Caregiving identities of women with a brother or sister with cerebral palsy

By

Yeh-chen Kuo

Ad Personam Program

School of Social Work

Department of Educational and Counseling Psychology

McGill University, Montreal

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of Doctor of Philosophy

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Abstract

This study examined the caregiving identities of Taiwanese women who have siblings with cerebral palsy. It is based on 12 in-depth qualitative interviews with 6 women who were at least 20 years of age, each of whom self-identified either as the family member most involved in caregiving or as the only sister of the sibling with cerebral palsy. The results of the study suggest that the provision of current and future care to siblings with cerebral palsy is a complex phenomenon that contributes to how these women view themselves. Caregiving is informed by four processes associated with the provision of care to their siblings: (a) caring through interpretation (b) caring through transformation (c) caring through protection and (d) caring through sacrifice. Engaging in these four processes of providing care to others created unique considerations and tensions in carrying out other roles these women assume in their lives. More specifically, these tensions had to do with their negotiation of relationships with their mothers, considerations pertaining to who they will marry or have already married, the denial of their right to inherit family properties, as well as their desire and expectation to provide ongoing care to their sibling with CP after marriage.

In the study, we observed that these women internalized the sexual division of labour in their families and in their culture; they perpetuated the gender system

that requires mothers and sisters to engage in family care. Therefore, greater attention must be brought to the promotion of a more equitable sharing of caring tasks by men and women in the family and to the designing and implementing of long-term care policies adapted to the unique characteristics of Taiwanese society.

L’identité d’aidante naturelle des taïwanaises avec frères ou sœurs atteints de paralysie cérébrale

Résumé

Cette étude a examiné l’identité d’aidante naturelle des taïwanaises qui prennent soin de leurs frères ou sœurs atteints de paralysie cérébrale. Elle est basée sur 12 interviews détaillées avec 6 femmes âgées d’au moins 20 ans. Ces dernières se sont identifiées soit comme les uniques sœurs des personnes atteintes de paralysie cérébrale ou encore comme les personnes les plus impliquées dans la provision de soins. Les résultats de cette étude suggèrent que la provision de soins présents et futurs aux frères ou sœurs atteints de paralysie cérébrale est un phénomène complexe qui contribue à la perception de soi de ces femmes. Ce phénomène est influencé par quatre processus associés à la provision des soins : (a) soins par interprétation (b) soins par transformation (c) soins par protection (d) soins par sacrifice. L’implication dans ces quatre processus a crée pour ces femmes des considérations uniques et des tensions dans d’autres domaines de leur vie. Plus précisément, ces tensions sont liées à la négociation des relations avec leurs mères, à leurs choix de conjoints, à la répudiation de leurs droits à la succession, ainsi qu’à leurs aspirations et attentes relatives à la provision de soins continus à leurs frères ou sœurs atteints de paralysie cérébrale après le mariage.

Étant donné que les femmes ont assimilé la division du travail dans leurs familles et dans leur culture, et qu’elles continuent à vivre dans un système qui

demande que les mères et les sœurs s'impliquent dans les soins familiaux, plus d'attention doit être accordée à la promotion d'un partage plus équitable des soins prodigués par les hommes et les femmes dans les familles. Plus d'attention doit aussi être portée au développement de politiques de soins à long terme adaptés à la société taïwanaise.

Acknowledgement

I must first acknowledge my dissertation committee. I deeply appreciate the time and energy that committee members devoted to critiquing the different drafts of my manuscript. The experience of learning with Dr. Lucy Lach, Dr. Jeeseon Park, Dr. Julia Krane, and Dr. Ingrid Sladeczek was both enriching and enlightening.

I could not have asked for a better advisor than Dr. Lucy Lach. I especially wish to thank her for agreeing not only to chair my committee but also to reconfigure an entirely new committee for me. Coaching a Ph.D. student thousands miles away is never easy. Dr. Lach spent countless hours talking to me via the Internet, and made herself as available as possible to me when I flew back to Montreal to meet with my committee. She gently guided me through each stage of the process as I generated ideas, wrote my proposal, then completed the final paper. She has been my mentor, teacher and a role model ever since.

Throughout the process, Dr. Jeeseon Park gave me her incisive suggestions and unwavering support. I thank her for coaching me, encouraging me and leading me to move forward with confidence. Dr. Julia Krane showed me how to think critically and gave me very useful suggestions. I appreciate the fact that she challenged me and led me to reshape my worldview, enabling me to gain a new perspective on important matters. Dr. Ingrid Sladeczek was especially helpful in guiding me through the writing process. I thank her for pushing me to produce the best work I could.

I cannot forget the late Professor Dalfen. It was he who helped me take the first steps in this journey. I am indebted to him for making my doctoral studies possible.

My thanks also go to Dr. Wang Tsen-Yung (Frank). I have benefited enormously from his help with peer debriefing.

In the process of data collection, I met many wonderful women. As they participated in this study, they shared their stories with me and taught me valuable lessons that neither the classroom nor textbooks could have provided me. I thank them for giving me the passion and motivation to carry on.

In addition, I express my heartfelt thanks to Robin Lee, who proofread the Chinese excerpts and the corresponding English translation to ensure the validity of the translation, as well as to Sandy Huang, who translated the English excerpts back into Chinese. I also wish to thank Bruce Manson, who helped with the French translation of the abstract, and Laurie Rendon, who edited previous versions of my work. The help they gave me is so great that mere words cannot express my appreciation.

I owe an immeasurable debt to Mr. Yao, my former director at the Buddhist foundation where I once worked, as well as to his friends who donated money to help me complete my master’s and Ph.D. degrees. Before beginning this journey in Montreal, financial considerations were such that my plans to pursue higher education were nearly halted. Mr. Yao persuaded many of his friends to provide me with financial aid for three years, helping me finish the master’s degree and part of the Ph.D. degree requirements. Without their generous support, the completion of this degree would not have been possible.

Lastly, my deep gratitude is given to my parents, to my children, Lei and Yun, to my friends, Yuan-Jin Hong and I-Chen Chen, and to all of my colleagues at the university where I teach. Thank you for your solid, unflinching support. You have been my source of comfort, joy and inspiration.

Table of Contents

List of Appendices

> My fiancé will definitely break up with me if I postpone our wedding again. But what can I do? My youngest brother is still serving in the army. No one in my family is available to look after Ton-Ton, except me. . . . Looking after Ton-Ton consumes a great deal of time and energy. If my youngest brother takes over the caregiving responsibility after he’s discharged from the army, Ton-Ton will become a huge obstacle to his career. I can’t let that happen. . . . I can’t take Ton-Ton with me either. No husband would accept a handicapped brother as a dowry. Besides, we wouldn’t have room for him.
>
> —May, 29, whose brother Ton-Ton has cerebral palsy

CHAPTER ONE

INRODUCTION

Trends that include deinstitutionalization and increased longevity among persons with developmental disabilities have resulted in an increase in the amount of research that examines caregiver burden (e.g., Luescher, Dede, Gitten, Fennell, & Maria, 1999; Patrick & Hayden; 1999; Pruchno, 2003; Salvatori, Tremblay, & Tryssenaar, 2003). One of the major sources of burden identified among older mothers caring for adult children with a developmental disability has to do with their worry about what will happen to their children when they are no longer able to look after them (Salvatori, Tremblay, & Tryssenaar, 2003). The call to address this concern was made at a recent national research consensus conference in Canada entitled *Access Ability: Policy and Research Priorities for Children and Youth with Special Needs* attended by caregivers, practitioners, researchers, administrators and policy makers in Vancouver, British Columbia. A panel of caregivers of adults with various types of disabilities spoke eloquently about the need to address issues regarding the long term care of their children.

Future care for persons with disabilities is a cross-cultural phenomenon. In

Taiwanese families, this concern intensifies as parents age (Huang, 1997). When parents are no longer able to provide care, the most likely substitute caregiver is a sibling of the individual with the disability (Horwitz, 1993). Support patterns tend to be channeled through the strongest familial bonds: those between spouses and then those between parents and children. When such close ties do not exist, more distant relatives increase their supportive involvement. Evidence obtained from a Taiwanese survey of the living requirements of individuals with a physical or mental disability (Ministry of the Interior, 2001) support Horwitz's (1993) findings. Seventy six percent of people in Taiwan who have a congenital disability such as cerebral palsy (CP) are not married. Among single people with disabilities who require varying levels of ongoing care, the caregiver is most likely to be the mother, followed by the father and then a sibling. Given this pattern, it is likely that siblings will increasingly be called upon to become involved in the lives of persons with CP in significant ways after their parents are no longer able to provide care. However, there is a paucity of research that examines how adult siblings experience caring for their brothers or sisters with disabilities.

The lack of attention to how siblings experience their caregiving roles, how female and male siblings differ in their experience of this role, and how these roles are informed by the social-cultural context within which they live, means that Taiwanese policies regarding the care of such individuals have not included the perceptions of this very important stakeholder group. In many ways this issue is not unique to Taiwan as others have similarly questioned how best to support individuals with disabilities and their nondisabled siblings when parents are no longer able to provide care (McGraw & Walker, 2007). What is unique to

Taiwan is that Confucianism ideals prevalent in Taiwanese culture to this day continue to dictate various roles that women are expected to carry out. As a result, Taiwanese women in contemporary society also experience pressure to keep up with other roles expected of modern career women. Within this context, assuming a role of a caregiver may add a layer of complexity to Taiwanese women's caregiving identity. Against this social context, this study will specifically focus on the lived experiences of sisters who have a brother or sister with cerebral palsy.

The limited empirical evidence that has examined sibling involvement has focused on identifying predictors of who will provide care based on factors such as gender, education, affiliation to sibling, family climate, and sense of obligation, siblings' helping behaviours, and the nature of future plans that siblings have for their brothers or sisters with chronic illnesses and disabilities (Bigby, 1997; Greenberg, Kim, & Greenley, 1997; Griffiths & Unger, 1994; Horwitz, 1993, 1994; Horwitz & Reinhard, 1995; Horwitz, Reinhard, & Howell-White, 1996; Horwitz, Tessler, Fisher, & Gamache, 1992; Krauss, Seltzer, Gordon, & Friedman, 1996; Orsmond & Seltzer, 2000; Pruchno, Patrick, & Burant, 1996; Rimmerman & Raif, 2001; Seltzer, Begun, Seltzer, & Krauss, 1991; Smith, Hatfield, & Miller, 2000). Only one study (McGraw & Walker, 2007) has examined how nondisabled sisters understand themselves and their siblings with developmental disabilities. Although informative, these studies do not address the complex processes that occur in families as parents and sisters assign caregiving functions. Furthermore, these studies have been exclusively conducted in Western cultures. Given that persons interact on the basis of their individual symbolic understandings and continually adjust their actions in response to their environment and culture, culture influences how people think, behave, make judgments, and virtually affect every aspect of daily life (Amankwaa, 2005; Blumer, 1969). Individuals interact on the basis of their individual symbolic understanding and continually adjust their actions in response to their environment and culture. Therefore, how sisters experience their caregiving roles cannot be understood from a disengaged vantage point or apart from context (Kearney, Murphy, & Rosenbaum, 1994). Applying theoretical frameworks that address women's caregiving that have been developed mainly in Western societies to non-Western countries is not straightforward as the unique perspective and the impact of culture on the caregiving identities may not be given full consideration.

In order to broaden the knowledge base and provide a comprehensive understanding of Taiwanese women's caregiving identities, the following research questions will guide the process of inquiry:

1. What are women's caregiving identities to their brothers or sisters with CP?
2. How are their caregiving identities constructed in the Taiwanese context?

This study will pay specific attention to certain elements of Taiwanese culture that are essential to the construction of women's caregiving identities, and to how women negotiate their caregiving identities given their roles as sisters to their siblings, daughters to their mothers and/or fathers, and partners to spouses or potential future spouses.

Theoretical frameworks and empirical studies that inform our understanding of caregiving will be reviewed in Chapter 2. Key constructs in theories and relevant findings that are based in Western as well as Eastern cultures are reviewed and their relevance to the study of sisters of adults with cerebral palsy is explored. The review of theoretical frameworks that were developed mainly in Western societies and Chinese culture provide us with an understanding of how disparate these perspectives are and challenge us to examine ways in which they diverge and converge. Similarly, reviews of the relevance of findings from quantitative and qualitative studies that have examined caregiving provides us with a sense of what has been studied, how it has been studied, and what the specific gaps in knowledge are.

Chapter 3 covers how the nature of cerebral palsy informs sisters' caregiving identities to their siblings with cerebral palsy and the challenges associated with the provision of providing care to individuals with cerebral palsy. The first part provides the reader with a sense of the complexity of care associated with cerebral palsy (CP). It begins with an overview of CP, including types of CP and related health conditions. In the second part, the impact of caregiving demands on caregivers to persons with CP and the typology of caregiving are elaborated.

Chapter 4 examines the policy context of caregiving to individuals with CP in Taiwan. Assumptions and values that underlie the Taiwanese government's current long-term care policies are made explicit as is the way in which the dominant medical model of funding contributes to creating additional caregiving issues.

In order to answer the research questions, a phenomenological methodology has been adopted. This is described in Chapter 5. The analysis is based on two interviews conducted with six women who are sisters of adult siblings with CP over a 6 month period. Their narratives have been analyzed to represent their experiences, the tensions and conflicts that they encountered, and the creative ways in which they sought solutions.

Findings are presented in Chapter 6. It is here that the pride, grief, tension and courage of these six sisters are rendered explicit. Caring through interpretation, transformation, protection and sacrifice are the key processes that were identified in the analysis. Each of these processes is further informed by the way in which the role of sister intersects with the role of daughter, spouse and citizen of the state.

Chapter 7 discusses the findings in relation to existing literature. Issues such as patriarchal and gendered nature of care in Taiwanese society, the impact on sisters' career choice, strained relationship between mothers and sisters due to sisters' caregiving identities as transformer and protector, the impact of anticipatory caregiving to unmarried women and denial of right to family inheritances and right to provide care which reflect the devaluation of women's contribution in Taiwanese society are discussed. Chapter 8 discusses implications for research, practice and policy.

CHAPTER TWO

CAREGIVING IN WESTERN AND CHINESE SOCIETY

2.0 Introduction

The theoretical frameworks that contribute to the understanding of the construction of caregiving identities in this study include caregiving theories developed in Western and Chinese societies. In the first part of this chapter, four Western-based theoretical frameworks will be reviewed. I develop a typology to differentiate 4 perspectives on caregiving identity. The *natural perspective* refers to theories that treat caregiving as a ‘natural’ female phenomenon (e.g., maternal feminism). The main assumption among theories in the *relational perspective* is that gender differences in caregiving identities emerge from early childhood socialization experiences and the mother’s central role in identity formation (e.g., psychoanalytic feminist theory). Theories that treat the construction of caregiving identities from an *interactional perspective* focus primarily on the ways in which an individual’s interaction with different aspects of their social network inform an individual’s sense of self and their caregiving identities (e.g., role theory, symbolic interactonism and role-identity theory) are reviewed in the third perspective. The fourth perspective refers to theories that examine the mechanics by which *gender inequity* in caregiving identities are created, maintained, and changed (e.g., liberal feminism and radical feminism). These perspectives emerged in response to a recognition that theories claiming that identity is built through interactive efforts underemphasized the role of power in the process of constructing caregiving identities, thereby necessitating a need to pay attention to structures that contribute to these inequities.

In addition to theoretical frameworks that have been developed mainly in Western societies, Confucianism will be discussed in the second part of this chapter. Confucianism is the dominant moral philosophy and counterpart to Western thought in Taiwan. It is a dominant moral philosophy that guides the culture and behaviour of people in Taiwanese society (Cai, 2004). As such, a discussion and analysis of Confucianism will enhance the understanding of how caregiving identities are constructed in Taiwanese society.

An analysis of caregiving theories and empirical studies in Western and Chinese society will identify similarities and differences among theoretical frameworks and will provide the basis for understanding the tensions that Taiwanese women are exposed to in the process of caregiving.

2.1 Caregiving Theories and Empirical Studies in Western Society

2.1.1 The Natural Perspective on Caregiving Identities

The natural perspective emphasizes that group members who share similar attributes also share a unified sense of self. These shared attributes are natural or essential characteristics and emerge from physiological traits, psychological predispositions, regional features, or the properties of structural locations. Group members internalize these qualities, share similar social experiences, and construct an identical sense of self (Cerulo, 1997). Based on differences in male and female reproductive anatomies and brains, there is an assumption that women have instincts to make them good providers of hands-on physical and emotional care, while males have the instinct to be good providers of economic support. Women do what comes naturally to them as mothers, wives, and daughters, while men do what comes naturally as fathers, husbands, and sons (Hooyman & Gonyea, 1995). Therefore, men’s and women’s care patterns and caregiving identities are inherently different.

Women’s caregiving identities are not only confined to private spaces where they perform their roles as mothers, wives, and daughters. Historians of women identified maternal feminism as the underlying ideology that spurred the movement of women into the public sphere. In Canada, for example, middle and upper class women moved into the public sphere in the late nineteenth century. They were determined to play a part in the changing society. Some women found positions as teachers in the public school system, while other women became involved in voluntary charity-based work in the health and social service sectors. The care of dependent children, the establishment of health services for poor women, the education of the young, and the abolition of alcohol were some of the issues these women began to address (Kealey, 1979, cited in Baines, 1998b). All of these public roles were seemingly extensions of the private caregiver roles that women were already occupying. As a reform movement, women accepted the reality that they were responsible for caring about and for dependent groups, and were determined to extend their caring roles to the larger society (Baines, 1998b). Women transferred the values and caring functions they had learned and practiced within the home and the community to new fields of work, such as caring for the sick, the aged, and the young. They developed skills that they recognized as essential to transfer to the public sphere (Baines, 1998b).

Similarly, maternal feminism views women’s caregiving identities as emerging from inner nature, not from social roles they obtained through interactions with family or society. “It is not a woman’s position as wife or mother that qualifies a woman for the task of reform, but the special nurturing qualities which are common to all women gives her the duty and the right to participate in the public sphere” (Kealey, 1979, cited in Baines, 1998b, p. 25). Consistent with the natural perspective, maternal feminism stresses the differences between women and men. In doing so, it does not strive to create a society that is free of gender distinctions. Rather, maternal feminism adopts what can be called a ‘woman-centered perspective’, one that emphasizes female values that are embedded in and define women’s unique experiences and positively connotes women’s growing autonomy and the extent to which women have imposed their values on society (LeGates, 2001).

Although maternal feminism was in many respects a narrow, biological, and conservative view of women's caring role, it empowered women working in hospitals, church-based social services, and schools and fostered a feminine consciousness and the solidarity of women (Baines, 1998b). Carrying their caregiving role into the public domain, women became more autonomous, independent, and were exposed to social and educational opportunities that had previously been denied. The paradox was that although maternal feminism provided a rationale for women to work outside the home and supported their increased autonomy, it also reinforced the traditional role of women as caregivers.

Women today continue to engage in caregiving functions, both privately and publicly. These functions continue to be treated as ‘natural’, minimizing the need for education, training, or remuneration for these functions. Cancian and Oliker (1999) argued that this perspective justifies low wages for paid caregivers, devalues and undermines the respect and reward that caregiving work deserves.

Maternal feminism committed to a female political consciousness that was grounded in the virtues of the private and domestic sphere, especially in the practice of mothering and the attitude of maternal thinking to community and society (Dietz, 2002). This perspective can be applied to understanding the high percentage of women's representation in the professions such as education (e.g., preschool teachers 99%; elementary school teachers 67.6%) (Directorate General of Budget, Accounting and Statistics of Executive Yuan, 2001) and nursing (99.5%) (The National Union of Nurses Associations, Republic of China, 2008) in Taiwanese society. Little is still known about the extent to which Taiwanese women have translated their caregiving role from the family into the public domain. Similar social and economic changes have taken place in Taiwan without a critical analysis of the implications, particularly for women who are caring for brothers or sisters with CP. It is therefore a useful framework within which to reflect on the extent to which caregiving provided by the family is extended into paid or unpaid caregiving roles.

2.1.2 The Relational Perspective on Caregiving Identities

The second set of theories address the construction of caregiving identities from a relational perspective. From this perspective, a caregiving identity is not an individual trait that is based on one's physiology; rather, it is the outcome of early childhood socialization experiences and the mother's central role in personality formation.

In this perceptive, men and women differ in caregiving identities and other aspects of behaviour because they are taught to be different from the moment of birth. Gradually, through interactions with their mothers, they acquire the traits, behaviours, and attitudes that are defined as masculine or feminine (Kimmel, 2004). Thus men and women are regarded as not necessarily born different but as becoming different through the process of socialization.

Early childhood socialization experiences and the mother's central role in personality formation are presumed to underlie gender differences in care. It has perhaps been best described by Nancy Chodorow in *The Reproduction of Mothering.* Chodorow (1978) examined maternal parenting as a central factor in the creation of gender differences. She argued that the sexual division of labour is rooted in women's mothering and results largely from an unconscious psychodynamic process that occurs between the mother and child in the earliest stages of development:

> Women's mothering does not exist in isolation. It is a fundamental constituting feature of the sexual division of labour. As part of the sexual division of labour . . . it consists in psychological and personal experience of self in relationship to child or children. (p. 32)

Chodorow (1978) argued that male and female roles were reinforced in children through different relationships between mothers and sons or mothers and daughters. The differences influenced the sexual division of labour and reinforced that caregiving is identified with women. Women, as mothers, produced daughters with mothering capacities and the desire to mother. These capacities and needs were built into and grew out of the mother-daughter relationship itself. By contrast, women as mothers produced sons whose nurturing capacities and needs were systematically curtailed and repressed.

This prepared men for their diminished affective family role later in life, and for primary participation in the impersonal extra-familial world of work and public life. Chodorow's argument was supported by the findings of Leaper, Leve and Strasser's (1995) study which found out that mothers did treat and experience sons and daughters differently. In their study, mothers (both married and single) were videotaped in their homes while playing with their preschool-age daughter or son (mean age = 45.5 months). Mother-child pairs played with both a masculine-stereotyped toy set (toy track with cars) and a feminine-stereotyped toy set (toy foods and plates) for 8 minutes each. They observed mothers to be better at supporting gender-typical play rather than cross-gender play activity (Leaper *et al.*, 1995).

Related to the sexual division of labour in caregiving, mothers may expect daughters' extensive self-sacrifice without considering that daughters have needs for their own independence and autonomy (Donorfio & Sheehan, 2001). Some researchers (e.g., Boyd, 1985; Chodorow, 1978) have shown that mothers and daughters do experience conflict over separation and individuation, particularly when daughters are younger. Tensions can arise between mothers and daughters as they negotiate relationships with one another. For example, mothers sometimes place a higher value on their sons compared with their daughters (e.g., Hill & Zimmermann, 1995). Mothers tend to require more household labour from their young daughters than from their sons (Benin & Edwards, 1990; Demo & Acock, 1993; Gager, Cooney, & Call, 1999). Tensions can intensify when mothers intrude upon or are critical of their daughters' lives (Fingerman, 1996). As daughters grow older, they may have difficulty being responsive to their mothers' relational and instrumental needs because of adherence to sociocultural values regulating filial obligations that favour husbands and children (Rossi & Rossi, 1990; Walker, Pratt, & Wood, 1993).

Despite the tensions between mother-daughter relationships, mothers and adult daughters tend to build positive relations with one another in later life. Findings from empirical studies suggest that close connections between aging mothers and their caregiving daughters are common (Sheehan & Donorfio, 1999; Walker & Pratt, 1991), particularly in the aspect of fostering each other's autonomy. Mathews and Rosner (1988) highlighted how adult daughters seem to develop a principle of least involvement, providing no more care to their mothers than is needed to maintain their own and their mothers' independence. Mothers, in turn, want their adult daughters to be mature and independent (Ryff, Young, Essex, & Schmutte, 1994). The findings of McGraw and Walker's study (2004) also illuminate how aging mothers and their adult daughters can work to create positive caregiving ties. Their relationships appear to be a product of their purposeful attention to each others' lives, support of each others' autonomy, and cooperation to resolve tensions.

The above studies contribute to our knowledge regarding mother-daughter caregiving relationships. However, these studies were conducted in Western cultures and do not address the quality of the mother-child relationship when caregiving for a physically impaired sibling is involved. The purpose of this study is to explore how adult sisters of siblings with CP experience their role in the context of their family. In doing so, the nature of the mother-daughter relationship will be examined.

Expanding on Chodorow’s argument, Gilligan (1982) concluded that women have an ‘ethic of care’ that reflects both their sensitivity to others and their responsibility for caregiving. Compared to men, women place more emphasis on relationships and interpersonal connections, while men are more likely to emphasize more depersonalized group memberships and the importance of group identity (Gabriel & Gardner, 1999; Maddux & Brewer, 2005; Seeley, Gardner, Pennington, & Gabriel, 2003).

Chodorow (1978) also identifies that one of the ways in which women have been characterized is through their ‘being’, whereas men have been characterized through their ‘doing’. Performing emotionally expressive tasks within the home and attending to family members’ socioemotional needs is viewed as central to women’s identity, whereas men tend to define themselves in other ways, most frequently as economic providers for family members and mediators with the world outside the family (Dressel & Clark, 1990; Walker, 1992). In a grounded theory study that examined the parenting identity and role of fathers who parent a child with juvenile rheumatoid arthritis (McNeill, 2007), behaviours of these men divert from masculine stereotypes, as indicated by their high level of commitment and involvement with their child. However, a presence of traditional fatherhood roles among these men was evident in their behaviours such as providing and protecting.

When women’s being is characterized by a nature of ‘caring-about’, their doing is characterized by the ‘caring-for’ tasks that they perform. This assumption provides a rationalization for women to choose caregiving work in the public sphere as nurses, home health care workers, social workers, and teachers, or in the private sphere as unpaid caregivers. As a result, women predominate as both unpaid and underpaid caregivers (Lackie, 1982; Lackey & Gates, 2001; Phillips, 1997; Poznanski & McLennan, 2003). The rationalization that nurture is central to women's identity may contribute to women's limited career choices, which in turn may prohibit women from reaching their fullest potential (Chase, Wells, & Deming, 1998; Lackey & Gates, 2001; Lively, Friedrich, & Buckwalter, 1995)

These psychologically-based explanations have been criticized for postulating a uniform feminine personality distinct from a masculine personality, thus underestimating differences and variations among women and among men. Kimmel (2004) argued that explanations of women's caregiving based on the relational perspective have two fundamental assumptions:

1. Women and men are markedly different from each other.
2. Differences *between* women and men are far greater and more decisive than the differences that might be observed *among* men or among women.

In other words, this perspective assumes that gender differences are inevitable. Walkerdine (1989) argued that these gender differences are fictions with no firm basis in reality and that this explanation of women's caregiving "play[s] these fictions and their dualism, instead of questioning the very strategy and its role in countering the threat of female power and thereby participating in the oppression of women" (p. 206).

Responding to charges that her work strengthens problematic male–female dualisms and essentializes women, Gilligan (1995) clarified:

> not because care is essentially associated with women or part of

> women's nature, but because women for a combination of psychological and political reasons voiced relational realities that were otherwise unspoken or dismissed as inconsequential. (p. 123)

Indeed, male–female differences exist in caregiving within the home and in the paid workforce. However, it is not simply because men and women are treated differently as children, but because they also confront different gender-based socially structured opportunities as adults. It is also not because women and men have inherently different capacities, needs, or desires. Instead, gender-based institutional norms and practices have historically denied women access to essential resources, including power, prestige, and property. As a result, they are offered different avenues for the expression of their caregiving (Hooyman & Gonyea, 1999).

The relational perspective has underemphasized underlying power dynamics. It reinforces traditional sexist orientations, perpetuating women as 'other' or as the 'second sex' (Freeman, 1990). Also, it does not fundamentally address how women and feminine traits within the private sphere of the home are valued (Hooyman & Gonyea, 1999).

The relational perspective serves as a useful theoretical framework for understanding women's identity development as a result of mother-daughter relationship in early childhood which consciously and unconsciously reinforces caregiving as identified with women. However, the application of this theory has remained primarily rooted in the Western experience and critical reflection of its relevance and application to women in different cultures needs to be examined, particularly in relation to how it shapes women's caregiving identities in the Taiwanese context.

2.1.3 Interactional Perspective on Caregiving Identities s

Another perspective that addresses the construction of caregiving identities is an interactional one insofar as meaning-making is treated as something that emerges through a social and interactive process (Blumer, 1969). The current study is particularly relevant to role-identity theory which has been informed by role theory and symbolic interactionsim (Stryker, 1980) and can be applied to understanding the construction of caregiving identities. Role-identity theory suggests that when a person assumes any social role, he or she internalizes the socially constructed behavioural expectations associated with that social position as a role identity. A person's combination of role identities at any given time is the basis for the person's "self" (Marks, 1998).

According to role theory, individuals occupy positions in social structures, and each position has a set of roles that has expectations or behaviours associated with it (Fredriksen-Goldsen & Scharlach, 2006; Payne, 1997). However, identity is not simply constructed by expectations held by an individual. Rather, it is negotiated through a socially interactive process of meaning making. Through the interaction within “enduring, normative, reciprocal relationships with other people” (Thoits, 1991, p. 103), information about socially acceptable norms is transmitted, internalizing the expectations of others and thus creating identity (Amankwaa, 2005; Perlman, 1968). Relationships also develop feedback concerning appropriate behaviour (Bird & Schnurman-Crook, 2005). Through the process of internal dialogue and interaction, meanings emerge, are negotiated, stabilized and transformed (Forte, 2005). Individuals’ caregiving identities are thus constructed.

Individuals’ interpretation of their world stems from their perceptions of self. In the symbolic interactionist perspective, the ideas of perception of self include perceptions of how they appear to others, perceptions of other person’s judgments of them, and some self-feelings that arise from these perceptions (Longmore, 1998). These perceptions of self are reflected in Cooley’s ‘looking-glass self’ (as cited in Longmore, 1998, p. 45), which suggested that a person’s perception of self is reflected in others’ representation of that individual (Amankwaa, 2005). The labeling process extends the explanation of self that enables individuals to interpret the responses of society by taking the role of the ‘generalized other’ (Shott, 1979). This means that the person interprets their world from the responses of others in society and is able to translate society’s response to their actions (Forte, 2005). Thus, social action arises from constant reformulation of self-image and expectation in any given context (Kearney, *et al*., 1994).

Identities provide behavioural guidance to individuals and form a sense of self. From the perspective of role theory, society offers various social positions and roles to its members. The specific position assigns the person with scripts for their behaviour and interactions. These social positions and their related roles provide the principal organizing framework and structure an individual’s self-model and identities (Thoits, 1991; Turner, 2002).

Identity cannot be understood from a disengaged vantage point or apart from context (Kearney *et al.*, 1994). Persons interact on the basis of their individual symbolic understanding and continually adjust their actions in response to their environment and culture. In sum, symbolic interactionism emphasizes that the meaning brought to a situation, and the persons’ interpretation of the situation, is influenced by a person's social interactions with others and the socio-cultural environment in which they exist (Blumer, 1969, Amankwaa, 2005). This point of view can help researchers explain culturally different interpretations to similar social experiences which further construct unique caregiving identities in certain society.

Within this perspective there are two principles that contribute to the understanding of the phenomenon of occupying multiple roles. The first principle is that carrying a number of different social roles can influence an individual's well-being negatively (the model of role strain) or positively (the model of role enhancement). The second principle is that identities are arranged in a hierarchy, with the most salient taking precedence across multiple situations (Stryker & Serpe, 1994).

The model of role strain posits that the enactment of multiple roles has the potential for introducing conflicting behavioural expectations leading to role overload or role conflict. Pressures and demands associated with multiple roles may exhaust one's personal resources and negatively affect physical and mental health (Marks, 1998). Individuals are more likely to find difficulties in meeting demands from multiple competing roles. Performing multiple roles can result in competition for the individual's limited amount of time and psychological and physical resources. This increases the likelihood that the individual will experience increased levels of stress (Kim *et al.*, 2006).

Research focuses on the extent to which the number of social roles that a woman occupies is associated with a range of measures of health. This model is supported by at least some studies indicating that combinations of roles can result in negative effect on women’s psychological health. Stephens and Townsend (1997) demonstrated that the stress related to providing care for an ill parent was aggravated by three additional roles (i.e. mother, wife, and employee) that the participants simultaneously occupied. The findings in the Kim and colleagues’ study also demonstrate that the multiple roles of caregivers carried out simultaneously are likely to compete with each other in the context of the caregiver’s limited psychological resources, resulting in heightened feelings of being strained by the cancer caregiver role and increased negative affect (Kim *et al.*, 2006).

Contrary to the argument that role strain can have a negative impact on women’s well-being, the model of role enhancement (Sieber, 1974) suggests that multiple roles can have an opposite effect (e.g., Marks, 1977; Moen, Dempster-McClain, & Williams, 1989; 1992) and bring psychosocial benefits to women (Repetti, Matthews, & Waldron, 1989). Multiple role occupancy can be a source of increased financial resources through job earnings or a spouse's financial contributions and provide access to social support. Occupying several social roles can also provide the individual with a range of sources of positive social interaction, pleasurable activity, achievement, status, self-esteem and mastery, all of which buffer stress and depression (Chumbler, Pienta, Dwyer, 2004).

