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Never~ending caring:

The experiences of caring for a child with cerebral palsy

**A thesis presented in fulfillment of the requirements for the degree of
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in
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Abstract

Cerebral palsy is one of the chronic conditions which have become a serious health burden worldwide. Consequently, this health burden involves healthcare as a whole, regardless of whether the focus is on the macro or micro system. Glaserian grounded theory was employed to explore and explain the experiences of families who have a child with cerebral palsy, particularly in the Thai cultural context. Unstructured interviews and participant observations were used along the process of data collection from 15 families who have a child with cerebral palsy. Data encompassed a variety of qualitative data sources: interviews, observational field notes, personal documents, pictures, drawings, and information from a literature review. The process of data analysis was guided by Glaserian grounded theory throughout the processes of constant comparative analysis to generate a substantive theory. The substantive theory comprised three core categories: **Enduring despair, culture of obligation and responsibility and living with**, which were integrated into the basic social psychological process of *never-ending caring*. The metaphor of a waterwheel was used to depict the basic process. The substantive theory of *never-ending caring* for a child with cerebral palsy provided an explicit understanding of the experiences of these families in day-to-day living with, and care of, a child with cerebral palsy. It is hoped that this understanding will be a constituent of health care – particularly of people with chronic conditions, whereby the practice of healthcare professionals will improve, thus enhancing the efforts of their work to achieve the ultimate goal of improving the quality of life of children with cerebral palsy and their families.

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Preface

The research topic for this thesis was born from my experience as a Neonatal Intensive Care Unit nurse. As a NICU nurse, I played an important role in taking care of newborn babies who needed special care of respiratory, fluid and electrolyte management, glucose management, infection control and temperature control. Besides the clinical care of babies, I also supported their families, including parents and grandparents, both at an emotional level and in the provision of information. I explained to the family the baby's clinical condition and what treatment he/she was receiving as they, on behalf of the baby, had the right to know the information. Eventually, the happy time would come when babies were discharged to go home with their parents. All health professionals were proud of their contribution to caring for the babies. It is a wonderful moment in time to see babies go home with their families after they had spent lengthy periods in hospital since they were born. I hold vivid memories about these special moments, when parents and grandparents had big smiles on their faces.

I tried to meet the goals of neonatal intensive care – firstly to try to save all babies' lives as well as to prevent as far as possible, any complications which might occur to them during their treatment. The lives of some babies, who had severe health conditions such as hypoxia, respiratory distress syndrome, prematurity, very low birth weight, hypoglycaemia, and congenital abnormalities such as hydrocephalus, meningitis, spina bifida, were able to be saved. However, they sometimes had unavoidable complications such as Retinopathy of prematurity¹ (ROP). I have a clear memory regarding one case of hydrocephalus;

¹ Retinopathy of prematurity (ROP) is oxygen toxicity in the premature baby who has body weight <1 kg and gestational age < 28 wks; this is the most common morbidity in the premature baby (Enzman Hagedorn, Gardner, Dickey, & Abman, 2006).

we were very concerned about the future of the baby. I discussed with my colleagues the quality of life of the baby and his parents. How could he survive without his parents? The discharge time of this case was totally different from the first ones whereby we were concerned about how the family would take care of the baby. I felt quite ambivalent about the outcome of our work as nurses and feelings of sadness remain with me today.

That experience inspired me to research what is going on in the families who have a child with a chronic health condition after the hospital discharge. Prematurity and very low birth weight infants have a high risk for neonatal and infantile mortality and morbidity (Gardner, Johnson, & Lubchenco, 2006), in which cerebral palsy is one of these consequences. This serious complication requires long-term care from many persons who are relevant to the child such as health professionals, non-health professionals and their families. Thus this study focuses on the experience of families with a child with cerebral palsy, in the Thai context.

Chapter 1

Significance and background of the study

สำหรับโลก อาจเป็นเพียง แค่เสียงหนึ่ง
สำหรับแม่ แม่จึง...ฟังเสียงใน
พูดเสียง พุดกับแม่ แม่เข้าใจ
เสียงเสียงให้ แม่ฟัง...ดังดังนะจ๊ะ

To the world, it might be just a noise
To me, your mother...it's crystal clear your voice.
Speak my darling, speak to me; I hear and know.
Mother longs to hear, keep it very loud my dear...your voice.

Memoir of ID 6's Mother
(reprinted with permission)

Introduction

This grounded theory study articulates what is going on in families who have experienced living with a child with cerebral palsy, in the Thai cultural context. In particular, the study focuses on the basic social process by which these families get through their situations day by day. Symbolic interactionism provides an appropriate lens for interpreting the experiential aspects of the families' behaviour as they provide care for a child with the chronic condition of cerebral palsy. It is hoped that a deeper understanding of the experiences of these families will improve the quality of health professionals' work and the quality of life of children with the condition and their families. This chapter outlines the significance of and background to the research inquiry, and provides an outline of the study.

Significance and background of the study

Chronic conditions have become a serious health burden worldwide because of the advancement of technology and medical science as well as success in public health and overall community and society development (Allen, 2004; Corbin, 2001). Consequently, this health burden has an effect on healthcare as a whole, regardless of whether the focus is on the macro or micro system. Thailand faces the same rise in chronic health conditions. Recently the United Nations International Children's Emergency Fund (UNICEF) (2007) has revealed that the infant mortality rate and the under-five mortality rate have declined over the past two decades (1970-2005) from 74 to 18 and 102 to 21 per 1,000 live births respectively. Over the same period, the expectation of life at birth has risen from 60 to 71 years. Consequently, childhood chronic health problems, which are one of the results of these changes, have become more and more burdensome issues.

The term *chronic condition in childhood* means a physical or physiological impairment, or mental condition, which affects children's abilities to function normally in the environment and to maintain their daily activities such that they require long-term care lasting over 3 months (Hayes, 2001; Thomas, 1987; Schlomann & Schmike, 2007). Consistent with the terminology related to *chronic health conditions*, the World Health Organization (WHO, 2001) published the framework of International Classification of Functioning, Disability and Health (ICF) to describe and measure *health* and *disability* in both individual and population levels. The ICF framework views *disability* as biopsychosocial rather than a biological dysfunction. Furthermore, the ICF framework is underpinned by a focus on equality for all people in society. Consequently, environmental factors including physical, social and attitudinal influences are regarded as barriers to an individual's functioning; as illustrated in the ICF definition of *disability* as follows:

an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (WHO, p. 213).

According to WHO estimates, approximately 10% of the world's population (600 million people) are disabled persons – around one third of this number are children (WHO, 2007). In Thailand, the number of persons identified as having disabilities varies significantly since it has been calculated by different surveys, which have defined different types of disability. One study by the National Statistical Office, which produced a nationwide survey on health and social welfare in 2001, identified the number at approximately 1.8% of the population (1,100,761 persons) while the other surveys conducted by the Ministry of Public Health (1991/92) estimated the number to be 8.1% of the total population (4.8 million persons) (the Ministry of Social Development and Human Security: MOSDHS, 2002). According to the study by the National Statistics Office, the majority of people with disabilities live in rural areas. Congenital anomaly was reported as the leading cause of disability (43.8% in 1999). In the period 1994-2006, the MOSDHS reported 540,366 persons registered as having a disability. Half of these people (204,122) live in the northeast of Thailand and approximately half (97,409) of those with a disability living in that region have a physical impairment. As a result, chronic conditions have become one of the country's major health problems. Therefore, the 9th National Economic and Social Development Plan (2002-2006) was established to improve the quality of life of all Thai people, and the National Plan of Quality of Life Development (2002-2006) has also been developed by the Ministry of Social Development and Human Security for enhancing the quality of life for people with disabilities.

The National Plan has a vision that “people with disabilities have potential to be self-independent, have better quality of lives in society, live happily and creatively and contribute to the development of the country” (MOSDHS, 2001, p. 1). One of the objectives of the Plan is “to support people with disabilities, their families, communities and societies to have positive attitudes towards people with disabilities and be involved in their quality of life development” (MOSDHS, 2001, p. 1).

Moreover, the Ministry of Social Development and Human Security has employed the strategy of Community Based Rehabilitation (CBR), which was created by the International Labour Organization (ILO), United Nations Educational Scientific and Cultural Organization (UNESCO), and World Health Organization (WHO) for enhancing the quality of life of all disabled people in Thailand. A review of CBR activities in Thailand (Cheausuwantavee, 2005) showed that there were few rehabilitation projects in Thai communities that could be classified as community-based rehabilitation – most projects were run as outreach services from institutions. Community Based Rehabilitation is reviewed further in Chapter Two in term of the way international policy influences the national plans and policies in Thailand.

The current framework of care for children with chronic health conditions shifts the responsibilities for care from professionals to the family and to the community (Hayes, 2001; Schlomann & Schmike, 2007). Despite the fact that national policies have been established with explicit aims for improving the quality of life of people with disabilities, including their families, the policies could not be practically implemented (Cheausuwantavee, 2005) and thus families still need more support from both healthcare professionals² and non-health care professionals³ to improve the quality of their lives. Even though study in the area of chronic health conditions has been prolific, particularly with regard to severe conditions, there is not much more understanding about how to care for families who are living with a child with a chronic condition.

The study

In this study, I explored the experiences of families with children with cerebral palsy, which is one type of disability that involves “a disorder of muscle control

² Health professionals refer to nurses, physicians, physiotherapists, occupational therapists etc.

³ Non-health professionals refer to teachers at special schools, baby sitters and other families who have the same situation.

that causes difficulty with moving and positioning the body. A small part of brain that controls movement has been damaged early in life or after birth, whilst the child was still a baby” (WHO, WCPT, and WFOT, 1993, p. 1). The disability “permanently affect[s] body movement and muscle coordination but [symptoms] aren’t progressive, in other words, they don’t get worse over time” (National Institute of Neurological Disorders and Stroke, NINDS, 2006, p. 3).

In order to understand the experiences of families with children with cerebral palsy, particularly in the Thai cultural context, the research question of this study addresses the basic social psychological process by which the participants – including a child with this condition – get through their challenging circumstances. In this research I explored their experiences by using two main data gathering processes: unstructured interviews and participant observations. In addition, a variety of qualitative data sources – such as personal documents, pictures, drawing, and information from literature review – were also used as data.

The purpose in the study was to develop an applicable theory that identifies the basic social psychological processes of families who have experienced living with a child with cerebral palsy. The theory will contribute to better health care in Thailand because it will be useful for improving the quality of health professionals’ efforts to encourage families who live with a child with cerebral palsy, or a child with other chronic conditions, to achieve the maximum possible quality in their lives.

The thesis outline

This thesis is composed of ten chapters. In Chapter One the significance and the background of this study are described. I then present the purpose and research question to delineate the scope of this inquiry.

The Policy and the Plan, which are related to chronic health conditions, especially amongst persons with disabilities, are presented in both international and national views in Chapter Two. I explore more about the influence of healthcare policy and the National Plan for Thai people with disabilities and their families. Furthermore, I review in more depth the health condition of cerebral palsy in terms of incidence and etiology, classification, diagnosis, treatment, nursing management, and physical and occupational therapy. Other chronic health conditions are also reviewed.

In Chapter Three I present grounded theory methodology which provides a suitable method to generate a substantive theory. I employed unstructured interviews, participant observations methods, and a range of qualitative data sources to grasp the realities of the participants.

The research findings are described in Chapters Four to Eight. An overview of the findings, the experiences of *never-ending caring* of the families who have children with cerebral palsy, is introduced in Chapter Four. I depict, by use of a diagram, the experience of *never-ending caring*, which is the basic social psychological process (BSPP) of this study. Then, I present the first core category **enduring despair** and the theoretical proposition facing the situation, which is the first stage of the BSPP. **Enduring despair** has a subcategory *suffering and blaming* that consists of three main concepts: **finding reasons and blaming**, **expression of suffering** and **the burden of care**. The properties of each concept are presented in this chapter.

In Chapter Five I present the second core category **culture of obligation and responsibility** and the theoretical proposition *learning to deal with the situation by themselves* which comprise the second stage of the BSPP. The second core category demonstrates how the participants deal with challenging circumstances, and how their beliefs and a culture of obligation and responsibility shape their responses to those situations.

The third core category **living with** and its theoretical proposition *learning to live with*, and care for, a child with cerebral palsy comprise the third stage of the BSPP. The third category has two subcategories: ***learning to live with the situation*** and ***preparing for an uncertain future***. In Chapter Six I present the first subcategory ***learning to live with the situation*** which includes four main concepts: **dealing with the situation**, **strategies to bring up**, **physical health treatment**, and **having positive feelings**. Their properties are introduced in this chapter.

The second subcategory ***preparing for an uncertain future*** is presented in Chapter Seven. There are three main concepts in this category such as **hoping for acceptance in society**, **planning for the future**, and **vulnerability of a child with cerebral palsy**. The properties which support the theoretical concepts are presented in this chapter.

In Chapter Eight I introduce ***never-ending caring*** as the basic social psychological process (BSPP) of this grounded theory study. In order to further depict the experiences of the participants, I then present a visual image of this study as comparable to the process of a waterwheel (a common sight in rural Thailand).

In Chapter Nine, I discuss the findings in relation to extant literature, and the implications of ***never-ending caring*** for practice, education and research, respectively. The limitations of this research inquiry are also presented. This theory provides an understanding of families' experiences of living with a child with cerebral palsy, to enable professionals to improve the quality of their efforts in both practical and educational areas for encouraging the families to achieve optimum quality in their lives. The substantive theory may also have relevance to other families who have the same situation, to enable them to pass through challenging circumstances more easily, then live with happiness in their conditions.

Conclusion

The number of people with chronic health conditions has been increasing, causing serious health problems worldwide. Cerebral palsy is one example of a chronic health condition that develops in childhood and seriously affects families, as the responsibility of caring for a child with this condition shifts from health professionals to the family and inevitably, to the community. Thailand is concerned about this serious health burden. Therefore, many laws and policies have been established in order to solve the health problems and to enhance the quality of life for all people with disabilities in Thailand. However, people with chronic illness and disabilities and their families are still faced with a serious health burden since the policies have not yet been implemented in practical ways. Furthermore, living with a child with a chronic condition is a unique experience whereby each family has to manage their situation by themselves as each new challenge arises. Thus, this research focuses on the experience of families in order to help healthcare professionals understand the situation of families who are required to provide ongoing care of children with cerebral palsy. It is hoped that such knowledge will improve the practice of healthcare professionals and give new understandings to underpin efforts at community-based rehabilitation. Such efforts may benefit children with cerebral palsy and their families as they reach toward the optimal quality of life consistent with their condition.

Chapter 2

Literature review

Introduction

In Chapter One I introduced the significance and the background of this study in relation to the situation of chronic health conditions, which is one of the causes of disability, particularly in childhood. The plans and policies relevant to persons with disabilities were also briefly presented in both their international and national aspects. In this chapter, I review in more depth the plans and policies for people with disability from international and national perspectives. Moreover, the health condition of cerebral palsy is delineated in more depth in terms of incidence and etiology, classification, diagnosis, treatment, nursing management, and physical and occupational therapy. Other chronic health conditions are also reviewed.

A literature review becomes a problem for generating a substantive grounded theory. Considering the aim of generating the theory without any preconceived concepts – so far as is possible – Glaser (1998, p. 67) suggests that the researcher should do a literature review in the substantive area being researched “when the theory is nearly completed during sorting and writing up” but “do not do a literature review in the substantive area and related areas where the research is to be done”. From his point of view, Schreiber (2001) has an argument that all research – including grounded theory – needs a literature review from the initial step of research inquiry. For instance, in the area of nursing research, the researcher brings his/her own knowledge to the study, including an existing background of familiarity with the literature on professional and popular relevant issues. In addition to doctoral research study, when developing a dissertation proposal, Ph.D. students need to do a literature review in more depth in both

areas of interest and relevant context in order to identify the significance of the problem which is the subject of their thesis.

The development of international policies for people with disabilities

In the early 1970s, the WHO initiated a new policy for disability and rehabilitation, that originated from concern about the gross inequality in the health status of people within developing and developed countries, as well as within countries (Helander, 2007). An initial task arising from the new policy was to estimate the prevalence of disability, particularly in relation to the needs of people with disability for rehabilitative health services – estimated to be around 390 million or nearly 10% of the world population (4 billion in 1974) (Helander, 2007). Consequently, the WHO established new programmes for disability prevention (recognising that about 50% of health conditions causing disability could be prevented); and for community-based rehabilitation (CBR). A situation analysis in 1974 of existing rehabilitation services in developing countries concluded:

- Rehabilitation services are practically non-existent or grossly inadequate in developing countries;
- There is an apparent lack of national planning and coordination of services (medical, educational, vocational and social etc.) in most countries;
- Medical rehabilitation services have usually concentrated on institutional care, with a low turnover of patients at a high unit cost;
- When advanced rehabilitation services and technology have been introduced in developing countries, the result has often been discouraging or a complete failure. (Helander, 2007, pp. 3-4).

These findings, and a number of country-wide field visits to study the situation of disabled people in developing countries, underpinned the focus on community-based rather than institution-based rehabilitation programmes (Helander, 2007). Over time, the WHO CBR programme has been developed

into a manual that was revised and published in 1989 with the title, *Training in the Community for People with Disabilities* (ILO, UNESCO & WHO, 2004).

In the 1990s, the WHO cooperated with other United Nations agencies to promote and enhance the implementation of CBR programmes. In 1994, a “Joint Position Paper on CBR” was produced by the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO), the United Nations Children’s Fund (UNICEF) and the WHO, with the stated purpose “to promote a common approach for the development of CBR programmes” (ILO, UNESCO, UNICEF & WHO, 2002, p. 1). It was recognised that, even though there had been progress in implementation of the CBR programme over the two decades since its inception, many people with disabilities still did not have their basic needs for rehabilitation services met, and were not enabled to achieve equal rights in education, training, work and participation in their community. Therefore, in an attempt to provide human rights and equal opportunities for all people with disabilities consistent with other community members, the joint CBR paper was revised in 2004 with the title, *CBR: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of people with disabilities* (ILO, UNESCO & WHO, 2004). Within this paper, CBR was defined as “a strategy within general community development for the rehabilitation, equalization of opportunities, and social inclusion of all people with disabilities” (p. 2). To ensure that people with disabilities can access at the benefits of the Convention of Rights, the goals of CBR were established as follows:

1. Supporting people with disabilities to maximize their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large;
2. Activating communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation;
3. Facilitating capacity building, empowerment and community mobilization of people with disabilities and their families (ILO, UNESCO & WHO, 2004, from the website of WHO: Community-Based Rehabilitation (CBR) p. 1).

To achieve those goals, the CBR programmes need to be “implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational and social and other services” (ILO, UNESCO & WHO, 2004, p. 2). Nearly 100 countries around the world, including Thailand, have been reported to apply the CBR strategy in their context (WHO, 2008).

In Thailand, the CBR strategy was introduced by non-government organisations (NGOs) in the 1980s. Cheausuwantavee (2005), reviewed available documents and CBR projects in Thailand and reported that the majority of rehabilitation projects in the Thai community were outreach services from institutions, and thus did not conform to the original concept of CBR. Cheausuwantavee suggested that “the evolution of concepts of CBR in Thailand is an ongoing process” (p. 51). He noted that there are many laws and policies in Thailand for decentralization, and promotion of human rights and community participation of people with disabilities, however these laws and policies have proved difficult to implement in a practical manner.

The development of national plans and policies for persons with disabilities in Thailand

The National Plans and Government Policies regarding people with disabilities have the ultimate goal to improve the quality of life of those persons. It will therefore be helpful to understand the main legal instruments for disabled persons in Thailand, prior to the exploration of the realities of families living with a child with cerebral palsy.

According to the First National Economic and Social Development Plan (1961-1966), the government demonstrated that it was concerned about persons with disabilities by setting up health policy such as improving health care in order to

prevent the occurrence of disabilities. In this plan, disabled persons were identified as “a special target group” (Bureau of The Empowerment for Persons with Disabilities, Thailand Website, 2001, p. 1). At this time, people with disabilities did not have access to rehabilitation and education – they were not allowed to go to school. These disadvantages were rectified by the Rehabilitation of Disabled Persons Act, 1991, which defined a person with disability as “a person with physical, intellectual or psychological abnormality or impairment” (Bureau of The Empowerment for Persons with Disabilities, Thailand Website, 2001, p. 1). Disabilities were classified into five categories: “hearing (deafness and hard of hearing); vision (blindness and low vision); mobility or physical disability; mental disability; and development and learning disability” (p. 1). The Act defined “Rehabilitation of Disabled Persons” as “the improvement of the potentials and capacities of disabled persons through medical, educational, and social methods and vocational training in order to provide them the opportunities to work or lead their lives equal to that of the non-disabled” (p. 1). This Act provided entitlement to healthcare services – such as medical and rehabilitation services – to improve their physical development, as well as protecting the rights of disabled persons – they all have the right to receive services such as education, employment and support from the community like other people (Asia-Pacific Development Center on Disability (APDCD), Website, 2007). Furthermore, many Ministerial Regulations for implementation of the Act were enacted; for example, Ministerial Regulation No.1, 1994 was enacted to enhance the employment of disabled persons and to establish a Fund for the rehabilitation of disabled persons. To provide healthcare services for people with disabilities, Ministerial Regulation No.3, 1994 was established for medical rehabilitation services and expenditure on nursing care and medical equipment.

In landmark legislation of 1997, the Constitution of the Kingdom of Thailand was enacted that protects the rights of persons with disabilities by eliminating all restrictions over them and removing the previous prohibitions. A good example of this is stated in Section 30 as, “all persons are equal before the law and shall enjoy equal rights and all discrimination based on physical or health conditions

is prohibited” (APDCD, Website, 2007, p. 4). The implementation of this Constitution enhances many dimensions of society such as “citizen participation, transparency, empowers local communities, and improves the public sector government” (p. 1).

In 1997-2001, the government instituted two important National Plans that are related to disabled persons: the National Plan of Rehabilitation and the 8th National Economic and Social Development Plan. The 8th Plan aims to enhance the quality of life for all Thai people. In relation to persons with disabilities, the plan is focused on people-centered development by adopting strategies for providing services and support as well as for enhancing the potential for self-reliance of disabled persons and encouraging them to become further involved in social development. It is interesting that this plan made provision for free services from the government such as rehabilitation, education and job opportunities. Consequently, the 9th Plan (2002-2006), which draws upon lessons learnt from implementation of the 8th Plan, emphasises people-centred development as well as enhancing equality for all. One of the objectives of the 9th Plan for persons with disabilities is to improve social services and facilities which they can access equally; social security is also provided (APDCD, Website, 2007).

The National Plan of Quality of Life development (2002-2006), which is developed from the National Plan of Rehabilitation (1997-2001) and is related to the 9th Plan, was developed by government, and nongovernment organisations and organisations for disabled persons. The Plan focused on holistic people-centred development which is more concerned about their contexts – particularly their families, communities and societies. To illustrate, some of the objectives of this plan are as follows:

1. To enhance the quality of life of people with disability in terms of physical, intellectual, mental, social and spiritual aspects to the full potential of each person.
2. To support people with disabilities, their families, communities and societies to have positive attitudes towards people with disabilities and be involved in their quality of life development.

3. To promote people with disabilities, their families, communities and societies including the persons involved in the quality of life development to realize their rights and duties and make contribution to the economic, social and political development of the country (Bureau of The Empowerment for Persons with Disabilities, Thailand Website, 2001, p. 1).

To achieve these objectives, a new Law has been enacted entitled “Empowerment of Persons with Disabilities 2007” that has been in “effect since it was promulgated in the Royal Gazette on 27 November 2007” (Asia-Pacific Development Center on Disability, 2008, p. 1). The law focuses on “a rights-based approach to disability and enhances more participation of persons with disabilities in policy-making bodies at the national, provincial and organizational levels” (p. 1). Thus the Thai government has been active over the past two decades in attempting to address the needs of people with disability by enacting laws and policies. However, as previously noted, Cheausuwantavee (2005) has drawn attention to the difficulties in achieving effective implementation of these laws and policies in a practical manner.

In addition to reviewing the National Policies and the Plans, which should influence the experiences of the families living with a child with cerebral palsy, I found it useful to review literature on the health issue selected for study, cerebral palsy, in order to better understand the realities of families living with a child with the condition.

Cerebral palsy

Cerebral palsy is “a disorder of muscle control that causes difficulty with moving and positioning the body. A small part of the brain that controls movement has been damaged early in life or after birth, whilst the child was still a baby” (WHO, WCPT, & WFOT, 1993, p. 1). This disorder permanently affects body movement and muscle coordination but the symptoms do not get worse over time (NINDS, 2006). The condition of cerebral palsy was first described in 1861,

by William Little, an English surgeon, and the disorder was named Little's disease. In 1897, Sigmund Freud argued that cerebral palsy is the result of hypoxia during the process of birth, or alternatively that it might occur during the process of brain development of the fetus in the uterus (NINDS, 2006). After that the wide study of NINDS in the 1980s discovered less than 10 % of the causes of cerebral palsy occur during the process of birth.

Etiology

Recently, understandings of the etiology of cerebral palsy have transformed – in the past, birth asphyxia was identified as the major cause of cerebral palsy, but now it is viewed as a minor cause (MacLennan, 1999; NINDS, 2006). At present, the results of many studies show that the etiology of cerebral palsy mainly depends on a number of risk factors during antenatal, labour, perinatal, and postnatal conditions. However, most cerebral palsy cases are identified as having an unknown etiology (NINDS, 2006). Table 2.1 demonstrates the list of causes of cerebral palsy in relation to each conditioning period: prenatal, labour, perinatal and postnatal. Noetzel and Miller (1998) found that the highest risk of developing cerebral palsy occurs during the period of pregnancy through to the delivery process – approximately 75-90% of the causes, whereas only 10-25% occur after labour. Prematurity has been reported to be the most important cause of neonatal and infantile mortality and morbidity; cerebral palsy is one of the latter consequences (Dizon-Townson, 2001). However, Gray, Jones, and O'Callaghan (2001) found that corticosteroid treatment reduces the risk of cerebral palsy in very low birth weight infants with a gestation age of 24-27 weeks. Consistent with the finding of Gray and his colleagues, Greenwood, Yudkin, Sellers, Impey, and Doyle (2005) found that the process of inflammation in the antenatal period plays a crucial role in the etiology of cerebral palsy for both term and preterm infants.

Table 2.1 Causes of Cerebral Palsy

Conditioning Period	Causes
Antenatal	<u>Maternal</u> Health status: Malnutrition, diabetes, hyperthyroidism, Infection, genetic abnormalities, seizure disorder etc. History of pregnancy: Previous child with development, premature baby, fetal death, polyhydramnios, Drug use: Thyroid, estrogen, progesterone etc. Exposure to radiation or toxin <u>Gestational</u> Genetic syndrome: Chromosomal abnormalities Pregnancy Problems: Multiple fetuses, Problems in placental Functioning, Rh incompatibilities, Exposure to teratogens Fetal problems: Congenital malformations, brain Malformation, Fetal development abnormalities
Labour	<u>Complication during the process of delivery</u> Prolonged labour, Premature rupture of membranes Abnormal presentations, Birth trauma/injury Asphyxia, Premature labour Preeclampsia
Perinatal	<u>Problems after birth related to premature baby</u> Kernicterus (hyperbilirubinemia of the newborn), Seizures Intraventricular hemorrhage (IVH) Periventricular encephalomalacia (PVL) Persistent pulmonary hypertension in newborn (PPHN) Intrauterine growth retardation, Low/Very low birth weight Days on mechanical ventilation Sepsis and/or central nervous system (CNS) infection
Postnatal (childhood)	<u>Brain injury</u> Meningitis/encephalitis/infections Exposure to toxins via ingestion or inhalation Traumatic brain injury/Stroke
Unknown	

Data from Mandleco, B. L., Wellington, M. C., & Wayner, R. F. (2007). Neurological alterations. In N.L. Potts & B.L. Mandleco. *Pediatric nursing: Caring for children and their families* (2nd ed., pp. 1103-1111).; Greenwood, C., Yudkin, P., Sellers, S., Impey, L., & Doyle, P. (2005). Why is there a modifying effect of gestational age on risk factors for cerebral palsy? *Archives of Disease in Childhood Fetal and Neonatal Edition*. 90, 141-146. MacLennan, A. (1999). A template for defining a causal relation between acute intrapartum events and cerebral palsy: International consensus statement. *BMJ*, 319, 1054-1060. National Institute of Neurological Disorders and Stroke (NINDS). (2006). Cerebral palsy: Hope through research, www.ninds.nih.gov/health_and_medical/pubs/cerebral_palsyht.htm; Nehring, W. M. (2004). Cerebral palsy. In P. J. Allen & J.A. Vessey. *Primary care of the child with a chronic condition* (4th ed., p. 328).

Incidence and Prevalence

Over the last three decades, the prevalence of cerebral palsy has remained steady – for example, approximately 10,000 infants in the USA develop the condition in each year – even though the number of very low birth weight infants and premature babies has been increasing (Lorenz, Wooliever, Jetton and Paneth, 1998; NINDS, 2006). In Thailand, the number of disabled persons has been increasing; mainly because of the decrease in the infant mortality rate of both infants and children under five (UNICEF, 2007). Significantly, premature babies grow up with “serious long-term complications – cerebral palsy, respiratory disease, blindness and deafness” (Dizon-Townson, 2001, p. 57).

Diagnosis

Diagnosis of cerebral palsy is based on the findings of clinical manifestations, which demonstrate persistent abnormality of neuromotor skills and an impairment of the motor function – it can be detected by delayed attainment of milestones of motor development. It is difficult for the doctor to make a reliable diagnosis, therefore many children are diagnosed as having cerebral palsy in the first two years of their lives or up to four to five years of age in mild cases. To investigate cerebral palsy, the doctors evaluate both the motor skills of the child and the medical history of the child. In addition, with the advancement of technology and medical science, neuroimaging techniques may be used for detecting the location of abnormalities of brain function such as cranial ultrasound, computed tomography (CT) scan, and magnetic resonance imaging (MRI) scan (Allen, Donohue, & Porter, 2006; Behrman, Kliegman, & Jenson, 2004; Mandleco, Wellington, & Wayner, 2007; NINDS, 2006). The clinical manifestation of cerebral palsy is mainly classified into four major types: spastic, dyskinetic, ataxic and mixed type of cerebral palsy. Furthermore, the topographic distribution also indicates abnormalities from the part of body that is involved. (see Table 2.2)

Table 2.2 Classification of Cerebral Palsy

Classification of cerebral palsy	Type		Characteristics
	Spastic	Diplegia	<ul style="list-style-type: none">● The most common form of CP● Affects all the extremities, the legs are more affected● Hyperactive of Tendon reflexes; muscle stiffness● Toes point up● Tightness for leg muscles; walk as scissoring● Mild or minimal involvement of the upper extremities; may not be recognised until school age● Normal in both intelligence and language skills● Occurs in 25-35% of CP
		Quadriplegia	<ul style="list-style-type: none">● The most severe form of spastic CP● Involvement of both upper and lower extremities; severe stiffness in all extremities but a floppy neck● The lower more severely affected than the upper; rarely able to walk● Medical complications, seizures, moderate-to-severe mental retardation, sensory impairment● Speaking and being understood are difficult● Occurs in 40-45% of CP
		Hemiplegia	<ul style="list-style-type: none">● Involvement of one side of the body; the upper limbs are more involved● Can walk later and on tip-toe because of tight heel tendons● The arm and leg of the affected side are frequently shorter and thinner● Some will develop an abnormal curvature of the spine (scoliosis)● Speech will be delayed, at best, may be competent● Intelligence as normal● Medical complications, sensory impairments, growth retardation● Occurs in 30-40% of CP
		Double Hemiplegia	<ul style="list-style-type: none">● Affects both sides of the body● Notice: the difference from spastic quadriplegia (the upper extremities are more affected than the lower)
	Dyskinetic	Includes: Athetoid, and Dystonic	<ul style="list-style-type: none">● Characterised by slow and uncontrollable writhing movements of the hands, feet, arms, or legs; Difficult to sit straight or walk● Some hyperactivity in the muscles of the face and tongue; grimace or drool● Intelligence rarely affected; this type occurs in 10-15% of CP
	Ataxic		<ul style="list-style-type: none">● Walk with an unstable; wide-based gait and difficult to move a hand or arm voluntarily● Increased or decreased muscle tone● Occurs in 5-10% of CP
	Mixed		<ul style="list-style-type: none">● Found more than one type of motor pattern; no one pattern dominant

Data from Behrman, R., Kliegman, R., & Jenson, H. B. (2004). *Nelson textbook of pediatrics* (17th ed.). Philadelphia, Pennsylvania: Saunders.; Allen, M. C., Donohue, P. A., & Porter, M. J. (2006). Follow-up of the neonatal intensive care unit infant. In G. B. Merenstein, & S. L. Gardner. *Handbook of neonatal intensive care* (6th ed.); Nehring, W. M. (2004). Cerebral palsy. In P. J. Allen & J. A. Vessey. *Primary care of the child with a chronic condition* (4th ed., pp. 330-331).; National Institute of Neurological Disorders and Stroke (NINDS). (2006). (2007, July 31). Cerebral palsy: Hope through research. Retrieved 2006, July, from http://www.ninds.nih.gov/disorders/cerebral_palsy/detail_cerebral_palsy.htm

Treatment

Cerebral palsy cannot be cured, but there is a range of treatments to enable children with this condition to improve their capabilities of movement, locomotion, and communication skills to the optimum of their potential. Therefore, after diagnosis of the condition, treatment should begin as soon as possible because the children with cerebral palsy can overcome their developmental disabilities as well as the new ways to attain milestones of their motor development. Table 2.3 presents the six forms of treatment that are often used for cerebral palsy (Mandleco et al., 2007; NINDS, 2006).

Table 2.3 *Treatments for Cerebral Palsy*

Form of treatment	Objectives	Examples
Therapies	To improve developmental disabilities	- Physical - Occupational - Speech - Counselling and behavioural - Neuromuscular electrical stimulation
Orthopedic devices or Mechanical aids	To support individually persons with disabilities who can not move independently	- Braces - Splints - Casting - Wheelchairs - Rolling walker - Scooters and tricycles
Adaptive equipment for communication aids	To compensate for muscle imbalance, improve posture and walking, and increase independent mobility	- Computers - Symbol boards - voice synthesisers, Talking typewriter
Surgery	To correct anatomical abnormalities; to reduce muscles spasms; to improve muscle tone	- A selective dorsal root rhizotomy - Orthopedic- collective such as tendon transfers, muscle lengthening - Neurologic such as neurectomies
Medications	To control seizures; to relax muscle spasms; to relieve constipation; for infections and to alleviate pain	- Antibiotics - Pain killers - Muscle relaxation
Special education	To enhance capabilities of children	- Early intervention programmes - Specialized learning school programs

Data from Mandleco, B. L., Wellington, M. C., & Wayner, R. F. (2007). Neurological alterations. In N. L. Potts & B. L. Mandleco. *Pediatric nursing: Caring for children and their families* (2nd ed., pp. 1103-1105). ; Behrman, R. E.; Kliegman, R. M., & Jenson, H. B. (2004). *Nelson textbook of pediatrics* (17th ed., pp. 2024-2025).; National Institute of Neurological Disorders and Stroke (NINDS). (2006). Cerebral palsy: Hope through research, www.ninds.nih.gov/health_and_medical/pubs/cerebral_palsyhtr.htm; Nehring, W. M. (2004). Cerebral palsy. In P. J. Allen & J. A. Vessey. *Primary care of the childwith a chronic condition* (4th ed., pp. 330-331).

In the following section, I review literature in the field of chronic illness including chronic conditions in childhood, in order to identify the area of interest under research as the experience of families, who live with, and care for, a child with cerebral palsy.

Experience of families toward chronic conditions

Parents and caregivers

Numerous studies reveal the parental response toward chronicity in terms of negative aspects. The negative outcomes become involved into their family lives (Knaft & Zoeller, 2000; Lam & Mackenzie, 2002). In the Hong Kong study by Lam and Mackenzie (2002) about the experiences of Chinese mothers who have a child with Down syndrome they noted that they used the strategies of avoidance, self-reliance, and seeking social support to deal with this particular situation. They also reported that some fathers could not accept their child with Down syndrome because “these children could not help pass on the family name and caused the family to *loss face*” (p. 228), while this particular situation impacts on the mothers’ life in terms of “*social restrictions*” (p. 231) including avoiding social contact. The mothers restricted their social activities because they worried about caring for the child in society. As a result of having a child with Down syndrome, the mothers also kept away from getting in touch with their friends since they did not want them to know, so they tried to avoid social contact.

Knaft and Zoeller (2000) explored the perspective of American parents who have a child with chronic illness, focusing on how mothers and fathers view their experience and its impact on both individuals’ and family life. They reported that the mother emphasised the impact of the chronic illness situation on family life, whereas the father minimised the impact. According to the study by Hirose and Ueda (1990), the Japanese mothers responded to the diagnosis with emotion

while the fathers dealt with the problem with realistic views. A number of studies across countries, such as Australia, Canada, and the United States of America, report that even though parents experienced much in relation to the downside of the situation, such as having a sense of chronic sorrow, despair and loss, they also had some positive feelings since the birth of their child (Chimarusti, 2002; Glasscock, 2000; Gravelle, 1997; Green, 2002; Keamey & Griffin, 2001; Rehm, 2000). Parents shared experiences as being positive when their children can do little things and the most important thing is the child not dying. As long as they face the adversity, the perspective within their personal beliefs and values changes, becoming stronger (Gravelle, 1997; Keamey & Griffin, 2001; Rehm, 2000; Saiki-Craighill, 2002). During encounters with the challenge circumstance of being a mother of a child with cerebral palsy, the mothers reported that the family relationships became strong and the quality of life of the child was able to improve by a positive caregiver role and learning more about the condition (Glasscock, 2000).

Consistent with parents' perspective, Davies, Gudmundsdottir, Worden, Orloff, Sumner and Brenner (2004) explored the experiences of American fathers who have a child who received care in a home-based hospice programme, and explained these fathers' situation with the metaphor of "living in the dragon's shadow" (p. 112). The metaphor reflected the fathers' perception of living and dealing with this particular situation by using "a conscious, active, continuous process that required strength, willpower, and work" (p. 118) as "battling with the dragon (the illness)" (p. 112) in three aspects: "battling with uncertainty, battling with responsibility, and battling with everyday disruption" (pp. 118-119).

Furthermore, many researchers report the situation of chronicity has more impacts on one's life in both psychological and physical effects (Glasscock, 2000; Glendy & Mackenzie, 1998). Glendy and Mackenzie (1998) explored the experiences of Chinese families who took care of a relative with a serious mental illness at home. The inquiry found that the carers of relatives with a serious

mental illness had much distress, including a mixed sense of feelings such as anger, disappointment and frustration. In addition, Glasscock (2000) used a phenomenological study to explore the experience of American mothers who have a child with cerebral palsy in which he found that they are burdened in direct relation to their day-to-day caring for children with cerebral palsy.

Culture plays an important role on caring over a long time in childhood whether the problem is a chronic illness or a chronic condition. Elfert, Anderson and Lai (1991) studied the perception of parents of children with chronic illness in which they employed a phenomenological method to explore the perceptions of 16 Chinese immigrant families and 15 Euro-Canadian families. They found that there were significant differences in perspective of those parents. The Euro-Canadian parents view the child with a chronic illness or chronic condition as normal, but he/she has defects in only particular aspects of the his/her life. Meanwhile, the Chinese parents see the illness and its consequences as affecting the children in their whole lives in the present and the future of the children. Consistent with the longitudinal study by Martinson et al. (1999), in which they aimed to compare the behaviour of Chinese and Caucasian North American caregivers, who took care of a child with cancer. The researchers reported that the Chinese family used supplemental care methods such as using herbal and nutritional remedies including therapy of touch for recovering the health condition and enhancing the lives of children with cancer. They were more isolated in their own families with limited support from outside resources. Meanwhile, Caucasian families emphasised exercise, and obtained more support from social and community resources such as extended family, friends, neighbours and health professionals.

Siblings

Many studies in child healthcare literature reveal siblings' responses toward childhood chronicity in both negative and positive aspects (Havermans & Eiser, 1994; Murray, 1995, 1998, 2000, 2001, and 2002). Havermans and Eiser (1994)

explored the perspective of healthy siblings who have a brother or a sister with cancer and focused on how the siblings perceived their lives. The study showed that the siblings experienced negative impacts of having a brother or a sister with cancer, such as worry, jealousy and feeling left out. However, the siblings also reported some benefits from the situation; for instance, they valued life more, and felt more mature. Similarly, the study by Murray (1998), which explored the experience of one 14-year-old child who experienced being a sibling of a child with cancer, reported that the sibling gains more benefits by developing a sense of empathy such as understanding, feeling, and concern for others, and having personal growth and maturation.

To gain more understanding of American siblings' responses toward childhood cancer, Rollins (1990) used the Kinetic Family Drawing - Revised to approach their perspectives. The analysing of drawing and discussion reflected their negative feelings and relationship between family members – lack of communication among family members. Similarly, a longitudinal study of healthy Chinese siblings in Taiwan, which explored behavioural responses of the siblings toward having childhood cancer in the family, revealed that reducing family communication was one of the major stressor themes (Wang & Martinson, 1996). Consequently, several researchers noted that some siblings preferred being alone and kept their feelings inside (Evans, Stevens, Cushway, & Houghton, 1992; Wang & Martinson, 1996). At this point, some researchers noted that the siblings also need emotional, instrumental information, support to deal with the particular situation and to maintain as normal some aspects of their lives (Havermans, & Eiser, 1994; Murray, 1998, 2002).

In Thailand, Lam-chang, Chontawan and Tosilakul (2003) explored the perceptions of 20 HIV – infected Thai children toward the illness after an informed story telling with a comic book. The inquiry reported that the children understood that germs are the cause of their condition but they were not able to explain how it worked. Besides this, the researchers also noted some negative aspects that caused the children to have hardly any friends. Consistent with the

study by Rungreangkulkij, Pothkamin and Rujiraphas (2001), which aimed to explain the impacts on 13 families who have a child with cerebral palsy and the adaptation process of families, reported that this challenging situation affected a diversity of families in both positive and negative aspects such as “on other family members, on family finance, family life cycle, and feeling difference from others, and family resiliency” (p. iii). Moreover, the study by Vattanasilp et al. (2001), explored the conditions of children with cerebral palsy and the capacities of the caregivers, including the compliance with rehabilitation activities at home. The inquiry revealed that the main caregivers were mostly mothers and grandmothers – less than half of the caregivers irregularly performed passive exercise and positioning for a child with the condition on account of “lack of knowledge, ignorance, negative attitudes and family problems” (p. vii). The study noted that these reasons had much more impact on rehabilitation for a child with cerebral palsy at home, and was the reason why the children with cerebral palsy still had more severe deformities. This important point led me to this research inquiry in order to find out what is going on in such families, with an ultimate goal that the research findings will be meaningful and useful for solving some of the problems of long-term care such as caring for a child with cerebral palsy.

