

# BEING AN OLDER HUSBAND CAREGIVER IN SOUTH KOREA

by

WON JEE CHO

(Under the Direction of Denise C. Lewis)

## ABSTRACT

The rapid growth of the aging population has raised concerns about long-term care for the elderly in South Korea. Traditionally, the family, particularly the daughter-in-law or wife, has been considered as a primary source for eldercare. With the increasing unmet needs of family caregivers, older husbands are increasingly engaging in spousal care. Yet, little is known about the experience of older husbands caring for their wives with chronic disease because of the numerical predominance of women in eldercare. The purpose of this study was to understand what older husbands experience while caring for their wives with illness and/or disability and how they refashion themselves as spousal caregivers in Korean society. This study is a phenomenological one, focusing on the lived experience of being an older husband caregiver in South Korea. The following research questions guided this study: (a) what are older husbands' experiences of spousal caregiving inside and outside the caregiving situation in everyday life? and (b) what is the essence of 'being an older husband caregiver' within multiple contexts in Korean society? In-depth interviews were conducted with 23 men aged 60 and over who, as primary caregivers, have taken care of their wives and were selected using criterion sampling. Phenomenological data analysis was used to derive essential themes from their accounts of the lived experience in spousal caregiving. Findings revealed that, on the transition to caregiving,

older husbands were confronted with emerging tasks and expanding family roles. After entry into spousal care, as the spouses' health status changes, caregiving husbands continuously adjust to changes occurring in the multiple, intertwined contexts and manage or modify the caregiving situation for their caregiving activities and the quality of care. Older husbands identify themselves as a caregiver by both personal and social recognitions. These findings contribute to an initial understanding of the complex, dynamic, ongoing process of being an older husband caregivers in the multiple, interrelated contexts. Based on these findings, implications for future research, practice, and policy were made and presented.

INDEX WORDS: Spousal Caregiving, Older Husband, Caregiver, Transition,  
Phenomenology, South Korea

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## DEDICATION

This dissertation is dedicated to my father J.W. Cho, who had eagerly waited for a very long time but cannot be pleased with me, and to my mother, J.O. Kwon, and my sister's family, W.J. Cho, D.Y. Kim, and G.E. Kim. This work certainly would not be possible without their infinite love, support, and patience.

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## CHAPTER 1

### INTRODUCTION

The family has traditionally been considered as the primary source for caring for an older adult with illness or disability. Patterns and outcomes associated with family caregiving have been crucial issues in research on eldercare (e.g., Adams, 2006; Alexander & Wilz, 2010; Allen, Goldscheider, & Ciambrone, 1999; Choi & Marks, 2006; Guberman et al., 2006; Horowitz, 1985; Kim & Schulz, 2008; Wolf, 1999). Most of these eldercare studies focused on the impact of caregiving on health and quality of life of family caregivers. This scholarly discussion on family caregiving has maintained a unified or monolithic perspective on family caregiver role acquisition as an unexpected, stressful life event of worsening health and reduced subjective well-being of the family caregiver (e.g., Adams, 2006; Bookwala & Schulz, 2000; Choi & Marks, 2006; Marks, Lambert, & Choi, 2002; Pearlin & Aneshensel, 1994; Pinquart & Sörensen, 2004; Raschick & Ingersoll-Dayton, 2004).

However, the extensive predominance of female over male caregivers in eldercare has led to an empirical focus on female caregivers' experiences of care provision and caregiving burden or strain. Comparative studies on family caregiving by women and by men re-identified the numerical dominance of female caregivers in family caregiving and illuminated female caregivers as the higher-risk population for caregiver stress and health problems, thus strengthening the gendered nature of caregiving (e.g., Allen, 1994; Ashley & Kleinpeter, 2002; Bookwala & Schulz, 2000; Cancian & Olicker, 2000; Lee, Dwyer, & Coward, 1993; Miller & Cafasso, 1992; Raschick & Ingersoll-Dayton, 2004). In research on eldercare, taken-for-granted

notions of caregiving as “women’s work” contributed to create theoretical, empirical blindness toward male caregivers. The marginalization of male caregivers in the discussion of eldercare also led to limited understanding of their caregiving commitments and contexts.

After the emergence of studies in the mid- to late 1980s noting the growing number of male caregivers and assessing their potential contributions to eldercare (Fitting, Rabins, Lucas, & Eastham, 1986; Stone, Cafferata, & Sangl, 1987; Tennstedt, McKinlay, & Sullivan, 1989), men, as a new, noteworthy caregiver group, began to be included into the empirical discussion of caregivers’ experiences (e.g., Allen, 1994; Archer & MacLean, 1993; Bookwala & Schulz, 2000; Chappell & Kuehne, 1998; Ducharme et al., 2006; Harris, 1993; Harris & Long, 1999; Miller, 1996; Russell, 2007a). In research on male caregivers in eldercare, much more attention often has been paid to older husbands than younger husbands, sons, and other male relatives in that older men, who felt less burdened by familial, work, and social role obligations than younger and mid-aged men, were more likely to become involve in providing care to their spouses with illnesses or disabilities (e.g., Bookwala & Schulz, 2000; Bowers, 1999; Calasanti & Bowen, 2006; Calasanti & King, 2007; Cassells & Watt, 2003; Jansson, Nordberg, & Grafstrom, 2001; Ribeiro, Pául, & Nogueira, 2007; Russell, 2007a; Sandberg & Eriksson, 2007). Some studies continued to undervalue or underestimate older husbands’ commitment to the caregiving role by comparing older husband caregivers’ roles with patterns associated with female caregivers (Allen, 1994; Fitting et al., 1986; Lutzky & Knight, 1994; Miller, 1990b; Stone et al., 1987). Other researchers asserted the need for understanding men’s caregiving in a broad perspective as a distinctly different experience from women’s (Ashley & Kleinpeter, 2002; Barusch & Spaid, 1989; Miller, 1990b; Pruchno & Resch, 1989; Robinson-Whelen & Kiecolt-Glaser, 1997).

Despite the increasing interest in elderly men's involvement in caregiving across cultures, in Korean society older husbands, as potential, significant caregivers, have not received social, scholarly attention in the area of caregiving. By Confucian patriarchal beliefs that still remain as the fundamental familial value and principle in the modern Korean family, daughters-in-law have been at the center of the theoretical and empirical discussion of caregivers in eldercare (e.g., Choi, 1998; Chun, Knight, & Youn, 2007; Han & Kim, 1994; Jo, 2003; Kang & Han, 1997; Kang, 2006; Kim, 2001b; Kim & Lee, 2003; Lee, 2002; Sung, 1990). The concentrated focus on female caregivers, including daughters-in-law and wives, has strengthened the gendered perspective on caregiving in Korean society, thus resulting in the lack of knowledge concerning different types of informal caregivers, particularly older husband caregivers, in eldercare (Kim, 2001b; Levande, Herrick, & Sung, 2000).

However, dramatic demographic changes in South Korea (e.g., falling fertility, declining birth rates, and rising life expectancy rates) and rapid industrialization and urbanization in South Korea have led to changes in family size and structure and family-related culture (Choi, 2009; Chung, 2011; Han, 1996; Oh & Warnes, 2001). In modern Korean society, declines in multi-generational living arrangements and numbers of children contributed to weaken traditional cultural moral values and practices of parent-child relationship that obligated adult children, mainly daughters-in-law, to take primary responsibility for frail or ill parents (Choi, 2009; Chung, 2011). Another consequence of modernization in South Korea is that a wife or husband, rather than adult children, emerge as key, preferred caregivers who can provide physical and emotional care to ill or disabled care older adults (Choi & Eun, 2000; Chung, 2011; Han & Son, 2009; Shin & Han, 2011). Korean statistics indicate 50.4% of primary caregivers are spouses aged 60 and over and 26.2% of spouse caregivers are husbands (National Statistical Office, 2008); thus,

evidencing the significance of spousal caregivers and the potential contribution of husband caregivers as primary caregivers in eldercare. Moreover, an ongoing growth of the population aged 65 and older (3.8% in 1980, 11.0% in 2010, 14.3% in 2018, and 20.8% in 2026 (National Statistical Office, 2010)), will continue to fuel interests in the position of spouses, particularly older husbands, as primary family caregivers in family caregiving. Despite a gradual, numerical increase in older husband caregivers, the number of studies on male caregivers in eldercare is still quite small and provides limited knowledge of their experience of being a spouse caregiver in Korean society (Choi & Eun, 2000; Han & Lee, 2009; Han & Son, 2009; Lee, 2005; Lee & Kim, 2009; Shin & Han, 2011). These quantitative and qualitative studies focused on husband caregivers' experiences performing caregiving tasks and the impact of their caregiver roles on their own health and subjective well-being. Yet, little is known about the *actual process* of "becoming a spouse caregiver" within a diversity of contexts, such as familial, work, and social milieus, in later life. Therefore, it is necessary to follow older husbands' experiences through an in-depth description of multidimensional experiences of caregiving, in their own voices, as they travel the pathways of spousal caregiving. This study will offer an overall picture of changes in older husband caregivers' lives and identities within multiple, interlocking contexts and will open up a new perspective on eldercare in Korean society.

