The Hong Kong Polytechnic University

School of Nursing

THE LIVED EXPERIENCE OF
HONG KONG CHINESE MOTHERS OF
EXTREMELY LOW BIRTH WEIGHT PRESCHOOL CHILDREN:
A PHENOMENOLOGICAL STUDY

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A thesis submitted in partial fulfillment
of the requirements of the Hong Kong Polytechnic University
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CERTIFICATE OF ORINIATLITY

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 that has been accepted for the award of any other degree or diploma, except where due acknowledgement has been made in the text.

CHENG YEE MEI GRACE

Abstract

The birth of a child conveys expectations, new challenges and responsibilities, and the start of a new phase of life for the infant and mother. Yet, the birth of a premature infant is represented in previous reports as a traumatic, stressful and insecure time-dependent process to the mothers. Although studies pertaining to the western culture have reflected a long standing interest on the impact and stress on the families perceived by the parents of very low birth weight children, little attention has been given to the mothers' lived experience in caring for an extremely low birth weight (ELBW) child during the preschool years in the Chinese culture.

This hermeneutic-phenomenological inquiry was conducted to uncover the mothers' experience of living with ELBW preschool children. The purpose of this study was to describe and interpret the mother's experience so as to provide health care professionals with an increased understanding and insight about this experience.

Twelve mothers were recruited for in-depth interviews that were audiotaped and transcribed verbatim. Supplementary information from field notes was also used to enhance understanding of the mothers’ experience. The process of analysis was guided by the methodological process of a nursing inquiry adopted from Ray (1991), together with the phenomenological hermeneutic ideas from van Manen (1990). The process of data analysis was cyclic and summarized into three core phases. The first phase aimed for a naïve understanding of the text. The second phase was the structural analysis composed of descriptive reflection and interpretive reflection to elucidate the experience of mothers. In the third phase, the text was considered as a whole again to obtain a critical understanding of the experience.

From the mothers’ narrations, seven metathemes emerged through deep reflection. The first four metathemes reveal the fundamental existential nature of the experience of extremely-low-birth-weight and they are:

✧ *Transforming in Corporeal – Embodying Motherhood*

✧ *Changing in Temporal – Living with Uncertainty*

- *Changing Relationships – Shaping the Caring Labyrinth*
- *Interacting with the Environment – Anticipating and Intervening*.

The remaining three metathemes reveal the transcendent meanings of the experience are:

- *Getting To Know and Understand*
- *Asserting Life in Pending Loss*
- *Transcending to Spirituality*.

Together with the metathemes and themes central to this experience of extremely-low-birth-weight, a metaphor: *Surmounting barriers one after another over the long journey* emerged. Further reflecting on the metathemes and metaphor, the unity meaning: *A Meaning of Life: Each Day a New Day* was revealed.

This research suggests an imperative notion that nurses and healthcare professional should emphasize a holistic care approach engaging into the mothers' psycho-social-spiritual world so as to get a closer focus on to the complexity of their needs. Recognizing the experiential knowledge of mothers, healthcare

professionals should involve mothers as partners within caring interactions and decision-making. Nurses are encouraged to maintain an inter-subjective relationship with the mothers to achieve mutual planning of care with mothers in facilitating their care management of ELBW children at preschool age.

Publications

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Glossary

The operational definitions of terms used for the purpose of this study are as follows:

Extremely low birth weight

1. "Extremely low birth weight" (ELBW) is used to describe the child who weighs 1,000 gram or less at birth (Gunderson & Kenner, 1990).
2. "Extremely-low-birth-weight" refers to the experience of living with the ELBW child.

Experience

1. "Experiences" refers as the multiple episodes, occurrences, events or happenings.
2. "Experience" refers to the feelings, emotions, perceptions, attitudes, events, meanings of events, reactions to events, and functions or roles that are being explored in understanding the participant's experience as whole in phenomenological approach (Crotty, 1996).

Low birth weight

"Low birth weight" (LBW) is used to describe the child who weighs 2,500 gram or less at birth (Gunderson & Kenner, 1990).

Mothers

"Mothers" refers to the natural biological mothers of the children born with extremely low birth weight.

Premature / preterm

"Premature" or "Preterm" is used interchangeably to describe infant born before 37 completed weeks of gestation calculated from the onset of last menstual period (Llewellyn-Jones, 1982).

Preschool

"Preschool" refers to the age of children between 3 to 5 years, before entering primary education.

Very low birth weight

"Very low birth weight" (VLBW) is used to describe children who weigh 1,500 gram or less at birth (Gunderson & Kenner, 1990).

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CHAPTER 1

Introduction and Background

Introduction

> *You are feeling sorry at this moment, then today is already the worst. Tomorrow will not be worse than today. Difficulties, you have overcome. There will be no more difficulties, no more. Then every difficult day will be passed. You see, instead of sitting there and thinking how sorry the old days were, would it be better you think about how to live the future, how to make the future better.*
>
> *(Jing – Mother of Jun-wei)*

This encouraging quote, expressed by the mother of a child born with extremely low birth weight (ELBW) who participated in this study, conveys the ideas of letting go the past, living in the present and striving for the future, that the mother embraced. The unhappy past has gone and the uncertain future is to come; living the present to its fullness is the striving force for the mother and the child. The child, the mother and the experience of extremely-low-birth-weight are interweaving, forming a dynamic and constant changing assemblage. Nevertheless, parents of prematurely born children expressed more stress than those of full term children, and they reported difficult parenting of these premature children as related to their behavioral and developmental problems (Miles & Holditch-Davis, 1997).

The birth of a child can bring joy, excitement and the start of a new phase of life for the infant and mother. It may convey expectations, wonder, new challenges and responsibilities to parents as they adjust to the new family member. The birth of a premature infant, including ELWB infant, is reported in previous studies as a traumatic, stressful and insecure time-dependent process to the mothers (Holdotch-Davis, Barrlett, Blickman & Miles, 2003; Jackson, Ternestedt & Schollin, 2003). Since ELBW infants are high risk infants and require technological care in the neonatal intensive care unit immediate after birth, contributing to the stress and insecurity of mothers would be the overall stressful environment in the neonatal intensive care unit (NICU) (Miles, Funk & Carlson, 1993; Franck, Cox, Allen & Winter, 2005; Seideman et al., 1997), their experience of dilemma in decision of life-and-death (Hurst, 2005a), and their feelings of helplessness as related to the long separation from the infants (Werceszczak, Miles & Holditch-Davis, 1997).

The advances in medical technology and improvements in perinatal care in recent decades, in particular the employment of antepartum corticosteroids and neonatal surfactant therapy (Agustines et al., 2000), have altered the survival age, management and outcomes for ELBW children (Fanaroff, Hack & Walsh, 2003). Likewise, the quantity of care and investment a mother has to put into the day-to-day activities in caring for an ELBW child have undoubtedly changed. The repetitiveness of childcare routines and the lack of reinforcement accompanying parenting of a premature child might be a source of parental frustration that would be considered within the large family context together with other parenting issues (Swartz, 2005). Although similar experience may exist for other mothers of term children, those having a high risk premature child, including ELBW child, are reported to have greater psychological stress such as depression and anxiety than mothers of low risk or term infants (Eisengart, Singer, Fulton & Baley, 2003; Tommiska, Ostberg & Fellman, 2002; Singer et al., 1999).

Numerous studies pertaining to the western culture have been reporting the stress perceived by the parents in coping with the needs and problems of VLBW children during early infancy (Cronin, Shapiro, Casiro & Cheang, 1995; Gennaro, 1996; Gennora, York & Brooten, 1990; Lee, Penner & Cox, 1991; McCain, 1990; Nelson, & Edgil, 1998; Robson, 1997). Although the neurodevelopmental outcomes of the ELBW child are more likely to be predicted (Voss, Neubauer, Wachtendorf, Verhey & Kattner, 2007), little attention, either local or overseas, has been given to the mothers' lived experience in caring for an ELBW child during the preschool years. This phenomenological research explores the experiences, feelings and thoughts of the mothers who are mostly the major caretakers for their ELBW preschool children at about three to five years old. This study seeks to understand how the mothers view their experience in living with an ELBW child, find meaning in their life world, view themselves and perceive the impact of raising a child with extremely low birth weight. It is fundamental to this study to consider the reciprocal relationship between mother and child as of them each develops and constructs a sense of ties and bonds on interaction with the other (Klaus & Kennell, 1976). The goal of this study is to provide an increased understanding of and insight into these issues.

Background of the Study

Birth weight is an important indication of infant health. Newborns who weigh 2,500 gram or less are classified as low birth weight (LBW), and those newborns who weigh less than 1,500 gram and less than 1,000 gram are described as very low birth weight (VLBW) and extremely low birth weight (ELBW) respectively (Gunderson & Kenner, 1990). Since most of the physiological structures, including the vital systems, are inadequately developed at time of birth (Larsen, 1993), these ELBW infants have a greater risk of mortality and premature death. According to the Hong Kong Population Health Profile Series published in 2006, among the leading causes of infant death in Hong Kong in 2004, disorders related to length of gestation and fetal growth (including all LBW infants) accounted for 9.9% of all infant death (Center of Health Protection, 2006).

With clinical and technological advances in perinatal and neonatal care, the survival rate of the ELBW infants has been dramatically improved in the past decades. In the United States, the survival rate of infants born with birth weight 500 to 999 gram increased from 49% from 1982-1989 to 67% in 1990-1998 (Wilson-Costello, Friedman, Minich, Fanaroff & Hack, 2005). Similarly in Hong

Kong, the survival rate of those live births with birth weight less than 1,000 gram irrespective of any major congenital anomalies, increased dramatically from 62.1% in 1994 to 76.2% in 1999 (Hong Kong College of Obstetricians and Gynaecologists, 2004). This present study was conducted in 1999 to 2002 when these ELBW children were reaching the preschool age.

However, the emphasis of concern regarding ELBW infants has been shifting from mortality to morbidity. Despite an increase in survival of ELBW newborn, the neonatal and early childhood morbidity did not change appreciably. In the United States (Wilson-Costello et al., 2005), the increase of survival rate of ELBW infants from 49% (1982-1989) to 67% (1990-1998) was accompanied by an increase in neonatal morbidity rates including rates of sepsis (37% to 51%), periventricular leukomalacia (2% to 7%) and chronic lung disease (32% to 43%). Furthermore, the prevalence of neurodevelopmental abnormalities among ELBW survivors is on the rise. At 20th months of corrected age, increase in neurological abnormalities observed included cerebral palsy (16% to 25%) and deafness (3% to 7%) (Wilson-Costello et al., 2005). These figures reveal that the lives of ELBW infants have been prolonged but they are more likely to have developmental delay and health problems that are mostly confirmed in the preschool years.

The discharge of a premature infant from the neonatal intensive care unit is both a joyous yet delayed homecoming and stressful transition for families. The parents, usually the mothers, resume care for the infant who until that day of discharge has been relying on the 24-hour care by a team of highly skilled professionals. During the infants' long stay in the sophisticated neonatal intensive care unit, the parents have been playing the role as visitors and experiencing an alteration of parental role in coping with the stress that arises from the physical and psychosocial environment or because of the illness of the infant during the hospital stay (Heerman, Wilson & Wilhelm, 2005; Holdotch-Davis, Barrlett, Blickman & Miles, 2003; Miles, Funk & Kasper, 1991; Miles, Funk & Kasper, 1992; Seideman et al., 1997). Mothers have reported feeling guilt over their failure to carry the infant to term, uncertainty about the infant's condition, sadness and helplessness as related to their loss of anticipated maternal role (Holditch-Davis & Miles, 2000).

After the previous long separation, the parents, especially the mothers will be resuming the full-time parental role in their own homes, becoming the crucial and 'permanent' caretakers in optimizing the health of the infant. However, these ELBW survivors might require long term medical attention and special care as they might have subsequent developmental and psychosocial condition (Schmidt et al., 2003; Anderson & Doyle, 2003). Other than the neurological problems, a high incidence of behavioral problems has been noted in ELBW children, which often adversely affects the school performance and development of social relations of these children. However, behavioral and cognitive functions of ELWB children might not be clearly noted in infancy but were mostly confirmed at their preschool age when they are expected to achieve certain developmental tasks (Collin, Halsey & Anderson, 1991; Voss et al., 2007). In parenting the premature children, the mothers would experience higher stress and anxiety (Eisengart et al., 2003). Psychological distress, especially depression, anxiety and obsessive compulsive behaviors of mothers of high-risk VLBW children were identified to persist for years though the severity varied over time (Singer et al., 1999). Increased parental stress was present during their early childhood as contributed by the developmental status of the infant and the quality of the infant-parent relationship (Robson, 1997), and continued in the following years and affected the family in terms of financial burden, familial and social impact and personal strain (Cronin et al., 1995) and negative marital relationship (Saigal, Burrow, Stoskopf, Rosenbaum, & Streiner, 2000).

The researcher’s interest in the mothers having an ELBW child emerged long before this study. The researcher of this study used to be a clinical nurse working in the paediatric wards in particular the NICU, caring for the ELBW children and the families, mostly mothers, in the NICU as early as the babies were born, the researcher witnessed all the common problems and complications of ELBW infants, both primary and secondary such as respiratory distress syndrome, hypoglycemia, hyperbilirubinemia, intraventricular haemorrhage, patent ductus arteriosus, necrotizing enterocolitis, bronchopulmonary dysplasia, retrolental fibroplasias and infections, and was often concerned about how these mothers experienced these conditions. The mothers’ stress during the acute phase of the condition was likely to be addressed by healthcare workers during the hospital stay of the infants. However, their perspective of experience during the subsequent years was not well recognized by health care professionals, and thus leading to a lack of knowledge for the provision of care in continuum, both in the hospital and the community.

In Hong Kong, ELBW infants born in the era when the medical advancement of corticosteroid and surfactant therapy have been widely used, are now just reaching school age. However, there is not any research on the experience of the mothers in caring for their ELBW children at home during their preschool years and in the Chinese culture. In view of the lack of knowledge regarding the mothers' experience, it is essential for health care professionals to recognize the psychosocial support that these mothers and families require in particular during the preschool years of the ELBW children. Thus, this study attempts to understand the lived experiences of the Chinese mothers of ELBW children during their preschool years in Hong Kong, who have been discharged home after staying in the neonatal intensive care unit. Previous studies pertained to the western culture, whereas this study aims to provide an understanding of the experience of mothers in a Chinese perspective for the nursing practice.

Significance of the Study

This study seeks to search and deepen understanding of the lived experience of mothers who have been caring for the ELBW children during the preschool years.

It explores the meaning of the mothers' experience that the mothers perceive in living with the ELBW preschool children. It is hoped that the findings of mothers' experience will help healthcare professionals to gain a deeper understanding about their needs. In addition, nurses will gain insight from the study findings of the lived experience of these mothers and will be helped in planning for the provision of necessary support and appropriate care for the mothers and parents during the preschool years.

At present, previous studies pertaining to the western culture have focused on the long lasting impact on the families, such as financial, familial, social and personal issues, perceived by the parents of VLBW children (Cronin et al., 1995; Gennaro, 1996; Gennora, York & Brooten, 1990; Lee et al., 1991; McCain, 1990; Nelson, & Edgil, 1998; Robson, 1997; Jackson, Ternestedt & Schollin, 2003; Swartz, 2005). They did not provide an in depth understanding about the mother's experience and feelings, or her view of the meaning of her life. Few studies describe the coping and caring experience of the mothers of ELBW children during the preschool years, basing on the mothers' own perspectives.

Given that no empirical study on the lived experience of mothers of ELBW child has ever been conducted in Hong Kong, this study, adopting a phenomenological approach, intends to uncover the meaning of the lived experience of Hong Kong Chinese mothers of EBLW children during the preschool years. This study is carried out using a hermeneutic phenomenological approach (van Manen, 1997), with an attempt to illuminate themes that provide insightful descriptions of the lived experience of the mothers, so as to facilitate nursing care planning based on an understanding of the various lived experiences arising from mothers' telling of their descriptions of a life event experience.

This phenomenological study of experience of mothers of ELBW children following the infancy period is of both conceptual interest and clinical importance, attempting to focus on the perspectives held by the mothers and how these perspectives influence the mothers' dealing with ELBW experience. The goal in this study is to explore the everyday lives of the mothers and the changes in their realm of familiar and taken-for-granted. The researcher wants to describe and interpret the mothers' perception of reality and to understand the meaning of the mothers' life in caring for an ELBW child during preschool years.

This study aims to reveal the experience of mothers of ELBW children as there is a consensus that mothers are most often the primary caretakers of ELBW children (Woollett & Marshall, 2000). Although fathers might experience similar parental transition, mothers were found to experience heightened psychological distress during the transition to parenthood (Dulude, Belanger, Wright & Sabournin, 2002). In the Confucian tradition of Chinese, the mother's familial role in child caring is still regarded as most important (Ho, 1986). During the internalization of parenthood of parents of preterm infants, although both mothers and fathers described similar parental roles such as concern for child, insecurity, adjustment and relationship with the child, mothers experienced more responsibility and control of care and a need to be confirmed as a mother (Ternestedt & Schollin, 2003). Mothers of ELBW infants were found to experience significantly more stress than the fathers in respect of role restriction, incompetence and spouse relationship problems (Tommiska et al., 2002).

The researcher also expects the findings of the study to provide an in-depth understanding of the caring experience of these mothers of ELBW children. The findings from this study will be directly relevant to the local context and hopefully, can provide information to health care professionals for necessary education, practice and care policy planning in supporting the mothers and families of ELBW children.

Aim and Objectives of the Study

The aim of this study is to seek an understanding of the lived experience of mothers who have been taking care of their ELBW child during the preschool years. In this study, the mothers' descriptions of experience are the basis. The guiding question for this study is: "What is it like to be a mother of an extremely low birth weight child during the preschool years?"

It is expected that this study will make a useful contribution to an understanding of the lived experience of mothers of ELBW children so as to identify the appropriate healthcare strategies in the provision of adequate support and relevant services to the mothers and fathers of ELWB children during the preschool years. The specific objectives of the study are:

1. To describe and interpret the lived experience of the mothers living with an ELBW child during the preschool years in a Chinese context.

2. To describe the impacts of the extremely-low-birth-weight on the family during preschool years of the ELWB children in a Chinese context.

3. To identify the characteristics of coping strategies and caring tasks of Chinese mothers of ELWB children during preschool years.

4. To describe the meanings of the mothers’ lived experience of caring for the ELBW children during preschool years in a Chinese context.

Organization of the Thesis

The thesis is organized into six chapters. In Chapter 1, the background and significance, aims and objectives, rationale of the study, and operational definitions are stated. In Chapter 2, the literature review provides an overview of the significance of ELBW children in health care including the prevalence and specific developmental outcomes. Chapter 3 is the literature review exploring the psychological and social responses to the outcomes in child caring as related to the process of transition into parenthood and the adjustment in the families. The methodology presented in Chapter 4 explicates the philosophical foundation of phenomenology and hermeneutics, the relation of phenomenology and hermeneutics with human science and nursing; and describes the setting and context of the study, the process of the inquiry, the analysis of findings, and the credibility of the study. Chapter 5 summarizes the themes and metathemes emerged from interview data. A story of a mother, which was reconstituted from the interviews and observations, is used to illustrate the unique experience of the mother. Chapter 6 presents the discussion on the findings, the unity of meaning revealed form the study and recommendations for healthcare professionals. In chapter 7, based on the findings and limitations of the study, an account of the nursing implications and recommendations on nursing practices, education and future research is presented.

CHAPTER 2

Literature Review: Impacts of Extremely-Low-Birth-Weight

The purpose of literature review in qualitative study is to sensitize the researcher to the area being investigated and the adequacy of investigations, facilitating the researcher to merge or contrast ideas during the process of data interpretation and after data generation. The literature review in this study attempts to focus on the literature related to the content of the study that includes issues regarding ELBW children and the families. Since the researcher's intent is to remain free of presuppositions about the phenomenon to be studied, the substantive literature review was delayed until the analysis of primary data had been commenced (Carpenter, 1995; Porter, 1993).

Introduction

In the 1980's, small gestation age or very low birth weight and respiratory distress syndrome has been the leading cause of neonatal death (4 weeks after birth). Those extremely immature infants (less than 26 weeks), who were born barely past the halfway point of the normal 40-week gestational maturity, would not be able to survive in the extra-uterine environment. However, with advances in perinatal and neonatal care, the neonatal survival rate of prematurely born infants, including ELBW infants, has been dramatically improved in past two decades. In

Hong Kong, the number of live birth weighed < 1000 gm increased from 45 out of 68,637 live-born infants in 1995 to 110 out of 49,796 in 2004 (Hong Kong Hospital Authority, 2006). The survival rate of these premature infants with birth weight less than 1000 gm also increased from 62.1% in 1994 to 76.2% in 1999 and 79.2% in 2004 (Hong Kong College of Obstetricians and Gynaecologists, 2004).

Improved mortality has not been accompanied by a decrease in morbidity among the ELBW infants. Increasing survival of these ELBW infants has resulted a steady increase in prevalence of ELBW children with neurological and developmental disability over time. In the United States, it was reported that an increase in survival rate of ELBW infants from 49% (1982-1989) to 67% (1990-1998) was accompanied by an increase in neonatal morbidity rates including rates of sepsis (37% to 51%), periventricular leukomalacia (2% to 7%) and chronic lung disease (32% to 43%). Increase in neurologic abnormalities was also observed including cerebral palsy (16% to 25%) and deafness (3% to 7%) (Wilson-Costello et al., 2005). The parents of ELBW children have already experienced a premature and abrupt end to pregnancy and are often unprepared to become parents at such early stage of gestational development. These ELBW survivors with chronic illness and neurological problems might require special and complex care and thus would contribute to the stress that the parents have been coping with.

This suggests that although advances in medical technologies has improved the viability of ELBW infants who would otherwise have not survived, accompanied would be the subsequent morbidity and developmental problems that probably be a major source of stress for the parents concerned. The following review in this chapter will provide background information related to extremely low birth weight, including an overview of gestational immaturity that contributes to the subsequent neurological abnormalities and developmental disability; normal developmental milestones of preschool children; birth weight and birth rate; improved mortality; physical growth and development; behavioral problems and functional difficulties of the ELBW children. In view of the relative dearth of descriptions focused explicitly on ELBW children until recent years, the literature on VLBW and LBW has also been reviewed.

Gestational Immaturity of Extremely Low Birth Weight

Birth weight and gestational age are the important indications of a newborn's health. Infant is classified as premature when born before 37 completed weeks of gestation and defined as low birth weight if weighs less than 2,500 gram at birth. (Llewellyn-Jones, 1982). Infants born prematurely with low birth weight have a greater risk of mortality and premature death as they are less adaptable to extra-uterine life. Agustines et al. (2000) in the United States also suggested that the mortality rate among ELBW infant weighed 600 gm or more, was higher than those weighed less than 600 gm, while the mortality rate decreased with increasing gestational age. According to the Hong Kong Population Health Profile Series (Center of Health Protection, 2006), among the leading causes of infant death in Hong Kong in 2004, disorders related to length of gestation and fetal growth, including all low birth weights, accounted for 9.9% (or 12 registered death) of all infant deaths.

Extremely low birth weight newborns are often referred to as high risk infants who are born prematurely at 24-25 week gestation. The survival of these extremely premature infants in the extra-uterine environment is unlikely without advanced medical technologies, especially intensive respiratory assistance. To understand their unique problems and special needs of the extra-uterine life, it is necessary to have a basic working knowledge of the embryological and physiological development of the infants born at 24-25 week gestation. Table 2.1 below shows a summary of the embryological and physiological development of a human fetus.

Human development begins when the ovum from the female is fertilized by a sperm from the male, producing a single cell zygote. The single cell zygote marks the beginning of a multicellular organism, the human infant. During the first four week after conception, the development of a human embryo begins. The zygote then undergoes rapid mitotic cell division in the stage of cleavage and the primitive forms of organs and systems are developed through the process of organogenesis. The period from weeks 4 to 8 is extremely important as it marks the beginning of all major external and internal structures. As shown in Table 2.1 below, the heart begins beating during the fourth week, the upper and lower limb buds appear, the eyes and ears are forming and the mandible and maxilla begin to shape. By the eighth week, the embryo has human characteristics. The intestines herniated into the umbilical cord, the digits of the hands are webbed and the toes are distinct. Week 9 marks the beginning of the fetal period that extends until birth. From weeks 9 to 25, fetal growth continues unless interrupted. By the twentieth week, the genitalia can be identified, erythropoiesis takes place in liver and spleen, urine formation begins, skin is covered with vernix caseosa and hair on scalp is visible. The fetus only begins to gain weight from weeks 21 to 25 while most of the fat is laid down in the final trimester. So the lack of fat deposit gives the skin a wrinkled and translucent appearance. It is at this juncture, the production of surfactant in the lungs begins.

An infant born at 24-25 weeks does not have the opportunity to accomplish the fetal development from 26 week to term. It is by week 26 onward, that extra-uterine life is possible as the lungs are capable of breathing air for the first time. It all depends on the adequacy of pulmonary vasculature lying in the alveoli for gaseous exchange and the maturity of the central nervous system that initiates the rhythmic breathing movement. Another factor that influences the viability of extrauterine life is the capability of the central nervous system to initiate and maintain respiratory movement. As shown in Table 2.1, it is by weeks 26-29 that

Table 2.1: Summary of embryological and physiological development of human fetus
(Extracted from Gunderson and Kenner, 1990)

Period	Gestation	Development Process	Significant landmark
Fertilization and Early Development	Day 1 to Week 4	✧ Fertilization ✧ Cleavage ✧ Blastocyst formation ✧ Process of folding ✧ Organogenesis	Day 11 ✧ Primitive placental circulation Day 13 ✧ Umbilical cord emerges Day 16 ✧ Organogenesis begins – primitive heart, septum traversum (diaphragm), mouth, foregut
Embryonic Period	Weeks 4-8	✧ Beginning of major internal and external structure ✧ Highly susceptible to teratogens	Week 4 ✧ Heart beats, limb buds, eye and ears begin forming Week 6 ✧ Eyes obvious, elbow, wrists and finger rays Week 8 ✧ Human characteristics, intestines herniated in to umbilical cord, hands are webbed, toes are distinct
Fetal Period	Weeks 9-25	✧ Fetal period begins	Week 9-12 ✧ Genetalia differentiation begins ✧ Visible intestinal loops ✧ Well developed upper limbs Week 13-16 ✧ Rapid fetal growth Week 17-20 ✧ Distinct masculine or feminine genetalia ✧ Lower limbs well formed By 20th week ✧ Quickening movement ✧ Skin covered with vernic caseosa and lanugo Week 21-25 ✧ Begins to gain weight ✧ Lungs begins to produce surfactant
	Weeks 26-Term	✧ Continue fetal growth	Week 26 ✧ Maturation of lungs and central nervous system for breathing ✧ Week 26-29 ✧ Erythropoiesis in bone marrow ✧ White fat deposition to 25% as at term – wrinkled skin Week 30-34 ✧ White fat deposition to half as at term Week 35-38 ✧ Fat deposition to be completed

the central nervous system is mature enough to initiate rhythmic respiration. At this same time, erythropoiesis occurs in the bone marrow and the white fat deposition comprises about 3.5% of total body weight. From weeks 30-34, the white fat content rises to around 7-8% of total body weight, that is about half of the total body fat on a full term infant. During the final stage at weeks 35-38, the major development is the additional of more white fat. By end of week 38, white fat constitutes approximately 16% of the total body weight (Gunderson & Kenner, 1990).

Most of the structure for the developing fetus is laid down in the early weeks of life, except the respiratory system, which is one of the last to develop. By week 23 the alveolar type II cells in the lungs begin to produce surfactant, a mixture of phospholipids and surfactant proteins that reduces the surface tension of the liquid film lining the alveoli and thus facilitates inflation. It is a necessary substance that prevents the lung alveoli from collapsing and interfering with the exchange of oxygen and carbon dioxide. Inadequate pulmonary surfactant is the prime cause of respiratory distress syndrome in premature infants, resulting in death in premature infants (Larsen, 1993). As the maturation of the physiological systems and vital organs takes place from week 26 onwards, the life of extremely premature infant born at weeks 24-25 gestation with extremely low birth weight in the extra-uterine environment is at high risk. Survival of these infants was not likely in the 1960’s before the advanced development of medical technology and complex neonatal intensive care services.

Developmental Milestones through Preschool Years

The years between birth and preschool years of age are a time of dramatic growth and development. The combined biologic, psychological, cognitive, spiritual and social achievements during the preschool period (3 to 5 years) prepare preschoolers for their most significant change in lifestyle – entrance into school. Although children develop at their own pace, certain stages of development happen in basically the same order for all children. However, infants born prematurely are different in many aspects of development that may be a consequence of the immaturity at birth and related to perinatal problems, which will be reviewed in subsequent sections.

Although parents of premature children are usually advised to observe the development of these children according to the corrected age – starting with the expected birth date, rather than their actual birth date, parents are eager to compare the difference in expected development and actual achievement. Parents naturally notice the progress of their child’s development as they compare them with other children of similar chronological age – especially in preschool. To understand the difference from developmental landmarks of children born prematurely, it is essential to have a crude background knowledge of the normal developmental milestones of those children born at term. In assessing the developmental and functional outcomes of children at preschool age, it is important to observe activities of self mobility like walking and climbing stairs;

and also perceptual motor skills as they impact on feeding, dressing, drawing, and conceptual skills in pragmatic language, social interactions during play and social learning (Msall & Tremont, 2002).

For preschool children, successful achievement of previous levels of growth and development is essential to refine many of the tasks that are mastered during the toddler years (12 to 36 months). In general, the rate of physical growth slows and stabilizes during the preschool years. The average weight gain is about 2.3 Kg per year, and the height increase is 6.75 to 7.5 cm per year. During this period, most children are toilet trained. Motor development consists for the most part of increases in strength and refinement of previously learned skills. Both gross and fine motor skills are well established by age 5 when the child skips on alternate feet, jumps rope and begins to skate and swim. Advancement on development of fine muscle coordination is also shown as children progress from scribbling to picture making. Preschoolers assume that everyone thinks as they do and they learn from play to understand, to adjust and work out life experience. Preschoolers increasingly use language without comprehending the meaning of words particularly the concept of right and left, causality and time. The preschool years play an important role in the development of body image and to the person’s overall sexual identity and beliefs. During the preschool period, the individual-separation process is complete and preschoolers have overcome much of their anxiety regarding strangers and the fear of separation. Preschoolers become increasingly aware of their position and role in the family and demonstrate their sense of autonomy by verbalizing their request for independence and perform independently with their much-refined physical and cognitive development (Wong, 1995).

The growth and development of prematurely born children are affected by various factors that include gestational age at birth, physical measurements at birth and at discharge from hospital, length of hospitalization and of course the medical diagnosis and its severity, treatment and response (Wong, 1995). For ELBW children who are born at week 24-25 gestation, their development landmarks would be measured by the corrected age, otherwise they would be assessed as about 15-16 weeks behind those with similar chronological age. Nevertheless, considerations should be taken into account the possible medical problems of the ELBW child that would also contribute to the substantial delay of development.

Mortality of ELBW Infants

During the past two decades, with significant clinical and technological advances in perinatal and neonatal care and the introduction of surfactant replacement therapy in late 1970’s, dramatic increase in survival rate of the ELBW infants in the past decades has been well documented. In the United States (Wilson-Costello et al., 2005), the survival rate (to 20 months corrected age) of ELBW infants with birth weight between 500 gm to 999 gm increased from 49% (1982-1989) to 67%

(1990-1998), accounting for 18 additional survivors per 100 live births. Changes in perinatal management and care have contributed to an increase in the mortality rate of ELBW infants. With increased practice in Cesarean section from 17% to 27 % and delivery room intubation from 54% to 72% infants with birth weights of less than 750 gram. Survival increased from 23% to 43% and the increase of survival was significant at weight of 600 to 700 gram and at 24 weeks gestation and greater (Hack, Friedman & Fanaroff, 1996). Another retrospective cohort study in the United States also suggested that the mortality rates among ELBW infant weighed 600 gm or more was higher than those weighed less than 600 gm and the rate decreased with increasing gestational age. The survival was found associated with the employment of antepartum corticosteroids or neonatal surfactant (Agustines et al., 2000).

Survival rates of ELWB differed between genders. Stevenson et al. (2000) reported that male infants had a significant higher mortality rate than female at similar prenatal and perinatal situations. Boys were more likely to have low Apgar score, need intubation and resuscitation medication. Besides, morbidities among boys were of higher prevalence. Other than pulmonary morbidity, intracranial haemorrhage and urinary tract infection were more common.

Improved ELBW mortality was also reported in Asia countries. In Taiwan, a comparison was made on the outcomes of neonates born with birth weight of 500-999 gm without major anomalies between the periods from 1988 to 1992 and

1993 to 1996, with the introduction of exogenous surfactant and modern neonatal care in the latter. The incidences of the ELBW infants increased from 0.23% to 0.59% in the respective periods while the early neonatal mortality rate significant decreased from 43% to 14%. (Tsao, Wu, Teng, Tang & Yau, 1998).

Reviewing the health statistics in Hong Kong, improved survival of ELBW children is also observed. Early in 1980’s, short gestation or unspecified birth weight and respiratory distress syndrome has been the leading cause of neonatal death (4 weeks after birth). Those extremely immature infants, who were born barely past the halfway point of gestational maturity, would not be able to survive in the extrauterine environment. However, with advances in perinatal and neonatal care, the neonatal survival rate of prematurely born infants, including ELBW infants, has been markedly improved.

In Hong Kong (Hong Kong Hospital Authority, 2006), the crude birth rate has been in decreasing trend since 1960’s and the figures of known births continue to decrease from 68,637 in 1995 to 49,796 in 2004 (a decrease of crude birth rate from 11.2 to 7.2 per thousand population). At the same time, the number of neonatal deaths has also been declining from 173 to 76, that is a decrease of neonatal mortality rate from 2.5 to 1.6 per 1000 live births. Regardless of the decreased birth rate, the number of live birth weighed less than 1,000 gm increased from 45 in 1995 to 110 in 2004 (See Figure 2.1 below). Moreover, the survival rate of these infants with birth weight less than 1,000 gm also increased from 62.1% in 1994 to 76.2% in 1999 and 79.2% in 2004 (Hong Kong College of Obstetricians and Gynaecologists, 2004).

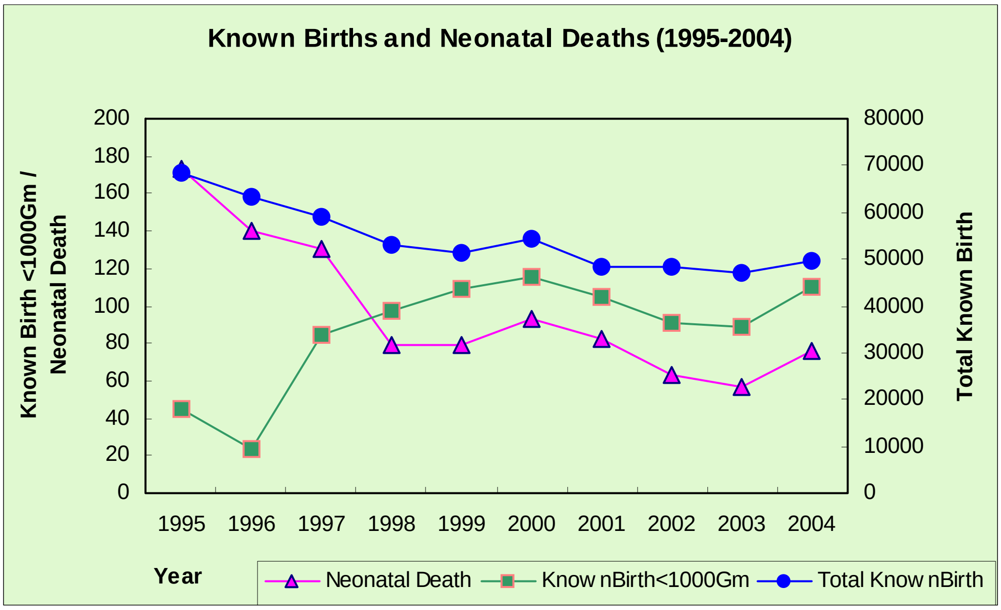
The increase in survival was not accompanied by a significant improvement in neurodevelopmental morbidity and cognitive function. On the other hand increasing survival of these infants has resulted in a steady increase in the prevalence of children with disability over time. Moreover, developmental sequelae have been found to persist throughout the childhood into adolescence. The discussions on the growth and developmental outcome of ELBW unfold in the subsequent sections.

Growth and Developmental Outcomes of ELBW Children

Neonatal Morbidity and Developmental Outcomes

In the United States, Wilson-Costello and colleagues (2005) reported that increase of survival rate of ELBW infants from 49% (1982-1989) to 67% (1990-1998) was accompanied with increase in neonatal morbidity rates including rates of sepsis (37% to 51%), periventricular leukomalacia (2% to 7%) and chronic lung disease (32% to 43%). Increase in neurological abnormalities at 20 months of corrected age was also observed including cerebral palsy (16% to 25%) and deafness (3% to 7%).

Figure 2.1: Trend of Total known Births, Known birth<1000 gm and Neonatal Death, 1995-2004



Source: Based on the Known Birth Statistics provided in the Hospital Authority Intranet (Report generated on 23 December 2006)

Neonatal morbidity of the ELBW infants is significantly related to the subsequent development of disabilities. In a cross cultural multicenter study in Canada, United States, Australia, New Zealand and Hong Kong (Schmidt et al., 2003), ELBW infants with birth weight 500 gm to 999 gm were recruited and the neonatal morbidity, including bronchopulmonary dysplasia (BPD), ultrasonographic evidence of brain injury and severe retinopathy of prematurity (ROP), and neurological developmental outcome at 18 months were reviewed. Schmidt and colleagues (2003) reported that during the neonatal period, 45% of the infants developed BPD, 21% had brain injury and 10% had severe ROP. Out of the 876 survivors at 18 months, 110 (13%) developed cerebral palsy, 229 (26%) had cognitive delay, 20 (2%) had hearing loss requiring amplification and 16 (2%) had bilateral blindness. This report suggested the rate of 18-month outcome was significantly correlated with the number of the neonatal morbidities. The rate was 18% for children free of BPD, brain injury and severe ROP, and the corresponding rates with one, two and all three neonatal morbidity increased to 42%, 62% and 88% respectively.

Visual impairment is one of the adverse developmental outcomes of ELBW survivors and it is highly related to ROP, a severe neonatal morbidity of prematurity. In Australia (Hebbandi et al., 1997), it was reported that among a group of 69 ELBW survivors at 5 years, 30 (43%) had some form of ocular disorder. Nineteen (27%) had reduced visual acuity of < 6/6 and three of these were blind. Myopia > -0.5 dioptre was noted in eight (12%), hypermetropia > or = 2.0 dioptre in five (8%), astigmatism in seven (11%) and strabismus was present in nine (14%) of the cohort. There was a significant relationship between the incidence of ocular disorders and ROP. However, even those premature children without ROP had a 31% incidence of ocular disorder at 5 years.

Impairment in psychomotor development and hearing was also reported. Factors found to correlate with neurodevelopmental problems included necrotizing entercolotis, steroid used for chronic lung disease and male gender. Moreover, it was noted that neurological, developmental, neurosensory and functional morbidities increased with decreasing birth weight (Vohr et al., 2000). Hospital interventions are potential contributory factors to the neurologic developmental defects too. ELBW Infants with sensorineural hearing loss were found to have significant increase days ventilated and in oxygen. The risk for potentially preventable risk factors for sensorineural hearing loss was increased for infants who spent more than 90 days in oxygen (Leslie, Kalaw, Bowen & Arnold, 1995).

Neonatal infections are a frequent complication among ELBW infants and are associated with short term sequelae and an increased risk of death. Stoll and colleagues (2004) reported that a majority of ELBW survivors (85%) had at least one infection during their hospitalization after birth. ELBW infants with infection were significantly more likely to have adverse neurodevelopmental outcome including cerebral palsy and visual impairment. Infection during neonatal period was also associated with impaired head growth of the ELBW infants, that is a known predictor of poor neurodevelopmental outcome.

In measuring the morbidity, neurological development is one of the major problem areas for ELBW survivors. It is clear that morbidity of ELBW has not decreased with improved mortality; on the contrary, the prevalence of poor developmental outcomes resulting from ELBW is on an increasing trend. It is expected that the significant long term developmental and learning sequelae, and the resulting socioeconomic issues will be the substantial source of stress to the parents and families of ELBW children.

In Hack and colleagues’ (2000) study, ELBW survivors weighed less than 750 gram at birth, subnormal Mental Developmental Index scores (MDI <70) were recorded by 42% of the studied children, and neurodevelopmental impairment was found in 48% of the children at 20 months corrected age, 15% had cerebral palsy and deafness was found in 9%. Similar prevalence of subnormal MDI was presented in another multi-centered, retrospective and comparative study of children at 18-20 months corrected age with birth weights of 501 to 1000 gram, born in the periods 1993 to 1996 and 1996 to 1999. Neurodevelopmental impairment were found similar and the prevalences of MDI <70 were 40% and 47% for respective periods (Hintz, Kendrick, Vohr, Poole & Higgins, 2005). Similar findings in MDI were also reported in Shankaran and colleague’s (2004) study on ELBW children at 18-22 months corrected age. It was suggested that predictors of MDI <70 were neonatal morbidities such as grade III-IV intracranial haemorrhage, periventricular leukomalacia and steroid for BPD (Shankaran et al., 2004).

Regarding the adverse long term effect of the neurological development of ELBW children, Mikkola and colleagues’ (2005) study in Finland revealed that only one quarter of the ELBW children was classified as normally developed at the age of 5 years. In the report, 20% of the ELBW children had major disabilities, 19% had minor disabilities and 61% showed no functional disabilities yet had subtle departures from normal. As shown in Table 2.2, cerebral palsy was found in 19%

of ELBW children, 4 % required a hearing aid and 30% had ophthalmic findings.

Statistics explicitly referred to ELBW morbidity and developmental outcome in Hong Kong across time is few until recent year. In Ting and colleagues' (2007) retrospective cohort study of 234 ELBW babies born between 1993 and 2002 at a tertiary perinatal center, the mortality, major morbidity and early neurodevelopment outcomes were compared by dividing them into 2 period vis the early surfactant era (1993-1996) and the recent surfactant period (1997-2002). Significant changes noted among the babies born in the recent surfactant era included improved survival till discharge (84.7% vs 56.4%), reduction in prevalence of retinopathy of prematurity (16.2% vs 29.0%) and severe intra-ventricular hemorrhage (13.6% vs 30%). For the neurodevelopment outcomes among survivors, significant decrease was found in visual impairment (5% vs 20%), while reduction in prevalence of cerebral palsy (12.5% vs 15.2%) and hearing impairment (3.8% vs 6.5%) was also observed but not significant (Ting, Wong, Goh & Lam, 2007).

Physical Growth of ELBW Children

As with birth weight, the growth rate of ELBW children is an important health indicator as ELBW infants are at risk of poor growth beginning immediately after birth. ELBW infants have to adapt to the stress of the extra-uterine environment, they might not achieve a rate of growth that is expected during the intrauterine period. The slow physical growth of ELBW children is described in the subsequent sections.

ELBW infants develop a growth deficit during the first few weeks of life that not only persists but worsens during hospitalization. In Steward and Pridham's study (2002) in the United States, 89% of the hospitalized ELBW infants had a weight less than 10th percentile at the time of hospital discharge. The mean discharge weight was significantly less than the median weight of a fetus of comparable gestational age (Steward & Pridham, 2002).

The growth rate of ELBW children is not hastened after hospitalization as expected. Both the height and weight of these children maintain a subnormal level throughout the childhood till the age of adolescent. In the United States, Hirata and Bosque (1998) reported that the mean height, weight and head circumference of ELBW children were below the 50th percentile at preschool years and barely crossed into higher percentile as they reached adolescence.

Similarly, a study in Australia also reported that ELBW children were significantly lighter and shorter than those born with normal birth weight at 5 years of age. It was suggested that by early adulthood, these ELBW children were able to attain average weight, and their heights were persistent with their parents' height. However they were relatively heavy for their height (Doyle, Faber, Callanan, Ford & Davis, 2004). A Swedish national cohort of all extremely immature children born without severe motor disability from 1990 to 1992 reviewed that these children attained poor growth in both weight and height through the early childhood and preschool years, then followed by catch-up growth up to age of 11 years (Farooqi, Hagglof, Sedin, Gothefors & Serenius, 2006).

A Canadian regional population study reported that the body size of ELBW children at age 3 years was significantly smaller in weight and height as compared with their peer with normal birth weight. When they reached adolescence age of 12-16 years, they were 5.8 cm shorter than term controls and the mean body weight was 5.8 kg lighter than the controls (Saigal, Stoskopf, Streiner & Burrows, 2001). Similarly in the United Kingdom, ELBW adolescents without major neurodevelopmental impairment attained growth parameter within 2 standard deviations of the mean, yet they were comparably shorter (by 4.8cm in height) and lighter (by 9.1kg in weight) than those with normal birth weight. Yet, the body composition and sexual maturation were found similar between the 2 groups (Peralta-Carcelen et al., 2000).

Information regarding the physical growth of ELBW children in Hong Kong is limited. Lam and colleague’s study (1995) on LBW children suggested that the catch-up growth in height was incomplete for infants born less than 2500 gm between 1988 and 1993. The catch-up-growth for the small-for-gestational-age group (SGA) group was 33-35% at 6 and 12 months, and 7-12% for the appropriate-for-gestational-age (AGA) group (Lam, Karlberg, Low & Yeung, 1995).

Behavioral and Functional Difficulties

Those ELBW infants first born in the post-corticosteroid and post-surfactant era are now reaching school age. The outcomes of this population at school age can provide more definitive answers regarding their expected developmental outcomes.

Other than the physiological problems such as cerebral palsy, mental retardation, deafness and blindness, high incidence of behavioral problems have been noted in ELBW children. The behavioral problems often adversely affect the school performance and development of social relations of these children. However, behavioral and cognitive functions might not be clearly noted at infancy. ELBW children classified as ‘normal’ in cognitive and motor function during their infancy, were discovered to be below average when being assessed again at their preschool age (Collin et al., 1991).

Cognitive and educational difficulties are usually identified in preschool age. In the United States, nondisabled ELBW children attained significant lower scores in all cognitive measures than those of heavier birth weight at preschool age (Halsey et al., 1993). ELBW preschool children were also found to have lower intellectual quotients (IQ), motor quotients and other respective language measures. Preschool cognitive and language functioning seemed to be affected by both prenatal and birth influence (preterm status) and postnatal influence (variable of social economic status), while motor score were related to preterm status only (Kilbride, Thorstad & Daily, 2004).

Compared with children of normal birth weight, ELBW children are more likely to suffer chronic conditions at preschool age. At age of 8 years, functional limitations were found in 64% of ELBW children and in 20% of normal weight children, compensatory dependent need was 48% vs 23%, limited academic skills 37% vs 15%, poor motor skills 47% vs 10% and poor adaptive functioning was 69% vs 34% (Hack et al., 2005).

ELBW survivors continue to display behavioral, educational and cognitive impairment till school age. In Australia, ELBW survivors at age 8 years scored significantly below those born with normal birth weight on the full IQ score, indices of verbal comprehension, perceptual organization and processing speed. ELBW children performed significantly worse on tests of reading, and the prevalence of attention difficulties, internal behavioral problems and immature adaptive skills were higher (Anderson &Doyle, 2003). ELBW children are more likely to have developmental coordination disorder (DCD) and this also contributes to their difficulties in school. In Canada, about 50% of ELBW children were identified to have DCD at school age. ELBW children with DCD had significantly lower performance IQ and were more likely to have learning difficulties in arithmetic (Holsti, Grunau, & Whifield, 2002).

Functional difficulties of ELBW children at school age (8-10 years) showed little cultural variation. According to a comparative study in four countries, namely Netherlands, Germany, Canada and USA (Hille et al., 2001), it was revealed that the three dimensions of attention, social and thought problems are an indication of experience specific to children who were born with extremely low birth weight. ELBW children were found to have higher problem scores than normative or control children (Hille et al., 2001).

School difficulties of ELBW children will extend even to adolescence. The literature shows that the utilization of special education resources tends to continue throughout the teen years. The ELBW teenagers continued to function significantly less well in their intellectual and achievement measures compared with their age-matched peers. In Canada, eighty percent of the ELBW children who required special remedial resources at 8 years of age, continued to have school difficulties in adolescence (Saigal, Hoult, Streiner, Stoskopf & Rosenbaum, 2000). ELBW adolescents have higher rates of functional limitations. Other than physical growth deficiency, mental or emotional deficiencies, restrictions in physical activities, inability to participate in sports and visual difficulties were included. These children had an excessive need for special education, counseling, physical and occupational therapy (Hack, Taylor, Klein & Mercuri-Minich, 2000). Intellectual development was suggested to be influential to the behavioral and social development of ELBW children. In Hoff, Hansen, Munch and Mortensen's (2004) study on extremely premature children at 5 years of age in Denmark, it was reported that the extremely premature children exhibited more hyperactive behavior and had poorer social skills that the term children. However, for those ELBW children with normal intellectual development, there was no difference from the term children in regard to their behavioral and social development.

Being premature has an important life impact on all aspects of functioning in the ELBW child. Not only the parents and families, but also the children themselves suffer from a great burder of morbidity and developmental problems. Adolescents who were born ELBW reported a higher number of attributes affected, as well as more complex and severe limitation in cognition, sensation, self care and pain. However, the majority of them viewed their health-related quality of life as quite satisfactory (Saigal et al., 1996). It was also reported that ELBW teenagers did not differ significantly from those of normal birth weight on most dimensions of self esteem. Yet, gender and birth weight effects emerged in rating certain domains. Females gave lower rating to themselves for the physical appearance and ELBW teenagers themselves lower in atheletic competence (Saigal, Lambert, Russ & Hoult, 2002).

Information regarding the behavioral and functional difficulties of ELBW preschool children in Hong Kong is sparse. In Lau and colleagues' (2006) study on parents' perception of life of preschool children at risk or having developmental disabilities, it was reviewed that the overall well-being of and psychosocial health perceived by mothers of children with high risk of a developing disability was significantly lower than those without developmental problems. Parents perceived that the most important challenges faced by their children as being social and emotional functioning (Lau, Chow & Lo, 2006).

Unlike physical disabilities that may be observed visually, behavioral and cognitive problems could only be realized as the child reaches school age, when the difficulties in learning and achievement of school performance emerge. The uncertainty of cognitive outcome of ELBW children is a substantial source of stress to the parents and families.

Summary

This chapter has attempted to give a brief description on extremely-low-birth-weight regarding the gestational immaturity, mortality and morbidity, physical growth and neurologic developmental problems, behavioral and functional difficulties. Providing a general understanding of the progress of life of an ELBW child after birth, it aims to show that the life of ELBW infant is preserved with advanced medical technology, nevertheless some of them still require long term and specialized care. Throughout the years when the child undergoes medical interventions for the health problems and close surveillance for the potential adverse developmental outcomes resulting from extremely-low-birth-weight, both the child and parents will experience physical and psychological stress. The impacts of caring the premature children with special needs on parents and families will be discussed in the following chapter.

CHAPTER 3

Literature Review: The Impacts of Caring for Children with Prematurity on Parents / Families

Introduction

Anticipating the child’s birth, the parents, especially the mothers, hold many fantasies about what their children will be like. The mother-to-be may be dreaming of her baby as perfect with all the best from herself and her husband. The baby may be counted on to provide reinforcement and pleasure in representing the embodiment of her fantasies (Mori, 1983). Parents-to-be may have been preparing for new parenthood since or even before pregnancy. Birth, even though anticipated, will be a crisis if the event is perceived as disturbing old habits and relationship and eliciting new responses (Wong, 1995). The birth of a child can bring joy and excitement, as well as challenges and responsibility to the parents as they adjust to a new family member.

As for mothers of ELBW infants, the childbirth may be a stressful and traumatic event as they have experienced a premature and abrupt end to pregnancy and are often unprepared to become mothers at such early stage of gestational development. Other than a normal transition to parenthood, mothers of ELBW infants will have to deal with the additional stress and coping with the unprepared and traumatic event with the early birth of an extremely premature infant.

Literature presented in this chapter is related to issues of parenthood transition, feministic perspective on motherhood, parent-infant attachment, and impacts of caring for ELBW children on their parents / families. The review on these related issues will provide a vantage point from which the author can view mothers' experiences, gain understanding and identify pertinent issues and questions. As studies directly describes the lived experience of mothers of ELBW children are scarce, a review is made on the existing empirical studies related to impacts of prematurely born children, including ELBW children on parents and families. Each of the issues will be discussed for they contribute to some understanding of mothers' experiences and form the backdrop before which the author can place each mother's experience.

Parenthood in Transition

As with any major transition in life, becoming a parent is a turning point during which a person's life course takes a new direction requiring adaptation or change in life and behaviors. The transition to parenthood involves various sequential events, such as the plan to have a child, pregnancy, childbirth and care of the child (Salmela-Aro, Nurmi, Saisto & Halmesmaki, 2000; Wong, 1995). For women, pregnancy is a significant change during the transition to parenthood as it consists of a sequence of interdependent and qualitatively differential phases. Major changes in physiology, appearance and the body on the one hand; and in social relationships, role demands and life structure on the other will occur as the pregnancy progresses (Myles, 1982). Nevertheless, pregnancy would also appear to be the most stressful period for men undergoing the transition to parenthood. In Condon and colleagues' (2004) study of first-time fathers in New Zealand, highest symptoms levels were observed during pregnancy with little change in 3 months, and sexual function appeared to deteriorate markedly with minimal recovery by the end of the first year (Condon, Boyce & Corkindale, 2004).

Childbirth denotes an end to the pregnancy and it, agreed or not, incurs a crisis that calls for the parents to make drastic adjustment during the first few weeks of the infant's life. During pregnancy women became more interested in goals related to childbirth, the child's health and motherhood, while they were more interested in family-related and health-related issues after childbirth. As the birth of a new child is always a unique event that requires women to restructure their personal life whether they have had previous children or not, changes in birth-related goals did not differ between primiparous mothers and multiparous ones. Whereas, changes in personal goals were less substantial among men during the transition to parenthood (Salmela-Aro, Nurmi, Saisto & Halmesmaki, 2000). To successfully deal with this forthcoming transition in the life span, Wong (1995) suggested that parents would construct or reconstruct their personal goals based on 3 focuses, 1) survival – to promote the physical survival and health of their children so as ensuring that the children live long enough to produce children for their own; 2) economic – to foster the skills and behavioral capacities that the children will need for economic self-maintenance as adults; and 3) self-actualization – to foster behavioral capacities for maximizing cultural values and beliefs.

Common factors affecting transition to parenthood are known to include parental age, father involvement and parental education (Knauth, 2000; Wong, 1995). Besides, during the transition to parenthood, any changes in parent's satisfaction with family function or the perceived importance attributed to the family relationships would affect the parents' sense of competence in the transition to the parent role. Knauth (2000) suggested that satisfaction with family functioning was significantly more important for the mother's sense of parental competence than it was for the fathers'. Other factors influencing the transition to the parental role include previous experience, marital relationship and special characteristics of the infant such as infant with potential or actual special care needs (Wong, 1995). Dulude, Belanger, Wright and Sabournin's (2002) study reported that all parents, mothers in particular, experienced heightened psychological distress during the transition to parenthood. It was also observed that high-risk pregnancy that presented a serious risk to the health of the mother, the fetus, or both such as placenta previa or threats of premature delivery, did not affect the final outcome of the parents' psychological adaptation to the life threatening event, however, it affected the process through which parents adapt to parenthood, especially when parents were expecting for their first child.

Increased anxiety and depressed mood are to be expected during important life span and such phenomenon over the period of pregnancy and early parenting has been studied. Matthey and colleagues’ (2000) study on paternal and maternal depressed mood during the transition to parenthood in Australia reviewed that the cumulative incidence of depression by 12 months postpartum for mothers and fathers was 27.3% and 10.1% respectively. It was apparent that mothers had a higher risk for postpartum depression and it was suggested that a woman’s relationship with her own mother was important in the early postpartum stage. For the man, his relationship with either his mother or father was associated with his mood level early on (Matthey, Barnett, Ungerer & Waters, 2000). Support from the maternal mother was found to be the single most important factor maintaining motherhood throughout the first 9 months after birth in Cronin’s (2003) study. These echo with Wong (1995) that for successful adaptation to the stress of transition to parenthood, relationship with family, friends, and community are essential.

The transition to parenthood is developmental. This transition can create excitement and eagerness for the new family structure, but fears and threats also emerge during this major change in family life. It has been reported that during pregnancy and over the birth of a baby, families experience the transition to parenthood as either a crisis or merely a change (Goldstein, Diener &

Mangelsdorf, 1996). Whereas, Wilson and colleagues (2000) reported that small but invariably negative changes were observed in family dynamics across the transition to parenthood with the first and second baby; and the most consistent change was an increase in role conflict with mothers reporting a greater increase than fathers (Wilson et al., 2000).

For parents of prematurely born children, they may be experiencing a different transition to parenthood as the child comes to their life unprepared. Jackson and colleagues (2003) described the internalization of parenthood of parents of preterm infants as a time-dependent process and four syntheses of experiences were observed: alienation, responsibility, confidence and familiarity. Both mothers and fathers described similar parental roles such as concern for child, insecurity, adjustment and relationship with the child, while mothers experienced more responsibility and control of care and a need to be confirmed as a mother (Jackson, Ternestedt & Schollin, 2003). In Swartz's (2005) meta-synthesis of ten qualitative studies on the process of parenting preterm infants, five themes emerged: adapting to risk, protecting fragility, preserving the family, compensating for the past, and cautiously affirming the future. It was described that parents confronted and coped with known risk and interventions necessary to sustain infant's life during the immediate period after birth. The parental feelings of vulnerability were closely associated with the process of providing protection. The process of compensating for the infant's past experiences in the NICU was closely aligned with the theme of protecting fragility. With the birth of a preterm infant, parents and the family were faced with additional stresses that challenged their coping abilities and brought about changes in role relationships which demanded a higher level of coping and communication in the family. When the parents emerged from these initial stages, they would tend to reaffirm their family unit and reconnect with extended family members and friends (Swartz, 2005).

Motherhood – Feminist Perspective

Motherhood role is the most characteristic of femininity in that only women are biologically capable of conceiving, giving birth and breast-feeding infants. Motherhood is central to all women's lives, whether or not they become mothers, to the way in which they are defined by others or to their perspectives of themselves (Nicolson, 1992; Phoenix & Woollett, 1991). Motherhood is generally seen as an essential stage in women's adult development and providing them with a central identity as women and as adults (Woollett & Phoenix, 1991). Moreover, women are 'naturally' given the responsibility for childcare and the role of mothering. Despite women's participation in the paid labor force and the fact that financial independence has been increasing, woman's care of child remains consistent with mothering and has endured as one of the universal elements of sexual division of labor. Women are still taking greater responsibility than fathers for family roles including arrangement for childcare (Woollett & Marshall, 2000).

