect, it was expected that these physiological parameters would gradually drop to a lower level than the baseline readings after the interventions (Chan et al., 2005). To standardise the physiologic monitoring, both heart and respiration rates were taken for 3 consecutive minutes, and the average values per minute were recorded. Both rates were measured before the intervention as baseline data, at midterm to assess the progress at the end of 10th session, at the first post-intervention assessment immediately after completion of the interventions (i.e., at the end of 20th session) and at the end of the 12th week to detect the carryover effect.

3.6 Participants' Socio-Demographic and Clinical Data

The socio-demographic and clinical data sheet (Appendix XIII) included information about each participant's sex, age and personal characteristics. Other co-morbidity conditions, such as epilepsy and cerebral palsy, were also documented.

The collected data were analysed to present the characteristics of the participants and to identify any randomisation bias in the group assignments.

3.6.1 Semi-structured face-to-face interviews

The main purpose of the individual semi-structured interviews was to supplement the findings of the quantitative study. Since the study participants were unable to communicate verbally, their primary nurses were invited to critique the effectiveness of individual interventions. In these semi-structured face-to-face interviews, individual primary nurses were required to share their perceptions of the strengths and weaknesses of the interventions used on their designated participants in terms of improving their challenging behaviour. Convenience sampling and qualitative content analysis were adopted. The overall goal was to understand from their clinical observations of and working experience with the residents under their care whether the interventions affected the residents' behaviour during the intervention period.

The development of the interview questions was based on the literature on the expected demands and benefits of psychosocial interventions on residents with ID or SPID. With reference to previous studies (Hutchinson & Kewin, 1994; Lindsay et al., 1997; 2001; Vlaskamp & Nakken, 1999), the perceptions of healthcare staff on social and recreational activities and services were determined to satisfy the health care of people with ID and their potential effects and difficulties. If they did not perceive any beneficial effect, they would not implement the planned schedule (Vlaskamp & Nakken, 1999). The interview questions are shown in Appendix XIV. Although guided questions were used, the semi-structured interviews were flexible and allowed the interviewees free expression through

open-ended questions. The narrative data provided a better understanding of the primary nurses' perceptions of the feasibility and benefits of delivering specific interventions (MT and/or MSE) in the usual care environment. It was exceptionally valuable to obtain opinions from the frontline staff about the use of new practices/interventions, and the integration of effective interventions into the daily routine to reduce anxiety and challenging behaviour if the interventions were perceived as beneficial to the residents. The interviews also explored the factors influencing and current strategies for managing challenging behaviour in the usual care environment.

Individual interviews with the primary nurses were conducted after the second post-test (2-week after intervention). Open-ended questions were adopted and there was no time limit for their sharing. The interviews ultimately lasted between 35 and 45 minutes, including additional questions asked to clarify the interviewees' responses. Rephrasing or paraphrasing the questions was essential for the interviewees to understand the contents of each question. All of the interviewees' responses were audio recorded with their consent.

As the researcher had been working in the research setting for more than 18 years, there had many personal relationships with the interviewees that might have affected the non-judgmental or neutral attitude towards them. Mayan (2009) emphasised that biases and preconceptions to interviewees contaminate the data. In addition, if the interviewees had negative comments or criticisms about the interventions, they might not have been willing to fully disclose them in the interviews to avoid embarrassment or negative feelings if the researcher acted as an interviewer. Hence, the researcher trained an independent interviewer (a retired nurse) to conduct the interviews, with training taking place through a half-day

workshop and supervised practise. An interview guide was given to enhance her interviewing skills. The purpose of the interviews was repeatedly emphasised to enhance her understanding of the importance of the study before starting the interviews.

Apart from the interview guide, the nurses' demographic data were collected during interviews, particularly their genders, age ranges, professional qualifications, years of experience working with people with ID and any specialty training obtained. After each interview, the researcher and interviewer listened to the audio records. Recommendations were made, when necessary, for improving questioning techniques after the first and second interviews.

3.7 Data Collection Procedure

3.7.1 Quantitative data

All of the recruited participants were required to stop their existing MSE and MT activities and stay in their usual care environments for the 1-month washout period to rule out residual effects on the residents under study. At the end of the washout period, baseline data (T_0) were measured and identity codes were given to each participant before group randomisation. The participants were evenly distributed into four study groups (i.e., MSE alone, MT alone, combined MT-MSE and usual care only group).

The raters of the BPI-01 were the frontline nurses of the individual units. Cronbach's alpha of internal consistency was 0.94, which was relatively higher than the 0.83 value of the original study (Rojahn et al., 2001). The direct care staff of the training centre were responsible for acting as enablers for the three study groups.

The massage therapist was the enabler of the MT and MT-MSE groups. Unlike the rating of the BPI-01, the raters of other outcome measures, such as heart and respiration rates and the BC and AOC scores, did not require any familiarity with the participants. Hence, two raters with healthcare backgrounds were recruited and trained for behavioural observations. Before the observations were started, the raters were trained to administer the AOC and BC. The inter-rater reliabilities of all observational measures were calculated, with the AOC reaching 82.7% in the main study, which was slightly higher than the 80% of the original study (Vlaskamp et al., 2009) and the 76.5% of the pilot study. The intra-class correlation reliability of individual alertness levels ranged from 0.95 to 1.00 except for the agitated/discontented level, which was 0 due to the lack of occurrence throughout the observations. Cronbach's alpha coefficient of stereotypic or maladaptive behaviour was 0.90, whereas the coefficient of adaptive behaviour was 0.91. The inter-rater reliability of the BC was between 0.86 and 0.89 for stereotypic behaviour and between 0.87 and 0.90 for adaptive behaviour in the main study, which was better than in the pilot study and comparable with that in the original study by Shapiro et al. (1997), in which the inter-rater reliability was 0.95.

The designated care staff helped connect the physiologic monitor to record the heart and respiration rates at the end of the intervention according to the assessment schedule. Both rates were taken for 3 consecutive minutes and averaged according to the value per minute. All of the participants underwent 10-week interventions according to group assignment. Four outcome measurements were undertaken in the main study at specific time points, including data at baseline (T_0), interim data midterm through the interventions (T_1), data

immediately after completion of the interventions (T_2) and the carryover effect at the end of week 12 (at the 2-week follow-up, T_3).

3.7.2 Qualitative data

All of the semi-structured face-to-face interviews were conducted after the completion of the entire study period. This allowed for comparison of the behavioural changes between interventions and usual care over the previous 12 weeks. Only the primary nurses of the participants who were assigned to treatment groups were invited. After they had signed the consent to participate the study, arrangements were made for them to attend the intervention sessions with their designated residents to observe their reactions to receiving their assigned interventions. The interviewees were required to attend at least one session and were welcome to join as many sessions as they wanted. With their written consent, all of the interviews were audio recorded for the qualitative content analysis. The interviewees were invited to a comfortable place (or meeting room) with a sofa for the interviews. In addition to appraising the interventions, they were invited to share their personal experiences with managing challenging behaviour and their perceptions of the factors of challenging behaviour and its preventive measures. At the end of the interview, each interviewee was given a supermarket coupon to thank them for his or her participation.

3.8 Methods of Data Analysis

3.8.1 Quantitative data

All of the quantitative data collected were analysed using the statistical software IBM SPSS for Windows, version 21. Descriptive statistics were used to

summarise the socio-demographic and clinical data, such as age, sex, mobility level and feeding mode. The normality of the outcome measures was checked, which revealed that all of the continuous data did not fulfil the normal distributions (univariate and multivariate normality). Hence, a nonparametric test was used to analyse the baseline data of the outcome measures to identify any randomisation bias in the group assignments. The Generalised Estimating Equations (GEE) test can be used for both categorical and continuous data (Zegar & Liang, 1986), as well as missing data (by complete case analysis method). Thus, it was used to identify the interaction effects (i.e., time and group effects) between groups and time effects within groups from baseline to immediately post-intervention and from baseline to the 2-week follow-up, namely from T0 to T2 and from T0 to T3, respectively. As a rule of thumb, estimates are probably asymptotically unbiased for samples greater than 50 (Cook, 2015). When significant differences were found in any outcome variables between groups, contrast comparisons were automatically carried out following the GEE test. The level of significance of all statistical tests was set at 0.05 (two-tailed).

Intention-to-treat principle (Montori & Guyatt, 2001) has adopted to preserve the maximum number of sample size into data analysis, hence, the statistical power would not be markedly affected. However, the estimation of treatment effect would be conservative because the imputed data might dilute the intervention effect of the completed data if large missing data existed (Gupta, 2011). In the present study, three out of 129 datasets were required to impute the missing data, share 3.9% of the data for analysis. Multiple imputation method was employed to impute the missing data because it adopts maximum likelihood–based approach with generating 5 imputation models for selection. Generally, the pooled

imputed data are used for modelling missing data in quantitative studies because of high precision and best results of data analysis (Molenberghs & Kenward, 2007). Hence, the pooled imputed data of multiple imputation method were used for data analysis in the present study.

3.8.2 Qualitative data

Since the study participants were unable to communicate verbally and feedback whether they enjoyed the interventions or the interventions could help them to relax. Primary nurses were supposed to take care of them holistically, and invited to critique the effectiveness of the interventions. As mentioned, the collected qualitative data were used to supplement information of quantitative data.

With reference to previous studies (Hutchinson & Kewin, 1994; de Bunsen, 1994; Vlaskamp & Nakken, 1999), the interview guide was developed to recognise the interviewees' perceptions on the interventions. As commented by Vlaskamp and Nakken (1999), if the direct care staff did not perceive any beneficial effect of the intervention, they would not implement the planned activities as schedule.

In order to let interviewees' freedom to express themselves without the hesitation of embarrassment because of negative comment in the interviews, an external interviewer was recruited to conduct the interviews. Apart from interview guide, they were encouraged sharing their personal experiences and/or alternative interventions in management of challenging behaviour.

Concerning the rigor of the qualitative study, started from data transcription, the researcher selected one of the longest audio-recorded interviews to transcribe

verbatim into written Cantonese and then translated it into English. A bilingual tutor with a healthcare background was invited to transcribe and translate the same audio-recorded interview independently. Another experienced qualitative researcher then checked the quality of the two English translations. A high level of agreement on the translated contents was reported with minor amendments made.

After the translation was checked, all of the other interview audio records were transcribed into written Cantonese verbatim. The completed verbatim transcripts were brought back to the interviewees to clarify them, check their accuracy and establish their credibility (Streubert & Carpenter, 2011). After all of the interview audio records were checked, the interview data were subjected to qualitative content analysis (Elo et al., 2014; Graneheim & Lundman, 2004).

The written contents were repeatedly read and reviewed to identify common meanings or similar wordings. The major wordings of the contents were identified and coded accordingly. The basic coding units were expressed in terms of words, phrases or sentences related to the benefits and shortcomings of the interventions, the factors nurses perceived as part of challenging behaviour and possible prevention and management strategies for challenging behaviour based on their clinical experiences. To enhance trustworthiness, the initial coding of the first two interview transcripts was shared with an experienced qualitative researcher to ensure agreement between the descriptive codes and clarify any uncertainties about the coding methods. Similar coding rules were then applied to the remaining qualitative interview data. Coding was checked with the experienced qualitative researcher again after the completion of all interview transcripts to maintain consistency.

Similar coding was clustered together. All coding then summarised and condensed into categories and subcategories with relevance to the interventions used to manage challenging behaviour, until all similar contents were coded into one of the categories and subcategories (Elo et al., 2014). The meanings of all of the identified categories and subcategories with supporting verbatim data were checked against the objectives of the semi-structured interviews (Streubert & Carpenter, 2011). The final categories and subcategories were discussed with two qualitative researchers (one of them was the experienced qualitative researcher) and confirmed with my supervisor to increase the trustworthiness.

3.9 Summary of Study Methodology

A mixed methods research design was adopted. In the quantitative part, a randomised controlled trial was conducted and the outcome measures of the three intervention groups, namely MSE, MT and MT-MSE, and one control group were compared. The duration of the study was 12 weeks. The outcome measures included primary outcomes, which consisted of the frequency and severity of challenging behaviour, and secondary outcomes, which consisted of physiological states (i.e., heart and respiration rates), maladaptive and adaptive behaviour and alertness levels. These behavioural and physiological outcomes were measured at recruitment before the groups were assigned, at the fifth week in the midterm of the interventions to assess progress, at the tenth week immediately after the completion of the intervention and at the twelfth week (i.e., 2 weeks after the completion of the interventions) to evaluate the carryover effect. All of the study participants

stayed in their usual care environment between weeks 10 and 12 without interventions. The research setting was a 500-bed specialty residential care for adults with SPID. Overall, 131 residents were recruited. Two dropped out before the midterm assessment because of poor physical health. The final data analysis involved the remaining 129 datasets.

In the qualitative part, the primary nurses of the study participants who randomly assigned to one of the interventions were invited to participate in the semi-structured interviews to share their perceptions of the strengths and weaknesses of the interventions used on their designated participants, especially their effects on challenging behaviour. Convenience sampling was adopted. Only 15 of the 64 primary nurses agreed and signed the consent form to participate in the semi-structured interviews. However, two withdrew due to personal engagements. Ultimately, 13 nursing staff were successfully interviewed using the interview guide. Qualitative content analysis was used to analyse the interview contents.

CHAPTER FOUR

PILOT STUDY

4.1 Study Overview

In view of the lack of similar research available for reference, the purpose of the pilot study with a pre- and post-test design was to examine the feasibility of implementing a larger scale randomised clinical trial in the research setting that included recruitment of research subjects, group assignment, application of interventions, collection of outcome measures and data analysis procedures. The pilot study was conducted between February and May 2013. As the main goal of the study was to reduce challenging behaviour, presenting one or more forms of challenging behaviour was an inclusion criterion. One nurse assessor from each of the 10 units under study was invited to assess residents living in the same unit regarding the frequency and severity of their challenging behaviour. Ten assessors were recruited, and each had worked in his/her respective unit for more than 2 years.

The eligible subjects with SPID from each of the 10 units were listed in alphabetical order, and 6 of them were randomly selected using random computer-generated numbers (Knuth, 1998). Forty-seven residents were recruited with proxy consent from their guardians, underwent a 1-month washout period, completed the baseline measurement and were randomly assigned to one of the four study groups (MSE alone, MT alone, MT-MSE or usual care only) by drawing labelled cards. Interventions were given twice per week for 10 consecutive weeks. Immediately after the interventions, the participants performed the post-test, in which the same set of outcome measures as the baseline measurement was

administered. Evaluating the results was supposed to address the feasibility of the study methods and procedures of the main study. The pilot study also attempted to assess the effectiveness of MSE and MT, either separately or combined, in reducing challenging behaviour in people with SPID in residential care. Recommendations for future studies were also made.

4.2 Research Setting

The research setting was an institution exclusively for adults with SPID. It provided infirmary care and comprised 10 units with 500 beds and a daytime activity centre. All of the residents required assistance from direct care staff in their daily living activities. A local survey of the prevalence of challenging behaviour was carried out in 2011 (Lee & Tso, 2011), in which approximately 69% (more than 300 residents) of all of the residents exhibited at least one form of challenging behaviour, such as aggressive behaviour, SIB and SSB.

4.3 Sampling

4.3.1 Sample size calculation

When calculated the sample size of the pilot study, an experimental study was considered for reference in the beginning because two outcome measures were the same as the present study. However, the effect size of the primary outcome of the experimental study was small with requiring approximate 300 subjects per group (Chan et al., 2005) that was out of target population size. As a result, the sample size of the pilot study was estimated with reference to the findings of the controlled trial by Shapiro et al. (1997), in which the participants' maladaptive behaviour was one of the outcome measures, same as this study. The size of

Cohen's d effect on challenging behaviour at post-test was 1.40, indicating a large effect. Therefore, the required sample size was approximately 11 for each group (i.e., 44 for the 4 study groups) at a 0.05 significance level, a study power of 0.80 (Portney & Watkins, 2009) and an attrition rate of 20% (Shapiro et al., 1997). Due to uncertainty surrounding the response rate, 60 participants were randomly selected (n=15 for each group) to ensure a sufficient number of subjects to meet the minimum sample size (11 per group) if no more than 16 (27%) refused to participate.

4.3.2 Recruitment and randomisation

Before the pilot study started, it was found that approximately 59% (n=291) of the residents with SPID exhibited at least one type of challenging behaviour in the previous 2 months, as reported by the clinical assessors of the individual study units. The surnames of these eligible potential subjects were numbered and listed in ascending alphabetical order for each of the 10 units individually. To minimise the differences in the characteristics and environments of the units between groups, equal numbers of subjects were then randomly drawn from each unit using random computer-generated numbers created by an independent statistician. With an expected 75% response rate, 60 eligible residents (i.e., n=6 from each of the 10 units) were invited to participate. Ultimately, only 47 proxy consents for participation were received (i.e., a response rate of 78%).

4.4 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were the same as in the main study. Before starting the interventions, all of the participants underwent a 1-month

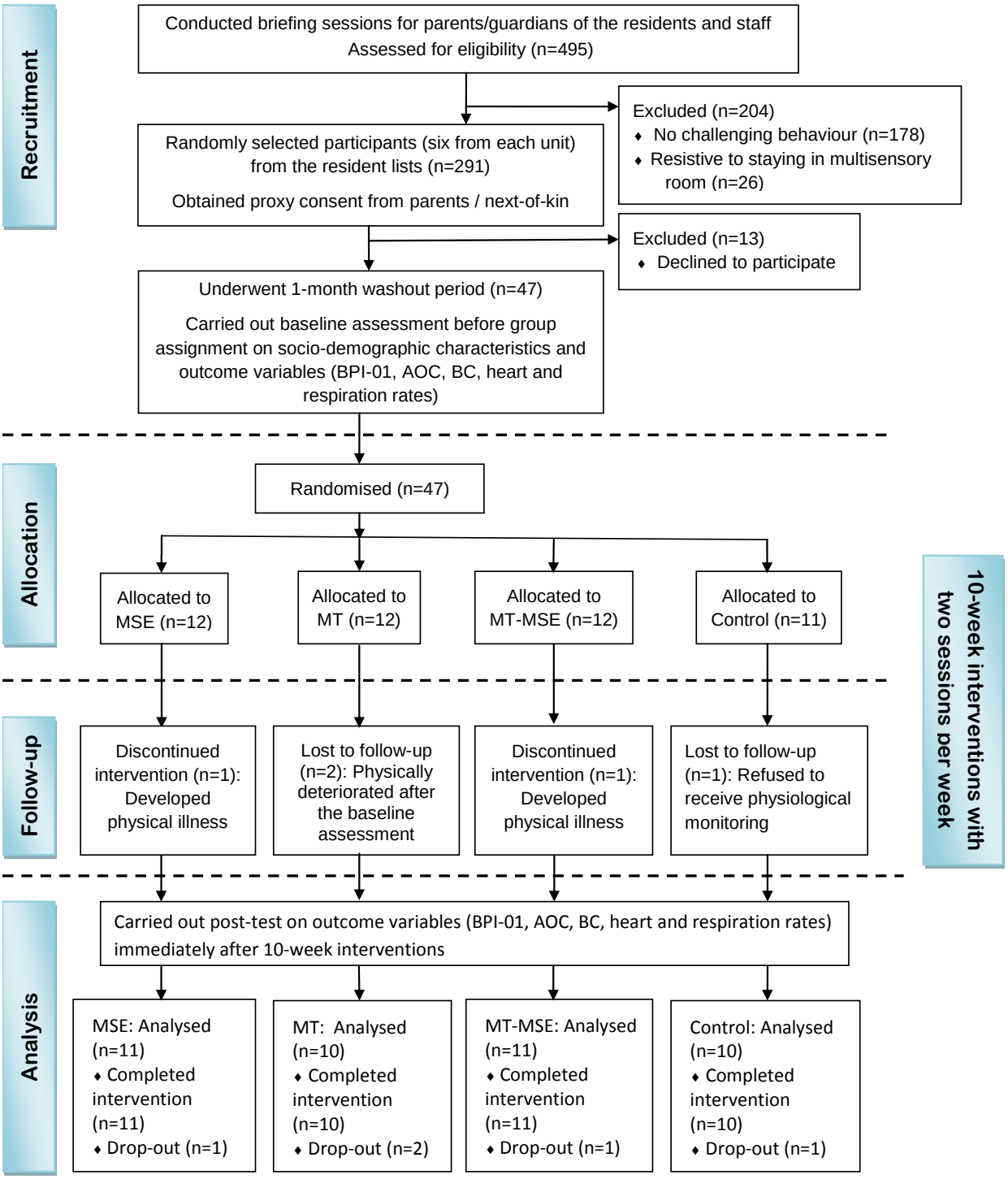
washout period to eliminate any residual effects of other recent MT and MSE interventions. Each participant was given an identity code by a research assistant to maintain their anonymity and to blind the clinical staff and outcome assessors to their group assignment. At the end of the washout period, baseline measurements (and demographic data) were taken. A clinical staff who was blind and concealed to the participant list in each unit was invited to draw the labelled cards for group assignment. Each participant was then randomly assigned to one of the four study groups (i.e., MSE alone, MT alone, MT-MSE and the c3.3ontrol or usual care group). A flowchart of the sampling and study procedures according to the latest CONSORT statement (Schulz et al., 2010) is shown in *Figure 4.1*. Ultimately, 42 of the 47 participants completed the pilot study, with an approximate 11% attrition rate. Four dropped out due to physical problems and one refused to be physically monitored in the study.

The recruitment process started in February 2013. It took more than 1 month to recruit enough subjects, as some letters failed to reach their next-of-kin. The correspondence addresses were verified with the next-of-kin/family members before resending them the information sheets and consent forms.

4.5 Interventions

After the baseline assessment, all of the participants received their assigned 10-week interventions, namely MSE alone, MT alone, MT-MSE or usual care. The second measurement was made immediately after the interventions were completed.

Figure 4.1. Flow diagram of the pilot study and sampling procedure



BPI-01: Behaviour Problem Inventory; AOC: Alertness Observation Checklist; BC: Behaviour Checklist; MSE: Multisensory environment; MT: Massage therapy; MT-MSE: Massage therapy in multisensory environment

Two nurses with rich experience in caring for people with ID who were trained by a qualified massage therapist served as the therapists conducting MT in the pilot study. During their training, their compliance rate to the massage protocol was found to be at least 90%. The qualified therapist performed regular monitoring to ensure treatment fidelity, especially in the first two sessions. Surprise checks in subsequent sessions were also performed.

Generally, one direct care staff took care of six to seven residents during their daytime duty shifts. An enabling approach was adopted to the residents' behavioural manifestations during interventions to allow their free behavioural expression. To balance the enabling approach for all study groups, social attention and physical contact through 20-30 minutes of toy playing was provided to the participants of the usual care environment whenever the treatment groups underwent their intervention sessions. Each intervention offered twice per week for 10 consecutive weeks, and each session lasted between 20 and 30 minutes.

4.6 Measures

Given the residents' cognition and communication deficits, self-report measures completed by the residents would not have been appropriate. Instead, observational measures on behavioural manifestations and physiological changes would be appropriate to evaluate the relaxation effect among these participants. The outcome measures were categorised into two levels: (1) the primary outcome measures of behavioural problems using the BPI-01 (Rojahn et al., 2001) and (2) a few secondary outcome measures on heart and respiration rates and alertness level using the AOC (Vlaskamp et al., 2009) and adaptive and maladaptive behaviour using the BC (Shapiro et al., 1997). The details of these outcome measures can be

found in Section 3.5.

The BPI-01 was the primary outcome measure used to evaluate the sustainable effect of the interventions on a few common forms of challenging behaviour (in terms of frequency and severity) among the participants with SPID in the usual care environment (Rojahn et al., 2001). BPI-01 captured three dimensions of challenging behaviour: SIB, SSB and aggressive/destructive behaviour. One frontline experienced nurse who was familiar with the residents' behaviour in the usual care environment was invited to rate the challenging behaviour exhibited by the subjects during the previous 2 weeks. The assessors were blind to the participants' group assignments. The intra-rater reliability of the BPI-01 was very satisfactory in this study (ICC=0.88), and was higher than the 0.76 ICC value in the original study (Rojahn et al., 2001).

The secondary outcomes included heart and respiration rates, alertness level and adaptive and maladaptive behaviour. Heart and respiration rates are physiological data that reliably indicate individual relaxation level (Croghan, 2009; Hegarty & Gale, 1996). The mechanism of relaxation is believed to activate parasympathetic nerves and suppress sympathetic activities (Fraser & Ross Kerr, 1993; Moraska et al., 2008). Both heart and respiration rates were measured by a physiologic monitor continuously for 3 minutes after the interventions and finalised into their average values.

The AOC was developed by Vlaskamp et al. (2009) to detect the alertness state of people with SPID by indicating their interactions and engagement with their immediate environments or external stimuli. Such interaction and engagement involves attention, responsiveness and concentration. There have four levels of alertness in AOC, including active; inactive and withdrawn; sleepy and drowsy; and

agitated, restless and discontented. A colour code is attached for each alertness state, i.e., green for active, amber for inactive, red for sleepy, and blue for restless. The residents' responses to environmental stimuli were observed at 20-second intervals for 15-20 minutes during the interventions (Vlaskamp et al., 2009). The percentages of the occurrences of various alertness levels in the treatment and control groups were compared. The inter-observer agreement was 76.5% in this study, which was slightly lower than the 80% set by Vlaskamp et al. (2009).

The BC was used to assess maladaptive and adaptive behaviour. It consists of 22 items, 16 of which are for maladaptive behaviour, such as SSB, and 6 of which are for adaptive behaviour, such as initiation of communication attempts, rapport building and concentration (Shapiro et al., 1997). The BC has been validated for the MSE intervention (Chan et al., 2007; Shapiro et al., 1997), using observation schedules with 1-minute intervals during 15- to 20-minute interventions. The inter-rater reliability of the BC was satisfactory with an inter-class correlation of 0.66 for maladaptive behaviour and 0.80 for adaptive behaviour in this study, similar to that of the original study (Shapiro et al., 1997).

Finally, a demographic and clinical data sheet was used to collect the relevant data, such as the participants' genders; ages; medications; mobility levels, from ambulant to bedridden; feeding modes, from self-feeding to enteral feeding; and types of sensory deficit, from the residents and/or the clinical records of the study units. Comorbidities of other neurological disorders, such as epilepsy and cerebral palsy, were also recorded.

4.7 Data Collection Procedure

Following the recruitment exercise, 1-month washout period was applied to each participant to rule out the residual effect of recent MSE and MT interventions. At the completion of washout period, baseline assessments, including the BPI-01, heart and respiration rates, the AOC, the BC and the demographic and clinical data sheets, were carried out for the participants.

After the random study group assignments, the clinical raters/assessors from individual units were responsible for completing the BPI-01s for their residents, as they were familiar with them and could thus assess and rate the manifested behaviour of the participants in the usual care environment. The BC and AOC were assessed by two trained observers who were blind to the participants' group assignments. Two designated care staff served as enablers and helped connect the physiologic monitor to record the participants' heart and respiration rates at the end of the intervention sessions. Both heart and respiration rates were then taken for 3 consecutive minutes, and the average values per minute were recorded.

All of the participants underwent one of the 10-week interventions (two sessions per week) according to the group assignment. After completion of the 20 intervention sessions, heart and respiration rates were taken, and the AOC, BC and BPI-01 were completed to evaluate the immediate effects of the interventions.

4.8 Data Analysis

All of the quantitative data collected were coded and analysed using IBM's SPSS for Windows, version 21. Descriptive statistics were used to summarise the demographic and clinical data and outcome scores. To examine the group differences of categorical demographic data, such as sex, activities of daily living

and types of neurological disorders, the goodness-of-fit chi-square test was used. Due to the small sample size and data skewness, a nonparametric Kruskal-Wallis H test was employed to compare the mean ages of the four groups at baseline and to analyse the outcome variables (the BPI-01, heart and respiration rates, the BC and the AOC). If the outcomes revealed significant results, a Mann-Whitney U test was performed to compare the post-test scores of each significant outcome across the four groups in pairs to identify their relative treatment effects.

4.9 Results

4.9.1 Participants

A total of forty-two out of forty-seven participants completed the interventions and outcome measurements. Three participants withdrew from the study after group assignment due to their refusal of physiologic monitoring (n=1) or physical illness (n=2). Another two dropped out during the intervention period because of poor health. These dropouts accounted for an attrition rate of 10.6%. The final 42 participants comprised 60% women (n=25), with a mean age of 43.40 years (SD=10.92; ranging from 18 to 64 years of age). There were no significant differences in the characteristics between those who dropped out and those who remained in the study (using the chi-square or Fisher's exact test, all p-values >0.10).

4.9.1.1 Descriptive data

In daily care, approximately half (48%) of the participants required movement restrictions, such as body alignment supports, safety belts and limb holders. Regarding to their comorbidities, 31% had cerebral palsy and

approximately 62% suffered from epilepsy, whereas 88% needed regular medications to control seizure attack and other health conditions. Approximately 76% of the participants required staff assistance in continence care, feeding and physical transfer. All of them required assisted or trolley bathing. Participants with hearing and visual impairments shared approximately 9.5% and 33% respectively. 79% had traceable relatives. The demographic and clinical characteristics of the participants showed no statistical differences between the four groups ($p>0.17$) and are summarised in *Table 4.1*.

4.9.2 Results of outcome measures at baseline

After the washout period, baseline measurements were taken for all of the participants to check for any randomisation biases. The mean scores and standard deviations of the outcome measures (the BPI-01, physiologic measures, the BC and the AOC) of the four study groups at baseline are summarised in *Table 4.2*. The four levels of alertness (green, amber, red and blue) of the four groups are summarised in terms of frequency and percentage. Comparisons of the outcome variables showed no statistical significance ($p=0.076$-0.979), indicating the homogeneity of the four study groups at baseline.

Table 4.1. Participants' demographic and clinical characteristics (N=42)

Characteristics	Total (n=42)	MSE (n=11)	MT (n=10)	MT-MSE (n=11)	Control (n=10)	Pearson chi-square χ^2	p-value
Mean age (SD)	43.4 (10.92)	45.64 (6.93)	41.7 (14.43)	42.27 (11.79)	43.9 (10.79)	1.05#	0.790
Sex						0.32	0.956
Male	17 (40.5%)	5 (45.5%)	4 (40%)	4 (36.4%)	4 (40%)		
Female	25 (59.5%)	6 (54.5%)	6 (60%)	7 (63.6%)	6 (60%)		
Adaptive support						3.23	0.364
Yes	20 (47.6%)	5 (45.5%)	7 (70%)	5 (45.5%)	3 (30%)		
No	22 (52.4%)	6 (54.5%)	3 (30%)	6 (54.5%)	7 (70%)		
Bathing mode						1.85	0.688
Assisted	6 (14.3%)	3 (27.3%)	1 (10%)	1 (9.1%)	1 (10%)		
Trolley	36 (85.7%)	8 (72.7%)	9 (90%)	10 (90.9%)	9 (90%)		
Cerebral palsy						1.50	0.758
Yes	13 (31%)	4 (36.4%)	4 (40%)	2 (18.2%)	3 (30%)		
No	29 (69%)	7 (63.6%)	6 (60%)	9 (81.8%)	7 (70%)		
Continence level						0.75	0.963
Yes	10 (23.8%)	3 (27.3%)	3 (30%)	2 (18.2%)	2 (20%)		
No	32 (76.2%)	8 (72.7%)	7 (70%)	9 (81.8%)	8 (80%)		
Epilepsy						2.29	0.559
Yes	26 (61.9%)	7 (63.6%)	8 (80%)	6 (54.5%)	5 (50%)		
No	16 (38.1%)	4 (36.4%)	2 (20%)	5 (45.5%)	5 (50%)		
Feeding mode						8.86	0.421
Independent	10 (23.8%)	3 (27.3%)	3 (30%)	3 (27.3%)	1 (10%)		
Assisted	11 (26.2%)	3 (27.3%)	1 (10%)	4 (36.4%)	3 (30%)		
Dependent	17 (40.5%)	5 (45.5%)	3 (30%)	3 (27.3%)	6 (60%)		
Enteral	4 (9.5%)	0	3 (30%)	1 (9.1%)	0		
Hearing loss						4.42	0.170
Yes	4 (9.5%)	3 (27.3%)	0	1 (9.1%)	0		
No	38 (90.5%)	8 (72.7%)	10 (100%)	10 (90.9%)	10 (100%)		
Medication						3.28	0.362
Yes	37 (88.1%)	10 (90.9%)	9 (90%)	8 (72.7%)	10 (100%)		
No	5 (11.9%)	1 (9.1%)	1 (10%)	3 (27.3%)	0		
Mobility level						5.14	0.526
Ambulant	10 (23.8%)	4 (36.4%)	1 (10%)	2 (18.2%)	3 (30%)		
Chair-bound	29 (69%)	6 (54.5%)	8 (80%)	8 (72.7%)	7 (70%)		
Bedridden	3 (7.1%)	1 (9.1%)	1 (10%)	1 (9.1%)	0		
Traceable relative						0.55	1.000
Yes	33 (78.6%)	8 (72.7%)	8 (80%)	9 (81.8%)	8 (80%)		
No	9 (21.4%)	3 (27.3%)	2 (20%)	2 (18.2%)	2 (20%)		
Visual impairment						2.16	0.585
Yes	14 (33.3%)	2 (18.2%)	4 (40%)	5 (45.5%)	3 (30%)		
No	28 (66.7%)	9 (81.8%)	6 (60%)	6 (54.5%)	7 (70%)		

MSE = Multisensory Environment, MT = Massage Therapy, MT-MSE = Massage Therapy in Multisensory Environment, SD = Standard Deviation,
 # Kruskal Wallis test used for comparing the mean ages between groups.

Table 4.2. Baseline assessment of different outcome measures in terms of mean and standard deviation (N=42)

Variables	MSE (n=11) Mean (SD)	MT (n=10) Mean (SD)	MT-MSE (n=11) Mean (SD)	Control (n=10) Mean (SD)	Kruskal -Wallis H test	p-value
Primary Outcomes						
Behaviour Problems Inventory (BPI-01)						
Frequency of CB	11.55 (8.07)	9.10 (7.49)	14.18 (11.90)	14.00(12.18)	1.61	0.657
Severity of CB	7.09 (6.30)	5.80 (3.74)	7.91 (6.28)	8.30 (8.45)	0.19	0.979
Frequency of SIB	2.91 (2.47)	2.60 (3.24)	5.09 (3.45)	2.00 (2.31)	6.96	0.073
Severity of SIB	2.27 (2.61)	1.60 (1.84)	3.09 (2.51)	0.90 (1.29)	6.28	0.099
Frequency of SSB	6.82 (6.13)	4.80 (4.71)	8.82 (10.27)	9.70 (9.41)	1.57	0.667
Severity of SSB	3.45 (2.73)	3.20 (3.16)	4.64 (5.59)	5.60 (6.93)	0.36	0.949
Frequency of aggression	1.82 (3.60)	1.70 (2.91)	0.27 (0.91)	2.30 (4.19)	3.18	0.365
Severity of aggression	1.36 (3.04)	1.00 (1.49)	0.18 (0.60)	1.80 (3.16)	3.20	0.362
Secondary Outcomes						
Physiologic monitoring						
Heart rate	81.73 (11.57)	80.20 (18.56)	77.00 (13.89)	81.80 (13.78)	0.63	0.889
Respiration rate	16.82 (2.56)	17.40 (4.09)	18.09 (4.09)	20.00 (3.40)	4.71	0.194
Behaviour Checklist (BC)						
Amount of MB	3.46 (5.65)	6.60 (6.77)	11.46 (8.03)	6.20 (6.80)	6.87	0.076
Duration of MB	3.36 (5.45)	5.90 (5.55)	9.27 (5.18)	5.70 (5.95)	6.33	0.097
Amount of AB	6.36 (8.02)	3.00 (4.35)	4.55 (6.62)	5.40 (5.69)	3.20	0.362
Duration of AB	5.55 (6.46)	2.80 (4.08)	3.91 (5.07)	1.90 (4.68)	3.45	0.328
Alertness Observation Checklist (AOC)@						
Green: active **@**	39.39% (0.39)	23.78% (0.24)	32.32% (0.32)	49.78% (0.50)		
	17.73 (21.14)	10.70 (15.62)	14.55 (20.17)	22.40 (22.36)	1.06	0.788
Amber: inactive **@**	28.48% (0.29)	42.22% (0.42)	33.13% (0.33)	18.44% (0.18)		
	12.82 (18.08)	19.00 (17.98)	14.91 (20.12)	8.30 (15.03)	2.22	0.528
Red: sleepy **@**	32.12% (0.32)	34.00% (0.34)	25.86% (0.26)	31.78% (0.32)		
	14.45 (20.34)	15.30 (18.43)	11.64 (18.47)	14.30 (20.12)	0.31	0.959
Blue: agitated **@**	0.00% (0)	0.00% (0)	8.69%(0.09)	0.00% (0)		
	0 (0)	0 (0)	3.91 (12.96)	0 (0)	2.82	0.421

@ Percentage of occurrence of alertness level (percentage converted into decimal figures)

AB=Adaptive Behaviour, CB=Challenging Behaviour, MB=Maladaptive Behaviour, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, SD=Standard Deviation, SIB=Self-injurious Behaviour, SSB=Self-stimulating Stereotypic Behaviour

4.9.3 Main treatment effects (between-subject tests)

According to all of the observation records, agitation (blue) was not observed in any of the study groups. Hence, this alertness level was excluded from the data analysis. By using Kruskal-Wallis H tests for analysis, the interaction (group×time) treatment effect was only significant in the alertness levels of the participants, in which the active state (H=15.46, df=3, p=0.001, effect size=0.72) and inactive state (H=11.24, df=3, p=0.01, effect size=0.71) were significantly different between groups at post-test. The main treatment effects on the study outcome measures in the four study groups are shown in *Table 4.3*. According to the percentage change between active and inactive states, the active state was greatly decreased in the MSE and MT-MSE groups from 39.39% to 16.06% and from 32.32% to 2.83%, respectively, whereas the inactive state increased from 28.48% to 73.33% and from 33.13% to 94.34%, respectively.

Contrast comparisons of the two significant outcomes on alertness level were performed using the Mann-Whitney U test to identify groups showing significant differences in these two outcomes at post-test. The MT-MSE, MSE and MT participants showed significantly lower amounts/occurrences of active state than the control group at post-test, with large effect sizes (U=10.00, p=0.001, effect size=1.60; U=20.50, p=0.010, effect size=0.86; and U=20.00, p=0.017, effect size=0.76, respectively). The results of the Mann-Whitney U tests also revealed that the MT-MSE group had significantly more frequent or a higher amount of inactive state than the control and MT groups, with large effect sizes (U=11.00, p=0.001, effect size=1.39; U=26.00, p=0.015, effect size=1.19, respectively). The contrast comparison results of the treatment effect on the AOC across the four study groups using the Mann-Whitney U test are shown in *Table 4.4*. The MT-MSE

group demonstrated the lowest active state levels and the highest inactive state levels of all four groups, showing that the MT-MSE participants were largely in a state of inactivity.

