EXPLORING QUALITY RELATIONSHIP OF FAMILY CAREGIVER OF PATIENTS WITH HEAD AND NECK CANCER

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EXPLORING QUALITY RELATIONSHIP OF FAMILY CAREGIVER OF PATIENTS WITH HEAD AND NECK CANCER

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ABSTRACT

The purpose of this study was to explore the meaning and process of quality relationships of Thai family caregivers with head and neck cancer (HNC) patients. This study's findings were obtained from the in-depth interviews and observation data of caregivers taking care of their HNC patients. Grounded theory was used to capture the evidence in this study. The participants were 15 family caregivers who were 13 spouses (twelve wives and one husband), while two were sons. The meaning of quality relationship in the perspective of Thai caregivers with HNC patients refers to the feeling of love, sympathy, caring, and connectedness. Feeling of love was defined as the feeling of caregivers to return the care-receiver's love. Sympathy was defined as the caregiver's feeling toward their care-receiver's having cancer, suffering from the disease, and feeling sad for their care-receivers. Caring was defined as the caregiver's feeling of concern and worry about their care-receivers. Connectedness was defined as the caregiver's feeling of becoming closer to the care-receivers unlike previously, since their caregiving. The quality relationships of Thai caregivers with HNC patients is a shaped of dynamic process that can be broken down into three phases: the reason to be a caregiver (Phase 1), quality relationship (Phase 2), and provision of care (Phase 3). In addition, it is important to note that the Thai cultural context influences every phase of quality relationships. Quality relationship is not static but dynamic.

The implications of these findings to nursing practice can be used to design nursing care strategies to help family caregivers continue providing good care for their patients. Nurses and other providers should integrate scientific, religious, and cultural knowledge into their clinical practice for promoting quality relationships between caregivers and care-receivers and quality of care in family caregivers and HNC patients. Health care professional teams who are responsible for cancer care should focus on quality relationships between caregivers and care-receivers so as to promote it and also to promote caregiver's continuing caregiving role although the caregiving situation is very difficult for them.

KEY WORDS: QUALITY RELATIONSHIP / CAREGIVER / HEAD AND NECK CANCER

200 pages

การศึกษาสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแลในผู้ป่วยมะเร็งศรีษะและลำคอ
EXPLORING QUALITY RELATIONSHIP OF FAMILY CAREGIVER OF PATIENTS WITH HEAD AND NECK CANCER

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คณะกรรมการที่ปรึกษาวิทยานิพนธ์: ยุพาพิน ศิรโพธิ์งาม,D.S.N., MARGARET I.WALLHAGEN, Ph.D., สุปรีดา มั่นคง, Ph.D., ธิราภรณ์ จันทร์ดา, Ph.D.

บทคัดย่อ

การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อศึกษาความหมายและกระบวนของสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแลผู้ป่วยมะเร็งศีรษะและลำคอในประเทศไทย โดยใช้ระเบียบวิธีวิจัยเชิงคุณภาพโดยใช้วิธีการวิจัยเชิงทฤษฎีพื้นฐานอาศัยข้อมูลที่ได้จากการสังเกตและการสัมภาษณ์เชิงลึกของญาติผู้ดูแลผู้ป่วยมะเร็งศรีษะและลำคอจำนวน 15 รายซึ่งประกอบด้วยคู่สมรส 13 ราย โดย 12 รายเป็นภรรยาและอีก 1 รายเป็นสามี ที่เหลืออีก2 รายเป็นลูกชาย

ผลการศึกษาพบว่าสัมพันธภาพที่มีคุณภาพตามการรับรู้ของญาติผู้ดูแลผู้ป่วยมะเร็งศรีษะและลำคอประกอบด้วย ความรู้สึกรัก สงสาร ห่วงใย และผูกพันของญาติผู้ดูแลที่มีต่อผู้ป่วย โดยญาติผู้ดูแลได้ให้ความหมายความรู้สึกรัก หมายถึง ความรู้สึกที่ญาติผู้ดูแลมีต่อผู้ป่วยเพื่อตอบแทนความรักของผู้ป่วยที่มีมาให้ตน ความรู้สึกสงสารเป็นความรู้สึกที่ญาติผู้ดูแลมีต่อผู้ป่วยจากการเจ็บป่วยและทุกข์ทรมานจากโรคมะเร็งและรู้สึกเศร้าต่อผู้ป่วย ความรู้สึกห่วงใย หมายถึง ความรู้สึกเป็นห่วงและกังวลที่มีต่อผู้ป่วย และความรู้สึกผูกพันเป็นความรู้สึกใกล้ชิดผูกพันที่ญาติผู้ดูแลรู้สึกต่อผู้ป่วย กระบวนการเกิดสัมพันธภาพที่มีคุณภาพเป็นกระบวนการที่เป็นพลวัตสามารถเปลี่ยนกลับไปมาได้ทั้งนี้สามารถแบ่งได้เป็นสามระยะ ได้แก่ ระยะแรก เหตุผลหรือแรงจูงใจในการก้าวเข้าสู่การเป็นผู้ดูแล ประกอบด้วย ความรู้สึกรัก สงสาร การมีพันธะสัญญาที่จะดูแลกันระหว่างญาติผู้ดูแลและผู้ป่วยและการรับรู้จากบทบาทความรับผิดชอบที่ตนเองมี ระยะที่สอง สัมพันธภาพที่มีคุณภาพประกอบด้วยความรู้สึกรัก สงสาร ห่วงใย และผูกพัน และระยะสุดท้ายซึ่งเป็นผลที่เกิดจากกระบวนการของการมีสัมพันธภาพที่มีคุณภาพคือ ความตั้งใจที่จะดูแล ซึ่งปัจจัยที่มีความเกี่ยวข้องในทุกระยะคือความเชื่อและอิทธิพลของสังคมและวัฒนธรรมของไทย

ผลที่ได้จากการศึกษาครั้งนี้ สามารถนำไปประยุกต์ใช้ในการวางแผนการปฏิบัติการพยาบาลโดยใช้เป็นแนวทางในการกำหนดแผนการรักษาพยาบาลเพื่อส่งเสริมและสนับสนุนให้ครอบครัวและญาติผู้ดูแลยังคงอยู่ในบทบาทของการเป็นผู้ดูแลและให้การดูแลที่มีคุณภาพสำหรับผู้ป่วยมะเร็งศรีษะและลำคอต่อไป แม้ว่าสถานการณ์ของการให้การดูแลผู้ป่วยเหล่านี้ กลุ่มญาติผู้ดูแลอาจต้องเผชิญกับสถานการณ์ที่ยากลำบาก อย่างไรก็ตาม พยาบาลและผู้ให้บริการอื่น ๆ ในทีมสุขภาพ ควรบูรณาการความรู้ทางวิทยาศาสตร์ ศาสนาและวัฒนธรรมเพื่อนำไปประยุกต์ใช้ในการปฏิบัติการทางคลินิกในการส่งเสริมความสัมพันธ์ระหว่างญาติผู้ดูแลและผู้ป่วยให้มีความสัมพันธ์ที่มีคุณภาพเพิ่มมากขึ้น เพื่อมุ่งสู่การเพิ่มคุณภาพของการดูแลผู้ป่วยมะเร็งศรีษะและลำคอ ทั้งนี้บุคคลากรในทีมสุขภาพผู้ที่รับผิดชอบในการดูแลกลุ่มผู้ป่วยมะเร็ง ควรมีความตระหนักและให้ความสนใจต่อความสัมพันธ์ที่มีคุณภาพระหว่างญาติผู้ดูแลและผู้ป่วยเพิ่มขึ้น เพื่อเป็นแนวทางในการส่งเสริมให้ญาติผู้ดู ดำรงบทบาทและให้การดูแลผู้ป่วยอย่างต่อเนื่องและมีคุณภาพต่อไป

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INTRODUCTION

Background and significance

Head and neck cancers (HNC) are a specific group of diseases involving one or more anatomic sites, including oral cavity, larynx and pharynx, nasal cavity and sinuses, ear and salivary glands (Blomberg, Nielson, Munk & Kjaer, 2011). This cancer is more common in men and is associated with heavy alcohol use and smoking (Luckett, Britton, Clover, & Rankin, 2011). Indeed, a quarter or more of oropharyngeal, esophageal, and laryngeal cancers worldwide can be attributed to alcohol, and around half of HNC patient continue to use alcohol post-diagnosis (Boffetta, Hashibe, La Vecchia, Zatonski, & Rehm, 2006). Moreover, most of HNC tumors are squamous-cell carcinomas that grow rapidly and the 5-year survival rate is only 50% (Sciubba, 2009). The nature of this cancer requires aggressive forms of treatments that are often associated with many adverse effects. Therefore, the rates of depression, anxiety disorders and low quality of life among HNC have been more frequently reported than those reported among patients diagnosed with many other types of cancer such as breast cancer, melanoma, colorectal, prostate and gynecological cancers (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Moreover, they have been reported to have greater psychological problems and functional disabilities than other cancer patients because of the location of the disease and treatment (Nympha & Joseph, & Thomas, 2014).

A contributing factor for higher rates of distress in this patient population is the symptom burden from the disease itself including difficulties with breathing, swallowing, speaking, and eating (Braz, Ribas, Dedivitis, Nishimoto, & Barros, 2005; Broberger, Tishelman, von Essen, Doukkali, & Sprangers, 2007); body image concerns and reduced social contact associated with disfigurement from treatment such as facial surgery among oral cancer patients (Callahan, 2004; Dropkin, 1999; Schliephake & Jamil, 2002); and higher rates of stigma and self-blame associated with

behaviors such as smoking and alcohol use (Sehlen et al., 2003). HNC strikes at the most basic of human functions in abilities to communicate, eat, and interact socially. Therefore, patients diagnosed with head and neck cancer might be at high risk of psychological and physical problems that affect not only the patients themselves but also their family caregivers.

Family caregivers for patients with head and neck cancer are a very important group because they deal with both the psychological and physical problems of the care-receivers/patients. In addition, caring with head and neck cancer patients may provide unique difficulties because of the centrality of this area and the specific roles in social and emotional expression and communication; changes in their anatomy or functioning can have devastating consequences (Jones, Lund, Howard, Greenberg, & McCarthy, 1992). In particular, caring for a family member with head and neck cancer who is undergoing cancer treatment such as chemotherapy, radiotherapy or surgery, may cause physical and psychological distress. Greater involvement in caregiving tasks, such as assisting their patient with daily activities and symptom management, giving emotional support, helping manage the household finances (Given, Given & Kozachik, 2001) and providing care for 24 hours every day. Therefore, caregivers were more likely to experience poorer psychological health such as higher levels of emotional distress and more symptoms of anxiety as compared to both population norms and the scores of persons with HNC (Verdonck-de Leeuw et al., 2007). Furthermore, caregivers who perceived greater disruptions to their lifestyles and schedules had high levels of emotional distress. For example, distress experienced by spouses was related to the presence of a feeding tube in patients (Verdonck-de Leeuw et al., 2007). In Thailand, HNC was the most common cancer in men. Oral cancer ranked fourth as the most common cancer in male and seventh in females (Kerdpon & Sriplung, 2001). However, only a few studies focused on the group of family caregivers with HNC patients (Kitrungrote, Chanprasit, Sutharangse, & Cohen, 2008; Prechavittayakul, 2006; Wongchuay, Kitrungrote & Petpichetchain, 2010).

In general, the family member's motives to care for their relative with a chronic illness were derived from an interaction among obligatory and discretionary reasons, the quality of the relationship such as love or affection, and the prior relationship between caregiver and care-receiver (Walker, Pratt, Shin, & Jones, 1990).

Such relationship may be at good quality or less positive during the caregiving process. Good quality relationship are important motivation leading the caregiving willing to take care of patient effectively and continuously even in difficult caregiving situation. Many researchers found that the experience of cancer caregiving is known to affect the relationship between the caregiver and care-receiver (Lee & Bell, 2011; Ussher, Wong, & Perz, 2010). Cancer patient was reported to influence positively on some couple relationships (Badr & Taylor, 2006), bring people with cancer and their partners closer together (Dorval et al., 2005), through the experience of greater intimacy (Manne, Ostroff, Rini, Fox, Goldstein, & Grana, 2004). Moreover, caregivers generally did not perceive the care they provide as burden when such care was regarded as a relational commitment to show their love and support for the patient (Mok, Chan, Chan, & Yeung, 2003). Caregiving experience is likely to vary by caregivers' relationship to care-receivers because different kinship obligations. In general, the closeness of the familial relationship is directly linked to the amount, type, and duration of care provide. As a rule, relatives who are more closely related to the care-receiver provide greater amounts of care (Montgomery, Rowe, & Kosloski, 2007). Furthermore, caregiving has a significant impact on the caregiver and care-receiver relationship as well as on the individual actor and can bring change to relationship between caregiver and care-receiver. The important of the dyadic relationship cannot overstate since caregiving occurs within the context of ongoing relationships between caregiver and care-receiver.

Quality relationship is one concept that has gained the attention of researchers from a variety of disciplines, including psychology, sociology, family studies, and communication (Fincham & Rogge, 2010). In nursing research, quality relationship had received attention in various groups such as the relationship between nurse and patient as partnership relationship (Gallant, Beaulieu & Carnevale, 2002), and family and their patients. It has two distinct yet related dimensions as positive and negative evaluation of quality relationship. However, the enemy of scientific progress, conceptual confusion, and the literature are littered with a large number of terms, such as satisfaction, adjustment, success, happiness, companionship, or some synonym reflective of the quality relationship such as mutuality, intimacy, and reciprocity.

These terms tend to be used interchangeably and the conceptions and operationalization of quality relationship are inadequate.

In family caregiving research, quality relationship is one of relationship concept that most of caregiving research had received attention (Archbold et al., 1990; Shim, Landerman, & Davis, 2011; Schumacher, Stewart, Archbold, Caparro, Mutale, & Agrawal, 2008). It is very important because if caregiver and care-receiver have good quality relationship it can contribute to positive outcome both caregiver and care-receiver. Furthermore, caregiving literature has shown that good quality relationship allows caregivers to continue caregiving despite objectively difficult situations (Hirschfeld, 1983), while a less positive (or lower perceived) quality relationship has been linked to a caregiver's sense of role captivity and burden (Archbold, Stewart, Greenlick, & Harvath, 1990; Lawrence, Tennstedt, & Assman, 1998; Williamson & Schulz, 1990), anxiety, frustration, and time cost (Walker, Martin, & Jones, 1992), tension (Fingerman, 1996) and lower levels of care-receiver's well-being and family satisfaction (Carruth, Tate, Moffett, & Hill, 1997).

Quality relationship between a caregiver and care-receiver may be a key concept in caregiving for patients with head and neck cancer because the caregiver must deal with the many problems experienced by the care-receiver during the treatment for cancer. These include the effects of the treatment itself and the care-receiver's need for both physical and psychological support. Whether quality relationship between the caregiver and care-receiver is high or low can influence whether the outcome of the interaction is positive or negative for either of them.

To date, most of research exploring quality relationship within a caregiving context has focused on family caring for older members or frail elderly (Archbold et al., 1990; Archbold et al., 1995; Lyons, Stewart, Archbold, & Carter, 2009; Yamamoto-Mitani et al., 2003), and chronic disease such as Alzheimer's disease (Lawrence et al., 1998; Shim, Landerman, & Davis, 2011), Parkinson's disease (Carter et al., 1998), very few studies have been done on caregivers with cancer patients (Scherbring, 2002; Schumacher, Stewart, & Archbold, 2007; Schumacher, Stewart, Archbold, Caparro, Mutale, & Agrawal, 2008). In addition, the majority of studies have investigated changes in quality relationship following the onset of the disease (Ablitt, Jones, & Muers, 2009), the impact of cancer on quality relationship

between caregiver and care-receiver (Lee & Bell, 2011). Most of these studies reported a decline in quality relationship.

The quality relationship were defined in terms of intimacy (Morris, Morris, & Britton, 1988), mutuality (Archbold et al., 1990; Jeon, 2004; Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007), reciprocity (Eloniemi-Sulkava et al., 2002), and love (Sprecher & Fehr, 2005). However, conceptual clarity is often lacking. Some of the concepts have been used interchangeably or have become one of the dimensions of another concept. At the same time, the differences or the rationale for the different terms used have not been clearly explained, such as mutuality and reciprocity. Mutuality has been conceptualized as being composed of 4 domains: love and affection, shared pleasurable activities, shared values, and reciprocity (Archbold et al., 1990). Yet reciprocity is further conceptualized as being composed of warmth and regard, intrinsic reward of giving, love and affection and balance within family caregiver. Mutuality refers to the degree to which the two parties agree on their interpretations of the promise and commitment each party has made and accepted whereas reciprocity refers to the degree of agreement about the reciprocal exchange (Dabos & Rousseau, 2004). Reciprocity is more focused on the activities of interactional exchange behaviors, while mutuality includes the feeling, relationships and mutual exchange perspectives. Moreover, intimacy is more focus on the communication and disclosure between partner relationships and usually explains in marriage relationship.

Because studies have varied in how they have defined quality relationship and have been developed based on different theoretical frameworks and different meanings, it is necessary to explore the various conceptualizations in order to form a definition for use in the current study. The following discusses the various ways in which quality relationship has been defined and presents a definition based on the most common and consistent themes identified in the literature. These include 4 concepts as follows: intimacy, mutuality, reciprocity, and love.

The first concept, intimacy is an essential concept of many interpersonal relationships. Its definitions were built on various psychological and sociological perspectives. General definitions were usually based on their author’s, personal interpretation of the meaning of intimacy (Bilow & Mendelsohn, 1982) or were part of

a larger theoretical model (Erikson, 1963). Intimacy was defined by Webster (1996) as “the state of being intimate, as in a close personal relationship, close association, a relationship marked by depth or breath of knowledge, on interweaving, or being familiar” (Webster,1996). Some theorists defined intimacy as a quality of interactions between persons: individuals emit reciprocal behaviors that are designed to maintain a comfortable level of closeness (Laurenceau, Barrett, & Pietromonaco, 1998).

Intimacy develops from the ongoing disclosure and response to disclosures between partners. Self-disclosure is a central communication strategy that is used to develop and maintain intimacy in the intimacy process model proposed by Greeff and Malherbe (2001). They gave the definition emphasizing one or more of the following three characteristics: behavior interdependency, fulfillment of needs, and emotional attachment (Greeff & Malherbe, 2001). Furthermore, Timmerman (1991) presented a concept analysis of intimacy based on a framework advocated by Chin and Jacobs (1987) drawing upon literature and research from psychology and psychiatric medicine. She found that self-disclosure was a basic dimension of intimacy but was also accompanied by the elements of trust, reciprocity, and emotional closeness. She defined intimacy, as delineated in the scholarly literature, as composed of 4 dimensions: trust, closeness, self-disclosure, and reciprocity (Timmerman, 1991). Trust is a feeling of safety in sharing one’s thoughts and feelings with another where an element of confidence exists concerning what the other individuals might do (Meize-Grochowski, 1984). Closeness or a close relationship has been defined as enduring, with strong, frequent, and diverse causal interconnections, with the individual within that relationship committed to the relationship. Self-disclosure is defined as the confiding of deeply personal information to another as basic dimension of intimacy. The last dimension, reciprocity, is defined as a mutual, sharing exchange. As a condition for intimacy, reciprocity has been described as sharing equally in being with each other. Both of individuals have responsibility for participating in the relationship. The condition of intimacy as a process about two of person feels trust each other and they perceive feeling of emotional closeness between them. Both of them must be able to openly communicate (self-disclose) thoughts and feelings. Moreover, they must have reciprocity within their relationship.

Some researchers defined intimacy as a close relationship but emphasized that this relationship is not a dichotomous concept or a static state; rather the level of intimacy can change over time in specific relationship (Timmerman, 1991). Despite with different opinions on the definition of intimacy, many theorists agree on the features that constitute an intimate interaction (Berscheid, 1985; Hatfied & Rapson, 1993; Levine, 1991). The components of intimacy identified by most theorists involve 4 aspects, i.e. love and affection, personal validation in term of acceptance or individual's feeling free to open up, trust and self-disclosure**.** In sum, intimacy has been operationalized in many ways, using varied definition. This concept adopts an individual-level conceptualization of the role of the marital relationship.

For the second concept of mutuality, it had been studied as a way of being in respectful relation to another (Buber, 1936 as cited in Henson, 1997) and examined as a necessary element of healthy relationship (Erikson, 1968). A general definitions, was defined by Webster (1996, p768) as "an experience, performed by each with respect to the other-reciprocal; having the same relation toward the other; having in common-shared; an organization in which there is no stockholders-profits, losses, and expenses are shared. Several synonyms for mutual include give and take, belonging equally to, collaboration, and common consent".

In the field of caregiving, it was defined as the positive quality of the relationship between the caregiver and care-receiver (Archbold et al., 1990). This concept had been used widely in caregivers with older population (Archbold et al., 1995; Lyons, Stewart, Archbold, & Carter, 2009), Parkinson's disease receiver (Tanji et al., 2008), dementia (Steadman, Tremont, & Davis, 2007) and cancer (Schumacher et al., 2007; Schumacher et al., 2008). A number of researchers refer to mutuality as quality relationship (Lyons et al., 2009; Sanftner, Tantillo, & Seidlitz, 2004; Schumacher et al., 2007; Schumacher et al., 2008). Mutuality has also been explained as patterns of feelings, thoughts, and activities in relationships that are characterized by empathy, engagement, authenticity and empowerment (Genero, Miller, Surrey, & Baldwin, 1992). Riggs (1978) described mutuality as the conscious acceptance by both parties in a relationship of the goals, modes and codes of the interchange. Describing marital relationship, Stephen and Markham (1983) stated that mutuality is the extent to which couples have developed a conjoint or relational worldview. This coincides with

Tronick's (1977) perspective that mutuality is the achievement of the intersubjectivity. Buber (1937) discussed mutuality as a co-constituted reality where each person is made present by the other (Hagerty, Lynch-Sauer, Patusky, & Bouwsema, 1993). The sharing of characteristics, sentiments or goals is Wynne's (1984) conception of mutuality. On the other hand, Archbold and colleagues (1990) proposed that mutuality is composed of four dimensions: love and affection, shared pleasurable activities, shared values, and reciprocity (Archbold et al., 1990).

Mutuality is a central construct of the self-in-relation theory, defined as the reciprocity interacts in indirection sharing of thoughts and feelings in close relationships, permitting partners to truly know and be known by each other. Moreover, mutuality is reflected in communication characterized by engagement, interest, empathy, validation, and authenticity (Kasle, Wilhelm, & Zautra, 2008). Even though, mutuality has been operationalized in various definition, many theorists agree on the components of mutuality identify involve 4 aspects, i.e. love and affection, shared pleasurable activities, shared values, and reciprocity (Archbold et al., 1990; Lyons et al., 2009; Sanftner, Tantillo, & Seidlitz, 2004; Schumacher et al., 2007; Schumacher et al., 2008).

The third concept is reciprocity. Studies carried out by psychologists and economists, and literature in sociology, ethnology and anthropology emphasize the omnipresence of reciprocal behavior. Reciprocity was defined by Webster's (1996, p 976) as "equivalent or corresponding exchange given in return". It refers to the degree of agreement about the reciprocal exchange, given that commitments or contributions made by one party obligate the other to provide an appropriate return (Dabos & Rousseau, 2004) whereas Gouldner (1960) clarified reciprocity as a pattern of mutually contingent exchange of gratifications.

Reciprocity refers to the normative obligation of the recipients of help to assist people who provided that help to them. However, several researchers defined reciprocity as a process that occurs over the entire life course, where current support might reciprocate for past support or for anticipated future support (Antonucci, Fuhrer, & Jackson, 1990). For Antonucci and colleagues, the degree of reciprocity is a central criterion on which individuals evaluate the state of their relationship and is a critical factor that determines the amount and type of exchange among kin- relationship in the

general population (Antonucci, et al., 1990) whereas Buunk and colleague (1993) viewed reciprocal exchange is oriented toward meeting the needs of the group with whom one is affiliated rather than repaying a resource to a specific individual (Buunk et al., 1993). In summary, reciprocity had been defined in various perspectives and had been examined from the perspective of caregiving with older patient (Kuijer, Buunk, & Ybema, 2001; Neufeld & Harrison, 1998). Despite with different opinions on the definition of reciprocity, many theorists agree on the components of reciprocity involve the process of giving and receiving.

The last concept usually discussed as a domain of quality relationship, in addition to intimacy, mutuality, and reciprocity, is love. The meaning of love varies from source to source. The dictionary definition describes love as a feeling of affection or attachment (Webster, 1996). A type of love can be experienced for a variety of others, including all of humankind. Sprecher and Fehr (2005) defined love as an attitude toward others, either close others or strangers or all of humanity, containing feelings, cognitions and behaviors that are found on caring, concern, tenderness, and an orientation toward supporting, helping, and understanding the other, particularly when the other is perceived to be suffering or in need (Sprecher & Fehr, 2005). Sternberg (1986) has offered a triangular theory of love which characterizes love styles in terms of intimacy, passion, and decision or commitment (Sternberg, 1986). The intimacy component refers to feelings of closeness, connectedness, and bondedness on experience in loving relationships. The passion component refers to the drives that lead to romance, physical attraction, sexual consummation; and the decision/commitment refers to, in short term, the decision that one loves someone else and in the long term, the commitment to maintain that love (Sternberg, 1986). Moreover, love, in particular, is more than a feeling. It is a complex tendency to think and act in certain ways toward another person (Shaver & Hazan, 1988).

The amount of love one experiences depends on the absolute strength of these three components, and the kind of love one experiences depends on their strengths relative to each other. The three components interact with each other and with the actions that they produce and that produce them so as to form a number of different kinds of loving experiences.

Shacham –Dupont (2003) found that scholars variously defined love as an attitude, specific behaviors, cognitive predispositions, an expression of the neural-based bounding system, a dyadic phenomenon, and as a complex functional whole including appraisals, appreciations, patterned physiological responses, action tendencies, and instrumental behaviors. Features or element of compassionate love included: altruism (compassionate love is a type of sharing that is selfless), helpfulness (helping or willingness to help, someone in distress), care and concern (observable, meaningful behaviors that demonstrate concern and care for the welfare of the others), empathy, sympathy, tenderness, and so on (Fehr & Sprecher, 2009).

From the literature review, the majority concepts and definition of quality relationship was developed and have been studied in the western culture, studies to examine concepts or meanings from different culture perspectives are still crucial. In Thailand, there are few studies that focused on the concept of quality relationship among Thai family caregivers and care-receivers. These studies were mostly quantitative and did not explore the quality relationship in perspective of Thai meaning. Rather, they dealt with the primary caregiver of elders, chronically ill adults with either physical or mental health problem, or children with chronic diseases. Several researchers defined positive quality relationship as love, understanding, sympathy, willingness to help, and acceptance (Enz & Rongsopasakul, 1998). Even though the Thai instrument for measuring mutuality in family caregiving had been translated to Thai language in some research (Wirojratana, 2002), it was found that mutuality (quality relationship was not correlated with predictability). This finding showed that mutuality is not a central concept as in the U.S. It may be explained by the difference in Thai and U.S cultural values (Wirojratana, 2002). Some researcher explored the concept that may be appropriate in Thai culture such as the concept "*Katanyu katavedi*" (Kespichayawattana, 1999). This concept focuses on relationship between parents and children caregiving who take care for their elderly parents. It may be not appropriate in HNC patient that have different context of caregiving.

In qualitative studies, most of research had reported that relationship is an important role of caring in family caregiving such as in one ethnographic study on family with breast cancer which has found that good relationship, with affection and closeness in the families, played a significant role in a family's emotion, physical, and

spiritual support, which in turn help patients to adjust well to breast cancer (Junda, 2002). One grounded study found that most of the caregivers continued to care for the child with HIV because of a sense of responsibility and duty as well as feeling of love, attachment, and sympathy (Thampanichawat, 2008). Only 3 studies have investigated caregivers of patients with head and neck cancer and focused on the experience of caring for patients undergoing radiotherapy (Kitrungrote, Chanprasit, Sutharangse, & Cohen, 2008; Prechavittayakul, 2006), preparedness for caregiving and caregiver role strain (Wongchuay, Kitrungrote & Petpichetchain, 2010). The study by Kitrungrote and colleague (2008) found that after the caregivers' spouses were diagnosed with HNC, they wanted to take care of the spouses and give them love, closeness, and warmth. Caregivers assumed the caregiving role not only because of a sense of moral obligation created by Thai social expectations but also because of a feeling of gratitude for past expressions of kindness. Other studies on caregiving experience suggested that powers of love, intimacy, trust, and a feeling of gratitude motivate spouses to become primary caregiver (Limpanichkul & Magilvy, 2004). However, none of them had explored the meaning and component of quality relationship.

Thailand possesses some unique cultural features that make the study of caregiving especially intriguing. Thailand holds strong to Buddhist-based ideological system, strong family ties, kinship that influenced the caregivers' viewpoints. Buddhist caregivers believed that the past deeds of the patients and themselves from previous lives caused the patients to become ill and caused them to become their caregivers. They accepted the *Law of Karma* and would continue providing care to their patients until the previous action was repaid or until both of them passed away (Caffrey, 1992; Kespichayawattana, 1999). Caregiver also identified a sense of responsibility and duty as well as feeling of love, attachment, and sympathy as reasons for becoming caregivers (Subgranon & Lund, 2000)

Caregiver's research on quality relationship between caregivers and care-receivers is needed for the following reasons. First, as previously mentioned Thailand is still lacked of research to explore the perception of quality relationship among Thai caregivers, lacked of the measurement for measuring the quality relationship that appropriate in Thai culture, and lacked of interventions that focus on quality relationship. Second, although there are numerous studies on family caregivers with

HNC patients in Thailand, none of them had explored quality relationship between caregivers and care-receiver from the perspective of caregivers. So, there is little information available on quality relationship of family caregiver with HNC patients. Moreover, based on the Thai culture, studies to examine concept of quality relationship between caregiver and care-receiver are still crucial. In Thai sense "quality relationship" is a very sensitive issue since most of Thai people usually avoid to express and evaluate their relationship between family members. This word had been hence rarely used in Thai cultural context. Before the similarities and differences between the concept of quality relationship in family caregiving in Western and Thailand can be identified, the concept needs to be explored.

Therefore, the purpose of this study was to explore and describe quality relationship of family caregivers who provide care for HNC patients undergoing treatment. This study had been the first of its kind carried out in family caregivers caring for patients with head and neck cancer in Thailand. Quality relationship is a key component that affects family's willing to take good care of relative patients. Despite the changed caregiving context and the need of caregiver to take care of the patient in very difficult situation with the sense of burden or stress. Better understanding about quality relationship between caregiver and care-receiver from the perspective of the caregiver would provide nurses with a better understanding of the role of quality relationship in caregiving and will aid the development of the appropriate measurement of quality relationship and more effective interventions to address these issues so as to enhance the well-being of caregivers and care-receivers alike.

The purpose of this study and research questions

The overall objective of this research was to explore and describe quality relationship of family caregivers based on the perspective of Thai caregivers with HNC patients. The research questions were as follows:

1. What is the meaning of quality relationship in family caregivers with HNC patients?

2. What are the process of quality relationship from the perspective of family caregiver with HNC patients?

CHAPTER II
LITERATURE REVIEW

To provide a broad context for an understanding of the quality relationship of family caregiver with HNC patient and how they perceive and interpret their experience with HNC, this chapter proceeds with a review of selected literature that is relevant to the current study. To gain a beginning understanding of how families perform, and are affected by their caregiver roles, it is necessary to review 1) the nature of caregiving in cancer caregiving context; 2) caregiving demands related to HNC patients; 3) Thai culture context that affect to caregiving situation; 4) quality relationship and related terms with quality relationship.

1) Nature of caregiving

Caregiving is a complex process and there are many factors which many influence how the caregiver adapts to their caregiving role. The caregiving role is created through interaction between the caregiver and care-receiver and between the dyad and others (Schumacher, Dodd, & Paul, 1993). The assumption of a caregiving role presents challenges to existing family system, influenced by such factors as context of caregiving and motive of helping. Archbold and colleague (1986) defined the nature of caregiving role by looking at amount and type of direct care and managed caregiving tasks which are: personal care; housekeeping; protection; transportation; handling behavior problems; financial; legal; and health decisions; medically related; little extras; and managed care (Archbold et al.,1986 as cited in Kespichyawattana, 1999). Whereas, Fletcher and colleagues (2012) reported the highlight context of cancer family caregiving as personal and social characteristics, including features of personality, social support, and quality relationship has expanded to such a great extent in the decade from 2000 to 2010. Fletcher and colleagues (2012) found that some of the personal characteristic context are relatively fixed such as gender, age, race, ethnicity, and kinship relationship whereas some social

characteristic context tend to be stable although they may change such as personality, living arrangement and socioeconomic status.

Furthermore some contexts are dynamic and may vary with changing circumstance such as health, work, finances, social support, family function and quality relationship. Among the caregiving contexts that influence the experience of caregiving, the most significant are gender (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Ussher & Sandoval, 2008), age (Carter, Lyons, Stewart, Archbold, & Scobee, 2010), living situation, socioeconomic status, and type and quality relationship between the caregiver and care-receiver (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). The most important contextual features have to do with caregiving arrangement, that is whether the caregiver is primary or secondary, and the kin relationship between caregiver and care-receiver (Goodhead & Mcdonald, 2007). Thus, kin relationship, whether the caregiver is a spouse, daughter or other relationship, probably makes more different than any other factors in determining the degree of commitment to provide care. For example, when there is a competent spouse, that person almost always is the primary caregiver and needs to be involved in assessment and treatment. With children, including daughters-in-law, the degree of commitment is more varied. The caregiver's various roles and responsibilities can either take away from or enhance ability to provide care.

Further the context of personal and social characteristics are influence to cancer caregiving experience. The context of cultural is one of the contexts that emerge and influence to cancer caregiving experience (Fletcher, Miaskowski, Given, & Schumacher, 2012). In Thailand, the cultural influence in Thai families as religious beliefs, rural and urban considerations, family relationship, societal values, sexuality, and masculine and feminine roles, (Pinyuchon & Gray, 1997) are important influence Thai caregiver to taking their caregiving role and continuing their caregiving role. The family structures in Thailand are both extended and nuclear families (Punyahotra & Dennerstien, 1996). Extended families are usually comprised of maternal grandparents, married daughters, unmarried daughters or unmarried son and can be found in rural area. Nuclear families usually comprised of family member not more than two generations, especially in the urban area.

The dominant religion in Thais is Buddhism. Societal values in Thai families are a variety of way such as children are taught to respect older people and people of higher status, parents, elders, priests and teachers (Moore, 1974). Further sexuality is a taboo topic in Thais. They usually view sexuality as something that has to avoid discussing. As Masculine and feminine role traditionally in Thailand, female family members carry the responsibility as care providers for family members who become ill. As such, most of the mothers, sisters, and wives provide care for patient with HIV (Ruangiratain, 2003; Thampanichawat, 1999; 2008); patient's mother or wife care for traumatic brain injured patients (Samartkit, 2008); youngest daughter and unmarried adult children care for elderly parents (Kespichayawattana, 1999; Caffrey, 1992); and spouse are most often HNC patients' primary caregiver (Kitrungrote et al., 2008; Wongchuay et al., 2010).

In sum, the important six culture context that influence on Thai family cancer caregiving experience composed of Buddhism belief, rural and urban considerations, family relationship, societal values, sexuality, and masculine and feminine roles. Cancer caregiving role requires the individual to response flexible to a wide range of need as they arise. Motivation is pivotal issue in caregiving (Strawbridge & Wallhagen, 1992) because caregiver must be motivated to accept responsibility and expand time and effort required to provide effective support (Feeney & Collins, 2003). If caregivers are not sufficiently motivated, then it is likely that they will provide either low level of support or ineffective caregiving. Thus caregiving motivations are likely to play important role in determining the quality of caregiving that is given in a relationship.

Motivation can explain the reasons why a person engages in a particular behavior, such as helping someone (Quinn, Clare, & Wood, 2010). According to the literature, people may be motivated to provide care for many reasons, such as motivated to help others based on the connection between obligation and discretionary motivation and quality relationship (Walker et al., 1990), feeling of duty and responsibility (Quinn et al., 2010). In exploring obligatory and discretionary motives for caregiving, Walker and colleague (1989, p. 206) found that "relationship obligation" or the sense of duty to provide care was the most frequently mentioned reason for caregiving by the 72 daughters in their study, followed by "moral beliefs"

or “the right thing to do”. However, some theorist identified specific motives for helping yielded two types of explanations. One assumes that helping serves an egoistic or self-serving motive, while the other centers on empathy and altruism (Batson & Coke, 1983 as cited in Schulz, Biegel, Morycz, & Visintainer, 1989). Doty (1986) proposed that family caregiving may be primarily motivated by three factors: love and affection felt towards the individual, a sense of gratitude and desire to reciprocate past caregiving or help, and social norms of spousal or filial responsibility.

Different types of motivations may occur at different times during the caregiving process. Schulz and colleague (1989) proposed that in the early stages caregivers may be motivated by altruistic motives as they feel empathy towards care - receiver with Alzheimer’s disease, whilst in the later stages, when care-receiver’s cognitive functions have declined, caregivers may be more egotistically motivated. Some researchers reported that the caregivers’ culture and kin-relationship could influence motivations to provide care. Kabitsi and Powers (2002) found that Greek caregivers rated motivations to care as more important than American caregivers whereas Lee and Sung (1997) compared American caregivers with Korean caregivers and found that Korean caregivers had significantly higher filial obligation scores and significantly lower filial affection scores than American caregivers. These studies provide evidences that a person’s motivations to provide care can be influenced by their culture and the person’s kin relationship to the care-receiver.

Wallhagen and Yamamoto- Mitani (2006) explored how culture influenced American and Japanese caregivers’ reasons for caregiving. They found that both American and Japanese caregivers felt they had a moral obligation to provide care, which was derived partly from feelings of reciprocity. Americans caregivers were more strongly motivated by feelings of attachment to the care-receiver, and attachment had an important role in the maintenance of caregiving. Japanese caregivers emphasized that it was their role in the family that required them to take on the caregiving task.

2) Caregiving demands related to HNC patients

HNC patients are a particularly important group of cancer disease because this disease usually involving special organ such as oral, nasal and ear that effect their

important activity. Moreover, it requires aggressive forms of treatment that are with many adverse effects. In particular, HNC patients who are treatment such as chemotherapy, radiotherapy or surgery, consequentially may cause limit their social interaction and psychological distress. Especially if they involve loss of physical functioning such as difficulties with breathing, swallowing, eating (Braz, Ribas, Dedivitis, Nishimoto, & Barros, 2005; Broberger, Tishelman, von Essen, Doukkali, & Sprangers, 2007); loss of speech and facial disfiguration. The first line of care for people with HNC disease is usually a relative or spouse, which places new demands on the new caregiver.

Caregiving demands are the activities caregivers undertake in response to the illness (Schumacher et al., 2008). Weitzner and colleagues (2000) identified a number of caregiving demands in cancer patients including the following: assisting the patient with activities of daily living, managing disease symptoms and treatment of side effects, handling patient behaviors and emotions, coordinating or administering treatment in the home, and driving the patient to treatment. These continue to be core demands of the family caregiving role (Given et al., 2001; Given, & Sherwood, 2006).

In addition, specific demands of caregiving were reported in HNC patients such as difficulty with speech, breathing, and ability to eat and drink. Moreover, treatments for this cancer often affect feeding difficulties, dysphagia, respiratory symptoms, xerostomia, oral mucositis, weight loss, pain and communication difficulties. These conditions often occur in HNC patients and need a special care from their caregivers.

Examples of major assistances needed by most HNC patients from their caregiver are indicated below.

(a) Assistance with activities of daily living. They include basic tasks such as bathing, dressing, eating, and using the toilet, as well as more complex tasks such as housekeeping, money management, and transportation.

(b) Special care activities and emotional support. They involve such as wound care, feeding tube, suction and tracheotomy tube care and emotional support.