Conclusion

The literature review on the Plans and their Policies, which is related to people with disability, in both international and national views, and the health conditions of cerebral palsy are employed as “theoretical sensitivity” throughout this grounded theory inquiry as this will enable the researcher to grasp the meaning of this particular situation, living with, and care for, a child with cerebral palsy.

Chapter 3

Design and methods

Introduction

This research contributes a substantive theoretical explanation of the experience of day-to-day living with, and care for, a child with cerebral palsy in the context of Thailand. The research inquiry required a research methodology that would be able to capture the meanings of human interaction and the concept of phenomena through the participants' perspectives and to clearly identify their definitions, meanings, values and understandings of this particular social phenomenon. Therefore, grounded theory was selected as an appropriate research methodology for this research inquiry. Grounded theory and its philosophical underpinning, symbolic interactionism, are explored in this chapter.

The historical development of grounded theory methodology, including the issue of *methodological split*, is discussed. The rationale for the selection of the Glaserian grounded theory method for this study, and the suitability of the methodology for the social phenomenon under study is explained. The relevance of grounded theory methodology to the generation of nursing knowledge is also discussed. In the last part of this chapter, I explain the research design and the implementation of this research inquiry, to explore the social phenomenon of the experiences of families who live with a child with cerebral palsy.

Symbolic interactionism

George Herbert Mead laid the foundations of symbolic interactionism in which he was inspired by three major influences: the philosophy of pragmatism, the work of Charles Darwin and behaviourism (Morrione, 2004; Charon, 2004; Hewitt, 2007; Mead, 1934). Mead applied the ideas of pragmatism to create an

important foundation for understanding the nature of truth of human beings. He believed that humans interact with the world by interpreting and defining the social object of the situations where they are involved, including within themselves. The theory of evolution of Charles Darwin also influenced Mead's thinking that human beings, as social animals, are active participants towards their environment and even within themselves – thinking is the action of mind. Mead argued strongly that “behavior is *not simply physical*” (cited in Charon, 2004, p. 34) to be understood by being directly observed as the behaviourists believed.

Symbolic interactionism provides a theoretical perspective for qualitative research, including grounded theory inquiry, whereby there are three basic premises (Blumer, 1969; Crotty, 1998). The first premise focuses on meaning, in that “human beings act toward things on the basis of the meanings that the things have for them” (Blumer, 1969, p. 2). The second premise emphasises social interaction in which “the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows” (Blumer, 1969, p. 2). And the third premise is based on the interpretative process in which “these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters” (Blumer, 1969, p. 2).

Symbolic interactionism was employed as the theoretical framework of this study in the light of the essential concepts such as perspective, symbol, self, human mind, society and social interaction. Human beings use their own perspectives to approach reality and they use symbols as social objects for communication with others and within themselves (Blumer, 1969; Charon, 2004). The researcher, therefore, used symbols as a guide to comprehend the participants' situations from their points of view.

Next, both self and human mind are essential for human interaction. They always occur simultaneously. The self can be a social object for others – meanwhile, it also can be an object for itself. Mind is individual action toward itself such as

thinking (Mead, 1934; Blumer, 1969). Thus, the self and mind are important for human communication regardless of whether that communication is with other people or with oneself. If the researcher establishes a good rapport and trust with the participants, they will allow the researcher to hear their conversation with themselves. That means the researcher will have a good chance to get close to their realities.

Human society demonstrates the interaction of human beings in which they integrate all concepts of symbolic interaction to communicate with others. In the light of human social interaction, the actions of human beings intertwine with one another. To put it simply, *A* interacts with *B* in which *A* takes *B*'s actions into account in *A* actions by using mind action to interpret *B*'s actions, then *A* decides to act toward *B*, in the same way as *B*'s actions (Mead, 1934; Blumer, 1969; Charon, 2004). Mead named this process “the use of significant symbols” while Blumer used another term “symbolic interaction.” The researcher will comprehend the participant's world that consists of the families who live with a child with cerebral palsy through their interactions.

Thus, in order to understand the participants' realities from their points of view, the researcher employed “symbolic interactionism” as a philosophical underpinning for this grounded theory inquiry.

Grounded theory methodology

According to two sociologists, Barney Glaser and Anselm Strauss, from *Awareness of Dying*, 1965 to *The Discovery of Grounded Theory: Strategies for qualitative research*, 1967, grounded theory was firstly introduced as a new approach to social science research for generating a substantive theory which explains the social phenomena under study (Glaser & Strauss, 1967; Stern & Covan, 2001; Wuest, 2007). In grounded theory symbolic interactionism is employed as the philosophical underpinning for exploring human beings'

behaviour. To understand the participants' world from their perspectives as they understand themselves, the researcher – as a social object – tries to get close to their reality as much as possible, and then attempts to discover “what is going on in the situation” by interpreting the meanings of social interactions, which need to employ symbols to convey the meaning (Blumer, 1969; Bowers, 1988). The perspectives indicate human interactions, including individuals interacting within themselves, which are the results of a dynamic process of symbolic meaning and self-interpreting toward social interactions. Therefore, the grounded theory approach is suitable and useful for studying in “fieldwork”, “where the minutiae of interaction provide the focus for the study, and where the processes of meaning construction are important” (Grbich, 2004, p. 158).

Methodological development

In order to attempt to improve the theory-research gap, in the 1960s, two sociologists – Anselm Strauss and Barney Glaser – developed grounded theory drawing upon their backgrounds in, and knowledge of, two distinct paradigms of qualitative and quantitative research. They stressed that grounded theory is a unique methodology, which significantly departs from both research paradigms. In their book, *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss, 1967), they demonstrate how to generate a substantive theory from the data originating from the reality by using an inductive research method. That theory provides a theoretical explanation which works with human beings' behaviour in the social phenomena of interest. In other words, the theory not only explains “what happened” in the situation, but it is also used for predicting the future and interpreting the situation about “here and now” (Glaser, 1978; Glaser & Strauss, 1967). Consequently, grounded theory has been presented as an inductive research method which has a special aim to generate a theory from the theoretical emergence of substantive data. It is not for the purpose of verification of the data. This is an important assumption of “classical” grounded theory that was mutually established by the two co-originators, Glaser and Strauss (Glaser & Strauss, 1967).

Over time, according to the works of Glaser (1978, 1992), Strauss (1987) and Strauss and Corbin (1990), a divergence in perspective and in the methods by which they used the procedures in the data analysis process resulted in a methodological split into Glaserian and Straussian grounded theory methods (Benoliel, 1996; Duchscher & Morgan, 2004; Robrecht, 1995; Stern, 1994; Walker & Myrick, 2006). The “forcing” and “emergence” of the data became the significant issues of debate between them so Glaser published *Basics of grounded theory analysis* (1992) to respond and explain how his data analysis methods differed from those of Strauss. Glaser criticised the 1990 work of Corbin and Strauss declaring that it “is not grounded theory” and renamed it “full conceptual description” (p. 124). Glaser adheres to the original grounded theory methods, in which the theory arises directly from the data. In other words, he argues that the researcher should let the data “emerge” rather than “force” or select them to “fit pre-conceived or pre-existent categories or discard in favor of keeping an extant theory intact” (Glaser, 1978, p. 4); or by using directive questions which will lead the data to preconceived conceptions (Glaser, 1992). Stern (1994) clearly articulates the distinction between Glaser and Strauss in terms of the methods by which they explore the data related to the social phenomena of interest.

The crux of the dichotomy is, I think, that Strauss, as he examines the data, stops at each word to ask, “What if?” Glaser keeps his attention focused on the data and asks, “What do we have here?” Strauss brings to bear every possible contingency that *could* relate to the data, whether it appears in the data or not. Glaser focuses his attention *on* the data to allow the data to tell their own story. (Stern, 1994, p. 220)

This debate was played off in a series of publications by Glaser (1992, 1993, 1994 & 1995) and Strauss and Corbin (1990 & 1994). Glaser and Strauss have each developed more literature regarding how to conduct a “grounded” theory, and to generate a substantive theory from the data. Straussian grounded theory, which was established by Strauss and his student, Juliet Corbin, emphasises the procedures and the analytic tools that they provide for undertaking the grounded theory method (Cowley & Heath, 2004; Strauss & Corbin, 1990, 1994, 1998;

Walker & Myrick, 2006). These procedures and analytic tools are intended to enhance the “theoretical sensitivity” of the researchers, however the techniques could be argued to force the data in pre-determined ways.

In the meantime, in Glaserian grounded theory, Glaser developed a range of works (1978, 1992, 1993, 1994, 1995, 1998, 2001, 2003, & 2005) in which he adheres to the original tenet of “classical” grounded theory by maintaining the aim of generating an emergent theory which does not allow any forcing of the data into preconceived ideas.

To conclude, Glaserian grounded theory was selected as a suitable method for this research inquiry on account of its adherence to “classical” grounded theory methods, as outlined above. I trusted that it would enable me to explore what is going on in families who have experienced living with a child with cerebral palsy, in order to generate a substantive theory which “works” within the Thai cultural context. In other words, the theory should be able to explain “what happened” in the situation, to interpret “what is happening there” and also to predict “what will happen in the situation under study”. It should not only “work” but should also be a practical theory for the substantive area under inquiry.

Glaserian grounded theory

Glaserian grounded theory holds the same philosophical underpinning, symbolic interactionism, as “classical” grounded theory. In order to understand the reality of the participants, the researcher, as a social being, needs to enter into their world. Previous knowledge and experiences of the researcher are used to support theoretical sensitivity on the part of the researcher, and to enhance the understanding of participants’ behaviour from the expressed views of the participants, through their interpretation of themselves and the definitions they share in the social interaction. The methodology enhances the researcher’s ability

to capture and maintain the meanings of the participants' behaviours under inquiry, which arise from social interaction at both the symbolic and interactional levels, by using observation within the context of the particular situation (Baker, Wuest, & Stern, 1992; Blumer, 1969; Chenitz & Swanson, 1986).

The main purpose of Glaserian grounded theory is to generate an inductive theory as a process from life experience in social phenomena by using the constant comparative method (Glaser & Strauss, 1967). Using the constant comparative method, the researcher starts open coding the data in every way possible in order to break the empirical bond of the data as an analytic piece. Then, the analytic pieces are conceptualised into codes, called *in vivo codes* – the substance of the symbols that the participants use in social interaction such as words, body language and signs. All the data, from the variety of sources that relate to what is going on in the area researched, such as interviews, field notes, memos, documents and literature, are coded in the substantive coding.

The initial codes are compared by using the constant comparative method in which similar data are grouped, and then placed in similar concepts and categories, while different data will create new concepts and categories. In theoretical coding, a new incident is compared with previous incidents, and then put it into a concept and category in the same and/or different coded groups. The processes of gathering, coding and analysing data are significantly driven by theoretical sampling, which is “the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (Glaser, 1978, p. 36). This technique enables theoretically substantive codes, concepts and categories to be explored and developed by using probing questions. Data collection and analysis simultaneously continue by the researcher's employing the constant comparative analysis of the data in order to categorise their similarities and differences until the substantive codes, concepts, and categories generated become theoretically saturated – no more new

substantive codes, which could be developed into properties of the categories, emerge from the data (Glaser & Strauss, 1967; Glaser, 1978, 1992, 1998, 2001).

Conceptualisation is an essential process for generating a substantive grounded theory. Theoretical memos, which “are the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (Glaser, 1978, p. 83), enhance the conceptualisation of ideas about substantive codes, concepts, categories and their properties. As a result, the emerging concepts and categories are lifted up from the raw data in more abstract form. Theoretical codes enable the researcher to conceptualise the substantive codes and other categories into a higher level abstraction with the emergence of a core category which holds relationships with all the other categories. The core category is called the *basic social process* (BSP) which best represents the fundamental patterned processes of behaviour of the social phenomenon researched. There are two types of basic social processes: basic social psychological process (BSPP) and basic social structural process (BSSP) Glaser defined them as follows:

A BSPP refers to social psychological processes as becoming, highlighting, personalizing, health optimizing, awe inspiring and so forth. A BSSP refers to social structure in process – usually growth or deterioration – such as bureaucratization or debureaucratization, routinization, centralization or decentralization, organizational growth, admitting or recruiting procedures, succession, and so forth (Glaser, 1978; p. 102).

Grounded theory and Nursing

Since grounded theory was developed, it has played a leading part in the development of social science theory including nursing research. Grounded theory has been extensively applied across the social sciences disciplines in nursing and health care (Benoliel, 1996; McCann & Clark, 2003b; Morse, 2001; Wuest, 2007). Consistent with the basic tenets of grounded theory, it is focused on human action and interaction, the theory which is derived from this methodology is explanatory theory of human behaviour in particular social

phenomena under study (Morse, 2001; Wuest, 2007). Thus, it is useful for practice disciplines.

The development of theory is important for nursing practice. The theory should be practical for specific nursing practice (Barnum, 1998). To date, grounded theory has had considerable influence on the generation of nursing knowledge. It has been employed to explore human behaviour in terms of interpersonal activities between, for example, nurses and patients and others within the experiences of patients and their families (McCann & Clark, 2003a), and to provide a theoretical explanation of the social processes of those groups of people who have experienced living with health conditions. Nurses and other health professionals are able to apply the understanding of patients' life situations related to their health conditions to improve the process of nursing and health care.

Study design

In the following sections, the implementation of the design and methods as used in this grounded theory inquiry is detailed. I will start by introducing the three sampling strategies which were employed to select the participants in this study. Then, participants' characteristics will be discussed in terms of the variation in their experiences. Ethical considerations and methodological rigour will be discussed with examples of how these issues were addressed throughout the research inquiry. Then the processes of data collection and analysis will be described with examples.

Sampling strategy

Consistent with grounded theory methodology, purposive sampling was employed to identify the participants, who were "information-rich", for this research inquiry. Purposive sampling is "a nonprobability sampling method in

which the researcher selects participants based on personal judgment about which ones will be most informative” (Polit & Beck, 2008, p. 763). The researcher selects the participants according to their knowledge regarding the issue being researched by using the criteria of theoretical purpose and relevance, rather than focusing on structural circumstances such as age, economic status, or educational level (Glaser & Strauss, 1967; Morse, 1991). Thus, I deliberately sought families who had varied experiences of living with a child with cerebral palsy. I also recognised that the varied classifications of cerebral palsy might affect their experiences.

According to Morse (1991), primarily, the most appropriate participants should be identified before commencing the process of gathering any data. Acknowledging this point of view, I found three special institutes for disabled children, which have different organisational structures, which might lead to varied experiences for the families of these children.

The first special institute, named The Special Education Center in Region 9, Khon Kaen, Northeast of Thailand, is a centre for developing the potential of severely disabled persons who are unable to study. At the centre, the caregivers stayed with the children throughout the process of training, which operated from 9 a.m. to 12 noon on weekdays. The second institute, named Khon Kaen Special Educational School, is a boarding school for disabled children. This school provides education for children who are able to study, from kindergarten level to secondary education. The parents were allowed to collect their children on the weekend or school holidays during semester break. Therefore, the parents of children attending this institution could work during school time. At the third institute, The Mary Immaculate School for Disabled Children, the parents or family members delivered the children to school, exactly like an ordinary school. The parent could not stay with the child while he or she learnt and practiced with the teacher. It was expected that the diversity of the organisation of the institutes may be closely related to the experiences of the families. Most participants were

recruited from these three institutes. In addition the researcher used a snowball sampling technique to gain more participants who met the criteria of the study.

Snowball sampling, one type of convenience sampling, was used for obtaining participants who were recommended and supported by someone who was already a participant, and who had a specific experience of living with a child with a chronic condition (Morse, 1991; Polit & Beck, 2008). To illustrate, in the second family interviewed, the mother suggested that I interview her friend, who had a thirteen-year-old twin boy with the same condition of cerebral palsy. It was also suggested by the baby sitter, who was a close friend of the babysitter of the above family, because the children from both families were in the same training programme at the same school. The babysitters from both families often shared their experiences after the training class. I considered it might be useful for my study to gain more participants who had experience of raising a twin with cerebral palsy for more than ten years. Furthermore, I also employed theoretical sampling to explore the emergent concepts and categories in the process of gathering and analysing data.

Glaser and Strauss (1967) defined *theoretical sampling* as “the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges” (p. 45). In other words, the researcher needs to be guided in the processes of gathering and analysing data by theoretical sampling in relation to the outcomes which emerge during analysis, and then make a decision on the data collection process for further exploration, clarification, verification, and saturation (Glaser, 1978, 1998; Morse & Field, 1995; Wuest, 2007). In order to explore and clarify the concept of *karma*, which emerged from the interviewing of the first family, particularly in relation to the grandparents who looked after the four-year-old-girl with severe cerebral palsy, I decided to gain more information regarding this concept by interviewing a second family who faced a similar situation. I used field notes for identifying the emergent ideas regarding the relationships within the data, which were observed

from the field, and then planned to explore the data further in the same participant and/or the others (Morse & Field, 1996). The following field note (Figure 3.1) demonstrates theoretical sampling for exploring the data about social support further.

To recapitulate, both purposive and snowball sampling were the most appropriate strategies for this research inquiry since they provided participants who were information-rich in relation to the particular situation; having experienced living with a child with cerebral palsy. Morse (1991) addressed the advantage of snowball sampling; if the first participant trusts the researcher, he or she will introduce and inform the next participant with a positive feeling toward the researcher and the study. However, a disadvantage might occur when the participants do not trust the researcher, for instance, the participant who is recommended might be an inappropriate case, then the researcher might waste time with a false lead (Morse, 1991; Llewellyn, Sullivan, & Minichiello, 1999). To minimise the bias, in the process of gathering data, I tried to establish a good rapport and to engage into the participants' world as an "insider" in order to develop trust between the researcher and the participant.

3:30 p.m. 31 May 2005 at ID1's house, Khon Kaen province, Thailand

I visited ID1's family without making an appointment. I met the grandfather first while ID1 was sleeping in the cradle. I greeted him with "Sawadee Ka" then he told me that the grandmother was cooking in the kitchen. When I saw the grandmother in the kitchen, she was picking up the jackfruit seeds. She invited me to taste it. I tried some. It was a very nice flavour. Then I asked her about her son who had an accident; she said he needed the wound dressed every day. Therefore, she had to ride the motorcycle holding ID1 in her arm in order to take him to the health centre in the village. She expressed her feeling that she was afraid that ID1 might fall - that means she carried ID1 with her when she visited her son! She said that she had wishes - ID1 could take care of herself at least by feeding herself by holding a bottle of milk - these were her wishes concerning ID1.

The grandmother invited me to go out to watch her cattle around there, near the pond - around 200 metres from the house. Grandmother and ID1 always went out without an umbrella. She had to take care of ID1 and do the housework as well as taking care of the cattle, ducks and chickens. After that, we had to come back home because it was raining. Then, it was time for the dinner of ID1; grandmother prepared rice congee with pork. Grandmother sat with her legs crossed on the floor, and then ID1 was laid down on her legs. She blended boiled rice with pork until it became fine. Then she started feeding ID1 with a couple of teaspoons of water, then rice, respectively. She kept talking and sang a favourite song for ID1 that made ID1 have a big smile, sometimes. I said goodbye to grandmother and ID1 when they finished the activity around 5 p.m.

Today, I learnt more about their daily activities where the grandmother had to handle both responsibility for taking care of the child and also running her household. I also learnt how she managed her situation taking care of her son and granddaughter simultaneously. At this point, I would like to know about "the social support" of this family. Who does get involved with this family? How does he/she give them support?

Figure 3.1 *Theoretical field note and theoretical sampling*

Participant characteristics

The participants of this study came from fifteen families who have experienced living with a child with cerebral palsy. The forty-nine participants include all family members – parent/s, grandparents, siblings, two children with cerebral palsy, and the neighbours who take part in caring for the child. In addition, babysitters, a teacher and a physiotherapist, who worked with some of the children, were included in the study. Thirteen children with the condition could

not communicate well. One third of the families experienced living with a child who has a severe condition such as quadriplegia – having a floppy neck and a severe stiffness of both upper and lower extremities, who cannot walk or sit by him/herself, and their abilities to speak or to understand are very poor – they just cry and smile. Most children were classified as having Spastic Diplegia with muscle stiffness in the lower limbs more than the upper – they were able to go anywhere by walker, or wheelchair – and most could speak some words but not clearly, however, they could understand and communicate by using non-verbal communication. Approximately half of the children needed total care from the main caregiver in order to maintain their daily life, while less than one third of the cases could take care of themselves, they still needed some help from caregivers – only one case did not want any help. Moreover, the children had a wide range of ages, between 4-16 years, and varied in order of birth – half of them were the only child of the family, and the rest had older siblings and/or younger brothers or sisters – one case had a twin brother.

Consistent with the Thai-culture of obligation and Buddhist beliefs, one third of grandparents were involved in caring for the child – one grandfather experienced being the main caregiver for fourteen years after his retirement, and two grandparents (one grandmother, one grandfather) had relinquished their jobs to take care of their grandchildren. The oldest child in each family also was influenced by the culture of obligation – five brothers and one sister participated in caring for their affected sibling. For example, one sister, who had a fourteen-year-old sister with Spastic Diplegia, had taken care of her sister since she was young. In this case the youngest brother also took care of his older sister, sometimes.

The majority of the families were nuclear families, only one third were extended families where the grandparents and other relatives lived in the same house with the children and their families. Half of the children lived with their biological parents – most lived with the biological mother and approximately one third of the mothers raised the child as a single mother. In some families babysitters were

hired to take care of children with the condition, on an ongoing rather than a casual basis– the longest period was thirteen years. One babysitter was related to the child as his aunt. One of two step-mothers took responsibility as the main caregiver of her step-daughter who was an eleven-year-old girl with severe cerebral palsy. The levels of education of the caregivers, particularly parents and grandparents, varied from primary school to tertiary education – two fathers and six mothers had finished primary school and two fathers had finished secondary school; two fathers and two mothers had graduated with their Masters degrees. Most parents worked as employees with low pay, less than one third of parents worked as government officers. They sometimes needed some help – for taking care of the child – from their neighbours – three of four neighbours were not related to the families, and the rest were their relatives who were willing to give the family a hand to take care of the child, when the main caregivers were busy or had to go out. The last group of people, who were related to the children with cerebral palsy, were health and non-health professionals – the physiotherapist, who worked at the boarding school for disabled children and the teacher, who worked at a special school, were included as participants in this study.

Ethical considerations

This study involved human lives, thus in the first place, the research proposal needed to be approved by Massey University Human Ethics Committee (MUHEC) in November 2004 before any data could be gathered. Initially it was intended that the Physical Therapy Clinic in the Physical Therapy Department, Faculty of Associated Medical Sciences, Khon Kaen University would be used as a site for contacting families. Ethics approval was granted by the Khon Kaen University Ethics Committee for Human Research, in December 2004 (Appendix 3). However, the research setting was changed to the three special institutes for children with disabilities because, at that time, there were only a few children with cerebral palsy receiving service at the Clinic. The change of sites was re-approved by MUHEC in April 2005 (Appendix 4), with permission from the three special institutes (Appendix 5, 6, and 7). Consequently, the

MUHEC Code of Ethical Conduct for Research, Teaching and Evaluations involving human participants was followed in this study by focusing on: informed consent, respect for privacy and confidentiality, minimisation of harm to participants, respect for persons, and social and cultural sensitivity.

Each family who was willing to participate in the study was given the Participant Information Sheet (Appendix 1), which was translated into the Thai language (Fischman, 2000; MUHEC Code, 2004; National Commission, 1979; Tymchuk, 1992). To ensure that the participants comprehended the information, I reviewed with them the details of the study, in particular their rights in relation to participation in this research inquiry, before completing the process of *informed consent* (Appendix 2). As the participants include children with cerebral palsy and their siblings, parental permission followed by verbal assent was used for the children (Koocher & Keith-Spiegel, 1990; Stanley, & Sieber, 1992; Tymchuk, 1992).

For example, with the first family, I made an appointment with the grandmother, whom I met while she was taking care of a four-year girl with cerebral palsy at the Special Education Centre, to visit her family at their home. I introduced myself and the study to all family members: the grandparents, mother and stepfather. To ensure that they had understood the study, I repeated to them a detailed explanation of the Participant Information Sheet, such as how to participate in this study and the rights to withdraw from the research participation at any time without giving any reasons. After they had a full understanding and made a decision to participate in the study, I asked the mother to complete the process of informed consent (Appendix 2). I then expressed my appreciation of their agreement to participate in this study by saying the words, with honesty, “Your experiences are valuable for everyone who has the same situation and can learn from yours. I could not find them from any book in the bookstore. So, I would like to learn from your experiences.” As I had a great admiration for them, they were more willing to share their experiences in the process of unstructured interviews.

The *privacy and confidentiality* of the participants were assured throughout the research inquiry. All research participants and their information were respected. Anonymity was employed for protection of the privacy and confidentiality of participants. For example, the participants and their information were identified by creating a group of letters and numbers such as ID1 refers to a child with cerebral palsy in the first family; ID3-GM refers to the grandmother of a child with cerebral palsy in the third family. All participants' information including personal data, pictures, and drawings, are used with permission. Where pictures have been used, a strip to blur the identity of the participant has been added. The recorded interviews were transcribed in Thai by physically blind persons and tertiary students. The transcribers were informed verbally regarding the confidentiality of the data and completed a confidentiality form for transcribers. The transcriptions were then translated by people who were bilingual in English and Thai, particularly I-San dialect⁴, and they also completed the confidentiality form for translation (Folkman, 2000; MUHEC Code, 2004).

Ethically, the researcher is concerned about *risk of harm* to all participants. Thus, in this study I had a precise aim regarding this ethical principle in order to conduct research doing no harm to the participants, while they are able to gain maximum benefits. The natural benefits that occur between the researcher and the participants are communication with courtesy, good rapport, cultural sensitivity and good care. As the result of research participation, vulnerable participants – such as children with cerebral palsy and their siblings – enjoy the research experiences. Ultimately, it is imperative for estimating research benefits that the quality of life of children with chronic conditions and their families will be improved. Meanwhile, results of this research can clarify the particular problems of healthcare in the community. In particular, the research findings may be useful for developing the networks and resources of caring for children with chronic conditions (Thompson, 1992; Sieber, 2000).

⁴ I-San dialect is common used in the northeast of Thailand.

Respect for persons is the basic ethical principle for conducting research with human participants. All participants were respected as worthy persons who shared their personal dignity, behaviour, attitudes and beliefs regardless of whether these were cultural beliefs or religious beliefs. I also respected their privacy and autonomy even where they have diminished autonomy such as being an immature sibling or an incapacitated child with cerebral palsy (Smith, 2000; MUHEC Code, 2004). The participants had the right to decide whether to participate in this study or to withdraw their participation at any time or to refuse to give any information – in which case they would not need to give any reasons for this rejection (National Commission, 1979; Thompson, 1992; MUHEC Code, 2004).

Although this study was conducted in the researcher's homeland, the northeast of Thailand, ethically I was – as the researcher – still concerned about *social and cultural sensitivity*. I respected the decisions of all groups of people who participated in this inquiry and would discontinue participation at any time requested. In addition, their culture was respected in terms of attitudes, values, lifestyles and actions, particularly their social and cultural property of arts and traditions. I met participants at the educational institutes and interviewed them at their homes. The collaboration between the researcher and the participants is important for culturally sensitive research; it is important that the researcher is able to take membership of the cultural groups while trust is established gradually (Sieber, 1992; MUHEC Code, 2004).

Methodological rigour

Glaserian grounded theory (Glaser, 1978) provides the explicit criteria – “*fit*”, “*work*”, “*relevant*”, and “*modifiability*” – for establishing methodological rigour. The criterion of “*fit*” demonstrates how the substantive grounded theory is faithful to the realities of the substantive area under inquiry through its ability to correspond closely with the data. To achieve this ability, the researcher must allow the data to emerge by themselves, not force the data into preexisting ideas.

Then, the theory eventually is able to reflect the realities of the substantive area. The criterion of “*work*” indicates the substantive grounded theory’s ability to be used to explain, interpret and predict the facts of the substantive area under study. In the light of workability, it is not only academic persons who utilise the theory, but the people working in the field also apply it themselves. Thus, the theory must make sense and be readily understandable for anyone who may be concerned with this area.

According to Glaser (1978), the theory “must be *relevant* to the action of the area” (p. 5). To achieve this criterion, the researcher must allow core categories and the basic social process to emerge without other preconceived theories. Furthermore, *modifiability* is one of the criteria for judging the quality of grounded theory as a theory. Consistent with the notion that substantive grounded theory is generated from empirical data of social phenomena, which constantly changes, the criterion of modifiability plays an important role in validating that substantive grounded theory is appropriate for the social phenomenon under study.

The demographic diversity of the participants led to a wide diversity of their perspectives, which were explored in terms of experiencing living with a child with cerebral palsy, by using the constant comparative method throughout the process of gathering and analysing the data of grounded theory methodology.

Data collection

In order to understand the participants’ realities, and then to depict their concerns, actions and behaviours in terms of the basic social process which they normally use to get through the particular situation (Chenitz, 1986; Morse, 2001), I chose two main data gathering processes: unstructured interviews and participant observation. In particular, I used participant observation techniques in the preliminary part of participant selection. Furthermore, I employed a variety of qualitative data sources – field notes, personal documents, pictures, drawings

and literature reviews – as “the data” which needed to be constantly compared to clarify the emerging concepts (Glaser, 1998, 2001; Schreiber, 2001).

Participant observation

Firstly, I engaged in their world by using participant observation, which is a method in which the researcher spends a length of time involved in the participants' world with the specific purpose of learning their culture, through daily activities, rituals, interactions by observing what happens there (Dewalt & Dewalt, 2002; Russell, 1999). I spent around three weeks with the families who have a child with cerebral palsy during the physical therapy class at the first special institute, The Special Education Center in Region 9, Thailand. At that time, I, as a participant observer, had a chance to establish rapport with the families and the children with cerebral palsy as suggested by Lincoln and Guba (1985), which is the way to learn their culture and which will build trust with them eventually. From this point of view, I learnt their daily activities by observing interaction among children with cerebral palsy and their caregivers.

I also used participant observation alongside interviews in the process of gathering data at the homes of participants. In some families, I took part in caring for a child with cerebral palsy by rocking the cradle, and giving the caregiver a hand by holding the child in my arms when the caregiver had to do something else. Sometimes, I was invited to have lunch with them. That was a great chance to establish mutual connection and relationships with them as an “insider” and then to observe how they manage their daily lives. Then I took field notes after visiting the family.

Unstructured interviews

Unstructured interviews, which are like natural conversations to the participants being studied, are a suitable method for gathering data in grounded theory inquiry, since the unstructured interview “is concerned with the unique, the idiosyncratic, and the wholly individual viewpoint” (Guba & Lincoln, 1981, p.

156) in which the researcher as the interviewer needs to pay more attention to what the participants say, and completely rely on their stories (Lincoln & Guba, 1985). Significantly, the interviewer does not know what the participants' stories will be, thus, the interviewer does not have any plan regarding the natural order of questions ahead (Chenitz, 1986; Lincoln & Guba, 1985; Morse & Field, 1996). Therefore, I began unstructured interviews, which normally were conducted in the participants' homes as they wished, by applying the questioning techniques of funnelling, story telling, probing, interpreting, using follow-up and silence, taken from Kvale (1996) and Minichiello et al. (1999). I employed broadly open-ended questions, which were based upon the research question and aimed to explore the participants' experiences – "Could you please tell me about your experiences since the child was born?" Or, "What was going on in your life after the child was born?" Consequently, depending on the emerging findings from the previous interviews, in which I, as the interviewer, had listened actively, I kept the interesting issues in mind as suggested by Kvale (1996) in the process of follow-up questions, by asking the participant about more specific issues later, and encouraged them to describe them in narrative form. For instance, "As you just said 'life is life', what do you mean by that? Could you please explain more to me on that?"

Unstructured interviews were conducted in the Thai language and took approximately 60 to 100 minutes for teenage and adult participants, while interviews with children ranged from 45 to 60 minutes. In order to retain the meaning of the participants' words, I used tape recordings with oral permission from the participants during the process of gathering data then the interviews were transcribed verbatim as described earlier. To verify the accuracy of the transcriptions, I listened to each tape while reading and correcting the initial transcription. I ensured the accuracy of the translation by first explaining the context of the interview discussion to the translator prior to the translation, then rechecked the translated interview. I sometimes had further discussion with the translator to clarify sections of the translation that I found did not accurately reflect the meaning expressed by participants.

Data analysis

In grounded theory, gathering and analysing data occur simultaneously as dynamic processes. These processes required theoretical sensitivity in the researcher to detect what actually happened in both the research field and the data, and to remain open for emerging concepts and categories from the data (Glaser, 1978). Therefore, the researcher needs to be sensitive to each aspect of the data which might come from interviews, observation, field-notes, documents, pictures and drawings – considering, listening to all the data they reveal. During the process of analysing data, the researcher needs theoretical sensitivity for generating concepts and categories which emerge from the theoretical codes, and then integrating them into the substantive theory (Glaser, 1992).

Glaser (1978) suggests that the researcher has to trust in his/her ability, and in the grounded theory methodology, by maintaining as few as possible preconceptual ideas. From this point, even though I had prior experiences in that I was a Neonatal Intensive Care Unit nurse and I reviewed literature regarding cerebral palsy and other chronic conditions for developing the research proposal, I employed this sort of knowledge as theoretical sensitivity in this research inquiry. Schreiber (2001) claimed that researchers might use their knowledge related to the study to utilise theoretical sensitivity and theoretical sampling.

Substantive Coding

To generate an emergent set of concepts and categories, I followed the methods of Glaserian grounded theory by employing the constant comparative method throughout the analysis process. I started with open coding from the interview transcripts line-by-line, and highlighted each incident in different colours in the right-hand margin (Glaser, 1978; Glaser & Strauss, 1967; Morse, & Field, 1996) (see Table 3.1 and 3.2).

Table 3.1 Excerpt from Data

Data	Excerpt from data
F: Well, I do not have much feeling about it. I think it is really normal to have such a feeling between father and daughter. As a father, I think it is my obligation to give my full support in raising my daughter. At first, we did not know that she (ID5) was going to be like this. It might be because at that time she was not delivered from her mother yet. Also, her mother must give birth to her by operation. At that time, I did not know that her mother had cancer. (ID5-F-1- P. 1)	<p>- Well, I do not have much feeling about it. I think it is really normal to have such a feeling between father and daughter. As a father, I think it is my obligation to give my full support in raising my daughter.</p> <p>- At first, we did not know that she (ID5) was going to be like this.</p> <p>- It might be because at that time she was not delivered from her mother yet Also, her mother must give birth to her by operation. At that time, I did not know that her mother had cancer</p>

Table 3.2 Generating Codes

Excerpt from data	In vivo Codes	Theoretical note/memos
<p>- Well, I do not have much feeling about it. I think it is really normal to have such a feeling between father and daughter. As a father, I think it is my obligation to give my full support in raising my daughter. (ID5-F-1- P. 1)</p> <p>...So, I made a decision to "plong⁵" because I realise the fact that he could not be normal. I do "plong". I also do "thum jai⁶" about him, my son even he has this conditions he is my son. I cannot even though abandon him. (ID8-F-1-P11-14)</p> <p>- If ID15 gets older, I have to take care of her because I am the oldest child. I have to look after her because my brother is too young to do this...As she is my sister, if I do not look after her, who else is going to do this? It is impossible for her mother to take care of ID15 forever. As in sequence, I am the next one who has to take care of her since she is my sister. This is my feeling. (ID15-S-1-P. 15)</p>	<p>Normal Feeling of father & child Obligation Giving full support Raising a child</p> <p>Doing "plong" with the child who could not be normal Doing "thum jai" about the child Son Cannot abandon the child</p> <p>Have to take care of the child The oldest child Being sister Brother too young to take care of the child In sequence Being the next one who has to take care of the child</p>	<p>Obligation & responsibility of father to take care of the child</p> <p>Using the Buddhist ways to accept the situation, so Buddhism plays a role as the underpinning of obligation and responsibility of father toward the child</p> <p>Culture of obligation and responsibility of the oldest child to take care of sibling particularly with condition</p>

Subsequently, I compared the incidents with other incidents, then the concepts and categories emerged from the data. In order to verify and refine codes,

⁵ Plong means a deliberate thinking about a “thing” which can see the truth of the “thing” as it is, then can set the mind to be calm.

⁶ Thum-joi means to realise the fact or to accept a “thing” that we cannot change anything about it.

concepts, and categories, I employed the questions outlined which are suggested by Glaser (1978) (see Figure 3.2) for comparing the incidents with previous incidents and categories, and then each category with other categories, respectively. Open codes were grouped into clusters which had similarity of content (Glaser, 1978; Glaser & Strauss, 1967; Morse, & Field, 1996).

- What is this data a study of?
 - What is happening in the data?
 - What category does this incident indicate?
 - What property of a category does this incident have?

Figure 3.2 Questions used for the process of constant comparative analysis
Data from Glaser, B. G. (1978) *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.; Swanson, J. M. (1986) Analysing data for categories and description. In Chenitz, W. C. & Swanson, J. M. (Eds.). *From practice to grounded theory* (pp. 121-132). Menlo Park, CA: Addison-Wesley Publishing Company.

During the process of constant comparative analysis, some concepts emerged from the data after open coding; I put them on the door to see how they linked together (see Figure 3.3), and identified some relationships between them.



Figure 3.3 *Putting some theoretical codes on the door*

During the process of analysing data, more and more concepts and categories emerged, I could not place them all on the door; then I depicted a “Mind map” (see Figure 3.4) that included all of the concepts and demonstrated the relationship between the concepts and some properties of each category. I used the “Mind maps” as one form of theoretical memo, which is “the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding” (Glaser, 1978, p. 83). Theoretical memos are aids to monitor theoretical thinking during the process of data analysis as further illustrated in textual form in Figure 3.5.

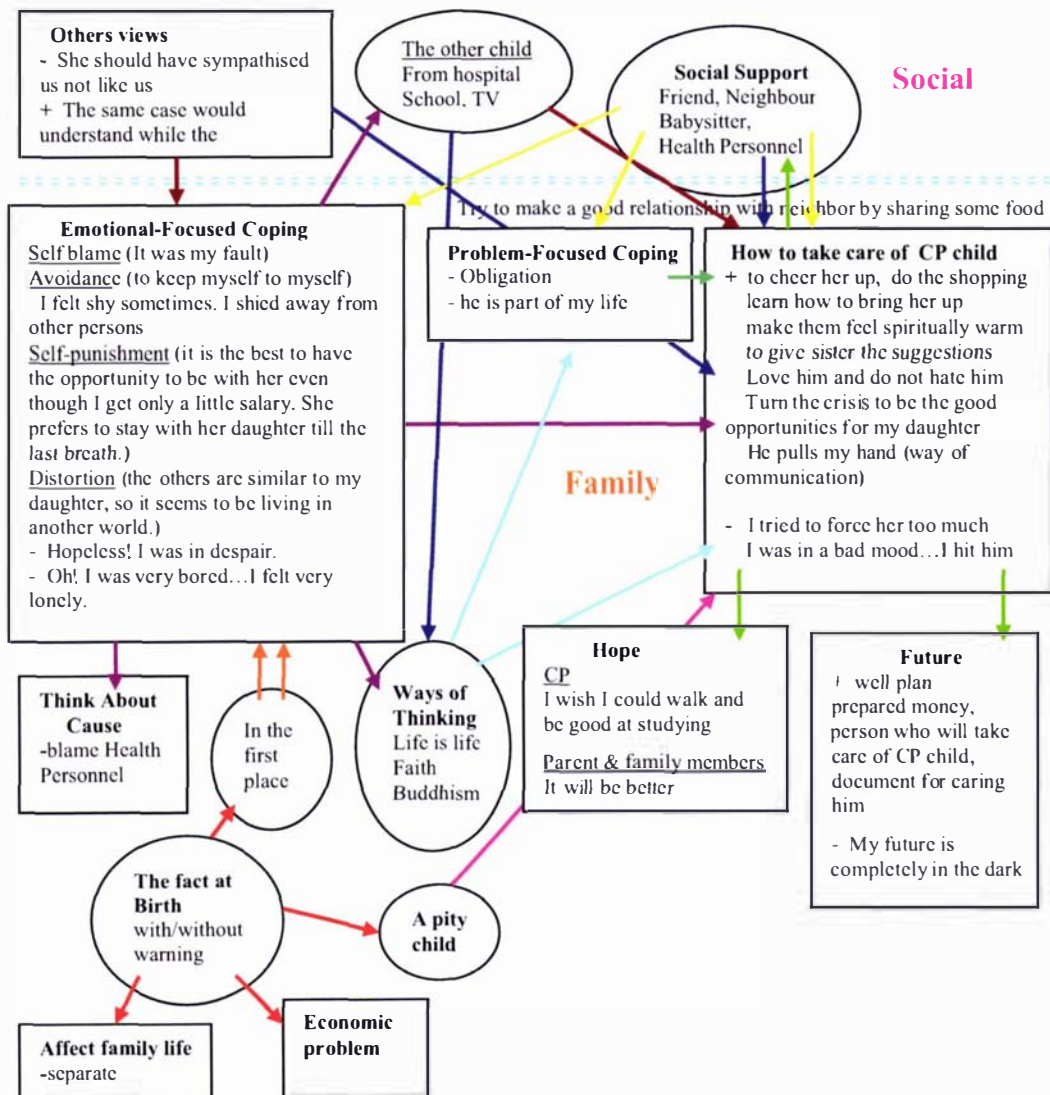


Figure 3.4 Using "the mind map" as a "theoretical memo"

At the time of constructing the mind map, I unwittingly borrowed the concept of coping as a lens to view the data, which seemed to have an "emergent fit" with this "preconceived" concept; then, I was immediately reminded of the procedure by my supervisor. Consequently, I turned back to the fundamental grounded theory process by reading and rereading the data without any preexisting concepts and used the questions that were suggested by Glaser (1978, p. 57) (see Figure 3.2) to find out "what is actually happening in the data". I also used peer debriefing with my supervisors and by presenting at Doctoral School. Peer debriefing is a technique for establishing credibility where the researcher allows

external experts to review and explore all aspects of the process of the inquiry (Lincoln & Guba, 1985; Polit & Beck, 2006).