4.9.3.1 Primary outcomes

The primary outcomes were the frequency and severity of challenging behaviour, which was statistically insignificant (p=0.657-0.979) along with its three subscales (p=0.073-0.949). According to the mean scores of the three subscales, the participants exhibited higher levels of SSB (M=2.30-9.70) than SIB (M=1.40-5.09) and aggression (M=0.18-4.30).

Table 4.3. Treatment effects on different outcome measures in terms of mean and standard deviation (N=42) (Final data)

Variables	MSE (n=11) Mean (SD)	MT (n=10) Mean (SD)	MT-MSE (n=11) Mean (SD)	Control (n=10) Mean (SD)	Kruskal -Wallis H test	p-value
Primary Outcomes						
Behaviour Problems Inventory (BPI-01)						
Frequency of CB	8.73 (9.28)	9.70 (12.20)	12.82 (13.08)	17.60 (22.54)	0.94	0.817
Severity of CB	5.09 (5.99)	4.30 (4.52)	7.82 (8.32)	10.40 (15.71)	1.06	0.787
Frequency of SIB	1.82 (2.48)	3.30 (3.74)	3.64 (3.01)	3.70 (4.40)	2.38	0.498
Severity of SIB	1.45 (2.38)	1.40 (1.35)	2.27 (2.20)	2.30 (3.53)	1.48	0.687
Frequency of SSB	5.45 (6.67)	4.30 (6.68)	8.55 (10.89)	9.60 (12.49)	1.93	0.588
Severity of SSB	2.45 (2.38)	2.30 (3.59)	4.91 (6.52)	5.60 (8.66)	1.51	0.680
Frequency of aggression	1.45 (2.51)	2.10 (4.48)	0.64 (1.43)	4.30 (9.32)	1.46	0.693
Severity of aggression	1.18 (2.40)	0.60 (1.08)	0.64 (1.43)	2.50 (5.89)	1.04	0.792
Secondary Outcomes						
Physiologic monitoring						
Heart rate	73.45 (10.25)	71.70 (16.63)	74.27 (9.03)	76.30 (13.21)	0.33	0.955
Respiration rate	17.73 (3.52)	16.10 (3.81)	16.55 (2.98)	16.80 (2.39)	1.25	0.740
Behaviour Checklist (BC)						
Amount of MB	3.27 (5.99)	3.00 (4.81)	3.82 (6.35)	1.80 (2.62)	0.24	0.971
Duration of MB	3.27 (5.99)	3.00 (4.81)	3.73 (6.21)	1.80 (2.62)	0.24	0.971
Amount of AB	0.32 (0.72)	1.10 (1.66)	0.27 (0.91)	4.10 (5.43)	6.70	0.082
Duration of AB	0.32 (0.72)	1.10 (1.66)	0.27 (0.91)	4.10 (5.43)	6.70	0.082
Alertness Observation Checklist (AOC)@						
Green: active **@**	16.06% (0.16)	18.67% (0.19)	2.83% (0.28)	48.67% (0.49)		
	7.23 (16.25)	8.40 (17.77)	1.27 (4.22)	21.90 (17.72)	15.46	0.001**
Amber: inactive **@**	73.33% (0.73)	52.67% (0.53)	94.34% (0.94)	51.33% (0.51)		
	33.00 (19.27)	23.70 (20.67)	42.45 (8.44)	23.10 (17.72)	11.24	0.01*
Red: sleepy **@**	10.61% (0.11)	28.67% (0.29)	2.83% (0.03)	0% (0)		
	4.77 (13.53)	12.90 (18.77)	1.27 (4.22)	0 (0)	6.75	0.080

***p<0.05, **<0.01, ***<0.001 @ Percentage of occurrence of alertness level (percentage converted into decimal figures)**

AB=Adaptive Behaviour, CB=Challenging Behaviour, MB=Maladaptive Behaviour, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, SD=Standard Deviation, SIB=Self-injurious Behaviour, SSB=Self-stimulating Stereotypic Behaviour

Table 4.4. Comparison of treatment effects on the Alertness Observation Checklist using the Mann-Whitney U test

AOC/Group comparisons		MSE vs. CTL	MT vs. CTL	MT-MSE vs. CTL	MSE vs. MT	MSE vs. MT-MSE	MT vs. MT-MSE
Green: active	U (p)	20.50 (0.010*)	20.00 (0.017*)	10.00 (0.001**)	53.50 (0.877)	54.00 (0.475)	48.00 (0.418)
	Effect size	0.86	0.76	1.60	0.07	0.50	0.55
Amber: inactive	U (p)	31.50 (0.088)	46.50 (0.788)	11.00 (0.001**)	41.00 (0.283)	43.00 (0.117)	26.00 (0.015*)
	Effect size	0.54	0.03	1.39	0.47	0.64	1.19

***p<0.05, **<0.01, ***<0.001**

AOC=Alertness Observation Checklist, CTL=Control, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level

4.9.3.2 Secondary outcomes

Of the three secondary outcome measures, only the active and inactive states of the AOC showed statistically significant differences between study groups as described in the main treatment effects. Although the mean difference was also noted between the pre- and post-tests of the physiological signs (heart and respiration rates) and the BC (maladaptive and adaptive behaviour), it was not statistically significant (p=0.076-0.971) between groups. The small sample size could have been the cause.

4.10 Discussion

4.10.1 Overview

The purpose of this pre- and post-test study was to examine the feasibility of implementing a larger scale randomised clinical trial in the same setting that includes recruitment of research subjects, group assignment, application of interventions, collection of outcome measures and data analysis procedures.

The results of the pilot study also shed light on the refinement of the study process if unusual circumstances are identified. In the following paragraphs, the significant findings and their contributing factors are discussed. The possible reasons for insignificant outcome measures are also addressed. Generally, changes in alertness level were statistically significant. The combined use of MT and MSE probably induced a greater relaxation effect in the participants and focused their attention better, representing higher levels of inactive state and passive alertness than the other study groups. The frequency of challenging behaviour in control group was persistently higher than other treatment groups, likewise, three treatment groups yielded lower heart and respiration rates than the control group, although these outcome measures were not statistically significant that might be due to small sample size.

4.10.2 Alertness states

Amber (i.e., inactive and withdrawn) was the major colour shown in the AOC across the four study groups after the intervention which was supposed withdrawn and disinterest to external stimuli, but their presentations were different from the description of the instrument. It was especially found in both the MSE and MT-MSE groups, showing significant change from the active to inactive states during the interventions. The results of such observations were not reflected in the behaviour of the participants, they showed no body movement but demonstrated enjoyment and maintained eye contact with the immediate environment. Since AOC was a newly developed instrument in 2009, and never used in Hong Kong setting. One of the original authors of the AOC was consulted and replied that they also noticed this phenomenon. They separated the green active state into two

categories: the active alert state (green 1), where body movement was exhibited, and the passive alert state (green 2), where no body movement was exhibited but the person was still in contact with the immediate environment (Munde et al., 2012). Hence, two new categories were added in the main study under the green active state (i.e., active alertness and passive alertness).

Munde (2011) defined the active state as the right moment at which participants focused on the environment and actively engaged in terms of concentration, responsiveness and social initiation. Those demonstrating active alertness usually present more body movements and initiative in social contacts, whereas those demonstrating passive alertness may have limited physical movements and behave as passive recipients of the external/social environment (Munde et al., 2012). People demonstrating passive alertness are more likely to be in a state of relaxation than those demonstrating active alertness (Munde & Vlaskamp, 2015). The findings of this study suggest that the upsurge of inactive state after the intervention, especially MT-MSE and MSE, gave an impression of relaxation that the participants were more likely in a state of passive alertness rather than in a state of social withdrawal. Having confirmed this, further studies with using new AOC version to explore or differentiate between active alertness and passive alertness and their relationships with the inactive state are recommended.

Both the MSE and MT-MSE participants were generally passively engaged in multisensory stimulations and showed little self-initiated responses to the stimuli. According to previous studies (Munde et al., 2009a; Vlaskamp et al., 2003), MSE promotes passivity in these participants due to their limited perceptual capacity and low information processing in response to overwhelming sensory stimulations. Excessive sensory stimulations can easily make people with SPID feel exhausted

and/or become motionless. Such brief exhaustion has been described as waves, with a period of nonalertness followed by a period of alertness and a switching between inactive to active, or vice versa, within 1 to 2 minutes (Munde et al., 2012). Therefore, attention span and social contact with the immediate environment can be maintained. In addition, switching between different levels or states of alertness is common. Due to the rapid shifting between passive alertness and active alertness, the change of alertness levels may not be immediately noticed by the onsite observer. Use of video recording is recommended to enhance inter-observer reliability (Munde et al., 2011; 2012). The delineation of the active state into the active and passive alertness enhances the precision of the AOC observation data (Munde et al., 2012).

In addition, the sleepy and discontented (or restlessness) states were markedly reduced in the four study groups following the 10-week interventions. Such phenomena indicate that the residents generally dozed off during the day or exhibited a temper and restlessness when they were not engaged. A positive and meaningful activity may affect alertness level to facilitate relationship building and engagement with the environment (Munde & Vlaskamp, 2015).

4.10.3 Frequency and severity of challenging behaviour

From the observation data, it was found that the frequency and severity of challenging behaviour steadily increased in the control group, although it was not statistically significant. This indicates that manipulating environmental activity may influence the exhibition of challenging behaviour (Ali et al., 2014). As the BPI-01 data profiles were behavioural summaries of the previous 2 weeks in the usual care environment and other outcome measures were obtained during and

immediately after the intervention sessions, the sustainable therapeutic effects of the interventions may be weakened by robotic routines and inadequate staff support and care. In addition, the responses of the direct care staff may aggravate the likelihood of challenging behaviour, especially when they consider or perceive such behaviour to be habitual or attention seeking, thus not making any intention to intervene. Such stereotypical views may promote the manifestation of challenging behaviour in the usual care environment (Lambrechts & Maes, 2009; Lambrechts et al., 2009). Therefore, adopting a new service model, i.e., the PBS model, can be considered for the implementation of more proactive strategies for relieving the vulnerabilities of SPID residents, such as by optimising the medical treatment of sensory and physical health problems, providing an enriched usual care environment and actively engaging residents in meaningful activities (Hastings et al., 2013). Interestingly, the amount and duration of adaptive behaviour in the control group were higher than in the intervention groups. Likewise, maladaptive behaviour was lower than in the intervention groups. Although the observational data were not statistically different between groups, this might have been due to the toy playing period in the control group, during which behaviour was guided in a more constructive way (Munde & Vlaskamp, 2015).

4.10.4 Relaxation state

The use of massage was supposed to enrich the relaxation of participants with vision and hearing loss through physical touch. The results could not affirm this assumption. In Evenhuis et al. (2001) and Munde et al. (2011), visual and hearing impairments were accounted for in 50% and 25% of the participants, respectively. This study had fewer subjects with visual (33%) and/or hearing

(9.5%) impairments. Such a difference might have affected the residents' overall level of appreciation for the sensory stimulations used. In addition, conducting MT in a usual care environment might have been affected by the usual care environment in which the routine and other residents' behaviour could interrupt or lower the residents' appreciation for the tactile sensation provided by MT. Generally, the therapeutic effect of MT could not be identified in individual outcome measures.

According to informal comments from the direct care staff, the small sample size did not reflect the authentic effects of individual interventions. The time of intervention given was better arranged at non-peak hours, so that it would not affect the usual care of the participants (e.g., bathing). Maximising the use of the quiet corner in the usual care environment where the intervention was carried out was suggested to decrease the disturbance to other residents. Other limitations of the study are addressed in the following paragraphs.

4.10.5 Limitations of the pilot study and implications for the main study

There were a few essential study limitations. The research was conducted in one residential care institution in which the homogeneity of the daily living pattern might have overshadowed the diversity of individual characteristics, daytime activities and the infirmary care programme. Therefore, the findings may not be representative of people with SPID in various healthcare settings.

As the mean scores of frequency and severity of challenging behaviour were generally modest (ranging from 8 to 18, with the highest scores between 156 and 208), it was difficult to set a threshold level for the inclusion criteria for subject recruitment. In addition, the sample size calculation of this study was overly

optimistic. Based on the BC findings in Shapiro et al. (1997), with a single-group crossover design, the relatively small estimated sample size in this study might not have had sufficient power to detect significant differences in the BC and AOC at post-test. Hence, the sample of future controlled trials (or the main study) should be bigger with an appropriate medium effect size (e.g., Cohen's d=0.4-0.6) to achieve a study power of 0.80 and a significance level of 0.05.

The use of toy playing might stimulate the subjects' alertness levels and unavoidably affect the outcomes of adaptive behaviour, such as subjects' concentration to the stimuli and use of eye contact. Furthermore, individuals with SPID need the presence of caregivers to bring their attention to the immediate environment or they may ignore their surrounding (Vlaskamp et al., 2003). Therefore, the use of toys with social interaction should be treated as another mode of intervention for these residents. Thus, in the main study, toy playing was not used in the control group.

To improve MT study outcomes, a quiet and less distracting environment should be provided during the intervention sessions, as a disturbing environment may devastate the appreciations of MT and consequently compromise the individuals' relaxation state.

Overall, MSE and MT-MSE positively changed the alertness level from the active to inactive state and decreased maladaptive and adaptive behaviour. However, no effect on the frequency or severity of challenging behaviour was observed in the four study groups. The possibility of the mental exhaustion due to the standard sensory inputs might weaken the responses to the external stimuli, the adjustment of MSE dosage in the main study might accelerate the pervasiveness of inactivity. Hence, the MSE protocol would remain unchanged in the main study.

In fact, the sample sizes in the four study groups were too small, further testing of the intervention effects with a larger sample in the main study was necessary.

Another limitation was the prolonged recruitment period. The addresses of the family members should be carefully verified before mailing the consent form. These suggested changes were implemented in the main study.

4.11 Conclusions

The MT and MSE interventions did not induce an adequate relaxation effect to reduce the frequency and severity of challenging behaviour after the 10-week intervention period. However, the combined effect of MT and MSE increased the inactivity and passivity of the participants, presenting a more relaxed manner than the two single interventions. A well-defined description of the active alertness and passive alertness levels of the active state in the AOC scale could deliver a clear and precise understanding of the alertness states. Measurement refinements (e.g., the AOC), a better recruitment procedure (e.g., ensuring correct mailing addresses) and a larger sample size are recommended to improve internal validity for future studies. These factors facilitated the implementation of the main study.

CHAPTER FIVE

QUANTITATIVE RESULTS OF THE MAIN STUDY

5.1 Introduction

This chapter describes the results of the participants' quantitative outcomes after the interventions. The qualitative interviews investigating the nurses' perceptions of the interventions are addressed in the next chapter. This chapter provides a description of the demographic and clinical characteristics of the sample, such as age, sex and modes of daily living activities, and the baseline data (T_0) of the outcome measures (frequency and severity of challenging behaviour, heart and respiration rates, alertness state and adaptive and maladaptive behaviour). The outcome measurements during the interventions are presented to check their progress at the midterm of the treatments (i.e., at week 5 or the 10th session of the interventions, T_1). The treatment effects are reported by comparing the outcome scores of the participants from the four study groups (i.e., MSE only, MT only, combined MT-MSE and control group) between baseline (T_0), immediately after completion of the interventions (i.e., at week 10 or the 20th session, T_2) and the carryover effect evaluated at 2 weeks after completion of the interventions (i.e., at week 12, T_3).

5.2 Results

5.2.1 Sample characteristics

Overall, 131 participants were recruited and assessed at baseline. After they were randomly assigned to one of the four study groups, two dropped out due

to severe physical illness and being unable to receive MSE intervention. The remaining 129 participants continued the study, and 126 participants completed all of the outcome assessments from T_1 to T_3. Three participants could not participate throughout the entire study period. Two discontinued the interventions after T_1, as one was transferred to another clinical unit and the other one passed away suddenly. Another participant completed the interventions and the first post-test (T_2) immediately after intervention, but then had a long period of home leave and was thus unable to complete the post-intervention assessment (T_3). Under the intention-to-treat principle, the missing data for these three participants were imputed using multiple imputation method (Montori & Guyatt, 2001). The overall attrition rate was 3.8% and the final sample (n=129) consisted of 63 males (48.8%) and 66 females (51.2%), with a mean age of 47 years (SD=10.89; ranging from 18 to 64 years of age). Though no literature has mentioned the impact of age on manifestation of challenging behaviour, considering the wide age range of participants, the age variable was put into covariate against frequency of challenging behaviour in the GEE. The results showed statistically insignificant [Wald $\chi 2(1)=0.47$, $p=0.492$], i.e., the wide age range showed no effect on frequency of challenging behaviour.

In view of the comorbidities, more than 20% had cerebral palsy and approximately 66% suffered from epilepsy. Approximately 93% were taking regular medications, 76% of whom were taking antiepileptic and psychotropic drugs. Yet, epilepsy and psychiatric illness are not identified as risk markers for challenging behaviour (McClintock et al., 2003). In the research setting, antiepileptic and psychotropic drugs were often interchangeably prescribed to the residents to control epilepsy, unstable mental conditions and challenging behaviour.

No clear drug regime for treating a particular condition was delineated, as the effects of most antiepileptic and psychotropic drugs cover tranquilising and/or sedative properties (Ali et al., 2014; Allen, 2009). Similarly, drug changes were not perceived as a confounding variable if random sampling was used for the study and if the difference in this change between groups was tracked and compared (Green et al., 1994). Therefore, these variables were assessed and eventually showed no significant differences between the study groups ($p>0.05$) by using Kruskal-Wallis test. When the data of "antiepileptic and psychotropic drugs" were put into covariate against frequency of challenging behaviour in the GEE, the results showed statistically insignificant, i.e., no effect on challenging behaviour [Wald $\chi^2(1)=1.86$, $p=0.173$. The treatment effect of primary outcome measure will be discussed in sections 5.2.4 and 5.2.5 later.

More than half (51.2%) of the participants required adaptive physical support, such as body alignment supports, safety belts and/or limb holders, in their daily care. More than 70% of them required staff assistance in continence care, feeding and physical transfer. All of them required assisted and/or trolley bathing. 77% of the participants had traceable relatives. Approximately 22% and 31% of them had hearing and visual impairments, respectively. When the data of "sensory impairment" were put into covariate against frequency of challenging behaviour in the GEE, the results also showed statistically insignificant, i.e., no effect on challenging behaviour [Wald $\chi2(1)=0.03$, $p=0.856$].

Generally, the demographic and clinical characteristics of the participants showed no statistical differences between the four study groups (using the chi-square test, $p=0.07$-0.98), and are summarised in *Table 5.1*.

Table 5.1. Participants' demographic and clinical characteristics (N=129)

Characteristics	Total (n=129)	MSE (n=31)	MT (n=32)	MT-MSE (n=32)	Control (n=34)	F value or χ^2 test	p-value
Mean age (SD)	47 (10.89)	45.29 (10.52)	48.22 (11.77)	46.22 (11.25)	48.12 (10.39)	0.55#	0.648
Number of antiepileptic and psychotropic drugs taken						24.46	0.141
Range	0-6	0-5	0-4	0-4	0-6		
Mode	2	2	0	1 & 2	0		
Median	1.5	2	1	2	1		
Sex						0.21	0.977
Male	63 (48.8%)	16 (51.6%)	16 (50%)	15 (46.9%)	16 (47.1%)		
Female	66 (51.2%)	15 (48.4%)	16 (50%)	17 (53.1%)	18 (52.9%)		
Adaptive support						3.05	0.384
Yes	66 (51.2%)	18 (58.1%)	15 (46.9%)	13 (40.6%)	20 (58.8%)		
No	63 (48.8%)	13 (41.9%)	17 (53.1%)	19 (59.4%)	14 (41.2%)		
Bathing mode						1.39	0.708
Assisted	20 (15.5%)	4 (12.9%)	7 (21.9%)	4 (12.5%)	5 (14.7%)		
Trolley	109 (84.5%)	27 (87.1%)	25 (78.1%)	28 (87.5%)	29 (85.3%)		
Cerebral palsy						3.19	0.364
Yes	30 (23.3%)	7 (22.6%)	6 (18.8%)	11 (34.4%)	6 (17.6%)		
No	99 (76.7%)	24 (77.4%)	26 (81.3%)	21 (65.6%)	28 (82.4%)		
Continence level						3.62	0.306
Yes	33 (25.6%)	8 (25.8%)	12 (37.5%)	6 (18.8%)	7 (20.6%)		
No	96 (74.4%)	23 (74.2%)	20 (62.5%)	26 (81.3%)	27 (79.4%)		
Epilepsy						2.49	0.476
Yes	85 (65.9%)	23 (74.2%)	19 (59.4%)	19 (59.4%)	24 (70.6%)		
No	44 (34.1%)	8 (25.8%)	13 (40.6%)	13 (40.6%)	10 (29.4%)		
Feeding mode						4.60	0.868
Independent	38 (29.5%)	7 (22.6%)	13 (40.6%)	8 (25%)	10 (29.4%)		
Assisted	24 (18.6%)	7 (22.6%)	5 (15.6%)	6 (18.8%)	6 (17.6%)		
Dependent	55 (42.6%)	14 (45.2%)	10 (31.3%)	15 (46.9%)	16 (47.1%)		
Enteral	12 (9.3%)	3 (9.7%)	4 (12.5%)	3 (9.4%)	2 (5.9%)		
Hearing loss						2.09	0.554
Yes	29 (22.5%)	6 (19.4%)	8 (25%)	5 (15.6%)	10 (29.4%)		
No	100 (77.5%)	25 (80.6%)	24 (75%)	27 (84.4%)	24 (70.6%)		
Medication						6.49	0.090
Yes	120 (93%)	30 (96.8%)	29 (90.6%)	32 (100%)	29 (85.3%)		
No	9 (7.0%)	1 (3.2%)	3 (9.4%)	0	5 (14.7%)		

Characteristics	Total (n=129)	MSE (n=31)	MT (n=32)	MT-MSE (n=32)	Control (n=34)	F value or χ^2 test	p-value
Antiepileptic and psychotropic drugs						7.15	0.067
Yes	98 (76%)	28 (90.3%)	21 (65.6%)	26 (81.3%)	23 (67.6%)		
No	31 (24%)	3 (9.7%)	11 (34.4%)	6 (18.8%)	11 (32.4%)		
Drug change						2.32	0.509
Yes	17 (13.2%)	2 (6.5%)	6 (18.8%)	5 (15.6%)	4 (11.8%)		
No	112 (86.8%)	29 (93.5%)	26 (81.3%)	27 (84.4%)	30 (88.2%)		
Mobility level						1.73	0.943
Ambulant	32 (24.8%)	7 (22.6%)	10 (31.3%)	6 (18.8%)	9 (26.5%)		
Chair-bound	71 (55%)	17 (54.8%)	17 (53.1%)	19 (59.4%)	18 (52.9%)		
Bedridden	26 (20.2%)	7 (22.6%)	5 (15.6%)	7 (21.9%)	7 (20.6%)		
Traceable relative						4.31	0.230
Yes	100 (77.5%)	27 (87.1%)	21 (65.6%)	25 (78.1%)	27 (79.4%)		
No	29 (22.5%)	4 (12.9%)	11 (34.4%)	7 (21.9%)	7 (20.6%)		
Visual impairment						2.92	0.404
Yes	40 (31%)	12 (38.7%)	8 (25%)	12 (37.5%)	8 (23.5%)		
No	89 (69%)	19 (61.3%)	24 (75%)	20 (62.5%)	26 (76.5%)		

[#] ***F value***

MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment; SD=Standard Deviation

5.2.2 Outcome scores at baseline

The results of the baseline outcome assessment are summarised in *Table 5.2*. As shown in *Table 5.2*, there were no significant differences in any of the outcome scores at baseline between the four study groups (p=0.108-0.973). The mean scores of the subscales (SIB, SSB and aggressive behaviour) of challenging behaviour (primary outcomes) also showed non-significant differences and ranged between 0.26 and 7.39, with standard errors from 0.33 to 1.12 and p-values between 0.512 and 0.888. There was a wide range of SSB exhibited among the participants, whereas aggressive behaviour was displayed the least often, perhaps due to the frequent use of physical restraints or relevant devices and the prevalence of physical

disability (more than 75% were chair-bound and bedridden) in the units under study.

Regarding the secondary outcomes, there were no significant differences in the physiological signs of heart and respiration rates of the four groups. Their average values were approximately 81-84 bpm (p=0.973) and 17-20 Bpm (p=0.108). From the mean values of maladaptive (M=2.20-4.99) and adaptive (M=0.06-0.88) behaviour, the participants appeared to be more often engaged in maladaptive behaviour at the baseline measurement.

According to the percentages of the different types of alertness, inactive and withdrawn (ranged from 48.45% to 66.47%) and sleepy (ranged from 20.82% to 43.01%) behaviour were the most common in the study groups (p=0.207-0.375). Indeed, none of the participants showed discontented or restless behaviour.

Table 5.2. Baseline assessment of different outcome measures (N=129)

Variables	**MSE (n=31)**	**MT (n=32)**	**MT-MSE (n=32)**	**Control (n=34)**	**Kruskal-Wallis H test (df=3)**	**p-value**
	Mean (SE)	**Mean (SE)**	**Mean (SE)**	**Mean (SE)**		
Primary Outcomes	*Behaviour Problems Inventory (BPI-01)*					
CB_frequency scale	9.91 (1.79)	11.48 (1.76)	9.08 (1.74)	6.88 (1.73)	1.77	0.622
CB_severity scale	5.13 (1.30)	5.74 (1.29)	4.81 (1.28)	3.67 (1.27)	1.57	0.666
SIB_frequency scale	3.22 (0.55)	2.70 (0.54)	3.22 (0.53)	2.38 (0.52)	0.92	0.821
SIB_severity scale	1.82 (0.35)	1.53 (0.34)	1.87 (0.34)	1.42 (0.33)	0.64	0.888
SSB_frequency scale	6.15 (1.12)	7.39 (1.10)	4.61 (1.09)	4.26 (1.07)	1.48	0.686
SSB_severity scale	2.99 (0.70)	3.41 (0.69)	2.21 (0.68)	2.04 (0.68)	2.31	0.512
Aggression_frequency scale	0.62 (0.47)	1.35 (0.46)	1.22 (0.46)	0.37 (0.45)	1.13	0.769
Aggression_severity scale	0.40 (0.37)	0.76 (0.36)	0.73 (0.36)	0.26 (0.35)	0.92	0.821
Secondary Outcomes						
Heart/minute	83.59 (2.62)	83.46 (2.58)	83.90 (2.57)	80.80 (2.50)	0.23	0.973

Variables	MSE (n=31)	MT (n=32)	MT-MSE (n=32)	Control (n=34)	Kruskal-Wallis H test (df=3)	p-value
	Mean (SE)	Mean (SE)	Mean (SE)	Mean (SE)		
Respiration/minute	17.44 (0.54)	19.58 (0.53)	18.18 (0.53)	18.03 (0.51)	6.07	0.108
Behaviour Checklist (BC)						
Amount of MB/minute	4.39 (1.18)	4.77 (1.16)	2.20 (1.17)	4.99 (1.13)	2.84	0.416
Amount of AB/minute	0.06 (1.05)	0.88 (1.04)	0.69 (1.04)	0.24 (1.01)	2.10	0.553
Duration of MB (minutes)	3.27 (0.89)	4.07 (0.88)	2.21 (0.88)	4.42 (0.85)	2.67	0.446
Duration of AB (minutes)	0.07 (0.71)	0.85 (0.70)	0.66 (0.70)	0.22 (0.68)	2.10	0.553
Alertness Observation Checklist (AOC)@						
Green 1: active alert **@**	5.41% (0.05)	4.65% (0.05)	3.71% (0.04)	5.02% (0.05)	1.10	0.799
Green 2: passive alert **@**	1.90% (0.02)	8.05% (0.08)	4.84% (0.05)	3.72% (0.04)	0.99	0.803
Amber: inactive **@**	54.39% (0.54)	66.47% (0.67)	48.45%(0.48)	60.49% (0.60)	3.11	0.375
Red: sleepy **@**	38.30% (0.38)	20.82% (0.21)	43.01% (0.43)	30.77% (0.31)	4.55	0.207
Blue: discontented	0	0	0	0	0	1.000

@ Percentage of occurrence of individual alertness states (percentage converted into decimal numbers)

AB=Adaptive Behaviour, CB=Challenging Behaviour, MB=Maladaptive Behaviour, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, SE=Standard Error, SIB=Self-injurious Behaviour, SSB=Self-stimulating Stereotypic Behaviour

5.2.3 Interim progress of the outcome measures

As the intervention spanned over 10 weeks, the progress of the participants was checked with outcome measures at the end of week 5. The mean scores and standard errors of the outcome measures at the baseline and interim assessments are shown in *Table 5.3*. The results of the primary outcomes (frequency and severity of challenging behaviour) showed no significant improvement in the four groups, thus indicating no significant differences between them.

Regarding the secondary outcomes, significant interaction effects between respiration rate [Wald $\chi^2(3)=10.18$, $p=0.017$] and passive alertness of the AOC [Wald $\chi^2(3)=9.23$, $p=0.026$] were noted between the groups. Group effects were

also identified on both the respiration rate and passive alert of the AOC [Wald $\chi^2(3)=8.08$, $p=0.044$ and Wald $\chi^2(3)=13.10$ $p=0.004$ respectively]. The mean values of respiration rate ranged from 17-20 Bpm, passive alertness ranged from 30.72% to 58.54% at the interim assessment. The MT-MSE participants showed the lowest respiration rates and highest passive alert state levels than the other study groups. Statistically, the MT-MSE group had significantly lower respiration rates than the control group (mean difference=2.68, p=0.001). The MT-MSE group had significantly higher passive alertness levels than the MSE (mean difference=10.96, p=0.001) and control groups (mean difference=13.38, p=0.0001). The contrast tests of respiration rate and the passive alert of the AOC between the groups are presented in *Table 5.4*.

According to the percentage changes in the AOC of the four study groups, the dominant alertness states of the baseline assessment were the inactive (ranging from 48.45% to 66.47%) and sleepy states (ranging from 20.82% to 43.01%). At the interim assessment, the main alertness state changed to the passive alert state (ranging from 30.72% to 58.54%) in the four study groups, indicating that most of the participants paid more attention to their immediate environments and felt relaxed.

Time effects of the within-group comparisons were detected in many secondary outcomes, i.e., heart rate [Wald $\chi^2(1)=4.10$, $p=0.043$], amount and duration of adaptive behaviour [Wald $\chi^2(1)=15.84$, $p=0.0001$ and Wald $\chi^2(1)=17.47$, $p=0.0001$, respectively] and the four alertness levels including active alert [Wald $\chi^2(1)=18.65$, $p=0.0001$], passive alert [Wald $\chi^2(1)=102.47$, $p=0.0001$], inactive state [Wald $\chi^2(1)=52.11$, $p=0.0001$] and sleepy state [Wald $\chi2(1)=36.43$, $p=0.0001$]. The within-group comparisons of the mean scores between the baseline and

midterm assessments of the outcome measures are shown in *Table 5.5*. Primary outcomes and the amount and duration of maladaptive behaviour showed no effects at all between and within the groups.

The frequency and severity of challenging behaviour showed insignificant results, though there is insidious decreasing progress within each study group between the baseline and midterm assessments. Time effect was found in heart rate but unable to identify which group had significant change, probably the effect was very small (p=0.043). Significant differences in the amount and duration of adaptive behaviour were found in all of the study groups (p=0.011-0.0001 and p=0.002 - 0.00, respectively). Likewise, significant changes were also noted in the alertness levels in all of the study groups, including the active alert state (p=0.001-0.008), passive alert state (all p=0.0001), inactive state (p=0.0001-0.006), and sleepy state for those in the MSE, MT-MSE and control groups (p=0.024-0.0001), whereas the within group effect of MT was not statistically significant. It is important to note that no discontented or restless behaviour was observed in the four groups during the interim or other study periods. Hence, the blue discontented state was not assessed or presented in the final outcome analysis (for T_2 and T_3).

Table 5.3. Mean scores and standard errors of the outcome measures between baseline and midterm measurements (N=129)

	MSE (n=31)		MT (n=32)		MT-MSE (n=32)		Control (n=34)		GEE (Time)		GEE (Group)		GEE (Time*Group)	
	T_0 Mean (SE)	T_1 Mean (SE)	T_0 Mean (SE)	T_1 Mean (SE)	T_0 Mean (SE)	T_1 Mean (SE)	T_0 Mean (SE)	T_1 Mean (SE)	Wald χ^2 (df=1)	p-value	Wald χ^2 (df=3)	p-value	Wald χ^2 (df=3)	p-value
Primary Outcomes														
Frequency of CB	9.91 (1.79)	7.74 (1.90)	11.48 (1.76)	7.83 (1.87)	9.08 (1.74)	6.99 (1.84)	6.88 (1.73)	6.73 (1.83)	0.96	0.328	5.42	0.144	1.81	0.612
Severity of CB	5.13 (1.30)	4.16 (1.32)	5.74 (1.29)	4.84 (1.31)	4.81 (1.28)	4.44 (1.30)	3.67 (1.27)	3.56 (1.29)	0.14	0.707	4.87	0.182	0.47	0.926
Secondary Outcomes														
Heart rate	83.59 (2.62)	79.22 (2.55)	83.46 (2.58)	79.15 (2.51)	83.90 (2.57)	78.04 (2.50)	80.80 (2.50)	80.76 (2.43)	4.10	0.043*	0.08	0.995	1.54	0.674
Respiration rate	17.44 (0.54)	18.32 (0.60)	19.58 (0.53)	18.20 (0.59)	18.18 (0.53)	17.08 (0.59)	18.03 (0.51)	19.76 (0.58)	0.005	0.943	8.08	0.044*	10.18	0.017*
Behaviour Checklist (BC)														
Amount of maladaptive behaviour	4.39 (1.18)	4.91 (1.23)	4.77 (1.16)	5.79 (1.21)	2.20 (1.17)	3.15 (1.22)	4.99 (1.13)	5.02 (1.18)	0.64	0.425	5.34	0.149	0.22	0.975
Amount of adaptive behaviour	0.06 (1.05)	3.64 (1.05)	0.88 (1.04)	5.26 (1.03)	0.69 (1.04)	4.21 (1.02)	0.24 (1.01)	2.81 (1.00)	15.84	0.000 ***	3.14	0.371	0.86	0.835
Duration maladaptive behaviour	3.27 (0.89)	3.55 (0.92)	4.07 (0.88)	4.88 (0.91)	2.21 (0.88)	2.85 (0.92)	4.42 (0.85)	4.76 (0.88)	0.81	0.367	6.55	0.088	0.11	0.991
Duration adaptive behaviour	0.07 (0.71)	2.57 (0.64)	0.85 (0.70)	3.37 (0.62)	0.66 (0.70)	2.88 (0.62)	0.22 (0.68)	2.05 (0.60)	17.47	0.000 ***	3.56	0.313	0.32	0.956
Alertness Observation Checklist (AOC)														
Green 1: active alert @	5.41% (0.05)	29.60% (0.30)	4.65% (0.05)	22.38% (0.22)	3.71% (0.04)	25.26% (0.25)	5.02% (0.05)	24.28% (0.24)	18.65	0.000 ***	0.97	0.810	0.55	0.908
	2.45 (2.65)	13.36 (2.41)	2.10 (2.61)	10.06 (2.36)	1.67 (2.60)	11.58 (2.34)	2.24 (2.53)	10.63 (2.30)						
Green 2: passive alert @	1.90% (0.02)	35.17% (0.35)	8.05% (0.08)	46.51% (0.47)	4.84% (0.05)	58.54% (0.59)	3.72% (0.04)	30.72% (0.31)	102.47	0.000 ***	13.10	0.004**	9.23	0.026*
	0.86	15.87	3.64	20.91	2.18	26.84	1.66	13.45						

	MSE (n=31)		MT (n=32)		MT-MSE (n=32)		Control (n=34)		GEE (Time)		GEE (Group)		GEE (Time*Group)	
	T_0 Mean (SE)	**T_1 Mean (SE)**	**T_0 Mean (SE)**	**T_1 Mean (SE)**	**T_0 Mean (SE)**	**T_1 Mean (SE)**	**T_0 Mean (SE)**	**T_1 Mean (SE)**	**Wald χ^2 (df=1)**	**p-value**	**Wald χ^2 (df=3)**	**p-value**	**Wald χ^2 (df=3)**	**p-value**
	(2.58)	(2.31)	(2.53)	(2.27)	(2.52)	(2.26)	(2.45)	(2.20)						
Amber: inactive state @	54.39% (0.54)	28.32% (0.28)	66.47% (0.66)	21.84% (0.22)	48.45% (0.48)	10.14% (0.10)	60.49% (0.61)	32.75% (0.33)	52.11	0.000 ***	7.64	0.054	2.46	0.482
	24.61 (2.97)	12.78 (3.07)	30.04 (2.93)	9.82 (3.03)	21.82 (2.94)	4.65 (3.02)	27.01 (2.84)	14.34 (2.94)						
Red: sleepy state @	38.30% (0.38)	6.91% (0.07)	20.82% (0.21)	9.27% (0.09)	43.01% (0.43)	6.06% (0.06)	30.77% (0.31)	12.24% (0.12)	36.43	0.000 ***	2.69	0.442	5.20	0.158
	17.33 (2.63)	3.12 (2.77)	9.41 (2.58)	4.17 (2.74)	19.37 (2.58)	2.78 (2.74)	13.74 (2.51)	5.36 (2.65)						

***p<0.05, **<0.01, ***<0.001 @ Percentage of occurrence of alertness state (conversion of percentage into decimals)**

CB=Challenging Behaviour, GEE=Generalised Estimating Equations, MD=Mean Difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level, SE=Standard Error

Table 5.4. Contrast tests of mean scores on significant outcome measures (respiration rate and passive alertness state) at the interim measurement

Interim Progress	Respiration Rate		Passive Alertness State (Green 2)	
T_1	MD	p	MD	p
MSE vs. CTL	1.44	0.076	2.42	0.437
MT vs. CTL	1.56	0.054	7.46	0.016*
MT-MSE vs. CTL	2.68	0.001**	13.38	0.000***
MSE vs. MT	0.12	0.889	5.04	0.115
MSE vs. MT-MSE	1.23	0.135	10.96	0.001**
MT vs. MT-MSE	1.12	0.169	5.93	0.057

***p<0.05, **<0.01, ***<0.001**

CB=Challenging Behaviour, MD=Mean difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level

Table 5.5. Comparison of mean scores on significant outcome measures within groups between the baseline and interim assessments (N=129)

	MSE (n=31)		MT (n=32)		MT-MSE (n=32)		Control (n=34)		GEE (Time)	
T_0 to T_1	**MD**	**p**	**MD**	**p**	**MD**	**p**	**MD**	**p**	**Wald χ^2 (df=1)**	**p**
Heart rate	4.37	0.230	4.31	0.224	5.86	0.099	0.004	0.976	4.10	0.043*
Amount of adaptive behaviour	3.58	0.022*	4.38	0.002**	3.52	0.014*	2.57	0.056	15.84	0.000***
Duration of adaptive behaviour	2.50	0.009**	2.52	0.004**	2.22	0.010*	1.83	0.023*	17.47	0.000***
Green 1: active alert	10.91	0.001**	7.96	0.003**	9.91	0.001**	8.39	0.008**	18.65	0.000***
Green 2: passive alert	15.01	0.000***	17.27	0.000***	24.66	0.000***	11.79	0.000***	102.47	0.000***
Amber: inactive	11.83	0.006**	20.22	0.000***	17.17	0.000***	8.38	0.000***	52.11	0.000***
Red: sleepy	14.21	0.000***	5.24	0.108	16.59	0.000***	8.38	0.024*	36.43	0.000***

p<0.05, **<0.01, ***<0.001; #*interaction effect existed

CB=Challenging Behaviour, GEE=Generalised Estimating Equations, MD=Mean Difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level

5.2.4 Overall treatment effects

The mean scores and standard errors of the outcome measures at baseline (T_0), immediately after intervention completion (T_2) and up to 2 weeks post-intervention (T_3) are shown in *Table 5.6*. The overall interaction effects (group×time) were found in respiration rate [Wald $\chi^2(6)=25.97$, $p=0.0001$], amount of adaptive behaviour and duration of adaptive behaviour [Wald $\chi^2(6)=13.75$, $p=0.033$; and Wald $\chi^2(6)=14.64$, $p=0.023$ respectively], and passive alert of AOC [Wald $\chi^2(6)=12.59$, $p=0.050$]. Of the four outcome measures, only respiration rate and amount and duration of adaptive behaviour revealed interaction effects with statistically significant differences in terms of group and time effects.