Caring with HNC patients is a very difficult task for family members because they have to undertake new and demanding responsibilities associated with the caregiving role. Caregiving responsibilities also cause a disruption in caregivers'

routines (Cameron, Franche, Cheung, & Stewart, 2002), and their ability to participate in valued activities is restricted such as caring for a family member who is having difficulty eating and drinking or is dependent on tube feeds. In addition, the caregiving demands of HNC patients that result from their illness and its treatment also constitute more difficult tasks for caregivers. Caregivers may provide extraordinary uncompensated care that is physically, emotionally, socially, and financially demanding, hence resulting in the neglect of their own needs. All of the caregiving process depends on the nature of particular person who is willing to take caregiver role.

3) Thai culture context

Thai culture is very important to both individuals and groups because it affects their patterns of living. Thailand is a country in Southeast Asia Region with a traditional view of the hierarchy of social and family obligations (Choowatttanapakorn, 1999). Most of Thai people believe in and practice the "gratitude system" (among many strong doctrines), which obligates them to show gratitude to their parents (Jullamate, 2008) or other people who has helped him or her. The reason of this Thai hierarchy can be described into the religious context and indebtedness of relationships in Thai Society and family. It can be provided as a major key to understanding Thai behavior. Therefore, the religious context of Thai people and indebted of relationship in Thai Society can be explained as below.

3.1) Religious context

Thai culture has been nourished and shaped by a variety of concepts. One of the main concepts is religion. Buddhism as the national religion of Thailand (Choowatttanapakorn, 1999) may be a contributing factor on the hierarchal system, importing and shaping to the Thai way of life. Therefore, Buddhism in particular plays a very important role in the everyday life of the people of Thailand. The core teachings of Buddhism deal with the concept of cause-effect nature of life. The teaching of Buddhist centers primarily on human existence consisting of life, suffering, death and the way out of it (Ratanakul, 2004). Based on Buddhist teaching, there are Four Noble Truths *(ariyassacca*) which refer to the truth of suffering *(dukkha),* the causes of suffering *(samudhaya*) the method of end suffering *(nirodh*),

and the Noble Eightfold Path that leads to the cessation of suffering (*magga)* (Ratanakul, 2004).

In addition, most of the Buddhists believe in *law of karma* that includes physical, verbal, and mental actions. It is believed to result from accumulated past *karma* in the form of *boon* (merit) and *barp* (demerit). *Karma* is the notion of action in which the good actions are called *boon* (merit) and bad actions are called *barp* (demerit). Therefore, the Thai Buddhism holds that as a consequence of one's action the power of *karma* is endlessly present to manifest itself in the life of the individuals (Siayasak, 2006). Moreover, the essential doctrine of Buddhism is merit-making that is the central part of the religious experience of the Thai Buddhism. The acts of merit making can be described in various ways such as an action in support of the monks and the temple, giving food to the monks daily, ordination into the monkhood, and provision of support for one's parents, elders, and charitable causes. The important acts of making merit that can be motivated the most of family caregiver taking the caregiving role is the provision of support for one's parents, elders and charitable causes. Examples of gaining merit are done by giving goods, comfort, or money to one's parents, elders, the blind, the poverty-stricken, or the orphaned.

Therefore, Buddhism has a significant influence not only the everyday life of the Thai family but also on caregiver in caregiving situation. According to Buddhism perspective and core concept of teaching about cause-effect, Buddhism motivates Buddhists for doing good deeds by merit-making, the feeling of common good and doing way of the good, loving-kindness and *Nibbanic* motivation. The Buddhist motivation for doing good deeds such as the concept of merit based on the *law of karma*, connected with better rebirth and worldly enjoyment hereafter as consequences (Payutto, 2008). Therefore belief in Buddha's teaching has a great influence on the daily living of Thai caregiver. Many studies related to Buddhist belief such as by Wongsawang and colleague (2013) conducted a grounded dimension analysis to understand how Thai families care for dependent older adult. The finding showed that common to all participants who were family caregivers for their older adults began from a strong sense of obligation and their belief in Buddhist philosophy (Wongsawang, Lagampan, Lapvongwattana, & Bowers, 2013). This study confirmed the prior research that Thai people continue to act in accordance with Buddhist's belief

for repayment and obligation to their older family members (Limpanichkul & Magilvy, 2004; Sethabouppha & Kance, 2005; Subgranon & Lund, 2000). As reported in another study, religious belief also encourages some caregivers to maintain caring for their elderly stroke relatives even they felt that caregiving is an unavoidable task but they cannot abandon or leave their care-receiver (Subgranon & Lund, 2000).

Furthermore, some researchers found that cultural, societal-economic, and religious contextual factors played important role and influenced motivation of caregiving. Thai culture and norms set expectation that the family will take full responsibility for the care of elderly members (Kespichayawattana, 1999). Caffrey (1992) reported that the primary motivations for caregiving to the elderly in Northeastern Thailand were identified as: fulfilling the expected cultural norm of filial obligations; love or affection for elder; a desire to reciprocate for past services and to build up future merit for themselves whereas maintaining love and hope emerged as a core theme describing the primary caregivers' obligations and motivations to continue providing care for Thai children with HIV infection (Thampanichawat, 2008). Moreover, Thai Buddhist caregivers strongly believed that the reason why they had to take care for their seriously mentally ill family members was the result of the law of karma in the past life and this life (Sethabouppha & Kance, 2005).

3.2) Indebtedness of relationship in Thai Society

One of the possible reasons of the hierarchical nature of Thai society is the concept of "*bunkhun*" in Thai language. It can be described as any good thing, help or favor done by someone which entails gratitude and obligation on the part of the beneficiary or patron-client relationship (Taylor, 1997). Komin (1990) described the meaning of *bunkhun* as a psychological bond between someone who, out of sheer kindness and sincerity renders another person the needed help and favor, and the latter's remembering of the kindness done and his ever-readiness to reciprocate the kindness (Komin 1990).

The concept of *"bunkhun"* may be the most important aspect of social relationships in Thailand. The people who are the giver of "*bunkhun*" are seen as having mercy and kindness and the receiver of *"bunkhun"* will have the feeling of gratitude and indebtedness (called by the Thais as *pen ni bunkhun*) (Taylor, 1997). This quality is particularly applicable to the interaction between people of

different status levels where the superior or stronger person behaves sympathy to those who below them. The *bunkhun* relationship may be strongly feeling within the family caregiving situation. Normally, the *bunkhun* relationship continues amicably and respectfully between the two parties through continuous cycles of giving, receiving and reciprocating that may be similar in the concept of reciprocity in western culture perspective. One result of *bunkhun* relationships in Thai society is that it produces strong social bonds in the family caregiving situation. Some researcher indicated that caregivers reported to maintain caring for their elderly stroke relatives even they felt that caregiving is an unavoidable task but they cannot abandon or leave their care-receiver because of their beliefs based on the *bunkhun* system. Most of the caregivers explained caregiving as a way of returning gratefulness to their elderly relatives (Subgranon & Lund, 2000).

This review illustrated that the Thai culture may be an important influence that guides the behavior of individual caregivers and influences the roles individual caregivers play within their family and for their care-receivers. Religion has a great influence on the daily living of Thai caregiver who mostly are Buddhists. Caregiver's motivation and caregiving context can be influenced by kin-relationship of the caregiver to care-receiver and also by cultural norm. Some research reported that the caregivers who had a good pre-caregiving relationship with the care-receiver were motivated to care for their partners through love and a desire to continue and maintain their relationships (Morgan & Laing, 1991). Therefore, caregiver's motivation to provide care can impact on the establishment of the caregiving relationship and the connection between motivation of caregiving and quality relationship between caregiver and care-receiver may influence caregiver's and care-receiver's well-being and good quality of care. Quality relationship is an important concept since it not only connects to caregiver's motivation but also affects either positive or negative outcome of caregiving.

4) Quality relationship and related terms with quality relationship

The influences on the caregiver's decision to take on the caregiving role, and changing nature of the relationship with care-receiver may affect the outcomes of caregiving. According to the literature review, quality relationship impact on various

outcomes. A study by Morgan and colleague (2011) in cancer caregiver using Structural equation model found that quality relationship impacts both quality of life in patient and cancer caregiver (Morgan, Small, Donovan, Overcash, & McMillan, 2011). Quality relationship did mediate the patients' quality of life positive, despite the stress. The relationship had a direct, positive effect on the quality of life of both members of the couple, and this was despite pain and influenced negatively by the symptom pain. Distress, general health, and mental health indicators exhibited a decrease in their quality of life from pain and cancer, particularly for the patient, but there was a positive effect from the relationship.

Lyonette and Yardley (2003) indicated that poorer quality relationship with older person was the most significant predictor of caregiver stress in a sample female caregiver, taking precedence over care-related and work related factors. For caregiver satisfaction, better quality relationship and greater intrinsic motivations to caregiver were the most significant predictors. Higher quality relationship of past and current report greater caregiver satisfaction (Lyonette &Yardley, 2003).

The same result was found in the study by Snyder (2000) that caregiver-receiver quality relationship had impact on burden and satisfaction (Snyder, 2000). The in-depth interviews demonstrate the importance of quality relationship defined by communication, sense of family orientation, level of reciprocity, shared activities, and conflict. The key element impacting burden and satisfaction in shared-residence situations was the quality relationship between the caregiver and care-receiver. The quality relationship was defined by sense of family orientation, reciprocity, shared activities, and conflicts as well as communication and interaction.

In addition, Cicirelli (1993) and Pohl and colleagues (1995) had examined quality relationship in mother-daughter caring and found that the quality relationship in diverse older person care situation predicts the level of caregiver satisfaction. However, a comparison of responses concerning functioning level of the care-receiver, employment, and support indicated that these factors were not consistently related to burden and satisfaction. The critical element which emerged as crucial to the level of perceived burden and satisfaction for caregivers and care-receivers was quality relationship between caregiver and care-receivers. More than any other elements,

quality relationship accounted for the differences in the amount of burden and satisfaction.

Steadman and colleadgue (2007) found that on average caregivers reported high levels of pre-caregiving relationship satisfaction. A close prior relationship and high levels of pre-caregiving relationship were related to reports of lower burden (Steadman, Tremont, & Davis, 2007; Williamson & Schulz, 1990). Caregiver who had a highly communal (reciprocal) pre-caregiving relationship continued to perceive their past and current relationship as rewards and were less depressed and less likely to potentially harm the care-recipient (Williamsom & Shaffer, 2001). Pre-caregiving quality relationship can impact on how the caregiver reacts to changes in the care-recipient. High levels of relationship satisfaction were related to less reactivity to memory and behavioral problems, and more effective communication (Steadman et al., 2007).

Yeh, Wierenga and Yuan (2009) studied about the influences of psychological well-being, quality of caregiver-patient relationship, and family support on health of family caregiver of cancer patients in Taiwan. A sample of 91 family caregivers of hospitalized cancer patients completed the Care Reaction Assessment and Psychological Well-Being Scale. The psychological well-being and the quality of the caregiver-patient relationship of family caregivers were found to be significantly positively correlated with caregivers' health. The lack of family support was found to be significantly negatively correlated with caregivers' health. Psychological well-being, quality of caregiver-patient relationship, and family support accounted for 59% of the variance in caregivers' health. The relationship between patients and family caregivers as “shared care” refers to a pattern of interdependent interaction consisting of communication, negotiation, and reciprocity. Family caregivers who had a better quality of patient-caregiver relationship experienced a lower negative impact on their health status (Yeh, Wierenga, & Yuan, 2009).

Further, Winter’s (2011) study found that the quality relationship between individuals with dementia and their family caregivers has an impact on important clinical outcomes for both. Quality relationship affects caregivers’ desire to place their relative in nursing home (Winter, Gitlin, & Dennis, 2011). They used a communal relationship that is defined as one of mutual demonstrations of concern for and

responsiveness to one another's needs. Caregivers are instructed to think about "the type of interactions you had with the relative before"

A poor quality of pre-caregiving relationship was related to more negative caregiving outcomes, such as strain and depression, and was negatively related to quality of life and caregiving satisfaction (Kramer, 1993; Morris et al., 1988). Closer affection between the caregiver and care-receiver had a positive effect on caregiver's health, with lower resting diastolic blood pressure and reduced impact of stressors in subsequent heart rate reactivity (Uchino, Kiecoltglaser, & Cacioppo, 1994).

A study by Morris and colleagues (1988) reported factors affecting the emotional wellbeing (Morris et al., 1988). The qualitative aspect of the caregiver's relationship with the dementia sufferer may play an important role in mediating the degree of subjective burden and may also be an important factor mediating emotional distress (Zarit, Reever, & Bach-Peterson, 1980).

Lawrence, Tennstedl, and Assman (1998) investigated the association between the quality of the caregiver-care-receiver relationship and negative health outcomes associated with caregiving including: perceived caregiving overload, role captivity (i.e, feeling trapped in the caregiver role), and depression. Participants included in the study were 188 family caregivers (e.g. spouses and children) of functionally disable elderly adults. Current quality relationship was measured by four items from University of Southern California Longitudinal Study of Three- Generation Families measures of positive affect (Mangen, Bengtson, & Landry, 1988). The items assess about general closeness, and communication. The results called for a reversal of perspective: the quality relationship was impacting the perception of burden that follow, and satisfaction.

The systemic review of quality relationship between caregiver and care-receiver and its impact on the caregiver and care-receiver well-being was reported by Quinn, Clare, and Woods (2009). They reported that caregiving can pose an impact on the quality relationship. In addition, pre-caregiving and current quality relationship appear to have an impact on caregiver's well-being. However, by including both female and male caregivers, Wright (1998) found that both caregivers and the control group reported similar levels of past and current affection. Whereas de Vugt and colleague (2003) observed that the majority of caregivers rated their pre-morbid

relationship very positively and rated the current relationship slightly less positively, with the most deterioration occurring in communication with the care-receiver. The deterioration of quality relationship is specifically associated with the presence of behavioural problem, notably, apathy, in patients with dementia (de Vugt et al., 2003).

Based on the literature, quality relationship had been studied in various contexts and motivations of caregiving. The majority of the studies did not clearly define the meaning of quality relationship and most of the study used different measures of quality relationship. These measures examined different dimensions of quality relationship for instance relationship rewards (Williamson & Shaffer, 2001), intimacy (Morris et al, 1988) or mutuality (Gallagher-Thompson, Canto, Jacob, & Thompson, 2001). The studies also varied in the number of questions used to measure quality relationship. Some have examined quality relationship using only single-item measures (Mui & Morrow-Howell, 1993).

The literatures suggested that many previous researchers who have examined personal factors have selected only a specific aspect of quality relationship as the focus of their work, such as mutuality (Archbold et al., 1990), conflict and closeness (Townsend & Franks, 1995) or sociability (Goldsmith &Goldsmith, 1995). Other researchers have examined aspects of quality relationship among specific groups of carers, such as intimacy in mother-daughter relationships (Walker, Martin, & Jones, 1992), attachment and conflict in mother-daughter relationships (Pohl et al., 1995), differences in closeness of the relationship between wife and daughter carers (Seltzer & Li, 1996), or difference in quality relationship between co-resident daughters and daughter-in-law and older person (Peters-Davis, Moss, & Pruchno, 1999). Several studies used items from the positive affect insides (Bengston & Schrader, 1982 as cited in Lyonett & Yardley, 2003) to measure quality relationship in older person care relationship (Lawrence et al., 1998).

Those studies were based on different contexts, motives of caregiving, and theoretical frameworks and the literature review suggested that quality relationship had been studied in various concepts and impact on various outcomes. Here, the meanings of quality relationship when defined as various concepts such as intimacy, mutuality, reciprocity, and love which will be presented as follows.

4.1) Quality relationship when defined as intimacy

The concept of intimacy defined as quality relationship had been studied in various groups of caregiver. Written works on the subject of intimacy tend to centre on adult, often sexual relation, theorizing them in terms of individualized, negotiated interactions (Gillies, 2003). Despite the variety of definition and operationalizations of intimacy, all have at least one important aspect in common as a feeling of closeness and connectedness that develop through communication between partners. One model is the interpersonal process model of intimacy, originally proposed by Reis and Shaver (1988). Many researchers explored and studied intimacy concept by using the interpersonal process model (Laurenceau, Barrett, & Pietromonaco, 1998; Laurenceau, Barrett, & Rovine, 2005; Manne et al., 2004).

The meaning of intimacy was adopted from Reis and Shaver's (1988) defined as a process in which one person expresses important self-relevant feelings and information to another and, as a result of other's response, comes to feel understood, validated, and cared for. This interpersonal process model emphasizes two key components of intimate interactions: self-disclosure and partner responsiveness. Self-disclosure is referred to the communication of personally relevant and revealing information to another person. The listener responds by disclosing personally relevant facts, thoughts and feelings to the speakers. Partner responsiveness contributes to the development of intimacy in close relationships (Reis, Clark & Holmes, 2004)

Manne and Badr (2008) studied intimacy as view of couples' intimacy-enhancing intervention for breast cancer patients and their partners. The study expressed the importance of viewing cancer from a relationship perspective and evaluated the impact of cancer on the quality of marriage. The meaning of intimacy used in this study was defined as the willingness to disclose information about private topics to another person (Altman & Taylor, 1973 as cited in Manne, et al., 2004) or an interaction that is physically proximate or nonverbally engaging (Hall, 1966 as cited in Manne, et al., 2004).

Manne and Bard (2010) examined the associations between three types of cancer-related support communication (self-disclosure, perceived partner disclosure, and protective buffering), intimacy (global and cancer-specific),

and global distress among patients coping with either head and neck or lung cancer and their partners. The result suggested that the global and cancer-specific intimacy fully mediated associations between self- disclosure, perceived partner disclosure and distress; global intimacy partially mediated the association between protective buffering and distress. Moreover, lower levels of distress were reported as a function of global and cancer-specific intimacy, but these associations were stronger for partners than for patients

Another study by Manne and colleagues (2010) evaluated intimacy as a mechanism for the effects of relationship-enhancing (self-disclosure, mutual constructive communication) and relationship-compromising communication (holding back, mutual avoidance, and demand-withdraw communication) on couples' psychological distress. The study was conducted in seventy-five men diagnosed with localized prostate cancer in the past year and their partners who completed surveys about communication, intimacy, and distress. The result showed that the association between mutual constructive communication, mutual avoidance, and patient demand-partner withdraw and distress could be accounted for by their influence on relationship intimacy. Intimacy did not mediate associations between self-disclosure, holding back, and partner demand-patient withdraw communication and distress (Manne, Badr, Zaider, Nelson, & Kissane, 2010).

The study by Greef and Malherbe (2001) has affirmed that intimacy is related to both couples' relationship satisfaction (Greef & Malherbe, 2001) and the psychological health of individual partners (Prager & Buhrmester, 1998). Moreover, lack of intimacy is one of the most common reasons for seeking couple therapy (Doss, Simpson, & Christensen, 2004). Therapists identify deficits in intimacy as one of the most damaging problems in relationships and as the most difficult problem to treat (Whisman, Dixon, & Johnson, 1997).

However, key component of intimacy such as disclosure had been studied by Porter, Keefe, Hurwitz, and Faber (2005). They examined patterns of disclosure on cancer-related concerns between patients with gastrointestinal (GI) cancer and their spouses, and associations between patient and spouse disclosure and patient adjustment, spouse adjustment, and aspects of relationship functioning (Porter, Keefe, Hurwitz, & Faber, 2005). A sample of 47 patients and 45 of their spouses

completed a measure of disclosure which included ratings of their level of disclosure and level of holding back from disclosure of cancer-related concerns. Patients completed a measure of quality of life, spouses completed a measure of caregiver strain, and all participants completed measures of psychological distress and relationship functioning (intimacy, empathy, and partner avoidance and criticism). Data analyses revealed that patients and spouses reported moderately high levels of disclosure and low levels of holding back, with patients reporting higher levels of disclosure than spouses. Among patients and spouses, low levels of disclosure and high levels of holding back were associated with poorer relationship functioning. There were also some indications that high levels of holding back, and to a lesser extent low levels of disclosure, were associated with increased psychological distress for both patients and spouses. However, there were no indications that patient or spouse disclosure was harmful for the other person.

Patient and spouses who disclose to each other are likely to have better individual adjustment, including lower levels of psychological distress, better quality of life for patients, and lower levels of caregiver strain for the partner. Disclosure of thoughts and feelings may facilitate patients' adjustment to cancer by providing opportunities for validation and finding meaning in the experience (Lepore, Silver, Wortman, & Wayment, 1996). In families where cancer can be discussed openly, patients report fewer emotional and physical complaints and higher levels of self-esteem and perceived control (Mesters et al., 1997). Among women with breast cancer, those who reported talking about their cancer-related feelings displayed less depression and greater well-being (Cordova, Cunningham, Carlson, & Andrykowski, 2001), and those who rated talking to their husbands more helpful reported less psychological distress (Pistrang & Barker, 1995). For spouses who are often the primary caregivers, disclosure may also lead to better understanding of the patient's physical and emotional needs thus lessening caregiver strain. One study found that when cancer patients and their family members had similar perceptions of the patient's pain, patient reported less mood disturbance and better quality of life, and family members had lower levels of caregiver strain (Miaskowski, Kragness, Dibble, & Wallhagen, 1997). Moreover, patients and spouses who are able to disclose their cancer-related thoughts and feelings to each other may demonstrate enhanced

intimacy, empathy, and marital satisfaction, which in turn are associated with better individual adjustment (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Pistrang & Barker, 1995).

In a qualitative study in spousal caregivers of persons with mild memory loss and dementia experience in issues of intimacy and sexuality, the researcher defined intimacy as the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal relationship (Davies et al., 2010). Fourteen dementia and nine mild memory impairment (MMI) spousal caregivers participated in focus groups conducted between 2008 and 2009 at the Stanford/VA Alzheimer's Research Center. Dementia caregivers reported more difficulties with communication, cohesion, and perceptions of increased burden than their MMI counterparts. Both groups indicated reduced sexual expression due to physical limitations; substitute activities including hand-holding, massaging, and hugging were noted. Both groups reported difficulty anticipating the future of the relationship due to present stressors. While dementia caregivers could consider future romantic relationships with others, MMI caregivers were primarily able to consider future relationships only for companionship and emotional intimacy.

In summary, intimacy concept had been studied in couples' relationship that affect couples' level of psychological and marital adaptation (Manne et al., 2008), both couples' relationship satisfaction (Greef & Malherbe, 2001) and the psychological health of individual partners (Prager & Buhrmester, 1998). Intimacy was used to approach to understanding cancer, Alzheimer, dementia in the marital context. Key constructs are disclosure, processing, and how others facilitate an individual's processing of an event. This concept adopts an individual-level conceptualization of the role of the marital relationship.

Although Thai research had studied on spouse caregivers such as the experience of Thai women caring for their husbands living with HIV/AIDS (Ruangjiratain, 2003); experience of caregivers of spouses with HNC undergoing radiation therapy (Kitrungrote et al., 2008; Wongchuay et al., 2010), none of intimacy concept had been reported in Thai caregiving. Traditionally the marital context was influenced by Thai social values such as gratitude. When a person has done something for someone, he/she owes gratitude to that person. Some women applied this value to

their marital relationship because their husbands have been good to them in the past, for example, being a family man or a good provider, women felt grateful to him and provided care in gratitude for his merit (Ruangjiratain, 2003). Further, women perceived that it is the wife's role and responsibility to provide care for the sick husband. In addition, accepting care for husbands due to the sense of sympathy, care, warmth, attachment, companionship, love, duty and obligation was reported by women.

4.2) Quality relationship when defined as Mutuality

Quality relationship, when defined as mutuality, has also been studied in various groups of caregivers for persons with cancer as well as older adults. Mutuality can be defined as a connection with or understanding of one another that facilitates a dynamic process of joint exchange between people. The process of being mutual is characterized by a sense of unfolding action that is shared in common, a sense of moving toward a common goal, and a sense of satisfaction for all involved. Mutuality precedes attainment of a goal that is satisfactory (Henson, 1997).

Hirschfeld (1983) presented the concept of mutuality, which emerged as the crucial factor on continuing home care versus institutionalization from qualitative study (Hirschfeld, 1983). In qualitative data analysis, mutuality between the supportive and the impaired family members emerged as the key variable for families managing life with senile brain disease. It grew out of the caregiver's ability to find gratification in the relationship with the impaired person and meaning from caregiving situation. Another important component to mutuality was the caregiver's ability to perceive the impaired person as reciprocating by virtue of his/her existence.

The concept of mutuality was explored in the context of caregiving by Archbold et al. in 1990. The concept of mutuality was derived from non-Hispanic white population in older adult dyads. They used a conceptual framework that drew largely from role theory and was the basis for the development of the family caregiving inventory that measures of mutuality. Based on viewing caregiving as a role, they also wanted to know how caregivers described the quality of their relationship with the care-receiver and how that relationship affected caregiver role strain. Their focus was on caregiving situation in which a family member or friend provided extensive levels of care in the home to an elderly care-receiver who

was moderately to severely impaired, either physically or cognitively. Mutuality was defined as the positive quality relationship between caregiver and care-receiver, comprising four dimensions; i.e love and affection, shared pleasurable activities, shared values, and reciprocity (Stewart & Archbold, 1992). They collected data by interviewing with the caregivers and care-receivers which were conducted simultaneously in 6 week time period and 9 month time period. In addition, the most important result in this study was the magnitude of variance in many aspects of caregiver role strain that can be explained by mutuality. As stated in the study by Archbold et al. (1990), mutuality for caregiving was associated with lower levels of caregiver role strain for some but not all aspects of strain such as strain from direct care, increased tension, and global strain.

Following the studies of Archbold and colleagues, mutuality concept had been used widely in caregivers with elder population, Parkinson's disease, dementia and cancer. In a study by Schumacher and colleagues (2007, 2008), they explored whether quality relationship and preparedness moderate the effects of caregiving demand on caregiver outcomes during cancer treatment; and to test a model of family caregiving derived from the interactionist approach to role theory that hypothesized that three caregiving role implementation variables (caregiving demand, mutuality between caregivers and patient, and preparedness for caregiving) would predict multiple caregiving-specific and generic outcomes with different patterns of association across outcomes. The result show that the association between demand and difficulty depends on levels of mutuality and preparedness and that the high mutuality-high preparedness combination moderates or lessens the demand-difficulty association and the association between demand and total mood disturbance depends on levels of mutuality and preparedness. Moreover, demand was associated most strongly with caregiving difficulty and global strain. Mutuality was associated most strongly with caregiver anger.

Moreover, Bambauer and colleague (2006) studied mutuality and specificity in rates of mental disorders between advanced cancer patients and their caregivers. The data was obtained from 168 non-genetically related patient-caregiver dyads participating in the multi-site. This study demonstrated the mutuality of psychiatric disorders in both advanced cancer patients and their informal caregivers.

Specifically, the presence of anxiety disorders in one partner (either caregiver or patient) was associated with a greater likelihood of anxiety disorders in the other (Bambaure et al., 2006). Furthermore, in breast cancer patients, perceived mutuality in couple relationships was associated with less depression, better quality of life, and more self-care agency (Kayser, Sormanti, & Strainchamps, 1999). Similarly, perceived mutuality in couple relationships was associated with less depression and discriminated between women with eating disorders and healthy controls (Sanftner, Tantillo, & Seidlitz, 2004).

Carter and colleague (1998) studied the experience of spouses giving care for their partner with Parkinson's disease (PD) and determined whether their experiences differed by stages of the disease. The result showed that mutuality as the positive quality of the relationship between the caregiver and care-receiver, as perceived by the caregiver, was significantly lower at stages 2, 3, and 4/5 than at stage 1. In addition, mutuality was lower at stage 4/5 than at stage 2 (Carter et al., 1998). The mean number of year since diagnosis of PD for each of the stages was stage 1, 5.6 years; stage 2, 5.9 years; stage 2.5, 5.4 years; stage 3, 8.5 years; and stage 4/5, 12.5 years.

Kasle and colleague (2008) examined physical and psychological health outcomes of married/partnered patients with rheumatoid arthritis (RA) in relation to their perceptions of their own responsiveness (self-mutuality), their partner's responsiveness (partner-mutuality), and combined responsiveness (overall mutuality), and to examine potential sex differences in the links between mutuality and depressive symptoms. This study investigated relational mutuality, a positive relationship quality of connectedness described in a theory of women’s psychological development, self-in-relation theory. Mutuality is defined as the reciprocated interest in bidirectional sharing of thoughts and feeling in close relationships, permitting partners to truly know and be known by each other. Mutuality is reflected in communications characterized by engagement, interest, empathy, validation, and authenticity. Mutual partners respond in ways that encourage authentic expression within the relationship. And can even disagree on issues while maintaining close connection. Mutuality is believed to promote self-awareness and the emergence of identity, a self-in-relation, through mutual psychological cultivation and growth. The

result found that RA patients' perceptions of mutuality in conversations with spouses/partners predicted better health across a spectrum of outcomes. Overall mutuality and partner-mutuality predicted fewer depressive symptoms for both men and women, but self-mutuality appeared more important for women than for men (Kasle, Wilhelm, & Zautra, 2008).

Mutuality concept had been studied on the impact of relationship between timing of caregiving. Lyon and colleagues (2007) examined mutuality in care dyads over time, and the impact of health changes on the quality of the care relationship. They examined mutuality in 103 care dyads over 20 months, and the enduring and contextual impact of older adult and family caregiver health on changes in mutuality. Care dyads consisted of frail older adults and their family caregiver. Older adults reported higher levels of mutuality than family caregivers, but their mutuality declined significantly faster over time. This study shows the importance of examining time-varying covariates in the care dyad (Lyons et al., 2007). In longitudinal study over a 10-year period was conducted to examine the roles of optimism, pessimism, mutuality, and spouse gender in predicting role strain in PD spouses. This design was used to study 255 spouses of persons with PD over a 10-year period, with data points at baseline (Year 0), Year 2, and Year 10. The result demonstrated that high mutuality and optimism and low pessimism at baseline played important protective roles against increased role strain at Year 10. In this study mutuality scale measures the positive aspects of relationship quality; the interactive nature of mutuality is reflected in its dimensions of reciprocity, love, shared pleasurable activities, and shared values. Mutuality was negatively associated with strain from tension for wives but not for husbands, wives with low levels of mutuality experienced significantly increased levels of strain from tension compared to wives with high levels of mutuality.

The Study by Shim and colleagues (2011) used secondary analysis of longitudinal data on correlates of care relationship mutuality collected from 91 carers of people with Alzheimer's disease and Parkinson's disease in the control group of a randomized trial of home-care skill training. Multilevel models for change were used to explore whether care-receiver functional ability, caregiver gender, depressive symptoms, kin relation to care-receiver (spouse, non-spouse) and years of

caregiving experience were related to caregivers' perceptions of care relationship mutuality over a 12-month period. Data collection took place between 2003 and 2008. The finding indicated factors related to lower mutuality for these caregivers were caring for care-receivers with lower functional ability, shorter length of caregiving experience and higher levels of depressive symptoms for caregivers (Shim, Landerman, & Davis, 2011).

In Parkinson's Disease (PD), increased mutuality was associated with less PD severity, less caregiver burden and less depression of both the spouse and PD care-receiver (Tanji et al., 2008). Tanji and colleagues (2008) defined mutuality as the quality of interaction or reciprocity of sentiment in a relationship. The result found that mutuality was correlated with disease severity and disability of the partner with PD, but was not associated with the physical health of the spouse.

In sum, quality relationship when defined as mutuality had been widely used in caregivers with elder population, Parkinson’s disease, dementia and cancer. The impact of mutuality had been studied other than the intimacy concept and impacts on caregiving-specific and generic outcomes with different patterns of association across outcomes such as role strain, mood disturbance, and psychological well-being (Archbold et al., 1990; Kasle et al., 2008; Schumacher et al., 2007; 2008). This concept can explain in the caregiving context not only spouse caregiver or marriage relationship but also other family relative such as daughter, mother or son. The process of being mutual is characterized by a sense of unfolding action that is shared in common, a sense of moving toward a common goal, and a sense of satisfaction for all involved. The components of mutuality are of a very broad concept including such as love and affection, shared pleasurable activities, shared values, and reciprocity. Most of the research reported various outcomes impacted by mutuality.

In Thai caregiving research, mutuality concept had been reported in the context of family caregiving with traumatic brain injuries patient (Samartkit, 2008), stroke patient (Prawtaku, 2006) and cancer patient (Phigbua, 2005). All of them adopted a quantitative study and used mutuality concept developed by Archbold and colleadge (1990). Some research defined mutuality as “supportive relationship”. Mutuality affects the reward of caregiving and caregiver’s health. Most caregivers explained that the caregiving situation allows them and their care-receivers

to have more time spent together and to share their love, closeness, and pleasure in day–to–day interactions with the care-receiver (Samartkit, 2008). Particular components of mutuality such as love and reciprocity may be a dominant domain in Thai culture. A number of studies reported that this component was the motive for family members' decision to become primary caregiver.

4.3) Quality relationship when defined as Reciprocity

The concept of reciprocity has also been examined in caregiving research. Hamilton and Sandelowski (2003) explored the dynamics of supportive relationships from the perspective of older African Americans diagnosed with and treated for cancer. They are an exemplar population for studying reciprocal relationship. The meaning of reciprocity defined as giving is receiving, and receiving is giving that is the key finding from interviews conducted with 28 African American women and men with cancer who were active participants in dynamic relationships characterized by both giving and receiving. Moreover, the finding showed that persons with cancer participate in a variety of reciprocal relationships throughout their illness trajectory. Their translation of reciprocity as giving back when there was an identified need and available resource allowed these participants to remain integrated in their networks (Hamilton, & Sandelowski, 2003).

Kuijer and colleagues (2001) examined differences between couples facing cancer and healthy couples with regard to perceived quality relationship. The result showed that both patients and their partners reported more positive changes in their relationship than did healthy participants and no differences with respect to relationship satisfaction: patients with cancer and their partners were satisfied with their relationship. In addition the study examined whether and how time since diagnosis and the patient's physical condition moderated the association between perceived equity and quality relationship. Perceived equity is defined as the balance of give-and-take in couples facing cancer that guided by equity theory. When the individuals receiving disproportionately few rewards are expected to feel underbenefited; those receiving disproportionately many rewards are expected to feel overbenefited. The result of this study showed that patients with cancer felt more overbenefited in their relationship than did healthy people, whereas their partners did not feel under benefited; they felt as equitably treated as did healthy people. Moreover,

perceived equity was related to quality relationship: all participants (patients, their partners, and healthy people) generally reported the lowest quality when they felt under benefited in their relationship (Kuijer et al., 2001).

In contrast, the study by Kuijer and colleagues (2002), explored the equity concerns among couples in which one of the partners was diagnosed with cancer, and found that couples with a male patient only felt more overbenefited in their relationship than their partners (Kuijer, Buunk, Ybema, & Wobbes, 2002). Moreover, it was found that the partners of these patients did note, as was expected, that they felt underbenefited in their relationship. The main focus of this study was on the association between perceived equity on the one hand and relationship satisfaction and emotions on the other. It was found that in general patients seemed most sensitive to underbenefit (i.e. they felt least satisfied), and experienced on average least positive and most negative affect when they felt underbenefited. Particularly, patients who were physically impaired felt dissatisfied and angry when underbenefited. The partners of these patients were in general equally sensitive to inequity in both directions, regardless of their ill partner's physical condition.

Kuijer and colleagues (2004) evaluated the intervention of brief counseling program directed at couples confronted with cancer. The results showed that after the intervention, both patients and their partners reported lower levels of perceptions of underinvestment and overbenefit, and higher levels of quality relationship. Moreover, among patients, psychological distress decreased after the intervention. These effects were generally maintained until follow-up three months later. Further, the more patients experienced a decrease in perceptions of inequity after the intervention, the higher they rated the quality of their relationship immediately after the completion of the intervention and three months later (Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004).

Reid and colleagues (2005) investigated whether self-esteem and intrinsic motivation influence the relationship between reciprocity and caregiver burden. Primary caregivers (N = 56) of a patient with a disability, illness or frailty due to aging were recruited via carer organizations. Caregiver burden can be alleviated by a sense of reciprocity or balance in the give-and-take between a caregiver and care-

receiver (Dwyer & Miller, 1990). The result suggested that reciprocity decreased caregiver burden directly, although self-esteem did partially mediate the relationship between reciprocal warmth and emotional burden. Contrary to predictions, self-esteem and intrinsic motivation enhanced rather than diminished the impact of reciprocity on burden (Reid, Moss, & Hyman, 2005).

Neufeld and Harrison (1998) explored reciprocity in the relationships of men caregivers of cognitively impaired older adults. This study identified the context in which reciprocity was present or absent, the characteristics of reciprocity in caregivers' relationships with the care recipient, family and friends, and the men's feelings about reciprocal social support during caregiving. Twenty-two men caregivers were interviewed three times over 18 months. Study findings were confirmed in a focus group discussion with seven caregivers. Three variations in reciprocity in the men's relationship with the care recipient were identified: waived reciprocity generalized reciprocity and constructed reciprocity. Those experiencing constructed or generalized reciprocity described positive feelings, whereas men identifying waived reciprocity described either positive or negative feelings. When reciprocity was absent the men described giving care on the basis of obligation with either mixed or negative feelings (Neufeld, & Harrison, 1998).

To conclude, reciprocity concept had been examined from the perspective of caregiving with older patient. Its impact were found on the relationship satisfaction (Kuijer et al., 2001), caregiver burden (Reid et al., 2005), and positive feeling (Neufeld & Harrison, 1998). This concept was mostly reported in the motivation and context of caregiving.

In Thai caregiving research, reciprocity is viewed a key factor affecting family’s decision to become primary caregiver, and reported in the elderly caregiving situation. Some researchers identified the experience of caring for father who suffered renal failure. Caregiver described how difficult it was to care for their father; however, they felt happy because they did not perceive caring for their father as a burden. They were willing to care for their father with their love and reciprocity (Pornteesud, 1996 as cited in Wirojratana, 2002). Other researchers explored some concepts approximately to reciprocity such as “*katanyu katavedi*” (filial piety) and refers specifically to the parent-child relationship (Kespichayawattana, 1999). The

concept of "*katanyu katavedi*" refers to all the benefits which were bestowed upon the children (called "*bunkun")* and the sense of gratitude towards parents (called "*katanyu*"), and refer to the obligatory actions of paying back to parents (called "*katavati*").

4.4) Quality relationship when defined as love

The concept of love is usually involved other conceptualizations of quality relationship, such as mutuality, reciprocity and intimacy. The concept of love, by itself, has rarely been explored in the context of caregiving. However, Mcintyre and Cole (2008) studied love stories about caregiving. Love Stories is a spoken-word performance created from data gathered from family caregivers about their experiences of caring for a loved one with Alzheimer's disease. Loving care brings to the person with dementia opportunities for attachment, identity, inclusion, occupation and comfort (Mcintyre & Cole, 2008).

In brief, love concept was a basic component reported in motive to helping as family caregiver. In Thai caregiving context, love is a pivotal component that impacts on the caregiver's continuing to care for their care-receiver (Thampanichawat, 2007), and the power of love motivated family members to take care of their patients (Kitrungrote, et al.,2008; Limpanichkul & Magilvy, 2004; Prechavittayakul, 2006).

In conclusion, quality relationship and related terms with quality relationship had been studied in various groups of chronic illness such as Alzheimer's disease, dementia, and cancer, and various groups of caregiver such as spouse, children, other relatives, or friends. The concept of quality relationship is very broad and different concepts and outcomes had been studied. Each concept affects varied outcomes such as the level of intimacy impact of the quality of marriage, caregiver distress (Manne & Badr, 2008; 2010), physical health and relationship satisfaction (Greff & Malherbe, 2001). Most of study usually focused on relationship between patient and spouse (Davies et al, 2010; Greef & Malherbe, 2001; Lepore et al., 1996; Manne et al., 2010; Porter et al., 2005). Mutuality impacts caregiving-specific and generic outcomes with different patterns of association across outcomes such as role strain, mood disturbance, and psychological well-being (Archbold et al., 1990; Kasle et al., 2008; Schumacher et al., 2007; 2008). This concept had been used

widely in caregivers with elder population, Parkinson's disease, dementia and cancer. Reciprocity concept had been examined in caregiving research from the perspective of caregiving with older patient. It had impact on relationship satisfaction (Kuijer et al., 2001), caregiver burden (Reid et al., 2005), and positive feeling (Neufeld & Harrison, 1998). Some research did not clearly define the meaning of quality relationship but reported impacts on caregiver satisfaction, health outcome (Lawrence et al., 1998).

