The Experience of Being a Taiwanese Mother of a Child with Cerebral Palsy

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Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

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Yu-Ping Huang
Synopsis

Cerebral palsy (CP) is the most common cause of physical disability in children. Disabilities are associated with walking, sitting and hand function. The nature and severity of impairments varies but in all cases the demands placed upon caregivers is significant. Many care-giving studies have examined the effects of having a child with CP in rational and functional aspects. Few studies have aimed to gain a better understanding of the meaning of the care-giving experience and there exists no literature that undertakes a hermeneutic phenomenological approach to explore the Taiwanese mothers’ lived experience of raising children with CP.

This study adopts a hermeneutic phenomenological approach informed by the philosophical worldviews of Heidegger and Gadamer. Heidegger’s philosophy provided me with guidance to explore the meaning of experience attributed to everyday practical care-giving for a mother of a child with CP in Taiwan. While Gadamer guided me to understand and interpret the meaning of stories mothers shared, through the fusion of horizons.

Meaning was disclosed through an exploration of the life-world of 15 mothers, voluntary participants recruited from a medical centre located in the metropolitan area of Middle Taiwan. Through stories of everyday care-giving the participating mothers revealed the importance of their family background which influenced how and what they experienced, the importance of being supported by family, and the significant influence of a traditional Chinese culture. Some participating mothers shared their experiences of anticipated pleasure of becoming a parent and how this was destroyed. All participating mothers expressed their concern as they realised that something was wrong with their children. They described their experiences of learning the diagnosis of CP and feeling out of control and powerless. Many mothers experienced a sense of disbelief, a profound sense of loss for their anticipated 'ideal' children, feelings of no hope, and a gradual learning to accept their children and through this a feeling of empowerment to search for new possibilities for the future.

This study reveals meaning embedded in the modes of Being situated in Taiwanese culture and family, Being engaged in everyday practical care-giving for a disabled
child, Being concerned when facing barriers to what is defined as quality care and
Being able to seize possibilities for a positive and hopeful future. Such findings
challenge nurses and health care practitioners to reflect upon what it is about
experiencing Being that makes such an existence meaningful for mothers caring for
disabled children, and how this fuller knowing is integral to a new conceptualisation
of family health practice and disability care. A conceptual redefinition of family and
disability practices which fosters coping and engagement, promotes a context of
collaboration that is open, respectful, stress-reducing, manageable and therapeutic for
all involved.
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Dissemination of Study Results

Refereed Publications


Conference Presentations


Chapter 1

Background to Study

Introduction

Cerebral palsy (CP) is the most common cause of physical disability in children and is used as a broad definition to cover an injury to the immature brain that is non-progressive. It is a condition that is defined as a chronic disability that presents with a cluster of clinical signs related to posture and motor impairment by virtue of abnormal muscle tone and movement (Platt et al., 2007; Reid, Lanigan, & Reddiough, 2006). Even though it is a non-progressive disease it will worsen without any rehabilitation or treatment. Hence, long-term care and follow-up is required in order to maintain or improve a child’s condition (Koman, Smith, & Shilt, 2004; Singhi, Jagirdar, & Khandelwal, 2003).

Prevalence of Cerebral Palsy

Cerebral palsy is the most common cause of physical disability in children as supported by related global demographics. Globally, its prevalence rate is constant but may vary between countries. Asian data indicate that the prevalence of CP in different provinces of China was 1.92 per 1000 children in 1997-1998 (S. Li et al., 2001). In Japan, the rate was 1.34 per 1000 for 6-year-old children in 1977-1991 (Suzuki & Ito, 2002). In Hong Kong, the prevalence of CP in primary school children was 1.3 per 1000 children in 2003-2004 (Yam et al., 2006).

In Australia, the prevalence of CP was 2-2.5 per 1000 live births in 1979-1992 (Stanley, Blair, & Alberman, 2000, p. 29). Reid et al. (2006) focused on post-neonatally acquired CP in Victoria, Australia, which revealed the prevalence rate of CP for the last three decades from 1977 to 1999 was 1.98 per 10 000 live births. The recent data of prevalence of CP and CP-like disabilities was 33,800 people in 2003 (Australia Institute of Health and Welfare (AIHW), 2006).
In the United Kingdom, rates are very similar. For example, an investigation by Parkes, Dolk, Hill, and Pattenden (2001) in Northern Ireland, showed the prevalence of children with CP in 1981-1993 was 2.24 per 1000 of live births. A recent prevalence rate of CP in Northern Ireland from 1981-1997 was 2.2 per 1000 live births (Dolk, Parkes, & Hill, 2006). It signifies the stable rate of prevalence of CP in this country. In North-East England, Colver et al. (2000) reported the incidence of CP climbed gradually from 1.6 per 1000 of neonatal survivors in 1964-1968 to 2.45 in 1989-1993 and the ascertained cases with severity exceeded 30%. Recently the prevalence of CP was estimated about one in every 400 children suffering from the condition of CP and about 1,800 babies are diagnosed with CP each year in Great Britain (SCOPE, 2007). Generally speaking, the prevalence of CP in UK was 2 children per 1000 births (Capability Scotland: Turning Disability into Ability, 2007).

In the United States, the prevalence of CP was 1.7 per 1000 live births from 1975-1977, 1.8 from 1981-1985, and 2.0 from 1986-1991 (Winter, Autry, Boyle, & Yeargin-Allsopp, 2002). Karapukar Bhasin, Brocksen, Nonkin Avchen, and Van Naarden Braun (2007) focused on 8 year old children with CP. Their results suggested that prevalence of CP was 3.6 per 1000 population for 1996 and dropped to 3.1 per 1000 population for 2000. Resources from the CP website showed the prevalence of CP in United States was about 8,000 infants and 1,500 preschoolers were diagnosed with CP each year. Approximately 750,000 children and adults suffered from one or more symptoms of CP (Special-Needs-Hope.Com, 2006).

From this data, it can be seen that there is little difference between prevalence rates in Western and Asian countries. The increase in the prevalence rate of CP has been attributed to technological advances in the neonatal intensive care where a greater number of premature babies and high-risk infants are surviving (Colver et al., 2000; Koman et al., 2004; Liu, Li, Lin, & Li, 1999). This suggests that the prevalence of CP will increase in the future as technological advances in the area of neonatal intensive care also increase. As more children survive with CP then more parents will experience the challenges and rewards associated with caring for a child with such a disability.
Treatment and Prognosis of Cerebral Palsy

Every child with CP will have associated impairments, which may differ depending on the severity of the injury to and the location of the lesions in the brain (Fung et al., 2002; Koman et al., 2004; Nordmark, Hagglund, & Lagergren, 2001). CP affects different body systems and includes impairment to both gross and fine motor systems (Koman et al., 2004; Singhi et al., 2003). Disabilities are associated with walking, sitting and hand function (Jacobs, 2001; Koman et al., 2004). Oral dysfunction results in feeding and nutritional intake problems (Fung et al., 2002; Motion, Northstone, Emond, Stucke, & Golding, 2002; Pharoah, 2007). Inability to communicate and speak can be a challenge (Fung et al., 2002; Nordmark et al., 2001). Certain health problems are common such as aspiration pneumonia and other respiratory diseases. Mental retardation, defects of hearing or seeing, convulsions, behavioural and emotional disturbances are also common (Fung et al., 2002; Koman et al., 2004; Nordmark et al., 2001; Singhi et al., 2003).

Because of the varied nature of associated impairments and the severity of disability associated with the range of possible impairment, a wide range of medical treatments and therapies are required to assist in supporting the quality of life for children with CP and their caregivers. The demands placed upon the primary caregivers are substantial.

Responsibility of Care

Liao (1995) conducted a survey in Northern Taiwan and found that 72% of primary caregivers for children with CP at home were their mothers. In the United Kingdom, Parkes, Donnelly, Dolk, and Hill (2002) surveyed children with CP and found that 92% of the primary caregivers were mothers. In the United States, Lin (2000) investigated children with CP from 12 United Cerebral Palsy associations. Findings revealed that 89.4% of primary caregivers were female, the majority being biological mothers. In Australia, a survey by Pritchard, Colditz, and Beller (2005) of children with disabilities, including CP, found that 98% of mothers were primary caregivers. From the above studies, evidence clearly demonstrates that mothers bear the primary care-giving responsibility for children with CP.
In summary, it is clear that CP is the most common physical disability in children. Global prevalence rates are constant. CP is associated with impairments affecting multiple body systems resulting in severe health problems both physical and mental. The nature and severity of impairments varies but in all cases the demands placed upon caregivers is significant. Mothers have been shown to bear the primary care-giving responsibility.

The Taiwanese Mother of a Child with the Disability

The role of the maternal caregiver is linked to women’s roles in Chinese traditional culture. Chinese culture has been influenced by Confucius (Lang, 1968, p. 8). The purpose of marriage is to maintain the paternal line into the future as well as support the family to flourish and maintain the family honour and reputation (J. D. Lee, 1996). The next generation is the first priority for married women so giving birth becomes a major and primary responsibility for Chinese women. When women become mothers they are expected to sacrifice themselves for their children (Baker, 1979, pp. 21-22; E. Lee, 1999, p. 231). Although the position of contemporary women in Chinese society is changing, traditional values and beliefs remain important guides that shape female behaviour (J. D. Lee, 1996).

Giving birth to a child with a disability impacts on the mother’s ideal concept of “perfect motherhood” (Pun, Ma, & Lai, 2004). A child with a disability is regarded as a disruption to ancestry, especially when the disability is visible. It leads to social stigma because it is contrary to the Chinese collective value and cultural expectation that professes the importance of not being different from others. A child with a physical impairment evokes feelings of fear, shame and disgrace for the family, because of the Chinese belief that a child’s physical disability is inherited from the mother’s body or from the bodies and souls of ancestors. Thus family members and society blame mothers for causing this misfortune. Mothers may experience dissociation from their families and their disabled children can experience marginalisation by family and community (Holroyd, 2003; Pun et al., 2004).
The Nature of Care-giving

Empirical research in the area of care-giving for disabled children can be grouped into a number of discreet categories: the “doing” and demands of care-giving; the burden of care which is automatically converted to stress and strain; the effect of activities upon health and well-being; and the types and impact of relationships with relatives and professionals on the experience of care-giving. Hence this body of research focuses upon the distinct care-giving tasks that are measured in terms of type, function, frequency and pattern. This approach has been deemed important in terms of predicting effect in terms of stress, strain, lifestyle challenges and ultimately well-being (Eker & Tuzun, 2004; Mobarak, Khan, Munir, Zaman, & McConachie, 2000; Roberts & Lawton, 2001; Warfield, 2001; Witt, Kasper, & Riley, 2003).

The problem with this empirical and practical research focus is that it exploits the productive elements of a certain conception of care-giving. The parameters of existence are set by a particular set of care-giving tasks extrinsic to self. A key critique of this body of knowing is that it prevents us from seeing, in fact blinds us from seeing, the living centre from which all existential possibilities radiate. In practical terms, the importance and significance of care-giving, disability and the day-to-day challenges within the life-context remain hidden, and the ability to understand care-giving, shaped by meaning and commitment, is hidden or ignored (Holloway & Wheeler, 2002, pp. 4-7; van Manen, 1990, pp. 2-7).

Qualitative studies have discovered variations in care-giving practices, emotional adjustments and resolutions that have gone well beyond the understandings captured in the empirical body of literature (Green, 2007; Kearney & Griffin, 2001; Landsman, 1998; Taunt & Hastings, 2002). A range of studies have described meaningful dimensions of care-giving that have not been previously noted in more empirical, abstract, risk and burden research on care-giving. These studies critique the dominant focus on empirical research that blinds practitioners and nurses from gaining an awareness of the importance of gaining insight into distinctly human concerns and practice. This thesis argues that attention needs to be given to research that balances the body of knowledge and emphasises the importance of understanding the human experience of caring, in this study, as a mother caring for a child with CP.
As nurses we are best placed to support maternal caregivers to shape their lives in meaningful ways if we have the capacity to learn what is worthwhile and significant to them. So instead of describing maternal care-giving in terms of type, frequency or task, it is important to describe the care-giving role shaped by human concerns and purpose. This study aims to raise nurses’ awareness of the importance of gaining insight into distinctly human concerns and practices. It is argued that such learning manifests itself in maternal caregiver’s everyday activities and relationships. Therefore this study adopts an interpretive approach, specifically a hermeneutic phenomenological approach, to gain insight into the phenomenon under study. Such an approach focuses upon the everyday existence, lived through the mother’s care-giving experiences, caring for a child with CP.

The Aim of the Study
The aim of this study is to illuminate Taiwanese mothers’ everyday habits and caring practices, their relationships and motivations to care for their children with CP. This study aims to present a different portrait aimed at promoting meaningful care-giving experiences which foster health, well-being and inform practices, rather than focusing on intervention when caregivers are not functioning well or on the point of breakdown.

Research Purpose
Specifically, the purpose of this hermeneutic phenomenological research is to gain a better understanding of the phenomenon of care-giving for a Taiwanese mother of a child with CP. Specifically, the research seeks to better understand the meaning and experience of care-giving for Taiwanese mothers with children who have CP by:

1. Exploring the ways in which such care-giving is significant and meaningful.
2. Conceptualising new ways of approaching health/nursing care that support mothers’ everyday care-giving.

Research Approach
The goal of phenomenology is to understand everyday skills, practices and experiences, to find commonalities in meanings, skills, practices and embodied
experiences (Dreyfus, 1994, p. 4). In particular, hermeneutic phenomenology focuses upon the question of how people come to understand. It offers a mode of inquiry which aims to discover meaning and achieve better understanding. Hermeneutics focuses upon the understanding and interpretation of everyday practices and discourses, namely the structure of everydayness (Dreyfus, 1994, pp. 34-35).

A number of assumptions informed by the philosophical world view of Heidegger (Heidegger, 1927/1962) provide theoretical guidance in revealing and interpreting everyday care-giving experiences. Firstly, caregivers as human beings possess the capacity to reflect upon the nature of their existence in such a way that personal meanings are uncovered and rendered publicly visible. Secondly, the essence of how caregivers exist in the world is influenced by their background, shaped by a particular period of historical time, culture, language and family. Thirdly, the ways in which caregivers engage in activities and relationships serves to illuminate the significance of everyday caring. Fourthly, understanding personal concerns provides access to the ways in which existence as a caregiver is deemed meaningful. And finally, seizing possibilities for meaningful existence is possible as caregivers are temporal beings capable of attributing meaning to their involvement in present day care-giving practices, as influenced by the past, and anticipated in the future (Kellett, 1997).

The Research Question

The research will explore the question:

What is the meaning of Being a mother engaged in caring for a child with CP?

Ultimately, this is an ontological question driven by a desire to understand what it means to exist in the everyday life of a mother who cares for her child with CP. Everyday experience gives reason for reflection upon the adequacy and appropriateness of care-giving behaviour. Understanding meaning in the context of life, and the hermeneutic phenomenological approach chosen, facilitates a process for explicating those modes of Being that disclose what is meaningful about such an existence. Therefore, this study aims to probe and reveal the deep insight, the closeness of experience that is embedded within the nature of everyday care-giving activities and relationships encountered in living the life of a mother who cares for a
disabled child. Such knowledge is important and desirable as attention to lived experience enhances the quality of existence for all people involved in care-giving processes. Importantly, such research will assist nurses to gain insight into how the everyday lives of mothers who care for children with CP can inform and challenge their practice.

**Summary of Thesis**

In chapter one I present the justification for studying maternal care-giving for a child with CP. The body of research that examines mothers’ care-giving for children with CP primarily focuses upon stress and burden and the associated health outcomes. Such knowledge hinders us from gaining insight into the existential possibilities of care-giving which can enhance maternal identity and self-worth. This chapter argues for the need to look at care-giving experiences from a different perspective, one that discloses the meaning of being a mother caring for a child with CP. Following this justification this chapter provides a rationale for the chosen research approach, articulates the research purpose and poses the research question.

Chapter two explores the context of maternal care-giving in Chinese society. A review of the body of quantitative care-giving studies is presented and the limitations examined. Such examination provides a platform for reviewing qualitative care-giving studies and commenting upon their contribution. Finally, the contribution of this study is examined within the context of the existing body of literature informing this topic area.

Chapter three describes ontological-hermeneutics as the research methodology chosen to explore the lived experience of being a Taiwanese mother of a child with CP. An overview of the philosophical worldviews of Descartes, Husserl, Heidegger and Gadamer are presented. It will be argued that Heidegger’s philosophy provides direction in revealing how meaning in everyday care-giving is disclosed. Gadamer provides guidance in generating understanding of such meaning through interpretation of the stories shared by the participating mothers.
Chapter **four** presents detailed information that outlines the process of the study. The hermeneutic method devoid of a rule-bound structure is described in terms of collecting information and interpreting the stories shared. The circular character of the process of understanding is described as a movement between the whole, in which the parts are understood, to a change in the sense of the meaning of the whole because of the confrontation with the detailed parts. The nature of maternal care-giving is uncovered by looking within shared meaning to reveal modes of existing as a human being who finds herself striving to ascribe meaning to everyday existence and experience.

In chapters five to eight, the findings of this study are discussed. In chapter **five** I write about the mothers’ family background, experience of pregnancy and birth, recognising something was wrong and learning the diagnosis. In chapter **six** I discuss the ways in which mothers engage in everyday care-giving activities by exploring new and different roles aimed at supporting quality care. In chapter **seven** I examine care-giving barriers defined in terms of how they thwart possibilities for quality care. In chapter **eight** I discuss that capacity of seizing upon possibilities for self and future care-giving experienced by those mothers who project their vision of care-giving positively towards the future.

In chapter **nine** and **ten** the results of this study are reviewed in light of the existing body of literature relevant to the topic area. The contribution and limitations of the study are examined, together with a discussion of the implications of the study. Implications are examined in terms of the benefits of revealing information that helps nurses to reflect upon their beliefs, values and care practices in supporting women with disabled children. Ways of reconceptualising approaches to practice are examined to highlight the original contribution of the findings of this study.
Chapter 2
Taiwanese Motherhood in Context

Introduction
This chapter will discuss the findings of a literature review that provides insight into the context of providing daily care for disabled children with CP from the perspective of Taiwanese mothers. Chinese culture and family relationships will be explored in order to gain insight into Taiwanese maternal care-giving in its cultural context. Hence, women’s roles and their situatedness in the family and society will be discussed. The concept of “face” and being a “good” mother will be examined in terms of how such cultural understandings shape attitudes, perceptions, expectations and behaviour. Details of the search strategy guiding the review process are outlined together with a discussion of the refining processes undertaken to reveal a range of conceptual areas that provide an overview of the current body of knowledge informing our understanding of mothering and disability. In particular, this chapter discusses: daily care-giving from the time of experiencing a complicated pregnancy, engaging in postpartum rituals, hearing the diagnosis, being involved in daily roles and experiencing the barriers and the rewards associated with long term care-giving for a disabled child with CP.

Chinese Culture and Family Relationships
The Chinese social context provides insight into Taiwanese mothers’ daily life experiences. Chinese culture has been deeply influenced by Confucius (B.C. 551-497) (Lang, 1968, p. 8). Confucius pays close attention to family and relationships so the Chinese culture can be regarded as a family culture. The family holds the highest value to an individual. Family life is an important indicator for everyone. Because of practical reasons family provides various supports to family members, but also nurtures them to develop ideal human relationships aimed at ensuring a stable social life (Baker, 1979, pp. 11-12; Hwang, 1987; Lu & Lin, 1998).

Confucianism argues that the social context defines and gives meaning to the self, so relationships or interactions with others are crucial to an individual’s identity and
roles (Lau, 1996, p. 360). In Confucianism, a number of human relationships are associated with family relations: father/son; elder brother/younger brother; and husband/wife. The relationship of father/son can be extended to the relationship of mother/son or daughter or father/daughter. Similarly, the relationship between brothers may be included and also the relationship between brothers and sisters. Each relationship is attributed a status of superiority or inferiority along a hierarchy that provides every family member with guidance in terms of their personal position, duty, and obligation to regulate their behaviour in given circumstances. Such guidance is deemed important in maintaining family harmony and meeting social expectations (Baker, 1979, pp. 10-15; Lam, Tsang, Chan, & Corrigan, 2006; E. Lee, 1999, p. 230). In other words, an individual’s needs and opinions are secondary to the social harmony of family (Lam et al., 2006).

The Chinese family is dominated by males in a patriarchal society, so male grandparents, fathers, and husbands are significant people who have the highest authority, power and impact on family life (E. Lee, 1999, pp. 230-253). Women, on the other hand, are expected to be adaptable in demonstrating obedience, timidity and reticence in relations with their husband, brothers, parents-in-law, and sons (Lang, 1968, p. 8). In addition to gender, generation and age are also significant. All family members, except the father, should respect and show obedience to the mother due to her senior position in terms of generation and age. The young son/daughter should respect and listen to their elder brothers/sisters, their father and mother.

For a married woman, the relationship with her mother-in-law is the most important and her first role right after marriage. Parents-in-law are her top priority and present relational opportunities to demonstrate her obedience. Her husband is her second priority (Baker, 1979, p. 16). Filial piety provides the most significant guidance in shaping relations between obedient children and their parents or parents-in-law (Baker, 1979, p. 102). Carrying out filial piety is to fulfil responsibilities and meet social expectations, which can bring honour to their family. Filial piety also serves to avoid facing criticism from others (Chao & Roth, 2000).
The Concept of Face
Every family member has a responsibility to bring honour to their family. The feeling of honour is linked to the concept of face. The term face guides people in traditional Chinese society, valuing some kinds of qualities and judging people’s social position and prestige in their social network. Such qualities include physical appearance, ability, achieved status and wealth. “Having face” provides possibilities to improve one’s personal social status as well as promoting one’s quality of life. Conversely, “losing face” is of primary concern, which may led to injury to one’s self-esteem, personal harmony and emotional peace (Hwang, 1987).

In addition to possessing good qualities, living up to personal role expectations is crucial to “save face”. By losing face people can experience personal shame, self-inferiority, self-debasement, self-defectiveness and social rejection. Furthermore, their families and ancestors can be involved in the event of losing face and can be treated in the same way. Having or saving face for Chinese people is viewed as being as important as their life, so they are always sensitive to judgement or evaluation from others. According to an old Chinese saying “family scandal should not be made public”, so it is a universal strategy for the family to cover up the things they feel shameful of in order to avoid losing face (J. Li, Wang, & Fischer, 2004). Hence the issue of face or being judged by others impacts on the Chinese family unconsciously or consciously.

Married Women’s Role and Responsibility
The major function of a married woman for her husband’s family is producing the next generation and providing labour to support family work and serve the men in the family (Baker, 1979, pp. 21-22). Giving birth to a child is a fundamental and significant event for the family since it signifies the family clan and ancestral lines will be continued for generations to come and ensures the traditional kinship structure and family prosperity. This is called chuanzong jiedai (傳宗接代) (Baker, 1979, p. 27; Lau, 1996, p. 11). Importantly, the birth of a child ensures the continuum of ancestors and future descendants, so it demonstrates one kind of showing filial piety (Baker, 1979, p. 27). The significance of the woman’s ability to give birth to a child is
demonstrated by the acceptance of her husband divorcing her if she is discovered to be barren (Baker, 1979, p. 45).

**Being a “Good” Mother**

In Confucianist terms, having 'good' offspring can honour past ancestors and future descendants in terms of familial reputation and nurture Chinese familial collectivism (J. Li et al., 2004). Given this context, an anticipated 'healthy' baby is the biggest concern for a pregnant woman. The concept of motherhood begins with a woman’s pregnancy. The expectant woman follows and embodies cultural rituals, gains knowledge from others, books, or media, and develops a new mothering identity, informed and shaped by cultural and historical norms, beliefs, and expectations. The expectant woman is expected to carry out a set of “right” actions or behaviour to demonstrate her capability of being a 'good' mother. This ideology of expectant mothering has been regarded as common fulfilling global social norms and expectations. Society not only provides education programs or counselling for all expectant women but establishes and enforces laws to protect these women, so the maternal responsibility becomes a social responsibility (Copelton, 2007; Liamputtong, 2006). In this context, experiencing high-risk pregnancy, preterm labour, or prolonged labour, possibly giving birth to a disabled child, threatens the women’s concept of being a 'good' mother.

**Disability and Disharmony**

In Chinese society disability is viewed as a condition of disharmony in terms of deviating from the hierarchical structure of human relationships. Acceptance of disability is difficult because it threatens social harmony (Lam et al., 2006). For example, Chinese families believe in the concept of reciprocity and mutual responsibility. The parents have obligations to take care of their children when their children are young and their children will attend to their parents when they are too old to work (Baker, 1979, p. 71; Hwang, 1987). Parents or grandparents may not be able to expect the person with a disability to have the ability to reciprocate by caring for them. From a Buddhist point of view, a disability is regarded as punishment or divine intervention from the supernatural world in consequence of bad deeds from the
previous life (Lam et al., 2006). Persons with disabilities according to Chinese cultural beliefs are a social burden due to their uselessness (McCabe, 2007).

**Disability and Stigma**

Disabled persons are often stigmatised in Chinese society because of their different physical appearance. This often results in rejection due to loss of face and favour (Holroyd, 2003; Lam et al., 2006). Holroyd (2003) argued that the person with a physical disability is often regarded as having no social status, nor legitimate position in society and as such experiences a deprivation of personhood and in fact experiences a sense of “non-personhood”. From a kinship perspective, the person with a disability can bring a great deal of shame to the family, upon his or her ancestors, upon present family members, and upon future descendents. Stigma results in family members experiencing the potential of being criticised or disgraced in public, which often leads to social isolation and family conflict as outsiders blame family members for not being responsible, behaviour that has resulted in the birth of a disabled child (Lam et al., 2006). McCabe (2007) stated that the Chinese believe the father would lack respect from others when his child with a disability is perceived to have no future. This results in the family keeping the child at home or sending the child to live in another remote area. According to Chinese saying, this disgraceful event should only be known or discussed within the family, not by people outside the family (J. Li et al., 2004).

Family is an important resource for married women since Chinese women are expected to emotionally and economically rely on their husbands or parents-in-laws after marriage (Chen, Williams, & Wong, 1991, p. 300). Keeping harmonious relationships with their husbands’ families is important. Raising a disabled child may increase family conflict by bringing shame to the family (Lam et al., 2006). In these circumstances, family members do not expect to receive reciprocity from a disabled child and they view physical impairment as shameful and consequently marginalise themselves from the child’s care (Holroyd, 2003). Rejection from the parents-in-law, and the mother-in-law in particular, creates a huge challenge for mothers (Pun et al., 2004), because according to Chinese ritual married women should have a close relationship with their mother-in-laws and attend to her well, especially as the
mother-in-law holds a dominant position and power within the household, the context of child care. Conversely, the married women should keep a distance from the men in the family such as her father-in-law and brothers-in-law (Baker, 1979, pp. 42-45; Lang, 1968, pp. 47-48).

According to Confucian thought, the superior, father, elder brother, husband, has the power to make decisions and is responsible for resource allocation within the family. Chinese ritual assumes that the inferior, son, and wife should obey the superior’s decision and power (Hwang, 2000). Therefore, experiencing rejection from grandparents and husbands may result in some mothers experiencing shortages of resources and finding caring more burdensome. Despite such a situation, mothers remain in unhappy marriages or stressful families because they are hoping to maintain the best life and resources for their children. This fuels their motivation to sacrifice their lifetime happiness (Chen et al., 1991, p. 299).

Successful mothering is associated with a child who will become self-sufficient and productive. Family members devalue the worthiness of the mothering investment for a disabled child and her maternal status as they link the disabled child with being “unproductive and burdensome” for society (McKeever & Miller, 2004). Hartley, Ojwang, Baguwemu, Ddamulira, and Chavuta (2005) found that Ugandan mothers with disabled children were rejected by their family members. People in Ugandan believed that children with disabilities should be restricted at home due to feelings of shame and embarrassment for their family. The results were supported by Kearney and Griffin (2001) whose results suggested that parents felt isolated, rejected, angry, hurt, failure and despair when family members regarded the child with a disability as hopeless. Green (2007) argued that the perception of stigma in terms of devaluing the child from others in their community significantly increased the mother’s objective burden since it worsened the mother’s perception of daily caring stress. However, McKeever and Miller (2004) found that mothers would allow others to see their children’s worth in society by emphasising the child’s “normal” development, not only their disabilities. In this way they stood up for their children against social stigmatisation.
Search Strategy

The literature review involved a search of the databases of MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycARTICLES, PsycEXTRA, PsycINFO and Women’s Studies International. The keywords “mother”, “child with disability”, “child with cerebral palsy”, “high-risk pregnancy”, “preterm labour and mother”, “diagnosis and parent”, “Chinese” and “Taiwan” were used. In order to manage the large number of articles, those published in the past ten years from 1997-2007 were reviewed initially. However, to demonstrate the historical trends evident in this body of knowledge, papers published during the last twenty years, 1987-2007, were used. Initially 250 papers were identified. Then 82 articles were selected and reviewed in this chapter. Some articles were an exception in terms of being published before 1987, because they were original papers relevant to the research topic and highly regarded as “landmark” publications.

A number of inclusion criteria, assisted in refining the search strategy: studies focusing on mothering a child with CP or disability; studies focusing on being caregiver of a child with a disability; studies focusing on Chinese or Asian culture and the health care system; studies with a demonstrated research methodology. Exclusion criteria included: anecdotal papers; studies focusing on adult children; studies focusing on children living in residential care; studies focusing on mothers living with substance abuse as care-givers; studies focusing on teenage mothers of a child with disability; non-English papers, and abstract only articles.

This review revealed a number of key themes that provide a framework for the remainder of this chapter. The literature will be examined in terms of how it provides insight into the following experiences: daily care-giving from the time of experiencing a complicated pregnancy, engaging in postpartum rituals, hearing the diagnosis, being involved in daily roles and experiencing the barriers and the rewards associated with long term care-giving for a disabled child with CP.

The Complicated Pregnancy and Labour

Undergoing an atypical pregnancy and delivery of a disabled child, the mothers experienced perinatal grief because of loss of their “perfect” babies due to their
babies’ appearance, medical condition, or associated impairments (Ellis, 1989; Gordeuk, 1976). Through different ways, such as hearing sound from the Doppler, seeing the image from ultrasound, and touching, the expectant woman starts to build up and fantasise about her baby’s image, namely “wished for child”, from the time of her pregnancy. Loss of the perfect baby not only results in the mother losing her “ideal” baby, but also experiencing feelings of no hope for the future due to family lack of acceptance (Ellis, 1989; Gordeuk, 1976). Furthermore, Rubin (1976) indicated when the babies did not meet the family expectations then rejection could become an issue.

For mothers to be, the unusual pregnancy and labour process not only threatened the anticipation of a 'normal' pregnancy and birth experience, but also threatened their babies’ safety. In order to keep hope of having a good outcome in terms of a healthy baby, the pregnant women would do anything to contribute to their babies’ health and safety. They sought medical care, complied with all treatment, carefully monitored physical symptoms, accepted support from health professionals, decreased activities or circumscribed to periods of bed rest, suspended their lives, temporarily giving up their responsibilities for other children or housework, changed their lifestyle, and prayed for support using their faith in religion (Cunningham, 2001; MacKinnon, 2006; McCain & Deatrick, 1994; Schroeder, 1996).

Experiencing an unsafe pregnancy or labour process could arouse the pregnant women’s emotional responses, including feelings of vulnerability, fear, anxiety, worry, uncertainty, loneliness, depression, loss and grief (Cunningham, 2001; Leichtentritt, Blumenthal, Elyassí, & Rotmensch, 2005; MacKinnon, 2006; McCain & Deatrick, 1994; Price et al., 2007; Schroeder, 1996). A sense of losing control and experiencing powerlessness arose not only because of possessing no alternative choices of treatment, but also no control over their bodies, pregnancies, and labour process. Health care professionals however had the power to totally control the whole process and they did not always involve the expectant women in the medical decision making (Cunningham, 2001; Nystedt, Hogberg, & Lundman, 2006; Schroeder, 1996). In such circumstances, the pregnant women would feel angry due to abandonment receiving little guidance from health professionals (Schroeder, 1996).
Nystedt et al. (2006) revealed that women suffering from prolonged labour were dissatisfied with health providers who did not listen to them and did not care about their wishes and concerns. This led to a loss of confidence and greater suffering from labour pain. These findings were supported by Barlow, Hainsworth, and Thornton (2007) who found that women experiencing preterm labour reported health professionals did not believe their complaints and did not take them seriously so delaying the diagnosis and only belatedly dealing with their problems.

Beck (2004) in her descriptive phenomenological study of 40 mothers experience of birth trauma revealed that women’s expectations of their labour and care vanished when they encountered staff who they perceived possessed little interest or concern about them as unique individuals. They received no reassurance when they faced their difficult time during a traumatic birth leaving them with feelings of being abandoned, alone and experiencing a loss of their dignity. The mothers used such terms as mechanical, arrogant, cold, technical, and lacking empathy to describe the care they had received. Their experience resulted in them losing their trust in health providers and feeling disempowered whilst receiving unsafe care for self and their infants.

Women felt satisfied when health professionals could provide them with information about their current situation that decreased their anxiety and assured them that their condition was 'fine'. During labour, a woman liked to be treated as a person, not a patient, to be cared for and listened to (Bowers, 2002).

**Postpartum Rituals**

In Chinese society, the woman after childbirth has the right to practice the traditional postpartum ritual of *doing the month*, namely *zuo yuezi*, which allows for a period of thirty days of confinement at home to follow a set of specific practices, including having special types of food and more rest and sleep, maintaining emotional stability that prevents crying and being exposed to negative emotions. 'Doing the month' helps postpartum woman recover their health and prevents them experiencing future illness. This ritual is deemed important as the Chinese believe that childbirth leads to a woman’s body losing inner physical balance and energy. 'Doing the month' presents an opportunity to regain strength, energy and balance.
Another important purpose of 'doing the month' is to have time to bond and nurture her newborn baby, learning how to attend to her baby to ensure her baby’s health. The time is for the family to transit to a new situation with joy and good future since they regard the child as the wealth of a family (Brathwaite & Williams, 2003; Kartchner & Callister, 2003; Leung, Arthur, & Martinson, 2005; Liu-Chiang, 1995). Liu-Chiang (1995) indicated that postpartum women found ways to integrate self into the practice of doing the month and thus obey the traditional rules.

**Hearing the Diagnosis**

In Chinese culture children are expected to satisfy their parents’ anticipations or wishes to become “dragon” for a boy or become “feng” for a girl (望子成龍/望女成鳳). This translates into children becoming successful and significant persons contributing to mainstream society. Parents hope their children will grow up healthy with good morality, intelligence, physical health, and beauty (Lau, 1996, pp. 12-22). Parents do not expect that their children will live with any physical impairment or that anything could go wrong with their children, since they always have high expectations for their children. Hearing the diagnosis of disability, parents’ reactions include shock due to loss of their expectations, denial and refusal to accept the diagnosis, anger and blaming of the medical system due to the poor quality of treatment, fear and uncertainty owing to not knowing the extent or degree of the disability and associated impairment (George, Vickers, Wilkes, & Barton, 2007) and feeling disempowered and overwhelmed with uncertainty of an unpredictable future life (Graunegaard & Skov, 2006). Tattersall and Young (2006) interviewed 45 parents/caregivers of deaf children. Findings indicated that health professionals should be sensitive to the mothers’ practical and emotional needs in terms of a “gentle” approach during the period of diagnosis. Being approachable was important when the mothers were under stress, but health professionals gave them the impression of lacking “people skills” and not being a “people person” in terms of caring for their emotions.
Health care professionals' behaviour and communication style when revealing diagnoses have been described in terms of being inconsiderate, unhelpful, insensitive, dishonest, not open enough, lacking sympathy, being unsupportive and being told alone. Such behaviours thwart the possibility of developing a trusting relationship and compound the parents’ feelings of grief and diminish their ability to adapt (Baird, McConachie, & Scrutton, 2000; Dagenais et al., 2006; George et al., 2007; Quine & Rutter, 1994; Tattersall & Young, 2006). Mir and Tovey (2003) state that when the physicians only provided negative information about the child’s brain damage to Asian parents in England, this resulted in them having difficulty in accepting and coping with their situation. Graunegaard and Skov (2006) revealed that parents felt that physicians only focused on their children’s disability, symptoms and the lack of abilities due to disability, but not their children’s potential and possibilities. Glaun, Cole, and Reddhough (1998) indicated that a lack of communication or not involving the parents in the diagnostic process not only caused disagreement with the diagnosis or extent of the children’s disability between parents and professionals, but also hindered parents from utilising early intervention services and communication with professionals.

Delay in receiving the diagnosis has been supported in many studies. The findings suggested that parental satisfaction with medical service was related to receiving an early diagnosis. The parents would have a long period of anxiety and uncertainty after their children showed that something was wrong and before diagnosis was confirmed (Quine & Pahl, 1987). Graunegaard and Skov (2006) indicated that parents felt powerless not knowing the diagnosis, so their satisfaction with the diagnostic process was determined by the accuracy of the diagnosis being given in a short period of time. The parents often felt grief, disappointment, frustration, or anger due to the delaying of the diagnosis because the physicians did not take their concerns seriously enough or dismissed their early concerns. Health professionals regarded their concerns as neurotic or over anxious since they believed their children’s developmental delay could be improved after time passed (Baird et al., 2000; George et al., 2007; Mir & Tovey, 2003; Quine & Pahl, 1987; Rannard, Lyons, & Glenn, 2005).

When delaying the diagnosis, the physicians’ competence and experience was questioned and trust and satisfaction no longer existed with the quality of medical
care (Graungaard & Skov, 2006; Mir & Tovey, 2003; Quine & Rutter, 1994). The mothers wanted to be included in the medical team to be treated as health professionals’ partners to engage in their children’s diagnostic process (Graungaard & Skov, 2006). The mothers could trust health professionals when they were honest and open to them (Tattersall & Young, 2006). Early diagnosis enabled them to start to see how to manage their children’s problems and start to rearrange their lives (Buelow & Shore, 2006; Fitzpatrick, Graham, Durieux-Smith, Angus, & Coyle, 2007; George et al., 2007; Rannard et al., 2005).

After receiving the diagnosis, the information functioned as building up the picture of their children’s condition, treatment, and expected outcome. Mothers felt reassurance, adjusting to their lives and preparing for their future. Plans for the daily management of their children’s condition, establishing control, decreasing anxiety, and building confidence were able to be developed (Baird et al., 2000; Hummelinck & Pollock, 2006; Quine & Rutter, 1994; Tattersall & Young, 2006). It was the future of unexpected uncertainty that exhausted mothers and parents (Graungaard & Skov, 2006).

**Conceptualisation of Maternal Care-giving**

The Chinese girl has been trained to take responsibilities for doing housework and caring for other children at home in order to be able to be a good wife, mother, and worker for her husband’s family (Baker, 1979, p. 41). Lee (2002) discusses this process as a kind of internalisation of values based on gender and age since the Chinese women have learned and observed their own mothers from a very young age. Lee (2002) interviewed 20 working Chinese women, who believed that to be a mother one must assume four major roles, namely being a wife, mother, housewife and care-giver. Although the participants had full-time jobs, childcare was still viewed as the major responsibility of the woman. Domestic helpers, such as Filipina and Indonesian helpers, according to Chinese belief cannot substitute for a Chinese mother who is responsible for providing attention and care aimed at nurturing a child’s development and health.
In Chinese society, the parent-child relationship is much more important than the conjugal relationship of the couple (C. F. Chang, 2006), so the child is the centre of the mother’s life. Social expectations and gender play a vital role in shaping and defining the maternal identity of Chinese mothers. The characters of Chinese mothers have been described as self-sacrificing, suffering, guilt-inducing, and over-involved with their children (E. Lee, 1999, p. 253). The mother is expected to not only provide nutrients, affection, caring, and support (E. Lee, 1999, p. 231), but also be concerned about their children’s financial security (Chen et al., 1991, p. 301).

**Care-giving burden and tasks**

Maternal care-giving studies over the past two decades have detailed the demands placed upon mothers who provide care for disabled children. Roberts and Lawton (2001) investigated 35,000 severely disabled children in the U.K. This data indicated that the children with severe CP often presented with physical impairments, chewing and swallowing difficulties, behavioural problems, constant crying, poor sleep, requiring around the clock medication or tube-feeding. These children needed extra care with washing, dressing, meal times, use of toilet, keeping occupied during the night and continuing care. These additional care activities required their parents to expend more time and energy in looking after their disabled children. Such extra care has been defined as burden. Warfield (2001) surveyed 122 mothers of children with disabilities and found that parents experienced greater levels of stress when they had higher parenting demands in terms of care-giving difficulty, including bathing, feeding, toileting, getting the child to sleep, dressing, daily health, organizing play, comforting, supervising, dealing with school or day care, taking the child to the doctor, and assisting the child to move.

Witt et al. (2003) conducted a survey of 4,939 parents of children with disabilities. They reported that if the children had self-care or mobility, communication, and social/learning limitations, then parents were more likely to experience work-related burden, because parents had to resign from work or change work hours in order to take care of their disabled children. The more functionally limited the child was the greater the burden to the parents. A child with social or learning-related functional limitations needed more outpatient mental health care which also placed an extra burden on their parents. Eker and Tuzun (2004) also found that mothers caring for
children with gross motor function impairment experienced more physical pain, poor general health, lacked vitality, had limited social functioning, and challenged mental health when compared with mothers caring for children with better motor physical function.

Mobarak et al. (2000) suggested that mothers had greater stress when caring for children with behavioural problems. It was often reported by mothers that their children’s lack of independence in daily living skills, not going to sleep, night wetting, day wetting, soiling, hyperactivity, being miserable, waking at night, attention-seeking, and temper tantrums caused great care-giver stress. These results were supported by Ones, Yilmaz, Cetinkaya, and Caglar (2005) and Keller and Honig (2004) who suggested that the children’s behaviours made care-giving difficult for their parents. Specifically, Pun et al. (2004) indicated that children’s behavioural problems left their Chinese mothers feeling exhausted and emotionally and physically strained. They also felt frustrated and embarrassed when dealing with the children’s behavioural problems in public places. Moreover, Floyd and Gallagher (1997) whose results suggested that 231 mothers and fathers of children with mental retardation reported the greatest time demands, namely caring demands, when their children had behavioural problems, while the mothers experienced fewer time demands when their children only had mental retardation but no behavioural problems. The authors indicated parental stress was more strongly linked with children’s behavioural problems than with the children’s disabilities. Skok, Harvey, and Reddihough (2006) stated that mothers of children with CP experienced higher stress in their lives when it was unpredictable, uncontrollable and overloaded.

**Care-giving demands and routine**

In order to elucidate further the perception of a mother’s caring demands for a child with a disability Glasscock (2000) undertook a descriptive phenomenological study of 15 United States mothers experiences of caring for children with CP. The theme *caregiver burden* was described in terms of mothers needing a great deal of time, energy and emotional strength to provide care. Doing exercises for their child everyday was necessary because their children were physically stiff after waking up in the morning. Giving attention and time to prepare their children’s diet provided their children with the best chance to grow up and develop. They even had to do their
housework after midnight when others were asleep. They also kept an eye on their children at all times. Their sleep was light to maintain vigilance of their children. Sawin et al. (2003) discuss the concept of “the ever-present monitoring and managing” that is a central aspect of the experience for parents of children with spina bifida.

The daily care routine was explored by Helitzer, Cunningham-Sabo, Vanleit, and Crowe (2002) who interviewed 10 mothers of children with disabilities. The term “overwhelming routine” was applied to describe their daily life since mothers felt exhausted in performing multiple tasks associated with their domestic workload, child care tasks and services, and marital roles. Keeping aware of any possible crisis, living with tight schedules, needing to be flexible with very little time for themselves all contributed to this sense of being overloaded. One mother described her routine as having to wake up around 4:30am to commence the breakfast routine. It took a long time to feed her child, and then she had laundry to organise, mowing the lawn, keeping the child entertained, making the beds, washing the dishes, cleaning the floor, taking the children for a walk, doing some of her own work related to her job, putting the child down for a nap, preparing for dinner and feeding her other children, bathing her children, and putting them to bed. She felt very exhausted and lonely. For these mothers, keeping their lives organised, structured, routinised at all times enabled them to possess a sense of control and feel their life was manageable, but they were also very aware of how easily the balance could be toppled and their lives completely disrupted.

**Maternal well-being and quality of life**

Carrying out daily tight schedules and routines for the child with a disability occupied most mothers’ life experiences. McKeever and Miller (2004) found that mothers always took on care-giving responsibilities alone and performed skilled treatments such as physiotherapy, suctioning, urinary catheterizations, administering medication, spoon or tube feeding, and lifting and positioning. Many researchers have examined the relationship between care-giving stress and burden and parents’ well-being or quality of life. Eker and Tuzun (2004) stated that mothers of children with CP had lower quality of life than mothers of children with minor health problems, such as poor general health, vitality, social functioning and mental health. Mothers of children
with CP experienced poorer role physical problems, which meant their work or other daily activities had been hindered by their personal physical health. Mothers also experienced intensity of bodily pain that impacted on their work both inside and outside the home due to their heavy care-giving duties, such as lifting and turning, bathing, helping the child use a toilet, getting their children to sleep, dressing, and assisting their children to move. These findings were supported by Ones et al. (2005), who argued that mothers of children with CP reported a lower quality of life than mothers of healthy children. In particular their quality of sleep, energy levels, sense of social isolation, felt pain, physical activity, and emotional reactions all influenced their everyday lives. Hartley et al. (2005) found that mothers of children with a disability had insufficient time to rest, so fatigue and lethargy were commonly experienced.

Floyd and Gallagher (1997) found that mothers reported the constant demands from caring for their disabled children limited self or family members’ growth and development. The mothers also had the highest depressive reaction in terms of feelings of unhappiness and distress when their children had behavioural problems. The parents felt pessimistic about their mentally retarded children’s prospects of achieving self-sufficiency and worried about their ongoing responsibility to provide care for their children. Similarly, Veisson (1999) revealed that mothers and fathers of children with a disabilities experienced negative moods, pessimism, sleep disturbance, loss of libido, and depressive symptoms compared to parents non-disabled children. Mothers experienced a higher score than fathers of children with disabilities. The parents of children with disabilities experienced more negative emotional states, including pressure, tiredness, desperation, displeasure, sadness, depression, helplessness, being worried about their children’s future, and feeling sorry for their children and themselves, while parents of non-disabled children experienced more positive emotional states, such as being happy, glad, satisfied, proud, grateful, pleased, hopeful and happy for their children.

By exploring mothers’ caring confidence with the caring demands of the children with disability, Barlow, Cullen-Powell, and Cheshire (2006) recruited 78 mothers of children with CP. Their findings indicated that mothers experienced being more anxious and depressed when they had lower self-confidence in their ability to satisfy
their children’s caring demands in terms of children’s psychosocial well-being. Moreover, Holmbeck et al. (1997) invited 28 fathers and 27 mothers of children with disabilities and compared them with 55 parents of able-bodied children. Findings indicated that mothers of children with disabilities perceived lower levels of parental competence, which meant mothers experienced more problems raising children than expected. Mothers of children with disabilities experienced more adaptation difficulties than those mothers of able-bodied children, less adaptability to change including finances, home, environment, occupation, and their own and their children’s development.

**Barriers to Care-giving**

Research studies indicate that maternal care-giving barriers revolve around relationships with others in the family in terms of grandparents, husband, child with a disability, healthy siblings, and outside the family such people as teachers, child’s peers at school or health professionals in the health care system. Care-giving barriers include taking care responsibility alone, loss of independence and carrying out in-home programs for the disabled child, experiencing negative feelings towards siblings, feeling unable to cope with dual/multiple roles, exclusion from school and being the recipient of poor medical care.

**Being alone**

Findler (2000) found that mothers of children with disabilities received more support from their own parents than in-laws. Those mothers were more satisfied with the support from their own parents than from their in-laws. Furthermore, Trute (2003) suggested that mothers of children with disabilities had lower levels of depression when they received emotional support from their own parents and mothers-in-law. However, practical support was not linked to decrease mothers or fathers’ depression or parental stress.

In agreement, Pit-ten Cate, Hastings, Johnson, and Titus (2007) argued that grandparents were significant resources for parents of children with disabilities in providing financial support, assistance with therapeutic tasks, baby-sitting, discussing problems, and helping with housework or shopping to support parents’ well-being.
More significantly, Lindblad, Holritz-Rasmussen, and Sandman (2007) reported that parents of children with disabilities felt gratified when their disabled children were accepted by other family members. This signified their acceptance, not rejection, so family members were willing to learn about their children’s disabilities and to develop a closer relationship with the children. The parents could also trust other family members due to their willingness to engage in childcare. From another perspective, Mitchell (2007) stated that harmonious and close relationships with grandparents can contribute to a family’s ability to positively cope with the event of having a disabled child at home. If the child with a disability did not meet the grandparents’ expectations, there would be less involvement in the child’s care. No support or caring from grandparents induces family tension and conflict, nor does it reduce parents’ emotional stress and care-giving burdens.

The husband’s attitude is also important. According to Keller and Honig (2004) fathers of children with disabilities lack emotional closeness with their children. In agreement, Hartley et al. (2005) argued that fathers of children with disabilities were not usually involved in helping with their children’s daily care, but acted only as “gatekeepers” to control the finances and make decisions about the children’s treatment. Mothers of children with CP in Glasscock’s (2000) study stated that help from their husbands, such as laundry, the dishes, changing diapers, allowed them to have more time working with their children with CP and was an important support. Different results were found by Button, Pianta, and Marvin (2001), whose results suggested that male partners being involved more in children’s care increased mothers’ stress when the children with CP were more severely impaired. The authors explained that partner involvement interrupted the mother’s daily care-giving routines and the fathers in this study lacked specific skills for taking care of the child.

Hartley et al. (2005) found that mothers bore all primary care-giving responsibilities for their disabled children, so they always lacked time for other chores, responsibility and community activities. In agreement, Lewis, Kagan, Heaton, and Cranshaw (1999) found that mothers were expected to resign their job to shoulder major responsibility, being constantly available to care for both the children with disabilities and other family members due to gender ideology.
Relationships – balancing independence and overprotection

Realising their children’s disabilities influenced the quality of child-mother relationships in a way that was different from mothers of healthy children (Harden, 2005; Larson, 1998). The mothers would blame themselves and feel guilty for their children’s injuries due to failure of their maternal responsibilities (Graungaard & Skov, 2006). For Sawin et al. (2003), “blended parenting” described the relationship between parents and their children with disabilities. Such parents wished their children to have an independent life, but they could not help keeping close supervision over their children and becoming overprotective in their aim to shield them from harm. Relationship tensions increased when there was no consensus on the level of independence between parents and their children. Pascall and Hendey (2004) stated that relationship tension became obvious when the mothers were pushing their children for independence, but regarded their children as vulnerable and worried about their ability to live independently. The parents could be resources and support independent endeavour through providing support in care, advocating and negotiating on their children’s behalf and always engaging in hopeful and positive forward thinking. In contrast, the family could be a place to hinder the child from independence due to the strong interdependence of parents and their children. Sanders (2006) argued that overprotection caused the child with disability to possess lower self-esteem, experience feelings of incapability, become self-centred, and feel less respected by others, and ultimately be denied possibilities for self-growth.

Relationships – parent or full-time caregivers?

Performing therapy or rehabilitation programs at home was an important aspect of mothers caring for their children with disabilities. Leiter (2004) interviewed and observed 31 families. The findings discovered that the maternal role became a barrier to successfully carrying out effective therapy at home because of responsibility for other children, family members and other chores. They experienced ineffective therapy when they tried to integrate therapy into their daily life and play. A few mothers even indicated they would prefer to “just” stay in the role of mother and refuse to take the therapist role, but they felt guilty when they may not have done enough for their children.
Similarly, Galil, Carmel, Lubetzky, Vered, and Heiman (2001) surveyed 193 parents of children with disabilities. The findings suggested some obstacles to compliance with the therapy at home, including the employment of the mother, having many children, feeling a burden of caring for the child, experiencing a lower level of satisfaction with the support services, possessing a weaker belief in the effect of the therapy, possessing less hope, having stronger feelings of self-pity, and having low levels of education. Furthermore Kirk, Glendinning, and Callery (2005) argued that parents viewed their home as a medical environment, a “mini-hospital” when caring for their technology-dependent children and the presence of medical equipment compounded this view. Parents felt resentful when their care-giving role went beyond their parents’ role, especially when they regarded themselves as full-time nurses and therapists trapped by the relentless demands of providing care.

**Relationships – sibling rivalry**

Healthy children could become a support for the mothers when raising the children with disabilities because of sharing care-giving activities or housework with their mothers (Hartley et al., 2005; Hinojosa, 1990). Lindblad et al. (2007) revealed mother’s feelings of ambivalence since they did not want to put caring stress on to their healthy children, but their healthy children offered a lot of practical assistance in looking after their disabled sibling or in doing housework. Fleitas (2000) argued that healthy siblings, especially older sisters, often could not escape from taking care of their disabled siblings to ease their mother’s caring load. Healthy siblings also felt lonely, resentful, and jealous when their disabled siblings became the centre of concern for the whole family and got special privileges and gifts. Healthy siblings could feel embarrassed when they noticed others’ responses to their disabled siblings differences in appearance or behaviours. These findings were supported by Pun et al. (2004) who stated that Chinese mothers often blamed self since healthy siblings felt shameful or suffered from having imperfect siblings.

However, Dallas, Stevenson, and McGurk (1993) argued that one positive aspect for siblings caring for the disabled children was increasing their social competence and nurturing behaviours. Increasing siblings’ caring and sensitivity and developing a greater maturity and responsibility were reported by Taunt and Hastings (2002). The siblings relationship could impact on the mother’s well-being. Bat-Chava and Martin...
(2002) found that parents experienced anxiety when sibling relationships were negative.

**Relationships – maintaining dual roles**

Mothers of children with disabilities modified their paid employment in order to fulfil their primary maternal caring responsibilities for their children with a disability (McKeever & Miller, 2004). Lewis, Kagan, Heaton, and Cranshaw (1999) reported that mothers felt guilt and conflict as their employment forced them to leave their care-giving responsibilities in the hands of others. Similarly, Green (2007) found that having a dual role in terms of being an employee and main caregiver at home caused stress and burden greater than being able to stay at home without paid employment elsewhere. Working mothers faced role conflict when caring demands influenced their commitment to meet their employment expectations.

Despite this role conflict, working for pay was important for mothers. Parish and Cloud (2006) argued that parents of children with disabilities needed to work to avoid poverty due to the extensive costs related to specialised therapies, home modifications, adaptive equipment, medications and educational services. Lewis et al. (1999) named working outside as economic benefits. Support from social welfare was unable to cover all their expenses of taking care of the disabled child and forced mothers into the workforce where an economic benefit could be realised. Another benefit for working mothers was psychological, where working outside the home, provided them with personal space, saving their sanity, not feeling pity or isolated, gaining self-esteem and fuelling their personal value (Lewis et al., 1999).

**Relationships – exclusion from school**

Mothers of children with disabilities were full of expectation and anticipation of the learning their children could acquire within the school situation (Hartley et al., 2005). However, Hartley et al. (2005) indicated that disabled children were often rejected by their peers and teachers, even abused by peers. In agreement, McCabe (2007) found that parents in China experienced their children with disabilities being rejected from school due to their lack of self-care skills, so they were worried about the acceptance of their children into the school community. They were also very concerned about the teachers not being able to provide individual support to meet their children’s special
needs in a classroom where they had to cater for many children’s needs simultaneously. They questioned the teachers’ specialised skills or their willingness to teach their disabled child (McCabe, 2007). Morse, Wilson, and Penrod (2000) reported that school teachers in the mainstream lacked the ability to offer a better learning environment to compensate for children’s disabilities and promote and sustain their learning.

Cole (2005) used the term “inclusion” to express the mothers’ inner voices that expressed a need for their children to be included and welcome in the school environment. However, they encountered passive, resistant, and non-accepting attitudes from school. Cole (2005) highlighted how mothers communicated their concern relating to whether their children were treated with dignity and care. Such concern was demonstrated in their need to carefully monitor the children’s school life to ensure inclusion, comfort and safety. Mothers wished their children could be like other children, to have equal opportunities and be treated as normal. Those mothers tried doing anything to ensure their children were included, but they had to learn to balance between the philosophy and the reality of inclusion in achieving the best for their children.

**Relationships – nurses and other health professionals**

The importance of family-professional partnership and collaborative relationships has been examined in a number of studies (Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006; Frain et al., 2007; P. Lee, 2007; Young & Klingle, 1996) that emphasise the importance of involving all stakeholders in the child’s care, including family members. Young and Klingle (1996) found that those patients who could make a commitment to their health care decisions and became involved experienced increased satisfaction with the service received. Conversely, Denboba et al. (2006) who undertook telephone surveys of caretakers of 38,666 children with special health care needs, found that increasing missed school days, increasing difficulty accessing speciality care, dissatisfaction with services, and disappointment with unmet needs were the result of poor participatory relations.

Parents were often dissatisfied with the quality of their relationships with health professionals. Research findings from Kearney and Griffin (2001) found that parents
felt angry and experienced despair, powerlessness and helplessness when professionals gave less than hopeful information relating to their disabled children’s development and condition. Mir and Tovey (2003) interviewed Asian carers in England and found that carers built up their expectations according to professionals’ attitude. Parents tended to concentrate more on the negative aspects of their children’s condition when professionals predominantly focused on the children’s negative brain function and cognitive abilities. Such interactions left parents with pessimistic expectations and fear about their children’s future and they had difficulty in accepting and dealing with their children’s problems.

Kearney and Griffin (2001) found that some mothers were able to demonstrate their “defiance” of physicians’ prediction of poor progress and prognosis in order to keep hope in their mind and stay motivated to work towards an improved future. Moreover, mothers in Larson’s (1998) study revealed that some health professionals only focused on the disabled child’s diagnosis and did not respect the child as a human being, acknowledging the child’s personhood and humanity. Asian carers of children with CP in Mir and Tovey’s (2003) study felt powerless when service providers delayed their responses or the responses to their request for help were inappropriate. Such experiences led to emotional distress.