According to the model of role enhancement, the person with additional roles is more likely to function better in playing the target role. Forgays and Forgays (1993) found that women who combined paid work, marriage, and motherhood were actually less stressed than married mothers without paid employment. Employed women who care for children have reported better physical and psychological well-being than unemployed women who care for children (Waldron, Weiss, & Hughes, 1998; Pavalko & Woodbury, 2000).

Even when raising adults with an intellectual disability, mothers who were unemployed and unmarried had markedly poorer well-being than mothers who were married, employed, or both (e.g., Eisenhower & Blacher, 2006). This finding is consistent with previous research among mothers of school-age children and adults with an intellectual disability. Gottlieb (1997) studied the role enhancement effect among single mothers of children with an intellectual disability and found mothers who had three roles - involvement with an intimate partner, employment and motherhood - experienced less depression and better health than single mothers who were unemployed and without an intimate partner.

The existing findings provide contradictory evidence: some support the model of role enhancement, and others support the model of role strain. It suggests the importance of potential moderating factors (Repetti, 1998) such as role combination (Kim, Baker, Spillers, Wellisch, 2006), caregiver’s sense of voluntariness in their roles (e.g., Marks, 1998), and the person’s skill in managing multiple roles (e.g., Lee & Powers, 2002).

It is possible that different combinations of roles may differ in the extent to which they contribute to stress and satisfaction. Some studies have demonstrated that employed caregivers report less caregiving strain and better emotional adjustment than those who are not employed (Stephens & Townsend, 1997; Dilworth & Kingsbury, 2005). However, employed women with younger children have reported greater conflict between their roles as employee and parent, and consequently result in greater psychological distress compared to employed women with older children (Rosenbaum & Cohen, 1999; Thompson, Beauvais, & Lyness, 1999; Pavalko & Woodbury, 2000; Stephens *et al*., 2001; Halpern, 2005). These findings support the model of role strain which suggest that when caregiver possesses additional parental role with younger children, multiple role occupancy has an adverse impact on the caregiver. However, in the case of women carrying multiple roles as employee and caregiver without younger children, the findings support the model of role enhancement.

A recent study examined the extent to which informal cancer caregivers perform multiple social roles and how these influence their psychological adjustment. One of the hypotheses was that role combinations are one of the factors that mediate the results of multiple role occupancy. Kim and colleagues found that performing two additional roles (employee and parent) had a greater aggravating impact on the caregiver’s cancer caregiving stress. On the contrary, an additional employee role with an absence of a parental role had a greater beneficial impact on the caregiver’s management of meaning while providing cancer care (Kim *et al*., 2006). The authors suggest that the beneficial impact of performing multiple roles applies to employed caregivers but does not for employed caregivers who also have a parental role.

The effects of multiple role occupancy may also depend on the intensity of care and whether the caregiver is voluntary or not. Marks (1998) investigated the extent to which work-family conflict accounts for the negative effects of caregiving on midlife well-being by examining the effects of caregiving for disabled children, spouses, parents, and other kin and non-kin on multiple positive and negative dimensions of psychological well-being and development using data from a population sample of employed, middle-aged men and women respondents in the Wisconsin Longitudinal Study 1992-1993 (n = 5,782). Marks (1998) hypothesized that the nature of contemporary social organization generates conflicting demands across the role identities of employee and caregiver and that this conflict is an important factor in accounting for the negative effects of caregiving on well-being. The results of this study confirmed that caregiving was associated with more psychological distress for women who were caring for a disabled child, spouse, or parent in or out of the household. Caring for others in addition was also associated with more hostility for women. Caring for a disabled child and a spouse were associated with poorer health for women. Among men, only spousal care was associated with negative effects on well-being. Men who provided care to spouses reported more psychological distress, more hostility, less purpose in life, and less environmental mastery than men who did not provide care. However, in the majority of cases, the caregiver role was not associated with well-being that was different from the well-being of non-caregivers. In fact, contrary to the hypothesis of negative effects of caregiving, a few positive effects were noted for male caregivers. That is, assuming the caregiver role for someone other than an immediate family member was associated with less psychological distress, more positive relations with others, more purpose in life, and more personal growth for men. It is likely that providing ‘other’ care is more voluntary and less intense than providing care to a disabled child, spouse, or parent. This may account for the different results of multiple role occupancy.

Lee and Powers (2002) believe the discrepancy in results related to multiple role occupancy can be attributed to management skills. For example, young women cope best with one role and middle-aged women cope best with multiple roles. A number of explanations may be possible. The authors argue that successful occupancy of multiple roles requires time management skills, and women may acquire these skills as they move through life. Middle-age women occupying multiple roles may have developed these skills over time, suggesting that the younger women may also develop effective coping strategies by the time they reach middle age themselves.

In addition to the above competing models, the second perspective that I adopt in an attempt to understand the phenomenon of occupying multiple roles is the model of identity salience which proposes identities are arranged in a hierarchy, with the most salient taking precedence across multiple situations (Stryker & Serpe, 1994). This means that in cases in which there is a conflict between expectations for behaviour, the identity of higher salience would be enacted.

The salience of a particular role has implications for one's engagement in that role. Some research suggests that the more salient a role is to an individual, the more time and emotion are invested in that role (Burke, 1991; Stryker & Serpe, 1994). Bird and Schnurman-Crook (2005) conducted a qualitative study of 15 dual-career couples and examined the connection between partner-professional identity and coping behaviours implemented in response to work and family stressors. The findings did not support the model that identities are arranged in a hierarchy with the most salient taking precedence across multiple situations. In their study, participants identified both professional and family identities as prominent. They spoke of being heavily committed to both identities and made significant attempts in each to match behaviours to identity standards. This suggests that balance rather than hierarchy more accurately describe the identity alignment.

Caregiving literature concerning the effects of competing identities tends to focus on the extent to which the number of social roles that a woman occupies is associated with a range of measures of psychological and physical health (e.g., Perry-Jenkins, Repetti, & Crouter, 2000). Less often do researchers focus on the process of how women experience the demands of multiple role identities. No study has examined the impact that multiple role identities have on sisters of individuals with CP. This study will address this gap by examining how these young women manage the demands of multiple and possibly competing roles.

Role-identity theory can be applied to the study of sisters of siblings with CP insofar as it provides a way of understanding perception of self, cognitions, and behaviours of female siblings in a Taiwanese social context. Examining how these women experience relationships and interactions with significant others in their life, the meanings these relationships and interactions have in their life and the extent to which these processes are connected to growing up with and having a sibling with CP, will be better understood.

According Fuss (1989), one of the flaws in the interactional approach is related to the fact that the interactional approach implies identity categories built through interactive effort. Such a stance underemphasizes the role of power in the interactive process. Theoretical frameworks introduced in the following section addresses the issue of role of power by introducing gender inequity perspective on caregiving identities.

2.1.4 Gender Inequity Perspective on Caregiving Identities

Early feminists did not articulate how women's caring for family members across the life course had severe negative psychological, physical and economic consequences for women. This lack of attention to women's caregiving responsibilities across the life span began to shift in the 1980s. The dramatic growth in the number of elderly and disabled people requiring long-term care combined with policy expectations that families provide such care provided the impetus for research that focused on family care of elderly and disabled persons. Given the predominance of women in the caregiving role, caregiving as a women's issue emerged (Baines, 1998a; Hooyman & Gonyea, 1999).

Feminism is characterized by multiple viewpoints, some of which include conservative, liberal, radical, socialist, cultural, and womanist (or woman of colour) feminisms (Crawford & Unger 2000; Liss, Hoffner, & Crawford, 2000). Of these, liberal feminism and radical feminism specifically address gender inequity in caregiving and how this inequity informs and constructs caregiving identities (Liss et al. 2000).

Gender inequity is supported by ideologies that view women as natural caregivers, by the devaluation of care work and by the obsession with separate spheres of public and private domains. Contrary to the natural perspective that assumes women have instincts to make them good providers in physical and emotional care, liberal feminism argues that women have been confined to the roles of wives and mothers. In this perspective, gendered characteristics such as women's caregiving abilities, may seem biological but are really social products

(Lorber, 1998). Given their culturally appointed nurturing role, mothers have filled the vacuum left by the unmet promises of community care, and as a result the responsibility for caregiving work has fallen heavily on women. Because of their affective links with the family, it falls to women to serve and maintain the family; thus the existing community care policies compound the stress that women experience as caregivers (Hooyman & Gonyea 1999).

Men's devaluation of women's paid and unpaid work is another aspect of the ideology that contributed to understanding gender inequity. The liberal feminist perspective identified that care work is badly rewarded because care is associated with women (England, 2005). Research shows that predominantly female jobs pay less than male jobs, after adjusting for measurable differences in educational requirements, skill levels and working conditions (England, 1992; Kilbourne, England, Farkas, Beron, Weir, 1994; Sorensen, 1994; Steinberg 2001; England, 2005). This devaluation maintains gender inequity insofar as women do not have the same means for autonomy and self-determination. Under such oppressive and subordinate positions, women limit their choices to caregiving and caregiving related employment roles (Collins, 1990).

One of the main tenets of radical feminism is that gender and gender inequity emerged from the separation of public and private spheres. According to this perspective, women perform caregiving work not because it is natural, but because of the dominant societal ideology of separate public and private spheres for men and women (Downs, 2004). Such artificial distinctions have developed because Western society extols the virtues of independence and individualism and seeks to distance itself from basic life events such as birth and dying. Therefore, women, who represent the private sphere, experience societal expectations that they will respond to these basic life events by becoming caregivers. The distinctions between public and private spheres contributes to the low value placed on the work of women in the home, societal disregard of the economic cost that caregiving places on women, and the lack of public support for governmental and corporate policies that meet the needs of dependent citizens (Hooyman & Gonyea, 1999).

One underlying bond between *liberal feminism* and r*adical feminism* is the agreement that women's caregiving is affected by power inequities and injustices inherent in patriarchal structures and that caregiving is devalued as a result. By making the social construction of caregiving identities explicit, feminism directs attention away from the individual and toward the structures and processes that not only shape experiences and meanings pertaining to caregiving but also construct caregiving identities.

Applied to the Taiwanese context, the aforementioned two Western-based approaches of feminisms have the potential to expose how the predominance of unequal gender power relations may influence, create and interpret Taiwanese women's caregiving identity. There is a decided absence of feminist scholarship in Taiwan reflecting on this issue and certainly none that focuses on sisters of siblings with CP. Women of colour have criticized feminist thought for being focused on women's experiences who are white and middle-class (Asante, 1996; Banks-Wallace, 2000). Women of colour scholars argue that these perspectives do not fully explain the realities of women with colour (Shambley-Ebron & Boyle, 2004). In an effort to understand the complexity of this particular criticism, it is important to incorporate and reflect on the dominant ideology that has influenced Taiwanese culture. It will provide a context against which to compare and contrast the ideologies that have emerged in Western culture.

2.2 Caregiving Theories and Empirical Studies in Chinese Society

In Taiwan, cultural assumptions are by and large informed by Confucianism. For example, the rulers of many dynasties included Confucianism in the Imperial examination[1] and they ensured the hiring of officials who would successfully embody the Confucian ideals for civil service (Fang *et al*., 2003). Given the systematic support that Confucianism has received by the bureaucracy, this intellectual tradition has dominated Chinese thought for over two millennia and as a result, one of the most systemic and prolonged patriarchies in human history has been sustained (Herr, 2003).

Confucianism is comprised of several comprehensive and interwoven notions that are closely related to the Chinese understandings of the origin of life. The Chinese do not conceive God as a transcendent creator as Christians do; they regard their lives as the continuation of their parents’ physical lives, and they conceptualize themselves consciously as living in a network of interpersonal relationships that are characterized by two dimensions: *Shan–Shia* and *Nei–Wai*. Whereas Shan–Shia (up–down) implies superiority versus inferiority (Hwang, 1999), Nei–Wai (in–out) defines boundaries within dyadic relationships (Chan, 2000).

The Confucian conception of the self is interpersonal (Ames, 1991). Self

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[1] The Imperial examinations in Imperial China determined who among the population would be permitted to enter the state's bureaucracy.

emerges only in a net of five cardinal human relationships that portrays relationships in an ordered hierarchy within the family and the state. Self is expected to play definite roles. It is in the process of performing these roles, and performing them well, that an individual acquires a unique identity and reaches self-actualization in relation to specific others (Herr, 2003).

Shan–Shia (superior–subordinate). Specific duties were prescribed between each of the participants in five sets of cardinal relationships. Between father and son, there should be affection; between ruler and subjects, righteousness; between husband and wife, attention to their separate functions; between elder brother and younger, a proper order; and between friends, friendship (The Doctrine of the Mean, trans. 1998, chap. XX, p.406)[2]. These five cardinal rules sustain the five major dyadic relationships in Chinese society, proposing that societal interaction between members of each pair should be those between superior and inferior. According to these rules, women as wives are subordinate to men as husbands. A husband is to set an example for his wife (The Work of Mencius, trans. 1998, book IV, part II, chap. XXXIII, p.340-341). In turn, the advice to a wife is to be obedient: ‘slay the unfilial; change not the son who has been appointed heir; exalt not a concubine to be the wife’ (The Work of Mencius, trans. 1998, book VI, part II, chap. VII, p.437).

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[2] The relationship between parents and children were written as father-son relationship in the original scripture. This happens in the relationship between elder and younger sibling as well. The ignorance of women’s relationships with their parents and siblings in the original scripture tells us the invisibility of their experiences in the old day. However, this does not mean women do not need to follow the proper order of superior and inferior to their relatives. Therefore, I modify the original scripture to better reflect the real situation in Taiwanese context.

The relationships between a superior and an inferior party were originally based on reciprocity. Later, the interpretation was purposely manipulated toward unilateral submission to the superior (Hsu, 1975). In dyadic relationships of respect to a superior, the person who occupies the superior position should play the role of the resource allocator. A superior should also express intimacy, gentleness, righteousness, kindness, and benevolence. The person who occupies the inferior position will repay by expressing submission, deference, loyalty, and obedience to the instructions of his superior. Reciprocity is considered an appropriate method of distributive justice and is based on willingness rather than external force (Hwang, 1999). In this sense, father and son are urged to reciprocate with love for each other. Similarly, rulers and ministers should reciprocate with respect (*ching*) for each other (The Work of Mencius, trans. 1998, book III, part I, chap. IV, p.252).

Over time, reciprocity between superior and inferior faded and the unilateral payout to the superior was accentuated. In the parent–son dyad, because parents are respected as the originators and sustainers of one's life and one's children's lives, the offspring owe a debt to their parents (Lan, 2002).

Between the Song Dynasty (which began in A.D. 960) and the Ming Dynasty (which ended in A.D. 1644), an emphasis on self-sacrificial expressions reached its peak. The Twenty-Four Filial Exemplars comprehensively portrayed complete filial piety- the virtue governing intergenerational relationships in ethnic Chinese families (Lan, 2002; Ma, 2000; Yeh, 1995) which commences with the service of parents. During the Yuán dynasty (A.D. 1260-1368), Guo Ju-Jingō (A.D. 1279–1368) recounted the feats of children, nearly all male, from the age of the Emperor Shun (B.C. 2257) until his own era. The tales are widely known to most Chinese, and many of them extolled masochism (e.g., “Wú Měng Let Mosquitoes Consume His Blood”), career sacrifice (e.g., “Zhū Shòuchāng Abandoned His Career to Seek His Mother”), or sacrificing loved ones (e.g., “Guō Jù Buried his Son for His Mother”) to express filial piety (Ju, 1981). Even nowadays, self-sacrificing behaviour is still seen as the noblest expression of filial piety toward parents. For example, in 2003, all of the nominees for the Grand Reward for Filial Piety were noted for treating their parents, parents-in-law, uncle, or sibling in accordance with the principles of filial piety by serving, bathing, and dressing them during long illnesses without complaining (Chang, 2003). Self-sacrifice becomes the ultimate expression of human decency and is applied to each of the five cardinal relationships.

The text of Guo Ju-Jingō implicitly exhorts children to repay their parents for the material, emotional, psychological, and social provisions they have received. Although filial duty can be explained as an act of reciprocation involving intergenerational exchanges of resources and power (Pyke, 1999), it is more than that. Social ethics demand unconditional payback no matter how much or how little a person has received from his or her parents.

Analects’ description vividly portrayed the unilateral parent–child relationship. ‘The difficulty is with the countenance. If, when their elders have any troublesome affairs, the young take the toil of them, and if, when the young have wine and food, they set them before their elders, is this to be considered filial piety?’ (Analects, trans. 1998, book II, chap. VIII, p.148). Even when parents have committed immoral acts, children should exemplify unconditional filial piety by ‘conceal[ing] the misconduct’ of parents’ (Analects, trans. 1998, book XIII, chap. XVIII, p.270.). Herr (2003) argued that Confucious did not necessarily endorse unprincipled moral relativism. When parents act against rule, children may remonstrate gently. If parents thrice do not accept their gentle remonstrations, children are urged to follow them, wailing loudly. When parents are not inclined to listen, however, children should not complain but ‘shows increased degree of reverence’ (Analects, trans. 1998, book IV4, chap. XVIII, P.170). Even if parents do not mend their ways despite the children’s efforts, children must never overstep what is prescribed by their filial duty and must try to lead their parents in the right direction as best as they can.

The concept of Shan-Shia (superior-subordinate) that is characterized with unilateral sacrifice also applies to husband–wife relationships. Having no heir is seen as the worst way of being unfilial (The Work of Mencius, trans. 1998, book IV, part II, chap. XXVI, p.313), as the Chinese believe that they and their offspring are the continuation of their parents’ lives. A wife’s failure to produce a male heir constitutes one of seven compelling grounds for expelling her from the marriage. Women are required to sacrifice on many fronts because of the whole cultural scheme of prioritizing male descendants; for example, a husband has the right (as well as obligation) to take concubines in order to enlarge the possibility of producing a male heir.

The notion of Shan-Shia (superior-subordinate) has evolved in Chinese history. The virtue of filial piety was once held in an unshakable position in which offspring are unilaterally submissive to the superior. For a period in history, the notion of Shan-Shia was once suppressed to a despicable position, in which, filial piety was deem as outmoded cliché. Chinese plunged into chaos when the Imperial System fell in 1912. The elites of Chinese society believed that bringing in the ideologies of the Western world would be of great help to raise national power. With an advent of Westernization, Chinese society started to reevaluate traditional values (Yeh, 1995). Within this context, it seems important to examine the perception and manifestation the notion of Shan-Shia (superior-subordinate) in modern society.

Currently, many Confucian societies in East Asia are undergoing rapid economic change. Confucian societies all over the world have evolved from an agricultural economy into commercial or industrial ones. With these changes, people participate in various social groups and establish many instrumental ties with others outside the family (Hsu, 1975). Relationships that previously emphasized submission to authority have weakened as younger generations now find work away from their families, earn their own income, and are less dependent on their financial support for sustenance. As a consequence, parents have less power than before to make decisions about their children’s lives such as selection of spouses and their money expenditure (Hwang, 1999).

Does this change imply that the importance of the notion of Shan-Shia (superior-subordinate) is downfallen in East Asia where Confucianism is generally regarded as the most influential philosophy? Recent studies about Chinese communication patterns and conflict style preferences with parents show that intergeneration interaction is gradually fading from absolute obedience to a more egalitarian, reciprocal relationship that is based on more open communication; from conformity to a conversationally oriented style. Chinese family communication pattern styles have traditionally been avoidant, accommodating, collaborative, and/or compromising, not competitive (Ting-Toomey *et al.*, 1991; Trubisky, Ting-Toomey, & Lin, 1991; Yu, 1997). Recent studies reveal that although the competitive style is still the least prevalent (Zhang, 2007), the avoidant style of communication is now less prevalent (Zhang, Harwood, & Hummert, 2005). Zhang (2007) argued that Chinese children may not prefer the competitive and avoidant styles because the competitive style is too direct and confrontational in parent-child relationships and the avoidant is too passive and ineffective; as a result, they embrace more constructive styles. Zhang, Harwood and Hummert (2005) observed intergenerational conflict style differences in China. They found that older Chinese adults preferred the accommodating style. In comparison, younger Chinese adults, who are more open to Western ideas of equality, freedom, and independence, favour the problem-solving and the accommodating styles over avoidant styles. Yeh and Bedford (2004) conducted a survey with n=773 students from junior and senior high school in Taiwan. They enquired about the use of strategies to resolve conflict with parents and found that among five solution strategies (self-sacrifice, egocentrism, reframing, escape, and compromise[3]), reframing was the most

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[3] Yeh's (1995, 1997a) identified five solution strategies to resolve conflict and maintaining a filial relationship with parents from analysis of sequential in-depth interviews. The effective strategies include: (1) *Self-sacrifice:* self sacrifice requires children to give in to parental demands whenever conflict with parents arises. If the conflict refers to the benefit of parents or a third party (e.g., spouse, society, or country), children should carry out all duties to their parents first. (2) *Egocentrism:* egocentrism is the direct opposite of self-sacrifice. Filial virtues and duties are not the primary guides to behaviour. Instead, children attempt to obtain the most advantages or least harm to themselves in the solution

common. Reframing referred to recasting conflictual situations differently so that both sides attained their goals and neither party needed to sacrifice their demands.

With Chinese society gradually transforming from a self-closed Confucianism-oriented culture to an indispensable part of our international community in the past few decades, the juxtaposition of traditional values and the increasing modernization and globalization has inevitably affected family communication patterns, but relational harmony is still the most endorsed cultural value among Chinese young people (Zhang, Lin, Nonaka, & Beom, 2005). How Taiwanese women response to their parents who expect their children to perform filial piety, obey and conform without question? How Taiwanese women's cultural belief of Shan-Shia (superior-inferior) impact on their caregiving identities when they are no longer conformity and may not prefer the avoidant styles to respond to parents demands? These questions will be examined in this study.

Nei–Wai (inside–outside). Broadly speaking, the concept of Nei–Wai (inside–outside) determines resource and obligation allocation in Chinese families.

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process. (3) *Reframing*: reframing can be used to recast conflict situations into a new context such that both sides attain their goals and neither party need sacrifice any demands. (4) *Escape*: escape involves the child's attempt to either escape from the current conflict or to do nothing because of a lack of ideas about how to resolve conflict. Sometimes escape is a temporary strategy when the conflict situation is not so serious as to require an immediate solution. When the time comes that the issue must be resolved, the escape strategy will be forcefully transformed to one of the other four solution types. (5) *Compromise*: the child works to find a middle ground where both sides make some sacrifice in order to resolve conflict. Compromise may involve discussion or solving a conflict step by step or by first satisfying one side's needs, and then the other's.

Hwang (1999) described the structure of Chinese society as ripples caused by a stone's throw in a pond. Everyone is situated within the circumference of the water rings. Adopting this metaphor to the rule of resource and responsibility allocation, it is then more appropriate to allocate more resources and obligation to the individual who is closer to the center of the water ring than those who sit on the ring's edge.

The patrilineal system valuing the father-son dyad has placed primary resource obligations on the son, the one who is located in the inner ring of the ripple, while the value and resources of the daughter transfers to her husband's family upon marriage. In the historic concept of filial piety, children, notably sons, are obligated to provide for elderly parents while daughters-in-law hold a particular place in providing assistance with domestic responsibilities in caring for her parents-in-law (Liu & Kendig, 2000). Intergenerational exchanges between father and son dyads who are situated in the center of the ripple indicate a preference for the son through differential inheritance that favours the son economically. In exchange, parents expect that they will be cared for by their son (and his wife) during their aging years (Chappell & Kusch, 2007; Ng, Phillips, & Lee, 2002).

The pattern of father-son dyads located in the center of the ripple in Chinese societies has evolved over time. There is evidence that although the ideal of filial piety is still valued, its practice has been changing in Chinese societies, such as Hong Kong, China, Taiwan and among those who are Chinese but live away from their homeland. In Hong Kong, Lee, Yu, Sun, and Liu (2000) reported that for most elderly people, children are the primary source of subsistence-income, especially for those who are widowed or divorced. Sons are more likely than daughters to be regarded by elderly parents as the primary underlying source of help in the event of crises including sickness. When asked their preferred living arrangement, 35% of respondents regarded their sons as primary caregivers, as many as 17.1% considered their daughters as the most helpful persons in times of trouble or illness (Lee *et al.*, 2000).

Research addressing the practice of filial piety among the Chinese living abroad and how cultural maintenance is reflected in supporting parents shows a similar pattern. Chappell, Gee, McDonald and Stones' (2003) research about Chinese seniors living in British Columbia, Canada reported that these seniors prefer to live with children, and to name a son as the person they would turn to in an emergency. This suggests a maintenance of Chinese cultural patterns, even when away from their homeland.

In Taiwan, sons also generally carry the major responsibility for taking care of their older parents. In a study examining the patterns and determinants of support provided by adult children to their parents, particular attention was paid to differences in the helping behaviours of sons and daughters. 12,166 adult children from 2,527 families were interviewed. Sons generally carried the major responsibility for taking care of their older parents, and daughters fulfilled the son's roles when sons were not available (Lin *et al.*, 2003).

Even though seniors are much more likely to indicate that they are dependent on sons, the practice of hands-on caregiving to them has been undergoing considerable change, especially for daughters-in-law who are a major potential resource. Surprising, in Lee, Yu, Sun, & Liu’s study, only 2.7% named their children-in-law as the most helpful persons in times of trouble or illness. The result suggests that the traditional role of daughters-in-law is either not viable or is not acknowledged in Hong Kong (Lee, Yu, Sun, & Liu, 2000). Research conducted by Wong (2000), also in Hong Kong, reveals that daughters-in-law do provide instrumental caregiving to their parents-in-law, but they do not feel it is their direct responsibility or obligation. Rather, they view such caregiving as a form of support for their husbands. One wonders about the extent to which their endorsement or acknowledgement of real support is based on traditional understandings versus actual care provided.

Along with the minimization of daughters-in-law in the support provided to their parents-in-law, it is also important to understand the complexities involved in the involvement of daughters in the care of their own parents. Yu, Shilong, Zehuai, and Lie (2000) reveal that, in Guangzhou, China, approximately the same proportion of sons and daughters (18.7% and 17.7%) are involved in caregiving (Yu *et al.*, 2000). In a study exploring the changing dynamics of gendered familial caregiving in urban China, daughters' families also provided financial assistance for parents at a level that was comparable to sons' families (Zhan & Montgomery, 2003). These findings challenge the way in which filial piety as practiced today in comparison to how it is represented historically.

In sum, changes in family and economic structures are quite likely to alter the actual practice of the long tradition of familial care as Confucian societies continue to globalize their economy (Zhan & Montgomery, 2003). Irrespective of the patrilineal system that values the father-son dyad, the practice of gender caring in Chinese family is undergoing considerable change.

Nei-Wai also applies to the conceptualization of gender in the Analects (trans. 1998) and the Work of Mencius (trans. 1998), both of which address the assignment of functions through division of labour. This idea is expressed in the saying nan-chu-wai, nu-chu-nei (males are primarily in the outer, females are primarily in the inner). Women handle the domestic affairs such as nurturing children, cooking, weaving, and other household work. Men handle public and social affairs such as farming and commerce, and some hold government offices (Chan, 2000)**.** Women are confined to the Nei, the familial realm of domestic skills and household management, and men to the Wai, which is the realm of literary learning, officialdom, and personal fulfillment. When people introduce their spouse to others, women usually address their husband as “wai chi” (outside people) and men address their wives as “nei chi” (inside people). The boundary between the sexes is ritualized.

In recent decade, the strict division between Nei and Wai has become more blurred. For example, the female labour force has expanded at an average rate of 2.2% per year from 1991 to 2001 (Directorate General of Budget, Accounting and Statistics of Executive Yuan, 2002). Also, men in modern Taiwanese society cross the boundary of Nei and Wai by participating in family chores. However, these men still subscribe to traditional assumptions about gender - they tend to see themselves as helpers to their wives, and do chores such as cooking and grocery shopping as a hobby rather feeling fully responsible for them (Mo, 1996).

A review of the literature suggests that Nei-Wai can be applied to the analysis of how resource and obligations are allocated in families and how labour is divided based on gender. However, there is no empirical evidence to examine how the notion of Nei-Wai constructs Taiwanese women's caregiving identities to their brother or sister with CP.

The meaning of Confucianism goes beyond a set of references by which ordinary people deal with social relationships. It has been internalized through socialization, and it has become the highest mark of morality. For the followers of Confucianism, self-actualization occurs within the confines of human relationships, and maintaining harmonious relationships is the point of departure for becoming truly human (Herr, 2003). However, it is still not clear how these sisters in contemporary Taiwan manage to fulfill her multiple roles as daughters to their mothers and fathers, sisters to their siblings with CP, and wives to their husbands, and current or potential daughters-in-law. These familial roles further intersect with school, work and friendship roles.

There are clear differences between Western-based and Eastern theoretical frameworks. However, their convergence exemplifies the influences that operate in the lives of Taiwanese women. Understanding them, how they converge and diverge, provides a framework for understanding the potential tensions that Taiwanese sisters of siblings with CP, in the contexts of modernization and globalization, experience. The first point of convergence lies between the natural perspective and Confucianism in that both perspectives endorse natural caring. That is, these two approaches both believe that women's caregiving is naturally developed. Such beliefs may influence how women feel about themselves as caregivers. Also, both the relational perspective and Confucianism view the self as emerging in an interpersonal context. It is in the process of interacting with individuals in specific relationships that self-identity is formed.

Despite these similarities, some major differences emerge in relation to moral responsibility in caregiving and care principle. Liberalism views the human self as independent, autonomous, free and equal. In this stand, individuals are not obligated to form caring relationships. Individuals are perfectly legitimate to choose to care or not to care (Herr, 2003). On the contrary, in Confucianism, it is an ethic of responsibility to offer care to family members, whether one feels inclined to do so or not. Liberal feminism treats caring for others as voluntary whereas Confucianism defines caring for others as a moral responsibility.

The second disparity has to do with the difference between maternal feminism and Confucianism in the principle that addresses the distribution of caring resources to family members and non-family members. Maternal feminist view women’s caregiving role as extended to non-related others and as expandable to the public domain outside that of families. Unlike maternal feminism, Confucianism advocates that caring responsibilities belong to the private sphere (Herr, 2003). Following the principle of Nei-Wai, followers of Confucianism believe that caring resources should be drawn from one’s nearest social circle, such as parents and children.

In this chapter, connections and prevailing ideologies of Confucianism that inform Chinese cultural belief systems have been identified as have major Western-based principles from theories that inform the nature of caregiving. The next section will discuss a pertinent body of literature pertaining to the meaning of caregiving, a major focus of this study.

CHAPTER THREE
CP AND THE CAREGIVING EXPERIENCE

In Taiwan, the care of family members with disabilities is a legal responsibility of the family (Liu & Tinker, 2001). While playing a central role in the provision of care to individuals with CP, the level of care they require along with the long-term nature of their care suggests that caregivers are similarly affected. Their attendance to and active participation in meeting the needs of individuals with CP during all phases of development likely exposes them to the same kind of stress and compromised health documented by Brehaut *et al*., 2004. They not only attempt to overcome the difficulties and complications arising from caregiving but also may face the challenges of not being able to satisfy their own social needs (Ones, Yilmax, Cetinkaya, & Caglar, 2005).

To understand the challenges of providing care to people with CP and to appreciate what sisters of individuals with CP experience, this chapter covers two areas. The first part of his chapter will begin with an overview of CP, including types of CP and related health conditions. Next, two dimensions of caregiving experiences in the literature will be discussed. The first dimension describes the impact of CP on caregivers' physical and psychological health, factors influence the health outcomes of caregivers and the effectiveness of formal supports that may ameliorate caregiver burden. The second dimension aims at developing a typology of caregiving according to caregivers' experience that may provide useful knowledge for understand women's caregiving experiences and contributes to our understanding of how these experiences construct their caregiving identities.

3.1 Overview of CP

Cerebral palsy (CP) is a group of disorders of the development of movement and posture, causing activity limitation (Bax, *et al.*, 2005; Shevell & Bondenstiner, 2004) resulting from lesions of the brain occurred in the developing fetal or infant brain (Shevell & Bondenstiner, 2004). The prevalence of cerebral palsy is 2-2.5/1000 children in the Western world (Missiuna, Smits, Rosenbaum, Woodside, & Law, 2001). The disorder is non-progressive and often accompanied other neurological disabilities include disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder (Bax, et al., 2005; Shevell & Bondenstiner, 2004).

The syndrome frequently includes paresis, in-coordination, and involuntary movements. Although motor dysfunction in addition to other sensory, visual, hearing loss, cognitive, and verbal impairments are the defining clinical feature of CP, learning difficulties and behavioural problems are co-morbid features (Ones *et al.*, 2005). The activities most often affected are walking, hand and body coordination, speech, and swallowing. Depending on the area of the location and severity of the damage to the motor cells affected in the brain, the damage may produce combinations of impairments in any or all of these functions as well as in breathing, bowel and bladder control (Miller, 2005). Activities pertaining to self-care functions such as feeding, dressing, bathing, and mobility are affected (Miller, 2005). Consequently, caring for a child with complex impairments at home has physical and psychological implications for the caregiver (Brehaut *et al.*, 2004; Raina *et al.*, 2005).