Caregiving with HNC are specific groups that need caregiver provide care specifically unique difficulties because of the centrality of this area and the specific roles in social and emotional expression and communication (Jones, Lund, Howard, Greenberg, & McCarthy, 1992) and the nature of HNC patient is more common in men and is associated with heavy alcohol use and smoking (Luckett, Britton, Clover, & Rankin, 2011) that may be different in the context of caregiving such as most of caregiver was women, wife's patient. Literature review found that, quality relationship between caregiver and care-receiver with HNC had been explored by intimacy concept and context of spouse caregiving (Manne et al., 2004; 2008; 2010) in the western culture.

Quality relationship between caregiver and care-receiver is an important issue due to the fact that it not only motivates the family to take caregiving role but also impacts on all of the caregiving process. In Thai literature, we know certain components of quality relationship such as love and reciprocity that motivate the family's taking care of their family. However, none of the studies explored and described the quality concept in Thai culture. Therefore, qualitative study that employed grounded theory methodology was most appropriate for explore and explain this concept in Thai context. Quality relationship between caregiver and care-receiver in Thai context may be different from those expressed by western countries. Good quality relationship helps caregiver continue their caregiving role and good quality of caregiving. We know that our Thai social and cultural ways strongly influence the family to take care of ill family members but quality relationship may be a key component that affects family's willing to take good care of relative patients.

To sum up the literature review in this chapter, the content were described, analyzed and organized in four sections: 1) the nature of caregiving in cancer caregiving context that is a complex process and there are many factors which

many influence such as the highlight context as personal and social characteristics, and cultural context; 2) caregiving demands related to HNC patients that are the activities caregivers undertaken in response to their care-receivers. It composed of assisting their patient with activities of daily living and specific demand such as wound care, feeding tube and suction; 3) Thai culture context that affect to caregiving situation composed of religious context and indebtedness of relationship in Thai society; and 4) quality relationship and related terms with quality relationship composed of various concepts such as intimacy, mutuality, reciprocity and love. Based on the literature review in this chapter, it can be used to stimulate theoretical sensitivity by providing ways of interpreting data and used as secondary sources of data for developing questionnaires. Furthermore, it can be used as a guide in the selection theoretical sampling and supplementary validity.

CHAPTER III
METHODOLOGY

A grounded theory approach was used in this study to understand quality relationship in Thai HNC caregivers, and how caregivers describe their relationships with the care-receiver. Grounded theory has its origin in sociology, particularly symbolic interactionism, and was initially developed in the 1960s during the collaboration of the sociologists Barney Glaser and Anselm Strauss who worked together on research about health professionals' interaction with dying patients (Holloway & Wheeler, 2010). They developed both a new philosophical approach to research and a method to identify basic social processes within the context in which these processes occurred (Morse & Field, 1996). Moreover, it focuses on the discovery of new theory and can explain phenomena in a social world. Grounded theory can be used to study particular phenomena in a natural setting and is, therefore, useful in exploring the phenomenon of interest because it allows for an in-depth examination of the practice, behaviors, beliefs and attitudes as the quality relationship between caregiver and care-receiver. In order to develop a theoretical understanding of the meaning and process of quality relationship in caregiver with HNC patients based on the individual caregiver's view point, it is important to study the phenomenon through the lens of grounded theory methodology. It is useful when a phenomenon, in terms of the individual's point of view, has not been identified, or the phenomenon has not been investigated and has limited information (Streubert & Carpenter, 1995). As little is known about quality relationship in Thai family caregivers of persons with HNC, grounded theory is well-suited to explore and explicate its meaning in this context.

The theoretical framework for grounded theory has its roots in symbolic interactionism, focusing on the processes of interaction between people exploring human behavior and social roles (Holloway & Wheeler, 2010). Symbolic interactionism explains how individuals attempt to fit their lines of action to those of others (Blumer, 1971), take account of each other' s acts, interpret them and

reorganize their own behavior (Holloway & Wheeler, 2010). This theory is a useful concept to aid the work of exploring the person's self in interaction with others in the sub-cultures of society, and for analyzing processes within those interactions (Walker & Myrick, 2006).

Symbolic interactionism- history and tenets

Symbolic interactionism is both a theory about human behavior and an approach to inquiring about human conduct and group behavior (Annells, 1996). The major American social interactionist theorist who articulated interactionist thought is George Herbert Mead (1934). The basic tenet that emerged from Mead's interactionist perspective was the essential defining of self through social roles, expectations, and perspectives cast on self by society and by those within society (Annells, 1996). Mead explained how one is able to become an object to oneself through the words "I" and "Me". "I" is the creative, unpredictable aspect of the self, reactive to the immediate situation. The situation provides the motivation for change and new understanding. "I" is only known in memory as one reflects on action. The "Me" is the organized set of attitudes of others, which one assumes as part of a social group or society. The "Me" is visible as habitual, conventional action and conscious responsibility (Mead, 1962 as cited in Crook, 2001).

According to his social philosophy, symbolic interactionism termed by Blumer (1969), he views humans as active creators in their world. What makes human beings unique is their symbolic ability to define their situations and shape their actions. Research based on symbolic interactionism emphasizes how people view their circumstances, how they interact, and how these processes change (Wilson & Hutchison, 1991). Moreover, the symbolic interaction perspective that was coined by Blumer (1969) consists of seven principles. Human beings are endowed with a capacity for thought and that capacity is shaped by social interaction. Through social interaction people learn the meanings and symbols essential to expression of thought. This understanding in turn allows people to carry out action and interaction. As people interpret their situations, they modify the meanings and symbols used in action.

Modifications are possible because people possess the ability to interact with themselves and to examine possible courses of action and the consequences of each action. Interaction within the self and with others allows people to understand a situation and make choices. The social context for interaction is society and society develops as a result of the interwoven patterns of interaction and action (Crooks, 2001).

Symbolic interactionism is a process of attempting to understand the meaning of what is happening when the person interacts with the social or object world, in order to know how to act. Symbolic interactionism focus on the interaction between the actor and the world; a view of the actor and the world as dynamic processes and the importance of the actor's ability to interpret the social world (Crooks, 2001). Blumer (1969) described the distinctive character of human relationships as having the ability to construct and share meanings. Therefore, the context of this study on quality relationship among Thai family caregivers of persons with HNC can be clearly explained by using grounded theory methods and symbolic interactionism. They can guide to understand the interaction between a caregiver and care-receiver in their quality relationship.

Process of grounded theory

Generating theory that is faithful to and illuminates the area under study (Strauss & Corbin, 1998) is the primary purpose of grounded theory. Through the use of grounded theory techniques, including a constant comparison of data, theoretical sampling and the use of a coding paradigm to assure conceptual development and density, substantive theory can emerge (Strauss & Corbin, 1990). The methodology of grounded theory includes the following steps.

(a) Data gathering method

Data for a grounded theory study was collected from an open-ended interview alone or through a combination of observation, or documents (Streubert & Carpenter, 1995). The gathering of data does not finish until the end of the research because ideas, concepts and new questions continually arise which guide the

researcher to new data sources. The researcher collects data from initial interviews or observations and takes their cues from the first emerging idea to develop further interviews and observations. This means that the collection of data becomes more focused and specific as the process develops (Holloway & Wheeler, 1996).

(b) Literature review

The literature tends to be useful in somewhat different and specific ways (Strauss & Corbin, 1998). The literature can act as the foundation for developing general theory. It has various uses in grounded theory and can be used to stimulate theoretical sensitivity. In addition, it can be used as secondary source of data, to stimulate questions and direct theoretical sampling but it can hinder creativity if it is allowed to stand between the researcher and data (Strauss & Corbin, 1998).

(c) Concurrence of data collection and analysis

Data collection and analysis occur concurrently and is based on the constant comparative (Baker, Wuest, & Stern, 1992). The constant comparative method is a hallmark of grounded theory studies. Constant comparative analysis involves the use of explicit coding and analytic procedure (Glaser & Strauss, 1967). There are three levels of coding procedure: open, axial, and selective coding.

Analysis begins with open coding. Strauss and Corbin (1990) defined open coding as “the process of breaking down, examining, comparing, conceptualizing, and categorizing data. Open coding is a word by word, line by line analysis that occurs every time data are collected (Glaser & Strauss, 1967).

One initial category and relationship will be developed during open coding; the next stage of coding involves specifying the codes that will be developed more rigorously. Strauss and Corbin (1990) referred to axial coding as “a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. This is done by using a coding paradigm involving condition, context, action/interactional strategies, and consequences (Strauss & Corbin, 1990).

Selective coding (Strauss & Corbin, 1990) is the last coding process in grounded theory methodology and involve the selection of core category. Selective

coding involves the processes that systematically relate the core category to other categories and integrate and refine the categories into theoretical construction. The purpose of selective coding is to integrate the categories around the dimension level to from theory core categories (Strauss & Corbin, 1990).

Sampling in grounded theory associated with explicit sampling for information to refine and develop theory, rather than containing notions for representativeness or randomness. This process of data collection is controlled by the emerging theory (Strauss, 1987). Strauss and Corbin (1990) stated that the focus of theoretical sampling changes according to the type of coding one is doing.

In an open coding phase, theoretical sampling is open to those persons, places, and situation that will provide the greatest opportunity for discovery. The researcher chooses initially who can provide a relevant source of data, and this relevance is determined by the requirements for generating and delimiting the theoretical codes. It is preferable to be purposive or systematic to obtain data are relevant to the research question.

In the axial coding phase, the researcher uses relational or variational sampling, either purposive or systematic, to locate more data which can confirm and elaborate categories, identify relationships between them or suggest limits to their applicability.

In the selective coding phase, the researcher uses discriminate sampling, which involves deliberate and directed selection of further data from persons, sites or documents to confirm and variety the core category and theory as a whole, and to ensure that the theoretical account is saturated.

Method and procedures of the study

The research methods and procedures employed in this study are based on Strauss and Corbin's (1990, 1998). The following identifies the grounded theory method to study perspective of quality relationship in Thai caregivers of patients with HNC.

Setting

Study participants were recruited from Ramathibodi hospital's tertiary care hospitals in Bangkok and Lopburi Cancer hospital's one of the National Cancer Institute in suburb area, Thailand. These health care facilities provide services for advanced HNC care and treatment in the country. Moreover, they have home health care center to take care of both the family and patients. The majority of the HNC patients served in these clinics were from the metropolitan Bangkok and suburb area; however, the clinics also serve HNC patients from all over the country who seek the best care available. The sample included family members who were primary caregivers of HNC patients and who are providing care for these patients during treatment or after treatment less than one year at homes, hospitals, or family caregivers' current residences.

Participants

All participants were asked for their willingness to participate in this study. Purposive selection was used both criterion-based and theoretical sampling. Criterion-based sampling is the selective recruitment of participants according to preconceived criteria relevant to a particular research question (Haber, 2002).

Criterion- Based Sampling

Criterion-based sampling involved seeking caregiver who had experienced in taking care for their HNC patients in Ramathibodi hospital, as tertiary care and Lopburi Cancer hospital, as one of the National Cancer Institute in suburb area. Caregivers were eligible if they:

(a) are over 18 years of age.

(b) live with their HNC patient.

(c) identify themselves as the primary caregiver who is providing day-to-day care to a relative at home.

(d) are not suffering from a life-threatening illness that would prevent them from continuing in the caregiving role over the length of the study.

(e) are not financially reimbursed for caregiving activities.

(f) have been a caregiver for a minimum of 6 weeks prior to the study.

HNC patients are individuals who:

(a) have a medical diagnosis with primary original of HNC and are in treatment or after treatment less than one year.

(b) are over 18 years of age.

(c) are not suffering from a serious concomitant illness likely to result in death during the study period.

(d) are dependent in one or more of the following ADLs: bathing, dressing, toileting, transfer such as getting in or out of a chair, continence, and feeding and dependent in one special care activities such as wound care, suction, and tube feeding.

Theoretical Sampling

Theoretical sampling refers to sampling on analytic grounds developed in the cause of the study (Strauss & Corbin, 1998). It was employed to achieve a theoretically complete account of quality relationship of family caregiver with HNC patient. The researcher began using theoretical sampling on the basis of concept that has proven theoretical relevance to the evolving theory, to refine the concept. For example, in my pilot study consisting of four participants, the emerging categories such as “reason to be a caregiver”, “perception of quality relationship”, “perception of quality of care”, and “perception of cancer disease” guided theoretical sampling within the next participants and interviews. In addition, I found that women and men reported their reason to be a caregiver in difference issues; for example, female in wife’s role had reason to be a caregiver based on their responsibility whereas male in husband’s role had reason to be a caregiver based on their feeling about love and concern. Moreover, all of the four participants did not understand the word “quality relationship” as they said it was very difficult to define and cannot explain what is the meaning of quality relationship in their perception. Therefore, these results guided me to interview both male and female. Other than guiding me to screen caregivers who are in wife’s role and husband’s role, I also seek caregivers with different roles such as

son, daughter and others. On the basis, these data guided me to change and adapted interview guide to get more specific information in the next interview.

Theoretical sampling continued until theoretical saturation of each category was reached. Strauss and Corbin (1990) defined it as no new data are added to the category; the dense description of the category occurs, along with variation and process and the relationships between categories are integrated and validated. In this study, the researcher interviewed the next participant after adapting interview guide and then comparing and analyzing the coding to the last participant. The researcher used the interview result from the previous participant to plan for interviewing the next participant, and this was done repeatedly for all of the 15 participants. The result saturation obtained can explain and describe the process of quality relationship**.**

Theoretical Saturation

The saturation refers to the completeness of all levels of codes when no new conceptual information was available to indicate new codes or the expansion of existing ones. The sample size is determined by the data generated and the analysis of the data. In this study, the concept appeared as similar incidents were found after my interviews with six participants. These respondents were selected on the basis of having caregiving role; with varied characteristics such as age, sex, wife's role, husband's role and son's role, education level, as well as varied duration of care with their care-receivers. I collected data until saturation was achieved. Therefore, the sample of this study was 15 participants consisting of 12 women and 3 men who were interviewed to meet theoretical saturation.

Recruitment process

The aim of this study was to explore and describe quality relationship of Thai caregiver with HNC patients. In order to accomplish this, a diversity of perspectives or experiences is necessary (Hutchison, 1993). Therefore, study participants included caregivers with variation in age, gender, socioeconomic status, educational level, occupation, relationship with care-receiver, length of time in caregiving role, and the level of dependency among care-receiver. These diverse factors are considered since previous studies indicated that they may influence caring

behaviors and perceptions of family caregivers. In order to obtain the desired diversity among family caregivers, the following steps were applied.

1. Ramathibodi hospital in Bangkok and Lopburi Cancer Hospital in suburb area were selected as sources of information regarding HNC patients and their family caregivers.

2. Letters were sent to these hospitals to request for their permission to conduct the research and to obtain information regarding HNC patients who used the service in these facilities.

3. Upon receiving the approval from the Research Committee for Ethics of Mahidol University and Lopburi Cancer hospital to conduct the study in Ramathibodi Hospital and Lopburi Cancer hospital (see Appendix A), I contacted and provided information about the study to nurses and physicians who were in-charge of the clinic in the study.

4. In each hospital, the recruitment and assessment team, which includes the researcher and a nurse, identified HNC patients who meet the study criteria based on their health records.

5. The family caregivers selected from the population frame were based on their background data in order to obtain a study sample with the desired characteristics. The potential participants were given an overview of the study, and were asked to establish mutually agreeable times for in home interviews to occur, if willing to participate. Written consent from each subject participant was obtained prior to commencement of the interview.

Human subject protection

Before asking the participant to sign the consent form (see Appendix B), the research proposal was submitted for review and approval by the IRB committee, Mahidol University, and each of the Research Ethics Review Committees of Lopburi Cancer hospital in Lopburi province, Thailand. Prior to entering the study, each potential participant was informed about the purpose, nature of the study and the rights as a participant. In this way, those who do not want to participate in the study was able to do so based on a full understanding of the study's procedures and purpose. On the

first day, the full purpose of the study, the method, the potential risks and benefits to the participant in taking part in the study, and the protection of confidentiality were explained verbally to each participant. After that, permission to tape-record and conducting interview was established and an oral consent was taped then informed consent was reviewed with each participant.

Furthermore, the researcher very concern about confidentially and safety of the participant and their care-receivers in all process of study. Confidentiality was the most serious concern when conducting research that involves the quality relationship between caregiver and care-receiver. Caregiver's perception on quality relationship is a very sensitive issue. Suitable approaches were used to ensure the confidentiality of the participants and their care-receivers in this study.

In order to insure the confidentiality and anonymity of the participants and data, I myself as the researcher transcribed all of the tape-recorded interviews. After completing the study, the tapes will be erased. The participants' names were replaced with a numerical code number. Other identifiers such as the participants' address or location of the interview were removed from the transcripts. All of the written data was kept by the researcher in a safe place at all times and will be destroyed within five years. Only the researcher will have access to the files and audiotapes.

During the process of data collection through the interviews, some of participants had developed a sense of discomfort or emotional distress with some questions or stories that some had cried. The researcher the used some methods to help with participant's feeling as described below.

(a) The interview nature and some questions asked might have caused participant's discomfort. The researcher asked the participants to feel free to say directly when they did not want to respond to a specific question or did not want to talk about a particular subject. In this study despite with some questions of very sensitive issues such as that about their relationship with care-receivers, all of them were willing to explain their experiences with the care-receivers.

(b) During the interview, some of the participants had cried while recounting their stressful experience. The researcher asked them whether they want to stop or continue the interview. Every participant had the right to discontinue at any time during the interview or to withdraw from the study without any effect on the

services or benefits they and their care-receiver receive at the hospital. However, all of the participants agreed to continue the process of interview after they calmed down from such stressful experience.

(c) The researcher followed up by phone the participants who had emotional problem during the interview. All of the participants in this study can handle their stress and discomfort and needed no assistance.

Data collection techniques

After receiving the approval from the research committee for Ethics of Mahidol University and Lopburi Cancer hospital to conduct the study in Ramathibodi hospital and Lopburi Cancer Hospital, I contracted and provided information about the study to nurses and physicians who were in-charge of the clinic in the study. I approached all of the participants myself before collecting data and all of them were informed about the process, procedure and benefit of the study. Written consent from each subject participant was obtained prior to commencement of the interview. To obtain the data, there are the methods as follows:

The primary data collection techniques included an in-depth interview, and observations. I interviewed each participant and spent 30 to 70 minutes each time with individual participants. The participants were asked to talk about their relationship with the care-receiver prior to cancer diagnosis, after diagnosis, and during caregiving process, how their relationships affect their lives, and how they responded to the relationship. The interview guide was developed first in Thai by the researcher based on the aim of the study and was approved by thesis advisors to ensure that the questions used were valid and appropriate for the purpose of the study. After that, the approved interview guide was translated into English language by the researcher, major advisor, expert in caregiving research and expert in grounded theory research. The interview guide shown in Appendix C was revised from my preliminary work I had already done in four interviews. It contained open-ended questions and revised by the researcher to be more focus on capturing information about major categories such as " feeling about their relationship between participant and his/her care-receiver" and change some words to make it easy to understand such as using

"what is your feeling" to replace "what is your perception of quality relationship". From the major categories, if participants fell into groups, I asked how they took care for their care-receiver. I used only one opening question asking participants to explain their experience in their caregiving role. I encouraged the participants to clarify and elaborate the detail of their experience and relationship.

Each participant was interviewed once or twice depending on how much the information I could get from the first interview. The first interview was done in person. The second one was done in person or by telephone in order to follow up and make sure that I understood everything correctly and it allowed time for participants to think back about their experience. I did the second interview by telephone in case I could not do the interview in person; for example, the participant did not live in Bangkok or they felt uncomfortable if I visited them at home. In the second interview, five participants were interviewed by telephone. Observation was going on while interviewing the participants in this study. In grounded theory research, this observation focuses on the interaction in a situation and the analysis focuses on the symbolic meaning transmitted via action. The analysis looked at the interaction, patterns of interaction, and their consequences. During interview, I also observed the participant's action, appearance, feelings, and interaction with the care-receiver, family, and living environment that relate to the caregiving situation.

Data Collection Procedures

Prior to the interview, the researcher was engaged in general conversation with the participants to establish rapport and trust for gaining access. Then, an in-depth interview, the main method of data collecting, was conducted. The data from other sources were also obtained through interview. A field note was written after each interview.

The researcher was the major research instrument of this study. The researcher's socio-cultural background was provided to the reader to reflect the position taken in conducting this research. An interview guide, a demographic data form, and field notes were used for collecting data. The researcher played a major role in the process of inquiry, not only in interpretation of data and presentation of research

results, but also in development of the research question; therefore, the researcher's voice was apparent in this research.

Field Notes

Field notes were used throughout data collection to record what occurred during the interviews based on watching and listening with little interpretation. Certain aspect of the interview setting help remind the researcher of the events, actions, and interactions, and trigger ideas and reflections. The field notes were written as soon as possible after each interview to minimize the potential of loss of accurate recall. The field notes were reviewed and used to supplement audio-tape transcription to enhance the understanding of each participant's interview.

Data analysis procedure

Interview transcripts and field notes were analyzed using the procedures of grounded theory. Data analysis of grounded theory composed of open coding, axial coding and selective coding (Strauss & Corbin, 1990), as described below.

(a) Open Coding

Open coding is the initial phase of grounded theory analysis. During this stage, concepts are identified and developed in terms of their properties and dimensions. Similar events and incidents are grouped together and coded to capture similarity. In this stage, I reread each transcription many times and then began examining the data line by line and placed conceptual labels on each discrete incident, idea, and event. While coding, I asked myself "What was the major idea brought out in this line?" In this way, connection, courses of events and hidden massage were identified. An example of one female participant in my preliminary work and coding names is presented in Table 3.1.

Table 3.1 An example of coding names in open coding

Interview	Coding names
R: Could you please tell me about your caregiving experience, beginning from since when that you've started to take on the caregiving. P: Uuh, it's started since April 2013. It's that I have to look after him, it's my duty, we have shared both happiness and suffering. I am willing to do so, it's nothing but I am worried about him (crying tears), sympathy him.	• reason to be caregiver: - Taking on the caregiving because of obligation. - Shared happiness and suffering. - feeling sympathy.

In the example, I got the participant's reason to be caregiver. How did she come to care for her husband? She said she come by herself and her feeling with her husband is sharing both suffering and happiness because they spent time together for long time ago, her responsibility as wife's role, and feeling sympathy.

Like the above example, in this study, I reread interview transcripts of each participant to conceptualize and place names line by line. The product of this analytic immersion was collection of codes for all cases. Next, to discover anything new in data and to gain greater understanding, I used the procedures of comparative analysis and asking questions. The codes data, or concepts were compared against each other for similarities and differences, categories or patterns begin to create. An example for presenting coding comparison was described in Table 3.2

Table 3.2 Examples of coding comparison

Codes	Case 1	Case2	Case3	Case4
Reason to be caregiver	-my obligation -have shared both happiness and suffering. -willing to do -felt sympathy. -he love me and I love him.	-willing to take care. -no one else.	-people with cancer will not live long. -wife's obligation -feeling of love	-she loves me while I have nothing. - felt sympathy -feeling of concern

After labeling concept, I did in terms of properties and dimensions of coding. Properties are defined as the characteristics of a coding or category and dimension as location of a property along a continuum or range (Strauss & Corbin, 1998). The next step was to develop categories. The question that I asked myself was "what was this and to what incident did it relate?" The concepts appeared as similar incidents were grouped together under more abstract concept called a category. In this study, name of categories came from the pool concepts already discovered in data and the literature, or they were my invention. Examples of these categories, their properties, categories, dimensions and their codes were described in Table 3.4.

Table 3.3 Examples of properties and dimensions, and codes of categories

Categories	Codes	Properties	Dimension
Reason to be caregiver	-feeling of sympathy	Intensity	Negative
	-Love		Positive
	-Responsibility		Neutral
	-No one else		
Giving meaning of quality relationship	-Love	Intensity	High –low
	-Sympathy		
	-Caring		
	-Connectedness		

After grouping concepts into categories, I also developed code notes and memos to record my ideas about the connections between data and analytic schemes. Here is an example of one female participant in my preliminary work:

Case #1: A Thai female, thin and tall, with exhausting look. During the interview she cried fitfully. She talked about her experience in taking care of her husband. She took on the caregiving all by herself without anyone else. She takes care of her husband with ADLs care including food preparation and tube feeding, suction, bathing, and toileting. Her husband had the problem with self breathing and relied on respirator at all time. She cried fitfully and said that her reason to take care of her husband is that her husband loves her and she loves him too. She worried about her husband and feeling of sympathy him. It is the feeling of shared

happiness and suffering, and it is her obligation as his wife; she is willing to take care of him.

Memo: She gave information about her experience in taking care of her husband suffering from cancer for 5 months. Regarding her previous relationship with the husband, she said it has been good. They married and have lived their life together for about 34 years which was very long. It corresponded to her words of what she feels and takes care of her husband because they both have shared happiness and suffering.

As observed from her reaction and expression towards her husband during the care, it was gentle, with smile, eye contact, holding hands all the time during care activities such as bathing. She told about her feeling toward her husband that it is the sense of love, concern, sympathy, with the thought that taking care of the husband is the wife's obligation. Other than that, it is the link from previous feeling of love between her and her husband without only sexual relation. For this first case however, it was very difficult to describe it in the sense of quality relationship or have her explain it. She described the meaning of quality relationship as love, caring, and sympathy. Based on her meaning of love, she defined love is the feeling of affection between her and her husband without only sexual relation. The meaning of caring in this case refers to the feeling of concern with her husband because they spent time together very long time. Feeling of sympathy refers to her feeling about her husband suffering from cancer disease. Next is case # 2 for a comparison.

Case# 2: A Thai female, with smiling face. She told about her experience in taking care of her husband, starting from her first observing her husband's abnormality with a mass at the neck. Since her previous obligation was only a housewife without that much rights and their previous relationship is that they left each other alone without much intimacy, so she just act as observer on the symptom of her husband and watch from a distance. Until the illness turn serious with obvious mass that she began to dress his wound and her husband agreed to an examination with an advice from his supervisor and his sister. She felt that her husband never believed her and also scolded her.

Regarding the characteristics of this family relationship, her family is a nuclear family type with 3 members, i.e. father, mother, and a daughter aged 26 years currently furthering a master degree program at Bangkok University. About their living before her husband's illness, her husband took the role of head of household and her obligation was housekeeping. When asking about her reason to take care of her husband, she said it is the obligation of wife, and her husband has no one else. Besides, she is the one who has most free time because she does not work. Asking about the care, activities done for her husband, she takes care of tube feeding and dresses the wound at the neck. While giving care, her husband was upset for what she did for him and was moody intermittently. She has intention to look after her husband is much different from that of the caregiver Case #1. This is because when asking about her feeling toward her husband, this Case#2 was not sure whether or not what she thought of her husband is love, rather she felt it is her obligation to take care of her husband by his status on her capability. She did not feel stress or tortured as in Case#1. On observing the interaction between the caregiver Case#2 and her husband during his hospitalization, it was found that she came on visiting schedule and sit watching her husband but neither talking nor holding hands. Sometime her husband was moody and argued but she kept silent, just sit and listen.

In conclusion, in open coding, I conceptualized, gave name, compared cross codes, and created categories and their properties and dimension. Moreover, I developed my codes and memos during open coding (see Appendix D).

(b) Axial Coding

The next stage, axial coding was employed by linking subcategories to a category. The purpose of axial coding is to look for how categories relate to their subcategories as well as to further develop categories in terms of their properties and dimensions. The process involves sorting the information and searching for patterns. Therefore, the processes of open and axial coding were preceded together, as the interview data were coded and clustered into categories in open coding and then compared and examined their linkages in axial coding. Categories and their properties and dimensions were developed at the same time that the relationship was sort out. Subcategories were linked to a category in several relationships such as causal condition, action/reaction strategies, and consequence. From the previous example,

"reason to be caregiver" and "giving meanings of quality relationship" led to the occurrence of this study "provision to care" was a consequence of quality relationship.

(c) Selective Coding

The final coding procedure is selective coding. Selective coding is the process of validating the relationship between a core category and other categories. The core category can be identified by its centrality, frequent occurrence, good connections to other categories and implications for more general theory. The purpose of selective coding is to integrate the categories along the dimension level to form a theory (Strauss & Corbin, 1998). During selective coding, every category in opened and axial coding was compared with the core categories. These relationships were then validated through comparison with existing and new data.

To give an example from my preliminary work, after redefining all categories, I did have a tentative core category. It was "reason to be caregiver, quality relationship and provision to care. In this step, I asked myself to explore "what was the quality relationship that Thai caregivers with HNC patients that promotes caregivers to care for their care-receivers? I recorded memos and draw diagrams that represent the linkages (Appendix D). I wrote a general descriptive overview, or story line, and verify it with the participants.

Regarding data analysis in this study, meetings with my advisors, and 2 co-advisors in Thai was very important. Initial meeting was arranged for the discussion about interview and open coding after I independently coded the first two interviews. I, my advisors, and 2 co-advisors met approximately every four or six weeks in the five-month-period of data collection and analysis. Subsequent meeting involved the discussion of data analysis, emerging categories and their properties, and linkage among categories. Transcripts, memo, and diagrams derived from the analysis were provided for my advisors and co-advisors in Thai language. The last meeting involved discussion of the conceptual model.

Rigor in the research

Rigor in qualitative research is required to prevent error of either a constant or intermittent nature. Thus, the researcher must show that the study is rigorous by establishing trustworthiness (Sandelowski, 1986). The establishment of trustworthiness in this study includes credibility, transferability, dependability, and conformability (Sandelowski, 1986).

Credibility

Credibility refers to the believability, fit and applicability of the findings to the phenomenon under study (Glaser & Strauss, 1967). A qualitative study is credible when it presents such faithful descriptions or interpretations of human experience that the people having those experiences would immediately recognize them as their own, from reading the descriptions or interpretations (Sandelowski, 1986). However, the factors that interfere with credibility include: 1) historical antecedents leading up to research; 2) changing relationships between participants and researcher; 3) informant mortality; 4) difference between those studied and those not studied; 5) the reactive effects of the presence of the researcher; 6) contamination of the researcher by unit under study.

In grounded theory, credibility is achieved by methodological techniques which include: 1) using the constant comparative method, where data are continually validated by triangulating the information that is gained from in-depth interviews, field observations, and other documents; 2) the theoretical sampling is flexible to verify information from multiple sources and participants, thus the relation between theoretical sampling and explanation is iterative and theoretical led. The theoretical sampling method also includes finding negative or deviant cases that add different dimensions of knowledge to information of the emergent theory (Mays & Pope, 1996). Strauss and Corbin (1998) stated that the grounded theory approach is an attempt to verify its resulting hypothesis through comparisons with incoming data.

Therefore, the four methods were used: 1) prolonged involvement; 2) triangulation; 3) peer debriefing in order to enhance the credibility of the data collection and analysis.

1) Prolonged involvement is a goal of building trust. However, building trust as goal was not an easy task in a limited time of this study. I was confident that there was a good relationship between participants and me, which encouraged them to share their experience and their feeling about relationship with their relative patients. I noted that in the second time of interview, the participants usually explained in more details their feeling and experience in their caregiving situation.

2) Triangulation of different data was used to increase credibility of the findings by using different modes, such as observation, in-depth interview, and field notes that were written by the researcher.

3) Peer debriefing refers to an activity that provides an external check on the inquiry process. In this study, peer debriefing involved three university instructors who are experienced in qualitative and caregiving research. Each instructor read the findings independently and confirm or question the categories and emerging sub-categories.

Transferability

A test of transferability is passed when the findings are grounded in and reflect the phenomenon being studied and when the readers of the descriptions, explanation or theory derived from the data find them meaningful in terms of their own or other familiar contexts (Holloway & Wheeler, 1996). In this study, transferability was ensured by explaining the quality of relationships and how they change or don't change during a caregiving situation and also how this affects the individuals involved.

Dependability

Reliability in quantitative research refers to the consistency, stability, and dependability of a test or testing procedure (Sandelowski, 1986). In a qualitative study, dependability is used to substitute criterion for reliability and one of the ways in which a research study may be shown to be dependable as opposed to consistent is for its process to be audited, that is, external checks are made (Holloway & Wheeler, 1996).

In this study, the dependability of the interpretation process was increased by having nine samples of interview transcriptions analyzed by myself and my

advisors and 2 co-advisors who have experiences in qualitative and caregiving research. The concepts and categories were compared and discussed to agreement.

Confirmability

Confirmability means that the data are linked to their sources in a way that allows the reader to establish that the conclusions and interpretations arise directly from the data (Holloway & Wheeler, 1996). Guba and Lincoln (1981) suggested that conformability was achieved when credibility, transferability, and dependability were established. Furthermore, the researcher very concerns about the validity procedure that shifts from the researcher to participants in this study. I used the method of member checking by calling to three of the participants to talk about the data and interpretating back to the caregivers so that they can confirm the credibility of the meaning and characteristics of quality relationship. Throughout this process, the researcher asked the participants if the categories make sense. In this way, the participants add credibility to my study by having a chance to react to the data and the final narrative.

CHAPTER IV
RESULTS

The purpose of this study is to explain the meaning of quality relationship in family caregiver with HNC patients and explore the process of quality relationship by using the grounded theory methodology. The study findings are presented in 3 sections. The first section focuses on the characteristics of participants. The second section is to explain the meaning of quality relationship on perspective of family caregiver with HNC patients. The third section is to provide an overview of quality relationship process in Thai HNC caregivers and focuses on the causal condition of reason to be a caregiver, which is the first phase in quality relationship process; quality relationship as core category that is a central explanatory concept pertaining to the phenomena under study; as reaction/interaction from the caregiver for maintain quality relationship; and provision of care is the consequence of quality relationship process.

In the presentation, the constructs and the concept emerge from the raw data in each phase are presented. Statements from interviews are quoted with identification numbers and transcripts line numbers. Interaction patterns are observed and described including the caregivers' actions, appearance, feelings, and their interactions with family, and living environments as related to caregiving situations. However, in some instances the participants felt uncomfortable to be observed in various activities, so the researcher would forgo observation of those activities.

Section 1: Characteristics of participants

The participants in this study were 15 family caregivers. The majority were spouses (13; 12 wives and one husband) while two were sons. The participants who defined themselves as primary caregivers ranged in age from 23 to 67 years with the mean age 50.86 years (SD 10.09). Their education level ranged from primary to vocational education. The majority of participants (n=10) had primary education level.

Three of caregivers still working even their taking care of their care-receivers. All were married, and four of them reported their current second marriage. The majority are Buddhists (n=14). Their mean caregiving experiences with 6 months, ranged between 2 months to 1 years and 8 months. Only one caregiver reported with 2 months of caregiving experiences. All of the caregivers (n=15) explained their caregiving activities related to providing ADLs care, and most of them reported special care activities including wound care (n=12) for such as jejunostomy wound and tracheostomy care. All of the caregivers had to prepare food for tube feeding and feed their care-receivers. Among the care-receivers diagnosed with HNC, there are 13 spouses (12 husbands, one wife), and two fathers. Their mean age is 55.17 years (SD= 8.63), ranged between 43 - 79 years. Regarding educational level, the majority of them (n=8) reported with primary education. Most of them are married (n=14) and 5 reported second marriage. Only one care-receiver had employee status. All of them are Buddhists. The types of cancer treatment varied: two cases with radiotherapy only, the rest combined with other treatments such as chemotherapy (n=9), surgery (n=1), surgery and brachytherapy (n=1), and surgery and chemotherapy (n=2). Furthermore, most of the care-receivers in this study (n=10) was diagnosed with HNC stage 4. All of the cases had a feeding tube and five cases had tracheostomy tube.

Overview of the characteristic of caregivers and their care-receiver

This overview describes the relationship characteristics between caregiver and their care-receivers and the interaction patterns of caregivers in caregiving situations including caregiver's action, appearance, feeling, and interaction with their care-receivers, family, and living environments. There were fifteen cases in this study. In three of the fifteen cases, case #10, case #13, and case #14 the interaction patterns between caregiver participants and their care-receivers during activities were not observed and described because the participants felt uncomfortable to be observed. Each case of the relationship characteristics between caregivers and their care-receivers was depicted.

Case #1

A female caregiver aged 53 years, a Buddhist, was married, completed vocational education, and currently works as a housekeeper at a condominium. She has experienced taking care of her husband with esophageal cancer stage 4 for about 6 months. She helps him with ADLs care including bathing, food preparation, and toileting. Special care activities are jejunostomy tube feeding, tracheostomy care, wound dressing around jejunostomy tube, and suction. Prior to taking on this caregiving role, she said she has been married and lived with her husband for about 34 years with one adult child who has her own family. She and her husband live by themselves. Before being diagnosed with cancer, her husband has been in government service at the Department of Corrections, and he resigned after falling ill with cancer. She is the only one who take care of him all along for his illness while remains an employee at the condominium. During the time of care, she has to commute upstairs at 7 floors and downstairs between her office and his room since she is still at work but can make time to look after her husband.

Based on the researcher's observation of interaction between the caregiver and care-receiver, it was found that during the care-receiver's hospitalization, the caregiver came to take care of her husband at all time during her visit. Activities she had been doing are bathing, and massage. Both held their hands and smiled very frequently when they spent time together. However, sometimes it was noticeable that she cried in front of her husband and looked weary but she came and look after her husband every day.

Case#2

A female caregiver, aged 62 years, a Buddhist, was married, completed the 4^{th} grade of primary school, and is a housewife. Prior to taking care on this caregiving role she has been married and lived with her husband for about 27 years with a daughter who stays with them. She experienced taking care of her husband with parotid gland cancer stage 4 for about 2 months. She takes care of his ADLs including bathing, food preparation, and toileting. Special care activities are nasogastric tube feeding, tracheostomy care, and wound dressing around his neck. The characteristic of this family is a nuclear family type; there are three of them, i.e. the caregiver, her

husband and a daughter aged around 26 years currently in a master degree program of a university in Bangkok. For their living prior to her husband's illness, her husband took role as head of household, while the caregiver just do the housekeeping. For any family decisions, her husband makes any decision alone without consulting with or asking for her opinion. During the caregiving situation, the care-receiver showed that he was upset for what was done for him by the caregiver, and become moody every now and then.

As suggested by the observation of interaction between the caregiver and her husband during his hospitalization, the caregiver came on visiting schedule and sit down watching her husband without any words from them or holding hands. Sometimes the care-receiver was irritable but the caregiver kept silent and did her care without talking.

Case #3

Female caregiver aged 54 years, a Buddhist, was married, completed vocational education, and has resigned from government service for about 1 year because she has to take care of her husband suffering from nasopharyngeal carcinoma stage 4. She said that she has been married with her husband for 6 years but she knew he had cancer 2 years before she decided to marry him as she thought he was cured. Her husband had one adult child with his ex-wife before he married with her. Not long after living together, her husband's illness recurred after their spent time together 3 years. During this time of illness, her husband can endure neither to radiotherapy nor chemotherapy because of his physical intolerance. Moreover, the side effect from the previous treatment causes him blindness in one eye and impairment in one ear. For this time, her husband decided not to repeat radiotherapy and chemotherapy. She used an alternative treatment by seeking and having herbal medicine obtained from many sources. Once having someone's recommendation, she took her husband around. Until her husband get worse and had breathing difficulty that she took him for tracheotomy. Now the caregiver is responsible for taking care of her husband by helping with ADLs including bathing, food preparation, and toileting. Special care activities include jejunostomy tube feeding, tracheostomy care, and wound dressing around jejunostomy tube.

The caregiver felt that she had to take this role because her husband thought it is the wife's obligation to look after her husband and the loved one. With her past experience of her mother's illness that she did not do much for her, this time it's her will to take good care of her husband. However, she felt that she has to take on this duty she dislikes and is unskilled but unavoidable. Despite her exhaustion she has to do it because her loved one might not be with her that long. The caregiver concluded her relationship with her husband as love and she will do her best for him while their relationship has been more closeness than before. She thought her husband pities and loves her more. However, from her self-assessment for what she has done for her husband, she indicated she did her best but not yet good enough because she cannot keep on schedule, for example, she was unable to prepare blenderized food for husband on time.