Significant group effects were found for respiration rate [Wald $\chi^2(3)=43.68$, $p=0.0001$], amount and duration of adaptive behaviour [Wald $\chi^2(3)=15.98$, $p=0.001$; and Wald $\chi^2(3)=13.82$, $p=0.003$ respectively]. Other group effects were found in frequency and severity of challenging behaviour [Wald $\chi^2(3)=9.39$, $p=0.025$; and Wald $\chi^2(3)=8.09$, $p=0.044$ respectively], and sleepy state of the AOC [Wald $\chi^2(3)=10.17$, $p=0.017$].

The time effect was prevalent for secondary outcome measures ($p<0.0001$), except for primary outcome measures (frequency and severity of challenging behaviour), heart rate and amount and duration of maladaptive behaviour ($p=0.350$-0.926).

Table 5.6. Mean and standard error of primary and secondary outcome measures from baseline to carryover (N=129)

	MSE (n=31)			MT (n=32)			MT-MSE (n=32)			Control (n=34)			GEE (Time)		GEE (Group)		GEE (Time*Group)	
	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	Wald χ^2 (df=2)	p value	Wald χ^2 (df=3)	p value	Wald χ^2 (df=6)	p value
Primary Outcomes																		
Frequency of CB	9.91 (1.79)	7.52 (1.79)	7.38 (1.79)	11.48 (1.76)	7.91 (1.76)	7.34 (1.76)	9.08 (1.74)	6.19 (1.74)	6.58 (1.74)	6.88 (1.73)	6.78 (1.73)	5.12 (1.73)	2.10	0.350	9.39	0.025 *	2.94	0.817
Severity of CB	5.13 (1.30)	4.07 (1.30)	4.04 (1.30)	5.74 (1.29)	4.74 (1.29)	4.27 (1.29)	4.81 (1.28)	3.54 (1.28)	3.81 (1.28)	3.67 (1.27)	3.88 (1.27)	2.85 (1.27)	0.48	0.786	8.09	0.044 *	1.95	0.924
Secondary Outcomes																		
Heart rate	83.59 (2.62)	78.98 (2.62)	78.47 (2.62)	83.46 (2.58)	80.58 (2.58)	79.93 (2.58)	83.90 (2.57)	79.79 (2.57)	80.46 (2.57)	80.80 (2.50)	83.72 (2.50)	84.25 (2.50)	1.72	0.423	1.64	0.650	4.40	0.622
Respiration rate	17.44 (0.54)	16.11 (0.54)	15.77 (0.54)	19.58 (0.53)	17.16 (0.53)	16.52 (0.53)	18.18 (0.53)	15.74 (0.53)	15.93 (0.53)	18.03 (0.51)	19.33 (0.51)	19.29 (0.51)	16.19	0.000 ***	43.68	0.000 ***	25.97	0.000 ***
Behaviour Checklist (BC)																		
Amount of maladaptive behaviour	4.39 (1.18)	3.66 (1.18)	4.06 (1.18)	4.77 (1.16)	2.18 (1.16)	5.57 (1.16)	2.20 (1.17)	5.07 (1.17)	4.44 (1.17)	4.99 (1.13)	4.96 (1.13)	3.00 (1.13)	0.15	0.926	0.20	0.977	9.56	0.144
Amount of adaptive behaviour	0.06 (1.05)	6.80 (1.05)	0.93 (1.05)	0.88 (1.04)	8.21 (1.04)	6.62 (1.04)	0.69 (1.04)	4.06 (1.04)	1.23 (1.04)	0.24 (1.01)	5.05 (1.01)	4.59 (1.01)	63.23	0.000 ***	15.98	0.001 **	13.75	0.033 *
Duration of maladaptive behaviour	3.27 (0.89)	2.93 (0.89)	3.54 (0.89)	4.07 (0.88)	2.22 (0.88)	4.82 (0.88)	2.21 (0.88)	4.09 (0.88)	4.37 (0.88)	4.42 (0.85)	3.79 (0.85)	2.81 (0.85)	1.21	0.546	0.49	0.921	8.89	0.180
Duration of adaptive behaviour	0.07 (0.71)	5.29 (0.71)	0.84 (0.71)	0.85 (0.70)	5.43 (0.70)	4.78 (0.70)	0.66 (0.70)	3.32 (0.70)	1.21 (0.70)	0.22 (0.68)	4.68 (0.68)	3.70 (0.68)	78.50	0.000 ***	13.82	0.003 **	14.64	0.023 *

	MSE (n=31)			MT (n=32)			MT-MSE (n=32)			Control (n=34)			GEE (Time)		GEE (Group)		GEE (Time*Group)	
	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	T_0 Mean (SE)	T_2 Mean (SE)	T_3 Mean (SE)	Wald χ^2 (df=2)	p value	Wald χ^2 (df=3)	p value	Wald χ^2 (df=6)	p value
Alertness Observation Checklist (AOC)																		
Green 1: active alert @	5.41% (0.05)	36.29% (0.36)	21.85% (0.22)	4.65% (0.05)	39.66% (0.40)	31.49% (0.31)	3.71% (0.04)	29.68% (0.30)	23.53% (0.24)	5.02% (0.05)	32.73% (0.33)	24.90% (0.25)	51.81	0.000 ***	1.76	0.623	1.40	0.966
	2.45 (2.65)	16.27 (2.65)	9.76 (2.65)	2.10 (2.61)	17.50 (2.61)	14.20 (2.61)	1.67 (2.60)	13.37 (2.60)	10.66 (2.60)	2.24 (2.53)	14.85 (2.53)	11.19 (2.53)						
Green 2: passive alert @	1.90% (0.02)	42.63% (0.43)	25.23% (0.25)	8.05% (0.08)	43.73% (0.44)	36.30% (0.36)	4.84% (0.05)	58.15% (0.58)	20.22% (0.21)	3.72% (0.04)	39.70% (0.40)	36.69% (0.37)	95.87	0.000 ***	1.90	0.594	12.59	0.050 *
	0.86 (2.58)	19.11 (2.58)	11.27 (2.58)	3.64 (2.53)	19.30 (2.53)	16.37 (2.53)	2.18 (2.52)	26.19 (2.52)	9.16 (2.52)	1.66 (2.45)	18.01 (2.45)	16.49 (2.45)						
Amber: inactive @	54.39% (0.54)	15.64% (0.16)	26.51% (0.27)	66.47% (0.66)	12.67% (0.13)	26.16% (0.26)	48.45% (0.48)	5.99% (0.06)	37.46% (0.37)	60.49% (0.61)	19.95% (0.20)	25.14% (0.25)	101.94	0.000 ***	1.00	0.802	8.07	0.233
	24.61 (2.97)	7.01 (2.97)	11.84 (2.97)	30.04 (2.93)	5.59 (2.93)	11.80 (2.93)	21.82 (2.94)	2.70 (2.94)	16.97 (2.94)	27.01 (2.84)	9.05 (2.84)	11.30 (2.84)						
Red: sleepy @	38.30% (0.38)	5.44% (0.05)	26.42% (0.26)	20.82% (0.21)	3.94% (0.04)	6.05% (0.06)	43.01% (0.43)	6.17% (0.06)	18.79% (0.19)	30.77% (0.31)	7.63% (0.08)	13.26% (0.13)	44.91	0.000 ***	10.17	0.017 *	5.43	0.490
	17.33 (2.63)	2.44 (2.63)	11.80 (2.63)	9.41 (2.58)	1.74 (2.58)	2.73 (2.58)	19.37 (2.58)	2.78 (2.58)	8.51 (2.58)	13.74 (2.51)	3.46 (2.51)	5.96 (2.51)						

***p<0.05, **<0.01, ***<0.001 @ Percentage of occurrence of alertness state (percentage converted decimal numbers)**

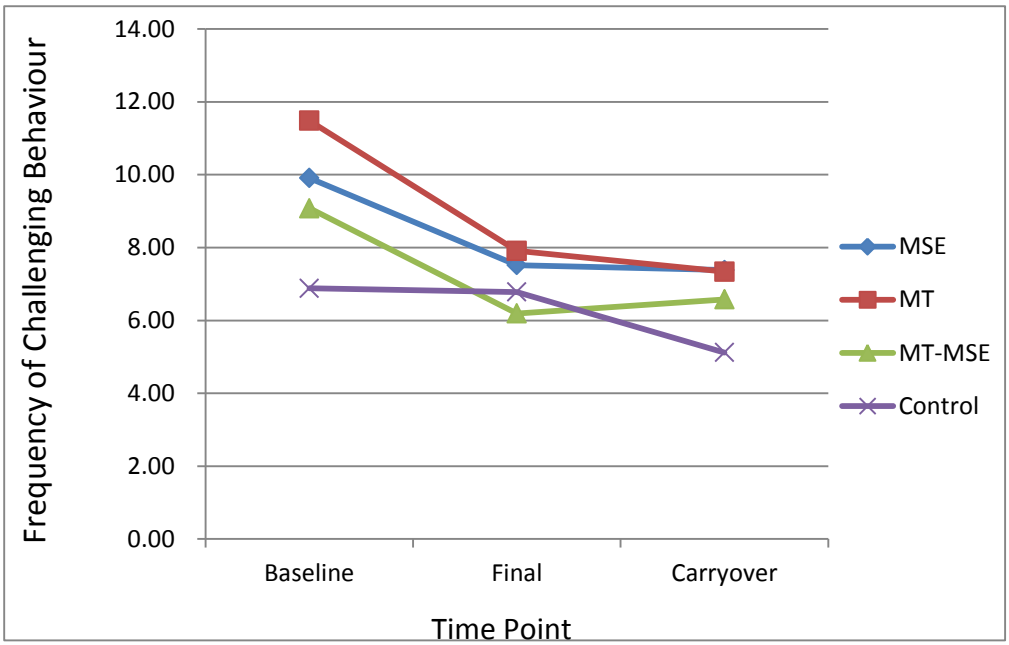
CB=Challenging Behaviour, GEE=Generalised Estimating Equations, MD=Mean difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, SE=Standard Error, p=significance level

5.2.5 Between-group effects

The contrast tests performed on the significant outcome measures using their mean differences and significance levels are presented in *Table 5.7a and 5.7b*. The pairwise between-group comparisons of the frequency and severity of challenging behaviour showed that no individual pair-test was significantly different between groups. The maximum mean difference was found between MSE and control group; and MT and control group at T_3 (2 weeks post-intervention) with resulting 2.25 (p=0.173, effect size=0.23, observed power=14.8%) and 2.22 (p=0.182, effect size=0.22, observed power=14.7%) respectively. All study groups decreased frequency and severity of challenging behaviour at two post-intervention measures.

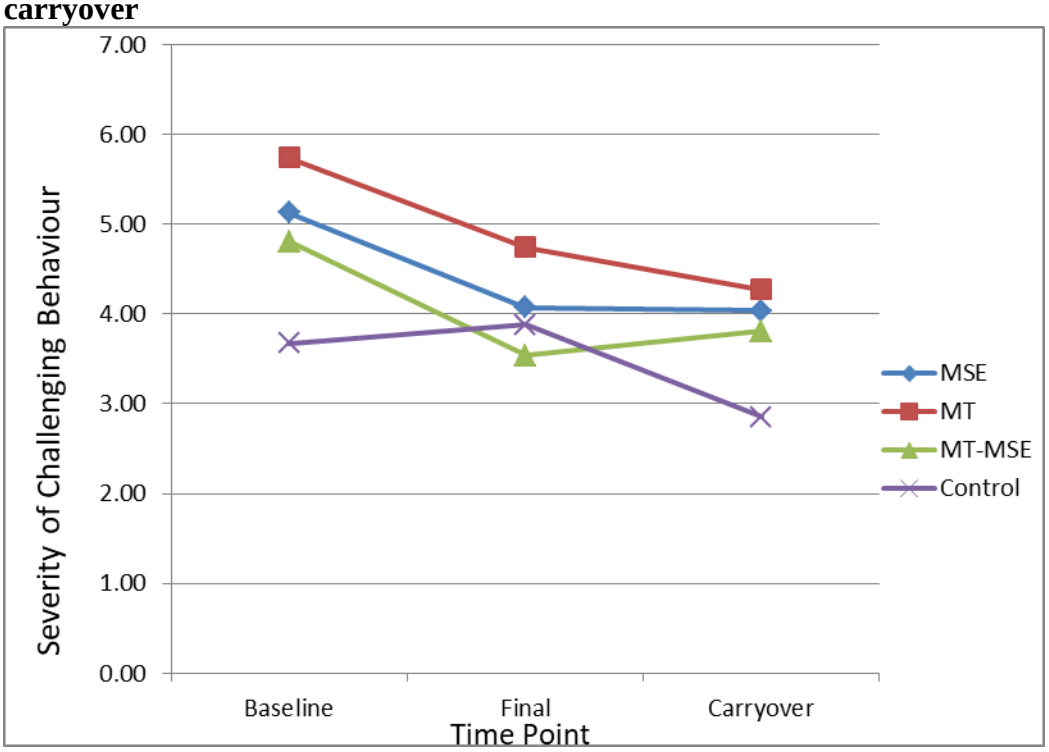
Though control group had lowest frequency and severity of challenging behaviour, the magnitude of change within group was the modest than other three intervention groups (the mean difference between baseline and 2-week post-intervention was 1.76 and 0.82 respectively). The highest frequency and severity of challenging behaviour were MT and MSE, but the magnitude of change within group was greatest in MT (the mean difference between baseline and 2-week post-intervention was 4.14 and 1.47 respectively), then MSE and MT-MSE (where the mean difference between baseline and 2-week post-intervention was 2.53 and 1.09 for MSE; and 2.50 and 1.00 for MT-MSE). The reasons of these results will be discussed in section 7.2. The decreasing trend of the challenging behaviour (especially for intervention groups) implied that the transition of treatment effect from intervention location to usual care environment. The changes of frequency and severity of challenging behaviour from baseline to carryover (T_3) in the four study groups are depicted in *Figure 5.1 and Figure 5.2*.

Figure 5.1. Change in the frequency of challenging behaviour from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

Figure 5.2. Change in the severity of challenging behaviour from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

Table 5.7a. Contrast tests of significant outcome measures on mean differences and significance levels from immediately after treatment (T_2) to carryover (T_3)

Overall Treatment Effect	Frequency of challenging behaviour				Severity of challenging behaviour				Respiration Rate				Amount of Adaptive Behaviour			
	MD	**p**	**ES**	**%**	**MD**	**p**	**ES**	**%**	**MD**	**p**	**ES**	**%**	**MD**	**p**	**ES**	**%**
MSE vs. CTL (T_2)	0.74	0.653	0.07	6.0	0.20	0.833	0.03	5.1	3.22	0.000 ***	1.08	99.1	1.75	0.240	0.30	22.5
MSE vs. CTL (T_3)	2.25	0.173	0.23	14.8	1.20	0.198	0.16	10.0	3.51	0.000 ***	1.18	99.7	3.66	0.014 *	0.62	70.9
MT vs. CTL (T_2)	1.13	0.495	0.11	7.4	0.86	0.361	0.12	7.6	2.18	0.003 **	0.73	83.9	3.16	0.032 *	0.54	58.7
MT vs. CTL (T_3)	2.22	0.182	0.22	14.7	1.42	0.130	0.19	12.3	2.76	0.000 ***	0.93	96.5	2.04	0.166	0.34	28.8
MT-MSE vs. CTL (T_2)	0.59	0.722	0.06	5.7	0.34	0.721	0.05	5.4	3.59	0.000 ***	1.20	99.8	0.99	0.498	0.17	10.5
MT-MSE vs. CTL (T_3)	1.45	0.383	0.15	9.1	0.96	0.306	0.13	8.3	3.35	0.000 ***	1.13	99.5	3.36	0.022 *	0.57	64.0
MSE vs. MT (T_2)	0.39	0.825	0.04	5.3	0.66	0.510	0.09	6.5	1.04	0.162	0.35	28.4	1.41	0.345	0.24	15.9
MSE vs. MT (T_3)	0.04	0.984	0.004	5.0	0.22	0.825	0.03	5.2	0.75	0.313	0.25	16.8	5.70	0.000 ***	0.97	97.1
MSE vs. MT-MSE (T_2)	1.33	0.434	0.13	8.3	0.53	0.581	0.07	6.0	0.37	0.616	0.12	7.8	2.74	0.068	0.47	45.8
MSE vs. MT-MSE (T_3)	0.80	0.639	0.08	6.2	0.23	0.808	0.03	5.2	0.16	0.825	0.05	5.5	0.30	0.842	0.05	5.5
MT vs. MT-MSE (T_2)	1.73	0.286	0.17	10.7	1.19	0.190	0.17	10.1	1.42	0.054	0.47	47.3	4.15	0.006 **	0.71	80.6
MT vs. MT-MSE (T_3)	0.76	0.637	0.08	6.1	0.46	0.616	0.06	5.7	0.59	0.423	0.20	12.3	5.40	0.000 ***	0.92	95.6

***p<0.05, **<0.01, ***<0.001**

CB=Challenging Behaviour, ES=Effect Size, %=Power, MD=Mean difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level

Table 5.7b. Contrast tests of significant outcome measures on mean differences and significance levels from immediately after treatment (T_2) to carryover (T_3)

Overall Treatment Effect	Amount of Adaptive Behaviour				Duration of Adaptive Behaviour				Green 2: Passive Alert				Sleepy State (Red)			
	MD	**p**	**ES**	**%**	**MD**	**p**	**ES**	**%**	**MD**	**p**	**ES**	**%**	**MD**	**p**	**ES**	**%**
MSE vs. CTL (T_2)	1.75	0.240	0.30	22.5	0.61	0.537	0.15	9.5	1.10	0.749	0.08	6.1	1.02	0.777	0.07	5.9
MSE vs. CTL (T_3)	3.66	0.014 *	0.62	70.9	2.86	0.004 **	0.72	82.9	5.23	0.130	0.36	31.1	5.84	0.105	0.40	36.2
MT vs. CTL (T_2)	3.16	0.032 *	0.54	58.7	0.75	0.442	0.19	12.0	1.29	0.706	0.09	6.6	1.72	0.629	0.12	7.7
MT vs. CTL (T_3)	2.04	0.166	0.34	28.8	1.09	0.269	0.27	19.8	0.12	0.971	0.01	5.0	3.23	0.366	0.22	14.6
MT-MSE vs. CTL (T_2)	0.99	0.498	0.17	10.5	1.36	0.165	0.34	28.6	8.18	0.017 *	0.57	64.3	0.68	0.848	0.05	5.4
MT-MSE vs. CTL (T_3)	3.36	0.022 *	0.57	64.0	2.48	0.011 *	0.63	72.2	7.33	0.033 *	0.51	55.0	2.54	0.477	0.17	10.9
MSE vs. MT (T_2)	1.41	0.345	0.24	15.9	0.14	0.887	0.04	5.2	0.19	0.957	0.01	5.0	0.71	0.847	0.05	5.4
MSE vs. MT (T_3)	5.70	0.000 ***	0.97	97.1	3.95	0.000 ***	1.00	97.7	5.10	0.150	0.36	29.2	9.06	0.013 *	0.62	69.2
MSE vs. MT-MSE (T_2)	2.74	0.068	0.47	45.8	1.97	0.049 *	0.50	50.7	7.08	0.044 *	0.49	50.1	0.33	0.927	0.02	5.1
MSE vs. MT-MSE (T_3)	0.30	0.842	0.05	5.5	0.38	0.708	0.09	6.6	2.11	0.549	0.15	9.0	3.29	0.368	0.23	14.5
MT vs. MT-MSE (T_2)	4.15	0.006 **	0.71	80.6	2.12	0.034 *	0.53	56.8	6.89	0.046 *	0.48	48.8	1.04	0.773	0.07	5.9
MT vs. MT-MSE (T_3)	5.40	0.000 ***	0.92	95.6	3.57	0.000 ***	0.90	95.0	7.21	0.037 *	0.50	52.4	5.77	0.110	0.40	35.4

***p<0.05, **<0.01, ***<0.001**

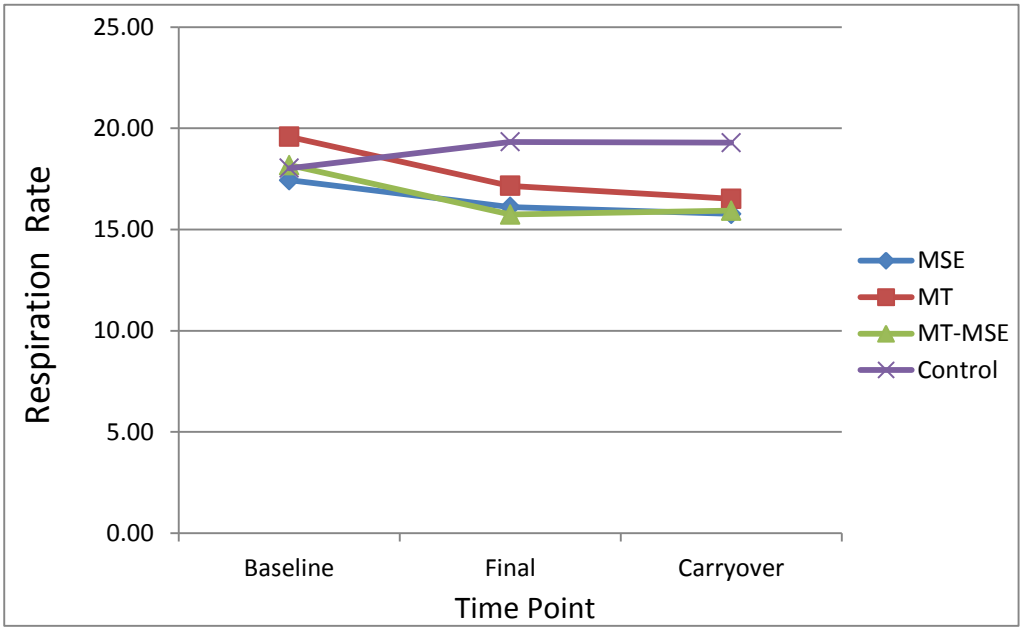
CB=Challenging Behaviour, ES=Effect Size, %=Power, MD=Mean difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level

The respiration rate of intervention groups demonstrated significantly lower than the control group at both T_2 (immediately after intervention completion) and T_3, where their mean differences ranged from 2.18 to 3.59, p-values from 0.003 to 0.0001 and effect sizes from 0.73 to 1.20. The lowest respiration rate at T_2 was in the MT-MSE group and that at T_3 was in the MSE group. The greatest mean difference in respiration rate was identified between the MT-MSE and control groups (mean difference=3.59, p=0.0001, effect size=1.20, observed power=99.8%) at T_2. The MSE group showed the greatest mean difference in respiration rates compared with the control group (mean difference=3.51, p=0.0001, effect size=1.18, observed power=99.7%) at T_3. The MT group demonstrated a lower mean difference with the control group than the MSE and MT-MSE groups.

Generally, the MT-MSE demonstrated the lowest respiration rates at the midterm and endpoint of the interventions. Although the MT group also showed lower respiration rates at the end of the interventions than the control group, the changes were less significant than for the MSE and MT-MSE groups. The control group participants maintained higher respiration rates than the three intervention groups throughout the entire study period. At the 2-week follow up study (T_3), the MSE group demonstrated the lowest respiration rate, followed by the MT-MSE group and then the MT group. A low respiration rate was perceived as representing

low physiological arousal with low activity levels, implying a state of relaxation and inactivity. The change in respiration rate from baseline to carryover (T_3) in the four study groups is depicted in *Figure 5.3*.

Figure 5.3. Change in respiration rate from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

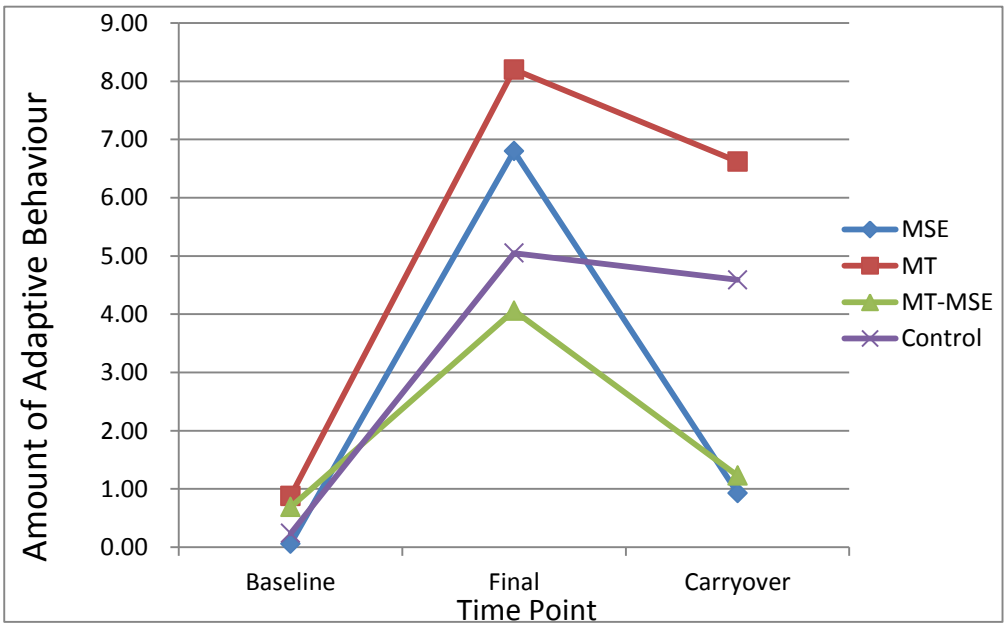
The MT group indicated the most and longest duration of adaptive behaviour compared with the other three groups at T_2 and T_3. The mean differences in the amount and duration of adaptive behaviour between the groups at T_2 were statistically significant. The mean difference of amount of adaptive behaviour between MT and control group was 3.16, p=0.032, effect size=0.54 and observed power=58.7% at T_2. The mean difference of amount and duration of adaptive behaviour between MT and MT-MSE was 4.15, p=0.006, effect size=0.71 and

observed power=80.6% and 2.12, p=0.034, effect size=0.53 and observed power=56.8% respectively at T_2.

At T_3, four pairwise contrasts showed statistically significant as shown in *Table 5.7b*. The mean difference between the MSE and MT groups in the amount and duration of adaptive behaviour (mean difference=5.70, p=0.0001, effect size=0.97, observed power=97.1%; and mean difference=3.95, p=0.0001, effect size=1.00, observed power=97.7%, respectively) was statistically significant. Apart from the MSE and MT groups, the pairwise contrast of MT and MT-MSE groups also showed statistically significantly different in the amount and duration of adaptive behaviour (mean difference=5.40, p=0.0001, effect size=0.92, observed power=95.6%; and mean difference=3.57, p=0.0001, effect size=0.90, observed power=95%, respectively). The mean difference between the MSE and control groups in the amount and duration of adaptive behaviour (mean difference=3.66, p=0.014, effect size=0.62, observed power=70.9%; and mean difference=2.86, p=0.004, effect size=0.72, observed power=82.9%, respectively). The mean difference between the MT-MSE and control groups in the amount and duration of adaptive behaviour (mean difference=3.36, p=0.022, effect size=0.57, observed power=64%; and mean difference=2.48, p=0.011, effect size=0.63, observed power=72.2%, respectively).

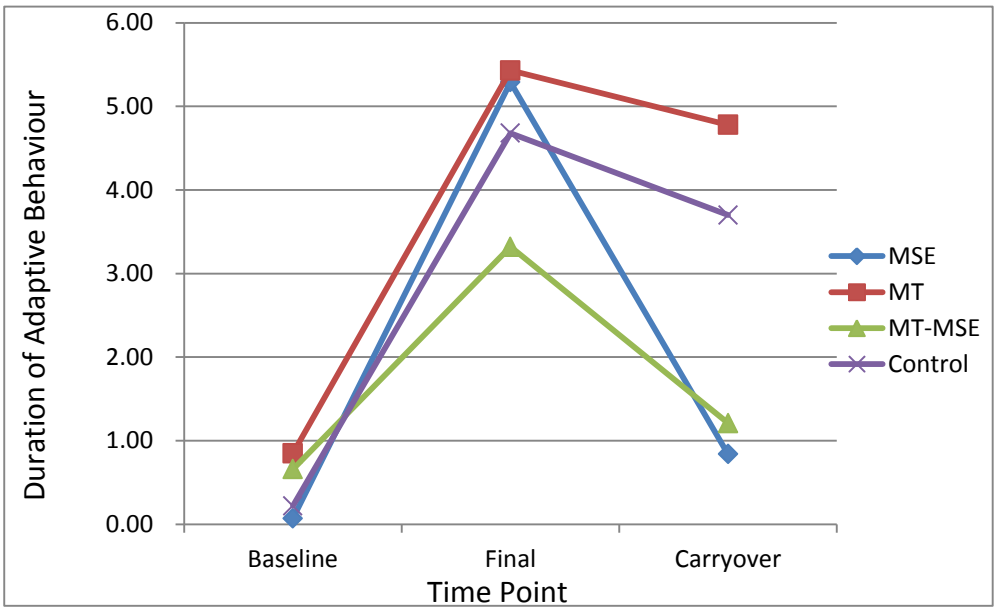
The changes in average amount and duration of adaptive behaviour were very significant between baseline to T_3 (see *Figures 5.4* and *5.5*). Generally, the MT group participants consistently showed a higher amount and a longer duration of adaptive behaviour than the other three study groups.

Figure 5.4. Change in the amount of adaptive behaviour from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

Figure 5.5. Change in the duration of adaptive behaviour from baseline to carryover



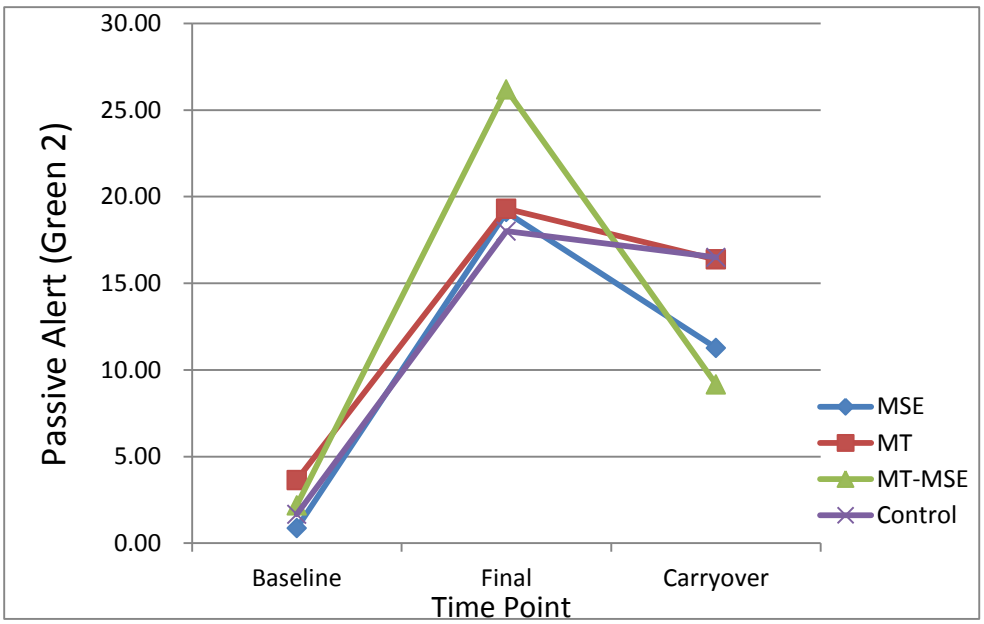
MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

The shift of passive alert was very abrupt and undulation in MT-MSE from baseline to T_3 (carryover time point). The change pattern of MT-MSE was paradoxical between T_2 and T_3. MT-MSE attained the highest passive alert than other study groups, indicating the prevalence of relaxation among the participants at T_2, but it dropped to the lowest level at T_3. Passive alert (approximately 58.15% in MT-MSE, 43.73% in MT, 42.63% in MSE and 39.7% in control group) and active alert (about 39.66% in MT, 36.29% in MSE, 32.73% in control group and 29.68% in MT-MSE) shared almost 90% of AOC at completion of the interventions (T_2), similar to the outcomes of the midterm assessment.

The mean difference between the MT-MSE and control groups was 8.18, p=0.017, effect size=0.57, observed power=64.3%; the mean difference between the MT-MSE and MSE groups was 7.08, p=0.044, effect size=0.49, observed power=50.1%; and the mean difference between the MT-MSE and MT groups was 6.89, p=0.046, effect size=0.48, observed power=48.8% at T_2. At T_3, the passive alert of MT-MSE markedly dropped to 20.22%, whereas MT and control group only slightly lowered to 36.3% and 36.69% respectively. The mean difference between the MT-MSE and control groups was 7.33, p=0.033, effect size=0.51, observed power=55%; and the mean difference between the MT-MSE and MT groups was 7.21, p=0.037, effect size=0.50, observed power=52.4%.

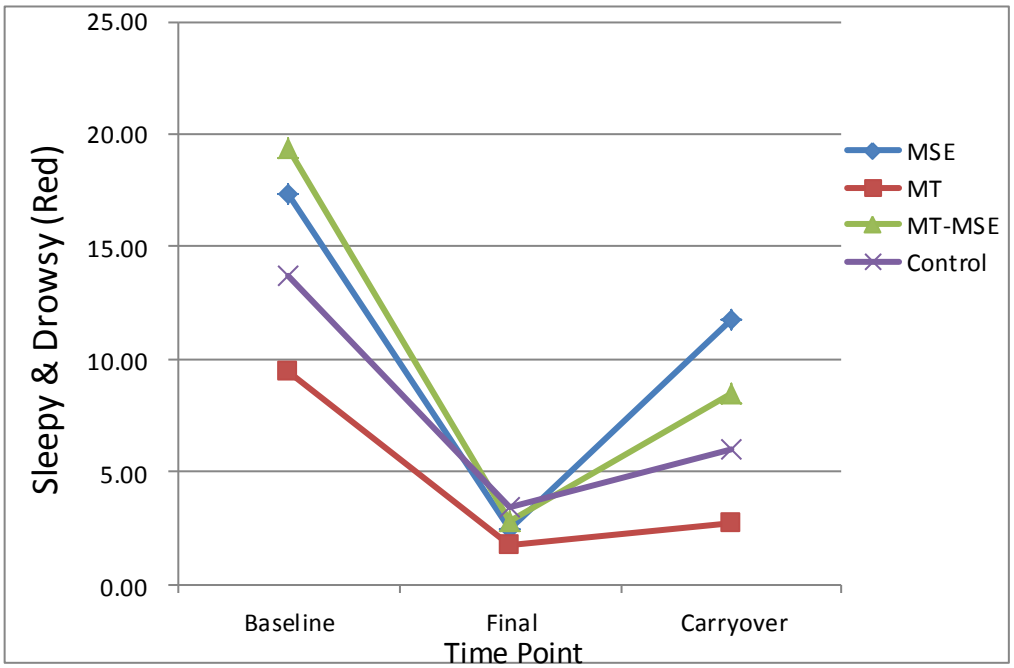
The sleepy state was only statistically different between MSE and MT groups at T_3. The MT group participants exhibited the lowest level of sleepy state than other study groups. The mean difference between MSE and MT was 9.06, p=0.013, effect size=0.62, observed power=69.2% at T_3, approximately 6.05% in MT group and 26.42% in MSE group. The changes in the passive alert and sleepy state of the AOC from baseline to the 2-week follow-up for the four study groups are presented in *Figures 5.6 and 5.7*.

Figure 5.6. Change in the passive alert state (green 2) on the Alertness Observation Checklist from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

Figure 5.7. Change in the sleepy state (red) on the Alertness Observation Checklist from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

In fact, the alertness levels of individual groups at the 2-week follow-up (T_3) were very different, for instance, MT-MSE group was dominant in inactive states (37.46%), MSE group evenly distributed into inactive (26.51%) and sleepy (26.42%) states; while MT group mostly maintained at active (31.49%) and passive (36.3%) alerts, and the control group shifted between passive alert (36.69%) and inactive state (25.14%).

The dominant alertness levels at the baseline were the inactive (66.47% in MT group, 60.49% in control group, 54.39% in the MSE group, and 48.45% in MT-MSE group) and sleepy states (43% in MT-MSE group, 38.3% in MSE group, 30.77% in control group and 21% in the MT group). Generally, the participants of the MT group progressively shifted from inactive alertness to alert state (involved both active and passive alertness) from baseline to T_3, whereas the MT-MSE group transited from inactive and sleepy to passive alert and then returned to the inactive state at the follow-up study. The MSE group participants increased their arousal from the inactive and sleepy states to passive alertness, and then evenly distributed into the inactive and sleepy states at the follow-up study. Similar to MT group, the control group shifted from inactive to active and passive alertness in T_2, and then diverged to passive alertness and inactive state in T_3. Apart from physical disablement and immobility, relaxation effect may be the cause of inactivity and motionless with maintaining social contact with the physical surroundings upon completion of the interventions. Throughout the study, no participant demonstrated the discontented or restless alertness level.

5.2.6 Within-group effects

Many outcome measures showed significant improvements within the groups across the three measurement time points (T_0, T_2 and T_3), as shown in *Table 5.8*, except for primary outcomes, heart rate and amount and duration of maladaptive behaviour which displayed individual change pattern between four study groups. The significant outcome measures included respiration rate [Wald $\chi^2(2)=16.19$, p=0.0001], amount and duration of adaptive behaviour [Wald $\chi^2(2)=62.23$, p=0.0001; and Wald $\chi^2(2)=78.50$, p=0.0001 respectively] and all alertness levels of AOC, including active alert, [Wald $\chi^2(2)=51.81$, p=0.0001], passive alert [Wald $\chi^2(2)=95.87$, p=0.0001], inactive state [Wald $\chi^2(2)=101.94$, p=0.0001], and sleepy state [Wald $\chi^2(2)=44.91$, p=0.0001].