3.1.1 Type of CP

CP may be classified according to either the location of the brain injury or the resulting mobility limitation. According to the location of the brain injury there are three types of CP: (a) spastic CP, which is caused by damage to the cortex and presents as muscular stiffness; (b) athetoid CP, caused by damage to the basal ganglia and presenting as ill-coordinated movements; and (c) ataxic CP, caused by damage to the cerebellum and presenting as unsteady, random movements. Each of these types may be mild, medium, or severe. It is most common for children to appear to have mixtures of more than one type or to express different types at different times (Bridge, 1999).

Classified according to resulting mobility limitations, the types of CP include (a) quadriplegia, involvement of all four limbs; (b) diplegia, significant leg involvement with little effect on the arms; and (c) hemiplegia, involvement of the ipsilateral arm and leg (Koman, Smith, Shilt, 2004).

3.1.2 Other Conditions Associated With CP

Brain injury sustained in early childhood increases the likelihood of other problems occurring or developing. The severity of CP varies by person, according to the location and extent of the injury. Some individuals therefore might have none of the following conditions, while others might have a combination of them at varying in degree of severity (Bridge, 1999).

3.1.2.1 Intellectual Disability

With CP the extent of cognitive impairment varies from severe to mild, as do the physical manifestations. According to the database that was set up to include information on over 6000 children with CP in Europe, around 20% of the children were found to have severe intellectual deficits and were unable to walk (Cans & Guillem, 2002).

Intellectual disability could influence the performance of activities of daily living. Previous research has focused on disorders of movement and posture development that cause activity limitations. In a review article, converging evidence suggested that in addition to movement execution impairments, impairments in movement planning may also limit the performance of activities of daily living (Steenbergen & Gordon, 2006).

Whether or not children with CP have sustained cognitive damage that is physiological in origin, their intellectual ability might be affected because their access to learning opportunities maybe restricted (Bridge, 1999). However, the levels of restriction are varied which depends on external physical, social, and attitudinal environment, in other words, where the child with CP live (Hammal, Jarvis, & Colver, 2004).

3.1.2.2 Speech, Eating, and Visual Impairment

Persons with CP have in common disorders of movement. It is misleading to think the damage is only confined to limb movements. The mouth muscles that control speech and eating may be impaired as well. The eye muscles also may not function well, leading to sight or focusing difficulties such as constant squinting (Bridge, 1999).

Speech problems can be generally attributed to three major factors: motor production of speech, actual language and central processing difficulties, and hearing loss. Among these factors, motor production of speech is the most prevalent, while hearing impairments may be a factor in some 20% of such instances. With increasing age, pulmonary changes, breath control, and voice volume and capacity can be affected, generating further speech problems. Speech difficulties may present an intricate set of problems. Persons with CP may have learning disabilities that interplay with cognition and language production. The complex interaction between motor and cognitive processes can make receptive and expressive communication as well as interaction a frustrating ordeal (Turk, Overeynder, & Janicki, 1995).

3. 1.2.3 Gastrointestinal System

To persons with CP, the major gastrointestinal (GI) complaints are vomiting, constipation, and swallowing. A study by Del Giudice *et al*. (1999) described the prevalence and nature of gastrointestinal symptoms in 58 children with CP (ranging in age from 6 months to 12 years) who attended a pediatric neurology outpatient clinic. The results showed that 92% of children with CP had clinically significant gastrointestinal symptoms. Swallowing disorders were presented in 60% of patients, regurgitation or vomiting in 32%, abdominal pain in 32%, episodes of chronic pulmonary aspiration in 41%, and chronic constipation in 74%. The researchers concluded that children with CP exhibited diffuse GI clinical manifestations, mostly due to disorders of GI motility and not related to any specific abnormalities of the brain.

Vomiting is frequently the result of delayed gastric emptying, which predisposes patients to gastroesophageal reflux. Vomiting has especially plagued these children and becomes more severe as they progress through adolescence (Del Giudice *et al.*, 1999).

Constipation is frequent. Abnormal autonomic control of gastrointestinal motility (Goyal & Hirano, 1996), immobilization, and inadequate oral intake (Giudice, 1997) are probably important concurrent factors.

Swallowing problems may stem from cognitive impairments or oral motor apraxia. Functionally, individuals with CP have mild to severe difficulties with management of oral secretions in addition to dysphagia (Senner, Logemann, Zecker, & Gaebler-Spira, 2004).

3. 1.2.4 Aspiration

Patients with severe motor impairment are at increased risk of aspiration of food into the airway. Among persons with severe developmental disability, those with quadriparesis have more likelihood of encountering aspiration problems than those with less severe movement disorder (Hoffman, 2000). As mentioned earlier, movement disorder is not confined to limb movement; it influences the entire movement system and affects such actions as swallowing and speaking. Aspiration problems may result from swallowing dysfunctions or from impaired gastric emptying, which causes reflux into the esophagus (Rapp & Torres, 2000). Changing the consistency of the solid and liquid diet, teaching techniques to protect the airway, and proper positioning during and after meals can decrease the occurrence of pulmonary involvement (Rapp & Torres, 2000). However, it is also known that aspiration pneumonia is strongly associated with profound intellectual impairment. Even when a variety of precautions are taken, individuals with CP who have profound intellectual impairment are still under the threat of death caused by respiratory problems (Blair, Watson, Badawi, & Stanley, 2001).

3. 1.2.5 Musculoskeletal System

Musculoskeletal disorders may necessitate surgical interventions for the purpose of prevention and improvement. Persons with CP often encounter curvature of the spine and hip displacement (Graham & Selber, 2003). Hip dislocation is present in 30% to 60% of children with CP who have not walked independently for 5 years. The gradual dislocation of the hips may result in problems with movement development, posture, and, later on, pain that affects functions such as hygiene and ability to sit (Pountney & Green, 2006). Surgical intervention can help to maximize the potentiality of persons with CP (Graham & Selber, 2003).

The multifaceted challenges posed by CP require of the caregiver not only a great amount of time, physical strength, and stamina, but also the psychological ability to deal with day-to-day demands such as dressing, grooming, and toileting. In the following section, a literature search reveals how these caregiving demands may impact caregivers psychologically and physically.

3.2 Caregiving Experience

A wide array of studies discusses caregiving experiences in the literature. Two dimensions will be discussed in the following sections. The first dimension describes the impact of CP on caregivers' physical and psychological health, factors influencing the health outcomes of caregivers and the effectiveness of formal supports that may ameliorate caregiver burden. The second dimension aims at develop typology of caregiving according to caregivers' experiences.

3.2.1 Caregiving Experience: Impact of CP on Caregivers' Physical and Psychological Health

Caring for a child with CP can have implications for caregivers' psychological and physical health. To examine whether these demands impact caregivers psychologically and physically, Brehaut *et al*. (2004) obtained data from publicly funded children's rehabilitation centers in Ontario, Canada, on n=468 caregivers of children with CP. Their functioning was compared to a nationally representative sample of the Canadian population in two large-scale Canadian surveys: the National Population Health Survey (NPHS) and the National Longitudinal Study of Children and Youth (NLSCY). The results showed that these caregivers reported a variety of physical problems—including back problems, migraine headaches, stomach and intestinal ulcers, asthma, arthritis and rheumatism, and pain—as well as a greater overall number of chronic physical conditions. Although this was a cross sectional study, their findings suggest that differences in the health status of parents can be at least partially explained by the demands of children's disabilities, and that caregivers of children with CP are more likely to have a variety of physical health problems.

The same team used a stress process model to examine direct and indirect relationships between child health, behaviour, and functional status, caregiver characteristics, social supports, family functioning, and caregivers' physical and psychological health outcomes. The researchers concluded that the practical day-to-day needs of the child directly challenged physical health of caregivers (Raina et al., 2005).

The finding that caring for a child with CP can have implications for the physical health of the caregiver is also supported by Turkish researchers. Eker and Tuzun (2004) conducted a survey to compare the quality of life between forty mothers with a child diagnosed with CP and 44 mothers who had a child with minor health problems. They administered sensitive instrument to measure the impact of CP on caregivers' physical health. Caregivers of children with CP indicated that their physical health interfered with work or other daily activities more than did caregivers in the comparison group. The same result was found in the subscale that rated the subjective intensity of pain and the effect of this pain on normal work both inside and outside the home. Mothers' role in caregiving covers a very wide range of activities. Some of these tasks, such as heavy lifting and turning, bathing, helping the child use a toilet, getting the child to sleep, dressing, and assisting the child to move, can place physical strain on caregivers. Manual handling may indeed be a contributing factor to caregiver's physical problems (Eker &Tuzun, 2004).

Psychological health has been the subject of a number of studies, with evidence showing that caregivers of children with disabilities are more likely to experience depression. Face-to-face interviews were conducted with n=46 mothers of children with CP and n=46 mothers of children without CP to evaluate mother's depression score (Ones *et al*., 2005). There was a significant difference in depression scores between mothers of children with CP and mothers of healthy children, indicating that mothers of children with CP had a higher prevalence of depression. Eker and Tuzun (2004) also found that mothers of children with CP had scores that were indicative of anxiety or depression related symptoms compared with those who have children with minor health problems. Compared to mothers of children without CP, findings in both studies (Eker and Tuzun, 2004; Ones *et al*., 2005) indicate that caring for children with CP have implications for caregivers' psychological health, especially in the depressive symptoms.

There are a number of factors that influence the health outcomes of parents who are raising a child with a developmental disability. Care-recipients' characteristics, such as their levels of disability (Leonard, Johnson & Brust, 1993; Saddler & Hillman, 1993) and behavioural disorders (Raina *et al*., 2005) are associated with caregivers' psychological health. For caregivers of children with CP, severity of the disability in terms of the level of independent functioning in daily life was found to be an important predictor of maternal depression (Baird, McConachie, & Scrutton, 2000, Button, Pianta, & Marvin, 2001; Ong, Afifah, Sofiah, & Lye, 1998). Others have demonstrated that the presence of behaviour problems in the child with CP was related to parental stress and well-being (King *et al*., 1999; Mobarak, Khan, Munir, Zaman, & McConachie, , 2000; Wanamaker & Glenwick, 1998; Raina *et al*., 2005). However, the extent to which severity of disability and depressive symptoms are linked is contentious as a number of studies do not support these findings (e.g., Horton-Vensters & Wallander 2001; Manuel, Naughton, Balkrishnan, Paterson, & Koman, 2003; Ones, *et al*., 2005).

Compromised psychological and physical health of caregivers can be ameliorated by formal support such as respite care (e.g., Adler, Ott, Jelinski, Mortimer, & Christensen, 1993; Zarit, Stephens, Townsend, & Greene, 1998). However, reviews of empirical studies show diverse and somewhat contradictory results pertaining to the use of respite care and its impact on caregivers' levels of stress, depression, subjective or objective burden, life satisfaction, physical and/or emotional well-being. Zarit *et al*. (1998) conducted a quasi-experimental study in the USA of psychological benefits to family caregivers of adult day care for people with dementia, at 3 months (n=324) and 1 year (n=193). They found that caregivers using day care had significantly lower levels of overload, worry/strain, depression and anger at 3 months, and significantly lower levels of overload and depression at 1 year. They were benefited significantly more than those using no day care in terms of caregiver depression and caregiver burden (Zarit *et al*. 1998). Adler (1993) conducted a study in the United States to understand whether caregiver feelings of burden and depression were affected by an institutional respite care stay or not. Thirty-seven individuals with dementia and their caregivers were studied before and after a two-week in-hospital respite stay. The findings revealed that caregivers exhibited an improvement in burden and depression during the respite study, but by two weeks post-respite, caregiver depression scores returned to pre-respite care values. Mui (1992) also reports that perceived lack of respite care is significantly associated with caregiver depression for African American but not for White caregivers.

Gottlieb and Johnson (2000) conducted a study using a pre- and post-test design for caregivers of older people who continually and regularly attended a day care respite programme for 5 months (n=58 of total 103). They found a significant decrease in caregiver anxiety, somatization and perceived stress, but not in depressive mood or life satisfaction. Cox (1997) conducted interviews (before and after) with 228 caregivers of people with Alzheimer’s accepted into both in-home and day care respite programs. After 6 months of respite, half the caregivers who completed the respite programs were reported to have a significant decrease in burden scores, but no change in levels of anxiety, depression or personal gain (Cox, 1997).

Although results regarding the extent to which respite use is associated with a decrease in caregiver burden, depressive symptoms and stress are contradictory, there is agreement on caregivers' satisfaction with respite care services. Practical benefits for caregivers are commonly acknowledged, such as allowing time to rest and relax, freedom to pursue other activities, improve self-esteem, feeling secure about possible breakdown of care arrangements, improvement in family relationships and sleep patterns (Kosloski & Montgomery, 1993; Strang & Haughey, 1999; Perry & Bontinen, 2001; Mohide, 2002).

In sum, the current literature, caregiving demands do impact caregivers, majority of them are mothers, both psychologically and physically. There is a lack of discussion in the body of literature about how these mothers' physical pain, depression and anxiety impact on family relationships, especially with sisters, and further construct these sisters' caregiving identities.

3.2.2 Caregiving Experience – Typology of Caregiving

The development of typology on caregiving is complex as it requires an interpretation of a caregiving relationship or situation. This cannot always be observed and when it is, similar actions can have different meanings (Bowers, 1987). Perception of the caregiving experience is also contingent on whose evaluation is solicited and how it is solicited.

Most research and policy on informal caregiving among older people refers to caregiving as instrumental activities of daily living (IADL; i.e. help with laundry, cooking and house cleaning) or personal activities of daily living (PADL;

i.e. help with personal hygiene, feeding and getting dressed) (Ekwall, Sivberg, & Hallberg, 2004; Nolan, Keady, & Grant, 1995). Practitioners' perceptions of the work that is accomplished by caregivers refers to caregiving as a series of tasks that emphasize instrumental activities of daily living, such as housework, meal preparation, and less tangible forms of support, such as encouragement, advice giving, visits, and outings were most common (Ekwall *et al*., 2004; Guberman *et al.*, 2006). The scope provides us with an understanding of the tasks and perhaps ‘burden’ or ‘load’ but limited to the physical dimensions of caring and fails to capture the dynamic nature of informal care (Jegermalm, 2006).

In order to broaden the understanding of the meaning of caregiving to caregivers, some of the researchers have interviewed caregivers about the nature of tasks and responsibilities they carry, their experience of these tasks and responsibilities, and how these are reconciled in their lives. In a study about the tasks carried out by caregivers, Jegermalm (2006) collected data in a Swedish county in 2000 to learn more about the nature of care provided. The sample of 2,697 individuals ranged in age from 18-84 years. A telephone survey provided information about the types of care provided to care recipients, prevalence about different types of care, and who provided the care. There was a distinct separation between caregivers who provided personal care in combination with other caring tasks, and those who provided care that did not involve personal care. Caregivers in the former category were typically women, usually an elderly wife who provided many hours of personal care for a husband with whom she lived, or a daughter who provided personal care for a mother with whom she did not live. Among those not providing personal care, there were three categories of caregivers- (1) keeping company and/or keeping an eye on, (2) practical help (any combination of housework, paperwork, taking out, gardening etc.) plus keeping company and keeping an eye on, and (3) practical help only. Men were most likely to provide practical help only, while women often kept someone company/kept an eye on someone. Jegermalm (2006) contends that one might assume that the relatively high availability of social care services provided by the public welfare system in Sweden would minimize gender role differences with regard to informal care. However, the results obtained from the study seem to describe a similar pattern of gender roles as described in other studies that women overall, and especially older women, provide most of the personal care for a large number of hours.

Another branch of studies about the caregiving experiences has described and analyzed caregiving in terms of the intentions of the care. Bowers (1987) interviewed adult children caring for their elderly parents diagnosed with various degrees of dementia. Most of these adult children were women. Recognizing that much of the work of caregiving was invisible, she entered into the research process with the objective of understanding purpose rather than task, and developed five types of care.

First, there is *anticipatory care* which begins many years before any actual help is required. This kind of care can have a profound effect on the caregiver's life as major life decisions can be influenced by such anticipated future needs. The second type of care is *preventive care* which involves activities such as checking medication and meal preparation. *Supervisory care*, the third type of care, is required when the assistance with actually taking medication is needed. As the need for direct assistance increases, the process of caregiving reaches the stage of *instrumental care*. The fifth type of care, *protective care* underpins the whole model which refers to the maintenance of the self-esteem of those being cared for. The purpose of protective care is to minimize awareness of failing abilities and maximize the extent to which the individual perceives themselves as independent. Bowers (1988) later substituted the concept of preventive care with *preservative care* as it captured the importance of preserving as much of the care-for person's sense of self as possible.

Bowers' model has made a contribution in moving the debate on care away from instrumental aspects of care. However, the model is limited to intergenerational and dementia care and fails to fully account for a longitudinal perspective (Nolan *et al*., 1995). Nolan and his colleagues (1995) reconceptualized Bowers' model which can be applied to a more diverse set of caregiving circumstances. They synthesized a number of studies that included more than 150 semi-structured interviews addressing evaluation of the provision of services for caregivers. During that process they redefined the meaning of anticipatory and protective care. Anticipatory care is far more than an activity that is 'invisible' and 'deliberately not shared with the parent in case it causes offence' (p. 260). Anticipatory care changes in character over time. In progressive conditions, the anticipation can change from speculative anticipation where the caregiver has little or no information to inform their anticipation. In the latter form of anticipation, caregivers have access to adequate knowledge to aid the identification of likely future needs which facilitates the development of a more rational forward planning. Responding to Bowers' model which emphasizes protective intention, Nolan and colleagues believe that keeping thoughts about the future away from the cared-for-person and other family members has the potential to create a family crisis. Avoidance of any discussion about the future may catapult the family into a state of distress when faced with deterioration in functioning.

In terms of protective care, Nolan and his colleagues (1995) argue that keeping cared for people unaware of their failing abilities and preserving the cared-for person's sense of self is a type of care is consistent with denial as it covers up the extent of dependency. Oftentimes, this strategy is not in the best interests of either the caregiver or the cared-for person, as it has the potential to generate additional challenges. Nolan and his colleagues propose *reconstructive care* which refers to an active effort to develop new and valued roles for the cared-for person.

Aberg, Sidenvall, Hepworth, O'Reilly, & Lithell (2004) explored the caregiving experience from the perspective of informal caregivers who gave care to seniors (aged 80 to 92 years) whose main diagnoses necessitating rehabilitation were hip fracture (n = 6), stroke (n = 5), spinal injury (n = 1), respiratory insufficiency (n = 1), and consequences of a fall (*n* = 1). They interviewed 14 caregivers (aged 42 to 82 years) from Sweden. All but one informant was raised in Sweden, and 12 of them were women. Care provided by the caregivers fell into three categories: social-emotional caregiving, proxy caregiving, and instrumental caregiving. These aspects of caregiving were instrumental in facilitating care recipients' life satisfaction in terms of activity, independence, environmental and adaptive factors. Social-emotional caregiving was provided by maintaining contact, such as face-to-face contacts, telephone contact or occasional visits. Proxy caregiving included activities such as checking up, arranging, planning, and managing things on behalf of the care recipients. Instrumental caregiving included assisting with carrying out household tasks such as cleaning, shopping, and washing. The three caregiving categories were expressed as protective care as the care recipient was protected from the consequences of disease, activity limitations, and dependence on help, all of which were perceived as threats to the care recipients' life satisfaction. In the case of social-emotional caregiving, the protective purpose meant support for a positive self-image, personal competence and self-worth. The protective purpose was most pronounced in relation to the proxy caregiving, which involved efforts to prevent and protect the care recipient from experiences of physical and emotional harm by facilitating safety and the provision of good formal care. The protective purpose of the instrumental caregiving was less apparent but still evident, in that providing and doing things for the care recipient was aimed at protecting the person's health status and integrity.

Based on Nolan's model of informal caregiving, Ekwall, Sivberg and Hallberg (2004) conducted a postal survey investigating dimensions of caregiving activities among elderly caregivers who were over 75 years of age in the southern part of Sweden. The distribution of caregiving activities among male and female caregivers showed that supervisory, instrumental and anticipatory care was the most prevalent. The most common type of activity was supervisory care in terms of providing assistance with practical things outside the home of the care recipient, such as helping in contacts with the hospital (57%). In this type of caregiving activities men were more involved than women. Caregivers adapted their own activities to prepare for the future (e.g., anticipatory caregiving) and this was performed by about 52% of the sample, in similar proportions for men and women. There were 35% of caregivers doing activities such as keeping in touch with care recipient to prevent problems, monitoring the elderly person's health behaviours (e.g., preventive care). Women were significantly more often involved in keeping in touch with care recipient to prevent problems than were men. Caregivers were involved in personal activities of daily living (14%), such as i.e. help with personal hygiene, feeding and getting dressed), far less often than with other aspects of caring activities such as supervisory, anticipatory and preventive care.

The studies reviewed indicate that there are many aspects of caregiving that are less visible and unless inquiry focuses on uncovering these dimensions, they remain unrecognized and devalued. When examining the caregiving experience, it is important to include other aspects of caregiving that go beyond that of instrumental and personal care. Dimensions and intentions of care is one way of provides us with a way of understanding the caregiving experience of women with a sibling with CP, what this experience means to them and how this contributes to the construction of their caregiving identities.

CHAPTER FOUR
CAREGIVING IN THE TAIWANESE CONTEXT

In this chapter, Taiwanese long-term care systems that are part of the context constructing women's caregiving identities will be discussed in the first section. Limited studies regards to caring people with CP in Taiwan will be presented in the second section.

4.1 Long-Term Care in Taiwan

For approximately thirty years, the concept of deinstitutionalization as a means of human service has garnered a worldwide audience (Dalamagas, Dalfen, Rowe, 2000) and has successfully shifted service provision from segregated institutional settings to the community (Traustadottir, 2000). With the principle of normalization as its catalyst, deinstitutionalization, as a movement, originated in Scandinavian intellectual disability service practices in the late 1960s (Wolfensberger & Thomas, 1983). Deinstitutionalization has since been elaborated, universalized, and systematized in North America (Dalamagas *et al.*, 2000).

As part of the trend toward deinstitutionalization, community care has been regarded as the ideal that would provide people with disabilities with the support they need (Bamford *et al.*, 1998). In the 1970s, community care was a strategy for actualizing deinstitutionalization through community involvement. In the 1980s and 1990s, care by the community was conceptualized as a less expensive substitute for government involvement (Pascall, 1986). Currently, the ideology of community care legitimates minimal public activity in the private sphere of the family and shifting caregiving responsibilities from the institution to the family (Bamford *et al.,* 1998).

Similar to other parts of the world, Taiwanese public policy has counted on families to provide care to familial dependants. Taiwan's People with Physical and Mental Disabilities Protection Law emphasized informal support networks at home as the most preferred form of caregiving for people with disabilities "…to reinforce the willingness and capability to take care of the disabled at home" (Article 40).

Policy that delegates caregiving responsibility in the informal sector is based on traditional models of cohabitation as the ideal Chinese household pattern. The pattern of cohabitation started from the Eastern Han (A.D. 25-220) and occurred at a time when it was common practice for parents and adult children to cohabit in the same household. In Ton and Song dynasties (A.D. 679-1278), this social custom of cohabitation became strict and was reinforced by law. According to the law, siblings who separated their property and residence with parents and other siblings were guilty, unless their parents and grandparents were deceased (Yeh, 1998). Although the principle of this residential arrangement was undermined when booming capitalistic economies emerged, separate residence with aging and disabled family members is still not a dominant residential pattern (Hsu, Lew-Ting, Wu, 2001). Placing frail family members out of a home is considered to be a violation of the social norm.

However, close examination of long-term care funding reveals that considerable resources are directed toward non-home-care services. Taiwan's various long-term care services are funded by medical, veteran, and social services systems, each with its own mission, policies and regulations (Su, Chen,

& Wang, 2005). The social service system is emphasizing the building of long-term care institutions, the health system encourages hospitals to establish nursing homes, and the veteran system places clients who need long-term care in the veterans' home (Wu, 2001). Policy favouring institutional care and ignoring the building of support for home care can be attributed to the over-reliance on a biomedical model in building long-term care systems.

Along with this rapid pace of development in biomedical sciences, medical care continues to shape knowledge about the body and expectations about medical intervention, and contributes to the growing power of the biomedical model in shaping the treatment of chronic illness and disabilities (Kaufman, Shim, & Russ, 2004). Governmental funding in Taiwan primarily supports biomedicalization of services which values the medical system and produces institutional solutions built around local general hospitals, psychiatric hospitals, or nursing homes. The Three-Year Long-Term Care Project for Seniors, which was conducted by Taiwan's highest health authority, included plans to increase the number of nursing home beds from 11,430 to 18,480 (Executive Yuan, Department of health, 1998).

The biomedical model of funding undermines the possibility of having a well-funded and comprehensive system of home care services. As government plans allocated increased funding for institutions, it would necessarily mean cutting the budget for home care services. With a limited budget for home care services, the eligibility for means-tested home care service is increasingly restricted and determined according to the incomes of the individuals who apply as well as the incomes of their close relatives. It is worth noting that under the

Public Assistance Act, *income* includes not only that of the individual who applies, but also the incomes of the spouse, parents, and children, as well as siblings who live in the same household. Thus families, in the broadest sense, are expected to deplete their own resources before turning to the government for assistance, regardless of whether the family members want to or not.

As caring for aging and disabled family members is still not a dominant residential pattern in Taiwanese society, long-term care services were supposed to be oriented toward home-care service. Instead, they have been shaped by a biomedical model, favouring institutional care and ignoring the building of support for home care. Within this context of lack of support from public resources, how women's caregiving identities are constructed will be addressed in this study.

4.2 Studies of Individuals with CP in Taiwan

The majority of studies on CP in Taiwan focused on the medical aspects, such as (a) identifying etiology and risk factors of CP; (b) maximizing ambulation by training (Hwang & Liao, 2004), surgery (Wu, Huang, & Chang, 2001) or botulinum toxin (Wu *et al.*, 2004) ; and (c) improving the speech ability of children with CP (Huang, 2001; Liu, 2004). Only two studies, both undertaken by scholars in the nursing field, have explored the experience of providing care to a child with CP.

Liang and Luo (1999) conducted a case study to identify stressors of a mother providing care to a child with both CP and leukemia. The mother's stressors included feeling puzzled about what had happened to her child; competing demands associated with the various roles that this mother had in her life (mother of healthy children, mother of a hospitalized sick child, and substitute for her unemployed husband as the family breadwinner); expectations from her family of origin; financial burdens; and marital discord. She coped with the ordeal by interpreting the situation as a mechanism of karma, convincing herself that she needed to pay for a sin she had committed in a past life by confronting the agony of having a child with both a severe illness and a severe disability.

Similar themes were drawn from Chao's (2002) interviews of 10 mothers of children with CP. The mothers in Chao's study and the mother in Liang and Luo's study were anxious about the unclear etiology and unpredictable prognosis, and they sought for miracles by considering or using unorthodox medication. Interestingly, the mothers in both studies were unanimous in believing that it was their destiny in life to have a child with CP.

These two studies describe how mothers provide care to their young children with CP by elaborating on their stressors as well as their attributions and meanings related to being a caregiver. Similar caregiving studies have been conducted in other fields such as mental illness, dementia, developmental disabilities, focusing on caregiving issues among mothers (e.g., Lee, Mao, Chen, & Shen, 2000), daughters and daughters-in-law (Wang, 1994). No study has focused on the caregiving among sisters. The absence of research on caregiving warrants this study of sisters' caregiving experiences with their siblings who have CP and how these experiences inform these sisters' caregiving identities in a Taiwanese context.

CHAPTER FIVE
METHODOLOGY

The purpose of this study was to explore women's caregiving identities to their siblings with CP, and how these sisters' caregiving identities are constructed. A phenomenological approach was used to explore the day-to-day lived experiences of adult sisters who have a sibling with CP. I sought to uncover the essence of, describe and interpret the meaning of their lived experiences, and then to illuminate the patterns of these sisters' caregiving identities. Before detailing the specific methods, it is first necessary to clarify the reason for adopting a phenomenological methodology. In the section that follows, I elaborate the research design, the procedure of data collection and analysis, and the strategies used to ensure the rigour of this study.

5.1 Choosing Phenomenology

Adopting a phenomenological methodology allows a researcher to acquire the perspectives of the study participants, and to reveal patterns that are based on the same essential meaning when they are perceived over time in different situations. The researcher uncovers the unchanging structure that exists within different reflections and various appearances on repeated occasions (Valle & King, 1978).

Phenomenology was chosen as the methodology for this study because it provides an opportunity to explore how sisters, who will be one of the most important resources to their siblings with CP in the future when their parents are no longer able to provide care, narrate their caregiving experiences (Creswell, 1998). Patterns and tensions regarding their caregiving identities that emerge from their narratives will be described. In the following section, I introduce phenomenology and my position as a researcher in this study.

Phenomenology has a long philosophical heritage that has roots in the philosophical perspectives of Edmund Husserl. Husserl concerned himself with the “whatness” of phenomena in order to further deliberations regarding the essential qualities of those phenomena. He claimed that the essence of things was not granted the status of ultimate objective reality. Rather, the essence of a phenomenon was made distinct according to how an individual experienced it and gave it meaning (Creswell, 1998).

Husserl used the terms *noema, noesis,* and *intentionality* to demonstrate how a pure description of a phenomenon could be developed. *Noema* was Husserl’s way of describing the immediate phenomenon of seeing. It is neither the phenomenon nor the object; it is the appearance of the object that has a reality in and of itself. *Noesis* is the conscious examination and description of one’s experience of seeing an object, which involves the bringing together of sensory data, previous experience, evaluations of similar phenomena, and memories, as well as social evaluations. All of these allow the individual to identify a range of possible meanings for the experience. The object that appears in perception varies in terms of when it is perceived; from what angle; and with what background of experience and orientation of wishing, willing, or judging—always from the vantage point of a perceiving individual (Moustakas, 1994).

The mind can focus on real objects that can be seen, touched, or heard, or it can focus on images, concepts or memories. There is an intention involved in selecting the focus of attention. Thus the act of consciousness in relation to the object of consciousness is referred to as *intentionality* (Husserl, 1931; Moustakas, 1994). Thus consciousness and experience are never just internal. There is an interaction between the outward appearance and inward consciousness, and this interaction is based on memory, image, and meaning (Creswell, 1998; Todres & Holloway, 2004).

Yet, phenomenology does not simply iterate what is already given and understood in lived experience. It seeks a "transcending [of] theoretical understanding that goes beyond lived experience to situate it, to judge it, to comprehend it, endowing lived experience with new meaning. Without this transcendence, phenomenology would be superfluous" (Burch, 1989, pp. 191-192). Husserl offered us the transcendental phenomenology, which facilitates a derivation of knowledge grounded in lived experience. The aim of transcendental phenomenology is to identify a general structure that encompasses all the protocols of the phenomenon (Karlsson, 1993). This methodology includes the stages of epoche, transcendental-phenomenological reduction, and imaginative variation (Moustakas, 1994).

Epoche is a Greek word meaning to refrain from judgment, to stay away from the everyday and ordinary way of perceiving things. In the natural attitude, we hold knowledge judgmentally and perceive things in an ordinary way. A researcher requires a new way of looking at things, a way that requires that we learn to see what stands before our eyes, what we can distinguish and describe (Moustakas, 1994). "In the Epoche, the everyday understandings, judgments and knowings are set aside, and phenomena are visited, freshly, naively, in a wide open sense, from the vantage point of a pure or transcendental ego" (Husserl, 1931, pp. 144-145).

When the phenomenon is perceived and described in a fresh and open way, the researcher proceeds to the stage of transcendental-phenomenological reduction and derives a textural description of the meanings and essences of the phenomenon. Finally, at the last stage, that of imaginative variation, the researcher grasps the structural essences of experience. Through this serial process, the researcher uncovers the meanings integrated with the textural essences of the transcendental-phenomenological reduction in order to arrive at a textural-structural synthesis of meanings and essences of the phenomenon or experience being investigated (Moustakas, 1994).

The concept of epoche requires that the researcher set his or her experience of the natural world aside and bracket out those perceptions when interpreting human experience. Husserl proposed that by doing so and by thus transcending the distortions of history, culture, and society, the researcher would achieve pure consciousness (or transcendental consciousness) and be able to identify the true nature or essence of the experience (Moustakas, 1994).

In the later 20th century, this understanding of the researcher's position changed radically, particularly as a result of the thinking of Martin Heidegger. Heidegger was a student of Husserl. The experience of *Dasein* ("being there") was the starting point for Heidegger's hermeneutic method: Being was apprehended through what he termed the *forestructure* of understanding, and then expanded through a preliminary grasp of the structures of being to an apprehension of being itself. The forestructure allowed a researcher to grasp the existential and a renewed experience of *Dasein* (Penoyer, 2005). In order to access this cycle of meaning and interpretation, one must “endeavour to leap into the ‘circle’” (Heidegger, 1962, p. 363) to make sure that he or she has a full view of Being. The researcher who takes this position does not stand outside the circle and analyze an object. Rather, the researcher participates in the structures of Being that enables him or her to understand the Being (Heidegger, 1962). This method contrasts with Husserl’s transcendental phenomenology, which required the researcher to bracket out his or her experience of the natural world.

