Restoring Harmony in the Life of Taiwanese Families Caring for Adolescents with Cancer: A Grounded Theory Study

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Statement of Originality

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

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Li-Chyun Yeh
Abstract

Adolescence is a particularly challenging period of life, and suffering from cancer compounds the challenges for the adolescent and significantly influences family functioning with respect to roles and responsibilities. Research indicates that treatment outcomes and survival rates from cancer in the adolescent population are generally poor. Most research focuses on symptom management and the identification of effective medical treatments for this group. There is a dearth of research exploring how caring for adolescents with cancer impacts on their families, particularly examining how caregiving influences family roles and responsibilities.

At the time of a cancer diagnosis, changes occur in the patterns of family functioning in areas such as roles, relationships, daily routines and interactions. In traditional Chinese society, families accept a moral duty to take care of their sick children, which is grounded in the Confucian ethical system of role relationships. Accommodating for changes in family roles and relationships continues when the unwell adolescent is discharged from the hospital and the family assumes the primary caregiving role at home. Restoring harmony, happiness and peace are significant goals in the promotion of health and prevention of illness. In the Taiwanese context this is a particularly stressful time for most families as they receive little support from community-based services in caring for their children with cancer at home.

This study used a grounded theory methodology to explore the impact of caregiving for adolescents with cancer on roles and relationships in seven Taiwanese families (27 participants), consisting of parents, an adolescent with cancer and his or her siblings. These participants were recruited from a medical centre located in Taipei in North Taiwan. This study adopted face-to-face, one-to-one, in-depth interviews to collect data, and used Strauss and Corbin’s coding procedure to develop a substantive theory that identifies the impact of caring for adolescents with cancer on Taiwanese family roles and relationships. Families described themselves as experiencing the broken chain of family life. While the threat to life was being faced, lost or disrupted, expectations of continuity and coherence seriously challenged the fulfilment of familial roles and relationships.
The study findings showed how families managed this disruption to family life by moving through a cyclical series of phases that included: confronting disruptive events; accommodating change and repairing the broken chain of family life. The ability to confront, accommodate and repair was governed by how well families managed the process of restoring harmony to everyday family roles and relationships within the Chinese cultural context. All of the families in the study thus strove to restore a harmonious family life, even when the adolescent suffered relapse, the family would revert to the first phase and start again.

The findings have implications for Taiwanese families in perceiving, adjusting to and fulfilling the altered roles and relationships associated with caring for an adolescent with cancer at home. The implications and recommendations are discussed in relation to the provision of support for parental decision making, the facilitation of supplementary services that sustain family caregiving, and suggested means for strengthening culturally sensitive community-based services in working with sick adolescents and their families. The delivery of appropriate care and services depends upon gaining insight into how caregiving influences family roles and relationships. How families manage the process of caregiving, or not, provides valuable insight required to inform recommendations for services and supports in a Taiwanese healthcare system that traditionally has not provided such assistance.
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Chapter 1  Background to Study

Introduction
Cancer in adolescents is considered a major stressor affecting development, and it raises a unique challenge for both adolescents and their families (Abrams, Hazen, & Penson, 2007). The World Health Organization (WHO) defines early adolescence as 10–14 years of age and late adolescence as 15–19 years (Tracy, 2004). Adolescents are neither old children nor young adults and they have their own socio-psychological challenges and developmental needs as well as their own unique position within the family dynamic (Tseng, Cleeland, Wang, & Lin, 2008). Because of these unique developmental needs, in recent years dedicated services for adolescents with health problems and their families have been acknowledged as important, particularly in regard to cancer treatments, which can be challenging and unpleasant, and significantly impact upon family interactions and relationships (Fiese, Spagnola, & Everhart, 2008). Compared with younger children, cancer in adolescents has shown less improvement in treatment outcomes (Ferrari & Bleyer, 2007), lower survival rates (Barr, 2007) and these Western findings are mirrored in Taiwan (Wu, Chin, Haase, & Chen, 2009).

Despite the recognised need for dedicated healthcare services for adolescents, recent studies (Ameringer, 2010; Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010) have shown that children with cancer receive a large part of their treatment at home. This places extra demands on family members who must perform a variety of tasks and manage the child's chronic condition (Klassen, Klaassen, Dix, Pritchard, Yanofsky, & Sung, 2010). This is a particularly stressful time for families. However, it is still not clear what impact caregiving for an adolescent with cancer has on family roles and relationships in the home and nor are the processes for managing change in family roles and relationships associated with caregiving well understood.

Taiwan differs from Western countries because of the strong influence of Confucianism, which values family concerns over those of the individual (Yeager, Glei, Au, Lin, Sloan, & Weinstein, 2006). This value applied to family ‘concern’ includes an expectation that families will care for their adolescents with cancer, and yet there is a dearth of literature that explores caregiving roles and relationships in Taiwan. Therefore, this study aimed
to explore the impact of caring for adolescents with cancer at home, and examine the processes of managing roles and relationships associated with caregiving in Taiwanese families.

This chapter provides the background to this study. Prevalence and survival rates from cancer in adolescents serve to illustrate the significance of cancer care for this age group. Chinese familism in Taiwan impacts upon the challenging years of adolescence and their consequential effect upon family functioning, roles and relationships. This chapter draws all these elements together to introduce the context and purpose of the study, justify the choice of research methodology and articulate a number of research objectives and questions. The chapter concludes with an overview of the eight chapters that make up this thesis.

**Prevalence of Cancer in Adolescents**

Epidemiological data indicates that certain cancers are predominantly found in adolescents. The incidence of lymphomas, leukaemia, brain/central nervous system and bone and soft tissue tumours all peak in the adolescent years (Bleyer, Barr, Hayes-Lattin, Thomas, Ellis, & Anderson, 2008). In the USA, the annual incidence rate in the ages 15-19 years is 218 per million, higher than in the age group 1-14 years (United States Cancer Statistics, 2007). In the United Kingdom, the annual total occurrence of cancers in adolescents aged 15–19 years is 183–200 per million, and the five most common cancers are malignant lymphomas, leukaemia, cancer in the brain and other parts of the nervous system, and bone cancer (Gibson, Mulhall, Richardson, & Edwards, 2005).

In Australia, the rate of cancer diagnosed among aged 15-19 years was 173 per million in 2007, again higher than in the under 14 year old group (Australian Institute of Health and Welfare, 2009). Melanoma is the commonest cancer in adolescents in Australia and New Zealand (Stiller, 2007). Other common cancers are similar to those in other Western countries including leukaemia, central nervous system cancers and lymphomas. In all Western countries the incidence rate of cancer in male adolescents is higher than in female adolescents (Baade, Youlden, Valery, Hassall, Ward, Green, & Aitken, 2010).
In Taiwan, the annual incidence rate of cancer in adolescence is higher than in any other ‘younger’ age group (Department of Health, 2006). The incidence of cancer in the age group 10–14 years is 175 per million; and in adolescents aged 15–19 years it is 215 per million annually, with leukaemias, brain tumours, lymphomas and bone and soft tissue disease being the most common forms of cancer in this group. The gender disparity in incident rate is consistent with Western countries (Department of Health, 2006). Overall, haematopoietic tumours are the most common malignancies in the adolescent age group, including lymphomas and leukaemias (Desandes, 2007).

**Survival Rates**

Medical and technological advances have dramatically improved 5-year survival rates among children and adolescents with cancer so that it is now approximately 73-78% (Desandes, 2007). However, while substantial improvements have been made to the overall survival of children with cancer who are younger than 15 years with an improvement average of 1.5%, less than 0.5% per year improvement is recorded for adolescents in the 15-24 years age group (Bleyer, Budd, & Montello, 2006).

Inclusion in regulated clinical trials is often associated with the improvement in survival rates from cancer. In the USA, the Children’s Oncology Group has data showing that more than 70% of patients younger than 15 years old entered into clinical trials, whereas only 10% of adolescents aged 15–19 years were included in clinical trials (Senior, 2006). The lower clinical trial participation rate has been deemed a partial explanation for the relative lack of progress in the 15-19 year old survival rates from cancer (Kapogiannis & Mattison, 2008).

Ferrari and Bleyer (2007) state that adolescent treatment outcomes are worse than those of children who have been diagnosed with the same types of cancer, such as leukaemia or sarcomas, while cerebral tumour survival rates remain lower than for any younger age group. Pritchard, Kaatsch, Steliarova, Stiller and Coebergh (2006) surveyed 15-19 year old adolescents and found that they had a substantially lower 5-year survival rate than 0-14 year olds for leukaemia (44% versus 73%) and bone tumours (48% versus 61%). Similarly, leukaemia (e.g. Acute Lymphoblastic Leukaemia) survival rates from
74% to 87% have been reported for those diagnosed between 1 and 9 years of age, but only 55 to 79% for those aged over 10 years (Eiser, 2007). Importantly, adolescents with cancer have been identified as being at greater risk than younger children for up to 15 months post diagnosis (Barakat, Marmer, & Schwartz, 2010; Hinds, 2010).

Senior (2006) suggests that the reasons for the low survival rate of adolescents with cancer could include fragmented treatment regimens and as noted, the lower level of recruitment of adolescents with cancer into clinical trials. As Jones (2008) explains, the shortage of adolescents willing to take part in clinical trials may be due to prolonged hospitalisation and long treatment regimes, and the subsequent low quality of life for adolescent patients.

Adolescence is a particularly challenging period of life, and suffering from cancer during this period compounds the challenges facing adolescents and has been found to significantly influence family dynamics (Hinds, 2010). As a result of the poor treatment outcomes and survival rates from cancer in the adolescent population, much research, including research from Taiwan, has focused on symptomology management and the identification of effective medical treatments for this group (Tseng, Cleeland, Wang, & Lin, 2008). It is important to note that families provide the majority of care for children with cancer at home (Christian, 2010). Home based caregiving for children with chronic conditions creates significant challenges and stressors for family members (Klassen, et al., 2010). As symptom management and treatment is an important prognostic determinant in this age group (Barr, 2007) family care at home for adolescents has been poorly explored, and rarely acknowledged as a significant area of focus in Taiwan.

**Family Caregiving: Roles, Relationships and Challenges**

Adolescent cancer and its treatment results in many challenges that impact on family roles and relationships (Barakat, Marmer, & Schwartz, 2010). In the US and UK, anti-cancer therapies and supportive care treatments are now routinely provided in outpatient or home settings by healthcare providers (Klassen, et al., 2010). This shift has increased caregiver responsibilities for the ill child in dealing with daily lives and has ramifications for the child’s entire family (Patterson, Holm, & Gurney, 2004). Care for a
child with a chronic condition at home may be accomplished at lower medical public cost but this leads to an increase in family cost associated with burden. Family burden has been described in terms of learning different skills for caregiving, coordinating specialty healthcare, and interfacing with a variety of systems, such as education and government agencies (Christian, 2010).

Studies have examined the roles that families undertake in caring for relatives who require cancer care (Schumacher, Stewart, Archbold, Caparro, Mutale, & Agrawal, 2008). Age, gender, employment, financial status and primary roles have been found to be associated with the availability, capability, and willingness to respond to caregiving responsibilities (Grinyer, 2009; Karantzas, Evans, & Foddy, 2010). Undeniably, primary caregivers are traditionally mothers who spend their time providing such care (Klassen, Raina, Reineking, Dix, Pritchard, & O'Donnell, 2007). Mothers have described the burden of caring in families in terms of demanding time commitment, siblings being cared for by others, marital strain, family isolation, uncertainty and the necessity of learning about cancer and associated treatment procedures (Dumont, Turgeon, Allard, Gagnon, Charbonneau, & Vézina, 2006). Clarke, Fletcher and Schneider (2005) described the demands on fathers in terms of reducing hours of paid work to enable them to juggle the demands of being the family breadwinner and providing child care to support their spouses.

Schumacher, Beck and Marren (2006) reported that caregiver perceptions of stress relate primarily to dealing with role conflict and tensions in family relationships. The most time consuming and difficult caregiving activities for both mothers and fathers are described in terms of giving emotional support to their children with cancer, and to other children in the family (Svavarsdottir, 2005). In addition, family stress may be affected by the family’s lifestyle and impact on the healthy siblings who are at high risk of psychosocial problems (Areemit, Katzman, Pinhas, & Kaufman, 2010). Parents’ and caregivers’ reactions to their adolescents with cancer differ between families, depending on family members and the sick adolescents coping skills (Wu, Chin, Haase, & Chen, 2009). Parents and caregiver reaction are also influenced by cultural beliefs which can present as a double edged sword. This aspect of culture will be examined in this study.
As Grinyer (2009) stated, dealing with the fear of their child's cancer metastasising was frequently identified by parents as an emotional burden. Not surprisingly, parents of children with cancer have been found to report higher levels of anxiety, depression and decreased life satisfaction when compared with parents of healthy children (Fotiadou, Barlow, Powell, & Langton, 2008). Parents’ (caregivers’) social lives were confined to the home, and contacts with friends and neighbours were significantly reduced (Klassen, et al., 2010). To date there is a dearth of literature that reports on how Taiwanese parents deal with this fear and social consequences.

For parents of children and adolescents with cancer, the stress of the caregiving role means that they could not easily fulfil their roles (Martinson & Yee, 2003). The diagnosis of cancer brings with it a set of new responsibilities and role expectations for mothers, such as providing comfort and paying attention at all times, accepting responsibility for technical tasks and managing the cancer treatment for their children (Klassen, et al., 2010). Mothers have consequently requested improved home care services to support the maintenance of their family members’ health, and assistance in providing spiritual support in maintaining their faith and hope for their families’ future (Huang, Yang, Lin, Chang, & Chen, 2007). Schumacher, Beck and Marren (2006) found that caregiver stress was compounded by the dearth of support from health professionals in assisting families to manage caregiving at home and in particular the emotional aspects associated with caregiving for a loved one with cancer.

People experience illness and caregiving in different ways depending on their culture, values and upbringing (Huang, Yates, & Prior, 2009). In this study, the Taiwanese family caregiving experience is explored within Chinese culture which provides a context for understanding how families manage the impact and change in roles and relationships associated with caregiving when an adolescent member has cancer.

In Taiwan, how families adapt to external challenges and relationships within the family is shaped by cultural beliefs and values that establish the norms and standards by which all aspects of society are measured (Tzeng & Yin, 2008). In Chinese culture, life events form what is known as ‘harmony and balance’ because wholeness and congruity among all parts of a family are important to Chinese people (Fan, 2000). All these elements point to the centrality of the family to life in Chinese culture and indicate the
high value placed on the family as the fundamental unit of society (Hui, 2008). In Confucian ethics, the ‘family’ is a broad concept in which a single family holds kinship with related families and thus with the broader society. This provides the model for the ‘ideal’ structure of relationships among family members and in the wider social system (Lam, 2003).

**Chinese Familism**

Chinese beliefs about social interaction and human relationships are affected by Chinese familism (Fan, 2000). Chang (2001) defines Chinese familism in terms of the traditional beliefs and attitudes that shape and guide how families function and individuals relate to one another. Chinese familism consists of a number of characteristics that highlight the significance of the collective entity, the importance of strong beliefs in emotional ties between all family members and the shared goal of striving for balance and harmony in family life (Chang & Kalmanson, 2010). Individuals possess clear perceptions of their obligations, and responsibilities toward the family in Chinese society (Lam, Chang, & Morrissey, 2006).

According to Wong and Chan (2006), Chinese culture, informed by traditional beliefs and values, influences how family and parent-child relationships are experienced. Marriage is considered to be a process of integration rather than individualisation, which leads to more complex family systems that include in-law relationships. The particular kinship norms of Chinese familism are defined as the core familial group (Lam, 2003). Thus, the family-centered network of relationships attributed to Chinese familism provides significant meanings to a variety of aspects of family life (Chen, Miaskowski, Dodd, & Pantilat, 2008).

Relatives, neighbours and friends are important people and often take courageous action, treating the adolescent and their family with sincerity and showing empathy by putting themselves in the position of the family dealing with cancer doing what they can to give support and help (Chen, Huang, Lin, Smith, & Liu, 2009). Chinese parents expect their children to be passive and obedient, whereas Western culture tends to encourage children to be active, independent, assertive and self-sufficient. This is highlighted in
the Confucian dictum that parents are always the right influence for parental control and discipline of their children (Lam, 2003).

The cultural symbols emblazoned on popular Chinese household items depict the values of long life, happiness, financial prosperity and good luck (Fan, 2000). The Chinese believe in and seek a satisfying social life, as well as happiness and peace, to promote health and prevent illness (Leininger & McFarland, 2006). Applying Confucian principles, parents have a great deal of influence in child-rearing and in fulfilling their filial obligations to the whole family (Wong & Chan, 2006). Taiwanese parents believe that children are a significant part of them when they are healthy, let alone when they are seriously ill; their children are their responsibility (Yeh, 2002).

**Grounded Theory**

Glaser and Strauss brought their viewpoints to the development of grounded theory. The methodology was introduced in the book, *The Discovery of Grounded Theory* in 1967. Through this book, Glaser and Strauss (1967) promoted grounded theory as a method to explore social processes to reveal the human characteristics of anticipating and responding to various life circumstances.

Grounded theory provides a way to study human behaviour in complex situations, aiming to generate theoretical constructs about basic social problems and basic social processes of everyday life (Charmaz, 2000). Since a grounded theory is inductively derived from data, it is likely to offer insight, enhance understanding and provide a meaningful guide to action (Strauss & Corbin, 1998). The intent of grounded theory is to generate a theory that explains how a basic social problem that emerged from the data is processed in a social setting.

Social structure and culture are two dominant conceptions of human life (Blumer, 1969). Grounded theory systematically interrelates through statements of relationships to form a theoretical framework that explains some relevant social, psychological, educational, nursing or other phenomenon (Strauss & Corbin, 1998, p. 22). Within this perspective, interpretations of a situation are influenced by a person’s social interactions with others,
underpinned by the cultural environment in which they exist (Benoliel, 1996). Grounded theory is a means of social research based upon symbolic interaction with a focus on interaction, action and processes (McCreadie & Payne, 2009).

The choice of the grounded theory approach for this study can be justified in three ways. Firstly, the grounded theory methodology is useful when there is little prior information about the chosen topic (McCann & Clark, 2003; Moghaddam, 2006). In the literature, the grounded theory methodology has been used to explore life experiences of Taiwanese adolescents with cancer (Yeh, 2002) and to explain the coping behaviours and processes of parental response to a child's cancer (Yeh, 2003). However, little is known about the changing nature of roles and relationships in families engaged in caring for adolescents with cancer, and how this process is managed, shaped and guided by beliefs and values inherent in Chinese culture. Secondly, as there is a dearth of available theory on the changing roles and relationships in Taiwanese families caring for adolescents with cancer, grounded theory provided the researcher with a formalised framework for generating a substantive theory grounded in the data. Thirdly, grounded theory has its origins in symbolic interactionism, a paradigm which holds that individuals engage in a world that requires reflexive interaction as averse to environmental response (Holloway & Wheeler, 2010). Therefore, in this study grounded theory was used to develop a substantive theory that explicates how Taiwanese families manage the impact of caregiving interactions on changing roles and relationships when an adolescent member has cancer.

**Purpose**

The purpose of this study was to explore the impact of caregiving for adolescents with cancer on family roles and relationships within the context of Chinese culture. Using a grounded theory methodology, the study explicates how Taiwanese families managed the changing roles and relationships associated with caregiving for an adolescent with cancer at home. The delivery of appropriate care and services depends upon gaining insight into how caregiving influences family roles and relationships. How families managed the process of caregiving, or not, provided valuable insight required to inform recommendations for constructing services and supports in a Taiwanese healthcare
system that traditionally has not provided such assistance.

**Research Objectives**

This study aimed to:

- Explore the impact of caregiving for adolescents with cancer at home on Taiwanese family roles and relationships.
- Examine and describe how family members perceive and experience changing roles and relationships associated with caregiving.
- Examine the processes undertaken by family members in managing familial roles and relationships associated with caregiving.
- Develop a substantive theory that explains how changing familial roles and relationships are managed in the process of providing care for an adolescent with cancer at home.

**Research questions**

The following research questions were posed:

- What impact does caregiving for an adolescent with cancer at home have upon Taiwanese family roles and relationships?
- How do Taiwanese family roles and relationships change when an adolescent with cancer requires care at home?
- How do Taiwanese families manage changing roles and relationships associated with caregiving?
Summary of Thesis

Chapter 1 introduces the background to the study, highlighting the prevalence of cancer and poor survival rates in adolescents when compared to younger children. The concept of Chinese familism and how it shapes and informs family roles and relationships in Taiwan is introduced. This chapter also provides a rationale for the choice of grounded theory as the chosen research methodology, articulates the purpose and study objectives, and presents the research questions.

Chapter 2 begins with a broad exploration of Chinese culture, including the influence of religious beliefs and the use of folk remedies, in order to provide a context for understanding familial caregiving roles and relationships in Taiwan. This chapter also examines Taiwanese family roles and relationships and discusses how culture shapes and informs caregiving responsibilities, and serves as a support in managing challenges faced in everyday caring.

Chapter 3 examines grounded theory as the research methodology used to explore the impact of caregiving for an adolescent with cancer on the roles and relationships within the Taiwanese family. The chapter provides an overview of the history of grounded theory, and defines grounded theory. The theoretical foundations of symbolic interactionism, informed by the theoretical works of George Herbert Mead and Herbert Blumer, are examined in detail. This theoretical background provides a context for examining tenets of grounded theory, in particular basic social processes, using literature, constant comparative analysis, theoretical sensitivity and theoretical saturation. These tenets are examined to provide an understanding of the research epistemology. Debated issues in contemporary grounded theory are also examined.

Chapter 4 presents the research methods used in the study. The content includes the research design and methods of procedure: sampling strategy; data collection and data analysis. The techniques and procedures of the coding process as per Strauss and Corbin’s mode of grounded theory are presented. In addressing the trustworthiness of this study, the guidelines of evaluation in grounded theory and data transcription and translation issues are examined. The ethical considerations of the study are discussed.
Chapters 5, 6 and 7 present the findings of the study. In Chapter 5 the basic social problem, *experiencing the broken chain of family life*, is identified as the core category. This chapter concentrates on an explication of the causal factors, those factors that depict the impact of caregiving and disease on family roles and relationships. Chapter 6 focuses on the consequences of the impact of caregiving on family roles and relationships. Consequences are examined in terms of the disruption to family roles and relationships, and the experience of strain brought about through changes in family roles and relationships.

In Chapter 7, the basic social process is examined in terms of the ability to confront, accommodate and repair. This process was governed by how well families managed the challenge of experiencing *the broken chain of family life* within the Chinese cultural context. This discussion examines a variety of intervening conditions and process modifiers. The chapter concludes by outlining the overall theory paying particular attention to Taiwanese roles and relationships within the family.

Chapter 8 discusses the substantive theory of *restoring a harmonious family life* as reviewed in the relevant literature and theories, namely caregiving theory, role theory and cultural theory. The study's limitations are presented, followed by a discussion of the implications, recommendations, and concluding remarks. The implications and recommendations are discussed in relation to: the provision of support for parental decision making; the facilitation of supplementary services that sustain family caregiving; and as suggested, means of strengthening culturally sensitive community-based services for adolescents with cancer and their families.
Chapter 2  Caregiving in a Chinese Culture

Introduction
This chapter offers a cursory review of the literature that is relevant to examining and exploring the challenges of long-term care at home for adolescents with cancer and their families in Taiwan. This literature review was conducted to assist the researcher to contextualise the study and to formulate parameters for the initial interviews. The thrust of conducting the cursory literature review in grounded theory is to assist the researcher to obtain background information about the topic of study and to discover new perspectives that have not been researched before. More specifically the cursory literature review does not involve an extensive literature review to verify concepts (Strauss & Corbin, 1998; Holloway & Wheeler, 2010).

The cultural context has a significant influence on the Taiwanese nuclear family, not only shaping beliefs, values, attitudes and perceptions, but also socially informing roles, responsibilities and relationships, and people’s responses to them. This chapter therefore begins with a broad exploration of Chinese culture, including the influence of religious beliefs and the use of folk remedies, in order to provide the context for understanding familial caregiving roles and relationships in Taiwan. This chapter also examines Taiwanese family roles and relationships and discusses how culture shapes and informs caregiving responsibilities, and serves as a support for people managing challenges faced in everyday caring.

Culture in Caregiving Context
In Chinese culture, the family is considered to be the basic social unit in which a person learns the appropriate ways of relating to others (Tan & Chee, 2005). The Chinese social context provides insight into Taiwanese family experiences, especially childcare, which is still viewed as the major responsibility of Chinese woman (Huang, 2008). Chinese perspectives on children with cancer are influenced mainly by the philosophical and religious beliefs of Confucianism, Buddhism and Taoism. Some Chinese parents may blame themselves for their child’s illness (Martinson & Yee, 2003) and they may negotiate with God if they are Christian or with Buddha if they are Buddhist; they may
pray to change the child’s fate by praying in the temple or at home, ask the child to wear a *Fu* (amulet), and become a vegetarian (Chen, Miaskowski, Dodd, & Pantilat, 2008). Indeed, Chinese philosophies and religions strongly influence how people live and think about health and caregiving (Leininger & McFarland, 2006).

Most importantly, the Chinese believe in a dominant kinship system of a “father-son dyad” with attributes of continuity and authority (Chao, 1995, p.147). Once a family member needs long-term care typically the mother becomes the caregiver and has no choice about assuming responsibility for this role extension (Chen & Boore, 2009). Lai (2010) reports that modern day Asian women living in Korean society tend to experience difficulties and conflicts between the social expectations of family caregivers and personal fulfillment.

Culture influences the process of making caregiving decisions. Caregivers use Chinese cultural beliefs to promote what they consider the best and most appropriate care for sick children (Liang, 2002). Thibodeaux and Deatrick (2007) point out that care behaviours differ in different cultures because of the variations in social structure and cultural values. Chinese cultural beliefs incorporating fatalistic attitudes, tolerance, and acceptance of illness, as well as moralistic views on the etiology of illness and adversity, influence the coping responses and caregiving practices of Chinese families (Martinson & Yee, 2003). Taiwanese live in a society strongly influenced by the traditions of filial piety and familism and these two traditional social values provide the moral basis for family-centred caregiving (Lee, 2004). In a society with these cultural beliefs, family members play more important roles in the care of sick patients and older people than in Western cultures (Hsu, Kung, Huang, Ho, Lin & Chen, 2007).

**Cultural Influences on Family Caregiving Roles and Relationships**

Their cultural background has a paramount influence on the Taiwanese nuclear family, affecting not only values, attitudes and perceptions, but also responsibilities and responses to them (Yang, Lengacher, Beckstead, & Shiau, 2008). According to Wong and Chan (2006), Chinese culture is derived in part from beliefs and traditions relating to family and parent-child relationships. Culture encompasses all aspects of the lives of
family members, which are perceived both as interrelated and interactive. It follows that Chinese culture shapes how Taiwanese families adapt to external challenges and relate to one another within the family (Fan, 2000).

Caregiving is a central focus of kinship work and is embedded in women’s gender roles as wives and mothers, and likewise their moral obligations; men’s responsibilities reinforce the role of breadwinner and propagate the values of filial piety in Chinese families (Spitzer, Neufeld, Harrison, Hughes, & Stewart, 2003). In Taiwan, Chinese familism influences the caregivers’ decision-making for the child during the cancer treatment, especially from kin such as family, relatives and elders (Liang, 2002). Kinship roles are relatively structured, and family survival is largely dependent on mutual obligations among family members (Chow, 2009). For example, fathers are usually described as powerful, calm, and having strong opinions. In contrast, mothers are described as gentle, kind, and more tolerant of different opinions. Parental roles have their meaning and purpose in caregiving of sick children in order to satisfy the unique needs of the children (Huang, 2008).

Huang, Mu and Chiou (2008) explored Taiwanese single-parent experiences and their family resources to assist in the care for a child with cancer. They found that Taiwanese family members face the difficulties together and share the family roles and burdens in a flexible way. Family co-operation and the family roles in Chinese cultural beliefs shape parents’ experiences.

**Chinese Cultural Beliefs**

Chinese cultural beliefs, including Confucianism, Taoism, and Buddhism, encompass diverse and sometimes competing schools of thought (Leung, 1996). Confucianism is undisputedly the most influential belief, forming the foundation of the Chinese cultural tradition and governing the entire range of human interactions in society (Fan, 2000). Confucius prescribed the five widely known cardinal relationships (Wu Lun; 五倫), principles for each, and the differing duties arising from the different status that each has in relation to the others (Tu, 1998) (see Table 2-1). This refers to the younger generation, that is children in relation to their parents and elders, and the older
generation, namely parents and grandparents in relation to their children. While the younger generation is considered in Confucianism to owe strong duties of reverence and service to their elders, in turn, these elders have duties of benevolence and concern toward their young. This theme consistently manifests itself in extensive filial duties on the part of children towards parents and elders, and the great concern parents have towards their children (Chow, 2009). Within these relationships, three pairings apply to family members (father and son, husband and wife, elder and younger siblings), with the most fundamental relationship being that between parents and children, as mentioned previously, where children are expected not only to care for their parents, but also to respect them (Tzeng & Yin, 2006).

<table>
<thead>
<tr>
<th>Basic human relations</th>
<th>Principles</th>
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<tr>
<td>Ruler and subject</td>
<td>Loyalty and duty (君臣有義)</td>
</tr>
<tr>
<td>Father and son</td>
<td>Love and obedience (父子有親)</td>
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<td>Husband and wife</td>
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<td>Elder and younger siblings</td>
<td>Seniority and modelling subject (長幼有序)</td>
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<tr>
<td>Friend and friend</td>
<td>Trust (朋友有信)</td>
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In Chinese societies, good parents are those who are willing to make sacrifices, who can provide their children with good health, and who are able to teach their children household chores at home in order to set an example (Lam, 2003). Chinese parents infuse values into their children, including respect for elders, filial piety and identification with Chinese culture (Tsai, Chen, & Tsai, 2008). Additionally, the parents of children are expected to care for them in this current life until they are firmly established, with the children reciprocating this effort as parents become older; hence, a Chinese adolescent with cancer cannot accomplish the duties expected of them (Jin, 2009).
Harmony in the Chinese Family

Chinese culture places great emphasis on a harmonious and balanced relationship with nature and on harmony and balance in social interaction (Leung, 1996). Individuals are socialised to avoid interpersonal conflict and to maintain harmony regardless of their desire to express their feelings and thoughts during social interaction (Chen, Cheung, Bond, & Leung, 2005). This is consistent with the fear of self-disclosure and social intimacy characterising ambivalent people, who likewise tend to be inhibited and unexpressive (Emmons & Colby, 1995). In Chinese culture, harmony emphasises fitting harmoniously into one’s environment (Smith, Peterson, Schwartz, Ahmad, Akande, Andersen, Ayestaran, Bochner, Callan, & Davila, 2002) in order to maintain mental health and enhance life satisfaction (Chen, Cheung, Bond, & Leung, 2005).

In Taiwan, the family is generally patrilineal, patriarchal and virilocal. The father is the family leader who has authority over all the other members. The members have a clear notion that a family ought to be “round” (圆) or to be a complete unit (Jordan, 1972, p. 92). Chang (2001) clearly makes the same point, of the familial aspect as being round, a genuine family circle that promotes harmonious feeling and that families emphasise the sense of togetherness, involvement and caring, within relationships in society. The most common prayer to ancestors and gods in Taiwan is for the harmony of the family.

Taiwanese interpret sickness in a family member as an instance of family disharmony. As Jordan (1972) indicated, family disharmony occurs not only when a member is sick, but when the member is sick because their family is failing to meet the ideal, harmonious circumstances. Filial piety emphasises harmony within the family or the integrity of relationship between parents and children (Jin, 2009). From the parents’ point of view, they emphasise devotion and self sacrifice within their childkeeper role, a role and relationship culturally defined by the precepts of filial piety (Chow, 2009). In Chinese culture the self is viewed as being connected with others and this also encourages families to maintain interpersonal relationships (Chen & Tse, 2008). The adolescent discourse reflects the cultural beliefs of harmony, respect for parental authority, obedience, and fulfilling parents’ expectations: the focus is on obedience and loyalty to the family (Lam, 2003).
Filial Piety

Filial piety (xiaoshun; 孝順) is a fundamental virtue for the Chinese way of life, one of the foremost duties of the eight principles of bade (八德). These are filial piety (xiaoshun; 孝順), brotherly love (di; 恭), loyalty (zhong; 忠), trust (xin; 信), propriety (li; 礼), righteousness (yi; 義), integrity (lian; 廉) and conscience (zhi; 羞) (Connection, 1987). Essentially, filial piety is one of the “right relationships” which Confucius advocated (Chow, 2009). The definition includes the responsibility of each person to respect their parents, obey them, take care of them as they age, advise them, and of course love them; filial piety is thus the foremost virtue in a Taiwanese family (Tsai, Chen, & Tsai, 2008). Confucius explicitly said, being filial is to be able to support. The main idea is to fulfill the desire and obey the parents’ wishes and to satisfy their needs and requirements. Thus, the desire to continue the family line is the parents’ expectation of their children (Fan, 2006). In the case of adolescents with cancer, as is the case in this current study, the above parental wish may be difficult to fulfil.

The Classic of Filial Piety states, “our body and limbs, our hair and skin are given to us by our parents, and we must be careful not to injure them: this is the beginning of filial piety” (身體髮膚受之父母不敢毀傷孝之始也 -《孝經》) (Jordan, 1972, p. 82). For their part, children should respect their parents, express gratitude to their parents for giving birth to them and raising them, and willingly accept reasonable parental discipline bestowed upon them (Lam, 2003). The pressure on parents who have to care for adolescents with cancer comes from this traditional view; they hope the children will grow up, marry and continue the family line, but when disease occurs this becomes secondary (Wong & Chan, 2006). If the child can cooperate with the medical treatment and his or her condition stabilise, this is the parents’ greatest wish. In Chinese culture the emphasis on filial piety or obedience to the parents is more pronounced than in Western culture. If cultural expectations are unmet, for example due to the values of young contemporary Taiwanese becoming more Westernized, parents or older adults might feel disappointment about such cultural characteristics fading or becoming lost (Hahn, Yang, Yang, Shih, & Lo, 2004).
The literature strongly indicates that Chinese parents perceive that there are three ways to be unfilial: by not honouring parents, by not supporting parents financially, and by not producing offspring, with the worst of these being not producing offspring. This gravest of the three cardinal offences against filial piety is expressed in a family's having no male heir (Leung, 1996). Parents possess great responsibility in their child-rearing practices, reflecting Confucian principles, and they aim to fulfil their filial obligations to their whole family (Lin & Fu, 1990). Another significant factor is religious beliefs which can provide spiritual support, peace of mind, and a sense of blessing for the family. The next section discusses religious beliefs and how they shape Chinese family life.

**Religious Beliefs**

Religious beliefs may enhance the ability of Taiwanese people to cope with suffering in their lives or in the lives of those requiring their care (Yeager, Glei, Au, Lin, Sloan, & Weinstein, 2006). Religious diversity has never been a significant source of conflict amongst Taiwanese people: their central idea of religion is the fulfilment of divinity (Yeh, 2001). Taoism is the most popular religion, and Buddhism is the second most common faith. Some people practise Buddhism exclusively, but most blend Taoist religious practices with elements from Buddhism and folk traditions (Department of Civil Affairs, Ministry of the Interior, ROC, 2010). Some religious teachings advocate that adolescents with cancer and their parents entrust their spirit to the gods to give them spiritual support. This gives them a sense of support from all sides: it helps them face the changes in their physical appearance during treatment and also helps them redirect the fear, worry, the unknown course of the disease, and other negative emotions, and face them positively (Tzeng & Yin, 2006).

Religion and spirituality are known to be significant for patients of all ages across cultures coping with cancer. Diagnoses of life-threatening diseases in children may elicit more prayer and perhaps even increase religiosity within families (Ecklund, Cadge, Gage, & Catlin, 2007). Religiosity is a measure of families' value systems, and spiritual well-being is an important component of overall health. Indeed, in most religions spiritual well-being is considered more important than physical well-being. As reported
in the McCurdy, Spangler, Wofford, Chauvenet and McLean study (2003), spirituality becomes more recognized as an important component of the health of a child diagnosed with cancer and their family.

As well as large temples, small outdoor shrines dedicated to local deities are very common in Taiwan; they can be seen beside roadsides, and in parks and neighbourhoods throughout cities and towns (Shih, Gau, Mao, Chen, & CH, 2001). These give people the opportunity to stop by and pray informally any time and provide a safe environment for meditation and various other forms of religious practices. As Yeh (2001) recorded, parents may visit a shrine to worship numerous deities for their child’s health. Families pray to their gods in their own individual way. Indeed, when faced with a life-threatening cancer affecting a family member, families may choose to rely on their religious devotion, and their religious beliefs and culture can therefore affect family medical decisions in ways that may ultimately impact on physical health (Vess, Arndt, Cox, Routledge, & Goldenberg, 2009).

Culture is a blueprint that guides peoples’ beliefs, values, and care experiences in promoting health and well-being, and influences families’ decision-making (Liang, 2002). To understand this discussion in a Chinese context, the following section reviews Taoism, Buddhism, belief in fate, belief in karma and folk remedies.

**Taoism**

There were 9,249 Taoist temples in Taiwan in 2010, 78.4% of all temples (Department of Civil Affairs, Ministry of the Interior, ROC, 2010). Taoism is a Chinese philosophy and religion claiming to promote a balanced lifestyle, which incorporates the ancient Chinese Yin and Yang philosophy (Wu & Tseng, 1985). Yin expresses concepts such as slow, soft, weak, diffuse, cold, dark and tranquil. Yin is generally associated with femininity, birth and generation. Yang, by contrast, denotes fast, hard, solid, dry, focused, hot, bright and aggressive. Yang is associated with masculinity (Patterson, 2000). Taoism focuses on the interdependence of all things together within the processes of nature. In the ideal state of nature, health is understood as a harmonious balance in the body and disease is understood as a state of affairs in which the basic harmonies of
life have been disrupted, for whatever reason, and so these harmonies need to be restored (Yeager, Glei, Au, Lin, Sloan, & Weinstein, 2006). In Taoism the key point of harmonious balance of the body and its environment is the balance of qi (also spelt: chi, ch’i). Qi is the source of life and forms the basis for the diagnosis and treatment of illness and for the promotion of health and the prevention of illness (Chen, Miaskowski, Dodd, & Pantilat, 2008). In Taiwanese culture, when a person is sick, the most common description of one’s sickness is “there is no yuanqi (vitality).” When someone is sick it means there is an imbalance of “Yin and Yang” (Yeh, Wang, Chiang, Lin, & Chien, 2009, p.741).

Maintaining a balance between the Yin (cold) and Yang (hot) forces governs health and moderates some of the eating practices of Chinese people. The designations ‘hot’ and ‘cold’ indicate the internal effects of the food, not its actual temperature. Chinese people drink teas and herbal soups to rectify hot and cold imbalances from inappropriate food intake or disease conditions (Fan, 2000). Taoists use incense in their religious activities.

**Buddhism**

Buddhism, on the other hand, introduces an entirely new view of life, seeing life as a realm of suffering and pain because of ignorance and desire. Disease is understood differently from the Buddhist’s perspective (Yip, 2003). One major difference between Taoism and Buddhism is the concept of karma. Karma refers to the idea that all actions are the display of thought; the will of humans is known as karma. Karma determines the Buddhist’s actions and position in life (Keown & Keown, 1995). Buddhists chant mantras and sutras, and practice meditation in the 2,308 (19.6%) temples found throughout Taiwan (Department of Civil Affairs, Ministry of the Interior, ROC, 2010).

An adolescent and their family may become Buddhists and vegetarians to decrease the parents’ guilt or to help them think that their child’s sickness is a lesson of life given by the gods. They may believe in Buddhism and choose a temple to worship in to be blessed and in return, pray to the family’s ancestors regarding blessing and safety for the whole family at home, for as long as it is good for their ill child (Yeh, 2001). Parents often think that a child’s illness means that Buddha is providing them with a situation leading them to read their hearts and to cleanse their sins, as well as promoting feelings
of gratitude (Weaver, Vane, & Flannelly, 2008).

As demonstrated in the above comments, Taiwanese families are either Taoist or Buddhist in their religious beliefs, which helps them understand their sick child's possible reincarnation, gives them peace of mind and prepares them for an unpredictable treatment outcome. The following section will describe Chinese parents’ beliefs in fate and karma.

**Belief in Fate**

In fundamental Chinese culture and medical thought the Yin and Yang forces maintain harmonious balance of the body and environment. Illness is perceived as a state of disharmony between the individual and his or her natural and social environments (Yeh, Wang, Chiang, Lin, & Chien, 2009). Buddhism has influenced Chinese culture for several thousand years. Fate, Inn and Ko (cause and effect) are the principles that encourage people to do good and do the right thing, and this determines their health (Chen, 2001). As Chen (1996) states, fate consists of many threads making a net; every thread is connected to another, and all are attached to central lines. When people are doing good for others and being good, they feel peaceful and have no guilt in their lives; this promotes their health.

Chinese people often talk about fate and god’s will. This is very similar to how Western countries represent ideas about the Christian God (Fan, 2000). Chinese people believe in fate and typically adhere to a religious philosophy in which the outcomes are all predetermined. This is expressed as a kind of destiny. Whether a person experiences a good or a bad life, with this divine power, anything can be done or can be resolved (Wong & Chan, 2006). It is painful and tortuous for the family with a child with cancer. Parents pray to Buddha as a means of spiritual support; the families must accept the distress while they are being tested along the path of the cancer treatment; they believe their child will be cured and that will be their fate (Chao, Chen, Wang, Wu, & Yeh, 2003).
Belief in Karma

The typical Taiwanese family believes that the cause of recurrent disease is the result of accumulated karma: it is “reincarnated” in the family and their children (Fan, 2000, p.4). Karma is that which comes back to people based on their actions. It means any kind of intentional action whether mental, verbal or physical. All good and bad actions constitute karma (Cheung & Lai, 1999). A person's karma determines what he/she deserves and what goals can be achieved. The Buddhist’s past life actions determine present standing in life and current actions determine the next life; all is determined by the Buddhist's karma (Carus, 2003).

According to Yeh (2001), Taiwanese parents tend to believe that they have done something wrong that has caused their child to suffer a terrible cancer journey and thus, the parent is being punished by no longer having karma available to them. It may be extrapolated from the above fate and karma belief that the unpredictability and uncertain course of the disease gives the child with cancer and their family anxiety, and the anxiety may stem from fear that the disease cannot be controlled and it will become increasingly serious (Ecklund, Cadge, Gage, & Catlin, 2007).

Taiwanese families are influenced by their cultural context, especially through their kinship, such as family, relatives and elders, and from religion and sometimes the advice of Chinese physicians (Liang, 2002). The latter includes folk remedies. These are discussed below.

Folk Remedies

Folk remedies emphasise integration and continuity. Differentiation between body and mind, person and nature, nature and the supernatural, the visible and the invisible, and Yang and Yin, have laid the basis for the Chinese culture (Chui, Donoghue, & Chenoweth, 2005). Folk remedies are culturally based practices and beliefs related to preventing and/or treating disease (Chen, Hung, Lin, Smith, & Liu, 2009). In Taiwan, parents resort to folk remedies more often when their children are sick (Yeh, 2001). As Chen, Huang, Lin, Smith and Liu (2009) explain, the three most frequently used folk remedies are spirit-calling, carrying a cross or incense bag, and wearing Buddha beads.
A common Taiwanese belief is that a child’s spirit (hun po, 魂魄) will easily become loose or less tightly bound to the body with any illness (Liang, 2002). Thus, spirit calling is a common cultural practise or folk remedy because this belief supports psychological and spiritual peace and ease for family practise within the Taiwanese culture (Chen, Huang, Lin, Smith & Liu, 2009).

The Chinese believe that cancer treatments disturb the balance necessary to maintain health. Thus Taiwanese families may use traditional Chinese and folk medicine to complement Western medicine for children with cancer (Liang, 2002). As Xu, Towers, Li and Collet (2006) stated, Chinese medicine may be practised concurrently with Western medicine. This situation is a practical approach and generally does not stimulate discordance. Most families use folk remedies, especially food therapy and stewing Chinese medicine, to increase body strength and energy in the face of the side effects of Western treatments. Parents look to folk care for proving magical powers to heal their children with cancer (Liang, 2002). Moreover, parents spend money to buy ‘Chinese health products’ to increase the child’s immunity, such as using tonics to strengthen the body, Chinese medicine to regulate the body functions, Chinese herbs too are used to prevent metastasis or reoccurrence, as well as providing another chance of a cure when Western medicine is ineffective (Martinson & Yee, 2003).

Folk remedies include such practices as temple worship, where the casting of prayer Jiao (筊) towards gods, specifically requesting the granting of certain outcomes about situations occurs; and using fortune tellers to nominate their ill child as god’s son to get through the difficult times, thus parents want to enable their ill child to be the Bodhisattva’s son (Yeh, 2001). As Chao, Chen, Wang, Wu and Yeh (2003) found, parents and their children with cancer attributed their illness to fate, environmental pollution and unhealthy diet, but they strongly disagreed that cancer was caused by infection, problems during pregnancy, heredity, previous wrongdoing, bad names or evil Feng-Shui. However, parental guilt was found to arise from blaming themselves for not

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1 Jiao (筊): The act of divination that is practiced in Taiwan makes use of Jiao. A Jiao is a piece of wood, the shape of a crescent moon, rounded on one surface and flat on the other. Wooden Jiao is widely used in temples to answer questions (Jordan, 1972).
taking good care of their children. Parents would try to make up for this by paying more attention to the diet and daily care of the child with cancer and their siblings (Yeh, Chang & Chang, 2005).

In order to rectify past sins, parents ask for help from Shamans (gods). They offer and burn incense to Shamans, and ask questions about their child’s health to them. The Shaman writes down the prescription to cure the illness on a piece of paper (Fu, as an amulet); the Fu carries a spirit from the Shaman which is worn as a necklace or burnt into water to bathe the child. This is aimed at separating the child from its past sin. The illness may also be explained as the result of parents’ past sins (Yeh, 2001).