Table 5.8. Within-group comparisons of mean scores on outcome measures across three time points (T_0 to T_3) (N=129)

	Time point	MSE (n=31)		MT (n=32)		MT-MSE (n=32)		Control (n=34)		GEE (Time)	
		MD	p	MD	p	MD	p	MD	p	Wald χ^2 (df=2)	p
Respiration rate	T_0-T_2	1.33	0.081	2.43	0.001 **	2.44	0.001 **	1.31	0.071	16.19	0.000***
	T_0-T_3	1.67	0.028 *	3.06	0.000 ***	2.25	0.003 **	1.26	0.082		
Amount of adaptive behaviour	T_0-T_2	6.74	0.000 ***	7.32	0.000 ***	3.37	0.022 *	4.82	0.001 **	63.23	0.000***
	T_0-T_3	0.87	0.559	5.74	0.000 ***	0.54	0.716	4.35	0.002 **		
Duration of adaptive behaviour	T_0-T_2	5.22	0.000 ***	4.59	0.000 ***	2.66	0.007 **	4.46	0.000 ***	78.50	0.000***
	T_0-T_3	0.76	0.445	3.93	0.000 ***	0.55	0.575	3.47	0.000 ***		
Green 1: active alert	T_0-T_2	13.82	0.000 ***	15.40	0.000 ***	11.70	0.001 **	12.61	0.000 ***	51.81	0.000***
	T_0-T_3	7.31	0.051	12.10	0.001 **	8.99	0.014 *	8.95	0.012 *		
Green 2: passive alert	T_0-T_2	18.25	0.000 ***	15.66	0.000 ***	24.01	0.000 ***	16.35	0.000 ***	95.87	0.000***
	T_0-T_3	10.40	0.004 **	12.73	0.000 ***	6.98	0.050 *	14.83	0.000 ***		
Amber: inactive	T_0-T_2	17.60	0.000 ***	24.44	0.000 ***	19.13	0.000 ***	17.95	0.000 ***	101.94	0.000***
	T_0-T_3	12.77	0.002 **	18.24	0.000 ***	4.86	0.242	15.71	0.000 ***		

	Time point	MSE (n=31)		MT (n=32)		MT-MSE (n=32)		Control (n=34)		GEE (Time)	
		MD	p	MD	p	MD	p	MD	p	Wald χ^2 (df=2)	p
Red: sleepy	T_0-T_2	14.89	0.000 ***	7.67	0.036 *	16.59	0.000 ***	10.28	0.004 **	44.91	0.000***
	T_0-T_3	5.53	0.137	6.68	0.068	10.86	0.003 **	7.78	0.028 *		

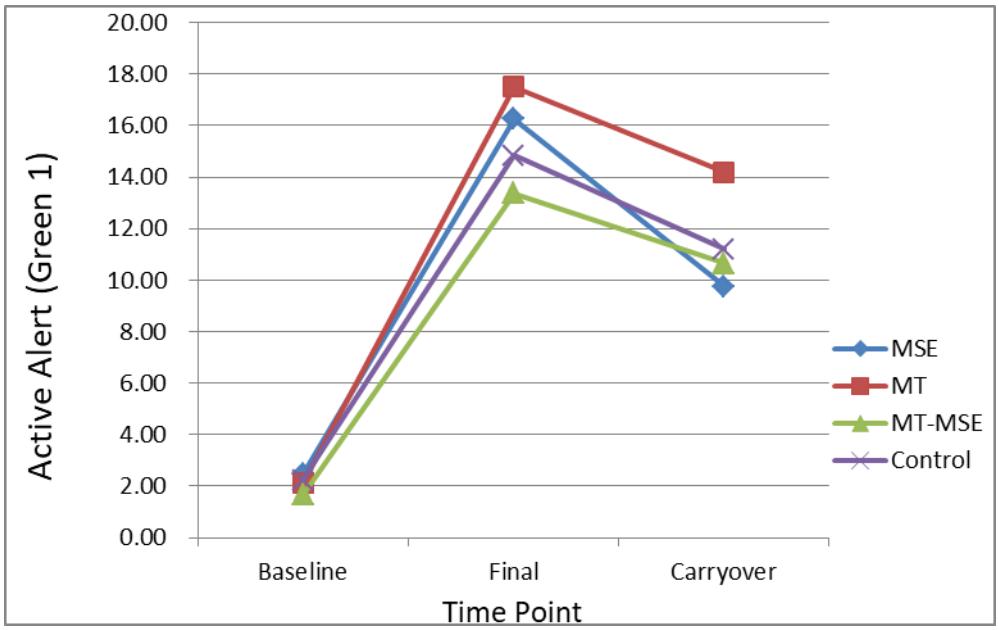
***p<0.05, **<0.01, ***<0.001**

CB=Challenging Behaviour, GEE=Generalised Estimating Equations, MD=Mean Difference, MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment, p=significance level

The primary outcomes, frequency and severity of challenging behaviour, only produced significant group effect, no interaction and time effects. Regarding the secondary outcomes, all of the outcome measures that showed interaction and group effects also showed a within-group effect. The respiration rate and adaptive behaviour showed significant differences between the baseline and post-intervention assessments, especially MT group. The time effects of respiration rate were more prominent in the three intervention groups (p=0.001-0.0001) than in the control group at T_3, likewise, the time effects of amount and duration of adaptive behaviour showed the mean difference within MT and control groups were consistently significant (p=0.001-0.0001) between three time points, whereas the mean difference within MSE and MT-MSE groups only significant between baseline and just after intervention (T_2). MSE and MT-MSE groups did not demonstrate a significant difference between baseline and the follow-up study, indicating that both mean values were similar (i.e., after the upsurge of adaptive behaviour at intervention completion) and then returned to almost the baseline level by the 2-week follow-up.

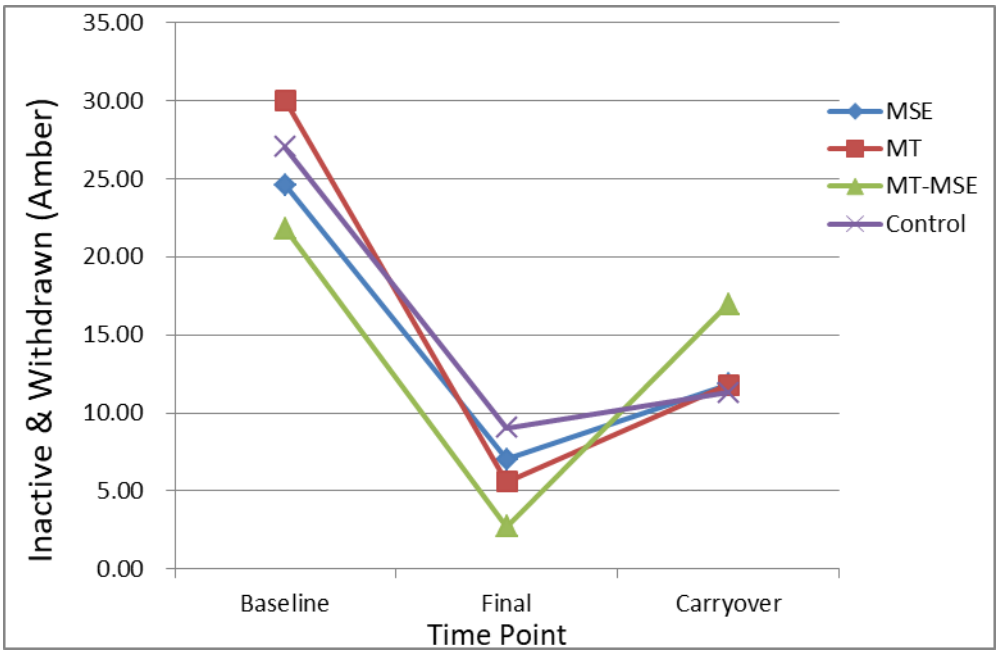
The time effects of alertness levels presented consistent changes between baseline and the two post-intervention assessments for the study groups. The change pattern of the time effects on active alert and inactive state are depicted in *Figures 5.8-5.9.*

Figure 5.8. Change in the active alert state (green 1) on the Alertness Observation Checklist from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

Figure 5.9. Change in the inactive state (amber) on the Alertness Observation Checklist from baseline to carryover



MSE=Multisensory Environment, MT=Massage Therapy, MT-MSE=Massage Therapy in Multisensory Environment

Generally, the MT group demonstrated significant mean differences between baseline and the two post-intervention measures in secondary outcomes, except the mean difference of the sleepy state between baseline and the 2-week follow-up (i.e., T_0 vs. T_3 with $p=0.068$). Similarly, the control group showed significant changes in the mean differences between baseline and the two post-intervention measures in all of the outcome measures, except respiration rate ($p>0.05$). The MT-MSE group demonstrated significant changes (i.e., $p<0.05$) in most of the outcome measures, except amount and duration of adaptive behaviour, and inactive state between baseline and the 2-week follow up (i.e., T_0 vs. T_3). The MSE group exhibited more insignificant differences (i.e., $p>0.05$) in respiration rate between baseline and just after intervention (T_0 vs. T_2); amount and duration of adaptive behaviour, active alert, and sleepy state between baseline and the 2-week follow up (i.e., T_0 vs. T_3).

5.3 Summary of Results

An interaction (group×time) treatment effect was found for respiration rate, amount and duration of adaptive behaviour, and passive alert of AOC in the four study groups. The primary outcomes (i.e., frequency and severity of challenging behaviour) only showed significant improvement in the group effect. Challenging behaviour gradually reduced in all of the study groups over time. Though MT had the highest, while control group had the lowest frequency and severity of challenging

behaviour, there was no pairwise contrast found significantly different ($p>0.05$). The greatest within-group mean difference occurred in the MT group between baseline and the two post-intervention measures (i.e., T_0 vs. T_2 and T_0 vs. T_3), then MSE and MT-MSE. The least or modest change between baseline and the 2-week follow up was control group.

For the secondary outcome measures, the participants in the MT-MSE and MSE groups indicated the lowest respiration rates at T_2 (M=15.74 bpm) and T_3 (M=15.77 bpm), respectively, whereas the control group maintained the highest respiration rates throughout the study (M>19.0 bpm). According to the hypothesis stated in Section 1.3, it was perceived that a lower respiration rate than the baseline level (found in the three treatment groups) indicated lower physiological arousal or activation of the parasympathetic system, which implied a more favourable state of relaxation. In fact, the heart rate also showed gradually reduced in all three intervention groups (M=78-80 Bpm), while the heart rate of control group was steadily increased (M>84 Bpm). However, the mean difference between intervention groups and control group did not achieve significant level in heart rate.

The therapeutic value of MT in increasing the amount and duration of adaptive behaviour was significantly higher than that of MSE and MT-MSE. The MT group demonstrated the highest amount and longest duration of adaptive behaviour of all study groups at T_2 and T_3. Only the mean value of the MT group at T_3 was significantly different from that of the MSE and MT-MSE groups, and

significantly different from control group at T_2. Although the amount and duration of adaptive behaviour of the MSE and MT-MSE groups steadily increased to the peak level at T_2, which was comparable with the MT group at the completion of the interventions, it abruptly declined to a low level at the follow-up study. The changes in the MT and control groups were less extreme between the completion of the intervention and the follow-up study.

The interaction effect also detected in passive alert of AOC, it all involved MT-MSE which rapidly shifted to the highest level (58.15%) at T_2, then swiftly dropped to the lowest level (20.22%) than other study groups at T_3. Hence, the significant differences were revealed between MT-MSE group and MT and control groups at T_2 and T_3, while only markedly different from MSE at T_2 because MSE also dropped to a lower level at T_3, similar to MT-MSE.

Apart from frequency and severity of challenging behaviour, respiration rate and amount and duration of adaptive behaviour, group effect was also identified in sleepy state of AOC. The MT group showed less of a sleepy state at T_2 (3.94%) and T_3 (6.05%) than the other three groups, where only the sleepy state of the MT group at T_3 was significantly different from that of the MSE group (26.42%). The participants in the MT group demonstrated less sleepy during and immediately after the interventions. This effect was maintained until the 2-week follow-up. In contrast, the participants in the MSE group showed relatively higher sleepy state than the other three groups at T_3.

According to the overall distribution of alertness states in the AOC, the pertinent alertness levels at baseline were the inactive (i.e., the highest was 66.47% in the MT group) and sleepy states (i.e., the highest was 43.01% in the MT-MSE group). Interestingly, the passive alert state was the most pertinent (i.e., the highest was 58.15% in the MT-MSE group) at T_2 and then both the passive alert (i.e., the highest was 36.69% in the control group) and inactive states (i.e., the highest was 37.46% in the MT-MSE group) at T_3. The hypothesis that "active" alertness would be the main alertness state after the interventions was thus partially supported in the MT at T_3 because MT had 31.49% in active alert and 36.3% in passive alert with total 67.79% in the alert state. Other two intervention groups drifted toward inactive and sleepy states with more than 50%. Nevertheless, the marked increase in passive alertness at T_2 instead of active alertness might have been due to the physical disablement of the participants, who were often motionless but could still maintain a certain level of social contact through facial expression.

Overall, the time effect was significant in the secondary outcome measures. MT group had more significant changes between baseline and the 2-week follow up than other study groups. Hence, the hypothesis that the combined MT-MSE intervention would significantly increase adaptive behaviour and the alert state (i.e., higher awareness to environment) more than the two single modes of intervention (MT or MSE alone) was not supported by the results of this study.

CHAPTER SIX

QUALITATIVE RESULTS OF THE MAIN STUDY

6.1 Introduction

This chapter describes the qualitative content analysis of the semi-structured interviews with 13 primary nurses. The content analysis focuses on the interviewees' perceptions of the usefulness of MSE and MT, the shortcomings or barriers of these interventions, the factors contributing to challenging behaviour among the residents with SPID and the management of challenging behaviour in daily practice.

6.2 Interviewee Characteristics

Thirteen of the primary nurses in this study were interviewed. All of them were female. They mainly ranged between 30 and 39 years of age (n=4, 30.8%) and 40 and 49 years of age (n=5, 38.4%). Seven (53.8%) worked as enrolled nurses and six were registered nurses, in whom, five (38.5%) had a Bachelor's degree in nursing or above. Their years of work experience in ID care ranged from 1.5 to 20 years (M=11.4, SD=7.1). Nine (69.2%) had at least one psychiatric/general nursing specialty qualification, such as outreach or general adult psychiatric nursing or infection control, whereas seven (53.8%) received specialty training in ID nursing. The characteristics of the 13 interviewees are summarised in *Table 6.1*.

Table 6.1. Interviewees' demographic characteristics (N=13)

Characteristics	Frequency (n=13)	Per cent (%)
Age range (years)		
20-29	2	15.4
30-39	4	30.8
40-49	5	38.4
50 or above	2	15.4
Education level		
Certificate of Enrolled Nurse	7	53.8
Diploma	1	7.7
Bachelor's	3	23.1
Master's	2	15.4
Ranking		
Enrolled nurse	7	53.8
Registered nurse	6	46.2
Years of working experience (mean±SD)	11.42±7.14	
Range	1.5-20	
1-5	4	30.8
6-10	2	15.4
11-15	2	15.4
16-20	5	38.4
Amount of specialty training		
0	4	30.8
1	6	46.1
2	3	23.1
Received intellectual disability specialty training		
Yes	7	53.8
No	6	46.2

6.3 Main Categories and Sub-categories Identified

To formatively evaluate the interventions (MSE-MT, MT alone and MSE alone), the primary nurses were requested to share their experiences with the interventions they participated in and their perceptions of the strengths and weaknesses of individual interventions in treating the participants' (SPID residents') challenging behaviour. The interviewees were also asked for their views on the

strategies used to manage residents' challenging behaviour and the potential factors contributing to such behaviour.

From the interview data of the 13 primary nurses, four main categories (each with two to four subcategories) were identified. They are listed in *Table 6.2*.

Table 6.2. Main categories and subcategories of primary nurses' perceptions of the interventions used and managing challenging behaviour

	Categories	Subcategories
1.	Perceived benefits of the multisensory environment and/or MT	● Providing a place or an activity for relaxation and enjoyment
		● Appraising massage therapy and the multisensory environment
		● Offering sensory stimulation to fulfil the needs of those with sensory deficits
		● Providing physical touch as a form of care and concern
2.	Enhancing intervention quality	● Increasing the doses of intervention
		● Providing a variety of intervention modalities
3.	Possible factors contributing to challenging behaviour	● Personal factors
		● External factors
		➢ Usual care environment
		➢ Work culture and attitude of direct care staff
		➢ Support from family members
4.	Managing challenging behaviour	● Identifying the purposes of challenging behaviour
		● Improving the physical environment
		● Engaging in meaningful activities
		● Implementing person-centred care

6.4 Perceived Benefits of the Multisensory Environment and/or Massage Therapy

The interviewees were invited to express their perceptions of the benefits of MSE and MT. All of the interviewees appreciated the interventions and suggested that they should be continued after the study period. Although three interviewees pointed out that the occurrence of challenging behaviour among the residents was not greatly reduced in wards after the interventions, they still supported the continuation of the interventions, as they could occupy the residents' free time and thereby reduce self-idling and provide social and stimulating environments with enhanced relaxation and passive alertness.

> *Additional service is always welcome and better than no service. More people approached the resident, which made her feel loved. More people touched her, which made her feel happy. Although I have not seen any great progress from the intervention, I welcome the programme. From my point of view, although there is no obvious improvement, the presence of an activity and a programme is always better than none. (Participant 4, paragraph 22)*

Their verbal comments on the perceived benefits could then be summarised and grouped into four subcategories: providing a place or an activity for relaxation and enjoyment, appraising MT and the MSE, offering sensory stimulation to fulfil the needs of those with sensory deficits and providing physical touch as a form of care and concern.

6.4.1 Providing a place or an activity for relaxation and enjoyment

All of the interviewees expressed that their residents felt relaxed and enjoyed the assigned interventions very much, as noticed from their body gestures and facial expressions. Most of the residents exhibited many more pleasant expressions and relaxed postures in wards during the intervention period. Two primary nurses predominantly supported the MSE intervention, as it allowed the residents to change from their usual care environment to a more stimulating and enjoyable environment. The majority of them agreed that MT in MSE would augment the beneficial effects of relaxation and enjoyment than the single intervention modes alone, as it involved wide varieties of visual, auditory and tactile stimulations in a comfortable environment.

Challenging behaviour significantly decreased or ceased during the intervention and even reduced for some residents after they returned to the usual care environment. Although some challenging behaviour recurred shortly after completion of the sessions, all of the interviewees (nurses) appreciated the interventions and indicated that they were worth continuing, as their SPID residents could enjoy the peaceful and relaxing moments there.

> *He looks very happy and comfortable. He becomes peaceful and very relaxed when he is being massaged. His challenging behaviour is significantly reduced when he engaged in massage therapy. (Participant 5, paragraph 28)*

It is good for people with challenging behaviour to participate in MSE, as they can leave the ward (the usual care environment) and interact with different people (staff of the training centre). (Participant 8, paragraph 54)

There is no spitting during massaging. Although it recurs shortly after completion, it's still worth continuing the massage therapy sessions, because he enjoys the time very much, he becomes very peaceful and, most importantly, his challenging behaviour stops during that period. (Participant 9, paragraph 49)

All except for one primary nurse admitted that the interventions made their residents behave very differently from those in usual care only. Five primary nurses disclosed that they had never seen such cheerful facial expressions in their previous interactions with the residents. All of the primary nurses affirmed that the interventions reduced or eliminated challenging behaviour during the intervention sessions. Although they acknowledged that the benefits could be short-lived, the enjoyment and relaxation the residents experienced in the intervention sessions had not been observed during their usual care.

6.4.2 Appraising massage therapy and the multisensory environment

In addition to relaxation and enjoyment, the primary nurses expressed other benefits of the interventions, such as social attention, happiness, increased social contact, rapport building, induced sleepiness and sense of worthiness. Six primary

nurses said that social attention was abundant during interventions, which satisfied the needs of those with attention-seeking behaviour. They believed that the social attention delivered by the interventions was different from that in daily usual care.

> *He treasures the moments of massage therapy, as he gets a lot of attention. I perceive it to be interpersonal contact. Even though, just staying with him is better than the usual care attention. (Participant 3, paragraph 24)*

> *She loves massage therapy because someone stays with her. Everybody loves to be touched, to be pleased, especially massage therapy. It is so comfortable. She laughs more frequently and her self-scratching behaviour decreases. (Participant 7, paragraph 47)*

The residents exhibited happiness during the interventions, which was sustained for a short period or at least 1 day after they returned to the usual care environment. Hence, the primary nurses appreciated the treatment sessions.

> *He recognises the massage therapist. Once he sees her, he becomes very happy and starts giggling. He looks very relaxed and comfortable. He is very willing to be massaged by Mary (massage therapist's pseudonym). He stays in the ward alone, and he scratches his skin and the disposable diapers. Hence, he is required to put on limb holders to prevent self-inflicting behaviour. During massage therapy, his hands are free and he demonstrates no such behaviour. When he comes back from the training centre, he looks very cheerful because he has just finished the*

activity there. (Participant 12, paragraphs 57-59 and 63)

Another primary nurse echoed that the interventions made her client more relaxed and happier than before and that challenging behaviour was subsequently reduced (Participant 2, paragraph 15). The residents were not only willing to receive the interventions, but also showed friendliness to the massage therapist and reached out their hands to explore the immediate environment, such as by touching nearby objects and toys after the intervention.

> *The client looks very happy and laughs more. She smiles with markedly increased frequency. During bedside care, she laughs, which makes the staff very happy. She increases laughing and hand movements. The activity level of hand movement is increased. She touches things to play. She appears more responsive when being approached. (Participant 7, paragraph 34)*

The primary nurses addressed the importance of social contact during the interventions. Most often, the residents were unoccupied and had no social interactions or personal contact with staff in usual care. Hence, the social contact in the interventions was perceived as positive and more favourable. During the interventions, the residents experienced more pleasurable interaction than in the routine care in the wards.

Five interviewees expressed that the increased social contact with the massage therapist also facilitated rapport building. When approaching the treatment

sessions, the residents made very pleasurable and welcoming gestures, appearing to look forward to attending the intervention sessions.

> *My client is very willing and eager for massage therapy [since trying it]. He stays very quiet and shows friendliness to the massage therapist by giving his hands. He looks very relaxed and does not exhibit any challenging behaviour during his massages. He shows high anticipation for the massage sessions, just like waiting for food. He becomes very quiet and cooperative. (Participant 3, paragraphs 20-21)*

> *The resident treats the therapist as her friend and looks forward to seeing her. She looks comfortable staying with the therapist. (Participant 6, paragraph 24)*

The effect of induced sleepiness was prominent for those residents who exhibited hyperactivity and poor sleeping patterns. The interventions facilitated relaxation and reduced the exhibition of challenging behaviour. MT appeared to have a remarkable effect on inducing sleepiness, as expressed by two primary nurses.

> *Initially, he still spat at others, even to the massage therapist. After several sessions, he became quiet and showed enjoyment for the session. No further saliva spitting behaviour has been noted. He looks very comfortable and falls asleep once returning to the ward. (Participant 9, paragraphs 40-41)*

He is blind and usually stays in bed and plays with his pillow. He scratches his skin and the disposable diapers. During massage therapy, he becomes very sleepy towards the end of the sessions and does not want to be disturbed. However, he still takes initiative to hold his hand out to the massage therapist to complete the massage for both hands. Then he falls asleep comfortably and looks very relaxed. (Participant 12, paragraphs 57 and 60-61)

Three primary nurses highlighted that the residents gained a sense of worthiness when they were preparing to receive the interventions. As described by the primary nurses, the residents were seldom engaged in meaningful activities in their usual care. Once the staff prepared them for the interventions, they felt cherished and showed smiling faces. An experienced nurse expressed that one of her residents was very excited when his name was called by the therapist to attend his MSE sessions:

He values social interaction and enjoys physical touch. When his name is called among other residents, it seems that he is the winner and awarded the service. He remembers and is accompanied for the intervention. (Participant 3, paragraph 37)

As mentioned, his challenging behaviour was over-reactivity when he heard his name was called. He bit himself and the limbs of nearby co-residents. After the intervention, he was completely relaxed. Now, he demonstrates calmness and directs to the source calling his name. The

frequency of [his] challenging behaviour has greatly reduced. Hence, I support his participation in this programme. (Participant 2, paragraph 14)

All of the primary nurses stated that one potentially effective strategy for managing challenging behaviour was to be actively engaged in the SPID residents' free time, so that they would not spend their free time in other ways. Four of the primary nurses perceived that through the repeated engagement of the interventions, their residents' challenging behaviour decreased in the usual care environment, and the residents had noticeably increased laughing episodes and happy moods.

He is relatively less tense and calmer than before [the interventions started]. Previously, he would bite himself or attack nearby residents when hearing loud voices. Such behaviour has greatly reduced in the last 3 months with increased engagement in activities [MT-MSE] and revision of his medication. (Participant 2, paragraph 11)

She looks happier and laughs occasionally. The frequency of laughing has markedly increased since the intervention. When we do bedside care for her, she laughs happily and makes our staff happy too. (Participant 7, paragraph 33)

Many of the primary nurses reflected that the best activities addressed the residents' individual interests. However, the leisure activities in the wards were limited.

More activities should be arranged for the resident with challenging behaviour to distract his attention. He should be encouraged and arranged to attend meaningful activities to gain satisfaction. (Participant 2, paragraph 7)

According to her preferred programme and special days or festive days…provide special items to her, such as music therapy. (Participant 6, paragraph 10)

I think other activities would make her [behavioural] change more noticeable, not only sensory therapy. (Participant 13, paragraph 42)

The primary nurses admitted that limited creativity, initiatives and resources restricted the application of and options for meaningful and favourable or pleasurable activities for individual residents.

6.4.3 Offering sensory stimulation to fulfil the needs of those with sensory deficits

Most of the primary nurses agreed that the MSE provided different sensory stimulations to enrich the purposive leisure activities of the residents during the intervention sessions. However, three of the nurses mentioned that they favoured MT with or without MSE for their residents with sensory deficits, as it could provide equipment for tactile sensation and physical contact. A resident with hearing and visual impairments and who was speechless benefited from the physical touch of MT, as described by one primary nurse. He frequently displayed shouting and

self-scratching behaviour. When he knew someone next to him or was being massaged, he kept quiet and did not exhibit self-inflicting behaviour (Participant 5, paragraphs 20-22). A few nurses also indicated other benefits of MT:

> *Massage therapy is appropriate for my client because he is dumb, blind and deaf. He cannot see the fibre-optic tails and lighting effects of the MSE at all. Only through physical touch, he feels social interaction and acknowledges the presence of others. Otherwise, he is very self-absorbed. (Participant 5, paragraph 27)*

> *He (with visual impairment) reduces peeling his lips and inflicting his hands while massaging. He enjoys massage therapy and lies in a relaxed posture in the MSE. He shows exceptional interest in the sound of water flowing, which makes him quiet. Generally, he shows limited response to music in the unit. (Participant 8, paragraph 44)*

> *She (with visual impairment) looks very relaxed and sits still when listening to music. No restlessness at all (but very restless in the unit). No skin-picking behaviour is noted in the MSE. If massage therapy is added, it would be more beneficial. (Participant 10, paragraph 65)*

Ten of the primary nurses expressed that the most frequent form of challenging behaviour was SIB, such as self-scratching and head banging, which could be related to limited sensory stimulations from the external environment,

especially for those with visual impairments. MT satisfied residents' need for tactile sensation, thus greatly reducing the frequency of SIB.

6.4.4 Providing physical touch as a form of care and concern

The primary nurses perceived that MT was very therapeutic for the residents, as physical touch gave them a sense of care and concern. Despite physical touch being common in certain forms of daily care, such as bathing, diaper changing and feeding, such routine physical touch was perceived differently than MT. The primary nurses perceived MT as a purposeful physical touch that gave the residents' physical and psychological pleasure, in contrast to the routine daily procedural care contact they experienced.

> *Massage therapy is better than other interventions because the increased physical touch and active engagement make her (the resident) feel cared for. She looks very relaxed during massage therapy. (Participant 1, paragraph 37)*

> *He looks forward to receiving massage therapy. During the one-on-one contact, he makes eye contact (with the massage therapist), as if he is expecting food from her. There is no challenging behaviour, he is very relaxed. Such contact is very different from the contact of being asked to take medication or being called to take a bath. It's definitely different from usual care contact. Based on my observations, he cherishes the moment of massage therapy. I perceive such contact is very humane. (Participant 3, paragraphs 22-23)*

6.5 Enhancing Intervention Quality

To ensure optimal interventions in future practice or research, the interviewees commented on the quality of the interventions used. Based on their observations during the intervention sessions and their own clinical experiences, two main suggestions were identified: 'increasing the doses of intervention' and 'providing a variety of intervention modalities'.

6.5.1 Increasing intervention doses

Six interviewees expressed that the doses of intervention needed to be increased in terms of session frequency and duration (or length) to sustain the residents' enjoyment and therapeutic effects over a longer term. They suggested increasing the number of intervention sessions from a minimum of three times per week to daily and increasing the duration of interventions to approximately 1 hour per session. They believed these changes could reduce the residents' challenging behaviour in the usual care environment.

> *I believe the major problems are insufficient manpower, limited resources and time constraints. If the resident could receive the intervention daily, I believe the therapeutic effect would be more persistent and noticeable. (Participant 2, paragraph 16)*

> *Too little has been done. The limitation is the resource allocation. If it is within your capacity, the intervention doses should be increased and the sessions should be longer. I definitely appreciate the interventions for the*

residents. (Participant 4, paragraph 37)

One of the interviewees particularly mentioned the personal buffer zone in the multisensory environment. She perceived that an increased personal buffer zone could 'augment the relaxation effect' (Participant 8, paragraph 55).

Three primary nurses addressed the positive behavioural changes that occurred after the interventions, such as increased smiling and laughing and decreased episodes of challenging behaviour in usual care. Eight primary nurses acknowledged some observable therapeutic effects of the interventions used, but they were only mild or short-lived behavioural change in the wards. They believed that the non-significant behavioural changes in the wards were probably due to the short duration and insufficient number of intervention sessions. Hence, they proposed adding extra manpower and resources to increase the doses and strength of the interventions. To ensure continuity of care after the study, extensive training and integration of interventions into routine care should be considered. The promotion of mindset and attitude changing among the direct care staff was especially important to combatting their resistance to rehabilitation programmes that they perceived as the additional workload, but in fact, these programmes are often missing to execute.

To sustain the therapeutic intervention, it should be carried out as a routine so that the therapeutic value can continue after the study. The most important thing is transferring massage skills to our staff. Not every staff has the competence to learn and practise massage. Hence, demonstrations and return demonstrations should be interactive until the staff gains confidence to perform. Peer support is important to

continuing the therapy. (Participant 6, paragraph 29)

The integration of the interventions into routine would face less resistance from the direct care staff if such interventions are emphasised as a basic need of the residents, just like eating. They (the direct care staff) know that residents need to eat. Thus, having them think of these interventions as meals would make them seem essential. (Participant 7, paragraph 61)

Three primary nurses proposed a few improvements for MT, such as installing an electric massage chair, performing full body massages instead of hands and feet only, playing soft music during the massage and/or carrying out MT after bathing. Four interviewees suggested that the interventions should be carried out away from the usual care environment or in a quiet corner of the usual care environment to enhance the treatment effect.

It is convenient to provide hand and foot massages in this treatment protocol. In fact, it is not enough. Full body massage should be considered. The limitation of the current treatment is insufficient doses. The enjoyment and relaxation would be maximised if the number of massage sessions and the duration of each session were increased. Some people like massage before bedtime. It would be more relaxing if they lie in bed or do the massage after taking a bath. (Participant 3, paragraphs 38 and 42)

If aromatherapy were added during massage therapy, they can smell a pleasant aromatic scent. Use of the Osim (electric) massage chair and music would double the therapeutic effect of massage therapy. (Participant 7, paragraph 55)

6.5.2 Providing a variety of intervention modalities

Five primary nurses expressed that offering a variety of intervention modalities could increase the options for engaging residents in meaningful and pleasurable activities during the day. Such modalities could actively engage the residents and prevent them from exhibiting challenging behaviour. Once a resident was fully occupied during the day, the quality of his or her sleeping pattern was enhanced, as described by one primary nurse.

The activities suggested by the primary nurses included aromatherapy, nail polishing, sound making, towel folding, garden strolling and outings. One primary nurse perceived that only activities without active motor movement were suitable for the residents due to their physical disabilities and restricted limb movements. The remaining interviewees perceived that due to their inability to verbalise, showing no resistance to certain interventions could indicate the residents' acceptance to participate in them.

If they (residents) don't show resistance to particular interventions, it means they accept. I think they have the right to enjoy any activity that the hospital can provide. If they like massage therapy, that means they enjoy the social interaction. The intervention should be continued and the duration and frequency of the massage sessions should be increased.

It may enhance their overall calmness. I think it is their basic need to have physical contact. Other good things may be hugging, playing, offering spacious environment, no boundaries limiting their movement and accessing the garden whenever they like. (Participant 3, paragraph 40)

To enhance the interventions, aromatic scents can be introduced simultaneously during massage therapy. Apart from physical touch, they can inhale a pleasant scents. During massage, similar to with the Osim massage chair, music can play in the background and therapy can progress according to the rhythm of the music. (Participant 7, paragraph 55)

6.6 Possible Factors Contributing to Challenging Behaviour

According to the conceptual framework of challenging behaviour (Hastings et al., 2013), contributing factors include biological and psychosocial vulnerabilities, such as biological influences, sensory deficits, physical and mental health problems and lack of communication capacity. The primary nurses were asked about the factors they perceived as contributing to challenging behaviour among the residents with SPID. These identified factors reflected and somewhat affected the strategies they selected for the management of the residents' challenging behaviour. Their knowledge and personal experiences on management of challenging behaviour may enlighten the service needs. Generally, the contributing factors could be categorised into two domains, namely personal (internal) factors of people with SPID and external factors such as ward environment, staff attributes and family.

6.6.1 Personal factors

All of the primary nurses expressed that some forms of challenging behaviour were caused by the personal factors of the SPID residents. Most of the primary nurses perceived attention seeking, insufficient sleep, oversensitivity to temperature change, intensity of sounds and particular voices and/or mood swings to be the major personal factors. The primary nurses expressed that due to their lack of communication capacity, the SPID residents exhibited challenging behaviour as a means of communicating and venting their dissatisfaction. Labelling behaviour as challenging behaviour was subjective. Therefore, managing these personal factors could be symptomatic and eradicating the underlying causes of the behaviour could be difficult.

> *The possible contributing factors [of challenging behaviour] include personal factors, such as physical discomfort, the immediate environment, the smell and the temperature. As they don't know how to express themselves, they use another [behavioural] form. We don't understand [what they want to express] and may misunderstand such behaviour as challenging behaviour. Due to their emotions, as mentioned, they don't understand [the environment] and they react to situations inappropriately, which is then perceived as challenging behaviour. (Participant 6, paragraph 1)*

> *As the residents themselves feel unhappy, they feel irritable, they don't know how to vent their feelings and they may exhibit challenging behaviour. (Participant 1, paragraph 1)*

6.6.2 External factors

The primary nurses identified three main external factors that they perceived as contributing to challenging behaviour. These included the usual care environment, the work culture and attitude of the direct care staff and the support of family members.

6.6.2.1 Usual care environment

The usual care environment mainly consisted of the physical setting, daily schedule and resources for entertaining the residents. In general, the interviewees perceived a noisy and congested environment and inappropriate room temperature as factors triggering challenging behaviour. Unexpected changes in the daily schedule and physical setting would create instability and thus cause restlessness and agitation among individual SPID residents, especially those with autistic or hyperactivity traits. If there were limited resources for providing structured and meaningful engagement, such as purposeful and effective rehabilitation programmes and leisure activities, the residents were more likely to exhibit challenging behaviour. Other contributing environmental factors included rigid and tight routines, lack of manpower to interact and organise meaningful activities and restricting movement to prevent injury. All of the interviewees expressed that insufficient manpower and resources was the major factor contributing to the occurrence of challenging behaviour. One interviewee highlighted the problem of institutional care:

> *Apart from the tight routine, there are many rules and regulations restricting their movements, making them unable to do what they want to,*

such as go to the toilet or the garden whenever they want to go. It is a poor outcome of taking care of 50 patients in a ward. The only focus is on cost effectiveness. Under these circumstances, we can only try to do our best. (Participant 3, paragraph 5)

Three of the primary nurses stated that challenging behaviour could be 'infectious' in a congested living environment. The disruptive behaviour of co-residents could influence the behaviour of other residents if no prompt intervention taken. Challenging behaviour between residents could increase, as they could learn such behaviour from each other to seek secondary gains, such as receiving more foods from another resident or visitors. In addition, some stereotypic behaviour of the residents disturbed other residents' sleeping patterns, such as yelling and screaming at night. Subsequently, insufficient sleep could increase the challenging behaviour of affected residents who slept poorly. Most of the interviewees reported that these residents were sometimes attacked by other co-residents as revenge, upon which frontline staff had to deal with their disputes and protect the fragile residents. One primary nurse admitted that challenging behaviour also caused a lot of stress to staff due to the incidents of violence and injury.

They (residents) are very impulsive and unpredictable. They would hit other residents and cause falls (by pushing other co-residents with unsteady gaits), or even pull residents from the sofa onto the floor causing head injuries. Such impulsive behaviour causes a lot of stress to the staff

because the nurse-in-charge always needs to prepare writing statements. We are unable to provide full protection to them (residents without challenging behaviour). The consequences of these incidents lead to complaints and dissatisfaction from relatives. (Participant 11, paragraph 46)

6.6.2.2 Work culture and attitude of direct care staff

Staff attributes and attitudes towards SPID could also affect the residents' exhibition of challenging behaviour. The most prominent way was the staff's perceptions or labelling of behaviour as challenging. Nine primary nurses indicated that the term 'challenging' was arbitrary and depended on staff's experiences and level of understanding of individual residents' behaviour.

One primary nurse reflected that everyone concealed extreme emotions and expressed them depending on the situation. If a form of behaviour was displayed at an appropriate time and place, it would be treated as emotional ventilation. Otherwise, it would be labelled as a challenging behaviour. For instance, if who felt frustrated went to the seashore to shout and cry without disturbing others, it would be treated as a normal expression of emotions or ventilation of feelings. However, if the same situation happened in a music theatre, their shouting and crying would certainly be perceived as challenging behaviour, as it would interrupt the audience's appreciation of music (Participant 4, paragraph 3).

Three primary nurses considered the cognitive level of the residents, who did not realise their behaviour was challenging. Their original intentions might have

been directed by their curiosity to explore the immediate environment or to test the staff's responses to the boring daily schedule.