Nevertheless, the ideology of women as natural mothers who are immediately able to care for their children, fulfilling their role of selfless carer and nurturer is very different to the reality of motherhood (Choi, Henshaw, Baker & Tree, 2005). Choi and colleagues (2005) also reported that women found themselves inadequate and unprepared for motherhood when their first baby was born. They suggest that being a mother is not so much as a part of women's 'natural' biological inheritance and that skills of motherhood and childcare have to be learned. Wilson and colleagues (2000) reported that mothers indicated increased role conflict during the transition to parenthood as the mothers' actual experience of the first year of motherhood did not match her expectations and they had to make the most role adjustments, and these role adjustments were greater than the fathers (Wilson, et al., 2000). Cronin (2003) also reported that first-time mothers were unprepared for the birth of their baby and motherhood. The need for physical, emotional and social support emerged throughout the birth experience, during the first week at home and up to 9 months.

Being unprepared and lacking experience, it is obvious that gaining support and information about baby care and mothering are the primary needs of new mothers. Aston (2002) revealed that the women who attended postnatal classes described themselves feeling unprepared, feeling physically isolated and having unexpected things happen after childbirth. They did not feel like a 'mother' and they thought there was a lot of information on baby care and mothering that they needed to learn. While doubting information given by family or friends and seeking "expert advice" from postnatal classes, mothers would explore all ways to become a normal mother. Hartrick (1997) discussed that women would have taken up roles and acted out of a life that had been modeled by their parents and others in the society, when they were striving to be a mother image. They tried to "follow the road to the good life" (Hartrick, 1997, p. 270) by copying the actions of people who were models in the society. As the women struggled to understand what was going on with them, they experienced criticism from themselves and others and they described themselves as "living in the shadows" (Hartrick, 1997, p. 272) that being a time of transition. After the process of recovering and discovering self, the women learned to listen to, trust, and nurture self. As the women reconnected with self, they described a shift from doing to living (Hartrick, 1997).

Tarkka (2003) described the important factors that contribute to building up competence of motherhood would include mothers' resources, ease of caring for the child, breast-feeding and social support received. It was observed that the more competent the mother felt and the more attached the mother was to her child, the better her coping. The better the mother's self-concept and relationship with the spouse were, the better she succeeded in taking care of the child. In Rogan, Shmied, Barclay, Everitt and Wyllie's (1997) study, social support was also described as one of the factors found to influence or mediate the actions and processes of becoming a mother. Other factors included previous experience of infants and the baby's behavior.

Mothers of prematurely born children may have different experience in motherhood as the process of transition to parenthood may be different. Jackson and colleagues (2003) had reported preterm mother’s need was to be confirmed as a mother. Infants born prematurely, especially those born with ELBW, require special care in the NICU and their mothers will begin their experience of parenthood in the unfamiliar and intimidating environment of the NICU. Heerman, Wilson and Wilhelm (2005) reported that mothers in the NICU experienced the transition from outsiders to partners. The mothers developed from outsiders to engaged parents along four continua: focus – from neonatal intensive care unit to baby, ownership – from their baby to my baby, caregiving – from passive to active, and voice – from silence to advocacy. It was described that mothers entered the continua at different points and moved at different rate towards “engaged parenting”. The extreme distress that many mothers experience after the birth of a premature infant and the neonatal intensive care unit hospitalization may bring about subsequent stress responses to mothers. Holdotch-Davis and colleagues (2003) reported that characteristics similar to a posttraumatic stress response were found in mothers of premature infants up to more than six months after their infants’ expected birth date (Holdotch-Davis, Barrlett, Blickman & Miles, 2003).

Parent-Infant Attachment

In 1969, Bowlby marked the milestone in the evolution of the attachment concept by defining attachment as a strong link between two people. He described the attachment process as being from the child to the parent, clarifying the reciprocal parent to infant attachment process. According to Bowlby (1969), attachment between a parent and child represents one of the strongest bonds in human experience and these attachment are instinctive and biologically driven, fostering survival by ensuring that children remain close to the caregivers who will provide for them. Klaus & Kennell (1976) first focused on the mother's perspective of the attachment relationship and they defined attachment as “a unique relationship between two people that was specific and endured through time” (Klaus & Kennell, 1976, p. 2). Attachment was referred as operating in two directions, a tie from parent to infant as well as from infant to parent. They also hypothesized that prolonged contact between mother and infant immediately after birth was crucial to the formation of an attachment bond that was in turn crucial to the survival and development of the infant.

According to Goulet and colleagues’ (1998) description of the maternal-infant attachment process for normal newborns, parent-infant attachment could be viewed as a reciprocal process between parent and child, flowing from one direction, beginning with acquaintance and moving over time (Goulet, Bell, Tribble, Paul & Langs 1998). The study also described that attachment was characterized as a commitment to love and to care for an infant, enabled through physical and emotional proximity. In the presence of proximity, commitment, and reciprocity, attachment would lead to the establishment of solid parenting skills, positive growth and development of the infant and the creation of a solid and lasting loving bond.

In Bialoskurski, Cox and Hayes's (1999) ethnographic analysis of attachment in the NICU, it was observed that the process of attachment was not automatic and that it may be considered as an individualized process associated with two dichotomies, overt and covert. This model of attachment embedding overt and covert characteristics in an attachment timeframe, required physical contact and early involvement between parent and infant to develop the 'strong link' (p. 67). Nevertheless, the complex nature of attachment in the NICU was discussed, yet the implications of uncertainty of outcome and proximity challenges in case of ELBW infants added to the attachment process was not emphasized (Schenk, Kelly & Schenk, 2005).

Apart from the implications of infant concerns (Bowlby, 1969; Goulet et al, 1998), attachment relationships between parent and infant were found to have a special impact on an adult's capacity to cope with challenges and stress, either directly or indirectly as an internal working model of attachment (Wilinger, Diendorfer-Radner, Willnauer, Jorgel & Hager, 2005). According to Willinger and colleagues' (2005) report, the representation of optimal parental bonding, featuring high care and low control, was associated with less parental stress regarding child and parental characteristics. It was also observed that those mothers who reported optimal parental bonding also reported the lowest level of parental stress.

Nevertheless, disruption in parent-infant attachment because of the infants' fragility and hospitalization has always been a concern of health care professionals as for its contribution to parental stress.

Impacts of Caring for Premature Children on Parents and Families

Since studies explicitly focusing on the lived experience of mothers with ELBW children are scarce, this section of discussion is based on the existing empirical literature related to impacts of caring for premature infants of high risk on parents and families. As the children born with ELBW are likely to be of high risk and require immediate and long term sophisticated care as early as in the neonatal period, the information reviewed provides the epistemological base of the study.

Dilemma in Decision of Life-and-Death

The imminent birth of an ELBW infant presents healthcare professionals and parents with difficult decisions regarding the management of the mother during labor and delivery and resuscitation and further management of the infant. Although technology has facilitated improved survival rates, yet outcomes are uncertain and cannot be reliably predicated. These dilemmas emerge because these extremely premature infants are at risk for disabilities such as cerebral palsy, blindness, deafness and other neurological disorders as discussed in Chapter 2. Addressing these dilemmas, questions will be posed on whether extremely premature infants should be resuscitated and who should decide. Savage and Kavanaugh (2004) suggested that seizing the opportunity to withhold a resuscitation intervention in the delivery room may be viewed as an approach to avoid unnecessary suffering to the infant and parents. Once the infant is successfully resuscitated, it will be more difficult to decide on the withholding or withdrawing life-sustaining treatment in the neonatal intensive care unit, by both professional staff and parents. It was also suggested that the attending neonatologist is the appropriate person to decide on whether the infant can be resuscitated and the parents should be involved as they are the ones to live with the result of decision.

Conflicts between parents and health care professionals regarding the treatment approach of extremely premature infants have resulted in lawsuits (Hurst, 2005a). Health care professionals may not have the same attitudes towards resuscitation as the parents. Martinez, Weiss, Partridge, Freeman and Kilpatrick (1998) reported that obstetrician’s opinion about delivery room resuscitation of ELBW infants are influenced by birth weight and gestational age thresholds, infant and parental factors such as congenital anomalies and parental wishes; and there is a limited willingness among physicians to allow a parent to participate in decision making in the delivery room. In Streiner and colleagues' report (2001), most parents believed that attempts should be made to resuscitate all infants, irrespective of condition or weight at birth; and the final decision should be made by the parents and physicians and not other bodies such as ethical committees or court (Streiner, Saigal, Burrows, Stoskopf & Rosenbaum, 2001). To avoid litigation, physicians have tended to defer decisions to parental request rather than adhere to their best judgment (Ballard, Li, Evans, Ballard & Ubel, 2002). Hurst, (2005b) suggested that the central focus to minimize legal risk in this situation should be the creation of a transparent decision-making process that includes the parents from the onset, obtaining their consent for the course of treatment at issue. However, it is assumed that parents will make decision that reflects the infant's best interests, but parents may be relying on information provided by the health care professionals, which may be biased or limited to reflect the physician's attitudes and beliefs about treatment for infants at that particular gestational age or with that specific condition. Parents may be choosing from limited options, or they may not object, or they may simply acquiesce rather than affirmatively decide (Savage & Kavanaugh, 2004).

Nevertheless, there is never a complete right or wrong answer in such an ethical dilemma (Wilder, 2000), and there are no clear-cut answers and there is space for further dialogue. Although, parents may prefer to play a more active but not autonomous role in decision-making, health care professionals should provide parents with clinical information critical for informed decision-making. Given that parents do not seek sole decision-making capacity, healthcare professionals should foster parental involvement in life-support decisions to the extent appropriate for local cultural norms (Anonymous, 2005).

Parental Stress in the Neonatal Intensive Care Unit

Infants born prematurely with ELBW are usually ill and require tertiary care in the NICU. Parental stress while the infants are staying the NICU has been well reported (Miles et al, 1993; Seideman et al., 1997). Descriptions on the family stressors usually start with the unfamiliar encounter in the NICU. The overall environment in the NICU may be a major source distress for parents and influencing their behaviors (Seideman et al, 1997), when stress is viewed as an individual's reactions to demands that approach or exceed the limits of coping resources, and stressors are physical and psychosocial elements of a situation that impose demands and lead to stress reactions.

Researchers believed that having a child admitted to a NICU, creates a very stressful situation to the parents. Not only the sight and sounds of the unfamiliar environment, but also the behavior and appearance of their babies were sources of stress to parents (Miles et al, 1993). When stress is viewed as an individual's reactions to demands that approach or exceed the limits of coping resources, parental stress is manifested by the alteration of or failure to achieve the expected parental role (Miles et al, 1993; Seideman et al, 1997).

In the NICU, parents experience role alteration as they are faced with a high technology environment that inhibits normal parenting activities. Highest levels of stress were indicated when parents felt they were being separated from their baby, helpless about how to help their baby to avoid pain and unable to protect the baby from pain. Werceszczak, Miles and Holditch-Davis (1997) reported that mothers of infants born preterm recalled their infants' suffering as one of the most stressful experiences of the hospitalization. Hurst (2001) reported that, regardless of their economic or educational background, the mothers of premature infants in the NICU experienced informational and interactional needs related to becoming a mother in the NICU and emotional safety in the NICU. It was also observed that the mothers demonstrated a repertoire of actions to vigilantly 'watch over' their premature babies to avoid resources from being drawn away from their infants. Brady-Fryer (1994) described the mothers' experience during infant's hospitalization in the NICU as a process of "forging a role" (p. 221) which enabled mothers to access the attachment relationship with infants, and through which the mothers ultimately formed a new role as a mother of a premature infant.

The stressful experience in NICU has a residual effect on the parents. Pinch & Spielman (1996) found that the experience in NICU remained a significant memory for the parents even at 4 years after discharge from hospital. It was reported that parents needed to weave this story into the whole life history of the family, and parents manifested substantially detailed recall of the experience once triggered.

Continuum of Impacts on Parents / Families through Preschool Years

Impacts of caring for premature children continue to exert on parents and families after the stay in hospital during the early childhood from infancy through toddlers years. Disruption in attachment because of the infants' fragility and hospitalization was reported in Mello and colleagues' study as a factor contributing to the stress for mothers caring their low birth weight infants at home. Mothers were particularly concerned about infant weight and growth (Mello, Rocha, Scochi & Lima, 2002).

Feeding of the preterm infant at home is one the challenges that the mothers have to overcome (Thoyre, 2000). Since the time after hospital discharge is a period of transition and ongoing maturation for the preterm infants, whose feeding abilities and patterns continue to evolve (Bakewell-Sach & Gennaro, 2004; Holditch-Davis, 2005). In Reyna and colleagues' qualitative study on mothers' experiences in feeding their preterm infants after hospital discharge, the three themes of mothers' experiences included interpreting infant behaviors, managing the feeding process and realizing knowledge gaps. It was described that mothers struggled with infant feeding in the initial weeks after discharge and experienced a period of transition

before comfort developed (Reyna, Pickler & Thompson, 2006).
Eiser and colleagues (2005) reviewed that mothers of preterm children at age around 2 years perceived their children as having lower quality of life, in terms of physical health, social and emotional function, and reported more physical health and behavioral problems of the child. Whereas, mothers' well being and distress were partly associated with the perception of difficulties of preterm children (Eiser, Eiser, Mayhew & Gibson, 2005). In Eisengart and colleagues' (2003) study, it was revealed that mothers of VLBW children up to the age of two years with high risk of medical problems and adverse developmental outcomes perceived significantly greater psychological stress than mothers of low risk VLBW or term children. It was found that sociocultural factors, rather than the severity of medical risk to children, exerted the main effect on the stress coping of mothers. It was suggested that both sociocultural sources of resiliency and biological risk factors should be considered when developing strategies to enhance coping and parenting skills in high risk populations.

In Tommiska and colleagues' (2001) study of parental stress in the families of two years old ELBW infants, it was reported that the birth of ELBW infant was a stressful event for parents. As the population of severe handicapped infants was small in this study, the findings reviewed that most parents of the children without severe handicap seemed to have recovered well by the time had reached the age of two. However, mothers indicated significant more distress than fathers with respect to role restriction, incompetence and spouse relationship problems. It was referred as the traditional role differentiation in which the fathers seemed to fulfill their main duties outside the home (Tommiska, Osterg & Fellman, 2001).

Parents continue to experience stress in caring for their prematurely born children through the preschool years. Singer and colleagues (1999) identified that psychological distress, especially depression, anxiety and obsessive compulsive behaviors persists in mothers of high-risk VLBW children from birth to 3 years though the severity varied over time. They also indicated that mothers of high risk VLBW children experienced higher parenting stress than those mothers of term children (Singer et al., 1999).

Another researcher has also described the parenting stress of parents of prematurely born children with less than normal weight. Robson (1997) identified that parenting stress in parents of LBW children at age of 5 years was related to multiple factors. Although the birth of a low birth weight infant and the neonatal medical risk still presented enduring contribution to parenting stress through the infancy period, the child’s developmental status and the quality of the child-parent relationship contributed significantly to the parental stress during early childhood.

In Miles and colleagues’ report of content analysis of qualitative interviews with mothers of prematurely born children at three years old, three major concerns of mothers in parenting were behavioral management, maternal feelings of protection and health and developmental concerns. Concern of behavioral management was the dominant theme in which difficulties with discipline and limit-setting in dealing with the behavior of their children were expressed. The feelings of protection was first reported when their premature children first came home from the hospital and continued till their children at age three. Mothers expressed ongoing fear and uncertainty about their children's well-being whenever they get sick and they were concerned about future development as a "residual from being premature". Frustrations were shared about how their children were "slow" and about having to explain why they were "so little." (Miles, Holditch-Davis & Shepherd, 1998)

Impacts on the Family Functioning

Following the birth of an ELBW child, the parenting experiences can be explained within the context of a sequence of concerns: the infant's survival, the appropriate development of the infant and the establishment of the infant-parent relationship. Having an ELBW child in the family may impose particular dynamics on the family functions. The family is considered a major environmental influence on the development of children, while each family member, including the child, contributes to the family's functioning influenced by both individual and dyadic factors. One of the individual factors is the child's behavioral style that can be correlated with the child's developmental or mental health evaluated in response to the child's ability to integrate into the existing interactions within the family.

The ongoing interactions are referred as the established identities within an individual when entering parenthood (Nelson & Edgil, 1998).

In Kennedy and colleagues’ qualitative study, analysis of interviews showed that the mothers of prematurely born LBW children expressed concerns about the nutritional care of their children and need for more information regarding nutritional care during the children’s first year of life. The decision making in feeding of the LBW children would influence the quality of life or the family’s satisfaction of life (Kennedy, Oakland & Brotherson, 2000).

Researchers attempted to identify the risk factors contributing to family functioning in families with VLBW children. McCain (1990) identified that mothers’ perception of role reciprocity and conflict was important element in the family functioning 2 to 4 years after birth of VLBW infants, and that was clearly related to the length of hospitalization of the VLBW infants. However, infant developmental status was not a contributory factor as the majority of the children in the study were developmentally normal.

Several authors presumed the association of VLBW and chronic illness and have measured the impact on families (Cronin et al, 1995; Lee et al., 1991; Singer et al., 1999). Financial impact, personal strains were reported in Singer et al.’s (1999) study among the mothers of high risk VLBW children at 2 to 3 years of age and these impacts persisted across time. Cronin et al. (1995) reported parents of

VLBW infants had significant impact on financial, familial and social, personal and mastery issues constantly across time even up to 5 years after the birth; and normality of infants had influential effect on the level of family impact. By contrast, Lee et al. (1991) found that parents of VLBW children of 1 to 6 years of age perceived capability in mastery; while similarly, normality was important in perception of family impact. However, normality did not affect parents' attitude towards saving all VLBW infants regardless of the possibility of handicap. Among those parents who had an opposite attitude, mothers were the majority. It raised concern on potential subsequent stress on mothers who bore most of the burden of raising handicapped children.

Another study suggested daily hassles in families with VLBW infants were related to lack of financial and social support and that the daily hassles and life strains of parents would be create a less favorable caregiving environment in the family, thus becoming potential precursors to the behavioral maladjustment of VLBW children up to age of 5 years (Tobey & Schraeder, 1990).

Drotar et al.'s (2006) study focusing on families with ELBW children at school age (8 years) showed that the total family impact was greater than in families of ELBW children than in the family of term children. The negative effect on the family in specific domains including the financial aspect, caretaker burden, and familial responsibilities was greater in the ELBW group. The study also reported that the neurodevelopmental outcomes and the functional impact of chronic conditions of ELBW children predicted the negative family impact within the ELBW group.

Nevertheless, impact of ELBW children on the family would be both positive and negative. Saigal and colleagues' (2000) study on families of ELBW adolescent children reviewed that the experience of having an ELBW child, even though the child was not disabled, remain as a significant impact on various aspects of the family including marital relationships, interaction with family and friends and the decision not to have further children. (Saigal, Burrow, Stoskopf, Rosenbaum & Streiner, 2000). It was reported that the ELBW child's health adversely affected their parents' emotional health, however, more parents of ELBW adolescents indicated that their child had brought their families closer, and a significant proportion of parents supported saving all infants regardless of their birth weight.

Chinese Parent and Child Care –
Cultural and Psychosocial Perspective

The Chinese culture is rooted in a history of five thousand years but the cultural values vary among the population of twelve billion resident in different provinces in the country. Although the Chinese in Hong Kong have been under the influence by a mixture of both traditional Chinese and western values and beliefs, most of the people are still bounded by the Confucian ideals that play a significant role to the formation of family ties and structures (Lee, 1985). Since this study focuses on a sample of Chinese mothers, to understand their unique experience and responses to life events, it would be helpful to have a brief discussion of the Chinese culture values and the stress coping abilities of parents in relation to child care.

Cultural Beliefs and Values Relating to Family

In the Confucian tradition, descriptions of human relationships are accorded in position of paramount importance. These are called Five Cardinal Relations constructed in hierarchical pattern (*wu lun* 五倫), namely those between sovereign and subject, father and son, elder brother and younger brother, husband and wife, and friend and friend (Bond & Hwang, 1986). From these descriptions of human relationships, three out of five are centred on family, demonstrating that Chinese people put much emphasis on interpersonal relationship in family.

The social structure of a Chinese family traditionally shows a great degree of sexual differentiation and tends to be male centred (Bond & Hwang, 1986). Males are expected to be concerned with “outdoor activities” while females should stay with “activities inside the family” such as minding children, cooking, dressmaking and housework. Women’s traditional familial role is still regarded as most important. A mother seems to assume almost total responsibility for the physical well-being of the child, making sure that the child is well fed, fully clothed and protected from hazard (Ho, 1986).

Another central feature of Confucianism is a code for moral conduct that holds both individuals and society in check, a means for bringing honor and avoiding disgrace, or loss of face, to the family name. If the family relationships are conducted in the correct order, then the state will also be in order. Confucianism provides an ideational force in its capacity to elicit fear of unknown consequences and such resultant emotions as shame, blame and disgust to the individual and the society as a whole (Gabrenya & Kwang, 1996). This reflects the fact that Chinese are concerned about they being respected or accepted by kin, friends and the society.

According to Bond and Hwang (1986), the concept of face has universal applicability and should not be interpreted as a culture-specific phenomenon of Chinese. Yet, the behaviour of enhancing face in Chinese society can be classified into six categories according to the target of the face behaviour, oneself or others. These include enhancing one's own face, enhancing other's face, losing one's own face, hurting other's face, saving one's own face, and saving other's face. Chinese tend to perform the face-work well to strengthen the interpersonal relationships (*guanxi* 關係). With family being perceived as the basic social unit, conflict arises inside the family will be handled deliberately as a kind of backstage behaviour that should not be brought to the front of stage where it could be exposed to 'outsiders'. However, any great achievement of family members should be publicized frontstage because it will not only enhance the status of the family as a whole, but also glorify the forebears as well (Bond & Hwang, 1986). Yang (1986) shows that Chinese put a great deal of emphasis on harmony and unity of the family. To attain the spirit of harmony in the realm of the intellect, Chinese people try to synthesize the constituent parts into a whole so that all parts blend into a harmonious relationship at the higher level of perceptual organization. As a matter of fact, Chinese people are highly sensitive to outside conflicts and inconsistencies, and they usually manifest a strong tendency to find some way to reconcile the incongruent parts in a higher integrated framework (Yang, 1986). This explains the strong family ties and responsibilities within the Chinese communities, and this mutual responsibility of interdependency among family members often serves as a strong and useful backup support for most people when crisis comes.

Another feature of Confucian tradition is self-discipline that implies that a person has an even temperament and is not easily disturbed, thus the person’s social conflicts and psychological stress are diluted (Cheung, 1986). The self-control strategies can be further explained by the shame-oriented culture of Chinese, upon which the two major influences are Confucianism and humanism. Confucianism is oriented towards shame through its emphasis on social norms and reference to ideal types as models of behaviour, and humanistic concerns in Chinese culture place great importance on harmonious interpersonal relationships especially among the extended family (Cheung 1986). This brings to understanding the self-directed coping strategies of some Chinese people who, when encountering adversities, often consider that nothing can be done except to accept reality through self-control or passive endurance.

Some indigenous beliefs in the Chinese culture significantly pertain in the Chinese families and demonstrate a role in the overall belief system and social behaviour of Chinese. In traditional Chinese thought related to health, the semen of the male is regarded as a source of strength and energy while menstruation is seen as unclean (Leung, 1996). This belief is strongly endorsed despite the proliferation of modern science. Another social belief that plays an important part in social influence is an indigenous concept of retribution that covers both positive and negative events. One of the beliefs regarding negative outcome is that retribution to a harm-doer does not necessarily have to occur to the perpetrator. It suggests that a bad deed will bring disasters to the descendants of perpetrators of result in the perpetrators having unfilial descendants (Leung, 1996).

The well known stoic and enduring characteristics of Chinese has been depicted in the famous story “The True Story of Ah Q” by the Chinese writer Lu Xun in between 1921-1922. The fictitious character “Ah Q” is famous for his coping mechanism of “spiritual victories”, who used rationalization and projection to deal with adversities. His deep-rooted need to maintain a victorious status even when actually defeated showed the Chinese obsession with maintaining a good appearance to all outsiders to be ridiculous at times. According to Lu Xun, under the enormous clash between Confucian traditional thinking and modern Western ways, Chinese people were obsessed with saving face, proud of the past, lacking new accomplishments, and accepting without question. Yet these coping strategies are still commonly seen among the Chinese people in response to life situation and stress in the present (Foster, 2006).

Parental Coping in Caring Children with Special Need

Parenting is never easy, and Chinese parents may be confronted with the cultural issues that further attenuate their parenting stress. Traditional Confucian beliefs emphasize parental responsibility for training children in obedience for proper conduct, for exercising self-control, and for the acceptance of social obligations (Wu, 1996a). Parents who fail to bring up their children to achieve these characteristics are considered to be inadequate. These cultural influences may have contributed to additional stress experienced by usual parents.

Kwok and Wong’s (2000) study on the Hong Kong parents with children study in kindergarten and primary school suggested that parents experienced parenting stress when they perceived their children as demanding, not acceptable and not reinforcing enough. Being more restrictive and authoritarian, Chinese parents would perceive their child less acceptable and less reinforcing in particular for parents with children in primary schools who are more independent and assertive.

Mothers were found to experience more parenting stress than fathers as it is the traditional belief that Chinese women should take up the nurturing and caring role for their children. In the same report, perceived parenting self-efficacy was found to intervene between parenting stress and mental health of parents. At same level of parenting stress, parents with a higher level of self-efficacy had better mental health while those with a low level had poor mental health. It was suggested that parents need more opportunities to experience positive parent-child interaction.

Leung and colleagues' (2005) study on child behavior and parenting stress in Hong Kong reported that one tenth of the parents participating the survey were experiencing difficulties with the behavior of their children at age of four years. It was also reviewed that parenting stress and children's behavior problems were associated with presence or absence of social support. Families with someone to share stress reported less frequency of perception of disruptive behavior in children. Besides, parental stress was also associated with household income. Families whose household income was below the median domestic household income reported higher parental distress than those with household income above the median domestic household income (Leung, Leung, Chan, Tso & Ip, 2005).

The above reviews provide a general understanding of the stress and mental status of ordinary Chinese parents of preschool children. With reference to the previous discussion, it wound not be unreasoning to anticipate the stress those parents would face should their children be other than normal or less than perfect, such as parents of children with disabilities or handicaps, and the parents of ELBW preschool children.

A study by Holroyd (2003) described the personal and public dilemmas that result when Chinese families care for children of age from 5 to 16 years with disabilities. One Confucian importance in parenthood is the cultivating of self-discipline for the acquisition of personhood. Caring for children with handicaps strained and violated the Chinese culturally expected order of parental obligations, as mothers of children with disabilities faced the inability to transmit cultural knowledge. Having children with handicaps caused disruptions to parent-child order, associating with images of discontinuity and the end of kinship obligations as parents sensed they would never become complete persons. Children with disabilities present a reminder of the disruption of the process of personhood and binding to ancestry, and this can give rise to shame and blame.

The feelings of shame and blame were also reported in Chow's (2001) study on the psychosocial dimensions of Chinese parents after the birth of children with cleft lips or cleft palates, or both. In relation to the perception of the birth of a child with cleft lip and cleft palate, the parents reported a strong sense of guilt and feeling responsible for the imperfection. Because of the feelings of guilt and shame, the parents were reluctant to seek help for fear of 'lose face'. The first coping mechanism the parents would resort was isolation and drawing themselves to introspection. The parents would approach the event in a rational manner and take all means to seek information, trying to find out the underlying cause and formulating remedial strategies and actions.

Feature of blame was also reviewed in Pun, Ma and Lai’s (2002) study on Chinese mothers of children of age from 3 to 17 years who had mental or behavioral problems requiring psychiatric consultation, and were described as mother-blaming and self-blame by the mother. When the child was perceived as a form of imperfection by significant family members, the general public and the mothers themselves; the mothering experiences were full of frustrations, ambivalence, stress and tensions. To strengthen the psychological well being in order to cope with the burden of care, mothers try to find some ‘redeemable features’ in the child. These good elements in the imperfect child help the mothers to regain self-confidence and pride and to defy the reality of their child’s imperfection and normalize their lives and living.

Lam and Mackenzie (2002) described the stress and coping experience of Chinese Hong Kong mothers of children of age between 2 and 6 years with Down’s Syndrome. The type of stressors and coping strategies changed overtime according to the child’s age in three stages, and copy strategies varied accordingly. Strategies commonly used were avoidance, self-reliance, and seeking social support. In stage one, the immediate stressor mothers encountered was facing the child who was completely different from expectations and the belief of ‘heaven’s punishment of ancestors’ wrong doing’. Bounding by emotion-focused coping, mothers tried to hide the ‘shameful affairs’ from outsiders to maintain face. In the second stage, whether the mothers accepted their children or not, they had to bear the major responsibilities of caring for the child even though they were extremely upset, demonstrating the traditional Chinese women’s roles. Problem-focused coping had been employed. In stage three, when the father’s acceptance of child increased and parental grieving resolved, mothers were less exhausted and would cope effectively and look for information and services in the community. The experience was acknowledged as negative, yet positive encounters were also related.

In Ma, Lai and Pun’s (2002) study on parenting stress and parenting investment on children of age from 3 to 15 years with emotional or behavioral problems, it was found that children’s symptoms had a negative impact on parents’ psychological and social well being, which in turn impacted unfavorably on the child. Parents adopted a ‘never-give-up- attitude and engaged in a range of activities, including information search, changes in the methods of parenting, attempts to reduce family stress, reliance on superstitious beliefs and reaching out for professional help and social services, believing that these would help the children. This indication of the resilience of parents in facing the child’s problem invited attention to shift the perspective of services from a patient unit to the family as a whole. Wong et al (2004) suggested that Chinese parents in caring for children with developmental disabilities needed to be equipped with practical parenting skills and information on developmental disability, and they needed to

have realistic expectations for the child. Parents also needed professional support to cope with caring task and activities. Education was recommended as a fundamental strategy to enhance parents' coping competence.
Although these studies are not directly focused on premature children, inferences can be made in that the coping process may also well apply in the situations of families with ELBW children.

Nevertheless, healthcare researchers have amassed much valuable information about the individual parent's experience of living with ELBW children and have specifically addressed the context of motherhood, the majority of the literature focuses on one of following shortcoming: prematurely born children were disabled or had chronic illness and / or this would impose negative impact on the families and parents. By limiting both the focus of investigations and range of data collection and the subsequent interpretations, these studies failed to illuminate the rich variety of experiences and differences in mothers' experiences.

The literature review revealed that an insufficient description and apparent misunderstandings regarding the actual daily living of the family with ELBW child and the daily mother-child relationship exist. While the problematic aspects of the childhood and parenting stress have received considerable emphasis, there is a notable lack of information regarding the measures used by mothers in the management of the events and changes.

This review exposed that little foundational information is available about the lived experience of mothers of ELBW children who are entering the age of schooling. The negative consequences of premature birth are covered extensively in the literature, but their implications for the day-do-day living of the mothers have received little attention. The paucity of research on the mother experience of living with ELBW children is indicative of the lack of investigation into the subjective experience of the mothers. Without a foundational understanding of the mother's experience of living with a child of ELBW, nurses will not be able to plan care and develop interventions to support these families and empower them in the management of challenges in subsequent years.

Summary

This chapter has attempted to briefly provide an overview on literature relating to issues of parenthood transition, feministic perspective of motherhood, parent-infant attachment, and impacts of premature children on the parents and families. The related stress and coping in caring for prematurely born children was briefly discussed. The cultural values and beliefs of Chinese addressing the relationships within families were also briefly reviewed.

It is found that the transition to parenthood is a developmental and stressful life event, requiring adaptation and change. Various sequential events are involved throughout the transition, including pregnancy and childbirth that imposes great stress upon both the parents and the family as a whole. Mothers tend to experience more stress as they undergo the major physiological changes and the changes in role demands and life structure. In addition, as one of the enduring universal elements of sexual division of labor in family, the role of child care by mothers remains consistent and women are still taking greater responsibility than fathers for family roles. Though childbirth is usually a happy event, the premature birth of a child with extremely low birth weight is always unforeseen and the parents and family are unprepared with the abrupt occurrence. These mothers begin their motherhood in the unfamiliar environment of NICU and need to be reconfirmed as a mother.

Attention to the many issues concerning the families living with ELBW children has been drawn, such as parental stress (Miles et al., 1993; Seideman et al., 1997). Researchers have reported responses of family from different aspects including the psychological (Singer et al., 1999) and socio-economic (Cronin et al., 1995; Lee et al., 1991; Singer et al., 1999). In these studies, comparisons were performed between different parent groups such as low / normal birth weight infants, high / low risk low birth weight infants, and between fathers and mothers. Studies were also conducted over time.

Nevertheless, human experience cannot be quantified with quantitative measures (Hull, 1997). The scarcity of research on the subjective experience of the mothers of ELBW children indicated the necessity of a qualitative research that purposes to understand human experience and to reveal both the process by which people construct meaning about their worlds and report what those meanings are (Hull, 1997). This study is aimed at exploring the lived experience of mothers in a Chinese population and the review on the Chinese cultural beliefs helps to explain how the traditional values dominate the mothers' behaviors. The findings and discussion in previous research on Chinese parents provide a general inference on the parental coping strategies and implication on healthcare.

In order to accomplish the goal of phenomenological research to understand human experience from the subject's perspective, the researcher has to set aside all these preconceptions, pre-understandings, and the existing bodies of scientific knowledge derived from the literature review. Rather, the works of other researchers are held 'in abeyance' and regarded suspiciously (Morse & field, 1996).

CHAPTER 4

Research Methodology:

Hermeneutic Phenomenology and Nursing Research

> *Research is to see what everybody else has seen, and to think what nobody else has thought. (Albert Szent-Gyorgyi, Hungarian Biochemist, 1937 Nobel Price for Medicine, 1893-1986)*

Inspired by the phenomenological hermeneutic philosophical perspectives from van Manen (1990), the researcher has adopted the research approach in nursing inquiry from Ray (1991) to describe and interpret the mothers' experience of living with ELBW children. This chapter discusses the considerations and rationale for choosing a hermeneutic phenomenology as the research approach in this nursing study. The philosophical underpinnings of the study and the historical overview of phenomenology are reviewed. The esthetic process used in the nursing inquiry is described.

Introduction

> *Phenomenological research, a research method that explores the humanness of a being in the word, is a drama, an interactive involvement of both the "researcher" and the "researched". For the*

> *researcher, the research drama is experienced as a dialectic between the inner commitment (the interest, the passion) and the outer activities (stating the question, establishing the approach, operationalizing the tasks, writing and rewriting*) *(Bergum, 1991, p55).*

The lived experience of mothers of ELBW children is studied using the nursing inquiry approach described by Ray (1991), basing on the philosophical perspectives of phenomenological hermeneutic from van Manen (1990). This study aims to both describe and interpret the nature of the lived experience. Phenomenology (descriptive) and hermeneutics (interpretive) are human sciences that study persons who are experiencing the life world (van Manen, 1990). Both description and interpretation, and esthetic knowing of the experience of lived experience are the means by which questions about the meaning of lived experience are illuminated (Ray, 1991).

This study seeks to integrate the description derived from the researcher's phenomenological reflections and hermeneutic interpretations to reveal the whole of the lived experience of mothers living with ELWB children at preschool age. This hermeneutic-phenomenological approach provides an understanding of subjective meaning, looking for the information revealed in the description given by the mothers. The researcher reflects on the lived experience of the mothers to discover the meaning within the lived experience, through the use of both description and interpretation.

“The movement towards advancing nursing as a human science, as a science and art, demands a new scientific approach… Nursing as a human science calls for a different type of methodology, on which demands participation and involvement in the experience of being human. ” (Ray, 1987, p.167). This study aims to explore, describe and interpret, the mothers’ experience of having ELBW children as it is lived and to sensitize healthcare professionals to this experience as lived. With an aim to uncover the experience and essence of what it means to be human (Ray, 1987), the researcher use the hermeneutic-phenomenological approach to reveal what is real in the lived experience of mothers with ELBW children, hoping the findings will contribute to a body of knowledge to the healthcare professionals.

For van Manen, “lived experience is the starting point and end point of phenomenological research” (1990, p.36). Phenomenology research always begins in the life world that is the world of natural attitude of everyday life (van Manen, 1990).

> Hermeneutic phenomenological research edifies the personal insight, contributing to one’s thoughtfulness and one’s ability to act toward others, children or adults, with tact or tactfulness… We might say that hermeneutic phenomenology is a philosophy of the personal, the individual, which we pursue against the background of an understanding of the evasive character of the logos of other, the whole, the communal, or the social (van Manen, 1990, p.7).

The hermeneutic phenomenological approach in this study is concerned with the description of the experience of transformation of life of mothers with ELBW preschool children, and with the interpretation that points to the nature or essence of this transformation of life.

To understand lived through experience is to go beyond the taken-for-granted aspects of life (Bergum, 1991). As the foundational approach of this study, phenomenology uncovers “meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized or sentimentalized” (Benner, 1985, p.6). In this study, the researcher seeks to explore the mothers’ realities, the way that the mothers shape and are shaped by their own lived world. This nursing inquiry is presented basing on the historical perspective of phenomenology and hermeneutics, and hermeneutic-phenomenology as the method. The following will provide a discussion of phenomenology in nursing, historical overview of phenomenology and hermeneutics as philosophy, application of hermeneutic as an approach for cultural studies, and hermeneutic-phenomenology as the method within this nursing inquiry.

Phenomenology in Nursing

> *Nursing is a human science, conducted by self-interpreting subjects (researchers) who are studying self-interpreting subjects (participants) who both may change as a result of an investigation*

(Benner, 1984, p.171).

Nursing is concerned with both the promotion of health and the treatment of illness and disease. Health and illness are lived experience and are accessed through perceptions, beliefs, skills, practices and expectations (Benner, 1999). Nursing continues to align itself with traditional science to improve practice or to favor the human science approach to reality and humanity. It is apparent that the human-to-human caring transactions of nursing cannot be explained or understood with traditional positivistic scientific approach. To advance knowledge in processes and concepts like caring, life, human relationship, suffering and so on, it is appropriate for nurses to choose a personal, unique and gestalt scientific model. The science paradigm for nursing must allow human phenomenon to emerge and still be investigated (Watson, 1999).

The emerging view that nursing as a human science that includes the art and science of human caring has been articulated by salient nursing leaders (Munhall, 2001b; Oiler, 1982; Watson, 1999). Benner and Wrubel (1989) noted that caring is a basic way of being in the world. Nurses focus on the lived experience in health and in stressful situations and provide care for people in the midst of health, pain, loss, fear, disfigurement, death, grieving, challenge, growth, birth, and transition on an intimate frontline basis (Benner & Wrubel, 1989). Nurse researchers and theorists have been questioning if the traditional quantitative research methodologies as adequate approaches for study of these human life experiences, which is often the focus of nursing researchers. The questioning of researchers and theorists focused on two folds. The first was whether measurement, categorization or statistical indexes were adequate to understand the person in his/her entirety; and the second was the ability of research to explain or predict human experience, or to capture relational patterns (Benner, 1985; Cohen, 1987; Oiler, 1982; Omery, 1983). Omery (1983) further advocated that “What was deleted in the objective scientific experiment, the subjective experience, was beginning to be perceived as more basic and real in the understanding of human knowledge and behavior than the codifications that the experimental researchers called data” (p. 54).

With all these questions, the differences between natural science and phenomenological perspectives were reviewed (Munhall, 1994). First, the natural science tradition has a reductionist approach, whereas the phenomenological approach is a holistic orientation to the study of the individual. Second, the natural sciences treat meaning as “facts”, whereas the phenomenological tradition remains that “meaning is contextually constructed as an intersubjective phenomenon” (Morse, 1991). Third, the natural sciences seek causal explanations, predictions and control, whereas the phenomenological approach seeks understanding and interpretation (Munhall, 1988). Fourth, the natural sciences are characterized by deductive reasoning, objectivity and statistical techniques; whereas in contrast, phenomenology is characterized by inductive reasoning, subjectivity, discovery and description (Ray, 1985). Keeping these thoughts, nurse researchers considered phenomenology as a research method that could provide understanding of the person's reality and experience, valued individuals and the nurse-patient relationship, and embraced a holistic approach to the person (Benner, 1985; Oiler, 1982) Phenomenology is becoming a promising approach for nurse researchers advocating these values, and indeed, nursing research using phenomenological approaches has proliferated in the past decade.

The philosophical notion of phenomenology was first introduced in nursing by Paterson and Zderad (1988) who viewed nursing as an existential human experience of being and doing with another. According Paterson and Zderad (1988), “phenomenology involves an openness to nursing phenomena, a spirit of receptivity, a readiness for surprise, and the courage to experience the unknown” (p. 76). Since then, nurse leaders suggested that phenomenology as a research approach in congruent with the study of nursing as human science (Leininger, 1985; Paterson & Zderad, 1988; Ray, 1990). This view was also shared by other nurse scholars (Munhall, 1994; Rose, Beedy & Parker, 1995), that nursing was moving towards an existential and humanistic approach being parallel to the philosophical basis as needed by a phenomenologist. Munhall (1994) contend that “the phenomenological perspective begs us to look at ordinary daily human life experiences in their context to discover meaning” (p. 3); and she further affirmed that “phenomenology, as a way of being, take us from this dazed perspective to a gazed perspective where we give, reflect, and attempt to understand the ‘whatness’ of ordinary life” (p. 4). In congruence with this conception, Rose et al.

(1995) suggested that “phenomenology clearly has the potential to generate knowledge for practice from practice, through the use of nursing theory rooted in phenomenological philosophy, as nursing research moves from the positivist to the humanist paradigm” (p. 1128).

Aiming at understanding the experiences and perceptions of the mothers of ELBW children during preschool age, the researcher in this study adopts a phenomenology research approach for this study to explore into the field of human science, and examining the human behaviors and the perceptions that affect the behaviors and outcomes. As suggested by van Manen (1990), human science research is the descriptions and interpretations of the text of life, and human science aims at “explicating the meaning of human phenomena and at understanding the lived structures of meaning” (p.4).

In choosing the phenomenological approach, the researcher in this study focuses on the meaning of the lived experience of the mothers of ELBW children, by using inquiries that involved description, interpretation and reflection of the experience, to advance knowledge in processes and concepts like caring, life, human relationship and suffering (Ray, 1999). In adopting a hermeneutic phenomenological approach, the researcher expects not only to describe the lived experience of the mothers of ELBW children, she also seeks to gain a credible insight closely into the mothers’ realm of having an ELBW child during preschool years. Munhall (1994) stated that “phenomenology directs our attention to meaning. Understanding the meaning has far greater value than focusing on the behavior. If we understand the meaning of a behavior or an experience, we are certainly on surer footing for doing whatever might be more useful" (p. 33). Van der Zalm, and Bergum (2000) support this view and contend that although hermeneutic phenomenology does not prescribe action for use in clinical practice, it does influence a thoughtful reflective attentive practice by its revealing of the meanings of human experience. In line with these ideas, the essence of the present study does not simply explore what and how things happened but also puts the focus on what the experience is like for these mothers and describes the experiential meaning of these experiences for the mothers. In doing so, it is hoped that nurses and the professionals in the healthcare team and community services will gain insights in enhancing understanding for these mothers and thus provide necessary support and services to them.

Philosophical Foundation of Phenomenology

> *Phenomenology is a philosophy, an approach, and a method.*
> *Possessed by a reverence for experience, it conforms to nursing's*
> *valuing (Oiler, 1982, p.178.)*

In adopting phenomenology as the research approach in this study, it is important to have an historical overview of the development of phenomenology as a philosophy. The history of phenomenology research and its strong philosophical basis on existentialism and humanism are further outlined in the subsequent sections.

The historical evolution of phenomenology was traced by Herbert Spiegelberg (1982) who chose the word “movement” as a means to express his belief that phenomenology was not a stationary philosophy (Munhall, 1994). As a branch of philosophy, phenomenology can be divided into three phases: preparatory, German and French (Cohen in Munhall, 1994). In the preparatory phase, phenomenology was first introduced as a method of inquiry by Frank Brentano (1838-1917) who was the forerunner of the phenomenology movement. He was the first philosopher to discuss the value of “inner perception” and the concept of “intentionality”. Brentano expanded the idea of “inner perception” as the immediate awareness of a person’s psychological phenomena, including the emotions, while maintaining attention to the external objects (Munhall, 1994). In this preparatory phase, the philosophers were able to describe the phenomenon (behavior) before testing the behaviors with a traditional scientific method, thus enhancing the nature of psychology (Munhall, 1994).

In the German phase, the prominent scholars dominating the movement of phenomenology were Edmund Husserl (1859-1938) and his student Martin Hiedigger (1889-1976). Husserl was, and is still, considered as the central figure and primary philosopher of modern phenomenological movement. Husserl’s intent was to understand the reality of things by going back to the reality itself as he explained “back to the things themselves” (Crotty, 1996). He attempted to restore the reality of human kind in the world and he brought forth the belief that the study of philosophy should have a new humanism but not only have rigor (Ray, 1985). He was disenchanted with the scientific position of positivism-empiricism, that is, the final truth lay in facts alone (Ray, 1990). Husserl believed that the world of everyday experience is not immediately accessible in the ‘natural attitude’, the taken-for-granted attitude, and he specified the use of the phenomenological study to describe the fundamental structure of the taken-for-granted life world (Cohen & Omery, 1994), to reveal with scientific exactness the life of consciousness in its original encounter with the world (Ray, 1985). Husserl was the first philosopher to propose the use of phenomenology as a creative attempt to apprehend meaning through the study of human experience (Munhall, 1994).

Heidegger was the second influential philosopher in the German phase. The most important concept of Heidegger’s phenomenology was the concept of “being”. Being, according to Munhall (1988) is how the individual participated in the cultural, social and historical contexts of the world. Shifting from Husserl’s epistemology – a theory of knowledge, Heidegger stated phenomenology as an ontology – a study of the mode of being in the world (Ray, 1990). Heidegger refined and converged Hussel’s phenomenology as existential phenomenology that aims to describe how phenomena present themselves in lived experience, in human existence (Ray, 1990). Heidegger also brought forth the interpretive (hermeneutic) phenomenology, which apart from description, emphasizes the search for interpretation from experience (Boyd, 1993). Rather than emphasizing epistemological concerns centering on issues of the relation of the knower to the known, Heidegger posed the fundamental question with ontology on “What does it mean to be?” (Leonard, 1994). In Heidegger’ phenomenology, the question of being is prior to the question of knowing and the answer to the question of knowing arises out of the answer to the question of being.

For Heidegger, phenomenology investigates “Da-sein” (being-in-the-world) rather than consciousness (knowing of the world). Heidegger attempted to show the ontological structure of understanding in terms of its orientation towards “Da-sein”. Heidegger explicated a threefold forestructure of understanding upon which all interpretation is grounded- fore-having, fore-sight and fore-conception (Plager, 1994). The forestructure that links understanding with interpretation in the ontological circle is the “essential foundation for everyday circumspective interpretation” (Heidegger, 1996, p. 140).

Heidegger implied that interpretation is inevitably interrelated to our understanding of things and phenomenology is interpretative (hermeneutic) as “phenomenon is rooted in the existential constitution of Da-sein, in interpretive understanding” (Heidegger, 1996, p. 143). Heidegger called interpretation the development of understanding through which we can grasp our possibilities within the context of the life world where we live. Heidegger stated:

> In interpretation, understanding appropriates what it is understood in an understanding way. In interpretation, understanding does not become something different, but rather itself. Interpretation is existentially based in understanding, and not the other way round. Interpretation is not the acknowledgment of what has been understood, but rather the development of possibilities projected in understanding. (1996, p. 189).

Gadamer, Heidegger's student, further elaborated on existential ontological hermeneutics. The hermeneutic circle from Heidegger was taken to describe the experience of moving dialectically between the part and the whole. Gadamer affirmed the position of researcher in the hermeneutic circle placed a stronger emphasis on language and. Gadamer claimed language and history supply the shared sphere in the hermeneutic circle (Koch, 1996). Gadamer advanced two positions of hermeneutics and both were making understanding possible: prejudgment – the preconception or prejudice or horizon of meaning that are part of the linguistic experience, and universality – a common human consciousness connecting the persons who express themselves and the persons who understand (Ray 1994b).

Gadamer described the hermeneutic circle as the fusion of horizons. In order to understand the meaning of things being studied, Gadamer argued that one remains open to and also embraces the meaning held by the text. To Gadamer, understanding is a mode of being, understanding is talking about existence.

Understanding, like conversation, is always a reciprocal relationship. Understanding is derived from personal involvement by the researcher in a reciprocal process of interpretation (Dowling, 2004). This task of understanding is achieved in research writing, by showing the way in which the researcher participates in making data, depicting the expression in the social context in which it occurred, and then showing how the horizons of the interpreter and interpreted are fused (Dowling, 2004).

The French phase of phenomenological philosophy grew from the German phase. This third phase of phenomenological movement was led by three key philosophers, Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980) and Maurice Merleau-Ponty (1908-1961), who brought preciseness to phenomenology, formulating the philosophy and science of existential phenomenology (Munhall, 1994). Among them, Merleau-ponty was most recognized for his influence on phenomenology as an inquiry and he advocated phenomenology as related to experienced time, space, body and human relations as we live them (Ray, 1990). Besides, the work of Merleau-Ponty has been identified in nursing as a perspective that shares nursing's concern for people as embodied beings (Munhall & Oiler, 1993). In Merleau-Ponty’s view, phenomenology is existential, oriented to lived experience, the embodied human being in the concrete world (van Manen, 2002). The aim of phenomenology is “concentrated upon re-achieving a direct and primitive contact with the world” (Merleau-Ponty, 1962, p. vii). Merleau-Ponty posited the belief that people bring their individual history and knowledge of the world as a unified experience that constitutes their consciousness. The way of experiencing the world is through perception, and the realm of perception shapes individual realities. Thus phenomenology provides an effort to describe human experience as it is lived (Munhall, 1994). For Merleau-Ponty, consciousness is life itself; it exists in the world through the body. “The world is not what I think, but what I live through” (Merleau-Ponty, 1962, p. xvii). Merleau-Ponty believed that phenomenology inquiry could never yield indubitable knowledge. He stated that “The most important lesson that the reduction teaches us is the impossibility of a complete reduction” (Merleau-Ponty, 1962, p. xiv), that full and final descriptions are unattainable.

Paul Ricoeur (Ricoeur, 1981), another French philosopher, was the inspiration for phenomenological hermeneutics as his theory of interpretation provides one approach through which researchers using hermeneutics can achieve congruence between philosophy, methodology and method (Geanellos, 1999). Ricoeur’s theory of hermeneutics acknowledges the interrelationship between epistemology (interpretation) and ontology (interpreter). Ricoeur focused on textual interpretation as the primary aim of hermeneutics and developed a theory of interpretation that took into account language, reflection, understanding and the self. Ricoeur notes the way interpretation moves forward from naïve understanding, where the researcher has a superficial grasp of the whole of the text, to a deeper understanding, where the research understands the parts of the text in relation to the whole and the whole of the text in relation to its parts – the hermeneutic circle (Geanellos, 1999).

Ricoeur’s theory of interpretation involves a search for metaphor of meaning of the text. For Ricoeur, what must be interpreted in a text is “a proposed world in which I would inhabit and wherein I could project one of our own most possibilities” (Ricoeur, 1981, p142). Ricoeur’s theory of hermeneutics includes explanation-- what the text (the parts) says; and understanding-- what the text talks about (the whole in relation to its parts). Ricoeur (1981) emphasized the importance of both explanation and understanding through dialectic of distanciation and apprehension. Recoeur claimed that distanciation was the necessary condition of understanding. For Ricoeur, this was the distance between the self and the other, between the near and the far that interpretation and understanding attempted to reduce. Ricoeur (1981) expressed that dialectic exists between distanciation and appropriation that allows researcher to identify the metaphor governing the text as a whole. Ultimately, this process illuminates the whole of the text through direct insight from reflection and appropriation. In conjunction with Gadamer’s hermeneutic of understanding, Ricoeur’s theory of interpretation warrants consideration as a method of textual analysis.

Prior to the further discussion of phenomenology as a research methodology, some significant concepts of phenomenology as a philosophy are briefly revealed: consciousness, embodiment, natural attitude, perception and experience (Munhall, 1994). Merleau-Ponty described consciousness as embodied awareness of primordial experience (van Manen, 2002). Merleau-Ponty discussed consciousness from an existential perspective that sets it firmly in the context of an embodied being-in-the-world (Crotty, 1996). For the term embodiment, Munhall (1994) explained this as a sensibility that through consciousness that people are aware of being-in-the-world, and it is through the body that people gain access to this world. Embodiment allows people to live in the world and understand the world in relation to themselves (Benner & Wrubel, 1989). Through embodiment one is conscious of another's existence in the world through the body. The body of another, like our own, is not inhabited, but is an object standing before the consciousness as empirical being. (Merleau-Ponty, 1962). The natural attitude is a mode of consciousness that espouses interpreted experiences, and this natural attitude is the experience and interpretation of the world handed down by preceding generations (Munhall, 1994). Experience and perceptions are defined as the original modes of consciousness of a person (Munhall, 1994). Perception is a person's access to experience in the world through his or her body and thus is personal and individualized depending on the context in which the person is experienced for interpretation and meaning. Munhall emphasized that interpretation of the experience from individual's unique experience of an event is critical. What is important from the phenomenological view is not to know what is happening but what is perceived as happening. The reality that phenomenologists are concerned with is the experience as the individual is perceiving it (Munhall, 1994).

As on the philosophical theme of phenomenology, Heidegger further elaborates the relational view in the understanding of experience. Heidegger believes that to be human is to “be-in-the-world” because an individual participates in cultural, social, and historical contexts of the world. Heidegger emphasizes the importance of this human participation in contribution to a person’s understanding of the world. Interpretation and self-understanding of the world that are handed down through language and culture are called “the background”, and that, like natural attitude, is critical because it provides conditions for human actions and perceptions (Munhall, 1994). Heidegger alleges that persons are self-interpreting beings who do not come into the world predefined but become defined during the course of living a life. He also posed that meaning is found in the transaction between a person and a situation; the person both constitutes and is constituted by the situation. However, the person grasps the situation directly in terms of its meaning for the self. The meaning of the situation is apprehended based on the taken-for-granted meaning embedded in skills, practices and language (Benner & Wrubel, 1989).

Hermeneutic as an Approach for Cultural Studies

> *Through the results of hermeneutic-phenomenological inquiry, we perceive a person’s particular situations and contexts. Through these we come to know the place in which the individual lives, the*

> *beliefs, values and culture of the individual’s world.*
>
> *(Van der Zalm and Bergum, 2000, p. 212).*

Further to the knowing of the “who”, the “how”, and the “what” of nursing practice, White (1995) proposed a pattern of sociopolitical knowing addressing the “wherein” and focusing “within the broader context in which nursing and health care take place” (p. 84). Hermeneutic-phenomenological inquiry contributes to this knowing that is necessary to fully grasp the essentials of another individual’s culture, and their cultural construction of meaning and reality (Van der Zalm and Bergum, 2000).

Hermeneutic phenomenological research is “a search for what it means to be human” (van Manen, 1990, p.12), through which a researcher come to a fuller grasp of what it means to be in the world of the individual, “taking into account the sociocultural and the historical traditions” (van Manen, 1990, p.12) that have given meaning to that researcher’s way being in the world. Even for the themes appear to be essential meanings, they are often “historically and culturally determined or shaped” (van Manen, 1990, p.107).

Humans are embedded in historical-cultural contexts and traditions that are shared with others in the community. Hermeneutical phenomenology shows that both the problems that a researcher trying to solve and his or her understanding of these problems are grounded in situational, cultural and historical contexts that can be brought to the fore; while an increased understanding of these situational, cultural and historical contexts could potentially bring up new insight into the solution of problems that plague nursing (Johnson, 2000).

In conduction of cultural studies, Saukko (2003, 2005) discussed a new multidimensional methodological framework that interlaces the different philosophical and methodological commitments of the paradigm. The three methodological approaches, and concomitant validities correspond to the hermeneutic (or dialogic), poststructuralist (or self-reflexive) and contextual dimensions to form the methodological basis of cultural studies.

According to Saukko (2003), hermeneutic approach does not claim to have access to some privileged “objective” position from which to describe the lives of others. Hermeneutic researcher does not review research in terms of describing other world from outside, but in terms of an encounter or interaction between different worlds. Poststructuralist research evaluate research in terms of how well it manages to unravel social tropes and discourses that, over time, have come to pass for a “truth” about the world. Poststructuralism argues that there is no “unbiased” way of comprehending the world. Therefore, valid research is known to “expose the historicity, political investments, omissions and blind spots of social ‘truth’” (Saukko, 2003, p. 21). Hermeneutic and poststructuralist approaches both emphasize that there are multiple “realities” and that the world looks different when observed from a different social place or historical time. This realist underpinning contradicts the contextual validity which refers to the capability of research to locate the phenomenon it is studying within the wider social, political context, and is committed to a form of realism that is bound to make statement of how the world “really is” (Saukko, 2005).

Saukko (2003) concurs with Richardson’s (2000) prismatic vision of research that described the combination of different methods in doing and writing research as “crystallization”. It points out that crystals are prisms that reflect externalities and refract within themselves to create different colors, patterns, and arrays when casting off in different directions. Applying this metaphor into research, reality changes when the methodological angle or perspective from which the researcher looks at it changes. Hence, methodologies and writing strategies are not seen as means of reflecting reality, presumably “objectively”, but as devices that the scholar uses to create and convey different realities (Saukko, 2003).

In this hermeneutic-phenomenological study of the lived experience of the Chinese mothers of ELBW preschool children in the context of Hong Kong, the researcher adopted the hermeneutic and poststructuralist approaches to draw attention to the different “realities” created from language and research. The researcher brought together the hermeneutic desire to understand the creative lived world of the mothers of ELBW children and her awareness of own pre-understanding that originates from her being-in-the-world, which continuously guided her perceptions and understanding, and reflected back to the research commitments.

Hermeneutic-Phenomenology as the Methodology

> *Phenomenological research is a human science that strives to "interpret and understand" rather than to "observe and explain" which is an approach normally found in natural science*
>
> *(Bergum, 1991, p. 56).*

As discussed in previous section, nursing has been advocated as a human science for the combination and integration of the science with the beauty, art, ethics and esthetics of the human-to-human care process in nursing (Watson, 1999). Human science aims at explicating the meaning of human phenomenon such as in literary or historical studies of texts, and interpreting the lived structures of meaning such as in phenomenological studies of the lifeworld (van Manen, 1990). Based on the philosophical underpinnings, phenomenology has been referred as a philosophical stance and a research method (Morse, 1991; van Manen, 1990).

To capture the interrelationship and interdependence of humanism and science in nursing, phenomenological approach as the explication of meaning in experience is one of the most promising qualitative method (Ray, 1985). Phenomenology is a way to recover and maintain the humanistic and scientific claims of nursing.

Using the components of structured reflection of the phenomenological method, nurses can describe the life consciousness of caring. The task of nursing is to explicate and examine the meaning of health experience and human relationship through the use of phenomenological inquiry (Ray, 1985).

In choosing phenomenological methodology as the research approach in this study, the researcher seeks to identify its specific differences from other qualitative methodologies. First, phenomenology requires no preconceived notions, expectations, or frameworks be present or guide the researchers as they gather and analyze the data (Omery, 1983). Second, the phenomenological method makes no assumptions that processes exist until they are discovered (Munhall, 1994). Third, the phenomenological researcher approaches the participant and the experience with an open mind, and accepts whatever data are given by the participant. All experiences communicated to the researcher are considered as valid sources of knowledge for the participants living the experience. Fourth, the philosophical basis of phenomenology originates with an existential phenomenological view, emphasizing a person as unique, possessing potential and experiencing opportunity for change (Munhall, 1994).