### **Purpose Statement**

The purpose of this study is to understand what older husbands experience while caring for their wives with illness and/or disability in multiple contexts and how they refashion themselves as spousal caregivers in later life in Korean society. The phenomenon on which the focus of this study is 'becoming and being an older husband caregiver' within Korean society. The phenomenological methods are used to analyze the lived experience of spousal caregiving in



later life. The following research questions guided this study: (a) what are older husbands' experiences of spousal caregiving inside and outside the caregiving situation in everyday life? and (b) what is the essence of 'being an older husband caregiver' within multiple contexts in Korean society?

### **Significance of the Study**

This dissertation is the first qualitative study that aims to understand the dynamic, multidimensional experiences of caregiving caused by changes in older husbands' status as spouse caregivers in various milieus, such as personal, familial, work, socio-cultural, and economic contexts in South Korea. This research will provide richly descriptive data about the dynamic, complex process of 'being an older husband caregiver' within various, intersecting contexts. In this study, in-depth understanding of older husbands' narratives will allow the researcher to see their spousal caregiving as the older husbands would see and perceive it themselves and to provide alternative perspectives on older husbands' caregiving experiences. This study will enhance the limited perspective and knowledge from cultural values and practices regarding family systems and relationships or transcultural gender discourse in eldercare discussed in Western and Eastern research. The findings of this study will help all researchers, policy makers, and social work professionals broaden their perspectives on family caregivers providing care to older adults with functional and/or cognitive impairments and better understand older husbands' challenges and needs in caring for their spouses in Korean society. In addition, this study will not only advance the current state of knowledge of male caregivers in eldercare within Korean society, but will contribute to the body of literature on spousal caregiving for the elderly across cultures by focusing on older husbands as caregivers. Finally, through the interview process, the participants would be encouraged to understand and reflect

how caregiving responsibilities and performances have influenced their lives and concepts of self in the later life.

## CHAPTER 2

### REVIEW OF THE LITERATURE

This literature review will provide theoretical and empirical perspectives to understand the emergence and position of older husband caregiver in eldercare and the Korean context of caregiving to consider the experience of older husband caregivers. The following relevant issues are examined: (a) caregiving and the emergence of men in caregiving literature, (b) older husbands as spouse caregivers, (c) the theoretical explanations of male caregivers and the gendered nature of caregiving, (d) husband caregivers in the Korean literature, (e) cultural and historical contexts of caregiving within Korean society, and (f) social and political contexts of caregiving within Korean society.

#### **Caregiving and the Emergence of Men in Caregiving Literature**

With the increased presence of male caregivers in a family caregiving situation, caregiver research began including male caregivers into studies of family caregiving or elder care, discussing the potential of men for caregivers, and observing their experience in caregiving in the 90's (Allen, 1994; Allen et al., 1999; Bowers, 1999; Kramer & Lambert, 1999; Miller, 1990b; Williamson, Shaffer, & Schulz, 1998). Through comparing with female caregivers' caregiving experience, researchers assessed the type and amount of care provided by male caregivers and the effects of care provision on their health and well-being (e.g., Alexander & Wilz, 2010; Allen, 1994; Allen et al., 1999; Ashley & Kleinpeter, 2002; Barusch & Spaid, 1989; Bookwala, 2009; Bookwala & Schulz, 1998, 2000; Chappell & Kuehne, 1998; Croog, Sudilovsky, Burleson, & Baume, 2001; Miller, 1990b, 1996; Pinquart & Sörensen, 2006; Skaff

& Pearlin, 1992; Sugiura, Ito, Kutsumi, & Mikami, 2009; Wallsten, 2000; Young & Kahana, 1989). However, many studies still suggested gender differences in caregiving activities and physical/psychological responses to the caregiver role and thus, stressed women-centered findings in caregiving tasks and outcomes. Compared with male caregivers, female caregivers performed more hours of care tasks and more intensive caregiving activities and were more vulnerable to the burden and stress of caregiving. In addition, discussions of family caregivers in elder care paid more attention to female caregivers' experiences than male caregivers' experiences in that the caregiving role was relatively consistent with women's previous roles before the entry into caregiving, such as the mother-wife role characterized by caring and nurturing traits, rather than men's previous roles that were primarily outside the home (Allen et al., 1999; Calasanti & Bowen, 2006; Chappell & Kuehne, 1998; Miller, 1996; Walker, 1992; Zhan, 2004). The observed gender differences and biases in caregiving supported the long-held assumption that men were not socialized to meet the physical and emotional needs of another person and thus were not recognized as a competent caregiver in elder care. The gendered comparative lens in the research on elder care also continued to view caregiving as an extension of women's previous roles in a society and as a life stressor for female caregivers rather than male caregivers.

Some researchers stressed the potential for missing men's lived experience of the caregiver role through comparing with women's and simultaneously, the need for listening to their stories about caregiving experience in their own voices for deeper understanding of male caregivers in elder care (Black, Schwartz, Caruso, & Hannum, 2008; Bowers, 1999; Cahill, 2000; Calasanti & Bowen, 2006; Calasanti & King, 2007; Ciambrone & Allen, 2002; Ducharme, Lévesque, Lachance, et al., 2007; Ducharme et al., 2006; Ducharme, Lévesque, Zarit, Lachance, &

Giroux, 2007; Harris, 1993, 1995, 2002; Harris & Long, 1999; Kirsi, Hervonen, & Jylhä, 2000, 2004; Kramer & Lambert, 1999; Lee, 2005; Lee & Kim, 2009; McFarland & Sanders, 1999; Milne & Hatzidimitriadou, 2003; Neufeld & Harrison, 1998; Parsons, 1997; Pierce & Steiner, 2004; Ribeiro & Pául, 2008; Ribeiro et al., 2007; Russell, 2001, 2007a, 2007b; Sandberg & Eriksson, 2007; Sanders, 2007; Sanders & McFarland, 2002; Sanders, Morano, & Corley, 2002; Shanks-McElroy & Strobino, 2001). Findings of these studies commonly emphasized that, contrary to the prevailing belief of caregiving as women's work, male caregivers also performed a diversity of caregiving tasks in relation to personal care, household tasks, and financial management and accepted the caregiving role as a natural family obligation to care for a frail family member. However, acclimating to new or unfamiliar tasks and duties, they faced a challenge for managing physical, emotional, and financial strains of the caregiving situation. Moreover, they focused on a new problem that male caregivers, not female caregivers, would confront in adjusting to the caregiving role. Taking on the responsibility for caring for the frail elderly, male caregivers experienced changes in their familial/social role status from breadwinner or worker to carer and a discrepancy between their previous roles and caregiving role (Calasanti & Bowen, 2006; Calasanti & King, 2007; Lee, 2005; McFarland & Sanders, 1999; Miller, 1996; Pierce & Steiner, 2004; Russell, 2007a; Sandberg & Eriksson, 2007; Wilken, Altergott, & Sandberg, 1996). Because the transition to caregiving was oftentimes a sudden and unexpected life event, they struggled to learn how to perform household tasks (e.g., cleaning, cooking, laundry, and shopping) and personal care tasks (e.g., bathing, dressing, transferring, and toilet care) that they had not been familiar with in their lives before caregiving transition. They also underlined that a sudden shift to the caregiving role could be more difficult for male caregivers than female caregivers. Thus, researchers concentrating on men's caregiving experiences

highlighted men's engagement in caregiving as a significant life event affecting their health and well-being and the need of broadening the women-centered perspective on elder care for in order to capture men's unique experience of adapting to the caregiving role.