According to the first time of telephone conversation about caregiving experience of the caregiver, she said her life has been more tiresome and difficult during this time than before because her husband is experiencing increased pain and there are more workload than previously. The caregiver has to prepare blenderized food, squeezed fruit and vegetable juice, dressing wound at his neck in the morning and evening times, and she cannot go to bed until around 1.00 a.m. Her husband is in bad cough with much sputum spread out in the house. Today she has a problem with abrasive hands with a lot of pain because they are always soaked all day during washing vegetables and his stuff. She also feels numb in her legs and figure tips but she did not see the doctor for she cannot follow the appointment in time because she has a lot of workload to finish rather than going to the hospital.

When asking the caregiver about how she is feeling, she said she has been very tired but what she can do, she said "Even I can't but I have to. I told my husband I can't make it, I have to go upstairs and downstairs so many times a day. My husband then gave me a massage on my legs and helped as much as he can. He tried to bath himself, and gave himself pain release because I can no longer endure deprived sleep. My husband is in much pain, the mass on his neck grows bigger. After his appointment visit to the doctor, he had to take paracetamol 6 times a day, so the doctor decided to give him oral morphine to relieve the pain but the condition has not much improved". According to the conversation, the caregiver consistently records her

administration of medicine to her husband, reflecting her attention despite her complaint of tiredness. Through the conversation, she laughed intermittently and repeated of her discouragement but no retreat.

Case#4

Male caregiver aged 49 years, a Christian, was married, finished grade 4 of primary education, and is self-employed in transportation. He was on his work while using the communication via telephone. Prior to taking care this caregiving role, he had been married and lived with his wife for about 20 years with 2 children. He has experienced taking care of his wife for 2 months after she was diagnosed with tongue cancer stage 2. He takes care of her in ADLs including food preparation, and transportation for visiting doctor. Special care activity is nasogastric tube feeding. During his wife's first chemotherapy, the caregiver kept attending and encouraging her. He looks prudent and calm and smiles while talking. The researcher's experience from the conversation with this caregiver suggests that his view on their relationship and the reason to be a caregiver differed from those of the previous 3 female caregivers. He viewed that the important things that lead him to take this caregiving role must at first be love, concern, and sympathy, while obligation comes later.

When asking about his feeling regarding his wife's illness, the caregiver felt sorry for his not knowing about her suffering from tongue cancer until it was late. He and his wife had together been through difficulties, but when it's time to be at ease, his wife became ill. He viewed that having cancer requires mental support and the caregiver should necessarily be only husband or wife or close ones to give the care-receiver encouragement. In his view on relationship, as his wife accepted and married him who has nothing he thought she loves him so much and that he has to take good care of her. He felt his life has changed because he won't have time for himself usual but he is willing to do this. He thought it has become his daily routine and if he fails to do it some days, he would feel something missing in life. He feels his feeling of love with his wife more than in the past when he came to take care of her because he felt sympathy her and he thought she has depended her life on him, decided to live with him.

Information obtained from interview via telephone conversation, the researcher made a telephone conversation with the caregiver because it was found that the care-receiver was not hospitalized for chemotherapy. The caregiver told that his wife experienced serious side effect from chemotherapy after the first administration. She had vomit and hair fall, and refused to receive treatment. The caregiver consulted with the doctor to change for other medication with less side effect as his wife cannot tolerate. She cannot eat. So she received another kind of medicine requiring no hospital admission, but she needs to come every day for radiotherapy. He was concerned that his wife will not recover because the doctor said changing type of chemotherapy may lessen treatment effect on the patient to be cured. He wants the researcher to talk to his wife as she is in stress and discouraged, so do the caregiver. The surgical wound in her mouth recurs, it is not certain if it was the effect of radiotherapy. They will wait for complete radiotherapy, and then he will take his wife to see the doctor in Singburi province for he thought about seeking complementary therapy. When the researcher asked him about this situation, he felt very worry and concern about his wife. However he felt that he has to take better care of his wife than in the past and gives her more encouragement and love as well.

Case#5

Female caregiver aged 51 years, a Buddhist, and has been married to the current husband for about 3 years and this is the second marriage for both of them. She attained grade 9, and works as an employee of the Department of Highways. She has experienced taking care of her husband for 3 months who was diagnosed with pyriform sinus cancer stage 4. She takes care of him with ADLs including bathing, food preparation, and toileting. Special care activities are percutaneous endoscopic gastrostomy (PEG) tube feeding, wound dressing around PEG. In addition she helps her husband especially in mental support because her husband thought of not wanting to live. Feeling discouraged from so much time spent in visiting doctor and examination in many sections each day including side effects of radiotherapy, her husband felt so suffering from neck pain. She said that it is her willing that she came to take care of her husband. However, she is also sad that the condition is so early for her but she can keep herself living with the disease. Regarding the caregiver’s view

on the relationship between her and her husband, she is happy when she saw her husband happy, she is not tired looking after him, she devoted all of her time to him, and she does her best and is happy to do so. She feels closer, with more love, sympathy, concern, and care for one another.

Based on self-assessment in taking care of the husband, the caregiver gave herself 80 against total 100 scores because she thought she had done her best with full effort. However there must be something lacked as her husband sometimes get upset. The caregiver said she thought she has been good but her husband still complains and is not satisfied.

From the observation during the care-receiver's hospitalization, the caregiver can visit him for some days since she has to work at the Department of Highways and it takes time to reach here because she stays far from the hospital. However, taking care of her husband at the hospital reflects her concern as they had eye contact, smiled to each other, and sometimes when her husband was unable to talk understandably, she communicated with writing. She thought that the relationship with her husband is in this way because they has just been married and lived together for only 3 years so they are still in lots of love.

Case#6

Male caregiver aged 49 years, a Buddhist, finished grade 7, a son taking care of his father with tonsil cancer stage 4. Previously he did the farming and after coming to look after his father, he let his wife take care of it instead. He has caregiving experience for 9 months with his father for his recurrent from tonsil cancer that he had 7 years ago. He helps with ADLs including bathing, food preparation, and toileting. Special care activity is nasogastric tube feeding. When asking him why he took on this main caregiver role in spite of having another three sisters. He gave a reason that since he is male and that makes it more convenient to take care of male patient in monkhood. However, other siblings also help during Saturday and Sunday. Besides, his wife helps prepare blenderized food. His other siblings stay apart so he thought it would be most convenient for him to do this role. He viewed that it is the child's role and responsibility to take care of father in time of illness.

Regarding the interview issue on family relationship, the caregiver said he worry and concern of him. Every time when he comes back home he thought of how his father would be doing now. When repeating the question and giving an example whether or not it is the same as the feeling he has toward his son. His answer is that it is love, concern and caring, and it is the obligation of children to parents.

Observing the interaction between the caregiver and his father, it was found that the caregiver stay overnight attending his father at the hospital. Unlike the visiting policy of Ramathibodi hospital, the caregiver took his father to Lopburi Cancer Hospital where relative is allowed to stay with the patient. He just lied down underneath the hospital bed in patient ward. However, as observed during his care for the care-receiver, they talk very little. Once finishing up feeding, the caregiver is out of the room sitting at the balcony; he is not with the care-receiver at all time.

Case#7

Female caregiver aged 51 years, a Buddhist, attained grade 3, has been married with her husband for about 9 years, the second marriage, earned no income and did not work since her husband falling ill 9 months ago. Previously, she had worked at the factory and resigned to do some trading in front of her house when her husband got worse. Most of her income is from borrowing it from her sister around 2,000 baht per month. She lives with her ex-husband's daughter who is currently in higher vocational education. She has 9 months of experience in taking care for her husband diagnosed with esophageal cancer stage 3. She helps him with ADLs, i.e. bathing, food preparation, and toileting. Special care activities are jejunostomy tube feed and wound dressing around jejunostomy. Based on a conversation with her, her husband has been diagnosed with cancer for about 1 year now and needs a surgery but her husband decided not to undergo the surgery with a reason of economic burdens like the study of her daughter and building home. Up until his condition became worse since last year that he had another examination but unfortunately the surgery cannot be performed because the mass grows big and the only thing that can be done is to have a surgery for jejunostomy tube to support his nutrition. She said the expense is her problem now.

On her view toward the relationship between her and her husband, she came to take care of her husband because he had no one and she felt sympathy him of having cancer. During the past, despite without nice words, her husband loves and has taken good care of her and her daughter as well, and there have never been conflict in the family. She expressed her feeling that after holding this caregiving role, she felt of increased closeness and connectedness than before that they each worked and were not living together. In brief, their relationship is explained as connectedness, sympathy, and caring. The caregiver concluded that quality relationship is understanding, love, sympathy, among which understanding is most important. Asking about her view regarding the care for her husband, she gave herself full scores because she will always look after him, never abandon him, and she thought she has done her best.

It can be observed from the interaction between the caregiver and her husband that she always sat by his side at the bed and asked if he wants anything while her husband stayed rest in bed all the time. During the time of interview she also explained about her situation like she had many problems with family income as she said most part of their family income was borrowed from her sister.

Case#8

Female caregiver aged 57 years, finished grade 4, in the role of wife taking care of her husband with tonsil cancer stage 2. Prior to this caregiving role, she has been a hired worker in farming. She had been married and lived with her husband for about 11 years and it is her second marriage. She has 6 months of experience taking care of her husband. She helps him with ADLs including bathing, food preparation, and toileting. Nasogastric tube feeding is special care activity. Interviewing with her suggested that she is in good mood and delighted that her husband will be going home soon. She talked about her feeling and pride of providing care for her husband. She assessed herself doing best care. Regarding her reason to take on this obligation, she thought it should be wife who will best cheer up her husband, no one can be better than wife and it is the obligation of wife. Besides she mentioned about love and felt that they must live together in old age.

To her experience of caring for her husband, she assessed that activities done for her husband are neither difficult nor complicated, compared to those even

more difficult faming job she can manage. Since taking this role, she felt her husband loves her more because of her taking good care of him.

While observing the interaction between the caregiver and her husband, it was found that the caregiver stayed overnight attending her husband at the hospital. She laid down underneath the hospital bed in the patient ward. As observed during her care for her husband, they talked and smiled very frequently because they knew from the doctor's orders that they would be home soon. After finishing up bathing, the caregiver sat on the chair near her husband's bed.

Case#9

Female caregiver aged 67 years, a wife, attained grade 4, has been married with her husband for 42 years, took on caregiving role for her husband with tongue cancer stage 4. Prior to this role, she did not work but it is only her husband who works to provide for the family by offering a transportation service on motorcycle. She has around 6 months of experience looking after her husband. She helps taking care of his ADLs including bathing, food preparation, and toileting, with special care activity of nasogastric tube feed. She talked about the symptom of cancer as infected wound and soon after completing the medication by the hospital, she will seek for boiled herbal medicine and other medicines for her husband. When asking her why, the caregiver expressed her thought that since it is his terminal stage, she must try something else for treatment.

The caregiver talked about her experience in taking care of her husband that she took on this obligation because she is his wife. During living their life together for 42 years, her husband has always been good to her. In time of wellness, they enjoy together, hence in time of illness how can she abandon him. Besides, she had experienced the care for her brother with Head and neck cancer until he was dead. This time she will put all effort and never leave him. In brief, the caregiver described her relationship with her husband that once he fell ill, she feels sympathy and concerned of him.

Based on the researcher's observation, the caregiver cried with the researcher. Her face was so sad. Occasionally she had eye contact with the researcher. She said she was worried for her bed-ridden husband. He might be worried that she

spends too much time speaking with the researcher. In addition, she is still concerned about the activity of nasogastric tube feeding for her husband.

Case#10

Female caregiver aged 47 years, a wife, has been married with her husband for 20 years, the second marriage, completed grade 4 of education. She takes care of her husband who has oropharyngeal cancer stage 4. Prior to this duty, she has been a daily hired worker, and once taking caregiver role, she quitted her work. She has experienced about 3 months looking after her husband about ADLs including bathing, food preparation, and toileting. Special care activities are gastrostomy tube feed and wound dressing around gastrostomy.

For issues captured from this caregiver, it was found that the caregiver did not talk much or express herself. The researcher had to lead by questioning and giving an example from findings of other cases. In brief, at first the reason given by her to step into this caregiver role is that her husband has no one. However when the interview was finished, the caregiver herself explained that she is willing to take care of her husband because he likes her to do so, but if he does not want to, she cannot. It means that the caregiver did not take this role because her husband had no one around as in fact he has his parents and his children who can take care of him. Therefore the true reason is that she is pleased to do so. When mentioning if her husband does not want her to take care of him, the caregiver seems to be tearful and sorry. She feels that they had been through difficulties together; she will take care of him no matter what. On the issue of relationship between the caregiver and her husband, she feels love, concern, and sympathy for her husband. After taking this caregiver role, she felt more love and sympathy toward her husband than previously that when her husband was not ill, she felt love but not sympathy for him. .

Case#11

Female caregiver aged 44 years with wife role, finished grade 4, has been married with her husband for about 22 years with 1 child, and takes caregiver role for her husband who has tonsil cancer stage 3. Prior to this caregiver role, she had been in trading goods but later quit. She has 4 months of experience taking care of her

husband. She helps with ADLs including bathing, food preparation, and toileting. Special care activities are gastrostomy tube feed and wound dressing around gastrostomy and tracheostomy care. Asking why she came to take this caregiver role, she thought he had no one. In time of wellness, they shared, in time of illness, how can she leave him, people will view her as bad. Besides, she thought having the disease her husband will not live long for he has been in consistent confusion and headache after radiotherapy. Regarding their prior relationship, the caregiver often quarreled with her husband because he is jealous and does not want her to talk to anyone else while the caregiver thought he does not love her, so they just live like that. Until her husband fell ill and told her that what he has done to her is due to his love for her. Regarding their relationship after her taking caregiver role, she felt more bond and sympathy, while her husband became more gentle and never complain as before.

Based on the researcher's observation of interactions between the caregiver and her husband, it was found that during her husband's hospitalization, the caregiver always sat by her husband's side. She was worried about his condition because she had to take care of him more than in the past. Sometimes he had to be restrained due to his confusion and headache. However, the caregiver still spoke with her husband, even though he was confused.

Case#12

Male caregiver aged 23 years, finished grade 3, is single, as a son who takes care of his father having glottis cancer stage 4. He had worked in a factory before taking this role, and later resigned for this duty. He has 4 months of experience in providing care for ADLs including bathing, food preparation, and toileting. His special care activities involve gastrostomy tube feed; wound dressing around gastrostomy, tracheostomy care and suction. He told that previously his relationship with his father is a kind of leaving each other alone because his father has new wife. He has never attached to his father since childhood, never even hugged or had meals together. When his father fell ill and his new wife did not take care of him, he had to resign from work to look after him because he thinks it is the son's obligation. After a period of time, he felt more closeness to his father. The caregiver assessed himself good at each activity although with some quarrel with his father. However, he thought

no one else can do these as good as him. Once taking this caregiver role for his father, the caregiver's behaviors have changed such as his stop drinking, smoking, and hanging out. However, an important point that the caregiver view himself to retain long in this role is that his sister and others provide for the expense during the care of his father.

It can be observed from the interaction between the caregiver and his father that the caregiver usually sat outside. Moreover, he walked around other patients' beds nearby his father's bed and talked with those patients more than he talked with his father. Sometimes he sat by his father side and cleaned around his tracheostomy wound when there was a lot of sputum.

Case #13

Female caregiver aged 45 years, completed grade 3, with the role of wife who has been married with her husband for about 36 years and have two children. She takes caregiver role for her husband with laryngeal cancer stage 3. Prior to this caregiver role, she has been a general hired worker, but quit now. She has 4 months of experience in providing care for ADLs including bathing, food preparation, and toileting. Special care activities are gastrostomy tube feed, wound dressing around gastrostomy, tracheostomy care and suction. According to the conversation with her, she said that this is the obligation she has to do since there is no one else. Her two children have their own families. She viewed that cancer is suffering, and if her husband dies, it will be alright as he will free himself from suffering. Asking about her feeling for this role, she said at first she was stressful and cannot sleep but when the time passed and she has seen some other patients who suffer more but can still smile, she came to think that they fight for themselves. Her husband can walk and help himself, so he has to fight too. She perceives the change in relationship that both of them have a sense of more concern and care and become closer than previously that they each just did their duty.

Case#14

Female caregiver aged 53 years, attained vocational education, a wife who has been married with her husband for about 30 years. She has been taking caregiver

role for her husband who has nasopharyngeal cancer stage 4. She works as a dressmaker at home and continues this job even when she has to take care of her husband. She has experienced taking care of her husband for 1 year during which she helps him with ADLs including food preparation and transportation, and special care activities of nasogastric tube feed, tracheostomy care and suction. She talked about her experience from the start of this role that it was because she loves him and they have lived together for long. According to the conversation however, it was found that she was rather concerned and had a relationship problem with her husband as she felt his behavior changed and he withdraws from family. He has never encouraged her. In addition, he has been in worse condition and needed tracheostomy tube surgery, hence more activities for her to take care of. She has been exhausted while receiving no expression of encouragement from her husband. Moreover, he clings to his girlfriend even more than before. Regarding her view about activities she did for her husband, she gave herself 8 against total 10 scores because she thought she cannot complete in some activities. When asking about the relationship between the caregiver and her husband, she viewed that taking on this caregiver role is not what she thought of as the role of wife, but it is because they have been together for so long, with love and concern. She thought no one else can do this as good as she does because she is the one who best understands his mind. In overall, she felt that her life has changed since she has taken this role due to the care-receiver's temper change. Her life changes because her husband changes.

Case#15

Female caregiver aged 58 years, finished grade 4, as a wife who has been married with her husband for around 30 years. She takes care of her husband with pyriform sinus cancer stage 4. Previously she had worked by selling grocery and later quit after taking this caregiver role. She has 1 year and 8 months of experience in taking care of her husband. She gives him care about ADLs including bathing, food preparation, toileting and transportation, and also special care activities of gastrostomy tube feed, wound dressing around gastrostomy, tracheostomy care and suction. She also helps with financial matter. She talked about her caregiving experience since her first step into this role.

In the first meeting with her, she expressed her feeling that she was exhausted and wished her husband dead so he will not be suffering as she herself cannot go on like this anymore. They have three daughters together, two of them work and have their own family, and the youngest one is still unemployed. She said that it is difficult and very costly taking her husband to see the doctor each time. She is the one who take him to the hospital because she does not want to bother her daughters from their work. After talking for a while, she cried as she felt she has long been caring her husband and she can no longer bear it. She want her husband to get over it and accept that the disease cannot be cured because as of now her husband still want to undergo radiotherapy and other treatment methods because he does not want to die. However, the attending doctor informed that the condition cannot be cured but only palliative treatment can be done. She wishes her husband dead without suffering. She felt her husband is just like the one who is drowning but struggling and suffering. He will not give up the treatment and wants to live, and does not accept that the disease is incurable now.

Before having a conversation with this caregiver, we had 2 informal dialogues. The formal conversation used the counseling room at Somdejpratepparatana building of the hospital as an interview room since the caregiver has to take her husband for follow up. The care-receiver is in serious pain. From the first two informal dialogues, the researcher had questions in some points because she thought about wanting her husband to die early as she has been too tired and has many problems in life. This opportunity allows for talking in detail and to know her reason and need why she wanted her husband to die. Inquiry and tracking from the history of previous relationship between the caregiver and her husband prior to his illness with cancer permit the researcher to know that they had poor relationship before; the caregiver was physically abused and had never been attended by her husband until he fell ill, while physical abuse continues when he was not satisfied with what she had done for him. When asking about her reason to be a caregiver, the details captured are somewhat different in terms of her belief about their previous *"karma"* that leads her to take care of him in this life. In view of love, however, she is still in love with him. Moreover, she viewed that she had done her best for all activities she takes care of for

her husband and she thought she had done enough comparing to other patients who had already passed away.

Based on the observation of care and interaction between the caregiver and her husband, it was found that during their waiting to see the doctor, the caregiver usually sat outside and let her husband stay in bed alone and there was no talk or asking if he wanted something. Her face looks stressful and weary. Comparing her expression between talking in person and on the phone, the researcher can perceive she felt more comfortable to reveal information via telephone. For this case however, many contacts took place allowing to know that in her mind she felt she had done for her husband with full capacity while she faced with many family problems.

In summary, the majority of the participants in this study were spouses (13; 12 wives and one husband) while two were sons. Their mean caregiving experiences with 6 months and had different situations of caregiving. Two caregivers reported caregiving experience only for 2 months (case#2 and case#4). All of the caregivers explained their caregiving activities related to providing ADLs care, and most of them reported special care activities including wound care (n=12) for such as jejunostomy wound and tracheostomy care. All of the caregivers had to prepare food for tube feeding and feed their care-receivers. Among the care-receivers diagnosed with HNC, there are 13 spouses (12 husbands, one wife), and two fathers.

The observed patterns of interaction included only the participant's actions, appearance, feelings, and the participant's interactions with the care-receivers, while family's interactions could not be observed. The family did not live in Bangkok, and they felt uncomfortable to allow the researcher to visit them at home. The interactions between caregivers and care-receivers can today be observed and described as most of the caregiver and care-receivers have better relationships than in the past. It was found that the relationships were poor between caregivers and care-receivers in only two cases; even though they spent more time together (Case#2, Case#15).

Section 2: The meaning of quality relationship in perspective of family caregiver with HNC patients

What is the quality relationship of Thai caregiver with HNC patients? and What are the characteristics of quality relationship that support a caregiver? These questions are predominantly concerned with how Thai caregiver with HNC patients described their quality relationship with their care-receiver. The most frequent responses to interview questions about the meaning of quality relationship were “I don’t know”, I don’t understand” and “I don’t know how to say”. Even though relationship between caregiver and care-receiver appeared to be significant feeling in their lives, they could not define it. One explanation of this lack of articulation might be that they often have difficulty expressing themselves verbally. However, the researcher modified the questions to capture the nature of Thai language and based on the observation of interaction between caregiver and care-receiver, it was found that quality relationship as perceived by caregivers is defined as the feeling of 1) love, 2) sympathy, 3) caring, and 4) connectedness with their HNC patients.

1) Love

“Love” is called “รัก *(ruck*)” in Thai language. Love is one among the characteristics of quality relationship as the meaning defined by most of the caregivers. “รัก *(ruck*)” in Thai language has a meaning close to a number of words in English language such as love and affection. According to the literature review, the word “*ruck*” in this study is very close to the meaning of love. Love can be studied as a relationship, as an attitude, as an experience (Fehr & Russell, 1991). Love is defined by Johnson (2008) as a primary human need, and as related to the attachment between partners. Moreover, it is seen as rational, full of give and take (Burns, 2000). The word “love” in the Thai language can be explained and used for a variety of people and relationships such as love between parents and their children, love between spouse and his or her partner, and love between family members. For example, the parents’ love for their children, a spouse’s love for his/her partner, kids’ love their parents, and family members’ love for each other.

Most of participants defined the meaning of quality relationship as the feeling of love. According to their feeling with their care-receivers, love is an important feeling the caregivers expressed. However it is very difficult to describe and explore because this word is very abstract for the caregivers. Most of them think this word is less important than action that they do to take care of their care-receivers. During the caregiving time, most of the caregivers expressed this feeling toward their care-receiver as they thought the person with HNC disease will not live long. Therefore, this study found that most of them reported their taking caregiving role based on the feeling of love as the first characteristic of quality relationship.

The meaning of love in this study can be described in various ways. For example, caregivers who were spouse mostly explored their feeing with their husband and wife in the form of desire to return the feeling of love to their spouse, as they experience how their spouse give them love and take good care of them. Furthermore they had lived together for a long time prior to the caregivers' taking on caregiving role.

Love is defined as the caregivers' feeling to return for the care-receiver's love extended to them. Most of caregivers define quality relationship as love. With their reason to be a caregiver from the history of their relationship, they base this role on love before taking care of their patients as most of them are spouses who have commitment to live together. Other than love from spouses, feeling of love can come from caregivers who are son because they thought they have to give it return this feeling to their father. Caregivers' feeling of love to their care-receivers did not happen suddenly but for a period of long time when they spent time together. A caregiver expressed her feeling that now she loves her husband even more. This is because when they were alright they didn't do much taking care of each other but just going places and eating out.

> *"He loves me and I love him, we share both happiness and suffering[1]" (Case# 1)*

"It's because everything I've done come from our love for each other. Everything I've done I am willing to do it. Sometimes I have to cook rice at eight pm. that I am usually in bed but I am willing to do so.[2]" (Case# 5)

"I have to encourage him that I love him, I'll take care of him. We are old we have to live together. You have to take care of yourself to live longer. I told him that I won't go anywhere, I'll continue to fight. You fight, I fight. Do you fight? I asked him. He said yes, and then we tacked. It's about 2 months that we are here[3]" (Case # 8)

2) Sympathy

The second characteristic of quality relationship referred to by most of the caregivers is the feeling of sympathy with their care-receivers. The Thai word "*สงสาร (songsarn*)" has a meaning close to some words in English language such as sympathy, pity, and empathy. However, the meaning of sympathy may clearly describe the feeling of "*songsarn*" that most of the caregivers explored in this study. According to the literature review about the meaning of sympathy, pity and empathy, sympathy is a key dimension of the quality of social relationship that is the feeling of the individual's readiness to feel sympathy for a person in distress and the motivation to benefit a needy other (Kienbaum, Volland, & Ulich, 2001). Kienbaum and colleagues (2001) defined sympathy as an emotional response that is elicited from the perception of another's emotional state and consists of the feelings of sorrow or concern for the needy other. This meaning differs from the meaning of pity that is intended it to mean the feeling of sorrow for others' suffering or misfortune, and the attendant's desire to be of help (Geller, 2006). However, American Heritage (2000) dictionary defined pity as closely equivalent in the meaning of compassion, especially when pity is deeply felt and accompanied by strong feelings of wanting to alleviate pain and suffering. Caregiver's feeling of *songsarn* (sympathy) is meant beyond pity because most of them expressed their feeling that include love, caring and connectedness that are not just the feeling of pity.

This feeling comes after their patients were diagnosed with HNC and the caregivers experienced the care-receivers' suffering from cancer, and it is their inner feeling. This feeling has various influences. Most of the caregivers have lived with the care-receivers for very long time, they feel sympathy seeing someone they love suffering from difficulties in eating and breathing, and severe pain due to cancer. They define this feeling of sympathy based on their feeling for their care-receivers' having cancer, suffering from the disease, and sorry for the care-receivers.

Sympathy is the feeling occurred after the caregiver's knowing that the care-receiver was diagnosed with cancer. This may be due to the influence of cancer belief or realizing of the care-receiver's suffering. The majority of caregivers expressed their sense of sympathy as follows.

> *"I want him to be normal as we have always lived together. I wish we spend our life together until we fall together but not leave this way. I thought of always being together, I said so. He said he does not know how long he can live. I told him that he would be alright "You will be OK after seeing doctor, so many good doctors. If you would go you must go in my arms, not this way". I soothed him. If he was stress, cried, I wiped away his tears, and sometimes gave him hugs and kissed on his cheek. I said "You'll be alright in a while (cry)", I always calm him. Here I do this way too. Sometimes I saw him in stress then I hug him, kissed him and said "You'll be alright in a while. I take you here to the doctor, many good doctors". I always hug and kiss him [4]" (Case # 7)*

> *"I felt sympathy and wish him recover, strong, and return to work as before, to sell goods. He can't work in the factory as he become old and refused by the factory. It's OK, we can sell things near the district office in front of our house. How much we can earn it's our pride that we can and we don't need to*

bother my sister. I want to help with this, because now I depend on my sister[5]" (Case #7)

"I felt sympathy with him being like this. His life shouldn't be in this way with the disease. At first I thought of his driving the car, I'm afraid he will be hit or with car crash, I only thought of those but never thought of this severe disease.[6]" (Case # 9)

3) Caring

Caring is the third characteristic of quality relationship expressed by most of the caregivers as the quality relationship with their care-receiver. The feeling of caring this study is very close to the feeling of "*ห่วงใย (huangyai*)"in Thai language. However, the word "*huangyai*" in Thai language can be translated into English language as caring. The nursing literature reviewed by Morse and colleagues (1990), identified caring with five categories from the perspectives of caring as a human trait, caring as a moral imperative or ideal, caring as an affection, caring as an interpersonal relationship, and caring as a therapeutic intervention. The category of caring as the interpersonal relationship may be close to the feeling of caring from caregiver toward their care-receiver in this study. Caring encompasses both the feeling and the behaviors occurring within the relationship. The feeling of caring include the aspects of showing concern and taking care the caregiver. Swanson (1991) described caring as a nurturing way to value other toward whom one feels a personal sense of commitment and responsibility. It is very close to the feeling of "*ห่วงใย (huangyai*)" defined by caregivers. A sense of caring might motivate the willingness to assist others.

Caring is defined as the caregiver's feeling of concern and worry about their care-receivers such as how the care-receivers feel, suffering or happy or sad. Caring has been more distinct than before after living their life together. This feeling may be due to their perception of the disease or various symptoms faced by the care-receivers. Some of the caregivers told that they feel more concern such as

"When he was not ill he can do anything, he take care of himself, and I take care of myself too. Each of us took care of ourselves, we all have burdens, I had to take care of the grandchildren. Here I concern much about him, whatever he did, he was tired, I helped him in everything.[7]" (Case # 9)

"It's not a sort of change but concern even more than before, not the same. When I stay home I do the hired work, cooking, taking care of my grandchildren to school. We separate duties, help each other.[8]" (Case #13)

4) Connectedness

Connectedness is the last characteristics of quality relationship that most of the caregivers explored their feeling with their care-receiver. The term "*ผูกพัน (pookpun*)" as a feeling explored by caregiver is very close to connectedness and attachment as translated into English language. The feeling of connectedness may be clearly described as the feeling from caregiver. Connectedness is very broadly defined as the extent to which a person perceives that he/she has a significant shared and meaningful personal relationship with another person, a spiritual being, nature or an aspect of one's inner self that described by Haase and colleadgues (1992), however the researcher found that the caregiver's perception of the extent of their connectedness with their care-receiver is associated with an increase of feeling close and connectedness.

Connectedness is defined as the caregiver's feeling of becoming closer to the care-receivers unlike previously after their staying together. It is emotional connectedness to their care-receiver. The sense of connectedness is defined as the caregiver's feeling for their care-receivers about their relationship experience that can increase or decrease their feeling of closeness and connectedness.

Sense of connectedness and responsibility toward the patient contributed to their maintaining of caregiver role even domestic domain after surgery or chemotherapy. Feeling of closeness is defined as the caregiver's feeling for their care-receivers about their sharing more time than in the past. The sense of connectedness is

defined as the caregiver's feeling for their care-receiver about their relationship experience that can increase or decrease their feeling of connectedness. There is a feeling among the caregivers that they become closer to the care-receivers unlike previously that they each did their own obligation. Since the care-receivers and the caregivers have to stay together almost 24 hours a day doing activities of daily living as well as special care activities such as wound care, feeding, the caregivers hence feel closer to their care-receivers.

Examples:

"Very close. Previously I thought he was alright, so we left each other alone. Sometimes he stayed out at the farm for one or two weeks then came back home. When he was still strong, he stayed at the farm to earn money. Here I sleep with my daughter just the two of us. My daughter goes to school, I go to work and come back to look after my daughter. It's one or two weeks that I can see my husband. Now he is ill, during this time we are close and never be apart.[9]" (Case #7)

Case 11 viewed that her relationship with her husband is better because of being close[10] (Case#11)

Section 3: An overview of quality relationship process of family caregivers based on the perspective of Thai caregivers with HNC patients

The findings from this study using grounded theory are presented as a conceptual model (Figure1) depicting the interacting pattern between variables that explain the process of quality relationship.

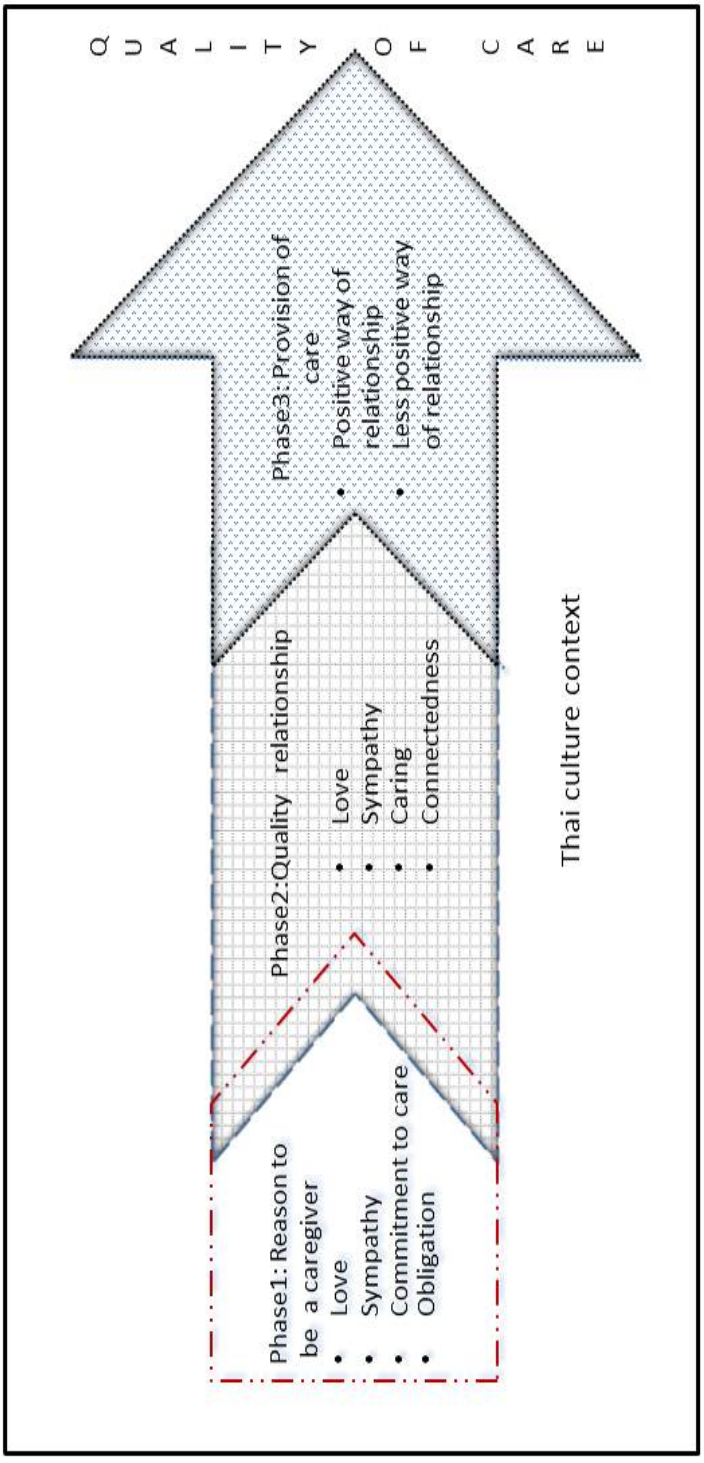

Figure 4.1 Quality relationship process in Thai family caregiver with HNC patients

The findings are presented in various types of relationship, categories, subcategories, properties and dimensions. Types of relationship composed of causal condition, action/interaction, consequences and intervening condition, (Strauss & Corbin, 1990). Through grounded theory analysis of interview data of this study, three phases were identified. However, the reader should not consider the phases as logical progression but as an overlapping with one another and the process of quality relationship is dynamic. The process of quality relationship consisted of three interactive phases: 1) reason to be a caregiver, 2) quality relationship, and 3) provision of care.

The first phase, reason to be a caregiver, is causal condition. It comprises f love, sympathy, commitment to care, and obligation.

The second phase, quality of relationship, is action/interaction in this relationship quality process. It involves love, sympathy, caring, and connectedness.

The last phase, provision of care, is the consequence of quality relationship. This consequence includes positive way of relationship and less positive way of relationship. The positive way of relationship refers to the feeling of willing to care, and do my best. The less positive way of relationship represents “doing as normal life”, and “doing good but not reach expectation”.

Intervening condition of quality relationship process is Thai culture context includes concern with Buddhist doctrine, concern about social expectation and Thai caregiver’ attitude toward cancer disease.

All constructs and concepts in this evolving theory “quality relationship process in Thai family caregiver with HNC patients are summarized in Table 4.1

Table 4.1 Initial study finding based on grounded theory analysis

Type of relationship	Categories	Subcategories	Properties	Dimension
Causal condition	**Reason to be a caregiver**		The reason to be a caregiver was defined as the caregiver's feeling on their role based on their feeling of love, feeling of sympathy, commitment to care and obligation.	Negative Positive Neutral
		Feeling of love	Feeling of love refers to the caregiver's reason of feeling affection with the care-receiver. Caregivers described their feeling of love to base their decision of taking caregiver role.	
		Feeling of sympathy	Feeling of sympathy refers to the caregiver's feeling toward the care-receiver's suffering from cancer based on their spending long time together. Such feeling rises due to the care-receiver's suffering from cancer and it symptoms as well as effect of cancer treatment.	
		Commitment to care	Commitment is an agreement to perform in a caregiver role. It is influenced by the history of relationship between	High intensity Low intensity

Table 4.1 Initial study finding based on grounded theory analysis (cont.)

Type of relationship	Categories	Subcategories	roperties	Dimension
			Caregiver and care-receivers. Caregiver role as the commitment to care is perceived by caregiver because they shared similar experiences to those of their care-receivers in the past. Caregivers believed that they were the one whom the care-receivers rely on, especially when the care-receivers had no one to take care of them.	
		Obligation	Obligation refers to caregiver's feeling of their role as unavoidable whether they are willing to care or not but they have to do it. Some caregivers believed that they were responsible for and had obligation of taking care of their care-receiver because they were related to them as spouse, or son. A caregiver's reported obligation to the individual is due to his/her social role and societal norms in the family and society. All of women take care of their husband.	High intensity Low intensity

Table 4.1 Initial study finding based on grounded theory analysis (cont.)

Type of relationship	Categories	Subcategories	Properties	Dimension
Action /interaction	**Quality relationship**		Quality relationship refers to caregiver's feeling toward their care-receivers with love, sympathy, caring and connectedness.	High intensity Low intensity
		love	Love is defined as the feeling of caregiver to return the care-receiver's love.	
		sympathy	Sympathy is defined as the caregiver's feeling toward their care receivers' having cancer, suffering from the disease, and feeling sad for their care-receivers.	
		Caring	Caring is defined as the caregiver's feeling concern and worry about their care-receivers such as the care-receiver's feeling of suffering or happiness in life.	
		Connectedness	Connectedness is defined as the caregiver's feeling of becoming closer to the care-receivers unlike previously since they stay together. It is emotional connectedness to their care-receiver. Sense of connectedness to and responsibility for the patient	

Table 4.1 Initial study finding based on grounded theory analysis (cont.)

Type of relationship	Categories	Subcategories	Properties	Dimension
			contributed to their maintaining caregiver role even domestic domain after surgery or chemotherapy. Feeling of closeness is defined as the caregiver's feeling toward their care-receivers about their sharing more time than in the past. The sense of connectedness is defined as the caregiver's feeling toward their care-receiver about their relationship experience that can increase or decrease their feeling of connectedness.	
Consequences	**Provision of care**	**Positive way of relationship**	The result of quality relationship that demonstrates in positive way. It involves the feeling of willing to care, do my best.	High intensity Low intensity
		Less positive way of relationship	The result of quality of care that demonstrates in less positive way of relationship. It includes doing as normal life and doing good but not reach expectation.	

Table 4.1 Initial study finding based on grounded theory analysis (cont.)

Type of relationship	Categories	Subcategories	Properties	Dimension
Intervening condition	**Thai culture context**		Thai cultural context influences quality relationship between caregiver and care-receiver which come into play and may push those with a less positive or negative relationship to take on the care role. The factors involve various significant sources such as concern with Buddhist doctrine, concern with social expectation and caregiver's attitude toward cancer disease.	High intensity Low intensity
		Concern with Buddhist doctrine	Concern with Buddhist doctrine influences the feeling of caregiver to take care of their care-receivers and continue their caregiver role.	
		Concern about social expectation	Caregivers concern about Thai social expectations such as expectations of gender roles, roles of spouse, and others in Thai family.	
		Caregiver' attitude toward cancer disease	Caregiver' attitude toward cancer disease influence caregiver's taking the caregiving role.	