> *Due to their severe and profound cognitive dysfunction, they do not recognise with socially appropriate behaviour and social boundaries due to their cognitive deficits. Once their basic or immediate needs are not satisfied, such as hunger, they will have temper tantrums, become emotionally upset and display destructive behaviour. Such behaviour is perceived as challenging in our point of view. (Participant 3, paragraph 1)*

The residents often exhibited challenging behaviour due to the very repetitive and tight routines in the wards and/or because the direct care staff did not exercise flexibility for individual preferences. One interviewee revealed that some direct care staff deliberately provoked residents to exhibit challenging behaviour and that the incidents of challenging behaviour subsequently increased when they were on duty.

> *Staff's attitude can influence the exhibition of challenging behaviour. The staff should understand the habits and behavioural patterns [of the residents], so that the manifested behaviour is not misinterpreted [as challenging]. (Participant 2, paragraph 1)*

> *Certainly, staff influences challenging behaviour. If a staff makes a positive comment to a resident, just like amazing music, she would love to*

continuously listen to this type of comment. If the comment is negative to her, the environment would be perceived as noisy and uncomfortable. Such a negative comment would stir up emotions and make her unhappy. That would definitely trigger the challenging behaviour. (Participant 6, paragraph 3)

All of the primary nurses mentioned that the attitude of direct care staff could sometimes provoke residents' negative emotions, rather than satisfy their needs. For instance, rude attitudes and raised voices could intimidate residents and make them agitated. Two primary nurses highlighted the importance of nonverbal communication and that staff should pay attention to their tone of voice and facial expressions when talking to residents with SPID. Despite a lack of verbal understanding, residents could sense or differentiate staff's attitudes through their tone of voice and nonverbal cues, such as gestures and facial expressions. Likewise, if there were no rapport between staff and resident, there would be no trusting relationship and thus the resident could neither cooperate nor follow the instructions given. Once a resident was forced to follow instructions in daily care, challenging behaviour could be presented to show their dissatisfaction or frustration.

Three primary nurses addressed the likelihood of challenging behaviour under the pressure of compliance to the tight routine. Due to insufficient manpower, most of the interviewees had no suggestions for the alternative management of challenging behaviour and expressed that they often felt helpless upon its occurrence.

Not every staff has same vision and same direction. They can be

inexperienced with and inconsistent in handling challenging behaviour. Hence, challenging behaviour may increase. I say 'handle' and not 'manage', which exhausts staff. Staff deal with challenging behaviour when it present and do not think about prevention. (Participant 3, paragraph 2)

Manpower is insufficient. Although we have the same number of residents and the same number of staff as other units, the activity level [of our residents] is extremely high and their behaviour is unpredictable. For instance, daily bathing seems like a simple task, but they can turn things upside down and make everything in a mess. If you stop their challenging behaviour, they may hit you in return. The fact is that we don't have sufficient manpower to control their behaviour. (Participant 11, paragraph 33)

Four of the primary nurses addressed the significance of familiarity in terms of staff, daily ward schedule and physical setting in reducing the occurrence of challenging behaviour. Frequent staff movements could increase the residents' sense of insecurity. Likewise, new staff did not understand the residents and meet their needs timely. Hence, a more consistent caring pattern and environment could minimise the occurrence of challenging behaviour. Further details will be described in section 6.7.2.

6.6.2.3 Support from family members

As all of the residents stayed in long-term infirmary care wards, visits from their families were important to maintaining bonds and enhancing family support. Five of the primary nurses mentioned that the frequency of family visits could influence the occurrence of challenging behaviour. The exhibition of challenging behaviour was obviously higher in the residents who infrequently or seldom received family visits than in those who received regular family visits. As mentioned by one primary nurse, challenging behaviour increased in a few residents after the day their families visited, probably due to the residents' frustration with their families' departure. Two of the primary nurses arranged regular phone contact between residents and their family members. These residents often presented less challenging behaviour. Family support and care could also facilitate the implementation of the least restrictive practices, especially for challenging behaviour.

> *He could turn his body upside down, but was unable to return to normal. To prevent self-suffocation, we needed to contact his family to get consent to use a safety vest to protect him. We fully explained the recent incidents to his family (jumping from the bed onto the floor) and our management actions, but we were still unable to prevent his dangerous act. The use of restraint was our last resort. His family was understanding and cooperative with our plan. Last time, after the family visited, they told us that the extreme behaviour (jumping from bed onto the floor) of that*

resident was due to their decreased visitation. The brought-in food was also almost exhausted. Hence, he acted impulsively to seek the family visit. In fact, we had thought of this reason and attempted to verify with the resident, but he refused to answer. (Participant 8, paragraphs 20-21)

6.7 Managing Challenging Behaviour

In the literature, the most common strategies for handling challenging behaviour in residential care settings are physical restraint, sedation and/or seclusion during or immediately after challenging behaviour is demonstrated (Emerson et al., 2000). However, the nurses expressed that these strategies were stressful to both residents and staff.

From the interview data, all of the interviewees addressed the purpose of the challenging behaviour, which was frequently inferred to be behavioural responses to the immediate environment. Generally, such responses were perceived as the intention to seek attention, access tangibles or escape or avoid the demands of the environment or people there. The nurses also perceived that improving external factors, such as the environment and daily schedule, was vital to the management of challenging behaviour. Hence, they proposed enhancing the environment, engaging in meaningful activities and implementing person-centred care (i.e., through tailor-made daily schedules).

6.7.1 Identifying the purposes of challenging behaviour

Challenging behaviour usually conveys a message or signals the immediate needs of residents with SPID. Generally, the primary nurses indicated that challenging behaviour could have any one of four purposes, namely attention seeking, sensory stimulation, access to tangibles and escape or avoidance of demands (e.g., having to bathe when they are not ready). More often, the primary nurses mentioned that attention seeking was the most common purpose of challenging behaviour, as a result of the boredom of long-term institutional living experienced by the residents. They seek social interaction and contact and new experiences or adventures to refresh themselves. One form of attention-seeking behaviour includes spitting. For residents with sensory deficits, the nurses identified SIB, such as eye poking, self-scratching and head banging behaviour as means for residents to increase sensory stimulations. As mentioned by four primary nurses, the SPID residents displayed challenging behaviour by nagging for food or items to which they wanted access. One primary nurse mentioned how one of her residents removed the metal ring from the soiled linen bag with her teeth. She then hoarded the metal rings tightly in her palms, possibly gaining a sense of security from its possession, and refused to leave the tangible object or have it replaced with something else. To avoid provoking challenging behaviour, the primary nurses would avoid the dislikes of their residents unless the objects or tasks were related to basic personal care, such as morning toilet, bathing or wound dressing. However, residents frequently screamed aloud to escape from such demands and would even hit others to avoid further contact with their dislikes.

The major purpose of challenging behaviour is to reflect boredom. They are trapped in a place where there is nothing special to attract their attention. Hence, they do something to draw people's attention to make themselves happy. (Participant 7, paragraph 4)

When the resident is not ready to do a task, such as bathing, she displays a temper and attempts to attack the staff to show her dissatisfaction. It is difficult to change daily routine to address the individual needs of individual residents. (Participant 9, paragraph 5)

Challenging behaviour is a learned behaviour to fulfil secondary gain. For instance, learning from a co-resident to snatch food from another co-resident to satisfy one's oral need. Some hit the nearby resident to test staff reactions. Hence, interventions must be taken in timely fashion to stop such behaviour. Otherwise, they may believe that there is no adverse consequences (to their challenging behaviour) and exhibit increasingly challenging behaviour. (Participant 10, paragraphs 3, 8 and 9)

Although certain forms of challenging behaviour may be associated with specific intents or purposes, none of the interviewees mentioned assessing such behaviour and the associated intents. All of the nurses had requested more manpower support in observing the residents' behaviour and communication patterns to find out their likes and dislikes (possible underlying reasons for challenging

behaviour) and/or increased social interactions and structured intervention programmes to manage their daily activities. This reflected their perceived importance of handling challenging behaviour. Eight of them emphasised the importance of teamwork and consistent approaches with clear instructions for effective communication with the residents. Those who were more experienced appeared to be more informed and skilled at managing challenging behaviour. In addition, staff training on both essential management skills and attitudes towards the challenging behaviour was perceived to be important. Reducing staff's negative feelings towards residents demonstrating challenging behaviour was frequently perceived to be crucial to the more effective management of that behaviour. The interviewees shared their communication skills with their colleagues and subordinates to minimise the provocation of challenging behaviour.

> *She displays a temper by throwing the food plate onto floor when there is something that does not belong to her close by. After recognising her preferences, we try to avoid provocation on this point, but sometimes staff may forget. When she attempts to throw the food plate, the supporting staff immediately apologises to her and she stops her temper. I try to identify the causes of challenging behaviour. Once identified, I share these possible causes with the supporting staff to avoid future accidental provocation. (Participant 4, paragraphs 10 and 15)*

In addition to identifying the possible causes of challenging behaviour, the interviewees indicated that the working experiences and enthusiasm of the staff affected their competence in managing challenging behaviour. In addition, the

importance of teamwork among direct care staff could facilitate the consistent management of individual residents exhibiting challenging behaviour.

> *If the staff is well experienced and committed to her job, the effect (of handling challenging behaviour) is very different. Other factors include consistency in handling the same resident, cooperation among working staff and the importance of teamwork. If there is no teamwork, it directly affects the residents. Find out the underlying cause of challenging behaviour and avoid provocation by the staff. (Participant 10, paragraphs 12-13)*

One interviewee further addressed that instructions given to residents or direct care staff had to be clear and simple, without any ambiguities.

> *Training given from nursing staff to supporting staff should emphasise consistency in handling challenging behaviour, because they (supporting staff) work closely with the residents. Hence, the impact of well-organised training is tremendous. The instructions must be clear; steps must be absolutely right. If the resident behaves in this pattern, you (the supporting staff) need to react correspondingly to make sure all steps are taken in order. There must be no ambiguity and everyone must be cooperative. This would facilitate handling [challenging behaviour]. (Participant 13, paragraphs 4-5)*

6.7.2 Improving the physical environment

All of the interviewees expressed that the current usual care environment had many constraints to residents, as mentioned in Section 6.6.2.1. The interviewees perceived that a quiet, well lit, spacious, comfortable and clean environment was the basic requirement for satisfactory residential care. Four of the primary nurses suggested playing music and television programmes based on the residents' preferences. Adjusting the daily schedule would be necessary to reduce the time constraints on completing the routine. For instance, late sleepers could be scheduled to bathe in the afternoon so that they would be more willing/ready to follow the schedule. Otherwise, they could exhibit anger or challenging behaviour when forced to bathe in the morning, when they were still very sleepy. Bedside lockers could be provided for residents to store their personal belongings, and a home-like environment with sofas in the dayroom, colourful decorations with flowers, plants and soft music should be offered. With so many suggestions for improving the physical setting, the interviewees indicated many difficulties in getting enough resources or facilities to achieve the improvements. The following data illustrate the suggested changes:

> *Too noisy, too congested and too hot – such conditions make people feel insecure and uncomfortable. To reduce challenging behaviour, I think the environment should be quiet and spacious and should make them happy. In addition, we need to look into the types of challenging behaviour of individual residents. For instance, if a resident displays violent challenging behaviour, such as by throwing chairs at others, it would threaten the safety of other residents, thus requiring a single room for this*

resident. This would provide a place for him to calm down and would protect others in a safe environment. (Participant 1, paragraph 2)

Space, comfort, no limits, no physical boundaries and no routine would allow them (residents) to go wherever they want to go. This would require sufficient facilities and a variety of choices to satisfy individual needs, such as eating, bathing and outings. In reality, direct care staff are functioning according to the daily routine. More resources are necessary, such as more clothes supply, so residents can change whenever they need to and various foods to share and eat whenever they want. (Participant 3, paragraphs 3-4)

Four primary nurses perceived staff stability as part of the environmental improvement. Low staff turnover could reduce the frequency of challenging behaviour through consistent nursing care plans for individual residents. The close relationships built between primary nurses and residents led to a better understanding and more efficient discharge of care plans that satisfied the needs of individual residents. The following data illustrate the perceived importance of this professional relationship in reducing challenging behaviour:

A familiar environment, a familiar daily schedule, a familiar staff, a natural and a home-like decorative environment can make residents feel at home. If they live comfortably with a sense of security, challenging behaviour would probably be reduced. (Participant 2, paragraph 2)

Our residents are intellectually disabled and they don't like psychiatric patients. They are very honest and reflect their true selves. Sometimes, the exhibition of challenging behaviour is related to the rapport between residents and staff. The more number of staff are familiar with the residents, the more the residents' needs can be fulfilled and the more likely they are to obey instructions. If the change of staff is too frequent, both staff and residents must adapt to each other. For instance, one of my residents likes to watch Jade, but someone changes to J2. He immediately becomes unhappy and exhibits challenging behaviour. In fact, new staff must understand the hobbies, habits and behavioural patterns of the residents. Otherwise, the exhibition of challenging behaviour will increase. (Participant 5, paragraph 3)

6.7.3 Engaging in meaningful activities

All of the primary nurses recognised that the active engagement of the residents in meaningful activities, especially during the day, could induce healthy daily living and improve sleeping patterns (by inducing sufficient fatigue). These activities should be structured, systematic and consistent. They should also be of appropriate complexity to correspond to individual residents' cognitive functions, thus inducing their interests, being achievable and providing satisfaction through the tasks. Meaningful activities could include painting and drawing, toy play, cosmetic classes and table-top tasks that occupied both hands and diverted their attention to task completion. Seven of the primary nurses mentioned the importance of tangible or food incentives in reinforcing engagement in an activity.

To reduce challenging behaviour, residents are assigned different activities to divert their attention. Their participation in meaningful activities in which they are interested and have the capacity to accomplish is encouraged. This allows them to gain satisfaction and achievement. When they complete the task/activity, verbal appraisal or their favourite gift is given. Subsequently, their challenging behaviour reduces. (Participant 2, paragraph 8)

Although all of the interviewees addressed the importance of effective communication with the residents in preventing challenging behaviour, only one interviewee suggested the need to train their social and communication skills to develop their social interactions and interests and to teach them how to appropriately communicate their needs without disruptive behaviour. The absence of concrete information on such training content reveals that such communication skills training is seldom conducted in clinical settings.

She can communicate verbally, but the staff works very fast without waiting for her response. We should ask her whether she is bathed and wait for her answer. I will remind myself to try this next time to maximise her capacity. (Participant 10, paragraph 79)

When the resident understands verbal instructions, I reinforce communication with her. The message should be clear and simple, so that she knows what to do. Once she follows the instructions well, verbal appraisal and tangible reinforcers are given. (Participant 13, paragraph 20)

As described by the interviewees, passive activities that did not require cognitive processing or active motor movement, such as MT and aromatherapy, were most appropriate for residents with SPID, as these residents often suffered from visual impairment, hearing loss and physical disablement. Hence, different kinds of sensory stimulation should be attempted to increase their awareness and responses to their immediate environments. Otherwise, they could remain absorbed in their inner worlds and invent their self-stimulating behaviour, which could involve self-inflicting and stereotypic behaviour.

> *Only massage therapy is appropriate for him because he is blind, deaf and dumb. He is not suitable for the multisensory room because he cannot see the lighting and visual effects of different equipment, and the soft music. He does not enjoy it at all, but he can feel physical touch and there is social interaction between him and the massage therapist. He looks like he enjoys it. (Participant 5, paragraph 16)*

6.7.4 Implementing person-centred care

All of the primary nurses revealed that the most important issue in managing challenging behaviour was understanding the residents' characteristics and the reasons underlying their behaviour. Nine primary nurses mentioned that rapport building was an effective strategy for preventing challenging behaviour.

> *In-depth understanding of the resident is necessary to identify the causes of their challenging behaviour so an effective method can be implemented (to*

deal with challenging behaviour). For instance, as mentioned before, the environment, the staff and the resident must all be considered. We need to offer a fixed daily schedule for activity and rest; maintain a stable workforce and reduce staff rotation; provide a comfortable and safe environment with no congestion or noise, and sufficient space for storage of personal belongings. Staff training must also be reinforced in the area of building rapport and mutual trust with residents. (Participant 2, paragraph 7)

Through regular assessment and communication with the SPID residents, the factors or issues related to daily care that triggered or underlie challenging behaviour could be identified. Early detection of mood swings was useful in preventing further manifestation of challenging behaviour by providing advice and comfort to the SPID residents. Person-centred care plans were perceived to be effective in reducing challenging behaviour, because this person-centred approach accurately addresses residents' personal needs. This mindset echoed the concepts of challenging behaviour as being closely related to the environment and caregivers' support.

If a resident has a past history of challenging behaviour, communication among the staff and deep understanding of the type of challenging behaviour exhibited and management method are needed. The staff should liaise with the resident's former primary nurse to formulate an appropriate person-centred care plan and reinforce mutual trust between current primary nurse and the resident. The resident should be

encouraged to communicate their needs verbally. If they cannot communicate verbally, you must have a friendly attitude, provide active care, listen patiently, observe carefully and understand fully (the reasons of challenging behaviour). All of these measures can reduce the exhibition of challenging behaviour. (Participant 2, paragraph 7)

Three primary nurses revealed that residents with better cognitive function required regular social interaction and attention because it provided appropriate channel for them to express their needs. A long-term trusting relationship could prevent the occurrence of challenging behaviour. Using attractive incentives to satisfy the residents' basic needs, such as snacks and delicious food, was perceived as important to strengthening the resident-staff relationship. The following data from one primary nurse illustrate this suggestion:

They usually nag for food or they want to play with you, as it can reduce their boredom. They usually look for someone to play with them. They are able to communicate. From my point of view, we need to care with a meticulous attitude, observe their likes and dislikes carefully and investigate what they really want. In fact, we need to pay attention to each resident in daily care. It takes time to do. When you observe a sign of temper, you must take action (at once before it escalates to challenging behaviour) by praising and redirecting his/her attention to a constructive task. (Participant 10, paragraphs 25-26 and 33)

When the aforementioned nursing actions did not reduce the exhibition of challenging behaviour, case medical officers were consulted for advanced behaviour management. It was the nurses' responsibility to report challenging behaviour to doctors, who would adjust the residents' medications to control extreme emotions and anxiety. The interviewees expressed that skin emollient was frequently used for residents who exhibited self-scratching behaviour. If self-scratching behaviour persisted, least restrictive practices, such as the use of mitten, gaiter and splint, one-piece garment, safety vest or time-out chair, might be required to protect the safety of the resident from further physical self-harm. For unmanageable challenging behaviour showing limited positive improvement in response to medication and treatment, chemical and physical restraint and/or seclusion were considered in the care plan as last resorts.

Once restrictive practices were used, family involvement became significant in the care plan, as guardian approval of restrictive practices had to be obtained. Three of the primary nurses mentioned family participation in managing challenging behaviour, such as by increasing the frequency of family visits and providing the appropriate materials to control behaviour.

> *The main problem is skin-picking behaviour, which causes abrasions and bleeding to her hands. In fact, we apply aqueous cream daily to her hands and her family brings cotton hand gloves for her to wear. Her family is supportive. They supply the clean gloves to the unit and take the soiled ones home for cleaning. She uses a pair of gloves daily. (Participant 10, paragraph 59)*

In general, families were invited to participate in the planning and implementation of the nursing care plan. Their support was very important to optimising the treatment strategies for managing challenging behaviour.

6.8 Summary of Qualitative and Quantitative Findings

6.8.1 Increasing adaptive behaviour during interventions

The participants of the MT group demonstrated the most and longest duration of adaptive behaviour compared with the other study groups at the two post-intervention measures, for which the results were statistically different from the MSE and MT-MSE groups at the 2-week follow-up. In parallel with the qualitative data, all of the interviewees observed that no maladaptive behaviour was exhibited by the residents during the interventions and that most of them appeared calm and relaxed. This observation coincided with the significantly increased levels of adaptive behaviour after the interventions, especially in the three intervention groups. According to the interviewees, the residents showed much more adaptive behaviour, such as maintaining eye contact with the therapist/enabler and reaching their hands out to touch things and the therapist. As suggested by a few of the primary nurses, MT was more suitable for those residents with sensory deficits, especially the blind and deaf, as they could not enjoy the music and lighting effects of the MSE. These comments were similar to the quantitative results where the residents who experienced MT alone demonstrated the highest frequency and longest duration of adaptive behaviour compared with the other intervention groups (Section 5.2.5). The primary nurses noted the different values of physical contact between MT and routine procedures. They believed that the social attention of MT could satisfy the

desire for attention seeking and could not be replaced by the attention provided during procedural care.

6.8.2 Inducing relaxation in the massage therapy and multisensory environment

The quantitative results revealed that the passive alert was very prevalent at T_2, especially MT-MSE which escalated to highest level and was significantly different from other three groups. However, the passive alert of MT-MSE dropped to the lowest level than other study groups and significantly different from MT and control groups at the 2-week follow-up. All interviewees appraised higher relaxation level in MT-MSE than other study groups in their on-site observations. They perceived that MT-MSE was most benefit and pleasurable to their residents than single mode MSE or MT if the intervention continued after the present study. In fact, such relaxation had reflected in the physiological changes. For instance, MT-MSE had lowest respiration rate and statistically different from control group just after the completion of intervention. The heart rate was also lower than the baseline, but not significantly different between groups

Most interviewees speculated that the augmented sensory stimulations of MT-MSE could accommodate residents with or without sensory deficit(s) but few interviewees perceived that MT was better than MT-MSE for residents with multiple sensory deficits because they could focus on pleasurable feeling of MT. Nevertheless, all interviewees identified that there was no residual advantage of MT-MSE in the usual care environment after the completion of interventions. Their observations were matched with the quantitative data as the passive alert of MT-MSE dropped to the lowest point at the 2-week follow up. They opined such

limited beneficial effect of MT-MSE in usual care environment due to insufficient doses and duration of the intervention.

6.8.3 Inducing sleepiness in the multisensory environment

Only the sleepy state was statistically different from the other alertness states. The residents in the MSE group exhibited the highest levels of sleepy state, significantly different from the MT group, which demonstrated the lowest sleepy state at the 2-week follow-up. The interviewees perceived that both the MT and MSE interventions could induce sleepiness in the residents, especially those demonstrating hyperactivity. Although there was no hyperactive subgroup in the outcome analysis, the sleepy state was relatively higher in the MSE group than in the other study groups at the 2-week follow-up. As expressed by the interviewees, the MSE environment was perceived as comfortable, relaxing and sleep-inducing during the interventions. However, sleepiness also occurred in the usual care environment at the 2-week follow-up, but insignificant.

6.8.4 No significant change in challenging behaviour

The primary outcomes (i.e., frequency and severity of challenging behaviour) showed statistical difference between the groups, but no pairwise contrast difference was identified. Though the control group had lowest level of frequency and severity of challenging behaviour, the improvement within group along 3 time points was only subtle and modest. Despite the steady decrease in the frequency and severity of challenging behaviour along different time-point assessments, a few of the interviewees noticed behavioural changes of their residents in the usual care environment. Many interviewees perceived no significant change in the

challenging behaviour of their residents in the usual care environment. They noticed differences in the challenging behaviour between the intervention sessions and the usual care environment, but not the progressive reduction of change upon completion of the interventions. They perceived the intervention effect to be relatively short-lived due to the pervasive effect of the usual care environment and more likely due to the insufficient doses (frequency and length) of the intervention sessions. Their observations did not match with the results of the outcome analysis that the frequency and severity of challenging behaviour showed statistical differences between the four study groups, but no pairwise group difference found. Therefore, the intervention doses and other personal and external factors should be considered to facilitate the optimal effects of the interventions used.

Other outcome measures that did not directly mentioned by the interviewees included physiological changes. As stated earlier, respiration rates of the three intervention groups were significantly lower than that of the control group. The MT-MSE group demonstrated the lowest respiration rate just after the interventions, whereas the MSE group demonstrated the lowest respiration rate at the 2-week follow-up. The control group residents maintained the highest respiration rates of the four study groups throughout the entire study period. Similarly, the participants of three intervention groups decreased heart rates over time, whereas those of the control group residents increased. However, none of these changes showed any statistical difference between or within the groups.

CHAPTER SEVEN

DISCUSSION

7.1 Introduction

This chapter discusses the treatment effects of MT-MSE and MT and MSE alone on the participants' outcomes. The treatment effects on the primary outcomes determine whether the interventions address the challenges of managing challenging behaviour in SPID residents at the 2-week follow-up. The treatment effects on the secondary outcomes were on these residents' heart and respiration rates, level of relaxation, alertness level and responsiveness and adaptive and maladaptive behaviour. Changes in alertness and the presentation of positive behaviour are two of several important issues that require thorough discussion.

Significant group improvements occurred in the frequency or severity of challenging behaviour among the participants of the three intervention groups compared with the control group. Similarly, five of the secondary outcome measures showed statistically significant differences between the three study groups and the control group. These secondary outcomes included the residents' respiration rate, average amount of adaptive behaviour, average duration of adaptive behaviour, passive alert and sleepy state alertness level.

7.2 Treatment Effect on the Primary Outcomes

The hypothesis for the primary outcomes (i.e., the frequency and/or severity of challenging behaviour among the participants in the three intervention groups would be significantly reduced compared with the control group) was partially supported. There was significant difference in between-group treatment effect on

challenging behaviour. However, no pairwise contrast group difference was found in all four study groups. Gradual improvements in both the frequency and severity of challenging behaviour over time were recognised.

The mean difference for the MT alone group between the baseline and the two post-intervention measurements of the frequency and severity of challenging behaviour was greater than that of the other study groups, whereas the mean difference of the control group had the smallest progression than three intervention groups, indicating no prominent change of behaviour pattern. The small sample size, the homogeneity of the individual units' atmospheres and individual tolerance to sensory stimulation might have weakened the robustness of the intervention effects. As suggested by the interviewees (nurses), the increased dose and duration of the MT and/or MSE interventions might reinforce the significant treatment effects and subsequently enhance the results of the pairwise comparisons between groups. According to the conceptual framework of challenging behaviour (Hastings et al., 2013), the factors contributing to the recurrence of challenging behaviour may include the pain reduction from natural painkiller (endorphins) an individual experience through SIB and their general low moods of psychosocial states (Hastings et al., 2013; Hayes et al., 2011). Several studies (Field, 2010; Field & Diego, 2008a) have shown that MT may relieve pain and elevate mood. Hence, the reduction of challenging behaviour in the MT group might have been due to pain relief and pleasure gain.

With reference to recent literature on management of challenging behaviour (Lotan et al., 2009; Singh et al., 2004), the sensory equipment was under manipulation and selectively offered to the subjects' personal choices, and changed upon their requests during intervention. The duration of MSE sessions was much

varied, depending on the tolerance of individual subjects. The shortest duration was 15 minutes up to the longest an hour (Lotan et al., 2009). The results of these studies revealed positive relaxation effect, and significant reduction of challenging behaviour (Lotan et al., 2009; Singh et al., 2004). Because of the randomised controlled trial, the present study offered same set of sensory stimulation equipment for all MSE participants, including their preferred equipment. The therapeutic effect of MSE might be undermined by the overwhelming sensory processing, leading to rapid shifting of responses.

Although the reduction of challenging behaviour was sufficient to achieve statistical differences between groups, no individual pairwise comparison was found significant. All of the interviewees (primary nurses) recommended that MSE and MT should be continued after the intervention sessions to sustain relaxation and positive behaviour over a longer period. In view of the limited available recreational resources in usual care, such meaningful programmes could be reinforced and become part of the SPID residents' daily care. As MT does not require any verbal responses or learned actions on the participants' behalf, it may be perceived as better-quality care or service than the daily routine (e.g., watching television and music appreciation) in terms of relaxation and physical contact, irrespective of its effect on their challenging behaviour (Cole & Burt, 2011). In fact, all of the interviewees were very supportive of the study interventions used and were willing to adjust the daily schedule to facilitate the continuous implementation of the interventions.

The enabling approach used by the enablers and therapists in the four study groups was consistent and comparable, the effects of social interaction and non-directive approaches on challenging behaviour might have differed (but not

significantly) between the intervention and control groups in the usual care environment. Social interaction and attention consist of sharing time together and promoting pleasure, which are mutually rewarding to the involved parties (Johnson, Douglas, Bigby, & Iacono, 2012). For instance, the enabler allowed the participants to freely choose their preferred sensory equipment in the MSE intervention, whereas the focus in the MT intervention was on creating pleasant experiences for the participants through physical touch. The main focus of MT-MSE intervention was creating a pleasant experience through physical touch in a sensory stimulating environment, where the participants could pay visual attention to the sensory environment if they were still awake. The focus for the control group participants was the enjoyment of the social interactions provided in the usual care environment.

As revealed in the results, the enjoyment of physical touch from MT could pacify the participants most by reducing the frequency and severity of challenging behaviour. The mean differences in these outcomes between the baseline and two post-tests were the greatest in the MT group. The possible reasons might be the activation of vagus nerve which could elevate mood and relieve pain by increasing secretion of serotonin and dopamine, and decreasing pain sensitivity (Field et al., 2007). However, the magnitude of change in the control group in the frequency of challenging behaviour was modest over time, between the baseline and two post-intervention measurements. As mentioned, the overwhelming sensory stimulation in the MSE could have curtailed the concentration of the MT-MSE participants on appreciating the pleasure of physical touch through MT (Munde, 2011). Nevertheless, the participants of all of the study groups appreciated the social contact and interaction during the interventions, and no agitated or discontented behaviour was observed throughout the study, which was comparable

with the findings of many previous studies (Hutchinson & Kewin, 1994; Lancioni et al., 2002; Lotan et al., 2009; Shapiro et al., 1997; Singh et al., 2004). This may be achieved irrespective of their behaviour and without any demand for learned actions (Hutchinson & Kewin, 1994; Lancioni et al., 2002). In this study, the enabling approach revealed no compelling effect in challenging behaviour.

As suggested by a meta-analysis of the effectiveness of MSE on reducing challenging behaviour (Lotan & Gold, 2009), assessment of outcome measures should be taken place in daily living context because it could truly reflect the generalisation of the given intervention as an immediate change of behaviour during intervention frequently occurred in a distinctive manner (Lotan & Gold, 2009). Hence, the frequency of challenging behaviour in the usual care environment was assessed in this study to accurately evaluate the clinical effectiveness of individual interventions in comparison with the control group.

Residents with SPID mostly rely on direct care staff to arrange their daily schedules, which can allow them time to actively engage in meaningful activities or be occupied in a passive and inactive state (Johnson et al., 2012; Mansell, Elliott, Beadle-Brown, Ashman, & Macdonald, 2002; Munde & Vlaskamp, 2015). Meaningful activities may include opportunities to socialise with others through daily activities or play / activity involving cognitive, physical and sensory stimulation with a sense of accomplishment (Mansell et al., 2002). Research on the attention and support from direct care staff in strategies for managing challenging behaviour has increased (Hastings et al., 2013; Lambrechts et al., 2009; Mansell et al., 2002). Yet, resident-staff interactions have frequently been reported as poor in quality, with physical contact mostly occurring only during routine care procedures, a lack of positive emotional exchange and the omission of planned leisure activities

when manpower is low (Chan & Yau, 2002; McConkey et al., 1999; Vlaskamp & Nakken, 1999). In addition, the negative responses of direct care staff to residents' challenging behaviour may further aggravate the likelihood of that behaviour, especially when they treat the occurrence of such behaviour as being habitual or attention seeking in nature and thus show no intention to intervene. Such a stereotypical view promotes the manifestation of challenging behaviour in the usual care environment (Hastings, 1997). The non-therapeutic usual care environment and activities compromised the positive effects of the interventions used in this study. As a result, the effectiveness of MSE and MT on the frequency and severity of challenging behaviour were undermined, thus no pairwise comparison was found significantly different. Nevertheless, the significant carryover effect (two weeks after the interventions) between groups has not been reported in previous studies (Chan et al., 2007; Martin et al., 1998).

As disclosed in the interviews, several interviewees (primary nurses) perceived that the usual care environment was not a therapeutic site in which to conduct behavioural or psychosocial interventions due to its high congestion, loud noise and busy daily schedule, which were also perceived as factors contributing to the residents' challenging behaviour.

Though the treatment effects of MSE and MT on reducing challenging behaviour was not markedly significant, the positive appraisal of nursing interviewees was prominent. Adjustment of treatment protocol with controlling the number of sensory inputs may match their sensory threshold without mental exhaustion. In corresponding with the components of the conceptual framework, the provisions of MSE and MT are only attempt to fit in the active engagement of meaningful activities, and relaxation measures. Other major components e.g.,

biological factor, applied behavioural analysis to identify function of challenging behaviour, and other people's behaviour, are untouched in the study. Short-term or immediate effect was significant in respiration rate, adaptive behaviour and alertness level. For longer-term effect, support from direct care staff is paramount to maintain the reduction of challenging behaviour in usual care environment.

In fact, the magnitude of change in the control group in the frequency and severity of challenging behaviour was modest between the baseline and two post-intervention measurements when compared with three intervention groups. The greatest magnitude of change was MT group between baseline and post-intervention outcomes. The less significant effect of MSE and MT-MSE may be degraded by the mental exhaustion of overwhelming sensory stimulations (Munde, 2011).

Considering the sensory threshold in future studies, the clinical effectiveness of MSE and MT-MSE may become apparent. In the present study, we cannot support the significant improvement of the interventions through scientific investigation but the interventions were fully supported by the interviewees (Section 6.4.1), at least they witnessed the significant behavioural change between the intervention and usual care. They appreciated the out of usual care environment to conduct the interventions because they perceived that sensory environment was more therapeutic than usual care environment.

From the economic point of view, it might not be worthwhile to spend money to set up sensory room, but from normalisation principle, sensory stimulation is a basic human need to develop motor skills and survival through experiences of the five sensory modalities (Ayer, 1998).

In view of the positive perception from the interviewees, and there are limited leisure alternatives for people with SPID, MSE is perceived as a pleasurable, enjoyable and highly humane approach (Lancioni et al., 2002; Slevin & McClelland, 1999). As a matter of fact, MSE is the only leisure resource in many long-stay care homes for adults with SPID. Hence, methods to increase its effectiveness are more productive than weaken its usage. For instance, a tailor-made MSE programme for individual SPID persons, but this would threaten the rigor of a controlled trial; or improving environmental variables, e.g., attitude of direct care staff, to sustain the therapeutic effect of interventions in usual care environment.

Managing challenging behaviour is a complex process, as its presentation or manifestation may serve several interwoven functions. For instance, skin picking may be a form of attention-seeking behaviour, as it may be obsessive compulsive; inadvertently, the behaviour is reinforced through food or tangible material and freedom from task demands. It may also be a secondary feature of mental illness, as SIB is usually associated with depression (Hayes et al., 2011; Ross & Oliver, 2002). Consequently, the mechanism contributing to challenging behaviour is obscure. Many more resources and advanced research methods and instruments may be required to determine the root causes of challenging behaviour (Ali et al., 2014; Emerson & Einfeld, 2011).

The conceptual framework of challenging behaviour (Hastings et al., 2013) proposes the adoption of the PBS model in residential care service. The PBS model emphasises proactive strategies for relieving the stress vulnerabilities of SPID residents, such as by providing medical treatment for underlying physical illnesses, offering effective pain management to enhance the appreciation of leisure activities and facilitating active engagement in meaningful activities. Environmental

enhancement is more likely to result from a reliable workforce, a predictable daily schedule, a relaxed atmosphere and freedom from demands on pursuing routine and joining disliked programmes rather than providing fancy decorations [National Institute for Health and Care Excellence (NICE), 2015]. Environmental factors that may elicit challenging behaviour should be eliminated. For instance, physical support should be provided to avoid the frustrations of task demands, and modification of task complexity may facilitate task achievement. Apart from increasing the personal buffer zone, providing reinforcement can also enhance the environment (NICE, 2015).

In addition, staff-resident relationships can be promoted through the unconditional attention to and support of residents from direct care staff (Hastings et al., 2013; Mansell et al., 2002). Active engagement in meaningful activities (e.g., MSE and MT) provides psychosocial support to engage the attention of SPID residents in a safe and emotional exchange atmosphere (Hastings et al., 2013). This can thereby reduce the display of challenging behaviour. In addition, SPID residents could explore their immediate environment through touch and build their independence by experiences different sensory stimulations that increase the opportunity of skills learning (Hulsegge & Verheul, 1987).

The interviewees perceived MT as beneficial to the participants with sensory impairments, as it allowed them to experience pleasurable feelings through physical touch. They noticed differences in the presentation of challenging behaviour between and within intervention sessions and the usual care environment. The SPID participants looked relaxed and full of enjoyment during the interventions. Though significant change of challenging behaviour was detected in the statistical analysis after completion of the interventions, many of the interviewees observed no

behaviour change between any two sessions or throughout the entire study period in the usual care environment, and they also perceived that the intervention effect was relatively short-lived due to insufficient doses (frequency and length of sessions) of the intervention used, thus providing non-significant changes in the challenging behaviour among the four study groups. Many studies involving MSE and MT for SPID people have evaluated immediate effects, such as reducing challenging behaviour (Ashby et al., 1995; Cuvo et al., 2001; Deakin, 1995; Lotan et al., 2009) and/or enhancing concentration, relaxation and responsiveness to the intervention (Croghan, 2009; Hutchinson & Haggar, 1994; Lindsay et al., 1997; 2001). However, few studies have examined both the immediate and long-term effects (Chan et al., 2007; Dossetor et al., 1991; Martin et al., 1998; Shapiro et al., 1997). Only one case study (Dossetor et al., 1991) showed effective eradication of challenging behaviour after 18 months of MT. Two other studies (Chan et al., 2007; Martin et al., 1998) showed reductions in challenging behaviour during the intervention, but no significant immediate changes compared with the control group at immediate or carryover effects (between 4 and 12 weeks) after MSE intervention. In this study, the therapeutic effects of MSE and MT gradually and just significantly reduced challenging behaviour between groups. The control group demonstrated a modest effect on reducing challenging behaviour in SPID residents, possibly as a result of residual enabling and social interactions that was comparable to the results of an earlier study (Martin et al., 1998). As different severities of ID and age groups have a variety of intensities of sensory drives and thresholds, various intervention patterns, considering the dose and length of the interventions, may be needed to accommodate individual needs and thereby produce optimal effects in future studies (Chan et al., 2010; Lotan & Gold, 2009).

Only four interviewees were aware of or identified the gradual reduction of challenging behaviour in their designated residents in the usual care environment in the study. Some of the interviewees believed that personal and external factors, such as physical health and environmental situations, could attenuate the optimal effects of the interventions used. They also noticed that the participants who benefited from the MSE were those who tended to seek sensory stimulation through challenging behaviour. Interventions matching a specific function of reducing challenging behaviour more effectively produced positive change in such behaviour. Therefore, the MSE may be more useful in reducing challenging behaviour in those who seek sensory stimulations than other interventions that are arbitrarily or inappropriately given (Denis, Van den Noortgate, & Maes, 2011; Emerson & Einfeld, 2011). The nature of the social interaction within the usual care environment could augment the intervention provided. For instance, positive emotional exchange in the usual care may reduce the frequency of challenging behaviour by replacing it with frequent engagement in social exchanges (Chan & Yau, 2002; Denis et al., 2011; McConkey et al., 1999). Nevertheless, most of the interviewees perceived that the carryover effect of the interventions on reducing challenging behaviour was absent in the usual care environment, although reductions in both frequency and severity of challenging behaviour were found in the quantitative (outcome) results. Their perceptions might have been affected by their brief and overall impressions of the residents' behaviour, as they were often occupied with the busy routine and did not have time to observe the residents earnestly. In addition, the staff's beliefs about challenging behaviour could have influenced their helpfulness and reporting of the residents' challenging behaviour. For instance, if they perceived challenging behaviour to be attention seeking and/or habitual, the likelihood that they would put

effort into fulfilling the residents' needs was low (Hastings et al., 2013; Poppes et al., 2010). If the change in challenging behaviour is insignificant and gradual or too rapid, it is recommended that videos be taken to observe or capture such subtle changes (Allen, 2009; Munde et al., 2012).