### **Older Husbands as Spouse Caregivers**

With rapid demographic changes and increasing interests in elder care over three decades, it was noteworthy that, with older wives, daughters, and daughters-in-law, older husbands began to emerge as significant caregivers taking primary responsibility for caring for frail elders (Black et al., 2008; Bookwala & Schulz, 2000; Bowers, 1999; Choi & Eun, 2000; Ducharme, Lévesque, Lachance, et al., 2007; Ducharme et al., 2006; Fitting et al., 1986; Han & Son, 2009; Harris, 1993, 1995, 2002; Kramer & Lambert, 1999; Lee, 2005; Lee & Kim, 2009; Milne & Hatzidimitriadou, 2003; Neufeld & Harrison, 1998; Pruchno & Resch, 1989; Ribeiro et al., 2007; Russell, 2001, 2007b; Sandberg & Eriksson, 2007; Sanders, 2007; Zarit, Todd, & Zarit, 1986). More attention was paid to elderly husbands as potential caregivers in elder care in that those who were retired were less burdened with time obligations to work and other family duties and were more likely to serve as primary caregiver to their frail or ill spouse (Chung, 2011; Lee & Kim, 2009; Lima, Allen, Goldscheider, & Intrator, 2008; Russell, 2007b). In addition, they were not reluctant to being a spouse caregiver in that 'doing caregiving' was accepted as a part of fulfilling marital obligations and as an extension of marital roles (Harris & Long, 1999; Kirsi et al., 2004; Lee, 2005; Miller, 1996; Neufeld & Harrison, 1998). The emergence of older husband caregivers in elder care led to augmenting an interest in their caregiving activities and health-related outcomes of care provision and thus, quantitative researchers attempted to include them into eldercare research (Allen, 1994; Ashley & Kleinpeter, 2002; Barusch & Spaid, 1989; Bookwala & Schulz, 1998, 2000; Chappell & Kuehne, 1998; Croog et al., 2001; Fitting et al., 1986; Han & Son, 2009; Lima et al., 2008; Miller, 1990b; Pruchno & Resch, 1989; Sugiura et al.,

2009; Wilken et al., 1996; Zarit et al., 1986). However, concentrating on gender differences in the quality of care, psychological response to the caregiving role, and coping strategies, these studies still highlighted the significance of women as the primary source of informal care to the aged and their emotional and physical problems associated with caregiver burden and stress. Even though caregiving for a frail or ill spouse was a complex experience for older husbands, older men in spousal caregiving were underrepresented in the caregiving research and then were portrayed as inconsequential or ineffective caregivers using a gendered yardstick. Thus, the quantitative research offered a limited picture of older husbands' experiences in the primary caregiver role in spousal caregiving.

Another attempt to center older husband caregivers around issues of care commitment and its impact on their lives arose from the limited perspective of the quantitative findings (Black et al., 2008; Bowers, 1999; Calasanti & Bowen, 2006; Calasanti & King, 2007; Ducharme, Lévesque, Lachance, et al., 2007; Ducharme et al., 2006; Ducharme, Lévesque, Zarit, et al., 2007; Harris, 1993; Kirsi et al., 2000, 2004; Lee, 2005; Lee & Kim, 2009; Lévesque, Ducharme, Zarit, Lachance, & Giroux, 2008; Milne & Hatzidimitriadou, 2003; Neufeld & Harrison, 1998; O'Connor, 2007; Ribeiro et al., 2007; Russell, 2001, 2007a, 2007b; Sandberg & Eriksson, 2007). In an attempt to learn more fully what it meant to be an older man caring for his frail or ill wife, these studies explored how men experience 'being a spouse caregiver' in later life without comparing them with those of female caregivers. First, the research on male caregivers focused on why they entered the caregiving role in the later life and described the meaning of caregiving commitment to their wives (Harris, 1993; Harris & Long, 1999; Lee, 2005; Lee & Kim, 2009; Neufeld & Harrison, 1998; O'Connor, 2007; Russell, 2001). In these studies, most husband caregivers highlighted spousal obligation in that the relatively healthy spouse ought to take

responsibility for providing care to his/her ill partner and they viewed their caregiving activities as a natural extension of marital duties and responsibilities. Providing care to their spouses was to maintain the status of a husband within marriage and to express marital commitment to their wives. In addition, these studies suggested that elderly male caregivers, as husbands, provided care to their spouses for various reasons. For example, commitment and responsibility for caregiving were perceived as an opportunity to express love and affection toward the spouse or a way to pay back for the spouse's devotion and care in marital life before the transition to caregiving (Harris, 1993; Harris & Long, 1999; Lee, 2005; O'Connor, 1999; Ribeiro & Pául, 2008; Russell, 2001, 2007a). Or, rather than deep feelings toward the spouse, a sense of responsibility and duty for caring for her was another motivation of older husbands to commit to the caregiving role (Harris, 1993; Harris & Long, 1999; Lee, 2005; Lee & Kim, 2009; Neufeld & Harrison, 1998; Russell, 2001, 2007a). These studies showed that older husbands could accept taking on this caregiving role as a natural entry into the caregiving world within a marital relationship and then that caregiving would be their major role in the later stage of life. In addition, they underlined that it research needed to go beyond the previous discussion concerning the qualification of older husbands as a caregiver in elder care.

For understanding older husbands' lives as care providers to their wives, researchers sought to grasp the full picture of what tasks they carried out and what they experienced in spousal caregiving through listening to their narratives of caregiving experience (Archer & MacLean, 1993; Black et al., 2008; Calasanti & Bowen, 2006; Calasanti & King, 2007; Choi & Eun, 2000; Harris & Long, 1999; Kirsi et al., 2000, 2004; Lee, 2005; Lee & Kim, 2009; O'Connor, 1999; Parsons, 1997; Ribeiro & Pául, 2008; Ribeiro et al., 2007; Russell, 2001, 2007a, 2007b; Sandberg & Eriksson, 2007; Sanders et al., 2002). First, some studies focused on the type



of caregiving tasks performed by older husbands in spousal caregiving and the management of new and unfamiliar task performance (Calasanti & Bowen, 2006; Choi & Eun, 2000; Harris & Long, 1999; Kirsi et al., 2004; Lee, 2005; Lee & Kim, 2009; O'Connor, 1999; Russell, 2001, 2007a, 2007b). These studies found that husbands were required to engage in a variety of new caring activities, including personal care, physical care, affective care, household tasks, household management and so on, and to repeatedly do these tasks daily. Because the new role as caregiver was unfamiliar in their previous and current life, 'doing caregiving' was perceived as a sudden change and as the start of a new role for them. Learning to live with this new role was also demonstrated as a struggle in dealing with the immense demands of caring and adapting to the changed personal, family, and social lives. Older husbands' experiences and feelings of caring for their spouses received additional attention on the care work as a journey to difficulty and unfamiliarity in a man's life (Archer & MacLean, 1993; Black et al., 2008; Calasanti & King, 2007; Choi & Eun, 2000; Harris & Long, 1999; Kirsi et al., 2004; Lee, 2005; Lee & Kim, 2009; O'Connor, 1999; Parsons, 1997; Ribeiro & Pául, 2008; Russell, 2001, 2007a, 2007b; Sandberg & Eriksson, 2007; Sanders et al., 2002). These studies highlighted that husbands experienced a variety of feelings associated with performing care work, such as a sense of loss, loneliness, depression, grief, social isolation, gratification, and satisfaction, and that caring was a complex experience for older husbands caring for their spouses. In addition, some researchers focused on how husbands coped with the everyday challenges and the negative feelings they experienced while they performed caregiving duties and tasks (Black et al., 2008; Calasanti & King, 2007; Choi & Eun, 2000; Harris, 1993; Lee, 2005; Ribeiro & Pául, 2008; Russell, 2001; Sandberg & Eriksson, 2007). Various coping strategies were used for dealing with an experience full of stress and hardship and for creating positive meanings in the caregiver role within this heart-breaking

care work. For example, Calasanti and King (2007) categorized strategies for coping with the negative emotions arising from spousal care into exerting force, focusing on tasks, blocking emotions, minimizing disruption, distracting attention, and self-medicating. They also emphasized that these strategies were characterized as approaches for solving task-focused problems and for supporting a sense of mastery and efficacy rather than for relieving negative feelings stemming from care work. Ribeiro and Paúl (2008) also suggested that, to accomplish caregiving tasks and to resolve challenges and difficulties, older male carers developed several coping responses such as finding support in spiritual beliefs, engaging in distraction activities, and seeking others' support.

The research on older male caregivers in spousal care moved beyond care provision and its consequences and simultaneously began to pay attention to men's gender identities in the women-dominated world of caregiving. Older men's identity of being a man as well as a caregiver became a significant issue for gaining insight into the complex and unique world of their caregiver role. In the research on elderly men caregivers, the acceptance of the caregiver role was demonstrated as a process of crossing gender boundaries and as a difficult experience of acclimating to the new role deviant from the notions of masculinity (Bowers, 1999; Calasanti & Bowen, 2006; Choi & Eun, 2000; Miller, 1996; Ribeiro et al., 2007; Russell, 2001, 2007a, 2007b; Sandberg & Eriksson, 2007). Older husbands, who were not accustomed to household, personal, and instrumental tasks, faced challenges in learning additional skills for managing these caregiving tasks, in particular in the realm of daily and personal care, and simultaneously experienced a discontinuity of gendered sense of self in their life and marriage. In these studies, 'doing caregiving' was illustrated as a process of adopting a feminine role and while keeping a masculine self in spousal care.