In order to compensate for physicians who only focus on diagnosis and demonstrate no respect for the child as human, Collins (1995) has argued that the nurse should act like a supporter and educator to provide complete and unbiased information to families in an empowering and empathising manner. Sen and Yurtsever (2007) found that over fifty percent of families wanted nurses to offer information or consult with them about their disabled children’s condition and care. Wong, Lai, and Wong (2006) found that receiving knowledge about their children’s conditions and progress enabled parents and family members to better understand their disabled children, decreased anxiety and stress and resulted in an increased acceptance of their children.

Chang and Lin (2007) state that nurses support of Chinese families is particularly important in encouraging them to look at positive qualities of their disabled children and to help them to accept their disabled children. Nurses play an influential and vital role given that in Chinese culture family significantly influences the experience of
providing day-to-day care for disabled children. Chang and Lin (2007) advocated the importance of parents recognising both the advantages and challenges that have the capacity to empower parents when dealing with their disabled children’s situations. Sen and Yurtsever (2007) pointed out that nurses were in the best position to give professional support to parents and disabled children because nurses had opportunities to access and retain contact with families in various settings, such as hospitals, health clinics, schools and in rehabilitation centres.

Although the mothers felt dissatisfied with health professionals’ communication and aspects of poor quality medical service, most mothers had a need to maintain a good relationship with service providers in order to sustain any possibility of benefit from the prescribed treatment and care for their children (McKeever & Miller, 2004). The Chinese regard physicians as “problem solvers”. They believe that physicians possess professional authority because of their medical knowledge and competence to provide a cure (E. Lee, 1999). Moreover, they use their power and authority to justify their control over medical decision-making processes. This paternalism results in too little information, opinions, feelings, or experiences being exchanged. The child’s and parent’s needs remain essentially unmet and their autonomy is often ignored (Da Silva et al., 2003).

The concept of parental involvement and parental participation optimally achieves the goal of collaboration between family and professionals and fosters family-centred care (Hutchfield, 1999). Stephans et al. (200) argue that family members should be involved in health care team as team members and experts in their children’s care, care planning, intervention and medical decision making. Every team member should contribute their knowledge and skills in order to gather and exchange all information and promote the best care in the family context (Stepans, Thompson, & Buchanan, 2002). Therefore, nurses should aim to sustain the families’ decisions-making skills (Collin, 1995). Acting as a **coordinator** nurses are in the position to support parents, disabled children, other family members and health professionals in working together (McEnhill, 1996).

Integral to this role is facilitating open communication amongst family members which is important in supporting decision making. Frain et al. (2007) advocates that
nurses are in key positions to teach families how to hold family meetings and facilitate open communication. Hutchfield (1999) and McEnhill (1996) argue that nurses should provide not only verbal information to parents and all family members, but also written information and opportunities to discuss and explore all possible options of care and resources that enable them to make the 'best' health care decisions for their disabled children.

Chou (2007) advocates that nurses as key members of the health care team in the role as collaborator should also facilitate the bringing together of a range of health professionals and families in the development of a holistic health care plan. Research clearly communicates that parents are satisfied with health care services when they have a positive relationship with health professionals based on mutual respect and feel enabled to participate in decision making that influences their children’s health care (Lutenbacher, Karp, Ajero, Howe, & Williams, 2005). Chang and Lin (2007) found that parents felt empowered when health professionals valued and listened to their opinions and involved them in making decisions about their children’s health care.

A challenge to nurses as collaborators of health care resides within the Chinese culture itself. Although the Chinese value the collective culture, behavioural and relational norms can thwart collaborative action. In Chinese culture, the public interest it put before self-interest and individual rights are subservient to those of the group. In this way individual autonomy is concealed (D. F. C. Tsai, 2001). Young and Klingele (1996) suggest that Asian American patients exhibit less assertiveness than the mainland American patients due to cultural influences and differences. Fitting into the group has always concerned people in a collective culture such as Chinese. Chinese culture informs 'correct' behaviour that is not too demanding and is less assertive. The aim is to maintain harmonious relationships with others. In communication with professionals, Asian people tend to use a passive language to voice their requests. They feel uncomfortable in undertaking an active advocacy role or directly demonstrating their disagreement or directly communicating their needs. Mir and Tovey (2003) found that only a few carers thought they should or could fight for their rights and make requests for provisions when their needs remained unmet.
Despite the cultural barriers to collaborative care, Landsman (1998) utilised the term “real mothers” to describe those mothers who had in-depth knowledge of their children and their needs and advocated for their children, especially when the quality of health care was not up to their anticipated standard and they felt threatened and vulnerable. Those mothers were worried that their children’s value and humanity were ignored or missed by others, so they persistently spoke out on their children’s behalf. Brady, Skinner, Roberts, and Hennon (2006) labelled such a role as “care manager” or “advocate”. Similarly, McKeever and Miller (2004) indicated that mothers value their maternal function of “acting on behalf” thus meeting the social expectation of being good mothers who engage in all caring as a means of ensuring their children benefit from the desired service and appropriate care. But these mothers would often experience conflicting relations with professionals or others when the child received what they perceived to be sub-optimal care. When in conflict with health professionals, they had accommodated over time and learned how to behave in order to prevent their child experiencing any deprivation of necessary care or being further devalued (McKeever & Miller, 2004).

Nurses have the opportunity to realise the importance of integrating Chinese culture into clinical practice and care. Collin (1995) argues that when encountering health care challenges, families and patients often turn to nurses for help as professional advocates. Advocacy for families can foster an interest from all family members in supporting disabled children at home (McEnhill, 1996).

The literature reviews a number of strategies that nurses can employ to address the needs of parents with disabled children. First, nurses should actively provide opportunities to parents for discussing their concerns and their children’s health condition. This platform provides opportunity for developing mutual communication and the building of rapport as well as fostering an egalitarian relationship (Sen & Yurtsever, 2007). Second, nurses should possess the ability to comprehensively assess families’ needs and communicate this information to other health professionals (Collin, 1995).

Beyond family-nurse relations, nurses as negotiators can apply negotiation and communication skills to bridge the gap between parents and other health professionals
thus improving communication and resolving potential conflicts. If necessary, nurses can also make referrals in order to access other resources for parents aimed at minimising uncomfortable relationships (S. T. Lee, Shieh, & Chiou, 2001) and accessing appropriate services.

Accessing rehabilitation services is in Taiwan viewed as the best way to improve the potential progress of children with disabilities, thus interaction between parents and the therapists becomes meaningful in daily care-giving experience. Leiter (2004) argued that parents experienced difficulty fitting rehabilitation programs into their daily lives. Challenges were experienced when there existed a lack of agreement between parents and the therapists about the children’s or families’ needs (Leiter, 2004). The parents also felt disappointed when the rehabilitation program was not innovative, started late, or failed short of expectation. Different expectations of responsibility for the children’s rehabilitation program also existed, the therapists thinking that the parents should bear more responsibilities for the program, while the parents expected the therapists should take on more responsibility (Watson, Kieckhefer, & Olshansky, 2006). Short, Schkade, and Herring (1989) concluded that parents were expected to be knowledgeable and skilful so as to handle their children’s rehabilitation training but lacked sufficient supervised experience to manage this situation.

The above conflict and dissatisfaction, Watson et al. (2006) suggested comes about because of the different perspectives of parents and therapists. Both sides had their own personal background, values, knowledge and experiences about the children. The authors used the term “variabilities” to describe their conflicting opinions, meaning the therapists did not take the family philosophy into account and failed to work towards the concept of family-oriented view. The feeling of uncertainty came into the parent’s mind when variabilities did not decrease over time. Parents were always hoping the therapists could understand their experiences of parenting and challenges of living with the child with disability in order to discuss the best intervention together and help the parents fit the rehabilitation program into their everyday life (Cohn, Miller, & Tickle-Degnen, 2000).
Nurses have a key role in bridging the gaps between family and professional therapists for disabled children. Authors Chang & Lin (2007) and Chou (2007) argue that nurses should perform home visits to assess the family environment, the strengths and limitations of undertaking a treatment program and care within the home and provide advice on how identified challenges can be addressed.

Nehring (2003) argues that nurses should interview parents to gain detailed information about their children, their concerns and perspectives and any past and current health care history including behaviour and parents’ expectations in terms of parents’ lived experiences. Information of family members’ attitude towards disabled children should also be included. Following assessment and gathering information, nurses should communicate with therapists and other professionals. Such information aids therapists and other professionals in designing suitable rehabilitation programs for their children.

Nurses have responsibilities to monitor and evaluate the quality of care the disabled children and their parents receive from multiple health care settings or professionals in terms of satisfaction (Lutenbacher et al., 2005) and make necessary referrals (Nehring, 2003). In order to make sure that continual care can be supported in a variety of health care settings, nurses should make contact with different settings to organise and coordinate different resources for disabled children and their families (Sen & Yurtsever, 2007).

**Positive Aspects of Care-giving for a Disabled Child**

Qualitative studies of the experience of mothering a disabled child have served as an important adjunct to empirical research that can be grouped into a number of discreet categories: the “doing” and demands of care-giving; the burden of care which is automatically converted to stress and strain; the effect of activities upon health and well-being; and the types and impact of relationships with relatives and professionals on a mother’s experience of care-giving. Qualitative studies have discovered variations in care-giving practices, emotional adjustments and resolutions that have gone well beyond the understandings captured in the empirical body of literature.
A number of meaning constructs emerge from the literature: love and joy; feeling self-growth and change; experiencing close family relationships; feeling confidence of improving my child’s quality of life; working towards normalcy; maintaining hope by following Chinese folk beliefs and therapy. Importantly, compared to the empirical literature that focuses on the demands, burden and strain of care-giving for disabled children, such research has uncovered the positive aspects and rewards that mothers experience from day-to-day involvement and engagement in the experience of caring for disabled children. Moreover, such studies clearly reveal the importance of appreciating the actual process through which positive reward is realised through everyday average experiences. In this way this body of literature opens one’s eyes to the dynamic and temporal nature of the experience of mothering a disabled child.

Love and joy
Loving the child was the biggest motivator for mothers to engage in their everyday care-giving (Brinchmann, 1996; Green, 2007; Kearney & Griffin, 2001; Larson, 1998; Pun et al., 2004). McCabe (2007) revealed that the child was a piece of the mother’s heart and body and parents were totally engaged in their care-giving for the child with a disability. Mothers of children with disabilities in Landsman’s research (1998) used terms such as “incredible”, “fighter”, or “a real spitfire” to describe their children “fighting” for their lives in the environment of the Intensive Care Unit. Kearney and Griffin (2001) described the feelings of joy experienced by parents of children with developmental disabilities as they survived an unfortunate event. Green (2007) revealed that mothers were proud of their children and appreciated their children’s inner worth. Joy and elation were experienced through the appreciation of little achievements and things the child could do no matter how “ordinary” (Hartley et al., 2005; Kearney & Griffin, 2001; Taunt & Hastings, 2002).

Experiencing self-growth and change
Through day-to-day caring for the child with a disability mothers learnt to appreciate people’s inner beauty, not merely their physical appearance (Green, 2007). They become more sensitive to other people who were “non-perfect” (Sawin et al., 2003). Taunt and Hastings (2002) pointed out that parents increased their sensitivity to the children, developed more patience and awareness of others and tolerance. They appreciated not only learning more about their children, disability, psychology,
special education, but also learning from their disabled children, other parents and professionals. They also experienced personal growth (Sawin et al., 2003) and experienced new feelings of enrichment in their lives (McKeever & Miller, 2004). Green (2007) describes the experience of becoming “better people”, dealing with difficult situations with courage and strength. Kearney and Griffin (2001) and Taunt and Hastings (2002) discuss the gaining or changing of perspective, beliefs and values that nurture an appreciation of what people have now and not to take things for granted. McCabe (2007) argued that Chinese parents who could see and feel their own strength and determination after having children with disabilities learned their important role in improving their children’s condition, such as borrowing money to support their children’s treatment, being confident to communicate with teachers to improve their understanding of their children, and possessing a willingness to change their work to accommodate for their care-giving responsibilities.

**Experiencing close family relationships**

Green (2007) applied a mix of quantitative and qualitative methods to explore the experience of mother of a child with a disability. Green interviewed 7 mothers living on the west coast of Florida in the USA to understand the benefits of caring for children with disabilities. Findings suggested that mothers perceived a deeper relationship with their family or friends because of their disabled children. In addition, Taunt and Hastings (2002) conducted research to explore the positive impact of children with developmental disabilities. They interviewed 14 white-European parents and surveyed 33 parents from US and UK via an electronic mail survey. Findings pointed out that parents’ experience of family interactions and dynamics were improved and family could spend more time together and become closer. Few parents experienced strengthening of their marriage. Parents felt that there was a family unit to face the event of disability together, not alone. For example, grandparents were willing to give practical help and find information for parents, so they were able to handle the challenges and difficulties.

**Feeling confident**

Kirk et al. (2005) revealed that parents of technology-dependent children were able to provide their children with individual care because of their experiential knowledge based on intensive care for their children and possessing medical knowledge learnt
from health professionals. These mothers would modify treatment regimens to satisfy their children’s personal needs according to their knowledge of their children. This was supported by Kellegrew (2000) who indicated that mothers possessed the ability to assess their children’s capability, cooperation and skills and thus adjust their daily care routines accordingly. Green (2007) stated one of the benefits of caring for a child with a disability was to become an expert not only in providing daily care but also in monitoring the available and relevant healthcare services. Landsman (1998) used the term “real” mother because they held themselves accountable and their nurturance-based knowledge and action supported their status of real motherhood.

Through providing care for their disabled children mothers developed a confidence in their ability to provide quality care. Pun et al. (2004) suggested that Chinese mothers knew how to create a quiet environment, be patient, kind and speak with a soft voice in order to provide optimal care for their children. Hinojosa (1990) described mothers who tried to let their children enjoy the rehabilitation program to increase the children’s willingness to be actively involved in the daily programmes. This motivation led to enhancing the outcome of such programmes (Hinojosa & Anderson, 1991). Mothers felt satisfied when they were able to help their children to manage their emotional and behavioural problems (Leiter, 2004). Brady et al. (2006) revealed that mothers of children with disabilities would engage in a variety of activities, such as reading or looking at books to improve the children’s communication or language development. The strategy of “bathing the child with words”, imitating productions, or expanding words was used to promote their children’s language ability. In addition, mothers were able to accurately respond to their children through their daily care-giving experience since they could accurately “read” the shrugs, grimaces and other non-verbal gestures.

Working towards normalcy
Rao (2001) used the term “inconvenience” to describe difficulties mothers encountered in their daily life due to their children’s disability. The inconvenience for their children was described in terms of exhibiting difficulty in expressing themselves, standing, or demonstrating other physical limitations. In order to diminish their children’s inconveniences, mothers provided various kinds of support to circumvent their difficulties to make it easier for their children to accomplish their daily tasks by
themselves, such as choosing specific types of clothing. They would choose natural ways to support their children to be involved in their family and community life, such as letting the children play with other children who could accept and play with their children. Teaching their children with skills to catch a bus was to support their children’s independence.

Landsman (1998) suggested that women of children with disabilities made a commitment to early intervention to reduce the gap from their children’s performance to their normal peers. Such commitment allowed their children to move toward normalcy, not merely accommodating their disabilities. They became involved in various early intervention therapies to not give up any possibility to foster progress in their children. Cohn et al. (2000) and Hinojosa (1990) stated that parents regarded therapy as hope so they were willing to engage in therapies for a significant length of time to ensure their children obtained maximal benefit and progressed to enable them to fit into mainstream society, sustaining their children’s confidence and self-esteem. In addition, Sawin et al. (2003) found that mothers trained their children with disability in the art of self-care skills to empower them to successfully overcome their disabilities and progress towards normalcy. They treated their disabled children as they treated other children to be involved in different activities and follow the same rules. Studies have argued that parents did not deny their children’s condition and were realistic, but believed in possibilities in terms of keeping hope in mind (Kearney & Griffin, 2001; Landsman, 1998; Larson, 1998) for a positive future.

**Maintaining hope**

Chinese folk beliefs and traditional therapies are common practices when the Chinese run into life’s difficulties or they need blessing for their life. The parents, patients, or their family members worship their ancestors since they deeply believe the ancestors possess supernatural powers to bless, protect, care, and give help to their descendants (Baker, 1979, pp. 72-73; Chan & Twinn, 2006). Praying to deities at temples to ask for blessing, to gain inner strength and peace to cope with their difficulties, or even change their fate is a common practice.

The Chinese request a charm or amulet or talisman from temples that their children can wear. They believe these charms possess powers from the deities, which can rid
one of bad luck and cure illness and protect health and life (Chan & Twinn, 2006). Asking for a better *feng-shui* of graves in terms of *geomancy* of graves is an important ritual in Chinese society since the Chinese believe it has its supernatural power to impact on the fate of a dead ancestor’s family. This means that the descendants can receive benefits from their ancestor’s good *feng-shui* of graves, such as good health, having successful offspring, increasing wealth and living a long life (Baker, 1979, pp. 100-101). Another commonly used therapy involves applying traditional acupuncture to treat the human’s interior organs. The Chinese believe through needles the inner physical *Yang* and *Yin* can be balanced and the inner blood can stimulate and nourish the whole body (Kim, Kim, Schwartz-Barcott, & Zucker, 2006).

Most Chinese people believe in Buddha, according to Buddhism, practicing observing one’s mind to realise and understand causes of unhappiness affects well-being. Buddhist belief states that one’s mind can be trained to transfer consciousness to positive thinking, so it can help mothers’ shape optimistic thinking in the face of their care-giving demands. A principle of Buddhism is that people should cultivate their ability for compassion, empathy, and loving kindness to both self and others, so people should treat others as they would like themselves to be treated (Nichol, 2006). The ideal state of well-being in Buddhist philosophy is to be free from afflictive tendencies of one's mind, to be fully aware of one’s potential ability, wisdom, compassion and creativity. In keeping with existential thinking, this helps people to focus on their potential possibilities and not be limited to present day feelings, thoughts and practises (Wallace & Shapiro, 2006).

**Conclusion**

Qualitative investigations have demonstrated the complexities and variability of care-giving relations and practices. Qualitative studies have described meaningful dimensions of care-giving that have not been previously noted in more empirical, abstract, risk and burden research on care-giving. It is the intention of this study to explore and extend further the conceptualisation of care-giving in considering the lived experience of mothers providing care for children with CP in Taiwan.
In order to support maternal care-givers to shape their lives in meaningful ways it is necessary to learn what is worthwhile and significant to them. Instead of describing maternal care-giving in terms of type, frequency or task, it is important to describe the care-giving role shaped by concerns and purpose. It is important to raise our awareness of the importance of gaining insight into distinctly humans concerns and practices. Such learning manifests itself in the maternal caregiver’s everyday activities and relationships. The next chapter outlines the hermeneutic phenomenological methodology chosen to shape and inform the research process that aims to gain insight into the phenomenon under study. Such an approach focuses upon the everyday existence, lived through the mother care-giving experiences caring for a child with CP.
Chapter 3

Methodology

Introduction
This chapter will outline hermeneutic phenomenology as a research methodology. The history of philosophy will be examined in order to present a platform for clarifying why ontological-phenomenology was chosen. In particular, it is argued that hermeneutic phenomenology provides guidance to explore, understand and interpret the everyday experience of care-giving for mothers of children with CP.

The Question of Philosophy
Cartesian inquiry can be traced to the rational theories of Rene Descartes (1596-1650). Descartes thought about humanity in terms of the combination of the mind and the body, the former hidden behind the behaviour, an entity not directly accessible, the opposite of the visible and functioning body. In this way, the rational paradigm supported the notion of dualism that separates the body from the mind (Barnacle, 2001, p. 4; Descartes, 1596-1650/1977, p. 219).

For rationalists, the mind is a person’s central point, because its function is for thinking. Thinking is evidence of self existence, so Descartes states “I think, therefore, I am” (Descartes, 1596-1650/1977, p. 222). The mind is always consciously focused towards outside things and people, namely, subject toward object. Therefore, rationalists argued that people themselves can be totally separated from their immediate environment as well as their world (Yegdich, 2000).

As rationalists believed that methodical systems and principles enabled us to understand human beings and their world. They believed proof could replace previous beliefs, traditions and experience. Therefore, the role of the context, feelings and experiences could be ignored and personal meaning and context could be detached from human beings (Horner & Westacott, 2000, pp. 68-72). This philosophy supports
the belief that eliminating one’s prejudice enables one to achieve true knowledge, beyond doubt (Descartes, 1596-1650/1977, p. 225).

**Empiricists** argued that people used their five senses, including smell, taste, sight, hearing, and touch, in order to know their world and build upon their knowledge about which kind of experience should be focused upon. Empiricists argued that principles of objectivity and control allowed humans to explore the causal explanation of the sense experience. Control meant that the elimination of some variable of the person in order to look at the relationship between different variables in the person, its aim, the exclusion of bias so as to enhance validity and accuracy (Polit & Beck, 2004, pp. 15-37). The suspension of personal belief, values and biases in order to follow a set of orderly and disciplined procedures was deemed vital in building objectivity (Polit & Beck, 2004, p. 14).

In summary, rationalism and empiricism studies human beings using controlled and systematic scientific methods. In order to ensure objectivity they separate human beings from their world and purposefully suspend meaning and interpretation in individual situations and contexts. In other words, human beings are detached from their environment and context. In addition, they divide humans into parts or variables in order to explore the relationship between such parts, for example, age and stress, job and stress. In this way, human beings are not regarded as unitary beings.

**Existentialism** argued that the central questions of philosophy should focus on existence, thereby placing special emphasis on the lived experience of the individual person. This way of thinking rejected the application of general principles to a unique person and individual experience. According to existentialists, what made the person unique and individual is the person situated within the context of his/her life and world. They argued that one can not be totally separated from others and live without any relationship within one’s world (Charlesworth, 1975, pp. 9-15). Therefore, existentialists argued it is the unpredictable and unsystematic phenomena which enable understanding of one’s experience (Charlesworth, 1975, p. 70).

**Edmund Husserl** (1959-1983) linked existentialism with phenomenology in order to combine the world of science with the life-world (Sadala & Adorno, 2002). For
Husserl, the aim of phenomenology was to understand one’s experience in one’s particular situation and world, not to control, predict, or find causal explanations, but rather to regard a person as a holistic human being (Van der Zalm & Bergum, 2000). Therefore, phenomenology gained insight into the person not from his/her physical nature, cause-effect analyses, impersonal forces or manipulation and control (Giorgi, 2005).

Husserl integrated the concept of mathematics into phenomenology in order to establish philosophy into a rigorous science which he believed could save human reason (Husserl, 1954/1965, pp. 2-7; Stumpf, 1994, p. 495). His idea was influenced by Descartes’ systemic doubt to build a more certain foundation for knowledge (Barnacle, 2001, p. 6; Stumpf, 1994, p. 495). Some of the key concepts which inform Husserlian phenomenology follow.

**Consciousness**

For Husserl, all knowledge of experience should be present in the human consciousness, namely, its logical structures. Husserl argued that data in the consciousness is not different from the phenomena of experience (Husserl, 1954/1965, pp. 10-12). The experience exists in the consciousness in a pure form without presupposition so that through “pure subjectivity” the phenomena of experience can be exactly described (Giorgi, 2005; Husserl, 1954/1965, pp. 22-24; Stumpf, 1994, p. 494).

**Intentionality**

Husserl proposed that consciousness was always aware of something in the world, because phenomenon always presented itself in consciousness, it is directed towards an intended meaning outside of things and people (Giorgi, 2005; Husserl, 1954/1965, p. 22; Sadala & Adorno, 2002). In this way, the person and the world were regarded as an indissoluble union (Crotty, 1996, pp. 38-39). Husserl named this intentionality, the structure of consciousness (Giorgi, 2005; Sadala & Adorno, 2002). What is present in human consciousness can be understood and investigated so he called these objectivities (Crotty, 1996, p. 40).
Bracketing
As consciousness was the source of all knowledge, Husserl attempted to establish pure consciousness. Also he believed this could not be gained from any presupposition or preconceived notion. Therefore, he attempted through epoche, bracketing, and phenomenological reduction to establish pure intentionality of consciousness and pure subjectivity. Epoche is derived from the Greek word meaning “bracketing” in order to establish the pure subjectivity and consciousness. In his terms, it implied the researcher could put aside their previous life experience, cultural situation, or presuppositions, namely prejudice about the world, in order to make the phenomenological study more precise (Husserl, 1971/1980, pp. 34-51; Sadala & Adorno, 2002; Yegdich, 2000).

For Husserl, phenomenological reduction had the same concern as it sought to suspend one’s knowledge of phenomena in order to allow the things themselves to become present in one’s consciousness, so a pure consciousness could be studied (Giorgi, 2005). Further, all questions that affected real factual existence could be eliminated in order to achieve the attitude of purely eidetic investigation (Giorgi, 2005; Husserl, 1971/1980, p. 35).

Essence
In Husserlian terms, the aim of phenomenology was to explore essence or the structure of the experience of the phenomena of under study (Husserl, 1954/1965, p. 5; Yegdich, 2000). For Husserl “essences are a priori, necessary as pure structures meaning that underpin all knowledge” (Yegdich, 1999, p. 84). Something exists in the phenomena prior to the process of phenomenological reduction. It may be called absolute essences or essential structures. It was important to describe an original and primordial phenomenon in consciousness in order to return “back to the things themselves” which were the components or meanings of the phenomena under study (Husserl, 1971/1980, p. 50; Paley, 1997).

In summary, Husserl argued phenomenology should be like geometric knowledge that is without any prejudice and existing doubt in order to establish pure consciousness and objectivity. He argued that experience of the world outside could be presented exactly in human consciousness. Through epoche, bracketing, and phenomenological
reduction he believed one could produce pure consciousness as the essential general structure of subjectivity.

The Question of Being
Ontology emphasises studying the meaning of Being. For Martin Heidegger (1889-1976) Being is the basis for understanding human beings. According to Heidegger, thinkers from the time of Aristotle to Descartes ignored the question of Being (Heidegger, 1927/1962, pp. 23-25, 44-46). He criticised rational and empirical theories for ignoring a person’s uniqueness and individuality, as well as their interaction with their environment and the world. The quest for Heidegger was not to question whether something existed or how to characterise such existence in terms of physical and/or mental entities, but to ask about the meaning of Being. He believed that in the ways that people existed in the world it was possible to reformulate the question so that ‘the question of Being’, what it means to be, became the quest of philosophy (Gelven, 1989, p. 23).

Philosophical Assumptions about Being
The following discussion examines a range of fundamental Heideggerian assumptions about Being a Taiwanese mother engaged in caring for a child with CP, namely that:

1. Humans are self-interpreting beings;
2. Human beings are situated and constituted;
3. Human beings are engaged in the world;
4. Human beings are concerned; and
5. Humans are temporal beings (Kellett, 1997).

1. Humans are self-interpreting beings
In Being and Time, Heidegger (1927/1962) set out to explore the deepest nature of an individual’s thinking when she or he was thinking as an existing human being (Stumpf, 1994, p. 503). His philosophy, through hermeneutic analysis, aimed to render understanding of the meaning of Being. The focus was upon unveiling the deepest insights, the intersubjective closeness experienced by people embedded within the nature of engaged and practical activities and relationships. It is because people possessed the ability to reflect upon the process of their existence whilst
engaged in meaningful activity that they were capable of seeking to understand the non-conscious ways of ascribing meaningful significance to a situation for self (Benner & Wrubel, 1989, p. 43; Kellett, 1997).

For Heidegger, the object of such inquiry was Dasein, the human existent capable of inquiring into its own Being, inquiring into being-there. As Heidegger stated “the essence of Dasein lies in its existence”. Existenz referred to Dasein’s awareness that it is. Thus, the question of Being was possible only because Dasein was capable of reflecting upon its existence, because Dasein was “ontological”, that is, concerned with the nature of its own Being (Heidegger, 1927/1962, pp. 12-14, 32-34).

In summary and applying this thinking to this study, mothers possess the ability to be conscious of themselves, interpret situations by reflecting upon their experience, and ascribe meaning and significance to such experience. Mothers possess the capacity to be in a situation in a meaningful way (Benner & Wrubel, 1989, p. 43; Kellett, 1997). Confrontation with ascribed meanings reveals the reality of existence for such mothers and Dasein provides the route to disclosing Being, disclosing reality.

2. Human beings are situated and constituted

Heidegger thought that human existence was different from the general concept of humanity, so he uses the term “Dasein” to represent it. Dasein comprises two parts: “da” signifies “here or there” and “sein” represents “to be” so the whole term simply means “being there”. A person is seen as being there in the world (Gelven, 1989, p. 27; Stumpf, 1994, p. 505). Heidegger defined Dasein as the ability of a human to explore its own Being in terms of everyday existence within some place, activities and practices. Heidegger argued that as one was already in the world, one was a part of the world (Heidegger, 1927/1962, p. 54, 79; Kellett, 1997).

The word “world” rooted in the Latin, means “earth” which broadly implies that the environment surrounding and affecting people is not just simply “there”. As people live in the world so the world is a priori and Being-in-the-world, actively existing, simply signifies that people find themselves in the world. The world is also a significant aspect of Dasein (Dreyfus, 1994, p. 40; Gelven, 1989, p. 57) as it signifies the relationship between people and things or other people (Gelven, 1989, p. 60).
Heidegger (1927/1962) stated that “world may stand for the public we-world, or one’s own domestic environment” (p. 65, 93). Being-in means the people or things in the world which we relate to, care about, and concern ourselves with (Dreyfus, 1994, p. 59). Therefore, Heidegger rejected Descartes and Husserl’s claim that knowledge could be gained from separating people from their world of concern and context (Gelven, 1989, p. 60).

Heidegger advocated that human beings were situated in meaningful activities, relationships and involvements, namely “Being-situated” (Kellett, 1997). Applied to this study, understanding what it means to be a mother caring for a child with CP involves confrontation with meaning attributed to context-specific practical activities. The Heideggarian concept of “Being-in-the-world” emphasises the importance of such context-specific activity. Meaning dwells within the “average everydayness” of caring for a child with CP and is communicated in the habits of such care-giving experiences. Being-situated makes it possible for mothers to understand themselves as well as attribute meaning to their everyday care-giving experiences. Being-situated also captures how mothers’ everyday care-giving experiences are shaped by their “background” (Kellett, 1997).

Dasein is constructed within a culture, what Heidegger referred to as fore-structure shaped by language, history and family. In Heideggerian terms, this background has a complex structure which the researcher must discover (Dreyfus, 1994, p. 8). Heidegger argued that such interpretation based on fore-structure, which includes fore-having, fore-sight and fore-conception. For Heidegger, people already possessed “something” in advance, such as background, everyday involvement, past experience, and so on. The something a person already had initially helped them to understand the situation they were in and the meaning of it. This something becomes part of the person so it may not be shown at a conscious level, but is non-conscious (Gelven, 1989, pp. 95-97; Heidegger, 1927/1962, pp. 150-151, 191-192). Therefore, he rejected Husserl’s study which focused on consciousness. Also he denied the rationalists who argued that the mind of the person intends to the world outside the person. In Heideggerian terms, the person, shaped by their world, cannot be separated as subject
from object. Being itself cannot be understood only at the conscious level (Dreyfus, 1994, p. 33).

For Heidegger, language, history, and culture constituted the world as well as everyday activities and practices. He argued that a person quite often did not notice these because they were taken-for-granted. Being could be covered up so extensively that it became forgotten and no question arose about its meaning (Heidegger, 1927/1962, p. 35, 59). Husserl insisted on bracketing and intentionality that allowed things in the consciousness to be studied objectively and scientifically, the person placing their presuppositions, prejudices and prejudices aside in order to allow things to show themselves (G. J. Mitchell & Cody, 1993, p. 174). Heidegger criticised this notion, because culture, language, history, fore-structure and the world already existed (Dreyfus, 1994, p. 74; Kellett, 1997). He insisted that any interpretation was only valid when culture, background, history, what he called fore-structure and language were taken into account. Therefore for Heidegger, there was nothing to bracket (Barnacle, 2001, p. 11; Kellett, 1997). Applied to this study, mothers’ experiences have been shaped by their fore-structure, culture, language, history of their world. Their understanding and interpretation of their situation of everyday care-giving activities are derived from this background.

In summary, the world of Dasein is situated and constituted by language, history, culture, and what Heidegger called fore-structure. Being-situated in the habits of everyday mothering makes it possible for a mother to understand the self, grasping meaning from context. Being-situated also captures the essence of how mothers exist in their world influenced by their background shaped by time, history, language, culture and family. Being constituted governs how mothers approach care-giving experiences and how they view, interpret and ascribe meaning to their everyday care-giving for their children (Kellett, 1997).

3. Human beings are engaged in the world
To gain an understanding of a mother’s experience, it is necessary to comprehend how she is involved in everyday caring activities and relationships. Dasein showed itself not through experience or thought, but rather through involvement with objects (things) and people (Dreyfus, 1994, p. 61; Kellett, 1997). In Heideggerian terms,
interpretation would never be successful unless background was understood in terms of the totality of involvement (Heidegger, 1927/1962, p. 150, 191). Heidegger emphasised that being-in-the-world was a being-with, which enabled people to have a common world and understanding. Relationships with the world derived from how one used it. One was concerned with having to do things. Heidegger named the three interrelated modes as ready-to-hand, unready-to-hand and present-at-hand. He rejected Husserl’s statement that the person should be separated from their environment, namely, subjects and objects (Heidegger, 1927/1962, p. 83, 114; Kellett, 1997).

In Heideggerian terms, in the ready-to-hand mode everything is functioning smoothly. The person’s involvement goes unnoticed often being taken-for-granted and is primarily focused on people’s everyday lives. Reality is reduced to a list of common practices and communication skills (Heidegger, 1927/1962, p. 74, 103; Kellett, 1997). Heidegger claimed that Dasein showed itself without experiencing its activity as caused by a mental state (Dreyfus, 1994, p. 76; Heidegger, 1927/1962, p. 69, 98). He argued that people do not develop practice from theory rather from experience of the world, which contradicts Descartes and Husserl’s claim that perception begins with mental activity (Dreyfus, 1994, p. 46). Therefore, Heidegger rejected Husserl and Descartes who only focused on people’s mental content and things outside the mind (Dreyfus, 1994, p. 63).

For Heidegger, when some form of breakdown occurred, people reverted to the unready-to-hand mode. New aspects of a practical activity were noticed, because this new situation needed a more precise kind of awareness in order to pay more attention to it. Therefore, the intentional consciousness was more involved, present and functioning (Dreyfus, 1994, p. 70; Heidegger, 1927/1962, p. 74, 103). Even in this mode, understanding and deliberating people’s actions or phenomena should always take the background of their world into account. Understanding could not be simplified as a mental content. Purely mental meant without consideration of the world, so it could not represent the human experience and real life (Dreyfus, 1994, p. 75). From this point of view, Heidegger objected to Husserl’s phenomenological reduction and bracketing, because it failed to think of the world (Dreyfus, 1994, p. 73). Related to this study, in this mode, mothers begin to become aware that their children
are showing evidence of developmental delay. They seek an explanation when their children are diagnosed as having CP, it is a new event for them, which involves an unready-to-hand mode of engagement.

In the third mode, present-at-hand, practical activity ceases as the mother of a child with CP, for instance, takes time to observe or reflect on their situation. Rationalists and empiricists believed that this was when skilled activity, theoretical reflection, observation and experimentation were best conducted in order to know that person (Benner, 1994, p. 73). However, Heidegger argued that detachment from the phenomena or disinterest could not help the phenomena to be clearly detected. He argued that if a person keeps distant from the phenomena then the nature of phenomena will only be focused on the limits of that person’s consciousness, not the whole nature of the phenomena (Dreyfus, 1994, p. 45; Kellett, 1997). He believed that only seeing the world or understanding the phenomenon from this mode was wrong (Gelven, 1989, p. 62). Therefore, for Heidegger this was only one aspect, the ready-to-hand mode could not be understood and discovered only through present-at-hand involvement. The present-at-hand mode was limited as it failed to take the world into account in discovering the person’s everyday life (Heidegger, 1927/1962, pp. 65, 93). In Heideggerian terms, research based on this mode would be limiting and fail to understand the total experience of the mothers’ world (Gelven, 1989, pp. 62-63).

In summary, a mother’s reality is constituted in involvement with others in the world. It is in the dynamics of everyday care-giving experience, how involvement in such care-giving is interpreted, that serves to articulate how mothers understand, interpret and ascribe meaning to everyday activities and relationships (Kellett, 1997). Such dynamics are not static factors that determine care-giving functioning. Importantly, it is the dynamics of the human experience of care-giving that reflects the underlying reality of everyday care-giving for mothers with children with CP.

4. Human beings are concerned
Another aspect of what it means to be a person is what Heidegger deemed “concern.” Because people and things matter to humans, they become involved in the world in their own particular way. Heidegger defined this way of being as concern. Concern
could be seen in the everydayness of Being-in-the-world. In addition, to provide oneself with something was another important meaning for concern (Heidegger, 1927/1962, p. 57, 83; Kellett, 1997). He argued that “…our everyday Being-in-the-world, which we also call our dealing in the world and with entities within-the-world, such dealings have already dispersed themselves into manifold ways of concern” (Heidegger, 1927/1962, p. 67, 95). Thus he argued that human beings relate to their world as “care” (Gelven, 1989, p. 66). Care for Heidegger may be indicated by worry, concern, love, or caring, and it is associated with Being-in (Dreyfus, 1994, p. 238). However, concern allows both the content and intents of a person to be described. Heidegger clarified the meaning of the preposition “in” as concern that described a particularly human way of being in the world (Benner & Wrubel, 1989, p. 48; Dreyfus, 1994, p. 238). Background allowed human understanding of the context. Furthermore, motivation was a way of understanding that people could reveal what personal concern related to. Heidegger (1927/1962) argued that human’s empathy relied on the basis of Being-with which made empathy possible (p. 125, 162). This thinking rejected the viewpoint of Descartes who regarded the human as an isolated subject, independent of context and personal feelings of concern (Benner & Wrubel, 1989, p. 88; Gelven, 1989, p. 126). Heidegger also dismissed Husserl who focused on pure consciousness as the way to study humans, as concerns are not always expressed in consciousness or exhibited in actions (Chesla, 1995; Kellett, 1997). Descartes and Husserl claimed that mental activities were essential for human action and perception. Heidegger held the view that in order to completely describe and understand the phenomena one should understand a person’s concern about their surrounding environment. He also insisted that human beings were embodied intelligent beings, because they were always concerned about and involved in their everyday practical world. Therefore, intentionality and consciousness should not be the only necessary roles in human activities (Dreyfus, 1994, p. 47).

In hermeneutic phenomenology, concern is one of the ways people understand a situation’s implications for themselves. During their lifetime, real world contents will change, and they will be placed in situations in which the old self-understandings are no longer completely relevant (Benner & Wrubel, 1989, p. 49; Kellett, 1997). Applied to this study, when a mother is advised that her child has CP she is concerned not only
about herself but how it will affect other family members as well. It is the change from ready-to-hand to unready-to-hand that gives mothers’ the space to reflect on practices that will no longer allow for smooth functioning. Concerns can be interpreted and described but not measured. Applying Heideggerian philosophy, rather than asking “how much?” one should ask “in what way is this person involved?” The challenge lies in interpreting those concerns that influence a person’s shared meaning in order to help, in this case, the mother to manage her new care-giving situation (Benner & Wrubel, 1989, p. 88; Kellett, 1997).

In summary, it is important to understand what mothers’ concerns are when caring for their children with CP, as well as how it affects their understanding and gives meaning to their lives. Heidegger viewed concern as a way of being involved in one’s own world, a ‘window’ to revealing what motivates, what is attributed worth and what determines how people approach everyday engaged involvement. Therefore, understanding concern is essential in providing access to the ways in which existence is meaningful. Concern exposes meaning.

5. Humans are temporal beings

Time, for Heidegger, played a central role in human existence. He shifted the traditional concept of time as a linear succession of “nows” to being-in-time. A human being with Dasein, “to be”, was always “to be temporal” (Heidegger, 1927/1962, pp. 18-19, 39-40; Kellett, 1997). Time for Dasein was finite and temporal. As temporality is the foundation of understanding one’s existence, it is limited. Therefore for time to be a meaningful concept, it must be established from one’s finite existence. Without consideration of time, the existence of Dasein loses its meaning, thereby making it nonsense (Steiner, 1978, pp. 98-99). “Time, presented as phenomenon, is history” (Gelven, 1989, p. 178).

In Descartes’ world human beings were not constituted by time, and attributes could be studied without considering their meaning in relation to each other (Benner, 1994, p. 54). Husserl only focused on present time in his theory of pure consciousness (Carman, 2003, p. 61; Gelven, 1989, p. 181). However, Heidegger proposed that a person existed in the world, in the present, but was influenced by the past and was “thrown” or projected towards the future. He believed that understanding of being
was only possible when considered in terms of time (Heidegger, 1927/1962, pp. 327-328, 374-376; Kellett, 1997). In Heideggerian terms, the past only had meaning in relation to what happened now or will happen tomorrow. The present is only significant when it is conceived as actually carrying out an action (Carman, 2003, p. 61; Steiner, 1978, pp. 98-106), the present is derived from the future (Heidegger, 1927/1962, p. 360, 411).

In other words, any meaningful event connects the future and the past to the now. Applied to this study, mothers of children who have been diagnosed with CP have to face the 'present moment' situation in which they 'lose' their perfect child. Moreover, in order to access quality care they must project themselves into the future. The past, present and future become linked as the mother grapples to make sense of her new situation (Kellett, 1997). Being-in-time provides her with the opportunity not only to analyse this stressful change but also to derive new coping strategies, drawing from her past, to deal with the present day and anticipate how the future will unfold.

In summary, in the Cartesian world, human beings were not constituted by time and attributes could be studied without considering their order or meaning in relation to each other (Benner, 1994, p. 54; Kellett, 1997). However, Heidegger proposed that understanding of being was only possible when considered within its past, present and future (Dreyfus, 1994, p. 244). Thus in Heideggerian terms, to understand the meaning of mothers’ care-giving it is necessary to consider time, namely, past, present, and future.

**Hermeneutics**

In this study, while Heidegger provided direction for revealing meaning in everyday care-giving experiences, Hans-Georg Gadamer (1900-2002) provided guidance in understanding such meaning derived from interpretation of the stories shared by participating mothers. The contribution of Gadamer’s philosophy will be reviewed in the context of the history of hermeneutics.
**History of Hermeneutics**

As a term, hermeneutics dates from the 17th Century but its theories and practice may be traced back to antiquity. The term is derived from the Greek word, “hermeneuein”, meaning to interpret. However many believe it owes its origins to the Greek god, Hermes, whose mission was not only to transmit the other god’s words to humans but also to translate for humans their meaning and intention (Polkinghorne, 1983, p. 218; Todres & Wheeler, 2001). Dilthey believed modern hermeneutics developed during the period after the Renaissance. Divorced from Catholic traditions, Protestants had no authority to decide questions of biblical interpretation (Palmer, 1969, p. 35). This was an important impetus for the development of some way to interpret and understand text. At the same time the rediscovery of and scholarly interest in classical texts created a need to render accurate understanding. A general theory of interpretation arose which could be applied to any text, sacred or secular (Palmer, 1969, p. 219).

**Frederick Schleiermacher (1768-1834)** believed hermeneutics was a way to systemically devise coherent rules which could be applied to all kinds of dialogue. Therefore, no longer was hermeneutics represented as a philological hermeneutic but rather as a “general hermeneutics”, a form that could be used to guide interpretation of texts, not just those in theology, but also in literature, or law. As a result, hermeneutics could be defined as the study of understanding itself (Palmer, 1969, p. 40; Sharkey, 2001, p. 20).

**Wilhem Dilthey (1833-1911)** thought the vital condition for understanding must take historical understanding into account (Palmer, 1969, p. 41). Temporality was deemed a necessary element for understanding as well as an intrinsic part of historical knowledge (Palmer, 1969, p. 117; Sharkey, 2001, p. 20). But Dilthey thought objectivity was the major principle to establish the aim of science. Methodical procedure was the way to ensure science achieved objectivity where everybody’s experience could be the same, as well as repeated by anyone (Gadamer, 1960/1975, pp. 310-311).

Heidegger and Gadamer rejected the meaning of hermeneutics as proposed by both Dilthey and Schleiermacher, they believed that truth could not be explored by method,
but should arise from the light of engagement with one’s world. Heidegger named this the hermeneutic of Dasein (Gadamer, 1960/1975, pp. 146-148; Palmer, 1969, p. 42).

A student of Heidegger, Gadamer borrowed from him his proposition that Being-in-the-world was a hermeneutical situation (G. J. Mitchell & Cody, 1993). For Gadamer, hermeneutics was a philosophy that explored the relationship between language and being, understanding, history, existence, and reality (Palmer, 1969, p. 42). Like Heidegger, he considered that all understanding and interpretation were derived from a history and language. Nothing we could understand could lie outside the historical. Therefore, he rejected the concept that human beings can be understood and pure truth be obtained by method (Sharkey, 2001, p. 21).

**Being and understanding**

The question of Being is related to understanding. The key point for grasping the meaning of being is understanding Being itself (Carman, 2003, pp. 14-16). Heidegger stated that “being is only in the understanding of the entity to whose being something like an understanding of being belongs. Being can therefore remain unconceptualised, but it is never not understood at all. … there is a necessary connection between being and understanding” (Carman, 2003, p. 17). In essence therefore, Heidegger emphasised understanding in a more practical way in which the person could manage a thing that was called “understanding of something”, so he rejected the concept that understanding had something to do with traditional ways of cognitive reasoning (Carman, 2003, p. 19). To analyse Being allowed everyday practices to be understood. Heidegger believed that hermeneutics was the process that made everyday lives understood by people. He recommended the use of hermeneutics to understand everyday practices and discourses (Dreyfus, 1994, pp. 38-39).

**To understand the text of language**

Gadamer believed that understanding and interpretation had the same meaning. He argued the interpreter could get close to the phenomena by understanding nature as historical (Gadamer, 1960/1975, pp. 274-275). In order to understand text the interpreter needed to bring his or her own culture, history and prejudice to the text. The interpreter’s horizon and text come together to complete the fusion of horizons in order to understand the text (Gadamer, 1960/1975, pp. 333-341; Sharkey, 2001, p. 28). Thus
Gadamer asserted that the process of understanding not only relied on the historicity of the text, but also the interpreter (Sharkey, 2001, p. 28).

Gadamer believed that experience should not only be an understanding of history but also culture (Gadamer, 1960/1975, pp. 10-11). Culture and history provided an easier way to understand human beings than science methodology (Gadamer, 1960/1975, p. 18). He argued that as the process of understanding was a historically-effected event so effective history meant history should be understood within itself and be able to show its effect. He believed that both the interpreter’s and one’s understanding belonged to effective history (Herda, 1999, pp. 62-64). He stated that “effective history means the relation of past and present in which the past constitutively determines the present through an interplay by bringing its tradition to bear upon it” (Gander, 2004, p. 125). He argued that our understanding and interpretation are always influenced by the effects of effective history, and it is always made aware by our consciousness so it can be called effective-historical consciousness (Gadamer, 1960/1975, pp. 305-306; Gander, 2004).

For Gadamer, culture and history were kinds of prejudices. Prejudices could help the interpreter move through their own historical circumstances in order to understand the meaning of the text in its own historicity, so the two historicities can be combined. There was no understanding without prejudice (Mueller-Vollmer, 1986, pp. 256-263). This he called the fusion of the horizons of understanding which mediated between the text and the interpreter (Gadamer, 1960/1975, p. 340). Gadamer advocated this concept of a “fusion of horizons” which signified that readers or interpreters with prejudgments, such as beliefs, values, and practices interpret from their understanding. Furthermore, the horizon between the past and present of the interpreter became a single new horizon of being (Gadamer, 1960/1975, pp. 257-258; Reeder, 1988, p. 219). Consequently, fusion between these two horizons was necessary and added accuracy to the interpretation of the text. That was why Gadamer rejected the objective knowledge concept of human science methodology (Gander, 2004, p. 130; Hekman, 1983). Therefore, in Gadamerian terms, the meaning of a text will vary because different interpreters possess their own history and language.
Human beings are linguistic beings so Gadamer argued that without language Being could not be understood (Herda, 1999, p. 47). He believed, the process of understanding and interpreting language was a circle that signified the connection between the whole and parts of text and history. The whole was understood from its parts and the parts form the whole as well as the relation between whole and parts. This circle he named the “hermeneutic circle” (Gadamer, 1960/1975, p. 261; Herda, 1999, p. 49; Reeder, 1988, p. 209).

The hermeneutic circle
Gadamer argued that the fusion of the horizons occurs when we want to achieve understanding of language (Gadamer, 1960/1975, p. 340). Gadamer believed “understanding the ‘things themselves’ is achieved through a fusion of horizons between things themselves and the interpreter’s prejudices and history. The hermeneutic circle was deemed a necessary and basic demand for all interpretation” (Carman, 2003, p. 59).

Such a process of interpretation signifies “the whole is understood from its parts and the parts form the whole and means that interpretation is at the base of a referential procedure” (Reeder, 1988, p. 209). Initially the text will be viewed as a whole. Gradually the meaning of parts of the text will become clearer forcing a revision of the whole text (Gadamer, 1960/1975, p. 236). Moving forward and backward between the whole story interpretation and the detailed part interpretation discloses the meaning of the text. The detailed part can modify the whole story interpretation, which can provide a significant context to the part. The aim of circle between whole and part enhances the ever deepening and rich understanding of the text (Dreyfus, 1994, p. 36; Gadamer, 1960/1975, pp. 258-259).

Methodology
By acknowledging the importance of developing a deeper insight into the meaning mothers’ ascribe to everyday caring for their child with CP, ontological-hermeneutics provides a philosophical orientation for disclosing and interpreting what it means to be a mother caring for a child with CP in a Taiwanese context. The following outline provides an overview of the guiding methodology shaping and informing the process of this study.
First, mothers as **self-interpreting** and self defining beings based on their understanding of their experiences in the world of raising their child with CP. They reflect on their experiences to gain an interpretation of their existence, making it meaningful and intelligible.

Second, mothers **constituted** by their culture, history and social context are **situated** in their everyday activities and practices. Being situated and constituted shapes how mothers make sense of their everyday existence.

Third, the nature of Being a mother of a child with CP can be understood by revealing how mothers are **involved** and engaged in their everyday practical care-giving activities and relationships.

Fourth, **concern** is one of the ways in which mothers understand their situation and the implications for themselves. Concern describes a particular mode of Being in the world, which reveals itself as care. The why of care-giving is understood in terms of matters and what motivates. Ultimately meaning is disclosed as understanding emerges through an interpretation of the experience of Being concerned.

Finally, as **temporal beings** mothers exist in the world capable of learning how to seize future possibilities of ascribing meaning to their involvement in present day caring practices, which is shaped and influenced by the past and one’s background.

**Conclusion**

In this study, Heidegger’s philosophy provides me with guidance to explore the meaning of experience attributed to everyday practical care-giving for a mother with a child with CP in Taiwan. Gadamer guides me to understand and interpret the meaning of stories mothers shared, through the fusion horizons. In the next chapter I will present the detail of the method and techniques employed in undertaking this study aimed at facilitating the process of gaining insight into the phenomenon of maternal care-giving.
Chapter 4

Method

Introduction
Heidegger argued that Being-in-the-world enabled human beings to interact and deal with the things and people around them. In this way humans are able to care about and concern themselves with things and people. People could not be considered in an isolated world or detached from their environment with others (Crotty, 1996, p. 84). Heidegger argued that truth is not something that we construct by using methods, because method could not provide full data to understand natural phenomena and human beings. Therefore, no rigid procedure and method can achieve hermeneutical understanding (Gadamer, 1960/1975, pp. 5-6). Gaining an insight into the nature of care-giving for a mother of a child with CP involves a process that would facilitate direct contact with the experience as it is lived. Such a process would have to be flexible and creative to facilitate interpretation (Dreyfus, 1994, pp. 18-19). This chapter will review and justify the recruitment processes, data collection and analytical techniques applied in this study.

Phenomenological Assumptions
The meaning of being a mother is posed daily and reflected in the nature and adequacy of caring behaviour. It is in this lived domain that the question of meaning ascribed to caring presents itself. Thus to understand the mother’s caring requires that people’s meanings remain contextually based and the research method chosen reflects the intent to explicate the Being of caring as a mother of a disabled child. Therefore the phenomenological method chosen in this study is one that guides the disclosure of the nature of Being immersed within the mothers’ everyday experiences of Being-in-the-world.

van Manen (1990, p. 131) has described the phenomenological method as a 'carefully cultivated thoughtfulness'. He states:
Phenomenology has been called a method without techniques. The 'procedures' of this methodology have been recognised as a project of various kinds of questioning, oriented to allow a rigorous interrogation of the phenomenon as identified at first and then cast in the reformulation of a question. The methodology of phenomenology requires a dialectical going back and forth among these various levels of questioning (van Manen, 1990, p. 131).

Insight into the nature of Being a carer “involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience” (van Manen, 1990, p. 77). Such a process is aimed to effect a more direct contact with the experience as lived. For van Manen such a process involves the interpreter in artistic activity. Thus the scope for flexibility and creativity in ways of interpretation is vital. Any rigid procedural method imposing objective rules on the art of interpretation would be inappropriate (Gadamer, 1960/1975, pp. 146-148).

van Manen thus discusses the dynamic interplay between the following research activities as a guide for interpretation. Each activity is described as:

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 conceptualise it;
3. Reflecting on the essential themes which characterise the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented (nursing) relation to the phenomenon; and

**Turning and Orienting to the Phenomenon**

To a mother caring for a disabled child the question of meaning of being is posed daily. Everyday events and situations give reason for reflection upon the nature and the adequacy of caring behaviour. Phenomenology is a philosophy which provides a means through which concern for the personal and situated may be incorporated into the research process.
The question that is at the heart of the professional and personal life of a nurse concerns meaning in caring. Interest in the topic of caring stems from a belief that human beings have a need to care and a need to be cared for. As human beings carers are capable of describing the nature and significance of such experience. Such description is characterised by personal knowledge and the meanings they ascribe to everyday caring experiences.

Nurses are responsible to practise with a full understanding of what it is like to be in this world as a mother caring for a disabled child. Only when such an understanding of what is worthwhile and significant to these carers is gained will nurses be in a position to assist in shaping their lives in ways which they ascribe meaning. Such learning announces itself in their everyday interactions and involvement in caring within the nursing home.

This study therefore aims to translate the primordial relation of care-giving as a mother of a disabled child into clearly defined concepts, to bring the Being of caring into our presence (van Manen, 1990, p. 50).

**The Phenomenological Question**

As Heidegger (1927/1962, p. 2) states we have forgotten a certain kind of understanding: what it means to be. Recalling what seems to have been forgotten involves the reflective process of questioning what it means to exist as a mother caring for a disabled child carer. Therefore this study is concerned with posing the question:

*What is the meaning of Being a mother engaged in caring for a child with CP?*

By asking such a question nurses are assisted to gain insight into how full understanding of the lifeworld of these mothers can inform and challenge their practice.
Entering the Field

In my initial proposal, I had intended to collect data from a public Medical Centre Hospital in North Taiwan and a second in Middle Taiwan, but in the event I collected data from the hospital in Middle Taiwan alone, because practically it was too far to travel between Middle Taiwan and North Taiwan and adhere to candidature requirements. In addition, I found that the outpatient schedule for disabled children at the hospital in Middle Taiwan was not only on a Tuesday afternoon, but also on Monday and Thursday afternoons, which offered me ample opportunity to contact a number of prospective participants in the one location. Thus I decided to collect data from a single venue.

The Participating Mothers

Fifteen voluntary participants were recruited from the public Medical Centre located in the metropolitan area of Middle Taiwan, a 1,515 beds hospital facility for in-patients. It is the only public medical centre hospital in central Taiwan. The average number of services for out-patients from 2004 to 2006 is 1,416,774 (Taichung Veterans General Hospital, n. d.). The hospital is located on the boundary between an urban and a rural area, so patients come from both the city and the country.

In seeking to understand the nature of the experience of caring for a child with CP, a purposeful sample was adopted to recruit participants who met a number of criteria (Fossey, Harvey, McDermott, & Davidson, 2002; D. Li, 2004; Shenton, 2004). As mothers have been shown to be the primary caregivers for children with CP, this study purposefully sought out mothers who have experience of the phenomenon under investigation. The inclusion criteria included:

1. Taiwanese mothers who were primary caregivers for children between the ages of 0-18 years with a CP diagnosis1;
2. Mothers who use Mandarin or Taiwanese as their primary language;

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1 The age of paediatric definition may vary in range from birth to 21 years, or from birth to 18 years (Hohenhaus & Frush, 2005). Generally, the most popular definition is either developmental stage or biological growth and development, age of children ranging between 0-18 years old, namely, from birth to adolescence (Serroka, 2003, pp. 3-15).
3. Mothers who was willing to share their care-giving experiences with the interviewer.

The exclusion criterion included that mothers of children with CP caused post delivery, for example, through an acute accident such as a car accident, or near drowning were excluded.

In my original proposal I had estimated that the number of participants would range from fifteen to twenty, and that in-depth conversational interviews would form the primary methods for collecting data. After interviewing fifteen participants I stopped recruiting participants because the interview data had reached saturation, that is, I began to recognise repetition of information after interviewing the fifth participant. No more new information, topics or themes were emerging from further participant interviews (Fossey et al., 2002).

Interviews are the most commonly used method for data gathering in phenomenological research. They allow participants to reflect on their care-giving experiences, recall, reveal and construct aspects of day-to-day caring for a disabled child. The aim of this study was to examine the understanding of the everyday care-giving experience of Taiwanese mothers. In-depth interviews are like conversations with friends, they are informal in style and engaging emotionally (Minichiello, Aroni, Timewell, & Alexander, 1995, pp. 101-102; Wengraf, 2001, p. 6). They provide an opportunity for the researcher to hear participants talk about their practical everyday experience, and through being encouraged to reflect on such experience, share their stories of care-giving. This method provided spontaneous opportunities for the researcher to 'see' below the surface of the stories shared and explore the expressive language. Therefore, the interview method was appropriated for the research.

**Recruitment Processes**

The study was brought to the attention of mothers with disabled children with CP in the following ways:
1. A poster (see Appendix A) was posted on the notice boards one month before the start of data collection in the Paediatric Rehabilitation Department inviting people who were interested to contact the researcher.