Van Manen (1990) introduced a human science approach for phenomenology and he viewed phenomenology not only as a philosophy of being but also as a practice of deliberate thoughtfulness, a quest for what it means to be human. From van Manen’s perspective, phenomenology describes how one orients to lived experience and hermeneutics describes how one interprets the ‘text’ of life. Van Manen (1990) stated:

> Natural science studies objects of nature, ‘things’, ‘natural events’ and the way that objects behave. Human science, in contrast, studies ‘persons’ or beings that have ‘consciousness’ and that act purposefully in and on the world by creating objects of ‘meaning’ and that are expressions of how human beings exist in the world (p. 3).

Van Manen (1990) observed that phenomenology is a study of essence of experience, which allows research to gain credible insights for a more direct understanding of the world.

In existential phenomenology, van Manen (1990) believes that all phenomenological human science research efforts are explorations into the structures of the human lifeworld, the lived world as experienced in everyday situations and relations. According to van Manen (1990, 2002), there are four fundamental existential themes that probably pervade the lifeworlds of all human being regardless of their historical, cultural and social background. The four existential themes: lived body (corporeality), lived time (temporality), lived other (relationality or communility) and lived space (spatiality) are heuristic guides for reflecting on human experiences. Lived body (corporeality) refers to the phenomenological fact that human are always bodily in the world. When one meets another person in his or her landscape or world one meets that person first of all through his or her body. Lived time (temporality) is subjective time as opposed to clock time or objective time. Lived time is a person’s temporal way of being in the world and the temporal dimensions of past, present, and future constitute the horizons of a person's temporal landscape. Lived space (spatiality) is felt space. Lived space is a category for inquiring into the ways a person experiences spatial dimensions of our day-to-day existence. Lived space is largely pre-verbal and human do not ordinarily reflect on it and is the existential theme that refers a person to the world or landscape in which human beings move and find themselves at home. Lived other (relationality or communility) is the lived relation one maintains with others in the interpersonal space that one share with them. One usually meets the other person in a corporeal way, directly or indirectly, so as to gain an impression of the other person. Meeting the other person, one is able to develop a conversational relation that allows one to transcend oneself.

From phenomenological point of view, in doing research, the inquirer questions the world’s very secrets and intimacies which are constitutive of the world, and which bring the world as world into being of him or her, and in him or her (van Manen, 1990). Van Manen referred this kind of research as a caring act through which we know which is most essential to being. van Manen’s (1984, 1990, 2002) defined phenomenology as a form of inquiry that includes the nature of phenomenological research and writing that is rooted in eight fundamental notions: 1) the study of lived experience, 2) the explication of phenomena, 3) the study of essence, 4) the description of the experiential meaning, 5) the human scientific study of phenomenon, 6) the attentive practice of thoughtfulness, 7) a search for what it means to be human, and 8) a poetizing activity. These fundamental ideas of hermeneutic phenomenology provide significant orientation to this study.

It has to be emphasized that van Manen's approach in doing phenomenological research is not a method as such as he echoed with Gadamer that "the method of phenomenology is that there is no method" (1990, p.30). van Manen described his approach in hermeneutic phenomenological research as a dynamic interplay among six procedural activities or methodological themes as listed below:

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualize it;
3. Reflecting on the essential theme which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented pedagogical relation to the phenomenon;
6. Balancing the research context by considering parts and whole.

(van Manen, 1990, p.30-31)

As asserted by van Manen, these procedural activities are not conducted in any particular order "by executing and completing each step" (1990, p.34). van Manen suggested "in the actual research process one may work at various aspects intermittently or simultaneously" (1990, p.34) as this is not a lineal approach or prescription for conducting research.

According to van Manen (1984), "phenomenology is the study of the life world – the world as we immediately experience it rather than as we conceptualize, categorize, or theorized about it" (p.37).

> Phenomenology research does this by reintegrating part and whole, the contingent and the essential, value and desire… It makes us thoughtfully aware of the consequential in the inconsequential, the significant in the taken-for-granted (van Manen, 1984, p.36).

Researching the lived experience deepens the understanding of the nature of everyday lived experience for the participants. In this study, the meaning and significance of mothers' living with an ELBW child is revealed in fuller and deeper manner through the uncovering and description of essences, the internal-meaning structure, or the nature of the experience. Exercising attentive thoughtfulness in searching for the meaning of life, the researcher illuminates the mother's experience and the meaning of the experience in a more caring and minding manner through the researcher's involvement with the mothers throughout the research process.

The strength of this study is in its phenomenological design that provides the researcher an opportunity to learn about the mothers' unique experience directly from their narrative in the interviews. The open-ended questions allow the mothers to reflect on and share thoughts and feeling about their experience, and the researcher is able to ask for clarification or elaboration when necessary.

Ray’s Caring Inquiry as an Approach to Hermeneutic-Phenomenology

Hermeneutic-phenomenology has both descriptive and interpretive elements (Ray, 1991; Van der Zalm & Bergum, 2000; van Manen, 1990) and its primary objective is the direct investigation and description of phenomena as experienced in life by using the practice of phenomenological reflection and writing to understand the forms of life (van Manen, 1990). Phenomenologists attempt to provide an understanding of the internal meanings or essences of a person's experience in the lived world by careful description of that experience, striving to understand experience rather than provide causal explanation of that experience (van Manen, 1990).

Van Manen (1990) did not advocate a set of step-wise procedures in his approach to doing phenomenological research, but rather argued that interpretation occurs through the deliberate act of describing aspects of experience in textual form. He suggested that all phenomenological descriptions have an interpretive element, and developed a discovery-orientated approach that avoids any predetermined set of fixed procedures and techniques. However, this approach, being distinguished by a lack of a prescribed method, is grounded in “a body of knowledge and insights ... (that) constitutes both a source and a methodological ground for present human science research practice” (van Manen, 1990, p. 30)

According to Ray (1990), as a method concerns itself with experience and the meaning of experience, phenomenology is known by understanding the essence of experience. Ray (1990) also remarked that experience is known through existential (being-in-the-world) and hermeneutic (interpretive) thought. Although hermeneutic- phenomenology does not prescribe action for use in clinical practice, it does influence a thoughtful reflective attentive practice by its revealing of the meanings of human experience (Van der Zalm & Bergum, 2000).

The hermeneutic-phenomenologic philosophical perspectives of this study, based on the work of Ray (1990, 1991) and van Manen (1984, 1990), form the guide of this nursing inquiry. The Hermeneutic-phenomenological perspectives in this study use both description that is concerned with the mothers’ experience of living with ELBW children, and hermeneutics that is the art of interpretation, a way to recover the nature of the lived experience of extremely-low-birth-weight, the interpretation of the mothers’ experiences through their stories (Ray 1990, 1991; van Manen, 1984, 1990).

Ray’s (1990, 1991) and van Manen’s (1984, 1990) fundamental ideas about hermeneutic-phenomenology are significant to this study. Researching the lived experience deepens the understanding of the essences or the nature of everyday lived experience for the mothers in this study. It is through the description of essences, the meaning and significance of living life with ELBW children is revealed in a fuller and deeper way through reflection and interpretation. Through the attentive practice of thoughtfulness and searching for what it means to be human, the researcher illuminates the mothers' experience and the meaning of this experience in a more thoughtful and caring way through the researcher's engagement with the mothers throughout the research process.

"The soul of nursing is seeking the good of self and others through compassionate caring. Healing and caring for oneself is vital to have the energy to compassionately care for others" (Turkel & Ray, 2004). The nursing discipline has both scientific and humanistic care dimensions. For nursing inquiry as the way of compassionate, the esthetic act of knowing about the meaning of the human health experience through the use of caring inquiry – an esthetic process in research that require "an investigation of one's own being in the process of the events of the research" (Ray, 1991, p.183).

> Esthetic knowing in caring research attends to creativity, sensitivity, and the quality of presences. It is an approach of describing and understanding the meaning of being and becoming through caring. In bringing to reflective awareness the nature of caring in the events experienced in the world of nursing, the researcher (and possibly the research participant) is transformed, contributing to the fullness of being and the call to deeper life – a life of

> integrated wholeness and openness to creative forces within and without (Ray, 1991, p. 183).

In conducting this nursing inquiry, the researcher obtained enlightening insights from the philosophical concept of caring in nursing from Ray (1991). The researcher aims to study a more meaningful philosophical foundation based on human rather than nonhuman values. She has chosen to be part of the method and involved in the research process rather than be distant, objectively remote and primarily concerned with the production of science. With this intent, the phenomenological approach of nursing inquiry by Ray (1991) is adopted. According to Ray (1991), the phenomenological inquiry is an aesthetic process that recognizes and senses the other. When a researcher engages in the phenomenological inquiry the “we” is enacted through the dialogic conversation created during the interview. In this nursing inquiry, it is through the description (phenomenology) and interpretation (phenomenological hermeneutics) and esthetic knowing of the experience of extremely-low-birth-weight that the questions about the meaning of extremely-low-birth-weight are illuminated (Ray, 1991).

Inspired by the phenomenological hermeneutic ideas from various sources (Bergum, 1991; Ray, 1991; Van de Zalm & Bergum, 2000; van Manen, 1990), the researcher follows the methodological process outlined in Ray’s (1991) caring inquiry as the guide to this research and is as follows:

1. The Intentionality of Inner Being of the Researcher
2. The Process of Dialogic Experiencing
3. The Process of Phenomenological-Hermeneutical Reflecting and Transforming
4. The Movement of Phenomenological-Hermeneutical Theorizing to a Theory of Meaning
5. Dialoguing with Written Texts: Examining Similarities and Differences
6. Credibility and Significance of the Process of Phenomenology of the Aesthetic Act (p. 184)

The following discussion on the method employed in this research is structured around the methodological schema of Ray (1991). The methodological outline for this phenomenological research “appears as a linear process, however, when doing phenomenology, the work is interwoven and a part of the researcher’s creativity” (Ray, 1990, p.176). The researcher has to emphasize that, in this study, the process of nursing inquiry was not a lineal approach proceeded by completing one step after another. Rather, the steps were intertwining with one another and occurred at many levels of description and reflection. The steps are numbered as subheadings in the following discussion, not to indicate an order of progression or of priority, but to facilitate the orientation of the readers.

1. The Intentionality of Inner Being of the Researcher

Ray (1985) described intentionality being “essentially a character or a property of acts that is always directed toward an object” (p. 89). Consciousness is in the world and is always intentional because “consciousness is always consciousness of something” (Ray, 1985, p.89), thus the study of experience reveals consciousness. Ray (1991) stated that the researcher begins the hermeneutic phenomenological inquiry by imagining the vision of the phenomenon – past and future within the present, listening to the “voices” within embodied consciousness, focusing on and identifying one’s presupposition, and practicing bracketing to hold in abeyance one’s prehistory and presuppositions about the phenomenon.

Centering is a way of putting oneself in the frame of mind for doing phenomenology (Ray, 1990). van Manen (1984) pointed out that, in the researcher’s abiding concern of questioning, the researcher finds himself or herself interested to be or to stand in the midst of something that makes the question possible in the first place. This endeavour is a “creative attempt to somehow capture a certain phenomenon of life in a linguistic description that is both holistic and analytical, evocative and precise, unique and universal, powerful and eloquent” (van Manen, 1984, p.43). To begin a study of lived experience, the researcher needs to orient in a strong way to the question of the phenomenon. The phenomenological researcher needs to feel called upon to investigate the topic under inquiry, engaging not only the rational faculties, but inviting participation of the heart and intuitive understanding of the researcher.

In this study, nursing knowledge is based on the human science perspectives that attempt to open new vistas and new possibilities for the inner subjective human experience; that operate on the principle of human experience as a source of knowledge. The researcher started with the orientation to the phenomenon of extremely-low-birth-weight by walking through her past experience in neonatal and paediatric nursing and her vision for the future development of nursing as a caring profession in the field. Interested in the experience of mothers and in the question of “what it is like” for the mothers to experience life with extremely-low-birth-weight, the researcher oriented to the research question using a hermeneutic phenomenological method through in-depth interviews.

“The problem of phenomenological research is not always that we know too little about the phenomenon we wish to investigate but we know too much” (van Manen, 1984, p.46). There would be tendency for the researcher to believe that he or she knows a lot about the topic already, from existing scientific knowledge and everyday knowledge contributing to an overload of preconceptions that can impede his or her openness to take in knowledge of the phenomenon and see it anew. Bracketing is a philosophical concept introduced to phenomenology by Husserl to suspend ones’ beliefs and assumptions, setting these aside, making oneself aware and be from them (Crotty, 1996). According to Ray (1985), bracketing (discounting) refers to holding in abeyance those elements that are irrelevant to the experience, detaching the meaning that a phenomenon has for the researcher. Ray (1994) further advocates that,

> For eidetic (descriptive) phenomenological study, you don't bracket your awareness, you bracket your presuppositions. You bracket some kind of theorizing about a phenomenon, and then you bring it back after you move it into a hermeneutic (Ray, 1994, p.134-135).

Nevertheless, in actual practice, "if we simply try to forget or ignore what we already 'know', we might find that the presupposition persistently creeps back into our reflections" (van Manen, 1984, p.46). Recognizing the extreme practical difficulty of total excluding one's assumptions and preunderstandings, van Manen (1984, 1990) suggested that researcher make his or her assumptions about a phenomenon explicit so that their influence on the study is transparent.

In this study, the researcher maintained openness to the possibility of bracketing oneself in human-to-human situations as she was aware that "research or research methodologies would never be absolutely 'objective' but always located, informed by particular social positions and historical moments of their agendas" (Saukko, 2003, p. 3). In this hermeneutic-phenomenological study, nevertheless, the researcher endeavored not to allow her assumptions to shape the data collection process and attempted to focus on the participants' experience rather than dwelling on her own preconceptions and presuppositions. The researcher started with the orientation to the phenomenon of extremely-low-birth-weight by walking through her past experience in neonatal and paediatric nursing and her vision for the future development of nursing as a caring profession in the field. The researcher maintained constant consciousness of her own preconceptions and presuppositions gained from previous clinical experience in the field and from the literature review related to the phenomenon as discussed in Chapter 2 and 3. Although the researcher delayed substantive literature review in order to facilitate a presupposition-free approach, she was constantly aware that previous influences would be present from the enormous variety of sources that she was subject to in her daily life, in her cultural and religious background and in her experience in neonatal and pediatric nursing. The researcher had to acknowledge that her mind was directed towards the experience of extremely-low-birth-weight as she understood. Instead of ignoring what was already known, the researcher made explicit her understandings, beliefs, assumptions and presuppositions, while holding them deliberately at bay during the process of interview, transcription and initial descriptive reflecting. Nevertheless, during the process of interpretive reflecting, the researcher’s initial horizon of pre-understanding in the experience of extremely-low-birth-weight was brought to intersect with the text and into being in the dialectic of consciousness. The notion of intentionality would also be applied in the subsequent reflecting process so the researcher would preserve the “subjectivity” of the experience as much as the participants saw. The researcher noted the importance of being aware of these preconceptions in the conduct of the study. The challenge perceived here was to not treat the preconceptions as ‘hypothesis’ to be tested by the study. Rather, the researcher kept conscious of their influence, while focusing on faithfully attending the lived experience revealed in the interviews with the mothers.

2. *The Process of Dialogic Experience*

According to Ray (1991), the process of dialogic experience first starts at the selection of participants for the study, and followed by engaging with the participants to discuss the roles and interviewer and interviewee; copresencing / sensing the other by recognizing the immediate impact of each other’s being on each other; conversing with participants in intensive dialogic interviews; and engaging in a cue-taking, talk-turning, researcher-bracketed, dialogical dialectical interactive process.

Selection of participants.

In qualitative research, the two principles of qualitative sampling adopted are appropriateness and adequacy (Morse & Field, 1996). Appropriateness is the identification and utilization of the participants who can best inform the research according to the theoretical requirements of the study. Adequacy means there is enough data to develop a full and rich description of the phenomenon (Morse & Field, 1996).

This study was conducted from 1999 to 2002. As revealed in the literature review in Chapter 2, in Hong Kong, the increase of live birth with body weight less than 1,000 gm reached a plateau from the year 1997 onwards. These survivors had reached the preschool age of three to five years at the time of the study. Thus a convenience sample of mothers of ELBW children was available.

Purposive sampling in qualitative studies helps to select the best informants and ensures that they are knowledgeable and representative of the topic by virtue of their experiences. Such participants are able to articulate and reflect on their experiences and are willing to participate in the study (Morse, 1991). This study was conducted in an acute hospital in Central Kowloon Cluster of the Hospital Authority, in which the neonatal intensive care unit has been providing care for those high risk neonates including ELBW infants from both public and private hospitals in the southern and central region of Kowloon. Being one of the biggest neonatal care centers in Hong Kong, referrals from hospitals in other regions and clusters are received. In this study, the target participants are the Chinese mothers of ELBW children in their preschool years. Participants communicated in Cantonese and were willing to describe their experience of living with an ELBW child. The researcher assured that irrespective of their children having chronic illness or disabilities, the mothers of ELBW children would face common life experiences and problems. Nevertheless, to reduce any unnecessary impact produced by extraneous variables, mothers of children with complete physical or functional loss, such as profound mental retardation or total blindness were not included. Teenage mothers and mothers who had known medical or emotional conditions which were likely to be provoked were excluded.

After approval was obtained to conduct the study in the hospital, the researcher identified a list of potential participants from the admission registry in of the neonatal intensive care unit. With the name list, the researcher traced the dates of appointment for the coming medical follow up of the ELBW children, then she would have direct contact the mothers or families of the ELBW children, and the ELBW children. The researcher expected that, during this first encounter in the ambulatory care center, she would be able to identify those mothers who would meet the inclusion and exclusion criteria listed above.

The researcher believed that the first contact before the actual interview aids selecting participants and helps build the foundation for interview relationship and substantiate the development of respect and trust to accomplish the goals of research. She approached the mothers or families of ELBW children at the ambulatory care center of the study hospital where the children had medical follow up and asked about their interest in participating in the study. The researcher introduced herself and explained the purpose and goals of the study to the mothers or the family members who accompanied the children. The role of participants in the study was explained, and mothers were told that they would be asked to describe their every day experiences with the ELBW children. The researcher explained to the participants that she was seeking their stories and descriptions of the experiences, and their meaning and perspectives about the experience of extremely-low-birth-weight would be emphasized in the study. An invitation letter (see Appendix I and Ia) that further explained the purpose of the study and clarified the data collection process was given to each invited mother. If the mothers agreed to participate in the study, appointment for an interview was then made with agreement from the mothers. The phone numbers and home address were obtained from the mothers or family members for subsequent contact. If the accompanying person was not the mother, the invitation letter would be given to the family member and a phone call would be followed to have direct dialogue with the mother for the invitation and arrangement of an interview.

In the ambulatory care center, the researcher had contacted a total of thirteen mothers who were considered as appropriate informants who fulfilled the selection criteria. Eleven mothers were invited face-to-face in the ambulatory care center of the hospital. One mother was contacted by phone after explanation was given to the paternal grandmother of the child in the outpatient clinic. All mothers immediately agreed to participate on being asked. Other than these participants, one selected mother could not be reached as the father, who brought the ELBW child to the ambulatory care center, expressed he and his wife did not like to recall the experience.

In qualitative research, determination of sample size is not based on set formula but on two principles (Morse, 1998). First, there is an inverse relationship between the amount of data obtained from the participants and the number of participants. The more information obtained from each participant, the fewer the participants required. Second, the greater the diversity inherent in the research topic, the longer it takes to reach saturation and the larger the sample size (Morse, 1998). According to Morse (1995), the greater the cohesiveness of the sample sharing the characteristics that address the research topic, the faster data saturation is obtained. Data saturation is defined as data adequacy and operationalized as collecting data until no new information is obtained. The quantity of data in a category is not theoretically important to the process of saturation. Richness of data is derived from detailed description, not frequency counts, and there is no priori sample size requirement (Morse, 1995). Morse (2000) further clarified that sample size in qualitative research is much influenced by the quality of data collected and the design of study. The greater amount of useful information obtained from each participant and the more and longer the interviews, the fewer the participants required.

This study began with no predetermined sample size and interviews were continued until there was no new description about the phenomenon. Redundancy of themes can be achieved even with small number of participants (Ray, 1990). In this study, redundancy of information began when the ninth mothers had been interviewed. Then, the researcher continued with three more interviews with new mothers to ensure redundancy of themes was achieved when there was duplication of similar ideas, meanings and descriptions. The researcher ended the data collection when a total of twelve mothers were recruited in the study. Profile of the participants were sought during interview and briefly described in Chapter 5.

Engaging with the participants.

Qualitative research aims to promote understanding and generate knowledge. For qualitative research, it is important for the researcher to see from the participant's perspective (Fontana & Frey, 1994) and to treat the participants as equals and a valuable source for insight knowledge (Olesen, 1994) in order to promote understanding and generate knowledge. It is essential for the researcher to establish rapport with the participants prior to the beginning of interview in particular for successful phenomenological interviews that would model "an intimate and personal sharing of a confidence with a trusted friend" with respect (Morse & Field, 1996, p. 72). Allowing the participants to choose the setting for interview at their own preference and ease would also help building trust (Morse & Field, 1996). The researcher's major goal was to even out the nurse-patient relationship with the image of nurse from "above" for a mutual interpersonal understanding relationship in a place where the mothers were the host and were more familiar and comfortable with.

In this study, prior to the actual interview, the researcher invited the mothers at the outpatient clinic or by phone to present the sincerity of the researcher and gain rapport and trust. Being conscious of her image as a senior nurse in the hospital, the researcher conversed casually with the mothers before interview started, attempting to put them at ease about confidentiality for they would be asked to share their personal life experiences during the interview. Mothers were reassured that their names would not appear in any text or publication, only pseudonyms would be used. The roles of researcher and participants were discussed during interviews. Informed consent (See Appendix II, III) was obtained prior to commencement of interview and the use of audiotape recording was explained.

The researcher purposely proposed to have interviews conducted in the mothers' own places at their convenience, aiming to put them at ease and to facilitate open conversation. Mothers were informed that one to one conversation would be expected and a place where she could talk without interruption was preferred. All except two interviews were conducted in their homes and two mothers chose to be interviewed at their work place where they run their own business. For the ten interviews conducted at the mothers' home, the conversations were conducted in the dining room, bedroom or kitchen between only the researcher and the mother. In some occasion, the children would join the interviews in the midway, especially when the fathers or family members could not keep them away from the mother for too long. For the two mothers who preferred to have interview at work place, one closed her self-run office and suspended business so that she could talk in privacy with the researcher. The other mother arranged the interview at her wholesaling shop after business hours in the presence of her female relative. The participants' home was considered to be the best venue for interview as the home environment provided a more secure and relaxing atmosphere for the participants to express their emotions, feelings and thoughts (Lauterbach, 1993). Furthermore, visiting the mothers at their home would help the researcher to have a better understanding of their home environment and family interaction of these mothers.

Dialogic conversation – phenomenological interview.

Qualitative research encompasses multiple data collection techniques and interview is generally the major mode (Morse & Field, 1996). Interview is a flexible technique that can allow the researcher to explore in great depth, and inter-personal skills can be used to facilitate cooperation and elicit more information. However, before embarking on a busy interview schedule, the researcher needs to be oriented to her or his question or notion in such a strong manner that she or he does not get easily carried away with interviews that goes everywhere and nowhere (van Manen, 2002).

In hermeneutic phenomenological human science, interview serves very specific purposes. It serves as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon. It also acts as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of an experience (van Manen, 1990). Interview also ensues as the researcher converses with the participants in a “cue-taking, talk-turning, researcher-bracketed, dialogical-dialectical interactive process based on the participants’ experience” (Ray, 1991, p. 185) to penetrate the meaning of and experience how the phenomenon is constructed for or understood by the other. During the process of interviewing, a copresencing relationship develops between the researcher and the participant through a recognition of the immediate impact of each other – the compassionate we (Ray, 1991). This caring relationship does not encumber the holding in abeyance of presuppositions, rather, it brings them more fully into awareness (Ray, 1991). This copresencing relationship enhances the communication and rapport.

In phenomenological interview, Ray (1991) emphasized the use of “dialogic conversation” as the kind of interchange desirable for phenomenological interview that does not simply imply a sharing of experience; but rather through the dialogue that the researcher can further probe or ask for meanings of the experience as interpreted by the participant. Bergum (1991) also recommended the circular “conversation” rather than linear one-side “interview” to better describe the actual process, as “conversation” implies a discussion and best captures the attitude of the interaction in phenomenology research.

The researcher of the present study was also the interviewer and adopted an open ended interview method to allow participants to provide detailed responses relevant to the study aim, and use their own words and talk about what really mattered to them (Morse & Field, 1996). For this phenomenological study, only a minimum number of broad, data generating questions were asked in order to arrive at detailed descriptions of the experience of extremely-low-birth-weight. An interview guide (See Appendix III and IIIa) was prepared with a leading question and several prompt questions. The leading question asked was “Can you tell me your experience as a mother of an ELBW child?” The prompt questions were also prepared to explore the information related to the significant events and challenges experienced by mothers during the years, how they affected the mother’s day-to-day lives, how the mothers coped with the events, and what types of support that they perceived helpful to them. The prompting questions would be asked along the course of conversation and not in a predetermined sequence and would only be asked when the mother was not conversant or was lost in her thoughts and not able to give a full account of the experience, aiming to help mothers recall their personal experiences. Throughout the dialogic conversation, minimal interruption was essential during conversation to allow extensive expression. The researcher has practiced non-directive interview techniques, including the use of open-ended questions, active listening, reflective silences, and repetition of statements and refocusing responses to facilitate mothers in their narration focusing on their experience (Fontanan & Frey, 1994). The researcher in this study checked herself consciously and attempted to stay comfortable in spells of silence and pause. To facilitate dialogue, the mothers’ descriptions would be elicited by taking cues from them and asking for an elaboration. “Can you tell me more?”, “Can you give an example of …?”, “Can you remember a time when…?” were questions used to obtain a detail description of the experience. “How did your respond when…?”, “What were you thinking of when…?”, “How would you describe your feelings when…?” were questions used to explore further and deeper reflection on the meaning.

For the purpose of the research approach, the researcher at this time of dialogic conversation deliberately held at bay her theoretical knowledge regarding extremely-low-birth-weight. This was not a part of her embodied consciousness but only an explanation of the phenomenon, as she moved from the lead question of the meaning of the experience and followed by the cue-taking, talk-turning interaction of the actual dialogue itself (Ray, 1991). Each interview was started with general talk as a warm-up and introductory questions were asked to gain rapport. All interviews were audio-tape recorded. The duration of interviews ranged from thirty to ninety minutes. Ten out of the twelve interviews lasted for an hour or more and only two interviews lasted for about thirty to forty-five minutes respectively. When the participant apparently came to the end of the story, the last question asked by the researcher was “Is there anything you would like to ask me?” or “Is there anything else you would like to tell me?” In certain participants, these revealing questions began the “real interview” as they began to tell “real stories” in their minds. Patience and silence were practiced and found to be a more tactful way of prompting the other to gather recollections and proceed with a story (van Manen, 1990). Non verbal cues included touch, smiles, affectionate sounds and glances.

Attentive and flexible interview techniques were used for interviewing the mothers in this study. During most of the interviews the mother sat next to the researcher. The mothers were asked to think of a specific event in their experience living with the ELBW children and to tell the researcher about that event. In actual fact, the mothers needed little encouragement to talk and were open and participatory in the conversation. The common interjection the researcher used was rephrasing the last sentence in a questioning tone or asked the question “Can you give an example of …?” In the conversations, there was consciousness of interaction between each mother and the researcher. All mothers were immersed in their own life stories that they shared with the researcher with full willingness and trust. There was a sharing of common concerns and experiences although the mutuality was inevitably skewed by the research intention.

The researcher was sensitive to the mothers’ emotional status during the interviews. Most mothers became tearful once their feelings were touched. Several mothers appreciated the interviews in which they would have a chance to vent their feelings with someone who would understand. Occasionally, the children would join the interviews in the midway, especially when the fathers or family members could not keep them away from the mother for too long. The mother-child relationship would be revealed through their interactions and was noted. Through the interactive interviews, the description of the experience of living with extremely low birth weight child was shared, revealing the meaning of the experience for the mothers.

Immediately following the interview, field note (See Appendix IV for an example) identifying non-verbal communication and facial expression and gestures that might not be audible in the tape were made to enable recalling of the interviews during process of transcribing. In the field notes, the researcher’s observations such as the atmosphere and environment of interview, and the interaction between the mother and child would be recorded. These observations occurred naturally during interviews and were analyzed simultaneously with interviews. All the interviews were audio-tape recorded and transcribed verbatim in Chinese with the field notes transferred on to them. Apart from the interviews and transcripts, the researcher had conducted follow-up telephone conversations with the mothers to recheck particular findings and clarify meaning of the narratives. Notes of clarification were jotted. The researcher performed all the taped conversation and transcription by herself, endeavoring to grasp the opportunity to immerse herself in the words of the mothers as she played and replayed the tapes, and wrote down word by word. The researcher found it helpful in the later unfolding analysis.

Stories were reconstructed from the transcripts and field notes derived from the in-depth interviews of individual mothers. Each story of the mother, incorporated with researcher’s insights, was presented as an ongoing narrative of events and history, and included the meanings that an individual mother gave to her lived experience. The stories illuminated the mothers' descriptions and perspectives of life with extremely-low-birth-weight and revealed the meaning of this experience. From meanings and insights revealed within each story, themes emerged that described the experience of life with extremely-low-birth-weight.

Ethical considerations.

Ethical issues are present in any kind of research. The nature of ethical problems in qualitative research is subtle and different compared with that in quantitative research (Orb, Eisenhauter & Wynaden, 2001). Qualitative researchers usually focus on exploring, examining and describing people and their natural environments. Embedded in qualitative research are the concepts of relationships and power between researchers and participants. The desire to participate in research depends on the willingness of the participant in sharing his or her experience. Qualitative researchers have to balance research principles as well as the well being of the participants (Ramos, 1989). Qualitative researchers should establish a set of ethical standard that guide their research in addressing the initial and ongoing issues arising from the qualitative research (Denzin & Lincoln, 1994).

In this study, the well-established ethical principles namely autonomy, beneficence and justice were used. According to Orb and colleagues (2001), autonomy refers to the respect and protection of human rights, including the right to be informed about the study, the right to freely decide whether to participate the study and the right to withdraw at any time without penalty. The second principle is beneficence and the emphasis in qualitative research is the adhesion to rules of confidentiality and anonymity, to protect the identities of participants from being publicized. The researcher has the obligation to anticipate any possible outcomes and be aware of sensitive issues and conflicts of interest. The third principle is justice, which refers to equal share and fairness. The distinctive features of this principle are to avoid exploitation and abuse of participants and the researcher should recognize the vulnerability and contribution of participants to the study.

In this phenomenological inquiry, approval to conduct the study was obtained from the Departmental Research Committee of The Hong Kong Polytechnic University and the Research Ethics Committee of Queen Elizabeth Hospital. The consent form, both in English and Chinese (See Appendix II, IIa), for the mothers was developed within the guidelines of the research committees. The research was conducted with full consideration of human rights (Munhall, 1988). Only adults over 18 years of age were included in the study. Prior to the conduction of individual interview, information regarding the purposes and objectives of the study was given and informed consent was obtained from the mother.

Prior to commencement of interviews, anonymity and confidentiality of both mothers and children were emphasized, and which were maintained throughout the study. Pseudonyms were used to identify participants and any other persons named in the interview such as nurses, doctors, relatives, friends and other disciplines or institutions. Participation in the study was voluntary. Mothers had every freedom to withdraw from or stop the interview at any time or refuse to answer any questions without penalty to the services they were receiving. Mothers were assured that they would have no bearing on the subsequent care their children if they chose not to participate the study or withdrew from the study. Every mother was given a fact sheet explicating the focus of the study and the rights as participants. The name and phone numbers of the researcher and the study supervisor were provided for the mothers in case they have any concern regarding the study.

Security precautions were taken to preserve privacy. The audiotapes were only be accessible by the researcher and would be kept in a locked cabinet for three years then erased after completion of the study. The transcripts and text was kept by the researcher and was only submitted to the supervisor of this study in the University during academic consultations.

During the interviews, the researcher was always aware of the possible psychological and emotional ramification on the participants. To avoid psychological effects that might inadvertently imposed onto the participants, the researcher acted according to the guidelines of humanistic communication proposed by Munhall (1994), and closely checked her interviewing skills, being an active listener, responding appropriately to what the participant had disclosed by not implying any judgment. The researcher would remain with the mothers when they showed emotional upset, until the crisis was over. In this study, one mother became submerged in her guilty feelings during the interview. The researcher turned off the tape recorder and stayed with her for another hour and resumed the role of a nurse and performed counseling until her emotions calmed down.

3. The Process of Hermeneutical-Phenomenological Reflecting and Transforming

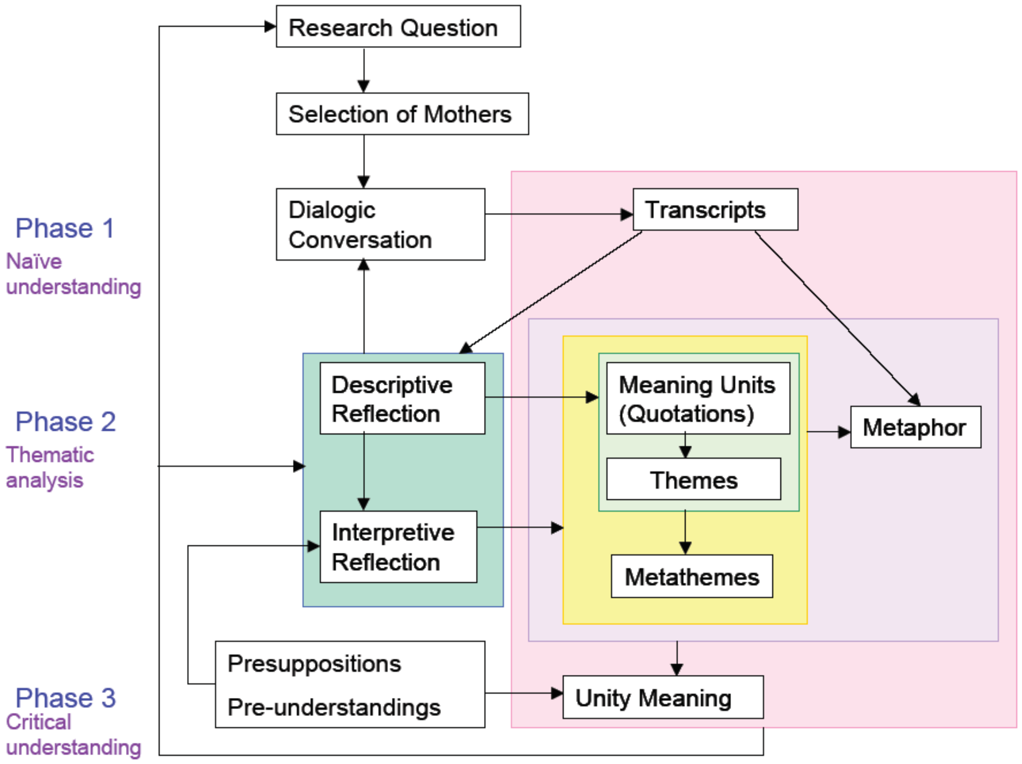
Reflection is the principle method of analysis for hermeneutic-phenomenology as phenomenological reflection enables the researcher to grasp the essential meaning of the phenomenon under study. For doing so, deep understanding and insight are required, involving “a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience (van Manen, 1990, p.77). The purpose of phenomenological reflection is to perceive the meanings of a phenomenon and to come to a reflective determination and explication of what that the phenomenon is.

As discussed in previous section, van Manen (1990) advocated that in his approach to doing phenomenological research, interpretation occurs through the deliberate act of describing aspects of experience in textual form. With an aim of grasping the essence, van Manen’s approach combines characteristics of descriptive and interpretive phenomenology. According to van Manen (1990), the methodological activities at various aspects in hermeneutic-phenomenological studies, including data collection and data analysis, occur intermittently or simultaneously.

According to Ray (1991), Hermeneutic-phenomenologic reflecting and transforming is a process in the flow of analysis, which begins with the researcher’s first encounter with the transcribed text. Engaging the first encounter, the phenomenon is described through reflecting and feeling the presence of the participants’ being in the researcher’s consciousness (Ray, 1991). The flow of analysis suggested by Ray (1991) includes:

- reflecting and feeling the presencing of the participants’ beings in one’s consciousness;
- transcribing the phenomenological data of the meaning of the art of nursing’ bracketed reflecting for a pure descriptive phenomenology;
- attending to the speaking of language in the texts;
- highlighting the descriptive experience of the art of nursing in the text;
- interpretive reflecting to reveal the immanent themes emerging from data;
- moving back and forth in understanding the meaning;

Figure 4.1: Cycle of Hermeneutic Analysis for this Study



- writing and transforming the themes in the transcribed text to create the metathemes which are linguistic abstractions of the themes;
- phenomenological reducing or intuiting; then composing linguistic transformation of data to theme, metathemes or metaphor which may be the transcendent experience.

As discussed previously, the process of nursing inquiry was not a lineal approach. Rather, the steps were intertwining with one another and occurred intermittently.

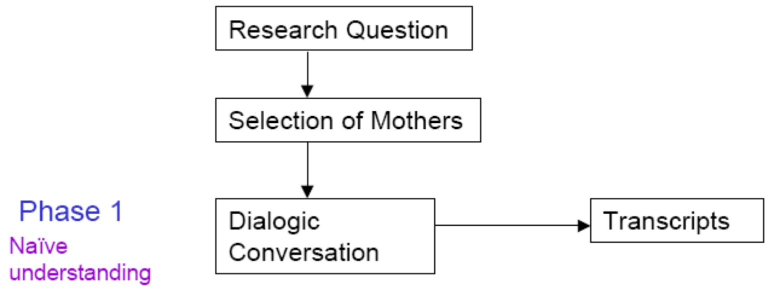
In congruence with Ray's (1991) process of analysis, this study followed through a cycle of hermeneutic analysis (See Figure 4.1 above). Integrating Ray's (1991) cycle of hermeneutic analysis into implementation, the researcher summarized the interpretative processes into three core phases: first phase of naïve understanding, second phase of thematic analysis with descriptive reflecting and interpretive reflecting, and third phase of critical understanding.

Naïve understanding.

The first phase aimed for a naïve understanding of the text and the each interview was read in an open-minded manner in order to gain an overall impression and a first grasp of the meaning of the text as the whole so as to obtain ideas for the forthcoming structural analysis (See Figure 4.2 below).

In the first phase of naïve understanding of this study, the researcher first listened closely to the spoken language recorded on audiotape after each interview and she performed the transcriptions verbatim line-by-line in Chinese with the supplementary information from the field notes that was made immediately after interviews. Then she read the transcripts while listening to the audiotapes again to recall the actual conversation and correct any errors in the written text. In the initial stages of data management each section of dialogue (question and answer) was arranged in numbered blocks and each line of interview transcript was

Figure 4.2: First Phase of the Hermeneutic Analysis – Naïve Understanding



numbered. The researcher then read each transcript several times in order to familiarize herself with the data. The researcher focused on the meanings that emerged, and wrote down any insights, hunches, and thoughts that came to mind during the readings. The researcher went back to the transcripts and highlighted the participants' language that illuminated their description of experiences**,** and wrote notes of meanings about these experiences in the margin of the transcripts. To preserve the essence of the meanings, all these writing and highlighting were conducted on the Chinese narrative text and the translation to English was performed only till after theme formation.

van Manen (1984, 1990) asserted that the experiences of the researcher are the ego-logical starting point for a phenomenological investigation. Reflectively sourcing his or her own experiences, the researcher contributes to his or her own orientation to the phenomenon, engaging him or her with the whole process in its various stages. van Manen (1990) wrote:

> In actual phenomenological description one often notices that the author "I"

> form or the “we” form. This is done not only to enhance the evocative value of a truth experiences expressed in this way, but also to show that the author recognizes that one’s own experiences are the possible experiences of others and that the experiences of others are the possible experiences of oneself (p.52).

Following each interview, the researcher treasured the journey back home as she took it as a period of preparation for re-entering her own world. During this journey, the researcher would jot a brief reminder of her observations and any occurrences during the interview, and her intuitive impression of the meaning of experiences, and this information would be compiled and put into the field notes. Things came to the mind of the researcher from all directions unstructured during the early readings.

The naïve understanding revealed that many aspects of the lives of the mothers of ELBW children were significantly affected by the ELBW children. The initial experience in the NICU and the subsequent transition from hospital to home, were some of the several conditions that made life difficult. The mothers were overwhelmed by the significantly small size of the ELBW children, and their lives were increasingly restricted by the time demanding child care such as feeding of the child. The birth of the ELBW children had altered the relationship between the mothers and the families. The mothers were living a different yet normal life while they endured the difficulties with their courage and positive perspectives.

The researcher was moved by the mothers' stories of being stigmatized and treated differently, being marginalized, and the tears that emerged as they told their stories.

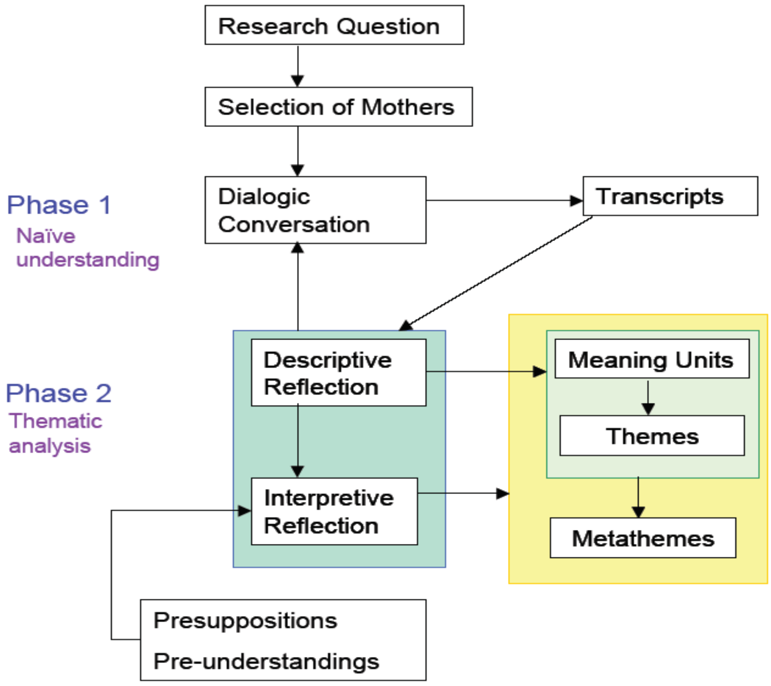
Thematic analysis.

As pointed out by van Manen (1990), thematic analysis is "fairly mechanical application of some frequency count or coding of selected terms in transcripts or texts, or some other break-down of the content of protocol or documentary material" (p.78). Thematic analysis is not a rule-bound process but a free act of "seeing". van Manen (1990) emphasized that, in phenomenology, it is lived experience that one is attempting to describe, and lived experience cannot be captured in conceptual abstractions. van Manen (1990) asserted:

> Ultimately the concept of theme is rather irrelevant and may be considered simply as a means to get at the notion we are addressing. Theme gives control and order to our research and writing (p.79).

van Manen (1990) pointed out that any lived experience description is an appropriate source for uncovering thematic aspects of the phenomenon it describe. He suggested three approaches toward isolating thematic aspects of a phenomenon, which include: the wholistic or sententious approach, the selective or highlighting approach, and the detailed or line-by-line approach. All these

Figure 4.3: Second Phase of the Hermeneutic Analysis – Thematic Analysis



should be used if possible to allow for a systematic reading and contemplating on the text, and leads to the isolating and identifying important or revealing statements.

The second phase of the analytic process in this study was the thematic analysis that composed of two levels, descriptive reflecting and interpretive reflecting (See Figure 4.3 above). The process was directed towards the structure of the text in order to gain an understanding of the text, through repeated readings of the texts in order to identify and discern ‘meaning units’ which would be condensed and organized into themes. The researcher conducted thematic structure analysis by moving back and forth between the whole and parts of the textual data employing van Manen's (1990) three approaches in thematic analysis, aiming for an understanding of the meanings while dialoguing with the data in consciousness.

In the wholistic reading approach, the researcher attended to the text as a whole and tried to identify the sententious phrase that might capture the fundamental meaning of the text as a whole. For example, in reading the following lived experience description of Qiao, one of the mothers in the study, the researcher could see that the mother was grieving with the loss of a health child:

> I thought it was unfair to the baby. He himself did not want it. If he understood what they said it would be miserable. "Why people can see and I cannot?" He can see now and…I will fix the eye for him first when we go out, so that we will not be pointed at. Not for the purpose of pretty, but at least…we don't have to hear something unpleasant. But his face will become asymmetrical gradually if he does not put it (prosthetic eye) on for long. However, it's painful to put it on. It hurts both when putting in on and taking it out. Also he will be in tears if draught blows on his eye… (5: 50. 1-5)

The mother sought for normalcy and she encountered both physical and emotional pain as she deal with the issues related to the developmental problem of the ELBW child. She tried to protect the child; she was thoughtful to the child's feeling and tried to treat the child fair. The researcher tried to formulate a statement to the meaning of the text as:

> The painful events for the children are reminders of the loss of a normal and healthy child for the mother.

As in the selective reading approach, the researcher listened to the tapes and read the transcripts again and again, attempting to look for statement(s) or phrase(s) that seemed particularly revealing the experience of extremely-low-birth-weight of the mothers. With the above description, examples are illustrated as follows:

"I thought it was unfair to the baby. He himself did not want it." – Mother needs to protect the rights of the child.

"Why people can see and I cannot?" – Mother seeks for normalcy.

"I will fix the eye for him first when we go out, so that we will not be pointed at." – Mother shares the harm imposing on the child and tries to prevent it.

In conduction of detailed reading, the researcher read through every single sentence or sentence cluster line-by-line and questioned for the meaning of experience being described in the sentence(s). With the above description, each sentence or sentence cluster was revealed for the meaning of experience as shown in the follows:

"I thought it was unfair to the baby. He himself did not want it. If he understood what they said it would be miserable." – shows how mother defends for her child and needs to have her child being treated with fairness.

"Why people can see and I cannot?" – Shows mother wants to seek normalcy.

"He can see now and…I will fix the eye for him first when we go out, so that we will not be pointed at. Not for the purpose of pretty, but at least…we don't have to hear something unpleasant." – Shows how mother tries to avoid stigmatizing views and words.

“But his face will become asymmetrical gradually if he does not put it (prosthetic eye) on for long. However, it’s painful to put it on. It hurts both when putting in on and taking it out. Also he will be in tears if draught blows on his eye…” – Shows how particular situations brings into the meaning of the experience.

In the process of hermeneutical-phenomenological reflecting and transforming, the notions of intentionality are still taken into account (Ray, 1991). Within this study, two distinctive levels of reflecting occurred, descriptive and interpretative.

a. Descriptive reflecting.

In phenomenological research, “it is imperative to stay close to experience as lived” (van Manen, 1984, p.56). van Manen emphasized that

> The point of phenomenological research is to “borrow” other people’s experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience (1984, p.55).

For phenomenological analysis, Ray (1990) required the researcher first give a linguistic description of the experience as it is written without causal explanations or interpretative generalizations. “The researcher follows the clues as the world of experience is opened up or disclosed, and records whatever comes into awareness as reflective analysis or thoughtfulness is practiced” (Ray, 1990, p.177).

In this study, through descriptive reflecting, the researcher read the transcripts of each mother's interview and any descriptive experience was highlighted, searching for an encompassing meaning that would reflect the whole of the text, a meaning that was not explicit but enveloped the experience. Meaning units transformed were written as closely as possible to the mothers' descriptions in the transcript, and were tagged along the lines of transcript. Because of the complexities of the human thought processes, certain lines of data overlapped and referred to more than one meaning unit. At this level of reflection, the researcher performed 'bracketed' reflecting to seek a pure descriptive phenomenological or receptive knowing in consciousness by setting aside her interpretive tendency in relation to her history and presuppositions about extremely-low-birth-weight (Ray, 1991).

b. Interpretive reflecting.

For van Manen, phenomenological reflection enables the researcher to grasp the essential meaning of the phenomenon under study. Emphasizing the creative, exploratory nature of phenomenological analysis, van Manen (1990) wrote:

> Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure – grasping and formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning (p.79).

According to van Manen (1990), linguistic transformation is not a mechanical procedure rather, it is a creative hermeneutic process through which the researcher is able to “create a text to which the themes, the fruit of the conversational relation are able to minister” (van Mane, 1990, p.100). It is a process in which the researcher captures the thematic statements in more phenomenologically sensitive paragraphs. “This is a process of writing notes and paragraphs on the basis of our reading and other research activities” (van Manen, 1984, p.61).

Interpretive reflecting is the process of hermeneutic thinking or unbracketed reflecting, that occurs to reveal the immanent themes within the language of the participants (Ray, 1991). This is the process to reveal the way the lived experience is described and is present to the researcher who, with deeper reflection and interpretation, transforms the themes to metathemes of experience, transforms the experience of individual into a more universal experience. In interpretive reflecting, the researcher’s preassumptions of the phenomenon, “the history or horizon of meaning of the researcher is brought into being in the dialectic of consciousness and the text” (Ray, 1991, p.186).

In interpretive reflecting, the researcher proceeded to an interpretation of the meanings. Unbracketed reflecting or interpretive reflecting is the foundation for hermeneutic phenomenological interpretation (Ray, 1991). It is through interpretive reflecting, the description of the lived world is revealed and presented. At this level of reflecting, rather than ‘bracketing’ her presuppositions in the experience of extremely-low-birth-weight, the researcher brought her historical understanding of meaning into being in the dialectic of consciousness and into the text. At this point of the analysis, the immanent themes emerged from the transcribed text within the language of the participants were written and transformed. Through a deeper reflection, these themes were transformed through interpretative reflection to universal metathemes which were the linguistic abstractions of the themes. It is through interpretative reflecting that individual experience is transformed into a more universal experience and the unity of meaning is revealed (Ray, 1991).

At this level of linguistic transformation, composing the transcripts of interviews and together with the researcher’s reflection to reveal the mothers’ experience, the researcher reconstructed the descriptive experiences into stories of the mothers. Through the use of narrative and reflection, the stories of mothers unfold to present the lived experience of the mothers. The mothers’ stories are presented as the sketches of their lived world, through which the readers are able to explore for deeper images of their lived world. The story of each mother has its own texture and its own meaning arise from the description of every day life. Each story leads to uncover the mother’s meaning of everyday life with ELBW child. Each story is unique with its own rhythm so that the readers can become aware of the personal events that create meaning within the lives of the mothers living with ELBW children.

The stories are contextualized to illuminate the richness of the mothers’ life experiences that offer a way to come close to human experience and transform the meaning into written text. In this report, the stories of the first five mothers recruited are presented. The story of the fifth mother is presented in the following chapter and the other four in Appendix V as examples for the use of reconstituted stories as a way of revealing the mother's experience.

Critical understanding.

In the third phase, the text was considered as a whole again to obtain a critical understanding. The presuppositions and pre-understanding of the researcher, the naïve reading, and the thematic analysis were all taken into account, and reflected upon. The process of interpretation is circular: the whole is understood by explaining parts, and the parts are included in the perception of the whole, in the presence of a dialectic between reflecting on the interview text and the literature.

The process of phenomenological analysis has no single form or stage, and is an iterative and cyclic process that takes place throughout the entire research endeavour from the first identification of the question to the last stage of writing. Lines of inquiry resulting from initial interpretations guided subsequent interviews and directed future sampling to provide deeper, richer understanding. In this study, for example, the initial interpretation of the narratives of the third mother (Jing) was different from those of the previous two informants as Jing articulated a great conflicting relationship with her in-laws and stressful experience regarding the difficult feeding of the ELBW child. Those interpretations were different from the interpretations that family relationship was positively maintained and childcare was well coped with as found for other informants. Assessment of the quality of mothers' relationships with their extended families and childcare in particular feeding were added as a new line of inquiry. This example illustrates the simultaneous process of interviewing, observing, identifying lines of inquiry, and interpreting.

"Writing is a reflexive activity that involves the totality of our physical and mental being" (van Manen, 1990, p.132). van Manen (1990) also suggested:

> To be able to justice to the fullness and ambiguity of the experience of life world, writing may turn into a complex process of rewriting (re-thinking, reflecting, re-cognizing) (p.131).

The researcher conducted the interpretative process through writing and rewriting of the summaries of central concerns and themes of each mother's story. From the summaries, exemplars emerged as significant excerpts characterizing specific common themes or meanings among the mothers, as these would be parts of stories or instances bearing similar meanings within other mothers' stories. For example in this study, once the theme of "self blaming" was identified as an exemplar from the fourth mother's (Feng) story, "self blaming" began to be recognized in other mothers' stories as well.

Emergence of themes and metathemes.

van Manen (1984) emphasized there is no conceptual formulation or a single statement can possibly capture the full mystery of a person's lived experience. He wrote:

> So, a phenomenological theme is much less a singular statement (concept or category) than an actual description of the structure of a lived experience. As such, a so-called thematic phrase does not do justice to the fullness of the life of a phenomenon. A thematic phrase only serves to point at, to allude to, or to hint at, an aspect of the phenomenon (1984, p.60).

In this study, the researcher, through interpretive reflection and insights, reconstituted the descriptive experiences of each mother into a story that reflected the lived experience of extremely-low-birth-weight for the mother. The writing of stories came out of reflections on the conversations, and the words in the stories belong to the mothers. The stories of the first six of mothers are presented as examples for the use of reconstituted stories as a way of revealing the mother’s experience. The story of the fifth mother, Qiao, is presented in following chapter on research findings and the other five stories of mothers are presented in Appendix V.

During this reflecting process, the researcher read the stories as a whole and identified the central concerns, important themes or meanings that were unfolding for individual informants. During the reading of stories as a whole, it was apparent that each story described a particular theme that came from the story itself. Nevertheless, the themes were discovered during the writing of the stories. Through further reflection, relationships between each mother’s descriptions of experiences were explored, and the commonalities between themes were revealed among all the stories in this study. Themes revealed in the reflection became the focal points, the commonalities of experience derived from the researcher’s reflective process of hermeneutic phenomenological interpretation. These themes became “the knots in the webs of our experiences, around which certain lived experiences are spun and thus lived through as meaningful wholes (van Manen, 1990).

Through a deeper reflection on the stories and text, the themes were linguistically transformed into metathemes of the experience, which were the linguistic abstractions of the themes. The researcher went through this interpretative process by moving back and forth between stories of mother and text, and a dialectic with other literature and philosophical writings. At this process, the work of other scholars could become a source of knowledge for the researcher. “Bracketed” experience or knowledge became “unbracketed” to advance phenomenological description and interpretation to phenomenological theory (Ray, 1990). According to van Manen (1984), themes that emerged are the threads that weave the experience together. To organize the writing, the themes were then woven into the description of the metathemes so to reveal a picture of the transcendent experience.

In this study, themes emerged regarding the mothers' life world of ongoing uncertainty as a sense of "lived time" and "transforming the experience through each day of life" were further transcended as the metatheme "living with uncertainty" as related to lived experience of changing in temporal. Through writing and rewriting, themes and metathemes were transformed more fully into a linguistic interpretation of the experience.

Phenomenological intuiting.

According to Ray (1991), phenomenological intuiting is a process of turning of nature of the meaning of the phenomenon by grasping the unity of meaning as a direct, unmediated apprehension of the whole of the experience. Ray (1991) also refers that a transcendent experience of knowing occurs when the researcher makes a connecting leap of insight and the separateness of phenomenon melds into a whole. "The universal is reached by a 'coming together' of the variations. Thus, variations or similarities of the experience are intuitively and authentically grasped and constituted in consciousness, the primordial material of sensation of which arises the knowing of the meaning of experience" (Ray, 1991, p.186).

In phenomenological intuiting, the researcher's personal efforts, experiences, and insights are the central means for examining the phenomenon under study and arriving at moments of disclosure whereby the phenomenon reveals something about itself in a new or fuller way. Phenomenological intuiting is rarely a single moment of revelation but is a rather gradual and unpredictable process (Seamon, n.d.). Phenomenological intuiting occurs at any time during the analysis in terms of a flow, or of a cycling and spiraling motion that has no clearly distinguishable steps or phases and a researcher may not recognize when and where this flow begins but only knows that the seed of “analysis” is already planted at his or her first data collection session (Seamon, n.d.).

“Reflecting on the data leads by the process of intuition to the apprehension of the gestalt, the universal essence, or the unity of meaning that can often occur prior to the completion of thematic analysis” (Ray, 1990, p.178). For this study, the process of phenomenological intuiting started right from the beginning and continued throughout the whole process of the research. In this study, several mothers described their life with extremely-low-birth-weight as a journey with unknown pitfalls one after another ahead. The mothers expressed the view that one would not know what follow the present crisis. Many themes were apparent in the descriptions of the journey such as themes of uncertainty, acquainting and adapting, and relationships. As these themes emerged, the researcher looked for similarities among mothers and grouped themes together as meaning structures. Thus the mothers’ metaphor of “Surmounting barriers one after one along the long journey” was recognized during reflection and multiple readings of the stories. In constituting the metaphor, the researcher stayed as close to the participant’s language as possible.

To possess the character of intuition, one can arrive at knowledge that grasps the ideal (essential image) or the unity of meaning, as intuition relates to the mode of awareness in which the object intended by it, does not only have meaning but is originally given in consciousness (Ray, 1990). In “keeping eyes open” through looking and listening (Spiegelberg, 1982), the researcher sought to further widen the metaphor “Surmounting barriers along the long journey” emerged from the experience of mothers to a unity of meaning in a new or fuller way – the meaning of life. Within the context of the researcher’s interpretation and insight, a unity of meaning of the experience expressed as “A Meaning of Life: Each Day A New Day**”** was revealed, which was recognized as a coming together of the variations and similarities of the experience, intuitively and authentically grasped and constituted by the researcher.

4. From Phenomenological-Hermeneutical Theorizing to a Theory of Meaning

A theory of meaning, emerging in the form of structure of the phenomenological meaning, is constituted by the descriptions, themes, metathemes, metaphors and transcendent unity of meaning (Ray, 1991). The movement from phenomenological-hermeneutical theorizing (interpreting) to a theory of meaning takes on the form of narrative, illustrating all the dimensions of the experience. The idea of theory in this sense is a way of giving form to the intentional acts of the research itself, where the researcher communicates to the world the integrality of understanding the aesthetic act itself. Theory in this sense aims at making explicit the universal meaning of the whole of the experience (Ray, 1991).

In this study, through thoughtful reflection on the descriptions, themes, metathemes, metaphor and the unity of meaning, the experience was fixed in time and transformed into the theory of meaning for mothers living with extremely-low-birth-weight as “A Meaning of Life: Each Day Another Day**”**. This theory of meaning is interpreted through a dialogic-dialectic process of the researcher and text as part of the reflection process, relating extremely-low-birth-weight as a human condition that becomes a way of life for mothers. Through the theory of meaning we come to understand fully the meaning of extremely-low-birth-weight for the mothers.