In summary, Chinese culture plays a significant part in how Taiwanese families view life events and respond to illness. Chinese culture is shaped by Confucian principles of harmony in the family and filial piety, as well as religious beliefs such as Taoism, Buddhism, belief in fate and karma and the use of folk remedies in caregiving.

**Conceptualisation of Family Caregiving**

Family caregiving is viewed as a dynamic, ongoing process, informed and shaped by different cultural beliefs and self-expectations regarding caregiving roles (Lee, 2004). Across cultures caregiving is a moral obligation owed to the dependent family member. As in most cultures, feelings of belonging, concern, responsibility and security are values central to Chinese culture but maintaining harmony and stability of family relationships is deemed imperative (Chang, 2001). Principles and ideals relating to interaction, expectations and self-expectation are clearly established and not usually open to question. These cultural values play an important role in sanctioning caregiver task performance (Zhan, 2004).

Family caregiving involves “extraordinary care, time, energy and money over potentially long periods of time”, and the result may be unpleasant and uncomfortable and psychologically stressful and physically exhausting (Schulz & Martire, 2004, p. 240). In particular, caregiving for children with cancer is a full time job and there is an increased burden and stress caused by the major impact that cancer has on the whole family, with the illness of one family member affecting family roles, communication
and overall life (Svavarsdottir, 2005). Despite current social values changes, to some extent the traditional norms and characteristics of family-centred caregiving are still deeply rooted in Asian countries. Taiwanese women are still exposed to the combined pressures of social and cultural norms for family caregiving and this may cause negative health outcomes for caregivers (Lin & Tsao, 2004).

Compared with Western studies, the caregivers in Asian countries present with a relatively high level of depression, and many caregivers rate their health as poor. Korean caregivers reported higher levels of depression and anxiety than Caucasian American and Korean American caregivers (Kim, 2001). Chinese culture influences how children and their families respond to the diagnosis and treatment and families worry greatly about the patient’s progress and symptom distress (Yiu & Twinn, 2001). In Taiwan, family caregivers are highly involved in their ill family member’s symptom management and must stay at the bedside to share the nursing and caregiving tasks (Lin & Tsao, 2004). Taiwanese parents bear the distress of looking after a child with cancer and hope their child will be successfully treated (Wu, Chin, Haase, & Chen, 2009). Both parents and adolescents feel sad and experience anxiety due to fatigue being persistent, not only through the diagnostic inpatient period, but also into the recovery period at home (Yeh, Wang, Chiang, Lin, & Chien, 2009).

Woodgate and Degner (2003) used grounded theory and illness narratives to construct the perspectives of 39 Canadian families threatened by their experience of cancer treatment for their children. These authors found that depressive symptoms are a common reaction of parents during the six-month period after the child was diagnosed with cancer. The study showed mothers averaged significantly higher levels of all forms of distress than fathers (Yeh, 2002). Mothers found it difficult and time-consuming to provide emotional support for both the child with cancer and their other children and to structure and plan activities for the whole family. Fathers found it difficult to manage work and organise time to care for the child at the same time (Svavarsdottir, 2005). James et al. (2002) study found that parents had to alter family schedules and routines, and one parent needed to terminate their job to care for their ill child. Loss of employment was only one reason for negative impact on a family’s economic status; other factors included additional medical expenses, and expenses incurred for
transportation and nutritional supplements.

A qualitative study of families of children with cancer in the United Kingdom, similarly found that most reactions caused by emotional stress occurred around the time of the diagnosis, with mothers reporting more symptoms than fathers (Earle, Clarke, Eiser, & Sheppard, 2007). The mothers’ depressive symptoms affected the parent-child relationship, resulting in ineffective childrearing, child behavioural problems, and the overestimation of problem behaviours in the children without cancer (Schumacher, et al., 2008). Similarly, a study by Yeh (2002) surveying 164 Taiwanese families of children with cancer at various stages after diagnosis, found mothers experienced significantly higher levels of depression, anxiety, and somatisation (bodily complaints such as headaches, nausea or fatigue) than fathers.

Yeh, Wang, Chiang, Lin and Chien (2009) explored distress symptoms of 144 Taiwanese cancer patients aged 10-18 years old and found over 40% of the sick children experienced a lack of energy, loss of appetite, drowsiness, sweating, worry, nausea, dry mouth, and pain, and lacked concentration. These symptoms impacted on their quality of life and caused caregivers stress. Members of the on-treatment group had significantly more distressing symptoms than those in the off-treatment group.

According to Woodgate (2006, p.409), worry and “keeping an eye” on the ill child were part of the siblings’ responses to cancer in their brother or sister. Siblings’ lack of involvement in caring for their ill brother or sister resulted in isolation peer group which caused stress and feelings of sadness and helplessness with respect to their sibling’s symptoms. Cultural barriers have been shown to be liable to contribute to this, as well as strands of belief about cause and effect, health and disease.

**Cultural Barriers to Family Caregiving**
Children in oriental cultures tend to be more conservative and hesitate to express their feelings, compared with children in Western cultures (Liang, Chiang, Chien, & Yeh, 2008). For example, in Taiwanese culture pain is considered as an unavoidable symptom that should be endured (Yeh, Wang, Chiang, Lin, & Chien, 2009). The family members would encourage the child to endure the pain, unless it was beyond their
ability to endure. In Western countries, parents and children learn together to participate in a process of seeking and evaluating cancer treatments and supportive care for the child. The caregiving itself takes different forms, and may have different emphases, such as children being responsible for their own care (Myra, Belasco, Goldman, & Belasco, 2007).

Taiwanese families believe cancer is a stigma associated with death; thus they do not discuss bad news and sorrow with their children or relatives (Liang, Chan, Lin, Ly, & Chen, 2006). Chinese parents are unwilling to provide information about the disease to their children. Given their understanding and experience of the disease, they find it difficult to tell their children about the treatments and prognosis (Yin & Twinn, 2004). Furthermore, parents tend to be less expressive of their affection towards their children because the Chinese emphasise family harmony through emotional restraint (Lin & Fu, 1990). In Chinese culture, men are expected to be strong and keep their affections silent and hence their unwillingness to discuss openly the child’s disease and its related problems (Yeh, 2004). As Wong and Chan (2006) showed, fathers of children with cancer did not receive needed support and felt left out of the direct chain of medical information; parents did not want to talk about bad news concerning the disease because of the psychological pressure, nor did they dare discuss the subject of death with their sick adolescent.

A similar belief was revealed by a qualitative study by Yin and Twinn (2004), who found that having difficulty being truthful about the cancer prognosis created a communication barrier among family members. Most Chinese parents were reluctant to share information about the disease with their children as they blamed themselves for the illness (Martinson & Yee, 2003). Family affairs are traditionally confined to within the family and disease is considered something shameful for family members to discuss with outsiders. This belief could be related to the concept of karma, even if a family is not Buddhist (Yeo, Meiser, Kristine, Goldstein, Tucker, & Eisenbruch, 2005).
The Family Experience of Coping with Caregiving
Taiwanese parents’ coping involved confronting the treatment, maintaining family, establishing support, maintaining emotional well-being, and searching for religious meaning in Taoism, Buddhism, and Catholicism (Yeh, 2001). Such beliefs can help parents to avoid guilty feelings, depression and interpersonal hostility resulting from misfortune, and generate hope towards coping positively (Wong & Chan, 2006). The parent seeks religion to gain psychological strength, to release their stress and develop coping skills to care for the child (Becker, et al., 2007).

Spirituality was also described as playing a key role in the coping experiences of parents from Western countries whose children had cancer (Miller, Vannatta, Compas, Vasey, McGoron, Salley, & Gerhardt, 2009). In Taiwan, the majority of caregivers used religious care practices to gain peace of mind and hope of a cure (Liang, 2002). Similarly, a qualitative study by Elkin, Jensen, McNeil, Gilbert, Pullen and McComb (2007), found that in the USA, the religious beliefs of 27 mothers of children with cancer were related to the psychological adjustment of both. Mothers reported an increase in religious behaviour following their child’s cancer diagnosis and less depression related to higher levels of religious beliefs. Mothers were more successful than fathers, in using social support, treatment strategies, seeking information, and turning to religion to maintain family life and to understand the medical situation of their child (Goldbeck, 2001).

People with cancer in Taiwan face a range of decisions and choices about treatment. The treatments may include Traditional Chinese medicine (TCM) and folk medicine, or some combination of these (Wang, 2007). Chang and Li reported that 61.3% of Taiwanese people with cancer receiving Western treatment at home used at least one form of complementary therapy (Chang & Li, 2004). TCM is used as a supplement to reduce adverse effects from cancer treatment and rebuild energy, although its effects are slow (Ferro, Leis, Doll, Chiu, Chung, & Barroetavena, 2007). Patients in Taiwan hold a passive attitude toward their medical issues. A few of the caregivers in the Liang study relied upon herbs or a secret recipe from a shaman, or friends’ and elders’ suggestions, especially when their doctor had a low rate of cure of cancer in children and adolescents (Liang, 2002).
Huang, Mu and Chiou (2008) found that Taiwanese single mothers learn to withstand hardship by making psychological adjustments; they build up a protective environment and fulfill their child’s wishes to avoid later regrets. The parent actively seeks multiple sources of information to strengthen their caring ability: the parent manages a huge number of medical expenses and experiences financial burden; but they call on internal family resources and arrange their affairs in a practical way (Huang, Ma, Shih, & Li, 2008). The resources encompass kinship, being together, giving support, and meaningful participation in the care (Yeh, Wang, Chiang, Lin, & Chien, 2009).

Adolescents themselves have been found to develop positive coping experiences through active participation in decision making, feeling secure about their medical treatment, and having positive interactions with healthcare providers (Tracy, 2004). Moreover, adolescents seek family support as a coping strategy, from their mothers in particular but also from friends, other relatives and healthcare providers. This support assists in reducing uncertainty and feelings of ambiguity associated with the illness and treatment complexity (Decker, 2007).

Encouraging hope is related to the coping experiences of positive reappraisal, which translates to how the adolescent creates positive meaning through their experience (Wu, Chin, Haase, & Chen, 2009). Woodgate (2005) found that families and adolescents were able to identify positive experiences during the illness, such as thinking that they were still the same person despite the disease and hoped for a good future.

Stegenga and Ward-Smith (2009) have identified significant issues related to peer support in adolescence. In a qualitative study, they found that the development of supportive relationships with other adolescents with cancer enabled young people to accommodate and get back to a normal life. Wu, Chin, Haase and Chen (2009) indicate that adolescents possess a desire for varying amounts and types of information. Providing reliable sources of information helps to prevent misinformation and assists adolescents increase their knowledge base and inform their coping skills. As Rew, Wong, Torres and Howell (2007) found, group intervention programs improved psychological adjustment, and problems such as depression and intrapersonal difficulties, and increased illness-related participation and communication.
The changes that occur in family roles and relationships also affect the siblings. Siblings are aware of the parental tendency to give priority to the needs and desires of the ill child over those of other family members (Ballard, 2004). Siblings of children with cancer experience a more serious burden from the illness than is perceived by their parents. Physical complaints and emotional problems remain mostly unnoticed, because distressed parents are more focused on the sick sibling’s physical health (Nolbris, Enskär, & Hellström, 2007). Siblings frequently reported worry, anger and guilt or jealousy about their or their sibling’s life being changed because of their suffering, resulting in the experience of sadness flowing on to other family members (Sidhu, Passmore, & Baker, 2005). Group interventions have been shown to also benefit siblings of children with cancer, significantly reducing symptoms of anxiety, depression and behaviour problems (Barrera, Chung, & Fleming, 2004).

In Australia there are currently four groups that provide support for adolescents with cancer. These are Camp Quality, Leukaemia Foundation, Seize the Day (Cancer Fund) and Canteen (Tracy, 2004). These groups provide peer support, counselling, accommodation and financial support. They give the best care for adolescents in order that their experience of cancer treatment is as positive as possible (Mashta, 2008). As suggested by Decker (2007), social support needs by adolescents may be very different from those of children or adults. In Taiwan, the foundation for Paediatric Cancer has intervened with several outreach programmes for children who are back at home or school, but these interventions are insufficient, owing to issues such as lack of funding and staff and focus on the needs of adolescents (Liang, Chiang, Chien, & Yeh, 2008). Adolescents are striving for independence and seeking to find their own identity as they move towards adulthood. Establishing and maintaining relationships with friends and classmates are deemed important for socialisation (Wu, Chin, Haase, & Chen, 2009).

In summary, attitudes and actions are affected by cultural beliefs and these create a social pattern in which the family members and caregiver experience stress and the burden of illness is primarily borne by both the caregiver and the family. Families, especially mothers, take on nursing and other caregiving tasks, but generally have few skills and resources. The stress and burden impact on family roles and relationships.
Families’ and caregivers’ reactions to their adolescents with cancer differ between families, depending on family members’ and sick adolescents’ coping experiences, and cultural beliefs in Taiwan (Wu, Chin, Haase, & Chen, 2009).

**Summary**

The dynamic of family caregiving and its health consequences may differ by culture because caregiving behaviours may reflect cultural values and beliefs. Chinese culture plays a significant part in how Taiwanese families view life events. The diversity of religious faiths in Taiwan protects and nurtures the whole family in hoping for safety through prayer towards recovery and consolation. More specifically, the Taiwanese consider family lineage, religious beliefs and events in life as progressive stages during their life cycle. It follows that Taiwanese parents envisage themselves as the guardians of their children in all facets of family life including wellness, and striving to maintain harmonious family roles and relationships within the family. This is in comparison to Western countries where the value of children independence is promoted and parental workload is reduced over time.

The next chapter provides an overview of the methodology by which the history, epistemology and theory informing grounded theory will be presented. Theoretically this study draws primarily on the theoretical works of George Herbert Mead (1934) in the field of social behaviourism, and the theory of symbolic interactionism attributed to Herbert Blumer (1969). The framework guiding the application of grounded theory draws predominantly on the works of Strauss and Corbin (1990; 1998). The next chapter will define key conceptual issues relevant to grounded theory. These issues include the theoretical tenets of symbolic interactionism, the basic social process, using the literature, constant comparison, theoretical sensitivity and theoretical saturation. The rationale for the use of grounded theory in this current study is also explained.
Chapter 3    Methodology

Introduction
In the present study, grounded theory as a methodology provides a useful tool for exploring the perspective of families and adolescents with cancer in Taiwan. The flexibility, openness, process-oriented, and collaborative underpinnings in grounded theory can be explicated in research that addresses this perspective (Corbin & Strauss, 2008). Identifying perspectives of participants will facilitate the development of a substantive theory which can be used by health care providers and policy makers to improve both conceptions of appropriate care and the provision of such care in supporting Taiwanese families and ill adolescents.

This chapter will begin with both an overview of the history and a definition of grounded theory as well as an exploration of the conceptual issues contested in grounded theory. The theoretical background of symbolic interactionism, informed by the works of George Herbert Mead (1934) and Herbert Blumer (1969), is presented as a foundation for grounding the subsequent examination of research methods, processes, findings and the discussion of findings. How key tenets of these underlying theories are applied to this study, and how they guide and inform the exploration of the impact of caregiving for adolescents with cancer on family roles and relationships within the context of Chinese culture, will be justified. Furthermore, basic social processes, the use of literature, constant comparison, and theoretical sensitivity and saturation as pertaining to grounded theory epistemology will be examined.

Historical overview
Grounded theory was originally credited to sociologists Barney Glaser (1930–) and Anselm Strauss (1916–1996). A host of publications reveal potential sources of variations between Glaser and Strauss on grounded theory. Glaser was originally educated and received training in quantitative research at Columbia University and formulated the techniques and procedures for both coding and testing hypotheses, generated from qualitative research methods (Eaves, 2001). Glaser was initially hired by
Strauss, a social scientist. Strauss was strongly influenced by symbolic interactionism, as developed by George Herbert Mead (1863-1931) and Herbert Blumer (1900-1987) at the University of Chicago. Rudiments of the grounded theory data collection and analysis methods were delineated in the late 1950s with Strauss’s and Glaser’s research on dying and their publication of *Awareness of Dying* in 1965 (Glaser & Strauss, 1965).

Glaser and Strauss (1967) developed the grounded theory method by providing written guidelines for systematic qualitative data analysis with explicit analytical procedures and research strategies. They called for qualitative researchers to move toward theory development (Denzin & Lincoln, 2000). From 1967, Glaser and Strauss developed the theory in different directions. A comparison of their original *The Discovery of Grounded Theory* (Glaser & Strauss, 1967) with Glaser’s (1978) *Theoretical Sensitivity* and Strauss and Corbin’s (1990; 1998) *The Basics of Qualitative Research* demonstrates the delicate but distinct differences in perceptions of the method between the two authors since its inception. In subsequent publications on grounded theory by Glaser and Strauss, the reader is clearly introduced to both authors’ ontological and epistemological standpoints (Duchscher & Morgan, 2004). Recently, Juliet Corbin (2008) has followed Straussian ideas on grounded theory in the later book *Basics of qualitative research*. Corbin who is a nurse and researcher, and Strauss’s co-author on the three books related to grounded theory in qualitative research (Strauss & Corbin, 1990, 1998; Corbin & Strauss, 2008). Following the death of Strauss in 1996, Corbin has continued to give researchers detailed steps in data coding from concept identification to theoretical development.

**Definition of Grounded Theory**

Grounded theory is a qualitative research method in which the researcher uses insight gained through the direct observation of a phenomenon to develop theory (Glaser & Strauss, 1967). Glaser (1978) advocates that the researcher take a systematic approach to the collection and analysis of qualitative data to create categories of conceptualisation to integrate patterns and develop a theory. The grounded theory method is helpful in organising data in order to support the systematic development of a theory. Strauss’s (1987, p.xi) grounded theory is ‘designed especially for generating and testing theory’.
Grounded theory is not purely speculative data; it is a conceptually dense theory that accounts for variations in social phenomena, and its original adoption by sociologists in other social sciences, and in practitioner fields, including health sciences (Strauss & Corbin, 1997). Most importantly, grounded theory is an empirical approach to the study of social life through qualitative research and analysis (Clarke, 2005).

Grounded theory affords a systematic approach to generate a theory that illuminates human behaviour as a social process among people in their interactional context (Glaser & Strauss, 1967). Human beings and a relationship with their shared meanings of reality can be defined through interaction between and among participants in the context of the phenomena of interest (Blumer, 1969). Grounded theory thus requires that the researcher advance a symbiotic relationship between data acquisition and theorising (Glaser & Strauss, 1967). In the development of grounded theory, techniques of constant comparison and theoretical sampling occur simultaneously (Strauss & Corbin, 1998). The constant comparative method involves the researcher comparing each incident within the data with the developing theory to ensure that each incident relates to the same concept. Theoretical sampling involves sampling data to explore the emerging theory; the theory is created from the data to facilitate and express what the participants are describing as their experience (Strauss & Corbin, 1998; Corbin & Strauss, 2008). It can be seen from the above that an important concept inherent in grounded theory is that it is grounded in the data and therefore reflects the social reality of participants experiencing the phenomenon (Holloway & Wheeler, 2010).

**Epistemology of Grounded Theory**

Grounded theory begins with a broad topic and allows theoretically relevant data to become evident (Denzin & Lincoln, 1998). According to McCallin (2003), grounded theory is useful in creating knowledge about the behavioural patterns of a group. The real experience is what determines the concept, and the resultant theory accurately reflects the data (Glaser, 2002). The grounded theory method has been used in different areas, such as health care and nursing practice, education and administration (Henderson, 1998; Holloway & Wheeler, 2010; Jeon, 2004).
As Strauss and Corbin (1997) state, grounded theory is considered to be a feasible method of research for socially based problems. Grounded theory is resilient because it accounts for variations and it is flexible in building up concepts from the coded data (Charmaz, 2000). Understanding roles and relationships in Taiwanese families with adolescents with cancer and their needs is a social issue.

Grounded theory is both a methodology derived from the assumptions and theoretical underpinnings of symbolic interactionism and a method for systematically deriving empirically based theories of human behaviour and the social world through an ongoing process of comparative analysis (Kendall, 1999). Grounded theory is informed by Mead’s and Blumer’s symbolic interactionism. Based on symbolic interactionism, grounded theory is concerned with the dynamic relationship between persons and society (Lomborg & Kirkevold, 2003). Therefore it is necessary to explicate symbolic interactionism in order to examine the theoretical basis upon which this thesis’s substantive theory of restoring harmony was developed.

**Symbolic Interactionism**

George Herbert Mead (1836-1931), was a social psychologist from the University of Chicago. Mead collected and published notes from his social psychology courses in a book titled Mind, Self, and Society in 1934. He emphasised self as being situated through interaction with the social world. Self was a product of social interaction, developed and refined through continual participation in society. Mead expounded on and taught the precepts of symbolic interactionism to his students at the University of Chicago, but little was published in the area of symbolic interactionism until after his death in 1931. Mead’s lecture notes on symbolic interactionism were synthesised into a theoretical system and published by one of his students, Herbert Blumer (1900-1986). Blumer contended that, interlinked, the basic premises of symbolic interactionism in Mead's work Mind, Self, and Society formed a distinct sociological perspective. He endeavoured to explicate Mead’s foundational work into a unique approach, the understanding of human behaviour. Further, he coined the term Symbolic Interactionism and subsequently consolidated much of Mead’s work into a distinctive sociological perspective as indicated above. Blumer’s 1969 book, “Symbolic
Interactionism” which is widely acknowledged as a sociological theory and a research approach. The concept of Mead’s view of social behaviourism and Blumer’s perspective of symbolic interactionism are examined below.

**George H Mead: Social Behaviourism**

Mead’s view of sociology has several basic dimensions (Mead, 1934). Firstly, Mead is concerned with studying actual human behaviour rather than social institutions and structures. Secondly, he is concerned with the meaning and significance of events in the everyday social world as selected by the reflective mind from an infinite range of possibilities. Thirdly, Mead contends that society merges in the individual life and in the history of the human species.

According to Mead behaviour is built upon the observation of the ordinary activities of social life, upon publicly available and commonly observable facts that people might notice about their lives together. For example, people take the role of the other, and through this role-taking can then orient their actions as well as their communication so as to participate effectively in community, fulfilling social expectations. Finally, Mead places a great emphasis on socialisation in childhood as the basis for acquiring the control of the “generalized other” and at the same time taking up a personal identity (p.90). For example, the child’s response to the parent tends to arouse in the child an attitude similar to that of the parent. Therefore, the child’s own response to that reaction of the family group leads the child to act in a way that is mirrored from the parental role. His/her behaviour has the same effect upon himself/herself that it has upon the adult parent. Thus importantly for Mead, the essential character of selfhood in each of us, the creation of personality, and development in the family are intertwined (Smith, 1991).

For Mead the change in the child from imitation to self-conscious action reflects the general processes of human development. Human beings possess and use this self-consciousness in all their social interactions (Mead, 1934). Through interaction individuals learn the ways of acting required by others and acquire the self-consciousness that is essential for the co-ordination of collective life in a society, such as sharing a culture and developing significant symbols of language (Wild, 1985). To
acquire significant symbols, people must take the role of the other, reacting to their behaviour as their partner does in interaction. In this study the concept of social behaviourism and in particular role-taking action will be explored.

Morris (1934) introduces Mead’s view of social behaviourism as experientially a derivative from social objects; the world of science is composed of that which is common to and true for various observers. The world of common or social experience is symbolically formulated. All objects in nature are not fixed stimuli but social objects constantly changing as human beings are defined and refined in interaction (Mead, 1934). As Blumer states (1969, p.68), social objects are defined according to “their use for people involved in a situation… the meaning arises from how the person is initially prepared to act toward it”. For example, physical natural objects (a tree, a flower), social objects (a student), and abstract objects (including ideas and moral principles) all have learned meanings (Ritzer, 1996). Indeed, Mead (1934) argued that social psychological analysis must begin with ongoing social interaction, as a social process from which the mind, self and society derive.

**Concept of Mind, Self, and Society**

The concept of mind, self, and society forms the basis upon which each individual receives, through experience, the reflective social self. Humans with minds and selves create a certain type of society; human society creates a unique being that processes mind and self. Also, mind and self are linked, and everything in turn is linked to symbols (Mead, 1934). The self becomes conscious and develops its mind, awareness of the other and their relationship, as well as knowing what modifications may be necessary to react to the other in order to progress the process. Mead (1934) argued persuasively that the development of the self-conscious is crucial in that the implicated ability to take the role of the other is essential for one’s participation in the coordinated activities of organised social life and gives one the tools for individual thought. Therefore in this present study the manner in which the participants consciously reflect and act towards each other in order to achieve a level of functioning and harmony will be examined.
In the human social environment an individual’s response is isolated and he/she stimulates themselves. They are self-conscious of what they are doing (Miller, 1982). One’s own stimulation becomes the consciousness of tendency and of its meaning, as the result of the responses. The consciousness is an especially complex metaphoric construction, providing a framework for interpreting remembered past, anticipated future, and the world around (Mead, 1934).

In the light of the above statement, mind is action made possible by the fact that humans have both symbols and self. Mind is that part of experience in which the individual becomes an object to himself/herself in the presentation of possible lines of conduct. This presentation takes place by means of the imagery of past experience and is dependent on the structure and functioning of the organism (Mead, 1934). On the other hand, mind means people take some control away from the stimulus; people are able to apply what they know to the situation, to make plans of what to do (Charon, 1998). It is the internalisation within the individual of the social process of communication in which meaning emerges (Miller, 1982). The most profound insight consists in understanding significant symbols, such as gesture, tone of voice and action. According to Mead (1934), a symbol is a conventional sign. That is, a symbol may be a bodily movement, a photo, and more often, a word. Indeed, people live in a complex, symbolic world that they must know in order to adapt to the world and solve problems.

Symbols are therefore defined in interaction, not established in nature; most human action is symbolic and full of significance, meaningful, conventional and arbitrary (Charon, 1998). For example, verbal language is a special kind of symbol; it is culturally constructed and is a socially established system (Morris, 1934). Hence from Mead’s perspective it is via symbols that interaction is defined or operationalised.

The significant symbol emerges when the one who makes it is aware of its meaning to the other, such as when one can anticipate the response it will evoke in the other (Mead, 1934). Language is a part of social behaviour, in the form of signs and symbols to communicate meaning to other people. The communication is a consequence of the particular context, such as movement, speech, writing, and assists us to find out what is the intent in the mind of the individual in using that symbol, and then attempt to
discover whether this symbol carries this intent in the mind of the other (Miller, 1982).

The symbolic resources of language in communication meet the need for meaning making as it arises, through expression, appearance and activity. This has allowed the emergence of many of the world’s rituals and religions that provide different cultures with concepts of what it means to be human. People thus legitimise their way of life as ordained by their ancestors as in the nature of things, and so give intelligible meaning to their life (Mead, 1934).

Mead (1934) expresses the self, as a process, not as a static thing. He described the self as interplay between two poles, each at the end of a continuum, which he called the “I” and the “Me”. The “Me” consists of the definitions of oneself given by society, as seen through the eyes of significant others. For example, our ongoing actions in the world as nurses, intelligent beings, women, and so forth are recognised as attributes of “Me”. The “I” refers to the source of impulse, intention and reflection which contains the uniqueness of the individual. All action arises from the conversation between the I and the Me, the “I” being the actor as subject and “Me” being the actor as object (Charon, 1998). From the viewpoint of symbolic interactionism, the “Me” represents the generalised other that controls or directs human behaviours. As previously indicated, the generalised other is understood as the “organised community or social group which gives to the individual his/her unity of self” (Mead, 1934, p. 154).

The self is socially created. The self develops through the same social process. When we speak, we understand ourselves as if from the perspective of our audience. We are part of our audience, sharing meanings in terms of shared symbolic meanings (Stryker & Serpe, 1982). According to Mead (1934) this distinguishes the human from the animal in that the self becomes an object to the organism itself. The organism as a whole becomes part of the environment as it is involved in the social context. The social process makes the individual an object to himself. In relation to this study, the adolescent child similarly develops his/her self through obedience to the group in which he/she is obliged to live by their own physical constitution. The child is involved in the relationship with their parents and siblings. In short, the child is part of the construct of the group in which he/she lives (Miller, 1982). In this study the concept of self and how
self is extended to significant other via the use of symbols, in the parent/significant other relationship, will be examined. This is in keeping with the key concepts of socially constructed symbolic interactionism.

**Society** shapes the self, so the self shapes society. In contemporary language, social interaction is constructed; society continually is being created and recreated (Charon, 1998). The family is the fundamental unit of reproduction and in the maintenance of the species: it is the single unit of the human social organisation in terms of which vital biological activities or functions are performed or conducted (Mead, 1934). Socially, the self has taken the attitudes of others into itself through the language process. It has become the others, and taken on the values of others as its own. The self assumes the role of the generalised other, its values, social interaction and process (Morris, 1934). People construct and reconstruct both a moral and environmental order, and in this define and refine expectation of behaviour in specific roles and contexts (Miller, 1982).

Mead (1934) expresses that there is an actual process of living together on the part of all members of the community which takes place by means of gestures. The gestures are certain stages in the co-operative activities which mediate the whole process, such as a family relationship and different role taking within this group, through interactions, because there is a social process in which the family can function responsibly. The relationship of the individual to the community becomes striking when people obtain mindsets that by their advent make the wider society a noticeably different society (Miller, 1982).

**Herbert Blumer: Perspective of Symbolic Interactionism**

Blumer (1969) contends that the basic premises of symbolic interactionism concepts that link the individual, self and inner conversations are rooted in Mead’s (1934) basic tenets of *Me, Self and Society*. Symbolic interactionism focuses on the meaning that things and events possess for people. Blumer writes that to “bypass the meaning in favour of factors alleged to produce the behaviour is seen as a grievous neglect of the role of meaning in the formation of behaviour [and] sees meanings as social products, as creations that are formed in and through the defining activities of people as they
interact” (Blumer, 1969, pp.3-4). What Blumer is alluding to here is that the focus in symbolic interactionism is on the generation of meaning and its interpretation. It is therefore the patterns of action and interaction that make up groups and societies (Ritzer, 1996).

Blumer (1969, p.2) argues that symbolic interactionism rests on three main premises: … [firstly] human beings act toward things on the basis of the meanings that the things have for them … [secondly] the meaning for such things is derived from, or arises out of, the social interaction that one has with one’s fellows … [thirdly] these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. Social life is seen as consisting of people’s actions. From this perspective, the social network becomes the product of different processes of symbolisation, and attribution of meaning, such as interpersonal communication, which can mean very different things in different cultural contexts (Stryker & Serpe, 1982). Through social interaction, people learn the meanings and symbols that seem inherent in expression of thought. For example, cultural values and norms need to be considered in understanding humans’ communication and developing interventions for promoting communication for people from diverse backgrounds. People accept the norms, values and social rules in order to create and uphold group life (Smith & Bond, 1993).

Social interaction focuses on interactions between an individual and others, a process that can form and reform human behaviour in the sense that interaction is lodged in acting individuals who align their actions to the actions of others by ascertaining what they are doing or what they intend to do. “Group action is the collective action of such individuals” (Blumer, 1972, p. 150); that is, human society can be referred to as anticipating the responses of others implicated with a person in some social action (Blumer, 1969). People share their experiences and through the processes of language acquisition and socialisation of the same cultural group, adapt to specific conditions, and these are dynamic and ever changing. In this present study the manner in which participants engage or do not engage in collective action (caregiving) and the manner in which this is manifested will be explored.
Human society is based on symbols; those symbols create and maintain the societies within which we exist (Blumer, 1969). People modify the meanings and symbols they use in their daily life to examine possible courses of action and the consequences of their action (Crooks, 2001). Symbols make our culture possible, they are the basis for ongoing communication and cooperation (Charon, 1998). The aim is to discover patterns and processes and to understand people’s real situation from their social interaction. In this regard, symbolic interactionism is a useful approach to the study of the ongoing relationship between the individual and society (Strauss, 1978). Symbolic interactionism assists the researcher to focus on how the family constructs and ascribes meaning to social interaction associated with providing care (disease, treatment, roles) for a sick adolescent member, and the impact caregiving has on family dynamics and relationships.

Strauss (1965) and his colleagues emphasise that society is continuously organising towards a negotiated order. Such a society would seem to envisage Mead’s version of the democratic ideal of unconditional sharing with freedom of expression of self and speech. Mead (1934) argued that the religious attitude, based upon the pattern of helpfulness in family relations, and the economic attitude of offering to others some surplus for what one-self needs, are potentially universal.

On the other hand, in collectivist societies, group memberships are much less negotiable, such as in Chinese culture. For example, in Chinese culture, what is one’s family of origin will be sufficient to specify many of the roles one will be required to take on in life. This situation finds expression in more equal allocations and resources among peers, more overt co-operation, a different perspective on intimate relationships, and a preference for un-ambivalent negotiation procedures within the family group (Smith & Bond, 1993). Strauss plays a central role in these elaborations of the social process, and in doing so follows Mead’s and Blumer’s concepts of symbolic interactionism.

In summary, grounded theory examines the perspectives and voices of the people concerned and generates further confirmation and refinement of new ideas through its
methods (Strauss & Corbin, 1998). Grounded theory, with its robust approach to symbolic interactionism, moves beyond developing sensitising concepts to generating inductively derived theories of the social world. The present study reveals the views of Taiwanese families and adolescents by seeking to understand the social construction of meaning and action (caregiving) by asking questions about points of view, cultural influences on action, and strategies regarding the day to day interactions amongst family members caring for adolescents with cancer. The aim is to understand the impact of caregiving on family roles and changes to relationships within such families. The elements of mind, self and society are dynamic, as described previously, and the realities depend deeply on attribution of meaning by the use and interpretation of symbols. In attempting to explore the impact of caregiving on adolescents with cancer at home on family roles and relationships, the present study therefore adopts grounded theory with its theoretical underpinnings in symbolic interactionism and the basic social process.

**Basic Social Process**

The BSP includes both basic social psychological process (BSPP) and basic social structural process (BSSP), “BSPP can become structural conditions which affect the nature of BSPP, and vice versa” (Glaser, 1978, p.103). This concept originated with Glaser and Strauss (1967), and was elaborated on in Glaser’s (1978) ‘Theoretical Sensitivity: Advances in the Methodology of Grounded Theory’. Glaser (1978, p. 106) described the basic social process as “fundamental patterns in the organization of social behaviour as it occurs over time”. Strauss and Corbin (1998) state, the BSP with its various components is essentially the elucidation of complex patterning. As such, BSP makes grounded theory unique among other methods, and cautiously unifies disparate pattern processes across diverse contexts and experiences of the phenomenon. Charmaz (2004) states that grounded theory methods are suitable for studying individual processes, interpersonal relations and the reciprocal effects between individuals and large social processes. The basic social process (BSP) is a central idea of the grounded theory method (Carpenter, 2007). The BSP is the core category around which the grounded theory is developed (Holloway & wheeler, 2010). The researcher uses grounded theory method to focus on answering the question, “what is the basic social
problem and basic social process that underlies the phenomenon of interest?” In the process of inquiry, researcher has an inescapable moral responsibility to be sensitive to the lives and circumstances of the people about whom they wish to share experiences and health behaviour.

Guided by the epistemology of grounded theory, in the following section the use of literature, constant comparison, the use of theoretical sensitivity and saturation will be discussed.

Using the Literature
Grounded theory has a different perspective on this matter from other research approaches (Punch, 2005). According to Strauss and Corbin (1998), the literature tends to be useful in somewhat different and specific ways. The important point is that the literature can hinder creativity if it is allowed to influence and direct the researcher in data collection and analysis. On the other hand, it is advantageous to conduct the cursory literature review in order to clarify concepts. Another view is put forward by Cutcliffe (2000), who suggests that a cursory literature review should precede data collection and analysis in grounded theory, for the purpose of identifying the current gaps in knowledge, and help provide a rationale for the proposed research.

Smith and Biley (1997) also argue that a detailed and comprehensive literature review is not the first stage in grounded theory. They state: “general reading of the literature may be carried out to obtain a feel for the issues at work in the subject area, and identify any gaps to be filled in using grounded theory… but it is important that the reading is not too extensive”. Punch (2005, p.159) states that the problem with reviewing the literature in advance can strongly influence researchers when they begin working with the data. Therefore in the present study, a cursory literature review was conducted to assist in the formulation of the research inquiry and to help in providing parameters for the initial interviews. In addition, during the research process, the literature helped the researcher to find examples of similar situations. During the writing stage, the literature was utilized as a source to confirm study findings.
**Constant Comparison**

Jeon (2004) advocates that constant comparisons be made during data analysis and collection to ensure that the researcher can actually construct a theory from the data. The purpose is to clarify concepts and research hypotheses derived from the data while producing precise descriptions (Glaser & Strauss, 1967). Strauss and Corbin (1998) explain that data gathering is driven by concepts derived from the evolving theory and is based on the concept of making comparisons. Constant comparative analysis is one technique considered to enhance theoretical sensitivity in grounded theory research. For Glaser (2002) constant comparison means to constantly code new data and compare them with already developed codes to generate concepts in order to generate a conceptual and saturated theory. This is supported by McCallin (2003), who states that researchers use constant comparative analysis in order to refine emerging concepts and categories. In the present study constant comparative analysis was used to develop the substantive theory.

**Theoretical Sensitivity**

Theoretical sensitivity is associated with grounded theory and is defined as “a personal quality of the researcher”, or how the researcher interprets the meaning of data and minor differences among data (Strauss & Corbin, 1990, p.41). As Giske and Artinian (2007, p.71) reported, “as more data were collected and analyzed, my theoretical sensitivity increased, enhancing more focused interviews”. Theoretical sensitivity is the ability of the researcher to increasingly develop and to conceptualise and formulate a theory by constant comparison of the data (Glaser & Strauss, 1967).

Glaser (1978) and Strauss and Corbin (1990) advocate the use of theoretical sensitivity in grounded theory. A paramount aspect of the grounded theory method is that the researcher must maintain theoretical sensitivity in every step of the research process (Jeon, 2004). Theoretical sensitivity needs to be applied to ensure that all the categories, dimensions, and properties emerge from the data (Henderson, 1998). As defined by Strauss and Corbin (1998), theoretical sensitivity assists the researcher to perceive the subtle nuances and meanings in the data and to recognise the connections between concepts.
Ambiguities in the different interpretations of grounded theory call for clarification of the epistemological and ontological premises. When a researcher explores the results of grounded theory research, the concept of truth is interpretation which influences the emerging theory (Clarke, 2005). As Cutcliffe (2000) stated, qualitative researchers believe that reality is constructed from human perspectives, sharing everyday life, and individual interactions and meanings of given situations and phenomena. However, most researchers using grounded theory do not discuss epistemological and ontological matters of truth and reality and some even fail to reflect explicitly on the quality or trustworthiness of their research (Lomborg & Kirkevold, 2003). One suggestion put forward by Polit and Beck (2008) is that researchers conduct grounded theory studies using both the original Glaser and Strauss (1967) and the Strauss and Corbin (1998) approaches, and take the usual criteria of theoretical saturation of their categories for ending the research. Polit and Beck’s suggestion has been used in conducting this study.

**Theoretical Saturation**

Theoretical saturation means no new ideas are arising from the data. The researchers are no longer developing properties of the category. When a similar situation repeatedly appears, the researcher is able to indicate that a particular category is saturated (Glaser & Strauss, 1967, p.61). Moreover, Glaser and Strauss (1967, p. 62) also mention that when saturation is reached, the researcher will often find gaps in his /her substantial theory. In this situation, the researcher attempts to maximize the variations of data in one category, and integrates categories to develop the substantive theory and rely on their theoretical sensitivity. As Strauss and Corbin (1998) state, as a category becomes saturated, the researcher exploits the dimensions and properties of the next category through analysing data. With no further ability to generate new information, saturation has therefore been reached.

Glaser and Strauss (1967, p. 73) point out that the researcher’s anxiety to know everything is not necessary for theoretical saturation. If the researcher is satisfied that the data are saturated within the process of constant comparative analysis, the attempt to wait “just in case something new” occurs in the field, often unnecessarily prolongs the
In this current study, theoretical saturation became obvious as categories developed and no new information was forthcoming, and there were no ‘holes’ (Lomborg & Kirkevold, 2003).

Once categories are saturated, the researcher rewrites memos in expanded form. The analytic work continues as sort and order memos so that the researcher may discover gaps or new relationships (Denzin & Lincoln, 1998). However, researchers may be flooded with data integration that they are unable to obtain the distance necessary to commit to a central idea or find gaps when they begin to write. Strauss and Corbin (1998) suggest that researchers go back into the field and selectively gather data about a category through theoretical sampling. In this situation, comparative analysis continues until no further properties or relationships of note are being generated from the data.

**Issues in Contemporary Grounded Theory**

In the last 15 years awareness has been raised in the literature about the different viewpoints put forward by the originators of grounded theory. The primary divergences are outlined below. A review of Glaser’s position (Glaser, 1978; 1992; 1998) shows that for him the inductive method for generating theory and the analytical process of abstraction and conceptualisation are the most important aspects of grounded theory. He has resisted any evolution of the method, believing that reality exists to be discovered; the researcher can be totally neutral in approaching data collection and analysis, and the data speak for themselves; these concepts are the only proper way to generate grounded theory and everything else has less legitimacy. Glaser (2006) further points out that generating grounded theory must emerge from the data, it does not necessarily require discovering all new categories or ignoring categories previously identified in the literature. A key issue of this criticism is that grounded theory analytical processes prompt discovery and theory development rather than verification of pre-existing theories (Eaves, 2001). In addition, Wilson and Hutchinson (1996, p. 123) point out that grounded theory has a generational erosive mistake, leading to the “undermining of the original canons for grounded theory research”. In essence, this methodological mistake refers to the Strauss and Corbin (1990) text, and subsequent debate and criticism from Glaser (1992). Rafuls and Moon (1996, p. 67) state that Glaser emphasises the
“emergent” process of theory development, whereas Strauss emphasises the “systematic” aspect of managing data analysis and synthesis. The outcome of Strauss and Corbin’s approach is a full conceptual description (verification), the researchers test working propositions or “provisional hypotheses” during the research (Holloway & Wheeler, 2010, p.187).

In this situation, Strauss and Corbin (1990, p.22) argue that “reality cannot actually be known but is always interpreted”. Furthermore, Strauss and Corbin (1998, p.171) confirm grounded theory is not discovered on pre-existing reality “out there”. The truth is that “theories are interpretations made from given perspectives as adopted or researched as a co-construction by researchers and participants”. Similarly, Charmaz (2000, p.523) asserts that the “grounded theorist constructs an image of a reality, not the reality that is, objective, true, and external”. The distinction between a constructionist and an emergent view is subtle but important because the emergent viewpoint implies reality or truth embedded in data (Corbin & Holt, 2005). Basics of Qualitative Research (Strauss & Corbin, 1990, 1998; Corbin & Strauss, 2008) provides a serviceable, applicable useful approach to research, and has played a central place in qualitative methodology for building an analysis, studying processes, and attending to how researchers create and view their social constructionist leanings (Charmaz, 2008).

In recent years, Clarke (2005), a student of Anselm Strauss, has published Situational Analysis: Grounded Theory after the Postmodern Turn, the essential bases on Strauss's ecological frameworks in his social worlds and arenas theory. Clarke has emphasised that pragmatism provides the basis for a broader approach to grounded theory. She proposes re-interrogation of the method, identifying the recalcitrancies of grounded theory, and renovation of the original grounded theory approach (Clarke, 2005, pp. 11-18). Clarke’s (2003, 2005, 2006; Clarke & Friese, 2007) continuous work on situational analysis skillfully moves grounded theory in this direction to all variants of the methods by clarifying the logic and use of grounded theory guidelines and thus has increased research accessibility.

Charmaz (2006) on the other hand attempts to move grounded theory into an interpretive future, her book, Constructing Grounded Theory: A Practical Guide
through Qualitative Analysis, emphasising the co-construction of meaning between the participants and the researcher, exemplifies this approach. Constructivist grounded theory explicates and renews the pragmatist tradition of Strauss in grounded theory (Charmaz, 2006). Charmaz suggests that the data form the foundation of the theory, while data analysis generates the concepts researchers construct. Constructivist grounded theory takes action as central, sees action as arising within social situations and structures, and attends to what and how questions (Charmaz, 2008, pp.134-135). Corbin and Holt (2005) argue that participants’ feedback not only contributes to the co-construction of the theory but also enables the researcher to make changes or modification to theory as needed. This approach differs significantly from the views of Strauss and Corbin. Especially in data collection and sampling phases, constructivist grounded theorist adopt several key methodological strategies to engage in systematic comparisons and conduct theoretical sampling. However, Strauss and Corbin’ (1990, 1998) focus on problem-solving, emphasising process, action, and interpretation, that show how people act to solve emergent problems.

The present study will explore the impact of caregiving for an adolescent with cancer at home on Taiwanese family roles and relationships using grounded theory. It is important to understand how family roles and relationships change in terms of function, accommodation and restoration. The following chapter presents both a description and justification of the research methods grounded in symbolic interaction for understanding the social phenomena of family roles and relationships. Thus, chapter four will include an explication of the research design, methods and procedures employed in the sample strategy, data collection and analysis phases. In addition, the ethical considerations of the study and steps to ensure trustworthiness of this study are examined.
Chapter 4  Methods

Introduction
This study adopted grounded theory because the value of the methodology lies in its ability not only to generate theory, but also to ground that theory in data (Strauss & Corbin, 1998). The cursory literature review indicated that presently there is little support for Taiwanese families caring for their children with cancer at home. The use of grounded theory research allowed for the development of a substantive theory which can be used to improve the services towards families and adolescents with cancer at home. This substantive theory is likely to lead health care providers and policy makers to provide appropriate care and service for these families.

The main features of grounded theory consist of coding and categorizing, constant comparative method, memo writing, theoretical sampling, and theory generation. In this chapter, sampling including theoretical sampling, data collection, data analysis including explanation of the constant comparative method and data coding, ethics and ensuring trustworthiness of data will be discussed. By providing a detailed account of the procedural steps the researcher in this current study ensured a clear audit trail so future researchers can undertake similar studies. The procedural steps in the research process are described in Figure 4-1.
The Sampling Strategy

Following ethics approval from the Griffith University Human Research Ethics Committee, letters were written to the head of the research department of the metropolitan Tri-Service General Hospital (TSGH) situated in North Taiwan, explaining the purpose and benefits of the study and requesting permission to access prospective families through the oncology and haematology out-patient clinics. The selected facility serves approximately 2,000 inpatients and 5,000 outpatients daily (TSGH, 2010).
Recruitment processes were not commenced until ethical approval for the study was granted.