2. An advertisement (see Appendix A) was placed in the Taiwanese CP magazine. This magazine is published every three months (February, April, July, and October).

3. I spent time at the doctors’ rooms within clinic times in the rehabilitation department on Monday, Tuesday, and Thursday afternoons. When mothers and children with a diagnosis of CP had finished their consult, I introduced myself and then invited them to a nearby private room to provide them with information about the study and their possible participation.

**Initial Contact**

**Personal approach**

Because of the different techniques employed to disseminate information about the study, initial contact with the participating mothers varied. Two participants contacted me by phone to advise of their willingness to participate in the study after seeing the poster in the rehabilitation setting. Eight participants were recruited from the outpatients department and another five participants were recruited from the rehabilitation setting.

This latter group became interested in the study when I was visiting the rehabilitation setting following an interview with one of the participating mothers. An unplanned and invited opportunity arose to join her with her son at his rehabilitation session to observe the setting and the interaction between the mother, her son and the therapist. As the rehabilitation setting was a single room all children and their parents were located in the same space. Whilst visiting, other mothers felt curious and came to talk. They had seen the poster on the noticeboard but had not responded. After spending a short time talking about the study additional mothers came forward to join the research. Five mothers were recruited using this method.

The remaining eight participants initial contact took place following their medical appointments in the outpatients clinic. Introductions were purposefully arranged to
occur following their appointments rather than before. This strategy enabled me to invite each mother to a nearby private room in order to have a quiet place to allow the prospective participants ample time to be informed about the study and potential involvement, but not be afraid of missing their number being called to see the doctor. The aim was to ensure a private location free from interruption for discussing the study.

**Initial Meeting**

For those participants who contacted me by phone after seeing the poster, I introduced myself first and chatted on the phone for a short time. Then, I asked whether we could meet so I could give them more detailed information. I met them in the hospital’s café near the lobby, a mutually convenient location. To explain detailed information about the study process with information sheet (see Appendix B) to participants face to face was important as it provided an opportunity to begin developing a rapport and mutual relationship during this initial contact (Powell & Amsbary, 2006, pp. 4-5).

To assist in the gaining of the mothers’ trust and the building of a good rapport at the initial contact, I introduced myself as a Registered Nurse and a university teacher with professional experience caring for children with cerebral palsy and their families. I explained the aim of the study and its purpose in gaining insight into mothers experience through an understanding of their everyday lived experienced in order to reveal the nature and significance of their maternal care-giving for their children with CP. I shared my thoughts that such insight would aid nurses and allied professionals, who were involved in their daily caring life, to appreciate the meaning they attributed to daily lives as caregivers so that care supports and services for their children could be improved.

Details of the research process were shared in terms of participant involvement. I explained that in-depth tape recorded conversations would be held over two interviews which may last from one to two hours. I explained the second interview was necessary in order to probe and clarify key aspects of their care-giving experiences and validate my developing interpretation.
Informed consent procedures were explained and reassurance was given that all information shared would be treated with the strictest confidence. Their real names would be replaced by pseudonyms to guarantee anonymity and no information was reported back to the hospitals at which their children received treatment (see ethical considerations). Time for discussion and answering questions relevant to the research process were made available. After gaining their agreement and the signing of the Informed Consent form (see Appendix C) and participant personal information sheet (see Appendix D), the first interview time and place was negotiated at a mutually convenient time and place. I told them that I would give them a call the day before the interview as a reminder. Participants were informed that they may contact me at anytime if they had further questions.

**First Interview**

Six mothers expressed that they were willing to be interviewed at the hospital whilst their children were receiving rehabilitation therapy. I also explained the interview conditions to the therapists and interns to show my respect and to gain their agreement to take care of the child whilst the interview was in process. Typically rehabilitation sessions took place in small segments over a two hour period leaving this time available for each interview.

A pre-arranged room was available in which each interview took place. This room was next to rehabilitation therapy setting. The therapists and interns were aware of the interview room location.

Another six mothers were interviewed at their homes where family members could care for their children. The remaining three mothers were interviewed at a café which had a quiet area. These mothers were those that were able to leave their children with family at home enabling them to talk freely without their child being present.

**Questioning Process**

Before the interview commenced participants were informed that they could stop the interview and the tape-recorder at any time. In this study, it was important to keep an open mind when listening to the participants’ stories and to be flexible in questioning
and probing to clarify and gain more detailed information (Thompson, 2002, pp. 138-147). Sufficient depth of information is a way to accomplish thick description that provides an opportunity to fully explore and accurately capture the essential meaning of the phenomena of Being a Taiwanese mother of a child with CP. Asking for more information gives privilege to the participant’s voice and knowledge and results in in-depth stories being shared (Chesla, 1995; Fossey et al., 2002).

Throughout each interview, I kept the study aims in mind. I accomplished this by commencing each first interview with a broad open-ended question that invited each mother to recall and share her story in a chronological fashion: “Can you tell me about your experience of caring for your child from the time of your pregnancy to the present day?”

The purpose for asking such an opening question was threefold. First, sharing such familiar information with its own chronology would assist the mothers to talk and feel comfortable with sharing their experiences. The use of such a strategy also aimed to relax those participants who felt a little intimidated by the tape recorder. Importantly, from a Heideggerian perspective, the meaning of Being and the modes and characteristics of Being are able to be visible when taking time into consideration (Heidegger, 1927/1962, p. 40). Second, such background information would later assist in better interpreting the meaning each mother ascribed to her caring today. Third, such questioning would allow the researcher to learn not only what was pertinent to the participant about those topics discussed, but also about the identity of that mother and how she constructed the self in relation to her lived experience of caring.

The interview explored the chronological events of each mother’s experience of pregnancy and birth of the child to the present day. In process, who, when, why, what, and how questions were posed to probe for background details, as well as questions that invited each mother to share her feelings, thoughts and experiences in revealing and constructing her history and stories of family, mothering and care-giving (Minichiello et al., 1995, pp. 101-102; Wengraf, 2001, p. 6).
**Interview Guide**

In order to assist each mother to recall and construct stories of their everyday experiences, prompts were used. To support this process a conversation guide was prepared. Prompts related to aspects of the experience were used to assist each mother to describe her:

1. Experience of pregnancy and birth of child with CP;
2. Experience from pre-diagnosis to diagnosis;
3. Feelings and thoughts when the child was diagnosed until the present day;
4. Experience with hospital and other health care services; and
5. Experience of everyday care-giving and family support.

The guide was literally that. The exact wording of questions and prompts, the order in which they were asked, and the probes for further detailed information were unique to each conversation and dependent upon the researcher’s relationship with the mother and the nature of participant responses during the conversation (Minichiello et al., 1995, pp. 88-92).

Most of the mothers enthusiastically shared their history divulging traditions and values. Little prompting was required on the researcher’s part throughout the initial conversation. The mothers naturally began talking about their experiences of pregnancy, birth and parenting without any prompting. They shared experiences of the onset of difficulties, how these were dealt with, the changes in their lifeworld and how events progressed.

It was at this point in the conversation that occasional prompts became particularly useful as present day experiences did not possess a chronological structure to guide the mothers in sharing their everyday experiences of caring.

All participating mothers were pleased to share their stories. Some mothers spent a small amount of time talking about their experiences of pregnancy or the labour process as everything was progressing normally, but they spent more time sharing their experience of how they had discovered their children’s problems and how they felt
about their experiences of daily care-giving. Other mothers shared more information about their experiences of pregnancy or labour because of the complications involved. All the mothers naturally mentioned the family relationship and the family dynamic after giving birth to the child with CP.

Most of the interviews lasted between one and two hours. Two mothers’ interviews lasted longer than two hours. One mother’s interview lasted for three hours from 6:30 to about 9:30 pm in the café. The mother felt comfortable to spend time to talk to me when her family members were willing to take care of her child at home. Another exceptional interview lasted three hours from 6 to 9 pm on the first day of interview, but the mothers felt that she had not finished her story, so the next day a second interview took place so she could continue her story.

**Follow-up Interview**

All fifteen participating mothers were interviewed twice. Before the second interview, I finished the verbatim transcription and re-read each transcription during which preliminary analysis commenced highlighting key aspects of the mothers’ daily care-giving experiences. Each follow-up interview provided an opportunity to return to the mothers to share and validate my developing interpretation of their experiences and probe specific areas that had been highlighted as significant during the first interview.

The preparation between interviews accomplished two goals. First, it disciplined the researcher to think about the data in relation to the research prompts allowing for a dynamic and unfolding process which evolved conceptually. Second, it showed the mothers that the researcher was seriously considering the experiences they had shared thus assisting rapport and trust building which resulted in the on-going collection of rich and useful data (Chesla, 1995; Fossey et al., 2002). All second interviews were tape-recorded and transcribed verbatim. Similar to the first interview, the length of the second interviews lasted from one to two hours.

The opening style of questioning in the second interview commenced with the broad question: “I have listened and read through the various aspects of your experience
since we last met and I would like to enquire more about some of the experiences you shared.” The subsequent probing questions were more specific and were developed from an appreciation of key aspects shared during the first interview. In order to assist the collection of reliable and rich data a range of questioning techniques were employed, for example, “could you tell me again when that happened?”, “could you tell me about that experience in more detail?”, “I have found some key aspects from the first interview. Do you agree with these aspects?” (H. J. Rubin & Rubin, 2005, pp. 173-181)

Journal Notes as Text
Journal notes were recorded immediately after each interview rather than during the interview process in order to prevent the mother from experiencing any distractions during the face-to-face interview. The journal notes consisted of contextual documentation, methodology documentation, analytic documentation, and personal response documentation (Rodgers & Cowles, 1993). Keeping such notes served as an audit trail (Koch, 1998; Rodgers & Cowles, 1993) which assisted in decision making and determining procedures related to the research process. It served as a traceable record articulating each step of research process (Lincoln & Guba, 1985, pp. 318-319).

Contextual documentation techniques were utilized to collect any detailed descriptive information during the interview process, such as a description of the person, their dress, appearance, mood, style of talking and acting, gesture, attitude, posture, vocal tone and pitch, facial expression, expression in her eyes, a description of the participant’s house or interview place, and so on. This information assisted in rebuilding and describing the scene in order to make data collection more comprehensive and ensure deeper data analysis. Methodology documentation techniques were adopted to record how potential participants were contacted, how rapport was developed and relationships maintained, and the research techniques employed were undertaken. This assisted in analysing the data and building the audit trail. Analytic documentation recorded detailed information about how the research data was categorized. Finally, personal response documentation was used to record thoughts and feelings, and reflect on the research process each day.
A combination of transcriptions and journal notes provided more complete and substantial information to aid me in organizing and sorting the research information and facilitated the development of an in-depth understanding and interpretation of the mothers’ care-giving experiences.

**Data Transcription**

The official data collection period lasted from December 2005 to June 2006. A transcriber assisted with producing a text document for each taped interview. I subsequently engaged in extensive editing of each transcript whilst listening to the tape recording. This technique was employed to ensure that each transcription was as close as possible to the mother’s narrative as shared. This process involved both verbatim transcriptions and journal notes and facilitated the beginning of experiencing the closeness to the data as I immersed myself in the mother’s care-giving stories.

**Data Translation**

In this study, all interviews were conducted in Chinese, but the study process and findings are presented in both Chinese and English for pedagogical validation purposes. Chinese is the researcher’s and participants’ first language, English is the researcher’s second language. The challenges of translation theory have been noted by Twinn (1997), who adopted an in-depth interview to understand six women’s perceptions of screening for cervical cancer in Cantonese in Hong Kong. All the transcriptions were translated into English in order to examine the influence of translation on qualitative research. The results demonstrated there were no significant differences in the major categories, but differences were found in sub-themes under major categories emerging from the data by virtue of the fact that it is difficult to exactly interpret some concepts because of the differences in English expression, meaning and grammatical style.

There were several translation challenges that should be discussed further to clarify why I adopted particular research techniques. The first challenge of translation concerns a lack of equivalent words in the original language equal to the target language (Carlson, 2000; S. Twinn, 1998). Twinn (1998) indicated that it was difficult
finding the same expression in English to accurately reflect the meaning in Chinese, especially in the art of conveying the participants’ feelings and experiences. In addition, Carlson (2000) argued that a literal word-by-word translation could make the sentence lose its structure and not be comprehensible in the target language. In this study, the target language was English. McGorry (2000) has suggested that the main purpose of translation should be to convey similar meanings to achieve the same connotative meaning between both source and target language.

Methodologically Twinn (1998) stated that taking this issue into account was important during translation, especially in the case of phenomenological research as the aim is to understand the essence of the phenomenon from the participants’ perspective, so the translation should be treated seriously in order to demonstrate validity of research process. She advocated that the key objective is to reflect or ‘catch’ the meaning of the story and maintain its essence. Twinn (1998) believed that this strategy is realistically achievable. Thus this study focuses not upon the literal translation but upon meaning itself.

Similarly, Neubert (2003) noted that the essence of content should remain the same after translation. To express full meanings of the source language was the highest anticipation for the translation. However, translators should try to convey full meaning as much as possible since it was inevitable that the end point will be an approximation. Neubert (2003) also suggested the importance of communicative translations that aim to keep translation as ‘normal’ communication for the target readers, so keeping it as simple as possible. This strategy was employed in this study.

The second translation challenge relates to grammatical differences. Yu, Lee, and Woo (2003) experienced the same challenges as Twinn (1997). Specifically, it is the subjective preposition and the relative pronoun that are different in Chinese and English languages, especially because there is no complex tense and personal pronouns in Chinese. This results in the passive voice in Chinese being difficult to express in terms of meaning. Hence, attempting to achieve literal translation renders the product incomprehensible.

The final challenge relates to how many translators should be involved in the process
of translation. Twinn (1997) found that transcripts given to two translators who worked independently resulted in discrepancies being noticed. Twinn suggested one translator to translate all interview contents in a study in order to maintain consistency in translation for reliability. The above issues would definitely affect the trustworthiness of qualitative research and quality of data analysis and outcome dialogue (Carlson, 2000; Twinn, 1997). This study employed one translator because of the time constraints of candidature. The researcher followed-up with extensive editing of all transcripts and journal notes as detailed earlier.

**Strategies for Minimising Language Differences**

In order to demonstrate research rigor, the steps and strategies of data transcription and data translation in this study were guided by a number of principles. In particular, to minimise the impact of language differences and the differences in communication of meaning in this research, the following translation steps were undertaken:

1. Each interview was transcribed in Chinese.

2. The interview transcripts were analysed in Chinese by the researcher.

3. Themes and selected quotes were translated into English.

4. Focused experiences and selected quotes were presented in Chinese and English alike. This technique enabled all the research supervisors to access the developing thesis text. The third supervisor, Dr David Lee enhanced the validity process undertaken involving both the translation and presentation of meaning as a bi-lingual academic from Hong Kong. Dr Lee speaks and writes fluent Chinese and English and has lived and worked in both cultures. The credibility of the translation and presentation of data was enhanced by using this member checking technique\(^2\).

5. Any ambiguities in meanings of words were noted in the data analysis and in the subsequent write-up of the results.

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\(^2\) The technique of formal member checking is to present the translation content to knowledgeable individuals to provide an opportunity to receive their comments, agreement, or correct errors in order to maintain the authenticity of the data (Lincoln & Guba, 1985, pp. 314-315).
6. The researcher only consulted with one academic expert who has extensive experience in translation from Chinese into English.

Data Analysis – The Hermeneutic Circle

The text for analysis included the transcripts from the interviews with mothers and the related journal notes. Together these texts presented a complete picture and allowed a deeper understanding of the relationship between the context and the everyday experience of Being a mother caring for a child with CP.

In hermeneutic phenomenological research, the goal of data analysis is to accurately capture the essential meaning of the lived experience in terms of achieving thick description so that the fullest and richest information is received from the participant (Chesla, 1995). The hermeneutic circle is one way of capturing this meaning. It is both a metaphor for and a process of interpreting experience or a text. In the hermeneutic tradition, understanding is described as a process of moving dialectically between a background of shared meaning and focused experience within it. The hermeneutic circle is a metaphor used to describe the experience of moving between the whole and its parts (Palmer, 1969, p. 87).

Care-giving experiences as the whole story

The analysis process involved listening to the audio-taped interviews, reading and re-reading the interview transcripts and compiling summaries of impressions of each mother’s history and experience of her everyday caring. This process was repeated using the journal notes collected during the process of data collection. To assist with the development of the initial interpretation of each story the following questions will be asked:

1. What is this mother’s background?
2. What are her values and traditions?
3. How has her background helped to shape her life experience?
4. How is she involved in everyday care-giving activities?
5. How has her care-giving experience evolved over time?
6. What do these experiences reveal about the nature of care-giving for a mother of a child with CP?
This process of questioning the data assisted in situating each mother within her historical and care-giving context. The process aided in uncovering the key aspects of the mother’s everyday experience of care-giving. A summary for each interview transcript was written which consisted of my main impressions and initial interpretation of their care-giving history and daily experiences. All summaries were written in English in order to receive supervision guidance from all the supervisors involved in the study. Writing summaries for each story was fundamental to my interpretive understanding in terms of providing a context for each mother’s care-giving experiences, so possible meaning could be revealed.

**Turning to the focused experience**

Turning to the parts, the transcripts would be re-read in order to gain insight into the focused experiences. The aim of this process was to identify the parts or individual aspects of everyday care-giving and illuminate specific ideas and meanings relevant to the research question. The parts identified aspects of the care-giving experiences which highlighted everyday interactions and relationships, significant incidents, reflections on past care-giving, barriers to care-giving, the effects of change on providing everyday care, and anticipated changes and/or possibilities for future care.

A memo was written beside the transcribed text. Each memo included a label which identified which part of the experience the text revealed. Line by line coding and labelling were implemented. This process of labelling and coding highlighted the similarities and differences in shared care-giving experiences which transcended the individual situation. Thus shared meanings were generated that assisted in developing insight into the experience of Being a mother and caregiver for a child with CP. The researcher discussed initial findings of labelling with supervisors to exchange different opinions and suggestions.

**Hermeneutic interpretation**

Hermeneutic interpretation followed this superficial interpretative process of developing insight into the whole and parts. The aim of hermeneutic interpretation is to look within the shared meanings, moving dialectically between whole stories (background of shared meanings), which defined individual parts (focused experience
within it), and parts which derived their meaning from the whole context in which they stand. The ultimate aim is to uncover those modes of Being which reveal the nature of the mothers’ everyday existence as they care for their children with CP.

**Trustworthiness of the Study**

**Credibility**

Credibility means any activity that enables the researcher to establish her research as trustworthy and valid. According to Lincoln and Guba (1985) there are some major techniques to achieve credibility. *Prolonged engagement* was achieved as the researcher has been studying this field of children with CP and their family for over seven years and has invested time to understand the culture and context (Lincoln & Guba, 1985, p. 301). *Member checks* were achieved during the second interview where participants had an opportunity to comment on the developing interpretation of their experience (Holloway & Wheeler, 2002, p. 165; Lincoln & Guba, 1985, p. 314).

One strategy to sustain the validity of data analysis in terms of credibility is to invite an expert in the area to validate the emerging findings. The principal supervisor is an expert in interpretive phenomenological research (Cutcliffe & McKenna, 1999). Moreover, the third supervisor, Dr David Lee enhanced the validity process undertaken involving both the translation and presentation of meaning as a bi-lingual academic from Hong Kong. The credibility of the translation and presentation of data were enhanced by using this member checking technique.

**Dependability**

Lincoln and Guba (1985) argue that the researcher should describe the process and context of the research in great detail. This enables the reader or another researcher to follow the process as well as provide the means for them to conduct similar research (p. 316). Particular attention to details which articulated the process of this study have been presented in the thesis. The researcher clearly justifies the choice of interpretive phenomenology as a chosen approach. Knowledge of this approach is articulated in the ways in which aspects of the study are undertaken and presented, for example, how the study question is posed, how the design was employed and all techniques
have been justified in relation to selecting and recruiting participants, data collection and data analysis processes (Fossey et al., 2002; D. Li, 2004; Shenton, 2004).

**Transferability**
In this study transferability has been demonstrated by providing detailed journal notes as well as transcriptions in order to allow another individual to acknowledge the process of the whole research (Lincoln & Guba, 1985, p. 316). In addition, the researcher provides contextual information in detail, such as the number of hospitals used to recruit participants and their characteristics, the criteria for selecting prospective participants, methods used to collect data, the number and length of contacts with potential participants and the number of participants interviewed (Fossey et al., 2002; D. Li, 2004; Shenton, 2004).

**Confirmability**
Confirmability allows each step of the research to be transparent, detailed and traceable, so as to assist the researcher in showing how data was gathered and analysed journal notes were kept detailing the research process. In this way an audit or decision trail demonstrates confirmability (Lincoln & Guba, 1985, p. 319).

**Ethical Considerations**
Ethics clearance has been granted by the participating Taiwanese hospital and Griffith University (see Appendix E and F).

I explained the research and procedures to the participants guided by the information package. This supported prospective participants to make informed decisions about their willingness to be involved in the study. Also I informed the participants about their right to withdraw from this study at any time or to stop tape-recording during the interview. I ensured the right to fair treatment for the child whether the mother participated or withdrew from the study. I did not discuss this research with the child’s doctor. In this way, the treating doctor was independent of the study (Fain, 1999, p. 174; Holloway & Wheeler, 2002, p. 43).
I required the participants to sign an Informed Consent form before tape recording and interviews commenced. There was no physical risk to participants. I discussed risks related to potential psychological distress, because the mothers may feel uncomfortable or have distressing memories recalled during the interview. If this had happened then I would have given emotional support to the participants and stopped the interview immediately (Holloway & Wheeler, 2002, p. 45; Streubert & Carpenter, 1999, p. 34). Far from participants experiencing distress, all participating mothers felt their involvement was therapeutic in terms of having someone to listen to their story and share their inner voice.

I used pseudonyms on tapes, transcriptions, and quotations, but kept the matching list of names separately from the tapes and transcriptions, in a safe place. The names of the participants and others, as well as the names of institutions mentioned were not shown in the transcription. The content of tapes, transcriptions and consent forms were only disclosed to the research team and transcribers. These data were locked in a cabinet in the researcher’s office and for 5 years will remain until they are destroyed (Holloway & Wheeler, 2002, p. 46; Morse & Field, 1996, p. 167). The rights mentioned above were continuous to the end of the study.

**Conclusion**

This study was based on and guided by the philosophical assumptions of interpretive phenomenology. As such, the method undertaken avoided a rule-bound approach and instead adopted a flexible interview process that utilised the skills of the researcher as an instrument in revealing rich phenomenological data that enabled the disclosure of meaning ascribed to Being a mother caring for child with CP. In the next four chapters the findings of the study will be examined.
Chapter 5

Family and Caring Histories

Introduction
Heidegger defined human beings as Being-in-the-world, “thrown” into a cultural environment with a background and history (Guignon, 1983, p. 68). Being-in-the-world explained how human beings are situated in their world with its everyday practices and activities (Guignon, 1983, p. 69). Through exploring the background of human beings’ institutions, culture and history, everyday practices and activities could be understood. Differing cultures contribute different meanings to social activities (Heidegger, 1927/1962, pp. 20-22, 41-43; Kellett, 1997). However, a human being is basically self-interpreting (Heidegger, 1927/1962, p. 51, 76). Human beings are always in their world dealing with people and things in the context of that world (Dreyfus, 1994, p. 103). Understanding the whole background and its referential familiarity shapes how people grasp and attribute meaning to their everyday existence.

The world is constituted by a meaningful set of relationships, practices and language, and these are shaped by background and culture. Complex values and belief systems guide people to interpret their situation as well ascribe meaning. The mothers’ past experiences and their family background shape their caring experiences in their particular contexts. Therefore, it is necessary to explore the participating mothers’ background and culture in order to better understand how they engage in their care-giving activities on a daily basis, as well as their significance and meaning.

In this chapter seven mothers and their children are introduced (see Appendix G and H). Their past experience of family life, the experience of pregnancy, recognising something was wrong and learning their children’s diagnosis are shared.
Family Background

Rong-Rong and Yuan-Yuan

After her marriage, Rong-Rong’s family lived with her parents-in-law. She worked full-time before giving birth to her third child, a girl who was diagnosed with a spastic diplegia type of CP. Yuan-Yuan is 7 years old and can walk with assistance. Yuan-Yuan can only communicate with others with simple words due to her hearing impairment. Rong-Rong has two sons who were studying in elementary school. Overtime, Rong-Rong’s social isolation had increased as her parents-in-law, would not allow her to have her own personal privacy or freely contact her friends.

I haven’t had my own personal phone since I married my husband. … For example, we only had a phone in the living room. My father-in-law was nasty to my friend when she called me. After that, she didn’t dare call me again. It was also inconvenient to talk on the living room phone. That meant that there was no one I could share my bitter experiences with. (E1: 66-75)

Rong-Rong’s father-in-law held the highest position of authority in this family. Also, he controlled the family finances. To pay for her own family living expenses, Rong-Rong had to rely on her father-in-law.

My father-in-law solely controlled the family finances. My husband worked with him together and only received an allowance. (E1: 113-114)

Spastic diplegia CP shows increasing muscle tone and abnormal movement to the four limbs, but legs are impacted more severely than arms (Kliegman, Marcdante, Jenson, & Behrman, 2006, P. 57). This term refers to all spastic diplegia CP in this thesis.
My husband did get a salary from my father-in-law, but was only given several thousand dollars per month. We asked for more from my father-in-law in case we ran out and couldn’t pay our expenses. When I had a job before, my sister-in-law helped me to look after my second son, because she just looked for a new job at that time. My mother-in-law asked me to give six thousand dollars to her. My husband didn’t give me his salary, but I had to give her money. My husband said I didn’t need to do so, but my mother-in-law already asked me to do it. Could I say no to her? … Even though we eat and live at home, we still have no money left over to save in the bank because of no money. (E2: 363-373)

Although Rong-Rong contributed a great deal to her husband’s whole family, she never gained any positive feedback from her parents-in-law.

At the beginning of my marriage, my brother-in-law studied in junior high school and two sister-in-laws were still students at ×× … and ×× school and were very young. … We built a new house after we were married, so all my husband’s salary had to be given to his family. … We had to help my husband’s brother and sister with their study and wedding. … We have done a lot for the whole family, but they [parents-in-law] never show any appreciation. I didn’t really want their appreciation, but they should treat us nicely and specially. No. They do not. In contrast, they treat my brother-in-law and sister-in-law better and helped them more. (E2: 396-411)

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No positive feedback, no experience of harmonious relationships with her parents-in-law made her home life a major source of stress.

I have had to tolerate a lot of things for a long time. … I didn’t have any freedom or autonomy. … I went back to my mum’s home weekly, but my mother-in-law accused me of going there every day. … I wasn’t willing to return to my home because my husband’s family filled it with stress. To be honest, I would rather fool around outside and go home later than earlier. I really didn’t want to go home. (E1: 635-670)

After having children, Rong-Rong resented the fact that neither she nor her children obtained any caring from her husband’s family. She felt she and her sons did not belong in this family even though she had married their son.

Any way, they [parents-in-law] always felt my two sons were really noisy. I didn’t want to keep the children distant from them. I would prefer to let my children accompany them to watch TV together after dinner, but my father-in-law complained my two boys were too noisy. … After a while, I let my children just go up stairs after dinner and did our business and things. (E1: 55-61)
Once I told my sister-in-law that I had been working like a horse and cow for this family for over ten years, but in your father and mother’s eyes I, as well as my children, are like persons outside the family. They didn’t think my children were their grandchildren. They regarded us as outsiders, so they didn’t dote on my children. … When I come home, I would say ‘Mum, I’m back.’ She just turned a deaf ear to me and wouldn’t respond at all. At that time, my mood was really bad. (E1: 738-744)

My mother-in-law took her daughter’s children but never my children to buy something. … She never came up to look at my children when they cried. … My oldest son was about one year old when he got enterovirus4. At the time I was pregnant with my second child. He just kept crying, crying, and crying in the middle night owing to an oral ulcer as well as being very hungry. No one bothered to look at what was happening to the child. … I just felt heartache for my three children [cry] because their grandmother did not dote on them at all. (E1: 176-188)

Rong-Rong’s husband not only left her alone to shoulder all caring responsibilities for their children, but also failed to assist her in communicating her thoughts with her parents-in-law.

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4 Enterovirus 71 is one kind of enteroviruses. Its symptoms include tender papulovesicular lesions in hands, feet, oropharyngeal mucosa, perineum, and buttocks, so it also named as hand, foot, and mouth disease. It can also induce viral meningitis, acute pulmonary edema and so on (Modlin, 2007).
We lived in an extended family so the husband’s role was very important. My husband went out every night. I had to face the situation on my own. … I just knew I had to take care of our children by myself. I could not get along with my parents-in-law … This kind of relationship needed my husband’s lubricating, … after all the two families came from two different backgrounds. … For example, I didn’t feel good that I couldn’t say it directly to my mother-in-law. I just tolerated the situation and kept doing the housework. At this moment, my husband should express my feelings to his mother, … but his personality prevents him from talking about the matter. (E2: 305-315)

In my mind, I felt taking care of the children should be a shared responsibility for their parents. … The children need their father and mother, although most of the time it will be the mother who takes care of their children. Yes, the father has to work, but the couple’s responsibility is mutual, not unilateral. (E2: 252-260)

Rong-Rong felt helpless and powerless when her husband only indulged in his own interests, but was not willing to establish a human connection with her and their children and did not have their future as a priority.

I thought it was related to his educational level and environment, because my husband had only graduated from junior high school and the environment he
worked in was all building sites and manual labour. … He didn’t ever think about what he could do for our children. They just grew up and that was all that mattered to him. But as I am a mother I would like to provide better things for my children. I would do anything for my children. Anyway, he wasn’t willing to take care of our children for me. No, not at all. He just played his Game Boy when he was resting at home. … I thought he should know what I did everyday. My husband … never asked me where I went or what I had done. He didn’t call me to ask where we were if the children and I hadn’t come home by 9 pm. … Even though I was very strict with my children, my children were afraid of me, but I felt our affection was quite good. (E1: 214-238)

The traditional Chinese beliefs and the tenets of her family education had given Rong-Rong the perseverance to endure all kinds of unpleasantness.

My beliefs were quite traditional. Also I had to take different perspectives into account. I couldn’t leave my children and family and just walk away like the young generation. I just couldn’t. … I care profoundly about what others think of me. My family taught me that I had to teach my children well. I didn’t want any one else to complain that I was the person who lacked family education, so I had to consider a lot of things carefully. I thought that I should put up with everything as much as I could. (E1: 670-675)
Lacking support from her husband and in-laws, the role of mother and responsibility, gave Rong-Rong the will to become an emotional supporter and main care-giver for her children.

I told my son not to be afraid when he fell over and cried, because I was there. Sometimes I told myself I had to be strong enough because most of the time it was just me with my three children at home. A lot of things my husband just didn’t know about. … In one blackout, I told my children that ‘you just closed your eyes and slept. Do not fear I will be sleeping beside you’. … Being a mother, I just felt that I was growing stronger and stronger, because I had no one else to count on. (E1: 571-582)

我兒子跌倒，我兒子在哭，我就跟我兒子講說不要怕，有事情媽媽在，有時候我會跟自己講說自己要堅強，因為…因為常常就只有我跟三個孩子阿，我很多事情發生或是有什麼事情發生，我先生都不知道，…有一次停電…我就說眼睛閉起來睡覺就好了，不要怕，媽媽在旁邊睡覺呀 … 其實你越當媽媽，你就會自己會…其實會越堅強，因為你已經…覺得沒有人可以靠呀！

Main Impressions/ Possible Meanings
- Experiencing a disharmonious relationship with her in-laws
- Feeling marginalised from her family
- Being alone
- Not belonging
- Being unsupported
- Adhering to traditional Chinese roles and relationships

Wen-Cian and Ming-Ming
Wen-Cian felt relatively fortunate because she did not live with her in-laws. Wen-Cian had a full time job as a qualified teacher in elementary school and also had knowledge of special education. Her husband also taught at the local university. She
had one older daughter and one younger boy. Her elder daughter, Ming-Ming, had been diagnosed with spastic diplegia CP and she could walk independently and express herself clearly. She was studying in elementary school.

I felt that I was quite lucky [here meant no living with her in-laws], but it had both advantages and disadvantages. … A lot of grandparents that I observed showed either over-ignorance or over-concern about their grandchildren. … If I brought up my child in my own way, I could do what I wanted because I would know what would really help my child. (N1: 2034-2054)

我覺得還蠻幸福的吧（指沒有跟公婆一同住），我覺得有好有壞啦，……尤其是對特殊孩子，……我看過哪種很多阿公阿嬤不是過度漠視、就是過度關心，……如果我們年輕人自己帶的話，我們就很清楚該給孩子什麼，妳就去做那樣的事情。

I graduated from the School of Education, but it’s a Junior College. … At that time, the school was only focusing on general education, but had no Department of Early Childhood Education. They started to set up a Department of Early Childhood Education in an evening class one year after I graduated. … I attended this course when they started running it. … After I had finished these credits, I was unable to get the credits justified and authenticated. That meant I didn’t get a certificate of special education. (N1: 2589-2595)

我是師專體系畢業的，師專只有專科嘛，……那時候只有師專，沒有幼教系，師專畢業一年後，剛好夜間部成立幼教，……我是第一屆的幼教系去修，……修了特教學分之後，……我連去拿去認證，就是說拿到合格證都沒有。

Wen-Cian would have preferred that her occupation was full of challenge rather than simply stable routine work. She always anticipated gaining more knowledge in her teaching field.

I liked challenges. I would try a new challenge and experience after staying at the same job. … I thought there was no challenge at all in teaching for a long time in a normal school, but special education was like a whole new
experience. … My father used to be an elementary teacher. … My father had always thought that teaching was the best job for women. My father couldn’t understand why I wanted to work in a private kindergarten as it was very busy. But I didn’t want to take the easy option. At that time, I just loved to work. I really loved my job. (N1: 2659-2698)

Wen-Cian was happy with her marriage, because she and her husband had reached a consensual family philosophy and had a strong affectionate bond.

I married when I was 25 years old [laugh]. I felt a little bit regretful that I had not had children earlier. I had been very insistent that I would only get married to him after he started to work. … I didn’t give birth to my first child right after I got married [she gave birth to her first child five years after her marriage]. … During those five years, we cultivated and reached our tacit understanding and had a disposition. … We had a tacit understanding that we never mentioned divorce and we never thought about it when we had a quarrel with each other. I think we have achieved a tight bond between us, … so I am quite happy. (N1: 1717-1733)

Wen-Cian valued her husband because he always gave her guidance and support. She was relatively satisfied with their mutual cooperation.
Sometimes I help him or he helps me. My husband always kept saying he was an army adviser and I was a general in chief, so he always gave me directions when I was fighting, fighting, and fighting in battles. I was an unthinking person, aimlessly fighting. He would give me a direction … and then I would do well. (N1: 1691-1695)

有時候他拉我一把，有時候我拉他一把，我先生常講他是那個軍師，我就是那個將軍，我就在那邊衝阿、衝阿、衝阿，往那邊衝、往那邊衝，他就在那邊指揮我，我這個人就是沒什麼大腦，我會亂衝，可是他會給我一個方向，… 我就會衝的很漂亮這樣子。

Wen-Cian believed the sense of security and protection her husband gave her was a significant part of her daily life.

When I was chatting with girlfriends of mine, he sat at another table. … He always accompanied me. Just for security. … It may be very late after chatting with them and he could take me home. … I thought this was very good because there was some one giving me protection but not bothering me. I became used to taking him with me … during that period of time, he regarded it as an opportunity to read his papers or was free to read his books and so forth. This was like a compliment. It was important to look at his merits. (N1: 1704-1716)

我們女孩子聊天，他坐別桌…然後就安全上面，你聊天聊的比較晚，他可以送你回去，… 結果發現對我來講，也好，有一個人保護我，可是不打擾我，久了就會覺得…習慣他，… 反正他可以藉機看 paper，他很自在看書阿什麼，… 所以說是互補啦，互補有時候就是你要看到對方的優點。

Possessing the same notions as her husband was very important, especially in the field of raising children.

I would leave the journal of pre-school education in the bathroom that I had subscribed to for a long time. … He would leaf through it while he used the bathroom, because there was nothing else in there. After reading it, he would discuss it with me. Through this, he increased his knowledge of educational
matters … And then he would know what was best for children. … Before I got married, my father taught me one thing that you didn’t give your husband long lectures like you would to your students [laugh]. … I found this way was quite good. … It was vital to share the same notions with my husband. (N1: 2306-2326)

Wen-Cian felt lucky that her husband totally supported her desire to keep her occupation and shared the house work with her.

I felt that I was very lucky that I could have my own career. Yes, I enthused over my job [laugh], really. To be honest, before, I put my job first and second was the family. Part of the reason was my husband’s high support. He assisted with the housework. … My husband lived on his own when he had studied at university. Both our fathers helped with the housework and so we felt it was really important to share the work. … Waking up in the morning, my father cooked breakfast. … My mum washed the clothes. Usually, mum cooked the dinner, but, sometimes, dad would do it often. … He was quite a good cook. My husband’s father cooked at their home too, because my mother-in-law still worked and his father had retired. … So my husband helped with the housework sometimes, such as doing the laundry. (N1: 2512-2519)
Main Impressions/ Possible Meanings

- Being herself
- Appreciating any positive challenge from her daily life
- Being supported by her family
- Sharing and valuing the same family philosophy as her husband

Shared meaning which transcend the particular – Family background

The participant mothers revealed the importance of their family background which influenced how and what they experienced when they had close interaction within their family environment. The environments of the family for the participant mothers were just like their world and they were aware of their Being in-the-world. Three shared meanings emerged from the stories of family background:

- The importance of being supported by family
- The importance of having the same family philosophy as their relatives
- The significant influence of a traditional Chinese culture

Rong-Rong lived in a traditional Chinese extended family and it had its distinct power-based hierarchical structure. Her parents-in-law possessed the absolute and highest authority to determine the family rules and decisions. As she was a daughter-in-law, she was expected to obey all the rules they made and show her submission and filial piety to all their reasonable and unreasonable requests to meet the social expectations of being a good daughter-in-law. She, therefore, succumbed to the rules of not being allowed to have personal friends, which resulted in a lack of a social support network in her daily life. Apart from her in-laws not showing their appreciation, it was not important to communicate one’s feelings and affection to others, which led to lower emotional support and affection connection. Feelings of lack of power over financial control caused Rong-Rong to feel dependent and lose her dignity as well. Rong-Rong felt that she and her children were not really accepted by her in-laws, which meant they could not obtain self-identity, belonging, and caring in
this stressful family context. Experiencing hopelessness and powerlessness through family relationships was impossible to avoid in Rong-Rong’s everyday life.

Rong-Rong’s husband was not involved in her and their children’s life world of everydayness, even his being at home was being for himself only, so she was not able to anticipate her husband assisting her in everyday caring activities. She believed that her husband was incapable of creating new or better possibilities for their present and future life, because he never planned a future for their family and he lacked an assertive attitude towards life in terms of a personal sense of responsibility. She, therefore, had to bear the caring responsibility alone. She felt anger at her husband and despair. She kept putting up with this situation and her husband, because she expected herself to fulfil the social expectations of being a good wife who respected and submitted to her husband. There was no mutual communication and affection with her husband, which signified that Rong-Rong did not gain any emotional support from him and could not expect him to bridge the gap between herself and her in-laws.

Rong-Rong possessed traditional Chinese beliefs and values so she expected herself to behave and live up to the expectations of others and society. As a mother, she expected herself to become a 'good' mother, it made her brave and gave her the will power to confront difficult situations and to be a mainstay for her beloved children. She came to acknowledge that she was the person who could give herself and her children new possibilities for the present day and the future. Her deep traditional beliefs, therefore, reconciled her to her stressful home life.

Wen-Cian did not live with her parents-in-law so she could make decisions on her own without pressure from her in-laws. She also preferred challenges rather than a stable situation in her career in teaching, so she had a strong sense of positive self-identity and self-accomplishment. That was a symbol of her strong self-confidence and emotional adjustment. This was a vital resource to assist her in coping with the critical events in her life.

Wen-Cian was satisfied with her marriage due to her husband’s total support and her tight affection bond with her husband. Her husband not only supported her teaching career and provided her with spiritual and emotional support by giving her direction
and protection, but also shared the same family philosophy towards their family and raising children. Wen-Cian felt her husband could always be there to aid her in being a good wife, because her husband did not believe a woman should take care of all the housework and serve him at home. In contrast with Rong-Rong, a happy home became a helpful resource assisting Wen-Cian to deal with the challenges in her daily life.

Both Wen-Cian and her husband’s parents possessed the notion that men and women should have equal power and share housework in the family, which had a significant influence on her and her husband’s definition of being good parents. In addition, she received formal training from the Department of Education and continually received this kind of information that cultivated her self-identification and self-awareness, so she experienced less constraint from traditional Chinese beliefs and tenets, which allowed her to act more flexibly.

**Experience of Pregnancy and Birth**

**Wen-Cian and Ming-Ming**

After five years of marriage, Wen-Cian experienced her first pregnancy. She collided with a student and took a short time off work when she was five months’ pregnant. When she was satisfied that there were no consequences, she returned to work. During the seventh month of her pregnancy, she experienced unusual vaginal bleeding and was hospitalised and confined to bed.

Although the physician had tried to comfort her with his firm promise that all would be fine during hospitalisation, this could not ease Wen-Cian’s feelings of anxiety and worry about her baby’s safety.

Due to unusual bleeding during my pregnancy, I was placed in hospital for confinement to bed. My doctor told me I had uterine contractions of which I was unaware. The expected delivery date was still far away for me. … However the uterine contractions and bleeding was a sign of a premature birth so I was admitted to hospital as a precaution … The doctor told me quite confidently that my condition was good and that I would be able to give birth
after eight months of pregnancy. That meant one month confined to bed. I still felt uneasy because they gave me four different drugs as well as four different bottles of drips. Both my arms had drips. I thought that my situation wasn’t as optimistic as the doctor kept saying. … I could still experience uterine contraction and bleeding. … The doctor kept comforting me, telling me that I would keep my unborn baby until I was eight months pregnant. … After eight months my foetus was still okay. To be honest, my mood became really bad whenever I worried about being hospitalized. The uterine contractions were happening with increasing frequency and dose of drugs was getting higher and higher. I just felt uneasy, even though the doctor kept comforting me. (N1: 32-56)

A feeling of intense uncertainty and anxiety filled Wen-Cian’s mind about the possibility of losing her unborn baby.

For a woman, giving birth to a child is an important turning point and experience. … I was living in a state of great agitation everyday when hospitalised because I had no idea what would happen to my body, especially as I was experiencing bleeding. Sometimes it was ten points dangerous for my condition, but my anxiety could be one hundred points. … In addition, I just felt uncertain about whether my unborn baby could be kept or not. (N2: 22-35)
Wen-Cian paid close attention to the condition and any changes of her foetus. The nurses did not take her concern seriously, so they made a wrong judgement about her medical situation without carefully checking.

During the day when I gave birth to my child … I thought she would be stillborn. I just felt that something was wrong with me … I told the nurses what I felt and the nurses thought that I was too nervous, because I cried so often during hospitalisation. I tended to cry when I was in my depressed mood. As I had been lying in bed for so long, the nurses thought I was too panicky and neurotic … I told them not to take off my foetus monitor. I just felt uneasy. … I found my baby’s heart beat was decreasing. The first time that happened occurred 13 days after I had been admitted to the hospital. I asked the nurses why this happened. They answered that it was very normal, because of the compression of the foetus on the uterus. Fortunately, my husband came over after finishing his teaching. … He went to the nurse’s station to request them to call the doctor to deal with this situation. Finally, because of my husband’s persistence, the head nurse called the doctor. … The resident doctor felt very nervous when he came. He told us there was a baby had died last time after the heart rate had decelerated three times. … He said “yes, we should feel nervous.” (N1: 57-83)
Wen-Cian’s caesarean birth was unexpected because she had been given unrealistically positive expectations by her physicians. She could not accept preterm labour and felt shocked and overwhelmed.

The evening of the same day, my husband’s and my eyes remained fixed on the foetus monitor. … My husband went to the nurse’s station when we saw for the third time the baby’s heart rate decelerate. But no one was there. When we wanted to call our doctor, … suddenly, a lot of people rushed in … and said, “Operation, operation.” I just burst into tears and cried loudly. Why so sudden? “I told you [health professionals] I felt there was something wrong with me but you told me that I was fine and now all of you are telling me I have to have an operation.” … I just cried at that moment and thought why this, because I had been assured I would have an eight month pregnancy. I wanted to resist having the operation. … During the day, I had told the nurses I had problems but they answered that there was no problem at all. In the evening, … I had the operation. I was really shocked and overwhelmed, because the doctor had promised me that there would be no problem keeping my foetus until at least the eighth month. I could not believe that I had to give birth now. I just felt incredible and cried. I had not fully prepared myself for this. (N1: 84-122)

Wen-Cian felt the physicians had cheated her, because she had totally trusted and believed them.
I felt that I was cheated, because the doctor had given me his promise [laugh]. I wanted to refuse to accept this new fact at that moment, because it was too rushed. I had no time to assert my right to say no. I just cried loudly. At that moment, I would rather have chosen to die. … I just felt I was cheated…that I had been told a huge, huge lie. I just couldn’t accept this development. … I had placed a great deal of trust in the doctor. … We trusted in and believed his profession from the time he gave me a prenatal examination. It’s a big gap between the anticipation and the reality. … For my entire life, I will never forget the whole process from prenatal examination to confinement to bed. It will be hard to forget it. It was a far more painful experience than bringing up my child, because it gave me both feelings of joy and bitterness, the feeling of bitterness could be balanced by joy. I thought that the process [meaning pregnancy and being confined to bed] was unbelievable. Yes, it was too overwhelming and shocking for me. (N2: 53-79)

Giving birth to a premature baby was contrary to her beliefs of being a “childbirth machine” in terms of being a mother of a child with a healthy body.

I thought I was a person suitable for pregnancy, like a hen I could continually give birth … like a childbirth machine [laugh]. I never imagined that I would encounter a problem during my first pregnancy; it seemed as if my head had been hit by a huge clap of thunder. It was so incredible, because physically I was in good health. (N1: 26-29)
我覺得我是那種很適合懷孕，可以當母雞型的那種人（笑一下），可以一直生孩子，很適合當生孩子工具的人，可是竟然沒想到才第一胎就碰到這種問題，就晴天霹靂的、不可思議的碰到這種狀況…早產，沒想到我身體太硬朗了，覺得不可思議呀。

Immediately after her delivery, her daughter, Ming-Ming, was given resuscitation and placed in the Neonatal Intensive Care Unit for several months. Inquiring everyday about her medical condition was a painful experience for Wen-Cian.

I contacted the doctor by phone everyday to inquire about my daughter’s condition. I wasn’t capable of visiting her right after my operation, because I wasn’t suitable to be out of the bed. … For me, talking on phone everyday was a very painful experience, because the doctors would tell me that her condition wasn’t good today. In my imagination, a bad thing happened everyday. (N1: 135-139)

然後我們每天透過電話跟醫生詢問，因為我不能去嗎，因為我剛開完刀，我也不適合下床，… 就用電話問，每天講電話都是一種很痛苦的事情，因為醫生又跟你講今天狀況不是很好，我的印象中，每天都有新的不好的事情在發生。

Wen-Cian had to make urgent medical decisions without having a medical background and enough support from the health professionals. She felt helpless and worried about whether her daughter would benefit from her decisions.

When I was discharged from hospital, she was still hospitalised. I felt as though I had headache when the doctor asked me “whether you wanted to give your daughter immunoglobulin⁵? If you wanted to, you have to go and buy it. It’s self-bought. We can only give it to your daughter after we receive it.” … After hearing that, I crazily made a lot of phone calls to consult people with a medical background. I started asking them what immunoglobulin was? What were its effects? What were its side effects and risks? My goodness, that really scared me to death. I worried about all kinds of treatments. The doctors only

⁵ Immunoglobulin is a type of protein to function as an antibody to protect the human body from infection (Ball & Bindler, 2008, p. 547).
wanted to get my answer. I felt how come I have to make this decision, if the doctor can’t decide. (N1: 140-148)

Ming-Ming had a series of medical problems, undergoing heart surgery. Wen-Cian felt that she might lose her daughter, so she felt very shocked.

My baby got Patent Ductus Arteriosus⁶. … The doctor was quite nice. He explained to me that my daughter had a heart problem and it has been treated by drugs. … But it couldn’t be controlled well, so the attendant doctor would come tomorrow and she might need surgery. It was a huge shock, like hearing a thunderclap. Why had this problem happened so suddenly? … The attendant doctor came and said she needed an urgent operation, or the consequences could be terrible. … Next day … The doctor told me that I should prepare myself for the worst, if she hasn’t been sent out thirty minutes after the completion of the operation, because she was too small to perform this surgery. Her body weight with oedema was 1700 grams, but actually it was only 1200 grams. She was just over ten days old. … The doctors had to open her chest to perform the surgery, because she was too small. As well because of her size a cardiac catheter couldn’t be used. Therefore, there were two scars on her body, ugly scars. (N1: 155-183)

⁶ Patent Ductus Arteriosus means that newborn babies still keep their fetal circulation in terms of the ductus arteriosus staying opening, which can lead to dyspnea, heart failure, and growth failure (Ball & Bindler, 2008, p. 751).
Wen-Cian was unable to follow the ritual of *doing the month* to not cry after giving birth, because she was worried about Ming-Ming’s condition. Wen-Cian felt disappointed with her daughter’s condition when she visited her daughter at the hospital.

My husband refused to allow me to go to the hospital to visit her during the period of time of “doing the month”. He suggested that I should take good care of myself during that period of time and not cry and so forth. My husband was afraid that I would feel too sad after seeing her terrible condition. … I went to see her once before I was discharged from hospital and I didn’t see her again after that. My husband thought that I had cried too much at home and that I would be far worse after seeing her in the hospital. My husband just felt this situation was too hard to bear, not to mention I was the mother and mentally vulnerable. … After almost two months, I had finished following the postpartum ritual of “doing the month”. I was going to go back to my work after that. I was able to go out after three months, so I asked my husband to take me to see her. I was really disappointed … really disappointed when I saw her. Her condition was really terrible. (N2: 115-140)

I went to see her. … I felt she was quite miserable. She only could have 1cc, or 2 or 3ccs of milk. I still have a vivid memory of that time. Before feeding her, the nurses have to check her digestive system. There was a lot of suspended matter in her undigested milk. The nurses said it didn’t matter, but I
thought, why doesn’t it matter. I just felt there was something wrong. Finally, it was proved that she had Necrotizing Enterocolitis\(^7\). She couldn’t be fed for one month. (N1: 192-197)

Ming-Ming’s ever-changing medical profile made Wen-Cian’s feel like her life was on a roller-coaster ride, being out of control, especially when she had to face the possibility of losing her daughter, which left her feeling petrified.

I was really scared that she [Ming-Ming] could pass away at any time. We did not dare to take a picture of her. At that time when she was in an incubator, some one told me I should take some pictures. I just felt scared to death. … I was very frightened of keeping too many pictures as they would cause me too much suffering. Her condition was too terrible. It was really terrible. It wasn’t easy to decrease the oxygen. Wow, it was going up again. Feelings of anxiety … I really felt that period was a time of great personal spiritual suffering. … Every time I looked at the number on the oxygen monitor, it was a torture for me. My mood was really … it was really terrifying when the number wasn’t good. My mood was just like a roller-coaster swinging up and down. (N1: 217-282)

\(^7\) Necrotizing Enterocolitis is a life-threatening inflammatory disease of the intestinal tract, which can lead to feeding problems, bloody diarrhoea, sepsis and a severe medical condition (Ball & Bindler, 2008, p. 935).
One time I thought she might die. … One day, I had to teach a night class after visiting her. During that time, she had a problem with her heart beat. It just kept increasing and increasing, to about 200 times [a minute]. … But they couldn’t find the reason. You know everyone just panicked, even the doctors. … They attempted many possible solutions, but they couldn’t find a way to deal with it. My goodness, I went to work crying after that. It really scared me to death. I cried and told my husband, ‘I have to see her one last time before she dies.’ … Finally, after a blood transfusion, she recovered. (N1: 258-270)

Wen-Cian felt relatively fortunate that no one blamed her.

I felt my biggest happiness was that I didn’t get any blame, from myself, my husband, or his family due to my daughter. No, no one blamed me either to my face or behind my back. I never heard anyone saying anything to blame me for causing my child’s problem. I thought this point was very important. I was quite fortunate. I didn’t blame myself, because I wasn’t willing to see this thing happen. No one wants to see their children have any problems. A premature delivery wasn’t something I had planned. Also, I had tried very hard to confine myself to my bed. I tried my best. Also, my husband didn’t blame me. He accompanied me throughout the whole process and he knew I hadn’t done anything wrong to hurt my child, so I was quite fortunate. (N1: 1135-1151)

還有一點是我最大的幸福就是說，我生個這小孩子，我沒有受過什麼責備，包括自己、先生跟夫家，沒有人…在我面前或是在我的耳朵裡面，我沒有聽過責備的話，任何責備是我…因為我造成今天這個孩子這個樣子，我覺得這一點很重要，…我說我這一點還蠻幸運的，我沒有自責，因為我覺得這個我也不願意啊，誰都不願意孩子有問題，她這個
Mai Impression/ Possible Meanings

- Anticipated pleasure destroyed
- Worrying about unborn baby’s safety
- Experiencing the possibilities of losing a child
- Being out of control and uncertain
- Mistrusting health professionals
- Feeling fortunate that no one blamed her

Hui-Hui and Guang-Hua

Hui-Hui and her own family were living with her parents-in-law. She is a housewife and cares for her three children, two boys and one baby girl. The second boy, Guang-Hu, has been diagnosed with a spastic hemiplegia 8 CP. He can walk and run independently and has no problem with communication in terms of verbal expression.

A difficult delivery process caused Guang-Hua to suffer disabling consequences. Hui-Hui’s family blamed her for her son’s condition because she had failed to give birth to a healthy boy.

The prenatal check-ups were normal. The problem emerged during the delivery. The doctor only said that it was a difficult delivery and the child was a little bigger than normal. My labour pain wasn’t quite … how can I say … seemed it wasn’t the time to give birth to my child. The doctor suggested letting the amniotic fluid come out first, but that didn’t facilitate the delivery process. The doctor said my condition wasn’t good. I gave birth in a clinic. Afterwards, many people blamed me for this, because they said that … the doctor lacked the necessary professional skills. … There was still a problem with my delivery. The doctor said he had to contact an anaesthetist to prepare

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8 Spastic hemiplegia CP shows its tight muscles and abnormal movement in the arms and legs on either the left or right side (Kliegman et al., 2006, p. 57).
for a caesarean. The doctor pushed me into delivering the child, because my amniotic fluid had already broken and it couldn’t provide protection to my child. During the procedure, he used vacuum suction. I think it probably … sucked on the baby’s head. When he was four months old, a blood clot was discovered. (C1: 21-32)

Hui-Hui did not get clear information from the physician on Guang-Hua’s condition right after giving birth.

I went to the clinic about eleven pm. The doctor said, “You might give birth tomorrow.” So I asked my husband to drive my mother-in-law home. My mother-in-law kept my husband at home to sleep and left me alone there. When they came to see me in the morning I had already been in the delivery room. My husband didn’t know how the doctor had dealt with my delivery process. Our child had already been born before my husband was called into the delivery room. At that time, my child’s heart beat seemed to stop beating and he lacked oxygen as well. The doctor rushed and notified ×× hospital to send an ambulance and started resuscitation. My child was stayed for a while in the intensive care unit. (C1: 72-81)

要生產那天晚上11點多去。那醫生說：「還沒有，還沒，應該是隔天才會生！」就叫我先生先送我婆婆回去。我婆婆都就留我先生在家睡覺，把我一個人留在那邊。隔天早上去的時候，我已經在產房了。產房醫生，醫生怎麼處理，我先生根本就不曉得，叫他進去的時候，就是小孩子已經出生了。可是那時後，出生的時候，好像心跳停止…他
After my baby was delivered, I saw the doctor spank my child but he didn’t cry at all, and oxygen therapy was used. … I didn’t know if he used anything else to resuscitate my baby. He also notified the nearest paediatric doctor to come to help. … I felt easy after I heard his voice, but I didn’t know it would become like this. (C1: 117-120)

Hui-Hui blamed herself for not taking others’ advice, the blame attributed to her from her mother-in-law had a far-reaching personal effect, but her husband gave her substantial comfort.

Actually I would think my mum saw my tummy was quite big so I should go to a bigger hospital. Everyone advised me to go to a bigger hospital to give birth, and [asked me] why didn’t I go there instead of to a small clinic. I felt some regret when I thought about it. If I had taken their advice, Guang-Hua wouldn’t have become like this. … My husband comforted me by telling me that it was Guang-Hua’s fate and his inexorable doom [ill luck]. After the doom passed, Guang-Hua would get better and better. (C2: 56-61)

At the time [when Guang-Hua stayed in the intensive care unit], my mother-in-law told me that the healthy unborn baby in my abdomen ended up unhealthy, because of me. (C2: 268-269)
Hui-Hui was expected to take good care of her personal health during the period of doing the month, but she could not help but cry and worry about Guang-Hua’s condition and any complication that would negatively impact on his later life.

The doctor said my child lacked oxygen while he was being born. I had no idea what complication would be caused. I hadn’t had this kind of experience before, neither had any of my family and relatives. … I worried whether that would cause any complications. I kept worrying about my child everyday and I suffered anxiety. Also, at home, I had to face my mother-in-law everyday. I can say that I cried and cried everyday during the period of doing the month [one month after delivery]. My mum told me that it wasn’t good to cry during this period, as it was bad for my future eye sight. (C2: 284-292)

Hui-Hui failed to give birth to a healthy boy, which caused her to contemplate suicide, however, Hui-Hui’s maternal responsibility gave her the will to face the reality to nurture him well and to look forward to future possibilities.