5. Dialogue with Written Text: Examining Similarities and Differences

Relating the themes and metathemes to literary writings in nursing and philosophy develops further insights for the researcher. This process gives the themes, metathemes, metaphor, and unity of meaning value in relation to existing theories and literary works, and subsequently suggests the implications and recommendations for nursing education, practice and research (Ray, 1991).

For the phenomenologist, the source of all work is the experiential life world of human beings (van Manen, 1990). In phenomenological writing, van Manen (1984) advocated collecting thematic descriptions from artistic sources as he wrote:

> A genuine artistic expression is not just representational or imitational of some event in the world. Rather, it transcends the experiential work in an act of reflective existence. An artistic text differs from the text of everyday talking and acting in that it is always arrived at in a reflective mood. In other words, the artist creates experience by transcending them (p.62).

The present researcher used texts in nursing, philosophy and literature to illuminate the richness of the themes, metathemes, metaphor and unity of meaning as descriptions and interpretations of the experience. Through a dialectic with these texts, a deeper meaning was revealed. Texts in nursing, philosophy and literature were subsequently used for nursing implications and recommendations. A dialectic was developed between existing knowledge and the meaning derived from this study concerning the experience of living with ELBW children.

6. Credibility of the Process of Hermeneutic Phenomenology

Although qualitative research is often criticized for appearing to be subjective, without demonstrable reliability and validity; methods have been devised to test these factors and so to ensure that these studies do attain credibility in traditionally quantitatively oriented circles (Altheide & Johnson, 1994; Appleton, 1995; Guba & Lincoln, 1989; Morse, 1991). In addressing the methodological rigor and maintaining the credibility of this study, the researcher made reference to Leininger’s (1994a) three criteria which are used heavily in supporting and substantiating phenomenology and hermeneutic studies, and they are namely credibility, saturation and meanings-in-context.

According to Leininger (1994a), credibility refers to the “truth” value, or “believability” of the findings that have been established by the researcher through observation, engagement or participation with informants.

> Credibility refers to the truth as known, experienced, or deeply felt by the people being studied (emic or local) and interpreted from the findings with co-participant evidence as the “real world”, or the truth in reality (this includes subjective, intersubjective, and objective realities) (Leininger, 1994a, p.105).

Since the researcher's etic (outsider's) views may be different, Leininger (1994a) suggested researcher keep in mind that “the informants are the primary gatekeepers and the researcher is the second gatekeeper” (p.108) for information and to substantiate findings.

In this study, all interviews were audio-taped and transcribed verbatim to preserve the richness of the information and allow for subsequent review. The researcher completed the field notes immediately after each interview to increase self awareness and provide information for subsequent reflection. Recognizing, believing and acknowledging are the dynamics of credibility (Ray, 1991) in this hermeneutic phenomenological research. The phenomenological evidence of the reality-as-meant has been affirmed as that which has been lived and communicated by the mothers. The researcher is endeavor to fulfill the ethical imperative to be true to, and to respect, the mothers' lived worlds and realities (Saukko, 2003).

To gain credibility, the reconstructed stories were discussed with five mothers for their comments. One mother (Yu) said:

> I don't have any comment and what you have told me is exactly the truth. She (the ELBW girl) is still that small and I am still concerned with her slow picking up of size.

Another mother (Shu) expressed her concordant comment:

> It was really an extraordinary experience and you have given a true description. In fact, we should see thing in an optimistic way and "look at the good side" of it. Yes, he (the ELBW boy) is getting close to normal level, though he is still smaller in size.

Credibility is achieved when the mothers, who have had the experience in study, recognize and acknowledge the researcher's interpretation of the experience.

Saturation is another criteria suggested by Leininger (1994a) for phenomenological studies. Saturation refers to “the full 'taking of occurrences' or the full immersion into phenomena in order to know it as fully, comprehensively, and thoroughly as possible” (Leininger, 1994a, p.106). It requires the researcher to have an exhaustive exploration of whatever phenomenon is being studied. The researcher needs to know fully whatever has been observed, presented or discovered by obtaining dense and thick (that is in depth and breadth) data. Saturation is achieved when the researcher finds no further explanation, interpretation, or description of the phenomenon under study by informants. In this study, as discussed in previous section on ***Selection of participants,*** saturation has been achieved with a total of twelve mothers recruited.

Meaning-in-context is the third criterion for rigor to be considered in qualitative research. According to Leininger (1991, 1994a, 1994b, 1995), meaning-in-context refers that the data become understandable with relevant meanings to the informants within their familiar and natural living and environmental context. To meet this criterion, the researcher has to understand the situations and activities described and be able to transfer them into a wider context. In this study, the researcher’s former clinical knowledge and experience in neonatal and paediatric nursing enabled her to find the meaning in the context. The researcher also made a special effort to keep the information given by informants unchanged. In considering the issue of translation on the rigor of the research process in phenomenological research, where understanding the essence of the phenomenon from the informants' perspective is the fundamental purpose of the phenomenological research design (Twinn, 1997), the researcher in this study carried out all transcriptions and translations herself who was also the interviewer. Thematic analysis was conducted with the original interview scripts in Chinese (spoken Cantonese). Translation into English was not done till preparation to thesis to preserve the essence of meanings.

In applying methodological rigor to this study, the researcher also addressed to the traditionally terms used in qualitative studies, including applicability, consistency and neutrality (Guba & Lincoln 1989, Sandelowski 1986).

Applicability in qualitative terms is related to external validity in quantitative research. Guba and Lincoln (1989) suggested that the idea of 'fittingness' is a more appropriate term in evaluating qualitative research. A qualitative study whose findings “fit”(Guba & Lincoln 1989) contexts outside the current research study situation can be described as having fittingness. This is further supported when readers view the study findings “as meaningful and applicable in terms of their own experiences” (Sandelowski 1986). Leininger (1994a) also stated that the researcher mentor is invaluable for developing and perfecting the skills of the researcher and for arriving at credible interpretations. In this phenomenological study, specific strategies have been identified for ensuring the applicability and credibility. For this study, the transcripts of the first three interviews and the themes identified were submitted to the academic supervisor for review and discussion till consensus was gained. Furthermore, six reconstructed stories with mothers' narratives in both English and Chinese were shared with two experienced nurses in the neonatal care unit, who were invited to read the stories and to identify emergent themes independently. Findings were compared with those of the researcher. In general, majority of the themes identified by the reviewers matched with those interpreted by the researcher. Discrepancies were mostly related to the use of different vocabulary and agreement could be reached after discussion. Interim findings and reports were also shared with peers in the local neonatal / paediatric scientific meetings and overseas research conferences and positive feedbacks were expressed upon the emergent ideas and implications for future practice.

In qualitative studies, reliability is referred as the consistency, repeatability, replicability or stability of a study in terms of the clarity and accuracy of the final research report (Guba & Lincoln 1989, Powers & Knapp 1990). Qualitative research "emphasizes the uniqueness of human situations and the importance of experiences that are not necessarily accessible to validation through the sense" (Sandelowski, 1986). The "concept of auditability" Guba and Lincoln (1989) was proposed to be the measure of consistency in qualitative research studies. It is suggested that a study and its findings are auditable when another researcher can clearly follow the "decision trail" (Koch, 1993) used by the investigator in the study. In this study, interview was used in to explore in depth the meaning of experience and to gain qualitative data; thus the interviewer/researcher was the data-gathering instrument. The reliability of the data elicited is therefore dependent upon the competency and ability of the researcher's interviewing skills and on any researcher bias (Field & Morse 1985). In this study, to increase reliability and consistency, the researcher conducted a pilot study to develop interviewing competence and an interview guide with leading question and prompting questions. The interview guide developed after the pilot study was reviewed for its content by three experts in the field. One was the academic supervisor of the study who was experienced in qualitative studies and had interest in understanding and providing psychosocial support to the mothers. Another expert was a clinical psychologist who was currently working in the hospital and the third was an experienced neonatal nurse who had been working in the field for more than twenty years. These experts offered help in vetting the interview guide to ensure its face validity. All interviews were audio-taped and transcribed verbatim to preserve the richness of the information and allow for subsequent review. This research report was written with a view to allowing the reader sufficient detail and information to check the “decision trail”.

Finally, confirmability is suggested as the criterion of neutrality in qualitative research (Guba & Lincolns, 1989), which requires the researcher to show the way in which interpretations have been arrived at through the inquire. According to Guba and Lincoln (1989), confirmability is established when credibility, applicability and consistency are achieved. Sandelowski (1986) argued that “auditability” is achieved when the researcher leaves a clear “decision trail” concerning the study from its beginning to its end. In this study, auditability has been attempted by the researcher clearly describing each stage of the research process, explaining and justifying what was done and why.

Summary

This research was an articulation of the researcher's description and interpretation insights about the experience of mothers living with extremely-low-birth-weight. In adopting a hermeneutic-phenomenological approach, the researcher of this study attempted to capture a phenomenological writing to bring to the language, the themes and metathemes in such an aesthetic way that the essence or lived meaning of the experiences would show itself. Given the aim to preserve the "subjectivity" of the experience of the mother, considerations were made to ensure interpretation would not be affected with presumptions and pre-understandings.

Aiming to facilitate trustworthiness and establish rapport with mothers, deliberations were made in creating a dialogic conversation instead of a one-way question-and-answer session so as to allow for expression of feelings and emotions in a more intimate manner. In considering data collection and analysis as an iterative process, information collection and reflection were performed almost in parallel. Ethical consideration in research process was an important concern of the researcher, who paid constant attention to respecting the rights of participants and ensuring there would be no harm, such as psychological stress, imposed.

The experience of living with ELBW children was captured in the stories and through the descriptive reflections and interpretative thematic analysis (van Manen, 1990), the process of interpretation through reflection within the process of hermeneutic circle. Quotations from the mothers were used to allow readers to follow the interpretative process in a more fully manner. This interpretative process will unfold in subsequent chapters.

CHAPTER 5

Report of Findings

Introduction

“Language is a central concern in phenomenological research because responsive-reflective writing is the very activity of doing phenomenology” (van Manen, 1990, p. 132). van Manen (1990) wrote:

> Phenomenology, like poetry, intends to be silent as it speaks. It wants to be implicit as it explicates (p.131)

In phenomenology writing, the quality is more important than the quantity. Sometimes it is better to remain silent than to speak or write. “Instead of committing the sin of ‘overwriting’ it is sometimes more important to leave things unsaid (van Manen, 1990, p.113). As asserted by van Manen (1990), the phenomenology writer would experience the unspeakable or ineffable life that might be beyond his or her linguistic competence. Hence, in such situations, borrowing words from other persons with verbal talent, such as a thoughtful poet, a philosopher or an author or fiction, would be helpful in phenomenological writing (van Manen, 1990). In both writing and reading phenomenology, the person needs to be sensitively attentive to the silence around the words by means of which he or she attempts to disclose the deep meaning the world (van Manen, 1990).

Although the phenomenological researcher is under no obligation to adopt any particular structure for phenomenological writing, van Manen (1984, 1990) suggested examples of ways to structure the writing, which may be used in combination with each other:

- ✧ Thematically, where the writing is organized around themes elicited from the data;
- ✧ Analytically, where the writing is conducted following the analytical procedures discussed in Chapter Four;
- ✧ Exemplicatively, where after the essential structure of the phenomenon is explicated, examples are employed to fill out and expand the initial description;
- ✧ Existentially, where the writing is wound about the existential notions of temporality (lived time), spatiality (lived space), corporeality (lived body) and communality (lived relationship);
- ✧ Exegetically, where the writing is arranged in a dialectical relationship with another phenomenological writer.

The report of findings of this study is written in a combination of exemplicative and existential structure of writing as suggested by van Manen (1984, 1990).

In this chapter, an exploration of the mother’s experience of living with an ELBW child will illuminate the themes and metathemes central to this experience, which unfold in the subsequent sections of the chapter. This chapter provides a brief description of the demographic characteristics of the twelve mothers in this study.

The story of one of the mothers, mother Qiao, is presented to demonstrate the use of reconstructed story as a way of revealing the mother’s experience of extremely-low-birth-weight.

To follow, each metatheme is described and illustrated with themes and excerpts from narratives. The presentation of narrative is organized in a pattern to reveal the findings through the processes of descriptive and interpretive reflections (Ray, 1991; van Manen, 1990) as discussed in Chapter Four. To organize the writing exemplicatively and existentially, each metatheme is introduced as a central heading, then the themes related to the metatheme are indicated as subheadings. Firstly, the “Descriptive Reflection” is the descriptive reflecting of the meaning of experience from the perspective of mothers, which provides a way of thinking on the thematic structures yielded from the experience. Exemplars of actual excerpts from the mothers’ descriptive experience introducing the perspectives of the mother are presented. Secondly, the “Interpretive Reflection” reveals a deeper understanding of the meaning through a dialogue with literature, reflection and writing performed in the interpretive reflecting process. Through this second interpretive reflection, the themes and metathemes are searched through in a questioning way.

Together with the themes and metathemes central to this experience of extremely-low-birth-weight, a journey of life along which twists and turns, and barriers and pitfalls are envisioned. The metaphor revealed by mothers strongly speaks about the way that mothers live their life as a long journey. Reflecting of themes, metathemes and the metaphor, the unity of meaning for the experience of mothers living with extremely-low-birth-weight is phenomenologically revealed.

Demographics of the Mothers

In the study, twelve mothers were recruited. Of the twelve conversations with mothers, ten were conducted at their homes and two were at their working place by their preference. All mothers were invited to narrate their own stories and experiences with extremely-low-birth-weight regarding to their feelings, emotions and responses to the events after the birth of the child throughout the years. Demographic information of mothers was briefly sought during interviews. A brief summary of the background and demographic characteristics of the mothers and the ELBW children is presented in Table 5.1 and Table 5.2 respectively.

Brief summary of the background and characteristics of the mothers

The mothers were aged from thirty-two to forty-five at the time of interview and most of them had completed secondary education in Hong Kong (See Table 5.1 below). All the mothers were citizens in Hong Kong, two of them came from Taiwan and one from Mainland China after marriage. All the mothers were

Table 5.1: Summary of characteristics of the mothers at the time of the interview

	Mother					
No.	Pseudo-name	Age	Occupation	Marital Status	Family members (including the ELBW child)	Remarks
1.	Pei	38	House wife	Married	Husband, 2 daughters	
2.	Rui	41	House wife	Married	Husband, 2 sons	
3.	Jing	32	House wife	Married Came from Taiwan after married	Husband, 1 son, 1 daughter	
4.	Feng	40	Clerical in private firm	Married	Husband, 1 daughter	Child care supported by child's paternal grandparents
5.	Qiao	44	Licensed property consultant (Self-run business)	Not 'registered' marriage	2 sons	Child care supported by domestic helper)
6.	Bao	35	Housewife	Married Came from Taiwan after married	Husband, 1 son	
7.	Yu	45	Housewife	Married	Husband, 3 daughters	
8.	Di	41	Textile wholesaler (Family business)	Married Came from Mainland China after married	Husband, 1 son, 1 daughter	Child care assisted by paternal aunt
9.	Wei	42	Accounting in private firm	Married	Husband, 1 son, 1 daughter	Child care supported by domestic helper
10.	Shu	40	Housewife	Married	Husband, 1 son	Stopped working after the child was born
11.	Ni	41	Housewife	Married	Husband, 2 daughter	Stop being baby sitter after the child was born
12.	Xiao	37	Clerical in Bank	Married	Husband, 1 son	Child care supported by domestic helper

Table 5.2: Summary of characteristics of the ELBW children at the time of the interview

Mother		**Child**					
No.	Pseudo-name	Age	Sex	Birth Wt (Gm)	Gestation	Siblings	Remarks
1.	Pei	2yr8mon	F	930	27 wk	1 sister (7 yrs)	
2.	Rui	4yr10mon	M	680	24 wk	1 brother (10yrs)	Coordination problems with fine muscles
3.	Jing	3yr6mon	M	700	26wk	1 sister (3 months) Twin brother died at neonatal	Asymptomatic vascular tumor in brain
4.	Feng	5yr4mon	F	670	26wk		Visible physical disabilities – loss of fingers of right hand, hearing and visual weakness requiring aids
5.	Qiao	4yr5mon	M	623	23wk 5dy	1 brother (19yrs)	Visible physical disabilities – loss of one eye with prosthesis, unsteady walking gait, neurological developmental problem
6.	Bao	3yr1mon	M	987	31wk		Potential asthmatic problem
7.	Yu	3yr1mon	F	894	29wk 3dy	2 sisters (18 to 20 yrs)	
8.	Di	4yr	F	720	28wk	1 twin brother	
9.	Wei	4yr	F	676	24wk	1 brother (18yrs)	
10.	Shu	4yr10mon	M	991	24wk		Closed colostomy
11.	Ni	3yr11mon	F	721	25wk 6dy	1 sister (20 yrs)	Closed colostomy
12.	Xiao	4yr7mon	M	940	27wk		Chronic constipation

married and were living with the husband except one who did not had a registered marriage and was living with her elder son and the ELBW child. Seven mothers were housewives, looking after their children full-time and the other mothers were working mothers. For the seven “full-time” mothers, two of them resigned from their jobs and one suspended her part-time job and chose to stay home for child care after the birth of their ELBW children. For the working mothers, three were supported by foreign domestic helpers and two were supported by the paternal grandparents or paternal aunt of the ELBW child in child care.

Hong Kong is geographically divided into eighteen districts. Providing health care services to the citizens in these districts are the twelve private hospitals and the forty-one public hospitals or institutions in the seven clusters of the Hospital Authority. The twelve mothers in this study were geographical distributed in nine different districts around the setting under study. Four of them were referred from the hospitals in other clusters of the Hospital Authority because of inadequate neonatal intensive service in the respective clusters, and two were referred from private hospitals. Two mothers were admitted to hospital by ambulance, and one of them delivered the ELBW baby at home. Most of the mothers experienced the sudden onset of premature labor, except for four whose early delivery was expected. Three premature deliveries were due to the physical complications during pregnancy of mothers, one was due to twin pregnancy and one was due to both maternal condition and twin pregnancy.

As for the children, six were girls and six were boys aged from two years 8 months to five years four months (See Table 5.2 above). Their gestational age ranged from 23 to 31 weeks. Six of them were the first child of the family, five were the second and one was the third. For the six ELBW children who had elder siblings, four of them had sisters or brothers aged eighteen years or above. Among the twelve ELBW children, two of them had visible physiological disabilities. One of them had hearing and visual weakness requiring aids and loss of fingers of right hand, and another one had unsteady walking gait, neurological developmental problem and loss of one eye requiring prosthesis. Eleven ELBW children were undertaking pre-primary education and one ELBW girl would be entering nursery in the coming months.

Stories of Mothers

Stories of mothers were reconstituted from the transcripts of interviews and together with the researcher's reflection to reveal the mothers' experience. Through the use of narrative and reflection, the stories of mothers unfold to present the lived experience of the mothers. The mothers' stories are presented as the sketches of their lived world, through which the readers are able to explore for deeper images of their lived world. Each story has its own texture and its own meaning arise from the description of every day life. Each story leads to uncover the mother's meaning of everyday life with ELBW child. Each story is unique with its own tempo so that the readers can become aware of the personal events that create meaning within the lives of the mothers living with ELBW children.

The stories are contextualized to illuminate the richness of the mothers' life experiences that offer a way to come close to human experience and transform the meaning into written text (Bergum, 1989). Descriptive themes derived from the stories are further reflected upon and the meaning of experience is linguistically transformed into the metathemes. The stories of the first six of mothers are presented as examples for the use of reconstituted stories as a way of revealing the mother's experience. The story of the fifth mother, Qiao, is presented in following session, in which most of the features of mothers' experience revealed are unfolded. The other five stories of mothers are presented in Appendix V.

Story of Mother Qiao

> *"Compared with the happiness now, life at three years ago was really… just like having a nightmare…Very frightened, but not knowing for what. I could not tell, could not tell in words. I could only describe that it was just like a rubber band being stretched so hard that it was going to split at any time. Very frightened and shaken, but not knowing for what. It was really helpless." Qiao said. (5: 76. 20-21, 102. 15-17)*

When the researcher met Qiao three days before the interview in the outpatient clinic, she was ready to talk right there. As requested by Qiao, the interview was held early in the morning in her office to minimize interruption and she even closed up her office temporarily during the conversation. She could not wait to start while the researcher was doing the introduction. During the dialogue, she cut short the occasional phone calls and resumed the conversation immediately.

Qiao was a working mother who was a licensed property consultant and running an agency on her own. Qiao was born in China and came to Hong Kong after secondary education. She ‘married’ (without registration) her husband when she was young. She was living with her two sons and both of them were bearing Qiao’s surname. The elder son was nineteen years old and was studying in university and the second son was Feng-xiao, the ELBW boy.

Feng-xiao was born prematurely with birth weight 623gram. He had stayed in the hospital for four months after birth. He had lost the sight in one eye and he had muscle weakness of both lower limbs and was using stabilizing splints for walking.

Recalling her painful experience with ELBW child in the early days, Qiao said, “Compared with the happiness now, three years ago it was really, just like having a nightmare…Those feelings of worried…nobody could help. You bore the worries by yourselves, inside your heart, (others) could not help anything… it was not describable… The most miserable was, after delivering the baby; I was at home, unable to sleep. The heart was like a stretched rubber band that was going to split. I was not sure if it was so called depression. When I went for a doctor and he said ‘It was depression after delivery, but you had a reason to be depressed.’ ...” (5: 76. 20-21; 102. 9-12)

The first sight on the baby was striking and unforgettable to Qiao. “I could see that…he was dark (in color), ‘sunbathing’ under those lights (phototherapy). You know…those newly born baby…dark and hairy. ‘Oh, is that my son? …Or is he the son of some Indian?’…So dark he was. It was dark and tiny. Just like…just like…now when I go to the market I dare not look at those skinless toads. He had flesh on the thighs only; all the rest of the body was bony. I was scared seeing that.” (5: 94. 6-8)

It was frustrating for Qiao to face all the uncertainties ahead. “At first, I did not accept what the doctors said. It was unreasonable. When you said that everything would not be viable, why did you save him? ‘His eyes were not all right’, said the doctor… and the next day he (the doctor) said, ‘He might have to take an oxygen bag with him to school, or he might have to use crutches.’ So, no one single thing would be good. So talking about that…everything, then I would cry after returning from hospital.” (5: 8. 9-11)

Taking the child back home was happy but the frustrations were unexpected. “When it’s time to leave the hospital, I was longing he would home sooner, but I was worried too. Could I manage at home? If I could not manage, would I waste others’ effort (in saving his life)? … However, I really wanted him to return home. I wanted him return home and did not want him to stay there (hospital) any longer. It had been too long … almost half a year…” (5: 96. 1-3)

Qiao realized that it would be a different story having the child at home taken care all by her. “The most difficult was when he was discharged home. Because when he was in the hospital, there were adequate monitors. He was being looked after by nurses at night and I could go home and sleep. But it was completely different when he returned home. It was I who had to take care of him day and night.” (5: 4. 1-2)

“It was different in the hospital because he got tube feeding there. If I was not there…even I was there, they did not use the bottle to feed. He was quite fat when he was there. After he returned home, he became thinner and thinner and I was very upset…After leaving the hospital and being taken care by me, he became thinner and thinner…getting thinner because he would not eat and also he threw up.” (5: 4. 7-8; 64. 4-5)

Qiao had gone through a transitional process to adapt her roles at home. She recognized that hospital practice were not transferable to home setting. “Very busy, say going to the child care center because he had to complete the vaccinations. And it was Chinese New Year. I rushed him out from the hospital for the New Year. I did not want him to stay in the hospital during the New Year. Then…I tried to simulate what had been doing in the hospital…I would bathe him both in the morning and in the evening. Later when we went for follow up the doctor said, ‘It’s not necessary. You don’t have to do the bathing early in the morning. That was just the schedule in the ward to fit the nursing routines’…” (5: 98. 1-4)

Qiao had to maintain high vigilance to watch out for the child’s health “At night time, I would not dare…not dare to have a proper sleep. During the early days when he was back from hospital, I had to get up at night to check if the tube (oxygen) was not displaced. And also that monitor (oximeter to monitor the oxygen level in capillary circulation)…let me see…I did not keep the monitor. They offered me the monitor at first but later they said it was not necessary, because he had ninety something (the percentage of oxygen concentration). So it was too bad because you had nothing to refer to, and you had to watch if there was (breathing)…I was afraid that the oxygen tube would be dislodged. Because he could not talk and he did not cry, you know. Because if it was dislodged….I had once seen him turning all black in the hospital when the tube was displaced. I was so scared….” (5: 78. 1-4; 80. 1-3)

Qiao even modified her living pattern to suit the child’s need. “I had once thought what I should do if he got fever. The thought just came up to my mind at that time. I used to live in those old building (without elevator but only very straight staircase) in Kowloon City. I purposely moved to this present place where there was elevator. I was afraid if we had to go to the emergency department late in the midnight... Lucky that there was no such happening. Just for one time that he had fever during daytime and had to stay in hospital for more than ten days. Yet it was because I was just worried and brought him to there myself.” (5: 42. 1-4)

To Qiao, feeding the extremely low birth weight child was a series of never ending frustrating tasks. “He would vomit in the midnight. Once after he had finished the milk… not knowing whether it was because I did not burp him properly or what. I was afraid that if I burp him he would throw up and waste the feeding, and then I did not do the burping. I just held him, and then he would belch and throw up. Almost all…in the flat where we live in the past …all the ‘four walls and eight corners (四面八方)’ had been splashed with his vomit… every corner. It was very miserable. Yet, I was afraid that he had not (eaten) enough, on the other hand also afraid that he would vomit…I would feed him again after he vomited…” (5: 4. 3-6)

“Vomit, after vomit you had to clean up. After cleaning up, you had to wash the clothing. But you could not put them in the machine, and you had to wash by hands. It was not the question of waste….I did not know…might be I was too anxious and other people would be different. He vomited, and then he ate. Later when he had porridge, then orange juice and this and that. Sometimes he, I thought he might get scared of eating. His mouth…and he always had to take medicine, and vitamins and this and that. He himself might get frightened of eating and he did not even open his mouth. He would not open up (the mouth) ….You see…how miserable when I was also afraid that he would be starved (if he did not eat after vomiting)…” (5: 44. 1-6)

Qiao recognized that her role and responsibilities of motherhood was non-transferable. She recalled the typical event. “No, no one could help, absolutely not. …I had once asked people to take care of him. ‘I am tired of taking care of him! Find someone to look after him.’ Somebody introduced me a helper who lived in Sau Mau Ping over that side. All at one time, I brought the cot, napkin and clothing to her place. I said when I got there ‘You take care of my son for me, I’ll pay you five thousand dollar net wages a month.’ I was willing to pay. I said ‘I am really tired and miserable.’ I had been really desperate for a period of time, very miserable and helpless. That person was kind, and was not working. She had a son studying in university, who also had lost sight of one eye. So, there should not be any discrimination and I was confident to let her care my son. But he (my son), after getting there, kept crying for entirely three hours. She then phoned me ‘Please come, I can’t manage. He cries and cries for three hours entirely.’ I had just returned home for three hours and he was there crying for three hours. I had not slept for several days already so I said ‘I do not take him, please let me sleep.’ Then she took him back to my home, with money, clothing and the cot. She brought all things back at one time by taxi. Then I knew that no one could manage him. There would be no one. Employing someone at home to care him is not workable; sending the child to someone was neither feasible. Then I gave up totally. For three years, I had been taking care of him by myself at home.” (5: 68. 1-15)

Qiao had hard times being viewed different. “When he did not walk, (other people said) ‘He can stand only. Oh! He is already three now but he can only stand!’ So what can you answer? Did it mean that we had not…had not done well and could not help him. Or his muscle was not well, or it would not be treated.” (5: 8. 3-5)

"When you went out, people would look at you. At that time, this eye (prosthesis) was not fixed yet. So it seemed that he had asymmetrical, big and small eyes. In the garden…a child…might be he was small and did not understand, approached and said 'Mommy you see, the child was blind!' So, he did not know how to say that he had different eyes. Might be he could not see clearly…" (5: 48. 1-3)
"Some people even…some even… you had asymmetrical, big and small eyes, they could see. They would stare at you, no matter how far you go the staring would follow you. Then I would look at them in return." (5: 52. 1-2)

"He can see now and…I will fix the eye for him first before we go out, so that we will not be pointed at. Not for the purpose of pretty, but less …we could hear less those unpleasant things (comments)." (5: 50. 2-3)

Living with 'little' child, Qiao felt 'little', inferior, herself. She describes with emotions, "During the two weeks when he first came back, carrying the oxygen bag…. everyone would ask. (Voice lowered, smile faded, eyes redden) Perhaps, I had not accepted…why people were looking at him all the time. I was afraid to let people know and I covered his face so that no one could see the tube at the nose. Once when I took him to the doctor and people asked why was his face covered. So, that time, others asked when we went for follow up; I said 'Oh, the air outside is polluted, and I am afraid he will breathe in the dust. It's nothing wrong.' I would not tell that it was the oxygen. I became…I myself had become…just like autism that I dared not see people. I would not see the relatives and friends, avoiding being asked. Every now and then, they would ask ‘Does he walk yet?’ In fact they showed concerns, but to me it is…being asked so many times and yet he had not walked yet. I did not know how to answer. So, not only taking care of him was difficult, and there were much more pressure from outside too.” (5: 4. 10-17)

She would withdraw from and avoid social contact. “It was New Year and people would come and visit. He was using oxygen; we have hired an oxygen machine at home. It would be face losing…so I did not want others to come. So that year, I told people ‘Do not come this year, come again next year.’ Pressure is there, when you have lot of relative and friends, it is problem…” (5: 46. 13-16)

Qiao tried to show people that she could cope successfully. “I must have him brought up well, to show the friend and relatives, to show the outside people that it is possible…possible to rear the child. It is not just like what they thought ‘Is it possible?’ I know they have such thought although they do not say it aloud in front of me. Yet the message would be relayed to me through people one by one. So I would have this thought ‘Well, later, I will bring him back and let you see.’ It might be the reason, with this added reason, I would force myself and try to push him grow up faster. In turn, it became harder to myself…” (5: 44. 8-12)

What built up Qiao’s confidence and hope was the minute improvement of the child’s development. “During the eye consultations in the first few months, they used a brown object to stimulate him. He had no response at all by then. He was almost one year old. I was so afraid that he could not see at all. But later, he was able to see bit by bit. You say, how very happy I was. And now walking…he can walk very well now. Just occasionally he will trip over when being pushed in crowded places. It is because he cannot maintain the balance. I am quite satisfied. Stress…there is just a little... Now it is worry, not stress. Now I am worried, if his eye will deteriorate. Others has recovered, I am not worried. He talks, I know he can utter single words. That meant he could speak. Later, I have confidence that he can talk. I am worried about the eye. And the right hand… the right hand. I want him to use the right hand but he won't, but you cannot not force him…" (5: 8. 15-19, 56. 1-4)

For the health care professionals, Qiao expressed appreciation and also expectation. "In the Ward X, the nurses were very nice. As compared with Ward Y, where we were transferred to later…they were much better. At least, they knew how to reassure the mothers….those in Ward Y were less… might be they were well trained in Ward X. So in there, they not only cared about your baby, they cared about the mother. They always consoled and comforted the mothers…I very much appreciated that the nurses in Ward X. I received Christmas card every year and I would return with photographs. So, their help to me was the greatest. And the doctors, of course I had to thank the doctors and nurses. If not because of them, he would not have such healthy development. We did our part at home, and the effort in the hospital was as important." (5: 2. 1-6)

With her experience, Qiao would take control and make recommendations. “The doctor did not let me go, but I begged him for discharge. I said ‘I will do anything you need. I will move to new house, I will buy new furniture’… It was because my baby had never smiled in the hospital. And he did not sleep well there because it was very noisy. That computer (monitor) was very noisy. It would alarm whenever it (the indicator) dropped. And those babies next bed would cry. Then I took him back…It was about half a month, when we returned for follow up, he could do without it (oxygen) anymore. It was half a month or so. Because, usually when he had ninety or ninety-two (percent of oxygen concentration) he did not need the oxygen. In the hospital, when others cried, he cried. Once he cried, he had not adequate effort, then the oxygen had to be increased. In fact, he could do without it earlier. Most of the time, during the doctor’s round, they would ask ‘Remove the oxygen and let him try.’ But the nurses would not dare to, for fear that in case he could not make it. Because whenever he cried, it (oxygen concentration) would decrease. Yet after returning home, he did not cry. He even smiled, and he slept well. So about half a month, it (oxygen) was no longer needed and I returned the machine.” (5: 46. 1-11)

Qiao would see that this was a unique experience that others would not understand. “I did not know how to explain to others. Every now and then others would ask. Others would not understand that he was born so tiny. Perhaps others would only think ‘Even he was born small, he could survive till that big, and then he should be normal’ but it was process that they would not understand at all.” (5:

8. 5-7)

“The difficulties would not be understood by anybody…” (5: 38. 1)

“Even if I have friends, I would not talk with them about my personal issues. And even if I would talk to them, they would not understand because they did not have the experience….” (5: 106. 1-2)

Qiao found that the interview provided her an opportunity to vent her feelings to someone who would understand. “Thank you very much for listening to me, allowing me to vent. Because you understand what I say, only you will understand. You know clearly, others will not understand, that how miserable it was. People will think that you are telling tales.” (5: 108. 1-2)

Emergence of Themes and Metathemes

In conducting the hermeneutic analysis discussed in Chapter 4, the researcher performed repeated reading of the reconstructed stories as a whole and identified the central concerns, important themes or meanings that were unfolding for specific informants. Exploring the relationships between each mother’s descriptions of experiences, themes were identified and metathemes were revealed through further reflection. Going through this interpretative process by moving

Table 5.3: The Seven Metathemes

Transforming in Corporeal – Embodying Motherhood
Changing in Temporal – Living with Uncertainty
Changing Relationships – Shaping the Caring Labyrinth
Interacting with the Environment – Anticipating and Intervening
Getting To Know and Understand
Asserting Life in Pending Loss
Transcending to spirituality

back and forth between stories and text, through writing and rewriting, and dialectic with other literature and philosophical writings, the researcher came up with seven metathemes that revealed the experience of mothers with ELBW children (See Table 5.3 above). The four fundamental themes and the three transcendent themes depict the mothers' life world as a whole, as they experience the every day situations and relations with ELBW children.

The meaning of mothers' experience in living with extremely-low-birth-weight can be considered to correspond with the four interconnected fundamental existentials described by van Manen (1990) as encompassing the life world of all human beings: lived body, lived time, lived human relations and lived space. The first four metathemes to emerge in this study are the fundamental existentials revealing the nature of the mothers' experience of extremely-low-birth-weight.

Table 5.4: Metatheme 1 - Transforming in Corporeal – Embodying Motherhood

Thematic Structure
Acquainting and adapting through own body
Enduring pain and suffering
Maintaining proximity
Developing awareness
Keeping vigilance
Maintaining balance
Balancing health and development
Balancing feeding and nurturing
Balancing weight and size

The First Metatheme:

Transforming in Corporeal – Embodying Motherhood

As phenomenological teaching tells us, people are always bodily in the world (van Manen, 1990). When one person meets another person in his or her world, one meets that person first through his or her body. It is in the physical and bodily presence that people both reveal something about themselves. At the same time, they are concealing something, though not necessarily consciously and deliberately, but rather in spite of themselves (van Manen, 1990).

This metatheme emerges to reflect the mothers' life world of being the mothers of ELBW children through the point of view of "lived body", revealing the mothers' embodiment with motherhood and transforming the experience through the body.

In the mothers' experience of embodiment, there is a deep significance in the sense that mothers and children are bone and flesh. The themes encompassed in this metatheme are acquainting and adapting through own body, enduring pain and suffering, maintaining proximity, developing awareness, keeping vigilance and maintaining balance (See Table 5.4 above).

Descriptive Reflection: Acquainting and Adapting Bodily

> *I have got used to it in these three years. The feeling of being restrained has gone. It seems like normalized. The life has become normal. (Yu – Mother of En-cheng) (7: 154. 3-5)*

Acquainting and Adapting through own Body

Many mothers describe an embodiment of motherhood as acquainting with and adapting to the life with an ELBW child – the 'body' and the living pattern. The embodiment of motherhood occurs when the mother acquaints and adapts the experience through her own body. Many mothers embody the experience as disturbance of sleep, especially during the initial encountering period. Pei says

> During the first year after she was back, I was so anxious and tense that I could not sleep. Once she got sick, you dared not sleep. (1: 68. 10-11)

The embodiment of motherhood is acquainted by some mothers as the embodiment of their child’s physical illness. Yu describes her physical reaction when her child is sick.

> When I spoke…my words shivered, seemed like I was crying. Even when I spoke to the taxi driver, it seemed that I was unable to talk….very anxious and frightened. (7: 88. 1-3)

Bao has an embodied illness in response to her son’s sickness.

> When he got sick, I had the feeling that I would get sick too. I knew that when he was sick I could feel the discomfort. (6: 194. 1-4)

Yu is also aware that the embodiment needs to be regulated so as to maintain physical health.

> Now I have hypertension and I know that… I cannot be too excited. That means I have to take things easy. I have to tell myself not to be too anxious… I always tell myself that I cannot let anything happen to me. I have to have myself relieved and not to be too anxious… Because she will depend on my caring for a long time … (7: 220. 1-2; 222.2-3; 224.1)

The acquainting and adapting was stressful and not only affected the physical health of mothers, but also brought about influences to their mental health too. Qiao compared the feelings of happiness at present with the stressful feelings in the past years,

> Compared with the happiness now, three years ago it was really, just like having a nightmare…Very frightened, but not knowing for what. I could not tell, could not tell in words. I could only describe that it was just like a piece of rubber band being stretched so hard that it was going to tear at any time.

> Very frightened and shaken, but not knowing for what. It was really helpless… I thought it had lasted for half a month. After seeing the doctor, I got recovered. The doctor gave me medication, might be sleeping pills. If I had not enough sleep, there would be a lot of thinking. It was sure that there was inadequate sleep. If you could not sleep, you would think and think, then you would get sick. (5: 76. 20-21; 102. 1-3)

Bao describes the tension effect of the experience on herself. She had had a very bad time that she nearly killed herself.

> When I had bad mood I would eat. My little boy could not eat…and …I did not know…I could not control. Since I had borne the child, I began to have this condition. Because he could not eat, I was very upset. Sometimes…once a few months…I would go out in about every four months…going out. Then I would go buy a lot of things… for no reasons, I would buy a lot of things. I would eat and eat whenever I saw food…That time, it seemed that…I had depression for nearly half a year. Just in this flat, I had thought about killing myself for more than ten times. I am telling you the truth. (6: 132. 1-4; 76. 3-5)

Bao considers killing herself as the solution of problem when she perceives double pressure resulting from not being understood by others in addition to the stressful child caring role.

> That time, when the boy was still small and I was cleansing the windows, I wanted…wanted to climb up there …and jump out to solve my problems. Because most of the time, others did not…were not able to understand me. And I could not do things well neither…I did not do well in the child care. Because the child was not fat…so I did not know what to do exactly. So the doubled pressure was very big. (6: 80. 1-4)

Jing recalls her stressful time when she was once at the edge of finishing her own life.

> Now when I look back, I should have been very upset by then. I did not know if I had that what you called depression. I did not know. He (husband) said, he said that he was afraid that I would throw the baby out. That time we lived on the 13th floor… I thought I would not, I had not thought about that. I just sat by the window all day, looking out and thinking. But I had not thought of jumping out or throwing the baby out. It was very difficult taking care of him at that time, because he was so small. (3: 30. 1-6)

Enduring Pain and Suffering

Mothers embody a great deal of obvious pain and suffering through living with the experience of extremely-low-birth-weight, through seeing the child's experience of pain incurred by its extremely-low-birth-weight and the interventions. Mothers also experience the emotional pain of the child and families including themselves through interactions with people around. The pain and suffering that the mother sees the child experience are the source of frustrations. The painful episodes start right after the ELWB child is born.

Mothers prefer to bear the pain for the children, yet realize that is not possible. Bao says,

> Because he had plenty of secretion and needed daily suctioning, and physiotherapy those things. Whenever it's time for suction, I felt that he was

> very poor. Having the suctioning like that, I felt that he was very poor. I would rather you give this to me, I had this idea. Whenever he got sick, I wished it would be I who got sick instead of him. I saw him so helpless there. Just like a lamb being sent to the slaughter (遭宰殺的羔羊)… (6: 202. 1-4)

Shu feels the pain of her child.

> Sometimes I would feel more painful when I saw him suffering so much at that time. At that time, while I thought and thought and it seemed… like I would be tearful. Thinking that he was suffering so much pain while being so very small. People say that small kids do not know pain. I would ask "Who say that they don't know?" Yes they do know, because they have nerves. (10: 54. 1-3)

The painful events for children are reminders of the loss of normalcy for the mother. Xiao recalls the event of an enema for her son with chronic constipation,

> Once he saw you take that bottle out, he started to cry …like calling for help…For many times I myself would cry too. I just thought…why…he was so small…it (regular bowel motion) was just something for normal people. It was not a problem for normal people. I would think that why he was so small yet had to be so miserable." (12: 76. 3-7)

The mothers encounter both physical and emotional pain as they deal with the issues surrounding extremely-low-birth-weight. The emotional pain is often related to the misunderstanding and rejection exerted on the child or the mother. Qiao captures the physical and emotional pain of living with a prosthetic eye.

> I thought it was unfair to the baby. He himself did not want it. If he understood what they said it would be miserable. "Why people can see and I

> cannot?” He can see now and…I will fix the eye for him first when we go out, so that we will not be pointed at. Not for the purpose of pretty, but at least…we don’t have to hear something unpleasant. But his face will become asymmetrical gradually if he does not put it (prosthetic eye) on for long. However, it’s painful to put it on. It hurts both when putting in on and taking it out. Also he will be in tears if draught blows on his eye… (5: 50. 1-5)

Extremely-low-birth-weight brings with it many painful situations ever since the premature labor process begins. All mothers experience the painful delivery process that includes the prior decision making for uncertainty. All mothers perceive the pain of all sorts of treatment and investigations including intubations, suctioning, numerous blood taking and injections in the neonatal intensive care unit. The painful events continue for those who have subsequent hospitalization. Many mothers experience the pain of the instant vomiting during feeding.

Shu experienced the open laparotomy for gut resection and colostomy, which are part of the treatment for necrotizing enterocolitis, followed by the stoma sore. Feng experienced the pain of cryo surgery of eyes that intends to retain the visual function, yet creates subsequent defects in the fingers.
Many mothers have experienced the emotional pain of the taunting from families who do not understand. The mothers convey their sufferings as physical and emotional pain, social isolation, inferiority complex, fear and breaking of relationships.

Through suffering, a new meaning and purpose for life emerges for mothers.

Compassionate care provided by family members and professional support from healthcare and social workers, acknowledges the mother’s suffering and creates new possibilities for the mothers. Despite the pain and suffering that are incurred with extremely-low-birth-weight, some mothers adopt a positive approach to the situation and see the good things instead of the bad ones. Xiao describes

> Although it had been a hard time, I found it quite interesting. Others would not have this experience. In fact you have really seen more … really more because you … in those months…had always been in and out the neonatal intensive care untie. You had really seen more things … you had learned a lot.” (12: 178. 3-5)

Maintaining Proximity

Despite the pain and suffering, mothers forget pain when they are in proximity with the children. Although the desire of proximity changes over time and all mothers convey it as unbearable when the children are out of sight and not being in close proximity. Yu experienced hesitation in touching the newborn baby.

> When I first saw her I dared not touch her because she was too small. I would not even touch her fingers. Very skinny and very tiny, I was afraid I would hurt her if I touched her. (7: 120. 10-12)

The first physical touch extremely-low-birth-weight is an entirely new experience. Shu explains,

> It was different from that experience of holding an ordinary newborn.

> Perhaps by then I did not have that feel, the feel was not yet too strong. There was not much feeling after holding him for once. Perhaps, we had not had any contact and the feel was not strong. But as he grew bigger and bigger, I can really touch him and all that, the feeling was very strong. (10: 42. 4-8)

Di cannot tolerate not seeing the children.

> I am very happy to look at them. I don't feel a bit of miserable, although sometimes I found it quite hard. But… I don't know how to say…I am very happy to see them…I don't feel miserable. Sometimes… it is quite confusing…I cannot tolerate not seeing them for just a moment, I will miss them. (8: 98. 1-3)

Developing Awareness

Life with ELBW children has taught mothers to be aware of subtle change that can occur at any time and for necessary modification of care and living.

Rui recognized the seasonal changes in relation to the child's health.

> When he started to have the vaccinations, he started to get sick. He always got sick such as common cold and influenza. When winter came… just at the beginning…it was winter again, I noticed that he started to have common cold and influenza. Then he would have shortness of breath … then would return to the hospital. (2: 30. 2-5)

Ni observes the attributing factors to the health of her ELBW child.

> She always has gastro-intestinal problems. Once when she had influenza…once when she had antibiotics… she did not have diarrhoea at the

> beginning, but the bacteria went to her guts very fast, and she got diarrhoea… (11: 62. 2-7)

Wei is able to watch out for potential developmental problems.

> I would observe which area of her was… comparatively… not too good. For example the hands … the coordination of the hand movements. In fact she was OK but just…she needed more training… for better coordination of the fingers. (9: 50. 1-3)

Jing shows confidence in monitoring the progress of development of the child.

> Because at home, we can also observe his performance at home. Perhaps he (doctor) can check… check very clearly, but we observe that there should be no problem with him. You can see that he can see. There should be no problem. (3: 42. 1-3)

Shu maintains constant observation for early identification of potential problem for early intervention.

> And I know the condition of my own son. Only when he was doing the major exercise…then he would become agitated easily. And the occupational therapist could observe the situation…if discovered earlier… If he had problem and that could be discovered earlier then relevant training could be arranged. That would be better than when you…gradually becoming bigger…and there was not any training in that aspect for him, then it would be worse… (10: 150. 9-11)

Awareness of the situation assists the mothers in identification of illness and problems, and the need for remedial actions.

Keeping Vigilance

Within the lives of mothers, there are circumstances and events that can lead to potential danger and threats related to the ELBW children. With previous painful experience regarding a child’s ill health during early life, along with the awareness of these potential situations, mothers maintain constant high vigilance. As Pei describes,

> Everything had to be very careful and hygienic, such as everything she ate… you had to wash hands before feeding her. You could never be careless as she would easily get diarrhoea if she had eaten just a little bit unclean. (1: 70. 6-8)

Being scared of the past poor experiences will be the trigger of vigilance. Qiao recalls,

> At night time, I would not dare…not dare to have a proper sleep. During the early days when he was back from hospital, I had to get up at night to check if the tube (oxygen) was not displaced. And also that monitor (oximeter to monitor the oxygen level in capillary circulation)…I did not have the monitor. They offered me the monitor at first but later they said it was not necessary, because he had ninety something (the percentage of oxygen concentration). So it was too bad because you had nothing to refer to, and you had to watch if there was (breathing)….I was afraid that the oxygen tube would be dislodged. Because he could not talk and he did not cry, you know. Because if it was dislodged….I had saw him turning all black once in the hospital when the tube was displaced. I was so scared…. (5: 78. 1-4; 80.1-3)

Sometimes, the children exercise the vigilance of the mothers. Feng recalls her conversation with her ELBW daughter,

> "Mom, I am sick, don't go asleep." I asked her why and she said "You just have a nap, but don't go asleep. Just close your eyes and you have to watch me."…I told her that mom was not able to sleep when she was sick. (4: 46. 1-3)

Maintaining Balance

Together with awareness and vigilance, is the need to maintain balance. In mothers' discussions, health and development, feeding and nurturing, weight and size are the focuses intertwining with one another in the balancing cycle. Mothers convey any changes in these focuses as indicators of the child's survival or life, and landscape of development. Mothers reveal these topics individually or correlatively as stressors or soothers themselves. Bao views the difference in maintaining balance of weight, feeding and health of the ELBW child as compared with normal weight ones.

> Once he got sick, not to say…not to think about eating. Yes, no appetite. Then it took a long time to recover. Other people recovered quickly. Getting sick, they would get well fast like blowing balloon. After getting well, then they would get fat quickly. But he was different…very…very slow. (6: 246. 1-2)

Balancing health and development.

Mothers are consciously aware of the health and development of the child throughout the years. Pei talks about the outcomes of changes of physical well being of her girl,

> After going back to the hospital and staying there for more than ten days, her weight decreased almost half… Staying in the hospital for ten days and she lost almost half of the weight. You know that it is very difficult for her kind of baby to gain a pound. She eats but does not absorb… (1: 70. 15-17)

Jing describes her worries regarding her son's development,

> Now I am worried about his walking, because he walks...on tip-toe. Once he walks, I can observe that part of his feet… you may say that is deformed. It's true, if it becomes worse, as he grows bigger the problem will be more serious. (3: 42. 26-29)

Ni describes how the feeding of her girl closely related her health,

> She had diarrhoea once she drank that milk. Perhaps she …might be allergic. She had already changed different formulae in the hospital. Then I changed to this formula…that was already the best one. The stool was not too loose… Any way, she has diarrhoea whenever she eats anything into the stomach. (11: 6. 1-3)

Balancing feeding and nurturing.

Most mothers of ELBW children perceive feeding as a difficult and tiring task. Feeding an ELBW child presents to the mothers as a chain of works which is both physically straining and psychological frustrating. Care tasks come as a routine cycle in the day as feeding, vomiting, then cleansing and washing. To deal with the difficult feeding of the child, mothers tend to develop their own feeding technique. Rui describes,

> Feeding him was difficult task because he did not eat much. It took a long time for every feed because he did not know how to suck. So, I had to make the bottle… make the hole (of the teat) bigger, and pressed and pressed on his tongue to squeeze the milk in his mouth. (2: 26. 6-10)

Feeding ELBW child is an endless task, and Jing describes the tiring cycle of feeding process,

> When he was small, it was really hard time. He was not like other babies. My daughter who I am now taking care is normal. She drinks milk…then till she is full, then I burp her, Uhh, that is done. But my son was different. He drank just a little bit, and when he was still drinking, then he would throw up, just spit up all back to you… I fed him day after day. During the whole night, I kept feeding him, making him to sleep, cleansing the floor. Day after day, feed after feed, I was repeating the same thing… (3: 30. 25-30)

To Qiao, feeding the ELWB child is not a single one-off task and she talks about the never ending feeding and related activities,

> He would vomit at the midnight. One time, after he had finished the milk…

> not knowing whether it was because I did not burp him properly or what…I was afraid that if I burp him he would throw up and waste the feeding. Then I did not do the burping. I was just holding him, yet he would belch and throw up. Almost all…in the house where we live in the past…all the ‘four walls and eight corners’ (四面八方) had been splashed with his vomit… every corner. It was very miserable. Yet, I was afraid that he had not (eaten) enough, on the other hand also afraid that he would vomit…I fed him again after he vomited again… (5: 4. 3-6)

Yu was aware of the effect of difficult feeding on her and she describes her own feelings while feeding her girl,

> Very troublesome, at first I found it very troublesome. Later I became… became very impatient and irritable because she ate….She had many feeds each day. Then it would be…she would vomit just a short while after she ate. Then …I had to… once again I had to change her clothes. I had to change all the clothes and trousers for her, and became…I became very irritable…at that time. But if she did not vomit, I would be very…very comfortable and happy because she had absorbed…taken all feed and had not thrown up. (7: 62. 1-4)

Yu also describes feeding as a fight between her and the child.

> In fact she still vomits now, but less frequently. Sometimes… when she drinks milk…just like when drinking the milk in the morning…when you feed her the last…you feed the last mouthful at the end of the feed, she will throw up if she did not like to. She will belch herself, not because of being over fed. It seemed like… “you force me… and I give you back.” I think she is like that… (7: 66. 1-4)

Mothers feed their children with food they perceive as good of nutrient. Ni talks about the choice of food regardless of the cost,

> Even if you gave her more, she would not eat… So I gave more swallow nest for her to eat. We… bought the swallow nest by catties... whenever we bought we bought a whole catty. She really took (absorbed) it, it was good for the eyes, and the protein was good for the eyes. You see that's why her eyes recovered…and her stomach and guts recovered. It was also good for her stomach…. She eats this since she was small. She has been eating it till now, though she eats less when becomes bigger… (11: 82. 1-5)

Xiao tries to understand the reason for her child's not eating and she conveys the meaning of feeding for her,

> I think he usually does not have the feeling of hungry. It seems that he is always full. I just think that …just like that most of the time he does not have the appetite. Yet…in fact I want him to be fatter, bigger. But it seems that… he does not like eating, not interested in eating. Then … but this one was just… in fact… after all these years I have to compromise. (12: 78. 2-5)

Balancing weight and size.

Mothers perceive the appearing weight and size of the child as new experience. The unanticipated appearance of ELBW infant in the neonatal intensive care unit is an entirely different image from that which they had been expecting. The strange and unforgettable appearance brings threats to mothers, who strive to balance a 'normal' weighed and sized child. Throughout the balancing process, mothers experience both frustrations and satisfactions. Pei views the weight and size of her girl as inappropriate and impossible as she first met her in the neonatal intensive care unit,

> So small a baby, when I went there and ‘Why she was inserted with so many tubes (the intravenous apparatus and vital monitors)! Is it possible? I was wondering. (1: 30. 1-3)

Qiao describes the striking and unforgettable sight,

> I could see that…he was dark, sunbathing under those lights (phototherapy). You know…those newly born baby…dark and hairy. Oh, is that my son?…Or is he the son of some Indian?…So dark he was. It was dark and tiny. Just like…just like…now when I go to the market I dare not look at those skinless toads. He got muscle on the thighs only, all the rest was bony. I was scared seeing that. (5: 94. 6-8)

Shu describes her first seeing of her ELBW son,

> It was very small, and very thin. There was no flesh…the ears… I looked at… there was no ears… Oh dear! …In fact the ears…those cartilages had not developed yet. They were just like those ears of the elephants. Later the nurses told me ‘Yes, the ears are there, each day…they gradually…will…slowly come out later.’ Oh…the ears were just like the elephant’s… just a flap of skin…that feeling. In fact all (organs) were not yet (well developed)…those fingers I touched, my finger was just big as his palm…the size of his palm. It’s really tiny. (10: 30. 3-8)

ELBW infants have different needs from normal babies and Ni conveys the special needs of the small sized baby,

> Both eyes were covered. Yes, having the phototherapy… eyes were covered…. I could only see that … she was not wearing any clothing and I

> could see that her heart … was there beating and beating (under the skin)… every terrifying. The fingers were so small just like those of a dolly. The napkins were special and I had to go to those…toys…Toyrus to buy the napkin. You could not get them in other places. It was quite difficult to find them. In case it ran out of stock, it would be bad and I did not know where to buy. (11: 44. 1-4)

To the mothers, smallness is related to weakness and Bao sees the weakness behind the small size,

> I plan to send him to school one more year later because he is too small. I am afraid that in the school… he is 'too frail to stand a gust of wind' (弱不禁風). Because he…I do not know how to say…'too frail to stand a gust of wind' – as the wind blows, he will fall. (6: 86. 1-2)

Di questions if the small sized child could stand the 'big' operation,

> So small the child, and here came the operation. Just a catty (about 12ounze) or two the body weight and here came the operation. You don't see much flesh so tiny the child. (8: 46. 9-10)

Wei expresses content to see the increase of weight,

> When you see that her weight is increasing, you will be OK. The weight is … she is progressively gaining pounds, and you will become… relieved. (9: 34.5-6)

Among the mothers, Yu is particularly concerned with the weight and size of the child. Yu conveys the magical meanings of decimal figures regarding the body weight.

> She gained weight so slowly. At that time…that time she was in the hospital… when she was about nine months in the hospital. Her weight was getting less and less, day after day. She was admitted in the hospital because of sick that time. I was very anxious that she lost one…just … just one marking or two (markings on the weighing scale). Just a decrease of decimal value, I would be very anxious. I was anxious regarding her weight at that time. I would be very anxious when I saw… once she was on the scale 'Oh, a decrease of decimal value or so and so again…' If it was those normal (children), even one pound less it would be no big deal for those elder children. It would be no big deal to have one pound less, because they were not thin. But for this child, just a difference of the decimal value would make me really anxious. (7: 150. 2-7)

Yu expresses her view that weight of the child is her major concern.

> She is always that tiny… Throughout the whole process of development she, only her mind has grown up, but the person (physical) has not. Then it seemed that she would be very pitiful if she were still like that in the future. I was only worried about this, no others…no other worry as she is normal as usual. **(**7: 48. 1-3)

Yu talks about the impact of how weight on the future of the child,

> If she does not grow, she won't have the ability… to earn a living. Who will employ you when you are so tiny? Even if you have good achievement in study…really good achievement in study, it is of no use. Isn't it? No one will trust you (that you have the ability) wherever you go. Even though you might have the ability, you might not have the energy to sustain. So I am still worried about this. Others are not…not that worrying. Only if you can grow, you have adequate height and size…even though if you do not study well you can earn a living. But if you are so tiny, and always so tiny…even you

> study well you cannot earn a living. (7: 112. 3-8)

> *When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves…In accepting this challenge to suffer bravely, life has a meaning literally to the end (Frankl, 1984, p. 135, 137).*

Interpretive Reflection: Acquainting through Embodiment

> *Our own body is in the world as the heart is in the organism: it keeps the visible spectacle constantly alive, it breathes life into it and sustains it inwardly, and with it forms a system" (Merleau-Ponty, 1962, p.203)*

In the phenomenological view, a person is viewed as a participant in common meanings (Heidegger, 1996). Rather than having a body we are embodied. It is assumed that our common practices are based on shared embodied perceptual capacities (Benner, 1985). Our bodies provide the possibility for the concrete action of self in the world. It is the body that first grasps the world and moves with intention in that meaningful world. It is this participation in a world along with the commonalities of embodiment that makes perceptions common, shared and mutually accessible (Merleau-Ponty, 1962). Once the mind and body are understood as a unified being, then the person can be seen as participating in a meaningful world.

According to Merleau-Ponty (1962), experience and perception are our original modes of consciousness. Perception provides access to the world as it is given prior to analysis of the world. “To perceive is to render oneself to something through the body ” (Merleau-Ponty, 1962, p42). Perception presents us with evidence of the world not as it is thought but as it is lived. “The world is not what I think but what I live through” (Merleau-Ponty ,1962, p. xvii).

Embodiment allows people to live in the world and understand the world in relation to themselves (Benner & Wrubel, 1989). Through embodiment one is conscious of another’s existence in the world through the body. The body of another, like our own, is not inhabited, but is an object standing before the consciousness as empirical being. (Merleau-Ponty, 1962). According to Merleau-Ponty (1962), as far as one has sensory functions, a visual, auditory and tactile field, one is already in communication with others taken as similar psycho-physical subjects, and people’s minds and bodies are always interrelated. People’s lives are both mental and physical, and to be human is to be simultaneously mind and body. Merleau-Ponty’s (1962) philosophy of embodiment is the “intentional arc”, a vehicle connecting the existential elements in the world: time, space, sexuality and speech, which “projects round to our past, our future, our human setting, our physical, ideological and moral situation, or rather which results in our being situated in all these respects” (p.136).