Explanatory concept pertaining to this study

Quality relationship is dynamic process. The quality relationship process of family caregivers based on the perspective of Thai caregivers with HNC patients is presented into three phases consisted of reason to be a caregiver, quality relationship, and provision of care and each of these phases is overlapping with one another. The first phase that the caregivers explored their feeling is reason to be a caregiver. The reason to be a caregiver is the causal condition in the process of quality relationship that is interchangeable with the caregiver's perception of quality relationship with their care-receivers. It composes of feeling of love, feeling of sympathy, commitment to care and obligation. The second phase of quality relationship is based on the perspective of caregivers in this study. It is comprised of feelings of love, sympathy, caring, and connectedness. Certain categories of the second phase appear to be the same as those categories in the first phase such as feeling of love and sympathy. The third phase considers the caregiver's perception about their provision of care. It is comprised of the positive and less positive ways of relationships. In addition, it is important to note that Thai culture context influences every process of quality relationship. It consists of concerns about the Buddhist doctrine, social expectations, and caregiver's attitude toward cancer disease. The detail of the explanatory concept is explained as follows.

Phase 1: Reason to be a caregiver

"How did you come to care for your care-receiver?", and "Can you tell me something about how you started to care for your care-receiver?" are main questions. Reason to be a caregiver, the first phase of quality relationship process. It is a causal condition as a set of events that influences the central phenomenon and creates the need for the core social process to occur (Strauss & Corbin, 1998). In the quality relationship process, caregivers consider to take caregiving role by using various reasons based on their prior relationship with care-receivers. The caregivers in this study described their reasons for caregiving which comprise the feeling of love, feeling of sympathy, commitment to care and obligation.

1) Love

Feeling of love is the causal condition that lead to caregiver's considering to take care of care-receiver. Based on the caregivers' responses in this study, most of them stated that it was their love with their care-receiver and that they take care of them in attempt to return the care-receivers' love extended to them. For example, they told that the reason to care for their care-receiver came from their love toward the husband. They said that they look after the care-receivers because:

> *"He loves me and I love him, we share both happiness and suffering[11]" (Case # 1)*

> *"It's because everything I've done come from our love for each other. Everything I've done I am willing to do it. Sometimes I have to cook rice at eight pm. that I was usually in bed but I am willing to do so.[12]" (Case # 5)*

> *"I have to encourage him that I love him, I'll take care of him. We are old we have to live together. You have to take care of yourself to live longer. I told him that I won't go anywhere, I'll continue to fight. You fight, I fight. Do you fight? I asked him. He said yes, then we tacked. It's about 2 months that we are here[13]" (Case # 8)*

> *"It's because of love. He has been ill, I thought who would take care of him as good as I do [14](Case #14)*

A caregiver as husband told that his reason came from his wish to return for the love the care-receiver gives him. If the care-receiver does not love him she would have not married and lived with him since she can choose to live with someone else who is better off than him.

> *"I accepted it, I sold the car, I have a car for business, it's the car we both work for it. I came from zero. I am the one with*

nothing while her family is better off, but she can love me while I have nothing. I thought about this.[15]" (Case #4).

Another case of wife taking care of her husband because she wants to return for her husband's taking good care of her and that she can live without difficulties.

"He didn't bring me up but has been married me for over 40 years, he is more than a brother to me. He has taken good care of me, never let me starve or get tired, never hit me, never complained anything even a little, but always ask if I want to eat or need anything, he bought me clothes and asked if I want anything.[15]" (Case # 9. "He has never left out anything but taken care for all in the family.[16]" (Case # 9)

2) Sympathy

Feeling of sympathy was reported by most of the caregivers as a reason to take care of the care-receivers in addition to their thought about the care-receivers' having no one around. It's the sympathy for the care-receiver's falling ill with cancer, so they take this caregiver role. The caregivers said that they feel sorry for the care-receivers' having cancer.

The caregiver Case # 7 told that she takes care of her husband because she sympathizes with her husband

"My feeling is only in one word that I sympathize with him; we've never been in quarrel or fight. Whatever I wanted he gave me, I just told him, except the moon and stars he can't make it. Everything I wanted, a mobile phone, a computer, I can have them all. But now without earnings, I have to think about it too.[17]" (Case # 7)

"I felt sympathy him for having cancer[18]" (Case # 10)

3) Commitment to care

Commitment to care is an agreement to perform in a caregiver role. It is influenced by the history of relationship between caregiver and care-receiver. Caregiver role as the commitment to perceived caring by caregiver is due to their sharing of similar experience with their care-receivers in the past. Caregivers believe that they are the one whom the care-receivers rely on, especially when the care-receivers had no one to take care of them. Most of the caregivers feel that when people live together and enjoy happiness together, if anyone in the family is in suffering, they should be around to take care of one another. In time of wellness, they enjoy together, hence in time of illness how can they abandon their care-receivers.

For example, there are caregivers who told that they take care of their care-receiver because they thought it is their history together that continues into the caring process.

> *"It is to share happiness and suffering, isn't it? But it's my will to do so, it's nothing but concern.[19]" (Case # 1) or "I told him that in time of comfort we share; in time of illness, how can I leave you.[20]" (Case# 9)*

> *"There's none but the 3 of us, father, mother, and a child. My siblings are on their own, I don't want to bother them. In time of ease, we enjoy it, in time of illness, how can we let others to take responsibility, so I myself take care of it[21]" (Case#11)*

4) Obligation

Obligation refers to caregiver's feeling that caregiving role is unavoidable whether they are willing to care or not, but they have to do it. Some caregivers believed that it is their responsibility and obligation to take care of their care-receiver because they were related to them as spouse or son. Caregivers reported this obligation is due to their social role and societal norms in the family and society. All women take care of their husband. Feeling of obligation to caregiving is the condition that forces caregivers to take responsibility for the care of their care-

receiver. With this reason, caregivers feel this caregiving role is unavoidable; no one else can do it, it is the law of karma.

For example, some of the caregivers talked about their taking caregiver role as they thought the care-receivers have no one around since they have their own family and hence it's implicitly the obligation. This feeling is considered a negative reason because at times when the caregiver was faced with difficulties during the care and became exhausted, it often affects the caregiver's bad mood.

> *Case # 11 said that "The patient has nobody but me, so I have to look after him and help him[22]" (Case# 11).*

> *Case #7 told that "If it's not me who else would take care of him, his siblings haven't showed up. They just visited, bought him some milk and went away. After that I have to take care of him.[23]" (Case#7)*

Furthermore, sense of obligation as family member might be influenced by Thai social belief and culture about the role of family members. There are 2 males who take caregiver role as they thought it's the obligation of adult children. Examples: A caregiver said

> *"As a child I have to accept it no matter what.[24]" (Case #6)*
> While Case #12 stated that *"No adult children would abandon their parents, I really can't do that. When my father was in short of money, I gave him. If I had no money, I asked for a loan and sent him money. If he didn't ask for it, I won't do that. Usually I only gave money to my mother because I am rather close and attached to her. If my father called me for money, I sent him.[25]" (Case#12)*

While most of the caregivers as wife thought that looking after the ill husband is their obligation and responsibility.

"It's our obligation, we cannot avoid it.[26]" (Case# 3)
"Because we are wife, aren't we? For us, the obligation of wife is to take care of husband.[27]" (Case# 3)

"It's difficult to say, we are wife, we have to take responsibility. Other than us who else would do that, even his parents want to but he didn't allow.[28]" (Case #10)

"Because we don't need other to do that, the best mental support is wife and girlfriend.[29]" (Case# 8)

"It's obligation, the obligation of wife.[30]" (Case#11)

In summary, the reason to be a caregiver was the first phase in the quality relationship in Thai caregivers with HNC patients and the causal condition in this process as well. In this phase, it explores the reasons to be a caregiver that comprise the caregiver's feeling about their love, feeling of sympathy, commitment to care and obligation toward their care-receivers.

Phase2: Quality relationship

Quality relationship involves action/interaction in the process of quality relationship. It was found that quality relationship as perceived by caregivers is defined as the feeling of love, sympathy, caring and connectedness with their HNC patients. Each of the characteristics of quality relationship can occur along different time during the caregiving and some of them are comparable to the reasons to become caregiver such as love and sympathy. In addition, each of the characteristic of quality relationship interacts with one another. For example, the feeling of love is there when they start taking care of the care-receiver, and along the way when both of caregiver and care-receiver spent more time together than in the past they develop to feel more caring and connectedness. Most of caregiver cannot describe what is the first feeling that they had but they know quality relationship must contain the feeling of love,

sympathy, caring and connectedness. Since most of the characteristics of quality relationship involve the caregiver's feeling, it can change overtime during the process.

Interaction between love and sympathy

According to the meaning of love from the caregiver's perspective, most of them explain their quality relationship as the feeling of love. "Repayment love" was cited by the most of caregivers who are spouse based on their self-explored feeling toward their husband and wife. From previously that they spent time together alone before the care-receiver was diagnosed with HNC disease, once the caregiver observed the care-receiver's suffering from cancer, its pain, inability to live normal life as before and even eating difficulty, the feeling of sympathy then develops along with love.

This feeling comes after the patients were diagnosed with HNC and the caregivers experienced the care-receivers' suffering from cancer, and it is their inner feeling. This feeling also has various influences. Most of the caregivers have lived with the care-receivers for very long time, they feel sympathy seeing someone they love suffering from difficulties in eating and breathing, and severe pain due to cancer. They define this feeling of sympathy based on their feeling for their care-receivers' having cancer, suffering from the disease, and sorry for the care-receivers. Examples: A caregiver said

> *"It seems I love her a bit more[33]" (case# 10)*

> Case#5, a wife in caregiver role, stated that
> *"Once I was aware of his cancer, I love him more and I want to take care of him more, give him everything and do anything for him[34]" (case# 5)*

> *"When we are alright, we haven't take much care of each other, we just going places having meals together. Once we fell ill, we give more care for one another. I'll see if he'd like me to look after him, it must be better than before.[35]" (case# 5)*

> *"Yes, but if you ask about when we are fine and when we fell ill, in the latter case we would have loved with sympathy and caring for one another more than before[36]" (case #5)*

Interaction between love, sympathy, and caring

Regarding the feeling of love and sympathy, when the caregiver spent more time taking care of their caregiver, the feeling of caring toward their care-receiver can rise. Most of caregivers reported their sense of caring as the feeling that come after they started their taking care role. They felt concern and worry about the care-receiver's feeling, their own caregiving activities, as well as worry about the care-receivers such as how the care-receivers feel, suffering or happy or sad. Caring has been more distinct than before after living their life together. This feeling may be due to their perception of the disease or various symptoms faced by the care-receivers. Some of the caregivers told that they feel more concern.

> *Example: Case#4, as a husband in this study, expressed his feeling with his wife who was diagnosed with tongue cancer stage 2. He told that his feeling of love is greater than that before his taking on caregiving role. He felt the word of the quality relationship very difficult to explain but he thought the feelings of love, sympathy and caring are very important for him. Furthermore, during his spending time taking care of his wife, he feels more love and sympathy.*

"I think I love her more than in the past31" (case# 4)

"I felt sympathy her, we have been together this long, I think if a woman had decided to live with me, she already depended her life on me, do you think so? I may be traditional I don't know but I think so. If she made her mind to live with me, suggesting that she must have confidence in me.32" (case#4)

> *"When he was not ill he can do anything, he takes care of himself, and I take care of myself too. Each of us took care of ourselves, we all have burdens, and I had to take care of the*

grandchildren. Here I concern much about him, whatever he did, he was tired, I helped him in everything.[38]" (Case# 9)

Case#7 expressed her feeling of love, sympathy and caring "I want him to recover as we have always lived together. I wish we spend our life together until we fall together but not leave this way. I thought of always being together, I said so. He said he does not know how long he can live. I told him that he would be alright "You will be OK after seeing doctor, so many good doctors. If you would go you must go in my arms, not this way". I soothed him. If he was stress, cried, I wiped away his tears, and sometimes gave him hugs and kissed on his cheek. I said "You'll be alright in a while (cry)", I always calm him. Here I do this way too. Sometimes I saw him in stress then I hug him, kissed him and said "You'll be alright in a while. I take you here to the doctor, many good doctors". I always hug and kiss him37". (Case# 7)

Case#2 "I am a kind of compromising, doing things for him to be at ease, and so my child. Mostly, I conform to him, it's OK for me but I want him and my child to be fine, so I am fine. If I'm but him fine, I cannot be fine too.[41]" (case# 2)
"I don't know if I love him but I am a kind of going easy, please but not displease him. For me anything is alright if it satisfies him, then I am happy. If I just concern myself but dissatisfy him, it's not that, not happy (laughing), I like doing thing to be happy.[42]" (case# 2)

Interaction between love, sympathy, caring, and connectedness

The sense of connectedness is defined as the caregiver's feeling for their care-receivers about their relationship experience that can increase or decrease their feeling of closeness and connectedness. Sense of connectedness and responsibility

toward the patient contributed to their maintaining of caregiver role even domestic domain after surgery or chemotherapy. There is a feeling among the caregivers that they become closer to the care-receivers unlike previously that they each did their own obligation. Since the care-receivers and the caregivers have to spend time together almost 24 hours a day doing activities of daily living as well as special care activities such as wound care, feeding.

Examples:

> *"Very close. Previously I thought he was alright, so we left each other alone. Sometimes he stayed out at the farm for one or two weeks then came back home. When he was still strong, he stayed at the farm to earn money. Here I sleep with my daughter just the two of us. My daughter goes to school, I go to work and come back to look after my daughter. It's one or two weeks that I can see my husband. Now he is ill, during this time we are close and never be apart.[43]" (Case#7)*

> *Case# 11 viewed that her relationship with her husband is better because of being closer. (Case#11)*

Example from case#12 and case# 13, they felt that the relationship with their care-receivers not change but they felt connectedness, closeness, and concern with their care-receivers more than in the past.

> *"He said it's more connectedness[39]" (case#12)*

> *"Just like that, it is concern, I asked him how he has been doing?, any mosquito bite?, if yes I blew them away with electric fan, I told him to go to bed.[40]" (case #13)*

Phase 3: Provision of care

Consequences are outcomes of the action/interactions taken in response to the central phenomenon. It involves caregiver's perception about their provision of care. Subcategories under the provision of care include positive way of relationship

such as “willing to care”, “do my best”; less positive way of relationship as “doing as normal life” and “doing good but not reach expectation”.

1) Positive way of relationship

“Willing to care” is the provision of care explained by caregivers based on their perceived good quality relationship in positive way between caregiver and care-receiver about their feeling of love, sympathy, caring and connectedness. All of these characteristics of quality relationship can be interaction between these feelings. When caregivers feel love and sympathy with their care-receivers, the feeling of caring and connectedness may follow. This is because in caregiving situation they spent more time together than previously. Positive way in quality relationship can be changed in the first step of caregiver’s decision to take care of their care-receiver because of their increased feeling of love, sympathy, caring, and connectedness than in the past experience. Although in their first step into caregiver role, for example, the caregiver cited that it is resulted by their feeling of obligation as children after spending time together during the care of their care-receiver, most of them felt closer and more concern to the care-receiver than in the past. When asking about their feeling in caregiver role, they said they themselves prefer and are willing to take care of the care-receiver since they believe they understand the care-receivers and the care-receivers want to be cared by them.

Example:

The caregiver Case #5 told about her feeling as caregiver that it is her will to do her best for the care-receiver.

The caregiver Case #2 expressed that her husband has no one around but she is willing to take care of him:
“I don’t know what to say, I am willing to do so because he has no one around, hasn’t he?, so I have to take care of him. It’s my will because he’s already been in this stage; I put my full effort for him.[44]” (Case# 2)

"It's my will, no one else to depend on, I am obliging.[45]" (Case#11)

"Do my best" in positive way of relationship happens in quality relationship process. When caregivers felt more love, sympathy, caring and connectedness toward their care-receiver than in the past, most of them paid attention in their caregiver role and put effort in all activities they have done for their care-receiver. Most of the caregivers viewed that what they have done for the patients are best. Largely, they gave themselves full scores of 10 or 100 scores for caring activities. This is because they viewed themselves as doing with all their capacity.

"I give myself full scores of 10 because I have taken care of him all the time, I won't go anywhere, never leave him. I feed him if he can't do it himself. I feed him even when drinking milk, water, porridge. At home I let him try to sip water by mouth or through a straw. I treat him like that[46]" (Case#7)

"Total 100 scores because I am confident that I do my best. I followed what was told by the doctor. When taking other medicine, I have to look into it, never let him take it ignorantly. If anything happens, I see the doctor or go to the hospital first, then consult with the doctor how to take medicine. The doctor will explain and I have to remember and follow that. He is in good condition consistently, no fever or feeling cold. I give him 100 %, the best[48]" (Case# 8, lines 302-309)

"I've done for 100 %[49]" (Case #9, line 275) "I thought I do my best, with full effort. In our life, this is the time to accept one another, help each other with all capacity. It's the terminal stage of life, we must help each other, I won't withdraw. I had been to my home yesterday. At first I told him that I'll go home perhaps spending the night, but actually I didn't, I just scare

him and ask him if he can stay alone. He said he can in daytime but not nighttime, he misses me and worries about me, he said so.[50]" (Case# 9)

"I give 10 scores because I put full effort.[51]" (Case#11)

"I thought I do my best, and I am happy, I didn't do that to expect any return, but with my heart, I do my best, I am willing to do, I am happy to do.[52]" (Case #5)

"Yes, I thought I do my best.[53]" (Case#7)

"I do my best.[54]" (Case#15, line105)

2) Less positive way of relationship

Less positive way of relationship can be found through the process of quality relationship between caregiver and care-receiver. Based on the feeling of quality relationship by caregivers regarding love, sympathy, caring and connectedness, caregivers reported having difficult time with their care-receiver and perceived their caregiver role as a result of feeling obliged, e.g., as wife to take care of husband or concern with Thai culture such as Buddhist doctrine. Moreover, they had less quality relationship in the past as the caregiver's feeling of love, sympathy, caring and connectedness did not increase in their first step into caregiver role. They viewed provision of care as "doing as normal life" or "doing good but not reach expectation".

"Doing as normal life" refers to caregiver's perception of caregiver role as normal activity they have to do in the past. They need not to change anything in their life style such as sleeping, eating and others. Caregiving role involves daily life routine. They need not to concern about their caregiver activities to be done for their care-receivers. Some of the caregivers thought that they themselves need not to adjust anything; they provide care for their care-receivers as the same in the past.

> *"I did not give a special care for him. I do as normal life just if he wants to eat I buy something for him. He can eat as much as he can. I had to clean his wound as routine of my life[55]" (case#2)*

"Doing good but not reach expectation" refers to the caregiver's perception of their provision of care in less positive way that can be happened in quality relationship process. Based on self-assessment on activities by some of them, they viewed what they had done for the patient as good but not reach expectation because there may be something imperfect and incomplete such as wound care or something not totally satisfied by the patient.

> *"Not full scores but 8 because there may be something left out, there must be. If 10, it is being with the patient all the time, must focus on everything. This is all I can do.[56]" (Case #12)*

> *"It should be 8. This is because sometime I left the sputum get stuck within the tube at the lid because I thought it will be replaced shortly but actually the sputum dried out, so I applied saline solution and removed it, wiped it away. Sometime I asked the patient and he said it's not sore but I noticed it turn red, I can't take it all out.[57]" (Case# 14)*

Intervening condition: Thai culture context

Intervening condition is the condition that influences all of the quality relationship process. Thai cultural context influences the quality relationship between caregiver and care-receiver that come into play and may push the caregivers with reason to be a caregiver, quality relationship and provision of care in positive or less positive way of relationship to take on the care. The factor comprises various significant sources. It consists of the concern about Buddhist doctrine, social expectation and caregiver's attitude toward cancer disease.

1) Concern about Buddhist doctrine

Concern about Buddhist doctrine influences the caregiver's feeling to take care of their care-receivers and continue their caregiver role. It composes of the influence of Buddhist doctrine such as in *law of karma* as determinant of the caregiver's taking care for care–receiver and a sense of redeeming for what had been done to the care-receiver.

Thailand is a Buddhist country, its beliefs are embedded in the lives of Thai people, including the majority of caregivers (n=14) in this study. Buddhist doctrines about the *law of karma* provides an influence over the caregivers' decision to become caregivers or coping with their care-receivers diagnosed with cancer. In addition, Buddhist doctrines had a great influence on the daily life of Thai caregiver who believes in the *law of karma*. This concept is explained in term of "cause and effect". A person who performs good acts earns good consequences, and the one who performs evil acts receive evil consequences. Buddhist caregivers believe that the past deed of the care-receivers and themselves in previous lives caused the care-receiver to become ill and caused them to become their caregivers. Furthermore caregiver's belief in karma is very powerful and affects Thai caregivers' behavioral patterns and attitudes towards life. Religious beliefs serve as mental support for the care-receivers, and as stimulant to provide care once they believe in the effect of *Karma*, and hence having peace and calm in mind when facing with stress. It also helps caregivers to retain their role as caregiver while confronting with difficult situations and exhaustion, i.e. as psychological support for the caregivers.

Three cases of caregivers (Case# 1, Case# 2, Case# 9) in this study reveals that their beliefs were influenced by Buddhism regarding "born, grow old, meet with diseases, and die like everyone else as the Truth of life", and their beliefs about the *law of Karma*. With this in mind, they came to understand life with the spirit to take care of care-receivers. They also viewed cancer faced by the care-receivers as something that can occur to anyone, and their death will occur for sure as for every human being.

> *Case#1 told about her experience when taking on the obligation of caregiver that her mental anchor that provides her spiritual*

> *support to take care of the care-receiver is the thought as a Buddhist, that is, "Born, grow old, meet with diseases, and die like everyone else as the Truth of life. Everyone has to die sooner or later. Her spirit thus rises[58]" (Case#1).*

> *Case# 9 used her beliefs about death to sooth herself about illness. She told her husband that "Knowing of having cancer stage 4, you have to be mindful and determine. Poo (called by wife following the word grandpa called by grandchildren) has to recover. It's common for people to be born, grow old, meet with diseases, and die." I just told him so. "It's not serious, you have to die, I have to die." I said so. "Who will die first or die later, I don't know. While I am caring for you, I might have high blood pressure and die[59]". (Case #9)*

Based on Buddhism doctrine related to the *law of karma*, Case#2 told she can restraint her mind with her husband's disease. She talked to her daughter about the illness of her husband and she thought

> *"it is alright if he would die. It depends on karma, how long he can live, it is karma, and I already get over it[60]". (Case#2)*

"*Law of karma* as determinant of care for care–receiver"

Most of the Buddhists believe in the *law of karma* that includes physical, verbal, and mental actions. They believed in the results of accumulated past *karma* in the form of *boon* (merit) and *barp* (demerit). *Karma* is the notion of action in which the good actions are called *boon* (merit) and bad actions are called *barp* (demerit). Therefore, the Thai Buddhism holds that as a consequence of one's action the power of *karma* is endlessly present to manifest itself in the life of the individuals (Siayasak, 2006).

In addition to the view of *karma*, all living being are born, grow old, meet with diseases, and die like everyone else, it is believed that the *law of*

karma determines their obligation as caregivers for care-receiver. For example:

Case#1 told about her experience in the care for her husband during doing various activities such as wound care, cooking, and suction.

> *"Her husband said that he feels sorry for her, so she told him not to do so but be sorry for himself. She believes in karma that she must have done something wrong to him so she has to take care of him in this life, and never thought of leaving but giving him care[61]". (Case#1)*

Either case of caregivers believe about bad deeds they had done so they have to take care of their husbands.

> *Case# 3 thought about karma-linked couple that lead her to take care of her husband "I thought of what I said we are a karma-linked couple, we must have shared merits and deeds to the extent that I have to meet him. I also thought "If I didn't marry you, I would have been easy and hang out with my friends and would have not resigned from government service. I can work without worry. But here I do that but concern this, I can't take it, I concern, I can't take it I would be nervous[62]". (Case# 3)*

> *Case #15 believes in the past bad deeds. "I feel that we might have shared our merits. In the past life, he might have taken care of me, so I return the care to him in this life. Thinking like this I won't become stress, I thought because of the past bad deeds that we met, just like we live together, take care of each other, this is it, I thought so.[63]" (Case # 15)*

"A sense of redeeming for what had been done to the care-receiver"

The essential doctrine of Buddhism is merit-making that is the central part of the religious experience of the Thai Buddhism. The acts of merit

making can be described in various ways such as action in support of the monks and the temple, giving food to the monks daily, ordination into the monkhood, and provision of support for one's parents, elders, and charitable causes. The important acts of making merit that can motivate most of family caregivers to take the caregiving role is the provision of support for one's parents, elders and charitable causes. Gaining merit can be by giving goods, comfort, or money to one's parents, elders, the blind, the poverty-stricken, or the orphaned, for example.

Buddhist teaching encourages people to do good deeds and refrain from bad deeds particularly those acts upon parents or benefactors. The present study showed that a caregiver as son with previous poor relationship with his father prior to taking on his role as caregiver for his father gave his reason that he thought taking care during his father's illness would help redeem of what he had done bad to his father in the past such as using harsh words and insult (Case#12). It reflects the influence of religious belief taught by Thai society for long regarding the practice toward parents and benefactors. Both cases of sons as caregivers in this study explained their reasons and beliefs about their caregiver role as a way of returning gratefulness to their father.

> *Example: Case #12 told that "I believe that taking care of the patient would help redeem for what I had done to the father in the past that I talk back badly to parents[65]". (Case#12)*

2) Concern about social expectation

In Thailand, it is a social expectation for family to take care of their family members who get illness. This social expectation influences the family caregivers' decision making process regarding whether or not to stay with their care-receivers once it was discovered that they had cancer and need care. One of the Thai social expectations about the role of family members when having someone in the family facing with difficulties or illness is that they have to help and care for each other. Thai children were taught to appreciate of what others did for them. To appreciate is to have a sense of gratitude which is demonstrated by appreciative behaviors. In Thai culture,

gratitude varies from feeling thankful to feeling obligated to do something in return. In particular, it is the belief in filial piety and expectation of women to take the obligation of care for family members. Most of Thai people believe in and practice the "gratitude system" (among many strong doctrines), which obligates them to show gratitude to their parent (Jullamate, 2008) or other people who has helped him or her. The reason of this Thai hierarchy can be described into the religious context and indebtedness of relationships in Thai society and family. It can provide a major key to understanding Thai way of behaviors.

A caregiver as an adult child believes that it is a must to look after parents in illness. It is a belief traditionally taught since childhood about the sense of filial piety in Thai society and that once becoming adulthood it is the obligation to take care of parents in return of their favor to care for us. If children do not take responsibility for caring of their parents in old age or in illness and with self-care inability, they would not be accepted by the society.

For example, Case#6 told that he has to take care of his father who has cancer because he is his son and as a male just as his father so it is more convenient for him than for other female children to do this work.

> *He said "As a child I have to take responsibility no matter what[66]" (Case #6)*

> *Case#12 told about why he takes care of his father in illness of cancer. He thought no children would abandon their parents. "I really can't do that. When my father was in short of money, I gave him. If I had no money, I asked for a loan and sent him money. If he didn't ask for it, I won't do that. Usually I only gave money to my mother because I am rather close and attached to her. If my father called me for money, I gave him.[67]" (Case#12)*

Other than the role of children to take care of parents as expected by Thai society, the roles of husband and wife with intimate relationship are also expected on

taking care of their couple in illness. In particular of gender expectation by Thai society, female should take the role of caring for family in household chores, food, and comfort of family members. These include housekeeping, cooking, and caring for family members in illness. If wife does not take care of her husband in time of illness, she would be blamed by the society for not taking proper role.

Furthermore, in most situations Thai husband is still seen as having more power than Thai wife. It is ideally expected in Thai society that wife shows respect to the husband. She is taught not to display her own superiority in either actions or speech. This means that traditionally a Thai woman is required to honor and obey her husband. Mostly, caregivers with primary role as wife would automatically take on the obligation in caring for their husband who was diagnosed with cancer.

Examples: Everyone automatically realize the role of oneself in taking care of the husband in illness.

> *"Oh, I am his wife. The obligation of wife is to take care of husband.[68]" (Case #3)*

> *"Because we don't need others to do that, the best mental support is wife or girlfriend[69]" (Case #8)*

> *"It's obligation, the obligation of wife.[70]" (Case#11)*

3) Caregiver's attitude toward cancer disease.

Caregiver's attitude toward cancer disease is an important influence that motivates the caregiver's taking the caregiving role. Intense fear of cancer was pervasive among all of the caregivers in this study. Strong fear is associated with many aspects of the disease, including death, pain, and the destruction or mutilation of a patient's body. Most of the caregivers in this study expressed the fear over suffering and pain that the cancer victims must endure that was consistently described as "cancer disease is suffering" and the person who was diagnosed with cancer will not live long. Most of them think about the care-receiver's dying if diagnosed with cancer. Most of them believed that "cancer equals to death."

The same result was found by Stenberg and colleagues (2012) that the caregivers experienced cancer as unpredictable, and were constantly worried about how the illness would progress. The fear diminished for some when the treatment was finished, while others lived with constant fear of that the patient might die, even a long time after treatment was finished (Stenberg, Ruland, Olsson, & Ekstedt, 2012)

Examples:

Case#2 said that "I feel anxious too, I'm afraid he would die too early, frankly speaking it's 6 months but it might be less than 6 months, that sort of thing. It's 1 year or less than 1 year, it's too early, I think it's too soon. But I think whatever will be, will be, I already prepared for it. If it can be hold, I would.[70]" (case# 2)

Case#3 "To cure cancer I admit it is impossible, it just prolongs our life. It's cancer we have to accept it and get over it but we have to try by all means. To get over it is for sure but when is the time, may be 1 or 2 years, 1 or 2 months we don't know but we find the way to cure it, to take medicine. With this medicine other people can recover but the doctor does not approve to take *this kind of medicine, traditional medicine.[72]" (case # 3)*

Case# 4 "I feel fear. It is cancer, I have heard everyone will die from it, right? When I lived in Prachuabkirikhan, it's someone I know, I attended the funeral, and I just make a joke it's the expensive disease. Now I experience it myself. I used to joke with her that she has cancer, the disease for the rich, the expensive disease. [73]" (case #4)

Conclusion

This chapter detailed characteristics of the study participants and categories generated from grounded theory analysis. The majority of participants were spouse caregivers and most of care-receivers are men who were diagnosed with HNC

stage 4. Only three of caregivers are still working during taking caregiving role. From grounded theory analysis, it was found that in the perspective of the Thai family caregivers who took care of HNC patients had very difficulty in expressing the characteristics and meaning of quality relationship. Even though the relationship between caregivers and care-receivers appeared to be a significant feeling toward each other in their lives, they cannot express their feelings well. The possible reason is that the words “quality of relationship” and “quality” are rarely used in Thai culture. In Thai language one usually uses the word that might represent more than the word “quality” such as “feeling”. However, after the researcher modified the questions to capture the nature of Thai language and culture, it was found that the quality relationship is a dynamic process and each phase overlaps with the others.

The first phase that the caregivers explored their feeling is reason to be a caregiver. The reason to be a caregiver is the causal condition in the process of quality relationship that is interchangeable with the caregiver’s perception of quality relationship with their care-receivers. It composes of feeling of love, feeling of sympathy, commitment to care and obligation.

The second phase of quality relationship is based on the perspective of caregivers in this study. It is comprised of feelings of love, sympathy, caring, and connectedness. Certain categories of the second phase appear to be the same as those categories in the first phase such as feeling of love and sympathy.

The third phase considers the caregiver’s perception about their provision of care. It is comprised of the positive and less positive aspects of relationships.

Furthermore, Thai culture context is the important influence every process of quality relationship. It consists of concerns about the Buddhist doctrine, social expectations, and caregiver’s attitude toward cancer disease.

Notes to chapter4

[1]“เค้ารักเราแล้วเราก็รักเค้า มีเวลาสุขเราก็สุขด้วยกันเวลาทุกข์เราก็ทุกข์ด้วยกัน” (case# 1, line 94-95)

[2]“เพราะทุกอย่างที่เราทำเพราะเรามีความรักให้กัน ทุกอย่างที่เราทำเราเต็มใจทำ บางที สองทุ่มนั่งนึ่งข้าวอยู่ ปกตินอนแล้ว แต่เราก็เต็มใจที่จะทำ” (case#5, line 447-450)

[3]“เราต้องให้กำลังใจเค้า เรานะรักตัว ก็มาดูแลตัวเอง เราแก่แล้วเราต้องอยู่ด้วย เราต้องรักษาตัวเองให้อยู่นานๆ กว่านี้อีก เราก็บอกเค้า เราไม่ไปไหนหรอก ฉันจะอยู่สู้อย่างนี้แหล่ะ แกก็สู้ ฉันก็สู้ แกสู้ไหมทิด เราก็บอก เค้าบอกสู้ เราก็ตบมือกัน ประมาณเกือบ 2 เดือนที่มาอยู่นี่” (case#8, line 203-208)

[3]“สงสารเค้า อยากให้เค้าเป็นปกติ อยากอยู่ด้วยกันมาตลอด อยากใช้ชีวิตอยู่ด้วยกัน จนกระทั่งที่ว่าใครคนใดคนหนึ่งจะล้มไปด้วยกัน แต่ไม่ใช่ไปแบบนี้ ความคิดนะ อยากอยู่ด้วยกันตลอด ก็เคยพูด แกก็พูด ก็ร้องไห้ ไม่รู้ว่าพี่จะอยู่ได้นานไหม แกก็พูด ก็บอกเค้าว่าพี่ไม่เป็นอะไร เดี๋ยวไปหาหมอก็หาย หมอเก่งๆ ก็เยอะ ถ้าพี่จะไป พี่ต้องไปในอ้อมแขนของหนู ไม่ใช่พี่ไปแบบนี้ ก็ปลอบใจเค้า ถ้าเค้าเครียดมา เค้าร้องมาก็จะเช็ดน้ำตาให้เค้า บางทีก็เข้าไปกอด ไปหอมแก้มเค้า เดี๋ยวก็หายเน๊อะ (ร้องไห้) พูดปลอบใจเค้าตลอด อยู่นี่ก็ทำ บางทีเห็นเค้าเครียดๆ มาก็เข้าไปกอด หอมแก้ม เดี๋ยวก็หายเน๊อะ แต่เค้าอายุเยอะกว่า พามาหาหมอแล้ว หมอเก่งๆ ก็เยอะ ก็จะกอดหอมแก้มกันตลอด” (case#7, line 437-450)

[4]“สงสารอยากให้เค้าหาย ให้เค้าแข็งแรงกลับมาทำงานได้เหมือนเดิม ค้าขายของ เข้าโรงงานไม่ไหว อายุมากแล้วโรงงานเค้าไม่รับก็ไม่เป็นไร ก็ขายของข้างอำเภอหน้าบ้าน ขายได้เท่าไหร่ก็มันยังภูมิใจว่าหาได้ จะได้ไม่ต้องรบกวนน้อง อยากจะช่วยตรงนี้บ้าง ตอนนี้ก็กินของน้องตลอด” (case#7, line 523-528)

[5]“สงสารที่เค้าเป็นอย่างนี้แหล่ะ ชีวิตเค้าไม่น่าจะเป็นอย่างนี้ ไม่น่าเป็นโรคนี้ ทีแรกคิดแต่ว่าเค้าไปวิ่งรถ กลัวรถจะชนมั่ง กลัวรถจะล้มมั่ง คิดไปทางโน้น ไม่ได้คิดถึงโรคร้ายอย่างนี้” (case#9, line394-397)

[6]“มากขึ้น จากตอนที่เค้าไม่ป่วย คือเค้าจะทำยังไงก็ได้ เค้าต้องช่วยเหลือตัวเอง เราก็ต้องช่วยเหลือตัวเอง ต่างคนต่างช่วยเหลือตัวเองนะปู่ เรามีภาระทั้งนั้น ฉันก็มีภาระกับหลาน ทีนี้เราก็ต้องห่วงเค้ามาก แกจะทำอะไร แกจะเหนื่อยก็ช่วยแกทุกอย่าง” (case#9, line408-412)

[7]“มันก็ไม่เปลี่ยนหรอกแต่ว่ามันเหมือนกับว่า มันอะไร มันจะมากกว่าเดิม ไม่ใช่เหมือนที่อยู่เหมือนเดิม บางทีถ้าอยู่บ้านจะออกรับจ้างอย่างนี้ คอยหุงข้าว ดูแลหลานให้ไปโรงเรียน ก็จะแยกแยะหน้าที่กัน ก็ช่วยกัน” (case#13, line349-353)

[8]“ใกล้ชิดมาก ตอนทีแรกที่ว่าเค้ายังดีอยู่ ก็ต่างคนต่างไป บางทีเค้าก็ไปนอนที่ฟาร์มเป็นอาทิตย์สองอาทิตย์ ถึงจะกลับบ้านมาทีนึงตอนที่แกยังแข็งแรงยังปกติดี ก็ไปนอนที่ฟาร์ม ด้วยความที่อยากได้เงิน อยู่นี่ก็นอน 2 คนกับลูก ลูกก็ไปโรงเรียน นี่ก็ไปทำงาน เย็นก็จะมาเจอหน้าลูกอีกทีหนึ่ง แฟนก็อาทิตย์สองอาทิตย์ก็ได้เจอหน้ากันทีหนึ่ง แต่ตอนมาที่แกมาป่วยนี่ ช่วงที่ป่วยนี้อยู่ใกล้ชิดกันตลอดไม่เคยห่าง” (case#7, line396-403)

[9]“R: คิดว่าความสัมพันธ์ระหว่างคุณลุงกับคุณป้าดีขึ้น เรารู้สึกว่ามันเป็นเพราะเราได้ใกล้ชิดกันมากขึ้นไหม

P: ค่ะ” (case#11, line 439-441)

[10]“เค้ารักเราแล้วเราก็รักเค้าแล้วเรามีเวลาสุขเราก็สุขด้วยกันเวลาทุกข์เราก็ทุกข์ด้วยกัน” (case# 1, line 94-95)

[11] “เพราะทุกอย่างที่เราทำเพราะเรามีความรักให้กัน ทุกอย่างที่เราทำเราเต็มใจทำ บางทีสองทุ่มนั่งนึ่งข้าวอยู่ ปกตินอนแล้ว แต่เราก็เต็มใจที่จะทำ” (case#5, line 447-450)

[12]“เราต้องให้กำลังใจเค้า เราน่ะรักตัว ก็มาดูแลตัวเอง เราแก่แล้วเราต้องอยู่ด้วย เราต้องรักษาตัวเองให้อยู่นานๆ กว่านี้อีก เราก็บอกเค้า เราไม่ไปไหนหรอก ฉันจะอยู่สู้อย่างนี้แหล่ะ แกก็สู้ ฉันก็สู้ แกสู้ไหมทิด เราก็บอก เค้าบอกสู้ เราก็ตบมือกัน ประมาณเกือบ 2 เดือนที่มาอยู่นี่” (case#8, line 203-208)

[13]“ก็ เพราะรักมั่งค่ะ เค้าป่วยเราก็คิดว่าใครจะดูแลดีได้เท่าเรา” (case#14, line 205-206)

[14]“ผมก็ยอม ให้ผมขายรถรักษาผมก็ขาย เพราะผมมีรถวิ่งอยู่ ผมถือว่ารถที่วิ่งเป็นรถที่เราทำกันมา ผมมาจากศูนย์ ในขณะที่ผมเป็นคนที่ไม่มีอะไรมาเลย แต่ทางบ้านเขาเป็นคนที่จะมีหน่อย แต่เขายังรักผมได้เลย ใช่ไหม ผมไม่มีอะไรเลย ผมก็คิดถึงข้อนี้แหล่ะ” (case#4, line88-92)

[15]“ไม่ได้เลี้ยงเรามา แต่มาแต่งงานกะเราสี่สิบกว่าปี เขายิ่งกว่าพี่เราอีก เขาก็ดูแลเรามาดี ไม่เคยให้อดให้เหนื่อยให้อะไร ไม่เคยทุบเคยตี ไม่เคยบ่นไม่เคยว่าไม่เคยด่า คำน้อยก็ไม่เคยว่า มีแต่แกจะกินอะไรไหม แกจะเอาอะไรไหม เสื้อผ้าฉันจะซื้อไปแกจะเอาอะไรไหม” (case#9, line319-324)