7.2.1 Challenges of managing challenging behaviour

Two key elements have been suggested to manage challenging behaviour, the PBS model and ABA. These approaches can reduce more than 80% of challenging behaviour in people with SPID by analysing the purpose of their challenging behaviour and subsequently taking follow-up actions to satisfy their identified needs (Furniss & Biswas, 2012; Hastings et al., 2013).

MSE and MT interventions were considered satisfying the five functions (purposes) of challenging behaviour through the multiple sensory inputs, enabling approach, pleasurable physical touch and freedom from demands afforded during the interventions. Most of the interviewees expressed that identifying the functions of challenging behaviour, making physical improvements to the usual care environment, engaging in meaningful activities and implementing person-centred care might be effective in managing challenging behaviour. Some of the interviewees mentioned physical discomfort as a possible factor contributing to challenging behaviour, but very few suggested that medical attention to the physical ailments of SPID residents could improve the management of their challenging behaviour, especially for chronic challenging behaviour that might overshadow the medical/physical needs of these residents (Ali et al., 2014). As mentioned previously, people with SPID are more vulnerable to developing health problems than the general population (de Winter et

al., 2011). Thus, regular medical physical checks are particularly important in preventing the occurrence of challenging behaviour (Hastings et al., 2013; Hayes et al., 2011).

Most of the interviewees acknowledged that challenging behaviour was exhibited to convey messages to others and addressed the needs of communication skills training. However, no one mentioned the use of AAC tools to facilitate staff-resident interactions. Generally, the interviewees did not demonstrate the knowledge to address the physical needs of the residents, the functions of their challenging behaviour or the skills required for communicating with nonverbal SPID people. It seems that a knowledge deficit among direct care staff is not uncommon in challenging behaviour management. Hence, the focus on developing communication and social functioning is also crucial to eliminating the recurrence of challenging behaviour (Hastings et al., 2013).

As shown in a prevalent study of challenging behaviour in institutional facilities, SIB and SSB were consistently demonstrated more than aggressive/destructive behaviour, which was restricted by the participants' physical inability to attack others (Poppes et al., 2010). A lack of knowledge of the adverse consequences of SIB also endangered the safety of the residents. For instance, the direct care staff did not stop the repeated head hitting of residents, which could lead to retinal detachment. They tended to define behaviour as challenging only when the behaviour affected the social order of the environment. As a result, direct care staff acted promptly to aggressive behaviour rather than the common self-injurious, self-stimulating and/or stereotypic behaviour (Hastings, 1997; Lambrechts & Maes, 2009; Poppes et al., 2010). Hence, staff training is essential to increase staff

awareness of the impacts of challenging behaviour on SPID residents' physical and psychosocial health.

Nevertheless, most of the interviewees in this study emphasised the need for person-centred care to reduce challenging behaviour in these residents. When frontline staff seek long-term strategies for managing challenging behaviour, staff training, environmental enhancement and engagement in meaningful activities are important factors for reducing challenging behaviour in the residential care setting.

In this study, MT was superior to MSE, and the combined treatment of MT and MSE was attenuated by brief mental exhaustion from intensive sensory stimulations in the MSE. There was significant change in the frequency and severity of challenging behaviour between the study groups, with showing lowest in the control group. In fact, the control group showed modest gradual improvements within groups while MT was the greatest improvement within group but statistically insignificant. The therapeutic effect of MT may result from pain relief and mood elevation (Field, 2010; Field et al., 2007). Several important reasons may account for the results of the primary outcomes in this study. These reasons include the small sample size, insufficient dose and frequency of interventions, no controlled MSE setting to accommodate individual sensory thresholds, lack of social support from the direct care staff in daily activities or care and the negative or inappropriate attitudes of the direct care staff towards challenging behaviour. Furthermore, the complexity of challenging behaviour could have also been a contributing factor, as one form of problem behaviour could have multiple functions or purposes, thereby complicating its management. Hence, staff training is essential to increase staff awareness of the impacts of challenging behaviour on SPID residents' physical and

psychosocial health. For instance, the use of the PBS model ensures that direct care staff provide enough assistance to enable SPID residents demonstrating challenging behaviour to actively engage in meaningful activities. Adults with SPID spend most of their time supported by direct care staff in the usual care environment. Thus, a greater focus on social interaction may increase their social awareness and responsiveness to the immediate environment (Johnson et al., 2012; Mansell et al., 2002). The PBS model consists of ABA, aiming to identify the underlying causes of challenging behaviour, and proactive strategies in the delivery of person-centred care and preventing the factors (e.g., emotional frustration and physical discomfort) contributing to challenging behaviour. Undoubtedly, providing training to all direct care staff and involved caregivers for assessing and managing challenging behaviour is vital to supporting SPID residents who frequently exhibit challenging behaviour.

7.3 Treatment Effects on Secondary Outcomes

The secondary outcomes involved heart and respiration rates, adaptive and maladaptive behaviour and alertness level. Only the effects on five secondary outcome measures, including respiration rate, amount of adaptive behaviour, duration of adaptive behaviour, passive alert and sleepy state, were sustained 2 weeks after completion of the interventions. In contrast to the primary outcome measurements, the first post-intervention assessment of the secondary outcomes was conducted in a quiet area or away from the usual care environment. Thus, the results better reflected the effectiveness of the interventions without the effects of the

usual care environment and its context. At the 2-week follow up, all outcome measures were assessed in the usual care environment.

It was hypothesised that the carryover effects (at the 2-week follow-up) of the three intervention groups would differ significantly from (or would indicate greater improvements than) the control group in the secondary outcomes. In view of the outcome data at the 2-week follow-up, significant effects were observed on some of the outcomes. First, respiration rate was reduced in all three intervention groups, and amount and duration of adaptive behaviour increased in the MT group. In addition, passive alert was prevalent in MT-MSE just after the completion of interventions, but abruptly decreased to the lowest level at 2-week follow up, and sleepy state was significantly reduced in the MT group.

It was also hypothesised that the combined MT-MSE intervention would have better outcomes for decreasing heart rate, maladaptive behaviour and increasing alertness state than each of the two single interventions (i.e., MT or MSE alone). However, these hypotheses were partially supported, especially the lowest respiration rate and the highest passive alert just after the completion of the interventions. These two outcome measures were significantly different from other study groups, indicating the relaxation state of MT-MSE just after the intervention. Whereas, the MT group persistently showed significant increases in adaptive behaviour and the least sleepiness compared with the other two intervention groups at the 2-week follow up. Furthermore, some of the interviewees also perceived that MT was better than MSE, especially for those with multiple sensory deficits.

7.3.1 Heart and respiration rates

The first secondary outcomes found to significantly improve either immediately or 2 weeks after the intervention were the participants' heart and respiration rates. A low to normal range of heart and respiration rates represents low bodily excitement (Schilling & Poppen, 1983). Therefore, people with low heart and respiration rates live longer, as they are not under stress and have longer resting thresholds (Rakhimov, 2011; Thaulow & Erikssen, 1991). The normal resting range of adult heart rate is 70 to 88 bpm (Fitzgerald, Weldon, & Scalia, 2016), whereas the normal range of adult respiration rate is 15 to 20 Bpm. People with chronic illness usually increase to 20 Bpm or above (Rakhimov, 2011). The heart rates of the three intervention groups ranged from 78 to 81 bpm and their respiration rates ranged from 16 to 17 Bpm at the 2-week follow-up. The mean values of heart and respiration rates indicated that the participants in all of the intervention groups (i.e., MSE alone, MT alone and MT-MSE) were in a state of relaxation, as their results in all post-intervention measurements were below the baseline readings and within the reference range of ordinary adults in a resting condition. Only the respiration rates of all of the intervention groups were significantly lower than baseline and the control group at the two post-tests. This indicated lower physiological arousal, thus presenting a state of relaxation or less anxiety in all three of the intervention groups. In contrast, the participants of control group persistently increased both heart and respiration rates along the two post-tests. Individual group differences are discussed in the following section.

7.3.1.1 Level of relaxation

As suggested in the literature review (Chapter 2), any intervention promoting relaxation can be of therapeutic value to people with SPID (Deakin, 1995; Lindsay & Baty, 1986; Schilling & Poppen, 1983), as muscle relaxation counteracts one's anxiety level and thus challenging behaviour (Chan et al., 2010). Relaxation not only reduces stress arousal behaviour, but also promotes the general well-being of residents with SPID (Chan et al., 2010; Kokoszka, 1992; Slevin & McClelland, 1999).

MT and MSE have been widely used in the ID field, particularly for people with SPID (Ayer, 1998; Croghan, 2009; de Bunsen, 1994; Munde, 2011; Munde & Vlaskamp, 2015; Vlaskamp et al., 2003). As illustrated by previous studies (Ashby et al., 1995; Ayer, 1998; Hutchinson & Haggar, 1994), the single or combined modes of intervention (MSE alone, MT alone and/or MT-MSE) used in this study had significant effects on enhancing relaxation of the residents with SPID (Lindsay et al., 1997; 2001). For instance, the participants of both MSE and MT-MSE groups showed relatively lower respiration rates than those of the other two groups, indicating a reduction of sympathetic activities in different internal organs, especially the heart and lung, which was comparable with the relaxation effect. Such lower respiration rates were not only found immediately after the interventions, but also sustained over the follow-up period.

Along with a high level of passive alertness, the MT-MSE group attained the lowest respiration rates at the first post-test (immediately after completing the intervention). The MSE group achieved the lowest respiration rates, along with relatively higher sleepy state at the 2-week follow-up.

One study attempted to use physiological signs along with alertness level (Munde, 2011). It was hypothesised that the physiological measurements of heart and respiration rates could validate the alertness observed among the residents with SPID (Munde, 2011). Munde (2011) showed that lower respiration rates corresponded to alert moments, whereas heart rates increased when alertness shifted and were higher in the alert state than in the withdrawn state, assuming the alert state was active in nature. When the subjects were agitated, all of their physiological parameters increased, including their heart and respiration rates (Munde, 2011). However, Munde's (2011) study had many shortcomings. For instance, the study did not include baseline assessments for comparison with the post-test, and only three subjects were examined. The study also did not clearly indicate whether the alert state was active or passive, as its presentation was rather different in terms of body movement (Munde, 2011). The increased heart rates might be due to the individuals' responses of enjoyment and excitement to the activities and thus resulted in activation of the sympathetic nerves. Another empirical study (Woods, 2014) reported that when residents with SPID were relaxed in the MSE, their breathing became shallower and slower, they looked sleepy and less irritable and they smiled and vocalised their pleasure (Woods, 2014). Other observational studies have unveiled that when there is no external stimuli or social support in the usual care environment, the alertness states of residents are dazed, sleepy and withdrawn (Guess et al., 1988; Guess & Siegel-Causey, 1995; Munde, 2011; Vlaskamp & Nakken, 1999). Hence, active support from direct care staff influences the attention and alertness level of SPID residents in the usual care environment (Guess & Siegel-Causey, 1995; Hastings et al., 2013; Mansell et al., 2002).

One study reported that pulse rates decreased by seven beats from the baseline measurement after three 10-minute hand massage sessions (Croghan, 2009). Although heart rates progressively decreased in all of the intervention groups and steadily increased in the control group during the study period, there was no significant difference in heart rate between and within groups over time. Nevertheless, a notable difference in heart rate was found in the MSE group, which was five beats lower than the baseline at the 2-week follow-up, but only three beats lower than baseline at the 2-week follow-up in the MT and MT-MSE groups. Controlled and clinical studies on MT and MSE have generally adopted objective measures, such as heart and respiration rates, as the outcome measures to confirm the relaxation state of people with severe ID (Chan et al., 2007; Croghan, 2009; Hegarty & Gale, 1996; Shapiro et al., 1997; Slevin & McClelland, 1999). However, only a few of them have shown statistical significance (Shapiro et al., 1997; Slevin & McClelland, 1999). Such non-significant results, similar to this study, might have resulted because the physiological arousals at baseline (and in usual care environment) were often very low and sustained relatively stable. Therefore, it would have been difficult to generate a significant change in the physiological status (e.g., reduction of heart or respiration rate) after undergoing the interventions. Furthermore, the relaxation effects of both MSE and MT are comparable (Ayer, 1998; de Bunsen, 1994). Thus, the three intervention groups had similar patterns of heart rate reduction across the different time-points. Although the average heart rate in the control group steadily increased over time (ranging from 81 to 84v bpm), the extent of sympathetic activity remained low, as the change of heart rate was still within normal range (Fitzgerald et al., 2016) and the alertness level was still in the passive alertness state. Therefore, the difference in residents' heart rates between

the three intervention groups and the control group was not large enough to be significant. Future research could consider modulating the duration and frequency of the interventions, sample size and/or environmental stimulations in usual care.

A few relatively longer-term (2-week) effects of the MSE and MT-MSE was primarily identified in this study; and these had not been reported in the recent MSE studies (Chan et al., 2007; Martin et al., 1998).

7.3.2 Levels of alertness

Apart from the respiration rate, interaction effect was detected in passive alert, while group effects of the interventions were detected in the sleepy state of alertness. Passive alert was very prevalent just after the completion of interventions in all study groups, in which MT-MSE obtained the highest level (58%) that was significantly different from other three study groups. Hence, the relaxation level of MT-MSE was dominant than single mode of intervention that several interviewees also shared similar observations. They believed that the augmented tactile stimulation and physical proximity through MT could strengthen the relaxation effect of MSE, especially favourable to residents with visual and hearing impairments. The relaxation effect could also be revealed in the lowest respiration rate, assuming the activation of vagus nerve of the parasympathetic nervous system.

The presentation of sleepy state includes sleeping, snoring, lowering of eyelids and involuntarily shaking of the head or body (Vlaskamp et al., 2009). The MT group showed the least sleepy state at two post-intervention measures (4-6%) than the other three groups. Only the sleepy state of the MT group at the 2-week follow-up was significantly different from that of the MSE (26%). Other alertness levels were found insignificant in the post-intervention assessments, including the

active alert (green colour) which focused on the immediate environment with body movement; and the amber inactive state, which turned their attention inward and withdrawn (Vlaskamp et al., 2009).

According to the overall percentage of various alertness levels, the major alertness states at baseline were the inactive state (over 66% in the MT group) and sleepy state (approximately 43% in the MT-MSE group). The passive alertness state became prevalent (approximately 58% in the MT-MSE group) immediately after completion of the interventions and extended to both alert (the active and passive alertness with approximately 68% in the MT group) and inactive states (37% in the MT-MSE group) at the 2-week follow-up.

It was hypothesised that participants would stay in the alert state, showing good awareness of and maintaining satisfactory social contact with the immediate environment, just after the interventions and would carry this effect over to the 2-week follow-up. The alert state consists of active alertness with body movement and passive alertness without body movement. The marked increase in passive alertness immediately after the intervention instead of active alertness might have been due to a state of relaxation and the constraint of physical capacity of the participants, who were often motionless but still maintained social contact with and awareness of the immediate environment. The upsurge in passive alertness was extended in all study groups immediately after the interventions, especially in the MT-MSE group, but passive alertness was sustained in only the MT and control groups at the 2-week follow-up. Both MSE and MT-MSE groups shifted to inactive and sleepy states at the follow-up. Such rapid alertness shifting in this study was also found in previous studies (Munde et al., 2012; Munde & Vlaskamp,

2015), which explained that the rapid and brief mental exhaustion due to intense sensory stimulations in the MSE altered their alertness levels (Guess & Siegel-Causey, 1995), especially when there was no social support from the direct care staff.

In contrast, the MT group showed the lowest sleepy state level of all four groups. In MT, the alertness state may be mediated by the activation of the vagus nerve of the sympathetic nervous system to become attentive and wakeful (Field, 2010; Field & Diego, 2008b). Studies of MT (Field, 2006; Field et al., 1996) have used EEG to capture brain waves before, during and after 15-minute MT sessions for medical students and staff during lunchtime. Increased beta and theta waves keep people awake during the day, and decreased delta waves which usually increase during sleep. A mathematic computation task was added after the MT session. The subjects who received 15-minute MT sessions on mathematic computations performed better than those in the control group undergoing relaxation activities in terms of task completion speed and computation accuracy. This may indicate that MT not only enhances one's attention and alertness, but also improves his or her cognitive performance (Field et al., 1996). This may also explain why the sleepy state of the MT group was low in this study: the delta wave decreased after MT.

Some of the interviewees perceived that the multisensory environment (including the MSE and MT-MSE) induced sleepiness in the participants, but the quantitative results of this study did not support their perceptions. Their perceptions might have been confused by the state of passive alertness, where the participants were motionless and inactive but maintained awareness of their surroundings (Munde et al., 2012). There was a significant increase in sleepiness in

the intervention groups at the 2-week follow-up, especially among the MSE participants. The return to sleepiness and inactivity in the MSE and MT-MSE groups could also be explained by the brief exhaustion of information processing after intensive sensory stimulations during the MSE sessions (Munde et al., 2009a; Munde et al., 2012).

Guess and Siegel-Causey (1995) described an individual's behavioural or attention state as having different levels of control and stability in terms of changing from one state to another. As presented in the literature review (Section 2.9), behavioural levels may include asleep and drowsy, awake-inactive-alert, awake-active-alert and crying/agitation states (Green et al., 1994; Guess et al., 1993; Guess & Siegel-Causey, 1995). The power or control of some behavioural levels is very strong and stable, being very resistant to change or permanent shifts to other states. For instance, deep sleep is a strong behavioural state and is resistant to perturbations or disturbances by environmental variables such as light, sound and environmental stimulations. In contrast, the strength of the inactive state is relatively weak, and thus after perturbations it shifts more readily to other states, either deep sleep or wakefulness (Guess et al., 1993; Guess & Siegel-Causey, 1995).

Guess and Siegel-Causey (1995) also described the shifting from sleepy state to passive alertness or other alertness states and then returning to the sleepy state or original baseline state as the butterfly effect. They explained that their work was built on previous studies (Guess et al., 1990; 1993; Wolff, 1993), in which the development of the behavioural and emotional conditions in infancy to students with SPID experienced similar natural rebounds to the sleepy and calm state. However, the butterfly effect was not seen in this present study. The major original state

(baseline) was inactive which was more readily to shift into other state(s) than the sleepy state (Guess & Siegel-Causey, 1995). As the butterfly effect has only been mentioned by Guess and Siegel-Causey (1995), recent studies of behavioural states have evolved across and been simplified to four levels of alertness (Munde et al., 2009a; 2009b; Vlaskamp et al., 2009).

Similar to Guess's studies (Guess et al., 1993), all study groups shifted from the major inactive state at baseline to passive alertness after 10-week environmental interventions (perturbations) and stayed in different levels at the 2-week follow-up, for instance, MSE group distributed almost evenly across four levels but major in inactive and sleepy states; while MT group maintained on active and passive alert, MT-MSE group shifted to inactive state, and the control group shared between passive alert and inactive state. It seemed that sensory tolerance might play an important part to influence the alertness of the MSE and MT-MSE groups because those studies adopting controlled MSE setting showed positive outcomes e.g., reduced challenging behaviour (Lotan et al., 2009; Singh et al., 2004), increased alertness (Munde et al., 2012; Munde & Vlaskamp, 2015). In contrast, studies using standard MSE protocol for all participants revealed minimal effect on reducing challenging behaviour (Chan et al., 2007; Martin et al., 1998). The variations of different alertness levels in control group were believed as a result of social support from the enabler (Johnson et al., 2012) and the active shifting of intervention groups. The only significant difference between control group and intervention group was MT-MSE in passive alert where MT-MSE attained the peak level of passive alert just after the interventions, and then shifted rapidly away from passive alert, hence the difference between MT-MSE and control group was significant at the two post-tests.

7.3.2.1 Alertness and responsiveness

Engaging with SPID residents is not an easy task due to their low cognitive ability and short attention span (Munde et al., 2012; Munde & Vlaskamp, 2015). Munde et al. (2009a; 2009b) reviewed studies of SPID students (Green et al., 1994; Guess et al., 1988; 1990; 1993; Guess & Siegel-Causey, 1995) and consolidated the descriptions of alertness/behavioural state. They further defined the levels of interaction with environmental stimulation in terms of attention and responsiveness, such as active and passive alertness (Munde et al., 2009a). Vlaskamp et al. (2009) strived to identify the right moment to introduce learning and personal development to children with special needs in special education. They later developed an assessment tool, the AOC, to examine the alertness state of these students. The optimal alertness level is the alert state, which can be subdivided into active and passive alertness. The alert state is defined as the moment at which one focuses on his or her immediate environment and is actively engaged in terms of concentration, responsiveness and social initiation (Munde et al., 2012; Vlaskamp et al., 2009).

Residents in active alertness demonstrate more body movement and initiative in social contact, whereas those in passive alertness demonstrate limited physical movement and behave passively in social interactions and towards the external environment through eye opening, visual tracking and visual gazing in response to stimuli (Munde et al., 2012). Nevertheless, people in the passive alertness state are more likely to be relaxed than those in the active alertness state (Munde, 2011; Munde et al., 2009a; 2012). In this study, the major response of SPID participants to different interventions was the alertness state, with active and passive alertness

contributing to 79% of the observed alertness level in MSE, 83% in MT and 88% in MT-MSE immediately after the interventions, whereas, approximately 72% of the control group was in the alert state in response to the social attention of and interaction with the enablers in the usual care environment. The upsurge of passive alertness immediately after interventions (sharing from 40%-58% between the four study groups) indicated the prevalence of relaxation state. Apart from the relaxation effect noted, the higher the percentage of passive alertness among SPID residents may be understood in terms of physical disablement and motor dysfunction, such that residents may demonstrate their interest in and enjoyment of the stimulations with eye contact and passive cooperation with the therapist (Munde, 2011).

However, the suboptimal alertness level would be the inactive state, in which a SPID person may be withdrawn and non-responsive to external stimuli, but may stay awake and more readily shift to another state if stimulation is provided (Guess & Siegel-Causey, 1995; Munde et al., 2012; Vlaskamp et al., 2009). According to experts' opinions, alertness can be described as a behavioural state in which 'an individual's level of interaction and engagement with the environment that becomes manifested and observable in his/her behaviour' (Munde, 2009b; 2011, p. 115). Alertness is closely associated with responsiveness, which describes the reaction of an individual to environmental stimuli offered in interactions with other people (Ashby et al., 1995; Munde et al., 2009b).

From the quantitative (outcome) findings of this study, all of the study groups maintained at alert state (including active alert and passive alert states) just after the interventions, whereas the MSE group participants shifted from inactive (54%) and sleepy (38%) states at baseline and returned to inactive (27%) and sleepy (26%)

states at the 2-week follow-up. The MT group initially occupied the inactive state (66%) at baseline and then maintained active (32%) and passive (36%) alertness at the 2-week follow-up. The MT-MSE group shifted from the inactive (48%) and sleepy (43%) states at baseline and then shifted to the major inactive (37%) and active (24%) alertness state at the follow-up. The control group primarily stayed in the inactive state (61%) at baseline and diverted to the passive alert (37%) and inactive state (25%) at the follow-up.

As observed by Green et al. (1994), the non-alert cognitive state before intervention may not be spontaneously shifted to alertness or responsiveness to the environmental stimulations during the interventions, indicating that the shift of alertness depends on the availability of environmental variables and the readiness of support from caregivers (Guess & Siegel-Causey, 1995; Vlaskamp et al., 2003). Similar to this study, all study groups shifted from inactive and sleepy states to active and passive alertness once environmental stimulation occurred in the course of interventions. The MT-MSE participants maintained the highest level of passive alertness under dual interventions of sensory stimulation and physical massaging. Then, the participants returned to inactive and sleepy states at the follow-up study, as mental exhaustion after intensive sensory stimulations had weakened their alertness to the immediate environment (Munde, 2011). As demonstrated by Munde and Vlaskamp (2015), if social support is available from the direct care staff, the alertness level of SPID residents is regained and contact is maintained with the environment. However, as there was no such support available to the MSE and MT-MSE groups during the carryover period in this study, hence, the mental exhaustion had overwhelmed to the participants and their alertness level became inactive and sleepy, especially MSE group. If the SPID residents had initiated an

activity by themselves, their alertness would have stayed active and sustained for a longer period than if the direct care staff had initiated the activity (Munde, 2011; Munde & Vlaskamp, 2015). The relatively high level of active alertness in the MT group (32%) at the 2-week follow up indicated the residual effect of vagal activity and simple sensory input without mental exhaustion. The alertness level of massage therapy was generally better than MSE and MT-MSE because the sensory stimulation of MT was more concentrated and restricted to tactile pressure. Due to the overwhelming sensory inputs from MSE, the capacity of information process of individuals with SPID became quickly exhausted and temporary shutdown to receive these unstructured stimuli (Munde, 2011). Most SPID residents are not well-prepared for excessive sensory stimulation at one time, hence, it is better to introduce basic sensory stimulation one at a time, so that they can manage gradually (Hulsegge & Verheul, 1987). Experts opined that controlled sensory environment could promote the alertness of SPID residents and emphasised the importance of individual preferences and tolerance (Munde et al., 2009b). As a result, the MT group participants could sustain their active and passive alertness and the control group participants could maintain their passive alertness and inactive state in the carryover period.

Considering the rapid attention shifting, it is difficult to detect the right moment for people with SPID to focus on the environment or to maintain active alertness over a reasonably long period (e.g., 10-15 minutes) in the MSE (Guess et al., 1995; Munde et al., 2009a). Alertness expressions are often subtle signals that may easily go unnoticed (Guess et al., 1995; Munde, 2011; Munde et al., 2012). Such rapid shifting of alertness levels between being alert and not being in contact with the immediate environment has been described as attention waves, which are

not easily or instantly noticed by onsite observers (Mudford et al., 1997; Munde et al., 2012). Hence, it might have been better to shorten the intervals of behavioural observation to less than 20 seconds or to take videos to capture the rapid shifting of alertness among the residents in this study.

However, some of the present study's findings were not in line with the literature, for example, a combination of visual and auditory stimuli significantly increased the alertness of SPID residents, especially those with visual impairments, whereas tactile stimulation was the least effective in activating their alertness (Munde, 2011; Munde et al., 2009b). In view of the present findings, tactile stimulation in MT group maintained the least sleepy state (only 6%) and a high level (approximately 68%) of both active and passive alertness at the follow-up. Most of the interviewees highly supported MT for their residents, particularly for those with hearing and visual impairments. Likewise, most of the interviewees perceived that MT-MSE would be the best intervention for inducing relaxation in residents with SPID compared with each of the two single-mode interventions. In fact, the MT-MSE attained a higher percentage of passive alertness (almost 59%) at mid-intervention and the first post-test (immediately after completion of the intervention) than the MT or MSE alone. These differences in passive alertness of MT-MSE were statistically significant from two single-mode interventions and control group. In addition, the MT-MSE group attained the lowest respiration rate at the first post-test, but not at the 2-week follow-up. Hence, relaxation induced by MT-MSE can be certain at the first post-test but such relaxation effect can reduce challenging behaviour is still sceptical because no pairwise group comparison was found significant in frequency and severity of challenging behaviour. More research on reducing challenging behaviour through relaxation via various

intervention approaches is necessary. Although a few interviewees perceived that MSE could induce sleepiness, especially for hyperactive participants, the quantitative data revealed that the increased sleepy level occurred at the follow-up only, not during the interventions. In fact, they were in the alert state with 36% in active alert and 43% in passive alert. This reflects the challenge or difficulties for clinical researchers in assessing alertness levels in people with SPID due to their rapid and irregular shifts between different alertness levels (Guess & Siegel-Causey, 1995; Mudford et al., 1997; Munde et al., 2012). In early studies, Guess et al. (1993) suggested that the body positions or postures of people with SPID could affect alertness levels. Recently, Munde and Vlaskamp (2015) also suggested that interaction initiatives from these residents and individual sensory inputs in the MSE (visual, auditory, tactile and vestibular stimuli) could affect and/or induce different levels of alertness. These approaches to arouse SPID people's alertness may be considered in future research.

The augmented effect of MT-MSE was only identified just after the intervention in the study as it might be adversely affected by overwhelming sensory stimulations, leading to temporary mental exhaustion in the 2-week follow up (Munde et al., 2012). With the support of the enabler, the residents' attention and responsiveness to the sensory environment could be maintained. Considering the results of outcome measures between the midterm and the first post-test were similar to MT-MSE in terms of respiration rate, active and passive alertness, manipulating the dose (frequency and duration) of MSE intervention may be considered in future research. However, it should take cautious because the outcome measures were not regularly checked throughout the study, variations may be possible in the behavioural pattern over the course of intervention. Nevertheless, manipulation of

MSE equipment / sessions may lessen the intensity of mental exhaustion. From the literature (Munde, 2011; Munde & Vlaskamp, 2015), the sensory equipment (e.g., auditory, visual, tactile, vestibular, olfactory, or gustatory) of MSE could be manipulated and presented separately or in combination with different presentation patterns. The sensory protocols were adjusted according to individual tolerance once SPID residents changed their alertness levels. Hence, the mental exhaustion was minimised.

The physiological parameters and alertness level of secondary outcomes were to evaluate the relaxation level that is the assumption to reduce challenging behaviour because it is believed that muscle relaxation counteracts anxiety, stereotypic self-stimulating behaviour (SSB) and challenging behaviour, as relaxation responses cannot coexist in fidgeting and uneasy people and, consequently, replace one's maladaptive behaviour (Chan et al., 2010).

This assumption was moderately supported by the results. As mentioned in preceding paragraphs, the results of MT-MSE attained the highest passive alertness and lowest respiration rate just after the interventions to indicate the relaxation effect, however, the decreasing frequency and severity of challenging behaviour of MT-MSE was not significant different than other study groups at 2-week follow up. Group effect was identified in the data analysis in both frequency and severity of challenging behaviour, but no individual pairwise group comparison was found significantly different, indicating the reduced magnitude of individual study groups was not extensive enough to achieve significance level. Since primary outcomes were measured at the usual care environment, as suggested by the interviewees, the intensity of the interventions should be reinforced to increase generalisability from one place to another place.

Several studies (Munde et al., 2009a; Vlaskamp et al., 2003, Vos et al., 2013) have revealed that improving the usual care environment may have similar effects on alertness and responsiveness states to using MSE. The improved environmental context may involve direct social interactions with SPID residents along with relaxation-inducing therapy, e.g., aromatherapy (Vlaskamp et al., 2003). Studies (Kaplan et al., 2006; Singh et al., 2004) also showed that activities involving physical movement could increase the alertness level of SPID residents, e.g., outdoor activity (Cuvo et al., 2001). Other influencing factors on alertness level included structured training programmes, and staff training to address the social needs of SPID residents (Munde et al., 2009a).

7.3.3 Adaptive and maladaptive behaviour

It was hypothesised that maladaptive behaviour would decrease in the three intervention groups and that adaptive behaviour would increase after intervention compared with the control group. Maladaptive behaviour decreased in the MT and MSE groups after intervention, but increased in the MT-MSE group, and no treatment effect detected between study groups. At the follow-up, the three intervention groups showed increased maladaptive behaviour compared with the control group, and no group difference was found.

The patterns of change in maladaptive behaviour corresponded to the shifting of the alertness levels in the MSE and MT groups at the 2-week follow-up. The forms of maladaptive behaviour observed were largely similar to inactive state SSB, such as thumb sucking, moaning, eye rubbing, rocking and rolling (Munde, 2011; Vlaskamp et al., 2009). A randomised controlled trial of MSE in a mental hospital was conducted with a random sample of 98 people with mild to severe ID and

comorbid mental illnesses. The ID people were randomly assigned into either the MSE group with 36 sessions or the control group with 36 activity sessions over 12 weeks (Chan et al., 2007). Most of the outcome measures were statistically insignificant between the two study groups, except the Checklist of Challenging Behaviour. There was a significant reduction in challenging behaviour in the control group after the 12-week intervention. The very crowded environment in the MSE and very limited changes in the MSE setting and stimulations made the mild ID participants feel very bored. Indeed, the therapeutic effects of MSE shown in the Snoezelen Dairy Card and interviewees mainly came from the increased physical contact of and social interaction between the subjects and enablers, but were not sustainable over the long term, such as for more than 1 week (Chan et al., 2007).

The manifestation of maladaptive behaviour (include stereotypic behaviour, SIB) may be an attempt to escape and avoidance of demand. Given this reason, it is expected that maladaptive behaviour is decreased in MT and MSE because there is no demand (Singh et al., 2004). In the present study, the amount of maladaptive behaviour was obviously decreased during interventions because subjects had already obtained sufficient stimulations. However, this postulation was not supported in MT-MSE, the reason was unclear. The recurrence of maladaptive behaviour of intervention groups at 2-week follow-up might be to maintain the pleasurable level of sensory stimulation as suggested by Singh's study (Singh et al., 2004). Another explanation of the increased maladaptive behaviour in the MSE and MT-MSE groups was due to their mental exhaustion to overwhelming sensory stimulation (Guess & Siegel-Causey, 1995; Munde, 2011). Thus, they responded by shifting to the inactive state with minimal social contact with the immediate environment, presenting SSB or falling asleep. The participants of MT group

achieved the highest maladaptive and adaptive behaviour at the 2-week follow-up. The MT group demonstrated the highest active and passive alertness levels of all of the study groups. In view of the high percentages of active and passive alertness noted (68%) at the 2-week follow-up, the MT group was more responsive to and focused on the surrounding stimuli, as the mechanism of MT could increase beta waves, keeping people awake during the day, and decrease the alpha and delta waves, which usually increase during sleep (Field et al., 1996; 2006). The participants in the MT group were attentive and responsive to the immediate environment and thus exhibited significantly more adaptive behaviour than those in the MSE and MT-MSE groups. In addition, studies have found that higher vagal tone which can be triggered by MT is associated with greater closeness to other people and more altruistic behaviour to show interest with immediate environment (Szalavitz, 2013).

The adaptive behaviour could be associated or affiliated with the existence of active and passive alertness in the two post-intervention measures, but only passive alertness was found statistically significant, especially the MT-MSE group, whereas, the active alertness level was not statistically different between the study groups. Only a few of the interviewees noticed increased adaptive behaviour in the usual care environment.

The amount and duration of maladaptive behaviour was lowest in the control group at the follow-up but had highest heart and respiration rates than other intervention groups, speculating SSB or maladaptive behaviour may be a presentation of enjoyment as a relatively high level of passive alertness maintained at the follow-up. The decreased maladaptive behaviour in the control group might have been due to low sensory inputs of the previous 10-week intervention. As suggested by Chan et al. (2007), the caregiver's attitude towards, support of and

emotional exchange with SPID residents were comparable with the sensory environment itself. Although control group showed reduction in amount and duration of maladaptive behaviour, as well as low frequency and severity of challenging behaviour at the 2-week follow up, the difference was not statistically significant at all.

7.3.3.1 Presentation of positive behaviour

Generally, the therapeutic effect of MT was significantly better than MSE and MT-MSE in this study. The participants in the MT group exhibited a significantly higher average amount and duration of adaptive behaviour than the other three study groups. Such increases in positive behaviour were sustained at the follow-up in the usual care environment.

MT has been used as a form of relaxation to relieve stress and anxiety for many years in different countries (Field, 2006; Field et al., 2007; Moyer et al., 2004). Literature reviews have indicated that the specific purpose of MT in terms of challenging behaviour is to divert attention from negative experiences and induce pleasure and relaxation to increase positive behaviour (Ali et al., 2014). Residents can subsequently earn social acceptance from caregivers and community members (Chan et al., 2010; Emerson, 2001). Another reason to adopt MT for relaxation is because the application of MT does not require the resident's cognitive capacity to understand (Ashby et al., 1995; Croghan, 2009; Slevin & McClelland, 1999; Solomons, 2005). Positive behaviour refers to communication, establishing interpersonal relationships, engagement, social awareness and concentration (Chan et al., 2010). From the perceptions of the interviewees in this study, physical touch in MT was better than the sensory stimulations provided by the MSE, as it fostered

social closeness and facilitated affective communication, especially for the participants with visual impairments (25% of the MT group and 31% of overall residents in the residential care unit). Physical touch is the clearest way for visually impaired residents to interact with the environment and to receive information from people and caregivers (Gale & Hegarty, 2000).

A study with a case study design was conducted for five SPID students ranging from 14 to 24 years of age (McEvoy et al., 1987). They received 16 consecutive weeks of 45-minute MT sessions twice or thrice per week. Two of the subjects dropped out due to touch aversion as a result of their autistic features. Three of the subjects demonstrated behavioural changes by showing improved physical conditions, increased verbalisation in social communication due to decreased SIB and agitation, increased functioning of hand use in skill acquisition, increased on-task behaviour and decreased challenging behaviour (McEvoy et al., 1987). Some of the interviewees also disclosed that positive behaviour persisted after the MT, such as increased finger movement and reaching out of hands to touch nearby objects, increased social smiling and giggling in the usual care environment.

Comparing the MT and MT-MSE groups, the amount and duration of adaptive behaviour of the MT group was over twice than those of the MT-MSE group, and differed significantly at two post-tests. The participants in the MT group might have been more focused on enjoying the pleasurable experiences of massage in a protected quiet area, whereas the participants in the MT-MSE group might have been distracted by all of the different sensory stimulations in the MSE with limited body movements (passive alert state) made. Hence, exhibition of adaptive behaviour decreased with multi-sensory stimulations (in the MSE or M-MSE groups). Nevertheless, the participants in the MSE group demonstrated more adaptive

behaviour than those in the MT-MSE group and significantly different at the first post-test, perhaps due to having their hands free to reach out in the MSE sessions. Therefore, activities in the MSE should be better planned and tailored to individual needs, and tested for the optimal effect on adaptive behaviour, e.g., use of controlled MSE setting and manipulation of treatment sessions.

In fact, the patterns of change in adaptive behaviour also followed the shifts of passive alertness in both the MSE and MT-MSE groups, starting with a low amount and duration of adaptive behaviour at baseline, increasing during intervention and finally returning to its original level at the follow-up. The MT and control groups sustained high and moderate levels of adaptive behaviour at the follow-up, respectively. The therapeutic value of MSE was perceived short-lived (Lotan et al., 2009). A possible explanation for such patterns in the MSE and/or MT-MSE groups may be closely related to the repeated episodes of exhaustions from the multiple sensory stimulations in the MSE group when supported by the enabler. In this study, the participants were able to uphold the adaptive and desirable behaviour by maintaining high responsiveness and attentiveness to their immediate environment (Munde, 2011; Munde & Vlaskamp, 2015). After the interventions were completed, the attention and physical contact support from the direct care staff in the usual care environment decreased a lot. Hence, the participants returned to their usual or original inactive states with SSB or even shifted to the sleepy state (Guess & Siegel-Causey, 1995; Munde & Vlaskamp, 2015).