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I developed the 2nd mind map under the "concept of coping". For this map, I divided "themes" into two big areas as they occurred, social and family, and I still retained "the fact at birth" as the original of this finding. Many directions became clearer than the first ones. Unfortunately, the serious point of this map was the "coping concept". This was not the way of grounded theory and it was an "external concept" and my supervisor, gave me suggestions. She was absolutely right. I remembered that I went to the field without any concept. I just would like to know "what is going on in that family" Then, within the process of analysis, I borrowed an "external concept" into my analysis.

Figure 3.5 *Taking theoretical memos*

Selective and Theoretical Coding

The next two levels of the coding process are selective and theoretical coding in which the coding is focused on selected variables, which are related to – and led to – the core variable, or the basic social process. The core variable offers a specific direction of data collection via theoretical sampling, and data analysis. The process of conceptual sorting was used for generating concepts, categories and their properties, which fitted the data, and then integrating them into the substantive theory, which works with the phenomenon (Glaser, 1978). Furthermore, I also employed the Six C's which is one of the theoretical 18 coding families (Glaser, 1978) for checking the variables which related to the basic process of experiencing living with a child with cerebral palsy. Which variable indicates the cause of this particular situation? Which variable indicates the consequence of the situation? And the last question, which is taken from Wilson (2004) is "What is the basic social process at work for this particular situation?" Table 3.3 presents all the concepts, categories, and core categories of the experience of *never-ending caring* for a child with cerebral palsy.

Table 3.3 The Experience of Never-Ending Caring for a Child With CP

BSPP ⁷	TP ⁸	Core categories	Subcategories	Concepts	Codes
NEVER-ENDING CARING	Facing the situation	Enduring Despair	Suffering and blaming	Finding reasons and blaming	Karma Health issues Blame themselves Blame health personnel & the treatment
				Expression of suffering	Having questions in mind Unexpected condition Negative self-feeling Experiencing social disgust
				The burden of care	Effect on family & social relationships Having health problems Effect on economic problems
	Learning to deal with the situation by themselves	Culture of Obligation & Responsibility	Having faith	Being Buddhist	Having a sense of acceptance Practising religious precepts Making merit
				Personal beliefs	Performing sacred ritual Beliefs in fortune-teller Having good luck
				Obligation & responsibility	Obligation of care Depending on family Reciprocity of care
	Learning to live with, and care for, a child with CP	Living with	Learning to live with the situation	Dealing with the situation	Learning about the situation Ways of seeking social support Ways of thinking Ways to release stress
				Strategies to bring up	Promoting the development of the child Providing psychological support
				Physical health treatment	Experiences of treatment Finding ways to rehabilitate
				Having positive feelings	Feeling happy Being proud of oneself and others Gaining spirit to fight from others
			Preparing for an uncertain future	Vulnerability of a child with CP	Suffering with oneself Being taken advantage of Sexual victimisation
				Planning for the future	Having a good plan for the future Unable to decide (Future in the dark)
				Living with hope	Hoping for acceptance in society Hoping with unrealistic wishes

The model of the “Table 3.3 The experience of never-ending caring for a child with cerebral palsy” was adapted from Wilson (2004). *Ngā Kairaranga Orunga: A Theory on the Weaving of Health & Wellbeing by Māori Women*. A thesis presented in fulfillment of the requirement for the degree of Doctor of Philosophy in Nursing. Massey University, New Zealand.

⁷ BSPP refers to Basic Social Psychological Process

⁸ TP refers to theoretical proposition

Conclusion

Glaserian grounded theory methodology, underpinned by symbolic interactionism, was used to guide the data gathering and data analysis in this study. A basic social psychological process was identified which represents the social and symbolic meaning of the experience of families who live with a child with cerebral palsy in the Thai cultural context. In the subsequent chapters, I will present the emergent theory as the experience of *never-ending caring* – the basic social psychological process of this social phenomenon of living with a child with cerebral palsy.

Chapter 4

Enduring despair

Introduction

In this chapter, I firstly introduce an overview of the experiences of the participants who live with a child with cerebral palsy as reflected in the basic social psychological process (BSPP) of this study: *never-ending caring*. Note that in this study I draw on the experience of those living with a child with cerebral palsy and not those who suffered the loss of a child with the condition, hence the participants in this study all experienced caring for a child with cerebral palsy as “never ending”. Figure 4.1 demonstrates the relationships among the basic social psychological process, three core categories and theoretical propositions in the diagram of *never- ending caring* for a child with cerebral palsy.

In this chapter, which is the first of five chapters of research findings of this grounded theory study, I assert that facing the situation – the theoretical proposition of the first category **enduring despair** – is the first stage of the BSPP. To illustrate how the participants face challenging circumstances throughout their lives, I begin with the first category **enduring despair** which is one of three core categories of this research. The other two core categories **culture of obligation and responsibility** and **living with** both form part of the emergent theory, and will be presented in chapters five and six, respectively.

An overview of the experience of *never-ending caring* for a child with cerebral palsy

This research inquiry contributes a substantive grounded theory that reflects the perspectives of the participants and provides a theoretical explanation of the experience of *never-ending caring* for a child with cerebral palsy (Table 3.3). The basic process illustrates how the participants face challenging circumstances and how they learn to deal, and live, with this particular situation.

This theoretical explanation includes three core categories: **enduring despair**, **culture of obligation and responsibility**, and **living with**. The first core category, **enduring despair**, describes how participants face challenging circumstances. It reflects the initial stage of finding reasons and allocating blame for this situation, the ongoing expressions of suffering, and the effects of the burden that this condition requires the participants to carry. Most participants found, and blamed, *karma*⁹ as an imperative cause of this condition.

The second core category **culture of obligation and responsibility** describes how participants learn to deal with the situation by themselves. It illustrates how their personal and religious beliefs and the Thai culture of obligation and responsibility underpin their behaviours in this situation and influence their daily lives. For example, the participants in this study employed Buddhist practices such as, Thum-jai and Plong, to enable them to accept their situation and be at peace.

The third core category **living with** demonstrates how participants learn to live with the situation in which they find themselves. There are two subcategories: ***learning to live with, and care for, a child with cerebral palsy*** and ***preparing for an uncertain future***. **Living with: *learning to live with, and care for, a child with***

⁹ *karma* means volitional actions of body, speech and mind which may be good or bad.

cerebral palsy focuses on the strategies they learn over time to bring up a child with this condition. **Living with: *preparing for an uncertain future*** describes their concerns about the place of their child in society and a future plan for when the parents or other caregivers are no longer able to provide care for the child.

This theoretical explanation is expressed as a diagram (Figure 4.1), that illustrates the important components of the substantive grounded theory of the experience of *never-ending caring* for a child with cerebral palsy. The diagram demonstrates the cyclical nature of never-ending caring as situations change for participants and they are alternately faced with new situations that evoke despair and then utilise their beliefs and cultural obligations to resolve or accept each new situation.

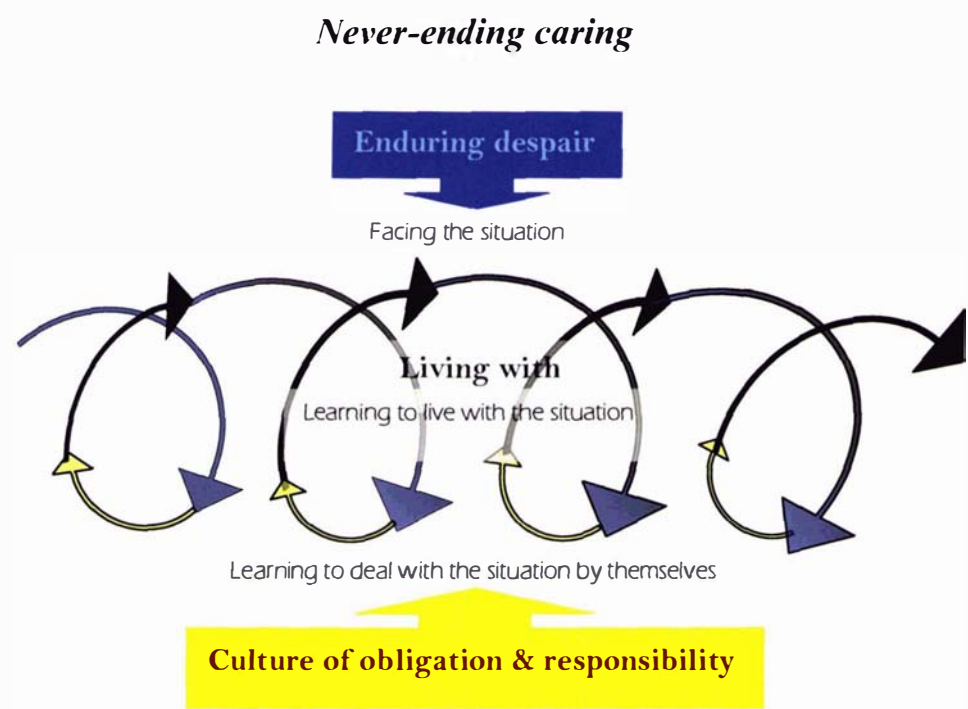


Figure 4.1 *Never-ending caring for a child with CP*

This cyclical process occurs repeatedly throughout their lives while taking care of a child with cerebral palsy. From the birth of the child with this condition, the

parents experience a sense of **enduring despair** as they face new situations, then try to deal with challenging circumstances by themselves, through employing their beliefs and the **culture of obligation and responsibility**. Consequently, the direction of the arrow changes to the opposite way when they set their mind to accept the situation. When they are able to get over, or manage, the challenging circumstance, then they can maintain their lives as usual; they will feel happy and become peaceful with their condition for a period of time until they face a new challenging situation. In the meantime, they learn a new point of view or technique to **live with** the situation. In each cycle of experience they learn different things in order to live with their situation as a normal life. The following sections describe the first core category in more depth.

Enduring despair

The first core category of BSPP: *never-ending caring* for a child with cerebral palsy is **enduring despair** which is illustrated in Table 4.1. The theoretical proposition facing the situation demonstrates how the participants face challenging situations. From their perspectives, a sense of despair is not present only at the first moment of having a baby with cerebral palsy, rather it recurs repeatedly throughout their lives as they take care of that child with cerebral palsy. The feeling of despair is elicited by both internal and external factors.

Table 4.1 Enduring Despair the First Core Category of *Never-Ending Caring* for a Child With Cerebral Palsy

TP	Core categories	Subcategories	Concepts	Codes
Facing the situation	Enduring Despair	Suffering and blaming	Finding reasons and blaming	<i>Karma</i> <i>Health issues</i> <i>Blame themselves</i> <i>Blame health personnel and the treatment</i>
			Expression of suffering	<i>Having questions in mind</i> <i>Unexpected condition</i> <i>Negative self-feeling</i> <i>Experiencing social disgust</i>
			The burden of care	<i>Effects on family & social relationships</i> <i>Having health problems</i> <i>Effects on economic problems</i>

To be more precise, ways of thinking about the situation become an internal factor that causes these feelings. Furthermore, the participants in this study also experience a sense of despair when they encounter bad experiences with other people in their daily lives. For instance, most participants experienced negative views from people in society towards their child, which they described as “social disgust”. Experiencing social disgust is one of the challenging situations that recur in the participants’ lives as they live with, and take care of, a child with cerebral palsy. Consequently, the sense of despair endures throughout their lives, rather than being a time-limited experience. Achievement of happiness, or peace of mind, is dependent on how they respond, and express feelings, towards a particular situation.

Enduring despair has a subcategory **suffering and blaming** which demonstrates how the participants face their situation. They have different ways of thinking and expression towards challenging circumstances and how these impact on their lives. The subcategory **suffering and blaming** consists of three main concepts:

finding reasons and blaming, expression of suffering and the burden of care.

Suffering and blaming: Finding reasons and blaming

The participants express their experiences as suffering the consequences of having a child with cerebral palsy and they try to find the reasons for the child having that condition. Blaming is the strategy that underpins the concept **finding reasons and blaming**. The codes of this concept include *karma*, *blame themselves*, *blame health personnel* and *health issues*.

In Buddhism, *karma* means volitional action that includes the actions of body, speech and mind (Gethin, 1998; Rahula, 1962). This means that if we have an intention to do something, then we think, we say and then do it. The volition of each action might be good or bad, and *karma* produces its effects, which depend on the volition of that action. As Rahula (1962) states, “the theory of *karma* is the theory of cause and effect, of action and reaction...” (p. 32). To put it simply, if we act a good *karma*, we get a good result. If we act a bad *karma*, we get the result of this action in a bad way. The result of *karma* will be with us even in our life after death, and then it will display itself as the nature of its actions (Rahula, 1962).

According to Buddhism, and Keyes and Daniel (1983) and Rahula (1962), human beings consist of two essential forces: physical and mental forces or energies. At the end of a being's life, the body still has the mental energies that have power to take another form. As a result of the theory of *karma*, the direction of re-existence is determined by a being's *karma*. Both good and bad effects will be within the new form, and then it will manifest itself. This process is called “reincarnation” or “rebirth”.

The participants reported trying to understand their condition by searching for the reasons why this particular situation happened to them. Most participants were Buddhist (98.41%), thus they blamed *karma* as the main cause of this

phenomenon. Many parents and grandparents who hold strong beliefs in *karma* – particularly the theory of *karma* and the concept of reincarnation – are informed by their traditional beliefs which are passed on from generation to generation. From their perspectives, *karma* might have happened in the past, which might be in the previous life or in the past of the present life; it then affects their lives in the present. In other words, they believe that they might have done something bad in the past, and the present situation is the consequence of their *karma*, as illustrated in the following quotations:

I think her parents might have done something wrong in the previous life...They might have broken frog's legs or toad's legs then she can't walk...I think about the consequence of karma that we killed animals, we broke their legs...at this point, I think the child didn't do anything like that but her parents have already done it in the past, then she can't go anywhere. (ID10-GF-1-P. 3-5)

I thought about karma which I have done in the past. I kept thinking that I have done something like bad deeds when I was young then the consequence of that acts upon my child. At that time, I did many things about which I can't tell you. I am pretty sure because of karma what I have done. I talked to myself why it did not happen to me, instead of my child. I felt sympathy for her. It is not the previous life. I think it must be the consequence of the acts in the present life. (ID10-F-1-P. 5)

Parents and grandparents are particularly concerned about the feelings of a child with cerebral palsy, because they think a child with this condition is a sensitive person and they feel pity for him or her. They do not tell a child with cerebral palsy about their belief in *karma* as a cause of his/her condition. However, the child receives this sort of belief from society by learning from the teaching at school and the temple. A fourteen-year-old girl with cerebral palsy stated that she studied the Buddhist subject at the boarding school from the monks. She learned more about the theory of *karma* and the concept of rebirth through videos and the teaching of the monks in which they follow the Dhamma¹⁰. She then realised her condition might be because of *karma*, as she shared;

I think because of karma that we did in the previous life. Suppose we killed animals or we broke their legs then we could not walk symmetrically. We have asymmetrical legs...Consequently, I think about me myself. Oh! Is it

¹⁰ Dhamma refers to the doctrine of the Buddha

right that I broke animal's legs then I was born to be like this? (ID11-CP-2-P. 3-4)

While the majority of participants employed the concept of *karma* to explain their situation, one mother, who has a sixteen-year-old daughter with cerebral palsy, gave a reason in terms of science as a realistic view instead of blaming *karma*. The different perspective from those of other participants may be explained by her background, as she is an educated person and works at a hospital. This is her explanation for the situation.

I have never thought about karma as if I have done something in the previous life. I have never thought like that. Then, when someone asked me about her, I would tell them it was because of a disease that she got when she was three months old...because of the illness. (ID2-M-2-P. 9)

Because of their beliefs about the consequences of *karma*, several participants respond to the situation by *blaming themselves*. Not only the participants who intended to do, or did, something accidentally during the pregnancy period that might be the cause of cerebral palsy blamed themselves, but a participant who did not do anything wrong also kept blaming herself. Self-blame occurs in both the mother and father. There seems to be a culture of self-blaming. The participants who did something wrong, including by accident, expressed feelings of an overwhelming sense of guilt and blaming themselves. The following quotation highlights their feelings.

I didn't blame karma. I blamed my action because I realise what I have done...It was my fault that I took a lot of medicinal wine (laugh). I wanted to increase blood flow so I drank a lot till I got drunk...It was my fault. It was not karma. Not at all... I as a mother did not pay attention to my baby. (ID7-M-1-P. 29-31)

One mother, who has a seven-year-old daughter with cerebral palsy, shared her experience of giving birth to her daughter on the road. She expressed her feelings with an overwhelming sense of self-blame and demonstrated how she delivered her daughter by accident. Even though the incident occurred seven years ago, she still has a very vivid memory and blames herself every time she thinks about her child.

If I didn't give birth to her that way, she wouldn't have been like this. It was my entire fault. It seems like making her suffer. She was supposed to be born a normal child, but it was because of me. So that's why I think it was my fault. As she is a human, how could she fall? I was standing then she fell down (on the road)... It was my fault. I thought of this alone...The accident happened because of me. If I had not been careless, it wouldn't have happened...Why did I do that even though I knew that she was coming out soon? Why did I stand like that? (ID9-M-2-P. 36-42)

Consistent with the culture of blaming, the participants in this study also *blame health personnel and the treatment* that was involved in the process of giving birth to a child with cerebral palsy as an important cause of this phenomenon. In spite of the fact that the health personnel gave them information, they still keep blaming the treatment and others at this point. It might be because they did not understand clearly, or they needed more information. They then try to find the reason to explain the situation in their own way.

I went to see the doctor at the clinic then he told me that it wasn't time to deliver yet. He suggested that I go home first. Therefore, I went home. If I had gone to the hospital, she would have been like a normal child. (ID9-M-1-P. 13)

The doctors just told me that ID5 was infected...with what kind of disease was she infected? ...I truly doubted what kind of drug that the nurse and the doctor gave to my wife. Did they try out some drugs on her? Is that right? Maybe they let her take something. Maybe they just received the new drug from the company or from elsewhere? (ID5-F-1-P. 3-4)

I didn't hear any cries when my baby was born. I was curious why the doctor didn't put it into the incubator which was prepared around there. He put it in front of my legs so long until he had finished wound sewing...I wonder whether the doctor thought my baby had died, that is why he didn't take it away quickly. (ID6-M-1-P. 1-2)

The doctor had an order to inhibit labour at the seventh month though he didn't do any examination; vagina opened yet or amniotic fluid came out yet. He didn't examine, did he?...I knew that the doctor intended to save the pregnancy until the ninth month. However, he should examine first. It was probably not. If it had been done, it would probably inhibit labour although vagina opened approximately 4 centimetres. Inhibition vaginal for 3 days via injection. Consequently, the fetus stopped movement. It didn't move any more. In my case, we really trusted the doctor. We depended on him because we didn't learn anything like the doctor did. So, we thought he did the right thing...They told me that the baby had some problems such as infection after labour, bleeding in its brain and something wrong with

spleen. I thought that the medicine might affect the fetus; it might be exhausted and could not move eventually. (ID1-GM-1-P. 1-4)

Furthermore, the participants – particularly parents and grandparents – thought that the health status of the mother and her baby at the periods of pregnancy and postpartum had a direct effect on the baby. Since they perceive it within a realistic view of life, they blame *health issues* as a major cause of this phenomenon. One participant is the father of a girl with cerebral palsy who is eight years old. His wife was diagnosed with lung cancer during her pregnancy, and died one month after she gave birth to her daughter with cerebral palsy.

It might be because at that time she wasn't delivered yet...I didn't know that my wife had lung cancer while she was pregnant...She delivered ID5 at the time that she was seven months pregnant. Well, she had to go to see the doctor because she was coughing every day...The doctor told us that she got probably about 5-6 months to live. Surprisingly, she only lived just one month after she gave a birth to ID5 on Aug 29...On 29 of Sept. then she passed away... When she was 7-8 months old, I doubted about her condition then I decided to go to the doctor...He told me that she had hypoxia then her brain was a little bit damaged. (ID5-F-1-P. 1-2, 5)

Two mothers described other *health issues* that they believed were the cause of cerebral palsy. The first mother, who has a twelve-year-old son with severe cerebral palsy, explained her health conditions.

I had the problem about uterus turned upside down. Because of this condition, when the egg was fertilised, it wouldn't move into the uterus; it attached near the cervix instead. Then when the egg started to grow around the seventh month of pregnancy, the cervix was fully dilated, which indicated that the baby was ready to be born... The baby had a blue colour when it was born. I didn't hear any cries from my baby. (ID6-M-1-P. 1)

The second mother has a sixteen-year-old girl with severe cerebral palsy who is unable to speak. They use non-verbal communication such as smiling and eye contact. She believed that the health status of the baby was the main cause of her daughter's condition.

She was given saline solution for a few days because she had very low birth weight at birth...When she was three months old her body started to seize...The doctor told me that she got meningitis...After she went out from hospital, she still had a convulsion...The doctor said she had not only meningitis but she also had water in her brain which was known as hydrocephalus...In order to drain water from her brain; the doctor

inserted a tube from her brain to her abdominal cavity around four times a month-once a week. (ID2-M-1-P. 1-3)

While finding reasons and blaming initially arise following the birth of the baby, these thoughts and explanations remain in their minds and are revisited with expressions of suffering.

Suffering and blaming: Expression of suffering

The second concept in the subcategory ***suffering and blaming*** is expression of suffering. The participants express their experiences as suffering towards the particular situation. Most parents and grandparents mention that suffering comes into their families after a child with cerebral palsy has been born. Inevitably it has always come up in their minds since that time. Furthermore, they often experience a miserable feeling when they communicate with other people in society in challenging circumstances. Therefore, a sense of suffering comes both from themselves and from other people.

The concept of expression of suffering comprises four codes: *having questions in mind*, *unexpected condition*, *negative self-feeling* and *experiencing social disgust*. To start with the first code, *questions* come up *in* the participants' *minds* when they initially face the situation. The questions remain with them for a long time even though they employ scientific reasoning and their personal beliefs to answer such questions. The questions differ, depending on how participants become involved in the situation. Parents and grandparents keep thinking about the reason why it has happened to them and what is the cause of cerebral palsy, while siblings and other family members, who participate in the process of caring for a child with cerebral palsy, have questions about their responsibility and relationships with their families. In the meanwhile, siblings hardly ever talk to their parent/s about their feelings; a child with cerebral palsy, who is able to communicate with others, keeps asking parent/s and caregivers to explain her/his condition in order to clear up any questions which come to mind. The questions might be with the participants throughout their lives. An older sister of a child

with cerebral palsy recalled her experience of taking responsibility at a young age, as the main caregiver of her sister with cerebral palsy. She still has a vivid memory that she had to carry her sister everywhere, even to go to the toilet. Then, the sensitive question came up in her mind. She often asked her sister this question when she felt exhausted, but she has never let her parents know about it.

I thought she shouldn't be born...Sometimes, I asked her with emotion why was she born! "Why were you born?" (ID15-S-1-P. 1-2)

Participants, including children with cerebral palsy who face challenging circumstances always have *questions in their minds*. The following quotations from a family with a twelve-year-old girl with cerebral palsy who cannot walk, illustrate that while everyone in this family faces the same situation of living with a child with cerebral palsy, they hold different views about the situation. Significant questions, which develop from their perspectives, come into their minds. From the parents' perspectives, when they found that their second daughter had cerebral palsy, they tried their best to obtain treatment and to take care of her, and wondered why she could not walk. The child with cerebral palsy, who has two siblings who are normal, opens her heart to let other people know what she thinks about her situation.

(ID10) "Mom, why is it I can't walk?" I (mother) said, "I don't know either. I myself really want you to be able to walk but you can't do that. Why is it you can't walk, ID10?" (ID10-M-1-P. 15)

Meantime the oldest child thinks that her parents pay more attention to her younger sister and brother. She also thinks that her parents give her sister and brother much love, more than herself.

There is not enough love from the family. I think my parents pay more attention to ID10...when brother argued with ID10, they would protect ID10 by taking her side...I think that they love her because she couldn't do anything and the one that they love most is my brother who is the youngest child...It might be mother, because father told me that he loves us equally...they always bought things for my sister and brother. So, I would like to ask them how they love their kids. Is it equally? (ID10-S-2-P. 1-3)

All participants held the same expectation as other people that a normal and physically perfect child is the only one they want. They never anticipated that their baby would not be physically perfect. So, when the child was born with

cerebral palsy, they felt shock about an *unexpected condition*. Certainly, they felt very disappointed with the situation. That disappointment turns into suffering. The following quotation illustrates the experience of a father who has an eleven-year-old girl with severe cerebral palsy. He used the metaphor of boxing to explain his shock.

I can say because it is my real life. It suddenly came into my life so I felt perplexed, much as the boxer was stunned. I was confused. It seemed like I was punched till I could not stand. Then I was counted out around 5 or 8 counts. (ID13-F-1-P. 2)

The participants, particularly those who are parents, express their experiences in a sense of *negative self-feeling*, which is grouped into one of four codes of the concept of expression of suffering, such as hurt, sorrow, pity, worry, loneliness, run out of drive and courage, powerlessness and despair and so on. Then, I theoretically categorised these expressions of suffering into two sub codes: an early stage of suffering and an ongoing suffering. A sense of suffering in the early stage means the negative feeling of the participants when they faced the situation at the first time or whenever they have experienced challenging circumstances. Meanwhile, the stage of ongoing suffering refers to the participants always keeping the negative feeling in their minds. This sort of feeling might be with them as long as they take care of a child with cerebral palsy or throughout their lives.

In the first place of facing the phenomenon, the participants respond with negative feelings. It is not only the mother who is affected by this particular situation, but the father also feels like that. In the following explanations, both parents recalled their experiences with the feeling of an overwhelming sense of suffering.

At first taking a look at my son's picture that my wife sent me, I thought that he looked like a disabled baby. I kept thinking about that...I was sure that it was true when she sent his picture the second time. Then I was deeply hurt by my son...I felt running out of drive and courage. I totally felt powerless at that moment...I felt extremely powerless. (ID8-F-1-P. 14)

On the day that we knew what was wrong with him (after his brain had been CT Scanned) I felt like, my heart had dropped. I felt deepest sympathy for

him that he was born disabled; I didn't feel sorry for myself, not at all... I held him and cried in front of medication counter...I cried and cried from 7 a.m. to the afternoon until my husband came to pick me up. It seems like tears become blood. (Cries again) (ID6-M-1-P. 7-8)

As they care for their child with cerebral palsy, challenging circumstances unavoidably come into the participants' lives. It might be a normal situation that usually happens in their daily lives but, from their viewpoint, it is really hard to get over it. They keep thinking about themselves, and then compare their situations with other people who have normal children. They are very sensitive to the reactions of other people in society; they always feel a sense of *negative self-feeling*. A mother shared the depths of her despair when she initially faced the experience of having a daughter with cerebral palsy.

I was lonely when I was at home. I was dispirited and bored with my life. I was exhausted and didn't have any energy to work. So, I just lay quietly at home. I was in despair. It seemed that I had reached the depths of despair "Mod-ali-tay-yak¹¹". I lived in stress and sadness with my daughter at home... I thought it was only me who has a child like this... it seemed like a melancholy atmosphere. I myself felt gloomy...Nobody felt like this. I could not explain what this feeling looked like. (ID9-M&CP-1-P. 3-4)

One of the strategies to bring up a child with cerebral palsy is to enrol the child at a boarding school. However, facing this situation causes inner conflict and suffering. On the one hand, parents did not want to leave their children there because they were worried how their child would survive at the school without them. On the other hand, they were concerned about the future, so they wanted their children to study as much as they could.

(ID8's mother left ID8 at the boarding school)...I had never left my child. Even though I was worried about him, I wanted him to study. In my heart, I was deeply concerned about him. It seemed like I had reached my last breath. I didn't want to leave him...(on the way to go home) I cried from when I left his school until I nearly arrived at my home (around 2-3 hrs by bus)...The teacher told me that the child cried until he fell asleep. It made me cry...I missed him so much...My husband and I awoke at night, then we were talking and discussing about why this world is dark. It is really dark. (ID8-M-1-P. 7, 16)

¹¹ Mod-ali-tay-yak refers to a sense of hopelessness, lacking motivation to live

I felt very lonely when ID9 wasn't around. I missed her so much till I would go crazy. I would be worried about her whether she was warm enough at night. It was a torture when I was at home by myself. (ID9-M&CP-1-P. 3-4)

The participants, particularly parents and grandparents, experience ongoing suffering in their minds even though many years have passed since the child with cerebral palsy was born. It seems like this sense of feeling will be with them as long as they take care of that child. The following quotations illustrate parental suffering.

It is the feeling of suffering as deep pain inside...Oh! I don't know how much I have suffered as she was born to be like this. It is a torment. My face looks much more serious. I look older than my age...What is the reason of the suffering? It is too hard to explain. I only know I have suffered and nobody can understand me...As he is only once a year visiting us, so he (husband) doesn't understand at all about the torment of a mother's feeling when I saw ID9 tugging her legs on the ground...It is really painful that I can't compare it with anything. It started when she wasn't like the others. How many years was it then? ...since she was only one year old. Now she is seven years old. If I think about it, I will suffer every day. If I enjoy my work, I might forget it for a while...Oh! I am really upset with myself (that she gave ID9 birth on the road)...I didn't intend to make her to be like this. However, the sin will be with me forever. It seems like I was going to kill my own child. (ID9-M-2-P. 36-42)

ID9's father said that he had the same feeling as me. If he could change anything, he would. If cutting off his legs could make her walk, he would do that. He also wants ID9 to be able to walk. He felt sympathy for his daughter, too. (ID9-M-2-P. 24-28)

It hurts me when I heard ID5 talk...She talked about "today, it was athletic sports at the school, and I (ID5) won the race with the first place overall." She has an inferiority complex because she could not walk; but she tries to make up a story to let us know that even though she is in this condition she could do like others do...I was truly hurt from listening to her. I really sympathised with her...Okay, she could not walk, but she wants to join the activity with others...I worried about her. For others that might not be the case, but I do! ...I pity her very much. (ID5-F-1-P. 12)

A sense of *negative self-feeling* or suffering is found not only in parents but also in siblings who face challenging situations. An example is found in a thirteen-year-old child who has a twin brother with cerebral palsy. He shared his feeling, which he has never shared with his mother.

Who else is going to sympathise with him if even I who am his brother doesn't? I think it is bad luck having a brother like this. By that I mean bad luck for both of us that he can't walk and I am unlucky having a brother like this. (ID3-B-1-P. 12)

Having questions in mind, unexpected condition, and negative self-feeling demonstrate a sense of suffering which comes up from the participants themselves – an internal suffering. From the participants' perspectives, it is quite hard to live with society because other people do not understand their situations. Often they feel hurt because of *experiencing social disgust*. It is an external suffering which is an uncontrollable and inevitable condition.

I couldn't explain how the neighbours look at my son, ID8. So, I thought that I didn't want ID8 to play with their children any more...They didn't allow their children to play with him around two years because he is a crippled child. They called him in Thai "Ai Ngoy or Buk Ngoy"¹²...The way they said that about ID8, it seemed like he must be mad because what he said didn't make any sense. They thought ID8 didn't understand what they said, but he did...They thought that he has mental retardation... Once, I went to a normal school with him, many children had crowded around us so that we could hardly breathe. Then, he wanted to play with them so he crawled to them, that made them run away...Neighbours were afraid that their children would be mentally retarded like my son. (ID8-M-1-P. 19-21)

Sometimes, I would close the doors and windows then keep myself to myself in the house to stay with my daughter because I was afraid of other people, who would walk around there, might see us and ask "Why is your child like this? Were you a drug addict when you got pregnant?" I didn't want anyone to ask me these questions...It was shameful to have a daughter with this condition. I felt ashamed when I saw other children, who have the same age as her, who walked or ran while ID9 just crawled. Oh! Crawling. That was why I didn't want to live at my hometown. I didn't want to live there any more. I felt deep sympathy for her when she wanted to play with other children, when she kept crawling to them, then they ran from her!! (ID9-M&CP-1-P. 4)

While the participant above chose to withdraw from contact with society at that point in her life, other parents wanted their children with cerebral palsy to enjoy the activities that normal children experience, such as to go shopping; even though society does not provide facilities for people with disabilities, such as a walkway for disabled persons who have a wheelchair, and suitable public

¹² Ai Ngoy or Buk Ngoy is an impolite word to call a disabled person who cannot walk

transport. One mother with a seven-year-old daughter with cerebral palsy shared her experience of shopping with her daughter and her colleague (both work at the boarding school for disabled children) who has a twelve-year-old son with cerebral palsy. Both children have limited mental ability.

Once I went to the market with ID8, ID8's mother, and my daughter, ID9. ...I took ID8 and ID9 to wait for ID8's mother around in front of the fruit shop. It seemed like her shop's view was blocked. So, she reviled us "Too long to sit here! When do you want to leave from here?" ...We were beside the shop because there was an umbrella - which provided shade for the children so that it might not be hot for children...She should have sympathised with us, not disliked us. I think she was disgusted with us because ID8's mouth was full of saliva while ID9 was sitting in the wheelchair. That was why she didn't want us to be around. (ID9-M-2-P.8-12)

A fourteen year-old-girl with cerebral palsy who is a high-school student at the boarding school for disabled children shared her experiences of going out in public:

People looked at me as if I was an alien when I went to the market. Why did they have to look at me like that? I just walked a bit abnormally. They looked at me like they have never seen something like this before...I was very annoyed because my condition isn't bad, but they looked at me like I am some sort of alien or joker...One day; I went to my friend's house. We walked together and I held her arm because she has crooked arms and legs but she can walk. People looked at us then I told her that we shouldn't care what they thought about us. (ID11-CP-2-P. 14-15)

In addition to the experience of suffering described above, participants also described the burden of care outlined in the following section.

Suffering and blaming: The burden of care

The burden of care is the third concept of the subcategory ***suffering and blaming***. The participants who are involved in the process of taking care of a child with cerebral palsy shared their experiences of the burden of day-by-day caring for that child, which has adverse effects on their lives and those of other family members.

The concept of the **burden of care** consists of three codes: *effect on their lives and having health problem*, *effect on family and social relationship* and *effect on*

economic problems. Living with, and caring for, a child with cerebral palsy is depicted by participants as *never ending caring*. Usually, children with cerebral palsy have problems controlling their movements, so they need assistance to maintain their daily lives. Caregivers describe the burden of carrying on day by day caring for a child with cerebral palsy and the effect of that caregiving on their lives and their health.

Do you know it is really hard to take care of him? It would be OK if he were a normal child but it is never-ending-caring (Laeng-mai-lu-jak-leaw¹³). I have to take care of him all day and night. I could not go anywhere...In fact, he always goes to sleep with his mother so I do not need to take care of him at night time...I sometimes feel stressed. I would like to go out to somewhere else. Whenever we go out, we have to go together. I have no more time for myself. (ID3-BS-1-P. 1)

I couldn't go anywhere - even go out with my friends - because my mum wouldn't let me. I felt annoyed with her sometimes. (ID15-S-1-P. 2)

Even though I looked after ID10 as other children, she still cannot walk. I kept thinking too much about her until I could not sleep. (ID10-M-1-P. 12)

The burden of care of a child with cerebral palsy depends on the condition and the age of the child. It is logical that when a child with cerebral palsy grows up; he/she becomes bigger, and the main caregivers such as parent, grandparent, sibling and babysitter, get older and older. They have to carry on day by day caring for that child. As a result, they feel tired, exhausted and suffer from pain.

I am fed up with this, anyway I have to do it and stay here...I have back pain, waist pain, and also leg pain because of getting older. I have a lot of pain because I always bend down and look up when I take care of him. At night, I cannot sleep well because I suffer from pain. I have never slept well. (ID3-BS-2-P. 15)

The word "exhausted" means physically tired because I get older. She is growing up, thus she is bigger, which makes it difficult when I have to carry her. (ID2-M-1-P. 12-14)

An older sister, who has a fourteen-year-old sister with cerebral palsy, shared her experience as the main caregiver of her sister when she was young.

¹³ Laeng-mai-lu-jak-leaw refers to unfinished caring, never-ending caring

Previously, we did not have any babysitter; I had to carry her around. At that moment I was a small girl, then I felt she was too heavy for me. Oh! So tired. I carried her everywhere, took her to the toilet etc. Sometimes, I felt so very tired and annoyed. (ID15-S-1-P. 1)

Following the entry of a child with cerebral palsy into a family, *family relationships*, and *social relationships* gradually change. Having a child with cerebral palsy affects all family members and many aspects of family relationships such as the relationship between husband and wife, children and parents, and parents and grandparents. The argument between children and their parents develops from a sense of an unequal love, while the problems of husband and wife arise from the complicated conditions, such as suffering from having a child with cerebral palsy, obligation and responsibility, and economic problems. As the following quotation demonstrates, this phenomenon involves the *family's relationships*.

In order to clear up the problem, I have decided to get a divorce. I don't need to think about it any more. No more thinking...(As her husband tried to kill her son who is a twin child with CP.) If I could do it, I would kill him. But if I did, I would be in jail. It is not worth if to do that. (ID3-M-1-P. 5)

Since we knew that ID7 has some problems as a disabled child, we both have much more stress. Then, it increased our conflicts...when he came back from work with feeling exhausted and he saw ID7 to be like this, he kept asking about her. We worried about her that she could not get well (become normal). At that time, I had an argument with my husband about this issue. (ID7-M-1-P. 6-7)

This phenomenon also gets involved in the relationship between parent and grandparent because of the cultural obligation of caring and a sense of shame about having a child with a visible disability. A good example of this is the situation of a single mother. Her husband passed away then left two sons, and one daughter with cerebral palsy behind. It is too hard for the widow to bring up her children alone. So, she needs some help from the grandmother sometimes. Unfortunately, she has conflict with her mother because of societal attitudes to people with disability, the grandmother's concern about engendering social disgust and the mother's expectation that – consistent with the culture of obligation – the grandmother should help the mother to take care of her children.

As she shared her feeling,

On top of that, I am always in conflict with my mother about ID7...Sometimes neighbours visited us while we had lunch, then ID7 loves to make conversation with them by asking and drawing attention by scratching with fingers. At this point, my mother told me that she didn't want ID7 to do that because she was afraid that they might be annoyed and disgusted with ID7 as her mouth was full of saliva and she can't stay still...Our ideas are always contrasting...She asked me, "Am I not ashamed?" I knew why she thought like that... She was angry that I sent ID7 and her brothers to boarding school. But I have no choice, no one can take care of them, even her, my mother. (ID7-M-1-P. 24-27)

Participants who were the main caregivers of a child with cerebral palsy have to spend much of their time taking care of the child. Consequently, time to join in activities with other people in society is restricted. That is to say, it *affects* their *social relationships*. This point can be illustrated by the following quotations.

I have to take care of her all the time, I can't join the wedding party of my neighbours or take a trip with them any more. How can I go?...If ID5 heard about this, she would go on a hunger strike as she wants to go too...As she can't walk, so I couldn't take her to join any ceremony such as "Ngan Bua¹⁴", "Ngan Katin¹⁵" at the temples. Since she is here, I couldn't go anywhere, except somewhere around here, went only for 20-30 minutes, just to bring gift and say hello to the host...my neighbours would say, I have a baby, can't join their trip...I myself really want to join with them but still worry about her, I dare not leave her alone. (ID5-BS-1-P. 5-6)

We have to take care of her so we could not go out for long. I was in a hurry when I went out to somewhere because I have to keep watching her all the time. It is such a heavy burden. We have to make decision. We could not join social activity so long. If I went to a cremation, my husband would have to take care of her at home. (ID12-M-2-P. 5)

As a child with cerebral palsy needs special care, each family in this study has to have someone who can spend all their time taking care of him/her. Although most families send their child to a special school for disabled children, they still need the main caregiver to take care of the child at home. Consistent with the Thai culture of obligation (addressed in more depth in Chapter 5), a parent, grandparent or sibling would be expected to take responsibility for the child. For

¹⁴ Ngan Bua¹⁴ refers to the ceremony for someone becoming a monk

¹⁵ Ngan Katin refers to the annual ceremony of Buddhism

several nuclear families, hiring a babysitter was the solution to this situation. Whether the main caregiver is a family member, or a babysitter, the income of the family is affected. As a result, they inevitably run into *economic problems*.

All problems including about money come simultaneously. I keep thinking how can I get money and manage my salary for all purposes? Is it enough for pocket money of the other child who goes to school, milk for a child with cerebral palsy, and other expenditure? (ID3-M-1-P. 3)

Mostly, ID7's mother consulted me about her family and economic situation. She wanted to change her job because of low pay - only 2,000 baht with 300 extra, so 2300 totally (around \$ 92 per month @ \$ 1= 25 baht)...She has three children and her husband died...As people live with hope so she spent a lot of money on the lottery. But sometimes she lost the lottery money; she can't go visiting her children. I understand she has hope...hope to win the lotto...because she has no other income. (ID16-PTA-1-P. 6-7)

If you (ID1) could walk, I would be comfortable. I said to her "You see I could not work anything after you were born and you could not walk." It was really hard to live because of decreasing income. It affected our family. If I worked, I could help our family for the utilities including electric and water payment. It could help my husband on the other hand. At this moment, it is short. (ID1-GM-1-P. 17)

Conclusion

In this chapter an overview was provided of the substantive theory that represents the experiences of families living with a child with cerebral palsy. The basic social psychological process of *never-ending caring*, is able to explain, interpret and predict this particular social phenomenon. The theoretical proposition, facing the situation, describes how the participants in this study face challenging situations not only at the birth of a child with cerebral palsy, but throughout their lives as they take care of that child. Those challenging situations result in expressions of suffering and the experience of the ongoing burden of caring that make up the first category presented in this chapter: **enduring despair**. In the following chapter, the category **culture of obligation and responsibility** will demonstrate how participants learn to deal with the ongoing challenging situations.

Chapter 5

Culture of obligation and responsibility

Introduction

In the previous chapter, I presented an overview of the emergent theory, “the experience of *never ending caring* for a child with cerebral palsy” and the first core category, *enduring despair*, which is located in the first process of the BSPP, facing the situation. In this chapter, I introduce the second core category, *culture of obligation and responsibility*, which is an imperative factor in moving to the second process of the BSPP, *learning to deal with the situation by themselves*. This core category demonstrates how the participants deal with challenging circumstances, and how their beliefs, and a culture of obligation and responsibility underpin their responses to situations.

Culture of obligation and responsibility

The second core category, *culture of obligation and responsibility*, and the theoretical proposition, *learning to deal with the situation by themselves* (Table 5.1) describe the underpinning of the participants’ actions and notions toward this particular situation, which draw on Buddhist philosophy and the Thai cultural context. That is to say, these imperative factors exert a strong influence on the sense of obligation and responsibility of parents and family members toward taking care of a child with cerebral palsy. Some participants have their own ways to deal with challenging circumstances in order to maintain their lives and to live with their conditions with a sense of tranquility.