[16] “เค้าไม่เคยทอดทิ้งอะไรเลย รับภาระหมดในครอบครัว” (case#9, line452-453)

[17]“ความรู้สึก ก็คือ พูดคำเดียวว่าสงสารเค้า สงสารเค้าที่ว่า หนึ่งไม่เคยทะเลาะกัน ไม่เคยตบตีกัน ลูกอยากได้อะไรเค้าก็หาให้ ขอให้บอก เอาไม่ได้คือเดือนกับดาว ที่ว่าให้ลูกไม่ได้ ทุก

อย่างลูกจะเอ่ยเอาโทรศัพท์ เอาคอม ลูกได้ทุกอย่าง แต่ตอนนี้ไม่มีรายได้อะไรเลย มันก็ คิดเหมือนกัน" (case# 7, line 348-353)

[18]"ก็สงสารเขาที่เป็นมะเร็ง" (case#10, line 296)

[19]"ต้องดูง่ะใช่ไหมค่ะ มันเป็นหน้าที่ของเราคือว่า สุขก็สุขด้วยกัน ทุกข์ก็ทุกข์ด้วยกันใช่ไหมค่ะ แต่ว่าก็คือเต็มใจดู ไม่มีอะไรเป็นห่วงแก" (case #1, line 6-9)

[20]"ก็บอกว่า ปู่ยามมีกินเราก็ยังกินด้วยกัน ยามเจ็บยามไข้จะทิ้งปู่ได้ไง" (case#9, line 113-114)

[21]"ก็ไม่มีใคร 3 คนพ่อแม่ลูก พี่น้องเค้าก็ต่างคนต่างอยู่ ไม่อยากรบกวนเค้า เราก็เวลาดีๆ ก็กินกันไป เวลาไข้จะมาให้คนอื่นเค้ามารับผิดชอบไม่ได้ ก็มาเองค่ะ" (case#11, line 162-164)

[22]"R: คิดว่าไม่มีใครแล้วนอกจากเรา

P: ค่ะ ต้องช่วยเหลือตัวเอง" (case#11, line165-166)

[23]"เป็นหน้าที่นี่แหละ ถ้าเราไม่ดูแลเค้าแล้วใครจะมาดู ถ้าเราไม่ดูเค้าก็ไม่มีใครมาดูเลย พี่น้องเค้าก็ไม่มา เค้าก็มาถึงเค้ามาก็มาเยี่ยมมาดู ซื้อนมให้ แล้วเค้าก็ไป หลังจากนั้นเราก็ต้องดูแลเค้าต่อ" (case#7, line 480-483)

[24]"ก็เป็นลูกยังไงก็ต้องรับ" (case#6, line 41)

[25]"มีลูกที่ไหนมั่งที่ทิ้งพ่อทิ้งแม่ หนูทำไม่ได้จริงๆ เวลาพ่อไม่มีตังค์โทรไป พ่อไม่มีตังส์เลย หนูก็จะเบิก ถ้าหนูไม่มีหนูก็จะกู้ ส่งมาให้แก ถ้าพ่อไม่ขอหนูก็ไม่ส่ง หนูจะให้แม่อย่างเดียว เพราะจะสนิทจะผูกพันกับแม่มากกว่า ถ้าวันไหนพ่อโทรไปขอเนี่ยหนูก็จะส่ง" (case#12, line 485-490)

[26]"มันหน้าที่ที่เราต้องทำนะ ถ้าเรา ไม่ทำก็ไม่ได้" (case#3, line 192-193)

[27]"อ้าว เพราะเราเป็นภรรยาเค้า ใช่ไหม คนเราหน้าที่ของเมียมันก็ต้องดูแลสามี" (case#3, line446-447)

[28]"มันพูดยาก เราเป็นเมียต้องมีความผิดชอบ แล้วพ้นจากเราแล้วใครเขาจะดู พ่อแม่เขาก็อยากดู แต่ลูกเขาไม่ยอมอย่างนี้" (case#10, line 493-495)

[29] " เพราะว่าเราไม่ต้องให้คนอื่นทำ กำลังใจที่ดีที่สุดคือเมียกับแฟน" (case#8, line213-214)

[30]"เป็นหน้าที่อยู่แล้ว หน้าที่ของเมียอยู่แล้ว" (case#11, line 485)

[31]"มากขึ้น จากตอนที่เค้าไม่ป่วย คือเค้าจะทำยังไงก็ได้ เค้าต้องช่วยเหลือตัวเอง เราก็ต้องช่วยเหลือตัวเอง ต่างคนต่างช่วยเหลือตัวเองนะปู่ เรามีภาระทั้งนั้น ฉันก็มีภาระกับหลาน ทีนี้เราก็ต้องห่วงเค้ามาก แกจะทำอะไร แกจะเหนื่อยก็ช่วยแกทุกอย่าง" (case#9, line408-412)

[32]“เพราะผมสงสารเขาน่ะ เราอยู่กันมาจนขนาดนี้นะ ผมคิดว่าผู้หญิงคนนึงถ้าเขาตัดสินใจอยู่กับเราแล้วเขาก็ฝากชีวิตไว้กับเราแล้ว คุณคิดว่าจริงไหม ผมอาจจะหัวโบราณก็ไม่รู้นะ ผมรู้แต่ว่าผมคิดอย่างนี้ ถ้าเขาตัดสินใจมาอยู่กับเราแล้วแสดงว่าเขาต้องมั่นใจในตัวเรา” (case#4, line 218-223)

[33]“เหมือนจะรักเขามากกว่าเดิมหน่อย” (case#10, line 309)

[34] “พอรู้ว่าเค้าเป็นมะเร็ง ก็น่าจะรักเค้าเพิ่มขึ้น อยากดูแลเค้าเพิ่มขึ้น ก็ให้ทุกอย่าง ทำให้ทุกอย่าง” (case#5, line453-454)

[35]“คนเราตอนที่ยังไม่เจ็บป่วยก็ยังไม่ดูแลกันเท่าไหร่ ไปโน่นไปนี่ไปกินอะไรด้วยกันเฉยๆ พอเราป่วยปุ๊บเนี้ย การดูแลให้กันก็จะมีเยอะขึ้น ก็จะดูว่าเค้าเต็มใจให้เราดูแลไหม น่าจะดีขึ้นกว่าเก่า” (case#5, line190-193)

[36]“ก็มี แต่ถ้าถามว่าตอนที่ยังไม่ป่วยกับตอนป่วย ตอนป่วยมันน่าจะรักกันมากขึ้น เห็นใจกัน เป็นห่วงหาอาทรกันมากขึ้นกว่าเก่า” (case#5, line200-202)

[37]“สงสารเค้า อยากให้เค้าเป็นปกติ อยากอยู่ด้วยกันมาตลอด อยากใช้ชีวิตอยู่ด้วยกันจนกระทั่งที่ว่าใครคนใดคนหนึ่งจะล้มไปด้วยกัน แต่ไม่ใช่ไปแบบนี้ ความคิดนะ อยากอยู่ด้วยกันตลอด ก็เคยพูด แกก็พูด ก็ร้อง ไม่รู้ว่าพี่จะอยู่ได้นานไหม แกก็พูด ก็บอกเค้าว่าพี่ไม่เป็นอะไร เดี๋ยวไปหาหมอก็หาย หมอเก่งๆ ก็เยอะ ถ้าพี่จะไป พี่ต้องไปในอ้อมแขนของหนู ไม่ใช่พี่ไปแบบนี้ ก็ปลอบใจเค้า ถ้าเค้าเครียดมา เค้าร้องมาก็จะเช็ดน้ำตาให้เค้า บางทีก็เข้าไปกอด ไปหอมแก้มเค้า เดี๋ยวก็หายเน๊อะ (ร้องไห้) พูดปลอบใจเค้าตลอด อยู่นี่ก็ทำ บางทีเห็นเค้าเครียดๆ มาก็เข้าไปกอด หอมแก้ว เดี๋ยวก็หายเน๊อะ แต่เค้าอายุเยอะกว่า พามาหาหมอแล้ว หมอเก่งๆ ก็เยอะ ก็จะกอดหอมแก้มกันตลอด” (case#7, line 437-450)

[38]“มากขึ้น จากตอนที่เค้าไม่ป่วย คือเค้าจะทำยังไงก็ได้ เค้าต้องช่วยเหลือตัวเอง เราก็ต้องช่วยเหลือตัวเอง ต่างคนต่างช่วยเหลือตัวเองนะปู่ เรามีภาระทั้งนั้น ฉันก็มีภาระกับหลาน ทีนี้เราก็ต้องห่วงเค้ามาก แกจะทำอะไร แกจะเหนื่อยก็ช่วยแกทุกอย่าง” (case#9, line408-412)

[39]“R: เราคิดว่าตั้งแต่เรามาดูแลพ่อเนี้ย ความสัมพันธ์เรากับพ่อเปลี่ยนไปไหม

P: ก็เหมือนเดิม

R: ความรู้สึกเรากับพ่อเปลี่ยนไปไหม

P: ก็ผูกพันกันมากขึ้น” (case#12, line 398-402)

[40] “R: แล้วตั้งแต่มาดูนี่เรารู้สึกว่าเราเป็นอย่างไรค่ะ เช่นใกล้ชิดกัน มากขึ้น รักกันมากขึ้นไหม

P: ค่ะ ก็อย่างงั้นเลยล่ะ ก็เป็นห่วง ก็ถามแกเป็นอย่างงัยบ้าง ยุงกัดไหม ถ้ายุงกัดก็เอาพัดลมเป่า ก็บอกให้นอน" (case#13, line336-340)

[41] "เราเป็นคนชอบยอม เราเป็นคนที่ทำยังไง ให้เค้าสบายใจ ให้แฟนสบายใจ ให้ลูกสบายใจ ส่วนมากเราจะเป็นคนยอมๆ เราไม่สบายไม่เป็นไรให้เค้าสบายใจให้แฟน ให้ลูก สบายใจเราสบายใจ ถ้าเราเอาแต่เราสบายใจเค้าไม่สบายใจเราก็ไม่สบายใจ" (case#2, line 387-392)

[42]"ไม่รู้เรารักเค้ารึเปล่าแต่เราเป็นคนแบบว่าเรายังงัยก็ได้ ขอให้ถูกใจเค้า เราก็ไม่รู้เรารักหรือเปล่า ขอให้ถูกใจเค้าไม่ใช่ขัดใจเค้า เราจะยังงัยก็ได้ ถูกใจเค้าเราก็สาบยใจ ถ้าเกิดเอาสบายใจเราไม่ถูกใจเค้ามันก็ใช้ไม่ได้ไม่มีความสุข นะ (หัวเราะ) ชอบทำอะไรที่สบายใจ" (case#2, line 394-399)

[43]"ใกล้ชิดมาก ตอนทีแรกที่ว่าเค้ายังดีอยู่ ก็ต่างคนต่างไป บางทีเค้าก็ไปนอนที่ฟาร์มเป็นอาทิตย์สองอาทิตย์ ถึงจะกลับบ้านมาทีนึงตอนที่แกยังแข็งแรงยังปกติดี ก็ไปนอนที่ฟาร์ม ด้วยความที่อยากได้เงิน อยู่นี่ก็นอน 2 คนกับลูก ลูกก็ไปโรงเรียน นี่ก็ไปทำงาน เย็นก็จะมาเจอหน้าลูกอีกทีหนึ่ง แฟนก็อาทิตย์สองอาทิตย์ก็ได้เจอหน้ากันทีหนึ่ง แต่ตอนมาที่แกมาป่วยนี่ ช่วงที่ป่วยนี้อยู่ใกล้ชิดกันตลอดไม่เคยห่าง" (case#7, line396-403)

[44]"พูดไม่เป็น ก็เต็มใจที่จะดูอยู่แล้ว เพราะว่าเค้าก็ไม่มีใคร ใช่ไหมล่ะ เราก็ต้องดูแลอยู่แล้ว เต็มใจดูแลอยู่แล้วเพราะว่าเค้าก็เป็นมาขั้นนี้แล้ว เราก็พยายามเต็มที่ให้เค้า" (case#2, line 263-266)

[45] "ก็เต็มใจ ก็ไม่รู้จะพึ่งใครก็ต้องเต็มใจ" (case#11, line 473)

[46]"เพราะว่าที่ให้ตัวเองเต็ม 10 เพราะว่า จะดูแลแกตลอด จะไม่ไปไหน จะไม่ทิ้ง กินไม่ได้ก็จะป้อน แม้แต่กินนม กินน้ำ กินโจ๊ก ก็จะป้อนแกตลอด อยู่บ้านก็เหมือนกัน ลองให้แกจิบน้ำทางปาก จิบได้ไหม หรือจิบจากหลอด จะให้แกกินอย่างนั้น" (case#7, line 468-472)

[47] "เต็ม 100 เลย" (case#8, line 300)

[48]"เพราะว่ามั่นใจที่สุดว่า เรานี่ทำดีที่สุด ในที่หมอบอกเรา หมอบอกยังไงเราต้องทำตาม จะกินยาข้างนอกเนี้ยเราต้องดูก่อน ไม่กินสุ่มสี่สุ่มห้า ถ้าเราเป็นอะไรต้องไปหาหมอก่อน นอนโรงพยาบาลก่อน แล้วก็ปรึกษาหมอว่ากินยังไง กินแบบไหน หมอก็ต้องบอก เราก็ต้องจำไว้ กินตามหมอ เค้าดีมาตลอดไม่มีไข้ ไม่หนาวอะไร ที่อยู่บ้านปวดฟัน ให้เต็ม 100 เลย ดีที่สุด" (case#8, line 302-309)

[49] "ทำให้ 100 %" (case#9, line275)

[50]"เราก็ว่าเราทำดีที่สุดแล้ว ทำให้เต็มที่ คือว่าชีวิตเรานะ มีช่วงนี้ที่จะรับกันได้ จะช่วยเหลือกันได้เต็มที่ คือวาระสุดท้ายของชีวิต ต้องช่วยกันไป แต่เราไม่ถอยไง ขนาดเราไปบ้านเมื่อ

วานนี้ ทีแรกบอกว่าฉันไปบ้านนะ บางทีอาจจะค้างสักคืนนึง แต่ไม่ค้างหรอก พูดขู่เฉยๆ แล้วแกอยู่ได้ไหม บอกอยู่ได้กลางวันน่ะ กลางคืนอยู่ไม่ได้ คิดถึงเมีย เป็นห่วงเมียแกว่าอย่างงั้น" (case#9, line278-285)

[51]"ให้ 10 เลยค่ะ, เพราะว่าเราทำเต็มที่แล้วค่ะ" (case#11, line 243,245)

[52]"คิดว่าเราทำดีที่สุดนะ แล้วเราทำแล้วมีความสุข เราไม่ได้ทำเพื่อจะหวังสิ่งตอบแทน เราทำด้วยใจ เราทำดีที่สุด คือเราเต็มใจทำ เรามีความสุขในการทำ" (case#5, line144-146)

[53]"จ๊ะ หนูว่าทำดีที่สุดแล้ว" (case#7, line 474)

[54]"ทำดีที่สุดแล้ว" (case#15, line105)

[55]"ไม่ได้ดูแลพิเศษอะไร ก็อยู่ปกติถึงเวลากินก็กิน เค้าอยากกินอะไรก็ซื้อให้เค้า กินได้แค่ไหนก็กิน แล้วก็ทำแผลแค่นั้นแหละชีวิตประจำวัน" (case#2, line 413-415)

[56] "ก็ไม่เต็มง่ะ 8 นี่ก็เพราะว่ามันอาจมีอะไรขาดตกบกพร่องมั่ง มันต้องมี ถ้าเต็ม 10 เลย คือต้องนั่งอยู่กับคนไข้แล้ว ต้องจี้ต้องทำทุกอย่างแล้วพี่ นี่คือหนูก็ทำได้ทุกอย่าง" (case#12, line 744-747)

[57]"ก็คงให้ 8 ค่ะ เพราะว่าบางทีเหมือนเสลดมันติดอยู่ท่อด้านในทางด้านฝาบางทีเราก็คิดว่าเดี๋ยวก็ต้องทำใหม่อยู่แล้ว แล้วมันแห้งติดค่ะ เอาน้ำเกลือชุบแล้วมันต้องงัดขึ้น เราก็ต้องเช็ดๆ บางที่ถามคนไข้เค้าบอกไม่เจ็บแต่เราเห็นมันแดงแล้ว เราก็เอาออกไปไม่หมด" (case#14, line 456-462)

[58]"ก็คิดอย่างคนนับถือศาสนาพุทธค่ะว่า เกิด แก่เจ็บตายเป็นของธรรมดา ทุกคนเกิดมาก็ต้องตาย ตายช้าตายเร็ว ก็เลยทำให้มีกำลังใจขึ้นมา" (case#1, line 371-373)

[59] "ก็ดีใจ ชื่นใจที่แกยังตั้งสติของแกได้ แกก็รู้ว่าเป็นขั้นที่ 4 แล้ว ก็บอกว่าแกต้องตั้งใจนะปู่ เราต้องหาย คนเราเกิดแก่เจ็บตายของธรรมดา ก็บอกกับแกเนี๊ยะ ไม่ต้องไปซีเรียสอะไรมาก แกก็ตาย ฉันก็ตาย ก็ว่างั้น ใครจะตายก่อนหรือตายหลังก็ไม่รู้ อย่างฉันมาเฝ้าแกเนี้ย ฉันเกิดความดันขึ้นตายก่อนแกล่ะ" (Case #9, lines 116-121)

[60] "เหตุผล แบบว่าได้ยินได้ฟังอะไรเยอะแยะ ด้วยวัยด้วยมั้ง ไม่รู้หลายๆอย่างรวมกันแล้วเราก็ไม่มีภารกิจ งานการที่ไปต้องทำนอกบ้านมันก็มีอยู่แค่นอกบ้านแค่นั้น มันก็เลยคิดว่ารู้สึกว่าปลงได้เยอะไม่รู้จะพูดว่าอย่างงัย อะไรจะเกิดก็เกิด ทำใจไว้ได้แล้วเตรียมทำใจ ตั้งแต่เขารู้ก้อนมันใหญ่ขึ้นๆ เราก็เตรียมทำใจไว้แล้วล่ะ ว่าสักวันหนึ่ง สักวันหนึ่ง เตรียมทำใจ เตรียมไว้เลย" (Case#2, lines 678-683)

[61] “เค้าก็จะพูดว่าสงสาร เราก็บอกว่าไม่ต้องสงสารหรอก สงสารตัวเองเถอะ เชื่อเรื่องเวรกรรมว่าชาติที่แล้วเราต้องทำอะไรให้ชาตินี้เราถึงต้องมาทำให้เค้า ไม่คิดจะทอดทิ้งก็จะดูแลกันไป (Case#1, lines 405-408)

[62] “มันก็คิดเหมือนกัน เราก็คิดว่าอย่างที่บอกเป็นคู่เวรคู่กรรมกัน คนเราทำบุญทำกรรมด้วยกันมาแค่นี้ เราก็ต้องมารับเจอเค้า ก็นึกเหมือนกันถ้าฉันไม่แต่งงานกับเธอ ป่านนี้ฉันก็ไปกินไปเที่ยวไปไหนกับเพื่อนฉันสบาย อาจไม่ต้องออกจากราชการ ทำงานก็ทำไปไม่ต้องมีกังวลอะไร แต่ทีนี้ทำตรงโน้นกังวลโน้นนี่ ไม่เอาอ่ะ ห่วง ไม่เอาดีกว่าเดี๋ยวประสาทเสีย” (Case #3, lines 581-587)

[63] “รู้สึกเหรอ ก็รู้สึกว่าเราก็อาจจะทำร่วมกันมาเนาะ ชาติที่แล้วเค้าอาจจะดูแลเรามาชาตินี้เค้าก็กลับมาดูแลเค้า มันก็ต้องคิดอย่างนี้จะได้ไม่เครียด ก็คิดว่ามันเป็นวิบากกรรมที่ทำกันมาเราถึงมาเจอกัน ก็เหมือนอยู่ด้วยกัน ต้องมาดูแลกัน อะไรอย่างนี้ ก็คิดนะ” (Case #15, lines 115-118)

[64] “ก็มีสวดมนต์ไหว้พระ ตอนนี้ก็เข้าวัดนะ บวชศีล มาฆะ วิสาขะที ก็ขอเค้าไป 3 วัน เพราะว่ามันไม่ไกลกับบ้านกับวัดเค้าก็ให้ไป ก็ไปทางวัด เข้าทางพระนะใจจะเย็นขึ้นแต่ก่อนก็หงุดหงิดนะ เวลาเค้าขัดใจอะไรเราก็หงุดหงิด แต่ก็ทำอะไรไม่ได้ง่ย ทำอะไรไม่ได้แต่ตอนนี้ไม่ค่อยหงุดหงิดเท่าไหร่ คล้ายว่าใจเย็นขึ้นเยอะ แต่ก่อนหงุดหงิดทำอะไรไม่ได้ ได้แต่โมโหอยู่กับตัวเอง เวลาขัดใจไม่ได้อย่างใจ เราก็โมโหแต่ใจเย็นลงเยอะ” (Case#2, lines 666-669)

[65] P: ก็รู้สึกดี อาจจะถ่ายบาปได้มั่ง

R: ไถ่บาปยังไง

P: เพราะหนูว่าหนูร้าย หนูเป็นคนพูดจาไม่เพราะ ตอนเด็กๆหนูก็เถียงพ่อเถียงแม่ (Case#12, lines 339-342)

[66] “ก็เป็นลูกยังไงก็ต้องรับ” (Case #6, line 41)

[67] “ใช่ๆ มีลูกที่ไหนมั่งที่ทิ้งพ่อทิ้งแม่ หนูทำไม่ได้จริงๆ เวลาพ่อไม่มีตังค์โทรไป พ่อไม่มีตังส์เลย หนูก็จะเบิก ถ้าหนูไม่มีหนูก็จะกู้ ส่งมาให้แก ถ้าพ่อไม่ขอหนูก็ไม่ส่ง หนูจะให้แม่อย่างเดียว เพราะจะสนิทจะผูกพันกับแม่มากกว่า ถ้าวันไหนพ่อโทรไปขอเนี่ยหนูก็จะส่ง” (Case#12, lines 485-490)

[68] “อ้าว เพราะเราเป็นภรรยาเค้า ใช่ไหม คนเราหน้าที่ของเมียมันก็ต้องดูแลสามี” (Case #3, lines 446-447)

[69] “เพราะว่าเราไม่ต้องให้คนอื่นทำ กำลังใจที่ดีที่สุดคือเมียกับแฟน” (Case# 8, lines 213-214)

[70] “เป็นหน้าที่อยู่แล้ว หน้าที่ของเมียอยู่แล้ว” (Case#11, line 485)

[71] “ก็กังวลเหมือนกัน กลัวเค้า กลัวเค้าตายไวเกินไป คือว่าพูดกันตรงๆนะ อยู่6 เดือน มันจะไม่ถึง 6 เดือน อะไรอย่างนี้ ปีหนึ่งหรือไม่ถึงปี มันจะไวเกินไป คิดว่ามันจะไวเกินไป แต่ก็คิดนะอะไรจะเกิดก็ต้องเกิด ก็ทำใจไว้แล้ว แต่ถ้าอันไหนมันยื้อได้ ถ้ามันยื้อเวลาไปได้เราก็อยากจะยื้อ (case#2, line 420-425)

[72]“คือมันรักษามะเร็งเราก็ต้องยอมรับว่ามันไม่มีทางหายหรอก มันก็ยืดชีวิตคนเราออกไป” (case#3, line209-211)

[73] “มะเร็งน่ะ เราก็ต้องยอมรับมันต้องทำใจ แต่ก็พยายามหาทุกวิถีทาง มันทำอยู่แล้วใจน่ะ แต่จะเมื่อไหร่เท่านั้นน่ะ อาจจะปีสองปี อาจจะเดือนสองเดือน เราก็ไม่รู้แต่เราก็ต้องหาวิธีการรักษากันกินยากัน คนอื่นเค้ายังกินหายเลยบางคนเราก็ต้องดิ้นรนกันไป แต่หมอเค้าไม่สนับสนุนให้กินยาพวกนี้หรอก ยาแผนโบราณ” (case#3, line656-662)

[74] “ผมก็กลัวดิ มะเร็งน่ะ พอได้ยินก็ตายทุกคนแหล่ะ จริงรึเปล่า ถ้าผมอยู่ประจวบฯ ก็เป็นคนที่รู้จักอ่ะน่ะ พอมีงานศพงานไร ผมก็ไปกะเขา ผมเคยพูดเล่นน่ะ เป็นอะไรเป็นได้ เป็นไอ้โรคใช้ตังค์ มาเจอกับตัวเองผมยังพูดเล่นกับเขาเลย เค้าเป็นมะเร็ง เป็นโรคคนรวย โรคใช้ตังค์” (case#4, line 469-474)

CHAPTER V
DISSCUSSION

The purpose of this chapter is to present the discussion. The research findings will be compared and contrasted with existing theories and concepts discussed in the literature, especially in relation to the concept that defines quality relationship such as mutuality, reciprocity, intimacy and love.

Discussion of the findings

An evolving theory in this study is the quality relationship process of Thai family caregiver with HNC patients. This evolving theory was studied from the perspective of Thai family caregivers where studies in this situation are lacked, i.e. the lack of studies related to the meaning of quality relationship and quality relationship process in Thai family caregiver with HNC patients. The topics of discussion aim to 1) present the characteristics of participants in this study, 2) present the concept and categories and portray why they were emerged, 3) describe why it was relevant or different from other studies, and 4) to explore whether the evolving theory is new or not, if it is new why it is new.

The characteristics of participants

The majority of participants in this study are spouses (13; 12 wives and one husband) and most of them are female, as also reported in previous cancer caregiving study in both the Western family caregivers (Stenberg, Ruland & Miaskowski, 2010) and Thai family caregivers (Meecharoen, Sirapo-ngam, Monkong, Oratai & Northouse, 2013) . In general, research on caregiving often reported that most of the caregivers are female who had their roles as wife, daughter, mother, grandmother or other female family member before taking the caregiver role (Meecharoen, et. al., 2013). Most of the caregivers based on their belief that this role

suits female. However, based on the principle of substitution, when caregiver and care-receiver are in different genders, there is a “strong sense of gender boundaries (Campbell & Martin-Mathew, 2003). However it differs from the result of this study that female caregiving member provided care instead of the male caregiver because of the reluctance of males to perform cross gender care. This is because in this study most of the caregivers are spouse and in particular spouses have the most intimate relationship with their married care-receivers, they often had commitment to care with their spouse before diagnosed with HNC. There are studies in Thai caregiver and Western caregiver of elderly stroke patients found that most of the caregivers are spouses (Anderson et. al., 1995; Bakas, Austin, Jessup, William, & Oberst, 2004; Meesuk, 2004; Niyomthai, Putwatana, Panpakdee, 2003; White, Poissant, Cote-LeBlance & Wood-Dauphinee, 2006). Studies in Thai caregivers with HNC patient reported most of the caregivers are spouse (Kitrungrote, Chanprasit, Sutharangse, & Cohen, 2008; Prechavittayakul, 2006; Wongchuay, Kitrungrote & Petpichetchain, 2010). However, it differs from a systematic review of family caregiving studies for patients with chronic illness in Thailand (Sirapo-ngam, 2003) in which most of the caregivers are adult children. It differs from this study that has only two caregivers were sons who have taking care for their father and have no daughter. This is because the prevalence of HNC tends to be increasing among the young Thai patients (Ferlay, Bray, Pisani, & Parkin, 2004 as cited in Chaisrisawatsuk, O-charoenrat, 2008). Therefore, most of caregivers in this study were spouse more than the adult children.

In this study the age of caregivers ranged between 23 and 67 years, with mean age of 50.86. This is similar to some other studies of cancer caregivers reporting the age range between 19-74 years and mean age of 47.14 (Meecharoen, et. al., 2013). The duration of caregiving is between 2 months and 1 year and 8 months, in which 2 – 6 months is common among most of the caregivers. Congruent with previous study is that most of the caregivers had caregiving experienced with their cancer patient for less than 2 years and most of the cancer patients were at stage IV (Meecharoen, et. al., 2013).

To understand an evolving theory of the findings of this study and present the concept, categories and portray why they were emerged, why it was relevant or different from other studies, and whether the evolving theory is new or not. The topics

for discussion are as follows: 1) reason to be a caregiver; 2) comparison and contrast of the meaning and characteristic of quality relationship with intimacy, mutuality, reciprocity, and love concept and explained the characteristics of quality relationship in this study that differs from other concept composed of sympathy, caring and connectedness; 3) provision of care; and 4) Thai culture context. The discussion presented in detail as follows.

1) Reasons to be a caregiver

The reason to be a caregiver is the causal condition in quality relationship process. It composes of feeling of love, feeling of sympathy, commitment to care, and obligation.

Decision to taking caregiving role of caregiver based on various reasons and influences. It can be from obligatory motive and discretionary motive for caregiving (Walker et al., 1990). Feeling of love, sympathy, commitment to care and obligation are the feelings that most of the caregivers in this study explained as their reasons to be a caregiver. People may be motivated to provide care for many reasons, such as to help others based on the connection between obligation and discretionary motivations and quality relationship (Walker et al., 1990), feelings of duty and responsibility (Quinn et al., 2010). However, some theorists identified specific motives for helping yielded two types of explanations. One assumes that helping serves an egoistic or self-serving motive, while the other centers on empathy and altruism (Batson & Coke, 1983 as cited in Schulz, Biegel, Morycz, & Visintainer, 1989). For example, there are caregivers who are egoistically motivated, provide care to obtain something for themselves such as reward, praise and respect from others, to avoid censure from others of feeling of guilt or to reduce their own distress. On the other hand, there are caregivers who are altruistically motivated are said to take care and give support because they feel love, concern and responsibility for their relative (Sand, Olsson, & Strang, 2010).

As the reasons to be caregiver in this study, it can be described that the feelings of love, commitment and sympathy are motivated by discretionary reason whereas obligation is motivated by obligatory reasons. Based on earlier work, it is predicted that caregivers will report both obligatory and discretionary motives for their

care-receivers (Walker et al., 1990). However, it is impossible to know which reason will be dominant in this study. This result differs from that in the study by Walker and colleagues (1990) who found that mothers reported discretionary motive for caregiving than obligatory motive.

Most of the caregivers in this study were spouse who had increasingly become aware of their partners' multiple physical needs, psychological distress and restrictions in social functioning that had brought about. They had learned that these consequences affected their whole family. Feeling of love and commitment during the relationship had been the foundation of developing ties of love. The caregivers were emotionally sensitive, conscious of each other's distress and moved by it. They felt sympathy and wanted to help. These results differ from Wallhagen and Yamamoto-Mitani (2006) that both American and Japanese caregivers felt they had a moral obligation to provide care, which was derived partly from the feeling of reciprocity. American caregivers were more strongly motivated by the feeling of attachment to the care-receiver, and attachment had an important role in retaining caregiving. Japanese caregivers emphasized that it was their role in the family that required them to take on the caregiving task. Furthermore results from the study by Sung (1994), comparing filial motivations of Korean caregivers with those of American caregivers, suggested that the top-priority motivation for parent care cited in both American and Korean are affection/love, repayment/reciprocity, and responsibility/obligation. Filial responsibility/obligation is the obligation of an adult child to assume caring for his/her parents and to meet the needs of aged parents. Motivation specific to Korean caregivers were respect, family harmony, and sacrifice which were not reported among American counterparts, and respect for parent was cited most frequently in Korean caregivers representing Korea social norm. Concern for politeness and deference toward elders is a traditional characteristic of Koreans. The characteristics are reflected in their behavioral culture such as using honorific language in speaking to the elderly, giving the best seat to the elderly, serving the elderly first, allowing the elderly to go through a door first.

In Thai caregiving context, love is a pivotal component that impacts on the caregiver's continuing to care for their care-receiver (Thampanichawat, 2007) as also found in this study, and the power of love motivated family members to take care of

their patients (Kitrungrote, et al.,2008; Limpanichkul & Magilvy, 2004; Prechavittayakul, 2006). For the feeling of love, the study result by Wanlaya (2008), showed that maintaining love and hope plays a major role in caregiving process for caring with their HIV children. However, the study by Cafferey (1992) found different reasons to be caregiver in which primary motivations for caregiver were identified as: fulfilling the expected culture norm of filial obligation; love or affection for the elder; a desire to reciprocate for past services and to build up future merit for them. The difference between the first and third is an attitude of obligation versus an attitude of gratitude. Affective bonding may be the most important motivator for children to continue caring for their parents. It differs from this study because most of the caregivers are spouse.

The finding from this study suggests that the majority of caregivers reported feeling of love to base their taking caregiving role. This differs from Subgranon and Lund (2000) in their study that the caregivers explained caregiving as a way of returning gratefulness to their elderly relative. In addition, love and attachment were found as the basis for most caregivers to provide care for their elderly patients. Their involvements in caring helped caregivers develop the feeling of love, attachment and sympathy toward the patients. Most of them explained that they had experienced love and attachment between them and their elderly relatives before and during their caregiving. Such difference might be due to the fact that most participants in this study are spouses who have intimate relationship with their care-receivers. The relationship between caregiver and care-receiver who were spouses can be described as the feeling of repayment of love rather than a way of returning gratefulness.

The feeling of love was the important reason to be caregiver in this study; most of the caregivers reported their taking care of the care-receivers because of their history of relationship such as feeling of love between caregiver and care-receiver. They spent time together for long even in the caregiving situation with low quality relationship and reported the feeling of love as the first reason to be caregiver.

Another reason addressed by most of the caregivers in this study is the sense of commitment to care by explaining that such feeling is due to their sharing of similar experience in the past with the care-receivers. These caregivers believed that they were the one whom the care-receivers rely on, especially when the care-receivers

had no one taking care of them. This same result was found in the study by Washington (2013) who explored the process by which family members and friends of hospice patients learned to provide care to their dying loved one. This study found that commitment to care is the central phenomenon that emerged from the data and served as core category from which the reminder of the theory was generated. This commitment resulted in a strong motivation for caregivers to relieve distressful symptoms experiences by the patient for whom they were providing care.

William (2007) described the dynamic of commitment in perspective of caregivers of patients undergoing blood and marrow transplantation that the importance aspect of caregiving is the dynamics that motivate and sustain family members and friends during caregiving. Moreover, research of caregiving in chronic illness showed that commitment to caregiving relationships is influenced by the history of caregiving participants (Phillips, Brewer, & Torres ,2001) and the level of commitment influences the meaning of the experience for caregivers (LoboPrabhu, Molinari, Arling- haus, Barr, & Lomax, 2005). Commitment to the caregiving relationship can be seen as the first step in caregiving, but it also is an ongoing dynamic throughout caregiving. Continued commitment by participants hold caregiving relationship together and provides impetus for caregiving activities.

Different from the study by Stockwell-Smith, Kellett and Moyle (2010), exploring the limiting and motivating factors that influence caregivers' use of respite services and the ability of currently available respite services to meet the needs of caregivers of frail older people, they found that commitment is a major theme in the sense of reciprocity. Caregivers saw their role as reciprocating the care and support they had previously received from their care-receiver or would expect to receive if the situation reversed.

Whisenant (2011) explored the experience of caregivers of patients with primary brain tumor by identifying themes of the caregiving experience specific to this population and found that commitment is sustained through enduring patient cognitive and behavioral decline. In Williams's (2005) model, he defined commitment as enduring caregiver responsibility that inspires life changes to make the patients priority.

According to Thai caregiver research, a particular striking result is that religion, culture, and traditional ways of life played major roles in influencing the commitment to providing care for family members. Buddhist caregivers follow *the law of karma*, the concepts of *boon* (merit) and *barp* (demerit). They believe that caregiving is a way to repay their past deeds, to gain merit, and to return gratitude to their elderly relatives. The same is true in the study by Kitrungrote and colleagues (2008) who found that being committed for life to spouse with the component of power of love, intimacy, and a feeling of gratitude toward their spouses had motivated them to care for their spouses diagnosed with HNC and undergoing radiation therapy. Caregivers described love as being a strong bond of affection and sympathy for their spouses, so they care for their spouses. The power of intimacy enables couples to develop a deep knowledge of each other. Trust is also the power that inspires both the caregivers and their spouses to endure stressful events. The result of such study described the reason to be caregiver most conform to what was found in this study in terms of caregiver's feeling of commitment to care, love, and sympathy. Despite these similar results, there are some different reasons that motivate the caregivers to take caregiving role. For example, the caregivers in this study did not address about the feeling of trust, power of intimacy, or sense of repayment of gratitude but mostly they talked about the sense of repayment of love.

This finding is consistent with the Chinese culture that reciprocity and obligation are the most common interaction patterns in the caring relationship between spouses and their frail partners. As explained by the interviewees, the marriage 64 philosophy of traditional Chinese is a promise to care for their spouse for the whole life, taking love as a life-long commitment and doing what needs to be done. On the other hand, marriage in traditional Chinese culture means a commitment to bear any difficulties between partners. Sometimes people are afraid of creating negative images and ruining their prestige if the spouses escaped from their responsibilities.

Feeling of sympathy is the reason usually expressed by Thai caregivers in this study. Feeling of sympathy refers to the caregiver's feeling toward the care-receiver's suffering from cancer as a result of their spending long time together. Such feeling rises as they observed the care-receiver's suffering from cancer and its symptoms and effects of cancer treatment. This reason also seemed to arise from the

discretionary reasons as also found in the study result of Kitrungrote and colleagues (2008). Similarly in Eisenberg's (2000) study, sympathy was defined as an understanding of another's situation, and involves feelings of concern for the other person that are not the same as those being experienced by the other.

Obligation is the last reason to be caregiver mentioned as most of the caregivers' feeling. Obligation refers to caregiver's perception of their role as unavoidable whether they are willing to care or not but they have to do it. Some of them believed that they have to be responsible for and have obligation of taking care of their care-receiver because they are related to them as spouse, or son. Obligation is the obligatory reason to be caregiver in this study. Most of caregiver research in the past suggested that a caregiver's reported obligation to the individual is due to his/her social role and societal norms in the family and society. Typically, every woman is supposed to take care of her husband. The study by Wongsawang and colleagues (2013) found that common to all participants was a strong sense of obligation (Wongsawang, Lagampan, Lapvongwattana & Bowers, 2013). In their study about family caregiving for dependent older adults in Thai families, adult children are also informal caregivers for their older parents, and that reciprocity and obligation towards frail parents are always the interaction patterns that motivate them to provide care. However, unlike the spouse's point of view, responsibility and reciprocity in providing care to older parents is rooted in filial piety. This is a common feature in Chinese society, in which a sense of love and norms of caregiving to older parents is the motive for them to provide long term care.

In this study, reasons to be caregiver vary. They can stem from obligatory and discretionary motives for caregiving. Feelings of love, sympathy, commitment to care and obligation are the feelings that most of the caregivers in this study described as their reasons to be a caregiver. Each caregiver had mix reasons to be caregiver and they did not know which reason is dominant. This finding is similar to previous studies in Thai caregivers who are spouse (Kitrungrote, Chanprasit, Sutharangse, & Cohen, 2008 but differs from those with caregivers taking care the elderly (Cafferey, 1992). Furthermore, reasons to be caregiver as observed in this study have one characteristic that is different from other studies, that is the caregiver's feeling of sympathy toward care-receiver. According to Thai culture context, it can be explained

that all of the reason to be a caregiver are influenced by Buddhist doctrine, concern about social expectation and caregiver's attitude toward cancer disease.

Most of the Buddhists believe in Buddhist doctrine about the *law of karma* that includes physical, verbal, and mental actions. It is believed to result from accumulated past *karma* in the form of *boon* (merit) and *barp* (demerit). Therefore, the Thai caregivers Buddhism holds that as a consequence of one's action the power of *karma* is endlessly present to manifest itself in the life of the individuals. Moreover, the essential doctrine of Buddhism is merit-making that is the central part of the religious experience of the Thai Buddhism. The important acts of making merit that can be motivated the most of family caregiver taking the caregiving role is the provision of support for one's parents, elders and charitable causes. Examples of gaining merit are done by giving goods, comfort, or money to one's parents, and their partner in this study. The same resulted as many studies related to Buddhist belief such as by Wongsawang and colleague (2013), they found that common to all participants who were family caregivers for their older adults began from a strong sense of obligation and their belief in Buddhist philosophy.