The growing presence of older men in elder care led to their inclusion in research on elder care and to an increased interest in their lived experiences of caring for their wives. The research on elderly male caregivers has offered evidence about the contribution and conceptualization of older husbands as caregivers in elder care. However, in the studies of male caregivers, discourse on gender in elder care often has missed opportunities for discussion of ‘being a caregiver and man’ in various circumstances. That is, husbands might struggle with reconstructing the meaning of being a caregiver, man, and husband in multidimensional contexts, such as the caregiving situation, parent-child relationship, and diverse interpersonal relationships. Therefore, there is a need for broadening insight into their experience of providing care for their wives within a diversity of contexts beyond the caregiving setting.

### **The Theoretical Explanations of the Under representation of Male Caregivers**

The research on caregiving has continued to conceptualize family caregiving as women’s work and to provide theoretical frameworks for understanding female domination in providing elder care. Empirical and theoretical work on eldercare examined the reasons that women assumed responsibility for the care of elderly family members and, at the same time, endeavored to explain why men were less likely to appear as the primary caregiver taking on the burden of care for elderly persons in family caregiving.

Of various theoretical explanations of feminine dominance as well as the under representation of men as caregivers in eldercare, psychoanalytic and gender feminists assert that caregiving is inherent in the identity of women rather than of men through highlighting gender differences in innate tendencies and instinctive behaviors (Abel, 1986; Gilligan, 1982; Noddings, 1984; Tavis, 1992). This perspective stresses virtues of compassion and empathy as women’s naturalized features, in contrast to the independence and emotional distance of men (Tavis, 1992). Women’s capacity for empathy and intimacy encourages them to have stronger emotional

ties with their family members and to perform most of the work associated with mothering and taking care of their family members throughout their lives (Chodorow, 1978; Markides, Boldt, & Ray, 1986). Furthermore, care and concern for others are central elements of women's identity and are central motivators for the entry into caregiving situations because the caregiving tasks and responsibilities are similar to their familial roles (Gilligan, 1982; Graham, 1983). Contrarily, men's separateness and competitiveness contribute to their lower levels of attachment to care recipients and psychological self-definition inappropriate to caregiving and thus lead them to be able to gain distance from the caregiving responsibility. That is, psychoanalytic and gender feminism views men as having a fundamentally different personality and identity, and these inner traits as the primary source of explaining the gendered nature of caregiving and the under representation of men as caregivers in eldercare.

Contrary to psychoanalytic and gender feminism focusing on the inner dynamics of the psyche, socialization perspective explains men's and women's unequal contributions to caring for frail elders as a result of learned behavior and internalization of the gender schema (Bem, 1993; Stoller, 1992). This perspective emphasizes that individuals learn to internalize role-related behaviors and attitudes in ways for being appropriately masculine and feminine (Howard & Hollander, 1997; Stoller, 2002). Because caregiving is socially linked with the "expressive" nature of women's roles and their "specialization" within the domestic domain (Dressel & Clark, 1990), it is viewed as a continuation of earlier responsibilities in women's lives (Pruchno & Resch, 1989). Thus, caring for an ill or disabled elder is seen as more natural for women than for men (Dressel & Clark, 1990; Stoller, 2002; Walker, 1992). On the other hand, men are socialized to focus on the external world and instrumental responsibilities and consequently view themselves as less skillful or proficient caregivers (Allen, 1994). Rather, even though men take

over the caregiving role, they are less likely to perform tasks of personal care (e.g., bathing, dressing, and feeding) and are more likely to perform male-oriented tasks (e.g., household or financial management) in that socialization throughout the life span affects the types of caregiving tasks they perform (Brewer, 2001; Dwyer & Coward, 1992). For understanding the structural inequalities based on gender in eldercare, this perspective highlights that gendered selves, which have been shaped through socialization, push men and women toward gendered lives and gendered choices to be a man or woman even within the caregiving context.

However, emphasizing the interplay of gender with social relations of production and reproduction, socialist feminists focus on the impact of social and ideological forces on men's and women's entry into eldercare, not on the internalized motivations emphasized by the socialization perspective and psychoanalytic feminists, to explain the gendered division of labor in caregiving (Stoller, 2002). From this perspective, the relative absence of male caregivers in eldercare emerges from the social and cultural assignment of unpaid domestic production to women (Horowitz, 1985). Specially, the inequitable division of labor in caregiving is reinforced by an ideology that has defined caring as women's natural expression of their attachment to and intimacy with others, particularly family members, and highlights the primacy of family responsibilities for women (Stoller, 2002). Because the ideology of caregiving derives from socially constructed ideas of masculinity or femininity describing behaviors, attitudes, and traits that a man or a woman should have and provides the social scripts modifying the ways that the norms of womanhood are enacted within the caregiving situation (Finch & Groves, 1983; Finley, 1989; Graham, 1983; Stoller, 2002), conformity to the norms of the ideology of caregiving leads men to refrain from taking over the caregiving responsibilities and participating in the caregiving tasks associated with the key family function of nurturing and caring (Finley, 1989; Hirsch &

Newman, 1995). Theoretical efforts to understand the under-representation of men as caregivers in eldercare focuses on the contribution of gender, as a social structure reflecting gender ideology, to different positions that women and men occupy as caregivers in eldercare, resulting in gender differences in caregiving responsibilities and burdens.

From these theoretical perspectives, the under-representation of men as caregivers in eldercare is considered a result of the male/female dichotomy reflecting “doing gender” or “doing family” for women and is discussed as a culturally common phenomenon reflecting the gendered nature of caregiving. Within the gendered context illuminated by these perspectives, older husbands have not been viewed as a caregiver appropriate to eldercare and have been marginalized in the discussion of eldercare. In Korean culture and eldercare research, feminine domination is also accepted as a natural phenomenon.

However, as a primary caregiver, daughters-in-law, particularly the eldest daughter-in-law, are socially obligated to take care of elderly people with illness or impairments in Korean society (Chee, 2000; Lee, 1998). Daughters-in-law have always been at the center of all spheres in relation to eldercare. Despite gradually increasing numbers of elder husband caregivers taking primary responsibility for spousal caregiving, they inevitably have been excluded from the discussion of eldercare. Little social attention has been paid to older husband caregivers. In the above-discussed theoretical frameworks for the gendered nature of caregiving, there are some limitations for understanding and describing excessive domination of daughters-in-law and the exclusion of older husbands in eldercare in Korean society. Therefore, beyond transculturally gendered perspectives on eldercare, it is necessary to broaden insight into cultural and socio-political contexts that are characterized as Korean caregiving culture and to grasp older husbands’ experience of providing spousal care within these contexts.

### **Husband Caregivers in the Korean Literature**

During the past decade, with the discussion of demographic and social changes in Korean society (e.g., growing older population, shrinking family size, declining traditional extended families, and growing women's participation in the work place and so on), husband caregivers began to emerge as the primary caregiver for their spouses with disabilities and/or illness in the research on eldercare (Choi & Eun, 2000; Han & Lee, 2009; Han & Son, 2009; Lee, 2005; Lee & Kim, 2009; Shin & Han, 2011). These studies highlighted a gradual increase in the number of older husband caregivers as an outcome of enlarging viewpoints on eldercare from a filial behavior to a marital obligation as well as of demographic and social changes. Although these studies have tried to open a new chapter in the elder caregiving story beyond the gendered lens on caregiving, the number of these studies on male caregivers in elder caregiving is quite small and limits our ability to fully understand their experiences on 'being a caregiver' in Korean society. First, three quantitative studies on spouse caregivers in elder care emphasized the significant role of older husbands in elder care in the present and future and actively drew them as the primary caregiver into the discussion of caregivers' experience on caring for frail or ill elderly persons (Han & Lee, 2009; Han & Son, 2009). These studies explored gender differences in the caregiving process (e.g., the impact of caregiving motivation, marital quality, and family relationship quality on caregiving burdens and rewards and the effect of caregiving motivation and social support on caregiving burdens) rather than in the caregiving experiences (e.g., caregiving activities, strains, and stress). Through gender differences in the linkage between individual and relationship factors and caregiving burdens and/or rewards, these studies underscored that older husband caregivers experienced different processes of becoming the primary caregiver and performing the caregiver role. For example, husband caregivers took on the caregiving role by their sympathetic sorrow for or affection to their spouses suffering from

illness or disability, while wife caregivers took on the role by marital duty or obligation. The gender differences in caregiving motivations forced husband and wife caregivers to experience the different processes of accepting and adjusting to the primary caregiver role. In providing care to frail or ill spouses, husband caregivers were more likely to get social support from family and friends than were wife caregivers, in that being a caregiver was not perceived as a normative gender role for men in Korean society. In this social context, husband caregivers felt less burdened by the caregiving role and learned more positive meaning through caregiving than wife caregivers. It evidenced that male and female caregivers differentially accepted their caregiving role and adapted their caregiving activities and contexts. However, it is still limited to deeply reach male spouse caregivers' lives surrounding caregiving circumstances beyond gender-sensitive perspectives in that these studies maintained the gendered lens on caregivers and paid limited attention to the voice of older husbands.