Merleau-Ponty (1962) describes the body as catching, comprehending, and spontaneously responding to the communications of another person. In this study, ELBW children experience pain and suffering inflicted on them due to their extremely-low-birth-weight, and the mothers of ELBW children are able to endure the pain and suffering that is a part of the illness experience, a part of the human world of meaning (Benner & Wrubel, 1989). In the mothers' experience, suffering acts as a catalyst that precipitates the intention toward spiritual liberation. Suffering also serves as a motivation for compassion and caring toward those who are suffering or suffer because they see suffering in those nearest to them (Taylor, 1989). Watson (1989) stated that subjective involvement in another person's suffering is possible when compassion, caring and concern exist. Mothers of ELBW child perceive the suffering the child experiences and suffer because the child suffers. The mothers are fully connected to the ELBW children in an embodied awareness, aware of their own bodies and aware of how their bodies must be for the children, thus, pain and suffering is transcended (Schroeder, 1992). With growing compassion and bonding, the mothers of transcend from a state of 'not dare to touch' at first encounter to 'not bear to leave" after first embrace. Through embodiment, the mothers come to know their children in a symbiotic way, assuring their sense of primordial security for the children (van Manen, 1990).

Embodiment is not simply a theory, but a different way of thinking about and knowing human beings (Wilde, 1999). Embodiment is a form of experiencing the world through the body in lived experience. As for nursing, nurses' engagement with patients considers their own embodiment as well as that of the patient. Embodiment and embodied engagement are interpersonal or relational experience between the nurse and the patient (Hess, 2003); and embodied engagement and dialogue are essential features of the patient-nurse relationship. In conducting this study, the researcher, as an embodied being, experienced the mothers' world and thereby engaged with the mothers' experience of extremely-low-birth-weight, in an attempt to understand and make meaning of their world and experience.

The Second Theme:

Changing in Temporal – Living with Uncertainty

Another fundamental existential theme in phenomenology is “lived time”, in that time is subjective time as opposed to clock time or objective time (van Manen, 1990). This is the temporal way of living in the world, and the temporal dimensions of past, present and future constitute the horizons of a person's temporal world (van Manen, 1990). A person encounters his or her past as memories, traces of forgotten experiences, the gestures that one adopted, the words that one speaks and the languages that one tie to the past. And yet, the past changes under the pressures and influences of the present. The past changes itself, as people live towards a future that they already see taking shape through hopes and expectation.

Table 5.5: Metatheme 2 - Changing in Temporal – Living with Uncertainty

Thematic Structure

- Experiencing time in different ways
  - Unprepared delivery
  - Uncertain of survival / pending loss
- Striving through uncertainty / unknowns
- Appreciating recovery / regain
- Living in the here-and-now
  - Treasuring the precious gift
  - Living life to its fullness

In the mothers' life world of extremely-low-birth-weight, mothers experience a sense of "lived time" as living with uncertainty, transforming the experience through each day of life. In the sense of lived time, mothers describe their experiences of ongoing uncertainty, bringing to the emergence of underlying themes of time a focus on the present, treasuring life as a gift and living life to the fullest. Encompassed in this metatheme are the themes: experiencing time in different ways, striving through uncertainty / unknown, appreciating recovery / regain, and living in here-and-now (See Table 5.5 above).

Descriptive Reflection: Living with Uncertainty

> *I don't know what the situation is. In fact I don't know what his condition is. I am just afraid his body…Will it some day…Will there be any problem hidden inside that is not being known. (Shu – Mother of Xian-Guan)*

Experiencing Time in Different Ways

Mothers living with extremely-low-birth-weight develop a new perspective of time. Time in the past few years since birth is not linear but more cyclic. Aspects of temporality are revealed through mother’s particular descriptions of time consciousness. In many instances, the time consciousness of the future is linked to particular events, events related to the well-being and weight loss of the extremely low birth weight child, from the past and present. The events are reflected in the occurrence and recurrence of the manifestations of extremely-low-birth-weight, physical well-being and developmental landmarks, advice and reminders from healthcare professionals and social workers regarding survival and recovery, and the changes within the child related to the ability to overcome or endure those events.

Many mothers describe their consciousness of time as being focused on the present, veiled by the past, with restricted views of the future. The experience of ongoing uncertainty bring to the emergence of underlying themes of time focused on the present, treasuring life as a gift and living life to the fullest.

Time and duration has a vital meaning for mothers of ELBW child. The longer the duration of the unprepared labor, the higher the chance of survival and quality of outcomes.

Unprepared delivery.

Unknowns and uncertainties begin as early as mothers recognize the premature delivery that most of them were not prepared for. Mothers are not prepared for the early comers. Some mothers are not even aware of the signs of labor onset. Jing did not know the time for the early delivery of twins though she had been informed. She explains,

> He (the doctor) said, “It will burst one day, just like a bursting balloon, but I don’t know when.” He could not tell you when, yet I always knew it would be premature delivery. Just not knowing when would be the ‘early’ labor, yet I had not thought that ‘early’. In fact, I did not have the sense of worried because I had not given birth before. Neither did I know whether it would be viable for twenty something weeks… (3: 20. 13-16)

Arising from the unprepared delivery, many mothers try to establish the cause of early child birth. Most often they put the blame on themselves and figure out some kind of unsuitable acts they have done contributing the preterm labor. Qiao relates her early delivery to her career,

> My baby was born early because I worked in this career; climbing staircases all the time. In fact, the doctor had told me to rest. I already had threatened abortion. And then, I always walked five and six floors when I was working on the old buildings in Kowloon City. And finally, might be too exhausting, walking up there with ‘internal strength’. So I hated this job and I quitted. I did not go get the license when the time came. I tried to escape from working in this career.” (5: 6. 8-12)

Yu experiences the changes caused by time – from planning to terminate the pregnancy, becoming loath to let go, then thinking back of the risk,

> I planned to have the operation (termination of pregnancy), but when the schedule and arrangement was made …it took too long. You know, it takes long for making appointment. Subsequently, I became loath to let go. (7: 28. 1-3)
>
> Kept on saying not wanting to keep (the pregnancy), but it seemed…fate seemed to give me a chance to have her back. Because, it was almost three months…more than three months when the appointment of operation was made. By that time…I was afraid by that time because it was also at risk if I got it aborted… (7: 118. 5-8)
>
> There would be pressure if I kept the child, I thought after I kept the pregnancy. And after I had borne the child, then I thought…then I knew it was just as dangerous if I kept the child. Then I thought, if I knew it earlier that it was so dangerous I would… make up my mind and aborted it….” (7: 118. 9-11)
>
> I love kids and I did not mean to give her up. I wanted…I wanted to keep her. But, saying not wanting…in fact I was really afraid… that I would not be able to take care of her…because of my old age and I did not have so much energy. Just like…now when she runs away fast and I find difficulties to chase her. It is mainly because I was old…and really not want to have (another child). Say if… if not because I was not bearing her already, I would really not want to have (any more children). (7: 118. 2-5)

Uncertain of survival / pending loss.

Uncertainty does not vanish after the child is born; instead, the intensity increases at the sight of the child. The physical appearance of the child is unexpected and striking to the mothers who have never thought about it. With the disclosure of the problems of prematurity one after another, more uncertainties occur as the outcomes are always unpredictable. The survival of the child is uncertain and not guaranteed. Pei notes,

> Everything depended on those machines, to maintain life. If the machine was removed, in fact he would…He…everything was relying on those machines to maintain life… I always asked: Why would the baby be like that? Would she be viable? How long would she stay in the hospital? (1: 40. 2-6)

At the beginning, mothers were encompassed by doubt and uncertainty about the child’s survival. They struggled to seek affirmation from the healthcare professionals and the responses were often not promising. Mothers describe their struggling to deal with uncertainty, while they reveal the feelings of pending loss. Bao conveys her feelings,

> Perhaps I could not get it out of my mind. Intuitively, I had the feeling that my son would not make it…It was ...very grey…the idea was very disheartened (灰心). I just thought that nothing could be done to change it.” (6: 104. 2-4)

Being uncertain about the survival of the child, the preparation for the new baby's returning home does not proceed. Yu says,

> But the nurses said that she was critical everyday. It really made me very anxious at that time. "Would there be any chance?" In my heart, I would always ask "Would there be any chance? Would she be viable?" Not until she was almost discharged then I began…began to accept. It is true. It is possible. Not until the day of discharge, I would still ask 'Could she make it?' The feeling at that time was very funny. Yes…I would not dare to buy too many things (for the baby)…buying things that might not… might not be necessary. I would think whether it would be necessary, so I dared not buy. Until she was discharged, then I dared to buy. Because I was afraid…had hesitation to prepare so many things here. Until she was discharged…until she was discharged then my heart was settled and I know it could be done. When there would be no problem and she had made it, then my heart was comfortable (relieved). Then…that meant…I could be relieved." (7: 124. 2-9)

Striving through Uncertainty / Unknown

Along with the gradual awareness of the possible worst outcomes, the lack of information, and an inability to predict outcomes increase the mother's sense of uncertainty. The uncertainty is an intrinsic component of the hard times throughout the years. Describing event by event, mothers reveal their bewilderment over the unknown future of the child. Many mothers expressed fear of the unknown. Feng says,

> But it was hard to describe…it was miserable after all. For the past five years,

> the pressure was very great. I was anxious all the time. Whenever she got sick, I would be very anxious and became a mess. I was anxious when she was sick. When she grows up, again I am anxious in finding school for her. Since I don’ t know which school will be good. She is not like any other ordinary children and you can choose any one you like. She is different. The psychological pressure is very great. And now, planning for primary school, the pressure is very big… don’t know which school would be good… (4: 138. 1-5)

The fear of the unknown is the most threatening factor for the mothers as they cannot tell what they are worrying about. Di explains,

> Now if you ask me to tell what I was worrying about and I could not tell, however, it seemed that there were a hundred of worries in my heart…. Just being worried…not knowing what would happen… (8: 36. 3-4; 38. 1))

Unknowns and uncertainties have driven the mothers out from the comfort of the familiar, and the awareness of the possibilities within extremely-low-birth-weight enables the mothers to change their perceptions of reality – the reality of knowing and unknowing. Jing conveys this feelings,

> At that time, I was just thinking … “Would it be good if he could be saved? And all problems would be unimportant?” Well, when his life was saved, you would hope that the eyes were no problem; when the eyes were all right, then you would hope that his brain was no problem….so and so. And I could see that everything was pre-planed (by the almighty). (3: 68. 3-5)

Mothers are confronted with the uncertain status and outcomes of extremely-low-birth-weight and exacerbations. Mothers grasp the certainty that a crisis could happen, yet not knowing when and to what extent. That is the reflective of the ongoing uncertainty that mothers experience. Jing shares this view,

> The MRI investigation showed that the left brain… at the back…there was a tumor by the blood vessel. So I asked the doctor how this happened and he said he did not know. Would it become bigger and bigger and he said he did not know. “We have to keep checking on that”, so he (the doctor) said. I asked what would happen if it grew bigger and bigger. He said, “When it grows bigger it will block the blood vessel, and when the blood cannot pass, the vessel will burst.” I asked when and he said he would not know. He said he could not tell…I asked what the age of the youngest case was and he said it was around seven to eight. So now, I can only…say that the dangerous period is seven and eight year old… (3: 42. 3-10)

Living with ELBW children, mothers learn to relieve the burden of uncertainty one by one when an answer is given to an unknown. This is exemplified by Rui,

> Before he could talk, I was worried about his intelligence. Before he could walk, I was afraid he was unable to (walk). Because he was slower in these sorts of development and I was worried... The day when he could walk, it seemed like lowering a “bag of load 包袱” (burden). When he could talk, I lowered another bag.” (2: 78. 6-9)

Uncertainty is a feature of the mother’s experience that persists. Many mothers reflect the myriad of emotions that fluctuate as they pass over the unforeseeable happenings. Ni says,

> I would be very upset. It would be miserable if she became blind... What could I do if she was blind and deaf. Fortunately that she was not. It was

> like…stepping across barrier one after another. The doctor said that there are plenty of barriers to surmount, step by step to overcome.” (11: 70. 1-3)

The experience of uncertainty creates tension in the ongoing future of the mothers, and the tension always exists as long as the mothers live with the unpredictability. Xiao describes the years after her boy returns home,

> From time to time when there are any little happenings, you will always have the feeling of breathless with fear… Just a little bit of ... the heart will beat and tremble whenever there is just a little happening… I will be very frightened… (12: 58. 2-3; 154. 1)

Appreciating Recovery / Regain

As time goes on, mothers learn to live with the uncertainty and learn to manage the fear associated with the unknown. They also learn to appreciate every infinitesimal situation and event that gives them cause to rejoice. Mothers have been encompassed by fear of uncertainty, until one day when they recognize the recovery of the child from pending loss. Bao’s word typify the sense of release,

> My son talked to me. When he began to talk to me, I felt that…when he talked to me…I felt... I did not know…everyday it was I who talked to him. Every time I did not have (response from him)…not know what he… When he began to respond to me, I felt…Ah, he has a life. I then felt like… to have a little achievement….Yes, my feeling…just like…He was a real baby, a human. I would have the sense of achievement. I felt that there was an answer for what I had done. Not like before…whatever you gave him, there

> would not be any response. No response, and your feeling would be…the feeling would be bad. (6: 106. 1-3; 188. 1-3)

Wei shares her rejoice as she witnessed the growth and development of her child,

> Raising her till this big now…. When she was one year old, she could walk and run…at one year or two. The bigger she grew, the happier we were… Taking care of her, seeing her growing and developing gradually, you would be very happy… (9: 56.1-2; 82. 2)

Yu describes the regain of bonding with the prematurely born child over time,

> After she had been born for a long time, I went see her. I did not…it seemed that I had no feeling at all. It might be because I had spontaneous deliveries for the first two children. The feeling was different. And this child had not been inside me for long. It had not been for long that I knew that she was in me. It had not been a long time that I knew that I was having her, because I had never thought about having her. It had been almost…almost two months when I knew that she was there. So till I had her borne, it was only five months that I knew her being there. And the bonding was not that deep. It was until later…later that the bonding was rebuilt. (7: 120. 5-10)

Living in the Here-and-Now

Treasuring the precious gift.

Overcoming barriers one by one, experiencing pending loss and then regaining, many mothers focus on the day-to-day happenings, indicating the significance of the present to them. Qiao describes her feelings,

> That’s why I treasure very much now. I have to have him within sight every moment. I treasure very much, just like regaining from loss (執番嚟). (5: 22. 7-8)

Living life to its fullness.

Living with ELBW children leads mothers to think about the amount of time they will have with their child, to lead the living life at present to its fullness. Jing reflects how she sees life differently with the unforeseeable happenings to her boy,

> Then I would think should it be like what the doctor said. If I put all my effort to take care of him, till he were twenty something. One day if he died because of stroke, then it would be unfair to me. But why…then…he would be very poor. Yet if he could live up till twenty something, that would be better. At least, he could have been to places and have fun… But if he died at teenage, then there would be a lot of places he had not yet visited. Then I would think that every time I had holidays I would take him to places and see more of the world. In case anything happened, he would not have…just come to the world but had never had fun. (3: 42. 15-19)

Interpretive Reflection: Living in Uncertainty

The present, like a note in music, is nothing but as it appertains to what is past and what is to come” (Walter Savage Landor)

君不見黃河之水天上來，奔流到海不復回。 (李白 – 將進酒)

This is the phenomenon of time experienced in extremely-low-birth-weight within the context of temporality between the mother and child. The temporality of the mother and child relation for the mother is hope for the child and the intentional expectation of becoming and growing toward normality and maturity. Time is experienced as uncertainty of fulfillment taking shape and form. Uncertainty is felt as a dynamic state in which there is a perception of inability to assign probabilities to outcomes (Penrod, 2001).

> *Everyman's life lies within the present, for the past is spent and done with, and the future is uncertain." (Marcus Aurelius)*

The onset of uncertainty is an outcome of the confusion that mothers experience in letting go of past reality, in sorting out ambiguities and reflecting on their new reality. The experience of uncertainty is triggered off by an event of which they had no prior knowledge and understanding.

> *The person suffers because of her or his present plight and inability to escape. Thus, uncertainty is related to the course and not to the outcome: when uncertain, the person has no other choice but to tolerate the present."(Morse & Penrod, 1999, p147)*

Morse and Penrod (1999) described uncertainty as a state when the person knows where she or he wants to go but cannot identify how to get there; the person may have choices, but the course of each remains unknown and cannot be evaluated nor compared. Uncertainty is when people do not have the information or the ability to “weigh the odds” or to understand the alternatives. Several mothers in the study conveyed uncertainty as never knowing when the next problem would show up, whether the problem would become better or worse in the next month or next year. The uncertainty poses an omnipresent threat to the mothers who find that they are living through experiences without answers. Mothers cannot ascertain what is lying ahead and planning of long term goals for the child is not realistic.

As the child grows and develops, the future and outcomes may become more or less predictable, mothers begin to live in a present with that has possibilities. As the past changes itself, people live towards a future which they already see taking shape (van Manen, 1990). Through living with extremely-low-birth-weight, mothers realize the uncertainty of future, yet they strive to live within the uncertainty and create possibilities for their future. Mothers sort through the ambiguity within their lives and create meaning out of the situations.

> *If time is similar to a river, it flows from the past towards the present, and the future. The present is the consequence of the past, and the future of the present (Merleau-Ponty, 1962, p.411).*

Uncertainty leads mothers to question and consolidate their actions to move forward and assume responsibility, despite their inability to figure out an answer or solution. Living with extremely-low-birth-weight, mothers look at the situation differently, and reflect more often on what they are doing in their lives. When mothers have a deeper appreciation of the event; they move from the recognition of uncertainty or the acknowledgment of suffering to the new level of acceptance. With acceptance mothers realize the significance of the event on their past, altered present, and irrevocably changed future. The future and alternative actions affecting that future are no longer incomprehensible; they become real as an achievable goal, and plausible routes are now considered. Morse and Penrod (1999) described this state of hope as “seeing the light at the end of the tunnel”. Hope is an expectation, so the *outcome* is not certain, but a goal and a path are identified. Uncertainty allows mothers to hope for the readiness to the extremely-low-birth-weight problem. Mothers talk about how unsettling it was to live with unknown and uncertainty. While out of the unknowns, mothers find new possibilities.

> *The secret of health for both mind and body is not to mourn for the past, not to worry about the future, nor to anticipate troubles, but to live the present moment wisely and earnestly (Buddha).*

The Third Theme:

Changing Relationships – Shaping the Caring Labyrinth

In the phenomenology literature, “lived other” is the lived relation people maintain with others in the interpersonal space that others share with them (van Manen, 1990). In a larger existential sense, people search in this experience of others, the communal, and the social aspects, for a sense of purpose in life and basis for living.

Mothers of ELBW children experience a special “lived other” as changing relationships in a search to shape the caring labyrinth, transforming the experience through connection with others. The mothers’ lived relation is highly charged with interpersonal and social significance. The mothers convey a significant sense of need for support and companionship through the experience of extremely-low-birth-weight. The themes encompassed in this metatheme are: Becoming a mother of the ‘small’ child, seeking normalcy and dignity, appreciating relationships with family, interacting with health care systems, isolating and loneliness, and unique experience – not being understood (See Table 5.6 below).

Table 5.6: Metatheme 3 - Changing Relationships – Shaping the Caring Labyrinth

Thematic Structure

- Becoming a mother of ‘small’ child
  - Changing roles – from hospital to home
  - Recognizing new responsibilities – no delegation/not release/no giving up
  - Unique relationship – protecting / disciplining
- Seeking normalcy and dignity
  - Being viewed as different
  - Being a “small mother / feeling “small”
  - Reasoning for being different
  - Struggling to be normal
  - Blaming self – feeling of guilt / failure
  - Recognizing / treating child with dignity / fairness
- Appreciating relationships with family
  - Relationship with spouse
  - Relationship with in-laws
  - Relationship with maiden family
  - Relationship with sibling of the child
- Interacting with health care systems
  - Feeling supported / neglected
  - Challenging / comparing
  - Taking control / losing control
  - Expecting more / suggestion
- Isolating and loneliness
  - Feeling rejected / left out
  - Maintaining silence
  - Retreating from social / restricted freedom
- Unique experience – Not being understood

Descriptive Reflection: Changing Relationships

> *The self denotes the 'organized consistent conceptual gestalt composed of perceptions of the characteristics of the [I] or [me] and the perceptions of the relationships of the [I] and [me] to others and to various aspects of life, together with the values attached to those perceptions.*
>
> *(C. R. Rogers, cited by Watson, 1999, p55)*

Becoming the Mother of a 'Small' Child

Mothers experience challenges as they care for an ELBW child, while following certain prescribed regimens and conducting particular activities necessary for the well being of the 'small' child. The unforeseen changes within life and the altered relationships diffuse into the context of the everyday life of mothers, a milieu that incorporates the role, obligations and responsibility of being the mother of an ELBW child. The introduction of an ELBW child into the mother's life, the mother's way of being in the world, transforms her routines. However, mothers are able to maintain and develop new patterns within their lives that help meeting the needs of the ELBW child.

Changing roles – from hospital to home.

As soon as the ELBW baby is born, the everyday life of the mother changes.

Mothers recognize that this change does not match with usual expected pattern. Mothers realize that they are playing some kind of unusual roles of motherhood. Di captures this change,

> I was just like…just like going for duty everyday. The ‘Doing the month 坐月’ (the convalescence month after delivery) that other people said… not even one day… I had not followed the practice. At 8 o’clock early in the morning, I got up, went to the hospital and sat there in the ward. I just sat there till six in the evening, just until people would not allow me to go in, then I went home. The next day I repeated the same thing, everyday the same. Later in another ward, everyday was the same. So, one month, ten months, it was just like…I said I was even more diligent than the doctors who worked there....” (8: 156. 13-20)

Subsequently, when the child is discharged from hospital and returns home, the mothers experiences the change of role again. Mother changes roles from visitor and part-time mother to full-time carer and mother. Transforming the experience in the hospital back to the home setting, several mothers simulate the duties of nurses and the environment in the hospital. Xiao recalls the first month when her son is back home,

> Leaving the hospital I was very happy, but when he returned home I was very anxious. I dared not sleep at night, watching him….for fear that at night he would…because… in the hospital, it always seemed that there would be nurses watching, even if any thing happened. Therefore, for the first month and so after he was back, I was still afraid during the nights. Because at the beginning…I always thought…would it be good… He did not…he did not sleep. I did not know whether it was because in the hospital, the lights were always on. When he returned home, with the lights off he was not… not

> sleeping so well. Moreover he… he was not like other babies. He …slept very little even as a baby he slept very little… At the beginning, with the lights on then I could not tolerate…. So we have to regulate the light gradually to dimmer and dimmer… He also had to adapt, he also took almost a week to adapt the he could sleep better. I was unsettling anxious when he returned home from hospital, I was very afraid. (12: 184. 1-8)

Resuming the roles of a full-time mother is challenging to the mothers. Qiao conveys her excitement and frustration when her son is about to return home.

> When leaving the hospital… I was longing his returning home sooner, but I was worried too. Could I manage at home? If I could not manage, would I waste others' effort (in saving his life)? … However, I really wanted him to return home. I wanted him return home and did not want him to stay there (hospital) any longer. It had been too long almost half a year… (5: 96. 1-3)

Qiao also says,

> The most difficult was when he was discharged home. Because when he was in the hospital, there were adequate monitors. He was being looked after by nurses at night and I could go home and sleep. But it was completely different when he returned home. It was I who had to take care of him day and night. (5:4. 1-3)

Recognizing new responsibilities – no delegation / no release / no giving up.

With the returning home of the ELBW child, new and different responsibilities emerge. The mothers assume responsibility for the life of another person, the ELBW child who has been taken care of by health care professionals in the hospital since birth. Mothers start to learn that the responsibilities are great and acquire the necessary skills and techniques from health care professionals. Shu explains,

> The (colostomy) bag had to be stuck very very tight to hold the stool, yet it still leaked. Once it leaked, the skin became sore within a day. But if there was no leakage, it healed quickly within one day. Perhaps the cells of little child worked fast and the wound healed faster than the adults. At the beginning, I did think that there would be no recovery as the sore was always there. Then the stoma nurse helped to find a method so that the bag could be fixed securely and would not leak. Trying this and that, at last we found one bag that could be fixed well and with minimal exposure of skin area. Later we were using this bag when after returning home. It was a model for adult that nearly covered half of his abdomen…" (10: 58.2-8)

Given the health problem and developmental condition of the ELBW child, mothers face new responsibility that comes from the medical regimen and rehabilitation program of the child. Ni recalls,

> And now… at the physiotherapy… they know that the ligament of his leg is a bit tightened. So… they ask me to go to the physiotherapy… We are going there every week, and to the swimming class (hydrotherapy) too… to the swimming class. Yes, he has a lot of these arrangements. Very busy… very busy… (11: 48. 7-9)

Mothers start to learn that the responsibilities of caring an ELBW child are great and unique to the parent. The responsibility is neither releasable nor transferable, and there is no giving up. Qiao says tearfully,

> No, no one could help, absolutely not. …I had once asked people to take care of him. I am tired of taking care of him!.. Somebody introduced me a helper who lived in Sau Mau Ping over that side. All at one time, I brought the cot, napkin and clothing to her place. I said when I got there, “You take care of my son for me, I’ll pay you five thousand dollar net wages a month.” I was willing to pay. I said, “I am really tired and miserable.” I had been really desperate for a period of time, very miserable and helpless. That person was kind, and was not working. She had a son studying in university, who also had lost sight of one eye. So, there should not be any discrimination and I was confident to let her care my son. But he (my son), after getting there, kept crying for entirely three hours. She then phoned me, “Please come, I can’t manage. He cries and cries for entire three hours.” I had just returned home for three hours and he was there crying for three hours. I had not slept for several days already so I said, “I do not take him, and please let me sleep.” Then she took him back to my home, with money, clothing and the cot. She brought all things back at one time by taxi. Then I knew that no one could mange him. There would be no one. Hiring someone at home to care him is not workable; sending the child to someone was neither applicable. Then I gave up totally. For three years, I had been taking care of him by myself at home. (5: 68. 1-15)

Bearing the un-transferable responsibilities, mothers are inhibited from normal living and social activities. Yu perceives the constraints in this ‘new’ life.

> I used to wake up and I could go to anywhere I liked… I just…walked out the door, then I could come back home at any time I wanted. But now I could not. When I woke up, I had plenty work to do. When I woke up I have to boil the bottles, I had to bathe the baby and I had a lot of things to do. It was like that now. I had to wake up in the midnight if she cried. I had to get up and

> see if she is all right. But in those days, I could sleep till sunrise and have nothing…nothing to bother. Now was different, I was worried if she… It was just like the beginning… beginning, the first time I became a mother, very nervous at that time. Oh no, I should be free to go anywhere the next morning but why that now I am not… (7: 152. 3-8)

Yu also recognizes the responsibility as long lasting,

> How can she take care of herself in future, when she is so small. I cannot look after her all her life. Then if she…say when I get more older, when I need her to take care of me in turn. Yet she may not be able to do so. If I were not there and there were no one to take care of her, she would be very miserable then. (7: 112. 1-3)

Financial implications also add to the new responsibilities of mothers. The increased expenses include extra requirements for daily living, medical consultation fees and additional medical accessories. Ni explains,

> The first private doctor she attended was very expensive, eight hundred fifty dollar every time, in Tsim Sha Tsui.… But, at the beginning, you had no choice. Other doctors out there did not work, they were not used to touch these (children). You had to see that one. Once, she had to continue to see him…till it cost me thousand dollars. Then she recovered from just the bronchitis, just the bronchitis and…you had no choice. Following that, she got diarrhoea… vomiting and did not eat anything. So what, I had to take her out, then it was eight hundred fifty. After coming back, I took her out again, another eight hundred fifty. I really…you try to calculate. It took entirely…she was sick for one whole month. Every time she had bronchitis, it lingered a long time. Now is better, she can see those general doctor that costs one hundred eighty a time. That is a great difference, one hundred eight to compare with eight hundred fifty each time… (11: 84. 1-11)

Yet with time, mothers find that they are able to integrate the new responsibilities into their living routine. They recognize that as the natural obligations of a mother. Rui says,

> Just as… when you have been with him for a longer time, you will not think this way (being difficult in bearing the heavy responsibilities), because after all, he is your child. (2: 106, 10-11)

Mothers accept the responsibility with total willingness. Just as Di says: "willing with whole heart" (心甘情願). (8: 82. 2)

Unique relationship – protecting / disciplining.

When talking about the relationship with their ELBW child, many mothers convey the building up of a unique relationship between mother and child that is not breakable by either. Feng describes her relationship with her daughter who is taken care by her grandmother,

> She does not like to sleep at her grandmother's house, she asks to leave when evening comes. She asks for me, to sleep with me. (4: 52. 1-2)

Proximity with the children is a way to protect the ELBW child. Di conveys,

> "….. At 8 o'clock early in the morning, I got up, went to the hospital and sat there in the ward. I just sat there till six in the evening, just until people would not allow me to go in, then I went home. The next day I repeated the same thing… everyday the same…… everyday was the same. So, one month,

> ten months, it was just like…Being there everyday, in fact I had nothing to do. Sitting there, you were of no help, you could not help anything. But I couldn't help worrying, thinking that I was there watching her…just in case anything happened, I could protect her." (8: 156, 13-22)

Bearing the role of parent, several mothers realize the power of protecting or disciplining. Shu puts it this way,

> We as parents, we had to help him. If we did not help him and gave up, and just let him be if he did not know, then he would not… know how to learn how he would learn… In fact if we as parents, we do not see him and did not care him, and just … rely on that 45 minutes training in the preschool training once a week… basically he could not absorb in that 45 minutes. We have to… return home… I would do what the teacher told me to. I would follow and do the same at home... (10: 74. 1-6)

Yu describes tearfully her own feeling after hitting the child,

> I had beaten him before, but it hurt in my heart after beating him. It really hurts in my heart. (7: 198. 1)

Jing conveys her conflicting behavior and relationship with the child,

> I will hit, I will hit little child, and I will hit in a heavy way… In fact my son is very attached, he is very attached to me. He is… a very good boy. Everyone see him a good boy among others. He is afraid of me, very much because I will hit him… (3: 42. 22-23; 52. 13-14)

However, mothers appreciate their choice over protection and disciplinary actions. Di describes her self control in situations of frustration and anger,

> I was very frustrated for myself, very angry and really frustrated. Yet, no matter how frustrated I would not…I would keep the vexed feeling in my heart. I would not scold them, would not. I would not scold them nor would I beat them… (8:102, 1-3)

Seeking Normalcy and Dignity

Inherent to the journey with extremely-low-birth-weight is a longing for normality with life. Many mothers view their child as no different from others of normal weight. Pei is satisfied with her daughter and says,

> Though she is tiny, everything is normal. At least, she speaks, she walks and she sees normally. It is the most important. (1: 125. 9-10)

Mothers want their children to lead a normal life among ordinary children. Ni says,

> But the development, her previous class teacher said 'She could make it and now…you should be relieved.' As she said, she should be within the average among other children. If she could not then it would be a big trouble…then she has to go to the special school. It would be too bad…. I don't want to go. Because others said that if you go (to the special school), you would become…there would be more problems… But she… at least she could catch up then you should let her be. Don't bother whether she is the last in the class or what. Do not expect she will be the first in there. At least she learns something. (11: 58. 1-4; 60. 1-3)

Despite the effort to maintain normalcy, the child's physical size and the interactions with others at home and outside home often bring their differences to light.

Being viewed as different.

Mothers are very conscious and sensitive being viewed as different. Bao conveys this feeling,

> People outside talked things…that were facts, “Oh, your son is so thin. Wow, you are so fat!” So and so… “Did you eat swallow nest, and this and that? Do you know this and that?” They said lot of things, and most of which were sarcastic. From when he was still small till now… (6: 132. 4-7)

Mothers receive questions and comments when they engage in ‘abnormal’ activities. Jing says,

> There ought to be something wrong when other normal babies go to the hospital. But we are not, we just go for checking up. So at that time, when we were still living there (with in-laws), every time when we went to the hospital, my mother-in-law would be very anxious “What’s wrong again. Don’t go if there is nothing wrong, so and so…” I said that there was nothing, just check up. I myself knew that he was not abnormal. That (follow up) would be something we should do, nothing weird. But others would think “So weird, there is nothing wrong but why to the hospital…” Just like recently he is learning to speak (speech therapy). “He has nothing wrong, why should he learn speaking”… (3: 38. 5-10)

Feng tried to avoid being viewed as abnormal, as different.

> Their views… were different. Because, once I brought the girl back (to her work place), when she was three years old. I did not know whether they showed their regards or what. Every one of them approached me and asked me, and looked at my daughter with very curious views. They looked at her, everyone approached and “This is your daughter and here (her hand) is so and so….” Then I had never brought her back a second time. (4: 80. 2-5)

Qiao describes her impolite response when being viewed as different.

> Some people even…some even… you had asymmetrical, big and small eyes, they could see. They would stare at you, no matter how far you go the staring would follow you. Then I would look at them in return.” (5: 52. 1-2)

Being a ‘small’ mother / feeling ‘small’.

Being the mother of a small child, mothers feel ‘small’ themselves. Bao describes this feeling,

> It seemed that …I was very stupid because of too much…. It seemed that there was nothing I could do…I would look down on myself, find myself being useless… (6: 226. 6; 228. 1)

Mothers hide themselves away to avoid views. Qiao says,

> During the two weeks when he first came back, carrying the oxygen bag….everyone would ask. Perhaps, I had not accepted…why people were looking at him all the time. I was afraid to let people know and I covered his face so that no one could see the tube at the nose. Once when I took him to the doctor and people asked why was his face covered. So, that time, others

> asked when we went for follow up; I said, “Oh, the air outside is polluted, and I am afraid he will breathe in the dust. It’s nothing wrong.” I would not tell that it was the oxygen. I became…I myself had become…just like autism that I dared not see people. I would not see the relatives and friends, avoiding being asked. Every now and then, they would ask “Does he walk yet?” In fact they were showing concerns, but to me it is…being asked so many time and yet he had not walked yet. I did not know how to answer. So, not only taking care of him was difficult, and there were much more pressure from outside too. (5: 4. 10-17)

Feng conveys her fear of exposing the physical defects of the child.

> I would see the hearing aid as very ugly, very unpleasant. So unpleasant that I would not dare to let her wear it. So…now…such…whenever going out, I would not let her wear it. I always covered it up with something for fear that other people could see. I was afraid… (4: 18. 60-92)

Feng recognized this psychological obstacle, yet she was not able to get past it.

> Even I put her photograph on my writing desk, I cover the fingers. They will not see that part. I just don’t know why I had this “ knot in my heart” (心結)… that I could not release. I dared not let people see… (4: 80. 5-8)

Reasoning for being different.

Several mothers reason for the difference. Pei defends her daughter being compared with another term child with low birth weight,

> I said she was born term with four pound while mine was born before due

> date. I see that my child was preterm with two pound while hers was term with four. Term with four pound would be much better as least she was term. You had been “eating” inside for so many months, you are small because you did not gain. My child was born before “adequate” time, she came out while she just started to develop… (1: 58. 2-4)

Yu describes the special requirement of feeding schedule of the ELBW girl,

> She is different from other ordinary children of age 3 years. For them, basically you do not have to plan (the feeding), just breakfast, lunch and dinner that simple. For me, it is different. I have to make the exact schedule at every four hours and give her feeding. Every four hours, here comes the milk feed, or the congee and so… (7: 158. 4-5)

Shu explained to others the comparative small size of her son,

> I said there was a great different. Those of seven months (gestation), in fact they had already developed well. But my son was born….having this and that (problem)…the heart was not close and having a hole… (10: 130. 5-10)

Struggling to be normal.

Mothers try all methods to seek normalcy. Feng tries to hide her daughter’s special needs, escaping the reality. She describes her strategy,

> I did not know if those teachers would admit her. When my daughter went for the admission interview for kindergarten, I did not put on the hearing aid for her. I did not know whether I was cheating the teacher or what. Until my daughter finished the interview and they accepted her, then I gave her back

> the hearing aid. I was afraid that they would not accept her if she was wearing the aid. (4: 54. 3-6)

Mothers strive to push up the development of the child so as to fit the normal world. Shu compares the development of her son with his cousins and seeks way to match the level. She says,

> I will talk with them about the current situation of general children, about how much they learn and the living patterns…So to match where my son is. I am not comparing but I have to know to what level should he has developed at that time. Then I will know… to observe my child when he reaches the level. If not, I will see if I can teach him so that he can catch up. Then later when he enters primary school, he can adapt easier. Primary school is different from kindergarten where they treat you as baby. Therefore now, I am worried he will not adapt when he goes to primary one… (10: 112. 11-15)

To show people that bringing up an ELBW child is possible, Qiao forces herself and pushes her son. Yet, she is aware of the additional difficulties,

> I must have him brought up well, to show the friend and relatives, to show the outside people that it is possible…possible to rear the child. It is not just like what they thought "Is it possible?" I know they have such thought although they do not say it aloud in front of me. Yet the message would be relayed to me through people one by one. So I would have this thought "Well, later, I will bring him back and let you see." It might be the reason, with this added reason, I would force myself and try to push him grow up faster. In turn, it became harder to myself… (5: 44. 8-12)

Blaming self – feeling of guilt / failure.

Mothers put the blame on themselves conveying guilty feelings. Bao blames herself for causing the premature delivery, as she says,

> I felt guilty and I would blame myself why that I had to go back to Taiwan at that time. Because I was very lonely at that time, because I was staying at home all by myself. Everyday… everyday eating the same… I missed the things in Taiwan. I had discomfort over the stomach. When I went back, I ate a lot and became very fat. But the weight just went to myself, and the baby did not absorb any…A lot of the processes…I would think…if I had not done that would it be better. (6: 252. 1-5)

Misunderstandings of in-laws add to Bao's guilty feelings,

> Once when she came and saw him vomit and asked "Was it because the food he ate dirty, or you had not washed those bottles clean?"... My mother-in-law was also looking after other grandchildren, one was three months elder than my son and the other was nine months elder. So in her experience, there should not be any such happenings. So it was hard for her too when she saw her son like that…could not drink anything and getting thinner and thinner. Yes, after returning home, he was getting thinner and thinner. So …that…the guilty feeling grew even heavier… (6: 68. 5-8)

Feng explains that she spoils the child in trying to compensate,

> She had very bad temper, perhaps if it was because I had spoiled her. So she was very irritable, she had very bad temper. My husband had told me not to spoil her. But I did not know, may be I thought…I felt sorry for her and I would love her more… (4: 96. 2-5)

Recognizing / treating child with dignity / fairness.

Mothers suggest the needs of the child to be treated with dignity and fairness. Jing describes,

> I seldom talked with him in earlier days. The therapist asked me “Do you know what the problem was?” I said I knew, it was because I talked too little. Because, when I had nothing to do, I would just sit in the sofa reading magazines and newspaper. He would play with himself over there, or I would ask him take a book and read by himself. I did not talk much. Now I have learned from the therapist, that I have to teach him speak. After I talk more with him, there is much improvement. (3: 88. 10-14)

Qiao shows concern for her son’s individual feelings,

> He can see now and…I will fix the eye for him first when we go out, so that we will not be pointed at. Not for the purpose of pretty, but less …we could hear less those unpleasant things (criticisms). (5: 50. 2-3)

Appreciating Relationship with Family

Introducing an ELBW child in the family, mothers recognize the altered relationship among members.

Relationship with spouse.

When talking about the support from husband, most often mothers make excuses for their husband that they are busy at work and childcare is woman's duty. Bao says,

> When my husband came home after work, because my emotion was very confused and low, sometimes I talked with him… He might not be able to help me. He himself was tired. Sometimes I asked him to help feed the baby, but that was something he mostly did not want. So basically, he could not help anything. (6: 60. 1-3)

Mothers may receive psychological support from husband, but little actual help in childcare. Shu describes this situation,

> When I was not happy…only…I would talk with my husband. Usually if… when I had any thing unhappy I would talk with my husband… (10: 102. 1-4)

> He was afraid that the child was so tiny that he dared not to hold him. He…he did not dare he said…because he was so tiny and soft…When I asked him to feed him he said "Oh No, I am afraid of choking him..." He would have a lot of excuses. Rather than he consoled me, I had to sooth him, "You do this and that and don't be panic." Then…everything I had to relay to him …When I came back (home), sometimes I was not able to take up (the responsibilities), I had to …do the house hold duties. Then when he came home from work and was tired, I would not ask him to help. When he was not tired, I would say, "The teacher said he had to do this and …" If he was not tired, I would say "The teacher said that today he has to do those training

> and so and so, so you do it with the boy… You do this with him, do the training with him and play with him.”…Say when I was preparing dinner or doing other things, I would ask him to be with the son and he would act just like a robot…. He was willing to help, so sometimes I would think if I was on my own…I would not be able to handle. And he was such… a child requiring so much attention and care and not like other children… (10: 154. 3-11)

Similarly, Jing perceived herself to have no support in child care from her husband.

> He said he was tired after work, standing all day selling things. I said, “Don’t think that only you are tired, I was tired too, I was tired waiting for you at home.”… Even during holiday, he would not help. He did not know how. Till now my son is three years old, he has never bathed him. Only because I had to stay in hospital for delivery of this baby girl. He… no escape this time… they were staying at home together and he had to bathe her... It may be the traditional concept of his family that the mother has to do all the things… Even after the child was born, he would not initiate to hold the baby when the baby cries. (3: 44. 3-10)

Relationship with in-laws.

Introducing an extremely low birth weight child into the family causes misunderstanding and conflict between mothers and the in-laws. The conflicts are obvious in the two mothers who came to Hong Kong after marriage. Jing conveys the relationship was especially difficult when the extremely low birth weight child returned home and they were living with the in-laws under the same roof,

> I don’t want my mother-in-law to touch to help. I don’t want her help. Perhaps it was my problem. But I don’t want her help me. Yet I had to hurry with washing the bottles, boiling the bottles. But I had to wait because the kitchen was small. When she was inside there I did not want to squeeze in there together with her. I did not want to be in there doing my thing while she was doing hers. Therefore I would always wait till late at night to do my things. My mother-in-law would ask: “Why not do it in the day time but now? Do it tomorrow.” I would not say a word. So at night, I would boil the bottles, do the washing. I did not like to wash the clothing together with theirs. Before that I would help them the washing. Moreover, she once said to me that I should not mix my clothing with the men’s to wash. I had to wash them separately. Why should there still be such thought nowadays. When I wash my husband’s clothing, she saw it when I took them out. She was not happy and said “Didn’t I tell you that you should not wash the clothing together? Now you are washing them together.” Therefore, I did all the work late at night. (3: 32. 9-18)

Jing’s difficult relationship with her mother-in-law is not without reason. She describes the condemnation from her mother-in-law,

> My mother-in-law told the nurse, “His mother (Jing) does not like to see the baby.”…and then at home, in front of me, she cried and said, “Other people have twins, we have twins; others have no problem, why it is like that for us….I don’t know what have you done. Something wicked…”…so and so…Then I was really unhappy. (3: 28. 9-12)

Bao describes her unpleasant experience when the child is criticized by the in-law family members,

> Some family members would say… said the child… so and so. Sometimes they talked about my son…something unpleasant. My son, ever since he was small, had big nostrils. “So big the nostrils. Always see you having cold…running nose… and the ‘hiu hiu’ sounds. Why would you be like that?” Perhaps, those adults might say it loosely without meaning, but I would feel that… Why would you say that to my son? I would be very upset… (6: 124. 2-4)

Feng depends much on her mother-in-law though she disagrees about childcare,

> I had said many times but grandmother did not let her wear it (hearing aid). Then I could only put her on the aid during holidays when I was at home. So…so …I talked to Mrs. Chang (the social worker) and I said, “Grandmother would not put it on for her. You talk to her.” I said, “It’d be better you talk to her. I had talked to her for many times but she would not listen to me.” Then grandmother now accepted… In fact grandmother had paid great effort and she helped me sometimes. She took her for physiotherapy and so. I had to work and I could not go with her too often. I could take her at most once a week, and together with grandmother. Yet it was grandmother who brought her for the care every time. I could not help, because I had to work and could not have day off too often. (4: 18. 69-75; 18. 89-92)

Relationship with maiden family.

Most mothers receive positive advice, encouragement and support from their own maiden family, especially their own mothers. Shu describes the help,

> My mother is different, she loves children. So if there is emotion, it will be

> better to have someone to talk with you, someone who concerns and talks with you. And my mother will seek information from around and says "So and so is also that small. Don't worry." (10: 100. 2-4)

Relationship with siblings of the child.

Mothers convey a feeling of guilt if the other sibling of the child still requires care from the mother. If the sibling is already grown up, mothers receive support and help. Rui questions if the performance of the elder son is affected because she might have paid less attention to him,

> I don't know if he was affected. Because he (the elder son), when he was small I thought he was all right. But now I notice that his school performance is getting worse. He does not concentrate on his study. But I don't know… when I look back, in fact his performance was not too bad when he was in primary one and two. But now I notice his school performance is bad… Sometimes I would think would it be because I had not spent adequate time on him. But it seemed not true; in fact I did spend plenty of time on his schoolwork. In fact I don't know… (2: 150. 1-7)

It is great encouragement to receive support from the sibling of the ELBW child. Qiao tells of her elder son's attitude,

> My elder son is now study in university. At that time, he was only fifteen. When we went to the hospital and saw that the baby was so small, he begged the doctor "Please save him. No matter what will happen to him, I will take care of him." I felt so much comforted. (5: 12. 5-7)

Interacting with Health Care Systems

Mothers living with extremely-low-birth-weight have frequent interactions with health care professionals and the health care system. ELBW children, after retuning home from the long hospitalization since birth, require regular follow up in the health care setting to monitor the ongoing progress and developmental status. Children with unresolved or chronic medical problems may need frequent visits to the doctors for treatment, and sometimes may need hospitalization for diagnostic studies or interventions of acute problems. Through these continuous interactions, the relationship with healthcare professionals becomes part of the mother's lived experience. Mothers describe positive and negative interactions in their ongoing relationship with health care professionals.

Feeling supported / neglected.

Positive interactions with health care professionals are identified as situations encompassing traits that have meaning for the mother. The situations occur at critical periods particularly in the course of the child's hospitalization. The positive interactions are described as situations fostering support, understanding and caring. Ni describes how well her girl was cared for,

> Those nurses, particular that nurse Ma, loved her very much. She was naughty, she would not sleep at night even she was tired. She slept at daytime.

> The nurse would cuddle her and sing to her all night till morning. How naughty she was! In the NICU, the nurses were perfectly good. You could not do the job if you did not have a loving heart. Once the alarm was on, they would rush and look at her. I must thank you nurses and doctors… (11: 20. 1-5)

Mothers of ELBW child are often seeking compassion, which is often conveyed to the mothers in the little gestures of care or a few words of encouragement. Qiao reveals her experience,

> In the NICU, the nurses were very good. They were better as compared with….They knew how to reassure the mothers….might be they were well trained. So in there, they not only cared about your baby, they cared about the mother. They always consoled and comforted the mothers…I appreciated that the nurses would send me Christmas card every year and I would return them photographs. They gave the most help, and the doctors. Both the doctors and nurses would be appreciated. If not because of them, he would not have developed healthily as such... (5: 2. 1-6)

Interactions that mothers convey as particularly negative are situations in which they perceive their child being neglected. Qiao repeats,

> I do not know if it is because I do not trust people or what. When he was in the hospital, I would leave only when they closed the door. I could not help worrying. I was afraid whether the nurses would be able to keep an eye on my child because one nurse had to take care so many babies… He cried all the time. When he cried he would kick and strike on the bed. I was afraid he would hit his head against the bars so I padded the bedsides with napkins, with a whole bag of napkins. Yet when I came the next day morning, his head was all red and blue, because the napkins were printed with several colors.

> The entire head was full of the colors. I thought if I had not padded the napkins, would his head get hurt… (5: 72. 1-9)

Challenging / comparing.

Through interactions with health care professionals in different settings, mothers compare and make ratings. Ni describes the difference between the two clinics where her child receive injections,

> She had the injection every month, the injection of B12... The monthly injection made her scared…the shots in the buttock. She could not have in the thigh, once she shook and twitched when they shot in the thigh. The doctor said "Sure, give it in the buttock, she is skinny." …Sometimes, it is troublesome. We had asked …the doctor for the prescription. We were very… troublesome sometimes. When we went to the child health center for the injection…the clinic in District A was better, the nurses there were good. But in the nurse in District B, I do not know whether she was trying to abase me. The doctor had stated clearly in the prescription …the date for the injection. There should not be any problem… But she requested that the prescription should state clearly… till when the injection should be given. However, the doctor in the hospital said 'I do not know till when she should have the injection.' He said 'You don't have to pay attention to her…(11: 64. 3-12)

Mothers also challenge the attitude of health care professionals. Qiao describes her experience of an encounter with a healthcare professional,

> One time when I went to the health clinic, the doctor said, "Do you know

> that you have wasted a lot of resources.” So he said. Do you thing I want it like that? I also know that it used up a lot of resources. But you don’t have to say that so straight forward… (5: 36. 2-4)

Taking control / losing control.

Through the experience, mothers gain expertise in caring for their child. As mothers acquire expertise, issues begin to arise within their encounters with health care professionals. Mothers may not be expert in the complex medical interventions, but they are keen on their consistent and attentive observations of the child’s minuscule changes and subtle progress. Control is an issue that mothers struggle with. Mothers take control over certain situations when they consider for the best benefit of the child. Qiao recalls,

> The doctor did not let me go, but I begged him for discharge. I said “I will do anything you need. I will move to new house, I will buy new furniture”…It was because my baby had never smiled in the hospital. And he did not sleep well there because it was very noisy. Those computers (monitors) were very noisy. It would alarm whenever it (the indicator) dropped. And those babies next bed would cry. Then I took him back…When we returned for follow up, we did not use it (oxygen) anymore…after about half a month. Usually when he had ninety or ninety-two (percent of oxygen concentration) he did not need the oxygen. In the hospital, when other babies cried, he cried. Once he cried, he needed more oxygen. In fact, he could do without it earlier. Most of the time, during the doctor’s round, they would asked to try removing the oxygen. But the nurses would not dare to, just in case he could not make it, because whenever he cried, it (oxygen concentration in blood) would

> decrease. And he did not cried when he returned home. He even smiled, and he slept well. So about half a month, it (oxygen) was no longer needed and I returned the machine. (5: 46. 1-11)

Feng explains how she came to take control of certain logistic arrangement,

> She had been undertaking the occupational therapy, but later…I thought that she might not need that. Sometimes I found that she was able to write … those things I could teach her at home. So we did not have to take the traveling and which was quite tiring to her grandmother. Within one week, she had to go for occupational therapy and physiotherapy, that would be too tiring going here and there. (4: 18. 92-96)

Expecting more / suggestion.

Through their experience, mothers convey the view that they expect more from health care professionals and they give suggestions. Bao suggests this,

> If I had the information on the issue earlier…though I was a nurse… Perhaps I might not know that I had this kind of condition…those problems of depression. My own emotions, all along, I was not able to manage properly. So when I faced the child, it seemed that the only thought was “could not be saved”… “Could not be saved”. Yes I had that attitude. If it were like what you said, it would be good and appropriate. If in the early days, there was those kind of education (to mothers with premature babies), perhaps, for more family members, and our families such as my mother-in-law and so… If you let me talk, it would not be convincing. If it were added with the perspectives of nurses, it would be better. It would be convincing, giving them the knowledge. ... In the hospital, if I …I had such condition, being

> educated first, perhaps I would not have had too…just as you said, too much those negative perspectives. (6: 220. 1-8)

Isolating and Loneliness

Throughout the journey of nurturing the ELBW child, mothers often face isolation within their own communities and fatigue resulting from managing their own emotional situations.

Feeling rejected / left out.

The greatest isolation and loneliness mothers perceive are within their family when they feel rejected by family members. Qiao describes her expectations of being accepted by family.

> The most important is that everyone will count him a share, will not look down on him, not like him. It's just that simple. If even the family members would not accept him, then I would be very upset. If you would care about him, although it was I who do the job, whether you would care or not, I would be very miserable if you would not care about him. The outside people have already viewed him strangely. If when you were at home it were the same, it would be too bad. Therefore family members are more important than those from outside. (5: 58. 2-7)

Jing expresses her feeling of being isolated in between her husband and her in-laws,

> I did not have my families (maiden family) here and I had no one to talk with. What my mother-in-law said to me, I had not told my husband. Because if I told him, whom he would believe? Me or his mother? So I did not say anything. So I had nowhere to talk when I was unhappy. And I did not want to tell my mother... (3: 28. 12-15)

Inadequate support from husbands can be an issue. Bao feels helpless and left out especially when taking care of her child alone at night,

> He would cry nonstop sometimes at night. Since my husband …my husband sometimes would be away for business trip, one whole week for the trip. He was not…and sometimes at night…nobody was here leaving me alone. I had to take care of the child by myself… It was very difficult for me to control his crying. At night, he would keep on crying for an hour. I did not know the reason. Sometimes, I would be there holding him like an idiot. Because, perhaps, if, sometimes my husband was at home, perhaps my feeling would be better, more sense of security. If only one, only one person to face the situation, once he cried I would not know what was wrong with him, and I would be more nervous… (6: 40. 1-2; 84. 1-4)

Maintaining silence.

Some mothers prefer not to talk with people regarding the extremely-low-birth-weight experience as they felt they are not understood. Ni says,

> It was not necessary to talk. But it was the parents day, they could listen what I told the teacher so they knew. Sometimes I would not talk, there was nothing to say. They said “Oh, you are so tiny.” I said of course he was tiny as he was so early… sometimes I would chat a bit but sometimes I would not. I would not purposely tell people, I thought it would not be necessary. (11: 206. 1-3)

Jing prefers to maintain silence until the issue would not be perceived as her concern, then she would discuss it,

> When I would talk about it, that issue would not be of any concern to me… when I would not mind any more… when it would not border me… would not be of any influence on me any more. Then I would talk… just like general talking… not of my concern. Then I would talk. If I were still concerned very much about it, usually I would not talk. (3: 98. 8-10)

Feng would not talk so as to avoid exposing the defects of her girl.

> I do not want people to see that she is different from others. Thus, to avoid… avoid to give so much explanation because they would ask ‘Why is like that?’ and so… Some colleagues did ask, but I did not want to answer. She thought that I would tell all to other people. I said, “Why should I tell people about my matters. Everyone has own privacy.” Indeed, only to very good friend, I will talk about it. Otherwise, it is not necessary for me to tell people. (4: 80. 1-2; 130. 1-3)

Given the poor relationship with the in-laws, mothers often prefer to keep silent and not talk about their feelings with husbands. Bao says,

> It is not easy to tell because… there is problem in the relationship between his family and I. Perhaps… because I have telling him that, ‘Your families

> are having negative… negative perceptions…' So… sometimes may be… If I really have to express myself… I do not… I would not discuss this issue… (6: 118. 1-3)

Retreating from social / restricted freedom.

Mothers of ELBW child perceive their freedom as being restricted for they are unable to participate in certain usual activities. They retreat from social activities as they try to protect the child with low resistance from getting sick in the 'unsafe' environment as well as to avoid unnecessary pressure on themselves. Pei noted that her retreat from social activities influences the elder daughter,

> Not going out…so having less freedom. It was not good to my elder daughter, not fair to my elder daughter. To the elder… I couldn't help. I would not go out …I could not take her out…so I could not go and she could not go neither. (1: 119. 5-6)

The perceived low body resistance of the ELWB is a factor that keeps the mother away from social activities. Bao describe her concerns,

> The external activities have decreased. The friends…some friends are in Taiwan, and my mother, I seldom contact them now. Because his body is not so…not like other children. Sometimes when we get back after going out, not long later he will get fever. It is strange and I do not know why. Therefore, becoming less, now I have less contact with my old friends. The social circle becomes smaller. (6: 98. 1-4)

Jing conveys the view that her retreat from social contact with the in-laws, triggers reactions of discontent from her family,

> So I took the child by myself. I would retreat in my room. I did not like to have any (contact)… with them. So they had lots to say at that time, “Not even allow the grandparents to hold the baby…so and so” … And they also said that I rarely brought the baby out to let people see… (3: 30. 14-17)

Qiao withdraws from and avoids social contact, to avoid ‘face losing’.

> It was New Year and people would come and visit. He was using oxygen, we have hired an oxygen machine at home. It would be face losing…so I did not want others to come. So that year, I told people “Do not come this year, come again next year.” Pressure is there, when you have lot of relative and friends, it is problem…” (5: 46. 13-16)

Unique Experience – Not being Understood

Bringing up an ELBW child is a unique experience to the mothers and other people may not understand the pressure involved. Most mothers perceive that other people do not have this uncommon experience, and so would not understand and would not be able to help. Rui claims that she did not receive any advice from others,

> In fact, no (advice from others received). Because nobody had ever experienced it. They were not able to share any experience with you. (2: 180. 1)

This is not a common experience and the related information is less. Shu says,

> She did not…did not have this personal experience. She actually did not have such information, and would not talk about… when you do not have such contact or not hear of such information in you everyday life… (10: 112. 1-2)

To Jing, this unique experience cannot not be understood by others and she does not bother to explain,

> People would not understand, would not pardon you because you were taking care of a premature baby. People viewed you as having a normal one. My mother-in-law and they said ‘Others raise baby, you raise baby, why do you have special way?’ I could say nothing. You see my son and you are not…you won’t understand. It would be useless to say too much. Wasting my “saliva” (energy to explain). (3: 30. 34-36)

Qiao sees caring for an ELBW child as a unique experience that others will not understand, yet she cannot explain,

> I did not know how to explain to others. Every now and then others would ask. Others would not understand that he was born so tiny. Perhaps others would only think ‘Even he was born small, he could survive till that big, and then he should be normal’ but it was process that they would not understand at all. (5: 8. 5-7)

Interpretive Reflection: Changing Relationships for Child Caring

> *Man is but a network of relationships, and these alone matter to him.*
>
> *(A. de Saint-Exupery, cited by Merleau-Ponty, 1962, p. 456)*

“The context of a person’s life is peopled, and the concerns that connect the individual to others shift with time” (Benner & Wrubel, 1989, p. 139). The challenges inherent in the experience of extremely-low-birth-weight creates a tremendous need in the mothers to develop a community of friends and family who are supportive and caring, who show by their words and actions that they will be with the mother and child throughout the physical and emotional thrilling journey.

Caring is the essence of humanity, and it is essential for human growth and survival (Leininger, 1988). Halldorsdottir (1991) states the modes of being with another in our world involve both caring and uncaring dimensions. The five basic modes of being with another are determined as life giving (biogenic), life-sustaining (bioactive), life-neutral (biopassive), life-restraining (biostatic) and life-destroying (biocidic). In Benner and Wrubel (1989), caring is described as the basis for altruism instead of altruism being the basis of caring. When the person is phenomenologically viewed as related to others and defined by those relationships, concern for others is not necessarily oppositional to or competitive with self interest. Caring for others contributes to a world where one can care and expect to be cared for. According to Watson (1985), among the basic psychosocial needs and behavioral systems identified with living, affiliation need being the closest to humanism, basically assumes that people need people. People need each other in a caring and loving way. A person needs to love, respect, care for him / herself, and treat him / herself with dignity, before the person can respect, love and care for others and treat them with dignity (Watson, 1999). Mothers in the study recognize the relationship with family, friends and the community. They find unfailing support and encouraging contacts; on the other hand they are exposed to insensitive comments and blunt questions. Several mothers experienced isolation and indifference that often led to feelings of powerless and humiliation; and the intensity of injury increases if the source is from close proximity such as their own families. Many mothers perceive never-ending support from their own maiden family especially from their own mothers. Mothers counteract these feelings of isolation and powerless by retreating passively or develop another circle of friends whom they can share their world in an active way. Benner and Wrubel (1989) state that when person gets ill, the person automatically takes membership in a new community in addition to the social world the person inhabits prior to becoming ill, and they can feel less stigmatized. This phenomenon applies to the mothers of extremely low birth weight child as well even though they were not ill themselves.