This core category has a sub-category, *having faith*, which consists of three concepts: being Buddhist, personal beliefs, and ‘obligation and

responsibility’. These concepts explain what lies behind the participants’ behaviours in challenging circumstances.

Table 5.1 Culture of Obligation and Responsibility the Second Core
Category of *Never-Ending Caring* for a Child with Cerebral Palsy

TP	Core categories	Subcategories	Concepts	Codes
Learning to deal with the situation by themselves	Culture of Obligation & Responsibility	Having faith	Being Buddhist	<i>Having a sense of acceptance</i> <i>Practising religious precepts</i> <i>Making merit</i>
			Personal beliefs	<i>Performing sacred rituals</i> <i>Belief in fortune-teller</i> <i>Having good luck</i>
			Obligation and responsibility	<i>Obligation of care</i> <i>Depending on family</i> <i>Reciprocity of care</i>

Having faith: Being Buddhist

The first concept, being Buddhist is an important underpinning of the participants’ notions. The participants employ Buddhist philosophy to deal with, and then set their attitude towards, the challenging circumstances that arise from having and living with a child or a sibling with cerebral palsy. The codes, which support this concept, are *having a sense of acceptance*, *practising religious precepts* and *making merit*. The first substantive code, *having a sense of acceptance* encompasses three sub codes: thum-jai, plong, let it go-let it be. The participants normally use the words thum-jai and/or plong in terms of acceptance, particularly when they face challenging circumstances in which they cannot change anything about the situation they face. Therefore they resign themselves to the inevitable consequences of the situation, which might be driven by karma. Therefore, whatever will happen to them, they just let it go and let it be since it seems rarely to affect them. These thought processes are internal factors which encourage the participants to face the situation with a sense of

obligation and responsibility to take care of a child with cerebral palsy throughout their lives, as the consequences of karma are reaped in the present life.

Participants use *thum-jai* and *plong* as psychological tools for resetting their mind in order to be able to live with their conditions. As challenging circumstances or situations recur throughout the participants' lives, they need to use these imperative factors, and their other beliefs, for dealing with – and maintaining – their lives as normal. *Thum-jai* and *plong* are personal processes, which need individual capability to realise the fact, including the consequences of their conditions, and then they will eventually reach a sense of peacefulness. In this study, two stages of acceptance were identified: in the initial phase, and after learning about the situation. Some participants are able to set their attitude up even in the first early stage of facing the challenging circumstances with an overwhelming sense of suffering. Others need more time to consider the facts, and the consequences of their situation before they can accept it as it is.

The following quotations demonstrate how parents deal with their situations by setting their attitude to accept challenging situations at the outset, with fulfilling an obligation and responsibility of parenthood. In the first excerpt, a mother described how her daughter had hydrocephalus when she was a baby. In order to drain fluid from her brain, the doctor had to insert a tube from the brain to the abdominal cavity. The tube repeatedly obstructed, and was reinserted. Finally, the mother made an important decision that affected both her daughter's and her own life, based on a realistic view of her daughter's health problems. The Buddha teaches followers to see the truth of problems or situations with a realistic view, when he says "If anything at all, it is realistic, for it takes a realistic view of life and of the world. It looks at things objectively (*yathabhutam*)" (Rahula, 1962, p. 17). He teaches followers to comprehend and realise the fact of "things" in the world, then to accept them as they are.

...So, I said to the doctor "It doesn't matter. I've already done *thum-jai*." He told me that if the parent wanted me to remove that tube, he was going to do it. Then it was going to affect the baby, such as head enlargement

and other conditions...I said it was OK. I did thum-jai already...Thum-jai means...it (this situation) has already happened. (ID2-M-1-P. 1-3)

The following quotation reveals the experience of a father who was working abroad while his wife gave birth to their son. He expresses his feelings with a sense of suffering about having a baby with the condition.

The first time I saw his picture, I didn't do thum-jai toward what it showed. But when I looked at it the second time, it became clearer so, it affected me much more deeply. This time, I was more convinced and I took it to my friends to look at. They said my child was disabled. Then I telephoned home to ask my wife about it and she said that our child was not completely healthy and suffered what is called delayed development. As soon as she said that, my thoughts swung straight to the point: that he was our child. I realised that he is my son, even if he had the condition, then I made a decision to do plong because I realised the fact that he could not be normal. So, I did plong. I also did thum-jai that it is an inescapable truth as he is our child, and although he is like this, we could never abandon him. (ID8-F-1-P. 11-14)

Similarly, a mother of a twelve-year-old son with severe cerebral palsy described an overwhelming sense of suffering, expressed as crying tears, which seemed to be blood, when she first received the result of a CT scan of her son; then she set her attitude to accept the situation.

So, I thought about it and realised I had to turn around. Crying was not helping. I had to fight from now on, for my child in everything. I had to work for his benefit. I thought of this and promised to myself that I was not to cry any more, but had to accept this condition and then care for him in the best way possible so that he could develop to the top of his potential. (ID6-M-1-P. 8) ...If we can do thum-jai, we will be happy because our child can depend on us...Must have courage and accept the situation of my child, that this is how it is...my child is like this and there is no shame. I accept him completely without any condition because he is mine born to me. It does not matter what his condition, I am glad he is mine. Therefore I accepted him as he is. (ID6-M-2-P. 1-2)

A father shared his experiences of bringing up an 11-year-old girl with severe cerebral palsy, in the absence of her biological mother. He articulates the obligation and responsibility of a father towards his daughter.

I must do my obligation to the best, as much as I can. It is my obligation like working...It is my "obligation and responsibility" towards my child like other people do...As I said thum-jai meant I did it as an obligation without any error, such as when she got sick, I have to take care of her. In the

first place, I was very discouraged about why my child was born to be like this. After I thought really hard, I found that the only way is I have to do the obligation to my best... Someone would ask, "What's wrong with her? Oh! She is a crippled child". It's an obligation of a father. I can't run away from this reality. I have to accept it...we can lie to others but not to ourselves. It will be useless to lie. So, I may not do my very best, but I will always maintain my obligation. (ID13-F-1-P. 2)

Even though the participants have already done *thum-jai* and/or *plong* when they first faced having a child with cerebral palsy, they need to maintain the attitude to live with their situation as normal. It is not only a sense of obligation and responsibility, the philosophy of Buddhism and other beliefs that are involved in the participants' notions for accepting a "thing", but the "thing" as a challenging circumstance itself also influences the process of acceptance. That is to say, the parents gradually realise the facts about the health condition and the progress of development of the child, which takes time; finally, they accept it, including the consequences of their conditions after learning the situation. Thus, the mother of ID2 expresses acceptance, although her child, now 16 years old, is able to do nothing except cry and smile.

Well, ID2 has already been born like this. It's an established fact so I care for her the best I can. The event is in the past. It's happened and she will be like this all her life. So, I accept the truth that there is no way that she will one day stand up and run around like other children. But I also accept the realities of her condition and that I have to do everything for her. Presently, I am happy living together with her. I do my best to give her all the happiness I can, and accept everything about her as she is. (ID2-M-1-P. 1-3)

Another father shared the notions about how he realised and accepted his life situation and that of his daughter [his wife died of lung cancer shortly after the birth of his daughter, who has cerebral palsy].

Basically life is life...Well, human beings, when we are going to be born then we will be born. When we have already been born then we must do, and live to follow the ways of our lives. There is no one who is different from others in this case. Why we have to think that it has to be us! The ideas are wrong, because the things that have happened to us are human nature...when we are already born to have a life then we must do our best to manage and follow the ways of life...Because of it, she must bear to have that kind of life. (ID5-F-1-P. 9-10)

A single mother of 13-year-old twins [the younger one has cerebral palsy] describes acceptance of the latter condition as a predestined situation.

I had already accepted him...By that I mean, in my dream, it seemed like ID3 asked me to stay with...Yes. I have a clear memory about the dream that he asked to live with (me)...the angel didn't finish making his legs. Then, he ran even though his legs were still wet. The fortune-teller told me that it is Karma which I did toward him, the same as the monk said. That is why he has been born and lives with us. He comes here as he asked. (ID3-M-1-P. 6)

A number of participants employed the concepts of karma and reincarnation to explain their situations, believing that cerebral palsy is the result of their volitional actions in previous lives. Consequently, they do *thum-jai* and/or *plong* to accept the consequences of karma from past actions: in the present or previous lives. From their perspectives, taking care of the child is the way to pay back their karma, even until the end of their lives. Thus, these participants totally accept the fact, which relates to the situation, by letting it go and letting it be as the consequences of their karma. At this point, they get ready to encounter challenging circumstances, so, whatever will happen to them, it might not affect them any more.

One grandmother explained her thoughts about being the main caregiver for her grandchild, a four-year-old girl with severe cerebral palsy, who has low vision, hearing loss, and a movement problem – she cannot sit by herself. The girl cannot speak any words, so she uses non verbal communication with others, such as smiling, laughing and crying. Besides caring for the child, the grandmother maintains her daily routine doing jobs such as sewing [on contract], housework, laundry, cooking and feeding the domestic animals – cattle, chickens, and ducks. She rationalises and accepts her situation completely, drawing on a Buddhist perspective.

In the previous life, I maybe used to order her to do something, as an employer. As a result, in this present life, she might treat me the same way. Therefore, I realised the fact, which I accepted emotionally as the cause or consequence of this situation (*plong*). (ID1-GM-1-P. 14-16) ...I think I have done it the best. So, what is going on in the future - it depends on her karma, like let it go, let it be. (ID1-GM-3-P. 6)

The grandparents of ID1 utilise a similar mindset to resolve the blame they attribute to health personnel and the treatment, for their grandchild's condition.

It would not have much more benefit for my granddaughter, if we had sued them... if we had sued them, my granddaughter would still stay in the same condition like this. So, we decided to do nothing, let it go. Why should we do that...It is useless to sue them. We might waste our money...My granddaughter would not get better. So, we just let it go... (ID1-GF-1-P. 26)

The aunt of the 13-year-old twin boy with severe cerebral palsy, who has been his main caregiver [babysitter] since he was young, also employs Buddhist philosophy to accept and maintain her situation.

I have already set my mind as thum-jai because I have no choice. Let it go. I have to accept it. There is no choice. How should I do? I could not go (to work) anywhere because there is no one to take care of him. So, I have to accept it and I have to do thum-jai. That is what I can do. Every day, I have to do this as my obligation. I do not want to think too much about this; I just try to do it as much as I can. (ID3-BS-1-P. 2)

A mother shared her understanding about her situation [she has an 11-year-old girl with athetoid quadriplegia who has very low vision and can only cry and smile].

Since ID12's conditions do not reach 70%, I have to do plong that we must take care of her until we die. So, I have done plong in which the "thing" that will happen depends on karma and the fate of the child (Let it go-let it be). (ID12-M-1-P. 4)

The next substantive code of the concept being **Buddhist** is *practising religious precepts*. The Buddha offers Buddhist codes of ethics for all human beings, in particular for Buddhists who follow the doctrine, to behave virtuously then live with others – including animals – in a sense of peacefulness and for the betterment of society. The Five Precepts is the basic Buddhist code that directs lay followers to refrain from morally bad behaviour, such as killing any living beings, stealing, sexual misconduct, lying, and using intoxicating liquor. The Eight Precepts offer more ascetic lifestyles for Buddhist lay persons who wish to practice more strictly. In addition to the basic precepts, followers are instructed to abstain from eating at an inappropriate time, from doing and attending entertainment performances including wearing and using decorative accessories, and from luxurious places.

The aim of the precepts is to help Buddhist laity who undertakes to follow these training rules and live without a sense of remorse (Wikipedia Website, 2007a, b).

The participants in this study follow the Buddhist precepts in order to release the severity of their karma from a previous life in the hope that the condition of the child with cerebral palsy will improve. Following the precepts releases their tension, and they reach a sense of peacefulness in their mind even though they have to carry on taking responsibility for the child or sibling with cerebral palsy. The following quotation illustrates how the participant deals with the situation by practising the precepts.

After the ritual was performed, things got better. I as mother had to abstain from all meat and practice the precepts, and the father had to abstain from eating beef ...In other words, I follow the Eight Precepts of not having sexual contact with my husband for the period of abstinence from meat, not killing any animal, not drinking whisky, or beer, not smoking, avoiding adulterous relations and so on. I have kept to this lifestyle for six years now, from the time our daughter was three or three-and-a-half years old. (ID12-M-1-P. 8-11)

In addition, most participants adopt the Buddhist practice of *making merit* – the last substantive code of the concept being **Buddhist**. Consistent with Kammatic Buddhism, Theravada Buddhism is concerned with merit-making for a future birth in the next life (Wikipedia Website, 2007c). The term “merit”, in Thai “bun”, refers to good karma or significant kinds of wholesome action in which the Buddhists have a specific purpose to gain good results in the future whether in this life or the next life. It is similar to planting seeds then expecting their fruits in the future (Gethin, 1998). Participants try to create meritorious actions to release the severity of their karma and in the hope that the condition of their children with cerebral palsy will improve – to a stage where they will be able to take care of themselves. The following quotations demonstrate how the mothers carry out their merit-making activities.

I try to make merit and to act virtuously (*Tam-bun*¹⁶ and *Tam-kham-dee*¹⁷). I give clothes to blind beggars. When I give food to the monks, I also plead by doing *Kaod-num*¹⁸ to *Jow-kram naay-wen*¹⁹ for my departed loved ones whom I may have harmed, and animals that I may have mistreated in my previous existence. I have no idea what I have done in my past lives, but I ask that the present adversity be lightened, and that ID12 will be enabled to help herself. We reach out to others too, for example, on her birthday ID12 made merit, buying 10kg of oranges and ice cream, which cost 600 baht to treat the disabled children at the school. Again, when somebody dies without relatives, we donate 100-200 baht to buy a coffin in support of them. (ID12-M-1-P.5-6)

I always make merit such as going to the temple and offering food to the monks, to follow *sila*²⁰ (the Five Precepts). Sometimes, I was to be the host for offering food to the monk (*Pra-tu-dong*²¹) who is on a pilgrimage. And, I also used to be the host for ordination of a child monk. (ID6-M-2-P. 6)

I had the opportunity to participate in merit-making on the Buddhist Lent Day at the temple; I joined the activity as a participant observer by offering food to the monks, praying the Buddhist doctrine, listening to the teaching of the monk, and having breakfast with ID3's mother and other people at the temple.

¹⁶ *Tam-bun* means to make merit or merit-making

¹⁷ *Tam-kham-dee* means to do good deeds

¹⁸ *Kaod-num* refers to a ritual to send the merit to the spirit [departed loved ones or Jow-kram Naay-wen] by pleading with religious words while pouring the water

¹⁹ *Jow-kram naay-wen* refers to the spirit of humans or animals which were mistreated in the previous life

²⁰ *sila* refers to the precepts

²¹ *Pra-tu-dong* refers to the monk who is on a pilgrimage

7:20 a.m. 21 July 05 at ID3's house, Khon Kaen province, Thailand

I went to ID3's house at 7:20 a.m. since I made appointment with ID3's mother to go to the temple. The mother and her neighbour, who is an old woman, prepared some food, water and the special things for offering for the Buddhist Lent Day, such as a pair of big candles, a pack of dark yellow towels. She looked familiar to ID3. At that time, ID3 was sitting on the floor with a chin-chest position in a sleeping suit. He looked unhappy. His mother told me that he would like to go with us. He was not allowed to go there if his babysitter (aunt) would not go there. So, he was crestfallen. I went to the temple with ID3's mother and the neighbour. This is an important day for Buddhism so there were too many people in the temple. The neighbour told me that ID3's grandmother just passed away last year. They (ID3's family and the neighbour) always go to this temple. I observed that the mother seemed familiar with ritual activities of Buddhism. After making merit, we had breakfast at the temple with the others. They showed me the important place of this temple. We came back home around 9:30 a.m. I met two boys who were playing computer games. One of them is ID3's brother. Then, the mother allowed me to interview her while ID3 sat there. I found it interesting that she mentioned about the notion of ID3's brother that he was not ashamed of having a brother with disability. I was really interested in his thoughts. So, I asked her to interview the boy later if he is available from his study. At this point, I would like to interview him next time. What is going on with him when he has a brother with CP? I will ask him to explain more about the notion. And, I also would like to interview the neighbour about how she got involved in this family.

Today, I as the participant observer learned more about the experience of this family through the Buddhist activity which is the way that this family chooses to deal with their situation.

Figure 5.1 *Theoretical field note of making merit with ID3's family*

Another mother of a sixteen-year-old girl with severe cerebral palsy had a different view of making merit. She undertook meritorious actions as a social activity and to make her daughter feel happy – not because of karma and the Buddhist spiritual life at all. As she shared;

Tomorrow I will take her to make merit at the temple. She likes going to the temple. There is a monk who keeps an eye out for her to sprinkle holy water on her, and she simply loves it...Rather, ever since I did thum-jai, I have taken my daughter to make merit and be involved in the very best activities we can. Taking her on merit-making trips is like giving her what everybody else has. It is social action. I don't have any other objective than this, because I have no expectations that the monks will heal her. They are not able to make her run, walk or speak. My only expectation is that when we go there, she will like it. As soon as I tell her, "ID2, we'll go to the temple today and offer gifts to the monks" she will be glad. As soon as we stop the car at the temple she is excited. She loves making merit and giving alms. But not just at the temple. I also take her to the welfare home, name *Baan Can Tong*, in order to donate pampers or money - 100 baht or so - and say, "Now, ID2 how about giving these to the children who don't have any, who haven't had the opportunities we have?" I think that these activities are the kind of social activities which ordinary children engage in, and if she goes out and gets involved, she will grow to understand that she is a member of this society and must live in it along with everybody else. (ID2-M-1-P. 2-4)

These substantive codes demonstrate how the Buddhist philosophy plays an important role in the participants' lives, and how they employ the ways of Buddhism to deal with challenging circumstances in order to maintain their lives as normal. In addition to Buddhist beliefs, participants also described personal beliefs they used to deal with situations in their lives.

Having faith: Personal beliefs

The second concept, which supports the subcategory ***having faith*** is **personal beliefs**. This concept encompasses the substantive codes *performing sacred rituals*, *belief in fortune-tellers*, and *having good luck*. Buddhism, particularly the concepts of karma and reincarnation which are derived from Brahmanism, a religion which originated in India, has had a strong influence on Thai Buddhists' beliefs. Furthermore, Thai Buddhism is heavily influenced by traditional beliefs, in regard to ancestral and natural spirits which are passed on from generation to generation. These traditional beliefs are held by lay people in particular, who cannot reach the essence of Buddhist principles and its philosophy. Consequently, both Buddhism and traditional beliefs play an important role in ways of managing and dealing with challenging circumstances of many people in Thai society, including some participants in this study. Some participants have a strong faithfulness toward sacred things and engage in *performing sacred rituals* to ask for help from the spirits.

I went to the spiritual house since I am familiar with *chao tee*²² (the sacred thing who protects the land) and I could contact with them. At that place, I started to light incense in each of the incense burners. Then, I talked to the spiritual grandfather, "*Pu*"²³, as my little granddaughter has already been born with many kinds of diseases, could you please help her?". I lighted incense in all the incense burners. At that time, I made a vow, "I will show you my granddaughter, if she would recover from all her health problems. Please save her life and do whatever you can do to help. Furthermore, please make her to be a healthy girl. I intend to bring her up throughout as all her life as I have said." Since that time, I have lighted the incenses both inside and outside my

²² *chao tee* refers to the spirit who protects the land

²³ *Pu* refers to grandfather; in this sense means the male spirit

house (See Picture 5.1). I have also respected them at the hospital. I would like to do this ritual activity until she gets well... I trust in faith rather than in people. (ID1-GM-P. 6-7)

She has had 8 operations, and has always had infections. She almost died, passing into shock several times. The only thing I have done is to request a nun, name *pra'mae ongtumm*, who has kept the Buddhist precepts and a vegetarian for 30 years. She comes from Taiwan and did this for me. She is celibate, never having married. I said, "I have an only daughter who was born with the condition. My wish is to have her live a long life with me." I petitioned her like this...and lit incense right outside the house. She improved. I gave her some sacrificial fruit to eat - the fruit we had used to make merit. I had to offer 200 baht as a meritorious gift to release my bad deeds (*thi-baap*²⁴) for the benefit of my daughter, and to extend her life. I burned a paper with her name on it at the base of the earthenware pot and the nun also placed a ceremonial spot on her forehead...Our child is like this and I think it must be because of my past incarnations. So, I seek the help of sacred things to release us from bad luck (*khod*²⁵) and the retribution of evil deeds in a previous life (*vi-bak-kram*²⁶). Someone advised me that it might be my karma in the previous life and they urged me to release bad deeds (*thi-baap*) both mine and my daughter's. So I did and I also released living creatures. I did it to free the significant animals such as cat-fish, eels, tortoises, and freshwater snails, and then I did *kaod-num* to send this merit to *jow-kram naay-wen*. The snail is to symbolise getting rid of bitter feelings which are not healthy, so that misfortune and sadness are carried away. The eel is released in water to carry away unhelpful things in its sliding, slippery and flowing motion. The catfish symbolises strength to contend with and to overcome obstacles and helps us to prepare to fight. And the tortoise lives a long time. The whole ritual releases both my evil deeds and my daughter's also, and lightens the weight of the retribution. If we do these things, people said things will improve. It may be that I incurred debts with ID12 in my previous life and she has come now to demand repayment. But she also has her own karma and has come like this demanding what is due. So in this life, may we do things which are good in order to respond like that. Care for her in the best possible way, to see the doctor and to keep her well, also to feed her food and milk. Release her bad deeds as well as my own, and lessen the weight of our adversity. (ID12-M-1-P. 4-6)

Oh, I avail myself of everything. If I think I can do it, I will use it. I took my child to Chumpae District to see a monk there. I presented my child to the

²⁴ *thi-baap* means to release the bad deeds

²⁵ *khod* or *khod kram* refers to bad luck

²⁶ *vi-bak-kram* refers to the retribution of evil deeds in a previous life

monk to reckon as his own and then performed a ritual to cut the karma (*Pi-tee dutt Kram*²⁷). I followed what others had said that if you hand your child over to a monk, then things will get better. (ID6-M-2-P. 6)



Figure 5.2 The burner incense in front of ID1's house

Following the birth of a child with cerebral palsy, participants also sought the advice and support of fortune-tellers who are able to tell them about prophecy, including something that might be the cause of the situation, and give suggestions to improve their conditions. When participants *believe in fortune-tellers*, they pay attention to follow the suggestions in order to release their karma and to succeed in an ultimate hope that the condition of the child will improve. A mother described consulting a spirit healer who advised her to follow Buddhist precepts.

²⁷ *Pi-tee dutt Kram* refers to a ritual to cut the karma

He is a spiritual healer (*nung tang nai*²⁸) who can heal diseases...This is what he told me, "It is because of mother's *karma* and the child's *karma*. The *karma* of the mother and the child have met, and therefore the child has to be like this...he suggested to me to practice the precepts, to make substantial acts of merit, to do meditation, and to say a prayer. He said these will make my heart merciful and joyous. When ID6 was a child, I could do meditation. I did it every night. (ID6-M-2-P. 8)

Some participants described *having good luck* that was attributed to the child with cerebral palsy. Several participants, especially parents and grandparents, reported experiences that they could not explain in any other way. The feeling of having good luck encouraged them to take care of the child over the long term. Some participants, but not all, attributed the good luck to Buddhism and Chinese traditional beliefs.

I am committed to caring for him and loving him and since he was born, my life has improved. Have you seen what the Chinese do with a disabled child? They set him down in front of the house in the same manner as *Nang Kwak*²⁹. The Chinese believe in this. I mean that I have a disabled child, so our lives can be improved. For instance, I have enough money to come and go on (though I am nowhere near being rich). From time to time, we have money given to us. Suppose we are completely without food in a month when the bills are too great, we may mention to someone that we have no milk for my child, and we will be given it. I often ask my colleagues for a loan. Well, I am able to have a house to stay in even though my monthly income is about this much...about my work responsibilities they seem to have improved. If I did not have the child with this condition, there is no way I could shift (from Kumphawa district). This is the important truth about having him. (ID3-M-1-P.8-9)

The Indian guy said "ID1 is a special person who has a virtue (*Khon-mee-boon*³⁰)". He also told me that I should bring her up the best, then I will be rich shortly...If we looked after her in the right way, we will get rich. At first glance, he said she is not an ordinary person but she is a virtuous girl. (ID1-GP-1-P. 6)

²⁸ *nung tang nai* refers to sit in meditation in order to prospect horoscope

²⁹ *Nang Kwak* refers to the Thai traditional Goddess who draws more people to support your business

³⁰ *Khon-mee-boon* refers to a special person who has a virtue

Other participants credited the child with cerebral palsy as bringing them luck, without any reference to religious beliefs. Belief that the child brings luck supports the decision of parents and other caregivers to devote their lives to bringing up the child despite the experiences of never-ending caring that such a decision entails.

(GF) We won an illegal lottery several times after she was born. My wife won many times for the small prizes (of the illegal lottery) because she bought small ones...(GM talked to ID1) Shortly, I (GM) will win a great prize of lottery for bringing you up. Is it right, baby? Normally, we buy bananas for ID1. My wife told ID1 that, "I have no money to buy any banana, baby." After that, she won the illegal lottery in the next few days. (Laugh) I (GM) said to ID1 "We have no money to buy bananas, baby." Then I won a small prize around 500 to 1,000 baht. It was enough to buy some bananas and other things...(GF) It is really funny that we often won the lottery when we were broke. I realise that it might be caused by her, my granddaughter. (GM) Soon, we will be lucky in a big prize, baby. (GF) She gives us luck. That means she helps us to win the lottery. (ID1-GP-1-P. 6-8)

I think ID2 tends to be lucky. That's what I have personally concluded. The more you encounter it, the less you are able to explain it. It is like receiving help when you are stressed or desperate. For instance, because of her health condition, she had to have a suction machine since she is unable to help herself at all. How gloomy I was! A machine cost ten thousand baht. How could I possibly get one? At that moment, one was donated through Social Welfare. I reckon it was good fortune...Another example is the link we have to win lottery. When we have no money, we always win the lottery. ...So, I feel that when we are together, we are free from problems and trouble. It is a belief I have that we will not have destructive issues in our lives...And the babysitter we have is the last of her kind. There are no more like her. She is more special than other people, and unique. There are actually no more babysitters like this one, who has been here for 13 years, loving our child this much. Yet she is not a relative of ours. So, I believe it is good fortune, or fate shining down on us, a blessing. I see this as compensation for us, and what I can say as *kum khoon*³¹. These are the things that I cannot explain. (ID2-M-1-P. 16-19)

I won the illegal lottery around 9 times. I thought that it might be because of ID12, who helped us. She also helps us to have our own house and to have a

³¹ *kum khoon* means to support

better life. In the past, we have the land, but we didn't have any house. Now, we have both land and house. (ID12-M-1-P. 8)

These personal beliefs play an important role in fostering acceptance of responsibility for taking care of a child with cerebral palsy.

Having faith: Obligation and responsibility

Obligation and responsibility is the third concept of the subcategory ***having faith***. Buddhism has long been integral to the Thai culture as it underpins the way of life, attitudes, and codes of behaviour of Thai, at both the family and society level (Limanonda, 1995). This concept clearly demonstrates how culture plays an imperative part in caring for a child with the condition. Initially, to understand the **culture of obligation and responsibility** in a sense of the Thai cultural context, it has been said that:

Perhaps the best way to comprehend Thai social values is to focus on its basic unit, the family, and in particular the rural family in its typical village setting. Generally this will be an extended family, with several generations living under one roof, or at least under several roofs within the same compound; and it is here that the Thai child learns codes of behaviour that will guide him throughout much of his later life,... (Thailand in the 90s (Revised Edition), the National identity, Office of the Prime Minister, 1995, p. 106)

Consequently, Thai people are traditionally inculcated with a sense of responsibility, such as doing housework and being a participant in taking care of younger siblings, particularly when parents are at work, in early childhood. The most important issue is that Thai children are taught to look after parents in their old age for repayment of the debt of gratitude, or their goodness. The prime moral responsibility, which is a prominent feature of the Thai concept of family, will be with Thai children throughout their lives and will be passed on to the next generation (Choowattanapakorn, 1999, p. 97; Limanonda, 1995, pp. 12-13; Thailand, the National identity, Office of the Prime Minister, 1995, pp. 106-107).

My analysis of the thoughts of families who have experienced living with a child with cerebral palsy suggested that the concept obligation and responsibility comprised three substantive codes: *obligation of care, depending on family*, and *reciprocity of care*. The following quotations illustrate a sense of obligation of care of the parents.

I have to be with my family. As my son, ID3, was born to be like this so I have to *thum-jai* about taking care of him. I couldn't leave him out like a lone dog, as other people did. I have to take up my responsibility, to earn money for bringing him up... Since he was born I realised that he would be a big burden to me as I knew that he would not be like a normal child, he will be a special person. However, I have to take care of him...his father abused him by crushing on his tummy and pressing a pillow on his face, he wanted ID3 die then ID3 would be no more a burden. I cannot do that. (ID3-M-1-P. 5)

Well, I think it is really normal to have such a feeling between father, and daughter. As a father, I think it is my obligation to give my full support in raising my daughter...I take care of her since then to now. I give my best to look after her, and never think of her as a trouble for my life. I have to do everything possible for my daughter. It is okay if I have to be starved, but my daughter must not be hungry. My daughter must be happy...This is my child and she is only my child in my mind...When she was already born to be my child, then I must do my best for her. (ID5-F-1-P. 1, 6, 10)

I had already created her life, so I have to take responsibility for this. I am a creator of her life. Is it right? Thus, I have to take care of her. I could not abandon her like other parents. (ID11-F-2-P. 15)

It is not only the biological parents who have this sense of responsibility, but a step-parent also reported this feeling.

As she was already born to be like this, we cannot abandon her. If we would do that, we were not good parents. I think we have to bring her up until...as long as she can survive. (ID1-SF-1-P. 10)

Many participants, who were the main caregivers of children with cerebral palsy, shared their notions regarding their lifelong commitment to the care of the child. A single mother of three children – two boys and a seven-year-old girl with spastic diplegia - described her situation:

However, it is impossible for her to become normal like us. And the ability of her cognitive thinking is slow. So, I have to look after her all of her life. Taking care of her forever. (ID7-M-1-P. 31)

A grandmother, who has provided care for her four-year-old grandchild since she was a baby, expressed her commitment to ongoing care as follows:

I think I will take care of her like this until the end of my life. I can say that until my last breath. (ID1-GM-3-P. 6)

A step-mother who has to take care of her step-daughter, [an 11-year-old girl with athetoid quadriplegia], explained that her husband has to work and the great grandmother, who formerly cared for the girl, died at the age of 84, so the step-mother had to quit her job to be the main caregiver [day and night]. She tries to do the best for this obligation since she loves her husband.

I seem to be her mother who has to take responsibility. I am in a hurry when I went to somewhere else...As I seem to be her mother, so, it is my obligation. I have to do my best as far as I can even until she dies or I die. (ID13-SM-1-P. 3)

The following quotations explicitly illustrate the Thai culture of obligation for caring a child with a disability. The predominant feature of the obligation is the hierarchies of responsibility. In the first case, after retirement, the grandfather became the main caregiver, since she was a baby, of a 14-year-old granddaughter with spastic diplegia. He expressed feelings of worry about the future of his lovely granddaughter and his attempts to ensure that the next generation would pick up the responsibility for caring.

If she could walk, then our problems are over to some extent. Then, she might look after herself. If she cannot walk, I told everyone, whether it's her older sister, or her brother or anybody else, "*Do not neglect her, ID15.*" (He spoke seriously and loudly.) I told them all, whenever their mother, and I had gone, the rest of us should take care of her. *It is absolutely imperative that you all do not neglect her.*" I insist on this. Look. When I talk about this, I feel... (tears well up). My heart goes out to her. When I told her brother, who is studying at primary school, "Do not ever neglect your sister; ID15, will you?" then he gave me his word "No grandfather, No grandfather." Her eldest sister also gave me her word of honour "Please believe me, grandfather, I won't neglect her one little bit". (ID15-GF-1-P. 9-10)

The grandmother, who had been the main caregiver since he was a baby, of a 13-year-old twin grandson with athetoid quadriplegia, passed on the important obligation of caring to her daughter [an aunt of the boy –a single woman and unemployed].

When grandmother was dying she pressed me, "You must look after ID3. Don't ever neglect him because he is your nephew." I told her "I am not sure that I could take care of him so far, mother." She had looked after him even when he was in the womb way back. She brought him up. I can say that she took care of him since he was born. So, she was truly concerned. (ID3-BS-1-P. 6)

Significantly, a sense of family obligation occurs not only throughout a lineage, but it also extends to persons who are not relatives. A babysitter, who has been taking care of an eight-year-old girl with spastic diplegia for more than five years, shared her worry about the girl. The babysitter has taken care of the girl [since her mother died of lung cancer when the baby was one month old] like one of her nieces and the girl has lived with her and sleeps with her at night. Significantly, the babysitter passed the obligation on to her daughter to look after the girl further.

Then, I said to my daughter, "You will have to look after ID5, because I will not be with you any more and her father will not take her with him. You should look after her. I take pity on her. We look after even dogs. Well here, we look after a human. We also earn money". That I said. (ID5-BS-3-P. 10)

Traditionally, the obligation and responsibility for caring in the Thai culture is *depending on family*. Through analysis of the data gained for this research inquiry I found that one of the predominant Thai concepts of family is obligatory ties of the family members. The participants, especially the grandparents, who are the main caregivers of the child with this condition, take the responsibility and obligations without a feeling of being inconvenienced for looking after a child with cerebral palsy, while sometimes, the siblings have a sense of burden of caring when they were young. The following quotations explicitly demonstrate how aging persons, such as grandfather and great-grandmother, take this moral obligation.

I can say that I took care of her since she was born, after she went out from hospital. At that moment, I had just retired from my work then I looked after her since then until now as she gets older like this. For this year, I do not look after her because she gets older...We have a very close relationship. She knows everything but she cannot talk and walk. Her parents hardly ever take care of her because they work in other places and they are also busy...So, I am the main caregiver (laughs). Grandmother also took care of her

but less than me. (Grandmother said) She seems to be his daughter. (ID15-GF-1-P. 1, 8)

My great-grandmother, before she passed away at 84 years old, also took care of my daughter, ID13. At that time, I had to work, so, she helped me to take care of ID13. (ID13-F-1-P. 10)

Consistent with the Thai concept of family, Thai children, particularly the oldest child, are culturally expected to take on the family obligations as well as the parents, so the children have to take care for their ageing parents giving financial, physical and emotional support. Birth order is an imperative factor for dictating the level of family obligation. That is to say, the birth order mirrors the hierarchies of responsibility. The following quotations clearly demonstrate the Thai culture of obligation and its expectations for the oldest child to be the first person who has to take further care of a sibling with the condition.

...at this moment, it might be mother. She told me that she was going to take care of my sister there (at her mother's school) in the next two years...When ID15 gets older, I have to take care of her because I am the oldest child, and my brother is too young to do this. I have to look after her since she is my sister. If I do not take care of her, is anyone going to do this? It is impossible for mother to take care of ID15 forever. As in sequence, I am the next one who has to take care of her since I am her sister...my feeling. As I have looked after her, so I have to keep doing this further because we are siblings, aren't we? I am not sure that if other persons looked after her, they would love her in the same way that we love. (ID15-S-1-P. 15)

Usually, the Thai culture of obligation is placed upon daughters rather than upon sons. However, some families have a particular situation that parents have to rely on the boy, such as with ID14's family. The father of two children – the oldest child is a normal teenage boy while the youngest one is an eight-year-old boy with spastic diplegia– is much more concerned about the family. Since his wife had encephalitis, he cannot rely on his wife to take care of the children without him, as he shared:

If they didn't have me... (Mother said) We could not survive. (laughs) (Father said) Yes, they could not survive. About ID14, I put my hope on his brother because he is normal...I don't know what I can hope with them. I told them "Unexpectedly, if I go out then die at no place anybody knows. Why do you simply quarrel all the time? How can you all survive? (ID14-F-1(2)-P. 21-22)

A sibling who is the oldest child, with one brother, and one younger sister with cerebral palsy describes a sense of family obligation of being the oldest child since his father passed away.

I will find a good job then send my mother money. If my brother has not yet finished studying, then mother will support him. That's why I will have to send mother money monthly. My mother is probably looking after my sister, ID7... I have to take care of my mother and my brother and sister. Then, father might feel good and then he might go to heaven. He would not be worried about us. Don't worry about us. (ID7-B-1-P. 16, 20)

Another imperative feature of the Thai culture is reciprocity – the moral system of giving and receiving. “Giving” can be financial and/or physical and/or mental support, then ‘receiving’ must return in the same way of the “giving”. To put it simply, *A* set up a moral system by giving *B* something, such as using financial and/or physical and/or mental support, then *B* pays *A* back the same kind of thing. This is consistent with my analysis in this study, which showed that the participants employed the system of *reciprocity of care* to deal with, and manage, their situations. The following quotation highlights the sense of reciprocity between a mother of a twelve-year-old son with spastic quadriplegia cerebral palsy, and her relatives in order to receive ultimate benefits in the future – the caregiver for the child in the future.

About the person who will look after him, I have this hope that I can rely heavily on my family because both younger aunt and older aunt would love their nephew, even though he is like this. He is the beloved of everyone. So, I trust that they could help me to look after him...We have been supported by these persons (the caregivers) for a long time. Normally, I have supported my relatives. As we have a child like this, we gave them more until they knew. They said that if I will not be with ID6 any more, they should be the ones who have to look after my son, ID6. (ID6-M-2-P. 3-4)

Another example clearly demonstrates reciprocity of emotional caring between a little four-year-old boy with spastic diplegia, and his non-relative neighbour. They shared a sense of love and affection for each other.

I felt pity for him when I first met him. I'd like to give him warmth and affection, that is the only thing I can do. After that, he came over looking for me again; I also gave him much more a sense of warm affection. I thought that as I give the boy happiness and love, it means I make merit. He seemed to be very happy when he hugged me...Sometimes I feel lonely, he can be my

friend. At this point, he can fill up what I want such as make me feel happy. Similarly, ID4 would like this thing from me; I also fill up for him...I think I just give him what he wants, then I will get a sense of happiness returned. I feel like my heart is full...I have fulfilled the sense of encouragement in my heart, that I can give him much more love and fill him up with happiness. (ID4-N-1-P. 11-12)

Conclusion

The core category **Culture of obligation and responsibility** demonstrates how the participants deal with challenging circumstances, and how their beliefs, and a culture of obligation and responsibility underpin their responses to adverse situations. The Buddhist philosophy and Thai culture play a significant role in enabling the participants to reconcile themselves to the situation in which they find themselves, and to live with a sense of happiness and peacefulness. In the next chapter, I will present the third core category **living with** which demonstrates how they learn to live with, and care for, a child with the condition. That is the next process of *never-ending caring*, the BSPP of this research inquiry.

Chapter 6

Living with:

Learning to live with the situation

Introduction

In the previous chapter, I presented the core category **culture of obligation and responsibility** which underpins the participants' behaviour in this situation. Two significant factors, religion and culture, have a strong influence on the way of life of the participants, and impact also on their ways of taking care of a child with cerebral palsy. The next core category **living with** and its theoretical proposition *learning to live with, and care for, a child with cerebral palsy* describe the next stage of the BSPP *never ending caring*. This core category comprises two subcategories: ***learning to live with the situation*** and ***preparing for an uncertain future***. The first subcategory is addressed in this chapter, while the second subcategory is presented in Chapter Seven.

Consistent with my earlier analysis, when the participants are faced with challenging circumstances, they try to use their beliefs to deal with the situation. For instance, when they experience social disgust from other people in society, they have an increased sense of suffering – are upset and sorry about their situation and themselves. Because their responses are culturally conditioned, they do not outwardly react in that situation. Rather, they make an internalised response, employing Buddhist philosophy to accept the situation – by doing *thum-jai* or *plong*. However, as illustrated in Figure 6.1, in each cycle of facing a situation and dealing with it, they learn more about living with, and caring for, a child with cerebral palsy.

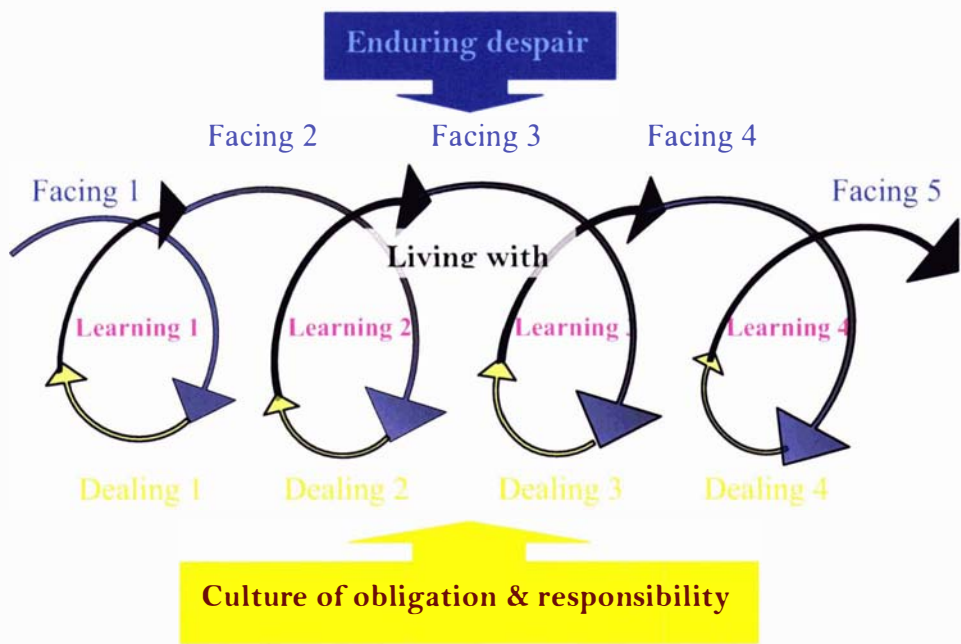


Figure 6.1 An explanation of the process of *never-ending caring* for a child with cerebral palsy

Learning to live with the situation

The first subcategory *learning to live with the situation* is supported by four concepts dealing with the situation, strategies to bring them up, physical health treatment and having positive feelings as outlined in Table 6.1 below.

Dealing with the situation

The first concept, *dealing with the situation* consists of four substantive codes: *learning about the situation*, *ways of seeking social support*, *ways of thinking*, and *ways to release stress*. These substantive codes reflect two differing aspects of dealing with the situation: for the sake of the child, and for themselves. The codes that indicate the outcome of managing the situation for the child are *learning about the situation*, and *ways of seeking social support*; while the other codes *ways of thinking*, and *ways to release stress* reflect how the participants themselves handle their situation.