Furthermore, social expectation in Thai culture as a set expectation that the family will take full responsibility for the care of family members who need special care. This social expectation influences the caregiver's decision making process regarding whether or not to stay with their care-receivers. Most of caregivers reported their obligation is due to their social role and social expectation in the family and society. This condition can be force caregivers to take responsibility for care of their care-receivers. The same resulted as the study from Caffrey (1992) that reported the primary motivations for caregiving to the elderly in Northeastern Thailand were identified as: fulfilling the expected cultural norm of filial obligations.

The last Thai culture context that influence caregiver' reason to be a caregiver is caregiver's attitude toward cancer disease. Intense fear of cancer was pervasive among all of the caregivers in this study. Most of caregivers in this study described cancer disease is suffering and the person who was diagnosed with cancer will not live long. The same resulted was found by Stenberg and colleagues (2012) that caregivers experienced cancer as unpredictable, and worried about how their care-receivers would progress. Whether the caregivers' reasons to be caregiver for their

care-receivers are egoistically or altruistically, both have been a subject for study debates in social and psychological fields for decades in western perspective but seldom discussed and studied in Thai cultural perspective. This issue may need to be explored more in Thai cultural context in the future.

According to the present study results, the process of quality relationship can be described into three phases. The first phase explains the reason to be caregiver. The certain categories of reasons to be caregiver are appeared to be the same as those categories of the quality relationship such as the feeling of sympathy and love.

Since quality relationship is a dynamic process, it may be the reason why these categories are interchangeable between the reason to be caregiver and the feeling of quality relationship. Furthermore the consequence of both the reason to be caregiver and quality relationship from the caregivers' perspective in this study was the provision of care that can change over time. The main questions of this study need to explore and describe the meaning and characteristic of the quality relationship in the perspective of Thai family caregiver with HNC patients. Grounded theory approach is considered more suitable to use in this study than the phenomenology method because it allows a clear explanation of the meaning and characteristic of quality relationship in the process of quality relationship and the interaction between each category found in the quality relationship.

In this study, the meaning and characteristic of quality relationship in the perspective of Thai family caregiver with HNC patients can be described within Thai context as the feeling of love *(ruk),* sympathy *(songsarn),* caring (*houngyai)* and connectedness (*poogpun).* These meanings of quality relationship in this context share some common characteristics that are compared and contrasted in the next sessions.

2) Comparison and contrast of the meaning and characteristic of quality relationship with intimacy, mutuality, reciprocity and love concept

Quality relationship within Thai context is very difficult to describe. The most frequent response to the interview questions about the meaning of quality relationship are "I don't know", I don't understand" and "I don't know how to say". Even though relationship between caregiver and care-receiver appeared to be significant feeling in their lives, they could not define it. One explanation for this lack

of articulation might be that they frequently have difficulty expressing themselves verbally.

Caregivers in this study described their quality relationship as the feeling of love, sympathy, caring and connectedness. Quality relationship emerged as a core theme describing the caregiver process and motivation to continue to caring even in difficulty situation for Thai HNC patients while facing difficult time and suffering from the disease and effect of cancer treatment. This category shows how Thai family with an emphasis on strong Thai culture, kinships, and Buddhist beliefs influences the quality relationship between caregiver and their care-receives. However, while the meanings of quality relationship in this context share some common characteristics, it differs from other studies in caregiving literature such as the concept of intimacy, mutuality, reciprocity, and love.

2.1) Comparison with intimacy concept

The concept of intimacy defined as quality relationship had been studied in various groups of caregivers. Written works on the subject of intimacy tend to center on adult, often sexual relation, theorizing them in terms of individualized, negotiated interactions (Gillies, 2003). Despite a variety of definitions and operationalizations of intimacy, all have at least one important aspect in common as a feeling of closeness and connectedness that develop through communication between partners.

Intimacy concept used to study in caregiving literature is defined as a process in which one person expresses important self-relevant feelings and information to another and, as a result of other's response, comes to feel understood, validated, and cared for (Reis & Shaver, 1988). Although Thai research had studied on spouse caregivers such as the experience of Thai women caring for their husbands living with HIV/AIDS (Ruangjiratain, 2003); experience of caregivers of spouses with HNC undergoing radiation therapy (Kitrungrote et al., 2008; Wongchuay et al., 2010), none of intimacy concept had been reported in Thai caregiving. Traditionally the marital context was influenced by Thai social values such as gratitude. When a person has done something for someone, he/she owes gratitude to that person. Some women applied this value to their marital relationship because their husbands have been good to them in the past such as being a family man or a good

provider, and women felt grateful to him and provided care in gratitude for his merit (Ruangjiratain, 2003). Further, women perceived that it is the wife's role and responsibility to provide care for the sick husband. In addition, accepting care for husbands due to the sense of sympathy, care, warmth, attachment, companionship, love, duty and obligation was reported by women (Ruangjiratain, 2003).

According to a number of theorists, intimacy is a multidimensional concept that includes evaluative, cognitive, and behavioral dimensions (Shaver, 1976). Thai research studies found that the caregivers' reasons to take care of their care-receivers are from the sense of sympathy, care, warmth, attachment, companionship, love, duty and obligation as a result of love, but all of them did not define this as the meaning of quality relationship in Thailand (Kitrungrote et al., 2008; Wongchuay et al., 2010). The result of this study on the meaning of quality relationship and the characteristic of quality relationship differ much from the concept of intimacy though most of the participants in this study were spouse. They mentioned that the meaning of quality relationship composed of the feelings of love, sympathy, caring and connectedness. Only one important aspect in common is the feeling of closeness and connectedness from intimacy concept that shares the same characteristic as in this study.

2.2) Comparison with mutuality concept

Mutuality can be defined as a connection with or understanding of one another that facilitates a dynamic process of joint exchange between people. The process of being mutual is characterized by a sense of unfolding action that is shared in common, a sense of moving toward a common goal, and a sense of satisfaction for all involved. Furthermore, mutuality is defined as the positive quality of the relationship between caregiver and care-receiver, comprising four dimensions, i.e love and affection, shared pleasurable activities, shared values, and reciprocity (Stewart & Archbold, 1992).

The result of this study displays only one component similar to mutuality concept that is the feeling of love. The majority of caregivers in this study did not define quality relationship in the characteristics of shared pleasurable, shared values and reciprocity rather they described it as the feeling of love, caring, sympathy and connectedness. Even most of them did not explained about the feeling of sharing

but in the process of quality relationship, the caregiver's feeling of caring and connectedness happened when they spent time together, sharing both happiness and suffering. That quality relationship from the caregiver's perspective in this study might be different from the concept of mutuality. According to my hypothesis at the start point, the particular components of mutuality such as love and reciprocity may be a dominant domain in Thai culture. The study result however suggests that it was not reciprocity component. The reason why the feeling of reciprocity was not reported in this study can be explained by the most of caregivers' expression through the feeling of love defined as "repayment of love". This feeling is close to the feeling of reciprocity. They defined the feeling of love in the sense of giving and exchange of love and everything that they had experienced. Even two of the caregivers in this study are son, they did not report the feeling of reciprocity but focused on the obligation that is the primary reason to be caregiver. They also reported the feeling of repayment of love from the past experience that their fathers took care of them.

The meaning and characteristics of quality relationship in this study may be different from mutuality concept in term of expressing feelings toward other people. In particular, the component of reciprocity may be different in term of expressing feelings. This can be confirmed by Wirojratana (2002) in her study, who used mutuality scale and had to adapt some items or change some words to help the caregivers understanding the meaning. She changed the word "warmth" to "*auarthon"* that is very close to the feeling of caring reported by the caregivers in this study. Similarly, Monkong (2003) suggested that some items of mutuality may not represent the precise meaning of mutuality, especially, in the dimension of reciprocity from her studied with the psychometric properties of the Family Care Actions Index (FCAI) in the Thai population. However, this study presents the same result as observed by Samartkit (2008). Most caregivers explained that the caregiving situation allows them and their care-receivers to spend more time together and to share their love, closeness, and pleasure in day–to–day interactions in the mutuality concept (Samartkit, 2008).

2.3) Comparison with reciprocity concept

Reciprocity had been defined in various perspectives and had been examined from the perspective of caregivers with older patient (Kuijer, Buunk, & Ybema, 2001; Neufeld & Harrison, 1998). Despite with different opinions on the

definition of reciprocity, many theorists agree on the components of reciprocity that involve the process of giving and receiving. Reciprocity refers to the normative obligation of the recipients of help to assist people who provided that help to them. However, several researchers defined reciprocity as a process that occurs over the entire life course, where current support might reciprocate for past support or for anticipated future support (Antonucci, Fuhrer, & Jackson, 1990).

In Thai caregiving research, reciprocity is viewed as a key factor affecting family's decision to become primary caregiver, and reported in the elderly caregiving situation. Some researchers identified the experience of caring for father who suffered renal failure. Caregiver described how difficult it was to care for their father; however, they felt happy because they did not perceive caring for their father as a burden. They were willing to care for their father with their love and reciprocity (Pornteesud, 1996 as cited in Wirojratana, 2002). Other researchers explored some concepts approximately to reciprocity such as "*katanyu katavedi*" (filial piety) and refers specifically to the parent-child relationship (Kespichayawattana, 1999). The concept of "*katanyu katavedi*" refers to all the benefits which were bestowed upon the children (called "*bunkun*") and the sense of gratitude towards parents (called "*katanyu*"), and refer to the obligatory actions of paying back to parents (called "*katavati*").

The meaning and characteristic of quality relationship in this study differ from the meaning of reciprocity concept. Caregivers reported their feeling of love, sympathy, caring, and connectedness. They did not explain their feeling about reciprocity. The components of reciprocity include warmth and regards (expression of esteem, gratitude between caregiver and care-receiver), intrinsic rewards of giving, love and affection (reflect the feeling of love and appreciation), balance within family caregiving (reflect balance between caregiver and family member) (Carruth, 1996). Only one component as the feeling of love that was explained by caregivers regarding their feeling about the meaning of quality relationship but it differs in the meaning of love. The meaning of love in this study is described as the feeling of caregiver to return the care-receiver's love. Its meaning is not the same as the feeling of love and appreciation in the reciprocity concept. One possible explanation may be that most participants in this study were spouse. The meaning and characteristic of quality of

relationship as explained by those sons of the care-receivers in this study is the feeling of love and obligation to return their father's love.

2.4) Comparison with love concept

The concept of love, by itself, has rarely been explored in the context of caregiving. The concept of love usually involves other conceptualizations of quality relationship, such as intimacy, mutuality, and reciprocity. As observed in this study, love is a key component that all of the caregivers described their meaning of quality relationship. Love is defined in this study as the caregivers' feeling to return for the care-receiver's love extended to them. Most of them defined quality relationship as love. With their reason to be caregiver from the history of their relationship, they based this role on love before taking care of their patients as most of them are spouses who have commitment to live together. Other than love from spouses, the feeling of love can come from caregivers who are son because they thought they have to return this feeling to their father. Caregivers' feeling of love toward their care-receivers did not emerge suddenly but for a period of long time when they spent time together.

Love is not a common topic to talk and discuss in Thai cultural family. Love is manifested in various forms and at various levels. The meaning of love in this study differs from those described in other studies. It is different from the meaning of compassionate love but defined as a type of sharing that is selfless, helpfulness (helping, or willingness to help someone in distress, care and concern (observable, meaningful behaviors that demonstrate concern and care for the welfare of the other), empathy, sympathy, tenderness (Underwood, 2009). Whereas love is an encounter in openness and trust, which in its nakedness may be experienced almost intimately as reported by Donorfio and Kellett (2006). As a qualitative study in grounded theory methodology, Donorfio and Kellett (2006) focused on daughters and frail mothers. They explored filial expectations and motivations and how incongruencies are met and negotiated. They found that personal motivators are love, respect, guilt, power, obligation, being responsible, companionship, fear of being alone, being able to love with oneself, feeling good, modeling for own children, and inheritance promised (Donorfio & Kellett, 2006)

The characteristics of quality relationship in this study that differs from other concept composed of sympathy, caring, and connectedness. Why these characteristics are different from other concepts such as mutuality, intimacy and reciprocity.

1) Sympathy

The feeling of sympathy is one of the characteristics of quality relationship that most of the caregivers explored their feeling toward their care-receivers' having cancer, suffering from the disease, and thus feeling sad for their care-receivers. This characteristic differs from other concepts of quality relationship developed from western perspective such as mutuality, intimacy, and reciprocity. Sympathy is a key dimension of the quality of social relationships when an individual is ready to feel sympathy for a person in distress and is the motivation that benefits the need of others (Kienbaum, Volland, & Ulich, 2001). The meaning of sympathy is often defined as an other-oriented response involving some vicariously induced emotion such as concern (Eisenberg & Fabes, 1990).

The same result was found in all Thai caregiver studies that most caregivers take care of their care-receiver because of their feeling of sympathy. For example, Thampanichawat's (2008) study explored the basic social and psychological processes of caregiving for Thai children with HIV infection and described the conditions influencing the process of caregiving from the perspective of primary caregiver. It suggested in this study the contextual conditions that the caregivers continued to provide care for children with HIV infection, including the sense of responsibility and duty; feelings of love, attachment, and sympathy; fear of losing the child; and maintaining hope. This result is consistent with those studies in Asian culture that views caregiving as an unavoidable task or duty and reported that caregiving is also provided out of love, sympathy, and attachment (Cho & Roth, 2000; Limpanichkul & Magilvy, 2004; Subgranon & Lund, 2000).

However, some theorists identified the feeling of sympathy as a specific motive of helping, with two types of explanations. One assumes that helping serves an egoistic or self-serving motive, while the other centers on empathy and altruism (Batson & Coke, 1983 as cited in Schulz, Biegel, Morycz, & Visintainer, 1989). Schulz and colleague (1989) proposed that in the early stages caregivers may

be motivated by altruistic motives as they feel empathy towards care-receiver with Alzheimer's disease, whilst in the later stages, when care-receiver's cognitive functions have declined, caregivers may be more egotistically motivated. Some researchers argued that the caregivers' culture and kin-relationship could influence motivations to provide care.

Despite limitation of language translation from Thai into English, the feeling of *songsarn* has a meaning close to some words in English language such as sympathy, pity, and empathy. However, the meaning of sympathy may clearly describe the feeling of "*songsarn"* that most of the caregivers explored in this study. Furthermore, the feeling of sympathy in this study share the same meaning as described by Eisenberg and Fasbes (1990) that sympathy involves the other-oriented desire for the other person to feel better and is not as merely feeling what the other person feels (Eisenberg & Fabes, 1990). In addition, the meaning of sympathy in this study is very close to the component of compassion or sympathy described by Feeney and Collins (2003) as the feeling of sympathy requires a focus on three interrelated components of feeling of love, concern, and interdependences; feeling of negative affect and distress; and motivation to help. This meaning supports the result of this study of why the caregiver's reason to be caregiver and the quality relationship of the feeling of sympathy are interchangeable. Furthermore, the interaction between feelings of love, connectedness, and caring had affected the feeling of sympathy. The feeling of sympathy in this study may be based on the Buddhism's influence in the *metta* concept. In Buddhism, "*metta*" involves goodwill, universal love, a feeling of heartfelt concern for all living being, human or nonhuman, in all situations. Moreover, Buddhist philosophy, "*metta*" is believed to guide caregivers with love, closeness, and sympathy (Payutto, 1995).

2) Caring

Feeling of caring is a feeling explored by most of the caregivers with their care-receivers in this study. Caring is defined as the caregiver's feeling of concern and worry about their care-receivers such as how the care-receivers feel, suffer, or become happy or sad. Caring has been more distinct than before after living their life together. This characteristic of quality relationship is different from the component of other concepts developed by western countries such as the concept

of mutuality, reciprocity and intimacy. Most of the caregivers reported the frequency they experience with the feeling of concern and worry about the care-receivers.

However, the literatures show that caring is a difficult concept to define and has been viewed from various perspectives (McCance, McKenna, & Boore, 1997). Morse (1990) reviewed the nursing literature and identified caring with five categories from caring perspective, e.g. caring as a human trait, caring as a moral imperative or ideal, caring as an affection, caring as an interpersonal relationship, and caring as a therapeutic intervention. The category of caring as the interpersonal relationship may be close to the feeling of caring between caregivers and their care-receivers in this study. Caring encompasses both the feeling and the behaviors occurring within the relationship. For example, the feeling of caring includes the aspects of showing concern and taking care of the caregiver. Swanson (1991) described caring as a nurturing way to value other to whom one feels a personal sense of commitment and responsibility that is very close to the feeling of "*ห่วงใย (houngyai*)" as defined by caregivers. A sense of caring might motivate the willingness to assist the other.

In Buddhism, caring refers to "*metta*", which involves goodwill, universal love, a feeling of heartfelt concern for all living being, human or nonhuman, in all situations. According to Buddhist philosophy, "*metta"* is believed to guide caregivers with love, closeness, and sympathy (Payutto, 1995). However, the meaning of caring in this study may differ from caring in Buddhism's perspective because most of the caregivers refer their feeling toward their care-receiver to the feeling of concern and worry. This feeling may rise from their view of relationship between caregiver and their care-receivers as most of them were spouses. The emotional involvement in each other's lives had resulted in strong mutual bounds and sensitivity to each other's situation. Most of them felt a sense of "*houngyai*" (caring) in terms of concern and worry rather than "*metta"*. In Thai family culture, the relationship between wife and husband is more likely expressed as concern and worry about the physical and psychological well-being of each other than a sense of "*metta*" that is usually found in the context of interaction between people in higher position to other in lower position like teachers feel "*metta*" toward their students. Even the

meaning of caring in this study differs from the meaning of caring in Buddhism philosophy; it may be strongly support that the characteristic of caring and sympathy has interaction each other.

3) Connectedness

Connectedness is one characteristic of quality relationship reported by most of the caregivers about their feeling in this study. It is defined as the caregiver's feeling of becoming closer to the care-receivers unlike previously since they have been together; it is emotional connectedness to their care-receiver. Feeling of closeness is defined as the caregiver's feeling toward their care-receivers for their sharing more time than in the past. The sense of connectedness is defined as the caregiver's feeling toward their care-receiver about their relationship experience that can increase or decrease their feeling of connectedness.

Although this characteristic of quality relationship is different from the concept as reviewed by the researcher in the chapter 2, it shares certain characteristic with the concept of intimacy such as the feeling of closeness. The same finding was found in the study by Whisenant (2011) that closeness is an important foundation for caring, and acquires a special dimension in the care of people with cancer and their relatives. The feeling of connectedness is defined by Whisenant (2011) as the feeling of caregiver's connectedness with the care-receivers, where meeting the care-receiver's needs is emotionally satisfying for the caregiver. The same result was reported by Ussher and colleagues (2010) who examined the impact of cancer on the relationship between informal carers and the person with cancer form the perspective of carers. They reported that a greater number of men talked about their relationship with the person for whom they cared being strengthened and feeling closer since the diagnosis of cancer. For example, some participants emphasized "togetherness", being able to share those times", spending quality time together, enjoying the time left together". The closeness developed during their spending time together also affected carers occasions through which to discover and appreciate the relationship.

A study by Stenberg and colleagues (2012) reported some caregivers' experiences living close to the patients with cancer. The caregivers described that their emotional bonds were strengthened toward the patients and others

who were closer. The sense of a shared experience of difficulty emotions, “fighting or struggling” together with the patient throughout the illness, led to strengthening their relationship that become deeper and stronger. The result is true in this study that the caregivers develop stronger sense of connectedness with their care-receivers than in the past because they had shared more time together than in the normal situation prior to the care-receiver’s diagnosis with cancer. As a result of spending more time together, most of them came to know and understand each other more than in the past.

3) Provision of care

The consequence of quality relationship in this study is the caregiver’s perception about their provision of care. It is the caregiver’s feeling after taking caregiving role. In the quality relationship process, the outcome of positive and less positive relationship can be explained by the caregiver’s perception of their quality relationship. The perception of provision of care in this study may not be able to explain in the context of impact of quality relationship as found in literature review because most of the characteristics of quality relationship in this study are emotional and inner feeling of the caregivers. Therefore, the consequence of this outcome may be reported as the feeling of their perception, for example, some caregivers felt their quality relationship with care-receiver as high level of love, sympathy, caring and connectedness, and that they might be fulfill to caring with the sense of willing to care for their care-receiver. According to the literature review, quality relationship affects various outcomes such as higher quality relationship in the past and present, reported greater caregiver’s satisfaction (Lyonette &Yardley, 2003); impact on burden and satisfaction (Snyder, 2000); and the systemic review of quality relationship between caregiver and care-receiver and its impact on the caregiver and care-receiver well-being as reported by Quinn, Clare, and Woods (2009).

Provision of care was a consequence from caregiver’s perspective with their quality relationship. During the time of their taking care of care-receivers, caregiver’s feeling with provision of care may change over time deepending on the interaction between subcategories of quality relationship such as the interaction from the feeling of love, sympathy, caring and connectedness. Even some caregivers reported experience about feeling of stress and exhausted, most of them talked about

positive way of quality relationship by the sense of willing to care for their care-receivers. This may be explained based on the reason to be caregiver and caregiver's perception of quality relationship. Most of them perceived this caregiving as their role that they had to do for their loved one with the feeling of commitment to care, sympathy, love, caring and, connectedness. This is true in the study by Mok and colleagues (2003) who found that caregivers generally did not perceive the care they provide as a burden. Rather, this care was considered a relational commitment that showed their love and support for the patient. However, this differs from one study of family caregivers' experience in taking care of their terminal cancer patients in Hong Kong, suggesting that caregivers experienced major types of difficulties connected with their relationship with the patient, their own emotional reactions to caring, the physical demands placed on them, and the social restrictions caregiving created (Loke et al., 2003)

4) Thai cultural context

Culture is one among the contexts that influences cancer caregiving experience (Fletcher, Miaskowski, Given, & Schumacher, 2012). Thai culture has certain characteristics with strong influence on caregiving and its consequences. For example, Buddhist culture affects norms and values of caring for Thai family members. In Thailand, cultural influences in Thai families such as religious beliefs, rural and urban considerations, family relationship, societal values, sexuality, and masculine and feminine roles, (Pinyuchon & Gray, 1997) significantly influence Thai caregivers to take on and continue caregiving role. According to relevant literature review, Thai cultural, societal-economic, and religious contextual factors play important role, influence, and motivate caregiving, for Thai culture and norms set expectation that any family will take full responsibility for the care of elderly members (Kespichayawattana, 1999). Results from this present study confirmed the past research that Thai people continue to act in accordance with Buddhist's belief in repayment and obligation to their older family members (Limpanichkul & Magilvy, 2004; Sethabouppha & Kance, 2005; Subgranon & Lund, 2000). As reported in another study, religious belief also encourages some caregivers to maintain caring for

their elderly stroke relatives even they felt that caregiving is an unavoidable task but they cannot abandon or leave their care-receiver (Subgranon & Lund, 2000).

Other than religious contextual factors that plays a major influential role on the caregiver's behavior that in Thai society children are expected to take care of their parents. Most of caregiver who were spouse concern about social expectation with their partner role. The roles of husband and wife with intimate relationship are also expected on taking care of their couple in illness. In particular of gender expectation by Thai society, female should take the role of caring for family in household chores, food, and comfort of family members. These include housekeeping, cooking, and caring for family members in illness. If wife does not take care of her husband in time of illness, she would be blamed by the society for not taking proper role. This means that traditionally a Thai woman is required to honor and obey her husband. Mostly, the caregivers with primary role as wife would automatically take on the obligation in caring for their husband who was diagnosed with cancer. In particular, the majority of caregivers in this study are female, reflecting the greater prevalence of HNC disease in male. The diagnosis of cancer can change the relational dynamic between patients with cancer and their caregivers, especially their intimate partners. Most of them continued the care for their partners with the feelings of love, sympathy, caring and connectedness. One issue specifically in Thai cultural context is the caregiver's attitude toward cancer disease.

Caregiver's attitude toward cancer disease is one of important influence that motivates the caregiver's taking the caregiver role and their behavior. Most of caregivers in this study expressed about the fear over the suffering and pain that the cancer victims must endure that were consistently described as "cancer disease is suffering" and the person who was diagnosed with cancer cannot live long. Most of them think about the care-receiver's dying if they had been diagnosed with cancer. They also believed that "cancer equals to death", so they try to do the good thing for their care-receivers before their passing away. The same result was reported by Ussher and colleagues (2010) that most of the caregivers talked about the relationship with the care-receivers for whom they cared being strengthened, and feeling closer since the diagnosis of cancer.

CHAPTER VI
CONCLUSION

The purpose of this final chapter is to present the conclusion in this study. Limitations of this study will be addressed, and the implications for research, theory development and practice will be presented.

Study conclusions

The purpose of this study is to explore the meaning and process of quality relationship of Thai family caregiver with HNC patients. This study finding was obtained from the observation data and in-depth interviews of caregivers who taking care their HNC patients. The grounded theory as method was used to capture the realistic evidence in this study. An evolving theory from this study has addressed by using the main question “What is the quality relationship of Thai caregiver with HNC patients?” and “What are the process of quality relationship that support the caregiving provided?.” The meaning of quality relationship in the perspective of Thai caregiver with HNC patients refers to the feeling of love, sympathy, caring and connectedness. The quality relationship process of Thai caregiver with HNC patients is broken down into the reason to be a caregiver (Phase1), quality relationship (Phase 2), and provision of care (Phase3).

The first phase, reason to be a caregiver, is causal condition. It comprises feeling of love, feeling of sympathy, commitment to care, and obligation.

The second phase, quality of relationship, is action/interaction in this relationship quality process. It involves love, sympathy, caring, and connectedness.

The last phase, provision of care, is the consequence of quality relationship. This consequence includes positive way of relationship and less positive way of relationship. The positive way of relationship refers to the feeling of willing to

care, and doing the best. The less positive way of relationship represents “living normal life”, and “Doing good but not reach expectation”.

Intervening condition of quality relationship process is Thai culture context includes concern with Buddhist doctrine, concern about social expectation and Thai caregiver’ attitude toward cancer disease.

Quality relationship between caregiver and care-receiver is an important issue due to the fact that it not only motivates the family to take on caregiving role but also impacts all through the caregiving process. The meaning of quality relationship in the perspective of Thai caregiver with HNC patients in this study had some characteristics both in common and in difference from other concepts such as intimacy, reciprocity and mutuality. In particular, the feeling of love in this study is described in different type of love as repayment of love. Quality relationship is not a static but dynamic process.

HNC patients are a particularly important group with cancer disease since it involves oral, nasal, and ear organs that effect major activities. Caring of HNC patients is a very difficult task for family members because they have to undertake new role and demanding responsibilities associated with the caregiving role. Caregiving responsibilities also cause a disruption in caregivers’ routines (Cameron, Franche, Cheung, & Stewart, 2002), and their ability to participate in valued activities is restricted such as caring for a family member who is having difficulty eating and drinking or dependent on tube feeds. In addition, the caregiving demands of HNC patients that result from their illness and its treatment also constitute more difficult tasks for caregivers.

Strengths and limitations

This qualitative study based on the grounded theory method provides more and deeper understanding of the quality relationship in the perspective of Thai culture. Based on the symbolic interaction belief, the pattern of behaviors and interactions between the caregivers and their care-receivers were observed with deeper understanding by interviewing with caregivers. The strengths and limitations have been described below.

Strengths

This study presented an evolving of the meanings and characteristics of quality relationship emerged during the time of data collection and the detail and process of quality relationship. These results have not been revealed in other previous studies. Moreover, the findings of this study point out the importance of Thai culture context that influences all process of quality relationship such as the importance of Buddhism declines. Thus, the study has the potential to inform nursing practice.

Procedural strategies added strength to the research findings. Triangulation of data was achieved by using of several data collection techniques included interviews, field notes, and observation.

Limitations of this study

This study explores the meaning of quality relationship in Thai caregiver with HNC patients. Participant in this study reported that quality relationship as feeling of love, sympathy, caring and connectedness. The process of quality relationship in caregiving situation is a dynamic process. This study has some limitations, first, data collection process represents the stories of 15 participants who are caregivers of patients with HNC within during or after treatment less than one year. It should be noted that the possible effects of selection bias could not be ignored because of the nature of convenience sampling. The participants who volunteered to be interviewed may have different perspectives than participants who did not volunteer to relate their experience. This may reduce the applicability of the study findings to other Thai caregivers of patient with HNC within different time of caregiving because quality relationship in the longer period of time might not be unfold and may be different meaning. Second, this study focuses only on caregivers, and thus quality relationship changes from the perspective of patients with HNC have not been assessed. Third, the sample mainly consisted of spouses who are female more than male of patients with HNC, so the data are more representative of caregivers of patients with HNC with these groups than of other group of caregivers. Last is the sample consisted of participants who are Buddhists. Caregivers from other cultures from different religious may have different interpretations of their experiences.

Implications for nursing practice

The meaning and process of quality relationship of caregiver with HNC patients provides nurses and other health care providers a comprehensive and culturally sensitive basis for understanding perspectives, beliefs, and caregiving behavior of Thai family. The present study result can be used to design nursing care strategies to help family caregivers continue providing good care for their patients. Therefore, nurses and other providers should integrate scientific, religious, and culturally knowledge into their clinical practice for promoting quality relationship family caregivers and HNC patients. Health care professional who are responsible for cancer care should focus on quality relationship between caregiver and care-receiver so as to promote it to patients and also to caregiver's continuing caregiving role although the caregiving situation is very difficult for them. The quality relationship between caregiver and care-receiver is very important and has a unique characteristics that found in this study, it still have no system for supporting and providing the caregivers and their care-receivers to maintain their quality relationship.

Recommendations for future research

The result from this study can capture the meaning and process of quality relationship that affect the feeling to provide care in the caregiver's perception. It might be very useful for future research to develop the measurement for evaluating quality relationship in Thai family caregivers. Based on the literature review, we found that quality relationship can effect quality of care and influence caregiver to continue their caregiver role. The diagnosis and treatment of HNC cancer can change quality relationship dynamics between cancer patients and their caregivers, which in turn impact both of them in their quality relationship and well-being. Thus, it is proposed that in the future more emphasis should be placed on the transactions between caregivers and patients as care partners. The research direction on caregiving experiences of families with HNC patients should focus on the caregiver-patient dyad as a unit. Furthermore the result from this study found that quality relationship is a dynamic process, follow up of quality relationship between caregiver and care-

receiver after five year survival may be clearly explain about quality relationship can be change overtime, time series collection may be appropriate for future research.

Quality relationship is a key concept that requires more concern and attention from health care profession than in the past. Most of the western and Thai studies have contributed considerable information about various aspects of quality relationship; however, the findings from western countries may not be applicable to Thai culture because caregivers' personal experiences in Western countries and Thailand differ by socio-cultural and religious contexts. Besides, quality relationship is variable in its meaning and characteristic, it may be desirable to study more specific into Thai culture.

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APPENDICES

APPENDIX A
DOCUMENTARY PROOF OF CLEARANCE ON HUMAN RIGHTS

บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

ใบรับรอง เพื่อแสดงว่า

ชื่อ – นามสกุล นางศิราณี เก็จกรแก้ว รหัสนักศึกษา G 5238750 NRNS/D

คณะ / สถาบัน / วิทยาลัย คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี และคณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล

เป็นผู้ผ่านการเรียนชั่วโมง " จริยธรรมการวิจัยในคน "

ในรายวิชา SICL 636 Professional Ethics

คณะ / สถาบัน / วิทยาลัย คณะแพทยศาสตร์ศิริราชพยาบาล

เมื่อวันที่ 6 เดือน มกราคม พ.ศ. 2554

ลงนาม.....

(รศ.ดร.สุชีรา ภัทรายุตวรรธน์)

อาจารย์ผู้รับผิดชอบรายวิชา / ผู้ประสานงานรายวิชา

ลงนาม.....

(ศ.พญ. วรวรรณ ปโยสวิญช์)

อาจารย์ผู้สอน

คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
๒๗๐ ถนนพระราม ๖ แขวงทุ่งพญาไท เขตราชเทวี กทม. ๑๐๔๐๐
โทร. ๐-๒๓๕๔-๗๒๗๕, ๐-๒๒๐๑-๑๒๙๖ โทรสาร ๐-๒๓๕๔-๗๒๓๓
Faculty of Medicine Ramathibodi Hospital, Mahidol University
270 Rama VI Road, Ratchathewi, Bangkok 10400, Thailand
Tel. (+66) 2354-7275, (+66) 2201-1296 Fax (+66) 2354-7233

Documentary Proof of Ethical Clearance
Committee on Human Rights Related to Research Involving Human Subjects
Faculty of Medicine Ramathibodi Hospital, Mahidol University

MURA2013/400

Title of Project	Exploring Quality Relationship of Family Caregiver of Patients with Head and Neck Cancer
Protocol Number	ID 06-56-46
Principal Investigator	Mrs. Siranee Kejkornkaew
Official Address	Ramathibodi School of Nursing Faculty of Medicine Ramathibodi Hospital Mahidol University

The aforementioned project has been reviewed and approved by the Committee on Human Rights Related to Research Involving Human Subjects, based on the Declaration of Helsinki.

Signature of Secretary Committee on Human Rights Related to Research Involving Human Subjects	..... Prof. Duangrurdee Wattanasirichaigoon, M.D.
Signature of Chairman Committee on Human Rights Related to Research Involving Human Subjects	..... Prof. Boonsong Ongphiphadhanakul, M.D.
Date of Approval	July 25, 2013
Duration of Study	8 Months

LOPBURI CANCER HOSPITAL

This is to certify that

Project Title	: Exploring quality relationship of family caregiver of patients with head and neck cancer
Principle Investigator	: Mrs. Siranee Kejkornkaew
Official Address	: Faculty of Medicine Ramathibodi Hospital, Mahidol University

Document acceptance:

1. Protocol Exploring quality relationship of family caregiver of patients with head and neck cancer
2. Curriculum Vitae
3. Informed Consent Form
4. Interview form Exploring quality relationship of family caregiver of patients with head and neck cancer

The aforementioned project have been reviewed and approved by Lopburi Cancer Hospital Ethics Committee for Human Research based on the Declaration of Helsinki and The ICH Good Clinical Practice Guidelines. Please submit the progress report every 6 months

Date of approval : 20/08/2013

Date of Expire : 19/08/2014

Signed S. Sangkittipaiboon

(Dr. Somphob Sangkittipaiboon)

Chairman of Panel Lopburi Cancer Hospital

Ethics Committee for Human Research

Record No 12/2013

Reference No. LEC5612

Official Address: Lopburi Cancer Hospital

11/1 Phahon Yothin Road, Lopburi 15000, Thailand

Tel. (036) 621800, 7523 Fax (036) 421679

Ethics Committee

Lopburi Cancer Hospital Ethics Committee for Human Research

Name and function On Committee (e.g.Chairman, Secreatary and ect.)	Profes sional/ Qualifi cation (S)	Affiliation (Place of work)	Gender (M/F)	Tick (✓) If member present When protocol Reviewed
1. Dr. Somphob Sangkittipaiboon	M.D.	Lopburi Cancer Hospital	M	✓
2. Dr. Wilawan Watcharaapapiboon	M.D.	Lopburi Cancer Hospital	F	✓
3. Dr. Suneeya Dussaruk	D.D.S	Lopburi Cancer Hospital	F	✓
4. Mrs. Yupa Sarunyusej	RN.	Lopburi Cancer Hospital	F	✓
5. Mr. Pongsakon Ongkuna	R.Ph.	Lopburi Cancer Hospital	M	✓
6. Mrs. Pawamai Taecheusai	M.T.	Lopburi Cancer Hospital	F	✓
7. Mrs. Chaweewan Jermsom	RN	Lopburi Cancer Hospital	F	✓
8. Mrs. Nipha Sangkittippaiboon	RN	Lopburi Cancer Hospital	F	✓
9. Miss Ruknisa Titarkart	RN	Lopburi Cancer Hospital	F	✓
10. Miss Uraiwan Duangkkaew	RN	Lopburi Cancer Hospital	F	✓
11. Miss Wanvisa Mungkornpet	RN	Lopburi Cancer Hospital	F	✓
12. Mrs. Sujira Foongfaung	RN	Lopburi Cancer Hospital	F	✓
13. Mr. Surin Uadrang	M.P.	Lopburi Cancer Hospital	M	✓
14. Mr. Thepphitak Wattanasarn	M.P.	Lopburi Cancer Hospital	M	✓
15. Miss Pimjan Pinsuntorn	RN	Lopburi Cancer Hospital	F	✓
16. Miss Rukkhana Ngamdee	LB.	Lopburi Cancer Hospital	F	✓

The above Lopburi Cancer Hospital Ethics Committee for Human Research member who are Independent of the investigator and the sponsor of the trial have voted provided opinion on the trial titled : ***Exploring quality relationship of family caregiver of patients with head and neck cancer***

Principle investigator : *Mrs. Siranee Kejkornkaew*

Cirtificate Number : *LEC5612*

Date of Meeting : *August 20, 2013*

Date of Approval : *August 19, 2014*

S. Sangkittipaiboon

(Dr. Somphob Sangkittipaiboon)

Chairman of Panel Lopburi Cancer Hospital

Ethics Committee for Human Research

APPENDIX B
PARTICIPANT INFORMATION SHEET AND CONSENT FORM

เอกสารชี้แจงข้อมูล/คำแนะนำแก่ผู้เข้าร่วมการวิจัย

(Patient/Participant Information Sheet)

ชื่อโครงการ การศึกษาสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแลในผู้ป่วยมะเร็งศีรษะและลำคอ (Exploring quality relationship of family caregiver of patients with head and neck cancer)

ชื่อผู้วิจัย นางศิราณี เก็จกรแก้ว

สถานที่วิจัย 1. โรงพยาบาลรามาธิบดี คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

2. โรงพยาบาลมะเร็งลพบุรี สถาบันมะเร็งแห่งชาติ

บุคคลและวิธีการติดต่อเมื่อมีเหตุฉุกเฉินหรือความผิดปกติที่เกี่ยวข้องกับการวิจัย

นางศิราณี เก็จกรแก้ว
สาขาการพยาบาลพื้นฐาน โรงเรียนพยาบาลรามาธิบดี
คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล
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หมายเลขโทรศัพท์ 089- 2043183
รองศาสตราจารย์ ดร. ยุพาพิน ศิรโพธิ์งาม
โรงเรียนพยาบาลรามาธิบดี คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี
มหาวิทยาลัยมหิดล 10400
หมายเลขโทรศัพท์ 02-2012013

ผู้สนับสนุนการวิจัย สภาการพยาบาลแห่งประเทศไทย

ความเป็นมาของโครงการ

ผู้ป่วยมะเร็งศีรษะและลำคอเป็นกลุ่มผู้ป่วยที่มีความแตกต่างจากมะเร็งในตำแหน่งอื่น เนื่องจากตำแหน่งที่เกิดโรคส่วนใหญ่มักอยู่ในบริเวณ ลิ้น ช่องปาก กล่องเสียง โพรงจมูกและต่อมน้ำลาย ซึ่งเป็นตำแหน่งที่มีความสำคัญอย่างมากในการดำรงชีวิตประจำวัน เช่นการรับประทานอาหาร การหายใจ และการสื่อสารกับบุคคลอื่นในครอบรัวและสังคม นอกจากนี้การรักษายังมีผลกระทบและภาวะแทรกซ้อนที่สามารถที่เกิดขึ้นอีกมากมายทั้งจาก การผ่าตัด เคมีบำบัด และรังสีรักษา เช่น ภาวะน้ำลายแห้ง การกลืนลำบาก การสูญเสียภาพลักษณ์จากการผ่าตัด ผลต่างๆเหล่านี้ทำให้ผู้ป่วยต้องเผชิญกับความเครียด มีภาวะซึมเศร้า คุณภาพชีวิตต่ำและปัญหาต่างๆทั้งทางด้านร่างกายและจิตใจมากกว่าผู้ป่วยมะเร็งในกลุ่มอื่นๆเช่น มะเร็งทางนรีเวช ต่อมลูกหมาก และเต้านม (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001) ปัญหาต่างๆเหล่านี้ไม่ได้ส่งผลกระทบแต่เพียงผู้ป่วยลำพังหากแต่มีผลไปถึงญาติผู้ให้การดูแลผู้ป่วยด้วย จากการศึกษาพบว่าญาติผู้ดูแลผู้ป่วยมะเร็งศีรษะและลำคอต้องเผชิญกับความเครียดและความยากลำบากในการดูแลผู้ป่วยเหล่านี้ซึ่งมีปัญหาทั้งด้านร่างกายและจิตใจจากผลกระทบของโรคมะเร็งและผลของการรักษา