Health professionals including nurses have been taught to and yet commented for avoiding personal interactions, and personal interactions as personal involvement is considered unprofessional. Watson (1999) advocates that the professional transpersonal caring relationship between the nurse and person within that the personal involvement of the nurse / person is directed away from one’s own self toward the other’s self. The nurse’ s feelings may be experienced and felt, not as a way of obtaining relief or help form patients, but as a part of being and becoming in the relationship. Apart from the world of family and friends, mother of extremely-low-birth-weight must also learn to survive in the world of health care system. Mothers enter the challenge of the strange world of white coats and uniforms, monitors and machinery, medications and procedures, and the altering states of anxiety as related to the unanticipated changes of the child. Mothers develop a close but distance relationship with the healthcare professionals.

According to Hallodorsdottir (1991) caring is a human mode of being with another and that is essential to human development. Caring is the total human mode of being and relating; a quality of engaging and investing in the other person. Mothers living with extremely-low-birth-weight seek relationships that are authentic, these may be relationships with family, friends and healthcare professionals. Mothers seek to find investment from others in their life. Through relationships with others, mothers connect with the world and gain courage to survive and sustain life:

> *"A man who becomes conscious of the responsibility he bears toward a human being who affectionately waits for him, or to an unfinished work, will never be able to throw away his life. He knows the 'why' for his existence, and will be able to bear almost any 'how'". (Frankl, 1984, p.101)*

The Fourth Theme:

Interacting with the Environment – Anticipating and Intervening

In the phenomenology literature, “lived space” is the felt space, the existential theme that refers people to the world or landscape in which people move to find themselves at home, the secure inner sanctity where people can feel protected and by themselves (van Manen, 1990). Lived space is cultural and social conventions in association, that give the experience of space a certain qualitative dimension. Lived space is a category for inquiring into the ways that people experience the affairs of their day to day existence, so to uncover more fundamental meaning dimensions of lived life (van Manen, 1990).

For mothers with ELWB children, lived space is a sense of interacting with the environment, transforming the experience through altering and merging into the environment.   Mothers’ sense of safety in the “home” and the threats in the “outside home” environment are revealed through their interaction with the felt space. The themes encompassed in this metatheme are seeing the threat / influence of the environment, being more anticipatory, and modifying / limiting (See Table 5.7 below).

Table 5.7: Metatheme 4 - Interacting with the Environment – Anticipating and Intervening

Thematic Structure
Seeing the threat / influence in environment
Being more anticipatory
Modifying / limiting

Descriptive Reflection: Being Aware of the Environment

> *Lived space is the existential theme that refers us to the world or landscape in which human beings move and find themselves at home.*
>
> *(van Manen, 1990, p.102)*

Seeing the Threat / Influence in the Environment

A person's relationship with the environment is ongoing yet taken for granted often. For mothers of ELBW children, the environment becomes something that is viewed in the context of the threats it poses. Rui describes the natural seasonal changes as threats to be avoided,

> In summer, we would not go to places of hot weather for fear of too hot. In Winter, we were concerned that it would be too cold. So we could not go anywhere. (2: 78. 2-4)

Living with the experience of extremely-low-birth-weight, mothers learn from their experience regarding the environment and the physical well being of the child. Feng says,

> When the weather changes, I am worried when the weather changes, the problems of lungs and air passage will come….. Every time after going out with her, I would be very stressful. Every time after going for activities with her, she would get sick. I was not sure whether it was because I brought her to the restaurant. I did not know if it was because I did not bring her out then she was not used to the air outside. I was worried that she was not used to the outside air. (4: 60. 6-9)

The threat of the environment includes all the objects that will be in contact with the child. Ni discovers that the stationary used in the school poses a threat to her daughter,

> She had allergy at the beginning and the skin was poor … seeing many doctors then…taking the topical medication from the hospital and it was just…it was just the same and not improved. Then subsequently…tried to investigate whether it was… those glue and the color crayon… So…I brought that bottle… of soap recommended by the doctor to her to wash. Then she had not any problem… (11: 128. 1-2)

Mothers recognize the need to prevent accidents. Yu explains,

> She does not let me hold on my hand. She runs all around carelessly once she is landed on the ground. Therefore, I will hold her in my arms….She always stumbles, she stumbles if she walks by herself…. (7: 78. 1; 80. 1)

Environment not only refers to the physical space, it includes a certain qualitative dimension in which we find ourselves and which affects the way we feel (van Manen, 1990). Mothers recognize risk in the environment related to certain psychological threats. Home is often considered to be the most secure and safe environment where we can feel protected by ourselves. The relationship among family members changes the environment in the home. Living under the same roof with the in-laws whom she has conflict with, Jing describes with frustration what she experienced within the four walls where she had shelter yet still suffered,

> Being in there, perhaps it is the problem of my mind set. Within one house, within one room, all the activities were there. In there, he vomits, sometimes he cries, and I have to clean the floor and do the washing… (3: 32. 7-8)

Mothers perceive the environment as threatening after they experience unpleasant encounters in that certain places. Qiao recalls,

> When you went out, people would look at you. At that time, the eye (prosthesis) was not fixed yet. So it seemed that he had asymmetrical, big and small eyes. In the garden, a child, might be he was small and did not understand, approached and said “Mommy you see, the child was blind!”. At that time, I used to go to the garden with him every morning, but after that incident, I had not been there for a period. Luckily that he did not understand. I would think about his feelings if he understood. Not even I could accept, would he accept if he knew? (5: 48. 1-5)

Being More Anticipatory

Most mothers talked about the awareness of threats within the environment that will cause harm to the child’s well being. Mothers are well aware of the low resistance of the ELBW child so they avoid the potential triggers within the environment. The food, the air, the weather changes and the proximity to medical care are all their concerns. Wei reflects this concern,

> I would not dare to take her out…until… I took her out when she became bigger. I dared go out with her for fear of the bacteria outside. The air was not good… (9: 36. 8-9)

Ni describes the lesson learned after Yu-yin had a severe reaction following mosquito bite,

> She is rather allergic sensitive. “Next time you go there, bring along those medication with you.” So the doctor said. I was smart that I had already requested from the doctor and brought along those drugs for common cold, cough, fever, diarrhoea and vomiting. In case any thing happened… (11: 130. 5-7)

Qiao describes her preparation for Feng-xiao’ return home,

> I used to live in those old building (without elevator but only very straight staircase) in Kowloon City. I purposely moved to this present place where there was elevator. I was worried what we should do if we had to go to the emergency department late in the midnight. (5: 42. 2-3)

Modifying / Limiting

Anticipating the threats and realizing the limitations of the ELBW child, mothers modify the living to fit their need. As Feng says,

> I will not use air conditioning now. A lot of living habits are changed. Now, I

> will not switch on the air conditioning even it is more than 30 degrees for fear that she will catch a cold. Yes, instead we will use electric fan. I will fan her, do sponging for her and dry her body. I am afraid that she will catch cold if I use air conditioning. I will not use air conditioning when she sleeps because she will turn around and drop the blanket and then catch cold. Now, a lot of habits are different. (4: 64. 8-12)

Interpretive Reflection: Interacting with the Environment

> *We are our environment; the human-environment is one field, and our positive and / or negative approaches to life are revealed in the very structure of our consciousness and environment, our world. (Watson, 2005, p.99)*

Nightingale (1992) views the environment as the encompassing context in which people live. She views the environment in a broader perspective, not only the physical environmental conditions like cleanliness, light, air and water. Environment includes also the construction and management of the organization. Nightingale comments that a person’s health or illness is a result of the environmental influence. For mothers in this study, the environment is consciously evaluated for its threats to the physical well being to the child. Through the attempts to control the environmental patterns that pose threat on the well being of the child, the mothers learn the patterns and recognize the child’s limits within the environment.

Van Manen (1990) discusses that lived space is the existential theme that refers human to the world or landscape in which human move and find themselves at home. The felt space is no longer the mathematical space in the dimension of length, width and depth. It refers as a category for inquiring into the ways we experience the affair of our day to day experience. There are the cultural and social conventions associated with space that gives the experience of space a certain qualitative dimension.

Many mothers in the study perceive psychological threats in the environment, that poses a sense of insecurity to themselves. Familiar with the environmental rhythms within their life, mothers appreciate method to manage these threats in a way that harmonious with their living patterns.

Watson (2005) suggests that people are their environment and the human-environment is one field. People are left to ponder how their consciousness is affecting their inner life and those of others in their field. People are participants throughout their own field of consciousness, creating their human-environmental field, for better or for worse.

The Fifth Theme:
Getting To Know and Understand

Within the experience of mothers living with ELBW children, there emerges a

Table 5.8: Metatheme 5 - Getting To Know and Understand

Thematic Structure
Lacking prior information
Seeking information
Sharing for similar experience
Gaining knowledge through experience
Using knowledge / applying knowledge
Bring meaning to the situation

sense of searching for meaning in life, mothers' seeking to capture knowledge on extremely-low-birth-weight for a better and clearer picture of the way ahead. This theme emerges to reflect that for mothers living with extremely-low-birth-weight experience, experiential knowledge is gained through living with extremely-low-birth-weight as a form of practical knowing. The themes under this metatheme are: lacking prior information, seeking information, sharing for similar experience, gaining knowledge through experience, using knowledge / applying knowledge, bringing meaning to the situation (See Table 5.8 above).

Descriptive Reflection: Getting to Know and Understand

> *Because we are in the world, we are condemned to meaning, and we cannot do or say anything without its acquiring a name in history.*
>
> *(Merleau-Ponty, 1962, p. xix)*

Lacking Prior Information

From the very first time the mothers witness extremely-low-birth-weight in the neonatal intensive care unit, they realize that they are encountering some kind of new experience that they have no prior information. Pei describes the experience,

> At that time, I would not think of so many after effects, would not think all this because I had not seen, had no previous contact. Seeing such scene in the television, I would ask why that the child be inserted with all these things. So horrible the baby! You would never know that your own child would be like that now. (1: 88. 18-20)

Feng notes**,**

> I did not know why the premature baby would have such low birth weight … I had never thought why that I would have premature labor. Would premature delivery be inherited? (4: 22 .1; 24. 1)

Yu says,

> I had never imaged there would be such a tiny baby. If not because I had such a baby, I would not notice others. Seeing my own child, now, I would start to notice those babies who were small. I had not realized and did not know whether other people would be aware. I had seldom heard about neither. (7: 144. 2-4)

As the child grows, mothers continue to meet new experiences that they do not possess the know-how to deal with. Shu says,

> In fact I did not know all these preschool education. I was referred to the assessment centre through the hospital. I did not know this was called

> preschool education… in fact that my child could apply …ever since birth. I did know even know… once the child was born and I could apply. Not until we got there we knew, if needed in any aspect, you could get the training from newborn to six years old. I then noticed that I was late already. So ignorant I was that I did not know anything... those people who do not know would miss the chance in fact… it should be the younger you teach him the better... We did not know, we did not have this kind of information before. (10: 108. 1-2; 12-13; 17-19)

Seeking Information

Inherent to the mothers' narratives is the lack of the availability of information regarding extremely-low-birth-weight. Mothers seek to learn more to gain understanding of the situation. Mothers seek information from various sources, including health care workers, families and friends, social workers, other mothers of extremely low birth weight child, books and media. Jing recalls,

> I had asked the doctor and he said that 'May be, to simply explain that there is a door in the stomach. He was small and premature, and the door has not yet developed in complete shape. As the child grows it will develop, then he will not vomit anymore.' And I accept this sort of explanation. (3: 34. 3-7)

Feng seeks information from professionals,

> When I have questions I will ask the social worker. I will phone and ask her which kind of school I should choose. Ask her to give me advices. (4: 124. 1-2)

Qiao seeks information through reading,

> I read a book a few days ago. It was about a mother whose child was having those muscular contracture or what. He was already five or six and still using the baby stroller. People in the street said 'Oh, he is so big and still using the stroller. You are spoiling the child.' The mother said, 'Yes, I am spoiling him. So what?' They did not know he could not walk. She said 'I love him very much.' She said that this sentence was for her boy to let him know that his mother was the one who care him most. So, this kind of books and TV programs are really good. (5: 52. 2-6)

Mothers grasp every opportunity to seek information. The researcher of this study, being a nurse, was another source of information during the interview. Pei asked,

> I want to ask you what food we should eat. What food will be better for her? (1: 141. 1-2)

Di questions,

> I do not know what is going on with other children. Did you interview other people? (8: 150. 1-2)

Sharing for Similar Experience

Mothers of an ELBW child gain a sense of knowing through experience sharing from other mothers of similar situations.

Bao recalls,

> Talking with those mothers…we knew some mothers when we were in the

> hospitals. Every now and then we will talk in the phone. 'How tall is your girl now? How's her eating?' We keep in contact and sometimes will go out and chat. We will interchange our feelings regarding the childcare. (6: 234. 2-4)

Gaining Knowledge through Experience

Through their own experience of trial and error, mothers acquire the skills in caring for the ELBW child. Xiao says,

> In fact I have tried many methods and tried to sort out what food to eat. It was until later that I found that if he did not have bowel open, I should not force him eat so much. In the old time, whenever I knew he did not have bowel open, I would give him lots of vegetable and fibers thinking that it would… But later I found it was the opposite. If you made him eat too much, the feces would become too hard and he could not pass out. In turn, I tried another method… eat less and let his stomach rest, and it might be better. (12: 132. 2-7)

Using Knowledge / Applying Knowledge

Acquiring knowledge, mothers note that the subsequent application of this knowledge is important. They acknowledge the usefulness of the knowledge and reveal their ability to put into practice. Bao explains,

> The knowledge should be able to help me. But if… I thought…it was

> because I could not get through the barrier. So , when I had to face the situation, even I had the knowledge, I was not able to put into practice within my own notions and concepts. (6: 172. 1-3)

Bringing Meaning to the Situation

Reflecting on what it would be like if the child had not been born prematurely, mothers recognize life with a positive meaning and perceive positive gaining from the experience. Meaning comes with knowing that something positive can be made from the experience. Bringing meaning to extremely-low-birth-weight makes the experience a reality. Xiao describe her reflection on the experience,

> But sometimes I think….I really have more experience than others…sometimes I will think back. So I say I have a lot… Sometimes when recalling, I feel…although it was miserable at that time, yet I feel quite… interesting. Basically, other people do not have such experience. In fact, you really have gained a lot of knowledge…Although it had been a hard time, I found it quite interesting. Others would not have this experience. In fact you have really seen more … really more because you … in those months…had always been in and out the NICU. You had really seen more things … you had learned a lot. (12: 178. 1-5)

Interpretive Reflection: Grasping the Meaning of Life

> *Meaning, structured by fore-having, fore-sight, and fore-conception, is the*

> *upon which of the project in terms of which something becomes intelligible as something. (Heidegger, 1996, p. 142)*

The situation of uncertain cure is made more difficult by the fact that it is not simply a situation of mental uncertainty in a stable situation. Living with uncertain cure can greatly affect the person's passage through normative life situations when those situations involve personal choice (Benner & Wrubel, 1989). The role of information is to reduce emotional response to stressful procedures that are often unavoidable in healthcare processes by promoting accurate expectations, increasing ability to predict and control, fostering realistic worries, reducing dreadful fantasies and leading sufferers to an intellectual understanding and evaluation of the situation (Watson, 1985). Without prior experience, the mothers participating in the study strive to seek for a meaning for the unknowns and uncertainties for the unplanned delivery and the unanticipated future of the child.

A person may have an illness that is "completely hidden from our eyes." To find solutions it is necessary to find meanings. A person's human predicament may not be related to the external world as much as the person's inner world as he or she experiences it (Watson, 1999). In this study, the mothers' knowledge is accrued over time and the mothers were often unaware of this process of acquisition, at least in the beginning. Mothers learn new possibilities in the context of practices that they become familiar with. Mothers learn from others through a range of response and interactions and meanings are gained.

Merleau-Ponty (1964) describes the understanding of experience as “the word is not understood or even heard unless the subject is ready to pronounce it himself” (p. 134). For mothers of an ELBW child, physical problems, medical interventions and the related knowledge become inextricably intertwined. Mothers experience situations related to extremely-low-birth-weight throughout their day-to-day living. Experiential knowledge is gained through living with extremely-low-birth-weight and is a form of practical knowing (Benner & Wrubel, 1989). Mothers who cope with extremely-low-birth-weight over time develop certain language patterns, habits, practices and expectations. Mothers develop a practical knowledge about how to live with extremely-low-birth-weight.

Information-seeking is a major coping strategy especially in fast moving and highly technical societies. New knowledge is generated about health hazards and health promotion. Each person needs to access this information to plan and respond to the challenges and changes (Benner & Wrubel, 1989).

Mothers in the study tend to seek optimal way to communicate with health care professionals. Mothers talk about their observations and recommendations for the medical care of the child and to the health care system. Mothers become expert in the care of their own child and seek to share their experience and knowledge in exchanging ideas with health care professionals.

The Sixth Theme:

Asserting Life in Pending Loss

Table 5.9: Metatheme 6 - Asserting Life in Pending Loss

Thematic Structure
Experiencing the ‘near loss’
Grieving with the loss
Recognizing / living with reality
Realizing gift of normalcy / life
Emphasizing the positives
Planning of future

Given the notion of living with uncertainty, extremely-low-birth-weight brings into nearness the possibility of loss or pending loss to the mothers. For mothers living with extremely-low-birth-weight, life and death are intertwined. In understanding the loss and near loss, mothers come to realize the meaning of life. The themes under this metatheme are: experiencing the ‘near loss’, grieving with the loss, recognizing / living the reality, realizing the gift of normalcy / life, emphasizing the positives, and planning for the future (See Table 5.9 above).

Descriptive Reflection: Experiencing the ‘Near Loss’

> *In fact I was bleeding deadly. The doctor said that if I were one step late, my life would be lost. (Feng – Mother of Yi-jie)*

Experiencing the ‘Near Loss’

For the mothers in this study, living with extremely-low-birth-weight brought death nearer, both the potential death of the child and of themselves. They first experienced this nearness at the very moment of giving birth. The experience revealed for them the value of life. They recall the experience as ‘near loss’, the returning of the almost lost, as Pei explains,

> I am really lucky. From fear for the pending loss till she gradually grow normally, and she is now preparing for school. Very very lucky I am. Sometimes I would think the girl is really a gift from the heaven. (1: 187. 13-14)

Yu says,

> I did not know what to fear, fear that she would disappear suddenly. That was what I am most afraid of… Saying that we did not want her did not want her, but it seemed to give me a chance to have her back… (7: 90. 1; 118. 5-6)

Grieving with the Loss

Death was a reality to the mother who had lost one of her ELBW twins. The death of this child brought into awareness death as a possibility for the living child. Jing describes in detail, after a long silence, the moment when the baby died,

> Perhaps because the doctor had talked to us before and we were prepared. And I thought, not that we did not have passion with him. He was born from

> you, and you had seen him for almost two weeks. But I thought if you were not able save him, it was no use to insist. He was not yet ready and everything was not ready. Therefore, I thought, the baby could hear, he heard what you said. That time the doctor said that he was losing him. They asked us to see him at six or seven o'clock. When I saw him, the heart beat and the blood pressure was very low. When my husband came in, he said he would go home and get a camera to take a picture for him. I agreed then he went home and returned by taxi. I stayed there myself. I was watching the baby and things were getting lower and lower just like going. Then I said to him 'Daddy went home to get a camera, will be back in a moment. You wait for your father.' Talking and talking, then things went up again and returned normal. Then his father came back. After he had taken the photograph, I said to the baby 'We will have baby again. This time you are not ready. You come again and be our son when you are ready next time.' The he was gone immediately**…** (3: 26. 1-12)

Mothers report grieving at the loss of the chance to give birth to a full term child. Qiao comments that more premature babies can be saved but this does not have a negative aspect,

> What do you say, good or bad? You have helped them to be alive, but they have handicaps. Will it increase the burden to the society? (5: 34. 1-2)

Recognizing / Living the Reality

Mothers realize their loss of a perfect child and how they adjust to living with extremely-low-birth-weight. They realize the importance of living the present, living the reality as the yesterdays has gone as dreams and the tomorrows are visions. Pei says,

> I was prepared that the first one to two years would be very difficult, bringing this kind of babies…I had this preparation in my mind. (1: 72. 7-8)

Shu says,

> Now it is no use for you to think back after these. I prefer to think about how to take care of him with greater care, to make him healthier. It would be better than thinking back about the past. (10: 104. 3-5)

Mothers talk about how they get themselves relieved and let go. Rui says,

> I will not let myself work till too tired. If I cannot finish, I will let it be. I will not give myself too much pressure and will not force myself to do the work. (2: 138. 5-6)

Jing says,

> You are feeling sorry at this moment, then today is already the worst. Tomorrow will not be worse than today. Difficulties, you have passed. There will be no more difficulties, no more. Then every difficult day will be passed. You see, instead of sitting there and thinking how sorry the old days were, would it be better you think about how to live the future, how to make the future better. (3: 34. 18-20)

Realizing the Gift of Normalcy / Life

Mothers' narratives clearly reveal how living with extremely-low-birth-weight brings a wealth of past experiences that shape and mold their present living and their view of the future. Living with extremely-low-birth-weight brings experience of near loss. Through living in nearness to loss, mothers realize new possibilities for life. Mothers realize the gift of normalcy. Pei notes with content,

> Seeing that she is all right now, I have this in my mind that she may be a gift from the heaven. From so tiny a baby till now every thing is normal, it may be a gift for me from the heaven. I feel better if I think it this way. (1: 131. 2-3)

Di says,

> He has no other problems**…** then I feel consoled. He can be brought up till now, I am content. Though you are tiny, all the others aspects are normal, I am content. (8: 136. 1-3)

Emphasizing the Positives

Mothers of ELBW children reflect on their ability to maintain a positive perspective. Within the study, mothers revealed that they could maximize self-content by interpreting situations from another positive point of view. Rui recalls her decision of having the child,

> When I looked back, I told myself I had not decided wrong. He came to be his elder brother’s companion. (2: 172. 3-4)

Qiao conveys an interesting view,

> I think that the baby has brought me good fortune. Because when I was pregnant…. I had not done the property business. I had not bought any

> property shares during the ‘97 stock turbulence, so I did not lose any thing. The present property I am living in, I bought in at the lowest price. The previous bought in at five millions, while it only cost me two million. So, something gained, something lost. (5: 84. 9-12)

Shu reveals the happiness that Xin-guan brings to the family,

> We become a lot happier. It’s true that when you have a child at home, you have someone to say something to. Although sometimes it is quite annoying…. he is naughty, the bigger the naughtier. He answers back…but it is a lot happier. (10: 64. 1-2)

Planning for Future

According to some of the mothers, maintaining a positive attitude does not mean there will not be any difficulties. It all depends on how you can get through them. Mothers of ELBW child view future as hope and expectations that the outcome is uncertain. Few mothers discuss the future planning for the child as they are unforeseeable visions. Feng is sure regarding the plan for herself,

> I am afraid and I will not dare to have another child. I am afraid that the second one will be like this again. The first is already so very difficult, if the second one were the same… (4: 10. 1-2)

Interpretive Reflection: Asserting life in "Near Loss"

> *When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us.*
>
> *(Helen Keller)*

Extremely-low-birth-weight brings into nearness to the possibility of the child's death. Mothers experience a closeness to death from the child's birth. The understanding of death, and the mothers' nearness to loss gives meaning to the ongoing day-to-day living.

Loss is an inherent component of all changes throughout life, and it may be positive or negative. Loss in its broadest sense exists when any aspect of one's self is no longer available to a person. Loss exists when a valued object or person is altered for an individual. Loss also refers to loss of one's image and one's private and social identity. The loss experience depends on the perspective, values and meanings that the loss has for the person who experiences it. Loss can be conceptualized in physical, psychological, sociocultural and spiritual terms, primarily or as a combination of all. (Watson, 1985).

In this study, mothers experience 'near loss' when the survival of the child is uncertain. Mothers are resolving the loss of a term child of normal weight while at the same time facing great uncertainty as to the survival of this ELWB child. A new perspective emerged for several mothers, a heightened sense of life, appreciating life more fully, and appreciating meaning in the everyday life. In the experience of the researcher, living with extremely-low-birth-weight used to be viewed as a pitiful event. However, it is revealed in this study that it is perceived as a gift for many of the mothers in the study).

The Seventh Theme:
Transcending To Spirituality

For mothers living with extremely-low-birth-weight, spirituality is acknowledged as the source of strength and courage, enabling them to deal with despair and suffering incurred in the journey of life. The theme describes mothers' transforming the experience through humanity and morality, with love. The themes under this metatheme are embracing faith / fate, actualizing hope / expectation, and living on humanity and morality – with love (See Table 5.10 below).

Descriptive Reflection: The Spiritual Triad – Faith, Hope and Love

> *But now abide faith, hope, love, these three; but the greatest of these is love.*
> *(1st Corinthians 13:13)*

Table 5.10: Metatheme 7 - Transcending to spirituality

Thematic Structure
Embracing faith / fate
Actualizing hope / expectation
Living on humanity and morality – with love

> A person's body is confined in time and space, but the mind and soul are not confined to the physical universe. The person's higher sense of mind and soul transcends time and space and helps to account for notions like collective unconscious, causal past, mystical experience, parapsychological phenomena, a higher sense power, and may be an indicator of the spiritual evolution of human beings (Watson, 1999, p. 50).

Of the mothers in this study, two are Christians and the others do not have any religious belief. One of the Christian mothers acknowledges spirituality in her experience of extremely-low-birth-weight. Most mothers believe the source of strength and courage that enables them to deal with the despair they experience is human nature and is particular the moral obligations of the role of a mother.

Embracing Faith / Fate

> *Faith is the substance of things hoped for, the evidence of things not seen.*
>
> *(Hebrews 11:1)*

Without referring to an explicitly religious belief, several mothers expressed a belief in fate or luck. Pei refers to her experience as fate and a gift from heaven,

> That’s why I say she is the luckiest one. So very low the birth weight of that 0.93 (Kg), yet she could be brought up till now just as any normal babies. It is…perhaps it is a gift from heaven. (1: 129. 6-8)

Yu implies there is a highest sense of power that holds the central command,

> Saying that we did not want her, but HE seemed to give me a chance to have her back… (7: 118. 5-6)

Shu talks about the recovery of Xin-guan’s eyes,

> Do not know why my son was so lucky that he did not have visual weakness. But I have heard that many others would have problems. (10: 140. 6-7)

Bao is a Christian and she recalls her faith in God as her major support,

> Then we all prayed for him together. The next day, not knowing whether it was because of my belief, the next day I fed him congee as usual and he could eat half of a bowl. Since then, nothing severe happened all along. Then he does not eat well only when he is sick. Others are normal. Therefore, the religious belief has given me very great support. (6: 212. 4-7)

Actualizing Hope / Expectation

> *The person has one basic striving: to actualize the real self, thereby developing the spiritual essence of the self, and in the highest sense, to become more Godlike. (Watson, 1999, p.57)*

Realizing that the life holds for them a great deal of uncertainty, mothers convey in the narratives hope for the positive future. Mothers convey hope in the form of uncertainty and worries. Mothers talk about hope for a cure, hope about the future, and hope for courage in enduring future comings. Mothers maintain hope in their living even during the hard times, as expectations through their actions towards the target of hope. Embracing faith or fate, they strive to actualize the hope, work out the expectations. Rui talks about taking chance when the child was born,

> The doctor did not agree to take chance. He said, “The child was very small and light weighed, a lot of development was not yet ready…and, you’d better have natural delivery.” Natural delivery meant that there would no resuscitation. That meant when abnormal heart rate was found, there would be no resuscitation or what so ever. I then said to my husband, “Till the situation now, why not we take the chance, then decide after he is born.” I did not think he would be abnormal at that time. (2: 106. 1-5)

Pei puts hope into action as child care,

> I simply hope that through bringing up carefully and consciously, striving for a few years till she is three or four when she is healthier. I am prepared that …till three to four years, hope that her body resistance will be better, healthier… (1: 113. 4-6)

Pei also talks about the planning and arrangement of education,

> I have found the school up there in that estate, in which her elder sister is studying. I hope that I can take her to school by myself. It is close to home and I can go by bus or just walk there. I hope that I can take her to school and look after her by myself. (1: 165. 1-3)

Feng consoles herself thus,

> When she was so small and very difficult to take care, I always said ‘Bigger,

> quickly become bigger, quickly become bigger, so that I would not be so miserable. (4: 132. 4-6)

Bao recalls,

> I hoped that for this feed, he would not throw up after feeding. Or, this time his feeding would be improved. Because he…since returning home from hospital, he had that problem with the bronchioles, with the ‘hiu hiu’ wheezing sounds. I hoped that this sound would not continue. (6: 44. 1-3)

Di reflects about the development of the child,

> Smaller size is not important if… just hope that she develops well… and not bother about small size. Most important is that there is no problem with the intellectual matters… (8: 54. 1-3)

Ni says,

> I hope that she can quickly finish this physiotherapy and have improvement. It will be better when there is not so many others things. (11: 138. 2-3)

Ni reflects on the importance of hope,

> Getting across barriers one after another. Hope that after passing this barrier, she would be better, that after this…she would not…not need to go to the Orthopaedics… I thought. So…the best would be…passing… the Paediatrics… but the Paediatrics would follow till ten…. I supposed they would follow her till bigger… when she is bigger, then it would have really getting across all completely… then she would…. Just hope that it would be over sooner. (11: 140. 1-4)

Shu recalls,

> I hope, he is now small, when he grows up he will not suffer that much. I can only have this in mind. I hope, always hope that… (10: 48. 1-2)

Shu also says,

> …I mainly hope that when he grows up, he can take care of himself. At least he can do this and I will be OK. I don’t ask for much… (10: 106. 4-6)

Shu reveals how she can help the child with expectation and hope,

> I hope that when he is small now, I have made effort to… help him as much as I can. Because when he grows up he will have his own thinking ……. Then in future, adding on with the ideas from mother or father, and referring to other’s ideas, he will have better development. (10: 168. 4-7)

Xiao talks about her simple but important hope for all mothers,

> In fact, I hope that he will be fatter, sort of bigger in size… I hope that he is normal and healthy, not be different from others. (12: 78. 3-4; 146. 1)

Living on Humanity and Morality with Love

> *If our humanness is to survive, we need to become more loving, caring, and moral to nourish our humanity, advance as a civilization, and live together.*
>
> *(Watson, 1999, p. 50)*

Throughout the conversations, it is revealed that love for the child is the basic instinct of all mothers. Mother’s love for the child is the human nature that motivates and provides strength to the mothers. It is through love that mothers embrace faith and actualize hope, enduring whatever comes up for the sake of their children. Pei says,

> You would not say, “So tiny, I do not want her.” You cannot say that, after all it is your flesh and bone. At that time, I thought in case she had any defect, I had to accept. (1: 183. 1-3)

Feng recalls her determination to keep the baby,

> But I said I would not, I would not give up. I asked why I should give up. This was the life that I myself had borne, the children that you give birth to. No matter what happens, it is your own child. I would not give up. (4: 34. 6-7)

Yu says,

> She did not want to, it was I who brought her to the world. I should give her adequate time to take care of her… (7: 166. 1-2)

Di simply describes her devotion in caring Yi-min,

> Willing with whole heart (心甘情願) (8: 82. 2)

Wei perceived moral duties,

> You have borne her and you have the responsibility to take care of her. (9: 82. 5)

Shu says,

> Whether he speaks or not, he is my own son. If he can speak, then I will try to see how I can help him. (10: 88. 2-3)

Interpretive Reflection: The Spiritual Transcendence – Actualizing Hope

> *The world of spirit and soul becomes increasingly more important as a person grows and matures as an individual and as humankind evolves collectively.*
>
> *(Watson, 1999, p.56)*

Watson (1999) defined human life as spiritual-mental-physical being-in-the-world, which is continuous in time and space. Only to the extent that a person has fulfilled the concrete meaning of human existence will the self be fulfilled. The meaning that a person has to fulfill is something beyond the self; it is never just self. The salience of the spiritual aspect of a person or race varies from individual to individual, from culture to culture, and within individuals.

The spirituality revealed in this study is mostly conveyed as humanity and morality with love for mankind. The presence of this spiritual element is frequently conveyed as the source for transcending the distress and uncertainty related to ELBW children. With faith, hope and love, mothers are able to envision and create a future of possibilities.

Faith and hope are always intertwined. Faith is not just a belief or knowledge about something. Faith, like hope, is a vision of the present with an expectation of the future. Morse and Doberneck (1995) defined hope thus:

> hope is a response to a threat that results in the setting of desired goal; the awareness of the cost of not achieving the goal; the planning to make the goal a reality, the assessment, selection, and use of all internal and external resources and supports that will assist in achieving the goal; and the reevaluation and revision of the plan while enduring, working, and striving to reach the desired goal (p. 285).

Frankl (1984) expressed a similar view that “those who know how close the connection is between the state of mind of a man – his courage and hope, or lack of them – and the state of immunity of his body will understand that the sudden loss of hope and courage can have a deadly effect” (p. 96).

Accepting the experience, mothers realize the significance of the event on their past, altered present and irrevocably changed future. To mothers, the future and the alternative actions changing the future are no longer incomprehensible. Hope is an expectation, so the outcome is not certain but goals and paths are identified. People now become future oriented, considering the new possibilities envisioned (Morse & Penrod, 1999). Mothers demonstrate an understanding of the present capacities of their children and possible functional outcomes. Mothers are able to maintain hope, ‘a belief in possibilities’ (van Manen, 1990, p. 123). Mothers begin to consider achievable goals and the plausible routes to achieve the goals, to actualize the hopes.

Despite the burdens and distress, mothers of ELBW child clearly have a deep love for their children. Prior (1989) suggests that the paradigm of compassion is the response of a human being for another, and the presence of a human form in a condition of suffering is the strongest stimulus to compassion. It is through love that mothers are able to support and care for the child unfailingly, to envision a future of hope. Mothers' love for the children in the study is expressed as care, concern and responsibility for the life and growth of the children whom they love unconditionally.

> *Love is the medicine that accelerates the process of healing. There is no other medicine but unconditional love.*
>
> *(Don Miguel Ruiz cited in J. Watson, 2005, p. 78)*

The Metaphor:
Surmounting Barriers One after Another over the Long Journey

In an even deeper reflection, the researcher, bringing into her personal experience and knowledge of the relevant literature, sought to provide a logical, systemic and coherent resource to conduct analysis and synthesis. Returning to the narratives and stories, orientating with the themes and metathemes central to this experience of extremely-low-birth-weight, the researcher envisioned the mothers' experience of extremely-low-birth-weight as a journey of life along with its twists and turns, barriers and pitfalls. The metaphor: *Surmounting barriers one after another over the long journey (踏上崎嶇漫長路　闖過一關又一關)* emerges to define the everyday realities of mothers who are living their life as a long journey.

The mothers described the experience as a thrilling journey in their life of feathery weight with heavy heart. There were twists and turns, barriers and pitfalls along the journey, reflective of uncertainties with the years of life. The journey began at onset of the premature delivery with knowns and unknowns, fear and joy ahead. Knowns were the potential developmental and medical issues listed by healthcare professionals, unknowns were the timing and severity of outcomes of these issues. Fear related to the unknowns and uncertainties; joy to the recoveries and regains. Not knowing what would come next, the mothers would hope that the ‘what’ would not come or would not be as bad as imaged. The mothers went on with the journey with extremely-low-birth-weight day-after-day, barrier after barrier. The mothers continued the journey making choices and learning new ways of living with the ELBW children. The stories of the mothers unfolded through the narrative and reflection. Within their descriptions, the metaphor of *Surmounting barriers one after one over the long journey* for mothers living with the ELBW children emerged from time to time.

As for the emergence of the metaphor, the researcher was enlightened by the mothers’ descriptions of barriers and blocks that they came across during the years living with the ELBW children. Ni described the myriad of emotions as she learned the unforeseeable outcomes from the doctor,

> I would be very upset. It would be miserable if she became blind... What could I do if she was blind and deaf. Fortunately that she was not. It was like…one step after one step to overcome (the barriers)... The doctor said that she has a lot of barriers to overcome…then one step by one step to overcome… so he said. (11:70, 1-3)

Throughout the study, mothers of ELBW children reiterated the belief that their experience was a unique one lived differently by each of them. Jing's description illustrates,

> People would not understand, would not pardon you because you were taking care of a premature baby. People viewed you as having a normal one. (3:30.34-35)

Living with an ELBW child is just like a life journey full of barriers, and ups and downs. Along the journey of extremely-low-birth-weight, mothers encounter the same mountains and see the same falls, yet each experiences the mountains and falls in a unique way. This is exemplified by Shu,

> At first, the doctor said that there was still a hole (in the heart) not yet close. I said 'How can it be to have a hole not close?' … Later I was very happy because… the happiest thing was… when he was transferred to the special baby care unit and had the ultrasound of the brain…when the blood clot had resolved… I was very happy. But the doctor said that the blood clot had resolved and there was a space. If he himself… developed well and without other complication, it would be all right. If… sometimes there would be fluid… fluid coming out in the brain, there would be problem. And subsequently there was nothing… almost one month later… he went for

> examination again at one year old, they said there was no more space. Then, I became relieved…Because they said that grade II intraventricular haemorrhage, could affect many thing… (10:130.6-13)

Mothers of ELBW children experience life in a more than traditional way. The time is not linear to the mothers in the study, as they seek to cope with an uncertain future in cyclic terms for the past few years. Changes and adjustments are common features in the descriptions of experience. Mothers in the studies describe life with an ELBW child as living with changes. Changes and adjustments occur as early as when the ELBW child is born, just as described by Yu,

> I used to wake up and I could go to anywhere I liked…just…walked out the door, then I could come back home at any time I wanted. But now I could not. When I woke up, I had plenty work to do. When I woke up I have to boil the bottles, I had to bathe the baby and I had a lot of things to do. It was like that now. I had to wake up in the midnight if she cried. I had to get up and see if she is all right. But in those days, I could sleep till sunrise and have nothing…nothing to bother. But now was different… (7:152.3-8)

Living with pending loss, increasing responsibility, uncertainty, and seeking for caring relationships are the common notions in the stories of the mothers. Each mother learns to live with extremely-low-birth-weight and perceive a meaning of life in doing so.

Becoming the mother of the ELBW child involves a movement from one journey of life to another; striving from being a “small” mother to being a “normal” mother. Attention to the movement itself, the movement from one journey of life to another, reveals the elements of transformation, which are contained within the mother's life. This life of living as a whole body-mind-spirit person strives towards being in a caring relationship within oneself, with others, with the earth, the world, the environment and with the highest sense of power. The whole of the experience of living with ELBW children described in the narratives of the mothers, expresses the unity of *A Meaning of Life: Each Day a New Day* in the journey.

Summary

This study seeks to describe and interpret the experience of mothers living with ELBW children. Like any other mothers or parents, they move onto the challenging journey of parenthood. Yet, the mothers living with the experience of extremely-low-birth-weight reveal that they live their life differently as a long journey along which twists and turns, barriers and pitfalls are envisioned as conveyed by the metaphor *Surmounting barriers one after another over the long journey*. Along the extremely-low-birth-weight, each mother perceives the landscapes in a unique way as each individual has different background, yet they get across the similar mountains and falls. The common patterns in experiences were revealed as intertwining fundamental existentials:

- *Transforming in corporeal – Embodying Motherhood*
- *Changing in Temporal – Living with Uncertainty*

- *Changing Relationships – Shaping the Caring Labyrinth, and*
- *Interacting with the Environment – Anticipating and Intervening.*

These four existentials intertwining with one and another can be differentiated but not separated.

Mothers living with ELBW children view life differently and seek a new perspective about life. Becoming a mother of an ELBW child involves the movement from one way of life to another, searching for transcendent meanings of the experience through:

- *Getting to Know and Understand*
- *Asserting Life in Pending Loss, and*
- *Transcending to Spirituality*.

The three metathemes reveal the mothers' self-actualization and self-transcendence in developing a new perspective of life.

The seven metathemes that form the lens through which the mothers' world with extremely-low-birth-weight are viewed. It is through these themes, "the knots in the webs" (van Manen, 1990) of the mothers' experience of extremely-low-birth-weight, the universes of meaning the mothers live through are made up. Attention to the movement itself, the movement from one journey of life to another, reveals the elements of transformation, which are contained within the mother's life. In a even deeper reflection, the researcher envisioned the mothers' experience of extremely-low-birth-weight as a journey of life and the metaphor: *Surmounting* *barriers one after another over the long journey* is revealed to define the everyday realities of mothers who are living their life as a long journey. Mothers of ELBW children view their experience of extremely-low-birth-weight as a way of being-in-the-world. Through living with ELWB children, realizing the values and integrating them in their life world, mothers gain a true meaning of life itself. Embracing the meaning of life, mothers gain courage to make their lives meaningful and living productively to their fullness, by engaging with their hope and love to their children.

CHAPTER 6

Discussion

In this discussion, the core aspect that the researcher keeps in mind is the nature of the knowledge generated. Since this study is phenomenological in nature, it is focused on increasing the understanding of and the sensitivity to mothers' experience of living with extremely-low-birth-weigh. The knowledge discovered in this study is not generalizable, but a clear picture can be visualized as to how the mothers of ELBW children are affected by extremely-low-birth-weight and how they experience it, the care and the changes in life. Since little is known from earlier studies about how mothers of ELBW children experience their life world, the findings in this study may thus be used to add understanding about mothers' meaning of living with extremely-low-birth-weight, their caring practices and coping behaviors, as well as to increase understanding of factors on which clinical recommendations for mothers of ELBW children can be made.

Bringing into the ingenious idea of prismatic vision of research discussed in Chapter 4, that there is always more to know as there are different realities on the same topic, the researcher attempts to provide a deepened, complex and thoroughly partial understanding of the topic – the lived experience of the mothers of ELBW children. In this chapter, discussion is made on the establishment of the unity meaning: *A Meaning of Life: Each Day a New Day*. Dialogue is also drawn from the perspective of parenthood development for the mother of an ELBW child and the impact on mothers in caring for ELBW children as related to pertinent literature. Specific focus will be put on the characteristics observed in terms of the mothers' caring behaviors and coping responses as pertaining to the cultural values and beliefs of Chinese. As there is not any study directly related to the experience of extremely-low-birth-weight among Chinese mothers, the researcher has attempted compare the findings in this study with other studies on parental coping with childhood illness or disabilities in a Chinese context. It is also attempted to identify the needs of mothers so as to reflect the adequacy of service and care provided.

A Meaning of Life: Each Day a New Day

> *What matters, therefore, is not the meaning of life in general, but rather the specific meaning of a person's life at a given moment. (Frankl, 1984, p.171)*

Ray (1991) believed that establishing a meaning of the lived experience is the dynamic of significance in a caring inquiry undertaken with hermeneutic phenomenological approach. Hermeneutic phenomenological research and caring inquiry moves from a simple presentation of final collective structures of experience to reflections of a unity of meaning with a rich narrative. It is through the movement of phenomenological theorizing to a theory of meaning that the researcher is able to bridge the participants' meaning of lived experience and the universality of human action as aesthetic (Ray, 1991). Bearing this notion in mind, the researcher engaged in the intention to move from the descriptions of the structures of experience and the mothers' metaphor to a unity of meaning of life, aiming to reveal how the mothers with experience of extremely-low-birth-weight gained understanding of the experience and surmounted the barriers in the long life journey.

The metaphor, *Surmounting barriers one after another over the long journey*, emerged from the mothers' descriptions of their experience and portrays the meaning of their journey of life. Mothers convey the experience as a different journey of life, along which extremely-low-birth-weight is integrated. The mother and the child are co-travelers on the journey involving with extremely-low-birth-weight. The experience of extremely-low-birth-weight affects the rest of the life of the mother and the family, affects the way mother develops roles within the family and in the society. New expectations and limitations emerge, resulting from the management of extremely-low-birth-weight. Mothers develop a close relationship with healthcare professionals for management of the child's physical health and arrangement of the subsequent educational and social needs.

Within the hermeneutic-phenomenologic view of extremely-low-birth-weight presented here, the researcher considers the taken-for-granted meaning evident in bodily skills, embodied intelligence and an understanding of the situation and the concerns of people as a whole. As nursing heritage is rooted in a holistic framework, the researcher espouses the essential concepts of care of the whole body-mind-socio -spirit person. The concerns, background meanings, skills and practice of the person set up what counts and also create possibilities within the person's life (Benner & Wrubel, 1989). In the mothers' stories, their need for understanding, caring, compassion, concern and support are described. Each mother is viewed as a unique experiencing person, a whole body-mind-socio-spirit entity deserving respect and dignity:

> *"What you have experienced, no power on earth can take from you."*
>
> *(Frankl, 1984, p.104)*

Applying Ricoeur's (1981) theory of interpretation in conjunction with Gadamer's (1976) hermeneutic of understanding, an understanding of the meaning of mothers' experience of extremely-low-birth-weight emerges. The metaphor is revealed from the text as a holistic insight, and the theory of meaning is an expression of understanding of the meaning of the mothers' experience of extremely-low-birth-weight in their existential life world. Reflecting on the metathemes and themes, the researcher comes to understand the meaning of the mothers' experience during the preschool years as *A Meaning of Life: Each Day a New Day*.

To Gadamer, understanding is a mode of being and is about existence. Understanding is derived from personal involvement by the researcher in a reciprocal process of interpretation within the hermeneutic circle (Dowling, 2004). In the hermeneutic circle, the researcher moves forwards from a superficial grasp of the meaning of the text as a whole, to a deeper understanding through recognition of the relationships of the parts to the whole; allowing understanding to be enlarged and deepened. Gadamer equates the metaphor of dialogue with the logic of question and answer; and a question is always related to an answer that is expected in the text. Understanding occurs when we surrender to the movement of question and answer, upon discovery of something new, something not recognized before (Koch, 1996).

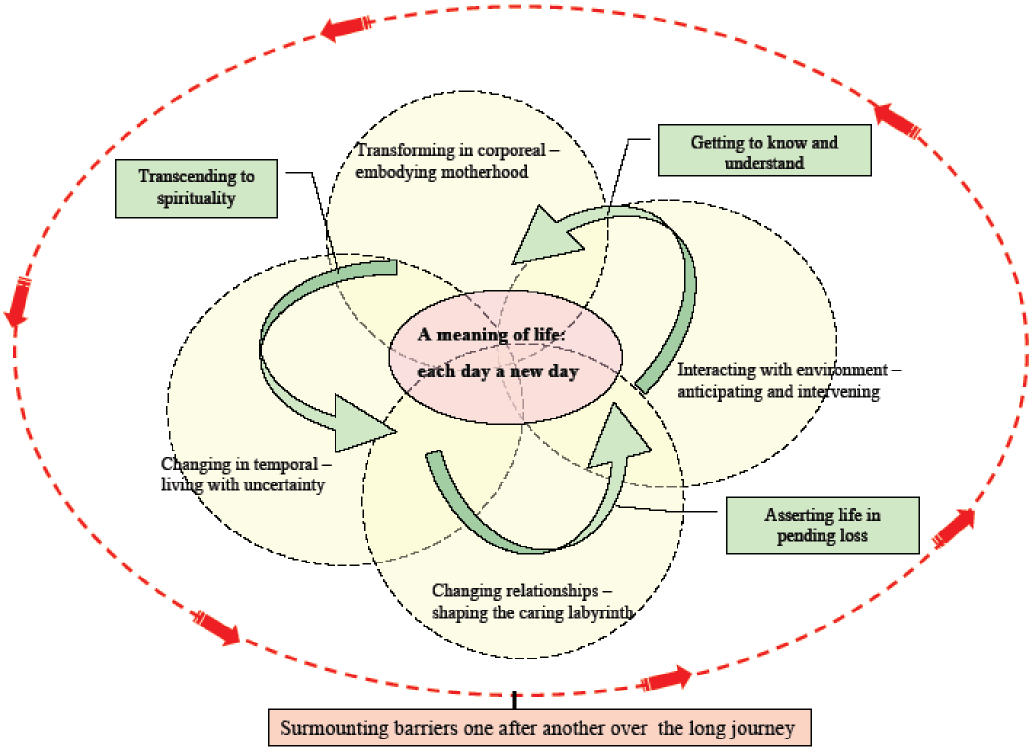
The researcher reflects on the themes, metathemes and the metaphor, the unity of meaning for the experience of mothers living with extremely-low-birth-weight is phenomenologically revealed as *A Meaning of Life: Each Day a New Day*. The themes and metathemes that emerge are not separate and freestanding, they are interwoven with each other to reveal a way of living for mothers living with extremely-low-birth-weight. Through reflective interaction and dialectical movement, the themes and metathemes become essential in revealing the whole of the mothers' experiences as the metaphor, and the theory of meaning in coming to understand extremely-low-birth-weight as *A Meaning of Life: Each Day a New Day*. Mothers reveal that extremely-low-birth-weight determines a particular way of life. Becoming a mother of an ELBW child involves movement from one way of living to another. Extremely-low-birth-weight integrates as a factor as the whole body-mind-socio-spirit person strives towards being in the right relationship within oneself, with others, with the environment and with the highest sense of power.

In this study the metaphor, *Surmounting barriers one after another over the long journey*, expresses the unity meaning – *A Meaning of Life – Each Day a New Day* – that is interlinking with the themes and the metathemes. The themes and metathemes illuminate the landscape of the journey of life with extremely-low-birth-weight, guiding, knowingly or not knowingly, the mothers, the researcher as well as the readers with holistic insight through the journey, providing a sense of time and place and illustration of important landmarks. Along the journey, mothers of ELBW children learn to let go the past and live in the present. Mothers strived for the future, living each day as a new day in the temporal cycle:

> *You are feeling sorry at this moment, then today is already the worst. Tomorrow will not be worse than today. Difficulties, you have already passed. There will be no more difficulties, no more. Then every difficult day will be passed.*
>
> (你現在覺得難過，那今天就最難過　喇，明天開始不會再有比今天難過。難過，難過，你都過了，再有什麼更難過，沒有喇。那麼天天都最難過就這樣渡過了。) *(Jing – Mother of Jun-wei)*

For the mothers with, the meaning of life is found in every moment of living. According to Frankl (1994), life never ceases to have meaning, even in suffering and death. A person can discover this meaning in life in three different ways: by creating work or doing a deed; by experiencing something or encountering someone; and by the attitude a person takes toward unavoidable suffering. The first way of achievement or accomplishment is obvious: a person who becomes conscious of the responsibility he or she bears towards a human being who affectionately waits for him will never be able to ignore the responsibility. The second way of finding a meaning in life is by experiencing something such as goodness, truth or beauty; by experiencing nature or culture, by experiencing another human being in his or her very uniqueness – by loving him or her. The third way of finding meaning in life is by suffering. Meaning in life may be perceived in spite of suffering, provided that suffering is unavoidable. A person must never forget that he or she may also find meaning in life even when confronted with a hopeless situation. When a person's search for meaning is successful, it not only renders him or her happy but also gives him or her the capability to cope with suffering. Frankl (1984) also suggests that what a person actually needs is not a tensionless state but rather the striving and struggling for a worthwhile goal, a freely chosen task. What he or she needs is not the discharge of tension at any cost but the call of a potential meaning waiting to be fulfilled by him or her.

Figure 6.1: Unity Meaning in relation to the Metaphor and Metathemes



In this study, the meaning of life of the participating mothers is depicted through the seven metathemes:

- *Transforming in corporeal – Embodying Motherhood*
- *Changing in Temporal – Living with Uncertainty*
- *Changing Relationships – Shaping the Caring Labyrinth*
- *Interacting with the Environment – Anticipating and Intervening.*
- *Getting to Know and Understand*
- *Asserting Life in Pending Loss, and*
- *Transcending to Spirituality*.

In this study, the seven metathemes, being the patterns and scenes of life interweaving with each other, can be differentiated yet are not separate and freestanding (See Figure 6.1 above). Each metatheme is essential and all are interrelated and interdependent with each other to reflect the unity meaning for mothers living with ELBW children – *A Meaning of Life – Each Day a New Day*. The first four themes are the fundamental existential themes: lived body, lived time, lived other and lived space (van Manen, 1990) that are seen to belong to the existential ground by way of which human beings experience the world. These metathemes are interrelated as a person can inhabit different life world at different time of the day, or in different space with different people. The other three metathemes reveal mothers' self-actualization and self-transcendence to develop a new perspective of life through their own ways of interpretation and perception. Through embodiment, time and uncertainties, living with the environment, relationships, spirituality, understanding and transcendence of meaning and, mothers come to know the experience of extremely-low-birth-weight as a way of life.

Bringing into the researcher's personal experience and knowledge of the relevant literature, returning to the narratives and stories, orientating with the themes and metathemes central to this experience of extremely-low-birth-weight, the metaphor: *Surmounting barriers one after another over the long journey* is revealed to define the everyday realities of mothers who are living their life as a long journey. Mothers of ELBW children experience life in a more than traditional way, the time is not linear as they linger to and fro with the uncertain future. Embodying motherhood, living with uncertainty and seeking for caring relationships are major notions in the stories of the mothers. Each mother learns to live with extremely-low-birth-weight and integrates it as a way of living a life.

This life journey of living as a whole body-mind-spirit person encourages being in the right relationship within oneself, with others, with the earth, the world, the environment and with the highest sense of power. Aiming to study a more meaningful philosophical foundation based on human rather than nonhuman values the researcher involved in the research process and part of the method, rather than be distant, objectively remote and primarily concerned with the product of science. Through engaging to and from into the themes, metatheme and metaphor, together with reflective interactions and dialectical responses, the whole of the experience of living with extremely-low-birth-weight described in the narratives of the mothers, expresses the unity of meaning as *A Meaning of Life: Each Day a New Day*, which was recognized as a coming together of the variations and similarities of the experience, intuitively and authentically grasped and constituted by the researcher.

Transforming in Corporeal – Embodying Motherhood

Mothers begin with developing a natural sense of extremely-low-birth-weight, becoming acquainted with the presence of extremely-low-birth-weight. Mothers embody motherhood in the experience of extremely-low-birth-weight and describe the experiential sense of ‘heart pain’, sleep disturbance, frightening and shaking. Through living with extremely-low-birth-weight, mothers recognize situations when threats are being posed to their living routine. Mothers reveal the experience of extremely-low-birth-weight as an immense part of their lives. Mothers reveal their awareness and consciousness of extremely-low-birth-weight. Experiences bring to the mother a special consciousness of changes within the child: starting to get sick, losing weight, eating less, walking more steadily, saying longer sentences. The existence of extremely-low-birth-weight develops an embodied sensing within the mothers.

Scientists adopt the stance of objective thought and do not acknowledge a body-subject as their proper subject matter (Priest, 2000). Healthcare professionals usually treat the child of extremely low birth weight from the objective perspective of illness and present the illness as a set of problems. The body is viewed as a symptom, presented with indicators of disorder in the body, like weight gain and infections. However, these disorders cannot be comprehended without the application of external meaning and categories. In embodying motherhood in the experience of extremely-low-birth-weight, mothers’ understanding of it differs from the objectification of extremely-low-birth-weight as a disease process requiring a categorization and particular treatment (Gadow, 1982), and mothers portrays the subjectivity of extremely-low-birth-weight that transcends all categorizations and expectations. Mothers embody motherhood in the experience of extremely-low-birth-weight and view the child’s body as a symbol. Likewise, they view these phenomena as expressions of personal meanings that cannot be ‘diagnosed’; that is, understood objectively, but can only be interpreted subjectively by the mothers themselves. Mothers view these as cues of the body’s need that call for attention. Attending to the subtle changes of the children, mothers are able to maintain balance of health, feeding and weight.

Mothers reveal the embodied perspective of extremely-low-birth-weight. Living with extremely-low-birth-weight is described by mothers as an experiential sensing of ‘heart pain’ (心痛) when they see the pain and suffering of their child. The verbal expression of emotions is typically somatic in orientation in Chinese language (Hsu, 1985). One Chinese saying also well illustrates the mother’s embodiment of child’s suffering is “Beat on the child’s body, pain in the mother’s heart” (打在兒身，痛在娘心). Mothers demonstrate their love and care to the child through expressing concern and taking care of the child’s bodily functions and needs.

Mothers reveal their increased awareness and vigilance for any subtle changes that indicate threats of the physical well being and developmental status of the child: the feeding and bowel movement, the seeing and hearing, the finger movement and the walking gait. The experience of extremely-low-birth-weight brings to the mothers a special consciousness of body weight and size. Mothers strive hard to maintain balance in regard to the health and development, weight or size gain, and feeding of the child. These three factors intertwine with one another in the balancing cycle: illness affects feeding causing weight loss, poor feeding causes weight loss and decreases resistance, low body weight increases chance of illness that affects feeding.

Mothers in the study described how they strive hard in becoming acquainted with and adapting to the life with extremely-low-birth-weight. The acquainting and adapting is stressful and not only affects the physical health but also impacts on the mental health of mothers. One mother describes the tension experience as “a rubber band being stretched so hard that it was going to tear at any time”. The embodiment of motherhood in the experience of extremely-low-birth-weight is described as disturbance of sleep especially during the initial encountering period, as embodied illness in response to the child’s sickness, or even as altered mental health with self harming ideas. Two mothers in the study describe their stressful experience at the edge of killing themselves.

Mothers in the study express concern about the weight and size of the children. Mothers in this study describe clearly the striking and unforgettable sight of their ELBW children in the NICU. They perceive the unanticipated appearance of extremely-low-birth-weight is an entirely strange image from what they have been expecting. The strange appearance brings threats to mothers as one mother revealed that the infant was so very small in size that he would not be able to undergo invasive and traumatizing medical interventions in the neonatal intensive care unit, “So small a baby, when I went there and ‘Why she was inserted with so many tubes (the intravenous apparatus and vital monitors)! Is it possible?’ I was wondering.” The experience in NICU remains a significant memory for these mothers for years even after discharge from hospital and the concern of weight gain and development is of particular importance to mothers of LWB infants. Despite the mothers’ desires of proximity with the ELBW child change over time, all mothers reported it as unbearable when the children are out of sight and not in close proximity. The first physical touch the ELBW child is an entirely new experience and some mothers experience hesitation in touching the newborn baby. This finding reveals the disruption in the mother-infant attachment.

The mothers in the study describe endurance of the suffering and recognition of the unique experience. The mothers convey their sufferings as physical and emotional pain, social isolation, feelings of inferiority, fear and breaking of relationships. Mothers experienced obvious pain and suffering through living with extremely-low-birth-weight – including the actual visualization of the pain and suffering that the child experiences, and the accompanying psychological tension. Despite the pain and suffering that incurred with extremely-low-birth-weight, the mother has a way of maintaining a positive approach to the situation. Through suffering, a new meaning and purpose for life emerges.

Changing in Temporal – Living with Uncertainty

The uncertainty about the extremely-low-birth-weight and the future life is a continuous experience common to mothers. The onset of uncertainty is an outcome of the confusion that mothers experience in letting go of past reality, in sorting out ambiguities and reflecting on their new reality. The experience of uncertainty is triggered off by the event that they have no prior knowing and understanding. Time and duration has a vital meaning for mothers of an ELBW child. The lives of mothers in the study begin to change as early as the unplanned delivery begins.