Table 6.1 Living with the Third Core Category of *Never-Ending Caring*
for a Child with CP (Part 1: *Learning to Live With the Situation*)

TP	Core categories	Subcategories	Concepts	Codes
Learning to live with, and care for, a child with CP	Living with	<i>Learning to live with the situation</i>	Dealing with the situation	<i>Learning about the situation</i> <i>Ways of seeking social support</i> <i>Ways of thinking</i> <i>Ways to release stress</i>
			Strategies to bring them up	<i>Promoting the development of the child</i> <i>Providing psychological support</i>
			Physical health treatment	<i>Experiences of treatment</i> <i>Finding ways to rehabilitate</i>
			Having positive feelings	<i>Feeling happy</i> <i>Being proud of oneself and others</i> <i>Gaining spirit to fight from others</i>

Learning about the situation demonstrates the varied ways that the participants find knowledge about how to raise a child with cerebral palsy – they learn from books, their own experiences, and others' experiences. For example, a mother with a twelve-year-old son with severe cerebral palsy described searching for knowledge related to his condition in order to care for her child:

Well, I look for information from books about nursing, physiotherapy, and caring for children with cerebral palsy and other things that relate to my child's disability. I find them and read them all, can you believe that?... My only one purpose is to grasp whatever I can to raise my child correctly. How do people do physiotherapy? I just find out its principles then adapt them to fit our situation as I see it. That's the way I do it. (ID6-M-2-P. 1, 8-9)

Some participants learn from their own experiences with their child. When they face a challenging circumstance, they try to understand what the problems are, then find suitable ways to handle the situation. The parents of an eleven-year-old girl with athetoid quadriplegia describe what they have learnt from their experience of looking after their child.

She (ID12) has to take medicine constantly to prevent convulsions. Children like this must be on anti-convulsion medicine all the time. In her case, she has a problem with keeping pressure on the brain within limits. Whenever the

weather is hot, she will have convulsions, and so we have to control the pressure in her head. We try to moisten her forehead and neck with a towel soaked in water so that the cooling effect will assist heat loss. In the hot season we have to do this almost every day, my wife and I take turn about sponging her. In the middle of the day, we do it a lot, but in the morning and evening, not much because it is cooler. Another problem is that she is apt to catch a cold easily. So, we try to prevent her catching this bug because it presents particular problems for a child with this condition. When nasal mucus collects they are unable to do anything about it and so they swallow it and infect their stomach. So, we should give her antibiotics because we don't know when mucus will enter her mouth. As soon as she swallows, she always vomits because the germ is a bacterium and as soon as it reaches the stomach, it immediately causes nausea. (ID12-F-1-P. 20)

Learning about the situation includes learning how to deal with feelings of shame about having a disabled sibling/child and the potential responses of others in society to that situation. For example, a boy with a younger sister with cerebral palsy was concerned about the reactions of his teenage friends at school.

At first, I could see that my sister, ID12, was abnormal. Whenever I encountered my friends, I was ashamed and dared not greet them. I hid my face from them. I was afraid that they would taunt or insult me...(after that) Well, I figured that she was just an infant who could not yet speak or walk and when I got used to that view, the old feelings vanished. I arrived at it for myself with help from my mother and father. My mother said, "You don't need to be ashamed. She is your sister and whenever anyone sees her, you have no need to be ashamed". You get used to it, you know. I thought that if I am not brave enough to greet my friends, I will always be ashamed. And the shame will grow. So, I decided to try greeting them, maybe in the morning at school, I will see if they taunt me or not. At first, I was not very daring, greeting them and then hiding my face, but now, I hail them and we stand and chat well. I tell them that my sister is unable to walk and cannot speak. (ID12-B-2-P. 1-4)

The mother of a sixteen-year-old girl with athetoid quadriplegia described a similar process by which she and her husband learnt to come to terms with the shame engendered by the potential for prejudicial questions and responses from other people.

Other people always ask us questions like 'Oh! What is the matter? Has it been since she was born?...How old is she? Can she speak?' We have to confront these questions and the staring eyes, which make you feel ashamed. It is right here that it is most difficult to overcome the crisis. We have to deal with many things including particular questions. So, we have to fight. It is not a battle with others but we rather battle ourselves. ...The important

thing is that we must reach the stage of acceptance - to accept the situation, accept yourself and your child and after that adapt yourself to the point of how you will use your life, and work out how your child will use her life together with you, and how she will take her place in society. This is adaptation. After we have reached acceptance and have adapted, we have to open up to society since, in fact, we live in society, in the world. Since I'd like my daughter, ID2, to be a part of society, I must open my life to society. Why don't we try a wee taste first, a trial run? When you have emerged through the door, how was it? It is important to take that first snap look-see. See the way they look at you then duck back inside. Then you will not have the courage to ever go out again if you take a trial run. But one person will have looked at you, and will probably not have asked because he/she might get used to us. Then, pop out again. And just steadily take each step of progress until you face the outside world. Whoever wants to see, come! Whoever has not seen and would like to then come and I will show them. But it is really hard to get through in each step of this crisis. (ID2-M-2-P. 2-3, 19-21)

The participants also learn how to raise the child from others' experiences by observing, hearing about the experiences of others, taking suggestions from others, and sharing experiences. The following quotations demonstrate learning by observing. In first example, the mother observed the way her daughter tried to imitate other people around her, then determined to give her daughter opportunities to meet others in society, so that she might learn normal behaviour.

It will be good, in that she will meet normal people and see what it is like. She will be joyful and be confident in her ability. She will also act in the same way that normal persons do, imitating them ...One example, she looked and imitated behavior of her brothers, who are normal children, whatever they were playing such as playing cards. They would deal out three places and the three of them would play together. And they would scream with delight, and as soon as she saw them screaming, she would copy. Again, if her brother wanted a drink, she would order one too then drink it like him. (ID7-M-1-P. 24-25)

In the second example, grandparents described searching for information and learning ways to rehabilitate their grandchild by observing how equipment to assist walking could be made from bamboo.

(GF) Well I searched for the knowledge from *Poom bpan-yaa chaao bâan*³² then tried to understand it, so that I might care for her to the full. I searched the local community for someone with special wisdom about it, asking the question, "What kind of care done in what way will result in her being able to walk?" This is the main point, an imperative one... We made the wooden instruments for practising walking in which we borrowed the idea of an old man at Udon province. (GM) Yes, he himself created the moveable instruments (for his grandson) from bamboo. (GF) The person like ID15 can use it for walking as a training tool. Then we made it. (ID15-GF-1-P. 3, 12-13)

Parents and the main caregivers are watchful and vigilant to learn new information about ways to treat or rehabilitate the child. Some participants learnt by hearing about others' experiences in the media.

I have watched one case on TV about a countryman who is a skilled craftsman to make a cart, pedal-car, etc. out of wood. It was on TV. He made things for his grandson then he could walk finally... he made wooden cars by himself, he did not buy any things, you know. He made them all... I got the point of view that we must look around for equipment that we can realistically acquire (laughs) or that we can make. I do my best... Whenever I meet disabled children I will show an interest. (ID14-F-2-P. 9-10)

I had seen the TV programme named "Joa Jai" which inspired me. The story about the mother, who is an Assistant Professor, has two disabled children. They were born as normal children but they got sick then became disabled children... Then, her mother talked about the issue of preventing menstruation by consulting the doctor for operation. That is the point I get from them... They had a plan for their children by setting up an appeal fund for their children... They were laying aside money for the children... So, I think I should have a plan like this... I got the point of saving money for children and about sterilization. At first, I had no idea about this. (ID15-M-1(2)-P. 1-2)

Others hear by word of mouth. The babysitter of an eight-year-old girl with spastic diplegia, reported hearing about the rape of a disabled girl, and of the concerns that news evoked in her, for the child whom she cared.

I've heard about an eleven-year-old disabled girl who was raped while she was lying down at home. I have not watched that news but my son told me - She has even more severe condition than ID5 - cannot speak any words nor go anywhere. So, at this point, ID5 is much better than her. Here, it is good

³² *Poom bpan-yaa chaao bâan* means the knowledge that emerges from the wisdom and experience of the lay persons

that ID5 can ask someone for help. But that girl is not able to do anything. She just lay down there...(ID5-BS-3-P. 10)

Participants seek, and respond to, suggestions from others such as their relatives, friends, health professionals, and the teachers at special schools for disabled children. A grandfather of a fourteen-year-old girl with spastic diplegia suggested to her parents that she be sterilised.

I suggested to ID15's parents as there are sexually perverted persons in our society and we sometimes might be careless, so they should give her sterilisation when she reaches puberty. I really emphasised this. In my opinion they should consult the doctor for sterilisation. ID15 is a beautiful girl. It might happen, if we were careless in a second. As the current news indicates it is always caused by a person who lives around us...This is a very important thing. If we were careless, it might happen. Then, she would get pregnant. It might become a big trouble. So, I suggested to her parents to do this...I have already had a talk with her parents. They will do this during semester break. (ID15-GF-P. 10)

In the next excerpt, a mother of a seven-year-old girl, whose husband works in another province, shared her anxiety about the progress of her daughter's development with her friends, and the teachers at the special school for disabled children. Those people suggested that she learn not to get her hopes too high, and to 'let it be'.

My friends told me that, as ID9 is like this, I should not raise my hopes too high otherwise I may be disappointed. Then, it might be hard to accept. They told me to let her do as much as she could and let her study as much as she could. Do not force her any more since her brain is not normal. It will be great that she could learn how to be in society. I usually asked the teacher at the special school about progress of her study such as "Is she able to write anything else?" So, he told me do not get my hopes up. I might be disappointed. Let it be as it can. I also asked the teacher how her development is so far. The teacher told me to let it be as she can be. (ID9-M-2-P. 23-24)

Participants learned to live with, and care for, a child with cerebral palsy through studying books, and learning from other experiences. They then applied this knowledge to solve health problems, and to improve the development of their child. Then, they shared their experiences with other parents and caregivers, both to encourage others and to seek new ideas for themselves.

At the special school, I met mothers who knew nothing about how to bring disabled children up. They would not speak with their kids since they thought that the children could not speak as they would call their children "*ii-sim*"³³. To save energy for taking care of the child, I suggested to them they should talk to the children. That is the way that I used with my son and it worked. For example, I told him everything such as what I was doing; what I was going to do. I often asked him, "Would do you like anything else, baby?" I told him every time I did it. Then, he would perceive it. When the time came that he could respond to us, it means his brain might develop gradually. Then, he would be able to answer us. And we would have a good communication with our child. Whenever I had a chance to meet with mothers, I always made suggestions to them all. I have sympathy for them because they don't have any information. As I have more knowledge so I would like them to try to do what I do, something like this. (ID6-M-2-P. 17)

When I meet other parents and caregivers anywhere, such as at the hospital where I meet them often, I can't just look at the disabled child in their care - I must go and talk to them. They are caring for children just like my own - I've got to talk to them, to make their acquaintance and ask questions. I mean, I would like to know about the things they do with their child, so I ask them. I might gain something which I have never seen or done for my child before, and I can pick it up and try it for her. And also, if there is any problem which my daughter is now free from, I can tell them. For instance for those with children who are very limp in their bodies, I told them, "Before this, my child was much more limp than this. It took time around three years for training her how to sit by herself, to crawl and to be able to do like this". They replied that they will try to do the same, because now they know how to go about it. I told them that they must encourage the child to sit on their own and to do things by themselves as much as possible. Some things you should not help them with and you don't have to help them with very much else - Urging them to keep doing things by themselves. Sometimes I ask them, "How is it that their child does not dribble, but my daughter dribbles?" They reply that at first, their child did indeed drool saliva, and they tried massaging the mouth area, following the suggestion of *mor*³⁴. When they visited the *mor*, he/she taught them how to do it. But my daughter won't sit still - she tosses her head away and gets annoyed in a moment. But we manage to rub and massage somewhat. A little bit each day by pressing and pressing around the molar area of the cheeks. It's difficult. We have made small gains. I mean, my child is not yet ready to let me do it. But if their child has improved in some aspect more than my daughter, then I will ask them, "How did you go about that?" and we will benefit from it. But if

³³ *li-sim* refers to an impolite word to call someone who hardly speaks and has less activities tend to be a person with stupor.

³⁴ *Mor* refers to the word that the villagers call health care providers such as doctor, nurse, pharmacist, and others

there is something that we have improved better than them, then I like to tell them how to go about it. If ten parents and caregivers meet, then there are ten techniques to share, aren't there? (ID7-M-2-P. 11-13)

In addition to learning about the situation, families needed to seek social support to care for the child with cerebral palsy as many of these children needed assistance day and night. The substantive code: *ways of seeking social support* encompassed seeking support from family members and relatives, friends and neighbour, babysitters, and the government. Consistent with cultural expectations, the participants ask for help from their family members first then they tried the next choice such as a relative – for example, the older and/or the younger aunt who do not live with the participants. The following quotations demonstrate how family members and relatives of the participants take part in caring for a child with the condition. The grandfather of ID4 was selected from his family as the first choice for taking care of a four-year-old grandson with spastic diplegia, because the mother had worked in another province since the boy was four months old. Consequently, the grandfather gave up his job to be the main caregiver.

At first, we were going to arrange for the relatives to take care of him. But his grandfather didn't want that person to look after ID4, then he said he could do this by himself...As the aunty said, "Because ID4 can't go anywhere, will the relatives be able to do a good job of looking after him?" Thus, ID4 should stay here, in his grandmother's house, where grandpa can take care of ID4...As grandpa offered that he was able to do this, he has done a reasonable job every day up to the present. (ID4-GM-1-P. 5-6)

A second family nominated the great-grandmother to be the main caregiver of an 11-year-old girl with severe cerebral palsy, with paid assistance from a neighbour for some lifting/carrying activities.

At first, my wife went to work; that is why great-grandmother had to take care of ID13. But now she has already died (at 84 years)...At that time, the great-grandmother fed her as she lay there, like this. For washing her, I pay a man who is living around there to carry her to the bathroom then great-grandmother lathers and washes ID13. When finished, the same man carries her into the bedroom where great-grandmother powders her body. (ID13-F-1-P. 10-11)

Besides locating a main caregiver, families still need help from others such as friends and neighbours who get involved whenever the main caregiver is busy.

About ID1, I always helped this family to look after ID1. When her uncle had an accident last week, I helped them to rock the cradle. (She always sleeps in the cradle). Anyway, I could not help them yesterday. So, the grandmother had to restrain ID1 with a bathing cloth round her [grandmother's] waist while she was riding a motorcycle to see ID1's uncle...Oh! I told her to drive slowly. I could not help her because I had to go to see the doctor. ID1 was too heavy to use a shoulder-strap. It was high-risk...There is only me to help them. Their relatives live in Kalasin province, which is far from Khon Kaen, approximately 3 hours by car. (ID1-N-1-P. 3-6)

As the main caregivers grow older and have health problems, and the child becomes bigger, another relative is sought, or permanent support from a babysitter may be required. A grandfather, who looked after his granddaughter for fourteen years after he retired from his work commented:

We hire a baby sitter to look after ID15 because she is a young woman now. It is too hard for me to take care of ID15 - too heavy to lift her. (ID15-GF-1-P. 1, 8)

Permanent support from babysitters releases families from the burden of caring. For example, the single mother of a 16-year-old girl with athetoid quadriplegia, who is not able to do anything except cry and smile, has used the same babysitter for 13 years.

About babysitter, I could not find any babysitter like her. This is a very special thing, to have a babysitter who has looked after my daughter for 13 years. She also loves ID2 as her own child. (ID2-M-1-P. 17)

Children who are born with cerebral palsy need special care and treatment from birth. Parents who work as government officers receive a full benefit from the government to refund the expenditure of medical treatment. Companies will support some medical expenditure of their employees. However, parents who have their own business, or are unemployed, have to pay full medical expenses should their child be hospitalised. One family described the financial stress the extended periods of hospitalisation of their child caused, until they were able to obtain a special card to cover the cost of future care.

(F) It cost 5,000 baht each X-ray at the hospital. About six times comes to 30,000. This is not including the cost of medication, etc. In the first month, we spent several thousands all used up. I remembered that I paid around 30-40,000 baht plus. (M) That's right. We paid about 1500 baht each and every day. (F) We paid every day for medicine and if there was an operation, or something else, we had to pay extra again. She was in the hospital for 2 years. (M) She was in and out of the hospital for a month here, half a month there, 15 days again....Finally we successfully applied through the hospital Social Welfare Department for the patronage of the king which entitles... free treatment into the future. Surprisingly though, since holding this card, she has not been sick at all. (ID12-P-1-P. 12)

In order to live with, and care for, a child with cerebral palsy, the participants in this research inquiry react towards the situation in various *ways of thinking*. This substantive code describes ways they structure their thoughts in order to continue the *never-ending caring*. The substantive code *ways of thinking* is divided into two sub codes: concern about caring for the child and focusing on dealing with the situation. Ways of thinking concerning caring for the child include keeping to oneself and turning the crisis to be a good opportunity, while thinking focused on dealing with the situation consisted of it's my business, like working at a restaurant, cultural response, and developing a routine.

A mother, the main caregiver of a 12-year-old boy with severe cerebral palsy, focused her thoughts on her child in order to avoid being engulfed by negative feelings.

The most important thing is if we are weak and wonder why our child has to be like this? Why do I have to go through this? Why do I have to face a situation like this? Then, we will become weary, weak and discouraged. We would not be able to be dependable and who would my child depend on? My child would not be able to depend on other people, especially 'papa' he is not going to do it, and all that is left is me; I must provide for my son. Therefore, I must not sit around fretting and worrying about what will happen to my child at this point in time. (ID6-M-2-P. 1-2)

Alternatively, a father with an eight-year-old daughter, tried to view the crisis as a good opportunity for parents and the child. He identified the potential benefits accruing from the situation in which he found himself.

...may be the bad thing that happened to us might turn out to be good. The bad thing that happened to us might make us stronger, more knowledgeable,

and (this situation) make us to be much more humane...It is not the good point, but we must create an opportunity out of crisis...Uhhh then, we must work harder! We must put more care on her, and we must...? The situation that we are in makes us stronger, become more responsible, become greater human beings, and has more consciousness to be greater human being...I mean that we must turn the crisis to be the good opportunities for my child. At least let her be happy to live even though she could not walk, right? I try to help her not to have an inferiority complex. (ID5-F-1-P. 10-12)

The participants in this study have a variety of ways of thinking about, or constructing, the reality of the situation they deal with on a daily basis. Their thinking is influenced by factors such as their personal background, the type of cerebral palsy, and the developmental progress of the child. A step-mother – the main caregiver of an 11-year-old girl with severe cerebral palsy since the ex-caregiver, the great-grandmother, died at the age of 84 – had to quit her job as a waitress at a restaurant. It is interesting that she links the obligation of caring for her step-daughter, who is able to do nothing except make a groan of pain, as a duty – like working at a restaurant.

Normally, I always move her to outside and feed her breakfast. Then, I give her a bath. In the evening, I also feed her and give her a bath, again. It seems like a duty as I worked at the restaurant that I had to set the table and keep everything tidy in the evening...then it developed a routine. (ID13-SM-1-P. 1, 3)

A single mother of a 14-year-old girl with severe cerebral palsy, shared the notion of it is my business, which she used for dealing with challenging circumstances.

Well, I have only one idea it is my business. It is clear that it is my business. I just think about this. That means other people do not help me with anything; they do not feed us and I can survive by myself. I have my own life; it is my business. I do not put anyone to any trouble. I spend my money shopping for my daughter. (ID2-M-2-P. 7-8)

Thai culture plays an important role in the participants' ways of thinking. When participants deal with challenging interpersonal situations in their daily lives, they respond by doing nothing even though they feel really upset with the situation. The following quotations demonstrate a cultural response, to situations

where participants (father and child with cerebral palsy) are the recipients of “social disgust”.

I didn't care about anybody, who surrounded and looking at me, because ID11 is my child...If they ridicule her, I will feel upset but I don't want to say anything. It really hurts when... (ID11-F-1-P. 9-10)

It was okay, let them talk. I didn't want to say anything. (ID11-CP-2-P. 14)

The condition of a child with cerebral palsy influences ways of thinking of the participants. Where a child shows little or no developmental progress in his/her daily activities, caregivers describe developing a routine.

Now, she is 16 years old. We get used to each other's ways. It is more like familiarity or routine... For ID2, she has a responsibility to go to school. My responsibility is to go to work. Like other children, in the morning, I as the mother send her to school then pick her up in the evening. But she is more special than others in that she goes to the special school for disabled children where she can choose at leisure to attend or not. It is completely trouble-free. This routine has been unchanged for 16 years and is now like normal everyday life for us. (ID2-M-1-P. 21)

The last substantive code in the concept **dealing with the situation** is *ways to release stress*. Talking with others who understand one's situation, listening to music, and working hard all day are ways to release stress.

... my friend name T (who is a disabled girl at the special school). We always consult each other, whenever we have some problems such as any pressing or painful issues. I always talk with her when I have problems. (ID11-CP-2-P. 11)

I felt better since I lived and worked at this school (the special school for disabled children). When I talk to other people, I no longer feel so sad. (ID9-M&CP-1-P. 3)

A baby sitter, the aunty of a 13-year-old twin with cerebral palsy, has spent all her days looking after the boy since he was a little child. The day-by-day caring seems like a never-ending task, however going to school with the child is a way of releasing the tension for her and for other caregivers.

At any time, if there are a lot of friends (other caregivers) there (at the special school for disabled children), we will chat several topics. We keep talking about everything that we can talk. About it is just for releasing our

stress from inside. ID2's babysitter always goes to the school because she has no trouble with ID2...I sometimes go to school with ID3 just to meet with teachers and have some practice... with the equipment... Going to school is being able to see the world; it gets me outside my house. (ID3-BS-1-P. 8)

Mothers of children with cerebral palsy share their experiences with a sense of shared "motherhood".

I watch the mothers when they pick up their children (the boarding special school allows the children to go back home on the weekend and during semester breaks); they love their children, don't they? They send their children to school and pick them up like normal people do. About a hundred mothers come and join with the activities on Mothers Day, 12 August of every year. They share their experiences, and then they all weep with love and concern for their children. ...in some families, the father could not accept their situation then fled. So, the mother had to battle on her own to this day. Some leave their children here then go out looking for work. They share their problems with tears. A mother expressed 'It is good for your children that they still have fathers. For me, I have nobody to help. He has already fled, so I have to battle alone.' They chat away to themselves in groups of three or four, talking of their children, that they want them to be better, to learn. They all have a hope for the child could learn then they will be glad. Anyone, who has the same situation like us, chat about suffering and then share their suffering (*Khuy-Took Phrub-Took*³⁵). (ID9-M-2-P. 8-9)

Living with a child with cerebral palsy lays great stress on all family members. An older sister, who has a younger sister with the condition, lives with stress about the extent to which her parents love her. She trusted her friends and the neighbour enough to raise her concerns with them.

[The oldest child thinks her parents love the younger brother and sister more than her]...I have never spoken about this with my mother and father. I have only talked to a friend about it. He said that it was none of his affair, it was a family issue and he told me to speak to my father about it myself. I also spoke to the neighbour who lives just next door and she listened to all I had to say. She is just an acquaintance. But when I told her about my mother and father, she said that they love me equally. But I have serious doubts. Sometimes I go over and relax with them. If I have any issue I want to get off my chest, then I talk with them about it. (ID10-S-2-P. 2)

A mother with a seven-year-old daughter with spastic diplegia lives with a much greater sense of despair because she continues to blame herself as the cause of

³⁵ *Khuy-Took Phrub-Took* refers to Chatting about suffering and then sharing their suffering

the girl's condition. She distracts herself from negative feelings by talking with friends, and listening to music.

When I am feeling dejected, I have no energy for work and no motivation for anything. When I begin to think about my situation, I hurry downstairs to see my friend. Whatever she says, I listen. I become absorbed in what she is saying and gradually forget my troubles. I do not keep myself to myself otherwise it is worse than before. I come down to see ID8's mother. She is a great company, and then little-by-little I forget my troubles. I avoid feeling alone by listening to songs or something, which gets me engrossed. Enjoyable songs release the tension a little and the sound takes me along with it to some extent too. It is good, and I forget what I was thinking about. (ID9-M-2-P. 30-32)

In contrast, a grandmother – who has taken care of her four-year-old granddaughter with severe cerebral palsy since she was a baby – releases her tension by working hard all day, in which she balances the positions of main caregiver, working, and housewife simultaneously.

Nobody could do like me. I have never had stress since I did housework all day until no more things to do. It made me forget everything. I had no more time to think about that. When my granddaughter went to bed, I was in a hurry to do my jobs such as cooking, sewing and laundering. A moment ago, I just came back from taking care of the cattle. I work all the time. I do non-stop working. (ID1-GM-1-P. 4)

These substantive codes demonstrate how the participants deal with the situation in order to live with, and care for, the child. By learning directly, and from others, they apply and create the strategies to bring up a child with cerebral palsy, as illustrated in the following section.

Strategies to bring them up

Strategies to bring them up is the second concept of the subcategory *learning to live with the situation*. The participants apply the knowledge they have gained regarding the health condition of their child to develop strategies to bring the child up. The concept consists of two codes: *promoting the development of the child*, and *providing psychological support*. Participants promote the development of their children by promoting appropriate stimulation, letting a CP

child take care of him/herself, making friends, sending to special school, and looking after as normal.

To begin with, the substantive code of promoting appropriate stimulation illustrates how the participants use their knowledge related to the condition to raise the child. A mother of a 12-year-old son with spastic quadriplegia followed advice from a doctor to stimulate the child in order to improve his development.

I took ID6 out and I kept talking to him as much as possible. As I was a modern mother, I started talking to him while he was still in the womb. I talked to him, played music for him even before he was born. I think he would be quite smart if he were a normal child. I just accepted that he was born in this way. So, I tried to give him stimulation even more. I did this by taking him everywhere I went when he was a few months old. I took him to a shopping mall because it had swings and lots of light and music. (ID6-M-1-P.6)

Several participants recognised that exposing their child to normal life in society was an important form of stimulation that may lead to the child imitating the behaviours of normal persons.

I realise that ID7 has limited opportunities. So, she should not be confined where she lives only in the house, but rather go out to meet other people in society...I'd like her to go and meet others like bring her to the outside world, not just her own group like this here. It will be good, in that she will meet normal people and see what it is like. She will be delighted then she will have confidence to show her real condition and to act in the same way that normal people do, imitating them. On the other hand, if we abandon her to live only with her family, she will not have any confidence to show herself rather like an oppressed child, silent. She will be brave enough to show her true self only with her family, those who are closest to her. But for outsiders, no. Being constantly with my child caring for her, I have observed her. She always imitates behaviours. Comparing it to when we were in Bangkok, I took her into the department store every week even though she dribbled. I took her in the wheelchair but I did not buy anything. Just wheel around idly...When I saw this happening (imitating normal behaviours), it is a good (signal to follow). (ID7-M-1-P. 24-25)

It's all about giving ID14 the opportunity to see and know things outside...for instance, we went to the Silk festival. Sometimes, I walked with him by holding his hand, then cuddling, and piggy-back. Got tired (laughs). Walking holding hands sometimes gets me way behind my friends. I have to get him on my back and run after them. Hey, (talk to the mother) where did they go? We went up the hill. I took him to Khunming in Loei province then walked into

the forest. Climb the rocks and whatever. Oooh, I almost fainted and fell (laughs). (ID14-F-1-P. 14, 20-21)

Participants hope for their child(ren) to be independent one day, thus they try to let a CP child take care of him/herself in order to improve his/her abilities to their full potential. The ultimate goal is that the child is able to conduct daily activities by himself/herself as explained by mother of a seven-year-old girl with spastic diplegia, and the neighbour of a four-year-old-boy with spastic diplegia.

My daughter (ID7) tries to help herself for taking a bath like brushing her teeth and cleaning her body with soap. She can do it but it is not clean enough. However, at the first place, let her take care of herself as training. If it is not clean, I will help her later. (ID7-M-1-P. 37)

ID4's grandmother said that he shouldn't drink water by himself when he is at home. He should be given it by someone. But I don't offer it to him. He has to get it by himself, dipping out a little each time because his hands are not strong enough. I train him how to take a drink by himself. Desserts - I train him how to eat them by himself. If he wants a plate, he goes and gets one, picking one up and bringing it and then eating of his own accord. If he spills it, he has to get a cloth and wipe it up. I don't do it for him. I tell him, "I'm not going to do things for you because in the future, who will do things for you?" I teach him like that. "Granddad is already old, so he won't be helping you. And I won't." He does everything himself. If he dribbles, I get a cloth for him to wipe it. I make him do it himself...I do not [express] disgust that he walks on hands and knees then without washing the hands. I don't [express] disgust at him at all. If he wants to eat something, we can share having food together...I think that this is not just giving him a sense of love and affection, but it is about training him as well. (ID4-N-1-P. 18)

All children, regardless of their disabilities, need friends. Parents noticed that the development of the child significantly improved when they encouraged the child to make friends. A mother of a seven-year-old girl with spastic diplegia found that her daughter's confidence markedly improved when she made friends at school.

When we lived in the village, she had no friend - but now she has more friends to play with. Generally, children feel joyful when they have friends. Now, ID9 seems to be more cheerful and is brave to speak and act out. When she was at home she was a very shy girl. Now, when guests come to visit the school she greets as, "Wat dee ka, wat dee ka" She has more confidence to talk. Before this she didn't dare to talk at all...Well, I think that she is inspired by

her friends to walk and do other things. So, she feels enthusiastic about training to walk. (ID9-M-2-P. 2-4)

A 14-year-old girl with cerebral palsy, vividly portrayed her joy and happiness about her experience of being part of a group of friends.

Since I was young, I had a friend next door, a boy. We have played together. But now we are not close friends because he studies in another school. In the past, wherever we went, we went together...following closely. We would go fishing and collecting vegetables. Ooee! How we did enjoy it! I really enjoyed doing those things...He would believe in me. Suppose I said "Hey! Let's take me fishing" He would go. Or "Let's collect guava" he would take me there. If I invited him somewhere, he would take me. He rode a bicycle, doubled up with me. Ooee! What fun! ...After that his friends formed our own group. Thus, all of my friends were boys. (ID11-CP-2-P. 11)

A father, with an eight-year-old son with spastic diplegia, described the advantages and disadvantages of having disabled children and/or normal children as friends in relation to the development of his child.

The thing with children is that they need a friend, isn't that right? ID14 is a buoyant good humoured person who enjoys life. If he has friends, he will enjoy life to the full. Then, his speech and other things will develop as a result, especially if he has friends such a normal child. He will try to develop by himself by keeping up with their peers. If he still stays with friends as a disabled child, the development might not have a much greater improvement as having normal friends. But there could be a problem. I am afraid that it might have a problem when... If the children like to tease and joke about each other there could be a problem since he is not a normal child, so he can not come and go with others. They might ridicule him as a mentally retarded person, then he might think about this. I am afraid that he might be disturbed. That causes lose of confidence. He might be an unconfident person. But to date, there has not been any problem. It has both positive and negative outcomes here. We always encourage him to go along with another child. If the child understands him, it is good. Some children do understand that he can't go anywhere, then they are great company to play with. They mingle together. For instance, a little girl next door (a normal child), sometimes she comes and plays with him. It is a good thing. If some children don't want to play with him because he can't go anywhere, that is a problem. Actually, he would like to play with others. (ID14-F-2-P. 1, 6)

Figure 6.2 shows a drawing [reprinted with permission] by ID14 of himself and his friends – disabled children who attend school with him. His close friend – an eight-year-old girl with spastic diplegia [ID5] – is positioned closest to him.

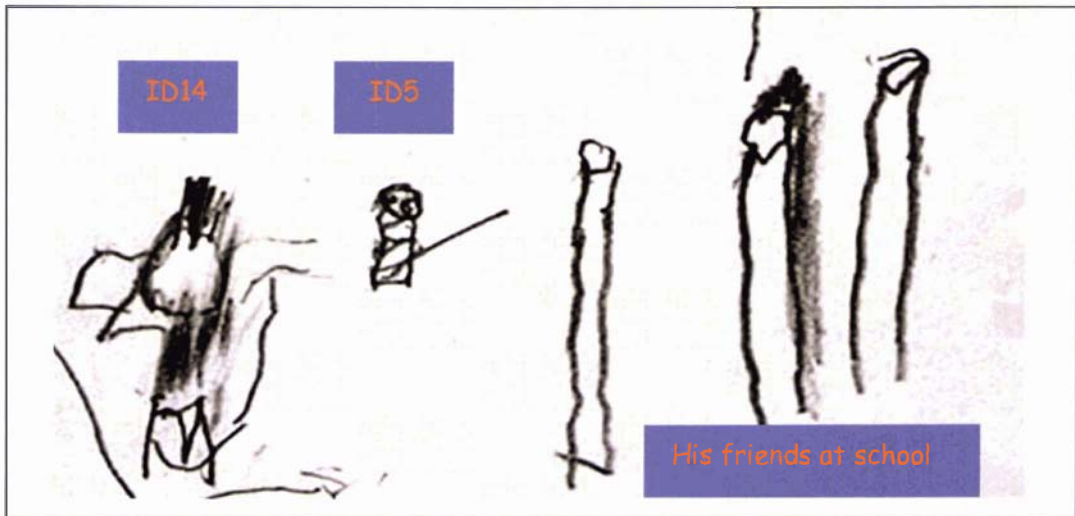


Figure 6.2 *The drawing of friends by ID14* reproduced with permission of ID14's father

Figure 6.3 illustrates a theoretical fieldnote about the importance of such friendships reinforcing the childrens' engagement in the programmed activities at the school and thus supporting their development.

9 a.m. 15 Nov 2005 at The Third special school, Khon Kaen province, Thailand

As I told ID5 that I will visit her at school, I went to the school in the morning. I met ID17, - a teacher, and her colleagues while they were preparing disabled children to practice their capabilities. ID5 and ID14 are close friends. ID5 was set to stand in a portable circular-tool for walking by the trainer; ID14 was training by cycling a small bicycle. ID5 called her friend, ID14, to wait for her when he cycled far away. Then, he cycled back immediately. Because of her condition, she always walked following him. Basically, they are trained together - ID17 told me that it is a good idea to train them simultaneously because they are mutual friends who always encourage each other to do their practice. ...after training it was time for writing practice...ID5 wanted to show me ID14's work that, from her view, is very good. At the writing class, ID14 practiced writing his name and their friends in a page. He can do it very well while ID5 made lines in different shapes as a model such as a circle, and straight line. ID5 said that ID14 has beautiful handwriting, especially when he writes her name. ID5 has good development of speech like a normal child while ID14 has better handwriting and gross motor skills.

Today, I learn more about the importance of mutual support between disabled children -the teachers at the special school realised the advantage of having friends work together in the programme of training. The children with the condition will gain more benefit to have a good chance to learn from each other. Then, their development will be improved.

Figure 6.3 *Theoretical field note about the advantage of having friends*

Concerned to promote the development of their child, some parents tried taking their children to a normal school, before deciding that to send the child to special school was an appropriate way to promote their physical, psychosocial, cognitive and language development.

I have tried hard. I really wanted my child to go to school. At that stage she was almost ready to go to kindergarten school and I was thinking of looking for the teacher to come and teach her there (laughs). I don't know. My desire was for her to gain an education of some sort, so I took her to the village school. But I went in with her and stayed with her. It's an ordinary school, and at midday the kids ran around chaotically and my daughter was left alone sitting by herself. At first I thought that she might learn along with her friends, but she cannot do it. She is different from them. She cannot take instruction. She does not listen to the teacher, and the teacher has no time for specific work with her. There are lots of children around 20-30, and for one teacher to take care of her is impossible. She is not interested at all. She does not realise to make friends with other children. When the teacher speaks, she alone is the one playing about. It could not continue, so I withdrew her from there after one semester. Meantime, someone advised me to go to another school at Udon province. I went there; it is the Centre for deaf persons. Then the director said they do not take the child like this because all other children there can actually walk. Then, she suggested to me to go to this special school for disabled children in Khon Kaen. (ID9-M-2-P. 8-10)

The special schools provide physiotherapy and basic living skills training in addition to literacy, depending on the condition of the child. Parents described facing some opposition from neighbours or family members who interpreted sending the child to the special school as sending them away from the family.

The neighbours said, "Why would you send her away? Do you want to torture her?" They spoke in this manner. They did not understand that the school had other benefits. That it wasn't a school that just taught lessons. I told them that it also improves the condition of the children, offering physiotherapy and everything else. How was I to last the distance with a monthly salary of 2000 baht? I would do it for my child, to see her condition improve. She is beginning to show it now - practising walking, practising this and that. The teacher, actually she is a physiotherapist, treats her once per week. Each week she gave her a massage, and flexes her arms, flexes other parts of her body in the way of physiotherapy. I think about this and believe that I made the right decision to bring her here (to the special school for disabled children). (ID7-M-1-P. 25)

At first, my wife's mother didn't want me to bring her there because she had no idea about the school. Then she thought that it might not be a good idea

to let ID11 stay there without family, as we live as an extended family with parents and grandparents in the household. For myself, my heart went out to my child and so I brought her here to learn. I thought it would work all right. I thought that if I do not push for her, nobody else will and she will learn nothing. I told the grandparents that the special school looks after all the children well. They would care for her better than we could. If we would not let her go to school, then she will not know anything, and have no understanding. I really want her to go to school. If she just knows how to read and write, I will be glad. (ID11-F-1-P. 7)

The final way that participants promoted the development of the child was looking after [the child] as normal. Parents encouraged all family members to follow this strategy. For example, a father, with three children - the youngest an 11-year-old with severe cerebral palsy, set the family norm that she be treated the same as other family members.

We do things in the normal way, so family is family. It is not about one being disabled. We must accept ID12 as one of the members of our family. We cannot separate her from the family and cast her out in disgust. We have to establish in the minds of others the same approach to her as we have ourselves. To encourage them to love her as we do. If we make her too special, she will become like a sacred thing on an altar, which cannot be touched under any circumstances! So, we care for her in the same way that we would care for an ordinary member of the family. That way, there is no fuss. (ID12-F-1-F5,7)

Similarly, a single mother, who has a sixteen-year-old girl with severe cerebral palsy, describes taking care of her daughter as if she were a normal child.

...And I give her a chance to use her life as normal children. It doesn't matter that she is like this. Normally we go to supermarkets and department stores. ID2 likes it. Maybe it is because she can see the coloured lights. It is cool and we can walk around with the special wheelchair from those. She can see this and that and becomes contented - she feels happy. Even while lying down in the car - when we turn towards a certain department store, she always gets excited. She also relaxes in a wheelchair in the village but lately we have not done that because there are a lot of mosquitoes - the dengue fever type - and I am concerned about it. She relaxes in this way out the front of the house too...Sometimes, we listen to music, watch videos, and dance - I support her to stand and then we dance together. Then at night, if I am not too lazy I tell her stories, take her for night prayer chants in short prayers such as *na-mo-ta-sa ara- hung-sum-ma*. Then asking for holy forces to protect us and give us a good lifestyle and health and so on. She laughs. These are the things we do continually. (ID2-M-2-P. 2-3)

Children with cerebral palsy are very sensitive to the reactions of the main caregiver and other family members, who are involved in the process of caring for them. Thus the parents emphasise the need to *provide psychological support* by giving spiritual warmth, and involving siblings. The father of three children – the youngest child is an 11-year-old girl with athetoid quadriplegia - tries to encourage the brothers to give her spiritual warmth by touching, playing, and holding her with love, practices that he believes directly affect her immunity. In other words, from the father's perspective, spiritual warmth develops within the child from a sense of being loved. This sort of feeling cannot grow without love.

Generally disabled persons will lack friends because they cannot go anywhere to find this kind of friends. As a result, some sort of feelings are completely absent from their minds. This is especially so in the matter of feeling love - feelings which accompany various kinds of love. We have to find ways of giving these feelings to them. That is the need to be touched from other, like normal people. With ID12's brothers, hence, they must give her a touch which I have to strongly encourage them to play with the girl each day. This strategy works with her condition because she is encouraged physically and emotionally; it also helped to build up immunity, as a result of the closeness that we gave her. In other words, she might feel that she wants to live. She is unable to tell us this, but we can see it. Illness is reduced because she has encouragement. Her body improves, along with her sense of worth, and she gains more immunisation by means of the feelings of intimacy. Therefore this is very important for giving her encouragement and it's good for her and it's not something that you would have to buy. Go and touch, go ahead, big brothers - everyone go and play with little sister. (ID12-F-1-P. 5-7, 9)

Similarly the father of two girls, one eight-year-old girl with spastic diplegia describes responding warmly to his daughters offering sympathy and love to give them spiritual warmth.

I just really want to cheer her up, and to be happy. I don't want her to suffer. I have to give her warmth on every matter of her life, in order for her to not feel like she is having the inferiority complex...Until now, whenever ID5 or her sister sees me then the very first things that they would do are kissing, and hugging me (ID5 and her sister live with a babysitter while the father lives in another place). Those are the things that I give them both. I just want them to be spiritually warmed. I always talk to them "come on, give papa a kiss; come on baby, give papa a kiss first. Give me a hug first" I make them feel spiritual warmth. (ID5-F-1-P. 12-13)

Another father, of a 12-year-old girl with spastic diplegia, tries to encourage his daughter by using the technique of social comparison to compare her situation with that of other children at the school, then points out the advantages of hers.

ID10 told me that there is no father or mother to pick up some children at the school. For instance, on the Mother Day, for these children, there is no father or mother to join the activities, so the children respect as 'Wai'³⁶ teachers instead. At this point, I tell my child, "It is good that you have both father and mother". On that day, my wife and I joined in the activities along with our daughter. I believe it is better than many children at the school, and a good point of comparison for us to use. It can help to encourage our daughter much more. Some children have only mothers and they do not know where their fathers are. The mothers do not come to visit all that often either. In our case, we have both mother and father present together - that is the best possible. We are not the same as mere friends. I encourage my daughter in this way. I always tell her, "I as your father will never, ever leave you". It gives her encouragement to press on and apply herself to school work. (ID10-F-2-P. 15-16)

Participants are concerned about the feelings of their child with cerebral palsy. The granddad of ID4 has learnt to encourage rather than scold him.

We have to encourage him, flatter him occasionally. "That is not the right way. It should be like this. This is a good thing to do". If we scold him, it won't work. We must allow him to speak first then correct him little-by-little. And another thing, we don't spank him. Such children as these get a sense of inferiority as soon as they are spanked. They are not the same as normal children. I have never hit the boy, only ever instructed him. I have never struck him, but if he does wrong I just say, "Hey ID4 I might get angry, and then I will not speak with you", in the same way his grandmother teaches him. "If granddad gets angry with you, he won't live with you any more". He will cry immediately, and then in a short time, I comfort him by saying, "There, there. I am not angry any more now." (ID4-GF-1-P. 7, 8)

Siblings are also drawn in by parents to provide psychological support to children with cerebral palsy. An example is the father of an eight-year-old boy with spastic diplegia, who suggests that the older brother lets the child win a game sometimes so that the child feels good about himself.