I used to contemplate suicide, really, when I felt really depressed during the period of doing the month, whenever I thought about my child’s condition different from normal children, and his grandmother’s attitude towards him. However, if I passed away, there would be no one else who could take care of him. After that I regarded my child as my spiritual guide who I had to raise and give him all my best. (C2: 476-481)
Hui-Hui felt that she was not being given correct or substantial information from health professionals about Guang-Hua’s condition. She felt they may be deliberately misinforming her with insufficient information.

Everyday, because I couldn’t go to the hospital and I wanted to know how he was getting on, I called and asked the nurses about his condition. Always the nurses replied that his condition was quite good, quite good. After a long hospitalisation, he was eventually discharged. But, day after day, I would think they had lied to me [smile], because my child’s condition didn’t actually seem to be that well, but they had always said he was fine. (C2: 270-274)

我每天都有打電話去醫院問情況，那沒有親眼去看，也不曉得，護士小姐都說不錯、不錯，可是一天拖過一天，拖這麼久才出院，對阿，那時候也想說會不會是在騙我（笑一下），想小孩子情況可能不太好，她也都說很好，不曉得。

Main Impressions/ Possible Meanings

- Anticipated pleasure destroyed
- Worrying about her baby’s safety
- Being out of control and uncertain
- Being blamed
- Feeling depressed and contemplating suicide
- Mistrusting health care professionals

Shared meaning which transcend the particular – Experiencing of pregnancy and birth

Some participant mothers went through the normal process of pregnancy or birth, but others experienced threatened abortion during their pregnancy or resuscitation of their
new born babies immediately following delivery. Still others had no problem with their pregnancy and delivery process. Any physical change or unusual symptom happening alerted them to a danger for their unborn babies and they started to worry, deal with their own reaction to their babies and closely interact with the medical system, which meant they couldn’t take their pregnancy or delivery process for granted again. Five shared meanings emerged from the experience of pregnancy and birth:

- Anticipated pleasure of becoming a parent destroyed
- Worrying about the baby’s safety
- Being out of control, uncertain and anxious
- Feeling like I was to blame
- Experiencing mixed support from family
- Mistrusting health professionals

Wen-Cian took her smooth pregnancy for granted, until she experienced uncontrollable vaginal bleeding and was confined to bed to rest. This situation destroyed her previous beliefs and anticipation of having a normal pregnancy and led her to experience anxiety and uncertainty. Wen-Cian’s understanding was that mothers should provide the safe environment to nurture their unborn babies and eventually give birth to healthy sons or daughters. She, however, felt a loss of the possibility of having an 'ideal' motherhood, because she feared she might lose her unborn baby or her baby may not be safe due to her physical symptoms. Wen-Cian’s daily feelings were full of uncertainty and anxiety when she felt that any slight change in her symptoms may lead her closer to the possibility of losing her child.

Wen-Cian adhered to the physicians’ advice to be confined to bed to protect her unborn baby from preterm birth provided her with the possibility of having a healthy new born baby. She also carefully observed her unborn baby’s condition and her physical symptoms in order to fulfil her maternal responsibility of ensuring the safety of her unborn baby. She felt shocked, cried, and wanted to refuse the unexpected caesarean birth to a premature baby that signified a loss of her hope of her anticipated 'ideal' healthy baby and motherhood. This was an overwhelming and shocking situation for her, not only because she lost control over her physical situation, but also
because of her self-doubt about whether her body was capable of nurturing her foetus to maturity, which negatively impacted on her maternal identity. She started re-evaluating her present condition which had been based on her assumptions of what constituted a normal pregnancy and motherhood.

Wen-Cian felt greatly disappointed when she visited her premature daughter in the Intensive Care Unit, because she felt a sense of loss for her ideal anticipated healthy baby and her 'normal' motherhood was destroyed. She felt uncertainty and it was like riding a roller-coaster swinging up and down due to Ming-Ming’s unpredictable medical condition. That was out of her control and prevented her from seeing the possibilities for improvement and new possibilities for the future. She was reluctant to take a picture of her daughter because of the possibility she could lose her new born baby. She was too worried that she had not embodied herself in the traditional Chinese ritual of doing the month by crying. However the importance of her maternal role led her to put her daughter as her first priority, not her personal health.

Wen-Cian placed great trust in the health professionals and hoped they would help restore her sense of control in times of critical medical crisis. Wen-Cian felt the physicians and nurses did not provide her with empathy and complete medical information to communicate possibilities for her baby with her to give her some preparation and control when her previous complaints and concerns were not heard or cared about. However, they overlooked her worries and gave her false hope and promise to anticipate, so she experienced a sense of loss of control and lost hope due to the unexpected preterm birth. She cried and felt cheated by the health professionals and was unable to accept the reality of her situation. It was utterly different from her expectations, leaving her with a sense pessimistic anticipation about a good outcome in the future. She felt that her interaction with health professionals resulted in her loss of trust in their professions.

Wen-Cian regarded any treatment for Ming-Ming in the intensive care unit as a possibility of being cured or improving, but it was controlled by health professionals. She was not given sufficient time nor information to empower her to make medical decisions, leaving her feeling shocked and disempowered, because she lacked confidence with her decision about whether the best decisions to improve the
possibilities for her daughter and to protect her from medical harm. Poor communication left Wen-Cian feeling little confidence in her healthcare providers’ professional skills and knowledge.

Wen-Cian felt fortunate because she was not blamed about Ming-Ming’s condition by any of her family members and she did not blame herself. She was able to constantly keep a positive self-identity, which provided her with opportunities to look to future possibilities and not be limited by present difficulties. In contrast, she turned her efforts to preventing herself from having a preterm labour, which enabled her to strengthen her self-evaluation and feelings of self-worth in terms of being a dutiful mother.

During the delivery process, Hui-Hui experienced a loss of control, worry, and uncertainty over the safety of her baby due to the prolonged labour. Even the delivery process was out of the health professionals’ control, enhancing her feelings of insecurity and disempowerment. Guang-Hua suffered from a lack of oxygen and struggled for life. This experience damaged her concept of mothering in which she had anticipated a healthy child and normal motherhood, which had been built up over a long time during her normal and smooth pregnancy. She questioned her maternal capability to protect her son from physical harm. Depressed and sorrowful, she cried and even thought about suicide, because the traumatic delivery seemed to ruin their future possibilities. She experienced strong feelings of uncertainty as she possessed no answers. She was unable to adhere to the traditional postpartum ritual of doing the month. In time, her motivation to provide quality care and work towards a brighter future for her son, helped her to look forward and essentially anticipate the future with hope rather than live with chronic sadness.

Hui-Hui was critical of the health professionals who she believed had demonstrated poor medical assessment and judgment during her delivery. This she blamed on their lack of professional knowledge and skills, which resulted in Guang-Hua suffering a lack of oxygen during the delivery process and what she defined as sub-standard medical care. She also was not able to get a clean picture of the process of delivery and her son’s condition at the hospital after birth, because the health professionals did not provide her with sufficient and immediate information to let her have a sense of
control. A lack of honest communication led to her feeling disempowered and a mistrust of health professionals.

Hui-Hui blamed herself for causing Guang-Hua’s physical harm. In terms of being a dutiful mother she felt she should have protected him from life’s dangers. This feeling was compounded due to her mother-in-law’s negative feedback and blame for not giving birth to a healthy boy. Such feedback let Hui-Hui feel no hope to anticipate Guang-Hua’s future possibilities, which could possibly lower his quality of life in the future that contributed to her negative image of her motherhood and maternal role. Feelings of guilt and the non-supportive attitude of her mother-in-law lowered her self-value and self-identity in terms of being a good mother.

**Recognising Something Was Wrong**

**Ai-Ai and Shui-Bian**

Ai-Ai became a housewife after her marriage and had three children. Her second son, Shui-Bian, who was a thirty-one week premature baby is now five years old and was diagnosed with a type of spastic diplegia CP. Shui-Bian has no problem with independent walking, running and communication.

Ai-Ai felt quite happy with Shui-Bian’s condition due to his normal sensory function, because the physician only focused on her son’s vision and hearing function.

The doctor told me he might run into some possible problems that tend to happen to premature babies. So the doctor always focuses on checking his eye sight and hearing functions. We only paid attention to these problems and we hadn’t perceived his developmental problem at that time. Also we didn’t know whether his development was delayed or not. In addition, his eye sight and hearing functions were okay so we didn’t think about that too much. (K1: 82-87).

因為早在我早產的時候，醫生就有跟我講說他可能會面臨哪些問題，可是他一直都是眼睛跟聽力，因為先做眼睛、聽力的檢查跟聽力的追蹤，那時候就只有注意這個，那往後的發展在那時候都還沒有表現出來，我們也不知道他有慢、沒有慢，而且加上那時候做視力跟聽力都是 ok，所以我也沒有去想那麼多。
Dysfunction in Shui-Bian’ left hand created challenges in carrying out his activities of daily living that aroused Ai-Ai’s attention, and led her to seek treatment and rehabilitation. She felt angry with the poor rehabilitation support she received due to the therapist’s lack of patience and professional skills.

Apart from his hand always fixed like this [Yu-Yu used her left hand to show his thumb sticking with his point finger in terms of thumb’s function]. I found this when he was about ten months old, so we started looking for the doctor’s help. (K1: 87-89)

At that time, I only cared about his hand function. He could sit, but his hand wasn’t able to open. When he wanted to grasp the toys, his hand was just like a shovel to scoop it up. (K1: 119-121)

Because he was unable to separate his left thumb from the other fingers [pointing her left hand], it looked odd when he wanted to grasp something. … We started rehabilitation at the ×× hospital. … Actually the effect of rehabilitation was not good, because my son only kept crying, crying and crying. The therapists also were not good either. The therapist just held a ball, grabbed his hand, and only pushed him hard to hold the ball with his thumb open. … He cried about thirty minutes which was the length of the session. Yes. After that I never attended there again. (K2: 95-107)
Ai-Ai felt powerless and angry because the physicians gave the wrong diagnosis and treatments, which meant that Shui-Bian suffered from unnecessary medical procedures while seeking professionals’ help from multiple medical facilities.

I started taking him for treatment when he was about ten months old. About the age of one year old … we went to ×× hospital. The doctor told us he had a Trigger finger. We then went to ×× hospital [another hospital] to receive surgery. But he didn’t have a Trigger finger after surgery. After the surgery, the doctor told us it wasn’t a trigger finger. It was the wrong surgery, so the doctor introduced us to ×× hospital [another hospital]. … We went to that hospital. The Dean of the hospital didn’t know what the problem was, so he suggested for us to go to another ×× hospital [name of Medical Centre]. … The doctor [at the Medical Centre] advised my son to wear rehabilitation gloves first, and my son’s hand was able to open after wearing that. A skin graft was done about the age of one and half years old because the skin was adhering together. … The hand is so important. He couldn’t grasp things without opening all his fingers. (K1: 88-97)

9 Trigger finger is caused by the thickening in the flexor tendons of fingers or thumb that produce its flexion deformity. It can be corrected by surgery to release the tendon sheath to restore movement (Kliegman et al., 2006, p. 914).
Even though my child was very small due to preterm labour, I felt he grew up very quickly. His first few developmental steps such as rolling over were okay, so we didn’t think about it too much. Turning his body over and lifting up his head was no problem at all. He could sit down well too, but he wasn’t able to sit up by himself. I had to hold him to let him sit up and then he was able to sit well. When he started to crawl, he only used both his arms to crawl forward and both legs did not move at all [the mother demonstrated how a soldier crawled in battle]. His body from waist down had no strength or power, so we just started realising something was wrong with him. (K1: 74-82)

Actually his sitting posture was quite good when he was little, just like the average child. He could open his legs. Muscle tone gradually increased over time. He sat with “W” posture. He was able to crouch down as well as sit cross legged when he was very little. That was OK. But I did not know what the muscle tone was showing. I started realizing the muscles of his legs were getting tighter and tighter. It became obvious especially when he grew older. I felt very odd. I really took it seriously when he started to crawl with his two arms, as he was not able to move his legs. The muscle tone in his legs became tighter and tighter. (K2: 110-107)
Ai-Ai felt angry because the health professionals performed the developmental assessment without professional skills and attitude, which led her to mistrust the outcome report. She also felt powerless as she waited too long to get the final diagnosis of CP.

When he was about ten months old, one doctor suggested that I bring my child to take the assessment examination at the ×× Medical Central hospital. The examiner gave me the diagnosis of developmental delay. The main problem was I didn’t have a good impression of the examiner. Shui-Bian was too little and he feared strangers so he just kept crying and crying when the examiner asked him to do something. He never tried to comfort him or gave him the chance to warm up. He just wrote down the term of developmental delay. How could I accept this report when I received it. I just felt very angry about this, which also delayed me seeking treatment. … The doctor suggested that I go to ×× hospital [another hospital] instead. The doctor gave him a computed tomography scan soon after we had arrived at that hospital. I remembered very clearly, we took the scan on February 23rd and we got the result of the exam in June. There was four months delay in receiving the diagnosis and the diagnosis was CP. (K1: 101-131)

我有先去××醫藥學院，那時候醫生介紹我去做評估，評估他就直接給我寫遲緩，問題是我那時對那個做評估的先生很感冒，因為咕咕很怕生，小 baby…早產兒都很怕生，他們叫他做什麼，他就是一直哭一直哭，他也沒有去試著去帶動他，或者試著去安慰他，他就直接寫發展遲緩，寄來的報告你那時候叫我怎麼能接受，所以我那時候就是覺得，我那時候就是因為對××這件事情很生氣之外，然後我就有點又 delay 了，… 有一個醫生…要不你就不去××，那你就去××，我才帶咕咕來××，來××之後，醫生就馬上給他排磁震照影，而且我記的很清楚，我們二月二十三號照磁震照影，六月才看的到報告，一差就差就四個月，delay 了啊，一聽到報告就說他腦性麻痺。

Main Impressions/ Possible Meanings

- Realising that there is dysfunction
- Feeling angry and powerless because of a wrong diagnosis and treatment
- Mistrusting health professionals knowledge and skills
- Experiencing a long delay in receiving the diagnosis
Rong-Rong and Yuan-Yuan

Rong-Rong and her three children were sleeping together to allow her to care for her children in the same room. She recalled that Yuan-Yuan never cried before nine months old.

After giving birth, the doctor didn’t tell me that my baby had any problem so we just took her back home. … My child grew and gained her body weight normally up until she was five or six months old. I just felt she was a very well-behaved child. … When she was sleeping she slept beside her two older brothers and showed no response to that. … I thought she was used to the noisy environment. I was thinking that way. … Normally a child should cry but she didn’t cry at all until she was nine months old and then she knew how to cry, because she was really uncomfortable. Before she didn’t cry, even when she was hungry or her diaper was wet. Also children should get up to have milk during the night as my two older sons did, but she seldom woke up to have her milk in the middle of the night. (E1: 279-293)

The health professionals were unable to assist Rong-Rong to get an early medical diagnosis. Rong-Rong’s attention was aroused by Yuan-Yuan’s motor development lagging behind her age.

I took her to the Health Station to have her vaccinations when she was about six months old. There were some student nurses who said they would like to undertake a health check on my daughter. But they didn’t check my daughter’s head circumference. I thought the circumference of my baby’s head was so important. … Her milestone of rolling over was slower than other children. … We always went to a particular paediatric clinic in my home town for my
children’s common cold. The doctor just told me that I should pay attention to my daughter’s development and reactions at a certain age. About the age of nine months, she was unable to sit, except by putting her hands in front of her body to maintain her sitting posture. Also she wasn’t able to smile like other average children. No, she didn’t. Until at ten months old, the doctor finally suggested I go to the paediatric department at the ×× hospital to have further examinations. The paediatric doctor revealed the diagnosis of developmental delay to me after assessment. The rehabilitation started. (E1: 305-320)

大概 6 個月的時候，去衛生所帶她去衛生所打預防針，然後去衛生所好像有些是實習生吧，就說妹妹要做健康檢查，她說健康檢查也沒有說要量頭圍，小嬰兒很重要就是頭圍嗎，沒有量頭圍我們也沒有注意到。然後到最後我們總覺得說她翻身比一般人慢，然後我嫁過去後，因為我們固定在一個城鎮的小兒科看感冒，看小孩子的感冒，固定在那看，然後醫生就叫我們好像有一些反應叫我們要注意，像幾歲、幾歲要應該要有哪一些反應、發展，叫我們要注意，大概 9 個多月時候，她那時候一量頭圍就很小，她那時候連坐也坐不出來，她坐的話腰沒有力，她就是坐的手要放在前面硬撐他的身體，她小時候不會像其他小孩子一樣笑，都不會，她沒有，然後醫生叫我們要注意，大概 10 個月多吧，然後我們那個小兒科建議我們去要來××小兒科檢查，然後小兒科檢查是說發展遲緩，然後這樣子給你評估，評估過後就說是遲緩。

The diagnosis of developmental delay gave Rong-Rong hope. She was hoping that with therapy Yuan-Yuan would be able to be a healthy child in the near future.

I would wish... just like others would say her development was only a little bit late for her age. Developmental delay meant that there was still a hope for us. At the beginning, I would hope that she could walk soon after a short time. I would think this way. (E3: 444-447)

所以也是希望說…人家說…發育比較慢，就是說發展遲緩…就是說我們還是有一種希望，剛開始我們有一種希望說…可能不久之後就會走了怎麼樣，也是會這麼去想。

Rong-Rong suspected the diagnosis of CP on her own, but was not told by the physicians, which signified the physicians did not provide her with complete information to enable her to experience some sense of control over the situation.
The doctor didn’t tell me the diagnosis of CP. It was about one year later after the diagnosis of developmental delay. We had to keep appointments for follow up examinations at the hospital every half a year. One year later, I knew her problem was congenital cerebellum mal-development after looking at the medical picture. I didn’t know whether was the left cerebellum or right one. I looked at some papers on CP and cerebellum mal-development belonged with CP. Yes. … and knowing that, I didn’t have any special feelings, because I had already accepted it. It was one year gone. (E3: 423-431)

Main Impressions/ Possible Meanings

- Missing the early symptoms of CP
- Realising delay in motor development
- Regarding developmental delay as hope to catch up
- Lacking support information from health professionals

Ya-Ya and Ding-Ding

Ya-Ya has two girls and one younger boy, Ding-Ding, who has hemiplegia CP. He is 8 years old, can walk independently and verbally communicates with others. He is now studying at kindergarten and will soon go to a general elementary school to continue his studies.

Ya-Ya experienced difficulty in distinguishing normal development from abnormal, because she lacked professional knowledge.

I found he always kept his hand in a fist after he was born, even when taking a bath. His right hand sometimes would open, but his left hand never opened.
He was hospitalised at the age of seven months, because he had severe diarrhoea which damaged the skin on his bottom. … I asked the doctor to look at his hands and then he advised me to consult the rehabilitation department. The rehabilitation doctor came and used a triangular thing to knock on my son’s body and then he said my son’s hand and leg had problems so he needed to do further examinations. They took a Computer Tomography scan before he was discharged, … then we knew we had a problem. (H1: 48-55)

其實他生出來的時候就有發現了,因為他的手都是握拳頭,洗澡什麼都是握拳頭,那右手有時候會打開,但是左手就是一直不打開,然後到七個多月他住院,因為他拉肚子拉到屁股都破皮,… 那我就請醫生順便看,那他就叫我看復健科啦,然後復健科來看… 有敲嘛,用三角形那個敲,然後就說手跟腳有問題啊,要做檢查,那就說出院要做那個腦部的電腦斷層, … 才知道有問題。

Ya-Ya regarded her baby’s hand being kept in a fist as a normal condition. While Ding-Ding was very little, that gave her hope he could finally be a healthy boy over time.

I thought it was normal for a little child to often keep his hands in a fist. So I didn’t think I should take him to have further examinations. … Normally when a child is about seven or eight months old, he should be able to use both hands in turn to take things from one hand to the other and do other things as well, but he never used his left hand. He only used his right hand. (H1: 75-81)

我是想說小孩子都還那麼小,通常手都是握拳頭,所以沒有特別帶去檢查。… 因為七、八個月的時候,通常應該是會拿東西交換手啊…什麼的都會啊,可是他都是不用左手,都是用右手啊。

Main Impressions/ Possible Meanings

- Arousing her attention to the abnormal function
- Finding it difficult to distinguish between normal and abnormal
- Keeping hope that her baby could be normal later on
Shared meaning which transcends the particular – Recognising something was wrong

All participating mothers expressed that the delay in their children’s developmental milestones had led to them realising that their children had problems dealing with their physical or daily activities. Four shared meanings emerged when realising something was wrong and seeking medical assistance:

- **Realising delay of developmental milestones**
- **Keeping hope of having a healthy child**
- **Being out of control and powerless**
- **Mistrust of health professionals’ knowledge and skills**

In Ai-Ai’s mind Shui-Bian was a well-developed child, apart from problems with his left hand, since he had no problem turning his body over or lifting his head, except his left hand, so she was full of hope for a rewarding motherhood. Focusing on the normal part of his development gave her a ray of hope to anticipate he could still be a healthy boy. To anticipate the hope, Ai-Ai denied the diagnosis because it contradicted her past image. Ai-Ai started realising there was something wrong and felt “odd” when Shui-Bian showed difficulties in sitting and crawling. Such realisation meant that hope was destroyed and the situation was out of her control and the old ways of taking care of him did not work any more. Such realisation forced her to face the possibility of an abnormal physical condition and she started worrying about him. Such realisation also changed her ideal image of anticipated motherhood. Seeking help and support from the medical system was necessary to regain her sense of control and hope of improvement to see future possibilities.

Ai-Ai experienced mistrust of the health professionals before gaining an accurate diagnosis of CP. The health professionals only focused on local problems in terms of Shui-Bian’s left hand, but failed to give a holistic examination and possessed insufficient knowledge on CP to find out the real problem. Ai-Ai felt angry and powerless as Shui-Bian suffered from mistaken diagnosis and treatments after trying multiple medical facilities. Seeking optimal medical care for new possibilities was vital, but it was not provided by the medical system. Sub-standard medical care led to
Shui-Bian’s low quality of life and loss of hope of being cured or improved. Ai-Ai denied the diagnosis of development delay due to the health professional’s poor professional performance and lack of communication skills and patience with him. This resulted in delaying treatment, because Ai-Ai considered that the medical care was of low quality and she mistrusted health professionals.

Rong-Rong discovered that Yuan-Yuan lacked an emotional response to stimulus, but she would prefer to believe her daughter was a well-behaved child than an abnormal one. As Yuan-Yuan was obviously delayed in her motor development, Rong-Rong kept hoping she could “catch up to her age”. Her hope, however, was destroyed when she was not able to see Yuan-Yuan’s developmental milestones progress with time. Experiencing unanticipated outcomes pushed her to seek assistance from the health professionals, because she was unable to completely handle the situation using her previous strategies. When the physician confirmed a diagnosis of developmental delay, Rong-Rong hoped that her daughter’s development would improve in the near future, because it was only delayed. However, her anticipated ideal motherhood had to change. One year later, she suspected the diagnosis of CP on her own by looking up text books. She felt she was able to accept the diagnosis, because her acceptance opened her mind to possibilities of therapy and treatment. She tried to continue to hope and to look into the possibilities to move forward to the future.

Rong-Rong thought she was not able to be notified of Yuan-Yuan’s problems as early as possible, because the health professionals neither performed a physical examination thoroughly and carefully, nor suggested to her that she search for further opinions. Rong-Rong felt that health professionals were careless or lacked knowledge about CP, which was not enough to ensure that Yuan-Yuan received optimal medical assessment and diagnosis. So she felt that she was not able to be empowered to have control over this matter, but felt disempowered. She lost trust and confidence with the health professionals in clinics and felt that they had provided sub-standard medical care in terms of their professional knowledge and skills.

Although Ya-Ya discovered Ding-Ding was unable to use his left hand as other normal children, she still kept observing him and hoped for a better future outcome. Observation meant Ya-Ya still kept hoping that Ding-Ding’s hand function could be
improved over time. So she did not actively seek help from the medical system at that period of time. However, once Ya-Ya expressed her concerns to the health professionals, she was provided with sufficient consultation and medical support to make an accurate diagnosis in a very short time. She did not experience negative emotions or powerlessness when seeking help, but trusted in the health professionals’ knowledge and skills. The standard of care enabled Ya-Ya to feel comfortable and confident with the medical system, without doubting their competence.

Learning the Diagnosis

Wen-Cian and Ming-Ming

Wen-Cian cried and felt overwhelmingly shocked when hearing the diagnosis of CP, especially when the physician had given her a false hope of expecting a healthy daughter. She also felt angry and lost trust in the physician for a delay in discovering the diagnosis, and for not taking her concerns seriously.

She was at her corrected age of three months. It was August, summer. She was unable to lift her head and her whole body was just too floppy. I told the doctor “I felt there was something wrong with my daughter, because she shouldn’t be so floppy. Three months old, she should be able to lift her head already.” The doctor answered “oh, premature babies are usually slower in achieving their developmental milestones. That will be fine.” I chose to believe the doctor and didn’t doubt his words because we have followed him for a long time. I felt okay. The third month, the fourth month, the fifth month, the sixth month, the doctor kept saying it was okay at her age of six months. One day the Premature Association Foundation actively contacted me for further follow-up because my daughter was a premature baby with extreme low body weight. They came to do developmental tests on my daughter. … Wow, you know the outcome of the test. My daughter had problems with developmental delay. It was just like a thunderbolt hit my head. The doctor kept telling me there was no problem with my daughter. But the Foundation told me all developmental areas were delayed, including motor development. … The people of the Foundation asked me did I take any computed tomography scan. No. I had no idea about this scan. I just did
whatever the hospital asked me [to do]. My daughter only had took an ultrasonic examination. I totally had no idea about this kind of investigation, because I had no medical background. … Finally the doctor prescribed this investigation. The doctor told me there was brain damage on the motor area of her brain. I couldn’t help but burst into tears on the spot. I said “why, why didn’t you tell me to take this investigation before?” (N1: 308-329)

I felt pain and suffering when her problem had been probed. That was a huge strike and overwhelming for me when I had heard that I had a special needs child. … I almost believed my daughter was fine after the doctor kept telling me she was okay. So hearing bad news was like a bomb exploding, which hurt me once more and it hurt me really deeply. Just like losing my expectations. (N1: 362-371)

Wen-Cian had paradoxical feelings about the diagnosis. She felt release due to knowing the diagnosis that solved her long time worry and suspicion of Ming-Ming’s
odd condition, but it was hard to accept the diagnosis at that moment because it destroyed her hope of being a mother of a healthy daughter.

I really … I wanted to kill the doctor. I couldn’t accept this because the doctor delayed my daughter’s diagnosis for quite a long time. … To be honest, I felt relief after I took time to contemplate and reflect on it, because at least I knew the reason. … Before I just felt there was something a little odd with my daughter, but now I have the answer. Knowing the answer was better than not knowing. … At that moment, I wasn’t able to accept it, because I felt I was cheated by the doctor. … Wow, it was really like giving a capital sentence. She was really sick. Before she only appeared to be a little bit slow, just a little bit slow. … Experiencing a period of time of sadness, I just felt relief due to knowing the reason. (N1: 3686-3692)

Hearing the diagnosis was like a miserable event and she tried to reject Ming-Ming in order to distance herself from the truth.

I wasn’t able to accept it at the period of diagnosis, even though I demonstrated that I was quite strong. Actually I did reject my daughter for a short period of time. I asked why I had this kind of child? Why was my life so miserable that I had given birth to this kind of child? Why was I the mother of special child? I would be lying to you if I said I never experienced a low mood and depression. … I would ask why the gods treated me so unfairly. There are a lot of people who give birth to normal children, so why me? (N1: 3740-3748)

所以有一點點我覺得當下我會不能接受，雖然表現的還滿堅強的，事實上我說自己心裡面曾經有排斥過，排斥過就是，我說我真的有排斥過自己的孩子，大概就是那個時段，
就剛診斷出來，你會覺得說為什麼我的孩子是這樣，為什麼我就那麼悲慘要生到這樣的孩子，為什麼我是一個特殊孩子的媽媽，你說心裡面沒有經過這種低潮期是騙人的啦，…就是說為什麼老天爺對我那麼不公平，為什麼是我，很多人都為什麼是我？為什麼是我?

Permanent damage from CP meant that there was no hope of being cured, and there was nothing that would let Wen-Cian hope for future possibilities.

The trouble was that CP was permanent damage. … That was unable to be cured by treatment. … There was no hope when the doctor wasn’t capable of telling me how serious the damage was. … I thought it’s curtains. What should we do for our future and the rest of our life? I really had a disabled child … my child’s whole life. I imagined my child would end up like some very severely disabled children … at an institution. … and her whole life might be like this. (N1: 3706-3725)

可是麻煩的是說腦性麻痺是永久傷害，… 那時候是沒什麼希望了吧，你會覺得說，醫生都不知道，… 可是想完蛋了，怎麼辦，一輩子將來，我真的生了一個這樣的小孩，我孩子一輩子，你會想到那種很重殘的那種孩子影像就會…出現，那你從前在那種特殊機構裡面，… 就覺得說大概一輩子就這樣子了。

The physician gave Wen-Cian uncertain information that signified that they might lose the positive future to hope for, but expanded her worry about Ming-Ming’s future problems.

Furthermore, I asked whether CP would affect my daughter’s intellectual condition. The doctor answered ‘no one could guarantee this, but we can only wait and see as she grows older. So only time could tell. Her language and other areas of development could be affected, too.’… To be honest, I was very concerned about her IQ. He said that my daughter’s IQ wasn’t able to be known now because she was too young to take the test. Oh. You know I had to keep worrying about this problem until the age of three years. (N1: 330-374)
再過來，智力會不會傷到，醫生說：「這誰都不敢給你保證，要大一點，看他的發展有沒有出來才知道有沒有傷到，什麼語言、什麼各方面都有可能會傷到。」，...坦白說我們第一個就是問 IQ，他說大一點再說吧，現在說測不出來，喔~你知道嘛，就抱著一顆擔心的心到三歲。

**Main Impressions/ Possible Meanings**
- Mistrusting health professionals
- Disbelieving the diagnosis
- Losing expectations of a healthy daughter
- Losing hope to anticipate for the future

**Li-Li and Hua-Hua**

Li-Li worked part-time and has two children. She gave birth to her older daughter, Hua-Hua, by caesarean and the operation process was normal. When Hua-Hua was twenty days old, she contracted a fever and was hospitalised for twenty days. Hua-Hua is 14 years old now and studying in a regular junior high school. She has a diplegia type of CP and is not able to walk and uses a wheelchair.

Li-Li ignored her daughter’s abnormal physical signs and symptoms, because she denied her daughter was a disabled child. So she visited different hospitals for further tests to confirm the diagnosis.

She was very cute, very cute when she was little. … She grew up with time. I found it was a little bit strange when she stood up and her toes turned in. When she sat in a baby walker she could move it along. I felt her legs were fine. But she stood on her toes and her legs would shake when she stood up. I took her to the ××, ××, ×× hospitals [three different hospital names] as soon as possible. We went to ×× hospital [the first hospital] first and the doctor told me my daughter had CP. … When the results came out I didn’t believe them. I thought my child’s leg was fine and the orthopaedic examination was normal too. Everything was normal. Her right hand was normal, but her left hand was a little bit strange. She could not stretch her left hand. … The doctor told me before, but I just ignored them. I thought there was no problem at that time.
The physiotherapist helped me to look at her hands and found her left hand had no power and could not stretch. That was when she was about six years old. We had her examined again, again and again at the ×× hospital [the last hospital], for several months. ... After almost half a year the results confirmed it was CP. (D2: 29-48)

The diagnosis of CP and its “disabled certificate” signified that Hua-Hua was a handicapped child, which meant Li-Li lost hope that she would have a healthy child.

This painful event led Li-Li to worry about Hua-Hua’s future life. She was concerned about future possibilities.
I didn’t know she would become like this after a fever. … It was very hard to accept this fact. To be the mother, it was impossible to accept this situation. … I worried to death. I worried about how I would take care of her afterwards. How should I help her to grow up with this? What was her thoughts and attitude toward this after she grew up? I always felt great pain when I thought about this [cry] … I wasn’t able to fall asleep in the night when I thought about what I should do and how to go about it. (D1: 629-641)

In time, Li-Li opened her mind to accept the reality to see into the future to let their life move forward to the future because of her responsibilities.

In the beginning, I would take this matter very seriously and wasn’t able to open my mind. So I would think of taking my child with me to die together. I would think this way. But after thinking about it twice, I opened my mind to let our life move further. It’s no use if you can’t move ahead. I gave birth to her. I should take care of her. It’s impossible to abandon her. (D1: 987-990)

剛開始我會想不開，我會想說不如大家一起死一死，會這樣想，有時候然後想一想，想開一點了，日子總是要過，你日子不過要怎麼辦，總是生下來了，你就要照顧她，不可以放著不理她。

She is my daughter since she was born. … Don’t abandon your child or send her to an orphanage. The children in the orphanage are quite poor. … When I thought about this kind of situation, I knew I had to be brave to go on with my live in terms of bringing her up anyway. Regardless how ‘ugly’ she is, I gave birth to her and she is my child. I wasn’t able to abandon her and not care about her. … No matter how, she still is my beloved daughter. … I am the mother. I gave birth to my daughter so I had a responsibility to take good care of her. … I had responsibility to raise her. (D1: 93-111)
Ciao-Ciao and An-An

Ciao-Ciao resigned her job due to unusual bleeding during her pregnancy. An-An is the first and only child of Ciao-Ciao. An-An was suffering from prolonged delivery process and was resuscitated at birth. Ciao-Ciao was told An-An had epilepsy the day after he was born and he had to be hospitalised for one month. The physician gave a diagnosis of spastic quadriplegia CP to her during hospitalisation. He is eight-months-old now and can not lift his head, turn over his body and make social smiles.

Ciao-Ciao felt the diagnosis of CP like “hell” and “the end of the world”, because by giving birth to a disabled child she was unable to live up to social expectations of having a healthy baby.

At that moment, my mood was really… really bad and down [put her eyes down to look at floor]. [pause] … I felt that was the end of the world [voice became quiet and low]. (O1: 126-142)

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10 Spastic quadriplegia CP indicates that hyper-muscle tone affects all four limbs (Ball & Bindler, 2008, p. 1076). This term refers to all spastic quadriplegia CP in this thesis.
那時候真的是…心情真的是很低（眼睛往地上看）（停了下來）。…我覺得是…世界末日（聲音非常低，音量非常小）。

For me personally, I felt I had dropped from heaven to hell, so I wasn’t able to feel joyful and happy about giving birth to my son. It was sad and miserable to face a problem like this. (O1: 737-741)

就好像是從天堂到地獄，對我個人來講，就覺得說生知喜悅，好像面對這樣的問題就會很難過。

People’s expectations are always of a healthy, happy, vigorous baby. But my son didn’t meet these expectations. (O1: 621-622)

因為現在人期望的標準就是健康、快樂、活潑，那我們沒有啊。

The physician revealed An-An’s diagnosis and condition as a very severe condition, which gave her no hope of anticipating future possibilities.

[After hearing the doctor told Ciao-Ciao the diagnosis of CP] I just could not help but burst into tears and crying loudly on the spot [said it without hesitation]. I was shedding tears and weeping over what he said to me. [pause]… [I] just felt very sad. My husband hated that doctor very much because he explained that our child’s condition was very serious. He said my son’s condition was moderate to severe and that he had mental retardation, … also that my son’s four limbs will be paralysed. (O1: 787-794)

在那邊痛哭流涕（毫不思索的立即講出來），他講的讓我痛哭流涕，…很難過啊，所以我先生就很討厭那個醫生哪，他說怎麼講的那麼重度。他說以後會中重度（加重語氣，帶有一點生氣的口吻），智能不足，…四肢會癱啊。

My husband felt that doctor should be like ××× [another doctor’s name] … who gave us encouragement in terms of his future … especially for my husband who wasn’t specialised in this field. He should say we should take him to rehabilitation often in order to improve his ability. … My husband couldn’t stand it when the doctor said something was too serious. … I felt very
sad and sorrowful when I faced him every day. I didn’t know how to face him
to raise him up [voice became quite and weak]. (O1: 1030-1047)

我先生說他應該像×××(別的醫生的名字) … 就是要鼓勵的話說就是未來…就是對他們
這種非專業的…應該講說你一定要常常帶他做復健啊，提升他的能力，…他覺得你跟他
講重度，他受不了啊，… 就是他每天面對他的時候，就會覺得很悲傷啊，我不曉得要
怎麼看他長大 (聲音變小變弱)。

It was hard for Ciao-Ciao to accept her disabled son, but she understood that
acceptance was the best way to allow them to move forward toward their future
possibilities.

I always kept telling myself to accept him, but could I really accept him? Oh,
sometimes I felt I was unable to accept him. … But I told myself to accept
this. If I didn’t, what should I do? It was impossible for me to give him up.
That wasn’t my personality. I had to face it when encountering things like this.
… If I was unable to accept him, then I could not expect others to accept him.
(O1: 804-810)

其實我都一直告訴自己要接受他，可是你能夠接受嗎，哦，我就覺得有時候很不能接
受，…就是你要告訴自己要接受，如果不接受，要怎麼辦呢！要放棄他，不可能吧，就
好像不符合我們的個性，好像事情來就是這樣子，就是去面對他，… 你都不接受，別
人還會接受嗎。

Main Impressions/ Possible Meanings

- Feeling loss of the 'ideal' child to live up to social norms
- Finding it hard to accept the diagnosis
- Feeling no hope
- Trying to accept the diagnosis and move forward to the future
Shared meaning which transcend the particular – Learning the diagnosis

All participating mothers underwent a painful ordeal when they were told their children had been diagnosed with CP. Their everyday life and world of being a mother of healthy child was torn, so they had to re-acknowledge their life change and re-organise their lives. Four shared meanings emerged from the experience of hearing the diagnosis:

- Disbelieving the diagnosis
- Losing the anticipated 'ideal' child
- Feeling no hope
- Accepting their children and searching for new possibilities for the future over time

Wen-Cian was not able to accept and believe the diagnosis when the physician revealed that her lovely daughter had CP, especially the physician kept giving her false hope to believe and look forward to having a healthy and ideal daughter. She felt the diagnosis of CP was like a capital punishment. It had significant influence not only on her daughter since it signified there was no possibility of being cured and no hope for her future, but also on herself since she lost her anticipation of a healthy daughter so she had to change her role identity of being a mother of a child who had gone from being healthy to having a disability. She, therefore, experienced a short-term rejection of her daughter, because she needed time to re-organise her feelings and gain a new image of her daughter and her role.

Paradoxically, Wen-Cian, on the other hand, felt release after knowing the diagnosis of CP, because it confirmed her long-term suspicion about her daughter’s delay in motor development. She accepted the reality to face this turning point that provided her with an opportunity to re-organise their lifestyle and offered her a new direction to better manage their situation. The turning point let her open up to new possibilities of helping her daughter in the future.

Wen-Cian felt angry and helpless when the health professionals did not take her suspicions seriously, but only gave her false hope that her daughter was a healthy girl,
which contributed to delay in diagnosis and loss of better possibilities to receive early treatments. She felt cheated by the health professionals, so she lost her trust in their professional knowledge and judgement. She also felt she was not able to obtain sufficient professional support to assist her to start searching for new possibilities for their future when they were unable to provide clear information on her daughter’s prognosis.

Li-Li ignored Hua-Hua’s unusual motor movements, since she believed her daughter was her anticipated healthy child. Li-Li denied the diagnosis of CP that announced her daughter as a disabled child, so she carefully sought multiple opinions at a variety of hospitals in the hope that the diagnosis of CP would be proved to be wrong. Li-Li experienced profound sorrow and contemplated suicide when the diagnosis of CP was not changed after repetitive medical examinations. Present day diagnosis of CP and the disabled certificate communicated her loss of her ideal healthy child and her ideal mother role was destroyed, so she regarded the diagnosis of CP as a capital punishment that left her with no hope and no possibility of cure and a sense of foreboding for her daughter’s future life.

Li-Li worried about her daughter's future possibilities feeling powerless to support her into the future over time. She finally opened her mind to take over the role of being a mother of a disabled child after contemplating on her role of being a mother and the maternal responsibilities. She expected that she herself should provide the best environment full of family affection to bring up Hua-Hua and should bear the responsibility in terms of her child’s everyday care from present day to the future to look for any new possibility to move ahead to their future.

Ciao-Ciao felt it was like “the end of the world” and “being in hell” for giving birth to a disabled son who was unable to live up to social expectations of a healthy child. It was hard to face the reality of loss of her perfect son. She was unable to feel joy in her role of motherhood after giving birth like many other mothers of normal children. Realising the loss of a healthy boy forced her to modify her ideal role of mother when the physician revealed the diagnosis of CP to her. Ciao-Ciao, however, realised that acceptance was the best way to provide her with hope to gain insight into the future possibilities to encourage her to move toward the future, not just indulge in her
negative feelings. Ciao-Ciao felt it was difficult to adapt herself to the diagnosis of CP, because she and her husband were informed of the diagnosis by the physician without hope and positive information. Loss of hope or possibilities for their son’s future let her feel there was no support to assist her in overcoming the difficult time, but felt alone to face the reality.

**Interpretive Summary**

The participating mothers’ family past lives and Chinese traditions were shaped by their beliefs, values and their role identity as women and mothers. Their everyday practices, habits, and experiences were governed by their family philosophy. Through interpretation of the participating mothers’ stories of their past experience assisted me in better understanding their attunements, moods and concerns. Giving birth to healthy children and being good mothers were the biggest expectations of Chinese society for married women. When their smooth pregnancy, delivery, and children’s development were interrupted in terms of being different from their anticipations or experiences, they commenced to pay close attention to the process. They were not able to take it for granted any more, since it became so significant, important and apparent. Realising something was wrong with their process of pregnancy, delivery, or their children’s development led to feelings of uncertainty and being out of control. This feeling was compounded when the health professionals did not empower the mothers by providing sufficient knowledge and empathy. Importantly, they still kept hoping for a good outcome, because they believed their children could still be healthy and that health professionals could help them to regain control over their unbalanced daily life.

The participating mothers’ anticipation of having healthy children was destroyed and they lost their 'ideal' children when hearing their children had been diagnosed with CP. They expected that they could have a normal motherhood, which also fulfilled the anticipations of society of providing their children with a healthy body, which would maintain their husband’s family honour and prosperity, as well as saving face in their community. They experienced emotions of disbelief, rejection, sadness, crying, and contemplated suicide because they felt no hope for the future. They also felt
uncertainty about their children’s future when health professionals did not empower them to completely understand the prognosis of CP. On the other hand, some possessed the ability to reflect on their experiences and re-think all possibilities for their future, so time was necessary to adjust to their new situation. For some, after learning the diagnosis, they were able to re-organise and re-control their lives and move ahead, which resulted in diminishing their feelings of uncertainty and being out of control.

Having gained a preliminary insight into the state-of-mind, moods and values that shaped these mothers experiences, I found myself asking a number of questions, questions I believe mothers might be asking themselves when experiencing a disordered Being-in-the-world - How has my perception of motherhood changed? How is meaningful parenting possible now? How will engagement in caring for my child be experienced in the future? How might everyday care-giving activities illuminate what is meaningful for me as a mother? Thus in the next chapter discussion will explore how mothers search for new possibilities to care for their disabled children, which will serve to uncover what motivates these mothers to engage in particular care-giving activities.
Chapter 6

Engaging in Everyday Care-giving

Introduction

To understand involvement is to consider one’s actions in the significant context of meaningful activities undertaken for the sake of some practical purpose (Dreyfus, 1994, pp. 91-92). In the Heideggerian concept, Being-in-the-world, the “in” symbolises involvement. Dasein shows itself not through experience or thought, but rather through involvement with objects (things) and people (Dreyfus, 1994, p. 61; Kellett, 1997). For Heidegger, interpretation would never be successful unless the background was understood in terms of the totality of involvement (Heidegger, 1927/1962, p. 150, 191; Kellett, 1997).

In this chapter I will present five new mothers and their children (see Appendix G and H), and re-visit one mother introduced in the previous chapter. I will reveal their experience of losing their anticipated 'ideal' children and consequently questioning their new and changed roles as mothers, including the role of therapist, expert family carer, educator, protector, preserver, provider, advocate, and interpreter. Mothers’ switched their different roles depending on their disabled children’s personal condition and preferences. When switching roles, they continually searched for new ways and strategies to fulfil their maternal responsibility and establish their identity as mothers. Strategies are discussed in terms of how they support the provision of quality care.

Jhen-Jhen and Kang-Kang

Kang-Kang was the only child of Jhen-Jhen, a 16 months old boy. He suffered a lack of oxygen during the delivery process and consequently has a spastic quadriplegia type of CP and its associated impairment of epilepsy. His epilepsy was hard to control well by medicines, so his development and daily life was significantly influenced. He is not able to move his body. He is incapable of communication with others verbally, only by making sounds.
A care priority for Jhen-Jhen focused on relieving Kang-Kang’s discomfort because of the unpleasant taste of his medications. Over time she had discovered the best way and time to provide him with personal care based on her ‘local’ knowledge of his personal preferences and her evolving practical care experience. She felt contentment when the ways she provided care created the possibility to decrease his epileptic attacks or lessen his distress during the administration of drugs, both factors that negatively affected his quality of life.

To feed him his drugs, … I thought the best time was … when he was asleep … he would almost wake up and his mouth would move … seemed he liked to drink something. I used the nipple at the top of his feeding bottle … and let him suck first. If he continued to suck, then I would drop some water in and let him suck. If he kept sucking, I would give him the Depakine11 mixed with sugar. As it didn’t touch his throat directly, it would feel less unpleasant. I felt very happy when he finished it without any discomfoting reaction [laugh]. … He would totally refuse to take the drugs after waking up, because he knew the flavours and he would just let them dribble out his mouth. At that time, I had to use a syringe to feed him the drugs. (A2: 175-185)

Jhen-Jhen’s commitment to provide care in ways that communicated commitment and ensured comfort for Kang-Kang were further revealed in her account of providing hygiene care in ways that prevented any possible stimulus which could induce epileptic attacks that would threaten Kang-Kang’s physical comfort and safety.

11 Depakine can be used as second-line treatment of generalized seizure or status epilepsy. Its side effects include dyspepsia, nausea, sedation, tremors and so on (Ball & Bindler, 2008, p. 1044).
Because he was having such serious convulsions, we washed each part of his body separately. When we took off his clothes, he started to shake. … He kept shaking after we put him into the bath. … We had to prepare two to three buckets of hot water, especially in winter. After washing his face and head … we then rolled up one of his sleeves and washed and dried that arm. We then rolled up the other sleeve and washed that arm. After changing him into new clothes, we finally washed his buttocks and his legs. It needed two or three people to bathe him. My father would come in to help to comfort him when he had his epileptic attacks during bathing. My Mum and I would hold him and dry him. (A2: 71-86)

Kang-Kang lacked the ability to communicate his feelings and needs to others. Jhen-Jhen patiently and carefully developed new ways to communicate with Kang-Kang, such as observation of his non-verbal language and using a trial-and-error approach. Such engagement set up possibilities to communicate and understand Kang-Kang that facilitated providing personal care and provided an avenue for expressing her maternal love and experiencing a human connection and attachment.

He was too small to speak out his feelings so I needed to guess his feelings and thoughts carefully. (A1: 676-677)
Even though he wasn’t able to speak, his facial expressions, such as mouth shape, warned you to give him comfort as soon as possible [laugh]. He used a variety of crying sounds and mouth shapes to express himself. … This was his language. … His Aa sound contained many different pitches and tones and each had a different meaning for me. (A3: 146-155)

Jhen-Jhen refused to use an artificial feeding tube to ease her caring load, because she wanted to not only preserve Kang-Kang’s physical functioning as near normal as possible but also not deprive him from the physical stimulation associated with eating. For Jhen-Jhen it was important that Kang-Kang maintained an appearance as similar to normal children as possible. She viewed this as a one way of maintaining his dignity and fostering an environment for him to grow up with a healthy mind non-threatened by psychological harm.

When he was hospitalised, he didn’t use his mouth to eat anything. When my mum visited him she said “he moved his mouth and he seemed that he wanted to eat something.” … I thought if he felt thirsty he couldn’t drink through his mouth. I thought it [using a feeding tube] was not a natural thing to do. … Eating food and drinking are his basic needs. If these basic needs couldn’t be satisfied, then I didn’t know whether it may influence his psychological well being or make him become obsessive-compulsive. … He could keep his memory for eating if we continued oral feeding. If not, he could lose his memory for eating. (A3: 665-679)
Jhen-Jhen thought that being there for Kang-Kang was meaningful, because it provided him with a sense of security and she could give him comfort any time according to his personal needs. Her presence enabled her to monitor and maintain a high standard of care over twenty-four hours a day.

His sleeping patterns were different from ours, for example, sleeping during the daytime and staying awake most of the night. His epileptic attacks always happened when he wanted to sleep and they prevented him from sleeping. I had to hold him from 7 or 8 pm to 4 or 5 in the morning. He only fell asleep because he ran out of energy and then he would sleep until 2 or 3 pm. … I just stayed with him always no matter day or night. … I would take a short nap from 8 or 9 pm while my mum looked after him and wake up about 11 or 12 pm to take care of him until the next day. … Sometimes I would take care of him from 6 pm to 4 am the next morning and then my mum would wake up and take over after that. (A1: 277-291)

有一段時間,那兩個月就日夜顛倒,因為他每次要入睡之前,就一定會發作,就一直睡不著,常常晚上七、八點一直抱著他,抱到天亮四、五點,因為他就一直被干擾,一直睡不著,到天亮累到身體沒有力氣了,他就一直睡到下午二、三點。… 日夜顛倒就陪他日夜顛倒吧, … 後來晚上八、九點,我媽媽會讓我先睡覺, … 大概十一、二點睡醒了就幫忙弄小孩,就換我媽他們去睡覺,不然就是我就下午六點帶他到清晨四點,我媽媽就起床了,換我媽媽帶他這樣。

**Main Impression/ Possible Meaning**

- Preventing any discomfort or harm
- Learning new ways of communicating and caring
- Valuing attachment and human connection
- Maintaining dignity and “normality”
- Making sacrifices through total commitment
**Mei-Mei and Tang-Tang**

Mei-Mei was a housekeeper who had two children. Tang-Tang her six year old daughter was diagnosed with spastic quadriplegia CP. Tang-Tang experienced frequent epileptic attacks, was not able to move her body on her own and was not able to express herself verbally. She had to rely on medical technology to support her life.

Mei-Mei felt confident in manipulating the technology and conducting the necessary technical tasks because of her developing knowledge and skills in using medical equipment to maintain Tang-Tang’s respiratory function, comfort levels, and support safe sleeping. Her strong motivation to improve her daughter’s everyday quality of life motivated her to overcome her fear in order to learn all technical skills and sacrifice her sleep to provide her daughter with personal care.

I didn’t sleep a lot. … For example, we always went to bed about 11 or 12 pm, but I had to get up to check whether her ventilator had enough water or not. Her sputum would become very dry if there was no water in her ventilator. … She had to use BIPAP¹² [Bilevel Positive Airway Pressure] during night time sleeping, because it could give her a better quality of sleep. Without it, it would make her breathing more difficult, so she used a nasal cannula during the daytime and used ventilation during the night time. … I had to learn these skills. … I didn’t feel any fear because she needed my help. … She needed suctioning when she was very little, about one year old. … BIPAP started to be used at the end of last year. … I just kept using it and I got proficient in doing it, because she needed it. (I2: 787-810)

¹² Bilevel Positive Airway Pressure keeps the lungs open during the entire respiratory cycle to reduce dyspnea, decrease respiratory rate and use of accessory muscles, and improve blood gas values (O'Neill, 1998).
Mei-Mei felt satisfied when Tang-Tang could benefit from not only her local judgement and management, but also from her personal approach to her care that aimed to ease physical comfort. Secure in her knowledge and skills she would rather perform all caring activities on her own. She believed others were not able to make the same sacrifice and this would potentially threaten the quality of care, life experience and everyday existence of her daughter.

I knew my daughter very well actually. If some one else was to come and take care of her, I didn’t think they could do it. I didn’t praise myself [laugh]. Yes, for example, yesterday morning her oxygen level was only 80 or 81, and then I knew what things had to be done to handle this situation, such as, eating white rice soup [porridge] without salt and knowing how much she can eat, and so forth. (I2: 1220-1225)

因為其實我真的是太了解她了，她要是別人來照顧的話，別人沒有辦法照顧的，不知道是我自己自誇還是怎樣（笑出來），對啊，比如說像她昨天早上，她氧氣濃度幾乎只有80、81而已，就一個早上，然後我就知道要怎麼處理，吃的方面就只吃清粥，像那種東西… 不加鹽那種東西，只能吃那種東西，吃多少，然後再來要怎麼樣。

My parents-in-law hired a servant before and they thought that the servant could totally take care of my daughter. I just couldn’t accept the servant taking over all caring responsibility for my daughter. … My thought was that the servant was always careless and thoughtless, because she saw it only as a job. I felt the servant did not really care with her heart for my daughter. … My daughter really needed a person who was very careful and attentive. … I would prefer to do it myself as I didn’t want my daughter to be treated this way. Once, the servant helped my daughter with chest percussion in a prone position. My daughter’s eyes couldn’t close when a foreign body touched her eyes. … One of my daughter’s eyes just became red and wept after percussion because her eyes were irritated by the servant’s clothes. I just felt my heart was very hurt. … Therefore, I insisted that I had to take care of my daughter myself. I tried to meet my family’s requirement so my sleep was really rare. (I1: 303-325)
之前有找過，可是因為他們的想法就是說，我外勞找來了，… 我妹妹要完全交給他，可是我做不到，… 可是我是覺得說外勞他總是比較粗心，他只是把這個當成一份工作，… 你會感受到這個外勞是不是真的很細心，因為我們妹妹是需要一個很細心的外勞來照顧的，… 那我自己來嘛，我不要我的小朋友被這樣子對待，因為曾經有一個外勞，他在幫我們妹妹拍背的時候，我們妹妹要趴著拍背，因為我們妹妹她眼睛不會眨，她碰到異物，她眼睛不會閉，… 結果那一天他拍背拍好抱起來的時候，我看我們妹妹一隻眼睛，眼淚一直滴、一直滴，整個眼睛都紅掉了，那個心有多痛你知道嗎，… 所以我還是要自己帶就對了，我就盡量把我的時間分開，所以我的睡眠時間很少。

Mei-Mei believed that in order to create a better life for Tang-Tang it was important to raise her as a 'normal' child. This belief motivated her to provide multiple opportunities for contact with the social environment, opportunities to engage in activities that fostered stimulation. Searching for stimulating involvement outside of their home provided possibilities to share their life and joy together and nurture their connection and attachment.

We used to go out for a walk often. Definitely some people would come to have a look at her … because she had a nasal-feeding tube. … The people would come and look at me when I fed some water to my daughter. … I just let them have a look at her. … If some one else asked me something, then I told them she was sick. … I had to force myself to accept this, because I knew I had to step out of my personal world. … I treated my daughter as a 'normal' child so we couldn’t hide her at home. When a doctor asked me “did I take my daughter out often?” I said “no, except if we had to go somewhere specifically.” The doctor said “no, you shouldn’t do this. Contact with the outside could do better for both my daughter and myself.” After hearing that I bought a baby carriage and started taking her out and had contact with others, because I wanted my daughter to have a normal development. (I1: 440-476)

其實以前就時常帶我們妹妹去散步，鼻胃管裝著，… 然後一定會有一些人 … 走過去看一下，… 然後餵開水的時候，就有小朋友就在旁邊看，就讓他們看，… 有人問我的話，小朋友怎麼啦？我就跟他說，生病了不舒服。… 強迫自己接受，因為我知道說一定要走出去，… 不過我是覺得說要把我們妹妹當成一個正常的小朋友來看，不能把她藏
Mei-Mei felt strongly about not consenting to the medical suggestion of a tracheotomy for Tang-Tang. Mei-Mei had a strong motivation to maintain a normal appearance, promote dignity and protect from potential physical pain and psychological harm.

The doctors discussed the issue of tracheotomy with me last time, but I said no to them. (I1: 660-662)

因為...那個算是比較侵略性的,...這裡如果又開一個洞，就會有卡卡的感覺，然後她皮膚又不好，這邊要綁個帶子固定它，如果說氣切對她來講有幫助的話,...我接受，...氣切的一個原因就是因為他的痰多，...如果單純這個原因的話，我就算了啊，...而我的小朋友並不是因為說裝下去就會慢慢慢慢好起來，...如果說裝了會一直好起來，我當然會裝啊，裝了不會好起來，...多受罪的，不想要讓她再受罪了。
My daughter had a sweet tooth. … My daughter liked pumpkin soup. … If she felt full, we had the same feeling too. … We all regarded my daughter’s needs as first priority. (I2: 1012-1030)

我們這個很愛吃甜的耶， …妹妹妳喜歡吃南瓜， … 一個人飽，全家人就飽了， … 都是以她為第一優先。

A day only has 24 hours. I wasn’t able to gain more time from 24 hours. Sometimes my husband felt sympathy for me so he would ask me to go for a stroll around the streets or do something else. I said I was fine. Actually I didn’t care about this, you know. I didn’t care about whether I had time for myself or not. I didn’t care about this issue. As long as my children were fine then I would be fine too. I just gave all my time to them. (I2: 623-627)

因為你時間就是這個樣子而已啊，有啦，有時候我先生會捨不得啦，就叫我出去逛逛幹嘛的，我都說沒有關係，其實我不在乎，你知道嗎，我不在乎說我是不是有自己的空間還是幹嘛的，我不會很 care 這個問題，只要是他們好好的，我就是把時間都給他們就對了。

Main Impression/ Possible Meaning

- Feeling confident in managing medical technology to provide personal care
- Mistrusting others to provide a quality standard of care
- Maintaining her daughter’s dignity and normality
- Protecting from physical discomfort and psychological harm
- Making sacrifices through total commitment

Ya-Ya and Ding-Ding

Ya-Ya felt satisfied when Ding-Ding was happy to cooperate with her doing rehabilitation everyday. It meant they shared a common goal and worked together to achieve it. She felt confident to perform effective rehabilitation exercises fuelling her sense of being able to make a useful contribution to her son’s care. Her involvement
in her son’s rehabilitation provided a platform for developing a mutual trust in one another and a strong personal bond.