For all mothers in the study, the living in uncertainty is characterized as an intensive period of disruption and disorganization following the birth of the extremely low birth weight child. The living in uncertainty continues throughout the preschool years while the transition to elementary school is the major milestone. During this time, mothers struggle to gain control of situations that seem to be uncontrollable.

Mothers reveal that they experience time differently from the time the child was born onwards. Mothers describe their consciousness of time as being focused on the present, veiling by the past, within limited views of the future. The past determines much of how the mothers perceive present and the future. Time is focused within the here-and-now, whereas future is undetermined. Time is concerned in its relationship to the ordered series of phenomena of the skies, to the development of the world of nature on earth and to the descriptions for human activities (Loewe, 1995). The cyclic view of time is the idea of constant and irretrievable repetition as on a cycle. It may be suggested, in human psychology, that a view of time as being ever repetitive could satisfy a craving of human beings for permanence, reconciling them to the brevity of their own transient existence. By contrast, the linear view of time may allow for successive units or lengths to follow one after the other without implying any essential relationship (Loewe, 1995).

Mothers in this study describe time in more cyclic terms for the past few years. Living in the here-and-now, the mothers become more accepting of what each day brings. The mothers gain a new awareness of life and treasuring life as a gift through living each day to the fullest. With uncertainty of the future, the mothers view life more realistically with the knowing and unknowing. Though not thinking too far ahead, the mothers plan for the near future with hope that is germinated when recovery of the child from pending loss is recognized, when an answer is given to an unknown**.**

According to Frankl (1994), a person should stop asking about the meaning of life, and instead, should think of oneself as those who were being questioned by life in every moment. “It did not really matter what we expected from life, but rather what life expected from us” (Frankl, 1994, p. 98). Sometimes a person may be required simply to accept fate, to bear his cross. Every situation is distinguished by its uniqueness, and there is always only one right answer to the problem posed by the situation at hand. When a person finds that it is one's destiny to suffer, this person will accept his or her suffering as his or her task. A person's unique opportunity lies in the way in which he or she bears the burden.

The uncertainty is an intrinsic component of the hard times throughout the preschool years for the mothers of ELBW children. The experience of uncertainty creates tension in the ongoing future of the mothers, and the tension always exists as long as the mothers live with the unpredictability – the unplanned delivery, uncertain survival of the child, unexpected and striking physical appearance of the first sight of the child and the unpredictable outcomes. Within the lives of such mothers, there are also circumstances and events that can lead to potential danger and threats related to the extremely low birth weight children, and are likely to incur additional stress and tension to the mothers.

In the study, the mothers experience time in the modality of hope that they cherish for the wellness and happiness of the child. Especially meaningful are the lived time experiences of those special days and times when there are significant events related to the child – the day the child made the first step, said the first word, smiled for the first time. Mothers share the same history with the child with happiness and worries.

Changing Relationships – Shaping the Caring Labyrinth

Extremely-low-birth-weight requires the mothers' acceptance of new responsibilities, and requires them to maintain openness to the new and changing roles posed by an ELBW child. Mothers are confronted with the demand for change. Mothers are challenged as they care for the ELBW child by the various regimens and activities required to maintain balance within the family life. They have to meet the challenges of this new way of life and to come to know what is expected of them. The mothers in the study move from one way of being in the world to a new way of life, through the new reality of giving and receiving, being and doing for the extremely low birth weight. Enduring the sufferings and challenges with the ELBW child, mothers perceive their relationship with the child being unique. The mothers put caring for the ELBW child before other commitments, thus impacting the mothers' lives and their relationships with spouse, other children and others.

Bringing up an ELBW child, mothers often experience isolation within their own communities and encounter fatiguing problems in managing the child's care as well as matters related to their own physical and psychological wellness, but with limited resources and support. Mothers face special demands and circumstances of the children as they grow and move toward school age.

Mothers talk about the unpleasant experience of being viewed as different and they feel ‘small’ themselves and blame themselves and report suffering guilty feelings. Mothers endure and live with the challenge of trying to be normal in the world where the children are seen as different. Mothers seek dignity and normalcy for their child in their interaction with others that the children are not ‘abnormal’ but just being born prematurely with extremely low birth weight.

In the study, mothers clearly convey the experience of “being different in the world where we live” and how they struggle in the life of “seeking normalcy and dignity”. Mothers view their child as not different from others, yet they are very conscious and sensitive to being viewed as different in the world where they live. Mothers often make comparison with normal weight and describe a different life pattern. Obviously, the child’s physical size and the special needs of child, and the interactions with other members at home and in the outside world often bring to light their differences. Being the mother of a small child, mothers lose self esteem and feel ‘small’ themselves. Mothers convey fear for exposing the physical defect or special need of the child. They isolate themselves to avoid social contact and they try to hide the ‘shameful affairs’.

Chinese feel that relatives are most trustworthy and dependable, and should take care of its own members and should not intrude into other people’s affairs. On the other hand, Chinese will not share what they consider shameful or failure with ‘outsiders’ to avoid ‘losing face’ (Hsu, 1985). This study reveals that mothers seek help from others in a variety of ways, but most significantly want the care and support from their spouse and families including the in-law family. Mothers expect limited help from their husband in terms of childcare and make excuses for their being busy at work, considering childcare as a woman's duty. Mothers appreciate relationships with the in-law family and expect support from it. In negative interactions with the in-laws, the mothers felt neglected and disregarded. The Chinese family model in Hong Kong is a mix of traditional and modern. The traditional extended family has been replaced by the nuclear family; however, the relationship to the extended family continues to be very close. The traditional Confucian beliefs of an accepted family hierarchy based on age, gender, and generational status are still valued by the society (Bond, 1986). Mothers experience ambivalence in relationship with spouse and in-laws within the traditional Chinese hierarchical family characterized by the authoritarian role of the father and the typical in-law conflicts, when there is loyalty split between the vertical ties of parents – children and horizontal ties of husband – wife, while the former is seen as more important by the spouse.

Mothers in this study reveal how extremely-low-birth-weight changes their interactions with their friends and others within the community. Mothers find extremely-low-birth-weight a unique experience that others do not understand and are not able to help with. Through the experience of loneliness and isolation over time, mothers strive to seek relationship with those who are thoughtful and caring. Mothers appreciate the relationship with those who are there to lend support during bad times. Yet, this relationship is confined to limited 'outsiders' who are the professionals in the healthcare and social work systems.

Mothers face the day-to-day challenge of living in a world where others are unfamiliar with extremely-low-birth-weight. The mothers and the children have to maintain close relationships with the healthcare system from which the children receive attention and treatment. Faced with the daily routine of medications, therapies and treatments, mothers learn how to negotiate within the healthcare systems. The relationship with healthcare professionals is viewed as a challenge and a struggle to be recognized for their unique intuition and expertise. Mothers value the relationship with healthcare professionals for fostering support, understanding and caring. Negative interactions are situations when mothers perceive their child as being neglected or treated differently.

Mothers clearly speak of and question the decision of life support when the extremely low birth weight infant is born. Mothers express willingness to accept whatever outcome because this is their child. Difficulties and discord arise when healthcare professional’s orientation towards cure and acute problems of an extremely low birth weight child fails to take into account the long term nature of extremely low birth weight and the resulting significance of the experience of the mother and family.

These challenging encounters within the experience of extremely-low-birth-weight require the mothers to locate and act on their own values and maintain an openness to the new and changing roles that posed by extremely-low-birth-weight. In the experience of extremely-low-birth-weight, the unforeseen changes within life and the altered relationships diffuse into the context of the everyday life of mothers, a milieu that incorporates the role, obligations and responsibility of being the mothers in the study. Being conscious of their responsibilities, the mothers recognize the reason for their existence and are able to maintain and develop new patterns within their lives that help meeting the needs of the ELBW child. A mother who is always conscious of her responsibility towards the child who affectionately waits for her and the nontransferable duty, will never be able to throw away her life. She knows the “why” for her existence and will be able to bear almost any “how” (Frankl, 1994). Mothers discover their meaning of life by responding to life, by being responsible (Frankl, 1994). Mothers of extremely-low-birth-weight realized their supreme values in the world, through the sacred deeds or chosen task – being a mother of an ELWB child.

Interacting with the Environment – Anticipating and Intervening

The awareness of threats that the environment poses to the child develops before the child is taken home. Mothers recognize the need to initiate changes within the environment to avoid threats whenever possible. Mothers, knowing that the ELBW child is weak and has poor resistance, are more vigilant of the changes in weather and seasons and extremes of temperature as child easily gets sick in such an environment. Avoiding polluted places and keeping the physical home environment clean are the ways to provide a safer environment. Living with extremely-low-birth-weight, mothers know the limitations and restrictions. Mothers live with restrictions that are closely interrelated with the physical well being of the child.

According to Watson (1985), a person's health-illness behavior may be motivated by an attempt to feel safe in an environment that is unknown, depersonalized or perceived threatened. In addition to the external environment, the unknowns of the person's health-illness concerns and worries threaten the internal safety. Throughout the life time, the person develops patterns of thought and action to explore the environment and determine whether it is safe or unsafe. When a person is young, ill or dependent, other people are responsible for providing a supportive, protective or corrective environment. Mothers in this study are in a rhythmic interchange with their environment, knowing when there is threat and danger. The awareness of limitation and restrictions are the reminders of the specific needs of the ELBW child. Experiencing life with extremely-low-birth-weight, mothers develop new awareness of the environment.

Getting to Know and Understand

Mothers in this study express their need to gain understanding and knowledge regarding extremely-low-birth-weight so that they can create a sense of structure and control of their lives. Through experiencing extremely-low-birth-weight, mothers describe gaining understanding and knowledge of extremely-low-birth-weight and the context and meaning pose for their lives.

A person grasps a situation in terms of its meaning directly for oneself. Benner and Wrubel (1989) suggest that meaning is made possible to oneself through embodied knowledge, the meaning and understanding of being, and through things that matters the person. Embodied intelligence means not only being with a mind-body unity, but also being in a situation in meaningful way. All aspects of embodied intelligence make possible a non-reflective grasp of a situation in terms of its meaning for the self.

Living with extremely-low-birth-weight, mothers are striving to mould a pattern of life that was embedded within the concern for and the responsibility to care for the child. The abilities of mothers to grasp the situation differ and change over time. Yet, there are patterns that characterized the experiences of all mothers. With the premature delivery, mothers are thrust onto a different road along which the life journey with extremely-low-birth-weight starts. Trying to make sense out of this new reality, mothers ask why this occurs and try to give a reason and explanation for the premature delivery. Most mothers report similar initial response to first encounter with the child; and the responses vary as time goes on.

Focusing on the positive aspect of their hardships, mothers are able to develop a sense of control and seek solutions for the problems. Learning to take charge of the caring activities, mothers recognize a positive meaning for their life with extremely-low-birth-weight. The powerlessness and bewilderment are progressively replaced by a growing awareness that the world is ever changing, allowing the mothers to remain optimistic in dealing with the situations that arise.

Asserting Life in Pending Loss

Mothers of ELBW children experience nearness to death and life. Mothers experience a conflicting situation – the expected new baby has come and but may not stay. As time goes on, they recall the experience as ‘near loss’, the returning of the almost lost. Although death is a possibility yet the word ‘death’ is never mentioned. Mothers refer to death as ‘loss’ or ‘disappearing’. In general, Chinese view death as misfortune. Speaking the word death will bring about bad luck. This historical attitude towards death can be observed in the mothers’ narrative. However, the threat of unanticipated future, early death of the child being the worse, is present and will intensify should the child’s well being be affected.

Modern Chinese parents place great emphasis on the competence and academic achievement of their children (Ho 1986). Within the Chinese culture, the achievement that includes the school performance, social manner and career development, of a child is related to the worth of the parents in particular the mothers (Wu, 1996b). Mothers are concerned about effect of lack of normalcy on the future academic accomplishment of the child. After initial grieving for the loss of a perfect child, mothers adjust to living with extremely-low-birth-weight. Nevertheless, over time, they realize the importance of living the present, living with the continuance of imperfection while maximizing self-content with the gift of maintaining normalcy.

Transcending to Spirituality

Mothers living with extremely-low-birth-weight use to refer their doings as the human nature and the moral obligatory role as a mother. As one of the mothers in the study says, “You have borne her and you have the responsibility to take care of her.” This well describes the Confucian tradition that certain relationships are accorded a position of paramount importance and all parties to the relationship are circumscribed by rules of correct behaviors and roles (Bond, 1986). It is the role of the mother to take care of the child she gives birth to.

Without acknowledging explicitly a religious belief, mothers convey the presence of fate or luck. In Hong Kong, there is no specific local religion, instead there is a variety of belief and religious practices. Buddhism and Daoist are considered as the ‘traditional Chinese religions’ (Liu, 2003). Originating in Buddhism, an important external attribution for success or failure in interpersonal and person-object relationship among Chinese may be embodied in the concept of *Yuan* (緣). It is the post hoc explanation for a personal outcome by alluding to fate, predetermination and external control (Cheung, 1986). Believing in fate or *Yuan*, mothers are able to maintain interpersonal harmony while ridding responsibility for the situation and reducing the sense of self-blame or blame on others.

Hope becomes important as mothers view the future of the child. Hope provides strength at times when mothers are dealing with uncertainties. Mothers put hopes into action and direct towards their target. Striving for oneself, seeking resources, appealing for supernatural power and / or letting nature take the course (Cheng, 1986) are the coping strategies that the mothers adopt to deal with their difficult situations.

Through the conversations with the mothers in this study, it is revealed that love for the child is the basic instinct of all mothers. Mother’s love for the child is the human nature that motivates and provides strength to the mothers. One way of finding a meaning in life is by experiencing something such as goodness, truth or beauty; by experiencing nature or culture, by experiencing another human being in the very uniqueness – by loving him or her (Frankl, 1984). Frankl wrote "The truth that love is the ultimate and the highest goal to which man can aspire... The salvation of man is through love and in love" (1984, p.58). No one can be fully aware of the very essence of another human being unless he or she loves that person. By his or her love, he or she is enabled to see the essential traits and features, and which is potential in the beloved person. By his or her love, the loving person enabled the beloved person to actualize these potentialities. It is through love; mothers with extremely-low-birth-weight embrace faith and actualize hope, enduring whatever comes up for the best of their children.

The spiritual dimension is an important component that provides a meaning and purpose to the life of the mothers. Faith and hope should be encouraged and respected as significant influences in promoting and maintaining health (Watson, 1979), and healthcare professionals must not ignore the important role of faith-hope in the caring process.

Caring and Coping in Motherhood Development

The findings in this study reveal what it is like to be a mother of an ELBW child during the preschool years. Through a process of in-depth interview and thematic analysis, the insights derived from this study support the findings of other studies on the transition of parenthood and motherhood as discussed in Chapter Two. Like any mothers, the Chinese mothers of ELBW children come across similar parenthood transitional sequential events, which are brought forth by the birth of healthy term infants including adjusting to pregnancy and childbirth to the coping with physical demands in childbirth and care of the child. Nevertheless, the perceived process of transition to parenthood is reported as different for parents of prematurely born children (Jackson et al., 2003; Miles & Holditch-Davis, 1995; Miles, et al., 1998; Swartz, 2005). Mothers of prematurely born children adopt a “compensatory parenting style” (Miles & Holditch-Davis, 1995) as related to the maternal feelings of protection regarding their concerns of the behavior problem and health development of prematurely born infants (Miles et al., 1998). The findings in this study also reveal that the mothers’ lived experience is highly charged with interpersonal and social significance as related to the traditional Chinese beliefs and values that are exerting on mothers’ perceptions of the experience in motherhood development, their caring behaviors and coping responses.

Roles and Responsibilities

Internalization of parenthood is described as a process over time and the structure of the phenomenon is referred as gradual change of feelings of alienation and responsibility to confidence and familiarity (Jackson et al., 2003). Similarly, Heerman and colleagues (2005) report that mothers in the NICU experience the transition from outsider to partner, entering the continua at different points and move at different rate towards “engaged parenting”. Mothers of prematurely born children may have different experience in motherhood as the process of transition to parenthood may be different as these mothers experience more responsibility and control of care and they need to be confirmed as a mother (Jackson et al., 2003). In this study, extremely-low-birth-weight brings to the mothers' new responsibilities and requires them to maintain openness to the new and changing roles posed by extremely-low-birth-weight. Mothers of ELBW children reconceive their roles from passive outsiders to active advocators. Mothers of ELBW preschool children continue encounter challenges as they care for the ELBW child following various regimens and activities of care, while at the same time maintaining balance within the family life with ELBW child during the preschool years. Mothers learn that the responsibilities of caring an ELBW child are great and unique to the parent. Mothers reveal these ties and responsibilities in caring for the ELBW children are neither releasable nor transferable, and there is no giving up.

The "never-give-up" attitude of Chinese parents has been reported in Ma and colleagues' (2002) study on parenting stress and parenting investment on children with emotional or behavioral problems in the Chinese context. As discussed in previous chapters, in Chinese culture, women's traditional familial role is regarded as most important and a mother is expected to assume almost total responsibility for the physical well being of the child, making sure that the child is well fed, fully clothed and protected from hazard. Besides, with much emphasis on harmony and unity, Chinese are taught to be responsible and take up responsibilities. With the returning home of the extremely low birth weight child, mothers experience emergence of new and different responsibilities. Mothers start to learn that the responsibilities are great and unique to her as the mother, and the responsibility is neither releasable nor transferable to other people. Being conscious of the traditional familial role and the strong sense of responsibility, the mothers find that they are able to integrate the new responsibilities into their living routine and accept the responsibility with total willingness – as one mother says “willing with whole heart” As one of the mothers in the study says, “It was I who brought her to the world. I should give her adequate time to take care of her…” This well describes the rules of correct behaviors and roles expected in the Confucian tradition regarding the parent-child obligation, women’s child caring role and the self-discipline regarding one’s own responsibility (Bond, 1986).

Seeking Normalcy and Dignity

Seeking normalcy and dignity has been noted as a concept pertinent to the life of families of children with chronic illness (Hegedon, 1993) who describe their lives as normal yet different and they used strategy of normalization differently. Bearing the un-transferable responsibilities, mothers of ELBW preschool children in this study are inhibited from normal living and social activities. Mothers of ELBW children describe their experience of being different in the world where they live and how they struggle to normalcy and dignity. Mothers reveal their lives as normal yet different. They contend that they see their child as no different from others, yet they are constantly comparing with the different life pattern of those who were born with normal birth weight.

Extremely-low-birth-weight brings new possibilities demanding a redefinition of the mothers' role in life. In this study, the important lived relations of the mothers are those with the ELBW child, family, friends and healthcare professionals, and all are affected. The mothers in the study move from a normal way of being in the world to a different way of life. Enduring the sufferings and challenges with extremely-low-birth-weight, mothers perceive their relation with the child being unique. The mothers put caring for the ELBW child before other commitments, thus impacting the mothers' lives and their relations with spouse, family and others.

Protecting and Disciplining

During the immediate period after birth, parents of prematurely born infants confront and cope with known risk and interventions necessary to sustain infant's life. The parental acquaintance of the vulnerability and fragility of the ELBW children bring to light their responsibility of providing protection to the children (Swartz, 2005). Aligning with the concept of protecting fragility, parents of premature children adopt a protective parenting style to compensate for the infant's past experiences in the NICU. The feelings of protection have been first reported when their premature children come home from the hospital and continue till their children at age three (Miles & Holditch-Davis, 1995).

In this study, mothers of ELBW children continue their roles of protection ever since the child is born till preschool age. This role of protection is conveyed as an unbreakable relationship between mother and child. The role of protection is not necessary be an intervention against risk. Protection may simple be the presence and proximity of the mother with the ELBW child. It is reported in previous discussion that the mothers of LBW infants endeavor toward attachment by visiting and participating the care of their infants (Mello et al., 2002). To maintain balance of health and development, mothers of ELBW children in this study reveal their increased awareness and vigilance for any subtle changes that will indicate threats of the physical well being and developmental status of the child. Mothers express great desire for proximity with the ELBW child and all mothers reported that it is unbearable when the children are out of sight. As a mother (Di) says, “Sitting there, you were of no help, you could not help anything. But I couldn’t help worrying, thinking that I was there watching her…just in case anything happened, I could protect her.” In this study, mothers protect their ELBW children from environmental threats both physical and psychological. Mothers learn their limitation and become more anticipatory, and they will modify their living to fit their needs.

Mothers of prematurely born children at 3 years old reported concern of behavioral management and difficulties with discipline and limit-setting in dealing with the behavior of their children (Miles et al., 1998). Further to the protecting roles, disciplining is revealed as the parental responsibility of mothers of ELBW children in this study. Traditional Confucian beliefs emphasize parental responsibility for training children for obedience and proper conduct, for exercising self-control, and for the acceptance of social obligations (Wu, 1996). It is said that family discipline must begin as soon as the child can eat and begin to learn things. Parents will be criticized for spoiling their child and they themselves will have to suffer for the consequence.

Chinese parents nowadays still manifest strong beliefs in this ancient teaching and practice accordingly in raising their children. The mothers of ELBW children convey the building up a unique relationship between mother and child. They are well aware of the ancient teaching and yet they have a strong obligation to protect the children who they consider as vulnerable. Unconsciously or consciously feeling guilty for the mishap and blaming themselves, some mothers will be spoiling their children while trying to compensate for them. Nevertheless, they may well experience a dilemma in exercising both affection and discipline in raising the children.

Balancing Triad of Health, Weight and Feeding

Mothers of prematurely born LBW children expressed concerns about the nutritional care of their children and the decision making in feeding of the LBW children would influence the quality of life or the family's satisfaction of life (Kennedy et al., 2000). Particular concerns of weight gain and development has been revealed by the mothers of LBW infants as important concern in the first month after hospitalization (Mello et al, 2002). In this study, mothers reveal their awareness and consciousness of extremely-low-birth-weight with special consciousness of changes within the child such as illness, weight loss and poor feeding. For mothers of ELBW children, health and development, body weight or size, and feeding of the child are revealed as the important triad that they are most concerned about.

In Chinese culture, women's traditional familial role is regarded as most important and a mother is expected to assume almost total responsibility for the physical well being of the child, making sure that the child is well fed, fully clothed and protected from hazard. It is reported that the Hong Kong parents of chronically ill children emphasize the importance of nutrition in assuring the child's well being and highlighted the role of certain foods of high cost (Fawcett, Baggaley, Wu, Whyte & Martinson, 2005). Overwhelming concern with the health of child with chronic illness was also observed among the Hong Kong parents. Concerns of food quality and eating behaviors of preterm children are also reported in an Australian study on parents' perceptions on preterm toddlers aged 1.5 to 3.5 years. (Cerro, Zeunert, Simmer & Damiels, 2002). In this study, it is observed that mothers are particularly concerned with feeding, and the importance of nutrition for ELBW children is very much highlighted. As discussed in the mothers' perception, feeding will affect the other two elements, health and weight, in the balancing triad. Mothers will feed the children with food they perceive as good of nutrient. One mother talks about the choice of food regardless of the cost: "So I gave more swallow nest for her to eat. We… bought the swallow nest by catties".

Embodying Pain and Suffering

The concern of pain as a major factor that contributes to the stress of mothers has been reported in previous studies on parental stress in the NICU (Shields-Poe & Pinelli, 1997; Gale, Franck, Kools & Lynch, 2004; Miles et al., 1993). The long term effect of maternal stress related to infant pain is also documented in Werceszczak and colleague's (1997) study on mothers after the infant being discharged from the NICU. Mothers in this study describe clearly the unforgettable sight of their ELBW children in the NICU. The strange appearance and small size of the ELBW infants bring in threats to mothers as regarding to the survival of the infant, as one mother describes, "So small a baby, when I went there and 'Why she was inserted with so many tubes (the intravenous apparatus and vital monitors)! Is it possible?' I was wondering." This finding concurs with the findings in Pinch and Spielman's (1996) study that the experience in NICU remains a significant piece of memory for the parents even after discharge from hospital for years.

In this study, mothers of ELBW children experience a change in their familiar body and their life world as transformed through their own body. In this study, it is clearly revealed that the mothers of ELBW children embody the pain and suffering of their child. Each mother is able to describe the specific situation when pain was encountered. Living with extremely-low-birth-weight is described by mothers as an experiential sensing of ‘heart pain’ when they saw the pain and suffering of their child. Mothers’ endurance of pain of ELBW children is not only revealed during the child’s hospitalization, but also continues during the preschool years especially when certain pain inducing procedures are required during the daily living routine. In enduring the pain and suffering of the child, mothers convey their embodiment of physical and emotional pain, and experience of social isolation, inferiority, fear and breaking of relationships. Nevertheless, mothers of ELBW children also reported experiencing loss of control regarding the pain of the child. It is through the endurance of pain, a new meaning of life and purpose emerged as a driving force for mothers in maintaining a positive approach to the situation.

Mothers in the study describe how they strive hard in acquainting and adapting to life with extremely-low-birth-weight by embodying with the extremely-low-birth-weight. It was through “lived body” that mothers are corporeally in the world and they meet their ELBW children through bodily appearance. In this study, the acquainting and adapting is both physical and mentally stressful to the mothers, as one mother described the tension experience as a piece of “a rubber band being stretched so hard that it was going to tear at any time”. The mothers embody the experience of extremely-low-birth-weight with symptoms of distress as disturbance of sleep and self-harming behaviors. The findings on mothers’ stress concur with previous discussions on persistent stress in parents of prematurely born infants during early childhood in western countries (Eisengart et al., 2003; Robson, 1997; Holdotch-Davis et al., 2003; Singer et al., 1999; Tommiska et al., 2002).

Shame and Blame

Mothers of preterm infants have a feeling of loss and guilt about the events that happened to them (Jackson et al., 2003). Similarly in this study, most mothers convey a loss of a normally weighed child and a feeling of guilt about not having a normal pregnancy and delivery. Cultivating of self-discipline for the acquisition of personhood is another important Confucian factor in Chinese parenthood. When the ELBW child is perceived as a form of imperfection, the Chinese culturally expected order of parental obligations is violated and the mothers faced the inability to transmit cultural knowledge. The mothers put the blame on themselves and conveying guilty feeling for bringing in the premature children. Some mothers are blamed by the extended family in particularly the in-laws.

Feature of blame was also reviewed in Pun and colleagues’ (2002) study on

Chinese mothers of children who had mental or behavioral problems requiring psychiatric consultation, and were described as mother-blaming and self-blame by the mother. A sense of unrecognized or not explicitly expressed guilt has also been reported in Chow’s (2001) study by parents of children with cleft lips and or cleft palate. In this study, several mothers feel ‘small’ themselves and hide themselves away to avoid being looked at. The mothers fear to take their children out and show their children to others so as to avoid contempt and unpleasant responses. Well versed in the indigenous concept of retribution the mothers of ELBW children feel shameful that the coming of the ELBW child would be due the bad deeds of the ancestors, for they would be seen as the ones who have done wrong. Within the shame-oriented culture of Chinese and the Confusion tradition of self-discipline, the mothers would feel shameful for not exercising self-discipline during pregnancy, be it they were conscious of or not.

As discussed earlier, modern Chinese parents place great emphasis on the competence and academic achievement of their children (Ho, 1986). Within the Chinese culture, the achievement that includes the school performance, social manner and career development of a child is related to the worth of the parents in particular the mothers (Wu, 1996b). Most mothers in this study are concerned that the future academic accomplishment of the ELBW children will not reach the ‘normal’ level as required for entering schools in the main stream. The families, in particular the mothers, fear losing face.

Some mothers experience an uneasy feeling due to ‘losing face’, and they demonstrate reactions to save face that include compensatory actions, retaliatory actions and self-defense (Bond & Hwang, 1986). To restore face, some mothers pay extra effort in bringing the child back to “normal” or work hard to enhance her social status as compensation. Some mothers choose to express dissatisfaction either directly or indirectly to fight back. Others choose to cope with the face losing situation with self-defense by de-emphasizing the severity of the situation. The interviews with mothers reveal that these reactions are used both singularly and in combination. The behavior of maintaining face has also been reported in Lam and Mackenzie’s (2002) study on stress and coping experience of Chinese Hong Kong mothers of children with Down’s Syndrome. In trying to shift away from everyone’s view as different in this world, mothers of ELBW child isolate themselves to avoid social contact so as to hide this “shameful” event from others. This finding is similar to Lam and Mackenzie’s (2002) local study that Chinese mothers try to hide the “shameful affairs”, the birth of an ‘abnormal’ child from outside to maintain face.

Changing Relationships for Caring Support

Despite mothers’ efforts at maintaining normalcy, the child’s physical size and the special needs of child often highlight their differences. Mothers of ELBW children clearly express their desire to be understood. Chinese feel that relatives are most trustworthy and dependable, and ones should take care of its own members and should not intrude into other people's affairs. On the other hand, Chinese will not share what they consider shameful or failure with 'outsiders' to avoid 'losing face' (Hsu, 1985). However, as opposed to their expectation, some mothers of ELBW child do not perceive understanding and support from members of close family, particularly the in-laws. Rather, they experience blame, lack of understanding and support from family members including the husband. This finding on lack of family support concurs with the observations in another study of Chinese mothers of imperfect children (Pun et al., 2004). Fawcett and colleagues' (2005) study on parents of children with chronic illness also reported the strong sense of loss of family equilibrium in the Hong Kong parents who feel responsible for disappointing older family members for being unable to protect the child from illness.

During the interviews in this study, quite a number of the mothers indicate that they try to seek more information regarding the care of the child from various sources, however, they also emphasize that they have hesitation to talk about the ELBW child with others or to seek help from others. Most of the mothers will only talk about their children unless they feel comfortable with other person, and they think that person will have the same understanding as they have. The mothers consider having an ELBW child as a shameful family event that should be handled as a kind of backstage behavior and should not be brought to the front of stage where it could be exposed to 'outsiders' who might not understand and lead to loss of face (Bond & Hwang, 1986). Some mothers may consider that expression of negative emotions implies an inability to cope and that is no acceptable to others. The appropriate times for them to express freely would be in situations when they perceive that they would be fully accepted and it would normal for them to feel negative with the entity. A few mothers say that it would be of no use telling others as they perceive that other people would not understand their experience. One mother expressed the view that she will only talk until she feels that the issue is no longer an emotional matter to her.

The mothers' reluctance to seek help may also be explained by the idea of compensation in mothers who feel that they have not done justice to the child, so they strive to compensate for the loss. Another explanation is that the mothers view the caring of the ELBW child as their sole responsibility that should not be delegated to others. The mothers try hard to shoulder all the burdens by themselves instead of leaving to them someone else, even though sometimes help may be readily available.

In seeking normalcy and dignity, mothers found extremely-low-birth-weight a unique experience that others do not understand. Facing special demands and circumstances as the children grow and move toward school age, mothers of ELBW children changed their interactions with their friends and others within the community as they found difficulty in maintaining normal relations with their friends and others within the community. Rather, the mothers maintained close relationships with the healthcare system where the children receive attention and treatment.

Mothers are disappointed, as they perceived inadequate support from their families, whom they expect to be dependable and trustworthy. On the contrary, mothers perceived misunderstandings and conflicts with family members, mostly the in-laws, as related to the child's health and development and the related childcare required. Feeling betrayed and disappointed, mothers prefer not seek help from them. For the mothers in the study, health care workers are seen as their primary source of help, and are the major persons to help and give instruction in child health management. After the long hospitalization of the ELBW children, the mothers have built relationships (*guanxi* 關係) with the health care workers whom the mothers consider as insiders (*zijiren* 自己人) to whom they can express their inside stories (Gabrenya & Hwang, 1996). Most mothers value the relationships with healthcare professionals for fostering support, understanding and caring. It is obvious that the mothers express a strong reliance on the health care workers whom they regard as the persons knowing best of the child's health status and developmental problems. Establishing rapport with the researcher who is a nurse, most mothers in the interviews were very participatory and vocal about their experience, starting from their anxiety at the premature labor to the worries and concerns at the very present moment. This is because they feel that the researcher shares the same understanding as them. Some of the mothers saw the interviews as a good opportunity for them to purge their emotions and feelings, and they are thankful to the researcher for giving them a chance to vent.

Decision of Life-and-Death

Mothers of ELBW children reveal that they valued the relationship with healthcare professionals for fostering support, understanding and caring. Yet, they also describe difficult interactions they have experienced with health care providers especially in situations when mothers perceive their child being neglected or treated differently. Some mothers in particular question the decision of life support at the very beginning when the extremely low birth weight infant was born. Mothers clearly speak of their willingness to accept whatever outcome for their children, yet their involvement in decision-making is not extensive. Partridge and colleagues' (2005) international study in seven cities (Taiwan, Hong Kong, Singapore, Kuala Lumpur, Tokyo, Melbourne and San Francisco) reveals that in Hong Kong, parents of VLBW infants in the NICU prefer to have joint decision-making when making decision for actual resuscitation of the infants, while they consider that parents should listen to the physicians' opinion which has to be taken into consideration when making decisions. Similar description is found in Saigal and colleagues' (2000) report that parents are willing to take a chance in saving the premature infants who have increased chance of disability, while parents ask for involvement in decision-making (Saigal, Burrow, Stoskopf, Rosenbaum & Streiner, 2000). Savage and Kavanaugh (2004) opine that decisions should be based on who can be saved rather than who should be saved basing purely on the consideration of possibility of disability. Nevertheless, making decisions for the high-risk infant while balancing interest of all parties is no easy task; it is paramount that parent’s consent should be obtained through transparent decision making process with mutual communication of everyone involved (Hurst, 2005b).

Living with Uncertainty

In this study, each individual mother of an ELBW child views her experience as unique and there is an additional cascade of stressful adjustments in maternal recovery from high-risk pregnancy, uncertainty about the survival and outcome of the ELBW infant, the constant stress during the hospitalization in the NICU, and the continual challenges in assuming the role and responsibilities of a mother in caring the ELBW child at home. The themes commonly emerge in this journey of life bring to light the many features associated with being a mother of an ELBW child and reaffirm that this experience as encompassed with uncertainties and unknowns.

Despite the mothers striving hard to maintain a balance of weight and health of the ELBW children, they live with uncertainty. Mothers in this study describe time as more cyclic in nature for them. Living in the here-and-now, the mothers become more accepting of what each day brings to them. For all the mothers in the study, the living in uncertainty is characterized as an intensive period of disruption and disorganization following the birth of the ELBW child. During this time, mothers struggle to gain control of situations that seem to be uncontrollable. This sense of uncertainty revealed in this study concurs with the findings in a previous study in the US that families with medically fragile children evolve through an initial disruption and disorganization to organization in another level, trying to gain control of uncertainty and learning to live in the uncertainty (Tomment, 2003). Fawcett and colleagues' (2005) study also reports the sense of uncertainty in Hong Kong parents of children with chronic illness.

Extremely-low-birth-weight brings to the mothers a sudden awareness of the finiteness of life and leads to a reorientation in present time through retrospective reflections and reevaluation of life. Mothers of ELBW children experience a different transition because the ELBW children come into their life as unprepared. As one mother reveals, “Just not knowing when would be the ‘early’ labor.” The “lived time” experienced by mothers of ELBW is presented as unpredictable and unanticipated. Each mother's story reveals how the mother strives through the uncertainties differently, yet all mothers describe how they maintain their living the ‘here-and-now’. This finding is consistent with the findings of Jackson and colleagues' (2003) description of the internalization of parenthood of parents of preterm infants as a time-dependent process in Sweden. As time goes on, mothers learn to live with the uncertainty, to manage the fear associated with the unknown, and to appreciate every infinitesimal piece of situations and events that give them rejoice. This finding is consistent with Swartz's (2005) discussion that parents of preterm infant affirm the future in a cautious way.

Understanding the Meaning

As revealed in previous studies, mothers of premature infants in the NICU experience informational need related to becoming a mother in the neonatal intensive care unit (Miles et al, 1993; Hurst, 2001). The mothers of ELBW children in this study clearly reveal their desire to gain and understanding of extremely-low-birth-weight and the meaning posed for their lives, challenges are not only confined to the acute stage during hospitalization, but also extend to the subsequent preschool years.

The theoretical process of caring revealed in literature describes caring as a nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibilities (Swanson, 1991). It is also suggested that one would strive to understand the event as it has meaning the life of other whom one cared for; and when understanding occurs, the selves of both care provider and recipient are engaged. The mothers of ELBW children, within the primary caring relationship – mother-child relationship, are the care provider of the ELBW children and recognize the children as significant being. From a sense of responsibility and love, the mothers of ELBW children strive to understand the personal reality of the ELBW child whom they care for. Living with extremely-low-birth-weight, mothers are striving to mould a pattern of life that was embedded within the concern for and the responsibility to care for the child, based on an understanding of the context of extremely-low-birth-weight.

As discussed in literature review, the well known stoic and the enduring characteristics of Chinese coping strategies are still commonly seen among the Chinese people in response to life situations and stress. Chinese people are obsessed with saving face and accepting without question. Chinese people, when encountering adversities, consider that nothing can be done except to accept the reality through self-control or passive endurance (Cheung 1986). In this study, the mothers encounter both physical and emotional pain as they deal with the issues surrounding extremely-low-birth-weight. The emotional pain is often related to the misunderstanding and rejection exerted on the child or the mother. Many mothers have experienced the emotional pain of the taunting from families who do not understanding. In this study, the sufferings of mothers encompass the physical, psychological and social aspects in terms of feelings of pain, isolation and fear. It is through suffering, that the mothers realize a new meaning and purpose for living. New possibilities are created to the mothers through the compassionate care and support provided by family members and professionals. Pertaining with traditional values and cultural beliefs, the mothers recognize their own ways in maintaining a positive approach to the situation.

Spiritual Transcendence and Rationalization

Religion-based coping is reported as not related to mothers' psychological distress in Eisengart and colleagues' (2003) study on coping and psychological distress in mothers of VLBW young children at birth and at 24 months postpartum. However, without acknowledging overtly a religious belief, the mothers in this study did convey a belief in fate or luck. Although there is no single religion in Hong Kong, the spiritual dimension is an important component that can provide a meaning and purpose to the life of the mothers.

Mothers of ELBW children see their actions as the product of human nature and the moral obligations of a mother. It is the role of any mother to take care of the child she gives birth to. As the care provider within the primary caring relationship, mothers of ELBW children sustain faith in believing the child’s capacity to get through the transition and fact a future with meaning (Swanson, 1991). In this study, the lives of the mothers are riddled with challenges to the survival of their ELBW children, and the fulfillment in caring may be beyond reality for human experience. In caring for the ELBW child, the mother holds the child in esteem and believing in them. In this caring relationship, the mothers maintain a hope-filled attitude and realistic optimism in dealing with uncertainties. Hope becomes important as mothers view the future of the ELBW child and put hopes into action.

In this study, the mothers also use rationalization and projection to deal with adversities, as discussed in the literature review on Chinese values. It is revealed in the interviews that most mothers try to find a reason for the premature delivery and try to figure out if they have done anything inappropriate. Regarding the condition of their ELBW child, most mothers suggest that, either they said it themselves or they heard people say, it is fortunate that the condition is not the worst. Within the study, some mothers are used to emphasize the positives and reveal that they can maximize self-content by interpreting situations from another positive view. The narratives of mothers clearly reveal how living with extremely-low-birth-weight brings a wealth of accrued experiences that shapes and molds their present living and their view of the future – new possibilities for life. This depicts the coping mechanism of “spiritual victories” of the fictitious character “Ah Q” who used rationalization and projection to deal with adversities. Nevertheless, usually there would not be a reason for every happening that could only be explained by the highest power, God. Mothers convey a reliance on the presence of *Yuan* (緣), that is the post hoc explanation that any personal outcome would have been predetermined.

Needs of Mothers in Coping with Extremely-low-birth-weight

The knowledge discovered from this phenomenological study does not serve the purpose of generalization. However, the researcher has tried to examine the findings to identify the needs of mothers in coping with the experience of extremely-low-birth-weight, aiming for a further explication and understanding of the lived experience of these mothers. It is hope that from this discussion, insight would be gained into mothers’ needs and the services provided to both the mothers and ELBW children.

Understanding the Needs for a Body-Mind-Social-Spirit Person

Revealing the unique meanings of life of the mothers in a more holistic approach to understand them in the context of their world can help health care providers in planning more sensitive and knowledgeable care for the mothers and families. To gain understanding of mothers' needs and provide care for them, nurses should engage their subjectivity at work and take into account their own embodiment to appreciate of mothers' embodiment (Gadow, 1999). In the management of extremely-low-birth-weight, nurses need to reinforce and apply the mothers' experiential knowledge. Caring only occurs when the recipient of care is recognized and experienced as a person. Nurse must know the person to understand the person's need and transform that knowledge into action (Sherwood, 1991). The mothers in this study reveal the needs to maintain the total well being and harmony within body, mind, society and spirit.

Physical needs.

As indicated in the study, taking care of an ELBW child at home is a chain of tiring tasks and the process of adapting is stressful and affects the physical health of mothers. The most obvious example is tasks of feeding that present to the mothers a series of labors that are both physically draining and psychological frustrating. The sequence of work comes as a cyclical routine in the day as feeding and vomiting, followed by cleansing and washing. Need for physical support may be related to the physical limitations of the mother due to ill health or the threat from the physical environment imposed on the health of the child. Despite most mothers considering childcare as their sole responsibility, some mothers reveal an expectation of support in child care from family members but in vain. In this study, the “physical” support from the father, be it just the physical presence or the actual participation in child care task, is appreciated by the mothers.

Besides, the mothers need to know that their babies’ physical care is attended and their pain and sufferings are addressed to. Assurance of physical care to the infants may help alleviate mothers’ emotional stress.

Psychological / emotional needs.

The mothers in the study were completely overwhelmed by the unanticipated arrival of the ELBW children, and experienced great shock at the first sight of the ELBW infant and at the first encounter of the unexpected scene in neonatal intensive care unit. Although the psychological stress continues throughout the subsequent days in facing all kinds of uncertainties and threats, pits and falls; it is well recognized that the most vulnerable phase is during the time in the neonatal intensive care unit and the initial post-discharge period in caring for the child all by themselves at home. Emotional support with high sensitivity and informational support with comforting remarks are indicated as important for supporting the mothers. The findings in this study reveal that positive interactions with health care professionals at critical periods particularly in the course of the child's hospitalization are identified as situations encompassing traits that have meaning for the mother. The positive interactions are described as situations fostering support, understanding and caring.

As discussed in previous chapters, the mothers saw the interviews in this study as a venue for expressing their feelings and ventilating their distress and concerns, and a means to seek more information on the management of their ELBW child. Mothers also clearly longed for emotional support from the fathers who, in turn, are usually silent about their feelings as recalled by the mothers.

Social needs.

From the findings of the study, a great concern regarding psychosocial perspectives in the experience of mothers is revealed. Feelings of shame and guilt, being blamed and criticized are unbearable yet common among the mothers in this study. The mothers describe expectations of being accepted by others, in particular the family members. The greatest isolation and loneliness mothers perceive is within their family when they feel rejected by family members. Inadequate support from husband and the in-law family seems to be an issue. Perceiving no support and not being understood, mothers prefer not to talk with people and withdraw from social settings and avoid social contact, to avoid “face losing”. Mothers retreat from the social activities as they try to protect the child with low resistance from getting sick in the ‘unsafe’ environment as well as to avoid unnecessary pressure to themselves.

Most mothers perceive that other people do not have the uncommon experience, and they do not understand, are not able to help or to provide advice.

Informational needs.

Mothers in the study reported having insufficient information regarding extremely-low-birth-weight and the care of the ELBW child. Also clearly revealed in the mothers’ narratives are their time consciousness and concerns regarding uncertainties. In caring for the ELBW children, the mothers require indication of the meaning of what has happened to them. Mothers of ELBW children speak of the need of support and advice on childcare after the child is discharged from hospital. They have to make adjustments to their role and relationship with the child during the transitional period from hospital to home. Mothers need essential information, guidance and health education, that can help them in focusing on the here-and-now and make plans and targets along the timeline accordingly.

Spiritual needs.

Given all kinds of uncertainty and unpredictable happenings, for mothers of ELBW children, spirituality is acknowledged as a source of strength and courage, enabling them to deal with despair and suffering incurred in the journey of life. The spirituality revealed in this study is mostly conveyed as humanity and morality with the love of mankind. Most mothers acknowledge the source of strength and courage that enables them to deal with the despair during their experience is human nature and the moral obligations of a mother. Without acknowledging religious belief, several mothers believed in fate or luck. Realizing that life holds for them a great deal of uncertainty, mothers convey in the narratives hope for a positive future. Mothers talk about hope for a cure, hope about the future, hope for courage in enduring the future comings. Mothers maintain hope in their living even during the hard times. Embracing faith or fate, they strive to actualize the hope and work out the expectations.

Summary

Within the hermeneutic-phenomenological view of extremely-low-birth-weight, the exploration of the mother's experience of living with extremely-low-birth-weight is illustrated through the themes and metathemes central to this experience. Living with an ELBW child, the mothers experience a similar yet different life as some other mothers do. Similar to those parents of children with special needs, including the prematurely born or chronically ill, mothers of ELBW children strive hard to maintain the important triad of health, weight and feeding, hoping to achieve the presumed normalcy and dignity while living in uncertainties. In enduring the pain and suffering of the children as perceived by the mothers, mothers experience changes in relations with family members and the social world, including the health care systems. In coping with the new roles and responsibilities as a mother caring for the ELBW child, mothers explicitly strive to get an understanding of meaning of life and gain a driving force by transcending the experience through spirituality.

Regarding the Chinese cultural background of the mothers in the study, it is observed that the ways Chinese mothers respond to adversities are influenced by traditional beliefs and values. It is observed that the experience of extremely-low-birth-weight affects the rest of the life of the Chinese mother and the family in the way the mother develops roles and relationships within the family and in the society. New expectations and limitations emerge, resulting from

the management of extremely-low-birth-weight. Mothers develop a close relationship with healthcare professionals for management of the child’s physical health and arrangement of the subsequent educational and social needs.

Compassionate care from family members and professional support from healthcare and social workers are essential to acknowledge the mother’s suffering and create new possibilities for them. In doing this study, it is the desire of the researcher that the understanding of the mothers’ experience will help to bring forth a more comprehensive care planning for the mothers and their children. In the next chapter the implications for nursing and future research will be explored further.

CHAPTER 7

Implications And Recommendations

This study has used hermeneutic phenomenological approach and the researcher has attempted to provide an understanding of the meanings of the mothers' experiences of living with extremely-low-birth-weight, rather than make direct recommendations to nursing practice without interpreting mothers' perspective. Therefore, the discussions and recommendations made as a result of this study are based on a greater understanding of what might be essential elements of mothers' experiences. As such, the findings of this study can serve as useful considerations when promoting the health of mothers of ELBW children during the preschool years.

In the following sections, basing on the findings and discussions in the previous two chapters, the researcher attempts to discuss the implications for nursing practice and nursing education. Limitations of the study are reviewed and recommendations for future research are discussed. Personal reflections will be included to provide a glimpse of the journey that the researcher underwent through during the process of this phenomenological research. It is hoped that from the discussion, further insight would be gained for the planning of care and services for the mothers and their ELBW children; and for the future development of nursing education and research.

Introduction

The metaphor of *Surmounting barriers one after another over the long journey* conveyed by the mothers in this study invites nurses to view the mothers from a different angle and through a different lens. Healthcare professionals are asked to see the mother and child as experiencing beings who seek to be understood, cared for, and treated as individuals meriting normalcy, respect and dignity. Nurses are requested to revisit their roles and responsibilities not only according to the complexity of symptoms within the scope of illness, but as the problems within the context of an experiencing life. Healthcare professionals are invited to take a new approach to the management of extremely-low-birth-weight through engaging the mother and the family living with the condition. Nurses have to look into the mothers' experience from a holistic view.

In the study, it is revealed that the mothers may not possess the professional knowledge regarding the care of the ELBW children, which is held by the healthcare professionals. Yet, the mothers have been confronting the physical, psychological and social meanings of the children's situations with their own knowledge and expertise. The mothers try to discover the particular features of their own situations, and through their actions and reflections they acquire their own expertise in the care for their children. The mothers seek to discover their special position in childcare and acquire expertise through learning from experience regarding the child's condition and necessary care.

Nevertheless, mothers living with extremely-low-birth-weight have frequent interactions with health care professionals and the health care system. Although mothers value the relationships with healthcare professionals and they reveal their support to the notion of becoming partners with healthcare professionals within caring interactions and decision-making, differences between mothers' views of their children's condition and care with those of healthcare providers are revealed. Mothers convey negative feelings for unmet expectations and they try to take control of the childcare as far as their capacity permits.

The difference in views suggests a gap between the mothers' needs and the services and care provided. Healthcare professionals are asked to revisit the existing approach in care and take into account each mother's lived experience in caring the ELBW children as a unique situation with a view of shared understanding.

Implications for Nursing Practice

> *If nursing is a world where we live, rather than a service we provide, then they [patients] and we together constitute it, inhabit it, each depending upon the other to share local knowledge about where safe passage may be found.*
>
> *(Gadow, 1995, p. 212)*

In an attempt to bridge the gap of needs and care provision, nurses should make the move to actualize humanistic nursing that is stemming from the nurses' authentic commitment as a kind of being with and doing with (Paterson & Zderad, 1988). Understanding that the health care professionals would be crowned with the significant role as insiders (*zijiren* 自己人) within the lived experience of mothers, instead of considering themselves as a passer-by whom the mothers meet by the side of the road, nurses have to see themselves as accompanying persons walking through the journey together with the mothers. Rather than viewing the mothers' needs from the perspective of the professional hierarchy, nurses have to engage themselves together with mothers along the passage that they walked through.

> *"Nursing practice invite nurses to embody caring practice that meet, comfort, empower and advocate for vulnerable others" (Benner, 2000, p. 5).*

Instead of seeking understanding from predefined professional needs established by the diagnosis-based model, nurses should aim to know the mothers' experience as it is lived within their perspective. Each person lives his / her world in a different way, and each person gets to know the world from a different perspective. Individual mother's story reveals the importance of treating each mother as a whole and as a unique being with individual needs and experiences, and viewing the mother as a person including physical, intellectual, emotional, social and spiritual components. The metaphor *Surmounting barriers one after another over the long journey* revealed by mothers provides nurses with a broaden view regarding the mothers' coping with the experience of extremely-low-birth-weight. Thus, nurses have to engage into the mothers' physical / psycho / social / spiritual world so as to get a closer focus on to the complexity of their needs and difficulties they encounter as unique to individual mother's journey of life.

In bridging the gap of existing services and needs of mothers as reviewed in the study, nurses are encouraged to initiate care planning for the mother-and-child as a whole because usually the ELBW child is the sole focus of care. Nurses in different settings should work in collaboration to maintain a continuum of care and support while there is a variance between tertiary and primary health services. Inadequate informational and social support is also recognized in the mothers' descriptions, nurses are asked to provide comprehensive and consistent information and to facilitate sensitive emotional and social support to the mothers of ELBW children.

Planning of care for the mother-and-child

Clearly conveyed in the study is the symbiotic relationship of the mothers and their ELBW children and they are intimately close as flesh and bone (骨肉). The mothers are fully connected to the ELBW children in an embodied awareness in assuring their sense of primordial security for the children. Incorporated in the care plan for the ELBW children should also be a plan of care and support to the mothers. In planning the care for the ELBW children and their mothers, nurses need to reinforce and apply the mothers' experiential knowledge. In order to gain the experiential knowledge of the mothers, to know a mother in her unique individuality, nurses have to maintain an inter-subjective relationship with the mothers. This relationship must be one of the here-and-now as well as the human-to-human care relationship between nurses and mothers within the realm and the philosophy of caring. Through maintaining a reflective relationship with mothers, nurses are able to achieve mutual planning of care with mothers in facilitating the care management of ELBW children.

The plan of care should begin as soon as the child is borne and transferred to the NICU. Early commencement of interventional program for parents during the NICU stay will result in less maternal stress in NICU, stronger parental beliefs, more positive parent-infant interaction in the NICU, less maternal anxiety and depressive symptoms after hospitalization, and a reduced length of stay for preterm infants (Melnyk, et al., 2006). Nurses have significant responsibility for supporting parents in the NICU, teaching them how to handle and care for their infants, and assessing parental readiness for discharge (Bakewell-Sachs & Gennaro, 2004).

Continuum of care and support

Helping the mothers move from a parenting experience that is technological and medicalized to one that is individualized in home setting is an essential nursing role performed by neonatal and paediatic nurses in the tertiary hospital. It is important to empower and engage the mothers in child care during the stay in the hospital, and continue to provide information to mothers about the ongoing health need of their infants as time for discharge approaches. The teaching during infant's stay in the hospital is to provide anticipatory guidance and to provide information that will help them to successfully take up the parenting roles after the infant is discharged home (Bakewell-Sachs & Gennaro, 2004).

Continuous support to parents of premature children after the hospitalization in considered significantly important (Holditch & Miles, 1997). As revealed in the descriptions of the mothers of ELBW children is the service gap between tertiary and primary health services. The transfer of service support from the hospital team to the primary healthcare providers is necessary and must be intentional so that the mothers and families know clearly where to turn and to whom (Bakewell-Sachs & Gennaro, 2004). Increasing communication between primary and tertiary health settings will help narrow the gap of service.

It is desirable to include in the hospital discharge plan with information indicating to whom the mothers or parents should call for support at the early time after discharge. Introduction of a hotline for the mothers of ELBW infants after discharge may be beneficial in supporting the mothers during the initial transitional period (Thome, 1999). As revealed in this study the mothers of ELBW children are reluctant to seek help and it will be more beneficial if there is a nurse-initiated telephone follow-up program to enquire the mothers about their progress in childcare. On the other hand, the healthcare professionals in the primary and community services should also enhance understanding of the needs of these mothers as related to the care of the ELBW children.

Providing comprehensive and consistent information

Mothers of ELBW children express need of information not only about the potential disabilities and complications; they seek for information on what rehabilitation program or treatment protocol that would help the children in regaining optimal normalcy. The need for information regarding social support and community services where they can seek help after discharge from hospital is also expressed. Information related to the arrangement of education for the child is the significant concern.

Nurses should be sensitive to services and resources available, including access to education and community services, in assuring care continuum for supporting the mothers during the adaptation period. Nurses are appropriate persons for facilitating the parents support groups in which mothers can share information and gain support (Bakewell-Sachs & Gennaro, 2004; Logsdon & Davis, 1998; Melnyk, Feinstein & Fairbanks, 2002; Preyde & Ardal, 2003).

Also clearly revealed in the mothers' narratives are their time consciousness and concerns regarding uncertainties. In planning of the goals for the ELBW children, nurses may provide essential information and guidance and health education (Bakewell-Sachs & Gennaro, 2004; Loo, Espinosa, Tyler & Howard, 2003), and lead their focus to the here-and-now and make plans and targets along the timeline accordingly. Commencement of informational interventions should be early in the NICU and shortly after discharge from hospital so as to ameliorate the development of negative parent-child interaction patterns as well as adverse child developmental outcomes (Melnyk, Feinstein & Fairbanks, 2002).

Facilitating sensitive emotional and social support

Inherent in the experience of extremely-low-birth-weight is mothers' need to develop relationship with a community that is supportive and caring. Mothers seek for relationships that are authentic for the caring of the ELBW children. Family members and relatives are the trustworthy and dependable persons to the mothers. Involving significant family members of the mothers in the care program, especially the fathers of ELBW children, providing them with similar understandings of the conditions and needs of the children would strengthen the caring relationship to the mothers as implied.

Mothers seek to maintain a relationship in a new community where they may get information, where they feel being understood and cared for, where they have a sense of belonging and feel less stigmatized. If possible, it will be beneficial for the hospital to establish a support group composing mothers or parents of ELBW children to provide network and support among parents with similar needs. The support group can provide a channel for parents to express themselves and act as a resource link to further information on special care and management of the child in the subsequent years. Including the buddy support program by trained peer in the care plan to support mothers deal with the stress during hospital stay (Preyde & Ardal, 2003) will be helpful. Support from mothers with similar experience after discharge will also be helpful when the infant has been discharged to home (May & Hu, 2000).

As mentioned in previous discussion that mothers demonstrate a strong reliance on the health care workers, in particular the NICU nurses with whom they have developed a trusting relationship. Initiating nurse guided programs that help mothers of ELBW children in identifying social support (Logsdon & Davis, 1998) and informational and behavioral interventions (Melnyk, Feinstein & Fairbanks, 2002) would be effective in supporting the mothers to build up a caring relationship in the community.

Furthermore, mothers in the study talk about their concerns regarding the education of the child. Mothers express worries about their child's school placement. They have great resistance that their children being rated below normal and have to study in special schools. Having a child studying in special school will carry a social stigma for the mothers. Mothers should be encouraged to participate in the support group, if any, to evaluate and share information on educational opportunities provided for their children. Nurses and healthcare professionals are in an excellent position in providing relevant information regarding the developmental status of the ELBW children and make necessary reference for school placement.

Implications for Nursing Education

This study generates, in a holistic way, information on the understanding and interpretation of the mothers' experience of extremely-low-birth-weight and describes the interrelationship of extremely-low-birth-weight and the life of mothers. Knowledge generated in this study provides an informational base for education planning and for the reformation of the content of care for the ELBW child with emphasis on the essential role of mothers. Nurses should be able to recognize the barriers and difficulties embodied by mothers in caring for their ELBW children. Nurses should recognize that the life experiences promote growth of the mother as an individual and the family as a whole. Communicating the resulting knowledge in nursing education, can provide guidance for the formulation of care plans and nursing practice that not only provide support for the physical needs of the ELBW children, but also for the psychological, social and spiritual needs of the family as a holistic unit. Nurses should also realize that support for these mothers has to be continued in the primary healthcare services after hospitalization, and nurses in the community services should expand their understanding of the needs and relevant care for the mothers of ELBW children.

The stories provide an understanding of a new way in information gathering during the nursing process in holistic nursing care model. Nurses can benefit from the stories of mothers living with extremely-low-birth-weight and can increase sensitivity to each mother’s experience and its unique meaning. Knowing the meaning of life of the mothers, nurses should be able to appreciate a holistic caring approach during interaction with the mothers of ELBW children. The meaning of extremely-low-birth-weight as a journey of life also provides nurses with an understanding of the mother’s lived experience of extremely-low-birth-weight in a new way, other than the usual quantitative measurement of stress level and coping strategies.

Limitations of the Study

This hermeneutic-phenomenological study provides insight into how mothers live with the experience of extremely-low-birth-weight. The study reveals the meaning of the mothers’ experience as a whole within a socio-cultural construct. Given this study design, the understanding of the experience of the mothers of ELBW children is confined to the twelve mothers who participate in this study within the Chinese Hong Kong culture. The assumption is that they all presented their experience truthfully and accurately. This biased sample is considered to be a must and the researcher purposively selected those participants who had experience – “the most experience – in the topic of interest” (Morse, 1998).

The concern of the sample size is considered. A total of twelve mothers were recruited as purposive informants in this qualitative study. In determining the sample size, the clarity of research topic and the quality of information obtained from interview are important elements. The researcher maintained the topic of the study clear and obvious so that the information was readily obtained in the interviews and data saturation could be achieved without requiring a large sample. The mothers participated in this study not only possessed the experience in the topic of study, they were all able and willing to express themselves and share the intimate experience with the researcher. Given that the data obtained were on target, contained less dross and were rich and experiential, data saturation could be reached with fewer samples (Morse, 2000).