The study employed both initial/purposive sampling and theoretical sampling. The participants were chosen from the paediatric doctor's outpatient rooms of the oncology and haematology clinic and cancer help workshops of the aforementioned hospital. The researcher undertook a range of procedures to recruit potential participants. These included the researcher doing the following activities:

- posting “cancer help workshop” advertisements on the notice boards in the paediatric ward and paediatrics outpatient clinics inviting people who were interested to contact the researcher;
- attending cancer help workshops with paediatric doctors and social workers. These workshops were held once a month in the hospital. At these workshops the researcher gave comprehensive cancer care information. At the workshop, the researcher invited families to participate in the study; and
- attending the paediatric doctor's outpatient rooms of the oncology and haematology clinic on Tuesday and Thursday afternoons where the doctor introduced the researcher to potential participants.

Regardless of the mode of contact, the researcher invited potential participants to a private meeting in order to explain and discuss the research purpose, objectives, risks and benefits of the study, and to offer an opportunity to ask questions. This was followed by an invitation to be involved in the study and a review of the information package and consent procedures.

Five families were recruited from the outpatients department, and two families were accessed and recruited through the hospital based cancer help workshops. Participants who expressed an interest in taking part in the study were given an information sheet for parents (Appendix A); for adolescents/ siblings (Appendix B); and consent form provided for parents/caregivers (Appendix C). The researcher needed parents’ or caregivers’ understanding of, and permission to conduct this research. If the participants were under 18 years of age the researcher gained their parents’ or caregivers’ permission.
for participation. Demographic data were also collected from participants (Appendix D). Information sheets, consent forms, and demographic data for prospective participants were produced in both English and Chinese.

**Initial / Purposive Sampling**
The initial purposive sample involved seven Taiwanese families with a variation of 4-5 participants per family. A total of 27 family members, consisting of seven mothers, six fathers, seven siblings and seven adolescents with cancer participated. The study sample was recruited from participants who met a number of inclusion criteria. The purposeful sampling technique selected participants who had experience of the phenomenon under study and who accepted and were able to share detailed information about their experience. Thus, this study’s initial/ purposive sample was selected according to the following criteria:

- adolescents (15-19 years old) who had received cancer treatment over one year;
- families (father, mother and siblings) who provided care for adolescent members with cancer and resided in the same household; and
- family members who were willing to share their experience.

**Theoretical Sampling**
Strauss and Corbin (1998, p.73) define theoretical sampling as “sampling on the basis of the emerging concepts, with the aim to explore the dimensional range or varied conditions along which the properties of concepts vary”. The aim of theoretical sampling is to ensure that the researcher takes full advantage of the available opportunities for comparison between events (Strauss & Corbin, 1998). Theoretical sampling guided by significant ideas emerged from the data (Cutcliffe, 2000), so the researcher was sampling data and not participants, although participants clearly had to be used to obtain this data (Tracy, 2004). In order to fully explore the nature of interactions within Taiwanese families who had adolescents with cancer, the subsequent sample was based on theoretical sampling which maximized opportunities to develop concepts in terms of their properties and dimensions, uncover variations and identify
relationships between categories. The theoretical sampling guide (Table 4-1, p.67) assisted the researcher to explore the dimensions of family roles and relationships for the participants.

The theoretical sampling guide for this research was based on the following rationale. It was anticipated that the adolescent’s gender may have an influence on the interview data (Tracy, 2004), and siblings may also affect family roles and relationships; therefore adolescents with and without siblings were included in the research to help identify the importance of the latter for the adolescent with cancer. The treatment stage was also identified as having the potential to influence the family roles and relationships of the adolescent with cancer (Woodgate, 2004; Wu, 2009). The theoretical sampling guide was developed from evidence in the data analysis and emerging categories (Holloway & Wheeler, 2010).

Table 4-1  Theoretical sampling guide

<table>
<thead>
<tr>
<th>Gender</th>
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<tbody>
<tr>
<td>Male adolescents with cancer</td>
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<td>Female adolescents with cancer</td>
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</table>

<table>
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<tr>
<th>Siblings</th>
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<tbody>
<tr>
<td>Adolescents with cancer who have siblings</td>
</tr>
<tr>
<td>Adolescents with cancer who do not have siblings</td>
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<table>
<thead>
<tr>
<th>Treatment stage</th>
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</thead>
<tbody>
<tr>
<td>Adolescents with cancer who are over one year into treatment</td>
</tr>
<tr>
<td>Adolescents with current cancer who are still on treatment</td>
</tr>
<tr>
<td>Adolescents with cancer who have finished treatment</td>
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<table>
<thead>
<tr>
<th>Parents’ marital status</th>
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</thead>
<tbody>
<tr>
<td>Adolescents with cancer who live with both parents and siblings</td>
</tr>
<tr>
<td>Adolescents with cancer who live with one parent and one sibling</td>
</tr>
</tbody>
</table>
Participant Demographics

Participant demographic information of the 27 family members is shown in Appendix H-1. Mothers ranged in age from 43 to 51 with a mean age of 46. Fathers ranged in age from 43 to 53 with a mean age of 48.3. Seven of the siblings (5 sisters and 2 brothers) ranged in age from 15 to 22 with a mean age of 18. Of the 7 adolescents with cancer, 4 were boys and 3 were girls; the mean age was 17.7 years with a range of 15 to 19 years.

With regard to marital status, most parents 12 were married, with one mother being divorced for 10 years and living with her children. Her divorce had occurred 9 years before her daughter was diagnosed with cancer. In terms of religious beliefs of the parents, two couples had no specific faith; 8 were Taoist, and 3 were Buddhist; their religion gave the family spiritual support.

Regarding the education level of parents, 6 had completed high school education, 5 were university graduates and 2 had completed primary high school education. The majority of caregivers were mothers: 4 provided care from 9-16 hours/day, while 3 provided care for 17-24 hours/day for sick adolescents.

Adolescent demographic information is included in Appendix H-2. The majority of adolescents had leukaemia, one had a brain tumour, one lymphoma and one a left ovary tumour. Of the total number of adolescents, 100% had chemotherapy, and 4 had combined therapy including surgery, radiation or peripheral blood stem cell transplantation and chemotherapy. 2 adolescents had finished their treatment and 2 had experienced relapse.

To protect participants’ confidentiality and anonymity, the seven families included in this study are identified using pseudonyms for their family names: Yeh, Wang, Sue, Kung, Wu, Liu and Hung. These names were chosen at random so as not to reveal the participants’ identities.
Data Collection
In the present study, in depth, semi-structured interviews were conducted with each member of the seven Taiwanese families. Participants were interviewed in their own home thus establishing a safe and comfortable environment for sharing the participant’s personal experiences and attitudes as they actually occurred (DiCicco Bloom & Crabtree, 2006). In addition, the researcher interviewed all participants separately to gain accurate data; thus, parents, siblings and adolescents were individually interviewed to establish an open atmosphere of trust so that the participants would feel free to share their feelings and experience (Gray, 1994; Maxwell, 2005). Participants were informed that they may contact the researcher at any time if they had further questions and that they would receive a phone call the day before the interview to confirm their willingness to participate and to inform them of the appointment time and place (Henderson, 1998).

Interview Approach
In Taiwan, the common language is generally Chinese or Taiwanese, or a combination of both. In order to communicate effectively in the interview process, the researcher, for whom Mandarin and Taiwanese are native languages, communicated in the participant’s preferred language in order to gain trust. Establishing rapport is also critical in conducting interviews. As Fontana and Frey (2000) stated, the interviewer’s language should be understood by the participants and interviews must be conducted in the participants’ language. Therefore, the researcher conducted all the interviews in Chinese which was also the language of the participants.

Mothers were pleased to share their experiences of caring for their sick children and commented on their roles and relationships with the adolescent with cancer. The interviews with five of the mothers lasted up to two hours. Two interviews took three hours; participants were eager to spend time talking to the researcher about their caregiving experience at home especially where they had experienced a relapse in their child’s condition. The fathers’ interviews took approximately 45-70 minutes to complete. Most of the fathers expressed appreciation for their wife’s efforts in taking care of the sick child. The healthy siblings spent a comparatively smaller amount of time talking
about their experiences of lifestyle change and their responsibilities; however, they spoke energetically during the 25-45 minute interview. The interviews lasted between 60-95 minutes for the sick adolescents. They spent more time sharing their physical and psychosocial distress and how they felt about further concerns, such as school and work.

To ensure clear interpretation of meaning, three mothers, one father, two adolescents and two healthy siblings each took part in a follow-up interview, choosing for reasons of time constraints to do this by phone. The interviews were recorded and transcribed, and took 20-40 minutes each.

**Questioning Process**

The grounded theory interview is flexible to ensure that data generation is not constrained by the structure of questions; a process of utilising broad and open questions is used to gather participants’ perspectives on the meanings or experiences that the researcher intends to explore (Wimpenny & Gass, 2000). Before the interview commenced, the researcher informed participants that they could stop the interview and have the recorder turned off at any time thus enabling the family member to decide upon the information recorded. It was important to keep to general and open questions, such as “Can you tell me about your concerns about the disease?”, “Can you describe a typical day in caring for your child?”, “Can you tell me about your experience with your ill sibling?”, or “Tell me in more detail about that,” to encourage participants to share their ideas and knowledge about care practices used in caring for a child with cancer.

Following the initial open questions, parents were asked questions concerning the issues they faced when caring for a sick adolescent by interview guide (Appendix E). Although the order varied in which the fathers, healthy siblings and sick adolescents spoke, the mothers in this study wanted to talk first. Participants preferred to speak after dinner, because traditionally the family would be at home for dinner, although two mothers preferred a time before lunch, being employed part-time in the afternoon.

The process of sampling and data collection continued until no additional concepts and information emerged from the data analysis, and theoretical saturation had occurred.
(Punch, 2005, p. 158). To support the interview process, the additional questions which were directed by the participants’ responses were required beyond those contained in the interview guide. The guide included three categories: parents, healthy siblings and adolescents with cancer (See Appendix E).

Data Transcription and Translation

Transcription of recorded interviews has become the norm in most qualitative research (MacLean, Meyer, & Estable, 2004). However, Easton, McComish and Greenberg (2000) have reported that transcription errors can be as simple as inaccurate punctuation (e.g., its and it’s) or as serious as mistyped words that change the entire meaning of the sentence (e.g., we’ll probably have to adopt that, when the actual word is adapt). Other errors can be caused by jargon or other barriers, such as slang terms or words specific to a culture which can lead to misinterpretation or mistranscription, such as milieu is transcribed as mail heap (Easton, McComish, & Greenberg, 2000). The authors suggested ways of avoiding some pitfalls of transcribing and recommend that, ideally, the researcher should be the interviewer and the transcriber.

Irvine et al. (2007) have suggested that to minimise any misinterpretation during the interviews, non-verbal communication requires careful thought since there are clear differences in the way that gestures, posture and eye contact are used in different cultures. For example, some fathers in this study sighed to express their powerlessness. Most mothers turned their heads or closed their eyes when they described how the sick children suffered, expressing their sorrow. The parents used a praying gesture when they spoke the name Bodhisattva, which expressed respect. The healthy siblings and sick adolescents stood up or turned on their computer during interviews. This movement told the researcher, “I do not want to talk anymore” or “I do not know how to answer this question”. The researcher wrote memos (see Appendix I-2) in order to carefully record participants’ perceptions (Halcomb & Davidson, 2006).

Another strategy to avoid transcription errors is to employ a professional translator to ensure a high degree of accuracy (Huang, 2008). In the present study, a bi-lingual accredited translator with over 5 years’ translation experience was employed to check
the accuracy of the translation process. As Twinn (1997) suggested, it is important to use only one translator to translate interview content from Chinese to English in order to maintain consistency and reliability in the analysis of the data.

Twinn (1997) has found translation challenges between the original, transcribed Chinese text and the English translated text as the Chinese language is complex, and it is often difficult to find equivalence of meaning when dealing with issues such as syntax differences between the Chinese and English languages. Similarly, a study by Yu, Lee and Woo (2003), found that it is quite difficult to find direct adequate equivalence of features in English and Chinese as, for example, the Chinese language contains no complex tenses. The researcher and the translator in this study double checked common mistakes that could have been caused by the use of tense during the interviews. For example, one mother stated, “My son told me, ‘I have grown up, I know what I am doing, do not worry about me. Your worry is my pressure.’” The researcher and translator were careful to translate her meaning in the appropriate tense.

MacLean, Meyer and Estable (2004) reported that errors lead to more inaccuracies in transcription and introduce a greater potential for misinterpreting the data at the analysis stage. As an example, one father used a Chinese proverb, “貧賤夫妻百事哀”. There are many meanings of this proverb for Chinese speakers. The researcher and translator needed to focus on the participant’s situation and correctly estimate the participant’s intention. In this case, the researcher and translator understood that the participant wished to express the idea that “poverty competes with love as the major influence on a family and their strength”.

Vocabulary is also a significant translation issue. As Shyu, Archbold and Imle (1998) point out, it is difficult to find an English word for a concept in Chinese. When this occurs, the researcher can directly transcribe the Chinese word phonetically with detailed descriptions to preserve the meaning of the concept. For example, in the present study, in order to translate the concepts of Kuan Yin (觀音) Bodhisattva and Bai-bai (拜拜) correctly, the researcher and translator needed to check the Chinese dictionary and religious books and include English footnote descriptions of the concepts.

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Chinese is the first language of the researcher and participants, English is the researcher’s second language. Twinn (1997) indicates that transcripts might work best when analysed in the original language rather than being translated prior to analysis. In the present study, the following steps were taken to minimize the impact of language differences:

- After each interview, the recorded Chinese text was immediately transcribed by the researcher.
- The interview transcripts were checked for context and content accuracy before the researcher began the data analysis.
- The interview transcripts and the coding, as well as labelling, were documented in Chinese by the researcher, and were not translated into English in order to reduce the risk of losing or changing conceptual meaning during translation into English.
- Data were then analysed concurrently with data collection following Strauss and Corbin’s (1998, 2008) coding method.
- Themes were developed in Chinese by the researcher, and then translated from Chinese to English by both the researcher and the translator.
- Indexing and partial transcriptions were presented in both English and Chinese by the researcher and translator.
- Peer review (colleagues of the researcher) was used to ensure that categories and a core category were supported with data (Irvine, et al., 2007)
- The researcher consulted with the translator when transcripts and coding data revealed any ambiguities in word meanings.

**Data Analysis**

This present study used Strauss and Corbin’s coding procedure to develop a substantive theory that identified the impact of caring for adolescents with cancer on Taiwanese family roles and relationships. Data analysis was conducted simultaneously with data collection (Charmaz, 2006) The constant comparative method was used to analyse the data. This involved the researcher looking for similarities and differences in the data and considering their next questions to clarify the emerging concepts. These processes resulted in the categories being saturated. Categories were considered to be saturated when no new information seemed to emerge during coding, that is, when no new
properties, dimensions, conditions, actions or consequences were seen in the data (Strauss & Corbin, 1998).

In addition, member checks were undertaken when the findings were shown to three participant families and a few amendments were made (Holloway & Wheeler, 2010). Subsequently, the three families indicated that the findings were true to their experience and they requested a copy of any publication.

In the present study, I engaged in theoretical sensitivity by being aware of my values, beliefs, and predispositions that impacted upon data collection and analysis as supported by Holloway and Wheeler (2010). For example, I wrote memos during interviews, recording such details as participant body language, tone of voice, eye contact and parent interest in preparing folk remedies. I used these as cues for questions and responses and they helped me to reflect later on my observations, in order to minimize bias in the data collection.

During the coding and analysis procedures in the present study, theoretical sampling and memo writing, including diagramming continued until the data were saturated and the substantive theory had been developed. As Hwang (2008) has indicated, computer software programs offer many advantages for managing qualitative data. Sophisticated theory building software can assist the researcher to build relationships between concepts, develop hierarchies of code, diagram, and create hyperlinks to build up non-hierarchical networks (Polit & Beck, 2008). In the present study, qualitative software ATLAS.ti 5.0 was used which is described below.

**Data Organisation**

The researcher used ATLAS.ti 5.0 (Lewis, 2004) to manage the large volumes of narrative text from interviews, to assist with coding and categorising of data. This began with the management of coded files. Each participant was allocated a code indicated through family names (pseudonyms, e.g. Yeh family=Y) and relationship (e.g. mother=m; father=f; brother sibling=bs; sister sibling=sb; adolescent=A). Each file represented an interview and its transcript. This identification was used during analysis.
in order to ensure that participants from the various families had codes in their family name and family relationship sequence. Second, a list of the participant codes was made to refer to details of codes for all the participants and interview data. Seven families were involved in the study and as stated earlier, the interviews were transcribed in Chinese. The computer was coded according to the identifying family name and relationship; for example Ym is identified the Yeh family from the mother. Finally, ATLAS.ti 5.0 assisted the researcher to manage codes from data and organise them. For example, when the researcher’s code was “physical distress”, the software would count and cluster the number of entries in this code. The aim was to assist the researcher to create further categories. Strauss and Corbin’s (1998) analytical framework was used. The main data analysis procedure is described below.

**Data Coding Procedures**

Grounded theory uses three levels of coding as per Strauss and Corbin’s protocol (1998). These are open, axial and selective coding. These three levels of coding were used in this present study.

**Open Coding**

Open coding was performed as the first step. The purpose was to assist the researcher to carry out the steps of theory building including conceptualising, defining categories, and developing categories in terms of their properties and dimensions, later to relate categories through hypotheses or statements of relationships (Strauss & Corbin, 1990, pp. 84-39). Interview data were analysed using line by line coding. The process identified concepts and their properties and dimensions in the data (Moghaddam, 2006). Specifically, at the beginning of a study, open coding enabled the researcher to generate categories quickly and to develop concepts. In the open coding phase, microscopic analysis was used in questions to identify who, when, what, how and why of the theory (Strauss & Corbin, 1998, p.66).

The researcher initially fractured data, line by line, in order to discover all possible aspects of issues and ideas contained in the data. The microscopic fracture of the data generated numerous codes which could be clustered in similar groups and gain meaning.
for developing concept. The concept should contain codes that explain a similar issue (Strauss & Corbin, 1998). The researcher in this study, used experience and knowledge to develop the theoretical sampling guide and helped in the selection of the interviewees to gain the best data. Through using a line by line approach to analysis, the researcher explored each word, phrase and sentence of the data, and fractured the data into the codes for comparison between the data and the constant comparative method (Strauss & Corbin, 1998, p.201).

Comparing incident with incident in order to classify data for similarities and differences, also helped the researcher to sensitise possible properties and dimensions (Corbin & Strauss, 2008, pp.73-74). In this coding period, names of concepts and categories sometimes changed with the addition of new data, and also the researcher attempted to condense codes together into groups of similar concepts and categories were formed (Holloway & Wheeler, 2010). This is reflected in the following (Appendix I-1) interviews when these codes have been identified as being about the same topic and combined into a concept.

The open coding was undertaken in Chinese as a means of ensuring the preservation of the participants’ meanings. However, the data from open coding were also labelled with codes in English for the purpose of future analysis. The computer software ATLAS.ti 5.0 was utilised during open coding, and the researcher identified 168 codes from seven families’ interviews. Forty three concepts were developed from these codes, which the researcher was further able to cluster into a category. A category is a more abstract approach to data organisation and explanation for a diversity of issues about a similar concept, which are then drawn into categories. The researcher gave each category a definition to assist in understanding the category.

**Axial Coding**

The second step in analysing the data was axial coding. In axial coding, categories were systematically developed and linked with subcategories to help build theory. Strauss (1987, p.64) points out that axial coding is building “dense texture of relationships around the axis of a category”. The purpose here was to begin the process of
reassembling data that were fractured during open coding. Researchers consider theoretical saturation is reached when no new information, no new properties, or relationships emerge during analysis (Strauss & Corbin, 1998, p. 124).

At this stage in this study, it was assumed that broken family life was a major category because this category linked and integrated most concepts (e.g., disharmony, living with distress, lives on hold, lifestyle change and set-back in life). Through recursive analysis with categories, identifying the basic social problem and basic social process were discovered by re-analysing all concepts and categories, and by asking questions about “what causes disharmony in Chinese cultural beliefs?” “What is the underlying meaning and purpose of these categories and their properties?” “What is the aim of these categories collectively?” Asking questions and thinking about some of the answers assisted the researcher to understand the problem from the participants’ perspective. Yet some answers provided cues for the researcher to think about what concepts needed to be investigated in the data, and to provide the existing categories in order to draw possible relationships with these concepts (Corbin & Strauss, 2008, p. 70).

**Selective Coding (Core Category)**

Selective coding is the last stage of data analysis and has three steps. The researcher analysed the data to identify the core category of the study. Strauss and Corbin (1990, pp.117-118) pointed out that explicating the story line, is the first selective coding step; relating subcategories around the core category by means of the paradigm is the second step. The third step involves relating categories at the dimensional level. The subsequent steps are validating categories, relationships, and filling in categories to integrate and refine the core category. The core category represents the main theme of the research and it is the central phenomenon around which other categories are integrated (Strauss & Corbin, 1998, p.145).

The story line is the first step of this stage of theory development (Strauss & Corbin, 1990). The story line is a narrative in which incidents in the data can be fitted; it is a descriptive narrative about the central phenomenon (Goede & Villiers, 2003). The narrative enables a move to conceptualization (Strauss & Corbin, 1990, p.120). The
story line in the present study took the following form: When an adolescent in Taiwan is diagnosed with cancer, the disease and its treatment have a profound effect on roles and relationships within the family. These effects can be physical, psychological and even financial distress. Family caregiving is important, in keeping with Chinese cultural values and beliefs. Although families embrace the challenge, it can mean a bitter-sweet burden for the parents, and living with distress for the whole family. Familiar roles and relationships are disrupted causing strain. Parents may feel they are putting their lives on hold. There can be lifestyle changes for the sick adolescent’s siblings with the adolescent having the sense of having a set-back in life. These causes and effects are underpinned by Chinese culture intrinsically affecting the chain of family life and creating the sense that it is ‘broken’. The researcher expanded the concept of ‘experience of the disease’ by relating it to ‘caregiving’. The result was characterised by a series of challenges and problems that could be traced back to the cultural condition.

The core category evolved out of the list of existing categories. Various categories need to be integrated to form a theory; as Corbin and Strauss (2008, p. 104) state, “a researcher studies the categories and determines that though each category tells part of the story, none capture it completely”. Therefore, the researcher in this study used several techniques to develop the core category, such as writing the story line, making use of diagrams, reviewing and sorting memos, which aimed to find an intersection between all the important categories in this study.

The core category was used to explore the basic social process (BPS), because central to grounded theory is the identification of BPS to explain the social phenomenon under investigation (Fagerhaugh, 1995). Another characteristic of a BPS is that it solves a basic social problem (Glaser & Strauss, 1967). In the present study, the basic social problem (core category) for adolescents with cancer and their families was experiencing the broken chain of family life. The basic social process labelled by the researcher as restoring a harmonious family life (see Chapter 6), aimed to resolve the basic social problem.
Memos and Diagrams
Throughout the data collection and analysis period, the researcher engaged in memo writing and diagramming. Memos and diagrams are useful for researchers to code data and are an essential procedure in the data analysis process (Henderson, 1998; Holloway & Wheeler, 2010). Complementing and explicating diagrams provide visual representations of relationships amongst concepts (Strauss & Corbin, 1998). Glaser (1978) and Strauss and Corbin (1990, 1998) used memos as a reflective tool to record the researcher’s abstract thinking about the data. Memo writing is essentially a reflective process that provides the researcher with an opportunity to remember, question, analyse and create meaning about the time spent with participants and the data that were generated (Mills, Bonner & Francis, 2006).

The memo shown in Appendix I-2 helped to develop the focus of the theory in this study. The process of writing memos was used throughout the study to help conceptualise the data and clarify the researchers’ thoughts on what was happening. Memos allow the relationships between the categories and the central category to be identified in order to develop a substantial theory (Tracy, 2004). According to Strauss and Corbin (1988) there are three forms of memo that occur in a grounded theory analysis. These are code notes, theoretical notes and operational notes. Code notes are utilised to describe the process of coding, theoretical notes explain the researcher’s thoughts on theoretical sampling, and operational notes relate to the thoughts on the procedure of developing a substantive theory.

Ethical Considerations
There were three phases in gaining access to the participants for this study: first, obtaining ethical approval from Griffith University Human Research Ethics Committee (Appendix F); second, obtaining the permission from the Tri-Service General Hospital (Appendix G); third, gaining the consent of the participants to be interviewed.

The researcher had a responsibility to ensure that the rights of participants were protected. The conduct of this research involved the collection, access and/or use of participants’ personal identification information. The information collected was
confidential and was not divulged to third parties without the participant’s consent. The researcher knew who the participants’ confidentiality was safeguarded at all times.

Prior to the interview, written consent was obtained from the participants. Permission to record the interviews was sought from participants. These participants were informed that participation was voluntary and they could withdraw their consent at any time during the study without penalty. During the interview, it was possible that participants might recall some unpleasant memories or experiences. The researcher was experienced in caring for such families, as a Registered Nurse with oncology nursing experience and supporting those who were distressed. However, if the participants asked for other support, they were given information to contact a hospital counselling service for assistance, free of charge.

The participant’s name or any identifying information was not disclosed to anyone, apart from the research team. The transcribed data will be locked in a cabinet at the researcher’s office in the School of Nursing and Midwifery of Griffith University for a period of 7 years after which time it will be destroyed as per National Health and Medical Research Council (NHMRC) guidelines (2007). The data will be erased following transcription and following verification from participants/translator regarding the authenticity to avoid voice identification.

**Trustworthiness**

Trustworthiness of qualitative research includes credibility, dependability, transferability and confirmability (Lincoln & Guba, 1989). Clissett (2008) described the issue of trustworthiness in qualitative research as important. A major criterion for establishing credibility is a member check. According to Holloway and Wheeler (2010, p. 305), member checking is to present the translated content to participants to provide an opportunity to receive their comments, agreement or correct errors in order to maintain the authenticity of the data. Member checking with family caregivers and adolescents was conducted to ensure that the findings were accurate representations of their experience. In order to avoid personal biases during this study, the researcher clearly described the study purpose, the data collection and analysis methods. As Graneheim
and Lundman (2004) have stated, a credible interviewer addresses the intended focus and selects the most suitable meaning unit and judges the similarities and differences between categories. In this study, any confusion during the interview content was elucidated through separate conversations with both translator and participants.

Linked with dependability, it is necessary to underline the trustworthiness of the process (Guba & Lincoln, 1989). Dependability involves both factors of instability and factors of phenomenal or design induced changes; thus, replicating the study with the same or similar participants in the same or similar context would produce similar results (Clissett, 2008). Rolfe (2006, p. 305) points out that dependability relates more to “reliability”; that is, the degree to which data change over time and developments in the researcher’s ideas during the analysis process (Graneheim & Lundman, 2004). Dependability can be achieved by keeping records of key features in interactions and any change in the emergent design of the study, together with a justification for any decisions that were made (Clissett, 2008). In the present study, the details of data analysis enable readers to follow the process that the researcher has gone through, such as interview guide, the complete transcriptions of the interviews, memos and conceptual diagrams were collected and analysed; these sources of data were used to show the linkages between emerging concepts.

With respect to transferability, a rich and vigorous presentation of the findings together with appropriate quotations will enhance transferability (Graneheim & Lundman, 2004, p.110), which is a form of “external validity” (Rolfe, 2006). In the present study, the researcher made a clear and detailed specification of the conceptual linkages, the tape recordings, memo writing and data collection methods to help ensure confirmability of the data. To enhance contextual transferability, theoretical sampling was used to develop meaningful data until saturation of the core category was reached.

In the present study, open questioning promoted the participants’ thoughts about their experiences, and more specific questions was asked in relation to certain events, behaviour, such as caregiving adolescents with cancer at home, feelings and experiences. In addition, as the researcher I have many years of experience caring for children with cancer. I am aware not to be judgmental, never comment on responses, only concentrate
on eliciting information, thoughts and explanations of feelings. Hence, I attempted to assume an impartial mindset in order to obtain the most unbiased data from the participants. As Strauss and Corbin (1990) explained, researchers need to step back from the research situation in order to obtain true data from the participants.

Summary
Grounded theory was used to identify the impact of caregiving for an adolescent with cancer on Taiwanese family roles and relationships. Data were collected using semi-structured interviews with adolescents and their family members. The trustworthiness of the grounded theory approach offered a set of clear guidelines from which to build explanatory frameworks that specified relationships among concepts. Strauss and Corbin’s (1998) procedure for data analysis was used. The constant comparative method was applied to define a core category and a storyline as the main outcomes of analysis. Theoretical sensitivity was used to ensure that all the categories, dimensions and properties were generated from the data. The data were collected and analysed until saturation of the categories was reached and no new information was forthcoming. Using this method helped to examine how family roles and relationships change as a result of caregiving for an adolescent with cancer at home. The following Chapter will present the basic social problem of experiencing the broken chain of family life when caring for a sick adolescent with cancer.
Chapter 5
The Basic Social Problem:
Experiencing the Broken Chain of Family Life

Introduction
This chapter presents the basic social problem of this study. The aim of the study is to explore the impact of caregiving for an adolescent with cancer on the roles and relationships within the Taiwanese family, and examine how family members perceive and manage caregiving for an adolescent with cancer at home. The study questions are related to the perspectives of both adolescents with cancer and their family and these are elicited and described. Data analysis indicated that the basic social problem experienced by both the adolescent and family (7 families’ demographic characteristics of these participants are depicted in Tables in the Appendix H-1 and H-2) affected many aspects of their lives and resulted in the fragmenting of normal sequences of life events. This problem, *experiencing the broken chain of family life*, was identified as the core category. Underpinned by Chinese cultural beliefs related to Chinese familism, filial piety (*xiao shun*) and religious faith, this core category is defined and examined within the parameters of symbolic interactionism.

Causal factors include the impact of disease and family caregiving on family roles and relationships, and the consequences include disruption to and experiencing strain through change in those roles and relationships. Both the causal factors and consequences are discussed within the context of the Chinese culture. This chapter concentrates on the causal factors, while Chapter 6 focuses on the consequences of the impacts on family roles and relationships. Chapter 7 presents various intervening conditions that comprise basic social processes used by adolescents and their families in managing the experience of the ‘broken chain of life’. In particular, symbolic interactionism as overarching these intervening conditions is explained.
Experiencing the Broken Chain of Family Life

In Chinese culture, the chain of life signifies wholeness and congruity within all parts of the family, such as roles and relationships. Each aspect is as important as the one that precedes, follows or overlaps it. One weak, or missing, link will halt this natural interconnection and thus, the chain of life will be broken. Wholeness includes not only the physical, but also the spiritual, emotional, moral, financial and occupational factors, which are all needed for wellbeing.

Taiwanese parents hold family bonds as sacred and these bonds are rooted in love and concern for the children, and emerge from the construction of cultural and dynamic family relations. Mostly, Buddhist families believe that cancer is the result of bad karma and relates to fate. The parents become totally devoted to taking care of the adolescent’s everyday needs, developing perspectives on caring practices, and learning the intricacies of health care, when an adolescent has been diagnosed with cancer. This results in a great burden, involving emotional stress such as guilt and anxiety, which can affect family bonds and perception of roles. Hence, the whole vision for the future for the family, the sick adolescent and healthy siblings can appear to them as shattered, or broken. This is epitomised in the following quote from a mother:

> When I knew my son had leukemia, I thought, why did God treat me like this? I cried out loud because I felt guilty and was anxious about the possibility of losing my child; I could not honour the ancestors. Every family member’s nerves were very taut as their closeness and connection might be broken at any time, like the chain of life was broken (mother, Wang family).

One healthy sibling commented:

> My young sister suffered and we all shared that experience. She went along with the treatment, but we did not know if her condition would become more stable or deteriorate. I recognised that my sister’s situation was as painful for us as it broke our

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2 4 out of 7 families in this study had a shrine in their house, where they prayed to gods and ancestors at least once a day for blessings to help their sick child become well again.

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The experience of parenting children with cancer causes stress in families. The shock and distress of the diagnosis and treatment, followed by the disruption to normal patterns of family life, are expressed through the experience of the broken chain of family life. The expression ‘the broken chain of family life’ highlights how important Chinese cultural values are in defining caregiver task performance. Mainstream beliefs for most Taiwanese families are grounded in Confucianism. These families are taught, and live, according to the values of Confucianism and their cultural beliefs. Within this tradition of thought and practice each family member has a responsibility to contribute to their family, which emphasises relationships and moral obligations. Because of the uncertainty regarding the long-term consequences of treatment, parents in this study reported overwhelming feelings of distress at seeing their sick adolescents suffer the physiological and psychological consequences of the chemotherapy treatments. This added to their sense of helplessness. This quote from one father brought this out clearly:

My family life suffered, you could not imagine. We faced distress in everyday life when we saw the ‘toxic’ [chemotherapy] damage to my daughter physically and emotionally... I didn’t know what to tell my daughter to feel, only be there with her (father, Hung family).

The data revealed that most families in the study were under pressure and experienced a sense of helplessness when faced with lifestyle changes and the ‘weight’ of their responsibility. They experienced fatigue associated with treatment and the burden of caregiving, as highlighted by the following quote:

Why did I have such bad luck and why did it happen to my child? We did not have cancer in our family history. A fortune teller said that my son’s illness was that Buddha was giving us the situation... I felt so helpless about my responsibility (mother, Kung family).
Sick adolescents and their family also experienced uncertainty regarding the long-term consequences of treatment. Cancer treatment and its side effects were particularly devastating to adolescents because of striking changes in appearance, isolation from peers and forced dependency. These problems created great difficulty for most of the sick adolescents undergoing treatment. One sick adolescent confided his experience as follows:

*I could not imagine how awful my treatment would be. This was very painful for the whole family, not just for me. I tended to ignore that my appearance had changed and went along with all the treatments, but I doubted that my treatment would have a good outcome when a relapse occurred this year* (Sick adolescent, Yeh family).

Some parents believed that cancer was associated with karma; that is, the bad consequences of deeds done in a previous existence. For example, one father, from the Yeh family, stated: “It was all prearranged; there was nothing we could do, and we could no longer even have any offspring”. Conversely, for other families a new attitude towards life developed because of the cancer experience. Accepting fate and trying to understand the treatment in order to help their sick adolescent to relieve their suffering became a motivation. One such adolescent said:

*I felt so sorry for my parents and younger sister. They needed to focus on my situation and suffered a lot of stress, especially my mum who needed to ask for leave from work to look after me in the hospital and at home. I tried to confront this change but still thought the disease was my fate as my mum said* (sick adolescent, Wang family).

One mother commented:

*My family life was broken but I would accept this change and look after him whole-heartedly because the master in the temple told me my son’s disease was associated with fate or karma; I needed to endure lots of suffering in order to gain a good future*
and we should take it (Mother, Kung family).

In summary, these influences disrupted everyday habits and routines, and affected how the whole family faced significant challenges and managed conflicts when they found themselves living with a life-threatening illness. Families dealt with the sick adolescent’s situation by managing the activities of daily living and providing care that required a strong obligation to engage in activities that were non-negotiable and part of their fate. Family members therefore adjusted the manner in which they interacted with each other and with the sick adolescent through moving away from the usual way they interacted with each other.

**Causal Factors of Experiencing the Broken Chain of Family Life**

This study recognised the importance of family interactional processes that related to the aspect of the broken chain of family life. Data analysis revealed that there were two conjoined causal factors for the ‘broken chain’. These two factors were interrelated in that the adolescent and their family interacted in ways indicating that their lives had totally changed because the disease had impacted on family roles and relationships. Taiwanese family life is dominated by parent-child relationships: parents are continuously accessible throughout the child’s adult life. Family involvement in the care of a sick adolescent is more a designated responsibility and role expectation. Thus, the two causal factors included the impact of the disease on family roles and relationships and the impact of family caregiving on these. The factors presented themselves separately because the adolescent and their family described different situations and elements of the experience of having cancer. These two factors led to consequences for the family. Firstly, disruption to family roles and relationships included the notion that parents’ own lives were ‘on-hold’, healthy siblings felt the impact of lifestyle changes, and the sick adolescents perceived they were set-back in life. Secondly, strain on family roles and relationships included conflict in caregiving, communication barriers and the sense of a loss of control in family life. The symbolic meanings in interaction were modified, causing confusion, with disrupted processes of symbolisation (see p.42). The causal factors and consequences are depicted in figure 5-1.
Figure 5-1  The basic social problem (core category): experiencing the broken chain of family life
Impact of the Disease on Family Roles and Relationships

The impact of the disease on family roles and relationships had many facets. Caring for an adolescent with cancer affected the family physically, psychosocially and financially. These elements impacted upon parents, siblings and the adolescent who was ill, which manifested as a perceived increased vulnerability due to the cancer ‘invading’ the family. The adolescents and their families in this study experienced the impact of the disease on family life both in the hospital and at home. As one father stated:

*My wife looked after our sick son in the hospital and I looked after my older son but he did not like me to stay home with him. He complained lots, but I tried to be both a father and a mother; my mind felt exhausted* (father, Kung family).

The mothers in this study were constantly under pressure while caring for the adolescent with cancer, presenting them with uncertainty about the outcome of the disease. These feelings of uncertainty were continuous. This is highlighted in the following quote by one mother:

*You had to be very careful taking care of him and withstand lots of pressure because I thought I did not take good enough care of him before. Now the treatment is over, but I am still so nervous that I keep getting up at night to check on my son’s condition; it is ongoing* (mother, Liu family).

The data revealed that disease impacted on the family financial situation because three mothers took leave to care for the sick adolescent and wanted to buy some health products and folk remedies which were expensive, as one mother said:

*I would spend a lot of money to buy the health products and attend folk treatment... as I knew my husband’s income was very tight because of my son’s treatment, but I wanted to try different ways to keep his condition stable* (mother, Sue family).
One sick adolescent added:

*I had to listen to my mother’s suggestions to eat healthy products every day, such as Noni [natural herbs products], but these were expensive in price, so my father would work extra-time to make more money for me* (adolescent, Wang family).

In summary, the causal factors of the impact of the disease on the family roles and relationships included complex, unpredictable and uncontrollable treatment involving physical and psychological distress, and insufficient income and family expenses, which resulted in financial distress. The following section will present the physical, psychosocial and financial effect of the disease on family roles and relationships.

**Physical Distress**

As with others undergoing cancer treatment, adolescents face a series of invasive chemotherapy treatments that typically cause physical distress, such as pain, vomiting, fatigue, myelosuppression\(^3\) and change in appearance, especially hair loss. Hair loss causes dissatisfaction with physical appearance because not only does the change signify that the person is sick, but it also reminds them that they are different from their peers. From this, it may be inferred that body image is an important aspect in the lives of adolescents. Data analysis showed that those adolescents who had experienced treatments knew that side effects could not be predicted. The following comment exemplifies this:

*I care very much about looking good in appearance, and I am afraid my face will become ugly and swollen because of taking steroids, like someone who is very seriously ill, or a person in a movie I saw… If I looked like that, I wouldn’t want to go out* (sick adolescent, Wang family).

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\(^3\) Myelosuppression: is defined as decrease in bone marrow function as in association with cancer chemotherapy, it may lead to neutropenia, anemia, or both, resulting in an increased risk of infection, fatigue, diminished quality of life, and reduced survival (Nirenberg, 2003).
One sick adolescent stated:

_My mouth was full of ulcers; I could not eat anything for two days. Also, my blood [Red Blood Count] got too low twice and my doctor ordered two blood transfusions, but I had blood allergic reactions, suddenly I could not breathe... I was very seriously sick_ (sick adolescent, Hung family).

Another sick adolescent explained how classmates seemed to perceive her appearance:

_Some male classmates laughed at me, pointing at my face and saying that I did not have eyebrows. I wore a headscarf, and then a boy from next door would tease that he wanted to talk to the ‘boy’ who was wearing the headscarf_ (sick adolescent, Wu family).

One sick adolescent also commented that she felt unhappy about her appearance, as highlighted by this quote:

_When I took a shower and saw myself in the mirror, I hated myself, I was disgusting, so, I did not want my classmates or friends to come to see me because I didn’t want to be tagged as a cancer patient who was weak, ugly, got tired and was infection prone_ (sick adolescent, Sue family).

This impact of the disease had an ongoing influence, compounded by an increase in the intensity and severity of newly emerging symptoms. In this study, most of the adolescents stated that pain was the most significant symptom that caused suffering. The severity of pain was related to repeated invasive procedures, such as lumbar punctures and bone marrow aspirations, and the multiple side effects of chemotherapy, as

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4 Lumbar puncture: the aim is to collect cerebrospinal fluid to assess a patient’s diagnosis or determine further treatment, such as inject medications for chemotherapy in acute lymphoblastic leukaemia (Ljungman, Gordh, Sörensen, & Kreuger, 2001).

5 Bone marrow aspiration: is carried out principally to permit cytological assessment of bone marrow cells. It is indicated in leukaemia, lymphoma, and microcytic anaemia or suspected multiple myeloma. The posterior iliac crest is generally the preferred site of aspiration (Bain, 2001).
reflected in the following quote:

*When my son received the chemotherapy injections, it was painful for him. The pain was unbearable and he beat the bed frame so loudly that the noise kept the patient in the next bed awake; my son said the pain was so awful that he would want to kill the doctor* (mother, Kung family).

Likewise, another sick adolescent commented:

*Chemotherapy made my blood vessels stiff and it was not easy for the doctor to find new blood vessels for injection. I became more and more afraid of the injections. Otherwise, I had a severe pain in my right leg; the doctor said it was due to taking steroids and it caused bone necrosis, so I needed an artificial hip replacement* (sick adolescent, Wang family).

It was evident in the data that male adolescents with cancer expected to spend increasing social time with friends or doing peer-group activities, but they often experienced lack of sufficient energy, to the extent that it was difficult to be involved in any social activities. They complained that their physical strength was getting worse and that the disease and treatment affected all aspects of their lives. One sick adolescent explained this situation this way:

*I was tired easily after treatment. It was probably that I spent a lot of time staying home and my body was very different than before. I was terrible in gym at school, I ran 800 metres very slowly because my physical strength was weaker; my body stamina was also weak* (sick adolescent, Kung family).

Another sick adolescent added:

*I didn’t like losing hair, having a swollen face or severe mouth ulcers because I could not eat correctly to maintain my weight or physical strength after treatment. Most importantly, my friends might not want me to join their sports group because
they were scared to hurt my body (sick adolescent, Liu family).

More than this, the adolescents suffered symptom distress and mood swings because of medication and the demands of treatment. The females among them had to deal with additional expectations in their life, particularly the special challenges posed by physical defects, such as reduced hair growth. They worried about changes in their physical appearance more than the male adolescents with cancer. An example that supports this is cited below:

After I got sick, I did not want to be close with my boyfriend because I felt I had become very ugly. I lost all my body hair, my stomach got very big, and I did not want him to kiss me or touch me (sick adolescent, Wu family).

The female adolescent was also concerned about possible infertility in the future because of the side effects from the chemotherapy, as reflected in the following quote:

The worst part of chemotherapy was it had damaged my right ovary. It was the first time I cried since I had this disease because it meant that I probably would never conceive a baby (sick adolescent, Hung family).

There is an extremely strong cultural pressure in Taiwan for a woman to have a child, and the same person added:

My periods have stopped for six months now and I do not know when they will begin again. Maybe because I have a boyfriend I felt it even harder to accept, even though my boy friend had said, “If we cannot have a baby, we can adopt one.” But that made it feel even more difficult to accept the fact that I could not have my own child (sick adolescent, Hung family).
As for school work, the data revealed complaints about how the treatment of the disease affected memory and learning ability, so that adolescents needed a longer time to study than other, healthy students. As one sick adolescent explained:

*My problem is how to study, because my brain is affected and unable to think too much. I easily forget something I just memorised. I cannot always gain good scores in school tests; my mother naturally thinks it’s the effect of chemotherapy* (sick adolescent, Sue family).

The data showed that the physical effects on the healthy siblings depended on factors such as witnessing the physical changes, the deterioration and the pain experienced by their ill siblings. Three healthy siblings were concerned about their own physical situation and were worried that cancer was a hereditary disease. They could not sleep well when ill siblings were staying in the hospital. One healthy sibling explained:

*I saw my brother in the hospital, he looked so terrible, I knew it [cancer] was not easy to accept and it really affects everything in my mind. I could not sleep well because of nightmares, and I worried about my own health but I thought my parents did not have time to look after me* (younger sister, Wang family).

Two healthy siblings noted that their temper worsened and they lost weight when their ill brother and mother stayed in the hospital for over two weeks. One of the two commented:

*I did not want any food to eat at home. My father complained about this and it made me get angry easily without any reason,, and I blamed myself for that. I just thought “what I can say” or “what can I do” that will help my mother and ill brother come home soon* (older brother, Hung family).
Physical health symptoms associated with stress were often experienced by mothers caring for their adolescent children with cancer. Mothers had no complaints or regrets about taking care of their children whole-heartedly as they endured the intangible responsibilities associated with this role. Mothers worked hard taking care of their sick adolescent, which affected their own health. They often complained of insomnia, anorexia, headache, and abnormal menstruation patterns. This is described below:

*I had excessive bleeding many times in my menstruation period, I felt vertigo and it was hard to breathe when I got up. The doctor said it might be a stress induced hormone problem. He suggested to me that I take some rest. But how could I rest... I had to work together for the best for my son* (mother, Sue family).

Fathers also emphasised fatigue, aches and pains; for example:

*I got really tired after caring for my son for only two days in the hospital, I got back pain and a sore waist, but my wife took care of my son continuously for months. It was tough on my wife to look after my son. She did not sleep well, frequently complained of headaches* (father, Wang family).

The quotes above indicate that parents struggled with the adolescent’s condition and the progress of the treatment, and that this influenced parents’ health and their ability to control illness in themselves. The adolescents saw themselves according to how they thought other people saw and were affected by them, as highlighted here:

*Chemotherapy was painful, it was torture for my son; we had thought of the worst, but there was nothing we could control, especially when the symptoms reappeared. I saw my son depressed often, he cried and feared that he might die ugly and abandoned by his friends* (mother, Yeh family).