When we went to the hospital to do rehabilitation, he would struggle with the therapists and cry. There were several staff trying to catch him, so the therapist suggested to me to do it at home myself. All children could lay down well to do rehabilitation, but he just kept running and chasing, so they couldn’t do much for him. Therefore, the therapist said that I should just stretch his leg and arm at home on my own to prevent it from atrophying, so we didn’t take rehabilitation at the hospital any more. … Anyway, I regularly helped him stretch his leg and arm everyday before sleeping. He wouldn’t cry or struggle, except it really hurt him and he would say he felt hurt. (H1: 191-208)

It was impossible to ask my son to lie down and let his father stretch him. My son won’t let my husband stretch his limbs. However, my son would lie down on the bed when he saw that I was waiting to stretch his leg and arm. We were already used to it. (H2: 349-351)

Ya-Ya felt she had a responsibility to protect Ding-Ding from any possible physical harm as a result of treatment. She carefully assessed the advantages and disadvantages of medical treatments to ensure any intervention would not negate the positive advancements made from previous rehabilitative efforts.
Some one mentioned acupuncture on the head. I was quite frightened of it. Some one also suggested to me to take him for an operation. … I saw a person at the rehabilitation department who could walk, but he wasn’t able to walk after the operation. There were twins … a long time ago, they received an operation. They weren’t able to walk at all after the operation, but before they could walk a little bit. After hearing that, I didn’t dare to do it at all. … When we were examined at the ×× hospital, the doctor told me that it couldn’t be cured by drugs or an operation. Yes, that was why I didn’t try other treatments, except stretching his tendons. … No, I would fear that my son’s IQ was fine now but he might become a silly boy after acupuncture. (H1: 493-505)

Ya-Ya aimed to support Ding-Ding to be as independent as possible by providing him with necessary supports to achieve this goal. She would carefully select a certain type of clothing to compensate for his physical functional disability that potentially hindered him in maintaining independent self-care skills, outside the home in particular. It was important to promote and preserve his physical functioning to achieve optimal independence and life quality.

The CP affected my son’s right side of his brain, so his left side of his body was affected [she used her right hand to point out her left side of her body]. He seemed quite normal now. But putting on pants caused him a little trouble, for example he had trouble dealing with the zip on his coat or pants. … He was troubled by buttons too. There was no problem dealing with the bigger button, but only the small ones. … I tried to buy the pants with elastic and no zip and button. I also tried buying shirts with no buttons either. I would prefer to buy clothes that he can put on over his head. He can do it. … Yes, otherwise I feared
that his teachers couldn’t help him at school when they were busy. (H1: 111-128)

Ya-Ya felt communicating Ding-Ding’s physical condition to his teachers was meaningful to protect him from his teachers’ misunderstanding and the pressure from his peers, especially when school life became a significant part of his life journey.

I had to go to his school to talk to the teachers about his condition. …he was too small to describe his condition clearly. The teachers might not be able to understand what he said, so I had to talk to the teachers. (H1: 647-654)

The teachers had a longer time staying with my son. … I sent him to school at eight o’clock in the morning and he came home about five or six o’clock in the afternoon, so he spent more time staying at school than at home. His teachers could see his condition more than I could … so I had to keep in contact with the teachers often. (H2: 596-601)

Main Impression/ Possible Meaning

- Sharing and working together to achieve the same goal
- Protecting from side effects of treatment that hinder independence
- Finding alternative ways to preserve independence and life quality
**Shu-Jhen and Jhih-Zong**

Shu-Jhen is a housewife with one daughter and a younger son and they live with her parents-in-law. Jhih-Zong has a type of spastic diplegia CP and is not able to walk and uses a wheelchair, but can clearly communicate with others. He is now seven years old and studying at a special education class in general elementary school.

Shu-Jhen considered it was crucial to keep Jhih-Zong’s physical functions and posture in the best condition owing to his abnormal muscle tone, especially when he was away from her and studying at school, so she acted as her son’s advocate and expressed and communicated her son’s needs to school administrators and teachers in order to gain better physical support for her son from the school. She, however, felt disappointed and frustrated when the school staff failed to provide her son with what she perceived to be basic personal care and this resulted in her need to closely monitor and accommodate for the less than desirable quality of support her son experienced during school hours.

As my son was the only one needing a wheelchair and standing frame, I expressed to the school staff that my son needed their help at school. … I also brought up the issue … that when my son used his wheelchair he got into trouble using the school desk. I asked the teacher if it was possible to ask a manual worker to take the drawer out of the desk so my son’s wheelchair could be moved closer in. However, the teacher didn’t do this favour for me. … He needed a ‘H’ safety harness and separator\(^{13}\) when he sat in his wheelchair, but his teachers never helped him to do that. I helped him to put his body in the right posture after I arrived at school to pick him up. … When I saw him after school, his body was just totally in the wrong posture and distorted. (L1: 385-402)

\(^{13}\) H safety harness and separator, function as positioning devices to keep skeletal alignment, reduce muscle tone and prevent contractures (Ball & Bindler, 2008, p. 1077).
後像他坐在輪椅上面，可能需要綁 H 帶啊，還有分腿器啊，可是他們老師不會去幫他做這個事情，就是我帶他去的時候，就是趕快幫他綁好，... 可是我去接他的時候，他就是完全都走樣了就對啦。

I tried to keep telling his teachers to use the safety harness to support him. ... but the teachers just failed to do it. (L1: 408-412)

我就一直跟老師強調說你就讓他綁著這樣子，... 但是就是老師不會做到。

Shu-Jhen’s monitoring role aimed to gain the support of the teaching staff in preserving her son’s dignity and self-respect. She tried patiently to advocate for her son and offer the simplest and effective advice on how best to manage her son’s needs.

The teacher didn’t know how to put his diaper on the correct way. You know. As long as the diaper could be folded around that would be fine for her. Sometimes when my son came home his diaper was crooked or the diaper wasn’t wet but his pants were wet [laugh]. ... I had to buy a specific type of diaper that could be used in both directions. It was convenient for the teachers to use. I wanted his teachers to pay more attention to his study so I didn’t ask them to help my son with a lot of physical assistance. ... At the beginning I told the teachers several times they didn’t put the diaper on the right way. ... But they still had problems doing it so my son’s pants often got wet after school. ... Sometimes the teacher weren’t able to accept the parents when they complained too much, so I tried to tolerate it and cleaned it on my own after going home. (L2: 215-232)

他就沒有方向，你知道嗎，他就覺得... 就把他包起來就好了... 有的時候回來就歪一邊，或者是包了，尿布沒有濕，可是褲子濕了（笑一下），... 我就就還特地去買那種雙向包的，就是可以貼在後面、也可以貼在前面的那種尿布給老師，說方便老師使用，我覺得這樣減少老師幫涵誠做很多事情，然後讓他注重在他們的教學上面。... 那個尿布包錯邊了，然後一開始我跟他講了很多次說，... 但是一開始還是沒有辦法做到就對了，常常還是... 下課了，怎麼褲子溼掉了這樣子。... 有時候怕你過於要求老師，老師沒有辦法接受家長，所以我就盡量說好吧，沒關係，我回去再幫他處理。
For Shu-Jhen it was important to provide a home environment full of teaching materials, educational toys and learning opportunities aimed at enhancing Jhih-Zong’s developmental potential. She sacrificed her personal material needs to nurture her son in a stimulating environment. Her role as provider was important and defined in terms of positively contributing to her son’s life quality as well as improving her maternal satisfaction and self-worth in experiencing his pleasure.

My husband gave me three thousand dollars to buy clothes, but I would rather spend the money on buying my son’s toys, books, or teaching materials. I put a lot of emphasis on the books. … But other family members weren’t able to accept this and they asked why I had to buy a lot of books, especially when I lived with my parents-in-law. … The reason was my son was unable to walk, so I couldn’t take him to play on the slide or ride a bicycle. Therefore, I would buy a lot of stuff to let him play at home and I thought this was the right thing to do and I should do it for my son. (L1: 628-643)

就是可能他爸爸說我有三千塊，我可以給你買衣服，那我寧可把這個拿去買他的玩具、教具或者是書這樣子，就是我很重視這個書籍這樣子。… 但是家人會比較不接受，會覺得說你怎麼買那麼多書這樣子，然後因為又是住在家裡跟公公婆婆住，… 可是我就會覺得說因為他不會走路，我不可能帶他去溜滑梯，我不可能帶他去騎腳踏車，所以我會買很多東西讓他在家裡使用，對，我會覺得說這是應該的。

I tried to take my son out as much as possible. … Yes, my husband and I would like to go shopping. We took him to a department store often so he had the opportunity to look at a lot of different things. Also he was sensitive to the movies or advertisements on TV, or songs. … Actually these were little tiny things, but they could benefit my son. (L1: 664-671)

就是會儘量帶他出門啦。… 對啊… 我跟爸爸就都很喜歡逛街，我們都是帶他去逛百貨公司，就是讓他看好多、好多東西這樣子，像他對電影啊、對電視廣告那種東西都很敏感，或者是對歌曲啊，… 其實這些小事情、小細節對他來講都是有收穫的。
Main Impression/ Possible Meaning

- Feeling angry and frustrated when receiving sub-standard care
- Advocating for her son’s personal needs
- Constantly monitoring the care quality
- Providing a learning environment and educational opportunities
- Sacrificing her personal material needs

Fang-Fang and Jing-Jing

Fang-Fang became a housewife when she got married and now she has two daughters. The youngest daughter, 13 years old, has a type of dystonia\(^\text{14}\) CP and an associated impairment of epilepsy and is studying in a special education class in the sixth grade at elementary school. Jing-Jing lacks the ability to speak and she can only walk with the assistance and guidance of others.

Fang-Fang felt her previous servant was not able to reach her care standard in terms of physical cleanliness, so she took over the control of care quality. She felt satisfied when she found a new way to bath her large daughter to provide a useful way to contribute to her daughter’s daily cleanliness in terms of quality of life. During the bathing process, she also applied her daughter’s personal likes to comfort her and to give her a better personal care. Being an expert family carer, she realised providing for those “little things” contributed to providing quality care and the feeling of being useful for making a positive contribution.

The last servant didn’t help her wash hair or bath well. … Not clean enough, so I bathed her on my own. … It was becoming difficult to bath her when she was getting older. I felt my body could not bear it after helping her washing her hair, especially she just got bigger and bigger. Her father would help me sometimes. … After that I thought I needed to think of an alternative way. … I just let her sit on the water closet, and then started with her brushing her teeth … then washing her hair in a sitting position, … and washing her legs and bottom in a standing up position. I had to sing songs like in advertisements

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\(^{14}\) Dystonia CP is a kind of athetosis CP that affects the muscles in legs, hands, feet, face or throat by slow uncontrollable movements (Koman et al., 2004).
when I was washing her in order to distract her attention. Otherwise she would easily lose her temper. I could clean her much better this way. (B2: 67-85)

可是我覺得像上一次那個菲律賓，我也覺得她…就是幫她洗頭、洗澡，沒有用乾淨，後來就是我自己幫她洗啊，… 就大一點的時候，真的是很不好洗，因為也是要洗頭，要這樣幫她洗好頭真的會受不了，而且越來越來越大，後來剛好是她爸爸，那一陣子還都會幫我，…這樣我要想個變通的方法，… 我就想說那就是讓她坐在馬桶上面，就是從刷牙開始，因為她這樣子，她也聽不懂，也不會做，我都是利用洗澡的時候，幫她刷牙，… 就洗頭就坐著這樣洗，… 就站起來洗腳、洗屁屁，就和她…就是唱一些譬如像廣告的歌，… 分散她的注意力，不然她很會生氣，後來就覺得，嗯！這樣洗反而更乾淨。

Fang-Fang was very sensitive to unique independent living skills which Jing-Jing needed for her daily life, but it could be easily taken for granted by others. She, therefore, actively kept reflecting on and re-evaluating the training process of rehabilitation in the hospital to advocate for detailed self-care skills that her daughter needed to achieve the best possibility of becoming more independent. She felt satisfied when her advocating role could contribute to Jing-Jing’s quality of life, which also resulted in improving her personal sense of usefulness and self-worth.

I would look at my daughter’s condition and then … I would discuss with the therapists whether or not we should change the training program. For example, to train my daughter to self-feed. At that time, I brought a cake, egg, container, and a spoon. … She didn’t know how to eat, so we had to teach her. At the beginning of training, she wasn’t able to scoop up the food and put it into her mouth, so she felt very angry. … Now she can feed herself a bowl of rice or even rice-gruel. (B1: 381-391)

像我現在會看她到什麼程度，… 是跟她商量說那現在我們是不是，我們是不是該…說… 改變就是教她哪一些動作，比如說訓練她自己吃飯，那時候就每天拿一個蛋糕、蛋啊，帶一個盒子帶一個湯匙，… 就是要給她教，因為她不知道要怎麼吃 … 剛開始練的時候，舀起來到嘴巴，夾不到嘴…吃不到就很生氣，現在就可以很好很好吃一碗飯，吃飯、吃稀飯可以。
Actually she was able to sit up soon after she came to this hospital. … I felt something was wrong with my child’s learning process from the position of lying to sitting. She could sit, but couldn’t change from lying. She always needed someone to help her or she used the wrong posture to get up. I asked the therapist ‘why didn’t you teach my child to learn the process of changing the position from lying to sitting?’ … After that the therapist started teaching her that action. (B1: 317-321)

Fang-Fang set a good example to her family by entirely involving herself in providing the best care to Jing-Jing, which could educate her family on how to provide care to Jing-Jing and what was the care standard. The caring standard was able to be maintained when all family members reached consensus and possessed a willingness to be involved, which led to her better quality of life. That also signified the family members were willing to set up a human connection with her disabled daughter in terms of acceptance and support.

We all lived together, I didn’t teach her [older daughter] on purpose, but she always looked at what I did and then she would know how to do. Sometimes I needed to go out in the evening for a short time, I would tell my older daughter to prepare the drugs for her sister and how many tablets and it should be done correctly. She would help me do it. … Sometimes she helped her sister bath. She had watched me doing it from when she was very small. I would teach her to do different things, so she was able to help her sister with meals, bathing, dressing, and so forth. (B1: 722-728)

其實我們都在一直在一起，不用教，看就知道，像有時候晚上我要出去一下，我就交代她說妹妹吃那個藥、幾顆唷、要算對唷，她會幫忙做，所以她以前，還比較小的時候，… 她還會幫她妹妹洗澡，所以自從小看都一起啊，我會教她做啥做啥，會餵她吃飯…會幫她洗澡…穿衣服什麼都可以。
Main Impression/ Possible Meaning

- Making commitment to control the quality of care
- Being advocate for independent skills and quality of rehabilitation
- Setting a good example of high quality of care
- Providing personal care
- Valuing family connection, involvement and acceptance

Feng-Feng and Cyun-Cyun

Feng-Feng works for her husband’s family business as a full-time worker, but she may take time off as she wishes. Her husband often takes business trips away from home and does not have many opportunities to spend time with their son Cyun-Cyun who is three years old and has a diagnosis of spastic monoplegia\(^{15}\) CP. He can walk independently but has problems with communication.

Feng-Feng lives with her parents-in-law and she has paid a great amount of attention to dealing with their thoughts and attitudes towards Cyun-Cyun, because they possessed the highest authority to make all decisions at home. To gain any form of support from them by teaching them to have positive thinking and knowledge could provide her son with the best quality of treatment and life. On the other hand, sharing the same treatment goals and values within the family would improve the connection and cohesion of the family unit.

My parents-in-laws saw my child’s progress and growth, although he still lagged behind his age. My mother-in-law would say ‘his development was a little bit slow for his age, because he was a premature baby. It’s fine to take time to learn slowly. He would get better and better with time and finally he would be OK. For example, he wasn’t able to walk when he was just over one year old, but he is able to walk very well now. My mother-in-law would know that my child could do anything, but he needed to be taught and needed a chance to learn it. However, his progress was relatively slow. The 'ordinary'  

\(^{15}\) Spastic monoplegia CP means that persistent high muscle tone and stiff movement involves one of four limbs (Ball & Bindler, 2008, p. 1076). This term refers to all spastic monoplegia CP in this thesis.
children could do things after you taught them once, but my son may need five or ten times. He could do it but he needed our patience to teach him. Yes, they had this kind of concept now, so they could support me to take my son to attend any rehabilitation class. They knew my son couldn’t make progress without it. They supported all treatments or examinations my child needed. They perceived positive information, because I gave them all positive information. I thought I needed to educate the people around me to accept my child. (J1: 334-349)

Whenever I learnt a new method from the rehabilitation centre, I would go back and teach my mother-in-law and the Vietnamese maid. During my working hours, my mother-in-law would help to do rehabilitation, stretch his legs or teach him to walk up the stairs. (J1: 324-327)

Feng-Feng shared and provided her husband with news of Cyun-Cyun’s medical condition and daily events in the hospitals, which involved her husband in their son’s life world and promoted his understanding of their son’s situation. She and her husband pursued the common goal of accessing the best quality care available to support their son developmentally and to improve possibilities for positive family relations. Such a motivation fuelled their desire to educate their son and seek out all possibilities to enhance his development and associated functional abilities. Such progress was deemed the foundation for good quality family life and relations.
I took the majority of care of my son. It’s me who interacts with the therapists and the doctors, so I was very clear about my son’s condition. My husband would feel fear if he had no idea about our child’s condition. I believed he felt fear more than me. He understood our child’s condition through me. I would e-mail him if there was any report or something about our son’s examination, and then he would understand our son’s last condition and knew how to use the correct ways to interact with him. The attachment could be improved between them. (J1: 1019-1027)

我會自己處理我們兒子的後續就診，我知道比較清楚他的狀況，因為當然有時候他爸爸也需要知道，如果他爸爸不知道他會怕的，所以其實是由我去跟治療師、跟醫生去互動，他才會知道。我會跟他講他的治療進展，如果寫信給他，那是會比較真實一點的，他才比較清楚關於治療進展，甚至跟醫生的互動。他會知道現在病情的轉變，我會跟他在電話裡、在信件裡進行互動，他到时候就知道現在的狀況，他可以知道他自己應該如何跟孩子互動。但是這樣子他就比較清楚現在的狀況，如果他比較清楚，他比較清楚現在的治療進展，他就比較清楚現在的狀況，他就比較清楚現在的治療進展，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的狀況，他就比較清楚現在的状况。
Feng-Feng realised that being there and staying with Cyun-Cyun patiently was important to protect him from dangers that he was too young to understand, which were compounded by his low level of cognitive functioning.

He is two years almost three years old, but his cognitive ability was only one year old. That meant his gross motor skills were developed but his cognition skills weren’t developed well … the gross motor and cognitive ability didn’t match, which could put him in a dangerous position so he needed someone to care for him all the time. (J1: 1389-1391)

像我剛剛講的那個洗澡的那個動作,躲到水裡面去,他以為這件事情是好玩,他不知道那個叫危險,所以他的認知跟他的動作配不起來，… 就像我們家的那個小妹妹,你跟她講說不可以爬高,爬高危險, ... 這樣她就知道那個是危險的,不可以的。弟弟到目前為止,不聽就是不聽,照樣上去,所以變成是必須有人很長時間的去顧他,那像很多時候他會不曉得說這個東西是危險的。

Feng-Feng carefully monitored and evaluated the therapists’ professional skills and attitude as well as Cyun-Cyun’s reactions to the rehabilitation. She felt self-gratification and worth when the treatment choices made a significant contribution to Cyun-Cyun’s developmental progress and his life quality.

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I won’t criticise a therapist’s attitude, but I would not choose his/her class if I thought the therapist was not good enough, because it just wasted my time and it was useless. I would rather follow an earnest therapist. … A good and well-trained therapist could let me feel strongly that my son’s progress was very fast and really improved a lot in a very, very short time. … He was able to use his fingers to dig out toys [the mother used her pointing finger to demonstrate the action of digging out] after practicing one month at a new facility, but all his fine motor skills weren’t developed after a half year fooling around at the previous facility. … The therapist also taught me how I should work with him at home, so my son’s progress could be improved very fast within a month or a half month. … So the therapists were so important. (J1: 825-847)

我不會去批評一個老師他的工作態度，對，我只能選擇我不上他的課，就不上，去也沒用，浪費時間，不如在認真的這個老師這邊，…一個好老師、能力夠的老師，他能夠在很短、很短、很短的時間之內給你很強烈的感覺，就是孩子進步很快，… 可能在這邊混了半年了，然後所有的細動作都沒有出來，在那邊一個多月，手指頭會用了，會這樣摳摳摳摳玩具出來（用食指在挖的動作），… 然後老師會告訴我們回家要怎麼教，那是不是相對應的孩子進步是不是就很快，短短的一個月、半個月，… 所以師資很重要。

The good and devoted therapists would notice a lot of detailed things, but quite a few therapists just fooled around. I could feel it from my son’s reactions. We have been doing rehabilitation for a long time, so I could tell if the therapist was good or not after the therapist gave two lessons to my son. (J1: 850-853)

等於好老師、很認真的，會幫你去注意很多很多細節，有很多，可是還是有很混的。你從孩子的反應 … 你就感覺的到。做久了，老師大概上了兩堂課，我們大概就知道這個老師行還是不行。

**Main Impression/ Possible Meaning**

- Teaching and involving all family members in care
- Valuing family connection and cohesion
- Sharing the same goal within the family
Wanting the best

Shared meaning which transcends the particular – Engaging in everyday caring activities

The participating mothers perceived their motherhood was changed from the anticipated ideal mother role to being a mother of a disabled child. This placed them in a desituated situation where their taken-for-granted perception of motherhood was no longer possible, so searching for new ways and re-constructing their maternal roles was required. Seven shared meanings emerged from the stories of engaging in everyday caring activities and eight maternal roles were illuminated by their daily caring activities:

- Promoting possibilities for communication human connection and attachment
- Striving for “normality”
- Preserving their children’s independent physical function
- Protecting from discomfort and harm
- Possessing 'special' knowledge and skills and educating family
- Providing a stimulating positive environment and learning opportunities
- Advocating for a quality standard of care

Jhen-Jhen became aware that Kang-Kang lacked normal oral function, so learning how to interpret her son’s non-verbal language and find possibilities to communicate with him and understand his wants and needs was important. Being able to communicate enabled the setting up possibilities for mother-son connection and bonding as well as fostering a positive environment for conveying maternal love. Jhen-Jhen said ‘no’ to an artificial feeding tube to not only maintain her son’s dignity as she made a commitment to raise him as a normal child, but also prevent him from the deprivation of oral stimulation in terms of psychological harm. On the other hand, providing personal care and meeting her son’s individual needs without subjecting physical discomfort and harm was significant, so she carefully took time to bath him and feed him his medications, informed by her 'local' knowledge and skills acquired from being engaged in the everyday care of her son. Being there for Kang-Kang to
provide him with personal care any time was meaningful, because Jhen-Jhen regarded it as a time to share the moment with him to convey her love and provide him with a sense of security. These caring activities mattered as they provided the means of enhancing her son’s quality of life. In striving to reach such a goal Jhen-Jhen experienced a sense of satisfaction and worth in her maternal role.

Mei-Mei believed that she was the only person who could provide a high quality of daily care to Tang-Tang, because her maternal love and responsibility motivated her to happily sacrifice her sleep and leisure activities to devote herself to Tang-Tang’s personal care. Mei-Mei realised Tang-Tang’s life had to be supported by medical technology. Such care needs encouraged her to manage the medical equipment and condition with the knowledge and skill of a competent therapist. She, therefore, mistrusted others that they could offer such a care standard as she did. She felt her heart “hurt” when the care standard was lowered, but felt satisfied when her efforts had any positive outcomes to better her daughter’s life quality. Quality of life was defined in terms of maintaining dignity, aiming for normality and protecting the child from physical and psychological harm.

Yu-Yu felt satisfied when she could confidently perform daily rehabilitation with skill. When they were doing rehabilitation together everyday, they shared a common goal of preventing physical function degeneration, which resulted in quality of physical function and life enhancement. During the process, a strong bond and human connection between them was nurtured. Yu-Yu acknowledged her son had difficulties in accomplishing certain daily self-care skills. She found ways to help him to be able to complete his personal care independently. Preserving his ability to act for himself could not only better his self-image and self-esteem, but also experience a normal and high quality of life.

Shu-Jhen felt disappointed and angry when Jhih-Zong received sub-standard care at school because teachers failed to provide care to meet her son’s personal needs of hygiene and physical function. It was important to actively express his unique needs according to her special knowledge of her son to his teachers to arouse their attention and improve the quality of care at school. In addition to advocating for Jhih-Zong, Shu-Jhen continually monitored carefully the care quality he received. To offer an
environment in terms of both home and outside home full of learning opportunities and stimulation was vital since it could optimise his cognitive developmental and enable him to reach social standards that facilitated his integration into society. For these reasons her son’s education was important and barriers that thwarted possibilities to attain such learning caused anxiety and concern and warranted immediate challenge. Jhen-Jhen was motivated to create a normal existence as for any other ordinary child for her son. Seeing her son grow up as a socially adjusted person who could integrate into society provided meaning, it mattered.

Fang-Fang had a strong intention to control the quality of care, so she would rather carry all caring activities on her own for Jing-Jing than rely on others. She believed her maternal love and 'special' knowledge of her daughter let her make such a commitment to a high quality of care, especially finding new ways to bath her daughter was worthwhile when she grew older. Fang-Fang actively kept reflecting on what independent skills Jing-Jing needed to let her be able to act independently, so she advocated for Jing-Jing to the health professionals to ensure the best quality of rehabilitation, which could contribute to her better quality of life. Fang-Fang successfully educated her family members. When other family members were willing to follow her footsteps that ensured not only the same standard of care could be maintained, but also that family connection and support were established, which led to feelings of satisfaction and usefulness for all.

Feng-Feng actively and constantly educated other family members about Cyun-Cyun’s medical condition and care needs to gain their understanding and find support in achieving a high standard of care for her son. Maintaining family connection and cohesion, which could benefit both her son’s physical and psychological well-being were important in realising a better quality of life. Feng-Feng highly valued her knowledge of her son’s rehabilitation program, so she was empowered to carefully monitor and evaluate the therapists’ attitude and skills to design the optimal program for her son aimed at maximizing his developmental progress. Looking for “little toys” for Cyun-Cyun to provide the best practice environment at home were important as she felt useful when these “little things” could contribute to his better development and the goal of achieving a better life. Feng-Feng valued what could be perceived by others as trivial caring activities,
because they contributed to nurturing her relationship with her son and ultimately improved the quality of their lives.

**Interpretive Summary**

The participating mothers experienced a strong sense of losing their 'ideal' mothering role. Searching for new meanings, finding new possibilities to care presented a need to adjust and accommodate for their day-to-day caring activities. Constructing possibilities to care fostered quality of care for their disabled children which was significant and important. Such involvement contributed to each mother’s maternal existence and shaped their self-identity and sense of worth as mothers.

Physical safety and comfort was the basic and most important issue for these mothers. They took their role as *protector* very seriously, because their children were so vulnerable and exposed to a large number of medical treatments that put their children at risk of physical harm and discomfort, that could lower the quality of care and upset their children, which negatively affected their children’s quality of existence. Making medical decisions carefully or making a commitment to engaging in time to be there to accompany their children or be involved in physically consuming caring activities were ways of protecting their disabled children. On the other hand, the mothers refused to use artificial material to meet their children’s needs, such as a feeding tube. They preferred to spend time and energy engaging in the caring activities to maintain their children’s normality and dignity, protecting their children from psychological harm. A feeling of maternal responsibility and love made them happy to sacrifice their personal needs to maintain the same standard of care all the time in terms of protecting their children from physical and psychological harm. The participating mothers felt a sense of usefulness and self-worth was experienced when their role of protector was performed.

Acting as an *expert family carer*, the participating mothers felt gratification and self-worth with their everyday lives when their unique disabled children could gain a high quality of care from them. They possessed 'special' knowledge of their children to provide them with personal care that was based on their children’s likes and dislikes, aspects of medical and technical knowledge, and their medical history. They
also constantly found new ways to better their caring skills to provide the best quality of care. Willingness to make a commitment and sacrifice, and their valuable maternal love and responsibility, ensured their children’s quality of care in terms of quality of life, which also met expectations of society to be a 'good' mother. These mothers found it difficult to accept that others could replace them in such care-giving activities and some would actively oppose others from taking on such roles and mistrust would develop as a consequence.

The participating mothers felt confident in performing rehabilitation or medical skills for their disabled children, as well as making informed assessments and adjustments in their children’s daily care and treatment, because they were willing to dedicate themselves to the high quality of medical care. Possessing such therapy skills and knowledge was built on their long-term learning process and they immersed themselves in a medical environment, acting as expert therapists, which aimed to improve or maintain their children’s physical functions or daily life quality. Such experience motivated them to “keep going”. In addition to daily medical care routine, knowing how to deal with their children’s ever-changing condition according to their local knowledge and skills gave them a sense of satisfaction and worth. On the other hand, the mothers and their disabled children shared a common goal on the treatment and rehabilitation program, so the attachment, bonding, and human connection could also be established in meaningful ways. All their commitment and efforts could positively contribute to their disabled children’s quality of life, which enabled them feel purposeful and satisfied.

Being a provider, offering a stimulating environment and learning opportunities to maximise potential was vital in being a mother of a child with CP, because of the need to combat developmental delay. They, therefore, provided educational toys, books, or activities at home or outside the home that would positively contribute to their children’s developmental progress. This strong motivation encouraged them to provide all possible “little things” to improve their children’s quality of life. They enjoyed being with their children when providing learning activities and they experienced mother-child bonding and affection, which led to a positive contribution, as they were raising their disabled children as normal children. That gave them a
sense of purpose and they felt useful in offering the best learning environment and opportunities for their children.

Possessing a standard of care in their mind, the participating mothers would act as advocates actively communicating to others their thoughts and wishes for a care standard aimed at improving their children’s ability to function and experience the best possible quality of life. They realised they had to monitor care standards, because they believed their disabled children could count on them due to their maternal love and sense of responsibility. They felt satisfied and worthwhile when their disabled children experienced a consistent care standard owing to their advocacy.

As educators, the participating mothers taught family members to understand their disabled children’s medical condition and how to competently be involved in, and the importance of, caring activities that maintained the standard of care. The mothers realised other family members should also learn new skills and ways to interact with the disabled children, because their children were different from other children who did not live with disability. The human and family connection and bonding could be established when other family members were willing to make positive contributions due to valuing and accepting the disabled children. The mothers played an educator role to build a bridge between the family and the disabled children in an attempt to enhance their relationship and involvement.

Maintaining communication with their disabled children was crucial, especially when their children were not capable of expressing themselves due to a lack of proper oral function. The participating mothers felt meaningful in learning and finding all new possible ways of communication to understand and satisfy their children’s wants and needs and provide personal care to them. They acted like an interpreter to carefully decipher their disabled children’s non-verbal language and clues to foster mutual communication. They felt satisfied and worthwhile when they successfully completed the goal of ensuring their children’s quality of life in terms of constantly re-evaluating and re-adjusting interpretation of their children’s non-verbal language and expressed wishes. Human connection and bonding could also be experienced through the process of communication.
Physical impairment resulted in their children having difficulty in accomplishing certain daily self-care tasks. In order to preserve their independent physical function to act for themselves in terms of independent life, the participating mothers would play the role of **preserver** to look for the alternative ways to compensate for their functional disability to enhance their independent ability. Completing all self-care skills by themselves meant they could have a better quality of life and their self-image and self-esteem in terms of psychological well-being could be improved. The mother felt satisfied and gratified when they witnessed their children’s independent function.

Switching their caring roles from time to time or from place to place meant the mothers needed to sacrifice their needs and adjust to their children’s personal situation or context. They expected themselves to be responsible mothers that let them place their children’s needs before their own so they accepted the challenge of daily care and felt more comfortable with an interrupted caring routine. Therefore, they viewed their sacrifices and commitment as a way to better the quality of care experienced by their children.

Gaining an insight into meaningful caring is possible. My personal understanding of mothers’ daily caring existence relied on their everyday care-giving experiences. I started to reflect further. Why do mothers care? What motivates these mothers to care? How do mothers grasp meaning in everyday caring? How is Being-in-the-world as a mother defined when constraints thwart possibilities to care? What abilities are developed in the process of caring for a disabled child? Thus in the next chapter, discussion of what challenges and constraints mothers in their caring roles illuminates meaning that defines Being-in-the-world.
Chapter 7

Barriers to Care-giving

Introduction

One aspect of the Being of Dasein is care that can be easily understood and interpreted as a kind of caring after one has deeply reflected on self. To be involved with people and things within the world signifies care for people in terms of concern and care about things. People engaged in their daily tasks within their world have been thrown into the world and they become aware of their difficulties and limitations during the process. Care is a central locus of Dasein (Gelven, 1989, pp. 119-122). Concern can be seen in the everydayness of Being-in-the-world (Kellett, 1997). However, when previous strategies and methods have been disturbed, then one’s intentionality and concern are questioned (Dreyfus, 1994, p. 62). In mothering, caregivers in their everyday caring activities are involved with people and thus demonstrate their being-concerned.

In this chapter, I re-visit two mothers introduced in the previous chapter and present two new mothers and their child with CP (see Appendix G and H). The participating mothers’ experience of barriers to care-giving are described in terms of experiencing difficult relationships with others, being marginalised, feeling burdened by primary care-giving responsibilities, experiencing family conflict because of care-giving demands, learning to balance being over-protective and encouraging independence, and experiencing limited support.

Sin-Sin and Bing-Bing

Sin-Sin was living with her parents-in-law and the family of her brother-in-law and their two children in a rural area. All the extended family members worked together in their own field. Bing-Bing the five years old son has been diagnosed as a spastic quadriplegia CP with mental retardation. He is incapable of moving his own body and has no ability to express himself verbally. He has a 6 years old sister who is studying in a general elementary school.
Sin-Sin experiences difficult relations with all her family members, including her husband. She recalls her husband’s unwillingness to share the caring responsibility for their son. Sin-Sin believes that her husband does not value their son and avoids building a deeper attachment to him.

My husband’s interest was raising pigeons. … Sometimes I thought he treated his pigeons nicer than his son. … I felt very angry and cried when sometimes I thought about this. Sometimes I asked him to take our son to the doctor. He wouldn’t do it, so I had to do it myself and I just felt very angry. I just ignored him. The only person you can count on is yourself. My child’s condition would only get worse if you waited for his father to help. As I said, the gods will look at what a person is doing. His father would understand later on. (G2: 277-287)

我的丈夫興趣就是養鴿子, … 因為你有時候認為他對待鳥比對待他兒子還好, 但是你會感覺說…那就不要理他啊，有時候自己想一想會很生氣，自己也會流淚啊，有時候叫他載兒子去看醫生，他也不要，然後你就要自己來啊，然後你就會很生氣，你就是覺得說不要理他啊，你就期望自己當母親的來載啊，你如果要期望爸爸啊，孩子放在那裡，那會越來越嚴重啊，就我說的人在做，天在看。以後他爸爸就會了解了。

My daughter said to my husband why does he always dote on a boy like my brother-in-law’s son who can walk and run. … I said it to my husband ‘did you know how I felt when I heard my daughter saying that.’ (G2: 349-354)

我女兒就跟他說爸爸都比較疼男生怎樣的，像我大哥那個兒子啊，那個是會走、會跑，…我跟他爸爸講說你看，連小孩都會跟我這麼說，那我這個做媽媽的，聽到的時候是什麼感受。

Despite the demands of day and night care for Bing-Bing, Sin-Sin feels alone in her sole responsibility of meeting her son’s needs.

Sometimes my husband didn’t know my son was sick when he was sick. … For example, I knew my son had a fever because my son could nod or shake
his head to answer my asking, but my husband didn’t know it. … I would nurse my son to sleep when I saw he was uncomfortable. I sat up or lay down to let him lie prone on my chest. … I sat up to keep myself awake. I got some sleep after he slept, but I had to get up to cook after a short time of sleep. (G2: 987-997)

像這個小的，有時候生病啊，還很他還知道會不會，講要時就點頭，講不要時就搖頭，就是知道他發燒，他爸爸就不知道，…如果我看到孩子難過，我一定抱著他睡，… 我就不敢睡，我就坐著。還是躺着讓他趴在我身上睡，他睡著了，再換我來睡，可是一札眼，又要起來煮飯了。

Sin-Sin’s relations with her parents-in-law are also difficult and strained. She feels unhappy and helpless when she witnesses the treatment her son experiences at the hands of her father-in-law.

We had four kids in our home, including my son. The other children could walk and run. He [father-in-law] stated to my child that ‘you cannot walk and speak, only eat, so I won’t give you any more food. It would be easier on the whole family if you could walk.’ I felt very unhappy when my child was often treated like this. (G1: 236-240)

為了這個小孩，常常被這樣子，你的心理會很不高興，因為我們家有四個小孩子連他嘛，每個人都可以走、可以跑，然後他就說‘你都不肯走，也不肯講話，只顧吃，那就不要讓你吃，你如果會走，整家的人都會很輕鬆。’

One time when I was drying my hair after washing it, I looked at my son through the window glass in my room, because it reflected our living room. I saw my son wasn’t willing to let my father-in-law hold him, so my father-in-law kept pinching and hitting him so many times [said with an angry voice]. … He wasn’t playing with him. He was really hitting him and pinching him. (G2: 45-52)

然後就是有一次，我在洗頭，我吹頭髮的時候，我們那個…從房間的玻璃，窗戶的玻璃剛好反照到我們的客廳，結果孩子不給他抱，他就一直捏他、一直打他，很多次(用生氣的口吻)，… 不是說在玩耶，他就是一直打他、一直捏他。
Sin-Sin recalls how such difficult relations also extend to her mother-in-law who would often demonstrate her unwillingness to engage and support with Bing-Bing’s daily care.

One day we wanted to have a tooth extracted and then we went to the paediatric department. It was a rainy day. ... My daughter had to visit the doctor and my son as well. ... My father-in-law asked my mother-in-law to help me with this, but my mother-in-law just kept saying no. After seeing that, I said that’s fine. I could take my children to see the doctor all by myself. (G2: 98-103)

那天就是去看拔牙齒, 又去看小兒科, 然後又下雨, ... 姐姐要去看, 弟弟也要去看, ... 我公公就一直說叫我婆婆幫我帶, 我婆婆就一直不要就對了, 然後我也不想... 我說不用, 我自己帶去就好。

Sin-Sin’s family clearly communicates their lack of acceptance of Bing-Bing by communicating their concern over resources being used to support his daily care and meet his needs. Any interventions that result in excessive effort or cost result in negative and destructive family communication.

If my son had to be hospitalised owing to sickness, my parents-in-law were unable to accept that. They would scold for spending money and needing someone to look after my son at the hospital. It was impossible to ask my mother-in-law to go to the hospital to take care of my son, so I had to do it all by myself. (G2: 121-127)

你就是因為生病起來, ... 住院老人家比較不能接受, 他們就又會在那邊罵, 要花錢啊, 就是要有人來這陪他, 這個小的, 你要婆婆去陪他, 不可能啊, 就是我們要自己啊。

I went to talk to the teacher to let my son go to school, but my husband and my mother-in-law didn’t agree with me at the beginning. ... She is the older generation and would think what this kind of child could gain from learning, for him to go to school was just a waste of money. (G2: 939-942)
Sin-Sin felt powerless and helpless when Bing-Bing received suboptimal long-term medical treatment due to the lack of common values and support within the family.

We had tried acupuncture for one year, but time investment was needed to gain its effects. … We couldn’t only consider ourselves, because we lived with my parents-in-law after all. They would complain when we came home late and they couldn’t see the effects of acupuncture after one year of treatment. I didn’t argue with them over it. Its effects may not be seen under one or two years of treatment. It may need a longer time to feel its effects. (G1: 148-157)

去試過一年，因為針灸要長期，…我們不能想說只考慮到我們，因為現在畢竟都住在一起，你就是…怎麼講…而且那麼晚，公公婆婆他們又想說針灸那麼久一年啊！…都沒有起色，因為我也不想跟他們講說，這種東西本來就要長期，不是一年兩年就看的出來。

Lack of medical services close to home compounded the difficulties Sin-Sin experienced in acquiring quality treatment and care for her son.

No hospital in our county was available for treating squinting eyes and weak eye sight so we had to go a place far away from home. He had a problem with focusing his eyes and was unable to see things clearly. … It’s important to treat the problems early, no matter if it is weak eye sight or squinting. … Now he was studying at school. … Otherwise, his eye problems could get worse and worse, especially as he was a special kid. (G2: 699-707)

做斜視、弱視啊就要帶到比較遠的地方，因為在這邊的醫院還沒有能力可以做啊，沒辦法看，…他的眼睛沒有辦法對焦啊，…因為你有弱視，要早期治療啊，…因為就是他去讀書，…不然會越來越嚴重，而且又是他這種小孩。
To protect Bing-Bing, Sin-Sin avoided situations where others were required to take responsibility for his care. In this way she feels assured that Bing-Bing experiences the best possible quality of care.

I would prefer to take care of my son on my own and not let my father-in-law look after my son. I let my son follow me wherever I went, such as when I was bathing or toileting, or I let him stay with his sister in our room. (G1: 265-267)

我們也不太想要讓他帶，我寧願我在洗澡，他跟我去廁所，也沒有關係，或者是讓他跟他姐姐一起在房間。

Sin-Sin’s concern extended to relinquishing the care to others outside of the family.

I had to let him go to school, even though I felt a little bit worried at the beginning. If the mother could not step out of her world and stayed at home forever, it would harm this child badly [nod her head]. Therefore, I decided to send him to school and have the teachers teach him, but I would stay in contact with the teachers. … He needed the professionals to teach him. (G2: 942-949)

剛開始做媽媽的也會很捨不得，…但是還是要讓他去啊，如果媽媽走不出來，永遠是在這裡面，也是害死這個小孩（點頭說著），對啊，所以就把他送到學校，就是要麻煩老師，就是要跟老師常連絡，… 就是由專業人員去教。

Sin-Sin was always worrying about the quality of daily care of Bing-Bing so she always placed him as her first priority. She did not care about her personal needs or physical discomfort. Until Bing-Bing could get a good quality of care, she felt she had no reason to relax.

Last time I felt my appendix caused the pain my husband rushed me to the emergency room at the hospital. … The doctor asked me to stay in hospital for observation after the injection of a painkiller. I refused to and I insisted on going home, so I had to sign my name on the consent form to show my willingness to leave the hospital. I wanted to go home to take care of my son,
because my mother-in-law wasn’t able to take good care of him. … I wasn’t worrying about my daughter actually, because she knew she could go to her grandpa, grandma, or aunt for help. But my son wasn’t able to do this. He wasn’t able to run and walk. He couldn’t get food on his own when he was hungry, but his sister could. I always put him in the first priority and worried about him. (G2: 897-908)

像颱風那天啊，哦，盲腸也很痛啊，叫我先生載我去打點滴，掛急診，… 我止痛針大一打，要我留院觀察，因為掛急診就是要留院觀察，要不然回去就要寫切結書，我說好，你給我寫一寫，我要回去，我那個早產的沒有人…我婆婆沒辦法照顧，…大的還比較沒關係，她懂的去找阿公、阿爸、阿嗎、伯母，可是這個小的不會啊，他不會走、不會跑，餓了也不會去拿東西來吃啊，但是姐姐可以啊，他就是…會比較煩惱啊，你要做什麼事情，都要把他放在前面啊，對啊，沒辦法。

Main Impression/ Possible Meaning

- Being compelled to be a sole carer
- Lacking family cohesion and support in providing daily care
- Striving for possibilities of improving developmental potential
- Feeling frustration given limited access to medical care resources

Yu-Yu and Ku-Ku

Yu-Yu is a housewife who has two children one of whom is boy child with CP, Ku-Ku, was four years old. He grew up normally until Yu-Yu realized Ku-Ku was walking with an imbalance and on his toes. His diagnosis of CP was a type of spastic monoplegia and he can walk independently and express himself well. His sister is six years old.

Yu-Yu’s husband often gave a negative appraisal of Ku-Ku and denied him, simply because of his outside appearance of physical disability. Sharing no common belief or attitude towards Bing-Bing, Yu-Yu and her husband were unable to work together to achieve the same goal of providing the best environment to support their son.
My husband was rather pessimistic. He was always thinking if the child could not be eventually be cured, what would we do? A child like this...walking like this... He felt his walking wasn’t very stabilized as well as a lack of physical balance, so it was easy for him to fall over often. My husband always thought what should he [Ku-Ku] do after he grows up? Then my husband started telling my son ‘you had to make as much effort as you could [laugh]. … Otherwise how could you manage your later life? After growing up, a boy has to take on a lot of responsibility. Now you are like this … you aren’t able to walk well and aren’t able do anything well, then what can you do?’ (F1: 195-204)

Yu-Yu felt angry and powerless and argued with her husband to advocate for their son, to protect him from possible psychological harm. She encouraged her husband to look at Ku-Ku’s positive qualities and learn to accept what their son was and to let him grow up with a healthy mind as an ordinary child that would lead to a better life.

My husband often told my son his condition was very serious. Sometimes I felt very angry about it. Lately I felt really angry when I heard my husband say it with a very negative tone of voice to our son, so I told my husband ‘the only problem with our son’s legs was higher muscle tone. His walking was fine and he isn’t a cripple. You didn’t need to regard your son as a person whose brain and nerves are all broken down. Our son wasn’t as bad as you thought. He just had a little bit of a defect and was not perfect, even though a healthy child could have little defects too.’ … Because I felt my husband’s negative thinking wasn’t good for our son, as he was just over three years old now, he may know something, but not very much. He couldn’t understand all the
meanings of what you say to him. However, he can do better if we encourage him. (F2: 359-370)

不避他是本身他是...在家裡都很常跟弟弟講的很嚴重，我就會覺得有時候我就很生氣，
像最近有一次比較嚴重，我就很生氣，我就跟他講說‘你兒子也不過是腳的張力比較強，
走路也還好，也沒有到殘廢的地步，你不要把他講的好像他整個腦子啊，整個運動神經
都已經壞掉那樣子。不要把你兒子想像成什麼都不行那樣子，有一點點缺陷不是那麼完
美 ... 就是健康的小孩，也是會有一點缺陷那樣子。’... 我是覺得那不是很好，因為他
現在才三歲多嗎，其實似懂非懂，其實你跟他講，他也不太了解你的意思，可是如果我
們鼓勵他，他會做的比較好。

Yu-Yu felt stress, powerless, and helpless when her husband left her alone to face an
enormous medical system and treatments. As a main caregiver, Yu-Yu’s caring needs
remained unmet since her voice and wishes had not been heard. Her husband’s lack of
engagement meant they were not able to share the same common goal. Her husband
also had no opportunity to appreciate how hard Ku-Ku had tried to overcome his
physical restriction to make any improvement.

For example, my husband would think about something when he was in his
office. He would tell me after he came home ‘to ask the therapist questions
when you went to the rehabilitation.’ He just threw questions at me and left
me to ask them when visiting the hospital and then explain to him when I
came home. At the beginning, I understood what the health professionals said
to me, but I wasn’t able to explain it well to my husband. So I told him “could
you come with me to the hospital next time and I would ask the therapist to
explain it to you.” but he just refused to and said “It’s fine as long as you
could understand it.” (F2: 346-356)

比如說爸爸他今天可能...他覺得想一想，他可能在公司想，想到什麼，他回來他就會跟
你講說‘你去做復健的時候，你去問一下老師什麼問題啊。’，就是會丟...就是那種要去
複診去問，然後回來跟他解釋，可是剛開始解釋的時候，比較不會解釋，可能老師跟我
們講的意思，那我懂，可是不知道怎麼回來轉述給他聽，那時候就會跟他要求說‘這樣
好了，你下次去的時候，你去一次，然後我麻煩老師跟你講。’，可是他就不要，他就說
‘好，那你懂就好了。’
My husband never accompanied my son to rehabilitation. He never had contact with other children with disabilities, so he felt our son’s condition was very severe. I have contact with different children with disabilities, so I could say my son’s condition was fine. (F1: 246-249)

Shortage of therapists and short rehabilitation sessions were another concern that became an obstacle to receiving optimal rehabilitation care. Yu-Yu felt that could slow Ku-Ku’s potential progress.

The therapist at the hospital got married so there was no therapist in that period of time [laugh]. We couldn’t do anything about it, but only took rest. My husband worried it might stop our son’s progress so we looked for a clinic near our home. … The content of rehabilitation was almost the same, but we could have a longer time doing rehabilitation in the ×× hospital, but the clinic only gave you half an hour since they had another child to do the program. … He was getting older now and we thought half an hour was not long enough for him, because he may play with the therapist for fifteen minutes or play around for ten minutes, but only practiced rehabilitation for ten minutes and then he may want to play with other toys. The time was just not long enough. … It wasn’t easy to get a therapist for children’s rehabilitation, for example, when we would go to a clinic to make a request for a lesson, … we might only be able to get one lesson per week. We would ask for more lessons, … but the therapists were fully booked. (F1: 496-526)
Main Impression/ Possible Meaning

- Negative appraisal from her husband
- Feeling angry and helpless when facing medical system alone
- Feeling helpless because of insufficient rehabilitation resources

Wen-Cian and Ming-Ming

Wen-Cian felt disappointed and disempowered, she lost trust in health professionals and her own ability for making medical decisions due to a lack of knowledge and support from medical staff.

Now a major problem is the holistic approach. We had not taken her for any examination of her hip bone. I never thought her hip bone would be a problem, but the doctor told us it was a little bit dislocated. I was quite worried about her feet, but the doctor told me I need not worry about it. ... The other day, someone told me my daughter had scoliosis. No one had given me the whole picture on what I should do. Every one just looked at a certain part and local problem. I really worried about this. ... I didn’t know when I should deal with some certain problems, so I didn’t miss the time for the treatment. ... I shouldn’t blame them for this. I should blame myself but I didn’t know what the best time for treatment was. Every doctor had their own idea for the best time of treatment. ... I had no idea what I should do now. ... I just felt tired and disappointed with the medical system. (N1: 992-1015)

現在很大的一個問題是整體的部份，像我們之前都沒有照過髖骨，我從來沒想到她髖骨的問題，然後×醫師跟我們說它有一點跑掉，我很擔心她的腳，可是醫生跟我講說不用擔心她的腳 … 那一天又有人跟我說她脊椎側彎，沒有一個人告訴我它整體，我該怎麼去處理，每一個人看一部分，一部分，每個人都是看局部的，我還蠻擔心的，… 什麼時候要去處理，如果又錯過了 … 我又不能去怪人家，怪我自己，可是我又不曉得什麼時間是適當的，而且每個醫生當下抓的點又不一樣，… 我已經不知道要怎麼辦，… 我覺得跑這個醫療就覺得有一點失望跟累。
As a result, Wen-Cian visited a number of hospitals to regain control over the medical quality of care but it was time and energy consuming.

I had to do better than the doctors [laugh]. I had to make decisions. Take eyes, for example. Opinions from three doctors were different. First one said that surgery was needed, but her vision is OK since she began wearing glasses. The second one said surgery was not necessary, but she needed a new pair of glasses. The last one said she didn’t need surgery, but this pair of glasses was OK. … If today it isn’t raining, I shall have to take her to visit a fourth doctor. (N1: 1056-1065)

我要變的比醫生還厲害 (笑), 要我決定, 譬如說眼睛, 三個醫生講的都不一樣, … 第一個說什麼要開刀, 鏡片度數吻合, 第二個講不開刀, 鏡片不吻合, 第三個講不開刀, 但是跟第一個一樣的, 鏡面吻合, … 要不是今天下雨，我本來還要帶她去看第四個醫生。

Wen-Cian compared two different rehabilitation facilities to know what the quality of rehabilitation should be to make sure Ming-Ming’s standard of rehabilitation care was satisfactory. Wen-Cian felt sad and discouraged when she acknowledged the insufficient rehabilitation materials and non-qualified setting that could possibly deprive her daughter of the opportunity to improve her developmental potential and progress.

My previous impression of ×× hospital was that it didn’t have a rehabilitation area for children with disabilities. She [another mother] told me now it had this part. … I felt very happy and went to have a look at it. At the moment when I opened the curtain [laugh] … I just felt ‘oh, my goodness’. … It was just a very small place and very crowded. Its teaching materials weren’t that much. … My impression of ×× hospital [another hospital] was very tidy and clean and always like a new setting. … Oh, to be honest, I felt the environment at ×× hospital was quite dirty and crowded, just like a shanty town [laugh]. (N1: 3470-3486)
我之前對  ×× (hospital name) 的印象是它應該是沒有小朋友的區塊，他那天跟我說有，… 我還很高興說，好，有小朋友的區塊就，那我就打開簾子的一剎那（笑），… 到現在我還是覺得說天哪… 就那麼一小塊，然後好擁擠，然後教具真的也沒有很多，…  ×× (another hospital name) 給我的感覺就是乾乾淨淨，永遠都是新新的感覺，…  ×× (hospital name) 給我的感覺，哦，講一句現實就是髒髒的，就是很擁擠，然後有點那種貧民窟的那種（笑）。

Wen-Cian felt sad and frustrated when she saw that the therapists lacked enthusiasm about their work. The therapists did not respect or actively involve her in the rehabilitation or communicate with Wen-Cian about what exercises should be provided to Ming-Ming to give her an individual training program to reach optimal rehabilitation. That led to insufficient and sub-standard rehabilitation care and she felt no hope for her daughter’s developmental progress in the future.

The therapists just let her choose what she wanted to practice. I couldn’t say to him that my daughter already knew how to do it. I thought I could not interfere in his teaching. But I believed my daughter chose one tool that was too simple for her. … After half an hour I entered the therapy room and she hadn’t even finished it! The therapist only said, “Oh, hurry up. Oh, you better hurry up. You always act like this.” [The mother spoke and copied the therapist’s action to use her right hand to prop against her chin without energy and power]. Oh [heave a sigh], I just thought why did I come here today and this session had been just wasted my time. … The session only took half an hour, … but it took us more than two hours to go there and back home. I felt depressed that my daughter couldn’t get anything from the rehabilitation session. I just felt sad. (N1: 3436-3447)

那老師已經讓她翻、讓她選，那我也不便說什麼，說那個孩子已經會了，我想我不能介入這樣一個，可是我相信那個東西對我女兒來講太容易了，… 竟然也沒想到我半個小時進去之後，她竟然還沒拼完，老師在那邊，快一點啦，快一點啦，你都這樣（模仿復健師一手撐著自己的臉頰，很沒有精神及無力的語氣），哦（嘆了一大口氣），我心裡想，我今天來這一趟幹嘛，會有一點覺得浪費，去那邊半個小時，… 來回兩個多小時，實際上… 上課你會，有時候你會覺得很沮喪，我那時候跑那麼一趟做不到東西，我都會很難過。
Wen-Cian and her husband understood that they had the right to ask therapists to make an individual rehabilitation plan. Wen-Cian feared that arguing with the therapists could damage their relationship, and that the poor relationship could negatively impact on Ming-Ming’s program quality.

My husband felt very angry during that period of time, so he asked me to request the therapists to make a plan for our daughter, an individual plan. … My husband kept asking me to do it. Oh, my goodness, could I dare do that. If I did, perhaps no one would be willing to take care of our daughter, also no one did this kind of thing before. I knew I had the right to do it, but I did not have the guts. … Firstly, I didn’t feel comfortable to ask it after we were familiar with the therapists. Secondly, I could tell you no one liked a demanding mother. I was struggling with it. … I told my husband that every therapist had to service a lot a lot of children, so we couldn’t make excessive demands. I just felt that I troubled someone when I asked them to do something. … some therapists even thought that you did not have the right to ask them to do something. (N1: 1444-1466)

Wen-Cian felt bothered when Ming-Ming often received rehabilitation training from different therapists due to their rotations. Wen-Cian was worried that having a new therapist meant an unexpected change and the consistency and persistence of the program would be a problem, which would lower the quality of rehabilitation care.

The previous medical facility we went to, the therapists changed often. The parents could not easily adapt themselves to the therapists, because the
therapists needed time to communicate with their students. For my child, … especially in rehabilitation, every therapist emphasised a different point in terms of training programs, so the program would be changed due to different therapists. After rotation, the previous therapist may hand over his/her job to other therapists, but I didn’t believe this happened. Different rehabilitation program may happen because every therapist had their own outcome for assessment and opinion. … This did really bother me. (N2: 1418-1425)

To gain a better quality of rehabilitation program, Wen-Cian searched for a variety of medical facilities to find one with optimal rehabilitation quality. Gaining support from therapists let her have the hope of her daughter improving.

After I went to the clinic, the therapist in the clinic let me feel … he let me know that therapists did not let the children leave right after thirty minutes. … He would continually help my child do the rehabilitation if the next child had not come yet, or even if the next child had already come, he would give my child a little more time to help her practice some kind of exercise or posture if he felt my child was not doing well. … I felt very satisfied so far when I looked at him at this point. That meant he demanded a higher standard which was better for my child’s training. (N1: 3345-3359)

to這個診所之後,那個老師我是覺得說,他就是讓我看到說…原來不是說每一個老師都是三十分鐘到就就把孩子, …下一個小朋友沒來,他繼續幫你做,就算下一個小朋友來了,他覺得你今天還不夠,他就說再把她留一下,再讓她做一個姿勢,或再做一個動作,就讓她再執行一下這樣子, … 他這一點做的讓我到現在…我都覺得說很好,就是說他要求很高, 所以相對就是對孩子的訓練會比較好。
Performing it [rehabilitation program] would be a stress and a burden. How can I say … We were too tired and busy. … We had trouble doing it regularly, which made me feel guilty, because it was my duty [laugh]. While we were stretching her legs at home, … the phone would ring or friends would come to visit us at our home. Whatever happened, it would be interrupted. (N1: 457-463)

我覺得很痛苦，每次拉筋是我覺得那種是拉……所以為什麼我們家之前拉筋做的很不確
實，就是因為做的……親子關係會變得很差，真的，……我老公每次一拉就氣，氣就
乾脆就放棄了，哭嘛，……為什麼你要這樣，因為又坳不下去，你又壓不下去的時候，
她因為哭……愈用力，你就愈壓愈氣，就變成誇她也難過，她哭了，……，所以就為什麼我
們要花很多時間去外面給老師拉筋，就這樣，因為你自己狠不下那個手啊。

Wen-Cian also experienced concerns about Ming-Ming’s social and educational development. She felt sad and powerless when Ming-Ming was excluded from her peers. She felt that there was no common ground and connection with her peers.
Ming-Ming was not able to share her personal experience with them, which resulted in a feeling of isolation and an unhappy school life.