Within this group of mothers, although all are Chinese Hong Kong residents, two of them are of Taiwanese origin and the developmental outcomes of the ELBW children vary. Thus, specific differences in experience are not described explicitly in this study, as it is not an aim. The researcher recognizes, too, that the study does not provide a basis for comparison or generalization. Rather, this study intends to capture a detailed understanding of the meaning of Chinese mothers' experience and uncover the richness and depth of their experience.

It is also important to consider the impact of the researcher's interests and experience on this population. In phenomenological research, descriptions of the experience substitutes for measurement and may introduce subjectivity, while bias may affect both interpretation and possibly have an effect on the interview process. The researcher has taken steps to ensure trustworthiness and that the work is free of bias, but also has to acknowledge that personal experience, interest and familiarity with the subject may pose threats. Equally important, a level of experience, interest and familiarity with the subject is desirable in phenomenological research to enhance the interview process and the ability to relate to and hear each participant, and facilitate the communication of understanding and respect for participants' experiences. In this study, most mothers express a certain sense of appreciation for having an opportunity to describe their experiences and views to someone who "would understand".

In this study, the mothers were interviewed using their first language, Cantonese, to 'maximize the quality of data' (Twinn, 1998). However, the researcher acknowledges that stemming from the lack of similarity in grammatical structure and vocabulary between Chinese and English, any translation errors would compromise the rigour of the research (Schmieding & Kokuyama, 1995). Potential threats to the credibility of the study emanate from the translation of the mothers' descriptions in spoken Cantonese to the researcher's interpretations in written English (Twinn, 1998). In this regard, the researcher, being a native Chinese while having a bilingual background in both academic achievement and professional practice, has conducted the analysis and translation by herself. The researcher has also gained consensus on the translations and analysis from her academic supervisor who masters expertise in both Chinese and English.

The researcher also recognizes the concern of credibility and adequacy of information as the hermeneutic analysis is based on single interviews with mothers. Adhering to the concept of narrative truth, temporality and liminality (Sandelowski, 1993), the research hesitates to adopt the idea of validating the information collected in the first interview against the information revealed in another conversation in which the mothers would have new experiences and see things differently. Nevertheless, all the mothers were ready to talk as soon as the conversation commenced as prior to the actual interview, the researcher has already engaged the participants by performing invitation at the ambulatory care centre, gaining rapport and trust and explaining the purpose and process of study. The places of interviews were chosen by the mothers and they were free to express their feelings, emotions and thoughts in a secure and relaxing atmosphere. As the interviews were conducted with minimum interruption technique, the mothers performed most of the talking as they were immersed in their own life stories that they shared with the researcher with full willingness and trust.

Nonetheless, this study can be considered as a catalyst to trigger the initiation of future studies in exploring the mothers or parents' experience in different categories. The attempt in this study to understand the experience of mothers of ELBW children may provide a base for future examination of mothers or parents' responses to the birth of children with a range of other developmental needs.

Recommendations for Future Research

This study provides an insight into how mothers experience extremely-low-birth-weight. It also reveals the meaning of the life of mothers, focusing on their experiences. Through the understanding of mother's experience, several themes are uncovered as ways that mothers experience the world. These findings provide evidence and directions for future study on the deeper meaning of each theme within the experience of extremely-low-birth-weight, but separate studies describing the deeper meaning of pain, uncertainty, relationships, hope and spirituality within the lives of Chinese mothers living with ELBW children in the Hong Kong context are required.

This study offers an approach to illuminate the multiple realities of the experience of mother living with extremely-low-birth-weight during the preschool years. Revealed in this study is the temporality of the experience of mothers. The mothers describe their responses to the life world as ever changing, as related to the perceived experience in the neonatal care unit, the health outcomes and developmental progress of the child. Further studies revealing mothers' coping at different stage of the life journey, such as on admission to and discharge from the neonatal intensive care unit, and their ongoing experience beyond the early childhood would be useful in further understanding the development of parenthood of the mothers. Future studies revealing the experience of other family members, in particular the fathers and the children themselves, will be helpful in providing a wider view on family coping with extremely-low-birth-weight.

More studies should also be carried out on the meaning of caring within the mother's interaction with healthcare professionals, as nurses and healthcare professionals should have an understanding of the experience, services and interactions that are most effective for these mothers. Future studies can also be conducted to reveal the meaning of caring from the perspective of healthcare professionals caring for ELBW children.

Personal Reflections

As a novice in qualitative research, ever since the commencement of this study, the researcher has been facing a range of challenges both upon her intellectual competence and emotional threshold. On completion of the study, the researcher would like to share her personal reflections that she gained through conducting the study. In doing so, the researcher will present herself in the first person, I.

To gain an understanding that phenomenology is a philosophy, an approach, or perspective to living, learning and doing research is never an easy task for a first time qualitative researcher. For a long time, I was hesitating at the crossroad to identify the appropriate research strategy for the phenomenon I was going to study. In choosing phenomenology, I must accept and live with its ambiguity and uncertainty, follow impulses, respect intuition, await appearances, and respect the stories the mothers tell of their being in the world. And yet, all these factors are not within the traditional law of science and research that advocates a great reverence to concrete structural methods. The greatest challenge was to strive through resistance and misunderstandings imposed from various directions.

This nursing inquiry has given me an extremely rewarding and fulfilling experience. Researching how mothers live with ELBW children has revealed the many challenges that the mothers face. The challenges of the mothers are reflected in the stimulating and emotional conversations they held with me. Immersing in the mothers' world, thinking about and integrating their experiences into my life and my nursing practice, a new understanding and values regarding mothers living with an extremely low birth weight child emerges. A deeper view of the meaning of being human, being-in-the-world is uncovered.

As human beings, we begin the longest relationship we will have in life, the relationship with our parents, in our infancy. This relationship is our first, and it continues long after our parents are dead (Becker, 1992). In this study, we are allowed to see the beginning of a parent-children relationship within which mothers care for their children without expecting reciprocation. It is within this loving relationship that the children learn to seek love and to love.

Through the nurse-parent interaction, both the mothers and the nurse researcher have benefited from the research process. The mothers found the opportunity to tell the nurse researcher their stories to be a helpful experience. As the nurse researcher, I have also been allowed to use a research strategy near and dear to my heart. Reflecting on the meaning of life that emerges from the mothers' experience, I have the very valuable chance to learn and grow with the mothers. I want to thank all the mothers for their generosity and trust on me. I am particular inspired with Jing's words about overcoming difficulties in life, *"You are feeling sorry at this moment, then today is already the worst. Tomorrow will not be worse than today. Difficulties, you have already passed. There will be no more difficulties, no more. Then every difficult day will be passed."* This quote has been giving me courage and support throughout the entire research process and will be accompanying me throughout the years to come.

To conclude, I would like to share my reflections from the homily in the church on the 31st December 2006, the Holy Family Day:

- Being father and mother, parent and child; it is a matter of continuous life learning. Every one in the family learns from each other.
- Happy family is not without problems or pitfalls, not without disagreement. Happy family is about love and trust.
- Families grow and learn from problems and difficulties, in joy and sorrow.
- Have faith in God, let go. You will never know what will happen. The result is not immediate, 1 year or 10 years, you will never know when.
- So, have trust in the family, have faith in God.

Living in one single world, we all see the same sun in the day and moon in the night. But having a unique heart and mind, we experience the solar brightness and the lunar gentleness in our own unique ways. The universal rules are constant, yet the varying experiences of individuals make the fullness of life.

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邀請書

研究題目：The lived experience of Hong Kong Chinese Mothers of extremely low birth weight preschool children: a phenomenological study
（香港「嚴重輕體重」學前兒童的母親的生活經驗）

研究員：鄭綺薇小姐（電話：9302 、）
理工大學護理及醫療系博士研究生）
伊利沙伯醫院中央護理部護士經理

親愛的家長:________________ (　　　　　之母)

現誠意邀請你參與上述研究，是項研究目的為加深了解母親們的生活體驗和感受，從而分析她們所承受的壓力及適應方法。

研究會以面談訪問形式進行，會談需時約四十五分鐘至六十分鐘，會談當中，會問及一些關於身為一個「嚴重輕體重」學前兒童的母親的體驗和感受；為避免訪談之過程受到干擾，訪問過程會以錄音記錄，而錄音帶將由研究員個人保管，只作研究用途，絕不會給予他人收聽，並且在整個研究完成後，錄音帶將會被銷毀，母親及孩子的名字是絕對保密，但在研究報告中可能會引用一些不記名的訪談內容。這項研究可能對母親沒有直接的利益，但所得的資料可供日後的服務改善作參考。

多謝你參與及支持是項研究。如有疑問，可與上述研究員聯絡。

訪談日期: ____________________ 時間: ____________________

訪談地點: ____

Invitation

Project Title: ***The lived experience of Hong Kong Chinese mothers of extremely low birth weight preschool children: a phenomenological study***

Principal Investigator: **Cheng Yee-mei, Grace, PhD Student, HKPU**
(Tel: 9302)

Dear Parent: ______________ (Mother of)

You are cordially invited to participate in the captioned research. The purpose of this research is to help the local healthcare providers in further understanding of mothers' experiences of stress and coping in having an extremely low birth weight (ELBW) child in the family.

An Interview will be conducted and which will last approximately 45 minutes to one hour. During the interview questions will be asked regarding your feelings and experiences as a mother of an ELBW child. The interview will be audio-taped and the tape will only be assessed by the researcher and used for the purpose of this research. The tape will not be shared with other people, and will be destroyed after completion of the study. The names of the mother and the child will be kept strictly confidential, and only anonymous quotations will be used in the final report. There may be no direct benefit to you as a participant of this study, but the information obtained will provide good reference for future improvement of healthcare and services.

Thank your for your participation and support in the study. For any question, please contact the above named researcher.

Date of Interview: ________________________ Time: ________________

Place of Interview: ____

Appendix II

同意書

研究題目 : The lived experience of Hong Kong Chinese Mothers of extremely low birth weight preschool children: a qualitative study
(香港「嚴重輕體重」學前兒童的母親的生活經驗)

研究員 : 鄭綺薇

是項研究目的為幫助本地醫療服務者加深對「嚴重輕體重」學前兒童的母親們的生活體驗和感受的認識，從而分析她們所承受的壓力及適應方法。會談需時約四十五分鐘至六十分鐘，會談當中，會問及一些關於身為一個「嚴重輕體重」學前兒童的母親的體驗和感受；為避免訪談之過程受到干擾，訪問過程會以錄音記錄，而錄音帶將由研究員個人保管，只作研究用途，絕不會給予他人收聽，並且在整個研究完成後，錄音帶將會被銷毀，母親及孩子的名字是絕對保密，但在研究報告中可能會引用一些不記名的訪談內容。這項研究可能對母親沒有直接的利益，但所得的資料可供日後的服務改善作參考。

本人: ________________ 現同意參與是項研究。

- 本人明白參與是項研究不會影響本人的健康。
- 本人現同意參與會談，及准許錄音，本人明白會談之錄音帶將會被銷毀，而日後的研究報告不會涉及本人的姓名。
- 本人明白自己有權拒絕會談中的問題，及隨時終止參與研究。
- 於會談中本人有機會提出關於研究的疑問，並得到滿意的答覆。

參與者簽名: ______________________ 研究員: 鄭綺薇
(聯絡電話: 9302)

日期: ______________________

預約會談日期: ____________________ 時間: ____________________
訪談地點: ____

Consent Form

Project Title: ***The lived experience of Hong Kong Chinese mothers of extremely low birth weight preschool children: a phenomenological study***
Principal Investigator: **Cheng Yee-mei, Grace, PhD Student, HKPU**

The purpose of this research is to help the local healthcare providers in further understanding of mothers' experiences of having an extremely low birth weight (ELBW) child in the family. Each interview will last approximately 45 minutes to one hour. During the interview questions will be asked regarding your feelings and experiences. The tape will not be shared with the hospital staff, but the final report, containing anonymous quotation, will be available at the end of the study. There may be no direct benefit to you as a participant of this study, but there may be change in care to mothers of ELBW children in future following the completion of this study.

THIS IS TO CERTIFY THAT I, ______________________________

hereby agree to participate as volunteer in the above name project.
I understand that there will be no health risk to me resulting from my participation in the research.
I hereby give permission to be interviewed and for this interview to be audio tape recorded. I understand that, at the completion of the research, the tapes will be erased.
I understand that the information may be published, but my name will not be associated with the research.
I understand that I am free to deny any answer to specific questions during the interviews. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty.
I have given the opportunity to ask any questions about the study I want, and all such questions have been answered to my satisfaction.

______________	______________
Participant	Researcher
	Contact No. 9302

Appendix III

The Lived Experience Of Hong Kong Chinese Mothers Of Extremely Low Birth Weight Preschool Children: A Phenomenological Study
(香港「嚴重輕磅」學前兒童的母親的生活經驗)

會談指引

請你形容一下作為「嚴重輕磅」學前兒童的母親的經驗
  你可曾記得…?
  你當時的反應怎樣?
  你當時心裡想什麼?
  你可否形容一下你當時的反應 / 情緒 / 感受…?
  你怎樣形容你當時的感受…?

你可否回想一件最難忘的事
你可否回想一件你最難受的 事 / 物?
你可否舉例子…?
你可解釋詳細一些…?

你怎樣解決 / 處理 你所提及的困難?
那些人 / 物 你認為有助你解決你所提及的困難?

剛才靜默的時候，你在想著什麼?

你可有問題要問我?
你可還有事情要告訴我?
你可有想起什麼事情要跟我談?

注.
此會談指引所有問題只供提示用，而並不規限敘述的次序及內容

Appendix III_a

The Lived Experience Of Hong Kong Chinese Mothers Of Extremely Low Birth Weight Children: A Phenomenological Study

Interview Guide

Can you tell me your experience as a mother of an ELBW preschool child?

Prompting questions
Can you remember a time when…?
How did your respond when…?
What were you thinking of when…?
Can you describe your responses / emotions / feelings when…?
How would you describe your feelings when…?

Can you think of an event that is most unforgettable?
Can you think of any event / thing that you reckon as really bad?
Can you give an example of …?
Can you tell me more?

How did you solve / manage the difficulty you mentioned?
Who / what do you think as helpful in solving / managing the difficulty mentioned?

What were you thinking just now when you were in silence?

Concluding question
Is there anything you would like to ask me?
Is there anything else you would like to tell me?
Is there any thought at your mind you would like to talk with me?

Thank you for participating the research. I will transcribe the audio tape, and may contact you again to clarify any questions.

NB.
The questions in this interview guide only serve as prompts to facilitate narration and do not govern the sequence or content of narration.

Appendix IV

Field-Notes

Participant Code: *ELBW_3* **Interview Date:** *3.6.2000*

Starting Time: *10:00 am* **Ending Time**: *11:30 am*

Location of interview: *Home of participant*

People present: *The whole family, the participant, her husband, the ELBW boy and the new baby girl, were at home. The husband intended to join the meeting at the beginning and went into the bedroom after explanation given by researcher. He left alone at first leaving both children behind, yet the mother asked him to bring them with him. The researcher and the participant talked in the sitting room alone. In the middle of the interview, the boy joined us then the father brought out the sleeping baby too and he himself returned to the bedroom. Then, occasionally, the mother had to attend the baby and settled the boy's request during the interview.*

Non verbal behaviours:

e.g. tone of voice: *firm, fluent Cantonese with Mandarin accent, slow but clear*

posture: *mother was sitting on a stool at the same level at the sofa where researcher was sitting*

facial expression: *tense, showed dislike and discontent when talked about her relationship with husband's family, firm to the boy (unconsciously but would be her usual behavior) and tried to soften her voice to the boy intentionally sometimes which the boy showed uneasiness but he liked it. Comparatively, she was more tender to the baby girl. She sometimes behaved indifferent behavior especially concerning the family of her husband.*

eye movement: *firm and strict when giving out order to the boy*

forcefulness of speech: *reinforced the family of her husband was bad to her but she didn't care*

body movement: *not much*

hand gesture: *not much*

Researcher's impressions: (e.g. discomfort of participant with certain topics, emotional response to people, events or objects)

Participant was a young and modern mother who was a Taiwanese came to HK after marriage. She was willing and participatory in expressing her opinion and feelings though she said that she did not like to share her feelings with others. Most of the time she mentioned her unhappy relation with husband's family, which seemed apparently bothering her very much. She tried to convince the researcher and herself with reasons and logic. It might be typical 'in-laws' relationship complicated with additional factors such as the husband was the only son in the Chiu-chow family, the wife was a Taiwanese having previous career as tourist guide and the birth of an ELBW twin child with the other twin died. Participant did not show much her feelings, tried to be 'reasonable' and be sensible. Researcher realized that there might be potential problems such as marriage problems, behavioral problem of the child and even child abuse due to mother's unresolved psychological problems.

Technological problems: *the tape finished at 60 minutes without being noticed, so the last few (about 15 minutes of the interview was recorded by memory*

Other remarks: *Interview ended with casual talk and brief advice on interpersonal skills. Advised the mother to talk to someone she trusted and she was welcomed to call the researcher if she felt comfortable to.*

Appendix V

Examples of Stories of Mothers

Story of Mother Pei – Mother of Yi-le

> *"It's really a bitter experience, taking care of her is really bitter" Pei said. (1: 68. 1)*

Pei and the families, husband and two girls, lived in a self-purchased flat in a new satellite city. She and the girls greeted the researcher at the door with curious but excited smiles, seemed to expecting a friend's visit. Pei asked her husband to stay and look after the children then she led ther researcher in the children's room. The researcher sat on a child's stool and she sat on the bed. Occasionally, the little girl Yi-le cried for mother and knocked on the door, Pei was so engaged in the conversation and paid no response to her.

Pei had two girls, the first was born full term with normal weight, and the second child was the prematurely born girl Yi-le with weight of 930gram. Yi-le went home after staying in the hospital for more than ten weeks and survived without any obvious developmental complications.

Pei was very willing and participatory. However, she might be preoccupied with her previous participation in another telephone interview on the NICU experiences, she often voluntarily focused and described in details regarding certain areas especially the hospital events. She showed uneasy when talk about topics which she seemed not prepared for, such as the experience at home and reflections on her experience.

Pei was tangling deeply in the memory of acquainting the insecure experience during the NICU days. As she conveyed that the experience was so stressful that she had sleep disturbance. “When I went home, I was very upset, could not sleep at night, thinking of the baby all the time” **(**1: 32. 1-2**)** “At night I would get awaken from sleep on and off. ‘Looking’ at the news reporting in the television without listening, I did not know what’s going on there…” (1: 40. 6-7) She would never forget the experience “It’s unforgettable, I will never forget this in my life.” (1: 111. 1-2)

Starting from the unprepared labour, to Pei, everything was not within control and prediction. The size of the child was the apparent trigger of uncertainties as everything seemed to be inappropriate or impossible. “So small a baby, when I went there and… ‘Why she was inserted with so many tubes (the intravenous apparatus and vital monitors)! Is it possible?’ I was wondering.” (1: 30. 3-4) “Couldn’t image she is so small! I dared not touch her. Even the nurse reassured that I could touch her limbs, I dared not to. I was scared to see her being so small.” (1:36. 3-5)

On the other hand, the proximity with the child lessened the anxiety. “Anxious and happy, when I held her in my arms.” (1: 101. 1) Pei felt content when in close proximity with the child and the positive feeling would overcome her physical strain. “At that time, not at all tired, not feeling exhausted. I got to see her, then I feel at ease.” **(**1: 111. 2-3)

Normalcy was the focus concern, regarding both the cognitive development and weight gain. “Though she is tiny, everything is normal. At least, she speaks, she walks and she sees normally. It is the most important.” (1: 125. 9-10) She rephrased the comments from others regarding the child with grievance “Her grandmother said that at last she looked like a normal baby after six months!’ When she first came back, she looks ugly. Her father said she looks like a little monster because she was grey and hairless.” (1: 56. 2-3, 5) Pei defended when being ask if she cared about what other people commented “I don’t think people should see her as abnormal. The most important is how we parents see her. As parents, we should know best as we are the one who take care of her…I would not think why people will see her abnormal. But I think she is developing quite well. The IQ is not bad….” (1: 187. 3-6)

Pei perceived increased responsibility upon the child as she stated “Such a baby…the life could be saved. I told myself I have to be very conscious in taking care of her.” (1: 125. 1-2) This responsibility could not be transferred to others because of the unique relationship between her and the child. She herself could not let go and the child would not accept any other carer. “I would be worried and I have to take care of her all by myself. Everything I have to …because I have been taking care of her; and I am afraid that she would not follow strangers neither.” (1: 179. 4-5)

In addition to the increased responsibilities, there were addiontal financial concerns for living with extremely-low-birth-weight. Pei said, “We have spent more money, I noticed. And because we have to buy those fresher foods, better food for her, hoping that she would have better resistance with better food.” (1: 119. 1-4) “The financial burden is increased. Such as in those days, I had to take her back to the hospital for follow up…suctioning (chest physiotherapy)… everyday by taxi. It took more than three hundred dollars for the going and returning.” **(**1: 123. 4-7)

With an ELBW child, the family became more aware on the developmental milestones. “I was worried, worried that she could not hear, and could not speak. About 6 months after she was back… I always played music by her ears to see her response… And the television, I also watched if she could see, if she had response... I was particularly conscious about her hearing and seeing and …if she could walk ….” (1: 169. 1-6)

Pei also strived to keep high vigilance and prevent the child from getting sick. “During the first year after she was back, I was so anxious and tense that I could not sleep. Once she got sick, you dared not sleep. Because she had… pneumonia and dyspnoea. Because of dyspnoea, she had to return to hospital for more than ten days.” (1: 68. 10-12) “Everything had to be very careful and hygienic, such as everything she ate, you had to wash hands before feeding her. You could never be careless as she would easily get diarrhoea if she had eaten just a little bit unclean." (1: 70. 3-5)

Pei gained support from the relationship with family and she perceived significant support from her husband. "All these years, it was he …who kept telling me to be relaxed and not to be worried." **(**1: 177. 1-3) She recalled that her husband had an optimistic view "He said 'Don't get worried for those minor things. She (the child) is already a lucky one. Basically she is very very lucky. You don't have to be worried all the time. Children always have common cold and cough.'" (1:175, 3-5)

Pei related about the restrictions and limitations that the child imposed on family life. "Not dare to take her out to public places, not even to the market. Her body was so very weak and she easily got sick. So I would not take her out." (1:68, 1-4) The restrictions in turn created the feelings of guilty upon the elder child. "Not going out…so having less freedom. It was not good to my elder daughter, not fair to my elder daughter. To the elder… I couldn't help. I would not go out …I could not take her out…so I could not go and she could not go neither. That time, hired a domestic helper, that woman was good, sometimes when she went swimming in the summer or to the Ocean Park...she would take my daughter with her … I said 'I do know it was miserable', not only I was miserable myself but to my elder daughter too… She was just a kid of five and loved to play, but she could not even go downstairs for cycling… It lasted for several months. For almost one whole year, other than going to school… she would not go out not even to the restaurant or McDonald…” (1:119, 5-9)

Pei saw the change of feelings as time passed and things happened. “You will be very happy, (to see her gaining weight) from two pound to more than three pounds. Don’t you know, at that time, just a little weight gain would make me very happy.” (1:101, 1-2) “The most rejoiced is now that she is more than two years old. At least, she gets sick less frequently, her resistance is better.” (1:185, 14-15)

Living with extremely-low-birth-weight has brought Pei in the nearness of death, the near loss. “I am really lucky. From fear for the pending loss till she gradually grow normally, and she is now preparing for school. Very very lucky I am. Sometimes I would think the girl is really a gift from the heaven.” (1:129, 6-8)

The health of the child was Pei’s major concern at present. She foresaw and anticipated the life would be becoming better in a few years “Not hope for anything…just hope that, striving for a few year more, her health will be better at the age of three to four. I am prepared for (this kind of life) till three to four years old, when her resistance is improved, health is better. I am prepared for that with this premature baby.” (:113, 4-6) “I just hope that she will not have so much illness.” (1:147, 1)

Story of Mother Rui – Mother of Jin-ho

> *When I looked back, (I told myself) I had not decided wrong. Perhaps, he came to be the companion of his elder brother.* (2:172, 3-4)

Rui was a full time housewife who took care of the family mostly by herself as her husband had been taking part time study for the past years.

Jin-ho, born with birth weight 680 gram, was having the second year of kindergarten. Jin-ho caught up with normal development with some fine movement coordination problems. He was just energetic as any young boys and was trying interfering the interview by asking his mother for all sorts of thing and making noises with his elder brother. Just like any kids, he tried to seek mother's attention in presence of other people.

From the very start, Rui had been internalizing the experience and described calmly that it was not that difficult to take care of the child because of her previous experience of raising the elder one. "I could manage, because I had been taking care for the elder son for years. therefore I was used to it…I think I was used to it. Taking care of the elder one and taking care of this child…when I think back now I do not feel…because… it was more or less the same." (2:78, 2-6; 156, 3-4) Taking care of the child was not a problem, but the health of the child would be the cause of worries. "Difficult, I don't feel very difficult (taking care of the child), but worried…I was worried. At that time I would be worried but didn't know what I was worrying about. Say, if he got sick I would not know what to do…" (2: 44, 1-2)

It hurt to see the child's suffering and pain during the during the NICU days. "If everything was not ready, I would rather…when he had not had much sufferings, I would rather he *was not here* (Cantonese saying – 'died')." (2:106, 6-9) "The first time I saw him, (it hurt) in my heart…seeing him…I felt that was very poor, he looked very painful…with all those insertions (injections and needles). In fact when I touched his hands, the bones were so soft and tender. I was afraid and I did not dare to move him." (2:120, 1-3)

Though Rui did not say much regarding the weight and normalcy, they were the concerns as she gave a tearful remark regarding the light weight at birth. "I was worried at the beginning, because after all, he was born with low birth weight." (2, 78, 6-7) "The first time I saw, he was really very small and inserted with many things. Then I was really worried, worried if he would be abnormal." (2:106, 6-7)

The life of uncertainty began at the onset of the unprepared labour, yet Rui was optimistic. "In fact the doctor did not agree to take chance. He said 'The child is very small and light weighed, a lot of development may not be ready…and, you'd better have natural delivery.' Natural delivery meant that there would be no resuscitation. That meant when abnormal heart rate was found, there would be no resuscitation or what so ever. But I then said to my husband, ‘Up till this situation now, why not we take the chance, then decide after he is born.’ I did not think he would be abnormal at that time.” (2:106, 1-5)

To take care of the ELBW child in addition to the existing family, Rui learned to take control. “Since my elder son was just entering primary one. Then problems came. I had to go to the hospital daily to see him and yet he was not having special problem. Just the feeding … and the physiotherapist was teaching him to eat and it seemed… was not progressing that well. Yet, if I went to feed him and it seemed better. But I had to spend time to feed. So I thought… I did not want to linger too long. Then I told the doctor that I would take the child home because my elder son was entering school. So the doctor said ‘If you can manage, you can go home’.” (2:26, 1-6)

Rui kept watching for the developmental milestone of the child. “Before he could talk, I was worried about his intelligence. Before he could walk, I was afraid he was unable to. Because he was slower in these sorts of development and I was worried... The day when he could walk, it seemed like lowering a bag of load (burden). When he could talk, I lowered another bag.” (2:78, 6-9)

To overcome the feeding problem of the ELBW child, Rui had tried various feeding technique. “Feeding him was difficult task because he did not eat much. It took a long time for every feed because he did not know how to suck. So, I had to make bottle, make the hole (of the teat) bigger, and pressed and pressed on his tongue to squeeze the milk in his mouth." (2:26, 6-10)

Living with an ELBW child, Rui recognized certain restriction and modified the usual pattern of life. "For the first one to two years, we really went out less often. I dared not go to crowded places. Only recently, we would go to farther places, such as Shen Zhen. In the early days, we dared not. In summer, we would not go to places of hot weather for fear of too hot. In winter, we were afraid that it would be too cold. So we could not go anywhere. But, so I felt like being restrained all days, just like being restrained…"(2: 78, 1-4)

The ELBW child brought Rui a busy life. "In fact taking care of him was not difficult. But as he grew bigger and I had to carry him going here and there for physiotherapy and occupational therapy…and the follow ups, I had to carry him going here and there, that was tiring. In fact child care was not difficult. " (2:140, 6-8) In this regard, Rui considered the light body weight was an advantage. "When he could walk by himself, it was not tired any more. Because he walked sometimes and I did not have to carry him. Moreover, he was not that heavy, it would not be too tiring to carry him on my back." (2: 176, 3-6)

Living with an ELBW child was time demanding and the time for other sibling should not be deprived of. Rui expressed that "I don't know if he was affected.

Because he (the elder son), when he was small I thought he was all right. But now I notice that his school performance is getting worse. He does not concentrate on his study. But I don't know… when I look back, in fact his performance was not too bad when he was in primary one and two. But now I notice his school performance is bad… Sometimes I would think would it be because I had not spent adequate time on him. But it seemed not true; in fact I did spend plenty of time on his schoolwork. In fact I don't know…. " (2:150, 1-7)

Rui was aware of the unexplainable but uncomfortable feelings of talking about the child with others. "It was not good when people talked about the issue. I had bad feelings inside and I easily got tearful. It did not happen when I was with him (the child). But when other brought up the topic, or when he was not well, then I would not feel comfortable inside. Worried…it's not worried, anyway it was not comfortable." (2: 124, 6-11)

Rui was optimistic and viewed things with positive perspective. "Before he was one year old, physiotherapy had already been started. He was slow in turning position, so we started to teach him turn. In fact, gradually…gradually, it was noticed that he had better progress than others…It might be because before the problems developed, he had been under monitored." (2: 80, 1-5) **"**When I looked back, (I told myself) I had not decided wrong. Perhaps, he came to be the companion of his elder brother." **(**2:172, 3-4)

Story of Mother Jing – Mother of Jun-wei

> *I said to myself, I encouraged myself 'You are feeling sorry at this moment, then today is already the worst. Tomorrow will not be worse than today. Difficulties, you have passed. There will be no more difficulties, no more. Then every difficult day will be passed. You see, instead of sitting there and thinking how sorry the old days were, would it be better you think about how to live the future, how to make the future better.' (3, 34, 13-20)*

Jing was a young mother and she was a Taiwanese who came to HK after marriage. She used to work as a tourist coach before marrying her husband who was the only son in a Chao Zhou family. Jing had had delivered a pair of twins and Jun-wei was the first twin who survived. The second twin son died in the NICU soon after birth. Jing had just borne another younger girl who was about three months old.

Jun-wei was three years old without any severe developmental problem except the small body size and walking gait defect. What made Jing worried was the tumor found near the blood vessel in the brain, which would be a potential 'bomb'.

Jing' husband intended to join the meeting at the beginning and retreated in his room after explanation given by researcher. He went alone at first leaving both children behind, yet Jing asked him to bring them with him. Jing and the researcher talked in the sitting room, and in the middle of the interview, Jun-wei came out and joined the group then a moment later the father brought out the sleeping baby too. Then he himself returned to his room. So the interview continued in the presence of Jun-wei and the baby girl. Occasionally, Jing had to attend the baby and settled the boy's request.

As early as Jing knew about the twin pregnancy, she lived with unpredictability and unknowns. "He (the doctor) said 'It will burst one day, just like a bursting balloon, but I don't know when.' He could not tell you when, yet I always knew it would be premature delivery. Just not knowing when would be the 'early' labour, yet I had not thought that 'early'. In fact, I did not have the sense of worried because I had not given birth before. Neither did I know whether it would be viable for twenty something weeks…" (3:20, 13-16)

The size of the ELBW child was the first striking scene. "I did cry at that time. I could only see that he was really small, very small and inserted with so many tubes. I found him not like other babies." (3: 62, 8-9) "They had to stabilize him. What did they use? They used those 'ice cream stick' to fix his hand. His hand was so small that they had to use 'ice cream stick.' I could see that…and his head was so tiny, just like a cat. Yes, it really looked like a cat, I could remember clearly." (3: 58, 4-6)

Child’s sufferings were something Jing could not bear. “I would see that he was very miserable. So small his hands, he was so tiny and he had those injections, inserting here and there… then here and there…” (3: 58, 1-2)

Jing had much uncertainty to strive through. “At that time, I was just thinking … ‘Would it be good if he could be saved? And all problems would be unimportant?’ Well, when his life was saved, you would hope that the eyes were no problem; when the eyes were all right, then you would hope that his brain was no problem….so and so. And I could see that everything was pre-planed (by the Highest).” (3:68, 3-5)

Feeding an ELBW child was a series of tiring tasks. Jing illustrated “When he was small, it was really hard time. He was not like other babies. My daughter who I am now taking care is normal. She drinks milk…then till she is full, then I burp her, ‘Uhh’… that is done. But my son was different. He drank just a little bit, and when he was still drinking, then he would throw up, just spit up all back to you…..I fed him day after day. During the whole night, I kept feeding him, making him to sleep, cleansing the floor. Day after day, feed after feed, I was repeating the same thing…..” (3: 30, 25-30)

Jing was living with unpredictable event. “Lately I was afraid that he, the MRI investigation showed that… the left brain, at the back of the brain, there was a tumor by the blood vessel. So I asked him (the doctor) how this happened – he said ‘Don’t know.’ Would it become bigger and bigger – he said ‘Don’t know. We have to keep checking on that’, so he (the doctor) said. I asked what would happen if it grew bigger and bigger. ‘When it grows bigger it will block the blood vessel, and when the blood cannot pass the vessel, it will burst.’ I asked when. He said he would not know. He said he could not tell. So now it is hard to say’ (3, 42, 3-8)

With the potential but unpredictable happening, Jing learned to be more aware with the extremely low birth weight child. “I asked the doctor what should we pay attention to? …He said it was just like stroke. If you are an adult, you can tell him be calm and not to get angry so and so. But for a child, if you ask him to slow down and not be too fast, he would not understand. And the doctor said ‘Sure, these sorts of things would not be taught. But you should ask him be slow and not too hurry.’ Yet, how could the child understand all these!” (3: 42, 10-14)

Having an ELBW child was a unique experience. “People would not understand, would not pardon you because you were taking care of a premature baby. People viewed you as having a normal one. My mother-in-law and they said ‘Others raise baby, you raise baby, why do you have special way?’ I could say nothing. You see my son and you are not…you won’t understand. It would be useless to say too much. Wasting my saliva (energy)…” (3, 30, 31-35)

With the extremely-low-birth-weight, Jing recognized the relationship with family changed. Jing perceived no support in childcare from her husband “He said he was tired after work, standing all day selling things. I said ‘Don’t only think that you are tired, I was tired too, I was tired waiting for you at home.’ … Even during holiday, he would not help. He did not know how. Till now my son is three years old, he has never bathed him. Only because I have to stay in hospital for delivery of the baby girl, he… no escape this time, they were staying at home together and he had to bathe her... It may be the traditional concept of his family that the mother has to do all the things… Even after the child was born, he would not initiate to hold the baby when the baby cried.” (3:44, 2-10)

Jing expressed a difficult time with the in-law’s family after the birth of Jun-wei, the ELBW child. This bad in-law relationship was signigicant in adding meaning to the experience of Jing. “My mother-in-law told the nurse that ‘His mother (Jing) does not like to see the baby.’…and then at home, in front of me, she cried and said ‘Other people have twins, we have twins; others have no problem, why it is like that for us….I don’t know what have you done. Something wicked…’…so and so…Then I was really unhappy.” (3:28, 9-12)

Jing recognized the change of relationship “Of course, there was change in our family, and it was a big change… My relationship with them was different. I thought they have let me see things most clearly…I don’t know whether I know them better and see they clearer or they see me clearer…a lot of things. Because, when I was still bearing the children, there was not yet, not yet plan to renovate the house and change the room (for a bigger one). Then after the children were born and one was dead, while waiting for the child to return home, starting the renovation and waiting for his return. During that period of time there were a lot of ‘talkings’ …. And my attitude had also changed greatly.” (3:82, 1-5)

Jing confronted when being viewed as different. “There ought to be something wrong when other normal babies go to the hospital. But we are not, we just go for checking up. So at that time, when we were still living there (with in-laws), every time when we went to the hospital, my mother-in-law would be very anxious and said, ‘What’s wrong again. Don’t go if there is nothing wrong, so and so…’ I said that there was nothing, just for check up. I myself knew that he was not abnormal. That (follow up) would be something we should do, nothing weird. But others would think ‘So weird, there is nothing wrong but why have to go to the hospital…’ Just like recently he is learning to speak (speech therapy). ‘He has nothing wrong, why should he go learn speaking’…” (3:38, 5-10)

Jing had feelings of isolated and loneliness. “I did not have my families (maiden family) here and I had no one to talk with. What my mother-in-law said to me, I had not told my husband. Because if I told him, whom he would believe? Me or his mother? So I did not say anything. So I had no where to talk when I was unhappy. And I did not want to tell my mother...” (3:28, 12-15) Jing would retreat from social contact with the in-laws. “So I took the child by myself. I would retreat in my room. I did not like to have any (contact)… with them. So they had lots to say at that time. ‘Not even allow the grandparents to hold the baby…so and so’ … And they also said that I rarely brought the baby out to let people see…” (3:30, 14-17)

Jing would keep things to herself and would not seek help. “It was my character, I would not like to ask people to do thing (help). Instead of asking people, I would do it myself. I am like that. So I rarely ask him (her husband) to help me. Instead of making the request, I would have finished by myself already.” (3: 44, 16-18)

After the ELBW child was born, Jing had a stressful time and was once at the edge of ending her own life. “Now when I look back, I should have been very upset by then. I did not know if I had that what you called depression. I did not know. He (husband) said, he said that he was afraid that I would throw the baby out. That time when we were living on the 13th floor… I thought I would not, I had not thought about that. I just sat by the window all day, looking out and thinking. But I had not thought of jumping out or throwing the baby out. It was very difficult taking care of him at that time, because he was so small.” (3:30, 1-6)

The experiences made Jing see life differently. “Then I would think should it be like what the doctor said. If I put all my effort to bring take care of him, till he were twenty something. One day if he died because of stroke, then it would be unfair to me. But why, then, he would be very poor. Yet if he could live up till twenty something… that would be better. At least, he could have been to places and have fun… But if he would die at teenage, then there would be a lot of places he had not yet visited. Then I would think that… every time I had holidays I would take him to places and see more of the world. In case anything happened, he would not have…just come to the world but had never had fun.” (3: 42, 15-19) Jing described quite a unique relationship and interaction with Jun-wei, that could be observed when Jing gave out order to Jun-wei with strict and sharp glance. “I treat children in a very …very... What I think is… right is right, and wrong is wrong. I will beat, yes I will beat children. And it (the beating) will be quite severe.” (3:42, 22-23) “In fact my son is very attached**…**very attached to me. Yet he is a very good child…He is afraid of me, very much, because I will beat him….” (3: 52, 13-14)

Jing would seed positive perspectives to the child. “If you do not let him know that you consider him to have inferiority complex, then he will not have. If you have this in mind then he will. I think his concept is given by the parents. So, don’t behave in such a way that he will have such feeling.” (3: 42, 34-36)

She tried to convince the research and herself with reasons and logic. The researcher got deeply disturbed after the interview, with much concern of Jing, the child Jun-wei, and the whole family.

Story of Mother Feng – Mother of Yi-jie

> *I would see the hearing aid as very ugly, very unpleasant. So unpleasant that I would not dare to let her wear it. So…now…such…whenever going out, I would not let her wear it. I always covered it up with something for fear that other people could see. I was afraid…(4:18, 60-62)*

Feng was working mother who was humble and timid. She was willing and participatory in pouring out her experience and feelings while jumping form topic to topic all the time. She was overwhelmed with guilty feelings concerning the girl's loss of fingers of the left hand and other handicaps due to premature delivery.

Feng depended a lot on the paternal grandparents of Yi-jie for they had been supporting in childcare since birth, though she hinted that there was disagreement on the care of the child sometimes. The researcher met the grandmother in the outpatient clinic when she brought Yi-jie for follow up. Grandmother accepted the invitation and the researcher made a call to confirm with Feng for the arrangement of interview.

Yi-jie was the first and only girl of Feng. She was born at home prematurely one night in the wintertime. She weighed 670gram and had stayed in the hospital for more than two months. Yi-jie survived and was found to have visible developmental complications including visual weakness, partial hearing loss, and loss of fingers of the left hand.

The researcher recognized that, through the conversation, she should have met the child during her clinical practicum in that training institution where the ELBW baby had the heart surgery. Since the baby was transferred from the researhcer’s parent hospital, the researcher was particular interested in this baby and had tried special techniques with extra care on her hand, hoping to ‘preserve’ the fingers of the child. Yet, the researcher had completed her clinical attachment and left before she knew the outcome.

Feng and the researcher had their interview in the mother’s home. The husband was out working and the girl was stay with the grandparents in their home nearby. During the conversation, Feng burst out into tears and cried for several times. At one time, ther researcher had to suspend the interview and stop the tape recorder, and performed counseling.

Feng was conscious of Yi-jie’s health symptoms. “I observed closely. Every time she got sick, I was unable to sleep. I would feel her forehead… here and there and the forehead to check if there was fever.” (4:44, 1-2) Feng described one situation when Yi-jie had an emergency. “She is always like that. Every time she had to go to hospital, it was because of shortness of breath. Once she got the attack, she would become chilled and the hand and foots would turn purple…lips and limbs would turn purple. Immediately we would send her to the emergency room. But usually, we would not call ambulance, we would go immediately by taxi. Whenever the doctor saw her like that, they would admit her in the hospital. Usually it's the airway. Till she is big now…recently…just a few days ago she still had fever. Once she had fever, she would have chills all day, shivering hands and all that…" (4:42, 1-5)

Feng recalled the child was also aware of her own problems "She said to me 'Mommy, I am sick, don't go asleep.' I asked her why and she said 'You can just have a nap, but don't go asleep. Just close your eyes and you have to watch me.'…I told her that mom was not able to sleep when she was sick." (4:46, 1-6)

Staying in hospital with the child became Feng's life routine. "In those days, she would go to hospital almost once a month. I almost…in the hospital…almost stayed in the hospital at least one week a month. Days and nights, I stayed there with her. Grandmother would stay with her during the days and I went to work. I, without any sleep, I went to work direct. Then in the evening, I returned to the hospital. I took turns with my husband, on alternative day..." (4: 18, 1-9)

The uncertainties brought by the ELBW child came up one by one. "He (the doctor) told me one by one. I was frightened, frightened for this and for that, everything. Lucky is that now...but her lungs…her lungs are weak. Her eyes, now, the recent investigation said that she had eye weakness, but it was correctable. That is visual weakness or…astigmatism…so to correct it. She is also using hearing aids. I was unable to accept at first when she used the aids. The doctor said that her ears…she had mild hearing loss…but I could not accept….There were still a lot, say the brain and lungs…all the internal organs. Almost all...the whole person. Because she was born unready. The lungs inside and so on were not ready. So he told us a lot…everything would be possible. I was very scared. ” (4:18, 50-55)

The stress for Feng lasts for years “It was very miserable, really, very miserable. But it was hard to describe…it was miserable after all. For the past five years, the pressure was very great. I was anxious all the time. Whenever she got sick, I would be very anxious and became a mess. I was anxious when she was sick. When she grows up, again, I am anxious in finding school for her. Since I don’t know which school will be good. She is not like other ordinary children and you can choose any one school you like. She is different. The psychological pressure is very great. And now, planning for primary school, the pressure is very big, don’t know which school would be good…” (4:138, 1-5)

There was no return. After bringing Yi-jie to the world, would Feng leave her alone? “I would not, I would not give up. I said why I should give up. It was a life. That was my own child whom I myself brought to the world. No matter what, it was my own child. I would not give up.” (4: 34, 6-7) Feng said that she insisted because of the mother-daughter bonding. “I did not know why myself. I knew… might be gut feeling…I knew that…She was my daughter and I would not give her up. I insisted to save her.” (4:40, 1-2)

Feng tried to avoid being viewed as abnormal, viewed as different. “Their views… were different. Because…once I brought the girl back (to her work place), when she was three years old. I did not know whether they showed their regards or what. Every one of them approached me and asked me, and looked at my daughter with very curious views. They looked at her, every one approached and said,‘This is your daughter and…here (her hand) is so and so….’ Then I had never brought her back for a second time” (4:80, 2-5)

To hide the abnormalities, Feng escaped from reality. “All along until she entered the second grade of kindergarten. When she was studying in nursery class I would not let her use the hearing aid. For months, the teacher did not know that she needed a hearing aid” (4: 18, 56-58) “I did not know if those teachers would admit her. When my daughter went for the admission interview for kindergarten, I did not put on the hearing aid for her. I did not know whether I was cheating the teacher or what. Until my daughter had finished the interview and they had accepted her, then I gave her back the hearing aid. I was afraid that they would not accept her if she was wearing the aid.” (4:54, 3-6)

The handicap of the child was a great stigma to Feng herself. Feng could not face reality of the physical defects of the child. She felt inferior. “I was really upset when I saw her hand. I was unable to face, unable to face reality. In fact…I always…when she was small…when I went out with her, I always covered her hand. I would not dare to let people see, because I was afraid that when people see that they would tease us…” (4: 18, 42-46)

“I would see the hearing aid as very ugly, very unpleasant. So unpleasant that I would not dare to let her wear it. So…now…such…whenever going out, I would not let her wear it. I always covered it up with something for fear that other people could see. I was so afraid…” (4: 18, 60-62)

“Even I put her photograph on my desk, I would cover the fingers. They won’t see that part. I just had this psychological obstacle, a knot that I could not release. I dared not let people see…” (4: 80, 5-8)

Feng was deeply overwhelmed with her guilty feelings and cried. “I did not know if it was because I had not accompanied her for the cardiac catheterization surgery, then it caused the hands like that. I always blamed myself, as I did not know if it was because I had not made a day off and accompanied her… Because when she had her eye surgery, I called a day off and accompanied her, staying outside there and waiting for her all day. Although even I accompanied her, I knew that I did not help much. And she was inside… so small, even though I was there, it was not of much help. It might be my psychological … ” (4: 18, 38-42)

"I, because I thought that I brought her to the world and it made her like that…" (4:20, 1)

"I thought, for the past few years, I had been really depriving her a lot. After she left the hospital till one year old, I knew that she needed the hearing aid but I did not give her. I waited till she was three year old, three and a half, then I let her have it. I thought I had deprived her a lot, and now she knew nothing…" (4: 58, 3-5)

With the guilty feelings for the child, Feng tried to compensate. "She had very bad temper, perhaps if it was because I had spoiled her. So she was very irritable, she had very bad temper. My husband had told me not to spoil her. But I did not know, may be I thought…I felt sorry for her and I would love her more…" (4:18, 109-111)

"She scolds me, she will hit me. I don't know whether it is because I have spoiled her. She listens only to her father, she does not afraid of me and will hit me. My sister said that I… and my husband had said 'If you allow her to hit you as a habit, when she grows up you will know. It will be bad if she hit you all the time, forming a habit to hit you… " **(**4: 96, 2-5**)**

"May be I want to compensate…but in fact am I doing her no good (allowing her such behaviour)?" (4: 100,1)

Feng recognized family relationship. She sought excuse for not perceiving much help from her husband. “He would not face reality. He was afraid because the doctor told him there would be a lot of complications. He was afraid of this and that. Perhaps he dared not to face reality because he had nobody to talk to. No one talk to him, at that time I was upset and I would not talk to him …. I was lucky to have my sister to talk to but he had no one. His sisters and (relatives) …all were in China, so there was nobody to talk with him. I myself was upset too (at that time) and how could I talk to him…. And his parents were old, and not knowing what to say to him. It would be difficult for old people to …as they did not want to see their grandchild like that neither…” (4: 70, 1-9)

Feng depended much on her mother-in-law although she found disagreement in childcare. “I had said many times but grandmother did not let her wear it (hearing aid). Then I could only put her on the aid during holidays when I was at home. So…so …I talked to Mrs. Cheung (the social worker) and I said ‘Grandmother would not put it on for her. You talk to her.’ I said ‘It’d be better you talk to her. I had talked to her for many times but she would not listen to me. Then grandmother accepted now…” (4:18, 69-75) “In fact grandmother had paid great effort and she helped me sometimes. She took her for physiotherapy and so. I had to work and I could not go with her too often. I could take her onlt once a week at the most, and together with grandmother. Yet it was grandmother who brought her for the therapy every time. I could not help, because I had to work and could not have day off too often. So…” (18, 89-92)

Feng experience a great change in living pattern as she retreated from social activities. The physical health of child was one of the reason “After the birth of my daughter, I had never gone for ‘drinking tea’ with my husband. Not dare to go.” (4: 60, 12-13) “Whatever living patterns, all were changed. For example, when it was the birthday of my parents, I would go by myself. I would not dare taking her with me. Then my husband had to look after her. Only either one of us would go. So I went and my husband stayed and looked after her…” (62, 1-4)

The change included some minor daily habit. “I will not use air conditioning now. A lot of living habits I have are totally different. Now, I will not switch on the air conditioning even it is more than 30 degrees for fear that she will catch a cold. Yes, instead we will use electric fan. Or I will fan her, wiping her body and drying the sweat. I am afraid that once I switch on the air condition, she will catch cold again. I will not use air conditioning when she sleeps. Sometimes, we have the air conditioning on and she will roll over to both sides and drop the blanket. Then she catches cold again. A lot of habits are different now.” (4: 64, 8-12) Feng recalled “Every time after going out with her, the psychological stress would be very great. Every time after going for activities with her, she would get sick. I was not sure whether it was because I brought her out to dinner or ‘drinking tea’ in the restaurant. I did not know whether it was because I did not bring her out then she was not used to the air outside. I was worried that she was not used to the outside air...” (4: 62, 4-6)

Feng was conscious of the financial issues, “Those hearing aids, we have to buy. It is expensive even for one piece. It would cost about six thousand dollars for a pair. Hearsay that it has to be replaced in 5 years. It is under good maintenance, it would be more durable... If the child always drops it on the floor, it is easily damaged when being dropped on the floor. Then you have to by again. The hearing aid was the most expensive, and the glasses did not cost that much. Therefore, I would fix the hearing aid for her with a safety pin to prevent from dropping. She was still a child and did not understand. She would scratch and scratch when it was itchy. Sometimes it would be really itchy inside the ear with that part hanging on the ear. I am afraid it will drop when she scratches her ears. So I fix it.” (4: 66, 1-7)

Feng tried to find positives from the remaining ‘not the worst’. “Now it is fortunate that my daughter, her hand still can write, and do a lot of thing. Only that it is not beautiful. The doctor said that there was no problem with the eyes…. The doctor said that they were quite all right. Only when there is no problem with her eyes, then I get relieved.” (4: 18, 45-46)

Story of Mother Bao – Mother of Ron-Jia

> *When he got ill, I would follow and get sick, very upset………When he said the word ‘Mom’, I was rejoiced. It seemed like something I had done…seemed to have a bit achievement.* (6:194, 1; 110, 1-2)

Bao was a nurse in Taiwan who came to Hong Kong after marrying her husband. She lived with the boy, Ron-jia and her husband who would often left Hong Kong for work.

Ron-jia was the first child in the family and he was born early with birth weight 987gram. He had stayed in hospital for about two months and caught up with the development without obvious developmental problems except for small size.

Bao was with her friend, her husband and the child when I arrived. Bao asked her friend to leave so that she could talk with me alone. Her husband and the child retreated into another room.

Bao had a wish, a realistic and reasonable but not easily achievable wish for extremely low birth weight. “At that time I wished that this feed will, just after this feed he will not throw up. Or, this feed, his feeding condition will be improved. It was because his… once after he was discharged and returned home, the problems with the airway were already there. There were the ‘hiu hiu’ sounds.

I wished that those sound would not continue.” (6:44, 1-3)

Bao was aware of the influence of the experience on herself. She had had a very bad time that she nearly killed herself. She recalled “When I had bad mood I would eat. My little boy could not eat…and …I did not know…I could not control. Starting from when I borne the child, I began to have this condition. Because he could not eat, I was very upset. Sometimes…once a few months…I would go out in about four months…going out. Then I would go buy a lot of things… for no reasons, I would buy a lot of things. I would eat and eat whenever I saw food.” (6:132, 1-4)

“That time, it seemed that… I had depression for nearly half a year. Just in this flat, I had thought about killing myself for more than ten times. I am telling the truth.” (6:76, 3-5)

Ron-jia’s health problem was the major cause of Bao’s problem. “When he got sick, I had the feeling that I would get sick too. I was very upset. When he was sick for the first time, then was sick…sick…sick…like that and I did not know…that…that…that illness…his condition continued till now, I still had the feeling of frustration… that frustration I could not remove, could not let go. I knew that when he was sick I could feel the discomfort...” (6:194, 1-4)

Bao would prefer the sufferings of Ron-jia to be on her “Because he had plenty of secretion and needed daily suctioning, and physiotherapy those things. Whenever it’s time for suction, I felt that he was very poor. Having the suctioning like that, I felt that he was very poor. I would rather you give this to me, I had this idea. Whenever he got sick, I wished it would be I who got sick instead of him. I saw him so helpless there. Just like a lamb being sent to the slaughter (遭宰殺的羔羊)…” (6:2-2, 1-4)

Bao realized it was a real life when the child interacted with her. “My son talked to me. When he began to talk to me, I felt that…when he talked to me…I felt. I did not know…everyday it was I who talked to him. Every time I did not have (response from him)…not know what he… When he began to respond to me, I felt… ‘Ah, he has a life.’ I then felt like… to have a little achievement….Yes, my feeling…just like…He was a real baby, a human. I would have the sense of achievement. I felt that there was an answer for what I had done. Not like before…whatever you gave him, there would not be any response. No response, and your feeling would be…the feeling would be bad.” (6:106, 1-3; 188, 1-3)

Feeding the extremely low birth weight child was frustrating experience. “I was worried about him. Why would he be like that, his health. Sometimes, he did not even drink. He did not drink when it should be time for milk feeding. He did not even drink. Even if he would drink, he would just drink one ounce or two… but taking two hours for one ounce of milk. A very bad appetite he had. When he was small, doctor had tried to give him medicine to improve the appetite… But there was not improvement at all. After feeding, he would throw up, after feeding he would throw up; and I would only clean and wash everyday...” (6:40, 2-10)

The feather-like weight of the child was Bao’s worry. Increasing the weight of ELBW child was the target, but not easily achieved. “Once he got sick, not to say…not to think about eating. Yes, no appetite. Then it took a long time to recover. Other people recovered quickly. Getting sick, they would get well fast like blowing balloon. After getting well, then they would get fat quickly. But he was different…very slowly…very slowly (he recovers).” (6:246, 1-2)

To Bao, the feather-like weight was related to weakness and and lack of strength. “I plan to send him to school one more year later because he is too small. I am afraid that in the school… he is ‘too frail to stand a gust of wind’ (弱不禁風). Because he…I do not know how to say…‘too frail to stand a gust of wind’ – as the wind blows, he will tumble.” (6: 86. 1-2)

‘Light weighing’ seemed to have another meaning in Bao’s journal. She perceived herself as useless and least important. Being viewed as different was not a pleasant experience. “Some families would say… said the child… so and so. Sometimes they talked about my son…something unpleasant. My son, ever since he was small, had big nostrils. ‘So big the nostrils. Always see you having cold…running nose… and the ‘hiu hiu’ sounds. Why would you be like that!’ Perhaps, those adults might said it loosely without meaning, but I would feel that… ‘Why would you say that to my son’ I would be very upset…” (6:124, 2-4)

Bao would put the fault to herself “It seemed that …I was very stupid because of too much…. It seemed that there was nothing I could do…I would look down on myself, find myself being useless….” (6:226, 6; 228, 1)

Bao would put the blame back to herself for the cause of prematurity. “I felt guilty and I would blame myself why that I had to go back to Taiwan at that time. Because I was very lonely at that time, because I was staying at home all by myself. Everyday… everyday eating the same… I missed the things in Taiwan. I had discomfort over the stomach. When I went back, I ate a lot and became very fat. But the weight just went to myself, and the baby did not absorb any…A lot of the processes…I would think…if I had not done that would it be better.” (6:252, 1-5)

Bao recognized her poor relationship with the in-laws due to miscommunication and misunderstanding. That was upsetting too. “Once when she came and saw him vomit and asked ‘Was it because the food he ate dirty, or you had not washed those bottles clean?’ Those were the bottles bought before…. she meant that was it because I did not wash the bottles clean and he would vomit like that. I said no, the doctor said that because he had a shallow stomach. He would not absorb after all. He drank, and it was OK, considered good sign. You would not expect he had to… had to swallow... My mother-in-law was also looking after other grandchildren, three months different in age with my son. The elder was nine months different. So in her experience, there should not be any such happenings. So it was unacceptable to her when she saw her son like that…could not drink anything and getting thinner and thinner. Yes, after returning home, he was getting thinner and thinner. So …that… (long sigh) the guilty feeling grew even heavier…" (6:68, 1-8)

Inadequate support from husband seemed to be an issue. Bao felt helpless and being left out. "He would cry nonstop sometimes at night. Since my husband …my husband sometimes would be away for business trip, one whole week for the trip. He was not…and sometimes at night…nobody here leaving me alone. I had to take care of the child by myself….. It was very difficult for me to control his crying. At night, he would keep on crying for an hour. I did not know the reason. Sometimes, I would be there holding him like an idiot. Because… perhaps… if… sometimes my husband was at home, perhaps my feeling would be better, more sense of security. If only one, only one person to face the situation, once he cried I would not know what was wrong with him, and I would be more nervous…." (6:40, 1-2; 84, 1-4)

Bao expected more support from health care professional. "If I had the information on the issue earlier…though I was a nurse… Perhaps I might not know that I had this kind of condition.…those problems of depression. My own emotions, all along, I was not able to manage properly. So when I faced the child, it seemed that the only thought was could not be saved…could not be saved. Yes I had that attitude. If it was like what you said, it would be good and appropriate. If in the early days, there was those kind of education, perhaps, for more family members, and our families such as my mother-in-law and so… If you let me talk, it would not be convincing. If it was added with the perspectives of nurses, it would be better. It would be convincing, giving them the knowledge. ... In the hospital, if I …I had such condition, being educated first, perhaps I would not have had too…just as you said, too much those negative perspectives." (6:220, 1-8)

Bao had described an example of dependence on spiritual support that helped resolving her stress and overcoming the idea of self-harm. "Might be because I am a Christian…At one time I …that time I was cleaning the windows. That time, the boy was still small and I did window cleansing. I wanted…wanted to get up there…and jump out to solve my problems. Because most of the time, others did not…were not able to understand me. And I could not do things good neither…I did not do good in the child care. Because the child was not fat…so I did not know what to do exactly. So the double pressure was very big. Then, every time I had such… such an idea of jumping (out of the window)… when that idea came, I would think of a song… sing in my heart… keep singing the song. If I …the song said… You are living for… you have to put your heart and mind together as one. It said if you live you have to put your heart and mind together as one. So I thought in my heart. I said I …at that time because… My families viewed me as such bad, and I saw myself as useless because however I did I would not do it well. Because of my son, I could not change…change back. So, the song was so sung. Every time I sang the song, I was saying... ‘God bless me, am I that good…How can I be with you when I saw myself as useless…’ So every time I had that idea (killing herself), just like this song, I would sing it in my heart. I did not know… this was the fact. I found it difficult to let you understand… The religious belief had given me a very great support.” (6, 80, 1-11; 212, 7)