Sometimes ID14 and his brother play together, and then the brother won't let him win. I said to the brother, "As your little brother is like this, how

³⁶ *Wai* refers to Thai traditional ways to respect and greeting other people

about letting him win?" For instance, they play such a fighting game like that. The elder always gains victory over the younger, instead of letting the younger brother win in some games. That will give him encouragement, when otherwise he might feel disillusioned or some such, I don't know. I told the big brother that he should pretend to lose like this...That means when he is able to win the game then he feels glad with his capability to do that. We try to encourage ID14 in every issue ...we always encourage the older brother to help the younger, to take a part in his development as well as helping father and mother. (ID14-F-1(2)-P. 8-9)

Likewise, the father of an eight-year-old girl instructs her older sister to take care of her sister and to be nice to her; and the older sister of ID15 challenges the behaviour of her younger brother when he is upset by ID15, giving suggestions to the younger brother to show more understanding and caring.

Whenever ID5's sister... talks about the inferiority complex of ID5 then I am going to blame her every time. I always teach her repeatedly to take care of sister, but she is still a kid. She is really not getting the things that I try to teach her yet...Sometimes she would care more about her friends rather than the younger sister. However, I would give her the suggestions on everything in order to treat her sister the right way. I have to tell her "You have to pick up this for your sister or turn back then give ID5 a hug first." Well, she would not follow my instruction, but I must inform her about it. (ID5-F-1-P. 15, 22-23)

ID15's brother sometimes gets angry with ID15 so I told him "Look at her face, did she know anything about you?" I always told him to take care of her. "I have to tell you because she can not walk. If you get older, you have to carry her, not me." I told him like this. Another example, she was excited with computer game meanwhile he told mother that ID15 seized the computer game from him. Then, he got angry with her and cried. So, I told him "please look at her face, did she know that you are angry with her?" Then, he felt better. He is also concerned about ID15. I sometimes told him to look after her when we went out. "Stay with her and do not allow anyone to do anything to her. He said, "OK". (ID15-S-1-P. 4)

Physical health treatment

Physical health treatment is the third concept of the subcategory *learning to live with and care for a child with cerebral palsy* which encompasses the substantive

codes *experiences of treatment* and *finding ways to rehabilitate*. Even though the participants realised that this condition can not be cured, they still hold hopes to find ways to treat it.

The first substantive code, *experiences of treatment*, comprises experiences of medical treatment and trying alternative treatment. Children with cerebral palsy may be recommended various types of treatment, dependent upon their conditions. The children may be referred to a range of specialists with different fields of expertise, such as occupational and physical therapist, orthopedist, speech therapist, developmental psychologist, and educator, for assessment and recommendations for treatment. Physiotherapy and other therapies can maintain the function of the other parts of the brain (Behrman, Kliegman, & Jenson, 2004; Jacobson, Mulick, & Rojahn, 2007; Miller & Clark, 1998; National Institute of Neurological Disorders and Stroke (NINDS), 2006).

The mother of a 12-year-old with spastic quadriplegia described her experiences of seeking medical treatment for her son.

We went to the doctor and he gave us pills to treat convulsions. The medicine reduces much convulsion and when he has taken it he seems to be quiet and slow, drowsy all day. I decided not to let him have it. When he has taken it, it made him slow and like a person who could not set his mind to think. Only let him take the medicine to lessen the seizure. He just finished last year. Because I know his condition that he rarely has this problem - around several months he would have only one seizure. (ID6-M-2-P. 10)

I took him to have his shoes made. Here the specialist who cut the shoes told me that it needs to be checked by orthopedist first. Then, the orthopedist suggested doing operation because his feet have an abnormal position that needs an operation for stretching the tendon. It was decided to operate without thinking whether it was going to hurt him or not. I just wanted him to get better...After the operation, he had casts on. When I first saw him, I felt sorry for my son. I had never thought that he would be like this. I just wanted him to be able to walk. I observed that the doctor made unequal casts - one foot is like this and the other one is like that. So, his feet were twisted. Significantly, he felt itchy. It was torture because he had to have the casts on for three months. It was better when the doctor cut the casts. His feet have no problem - abnormal position. But he still has other problems such as he walks with putting weight inside like this. (ID6-M-2-P. 11)

The participants in this research inquiry were informed by health personnel that this condition could not be cured, and advised to keep practising physiotherapy in order to maintain the normal part of the brain which might compensate for the damaged area.

The doctor said that her brain was not normal. For that reason, we have to keep doing physiotherapy in order to stimulate some part of the brain around the damaged areas and maybe compensate to some extent. But it will be difficult to completely restore her to normality - there are no drugs to treat this. (ID5-F-1-P. 3)

However, they continued to search for other forms of treatment. Participants tried alternative treatments such as taking Thai herbal medicine, taking a bath with herbal medicine, trying Thai traditional massage, and other alternative ways. This practice of trialling a series of alternative treatments as well as medical treatments is illustrated by the following series of excerpts from the mother of ID6 cited above.

At Kow Din National Park, a person told me that her child was like this and she bought boiling medicine at the Rachabanjong temple. Then she fed the child; pouring it into the child's mouth for one year. After that the child was able to walk and could take care of himself but he looked drowsy. So, I took my son to the temple then brought the herbal medicine back. I fed him around one month as she said, "Give it to him glass by glass. Close your eyes and don't look at him to see how your child is". I could not do it. I just fed him a spoonful at a time but I could not do it much because it is very bitter. I felt so sorry for my son. I tried it myself and it is very bitter. I decided to quit. We had enough. In the end, we gave up this sort of medicine. (ID6-M-2-P. 8)

After that, my elder cousin found the vine herbal name 'Yen', which might be good for ID6's condition and he brought it to me. He suggested to boil it, then use the herbal water in a bath for ID6. So I did, I used it to bath my child. I observed that my child would itch all over his body because it might have some sort of fluid come out from the vine. I followed his instruction by giving ID6 a bath with the vine herbal several times but it took time for the result. So, I did it for a while - not for a year. (ID6-M-2-P. 8)

I have a friend who suggested herbal medicine - what is it's name?...They make it in capsule form and you put it in water. It is very bitter. When you take it you have to hold your breath. But he got used to it and I have given it to him for a year. For this medicine, it worked obviously. I think when ID6 takes the medicine, it affects to release the spasm inside. Then he is able to

make expressive sounds clearer. Usually when he has spasm, the internal organs such as stomach, liver and kidneys should be in spasm. When we give him massage, it can relax only the external muscles. When he takes the medicine, I think it works, so I fed him for a long time. (ID6-M-2-P. 9)

After that then it's massaging traditional Thai style...They applied oil all over his body then started to massage firmly until my child cried. It is not doing as physiotherapy but it seems to help - it relaxes the muscles of his limbs. I had to bring him to the massage every day; we had to wake up in the early morning in order to get in the queue at 6 a.m. (ID6-M-2-P. 9)

A 12-year-old girl with spastic diplegia, when asked to write what she wanted me to know about herself, described the sequence of seeking treatment from doctors and taking Thai herbal medicine as a part of seeking to be able to walk.

When I was little, Mum took me walking and I walked 2 or 3 steps, then no more. Since then, I have not been able to walk and have arrived in this condition today. Mum has taken me to see several doctors, but without results. Then, she got some herbal medicine that is around there. She tried to treat me with the herbal but it didn't work. So then I began school when a person told us about a school for disabled persons at Khon Kaen.

Figure 6.4 *The record of a child with cerebral palsy* reproduced with permission

Furthermore, some participants in this study tried other alternative folk treatments in the hope that their child could learn to walk. For instance, the parents of a 14-year-old girl tried the folk treatments of snake gliding and crawling under elephant's tummy. They believed that the procedure of snake gliding might help the girl's condition improve so that she could walk. Meantime, crawling under elephant's tummy was believed to make her stronger.

She walked slowly with her hip. At that time, she was able to move like that. Then, at age of three, I took her to snake specialist. I just wanted her to be able to walk. He got the snake to glide over her legs. I think she definitely improved. People keep saying that he treats persons who have this sort of problem by means of snakes, so everyone goes. I forget the name of the village he is in. it is a very big snake, with a patterned body, but I do not know what species it is. It is about twice the size of my arm. He asks the people who cannot walk to lie down side-by-side and then he gets the snake to slither over their legs. That is the treatment. He claims that it will improve the

condition, and that they will be able to walk. I have taken my daughter twice. (ID11-M-1-P. 2-3)

We follow the recognised treatments as well as that with the snake...The snake glides over the legs, and it makes the condition improve. It is a python. There is no danger because there is a snake specialist there, and nothing harmful will happen. I only want my daughter to be able to walk. There is another treatment - I took her to pass under the belly of an elephant. People said she would gain strength by doing this so I took her. I take her to every treatment there is. Any treatment which people speak well of, I take her to them all. (ID11-F-1-P. 6-7)

In addition to seeking medical and alternative treatments for their child, participants actively engaged in *finding ways to rehabilitate* the child. The substantive code *finding ways to rehabilitate* consists of practising at physiotherapy, adapting or creating equipment for practising, doing exercise or games for increasing muscle tone, and practising in Thai traditional ways.

The participants began taking the child to physiotherapy at the hospital once the doctor informed them about the health condition of the child.

Both of us (ID9 and I) always went together (doing physiotherapy at the hospital)...I brought her to the Udonthani hospital when the doctor made an appointment every 3 months. Every time to go to the hospital, I had to carry her then took a bus to go there. We went there for practice but they didn't do anything else. It was just practice around 30 minutes then went back home. There were so many children there. About 50 kilometres from my house to the hospital. It also took a very long time waiting for the doctor. We spent half-day waiting. We went there in the morning then went back home about 1 p.m. in the afternoon. Then I practiced her as the doctor suggested such as bent her knees, let her sit on her knees and did things similar to that. I did that continuously. (ID9-M-1-P. 14-16)

I took her to the Physiotherapy unit at Srinakarind hospital when ID15 was about 18 months old. I had to carry her there continuously until all the doctors remembered me, and ID15 has been used as a case... They explained to me that her brain was severely deficient in oxygen and that she might be disabled. They sent me to physiotherapy with her. ID15 went every day in accordance with their advice. They said she should come to do physiotherapy to follow doctor's orders. So, we follow what the doctor advised us without a break. I took her to physiotherapy always until she reached the age when she entered school. (ID15-GF-1-P. 1-3)

Besides this, the participants tried to adapt and create equipment for practice based on what they saw at physiotherapy at the hospital. The mother of a seven-year-old girl with spastic diplegia described buying a tricycle, sitting the child on it and spinning the wheels for her. As well, she made rails for her to practice walking.

Well, then I bought ID9 a bicycle for her to ride, it is actually a tricycle, but she couldn't ride it. I then spin the wheels around. At that time, she could not do it by herself. I spun the wheels for her then spun around and around. Yes. I spun it while she sat on the tricycle. And I also made the rails for her to practice walking. She walked by holding on to the rail and other things. (ID9-M-1-P. 14-16)

The father and the babysitter of ID5 also created rails for walking designed to meet the particular needs of the child, including a lower support bar to separate her legs while she is walking and a sandy base for stability, as illustrated in Figure 6.5. Another mother, who has a 12-year-old son with athetoid cerebral palsy, adapted everyday equipment- a rice cart and bicycles- to actively encourage her son to walk. She expressed pride in her ability to provide equipment for her son.



Figure 6.5 *The equipment for training to walk from ID5's family* reproduced with permission

I trained ID8 to walk by pushing the cart used for carting rice. Yes, it has a bin on it and wheels on each side. I took the wheels off and gave it to him to push. He stands and pulls it. His legs act as the wheels as he stands and pushes, then walks after it. I encourage him by saying "oh, that's good, baby!" I let him practice with it. That was my own idea. I had an idea when I saw the cart, then I modified it by taking off the wheels. He pushes the thing around and it gives him walking practice...The other thing for training to walk is a bicycle. This is the second one that he guides himself by hand on this one. If he rides on it he will fall over. He guides himself with it, he gets himself along on it, so, he was able to walk with the bicycle. He also used the little bike with the trainer wheels he could sit on. He loved to bike it until it was broken. Now, he is too big to ride it. He enjoyed riding it - this bicycle has wheels that can bring him to wherever he wants to go. The important thing is that he was able to keep himself balanced with the bicycle. The three-wheeled one with pedals. As soon as we get a new one, he will be happy and content. I am able to do every thing for my son. (ID8-M-1-P. 12-13, 23)

Another father of an eight-year-old boy with spastic diplegia described buying a trolley from the supermarket to train his son to walk. Comprehending the nature of children he created specific equipment that integrated playing with practising to walk. For example, to encourage the boy to walk, he asked a little girl, who lived nearby to be company by sitting in the trolley. In addition he created other equipment as illustrated in Figure 6.6 and Figure 6.7 below.

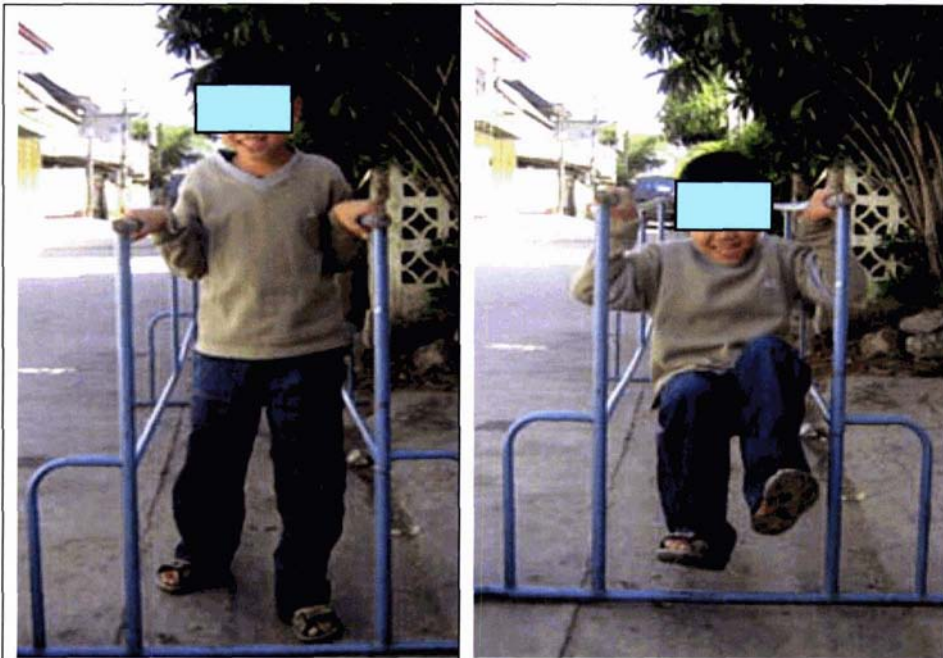


Figure 6.6 Tools designed for training ID14 to walk

Note: These pictures are reproduced with permission of the father of ID14.

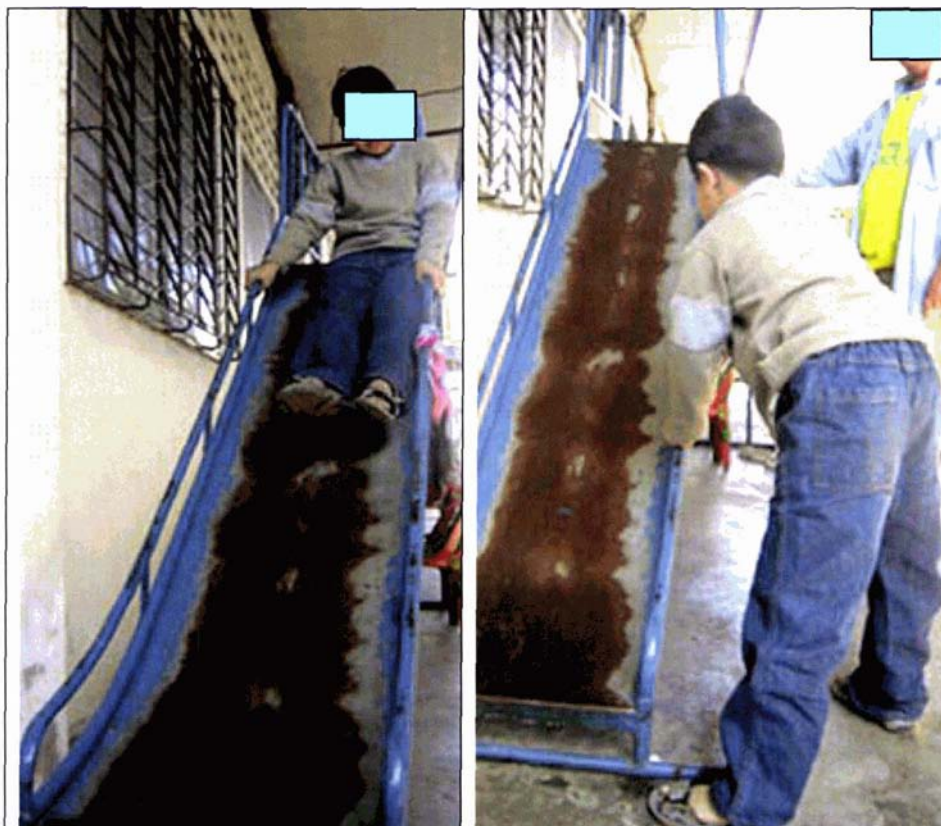


Figure 6.7 Tools designed for training ID14 to walk

Note: These pictures are reproduced with permission of the father of ID14.

I created a specific thing for training to walk that has double long rails (see Figure 6.6). I designed it by myself then asked a friend to make it. That was another thing, the slide (see Figure 6.7). I urged ID14 to climb up on it to play. He can both climb up and slide down, but it doesn't have a railing so we tried some wood to link between the down side and the raised side. He has to walk past by grabbing the wood and climbs up this way. It is the way for training and playing simultaneously. It worked. At first, he really loved it; he spent all day on it as well as the rails, but, after a long time, he gets bored with these (laughs). (ID14-F-2-P. 6)

Several participants tried to find other ways to rehabilitate their child such as doing exercise or playing games for increasing muscle tone. Not only the parents, but neighbours also try to encourage them.

I would like the boy to be stronger. Normally he likes boxing the most. I tell him to embrace my neck and butt with his knee. When he falls over flat, I tell him to put a cushion down first. That way his head will not hit the floor and cause pain. He nodded his agreement. I try to teach him how to fall on both sides. He is not strong on the left. So I tell him to use his right arm to support himself when he is about to fall on the left. I make him box on his

left often. If he doesn't comply, I won't play. He is stronger now. If his legs entangle (scissor position) like this, I get him to use both hands and disengage them. "Well, uncross them of course!" He will try and do it, and he laughs. When he falls, and his head lowers too, I count, "One. If I reach ten, you've lost. It's now two. Hurry. Get up!" I count. "Right. One...two....it will be three already!" On "three" he will hurry to get back up. Sometimes we kick a ball, or throw a football. We kick it like this and catch it like this. In this way I play with him, because I would like him to be strong. (ID4-N-1-P. 2)

Normally, in the early morning, I went out for a jog or walk first. In the meanwhile ID14 has already prepared himself then he went for a walk with me. When he walked passed the market the stallholders shout out "hey, running, running". He didn't answer anything, just laughed. If he was near the corner shop here, they will shout out, "OK, swing your arms" and he swung his arms "sometimes we walk 2 or 3 times round". He did not feel tired at all. (ID14-F-2-P. 9)

The most popular way to rehabilitate the child is by training him/her to walk with bamboo railing as illustrated in Figure 6.8 below. Parents described other ways to train the child such as digging a waist deep hole to stand the child in, that enabled the caregiver to concurrently carry out other activities of daily living such as cooking or harvesting rice in the fields.



Figure 6.8 *The bamboo railings for walking training*

Note: These pictures are reproduced with the permission of the mother of ID15.

Then, my neighbours told us to cut bamboo and make two long railings like this. So, there were long parallel bars where we built it under the tamarind tree at the back of the house. They were just the right size for his hands. My son did it barefooted - that was comfortable for him. This is the second rails because he enjoyed walking with the rail... Sometimes, I trained him to stand alone by digging a small hole that is just right for him with the depth of his waist; put him standing in the hole and then cover with soil. I gave him some toys for playing with. He got tired and had pain in his legs when he stood for a long while. Then, I picked him up. Sometimes, he cried because small red ants in the sandy soil bite him. I really got angry with myself that I enjoyed doing housework such as cooking and other things. I was afraid that the ants might bit my son again, so I changed to the new hole around there. When this developed, I covered the old hole then dug the new ones for him again and again. Sometimes I went out to harvest rice and I also took him with me. I put him in the hole under a tamarind tree in the shade and give him toys along too. (ID8-M-1-P. 9-12)

Having positive feelings

The final concept in the subcategory ***learning to live with the situation*** is having positive feelings; this concept describes the feeling of peace and happiness that arises in participants' minds when they have accomplished facing the situation and learning to deal with the situation by themselves. The participants express their feelings with a sense of happiness even though they live with the burden of caregiving on an ongoing basis. This concept consists of three substantive codes: *feeling happy*, *being proud of oneself and others*, and *gaining spirit to fight from oneself/others*. The first substantive code *feeling happy* comprises being with, love them as they are, to be with a child with cerebral palsy, with small achievement, and being accepted by others. All of the participants, especially the parents, describe love of their child even if the child cannot do anything, cannot speak a word – the participants love him/her just as he/she is.

However, I love him. The more he is like this, the more I love him, and the more he is like this, the more I am concerned for him. Every day, I am really concerned for him. (ID8-F-1-P. 11-14)

Mothers, in particular, live with a much greater sense of suffering when they separate from the child, such as when the child goes to the boarding school for

disabled children. They may be worried about how the child survives without his/her mother. Does he/she take care of him/herself? Therefore, the parents are happy when they are with a child with cerebral palsy. One strategy reported to resolve this situation is to live and work at the boarding school with the child.

I'm happy to be with my daughter. It's great to be here. It's the best to have the opportunity to be with her. I'm satisfied. I don't want to struggle elsewhere. I don't want to work anywhere else because I want to stay with her. I concede even though I get a little amount of salary. I am happy to be with my daughter. I'm satisfied. When she finished her study we will go back home together. As I love her, I'm happy so I don't want to struggle anywhere else. (ID9-M-2-P. 4)...(ID9) Mom, I love you, mom...(M) I love you too. We both love each other. She always tells me that she loves me so much...(ID9) now, I feel like...I feel completely at my home here...to be here. (M) She said she felt like she lives at her home. (ID9-M&CP-1-P .8, 13)

All parents in this research have a sense of anxiety about their children. The condition of the child is a significant factor that weighs on the participants' minds and they still have a hope that the condition of the child might gradually improve. Thus small achievements on the part of the child bring happiness to the parents and/or caregiver. It might be easy for normal children to do something like writing their full name, alphabet, or number, but it is hard work for a child with cerebral palsy. Significantly, these activities indicate coordination of their fine motor and cognitive development.

I am truly happy bringing them up! I am just being happy, and have well accepted my child's capabilities (It is okay!). Even though when I heard my child sing a song following the song then that would get me really happy regardless if my child could sing very little of it. I am truly so happy when I heard my child reading Thai alphabets, even though she did not know the meaning of it but just can pronounce it that would be enough to get me real happy. I would tell others about it...She would draw a circle "This is an eye. Here, I am drawing you picture, papa." She is doing on her picture and she is okay. I am so happy for that very much (Oh ho)! (ID5-F-1-P. 19-22)

The Figures 6.9 and 6.10 below present work of children with cerebral palsy. The parents of these children are very happy with their capabilities. The first child, an eight-year-old boy with spastic diplegia, shows his ability to write the entire Thai alphabet sequentially even though the characteristics of a few letters are not correct – demonstrating cognitive development. In the same way, the

drawing of the second child, a 12-year-old boy with athetoid diplegia, is evidence of his mental and cognitive development whereby it illustrates the capability to distinguish between male and female. According to Kellogg (1970, 1979) and Santrock (2007) this drawing is classified into the pictorial stage, which is the highest of four stages of mental development. At this stage, children create work that is easily recognisable by adults. In this drawing he uses hair as the significant sex determinant as he has learned from society that the female has long hair whereas the male is identified by short hair.

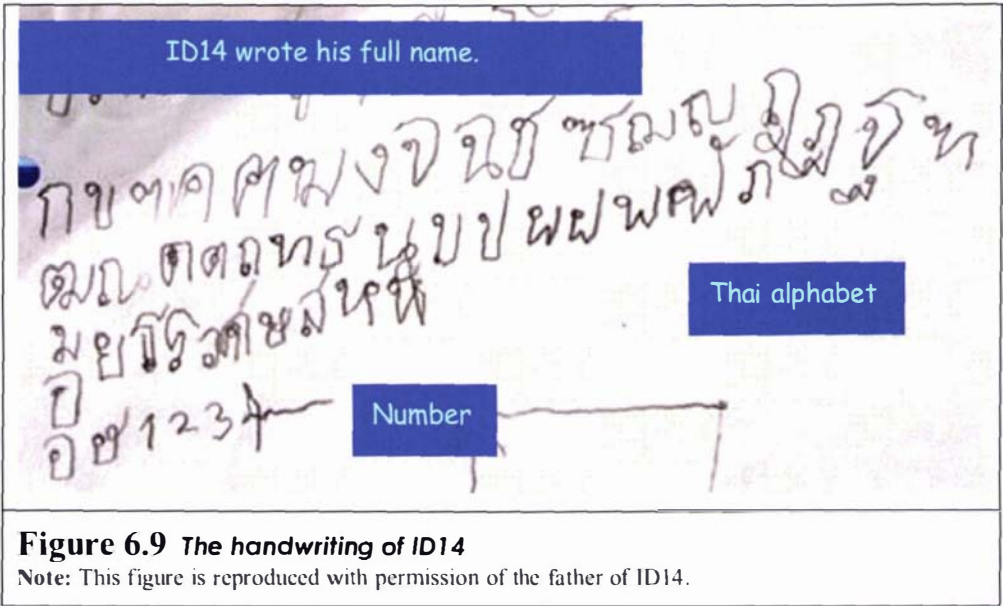
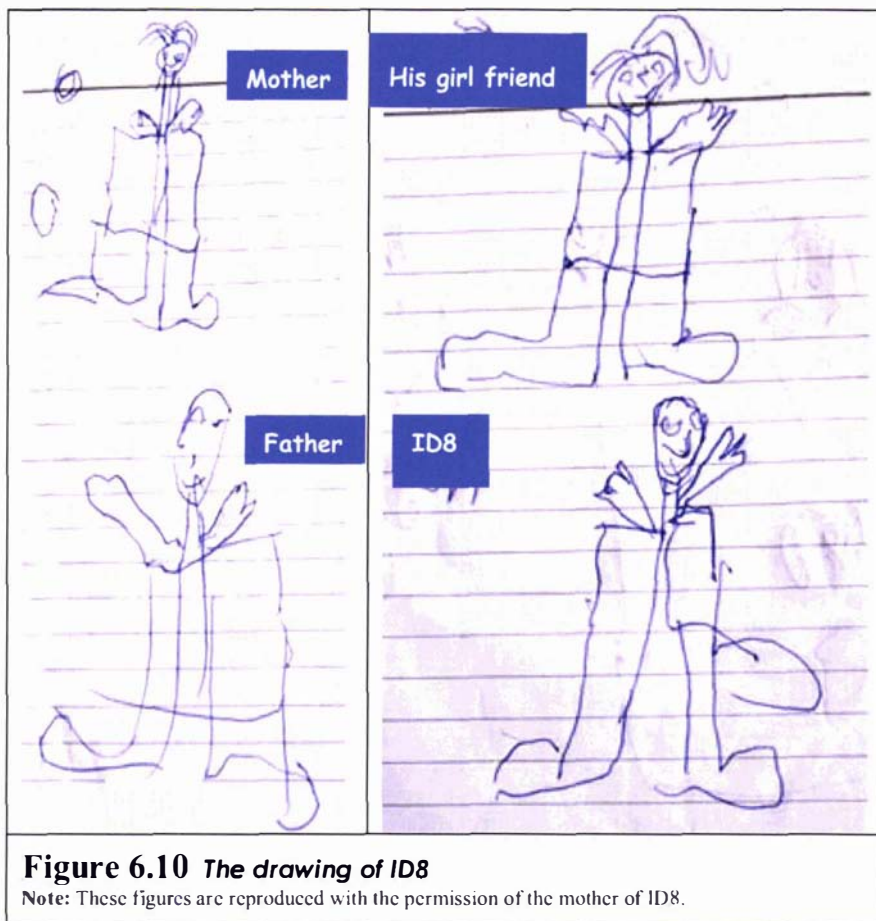


Figure 6.9 *The handwriting of ID14*
Note: This figure is reproduced with permission of the father of ID14.



A babysitter of an eight-year-old child described the father's joy that his daughter showed some [limited] progress in development.

While I was practising ID5 to sit by supporting her with pillows and a blanket, her father came to visit her at my house. At that moment, when he saw her, he cried with joy. Then, he gave his daughter a hand and asked her to hold his hand. She could hold his hand loosely...He was really happy till crying. He held his daughter then he gave her massage. (ID5-BS-1-P. 6)

Likewise, the mother of a little girl with spastic diplegia expressed her feeling of surprise and joy when she discovered that her daughter was able to walk with a walker. This discovery held much meaning for her – it meant that the ultimate goal, which is that the girl can take care of herself, nearly came true.

Then the doctor said, "Let me see how you can walk". So, ID7 grasped the walker then walked. (Laughs). "My goodness! How long has my child been walking?" The doctor said, "Of course she can walk. I am going, "Good heavens! Since when could she walk?" As soon as we reached the school - we had a walker because the doctor had ordered one for us - I wanted to show my friends in the kitchen where they lunched together. "Come quickly! To see

something!" (Laughs). I gave her the walker then she walked in front of them all. She was keen to please me. Tears flowed. I was overjoyed...Now she kept walking all the time. It is a new thing. And she is keen to please me. She walks every day. In the evening she hurries to finish her dinner then goes out to have walking competitions with friends...It is such a wonderful thing. She has lots of friends who cheer her on. They follow her and their cheering makes her grunt with the extra effort! Dear me, when events like this happen, there is no explaining it. I can honestly say that it is beyond explanation for me. This is as much as I hoped for. If she has achieved this much, it will not be long before it gets better and better all by itself. I am overcome with joy. I am so glad that words cannot describe how I feel. (ID7-M-1-P. 36-37)

As earlier discussed, the participants are very sensitive to the reaction of people in society. The children with cerebral palsy also feel uncomfortable and unhappy when they face challenging situations since they are more concerned about the reaction of their friends and other teenagers. However, they will be happy when they are accepted by others in the society. For example a 14-year-old girl with spastic hemiplegia, who had a wonderful experience of having friends when she was young, recalled her happiness that she was accepted to be part of 'the gang'.

When I was a child, I had a friend next door...He would believe in me...He accepted me. He accepted my condition... After that his friends formed our own group. At that time, all of my friends were boys...If they were in a large group, they would all trust me. They would take me there, take me here take me everywhere. Let's go collecting that, go collecting this, they would all go. No disagreements or opposition. They would be concerned for me, to the ultimate. Whatever I ordered, they would do it for me. They would help me. Washing my feet - very well too. Because we walked in mud when we went fishing. They served me very well indeed. They all accepted me. (ID11-CP-2-P. 11)

As long as they take care of a child with cerebral palsy, the participants realise that it is really hard to live with, manage and get through challenging circumstances that come inevitably into their daily lives. Consequently, they have developed a sense of admiration of people who are able to handle a challenging situation. *Being proud of oneself and others* is the second substantive code of the concept of 'having positive feelings'. The code includes being proud of themselves, a child with the condition, and others. The following quotations demonstrate how the parents are proud of a child with cerebral palsy

– because of their achievements, even when in the case of ID6 he was unwilling to disclose his abilities to the teacher.

ID5 has a good memory of what are the things that her babysitter had said (when we go shopping). Then, she would let me know what she wants beforehand...She has a very good memory on this matter, and would never forget it until I have already bought it for her. She would say like, "I still remember all right, papa."...she just straight asks for it, and I would tell her like, "Okay, papa went to see the thing that you want but it was not there then; when it becomes available papa will buy it for you all right." Even though I had told her so, she is still begging for it. (ID5-F-1-P. 19)

ID6 doesn't speak much. He always avoids eye contact. Perhaps he needs to get used to people before he will speak. *Phleng chaad*³⁷, *phleng khrainoh*³⁸, *phleng khaanaamnom*³⁹, whatever the song, he sings them all. *Phleng sanrasern phrabaramee*⁴⁰ included. But he would not sing to the teacher who conducted the tests, so he failed. He failed because he would not sing for the teacher to hear him. I have to guide him for this. I am the only one who knows the way to get him to sing a song. The teacher didn't know that way, so he didn't do it and so the teacher said, "I am going to give him to fail the test, you know". (Laughs). (ID6-M-1-P. 12)

The participants, in particular the parents who take responsibility as the main caregiver of a child with the condition, are proud of themselves that they can manage their situation and live a normal life. A mother of a 12-year-old boy with severe cerebral palsy expressed her feelings of pride in herself in response to the feedback from others about her parenting skills and knowledge.

The other people always said, "Where did they say the registration for the model mother is open? In my case, I don't even have to enter the competition they have already given the title to me. (Laugh) And the other people said that I am the most adept at dealing with this situation, being the iron lady, brave woman, and the best of the women and so on... I went to see Dr. R from Pra Mongkut she said "For you, I do not need to give you any more suggestions. You know it all. (Laughs)" Please tell. I don't know if there is something that I don't know. (ID6-M-2-P. 1, 8-9)

³⁷ Phleng chaad refers to the national anthem.

³⁸ Phleng khrainoh refers to a Thai classical song about the value of mothers.

³⁹ Phleng khaanaamnom refers to a Thai classical song about the value of breast milk.

⁴⁰ Phleng sanrasern phrabaramee refers to a Thai classical song normally used to respect the King.

A neighbour, who takes care of a four-year-old boy with spastic diplegia when the grandfather – the main caregiver – has to go out, describes her pride that she can give the boy love and affection.

I can give the little boy, ID4, affection and love and I get happiness back. He must be happy when he returns home and looks for grandmother. He must be glad. I think he must get a lot of encouragement. He feels happy. And I also feel happy that I can give him happiness. I can't give him any silver and gold, I cannot look after him but I can give him encouragement. The thing that he lacks, isn't that right? He doesn't have a father or a mother. And living with his grandparents, I am not a relative. We do not know each other. We are friends in the world. I just think that I can give him love and I get a sense of pride in doing this. I'm proud of the fact that I am able to give the boy feelings of happiness. (ID4-N-1-P. 11-12)

Furthermore, the health personnel and the non-health personnel, who are involved in managing the child with cerebral palsy, also develop this sense of pride from their work. A physiotherapist, who works as a teacher at the boarding special school for disabled children, shared her feeling of being proud of herself for her contribution to the progress of a child's development. Similarly, another teacher, who works at the third special school feels proud of herself that the children love her.

For ID7's mother, when she told me that her daughter could walk and she was really happy with first walking of her daughter, I took much more courage from them. I told myself that is my ability. When my colleagues said that, in this year, several children are able to walk, I am really glad to be a part of this success. (ID16-PTA-1-P. 28)

In the early morning, the grandfather sent ID15 to school after she had stayed home for a long while. When she first saw me, she started crying even when she was still in the car. I picked her up then she hugged me tightly and she had a big cry. I felt...I felt really glad that I am able to make children miss me like this. (ID17-TK-1-P. 19)

Likewise, the father of an 11-year-old girl with athetoid quadriplegia, is very proud of his wife, the step-mother of his daughter, who has given up her job to take care of the child as the main caregiver – day and night.

I am really glad that she (step-mother) can take care of my daughter even when she takes a pee or takes a bowel motion. I feel proud of her. (ID13-F-1-P. 8)

The last substantive code of the concept, having positive feelings is *gaining spirit to fight*. Most participants found that they are able to *gain spirit to fight* from within themselves and from observing other people, who face the same situation.

The spirit to fight has to come from myself. That means it is in our self and my daughter. It does not come from anywhere else, it is in us ourselves. We encourage ourselves such as this is ours, this is a person who actually belongs to me. This is a special thing. I am the only one she has in this world. (ID2-M-1-P. 9)

Then, the other thing is our child who is the spirit to fight of us. (ID7-M-2-P. 27)

A mother of a 14-year-old girl with spastic diplegia described using the technique of social comparison to gain spirit to fight.

I think that other people have much more trouble than I have. They have to work and they have no grandparents who can help them. They live with their children in a nuclear family...They are faced with the worst situation because both of their kids are disabled children. They are worse than mine, meanwhile I have some normal children (lightly laugh). ...I gain more spirit to fight from others who have more trouble than me. I think my situation is better than others. (ID15-M-1(2)-P. 2, 4)

From the participants' perspectives, *spirit to fight* is the result of considering their own situation, and that of others – as in the example above – then identifying some aspects of their situation that motivate and empower them to continue taking care of a child with cerebral palsy. *Gaining spirit to fight* is the counterpoint to the use of *thum jai* and *plong* (described in the previous chapter) to accept the situation as it is. Each of these techniques enables the participants to have positive feelings about their situation.

Conclusion

The core category **Living with** demonstrates how the participants in this research inquiry learn to live with the situation in which they find themselves. The first subcategory *learning to live with the situation* is supported by four concepts dealing with the situation, strategies to bring them up, physical

health treatment and having positive feelings. As illustrated in Figure 6.1, in each cycle of facing a situation and dealing with it, they learn more about living with, and caring for, a child with cerebral palsy and gaining satisfaction from their achievements and those of their child. In the next chapter, the second subcategory of the core category living with: ***preparing for an uncertain future*** will be presented. Just as the participants have learned from their own situations in the past and the present, the majority have a plan for taking care of the child in the future, even though they recognise the reality of this particular situation as an uncertain future.

Chapter 7

Living with:

Preparing for an uncertain future

Introduction

As previously described, three core categories: **enduring despair**, **culture of obligation and responsibility**, and **living with** are the cornerstones of the basic social psychological process of *never-ending caring* for a child with cerebral palsy. This chapter, which is the last of four chapters of research findings, elaborates the supporting data for the second part of the core category **Living with: *preparing for an uncertain future***. This process reflects how participants address their concerns about the future of the child and what preparations they make for this.

Preparing for an uncertain future

The subcategory *preparing for an uncertain future* indicates the great sense of worry and love of the parents and the caregivers that is directed toward the future of their child with cerebral palsy, even though they realise that the future is uncertain. Some participants create a future plan for the child, based upon what they have learned from both their previous and present experiences, while others are not able to find the way out of their situations. This subcategory consists of the three theoretical concepts: vulnerability of a child with CP, living with hope, and planning for the future (Table 7.1).

Table 7.1 Living with the Third Core Category of *Never-Ending Caring* for a Child with Cerebral Palsy (Part 2: *Preparing for an Uncertain Future*)

TP	Core categories	Subcategories	Concepts	Codes
Learning to live with, and care for, a child with CP	Living with	<i>Preparing for an uncertain future</i>	Vulnerability of a child with CP	<i>Suffering within oneself</i> <i>Being taken advantage of</i> <i>Sexual victimization</i>
			Planning for the future	<i>Having a good plan for the future</i> <i>Unable to decide (Future in the dark)</i>
			Living with hope	<i>Hoping for acceptance in society</i> <i>Hoping with unrealistic wishes</i>

Vulnerability of a child with CP

The concept of vulnerability of a child with cerebral palsy describes how the participants recognise the child with cerebral palsy as a vulnerable person. Children with cerebral palsy have problems in relation to the brain’s ability to control movement and posture, depending upon the severity of the damage to the brain as a result of diverse causes such as development, infection, metabolism, and genetic syndromes (Behrman, Kliegman, & Jenson, 2004; Miller & Clark, 1998; National Institute of Neurological Disorders & Stroke (NINDS), 2006). In this study, some children were not able to control their upper or lower limbs while others were affected in all of their extremities. Some children also had other health complications such as hearing loss, low vision, speech, behaviour, and intellectual problems. The children with cerebral palsy always have these “associated disorders including abnormalities of cognition, vision, hearing, language, cortical sensation, attention, vigilance and behaviour” (Miller & Clark, 1998, p. 6). Consequently, the participants, especially the parents and the main caregivers, were very worried about the future of these children.

The theoretical concept **vulnerability of a child with CP** is supported by three substantive codes: *suffering within oneself*, *being taken advantage of*, and *sexual*

victimization. An example of *suffering within oneself* is the prediction of a mother, who has a seven-year-old girl with spastic diplegia, about the future suffering of her child, once she becomes more aware of her situation. The mother describes her own despair whenever she thinks about the future of her daughter, and notices that the little girl might be beginning to be aware of the implications of her differences from others.

...when she grows up she will suffer just like I do. I think she will suffer from being abnormal and not like other children. When she starts to grow up I think she is going to suffer. She doesn't have any reactions right now... However, I notice that she sometimes thinks about herself. When we go to respect the Buddha's image she makes a wish to be able to walk. At that time, I think she knows a bit; she might have a few thoughts about that. (ID9-M-2-P. 24)

The following quotation illustrates a father's fears that his 12-year-old daughter with spastic diplegia is at risk of *being taken advantage of* in the future. He recognises the impact of her disability and that it will be difficult for her to survive without her parents. As a result he tries to encourage his daughter to become as well educated at the special school as she can.

If ID11 has better knowledge than other people, she can help herself, isn't that true? She has a problem with her legs but she has a good brain that makes sure that no one could deceive and take advantage of her even if they try it would be difficult for them to do because she would have knowledge. (ID11-F-2-P. 8)

Being taken advantage of is a perceived risk for girls and boys. However, participants, who are caring for a girl with cerebral palsy, are always aware about the feminine-vulnerable risk. They try to stay alert for information regarding *sexual victimization* then try to protect the child from risk of harm. A grandmother of an 11-year-old girl with severe cerebral palsy described the experience of finding that her granddaughter had been raped by a drunken neighbour while she was out, reinforcing her worries about the uncertain future of her granddaughter.

I felt regret that my granddaughter was raped. At that moment, I could not take good care of her. It was too late when I found her; she lost a lot of blood. I wanted to kill that guy. As the result, we must keep precautions since it might happen again. It is uncertain for the future. (ID13-GM-1-P. 10)

As a consequence of this incident, other families reported paying more attention to protect their girls from this sort of harm. For example, the older sibling of a 14-year-old girl with spastic diplegia reported her worry about her sister even though the girl was looked after by a babysitter.