This study fails to support the treatment effects or identify significant changes in heart rates and amount and durations of maladaptive behaviour between and within the study groups. The most possible reason for this is the relatively stable physiological states and the mean values between the baseline and post-intervention

measures (Fraser & Ross Kerr, 1993; Labyak & Metzger, 1997). The participants in the MSE and MT-MSE groups generally presented lower respiration rates than the control group and a significant difference between the baseline and post-intervention measures, appearing in a state of relaxation. The therapeutic effect of MT was prominent in other secondary outcome measures, such as amount of adaptive behaviour, duration of adaptive behaviour and sleepy state, showing that the MT group participants presented with positive behaviour and were more attentive and responsive to the immediate environment than the MSE and MT-MSE group participants.

Although the therapeutic effect of MSE was less significant than MT (MSE attained the lowest heart and respiration rates, and only respiration rate was statistically significant than control group), many of the interviewees still supported continuing MSE. In fact, many studies with insignificant results have postulated maintaining MSE for people with SPID (Chan et al., 2005; 2007; Martin et al., 1998; Tunson & Candler, 2010; Vlaskamp et al., 2003), as relaxation can be achieved in MSE, which fulfils the need for positive sensorial experiences. MSE is a high-quality and demand-free activity with costly equipment and decorative materials. From the interviewees' observations, challenging and stereotypic behaviour markedly decreased during intervention. Increased attentiveness and alertness and elevation of mood (Hayes et al., 2011; Munde, 2011) are also reasons for supporting the application of MSE as a structured leisure activity in the daily schedule.

An interesting outcome is that the behaviour presentation of the BC appeared to be correlated with specific alertness states of the AOC. For instance, the behavioural patterns of both maladaptive and adaptive behaviour seemed closely

related to the inactive and alert states, respectively. The presentation of maladaptive behaviour and inactive state involves SSB, such as thumb sucking, rocking and rolling, whereas the adaptive behaviour and alert state comprise active visual tracking, head turning towards the source of the stimulus and reaching out of the hands. The parallel shift of behavioural pattern was found in only the MSE and MT-MSE groups. It is worth investigating whether particular forms of behaviour are correlated with particular alertness levels or vice versa in future studies. If so, manipulating the alertness state may shape the behavioural patterns of SPID residents. Furthermore, manipulating the dose (frequency and duration) of MSE may predict behavioural change if the needs of the residents are sensory oriented. Based on the findings and discussion in this chapter, the implications of this study for practice and research and its conclusions are presented in Chapter Eight.

CHAPTER EIGHT

LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

8.1 Introduction

This chapter begins with a summary of this study's major outcomes and contributions to health service research, followed by a discussion of its limitations. It further discusses the implications of the study results from the perspectives of clinical practice, research, staff development and policymaking. It ends with recommendations for future research and the overall conclusions of the study.

8.2 Major Outcomes and Contributions to Health Service Research

A seminal paper (Heyvaert, Maes, & Onghena, 2013) recently postulated that mixed-methods research could synthesise knowledge on a complex research topic through analysis of both quantitative (summative) and qualitative (formative) data. This study adopted a mixed-methods research design and collected quantitative and qualitative data directly from the research participants, who provided first-hand information. Such information is important for future knowledge synthesis. Hence, the results of this study certainly contribute to knowledge synthesis with relevant research evidence on interventions for challenging behaviour. In fact, few randomised controlled trials have used a mixed-methods research design to study challenging behaviour in residents with SPID.

The phenomenon of sensory tolerance of individual SPID residents is worthy of further research, for instance, many studies adopted controlled MSE setting with various duration of treatment session (Lotan et al., 2009; Munde, 2011; Munde &

Vlaskamp, 2015; Singh et al., 2004). The primary outcomes were significant between groups, but unable to identify which group was statistically different from other study groups in pairwise comparisons of reducing the frequency and severity of challenging behaviour. There was no time effect detected despite the magnitude of change was very significant between the baseline and two post-test measurements (i.e., T_0-T_3) across the four study groups, especially MT group. In view of the short-term assessment after 5 weeks of interventions, the participants in the MT-MSE group demonstrated the lowest respiration rates and highest passive alertness states, which were all statistically and significantly different from the control group. Therefore, the thresholds of sensory tolerance must be considered in the three intervention modes, especially the MT-MSE intervention, to avoid overstimulation of the participants, as it may lead to their mental exhaustion. However, this assumption should be made with caution, as the change patterns of the outcome measures along intervention process may not be determined accurately in short-term assessments.

As mentioned, the use of MT and MSE are common in the ID clinical setting. However, no study has evaluated the effectiveness of combined MT and MSE treatment. Although the study results do not support the augmentative effect of the combined treatment in reducing challenging behaviour, the treatment did contribute more to the relaxation state in view of the lowest respiration rate and highest passive alertness than the other single-mode study groups just after the interventions. Further studies should determine the threshold of sensory tolerance through shorter and longer MT-MSE courses, ranging from 10 to 30 sessions, in a positive usual care environment to evaluate the frequency and severity of challenging behaviour,

adaptive behaviour, alertness state and objective physiological signs in residents with SPID.

The nature of physical touch appears more effective at producing positive behavioural changes in residents with SPID. Due to the nature of SPID, the study subjects could not verbalise their feelings. Therefore, the benefits and limitations of the interventions as perceived by their primary nurses would be useful for evaluating and improving interventions in future studies. All of the interviewed primary nurses perceived that the participants were relaxed by and enjoyed their assigned interventions. They particularly perceived that MT could maximise rapport building for and enjoyment of their residents with sensory deficits through physical proximity, social attention and contact and tactile stimulation.

Some of the interviewees highly agreed that MT was more suitable for residents with hearing and visual impairments, as physical touch allowed them to better connect with external stimuli or the environment. In fact, the participants in the MT group showed the highest amount and duration of adaptive behaviour compared with the other study groups.

Manipulating the dose (frequency and duration) of the treatment sessions could reduce challenging behaviour according to the primary nurses. There were improvements in some aspects of the residents' outcomes after the 10-week interventions. Most of the nurses perceived no significant changes in challenging behaviour in the usual care environment. Indeed, they noticed positive behavioural changes during the intervention sessions. They perceived the intervention effect as being relatively short-lived due to the pervasive effect of the usual care environment and insufficient treatment doses, which weakened the strength of the interventions.

This study has attempted to generalise the positive effect of interventions to usual care environment as it can truly reflect the effectiveness of the interventions (Lotan & Gold, 2009; Singh et al., 2004).

Some of the outcome measures were sustained over the 2 weeks following the interventions. The potential benefit of examining the carryover effect was to maximise the therapeutic cycle of individual interventions and service capacity under prevailing resources. The carryover effect could last for 2 weeks in the study, and some outcome measures showed very positive results, such as adaptive behaviour and less sleepiness during the day. More research is needed to explore circumstances that could lengthen the sustainability of the interventions.

This study identified the importance of service evaluation. From the perceptions of the interviewees, social attention and physical contact were beneficial in lessening challenging behaviour. However, many observational studies in natural settings have revealed that social contact and meaningful activities are inadequate. The therapeutic effects of the interventions were undermined by the chaos and noisy atmosphere of the usual care environment, which might have reduced any therapeutic behavioural change in the residents in the usual care environment. Although the person-centred approach emphasising the fulfilment of individual needs has been adopted for years in the research setting, its implementation in clinical practice is sporadic. The quantitative and qualitative results reflect that the gap between organisation policy and service delivery is considerably similar to Vlaskamp and Nakken's (1999) study, in which most activities were planned but ultimately not implemented. There should be closer monitoring or review of the routine care provided in residential institutions to ensure

structured, realistic and positive care planning and implementation for the residents in need of this support.

The AOC was first used in the study of challenging behaviour to evaluate the relationship between passive alertness and relaxation, and subsequently in the manifestation of challenging behaviour. In addition, the presentation of adaptive and maladaptive behaviour of the BC and the alertness state of the AOC appeared equal. For instance, the increase in adaptive behaviour was more significant in active and passive alertness, where attention and responsiveness prevailed, whereas maladaptive behaviour was frequently noted in the inactive state, with descriptions comparable with SSB. Thus, the relationship between the BC and AOC is worth examining to validate the assumed relaxation level in passive alertness.

8.3 Study Limitations

8.3.1 Generalisability

This study has a few important limitations. Its sample size was smaller than the 200 subjects estimated using a low-medium Cohen's f effect size (0.25) at α=0.05 and a study power of 0.80 in addition to a 10% attrition rate. With reference to the current quantitative data, the pairwise contrast comparisons between groups with statistically significant differences in respiration rate, amount and duration of adaptive behaviour, passive alert and sleepy state (i.e., $p \leq 0.05$) had medium to large effect sizes (i.e., 0.50-1.20). However, the effect size of primary outcomes, i.e., frequency and severity of challenging behaviour was very small (0.004-0.23). If the power set at 0.80, the minimum sample size of each group

would be more than 100 (Portney & Watkins, 2009). However, the actual group size was 31-34. Hence, the conclusions should be interpreted with caution.

The study was conducted in one residential care institute in which the homogeneity of daily living patterns may overshadow the diversity of individual characteristics, such as daytime activities and rehabilitation programmes, in different settings. As such, the findings may not be representative of people with SPID in other residential care settings. A study sample with a wider range of living patterns, such as home care and residential communities, is recommended for future studies.

The response rate of the primary nurses to the semi-structured face-to-face interviews also attenuated the generalisability of their shared experiences with the interventions used in the study setting. Initially, well-experienced primary nurses (i.e., with above 10 years of experience working with SPID residents) were to be interviewed. However, only 54% of the interviewees had such experience. Hence, the credibility of the qualitative data in developing basic principles for the management of challenging behaviour remains uncertain. In addition, including support staff who provide direct care and family members in the semi-structured interviews would be more comprehensive and informative in evaluating the effectiveness of the interventions.

8.3.2 Inclusion and exclusion criteria

As one of the selection criteria was to exclude restless residents who frequently exhibited severe challenging behaviour, those who were uncooperative and difficult to manage in the MSE were not included in this study. In view of the low scores of severity and frequency of challenging behaviour among the study

participants (ranging from 0 to 48 and 0 to 71, whereas the highest scores of the instrument could reach 156 and 208 for severity and frequency respectively), the degree of behavioural changes between the pre- and post-tests might have been restricted. It was also difficult to set threshold levels for challenging behaviour in the inclusion criteria, as there was no reference in the literature. This would have affected the total number of subjects eligible for the study and thus decreased the statistical input. In the future, inclusion of these difficult residents would be possible if the intervention is conducted in usual care environment, e.g., massage therapy / mobile sensory cart versus control groups.

8.3.3 Outcome measurements

In view of the rapid shift in alertness state, short observation intervals must be considered to capture the changes in alertness (e.g., from 20-second to 10- or 15-second intervals), thereby increasing the measurement accuracy. Another option is to videotape behaviour during the study, which would allow it to be reviewed repeatedly to ensure the precision of the outcome values and to enhance inter-observer reliability.

The selection of outcome measures should be more precise to identify behavioural changes. Due to the nature of observation over a reasonable time period, the BPI-01 is considered to be better for long-term / carryover and repeat assessments of the treatment effect than one-time measurements for each time point as the primary outcomes of the interventions.

As commented by the primary nurses, the intensity (dose) of treatment sessions in terms of their frequency and duration should be adjusted and enhanced.

For instance, the frequency of the interventions can be increased from twice to three times per week. Furthermore, setting the intervention time to 30 minutes for all three interventions would ensure equivalent time and frequency for outcome measurements. The unified duration of individual interventions could facilitate data collection and simplify the procedure of data analysis. However, the period of interventions may be reduced to 5 weeks to lessen the effect of sensory exhaustion for the MSE and MT-MSE groups, if necessary.

8.4 Implications

The purpose of the study was to examine the comparative effectiveness of MT, MSE and MT-MSE at reducing the frequency and severity of challenging behaviour and other secondary outcomes, such as respiration rate, heart rate, alertness and adaptive behaviour. Significant group effect on reducing the challenging behaviour was found in data analysis, but it was unable to identify which group was significantly different from other groups in the contrast pairwise comparisons. Many residents' relaxation (respiration rate), adaptive behaviour and alertness outcomes were much improved in one to three of these interventions, particularly in the MT group. This study has several implications for clinical practice, nursing research, staff development and policymaking.

8.4.1 Implications for clinical practice

The therapeutic effect of MT was found to be more prominent than that of MSE in the outcome measures of adaptive behaviour and alertness level, and the positive effects could be sustained for 2 weeks. As mentioned in the interviews,

transferring MT skills to frontline staff was suggested to allow for MT to be delivered to their residents daily in the usual care environment. If direct care staff are facilitated and supported in learning this skill, it is worth conducting MT on their residents in a protected, quiet and comfortable area of the usual care environment. The simple administration of MT can enhance service capacity without extra resources. It definitely benefits the recruitment of large sample size and increasing the dosage of MT for longer period.

As MSE is a standard activity in residential community and institutional settings, full utilisation of this expensive equipment would maximise the cost-effectiveness of service provisions. Considering sensory exhaustion is a result of repeated exposure to multisensory stimulation, the duration of MT-MSE and MSE interventions can be shortened to 5 weeks or less in each course to relieve the exhaustion effect while maximising its therapeutic value. However, this course of MSE can be repeated to sustain its therapeutic effects on residents' behaviour and relaxation. Another option is to reduce the sensory input and duration of each session based on individual preferences as this type of intervention often yields positive results in the studies (Lotan et al., 2009; Pagliano, 1998; Singh et al., 2004). In view of the results of the present study, MT has a more significant effect than the other interventions and can be applied in both MSE and the usual care environment to maximise its effects on behaviour.

8.4.2 Implications for nursing research

The concept of alertness levels is a new outcome measure in local research on people with SPID. More studies of this important concept in SPID are required in

local settings. The relationship between physical disability and alertness level in people with SPID and challenging behaviour is worth investigation given their passive and inactive responses to external stimuli.

In Munde (2011), three propositions were established, but these require further validation. First, one-on-one interaction with a direct care staff increased the alertness level of an individual with SPID for the first 5 minutes in MSE. Second, activities initiated by the individual with SPID appeared to prolong their alertness level more than activities initiated by direct care staff. However, the variables that trigger initiation from SPID individuals are still unknown. Third, visual stimulation was significantly associated with higher alertness levels than other types of stimulation. It was also shown that adding auditory stimulation could augment the effect of visual stimulation, especially for those with visual impairments (Munde, 2011). These findings have not yet been evidenced or described in other studies on SPID (Green et al., 1994; Munde et al., 2009a). Visual or sensory impairments and bodily deformities can deter interaction with the immediate environment. Therefore, the prevalence of challenging behaviour in people with sensory impairments may be higher than that of those without sensory impairments, as one main purpose of challenging behaviour is to seek sensory stimulation (Emerson et al., 2001; Evenhuis et al., 2001; McEvoy et al., 1987). As nursing service covers 24 hours in the clinical setting, the well-being of individual residents is the key performance indicator. It is justifiable to study staff-resident interactions in MT to evaluate its effect on challenging behaviour in clinical settings. Including restless residents may be feasible if the intervention is conducted in the usual care environment.

Although both the amount and duration of adaptive behaviour generally increased over time in all four groups actively engaged in the study, a transient clinical effect on participants' alertness states was also identified. Tunson and Candler (2010) emphasised that environment could affect the responsiveness to an immediate stimulus, but active involvement of the residents in daily activities of living or care was more significant at reducing challenging behaviour. Hence, methods of increasing the attention spans and activity levels of people with SPID deserve more investigation, given their cognitive and physical limitations.

As demonstrated in the quantitative results, SPID individuals have different sensory needs; hence the frequency and intensity of MSE intervention may need considering in future studies to achieve maximal beneficial effect (Chan et al., 2010; Lotan & Gold, 2009; Munde, 2011).

8.4.3 Implications for staff development

Studies have shown that an increased alertness state does not naturally increase social interaction (Munde, 2011). The input from direct care staff is essential in increasing the level of social interaction and in turn increasing alertness among individuals with SPID, who have difficulty making contact with their environment if left unattended (Guess et al., 1990; 1993; Munde & Vlaskamp, 2015). Therefore, direct care staff should not discontinue activities just because of their fleeting responses to a stimulus, but stimuli should be made explicit and individual residents should be able to choose them (Green et al., 1994).

Some of the interviewees suggested that transferring MT skills was important for the direct care staff to be able to deliver MT in the usual care environment.

Apart from engaging residents in a meaningful activity, it also promotes staff-resident interaction.

Some variables, such as body position and type of stimulation, can affect the alertness of people with SPID (Guess et al., 1993). Staff should pay attention to these variables and facilitate these individuals' contact with the environment. The importance of the long-term effectiveness of MT and/or MSE in reducing challenging behaviour is the priority of residential care delivery. As mentioned in previous studies (Hastings, 1997; Poppes et al., 2010), direct care staff are not likely to report challenging behaviour, especially SIB and SSB, due to their personal beliefs and lack of knowledge about challenging behaviour. Hence, staff training on the adverse consequences of challenging behaviour is indispensable to changing their attitudes in caring for SPID residents who engage in challenging behaviour.

Although this study did not address staff's attitudes and emotional responses to challenging behaviour, their beliefs and judgements are likely to affect SPID residents' experiences in their immediate environment in terms of their social contact, the nature of their interactions and the presence of meaningful activity. Hence, understanding staff attitudes may enlighten the process of recurring forms of challenging behaviour and their functions (Hastings et al., 2013). Introducing the PBS model may encourage staff to adopt positive attitudes towards SPID residents who exhibit challenging behaviour. Research is recommended to explore such attitudes and their affects on the management of such residents.

8.4.4 Implications for policymaking

As explained in Section 6.3, the therapeutic values of the interventions might have been undermined by the tight daily schedule and unpleasant atmosphere or the

arrangement of the usual care environment. These factors might have also contributed to the inadequate power to make significant changes in frequency and severity of challenging behaviour in the four study groups. All of the interviewees observed that the usual care environment was noisy and congested, and some suggested that interventions would be better conducted away from the usual care environment. If impossible, interventions such as MT should be conducted in a quiet corner of the usual care environment.

Residents spend many more hours in the usual care environment than they do in the therapeutic interventions and related activities. Thus, the usual care environment and its services are important factors in reducing challenging behaviour. For the people with SPID, caregivers can create a favourable environment in which the person can learn and experience (improving his feeling of wellbeing). The person-centred care approach has been adopted for more than 3 years in the study setting. However, no evaluation of its implementation has been conducted. As suggested by the literature (Allen, 2009; Hastings et al., 2013), implementing person-centred care alone may not be able to change severe challenging behaviour. Therefore, the service programme or approach should constantly be revisited to better understand the actual needs of the users and system.

A variety of psychosocial and behavioural management strategies, such as behavioural analysis and PBS, are necessary to manage obstinate forms of challenging behaviour in SPID residents. In fact, the PBS model includes person-centred planning and ABA. The PBS approach to managing challenging behaviour is proactive in that it focuses on identifying the possible causes of challenging behaviour and eliminating these causes before challenging behaviour is

exhibited. However, not all of these proactive strategies can be successful and thus reactive strategies should be considered (Allen, 2009; Hastings et al., 2013). Invariably, no matter how good the service system is, the support of stakeholders and policymakers is vital to successful implementation. Their support includes delineating access to the service and enhancing the quality of service delivery. The interventions provided may affect the cost of care if new services are implemented. They may also increase the workforce involved through required training and in implementation of the interventions. More importantly, the effectiveness of the interventions in reducing challenging behaviour and improving quality of life must be evaluated.

In comparison between MSE and MT in the present study, MT is more cost-effective than MSE in consideration of its expensive hardware installation and maintenance costs. However, if MT is the only intervention without other sensory inputs, it would be too monotonous in the long-term care. As demonstrated by Hulsegge and Verheul (1987), humankind needs to make his own environment and learn his independence through experiencing different sensory inputs. Staff-resident interaction can provide social connections but may not be enough to fulfil the basic drive of sensory needs (or stimulations). Through trusting relationship and secure environment, SPID people would be confident to step out and explore. MSE is a place for learning through physical pleasure. The most important sensory stimulation is ‘touching’, which can enhance one’s agility and strengthen his/her sense of control (Hastings et al., 2013; Hulsegge & Verheul, 1987).

8.5 Recommendations for Future Research

With MT and MSE being the major activities for people with SPID, the outcome measures of this study exhibit substantial results, especially the secondary outcomes and the carryover effect. More research on the therapeutic values of specific outcome measures, such as reduction of challenging behaviour, heart rate and maladaptive behaviour, is needed. Other indicators of relaxation may be chosen as outcome measures, such as alpha-amylase activity and cortisol and serotonin levels, galvanic skin response (GSR). In view of their limited cognitive information processing capacity, progressive sensory stimulations could be manipulated in MSE in future studies to avoid overwhelming stimulations at one time to reduce the intensity of mental exhaustion.

The overall improvement of the residents' outcomes in the four individual groups implies that the therapeutic values of social interaction and attention may be considered essential components of interventions in future research. Therefore, including restless residents should be considered if these interventions are conducted in the usual care environment. Interventions may include social engagement with interaction and attention, toy playing and attention in the usual care environment.

Sensory loss affects the appreciation of multisensory stimulations. However, it is difficult to exclude residents with visual and hearing impairments from consideration, as the prevalence of sensory defects is high in people with SPID. Some studies illustrated the sensory impairments up to over 50% in people with SPID (Evenhuis et al., 2001). Interventions that do not affect the enjoyment of activities for people with sensory defects may be considered in future research, such as aromatherapy, trampolining, acupressure and air bouncers. A meta-analysis of

evaluating 30 interventional studies on managing challenging behaviour revealed that no matter which intervention(s) was/were given, either used alone or in combination, the most important thing was intervention applied in the care delivery according to the schedule (Heyvaert, Maes & Onghena, 2010).

As shifting between alertness levels in people with SPID is rapid and complex, a number of factors influence these alertness states. These factors may include the participants' body positions (Guess et al., 1993); whether the interaction is initiated by a SPID resident (Munde & Vlaskamp, 2015); the effects of individual sensory inputs in MSE, such as visual, auditory, tactile and vestibular stimuli (Munde, 2011); and modifications to the direct care environment and staff attitudes (Mudford et al., 1997). These factors may be considered in future research, as they were not measured in this study. The overwhelming sensory stimulation may need to reduce and selective to individual preference, so that they are not endurance to the sensory stimuli, they can respond to their favourable stimuli to prevent passivity and cut themselves off from the immediate environment (Vlaskamp et al., 2003). Hence, assessment of individual tolerance level and frequency of MSE session is necessary.

The butterfly effect of alertness has been identified in other studies. The current study identified this pattern of change in the amount and duration of adaptive behaviour in the MSE and MT-MSE groups, not the alertness level which includes active and passive alert. Further investigation into whether alertness and adaptive behaviour are similar in nature and whether the alertness state would simultaneously increase adaptive behaviour in usual care is needed.

Munde (2011) attempted to investigate the relationship between physiological signs and alertness levels but produced inconclusive results. There might have been

methodological faults, such as no baseline data or control group for comparison. From the experience of direct care staff, distinguishing between the inactive and passive alert states was difficult and even mixed up, making early termination or reduction of activities in MSE common (Arthur, 2004; Green et al., 1994; Guess et al., 1993; Guess & Siegel-Causey, 1995; Munde, 2011). In Munde (2011), the participants in the alert state had higher heart rates than those in the inactive and withdrawn state, but there was no explicit confirmation of active alertness or passive alertness among the residents, as the physiological changes in the active movement and motionless states could differ. More research on the physiological measures of different levels of alertness is necessary to confirm the effect of relaxation on reducing challenging behaviour. Furthermore, how alertness states are related to challenging behaviour in people with SPID should also be examined.

8.6 Conclusions

MT, MSE and MT-MSE were tested under the assumption that relaxation could help reduce challenging behaviour in people with SPID, along with other physiological and behavioural outcomes. After 10-week interventions and a 2-week follow-up conducted in the usual care environment, MT and/or MSE had modest significant effect on frequency and severity of challenging behaviour, moderate to large effects on respiration rate, amount and duration of adaptive behaviour, and passive alertness and sleepy state. The interventions had only small effect on the heart rates, amount and duration of maladaptive behaviour, and active alertness and inactive state. MT was the most effective intervention in secondary outcomes, whereas the expected magnified effect of the combined MT-MSE treatment was only

supported just after the intervention, especially the respiration rate and passive alertness. The assumption of relaxation to reduce challenging behaviour was not proven in this study.

All interviewees reported that the general responses of the participants were calm and relaxed during and immediately after the interventions. This observed behaviour coincided with significantly increased levels of passive alertness, and adaptive behaviour, and low respiration rate after the interventions. Most of the primary nurses perceived the MT-MSE and MT treatments to be more beneficial than MSE treatment alone due to the close physical contact and pleasure the residents obtained from MT. Matching with the quantitative results, most of the interviewees did not observe any behavioural change after the interventions. They expected the increased dosage and frequency of interventions would produce positive results.

The quantitative and qualitative data indicate two important issues that need to be addressed in future research. The first issue pertains to the types of meaningful engagement with SPID residents. The second issue concerns the effect of environmental enhancement on challenging behaviour. Some variables may also influence the shift in residents' alertness, such as body position, initiation of stimulation, type of stimulation, environmental changes and staff input. If the social interaction is initiated by SPID residents, the active alertness would sustain longer than initiated by direct care staff. However, such initiation made by SPID residents is infrequent, hence the staff mediation is important.

In long-term care settings, residents spend more hours in the usual care environment than they do participating in structured activities. A therapeutic milieu in the usual care environment is vital to behavioural management. To prolong the

therapeutic values of the meaningful activities and stimulations provided by MT and/or MSE, the PBS model could be adopted for long-term benefits in managing challenging behaviour in people with SPID. Evaluating MT and/or MSE in combination with the PBS model of care in the usual care environment would be the direction of future studies to understand the optimal care for SPID residents in behavioural outcomes.

Appendix I

Information Sheet for Nursing Staff

Research Title:

An evaluation of the clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities

Background and Significance of the Study

I am going to conduct a research study on "the evaluation of massage therapy and multisensory environment for the residents with severe and profound intellectual disabilities (SPID)". This research is part of the fulfillment of a PhD course in the Hong Kong Polytechnic University. My supervisor is Professor Chien Wai Tong.

Many nurses working in the field of intellectual disability (ID) are involved in utilizing multisensory environment (MSE). Before recommending for its use, MSE should be proved to be useful in clinical setting in promoting relaxation and reducing the intensity of challenging behaviour in residents with SPID. Complementary therapies, like massage, are used to refresh body and mind as one approach for relaxation without any cognitive demands. This feature is particularly relevant to those severe and profound intellectually disabled residents as they do not need to understand the whole intervention process. If relaxation effect is affirmed, massage

therapy will be integrated into routine practice for all suitable SPID residents.

Invitation to Participate

You are invited to take part in this research. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information and take time to decide whether or not you wish to take part in this research.

Purpose of the Study

The aim of this study is to evaluate relative effectiveness of MSE and/or massage therapy in residents with SPID who receive massage therapy in MSE, activities in MSE alone, massage therapy in usual care environment, or usual care without any MSE and massage therapy. A face-to-face interview to the nursing staff will be conducted after the interventions to examine your perception on the effectiveness of the interventions based on your observations whether any behavioural changes of the residents occurred. Your valuable opinions to the change practice and the application of interventions into daily routine will be collected if the interventions are perceived beneficial to the residents.

What are the benefits of your taking part?

Your participation certainly enhances the understanding and management of challenging behaviour. All interview data will be audio-digitally recorded and all information obtained will be used for research purpose only. No information can be accessed by other people except the main investigator. All audiotaped interview records will be discarded after data analysis. Participants will not be identified by readers if in the form of reports or publications. Your valuable opinions may help to increase the usage of different complementary therapies to people with SPID to enhance their quality of life, especially for those with long-term hospitalization.

Enquiry

If you have any enquiry to this research project, please feel free to contact the investigator Ms. Jenny Chan at 9034 . If you have any enquiry about the ethical approval issue and/or dissatisfaction to the project, please contact the Human Subjects Ethics Sub-committee's secretary Miss Cherrie Mok, executive officer, Research Office (email: cherrie.mok@ , telephone number: 2766 6378). Correspondence address: Human Subjects Ethics Sub-committee, the Hong Kong Polytechnic University, Hung Hom, Kowloon.

Appendix II

Informed Consent Form for Nursing Staff (2 copies)

(Research Participation and Semi-structured Interview)

Title of Research Project:

An evaluation of the clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities (SPID)

Purpose of the participation and interview: To examine the nursing staff's perception on the benefits and limitations of the designated interventions, contributing factors of challenging behaviour, and their personal experiences in managing challenging behaviour.

Participation is entirely voluntary. It will not affect your job performance appraisal and employment if you refuse or withdraw to participate. If you understand the contents described in the information sheet and agree to participate in this interview, please sign below. Thank you for your support and participation.

Consent Form

I confirm that I have read and understood the information sheet for the study on "an evaluation of the clinical efficacy of massage therapy in a multisensory environment for residents with severe and profound intellectual disabilities (SPID)". I have had the opportunity to ask question and understand that my participation is voluntary, and that I am free to withdraw at any time without the need of giving any reason. I agree to take part in the study and participate the face-to-face interview.

Name of Participant	Date	Signature

CHAN Sau Lai Jenny

Researcher 9034	Date	Signature

Appendix III

Semi-structured Interview Guide (Investigator-constructed Questions)

Name (optional):
Gender:* Female / Male
Age range: * 20-29 / 30-39 / 40-49 / 50 or above
Year of experience working with people with SPID:
Educational level: * Certificate / Diploma / Bachelor / Postgraduate / Master / Doctor
Specialty training: * Intellectual disability nursing / Community nursing / Other(s):

_____

* Please circle the most appropriate answer

Thank you for interviewee's participation and give the explanatory notes to the interviewee to seek his/her informed consent (首先多謝你參加今次嘅面談，請睇一睇哩份文件解釋面談的緣因。若果無問題，請在這份同意書簽名). If the interviewee has problem(s) or question(s), please refer him/her to investigator for enquiry / clarification. The interview will be ceased until the interviewee agrees to sign the consent form.

If consent form is signed, start the questions to be asked, other questions can be added if necessary:-

Questions related to challenging behaviour:

What are the possible reasons for these challenging behaviours? (Probes: any environmental factors? Routine related issues? Any staff / human factors?)
你認為有什麼可能嘅因素導致挑戰性行為出現呢？(係咪環境因素呢?日常流程?定係職員/人為因素?)

What kind of factors/reasons may reduce or aggravate challenging behaviours?

係什麼下可減低或者加劇挑戰性行為出現呢？

What are the challenging behaviours of the residents usually found in your work setting?

係你工作裏面，有什麼挑戰性行為最為普遍?

Can you describe one recent experience of your resident's challenging behaviours and how to deal with the event?

可否形容你最近一次經歷挑戰性行為嘅情況同埋係點樣處理件事呢?

Do you think the ward environment may affect the frequency of challenging behaviours? If yes, what are the environmental factors and how to affect? If no, what factors that you think would effect on the frequency of challenging behaviours, and how does each of them affect the behaviours?
你認為病房嘅環境會唔會影響挑戰性行為嘅出現次數呢？如果有，你認為哩 D 環境因素係什麼呢？同埋佢哋點影響呢？如果無關係，你認為什麼因素影響挑戰性行為嘅出現次數呢？同埋點影響呢？

For your point of view, any preventive measures and alternatives can be taken for management of these behaviours?

你覺得有什麼措施或者方法可以處理挑戰性行為呢?

<u>Questions related to therapies:</u>

Based on your observation, are there any changes about the frequency of challenging behaviours on (name of participant) after the intervention? If yes, what are the changes? If no, please describe the current behaviours of the resident?
根據你嘅觀察，XXX 嘅挑戰性行為有無改變呢？如果有，你認為有什麼改變呢？如果無改變，你可唔可以形容一吓現在佢嘅行為比我聽呢？

What do you think about the effectiveness of the intervention used in this study (MT / MSE / MT-MSE)?

你認為現在研究中嘅方法(按摩加感官治療 / 按摩治療 / 只接受感官治療)，邊種方法最為有效呢?

Based on your observation, are there any changes about the challenging behaviours on your resident(s) during the past 2 weeks? If yes, what are the changes? If no, how is the current behaviour of the resident?" Probes: Any positive or adaptive behaviours observed? Any challenging behaviours are difficult to change? Why and how to deal with?

根據你嘅觀察，你覺得你嘅院友嘅挑戰性行為在過去兩個星期，有無改變？如果有，有什麼改變?如果無，依家嘅院友行為係點呢?有無正面或者好適應嘅行為?有無邊種挑戰性行為最困難改變?點解呢?同埋點處理呢?

What are your opinions on the intervention used?

你對現時嘅處理方法有什麼意見?

Do you think the observed intervention (MT-MSE, MT, and MSE) would be appropriate to your residents? If yes, explain why? If no, what kinds of intervention would be more appropriate to them?

你認為現在介入嘅方法(包括按摩加感官治療、按摩治療、或只接受感官治療)，對現時嘅院友是否適合呢？如果同意，點解呢？若果不同意，你認為什麼介入方法比較合適佢哋呢？

What are the strengths and limitations or weaknesses of the intervention? Any suggestion for improvement?

現時嘅介入處理方法，你覺得有什麼好處, 有什麼限制或者弱點? 有無意見可以改善?

What barriers that you expect if the intervention is integrated into routine practice? Any solutions to solve these barriers?

若將現時嘅介入方法作為將來日常流程中嘅活動，你預計會有什麼困難或阻礙出現? 有什麼辦法可解決?

What difficulties (state which/what aspects) that you have come across during the study period?

係研究進行期間，你遇到什麼嘅困難 / 問題？

All questions are finished. Thank you for your participation again.

所有問題已問完，再次多謝你嘅參與

Appendix IV

給家屬及監護人的資訊

給各家長、親屬、監護人有關按摩和感官治療臨床研究說明資料

研究課題:
評鑑按摩和感官治療對嚴重智障傷殘院友的鬆弛果效而減低帶有挑戰性行為的出現

簡介:

本人為香港理工大學護理學院的博士研究生，指導主管是錢惠堂教授，現正進行一項有關按摩和感官治療的研究，是次研究實為課程中的一部份。研究目的在於探索及評鑑按摩和感官治療的鬆弛效果會否影響挑性釁行為的出現。研究結果將會有助提升院友在復康過程中的服務及質素。

研究方法和過程:

研究將採用隨機對照臨床試驗方法以收集數據，每名獲邀請參與的院友都有機會接受按摩加感官治療、按摩治療、感官治療或接受日常生活環境的活動，每項治療會推行 10 星期，每星期會進行兩次，每次需時 15 至 30 分鐘不等，每次活動皆有職員照顧參與的院友。因要查究該些治療是否有鬆弛果效而減少挑戰性行為的出現，故此，被邀請參與的院友需要在介入研究前斷絕按摩和感官治療一個月，以免影響結果的準確度。若研究顯示正面結果，按摩和感官治療將推廣至全部適合的院友，作為恆常的治療。根據過往的文獻顯示，接受按摩或感官治療之後而出現不尋常現象或反效果是罕有的，極其量是沒有鬆弛果效。當收集數據完成後，護理同事有機會被邀請參與面談作深入研究有關挑戰性行為出現的因素。每次面談大約需時 45 分鐘。

風險及益處
按摩和感官治療的風險一般很低，極少數院友會有不良反應，例如皮膚現紅和頭暈，課堂過後，很快便回復正常，並沒有長久的後遺症。治療若証實有療效，按摩和感官治療便可推廣至所有院友接受。因此對智障人士來說將會是多一種另類治療的選擇。

資料保密性:

除研究者外，所有收集的資料和數據不會向外披露，絕對保密及不記名。當資料分析後，所有數據將會徹底毀滅。在研究過程中，倘若家屬基於某些理由而不願意讓院友繼續參與，你是有權隨時終止參與此項研究，而不會承擔任

何後果或影響院友應有的治療方案。此外，你須要明白，參與是次研究純屬自願性質，不會帶來院友個人金錢利益，也不會影響院友目前的護理情況。

查詢:

如對是項研究有任何疑問或意見，歡迎致電 9034 向本人查詢/反映。如你對是次研究有任何投訴，請聯絡香港理工大學人類研究操守委員會(Miss Cherrie Mok, 電話: 2766 6378, 電郵地址: cherrie.mok@) 聯絡。投訴地址: 香港理工大學人類研究操守委員會。

研究者: 陳秀麗
護理學院博士生

Appendix V

同意書 (家長、親屬、監護人代理) 一式兩份

研究題目:

評鑑按摩和感官治療對嚴重智障傷殘院友的鬆弛果效而減低帶有挑戰性行為的出現

研究目的在於探索及評鑑按摩和感官治療的鬆弛效果會否影響挑性釁行為的出現。研究結果將會有助提升院友在復康過程中的服務及質素。

是項研究會將參與的院友按平等機會分配到不同組別，包括按摩加感官治療、按摩治療、感官治療或接受日常生活環境的活動。為達到準確研究結果，參與的院友需要在介入研究前斷絕按摩和感官治療一個月。若研究顯示正面結果，按摩和感官治療將推廣至全部適合的院友，作為恆常的治療。

所收集的資料只作研究用途，個人資料將絕對保密。如你對是項研究有任何問題，請現在提出。如日後你對是項研究有任何查詢，請與研究員陳秀麗聯絡，電話：9034　　。

如你已明白以上內容，並願意代表院友同意參與是項研究，請在下方簽署。

簽署：　　姓名：

院友姓名：　　見證人：

關係：　　日期：

Appendix VI

Protocol of Massage Therapy

Hands (15 minutes)

1. Make sure the resident is comfortable, either lying down or sitting up, and that the arm is supported at the elbow, so that the hand can be moved freely
2. A small amount of vegetable oil is put on the palms of the therapist
3. Hold the resident's whole hand sandwiched for a few seconds
4. Hold hand firmly underneath with your fingers, use 'split the biscuit' method to open and stretch the dorsum of the hand
5. Use thumbs to work in small circles over the whole area of the dorsum, up between the bones of the hand and around the bones of the wrist
6. Turn the resident's palm up, massage with your thumbs in small circles over the whole palm
7. Hold the resident's hand with one of your hands, gently slide your fingers up form the base to the tip of the thumb / fingers. Pull a little as you go and twist your hand from side to side as opening a bottle with a corkscrew. Don't pull too hard, it is good to give the joints a gentle stretch but not to force them to crack
8. Gently rotate each ginger in a circle, then reverse the direction if the resident does not resist

9. Hold the whole hand sandwiched for a few seconds again before put it down

10. Do the other hand with the same pattern as above

Feet (15 minutes)

1. Make sure the resident is comfortable, preferably lying down. Prop it upon a cushion or on your own leg

2. Sandwich the foot between your hands

3. Hold the foot between the hands. Stroke firmly up the foot several times from the toes to the heel and ankle

4. Hold foot firmly underneath with your fingers, use 'split the biscuit' method to open and stretch the dorsum of the foot

5. Hold the foot with your fingers, go over the top of the foot with your thumbs working in small circular movements, and cover the whole dorsum

6. Draw your thumb up once along each valley between the tendons that run form the ankle to the toes

7. Next work over the sole of the foot, massage with your thumbs in small circles over the sole

8. Gently lift the heel up and work all around the heel with your thumbs and fingertips

9. Lay the foot down and circle the ankle bone with your finger-tips / thumb

10. Now go the toes. As with the fingers, pull gently as you slide from the base to the tip of each toe

11. Gently rotate each toe by holding at the tip. Rotation of the big toe is excellent for relieving head tension and headaches

12. End by holding the whole foot sandwiched

Adapted from Sanderson, H., Harrison, J., & Price, S. (1991). *Aromatherapy and massage for people with learning difficulties*. Birmingham: Hands On Publishing.