โดยธรรมชาติของการก้าวเข้าสู่บทบาทของญาติผู้ดูแลนั้น เกิดจากแรงจูงใจของบุคคลใดบุคคลซึ่งมาจาก การตระหนักรู้ถึงบทบาทความรับผิดชอบของตนเอง อาจมาจากความคาดหวังของสังคม ขนบธรรมเนียม วัฒนธรรม หรือจากการตัดสินใจเข้าสู่บทบาทของญาติผู้ดูแลด้วยตนเอง รวมถึงพื้นฐานของความรัก ความผูกพัน และสัมพันธภาพในอดีต ระหว่างญาติผู้ดูแลและผู้ป่วย (Walker, Pratt, Shin & Jones, 1990) ซึ่งสัมพันธภาพระหว่างญาติผู้ดูแลและผู้ป่วยนั้นอาจจะดีขึ้นหรือแย่ลงในระหว่างกระบวนการดูแลผู้ป่วยได้ สัมพันธภาพระหว่างญาติผู้ดูแลและผู้ป่วยมีความสำคัญอย่างมากต่อคุณภาพของการให้การดูแล และส่งผลกระทบทั้งทางตรงและทางอ้อมทั้งญาติผู้ดูแลและตัวผู้ป่วยเอง นอกจากนี้คุณภาพของสัมภาพที่ดีระหว่างญาติผู้ดูแลและผู้ป่วยยังส่งผลให้ญาติผู้ดูแลคงอยู่ในบทบาทของตนเองไปอย่างต่อเนื่องแม้ต้องเผชิญกับสถานการณ์หรือประสบการณ์ที่ยากลำบาก (Hirschfeld, 1983) ในขณะที่หากสัมพันธภาพระหว่างญาติผู้ดูแลและผู้ป่วยมีคุณภาพน้อย จะนำไปสู่การที่ญาติผู้ดูแลมีความเครียด ความเหนื่อยหน่าย ความวิตกกังวล ความคับข้องใจ และส่งผลกระทบต่อคุณภาพชีวิตของญาติผู้ดูแล

จากการทบทวนวรรณการที่เกี่ยวข้องกับสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแล พบว่าการศึกษาส่วนใหญ่เป็นงานที่พัฒนามาจากแนวความคิดและงานวิจัยทางด้านตะวันตก ซึ่งมีการนำมาใช้ในกลุ่มญาติผู้ดูแลผู้ป่วยที่มีความหลากหลายและแตกต่างกันไปตามแต่ละแนวความคิดที่พัฒนามา สำหรับประเทศไทย แนวความคิดเรื่องสัมพันธภาพที่มีคุณภาพได้ถูกนำมาศึกษาบ้างใน

กลุ่มของญาติผู้ดูแลผู้ป่วยหลอดเลือด สมอง (Samartkit, 2008) และบางงานวิจัยได้แปลเครื่องมือเกี่ยวกับคุณภาพของสัมพันธภาพซึ่งพัฒนามาจากงานวิจัยจาก ประเทศอเมริกา ซึ่งผลการนำไปใช้พบว่าเครื่องมือที่แปลอาจไม่เหสามะสมในบริบทของสังคมไทย (Wirojratana, 2002) เนื่องจากสังคมไทยเป็นสังคมที่มีลักษณะเฉพาะ มีความแตกต่างจากสังคมอื่นอย่างชัดเจน ประชากรส่วนใหญ่นับถือหลักคำสอนของศาลนาพุทธ มีความเข้มแข็งของความสัมพันธในครอบครัว หรือขนบธรรมเนียมต่างๆที่ถือปฏิบติกันมาในการให้การดูแลหรือปฏิบัติต่อบุคคลในครอบครัว สิ่งต่างๆเหล่านี้ส่งผลให้ สัมพันธภาพระหว่างคนในครอบครัวมีความใกล้ชิด และเหตุผลในการเข้ามาสู่บทบาทของญาติผู้ดูแล อาจแตกต่างจากสังคมทางตะวันตกได้ ที่ผ่านมายังไม่มีงานวิจัยใดที่ทำการศึกษาเกี่ยวกันแนวความคิด และความหมายของสัมพันธภาพที่มีคุณภาพ ตามแนวคิดและการรับรู้ของญาติผู้ดูแลในประเทศไทย ด้วยเหตุดังกล่าวนี้งานวิจัยนี้จึงมีความจำเป็นอย่างยิ่งในการศึกษาเพื่องเป็นข้อมูลพื้นฐานในการเปรียบเทียบ และพัฒนาเครื่องมือวิจัยที่มีความเหมาะสมกับบริบทของคนไทยมากขึ้น และยังช่วยให้บุคคลากรในทีมสุขภาพได้มีความเข้าใจและมองเห็นกลไกในการให้การช่วยเหลือสสันบสนุนญาติผู้ดูแลและผู้ป่วยให้มีสัมพันธภาพที่มีคุณภาพที่ดีต่อกัน ส่งผลให้เพิ่มการดูแลที่มีคุณภาพมากยิ่งขึ้น

วัตถุประสงค์

การศึกษาครั้งนี้มุ่งเน้นการอธิบายและให้ความหมายของสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแลผู้ป่วยมะเร็งศีรษะและลำคอ โดยอาศัยข้อมูลจากการรับรู้และประสบการณ์ของญาติผู้ดูแลผู้ป่วยมะเร็งศรีษะและลำคอ เพื่ออธิบายกระบวนการเกิดสัมพันธภาพที่มีคุณภาพตามการรับรู้ของญาติผู้ดูแลผู้ป่วยโดยมีวัตถุประสงค์เพื่อ

1. อธิบายการรับรู้ของญาติผู้ดูแลผู้ป่วยมะเร็งศรีษะและลำคอต่อการให้ความหมายของสัมพันธภาพที่มีคุณภาพระหว่างญาติผู้ดูแลและผู้ป่วยที่ได้รับการดูแล
2. อธิบายผลกระทบของคุณภาพของสัมพันธภาพที่มีต่อญาติผู้ดูแล
3. อธิบายสาเหตุและกระบวนการการเข้าสู่บทบาทการเป็นญาติผู้ดูแลและะอธิบายถึงเหตุและแรงจูงใจในการรับบทบาทเป็นญาติผู้ดูแล

รายละเอียดที่จะปฏิบัติต่อผู้เข้าร่วมการวิจัย

1. เมื่อผู้วิจัยได้รับการอนุมัติจากคณะกรรมการจริยธรรมการวิจัยในคนของคณะแพทยศาสตร์

โรงพยาบาลรามาธิบดี และ โรงพยาบาลศูนย์มะเร็ง ลพบุรี ผู้วิจัยจะติดต่อประสานงานกับพยาบาลประจำแผนกผู้ป่วยนอก หรือผู้ป่วยในในการช่วยทาบทามญาติผู้ดูแลผู้ป่วยมะเร็งศีรษะและลำคอ โดยสอบถามความสมัครใจเบื้องต้นในการรับฟังข้อมูลวิจัย โดยใช้แนวคำถามในการคัดกรองผู้เข้าร่วมวิจัยให้ตรงกับคุณสมบัติที่ตั้งไว้ หากญาติผู้ดูแลมีคุณสมบัติไม่ตรงตามที่ตั้งไว้ จะอธิบายให้ทราบว่าเขามีคุณสมบัติไม่ตรงและกล่าวขอบคุณที่สละเวลามาให้สัมภาษณ์

2. ในการเก็บข้อมูล ผู้วิจัยจะทำการสัมภาษณ์ญาติผู้ดูแลในสถานที่มีความเป็นส่วนตัวหรือตามแต่ผู้เข้าร่วมวิจัยมีความสะดวกใจจะให้สัมภาษณ์สัมภาษณ์ ผู้วิจัยจะทำการสัมภาษณ์ผู้เข้าร่วมวิจัย โดยใช้เวลาประมาณ 1 ถึง 2 ชั่วโมง โดยผู้วิจัยอาจขอสัมภาษณ์เป็นครั้งที่ 2 ในกรณีที่การวิเคราะห์แล้วพบว่า จำเป็นต้องขอข้อมูลเพิ่มเติม เพื่อช่วยในการอธิบายว่าปรากฏการณ์ที่เกิดขึ้นเป็นอย่างไรบ้าง โดยผู้วิจัยจะขอเบอร์โทรศัพท์ไว้ในตอนสัมภาษณ์
3. ในการสัมภาษณ์แต่ละครั้ง ผู้วิจัยจะอัดเสียงการสัมภาษณ์ลงเครื่องบันทึกเสียง โดยจะขออนุญาตจากผู้เข้าร่วมวิจัย โดยได้ระบุไว้ในเอกสารชี้แจงผู้เข้าร่วมวิจัยและหนังสือแสดงเจตนายินยอมเข้าร่วมการวิจัยโดยได้รับการบอกกล่าวโดยเต็มใจ หากผู้เข้วร่วมวิจัยไม่สามารถเขียนหนังสือได้ ผู้วิจัยจะขออนุญาติผู้เข้าร่วมวิจัยเป็นวาจา
4. หลังจากการสัมภาษณ์ผู้วิจัยจะบันทึกภาคสนาม เกี่ยวกับสภาพการณ์หรือบรรยากาศของสถานที่สัมภาษณ์ ปฏิกิริยาและพฤติกรรมของผู้เข้าร่วมวิจัยในระหว่างสัมภาษณ์ ปัญหาอุปสรรคที่เกิดขึ้น ความคิด ความรู้สึกของผู้วิจัย นำมาสรุปและวางแผนการสัมภาษณ์ในครั้งต่อไป
5. ผู้วิจัยจะถอดบทสนทนาจากไฟล์สำเนาบันทึกการสัมภาษณ์ลงกระดาษด้วยตนเอง โดยใชรหัสแทนชื่อผู้เข้าร่วมวิจัย และจะลบไฟล์บันทึกเสียงการสัมภาษณ์ทิ้งหลังการถอดบทสัมภาษณ์เรียบร้อยแล้ว ผู้วิจัยจะเก็บต้นฉบับการบันทึกเสียงไว้ในที่ปลอดภัยในคอมพิวเตอร์ และมีเพียงผู้วิจัยเท่านั้นที่สามารถเข้าถึงข้อมูลนี้ได้ ภายหลังจากการวิจัยเสร็จสิ้นผู้วิจัยจะลบไฟล์ต้นฉบับทิ้ง สำหรับเอกสารที่เกี่ยวข้องอื่นๆ ในการวิเคราะห์ข้อมูลจะเก็บไว้ในต้ที่ล็อคและจะทำลายหลังทำการวิจัยเสร็จสิ้น 5 ปี
6. เนื่องด้วยการวิจัยเป็นการเก็บรวบรวมข้อมูลโดยการสัมภาษณ์เชิงลึก จึงมิได้ส่งผลกระทบโดยตรงต่อร่างกายของผู้เข้าร่วมวิจัย หากจะมีผลกระทบบ้างในการทำให้ผู้เข้าร่วมวิจัยเกิดความเหนื่อยล้าและ เสียเวลาในการให้สัมภาษณ์ หรือในระหว่างการ

สัมภาษณ์ผู้ร่วมวิจัยอาจเกิดความอึดอัดกับบางคำถาม หรือเรื่องราวที่เล่าอาจทำให้รู้สึกไม่สบายใจ มาตรการที่ผู้วิจัยวางแผนไว้เพื่อรองรับผลกระทบดังกล่าวมีดังนี้

6.1 ก่อนการสัมภาษณ์ทุกครั้งผู้วิจัยจะกล่าวย้ำกับผู้เข้าร่วมวิจัยมีสิทธิที่จะปฏิเสธที่จะกล่าวถึงประเด็นที่ไม่ต้องการจะพูดถึงและยุติการให้สัมภาษณ์ได้ตลอดเวลา โดยจะไม่มีผลกระทบต่อการบริการและรักษาผู้ป่วยของผู้เข้าร่วมวิจัย

6.2 ในระหว่างการสัมภาษณ์ หากผู้เข้าร่วมวิจัยร้องไห้ รู้สึกเครียด ผู้วิจัยจะให้เวลาผู้เข้าร่วมวิจัยได้ปรับอารมณ์และเปิดโอกาสให้ผู้เข้าร่วมวิจัยตัดสินใจจะให้สัมภาษณ์ต่อหรือไม่ หากผู้เข้าร่วมวิจัยไม่ต้องการจะให้สัมภาษณ์ต่อ ผู้วิจัยจะยุติบทบาททันที่

6.3 หลังจากสัมภาษณ์ ผู้วิจัยจะประเมินและติดตามผู้เข้าร่วมวิจัยในรายที่สังเกตได้ว่ามีความเครียดเกิดขึ้นโดยใช้การโทรศัพท์หรือประเมินจากการพูดคุย หากพบว่าผู้เข้าร่วมวิจัยมีความเครียดเกิดขึ้นและต้องการความช่วยเหลือ ผู้วิจัยจะพิจารณาให้ความช่วยเหลือตามความเหมาะสมโดย ให้คำปรึกษา หรือส่งต่อผู้เข้าร่วมวิจัยไปยังศูนย์ให้คำปรึกษา เพื่อให้การดูแลที่เหมาะสม

6.4 ผู้วิจัยเป็นผู้ ทำการสัมภาษณ์เชิงลึกด้วยตัวเอง ข้อคำถามต่างๆได้รับการพิจารณาจากคณะกรรมการควบคุมวิทยานิพนธ์ แล้วว่าไม่มีข้อคำถามที่ทำให้เกิดความกระทบกระเทือนต่อจิตใจของผู้เข้าร่วมวิจัย

6.5 ผู้วิจัยแจ้งชื่อ ที่อยู่ และเบอร์โทรศัพท์ที่สามารถติดต่อได้ไว้ให้แก่ผู้เข้าร่วมวิจัยรับทราบ

ประโยชน์ที่คาดว่าจะได้รับจากการวิจัย

การศึกษาวิจัยครั้งนี้อาจไม่เกิดประโยชน์โดยตรงแก่ผู้เข้าร่วมโครงการในขณะนี้ อย่างไรก็ตามผลของการวิจัยจะส่งผลต่อการดูแลครอบครัว ญาติผู้ดูแลและผู้ป่วยมะเร็งศีรษะและลำคอ เพื่อการดูแลที่มีคุณภาพ ผลของการวิจัยจะช่วยให้พยาบาลและบุคลากรทางสุขภาพเข้าใจถึงลักษณะของสัมพันธภาพที่มีคุณภาพระหว่างญาติผู้ดูแลและผู้ป่วย การช่วยเหลือสนันสนุนให้ครอบครัวมีให้การดูแลผู้ป่วยอย่างมีคุณภาพ และมีผลกระทบทั้งญาติผู้ดูแลและผู้ป่วยน้อยที่สุด นอกจากนี้ยังเป็นข้อมูลพื้นฐานสำหรับการวิจัยเกี่ยวกับสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแล ในการพัฒนาเครื่องมือ และงานวิจัยอื่นๆที่เกี่ยวข้องต่อไป

การเก็บข้อมูลเป็นความลับ

ชื่อและรายละเอียดข้อมูลส่วนตัวของผู้เข้าร่วมโครงการจะถูกเก็บรักษาเป็นความลับ การรายงานผลการศึกษาจะเป็นเพียงข้อมูลวิเคราะห์โดยรวมเท่านั้น และจะไม่มีการระบุชื่อ รวมทั้งไม่เปิดเผยต่อสาธารณะ การเปิดเผยข้อมูลเกี่ยวกับผู้เข้าร่วมวิจัยต่อหน่วยงานต่างๆที่เกี่ยวข้อง กระทำได้เฉพาะกรณีที่จำเป็นด้วยเหตุผลทางวิชาการเท่านั้น ข้อมูลในการสัมภาษณ์ผู้เข้าร่วมวิจัยจะเก็บไว้เป็นความลับ และจะถูกทำลายโดยผู้วิจัยเมื่อเสร็จสิ้นการศึกษา

ถ้าท่านมีปัญหาข้องใจหรือรู้สึกกังวลใจกับการเข้าร่วมในโครงการวิจัยนี้ ท่านสามารถติดต่อกับ
ประธานกรรมการ
จริยธรรมการวิจัยในคน สำนักงานวิจัยคณะฯ อาคารวิจัยและสวัสดิการ คณะแพทยศาสตร์
โรงพยาบาลรามาธิบดี

หนังสือยินยอมโดยได้รับการบอกกล่าวและเต็มใจ

(Informed Consent Form)

ชื่อโครงการ การศึกษาสัมพันธภาพที่มีคุณภาพของญาติผู้ดูแลในผู้ป่วยมะเร็งศรีษะและลำคอ (Exploring quality relationship of family caregiver of patients with head and neck cancer)

ชื่อผู้วิจัย นาง ศิราณี เก็จกรแก้ว

*ชื่อผู้เข้าร่วมการวิจัย .....

อายุ .....เลขที่เวชระเบียน .....

.....

คำยินยอมของผู้เข้าร่วมการวิจัย

ข้าพเจ้า นาย/นาง/นางสาว ..... ได้ทราบรายละเอียดของโครงการวิจัยตลอดจนประโยชน์ และข้อเสี่ยงที่จะเกิดขึ้นต่อข้าพเจ้าจากผู้วิจัยแล้วอย่างชัดเจน ไม่มีสิ่งใดปิดบังซ่อนเร้นและยินยอมให้ทำการวิจัยในโครงการที่มีชื่อข้างต้น และข้าพเจ้ารู้ว่าถ้ามีปัญหาหรือข้อสงสัยเกิดขึ้นข้าพเจ้าสามารถสอบถามผู้วิจัยได้ และข้าพเจ้าสามารถไม่เข้าร่วมโครงการวิจัยนี้เมื่อใดก็ได้ โดยไม่มีผลกระทบต่อการรักษาที่ข้าพเจ้าพึงได้รับ นอกจากนี้ผู้วิจัยจะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะในรูปที่เป็นสรุปผลการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่างๆที่เกี่ยวข้อง กระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ลงชื่อ..... (ผู้เข้าร่วมการวิจัย)

..... (พยาน)

..... (พยาน)

วันที่ .....

คำอธิบายของผู้วิจัย

ข้าพเจ้าได้อธิบายรายละเอียดของโครงการ ตลอดจนประโยชน์ของการวิจัย รวมทั้งข้อเสี่ยงที่อาจจะเกิดขึ้นแก่ผู้เข้าร่วมการวิจัยทราบแล้วอย่างชัดเจน โดยไม่มีสิ่งใดปิดบังซ่อนเร้น

ลงชื่อ..... (ผู้วิจัย)

วันที่.....

หมายเหตุ : กรณีผู้เข้าร่วมการวิจัยไม่สามารถอ่านหนังสือได้ ให้ผู้วิจัยอ่านข้อความในหนังสือยินยอมฯ นี้ให้แก่ผู้เข้าร่วมการวิจัยฟังจนเข้าใจดีแล้ว และให้ผู้เข้าร่วมการวิจัยลงนามหรือพิมพ์ลายนิ้วหัวแม่มือรับทราบในการให้ความยินยอมดังกล่าวข้างต้นไว้ด้วย

* ผู้เข้าร่วมการวิจัย หมายถึง ผู้ยินยอมตนให้ทำวิจัย

APPENDIX C
INSTRUMENTS

Interview Guide (THAI): แนวคำถามในการสัมภาษณ์ ญาติผู้ดูแลผู้ป่วยมะเร็งศรีษะและลำคอ

รหัส.....

วันที่สัมภาษณ์……ครั้งที่สัมภาษณ์…….

<u>คำถามทั่วไป</u>

กรุณาเล่าให้ดิฉันฟังเกี่ยวกับประสบการณ์ของคุณนับตั้งแต่มารับหน้าที่เป็นญาติผู้ดูแล

<u>คำถามทั่วไป</u>

1. กรุณาเล่าเกี่ยวกับชีวิตของคุณก่อนมาดูแลผู้ป่วย (สืบสาวต่อเรื่อง ชีวิตส่วนตัว การแต่งงาน งานที่ทำ ชีวิตครอบครัว บทบาทในครอบครัวก่อนที่ญาติที่คุณดูแลจะป่วยเป็นมะเร็ง)
2. มีสิ่งใดในชีวิตประจำวันของคุณเปลี่ยนไปบ้างนับจากการวินิจฉัยโรคของญาติที่คุณดูแล
3. ก่อนการป่วยของญาติที่คุณให้การดูแล หน้าที่ของคุณในครอบครัวคืออะไร และหลังป่วยความรับผิดชอบของคุณเปลี่ยนไปอย่างไรบ้าง

<u>คำถามเฉพาะ</u>	**<u>คำถามที่ถาม</u>**
จุดประสงค์เฉพาะของการวิจัย	
1. เพื่อบรรยายถึงสาเหตุแรงจูงใจที่ญาติผู้ดูแลมารับบทบาทในการดูญาติที่ป่วย	1. คุณมารับหน้าที่ในการเป็นญาติผู้ดูแลได้อย่างไร/ คุณเริ่มที่จะมารับหน้าที่ในการเป็นญาติผู้ดูแลได้อย่างไร 2. มีบุคคลใดช่วยคุณตัดสินใจหรือแนะนำให้มารับหน้าที่เป็นผู้ดูแลญาติของคุณหรือไม่ อย่างไร
2. เพื่อบรรยายเกี่ยวกับบทบาทหน้าที่ของ	3. คุณให้การดูแลญาติของคุณอย่างไรบ้าง

<u>คำถามทั่วไป</u>

ญาติผู้ดูแล	4. คุณรู้สึกอย่างไรบ้างกับการที่มารับหน้าที่ดูแลญาติของคุณ 5. คุณมีบุคคลอื่นให้ความช่วยเหลือคุณในการดูแลญาติที่ป่วยของคุณหรือ ไม่ (ถ้ามี ให้ความช่วยเหลืออย่างไรบ้าง) 6. การมารับบทบาทเป็นญาติผู้ดูแลมีผลกับการดำเนินชีวิตของคุณหรือไม่ (ถ้ามีอย่างไรบ้าง) 7. การดูแลญาติของคุณมีผลต่อสุขภาพทั้งทางด้านร่างกายและจิตใจของคุณหรือไม่ อย่างไรบ้าง
3. เพื่อบรรยายถึงการรับรู้ของญาติผู้ดูแลที่มีต่อสัมพันธภาพระหว่างตนเองและญาติที่ได้รับการดูแล	8. ก่อนหน้าที่ญาติของคุณจะป่วยเป็นมะเร็ง คุณมีกิจกรรมอะไรที่ทำร่วมกันกับ.....บ้างหรือไม่ (อะไรบ้าง ยกตัวอย่าง) 9. สัมพันธภาพระหว่างคุณและญาติก่อนหน้าที่ป่วยเป็นมะเร็งเป็นอย่างไรบ้าง 10. คุณคิดอย่างไรเกี่ยวกับสัมพันธภาพระหว่างคุณกับญาติที่คุณให้การดูแล 11. ความสัมพันธ์ของคุณกับญาติที่คุณดูแลเป็นอย่างไรบ้างหลังจากที่คุณเข้ามารับบทบาทเป็นผู้ดูแล 12. เปลี่ยนแปลงอย่างไรบ้าง ยกตัวอย่าง
4. เพื่อบรรยายผล/การเปลี่ยนแปลงของสัมพันธภาพระหว่างญาติผู้ดูแลและญาติผู้ได้รับการดูแล	13. คุณคิดว่าสัมพันธภาพระหว่างคุณและญาติที่คุณดูแลมีผลการดูแลของคุณอย่างไรบ้าง 14. การเปลี่ยนแปลงของสัมพันธภาพระหว่างคุณและญาติที่คุณดูแลมีผลต่อ

<u>คำถามทั่วไป</u>

ชีวิตของคุณอย่างไรบ้าง

15. คุณมีวิธีการจัดการกับการเปลี่ยนแปลง/ ผลของสัมพันธภาพระหว่างคุณและญาติที่คุณให้การดูแลอย่างไรบ้าง และผลของการจัดการนั้นเป็นอย่างไร
16. คุณคิดว่าอะไรบ้างที่มีส่วนช่วยในการจัดการกับการเปลี่ยนแปลง/ ผลของสัมพันธภาพระหว่างคุณกับญาติที่คุณดูแล(เช่น ความเชื่อต่างๆ ความเชื่อทางศาสนา วัฒนธรรม)
17. คุณเข้าใจคำว่าสัมพันธภาพที่มีคุณภาพหรือไม่ อย่างไร
    ในการรับรู้ของคุณคิดว่าสัมพันธภาพที่มีคุณภาพระหว่างคุณและญาติที่คุณดูแลเป็นอย่างไร
    คุณคิดว่าอะไรที่มีผลต่อสัมพันธภาพที่มีคุณภาพของคุณ อะไรที่เป็นอุปสรรค

ข้อมูลส่วนตัวของญาติผู้ดูแล

ID# □□

1. เพศ □ ชาย □ หญิง
2. อายุ ปี เดือน
3. สภานภาพสมรส □ โสด □ คู่ □ หย่า
   □แยก □ม่าย
4. ศาสนา □พุทธ □คริสต์
   □อิสลาม □อื่นระบุ……
5. การศึกษาขั้นสูงสุด □ ประถมศึกษา □มัธยมศึกษา □อาชีวะ □ปริญญาตรี
   □ ปริญญาโท □ ปริญญาเอก □ อื่นๆ ระบุ
6. ขณะนี้คุณทำงานหรือไม่ □ ไม่ทำ □ ทำ
7. รายได้เฉลี่ยต่อเดือน □ < 6,000 บาท □ 6001-10,000 บาท
   □ 10,001-15,000 บาท □ 15,001-20,000 บาท
   □ > 20,001 บาทขึ้นไป
8. ความสัมพันธ์กับญาติที่ได้รับการดูแล
   □พ่อ □แม่ □ย่าหรือยาย
   □พี่ □น้อง □ลูกสาว
   □ ลูกชาย □ภรรยา □สามี
   □อื่นๆระบุ……
9. คุณมารับบทบาทเป็นผู้ดูแลญาติของคุณนานเท่าไหร่แล้ว .....งเดือน
10. คุณใช้เวลาในการให้การดูแลญาติของคุณนานเท่าไหร่ต่อวัน.....ชั่วโมง/วัน
11. ในบ้านที่คุณอยู่มีคนอื่นอีกหรือไม่ กี่คน.....คน
12. ที่อยู่ของญาติผู้ดูแล……...
    .....
13. คุณมีปัญหาทางด้านสุขภาพหรือไม่ □มี □ไม่มี
    อย่างไรบ้าง.....

ข้อมูลส่วนตัวของญาติผู้ได้รับการดูแล รหัส .....

ID# □□

1. เพศ □ ชาย □ หญิง
2. อายุ ปี เดือน
3. สภานภาพสมรส □ โสด □ คู่ □ หย่า
   □แยก □ม่าย
4. ศาสนา □พุทธ □คริสต์
   □อิสลาม □อื่นๆ ระบุ……
5. การศึกษาขั้นสูงสุด □ ประถมศึกษา □มัธยมศึกษา □อาชีวะ □ปริญญาตรี
   □ ปริญญาโท □ ปริญญาเอก □ อื่นๆ ระบุ

6. ได้รับการวินิจฉัยว่าเป็นมะเร็งเมื่อไหร่ ……
   ตำแหน่งที่เป็น(เช่น ศรีษะ, กล่องเสียง, ลิ้น) ……..
   เป็นมะเร็งระยะที่เท่าไร …….
7. รักษามะเร็งด้วยวิธีการได้
   □ ผ่าตัด □ เคมีบำบัด
   □ รังสีรักษา □ ผ่าตัดและรังสีรักษา
   □ ผ่าตัดและเคมีบำบัด
   □ อื่นๆ ระบุ……
8. ระยะในการรักษามะเร็ง/หลังจากได้รับการรักษามะเร็งนาน
   เท่าไร……เดือน
9. ต้องการความช่วยเหลือเรื่องใดบ้าง ให้เลือกตอบ
   □ ทำความสะอาดร่างกาย □ ทำแผล
   □ การพาเข้าห้องน้ำ □ การเคลื่อนย้าย เช่น ขึ้น-ลงรถเข็น
   □การรับประทานอาหาร □ การขับถ่าย อุจจาระ, ปัสสาวะ
   □ ช่วยเหลือทางด้านการเงิน
   □ ช่วยเหลือทางด้านจิตใจ ระบุ……...
   □ อื่นๆ ระบุ……

Interview Guide: Caregiver's Background Data

Code……..

Date: ……..Time: …….

General/ Opening Statement

Please tell me about your experience since your taking this caregiving role.

General Questions

1. Please tell me about your life before taking care of your relative. (Probe: personal life, marriage, work, family life, roles in family before your relative diagnosed with HNC).
2. Which parts of your life have changed since the diagnosis of your family member and how?
3. Tell me your responsibilities in the family before the illness of your family member, and how they changed now.

Specific/ Focused Questions	
Specific Aims	**Questions Ask**
1. To describe what are the caregiver's motives of care for their relative	1. How did you come to care for your HNC relative? /Can you tell me something about how you started to care for your HNC relative? 2. Do you have someone to help you make decision/ recommend you to take this caregiver role and how?
2. To describe what do Thai caregivers do as a caregiver.	3. What do you do for your relative as a caregiver? 4. How do you feel about taking this caregiving role? 5. Do you have someone to help you take

Specific/ Focused Questions	
Specific Aims	**Questions Ask**
	care of your HNC relative? If yes, what do they do? If no, why? 6. Does caregiving affect your daily life? If yes, how? 7. Does caregiving affect your physical and mental health? If yes, how?
3. To describe the caregiver's perceived relationship between oneself and care-receiver.	8. What did you do together before your HNC relative was diagnosed with cancer? 9. How was the relationship between you and your relative before diagnosed HNC? 10. What do you think about the relationship between you and your HNC relative before? 11. How is the relationship between you and your HNC relative after your taking caregiving role? 12. Describe how did you view about relationship change? Please give me example.
4. To describe the effects of relationship between caregiver and care-receiver.	13. How does the relationship between you and your HNC relative affect your life? 14. How does the affect/ change of such relationship pose any problems in your life? 15. How did you deal with the problems and what are the results? (please explain, what is the method) 16. What help you to deal with those

Specific/ Focused Questions	
Specific Aims	**Questions Ask**
	change/problems (such as religious belief, culture)? 17. What do you think about quality relationship? Do you understand about this word? How did you feel about your case relate to quality relationship? Tell me more when talking with quality relationship.(factors, obstracle, etc.)

Demographic data sheet' caregiver

ID# □□

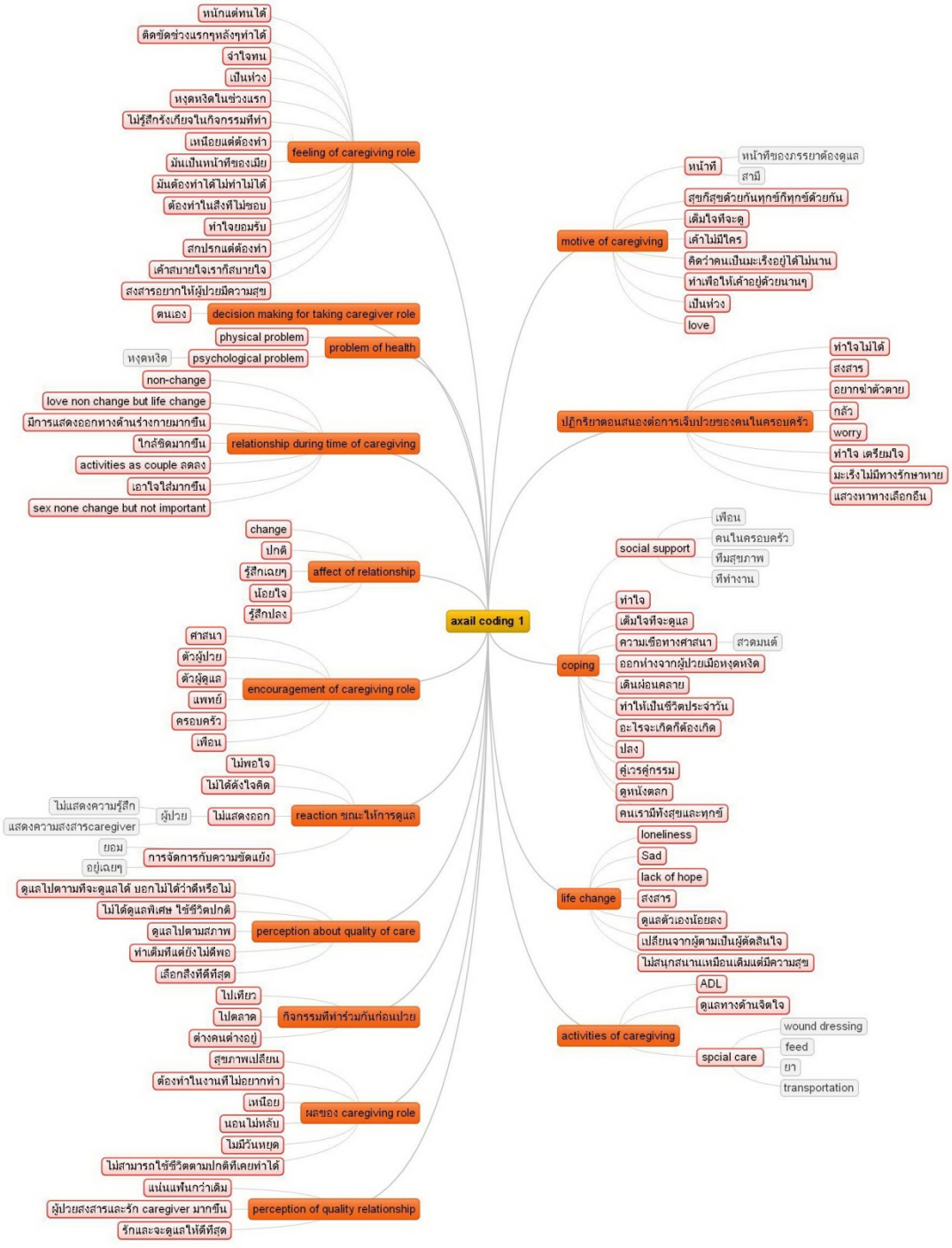
1. Gender □ Male □ Female
2. Age Year Month
3. Marital Status □ Single □ Married □ Divorced
   □Separated □Windowed
4. Religion □Buddhism □Christianity
   □Islam □Others, specify
5. Highest level of education
   □ Primary □Secondary
   □Vocational □Bachelor degree
   □Master degree □Doctoral degree
   □Other
6. Do you work or not? □ No □Yes
7. Family income per month
   □ < ฿ 6,000 □ ฿6001-10,000
   □ ฿10,001-15,000 □ ฿15,001-20,000
   □ > ฿20,001
8. Relationship of caregiver to patient
   □Father □ Mother
   □ Grandmother □ Elder sister/brother
   □Younger sister/brother
   □ Daughter □Son
   □ Wife □ Husband
   □Son-in- law □ Daughter-in-law
   □ Other
9. Length of time being the caregiver months /Years
10. Times spend per day for taking care of the care-receiver……hr/day
11. Number of other persons living in the same household…….persons
12. Caregiver's Address……

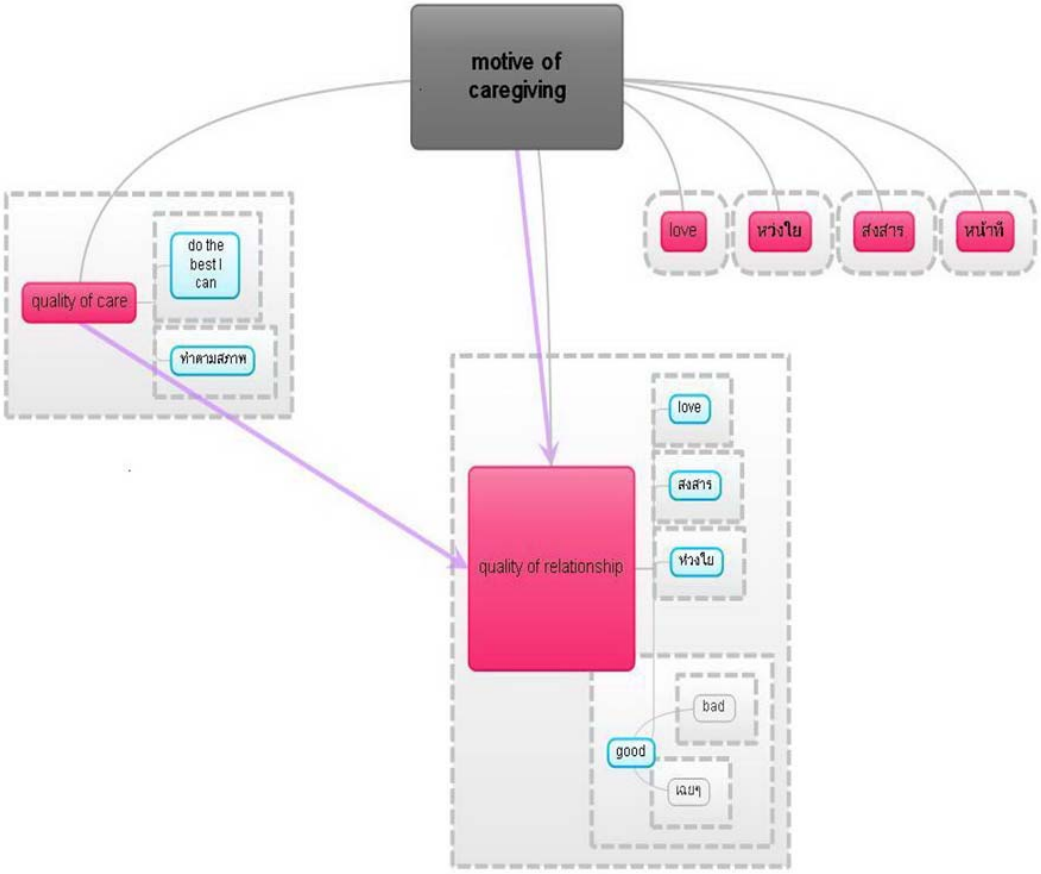
Care-receiver's Background Data

ID# □□

1. Gender □ Male □ Female
2. Age Year Month
3. Marital Status □ Single □ Married □ Divorced
   □Separated □Windowed
4. Religion □Buddhism □Christianity
   □Islam □Others, specify
5. Highest level of education
   □ Primary □Secondary
   □Vocational □ Bachelor degree
   □Master degree □Doctoral degree
   □Other (specify)……..
6. When diagnosed with HNC in your relative.....
   Type of HNC (i.e. head, larynges, tongue) ……..
   Stage of HNC……
7. Type of treatment
   □ Surgery □ Chemotherapy
   □ Radiotherapy
   □ Radiotherapy and Surgery
   □ Chemotherapy and Surgery
   □ Other……
8. What kind of help needed by your HNC relative?
   □ Bathing □ Wound care
   □ Toileting □Eating
   □ Continence □Financial support
   □ Transfer such as getting in or out of chair
   □ Psychological support……
   □ Other……

APPENDIX D
CODING PROCEDURES




motive of caregiving
love
หว่งใย
ส่งสาร
หน้าที่
quality of care
do the best I can
ทำตามสภาพ
quality of relationship
love
ส่งสาร
ห่วงใย
bad
good
เฉยๆ

BIOGRAPHY

NAME	Mrs. Siranee Kejkornkaew
DATE OF BIRTH	September 7, 1974
PLACE OF BIRTH	Phichit, Thailand
INSTITUTIONS ATTENDED	Mahidol University, 1996: Bachelor of Nursing Science. Mahidol University, 2003: Master of Nursing Science (Adult Nursing). Mahidol University, 2015: Doctor of Philosophy (Nursing).
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