Most disabled women have it done (hysterectomy). As they are young women they might have something such as a bad thing happen to them. It is a dangerous issue for them. I am afraid of when she goes to school she might have bad guys do a bad thing to her. The previous babysitter always liked pushing the wheelchair everywhere around here. Then, I got worried. There are men who are drunkards living around here. Significantly, ID5 is a good-looking girl. I was worried about the worst possibilities. I was afraid for her...The current babysitter stays here all the time. So, we are not worried now. She doesn't take ID15 around anywhere and is at home always. But the former one, she loved taking ID15 for a long walk. (ID15-S-1-P. 6-7)

The theoretical concept of vulnerability of a child with cerebral palsy indicates the major concern experienced by all participants regarding the vulnerability of a child with cerebral palsy. Consequently, the participants – in particular the parents and the main caregivers – attempt to formulate a plan for the future of the child in order that the child may be cared for in society, living as normal a life as is possible.

Planning for the future

Planning for the future is formulated amidst a great sense of worry and love on the part of some parents and the family members who take responsibility as the main caregiver of the child. Unfortunately, some participants cannot find an appropriate solution for the situation they find themselves in. The theoretical concept **planning for the future** includes two substantive codes: *having a good plan for the future*, and *unable to decide (future in the dark)*. The first substantive code *having a good plan for the future* consists of planning for treatment and rehabilitation, preparing for a future caregiver, and finding occupation and education for a child with CP.

Participants understand that their children will have a better quality of life in the future if they are able to look after themselves, thus they keep alert for new possibilities for treatment and rehabilitation. The mother of a 14-year-old girl with spastic diplegia describes her intention to follow-up a treatment facility in another province, having seen an item about it on television.

Well, I just saw it flash on the TV. I don't know much more than that. Chiangmai province has a scheme for disabled persons or something. I want to go there and check it out. But I have no idea exactly what they do. As I understand, they have acupuncture and I saw lots of disabled children. They were more severe than my daughter, ID15 - with twisted hands and legs. It specially serves disabled children. I would like to take grandfather along to check it out. After watching it on TV then we chatted together about it. There were so many disabled children who were worse than ID15... Some parents were interviewed and they said their children got better. There was only one place - at the Lan -Na hospital or something like that. I would like to go and try it out. Hopefully, the doctor can apply acupuncture with her legs. It might work because she is able to step. (ID15-M-1(1)-P. 6-7)

The sense of worry about the future of a child with disability stems not only from the biological parents, but also the main caregivers and neighbours, who are not related to the child, but have developed attachments to the child through contributing to his/her care. A babysitter, who has provided care for an eight-year-old girl with spastic diplegia for five years, expressed her concern about the future of the little girl.

At this point, I think a lot about the future. Once, the father used to talk to me about, "Please tell the teacher to try to encourage her to practice, so that she can eventually look after herself. She is a girl, and then very soon she will have a period. It will pose problems". Then he said that when she gets older and she is absolutely able to go anywhere, he will give her a hysterectomy. He spoke of this and thought the same as me. At first, I thought he did not think anything about this, but he was concerned about her. He worried about her. (ID5-BS-2-P. 10)

A neighbour of a family with a four-year-old grandson with spastic diplegia also worries about the child's future. Anticipating his future without his grandparents, she tries to train him to carry out daily activities by himself.

I think there may not be anyone to help him in the future, and then I want to help him to be able to care for himself. So, it won't be a burden of anyone else. When he grows up, and the grandfather gets older, whatever can be done? Further on, when he is grown up but is unable to care for himself, what

will happen? So, I must teach him to do it now. To eat of his own accord, not in a messy, uncouth manner; to drink water, in small amounts at a time to avoid choking. If he chokes, the brain will be affected. I feel that this is not just about building a relationship or offering love to him, but it is about training him as well. (ID4-N-1-P. 18)

In addition to searching for new treatments, the participants also continue to plan and develop special apparatus to support their children to become more independent. An explicit example of this is the plan of ID15's mother.

Living over there, I will make parallel bars for ID15 to practice. I will ask a mechanic man to weld new steel railings for her. When she was young, she could use the bamboo railings but now that she has grown, she cannot really use them any more because she is heavy. We will make them of steel. I talked with her father yesterday about this...Keep training her to walk. Now, it is steel parallel bars what we plan to do. (ID15-M-2-P. 7)

All the parents in this research worried about what would happen when the child had to live without parents. It was important to establish a succession plan for caregivers, based – where possible – on cultural obligation and responsibility – preparing for a future caregiver.

I have already prepared at the best for ID6's future. In case one day in advance when he has not got me; how will he live? To assume that he has to live with other people, I have to have a plan for that situation...for the person who will look after him. I have this hope that I can depend on my family, particularly both the younger aunt and older aunty would love their nephew even though he is like this. He is the beloved of everyone. So, I trust that they could help me to look after him. (ID6-M-2-P. 3-4)

Consistent with the expectation that relatives will provide care, some mothers attempted to save money in order to be able to support both the future carer and their child – a form of reciprocity for the obligation to care. The differing financial circumstances of each family meant saving was not always possible.

I trust that my family will be able to look after ID6. As we (mother's family) are not rich persons; we just have enough for living. So, if my child has to be their burden, it's important that he must have the means in wealth that he won't become a burden to them. In the meanwhile, it should support their living. They will have to look after him so it will not be convenient for them to go out to work. So, I prepared the repayment for the kindness for them. It might cover living costs so they would not have to be striving looking for a job. And it could not be the cause of why they would have to abandon him. So, I must prepare any amount of money for him. One day when I die all this

should be to his benefit. This is my thoughts. Anyway, I have never talked to his father about this. I think he should prepare for our child also but he is a man of few words. I prepared by saving money, treasures, land, and some benefits from our work such as the insurance money for government officer and this... money added up. It will be a lot may be around a million baht. I think it should be enough for the living costs of my child and the person who will take care of him. That's cash and the other treasures. If it's not enough in cash they can sell the treasures. It's up to them what they do, so long as it is beneficial that is OK. I won't be stuck on that point. (ID6-M-2-P. 3)

I try to save some money as little by little in order to have a fund. But, I don't know how I can save it because my salary is very little. (2,000 baht per month, around \$ 80 per month @ \$ 1= 25 baht). As I live here (at the school), it's great that I don't need to buy anything...Well, I would save a part of it for my child. (ID9-M-2-P. 9)

Parents also planned to buy equipment that would enhance the independence of their child and that could be operated within the capabilities of the child.

There's another thing, which I will buy for her. It's a kind of small vehicle which has buttons to press because she is able to use her hands. It looks like a motorcycle; it also has the brake. I've seen an old woman who is not able to walk much and her children bought one for her. If ID15 grows up, she will be able to get in then go to anywhere. She will be able to control by pressing it. Then, she can change the direction where she wants to go by pressing the buttons then use the brake and so on. I think she can use it because she is able to comprehend. That's the thing that I will buy her. (ID15-M-2-P. 8)

Where a child had less capacity for developing independence, one mother wrote a detailed plan for a future caregiver, which documented how to look after her son. This document arose from her concern about her son's feelings, knowledge of his abilities and limitations and a desire that he receive good care after she was gone.

...also needing to prepare documentation of what to do with ID6 (Figure 7.1, 7.3), what things that he likes (Figure 7.2). If he does this, what does it mean? These things are prepared. I still keep writing... Right now it's only pieces of records, not yet gathered and sorted...I fully intend to write about what does it mean if he does like this. I am more concerned about my child's feelings. Since most people don't understand his feelings what he really needs now. They always use the criteria of normal children to make a decision. Why don't you do this? Even the father, "Why don't you do it? Sit up straight, sit up straight, do it right now otherwise you will get spanked". Then, he got spanking even though he did not do anything wrong. He cannot do it because

of his condition. I want his father to understand that if he wants the child to be able to do it, he needs to press at this point. (Demonstrate how to massage the back bones) Then the child would be able to sit up straight. If he tells ID6 to sit up straight without giving him any physical support, he cannot do it. Other people are like that too. So, I think I have to write these things down. It's a record of how to take care of him. I have already recorded the feelings when he was born. I have written it for a long time. It's the record of the feelings which I just wrote it immediately when I had that feeling. I think I have to gather up all my recordings and compile them before I die. It's a record for understanding. (ID6-M-2-P. 4-6)

For your information

It is natural for all mothers to love their own children, whether they are normal or not. Particularly, the mother of a disabled child, that special relationship deepens. I have a great deal of special concern around how to sustain his daily life. If I am not there, then whoever substitutes for me must have a reasonable understanding of how to attend to the child. Because of this concern, as a mother I have written these notes on the ways to look after my child, for the sake of both my child's happiness and your own, and I ask for your sympathy. Please pay attention to understanding my child also. If I have the good fortune to be with my child until he is adult then it will be good. But if I have only limited merit and must pass on, then I am concerned that my child will receive the same kind of care that I would have given him, or similar tending to what I would do or close to it.

ID6's Mother

Figure 7.1 *The front page of the guideline document for taking care of ID6, written by the mother and reproduced with her permission.*

Brushing Teeth

1

ID6 is not usually obstinate and will allow his teeth to be brushed with good grace. Sometimes however, he will avert his face making it necessary to adopt the following strategy:

1. Tell him beforehand that you are going to brush his teeth. Reinforce that by saying it will make the teeth clean and strong, and make his breath smell nice enough for someone to kiss him.
2. Gather the toothbrush, a bowl of water but no toothpaste. Place them close by, and position ID6 on his back with his head raised a little.
3. Wet the toothbrush in water and begin brushing his teeth. Hold the brush firmly but when brushing, DO NOT PRESS. Do not put weight upon the brushing motion. Brush the top front teeth and the bottom, outside and inside. Then brush the molars, left upper and lower, then right upper and lower, including the gums and palate. DO NOT PRESS. Brushes everywhere with a light touch. During brushing, he may turn his head away. You must gently support his face, DO NOT SQUEEZE. Speak soothingly to help him understand or maybe sing this song:

Brush the teeth; brush the teeth, every day, for strong teeth

Or any song which deals with brushing teeth

After you have brushed every part, he is to rinse his mouth, but mostly he will swallow because he cannot spit. When you pour a little water into his mouth, tilt his face to one side and tell him to spit it out. If he doesn't spit, do not worry about it. If you see his mouth is not yet clean, get him to rinse 2-3 times.

The task is then complete.

Figure 7.2 A part of the document about "Brushing teeth" in the guidelines for taking care of ID6, written by the mother and reproduced with her permission.

Things he likes**2**

ID6 likes riding in a motorcycle sidecar, taking trips to places. He enjoys getting out of the house. Perhaps this is because he cannot go anywhere himself. So he can become bored and wants to get out and about. Maybe you could take him out each day (in the motorcycle). In the wheelchair, there is no limit to the trips you could take him on. But you should change the destinations regularly.

If you tell him to wait, he is likely to do so, but he can be annoying when he makes frequent demands. (Try to) divert his interest by inviting him to join in an activity, play a game, massage, flex the fingers, stretch legs and arms in gymnastic fashion, sing or tell a story.

DO NOT Do not allow him to become troublesome or to sulk by leaving him alone too long. He will feel abandoned and develop a bad mood and may bite his wrists and arms.

PLEASE DO Attend to him with love, and also understand his condition.

BEFORE GOING TO BED He loves being hugged, to be told a story, having his back scratched. These give him warm comfort and he sleeps deeply. Before sleeping, he must also have a full stomach and if at all hungry, he will not sleep. He will rise and ask for some dessert or milk and you should have a carton of milk in storage for him. (Chocolate-flavoured milk)

FAVORITE THINGS Listening to music. If you have tasks to do and must look after him simultaneously, then turn on music which he likes, and play the other side when it is finished or keep changing the cassette as often as he requests. You will be able to stay working for a long time.

If you empathise with him, ID6 is not difficult to care for. I ask you to please love him and understand his limitations, and respond to him according to his needs.

Figure 7.3 A part of the document about "Things ID6 likes" from the guidelines for taking care of ID6, written by the mother and reproduced with her permission

Parents also viewed having another normal child as a means of succession planning for future caregivers. This option was usually suggested by the mother, perhaps because she was more likely to be the main caregiver of a child, rather than the father. The mother of a twelve-year-old boy with athetoid diplegia, described how she broached the matter with her husband.

I spoke to my husband about wanting a normal child. "If you died, who is going to help me? I could not survive without my child. If I died, how can he survive in this world? So, I want another child, one who is normal". (ID8-M-1-P. 25)

Similarly, the mother of ID15 described a decision to have a third child to assist the older sister with future care of ID15.

If this child (ID15) had been born to be a healthy child, I would not have wanted the next one. Anyway, as I got ID15, so, I had another child six years later... Since I have known she is to be like this, I keep taking care of her...We had talked with my husband about the child being a disabled person. There was nobody to help us to look after her. So, we wanted another child because we think it is not enough that we just have the oldest child (who is normal). Well, ID15 is the same as not having anybody because she is a disabled person. There is a distance of age around 6 years in each one...It's good luck that we have a boy (the third child). His father really wanted a son. (ID15-M-1 (2)-P. 11, 14)

This strategy of having another, normal, child to assist with caregiving for the child with cerebral palsy was also adopted by step-parents. For example, a step-mother, who had to leave her job to be the main caregiver of an 11-year-old girl with severe cerebral palsy, expressed worry about the responsibility to care for the girl in the future, as the step-mother got older. Having, another, normal child was a way out of this situation from her perspective.

That's why I want another child in order to look after ID13. If she is still alive for a long time, then this child will grow up, and then look after her in our place, that's right? So, I want another, normal, child for looking after the sister because I get older and older each day. How can I raise her up? Anyway, my husband also wanted another child but he is afraid that it might get more troubles that another child might turn out to be a disabled child like ID13. He thought about that but I thought it might not happen again because we both are healthy. (ID13-SM-1-P. 7)

Considering the future of a child with cerebral palsy, the participants formulate plans for the education and occupation of a child with cerebral palsy. The plan varies depending on the condition and the capabilities of the child. The following quotations demonstrate how fathers plan for the education and occupation of the child. In the first instance, the father sets his hopes on the child learning to work with computers since she is able to sit by herself, to use her hands and to use verbal communication.

For the future, I'm taking a good look at it, but I still could not figure it out yet. But, I will do my best for her. Firstly, I must put her in school...After that, if she could do that then let her major in Computers, in which she would have a sitting type of work. (ID5-F-1-P. 7)

A second father, who has an eight-year-old boy with cerebral palsy, is thinking ahead to what his son could do, depending upon the capabilities that he develops. Currently the child is not able to walk independently, but can walk with apparatus. He can speak some words but not clearly.

I think it's good to have a plan that if he can walk; or if he can do anything though he is not able to learn anything or can learn as much as he can, then I would accept it. I would like to find an occupation for him. Since he has a good attitude, I think he might do something such as sell in a small grocery store just for survival...I wish he could do that. Then if he can study, I will give him full support for this because, recently, education focuses on a sense of importance among the disabled and special needs children who are able to share in class with normal ones. But, I think that it is difficult for them to enter into relationships with one another...We accept that whatever level he reaches, we will plan the future accordingly. He might stay at home. We may urge him into selling things in a small grocery store in which case he is able to study as much as he can. We would support that. We only think as far as that. I'm not bitterly disappointed. (ID14-F-1(2)-P. 4, 7, 23)

Taking into account the condition of her child, a mother of a teenage girl with spastic diplegia made a decision for the future of her daughter to let her stay at home with the family. ID15 uses wheelchairs rather than walks by walker, and is able to communicate by using non-verbal communication.

...anyway in about four years I think I will not let her go to school because she will be a young woman by then. (laughs softly). I will let her stay at home. To live there with me. (At her mother's kindergarten school). (ID15-M-2-P. 7)

Unable to decide is a substantive code that mirrors how some participants view their situations in the future – the future looks bleak. From their perspectives, it is very difficult to plan for the future. Even though they strive to work it out, they have unanswered questions in their minds, in particular the two significant queries: what will the future be and who will take care of? These are the most pressing questions that come up in their minds when they think about the future of the child without the current caregivers. These questions are particularly pressing where there are no alternative caregivers within a family network, as articulated by mothers who have only one child, and thus are unable to call upon siblings of the child to provide care.

I think if something happened to me (die), I would still think about my child, ID8. My husband would probably not think about it at all. As he said that if

he died, he would think nothing, it's over. Do not need to think about it any more. But, I think in a different way from him. If I died, how will he do? Then, my husband said that if we died, that means it's over, that's it. Why do you think too much? (ID8-M-1-P. 25)

I am worried about what is going to happen in the future...I'm not sure who is going to go to the other world first (who is going to die first). At that time, how is she going to live? Then I think, it doesn't matter, she can live with her dad. (ID2-M-1-P. 12-14)

While the situation of an uncertain future was experienced by all parents, and limited their ability to make firm plans for their child, some parents seemed unable to move forward to find acceptable solutions for any of their concerns. An explicit example of being unable to decide is the mother of a seven-year-old girl with spastic diplegia cited below, who expresses multiple worries about the future of her daughter, yet is quite unable to reach any conclusions.

When she becomes a young woman, will she be able to help herself in some way? I'm worried about it. She doesn't know what or how things happen. When she takes a shower by herself, she can do it but it doesn't clean. When she has a period, how should I do with this point? It seems to be completely in the dark, you know. It's completely in the dark. But it's not time yet. There is no need to think too much about it yet. When the time comes she might do it by herself. I tell myself it's not a big worry. I will just look after her steadily. When mother is not there, what will she do? Who will come and help, who will come and put her clothes on etc.? ...I'm worried about sex. It will reach at that point...I don't know what to do on this issue. I know it's impossible to keep watching her all the time. I sometimes have something to do. I don't know what to do about this. So, I just give her good care. For sterilisation, I do not dare to take her for sterilisation. I am afraid of hurting her. I sympathise with her. She has no idea what is going on. As an ordinary living then taking her off to be sterilised is a pathetic thing. I'm afraid to do it. I thought it might happen to her. I am more concerned about that so I cannot decide what I will do. I reach no conclusions. I don't know how I should do. Just wait and see...It is a tragic situation to me to take her from a happy home to sterilise her. It's completely in the dark. Whatever I think about, I get nowhere. I am worried about everything that could happen. I cannot resolve even one issue. My mind goes round in circles backwards and forwards. I'm confused. (ID9-M-2-P. 4-6)

A single mother of three children – the youngest child is a seven-year-old girl with spastic diplegia – shared her worry about her unresolved situation about who would be the main caregiver of the girl when the mother was no longer there. Even though she has two normal sons, she felt she could not rely on them.

She, ID7, is not able to look after herself. If she has no mother, how could she survive? As her two older brothers are male, so they are not the same as female. How will they take care of their sister? If she has no mother, how will they manage about their sister? And, how long will we be with her? If she grew up and then she can walk, go to the toilet and do other things, I will feel better...If she has no mother, how could she survive? Then, if her brothers have their own families, how will they take care of their sister? Their families if each of them has their own family, how should they do? When I thought about this I could not solve it. How should I do? (ID7-M-1-P. 31)

As attachment to the child develops from day-by-day caring, the participants, who take responsibility as the main caregiver of a child with the condition, have a much greater sense of worry about who will look after the child. Culturally, the main caregivers are grandparents, and the oldest child of the family. The following quotations illustrate the levels of concern of a grandmother, and an oldest child who each provide care for children with cerebral palsy.

If ID1 could go anywhere else by herself then I would be concerned less. I have much more concern about her when there is no mother and I as a grandmother (am not there) then who else would bring anything for her to eat. I truly have worries and concern for her. (ID1-GM-3-P. 6)

I will do my best to take care of her until death parts us. I think, it's better for her to go first. If I go first, who is going to look after her, she might have to wander around. Is there anybody who loves her like us? (ID15-S-1-P. 8-10)

Living with hope

Living with hope is a theoretical concept that mirrors how much the participants are concerned about the ability of children with cerebral palsy to sustain themselves, and to live with other people in society. The participants express their concerns through two kinds of hopes: *hoping for acceptance in society*, and *hoping with unrealistic wishes*. Participants who have had unpleasant experiences,

first hand, in relation to the attitudes of other people in society towards them and their child, have realistic expectations in relation to acceptance from society. Meanwhile, unrealistic hopes arise for the future of children with cerebral palsy, particularly in relation to how they will survive without the parents. The substantive code *hoping for acceptance in society* consists of accepting graciously children with cerebral palsy and family, and being a part of society. The participants in this research felt as though they are different from others, and if they were treated badly or feared being so, they developed a sense of inferiority. Therefore, they wish to be accepted graciously, which includes not looking down on, or reacting with disgust towards, children with cerebral palsy and their families, looking with sympathy, and giving a child with cerebral palsy a chance and a sense of spirit to fight.

The following quotations demonstrate the feelings of the siblings who have a sister or a brother with the condition. They are very sensitive toward the reaction of their friends or other people who are the same age as them. Firstly, a 13-year-old twin boy, whose twin brother has athetoid quadriplegia, opened his heart that he has suffered from having a sibling with the condition. When he went shopping with his family and walked along with his brother he felt like everyone, in particular teenagers, stared at his brother and him. Consequently, he felt uncomfortable and he tried to keep at a distance from his brother. At this point, he wishes other people would treat them as normal. Similarly, the other brothers, who have a little sister with spastic diplegia, let people in society know about their feelings. They have a hope to be treated as normal people in courteous ways – not looked down on, or reacted to with disgust, and treated with sympathy.

I would like to tell other people, do not stare at him, ID3. Treat him like an ordinary person. I don't like the way they treat him as a special child such as staring at him. I want them look on him as a normal person like them. It seems they are disgusted, and stare at us. (ID3-B-2-P. 16)

I don't want other people to disdain him. Don't insult us. If a family has a disabled sibling, then don't despise them. Because a disabled person also has a heart just like the rest of us but there is something about his arms and legs which are not like us. (ID7-B-1-P. 24-25)

My close friends didn't know that I have a sister who is a disabled person...my friends will mock as if, "Hey G, so you have a handicapped kid sister!" If they mocked, or teased me at all, I will tell them to stop and then I will tell my brother. (ID7-b-1-P. 11-12)

A mother of a twelve-year-old boy with athetoid diplegia shared her feeling with a sense of suffering about the situation. Then, she shared her hopes for sympathy from other people in society.

I would like everyone outside who comes and goes in the community to please look at us with sympathy. Do not look contemptuously on us or despise us but rather sympathise with us since we did not set out to be like this. Please try to sympathise with our feelings. As I am a mother so I have the deepest feelings. How do I explain about my feelings? I have bad feelings like a sensitive mind and having a sense of low value. It seems to heap up over me. Please encourage me. ID8, my son walks like...not quite normal. (ID8-M-2-P. 1-2)

A daughter of the babysitter of ID5 expresses concern about the feelings of the child, then suggests that everyone who lives in society should – give a child with cerebral palsy a chance and a sense of spirit to fight in order to prevent the child from feeling a sense of inferiority.

We should give the children like this a chance to do something, just as normal children get the chances. Don't blurt out "You can't do it". Let them play as children that age play. Don't go telling them, "No, you can't play with the others because you can't walk. I won't let you go with them". They will develop a sense of inferiority and a feeling of hurt. And, we should give them encouragement; look at them as a normal person. That is enough. (ID5-FM-2-P. 12-13)

Similarly a mother of a boy with athetoid diplegia seeks a chance for her son to be given a chance and spirit to fight.

When I talk to my son, I understand it all. So, I want other people to know that he is the same as other - normal - children, who have similar way of thinking...If they had not crowded around us then they would have come to play with him and given us spirit to fight, we would still be going to the school. (ID8-M-1-P. 19-21)

The expectation of being a part of society supports the substantive code *hoping for acceptance in society*. Participants in this study have a significant hope that people in society will understand their situation and accept children with the

condition and the families as a part of the society, so that the participants are able to handle their situation then live a normal life with a sense of happiness. A mother of a sixteen-year-old girl with severe cerebral palsy creates an interesting strategy for developing the understanding of other people regarding their situation by giving a chance to children living around her to learn the reality of an aspect in society – living with disabled persons.

This is the society to which ID2 gives an opportunity for other children who live next door to learn that in society, the same thing holds true. They will have a kind heart towards those who are like ID2 herself rather than taking the view that there is something wrong with them. Generally people would respond to her with questions, curiosity, whatever, but these children perceive that she is not well. So, they come and play with her then get used to the fact that she is like this... We open our hearts as we open our home, and these children are growing in their understanding that there are disabled children in the wider community just like this. At the very least I believe that these children will grow up to be good guys in the future because they have experienced in this way, and they will not be disgusted. Since they have learned, they get used to being with her; they always touch, show how much they love by kissing her on the cheek. Sometimes, they took care of ID2 as well, cuddling, feeding her milk and helping to change nappies. I am not saying that everyone should care for her all the time because she is handicapped and she is not able to fully look after herself. But ID2, even though she herself just lies, there she is able to inform and open the children's eyes to her condition. (ID2-M-2-P. 16-17)

A 14-year-old girl with spastic hemiplegia described the experience of being an object of ridicule when she was young. A group of teenagers jeered at her walking. This situation recurs as her walking still is not symmetrical – people look at her as a strange person. At this point, she has a hope to be accepted like a normal person in this society.

I would like other people to accept me...I want them to know that I am also a human and to think that I am like a normal person in the society. They do not need to say any words to me. I just want them to think that I am a person who is one of them. I then will be satisfied. (ID10-CP-2-P. 14-15)

The substantive code *hoping with unrealistic wishes* reflects that even though some participants realise the facts and the consequences of the child's condition, they still hold unrealistically high expectations, as to what the child might be able to do in the future. Given the condition of the child, these wishes are

unlikely to be successful, however such unobtainable hopes provide psychological support to participants in their daily lives.

The following quotations illustrate the wishes of some young children with cerebral palsy whose expectations are inspired by their parents. Even though they comprehend the fact that the condition of the child is hardly likely to improve, parents use unrealistic hopes to encourage the child to be able to live with his/her condition. A seven-year-old girl with spastic diplegia wishes to be good at study even though she is currently studying at kindergarten level. She also has another wish to be able to walk, however she prefers to use wheelchairs rather than to practice walking.

I (ID9) went by myself to respect as "Wai" the Buddha image." Mother - What did you ask for?" ID9- "To be a clever student...Mum, Mum, why didn't you give me a candle to offer for myself?" Mother - "We urged her to speak out the prayers to be able to walk, and to be good at studying and so on. She remembered all. (When she went to respect the Buddha image at the flagpole, how she had prayed). ID9 - "Please let me walk and please let me be clever at studying". (ID9-M&CP-1-P13)

Another example of this is the wish of an eight-year-old boy with spastic diplegia that is encouraged by his father. I observed the traditional activity for the "Loy kra-thong⁴¹" festival at the special school on 15th November 2005. Children brought "kra-thong⁴²" from their homes. All teachers and children joined in the activity by launching the kra-thong into a small swimming pool of the school, whereby the children, who were going to float the kra-thong, made a wish by themselves then let it into the water.

(R) At the Loy-Kra-Thong day we floated our offerings at the school. Father - "Do you remember?" (R) ID14 - "What did you pray for?" ID14 - "To be able to walk" (laughs), "to be able to walk" (laughs). Father - "That's right. You are able to walk soon. You are able to walk soon". ID14 - "To be able to walk, to be able to walk, to be able to walk." (laughs) (ID14-F&CP-P. 5)

⁴¹ Loy kra-thong refers to the annual Thai festival for, traditionally, showing how we honour the Goddess of Water. (*Thailand in the 90s*, The National Identity Office of the Prime Minister, 1991).

⁴² Kra-thong refers to a lotus-shaped vessel which, is traditionally, made of banana leaves and decorated with some flowers, a candle and three incense sticks. (*Thailand in the 90s*, The National Identity Office of the Prime Minister, 1991).

Where the children have a severe disability participants are more concerned about the future of the child, because they keep thinking that it is impossible to be able to look after the child forever. Then, they try to make unrealistic wishes for the child to be able to take care of himself/herself even though they realize that the wishes could hardly come true. A mother of a seven-year-old girl with spastic diplegia expresses her feeling with a great sense of worry about the future of her daughter. She has an ultimate hope that the girl will be able to take care of herself, a hope that from my perspective is not realistic given the severity of the child's condition.

The issue I am keen to resolve is that I really want her to be able to take care of herself. Find an occupation and be independent, not be a burden to anybody. In case I get too old, or fall down dead then I am taken from her. Then she can look after herself. My biggest worry now is what will she do to support herself? In case she doesn't have me for long. How will she survive? When she grows up, she will not have any relatives. In the future, when that time comes, who will she lean on? (ID9-M-2-P. 6)

Likewise, the step-father, who lives with a four-year-old with severe cerebral palsy, also set unrealistic expectations for the girl to be able to sit by herself and not to get sick, even though he realises the fact that, now, she is only able to lie down, smile and cry.

Anyway I will keep looking after her like this and I don't know if she will get better or not. I will do my best for her. The very least I want for her is to be strong and able to sit alone and to not get sick. Because, this kind of people if they get sick it would be difficult. They cannot tell us if they have some problems. If she has fever, we can touch and feel to find out. But, if she has other health problems that we could not find out by touching, like internal health problems, how should we do? For example, if she had abdominal pains, she could not tell us where the point was. The only thing she could do is cry. So, we didn't know what was going on with her. If it happened with adults who have the same situation like her, they can explain or point at abdomen or do anything we can guess that they might have a stomach pain. But ID1 doesn't know anything. That is why I won't let her get sick or have any health problems since we have not much ability to look after her. (ID1-SF-1-P. 6-7)

Grandparents who have experienced being the main caregivers of their grandchildren delineate their concerns about the future of their children. Like the parents, they have ultimate wishes and hopes for the children, in which the expectations deviate too much from the conditions of the children.

I wish he could walk, and accept and take responsibility for every aspect of his life so that he can share the burden of care somewhat. To start with taking care of himself, he should take care of himself when he goes to toilet and bathroom without any help from an adult. It shouldn't be a burden on an adult. I would like him to do these things himself and not depend on adults any more. (ID4-GF-1-P. 1, 5)

I think that my grandchild will be able to walk and to speak etc...As for walking ability, I would be so glad even if she could not walk normally. Never mind, if she could only get around. Even if she is unable to speak, it wouldn't matter. If only she could walk. That's my wishes. She knows how to interact properly with people. So, for her to be able to walk is my first wish. She would then be independent when she has grown up...In my heart, I would like her to completely recover as normal. (ID15-GF-1-P. 1, 8, 11)

Another example of the ultimate hopes of a young brother, who is the older brother of a seven-year-old girl with spastic diplegia, is illustrated below. He expresses his feelings toward the situation, and has a wish for his sister.

I would like my sister's disability to recover, and then she could walk...All this time, she has been handicapped. I don't want her to be like this. (ID7-b-1-P. 14)

These substantive codes reflect how the participants manage their concerns for the future through two significant hopes: realistic and unrealistic wishes. The participants employ the expectations as psychological support for a child with the condition, and also for themselves. Having hope for their future, realistic or unrealistic as those hopes may be, enables participants to continue to live with, and care for, the child day by day.

Conclusion

Living with, which is the third core category of the basic social psychological process *never-ending caring* of a child with cerebral palsy, is supported by two subcategories: *learning to live with, and care for, a child with CP* and *preparing for an uncertain future*. This process of the BSPP indicates how the participants learn from each challenging circumstance that they need to face and deal with,

and thus build their repertoire of knowledge and skills to care for their child. As each challenging circumstance comes into their life, they will face the new situation then learn to deal with it by employing their beliefs and the Buddhist philosophy. That is the cycle of the basic process by which they will move into another circle. In the same way, the process of a waterwheel, which is used in the following chapter, as a metaphor to depict the experience of the participants of this research inquiry, will rotate continually as *never-ending caring*.

Chapter 8

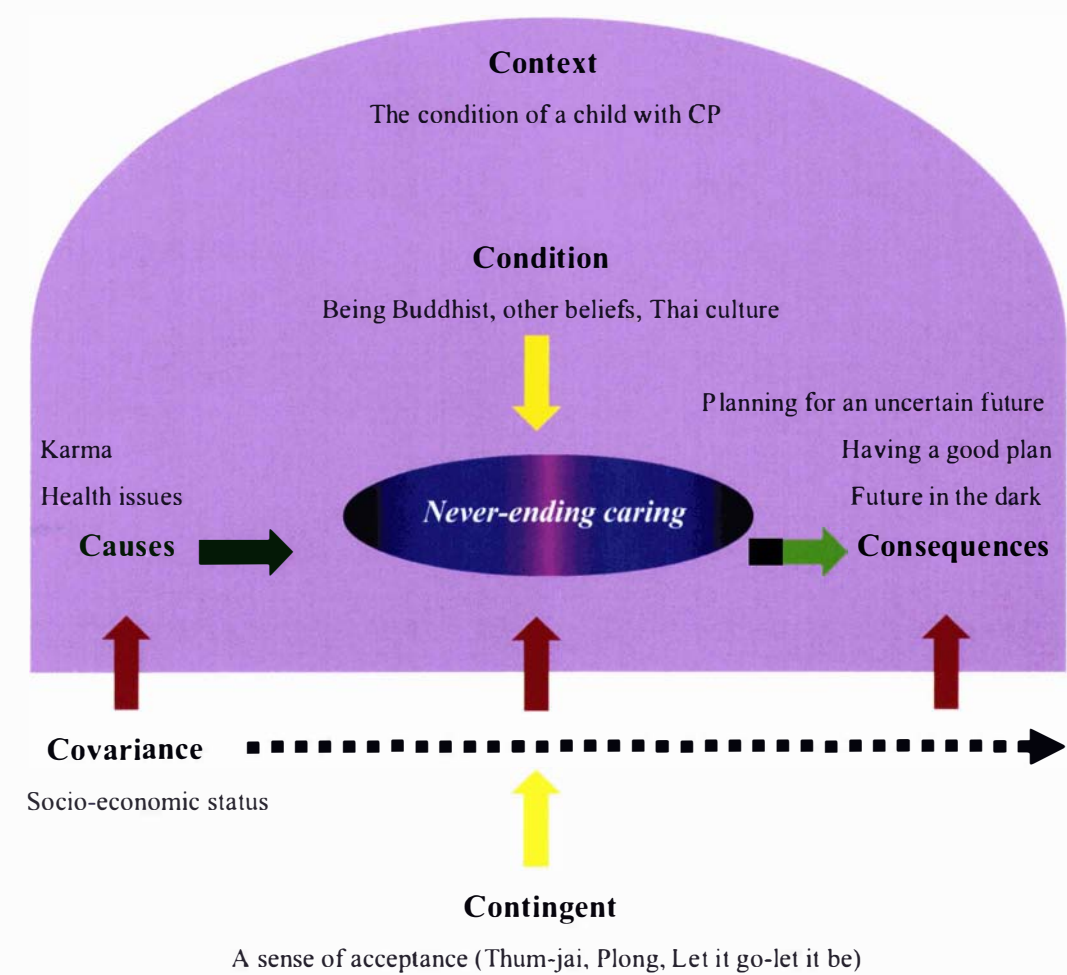
Never-ending caring

Introduction

In this chapter I present and argue the basic social psychological process of *Never-ending caring* for a child with cerebral palsy, based on the grounded theory analysis of this research inquiry. In order to understand the basic process that demonstrates explicitly how families living with a child with cerebral palsy, handle their situation, the theoretical components will be explicated in the light of the Six C's coding family of Glaser (1978) and the underpinning of symbolic interactionism. Then, in the light of the functional components of the theory, according to Meleis (2007), I will draw the theoretical framework based on the commonplaces of Stevens-Barnum (1998). Finally, to further explicate the basic process, I employ the metaphor of a waterwheel to depict the experiences of the participants in this study.

A Grounded theory of never-ending caring for a child with cerebral palsy

The diagram of never-ending caring for a child with cerebral palsy represents a substantive grounded theory which emerged from the analysis of the data. In light of the Six C's coding family of Glaser (1978), the significant concern of the participants about the phenomenon of living with a child with cerebral palsy is explained as *never-ending caring*, the basic social psychological process of this research inquiry (Figure 8.1).



■ The area of the Context of this phenomenon

Figure 8.1 Using the Six C's coding family of Glaser (1978) to explain the basic social psychological process of never-ending caring for a child with CP

The model was adapted from Glaser (1978). *Theoretical sensitivity*. Mill Valley, CA: Sociology Press.

The **Context** of the phenomenon under study refers to the conditions of the child with cerebral palsy. There are four types of cerebral palsy as outlined in Chapter Two (Table 2.2). Undoubtedly, the type of cerebral palsy and the severity of the associated conditions of the child have a strong impact on the experiences of those providing care for the child. Each family has a different way of managing this challenging situation. Culturally, the parents and the grandparents, who take up the initial responsibilities of the main caregiver for the child, pass on the significant obligation to the oldest child and other children, who are normal. Thus, while the child lives, the situation is experienced as never-ending caring for the child with the condition.

From the participants' perspectives, the **Cause** of this situation, which leads them to never-ending caring for a child with cerebral palsy, is attributed both to biomedical reasons and to their own religious beliefs. Several participants describe the causes of the child's condition in terms of the health issues of the babies and the mother. However, most participants still blame karma as the major cause of this phenomenon, consequently, they believe they have to pay back their *karma* by taking care of the child until the end of their lives or that of their child.

The **Covariance** of the situation reflects how the socioeconomic status of the family has a significant impact on the way of raising a child with cerebral palsy. Most participants live in nuclear families in which some are single mothers, which means that they have to hire a babysitter to look after the child. Some extended families manage their situation by arranging for a family member to be the main caregiver of the child – mostly grandparents take this responsibility, causing some to resign from their jobs. Caring for a child with cerebral palsy affects the socioeconomic status of all the families, however the financial impact differs according to the incomes of families.

As almost all participants in this study are Buddhist, the Buddhist philosophy, other beliefs and the Thai cultural context become the significant **Condition** of this phenomenon since these factors are important influences on participants' behaviours toward, and their understanding of, the situation they find themselves in. These factors have a strong influence on the way of raising the child with the condition in the Thai context. Participants learn to face the challenging circumstances that arise in a cyclical fashion throughout their lives with a sense of acceptance, by doing *thum-jai* and/or *plong* to realise the facts of the situation in which they cannot change anything, then they can set their minds to being normal. At this point, some participants do *let it go-let it be* for their situation, including what happened in the early stage of having the child and what will occur in the future. In other words, a sense of acceptance is the **Contingency** of this phenomenon.

Ultimately, as with the analysis of this research inquiry, the **Consequences** of the situation can be explained in terms of the future plan. Several participants, especially parents and the main caregivers, have a good plan for the future care of the child, even though they realise that it might be an uncertain future. One mother keeps blaming herself for the birth of her daughter on the road, an event to which she attributes the cause of her daughter's cerebral palsy, and remains stuck in a sense of despair. As a result she still has no plan for the future for both her daughter and herself – it seems like their future will be in the dark.

I will articulate the theoretical framework of the grounded theory of never-ending caring for a child with cerebral palsy based on the commonplaces of Stevens-Barnum (1998). The theoretical components consist of “person”, “others”, “interaction”, and “environment”, which will be explicated in the light of the symbolic interactionism.

Firstly, the **person** refers to the participants in this research inquiry, who have experienced living with a child with cerebral palsy. The person can be the family members including a child with the condition. In the light of symbolic interactionism, the participant, as a social object, has his/her own ways to deal with – and handle – challenging circumstances, which depend on the meaning that the participants attribute to the “object”. For instance, they might define a child with the condition, other people in the family and society as “the physical object” while their notions and other views are defined as “the abstract object”. They always use an interpretative process in their mind through social interaction with other people and also within themselves.

A good example of this is the reaction of the mother who was informed about the result of a CT scan of her baby. The mother, as the person, interacted with the doctor. As soon as the doctor informed her that the baby had the problem on his brain, she interpreted the terrible information in her mind, then she reacted with a long period of crying because the baby had much more “meaning” for her. At that moment, she acted within herself by thinking about the baby. Eventually,

she made a decision through an interpretative process to accept the situation by doing *thum-jai* – the result of interaction within herself in which she realised that the baby had a problem with his brain therefore he would grow up as a disabled child.

The **others** pertain to the people who are involved in the participants' experience of living with, and raising, a child with the condition. That is to say, as with my analysis, the others are the family members such as grandparents, siblings and their relatives who live with the family. Besides this, other people, who are not related to the child but who also take part in the treatment of the child's condition and the way of raising the child, are people in society such as neighbours, physiotherapists, teachers, doctors, nurses, other parents and caregivers, babysitters, friends, other people in society who face the same situation as they do. To illustrate, from the oldest sister's viewpoint, she plays a role as "the person" so the parents and the other family members and a child with cerebral palsy will be "the others" of their social interaction. In the meantime, if we focus on the perspective of a child with the condition, "the others" can be the other family members and his/her parents. Therefore, each participant plays a role in both "the person" and "the others" in the social interactions of their daily lives.

The **act** includes both interactions with others, and within themselves. As they learn to live with and raise the child with the condition, the participants in this study have to face challenging circumstances in which they need to interact with other people who surround them. Sometimes they have to encounter negative views from people in society, such as a sense of social disgust. Alternatively, they interact with other parents and caregivers who are willing to share their experiences with other families in the same situation. The participants also learn to interact within themselves in dealing with challenging situations by employing the Buddhist philosophy to accept the situation by doing *thum-jai*, *plong*, and *let it go-let it be*, then they are able to live with their condition with a sense of peacefulness.

The **environment** refers to the sociocultural environment in the Thai context that impacts on their behaviours towards the situation in both negative and positive ways such as the information from news and TV programmes, the negative views from other people, sharing experiences of having a child with the condition among the parents, the main caregivers, and babysitters. Some participants felt sorry for themselves when they faced social disgust from other people in society. Moreover, as long as they take care of a child with cerebral palsy, the health conditions of the child also impact on the way of life of the participants. They always feel happy with the progress of the child even though it is such a small achievement of what the child can do. On the other hand, the parents will be worried about their children if they have no progress in their development – cannot crawl, sit, or walk. Overall, the nature of all sorts of environments has the potential to influence their actions and notions regarding the situation. In the following section, I will explicate the process of never-ending caring for a child with cerebral palsy.

Never-ending caring for a child with cerebral palsy

The participants in this research inquiry have their own ways of thinking toward the situation which are directly influenced by both Thai culture and the Buddhist philosophy. They also integrate realistic experiences, thus they always learn from others who face a situation like theirs. The following assumptions underpin the process of never-ending caring for a child with cerebral palsy:

1. Each participant has his/her own way to face, and deal with, the situation. It is a unique way.
2. All participants have the potential to deal with the situation.
3. The severity of the situation is dependent upon the sensitivity of the participant.
4. The situation is allowed to get into one's mind and then use of the mind is the only way to deal with it. It occurs like a continuous cycle.