Appendix VII

Enabling Approach: The Roles of an Enabler

The enabling approach is described as a "sensitive, caring, non-directive approach in which an atmosphere of safety and security is created and free choice encouraged" (Hutchinson & Haggar, 1994, p. 20). Therefore, the main duties of an enabler will be:

- Share positive emotion with the residents without negative or judgmental comment on residents' behaviours
- Accompany the residents during their stay in the designated places
- Facilitate residents to make choice and explore immediate environment
- Support residents to gain maximum pleasure from their immediate environment, e.g. play sensory equipment in MSE freely
- Engage residents with warm interaction through both verbal or nonverbal means
- Provide enjoyable experience from the activity in which residents are involved

Adapted from Hutchinson, R. & Hagger, L. (1994). The development and evaluation of a Snoezelen leisure resource for people with severe multiple disability. In R. Hutchinson & J. Kewin (Eds.), *Sensations & disability* (pp.18-48). UK: Rompa.

BPI

THE BEHAVIOR PROBLEMS INVENTORY
(BPI-01)

Johannes Rojahn. Ph.D.

Name: _____

ID: _____

Date: _____

BPI Results Summary		
Subscales	Frequency scores	Severity scores
SIB		
Stereotyped Behavior		
Aggressive/Destructive Behavior		

SELF-INJURIOUS BEHAVIOR

Generic definition: Self-injurious behavior (SIB) causes damage to the person's own body; i.e., damage has either already occurred, or it must be expected if the behavior remained untreated. SIBs occur repeatedly in the same way over and over again, and they are characteristic for that person.

			Frequency				Severity		
		Never	Monthly	Weekly	Daily	Hourly	Slight	Moderate	Severe
1	Self-biting (so hard that a tooth print can be seen for some time; bloodshot or breaking of skin may occur)	0	1	2	3	4	1	2	3
2	Hitting head with hand or other body part (e.g., face slapping, knee against forehead) or with/against objects (e.g., slamming against a wall, knocking head with a toy)	0	1	2	3	4	1	2	3
3	Hitting body (except for the head) with own hand or with any other body part (e.g., kicking self, slapping arms or thighs), or with/against objects (e.g., hitting legs with a stick, boxing the wall)	0	1	2	3	4	1	2	3
4	Self-scratching (so hard that reddening of the skin becomes visible; breaking of the skin may also occur)	0	1	2	3	4	1	2	3
5	Vomiting and rumination (deliberate regurgitation of swallowed food with rumination)	0	1	2	3	4	1	2	3
6	Self-pinching (so hard that reddening of the skin becomes visible; breaking of the skin may occur)	0	1	2	3	4	1	2	3
7	Pica: Mouthing or swallowing of objects which should not be mouthed or swallowed for health or hygiene reasons (non-food items such as feces, grass, paper, garbage, hair)	0	1	2	3	4	1	2	3
8	Inserting objects in body openings (in nose, ears, or anus, etc.)	0	1	2	3	4	1	2	3
9	Pulling finger or toe nails	0	1	2	3	4	1	2	3
10	Inserting fingers in body openings (e.g., eye poking, finger in anus)	0	1	2	3	4	1	2	3
11	Air swallowing resulting in extended abdomen	0	1	2	3	4	1	2	3
12	Hair pulling (tearing out patches of hair)	0	1	2	3	4	1	2	3
13	Extreme drinking (e.g., more than 3 liters per day)	0	1	2	3	4	1	2	3
14	Teeth grinding (evidence of ground teeth)	0	1	2	3	4	1	2	3
15	Other:	0	1	2	3	4	1	2	3
			Frequency Total				Severity Total		

STEREOTYPED BEHAVIOR

Generic definition: Stereotyped behaviors look unusual, strange, or inappropriate to the average person. They are voluntary acts that occur repeatedly in the same way over and over again, and they are characteristic for that person. However, they do NOT cause physical damage.

		Never	Monthly	Weekly	Daily	Hourly	Slight	Moderate	Severe
16	Rocking back and forth	0	1	2	3	4	1	2	3
17	Sniffing objects	0	1	2	3	4	1	2	3
18	Spinning own body	0	1	2	3	4	1	2	3
19	Waving or shaking arms	0	1	2	3	4	1	2	3
20	Rolling head	0	1	2	3	4	1	2	3
21	Whirling, turning around on spot	0	1	2	3	4	1	2	3
22	Engaging in repetitive body movements	0	1	2	3	4	1	2	3
23	Pacing	0	1	2	3	4	1	2	3

24	Twirling things	0	1	2	3	4	1	2	3
25	Having repetitive hand movements	0	1	2	3	4	1	2	3
26	Yelling and screaming	0	1	2	3	4	1	2	3
27	Sniffing own body	0	1	2	3	4	1	2	3
28	Bouncing around	0	1	2	3	4	1	2	3
29	Spinning objects	0	1	2	3	4	1	2	3
30	Having bursts of running around	0	1	2	3	4	1	2	3
31	Engaging in complex hand and finger movements	0	1	2	3	4	1	2	3
32	Manipulating objects repeatedly	0	1	2	3	4	1	2	3
33	Exhibiting sustained finger movements	0	1	2	3	4	1	2	3
34	Rubbing self	0	1	2	3	4	1	2	3
35	Gazing at hands or objects	0	1	2	3	4	1	2	3
36	Maintaining bizarre body postures	0	1	2	3	4	1	2	3
37	Clapping hands	0	1	2	3	4	1	2	3
38	Grimacing	0	1	2	3	4	1	2	3
39	Waving hands	0	1	2	3	4	1	2	3
40	Other	0	1	2	3	4	1	2	3
			Frequency Total				Severity Total		

AGGRESSIVE/DESTRUCTIVE BEHAVIOR

Generic definition: Aggressive or destructive behaviors are offensive actions or deliberate overt attacks directed towards other individuals or objects. They occur repeatedly in the same way over and over again, and they are characteristic for that person.

		Never	Monthly	Weekly	Daily	Hourly	Slight	Moderate	Severe
41	Hitting others	0	1	2	3	4	1	2	3
42	Kicking others	0	1	2	3	4	1	2	3
43	Pushing others	0	1	2	3	4	1	2	3
44	Biting others	0	1	2	3	4	1	2	3
45	Grabbing and pulling others	0	1	2	3	4	1	2	3
46	Scratching others	0	1	2	3	4	1	2	3
47	Pinching others	0	1	2	3	4	1	2	3
48	Spitting on others	0	1	2	3	4	1	2	3
49	Being verbally abusive with others	0	1	2	3	4	1	2	3
50	Destroying things (e.g., rips clothes, throws chairs, smashes tables)	0	1	2	3	4	1	2	3
51	Being mean or cruel (e.g., grabbing toys or food from others, bullying others)	0	1	2	3	4	1	2	3
52	Other:	0	1	2	3	4	1	2	3
			Frequency Total				Severity Total		

Alertness Observation Checklist (AOC)

Descriptions of "Reactions to stimuli"

The table below provides the general descriptions of the four alertness levels and several examples of concrete behaviours.

Green - Active, focused on the surroundings	**Examples of concrete behaviours**
Active alert: the person is sensorially active. This refers to looking, listening, feeling, and smelling. These forms of activities are focused on the surroundings. In this context, the person can be focused on other people (caregivers, other people with disabilities) or materials in the room with active body movement.	Eyes open, active focusing, with the eyes, turning, head toward stimulus, eyes turn toward stimulus, body is erect, reaching for or grasping, an object, eating or drinking.
Passive alert: the person is sensorially active. This refers to looking, listening, feeling, and smelling. These forms of activities are focused on the surroundings. In this context, the person can be focused on other people (caregivers, other people with disabilities) or materials in the room without active body movement.	Eyes open, active focusing, with the eyes turn toward stimulus without body movement.
Amber - Inactive: turned inward	**Examples of concrete behaviours**
The person is active both motorically and sensorially. These forms of activity are not directed toward the surroundings, but are focused on the person's own body stereotypical movement, touching their own clothing.	Staring, picking at body or chair, pulling on bib or clothing, holding head downward or turned away, sucking, thumb, moaning softly, rubbing the eyes, rolling the head, rocking.
Red - Sleeping, napping	**Examples of concrete behaviours**
The person is asleep. Sleep-related vocalizations (e.g., snoring) and movements (e.g., tossing and turning, shaking the head or body) may occur.	Sleeping, eyelids lowered, snoring noises, eyes repeatedly opening and closing, limbs are limp and hanging down.
Blue – Agitated, discontent	**Examples of concrete behaviours**
The person demonstrates discontent	Crying, shouting or screaming, hitting or kicking objects or people, beating head, hitting, biting, scratching, or kicking self.

Appendix X

Alertness Observation Checklist (AOC)

Form C – Observation form for "Reactions to stimuli"

Participant's Identity Code:
Date:
Observed by:
Type of intervention: MT-MSE / MT / MSE / control (please circle the intervention that given)

Color codes:
G1 = Green - active alert with movement
G2 = Green – passive alert without movement
A = Amber - inactive and withdrawn, not responsive to immediate environment
R = Red – sleepy and drowsy state
B = Blue - agitated and discontented

Time (min:sec)	Color*	Time (min:sec)	Color*	Time (min:sec)	Color*
05	G1/G2 / A / R / B	25:20	G1/G2 / A / R / B	35:20	G1/G2 / A / R / B
10	G1/G2 / A / R / B	25:40	G1/G2 / A / R / B	35:40	G1/G2 / A / R / B
15	G1/G2 / A / R / B	26:00	G1/G2 / A / R / B	36:00	G1/G2 / A / R / B
15:20	G1/G2 / A / R / B	26:20	G1/G2 / A / R / B	36:20	G1/G2 / A / R / B
15:40	G1/G2 / A / R / B	26:40	G1/G2 / A / R / B	36:40	G1/G2 / A / R / B
16:00	G1/G2 / A / R / B	27:00	G1/G2 / A / R / B	37:00	G1/G2 / A / R / B
16:20	G1/G2 / A / R / B	27:20	G1/G2 / A / R / B	37:20	G1/G2 / A / R / B
16:40	G1/G2 / A / R / B	27:40	G1/G2 / A / R / B	37:40	G1/G2 / A / R / B
17:00	G1/G2 / A / R / B	28:00	G1/G2 / A / R / B	38:00	G1/G2 / A / R / B
17:20	G1/G2 / A / R / B	28:20	G1/G2 / A / R / B	38:20	G1/G2 / A / R / B
17:40	G1/G2 / A / R / B	28:40	G1/G2 / A / R / B	38:40	G1/G2 / A / R / B
18:00	G1/G2 / A / R / B	29:00	G1/G2 / A / R / B	39:00	G1/G2 / A / R / B
18:20	G1/G2 / A / R / B	29:20	G1/G2 / A / R / B	39:20	G1/G2 / A / R / B
18:40	G1/G2 / A / R / B	29:40	G1/G2 / A / R / B	39:40	G1/G2 / A / R / B
19:00	G1/G2 / A / R / B	30:00	G1/G2 / A / R / B	40:00	G1/G2 / A / R / B
19:20	G1/G2 / A / R / B	35	G1/G2 / A / R / B	40:20	G1/G2 / A / R / B
19:40	G1/G2 / A / R / B	40	G1/G2 / A / R / B	40:40	G1/G2 / A / R / B
20:00	G1/G2 / A / R / B	45	G1/G2 / A / R / B	41:00	G1/G2 / A / R / B
20:20	G1/G2 / A / R / B	30:20	G1/G2 / A / R / B	41:20	G1/G2 / A / R / B
20:40	G1/G2 / A / R / B	30:40	G1/G2 / A / R / B	41:40	G1/G2 / A / R / B
21:00	G1/G2 / A / R / B	31:00	G1/G2 / A / R / B	42:00	G1/G2 / A / R / B
21:20	G1/G2 / A / R / B	31:20	G1/G2 / A / R / B	42:20	G1/G2 / A / R / B
21:40	G1/G2 / A / R / B	31:40	G1/G2 / A / R / B	42:40	G1/G2 / A / R / B
22:00	G1/G2 / A / R / B	32:00	G1/G2 / A / R / B	43:00	G1/G2 / A / R / B
22:20	G1/G2 / A / R / B	32:20	G1/G2 / A / R / B	43:20	G1/G2 / A / R / B
22:40	G1/G2 / A / R / B	32:40	G1/G2 / A / R / B	43:40	G1/G2 / A / R / B
23:00	G1/G2 / A / R / B	33:00	G1/G2 / A / R / B	44:00	G1/G2 / A / R / B
23:20	G1/G2 / A / R / B	33:20	G1/G2 / A / R / B	44:20	G1/G2 / A / R / B
23:40	G1/G2 / A / R / B	33:40	G1/G2 / A / R / B	44:40	G1/G2 / A / R / B
24:00	G1/G2 / A / R / B	34:00	G1/G2 / A / R / B	45:00	G1/G2 / A / R / B
24:20	G1/G2 / A / R / B	34:20	G1/G2 / A / R / B	50	G1/G2 / A / R / B
24:40	G1/G2 / A / R / B	34:40	G1/G2 / A / R / B	55	G1/G2 / A / R / B
25:00	G1/G2 / A / R / B	35:00	G1/G2 / A / R / B	60	G1/G2 / A / R / B

* Please circle the most appropriate alertness state

Appendix XI_15-minute

Behaviour Checklist

Participant's Identity Code: Date:

Stereotypic Behaviour	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Flaps hands															
2. Twirls, twiddles signs															
3. Claps hands															
4. Hands on ears															
5. Eats, sucks clothes															
6. Mouths objects and fingers															
7. Spits															
8. Makes peculiar sounds															
9. Rocks															
10. Throws objects															
11. Bangs															
12. Flaps legs															
13. Pulls faces															
14. Tickles feet															
15. Screams															
16. Masturbates															
No. of behaviour															
Adaptive Behaviours															
1. Looks in mirror															
2. Explores, investigates															
3. Initiates contact															
4. Chooses activity															
5. Smiles, laughs															
6. Verbalizes															
No. of behaviour															

Please tick "√" if the behaviour exhibits at 1-minute interval observation

Behaviour Checklist

Participant's Identity Code: Date:

Stereotypic Behaviour	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
1. Flaps hands																														
2. Twirls, twiddles signs																														
3. Claps hands																														
4. Hands on ears																														
5. Eats, sucks clothes																														
6. Mouths objects and fingers																														
7. Spits																														
8. Makes peculiar sounds																														
9. Rocks																														
10. Throws objects																														
11. Bangs																														
12. Flaps legs																														
13. Pulls faces																														
14. Tickles feet																														
15. Screams																														
16. Masturbates																														
No. of behaviour																														
Adaptive Behaviour																														
1. Looks in mirror																														
2. Explores, investigates																														
3. Initiates contact																														
4. Chooses activity																														
5. Smiles, laughs																														
6. Verbalizes																														
No. of behaviour																														

Please tick "√" if the behaviour exhibits at 1-minute interval observation

Appendix XIII

Socio-demographic & Clinical Data Sheet

Participant's Identity Code:
Date:
Intervention start date:

Participant's Code:			**Ward Code:**
Gender:	M / F	**Age:**	
Drug Profile:		Date of revision:	
Anti-epileptic drug			
Psychotropic drug			
Other Sedatives			
Supplement			
Others:			
Any drug changed during intervention period:		Yes/No	
Adaptive support:	Yes / No	**Behaviour Therapy:**	Yes / No
Mobility level:			
Ambulant	Chair-bound	Bedridden	
Feeding ability:			
Self-feeding	Assisted feeding	Spoon-feeding	Enteral feeding
Sensory deficit:	Hearing defect	Visual defect	Others:
Associate diagnosis:			
Epilepsy	Cerebral palsy	Down Syndrome	Autistic spectrum disorder (ASD)
Mental illness :	Yes	No	
ADL ability:	Totally dependent	Partially dependent	Independent
Family support: (for the past 3 months)			
Weekly visit	Monthly visit	Irregular visit	No visit / NA
Apart from SIDACE program, any leisure activities in the past three months:-			
Sunbathing	Bus trip	Garden strolling	Others
Frequency/total incidents:			

Please circle the most appropriate answer

Appendix XIV

Interview Questions for Primary Nurses of the Study Participants

	Questions	Probing
	Questions related to challenging behaviour:	
1.	What are the possible reasons for these challenging behaviour?	● Any environmental factors?
		● Routine related issues?
		● Any staff / human factors?
		● Any other factors that you consider?
2.	What kind of factors/reasons may reduce or aggravate challenging behaviour?	● Any environmental factors?
		● Routine related issues?
		● Any staff / human factors?
		● Any other factors that you consider?
3.	What are the challenging behaviour of the residents usually found in your work setting?	● Aggressive behaviour?
		● Self-injurious behaviour?
		● Stereotypic behaviour?
		● Any other behaviour that you perceived as challenging behaviour?
4.	Can you describe one recent experience of your resident's challenging behaviour and how to deal with the incident?	● The most recent incident that impressed you very much in handling of challenging behaviour?
		● What management method(s) that you had used to resolve the incident?
5.	Do you think the unit environment may affect the frequency of challenging behaviour?	● If yes, what are the environmental factors and how to affect?
		● If no, what factors that you think would influence on the frequency of challenging behaviour, and how does each of them affect the behaviour?
6.	For your point of view, any preventive measures and alternatives can be taken for management of these behaviour?	● Any medical/physical measures?
		● Any psychological measures?
		● Any social measures?
		● Any other measures that you have taken?

	Questions	Probing
	Questions related to therapies:	
7.	Based on your observation, are there any changes about the frequency of challenging behaviour on (name of participant) after the intervention?	● If yes, what are the changes? ● If no, please describe the current behaviour of the resident?
8.	What do you think about the effectiveness of the intervention used in this study (MT / MSE / MT-MSE)?	● Any change on frequency of challenging behaviour? ● Any change on severity of challenging behaviour? ● Any adaptive behaviour seen? ● Any signs of relaxation and enjoyment seen?
9.	Based on your observation, are there any changes about the challenging behaviour on your resident(s) during the past 2 weeks?	● If yes, what are the changes? ● If no, how is the current behaviour of the resident?" ● Any positive or adaptive behaviour observed? ● Any challenging behaviour are difficult to change? ● Why and how to deal with?
10.	What are your opinions on the intervention used?	● Any beneficial effect? ● Any shortcoming?
11.	What are the strengths and limitations or weaknesses of the intervention?	● Any suggestion for improvement?
12.	What barriers that you expect if the intervention is integrated into routine practice?	● Any solutions to solve these barriers?
13.	What difficulties that you have come across during the study period?	● Please state the details if any

Appendix XV

Summary of Remaining Verbatim

The remaining verbatim of the semi-structured interviews is summarised in following table according to the four main categories and its subcategories of primary nurses' perceptions of the interventions used and managing challenging behaviour.

1. Perceived benefits of the multisensory environment and/or massage therapy

Subcategories	Relevant verbatim
Providing a place or an activity for relaxation and enjoyment	● MSE is a place for retreat. (Participant 2, paragraph 9) ● Every resident wants to be in sensory room, because the place has pleasant smell and enjoyable atmosphere. The spacious environment make them very comfortable and relaxed. If they could have their own choice, a monthly visit would be very appreciated and treated as precious moment. However, due to insufficient escort manpower, they need to wait. (Participate 3, paragraph 14) ● Bring them out of usual care environment is preferred because MSE is quiet and relaxed. (Participant 9, paragraph 55) ● It's a special activity to occupy his time and direct his attention to pleasurable touch (Participant 11, paragraph 70) ● The activity can increase her social contact with other people. In fact, she likes to draw attention from others, and made her feel being valued. (Participant 13, paragraph 32)
Appraising massage therapy and the multisensory environment	● Comparatively, MT and MSE are better than other activities because someone is staying with my resident, and enjoying the one to one service. (Participant 3, paragraph 36) ● If they show no resistance to the activity that means they accept. I perceive that our residents have the rights to fully utilise the hospital facilities, and any activity that provides to them. If they like massage therapy, it implies that they like social interaction as well. The activity should be continued if there is no rejection from the residents. (Participant 3, paragraph

Subcategories	Relevant verbatim
	40) ● I fully support any activity and new service to our residents because they are being cared. If I could offer the massage therapy, I would do it without delay, but due to manpower constraint, I cannot leave other routine tasks untouched. (Participant 4, paragraph 9) ● The consistent pressure from the massage therapy can give pleasurable feeling. If consent is obtained from relative, we must offer the activity to the resident. (Participant 6, paragraph 25) ● The massage therapy gives an opportunity to satisfy his attention seeking behaviour. His misbehaviour during the intervention is significantly reduced. (Participant 11, paragraph 82)
Offering sensory stimulation to fulfil the needs of those with sensory deficits	● Anyone likes to be touched and praised, especially massage therapy is a pleasurable activity. She is visually blind, hence, the massage therapy already fulfils her sensory needs. In fact, she seldom exhibits self-inflicting behaviour after the MT. The hand-mouthing behaviour is also markedly decreased. Though we have applied hand cream to her four times a day as routine treatment, her skin texture looks better nourished than before. It's probably caused by the massage oil. In addition, massage promotes blood circulation, hence, the redness over pressure point areas appear relieved. (Participant 7, paragraphs 43-45) ● Before the study, I saw a severe self-inflicting behaviour from her with lots of abrasion over both hands several months ago. Then I applied large amount of aqueous cream to protect her skin. Now, her hands get better after the intervention, and no severe bleeding noted from both hands since last time. I think the intervention meets her sensory needs. Subsequently, it reduces her self-inflicting behaviour. (Participant 10, paragraph 69)
Providing physical touch as a form of care and concern	● Our special residents with visual impairment need constant physical touch to arouse their interest to the surrounding. But in reality, there is no time to do at all. I feel frustrated indeed. (Participant 4, paragraph 7). ● As mentioned, he is deaf, dumb and blind. Hence, he is very self-centred and shows no interest to his external world. Without our physical guidance, he seldom walks by self. Hence, we have guided him through physical touch to the toilet and dormitory. He is only

Subcategories	Relevant verbatim
	suitable for massage therapy, and not MSE. Through frequent physical touch, he is more interactive and willing to follow instructions. The trusting relationship is established. (Participant 5, paragraphs 18 and 24) ● The sensation come from massage therapy is different from physical touch because the intensity of warmth and physical proximity are different. Massage therapy generates pleasurable feeling, and physical touch tends to be more functional in nature. Massage therapy is perceived as an advanced level of physical touch which is a basic level of care. (Participant 6, paragraph 11) ● It is acceptable to carry out sensory stimulation and massage therapy in ward level to minimise the robotic routine. However, it will keep the residents staying in ward for 24 hours. From my point of view, activities outside ward area are more therapeutic than remaining in one location. We can take fresh air and contact different people. Hence, the locations of leisure activities should be considered, not just by convenient. In fact, the chaotic daily routine may weaken the beneficial effects of MSE and use of physical touch. (Participant 8, paragraph 57-58)

2. Enhancing intervention quality

Subcategories	Relevant verbatim
Increasing the doses of intervention	● It should increase the frequency and duration of the interventions in a quiet area. As a basic human need, this kind of service is fundamental. In view of the short duration of the existing interventions, it is unable to reach the level of enjoyment and it just provides a basic physical contact, because there are so many constraints in the service patterns, in terms of number of sessions and duration of each session. Only a longer duration and increased frequency of the interventions can reveal the therapeutic values. (Participant 3, paragraph 40) ● More residents should be included in the study, and the duration of the interventions should be longer. It is too short to finsih the session and end the intervention period. I understand that manpower and resources are the main constraints. I always support any therapy to our residents, but the resources allocation need to address correspondingly. (Participant 4, paragraphs 38-40)

Subcategories	Relevant verbatim
	● The duration and frequency of the interventions are too short. Manpower should be increased. It is better to increase the session up to daily from Monday to Friday. (Participant 5, paragraphs 30-32) ● Daily session is preferable, or at least 3-4 times a week. (Participant 8, paragraph 59) ● The duration of each session should be longer, at least 45 minutes. Then we can take a break on these 45 minutes. The frequency should increase up to three times a week. (Participant 9, paragraphs 52-53) ● It is insufficient time to enjoy. The session should be increased. (Participant 11, paragraph 85)
Providing a variety of intervention modalities	● Aromatherapy has long history of its therapeutic properties and substantiated with clinical evidence. Hence, it should be considered in the interventions. Its value is undebatable. (Participant 4, paragraph 37) ● Essential oils should be added, especially for those with multiple sensory deficits, e.g., deaf, dumb, and blind. (Participant 5, paragraph 35) ● I think aromatherapy should be added to increase the sensory stimulations and make the subjects calmer than single treatment. (Participant 6, paragraph 20) ● Apart from sensory stimulations, cognitive training is suggested. From my residents with relatively high cognitive functioning, they play card games, and tell me how excited it is. As far as I know, a structured programme can reduce the exhibition of challenging behaviour because they are occupied with the activity, and such activity can induce relaxation to them, for instance, my case becomes relaxed when receiving massage and listening to soft music. As he is very sensitive to sound, he stays alert once heard the music. The frequency of session should be increased to more than twice a week. He will look more cheerful. Just like coming back from the training centre, he always smiles and looks happy (Participant 12, paragraphs 68-69) ● From my point of view, MSE is good for her, but to yield significant result, it should be more than MSE alone. She should be arranged to participate more training activities, e.g., day activity training centre. For this case, she is a bit hyperactive and she can manage more than one programme. (Participant 13, paragraph 35)

3. Possible factors contributing to challenging behaviour

Subcategories	Relevant verbatim
Personal factors	● The contributing factors of challenging behaviour of some residents are very peculiar. It may be caused by room temperature, sound from surrounding environment, but it does not mean noisy. Some residents are very sensitive. When we are playing music as entertainment, they don't like it and show very agitated. They display challenging behaviour just because they dislike the next resident who actually does nothing. These residents are very special. (Participant 1, paragraph 10) ● Some residents are unpredictable to display challenging behaviour because of trivial matter. They are easily trigger and get sullen. We even do not know the reason of such behaviour. I call them having unreasonable mind. These challenging behaviour are difficult to eradicate. (Participant 5, paragraph 4) ● The physical health of individual residents may affect their challenging behaviour. From my view, I will try to minimise their discomfort, and look into what are the causes of such discomfort. If they have any habit and emotions, I will pay attention to satisfy their needs. The top priority is to reduce self-harm, and provide safe environment. Their behaviour may be very obsessive to induce pain through self-inflicting act, e.g., eye-poking behaviour. Hence, uplifting their mood is necessary through MT and/or MSE. (Participant 6, paragraphs 4 and 6) ● Unstable mental state may make them very impulsive and unable to predict their behaviour. (Participant 11, paragraphs 3-4) ●
External factors	● Sometimes the daily routine creates the challenging behaviour. For instance, he is sleeping, but needed to wake him up to take medication, or take bath. Such interruption act may cause him unhappy or angry, so that challenging behaviour exhibits (Participant 1, paragraph 5) ● One of the residents was transferred from another unit where he had lived for more than 20 years. The strange environment and unfamiliar staff make him very anxious and uncooperative. He often dashes to door once someone is opening the main entrance in an attempt to escape from ward. For his safety sake, we always direct him away from the door and train him to do something to occupy his mind, e.g., folding towel.

Subcategories	Relevant verbatim
	Adaptation to new environment is not an easy task for persons with SPID. An orientation programme is set up to introduce the routine and paid staff. (Participant 2, paragraph 4) ● The process of communication includes expressive and receptive. If there is something wrong and unable to send correct message appropriately to the receiver. Challenging behaviour may exhibit to ventilate the uncertainty. (Participant 6, paragraph 5) ● Since most SPID residents are unable to comprehend verbal language, their responses are based on the intonation and facial expression of the sender. If the voice is too loud and rude, they will perceive as bad message. Hence, they may show challenging behaviour in return. Sometimes, his/her favourite towel is taken away by the caregiver with intention to wash it clean. Without knowing the reason, challenging behaviour may result. Sometimes, just simply unable to access their favourite item, hence, they display temper and challenging behaviour to ventilate their feeling. (Participant 7, paragraph 14) ● Environmental change is one of the factors to trigger challenging behaviour because of anxiety and fear. New staff may not be accepted by the SPID residents, who may exhibit challenging behaviour when being approached. (Participant 7, paragraph 24-25) ● The congestion and noisy environment, may stir up the emotions of some SPID residents who may display challenging behaviour. Sometimes, the challenging behaviour is caused by communication with loud voice unintentionally. (Participant 8, paragraph 2-3) ● Because of grievances against certain staff members, some residents would display challenging behaviour. Sometimes they may not necessarily hit the others but only particular two staff. Or when they know that these staff being on duty, they display temper, such as rolling on floor or throwing objects. Or possibly, some staff provoke the residents. (Participant 10, paragraph 14) ● In order to comply with the routine, she was requested to wake up earlier. Then, she displayed temper tantrum and slammed door. After allowing her to sleep as long as she wants, the challenging behaviour vanished. (Participant 10, paragraph 18) ● It relates to their caregivers. I think if the caregiver adopts a hostile attitude to the residents, they would dislike and be angry with it! If the voice is soft and

Subcategories	Relevant verbatim
	nice, they would behave better! But some residents are not. If your voice is nice to them, they may take advantage of you. So it highly depends on how best their caregivers understand the resident. (Participant 10, paragraph 37) ● The challenging behaviour is provoked by co-patients. I think they like the yelling and responses from the weak (resident) (Participant 11, paragraph 7) ● Challenging behaviour sometimes is infectious. The chaotic environment is likely to initiate challenging behaviour of some impulsive residents. Once there has disturbance in ward level, more and more incidents follow afterwards. I am not sure whether our residents learn from other behaviour, but definitely the number of challenging behaviour increases. They may think that the staff have no time to manage their challenging behaviour, hence, their behaviour is more disruptive and violent in nature. (Participant 11, paragraph 57)

4. Managing challenging behaviour

Subcategories	Relevant verbatim
Identifying the purposes of challenging behaviour	● For skin picking or self-scratching behaviour, it may be resolved if skin problem is treated. We will inform doctor to prescribe moisturiser. Indeed, self-inflicting behaviour of some cases is treated by applying skin ointment. Sometimes, the first ointment may not be effective, and then we ask doctor to prescribe another type. Once skin condition significantly improved, the self-inflicting behaviour, subsequently, decreased. Hence, trials of different skin ointments or moisturisers may need to consider. Another method to prevent self-scratching behaviour is to apply mittens, especially in the initial phase of treatment or recurrence of self-inflicting behaviour after completion of the treatment. Once there is no self-scratching behaviour, mittens will be removed. (Participant 1, paragraph 7) ● Stable work force is vital to manage challenging behaviour. Once there has new staff, some residents start to test the limits and display severe challenging behaviour if there is no consequence or the response of the new staff is not firm enough the control their behaviour. On the other hand, the service of the new staff may not be able to fulfil their needs; hence they

Subcategories	Relevant verbatim
	exhibit challenging behaviour to express their dissatisfaction. Hence, staff movement should take into consideration in management level. (Participant 4, paragraph 12) ● The immediate action is to separate the residents displaying challenging behaviour from other residents without challenging behaviour, otherwise, the condition would get worse. Then investigate the causative factors of the challenging behaviour, whether there have unmet basic needs or psychosocial issues. Satisfaction of human basic needs is the fundamental strategy to manage challenging behaviour. (Participant 6, paragraph 8) ● If the environment is too noisy, this may be the cause of challenging behaviour. Residents would feel relaxed in a quiet and peaceful environment. (Participant 8, paragraph 9) ● Though we are trying very hard to find out the rationales of the challenging behaviour, sometimes, the cause is intrinsic or mental state problem. In this situation, medication and supportive strategies are considered. For instance, use of special garments to limit the self-scratching behaviour. (Participant 8, paragraph 34-36)
Improving the physical environment	● To maintain a familiar environment, the fixture and decorative materials, furniture and personal belongings should be kept in the designated areas to provide sense of security and a safe place for them to live. Once they are familiar with the living place, the chance of exhibiting challenging behaviour is reduced. (Participant 2, paragraph 6) ● Spacious and comfortable environment, more manpower to interact with individual residents, or just accompany with them is good enough. With the application of aromatherapy, more physical contact, physical touch and massage would make the residents happy and relaxed. Once they feel being cared, the exhibition of challenging behaviour would be reduced. However, do we have sufficient resources to cover all 50 residents in one unit? (Participant 4, paragraph 8) ● Prevention is always the best choice than cure. In order to increase their preferences, we can put two neutral options at a time for them to choose, e.g., congee and porridge. Once they pick up the one they prefer, it will pair up the one that they don’t like, so

Subcategories	Relevant verbatim
	that the neutral option becomes their preferred choice. In addition, the new staff will only work with the resident when they are happy, or in the activity/event that they enjoy. With increasing such happy experiences, the resident would gradually show acceptance to the new staff. (Participant 7, paragraph 26) ● Staff should manage the resident with challenging behaviour at once. If the action is taken appropriately and timely. Other residents would learn and observe, so that the occurrence of challenging behaviour would probably decrease. (Participants 8, paragraph 10) ● When you praised her beautiful, she understood. Sometimes, before she had temper or noticed her unusual facial expression, I would reinforce her something to eat and praise her behaving good today. Then she would not have any temper throughout my shift and nothing happened. I would use this approach to handle her before she displayed any temper. If these things done after she had displayed temper tantrum, the effect was minimal. Because she should be punished right after her bad temper, and let her know that she did something wrong. Hence I would do it before she displayed temper. (Participants 10, paragraph 32) ● In fact I think the environment should not be too noisy! Not to mention the patients, if the patients were noisy, the mood of our staff members would also be affected a little bit. But we would not act out like the patients! Therefore I would separate nice patients from those having maladaptive behaviour in order not to affect other silent patients and their mood. May let them listen to music…many patients like listening to music and we need to know which kind of music they favour. And watching movie, they like it very much. Some like watching old Cantonese movies, whereas others like love story movies. Every patient has different preference. We know how to accommodate others, but may not be the case amongst the patients. I treat them as children. They like what they like, dislike what they do not prefer. (Participants 10, paragraph 36) ● The most important thing is a clear reward and punishment system. For the smart children, they understand what is reward, what is punishment. Indeed, patients can learn these things. (Participants

Subcategories	Relevant verbatim
	10, paragraph 41-42)
Engaging in meaningful activities	● Through the engagement with MT or MSE, no matter what behaviour presented at that moment, the resident should learn that these activities are pleasant and no pressure to stay with. It is especially precious for orphans because they don't have family members to visit. Hence the chance of being accompanied is treasured. (Participant 1, paragraph 32) ● Arrange more activities for the residents to occupy their free time constructively. Once they have been actively engaged, the exhibition of challenging behaviour is subsequently reduced because their attention is diverted to assigned activity. There would be no time for boredom. The decoration of the living environment is colourful and attractive, as it can uplift the mood from the stimulating environment. (Participant 7, paragraph 8) ● The institutional environment, in fact, is not stimulating, and full of boredom. Tight schedule routine and lots of tasks to follow… the most busiest persons are paid staff, while, most often, the residents are left unattended. In order to reduce their boredom and exhibition of challenging behaviour, the primary goal is to arrange constructive activities for the residents. In fact, any activity that can occupy their free time, and direct their attention is good to be attended. Hence, the use of multisensory room is most welcome for the residents. However, the transfer and escort duty are also needed to plan. That is the challenge that every caregiver faces in day-to-day care. (Participant 10, paragraph 16) ● In fact, for some bright residents with good upper limbs function, we would sometimes assign them to do simple tasks that do not work demanding in the ward! Actually, they are very willing to do so. In the past, we gave towels to them to fold, they were very happy with it. However, with the emphasis of preventing cross infection, this kind of simple task became little. For the wellbeing of a person, it is very good to do something in a day or being occupied. For example, bring them to the garden for strolling, they feel very happy! Just like we go out to relax and refresh. Likewise, our residents like going outside to see different things. Their mood would be undoubtedly uplifted. (Participant 10, paragraph 38 - 39)

Subcategories	Relevant verbatim
	● We will give some toys to the residents to play, especially toys with tactile sensory stimulation, or some table-top tasks, so that they are fully occupied. I usually encourage them to do by themselves, so that they are distracted from self-inflicting or challenging behaviour. For those with head-banging behaviour, helmet would be applied to prevent injury. Soft padding is added on the table-top or surfaces that they can reach. We will also report their behaviour to their medical officers occasionally. It is our duty to report their performance to doctor, who has the absolutely right and responsibility to adjust medication regime if necessary. (Participant 13, paragraph 52)
Implementing person-centred care	● The strategies should be tailor-made to individual residents. For instance, if she has head-banging behaviour, helmet and soft padding for bedside rails should be considered. If her cognitive function is able to comprehend simple communication, then she would be involved in the care planning, as well as her family. Through the discussion, we need to gain her cooperation, and increase daytime activities, either through training centre or from family support. Her interested activities would be included as far as possible. Sometimes, she may just need colour pens and paper, or individual toy box which is affordable in ward level. Periodical review is necessary. This kind of person-centred care has implemented for years, but may not apply to every resident. (Participant 1, paragraph 14) ● I think the application of MT and MSE should be based on their needs. For instance, if the resident does not present challenging behaviour, her session may be offered once a month or less than that, while the resident with severe challenging behaviour, very anxious and apprehension, the number of sessions should be increased to daily or at least thrice a week. It depends on their individual needs so that the available resources can be fully utilised. (Participant 2, paragraph 18) ● Most often, the exhibition of challenging behaviour is related to the results of interaction with the environment. If there has positive support elements in the usual care, for instance, soft spoken instruction and good rapport with caregivers. The presentation of challenging behaviour would be reduced. On the

Subcategories	Relevant verbatim
	contrary, if the clinical atmosphere is not therapeutic, like, dominant with reproached instructions, then rapport building is unlikely. Not all challenging behaviour are negative, sometimes, it may be caused by curiosity, and idleness. Hence, the need satisfaction should be addressed in the interventions. For instance, the pith of sound, some residents are very sensitive, especially with autistic features. Then, the choice of music or sound should be more conscious. (Participant 6, paragraph 4)

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