My daughter seemed quite good from her appearance, so most people would ignore her. I felt quite sad since she had always been alone when she was studying at school. For example, it was quite difficult for her to wear orthoses, shoes, or change shoes. Her classmates had already moved to the next class or spot. She would say that she didn’t want to go and just stayed at the class. After a long period of time, her interaction with her peers had changed. … Her classmates would think that my daughter was really different from them and this kind of isolation would become more and more serious. … One day, she told me tearfully she had no friend so she didn’t want to go to school. (N1: 581-589)

There was no common goal or philosophy between Wen-Cian and the teachers, because the teachers did not value her special knowledge of her daughter and failed to provide Ming-Ming with personal help, which led to her unhappy school life. Wen-Cian would sometimes keep silent, but she still tried to continually provide Ming-Ming with opportunities to interact with her peers to have a happier school life.

She is now studying at senior class in kindergarten, so she was quite sensitive. … I could feel that she became more and more withdrawn, so I would like to accompany her to help her with her interpersonal relationships. However, the teachers thought that I did too much for my daughter to help her build up her peer relationship, because it should be my daughter’s business. … For example, last time on her birthday, I bought a cake and some chocolate. I hoped that she could share the chocolate with her classmates on her own, but the teacher just took it away [wincing laugh]. … I was quite hurt, because I
just used this opportunity to help my child build up her relationship with other kids. I found different teachers had different strategies to handle their business. I did not know how to tell the teacher that I just wanted my daughter to give it to the children. … When we travelled I would buy some specialty goods to let her have an opportunity to interact with other children because of sharing the goods. (N1: 2735-2768)

然後她現在大班，實在是太敏感了，… 我覺得縮的越來越明顯，所以我會想要去陪伴她，去把這個地方…再幫她拉出來一點這樣，老師會覺得你媽媽是不是做太多，去幫她建立人脈，人脈應該是靠孩子，…像那次她生日，我買了蛋糕，還買了巧克力，我買巧克力是希望她去發給同學，後來是老師收起來（無奈笑一下），… 但是我會覺得媽媽很受傷，因為我是藉這個機會讓孩子去建立一些人際關係，我發現每個老師處理不一樣，我不曉得我怎麼去跟老師講我就是要她發給孩子，…那我會利用買名產的機會，我們去哪裡玩，有名產，藉由這樣的機會讓妳去分給孩子，那妳跟孩子分享的時候是不是有互動。

Wen-Cian felt alone in building up her daughter’s self-image when the teachers did not have the same education philosophy as her to assist her in giving Ming-Ming positive feelings of herself. They also seemed to lose hope of the possibility of possessing an academic life in the future when they had always received negative academic feedback.

I was quite worried about … if the teachers treated her like an ordinary child I could imagine what her academic performance would be …. [heave a sigh] in the lower rank. I could accept that but I was afraid that she might not be able to accept that. … For example, she had a pronunciation lesson and learned to write a phonetic notation. She got four stars for her work. I felt very satisfied with four stars. … She said she was not good at all, because ten stars were the best [laugh]. … I knew she could only get four stars from others’ point of view. Writing for her … it was difficult to ask her to finish all the writing due to her hand problem. So I felt quite happy when she could finish the whole page of writing in the class. She felt a little bit frustrated. It was not that we did not want her to be frustrated, but the frustration should be given little by little. From some teachers’ points of view, I am spoiling my daughter and I dote on
Wen-Cian felt a great anxiety and worry about Ming-Ming’s physical safety at school. The unexpected accidents not only hurt Ming-Ming’s physically, but also isolated her from her peers and limited her exploration of school life, which led to her to have a low self-identity and lower quality school life. However, Wen-Cian encouraged Ming-Ming to open her mind and practice rehabilitation exercises to become a stronger person, so that she could cope with the situation.

I was worried … worried that teachers would call and say she had fallen over, fainted, or gotten hurt. … As long as she was at school, I just worried about this problem. (N1: 3160-3164)

When I looked at those wounds and bruises on her knees after she came back from school, I really felt sad. She was knocked down by a child on the second day of school. … I could only turn my tears in on myself. … But from this point of view, I asked my daughter to learn how to forgive someone who knocked you down. You could not blame them, but yourself due to your unbalanced standing. … You did not fear others’ bumping, if you could stand
well. On the other hand, I would use this reason to ask her do well when we had rehabilitation class. (N1: 3179-3191)

像我女兒現在去學校讀書，我說每天跌回來，我看到那個膝蓋跌...那個傷口、那個瘀青，真的是，你會很難過，說剛去第二天就被小朋友撞倒，... 眼淚是往肚子裡面吞的，... 就這一點也是要叫我女兒學習就是說，... 就對你在碰撞方面，你一定要學習去原諒別人，你絕不能怪別人，你只能怪你自己還站不穩，... 因為我覺得說你今天站穩，你不怕人家撞，一方面你是要求她做復健的時候，會用這個理由去要求她。

Main Impression/ Possible Meaning

- Mistrusting medical advice
- Feeling frustrated and angry about poor rehabilitation support
- Feeling conflict between quality of rehabilitation and family relationships
- Inability to share educational philosophy with the teachers
- Worrying about her daughter’s peer relationships
- Worrying about her daughter’s safety at school

Li-Li and Hua-Hua

Li-Li found it difficult to find a balance between supporting her daughter’s development and spoiling her.

I thought I just tried to do my best when I had this kind of child, but it wasn’t good to spoil her all the time. However, she was quite pathetic if I didn’t dote on her, because with her physical disability she wasn’t able to catch up with others. But if I dote on her too much, that could spoil her and it was difficult to adjust the condition back. (D1: 169-172)

是覺得說你如果有小孩像這樣的情形，就是盡量，也不能說一直寵她，你不寵她又看她這樣可憐，行動不方便，每樣都跟不上人家，可是如果寵她寵太多，會變成習慣，以後你要把她調回來也很難調了。

She will turn fifteen next year. She grew up every day. I don’t know what she is thinking now. Sometimes she will scold me, that I caused her to become CP
and that it was all my responsibility. I felt very sad when I heard that. I took care of her and carried her to the bathroom. I had to hold and carry her more than ten times a day. I never ever complained about her. I did everything I could do and she treated me like that. Sometimes I just didn’t know what was in her mind and thoughts. … I just tried doing as much as I could. Something I really couldn’t do much about. (D1: 282-290)

Li-Li tried hard to teach Hua-Hua to open her mind to accept who she is and put her thoughts into perspective, because Li-Li did not want to give up hope for her daughter to have a good mental health and an open mind.

I could only advise her to open her mind. No matter what, she didn’t need to feel fear of being teased by others just because of her physical disability. All people can get sick, so you didn’t need to care about when they laugh at you. I just tried to give her these ideas, but I don’t know whether she could understand it or not [sob and tears in her eyes]. (D1: 349-352)

Facing the issue of sibling jealousy not only aroused the issue of sibling conflict, but also prevented Li-Li from providing a high quality of care to Hua-Hua, because Hua-Hua’s brother did not possess common goals with Li-Li and lacked the willingness to actively or passively assist Li-Li or his sister in gaining a better quality of care.
Her younger brother is now eleven years old. She and her brother are always fighting, fighting, and fighting with each other everyday. That makes me almost burn-out. One of them likes doing this the other wants to do that. My son can’t understand why I am so nice to his sister and not treating him in the same way. My thoughts are that my son has a healthy body and limbs so he could go out and have fun, but his sister can’t and she always has to rely on a wheelchair to go out. (D1: 341-345)

弟弟喔，他現在１１歲他也不知道，兩個人每天就是吵吵吵，吵到我都快崩潰了，我也不知道要怎麼講，一個這樣、一個那樣，他到現在也不知道我為什麼對姐姐那麼好，對他不好，因為我的心態是想說你有手有腳可以出去外面玩，他姐姐沒辦法，都要靠輪椅、坐輪椅、推輪椅出去外面。

My son asked “why did he have to let her do what she wanted to do?” I said to him “you are her brother, if you don’t yield to her, no one will.” (D1: 158-159)

他就說‘我為什麼讓她。’ 我說‘你不讓她，不然誰讓她。’

Li-Li felt that the school failed to provide Hua-Hua with a suitable learning environment by ignoring her personal disability and needs. She worried that the standard of Hua-Hua’s learning environment could result in her losing hope of having an independent life in the future, because of insufficient knowledge and skills. She thought that Hua-Hua might also lose her interest in studying at school, which would limit her learning experiences and perspectives on life.

I don’t know how to get her to the special resource class when she had to use her wheelchair. Her teacher asked whether I wanted her to attend this kind of class. The school lacks a ramp to access the class room and she is too heavy to be carried upstairs. The classes are mostly upstairs. How can I carry her up there? It is impossible to ask other students to help her to go there as well. So she has missed a lot of classes. (D2: 352-357)
推輪椅要怎樣上資源班，老師之前有問我要不要給她上資源班，我說她本身這麼胖啦，
學校也沒有做上下坡的路，教室不是在樓上，不然就是樓梯一層一層的，我怎麼上的去，
也不可能有別的小朋友扶她上去啦，不可能，所以有很多課程都上不到。

The toilet at the school affected Hua-Hua’s dignity, because she could not use it 
individually. Li-Li found the chance to express her wish to improve the toilet setting 
to keep Hua-Hua independent functions.

When she studied at elementary school the toilet was close to her classroom, 
so she had no problem in going alone. But now she has to take a long circle to 
the toilet [in junior high school]. … Sometimes she rushes to the toilet right 
after she comes home from school. She said ‘mum, hurry up, help me, I want 
to go the toilet.’ I said ‘why don’t you ask your classmates to help you go to 
the toilet?’ She said that she had difficulty in using the toilet, because it was 
too high and there is no handrail. They put a handrail in the toilet after I told 
them. (D2: 293-302)

就說…之前他們國小的時候，廁所在旁邊嗎，輪椅推出來比較近，她可以自己推，現 
在她要繞好大一圈才可以上廁所。… 有時候回來才趕緊要上廁所，她說‘媽媽，趕快 
抱我，我要尿尿。’ 我說你為什麼不叫同學推你進去，她說那個廁所很難上，很高，然 
後沒有扶杆啦，跟他們講以後才有扶杆啦。

There was no qualified teacher with special knowledge about disabled children in the 
general school to provide qualified teaching to Hua-Hua.

When she was studying at elementary school, the teachers asked me why I did 
not let her go to a special school, because she could only learn a little bit in a 
general school. She was unable to learn a lot in general school, because the 
teachers only had a little knowledge about the children with disabilities. (D2: 
333-336)

以前她唸的國小，那個老師也問我為什麼不讓她去特殊學校，特殊學校學的比較多，一 
般的學校沒辦法學那麼多，老師也比較不懂。
Li-Li experienced anger and frustration when the bus design did not meet their needs but affected Li-Li’s physical needs. The attitude of the bus driver not only harmed their dignity but also forced Hua-Hua to withdraw from social contact. To deal with this situation, Li-Li looked for another kind of transport and spoke to the bus driver about her daughter’s rights and needs.

I didn’t know how to drive a car when my daughter was little, so we always took the bus. Over the last two or three years, the therapists in ×× hospital told me we could take the bus that belonged to the government. Otherwise, I used to take the local bus. … Sometimes it took me a long time to get on the bus as I had to hold my daughter because she was quite heavy. It was too expensive to take a cab to rehabilitation, because we are working class people. … Some bus drivers were relatively nice, so they told me it was fine for them to wait for me to settle my daughter. But some bus drivers treated me very badly and said some bad words to me. He said ‘last time it was my bad luck to drive you. My bad luck is back because I have encountered you again.’ I talked back to the bus driver ‘what did you mean by saying that? We didn’t cut in the queue and waited for our turn. Why did you say that it was your bad luck to drive us. … I paid for my bus fare [said with angry tone]’. … I just settled down my daughter first and then got off the bus and took the wheelchair to the bus again. It only took two or three seconds. How can a bus driver be without any sympathy.’ (D2: 392-425)
It was a challenge for Li-Li to balance the two roles of being a financial provider and a main caregiver. Li-Li felt sad and helpless when Hua-Hua did not understand her difficulties. Conflict between the mother and daughter would occur and impact on their affection, bonding and connection.

Her father was thrown into unemployment for several years. He got a disability certificate from the last two years. … We got low-income family support from the government. I didn’t have a full time job, so I took any kind of job such as washing toilets or being a sweeper. I got two thousand NT dollars per month for washing toilets. Who likes washing toilets, but I didn’t care, as I wasn’t well-educated. I took all kinds of chances to do a job. (D1: 653-671)

Li-Li felt frustrated and powerless when she was not able to preserve Hua-Hua’s independent physical function due to her financial stress. Depending on Li-Li’s help, Hua-Hua’s dignity and body image had been affected, which led to a low quality of existence. In spite of the difficulty, Li-Li still carried Hua-Hua anywhere she wanted to go. That was the only way to solve the current situation.

I wasn’t able to carry her on my back after she was in third grade. … And then I let her wear and walk in callipers. … They had to be changed every two years. I feared that she would be hurt if she wore cheap ones. … I became upset if she felt hurt just because of her callipers. But I would have a financial problem if I had to buy better quality callipers. … I have still had to borrow money to have a good set made for her. She is quite tall and her feet have became bigger and bigger. So her feet didn’t fit into the callipers any more. Her third ones cost me about thirty thousand NT dollars and the fourth ones were about forty thousand NT dollars. … The government only supported us with half of the whole price. We spent thirty thousand NT dollars and the government gave us fourteen thousand NT dollars. (D1: 257-266)
背到三年級我就背不動她了，…然後我又做鐵鞋給她穿，…反正就是兩年要換一次鐵鞋，鐵鞋我又怕做便宜的，怕她穿了會痛，…小孩子痛，媽媽心更痛，做好一點，經濟又有問題，…是慢慢去籌錢，因為她人長高，腳也會長大，鞋子變小就不能穿，第三雙我做了一雙三萬的，第四雙做四萬的，…然後政府又補助一半而已，你做三萬，他補一萬四。

I couldn’t offer her the electric wheelchair which cost about sixty or seventy thousand NT dollars, because the grant-in-aid would not be enough to cover my expenses. To get the electric wheelchair, I would have to pay seventy thousand NT dollars. I don’t think I have the ability to pay that.” (D2: 308-310)

電動車那一個要六、七萬，我哪有能力付那個…去給她騎，因為補助不夠啊，東西一來，你就要一下子付七萬多塊，我哪有能力去付這個。

The door to bathroom was too small, so I had to carry her to the bathroom. I also had to carry her from her room to the wheelchair and push the wheelchair to the motorcycle outside the house. After taking her to school, I had to carry her off my motorcycle. I had to carry her almost ten times a day. (D1: 296-299)

輪椅推到這個門口，門口這麼小，然後我要移到浴室裡面，從後面房間裡面抱出來到輪椅，然後又推出來，又移到摩托車那裡，輪椅推出去，騎摩托車到學校還要把她抱下來，一天將近抱她十次阿。

Main Impression/ Possible Meaning

- Experiencing a poor relationship with her daughter with CP
- Living with sibling jealousy
- Losing hope for a better educational environment
- Being mistreated by public servants
- Feeling powerless because of lack of money
Shared meanings which transcend the particular – Facing the challenge and barriers to maternal caring

Concern is experienced when the mothers encounter the challenge and barriers of taking care of their children with CP. Caring experiences involve their day-to-day life within their family and other people or occasionally in their community in terms of their world. The meaning of Being-in-the-world can be defined through understanding their caring context and relationships. Seven shared meanings emerged from stories of concern when the mothers dealt with their caring challenge and barriers in their daily lives:

- Experiencing difficult relationships with others
- Being marginalised
- Feeling burdened as a sole primary caregiver
- Experiencing family conflict because of care-giving demands
- Learning to balance being over-protective and encouraging independence
- Experiencing limited support (family, medical, education, public, economic)

Sin-Sin experienced that Bing-Bing was marginalized by her parents-in-law who treated him without humanity, which was a barrier to building up a sense of belonging or love. Her mother-in-law devalued Bing-Bing’s learning potential and did not support his medical care, which became barriers to his developmental progress and standard of medical care. In traditional Chinese society, parents-in-law possess the highest authority in the family, so their decisions can influence daily care and quality of existence. Sin-Sin’s husband was unwilling to share caring responsibilities with her and was not motivated to build a relationship bond or human connection with their son. She, therefore, felt very lonely and lost the hope of any possibility of developing common values or goals for her family to work together. Lack of family cohesion threatened. In addition, Sin-Sin felt powerless and helpless when she felt uneasy about approaching qualified medical facilities or health professionals. She felt dissatisfied with her maternal role and lost self-worth when Bing-Bing’s caring needs remained unmet.
Yu-Yu felt alone in fighting to provide a positive family situation for Ku-Ku, and found it difficult to maintain a standard of care with her husband’s non-accepting attitude toward Ku-Ku. She thought her husband’s attitude directly impacted on Ku-Ku’s self-image and dignity and they did not share a human connection or bonding. Yu-Yu felt angry and helpless and lost hope of improving Ku-Ku’s developmental progress due to her husband’s unwillingness to be involved. Yu-Yu realised that being overprotective of Ku-Ku could place him in an isolated world that could mean that he could lose the possibility of becoming independent in mainstream society.

Yu-Yu felt powerless and anxious when there was no consistent medical information to support her in making the medical decisions. Yu-Yu felt that she almost lost her motivation to dedicate herself to the long caring journey when the physician gave medical information without hope. Lacking helpful medical facilities, a shortage of therapists, and short or inadequate rehabilitation sessions was a barrier to Ku-Ku’s developmental progress. Yu-Yu’s maternal identity and self-worth were affected, because she felt it was difficult to 'defeat' the medical system.

Wen-Cian’s needs for holistic medical approach and complete information were not heard. The health professionals did not include her as a member of the medical team or listen to her voice. She feared that Ming-Ming could lose the timely opportunities to manage her medical problems, which could worsen her condition and result in a lower quality of life. The therapists lacked enthusiasm about their work and they had been unable to provide her daughter with individual rehabilitation plans or meet her daughter’s personal needs. The therapists often rotated, so their previous relationships, goals, or efforts were not maintained. The poor rehabilitation program meant that Wen-Cian experienced a loss of possibilities for improving her daughter’s progress. Wen-Cian felt no trust in the medical system and feared her care could not meet Ming-Ming’s daily caring needs. She felt that she had not fulfilled her maternal role as advocate for her daughter.

Wen-Cian experienced concern over Ming-Ming’s social and educational opportunities as well as her physical development and function. Wen-Cian felt powerless and frustrated when the teachers disagreed with her educational
philosophies and beliefs, especially when Wen-Cian tried to help Ming-Ming with her peer relationship or encourage Ming-Ming by giving positive feedback. The teacher regarded it as barrier to Ming-Ming’s school life due to her over-protection. The school teachers, therefore, were unable to give individual help to Ming-Ming to assist her in adapting to school life. As a result, Ming-Ming experienced frustration with her peer relationships and academic performance, negatively influencing her self-identity and the quality of daily life at school.

Under financial stress, Li-Li was incapable of offering Hua-Hua high quality equipment to preserve her physical independent functions. Although Li-Li tried to balance the roles of being a bread-winner and main caregiver, she gained no understanding from Hua-Hua. Her personal feelings of conflicts increased, becoming a barrier to her relationship with Li-Li, as well as affecting her care. Li-Li also faced the issue of sibling jealousy. The sibling did not understand her concerns or worries or have the same goals. Hua-Hua’s care was not maintained at the same standard when her sibling was not willing to participate in her daily care. Family issues led Li-Li to doubt her ability to maintain a 'good' standard of care for her daughter, further impacting on her self-worth and satisfaction.

The school’s inability to provide a disabled-friendly environment to enable Hua-Hua to preserve her physical function independently not only affected her dignity, but also prevented her from attending all classes. The school also lacked qualified teachers with knowledge of disabilities to develop an individualized curriculum for Hua-Hua to meet her personal learning needs. Li-Li and Hua-Hua felt this would affect the opportunity of being independent in the future, due to insufficient knowledge and skills. Poor public transport design and bus driver’s public insulting remarks harmed Li-Li and Hua-Hua’s dignity, which pushed them to disconnect and withdraw from society losing opportunities to expand life experience. Li-Li felt powerless and helpless when she saw that there was no hope for Hua-Hua to have a better quality of life in the future.
Interpretive Summary

A sense of being marginalised could occur at home, community, school, or society. Rejection from others could hurt the child’s dignity and self-identity, when they experienced being excluded and felt no belonging, acceptance, empathy, or humanity. The children could withdraw from society or the relationships with others. Thus they could not enjoy their life and expand their life experiences, which resulted in a lower quality of life and losing the possibility of hope for an independent life in the future for their children. The mothers felt powerless and helpless when they could not protect their children from psychological harm in the uncontrolled situations, which could affect their feelings about their maternal role of protector and maternal identity. They also felt feelings of dissatisfaction and lower self-worth.

A poor relationship with their parents-in-law or husbands became an important issue in some families, because giving birth to a disabled child did not live up to the expectations of their family and caused loss of family honour and face in society. Some families did not value the child with CP, so the child missed important opportunities for treatment that the mothers felt lessened the possibilities for a cure or improving their developmental progress. When they gained no or little support, the mother felt alone in bearing the primary caring responsibility. These mothers worried that the quality of daily care could not be maintained, because other family members lacked the willingness to be involved in the children’s daily care, understanding the children’s personal preferences, or building up human connection or bonding with the children. The mothers’ caring needs had not been heard by their family, which could lower the children’s daily life and the quality of existence. They questioned their ability to fulfil their advocacy role, thus denying them the possibilities of feeling worth and satisfaction.

In their relationships with their children with CP, mothers had paradoxical feelings of encouraging them to be independent, while still protecting them from harm. The mothers realised that overprotection could result in their children losing possibilities of having an independent life in the future. However, they questioned themselves as to whether they had done enough for their children to meet traditional Chinese expectations of being 'good' mothers. Loss of perspective in dealing with their
children’s daily care could influence the quality of care their children received, which threatened their maternal role of expert family carer and they felt dissatisfied, experienced lower self-worth and suffered from a poor maternal identity.

Therapy at home could complicate the mother-child relationship, because of their children’s emotional responses to the therapy. Mothers experienced difficulty in balancing their roles of being mothers and being therapists, especially when their children were unable to develop the shared common goals or attitudes towards the therapy. Not only did that worsen their relationship or bonding with their children, but also possibly decreased their children’s potential progress. Poor quality rehabilitation practiced at home made them feel powerless and helpless, which could damage their maternal caring role of therapist and leave them feeling less satisfied and worthy.

Another family relationship difficulty was experienced when the siblings felt jealousy or stress or refused to participate in caring for the child with CP. The siblings may have difficulty in developing a good understanding of their mothers values, be unable empathise with their disabled siblings, or be reluctant to actively participate in personal individualised care activities. Because of these stresses, some siblings were unwilling to develop a close relationship or close bond with the child with CP, leading to a low quality of existence of child with CP. The mothers felt powerless and helpless when they could not teach the siblings to accept the child with CP with caring and understanding.

Poor medical support could result from health professionals attitudes because the child’s medical care needs had not been met nor were the mothers voices heard. Health professionals did not regard the mothers as members of the treatment team to communicate their 'special' knowledge of their children’s medical condition and this led to a lack of individualized care. Mothers felt frustrated and sad when their 'local' knowledge was not valued or recognised in supporting the quality of rehabilitation or medical care. Some health professionals put the medical issues before the children with CP, so they would not treat the children with humanity. They often gave information without a holistic assessment or providing hope, which made the mothers feel there was no hope for the future or support through the long caring journey. Feelings of mistrust of health professionals and poor care provision disempowered the
mothers. Their maternal role of advocate and care were undermined and they felt dissatisfied experiencing low feelings of self-worth.

Poor medical support meant that they found it difficult to access useful and qualified medical resources, resulting in poor or sub-standard medical care. The mothers kept visiting different medical services or therapists to find better care. Each time they found a new health professional or therapist they had to start over to communicate their concerns about their children, to build up a trusting relationship to ensure the quality of medical care could be maintained. They felt frustrated when they lost the best opportunities to improve their children’s condition. This often resulted in feelings of failure as an advocate, lower self-worth and dissatisfaction.

When they experienced insufficient support from the education system, the mothers felt powerless and helpless. The mothers were very concerned when they were not enough qualified teachers with 'special' knowledge of children with CP and their educational philosophies were not supported by the teachers. They were concerned when their voices had not been valued, and felt their children’s educational needs remained unmet. At times the children with CP would withdraw from school life and had difficulty in identifying with their peers, or there were barriers to them achieving their academic potential. The children in this situation could feel less enthusiasm or confidence with their academic achievements, negatively impacting on them achieving their academic potential. The mothers felt powerless when their children with CP were treated without care, because they were unable to be independent at school due to the lack of a disability-friendly environment. They were unable to expand their life experiences, and lost the possibilities to be independent. A poor school environment reduced their children’s school life to a sub-standard level.

Some mothers experienced financial stress, so they had difficulty in preserving their children’s independent physical functions. They lost the hope of acting for themselves and damaged their children’s self-image and dignity, which could negatively impact on their maternal role as preserver. On the other hand, the mothers also felt it was harder to maintain the quality of daily care when they assumed both roles of financial provider and main caregiver. Lessening the focus on their daily caring activities
conflicted with their central notion of placing their children’s care as their first priority.

Reflecting on their concerns led me to ask some essential questions. How do mothers anticipate the future for themselves and their children? How might mothers seize possibilities to care in ways that enhance their everyday existence? The mothers experienced some difficult issues with their family members and the people or environment around them. In the next chapter I will present how the mothers come to experience their situation in a positive and hopeful way. They provide stories of their experiences of learning how to seize future possibilities to care in a meaningful and self-fulfilling ways. They share their motivations to keep moving forward, even though they have to experience barriers to their everyday care-giving.
Chapter 8

Seizing Possibilities for Future Care-giving

Introduction

A person is situated in-the-world and experiences being in time, so Heidegger argued a human being is always temporal (Heidegger, 1927/1962, pp. 18-19, 39-40). The person exists in the world in the present, is influenced by past and is “thrown” or projected into the future (Kellett, 1997). Time is directional and relational and any meaningful event connects the past and future to the now.

For Heidegger, future is meaningful because people have to move to the future in their whole life time to anticipate and look forward to possibilities. The fundamental attitude of Being is toward a future and from a past (Gelven, 1989, p. 179). The future is the most important of Heidegger’s concept because it presents possibilities to render existence meaningful (Gelven, 1989, p. 182). It was such possibilities that allowed the participating mothers in this study to look at their future with anticipation of possibilities defined as meaningful.

In this chapter, I introduce four participating mothers and one new mother and their children (see Appendix G and H) whose stories demonstrate their sense of future possibilities, providing them with hope and anticipation. Such motivation fuels their desire to continue to be involved in their daily care-giving and not be relentlessly focused on present day challenges and difficulties. The participating mothers share their experience of six possibilities: searching for improvement; adjusting their expectations; appreciating the potential for enrichment through cherishing and treasuring; anticipating independence and seizing upon possibilities for self.

Fang-Fang and Jing-Jing

Fang-Fang felt frustrated when Jing-Jing’s situation could not be controlled well using traditional medical approaches, so she turned to the employment of multiple traditional Chinese rituals to exploit all possibilities to enhance Jing-Jing’s progress.
The anticipation of improvement provided her with the motivation to continually access alternative and diverse medical supports that might result in future benefits for Jing-Jing.

My child still stayed the way she was and wasn’t able to be cured. Although we took all kinds of examinations by the doctors’ orders, they couldn’t find any problem. Also we kept taking rehabilitation sessions, but her progress was still very slow. … The location of my grandfather’s grave in terms of feng-shui [風水] … the urn that held the bones of his body could be the problem. … My husband and I asked my husband’s classmate who was the expert of feng-shui. … We were quite happy to re-open and clean my grandfather’s urn. We did it without anyone’s knowledge, just wished it could better my daughter’s health. (B1: 260-282)

We also tried to “call back child’s frightened soul” [shou-jing, 收驚], to worship, change fate and so forth. All of these things wanted to get rid of bad luck. … Taking a glance at the kids coming to rehabilitation, nearly each one of them wore an amulet. (B1: 240-243)

To lower expectations was crucial when Jing-Jing’s progress could not live up to Fang-Fang’s expectations.

At the beginning I have been full of expectations, for example, when the Chinese New Year was coming, we expected her to walk after the Chinese New Year. This was our sincere expectations. When the Chinese New Year
passed, and then Tomb-Brushing Festival and Dragon Boat Festival came, and then we expected that she could walk on the Dragon Boat Festival, but she did not. Then Mid-Autumn Festival came, we hoped she could walk, but she did not. … As time passed, year after year, I was gradually able to open my mind and not think too much. I think that it doesn’t matter whether she can walk or not now, as long as she is safe and well. I don’t have a job and all I have to do now is accompany her to do rehabilitation and be hospitalized if it is needed. I give all my time to her. (B1: 346-353)

Over time Fang-Fang’s dedication in supporting her daughter in her rehabilitation programs has been rewarded by sharing in Jing-Jing’s functional achievements. Each milestone once achieved is then replaced by the next step along the journey to independent functioning, the ultimate goal.

I arranged everyday rehabilitation program which just focused on her walking. At the beginning, she couldn’t walk without the therapist’s guidance. She can walk with anybody’s guidance now. I mean she can walk no matter who is helping her in terms of staying with her. In my idea, this kind of walking isn’t independent walking. … My aim for her walking is that she can go anywhere she wants to go by herself. (B2: 447-455)

I會排每天復健, 就因為針對她現在走路嘛, 像她剛開始只有陳老師帶, 她才要走, 妳現在任何一個人帶她, 都可以走, 我現在我要的就是說, 任何一個人喔, 可以放手就讓她走, 妳跟在她旁邊就好了, 我說我一直不覺得她現在就是會走路, … 我說我要她可以自己去她想要的地方, 那才算是會走路。
Little by little … I had accepted her condition gradually and slowly. After looking at many children with the same condition, it opened my mind. … If she didn’t go for her rehabilitation, she might still be laying in bed and not be able to turn over, so I felt I made the right decision and had done the right thing. (B1: 638-642)

這樣一路走過來就慢慢、慢慢慢慢你就接受了啊，慢慢慢慢你看到那麼多小朋友那樣，你就比較釋懷了啦。…她沒有來做復健的話，她現在就是倒在那，連翻身都不會啦，…我就覺得…覺得自己也是有一點點說…我的選擇還是正確的，我的做法還是正確的。

Feeling gratified by Jing-Jing’s achievements Fang-Fang feels encouraged to be involved in caring activities and to look forward to the future possibilities realised by such improvements.

I feel content with the present situation now as long as she is progressing. A lot of people showed their envy of me that my daughter can walk with assistance. It is time… Because the length of time her experience accumulated, so she could experience improvement. … Not just give up. (B1: 499-501)

現在，… 覺得這樣滿好的，她有在進步就好了，反而現在還有人很羨慕我們，現在可以牽著她走，就是時間，時間會累積起來的 … 就是不要放棄。

As time has passed, Fang-Fang has been able to focus her efforts on future goals anticipating that Jing-Jing could possess more independent skills that would enhance her quality of life.

My biggest expectation for her now is … I hope … my ultimate goal is training her to be able to be independent. This is essential, because I will not be able to take care of her when I am old. At least her sister will feel easier when taking care of her, so I am teaching her to eat and walk now. (B1: 646-649)
我現在對她最大的期待就是…希望就是…最主要…我的最終目標就是訓練到她…她會自己生活自理，這個是最基本的，以後我老了，我沒有辦法照顧她，至少要姊姊照顧她的時候比較輕鬆，所以我教她那個…教她吃飯啊、走路啊。

Fang-Fang felt content after she had changed her perception and put things into perspective. She now anticipates the future positively because of the possibilities for Jing-Jing who has achieved a degree of functional independence, but also she looks forward to a period of time where she can put her own needs first if only for a short time.

Over last ten years I haven’t had time for myself … but all for my daughter, just helping her out with all kinds of things and taking her from place to place. … I felt a little bit easier when she can walk after training. … I just keep taking care of her, if I will have time I would like to visit different places. (B3: 166-188)

這十幾年我都為這個…為小孩子這樣子、這樣子，都只是為了小孩子東奔西跑，… 那現在就是訓練到她學著可以走的時候，我們也會比較輕鬆，…就是想說那就這樣子，那就是這樣子照顧她，就是有時間的話，可以的話，就到處走一走。

Main Impression / Possible Meaning:
- Accessing medical treatments in pursuit of possibilities for improvement
- Adjusting her expectations and changing her perspective
- Staying focused on positive progress
- Striving for optimal independent functioning for her child
- Beginning to acknowledge self

Ciao-Ciao and An-An
Ciao-Ciao found An-An’s development delay very stressful. Her experience lead her to doggedly pursue multiple treatments that would support her son to “catch up” and stay in touch with what was defined to be 'normal' development for children of An-An’s age.
Just like the others’ said, the children should be able to sit in the seventh month, crawl in the eighth month, and have the first teeth in the ninth month. I felt very nervous when my son didn’t follow the rules. His grandmother asked me whether he could turn his body over. I said no. He is still staying in the same condition, no matter what I feed him [heave a big sigh and frown]. (O1: 577-581)

人家說七坐、八爬、九發牙，對啊，你就是要符合那個發展，都沒有的話，你就會緊張啊，那阿嬤就說會不會翻身哪，我說都不會啊，所以我們這樣每天給他餵食什麼，他還是這樣（嘆了一口氣，皺一下眉頭）。

We took occupational therapy and physiotherapy and acupuncture. We went to ×× [hospital’s name] on Monday and … to ×× [another hospital’s name] on Tuesday, acupuncture on Wednesday. We rested on Thursday. Friday we went to ××× [another rehabilitation clinic], and got acupuncture again on Saturday. (O1: 451-456)

就職能跟物理，還有針灸。禮拜一××嘛，… 就禮拜二×××，禮拜三就針灸啊，禮拜四想休息一下，禮拜五就是那個×××啊，禮拜六也是針灸。

The occupational and physical therapy was focusing on his hands’ function and his rolling over. Yesterday, there was a mother who mentioned hippotherapy\textsuperscript{16} was good for the children with CP so she suggested to me to try it out. … I also wanted to ask for information about hydrotherapy. (O1: 554-558)

因物理跟職能都是著重他的手，就是他翻身哪，昨天去，有一個媽媽說那個馬術對腦性麻痺的孩子也很好，叫我們嚐試一下，… 那水療我也要去問看看水療。

The hydrotherapy could let his limbs move freely under natural condition. … The hippotherapy could let his spinal cord … improve his physical condition.

\textsuperscript{16} Hippotherapy also called horseback riding therapy since the Greek word hippos mean horse. The movement of the house can enhance gross functions of posture, balance, and mobility of children with CP (Sterba, 2007).
We have to help him move around because he cannot move his body on his own. (O1: 562-567)

水療…其實主要是讓他的肢體動作可以在很自然的狀況下，他可以行動自如，… 那馬術騎馬讓他的脊椎…對自己的身體狀況也會改善，…因為他都不會動啊，我們就要幫他運動啊。

The 'golden' early intervention period served as a great hope for Ciao-Ciao. This period of time was believed to be critical for enhancing An-An’s sensory functions of hearing and sight. It motivated Ciao-Ciao not to give up any opportunity to do anything that might assist in improving her son’s current condition. She maintained a high motivation always looking forward to working towards anticipated possibilities for improvement.

His reactions were a little bit slow when I spoke to him or interacted with him. … [pause] sometimes he didn’t have any response or maybe his eyes were unable to see, so when I called him he didn’t respond to me and he just acted like this [she copied her son’s action to close her eyes without moving her head to show no response to her voice]. … Sometimes his eyes … he looked like he wanted to search for the source of sound [she copied her son to swing to and fro with eyes open but without direction], … so the doctor said further examinations and observation were necessary later on. (O1: 528-537)

想說有時候叫他…有時候跟他互動，反應就是比較慢一點耶（先頓了一下再用類似說出自己懷疑的語調說著），有時候又完全沒有反應，還是他眼睛看不到所以你跟叫… 他就不理你，他就這樣子（學著孩子的動作，眼睛閉著，沒有轉頭的動作，就是沒有反應），有時候…想要…他的眼睛…好像要找那個聲音在哪裡…（學著孩子眼睛張開並向左右轉動著頭，露出尋找東西的樣子），… 所以那醫生是說…他是說再過一陣子再看看，再檢查。

The ××× [the doctor’s name] said his hearing may need further examination. Yes, sometimes my son could not hear very clearly when I talked to him. (O1: 474-476)
昨天×××（the doctor's name）也說他的聽力有沒有需要再檢查這樣，對啊，有時候跟他講，他很像不是很清楚。

We took an examination at ×× [hospital’s name] and … his visual nerve didn’t have any response. … but his eyes can still sense some light now so we gave him acupuncture as early as possible which maybe will give him a slim hope to lessen his problem. I went to acupuncture yesterday. (O1: 508-509)

[Hope] it’s really important, so you will get motivation to keep going. The 'golden' early intervention period is like the hope for me. (O1: 1056-1057)

Ciao-Ciao believed her maternal value was her professional knowledge that could benefit An-An’s daily quality of life. She sought formal education opportunities.

Preparing for The Institute of Early Intervention … I just tried to prepare for it, but I had no idea that I had passed the entrance test. However, I certainly knew I could learn more. … Then I will know how to take good care of him. I am just thinking whether I should go to work or not after my graduation. I probably prefer not to go to work because it will stop me taking him and doing the rehabilitation. However, my mother-in-law and my mum were hoping that I could get a job and let someone else look after my son. … My specific field is the subject of early intervention. If I went to work, my child won’t benefit from what I have learned and I will not be able to take good care of him. That isn’t good for my son, so my plan is take care of him myself and I not go out to work. His rehabilitation would be stopped if I went to work. He is my major concern. … My husband had the same notion as me in this issue. (O1: 1070-1079)
考早療研究所 … 那時候只是覺得有在準備考試就去試看看，我也不知道我怎麼會考上，但是更多的知識 … 我知道我會得到…，我自己會更知道怎麼帶他，我在計畫畢業之後要不要工作的問題，我覺得我不能工作因為這樣我才能帶孩子去復健，但是我婆婆和我媽媽都會希望我去工作，孩子就可以給別人照顧，… 但是我就想我自己是學早療的，那我自己的專長都沒有讓自己的孩子受惠，我沒辦法照顧好自己的孩子，孩子沒有好的基礎也不好，所以我計畫不上班還是自己帶他，去上班復建就停頓了，還是以他為主，… 在這方面我先生跟我有共同的理念。

Main Impression/ Possible Meanings:
- Searching out multiple forms of medical treatment
- Seizing upon the hope offered in the early intervention period
- Not giving up hope
- Educating self to enhance possibilities of providing optimal care

Ting-Ting and Fu-Fu
Fu-Fu is three years old and is the only child of Ting-Ting. She resigned her job after Fu-Fu was sick at the age of seven or eight months. He has been diagnosed with CP of spastic hemiplegia. Fu-Fu can walk independently and express himself, but has problems with his left hand and leg.

Fu-Fu was diagnosed with hydrocephalous when he was seven or eight months old. This condition resulted in high muscle tone and hemiplegia. The physicians blamed Ting-Ting for delaying seeking treatment. Her mother-in-law and relatives also questioned her asking her whether she had taken some food to cause Fu-Fu’s brain problems. Others reactions and blame provoked Ting-Ting’s feeling of self-blame and self-doubt in her ability to be a ‘good’ mother. After Fu-Fu grew up, others scolded Ting-Ting for not being a dutiful mother and controlling Fu-Fu’s bad behaviour. Ting-Ting often doubted herself and her ability to take care-giving responsibility for her son, a role expected of her.

17 Hydrocephalous in infants is often congenital anomaly causing abnormal accumulation of cerebrospinal fluid in ventricles of the brain. Its symptoms include enlargement of head, vomiting, poor feeding, irritability, delayed growth and movement, and so forth (Ball & Bindler, 2008, pp. 1060-1061).
Despite her long felt feelings of self doubt through self-reflection Ting-Ting has gained opportunities to examine her negative emotions and how they affect Fu-Fu’s quality of life and turn her situation into one that is positive.

I had to believe in myself again. Believing in myself is really important. You denied yourself just because of the child and you won’t be able to do a lot of things. You would burnout and start doubting yourself just because your child’s condition became a little bit worse. … For example … he was safe and sound when the enterovirus broke out before. But one time … I brought him to Taipei to visit my mother. He suddenly had a fever. … It was about 38 degrees. I was very nervous when his temperature wasn’t coming down, so we gave him an antipyretic the next morning. It didn’t work well. … We took him to the medical clinic in ×× [name of another county] to have further treatment. After the doctor checked my son, he said there were some oral ulcers in his mouth in terms of enterovius. … He told us we had to keep observing him. He had a fever two days in a row, so we felt uneasy. After arriving in Taipei again, we went to ×× [the name of the hospital]. … The doctor made sure my son had enterovius … so he was hospitalised for three or four days [laugh]. … Once he got sick. I didn’t dare tell my mother-in-law. … I would hear someone say, ‘How did you look after your child to let him come down with enterovirus.’ I really did not know why this happened, because I was so careful to look after him. … If he got sick, they would think this is the mother’s responsibility, because I took care of him all the time and my husband was quite busy. … Sometimes I had heard some one blamed me because my carelessness caused my son’s sickness. (M1: 1666-1705)
Ting-Ting realised losing confidence resulted in her losing perspective and seeing no hope. It was significant for her to reconstruct her care-giving confidence to work towards a better future.

I thought writing a diary was the way to vent my negative emotions and I would go back to look at it after writing for a while. I asked myself why did I care what people thought of me, but they couldn’t help me with my life. … I just kept asking myself this question. After reflection on it day by day, ok, I just let it go and pretend it never happened. I meant just put it behind me. … I kept telling myself I should stop indulging in my negative emotions. (M2: 842-849)

I wanted to write a diary is my release, that I go back and look at it after writing for a while. I asked myself why do I care what people think of me, but they couldn’t help me with my life. … I just kept asking myself this question. After reflection on it day by day, ok, I just let it go and pretend it never happened. I meant just put it behind me. … I kept telling myself I should stop indulging in my negative emotions. (M2: 842-849)

If I kept myself in the negative emotions that meant no more hope and I would become depressed, really. … If that really happened, where was my son’s future, because it is me taking care of him … and no one could help him out. That became my motivation to cheer myself up and to move further again. (M2: 1287-1291)

Now I felt better when I looked at things from another perspective. The key point is my son. I wasn’t able to change the way that others thought about me. It was meaningless but put more stress on me only. … I tried to construct
myself and didn’t care about others’ thoughts too much. The most important thing is my son. I felt good as long as my son was safe and sound. … because I have already done what I should do. (M2: 1401-1407)

我現在比較好一點, 比較不會這樣去想, 重點是孩子, 因為你無法去干涉別人怎麼想啊, 我一直去想別人怎麼想的時候, 讓自己的壓力真的是會很大, … 那我覺得很沒有意義啦, 就是盡量自我建設, 不要去 care 別人, 所以最重要的就是孩子, 孩子好就好了… 反正我已經做到我該做的事情了。

Fu-Fu’s good qualities and points were the best reward to assist Ting-Ting in accepting Fu-Fu’s situation to overcome her negative feelings. Fu-Fu was likened to a “sweet burden” that gave her motivation and energy to continue to engage in daily caring activities.

He was my sweet burden, because he gave me an enjoyable life. … When he gave me a sweet hug and acted in a pettishly charming manner, I just felt very warm and touched [smile]. … Even though I couldn’t gain affirmation from others, I gained affirmation from him. (M2: 1301-1308)

甜蜜的負擔啦, 因為他帶給妳的樂趣, 生活上的一些點點滴滴, 然後當他跟你撒嬌的時候, … 給妳甜蜜的抱抱啊, 妳會覺得好窩心喔(臉帶微笑), … 雖然別人沒有給我肯定, 但是我自我肯定啊。

Working towards what Ting-Ting described as a 'normal' child provided her with the positive anticipation she needed to care. Ting-Ting believed that Fu-Fu would be healthy in all physical and psychological aspects of life in the future.

I treated him as a 'normal' child. … At the beginning, others would think that my son was quite special so that became his excuse to do something wrong. I wasn’t thinking that way. The child will become the person the way you teach him. … I don’t think my son is any different from others [smile]. His physical movement may be slower than others, but he can learn and learn a lot of things. … For example, when we went out, I would tell him not to run in the restaurant. … I’m teaching him a lot of social manners. I would tell him right
away ‘you had to say sorry to him/her’ when he hit others or did something bad to others. (M1: 669-682)

When the child was sick, … I thought to be open-minded with a healthy attitude was so important. When the parents could normally face others, then the child could have the same attitude. (M1: 1835-1837)

Ting-Ting held the hope that her son’s unseen potential to learn something new would provide a platform for future achievement. She believed Fu-Fu had the capability to develop new skills to his advantage and in time overcome his physical disability.
My child will not be able to be a labourer in terms of the problem with his hands or legs [smile]. Relying on his brain is the better way to go [laugh]. … I will let him learn more things. … something can increase his brain function. Just trying to expand his knowledge, I wish Fu-Fu can receive more education and learn more things. (M2: 1000-1005)

I don’t have great expectations of him [laugh], as long as he can have a happy life, because of his brain damage before, I am not sure whether he can get a high education in the future. Of course, I feel he is quite clever so far. He can learn quickly when I teach him things and his memory is not bad as well. (M1: 1493-1497)

After these children没法去做工了 (浅浅的微笑), 动手、动脚的没办法, 大概靠脑了 (笑一下), …我就想说就是学一些, 真的要去一些动脑方面的东⻄耶, 那尽量让他学多一点知识吧, 我是希望 Fu-Fu 以后如果读书啊, 多学一点东西。可能多拓展一些知识吧, 我是希望 Fu-Fu 以后如果读书啊, 多学一点东西。

Ting-Ting can see the possibilities for self. She plans to strengthen her personal capacity in order to go back to work again when Fu-Fu can act for himself.

Fu-Fu has to go to rehabilitation at the moment, I will ask for an afternoon off from school to bring him to rehabilitation when he is able to study at school. I’m unable to have a full time job, because of the issue of sending and picking him up from school and rehabilitation. … I may find a job that can give me some free time and I can also earn and save some money. We may need money to use on some special occasion if something happened, just in case. (M1: 1587-1593)

因為×× (child’s name)目前還要復健, 就算去上學, 可能還要下午請假帶來復健, 這個接送的問題, 就沒有辦法讓我上正常的班, … 可能就是找一些能夠讓我時間自由的一些
Main Impression/ Possible Meaning:

- Reconstructing self-confidence
- Focusing on her son’s good qualities and sweet nature
- Believing in her son’s potential
- Anticipating her personal future plans

Wen-Cian and Ming-Ming
Wen-Cian is worried that Ming-Ming will always feel frustrated in love owing to her physical disability. She uses this concern as a motivation to seek out support for her daughter to reach her optimal potential in those areas where she shows interest.

Our biggest problem is our disability background. If my daughter encountered a healthy guy, he may not be able to accept us. I think that frustration, that frustration would be terrible. We will … try to search what is her advantage in the future … and then foster it. She will be able to have her status in her peers and society when she feels confident with her advantage and then she can affirm herself. … Whether she had confidence to break up with her boyfriend with optimism or elope with him or whatever [laugh]. This kind of problem could possibly happen in the future. (N1: 2947-2966)
According to our observations day by day, she is quite interested in art such as music, dancing, and drawing. She put a lot of effort into them. We knew her work was far behind her peers, but she still kept high interests. I would carefully choose good teachers and environment to give her opportunities to approach a variety of arts. … It is a good thing that she can enjoy learning them. (N1: 1298-1311)

Rehabilitation provides Wen-Cian with hope and future possibilities of improvement for Ming-Ming’s potential.

I can feel that my daughter has a huge possibility to be rehabilitated, so we still hold a great anticipation for her. Performing rehabilitation can let me see the future and hope, because her condition would go backwards and wouldn’t make any progress at all if we stop the rehabilitation. Therefore, I can say I cannot stop keeping moving forward, because I still hold a great anticipation and I am willing to spend time on it. (N1: 1392-1397)

應該說我們還對她抱有很大的期望吧, 就是說我們覺得她應該…就是她的可塑性還很大, 所以我們抱著很大的期望，就是說…我們做復健是看的到未來、是看的到希望的，而且復建那種東西不做，不進則退，所以我們會說這一條路是不能停的路啦，所以說就覺得說…還抱著一個很大的期望值啦，所以會很甘願把時間花在這個地方上。
Ming-Ming was quite happy with her drawing class. That made Wen-Cian feel her daughter could get benefit from this little thing, especially when the teacher was willing to develop a relationship with Ming-Ming and enthuse her.

I felt very touched that day. I hadn’t put the drawing class in the first priority since she had swimming and rehabilitation program, … so she hadn’t gone to drawing lesson for two months. When we went there again, the teacher saw her just like her relative who hadn’t been in touch for a long time. She said “Ming-Ming [her voice high and excited], I just thought about you yesterday and you are here now.” That moved me deeply because my daughter is liked by others, so my daughter loved to go there. … drawing class on Wednesday. She has not stopped reminding me not to forget this thing. When she felt happy in her learning, it can positively contribute to better rehabilitation effects. (N2: 554-562)

Wen-Cian was worried about Ming-Ming’s future career due to her eye problems. When Wen-Cian seized upon the unlimited possibilities Ming-Ming could have, she changed her perception to anticipate and engage in fostering Ming-Ming’s learning potential.

The doctor said her eyes had no function of stereoscopic vision, so she has a problem reading and studying microscopes. But I thought people, to be honest, should have unlimited possibilities. I thought it was OK that my daughter had a dream to become a doctor. … I would tell my daughter that to be a doctor you should study and work hard in your leaning. We use it to encourage her, but not suppress her. (N1: 1922-1927)
醫生說她立體感沒有，所以她對判讀那些東西...顯微鏡判讀上有問題，可是我覺得人，
坦白說，也有無限可能啦，我說 ok，女兒有一個醫生的夢想，... 比如說學習上，我們
可能說雖醫生可能要很認真讀書之類的，去激勵她，而不是去壓她。

Wen-Cian was very thankful that Ming-Ming gave her the valuable opportunity of
expanding their life experiences and putting things in perspective as well as
promoting her profession in her teaching field, which could help her face their future
possibilities with positive thoughts and attitude.

I was quite fortunate when giving birth to this kind of child. I was studying in
this field. For me, my daughter gave me a lot of credits. Firstly, she let me
contact more people and things, because of her I had to contact different
aspects or areas. Secondly, she also helped me with my profession and I knew
more how to interact with students' parents. So I would think my daughter is
my lucky star [laugh]. (N1: 1217-1222)

生到這種孩子，我算是幸運，是因為我自己是學這個，對我來講，我女兒真的有太多的
加分了，第一個讓我接觸的人事物變很廣，因為各個方面、各個層面都要接觸很多，弟
二對我的專業也有幫助嗎，而且在跟家長方面，你也更懂得與他們互動，所以我會說我
的女兒是我的福星（笑一下）。

Wen-Cian felt grateful and content with her present situation, because she can seize
upon the future possibilities not only for herself in terms of her personal career but
also for Ming-Ming to be able to be independent in the future.

I felt fortunate my child wasn’t in a serious condition. If my child was in a
severe condition, I would have no choice but to give up my job. ... because
she needed someone taking care of her 24 hours a day and how could she go to
school. Yes, I felt fortunate that my child’s condition still allowed me to work
out of the home to keep my job. My husband gave me support as well. I felt
really grateful. There is nothing more I could ask for. I feel I am content with
this. It’s good enough. ... Our condition may not be as good as others who had
a better condition than us, but we are really good enough when compared with
those who are in a worse situation than us. (N2: 926-933)
Attending a one night per week lesson outside the home allowed Wen-Cian to free herself from physical care-giving activities, but also satisfy her spiritual needs. She recognised it as fuelling the possibility to remain involved in her daughter’s care into the future.

There is a regular time to go back to school to recharge myself which is very good for me. … And I could possess time for myself one night a week. To be honest, my husband would be much busier than me at home, so I took more responsibilities for our children’s activities. When I had one day per week to go to the class, the children would not belong to me [laugh]. That was a kind of relaxation for me and I also got some answers to my doubts and questions, so I quite enjoyed going to class on Tuesday. It’s a wonderful time. … I think the important thing for the parents of special children was to give them a period of time to allow them to do things they wanted to do. (N1: 2204-2224)

I felt that I really gained a lot from the class, because I made some new friends and got to know other school’s situation. … just like exchanging information. Secondly, I could have my personal time to go back to school to sit in the class again. To be honest, some professors’ speech was not that good, so I was
unable to concentrate my attention on it. … I would let myself go back to my world to think about the things that happened during the day. … So I could re-organise my thoughts every Tuesday. I felt I was quite good. (N1: 2235-2251)

所以我覺得去上這個課對我來講收穫很大，收穫很大就是說又認識一些朋友，然後知道……別的學校怎麼樣，交流嘛，第二個我擁有自己的時間，又重回學校去坐下來，坦白說，有時候教授講的不好，……你實在聽不下去，……我就會讓腦筋回到自己的世界裡面，想想白天的事情……所以禮拜二那天，反而事情……思緒都可以整理的蠻清楚的，我覺得還蠻不錯的。

Main Impression/ Possible Meaning:

- Focusing on her daughter’s potential strengths
- Seeing rehabilitation as a hope
- Looking at unlimited possibilities
- Gaining a new perspective
- Appreciating possibilities for self

Feng-Feng and Cyun-Cyun

Feng-Feng has accepted that Cyun-Cyun has a disability and does not compare him to children who do not have disabilities. Positively, she recognises that her son’s situation has strengthened his character, dealing with things that other children have no experience.

I should face the fact that my child is different from other children with an acceptance attitude, so I should tell myself not to compare my child to others. My child is my child. … Every child has their own mission. … I would rather think my son experienced a harder life than me, because my child had to assume all treatment procedures. … The only thing we did was take him from home to hospital to receive the treatments. … When I think about this, I am able to accept my child who is an excellent child. He could tolerate a lot of stuff that other children didn’t, especially I had to force my child to receive those treatments. (J1: 267-288)
你自己能夠坦然的去面對你的孩子與別人的不同，應該是請你自我要求你自己不要去跟人家的孩子比，你的孩子就是你的孩子，…因為每一個孩子都有每一個孩子來這裡的使命，…就是你看我帶孩子辛苦，不如說孩子比我更辛苦，因為所有的療程都是孩子自己在承受，…我們其實只是做一件事情，就是把他從家裡帶出來療癒而已，把他從家裡帶到醫院，…就往這個方向想，我就很能接受說我的孩子他是很棒的，因為他承受別的孩子沒有辦法承受的，因為很多東西是必須去強迫這孩子的。

I can see his tenacity. … Other children would cry loudly when their legs were stretched, but my child chose to tolerate it. … Taking wearing a pairs of glasses for example, my son would choose to wear his glasses when I helped to put his glasses on. He accepted it, even though he didn’t like it and sometimes he would take them off. However, his compliance was quite good. (J2: 819-828)

你可以看的到他的韌性，…一個被拉筋的孩子，應該會痛哭失聲，可是這個孩子，他選擇他會很忍耐。…像這次戴眼鏡來講也是啊，你看這個孩子，他會選擇就是我要求他戴眼鏡，然後我把他戴上去，然後他會選擇就是接受，雖然他不喜歡的時候，他還是會拿掉，可是他的順從度還算很高。

Feng-Feng believes she is the source of Cyun-Cyun’s hope that is reinforced by her recognition of his value and worth.

I gave birth to my child and he is my child; he had no hope if I didn’t value him, because I am the person who gives him the hope. His hope will depend on what you give to him. You are like a light to his future. The brighter you are, the brighter his future will be and filled with hope. If the light was dim or dark, his future would be the same too. I will do what I think and I will make it happen. No matter what, anything related to the child, regardless good, bad, upsetting, or challenging, I regard as a process. I am very sure of one thing and that is to help him pave the way for his future, a bright future. If I do not do that, this child will be hopeless. That is how I feel. (J1: 518-529)
因為孩子是你生的，孩子是自己的，今天孩子是你自己的，你都不重視他了，那這個孩子就沒有希望了，因為他的希望是你給的，是你在前面點一盞燈給他，你今天你的燈越亮，他的路會走的越漂亮，如果今天你給的燈越暗，你甚至不給他燈，這個孩子這輩子就沒有光，所以我做我所要做的，我做我所想到的，我可以做我應該做的，我把所有跟孩子有關的事情，不管是好的、是壞的、是磨練、是考驗也好、是傷心難過也好，我都當作是一個過程，我一直都覺得這是一個過程，因為我一直都認定一件事情，就是我必須在前面為我兒子點燈，那我必須先去幫他把路打通，因為如果我沒有去幫他走這一段，陪他走這一段，這孩子沒有機會，沒有機會，我的感覺。

He had a problem turning over his body. … That made me feel quite frustrated as he was unable to roll over. … But at the moment when he turns his body over then I know he can actually do it. … He was stuck in the process of learning how to crawl for quite a long time, but finally he could master it. I have changed my attitude and thoughts after seeing that. I knew his progress was slow but he could do that. … I felt grateful when I used this kind of attitude to look at my son. … As long as I can give chances to my son, he will be able to improve slowly. (J1: 146-160)

在學翻身那一段，他一直都翻不過去，那一段我們比較挫折，… 那當他翻過去的那一刻，我們就覺得原來他也可以麻，… 他在學爬的時候也停很久，後來也會爬了，我的心情改變了，我知道他不是不會，而是他比較慢而已，… 那我以這樣的態度去看著孩子，我都很感恩啦，… 你只要願意給這個孩子機會，他都有可能…可以慢慢的進步。

When Cyun-Cyun made slow progress or his advancement were plateaued, Feng-Feng kept optimistic and reinforced his strengths in attempts bolster his motivation to continue to strive for improvement.