As these data show, physical distress experienced by the family members depended on such factors as side effects and outcomes for sick adolescents. The physical distresses
were often linked with psychological distresses, which are discussed in the next section.

**Psychological Distress**

Families had to face multiple changes brought about by the diagnosis of cancer. There was often bewilderment at the sudden changes in family life. The insights into side effects of treatment related to the chronic illness revealed greater than normal psychological distresses of various kinds, and interpersonal difficulties. One sick adolescent commented:

> I saw myself as so terrible and felt like an alien. I screamed why didn't someone tell me how stupid my hair looked? I cried often and broke all the mirrors until my classmates or other teen group members encouraged me (sick adolescent, Liu family).

The sick adolescents feared that they had changed in appearance because of the strong side effects of chemotherapy. It can be inferred that the adolescents’ psychosocial distress was associated with either a lack of behavioural control or body image changes. For example, when they had visitors at home, they would wear a hat or wig to greet the visitors. One sick adolescent said:

> I was afraid of others touching my hair until my hair grew a little bit and I did not like wigs; it looked unnatural when it got tangled. Therefore, I changed my wig very often and wore my hats at home (sick adolescent, Hung family).

A reason for distress in peer relationships was that the adolescents in the study often took irregular or long-term leave, hence distancing themselves from school life and a normal campus life. Data analysis showed that except for one adolescent, due to relapse during this year, sick adolescents wanted to stay with classmates in school because their illness and long treatment time led them to stay home for much of the time, so they lost contact with their old classmates. One sick adolescent explained:
When I got sick I stopped going to school, I feared that my classmates would not remember me because I took more than a year’s break. They did not visit or call me. I was disappointed and upset that we lost touch, especially with some of my classmates (sick adolescent, Wang family).

His mother added:

_School is the place where you can easily get infected with germs._

We were planning to let him take a one year break, but he was afraid that he would not catch up with other classmates... I would ask him to wear a mask, but he would not wear it to school. _He was afraid his classmates would ask him about his illness_ (mother, Wang family).

When sick adolescents returned to school, the academic learning and student interaction made their school life more challenging and difficult, involving such situations as the fear of not being able to keep up, the fear that other students would treat them differently, and the experience of shame related to needing extra assistance from the teacher. This quote plainly expresses this challenge:

_I was a stranger when I went to the school for the first time after treatment. I could not understand my classmates talking during the class discussion. I also did not know my teachers’ homework requirements every day. I felt so worried and fearful about my classmates that they did not want to accept me and let me join in their sports activities_ (sick adolescent, Kung family).

The above statements indicated that adolescents were concerned about their own health condition; they experienced fear and worry but they could not hide their desire to go back to school and wanted to spend more time with classmates. Since they had lost a lot of time due to the treatment, they cherished the time when they returned to school. It was evident that treatments affected body image and caused difficulties in adjustment to school, as illustrated by the following comments by a sick adolescent.
I had one semester being treated for my disease... My classmates thought I was seriously ill. Some classmates did not want to talk to me, and my physical condition made me feel weak after chemotherapy. I thus could not attend sports classes, just sat and watched them. It was difficult for me to accept these changes (sick adolescent, Hung family).

As commented above, having an appearance different from the peer group also evoked feelings of inadequacy that led to psychological trauma, impacting on self-esteem and peer relationship. Psychological distresses also impacted on the lives of parents and healthy siblings. Living with a life threatening illness, parents felt pressured and obligated to take care of their ill child. In Chinese culture parents, in particular mothers, expect their children to go through the normal life span of growing up into adulthood, getting a job, getting married and living within a family. However, when their adolescent child was found to have cancer these mothers experienced distress as their expectations became unpredictable. This was reported by the mother to be heartbreaking for them stating they would do anything to keep their sick adolescent alive. This quote highlights this point:

*My teenage son’s diagnosis of cancer was therefore a heartbreaking time. I had so many expectations of him [jobs, marriage and grandchildren], but things happened unpredictably. I ached for his suffering, in the realisation that I would keep his life in some way, even suffering burnout myself* (mother, Sue family).

Data analysis revealed that the father’s role of breadwinner in the family changed with his having to look after the healthy children. In Chinese culture, caregiving of the sick child normally falls on the mother of the family. When fathers took on the role of looking after the healthy children, data showed they experienced inadequacy as a caregiver and felt exhausted. This was because they had to hold a job outside the home as well as take care of the healthy child/ children. This resulted in the father experiencing distress. One father had this to say:
I was the breadwinner and second caregiver in the family who was willing to make sacrifices. However, my daughter did not appreciate my cooking and doing chores, she complained to my wife about the food, and I had accidentally dyed colour in her school uniforms. I tried to do better than before, but I felt my energy was spent (father, Wang family).

The study findings also showed that the healthy siblings’ daily life became dysfunctional and was not synchronised with conventional family life after the diagnosis of their ill sibling. The healthy siblings showed even more distress than the ill siblings, such as that their parents were overindulgent and overprotective of the ill siblings and feared confronting family members with negative feelings. One healthy sibling stated:

*My mother takes care of him 24 hours a day and she could not go out to work. All the family focused on him. I really did not like to stay home to look after him. Maybe I felt guilty and unhappy with him together in this house, it was tiring for me to stay home* (older sister, Yeh family).

One mother added:

*I thought I neglected my older son more. He said that I only looked after his younger brother, but I feel that he was upset with me* (mother, Kung family).

When the adolescents and their families talked about the impact of cancer on all family members, they reported serious suffering. They stated fear of the unknown of the future plus the shadow of death which was constantly present. One mother described her son’s situation like this:

*It was found that the cancer had metastasized to the spine, and tumours had grown in the brain again, and the chance for survival was only 20% to 30%. We were afraid losing him even though he was so brave in facing his condition* (mother, Yeh family).
The above findings show the impact of disease on roles and relationships through psychosocial distress. The treatment had ‘scarred’ the adolescents emotionally and damaged their social life through changes in appearance and peer group relationships. The parents and other healthy siblings faced a stressful life peppered by uncontrollable situations and events.

**Financial Distress**

In this study, financial distress also impacted on the family roles and relationships. The daily expenses were very high in Taiwan families caring for an adolescent with cancer, even though the adolescents had health insurance. All of the adolescents in this study had accepted the National Health Insurance (NHI) but burgeoning health costs and the fragmented services had led parents to experience financial burden. Data analysis showed that the mothers had resigned from their jobs or applied for unpaid leave once they learnt about the adolescent's diagnosis. The fathers spent much of their time earning money because the treatment of cancer was very costly, thus the adolescent could not have frequent contact with their father. One mother commented:

> The NHI covered my son’s medical services, however some new cancer drugs needed to be paid by us, and we did not have private insurance. Moreover, I wanted to buy vitamins or healthy food for supplement nutrition to my son. Finance was a big problem... When my son's condition was stable, I could then go out and work with peace in mind (mother, Hung family).

The father added:

> I would only have a little salary and worried about supporting the family. My working hours were from 2pm to midnight, and there were rest times in between for no more than 10 minutes, I

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6 National Health Insurance (NHI) is the current health care system in Taiwan. NHI program is a mandatory, single-payer social health insurance system. People are free to choose any of the NHI contracted hospitals or clinics to receive ambulatory or inpatient care services without a formal referral requirement or a family physician system (Cheng, Wei, & Chang, 2006).
didn’t feel tired while working. I had to work and it was not easy to find work those days (father, Hung family).

In addition, families experienced distress from the social pressures placed upon the male parent (the father) with respect to work, especially the fathers who had children with cancer. Fathers’ role as provider and protector was therefore severely challenged, as illustrated by one father’s comment:

*Family income was a big problem because my salary was just over NT30000 a month. One third of my salary was deducted and the rent was NT12000 a month, so there was not much left. My wife said poverty competes with love as the major influences on a family and their strength (貧賤夫妻百事哀), very sad!* (father, Yeh family).

Parents did not take medical leave to care for their child; the mothers often stopped working to care for an ill adolescent as they were the primary caregiver in the family and were also vulnerable to the loss of employment or advancement prospects. This situation affected the families’ economic future. This was illustrated in the following narrative:

*My wife needed to ask for leave often to look after my son in the hospital and at home. Although the company understood the situation and expected my wife back to work when the child’s condition gained control, we struggled for financial balance and this caused worry* (father, Hung family).

One healthy sibling added:

*My mother was working before and now she doesn’t, so it has enormous impact on our family. Sometimes, mother wants father to help her to take care of my ill sister, but the company deducted money from my father’s pay. Our house has been reclaimed by the bank and I don’t know how I can help* (older sister, Wu family).
Some mothers proposed they would take temporary leave from their job. Family income in such circumstances became necessarily constrained to keep expenditures within the limits of available income, as one mother stated:

*My boss’s wife allowed me to take leave temporarily, but the finances of the family had to maintain daily expenditures. For example, we would decrease contact with relatives or friends, and chose to stay at home or watch TV with the children instead of going out to save money* (mother, Wang family).

The above example indicates the financial issues faced by an average family. Most fathers paid hospitalisation or private insurance fees for their ill child and healthy children’s tuition fees, so the fathers claimed that work was much harder than before. Data analysis revealed that the industries faced very serious economic problems in Taiwan. Childhood welfare foundations could not give the adolescent and their family any financial leverage, such as in the areas of travelling expenses or new medicines fees, as currently the overall economic situation was not in a healthy state. One father cited his experience below:

*My job’s work time was over 10 hours every day and I didn’t want to suffer an unemployed situation… for my ill child, government health insurance could only cover the hospitalisation, we should be able to have private insurance cover for all treatment expenditures, such as traffic fees, thus I worked hard to pay these enormous fees* (father, Hung family).

One healthy sibling added:

*My mother had looked to the Childhood Cancer Foundation for assistance before and it appeared the assistance had now stopped. In this poor economy, who was going to donate money, but we needed more help to keep my ill brother going through this tough time* (older sister, Yeh family).
The above example shows that mothers who looked after their children had no superfluous time for work in order to earn more income; fathers would provide money for daily family expenditures, experiencing anxiety about the possibility of unemployment or reduced income. Adolescents with cancer also experienced both physical and psychological distresses, plus increased levels of parents and healthy siblings’ distress, which could lead both of the latter into physical and psychological discomfort. In this study, physical, psychosocial and financial distresses experienced by the family significantly impacted on roles and relationships in the family.

Impact of Family Caregiving on Roles and Relationships

The impact of family caregiving on family roles and relationships was another aspect of the family experiencing the broken chain of family life. This factor encompassed cultural values and beliefs, ‘bitter-sweet’ burden, and living with distress. Having this burden of care placed on them meant the family felt an increased vulnerability to cancer within the family. Caregiving also influenced how the parents experienced their burden, such as feeling pressure or sensing a loss of control and engaging in negative thinking. All parents hoped that their child would have a complete remission, but they still experienced numerous burdens throughout the treatments. One mother commented:

I wished God to bless my daughter to get over the cancer and be back to normal just like before. I felt strong obligation on my shoulders and faced different burdens associated with the multiple stresses of treatment, thus I accepted living a tough life (mother, Yeh family).

The quote below from one father reflects the scale of some parents’ caregiving burdens. These burdens influenced parents’ daily living and caused them health problems, such as insomnia, headache, and loss of appetite.

We would worry about my son’s treatment. Then, my wife and I could not get a good night’s sleep nor have a good meal until he was in remission. I knew my wife lost 5 kg, and many times
during activities. I had severe headache in the morning, and it influenced my job sometimes (father, Kung family).

Parents took on the burden of guarding the sick child carefully because in their experience their ill child’s treatments were miserable, and, afraid of losing the child, they did not know how to help, but they stayed with them continuously and paid a lot of attention to this type of disease and its treatments. Along with the impact of family caregiving on family roles and relationships, cultural values and beliefs contributed to an understanding that a Chinese family’s life is interdependent. This is described in next the section.

Cultural Values and Beliefs

It was evident from the data that cultural values and beliefs impacted on family caregiving and changing roles and relationships. Most parents gave greater emphasis to their cultural beliefs and religion to help them through the crisis of their adolescent’s illness. They reported worshipping gods as family protectors, and would donate money to the temple or memorials that had to do with religious ritual. These kinds of cultural and religious beliefs demonstrated their unconditional love for their children even though they were burnt out physically, psychosocially and financially. One mother described:

\[ I \text{ sincerely attended every activity in the temple, and wanted my son to be god’s son. Also, I followed monks, walking 1000kms in a special program to visit different temples, my feet were so painful every time, but I believed gods would understand my will to bless my sick son (mother, Yeh family).} \]

A father commented:

\[ My \text{ mother said that we needed to donate money to the temple regularly because the gods saw our attitude sincerely and they would forgive our sin and bless my son all the time. I agreed with my mum’s suggestion (father, Wang family).} \]
Three of the mothers thought that cancer was linked with fate or karma; that is, they or their ancestor had done something wrong in a previous existence, which had led to a negative effect on their sick adolescent. They blamed themselves or someone else sometime in the family for the sick adolescent’s condition. They seemed to have difficulty coming to terms with the sick adolescent’s treatment. For example:

_I knew Buddhists had to be vegetarian, and had never killed any creature, but my family ate lots of meat, so I need to kill chickens and fish at home often. My mother-in-law said my son’s illness was Karma because we killed lots of creatures. So we need to go to the temple to clean our sin. Did you know that I blamed myself a lot and would like to do everything for my son? When I saw my son’s suffering as a result of my fault (Mother, Sue family)._"

Another mother added:

_My daughter’s illness was from an unknown cause, but my aunt said it’s my ancestors who had done the wrong things, to punish this generation. We had to do more good things to restore my daughter’s health. When our family tried to do more volunteering in the community and temples, her condition was becoming stable, so I believed in fate, karma or other supernatural powers (mother, Wu family)._"

Two fathers thought their son’s illness was because there was some devil that had got into their sick child. They let their child wear an amulet, attended the three biggest memorial events in the temple every year and prayed to Buddha frequently. They wished it would resolve debts and let their son get back to being well again. As one father expressed:
My friend was a fortune teller, he said my son needed to wear a special Fu⁷ (符) and attend worship in Lo-San Temple (龍山寺) in order to avoid ghost or evil influence. I believed the Fu or worship were blessings for my son because my mum used these methods to treat me when I was very young (father Kung family).

The wife expressed her opinion in following quote:

My husband looked for a person who possessed a spiritual connection to come to the hospital to help my sick child get rid of “dirty something” [devil] in my son. Afterwards, my son’s condition stabilised, he thought that it was his work, but also I had worked hard to take care of my son (mother, Kung family).

The fathers could not be involved in the physical care the mothers gave their sick adolescent in this study. Two of fathers asked the mothers to learn Qi-Gong (氣功) or Tai-Chi (太極) to help the sick adolescents to maintain an immune system function. However, these complex care loads or coordinating assistance from cultural considerations, led to the mother experiencing emotional exhaustion. One mother stated:

I would love to accompany my son or husband to lean Qi-Gong or Tai-Chi, but did not like my husband pushing me so hard about this [three times per week], it made me feel overwhelmed (mother, Su family).

Most parents would seek different information about folk remedies to decrease the side effects of the treatment, such as Chinese herbs. In this study, extended family members were willing and ready to participate in the sick adolescent’s care. During the process of participation, some of the extended family members influenced the family’s routine or chose different remedies to decrease the side effects from treatments. Parents and the

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⁷ Fu (符): an amulet, it consists of any object intended to bring good luck and protection to its owner (Yeh, 2001).
sick adolescent experienced potential stresses deriving from their verbal or emotional support, which in turn impacted on the level of caregiving on family roles and relationships. One mother commented:

*I lived close to my parents and relatives, but I did not want them to worry about my sick child because they gradually increased the visiting hours and phone calls which made me feel exhausted. They bought food, but I did not know what the effect of it would be on my child. It could have been geckos or other Chinese herb soups* (mother, Wang family).

Another mother added:

*My mother-in-law provided different remedies [herbs, Holy water, and Tongji] for me to take care of my sick son. I would have liked to add Chinese herbs to the soup, and asked my son to cooperate to eat it, but my son complained that he did not want to be an animal test, I was so sad to hear this because I wanted him to keep safe and healthy* (mother, Su family).

Culture and religious beliefs impacted on parents’ caregiving behaviours, such as accepting different kinds of Chinese remedies, engaging in special worship in the temple and trying to learn Qi-Gong or Tai-Chi. Together with the presence of feeling overwhelmed, these were additional factors contributing to the ‘bitter-sweet’ burden of parents’ responsibilities. While prolonged exposure to suffering was directly evident in the data, parents reported difficulty ensuring caregiving by family members and that it helped the sick adolescent in the best ways.

**Bitter-Sweet Burden**

The bitter-sweet burden was the struggle that parents experienced in sacrificing their time and health, making caregiving a bitter burden for them, whilst at the time appreciating that their sacrifices opened up possibilities for gaining a positive outcome for their child that resulted in a motivating and ‘sweet’ experience. Bitter-sweet burden
was associated with the constancy of endeavouring to protect the sick adolescent as he/she assumed new responsibilities (e.g., cooperation with medical providers, acceptance of self-care) and was exposed to an expanding range of influences and dangers (e.g., side effects, relapse, school pressure). Added strain was experienced as parents often attempted to hide their own burden and tried to appear well to assure sick adolescents that they would return to health. One mother described her bitter burden:

Every time he forgot to take his medicine I would get very nervous and had to watch that he took medicine at home, or took the drugs to school with him. My health became worse when I looked after him ... I did not have time to rest because I needed to be keeping him safe (mother, Sue family).

The mother described the concept of sweet burden in the following quote:

The doctor advised that my son’s condition had become stable and that the treatment would finish this year. Do you know, any sense of burden from sacrifice disappeared. My husband said this feeling was a ‘sweet’ burden because we still worried about the potential for crisis from side effects of the treatment (mother, Sue family).

Mothers believed that their sacrifices and suffering were justifiable. Their parental obligations and the possibility of positive outcomes justified the sacrifices. They thought of experiencing their ‘bitter-sweet’ burden without any consideration of mental and physical exhaustion, and gladly turned sufferings into blessings. As one mother stated:

My son received chemotherapy and the side effects were serious vomiting and nausea. I could not sleep or eat until he felt much better. My husband saw me lose weight and I looked 10 years older than him, but I was not concerned about myself. Fortunately, the doctor’s treatment controlled my son’s relapse very well. I was so happy to know this (mother, Wang family).
It was apparent that the fathers in this study experienced the same obligation as their wives of caring for their sick adolescent. One father reflected this in the following comment:

*I wanted to work hard for my family, as I knew care for them exhausted my energy, but I received a positive quality from the relationship with my children. I thought this situation was bitter-sweet* (father, Wang family).

Parents shared responsibility with the sick adolescent but they thought about maintaining a balance between their supervision and thwarting the adolescent’s independence. The reason was they tended to protect their sick children, such as they did not allow the children to stay outside for too long, and made decisions for them. Parents recognised that this excessive protection might prevent their children from learning to make their own decisions, to become overly dependent on parental care, and even to lose their opportunity to learn to be independent, which might well shape their future roles and relationships. For example:

*Sometimes I thought that my parents’ concern about my health was an invisible pressure. They always told me to go to bed early, not to study too late but I needed to prepare for school exams often ... they knew I was stressed from my study more than the treatment, so my mum cooked soup or put a cup of milk out for me to maintain my energy for studying, but also she waited up until I went to bed* (sick adolescent, Sue family).

One mother added:

*My son told me: “I have grown up, I know what I am doing, do not worry about me. Your worry is my pressure.” Maybe I nagged too much. I had to let go as my son had grown up. However, he got pneumonia twice, and the doctor advised me it was critical. How could I look after him and also not treat him as a child* (mother, Yeh family)?
Some adolescents in this study did not like their mothers’ endless concern regarding studying too hard or wearing a mask when they went out, having to wash their hands frequently, and avoiding catching a cold. This was because their lives changed after treatment and the opportunities to make new contacts diminished since they were required to stay at home because of a greatly increased susceptibility to infection, and they perceived some pressure from school. In other words, parents feared that if their sick adolescent was faced with a ‘dangerous’ situation, it should be avoided and so parents would take good care and provide protection, for example:

*Now the most difficult issue of taking care of him was that he studied too late so he could not get enough time to sleep. I frequently went to his school and told teachers that if my son showed he was uncomfortable in any way [fever, a cold, injury from sport] (mother, Wang family).*

Sick adolescents said that their parents were a great support and that their relationship with their mother and father was important, but they sometimes felt ‘overprotected’. One sick adolescent described his feelings as follows:

*I knew that my family was very concerned about me, and I really appreciated them; showing enough concern was good, but not being overly concerned. I was 18 and I thought I knew what was right and wrong. The concern of my parents and others placed pressure on me* (sick adolescent, Wang family).

Although many adolescents voiced some complaints about their parents’ over-protection, they communicated gratitude to their parents. The mothers were burning themselves out for sick adolescents, and in the meantime fathers worked hard to earn enough income in order to buy healthy foods for their family. For example, one adolescent stated:

*I was sorry for the family; I intended to work, earn money, help the family out and lessen the family’s burden. Now, I could not, I only added to the burden [sad smile]. I could not do anything and my parents had to work harder to take care of useless me* (sick adolescent, Yeh family).
This adolescent’s experiences was similar to others’ in the study who brought up their feelings about being dependent on their parents as a result of the illness and treatment. The comment below explained his view:

_The problem now was taking responsibility for my parents’ mental states. I felt sad. Because of me, this led to family turmoil, they had to look after me and buy healthy food for me, but it was a big expense. I knew that I was the biggest burden in this family._

(sick adolescent, Kung family).

As data showed, each parent believed that he or she was carrying the greater burden, but this burden also endowed parents with the commitment to complete their responsibility to the family, as a ‘bitter-sweet burden’. Along with the presence of the family caregiving burden, an additional factor contributing to parents’ worry and fear about their sick adolescent will be described in next section.

**Living with Distress**

Families consistently explained that they never stopped worrying or being afraid while they were caring for their adolescent. Often they assessed and recorded the adolescent’s condition, including a few, mild physical symptoms of illness such as a fever or paleness. Specifically, if parents recognised that there was something wrong with their sick adolescent, they would call in a physician immediately. A mother stated:

_Because of this disease, I paid close attention to the response to the chemotherapy drugs; one time while he was receiving chemotherapy in the clinic, the nurse nearly mistakenly injected somebody else’s medicine into my son. I was frightened to death_ (mother, Yeh family).

The mother, Yeh, added:

_Another time, he and his classmates went out and he forgot to wear a mask, so he had a fever after he came back home; it was_
severe as he had pneumonia and he had to be taken into the Intensive Care Unit (sigh). Looking back on those days, I was so afraid of the prognosis and terrible side effects (mother, Yeh family).

The parents also highlighted how worried and afraid they were when their child was at home. Having the child at home highlighted the responsibility of ongoing infection care control and of constant monitoring of changes in condition and these had a negative impact on family life, as reflected in the following quote:

My daughter’s immune systems became weaker and she had to take anti-allergy medicines during the chemotherapy. We were afraid that she might get an infection because she often forgot to take medicines and wear a mask (father, Wu family).

Parents dealing with the experience of their child being treated for cancer often found they did not place pressure on their sick adolescent at home or in relation to school. They were afraid that a heavy load of school work on their child would cause a relapse, as reflected in the following quote.

How could he survive the pressure of the homework and physical demand for three years? Based on the records, there was an increase in the possibilities of relapse after going to school and I saw some relapsed cases that were all the result of pressure (mother, Kung family).

These findings point to significant parental concerns about the adolescent returning to school after treatment with poor resistance to disease and a high risk of infection. Many parents said that they gave up having high expectations of the ill child, such as good academic performance. They realised that health was more important than academic grades at this time. One father illustrated:

My son studied more than six hours a day and still worried that he could not catch up with his other classmates. He thought his
classmates would also stay home to study and prepare for the admission tests next January; we did not care about his achievements because I wanted my son to be healthy more than him getting into a famous university (father, Wang family).

Summary
The basic social problem stems from the symbolic interactionism perspective encountered by the adolescent with cancer and their family which led to the family experiencing the broken chain of family life. Lost or disrupted expectations of continuity and coherence seriously challenged the fulfillment of familial roles and relationships. ‘Experiencing the broken chain of life’ was the core category within the dynamic relationships in this study, linking and explaining all other subcategories (see figure 5-1).

The typical Taiwanese concept of family roles and relationships and the underpinning Chinese culture intensified the two main causal factors which led to ‘the broken chain of family life’. These factors were the impact of the disease and family caregiving on those roles and relationships. In the following Chapter 6, the consequences, again underpinned by symbolic interactionism, are examined in terms of disruption to family roles and relationships, and the experience of strain associated with burden and the challenge of living with unpredictability.
Chapter 6
Experiencing of the Broken Chain of Family Life: Consequences

Introduction
It was evident in the data that Taiwanese parents considered themselves as caring parents, nurturers or comforters acting as guardians for their children. They demonstrated adherence to Chinese cultural values. While facing the threat to life as well as the complex and lengthy treatment, the children were bound to follow the parents’ attitude towards family unity, support and ongoing edification of each member, with the aim of surviving the crisis and emerging stronger.

A significant consequence of the processes was the disruption that disease and caregiving had on family roles and relationships. Sick adolescents’ interactions related to their family members in terms of: parents placing their lives ‘on-hold’; healthy siblings’ experience of life-style change; and the sick adolescents’ sense of a ‘set-back’ in their life. Other strained roles and relationships experienced by parents were described in terms of conflict in the provision of care, an inability to openly communicate (due to the need to alter the manner in which they interacted with each other in order to make meaning of their roles and relationships) with other family members, and a sense of a loss of control within family life. These consequences are presented in this chapter. As previously explained in chapter three, it is only through symbols such as use of speech and actions used in interactions that communications can occur in people as reflected in symbolic interactionism

Disruption to Family Roles and Relationships
The disruptions caused to family roles and relationships were described in the previous section. Disruption was defined as a number of events that caused challenging changes in family relationships and roles affecting day-to-day functioning of the family. Families ascribed meanings to the sick adolescent’s situation within the dynamic relationships among factors, such as the increased stress and responsibility of caring for the
adolescent at home affecting both parents’ work and the family’s social lives. Some parents had become so upset caring for their sick adolescent that the effects remained for years following treatment. This was articulated by the mother of the Wang family, when she said: “our lives were always shadowed by this enormous life event”. Another mother commented:

Illness at this stage certainly disrupted my family! My husband felt exhausted by work, and my daughter had lost all her motivation and could hardly study. This created higher stress levels than I was able to cope with, with my ability (sigh) (mother, Hung family).

Since the parents had a need to take care of the sick adolescent, they alternated attending the hospital and being at home, which they reported made their daily life unbearable. In this study, most of the mothers were forced to take leave in order to be at the hospital and maintain the home life. Thoughts and concerns were apparent for the sick adolescent who needed substantial support, time and energy from parents. All this limited the attention that parents could give to their other children. As one mother reported:

I took leave and tried to play a good mother, but I could not manage it very well (cry)... my life was strictly controlled, narrow and exhausting. My son suffered so much from his treatment, and my daughter dropped her activities to stay home. How could I do what I needed to for my family? (mother, Wong family)

Further, parents often preferred healthy siblings to remain together in the family at home, with the father rather than with other carers, such as grandparents, relatives or friends. Separation from one or both parents during periods of hospitalisation inevitably disrupted the healthy siblings’ daily lives. Consequently, family social activities were cancelled due to the therapeutic regimen; the adolescents and their healthy siblings often complained of feeling ‘suffocated’ when they simply wanted to venture out and experience life. For example:
It was stuffy at home! My life was boring and I was isolated from my friends. We didn’t go for holidays together because my brother continued to suffer. We all suffered too! I prayed to God, wishing my life to be happy and normal. How could my life be healed? (older sister, Yeh family)

The healthy siblings in the family understood the reason why their sick sibling needed extra attention, but this did not stop them feeling upset about their daily lives. The adolescents expressed more conflict in getting on with their daily lives and planning for the future while wanting to be available for their parents. The healthy sibling had many expectations of life as one adolescent in the Wu family expressed: “the life they have is only lived in part because of this disease”. Parents put their own daily lives ‘on-hold’ because of their ceaseless love for their children. Siblings felt disruption because their sibling became ill, their social activities were restricted due to their ill brother or sister’s situation. The adolescents with cancer experienced a set-back in life because they knew the cancer was a serious threat to their life and they could not look to their future.

Parents’ Own Lives ‘on-Hold’
Disruption to the family roles and relationships was experienced by parents as putting their lives on hold for the sake of their sick adolescents. Parents noted how difficult it was for them to learn new skills and commit themselves to taking on the new chores or divisions of household duties. They adopted a more active role in their child’s care or the care of other siblings as was the case with the fathers. They also experienced emotional exhaustion associated with difficulty in balancing roles and obligations connected with work and family. These obligations were overwhelming and exhausting for the family who suffered such drastic changes while taking care of their adolescent with cancer. In Taiwan, gender roles remain rigid, with fathers being responsible for outside activities and mothers being responsible for chores within the home. The pressure of continuing to go to work in the midst of this ongoing treatment and family crisis was often costly to the family’s total wellbeing and contributed to their sense of alienation, guilt and conflict. As one mother commented:
My life is on hold, what my life would have been like, my obligations appeared to engulf my life, I had no other parts to my life, I could not get a break because I still worried about my child, he said he could care for himself, how could I believe that? (mother, Kung family)

This comment highlighted the point that an ill child’s condition created a burden on the mother; the fathers in this study supported this view:

My working hours were long. So I got back home a bit late, it was always my wife who took care of my children. We were depleted of financial and social resources; like a current of water or rolling waves, we had to face constant challenges (father, Wu family).

All of the mothers in this study usually stayed with their sick adolescent during hospitalisation. They had to learn treatment protocols, take care of medical management, transport their child to the clinic and administer medication at home, while continuing to perform previous household tasks to meet their family obligation. Mothers usually became the primary link between the family and the medical system. They assumed the major nursing role and relayed information to their husbands and other family members. This may explain why mothers reported more ‘maternal role strain’ than fathers did. For example:

When I was in the hospital I only needed to concentrate on taking care of my son; when I came back home, there might be more housework to do, or I might be busy doing other things such as look after the older son and my husband. I feared heavy loading in my life, I could not relax any second (mother, Kung family).

Thus it could be concluded that the disease affected every part of family life causing parents to be continuously fearful and bearing numerous stresses caused by caregiving. Another significant aspect was healthy siblings feeling lifestyle changes, as the next
Healthy Siblings and Lifestyle Changes
The principal value of Confucianism emphasises elder brother’s love, younger brother’s respect and son’s filial piety within families. The healthy siblings in this study experienced differing degrees of parental guidance in relation to altering their lifestyle to assist in caring for their ailing brother or sister. Some of the healthy siblings in this study reported stresses associated with living with a brother or sister who had cancer. Most parents learned to recognise and interpret stress reactions in their healthy siblings. However, parents spent time with their ill adolescent, just to ‘be there’ for them and all were made aware that it takes time to treat cancer. Thus, siblings were guilt-ridden, and felt resentment about the disruption in their lives and were angry at the impending loss of parental care and attention. This was illustrated in the following narrative:

*When my brother got sick, I used to go hungry while waiting for my father to take me home for dinner or cried not wanting to stay home alone. My parents hoped that I could look after myself quicker... they didn’t pay attention to me* (younger sister, Wang family).

When a healthy sibling felt unwell, or suffered any form of illness, such as a common cold or acute gastroenteritis, parents treated them in the same way they did the adolescent with cancer, offering the same level of attention and concern. Healthy siblings were comparing themselves to their sick sibling, and might feel unimportant or worthless if they did not receive similar attention to their more seriously sick sibling. A sister stated:

*If my older sister was sick and my oral mucous membrane was broken, dad and mum would look after my older sister first, cooked a meal for her and fed her medicine, but why did they not help me to apply medicine, cooking something light for me?* (younger sister, Wu family).
Some of the siblings said they felt sad about decreased interactions with friends because parents feared the ill sibling would contract an infection; as a result, healthy siblings could not go to a concert with friends. They felt different because unlike their peers, their activities were restricted because of their ill siblings. One sister depicts this:

   *I only hoped my mother could understand me and not control me so much because she didn’t have strength and time to spend with me at home... I knew my brother was afraid of infection so I took care of myself and not to take a cold home* (older sister, Yeh family).

The mother illustrated how she understood her daughter but her priority was to protect her ill son:

   *I would try to communicate and say to her, your brother is sick, and a relapse has occurred. I knew she was very angry with me for not allowing her to go to a concert. She made me a card with “I do not want to speak so do not knock on my door”* (mother, Yeh family).

On the other hand, the healthy siblings claimed parents did not like to talk about the illness at home. They thought their parents did not want them to know the facts, thus, they did not know much about what was happening to the sibling with cancer. Four healthy siblings explained they had talked about the illness with their parents and most of these discussions focused on the progression of the illness. The following narrative depicts this:

   *I did not know what to do because my parents did not want us to know about this disease or how to treat my younger sister. Fortunately, there was a lot of information on the internet, but I was still afraid of how this disease would affect my younger sister* (older sister, Wu family).

Another healthy sibling commented:

   *I did not know what kind of disease it was, this was just like part*
of the TV series, and it was terrible [death]. My mother always cooked healthy Chinese food for us, especially my ill sister should eat special [snake soup, rhinoceros horn] food, and our kitchen always strongly smelt of Chinese herbs (younger brother, Hung family).

In this study, a sibling noted that his father’s temper worsened so he didn’t want to communicate with him, but would chat with his mother and his ill sibling. Sometimes, the ill sibling continuously played “bridge” at home. The father describes this below:

There was one time they fought violently and I slapped the older son’s face, I think he must have been very angry with me. I forget why I slapped him; maybe it is the reason why he does not like me, I do not really know (father, Kung family).

The healthy sibling explained:

My dad favoured my younger brother more, and I tried to communicate with my dad but that was useless because he paid no attention to me. I would do a self review if I had done anything wrong (older brother, Kung family).

These family members needed permission to express ambivalent feelings about their ill sibling. There is an emotional bond between parents and their children that is essential to children’s development and happiness. Moreover, adolescents with cancer wanted to be given the chance to show that they were responsible; therefore they wanted to find a balance between being socially independent, yet medically responsible. This next section discusses the sick adolescent’s experience with this set-back in life, and the possibility of long term treatment inducing physical and psychosocial impact on their academic achievement and peer group relationship.
Sick Adolescents Set-Back in Life

Adolescents with cancer sensed that their illness set them back in life. The reason for this feeling could be directly or indirectly linked to the side effects of chemotherapy, causing feeling of extreme helplessness about their appearance changes. Since the treatment had scarred them emotionally and physically with such effects as sparse hair growth, facial swelling from steroids, limited mobility, changes in the skin and their memory, they expressed their distress about looking different from others. Thus, the unpredictability and uncertain course of the disease caused the sick adolescents anxiety, and the anxiety stemmed from the fear that the disease would become increasingly serious. One sick adolescent illustrated below:

*I would fill with anxiety about what my classmates thought the concave spot on my head was ugly. I tried to make sense of what had happened to me, but there was nothing I could change. I thought my life was hard to set-back normal or look forward future* (sick adolescent, Yeh family).

Another sick adolescent stated:

*My mother said “many cancer patients died of worry, but during 3 weeks hospitalisation, a day was just like a year long and seemed to live in mortuary”. I felt very terrible because I should bear this overwhelming pain and torture during the course of the illness* (sick adolescent, Wu family).

When adolescents with cancer were at home, they stated they perceived themselves to be normal, but felt a lack of normality in other parts of their lives, in contrast to what it was like prior to their diagnosis; for example, fear of further treatments and worry about relapse, and the psychological fear causing ongoing anxiety. One adolescent spoke about discovering how cancer treatments can be very painful and uncomfortable. The procedure could cure or kill him physically and psychosocially. In his nightmares, he worried about experiencing a relapse:

*I was afraid that I could not hang on any longer...treatments are a painful journey, and my chance of a relapse of the disease is*
below one percent; to me the pressure of one percent is very substantial and like a nightmare that always follows me (sick adolescent, Kung family).

The adolescents strived toward autonomy in their personal lives, especially in developing their own set of values. Body image was an important aspect of the psychological functioning of adolescents. However, the living space was confining because parents worried about protecting against every possible risk of infection. This resulted in less interpersonal interaction amongst their peers and more isolation from society. One sick adolescent depicted this:

I wanted to maintain my own way of life, but I could not, so I felt very unhappy and helpless. There was a period of time that I was feeling depressed and quarrelled with my parents often. When I was not sick, they did not restrict me attending school activities. As you know, nobody in the school was a wearing mask, it was only me, and I was like an alien separated from others (sick adolescent, Wang family).

As the adolescent was striving for autonomy, learning to take on adult roles and responsibilities, cancer treatment and prognosis of the disease process could cause worry, uncertainty, change in body image, and sense of loss. These experiences were common amongst the sick adolescents. They felt tired about having to take more time for study and for planning their lives. They resented that they could not perform at their best possible achievement level, as compared to their classmates. One sick adolescent noted:

The class time coincided with the treatment time, so I had to ask for leave often and thus my end of term marks suffer. It was because I should take leave when I was sick, otherwise I would be in school, but marks would be deducted for each leave; I and my mother complained that it was unfair for marks to be deducted for absences due to this type of sickness (sick adolescent, Hung family).
In Taiwan, adolescents’ school achievements are considered paramount in individual development, also in the promotion of family and their community, parents thus view school performance as the primary task of adolescence. Adolescents diagnosed with cancer, spoke of how they could not engage in the social activities and gain achievement in school. In the hope of being cured and be able to return to school and resume a normal life, the sick adolescents convinced themselves that no matter how painful the treatment was, they would endure it and cooperate with the doctor. When they returned to school, they liked to blend in with their peer groups. As one sick adolescent stated:

I followed the doctor’s protocol and endured numerous difficulties in conducting the treatment. All I could say was that I wanted health, coming back normal for my life [study and social life] and try to independence as my classmates (sick adolescent, Liu family).

In summary, the disruption to the family life included parents placing their own lives on hold, healthy siblings’ experiencing lifestyle changes and sick adolescents feeling they had experienced a set-back in life. Changes in family role and relationship, particularly the inability to take a normal part in the child’s life, created real tensions for parents and healthy siblings. Parents could not participate in any usual activities, and faced even more responsibility in taking care of their ill child; the caregiving for their adolescents thus added to the numerous burdens of family life. The next section discusses another consequence of experiencing strain through change to family roles and relationships. Practical, emotional and relational all occurred and a family status quo emerged.

**Experiencing Strain through Change to Family Roles and Relationships**

There is an emotional bond between parents and their children that is essential to children’s development and happiness. When a child is diagnosed with cancer, the demands of illness are added to the numerous strains on family roles and relationships, such as family life changes, particularly the inability to play a normal part in the family. For example:
Things changed when my wife stayed in the hospital taking care of our younger son two weeks at a time, sometimes it was even longer; husband/wife relationships would change, our family was split up, and my wife and I seldom see each other (father, Wang family).

The sick adolescents focused more on suffering than happiness, when facing the disease, they endured physiological, psychological and social pressures that placed a strain on family roles and relationships. For example:

*I blamed myself frequently because when my mother saw me I was miserable so she cried, father sighed often when he told to me, and my sister complained of my illness affected her social life* (sick adolescent, Yeh family).

It has previously been stated that the healthy sibling understood when a sibling had fallen sick, the family did not function like a normal family. Specifically, they faced their different challenges in their daily activities because of the ill sibling’s illness. After their sibling became ill, the whole family learned the importance of a healthy diet, did not stay up late, and knew how to take care of themselves. Parents would work very hard looking after the ill sibling; the other siblings would do their homework or read books, and tried not to let parents worry about them. The healthy siblings thought they should passively accept this situation and cut down the chances of getting into a quarrel with the ill sibling and parents. They wished that everything would go back to what it was like before their sibling got sick. In order to bring a sense of normalcy in their assigned cultural role and relationship family members, especially well siblings altered the way they interacted with the sick sibling, again highlighting the theoretical perspective of symbolic interactionism. For example,

*We were very upset when my younger brother got sick, but he had mom to keep him company. I knew my parents hoped that I could look after myself quicker. I used to go hungry and waited for my father to take me home for dinner or cried not wanting to stay home alone sometime... When my younger brother got well*
I would tell him not to use hands to touch his mouth frequently and so on (older brother, Kung family).

The above perceptions were supported by a younger brother who commented: When my older sister got sick, mother would try not to let me go to crowded places, she would ask me to wash my hands frequently. So, I seldom went out with my classmates because my mother was like a crazy woman when she felt stressed, anyway, it was very annoying for me (younger brother, Liu family).

Family roles and relationships evinced strain under the burden of caregiving, potentially resulting in conflicting opinions about the nature of the care, and interruptions to familiar patterns of activity. These are discussed in the following section.

Conflict in Caregiving

Strain on family roles and relationships drew attention to the fact that family conflicts in caregiving for the adolescents were threaded throughout the data. The adolescent and their family faced an especially difficult challenge in that they encountered a different environment involving a range of treatments, and increasing involvement with health care professionals. Also, living with a life threatening illness, there is a high possibility that parents could experience guilt and self-reproach about not having been effective advocates for their child during the diagnostic process. Parents seemed to learn from others’ experiences and the child’s response. Mothers had chosen healthy products and temple remedies to improve their ill child’s condition, but these products or remedies cost money, more than family daily expenditures. Fathers had different opinions from mothers. For example:

My wife saw advertising on TV or went to temples; she would buy different kinds of products for my sick child. She believed fortune tellers words and burned the blessed papers in the water, the both drinking water and bath. I argued with my wife frequently (father, Hung family).
On the other hand, parents expressed different points of view from their family members or relatives about using folk remedies in long-term care. Several parents’ perceived stress placed on them by family members and relatives because they bought ‘special’ folk medicine for the adolescents to take. Four parents did not accept these remedies in any way, before they checked with the doctors and believed that survival rates only increased dramatically through medical advancement. One mother had this to say about this situation:

_I was very grateful to my relatives or friends for providing remedies from different sources during this period, but if these remedies you got were not reliable, I feared what the consequences could be for my daughter and thought it might conflict with hospital treatment_ (mother, Sue family).

The statements above reflect that when relatives and friends saw unjust occurrences happen, they took action courageously, treated the adolescent and their family with sincerity, and showed empathy by thinking of others through putting themselves in their position. However, both the child’s condition and the progress of treatment influenced the family’s decisions about controlling the illness, and potentially affecting relationships, since dissonant caring strategies could occur. As one father commented:

_My family suggested too much information, but their concern for me was a source of stress. Sometimes there was no right or wrong, just what was best in that situation for my daughter_ (father, Wu family).

Thus it could be concluded that parents were continuously bearing numerous pressure caused by caregiving to ill children. Another significant aspect, parents did not like to openly communicate with family members, this situation influenced family roles and relationships, as this discussed in the next section.
Communication Barriers

Men are expected to be strong and not express their emotions within Chinese culture. Facing a cancer crisis, changed communication patterns occurring in the parent-child and the marital relationships in this study. Parents felt that the occurrence of cancer made their marital relationship stronger, but they were not able to talk about the situation of having a sick child with friends and relatives because these parents needed to save face in order to maintain a harmonious atmosphere within the sphere of friends and family. Especially, the fathers’ were unwilling to discuss the child’s disease and related problems openly. Fathers did not receive needed encouragement and support and felt left out of the direct chain of any medical information. They eventually received medical information about their children second-hand through their wives. The following comment illustrates this:

I usually didn’t actively tell my friends and relatives about my son’s situation, because it was only my business. However, my wife talked with family or friends and reported in detail on my son’s progress to me every day, I disagreed with her on this issue (father, Sue family).

Among the Taiwanese families, most of the parents did not feel free to be explicit about showing their emotions in communicating with their children, and were unable to openly communicate about the illness to avoid psychological distress and out of their desire to protect their children. Parents preferred to place burdens on older children, and healthy siblings were expected to respect their parents to ensure harmony in family life. One healthy sibling stated:

Our family members seldom communicate with each other, I seldom chatted with my mother when I got back home. Every time, I would like to know more about my brother health problems, but my mother would pressure me to study, I respected and kept quite in this family (sister, Wang family).
The healthy siblings were living a life fraught with contradictions and conflicts. The attitude toward a life-threatening disease was that family harmonies of life had been disrupted for whatever reason. As mentioned earlier, the parents who were caring for the sick children would not openly communicate with the other healthy siblings in a timely fashion; the healthy siblings were left not knowing the ‘real’ ill sibling’s condition and the current difficulties faced by the family and they were unsure how they could help the parents or the sick one. One example is cited below:

I knew my parents and sick sister suffered, but nobody told me what to do and where they needed my help. I wanted to share their responsibilities because we all lived together (brother, Wu family).

Another healthy sibling commented:

Because of my ill sister, we needed to pay close attention to the response of our health because I was so afraid of my ill sister and the threat of death, it was a sensitive subject of both my sick sister and parents, so they did not want to talk about this issue (older sister, Wu family).

The parents did not want to talk about this subject of illness because of the psychological pressure it may create and did not dare to touch the subject of death. Parents felt the children were part of them when they were healthy and more so when they were seriously ill. As well, the adolescents had their “heavy strain” experience. In this study, parents appeared to place importance on keeping their children’s lives as normal as possible and minimizing disruptions to them. Thus, the manner in which parents interacted with their children changed dramatically as demonstrated in their interactions with them. They were concerned about their children’s wellbeing and how they would be able to meet the needs for all their children. One father stated:

We were all surprised by my son relapse because we devoted were totally committed to take care for him, I had time to buy healthy food and my wife would continue to stew chicken soup for 4 hours for my son, so my wife and I must work together to
do our best (father, Wang family).

It must therefore be recognised that strain on family roles and relationships included conflict in caring for the adolescents and inability to openly communicate with each other. These circumstances have been found in Chinese families because they have lost control in family life. The following section will describe these situations.