To build a new perspective on men's spousal caregiving, three qualitative studies focused on their caregiving experience which was answered in their own voices (Choi & Eun, 2000; Lee, 2005; Lee & Kim, 2009). To construct a theory of husband caregivers' experience on caring for their spouses with chronic illnesses, Choi and Eun (2000) drew on personal descriptions of their transitions to caregiving and caregiving situations through interviews. In this study, the theoretical model was developed to delineate the multidimensional features of male caregivers' experience in spousal care. After the onset of the spouses' health problems, male caregivers underwent the decision-making process regarding performance of the caregiving role under effects of various factors (e.g., husband's concern about the illness, family support, economic problems, strategy for interaction and so on) and achieved a sense of companionship with their care recipients during the caring phase. They also highlighted their caregiving experience as a



three-phase process: the process of entering intervention and caring state of mind, the caring phase, and the phase of change in marital relationship. Because this study illuminated male caregivers' experiences in caring for their spouses with chronic illness over a broad age range through interviewing husband caregivers aged from 28 to 76 years, it provided a limited understanding of older husbands' lived experience on taking on caregiving responsibilities and being a caregiver in old age. To explore older men's caregiving experiences and adaptation process in spouse care, Lee (2005) interviewed five husband caregivers in their 60s and 70s caring for their spouses with Alzheimer's disease. Lee's (2005) research findings demonstrated seven themes of their experience on spousal caregiving in old age: late discovery of the disease due to ignorance to Alzheimer's, repentance at the negligence of their wives, transition of the role from a husband to a caregiver, experiencing both physical and mental crises because of troublesome behaviors, recovering from the suffering through various resources, adaptation of oneself to caregiving, and change and growth versus the remaining crisis. In this study, their caregiving experiences were depicted as a process of adapting to their caregiving role and of going through their own internal change and development as a husband as well as a caregiver. Lee and Kim's (2009) study was another qualitative research exploring older husband caregivers' experiences in constructing the meaning of spousal caregiving in the marital relationship and reconstructing gender identity in the performance of caregiving tasks through their own lens. Through analyzing four couples' life histories in marital relationship and caregiving, this study pointed out that the meanings of their entry into caregiving and provision of spouse care were influenced by the quality of the prior marital relationship, such as marital intimacy and marital interaction, and the caregiving role was accepted as a continuation of marital duty or obligation as a husband, rather than a renunciation of masculine gender identity.

Also, Lee and Kim (2009) highlighted the need to fully comprehend older men's involvement into the caregiving role within a gender-neutral perspective, not within a gendered perspective, on caregiving.

Although there have been a small number of studies attempting to identify men's experience on caring for their spouses suffering from health problems, they suggested that men's stories of providing care for their spouses were different from women's stories and that research was needed to develop a new theoretical framework for understanding men's caregiving experience. However, the small number of studies and the small sample sizes in the qualitative studies on older male caregivers were not enough to improve a limited understanding of older men's caregiving experience in Korean society. Mainly focusing on their experiences in performing caregiving tasks and being a caregiver as a man in Korea, the existing studies did not see a whole picture of care-caused changes that husbands have simultaneously or sequentially experienced in the multidimensional context in which they are embedded and of re-arrangement of their existing and emerging roles and relationships within the caregiving setting. It implies that, in Korean society, the way they see themselves as a caregiver and man in the caregiving role remains unclear. Thus, this current qualitative research has as the major objective to understand older husbands' lived experience of 'becoming and being a caregiver' in various dimensions after the entry into spousal caregiving in Korea. Drawing on their own descriptions of spousal caregiving experience, I intend to explore the issues of reshaping older husbands' position and identity as a caregiver and man in Korean society.

### **Cultural and Historical Contexts of Caregiving within Korean Society**

The predominance of female caregivers has been considered as a transcultural phenomenon in eldercare or family caregiving. It is unquestionable that women's caregiver roles and activities are a key agenda in eldercare in Eastern as well as Western cultures. Particularly,

in Korean and other Asian cultures, daughters-in-law have normally been highlighted as the primary care provider for the older persons and, at the same time, their parental caregiving has been put at the center of eldercare (Chee & Levkoff, 2001; Chun et al., 2007; Han, Choi, Kim, Lee, & Kim, 2008; Kim et al., 2009; Lee, Yoon, & Kropf, 2007; Youn, Knight, Jeong, & Benton, 1999; Zhan, 2004). Instead, older men have generally been demonstrated as care receiver, not as caregiver, in the research on elder care and thus have not been included into the discussion of caregivers' experience in the caring setting. Most of the empirical literature on eldercare focused on daughters-in-law's provision of caregiving tasks and emotional burden and distress compared with wives' and/or daughters' (Chappell & Kusch, 2007; Chee & Levkoff, 2001; Choi, 1998; Chun et al., 2007; Han & Kim, 1994; Han et al., 2008; Jo, 2003; Jones, Zhang, Jaceldo-Siegl, & Meleis, 2002; Kang & Han, 1997; Kim, 2001b; Kim & Lee, 2003; Kim & Theis, 2000; Kim & Min, 2006; Kim & Choi, 2007; Lee, 2002; Lee et al., 2007; Shin, 2008; Traphagan, 2006; Zhan, 2004; Zhan & Montgomery, 2003). These studies stressed that daughters-in-law played a pivotal role in care provision for impaired or frail older people in the family and that they were likely to be at greater risk for negative health problems in the performance of caregiving tasks. The prominence of daughters-in-law and marginalization of older husbands as the primary caregiver in eldercare are ideologically related to the systematic cultural rules maintaining the family system and operating family members' roles and responsibilities within family relationships.

In an eastern culture, familism, considered as a critical value regarding family structure in Korean society (Choi, 1998; Han & Kim, 1997; Kim, 2001; Knight et al., 2002), is defined as strong identification and attachment of individuals with their families (Brody, 1985). Because the values of familism stress that family-related responsibility has a higher priority than other responsibilities in an individual's life (Han & Kim, 1997; Knight et al., 2002), familism has clear

implications regarding family care for older adults. That is, within familism beliefs, provision of financial, physical, and emotional care for a frail or ill older adult is an inevitable or primary obligation imposed on the family (Choi, 1998). In this sense, it is shameful for the family to make use of formal services for eldercare. Furthermore, within Asian cultures (such as Korean, Japanese, and Chinese cultures), patriarchal family systems and Confucian ideology, as ethical practices and moral philosophy in interpersonal relationships, emphasizes strong male-dominated power structures that influence the norms of and the nature of family systems, structures, and filial piety in marital and parent-child relationship (Chappell & Kusch, 2007; Choi, 1998; Hashizume, 2000; Holroyd, 2001, 2003, 2005; Hwang, 1999; Janelli & Yim, 2004; Knight et al., 2002; Levende et al., 2000; Tsai, 1999; Zhan, 2004, 2005). The person's location within a hierarchical power structure, based on generation and gender, delineates the obligations, responsibilities, and privileges of roles within families (Huang & Ying, 1989). That is, older people had authority over younger people, whereas the latter must respect and obey the former. Supporting old parents, who became physically weak or ill and/or financially dependent, was naturally accepted as the primary duty of their children and the expression of filial piety for previous parental love and care (Lee, 1998). The strict division of labor or the separation of gender roles determined men's and women's roles and statuses in the family and society (Lebra, 1998; Lee, 1998; Slote, 1998). While men, as breadwinners, played an important role in economic production outside the house, women, who were responsible for inside the house, were primarily obligated to nurture their offspring and to take care of the family, including children and aging parents and to manage household affairs (Cho, 1998; Lee, 1998). Although Korea has undergone tremendous changes in traditional norms and values after rapid industrialization and modernization, Confucian and patriarchal concepts still are a pervasive cultural value dominating

interpersonal relationships in the modern family, continuing social expectations of women's primary responsibility for eldercare (Chee, 2000; Han, 1996; Lee, 1998).