The *never-ending caring* for a child with cerebral palsy is a continual process, the experience of which is dependent on how the participants face, and deal with, the situation. As long as they continue taking care of a child with cerebral palsy, challenging circumstances always come into the participants' lives, as a result they employ the Buddhist philosophy and their other beliefs to handle the situations and thus to maintain their lives as normal. At this point, some can manage their conditions, then live with a sense of peacefulness. In the meantime, others feel like it is too hard to deal with, thus, they live with a sense of ongoing suffering for a long while. These phenomena might happen again and again similarly, the direction of the arrow always moves like a cycle, all the time throughout their lives of *never-ending caring* for a child with cerebral palsy (see Figure 4.1). To further explicate the basic social psychological process (BSPP) of *never-ending caring* for a child with cerebral palsy, I employed the metaphor of a waterwheel, which is one of the traditional Thai irrigation systems, to illustrate the experience of families who have experienced living with a child with the condition in Thai cultural context (Figure 8.2). As with earlier analysis, the basic process consists of three processes: Facing the situation, learning to deal with the situation by themselves, and learning to live with, and care for, a child with cerebral palsy.

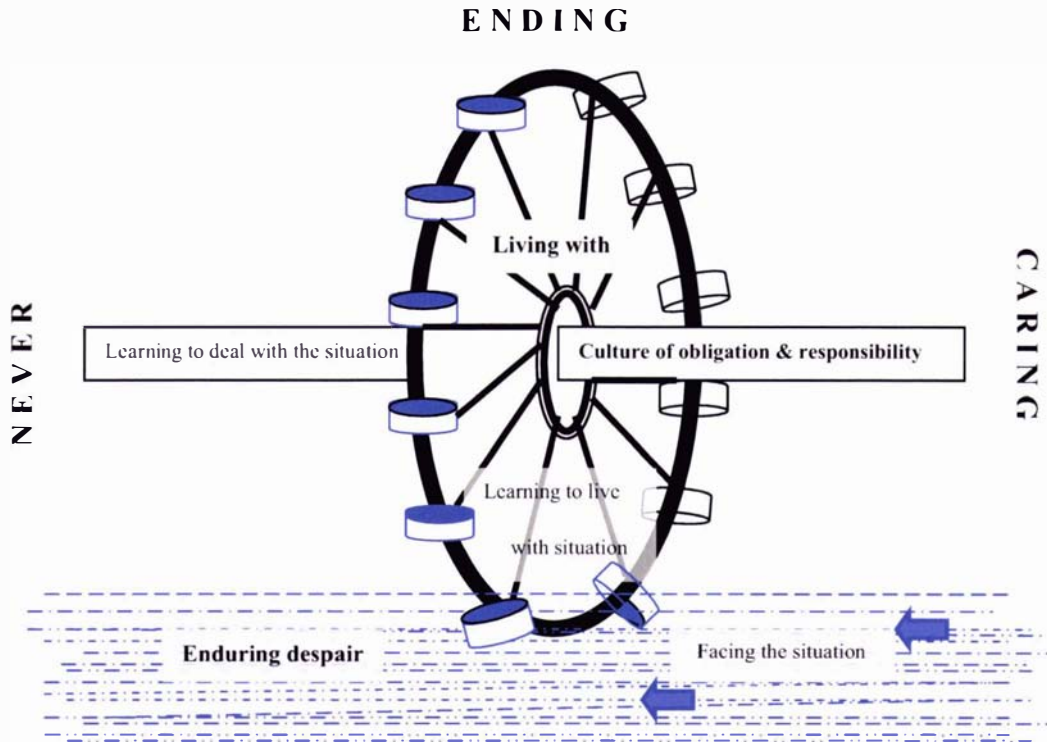


Figure 8.2 *The metaphor of a waterwheel*

Facing the situation

The substantive grounded theory of *never-ending caring* for a child with cerebral palsy emerged from the perceptions of the participants. The metaphor of the process of a waterwheel helps to draw the whole picture of their experiences. Then we can understand what is going on in their lives, particularly the basic process which they use to manage challenging circumstances. To begin with, facing the situation is the first process of the BSPP that is located in the first of three categories, **enduring despair**. This process illustrates how the participants face difficult situations, which happen not only in the early stage of having a child with the condition, but occur repeatedly throughout their lives while they take care of that child. From the moment that a child with this condition was born, the parents experience enduring despair through facing challenging circumstances again and again. Similarly, strong currents have much more power to be able to push water into the buckets of the waterwheel in which the water

represents the burden of caring for a child with cerebral palsy in their daily lives. As long as they take care of a child with cerebral palsy, the participants who take responsibility as the main caregiver of the child have a much greater sense of suffering in their minds even though many years have gone by. This feeling of suffering can be viewed as the amount of water that always fills the buckets of the waterwheel so that the waterwheel is too heavy to move. It reflects the burden of day by day caring for a child with the condition that they have to carry on throughout their lives.

Significantly, the participants are very sensitive toward circumstances that might be a normal situation happening in their daily lives. Inevitably, challenging situations always get into the participants' lives on an ongoing basis of living with, and taking care of, a child with the condition – likewise the current flows continuously through the waterwheel. Each participant responds in different ways. From their perspectives, some participants think it is hard to get over the situation while others can handle it. That is to say, the challenging circumstance might affect the sibling while it may not impact the parents, even though they live in the same family. Likewise, the current might directly affect some waterwheels so that it has more power to fill up the buckets. In the meantime, the same sort of current cannot produce any effect on the others. At this point, they might be surrounded by the sense of **enduring despair** throughout their lives, depending on how they respond to the particular situations, and how long they are going to hold this sort of feeling in mind.

In the next process of BSPP, learning to deal with the situation by themselves, will demonstrate how the participants in this study learn to deal with the situation by themselves by employing the philosophy of Buddhism, their other beliefs, and Thai culture to manage their conditions.

Learning to deal with the situation by themselves

Consistent with my earlier analysis, the participants live with a sense of suffering when they face challenging circumstances, then try to find the way to handle the situation. Most participants explain the particular situation by blaming karma as the main cause of this phenomenon. In the light of the Buddhist philosophy, their other beliefs, including the Thai culture of obligation and responsibility, play an imperative role in the depth of their responses and notions regarding the situation, thus they are able to release themselves from this suffering by doing *thum-jai* and/or *plong* to accept the situation. Consistent with a sense of acceptance is a personal process which needs the individual capability to realise the fact and its consequences. At this point, some participants are able to reach at the sense of peacefulness in a short period of time, while the others need more and more time to consider the fact. Therefore, some participants, who are able to set their minds to accept the situation as it is, will be able to live with their conditions, and then can maintain their daily lives as normal – living with a sense of happiness and peacefulness for a long while until the next challenging situation comes into their lives.

Consistent with the metaphor of the waterwheel, the participants in this study employ the philosophy of Buddhism, their beliefs, and their culture of obligation and responsibility to lubricate the floating axle of the waterwheel for driving the wheel, which carries the buckets that are filled with water into a cycle at different speeds. When the participants apply these significant influences to set their attitude toward the particular situation, the axle will run as an effective mechanism. If some participants do not use these sorts of factors, the wheel will get stuck and cannot move any more because of the rusty axle. When participants are able to deal easily with a challenging situation the wheel will go fast. In the meanwhile, others participants – who might be adults or children – feel that it is too difficult to deal with their conditions, therefore, the wheel will move slowly. It will take more time to push the wheel, until it reaches the top of the cycle. At that moment, they will be happy under their condition, and the water will be

gradually poured out from the buckets, and then they will reach peace of mind when the buckets are free from water. Significantly, this challenging circumstance has no more effect on the participants whenever they are able to employ psychological influences, such as the Buddhist philosophy, their other beliefs, and Thai culture, to deal with this sort of situation. In the same way, the currents have no more power to push water into the buckets. Furthermore, the participants can learn some point of view from the situation in order to improve their lives with their condition, particularly in their interactions with other people in society.

Learning to live with, and care for, a child with cerebral palsy

Basically, the participants learn directly from challenging circumstances which they have passed successfully. They also learn from other people who have the same situation as theirs. For example, some parents, who have a girl with cerebral palsy, have a much greater sense of worry with their daughter who is growing up to be a teenage girl. They learn from others, by watching the television programme to have their daughter sterilized. That is to say, in each cycle of their experiences, they will learn imperative issues in order to live with, and care for, a child with the condition. Compared with the metaphor of the waterwheel, after the participants accept situation A by doing *thum-jai* and/or *plong*, that means they realise the facts and the consequences of situation A, and they also learn how to live with this situation. Whether the situation continues to put pressure on them depends on how they think about it and how they deal with the challenging circumstance. For instance, participants, who dealt with the situation by avoiding it, or hiding themselves, remain affected by the situation. While those who are able to accept and learn to live with the situation, can move on in their daily lives. Therefore, the waterwheel that has an effective axle can run free from any resistance. That is to say, situation A has no effect on them any more. Whenever another challenge inevitably occurs in their lives, they need to deal with, and learn how to live with and handle, the new situation again.

Conclusion

The experience of families who live with a child with cerebral palsy in the Thai cultural context is a unique process which is resolved by the basic social psychological process of never-ending caring for a child with cerebral palsy. Even though they live in the same family, each member will have his/her own way to deal with the situation. Likewise, each person has his/her own waterwheel which is different in speed, amount of water in its buckets, and sensitivity towards the current. Some waterwheels might have a slow speed while others might have a quick speed even though they are in the same condition of the current. The process of a waterwheel helps us to understand a sense of the burden of caring and how hard it is for caregivers and families to get through this situation. It seems like an amount of water in the buckets of the waterwheel which they have to carry along day by day caring for a child with the condition.

Chapter 9

Discussion, limitations and implications

Introduction

Never-ending caring is the substantive theory which has been derived from this grounded theory research. The process of never-ending caring for a child with cerebral palsy helps us to understand what is going on in the families who live with a child with the condition in the Thai cultural context. Significantly, being able to understand the underlying ways of thinking of families about their situation is an effective means to enable both healthcare professionals and non-healthcare professionals, who work with these families, to enhance the quality of their efforts to encourage the families to achieve quality of life. This research inquiry has relevance for healthcare, particularly in relation to chronic health conditions; therefore, in this chapter, I discuss the findings in relation to extant literature, and the implications for practice, education, and further research, respectively. This chapter also includes the limitations of the study.

Discussion

The experience of families who live with, and care for, a child with cerebral palsy within the Thai cultural context, is a unique process that is elucidated by the substantive theory of *never-ending caring*. The theory is inductively derived from the data and reflects the beliefs and perspectives that underpin the participants' behaviour, particularly in relation to how they raise a child with cerebral palsy. Culture and religion play an important role during the experience of raising a child with this condition. A sense of enduring despair on the part of parents and caregivers in relation to the burden of caregiving and the uncertain

future of the child, and societal disgust in relation to children with a visible disability are important components of the experience of caregiving.

In this study, the main caregivers of a child with cerebral palsy were grandparent(s), or great-grandparent depending upon the characteristics of the family. This finding contrasts with other literature (for example, Baranowski & Schilmoeller, 1999; Green, 2001) suggesting that – in a western context – grandparents are more likely to provide a secondary support role than to be the primary caregiver in families with disabled children. Green found that grandparents were a common source of weekly assistance, while Baranowski and Schilmoeller identified a range of ways that grandparents assist including sharing coping strategies, advising about childrearing, assisting with errands, finding helpful information, helping access community resources and services related to disabilities, providing respite, offering emotional support to their grandchild's parents and keeping hope alive.

In Thailand, traditionally within an extended family the grandparent(s) was/were expected to take responsibility as the main caregiver(s) of a child with disability, while in a nuclear family the parent(s) had to manage by themselves. All families in this study faced problems as the grandparent or the great-grandparent aged and the dependent child grew bigger and heavier. Therefore, succession planning for a main caregiver was an issue for most families. In the Thai context, the *culture of obligation and responsibility* arising from Buddhist philosophy underpins the problem-solving strategies of participants in this study.

Buddhism...has borne a strong influence in Thai society. Buddhism, as interpreted in terms of cultural expressions, has long been associated with the Thai way of life, attitudes, and codes of behaviour of individuals at both societal and family levels. Moreover, in the past Buddhism played a very significant role in a person's life from childhood to old age. (Limanonda, 1995, p. 67)

The *culture of obligation* is intergenerational; siblings, particularly the oldest child, are positioned to be the next caregiver(s) to replace grandparent(s) and parent(s) in the future. Traditionally, older Thai children take responsibility to

look after younger siblings, then the older ones would request the younger ones to perform tasks (Smith, 1979).

All the Buddhist caregivers expressed belief in the law of karma as “Good karma (*kusala*) produces good effects, and bad karma (*akusala*) produces bad effects” (Rahula, 1962, p. 32), thus cerebral palsy could be understood as the result of their volitional actions in a previous life. As a consequence, they accepted this burden of obligation by taking care of the child as the way to pay back their karma, even until the end of their lives. These findings are consistent with those from prior research, which has demonstrated the meaningful and powerful contribution of religious beliefs (not only Buddhist beliefs) in people who encounter challenging situations (Burnard, Naiyapatana, & Lloyd, 2006; Marshall et al., 2003; Rungreangkulkij & Chesla, 2001; Subgranon & Lund, 2000; Yamey & Greenwood, 2004).

Further support for the impact of religious beliefs in the Thai context, was provided by an international study conducted by the WHO Quality of Life (QoL) Group in 18 countries across differing regions: Americas, Europe, the Middle East, Africa, and Asia, in which the aim was “to observe how spiritual, religious and personal beliefs (SRPB) relate to quality of life (QoL)” (WHOQOL SRPB Group, 2006, p. 1486). In this study, it was reported that “SRPB was highly correlated with all of the six WHOQOL domains: physical, psychological, independence, social, environmental and spirituality” (pp. 1486, 1488). Moreover, the study reported that, in relation to strength of belief, Thailand was one of five countries – including Brazil, Egypt, Kenya and Turkey – that were extremely religious. Of particular importance, the participants in my study employed a sense of acceptance from Buddhist philosophy, expressed as *thum jai*, *plong*, and *let it go, let it be* to deal with the situation of caring for a child with cerebral palsy. This finding is consistent with those from the study by Rungreangkulkij and Chesla (2001) that reported Thai mothers, who have adult children with schizophrenia, practised doing “*thum jai*” and thus created a calm environment in their families to deal with their children’s symptoms.

The participants in this study also experienced a sense of despair and had persistent suffering with their situations. Even though their children were born many years ago, the sense of despair and suffering remained with them since they inevitably faced new and recurrent challenging circumstances throughout their lives. This finding is consistent with those from the qualitative study by Rungreangkulkij, Pothkamin and Rujiraphas (2003), which used Colaizzi's method for data analysis in order to explore the impact on families of having and raising a child with cerebral palsy at home. The study reported that this challenging situation had a direct effect on the family in both positive and negative aspects such as "on other family members, on family finance, family life cycle, and feeling difference from others, and family resiliency" (p. iii).

The qualitative study by Gravelle (1997) that explored the experience of parents caring at home for a child with a progressive life-threatening illness, conceptualised the parents' experiences as "an ongoing process of 'facing adversity', as parents had continuously to redefine and then manage those changes resulting from the progressive nature of their child's condition." (p. 738). The cyclical nature of facing and managing adversity described by Gravelle, is comparable to the cyclical nature of facing the situation and learning to deal with the situation outlined in Figure 4.1 of my study. However the notion of 'facing adversity' is a softer and more abstract notion than that of **enduring despair** described by my participants.

A link could be made between the category of **enduring despair** in my study and the concept of chronic sorrow coined by Olshansky (1962) on the basis of his personal and professional experiences working with children with severe retardation and their families at a Children's Developmental Clinic in the USA. Olshansky explained the phenomenon of chronic sorrow as a natural and pervasive psychological reaction of parents who have a child with disability. He postulated that the intensity of the sorrow depended on factors such as the personality of the parents, religion, social class and their ethnic group; and that it varied from time to time, from situation to situation, and from one family to

another. Copley and Bodensteiner (1987, p.68) suggest that the defining characteristics of chronic sorrow experienced by parents include:

1. Periodic, inescapable recurrences of pain and sadness
2. Roller-coaster cycles of elation and depression fueled by denial.
3. Grief for the loss of the idealized normal child
4. Satisfaction and joy from the disabled child may coexist with chronic sorrow.

The concept of chronic sorrow has been widely utilised, particularly in relation to chronic health conditions (for example, Burke, Eakes, & Hainsworth, 1999; Gravelle, 1997; Lowes & Lyne, 2000; Northington, 2000). More recently, Green (2007) argues that the notion of severe emotional distress [chronic sorrow] has been over emphasized in research on caring for children with disabilities; and that both the benefits of caring for a child with disability and the negative consequences of stigma and socio-structural constraints have been de-emphasised. Both of the latter aspects are identified in my study.

While there are some points of commonality between my study and these previous studies, there are also points of difference. I argue that one strength of my study is that the substantive grounded theory of *never-ending caring* elucidates this particular phenomenon of living with, and caring for, a child with cerebral palsy in more depth than comparable studies, and without recourse to existing concepts and theory, such as adaptation and resilience (Rungreangkulkij, et al., 2003) or illness trajectory (Gravelle, 1997). Moreover, this research inquiry identifies the large influence of Buddhist philosophy and the Thai culture of obligation and responsibility on the ways in which participants in this research managed that process. To illustrate this phenomenon, the metaphor of a waterwheel (as explained in Chapter Eight) was used to depict how the basic process works; for example, the participants were able to release themselves from the sense of suffering in each challenging circumstance that inevitably came into their lives, by doing *thum-jai* and/or *plong* in order to accept those conditions. As a result, the personal process of acceptance enabled the

participants to reach a sense of peacefulness for a time, until a new challenging situation came into their lives.

Self-blame in relation to the cause of cerebral palsy was evident in this study. However, a sense of blame is not only developed in countries where a Buddhist philosophy predominates, but is found in a variety of societies. A sense of blame may relate to cultural and educational factors, including knowledge related to health conditions as discussed in previous studies conducted in Cuba, the Dominican Republic, Hong Kong, Japan, Puerto Rico, Taiwan and the United Kingdom (Chiu, 2004; Chiu, Wei, & Lee, 2006; Fernandez & Arcia, 2004; Ferriter & Huband, 2003; Pun, Ma, & Lai, 2004; Saiki-Craighill, 2002).

Because cerebral palsy is a visible disability, the participants in this study felt ashamed about having a child with this condition, particularly when they experienced negative perspectives, described as *social disgust*, from other people in society. People with chronic conditions experience social rejection and stigmatisation related to the visibility of their health conditions (Joachim & Acorn, 2000). For example, Siriwatanamethanon (2008) reported on the impact of experiencing social disgust on people with HIV/AIDS in the Thai context. Persons who have a visible physical disability such as paraplegia experience more social stigmatisation than others who have an invisible chronic health condition such as diabetes. These findings are consistent with a wide body of literature that relates feelings of suffering [enduring despair] from the experience of stigma (Fernandez & Arcia, 2004; Glendy & Mackenzie, 1998; Green, 2003; Holroyd, 2003; Westbrook, Legge, & Pennay, 1993).

Limitations of the study

The limitations of this study are as follows:

1. The research findings are drawn from the experiences of families who live with – and care for – a child with cerebral palsy in a rural Thai

context, particularly in the areas of Khon Kaen, Northeast of Thailand, so the findings cannot be generalised beyond this cultural context.

2. Qualitative research methodologies that search for rich meaning in words and actions of participants are challenging to carry out and report when data are collected using the Thai language and I-san dialect, and reporting is in English. Multiple translations are required in moving to and from between Thai, Isan dialect and English during cycles of data analysis. Finding appropriate words in English to maintain the meaning of participants' perspectives is not straightforward; hence some Thai words are included in this thesis.

Implications

Nursing practice for:

Long-term care for a child with cerebral palsy

As the results of this study reveal that the experience of families who live with a child with cerebral palsy is *never-ending caring*, I assert that children with cerebral palsy and their families should receive ongoing care and support in the form of case management. The theory *never-ending caring* elucidates how families handle recurrent challenging circumstances. As such, the theory has the potential to enhance the quality of nursing practice in order to improve the quality of life of children with the condition and their families. Nursing case management of children with cerebral palsy and their families should be offered by Advanced Practice Nurses (APN), who have specialised in pediatric nursing care. Case management should operate across the care continuum, commencing from the initial diagnosis of cerebral palsy. Many children with cerebral palsy have other associated deficits – “poor vision, strabismus or nystagmus, hearing loss, cognitive impairments, speech or language delays, seizures, and growth problems (Mandleco, Wellington, & Wayner, 2007, p. 1103)”. Consequently, they require special care from caregivers for maintaining their daily lives. Sleight (2005) explored mothers' experience of feeding children with cerebral palsy by

mouth and via a gastrostomy tube and highlighted the need for expert advice and support, consistency of care, and careful relationship building between professional and family that acknowledged family expertise and facilitated normal family life. These findings support my recommendation to involve APN support.

To provide good care for the children with the condition, the APN should take an important role as a coordinator of services of other relevant professionals such as paediatricians, orthopedists, physiotherapists, occupational therapists and paediatric nurses. Significantly, the APN should encourage the parents or the main caregivers, who take care of the children, to participate in caring for their children while in hospital, then they will be able to take care of the children at home and to manage their condition by themselves. Consistent with the findings of my study, the APN should pay attention to the culture, religious and personal beliefs of caregivers that influence their behaviours, particularly the ways of taking care of a child with the condition. In order to enhance the quality of life of these groups of people, the APN and the other relevant professionals should integrate their knowledge in terms of medical sciences and an understanding of the beliefs and experiences of caregivers in order to improve the quality of their clinical practice.

To maintain quality healthcare along the care continuum, before hospital discharge, the APN should formulate long-term care plans for the children with the condition and their families together, with other appropriate health professionals and the community nurses, who take responsibility in that area; the plan to be implemented through a home visit programme. As illustrated in my study, living with a child with cerebral palsy has a considerable effect on all family members. Therefore, the APN and the team should be concerned about them – not only the child. Consistent with the policy for people with disabilities, Thailand has employed the strategy of Community Based Rehabilitation (CBR),

which was created by the three United Nations Organizations⁴³, for enhancing the quality of life of all people with disabilities through an integrated community development programme. Cheausuwantavee (2005, 2007) reported some positive aspects, which are powerful for continuing the CBR process in Thailand. However, he identified negative aspects that affect sustainability of the CBR projects such as the problem of limitation in service delivery, lack of knowledge and skills of CBR workers regarding disabilities and rehabilitation, and negative attitudes toward disabled persons in society (Cheausuwantavee, 2005, p. 64).

As earlier stated, encountering the adverse attitudes of other people in terms of experiencing social disgust has much effect on the daily life of children with cerebral palsy and their families. Therefore, in order to enhance the quality of life of all people with disabilities, the APN should combine the concept of CBR and nursing management for implementing long-term care for children with cerebral palsy and their families.

It is important that the children with cerebral palsy and their families and the community should be involved in the creation and adaptation of the long-term care plan. All family members, who live with a child with the condition, become the most important resource for running CBR strategy while the community, including health and non-health professionals, will be used as the local resources. The community non-health professionals consist of community leaders, village health volunteers, including the neighbours who, sometimes, take part in caring for a child with the condition. With the collaboration of these groups of people, the quality of life of the children with cerebral palsy and their families will be improved.

Particularly notable in my study was the extent to which the participants shared their direct experiences with other families and simultaneously learned some

⁴³ The three United Nations Organizations consist of the International Labour Organization (ILO), United Nations Educational Scientific and Cultural Organization (UNESCO), and World Health Organization (WHO).

significant strategies for taking care of their children from other families. Consequently, a *spirit to fight* arises from the sharing. This knowledge can be applied to nursing practice as follows.

Enhancing sharing experience

Sharing experience is one of the effective ways that the participants in my study used to deal with a challenging situation. Participants always shared their experience with a sense of suffering with other people who face the same situation. This strategy is used as the psychological support for releasing tension and encouraging these persons in order to get over the challenging situation, then live with their situation as a normal life. Moreover, they also shared knowledge from direct experiences such as how they handled the situation whereby they employed their beliefs and the philosophy of Buddhism to deal with challenging circumstances. They were also willing to share how they learned to live with, and care for, a child with the condition. Therefore, the APN should coordinate with other appropriate healthcare professionals and non-healthcare professionals to encourage this activity then formulate it as a self-help group for raising a child with cerebral palsy.

Sharing experience as a psychological support

In the light of sharing as psychological support, the APN, other healthcare professionals and non-healthcare professionals, who work with a child with cerebral palsy and other chronic conditions, should promote support groups for families who have experienced living with a child with a chronic condition, both in hospital and in community settings such as the special school for disabled children. When children with the condition are hospitalised, the APN and other relevant healthcare professionals should encourage the parents, the main caregivers and other family members to share their feelings about the situation.

Significantly, the APN and other health professionals should understand and value their religious and personal beliefs about the situation, since these

significant factors have much influence on their behaviour – particularly the pattern of taking care of a child with the condition. Then, the health professional team should support the use of their beliefs to deal with the challenging circumstance by themselves. For example, using the Buddhist philosophy as a psychological tool for setting their attitude to accept the situation by doing *thum-joi* and *plong* then they will handle their situations and live with their conditions as normal a life as possible.

In the community context, the APN should coordinate with other health professionals who work in that area, such as nurses and the physiotherapist at the school, and also should cooperate with non-health professionals such as the teacher to encourage the parents and the main caregivers of children with cerebral palsy and other chronic conditions to share their experiences. Significantly, these people stand in the same view whereby it is easy to touch their mind with a sense of sympathy. They can read other people who face the same situation. Consequently, they will release stress, and gain more spirit to fight.

Sharing experience as knowledge

The families who have experienced living with a child with cerebral palsy or other chronic conditions, have their own ways to deal with challenging circumstances. They learn from those situations how to live with, and care for, the child. The participants in this study shared their experiences to learn new ways to solve problems of the child. Sharing experiences as knowledge should be included in the programme of health care and non-health care related to chronic health conditions. This knowledge could be shared in the support groups in the hospital or community context.

The APN and other professionals, who work at the special school for disabled children, should encourage the parents and the main caregivers in the families to

share their direct experiences of learning how to deal with, and care for, a child with the condition. For example, some families might share the experience of creating a special tool for the child to maintain his/her daily activities that can help other family members feel that it is much easier to take care of the child. Moreover, the team should integrate their knowledge in terms of medical sciences into the Thai traditional treatment for promoting rehabilitation of the children with the condition. Consequently, that will decrease the burden of care for the child, and increase the quality of life of a child with cerebral palsy and the family.

The APN and other relevant healthcare professionals could work to prevent or reduce the incidence of cerebral palsy and other chronic conditions by employing shared experience as knowledge for increasing a sense of awareness of the target group, who are pregnant at the antenatal clinic including the mothers who have a high risk of the condition. According to the National Institute of Neurological Disorders and Stroke: NINDS (2001) the risk factors of cerebral palsy are low birth weight and premature birth, multiple births, small for gestational age, and low *Apgar score*. Besides this, NINDS (2001) and Nehring (2004) assert that the maternal condition during pregnancy such as hyperthyroidism, diabetes, malnutrition, exposure to toxins or radiation, incompetent cervix, mental retardation or seizure disorder and infections, contributes to cerebral palsy. Families who have a child with a chronic condition could be invited as key informants to share their experiences of having a child with the condition. Therefore, the team includes the APN, nurses, physicians, physiotherapists, occupational therapists and the parents or the main caregivers of a child with the condition, who are willing to share their experiences.

In conclusion, families who have experienced living with a child with cerebral palsy need to be supported by healthcare professionals and non-healthcare professionals, including people in society. Both strategies of sharing experience as knowledge and as psychological support are influential ways of inspiring families who have a child with cerebral palsy to deal with, and live with, their

situation with a sense of happiness. Significantly, these strategies may also be used to prevent or reduce the incidence of cerebral palsy and other chronic conditions. Meanwhile, enhancing the quality of nursing practice by using a case management approach to maintain care for children with the condition and their families will improve the quality of their lives.

Implications for nursing education

The theory of *never-ending caring* enables us to understand the experience of living with a child with cerebral palsy. Children with disabling conditions need specific care since they all have unique health conditions. Several family factors, such as parent and family health, socioeconomic status, and education, are reported to have direct impacts on gaining access to healthcare services for the children (Allen, 2004). Living with a child with the condition has a great impact on the daily lives of all family members. Consistent with the substantive theory provides a practical framework of chronic conditions, the education and development of healthcare professionals in relation to chronic and disabling long-term care should be responsive to the larger picture of the experience of living with, and caring for, a child with a chronic condition, as well as the medical knowledge relevant to the condition. In particular, health professionals need to understand the ways of thinking of the caregivers, which is an imperative factor for enhancing the quality of the health-care service, and the quality of the families' lives.

The societal perspective toward visible disabilities should be considered as one of the influential factors that affect the quality of life of families. The curriculum for health professionals should include policy regarding chronic and disabling conditions, particularly the concept of Community Based Rehabilitation (CBR) with its goals of rehabilitation, equalisation of opportunities, and social inclusion of all people with disabilities, as outlined in Chapter Two.

Further research suggestions

Traditionally, at the end of any research inquiry, the researcher should suggest possible areas of further research in order to gain more knowledge that is relevant to the substantive area. The theory of never-ending caring for a child with cerebral palsy needs to be validated by exploring its fit and workability in relation to the experience of living with a child with other chronic health conditions. The process families use to get through challenging circumstances, should be further explored. Consequently, the result of research inquiry will be used as important parts of establishing the health policy and healthcare system, particularly for Thai people with chronic conditions and disabilities, consistent with the concept of Community Based Rehabilitation.

Traditionally, the concept of cultural obligation has a strong influence on the behaviour of Thai people. In this study, young caregivers such as the oldest child, who are culturally expected to undertake caregiving obligations for their family, accept this responsibility to be the main caregiver of a child with cerebral palsy. However with globalisation, Thai society is in transition and this may impact on levels of acceptance of cultural obligation of the oldest child to his/her family, particularly in urban society. This topic warrants further research. Furthermore, globalisation also impacts on the extent to which young people uphold religious beliefs and practices that underpin this substantive theory. Thus further research exploring the impact of societal transitions on families is recommended.

Conclusion:

The importance of the experience of never-ending caring

Children with cerebral palsy need long-term care as do children with other chronic conditions. The responsibility of caring for a child with a chronic

condition unavoidably belongs to the family and community rather than to health professionals. In the Thai context, families who live with – and care for – a child with the condition, have to shoulder this responsibility until the end of their lives. This burden of care affects not only the parents and the main caregivers, it also impacts on the daily lives of all family members. The participants shared their suffering in terms of physical, psychological and economic effects. Significantly, health professionals and non-health professionals, whose work is related to children with the condition and their families, should consider the effects and treat them as a family – not focusing only on a child with the condition.

Understanding the experience of families who have a child with cerebral palsy enables healthcare professionals and non-healthcare professionals to gain more insight regarding how families live with this particular situation and get through their challenging circumstances. This insight can positively inform their practice with people with chronic and disabling conditions and enhance the quality of the efforts of both groups to encourage the families to achieve quality in their lives.

The basic social psychological process of *never-ending caring* provides a way of understanding the lives of families caring for a child with cerebral palsy. This work is unique in that the basic process emerged from the perspectives of the participants in a Thai cultural context. This BSPP takes into account the differing experiences of differing family members, each of whom has his or her own ways to deal with, and handle, the situation. In terms of the metaphor of the water wheel, they experience differences in speed, amount of water in the buckets, and sensitivity towards the current. When facing a challenging circumstance, even though most are able to change an unpleasant situation to be a happy and peaceful condition by employing their beliefs, cultural obligation and the religious concepts to drive the wheel, it may take more or less time to achieve it. For the most part, family members cannot avoid challenging situations, rather they must face them and learn to deal with, and manage, each situation. With improved understanding of this substantive theory, health and education

professionals can play a greater part in improving the quality of life of children with cerebral palsy and their families.

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Appendix I – The Participant Information Sheet



*The Experiences of the Families with Children with disability
in Thai Cultural Context*

Information Sheet

Researcher Introduction

My name is Kuephan Klanakaradi, Ph.D. student in Nursing, School of Health Sciences, Massey University, New Zealand. My supervisor is Professor Julie Boddy. I am interested in the experiences of families with children with disability particularly in Thai cultural context. I would like to invite your family to participate in this study in order to gain more understanding about your experiences. Ultimately developing knowledge will be useful for improving the quality of health professional efforts to encourage families that live with a child with disability or a child with chronic conditions, to achieve the quality of their life.

Participant Recruitment and Participant involvement

Initially, families will be recruited from The Physical Therapy Clinic, Physical Therapy Department, Faculty of Associated Medical Sciences, Khon Kaen University, Khon Kaen, Thailand. If you have experience living with a child with disability, you will obtain the information sheets about this study and my address from this clinic. You will have more time to consider about participation in this study. At the first meeting at this clinic, I will talk with you about my study and give you the information sheet. I will answer your questions about this study. I will ask you your address and will make appointment with your family at home to follow up your decision about participation in this study. I will respect your decision-making. Refusing to participate in my study will not effect treatment at the clinic. If you are willing to participate, I will through the information sheet again with you and arrange for you to sign the consent form at your home. If you have any friends or acquaintances who live with the same situation, please

let me know. That is useful for my study that I will gain more participants and to understand more this particular situation.

Project Procedures

I will spend time and talk with your family about your experiences of living with a child with disability. I will take some note for important issue and use tape recording because I would like to capture all of your experiences. To make sure that you are willing to be audiotaped, I will ask you first and you can tell me at any time to stop recording. I will send you the written summary of the findings of this study. Significantly, the research information will be stored in a locked file cabinet at the office of the researcher at the Faculty of Nursing, Mahasarakham University, Mahasarakham, Thailand for five years after the last publications. Then, the researcher will destroy all the participants' information. My research supervisor, Prof. Julie Boddy, School of Health Sciences, Massey University and I will access these inquiry data.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Withdraw from the study at any time without effect on the treatment of a child with disability;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Choose the times and places for observation and interviewing that are convenient for your daily life.
- Ask for the audio tape to be turned off at any time during the interview.
- Be given access to a summary of the project findings when it is concluded;

Project Contacts

This research proposal has been reviewed and approved by both the Massey University Human Ethics Committee, PN Application 04/170 and the Human Ethics Committee of Khon Kaen University, Thailand, KKU Application HE471110. If you have any concerns about the conduct of this research, please contact persons who take responsibility as follows:

1. The researcher: Please feel free to ask for me at any time, Kuephan Klankaradi Department of Family Health, Faculty of Nursing, Mahasarakam University, Mahasarakam Thailand 44150. Telephone 66 43 754357, email:kuephan.klankaradi@uni.massey.ac.nz or kk_kue@hotmail.com
2. Khon Kaen University: Please contact the office of The Human Ethics Committee of Khon Kaen University, Research Affairs, Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand. Telephone 66 43 348373 or 66 43 242342-6
3. Massey University: Please contact Professor Sylvia V Rumball, Chair, Massey University Human Ethics Committee: Palmerston North, New Zealand. Telephone 06 350 5249, email:humanethicspn@massey.ac.nz

Appendix II – Informed consent



*The Experiences of Families with Children with Cerebral Palsy
in Thai Cultural Context*

Participant consent form

This consent form will be held for a period of five (5) years

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being audio taped.

I wish/do not wish to have my tapes returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: _____ Date: _____

Full Name-Printed _____

**Appendix III – Ethics approval by the Khon Kaen University
Ethics Committee for Human Research**



KHON KAEN UNIVERSITY

This is to certify that

The Project Entitled: The experiences of families with children with cerebral palsy
in Thai cultural context

Principle Investigator: Mrs. Kuephan Klanakaradi. et al.

Address: Ph.D. student in Nursing, School of Health Sciences, Massey
University, New Zealand.

Has been reviewed and approved by The Khon Kaen University Ethics Committee
for Human Research, based on the declaration of Helsinki

Date of approval: 19 November, 2004

Pyarat Tatsanavivat

Professor Pyarat Tatsanavivat, M.D.,
Chairman,
The Khon Kaen University Ethics Committee for Human Research

Record No. A.1.27: 11/2004
Reference No. HE471110

Office: 123 Mitrophan road, Dean office 6 floor,
Faculty of Medicine, Khon Kaen University, Khon Kaen, Thailand
Tel. & Fax: +66-0-4334-8373

Institutional Review Board Number: IRB00001189
Federalwide Assurance: FWA00003418

**Appendix IV – Ethics approval by Massey University Human
Ethics Committee**



Massey University

OFFICE OF THE ASSISTANT
TO THE VICE-CHANCELLOR
(ETHICS & EQUITY)
Private Bag 11 222
Palmerston North
New Zealand
T 64 6 350 5573
F 64 6 350 5622
humanethics@massey.ac.nz
www.massey.ac.nz

20 April 2005

Kuephan Klankaradi
Department of Family Health
Faculty of Nursing
Mahasarakam University
Mahasarakam
THAILAND 44150

Dear Kuephan

Re: HEC: PN Application – 04/170

The experiences of the families with children with cerebral palsy in Thai cultural context

Thank you for your letter dated 6 April 2005 outlining the change you wish to make to the above application.

The change, to recruit from three special schools where children with cerebral palsy are educated, has been approved and the revised information sheet to participants has been noted on file.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee. If over time, more than one request to change the application is received, the Chair may request a new application.

Yours sincerely

Dr John G O'Neill, Chair
Massey University Campus Human Ethics Committee: Palmerston North

cc Professor Julie Boddy
School of Health Sciences
PN351

**Appendix V – The permission form of the Special Education
Center in Region 9, Khon Kaen, Thailand**



Ref. 04007.150/ 264

The Special Education Center in Region 9
761 Moo14 Soi Punya Mitrapab Road
KhonKaen 40000
Thailand

March 17, 2005

Dear Ms.Klankaradi Kuephan

To respond to your request for permission to collect data at The Special Education Center in Region 9, you are welcome to commence your data collection as your convenience.

Sincerely yours,

(Manas Kaochaimaha)

Deputy Head of Center

Office no.

Tel.66-432-390-55

Fax.66-432-390-73

**Appendix VI – The permission form of the Khon Kaen Special
Educational School**



Ref. 04007.152/ 264

Khon Kaen Special Educational School

680 Moo 14 Mitrapab Road

Khon Kaen, 40000

Thailand

March 23, 2005

Dear Ms. Kuephan Klankaradi

According to your request for permission to collecting data at The Khon Kaen Special Educational School, you are welcome to collecting data as your convenience.

We look forward to work with you.

Sincerely yours,

A handwritten signature in cursive script, reading "Uruda Soodme".

(Uruda Soodme)

Director of School

Offiec No.

Tel. 66-432-464-93

Fax. 66-432-411-88

**Appendix VII – The permission form of the Mary Immaculate
School for disabled children**



โรงเรียนการศึกษาเด็กพิเศษพารีย์นิรมล

ตู้ ป.ณ. 109 อ.เมือง จ.ขอนแก่น 40000 โทร. (043) 241-032, 237-981

P.O.BOX 109 Khon Kaen 40000 Thailand Tel. no. (043) 241-032, 237-981

Ref. 303/2548

March 28, 2005

Dear Ms Klankaradi Kuephan

I would like to inform you regarding your request for permission to collect data from our school Mary Immaculate School for children with cerebral palsy. You are welcome to start data collection as your convenience. I had contacted children with cerebral palsy and their families about your study. I hope that they will give you a good cooperation. So, you can present the most accurate reports in your study.

Sincerely yours,

(Duangjan Soysud)

Principal of School

Office No.

Tel. 66-432-416-32

Fax. 66-432-416-32

Glossary

Thai

A

Ai Ngoy or Buk Ngoy

อ้ายง่อย บักง่อย

An impolite word to call a disabled person
who cannot walk

C

Chao tee

เจ้าที

The spirit who protects the land

I

I-San

อีสาน

Northeast of Thailand

li-sim

ອີໄມ

An impolite word to call
someone who hardly speaks and has less
activities tend to be a person with stupor

J

Jow-kram Naay-wen

เจ้ากรรม นายเวร

The spirit of humans or animals which
were mistreated in previous life

K

Karma

mind

กรรม

Volitional actions of body, speech and

which can be good or bad

Kaod-num

กรวดน้ำ

A ritual to send the merit to the spirit
[departed loved ones or Jow-kram
Naay-wen] by pleading with religious
words while pouring the water

Khoa (Khoa-kram)

Bad luck

เคราะห์ (เคราะห์กรรม)

Khon-mee-boon

A special person who has a virtue

คนมีบุญ

Khuy-Took Phrub-Took

Chatting about suffering and then sharing

คุยทุกข์ ปรีบททุกข์

their suffering stories

Kum khoon

To support

คำคุณ

L

Laeng-mai-lu-jak-leaw

Unfinished caring, never-ending caring

เลี้ยงไม่รู้จักแล้ว

M

Mor

The word that the villagers call

หมอ

health care providers such as doctor, nurse,

pharmacist, and others

Mod-alai-tay-yak

A sense of hopelessness, lacking

หมดอาลัยตายอยาก

motivation to live

N

Nang Kwak

The Thai traditional Goddess who draws

นางกวัก

more people to support your business

Nung tang nai

To sit in meditation in order to prospect

นั่งทางใน

horoscope

Ngan Bua

The ceremony for someone becoming a

งานบุญ

monk

Ngan Katin

The annual ceremony of Buddhism

งานกฐิน

P

Pi-tee dutt Kram

A ritual to cut the karma

พิธีตัดกรรม

Plong

A deliberate thinking about a 'thing' which

ปลง

can see the truth of the 'thing' as it is, then

can set the mind to be calm

Poom bpan-yaa chaao bâan

The knowledge that emerges from the

ภูมิปัญญาชาวบ้าน

wisdom and experience of the lay persons

Pra-tu-dong

The monk who is on a pilgrimage

พระธุดงค์

Pu

Grandfather; in this sense means the male

ปู่

spirit

S

Sila

The precepts

ศีล

T

Tam-bun

To make merit, merit-making

ทำบุญ

Tam-kham-dee

To do good deeds

ทำความดี

Thi-baap

To release the bad deeds

ไถ่บาป

Thum-jai

To realize the fact or to accept a 'thing' that

ทำใจ

we cannot change anything about it

V

Vi-bak-kram

The retribution of evil deeds in a previous

วิบากกรรม

life

W

Wai

Thai traditional ways to respect and
greeting other people

ไหว้