In choosing between the old phenomenology, which proposed using the method of bracketing to liberate oneself from the influence of personal experience, and the new one, which is based on the researcher’s putting herself or himself in the place of the other, the researcher needs to ask a fundamental question: Is it possible to separate the researcher and the researched when it comes to understanding human experience? The notion of *intersubjectivity,* which explains how humans understand others, answers this question. People understand by comparing the object of inquiry with what they already know; thus, learning is analogical in character. Schutz (1967) stated that:

> …everything I know about your conscious life is really based on my knowledge of my own lived experiences. My lived experiences of you are constituted in simultaneity or quasisimultaneity with your lived experiences, to which they are intentionally related. It is only because of this that, when I look backward, I am able to synchronize my past experiences of you with your past experiences. (p. 106)

It is by this means that the other becomes accessible to the researcher and the researcher's experience connects with the other's experience (Moustakas, 1994).

Acknowledging the importance of analogy in understanding another's experience, I believe that no individual can understand another's experience under the mental circumstance of bracketing his or her own life experiences. Thus, I engage myself in Heidegger's concept of being with others in the world rather than bracketing out my personal experiences in the process of this study.

A potential consequence of totally immersing oneself in the experiences of others is solipsism where the view of self is the only real knowledge that exists. How can the researcher be sure of not biasing the result by over generalizing his or her own experiences to others? It is necessary to employ a transparent method to discern the essential meaning of the researcher's experience from the experiences of others.

Moustakas (1994) suggested the autobiographical statement as a strategy to enable readers to understand the researcher's position and any bias that might impact the inquiry. The researcher begins by investigating his or her own self-awareness and explicating that awareness with reference to the research question. In my case, I had to examine my own intentional consciousness with regard to the experience of living with a sister with serious heart conditions before I could understand someone or something that is not my own. I describe this process in Appendix B of this dissertation. During the transcendental process, by asking myself questions, I challenged, confronted, or even doubted my understanding until an essential insight was fully reached. With persistent, disciplined, and devoted reflection, I ultimately deepened my knowledge of the phenomenon and overcame the illusion of solipsism (Moustakas, 1990).

5.2 Research Design

5.2.1 Sampling

Recruitment of participants for this study relied initially on purposeful sampling and later on snowball sampling (Patton, 1990). In these sampling methods, the researcher selected participants who had some depth of experience with the study questions and who were willing and able to reflect upon these experiences.

The criteria for choosing research participants has to match with the questions and purpose of the inquiry. In heuristic research, Moustakas (1990) has helpfully suggested some general factors to consider when setting the criteria for participant selection. These include age, sex, socioeconomic and education factors, ability to articulate the experience, cooperation, interest, willingness to make the commitment, enthusiasm, and degree of involvement. For the present study, I recruited adult female participants who were siblings of persons with CP. Female siblings were at least 20 years of age at the time of the interview. Legally, the age of 20 is considered the benchmark for becoming an adult in Taiwanese society. Also, women over 20 years of age are more likely to be facing multiple midlife roles related to marriage, parenthood, and career opportunities. Participants were either (a) the only sister of the person with CP or (b) the sister who self-identified as being the one most involved in caregiving.

To collect a large enough sample of females who had life experiences with siblings with CP, several types of recruitment techniques were used:

1. An advertisement (Appendix D) was posted in the newsletters and bulletins of universities, social service agencies, institutions, self-help groups, and organizations. These included the following: Ming-Hsin Unversity of Science and Technology, CP Association of Republic of China, Catholic Hua Kuang Social Welfare Foundation, and Eden Social Welfare Foundation, as well as Syin-Lu Social Welfare Foundation, which provides services to persons with CP and their families. This technique recruited five participants for this study; one of these later dropped out.
2. The same advertisement was posted in the three most popular newspapers in Taiwan: *China Times, United Daily News,* and *Apple Daily*. This technique recruited no participants for this study.
3. Snowball sampling was also used to recruit candidates by current study participants. This strategy has been noted as a method that works well in identifying members of a population who are hard to reach (Rubin & Babbie, 1997). This technique recruited two additional participants for this study.

All seven women who responded fit my criteria of being over 20 years of age and self-defined as the most involved sister of a CP sibling, and all consented to participate in this study. One participant dropped out of the study as a result of an unexpected job transfer to a foreign country. I did not include the data that was collected from her first interview, for it did not generate new themes or categories for this study. They were interviewed twice.

The age range of the sisters was 21 to 55, with an average age of 35.17. The standard deviation was 14.32. The age range of the siblings with CP was 20 to 62, with an average age of 38.50. The standard deviation was 16.40. Three of the six siblings with CP needed assistance with activities of daily living, such as bathing, dressing, and getting in or out of bed or chair. Most of the participants (five out of six) lived in the same residence or in close proximity to their CP siblings and at least one of their parents. Only one sibling with CP lived in an institution. Participant's relationship to their sibling with CP, age, education, marital status, occupation as will as age, sex, degrees of speech comprehension, mobility, ability to conduct activities of daily living, toileting and self-feeding of her sibling with CP is listed in Table 1. A biography of each participant related to her caregiving experiences to her sibling with CP and family genogram is also presented in Appendix A.

It is always difficult to ascertain how many participants is enough for a study. In general, different qualitative methods require different sample sizes (Sandelowski, 1995). Morse (1994) recommended that phenomenological studies directed toward discerning the essence of experiences should include about six participants[4], ethnography and grounded theory, between 30 and 50 interviews and/or observations, and qualitative ethnological studies, about 100 to 200 units of observation.

However, Morse (2000) later clarified the assumptions underlying the

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[4] Janice Morse expanded the recommended numbers from 6 to 6-10 participants in her article which is published in 2002.

estimation of sample size.

> Estimating the number of participants in a study required to reach saturation depends on a number of factors, including the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each participant, the number of interviews per participants…. and the qualitative method and study design used. (p. 3).

Given this understanding, the number of participants required to reach saturation partly depends on the scope of the study. For example, in a study where the intention is to understand a very unusual or atypical manifestation of some phenomenon, one case may be sufficient (Sandelowski, 1995). In contrast, a study that is examining variation in a particular phenomenon, it is important to understand how diverse factors configure a whole. That kind of study would require a larger sample size (Sandelowski, 1995). As previously mentioned in this dissertation, this study adopted a phenomenological methodology approach to uncover the invariant structure (or essence) underlying the meanings of caregiving experiences. Given these criteria, six participants was deemed a sufficient number for this study (Russell & Gregory, 2003).

The scope of this study is not the only factor to determine the sample size. Another factor that is related to the sample size is that of research design. The research design of the current study produces two interviews per participant. In addition to the data derived from the formal interviews, additional informal contact occurred by telephone and e-mail for the purpose of clarification of comments. The sampling procedure proceeded until data reached the point of redundancy when there was no further information discovered.

It is worth noting that the estimated sample size, previously set as 7, should not become the indicator of the completion of data collection. Using estimated sample size as an indicator of how complete the data is criticized by Morse (2003) as a “cart-before–the horse” approach. Estimating sample size is therefore more useful at the proposal stage then the actual implementation stage. The completion of data collection of this study was the result of data saturation. After enough data had been collected to determine themes and categories and no new information was forthcoming, no more participants were needed. In other words, when the collected data was enough to construct representations of the phenomenon and its variability, the phase of data collection of this study was completed (Byrne, 2001).

Table 1 Characteristics of Study Participants and Their Siblings with CP

Participants	Shannon	Singing	Melody	Cherry	Rose	Linda
Relationships to their siblings with CP	The second elder sister	The only younger sister	The second elder sister	The second younger sister	The eldest sister	The eldest sister
Age	51	24	55	29	21	31
Education	High school	University	High school	University	College	University
Marriage	Divorced	Unmarried	Married	Unmarried	Unmarried	Unmarried
Occupation	Clerk (Social welfare)	Assistant (Clothing company)	Housewife	Kindergarten teacher	Housewife	Assistant (Trading company)
Age of CP sibling	44	27	51	62	20	27
Sex of CP sibling	Female	Male	Female	Female	Male	Female
Speech comprehensible	Yes	No	No	No	No	No
Locomotion	Wheelchair	Walk	Walk	Wheelchair	Walk	Wheelchair
Able to conduct activities of daily living	No	Yes	Yes	No	Yes	No
Using toilet	No	Yes	No	No	Yes	No
Self-feeding	Yes	Yes	Yes	No	Yes	No

5.2.2 Data Collection

Interviews were conducted between July to December of 2006. After permission was obtained from the Research Ethics Board of McGill University (See Appendix C for an approval certificate), participants who indicated an interest in the study (came forward through the advertisements described or were referred through snowball sampling) were contacted to determine their interest in the study and to inform them of the parameters of the study. I discussed the purpose of the study and how the findings would be used, and I described what their involvement would entail.

Participants were informed that the interviews would be audio recorded and that their identities would be protected. Before the interviews began, each participant was informed of the possibility that discussing how they experienced their role as a sister of a person with CP might stimulate some uncomfortable emotions and thoughts. In case this situation arose, I had contact information of counseling agencies on hand (see Appendix F). No participant needed the information throughout the interview. The participants were assured that they could withdraw from the study at any time without any consequence. This information was clearly stated in the informed consent form.

The interview guide was piloted by a participant who worked in a social service department and was capable of pointing out the questions that were not understandable to her. At the beginning, I followed a formal semistructured interview procedure, in which I asked questions and participants responded to the questions. Over time, I became more flexible and intuitive in my interviewing techniques, digging more deeply into the meanings of the participant’s experiences, and obtaining information about items initially not in my protocol.

The participant involved in piloting the questions was asked about the extent to which the questions were understandable. She provided feedback on the quality of interview questions and format. The interview guide was restructured and revised based on the feedback received. For example, I found that the questions as originally designed elicited only fragmented information from the participant. I decided to ask what McCraken (1988) called a *grand tour question*. The question, “What are your experiences of providing care to your sibling with CP?” allowing participants the freedom to tell their story without constraint.

During the interview, prompt questions were used for clarification and focus. For example, when asking “What does being a sister of your sibling with CP mean to you?”, I gave the following prompt to the participant: “Being a father can have different meanings for men. One man would say he is a breadwinner, and another would say he is an educator. What does being a sister to your sibling with CP mean to you?” The prompt questions were not intended to lead the participant but to encourage and elicit examples and meaning about the experience they were describing. They were oriented to specific instances, situations, events, and persons (Munhall, 1994).

Following the pilot phase, I arranged mutually convenient times for face-to-face interviews with the rest of the participants. The locations were chosen by participants according to where they felt a meeting would be most comfortable for them. Two of the participants, Cherry and Rose chose to be interviewed in my office at the university, while the others, Shannon, Singing, Melody and Linda chose to be interviewed in their homes. All of the interviews were conducted mainly in Mandarin (the official language of Taiwan) and occasionally were intermingled with Taiwanese dialect (The most popular dialects in Taiwan).

An information letter and two copies of the consent form (Appendix E) were presented to participants before the interviews began. Participants were provided with one copy of the consent form, and the researcher kept the other. Each participant was informed that additional contact might be requested in order to clarify the content and interpretation of their narratives.

Data were collected through in-depth, semi-structured interviews. Semi-structured interviews enabled the researcher to introduce the topic, then guide the discussion by asking specific questions (Rubin & Babbie, 1997). After initial warm-up questions, casual conversation helped begin relationships and put the participants at ease. I opened the formal phase of each interview with the grand tour question: “What are your experiences of giving care to your sibling with CP?” My intention was to invite the participants to begin to narrate their own sense of self and subjectivity without being overly constrained by my interests or the explicit goals of this study.

The first set of questions of the interview guide sought to uncover women’s caregiving identities in relation to their siblings with CP. Another set of questions was designed to gather information about how these participants’ other identities intersected with their caregiving identities. These questions were in an open-ended format, which allowed participants to describe their experiences from their own perspectives and in their own words (Patton, 1990).

Worth noting is that although the interview guide contained questions about specific topics, the interview protocol was used primarily as a guide, allowing me the flexibility to follow the narratives of the participants, ask follow-up questions, and probe more deeply when warranted. Moustakas (1990) pointed out that heuristic investigation typically employs extended interviews as a way of gathering information. He preferred to use the conversational interview or dialogue, which “relies on a spontaneous generation of questions and conversations in which the co-researcher participates in a natural, unfolding dialogue with the primary investigator" (Moustakas, 1990, p. 47). I adapted the order and wording of the interview guide in order to improve the flow of the interview and rapport with the participants, as well as to address additional areas brought up by participants. As topics and themes emerged, the interview guide could be revised for subsequent interviews. Please refer to the interview guide in Appendix G.

After initial questions regarding the sisters' background, such as age, family constellation, and occupation, as well as the etiology of their siblings' CP and the siblings' functional level, the first interview sought to uncover women's caregiving identities with respect to their siblings with CP. The first interview lasted approximately 90 to 120 minutes for each of the participants.

The objective of the second interview was to gather information about how these participants' other identities intersected with their caregiving identities. This interview provided additional time for participants' reflections. Analysis of responses from the first interview allowed me to follow up during the second interview on issues that were not entirely clear to me. The second interview lasted approximately 60 to 90 minutes for each of the participants.

The hours of interviews for Shannon were 185 minutes, Singing for 203 minutes, Melody for 155 minutes, Cherry for 174 minutes, Rose for 175 minutes, and Linda for 208 minutes. The total hours of interviews for all the participants are 18 hours 20 minutes.

After initial reviews of the transcribed interviews, I contacted study participants when necessary via telephone or e-mail in an effort to clarify any confusing data. I took detailed notes of any conversations or correspondence that took place and incorporated these insights into my analysis.

5.2.3 Data Analysis

Materials used in the analysis included transcripts of participants' narratives from interviews, my analytic memos, and e-mail communications, as well as media provided by participants. This section will present the materials, software, and procedures I used in the process of data analysis.

All interviews were tape recorded and transcribed verbatim by the researcher to become written descriptions of my participants' lived experiences (Van Manen, 1990). I transcribed tape recordings in the language that they were conducted as soon as possible after the interview. I did not ask anyone else to help me in this task because transcription is part of the interpretation process, an initial interaction with what is going to be converted into data.

Interviews continued as the previous ones were being transcribed and analyzed. The data were analyzed at the time of transcription and between interviews to ascertain that there was sufficient data to represent the various dimensions of the phenomenon. This concurrent and simultaneous method allowed for critical examination and use of previous experience and was crucial in determining the completeness of the data. When thematic analysis and determination of themes is complete, they should capture the essence of the phenomenon (Swanson-Kaufman & Schonwald, 1988). Verbatim transcripts of the interviews were produced and corrected, resulting in 243 transcribed pages.

Multiple analytic memos (Maxwell, 1996) were written after each interview, as well as throughout the analytic process, allowing me to record and begin to categorize my initial and ongoing reflections, questions, ideas, and analytic decisions. In addition, e-mail communications and media provided by participants were used to derive meanings and interpretation. For instance, Singing wrote me an e-mail to provide a timeline for the events she mentioned in the interviews, and Melody gave me a CD containing a 15-minute television interview with her sister who has CP.

NVivo data management software provided the technology for efficient coding. This software enabled me not only to manage a huge volume of textual documents, but also to store and retrieve data. With the help of the NVivo software, I started my coding process. I used a modification of the Stevick-Colaizzi-Keen method (Colaizzi, 1978), which has been used frequently in phenomenological studies. The steps are as follows.

Step 1: Describing the Researcher's Preconception

The analysis began with a full description of my own experience of the phenomenon: I had a sister with severe heart conditions, and I am an aunt of a young female who has a brother with CP. My profile is rendered explicit in order to reflect on any assumptions, biases, or preconceived notions the researcher may have about the topic of research. This strategy, which Moustakas (1990) called *initial engagement*, could greatly increase the quality of data analysis. Moustakas explained that "within each researcher exists a topic, theme, problem, or question that represents a critical interest and area of search" (p. 27). This strategy helps the researcher explore how their own lens my affect the interpretation of data in the later phase of data analysis. My profile, which clarifies the relationship between my lived experiences and research interests, will be presented in Appendix B.

Step 2: Horizonalization of the Data

Phenomenological data analysis is preceded by data reduction and a search for all possible meanings. The researcher finds and lists significant statements about how individuals are experiencing the topic (Creswell, 1998). At this stage, I identified words, phrases, and sentences that appeared to stand out as essential to the experience (Van Manen, 1990).

Step 3: Clusters of Meaning

These significant statements were then grouped into meaning units. I read the transcription of interviews and video, as well as e-mail from participants sentence by sentence, while at the same time attaching codes to the texts.

Step 4: Structural Description

At the fourth step, I looked at the codes very carefully, got a sense of the major themes that emerged from the data extracted from the sisters' stories of their caregiving experiences. I developed a framework of major themes and categories within the themes. These emerging themes provided insights into how these women made sense of the events and situations in their lives and are one way of assigning meaning to an experience. Therefore, they can be used as a means to arrive at a fuller description of the structure of a lived experience (van Manen, 1990).

I applied the tactics for meaning generation that Kvale (1996) introduced. These are (a) noting patterns and themes and (b) making contrasts and comparisons. Using the tactic of noting patterns and themes, for instance, I noted from the codes that the patterns of protector involved *protect from teasing and bullying by strangers and peers protect from abuse or neglect by a caregiver.* Using the tactic of making contrasts and comparisons, I compared the patterns to identify any similarities and differences in the construction of caregiving identities. For example, I noticed that not every sister who had a sibling who needed extensive help from others for their ADL would develop an identity as a caregiver in the aspect of physical care. Comparing the differences, I found out that for those families whose earnings are not sufficient to hire a formal caregiver, participants were easily recruited to be caregivers to their siblings with CP and to construct their caregiver identity related to this aspect of physical care. In contrast, for those families whose earnings were sufficient to hire a formal caregiver, participants did not take on the identity of caregiver in the aspect of physical care. The process of structural description uncovered the universal yet individual experiences of each participant, “like a skeleton that can be filled in with the rich story of each informant” (Swanson-Kaufman & Schonwald, 1988).

Step 5: Invariant Structure (Essence)

I then constructed an overall description of the meaning and the essence of the experience; this description will be elaborated in Chapter 6. Figure 1 provides an overview of the Stevick-Colaizzi-Keen method.

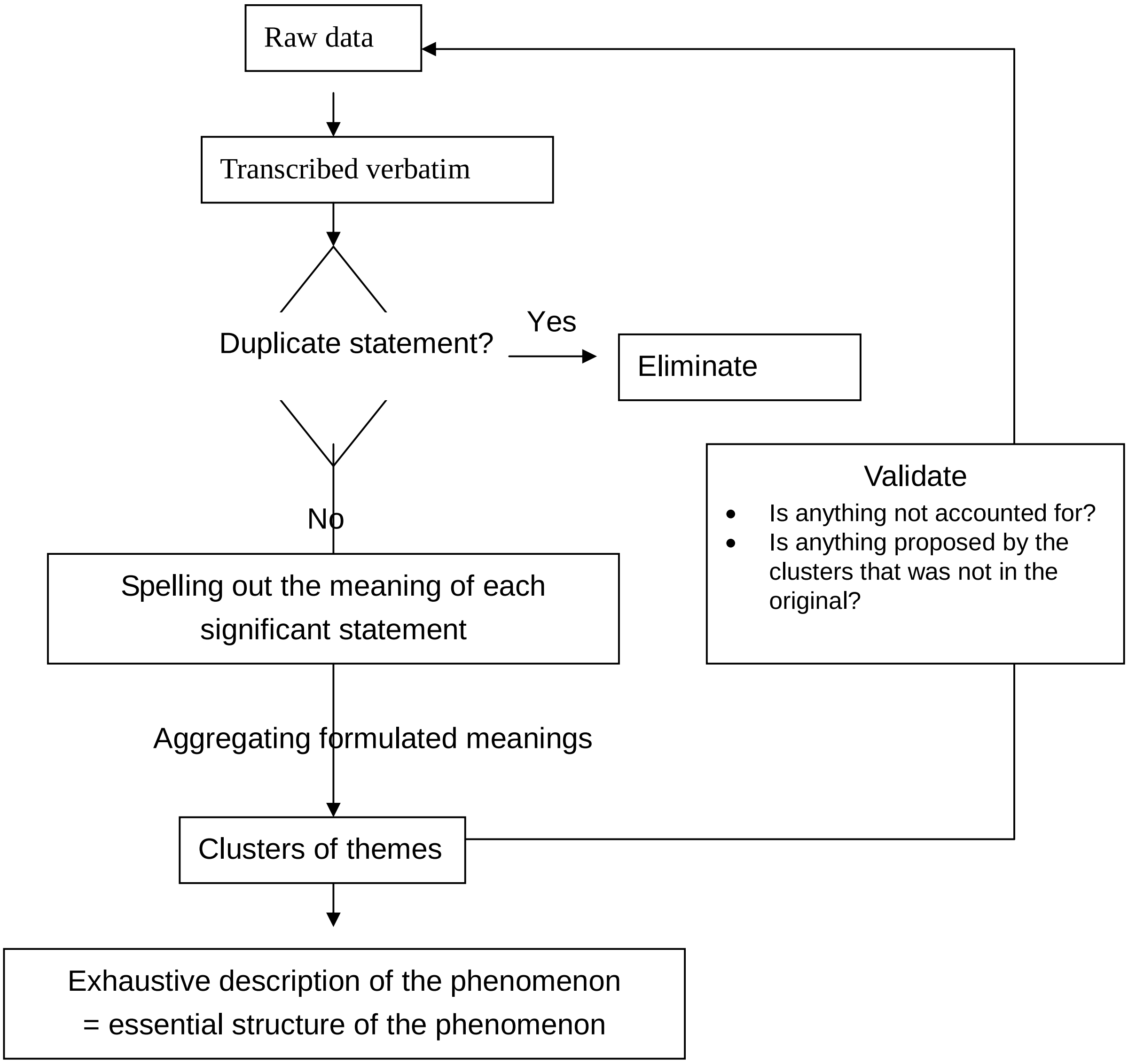

Figure 1. Charting showing the phenomenological analysis method developed by Colaizzi (1978).

5.2.4 Ensuring Rigour

Criteria for trustworthiness are often used to judge whether the quality and extent of study findings are believable to readers (Schwandt, 1997). The assessment of trustworthiness is based on the dimensions of credibility, dependability and confirmation, and transferability (Lincoln & Guba, 1985). The following section explicitly discusses the procedures for achieving all of these criteria.

5.2.4.1 Credibility

In quantitative research, *validity* indicates whether the research truly capture what it was intended or how truthful the research results are (Rubin & Babbie, 1997). In qualitative inquiry, *credibility* is the extent to which the findings accurately reflect the views of the participants (Lincoln & Guba, 1985). This study design contains four strategies that ensure credibility: (a) reflection, (b) member-checking, (c) peer-debriefing, and (d) translation strategies.

Reflection

In heuristic research, data collection begins with self-searching—in my case, my personal reflection of my own experiences as a sister of a patient with serious heart conditions. As Schutz (1967) stated, “everything I know about your conscious life is really based on my knowledge of my own lived experiences” (p.106). In this study, I attempted to understand the meanings that the experience of being the sister of a person with CP had for my participants. This understanding was reached from my viewpoint of being a sister who had a sibling with chronic illness, that is, the historical situation within which my understanding took place.

Understanding my participants’ interview texts from my particular point of view, however, does not mean I would blindly impose my point of view on their texts. During data analysis, I employed reflective journaling to record aspects of the interview and personal reflections. In doing so, I was drawn into conversation with my historical texts as well as those of participants. Conversing with the texts was an opportunity for me to compare my own history with those of the participants.

During the self-reflection, I did encounter differences between participants' experiences and my own. For example, during the initial analysis, sisters' intentions to restrict themselves to men who had more flexible images of married women were interpreted as a strategy to avoid being criticized as women who carried a defective gene. In the process of self-reflection, I constantly compared my own history with those of my participants and became vigilant that my own perspective, preexisting thoughts and beliefs influenced my interpretation. To be specific, I came to realize that sisters tend to restrict themselves to men who held less strong patriarchal beliefs as a strategy to avoid being pressured by their husbands or future parents-in-law to move away from their siblings with CP. The premature interpretation at that stage of initial analysis was actually based on my own preconceived notions and biases about phenomena. Therefore, my caregiving experience to a sister with serious heart conditions and her children (see Appendix B) can contributed to the trustworthiness and provided an audit trail for this study (Smith, 1999).

Member Checking

Member checking refers to seeking feedback from study participants about the data extracted from their respective stories (Guba & Lincoln, 1989). It ensures the mutual believability between researcher and the participants regarding the data (Lincoln & Guba, 1985).

Miles and Huberman (1994) suggested that this feedback could be solicited in different stages. It could be done in the early stages of a study with an interview transcript, or at a later stage after the data analysis has been done. In my case, I invited all of the participants to read and react to transcripts of their own interviews, rather than returning the results to them for verification. Morse, Barrett, Mayan, Olson, and Spiers (2002) argued that the problem with member checking is that:

> with the exception of case study research and some narratives inquiry, study results have been synthesized, decontextualized, and abstracted from (and across) individual participants, so there is no reason for individuals to be able to recognize themselves or their particular experiences (Morse, 1998; Sandelowski, 1993). Investigators who want to be responsive to the particular concerns of their participants may be forced to restrain their results to a more descriptive level in order to address participants' individual concerns (p. 7).

Hence my decision not to invite participants to provide feedback at the later stages of the study.

Each participant received her own interview transcripts in order to ensure accuracy. In the stage of member checking, participants share additional information required to increase clarity and provide reflections to her own transcripts. These additional data has been included in the analysis.

Peer Debriefing

Peer debriefing involves the use of an outside expert who checks on the inquiry process. These colleagues must be peers of the researcher and have a solid understanding of the methodological issues involved in the research (Lincoln & Guba, 1985). In this stage, peer debriefing were achieved through ongoing discussion with doctoral committee members and Dr. Wang Tsen-Yung (Frank), an assistant professor at the Institute of Public Health, Yang-Ming University, Taiwan who was invited to be the peer debriefer of this study for the following reasons:

1. Dr. Wang received his PhD from the Faculty of Social Work of the University of Toronto. One of his publications (Wang, 2002) especially relates to the field I am interested in. His professional background and specialty indicated that he would share ideas and ask questions in the inquiry process.
2. Dr. Wang is fluent in Mandarin, the language that I used to conduct and analyze the interviews. He is also familiar with English and with academic terminology in the field of social science.

Dr. Wang periodically met with me to share ideas and pose questions about my methods, procedures, and interpretation of the data, and he was of particular help in increasing my theoretical sensitivity to the characteristics of Taiwanese culture. Similarly, my doctoral committee provided input and reflection based on the exemplars they reviewed in previous drafts of this dissertation.

Translation Strategies

The main source of data in this phenomenological study was the narratives of participants. Interviews were conducted in Mandarin and Taiwanese, but the thesis was written in English. This situation inevitably involved translation. With the interviews conducted in one language and the findings represented in a different language, there was potential for distortion and misrepresentation. Translation involves more than literal, word-for-word matching, as intent, assumptions, and emphases are embedded in each language. It is therefore imperative to identify a process that will minimize this threat to validity.

A review of cross-cultural studies (e.g., Holroyd, 2003a,b; Hsu & Shyu, 2003; Lu, Trout, Lu, & Creswell, 2005; Wahl, Gjengedal, & Rokne Hanestad, 2002) indicated two translation approaches commonly employed by scholars to minimize the mistakes of distortion and misrepresentation. In the first approach, transcripts are translated into the target language and then back-translated into the participants' source language. In the second, the analysis is conducted in the participants' language and then the findings are translated into the target language. The decision to adopt one approach over another seems to depend on the researcher's ability to operate in both languages. Both procedures are described in the following paragraphs.

Studies that involve the translation of entire transcripts from one language to another tend to be ones in which the researchers operate in a language that is different from that of the participants. In these studies, all transcripts are translated for the purpose of helping the research team to understand the words and meanings of participants. An exploratory case study describing the needs of 21 individuals diagnosed with AIDS in rural China involved a research team that was composed of Chinese-speaking and English-speaking researchers from Nebraska, United States (Lu, Trout, Lu, & Creswell, 2005). In that study, translation occurred before the phase of data analysis. Once the interviews underwent initial transcription, a Chinese researcher, Lu, translated these from Chinese to English for the purpose of data analysis. Several pages of each translated interview were returned to a Chinese researcher, who back-translated the documents to Chinese for verification.

Likewise, Eleanor Holroyd, who is originally from New Zealand and is now an associate professor at the Chinese University of Hong Kong, had all the transcripts from her studies translated from Chinese to English. In Hong Kong, languages used by participants included Cantonese, Mandarin, and Fijian dialects, as well as English. In this case, the translation strategy ensured that the transcripts were all in one language before analysis began (Holroyd, 2003a, b). Holroyd and some of Lu's colleagues shared the same situation insofar as they did not necessarily speak or comfortably operate in the same languages as their participants.

Back-translation is one of the most common techniques used in cross-cultural research. It ensures the adequacy of processing the vocabulary and grammatical structure of the words while considering the individual situations and overall cultural contexts of the participants using the source language and the reader using the target language (Esposito, 2001). Back-translation includes generating an original transcript, translating it into the target language, checking the target-language version for grammatical errors and its ability to be understood by monolingual native speakers, and then translating this corrected version back to the original language (Brislin, 1970; Marin & Marin, 1991). This technique is helpful in identifying semantic errors in the translated version.

When researchers are familiar with or fluent in the language that the participants speak, translation usually occurs after the data is analyzed. In other words, data analysis is conducted in the participants' language. For example, in a study exploring social exchanges of caregivers in Taiwan, both authors spoke the same language as their participants. They chose to develop major categories and concepts in Chinese and then translate them into English (Hsu & Shyu, 2003). Similarly, three associate professors at Buskerud College and University of Bergen, Norway, conducted a qualitative study that involved interviews of 22 hospitalized patients in the dermatological unit of a Norwegian hospital (Wahl, Gjengedal, & Rokne Hanestad, 2002). The researchers chose to conduct the translation from Norwegian to English after data analysis was completed. According to the authors' comments, the timing of the translation was chosen to ensure the preservation of meaning in data.

Indeed, undertaking data analysis in the language of the interview is important to avoid compromising the quality of data obtained from non-English speaking populations. Twinn (1998) compared the data collected from two research projects running concurrently in Hong Kong. Both studies employed a case study design and used focus groups comprising Chinese women in Hong Kong. Two issues emerged from the complexity of transcription and translation of the Chinese data. The first issue had to do with translation when there was no true equivalent in the target language:

> Finding the appropriate English words to capture the meaning of the Chinese data was a continuing problem throughout the translation of the data. This issue raises questions about the extent to which the translated data accurately reflects the feelings and experiences of the participants represented in the categories developed in the data analysis (Twinn, 1998, p. 657).

The second issue raised questions about the grammatical style and the structure of the initial response in Chinese and the complexity of translating and interpreting this data:

> [In Chinese] tenses and personal pronouns are not used which adds to the complexity of making sense of the data. . . . Frequently responses are worded negatively although the informant is not disagreeing with the question (Twinn, 1998, p. 657).

Twinn concluded, on the basis of her own experience of the difficulties she had in translating and interpreting data that data analysis should be done in the original language of the interviews. Consistent with Twinn's recommendation, the translation from Chinese to English in the present study was undertaken after the data analysis was completed.

The interviews in this study were conducted in Mandarin or Taiwanese, the languages that the participants of my study used to express their experiences as sisters of individuals with CP. Because this dissertation was written in English, to protect the meaning of the Chinese data presented in English, I employed the advantages of both back-translation and conducting data analysis in the participants’ language. Several people participated independently in the following steps.

1. I translated Chinese excerpts that I used in the chapter on data analysis into English. In the translation process, I constantly referred back to the original Chinese transcriptions to ensure that the English translation corresponded to the participants’ meanings.
2. A linguist who is teaching English in the university I am affiliated with proofread the Chinese excerpts and the corresponding English translation to ensure validity of the translation. I made changes to the English version according to the translator’s recommendations.
3. Sandy Huang, an assistant professor who obtained her PhD degree from Arizona University, proofread results from the previous step and translated the English version back to Chinese.
4. I compared the Chinese and English versions and checked for inconsistencies.

This process was effective because the translation went through a number of filters. I compared the original and back-translated Chinese versions for any inconsistencies, mistranslations, changed meanings, cultural gaps, and lost words or phrases. When any difference was found, I consulted with the translators to find out why this had occurred and how the English excerpts could be revised (Marin & Marin, 1991).

5.2.4.2 Transferability

Transferability refers to the extent to which study findings can be generalized to other settings. The use of thick description in the presentation of findings contributes to transferability. This detailed description of the experiences of the participants and the context of the data collection will assist readers in judging the extent to which the findings can apply to other individuals in other settings (Lincoln & Guba, 1985). Malterud (2001) argued that although the aim of research is to produce information that can be shared and applied beyond the study setting, no study can provide findings that are universally transferable. Based on his recommendation, I clearly present a relevant sampling strategy in order to demonstrate thorough consideration of what an adequate degree of transferability would be.