**Loss of Control in Family Life**

Fear of relapse is difficult for both the adolescent and their family. The family faced the challenges of the child’s disease by making the most of their lives, with parents placing the focus on the needs of the children and trying to maintain a normal lifestyle. This altered the situation in determining how much responsibility the parents placed on their ill child, because this disease has affected a major part of their life. With the diagnosis of cancer, the priorities and perspectives of families had suddenly altered. It was observed in this study that some families struggled with new challenges in their understanding of their lives and their unwillingness or inability to express their roles or relationships. As one mother stated:

*My children were my heart, but my healthy older son complained “you all love the ill brother, why I did not have any [mother cooked dinner for him and played games often]; I knew you love my ill brother not just because he was sick* (mother, Kung family).

Another father commented:

*When my wife was too tired to take care of our son, she would lose her temper... She was grumpy. I knew her temper so I tried to avoid confrontation with her as much as possible. I always tried to share my wife's hard work; but I had difficulties, I had to work long hours* (father, Hung family).

In this study, some of the adolescents viewed themselves as being more dependent on their parents than their same age peers because of their illness and treatment. The
adolescents expressed the difficulty they had in facing their daily life and future. They knew that the parents were supportive in helping them to cope with the illness and treatment in daily life and they openly wondered whether the illness and treatment had strained the roles and relationships within the family. Adolescents in this study were found to react to increased dependence on parents through frustration and depression, thus exacerbating the problems with poor self-image and decreased confidence. This is expressed below:

*I deeply felt I could not do what my same-age peers could, and tried to increase my sense of personal responsibility for self-care, but the terrible treatment made me useless in this family. I was 18 years old, yet like a ‘baby’. You could not imagine what a difficult life my family was living* (sick adolescent, Su family).

The healthy siblings experienced the sense of loss of control of their daily life, such as curtailing after-school and other social activities. There were notes to take more chores within the family, more independence and responsibility regarding schoolwork. Some healthy siblings (15-17 year olds) in this study, social activities became limited with lack of freedom for them to carry on normal activities within one year of diagnosis. One healthy sibling commented:

*I should have respected my parents’ way of doing things [studying and cleaning]. But I really had lost so much control over the big things [camping or cycling with classmates one week], my mother just wanted me to stay home every weekend, my life was off track* (younger brother, Liu family).

In summary, the loss of the sense of control in family life showed parents were dealing with an adolescent’s situation by expending effort on managing daily living for all their children, while facing the threat to life of the adolescent’s disease and complex and uncontrollable treatment, the level of strain on their family roles and relationships continued.
Summary

Disrupted family roles and relationships resulting in strain associated with burden, and the challenge of living with unpredictability were consequences of the impact on family roles and relationships. The daily caregiving for sick adolescents led to disrupted roles and relationships in families because parents own lives were put ‘on-hold’, healthy siblings encountered lifestyle changes and sick adolescents endured a feeling of being ‘set-back’ in life. Families also reported on the interfaces of interpersonal relations citing the conflict in caregiving, communication barriers and loss of control in family life when caring from home.

In the following Chapter, the basic social process will be examined in terms of the impact of caregiving on Taiwanese family roles and relationships and the process of adaptation and accommodation as a means of managing the experience of the broken chain of family life from the symbolic interactionism perspective. This discussion examines a variety of intervening conditions and process modifiers. The chapter concludes by outlining the overall substantive theory of the family restoring harmony in their life.
Chapter 7
The Basic Social Process:
Restoring a Harmonious Family Life

Introduction
This study aimed to explore the impact of caregiving for an adolescent with cancer on family roles and relationships, and examine how family members perceive and manage caregiving at home within the context of Chinese culture in Taiwan. Data analysis revealed that the adolescents and their respective families were living with the basic social problem of ‘experiencing the broken chain of family life’. In this chapter, the basic social process, labeled by the researcher as *restoring a harmonious family life*, will be examined. Restoring in this study refers to the returning of family life to a harmonious state, in keeping with Chinese culture. In this chapter the way in which the family achieves a sense of harmony through altering the way they interacted with each other through the use of symbolic interactionism will be shown.

The basic social process underpinned Chinese culture and influenced both the adolescents and their family, giving them values and beliefs that led them to restore a harmonious family life through adjusting their family roles and relationships. The level of harmony achieved at any particular time, however, differed between the study families, depending on the condition of the sick adolescent. Two of the families experienced cancer relapse during the course of this study. Their experience highlighted the unpredictable and dynamic nature of caregiving for an adolescent with cancer. When relapse occurred these families reverted to managing confrontation, aiming once again to move towards restoring a harmonious family life.
Restoring a harmonious family life is depicted as a cyclical process shown diagrammatically in figure 7-1 overleaf. The process of restoring the broken chain of family life involved, predominantly, the adolescents and their family confronting the treatment, accommodating suffering, and repairing integral connections between family members. This chapter will describe this basic social process and provide excerpts from the data to substantiate this process.

**Phases of the basic social process**

The basic psychosocial process of restoring a harmonious family life was both dynamic and depended on reciprocal relationships, all of which underpinned Chinese culture. It involved three phases, comprising confronting the broken chain of family life, accommodating the broken chain, and repairing it (see figure 7-1). These three phases constitute a dynamic process. The first phase, *confronting*, involved making decisions in complicated situations and obtaining support from different sources. The second phase, *accommodating*, involved adjusting to family roles and relationships and promoting the sick adolescent’s condition. The third phase, *repairing*, involved maintaining hope for a good outcome and achieving a harmonious life. In this third phase of achieving a life of harmony, the sick adolescent and their family were determined to maintain their strategies throughout their cancer journey. It is in this phase that family members made changes to the way they would normally be expected to interact with each other in order to achieve a sense of harmony through engaging in symbolic interactionism.
Figure 7-1   The basic social process: restoring a harmonious family life
Phase 1: Confronting the Broken Chain of Family Life

Parents of adolescents with cancer in this study confronted enormous worry and experienced fear about treatment related complications. When parents were confronted with a diagnosis of cancer in their adolescent, a process started: they needed to make decisions in order to face numerous complicated situations, such as choosing a ‘good’ hospital, understanding treatment protocols and trying to explain to the sick adolescent his or her diagnosis. Data analysis revealed that parents felt shocked and distressed as they thought cancer would not happen to their child. Healthy siblings experienced lifestyle changes and sick adolescents feared for their uncertain future. However, the sick adolescent and their family expected to return to ‘normal’ patterns of life supported through their Chinese cultural beliefs and values. They believed they should cooperate and confront the different stages of the adolescent’s treatments despite side effects. This is highlighted in this quote by a mother:

The disease made our family life totally different and we felt so distressed. However, I was confident that my son would get well because he endured the treatment and cooperated with the doctor's advice. I thought our lives were restored to normal after one year (mother, Sue family).

One sick adolescent commented:

I tried to endure numerous serious side effects and confront the treatment; I just prayed to gods to control my disease, so I could go back to school and take part in social life again (sick adolescent, Yeh family).

On the other hand, parents sought support from family members, relatives, friends, and religious and medical providers to confront the diagnosis. Knowing the details of the treatment and prognosis were important. In this study, parents overwhelmingly reported that waiting and not knowing was a fearful experience. During the diagnosis time, the sick adolescent underwent frequent tests, the uncertainty of what they were dealing with and about their future that were very distressing, and they imagined the worst scenario and tried to search for further information to understand their illness and treatment
outcomes. As well, relatives and friends would arrange for parents to visit the temple to obtain a blessing or wear the Fu (amulet). One sick adolescent commented:

> My father and aunt would go to the temple to pray to Buddha, pleaded for a cup of holy water for me to drink and wore two different Fu for blessing. I totally understood that they wanted me to recover; I also looked for information from the internet, I didn’t waste time crying or feeling sad (sick adolescent, Liu family).

Confronting the broken chain of family life thus was the first phase of the basic psychosocial process. This phase involved making decisions in complicated situations, obtaining support from different sources, and resorting to interaction strategies which will be discussed in the next section.

### Making Decisions in Complicated Situations

Making decisions in complicated situations was instigated to confront the broken chain of family life of the sick adolescent and their family before any intervention could be undertaken. Data analysis revealed that the sick adolescent and their family had to confront long term life-threatening therapy and follow-up procedures. While the sick adolescent was moving in and out of the hospital, waiting and receiving diagnosis and undergoing treatment periods, the parents needed to make decisions to maintain their child’s safety and progress through the course of the treatment. The first decision was to choose the facility of treatment or doctor to gain good quality care. Two parents in the study threw Jiao (筊) to ask questions of different gods in the temple. Most mothers asked for information from friends or relatives who worked in hospitals, or health insurance companies. However, fathers made the final decisions in Taiwan. Most parents decided to seek a professional opinion from the hospital on this matter and ask for the doctor’s explanation. This was clear from the following comment:

> When I discovered my son had leukaemia, I called lots of friends for their advice about entering a large hospital to have a thorough check up again. My husband prayed to gods and made
the final decision [about the hospital]. We did not want to make the wrong decision for him (mother, Hung family).

Another father commented:

*My friend who works in the hospital said medical health care in Taipei is very convenient, we were lucky that there was a very good medical team to help us. So he suggested a good doctor for me. It was a blessing for my daughter. Otherwise, my family life would be a total mess* (father, Wu family).

As well, sick adolescents had to be admitted into the paediatric wards for the treatment of cancer in Taiwan. The mothers stayed with them 24 hours a day in these wards and were focused on the care setting and sharing of medical information in such an environment. As long as the medical care was perceived as major, the location of care was of secondary significance to the mothers, but the place of care was of central concern to the sick adolescent who did not want to be with young children. Consequently, the parents decided to live in single rooms in the paediatric ward to prevent the potential for their sick adolescent to suffer a physical or psychological effect, even though their financial status was worse as a result. This was because the patients had to pay extra for single rooms. One mother stated:

*It was not easy to have to be treated in a children’s ward; I knew my son disliked it there, he said the babies’ sound of crying was awful, but I could appreciate the staff’s caring and understanding. My husband thus paid out more to stay in this single room for two weeks* (mother, Wang family).

During the whole course of the treatment, the sick adolescents and their family logged on to the Internet to search for information about the disease and to establish the remission rates. Data analysis revealed that some parents considered bone marrow transplantation or peripheral blood stem cells transplantation for their sick adolescent; they believed this treatment would assist in the recovery of the normal cells in the blood according to the doctor’s professional view and medical reports. However, they had difficulty making this decision because the transplantation could easily lead to death.
through infection and or rejection, as reflected in the following quote:

    Our neighbour’s child also had a blood disease; he underwent bone-marrow transplantation but later died. The doctor did ask us before if we wanted to have a bone-marrow transplantation. We considered it for a long time, but decided not to have this form of treatment (mother, Kung family).

However, one sick adolescent commented:

    I had self-stem cell transplantation, and needed to remain in a sterile room for a month, but nobody knew about my fear of isolation. I could only talk to my family or friends through the intercom, I could not touch them because I would become infected. I was thankful of my parents’ decision because my condition was stable (sick adolescent, Sue family).

The above situation demonstrated that for both chemotherapy procedures and treatment strategies, the parents and sick adolescent knew the procedure they were undergoing took time and had been developed through years of medical research. According to the type of cancer, the time period for treatment could be several months to two or three years. They also understood cancer cells were very difficult to control. Even during a partial remission a relapse could occur. Thus most parents would combine Western treatment (chemotherapy, surgery or radiotherapy) with Chinese herbs or food remedies. They reported that simple (Western treatment) or combined treatment (Western and Chinese) was a complicated decision to make as they knew that they had to follow the doctor’s recommendations for treatment but also wanted to alleviate suffering by using Chinese remedies. The parents experienced great difficulty in their role as parents. In fulfilling that role parents kept the safety of their sick adolescent in mind. Thus, no matter how expensive or inconvenient the treatment, the parents persevered with the treatment prescribed by the doctors. One mother explained as follows:

    I saw some parents neglect the malignant nature of cancer and stop giving medicines to their child before a complete therapy, and seek other methods [folk remedies], but a relapse occurred.
I feared this situation, and told my son to endure the side effects (mother, Yeh family).

Another mother commented:

My friends suggested some Chinese herbs and medicines for me; I used them regularly, such as steamed chicken or beef, and my son disliked eating them, but felt his energy improved. I did not stop the doctors’ treatment, just made a different decision to help my son. My husband supported and paid for these ‘expensive’ fees totally (mother, Sue family).

While the sick adolescent stayed at home, they all wanted to go back to school. Schools have high expectations and normally give students a large amount of work to help them to enrol at a good university in Taiwan. The parents believed this work load would increase their adolescents’ self-esteem, make them more mature and give them the competitive edge in their study. However, parents considered their adolescent might have a poor immune system induced by stress, low physical strength, or undergo a relapse. Parents were also unable to teach their sick adolescent at home and they often did not have money to hire a private tutor. Parents would seek advice from medical and education professionals in order to make ‘right’ decisions for their sick adolescent. As one father stated:

Before the relapse, there was a lot of school pressure. Was it the pressure that caused cancer cells to relapse? Home education was not appropriate for my son. How could I make a good decision for my child? I listened to both the school’s and doctor’s advice (father, Wang family).

In the above instance, the sick adolescent commented:

My character was to ask for perfection, and I would complete every school teacher’s request. Maybe it was my character that hurt me a lot, I pondered too much and gave myself too much pressure. I told my parents this point. (sick adolescent, Wang family).
It was clear from the data that parents and their sick adolescent first needed to make decisions in complicated situations, such as choosing a hospital, living in a paediatric ward, treatment strategies and schooling. It is noteworthy that the sick adolescent and their family needed support from different sources as a way of confronting the broken chain of family life. In the above scenario, the sick adolescents and their families experienced different decisions in order to complete treatment and return to a normal way of life. They thus wanted to obtain support from different sources to gain more confidence to confront their distress and powerlessness.

**Obtaining Support from Different Sources**

Obtaining support from different sources was another strategy parents used to confront the broken chain of family life. Facing the uncertainty of treatment outcomes and fearing the sick adolescent’s relapse, parents were in need of different support from family members, other relatives, close friends, religious groups and medical providers. Data analysis revealed that support from the family was central to the well-being of the sick adolescent and this was generally associated with a return to the family home for care. The sick adolescent and their family endured and tolerated the cancer journey, negotiating with medical providers regarding the timing and approach to their adolescent’s treatment. Moreover, a supportive spouse was the most important resource for parents in this study and the adolescent’s illness had a definite impact on the state of the parents’ marriage. Spouses shared problems and confronted the clinical status of the sick adolescent or family matters together, as a mother expressed:

When I encountered difficulties, I would speak to my husband first. Any decision on the treatment for my son was discussed together and he made the final decision. We helped each other to face my son’s long treatment journey (mother, Sue family).

Another father commented:

We did not talk often before and conflicts between us were inevitable. When my son got sick, my marital relationship became closer. I thought without my wife taking care of my son, I really would not know what to do (father, Kung family).
From the above two comments it might be inferred that parents of sick adolescents turned to each other for support first and foremost before seeking support from others. It was evident from the data that healthy siblings needed to be obedient to their parents, and received love from other siblings in the family, due to Chinese values emphasising submission, social conformity and inhibition of self-expression. They would thus respect and listen to the parents’ arrangement and try to support their sick siblings by taking some responsibilities in the family. The diagnosis appeared to make the sibling relationship closer than before; as a result, the sick sibling and parents could gain support from the healthy siblings. For example:

I liked to help my parents to do chores after my study, and slept with my sick sister in the same room to look after her. She wanted me to help her with the homework or ask about school details. I would share my experiences with her. Hopefully, I could relieve my parents’ caregiving load, and give my sick sister support (older sister, Wu family).

One mother commented:

I appreciated my older son very much. While my younger son was sick, he would go to my older sister’s home to do his homework and maintained a fairly good score in his school. He could take care of himself; this was a big support for me and this family (mother, Kung family).

Taiwanese extended families (grandparents and relatives) in this study supported the sick adolescents and their families, including providing Chinese remedies and health products to parents; they also helped parents to take care of healthy siblings. Parents and their sick adolescent were more comfortable, receiving this extended family support, because this support network was more positive in maintaining family integration. The following quote highlights this:

My mother called and realized that my son had become seriously ill, she told my brother immediately, and then provided numerous
resources and bought healthy products for my son (mother, Wang family).

Another mother commented:

> When my daughter got sick, our family life got messed up. So, I did not go to my parents’ house for 2 weeks... They visited us often and provided traditional remedies [herbs, Buddha beads] for my daughter, very helpful (mother, Liu family).

Similarly, the sick adolescent appreciated the external family’s support, for example:

> My aunt’s husband treated me well. He often brought Buddhist books for me to read. He also bought me a necklace of Mercy Buddha. He often said we should live for this moment, should know what enough is, be appreciative, be forgiving and cherish what we have (sick adolescent, Hung family).

The parents would need someone to take care of the healthy siblings in order to spend more time focusing on the ill adolescent. However, parents could not pacify the healthy children’s emotions, telling them their ill sibling was sick and needed to be admitted to the hospital for treatment, and they would need to take care of their ill child temporarily. Healthy siblings felt sudden changes in their life. Extended family members expressed concern for the parents and their children. As one healthy sibling commented:

> I should be more independent as a mature child. So, my grandmother took care of me for two months and my aunt would pick me up to go to her house for the weekend when my parents stayed in hospital with my ill brother. I was grateful for them to accompany me during this tough time (younger sister, Wang family).

During the initial phase of the disease the parents received support in the hospital from other parents in the same situation and obtained crucial information related to the illness; parents could then make sense of their situation and confront the treatment of their sick adolescent. As a result, the mothers would build up support groups for sharing their
caring experiences for their sick child. For example:

We experienced the same situation as other mothers and helped each other in the hospital. We thought that real life experience was very important for us to endure the difficult times; thus, we had a mutual group for helping others (mother, Sue family).

Furthermore, the parents needed friends to share similar experiences to establish a positive network for understanding their suffering and progress of the disease in order to manage the side effects of the illness. Friends were open to discussing solutions, valued each other’s opinions and provided advice. Colleagues would also help parents to share their work load by arranging break times to take care of their sick adolescent, as one mother expressed:

When I first came into contact with this disease, lots of friends around my family wanted to help us. They offered lots of Chinese medications and caring experiences. Without their help, I did not know what to do (mother, Wu family).

One father also expressed this point:

I seldom took any leave of absence, but suddenly when I took three days off, my colleagues then found out that it was because of my son’s sickness. They often asked me about my son's condition and suggested to me to take days-off first, they would help me share my work load, and I was appreciative of them (father, Wang family).

Both the sick adolescents and healthy siblings were in the adolescents’ age bracket in this study, and they received peer group support and received the strength to go on in their lives, such as by using Blog or Facebook to exchange their life experiences and share information with each other. Three of the sick adolescents in this study did not want to tell their classmates about their personal problems. They only preferred to let
close friends know. Generally, healthy siblings did not talk with classmates or friends about their ill sibling’s problems. One healthy sibling reflected on this by the following comment:

   My teacher asked me about my ill sister’s problems, and wanted to visit me and my parents at home. I did not want my classmates to know my personal issues, just my one good friend knew and chatted with me on Facebook (younger brother, Liu family).

One sick adolescent commented:

   When I had the operation, one of my very good friends came to see me. I knew she was very busy attending class, but she took a break to come to see me. I was very happy. So I often wrote my feelings in my blog to her, she saw my blog and replied to me (sick adolescent, Wu family).

The obtaining of different sources of support for the sick adolescent and their family from their extended family members and friends was important. Receiving support from medical providers also helped the sick adolescents and their family with psychological care to cope with the life-threatening diagnosis of cancer, and gain knowledge of interventions to confront their stress from the treatment. Medical providers also made it easier for parents to take care of the sick adolescent physiologically. By taking away the symptoms of discomfort for the adolescent and their family, the medical providers were confident that sick adolescents were likely to accept the follow up therapy. One sick adolescent described:

   I had to go to the hospital to take chemotherapy every week. I looked on the positive side and accepted the side effects slowly. I cooperated with the doctor, and gained support from lots of nurses, they taught my mum how to take care of me, I could thus confront my physical changes (sick adolescent, Wang family).
One mother commented:

_The ones who could give me real help were the medical providers, especially when the doctor explained very clearly to us what might happen after my son was discharged from hospital and went back home, and the follow up treatment. I called him Buddha doctor_ (mother, Kung family).

Additionally, one sick adolescent and the family received financial support from Taipei-based Formosa Cancer Foundation. In this case the parents donated it back to another charitable institution, as the father explained:

_I thought with everyone's support, giving my daughter more caring, she would have the courage to face up to the disease, for example childhood cancer foundation volunteers, who provided publications, phone calls, one day trip to Taipei Zoo and supplied NT$5000 for medical fees, but I donated this money to the Buddhist Tzu-chi Charity Associations⁸ (慈濟功德會) (father, Wu family).

On the other hand, religious support was the most important way for the sick adolescent and their parents to consider the meaning of life. As data analysis revealed, most parents and their extended family members thought of cancer as their child’s fate or karma. They tried to increase their prayer in temples and small outdoor shrines in order to receive ‘Shamanic counselling and divination of a child’s destiny’. These religious places of worship gave the sick adolescents and their parents the opportunity to stop by and pray informally any time. They also provided a safe environment for meditation and various other forms of religious practices. In this study, mothers more frequently used religious support than fathers because most mothers stayed at home; religious affiliated groups easily provided for the needs and could arrange specific ceremonies requested by mothers to satisfy their spiritual need. One mother commented:

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⁸ The Tzu-Chi Charity Association (慈濟功德會) is one of the three largest Buddhist organizations in Taiwan. It was founded by the Buddhist nun, Cheng Yen, who established a large hospital in Hualien city in 1966. Also, the contributions are community service and outreach to medical, educational, and disaster relief (Hu, 1993).
I let my sick son to be Kuan Yin Bodhisattva’s \(^9\) son to get over the hard time. I also joined their Buddhist group for the counselling as various kinds of causes and conditions had shaped our destinies and eradicated karmic obstacles from past lives (mother, Yeh family).

The fathers would pray to the ancestors at home because it is easier to pray, as they were convinced that ‘loving people and loving gods are equally important’. They also went to the big temple three times a year to worship for their sick child, and this worship would obtain blessing in return for their family members, as reflected in the following quote:

\[
I \text{ prayed to my ancestors before I went to work which was as important as my daily life. They gave me faith and hope. I would also attend all the memorial events each year with my family. I wished it would let my son get back to being well again (father, Kung family).}
\]

Data analysis showed that the healthy siblings and the sick adolescents understood that their parents relied on the mighty power of the gods, and accepted to go to different temples or small outdoor shrines to pray. Three families in this study asked their children to recite Buddhist scriptures every two weeks in the temple. Parents or grandparents thought that this opportunity to recite god’s scriptures with earnestness and sincerity allowed the sick adolescent and their family to leave suffering behind and gain a blessing to the soul. One sick adolescent had this to say:

\[
\text{My family and I believe in Buddhism, and accepted that everyone came to this world to become disciplined. Every two weeks, my mother and I go to a temple to chant Buddhist scriptures; I also read these scriptures every morning and evening to wish for my own peace (sick adolescent, Liu family).}
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\(^9\) Kuan Yin Bodhisattva (觀音菩薩): the deity of Buddhism and has the supernatural power of assuming any form required to relieve suffering, also has the power to grant children in Chinese culture (Reed, 1992).
The healthy sibling commented:

Mum and grandma would like us [father and children] to go to the temple often to pray for blessing. If I pray, prayer should be answered; it is a strength that strongly supports my family (older sister, Yeh family).

In summary, it was found that the family members initially made decisions in complicated situations with their sick adolescent’s treatment of the cancer and obtained support from different sources to confront the broken chain of family life. Data showed that parents had become aware that they had made a range of challenging decisions. Complicated decisions revolved around therapy, emotional adaptation and supports, financial and study assistance. Thus, the sick adolescent and their family needed support from family members, friends, and medical providers and drew from their religious beliefs to confront long term life-threatening therapy and the management of follow-up procedures. This first phase of confronting the broken chain of family life led to the second phase of accommodating, which is described in the following section.

Phase 2: Accommodating the Broken Chain of Family Life

The second phase of the basic social process used by the sick adolescent and their family to deal with the basic psychosocial problem of experiencing the broken chain of family life was termed: accommodating the broken chain of family life. Accommodating was defined from the data as the sick adolescents and their families recognising that family life had been broken; requiring a flexible response to allocating roles and relationships to adjust to the adverse situation and be effective in assisting family members to manage the change in roles and relationships. Therefore, the family was in a position to promote the sick adolescent’s condition. It was evident from the data that the sick adolescents and their families needed to accept the broken chain of family life before they could consider undertaking any management strategy. This was indicated below:
My wife said family units are one, and that together we would be strong; we had to accept the issue as it came, and then together with family members to face the changes in our lifestyle. So my wife learned caring skills to help my son’s side effects as an assistant nurse. I helped to search for information from the Internet in order to gain more knowledge of the disease (father, Sue family).

One sick adolescent commented:
I should not keep thinking I was a patient, and tried to think about my mum. She was a single mum, and needed to take care of me and my younger brother. I thus told myself not to lose hope for relieving my mum’s burden and bring my family life back (sick adolescent, Liu family).

The mother added:
I was divorced over 10 years ago, and felt happy to see my children growing up. I told myself to endure this change and seek different sources to help my daughter cope with life as a patient. My son also accompanied his sister playing games at home because he did not normally stay home. (mother, Liu family)

The phase of accepting the broken chain of family life involved adjusting family roles and relationships and promoting the sick adolescent’s condition. Data revealed that Chinese culture deeply influenced the sick adolescent and their family to accept the family’s life change, the burden of cancer treatment and the forthcoming prognosis. Knowing how family and the sick adolescent accepted the cancer was a crucial step towards designing appreciative strategies to ease the stress of the treatment because they understood their own role in the problem and tried to put things right for the family. It was evident from the data that the family and sick adolescent had to undergo the first phase of confronting the broken chain of family life before they were able to move into this second phase of accommodating as one father commented:
I believed there was very little that could be done to change my son’s fate; this disease was a test from the god, so we accepted it and helped each other. As my wife said, family life was changed, but our hearts needed to be together to solve any problem (father, Yeh family).

One healthy sibling expressed her feelings as follows:

I took good care of myself and tried to keep the house clean. It was a big help to my parents and decreased their burden; they said gods were fair to give them an obedient daughter; I knew that filial piety meant doing the right thing and making parents happy. I tried to do more for my ill brother and parents, and just hoped my life would come back as before (older sister, Wu family).

Adjusting Family Roles and Relationships
Data analysis defined adjusting family roles and relationships as family members accepting the reality of the adolescent being diagnosed with cancer. They tried to adjust their roles and relationships with the sick adolescent, and became accustomed to understanding the treatment and follow up side effects. They also opted for a lifestyle change in order to properly manage their own way of life and balance their social activities. The data showed that adjusting—please make sure you use the word ‘adjusting’ throughout the thesis. I think I have used ‘altering’ in previous sections. Please change to whichever term you are using to be consistent the roles and relationships of the family was crucial during the illness and had a far reaching effect in the long term if physical, psychological and financial distress were to be limited. As a result, the sick adolescents could have a sense of belonging and a good experience to help them to accept the follow up therapy. It was also shown in the data that both family and the sick adolescent desired to control the disease and return back to a normal life. The parents would have input into all aspects of their caregiving and the healthy siblings cooperated with parents to ensure love in the family. Therefore, the family and sick adolescents adjusted their family roles and relationships after diagnosis. The
following quote depicts this:

I tried to play good mother, assistant nurse and counsellor; my husband had to be money maker, housekeeper and labourer; my other two children also helped me to take care of themselves, and care for their ill sibling. We all loved this family and wanted to adjust to life changes so as to come back to a normal life (mother, Wu family).

One sick adolescent commented:

My classmates all treated me as a normal person... So, my attitude changed to become braver and more patient and I treasured family time and my parents’ caring more. I could not continue thinking I was a patient anymore (sick adolescent, Hung family).

Furthermore, the mothers more often had the main responsibility for the care of the child with cancer and the fathers were more peripherally involved in childcare. This might reflect the different roles of mothers and fathers in the family’s roles adjustment. For example, the mothers needed to face every challenge that happened in the family, from the sick adolescent caregiving to keeping family life going. There just seemed to be an endless heavy workload day in and day out. They would reconcile with family members to find a mean point by them adjusting their family roles and relationships. Four mothers reported that they wanted to be like “thousand hands of Bodhisattva”, which meant that they could freely move and observe all things. Mothers played multiple roles in the family, such as housekeeper, caregiver, cook, counsellor and supporter; as well, they would adapt these roles promptly and efficaciously. One mother expressed how she became accustomed to accept this change:

I thought my son suffered more than me, so, I concentrated on taking care of him and tried my best to solve problems and conflicts in my family. Sometimes, I wished I was multi-handed to do numerous things, like Bodhisattva, not complaining to my family, and adjusting to a different role quickly that I should
learn from him [Bodhisattva] (mother, Sue family).

The mothers were more attentive to their sick adolescent and their roles were more flexible than the fathers’. After the adolescent was diagnosed and treatment had begun, the family had to work together to save their sick adolescent’s life; every member of the family became closer to each other, as one mother commented:

*I would quarrel with my husband and call my parents’ home to complain about my husband’s faults before. When my son got leukaemia, my husband and I would cooperate to solve any problem. I felt that the relationship in my family was closer than before* (mother, Kung family).

Data also revealed that the fathers played the role of head householder who had to bear all responsibilities and show a strong face throughout any difficulties. The fathers’ role included healthy sibling care, driving, providing emotional support for the mother and ill adolescent, visiting them in hospital, and discussing treatment with doctors. They stated that they might struggle with new challenges in their understanding of their lives and the sick adolescent’s progress. Their unwillingness or inability to express emotions to their family did not mean they did not want to do things for their sick child. For example, two fathers became vegetarians because a vegetarian diet would make their body and mind purer for praying to their ancestors. Four fathers’ religions changed; they did not believe in Buddha before their child got sick, but they relied on the Bodhisattvas’ mighty power to help their sick adolescents. Based on this concept was the reflection in certain notions of fatalism among Taiwanese families with respect to adapting to family roles and relationships. One father stated:

*After I studied the Buddhadharma and became a vegetarian two years ago, my family learned to understand their fate and therefore seemed to think that cancer had karma in our past lives. We all understood our roles and responsibilities in this generation, and would work hard together* (father, Yeh family).
Most of the healthy siblings in this study were performing caring or protective roles similar to a parent’s or a caregiver’s. In periods when the sick sibling was acutely ill this supporting behaviour was most obvious. On the other hand, when the healthy siblings were older than the sick sibling in their school, they wanted to protect their sick siblings, as if the sick sibling was a part of themselves. The relationship became more important and the bonds were tightened in the whole family, as one healthy sibling described:

*Other children laughed at my ill sister behind her back. I would be very angry and protective for her because she was the youngest in the family. I liked to help my parents to look after her, everyone loved her dearly* (older sister, Wu family).

Data analysis revealed that living together in the same house and sharing everyday life influenced the roles and relationships. Sharing a common background and outlook ensured that siblings knew each other. Two of the healthy siblings experienced their situation as being conflicting in Confucius’ principles ‘brothers must love each other respectfully’. They were not involved in providing care, and would complain about their lifestyle changes or that they were jealous because the parents put their emphasis on the sick sibling. Nevertheless the feeling of love was still there, as one healthy sibling commented:

*My parents would say they treated me and my ill brother equally without discrimination, I knew this was impossible, so I tried not to compare myself with him even though I felt jealous that my mum spent a long time looking after him. I understood the family situation and still loved my family* (younger sister, Wang family).

The healthy siblings were concerned about the ill sibling’s condition because they found it difficult to imagine that a healthy and vigorous brother/sister would become weak, lose their hair or stay in hospital for a long time. They also thought that if their ill sibling got well, then life would go back to normal. While it worried some (6 out of 13) parents to realise this was happening, they were happy for the healthy sibling to speak out about their worry and concern about their ill sibling. Some (5 out of 13) Buddhist
parents would share fatalism with their children, and then the older child would increase their responsibilities to look after their ill sibling and help out the family in different ways, such as helping with homework, doing chores or donating their bone marrow to the ill sibling, as reflected in the following quote:

*My mum told me I needed to donate bone marrow to my brother. Therefore, I had to watch my health and not get a cold. I hoped my brother would get well. Moreover, I would like to help my parents to keep the house clean and tidy for the welcome of my brother... definitely, helping my brother with his homework was my job also* (older brother, Kung family).

The experience of life threatening illness in the sick adolescent was likely to change the dynamics of the family roles and relationships both during the illness and for a considerable period afterwards. The sick adolescents reported that the healthy siblings treated them better than before. After the diagnosis, they began to understand how to relax, and began to value the chance to be with family and friends. They also changed their attitude and thought more about other people’s points of view. Thus, they did not have conflict with their family members, classmates or friends, even though they still fought with the disease and the treatment. They engaged in better behaviour than they had done before, and wanted to know more about how to take care of themselves. The following quotes describe this:

*After I got sick, my younger brother treated me well. He seldom cared about my health before, but now our relationship is good. Otherwise, the disease is a fact and cannot be avoided. I try to minimize the burden on my family and place value on my life, and be brave cooperating with the therapy* (sick adolescent, Liu family).

Another sick adolescent commented:

*To me, getting sick was very terrible. I was ashamed and rebellious to my parents, and did not like to cooperate with the doctor’s treatment. I also would not let other people know, and*
interact with friends as before. I saw some patient the same age as me, who were worse, but they could still take it, so I needed to change my attitude and take care of myself (sick adolescent, Yeh family).

In summary, the parents sustained their roles and responsibilities, and constantly emphasized their sick adolescent’s caregiving to the family because of the parent-child relationship as well as the fatalism of their religious beliefs. The parents played multiple roles for the cohesion of the family; the healthy siblings tried to accept their life changes and help the parents and ill sibling as much as they could; the sick adolescents also experienced a rearrangement of their way of life. The sick adolescent and their family did not want to see any relapse or worsening of the disease, thus they would adjust family roles and relationships to accept the broken chain of family life. This led to promoting the sick adolescent’s health as described in the following section.

Promoting the Sick Adolescent’s Health
Taiwanese parents regarded their adolescent child’s illness as their fate which they had to accept. They believed they were required to give time and attention to ensuring their child’s safety without experiencing physical and psychological distress. They therefore committed to providing care and seeking different information to promote their adolescent’s health in order to cope with the difficult time of the treatment. The concept of the child’s health was strongly associated with the cultural values of Taoism, in that the maintenance of the Yin and Yang balance ensures a smooth flow of the vital energy (Qi). Traditional Chinese medicines are prescribed to treat imbalances of both Yin and Yang in the body including herbal remedies and diet therapy. As well, Confucian belief emphasises that the whole family integrate with each other, which allows parents to increase their ability to care for the sick child and to endure the child’s suffering. Parents came to understand the majority of rationales for medical treatment. The parents and their extended family members were thus choosing culturally appropriate paths to travel the long and difficult journey as one mother described:
My family was able to face this disease bravely and calmly accept the treatment. We sought some resources to promote my daughter’s health. My mother and relatives suggested lots of Chinese remedies. I also knew Chinese herbal teas could maintain my daughter’s energy. I believed that everything was worth it, no matter how difficult it became (mother, Liu family).

One father commented:

The Chinese medicine doctors agreed to look into diets or Chinese remedies to improve my son’s energy. My wife knew Chinese remedies as an expert. I would also like to learn more about remedies from my wife (father, Kung family).

Additionally, the parents held distinct beliefs in the differences between the two medical systems for their sick adolescent. They believed that Western treatment is more scientifically based, and is more efficient at treating acute or infectious diseases. On the other hand, Chinese treatment is considered to be able to cure chronic problems and to eradicate the roots of a problem in a slower, gentler manner, and with fewer harmful effects than Western treatment. Parents would make the effort to observe and monitor related responses of the child when they had chosen Chinese medicine as a treatment during the illness. One father illustrated this as follows:

My wife believed in Chinese medicine for its gentle effect and its ability to eradicate the roots of the cancer and symptom relief. Perhaps her belief was from the traditional culture and was frustrated with the ability of chemotherapy when my son’s side effects got worse (father, Wang family).

All of the parents believed that their sick adolescent needed nutrition to fight the illness, and they used animal secretions and organs to cook special foods in order to strengthen the sick adolescent, such as if the adolescent’s disease was a related blood problem, the mothers cooked pig’s liver to strengthen the iron level, or cooked animal’s heart for increasing heart function in their sick adolescent. Also, they knew that healthy food would be likened to a tonic supplement as herbal supplements, such as red date, ginseng,
lotus and white mushrooms would increase appetite, giving strength and clearing away heat. They prepared food in expression of their love and concern, thus they liked to search for health food or herbal supplements from friends, extended family members, books or the Internet. One mother stated:

> I believed that eating the same animal organs, the people would absorb the same extracted nutrition from them. I saw in a book and on the Internet about cooked pig’s liver with ginseng and red date soup to give my daughter energy; she accepted and knew this food for her health (mother, Hung family).

Another father commented:

> I believed that food and medicine were equally important. As my mother said cancer was a ‘hot’ source in my son’s body, she bought lots of lotus and white mushroom products for helping my son’s progress… All we needed to do was to take care of his nutrition to fight against the disease (father, Sue family).

On the other hand, three mothers believed Chinese medicine was complementary therapy. They thought their sick adolescent’s fatigue or immune system problems were caused by a Yin and Yang imbalance in the body. Many hospitals in Taiwan have outpatient Chinese and Western cancer medicine. The mothers would visit Chinese medicine doctors and gain individual prescriptions to regulate and improve their sick adolescent’s immune system and maintain other body system balance, such as in the respiratory system, cardiovascular system and urinary system. However, the sick adolescents complained that the medicines were too bitter, they could not take them. So the mothers would say ‘a good medicine tastes bitter’ to persuade their sick adolescent or ask a doctor to use scientific capsules from traditional Chinese medicine, as reflected in the following quote:

> Chinese medicine could improve my sick son’s immune system, so I took my child to visit the doctor in outpatients for Chinese medicine. The doctor said my son’s problem needed a long time to maintain balance in his body system, I was continually patient with my son (mother, Sue family).
A sick adolescent commented:

I knew the Chinese medicine was good for my health, but they could not take it easily because the doctor gave me traditional powder. I understood when my mother said “good medicine is always bitter” but it was terribly bitter! To take them, I persuaded myself that the medicine was candy (sick adolescent, Sue family).

Two mothers with children in relapse had the highest stress level associated with their caregiving for their sick adolescents. They could bear the hardship and be brave in accepting their adolescent’s relapse and enduring a different Western treatment protocol. This treatment yielded more suffering to their sick adolescent, but they never gave up hope for any chance of a cure for their child. They would choose different ways to promote their adolescent’s progress, such as Feng-Shui (風水). They believed that the non-harmonious situation between their adolescent and the environment could cause a relapse of the cancer, so they would set the correct placement of furniture in the living room and change the sick adolescent’s room to build the environment in areas with good Qi. One mother described this below:

Why did the relapse occur? I thought Feng-Shui had influenced my son’s illness. I changed my son’s room to a east-south direction, the temple master said it was a different way to maintain my child’s condition and I believed this (mother, Yeh family).

Another mother commented:

The disease had only a 10% relapse, but why my son? My husband said the house Qi was not good for my son and we changed the furniture in my living room and decorated it with lucky plants in there. Hopefully this could create good Qi for recovering his health (mother, Wang family).
Six months after the diagnosis, all of the parents prayed for the lighting of a lantern in the temple (點光明燈)\(^1\) to help in accumulating the blessings for their sick adolescent. They registered for a lamp and paid money. The temples provided the lantern for the lighting of this prayer lantern which hung in the temple, and reported who they were, where they stayed and what they requested. The parents would register every year to promote their sick adolescent’s or family health. One mother stated:

*I prayed for the lighting of a lantern in the big temple. Gods would know my request. I wished it because my parents used this way for me until I married. I also believed this and promoted my son’s health and happiness* (mother, Sue family).

One sick adolescent commented:

*I loved to see my name in the red lantern and it hung in the temple all year. Gods would know who I was, my wish. Definitely, this gave me faith and bravery to face my disease as someone took care of my emotion and spirit* (sick adolescent, Liu family).

On the other hand, most of the mothers’ values and experiences would be chosen by the fortune teller who gave advice such as divination for their sick adolescent’s progress. Three mothers reported fortune tellers wanted them to do more virtuous and meritorious in deeds, do more repentance and reform, and recite the Buddha’s name more often. They accepted the fortune tellers’ advice and would donate money to a temple, and attend memorial events to promote their adolescent’s health. One mother commented:

*As Buddhists, I would donate money and attend memorial. I wished these would transfer merit to my daughter. I was appreciative of the fortune teller’s advice and letting me know this activities three time every year to bless my daughter’s health* (mother, Hung family).

\(^1\) prayed for the lighting of a lantern in the temple (點光明燈): family register for a lamp, temples provide the Red-Lantern type for lighting of a prayer lantern hung in the temple, and report who you are, where you stay and then your request (Chen, Hung, Lin, Smith and Liu, 2009).
Two mothers said they needed to repay their debts to their sick adolescents; they felt guilty of their past lives with the sick adolescent. They should endure the caregiving burden in order to gain their children’s health, but their husband did not agree with this attitude because they did not like their wife becoming unhappy and burnt out physically and psychologically. One father described this:

*My wife believed what the fortune teller said. I thought it was commercial and unrealistic, we held our life in our own hands, our son got sick, we had to face and cure it. So, I told my wife the best way to promote our son’s progress, first was to be happy every day, another was by cooperating with the doctor’s treatment* (father, Sue family).

Another father added:

*I did not agree with the fortune teller’s advice; it’s unfair for us because having such a sick son was due to some kind of cause and effect. It would be really tough for the parents, I deeply appreciated my wife taking care of my son, and really did not want my wife to feel sadness or guilt* (father, Wang family).

Some parents looked for bone-setters to alleviate pain, restore function and promote health and wellbeing in their sick adolescent. This was a practitioner for joint manipulation on the sick adolescent’s body, but the health insurance did not cover this folk remedy. Two fathers considered their financial status because it cost NT$ 800-1200 for each therapy. They went one time and gave up this treatment because they wanted their wife and sick child to learn Qi-Gong. It is a way to balance the Yin and Yang of the body to reduce stress, pain and boost the immune system. The sick adolescents felt Qi-Gong was good for their immune system as well as their chemotherapy because they did not get colds for a long time. The following quotes highlighted this:

*My sick son had sore leg muscles, and my sister suggested to me to take him to visit bone-setters in Sin-Dan. We saw lots of*
patients over there but this treatment course cost lots of money. I thought my friend could teach my wife and child Qi-Gong. Qi-Gong was also good for blood circulation to relieve pain in his legs (father, Kung family).

One sick adolescent commented:

I just followed and cooperated with them because I knew they were promoting my health for the best. So, my father wanted me to learn Qi-Gong with mother for six months. Qi-Gong was very easy to learn and practice, I saw the effect because I did not get colds anymore and could accept chemotherapy regularly (sick adolescent, Kung family).

Data analysis revealed that the parents would choose Chinese remedies and Western treatments for promoting their sick adolescent’s progress. The mothers had no choice but to care for their sick adolescent both in the hospital and at home. They provided care to ensure adequate monitoring and nurturing. They altered their own living schedule to stay with their sick adolescent to provide flexible care for their adolescent and reported their condition to the husbands and health care professionals. The fathers would support their wife and sick adolescents to promote their emotional well being. They also used scientific means to gain more information to promote their sick adolescent’s health. The following quotes described this:

I appreciated my wife telling me about my son’s follow up treatment and lab tests results. For example, when potassium was low in my son’s blood, I would try to search on the Internet to find foods high in potassium, and bought different foods to give my son choices... I gave care in a different way (father, Yeh family).

One mother commented:

I tried to be with my son all the time, and it was just like an invisible handcuff. So, I had more time to learn a good caring way from other mother’s experiences and nurses. Also, I knew how to monitor my child in any abnormal situation when he...
In summary, promoting the sick adolescent’s health was another aspect to accommodating the broken chain of family life. The parents provided Chinese complementary information on how the sick adolescents at different stages might use different remedies, for example, Chinese remedies, food therapy and folk therapy. Parents believed that their sick adolescent wanted to accept the long and miserable therapy. Therefore they needed to help them to relieve discomforting symptoms through the use of Chinese remedies or folk therapy which could maintain their good energy and alleviate side effects from Western treatment. As cancer was a prolonged stressful situation for the family, they determined the effectiveness of therapy to be considered as shown in the above data. Hence, the sick adolescents and their family were maintaining hope for a good outcome and for achieving a harmonious family by acting to repair their family life via changing the way they interacted with each other, as the next section will describe.

**Phase3: Repairing the Broken Chain of Family Life**

The third and final phase of the basic social process used by the sick adolescents and their families to deal with the basic psychological problem of experiencing the broken chain of family life was labelled repairing the broken chain of family life. This phase involved maintaining hope for a good outcome and achieving a harmonious family life. In the last phase, the context of Chinese culture was the dominant factor in understanding the cultural beliefs and values of parents, healthy siblings and their sick adolescents. Chinese cultural beliefs might help the sick adolescents and their families to gain positive aspects from the illness experience and establish hope for the outcome. Thus, this phase was dynamic focusing on positive aspects of the stressful situation and they hoped to achieve a harmonious family life in order to restore their family life which was broken. Repairing the broken chain of family life has been defined from the data as the sick adolescents and their families deciding to apply strategies in order to return to a normal life as much as possible and to alleviate their sacrifices and suffering. As evident in participants’ comments throughout this section, participants enacted their
strategies through the use of symbols in their interactions assisted by their cultural beliefs. For example:

My first and most important wishes were my sick son’s full recovery, looking forward to the end of the treatment and returning to a normal life. I also sincerely prayed to gods for providing harmonious circumstances around my family. Thus, I would think of paths to create a positive physical and psychological outcome for my child to accomplish his life roles [job, marriage, and children] (mother, Wang family).

One father commented:

My son’s disease had brought our family closer together. My life centred on my children. My wife and I cooperated very well for maintaining family integrity. So, it was good for the family that we could do it quickly because I hoped to see my family live a life of health and happiness at any time (father, Kung family).