When you magnify his improvement, it gives you the will to continue. … Definitely, he can get better and better, just time is needed. For example, his language had almost stopped progressing for half a year, it just stops or goes a little bit backward. However, he may make a great progress after that. We always kept thinking positively, but never thought negatively [smile]. I always control my mind to think positive instead of negative thoughts [smile]. After I have this kind of child, I have to keep my thoughts optimistic and aggressive. I
couldn’t go further if I wasn’t aggressive and positive enough [laugh]. (J1: 679-688)

你放大孩子的優點才有能量走下去啊!… 他一定可以更好，只是時間還沒有到而已，像他的學習，像他的語言，停了大概快半年有了，整個語言停下來（笑一下），可是最差也就停了而已，稍微的退步，他有可能是會突飛猛進的，我們都往好的地方想，絕對不往差的地方想，我都不往負面的想（微笑），我覺得遇到這樣孩子的媽媽，你的思想需要積極正面，你不夠積極正面你走不下去（開心的笑）。

Feng-Feng regarded Cyun-Cyun as a treasure and a gift of God, so she has always appreciated anything her son brought into her life. Her relationship with her son was viewed as one that presents her with precious opportunities to be a better person.

Regardless of the fact he was a premature baby … and he was not as good as other normal children. … I had always been thinking of him as a gift from God. If this was a gift from God, there must be a reason why he was given to me. Maybe because of my bad temper, God gave me a child to curb it. Or maybe because of the strictness in the way I treated people, a child would help to make it better. For a child, you had to be tactful, deliberate and show a lot of patience and effort. (J1: 102-110)

儘管說…後來孩子出生是早產，然後儘管他給我們的…不像一般孩子那麼的好，可是在我們的心態上來講，就我而言，我一直都覺得那是上帝的禮物，那上帝今天願意給我這樣的禮物，一定有他的理由，他的理由或許是因為，可能我的脾氣不好，他需要一個孩子來磨練我的脾氣，或者是我待人處世的部份可能需要比較周嚴一點，那他希望這個孩子可以給我這樣一個的周嚴的態度，因為孩子… 他是需要你比較婉轉，比較需要多的心血。

I didn’t complain why did God give me this kind of child? Why wasn’t God fair to me? Why were others’ children healthy and easy to bring up, but not my child? The only thought in my mind is that he is my child and he is my treasure. He will follow me for the rest of my life. Any decision I make will relate to him. (J1: 535-541)
I have not been怨天尤人 why God gave me such a child... why this is unfair... why others' children are healthy and easy to manage, but mine is not. I have only one concept that he is my child, my treasure, my future. Any decision I make is related to him.

Feng-Feng hopes that Cyun-Cyun will be able to manage his own life and finances independently. Searching for high quality rehabilitation programmes for Cyun-Cyun provides Feng-Feng with the purpose of devoting herself to such a possibility.

I will constantly and aggressively talk to the therapist if I knew my child could get a huge benefit from the therapist. The therapist may only give us one session a week. I don’t care about it, because having one session is better than none. After that, I will ask the therapist whether he/she is willing to give more sessions to my child. My husband’s attitude is to put more emphasis on our child’s learning outcome, because he knew my stress will be lessened when my child show his progress. (J2: 72-78)

We clearly know that this teacher is good for our child, so we will actively talk to this teacher. At most, one session is better than none. After that, we will ask the teacher whether he/she is willing to give more sessions to our child. My husband’s attitude is to put more emphasis on our child’s learning outcome, because he knew my stress will be lessened when my child show his progress. (J2: 72-78)

My idea of self-care, taking his age for example, my son is three years old now, but I will look at his future for the next 17 years. At that time, he will be able to survive in society and earn himself a living. We don’t expect he will earn a lot of money, but hope his interest will be his job. … That is he can take care of himself. … No need for us to worry about him, just like a normal 20 year old young adult. As I am the parent I want to enjoy peace of mind when he is in the working society. If he manages his own finances, the chances of him being conned or cheated are very slim. He can make judgement for his life. I don’t expect him to be rich or to support us. … I just hope he will support himself with his interest. (J1: 623-639)
Feng-Feng sees her working opportunities as Cyun-Cyun’s future opportunities, she enjoys working to set up the best financial plan for her son to have a better life in the future.

My son is the more important than anything else for me. I could give up my job, just to take good care of him. I am working hard outside. ... I have my own personal business in terms of direct sales. That is all for my son. I didn’t do it for anyone else. ... My son is the centre of my life. (J1: 1164-1167)

我覺得弟弟對我們來講比什麼都重要，就像我今天工作可以不做，我就要把弟弟顧好，我今天能在外面拼很多東西，...我還有自己的直銷事業，我也是為了弟弟，我沒有為誰，... 就等於說弟弟是我目前的生活重心。

When I decided to give birth to my son ... I had already communicated with my husband that when I gave birth to a child we would not expect the child to support us when we grow old. I am just hoping that we can have a child for company. That’s all. ... We didn’t have that kind of old traditional concept [to raising a boy to support us when we get old]. (J2: 1227-1231)

我當初我決定要生這個孩子，... 我就跟我先生溝通說我生小孩不是為了要養兒防老，我希望的是說能夠有一個孩子來作伴，是這樣子，... 因為現在已經沒有那個觀念了。

Main Impression/ Possible Meaning:
- Accepting a non-perfect child
- Focusing on her son’s positive qualities and strengths
- Using herself as an instrument of hope for her son
- Treasuring her son
- Striving for independence
- Anticipating sharing human connection

**Shared meanings which transcend the particular – Seizing possibilities for future and self**

To anticipate future possibilities provided the mothers with opportunities to develop insight into their present day situation. Involvement in care-giving activities guided by forward thinking aimed at achievement contributed to looking towards the possibilities of achieving positive goals. In broad terms, common goals were defined in terms of supporting the child to realise an independent future and experience a quality of life because of such achievement. Six shared meanings emerged from the mothers’ stories of seizing possibilities for future care-giving:

- Adjusting expectations and perspectives
- Seizing possibilities for improvement
- Reinforcing strengths
- Cherishing and treasuring their children
- Anticipating independence for their children
- Anticipating possibilities for self

Fang-Fang sought traditional Chinese rituals as possibilities of enhancing improvement of being cured. She drew hope from the alternative methods that motivated her involvement in care. Fang-Fang has continually adjusted her expectations over time according to Jing-Jing’s progress. Lowering her expectations meant Fang-Fang not only opened her mind to accept Jing-Jing’s current situation but also assisted her to focus on Jing-Jing’s achievements. This fostered contentment. Fang-Fang over time learnt to develop a new expectation aimed at possibilities. Such change enabled her to feel useful and worthwhile in her care-giving role. Her goal became one of striving towards her child’s independence.
Ciao-Ciao felt disappointed and frustrated when An-An’s developmental milestones were far behind his age and his vision and hearing impairments were becoming evident. New or different treatments signified hope, so Ciao-Ciao sought multiple treatments to grasp any possibility to support progress. The 'golden' early intervention period was a strong motivation to act and not give up any treatment possibilities that could make a major difference to An-An’s condition. Looking at the future possibilities to improve An-An’s quality of life assisted Ciao-Ciao in combating her present day frustrations. Gaining insight into the possibilities for self, through personal education and increasing her professional knowledge, assisted her in enhancing her son’s quality of existence.

As Fu-Fu was sick Ting-Ting’s confidence and self-worth easily collapsed. The 'tiny' criticisms and blame castigated by others compounded this situation and left Ting-Ting feeling angry and frustrated in her daily life. After standing back and self-reflecting, Ting-Ting was aware of her negative emotions that placed Fu-Fu in a vulnerable position exposed to what she deemed to be sub-standard care. She was able to change her perspective and approach and reconstruct her confidence and self-belief in her capability as a 'good' mother. This change afforded her a much less stressful daily existence and provided her with energy to focus on the positive aspects of her relationship with her child. Fu-Fu’s sweet hugs and good qualities became the best reward for Ting-Ting. Ting-Ting’s changed perspective focussed her towards striving to achieve normality for Fu-Fu because she wanted to focus on his merits and potential, not on his disability.

Wen-Cian knew she was not able to change Ming-Ming’s physical disability and was worried about her future life. However, paying attention to her daughter’s potential served as a means to foster an advantage for her daughter and assist her to develop skills required to face future challenges with confidence. Such engagement in care made her feel worthwhile. Ming-Ming possessing a positive attitude toward the drawing rehabilitation program and the teacher’s enthusiasm gave Wen-Cian hope to anticipate her daughter’s progress. Wen-Cian appreciated that Ming-Ming broadened her horizons and improved her profession, such philosophical thinking supported her in moving forward to look at the future possibilities with optimism. Keeping one night per week for attending class empowered her to feel free from her daily care-giving
responsibilities. She experienced self-growth and catharsis and developed a capacity to look forward to the possibilities of continuing involvement in her daily care-giving into the future.

Feng-Feng regarded Cyun-Cyun as a treasure. She totally accepted Cyun-Cyun and appreciated his positive qualities, especially in terms of his strength to tolerate treatment procedures. Feng-Feng regarded herself as an instrument of hope for her son as she was always providing opportunities and engaging in the best quality of care available to them. Looking forward to the future possibilities, Feng-Feng did not expect her son to follow the traditional Chinese practice of providing financially and caring for his parents in their later lives. However, she was full of anticipation that Cyun-Cyun would be able to stay with her to share their wonderful human connection together into the future.

**Interpretive Summary**

Searching for opportunities to support improvement led most mothers to pursue new and multiple treatments aimed at providing the best possibilities to achieve progress for their children. Progress was defined in achieving the milestones which would ultimately result in independent living for the child. The mothers saw engaging in such medical caring activities as important and meaningful to their maternal caring role and responsibilities. They did not “give up” in terms of treatment, but carefully grasped any “slim” hope to enhance their child’s developmental progress. This pursuit provided them with much satisfaction as such involvement enabled them to feel useful and worthwhile. They realised that any commitment from past to present day could positively contribute to their children’s future possibilities of being independent and living a quality life.

Adjustment in their personal expectations of achievement over time was important in helping them to understand that they were unable to change the medical outcomes for their children. Such change in perception allowed the mothers to develop a new sense of future, to positively anticipate new possibilities of engaging in daily caring activities. Such adjustment could not only help them overcome their frustration and stress, but also “open” their minds to accept their children’s situation and look at tiny
achievements with pleasure, feeling gratified for such progress. This perspective assisted these mothers in focusing on future possibilities with a positive and satisfying mind-set of how they could manage their challenging situations.

The mothers cherished their children with CP so they valued the time shared with their children and built strong human connections and bonds. Their cherishing provided them with a strong will to engage in providing a high quality of daily care that nurtured their children’s positive qualities and strengths. For self, they felt fortunate because their children broadened their horizons and aided them in putting life’s meaning into perspective. Feelings of self-growth enhanced their existence. This positive attitude was meaningful for them as it fuelled their continuing motivation and provided energy to pursue a high quality of daily care for their children.

Gaining a short period of time away from their daily care-giving provided some mothers with opportunities to have time for self. Valuing and recognising the importance of time for self helped them to continue their care-giving roles and responsibilities in a positive manner.

In the next chapter, the current body of knowledge that informs our understanding of mothering and care-giving for disabled children will be examined in light of the findings of this study. The chapter will examine new ways of conceptualising the ways in which nurses and allied health practitioners support mothers everyday care-giving.
Chapter 9

The Life-World of Mothering Children with Cerebral Palsy

Introduction
This chapter reveals meaning through an exploration of the life-world of participating mothers. Guided by inherent meaning revealed in the shared stories of participating mothers, relevant and current literature will be reviewed. This discussion aims to articulate the meaning embodied in the everyday experience of providing care for a child with cerebral palsy. This discussion serves to confirm and extend current ideas and conceptualisations of mothering disabled children. The next and concluding chapter will extend this discussion further by reflecting upon how such mothers can be better supported by nurses and health professionals in a Taiwanese context.

An Unexpected Pregnancy and Labour Process
In traditional Chinese society, the significance of giving birth to a child for women is fulfilling their obligation and responsibility to carry on the clan and ancestral lines for her husband’s family. There exists an expectation from themselves, their family, and society that they will give birth to healthy babies and ensure family honour by delivering a child that possesses the ability to compete with others to survive and perform well in society in the future (J. D. Lee, 1996; Lu, 2006).

The expectant women begin to build an attachment with their unborn babies in uterus and imagines and fantasises about the babies’ appearance and plans the future for their children during the period of pregnancy. They carefully adhere to traditional rituals or advice to protect their unborn babies to fulfil their mothering responsibility to give birth to “healthy” children (Wallerstedt & Higgins, 1994). In modern society, prenatal screening or technologies aim to detect foetal abnormality to treat or eliminate those foetuses with detected “defects” (Landsman, 1998; Remennick, 2006).

Ai-Ai recalled she was suffering from emotional and spiritual torture due to a poor relationship with her mother-in-law and the physical stress of providing daily care for
her older son while she was pregnant. Such emotions and concerns are totally contradictory to the traditional Chinese thinking that espouses the importance of keeping positive in mood and sustaining physical energy to ensure no harm is inflicted on your baby during pregnancy (Kartchner & Callister, 2003). Ai-Ai believes her family situation contributed to the unusual early onset of uterine contractions and the premature birth of her child. In agreement with Kartchner and Callister (2003), Chinese pregnant women believed negative moods and emotional health had a bad impact on their foetuses, causing them to have a poor character. Leung et al. (2005) confirmed that Chinese pregnant women perceived higher stress levels when experiencing conflict with their mother-in-laws, when compared to perceived stress when interacting with their own mothers. Dysfunctional relations lead to a situation where mothers did not openly and honestly reveal their opinions and feelings, despite their obvious need.

Wen-Cian experiencing unusual symptoms in terms of vaginal bleeding had her attention aroused that her pregnancy was not typical. She was given a medical order to be confined to bed in hospital, which left her feeling anxious about her unborn baby’s safety and well-being and uncertain about the anticipated outcome of her pregnancy (Leichtentritt et al., 2005; McCain & Deatrick, 1994; Price et al., 2007). Leichtentritt et al. (2005) found that women with high-risk pregnancies defined their experience as being different from “regular” pregnancies. These differences were described in terms of the loss of anticipated possibilities for an uncomplicated pregnancy with a desirable outcome. Price et al. (2007) indicated that high-risk pregnancies resulted in the mother’s fear, uncertainty, and stress, because plans and hopes would be threatened. In Heideggerian terms, experiencing high risk pregnancy is a situation of no longer being-there and being desituated (Heidegger, 1927/1962, p. 74, 103; Kellett, 1997) with expectations and anticipated possibilities threatened and in turmoil.

Wen-Cian adhered to the physicians’ advice of being confined to bed, closely observing and reporting her own physical symptoms and perceived foetus’s condition. This monitoring enabled her to communicate with health professionals, a contribution that she believed would assist her in preventing pre-term labour. Such involvement occupied Wen-Cian and enabled her to experience a feeling of purpose and worth for
making a positive contribution, hopeful of maintaining her baby’s well-being and realising a favourable outcome (MacKinnon, 2006; McCain & Deatrick, 1994; Schroeder, 1996). Schroeder (1996) argued that women believed that bed rest for them was important in the sense that this sacrifice provided hope for a successful pregnancy outcome in terms of their babies survival. In order to give birth to healthy babies, women regarded bed rest as “a small price” to pay regardless of its side effects, even the experience of “being in a prison”. Cunningham (2001) suggested that women felt powerless when they were unable to do anything related to the foetal health.

Wen-Cian lost her hope when the physicians decided to induce a pre-term labour. She cried, felt shocked, feared for baby’s safety and lost all anticipation for a full-term pregnancy (Barlow et al., 2007; Lowenkron, 1999; McCain & Deatrick, 1994). Beck (2004) revealed that the outcome of a healthy infant was significant for the mothers, their family and friends. Wallerstedt and Higgins (1994) argued a woman felt a sense of failure in giving birth to a premature baby and disappointment in her own body for being unable to or incapable of producing a healthy child. Rubin (1976) stated that ensuring safe passage for the unborn baby and protecting the baby from harm were the first important maternal tasks for a pregnant woman, so entering the delivery room during the second trimester would damage maternal identity and feelings of self-worth. Pre-term labour was experienced as a crisis event. Weiss, Saks, and Harris (2002) revealed that the term of “pre-term labour” for pregnant women meant “losing the baby”.

Ai-Ai sought emergency help from the hospital since she detected her uterine contractions at the thirty-first week of her pregnancy. To prevent the unwanted outcome, the physicians’ wrong judgement and management delay could not prevent its happening due to their valuing medical data more than her personal feelings (Barlow et al., 2007). Ai-Ai felt angry and powerless and lost hope when health professionals could not foster feelings of trust and provide optimal support (Leichtentritt et al., 2005). The results were supported by Barlow et al. (2007) and Nystedt et al. (2006) whose research revealed that health providers had not listened to mothers and had devalued their wishes. This had resulted in mothers experiencing a
sense of “not being believed” when they described their physical symptoms to staff, and this often led to delayed management of their problems.

A different experience was shared by Hui-Hui, who had a healthy and uneventful pregnancy, but a prolonged and difficult delivery which resulted in her son being starved of oxygen and requiring resuscitation measures. Hui-Hui lost her trust in health professionals believing she had been the victim of sub-standard medical care (Nystedt et al., 2006; R. Rubin, 1976). Asian Carers in Mir and Tovey’s research (2003) experienced mistrust of health care staff due to the delays, mistakes, insufficient concern, lack of appropriate action, and poor communication either during pregnancy or after birth. This contributed to their children’s medical condition and sub-optimal health care. Beck (2004) indicated that women felt that medical staff and clinicians betrayed their trust and that they felt powerless during their unsafe deliveries.

Hui-Hui was blamed by her mother-in-law for an unsafe delivery process causing the baby’s brain damage. Hui-Hui also blamed herself and experienced a deeply felt guilt at having failed to protect her baby from harm. Consequently, she began to doubt her maternal capabilities and her sense of adequacy and self-worth to fulfil her family’s and society’s expectation of being a 'good' mother (Jackson & Mannix, 2004; Koniak-Griffin, Logsdon, Hines-Martin, & Turner, 2006). Holroyd (2003) stated “blame” in Chinese culture signified women’s moral reputations had been challenged when giving birth to a handicapped child, because the child’s disordered body meant the disruption of ancestry and the end of kinship duty, especially if the handicap was found at birth. Jackson and Mannix (2004) argued that mothers would expose themselves to feelings of guilt, inadequacy, anger and self-blame when they experienced the burden of blame. Sorrow and depression followed the birth as Hui-Hui worried for her baby’s safety and the threat of marginalisation from her mother-in-law and family (R. Rubin, 1976).

Self-blame was experienced as Ai-Ai believed she had not followed traditional Chinese rituals in maintaining her emotional stability and avoiding the taboo of labile emotions and physical exhaustion during her pregnancy. Thus she believed she was responsible for not providing a safe and healthy environment for her baby (Brathwaite
Williams, 2003; Holroyd, 2003; Kartchner & Callister, 2003; Pun et al., 2004). Leuthner, Bolger, Frommelt, and Nelson (2003) found that women felt guilt because they failed to prevent the foetal abnormality and failed to meet the expectations of their husbands and families. Jackson and Mannix (2004) revealed that mother-blaming was a burden for women since they internalised this concept into their life and experienced distress due to their children’s misbehaviours or disease.

Mother blaming is pervasive in society meaning people expect the mother should bear the responsibility to take good care of her child and the child’s illness or outside the “norm” responded to the mother’s actions or lack of actions (Jackson & Mannix, 2004; Koniak-Griffin et al., 2006). Blame, however, was not found in Wen-Cian’s experience since she thought she did her best to prevent the unexpected event in terms of pre-term labour. Faerstein (2001) argued that people felt free to pay attention to mastery of the problem when they used self blame effectively, but utilized ineffectively, the anxiety could be overwhelming. For example, Hui-Hui attempted suicide due to self-blame and could not see hope for the future.

Wen-Cian, Hui-Hui, and Ai-Ai’s complicated pregnancies and deliveries negatively impacted on them adhering to the traditional Chinese postpartum rituals in terms of doing the month. These old traditional rituals have been viewed as a reward for the women participating in their pregnancy and childbirth and provide time to restore their health (Liu-Chiang, 1995). The participating mothers felt that they did not desire to get this reward since their babies were not “healthy” and did not meet social expectations. Having healthy children was like a hope to the participating mothers (Kartchner & Callister, 2003). They could not help but break the taboo to cry and feel depressed during the period of doing the month when they lost their hope and were too worried about their children’s medical condition (Leung et al., 2005; Liu-Chiang, 1995). On the other hand, doing the month for these mothers was complex as their babies were in the Intensive Care Units.

Grief happens to the mothers who experience loss of their imaged and wished perfect babies due to giving birth to impaired children or premature babies (Wallerstedt & Higgins, 1994). Wen-Cian felt a great disappointment and sadness seeing her premature baby for the first time in the Intensive Care Unit. Wallerstedt and Higgins
(1994) stated that a woman felt grief when her baby’s appearance provided evidence that her child was different from her hopes and fantasy. Ellis (1989) indicated that a woman had to learn to integrate her premature baby’s condition into her previous 'ideal' infant image to decrease the discrepancy from between the 'ideal' and the reality. Eakes, Burke, and Hainswort (1998) used the term “disparity” to describe the perception of current reality as different from the idealised. The gap between reality and the 'ideal' causes the experience of loss.

**Learning the Diagnosis of CP**

Hearing the diagnosis of CP of her son, Ciao-Ciao did not know the feeling of joy of giving birth, but felt like “dropping from heaven to hell” since her disabled son was unable to live up to her family and social expectations in terms of being a healthy baby. Li-Li disbelieved the diagnosis on first hearing it, a diagnosis which gave her a sense of “capital punishment” to come. Wen-Cian felt shocked and was not able to accept her daughter as a 'special' child which signified for her a miserable event. Wen-Cian and Li-Li demonstrated their disbelief upon hearing the diagnosis of CP. George et al. (2007) revealed that mothers found it hard to connect their children with children in an institution or with a severe condition. This image was different from their imagined and anticipated healthy babies.

All the mothers in this study demonstrated their deep despair and negative feelings towards the diagnosis since they realised their children were outside the norm of health, namely disability. The finding was supported by George et al. (2007), Gordeuk (1976), Graungaard and Skov (2006), and Mardiros (1982) all of whom suggested women’s dreams were broken due to loss of their anticipated normal children and their future became an unexpected uncertainty, with no hope for the future. In addition, Gordeuk (1976) argued that the lack of ability to give birth to a healthy child threatened the mother’s maternal identity and self-esteem, since the mother regarded the child as part of herself from the beginning of her pregnancy.

On the other hand, Wen-Cian felt relief after gaining the correct diagnosis as it solved her long term suspicions about her daughter’s delay in reaching the usual motor development milestones (Nuutila & Salantera, 2006). Knowing the diagnosis provided a function of certainty and a possible picture of the future to give her
direction to start the necessary treatment and manage the situation (Fitzpatrick et al., 2007; George et al., 2007; Graungaard & Skov, 2006). Graungaard and Skov (2006) argued that the function of knowing the diagnosis for parents not only created new images for their unexpected uncertainty about the future, but also identified possibilities for action.

Wen-Cian felt angry and powerless when the physician gave her “false hope” in terms of the waiting time to fix her daughter’s motor delay, and did not provide a practical intervention nor further examination. False hope negatively influenced her ability to positively anticipate (Simpson, 2004). Rannard et al. (2005) argued that parents showed their dissatisfaction with health professionals who only advised them to “watch and wait” and expect their children’s problems to fix themselves with time. Such care was deemed problematic as it did not meet their caring needs and overlooked their concerns. Graungaard and Skov (2006) stated that without diagnosis, the child’s situation in the parents’ eyes was more changeable and “looked so normal” and this hindered the parents from accepting the child’s disability. Delay in entering into an effective treatment system lead Wen-Cian to mistrust and be dissatisfied with the physicians’ knowledge and skills. She lost hope of receiving a better prognosis for potential development (Baird et al., 2000; Buelow & Shore, 2006; Fitzpatrick et al., 2007; Graungaard & Skov, 2006; Rannard et al., 2005; Simpson, 2004).

Furthermore, Wen-Cian felt uncertain and powerless when the physician gave her an ambiguous answer concerning her daughter’s intelligence. She was left with frightened emotions, unclear information and consequently possessed no sense of control and guidance to prepare for the future (Graungaard & Skov, 2006; Hummelinck & Pollock, 2006). Hummelinck and Pollock (2006) argued that parents felt confused, frightened, and anxious when their questions about their children’s prognosis were not answered by health professionals. Adequate information was a strategy to control and manage their children’s illness as well as assisting them to plan for the future. Knowing the prognosis provided parents with opportunities to ponder upon their future and make adjustments to their lives. Dagenais et al. (2006) indicated that well-informed parents experienced better adaptation to their children’s ongoing and long-term disabilities.
Ai-Ai felt a great mistrust in health professionals since their insufficient knowledge and skills about CP led to a series of wrong diagnosis and treatments that exacerbated her son’s condition. Loss of trust in health professionals meant keeping Ai-Ai away from the hope of a better future treatment for her son and living with future uncertainty (Baird et al., 2000; Buelow & Shore, 2006; Fitzpatrick et al., 2007; Graungaard & Skov, 2006; Tattersall & Young, 2006). Graungaard and Skov (2006) revealed the term “the diagnostic process” that involved gaining an accurate diagnosis needed through more tests and more appointments with doctors. A difficult diagnostic process, therefore, was like “fighting for the child” to request the doctors for more detailed examinations in a quick manner. Difficult and prolonged diagnostic processes led to the parents questioning the doctor’s words or skills.

Ai-Ai did not believe the diagnosis of severe developmental delay given by health professionals, because the developmental assessment process was too rough with a lack of professional standard. Ai-Ai felt angry and frustrated when seeing the way professionals treated her son with a lack of individualised care, poor manners and poor communication in terms of dehumanizing her son as well as not listening to her feelings and voice (Dagenais et al., 2006; George et al., 2007; Graungaard & Skov, 2006; Tattersall & Young, 2006). This lead Ai-Ai to feelings of abandonment by the health professionals (Leuthner et al., 2003). Larson (1998) indicated some doctors did not give sufficient time and opportunity to acknowledge the disabled children’s unique personhood, but only paid attention to diagnostic categories. Moreover, Graungaard and Skov (2006) stated that parents put emphasis on equality in co-operation with the doctors in the hope of being involved in the diagnostic process. Parents felt frustrated when the doctors failed to acknowledge their needs and possible contribution.

Although the physician gave an accurate diagnosis to Ciao-Ciao, she still felt angry when the physician disclosed her son’s diagnosis and prognosis as very severe without giving any positive information (Dagenais et al., 2006; Kearney & Griffin, 2001; Leuthner et al., 2003), this led to dissatisfaction with the physician’s insensitive attitude, caring and support (George et al., 2007). Hope for the parents was like motivation for action to look for treatment for their children and help them overcome their present negative emotional condition (Graungaard & Skov, 2006). Geogre et al.
(2007) argued that parents’ grief deteriorates due to the health professionals’ poor manners and communication skills. In addition, Tattersall and Young (2006) revealed that health professionals did not know how to deal with the parents’ emotions and stress feelings during diagnostic disclosure. Baird et al. (2000) suggested the feeling of dissatisfaction with diagnostic disclosure could contribute to parents’ current level of depression.

**Daily Care Engagement – Multiple Maternal Roles**

In this study, the multiple roles adopted by the mothers gave them each an identity that guided their maternal behaviour and motivation. Revealing the meaning that motivated engagement in maternal caring roles provided an opportunity to gain insight into their care-giving experiences (Landsman, 1998; McMahon, 1995, p. 20). The participating mothers, engaged in a variety of maternal roles such as therapist, expert family carer, educator, protector, preserver, provider, advocate, and interpreter. Most research discovered various maternal roles were carried out by the parents/carers of children with disabilities in order to satisfy their children’s unique needs, but may emphasise different aspects of care-giving (Hartley et al., 2005; Hinojosa, 1990; Kirk et al., 2005; Wogvatunyu & Porter, 2005).

In her role as therapist, Mei-Mei showed her strong motivation to ensure the provision of a high quality of medical care for her daughter. She actively sought to overcome her fear of performing skilled technical procedures such as dealing with gastrostomy, apnea, seizure attacks, physiotherapy, suctioning, and so forth, in order to ensure her daughter received optimal care twenty-four hours a day (Leiter, 2004; McKeever & Miller, 2004). Ya-Ya felt not only very comfortable and confident to carry out daily rehabilitation program with her son because she knew such engagement could lift up her son’s physical progress towards his better future, but also shared a common goal and human connection whilst engaged in such care-giving activities (Hinojosa, 1990; Piggot, Hocking, & Paterson, 2003; Short et al., 1989). Jhen-Jhen learned knowledge from the physician and proficiently used it to massage her son’s oral and cheek muscle to return his sucking ability when he lost his proper oral function after hospitalisation. From Jhen-Jhen’s point of view, keeping such functions could ensure her son’s quality of existence due to satisfying his sucking needs and maintaining his...
normalcy. In agreement with Leiter (2004), the mothers adopted the term “therapist” in regard to themselves to help their children with their special skills. However, an unclear boundary between “mother” and “therapist” often occurred since the mothers perceived the role of being a 'good' mother as synonymous with being a 'good' therapist.

McKeever and Miller (2004) stated that the mothers of children with CP had to provide their children with technically sophisticated daily care at home; some mothers spent up to eight hours per day carrying out disability-related care. Each mother had a high expectation of self, assuming a responsibility for possessing relevant information and an adequate knowledge and skill base to provide medical care (Brady et al., 2006; Guerriere & McKeever, 1997; Hartley et al., 2005). However, Kirk et al. (2005) indicated that parents felt a sense of resentment when the nursing role occupied most of their time. They regarded themselves as a 24 hour full-time nurse when they would prefer to remain “just” mothers.

In this study, although some mothers resented the blurring of the “therapist” and parent roles others were unable to relinquish the nursing role to others. As an expert family carer, Mei-Mei did not trust others to provide a high quality of care for her daughter. She questioned the professionals’ or others’ lack of 'local' and 'special' knowledge vital for maintaining an optimal standard of care (McKeever & Miller, 2004; Pun et al., 2004; Sallfors & Hallberg, 2003). Shu-Jhen knew what kind of food her son enjoyed and the best time to feed him in order to diminish her son’s constipation (Kellegrew, 2000). Sin-Sin and Jhen-Jhen expressed they were not willing to use respite care since they thought others could not provide an appropriate standard care due to not knowing their children’s personal preferences, medical history and daily caring experiences.

On the whole, most of the mothers in this study found a satisfying balance between their engagement as mothers and their roles as expert family carer. In agreement with Kirk et al. (2005) and McKeever and Miller (2004), it was found that some mothers had developed a confidence in providing daily care because of the mix of their knowledge having learnt from professionals in hospital and accumulated learning from their intensively personal care-giving experiences. Sallfors and Hallberg (2003)
stated that mothers worked like “the managing mother” to totally engage in their children’s caring routines and be sensitive to their children’s caring needs due to their sense of responsibility.

Valuing the maternal role of preserver, Ya-Ya only bought specific types of clothes without small buttons or zips to assist her son in completing his daily dressing (Rao, 2001). In order to compensate for their children’s hand dysfunction, Hui-Hui and Wen-Cian let their children wear the shoes without shoelaces so they did not need their fine motor skills and coordination function. Fang-Fang used a spoon with a special design to help her daughter finish her meals by herself. The aim of using alternative ways was to assist their children to preserve their independent ability to act for themselves (Sawin et al., 2003). Similarly, Rao’s research (2001) found that mothers helped their children with a variety of supports to sustain their self-care skills and compensate for their disabilities. Their aim was to ensure their children could take part in family and community life.

A number of mothers in this study required special assisted equipment to help their disabled children to preserve their independent function. McKeever and Miller (2004) confirmed that mothers of disabled children put in a great deal of effort to promote their children’s standing and walking abilities. The well-designed wheelchair not only helped children better master their environment but also gain others’ respect and promote their social position and visibility. In contrast, Li-Li felt frustrated and powerless when her role as preserver was threatened because of financial hardship that prevented her from providing optimal equipment to assist her daughter to walk independently. Pascall and Hendey (2004) indicated that parental encouragement, family support, right equipment, and a specially designed house were key components to foster the independent functioning of young people with disabilities.

Regarding the maternal role of provider, Shu-Jhen did not restrict her son’s learning potential or activities to home because of his inability to walk, but rather provided a variety of strategies to broaden her son’s cognitive ability such as reading, going out to the park or department store, to gain more experiences and knowledge (Brady et al., 2006; Pun et al., 2004). Hui-Hui provided her son with big toys to force him to use both his hands to be proficient in operating his dysfunctional hand. Yuan-Yuan
encouraged her two healthy older sons to play and talk to her daughter with a hearing impairment to gain more opportunities to improve her speaking, communication and social interaction (Brady et al., 2006). Brady et al. (2006) found that mothers who provided reading or looking at books, talking out loud to their children, expanding their children’s sentences to improve their communication skills. Pascall and Hendey (2004) stated that parents became the resources for fostering their children’s independence.

For Mei-Mei, the purpose of providing her daughter with the opportunity to contact the outside world was significant in improving her daughter’s psychological well-being and potential progress to move forward to be as “normal” as possible and to have a better life in the future. This goal gave her purpose in her maternal role and identity. Sawin et al. (2003) stated mothers who let their children attend different activities to have a normal life and not stay at home due to their physical disabilities. This gave Mei-Mei strength to take her daughter out with the nasogastric tube and not care about others’ strange staring and questioning. Craig and Scambler (2006) found in their research that not all mothers of disabled children have the confidence to venture outside the home because of their children’s highly visible nasogastric tube. They found this caused them to face unwanted public attention or others’ negative reactions.

Feng-Feng felt very satisfied with her maternal role of educator since she successfully involved her mother-in-law and her husband in her son’s daily care and understood multiple continuing rehabilitations were crucial for her son and also believed her son could develop like other ordinary children as long as they had patience and time for him. Feng-Feng felt her maternal identity and self-worth when her family members could accept her son and give love and share human connection with him, which contributed to his quality of daily existence and better life (Lindblad et al., 2007; Short et al., 1989; Trute, 2003). Yu-Yu educated her husband to look at their son’s positive and strong points and taught her mother-in-law how to deal with others’ curious inquiries. Yu-Yu believed her son would have a significant place in the family when her husband and her mother-in-law knew how to cope with their difficulty and seeing her son from a positive perspective (Lindblad et al., 2007). Lindblad et al. (2007) argued mothers were gratified when their disabled children could be accepted.
by family members and their children were involved in attached and devoted relationships in their family due to understanding of their children’s disabilities. Rolland and Walsh (2006) suggested having shared family beliefs could provide the family members with strength and capability to face adverse situation, but also think the issues related to disability were manageable and comprehensible.

Associated with the role of protector, Jhen-Jhen insisted on feeding her son via the mouth, not the nasogastric tube, even though sometimes feeding one meal took her more than two hours. She believed it was worth the effort to sustain her son’s normality and dignity and prevent him psychological harm. She also regarded the feeding time as precious time to interact and develop intimacy with her son (Craig & Scambler, 2006; Sleigh, 2005). In agreement with Sleigh (2005) the reason for feeding by mouth was regarded as the 'normal way' to feed children, but they did not deny their children’s disabilities.

Furthermore, Jhen-Jhen paid close attention to all caring activities such as bathing, giving drugs, feeding, and so forth to prevent her son from physical discomfort or pain (Kirk et al., 2005). Similarly, Kirk et al. (2005) indicated that parents carefully performed medical procedures in order to protect their children from harm, so they kept the high standard of care in their mind. Fang-Fang prevented her daughter from experiencing poor quality sleep, a common cold and took pains to protect her from epileptic attacks that could threaten her safety and quality of life (Sallfors & Hallberg, 2003; Wogvatunyu & Porter, 2005). Fang-Fang also trained her daughter how to protect herself when falling down. When Hui-Hui helped her son dress, she always thought about the side of his damaged arm first before dealing with the healthy arm. This protected him from harm (Sawin et al., 2003). Sallfors and Hallberg (2003) used the term “parental vigilance” to depict how parents paid close attention to their children’s physical and mental status.

As an interpreter Jhen-Jhen has learned how to interpret her son’s non-verbal language. She had discovered new possibilities for communicating with her son, not only to satisfying his care needs but also conveying her love for him. Fang-Fang read her daughter’s facial and emotional expressions to confirm her personal interpretation (Brady et al., 2006). Fang-Fang felt very confident with her maternal identity and
self-worth because her daughter’s difficulty in speaking did not stop her from understanding her wants and providing a high standard of care. In contrast, Sin-Sin sometimes did not know what problems caused her son’s discomfort due to his oral function impairment so she had to seek advice from different experts to assist her to regain her sense of control (Kellegrew, 2000). This finding was supported by Brady et al. (2006) who argued that mothers were concerned about communication with their children with language disabilities. They felt frustrated when they saw their children’s frustration due to their wants not being satisfied. Hartley et al. (2005) indicated not being able to interact with the child led to carer frustration and caring needs being unmet because of communication breakdown.

Related to the role of advocate, Shu-Jhen carefully monitored the care quality her son received at school. She strongly spoke out and communicated her son’s physical caring needs to school staff when her son received sub-standard care at school to maintain her son’s dignity and self-respect and physical comfort (Cole, 2005). Ai-Ai sent a letter of complaint to the hospital because her son’s rehabilitation program was stopped due to a shortage of the therapists which seriously interfered with her son’s potential progress. Ai-Ai also strongly voiced her needs to the director of the Rehabilitation Department to request reasonable therapists to allow her son’s program to be continued. Hui-Hui felt the interns of Rehabilitation Department were not able to provide standard rehabilitation program to her son, so she communicated to the therapists to make request to let qualified therapists, not interns to perform rehabilitation on her son to enhance the quality of the rehabilitation (Brady et al., 2006; Landsman, 2003; McKeever & Miller, 2004).

Landsman (1998) utilised the term “real mothers” to describe the mothers who advocated actively when worried that their children’s value and humanity were being ignored or missed by others. Similarly, McKeever and Miller (2004) indicated that mothers value their maternal function of “acting on behalf” thus meeting the social expectation of being 'good' mothers who engage in all caring as a means of ensuring their children benefit from the desired service and appropriate care. These mothers would often experience conflicting relations with professionals or others when their children received sub-optimal care.
Barriers to Maternal Care-giving

Having a child with a disability could bring stress and anxiety to the whole family since people in traditional Chinese society still possessed old thinking that a child’s parents, family members, or ancestors may have done some “misdeed” to cause the child’s impairment. This kind of social stigma could lead to social discrimination or rejection, especially from the husband or in-laws who would blame the mother for placing the family in this shameful situation (Holroyd, 2003; Pun et al., 2004).

Sin-Sin felt hurt, helpless and powerless when experiencing her son with a disability being marginalised, when her husband kept his distance from their son and her in-laws believed the child with a disability made them lose face. His inability to walk placed a burden on the entire family (Hartley et al., 2005; Holroyd, 2003; Keller & Honig, 2004; McKeever & Miller, 2004; Pun et al., 2004). Pun et al. (2004) revealed that “significant others” in Chinese society, husbands and in-laws in particular, had a major influence on the mother and her ability to deal with the child’s disability. The mothers felt isolated when the significant others were unable to share caring activities or could not understand the situation. Holroyd (2003) found some Chinese husbands of women of disabled children who stated that they would “pay any price to have a normal son” to regain their reputations.

Yu-Yu cried alone and was powerless when her mother-in-law restricted her son’s activities at home only to avoid being seen by others and being taunted behind her back. Yu-Yu had to give birth to another healthy boy to restore the family honour. Hui-Hui felt sad and hopeless when her mother-in-law considered CP to be the same as mental retardation and his obvious physical handicaps made their family lose face, so she refused to give any further treatment or education to the child as she believed such input was worthless (Hartley et al., 2005; McCabe, 2007). Larson (1998) pointed out that being handicapped had been regarded as God’s will as punishment for mistakes and signified the person’s past and continuing failure. McCabe (2007) found that the Chinese family would keep their children with disabilities at home or send them far away from home to prevent being discriminated against due to their children’s differences from others.
Devaluation from family members reinforced feelings of no hope since grandparents and husbands in traditional Chinese family have a significant impact on family life, and the family has the highest value to an individual in terms of providing access to resources such as economic support, religion, warmth, and affection (Hwang, 1987; E. Lee, 1999, pp. 230-253). The mother and her child who lost family resources and were excluded from the family leading to a lack of human connection, love, and belonging with the family, which further influenced her child’s self-esteem and quality of existence and future possibilities. Holroyd (2003) indicated handicapped children in Chinese culture meant “disruption to parent-child order” since the children could not return or reward their parents for their parenting and there existed the perception of a lack of reciprocal relationship. Also family members did not anticipate the handicapped children could become complete persons.

Sin-Sin’s family members were unwilling to be involved in her son’s care, so she had to bear all care-giving responsibilities. Although everyday care-giving was burdensome, Sin-Sin could not actively ask for help from her in-laws and her husband in caring for her son as she was a married woman who was expected to follow family hierarchy and obligation to respect and comply with her in-laws and husband. She had to assume the major responsibility of caring for the house and children to fulfil her ideal woman role in this traditional Chinese society. Also she could not complain about it in order to maintain harmonious interpersonal relationships within the family (Hwang, 1987; E. Lee, 1999, pp. 230-253). Sallfors and Hallberg (2003) named the fathers as “the waiting fathers” since they only passively engaged in their children’s caring activities. They would wait and see when the mothers needed their assistance, were more focused on the whole family’s business or spent more time with their healthy children. Most fathers in Harden’s research (2005) believed that caring responsibilities was not their primary role but their wives’ responsibility owing to differences in gender. It was not uncommon that the mothers lacked support from their husbands and felt alone in their caring responsibility.

The marginalisation not only came from the family but also happened in public places. Wen-Cian felt powerless and frustrated when her daughter had difficulty interrelating with her peers and her daughter was excluded by her teacher in terms of not giving her individual help to foster peer relations and improve her academic
performance (Cole, 2005; McCabe, 2007; Morse et al., 2000). Pun et al. (2004) argued that mothers experienced ambiguity when they were unable to get others to understand their children’s disabilities or their thoughts. Sanders (2006) stated when teachers or other people possessed an “attitude barrier” towards the child, it signified they lowered their expectations and set boundaries to their learning. In this way disabled children were the victims of personal prejudices.

Li-Li felt angry and helpless when the bus driver treated her and her daughter with disrespect. People’s negative attitudes could lead to the children with disabilities having access to fewer social experiences thus limiting possibilities for social integration and social adaptation. Poor self-concept and social skills were developed and the feelings of aloneness and isolation were inevitable, which led to their sub-standard life (Cole, 2005; Hartley et al., 2005; Sanders, 2006). Holroyd (2003) indicated that Chinese families often faced public ridicule when others outside the family saw their handicapped children, especially in public places. Similar findings have been supported by studies from Western and other countries with varying cultures. McKeever and Miller (2004) revealed that mothers felt social suffering when their children experienced discriminatory and exclusionary practices. Most people thought the mother should bear the responsibilities for her child’s stigma and marginalisation, because she ought to give her child a healthy body and mind. The mother was aware that her “place” as a mother was undermined because of the perceived low status of her child. Pun et al. (2004) argued that Chinese mothers’ mothering ability would be in doubt when their children exhibited any “bad” or “inadequate” performance or behaviours, which meant the criteria of being “good” mothers was judged by whether their children were perfect or not.

The first concern for women of disabled children relates to performing rehabilitation programs at home (Galil et al., 2001; Leiter, 2004). It was quite a challenge for Wen-Cian due to her daughter’s crying during times of stretching her legs. When her daughter was unable to develop the same attitude towards rehabilitation as her, the tension was increased and the quality of family life was affected. Wen-Cian felt not only frustrated and powerless over this situation, but also worried about her daughter’s progress being hindered. This was supported by Larson (1998) who argued that mothers felt a sense of incompetence when they were unable to follow and
perform the prescribed program according to the health professional’s advice. On the other hand, Hinojosa and Anderson (1991) indicated that mothers were willing to implement rehabilitation programs at home when they presented no stress for the child, the mother, and the rest of the family.

Yu-Yu was struggling with her son’s lack of motivation to obey her instructions to conduct rehabilitation program at home, although she has included some enjoyable activities suggested by the therapists. Her son still got bored with it, so how to maintain the rehabilitation program as interesting and fun was a significant concern to increase his motivation to engage in his program (Hinojosa & Anderson, 1991; Piggot et al., 2003). Hinojosa and Anderson (1991) found some mothers integrated the rehabilitation program into their daily lives but aspects of the program were different from the therapists advice. Yu-Yu however pointed out that her son would happily listen to her when Yu-Yu’s older daughter joined in the rehabilitation activities.

Contrary to Yu-Yu’s experience, Ai-Ai felt frustrated that her son with CP was easily distracted by his two brothers’ activities or others’ family recreation. That meant other family members could not possess the same attitude as her to assist her in performing effective rehabilitation at home. Ai-Ai also expressed her responsibilities for the other children, house chores, or family social life interrupted the home rehabilitation program (Hinojosa & Anderson, 1991), so conflict developed when there were difficulties in balancing family life and the quality of the child’s rehabilitation. Watson et al. (2006) stated “balancing competing needs” was a strategy to better the parent-provider relationship, because the needs of one family member could compete with other family members or the whole family, even the needs of the therapists could compete with parents, children, or family.

This study also found the child’s medical condition, such as severe epilepsy, could negatively prevent the mother from facilitating the rehabilitation program. Hinojosa and Anderson (1991) stated if the rehabilitation program was too time consuming it stopped some mothers doing it at home, even though the mothers thought it was important for their children. This finding was not supported in this study since they would feel guilty, as it was important to her child’s progress, when she did not fulfil her maternal responsibility to meet her anticipations or society expectations.
Another aspect of the relationship with the child with a disability was the parenting issue. Li-Li was struggling with wishing her daughter would become more independent while she actively attended to all her daughter’s needs (Sanders, 2006; Sawin et al., 2003). She helped her daughter with all her locomotion needs by carrying her as she accepted her daughter’s desire to give up walking in callipers. Li-Li also submitted to her daughter always asking for assistance with every task because of her feelings of guilt and pity. Her daughter got used to totally relying on Li-Li’s assistance which became her biggest excuse for not striving for independence (Pascall & Hendey, 2004; Sanders, 2006). Harden (2005) indicated parenting for such parents becomes regarded as a moral task, because taking care of the child is the parents’ responsibility. In Harden’s research (2005) he discovered that most of the parents problems were in letting their children gradually become independent. Furthermore, Pascall and Hendey (2004) revealed having too close family bounds and relationships could become a barrier for young disabled children to becoming independent, because this strong bond indicated less social relationships, opportunities, and skills for both parents and their disabled children.

Yu-Yu also overprotected her son by using home activities to replace outside programs (Harden, 2005; Sanders, 2006). Yu-Yu could not come to terms with her son having the ability to normalise (Morse et al., 2000). Isolation from others also protected Yu-Yu herself from not knowing how to deal with others’ inquiries when her son’s physical disability was seen by others. Her son’s social skills and knowledge were seriously damaged by her overprotection. Holroyd (2003) revealed that Chinese parents could perceive and experience public-social messages of blame and shame in their whole lives due to having a handicapped child. Such messages forced them to keep their distance and protect themselves from other people outside the family in terms of shame and loss of face.

The issue regarding healthy siblings varied from sibling jealousy to sharing caring responsibility. Li-Li experienced her healthy youngest son’s jealousy when Li-Li always asked him to yield to his older disabled sister or ignored his needs to satisfy his sister’s wants. Her son’s attitude of anger and resentment toward his disabled sister placed Li-Li in a difficult situation (Bat-Chava & Martin, 2002; Fleitas, 2000).
Li-Li doubted her maternal ability to teach her son to understand her and his sister. Sibling jealousy also prevented him from developing a human connection with his sister and sharing the same notions as Li-Li in supporting his sister’s quality of existence (Dallas et al., 1993; Fleitas, 2000). Sibling jealousy and fighting greatly troubled Li-Li since it was contrary to the traditional Chinese beliefs of valuing cooperation and sharing among siblings in terms of the emotional ties (E. Lee, 1999, pp. 230-231). These findings were contrary to Bat-Chava and Martin’s findings (2002) that indicated that siblings were largely satisfied with their relationships with their disabled siblings.

Wen-Cian’s son complained that his mother belonged to his older disabled sister because his sister not only occupied too much of Wen-Cian’s time and attention and love, but also enjoyed possessing privileges such as having more than one pair of glasses and going to swimming lessons (Fleitas, 2000). Wen-Cian felt it was hard for her son to accept his sister’s privileges as being strategies to fix or diminish her disability. Wen-Cian felt guilty for neglecting her son and also worried about his well-being. Ishizaki et al. (2005) found that psychological problems more frequently happened among siblings of children with disabilities than siblings of children without disabilities. The healthy siblings emotions became more intensified when they were younger than the children with disabilities, since they thought they should be pampered by their parents and older siblings (Dallas et al., 1993; Hartley et al., 2005).

Sin-Sin felt stressed and sorry for her older healthy daughter who had to share her caring responsibility (Hartley et al., 2005; Hinojosa, 1990; Lindblad et al., 2007). Her daughter complained about not being able to play freely like her peers, which negatively impacted on her daughter’s social activities and relations in terms of quality of daily life. Fleitas (2000) stated that siblings of a child with disability would be expected to take on more caring responsibility or housework. The siblings seemed to have no chance to negotiate their new role called “parentification”. This concept was shared in traditional Chinese culture, the eldest daughter was expected to take care of her younger siblings for her parents (E. Lee, 1999, p. 231). On the contrary, Fang-Fang felt gratified when her older daughter not only felt happy and willing to be involved in sharing her responsibility of care for her younger sister, but also
developed a positive attitude toward her sister’s disability (Dallas et al., 1993; Taunt & Hastings, 2002).

Regarding the aspect of family conflict, Li-Li’s husband only worked casually so financial difficulties became Li-Li’s major concern (Glasscock, 2000). Working part-time was necessary for Li-Li to maintain her family’s living standard and satisfy her daughter’s daily care needs (Lewis et al., 1999; McKeever & Miller, 2004; Parish & Cloud, 2006). Todd and Jones (2005) suggested that mothers having part-time rather than full-time work helped them to manage their work as well as fit in their caring duties for their disabled children. Some work was important for meeting the extra financial expenses related to medical treatment and care (Lewis et al., 1999; Parish & Cloud, 2006).

Li-Li thought doing all these things was a basic requirement for being a 'good' mother, but this concept was been challenged since her disabled daughter blamed Li-Li for not meeting her personal needs immediately. Li-Li started to doubt her maternal identity and purpose in life, feeling frustration and powerlessness when her daughter could not understand her difficulty in keeping a balance between mothering and working, especially assuming the care-giving responsibility alone (Green, 2007; Lewis et al., 1999). Harden (2005) revealed most parents found it hard to balance their children’s needs and their personal needs due to caring for disabled children. Sawin et al. (2003) pointed out that worry was a part of most parents’ lives because the children with disabilities were so vulnerable in their eyes.

Contrary to Li-Li’s situation, Shu-Jhen became a housewife after her marriage. Her family members thought taking care of her disabled son was her major responsibility because she was a full time mother. Traditional Chinese families possess strong beliefs and values that the next generation is the first priority for married women. When women become mothers they are expected to sacrifice themselves for their children, so they are not given any excuses to withdraw from this responsibility (J. D. Lee, 1996). As a consequence, her son got used to only relying on her to complete his daily care since no one could fulfil his needs in an effective way like Shu-Jhen. In this way Shu-Jhen developed a sense of helplessness. Feelings of stress and care burden were experienced since Shu-Jhen was not able to feel at ease from this full-time
caring responsibility (Glasscock, 2000; Harden, 2005; Lewis et al., 1999; Parish & Cloud, 2006). Harden (2005) revealed most parents felt “drained” by their disabled children and experienced care-giving burden. Zhan (2006) discovered unemployed Chinese care-givers had a higher level of depression. The Chinese care-givers had pressure upon them to fulfil their care-giving responsibility and meet social expectations in a traditional Chinese cultural context, but they received less reward or praise since it was deemed their familial duty.

Mei-Mei experienced family conflict due to the disagreements between her maternal role and her role of wife and daughter-in-law. Her in-laws complained Mei-Mei had spent too much time in looking after her disabled daughter and forgot her duty of being a daughter-in-law. Her husband also felt unhappy that Mei-Mei did not pay attention to family activities or give time to him and their healthy son. Conflict with her in-laws and her husband was inevitable since Mei-Mei totally engaged in sustaining her daughter’s quality of daily care so she was unable to follow the principle of filial piety to attend to her in-laws well or show her obedience to her husband (Lang, 1968, p. 47). Pun et al. (2004) found that mothers felt exhausted and easily lost patience due to their close monitoring of their children with disabilities, leaving little time for other family members or activities. In addition, the mothers lacked emotional support and understanding from family members.

Regarding interacting with the staff in the health care system, Yu-Yu was full of hope in accessing another physician’s help for enhancing her son’s medical condition. Chinese physicians in Confucian ideology receive the highest respect as they may bring peace and prosperity to people through the provision of successful treatments (D. F. C. Tsai, 2001). Yu-Yu felt a great disappointment and frustration when hearing no hope for her son’s future since the physician had poor predictions for her son’s future outcomes (Kearney & Griffin, 2001; Mir & Tovey, 2003). Simpson (2004) indicated that mothers may not be able to feel hope when health professionals lacked the ability to sustain their hope or help them find hope. In agreement with Graungaard and Skov (2006), parents found that doctors had different perceptions of their children since they regarded disability as a lack of abilities, not potential.
Yu-Yu also felt confused and angry when receiving inconsistent medical information and treatment options from different physicians (Molinari & Freeborn, 2006; Simpson, 2004). Simpson (2004) argued that receiving inconsistent information from health professionals made the mothers lose hope and made decision making about their children’s care difficult. Molinari and Freeborn (2006) stated that parents felt dissatisfied with health professionals due to a lack of needed information. The parents lost hope in professional interventions when they perceived different health professionals providing them with contradictory information or using trial-and-error approaches in their treatments.

Yu-Yu felt poorly informed about her child’s treatment and was disempowered by not being involved in making important medical decisions (Da Silva et al., 2003; Denboba et al., 2006). This threatened her role as a mother as she possessed few possibilities to ensure her child had access to potential opportunities to receive the best available treatment. Yu-Yu also was unable to look forward to grasp new possibilities when the physician provided her with knowledge without caring and empathy. The health professionals’ knowledge and attitude had limited contribution to her son’s positive and effective medical care and quality (Okamoto, 2007; Pun et al., 2004; Simpson, 2004). Simpson (2004) indicated that new possibilities can be anticipated when health professionals share their professional knowledge with a caring attitude. Parents feel able to trust and respect the richness of experience and hence possess faith in the possible solutions.

The medical system in Chinese society has a tendency to be paternalistic, supported by a traditional patriarchal culture that shapes the doctor-patient-family relationship and medical decision-making and de-emphasises the significance of parent or patient involvement in their own health care. This dynamic keeps the authority and power in the practitioner’s hands and has been referred to as a therapeutic privilege (Da Silva et al., 2003; D. F. C. Tsai, 2001; Young & Kingle, 1996). In agreement with Harden (2005) parents felt isolated when health professionals replaced their parenting responsibilities and excluded them from engagement in medical care. McKeever and Miller (2004) indicated that mothers had to learn to accept their place as subordinates in the medical system. Subsequent relations and interactions were necessarily not symmetrical, non-collaborative and usually for such reasons negative. Moreover, Da
Silva et al. (2003) argued that if the family and patient felt comfortable due to experiencing a harmonious physician-patient relationship then their anxiety could be decreased.

Yu-Yu lost her trust and felt disempowered due to sub-standard medical care. Finally, Yu-Yu refused to use this displeasure to avoid interpersonal and intrapersonal conflict (Da Silva et al., 2003). Similar to Yu-Yu’s story, Mei-Mei felt frustrated and helpless when some physicians treated her daughter as only a “patient” only focusing on dealing with her symptoms and ignoring her as a person. They exhibited no effort to communicate with her, to understand her thoughts and care-giving difficulties, giving her no spiritual support to comfort her anxiety and worries (Larson, 1998). Da Silva et al. (2003) suggested a blind and cold communication put the patient in an undesirable and deleterious situation. Likewise, Sanders (2006) revealed that parents felt disempowered when health professionals treated their children as “cases” or “problems” and clearly communicated their expectation for controlling and maintaining a distant relationship.

Wei-Cain viewed rehabilitation as hope for her daughter owing to sustaining her developmental progress and she believed the therapists professional skills could help fulfil her hope. Wei-Cain felt disappointment and anger when she saw the therapists “fooling” around and carrying out an ineffective training program, Wei-Cain felt her hope gradually disappearing (Watson et al., 2006). The parents in Watson et al.’s research (2006) regarded the role of the therapists as not being limited to therapist, but also advocate, friend, family, and mother. This finding was also supported by Hinojosa (1990) who found that mothers regarded the therapist as “the third parent” for their disabled children sharing in parental responsibilities.

The therapists excluded Wei-Cain from the rehabilitation session by not communicating with her. The therapists also did not value her 'local' knowledge about her daughter’s ability, which meant the training program was not an individual plan to enhance her daughter’s developmental progress. Wei-Cain and the therapists were not in a collaborative relationship (Anderson & Hinojosa, 1984; Watson et al., 2006). As a result, she mistrusted the therapist’s competence to foster her daughter’s potential progress (Watson et al., 2006). Watson et al. (2006) found the inclusion of the parents
in therapy was important since the therapists felt uncertain about their children’s diagnosis, prognosis, ability, temperament, cues, or reactions to the therapy, so therapists needed help from parents to read and understand the child to perform at their best.

Although Wen-Cian felt dissatisfied with the quality of the rehabilitation program, she chose to keep silent to maintain a harmonious relationship and not argue with the therapists to save face for each other. Watson et al. (2006) found that parents often strove to establish positive relationships with therapists in treatment settings. Part of the reason for such motivation was the lack of trust in the health provider’s competence or the total lack of consensus and communication about the child’s therapy. The parent-provider relationship always improved when the child’s developmental progress was sustained, but parent’s uncertainty never totally disappeared.