CHAPTER SIX
RESULTS

Participants in the current study provided unique insights into how sisters' caregiving experiences to siblings with CP shape their identities. There are four themes that capture the ways in which sisters describe providing care and caring for their sister or brother with cerebral palsy: interpretation; transformation; protection; and sacrifice. Each of these contributes to their identity as a sister and one who provides caregiving in their family of origin. However, when these processes are combined with their roles as employees, daughters to their mothers, future or current spouses to their husbands, and members of their family of origin, a number of important considerations and tensions emerge that inform their caregiving identities. These have to do with their career choices, negotiation of relationships with their mothers, considerations pertaining to who they will or already have married, the denial of their right to inherit family properties as well as to provide ongoing care to their sibling with CP after marriage. Each of these is elaborated in this chapter.

6.1 Caring Through Interpretation

Persons with CP who have speech impairments find it difficult to make their feelings and intentions understandable through the use of speech. When this is not an option, they use assistive devices, sign language, foot writing and/or gestures. However, the mechanisms that individuals with CP use to communicate with others are not always easily understood by others as the message may be communicated in an extraordinary manner. In such circumstances, sisters develop an expertise in knowing and anticipating and therefore interpreting what their sibling with CP thinks or wants as they are equipped with an intimate knowledge of these special communication skills. For example, Rose took sign language courses when she was a teenager. Her brother with CP expressed himself through sign language and Rose interpreted for him.

> When the cashier or the sales person in the grocery store is someone he doesn't know, he needs my help with interpretation. When my friends or my parents' friends pay us a visit, he asks questions such as 'How old are you?' in sign language, and I interpret for him.

Sisters invest time and energy with their sibling to develop mutually acceptable ways of communicating with one another. This involves not only understanding what their sibling with CP is trying to communicate, but communicating in understandable ways to their sibling with CP as well. Cherry, for example, had developed skills that enabled her to understand her sister’s gestures.

> She doesn't talk, but she responds to my question by gestures. Usually I ask her a yes or no question, and she responds to me by raising her hand to answer yes or leaving her hands on her lap to answer no. When my friends pay us a visit, I knew she was asking my friend, 'How old are you?' I simply knew. However, I still verified with her by asking, 'Are you asking how old he is?' She raised her hand to tell me I was correct.

Long term engagement in the lives of persons with CP is the main factor contributing to how sisters understand their siblings’ sometimes minimal cues. In this way, the communication pattern is one that is nuanced and sometimes unique to that relationship.

> She (sister with CP) dropped out of school at a very young age. All the Chinese characters she knows were learned from TV. She writes words on paper with her foot to talk to people, but usually the one who is reading has a hard time understanding what she's trying to say. But not me; I know the pattern of her writing. The mistake she usually makes is using the wrong character with the same pronunciation. I've spent so much time with her; I know everything about her in a glance. (Melody)

A lack of control over the muscles around their mouth and tongue can hamper the speech abilities of individuals with CP. The impairment can cause their speech to be incomprehensible or sound awkward and further obstruct their communication with others. Sisters are capable of understanding the unique ways their siblings with CP speak and help them to be understood by others by interpreting. Melody's sister with CP, counts on Melody to help her make contact with the business world.

> If you call her and she answers the phone, you would not have a clue what she's talking about. But I know what she's trying to say. So it's me who deals with everything in the outside world for her.

Observation and experience acquired over a lifetime together facilitate the acquisition of language and understandings that are mutual and unique to the dyad. Sometimes the understanding is so well developed that there is no need for any verbal exchange.

> Cherry: “When I was in Grade 9 or 10, my grandmother who had been providing care to my CP sister for decades, passed away. My sister was in grieving very deeply. Her bereavement lasted for quite a long time.”
> Researcher: “How did she express her grief?”
> Cherry: “I can easily detect her mood by her facial expression. The movements of her face are not obvious to people who aren't familiar with her, though. I mean, I've been with her for such a long time, I can tell how she feels. She looked pale and lacked energy. . . . I could just tell. She wanted to go with grandmother. She saw herself as a burden and believed it was better for her to leave with grandmother.”
> Researcher: “How did you know what she was thinking?”
> Cherry: “I asked her, and she raised her hand to let me know that what I asked was exactly what she was thinking.”
> Researcher: “But how did you know what to ask?”
> Cherry: “I just knew. Like I said, I've been with her for a long time. I knew what she thought.”

Like Cherry, Rose also attributed her capacity to interpret without any language exchange to her long-term engagement in her brother's life.

> I knew what he was saying even without sign language. After all, I've been living with him for such a long time.

The long term engagement between sisters and their siblings enables them to detect thought and intention. Cherry explained how she could precisely detect what her sister with CP thought after their grandmother died.

> We watch TV together all the time. Soap operas constantly have stuff like somebody dies and his very close loved one wanted to go with him. It is not that hard to guess what she is thinking….My father owned a clinic, people stopped by talking about things like life and death in the neighbourhood. My CP sister and I share the same topics, so I knew what she was thinking when I saw her in a glance.

The ability to understand what individuals with such impairments are communicating is attributed by sisters in this study to be a special talent that belongs to women only. Men are excused from not possessing qualities such as sensitivity and patience that are essential for accurate interpretation.

> He (CP brother) had a girlfriend who he met in the rehabilitation center and had been dating for three years. They broke up around Chinese New Year because of the objections of the girl's parents. He was very sad. I am the only person he could turn to because I understood both his unique pronunciation and his sign language... He did not talk to my youngest brother. My youngest brother would not be interested in this stuff or spend his time listening to his problems anyway. Girls are more sensitive and patient about these things than boys. (Rose)

> My brother's speech was slow, laboured, and repetitive. You need to pay a lot of attention and have patience to understand what he really wants to say. My father never understands my brother. Just like other men, my father had no patience. When my brother tried to express himself, my father suddenly took off in the middle of the conversation. (Singing)

The processes of developing an ability to interpret for siblings with CP is even sometimes viewed as inappropriate for men.

> We watch TV together…Men just don't watch these weeping things (soup operas). Do they? ... people stopped by talking things about life and death in the neighborhood. Men rarely gossip about things, don't you think? (Cherry)

To be an interpretor, sisters need to be physically present and spend considerable amounts of time with their siblings. Melody described the work she usually did for her sister with CP during business trips.

> You ask me what I did for her when we went on a business trip. Well, there were so many things; I don't even know where to start. In a word, everything. Whatever you can think of, such as checking into the hotel room, asking the counter to give us one more blanket when I found out she was cold . . . whatever you can think of.

Melody also helped her sister with CP negotiate with journalists who wanted to interview her sister, ensuring that the television and newspaper interviews went smoothly. She showed me one of the television programs that had recently been made. Watching the program, I noticed that when the host posed a question, it was actually Melody who answered, not her sister. One wonders if the questions were common ones, so familiar to this dyad, that there was no need for her sister to respond. Clearly, the interview would never have been possible without Melody's involvement as an interpretor, brokering the relationship between the media and her sister. Melody described these occasions as labourious and very time-consuming.

There is a Chinese proverb that says, a married daughter is similar to spilled water. It is not appropriate for a married woman to invest her time and energy in her natal home, unless the woman is divorced and is no longer constrained by her husband’s family. Shannon’s situation illustrates how this may be manifest. Her eldest sister regained her right to become involved in the caregiving required in her natal home after her divorce.

> Three years ago, my mother and sister were forced to move from their old

> house because it was in danger of collapsing. My eldest sister, who by then was divorced, invited her mother and the CP sister to move into her apartment and live with her.

For a married woman to dedicate time required to function as an interpretor to her sibling with CP, arrangements would need to be made with her husband and his family, ensuring that her responsibilities were met there before she commited any time and energy to her natal family. Consents from her husband and mother-in-law may be necessary.

> I had more time to help my sister when my son grew older and needed me less. My husband did not object to my involvement in my natal home. My mother-in-law did not live with us, so she kept her eyes half open… My brother-in-law was not happy that my eldest sister devoted too much time to her natal home. Since he retired, my sister could not visit my mother and CP sister's apartment like she used to. All she can do is deliver groceries to their apartment and call my mother at 5:00 pm every day. She used to spend a lot of time with my mother and my sister. Since the day he (the brother-in-law) retired, he became restless and uneasy, and looking all over for his wife whenever she's out of his sight.

In order to keep the privilege of looking after her natal home and the investment in time that interpreting requires, women demonstrated their loyalty to their husbands' family first.

> It is not possible for me to give her (sister with CP) a room in my apartment. I don't have enough room for her. . . . I have my mother-in-law. My mother-in-law doesn't live with us right now, but her health is getting worse. Although she can eat and walk without counting on others, I presume that sooner or later, my mother-in-law will come and live with us. If I host my sister in my apartment, it's like telling my mother-in-law, 'you are not welcome, and the room is taken'. My sister pays me half of her income. Not much, it is rather a symbol to show my husband's family that I take care of my CP sister as a job, not a favour to my natal home. (Melody)

The work of interpreting for their siblings with CP is rendered more complex by a number of other considerations: culturally prescribed notions of gender roles and responsibilities within one's family of origin and the family into which one is married. Sisters in this study defined the work of interpreting as women's work. The acquisition of this particular skill required dedicating time and energy as nuances and understandings developed over their lifetime were maintained through ongoing interactions. At times, the understandings were so well developed that only minimal verbal or nonverbal cues were required for participants to anticipate or know what their sibling was thinking, feeling or experiencing.

Within a cultural milieu that treated caregiving work as women's responsibility, especially the work of emotional care, sisters in this study described interpreting work as women's work rather than men's. Fathers and brothers were excused from listening and learning how to communicate with their daughter/sons or sister/brothers who have CP. Some of the sisters expressed the possibility that it would not even be appropriate for these men to take the time to develop the skills necessary for this level of communication. An account by one of the participants in this study reveals how a married woman struggled to reconcile competing identities as interpretor and wife and daughter-in-law to her husband and his family. The predominant cultural discourse strongly suggested that a married woman should be loyal and devoted to her husband's family. To be an interpretor, to dedicate the time and energy required, Melody legitimized the support she provided by claiming that the caregiving she provided was a job suggesting that it was more legitimate to engage in caregiving as an employee than as a sister.

The next theme discusses how sisters' caring through activities that facilitate transformation simultaneously introduces issues into the mother-daughter relationship. The tension in this relationship emerges from sisters who are also daughters challenge their mothers’ abilities to provide care. This act violates a cultural idea that is deeply rooted in the notions of Shan-Sha (up-down) which are derived from Confucianism.

6.2 Caring Through Transformation

Parents who have a disabled child are often unable to fulfill their caring responsibilities alone. Sisters have performed a variety of tasks since childhood to help their siblings with CP, including physical assistance, psychological support, and domestic chores.

> I've been changing her diaper since I was a little girl. Even now, I still change her diaper. She has diapers with her all the time. Any negligence can cause her serious eczema. (Linda)

> When I was a little girl, I scrubbed his back and washed his body. It was my job to bathe him, from undressing him to drying him properly. He can bathe himself now. All I need to do now is to check and see whether any shampoo is left on his hair and make sure he cleans behind his ears. (Singing)

Sisters accessed newer information regarding special equipment and resources than their mothers did. They introduced newer ways of thinking about the care of their sibling that were not within the scope of their mothers’ thinking. They introduced newer equipment that was commercially available or newer ways to provide their CP siblings with physical care. Shannon, for example,

> My CP sister put on a lot of weight after moving to an institution that provided better nutrition. The task of bathing her during her long weekend and holiday visits to my apartment became more difficult. I used bath chairs to aid in transferring her to the tub. It's safer for both of us. . . . She [the mother] had been taking care of her for several decades. She was too old to adopt new ways to make it easier for herself. I adopt new things and know how to make things easier.

In families who had invested a great deal in caring for their child, newer ways of caregiving were perceived as a luxury both in time and financial resources, and were viewed as unacceptable. To protect the physical well-being of their CP siblings, sisters urged their mothers to accept new ways. However, after the failure of introducing new ways of caregiving, sisters eventually took over the caregiving responsibility from their mothers' hands. For example, Linda's parents were tobacco farmers. Her mother needed to prepare three meals and two snacks per day for the workers on the farm, and the endless household and farm chores she had to do left her exhausted. It was simply not possible for Linda's mother to prepare mashed food and to spoon-feed her sister with CP for two hours per meal. Her mother chose to give the sister with CP sister, which was the quickest and most efficient way of getting the feeding done. Linda disagreed with the way her mother fed her sister and decided to take over the job.

> When my sister was little, the only food she could get was milk from a bottle. When I was in elementary school, I believed my CP sister was starving because all she had was milk. I asked my mother to give her something else, but she refused. She said she didn't have time. So I decided to try feeding her myself. I tried everything. It wasn't successful at first. It took a while for my sister to accept new foods. At last, I succeeded. It was a turning point when my sister started to eat solid food. I kept trying to find foods that would appeal to her. When she rejected a certain food, I tried another until she was willing to eat.

In addition to taking over the feeding from her mother, Linda also paid the price for introducing dispensable diapers. She started to cover the expense for dispensable diapers the day she got her first job.

> I've been changing her diapers since I was a little girl. When I was young, there was no such thing as a disposable diaper. Each filthy diaper needed to be washed and reused. I remember the balcony being full of cloth diapers. A heavy smell permeated the air. It was my job to wash diapers every weekend. It was especially unpleasant when there was stool in it….I never hated my sister because of the stinky diaper. I suggested disposable diapers to mother, she refused the new product and claimed it too expensive. She

> said if I insist on using dispensable diapers, the expense had to come from my own pocket. When I proposed the idea to her, I was still in school and unable to afford it. When I got my first job, I started to pay for the [disposable] diapers.

Sisters also try to introduce new ideas to change their mothers' passive attitudes or outdated ideas. In this study, participants unanimously hoped to persuade their mothers to train the CP siblings to live independently, instead of being overprotective of them.

> My mother forbade my sister to brush her own teeth or bathe herself, because she didn't want to see water dripped all over the place. It wasn't right to stop her from cleaning herself. (Shannon)
>
> We need to let him be independent after all. My brother depends on my mother for everything, and my mother got used to it. She unconsciously encourages my brother's dependency. She is not able to see this, but I am fully aware of it. (Singing)
>
> Sometimes he (the CP brother) doesn't get to the toilet in time, and he wets his pants. My mother said he shouldn't be blamed for his limitation. But it was not his limitation at all. (Rose)
>
> With my mother she gets away with everything, but not with me. When my mother is with her, she counts on my mother for everything. But when I'm with her, she doesn't dare ask me to do things for her . (Melody)

In terms of training persons with CP to groom and prepare meal for themselves, sisters believed they could do better than their mothers by adapting effective strategies to motivate their CP siblings achieving these goals.

> I placed a toothbrush that already had toothpaste on it in a place she could easily reach. She could take as much time as she wanted. I told her, 'Go ahead and make a mess! It's okay.’ My mother hated to see stains on the clothes and bought only dark colored clothes for my sister. Why not let her has the cloth she likes? For not to mess the beautiful dresses, she would be very careful when she brush her teeth. Now she lives with me. She doesn't have to wear things she doesn't like any more. I threw away the clothes she

> didn't like and bought new colorful dresses she wanted to wear. She dressed herself like Snow White. She even has a pair of Barbie shoes. She was so happy with her new outfits. I can see that she tries hard to keep the outfits neat and clean. (Shannon)

Generally speaking, because social activities and interactions outside their homes and institutions were limited, individuals with CP have few opportunities to test their own behaviours in outside surroundings and to experience people's reactions in various situations. Their sisters were aware of the exposure that their siblings needed and that their mothers valued the importance of occupational training.

> He had a certain spot on the Metro. It was a spot that made him feel safe. When he saw someone standing in that spot, he would just push the person away. He was lucky that nothing bad ever happened as a result. After witnessing my CP brother's rudeness to other passengers on the Metro, my mother decided to take him to the day program (for occupational training) by motorcycle. I stopped my mother from doing so, because it was not an ultimate solution. I told my brother, 'It would be helpful to make a gesture or nod your head to the person. People will understand what you want. Don't push people out of the way.' I knew he was sensitive about the way people looked at him. He suspected that people on the Metro were sneering at him behind his back. It was only his imagination. I asked him to copy The Heart Sutra[5]. The sutra tells us that visible form is only illusion. What you see is not what it is. I wished he could understand the teaching of the Heart Sutra through the activity of copying and realizing that when he was so convinced that people were sneering at him, it was not necessarily true. (Singing)

Rose also insisted on helping her brother to overcome his fear of strangers, even

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[5] Sutra copying is a common Buddhist practice in Taiwanese society. The Heart Sutra explains teachings on emptiness, the essence of the Buddhist Dharma, in very few words. People write the characters of the sutra repeatedly in silence and with awareness. In practice, the one who copies the sutra contemplates the essence of the world, and eventually releases himself or herself through the realization of the meaning of emptiness.

though her mother did not agree with her relentless actions.

> My grandfather often speaks sarcastically, so my brother is afraid of him. At Chinese New Year, I pushed my brother to greet my grandfather with Kung hei fat choi[6] and to claim a red packet from him. That was a good chance to help him overcome his fear of less friendly people. People are not always nice and patient to kids like him. He works in a gas station. Really, he has to get used to people who are less friendly. My mother wanted me to leave him alone when he was too scared to talk to my grandfather, but I still pushed him to do it.

Certain degrees of emotional strain in the relationships between sisters and their mothers arise when sisters introduced new ways of providing care to their sibling with CP.

> I have a feeling that my mother has been punishing me because I did a better job (of providing care to my sister) than her. When I was a little girl, I tried to convince her that multiple kinds of nutrition were important to my sister. She eventually realized that I was right, but she seemed to not appreciate it. I mean, she left the feeding job to me as if she was saying ‘since you are so brilliant, why don’t you do it by yourself?' (Linda)

For Linda, the cycle of arguing with her mother, taking the caregiving job over from her mother and paying for new products from her own pocket was repeated with the introduction of new ideas or practices.

> Later I fought with my mother because she gave my CP sister enemas when she had trouble with constipation. I argued with my mother, even fought with her, and asked her not to do this again. I showed her there were natural ways to solve the problem. I fed my sister high fibre supplements. It worked well. My mother witnessed the effectiveness of the supplements and realized that there were healthier ways than enemas to solve the problem of constipation…but I have had to pay for those fibre supplements

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[6] On Chinese New Year, unmarried junior members visit the senior members of the family, greeting them with “Kung hei fat choi,” which means Happy New Year. Usually after the greeting, the senior members give the younger ones red packets with cash in them.

> since then. Same thing happened with disposable diapers. Now I pay for the disposable diapers. It is not about money. It is like she is saying 'you have to pay for what you said'.

It seems that introducing new ways or new concepts of providing care to their siblings with CP does not result in gaining their mothers' appreciation. Instead, the tension in the relationship between sisters and their mothers increases. Sisters even receive negative feedback which they experience punishment from their mothers. For Linda, the consequence of introducing fibre supplements to replace enemas was that she was to pay for the new product from her own earnings.

Following failed attempts at direct advice to change their mothers' passive attitudes or outdated ideas, sisters stopped confronting their mothers directly. Instead, they colluded with male family members who have power in the family to influence their mothers, or found alliance with professionals instead. Melody, for example, was very clear that her sister with CP could do better in terms of grooming and feeding herself. However, Melody was not able to convince her mother not to do as much as she was doing. She persuaded her father to demand that her mother change.

> My mother has a soft hand. I tried to let her understand one thing - if my CP sister is capable of picking up a brush by her toes to paint, there was no reason she could not pick up a toothbrush to brush her own teeth. She just could not bear to see her suffer. So I changed my strategy to persuade my father instead. My father agreed with my point of view and hired constructors to adapt the facilities in the apartment according to my CP sister's need. The kitchen and the washroom were adapted for her convenience. At the beginning when my mother was trying to wash my CP sister's face, my father would sit on the bench and stare at my mother harshly. My mother dared not to go further, because she knew my father would be very upset. She just handed the towel to my sister. Since then, my CP sister has been doing things by herself successfully. Not only taking care of herself, she took care of my son when I was at work. She prepared his

> bottle and changed his diaper. She is proud of herself. Actually we all are. She loves to show off her cooking skills, like using her feet to cut the radish or entertaining her guests with beef stew that she made with her own feet.

Singing also encountered the same situation that failed to transform her mother’s over-protective attitude toward her brother with CP. She did not form an alliance with her father like Melody did for “family doesn’t mean much to my father”. She cooperated with the occupational therapist to persuade her mother not to over protect the CP brother.

> After witnessing my CP brother's rudeness to other passengers on the Metro, my mother decided to take him to the day program by motorcycle. I stopped my mother from doing so, because it was not an ultimate solution. We have to do something to make him change. But my mother just could not let go. I revealed this situation to Mrs. White (the occupation therapist). She agreed with my point of view and persuaded my mother to give my CP brother another chance. Mrs. White offered several ideas to soothe my mother’s worry and anxiety, such as giving my brother a mobile phone which would allow him to call home for help when he encountered danger; when my CP brother was late for the work for more than ten minutes, Mrs. White would call my mother to let her know.

When introducing new concepts and ideas that can improve the well-being of their siblings with CP, mothers are not the only persons that sisters need to convince. Sometimes sisters encounter pressure from extended family or community members. Shannon’s morality was questioned by relatives when she placed her sister with CP in an institution, especially under the circumstance that Shannon was now acting on her sister's behalf with regarding to financial matters. Rumours were spread in the community about how she took the money and threw her CP sister into the institution. Shannon defended herself.

> Before I took her away from my mother, they lived on the third floor. My mother didn't have the patience to take her downstairs. She was imprisoned

> in the apartment for almost three years. Moving her into my apartment would be a bad idea. Living with me would be the same as living with my mother. I have no time to take her outdoors. Her life would be as isolated. Now things are much better. It's like she's living in paradise. Compared to life with my mother, my sister is in paradise now. At least she can take a hot bath every day and go to rehab twice a week. Her legs used to cross like scissors; after the rehabilitation sessions, her legs became better. She has better mobility compared to the old days. She's better off living in the institution. She has friends and teachers who talk to her. It is hard to ask everyone understand. Every time when the issue 'how come your sister lives in the institution' comes up, I have to repeat this again and again.

When sisters consider the best interests of their brothers or sisters with CP and place them in the institutions, they also place themselves in a place where their morality is questioned due to the violation of social norms.

Sisters had performed a variety of physical and psychological tasks since childhood to support their siblings with CP. The theme of caring through transformation portrays how sisters believe they can do better than their mothers to improve their sibling's physical and psychological well-being. These sisters advocated and paid for new equipment to provide their CP sibling with physical care and adopted new ideas that facilitated teaching their siblings how to improve their psychosocial skill and self care abilities effectively. Sisters' desire to introduce new ways and ideas was often met with negative responses from their mothers and introduced a tension into the mother-daughter relationship. Informed by the cultural ideal that is deeply rooted in the notions of Shan-Sha (up-down) from Confucianism, sisters eventually stopped confronting their mothers directly, but collaborated with fathers who had power in the private domain as well as health professions who had power in the public domain to transform their mothers' outdated notions about ways of caring for their siblings with CP.

The transformation of the old cultural ideology to a new one, such as placing a sibling in an institution that can better meet their needs, is not accepted by extended family and community members. Sisters encounter resistance and criticism from family members, even when the transformation is in the best interests of their sibling with CP.

6.3 Caring Through Protection

Sisters are constantly in a state of worry that their CP siblings will become victims of bullying, teasing, abuse and neglect. Two sources of threat are experienced - strangers or peers and mothers. Caring through protection intersects with sisters' identity as daughters to their mothers. Protecting their sibling while maintaining and acting upon internalized cultural values regarding mother-daughter relationships creates a tension for these women that each reconciles in a different way.

6.3.1 Protect From Teasing and Bullying by Strangers or Peers

Almost all children with disabilities face teasing by peers at some point in their lives, especially when the disability is visible. Melody's sister has uncontrollable slow movements of her hands, arms, and face. She was frequently teased and bullied at school until she quit, refusing any form of intervention such as rehabilitation, and chose to hide herself in her small bedroom.

> She quit school very early. Kids were mean to her. She refused to go to school and chose to isolate herself at home. She did not want to be seen by others. She hid herself in the bedroom so well that my neighbours did not know of her existence. They thought I was the youngest in my family. She even refused to show up at my sister's and my weddings. (Melody)

The situation did not get better, even when Melody's sister became an adult. Incidents such as the following were not uncommon.

> She was severely discriminated against. Fifteen years ago, a kind of illegal gambling was very popular in Taiwan, similar to a lottery, called *Everybody*

> *Is Happy.* People went crazy searching for clues to the lucky numbers. Once when my sister and I were walking down the street, one of the people standing around the ticket booth yelled at my sister, ‘Hey, lunatic, give me a number’. I furiously tried to get back at him by calling him a *thirty-eight*[7]. The guy did not get angry at all. Instead, he filled in number 38 on the ticket.

Rose's brother with CP brother had similar experiences. One of the experiences she mentioned went far beyond teasing.

> He used to play basketball in an elementary school near our house. A bunch of kids threw stones at him. One of them picked up a stone and threw it at him, and the others started doing the same. Some of the stones hit him in the head. My brother ran home to tell my mother. My mother took him to see the principal of that school right away and busted those kids. The principal asked the one who started picking on my brother, 'Why did you bully him?' The boy said the way my brother played basketball looked funny. He has a problem with balance. It made him look unsteady and shaky.

Frequent incidents of teasing and bullying had prepared sisters for a lifetime of worry about their sibling with CP. In much the same way, incidents that called upon sisters to protect their siblings, prepared them for the protector role. Sisters were aware that their siblings with CP would venture beyond the boundary of the family, that their safety may be compromised, and that they should not be overly protective. However, even when siblings with CP were well prepared to face adversities, sisters still worried that their communication and social skills would cause them severe consequences.

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[7] In Taiwan, people with mental illness are sometimes seen as psychics who can give a sign to a gambler. But due to lack of consistency in providing correct answers, they are not respected as real psychics. *Thirty eight* in Taiwanese means a person who does rude or impolite things. The originality of 38 started around the 19th century before the Opium war (1840-1842). The British in China were harassing local people on a regular basis. The Chinese government forbade foreign people from coming in to Guan Zhou city except on three days each month - 8, 18, 28 to minimize the damage. Later, people called others who were rude and impolite as 38

Thinking about numerous incidents that their sibling with CP might encounter, sisters watched over their siblings at a distance.

> My brother is working at his first job, in a gas station. I was worried that people in the gas station would bully him. I sneaked to the corner of the gas station to monitor every movement of his coworkers and customers. I watched carefully to see what they were doing. I found that they were all decent people. No one did anything mean to him deliberately. There was one guy who had something wrong with his left hand. He was a year older than my brother. He was nice; he took good care of my brother. However, I still bought snacks and treats for his coworkers. Public relations are important. There is a saying 'No one would slap someone who is smiling'. If we treat them nicely, they will not be mean to my brother. (Rose)

> I witnessed my brother push people aside on the Metro. I worried that his impolite behaviour would provoke people's anger and that someone would beat him up to teach him a lesson. Probably other people thought he was not a normal kid, so no one actually did anything to teach him a lesson. However, I was worried that maybe one day, someone just would not buy it and would beat him up badly. I gave my brother a mobile phone to ensure that he could reach me at any time, in case he was attacked by strangers. I followed him secretly a couple of times to make sure he was all right. (Singing)

Individuals with CP face situations in which they are teased and bullied. Acutely aware of this, sisters in this study carried a desire to protect their siblings and engaged in efforts, either directly or indirectly, to protect but not to overprotect. The efforts were not confined to extra-familial situations as they were called upon to protect their sibling from abuse and neglect by other familial caregivers as well.

6.3.2 Protect From Abuse or Neglect by a Caregiver

Sisters attributed maternal abuse and neglect of their children with CP to a feeling of shame related to bearing a child with a disability as well as a sense of worthlessness of their child with CP. Feelings of shame are strongly linked to the social stigma associated with bearing a child who has a disability. In Chinese society, one of women’s life goals is to produce healthy heir to continue her husbands’ family line. In light of that context, having a child with disability could cause a great deal of distress to mothers as they may bring shame to the family. As a result, mothers who have a child with disability may try to hide their children from people outside the family.

For example, Linda's mother felt ashamed of having a child with a disability, and hid her sister with CP in the attic.

> My mother has a very strong sense of inferiority. She was ashamed of producing a cripple who can neither walk nor talk. My neighbour didn't know of my sister's existence for 26 years. Even when my sister needed a haircut, my mother chose a dark night, put her in the car quickly, and took her to a hairdresser far away from our house.

To Shannon’s mother, a baby with disability not only made no contribution to the family, but also wasted precious family resources. Her mother’s wish to dispose of her sister was evident in the following:

> She (the sister with CP) was not crying when she was born. My mother left her on the ground as if she were a piece of junk. She planned to bury her. Right at that moment, my father came home and stopped my mother from doing so. He asked the maternity assistant to come in again. The maternity assistant gave the baby a shot, and the baby started crying.

When Shannon was young, she took responsibility well beyond her years for maintaining her CP siblings’ survival. Shannon’s baby sister had trouble sucking the bottle, and it took hours to feed her. Shannon's mother often left the baby to cry unattended.

> My CP sister could not suck well and pushed the bottle back out with her tongue all the time. She often choked on the milk as well. It took time to feed my sister. On many freezing winter nights, my mother ran out of

> patience while feeding my sister. She left the baby and the bottle on the ground and went back to her bed. My eldest sister got up quietly and picked up the baby and the bottle from the ground. She fed the baby patiently until the baby finished the bottle.

Linda’s sister who lived in the attic, lay on the wood floor most of the time because it was difficult for her to sit still. Because she was eager to see what people were doing downstairs, she always lay on one side, facing the door. To provide her sister with CP some human contact, Linda would go upstairs everyday to talk to her, even though she was not sure whether her sister understood her words.

> Lying on the floor for 26 years on that side, it's not surprising that she has a spinal deformity. We call her little monkey, because her tailbone sticks out and makes her look like a monkey. Every day since I was a little girl, I've told her my secrets or what happened to me that day. Most of the time, she just blinks her eyes, stays very quiet, and has no response to my words. Sometimes she smiles or pats my hand or head as if she is comforting me. She can't talk, so we [family members] give her a monologue. All my family members take turns monologuing. Oh, yes, we're really good at talking to ourselves.

When young, there was nothing that these sisters could do to stop their mothers’ neglect and abuse. They remained silent and ignorant to their mothers’ behaviours, and sometimes were recruited by their mothers to be accomplices to their abusive behaviour.

> When my mother did something bad to us, we tolerated and avoided her. When she beat us up, we ran away or hid ourselves at a friend's house. We should have known my mother had been abusing my sister for a long time. We just pretended we don't know. (Shannon)
>
> My mother imprisoned my sister in the attic for 26 years. She felt ashamed to have a child who could neither talk nor walk. She did not want people to see her. My neighbour did not know of her existence until last year. Sometimes a friend called and said he or she was paying us a visit, and my mother's response was like, 'Hurry! Hide your sister upstairs!' We followed her demand without hesitation. (Linda)

As sisters grew older, they stood up to protect their CP siblings from their mothers' abusive language, behaviour and threats. They confronted their mothers directly.

> Sometimes she used language to humiliate my CP sister, such as saying 'she's useless'. When she said these things, I warned her, 'Don't talk to her like that. You're using language to abuse her. . . .' When my mother fought with my father, she threatened to kill my CP sister and then kill herself. My mother claimed that my sister was her responsibility, so she wanted to take my sister with her to the underworld. I shouted at my mother and said, 'If you want to kill yourself, go ahead, but leave her alone. She has her own life.' However, what I said did not change her a little bit. (Linda)

Direct confrontation was the least effective strategy. Sometimes, it even made things worse. Shannon's eldest sister tried to stop her mother from abusing and neglecting her sister. Her efforts were in vain and possibly contributed to an escalation in abusive behaviour.

> Three years ago, the house that my mother and my sister used to live in was about to be torn down by the military. My eldest sister, who by then was divorced, invited them to stay with her until the house was rebuilt. Right after they moved in, my eldest sister found out that our mother had been abusing and neglecting the CP sister constantly.
>
> When my sister was brushing her teeth, her saliva dripped on her pants. My mother slapped her on the face several times for making a mess. One day, my mother made a pot of noodles. It didn't taste very good, so there was a lot left over in the pot. My mother ordered my CP sister to finish it. My sister refused to obey her unreasonable request. My mother hit her hard and said, 'You cripple, you cripple, I order you to eat them up.' Out of fear of my mother, she finished whole pot, and she had very bad diarrhea later that night. Because of the diarrhea, she messed up her pants. Of course, she was beaten up again…It was cold in the winter. My mother had not bathed my sister for more than a month, not even when she had her menstrual period. My sister's house stank. One day, my CP sister wanted a hot bath so badly that she crawled to the bathroom and tried to bathe herself. When my mother came home and found out what she had done, she beat her up

> badly…My [CP] sister did not walk well. My mother kicked and pushed her when she got in her way. Once she even banged my sister's head against the basin repeatedly. My sister's head bled severely and she needed nine stitches. My mother claimed that she had the right to hit my CP sister whenever she wanted to, because she gave birth to her…The incidents of abuse and neglect happened every day. My eldest sister tried to take over the caregiving work again, as she had in the old days. She thought doing so would protect our CP sister. Contrary to what she expected, it did not work, and things got even worse. Our mother kept abusing the CP sister, as if on purpose.