Maintaining Hope for a Good Outcome

The data showed the importance of maintaining hope for a good outcome as the sick adolescents and their families maintained hope that they would get better and the disease would pass. Chinese cultural beliefs could help them gain positive aspects from the illness experience and establish hope for a positive outcome. The following four examples illustrated how different representative family members expressed their hope for a positive outcome to the sickness:

I believed the doctor used more advanced medicine to cure my son’s disease, and more information made our family understand this. Also, we prayed to my ancestors twice every day and they were able to bless my family further. So, we were not afraid of this disease and its miserable treatment. (mother, Wang family).
One father commented:

We stayed optimistic, helping my daughter to cope with medical treatments and daily hassles. As our family is all Buddhist, my daughter was god’s child. We sincerely recited god words and did good things for others. Thus, we accepted her situation to remain optimistic and to gain strength for her and us to face her disease. We believed in a good outcome for our family (father, Wu family).

One sick adolescent added:

I was able to use a scientific way to gain more information to promote my health. My parents thought that finding a good doctor was a matter of fate and destiny. I kept hope for survival across the stages of the disease because hope gave me the ability to endure the suffering. Another reason for this hope was that I did not want to upset my parents because of filial piety (sick adolescent, Yeh family).

One healthy sibling commented:

I did not want to think too much because my parents wanted me to be optimistic and maybe it could help my younger brother. I also wrote a get-well card to encourage him. If we kept hope continuously, Bodhisattva knew our wishes and he could gain health quickly (older brother, Kung family).

Two strategies used by the sick adolescents and their families varied according to the treatment and stage of the disease. The strategies involved family members and were varied and dynamic; they included negotiating and cooperating with medical providers in order to maintain hope for a good outcome. As the sick adolescent and their family perceived that this could not change the reality of having cancer, they worked to build hopeful images and goals as a method of motivation, such as talking about others who had positive outcomes, the survival rate and their hopes for the future. As one mother stated:
I asked the doctor about his survival rate and introduced people who had had good experiences and had successfully gone through this disease. If anyone suggested taking things to make my son feel better, I would go and buy them, I just wanted him to get well and have a good outcome (mother, Sue family).

Negotiating Care
The parents acknowledged that cancer was life-threatening, that it created a prolonged stressful situation and imposed difficult tasks in caring for the sick adolescents. They were relieved to learn that a cure was possible and negotiated with medical providers for the treatment and their child’s progress because they attempted to retain the vestiges of a good outcome throughout the illness. Specifically, two sick adolescent relapses occurred during this study, and the parents tended to stay optimistic by focussing on keeping higher survival rates in their mind. The following highlights this point:

I asked the doctor if there was any good treatment for my son’s situation; the doctor said that he needed another high dosage of chemotherapy to control a relapse. I didn’t know what this dose was, but the doctor said that they would be helpful and give hope after the procedure. If there was a chance for survival we would do it (mother, Yeh family).

Data analysis showed that most parents thought of cancer as a test or challenge from gods; it might serve as a way to strengthen their children’s determination to fight the disease and help them to face their stressful daily lives. They would negotiate with gods for reducing their worry and fear about their sick adolescent’s situation in order to move forward along the course in fighting the cancer. They made a vow to gods in the temple for the recovery of their child’s health, committing themselves to redeem their promise when the sick adolescent got well, such as preparing food or other products in appreciation of gods’ blessing, donating more money to publish Buddhist books and other products, or becoming a volunteer in the temple or shrine. One father illustrated
this as follows:

*I would pray and discuss my daughter’s illness with gods, hoping she got well comfortably. When my child’s condition was stable, I would like to prepare five fruits* [oranges, tangerines, apples, bananas, sugar cane] *and five vegetables* [lilies, edible fungi, mushrooms, cucumbers, peas] *to thank gods. Also, I volunteered in the shrine for cleaning the altar and surroundings every weekend* (father, Hung family).

Another mother commented:

*I asked the Jade Emperor\(^{11}\) (*玉皇大帝*) to bless my son’s stability because I knew this disease was his test. He gave my son the chance to cherish health and accept different life challenges. So, I made a vow to the god for maintaining a good outcome for his treatment. The god looked after my son and I bought a gold necklace and donated money to publish books, CDs and papers in the temple* (mother, Wang family).

On the other hand, five parents in this study were Taoists who hoped for longevity of life for their children. Taoism teaches that people ought to accept life and death as complementary aspects of reality and nature, but they did not want to think their adolescent would die of the disease. This was because parents liked making the decisions and claimed that this had to do with their ability to make a bargain with medical providers for the complicated protocols of the treatment. They would use simple methods to ensure good progress towards recovery for their children. For example, they focused on health for the body through diet, exercises and regulated breathing for Chi (Qi) through meditation and disengagement. One father stated:

*I could not let my son die of cancer because my life goals were health, simplicity and happiness. So, I stepped toward designing*  

\(^{11}\) *Jade Emperor* (*玉皇大帝*): is the Taoist ruler of Heaven and the status most honoured gods of the Chinese traditional religion pantheon (Liu, 2003).
appropriate exercise to increase my son’s physical energy and bolster his health. This exercise combined Tai-Chi and yoga strategies, and the doctor agreed and wanted me to make a DVD for other patients (father, Kung family).

One mother added:

We were a Taoist family and I knew about health from natural matters, such as eating more vegetables and fruits and took exercising to maintain our body balance. I thus watched over every detail when cooking, choosing organic foods and filtering water for my daughter’s energy. These could overcome the call of cancer (mother, Wu family).

It was also found that three sick adolescents negotiated the treatment with gods to maintain hope for a good outcome. They recited the Bodhisattva’s name with earnestness and sincerity and transferred merit to themselves two times every day. Two relapsed adolescents felt much better about their side effects from the treatment, and another sick adolescent did not change his physical distress but he felt more peaceful when he received treatment. They thought that probably with help from the Buddhas and Bodhisattvas, this would encourage them to keep up their hope and move forward. Their parents deeply believed in upholding the Buddha’s teachings. One sick adolescent described his feelings as follows:

After the relapse, I began to understand how to relax myself and believed the religious power. I recited the Bodhisattva’s words and name twice every day, he listened to my wishes and maintained my stable condition. I sincerely studied the Buddhadharma (beliefs, concepts) as my parents did (sick adolescent, Wang family).

Another sick adolescent expressed how she negotiated with the Bodhisattvas of the Earth (地藏王菩薩). She held her palms together, inclined her body and made a salute,

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12 Bodhisattvas of the Earth (地藏王菩薩): in the Chinese family, Earth Bodhisattva is more
as she stated:

*My mother took me to learn Buddhas in the temple. She threw bouys to ask the god [Earth Bodhisattva] about my health, she said the god wanted me to recite his name sincerely every day, and he would bless me when I received the chemotherapy. I saw the miracle of myself because I experienced serious vomiting but my heart was so peaceful and I felt no fear during my treatment period* (sick adolescent, Liu family).

The family often held religious beliefs which were to act in different ways in order to maintain their hope for the sick adolescent. Two mothers stated that they believed gods would bless their family, but they wanted to give up invasive and onerous treatment because they saw their sick children were miserable over the long journey. They negotiated with the doctor about their sick children’s suffering but did not receive good feedback. They tried to seek information from friends who suggested health products for effectively controlling cancer. One of the mothers informed her husband about alternative treatment, and he never gave up on any sort of treatment for his son. Another husband agreed with his wife’s opinion to withdraw the last dose of chemotherapy and bought some enzyme powder for his daughter. The following quotes illustrate this point:

*I saw my daughter was very miserable because of her treatment, so my wife and I told the doctor not to undertake the sixth chemotherapy. We bought some kind of enzyme powder for her to take. This enzyme powder was very expensive, but my friends strongly suggested that it could control cancer and maintain survival rate. Also, we relied on the awesome power of Bodhisattva* (father, Hung family).

The sick adolescent added:

*My parents asked me to take an enzyme powder every day. Taking enzyme made me feel active and the skin’s itchiness was compassionate and caring of the people who want to keep their health or prevent illness* (Kan’no, 2001).
getting better. If I did not take this enzyme, I would feel itching and have dry skin. My father said one bag of enzyme cost NT$30 and it was very expensive, so I had to take it (sick adolescent, Hung family).

The sick adolescents in this study reported that they experienced a variety of on-going losses due to the diagnosis and treatment. These included loss of health, lifestyle and concern for the future. They envied their classmates for having better lives than themselves, but they had come to realise that they were not alone and had much to appreciate and be thankful for, especially due to the care by family and friends who provided medical information to maintain hope for a positive outcome. They would thus negotiate with parents to let them go to concerts with friends or visit public places for social activities. One sick adolescent said:

*When I got sick, it made me lose a lot but I began to value my own body and family time together. I would correct my behaviour and think of matters from other people’s position. So I told my mother how to take care of me, and how I wanted to go out, such as with friends together to enjoy concerts* (the sick adolescent, Sue family).

Another sick adolescent commented:

*Please let me have a chance to live my life the way I want to live. I knew my family and some relatives sought lots of medical information for me to have to look after myself. I appreciated that, but I hoped that I could go with classmates for sport to improve my physical strength— that way I might be able to put more effort into my study* (sick adolescent, Wang family).

Additionally, the sick adolescents liked to negotiate with medical providers to reduce the suffering because they tried to maintain a renewed sense of confidence and gain courage to face life. However, what they most feared was that the doctor would not be able to find their peripheral blood vessels for taking a blood cell count or injecting medicines because chemotherapy made their blood vessels fragile and they might
rupture before the course of treatment had been completed. Two sick adolescents accepted the doctor’s suggestion to insert a central catheter in their cervical vein (e.g. Hickman tube or port-A). Five other adolescents tried to use peripheral blood vessels on their hands, as the following quotes from different sick adolescents indicated:

*Things were not meant to happen like this because I so feared the doctor could not find my blood vessels and hurt me so much. I wanted to spew when I saw the medicine every time. So I asked the nurse to find a good skilled doctor for me, and I would aggressively massage my blood vessels to become more elastic to accept this injection* (sick adolescent, Hung family).

Another sick adolescent added:

*My parents said I am so brave because I accepted the doctor inserting a Hickman tube. Actually, I feared they might puncture my peripheral vein on my hands, it’s so painful! I told myself to face any therapy because I wanted to stabilise and return to my normal life* (sick adolescent, Sue family).

It was clear from the data that the sick adolescent had negotiated with the medical providers, the gods and their parents before they could cooperate with them in order to maintain their hope for gaining a positive outcome. Most importantly, parents found negotiating with the medical providers and gods made their sick child collaborate with them and keep an optimistic attitude with regards to the treatment and outcome.

**Cooperating with Supporters**

As previously alluded to, the sick adolescents and their families would negotiate with someone in order to reach an agreement about how they were going to proceed regarding their hope. It was also observed that through cooperation they came to some consensus about how the important aspect of care was to be carried out. For example, the sick adolescent and their family were constantly adjusting to change and were transformed through the impact of the disease and caregiving on family roles and relationships. Parents thought that if anything was good for the sick adolescent they
would do it quickly. Hence, this made them cooperate with other family members and medical providers. This was plainly noted as shown below:

My wife would coordinate, arrange and manage services for the doctor’s appointments and our daily life. My children and I would cooperate very well with her because we understood coexistence in family life and wanted to move forward in fighting the disease together to gain a good outcome (father, Kung family).

One mother commented:

I knew that my son would not want us to worry so much about him. He was a perfect patient in the hospital because he was very cooperative with medical providers and obeyed the treatment steps for improving his condition; for example the doctor advised him to drink more water and do exercise, and he followed all these suggestions (mother, Sue family).

The parents needed to help each other when their child had this kind of disease. Data analysis revealed that most of the parents discussed the sick adolescents’ issues, such as treatment methods, and the use of healthy products or folk remedies. They were looking for more information to understand the whole situation in order to make a proper judgement and to collaborate. They preferred open cooperation with each other and their children in order to allow the family to continue to reside together peacefully. Therefore, the parents expressed an opinion that the best ways to manage during the diagnosis period and the occurrence of the relapse, was to communicate with openness about the sick adolescent’s situation with family members. This strategy could help the sick adolescent face the disease. An example is cited below:

I preferred a more open and frequent communication to make my son understand his treatment and how to cooperate with me and the doctor in the beginning. I knew he was so brave to search for information regarding the illness from different sources, and would like the doctor to tell him the truth of the illness because
he thought he had the responsibility of self-care (mother, Hung family).

One father commented:

I was not good at talking about facing my son’s illness but when his relapse occurred, I needed more chance to know his thinking and feeling in order to maintain his emotional well-being. I thus read books about “how to communicate with your teenage child”; my wife appreciated this (father, Wang family).

On the other hand, some sick adolescents stated that receiving chemotherapy was just like taking a rest because they did not have to study. They thought getting sick might be a good situation for them, the illness made them know different things that they had not yet experienced. They might join in the discussion to properly understand their own disease and the way of treatment, and to fully trust the medical providers. This allowed the adolescent and their parents to develop collaboration in their daily lives. As well, their parents stated that they lifted their pressure on their sick child’s academic performance, realising that health was more important than everything else, as one mother described:

My son once told me that his disease meant that he could take a rest because he was too tired to study, but when he got sick he could understand health was more important than studying. So, I would not let him to have pressure on the school work, and he cooperated in everything that was good for him (mother, Sue family).

The sick adolescent commented:

I met some friends in the hospital with similar experiences and they thought the treatment made them rest from the school pressure temporarily. I agreed with this point and wanted to experience and learn a lot of things in my life. I started to pay attention to my treatment course and accepted my parents’ arrangement (sick adolescent, Sue family).
The sick adolescents also focused on the belief that if they cooperated with parents and medical providers, their disease would be under control and they would gain a good outcome. Thus, they would survive and no longer have limits on their lives or need to endure medicine and other treatments. The following narrative depicts this:

*If chemotherapy could control this disease, I would try hard to cooperate with the doctor. Thus, my parents or relatives bought any alternative medicine or health products, asking the doctor first then providing them together with the doctor’s treatment* (sick adolescent, Wu family).

Another sick adolescent added:

*I would cooperate with the doctor’s therapy and take whatever food and drink my mother had prepared for me because I wanted to get better as soon as possible. I would like to return to normal life together with classmates. Hopefully, my mother will not restrict my social activities* (sick adolescent, Liu family).

Similarly, the healthy siblings stated that they understood their parents still loved them as before and tried to accept parents’ arrangement for their daily life, such as arranging someone to take care of them and telling them how many days they needed to stay in hospital. The healthy siblings also knew that their ill brother or sister was taking some kind of therapy and was suffering from the treatment. They wanted to help the parents and ill sibling going through this tough time. This meant that they added optimism and positive belief that the ill sibling would recover well and come back to the ‘normal’ lifestyle again. Thus, they helped with chores after study and looked after themselves regarding health and school achievement. The parents appreciated their healthy children’s cooperation in these things, as one mother said:

*My daughter consoled me and said she was 16 years old so she was old enough to be the housekeeper and to look after this family. So, I just paid more attention to her brother and kept thinking positively... Most importantly, she took care of everyone very well* (mother, Wang family).
One healthy sibling commented:

When I saw my younger sister get sick, I started to understand the importance of my health ... I would help my parents by my best, such as chores, study or look after my health. I hoped my ill sister would get well and come back home as before in our happy times together (older sister, Wu family).

In summary, data analysis showed that the sick adolescent and their family maintained hope for a good outcome in order to repair the broken chain of family life. They used negotiating and cooperating strategies in their interactions with each other to support the development of optimistic and positive thinking. Negotiation, which included religious belief, such as praying and attending religious services, helped to shape their sense of meaning and maintain hope. The parents negotiated with medical providers in relation to treatment and thus the progress of their sick child. The sick adolescent and their family gained strength to face the disease and were more likely to have better medical compliance because they took care to cooperate with the medical providers and family members.

Achieving a Harmonious Family Life

The data showed that in achieving a harmonious family life, the sick adolescent and their family experienced the family life being broken, yet their life could include healing. They supported and helped each other, enabling them to ride out the difficulty together in order to restore harmony and a peaceful co-existence within the family. The meaning of harmony in Chinese family belief is multifaceted. It is about sustaining holistic love and wellbeing and partaking of a symbolically vital responsibility. This belief provided a buffer against stress during family disagreements and allowed the family to be more effective in solving their daily life problems. The parents wanted to attain a harmonious family life and this led them into unconditionally sacrificing their own lives, based upon family ties. This understanding of harmony was manifest in the parents’ belief that their life was totally focussed on their children. They worked extra hard on the family obligations underlying cultural beliefs. One mother explained:
We became more sensitive to managing our daily life and being more thoughtful and considerate of others. My husband and I were working hard for my children because home is a place where we could feel safe and a sense of belonging. We shared undeniable responsibility, which could create harmony in a family (mother, Kung family).

Parents further stated that Confucius taught the importance of family and set rules of conduct and principles of thought that assist individuals to achieve harmonious relationships. This belief included who in the family should be responsible to manage the disease that was creating difficulty in negotiating differing role expectations. For example, living with the sick adolescents challenged parents and healthy siblings to adapt their family roles and relationships to accommodate the disease. Parents believed that their roles were to assist and encourage the sick adolescent to ultimately be more conscientious about self-care. The following examples illustrated differing approaches:

My job was taking good care of my sick daughter and encouraging her to learn self-care further, such as when acne grew on her face and became darker while she was taking medicine. I would teach her skin care and assist her to maintain her social confidence (e.g. about going to school) in order to achieve a harmonious relationship in the family (mother, Wu family).

One father stated:

The best way to live in harmony with my family was listening and assisting with their needs. I accepted my responsibilities and developed a sense of unwavering determination that would serve my family well and help my sick son to bravely face his disease (father, Sue family).

The sick adolescents’ role responsibilities encompassed managing their treatment courses well, not only for health benefits but out of respect for their families. Healthy siblings’ role responsibilities reflected an interdependent relationship with the sick
adolescent and parents. One sick adolescent felt a sense of responsibility for their family:

I knew how to cherish my health and respect my parents and younger sister. This meant taking responsibility for my own life and not letting them worry about me further. So I kept safe and took medicine every day in order to attain a harmonious and peaceful feeling in my family (sick adolescent, Wang family).

A healthy sibling added:

Our family seemed to be more harmonious because I would yield to my younger brother and be considerate that he was uncomfortable from the sickness. So I would try to make peace with him and understand my parents’ requirement for me to show responsibility (older brother, Kung family).

In addition, parents applied themselves to the raising of their children by providing material items, showing love and kindness and by meeting the spiritual needs of their children. The sick adolescent and their healthy siblings accepted the parents’ decision to change lifestyle patterns, and to cultivate optimism and faith in order to achieve a harmonious family life. Changing lifestyle patterns and keeping the faith were thus strategies used to achieve a feeling of harmony and repairing the broken chain of family life. The following narrative depicted this:

I was deeply appreciative of my parents and younger sister’s company and adjusting their lifestyle for me, they gave me faith and hope to receive my chemotherapy on time so there was no delay and helped me to be as strong as possible between each dose until the next dose (sick adolescent, Yeh family).

One healthy sibling commented:

When my sister came back home safely, I thought I should not be stubborn about things. I ate breakfast every morning and went to bed before 11pm to maintain my health and make my mother happy. I also believed my sister would get well because she became more considerate with the family and looked after herself (younger brother, Liu family).
All families in this study clearly achieved a harmonious family life. However, the families differed in the sense that the level of harmony was achieved. This was dependent upon the medical condition of their sick adolescent. In two families, relapse occurred, which provided a further challenge to the achievement of harmony, whereas families in which the adolescent was in remission, they achieved greatest harmony, as one mother stated:

I could not experience peaceful and harmonious feeling in my family when my son’s relapse occurred. My son needed to receive more treatment and suffered side effects and spent more time in the hospital. Our family life was broken again... He did not accept this situation because we had a good time together in his remission period and almost forgot his illness (mother, Wang family).

When the adolescent suffered relapse, the family would revert to confronting and begin the journey towards repairing once again. One sick adolescent commented:

When my relapse occurred, I had no control over what happened to me. My parents and I had to confront this bad news because life is so amazing and impermanent... What I learned from it, I had to appreciate it as much as possible (sick adolescent, Yeh family).

From the above perspective, the sick adolescent and the family wanted to achieve a harmonious relationship in order to repair the broken chain of family life. This harmonious family life was clearly perceived to be within the context of caring for an adolescent with cancer. They responded by thinking positively about the cancer and by following the treatment. Data revealed that they used changing patterns of family life and keeping faith as two strategies to achieve a harmonious life. The following section describes these changing patterns.
Changing Patterns of Family Life

The family members had to change lifestyle patterns as cancer was a prolonged stressful situation; however, the families thought these stressful events could promote positive life changes in every member. During the 6 months of the diagnosis period, most mothers left their job temporarily to be with the sick adolescent 24 hours a day; most fathers worked more hours or changed to a more flexible job in order to care for the healthy children at home. The healthy siblings needed to learn a new lifestyle and/or create interaction with other extended family caregivers, such as during meal and leisure times. As well, data showed that when the sick adolescent and their healthy sibling were both in the teenage stage, the family relationship comprised complementary patterns in which the mothers directed more of a given behaviour to the sick adolescent and the fathers directed more of a given behaviour to the healthy siblings. Parents tried to make the appropriate arrangements for the family’s daily life in order to manage the commencement treatment stage. One mother illustrated how she adjusted the family’s lifestyle:

_I did not have time to feel distress during the treatment of my son’s illness because I needed to arrange the new lifestyle for my husband and other children. My husband changed jobs to do insurance brokering for more flexible time for caring for the other children and helped me to solve the complicated situation_ (mother, Hung family).

The husband added:

_I made a new schedule when my son got sick. I went to my company at 6 in the morning to take my clients’ information, and then went to the hospital to see my son and wife at 10 am, bought lunch and went back to the office to put things in place for the afternoon. I did not know how to cook before, but I had to prepare dinner for the other children for their dinner and supervise their homework_ (father, Hung family).
One healthy sibling stated:

*I woke up at 7am to prepare breakfast for myself because my parents did not stay home. When my grandmother came here to care for me, I would wake up at 6am to eat rice porridge, and she asked me to go to bed at 10pm. I accepted her arranging my new lifestyle, and wanting me to be healthy* (younger sister, Wang family).

Moreover, parents reported that the older healthy siblings had a more positive involvement in their changed lifestyle and less conflict toward the family members during their younger sibling’s treatment period. This was explained in the data as the healthy siblings’ and parents’ perceptions of cohesiveness and harmony being linked with lower conflict within family members. The healthy siblings were help parents to accompany and encourage their sick sibling to think positively in order to overcome the disease and restore their normal life. For example:

*We all faced the disease very positively and bravely! I told my ill sister to live for the present... So I did not have any conflict with her after she got sick and accepted to help cook dinner, and do chores after dinner in order to reduce my parents’ burden* (older sister, Wu family).

One sick adolescent commented:

*My older brother and I are just like good friends, I would talk to him about things that happened at school or discuss computer games. I hoped he could be at home often, so he withdrew from the badminton club and rescheduled his school activities just to accompany me every night. He took care of me as a mother or teacher, such as reminding me to take my medicines every morning and helping me with homework at night* (sick adolescent, Kung family).

Data analysis showed that two sick adolescents had finished their therapy and the disease was now under control, which meant the sick adolescent and their family could
revert back to normal life. The sick adolescents wanted to discuss with their parents adapting to face school life, and their new life with their family. They knew it was not necessary to go back to hospital to take shots and medicines, and their life became more relaxing. Their physical strength and immune system gradually strengthened because they had protected themselves properly supporting a good chance of survival. Parents had encouraged them to have a positive outlook on life because they knew it would help the sick adolescent cope emotionally. They accepted their sick child’s suggestion about involvement in social activities with their peer group; parents also restored their own social life with relatives or friends. The sick adolescents stated that they felt like “birds” because of freedom from treatment and illness. They believed health was the best thing in the world and treasured family relationships. Below are examples of how sick adolescents would express their feelings:

*My doctor told me my disease was under control. I was happy to make new arrangements in my life, such as sporting, camping time and travelling in this semester. It was like a new beginning, I began to understand how to relax and value my health ... This feeling made me feel like a sparrow as I could fly everywhere to experience my life* (sick adolescent, Wu family).

Another sick adolescent commented:

*I escaped from the nightmare because I finished my terrible treatment. My parents helped me to enrol in high school and told the teachers about my situation. I attended any physical classes and student clubs in the school. I could enjoy my life as a normal person, like a bird, but my mum still reminded me. I went home on time and went to bed early, I tried to reschedule my timetable as I lived* (sick adolescent, Sue family).

As the above sick adolescents stated, the family interaction during the treatment was important for managing the disease. Parents and healthy siblings were familiar with the sick adolescent’s situation and accompanied to hospital until they were off the treatment. This situation was especially noticeable with the parents who sacrificed a great deal for
the sick adolescents, such as changing the family lifestyle to accord with the sick adolescent’s treatment time, and seeking good methods for effectively handling the progress of the disease. They believed that to keep a cohesive and harmonious relationship in their family, helped to make the sick adolescents brave and willing to finish their therapy. As one mother commented:

There was a saying that “the hearts of a mother and her child are connected” (母子連心). My son taking responsibility for his own life repaid me. I believed my son’s health was more important than everything, so we all agreed to adjust our lifestyle totally in order to coordinate with his different treatment periods. He knew our hearts and handled his suffering very bravenly until he finished treatment (mother, Sue family).

On the other hand, data revealed that two sick adolescents had relapsed and endured different treatment for controlling this disease, such as a long term intensive combination of chemotherapy, radiotherapy and/or even surgery. Their suffering made the family continuously change their lifestyle for helping the sick adolescents to face their tough treatment periods again, such as accompanying them to the hospital or decreasing social activities. They needed to endure more suffering after relapse, the reason being, there was no standard procedure for the therapy in Taiwan. They prayed to Bodhisattvas and contacted the doctor more frequently in order to go back to normal life. They needed this alteration to lifestyle for achieving long-term remission or to be cured. For example,

I needed to accept this bad news and keep brave together with my son when he had relapse. Most importantly, I spent more time cooking healthy food for balance of nutrients in order to increase his immune system, and need to accompany him to receive chemotherapy every time in order to contact the doctor more often (mother, Wang family).
One father commented:

*I prayed to Bodhisattvas in every temple when my son had the cancer in his brain again. He received surgery, radiotherapy and stronger chemotherapy. I was so proud of him because he faced his disease very bravely. We all want to work together for him to recover his disease; hopefully, our normal life could back to us* (father, Yeh family).

Healthy siblings also needed to arrange their lifestyle to support the sick adolescents by expressing their concern and love; they would become more responsible for taking care of themselves at home such as cooking meals for the family and decreasing their social activities. One healthy sibling expressed her feeling:

*I would stay home longer than before because my mum wanted to me to be more mature and look after myself and I cooked meals for my father when my mum looked after my brother in the hospital... Also. I could not attend some friends’ parties because my brother needed our company to go through very hard times during the treatment* (older sister, Yeh family).

The following example illustrates how sick adolescents expressed how relapse had led to re-adjustment to their lifestyle. One sick adolescent stated:

*After relapse, I wore amulets for blessing and keeping health because I believed when my mother said to fully trust gods and the doctor to maintain my emotional well-being. They tried to do lots of things for me, such my father worked so hard for maintaining financial balance, and he didn’t take any holidays; my younger sister became more sensible and polite to the family* (sick adolescent, Wang family).

In summary, it was found that the sick adolescents and their families who believed in changing their lifestyle patterns during the treatment, after treatment and relapse period were flexible in adapting to their life changes, such as school life, social activities and
family daily life. This encouraged and helped the sick adolescent to face different stages of treatment bravely. Keeping of faith was another strategy to create positive thinking for them going through a tough journey and achieving a harmonious circumstance in the family.

**Keeping Faith**

Keeping faith was defined from the data as the sick adolescents and their families as trying to see the good things in the treatment and progress, so as to focus on the positive in the future. This faith was believed to have been a tremendous source of support for most of these sick adolescents and their families throughout the cancer journey. They depended on advanced treatment and religious beliefs to give strength to the family to keep their faith to face their own life. Moreover, the parents were observed to keep faith believing that advanced medicines could completely cure the disease and ensure a good survival rate. The doctors conducted periodic monitoring after treatment had ceased, and observed the progress that the adolescents had gained during the 5 years of monitoring. Thus, the sick adolescents and their families believed the disease would become progressively more under control and normal life would be restored. They explained:

_I definitely could overcome various difficulties because I trusted medical advancement for controlling my disease. Even if something was difficult to handle, my mother wanted me to recite and pray to the god [Bodhisattva]. My heart was becoming peaceful and confident of the future. So I believed my life would come back to normal_ (sick adolescent, Yeh family).

One mother commented:

_I believed in the doctor’s experience and understood the five years survival rate was rising because of the good medical system and advanced knowledge about the treatment. So my husband and I did not fear because we were able to be good supporters for my daughter, and she worked hard on the treatment herself. My family members all fought this disease together_ (mother, Wu family).
Parents further stated that keeping of faith was a crucial step toward accepting the disease to ease the fear and stress of the treatment. In such instances, the parents claimed that they needed to give their sick adolescent optimistic and positive thinking. As previously alluded to, some parents believed in the notion of fatalism; in other words that the disease was their sick adolescent’s fate that there was nothing that could be done to change their present situation. Their fate was from the past lives and trying to put things right for their sick adolescent. For example, parents would ask family members to recite Bodhisattva’s name with earnestness and sincerity, for Bodhisattva would eradicate their family karmic obstacles. Family members reported that Western treatment combined with the Bodhisattva’s spirit power allowed them to maintain their faith in the treatment outcome. The following narrative depicted this:

*My son got cancer and relapse occurred. It’s my child’s fate or my family karma but I believed the god [Bodhisattva] was very compassionate and kind to us, and knew our suffering. He would give my son chance to survive, so I still kept chemotherapy one day for every week in the hospital, and twice every day or more recited his awesome name* (mother, Wang family).

One father commented:

*My mother suggested to me to go to Buddhist temples, often to bai-bai\(^{13}\) (拜拜). They would receive my wishes and help me in any way. I accepted this and hoped it could change my family fate or eradicate my son’s past life obstacles* (father, Kung family).

On the other hand, the sick adolescents explained that keeping of faith had given them successful treatment of the cancer, so they looked forward to a good future, which they described as a “dream come true”. However, the doctors told the female adolescents that chemotherapy would affect the function of their ovaries, which led them to wonder about their future. In such situations, the female sick adolescents stated their dreams

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\(^{13}\) Bai-bai (拜拜): a method to communicate with gods and a type of worship behaviour (Wolf, 1990).
included boyfriends, marrying and having their own children, as the teenage girl was normally filled with romantic hopes, such as being a good wife and a great mother. Thus, they were holding their dreams and kept their faith for recovering their health. As one female adolescent highlighted this point:

*The doctor told me to get married soon and have children because my right side ovary was removed and if other side relapsed then I would never get pregnant. My boyfriend would wait for me after I graduated from the university. I dreamed to get married and have a child, so I needed to think more positively and strengthen my faith to improve my treatment outcome* (sick adolescent, Hung family).

It was supported in the data that male sick adolescents appreciated their family who looked after them. These adolescents commented that they did not like to cooperate with the doctor’s therapy but they thought their family worked so hard for their prognosis, they felt ashamed and sorry for their family. They would follow the doctor’s treatment protocol and parents strove to keep optimistic about their future, such as finding a good job. Data also showed two adolescents would not like to let their classmates or friends know their problem, and did not like to interact with relatives and friends because they felt getting sick was terrible, and tried to blame themselves for having this disease. Their parents would seek male patients with the same experiences to encourage them and hope the gods would give them strength. Parents wanted them to have an open mind and maintain confidence in themselves. The following comments reflected the male adolescents’ point:

*I appreciated my family’s help because they endured a time of complicated treatment and my temper. I tried to do my best to accept the doctor’s advice and the treatment protocol. I wanted to get well to attend the exam for handicapped people. If I were to pass the exam, I could go to work at a government organisation, and it would be helpful for my life and family* (sick adolescent, Yeh family).
Another male adolescent commented:

*When I faced my disease, I would feel lonely and doubt the value of my existence. I blamed myself often. My mum saw me and called for help in the hospital. They introduced a same age patient to me, so I could appreciate that although he was worse than me, he was still keeping faith about his disease* (sick adolescent, Sue family).

It was found that the healthy siblings kept their faith for their ill sibling who commenced receiving shots for the treatment. They knew it was very difficult for their ill brother facing the long term side effects from the cancer or even possibly dying. They were willing to learn from their parents how to hold a positive attitude in order to encourage their ill sibling. They also used the Internet to ask people about their experiences, to be able to understand their ill sibling’s needs. They thought about their role and responsibilities for caring for their ill sibling, and sharing pleasures and pains together. This was because love within the family was very important to healthy siblings. As one healthy sibling stated:

*No matter how much he had changed, he was my brother! I hoped he was stable and did not have to go to hospital to have injections because they were so painful for him. So I asked facebook friends to provide some experiences about pain control or how to protect your hair loss ... the aim was keeping my brother’s faith to recover his health* (younger sister, Wang family).

Another healthy sibling added:

*When my older sister came back home safely, I thought it was a wonderful thing because having family together was most important, then I started to learn from my mum about how to protect her immune system. She was experienced as a nurse. I obtained more understanding about this disease from her in order to help my sister* (younger brother, Liu family).
Summary

In this chapter, the basic social process of *restoring a harmonious family life* was described and three phases were identified. Phase one included confronting ‘the broken chain of family life’. This phase encompassed making decisions in complicated situations and obtaining support from different sources. Phase two was accommodating ‘the broken chain of family life’ and this involved adjusting family roles and relationships. The third phase described repairing ‘the broken chain of family life’. In this phase, the sick adolescent and their family were maintaining hope for a good outcome and achieving a harmonious family life. They were developing negotiating and cooperating strategies for maintaining their hope. Likewise, they were changing lifestyle patterns and keeping faith to achieve the desired life of family harmony. These phases explicated the dynamic processes and adjustments to interactions by family members to bring about a degree of normalcy to family roles and relationship in order to restore harmony within the family unit. It was found that the basic social process was underpinned by the Chinese cultural context.

The sick adolescent and their family believed Chinese medicines, folk remedies and religious beliefs were guiding them to confront, accommodate and repair the broken chain of family life. They described these cultural beliefs as well as strategies conducive to meeting their desire to go through the tough journey of recovery from the disease and restore a harmonious family life. This process was also dynamic and adjustable in order to facilitate appropriate management at different stages of treatment and create harmonious circumstances in the family and so express parents’ unending love of the sick adolescent and their other children, even when relapse occurred. The families understood the challenges faced and maintained hope at this critical time.

The following Chapter discusses the findings of this study, limitations and a range of implications. Recommendations are highlighted that address issues that affect how family caregiving beyond the period of treatment is managed. The role of health providers and appropriate service provision for an adolescent with cancer and their family at home are examined.
Chapter 8  Discussion

Introduction
This study’s results provide information that informs a better understanding of, and insight into, how caregiving influences Taiwanese family roles and relationships when caring for an adolescent with cancer at home. The substantive theory of ‘restoring a harmonious family life’ as described in Chapter 7 depicts Taiwanese families as experiencing the social problem of ‘the broken chain of family life’ and engaging in the social process of restoring a harmonious family life. In this chapter, an examination of the substantive theory grounded in contemporary caregiving, role and cultural theories and relevant literature, will be discussed highlighting the significance of symbolic interactionism. Suggested limitations of the study and a range of implications and recommendations are provided in terms of how they inform a re-orientation and re-construction of health care service to better support Taiwanese families in their daily caregiving experiences at home.

Restoring a Harmonious Family Life
The data indicated that to deal with the problem of experiencing ‘the broken chain of family life’, the adolescents and their families predominantly strove to return to a harmonious state by adjusting their family roles and relationships within their families. In the following section, the theory of restoring a harmonious family life, as depicted in figure 8-1, will be discussed within the context of related theories and literature, more specifically caregiving theory, role theory and cultural theory.
Figure 8-1 A substantive theory of “Restoring a harmonious family life” in families caring for adolescents with cancer in Taiwan
The Theory of Restoring a Harmonious Family Life within the Context of Literature and other theories

Several theories inform various concepts and propositions that inform this substantive theory. Caregiving theory informs how family members experience both negative and positive aspects of caregiving. Caregiving can be experienced simultaneously as a burden and a gift, with the unpaid labour of caregiving consuming time and depleting resources enabling connectedness within the family (Schumacher, Stewart, Archbold, Caparro, Mutale, & Agrawal, 2008). Through symbolic interaction, family members construct, share and modify various experiences of the social world (Jeon, 2004). Parents in this study described their caregiving as a ‘bitter-sweet’ experience. This was characterised by the need to sacrifice time, and in some instances personal health, making it a ‘bitter’ burden for them, at the same time relishing the ‘sweet’ possibilities that such sacrifices could provide in terms of achieving a positive outcome for their sick child.

This caregiving experience describes a process which offered both parents and sick adolescents opportunities for personal growth as also supported by Lam (2003). Chinese parents are expected to live with their children, at least until the age of 18 years. As parents they are responsible for managing and supporting their offspring in relation to their general upbringing, their education and their religion. Legal and medical decision making on behalf of their children is also an important responsibility (Hui, 2008). Parents provide care for their sick adolescents beyond that which medical professionals are able to give, by confronting the fact of, and accommodating the disease, with the goal of restoring and maintaining a harmonious family life through changing the manner in which they interacted with each other which underpinned the concepts of symbolic interactionism (Hewitt, 2007).
**Role theory** informs the theory of *restoring a harmonious family life*, particularly in light of the Chinese cultural context. As Tan and Chee (2005) epitomised it, Confucian culture focuses on the concepts of hierarchy, loyalty and filial obedience. Confucian teachings places the family at the centre of an individual’s entire life, and view family relationships as primary in shaping role expectation and activities of daily life (Chan, Cheung, Mok, Cheung, & Tong, 2006). Role change generates multiple demands, resulting in role strain for members of the Chinese traditional family characterised by intergenerational bonds tied to kinship structures (White, 2005). Symbolic interactionism aims to explore the role of the concept of interaction in research within the discipline and cognate areas (Lehn & Gibson, 2011). Role theory highlights how the caregiver’s role helps to foster family connectedness and cohesion as flexible ways of actively managing caregiving situations associated with treatment outcomes and family life are developed (Kars, Duijnste, Pool, Van Delden, & Grypdonck, 2008).

**Cultural theory** informs the theory of *restoring a harmonious family life* as culture represents the encompassing expression of a person’s life (Tzeng & Yin, 2006). Wong and Chan (2006) described culture as based on those characteristics that are distinct or unique to certain people and that situates a family within a society. In this study parents took care of sick adolescents in concord with their perceived roles and expectations, which corresponded with Lu’s (2002) observation that the Taiwanese concept of health is strongly associated with the cultural values of role obligation and harmonious social relationships. The entire family changes the way they normally interacted with each other in order to enact their cultural beliefs (Yeh, 2004). People construct and reconstruct both a moral and environmental order, and in doing so define and refine expectation of behaviour in specific roles and contexts (Miller, 1982). The parents who honoured Chinese values experienced stress through juggling
various roles in an attempt to maintain balance and harmony in family life. The interrelationship between family obligation, spirituality and maintaining faith was significant in achieving this goal. This commitment to *restoring a harmonious family life* may be regarded as all the more sincere and challenging, considering that Chinese culture holds more pessimistic attitudes towards life-threatening illnesses and disabled people (Lam, Chang, & Morrissey, 2006).

Notionally, values, beliefs, attitudes and perceptions are affected by cultural background, but so are the responsibilities of, and responses to family caregiving. By using the study findings and reference to appropriate literature, aspects of caregiving, role and cultural theories will be discussed below as they shape caregiving responsibilities, roles and relationships in a Taiwanese context, and inform the theory of *restoring a harmonious family life*.

**Caregiving Theory**

Caregiving is provided in the context of a network of family relationships (Hunt, 2003). It is important to explore familial responsibility for the sick adolescent and how such responsibility is assumed by various members of the family. Caregiving for patients receiving cancer treatment may be so complex that preparedness and mutuality are essential for optimal caregiver outcomes (Wong & Chan, 2006). The caregiver status does not emphasise a position presupposing a fixed list of duties (Hewitt, 2007). Interaction among family is mediated by symbols and meanings, which are socially constructed and, through interpretation, afford the basis of family management. Researchers such as Schumacher, Stewart and Archbold (2007), and Schumacher, Stewart, Archbold, Caparro, Mutale and Agrawal (2008) comment that mutuality in the family caregiver-patient relationship, and preparedness for the
caregiving role, moderate the relationship between caregiving demands and caregiver outcomes during cancer treatment. As these studies suggest, caregivers with high mutuality and high preparedness can benefit from interventions designed to support these strengths across the duration of caregiving.

Blumer (1969) asserts that all social life is inter-subjective. Human experiences are inextricably social in nature. Family adaptation to chronic conditions in childhood has often been described as a process that begins with shock and distress at the time of diagnosis, and proceeds through a series of stages to an eventual resolution in which the family is able to reorganise and move forward (Christian, 2010). For example, mothers place importance on sick adolescent’s lives continuing as ‘normal’ as possible during the final phases of treatment and after treatment (Earle, Clarke, Eiser, & Sheppard, 2007). This present study found a similarity in the caregiving experience as sick adolescents stayed at home most of the time after treatment, causing parents to face considerable responsibilities in home-care management aimed at protecting their children and striving towards a good outcome during illness and treatment.

Confronting Responsibilities
The central role of the family in caregiving involves widespread agreement that one member of the family, often referred to as the primary caregiver, cares for the family (Kars, Duijnstee, Pool, Van Delden, & Grypdonck, 2008). In this present study, mothers had primary responsibility for the care of the child with cancer and fathers were more focused on financial support. The traditional role of the mother as the primary caregiver who bears the greatest responsibility for caring for the sick child was also observed by Yeh (2002). The present study also shares findings with Lee’s (2007) Taiwanese study of caregiving behaviours, which found that to some extent,
despite current changes, the traditional norms and characteristics of family-centred caregiving are still deeply rooted in family life. For example, the mother’s role encapsulates housekeeper, caregiver, cook, counsellor and supporter; the father’s role mostly involves working outside the home as the breadwinner.

Rather than being solely the responsibility of professional caregivers, who do not have the time or desire to give extra care to the sick adolescent, cancer becomes the entire family's concern, often requiring quite radical revision of understandings associated with interrelationships (Kim & Given, 2008). For example, it is a common belief that Chinese parents prepare food for children to express love and concern. Children enjoy food prepared by their parents and by doing so, also accept love and concern from parents (Wong & Chan, 2006). The parents included in this study resorted to food remedies to express their caring for the sick adolescent, such as preparing chicken soup which required four hours cooking, using animal body fluids and organs to strengthen the Chi (energy) through various nutritional approaches and buying Chinese herbal supplements to balance the Yin and Yang in the body (Xu, Towers, Li, & Collet, 2006). Grandmothers and other relatives also prepared special foods and contributed to the care of healthy siblings. The siblings themselves contributed by being as independent as possible. They would concentrate on their studies and make their own meals to lighten the load on their parents.

Confirming the tenets of symbolic interactionism, with its emphasis on constructed meaning, of interest in this present study was the association between ‘face concern’ and caregiving support. Parents in this study believed that the disease of cancer was associated with karma, that is, the bad consequences of deeds done in a previous existence in their family. Facing a cancer crisis, a few fathers were unwilling to discuss the child’s disease and related problems openly. Fathers therefore did not
receive much needed encouragement and support and often felt left out of the direct chain of medical communication and information giving. This study found that the cultural concept of ‘face’ is commonly identified as important in interpersonal relationships in Chinese culture (Chen, Cheung, Bond, & Leung, 2005). Fathers in the study eventually received medical information about their children second-hand through their wives.

Illustrating how individuals acquire the self-consciousness that is essential for the coordination of collective life in a society (Wild, 1985). Chinese people care about their public image and are very conscious about how others view them. They may regulate their social behaviour in such a way as to inhibit expressing their emotions and thus avoid losing face (Cheung, Leung, Zhang, Sun, Gan, Song, & Xie, 2001). This tendency was particularly evident in how culture influenced the family caregiving experience. Mothers would be able to talk about their situation of having a sick adolescent with friends and relatives because their responsibilities involved maintaining and promoting their child’s health. Fathers to save face were unwilling to openly discuss their child’s health condition and family challenges which further increased their stress levels.

**Family Roles and Relationships in Caregiving**

Through social interaction, people learn the meanings and symbols that seem inherent in expression of thought and people accept the norms, values and social rules in order to create and uphold group life (Smith & Bond, 1993). Highly significant evidence of this is that filial obligation is a strong, culturally prescribed value, which influences caregiving expectations in Taiwanese society (Lee, 2007). However filial obligation in this study influenced caregiving responsibilities described by participants as a ‘bitter-sweet’ burden. The parents sacrificed their time and occasionally health, making it a
‘bitter’ burden for them, but when their sacrifices resulted in a positive outcome for their sick child, then this burden transformed into a ‘sweet’ feeling. This expression of ‘burden’ was one of the most significant findings in this study. It highlighted how cultural values and beliefs impacted on family caregiving and led to subsequent changes in roles and relationships. The parents’ behaviour illustrated this impact as they strove to fulfill incompatible goals. Parents dealt with change in roles and responsibilities while taking care of their sick child. They significantly re-organised their lives as their children went through intensive and lengthy cancer treatments. Follow-up care at home required further reorganisation and adjustment.

As previously mentioned in the findings, if the sick adolescent was the only child, or male, the parents expressed more stress because they feared losing him and not being able to honour the ancestors. As Wong and Chan (2006) found, parents often had high expectations of their child. Pressure on parents came from their traditional aspiration: they hoped their children would grow up, marry and continue the family line.

For adolescents in this study the parental wish for descendants was difficult to fulfill because of the possible side effects of chemotherapy on reproductive health and fertility. Bashore (2007) and Zebrack, Casillas, Nohr, Adams and Zeltzer (2004) in their studies of young adult cancer survivors found that reproductive ability was a major concern and worry. In this study, a few sick adolescents grieved over the potential loss of their fertility. As Pacey (2007) found infertility is a common and distressing side effect of cancer treatment.