In the Confucian system, filial piety has long been the fundamental value and principle in family relationships and its core is to respect and care for elderly parents in the traditional and modern family (Liu & Kendig, 2000; Sorensen & Kim, 2004; Sung, 1998; Tsai, 1999). Because adult children have been expected to provide necessities for and to meet the needs of aged parents, elder caregiving has culturally been considered as a way of performing acts of filial piety (Chappell & Kusch, 2007; Chee, 2000; Chee & Levkoff, 2001; Choi, 2004; Chow, 2004; Chun et al., 2007; Chung, 2001; Janelli & Yim, 2004; Kim & Lee, 2003; Knight et al., 2002; Lee, 2002; Levande et al., 2000; Mehta & Ko, 2004; Shin, 2008; Sorensen & Kim, 2004; Traphagan, 2006; Zhan, 2004; Zhan & Montgomery, 2003). It implies that, for elderly people, adult children have been considered as the primary source of support and help in times of trouble or illness and that they naturally feel obligation and responsibility to care for their parents. In the Confucian patriarchal family system, which is characterized as the hierarchical organization of family members by generation and gender, primary responsibility for eldercare is imposed on the eldest son (Choi, 1993, 1998; Hashizume, 2000; Kim, 2001; Knight et al., 2002; Lee, 2002; Levande et al., 2000; Youn & Song, 1992). According to patriarchal ideology, however, because a married woman belongs to her husband's family, the eldest daughter-in-law plays a significant role of being responsible for providing practical and primary care to her husband's aging parents in the role structure of patriarchal family (Liu & Kendig, 2000). Therefore, the eldest son's responsibility for taking care of his parents extends to his wife and thus she is obligated to physically care for the aged parents-in-law. There is no expectation that the son himself will engage in eldercare directly (Chappell & Kusch, 2007; Han & Kim, 1997; Hashizume, 2000;

Kim, 2001; Levande et al., 2000; Zhan, 2004). In Korean society, emphasizing the role of daughter-in-law, particularly the eldest daughter-in-law, as the primary caregiver in eldercare, filial piety in the patriarchal family has strengthened the gendered nature of caregiving. Socially, older husbands are unlikely to be expected to take on the caregiver role when their spouse becomes ill or impaired functionally and/or cognitively. Although older husbands participate in spousal caregiving, they become marginalized in the Korean culture of caregiving. In addition, despite the gradual growth of older husband caregivers, their roles and activities are likely to be overlooked and undervalued in the theoretical and empirical discussion of eldercare.

### **Social and Political Contexts of Caregiving within Korean Society**

In contemporary Korea, rapid industrialization and modernization have fostered the values of individualism, independence, and material productivity, but Confucian values (e.g., family solidarity, filial piety, and self-sacrifice) have continued to be fundamental ethical and moral underpinnings in the family and society (Han, 1996; Palley, 1992; Shin & Shaw, 2003). In the face of changing family structure and family-related culture (e.g., population aging, increasing nuclear family, emotional nuclearization of the family, and weakening intergenerational reciprocity) (Choi, 2009; Han, 1996; Shin & Shaw, 2003), the Korean government has emphasized the traditional roles of family responsibility in a society and thus, has maintained the limited or minimal government role of offering public assistances to socioeconomically disadvantaged or impoverished families or individuals in the Korean social welfare system (Palley, 1992; Shin & Shaw, 2003). In addition, underscoring a traditional supportive role of families to maintain economic and medical security for the elderly, the Korean eldercare system has strongly implied a family-based approach to social and health services for older people with illness or impairment (Choi, 1996; Levande et al., 2000; Palley, 1992; SunWoo, 2004). For example, the long-term care services for older people with chronic disease or

functional limitation (i.e., nursing home care, home help services, adult day care center, and short-stay care facilities) were provided with different financial benefits levels on the basis of income level or were limited only to economically disadvantaged older people (Choi, 1996; Oh & Warnes, 2001; SunWoo, 2004). That is, beneficiaries of the Basic Livelihood Security (BLS) program or low-income older people were eligible for free- or low-cost social and health services for long-term care. Because most social welfare programs were not designed specifically for all older adults who needed eldercare, they could receive public assistance and services from social welfare programs that were not directly associated with eldercare, such as Basic Livelihood Security (BLS) program, the Korean national health insurance program, social benefits for persons with disability, and other social programs (Choi, 1996; SunWoo, 2004; Yoon & Eun, 1995).

With the ongoing demographic and familial changes (e.g., increasing proportion of the elderly living alone or living with the spouse and increase in married women's labor force participation), however, the shrinking capability of informal care and the rapidly expanding demands for public assistance contributed to the introduction of a social insurance for long-term care (LTC) in July 2008. The new LTC insurance scheme is a public assistance program providing facility or in-home care services to all those aged 65 and over with functional and/or cognitive impairments, even including younger people with geriatric illness (Kwon, 2009; Ministry of Health & Welfare, 2011). After the assessment of functional limitations by a local assessment committee of the National Health Insurance Corporation (NHIC), beneficiaries of the LTC insurance receive nursing home or in-home care services with different service and economic benefits based on three levels of functional status (i.e., persons who are completely dependent on other's help, who are fairly dependent on other's help, and who have some need

for other's help in all daily activities) (Kwon, 2009; Ministry of Health & Welfare, 2011).

Whereas the LTC insurance beneficiaries pay only 15% of in-home care service cost or 20% of institutional care service cost with government subsidy (20%) and National Health Insurance contribution (60-65%), recipients of the BLS program are exempted from copayment (Kwon, 2009; Ministry of Health & Welfare, 2011).

After the launch of LTC insurance, researchers have primarily focused on the effect of using social services for long-term care on beneficiaries or family caregivers' life quality and emotional state: care recipients' service satisfaction and/or life quality (Kim, 2010; Kim & Hwang, 2010; Kim & Bin, 2010; Shin, 2010) and changes in family caregivers or family members' stress and burden (Baik & Choi, 2010; Han & Son, 2009; Kim & An, 2009; Park, 2010; Park & Lee, 2011; Shin & Han, 2011). Except for Shin's (2010) qualitative research describing older women's positive perspectives on their functional status and caregiving situation after using home-visit bath services from the LTC insurance, most of these studies emphasized quantitative changes in LTC beneficiaries and/or their family caregivers' psychological well-being or life quality after using in-home care or nursing home care services of the LTC insurance.

Despite ongoing changes in social and political perspectives on responsibility for eldercare in Korean society, most social services and programs related to family caregiving for the elderly have retained a family-based approach to eldercare and thus, have provided considerably limited public assistance to care recipients and their family caregivers. The social and political contexts of caregiving reflect the premise that eldercare is a family problem rather than a social problem. In addition, the governmental and social policy for eldercare represents the socio-political position and meaning of older adults with illness or impairments and their



family caregivers within Korean society. Thus, it is essential to understand older husbands' caregiving experiences and settings within the social and political contexts of caregiving beyond the limited perspective on their caregiver role itself.

## CHAPTER 3

### THEORETICAL FRAMEWORK

#### **Phenomenology**

In this study, phenomenology was employed as the philosophical and methodological framework for the overall research process of investigating the experience of ‘being a husband caregiver’ in later life in South Korean society. Starting with Edmund Husserl’s (1859-1938) inquiry into subjective-objective relation, phenomenology was proposed as a new philosophical perspective denying the Cartesian dualism, a split between spirit and body, and stressing the intentional relation between minds and bodies (Daly, 2007; Moustakas, 1994; Patton, 2002). Adopting Brentano’s notion of intentionality as a characteristic of mental phenomena, which was distinguished from physical phenomena, Husserl asserts that objects appear to the person through conscious awareness and that consciousness is the basis of all experience and knowledge (Moran, 2000; Moustakas, 1994). Husserl argues that the lifeworld (*lebenswelt*), as a realm of self-evidence, is a reality which is pre-given, is experienced, or is remembered as the thing itself and is a layer that is inserted between the natural and social worlds (Daly, 2007; Moran, 2000). In Husserl’s view, by intentionally directing toward an object, description of a reality led one to reach the essential structure of consciousness (Moustakas, 1994). Objective reality could not be understood fully apart from the conscious experience of it (Daly, 2007). For Husserl, the purpose of phenomenology is the study of ‘the things themselves’ to understand the ultimate or fundamental essence of a phenomenon (Daly, 2007; Moustakas, 1994). He believed that knowledge of essences could be gained through *bracketing* or *epoché*, a process of suspending

any understanding and judgment about the phenomenon or setting aside everyday ways of perceiving things (Moran, 2000; Moustakas, 1994). The researcher was required to meet the phenomenon as it showed itself as described by participants for the unprejudiced and unbiased presence of the phenomenon so that it could be precisely described and understood. As the father of phenomenology, Husserl developed the concept and supplied a new and important foundation for philosophy and science.