The boundary between the parent-child relationship that is characterized as superior and inferior was not challenged. In this case, once the sister crossed that boundary, the mother escalated her abusive behaviour in an effort to establish and demonstrate her sovereignty.

In order not to offend their mother’s superior position, sisters appeal for help from men in their family who do have power. Using this strategy, sisters are able to stop their mothers’ neglect and abusive language, behaviour and threats. In traditional families, women follow rules that have been practiced for hundreds of years. An unmarried girl follows the instructions of her father; a married woman follows the instructions of her husband; a widow follows the instruction of her son (Chen, 2003). Sons, especially the eldest ones, have high status in Chinese families. To release her sister from the attic, Linda took advantage of this rule and united her brother and father in planning a family trip. This kind of activity had never taken place in this family since the day the CP sister was born.

> My mother has never listened to me. She valued a son more than a daughter. Last year, my brother was about to get his master’s degree. Right after his graduation, it would be mandatory for him to join the army for one year and two months. In the old days, young men could lose their life in this period of time in the army. So traditionally, before a young man would join the

> army, his family would do their best to fulfill his wishes. I urged my brother to take the advantage of this tradition – to propose a family trip to my mother which would allow our little CP sister to see the outside world. My brother actually proposed this plan to my mother. Not surprisingly, my mother declined the idea. My brother did not give up and kept begging my mother. Finally, my mother agreed with this plan, reluctantly though. We knew my mother would change her mind at the last minute, so we asked our father to stay firm when my mother suddenly pulled the whole thing off. Not surprisingly, again, she wanted us to have the trip without our young CP sister and her right before departure. My father said to my mother 'if you want to stay, fine, suit yourself. But she (the CP sister) is going with us.'

Appealing to professional intervention is another strategy that sisters apply to change their mothers' negligent and abusive behaviour. When Shannon found out that her mother had been abusing her sister with CP, she tried to use social workers to influence her mother.

> Before I took her away from my mother, I made a lot of efforts. For example, I called the social service agency and asked the social worker to talk to my mother, and made suggestion such as arranging for my sister to attend a day program. We thought if my mother could have a break in the daytime, she might not be so mean to my CP sister.

Linda skillfully advocated for professionals to intervene in an effort to alleviate how neglectful her mother was toward her sister with CP. This strategy was successful as it changed her mother's behaviour without harming the relationship between Linda and her mother.

> To apply for the wheelchair subsidy, it was mandatory to see a doctor. The doctor we saw was very nice. He praised my mother's contribution to my sister and claimed that my sister was the most beautiful and clean girl with cerebral palsy that he had ever seen. The compliment from the doctor meant a lot to my mother. I felt she would listen to each word that the doctor said to her. I asked deliberately about how to treat my CP sister's tailbone that sticks out and makes her look like a monkey. When the doctor realized the

> tailbone was caused by long term imprisonment in the attic, he encouraged my mother to take my sister outdoors every day. Now she (the mother) sees herself in a positive way and no longer hides my sister in the attic. She even listened to the doctor's suggestion and takes my sister to the rehabilitation center every day.

Having benefited from a doctor’s intervention, Linda’s sister now participates in a program at a rehabilitation center, and is no longer locked up in the attic.

> My parents take her to the rehabilitation center almost every day. People in that center love my sister so much. They play with her. For example, the therapist gave her a new assignment - to shake hands with people when you hear the words *shake hands*. People in the center knew my sister's new assignment. They come to shake hands with her all the time. The tobacco farm is busy lately. My parents had to stop taking her to the rehabilitation center for a while. My sister made noises to bug my parents, as if she were saying she wanted to go to the rehabilitation center. Occasionally my parents could not stand her pestering and put her in the wheel chair. She knew she was going to the rehabilitation center and burst out laughing right away. Meeting people makes her happy, no matter whether she understands their words or not.

The doctor also wrote a certificate to prove that the sister with CP needed an in-home assistant. The in-home assistant service provides Linda's mother with a welcome six-hour break every week and contributes to improve the life quality of Linda’s mother.

> She used to blame my sister for confining her in this house, and there was no way she could get out. Now the home care worker comes to replace my mother for a couple of hours every week. My mother can go to barber shop to have her hair shampooed and enjoys the massage service.

Professional intervention helped not only Linda's sister and mother, but also the relationship between her parents, between Linda and her mother, as well as between Linda’s family and the community.

> My father likes to have a couple of drinks with friends or relatives sometimes. My mother was not happy about this and argued with him for many years. Now my mother owns the most powerful weapon to stop my

> father from drinking too much. When my father wanted to meet with friends or relatives, my mother took my sister with her and joined my father's party. Because of my sister, my father drank tea only, and the friends and relatives dared not urge my father to have a drink. My mother was so happy about this. Actually, that was not the best part. The best part is that my parents finally have their own social life together. Without the doctor who encouraged my mother to take my CP sister outdoors every day, this would not happen.

Linda and her mother used to have conflict all the time because of Linda’s intention to protect her sister from her mother’s negligence. Physicians, therapists and social workers in a rehabilitation program successfully provided a buffer to the relationship between Linda and her mother, which further released Linda from the tension in her relationship with her mother.

> I feel more relaxed now. In the past, I spent a lot of energy trying to change my mother's wrong ideas. I don't need to do this any more because my mother listens to the professionals. Now I can sit back peacefully and watch my parents play with my CP sister. We don't need to hide my sister in the attic any more. Now my mother takes my sister with her to visit her natal home. She is no longer ashamed of my sister. The best thing is, my sister was finally allowed to join us for the Chinese New Year dinner. This was my heart's fondest wish for years, and it finally came true.

When their mothers do not mend their ways and continue to be abusive, sisters of persons with CP find it difficult to overstep what is prescribed by their filial duty and hold their mothers responsible. Instead, they defend their mothers’ abusive behaviour and make excuses for them. Shannon attributed her mother’s abusive behaviour to senile degeneration.

> Actually she cares about my sister. Not long ago, she told my eldest sister that she was wondering if my [CP] sister was dressed warmly enough. I think the reason she did those things was that she was too old and confused. Sometimes she told my eldest sister that my CP sister was actually the daughter of me and my father. She is simply too old and disoriented. She

> doesn’t know what she is doing or saying.

Linda believed it was feelings of guilt and shame that led her mother to abusive and threaten her sister verbally. She explained that her mother's verbal threats were actually mixed up with her feeling of guilt toward the CP sister. She thinks that her mother believed it was her negligence that had caused her sister to get sick.

> The night my sister got sick, my father was at the tobacco farm, and my mother was sleeping alone on the bed. She must have been very sound asleep not to be aware that my sister had a critical fever. When my father came home and discovered my sister's fever, it was too late. My mother blames herself. She thought, what kind of mother would neglect her child and sleep like a dead person? So when my mother threatened to kill my CP sister and then herself, I understood that she was saying it was her fault that my sister had CP. Since she was the one who was responsible for this mistake, she should be responsible until the day she died.

It is not only the strained relationships between sisters and their mothers that stress these sisters. The fear of being criticized as an unfilial daughter can make sisters feel overwhelmed.

> Placing my CP sister in an institution without my mother's consent is the last thing in the world I wanted to do. But I had to do it to protect my CP sister. If we kept ignoring what happened in there, soon my sister would die. One day, I took my sister away from my mother. My mother had all of her legal documents, including her bank book, bank card, and the deed to the apartment. I took her to the household registration office to apply for a new identification card. I also took her to the bank and other places to apply for new legal documents. This was to help her get rid of my mother's control and gain her own life. A few weeks after I took my sister to change her PIN number for her account, I went back to the bank again. A staff member told me that my mother had gone to the bank to withdraw money. When she found out that the PIN number for my sister's bank card was no longer valid, she spent the next half an hour in the bank, madly cursing my name. When the bank teller told me what happened that day, I was not sure how people around who overheard what she said would think about me. What kind of

> daughter would deny her mother's right to withdraw money without a notice? People might think that I was an unfilial daughter, but actually I was not. I was forced to do so. However it was not possible that I explain to everyone. I am innocent, but it is like I am not able to defend myself even though I have hundreds of mouths.

Maternal abuse and neglect of their children with CP can be attributed to the patriarchal system that exists in Taiwan and bestows upon women functions of reproduction and caregiving. The frustration of being accused as a failure to reproduce a healthy heir and to fulfill responsibilities of caregiving responsibility pushes mothers of children with cerebral palsy to the edge of tolerance where they perpetrators to their own children with CP.

While young and powerless, sisters do their best to protect their siblings from threats to their survival and well-being. When those threats are intra-familial, sisters must balance their filial duties with that of their instinctive and learned desire to protect their siblings with CP. In this study sisters learned from early experiences that direct confrontation of their mothers' abusive language, behaviour and threats was the least effective strategy, and sometimes would even make things worse. Appealing to fathers' and brothers' for help or to professional intervention to change their mothers' negligent and abusive behaviour were strategies that sisters found to be effective as this would prevent them from directly offending their mothers' sovereignty.

Encountering their mothers' negligent and abusive behaviour for years, sisters found ways of excusing or understanding their mothers. The alternative, to stand up to abusive behaviour, to challenge mothers directly was not socially sanctioned and sisters feared that they would be severely reprimanded as unfilial daughters, thereby suffering additional stigma and repercussions.

6.4 Caring Through Sacrifice

The last theme that emerged from analysis of the narrative data is that of caring through sacrifice - sacrificing resources, sacrificing heirdom and sacrificing choices regarding a future husband. The first sub-theme, sacrificing resources, refer to how the implicit demand from patriarchal systems for women to sacrifice their own time and energy to provide care to their CP siblings. The second sub-theme, sacrificing heirdom refers to how the same system demands that married women relinquish their legal rights to inherit property as well as their willingness to provide care to their siblings with CP. The last sub-theme, sacrificing choice related to a future husband highlights how single women anticipate sacrificing future possibilities related to a spouse in order to avoid being pressured by their husband or future parents-in-law to move away from their siblings with CP.

6.4.1 Sacrificing Resources

Sisters have been asked to sacrifice when they encounter instances of parents' differential treatment or unfairness in the distribution of precious resources. They feel frustrated for being asked to tolerate their CP siblings' sometimes unreasonable behaviour.

> Even now, I'm asked to tolerate my brother's behaviour. It's like I have to take it without any argument. For example, my brother doesn't allow any of my friends to come to our house. He isn't comfortable when strangers are around. But I like to have friends stop by our house. I tried bringing four or five friends to our house. When I introduced my brother to them, my friends greeted him with 'Hello brother.' I could see my brother was happy. Then I took my friends into my room for some girl talk. Not even an hour later, my brother started screaming. The screams were so harsh that a neighbour came by to see what had happened. He kept screaming until my friends left our house. I was frustrated, because my mother asked me to

> tolerate my brother's behaviour. My mother told me, he was afraid that people laughed at him behind his back. It took time for my brother to overcome his limitation. She persuaded me not to bring friends home before my brother was ready. Now I don't bring my friends home any more. However, I really want to share my life and my friends with my mother and my brother. I want them to know what I've been doing out there. (Singing)

> When we were young, my CP brother wanted to take toys or other things from my hands. Usually my mother demanded that I let my CP brother have whatever it was. Why should I? Now I feel less adamant about it. But back then, I couldn't see any reason I should sacrifice my rights and give him what I had in my hand. It was not his limitation. He could be taught. Things like that are still happening. Sometimes he peed in the hallway because he was so addicted to the TV program. The hallway stank. It was not his limitation. He could be trained. (Rose)

Parents’ differential treatment occurred in relation to the distribution of resources in daily life.

> We lived in a rural area. People believed river eel enhanced one's muscle strength. River eels were expensive, but my mother bought eels to feed my sister all the time. My mother stewed the eel so nicely that the bone was totally disintegrated. She used the consomme of eels to make congee[8]. My mother believed-and even now we all believe-it is the eel congee that helped my sister gains the strength to paint and do things with her feet. We are not entitled to have the eel congee. We are healthy people. It was for my sister only. (Melody)

Sometimes, sisters had to sacrifice time normally dedicated to studying, playing or socializing to provide care to their sibling with CP.

> My CP sister had trouble moving all the parts of her body. Her arms, legs, and trunk were all affected, so she needed a wheelchair to help her get around. She also needed someone to help her with toileting and grooming. Before my eldest sister got married, my mother left all the caregiving

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[8] Congee is a type of rice porridge that is eaten in many Asian countries.

> chores to my eldest sister. My eldest sister had to come home straight after school or work everyday to look after her sister. She never hung out with friends after school or work. If she did, my CP sister would be starved and smelly, because no one else would change her diaper. There was a year when my eldest sister was in fifth grade, my CP sister got diarrhea. Whatever my CP sister ate, it just came straight out. My mother ordered my eldest sister to quit school and stay at home to take care of my CP sister. She actually did stay home to care for my CP sister for a whole year. (Shannon)

One of the most precious things that sisters sacrificed is their mothers' attention. Throughout Melody's childhood, her eldest sister was more a mother than a sister to her. Because Melody's sister with CP required numerous hospitalizations, her mother barely had time to pay attention to her other children. Singing also spoke of her loneliness and how she felt invisible to her mother when compared to the attention that her mother gave her brother with CP.

> I did almost everything by myself. My eldest sister was three years older than me. She took me to school and was my substitute mother. My real mother belonged to my CP sister. (Melody)

> I feel so lonely. My mother gives my brother all the attention, with nothing left over for me. She applauds my brother heartily whenever he makes any progress, even a tiny bit. When I made progress, she took it for granted. I feel like I'm invisible to her. I'm like a supporting actress in a play; nobody notices me. Around the ages of 14 to 16, the feeling of being left out became stronger and stronger. I craved my mother's attention so much. I imagined if I did something bad, like skip classes or be late for school, probably my mother would come to me and ask, 'Why you are doing this?' I had been such a good girl that being bad would definitely get her attention. But I didn't do it after all. I didn't want to overwhelm my mother. She had plenty to worry about already. Even now, I still feel so lonely, and I've been lonely for such a long time. (Singing)

Although these sisters felt deprived for their mothers' love and attention, they were close allies in the provision of care to their sibling with CP. Melody felt it was so unfair that her sister owned her mother entirely. However, when her mother’s health declined, she took over exactly what her mother had been doing in the life of her sister with CP.

> I used to hate my sister. I believed she was a big stone who came to this world to strike my mother down. When my mother was 69, her health declined and she was no longer be able to care for my sister, so I took over my mother's caregiving role. My sister has loved painting since she was little. She used her right foot to draw the dragon goddess in the bitter sea, the character in the puppet show. She has trouble controlling the upper part of her body, so she has to use her feet to adjust the angle of her face and prohibit the involuntary movements of her hands. She adjusts the angle of her face so she can focus her eyes properly on the paper. She uses her foot to restrain her left hand so that the involuntary movements won't interrupt her work. It was not easy to find a teacher who was willing to teach a student with so many troubles in painting. When my CP sister was 27, my mother begged an artist who had experience working with people with disabilities to teach my sister painting. At first, the artist refused to take my sister to be his student. He said, 'I speak Mandarin only, you [the mother] speak Taiwanese only, she [the CP sister] cannot speak, how can we three work together?' My mother begged him repeatedly and said, 'This is the humble wish of my daughter, please help her dream come true.' The artist finally agreed to gave her a chance. Now it is my turn to devote time and energy and ask people to give my CP sister a chance and help her fulfill her wishes in the life.

When Singing's brother was one and a half years old, her parents did not understand why the brother could neither hold his head up while crawling nor sit up straight like other children of his age. When a physician gave them a diagnosis of CP, Singing's mother quit her job and Singing and her brother embarked on a rehabilitation journey.

> When I was little, I accompanied my mother and my brother to the rehabilitation center very often.

I gained an impression from interviews that Singing and her mother formed an inseparable unit that worked together to deal with troubles related to her brother. To be specific, Singing kept using *we* instead of *I* or *my mother* when describing events in their lives. For example, when she talked about her brother's refusal to use any assistant equipment, she used the subject *we* three times in the process of describing the event.

> The therapist recommended that he use a cane to support his body, but he refused to have one with him. *We* asked him why he didn't want to have a cane to protect him from falling. He didn't answer, but he insisted he did not want to have one. Probably he dislikes having people look at him in a strange way. He has a phobia toward strangers, but *we* still take him outdoors a lot, if he wants to go. If he doesn't want to go out, *we* just leave him alone at home.

Jobs in the caring fields or plans for seeking such careers were overrepresented among the women who participated in this study. The only exception was Linda. She was a pink-collar worker who is working in a commercial company. The rest of the participants were working in, or were planning to work in, a caring field at the time they were interviewed. Shannon was a social welfare assistant; Cherry was a kindergarten teacher; Rose was considering studying inclusive education at the university. Being a caregiver was at the core of the identities of the sisters of persons with CP siblings. Like Melody described: '…providing care to everyone in the building who needs me. I take care of my husband, child, and mother-in-law, as well as my youngest sister—who has CP—and my 85-year-old mother, who lives with my CP sister, even the dog that had been my CP sister's companion for 13 years needed to visit the veterinarian frequently. I see myself in this way, and people see me in this way as well'.

When I contacted Singing for the appointment, I saw how much she cared about her community and about people in general. It seemed that she wanted to take care of everyone, including strangers like me. In her career plan, Singing even deliberately chose a helping profession for the purpose of helping her brother with CP and other people with developmental disabilities as well. After high school, a teacher of Singing's brother referred him to a sheltered employment program, in which persons with disabilities worked in a self-contained unit, not integrated with nondisabled workers. In that program, individuals perform subcontracted tasks such as sewing, packaging, collating, or machine assembly. They are usually paid on a piece-rate basis. Because of her brother's limitations in cognition and mobility, Singing realized that working in this protected environment was the best situation for her brother. A career objective of her is to build a sheltered employment program to look after her brother and others like him.

> He learns things slowly, very slowly. I need to talk to him more than twice to make him understand new things. Probably only my family members understand what he is saying. Studying social work is one of my dreams. I plan to obtain a social work degree and establish a sheltered employment program for people with disabilities. My brother and other people with disabilities can live and work there, in which my mother and I can take care of them.

Sisters have been asked to sacrifice precious resources in daily life and sometimes have had to sacrifice time normally dedicated to studying, playing and socializing with peers to provide care to their sibling with CP. Among the sacrifices, the greatest has been the loss of their mother’s attention. Although sisters feel deprived in this regard, they are their mothers’ greatest allies in the provision of care to their sibling with CP. The sisters in this study were motivated either consciously or unconsciously to seek jobs in the helping profession or caring work.

The next sub-theme of sacrificing heirdom is related to how the patriarchal systems demands that married women relinquish their legal rights to inherit property as well as their willingness to provide care to their sibling with CP.

6.4.2 Sacrificing Heirdom

Parents usually designate their male offspring to take over the responsibility for their children with CP. As Cherry indicated when discussing her father's plan for her sister's future care, girls in her family were exempt from the responsibility:

> The plan is, once my father passes away, my brother will buy an apartment next to his own. My sister will live there, and a formal caregiver will come and take care of her 24 hours a day. My brother will take good care of her. It has been well planned.

In Taiwanese culture, women inherit family responsibilities and property only in rare and exceptional cases, for instance, when male heirs decline or are unable to step into the successor role. Shannon’s mother did not expect to have to care for her daughter with CP for long. She believed that soon after her son got married, she would be able to transfer the caregiving responsibility to her son, and her daughter-in-law would take over the caregiving work. Contrary to her expectations however, her son and daughter-in-law declined the arrangement.

> He [the brother] joined the army when he was in high school and lived in the military school dormitory. When he came home for a visit, my sister and I would leave my CP sister with him for a couple of hours so we could have a break. He helped her with toileting and feeding. Usually he left the bathing to us. Actually, he did not do many things for my CP sister, but those things were enough for him to get a sense of what it was like to care for my CP sister. He made up his mind to decline my mother’s demand to take over the caregiving responsibilities after he got married. He suggested placing my CP sister in an institution. My mother was furious about his decision and smashed his wedding picture with a broom.

In another example, Melody’s father designated his eldest son to be his successor. The plan was obstructed because the sister with CP refused to be cared for by her sister-in-law.

> I told her, ‘You need to accept the fact that you are the one who receives

> care. You have no right to choose who you want. You have no right to say you don’t like to have your sister-in-law take care of you. When you are asking a favour from others, you need to accept the fact that no matter who gives care to you, you have to say yes.’ My persuasion did not work. There is a large age gap between my eldest brother and my CP sister. When my brother married my sister-in-law, I was in the sixth grade, and my CP sister was only 10. My brother did not decline my father’s designation. It was my sister who refused my sister-in-law’s care. She was such a *gao-guai.*[9]

The unavailability of other siblings was another crucial reason for replacing the designated brother with other possible candidates who become the main caregiver to their sibling with CP. After Shannon's brother declined the caregiving responsibility, Shannon became the main caregiver to her sister with CP. She visited her sister in the institution regularly, and she hosted the sister in her apartment during long weekends and holidays. She also represented her sister when dealing with official paperwork. Shannon explained why she occupied the position instead of her eldest sister, who had actually been more involved in the life of her sister with CP in the past.

> My eldest sister's marriage ended three years ago. She has a son and a little granddaughter. Her son made a girl in her neighbourhood pregnant at a very young age. Then, when her son was serving in the military, the girl had an affair with another man. Her son divorced her and obtained custody of the child. Later, her son suffered from a major head trauma because of a car accident. He was not able to work to support his family, so my sister has to care for the whole family. There is nothing she can do for our [CP] sister.

Melody became the one who took over the caregiving responsibility also as a result of her eldest sister's unavailability,

> My brother-in-law (the eldest sister’s husband) was not happy that my eldest sister devoted too much time to her natal home. Since he retired, my

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[9] *Gao-guai* means nine-monster in Taiwanese. It refers to a person who is hard to g*et al*ong with, like nine monsters added up together.

> sister could not visit my mother and CP sister's apartment like she used to. All she can do is deliver groceries to their apartment and call my mother at 5 pm every day. She used to spend a lot of time with my mother and my sister. Since the day he retired, he became restless and uneasy, and looking all over for his wife whenever she's out of his sight.

Melody was more available than her eldest sister. Her husband and grown son supported what she was doing for her natal home.

> I became more available when my son grew older. My mother's health declined when she was 69 and became too weak to give care to my CP sister. So I took my mother's place. My husband and my son have no problem with this at all.

Sisters like Melody and Shannon, who took over their brothers' positions and become main caregivers over time, received some compensation such as money or family property from their natal family. Shannon has been living in her CP sister’s apartment with her son after her divorce. She has been exempt from paying the rent to her sister with CP as compensation for being a main caregiver.

> The old house we used to live in was military housing. It was too old and needed to be torn down. The government reassigned a new apartment to each household as compensation. The old house was registered under my father's name. Since my father had passed away, the sequence of inheritance to the new apartment by law was the spouse who has not remarried, the son who is serving in the army, and the unmarried daughter. In this family, only my CP sister is qualified to inherit the apartment, because my mother had remarried, my brother was not serving in the army, and only my CP sister had never been married. Therefore, she became the owner of the apartment. Now, my son and I live in her apartment. She didn't ask us to pay rent. I'm supposed to pay her back by taking care of everything for her.

Melody took over her mother's caregiving responsibility out of gratitude to her father, who gave her and her husband an apartment.

> Because of my sister's problem, my father built a complex on his land. All the families of my father's offspring live on this property. He thought that

> because my CP sister had various medical conditions and needed to be hospitalized every now and then, it would be better to have family around. My father gave one of the apartments in this complex to my husband and me. This saved us from having to live somewhere else and paying off a mortgage for 20 or 30 years. My father did not ask me to take care of my CP sister, but I believed it was something I ought to do.

In most of the cases, the male heir accepted the responsibilities. His sisters, willingly or not, accepted the arrangement.

> I asked my mother about this [future caregiving plan]. My mother said, ‘We will count on your youngest brother.’ (Rose)
>
> My parents agree that it’s my brother’s responsibility. (Linda)
>
> It’s my eldest brother. (Cherry)

If the family has property, inheritance usually goes to a son with the designated obligation. Sisters therefore lose their right to a share the family inheritance.

> We’re all well aware of that. My father plans to leave all of his money, house, and lands to my brother. We girls will get nothing when my father passes away. (Cherry)

Should parents (usually the father) plan to exclude daughters as a lawful heir, one way to circumvent equal inheritance to children of both sexes by law is to transfer the entire family estate to the sons so that there will be no inheritance at the time of the father's death. As in Cherry’s family, everyone in Linda's family also understands that only the male offspring will inherit all the family assets, as well as the obligations. Linda elaborated her father's plan and how her father tried to deny Linda's legal right to claim her inheritance in the future by registering or transferring his properties to his son.

> They [the parents] still believe they are counting on the son, not the daughter, in the future. My dad put a lot of thought into it. For example, he bought land recently, and the land is registered under my brother's name,

> not my father's. This act is a way of announcing who will be the boss in this household in the future.

Observing sisters’ reactions to the fact that only the brothers would inherit the obligations and the legal rights in the interviews, most of the sisters accepted the arrangement and showed little resentment. They believed they should sacrifice the right for family inheritances in order to let their CP siblings be well taken care of.

> He (the brother) has been given this mission from childhood. He will need this money and property to take care of my CP sister. (Cherry)
>
> When I asked my mother about this [future caregiving plan], my mother said, ‘We will count on your youngest brother.’ I have no objection that the property goes to him in the future. He is going to take care of my CP brother and my parents in the future after all. (Rose)

Other sister, such as Linda, questioned the fairness of the arrangement.

> My younger sister [the healthy one] complains about this arrangement to my father all the time, in a joking manner, of course '[My brother] does not even live in this house now. He knows nothing about how to give care to our CP sister, and you, old man, plan to give him all the money and ask him to take care of her for the rest of his life?'… Why does it have to be my brother's responsibility, and not mine? Let's face reality. For all these years, it's been my younger sister and I, we girls, who lived in this household and gave care to my [CP] sister and my parents. My brother comes home just once or twice a month. When my folks decide to give him all the money and transfer the responsibility to him who barely knows my sister, does it make any sense to you? He doesn't know about things such as diapers, food, rehabilitation . . . any of that stuff.

However, Linda dared not to challenge her father's arrangement.

> I told my father, I dared not think I could have my share. I would not claim my part. . . . I don't need his money.

Parents usually designate their male offspring to take over the responsibility for their children with CP. Only in rare and exceptional cases, for instance, when male heirs decline or are unable to step into the successor role and care receiver refuse parents’ plan, sisters replace brothers’ places and become parents’ successors. Sisters who took over their brothers' positions and became main caregivers received some compensation such as money or family property, if any.

In most of the cases, the male heir accepted the responsibilities and family property as well. Most of the sisters in this study accepted the arrangement and believed they should sacrifice the right to family inheritance in order to let their CP siblings be well taken care of. Only one sister questioned the fairness of the arrangement by asking why she was not entitled to same responsibility to care and equal right to inherit property.

The last sub-theme of sacrificing choices pertained to future husbands and illuminated the issue that single women were faced with letting go of good future husband candidates in order to avoid being pressured by their husbands or the future parents-in-law to move away from their CP siblings- even though they have never been designated to take on that responsibility after they were married.

6.4.3 Sacrifice Choices of Future Husband

As mentioned previously, most of the parents planned to transfer the caregiving responsibility to their sons when they were no longer able to provide care to their offsprings with CP. However, this did not mean that sisters planned to relinquish their responsibility to their brothers entirely. All of the unmarried sisters, except Singing who had no other siblings, indicated they would take turns with other siblings to care for their siblings with CP .

> Take turns, probably. The bottom line is, he needs somebody to be near him and keep an eye on him. (Rose)

> My dad said he would not leave any inheritance to his daughters. But it

> does not change our willingness to give care to our CP sister. If one day my brother cannot perform the duty that my father gave him, my second sister and I have agreed that we will take care of her according to our father's wishes. (Cherry)
>
> We shall count on each other. I believe we should share the responsibilities of giving care to our CP sister. It is for her well-being and also for the well-being of all of us. (Linda)

These unmarried sisters considered their siblings with CP to be a priority in their lives. They expected to live with or near their CP siblings in the future.

> We will live together. We have a house. We have a car. We can live in a simple style. (Singing)
>
> The bottom line is, he needs somebody to be near him and keep an eye on him. He is able to take care of himself, though. As long as I can watch him arrive home safely and ask him if there's anything he needs, it doesn't matter whether we live together, next door, or in the same neighborhood. Basically I want to live near him, as close as possible. (Rose)
>
> We will take care of her the way my father wanted my brother to. (Cherry)

In the last quote, Cherry was referring to her father's wish that her sister with CP live with the brother,

> Once my father passes away, my brother will buy the apartment right next to his own. He'll break down the wall and make two apartments become one.

The social practice in Taiwan is for the female spouse to move into her husband's home after marriage. In order to avoid being pressured by their future husband or her future husband’s family to move away from her sibling with CP, these single women planned to stay nearby and consciously limited their intimate relationships to men who held less patriarchal beliefs.

> When someone was interested in dating me, I told him the situation in my life frankly. I declared that my family came first, no matter what. (Linda)
>
> I will take care of him until we are old. If my partner cannot accept him [living with us], then there is no future between my partner and me. Family is my first priority. This is a concept that my mother passed on to me. (Singing)
>
> If they [future husband and parents-in-law] don't like my brother, then don't marry me. He is my brother. A blood relative is closer than a husband, who has no blood connection. (Rose)

It is not commonly seen or accepted in Taiwanese society for women to place their family of origin before their husband’s family. Cultural expectations of the role of wife and daughter-in-law come from various sources - parents, relatives, friends, and media. Rose recalls what her mother implied about the challenge that a married woman would experience if she planned to live with her sibling with CP.

> My mother asked me, 'What are you going to do if your youngest brother won't take care of your CP brother?' I said, 'It's not a problem. He can live with me.' My mother replied, 'It's not as simple as you think. What will your parents-in-law say about this? What will your husband say?'

As mentioned previously, Linda told potential dates that her own family came first. Linda recounted her cousin's reaction, also a reflection of how people regard a married woman who puts the needs of her natal home before that of her husband’s.

> My cousin condemned me by saying, 'How could you think that way? How could you be so selfish?'

The predicament of a young woman who has a sibling with a disability has been well portrayed by the mass media and broadcast to lay people.

> Probably I watch too much TV. We can see the same theme play in different soap operas again and again. When the parents of the boyfriend find out that the girl has a brother or a sister with disability, they strongly oppose the marriage. If it happens to me, I will still put my brother first and give up the relationship. I believe that all girls in my position will encounter this situation eventually. (Rose)

The difficulty of being a wife at the same time as being a sister of a person with a disability is illustrated by Linda's narratives, in which she talked about the experiences of a friend who also had a sibling with disability.

> I have a friend who lives near my house. Her sister is a girl with a mild intellectual disability. She complained that since the day she got married, she had been totally unable to help her natal home. She said she regretted getting married. She was totally controlled by her husband's family. Her husband did not allow her go back to her natal home to take care of her mother and sister when they were in need. She said she had the ability to give care but was not entitled to do so.

Linda told me about the consequences of planning to make her natal home as her first priority.

> Actually, my ex-boy friend broke up with me because he could not accept my priorities. At the beginning, he reminded me that it was not my responsibility to take care of my CP sister. I tried to change his mind, but it didn't work. So I just let him go. (Linda)

Although most of the parents did not plan to transfer the caregiving responsibilities to their daughters, all of the unmarried sisters still planned to take turns with other siblings to care for their CP siblings even after marriage, and expected to live with or near their CP siblings in the future. Their plan went against Taiwanese social practice that reinforced the place of female spouses in relation to their husband’s home after marriage. In order to avoid being pressured to move away from their siblings with CP after they were married, these single women limited their choices to men with less patriarchal beliefs.

The findings of this study indicate that messages of cultural expectations to a wife and daughter-in-law come from multiple sources such as parents, relatives, friends, and media. Within this context, sisters of individuals with CP either change their life plan or limit their choices of potential partners to avoid anticipatory obstacles that would keep them from maintaining their caregiving role to their siblings in the future.

CHAPTER SEVEN
DISCUSSION

Based on the experiences of six sisters of individuals with cerebral palsy, this study examined how the various roles that these women held informed their caregiving identities and how their caregiving identities were constructed. The provision of current and future care to siblings with cerebral palsy is a complex phenomenon that contributes to how these women view themselves and is informed by four processes associated with the provision of care to their siblings: (a) caring through interpretation; (b) caring through transformation; (c) caring through protection; and (d) caring through sacrifice. The sisters in this study were also students or employees, daughters, current or future spouses and daughter-in-laws. Engaging in these four processes of providing care to others created unique considerations and tensions in carrying out other roles these women assumed in their lives. More specifically, these tensions had to do with their negotiation of relationships with their mothers, considerations pertaining to who they will or already have married, the denial of their right to inherit family properties as well as their desire and expectation to provide ongoing care to their sibling with CP after marriage.