Legge (2008) has argued that the primary aim for Chinese children is to fulfil the parents’ desire for ongoing descendants, obey parental wishes and satisfy parental needs. They understand their culturally expected role. When sickness occurs the
traditional value of filial piety is threatened (Lee, 2004). This study found that some sick adolescents considered themselves to be undutiful because they had been diagnosed with cancer. Despite the obvious distress experienced because of threatened cultural duty, newly diagnosed adolescents and families often fail to consider their reproductive future during the early discussions of disease and treatment (Ogle, Hobbie, Carlson, Meadows, Reilly, & Ginsberg, 2008). In part this is explained by Wong and Chan (2006) who have argued that when disease occurs, consideration of ancestral lineage becomes secondary to the mere survival of the sick adolescent.

Parents in this study focused upon protection from treatment and encouragement for their sick adolescent’s willingness to undergo treatment to maximise their chances of gaining a good outcome for survival. Whether there was an improved prognosis or not, “being there” was uppermost in parents’ consideration and the “core of their existence” when parenting the child with cancer during treatment (Kars, Duijnstee, Pool, Van Delden, & Grypdonck, 2008, p. 1557).

Mothers in this study reported distress during the first six months after the child had been diagnosed. They reported difficulty balancing work and family life because of the pressure of new family caregiving responsibilities. Particularly, one single mother in this study had to bear the burden alone, and her children tried hard to learn how to self-care to lessen their mother’s burden. This finding is consistent with Huang, Mu and Chiou’s study (2008) in which single parents strove to build up a life for their children so that they could live with the illness and be brave when facing the treatment. On the other hand, most fathers either added working hours or changed to a more flexible job in order to care for the healthy children at home. This is consistent with findings in families that faced great challenges in caring for children with cancer (Kars, Duijnstee, Pool, Van Delden, & Grypdonck, 2008; Lam, Chang, & Morrissey,
This was also observed by Schumacher, Stewart, Archbold, Caparro, Mutale and Agrawal (2008) who described parents trying to anticipate their child’s feelings, protect them as advocates and monitor the sick child’s situation with health providers as needed. Mothers focused on involvement in caring for their child, and fathers, although reticent about showing their reactions and feelings in the home environment, and receiving information from their wives, tended to advocate for the child within the medical care system (Grinyer, 2009). In this study, spiritual and cultural beliefs and values shaped caregiving roles and responsibilities. Religious faith, family connectedness, Feng-Shui and recitation of the Buddha’s name were all important influences and supports in caregiving. For example, going to temples to pray and attending religious services, helped parents to shape their sense of meaning and maintain hope.

The caregivers, particularly mothers in this study, drew on prevailing cultural discourses about parenthood, which clearly influenced the context in which they cared for their child, and which shaped their reflexive constructions of their experiences. This concurs with Young, Dixon-Woods, Findlay and Heney (2002) who also found parents developed more experience in caring for their sick adolescents, making appropriate arrangements for the family’s daily life during the treatment stages. All of the parents in this study believed that their sick adolescent wanted to accept the long and miserable therapy. Thus, parents were dedicated to all aspects of their caregiving and the healthy siblings cooperated with the parents to ensure harmony in the family, even though at times, in the earlier stages of the illness and treatment, they were feeling some dissatisfaction about the inevitable changes in their own lives. Clearly in this study, the entire family changed the way they normally interacted with each
other in order to enact their strategies, based on their cultural belief, so as to restore familial harmony.

**Experiencing Caregiving Strain and Family Change**

Yi (2009) has argued that unique cultural characteristics may impair communication in Asian families. Cancer is extremely stigmatised and the survivors are blamed (Yi, 2009). When a child is diagnosed with cancer, the demands of illness are added to the numerous strains on caregiving (Lee, 2004). However, some researchers have asserted that while strain is an inevitable part of caring, being a caregiver can indeed provide opportunities for growth and challenge (Boss, 2001; Karantzas, Evans, & Foddy, 2010; Kim & Given, 2008). In this study, parents engaged in different caregiving roles. This finding is supported by Svavarsdottir (2005) who found that mothers reported higher caregiving activities than fathers. Fathers perceived that their wives were burdened by being the primary caregiver; some fathers reported that role obligations and choices contributed to a sense of guilt (Chesler & Parry, 2001). Similarly, the findings of this study are consistent with the profile expressed in the literature that showed mothers reporting more physical and psychological distress than fathers, and mothers experiencing higher levels of negative emotion than fathers, such as depression and anxiety (Yeh, 2002). These findings can in part be explained in terms of mothers being the primary caregivers for their sick adolescent children. Three of the working mothers in this study had to cease their employment or take temporary leave to care for the sick adolescent; they thus learned caring skills and absorbed new knowledge to confront the disease more directly than fathers.

Boland and Sims (1996) observed that family caregiving at home is a solitary journey; adolescents with cancer represent a family crisis (Grinyer, 2009; Chen, 2009). However, *restoring a harmonious family life* presents holistic love and well-being and
partaking in symbolically vital responsibilities within the family. This concept reflects that families endure the difficulty together in order to provide a buffer against stress. This leads them into unconditionally sacrificing their own lives, based upon family ties. This understanding of harmony is manifested in the parents’ emphasis on hope, and supports mothers to be more positive and active recipients of social support. This present study shares similar findings to a study by Hunt (2003), stating that positive caregiving includes caregiver esteem, an upliftment from caregiving, caregiver satisfaction, finding or making meaning through caregiving, and gaining from the caregiving experience.

Studies have shown that coping and social support are resources that influence the extent to which a strained situation, such as a major caring responsibility, affects psychological wellbeing (Chambers, Ryan, & Connor, 2001; Wennman Larsen & Tishelman, 2002). Parents adjust to their situation, and often seem to benefit from opportunities to gain instrumental knowledge and emotional support from others with similar challenges (Trask, Paterson, Trask, Bares, Birt, & Maan, 2003; Yeh, 2004). In this present study, congruent with cultural theory which influences family roles and responsibilities, Taiwanese extended families (grandparents and relatives) supported the sick adolescents and their families, including providing Chinese remedies and healthy products to parents; they also helped parents to take care of healthy siblings. Parents and their sick adolescent were more comfortable with the extended family support they received, because this support network was positive in maintaining a harmonious family life.
Role Theory
The theory of *restoring a harmonious family life* is also informed by role theory with respect to role expectation and role strain. Role theory uses interdisciplinary theory to describe and understand complex human behaviours in relation to culture, society and personality (Biddle & Thomas, 1966). Chinese beliefs about social interaction and human relationships are affected by Chinese familism (Fan, 2006). Role theory offers two major perspectives, centred on social structure and symbolic interaction (Hardy & Hardy, 1988). Both emphasise analysing social phenomena from the individuals’ perspectives to the social structure of lives. In Asian family roles, it is expected that family members provide care for the patient in the hospital and at home. The patient also expects that the family or health care providers provide all care (Wong & Chan, 2006). This expectation is the opposite of the predominant Western view, that the patient assumes self-care and health care will be provided by the nurses or other professional caregivers (Woodgate, 2006). The social network makes up the life of human groups, and involves reciprocal adaptation including a process of designation and interpretation (Salvini, 2010).

As Biddle (1979, p. 79) points out, “the best way of studying roles is to observe the characteristic behaviours of persons as they cope with real world problems and contexts”. Roles and relationships create a powerful social context in the present study because society is a dynamic process of ongoing activity vitally relying on symbolic interaction (Kendall, 1999). Symbolic interactionism was developed as an alternative account of social life to support exploration of family experiences, actions and social context (Crooks, 2001). It is reasonable to accept therefore that parents play multiple roles. There are numerous role expectations and strains, as witnessed by mothers in the present study who wanted to be like the “thousand hands of Bodhisattva”, meaning that they could freely move and observe all things, adapting
these roles promptly and efficaciously. Fathers played the role of head householder who had to bear all responsibilities and try to show a strong face throughout any difficulties. The mothers were more attentive to their sick adolescent and their roles were more flexible than the fathers’. Studies confirm that family role behaviours can be expected (Conway, 1988) and caregiving is a normative role in the family, simultaneously involving role expectations and strains (Lee, 2004).

Role expectations arise when a family caregiver is able to identify the attitudes, behaviours, and cognitions required and anticipated within the social structure (Hardy & Hardy, 1988). The role is played out in social interactions and provides a coherent and comprehensive view of social life (Schwandt, 1994). This social life enables sharing understandings and experiences of the members of society, which in turn creates social interaction (LaRossa, 2005). For example, Foster, Eeles, Ardem-Jones, Moynihan and Watson (2004) found the social role expectations placed on women include playing kin keepers, health promoters and support seekers.

Role strain derives from caregiving conflict, mismatched expectations, lack of resources and economic burden in addition to direct care (Lee, 2004). According to Schumacher, Stewart, Archbold, Caparro, Mutale and Agrawal (2008), the caregiving situation is a deep source of pressure affecting family caregiver outcomes during cancer treatment. The findings in the present study in support with Usita, Hall and Davis’s study (2004), found that caregiver strain created difficulties in carrying out the tasks and behaviours associated with role performance.

**Adjusting Family Roles and Relationships**

Relationship adjustments for adolescents are complex and particularly challenging for those adolescents experiencing cancer at this stage of life development. Studies
confirm that adolescence is a life period which implies the development of coherent self-identity and relationships with the social world. When evidence of cancer or its treatment is obvious, others in the environment may alter their responses to the child, causing the child to feel different (Grinyer, 2002, 2009; Harding, 2000). Grinyer (2002) found that adolescents with cancer are unlike other age groups’ who experience cancer. In agreement Decker (2006) found that although expressed emotion, identity and independence remain the same as for healthy adolescents, the experience of cancer treatment and its side effects can be particularly devastating to adolescents who are seriously unwell at a time in their lives when they are learning to negotiate their roles and relationships in preparation for adulthood.

In agreement with Huang (2008), in this study families needed to be flexible in dealing with role taking through adjusting family relationships in a manner that necessarily demanded a modifying of family relationships and interaction patterns. It is through these interactive patterns that family members were able to make meaning of their daily lives albeit disrupted by illness in a family member. As depicted in symbolic interactionism, people make meaning of their social world through interactions with others (Charon, 1998). This involved establishing a partnership or family connectedness to work together as a team. Families realised that their effort was directed at restoring balance by acquiring new resources and coping strategies, reducing demands and changes to the ways they viewed their situation (Trinidad, Chou, Unger, Johnson, & Li, 2003). This present study found, similarly to Da Silva, Jacob and Nascimento (2010), that mothers had to compromise their role of being responsible for the household and caring for their other healthy children, especially where the fathers would not be directly involved in caregiving for the sick adolescent. While the mother felt tired from taking care of the sick adolescent, the fathers also felt tired from work. Both parents experienced pressure and difficulties in balancing roles.
and their responsibilities in their family (Chesler & Parry, 2001). In the present study, the biggest difficulty in role change that resulted in role strain was expressed by the participating fathers. In agreement, Da Silva, Jacob and Nascimento (2010) have found that fathers do not always expect to take on increased home responsibilities.

Healthy siblings in this study also reported that their daily life rhythm changed because they had to help with household chores and assist ill siblings with solving problems related to school or peer interactions, as also found by Bursnall (2003). The findings in the present study in common with Yi’s study (2009) indicated that adolescents with cancer experienced positive family functioning when they received support from parents, healthy siblings and friends. Family adaptation, including communication and cohesion during the treatment of cancer, was found to be important. Trask, Paterson, Trask, Bares, Birt and Maan (2003) have reported that perceived family cohesion and adaptability have been reported as being strongly associated with the psychological adjustment in adolescents with cancer and positively associated with caregiving strain.

Parents in this study generally described healthy siblings as being close to their brother or sister about whom they worried. A study by Rehm (2000) showed that parents were more likely to talk about the protectiveness of healthy siblings and their own temporary neglect of siblings, but did not report an increase in sibling rivalry as a result. Yeh (2001) found that sick adolescents and healthy siblings adjust their roles and relationships in order to properly manage their own way of life and to balance their social activities. In the present study, the sick adolescent and healthy siblings experienced “siblings having to love each other respectfully”. Older healthy siblings had to increase their responsibilities in caring for their younger ill sibling. Clearly the study findings indicated that healthy siblings did not have the same life as before the
diagnosis. They understood that when a sibling had fallen sick that the family could not function as before. However, the healthy siblings faced different challenges in their daily activities because of their ill sibling’s illness. A clear example of the above statement is indicated in chapter 7 within participants’ comments where participants change their intra-family interactions to accommodate difficulties in order to attain a sense of normalcy and harmony. This is congruent with the tenants of symbolic interactionism (Denzin, 1992; Jeon, 2004).

A particular challenge for healthy siblings was their perceived experience of conflict between their own interests with school friends and their ill sibling’s needs, a view similarly expressed by Nolbris, Enskär and Hellström (2007). Hinds, Birenbaum, Pedrosa and Pedrosa (2002) found that when an adolescent’s relapse occurred, as it did in this study, the parents and healthy siblings sought different information to promote the sick adolescent’s progress in order to cope with the difficulties presented by the treatment. For example, parents increased their search for other possible medical treatments and care strategies as also reported by Bjork, Wiebe and Hallstrom (2005); healthy siblings would use the Internet to share information with their ill sibling (Greenfield, 2004). The healthy siblings in this study reported they felt they should passively accept this situation and reduce the chances of getting into a quarrel with the ill sibling and parents. Similar to La Guardia and Patrick’s study (2008), families perceived less conflict between siblings who were less defensive and experienced a stronger sense of satisfaction and commitment to their relationship.

The results of this present study also highlighted the importance of support derived from religious affiliations which could alleviate the pressure felt from role change. For example, Buddhist parents accommodated and expected role changes during the sick adolescent’s treatment as their fate. The parents accepted their child’s illness as
their fate (Wong & Chan, 2006). Relevant to this finding, Da Silva, Jacob and Nascimento (2010) also found that parents’ attitude towards their family bonds were strengthened when they were together; despite the difficult issues, they shared strategies for handling the situation and they supported each other. Hinds (2008) showed that social support from all family members was central to the wellbeing of the sick adolescent. However different types of support have been found to either strengthen or weaken family relationships (Yeh, 2002). Extended family (e.g. grandparents, aunts, uncles) in this study was observed to provide both positive and negative forms of support. On the negative side, extended family possessed too much control and could be over-bearing when offering caregiving support, which manifested in highly emotional conflicts for parents. This resulted in family disharmony and had a detrimental impact on family coping.

**Learning to Live with Unpredictability**

Families learning to live with unpredictable conditions and relationships, attempting to find the means to maintain a stable life, encounter increasing difficulties when faced with cancer (Elmberger, Bolund, & Lützén, 2000). Families or caregivers faced with unclear and changing role expectations may experience more role strain and stress and may not perform their duties effectively (Usita, Hall, & Davis, 2004). As Carrión (2005) pointed out, mothers reported that their role as wife was totally replaced by the mother caregiver role during the sick child’s treatment, which affected the marital relationship because they could only be a mother for the sick child, and could not fulfil being a mother and a wife. A study by Chao and Roth (2000, p. 79) found that Taiwanese women caring for their parents-in-law were “preserving harmony” as reflected in the caregivers’ strategies when facing difficulties because of caregiving constraints. Family caregivers reported various problems from their caregiving experiences (Martinson & Yee, 2003). Mothers in this study in common
with Karantzas, Evans and Foddy’s study (2010) found that they experienced conflict between their social roles, restrictions on activities, strain in marital and family relationships, psychological distress, and diminished physical health.

A few parents in this study did report negative changes in the emotions and behaviours of healthy siblings because siblings possessed little information about what was happening in their family in the time period of six months after diagnosis. This result is similar to findings by Wang and Martinson (1996) that reported that healthy siblings revealed major stressors associated with inadequate knowledge, reduced family communication and insufficient support. In the present study, healthy siblings lacked knowledge of their ill sibling’s condition provided by their parents; there was insufficient communication and support for dealing with the changes occurring for both the ill sibling and the family, as also found by Bayliss (2007). In addition, the extended family provided different support to sick adolescents and their families because they tried to communicate and understand each other’s needs. Whereas, the fathers were unwilling to discuss the sick adolescent’s treatment and related problems openly with their children, friends and extended family, the mothers in this study preferred to tell the truth to their children because they wanted them to understand the family situation to help them through this difficult time.

Minton and Pasley (1996) have argued that it would be helpful to be given knowledge about recurring patterns of behaviour, developed through interaction and communication, to achieve role expectations within family systems. Human communication is symbolic. People base their responses on the interpretations of each others activities and body language (Hewitt, 2007, p. 73). Good communication is important for stress management in a family because it enables the family members to reduce ambiguity, which is part of what makes changes so stressful (Patterson, 1988).
Lavee and May-Dan (2003) have emphasised that communication is important for parents and healthy siblings to cope with their adolescent’s illness. Sick adolescents and healthy siblings in this study wanted parents to tell the truth about the disease and treatment progress. As Wong and Chan (2006) pointed out, there is little evidence of the benefits or risk of telling the child the truth about a life-threatening disease, but giving clear and direct messages are critical family resources (Galvin & Brommel, 2000).

Cultural Theory
Cultural theory indicates that certain kinds of behaviours within family roles and relationships, embedded in Chinese culture, strongly influence attitudes and reactions in the context of the care environment as symbolic interaction to carry on participants’ lives (Chen, Miaskowski, Dodd, & Pantilat, 2008). Culture refers to how life is conducted by a particular group with its values, beliefs, norms, patterns, and practices that are learned, shared, and passed on through generations (Leininger, 1996). According to Wong and Chan (2006), Chinese people who attribute the causal relationships of their actions to internal control, are more likely to believe that effort will lead to favourable results, compared with those who believe that life events are controlled by fate.

Culture is also learned behaviour that shapes attitudes and encourages some types of behaviour over others (Chan, Cheung, Mok, Cheung, & Tong, 2006) and influences how families define and manage their children's cancer and most likely their children's adaptation to disease (Thibodeaux & Deatrick, 2007). Family hierarchy is intact and all family members adhere to their roles in a traditional Chinese family; the father’s authority is supreme and final for maintaining family integrity and harmony.
Sick adolescents who occupy subordinate positions in a hierarchical family structure accept what some might consider as unjust social arrangement as moral and cultural norms (Hui, 2008). This study shared similar findings with one in Hong Kong, in which parents thought of cancer as ‘yuan’ (predetermined affinity, 緣), as fate or destined by a former life. Especially when parents were Buddhist, they had to accept life’s vicissitudes and believed in gods blessing their sick child and other family members (Wong & Chan, 2006, p. 715).

Liberal Western ideologies have influenced family structures and relationships in Taiwan, but the Confucian familism of living over two millennia is not likely to be forgotten in a few generations, such as filial piety and parental authority (Hui, 2008). In Chinese societies, good parents are those who are willing to make sacrifices without any consideration of mental and physical exhaustion. The parent-child relationship also helps parents to sustain their spiritual lives, thus parents constantly emphasise their children’s obligation to the family (Tsai, Chen, & Tsai, 2008). It is through the interactive patterns that family members were able to actively interact with people from their point of view and in their cultural beliefs (Jeon, 2004).

Chang (2001) claimed that differences in emotional processes between Western societies and Chinese culture have roots in the self, affecting how emotion is experienced and expressed. Chinese people view emotional expression as a means to maintain interpersonal harmony rather than a true reflection of personal feeling (Chang, 2001). Striving for harmony underpins cultural norms of interaction and is considered virtuous in Chinese culture (Chen, Cheung, Bond, & Leung, 2005). As in Chen, Chen and Haase’s (2008) study, adolescents learned how to take care of themselves and through their experience of living with brain tumours, they developed the strength and resilience to be able to contribute to, or create harmony in their home.
environment. The *restoring a harmonious family life* theory clearly highlights the significance of the Chinese values of harmony in shaping and guiding all aspects of family life, roles, personal relationships and behaviour.

**Religious Support**

Religious beliefs enhance the ability of Taiwanese families to cope with suffering in their lives or in the lives of those requiring their care (Yeager, et al., 2006). As previously alluded to, cultural values and beliefs develop a wide variation in lifestyle, health behaviour, religion and language, and may affect how people perceive disease and caregiving (Huang, 2008). Some parents in this study believed in the notion of fatalism; in other words, that the disease was their sick adolescents’ fate and there was nothing that could be done to change their present situation. Where families were fatalistic Lam (2003) found that families strove to put things right for their sick adolescent and create a better fate for their future. For example in this study, a single mother often visited temples with the aim of gaining psychological strength to enable her to better support her daughter in facing her treatment. Significantly, Taiwanese families in this study offered prayers to the god of multiple temples because they believed that praying to more gods would gain more blessings for the sick adolescents.

Buddhism and Taoism contributed significantly to Taiwanese religious life. In this study, some parents were Buddhists and Tzu Chi Charity association members, who often used donations from worshippers to launch social welfare and relief projects or focus on community service to obtain blessing for sick adolescents from the gods. Other families in this study, as found by Jim, Richardson, Golden-Kreutz and Andersen (2006) prayed and attended religious services to give them a sense of strength and support. As (Wu, Chin, Haase, & Chen, 2009) have confirmed such support helped families and their sick adolescents to positively face the changes in

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their physical appearance during treatment and redirect their negative emotions and fear about an unpredictable future.

Families in this study clearly demonstrated how they used their strength of religious beliefs to face illness and caregiving challenges. They depended on religious faith and spiritual support to adapt to crisis (Rew, Wong, Torres, & Howell, 2007), praying at home as well as in the temple and reading from religious texts. This brought comfort and, as in Tzeng and Yin (2006) served as a coping strategy for these Taiwanese families. Also in accord with the present study, Pajevic, Hasanovic and Delic’s (2007) found that religious beliefs in adolescents enabled better control of impulses, providing better mental health stability. Both healthy siblings and sick adolescents wore _Fu_ and participated in recitation of texts in the home.

The families also practised _feng-shui_ at home and used folk remedies including cooking special foods in order to strengthen the sick. Messervy (2000) points out that _feng-shui_ is thought to change the atmosphere of a house and bring happiness, and assists in coordinating good luck in order to achieve harmony. Parents in this study asked _feng-shui_ practitioners to move furniture and use mirrors as shields to ward off malign influences on the sick adolescent. Culture entails not just shared interpretations of behaviours but also shapes and guides behaviour (Smith, et al., 2002) in terms of health-seeking behaviour, doctor-patient communication, treatment choices and outcomes (Chui, Donoghue, & Chenoweth, 2005). Even though family members in this study altered their interactions to achieve harmony they nevertheless ensured that such alterations in interactions were underpinned by their cultural beliefs and values. It was evident in the data that it was only through embracing cultural beliefs and values that any intra-family interactions made sense, in keeping with symbolic interactionism (Blumer, 1972; Hewitt, 2007).
One of the most significant findings in the present study was that parents considered finding a good doctor as a matter of fate and destiny. These were regarded as determined by gods and linked to religious faith in the power of prayer. Chinese medical ethics has consistently emphasised maintaining a reciprocal relation between physicians and patients (Guo, 1995). As Guo (1995) further explains, the justice and benefit concept of Confucianism instructs doctors to be honest and demonstrate a humanitarian concern aimed at ensuring that the patient has access to medical resources, as medicine is for living people, and that in a physician’s hands lies the life or death of a patient. As Smith (2004) has observed, cultural difference may depend more directly on the ways in which behaviours are interpreted, evaluated, and given meaning. The concept of the child’s health was strongly associated with the cultural values of Taoism, in which the maintenance of the Yin and Yang balance ensures a smooth flow of the Qi (vital energy). Thus, Western treatment combined with the Bodhisattva’s spiritual power allowed family members in this study to maintain their faith in the treatment outcome.

Achieving Harmony

The sick adolescent and their family in this study experienced family life being ‘broken’, yet positively responded in striving to promote balance and healing. They supported and helped each other in a collective effort to restore harmony and a peaceful co-existence within the family. The finding in this study are consistent with that of Bjork, Wiebe and Hallstroms’ (2005) who found that family life with a child with cancer was experienced as entering a different ‘broken’ world. They strove to feel hope through gaining a positive perspective and a sense of control over their life. The family needed to think positively and maintain hope for the future as also supported by Woodgate & Degner (2003).
The present findings support a view by Verna (2008) that keeping hope during every stage of treatment serves as a protection for the adolescent throughout the cancer experience. It is reported in the literature that being hopeful is important for parents, even in the face of drastic changes in their child’s condition (Callaghan, 2007). Adolescents in this present study valued family and friends who supported and worked with them to help cope with physical changes and fulfill desired roles and relationships. Acceptance and positive reinterpretation led to a greater sense of feelings of harmony and integration with life similar to Jim, Richardson, Golden-Kreutz and Andersen (2006).

Chen, Chen and Haase (2008) found that adolescents with brain tumours lacked abilities and opportunities to undertake their role obligations in Chinese society, but they pursued achieving a new social life and learning to master coping with their daily lives. They maintained the hope for a good outcome and for achieving a harmonious family life. Adolescents with cancer rebuilt hope to help themselves move on from their suffering and envision a hopeful future (Wu, Chin, Haase, & Chen, 2009). The findings of this study depict a similar view: the sick adolescent and their family endeavoured to maintain hope for a good outcome in order to repair ‘the broken chain of family life’. This finding also has parallels in Western studies; for example Woodgate (2005, 2006) found that adolescents face their disease optimistically in order to help reduce feelings of abnormality and to be able to move forward in the course of fighting cancer. For example, the sick adolescents used strategies to maintain a normal appearance and to conceal signs of illness. They used camouflage techniques, jewellery, and colour to conceal or minimize changes and enhance their appearance to gain confidence in their social life and relationships (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010).
Shared responsibility and the importance of facing the situation as a family group was clearly communicated in this study. This is consistent with findings in another Asian study conducted in South Korea showing that where family interaction is cohesive and positive, the sick adolescents’ cure rate is very high (Yi, 2009). Moreover, Wong and Chan (2006) made clear that Chinese cultural beliefs help Chinese parents cope with their child with cancer positively and decrease negative emotions because they quickly accept the reality and regard their child’s situation as their fate, a fate that they have to accommodate. They also identified positive aspects from the disease in order to strengthen their hope. These findings suggest that maintaining hope for a good prognosis is common to both Western and Chinese cultures, although the experience of accommodation may not occur in the same way. Chinese cultural beliefs help the parents to face the reality and regard their child's illness as their ‘fate’ that they have to accept. They are able to identify positive aspects from the illness experience and establish hope for the future (Wong & Chan, 2006, p. 710). Western families attempt intellectual mastery of the situation and take a more active role in managing the child's illness (Johns, Oland, Katz, Sahler, Askins, Butler, & Dolgin, 2009).

The cultural orientation to collectivism in Asian countries provides a set of values that include obedience to authority, and embrace social interdependence and concern with maintaining harmonious relationship with others (Jin, 2009; Leininger & McFarland, 2006; Wong & Chan, 2006). All families in this study clearly achieved a harmonious family life. However, the families differed in the sense that the level of harmony achieved depended upon the medical condition of their sick adolescent and their experience of relapsed health. Like the families in a study by McGrath, Paton and Huff (2005), families wanted their lives to be as ‘normal’ as possible in terms of roles and relationships experienced at familial, community and societal levels. Sick adolescents in this study liked to blend in with their peer groups, but they tired easily.
and required more time for study and for planning their lives. They resented that they could not perform and achieve optimally when compared to their classmates.

The parents in this study were convinced that if they kept their faith and believed in advanced medicines and their ability to completely cure, then survival possibilities were optimal. They believed Western treatment combined with the Bodhisattva’s spiritual power allowed them to maintain their faith in the treatment outcomes. It is reported in the literature that from four months after diagnosis, families, especially mothers, were encouraged by health providers to be optimistic in order to achieve a ‘normal’ life (Earle, Clarke, Eiser, & Sheppard, 2007). Yeh (2002) found that in the months following diagnosis, many parents and particularly mothers experienced frustration when striving to maintain a normal life as it took more time to accommodate than expected. They needed to redefine their perceived sense of normality by adapting to the changes, re-prioritising and attempting to achieve their new life in a way that they could control (Woodgate, 2006).

Healthy siblings were willing to learn from their parents how to possess a positive attitude as a means of encouragement for their ill siblings. As Huang (2008) stated, the cancer experience becomes a constant striving for normality. Sick adolescents spend a lot of time at home more than school and hospital, they want to accept and respect their parents’ decisions to adapt lifestyle patterns, and to cultivate optimism and faith in order to achieve a harmonious family life. Clearly in this study, the social network becomes the product of different processes of symbolisation, and attribution of meaning (Salvini, 2010).
**Limitations of the Study**

Although this study explored and described the perspectives of families who cared for adolescent members with cancer residing in the same household, grandparents and extended families were not included. In future research, the entire family system needs to be brought into focus, if the complex set of culturally shaped behavioural and emotional transactions involved in family roles and relationships are to be comprehensively understood.

Furthermore, the study only examined families associated with one hospital using qualitative research. It is therefore possible that the dimensions of disease and caregiving that were identified among these participants are only applicable to other populations experiencing a similar cancer trajectory in Taiwan. Future research is necessary to explore this issue with diverse methods, for example, combining quantitative study design with qualitative research, to clarify how the value of caregiving obligation impacts on family roles and relationships. In spite of these limitations, the findings provide a conceptualisation of family roles and relationships that provides a valuable insight into how caregiving roles and relationships affect Taiwanese nuclear families when an adolescent member requires cancer care at home. These findings are transferable to other families who find themselves in similar situations, involved in providing care for sick adolescents at home.

**Implications and Recommendations**

The findings of this study revealed that sick adolescents and their families underwent enormous changes in terms of their family roles and relationships, resulting in the family experiencing a break in the chain of family life and disruption to harmony in the family. The findings further revealed that the families received little formal support from the Government or health professionals. In order to restore harmony in
family life, these families underwent three processes, namely confronting, accommodating and repairing the broken chain of family life. This social process led to the development of the theory of *restoring a harmonious family life*. However, as the findings indicated, had these families received adequate support from the government and health professionals, the restoration of harmony would have been better facilitated.

A key contribution of the findings in this study is that they explain how families perceive and manage changing roles and relationships when caring for a sick adolescent with cancer in a Taiwanese home care context. These implications are important in order to raise the awareness of health care providers to the need to commit to re-orienting health care services that better support such families. The findings therefore provide insight into recommendations that target health care service support for Taiwanese families in perceiving, adjusting to and fulfilling the altered roles and relationships associated with caring for an adolescent with cancer at home in Taiwan.

This study’s recommendations are provided below (Table 8-1) with respect to healthcare service support and future research. In particular, the families need support by way of service providers giving them relevant information early so that they can make appropriate decisions for their sick child. Families also need supplementary services so primary caregivers can sustain the caregiving role without becoming physically exhausted and burnt out. There also needs to be greater interaction between families and health service providers to give families the emotional and psychological support they need.
Table 8-1 Recommendations for the study

1. Information to support parents in decision making
   - Increase frequency of workshops and contact time and workshops between healthcare providers and families.
   - Develop family counselling units.
   - Encourage families to be open about alternative therapy with the doctors.

2. Supplementary services for families to sustain caregiving
   - Support flexibility in work situations for parents.
   - Retrain caregivers to return to work and require companies to rehire caregivers.

3. Strengthening community-based services
   - Design appropriate strategies to ease the stress of the treatment.
   - Recognise the needs of adolescent students when they return to school after treatment for cancer.
   - Require peer networks to reduce unpredictability and uncertainty.
   - Strengthen community service policies to enable consistent funding to be made available for resources such as premises and staff.

Information to Support Parents in Decision Making

The findings of this study indicated that once parents were confronted with a diagnosis of cancer in their adolescent, a process started: they needed to make timely decisions in order to face numerous complicated situations. Parents in this study considered that they lacked much needed information in how the disease might manifest itself in their sick adolescent children. They perceived that this prevented them from making care decisions in relation to matters that greatly influenced their adolescents’ day-to-day lives. For example, sick adolescents’ and healthy siblings’ ability to attend school and participate in activities with peers were compromised.

In this study, the fathers were unwilling to discuss the child’s disease and associated problems openly, anxious because of karma about the possibility of responsibility for
the illness. They did not receive needed encouragement and support and felt left out of the direct chain of medical information, and fathers eventually received medical information about their children second-hand through their wives. As Tzeng and Yin (2006) suggested, families and patients have a right to know about all possible treatments and should be given opportunities to discuss possibilities for patients and their families within the Taiwanese health care system. Huang, Ma, Shih and Li (2008) have argued for an increase in the contact time between health care providers and families aimed at building a service that is more comprehensive and systematic. Hinds, Oakes, Hicks, Powell, Srivastava, Spunt, Harper, Baker, West and Furman (2009) have recommended workshops to assist family members to understand the sick adolescent’s physical and unique psychological needs outside of the health care environment in schools and the broader community.

All parents and adolescent children were concerned about the effects of cancer treatment on their fertility. This was especially significant to them because of the importance given in Chinese society to producing children. Ogle, Hobbie, Carlson, Meadows, Reilly and Ginsberg, (2008) have argued that nurses are in an ideal role to be educators about sperm banking for male adolescents and oocyte cryopreservation (egg freezing) for women, and ensure sick adolescents and their parents understand the process. Nevertheless, currently in Taiwan nurses do not train in the field of reproductive health. Moreover, fertility preservation raises complicated ethical issues, related to techniques, consent processes, cultural sensitivities and costs. Ideally, the decision about candidacy for fertility preservation will be guided by an institutional policy and shaped by a medical team, including a paediatric oncologist, fertility specialist, ethicist, and mental health professional as indicated by Fallat and Hutter (2008). Thus doctors need to be more aware of their responsibility to provide information about risks to fertility to sick adolescents and their parents early in the
diagnostic phase of cancer treatment, so that they have time to ask questions and make decisions. Moreover, family counselling units should be developed for sick adolescents and their families aimed at giving more information about future fertility (Fallat & Hutter, 2008). If adolescents choose to preserve sperm or ova for later access, a cost would most likely be involved for facility. One way to cover this expense would be to develop a specific medical insurance, currently not available in Taiwan.

The findings revealed that parents, whilst agreeing to passively go along with Western medical treatment for their sick child, also sought TCM to help their child to decrease the side effects of treatment regimes. According to Chui, Donoghue and Chenoweth (2005), there exists a need to develop standards for the use of TCM within the healthcare system. Medical providers in Taiwan are usually trained and practise in the Western medical tradition (Tzeng & Yin, 2006), but in this study, most of the parents chose Chinese medicine, herb treatment, folk remedies and food care to promote the sick adolescents’ health and decrease the side effects of Western style treatment. The critical issue is that sick adolescents and their families need to feel that there is a culture of acceptance that allows the issue of cultural practices to be raised. As Han, Liu, Xiao, Zheng, Ma and Ding (2011) have argued health care providers, especially oncology paediatric professionals, must consider and learn more about TCM to meet the needs of families and sick adolescents. Lee and Lin (2009) have advocated that government health policy should try to encourage families to be open about the alternative therapy with the physicians. The physicians also need more complete information about all treatment modalities when patients use both TCM and Western conventional medicine in their long term care.
Supplementary Services for Families to Sustain Caregiving

The present study clearly identified the need for health care providers to learn from the experience of families and sick adolescents by increasing their experience of working with families with the disease. Yi (2009) found that such experience helped them to reduce the worry when families felt uncertainty when faced with an unpredictable future. Barakat, Marmer and Schwartz (2010) have argued that community-based services including access to school, community nurses and special educators to coordinate the health care for the sick adolescent at home are an important service support. Tzeng and Yin (2008) have argued that this care system should become a standard component of service provision in Taiwan in order to relieve the families stress and burden related to caregiving roles and responsibilities. One way to lessen the burden for these caregivers is to have volunteers to do household chores, and for the Department of Health to appoint employees to oversee the necessary programs (Chiou, Chang, Chen, & Wang, 2009). At present this service is provided only for elderly patients, regardless of their specific health need.

Financial hardship is a clear finding in this study. The National Health Insurance (NHI) system in Taiwan does not currently cover long term care fees; this system emphasises physical and medical care in hospital (Li & Yin, 2005). As Tzeng and Yin (2006) have argued, health care providers need to devote time to acquire a sense of the needs of family members outside of the acute setting in the home context. Families, according to Christian (2010), provide the majority of care for children with chronic conditions at home. It can logically be concluded that health care providers should critically review Taiwanese health care policy and planning, giving attention to the provision of community-based care that support families in their caregiving roles and responsibilities. This proposed initiative is supported by the findings of this study. Tung (2010) has highlighted that one demonstration of this support would be
flexibility in work situations, such as positions being held open for parents who need to spend time with family; and the possibility of pensions for family caregivers who have to give up their paid employment. Other supports could include retraining on return to work and requirements for companies to rehire caregivers who take leave from work (Yen, Teng, Huang, Ma, Lee, & Tseng, 2010). During informal consultations, two mothers who had left work suggested that the Cancer Foundation could hire women with their experience as consultants.

**Strengthening Community-Based Services**

Chen, Chen and Haase (2008) have argued that specific community-based services which focus on adolescent care need to be developed. They have indicated that these services need to show understanding of this particular age group and their specific needs, including the importance of peer communication. Furthermore, Tzeng and Yin (2006) have advocated that family emotional support and counselling are necessary to enhance the ability of sick adolescents and their families to cope with the treatment problems, as well as ways to face relapses or death. As indicated in this study, parents of adolescents receiving treatment for cancer endured anxiety about problems they envisaged could be caused by the desire for education and the pressure to learn. They were afraid that a heavy load of school work would cause a relapse. Two of the mothers in this study blamed themselves and felt guilty about not being aware that relapse had occurred. This finding highlighted the need for parental-professional care teams to become more flexible and accommodating in defining the sick adolescents’ and their families’ need for services (Jin, 2009).

Wu Chin, Haase and Chen (2009) have claimed that knowing how family and the sick adolescent accept the cancer is a crucial step towards designing appropriate strategies
to ease the stress of the treatment because it enables professionals to understand their own role in the problem and how to help with managing the challenges. At present in Taiwan, no formal system exists for recognising the needs of adolescent students when they return to school after treatment for cancer. Seitz, Besier and Goldbeck (2009) have suggested that information for the school nurses and teachers is provided informally by the parents and its accuracy depends on the scope of their understanding of the disease and its follow up and how the student might be helped. The school nurse, teachers and parents of the sick adolescent need to co-operate to be aware of the students’ situation and communicate with each other in a systematic fashion (Harris, 2009). Adolescents with cancer should receive tutoring in order for them to keep up in school, and do well in entrance exams.

Currently in Taiwan, Cancer Foundations organise and manage workshop programs every day free of charge to cancer patients and their families. They provide psychological counselling, nutritional guidance, relaxation therapy, music therapy, and courses in stress reduction (e.g., Qi-Gong, yoga, massage). Hotline services are delivered over the phone by volunteer and oncology nurse practitioners are available to address a wide variety of patient and family needs including cancer treatment procedures, home-care issues and psychological support. Wu, Chin, Haase and Chen (2009) have argued that these programs should be enhanced by some specific focus on the psychosocial and physical health needs of adolescents. These foundations in Taiwan currently rely on donations and should be strengthened by government support and development. Huang, Ma, Shih and Li (2008) proposed that community service policies need to be developed that enable consistent funding to be made available for resources such as premises and staff.
Adolescents and healthy siblings are uncomfortable talking about their concerns. The present study indicated that the initial onset of the diagnosis of the disease resulted in high levels of negative emotions in the sick adolescents and their healthy siblings. Bayliss (2007) proposed that negative feelings may impact on adolescents’ ability to accept information when it is given, while a study in South Korea by Yi (2009) indicated Internet communication with friends allowed adolescents to feel comfortable about sharing information and provided a medium for communication. According to Hwang, Cheong and Feeley (2009), sick adolescents and healthy siblings require peer networks to reduce unpredictability and uncertainty. These findings concur with this study’s findings, in supporting the need to develop cancer teen groups that facilitate peer networks which foster comfort in communication and overcome a sense of difference and isolation.

Peer networks for sick adolescents and their healthy siblings are not well developed in Taiwan (Wu, Chin, Haase, & Chen, 2009). However, such groups assist in the development of understanding and compassion, and can help sick adolescents and their families integrate their medical experiences into life experiences. That is, utilising community-based services could make for a better quality of life by assisting psychosocial adjustment for sick adolescents and their families (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010). Thus, peer groups with the potential for empowerment need to be developed, especially with the sick adolescent’s siblings since the sick person is not the only one who requires support. Verna (2008) has suggested that meetings would incorporate activities and themes ranging from physical exercise to camping to managing interpersonal relationships and artistic self expression in such forms as painting, writing, and making films and music.
Health care providers should ensure that sick adolescents and their families have greater access to social activities (Decker, 2007). Health care providers could be easily accessible by phone, and they could call families to inform them of the upcoming activities. According to Huang, Ma, Shih and Li (2008), activities and transportation should be free of charge, or require a small co-payment. Moreover, general medical information should be provided on-line, and community nurses should give training in caregiving skills to caregivers (Li & Yin, 2005). These steps would substantially strengthen community-based services for sick adolescents and their families. The effectiveness of these recommendations are subjects for future research and would have important ramifications for policy implementation.

**Concluding Remarks**

Utilising a grounded theory approach, the present study discovered a substantive theory of caregiving for adolescents with cancer within the context of Chinese culture in Taiwan. This framework suggested that sick adolescents and their families experienced ‘the broken chain of family life’ due to exposure to the disease (which included a strong belief in accumulated karma as a causal factor) and demands of caregiving, which resulted in disruption and strain through change in family roles and relationships. The present findings suggested that the process of *restoring the broken chain of family life* predominantly involved the adolescents and their family confronting the treatment, accommodating their suffering, and repairing integral connections among family members, partly through performing cultural rites. Chinese culture shaped and guided interdependent family life, and placed great importance on smooth and harmonious interpersonal relationships with kin. Maintaining family connectedness and belongingness in Taiwan is a main priority when disruption through illness is encountered. This goal supports families to regain harmony when life threatens family life balance.
Parents’ keeping of faith was a crucial support in managing the impact of caregiving thrust upon the family because of the occurrence of a threatening health situation for their adolescent child. Faith assisted Taiwanese families to manage the fear and stress associated with the process of treatment and follow up caregiving at home. These findings point to a number of recommendations for the health care practice and future research. Health care practice includes constructing health care and establishing both peer networks and parental-professional caring teams. The aim is to assist the sick adolescent, healthy siblings and parents going through this journey, adjust to the difficulties presented by the treatment. Future research includes a critical review of health care policy, giving attention to aspects such as community service and the provision of community health nurses to work with the adolescents with cancer in Taiwan.

The following remark from a mother (Yeh family) reflects the significance of restoring a harmonious family life for Chinese families in Taiwan when confronted with illness:

*The lotus, every part of which can be consumed for nutrition, is associated with the Buddhist notion of sacrifice and so is symbolic of the Taiwanese family: the mother is the flower, the father is the supporting stem and the children are the seeds. The parents are willing to make any sacrifice to ensure the harmony of all the family members, the individual petals of the lotus. As I grew up in Chinese society, and learned from Confucian ethics to place great value on the family, so for me, the sickness affected the chain of family life and increases my duty to the family care system to restore harmony and repair the chain. My culture therefore also made me accept that the illness was the result of accumulated karma.*
Appendices
Appendix A-1 Information Sheet for Parent/ Caregiver

Study Title: Restoring harmony in the life of Taiwanese families caring for adolescents with cancer: a grounded theory study

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Principal Supervisor: Associate Professor Saras Henderson
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Telephone: 07 5552 8910 E-mail: s.henderson@griffith.edu.au

Background
Caring for adolescents with cancer has tremendous impact on the family, especially the parents. Families are involved in complex therapeutic interventions at home whilst balancing household routines. This demanding situation often has a negative impact on family roles and ultimately relationships, and the family is affected in a number of ways. The purpose of this study is therefore to explore the impact of caregiving on roles and relationships in the Taiwanese family.

Responding to these questions will assist health care providers and policy makers and those who implement policy in Taiwan to provide appropriate care and services for these families. The study is being undertaken for a PhD degree at Griffith University by Li-Chyun Yeh.
What Participation in This Study Involves
Involvement in the study will require you to describe the impact of caregiving for your child with cancer at home through interviews. In order to record your words exactly and convey your meaning clearly the interview process will be tape-recorded. Interviews may last approximately 50-60 minutes according to the content and progress of the interviews. All interviews will be scheduled at mutually convenient times and locations. To clarify any issues or concepts arising from the initial interview, you may be interviewed in a follow up interview. We hope that you will consider participation in this study, because your need and experience will assist health care providers and policy makers to understand and appreciate your experience and provide more appropriate help to assist you and other families to manage similar situations.

Consent to Participate
You are a voluntary participant in this study. You have the right to withdraw from or stop your involvement in the study at any time. You may also refuse to answer any question that makes you feel uncomfortable, or request that the tape be turned off during sections of the interviews. Whether or not you participate in this research does not affect your right to receive treatment. The researcher will not discuss this research with your doctor so the doctor will not be able to know whether you participated or decided not to participate in this study. We hope that you will consider participating in this study which may help with future delivery of appropriate care and services and to gain a better understanding of, how care-giving influences family roles and relationships when caring for your child with cancer at home.

Risk
This study presents no physical risk to participants. However, psychological risk, that is, experiencing distress associated with sharing sensitive information, is a possibility. The researcher has extensive experience in supporting adolescents and their families in distressed situations as a professional care-giver. If you become very distressed they may terminate the interview process at any stage or opt to turn off the tape recorder enabling them to determine what is recorded. If follow-up
counselling is required at any stage then you will be put in touch with a qualified counsellor.

**Confidentiality**
Your name or any identifying information will not be disclosed to anyone apart from the research team. Your anonymity will be protected at all times. The findings of this study may be published. However, no names or information which could identify any individual or organization will be recorded. On completion of the study, a report of the general findings from the study will be made available to you. The data will be locked in a cabinet at the researcher’s office in the school of Nursing and Midwifery of Griffith University for a period of 7 years and then will be destroyed.

**Complaints Mechanism**
Griffith University conducts research in accordance with the Australian National Statement on Ethical conduct in Research Involving Humans. If you have any concerns or complaints about the ethical conduct of the research project you should contact Shin-Nan Cheng, Chief Director of Paediatric and Haematology Department in Tri-Service General Hospital, telephone (02) 87923311 or e-mail: pedcsn@yahoo.com.tw. Similarity, if you have any concerns or complaints about the ethical conduct of the research project you should contact the Manager, Research Ethics on +617 37355585 or research-ethics@griffith.edu.au.