Since then, through continuous clarification and extension of phenomenology in different directions, later philosophers or phenomenologists (e.g., Heidegger, Schultz, Sartre, Merleau-Ponty, Gadamer, Giorgi, Polkinghorne, and van Manen) has widened and deepened philosophical and methodological features in research on everyday human experience (Dowling, 2007; Kakkori, 2009; Moran, 2000; Mortari & Tarozzi, 2010; Patton, 2002; van Manen, 1990). One of these philosophers, Martin Heidegger (1889-1976), redefined phenomenology and introduced the concept of 'being in the world' or 'being there' (van Manen, 1990). Shifting from the epistemological emphasis of Husserl to an ontological emphasis on understanding human experience as it is lived, Heidegger introduced the concept of 'Being-in-the-world' and was concerned with the nature or meaning of 'being in the world,' not 'human being' itself (Moran, 2000; van Manen, 1990). Emphasizing an indissoluble unity between a person and the world, he believed that meaning lies in one's transaction with a situation, which the individual and the situation co-constituted (Annells, 1996; Heidegger, 1962). He argued one's lived experiences are encounters with things occurring in a situation but all experience is interpreting and confronting with what has already been interpreted by himself or herself and by others (Moran, 2000). He viewed understanding or interpretation of lived experience as *the hermeneutic circle*, which was illustrated as the ongoing interplay between self-understanding and understanding of the world

(Heidegger, 1962). According to Heidegger, our experiences are interpretations of the world (Gorman, 1977; Moran, 2000). For Heidegger, phenomenology, called hermeneutic phenomenology, is a method of scientific philosophy to clarify the phenomenon of 'being' or lived experience (Heidegger, 1982; Moran, 2000). Heidegger (Heidegger, 1982) presented three basic components of phenomenological method (i.e., reduction, construction, and deconstruction) but emphasized 'reduction' as a starting point of ontological thinking and phenomenological investigation. Although reduction originated from Husserl's classical phenomenological reduction, it means 'leading back phenomenological vision from the understanding of a being to the understanding of the being of beings' (Heidegger, 1982, p. 21).

In addition, Alfred Schutz (1899-1959) applied Husserl's philosophical thoughts to the social world and the social sciences to form social phenomenology and served as the groundwork for the study of construction of social reality (Ajiboye, 2012). The works of Jean-Paul Sartre (1905) and Maurice Merleau-Ponty (1908-1961) played an important role in developing the existential phenomenology of Heidegger and expanding the influence of Husserl and Heidegger (Moran, 2000). Hans-Georg Gadamer (1900-2002), following Heidegger, integrated Heidegger's analysis of historicity and hermeneutic circle with Hegelian's conception of culture and tradition and developed a dialogical and linguistic process of understanding (Dowling, 2007; Moran, 2000). Amedeo Giorgi, Max van Manen, Donald Polkinghorne, and other phenomenologists contributed to methodological application of the phenomenological philosophical attitude and development of phenomenology as a methodological approach and research method (Dowling, 2007; Groenewald, 2004; Kakkori, 2009; Mortari & Tarozi, 2010).

A long debate in phenomenology by philosophers and phenomenologists led to the development of various phenomenological approaches in terms of ontological and

epistemological frameworks, a scientific methodology, and a research method. However, phenomenology has been regarded as the study of human experience and as a means of gaining understanding of the essences of lived experience (Patton, 2002; Polkinghorne, 1989). In this sense, phenomenology guided the overall research process toward an understanding of older husbands' experiences of spousal caregiving in South Korea. This study included phenomenological considerations in central questions, research assumptions, and orientation to participants, data, and methods. In this study, a phenomenological approach was employed to explore the lived experiences older husbands caring for their wives with illness and/or disability in Korean society, keeping out the researcher's knowledge and belief in relation to gender and eldercare. Therefore, theoretical perspectives, that emerged from the process of analyzing and interpreting the data, will be further discussed in the conclusion section. Also, a theoretical model will be suggested to display the lived experience of older husbands becoming a spouse caregiver.

## CHAPTER 4

### METHODOLOGY

#### **Data Collection**

##### **Recruitment**

When recruiting older husbands who have taken sole care of their wives after age 60, recruitment and retention issues arose as a primary research challenge. Research recruitment and retention issues include inaccessibility to the husband caregiver population, which represents about 13% of primary caregivers in eldercare in South Korea (National Statistical Office, 2008), constraints imposed by caregiver stress and burden, and caregiver's inability to participate due to lack of backup help (Amador, Travis, McAuley, Bernard, & McCutcheon, 2006).

Participants were approached and recruited through various channels, including the researcher's personal networks, churches, public health centers, Gu (borough) offices, hospitals, day care centers, senior welfare centers, and a nursing home, in the capital region of South Korea (i.e., Seoul, Incheon, and Gyeonggi-do). Snowball sampling was used to identify and gain access to participants. At the first contact with referees by telephone or visit, I explained the purpose of research and asked them to refer older husbands who fit the selection criteria. After identifying potential participants who met the research criteria and who accepted the invitation to research participation, the referees provided names, contact information, and, sometimes, brief family- and caregiving-related information. I then recontacted each potential participant by telephone to determine if he fit all inclusion criteria and to schedule the interview. Twenty-seven older husbands were recruited as potential participants.

Because most of the participants, who were caring for their wives without backup or other help, felt burdened by insufficient time and restricted geographic mobility for research participation, I had to be flexible in arranging a date and time as well as a place convenient for them. Several interviews had to be rescheduled or cancelled due to various reasons. One participant rescheduled a date and time for the interview three times because his wife's health suddenly deteriorated. Two potential participants cancelled the interviews because they felt very distressed and uneasy with the disclosure of privacy to a stranger after accepting the invitation to the interview. In addition, three interviews were cancelled by the researcher because it was determined that two potential participants did not satisfy the research criteria or because the researcher could not fully understand the other's accounts due to his communication difficulties following a stroke. Finally, 23 older husbands were selected for this study and were interviewed about their experience of spousal caregiving.

### **Participants**

Because phenomenological research seeks to describe lived experience of the phenomenon and to understand the essences of the phenomenon (Daly, 2007; Patton, 2002), purposive sampling (Patton, 1990) or criterion-based sampling (LeCompte, Preissle, & Tesch, 1993) was employed to select participants who were engaged in the same type of phenomena and who were able to provide rich narratives. Four criteria were used to obtain a sample for this study.

Participants must a) be men, b) identify themselves as the primary caregiver to their spouse with illness and/or impairment, c) had or have been a spouse caregiver after age 60, and d) live in the capital region of South Korea (i.e., Seoul, Incheon, and Gyeonggi-do).

The first three criteria were necessary as this study sought to understand older husbands' lived experience of spousal caregiving in everyday life and the essences of 'being a spouse

caregiver' in old age within Korean society. The last criterion ensured geographic proximity that was a practical consideration of traveling to the location of the participations. In addition, older husbands living in the capital region of South Korea were assumed to have similar urban neighborhood and community environments in which their caregiving settings were embedded.

The participants of this study included 23 older husbands who have taken primary responsibility for spousal caregiving after they reached age 60. Table 4.1. represents the demographic information of each participants. In a relatively wide age range of 62 to 82 years at the time of the interviews: seven were in their 60's, 13 in their 70's, and three in their 80's. The number of older husbands' children is the following: one participant had seven children, five had four children, ten had three children, two had two children, and one had one child. In terms of employment status, 19 older husbands were retired, but four were still employed. Living arrangements varied considerably: 14 husbands lived only with their wives, three with wife and adult children, three lived alone after wives' institutionalization, one lived alone after wife's death, one with wife, a divorced son, and grandchildren, one with adult child after his wife's institutionalization, and one with his wife and grandchildren.

Table 4.1. Participant Demographics

Residence	Name <sup>a</sup>	Ages <sup>b</sup>	Children	Employment Status	Living Arrangement
Incheon	Byeongkuk Lee	67	4	Employed	Alone
	Changsu Yu	73	5	Retired	Couple
	Daeman Kang	82	4	Retired	Couple



Euihan Kim	63	3	Retired	Couple w/ Adult Child & Grandchildren
Hyungwoo Yu	75	3	Retired	Couple
Jeonghwan Ahn	80	1	Employed	Couple
Jeonghyeok Lee	79	3	Retired	Couple
Jeongmin Hwang	79	4	Retired	Couple w/ Grandchildren
Kihyeong Hong	67	0	Retired	Couple
Kisang Kwon	75	4	Retired	Couple
Seonghyeok Park	69	0	Retired	Couple
Seongjin Noh	82	7	Retired	Alone
Seongmin Kim	72	3	Employed	Couple
Seungchan Yu	67	2	Employed	Alone w/ Adult Child
Seungil Im	71	3	Retired	Couple
Sungbeom Park	77	3	Retired	Couple
Taeseob Choi	76	2	Retired	Couple

	Woojin Kim	71	3	Retired	Couple w/ Adult Child
	Wooseong Kam	62	3	Retired	Couple w/ Adult Child
	Yoonseok Lee	77	4	Retired	Couple
Seoul	Sanggyu Cho	73	5	Retired	Couple
(Gyeonggi-do)					
Bundang	Kangho Park	79	3	Retired	Widowed
Suwon	Kyeongwoo Kim	68	3	Retired	Couple w/ Adult Child

<sup>a</sup> Pseudonyms are used for all participants.