Wei-Cian feared that the health professionals would deprive her daughter of access to necessary care or devalue her daughter and lower the quality of medical care received (McKeever & Miller, 2004; Watson et al., 2006; Young & Klinge, 1996). Realising access to and the potential for quality treatment was determined by health professionals, Wen-Cian had to learn to accept her place as a subordinate in the medical system. Young and Klinge (1996) argued Asian people did not believe in assertive communication to effectively sustain the quality of care, because asserting themselves, making requests, displaying aggressive disagreement are not accepted in traditional collective society. Furthermore, Hwang (1987) pointed out that showing deferential behaviour, inoffensive manners, being less aggressive and less socially extroverted meets Chinese social expectations and respects authority. Possessing the same cultural belief as Wen-Cian, Yu-Yu and Mei-Mei would rather escape from the lower quality of medical care system, than have direct conflict relationship with the health professionals. Feng-Feng changed to another medical facility to access rehabilitation sessions, so she could avoid having an argument with the therapists with poor skills (Watson et al., 2006).
Looking Forward to the Future Possibilities

Possessing a concern about her child being independent in the future, Ciao-Ciao combined traditional Chinese therapy with multiple Western therapies to sustain her son’s developmental progress. Every therapy signified a hope to Ciao-Ciao, so involving various therapies meant more hope to maximise his potential development in terms of meeting normal developmental milestones (Cohn et al., 2000; Hinojosa, 1990; Landsman, 1998). Hartley et al. (2005) argued “family solutions”, “formal or Western medicine” and “traditional medicine” were the major strategies to seeking a cure for the children with disabilities. In agreement with Hinojosa (1990), mothers lives were full of “therapy, therapy, therapy” because of their disabled children. Cohn et al. (2000) stated therapy could fulfil parental hopes and expectations in terms of sustaining their children’s skills and competence.

Ciao-Ciao felt disappointed and sad when seeing no progress, but she planned to seek different therapies and continue to involve present therapies. She believed there is hope if she did not give up on any therapy. Graugaard and Skov (2006) indicated carrying out all possible actions or treatments inside and outside the medical care system was the parent’s major responsibility and this action provided hope for their children. Any minimum progress could promise possibilities for her son’s better quality of life in terms of being able to act for himself and being accepted by society. That provided Ciao-Ciao with purpose to look into their future possibilities and see the whole picture, not be limited to present day frustrations (Cohn et al., 2000; Piggot et al., 2003).

Linking up their daily care-giving with religious beliefs, all the participating mothers in this study utilised religious beliefs to maintain their hope. Watts, Dutton, and Gulliford (2006) stated that practicing faith in God acted like spiritual resources to allow them to believe that they could generate strategies toward their better future and this religious hope gave psychological and mind strength to cope with present challenges and move ahead to the future possibilities. For example, Hui-Hui and Ya-Ya let their sons become “sons of deity”. It is believed that deities can protect their sons from potential harm and bless them with good health.
Fang-Fang tried to follow traditional Chinese practices in terms of *feng-shui* in the hope of improving her daughter’s progress when she felt disappointed with her daughter’s development using Western therapy (Lip, 1985, p. 23). Lip (1985, p. 32) indicated the Chinese believed the family’s dead ancestors were living in the graves with dampness or poor conditions which led to their bad lack or ill health. Cleaning the ancestor’s graves to bring back the good luck was a kind of hope for a better outcome. Fang-Fang also placed lucky charms or amulets with her daughter in the hope of bringing good luck and hope the supernatural powers would protect or improve her daughter’s health (Chan & Twinn, 2006). These findings were supported by the research of Chan and Twinn (2006) who indicated that the Chinese participants in their study followed and practiced traditional rituals, which were passed down from their parents, to assist them in purifying their sick partner’s sins, expelling and avoiding evil spirits and hoping for recovery. Su, Teng, and Yang (1995) also indicated that the aim for Taiwanese patients utilising folk practice was to try to change their fate and improve their fate in order to realise the best possible outcome. They also gained confidence and felt at ease from practicing the traditional rituals or customs.

The participating mothers in this study not only gained spiritual strength from practicing religious beliefs, but also obtained inspiration to maintain their positive thinking and attitude towards their children and their demanding care-giving responsibilities. Under the influence of Buddhism, the mothers were encouraged to value inner rewarding rather than the outward material or non-material rewarding, so they appreciated any gain from their daily care-giving. The mother also appreciated having the opportunity to take care of her disabled child since the centre notion for Buddhism is highly precious the ability to give to others than taking from others and respond to others’ needs (Nichol, 2006). Gaining support from religious beliefs was found from Western research. Sallfors and Hallberg (2003) indicated believing in God gave the parents the healing powers and provided them with hope to anticipate a better future.

Ting-Ting emphasised her son’s sweet smile or hugs were the best reward to help her face her day-to-day care-giving challenges (Green, 2007; Kearney & Griffin, 2001; Pun et al., 2004; Sawin et al., 2003). Kearney and Griffin (2001) argued that mothers
considered their disabled children to be beautiful and cheerful children that gave them strength to be able to face challenging situations. This finding is supported by Green (2007) who suggested that the intrinsic worth of the disabled children was valued by their mothers. Hui-Hui was very proud of her disabled son to have kind and generous attributes and to get along with his siblings. Feng-Feng perceived her son’s endurance of painful rehabilitation procedures gave her an optimistic outlook to predict a good outcome towards their future (Larson, 1998; Watts et al., 2006). Pun et al. (2004) suggested finding good elements of the imperfect child was important for the mother since they became strong points to redeem features of the child. However, Larson (1998) revealed that some mothers could not totally accept or deny their children’s disabilities.

Treasuring her son, Feng-Feng regarded her disabled son as a treasure and gift from God. She deeply appreciated her son to give her the opportunity to become a better person in terms of having patience and being nice to others. Such a deep belief of appreciation allowed her to move to action to seek pathways to continue to engage in her son’s better future life (Larson, 1998). Feng-Feng also viewed herself as “hope” to her son, believing her son could be nurtured to the best condition as long as she put all her efforts into providing opportunities for training or treatment to guide him towards a better future. This strong motivation was from her deep love and it assisted her in decreasing the strain of caring (McKeever & Miller, 2004). Similarly, McCabe (2007) used “dedication of parents” to describe the Chinese mother’s love for their children in terms of valuing their children by showing their determination to find any possible treatment to improve their children’s condition, even changing their work and lives.

Reconstructing her mothering confidence, Ting-Ting felt frustrated and powerless when she lost confidence in raising her disabled son due to others’ criticism (Pun et al., 2004). She tried writing a diary to “stand back” and evaluate her daily care-giving that provided her with opportunities to look at the whole picture, not focus on present day negative feelings. Ting-Ting was sensitive that her negative language and emotions had impacted on her son’s emotional and psychological development and lowered the quality of attachment (Holroyd, 2003). This was contradictory to her anticipation of being a 'good' mother. To re-think the meaning of good mothering, Ting-Ting reconstructed her mothering through re-building her confidence and
re-believing in her capacity of being a good mother. This reconstruction let her see new possibilities for energy to be involved in her long term care-giving responsibility. Pun et al. (2004) indicated that mothers overcame their initial self-doubt and developed self-confidence due to their commitment and determination to respond to their children. However, not every mother could develop a sense of being a 'good' mother due to a lack of patience, care or understanding. Larson (1998) also suggested that mothers thought they were not “successful” in mothering due to failure in raising future productive citizens, since these mothers linked their success with their children’s health, contentedness and progress.

Focusing on being 'normal', Ting-Ting valued the process of normalcy when she treated her son as a 'normal' child and taught him with 'right' behaviour to meet the social expectations since she seized upon his positive potential to reach the social standard (Landsman, 1998; McKeever & Miller, 2004; Sawin et al., 2003). McKeever and Miller (2004) revealed that emphasis on the children’s “normal attributes” aided their mothers in coping with their children’s disabilities. Normalization was significant for their lives. Ting-Ting would adopt some strategies to let her disabled son and their lives integrate into mainstream society and the outside world in terms of reconstructing their lives (Morse et al., 2000). Woolfson (2005) suggested that positive thinking that the event was manageable, not passive acceptance was crucial for the parent to adjust to the situation of having a child with a disability. Also parents were found to change their perception from viewing the child as a “disabled child” to as a “child” who could improve their personal growth, relations with others, and overall values.

In valuing any small achievement (Hartley et al., 2005; Kearney & Griffin, 2001; Taunt & Hastings, 2002), Fang-Fang felt grateful when looking at her daughter from a floppy physical movement to walking with assistance. Feng-Feng felt there was hope when her son could finally turn his body over. The small progress gave the mother hope to move forward to her final goal of being independent. Paying attention to the child’s positive outcome encouraged the mother hoping the future possibilities and having positive evaluation of the disabled child and herself in terms of the life of meaning and maternal identity and self-worth (Harden, 2005; Landsman, 2003; Larson, 1998; Pun et al., 2004). Landsman (2003) used the word “incredible” to
describe children’s progress in defeating their own physical disability. Moreover, Piggot et al. (2003) stated that the child’s progress was viewed as the best reward and motivation to continue to be involved in her daily tiring care-giving. Hinojosa (1990) suggested that mothers kept hoping their children’s development would continue to gain improvement, which helped them accept the uncertainties of their children’s future. McKeever and Miller (2004) indicated focusing on things the children could do assisted their mothers in valuing their children’s developmental independence, progress, and worth in society.

Adjusting the expectations, before reaching the final goal, Fang-Fang had to re-assess and re-build her expectations over time to provide her with new possibilities to be constantly full of motivation and find new pathways to engage in challenging daily care and not feel despair from current situation (Simpson, 2004). Although the goal has not being actualised, but keeping hope in her mind allowed her to have a strong belief to not only find pathways but also create strategies toward her wished goal in terms of her daughter’s independence (Larson, 1998). Larson (1998) stated that mothers had always experienced the tension of “embracers of paradox” in terms of experiencing the gap between their children’s current situation and their hope for the future, which gave mothers power to find solutions or seek out programs for their children. Simpson (2004) argued that people’s imagining of future possibilities did not necessarily completely rely on current situations, so the mother would set up a new definition of achievement to gain realisable possibilities to anticipate for the future.

Wen-Cian encouraged her daughter to broaden her horizons and gain new perspectives. She also experienced personal growth in developing her professional knowledge and skills in teaching. She highly valued her life and viewed it as being enhanced for having a disabled daughter (Green, 2007; Kearney & Griffin, 2001; McKeever & Miller, 2004; Sawin et al., 2003). Ai-Ai’s relationship with her mother-in-law was gradually getting better since she learned to look at things form various angles and started to realise her mother-in-law cares about her disabled son (Green, 2007; Taunt & Hastings, 2002). These findings were supported by Taunt and Hastings (2002) that mothers indicated their children with disabilities increased their sensitivity, opportunity to learn, expanded their social network, and experienced
changes in their perspective on life. McKeever and Miller (2004) also indicated that mother’s lives were enriched by their children with disabilities. Seizing upon those positive changes in life provided the mother with opportunities to look into herself and her child’s future possibilities. This supported her to overcome the day-to-day care-giving challenges.

Looking into the future possibilities, Feng-Feng planned to have her personal career as she anticipated getting more free time due to her son becoming more independent as time passed. On the contrary, Fang-Fang’s daughter had too many problems to live independently. Fang-Fang gained strength and conviction by looking at the positive experience of sharing time and anticipating the human connection she experienced with her daughter. These things gave meaning to her daily care-giving. Ciao-Ciao in anticipation of her graduation from her degree and her newfound professional knowledge and skills envisages that she will be able to positively contribute to her son’s potential progress.

These mothers not only gained insight into the future possibility from their children’s perspective but also for themselves. Their ability to look into their own possibilities for self assisted them to see the 'whole' picture and gain strength and motivation to cope with care-giving barriers and negative emotions related to care-giving responsibility, and move ahead to realise future possibilities. Similarly, women in the research of Helitzer et al. (2002) realised the importance of relaxing their extremely high expectations for their daily accomplishments, such as their daily domestic work, marital role or family subsistence. They began to shift their attention to self and caring about their own situation in terms of ensuring that could sustain their caring ability for their children with disabilities.

**Summary**

This discussion of findings provides nurses and health care professionals with opportunities to gain insight into and better understand mothers’ daily lives of care-giving for children with CP. Disclosing the meaning of the lived experience of providing daily care for a disabled child challenges practitioners to reflect upon their knowledge of mothers’ daily involvement, barriers, and motivations to continue to
engage in everyday maternal care-giving. The next chapter examines ways in which gaining in-depth insight and understanding encourages practitioners to reconceptualise the ways in which they can better support mothers caring for children with disabilities.
Chapter 10

Reflections

Introduction
In this chapter, the contributions and limitations of this study, recommendations for nursing, health care practice and future research, are examined. The aim of this chapter is to challenge nurses to reflect upon, and in the light of this study’s findings, reconceptualise how they support mothers in fulfilling their maternal role caring for disabled children in ways that are significant and meaningful.

Contributions
In this hermeneutic phenomenological study, the meaning of Being a mother engaged in caring for a child with CP has been illuminated by disclosing the modes of care-giving to which mothers attribute importance. The participating mothers engaged in a variety of different roles, each role having its own purpose and significance determined by how meaningful involvement facilitated care-giving that nurtured the potential ability and skills to satisfy their children’s life wants and needs. Striving towards achieving quality care for their children enhanced their existence as mothers of disabled children. Thus, this study contributes to the existing body of literature in highlighting how mothers engage in care-giving through their everyday involvement in specific roles that are purposeful and provide the means through which meaningful existence can be experienced (Hartley et al., 2005; Larson, 1998; McKeever & Miller, 2004; Pun et al., 2004).

This study adopted an ontological hermeneutic approach which provided philosophical and theoretical guidance to explore the practical everyday experiences of maternal care-giving through an examination of family background, past and present day experiences and future anticipations. Through the interpretation of their experiences this study provides an opportunity for nurses and health care professionals to appreciate how the mothers’ lives can be meaningful through everyday average engagement in their children’s daily care. In this way, the study
findings contribute to enhance the practical knowledge of a variety of health care professionals.

This study’s findings suggest that through engagement in the practicalities of care-giving each day mothers reveal their capacity of finding pathways to cope with everyday situations that arise as they raise their disabled children with CP. Such disclosure exposes both the demanding and relentless aspects of the care-giving but also positively highlights how mothers realise self-growth, gain a new perspective on life, realise purpose, worth and confidence in their maternal role, experience enrichment as they perceive their children as treasures, appreciate every aspect of their children’s achievements, and learn how to negotiate, accommodate and adjust their expectations so that new possibilities continue to fuel their motivation and continued care-giving engagement.

These findings provide nurses with the opportunity to better understand and acknowledge the importance of recognising those positive aspects of mothering that empower mothers to overcome caring difficulties and seize upon possibilities to see the whole picture and to move forward into their future (Kearney & Griffin, 2001; Kirk et al., 2005). Gaining such insight enables nurses to focus their practice in encouraging and supporting mothers to look at their strengths and their children’s merits to help them successfully cope with their maternal care-giving and realise their worth (Kirk et al., 2005; Landsman, 1998; Sawin et al., 2003).

As the participating mothers ability to care was fuelled by their positive experiences, barriers to their care-giving caused negative feelings of worry, anxiety and powerlessness. Hence this study highlights both the positive and negative experiences of maternal care-giving mothers. This knowledge is important as it exposes nurses to the possibilities of minimising the negative experiences and promoting the positive experiences. This approach is unlike the quantitative research approach that focuses upon examining and predicting characteristics of care-giving, for example, mothers’ stress levels and causes (Holmbeck et al., 1997; Mobarak et al., 2000), the relationship between stress and social support (Dyson, 1997; Skok et al., 2006), the relationship between well-being of mothers and children’s physical function (Barlow et al., 2006; Eker & Tuzun, 2004; Ones et al., 2005).
The existential perspective appreciates the ability of mothers to reflect on their care-giving experience, to see the whole picture and future possibilities, not only focus upon present day stresses and difficulties. This ability is changeable in that mothers experience both “good” days and “bad” days and can “swing” from feeling positive to negative and back again on a consistent basis. This experience is dynamic not linear, nor static. In this way mothers’ find new ways of adjusting to their situation in order to foster and sustain possibilities to engage in meaningful maternal care-giving. Thus this study reveals the meaning of Being a mother and perceived self-worth are enhanced when realising possibilities that foster the gratification experienced through living a meaningful life, where the emphasis is less on living with the stress or burden associated with the characteristics of care, and more about the meaningful possibilities associated with everyday involvement in caring.

This research approach differs from other qualitative research methods more commonly applied to explore the experience of maternal care-giving (Larson, 1998; Lewis et al., 1999; Pascall & Hendey, 2004; Rao, 2001; Todd & Jones, 2005), for example, the descriptive phenomenological approach (Glasscock, 2000), grounded theory (Kirk et al., 2005; Piggot et al., 2003; Watson et al., 2006), ethnography (Hinojosa, 1990; Holroyd, 2003), and mixed method (Green, 2007; McCabe, 2007; Taunt & Hastings, 2002).

In particular, this study focuses upon the experience of Taiwanese mothers caring for children with CP. Such knowledge contributes to understanding how these mothers engage in daily care within the context of a Taiwanese family and culture. There exists no literature that undertakes a hermeneutic phenomenological approach to explore the Taiwanese mothers’ lived experience of raising children with CP. Some qualitative researchers have undertaken studies in Mainland China (Holroyd, 2003; McCabe, 2007; Pun et al., 2004), but the majority of published research focuses upon mothers’ experiences in the United States (Kellegrew, 2000; Landsman, 1998; Sawin et al., 2003) and the United Kingdom (Pascall & Hendey, 2004; Sleigh, 2005; Todd & Jones, 2005).
Implications for Nursing Practice

Challenging Questions for Nurses
This study in adopting a hermeneutic phenomenological approach asks a number of challenging questions that invite nurses to reflect upon their everyday practice. For example:

1. How is it that maternal care-givers understand their maternal caring experiences? What maternal roles and abilities do mothers develop that enables them to adjust for caring difficulties and challenges when raising the child with CP?
2. How is it that mothers find and give meaning to their everyday practical care-giving activities?
3. What influences become barriers that hinder mothers in ascribing meaning to their daily caring experiences?
4. Can mothers possess the ability to look at the 'whole' picture and seize upon possibilities to move forward towards a hopeful future?

Personal values
By considering responses to these questions nurses are challenged to reflect upon the values and beliefs they possess in relation to disability and think about how such values influence supportive nursing practice. Importantly, the findings from this study provide direction in how better to support mothers through gaining insight into what is meaningful in their everyday care-giving.

Personal values and beliefs have the potential to effect nurses’ abilities to effectively support care that involves family members (Kirk et al., 2005; Lam et al., 2006). It is important that nurses and all health care professionals are sensitive to their personal attitudes and beliefs towards disability, such as regarding the disability as a tragic event or that disability inevitably leads to the loss of being independent. Personal values and beliefs can influence how people relate and interact with children with CP, parents and family members (Lam et al., 2006; Sanders, 2006).

To sustain nurses’ sensitivity to their own personal attitudes and values, nurses can practice writing reflective journals everyday to allow them to question and reflect on
their own attitudes, feelings, values, and experience to improve their self-awareness, interpersonal understanding, critical analysis of their experiences and link theory and their clinical experience. The aims of writing reflective journals are to cultivate their positive feelings and attitude to overcome their negative feelings and finally through a process of reflection feel enabled to commit to action (Chirema, 2007) in terms of having positive attitudes and values towards disability and demonstrate the ability of reliability, genuineness, warmth, caring and empathy (Briggs, 2006-7).

When nurses believe the disability is a tragedy (Woolfson, 2005) nurses have been found to lack the ability to help mothers develop strategies to see possibilities, experience hope, and recognise the positive experiences and rewards associated with care-giving (Kearney & Griffin, 2001; Larson, 1998). Lam et al. (2006) indicated that people in Chinese culture hold more negative attitudes towards disabled people due to their cultural beliefs and values. When Chinese nurses viewed the disability as a stigma, they tended to show their negative attitude. This reinforced the mothers’ feelings of shame and resulted in depression and frustrations, devoid of a hopeful future (Lam et al., 2006).

Watson et al. (2006) argued that nurses acting as destigmatisers was important for the family of a child with developmental problems. Nurses had significant roles as educators and supporters in teaching mothers and their families to focus on the positive qualities of their disabled children (Change & Lin, 2007). For example, to look at what physical ability or self-care skills or good character their children possessed and what medical condition have been controlled (Wong et al., 2006). The findings from this study, those that reveal how it is that mothers find and give meaning to their everyday practical care-giving activities, assist nurses to understand how to support mothers in ways that are significant and worthwhile for them.

**The concept of parent-child-professional partnership**

Findings from this study revealed that mothers became 'local' experts as they gained confidence in undertaking their various roles and engaging in the long-term involvement and commitment of providing daily care (Landsman, 1998; Larson, 1998). This study highlights the importance of such local knowledge in informing and enhancing the professional and technical knowledge provided by nurses and other
health care providers. It is the combination of local and professional bodies of knowledge that provide a breadth of insight into how to provide quality care for children with CP. To regard mothers as partners, to actively involve them in the care team through collaborative efforts that equally value and respect different roles and knowledge, is paramount to improving the quality of clinical care services (Mir & Tovey, 2003; Young & Klinge, 1996).

This study clearly supports such findings in arguing that the equal parent-professional partnership should be initiated when mothers and their children first have contact with nurses and health care professionals and should be a natural part of the developing partnership. In order to combine mothers’ knowledge with professionals’, the nurse should, in their role as coordinator, involve mothers and families in working with other health professionals to enable their voice and knowledge to be heard. Such information informs the development of individualised care plan and targets appropriate family service. Home visiting and regular contact with mothers and families can be carried out to follow their situation (Lindeke, Leonard, Presler, & Garwick, 2002; McEnhill, 1996).

Further, Woolfson (2005) argued that the responsibility of care and treatment is not solely one for parents, but both parents and the child (Woolfson, 2005). The child should be actively involved in the health team. The child is not an outsider to passively receive final decisions from others. This argument encourages nurses to seek the child’s opinions and assess their feelings about the treatment and rehabilitation goal. The aim is to ensure their understanding, so the expectations, personal responsibility, and goals are mutually shared by all involved in the process (Woolfson, 2005). Importantly, such engagement assists disabled children to develop skills and responsibilities in childhood that can lead to success in adult life. Mothers in this study did not feel alone or fearful, but kept optimistic about their children’s self-care skills and striving for independence when all care participants were working towards a mutual future goal (Sawin et al., 2003).

**Disclosing the diagnosis**

Regarding the issue of disclosing the diagnosis of CP, this study found that mothers’ reactions to hearing the diagnosis included shock, disbelief, denial and despair. Initial
perceptions of living a life of “capital punishment” were evoked through the experience of intensive negative emotions. The experience of the diagnostic process could affect the mother’s capability of seeing future possibilities for the child, herself and her family. This study highlights the need for nurses to reflect upon the communication shared with mothers at this time. A sympathetic and affective attitude to give emotional support and importantly hope when disclosing a diagnosis or examining the child’s progress, is vital in empowering these women to begin to see and be motivated by the potential of future possibilities (Dagenais et al., 2006; George et al., 2007; Quine & Rutter, 1994; Tattersall & Young, 2006).

The findings of this study clearly guide nurses to increase their awareness of how they communicate. This extends well beyond merely sharing information that focuses upon the characteristics of the child’s limited physical functioning and behaviour (Mir & Tovey, 2003). They should regard mothers as partners able to discuss their children’s diagnosis, future treatments and progress (Hummelinck & Pollock, 2006; Young & Klingele, 1996).

After physicians have communicated the diagnosis to the parents, nurses have an important role in providing time for discussion about the parents’ feelings and answering any questions patiently. The nurses are able with time to pay attention to the parents’ subtle cues and ensure that no information is missing, support the process of hearing the diagnosis (Thurgate, 2006). Furthermore, the nurses’ role of coordinator at this time ensures that parents are involved in assessment processes and such procedures validate their knowledge and ensure that outcomes and care suggestions are understood (Stepans et al., 2002).

The mothers in this study felt angry with the delayed diagnosis for either giving “false hope” or not taking their concerns seriously. The importance of nurses listening to, respecting and valuing mothers’ concerns and promptly arranging further examinations to find out any possible problems is clearly supported (Baird et al., 2000; George et al., 2007; Glaun et al., 1998; Mir & Tovey, 2003). The study findings indicate the importance of nurses working with mothers towards the early detection of a child’s problems thus enabling an earlier diagnosis and commencement of useful therapy (Rannard et al., 2005).
The role of nurses involves the screening and identification of high risk children in terms of developmental delay or disability (Lien, Wu, Chen, & Mao, 2005). Nurses possess knowledge and skills to assess children using developmental screening and diagnostic testing in order to identify children who are at risk of delay in the areas of motor, language, social interaction and hearing. The important aim is to identify possible cases and once confirmed start treatment earlier. Children’s nutrition, head circumference, body weight and height and other aspects of physical functioning are assessed holistically by nurses (Nehring, 2003; Stepans et al., 2002).

Sun and Yang (2006) emphasised that the public health nurses in Taiwan were in a significant position to identify children with developmental delay, because those nurses had an opportunity to undertake developmental screening when parents brought their children to health stations to receive vaccine injections. Following screening nurses are in a unique position to notify the parents of assessment results and make appropriate on going referrals for treatment and care (Sun & Yang, 2006). Public health nurses also visit the disabled child at home to provide psychological support and ensure that no misconceptions about the diagnosis exist (Hummelinck & Pollock, 2006; Stepans et al., 2002). Referral for counselling is possible because of this follow up care (Baird et al., 2000).

In this study, participating mothers communicated their need for an early diagnosis to provide them with hope and the means of accessing care, treatment and therapy associated with addressing their children’s needs in an timely manner. This situation created possibilities for improving the long-term prognosis for their children, fostering satisfaction with health care services and developing a trust relationship with nurses and other allied health care professionals (Baird et al., 2000; Mir & Tovey, 2003; Quine & Rutter, 1994).

The balance between sharing the diagnosis, allowing time to internalise the information and act on it, is a difficult one to facilitate in a positive way owing to the individual differences experienced by mothers receiving such devastating information. This study clearly identifies the need for nurses to allow time for mothers to experience and process their thoughts and find out answers to confusing questions.
that help to decrease the fear associated with an unpredictable future (Baird et al., 2000; Hummelinck & Pollock, 2006).

**Standards of care**

In this study, a key trigger to dissatisfaction and associated distress was perceived sub-standard health care. Mothers would engage with nurses and care professionals as advocates for their children intent on negating the less than desirable aspects of what they deemed to be sub-standard care and treatment. Their aim would be to secure the possibility of their children receiving optimal health care that improved the quality of life for their children (Landsman, 1998; McKeever & Miller, 2004). Mothers felt powerless and angry when receiving inconsistent information or insufficient information about their children’s treatment. Sometimes the mothers in this study kept silent or changed to other medical facilities to look for treatments. They avoided having arguments or asserting their opinions to health care professionals, because they were expected to respect the authority and professional knowledge of health professionals in a paternalistic medical system in Taiwan (D. F. C. Tsai, 2001). Power asymmetries can prevent mothers from participating and being involved in their children’s treatment and care (Kirk et al., 2005). However, communicating messages and setting up health care goals without involving mothers, can lead to ineffective and insufficient care (Leiter, 2004; Watson et al., 2006).

Nurses as advocates are able to communicate about the parents’ problems and wishes with other health professionals in order to reach a consensus of expectations and reduce the gap between parents and health professionals that can often result in misunderstandings and conflicts (Thurgate, 2006). Nurses as educators can teach parents to keep medical notes in order to better communicate with health professionals in an informed manner. The key for nurses is to cultivate parents’ confidence by providing knowledge about their children’s disease and condition and empower parents to communicate with other health professionals (Thurgate, 2006).

Thus to encourage parents to engage in the care of their children, nurses must share their power and sense of control with parents and family members (Corlett & Twycross, 2006). Empowerment and enabling of parents can sustain families developmental potential (Chou, 2007). Gradually, the supervisory role of nurses shifts
from the nurse to the parents as the parents’ knowledge and skills increases over time (P. Lee, 2007). Mothers in this study clearly communicated their wishes to be involved in the process of decision-making about treatment and care. Participating mothers believed this to be the optimal way to provide the appropriate and person-centred quality health care for their disabled children (Hummelinck & Pollock, 2006).

Nurses as educators have an important role in providing education to increase the knowledge of parents and improve their capacity to make decisions about their children’s care (Collin, 1995). Huang and Wang (2005) claimed that sharing and transferring must engage both nurses and clients in a process of decision making that involves equal responsibility and agreement on a plan of care. The partnership should be built on trust, mutual respect and informed by shared values that support the best health decisions for the disabled children (Huang & Wang, 2005).

Some mothers felt hopeless or helpless when health professionals only paid attention to the children’s diagnosis and symptoms and gave no hope for their children’s future progress or poor outcome. This deflated any perception of possibilities for a positive future (Graungaard & Skov, 2006; Mir & Tovey, 2003). The need for nurses and health care professionals to see the child as a person before the diagnosis or treatment and demonstrate respect for another human being is clearly supported. Mothers not only feel satisfied with health services when their children are visible to health professionals, but also develop the capability of coping with their situation (Mir & Tovey, 2003). The nurse’s role as supporter is vital in aiding the building of rapport and an egalitarian relationship based on mutuality (Briggs, 2006-7). When mothers were supported by nurses to appreciate their children’s positive potential, acceptance of their disabled children, positive interaction with their children and active searching for support resources resulted (Wong et al., 2006).

In this study, participating mothers felt angry and disappointed when they perceived that their children were receiving a poor quality of rehabilitation from therapists, such as a lack of an individualised rehabilitation program or what they perceived as therapists “fooling” around. This study found that to regard the mother as a partner and to appreciate that mothers’ valuable involvement benefited their children’s
progress. The importance of the therapy goal and content being supported and informed by the mothers 'local' knowledge and skills, in particular, through the exchange of knowledge about the children, family background, care philosophy and personal expectations of program, greatly enhanced the possibility of developing an individualized rehabilitation program.

Watson et al. (2006) found in their study that mutual communication assists the development of a therapeutic alliance and trust relationship that increases maternal satisfaction and self-worth. This study found that when mothers were not involved in setting up therapy goals or program, their motivation and confidence was negatively affected. In agreement with other studies, successful therapy is not only achieved by solely focusing upon the potential benefits of the child’s rehabilitation program, but also requires a sensitivity that serves the family and parents’ needs (Hinojosa & Anderson, 1991; Leiter, 2004; Watson et al., 2006).

This study clearly supports the need for nurses to demonstrate their professional knowledge and confidence in their practice. Demonstrated enthusiasm and devotion to their practice and to each child provided an important source of comfort for mothers participating in this study. Such findings encourage nurses to reflect upon how their daily practice provides hope to mothers who rely on such an experience to continue to engage in present and future care-giving. Through such practice nurses have the capacity to enhance the existence of Being a mother of a child with CP.

Experiencing difficulties performing a rehabilitation program at home was shared by many mothers in this study. For example the child felt bored with the home program, lacked willingness to cooperate with their mother, was frequently interrupted by other siblings or the need to complete household chores. All these incidences hindered mothers in providing a good quality of rehabilitation and maintaining a positive child-mother relationship at home. These findings highlight the need for nurses to re-think how rehabilitation programs translate in the home care situation (Hinojosa & Anderson, 1991). The need for flexible and interesting rehabilitation home programs that cater for the individual are required to promote the continuity of treatment and care within the home environment (Hinojosa & Anderson, 1991; Leiter, 2004). In addition, such programs should give encouragement and support to help mothers feel
confident in their knowledge and ability to carry out home based care. Programs that clearly highlight how the child is progressing provide the potential for supporting and motivating the mothers to engage in the daily demands of providing such care.

Nurses are in a significant position to ensure that parents are supported in undertaking home-based therapy in their home environment (Briggs, 2006-7; Chou, 2007). The need for flexible and interesting rehabilitation home programs ensure the continuity of treatment and care within the home environment (Hinojosa & Anderson, 1991; Leiter, 2004). Nurses can support other family members to assist with the rehabilitation program to ensure rehabilitation can be successfully performed in the home setting (Frain et al., 2007).

Ultimately, the most significant goal for all the participating mothers was to enable their children to possess self-care skills and the ability to care for themselves. Their key purpose was to ensure that their children aimed for independence and that the development and care process was of an optimal standard. A standard that improved the quality of their children’s lives.

**Traditional medical system**
The mothers in this study demonstrated that they did not possess information about all possible treatments. They felt that they had not been given a holistic explanation and examination of their children’s disease, nor guidance in how they could best maximise their children’s potential. They felt angry and disappointed with health care professionals whom they perceived were patronising and uncaring. Some mothers expressed their anxiety and shock when the physicians gave them too much bad news in a short time without giving them an opportunity to clarify their questions to decrease their feelings of fear and uncertainty. M. H. Tsai (2005) states that Taiwanese doctors get used to interviewing their patients in a fast pattern due to time pressures, providing no time nor opportunity to give the patients time to participate in discussion.

The traditional Chinese doctor-patient relationship is shaped by the Taiwanese cultural context. This culture supports a paternalistic and patriarchal society. The paternalist doctor-patient-family relationship and methods of medical decision making

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are common and not deemed to be inappropriate within such a context. In addition, the Taiwanese tend to conceal their personal rights and interest in a private manner away from public scrutiny. Therefore, the Taiwanese patient tends to lose their rights and autonomy (D. F. C. Tsai, 2001). The findings of this study further highlight the need for Taiwanese nurses to reflect upon their professional behaviour and become more aware of how they can support mothers to communicate openly and articulate their personal needs and opinions (Young & Klinge, 1996).

For nurses in Taiwan, the findings of this study challenge them to re-conceptualise how they think about parent-professional partnership in the traditional Chinese health care system to respond to these mothers and meet their children’s health needs. Without challenging the paternalism within the Taiwanese health care system, the rights of mothers to have revealed all possible treatments, examine their disadvantages and advantages, and to present opportunities to discuss possibilities for their children in an open and equal manner is lost. Possibilities to share different ways of knowing the children, that nurture the development of a sense of control in a challenging an unknown situation, are denied (Norfolk, Birdi, & Walsh, 2007; Schouten, Meeuwesen, Tromp, & Harmsen, 2007; Young & Klinge, 1996).

**Traditional Chinese family**

This study highlights the significant resource of family and the highest authority of the parents-in-law and the husband in traditional Chinese family life. Such authority as shared by participating mothers influenced opportunities for treatment and the acceptance of their children into the family. This study reveals that poor family support and dynamics will emerge when family members regard disability as a loss of face or a stigma. It was not uncommon for the family members to blame the mother for the child’s disability. In these circumstances, the families’ willingness to engage in child care was negatively effected.

Under such circumstances, the mother assumed care-giving responsibility alone (Hartley et al., 2005; Pun et al., 2004) and saw no hope for her child and self, as family members devalued the child and his/her treatment. Therefore, to involve other family members in the health decision-making and care-giving processes although vital for the successful implementation of treatments and care was not always possible.
for the participating mothers. Nurses have a major role and responsibility in terms of family education when such situations arise. Nurses should actively invite family members to a child’s rehabilitation or treatment sessions at the hospital and have regular meetings with them to allow family members to understand the child’s condition (Cohn et al., 2000; Watson et al., 2006). In addition, nurses should listen to their concerns and be sensitive to their caring needs to offer support. If necessary, the nurses should refer to social workers and work with them to solve their family’s problems (Hartley et al., 2005). In the role of supporter nurses can make appropriate referrals to meet parents and their children’s needs and be familiar with other disciplines and agencies and how they contribute to the children’s care (Thurgate, 2006).

Family sharing is another important purpose for meeting with family, to allow all family members to share their feelings and experiences to enhance their understanding and cultivate family support (Kirk et al., 2005). It can be viewed as a turning point to change family member’s values, attitudes, and manners positively towards the child with CP. Ow, Tan, and Goh (2004) revealed that family support was the major resource used by Chinese mothers taking care of their disabled children at home. The mother’s spouse was the central support resource, followed by her parents, then her offspring, and her siblings. Support from friends, extended family members, and formal sources were lower support resources. Thus family support is significant for those mothers since the Chinese believe that family harmony and balance within family relationships contributes to individual health and wealth as well as social balance (Kendall, 2006).

Issues of “face” also explain why family support is crucial. According to an old Chinese saying “family scandal (here indicates child with disability) should not be made public”, so it is a universal strategy for the family to cover up the things they feel shameful about to prevent others from knowing and the family losing face (J. Li et al., 2004). Under such circumstances, family support becomes the most important resource for those mothers. In addition, the mothers perceive their maternal identity and self-worth depends on whether their disabled children can be accepted by other significant family members, especially their in-laws and husbands (Pun et al., 2004). Therefore, family support signified that their children belonged to the family and
shared family love and caring, feeling secure in their human connection (Lindblad et al., 2007).

Giving family emotional support and counselling is necessary to enhance involvement of care and acceptance of the child with CP (Trute, 2003). Such family involvement enhances the child’s potential progress and family ties and reduces caring stress and burden (Trute, 2003). Although the child with CP is not a “perfect” child based on social expectations, the participating mothers in this study considered their children to be gifts from God that they treasured. The mothers believed that “perfect” motherhood did not depend on having a perfect child, but upon being able to positively contribute to their children’s quality of life (Pun et al., 2004).

In order to successfully involve all family members in childcare activities nurses need to assess the family dynamics, social support networks, attitudes toward disability, coping strategies and ability to problem solve (Frain et al., 2007). Educating families to build on their strengths and manage their challenges is an important role for the nurse (Frain et al., 2007; Wong et al., 2006). When family members increase their knowledge of disability they are better able to understand and accept their disabled children. The feeling of shame can be reduced and their commitment to childcare and ability to positively interact with their disabled children, with love, are enhanced (Wong et al., 2006).

Some mothers experienced challenges with parenting issues in terms of experiencing a poor quality of child-mother relationship. Some of the children in this study blamed their mothers for the disability and the mothers felt guilty about not giving their children a healthy body. These children considered their mothers should satisfy all their needs without delay and the mothers felt guilty and blamed themselves for not concentrating on meeting their children’s wishes. Nurses as educators can support in assisting parents to learn how to manage such challenging behaviours and modify and shape such behaviour (Nehring, 2003).

To reflect upon these findings focuses one upon the meaning of maternal care-giving shaped and influenced by family background and past experience. Negative relationships have an impact on the existence and meaning of being mothers and
impacts upon their ability to providing care for their children (Woolfson, 2005). The need for nurses to fulfil their role of supporter and educator to initiate some useful strategies to improve the mother-child relationship to support those mothers and their children in such circumstances is clearly indicated. Nurses have a role in providing practical knowledge for mothers, such as how to communicate with their children effectively, what are the better methods to teach their children, how to observe their children’s behaviour, and provide parents with useful resources and guidance on how to deal with their parenting issues and the children’s emotional reactions (Chou, 2007). Provision of support groups allow parents to share their experiences and gain support. Child-parent groups should be established to invite parents and their disabled children to participate in this group together to learn to share their inner thoughts and feelings to reach mutual understanding and improving relationship (Chou, 2007).

**Limitations and Recommendations for Further Research**

In this study some of the participating mothers experienced difficulties following the traditional Chinese ritual of *doing the month*. Engaging in this ritual was denied due to the diagnosis of CP, and in some cases impossible because of the children’s critical medical condition. Although not considered in detail in this study, and given the significance of this ritual for Chinese mothers, exploration of the experience of doing the month following the birth of a disabled and critically ill baby is an important area for future study.

Mothers in this study described their feelings of despair and confusion towards the children’s diagnosis. The art and skill of sharing the diagnosis was demonstrated in this study to be of major significance in the experience of giving birth to a disabled child. Given this, future research is required that focuses upon communicating such news to mothers and families. In addition, nurses and health care professionals should be invited to participate in such research to share their experience of revealing the diagnosis.

From my research results it was revealed that caring for children with CP not only impacted on their mothers, but also upon other family members. This study did not focus upon the experience of other family members but concentrated on the
experience of mothers as primary caregivers. Future research needs to involve other family members to explore such experience in a genuine family context. This might include significant others, namely the father, grandparents and siblings to have their voice heard and gain a better understanding of the phenomenon of raising children with CP from the family perspective.

The aim of this research was to understand the shared meanings of maternal daily care-giving for relatively young children in an intensive period of rehabilitation. Their experiences were discovered from past to present and towards the future. Future research might focus on a specific period of time, such as a newborn with CP, toddler and pre-school child with CP, school aged child with CP and adolescent with CP. Such foci can provide for a deeper understanding of the care-giving experience at specific times and stages of the child’s development and life.

The findings of this research can be a reference for developing further quantitative measures capable of examining a larger population of Taiwanese mothers. Moreover, in this study I did not explore the influence of Taiwanese policy on care-giving and disability. Future research might delve into how motherhood is constituted by policy in a Taiwanese culture. The role of community nurses and school nurses could be further explored, so a focus on community network resources and the nurse’s role and function in community and school could be further explored in a Taiwanese context.

**Conclusion**

This study employs a hermeneutic phenomenological approach informed by the philosophical worldview of Heidegger and Gadamer. The aim of the study was to gain a better understanding of the experience of care-giving for a Taiwanese mother of a child with CP. Findings revealed that Taiwanese mothers understood their care-giving experiences by engaging in their daily practical care-giving activities. Those Taiwanese mothers felt their lives were meaningful and were satisfied with their maternal identity and self-worth when they found pathways and possessed the abilities to perform their multiple maternal roles. They switched their maternal roles to adjust for the event of having children with CP in order to fulfil their care-giving
responsibilities to satisfy their children’s caring needs and to have a better quality of life.

However, they encountered some barriers within a Chinese society and culture to fulfilling their ‘ideal’ maternal roles of providing quality of care for their children with CP. These barriers provoked feelings of powerlessness, hopelessness, helplessness, sadness, and anger, because they diminished their hopes of positive anticipated possibilities. For some mothers their capability of seizing upon possibilities for self and their children allowed them to “step out” of their everyday care-giving activities and view the whole picture. This capacity enabled them to appreciate those “little” rewards in daily care-giving which fuelled, motivated and mustered the will-power to not indulge in the present powerlessness or frustration, but move forward to realise future positive possibilities for self and children. (Gadamer, 1960/1975)
Appendices
Appendix A: Advertisement and Poster

Sharing you experience

Mothers of Children with Cerebral Palsy

You are not alone any more. Do you want to share your experience of caring for your child with cerebral palsy with me? Your sharing can help people better understand your experience in particular it can help health professionals providing service and support, but also other parents in similar situations.

My name is Yu-Ping Huang. I am a Registered Nurse and a doctoral nursing student. I am conducting a research study that explores the caregiving experience for a mother of a child with cerebral palsy. I am looking for mothers of children aged less than 18 years old who are the main caregivers at home.

If you are willing to join this study, please do not hesitate to contact me. I would be pleased to answer any questions about this study. Please feel comfortable to dial any of the following numbers at any time.

Mobile phone: 0919-023-440
Work: (04) 2361-8562 ext 3021
Home: (08) 779-3738
I am looking forward to hearing from you.
分享您寶貴的經驗

腦性麻痺患孩的母親

從現今開始您不再寂寞的孤軍奮戰了，我們希望與您分享您在照顧腦性麻痺孩子的經驗，您寶貴經驗的分享將有助於我們更加瞭解您的經驗，尤其更可協助專業醫療人員提供更佳的服務品質及對您的支持，當然也協助有類似情境的母親。

我是黃玉萍，我是合法的註冊護士，目前也是博士班的學生，我欲探討“腦性麻痺患孩母親的生活經驗”，如果您小孩的年齡小於 18 歲，且您是家中的主要照個者，敬請並希望您與我分享您寶貴經驗。

如果您願意參與此項研究，希望您不猶豫的拿起電話與我聯絡，我將非常樂意回答您有關本研究的任何訊息，本研究乃是採不記名的方式，故您不用擔心您個人資料的外流，敬請以您方便的方式隨時與我聯繫。

行動電話：0919-023-440

辦公室電話：(04) 2361-8562 轉 3021

住家：(08) 779-3738

期待您的回音
Appendix B: Information sheet

The Experience of Being a Taiwanese Mother of a Child with Cerebral Palsy

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E-mail: u.kellett@griffith.edu.au
Associate Supervisor: Dr. Winsome St John
Contact Number: 61 7- 5552-8935
E-mail: w.stjohn@griffith.edu.au
Associate Supervisor: Dr. David Lee
Contact Number: 61 7- 5552-8849
E-mail: d.lee@griffith.edu.au

Background
The purpose of this research is to explore your care-giving experience as a mother of a child with cerebral palsy. Your valuable experience of caring will assist health professionals to know how to better provide more appropriate supports and services for caregivers in your situation.

What participation is this study involves
Involvement in the study will require you to share your everyday care-giving experiences through interviews. In order to record your words exactly and convey your meaning clearly the interview process will be tape-recorded. Interviews may last approximately two hours. All interviews will be scheduled at mutually convenient times and locations. If necessary you will be interviewed twice to offer you the opportunity to provide comment upon my evolving understanding of your experience. We hope that you will consider participation in this study, because your valuable story will assist health care professionals to understand and appreciate your experience and provide more appropriate help to assist mothers to manage similar situations.

Consent to participate
You are a voluntary participant in this study. Also you have the right to withdraw from or stop your involvement in the study at any time. You may also refuse to answer any question that makes you feel uncomfortable, or request that the tape be turned off during sections of the interviews. Whether or not you participate in this
research does not affect the right of your child to receive treatment. The researcher will not discuss this research with your child’s doctor so the doctor will not be able to know that you joined or decided not to join in this study.

Risk
This research will have no physical risk to you. You may feel uncomfortable discussing sensitive topics. I am experienced in supporting mothers in similar situations. However, I can arrange for a counsellor to support you if required. I will also follow up your situation by telephone or through a home visit.

Confidentiality
Your name or any identifying information will not be divulged to anyone apart from the research team. I will discuss with you the name and location you prefer me to use in the transcription so your anonymity will at all times be safeguarded. This data will be locked in a cabinet at the researcher’s office in the School of Nursing and Midwifery of Griffith University for a period of 5 years and then will be erased.

Complaints Mechanism
Griffith University conducts research in accordance with the National Statement on Ethical conduct in Research Involving Humans. If you have any concerns or complaints about the ethical conduct of the research project you should contact the Manager, Research Ethics on 38755585 or research-ethics@griffith.edu.au.

Privacy statement
The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be disclosed to third parties without your consent, except to meet government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purpose. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at www.griffith.edu.au/ua/aa/ve/pp or telephone (07) 3875-5585.

Yu-Ping Huang
研究說明單

(Information sheet)

研究主題：探討台灣母親養育腦性麻痺患孩的經驗

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背景

本研究的目的為探討您每日照顧腦性麻痺患孩的生活經驗，您的經驗將有助於專業人員了解如此寶貴的經驗，進而可更適當的提供支持及服務給有類似經驗的母親。

研究涉及的部份

本研究將藉由訪談而了解您的照護經驗，為正確紀錄您的會談內容及正確傳達您會談的意義，在會談過程將會以錄音的方式進行，一次會談約一到兩小時，約定雙方許可的會談時間及地點。視情況而定，可能需第二次會談，第二次的會談我將與您討論有關我對第一次會談內容的了解，以便有機會請您提供您寶貴的意見。藉由此一機會討論您的問題、想法及感覺，在此過程中您將發現會談對您的助益。為深入及完整的了解您寶貴的經驗，我們希望您參與本研究，以期專業醫療人員更可體恤並感激您的經驗，進而提供協助與此相似狀況的母親。

同意參與研究

您是自願參與本研究，您亦可在研究的任何過程退出本研究，您亦可在會談中要求終止錄音，或拒絕回答任何讓您覺得不適的問題，不論您所做的任何決定均不影響您孩子現在的所有治療。整個研究過程，您孩子的主治醫師並不知您是否有參與本研究，且我禁止將任何研究內容轉述給您孩子的主治醫生。

危險性

本研究對您並無任何身體上的危險，但在訪談過程中您或許會憶及一些較不舒服的往日經驗，因此我將隨時提供情緒支持，研究者以往有豐富的經驗可提供此一支持，如有需要，將會提供專業諮商者提供諮詢服務，且研究者亦會運用電話或家訪的方式繼續提供追蹤服務。
匿名及保密性

為確保資料的匿名及機密性，您的姓名及您在會談中所提及的任何姓名或地點將不會呈現在任何的紙本中，因此我將與您討論代替的姓名及地點。研究資料將被封鎖於研究者辦公室的資料櫃五十五年，之後即被銷毀，故您的資料並不會外流。

投訴專線

我了解任何有關本研究的倫理議題，如有任何疑問，我將可隨時連絡葛瑞菲斯大學的人體研究倫理評審委員會的成員，聯絡電話為617-3875-5585或經由電子信箱research-ethics@griffith.edu.au。

隱私權聲明

研究資料只會運用您匿名的資料，在未經由您的同意下，您的所有資料將不會外流，除非有任何與政府相關的法令規定。您的匿名在整個研究過程中將被徹底執行，如有任何疑問請與葛瑞菲斯大學的人體研究倫理評審委員會聯繫，網址為www.griffith.edu.au/ua/aa/ve/pp或電話(07)3875-5585。

如您有任何與本研究有關的問題或疑慮，請與黃玉萍連絡。
Appendix C: Consent form

The Experience of Being a Taiwanese Mother of a Child with Cerebral Palsy

Researcher: Yu-Ping (Sarah) Huang
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Contact Number: 61 7 –5552-8935 E-mail: w.stjohn@griffith.edu.au
Associate Supervisor: Dr. David Lee
Contact Number: 61 7 –5552-8849 E-mail: d.lee@griffith.edu.au

- I understand how I will be involved in this research and have had all questions answered to my satisfaction;
- I understand the risks involved;
- I understand that there will be no direct benefit to me from my participation in this research;
- I understand that my participation in this research is voluntary;
- I understand that if I have any additional questions I can contact the research team;
- I understand that I am free to withdraw at any time, without comment or penalty;
- I understand that the data will be securely locked in a cabinet in the researcher’s office for 5 years and then will be erased;
- I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3875-5585 if I have any concerns about the ethical conduct of the project;
- I agree to participate in the study.

Name of participant: 

Signature: 

Date: 

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參與研究同意書
(Consent form)

研究主題: 探討台灣母親養育腦性麻痺患孩的經驗

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- 對於我所提出的問題，我可以得到滿意的回答。
- 我了解參與本研究可能產生的危險性。
- 我了解參與本研究，我並無法自本研究中直接獲取任何利益。
- 我了解我本人是自我同意參與本研究。
- 我了解如果我有任何問題，我將可連絡任何研究小組中的成員。
- 我了解我隨時可由研究中退出，而不會遭受任何處罰或評論。
- 我了解訪談資料會被安全的鎖在研究者的研究室五年，之後即被消毀。
- 我了解任何有關本研究的倫理議題，如有任何疑問，我將可隨時連絡葛瑞菲斯大學的人體研究倫理評審委員會的成員，聯絡電話為 617-3875-5585。
- 我同意參與本研究。

參與研究者姓名: ____________________________

簽名: ____________________________

日期: ____________________________
Appendix D: Personal information sheet

The birth date of a child: ________/_______/_______

The gender of a child: □ boy □ girl

Type of rehabilitation
□ physical rehabilitation □ occupation rehabilitation
□ speech rehabilitation □ others ________________

The age of the mother: ________________

The occupation of mother: □ housewife □ part-time job □ full-time job

The education level of the mother: ________________

The marital status: □ married □ single □ defects

Numbers of children in the family: ___

Ages of every child:
個人基本資料單
Personal Information Sheet

患孩的出生年月日：_______ / _______ / _______

患孩的性別： □ boy □ girl

孩子復健的種類：
□ 物理治療 □ 職能治療
□ 語言治療 □ 其他 __________

母親年齡： __________

母親職業： □ 家庭主婦 □ 兼差工作 □ 全職工作

母親教育程度： __________

婚姻狀況： □ 已婚 □ 分居或離婚 □ 單身

家中小孩的人數： ________________

每位小孩的年齡： ________________
Appendix E: Ethics approval from hospital

Permission of Clinical Trial
Taichung Veterans General Hospital

Date: 28 July 2005

The project entitled, "The experience of being a mother of a child with cerebral palsy," (IRB TCVGH No.: 940204/522) submitted by the investigator Sen-Wei Tsai, and the sub-investigator Yu-Ping Huang, was approved by the Institutional Review Board of Taichung Veterans General Hospital on 28 July 2005 by the expedited review procedure. The approval will be reported at the 53rd full committee meeting of the IRB. This permission is valid to July 27, 2006.

Ying-Tsung Chen, M.D.
Chairman, Institutional Review Board, TCVGH

The committee is organized and operates according to GCP and the applicable laws and regulations.
Appendix F: Ethics approval from Griffith University

GRIFFITH UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE

07-Nov-2005

Dear Doctor Kellett

I write further to the additional information provided in relation to the conditional approval granted to your application for ethical clearance for your project "The Experience of Being a Taiwanese Mother of a Child with Cerebral Palsy" (GU Ref No: NRS/30/05/HREC).

This is to confirm receipt of the remaining required information, assurances or amendments to this protocol.

Consequently, I reconfirm my earlier advice that you are authorised to immediately commence this research on this basis.

The standard conditions of approval attached to our previous correspondence about this protocol continue to apply.

Regards

Gary Allen
Manager, Research Ethics
Office for Research
Bray Centre, Nathan Campus
Griffith University
ph: 3875 5585
fax: 3875 7994
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Cc:

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# Appendix G: Demographics of participating mothers

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Education</th>
<th>Occupation</th>
<th>Family type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jhen-Jhen</td>
<td>32</td>
<td>College</td>
<td>Housekeeper</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Fang-Fang</td>
<td>42</td>
<td>High-school</td>
<td>Housekeeper</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Hui-Hui</td>
<td>37</td>
<td>High-school</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
<tr>
<td>Li-Li</td>
<td>42</td>
<td>Junior high-school</td>
<td>Part-time</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Rong-Rong</td>
<td>35</td>
<td>High-school</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
<tr>
<td>Yu-Yu</td>
<td>36</td>
<td>High school</td>
<td>Housekeeper</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Sin-Sin</td>
<td>27</td>
<td>Junior high-school</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
<tr>
<td>Ya-Ya</td>
<td>34</td>
<td>High school</td>
<td>Housekeeper</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Mei-Mei</td>
<td>36</td>
<td>Junior college</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
<tr>
<td>Feng-Feng</td>
<td>30</td>
<td>College</td>
<td>Full-time</td>
<td>Extended family</td>
</tr>
<tr>
<td>Ai-Ai</td>
<td>30</td>
<td>College</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
<tr>
<td>Shu-Jhen</td>
<td>31</td>
<td>High school</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
<tr>
<td>Ting-Ting</td>
<td>33</td>
<td>College</td>
<td>Housekeeper</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Wen-Cian</td>
<td>37</td>
<td>College</td>
<td>Full-time</td>
<td>Nuclear family</td>
</tr>
<tr>
<td>Ciao-Ciao</td>
<td>35</td>
<td>College</td>
<td>Housekeeper</td>
<td>Extended family</td>
</tr>
</tbody>
</table>
**Appendix H: Demographics of children with CP**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>CP type</th>
<th>Education</th>
<th>Sibling’s age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kang-Kang</td>
<td>16 months</td>
<td>Quadriplegia</td>
<td>Non</td>
<td>Only child</td>
</tr>
<tr>
<td>Jing-Jing</td>
<td>13 years</td>
<td>Dystonia</td>
<td>Special Junior high school</td>
<td>One sister (17 years old)</td>
</tr>
<tr>
<td>Guang-hua</td>
<td>6 years</td>
<td>Hemiplegia</td>
<td>Kindergarten</td>
<td>One brother (8 years old)</td>
</tr>
<tr>
<td>Hua-Hua</td>
<td>14 years</td>
<td>Diplegia</td>
<td>General junior high school</td>
<td>One sister (4 years old)</td>
</tr>
<tr>
<td>Yuan-Yuan</td>
<td>7 years</td>
<td>Diplegia</td>
<td>Special kindergarten</td>
<td>One brother (11 years old)</td>
</tr>
<tr>
<td>Ku-Ku</td>
<td>4 years</td>
<td>Monoplegia</td>
<td>Kindergarten</td>
<td>Two brothers (11 and 10 years old)</td>
</tr>
<tr>
<td>Bing-Bing</td>
<td>5 years</td>
<td>Quadriplegia</td>
<td>Special kindergarten</td>
<td>One sister (6 years old)</td>
</tr>
<tr>
<td>Ding-Ding</td>
<td>8 years</td>
<td>Hemiplegia</td>
<td>Kindergarten</td>
<td>One sister (6 years old)</td>
</tr>
<tr>
<td>Tang-Tang</td>
<td>6 years</td>
<td>Quadriplegia</td>
<td>Non</td>
<td>Two sisters (12 and 10 years)</td>
</tr>
<tr>
<td>Cyun-Cyun</td>
<td>3 years</td>
<td>Monoplegia</td>
<td>Non</td>
<td>One brother (8 years old)</td>
</tr>
<tr>
<td>Shui-Bian</td>
<td>5 years</td>
<td>Diplegia</td>
<td>Non</td>
<td>Only child</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Two brothers (6 and 3 years)</td>
</tr>
<tr>
<td>Jhih-Zong</td>
<td>7 years</td>
<td>Diplegia</td>
<td>Special elementary school</td>
<td>One sister (8 years old)</td>
</tr>
<tr>
<td>Fu-Fu</td>
<td>3 years</td>
<td>Hemiplegia</td>
<td>Non</td>
<td>Only child</td>
</tr>
<tr>
<td>Ming-Ming</td>
<td>6 years</td>
<td>Diplegia</td>
<td>Special kindergarten</td>
<td>One brother (4 years old)</td>
</tr>
<tr>
<td>An-An</td>
<td>8 months</td>
<td>Quadriplegia</td>
<td>Non</td>
<td>Only child</td>
</tr>
</tbody>
</table>
References


Brinchmann, B. S. (1996). When the home becomes a prison: Living with a severely disabled child. *Nursing Ethics, 6*(2), 137-143.


Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine, 64*(1), 150-163.


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