**Privacy Statement**
The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be divulged to third parties without your consent, except government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purpose. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at Telephone: +617 3735-5585 or E-mail: www.griffith.edu.au/ua/aa/vc/pp.

The researcher thanks you for your consent and participation in this research.
研究主題：臺灣癌症青少年恢復和諧家庭生活的重要性：紮根理論研究
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背景
癌症的慢性病程顯著影響的青少年和他們的家人，尤其是父母親。不僅需要面對接受治療期間產生的身體症狀困擾及心理社會問題，另外，不可預測的疾病病程和在家照顧的持續護理需要被加以重視及關注。因此，藉由這項研究可以更好地提供適當的照顧和服務給癌症青少年和其家人，以提供社區照護模式給醫護專業人員及健康衛生決策者設計完善的醫療保健系統。這項研究將由澳洲格里菲斯大學（Griffith University）護理研究所博士候選人葉麗娟執行本研究。

研究涉及的部份
本研究將藉由訪談來瞭解家庭角色和關係的改變。為了正確記錄您的會談內容及正確傳達您會談得意義，在會談過程將會以錄音的方式進行，會談時間約50-60分鐘，約定雙方許可的會談時間及地點。視情況需要，可能需要用電話會談以澄清第一次會談內容的問題、想法及感覺。因爲我們非常重視您提供的寶貴經驗，以期能發展出社區照護模式給與相似狀況的家庭得以完善的照顧。

同意參與研究
您參與此研究完全自願，您如果拒絕參與本研究案將不會受到任何的處罰，也不會影響醫護人員對癌症青少年的照護。研究期間若是您選擇中斷參與研究將不會受到任何處罰，也不需提供任何的理由。我們希望您能考慮參與本研究，以期改善日後居家照護的品質。
參與研究的危險性
這項研究並沒有任何身體上的危險，但在訪談過程中或許會讓您聯想不愉快的生活經驗。請您立即讓我瞭解，我會隨即提供情緒支持，如有需要，將會轉介專業谘詢服務並會運用電話或家訪的方式繼續提供追蹤服務。

保護參與研究者個人隱私
所有的資料將受到絕對的保密。因爲研究的需要，將會請您提供個人基本資料如附錄 E 內容，這些資料只有研究者知道，絕不會對外公開或洩密。研究中將用代碼取代個人姓名與資料，為了保護參與研究個案的隱私所做的防護措施包括:日後的論文及研究發表所有資料是以整體資料做呈現，所以無法辨認個人資料；本研究完成後，歡迎參與研究者索取研究相關資料。參與研究者所填寫的所有資料與訪問資料將被保存在格里菲斯大學檔案資料庫 7 年，7 年後予以銷毀。

投訴機制
如果有任何疑問或想投訴有關本研究的相關問題，您可以打電話或寫電子郵件給三軍總醫院小兒血液腫瘤科錢新南主任，電話（02）87923311；電子信箱: pedcsn@yahoo.com.tw。您也可以隨時聯絡格里菲斯大學的人體研究倫理評審委員會的成員，聯絡電話為 617-37355585 or 電子信箱: research-ethics@griffith.edu.au

隱私聲明
研究資料是絕對保密的，未經過您的同意絕不會將資料提供給其他人。除非有任何與政府相關的法令規定時，但仍會持續保護參與研究個案的個人隱私以匿名方式使用。如果您仍有任何與本研究相關的問題或疑慮，請與葉麗娟連絡或與澳洲格里菲斯大學的人體研究倫理評審委員會聯繫，聯絡電話為 +617-37355585 or 電子信箱 research-ethics@griffith.edu.au。

感謝您同意參與本項研究
Appendix B-1  Information Sheet for Adolescent /Sibling

Study Title: Restoring harmony in the life of Taiwanese families caring for adolescents with cancer: a grounded theory study

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Telephone: 07 3735 5227  E-mail: u.kellett@griffith.edu.au

Principal Supervisor: Associate Professor Saras Henderson
School of Nursing and Midwifery, Gold Coast
Telephone: 07 5552 8910  E-mail: s.henderson@griffith.edu.au

Background
Caring for adolescents with cancer has tremendous impact on the family, especially the parents. Families are involved in complex therapeutic interventions at home whilst balancing household routines. This demanding situation often has a negative impact on family roles and ultimately relationships, and the family is affected in a number of ways. The purpose of this study is therefore to explore the impact of caregiving on roles and relationships in the Taiwanese family.

Responding to these questions will assist health care providers and policy makers and those who implement policy in Taiwan to provide appropriate care and services for these families. The study is being undertaken for a PhD degree at Griffith University by Li-Chyun Yeh.
**What Participation in This Study Involves**

Involvement in the study will require you to describe the impact of care-giving for your child with cancer at home through interviews. In order to record your words exactly and convey your meaning clearly the interview process will be tape-recorded. Interviews may last approximately 50-60 minutes according to the content and progress of the interviews. All interviews will be scheduled at mutually convenient times and locations. To clarify any issues or concepts arising from the initial interview, you may be interviewed in a follow up interview. We hope that you will consider participation in this study, because your need and experience will assist health care providers and policy makers to understand and appreciate your experience and provide more appropriate help to assist you and other families to manage similar situations.

**Consent to Participate**

You are a voluntary participant in this study. Also you have the right to withdraw from or stop your involvement in the study at any time. You may also refuse to answer any question that makes you feel uncomfortable, or request that the tape be turned off during sections of the interviews. Whether or not you participate in this research does not affect your right to receive treatment. The researcher will not discuss this research with your doctor so the doctor will not be able to know whether you joined or decided not to join in this study. We hope that you will consider participating in this study which may help with future delivery of appropriate care and services and to gain a better understanding of, how care-giving influences family roles and relationships when caring for your child with cancer at home.

**Risk**

This study presents no physical risk to participants. However, psychological risk, that is, experiencing distress associated with sharing sensitive information, is a possibility. The researcher has extensive experience in supporting adolescents and their families in distressed situations as a professional care-giver. If you become very distressed they may terminate the interview process at any stage or opt to turn off the tape recorder enabling them to determine what is recorded. If follow-up counselling is required at any stage then participants will be placed in touch with a
qualified counsellor.

**Confidentiality**

Your name or any identifying information will not be disclosed to anyone apart from the research team. Your anonymity will be protected at all times. The findings of this study may be published. However, no names or information which could identify any individual or organization will be recorded. On completion of the study, a report of the general findings from the study will be made available to you. The data will be locked in a cabinet at the researcher’s office in the school of Nursing and Midwifery of Griffith University for a period of 7 years and then will be destroyed.

**Complaints Mechanism**

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**Privacy Statement**

The conduct of this research involves the collection, access and/or use of your identified personal information. The information collected is confidential and will not be divulged to third parties without your consent, except government, legal or other regulatory authority requirements. A de-identified copy of this data may be used for other research purpose. However, your anonymity will at all times be safeguarded. For further information consult the University’s Privacy Plan at Telephone: +617 3735-5585 or E-mail: www.griffith.edu.au/ua/aa/vc/pp.

The researcher thanks you for your consent and participation in this research.
Appendix B-2
（Information Sheet for Adolescent /Sibling）

研究主題：臺灣癌症青少年恢復和諧家庭生活的重要性: 紮根理論研究
博士候選研究生：葉麗娟（康寧醫專講師）護理及助產研究所 Nathan 校區
電話：02-26321181（辦公室）, 0913009006 電子信箱：l.yen@griffith.edu.au
指導教授：Dr. Ursula Kellett 護理及助產研究所 Nathan 校區
聯絡電話：+61 7-37355227（澳洲） 電子信箱：u.kellett@griffith.edu.au
指導教授：Associate Professor Dr Saras Henderson 護理及助產研究所 Gold Coast 校區
聯絡電話：+61 7-55528910（澳洲） 電子信箱：s.henderson@griffith.edu.au

背景
癌症的慢性病程顯著影響的青少年和他們的家人，尤其是父母親。不僅需要面對
接受治療期間產生的身體症狀困擾及心理社會問題，另外，不可預測的疾病病程
和在家照顧的持續護理需要被加以重視及關注。因此，藉由這項研究可以更好地
提供適當的照顧和服務給癌症青少年和其家人，以提供社區照護模式給醫護專業
人員及健康衛生決策者設計完善的醫療保健系統。這項研究將由澳洲格里菲斯大
學（Griffith University）護理研究所博士候選人葉麗娟執行本研究。

研究涉及的部份
本研究將藉由訪談來瞭解家庭角色和關係的改變。為了正確記錄您的會談內容及
正確傳達您會談得意義，在會談過程將會以錄音的方式進行，會談時間約 50-60
分鐘，約定雙方許可的會談時間及地點。視情況需要，可能需要用電話會談以澄
清第一次會談內容的問題、想法及感覺。因爲我們非常重視您提供的寶貴經驗，
以期能發展出社區照護模式給與相似狀況的家庭得以完善的照顧。

同意參與研究
您參與此研究完全自願，您如果拒絕參與本研究案將不會受到任何的處罰，也不
會影響醫護人員對癌症青少年的照護。研究期間若是您選擇中斷參與研究將不會
受到任何處罰，也不需提供任何的理由。我們希望您能考慮參與本研究，以期改
善日後居家照護的品質。

參與研究的危險性
這項研究並沒有任何身體上的危險，但在訪談過程中或許會讓您聯想不愉快的生活經驗。請您立即讓我瞭解，我會隨即提供情緒支持，如有需要，將會轉介專業諮詢服務並會運用電話或家訪的方式繼續提供追蹤服務。

保護參與研究者個人隱私
所有的資料將受到絕對的保密。因爲研究的需要，將會請您提供個人基本資料如附錄 E 內容，這些資料只有研究者知道，絕不會對外公開或洩密。研究中將用代碼取代個人姓名與資料，為了保護參與研究個案的隱私所做的防護措施包括：日後的論文及研究發表所有資料是以整體資料做呈現，所以無法辨認個人資料；本研究完成後，歡迎參與研究者索取研究相關資料。參與研究者所填寫的所有資料與訪問資料將被保存在格里菲斯大學檔案資料庫 7 年，7 年後予以銷毀。

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隱私聲明
研究資料是絕對保密的，未經過您的同意絕不會將資料提供給其他人。除非有任何與政府相關的法令規定時，但仍會持續保護參與研究個案的個人隱私以匿名方式使用。如果您仍有任何與本研究相關的問題或疑慮，請與葉麗娟連絡或與澳洲格里菲斯大學的人體研究倫理評審委員會聯繫，聯絡電話為 +617-37355585 or 電子信箱 research-ethics@griffith.edu.au。

感謝您同意參與本項研究
Appendix C-1  Consent Form for Parent /Caregiver

Study Title: Restoring harmony in the life of Taiwanese families caring for adolescents with cancer: a grounded theory study

Researcher: Li-Chyun Yeh
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Principal Supervisor: Dr. Ursula Kellett
School of Nursing and Midwifery, Nathan
Telephone: 07 3735 5227 E-mail: u.kellett@griffith.edu.au

Principal Supervisor: Associate Professor Saras Henderson
School of Nursing and Midwifery, Gold Coast
Telephone: 07 5552 8910 E-mail: s.henderson@griffith.edu.au

I have read the information form and understand that:
• This research is to explore the impact of care-giving on roles and relationships in the Taiwanese family.
• I understand how I will be involved in this research with my child and have had all questions answered to my satisfaction;
• I understand that there will be no direct benefit to me or my child from my participation in this research;
• I understand that whether or not I decide to participate is my decision will not affect my child’s treatment and care given from the hospital or community;
• I understand that my participation and my child’s in this research is voluntary, and I may discontinue my participation at anytime without penalty or explanation;
• I understand that if I have any additional questions I can contact the research team;
• I understand that the data will be securely locked in a cabinet in the researcher’s office for 7 years and then will be destroyed;
• I understand that I can contact the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on +61-7-37355585, Taiwanese on +886-287923311 or if I have any concerns about the ethical conduct of the project;
• I agree for myself and for my child to participate in the study, and give my consent freely.

Name of Participant:
Signature:
Date:

Name of Parent or Caregiver:  Name of Parent or Caregiver:
Signature:
Signature:
Date:  Date:

Name of researcher:
Signature:
Date:
研究主題：臺灣癌症青少年恢復和諧家庭生活的重要性: 紮根理論研究
博士候選研究生：葉麗娟（康寧醫專講師）
護理及助產研究所 Nathan 校區
聯絡電話：02-26321181（辦公室），0913009006
電子信箱：l.yen@griffith.edu.au
指導教授：Dr. Ursula Kellett
護理及助產研究所 Nathan 校區
聯絡電話：+61 7-37355227（澳洲） 電子信箱：u.kellett@griffith.edu.au
指導教授：Associate Professor Saras Henderson
護理及助產研究所 Gold Coast 校區
聯絡電話：61 7-55528910（澳洲） 電子信箱 E-mail: s.henderson@griffith.edu.au

我已經看過本研究相關資料，而且：

- 我瞭解參加這項研究的目的是想知道居家照護對癌症青少年家庭的角色和關係的影響；
- 我已經完成瞭解這項研究，沒有進一步的問題;
- 我瞭解我和我的孩子參與這項研究完全是出自於自願的；我和我的小孩接受個別單獨的錄音訪談是一次，每次 50-60 分鐘。若是有需要，我和我的小孩可以接受日後的訪談；
- 我瞭解訪談期間若是我和我的小孩不想繼續接受訪談或是日後的與研究，並不需要提供任何的理由;
- 我瞭解讓我小孩參與這項研究與否將不會影響他在醫院的治療或醫護人員日後對他所提供的照護；
- 我瞭解所有訪談資料不會出現我和我小孩的姓名與基本資料；訪談的文字檔案及錄音帶會由葉麗娟保存於澳洲格里菲斯大學（Griffith University）資料庫中 7 年，7年後會予以銷毀；
我瞭解如果我有任何疑問，可以隨時聯繫康寧護理暨管理專科學校護理科葉麗娟老師，聯絡電話(02) 26321181 #201；也可以隨時聯絡格澳洲格里菲斯大學的人體研究倫理評審委員會的成員，聯絡電話為+617-37355585。

我同意我和我的孩子參加這項研究。

參與者姓名：
簽名：
日期：

家長或主要照顧者姓名：
簽名：
日期：

研究者姓名：
簽名：
日期：
Appendix D-1 Demographic Information Sheet (Families and Adolescents)

Please tick the space that most accurately describes your background and enter details as requested.

Code:

**Information on adolescent**

1. Age: ______ years old
2. Gender: [ ] male [ ] female
3. Time from diagnosis to study baseline: [ ] ≤ 6 months [ ] ≤ 18 months [ ] ≤ 24 months [ ] ≥ 24 months
4. Type of Cancer: [ ] Leukaemia [ ] Brain/CNS Tumours [ ] Lymphomas
   Bone and Soft Tissue tumours [ ] Others
5. Treatment of Cancer: [ ] Chemotherapy [ ] Radiotherapy [ ] Surgery [ ] Immune therapy [ ] others
6. Study: [ ] keeping at school [ ] home school [ ] temporary suspension of schooling [ ] others
7. Recurrence: [ ] Yes, frequency: ______ [ ] No

**Information on parents (caregiver)**

8. Age groups: [ ] 25-30 [ ] 31-35 [ ] 36-40 [ ] 41-45 [ ] 46-50 [ ] 51-55
   [ ] over 56 years old
9. Gender: [ ] male [ ] female
10. Relationship with adolescent

11. Religious belief of the family:

   [ ] Buddhism [ ] Taoism [ ] Christian [ ] Catholic [ ] No religious beliefs
   [ ] others
12. Duration of caregiving: _______________________
13. Martial status: [ ] single [ ] married [ ] divorced/separated [ ] Widowed
14. Educational level: [ ] Primary high school [ ] high school [ ] University [ ] others
15. Duration of care provided by caregiver:

   [ ] 0-8 hours/day [ ] 9-16 hours/day [ ] 17--24 hours/day
16. Family monthly income NT dollars:

   [ ] below 30000/dollars [ ] 30001-50000/dollars [ ] over 50000/dollars
17. What kind of social support do you have?

   [ ] Community health nurses [ ] Social worker [ ] Volunteer groups
   [ ] The paediatric cancer group [ ] Friends [ ] Others _______________________
18. Sibling living in the same household

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
</table>

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Appendix D-2  個人基本資料表（家庭成員和青少年）

請勾選正確和適當地描述您的資料

代碼：

日期：

青少年部份

1. 年齡：______ years old
2. 性別：□ 男生      □ 女生
3. 診斷癌症至今的時間：□ ≤ 6 months □ ≤ 18 months □ ≤ 24 months
   □ ≥ 24 months
4. 癌症類型：□ 白血病     □ 腦 / 中樞神經系統 □ 淋巴瘤
   □ 骨和軟組織腫瘤     □ 其他
5. 治療包括：□ 化學治療 □ 放射治療 □ 手術治療 □ 免疫治療 □ 其他
6. 就學狀況：□ 繼續中 □ 在家自學     □ 暫時休學 □ 其他
7. 複發狀況：□ 有，次數：______     □ 沒有

家長（主要照顧者）

8. 年齡：□ 25-30 □ 31-35 □ 36-40 □ 41-45 □ 46-50 □ 51-55 □ over 56 years old
9. 性別：□ 男生      □ 女生
10. 和患孩的關係：
11. 宗教信仰：□ 佛教      □ 道教     □ 基督教     □ 天主教      □ 無 □ 其他
12. 婚姻狀況：□ 單身     □ 已婚      □ 離婚       □ 分居     □ 其他
13. 教育程度：□ 初中     □ 高中     □ 大學       □ 其他
14. 照顧患孩已有多久時間：
15. 每天照顧患孩的時間：□ 0-8 hours/day □ 9-16 hours/day □ 17-24 hours/day
16. 家庭的月收入：□ below 30000 □ 30001-50000 □ over 50000/ dollars
17. 社會團體曾支持或幫助您，包括：□ 社區醫護人員 □ 癌症基金會 □ 社工
   □ 朋友     □ 親戚      □ 志工團體     □ 其他
18. 家中兄弟姐妹的人數與年齡：

<table>
<thead>
<tr>
<th>年齡</th>
<th>性別</th>
<th>年齡</th>
<th>性別</th>
</tr>
</thead>
</table>

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Appendix E-1  Interview Guide

The following questions will serve as opening questions to assist in understanding the impact of care-giving on roles and relationships in the Taiwanese family. The responses to these questions will be further explored with cues. The participants will be requested to give examples where required.

Parents / Caregiver Interview Guide

a) Tell me about your experience with caring for your ill child?

b) How has caring for your ill child impacted on family roles and relationships?

c) What about your wife/ husband’s roles? How have they changed? Please provide an example.

d) How has caring for your ill child affected your lifestyle (e.g. work or social life or caring for other healthy children)?

e) How do you manage conflicts in the family? When do they arise? What actions do you take when conflicts happens? Please give me an example.

f) How do you manage conflicts between work and the care-giving responsibilities? What actions do you take? Please give me an example.

g) How have you managed issues arising with the children, e.g. jealousy, anger and fighting?

h) What support do you receive from your family (spouse, relatives or parents) or social groups, such as friends?

i) What help do you wish to receive when facing your problems?

j) What help have you received in coping with your emotions?

Sibling Interview Guide

a) Tell me about your experience with for your brother/ sister who is unwell?

b) How has your ill brother/ sister impacted on family roles and relationships?

c) How has your ill brother/sister affected your lifestyle (e.g. activities, hobbies or leisure time)?

d) Do you feel anxiety, depression or jealousy about your ill brother/sister?
Appendix E-1 continued

e) If so, how do you manage your emotions and behaviour, can you give me an example?
f) What help do you want to receive in facing your personal issues?
g) What help have you received in coping with your own emotions?

Adolescent with Cancer Interview Guide

a) Tell me about your experience with this cancer treatment both in hospital and at home.
b) Do you think your family members’ roles and relationships have changed in any way since you were diagnosed with cancer?
c) How have you been adapting to current changes in your lifestyle and relationships with others (siblings, school-mates, parents and grandparents)?
d) How do you manage conflicts in the family? When do conflicts arise?
e) How do you manage the emotions and behaviour of your siblings, e.g. jealousy, anger and fighting?
f) What help do you wish to receive in facing your problems?
g) What help have you received in coping with your emotions?

Is there anything else that you think is important in understanding your family roles and relationships that we have not mentioned?
Appendix E-2 訪談指引

本項研究是懇切希望瞭解居家照護對癌症青少年家庭的角色和關係的影響。以下的問題指引會由研究者詢問您這些問題並會適時給予舉例說明。

父母/照顧者訪談部分

a) 告訴我照顧您小孩的經驗?
b) 自從您小孩診斷出癌症有影響到家庭角色和關係變化?
c) 請告訴我您的角色是否受到影響?能否舉例說明?
d) 如何調適目前的家庭生活型態（例如工作或社交活動或照顧其他家中小孩）?
e) 當有家庭衝突發生時您如何處理這些衝突?
f) 如何調整您的工作和照顧責任間的衝突?
g) 您如何處理其他兄弟姊妹間的情緒和行行為，例如：嫉妒、憤怒和打架?
h) 支持系統是您的配偶、親戚、朋友、父母或社會團體?
i) 當您面對問題時您需要是什麼幫忙?
j) 當您有情緒困擾時您如何因應?

兄弟姊妹部分

a) 告訴我你兄弟姊妹生病的經驗?
b) 你兄弟姊妹生病會影響到家庭角色和關係變化?
c) 你兄弟姊妹生病會影響你的家庭生活型態（同學，父母，個人情緒）?
d) 您如何處理生病兄弟姊妹間的情緒和行行為間的衝突?
e) 您會有焦慮、憂鬱 或是嫉妒生病兄弟姊妹?
f) 如果有上述的情形，您如何處理自己的情緒和行行為？能否舉例說明?
g) 當您面對困難時您需要是什麼幫忙?
h) 當您有情緒困擾時您如何尋求幫忙因應你的情緒?
青少年訪談部分

a) 告訴我你的住院和在家接受治療的經驗？

b) 您認為您的疾病有影響到家庭角色和關係變化？

c) 如何調適目前你的生活型態和人際關係(兄弟姊妹，同學，父母親和祖父母)？

d) 當有家庭的衝突時如何處理？

e) 您如何處理其他兄弟姊妹間的情緒和行爲，例如：嫉妒，憤怒和打架？

f) 當您面對問題時您需要是什麼幫忙？

g) 當您有情緒困擾時您需要如何協助因應？

請您想想，上述的問題是否還有遺漏的部分，如果還有請您在告訴我！
28 January 2011

TO WHOM IT MAY CONCERN

Griffith University Human Research Ethics Application – NRS/15/08/HREC

This is to confirm that Human Research Ethics Application NRS/15/08/HREC titled “The impact of care-giving for an adolescent with cancer on Taiwanese family roles and relationships: a grounded theory study” conducted by Ursula Kellett, Saras Henderson and Li-Chyun Yeh, was approved by the Griffith University Human Research Ethics Committee (HREC) on 15 July 2009. The authorisation for this research was issued from 15 July 2009 to 31 July 2010.

The HREC is constituted and operates in accordance with the National Statement on Ethical Conduct in Human Research (2007).

Please do not hesitate to contact me if you have any further queries about this matter.

Regards

Gary Allen
Senior Manager, Research Ethics and Integrity
Office for Research
Appendix G

Ethics Approval from Hospital

Institutional Review Board of
Tri-Service General Hospital
National Defense Medical Center

Letter of Approval

Date: Jul-10-2009
Protocol Title: The impact of care-giving for an adolescent with cancer on
Taiwanese family roles and relationships: a grounded theory study
Protocol number: 098-05-099
Protocol version: version date: 5-Jun-2009
ICF version: version date: 30-Jun-2009
Principal Investigator: Shin-Nan Cheng
Co-Principal Investigator: Li-Chyun Yeh
TSGHIRB Approval Number: 098-05-099
Expiration Date: Jan-9-2010

On Jul-10-2009, the Institutional Review Board of the Tri-Service General Hospital, National Defense Medical Center (TSGHIRB) approved the above named Protocol, Subject Information/Consent Form, and related materials.

Your ongoing responsibility to the TSGHIRB follows:
- any changes to the approved protocol and/or related materials submit for IRB approval before instituting these changes. Changes to eliminate immediate hazards to human subjects are the only changes that may be made prior to IRB approval.
- submit a protocol status update report for continuing review.
- submit a protocol status update report with your findings to the IRB office when your protocol is completed or terminated.
- report all serious and unanticipated adverse events in studies involving human subjects to the IRB immediately.
- use only copies of the enclosed subject information/consent form, flyers, etc. that bear the TSGHIRB approval date stamp.

If you have questions, concerns, or requests for more information, please contact TSGHIRB office at 886-2-8792-3311 ext. 10552.

Please reference your TSGHIRB approval number in all communications about this protocol.

Sincerely,
Chih-Shung Wong, M.D., Ph.D.

[Signature]
Chairman
Appendix H-1  Demographic Characteristics of Participants

N=27

<table>
<thead>
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<th>Characteristics</th>
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<td>No religious beliefs</td>
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<td>9-16 hours/day</td>
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<td>30001-50,000/dollars</td>
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### Demographic Characteristics of Participants (Adolescents with Cancer)

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<th>Code</th>
<th>Age</th>
<th>Gender</th>
<th>Age at diagnosis</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Current education</th>
<th>Caregiver</th>
<th>Siblings (age)</th>
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<td>Brain tumour*</td>
<td>surgery, chemotherapy and radiation</td>
<td>temporary suspension of schooling</td>
<td>mother</td>
<td>one sister(23)</td>
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<td>男</td>
<td>13</td>
<td>ALL *</td>
<td>chemotherapy</td>
<td>keeping at school</td>
<td>mother</td>
<td>one sister(16)</td>
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<td>13</td>
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<td>男</td>
<td>12</td>
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<td>mother</td>
<td>One brother(16)</td>
</tr>
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<td>13</td>
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<td>Surgery and chemotherapy</td>
<td>keeping at school</td>
<td>parents</td>
<td>2 sisters(22, 16)</td>
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<td>18</td>
<td>女</td>
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<td>女</td>
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<td>Left Ovary tumour</td>
<td>Surgery and chemotherapy</td>
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<td>mother</td>
<td>One brother(17)</td>
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* recurrence one year, still on chemotherapy  
♥ single mother, divorced over 10 years  
ALL: Acute lymphoblastic leukaemias  
AML: Acute myeloid leukaemias  
CML: Chronic myeloid leukaemias
### Appendix I-1 Example of the Conceptualisations Identified Through Open Coding

<table>
<thead>
<tr>
<th>Code/Concept</th>
<th>N*</th>
<th>Definition directing coding</th>
<th>Example excerpts from the transcripts (including the participants and code page number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A desire to live</td>
<td>15</td>
<td>Referencing to family hope for a safe and normal future.</td>
<td>• ...chemotherapy would be helpful and give hope after the procedure. If there was a chance for survival we would do it (mother, Yeh family, p.38).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Let me have a chance to live my life the way I want to live, to attend class normally (sick adolescent, Kung family, p.26).</td>
</tr>
<tr>
<td>Adjusting roles and relationships</td>
<td>33</td>
<td>Reference to accepting the situation and change resulting from illness, having a sense of belonging and accustomed to understanding.</td>
<td>• This family all loved each other and wanted to adjust to life changes so as to come back to a normal life (father, Wu family, p.32).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• I concentrated on taking care of him and tried my best to solve problems and conflicts in my family (mother, Sue family, p.17).</td>
</tr>
<tr>
<td>Affect on family life</td>
<td>58</td>
<td>Illness has influenced everyday habits and routines, and affected how the whole family faced significant challenges and managed conflicts.</td>
<td>• It has had a great different on the family, his disease certainly affected the whole family life (younger sister, Wang family, p.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• ...this disease immediately changed my career and totally disrupted my family life (mother, Kung family, p.11)</td>
</tr>
<tr>
<td>Appreciation</td>
<td>11</td>
<td>Parents shared problems and confronted the clinical status of the sick adolescent or family matters together.</td>
<td>• I thought without my wife taking care of my son, I really would not know what to do (father, Wang family, p. 23).</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>• I appreciated my older son very much… He could take care of himself; this was a big support for me and this family (mother, Kung family, p.33 ).</td>
</tr>
<tr>
<td>Bitter-sweet burden</td>
<td>38</td>
<td>Parents strove to fulfil incompatible goals to be able to care for the sick adolescent in the ways that they wished.</td>
<td>• ... My husband said this feeling was a sweet burden because we still worried about the potential for crisis from the side effects of the treatment, but we saw hope in the family for our future life (mother, Sue family, p. 7).</td>
</tr>
<tr>
<td></td>
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<td>• I knew care for them exhausted my energy, but I received a positive quality from the relationship with my children. I thought this situation was bitter-sweet (father, Wang family, p.5).</td>
</tr>
<tr>
<td>Significance of religious beliefs</td>
<td>59</td>
<td>Family members believe and are convinced that they rely on the power of the Gods, and go to different temples or small outdoor shrines to pray.</td>
<td>• I gave my sick son to Bodhisattva’s son to be able to get over the hard time (mother, Yeh family, p. 22).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• My family and I believe in Buddhism, and accepted that everyone came into this world to be disciplined (sick adolescent, Liu family, p. 15).</td>
</tr>
</tbody>
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*N* = Number of times the code appeared within and across interviews.
### Appendix I-1 continued

<table>
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<tr>
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<th>Example excerpts from the transcripts (including the participants and code page number)</th>
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</table>
| Chinese cultural values             | 57 | Holding in and repressing expression of cultural beliefs and values to help family members through the crisis of the illness, regarded as fate or karma.                                                                                                                                                                                                                       | • My mother-in-law said my son’s illness was karma because we killed lots of creatures (mother, Sue family, p. 8)  
• ...my aunt said it’s my ancestors who had done the wrong things, to punish this generation (Mother, Wu family, p.6)                                                                                                                   |
| Communication barriers              | 28 | General reference to family members not feeling free to be explicit about showing their emotions in communicating with each other.                                                                                                                                                                                                                                                   | • Our family members seldom communicate with each other; I seldom chatted with my mother when I got back home (younger sister, Wang family, p.4).  
• I knew my parents and sick sister suffered, but nobody told me what to do and where they needed my help (brother, Hung family, p.3).                                                                                                 |
| Conflict in care-giving             | 15 | Parents express different points of view from their family members or relatives about caring for sick adolescent.                                                                                                                                                                                                                                                                     | • She believed fortune tellers’ words and burned the blessed papers in the water, both the drinking water and bath. I argued with my wife frequently (father, Hung family, p. 7).  
• I feared what the consequences could be for my daughter and thought it might conflict with hospital treatment (mother, Sue family, p.6).                                                                                                                    |
| Cooperating with supporters         | 22 | Parents prefer open cooperation with each other and family members to allow the family to continue to reside together peacefully.                                                                                                                                                                                                                                                  | • I preferred a more open and frequent communication to make my son understand his treatment... (mother, Wang family, p. 28).  
• I would cooperate with the doctor’s therapy and take whatever food and drink my mother had prepared for me (sick adolescent, Liu family, p.24).                                                                                                 |
| Changing patterns of family life    | 52 | Positive involvement in their changed lifestyle and less conflict between the family members during sick adolescent’s treatment period.                                                                                                                                                                                                                                              | • I was happy to make new arrangements in my life... It was like a new beginning... (sick adolescent, Wu family, p.21).  
• I was concerned about the conditions of the therapy of my younger brother. So I would stay home longer than before (older sister, Yeh family, P.26).                                                                                                                              |
| Disease impact on family roles and  | 58 | Family members experience the impact of the disease on family life both in the hospital and at home.                                                                                                                                                                                                                                                                             | •...I quit my job; my whole life was not as it normally was (mother, Wang family, p. 3).  
•... my older son complained lots, but I tried to be both a father and a mother; my mind felt exhausted (father, Kung family, p.2).                                                                                                                                                          |
| relationships                        |    |                                                                                                                                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                                                                                                      |
| Financial distress                  | 18 | Reference to the mothers who look after their children have no superfluous time for work in order to earn more income; the fathers strive and provide money for daily family expenditure.                                                                                                                                                                                                 | • My wife said poverty competes with love as the major influences on a family and their strength, very sad! (father, Yeh family, p.8).  
• I knew my husband’s income might not be enough to pay for healthy products and children tuition fees, finance was a big problem... (mother, Hung family, p.6).                                                                                 |
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<tr>
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| Family bond       | 29 | Family bonds are sacred and are rooted in love and concern for the children, and in maintaining harmony in family life.                                                                                                       | ● My son’s disease has brought our family closer together. My life centred on my children (mother, Kung family, p.19).  
   ● I knew my parents and sisters made sacrifices for my health problem... I cherish the fortune I have already had (sick adolescent, Wu family, p.16). |
| Hold on lives     | 19 | Observation that family members who take responsibility for the care of sick adolescents literally putting their daily life on hold.                                                                                             | ● My life is on hold, what my life would have been like, my obligations appeared to engulf my life (mother, Kung family, p.4).  
   ● I really wanted to take care of my son, but I also needed to work, our family’s finances could not let me do that… (father, Wu family, p.3). |
| Harmonious life   | 59 | This understanding of harmony is manifest in the parents’ belief that their life is totally focussed on their children.                                                                                                       | ● We shared undeniable responsibility, which could create harmony in a family (mother, Kung family, p.33).  
   ● The best way to live in harmony with my family was listening and assisting with their needs (father, Sue family, p.28). |
| Keeping faith     | 44 | Family members are trying to see the good things from the treatment and progress, so as to focus on the positive in the future.                                                                                             | ● My heart was becoming peaceful and confident of the future. So I believed my life would come back to normal (sick adolescent, Yeh family, p.21).  
   ● I did not fear because we were able to be good supporters for my daughter… My family members all fought this disease together (mother, Wu family, p.19). |
| Life co-existence | 22 | Reference to family accommodating that suffering could bring a solution, and connections between family members.                                                                                                        | ● When I got cancer, the whole family felt the sickness (sick adolescent, Kung family, p.23)  
   ● My son’s illness affected the chain of family life and increased my duty to care for him… we were willing to make any sacrifice to ensure that the family went together through the difficult time (mother, Hung family, p.21). |
| Living with distress | 39 | Family members never stop worrying or being afraid while they are caring for the adolescent.                                                                                                                                | ● Looking back on those days, I was so afraid of the prognosis and terrible side effects (mother, Yeh family, p.5).  
   ● We were afraid that the heavy load of school work on him would cause a relapse (father, Sue family, p.2). |
| Loss of control   | 29 | Families may struggle with new challenges in their understanding of their lives or inability to express their roles or relationships.                                                                                     | ● I was 18 years old, yet like a ‘baby’. You could not imagine what a difficult life my family was living (sick adolescent, Sue family, p.3).  
   ● … my mother just wanted me to stay home every weekend, my life was off track (brother, Liu family, p.2). |
### Appendix I-1 continued

<table>
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<th>Example excerpts from the transcripts (including the participants and page number)</th>
</tr>
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</table>
| Making decisions for sick adolescents     | 26 | Reference to the parents needing to make decisions to maintain the sick adolescent’s safety and progress through the course of the treatment. | • My husband prayed to God and made the final decision. We did not want to make the wrong decision for my sick child (mother, Hung family, p.16).  
  • How could I make a good decision for my child? I listened to both the school’s and doctor’s advice (father, Wang family, p.15). |
| Maintaining hope                          | 49 | General reference to family members establishing positive aspects from the illness experience and establish hope for a positive outcome. | • We had confidence in the cure of the disease and our normal life returning (mother, Wang family, p.29).  
  • I kept a positive outlook for survival across the stages of the disease because hope gave me the ability to endure the suffering (sick adolescent, Yeh family, p.30). |
| Negotiating care                          | 21 | Parents are relieved to learn that a cure is possible and negotiated with medical providers or God for the treatment and their child’s progress. | • I asked the doctor there was any good treatment for my son’s situation… if there was a chance for survival we would do it (mother, Yeh family, p.25).  
  • When my child’s condition was stable, my wife would like to prepare fruits and vegetables to thank God… I volunteered in the shrine for cleaning the altar and surroundings every weekend (father, Hung family, p.21). |
| Parental responsibilities                 | 33 | Parents become totally devoted to taking care of the sick adolescent’s everyday needs, and learning the intricacies of health care. | • My wife knew Chinese remedies as an expert. I would also like to learn more about remedies from my wife (father, Kung family, p.22).  
  • I tried to play good mother, assistant nurse and counsellor; my husband had to be the money maker, housekeeper and labourer…We tried to learn more caring skills (mother, Wu family, p.20). |
| Physical distress                         | 46 | Adolescents face a series of invasive treatments that typically cause physical distress, such as pain, vomiting, fatigue and hair loss. | • I am afraid my face will become ugly and swollen from taking steroids, like someone who is very seriously ill (sick adolescent, Wang family, p.1).  
  • When I took a shower and saw myself in the mirror, I hated myself; I was disgusting (sick adolescent, Kung family, p.1). |
| Positive thinking                         | 43 | Focusing on positive aspects of the stressful situation. | • We stayed optimistic, helping my daughter to cope with medical treatments and daily hassles (mother, Wu family, p.15).  
  • I accepted his situation to remain optimistic and to gain strength for him and us to face his disease. We believed in a good outcome for our family (father, Sue family, p.16). |
<table>
<thead>
<tr>
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<th>Example excerpts from the transcripts (including the participants and page number)</th>
</tr>
</thead>
</table>
| Promoting health             | 33 | Provide care and seek different information to promote the adolescent’s health in order to cope with the difficult time of the treatment.                                                                                                                                                  | • My wife knew Chinese remedies as an expert. I would also like to learn more about remedies from my wife (father, Kung family, p. 19).  
  • I thought Feng-Shui had influenced my son’s illness… the temple master said it was a different way to maintain my child’s condition and I believed this (mother, Yeh family, p.21). |
| Psychological distress       | 36 | Reference to the illness revealed psychological distresses of various kinds, and interpersonal difficulties.                                                                                                                                                                         | • I cried often and broke all the mirrors … (sick adolescent, Liu family, p.2).  
  • I was afraid of others touching my hair until my hair grew a little bit and did not like wigs (sick adolescent, Hung family, p.2).                                                                                                                                                                        |
| Repairing the family life    | 44 | Family members decide to apply strategies in order to return to a normal life and alleviate their sacrifices and suffering.                                                                                                                                                             | • My first and most important wishes were my sick son’s full recovery, and returning to a normal life (mother, Wang family, p.33).  
  • My wife and I cooperated very well for maintaining family integrity...also to see my family live a life of health and happiness at any time (father, Kung family, p.30).                                                                                             |
| Restoring the life change    | 48 | Focus on collaboratively confronting, accepting and repairing family life.                                                                                                                                                                                                             | • … we could face complicated situations and accept our lifestyle changes. I believed that he got well and brought my life back (older sister, Yeh family, p.36).  
  • What is more important is that we must coexist and jump over whatever difficulty in order to restore of peaceful life (mother, Wang family, p.33).                                                                                                               |
| Strain on family life        | 39 | Family members face different challenges in their daily activities and create family roles and relationships tension.                                                                                                                                                             | • I blamed myself frequently… my mother saw me I was miserable so she cried, father sighed often when he told to me, and my sister complained that my illness affected her social life (sick adolescent, Yeh family, p.3).  
  • … mother was like a crazy woman when she felt stressed, anyway, it was very annoying for me (younger brother, Liu family, p.2).                                                                                                                                                                                                 |
| Support from different sources | 41 | Sharing similar experiences to establish a positive network for understanding sick adolescents’ suffering.                                                                                                                                                                       | • My aunt’s husband treated me well. He brought Buddhist books for me to read frequently (sick adolescent, Hung family, p.21).  
  • We experienced the same situation as other mothers and helped each other in the hospital… that real life experience was very important for us to endure the difficult times (mother, Sue family, p.19).                                                                                          |
Appendix I-2  

Example of the Memos

The following examples of transcript-to-memo procedure were taken from parts of interviews with sick adolescents and their families. Brief examples of how concepts were developed through memos are shown below. Highlighted in bold are the codes and concepts that best represented the data; these codes were very descriptive initially, but became conceptual, revealing more about development of concepts and categories in the present study.

Memo 1, 26/09/2010

**Losing, stress, Family life had been broken**

I thought, why did God treat me like this... the possibility of losing my child; I could not honour the ancestors... every family member's nerves were very taut as though their closeness and connection might be broken at anytime, like the chain of life had been broken (Mother, Wang family).

The mother holds family bonds as sacred and these bonds are rooted in love and concern for the children; the mother became totally devoted to taking care of the adolescent’s everyday needs, developing perspectives on caring practices, and learning the intricacies of health care when an adolescent has been diagnosed with cancer. The chain signifies wholeness and congruity within all parts of the family. Each aspect is as important as the one that precedes, follows or overlaps it. One weak, or missing, link will halt this natural interconnection and thus, the chain will be broken. Wholeness includes not only the physical aspects, but also the spiritual, emotional, moral, financial and occupational factors, which are all needed for wellbeing. This memo exemplifies that family was under pressure and experienced a sense of helplessness when faced with lifestyle changes and the ‘weight’ of their responsibility. They experienced fatigue associated with treatment and the burden of care-giving, the chain was broken for the family relationships and lifestyle. It also poses questions to be followed up in further analysis, such as causal factors included cultural beliefs and values, disease, or care-giving burden. Indeed, as analysis and memo taking continued, it became apparent as the core category in this study.
Memo 2, 09/10/2010

Difficult living, family felt the sickness, great suffering and pain

*My family faced both difficult living and experience in their life, which was brought on because of me. When I got cancer, the whole family felt the sickness... My mother said: family relationship was a chain, family needed to connect together. However, it introduced great suffering and pain for us* (Sick adolescent, Wang family).

The sick adolescent experienced uncertainty regarding the long-term consequences of treatment. Cancer treatment and its side effects were particularly devastating to adolescents because of striking changes in appearance, isolation from peers and forced dependency. These problems created great difficulty for most sick adolescents undergoing treatment. Families had to face multiple changes brought about by the diagnosis of cancer. There was often bewilderment at the sudden changes in family life. The insights into side effects of treatment related to the chronic illness revealed greater than normal psychological distresses of various kinds, and interpersonal difficulties.

Memo 3, 04/11/2010

Communication style (barriers or culture), psychological distress

*I usually didn’t actively tell my friends and relatives about my son’s situation, because it was only my business... I seldom chatted with my children when I got back home. However, my wife talked with family or friends and reported in detail on my son's progress to me every day, I disagreed with her on this issue* (father, Sue family).

Men are expected to be strong and not express their emotions within Chinese culture. Facing a cancer crisis, *changed communication patterns* occurred in the parent-child and the marital relationships in this study. Parents felt that the occurrence of cancer made their marital relationship stronger, but they were not able to talk about the situation of having a sick child with friends and relatives because these parents needed to save face in order to maintain a harmonious atmosphere within the sphere of friends.
and family. Especially, the father was unwilling to discuss the child’s disease and related problems openly. The father did not receive needed encouragement and support and felt left out of the direct chain of medical information. He eventually received medical information about their children second-hand through their wives. Among the Taiwanese families, most of the fathers did not feel free to be explicit about showing their emotions in communicating with their children, and were unable to openly communicate about the illness to avoid psychological distress and out of their desire to protect their children.

Memo4, 18/11/2010
Chain of family life, culture, harmony, restore, accept, karma

I grew up Chinese society, and learned from Confucian ethics to place great value on the family. So for me, the sickness affected the chain of family life and increased my duty to the family care system to restore harmony... my culture therefore also made me accept that the illness was the result of accumulated karma.
(Mother, Yeh family).

Endeavouring to take responsible for the family, parents have to bear all responsibilities and strongly face a difficulty in living. Fathers are mainly the economic provider, and mothers are housekeepers who chiefly care for children in Taiwanese family. Mainstream beliefs for most Taiwanese families are grounded in Confucianism. These families are taught, and live according to, the values of Confucianism and their cultural beliefs. Within this tradition of thought and practice each family member has a responsibility to contribute to their family, which emphasises relationships and moral obligations within families. The sick adolescent and their family experienced lifestyle changes and feared for their uncertain future. However, they expected to return to ‘normal’ patterns of life assisted by their Chinese cultural beliefs and values. Moreover, some parents believe that cancer is associated with karma; that is, the bad consequences of deeds done in a previous existence. Conversely for other families, a new attitude towards life developed because of the cancer experience. Accepting fate and trying to understand the treatment in order to help their sick adolescent to relieve...
their suffering became a motivation. This memo is about intensified cultural beliefs and values to help parents through the crisis of their adolescent’s illness. In this study, cultural beliefs impacted on parents’ care-giving behaviours, such as accepting karma/fate, attending special worship in the temple and trying to do good things to restore the sick adolescent’s health.

Memo 5, 26/11/2010
Managing daily life, safety and belonging, filial piety/ harmony

This disease made our life, habits, ideas and attitudes change, but we became more sensitive to managing our daily life and being more thoughtful and considerate of others... My parents were working hard for my ill sibling because home is a place where we could feel safe and a sense of belonging... which could create harmony in a family (healthy sibling, Kung family).

The healthy siblings’ role responsibilities reflected an interdependent relationship with the sick adolescent and parents. The family members supported and helped each other, enabling them to ride out the difficulty together in order to restore harmony and a peaceful co-existence within the family. Harmony is about sustaining holistic love and well-being and partaking of a symbolically vital responsibility. This belief provided a buffer against stress during family disagreements and allowed the family to be more effective in solving their daily life problems. As highlighted in the memo, harmony underpins Chinese culture and influences both the adolescents and their family, giving them values and beliefs that led them to restore family life through adjusting their family roles and relationships. The family wanted to attain a harmonious family life and this led them into unconditionally sacrificing their own lives, based upon family ties. Chinese culture places great emphasis on a harmonious and balanced relationship with nature and in social interaction (Leung, 1996). Generally in Taiwan, family is patrilineal, patriarchal and virilocal. The father also is the family leader who has authority over all the other members. The members have a clear notion that a family ought to be “round” (圓) or to be a complete unit (Jordan, 1972, p. 92). This healthy sibling respected their parents, obeyed them, took care of them as they age, this was filial piety main idea which Confucius advocated.
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