The processes and tensions that contribute to the caregiving identities of the participants in this study are consistent with Bowers' (1987) argument that much of the caregiving is invisible and influences sisters' relationships with others as well as their life choices. For example, caring through interpretation and sacrifice highlights sexual division of labour and its potential impact on women's career choices. Caring through transformation and protection draw our attention to how cultural beliefs of Shan-Shia (up-down) intensify tension in the mother-daughter relationship in Taiwanese cultural context. Caring through sacrifice reveals the vulnerability of sisters of siblings with CP in patriarchal systems where their entitlement to family inheritance and their wishes to provide care to their CP siblings after marriage are denied.

In the following section, the processes and tensions that sisters negotiate with roles expectations, such as daughters to their parents, wives to their current or future spouses, and daughters-in-law to their parents-in-laws, prescribed by the cultural norms of Taiwanese culture will be discussed. Four processes and tensions that will be discussed include *strained relationship between mother and sister* (tensions with mothers), *denial of right to family inheritances and right to give care* (tensions with parents), *the impact of anticipatory caregiving to unmarried women* (tensions with future spouses), *and gendered care and career choice* (tensions with current or future spouses, and parents-in-laws).

7.1 Strained Relationship between Mother and Sister

A factor that significantly affected the caregiving identities of the participants of this study was emotional strain in their relationships with their mothers. In most cases, these tensions emerged as a result of sisters’ commitment to their caregiving identities and processes such as transformation and protection. When participants challenged their mothers' abilities to care for the siblings with CP, or when participants tried to protect their siblings with CP from their mothers' maltreatment and negligence, the tension in the mother-daughter relationship increased. This pattern began during the childhood of the participants and continued on into their adulthood.

The Confucian conception of the self is heavily influenced by social relationships with others that are characterized by Shan-Shia (up-down) - hierarchical social relationships (Hwang, 1999). Traditionally, a junior person should show their respect to a senior. When people in the lower ladder of the social hierarchy offend their superiors, they would be criticized for not following the principle of filial piety which is the root of all benevolent actions (Analects, trans. 1998, book I, chap. II, p.138), and could be punished by their senior. Participants in this study adopted several strategies to negotiate with their mothers when they believed that their mothers' behaviours and attitudes would endanger the well-being of their siblings with CP. One of the attempts included directly challenging their mother, which goes against the cultural norm of Shan-shia. Not surprisingly, positive outcomes from this kind of strategy were very limited. Negative outcomes such as strained mother-daughter relationships arose, and abusive behaviour to siblings with cerebral palsy intensified, becoming more violent than before. Mothers' negative responses to sisters' intention to improve their CP siblings' well-being reflect mothers' demands for their daughters' obedience. This expectation is part of the cultural norm in Chinese families that requires the younger cohort to honour the strategic knowledge and skills of their elders with deference, respect, and compliance.

Apart from the pressures received directly from tensions in the mother-daughter relationship, sisters experienced pressure that emerged from their personal perception of others' judgement of them. As mentioned earlier, in the symbolic interactionist perspective, perceptions of self are reflected in Cooley's looking glass self (Longmore, 1998). If a person's perception of self is reflected in others' representations of that individual (Amankwaa, 2005), people interpret their world from the responses from others in society and are able to translate society's response to their actions (Forte, 2005). The role that the perception of others plays in the shaping of one's identity is even more important in the collectivistic cultures such as Taiwanese culture.

From the perspective of symbolic interactionism, it is expected that participants who violated the norms of their culture became concerned with how their behaviours would be viewed by others. For example, when Shannon took her sister with CP away from her mother after she found out her mother's abuse, it is no surprise that she would suspect that people see her as an extremely unfilial daughter. Filial piety means "not being disobedient" (Analects, trans. 1998, book II, chap. VII, p.148). People who disobey their parents can be criticized as "not distinguishable from dogs and horses" (Analects, trans. 1998, book II, chap. VII, p.148). In the doctrine, when parents act immorally, it is said "in serving his parents, a son (child) may remonstrate with them, but gently; when he sees that they do not incline to follow his advice, he shows an increased degree of reverence, but does not abandon his purpose; and should they punish him, he does not allow himself to murmur." (Analects, trans. 1998, book IV, chap. XVIII, p.170). When Shannon took her sister with CP sister away, the act of disobedience toward her mother can be condemned as overstepping what is prescribed by the doctrines of Confucianism as a daughter. In this sense, when a daughter disobeys her mother, the meanings of her actions represent not only the disruption of mother-daughter relationships, but also represents an act that is against the highest mark of morality to be a human. This could be criticized by society, and even by the sisters themselves.

However, sisters in this study did not passively endure their mothers' abusive or negligent behaviours when they found the strategy of direct challenge did not generate positive outcomes. Instead, they attempted to obtain power through a culturally sanctioned way, namely Shan-Shia (up-down) to improve the situations. Given that Chinese patriarchal systems grant fathers and brothers power over the mother, sisters appealed for help from male family members to negotiate and challenge their mothers. This strategy successfully alleviated sisters' tense relationships with their mothers. This finding is in line with the results of previous studies that suggest that the traditional notion of Shan-Shia (superior-subordinate) has evolved in modern Confucious society (Yeh & Bedford, 2004; Zhang, 2007; Zhang, Harwood, & & Hummert, 2005; Zhang, Lin, Nonaka, & Beom, 2005). These studies indicate that while the competing style is still the least preferred style of communication (Zhang, 2007), absolute obedience to parents is fading and an avoidant style is equally preferred (Zhang, Harwood, & Hummert, 2005). The finding of this study supports the trend that Chinese communication patterns and preferred style for resolving conflict tends to be that of a problem-solving approach (Zhang, Harwood, & Hummert, 2005), reframing the solution in such a way that both sides attain their goals and neither party sacrifices their demands (Yeh & Bedford, 2004). Sisters in this study, for example, applied strategies that allowed them to not challenge the mothers' superiority but still successfully fulfilled their caregiving obligation to their CP siblings.

On the surface, it may look like male family members rescued sisters in this study from the tension in the relationship with their mothers by exerting patriarchal power over the mothers. However, a closer examination of the basis for mothers' abusive and negligent behaviours, suggest two other possibilities. First, having a child with CP endangered a tremendous sense of shame in these mothers. According to the notion of Nei-Wai (inside-outside), women in Chinese society have been socialized and have internalized the goal of marriage as the continuation of the family (Gallin, 1994). Women who have not produced healthy heirs to continue their husbands' family line can be viewed as a failure and disgrace to the family. Second, these mothers were overburdened with heavy caregiving loads. Providing care to family members is one of the major functions that have been designated to women by social expectations in

Chinese society. The heavy caregiving burden likely contributes to their frustration and outrage. Furthermore, little support is provided or regarded as appropriate. The feeling of shame for not able to produce healthy heirs to continue their husbands' family line and frustration caused by endless caregiving work and a lack of additional support likely contribute to mothers' abusive and negligent behaviour toward their children with CP. Therefore, when sisters colluded with patriarchal power to fight against their mothers, it shall be kept in mind that patriarchal power is not the rescuer as what appears on the surface, but the real perpetrator. Quite on the contrary, it is actually the patriarchal system that defines women as a tool of reproduction and deprives women of autonomous power by exerting full caregiving loads that push women to the edge of tolerance. In some sense, these mothers are victims of the patriarchal system themselves.

In sum, sisters negotiated with their mothers when they believed that their mothers' behaviours and attitudes would endanger the well-being of their siblings with CP. Direct challenge to their mothers was one strategy, but seemingly to be the least effective one and caused tensions between mothers and sisters. Given that the patriarchal system grants patriarchal power over the mothers, sisters mostly appealed for support from fathers or brothers after the failure of direct confrontation with their mothers. Under the force of patriarchal order, the mothers accepted new and better ways of providing care to their children with CP, and the tension between mothers and daughters were successfully alleviated. Worth noting is, in appearance, it is the patriarchal system that rescued siblings with CP from incompetent or perpetrating mothers and successfully alleviated the tense relationships between mothers and daughters. Nevertheless, it is also the same system that contributes to mothers' maltreatment or negligence to their children with cerebral palsy and further caused the tension in mother-daughter relationships.

7.2 Denial of Right to Family Inheritances and Right to Give Care

Patrilineal belief, another major component of the patriarchal system also significantly affects the lives of the participants of this study. The participants in this study shared their families' ideals regarding family continuity through the male line, whereby the basic unit of ownership of family property was the father-son unit. This patrilineal concept dictates issues regarding legitimacy of the heir for property inheritance and family responsibilities in Chinese families. Women inherit property and responsibilities only in rare and exceptional cases, for instance, when male heirs decline or are unable to step into the successor role. In most cases, the male heir accepts the responsibilities and the right to inherit family property, and his sisters accept the arrangement, willingly or not.

In Taiwan, the ideological basis for specifying who is entitled to inherit properties and responsibilities to care, and who is not, is infused in day to day practices. Although sisters are anxious to provide care to their siblings with CP after they are married, they are subtly pressured or coerced to relinquish that role. Take Linda as an example, her father excluded her as a lawful heir by transferring the entire family estate to the sons so that there would be no inheritance at the time of the father's death. However, she did not agree with that arrangement as her brother barely knew anything about how to provide care to his sister with CP. Experiencing pressure to conform to the patriarchal norm, she stifled her voice and desire to care, and ‘dared not’, according to her words, advocate for her rights to family inheritance and to be the one to provide care to her sister with CP. Other participants, such as Cherry and Rose, also chose to accept the arrangement silently, but indicated little resentment. They believed that they should sacrifice the right to family inheritances in order to let their brothers have sufficient funds to take care of their siblings with CP. Sisters' experiences in this study reflect Taiwanese women's vulnerability in patriarchal systems in that their right to family inheritances and their wish to provide care to their siblings with CP after marriage is denied.

Although there was some variation in sisters' reaction to the fact that only the brothers would inherit family inheritance and responsibility, all participants agreed with the rule that the one who shoulders the caregiving responsibility in the future deserves to be compensated. None of them claimed that the care that they had provided with feeding, bathing, interpreting, and accompanying, or the love and commitment that they had demonstrated to that point, was as important as future caregiving responsibility. In other words, sisters in this study do not believe they deserve family properties by law like her male counterpart who has been designated with future caregiving responsibilities. Informed by liberal feminist school's argument, that women's care has been devalued and badly rewarded, and that this contributes to gender inequity (England, 2005). The ideology underpinning the sacrifice to the family inheritance that these women have made must be challenged. For decades, sisters assumed caregiving roles for their siblings who needed emotional support, protection, assistance with daily living, and interpreter services. The patriarchal system takes these contributions for granted and responds either with nothing or with a small dowry when the sisters get married. When a sister marries “out” of her natal family, she marries “in” to her husband's family to take over the caregiving work there. Obviously, in the patriarchal system, women's labour is not compensated, is treated as exchangeable and is not valued. The culturally constructed image of the gentle, virtuous, and persevering married woman who devotes herself to her husband's family and eschews her legal right to inherit family properties is a discourse loaded with patriarchal justifications for maintaining status quo. The cultural belief systems overlook, neglect, and ignore women's contributions and operate for the benefit of men and to ensure the optimal functioning of the patriarchal system.

In summary, families - families of origin and husband's families - are the location where the patriarchal structure exercises its power and exploits women's labour. Until the reasoning and the ideology behind the patrilineal beliefs are challenged, women's rights will forever be denied, and women's contribution to the family will never be valued or appreciated.

7.3 The Impact of Anticipatory Caregiving to Unmarried women

Caregiving to their sibling with CP not only affected the past and the present of the participants of the study, but the future of these women. As mentioned earlier, Bowers (1987) developed a typology of five types of care that are not as visible as instrumental care. In that typology, anticipatory care can begin many years before any actual help is required. This kind of care is invisible, but can have a profound effect on the caregiver’s life for their major life decisions.

Several sisters in this study expressed their wish to live with or near their siblings with CP in the future. This had an impact on their choices, even chances, regarding current and future husband candidates. In order to maintain their caregiving identity, sisters needed to be physically present in the life of their sibling with CP. Interpretation related to speech impairments, protection from strangers' bullying or teasing as well as caregivers' abuse and neglect, required sisters to be physically present to monitor possible risks. However, the patrilocal system bestows upon husbands the right to decide, according to the best interests of his family of origin, where and how his wife and children will live. Even under the protection of Civil Code 1002, which states that the domicile of the husband and the wife shall be decided by mutual agreement, social practice indicates that there is an expectation that wives move into their husband's home after marriage.

Single women, through listening to stories and interaction with parents, relatives, family and media, have constructed an image of a married woman's identity. Their ideas of power relations in marriage lead them to anticipate what will happen in their future marriage. Sisters' anticipatory care to their siblings with CP leads them to believe that they must give up some of the good husband candidates who or whose family members may insist on the patrilocal ideology. They want to avoid the consequences that the patriarchal system is likely to exert upon them, that is, being pressured by their husbands or husbands' families to move away from their siblings with CP. Therefore, when sisters plan to stay nearby their siblings with CP after they get married, choosing a man with less patriarchal beliefs, especially patrilocal beliefs, becomes a priority for them.

As delineated earlier, in the traditional Chinese patriarchal family and society, the belief in the five cardinal relationships is critical. These five relationships are those between father and son, ruler and subject, husband and wife, elder brother and younger brother, and friend and friend. The rules for each dyad specify the protocol for appropriate behaviour according to the position occupied. In this sense, before a woman gets married, the most salient role to her should be a daughter within her own natal family; when she is married, the most salient one to her should be a wife within her husband's patriarchal family unit. It means when a woman's marital status changes from single to married, the most salient role as a wife which should take precedence across multiple situations. Therefore, for a woman who proclaims it is not possible to follow the protocol of submission in her role as wife because her sibling with CP takes priority over her husband is acting against the expectation from society and may be placed under tremendous pressure from others and herself (Thoits, 1991).

Individuals are constantly exposed to discourses and examples that validate and reinforce what behaviours are appropriate for a married woman in a traditional Taiwanese family. The findings of this study indicate that the discourses of parents, relatives and the mass media, as well as the experiences of the participants and their friends, represent society's expectations that a married woman will be submissive and self-effacing for the sake of her husband's family. Given that Taiwanese society continues to reflect conventional gender expectations, it is possible that women in this study did not consider themselves able to resist these pressures. Thus, when they chose husbands, or considered the process of choosing a husband in the future, they tended to restrict themselves to men and their families who held less strong patriarchal beliefs in order to avoid facing complex and contradictory situations.

Although it may appear that these sisters ‘voluntarily’ excluded future husband candidates who would not accept their condition of placing their siblings with CP and natal homes as a priority, these sisters have actually been forced to restrict themselves to men who were and whose families had more flexible images of married women. Sisters in this study were aware that once married, a woman must sever formal ties with her natal family and that she would be situated toward the bottom of her husband’s family through the interaction within “enduring, normative, reciprocal relationships with other people” (Thoits, 1991, p. 103). Prospectively, they will hardly have an opportunity to help their natal family unless those with authority in their husband’s family allow them to do so. Therefore, when sisters choose to rebel against exploited lives in patriarchal families by refusing to step into the families that practice principles of patriarchal genealogy that position daughters-in-law at the bottom of the family hierarchy, they are actually sacrificing opportunities and limiting their options for their future marriage.

7.4 Gendered Care and Career Choice

Jobs in the caring fields or plans for such careers were overrepresented among the women who participated in this study. Women in this study chose or intended to choose work related to caring - such as social worker, teacher in the field of inclusive education, or homemaker. This finding is consistent with the findings from other studies (e.g., Lackie, 1982; Lackey & Gates, 2001; Phillips, 1997; Poznanski & McLennan, 2003) that have similarly documented how women with caregiving histories tend to choose caring or helping professions as their career. In an early study in this field, Lackie (1982) examined the histories of 1577 social workers and found that two thirds have had histories of caregiving roles in their personal life. Another noteworthy study compared the childhood and adolescent experiences of a group of nursing students to the experiences of a random group of individuals not involved in the helping professions (Phillips, 1997). A significantly higher proportion of student nurses reported adverse experiences in their childhood and teen years than did the individuals who are not in the helping professions. The student nurses reported a range of challenging circumstances in their early lives, including the death of a parent or sibling, the long-term illness of a parent, parental divorce, and a major family accident or disaster. In a similar vein, Lackey and Gates (2001) found that half of the female respondents in their study of 51 former young caregivers entered the caring or helping professions. The above studies were all conducted in the United States.

In a recent study conducted in Melbourne, Poznanski and McLennan (2003) interviewed 103 psychologists about factors associated with their choice of theoretical orientations in their counseling practice including cognitive-behavioural, psychodynamic, family-systemic, and experiential. Among the family-systemic psychologists, the most frequently reported family-of-origin experience was that of having to take some form of responsibility for other family members at a young age. A majority of respondents attributed their choice of a family-systemic orientation to such family-of-origin experiences.

Chodorow (1978) concluded that early childhood socialization experiences and the mother’s central role contribute to the sexual division of labour that underlies these women’s career choices. She argued that male and female roles were reinforced in children through different relationships between mothers and sons or mothers and daughters. Women, as mothers, produce daughters with mothering capacities and the desire to mother. By contrast, women as mothers produce sons whose nurturing capacities and needs have been systematically curtailed and repressed. Sisters in this study learned early that females are the major providers of care. They claimed men are not interested in caregiving activities. Furthermore, the cultural norms in Taiwan influenced by the Confucian patriarchal system do not encourage men to actively participate in caregiving activities. As a result, brothers are excluded from the caregiving works, especially emotional caring. McGraw and Walker’s (2007) study which analyzed 10 in-depth qualitative interviews to understand how nondisabled sisters understand themselves and their siblings with developmental disabilities report similar findings. They found each of the women in their study made sense of herself within a cultural milieu that required women to care for people with disabilities. They excused the men in their lives for not being involved with their siblings with disabilities. They reported that their fathers had been busy working to make a living and that their brothers were embarrassed or not around much when they were growing up. Both studies revealed that women had internalized the sexual division of labour in their families and in their culture, and complied to the gender system that required mothers and sisters to engage in family care.

Another way of understanding the significant role that caregiving activities played in these sisters' lives is that early caregiving experiences may have exerted their influence on adult career choices because the young caregivers were prevented from reaching their fullest potential (Lackey & Gates, 2001). In order to help maintain the family or to serve the family member who was in need, the children compromised their own needs, had no time for leisure, interests, and academic activities that would have facilitated development of their full potential. This argument was support by the findings of Chase, Wells, and Deming's (1998) study which examined the extent to which young adults perceived their having assumed a parentified role in their family of origin as a function of academic status and classification as children of alcoholics or nonalcoholics. They found that participants with low academic status reported greater caretaking responsibilities and scored more highly on parentification measures than students classified as having higher scholastic aptitude. Lively, Friedrich, and Buckwalter (1995) reported that schizophrenia also significantly affected sibling participants, particularly in the area of interests and leisure, even though no participant was a primary caregiver at the time of the study. Lack of engagement in leisure activities may have kept the siblings from developing their full potentials. In other words, caregiving work may have overshadowed what could have otherwise been pleasurable leisure times and may have deprived these women of opportunities. From this perspective, it could be hypothesized that caregiving work prohibited these sisters from expanding their interest, discovering their merits, and investing time in multiple activities, limiting their access to career choices that lay outside that of the traditional feminine career path they had taken.

Maternal feminism (Baines, 1998b) provides a different theoretical framework for understanding women's motivations that underpin their caregiving career choices. In the discourse of participants of this study, some of the sisters revealed their intention to obtain and increase their autonomy by choosing caregiving as a career. In Chinese traditional patriarchal systems that dictate family continuity through the male line, women belong to her husband's family after marriage and it is no longer appropriate to invest her time and energy in their natal home. In order to fulfill her desire to continue looking after her sibling with CP in the natal home, Melody, for example, took on caregiving as a job which brought in income that was paid by her sister with CP to her husband's family. This legitimized her role and provided her with the opportunity to provide care to her sibling with CP. Singing had a similar intention. To maintain her autonomy and right to provide care to her sibling with CP, she planned to build up a sheltered employment program where she could earn an income at the same time as she looked after her brother with CP as well as others like him. In other words, these sisters chose a career that would allow them to work around the constraints of the patriarchal system in providing care to their sibling.

In sum, Chodorow's theoretical development and maternal feminism provide us with ways of understanding why these sisters chose to commit themselves to collective caring at the familial and community levels in their adult lives, and to have no intention of pursuing more diverse avenues for their career. Providing care to their siblings limited opportunities during formative years that could have been filled with experiences leading to different career paths. From the perspective of maternal feminism (Baines, 1998b), caregiving career choices that these Taiwanese women have made is a strategy to obtain or maintain autonomy and to continue providing care to their siblings with CP. Taiwanese women have and experience no entitlement to decide whether to provide care to their siblings with CP after marriage. The implications of this will be discussed in chapter 8.

CHAPTER EIGHT
CONCLUSION

This study has attempted to look inside sisters' lived experiences with a sibling with CP in order to understand their caregiving identities and how their caregiving identities are constructed in a Taiwanese context. It fills a gap by providing material on sisters' accounts, who remain very much a hidden population. In the next section, I will discuss the implications of this study from the perspective of research, practice, and policy.

8.1 Implications for Research

8.1.1 Contribution to the Existing Body of Literature

This study adds to the body of caregiving knowledge in a number of ways. First, it examines how the care of siblings with CP intersects with the various roles that women hold (sister, daughter, spouse or future spouse) and contributes to a number of tensions that these sisters must resolve in order to come to terms with and express their caregiving identities. Sisters in this study experienced emotional strain with their mothers when they performed their caregiving identity as transformer which challenged their mothers' abilities of giving care to the siblings with CP. They also experienced tensions with their husbands (or future husbands), and sought to resolve the tensions by taking the caregiving to the siblings with CP as a job to legitimize their role or to choose a caregiving career to maintain their autonomy and right to provide care to their siblings with CP. It reflects a traditional cultural belief of Shan-Shia (up-down) that require sisters to obey and honour mothers' strategic knowledge and skills and culturally prescribed norms of gender roles to a married woman that favour the husband's family.

Second, it examines these roles and processes in a Taiwanese context using a feminist theoretical lens. Three phenomena in this study explicitly address the culturally based assumptions and challenges that these women face. First, when sisters engage in acts of protection, these take place in a cultural context where culturally prescribed norms inform what they should or should not do. Their desire to protect from harm is particularly challenging when the one their sibling must be protected from is a female family member. Sisters resolved this by appealing to male family members. Although this was successful, male patriarchy was reinforced. Second, as informed by maternal feminism, women pursuing a caring profession is one of the strategies that Taiwanese women use in a patriarchal system to obtain the right to provide care to their siblings with CP after they are married. Lastly, while unmarried sisters internalized patrilineal concepts that refer to issues regarding the legitimacy of heirs to property inheritance and family responsibilities, with the exception of one participant, all of the others in this study accepted that they would no longer provide care to their siblings with CP after marriage and accepted to denial of inheritance of family properties. They did so with silence and little apparent resentment. These phenomena reflect women's lack of conscious awareness of the value of their contributions to their families and to their siblings with CP as well as a total lack of entitlement to inherit family property and the right to proivde care to their siblings with CP like their counterpart male siblings.

This study has brought together Western-based theories and Eastern-based philosophies in an attempt to understand the emerging nature of caregiving identity in Taiwan. Women's caregiving role was constructed through the socialization experiences within mother-daughter relationship (Chodorow, 1978) as well as a focus on traditional cultural believes of Nei-Wai (inside-outside) concerning the nurturing tasks ascribed to women. Caregiving processes that sisters engaged in, such as interpretation and sacrifice have been constructed by cultural beliefs embedded in the latter. They internalized the concept of sexual division of labour to provide care to their siblings with CP and to excuse their brothers from caregiving work. The disproportionate energy and time that sisters have invested in providing care to their siblings with CP has compromised their own lives in ways that even they are not aware of.

Lastly, along with the trends of globalization, societies around the world are becoming multicultural (Rothenburger, 1990). Within a culturally diverse society such as Canada and United States, policy makers and service providers must deliver a service that is culturally sensitive and appropriate to meet specific needs of diverse ethnicities in their society (Narayanasamy, 2005). This study contributes to the recognition of cultural needs related to Chinese ethnicity in multicultural societies (Cortis, 2003, Duffy, 2001, Holl& & Hogg, 2001, Price & Cortis, 2000 & Fletcher, 1997) and provides guidelines in understanding how sisters respond to caregiving demands they encounter and how culture influences the way care is provided to their siblings with CP in a Chinese culture (Dilworth-Anderson, Williams, & Gibson, 2002). As such, the results of this study will allow researchers, policy makers, and practitioners to accurately interpret the meaning and nature of care, and provide appropriate support to sisters of siblings with CP that is based on Chinese cultural knowledge of care beliefs, values, and practices (Leininger, 1997).

8.1.2 Limitations of the Study & Suggestions for Future Studies

One of the limitations of this study rests in the sample, as the participants in this study were drawn mainly from social service agencies. As such, they have better access to social services resources and information than most people. Perhaps, their positive relationships with the social service agencies they were affiliated with is reflected in the extent to which jobs in the caring fields or plans for such careers were dramatically overpresented among the women who participated in this study. Moreover, previous research has demonstrated that family-centered early childhood intervention practices that involve family decision-making and action had positive effects on the well-being of parent and family (Dunst, Hamby & Brookfield, 2007; King, King, Rosenbaum, & Goffin, 1999). It is unclear to what extent the affiliation with these social service agencies influenced sisters' experiences and caregiving identities. Future exploration of the caregiving experiences of sisters who have fewer opportunities to access these resources would enhance our knowledge of caregiving.

The second limitation of this study rests in the strategy of member checking. In the study design, I decided to invite all of the participants to read and react to transcripts of their own interviews, rather than returning the results to them for verification. Although this strategy enabled the findings of this study was not limited in a descriptive level and confined in participants' individual concerns (Morse, Barret, Mayan, Olson, & Spiers, 2002), however, it also excludes participants with an opportunity to confirm accurate interpretations, correct errors, and challenge what they consider incorrect interpretations by the researcher (Dolye, 2007).

Religion is considered to be a powerful force that shapes human experience and identity. Nightingale (2003) conducted a qualitative research to interview five African-American and five white caregivers of persons with Alzheimer's disease. The findings of Nightingale's study reveal that all caregivers felt their spirituality and/or religious practices shaped how they approached providing care. Moreover, most of the participants stated that religious practices and spirituality affected how they felt about providing care and that religion and spirituality helped them deal with difficult challenges. Pearce, Singer and Prigerson's (2006) quantitative study investigated the association between religious coping, mental health and the caring experience, as well as potential explanatory mechanisms among 162 informal caregivers of terminally ill cancer patients. The results indicated that more use of positive religious coping strategies (e.g., seeking spiritual support, seeking a spiritual connection, collaboration with God in problem solving, religious forgiveness and benevolent religious appraisals of the stress of the caregiving role) were associated with more burden, but also more satisfaction. In contrast, greater use of negative religious coping strategies (e.g., assessed punishing God appraisals, interpersonal religious discontent, demonic appraisals, spiritual discontent and questioning God's powers) were related to more burden, poorer quality of life and less satisfaction, and was correlated with an increased likelihood of depressiong and anxiety, Given the important role that religion plays in the lives of people who experience adversity, the fact that religion did not surface as major theme in the findings of this research is somewhat surprising. In order to have a better understanding of the importance of different coping mechanisms among caregivers in religion, it seems beneficial to explore the intersection of religion and caregiving identities in future studies which may facilitate more sensitive care to caregivers of diverse religious groups.

As parents age and die, many siblings may be faced with having to make decisions for their brother or sister with CP. They might encounter disagreements in making decisions about medical treatments, purchasing if formal services or placement of the siblings with CP in long term care facilities is needed. There is a need for more research about siblings' decision-making processes as well as an examination of the role that contextual factors, such as siblings other obligation engagements, financial ability, or perceived social pressure, play in influencing the nature of decisions made and how these decisions are made.

Lastly, while this study examined caregiving identities of sisters of individuals with CP, it seems also important to explore brothers' caregiving identities to their siblings with CP. For example, in what ways do brothers provide care to their siblings with CP, and under what situations do brothers would relinquish their responsibility to provide care? This kind of study would contribute to understanding brothers' experiences of having a sibling with CP and their experiences of conforming to or going against social expectations that bestow responsibility on men.

8.2 Implications for Practice

The findings of this study imply that gender socialization plays an important role in the gender imbalance in taking on caregiving responsibilities. I argue that this type of practice is costly both for women and men. In order to move toward a more equitable division of caregiving responsibilities, it is important to promote nonsexist socialization and education to children. For example, families, teachers, curriculum, picture books, school books, and the mass media should depict adult women and men acting in more gender-neutral ways; men and women in video games can also be designed in nontraditional roles (Lorber, 1998). Moreover, providing women with affirming female role models, teaching women to critique gendered power relations, deconstructing gendered discourses in the family, school, and media are viable and effective strategies to awaken women's awareness.

Counseling and promotion of more equitable sharing of caring tasks by men and women in the family would help women not feel so trapped and compelled to provide care. Engaging fathers and brothers to increase their involvement and participation increases their capacities and competence in providing care. Sisters can benefit developmentally from sharing caregiving tasks. Mothers can also be relieved from heavy caregiving loads, decreasing their emotional stress that contributes to perpetrators of neglect and even abuse.

I also recommend a family-centered approach that focuses on meeting the needs of, and addressing all family members may facilitate the development of resilience. However, this approach needs to be used with caution within the cultural context of Taiwanese culture that emphasizes “face saving”. In order to save face, Taiwanese families with a child with cerebral palsy may try to hide such a fact from others. In some sense, a family-centered approach goes against the desire for such family secrecy because the approach requires families to make the information public, thus making these families reluctant to seek help. As such, practitioners may need to focus on concrete benefits that the families can garner from participating in a program when they advertise the program in order to counterbalance the possible hesitation that these families may experience. For example, parents may benefit from interventions aimed at enhancing their parenting and caregiving knowledge and skills which may exempt sisters from being a transformer and easing their tense relationships with mothers. Substantial strategies include helping families improve their communication, decision-making, and conflict-management skills when they encounter problems or have disagreement in caregiving methods or placement issues (Nosek *et al.*, 2004). The delivery of long-term care services is highly fragmented in Taiwan. Given the co-morbid conditions that individuals with CP presents with as well as the unique needs and values that each family holds, the effective delivery of long-term service is challenging. Families are often left to sort their own way through the health and social services delivery systems. Coordinating services such as personal care, respite care and/or day care to optimize their availability to families and providing families with knowledge about services they need would also be a preventative strategy to alleviate the burden (Nosek *et al.*, 2004).

8.3 Implications for Policy

The results of this study challenge assumptions embedded in long-term care policy in Taiwan. There is a decided absence of support services available to help families to provide care to persons with disabilities at home. Taiwanese long-term care policy emphasizes the delivery of institutional services ignoring what is needed support in-home care. As a result, home care is provided with a limited budget and over restrictive means-test procedures make it difficult to access. Barriers such as these are in contradiction to preferred living arrangements that are commensurate with values of care and cohabitation that are part of the traditional culture of Taiwan. Family members, especially female family members, pay the price for this gap in long-term care policy. Therefore, long-term care policy in Taiwan should be adjusted to reflect these values simultaneously paying attention to the burden that falls upon female members of the individuals with disabilities or terminal illness. In designing and implementing long-term care policies that address the unique characteristics of Taiwanese society, policy makers need to allocate more funding to build a comprehensive system of home-based care services.

Worth noting is, while the policy of home-based care services may be in line with social norms that value providing care to frail family members at home, this policy may perpetuate gender imbalance in caregiving. In other words, women, who have been seen as the “natural” caregiver, will inevitably be recruited to provide care. Thus, a policy of home-based care services may reinforce feminization of caregiving. One of the ways to counterbalance this problem could be to provide allowances directly to caregivers via social security and tax systems, proper wages paid by state or state agencies, or symbolic payments through care receiver to their caregivers (Ungerson, 2000). The financial assistance can help caregivers, whether men or women, to establish or maintain financial independence, thus keeping them from providing care without appropriate compensation .

Previous studies described caregiving as instrumental or emotional. The participants of this study provided a wide range of caregiving experiences that involved practical tasks, instrumental help, caring through interpretation, protection, transformation and sacrifice to advocate that their siblings with CP achieve a state of optimal physical, emotional, mental and social health. Achieving these outcomes requires physical care, time and emotional labour by sisters that have, until now, been invisible in Taiwanese society. In order for equity in sexual division of labour to be achieved, a redistribution in the responsibilities assigned to women, to men, to states, and to markets is required.

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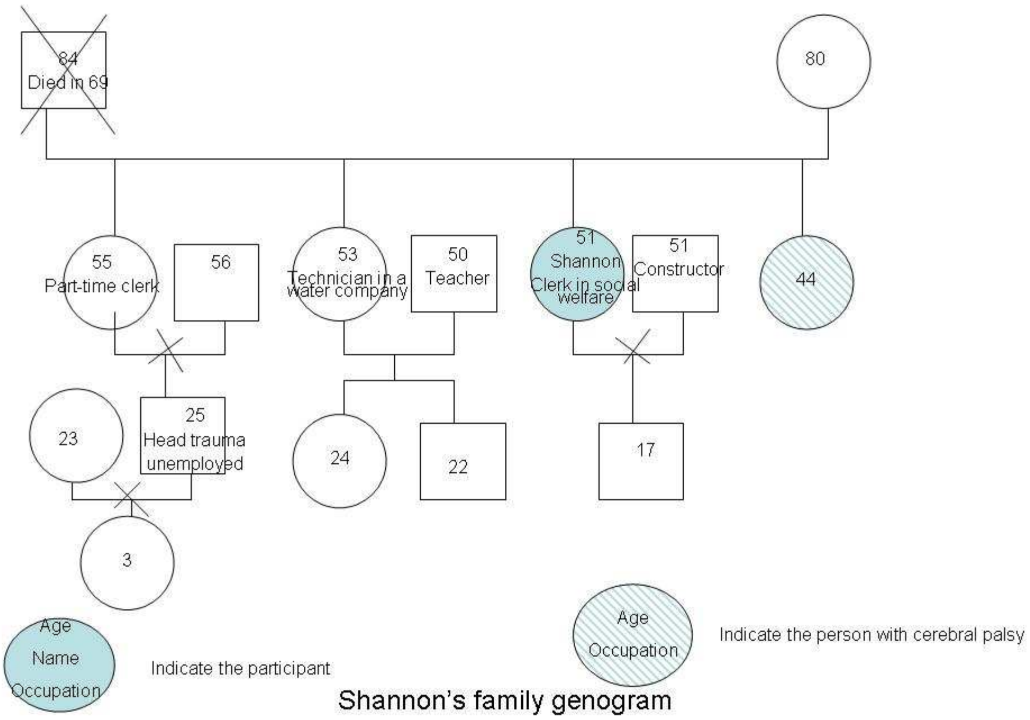
Appendix A
Autobiography and Family Genogram of Participants

Shannon

Shannon is a 51-year-old single mother who lives with her 17-year-old son in an apartment. She works as a clerk in a foundation that provides services to people with disabilities. After work, she attends social work classes at a university.

Shannon has a sister with quadriplegia CP. Her sister has trouble moving all the parts of her body. Her arms, legs, and trunk are all affected, so she needs a wheelchair to help her get around. She also needs someone to help her with ADLs such as toileting and grooming. In order to obtain the care that her sisters needs and services, Shannon and her eldest sister have decided to place the sister with CP in a long term care facility. The fees for the residency in long term care facility are funded by veteran systems for her father used to serve in the military until he passed away.

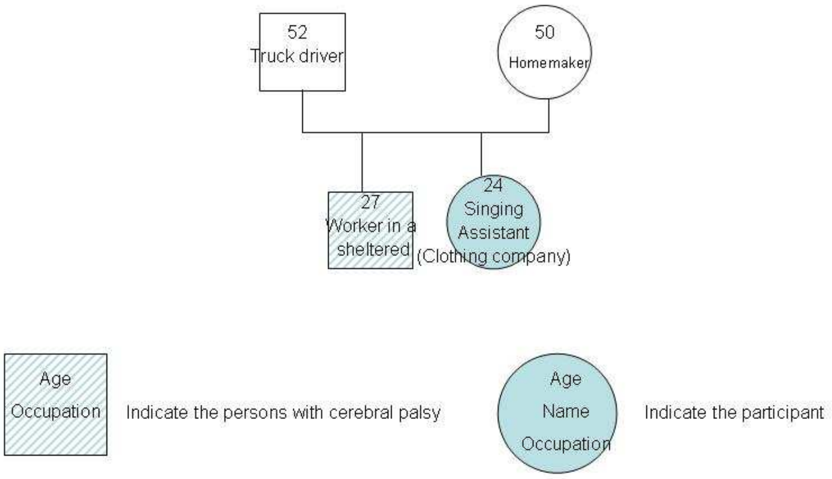


Shannon's family genogram

Singing

Singing is a 24-year-old woman who graduated from a university last year. She is an assistant in a clothing company. Singing’s brother is currently enrolled to a sheltered employment program, in which persons with disabilities worked in a self-contained unit, not integrated with nondisabled workers. In that program, individuals perform subcontracted tasks such as sewing, packaging, collating, or machine assembly. They are usually paid on a piece-rate basis.

Singing currently lives with her parents and her bother with CP. She is interested in helping people like her brother and plans to obtain a social work degree in order to establish a sheltered employment program in the future.

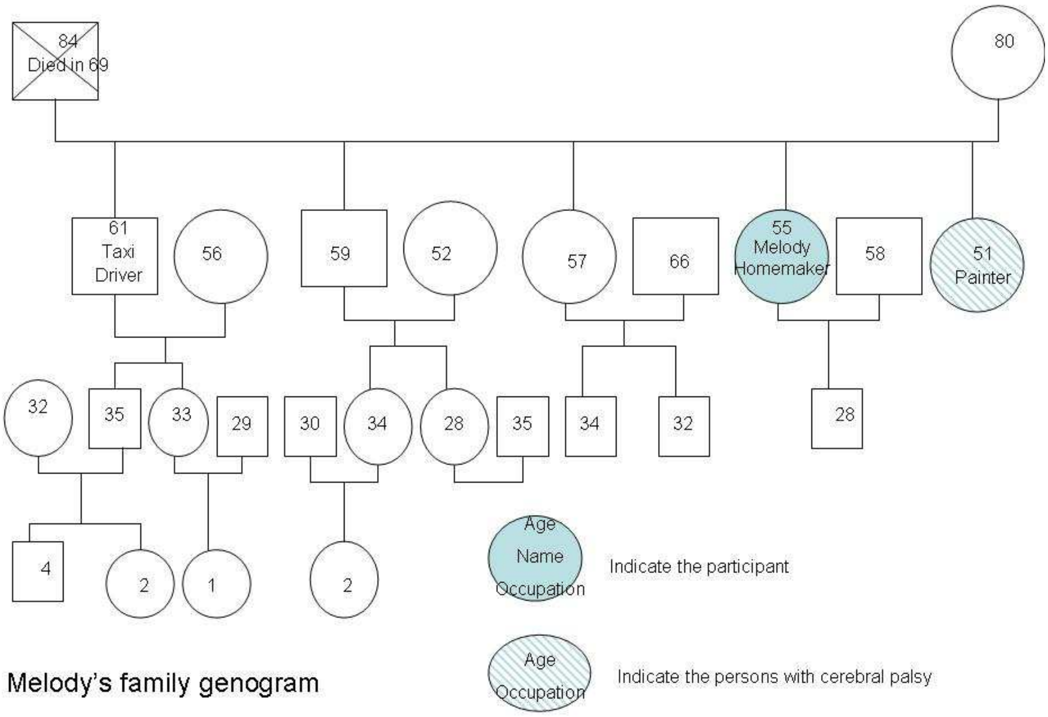


Singing’s family genogram

Melody

Melody is a 55-year-old housewife. She and her husband and their 18-year-old son live in a family compound that houses her parents and each of her siblings' families in separate apartments. Melody's sister with CP was born in an era when medical resources were not readily available and it was easy to be infected by contagious diseases. Her sister's CP was caused by encephalitis and a blood transfusion mistake.

Melody's sister with CP is an artist. She joined a company called The Mouth and Foot Painting Artists when she was 32 and has had a stable income since then. The company reproduces her paintings on commercial items such as post cards. Melody's sister encountered a major problem when she joined the company. Because of her speech limitations, she was not able to be interviewed by the media or participate in exhibitions to promote her art. To help her sister with these vital income related activities, Melody has been recruited to be her agent and major caregiver since then.



Melody's family genogram

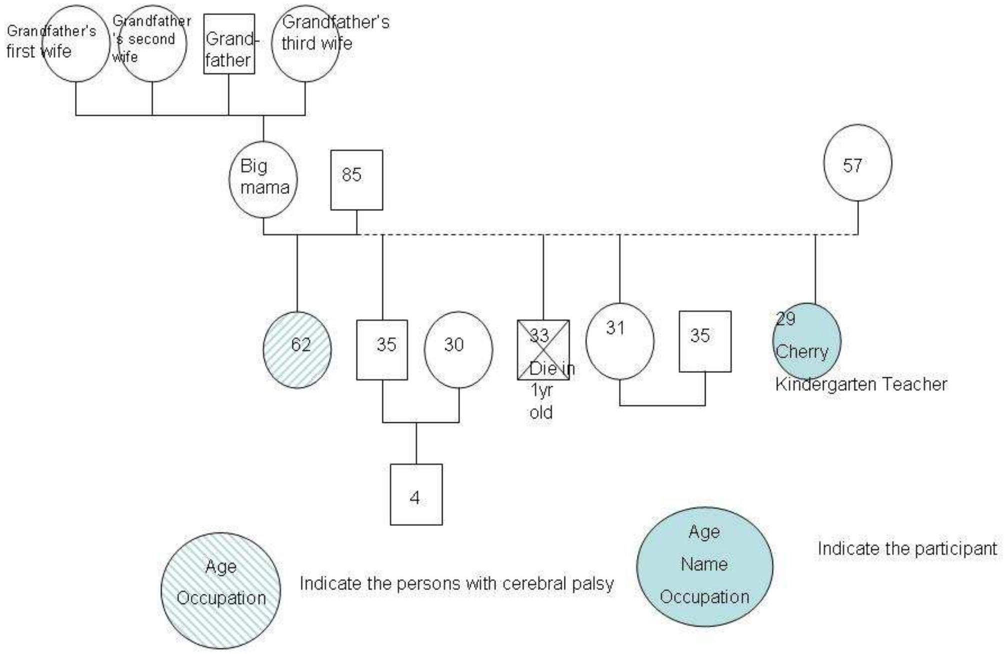
Cherry

Cherry is a 29-year-old kindergarten teacher. Her father is a doctor in central Taiwan. He has two wives and four children. Cherry’s big mama (her father’s legal wife) came from a distinguished family. Not long after she married, Cherry’s big mama suffered complications during childbirth, and her daughter was born with CP. The big mama had no other children.

When Cherry’s sister with CP was 26, the grandmother on her father’s side demanded that Cherry’s father take a concubine in order to produce a male heir. Feeling under pressure because having no descendants was considered the biggest sin in a Chinese family, the couple agreed to find a concubine to help them meet their obligations to the family. This is how Cherry’s mother became her father’s concubine.

Cherry’s mother’s first two children were boys. This made the paternal grandmother very happy. Unfortunately, the second boy passed away as the result of an accident. The grandmother urged Cherry’s parents to have more male descendants. After Cherry’s mother gave birth to two daughters (Cherry being one of them), her parents decided to stop trying to produce male descendants.

Cherry’s half-sister with CP sister has no mobility. She can neither feed nor dress herself. The only thing she can do is raise her hand. The sister with CP used to have three caregivers: the big mama’s mother, a male caregiver, and a female caregiver. After the grandmother passed away and Cherry’s second sister moved to the United States with her husband, Cherry became the one who helped her CP sister communicate with the outside world.



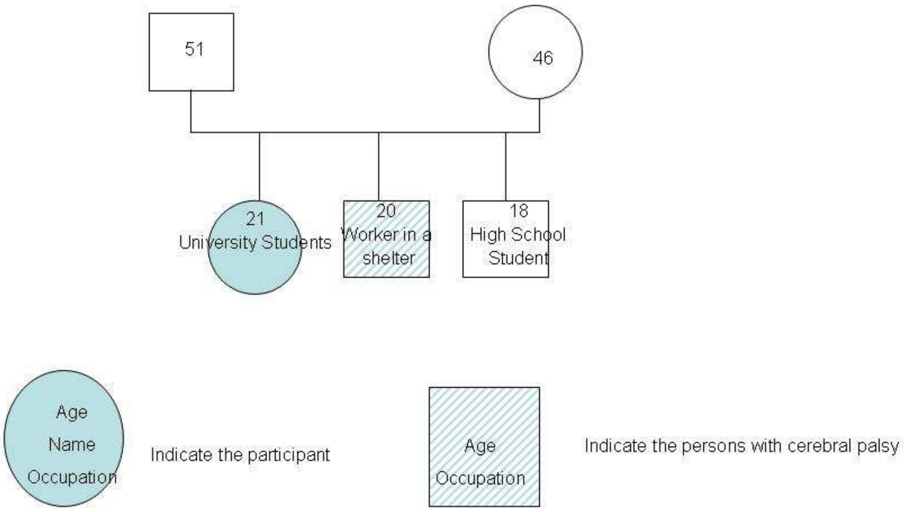
Cherry's family genogram

Rose

Rose is a 21-year-old woman who just obtained her college diploma in English translation. She was preparing for the university admission test at the time she was interviewed. There are five members in her nuclear family. Rose’s father is a builder, and her mother is a formal caregiver who provides respite care for seniors with dementia.

Rose is the eldest daughter in her family. She has two brothers. Her youngest brother is in the second year of high school. The brother with CP is a year younger than Rose. He is currently participating in a supported employment program and is working at a gas station. In that program, several persons with disabilities are trained and supervised in a small group and work alongside nondisabled employees.

Rose’s brother with CP had jaundice as a newborn and suffered brain damage as a result. He manages his daily activities slowly but successfully. The major challenge for him is his speech.



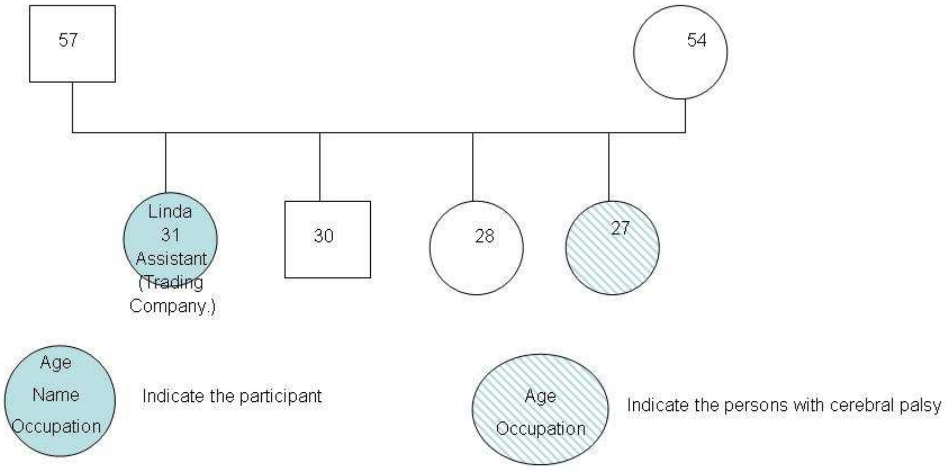
Rose's family genogram

Linda

Linda is a 31-year-old single woman who lives with her parents and her two sisters. She works at a trading company near her house. Her parents are tobacco farmers, and her 28 year-old-sister works in a factory. The 27-year-old sister is the one who has CP.

Linda has a brother who is 29 years old. He graduated from a prestigious university and holds a master's degree. He works in a high technology company as an engineer. He lives in another city and visits his parents' house once or twice a month.

The etiology of Linda's sister's CP has never been confirmed. The symptoms at the time of onset were high fever and seizures. The sister with CP has quadriplegia and needs assistance with diaper changing, feeding, bathing and toileting.



Linda's family genogram

Appendix B

Researcher’s Autobiography and Genogram

The Bodyguard of My Eldest Sister

I was the third child of a Taiwanese family in the 1960s. My eldest sister was a blue baby—a baby with a congenital heart malformation that robs the blood of oxygen. This life-threatening condition is often signaled by a bluish cast to the skin.

Luckily, my sister had corrective surgery to fix her problem when she was five. However, it seemed that although the surgery saved her life, it did not improve her health much. Her skin still turned blue, sometimes purple, especially when she got mad at me. When my sister and I had a fight, it was always I who surrendered first, because I was so afraid of seeing her skin turn blue again.

Looking back at the fear that accompanied me throughout childhood, I realize that my parents never blamed me or punished me for making my sister’s skin turn blue. Actually, I was afraid that if my sister died, all the money my parents had invested in her would be in vain. From the day I learned that my parents had borrowed a lot of money from relatives to save my sister’s life and carried the debt for a long time, I not only tried hard to avoid conflicts with my sister, I also tried to protect her at school and did not allow people to offend her in any way. My life was pretty much that of a bodyguard to my sister until she got married at the age of 20.

My Niece and Her Brother with CP

My niece was expecting a present she had been awaiting for many years: the baby brother her mother had promised her. She was unprepared for the loss of her mother. I was also unprepared for the loss of my sister. What should have been a happy occasion—seeing a baby coming into the world—became a tragedy.

When I saw blood all over the labour room, my intuition told me that I was losing my sister. After a long wait, a doctor told us that my sister suffered from amniotic fluid embolism. A blood clot was carried through the blood into my sister’s pulmonary artery, plugging a vessel within the lung and causing acute respiratory distress syndrome. No one except medical personnel were allowed to see her after she came out of surgery. From a remote distance, I saw lines and tubes all over her body. My brother-in-law, my parents, and other relatives and friends stayed in the hospital, wishing to give her strength to fight for her life.

My brother-in-law asked me to pick up my six-year-old niece at the nanny’s house and stay with her. One day, the paediatric intensive care unit of the hospital urged us to sign out the newborn baby, whose critical situation had been stabilized. The doctor warned us that the baby had suffered from anoxia for more than five minutes during the labour. It was very likely that he would develop neural symptoms after we took him home. Neural symptoms? The scary terminology made everyone reluctant to volunteer taking care of him before his mother got better. Suddenly, I felt a little hand pulling my shirt. I saw the small pretty face of my niece looking up at me as if to say, Please, please let’s take him home with us.

Thus I became the substitute mother of my niece and nephew. I took the two children to my home. My parents were not happy about the arrangement, because they thought the children were the responsibility of my brother-in-law’s family, especially because giving that family a male baby had caused my sister so much suffering. However, because the arrangement was to be only temporary, my parents did not argue much.

My sister passed away two months after she gave birth to my nephew. My brother-in-law was deeply grieved. After the funeral, I did not ask him if he wanted to take the children home with him. I said to myself, “He is a man after all. He knows nothing about raising children, especially a child with a medical condition.” Thus, I took on the responsibility of looking after my niece and my newborn nephew.

As the doctor predicted, I encountered numerous difficulties that were caused by the baby’s neural damage. The baby could not suck the bottle well and had occasional seizures. The doctor gave us the diagnosis of CP when my nephew was a year old.

At the same time that the doctor gave me the diagnosis, my boyfriend’s grandfather was dying. My future parents-in-law urged me to marry their son as soon as possible. They told me that it would not be appropriate to have a wedding during the mourning period, which would last at least two years after the grandfather passed away.

I was reluctant to get married at that time, as I wished to spend more time with my niece and my nephew. However, my parents also began urging me to get married. I was 27 at that time. If I missed the chance to get married before the grandfather passed away, I would have to wait until I was 29, and 29 was a bad luck year for all Chinese people. At last, I gave in to the pressure of my elders and agreed to the wedding.

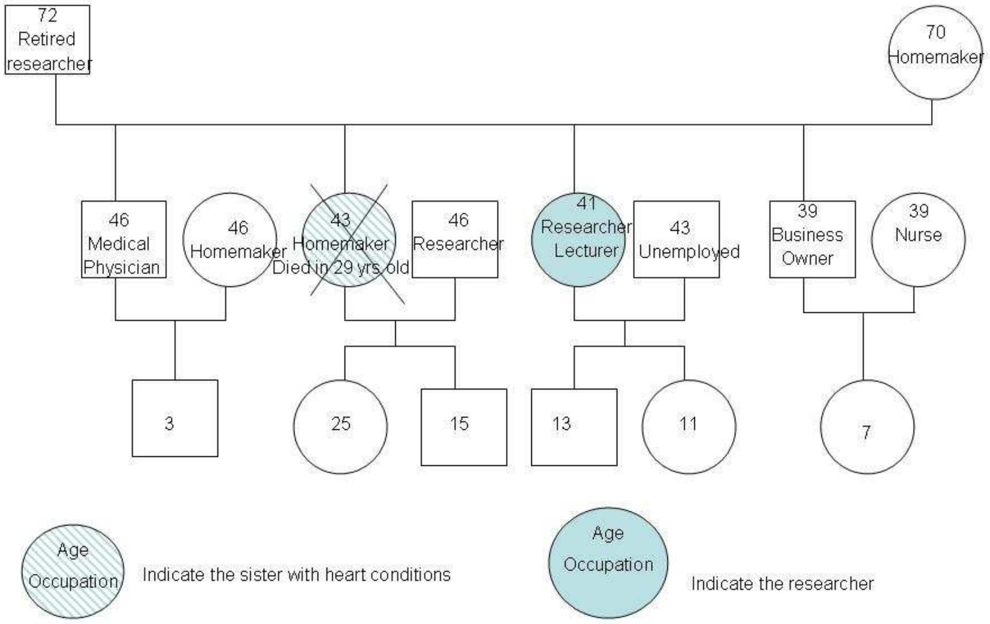
The day I got married, my niece sat beside me, holding my hand tightly as she had the first night she slept beside me. Before my husband-to-be came to take me to the wedding, I told my niece again what I had told her several times: that I loved her and her brother, but I had no right to take care of them once I married “out.” When I told her that her father would pick her and her brother up later, she burst out crying. Finally I could not hold back my own tears, and I messed up my wedding makeup.

After I got married, my niece and the nephew with CP were raised by an unmarried sister of my brother-in-law. I had my own child a year after I was married, and I saw my niece and the nephew only occasionally at family gatherings. My niece showed a talent for filmmaking when she was in high school. I encouraged her to study this specialty in college. Surprisingly, she chose physical therapy instead. When I asked her why, she told me that the film business was time consuming and the work schedule was unpredictable. She said she needed to choose a career that would allow her to look after her brother. That was the first time I realized how much she sacrificed for her brother.

Recently, my niece has been missing from family gatherings. I knew she must have encountered something major in her life. I finally reached her and had a long talk with her. She told me she needed to be alone and asked me to forgive her for disappearing from our lives. I invited her to tell me what had happened. She told me she had broken up with the man she had been dating for four years. I asked her what had happened. She said her boyfriend and all of his family were moving to mainland China. She said it was not possible for her to marry a man who would take her far away from her brother. I realized she was sacrificing herself again. I urged her to let go of her brother and pursue what she really wanted. I promised her that all of us, her three uncles and four aunts, would take care of her brother. She was silent for a few seconds. Finally she said to me, “All of you are willing to help, but who can guarantee your promise will last forever? Everything is changing. I am his sister. I am the only one who will never change.”

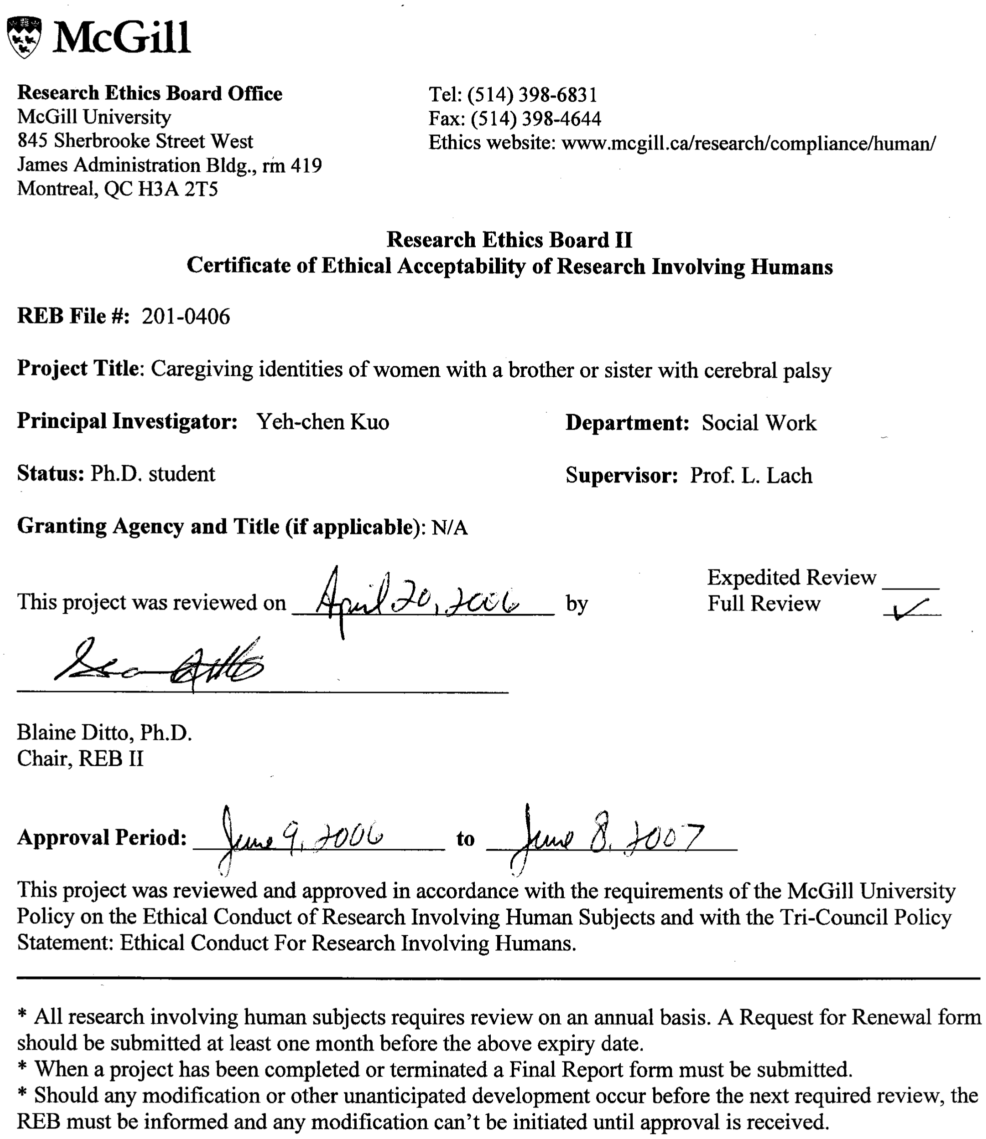
I knew what she was saying. Sixteen years before, I had betrayed her trust and abandoned her and her brother to get married. How could she believe my promises any more? I felt horribly guilty. I had betrayed not only the two children, but also my deceased sister. In failing to protect her children, it was as if I had failed to protect her.

My early experience of caring about and protecting my eldest sister with congenital heart malformation informed my actions, behaviours, and feelings later in my life. Revisiting my experiences in living with a sister with chronic illness, I recognized how I had acquired my caregiving identities, what my caregiving experiences meant to me, and what my caregiving identities were. My niece’s and my experiences motivated me to investigate the caregiving identities of women with a brother or sister with CP, and how do their caregiving identities are constructed.



Researcher’s family genogram

Appendix C
Certificate of Ethical Acceptability of Research Involving Humans



McGill

Research Ethics Board Office
McGill University
845 Sherbrooke Street West
James Administration Bldg., rm 419
Montreal, QC H3A 2T5

Tel: (514) 398-6831
Fax: (514) 398-4644
Ethics website: www.mcgill.ca/research/compliance/human/

Research Ethics Board II
Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 201-0406

Project Title: Caregiving identities of women with a brother or sister with cerebral palsy

Principal Investigator: Yeh-chen Kuo

Department: Social Work

Status: Ph.D. student

Supervisor: Prof. L. Lach

Granting Agency and Title (if applicable): N/A

This project was reviewed on April 20, 2006 by

Expedited Review ___
Full Review ✓

Blaine Ditto, Ph.D.
Chair, REB II

Approval Period: June 9, 2006 to June 8, 2007

This project was reviewed and approved in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Subjects and with the Tri-Council Policy Statement: Ethical Conduct For Research Involving Humans.

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* All research involving human subjects requires review on an annual basis. A Request for Renewal form should be submitted at least one month before the above expiry date.
* When a project has been completed or terminated a Final Report form must be submitted.
* Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received.

Appendix D
Advertisement

Yeh-chen Kuo, a Ph.D. candidate at McGill University in Montreal, Canada, is conducting a study to understand how sisters of persons with CP experience their role. If you are a woman over the age of 20 and have a brother or sister with CP, you are invited to participate in this study. If you are interested in participating in this study, please contact Yeh-chen Kuo at (03) 551-9829 or 0936-255-505. E-mail: guoyz@hotmail.com

Appendix E

School of Social Work
Wilson Hall
McGill University

Postal address:
3506 University Street
Montreal, PQ, Canada H3A 2A7

(514)398-7070
Fax: (514)398-4760

Consent Form
Caregiving Identities of Women with a Brother or Sister with CP

Dear study participant:

The purpose of this study is to understand how you experience your role as a sister of someone with CP. I am particularly interested in how other parts of “you” influence the way you experience this role.

Your participation will involve two interviews in your home or at another agreed-upon location. The first interview is expected to last about 1 hour, and the second interview is expected to last from 15 to 30 minutes. Between or after the interviews, you are welcome to contact me with any additional reflections you may have about our discussion.

Interviews will be audio taped with your permission. I will use the analysis of the interview for my doctoral dissertation and for publication. Any information you share with me will be strictly confidential. Your participation and comments will not be divulged to your family members. The electronic file of the audio recording and the transcript of your interview will be safely stored in a password-protected computer. These will be identified by numbers and will be accessible only by my supervisor and me. Neither your name nor the names of your family or friends will appear in any report.

Please check one of the following boxes to indicate whether your interviews can be audio taped. ☐ Yes ☐ No

There are no perceived physical risks associated with your participation in this research study. It is possible that discussion of how you experience your role as a sister of someone with CP and how other parts of “you” influence the way you experience your role may stimulate some uncomfortable thoughts and feelings. Should this occur, we can stop the interview to discuss what is happening, and I will provide referrals to support services that can help you. Participation in the research study is entirely voluntary, and you are free to withdraw from the study at any time without any consequence.

I would like to express many thanks for your willingness to participate in this study. Your contribution will add to knowledge that will benefit other sisters who are in the same situation as you. You may contact me at any time with questions about the study. You can also contact my supervisor. The contact information is as follows:

RESEARCHER

Yeh-chen Kuo
Ph.D. candidate, School of Social Work,
McGill University
Tel: (03) 551-9829 or 0936255505
E-mail: kuoyeh@must.edu.tw

SUPERVISOR

Lucyna M. Lach, MSW, Ph.D.
Assistant Professor
McGill University, School of Social Work
3506 University St.
Montreal, PQ, H3A 2A7
Tel #: +1514 398 7050
E-mail: lucy.lach@mcgill.ca

Date:______________________________Participant’s Signature:______________________

Date:______________________________Researcher’s Signature:______________________

Appendix F

Information on Professional Services

Organization	Services	Telephone number	Charge
Yo Yuen Social Service Foundation	Individual Counseling Couple Counseling Group Counseling Parenting Counseling	(02)2769-3319	Student: $40/hour[10] Individual: $60/hour Couple: $80/hour
Taipei Family Education Center	Family Counseling	(02)2541-9690	Free
Taipei Single Parents Family Service	Support Group Telephone Counseling Legal Aid Financial Aid Employment Counseling	(02)2558-0170	Free
Huaijen Counselling Center	Parenting Education Family/Couple Counseling	(02)2311-7155 (02)2311-7158	$50/hour
Christian Cosmic Light Holistic Care Organization_	Parenting Education Play Therapy Family & Marriage Counseling	(02) 2369-7933 (02)2362-7278	Individual: $20/hour Couple: $40/hour Family: $50/hour
Community Counseling Center, National Chanhua University of Education	Individual Counseling Family/Couple Counseling Test and Assessment/Evaluation	(04)728-9258	Intake: $20 Individual: $25/hour Family/Couple: $72/1.5hour Test & Assessment/Evaluation: $80 Individual supervision: $60/ hour

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[10] All charges are listed in Canadian dollars.

Appendix G
Interview Questions

Research Question 1: What are the caregiving identities of women with a brother or sister with CP?

1. What are your experiences of giving care to your siblings with CP?

    (a) What are the kinds of things that you do for your sibling with CP?

    (b) How were you assigned or willing to do these things? (What led you to take on this position?)

2. What does being a sister of your sibling with CP mean to you?

    (Prompt: Being a father can have different meanings for different men. One man would say he is a breadwinner, and another would say he is an educator. What does being a sister of your sibling with CP mean to you?

3. What were the messages that you received along the way that influence the meaning of being a sister of your sibling with CP?

    (Prompt: These might be messages from family members, community, cultural ideas, media, etc.)

Research Question 2: How do these women's other identities intersect with their caregiving identities?

4. How do the meanings of being a sister of your sibling with CP influence your life?

    (Prompt: For example, how do these meanings influence your social life, job, or how you look at your life?)