<sup>b</sup> There are two ways to calculate ages in Korea. However, in this study, all ages are calculated in the same way as the US ages.

Table 4.2 shows the characteristics of caregiving/illness trajectory among older husbands and their spouses. The current caregiving status is the following: 19 husband caregivers were currently providing spousal care (16 in home-based caregiving and three in hospitalization) and four had essentially completed spousal care after their spouses' death or institutionalization (three in nursing home and one dead). The length of providing spousal care varied from four months to 19 years; two husbands have taken care of their wives for less than one year, eight between one and five years, seven between five and ten years, three between 10 and 15 years, and three for more than 15 years. All older husbands have or had taken primary responsibility for long-term care. Because this study explored older husbands' lived experiences of spousal caregiving without any restriction on specific chronic illness or disability, various types of

spousal health problems are included. Although some of these problems would not have otherwise led to long-term care, when they were combined with other health problems, movement into the husband caregiver role was necessary. Some of these health-related problems were sudden occurrence of illness or injury, unexpected deterioration of chronic illness, diagnosis of disease, or gradual progression of disease. Eleven older husbands began to take care of their wives when their spouses were suddenly injured (e.g., toe fracture, head injury, and femoral fracture), developed a brain hemorrhage or stroke, or suffered from acute diseases, such as gallstones and shingles. Two husbands fulfilled caregiving responsibilities after their spouses' chronic illnesses, such as back pains and diabetes, suddenly deteriorated. Two husbands also became spousal caregivers when their spouses were diagnosed with cancers. However, eight older husbands, who have cared for a spouse with Alzheimer's disease/dementia or diabetes, were oblivious to their entry into spousal caregiving because they had not recognized their wives' diseases until the symptoms became moderately severe. At that time of recognition, these husband caregivers did not perceive a starting point of providing spousal care. Instead, it was during the interviews that they retrospectively recognized the beginning of being a spousal caregiver. Most spouses have suffered from progression of chronic disease (e.g., diabetes, Alzheimer's disease, dementia, Parkinson's disease, and arthritis), progression of disability (e.g., cognitive impairment and Activities of Daily Living (ADL)/Instrumental Activities of Daily Living (IADL) limitations), relapse of diseases (e.g., bedsores, shingles, and collapse), and/or subsequent incidences of disease or injury (e.g., back pains, femoral fracture, car accident, falling, cataract, hypertension, Alzheimer's disease, Parkinson's disease, stroke, kidney dysfunction, vertigo, depression, and toe gangrene). While three wives (i.e., Kyeongwoo Kim's,

Sanggyu Cho's, and Seongmin Kim's wives) have slowly but increasingly recovered their health and functional capability, 20 wives' health status has progressively worsened.

Table 4.2. Characteristics of Caregiving and Illness Trajectories

Caregiving Status	Name <sup>a</sup>	Initial Health Issue	Length of Caregiving <sup>b</sup>	Spouse's Illness Trajectory
Widowed	Kangho Park	Alzheimer's Disease	16	
Hospital	Jeongmin Hwang	Collapse Shingles	4	<ul style="list-style-type: none"> <li>• Relapse of Shingles</li> <li>• 2<sup>nd</sup> Collapse &amp; Femoral Fracture</li> <li>• 3<sup>rd</sup> Collapse &amp; Femoral Fracture</li> </ul>
	Kisang Kwon	Stroke	8	<ul style="list-style-type: none"> <li>• Slipping &amp; Rib Fracture</li> <li>• Falling &amp; Back injury</li> <li>• Falling &amp; Sacral Fracture</li> </ul>
	Sungbeom Park	Back Pains	10	<ul style="list-style-type: none"> <li>• Three Disc Surgeries</li> </ul>
Home	Changsu Yu	Head injury (Post-concussion)	13	<ul style="list-style-type: none"> <li>• Alzheimer's Disease</li> </ul>
	Daeman Kang	Alzheimer's Disease	9	
	Euihan Kim	Stroke	3	
	Hyungwoo Yu	Stroke	4	<ul style="list-style-type: none"> <li>• Frequent Collapses &amp; Blackout (Surgery Sequela)</li> <li>• Wrist Fracture</li> </ul>
	Jeonghwan Ahn	Arthritis	2	<ul style="list-style-type: none"> <li>• Vertigo</li> <li>• Depression</li> <li>• Alzheimer's Disease</li> </ul>
	Jeonghyeok Lee	Gallstone Heart Pains	10 MOS	

Nursing Home	Kihyeong Hong	Diabetes Progression	2	<ul style="list-style-type: none"> <li>• Diabetic Foot Syndrome</li> <li>• Back Pains</li> <li>• Eating Problems</li> <li>• Teeth Problems</li> <li>• Cataract</li> <li>• Urination Problems</li> </ul>
	Kyeongwoo Kim	Toe Fracture	2	<ul style="list-style-type: none"> <li>• High Fever (Overwork)</li> <li>• Back Pains</li> <li>• Femoral Fracture</li> <li>• Car Accident</li> </ul>
	Sanggyu Cho	Stomach Cancer	4 MOS	
	Seonghyeok Park	Stroke	7	
	Seongmin Kim	Femoral Fracture Osteoporosis	6	<ul style="list-style-type: none"> <li>• Femoral Fracture</li> <li>• Diabetes Complication</li> </ul>
	Seungil Im	Brain Hemorrhage	11	
	Taeseob Choi	Alzheimer's Disease	1	<ul style="list-style-type: none"> <li>• Hypertension</li> <li>• Arthritis</li> </ul>
	Woojin Kim	Femoral Fracture	5	<ul style="list-style-type: none"> <li>• Diabetes Complication</li> <li>• Cognitive impairments</li> <li>• Physical Disability</li> </ul>
	Wooseong Kam	Lung Cancer	1	<ul style="list-style-type: none"> <li>• Stroke</li> <li>• Alzheimer's Disease</li> </ul>
	Yoonseok Lee	Stroke	19	<ul style="list-style-type: none"> <li>• Vigor Loss</li> <li>• Vision Problems</li> <li>• Teeth Problems</li> <li>• Leg Pains</li> <li>• Lung, Heart, &amp; Bronchial Problems</li> </ul>
	Byeongkuk Lee	Slipping Sacral Fracture	7	<ul style="list-style-type: none"> <li>• Alzheimer's Disease</li> <li>• Parkinson's Disease</li> </ul>

Seongjin Noh	Alzheimer's Disease	16	
Seungchan Yu	Vision Problems (Diabetes Complication)	5	<ul style="list-style-type: none"> <li>• Cataract</li> <li>• Vision loss</li> <li>• Kidney Dysfunction</li> <li>• Toe Gangrene</li> <li>• Bedsores</li> <li>• Diabetes Complication</li> </ul>

<sup>a</sup> Pseudonyms are used for all participants.

<sup>b</sup> (Approximate) year(s)

Older husbands and their wives received various benefits of social welfare programs, summarized in Table 4.3. Five husbands were beneficiaries of National Basic Livelihood Security (NBLS) programs, but the others are not. Eight wives were recipients of disability benefits. Of the eight wives, five wives obtained the first-grade level of disability status, which represented severe functional and/or intellectual disability. Two wives were the second-grade level of disability status, which are those with moderate disabilities, and one wife was the third-grade level, defined as those with mild disabilities. Five wives used adult day care centers for the elderly with dementia or Alzheimer's disease. Thirteen wives were beneficiaries of national insurance for long-term care. Of the 13 wives, 10 wives received in-home care, but three wives received nursing home care.

Table 4.3. Characteristics of Social-Welfare Benefits

Name <sup>a</sup>	National Basic Livelihood Security Program	Disability Benefits	Adult Day Care Center	Long-Term Care Insurance
Kangho Park			X	
Kyeongwoo Kim				
Yoonseok Lee				

Sungbeom Park				
Hyungwoo Yu				
Kisang Kwon		X (2 <sup>nd</sup> Grade)		In-Home
Sanggyu Cho				
Kihyeong Hong	X			
Taeseob Choi	X		X	
Euihan Kim		X (1 <sup>st</sup> Grade)		In-Home
Daeman Kang			X	In-Home
Changsu Yu	X	X (1 <sup>st</sup> Grade)	X	In-Home
Byeongkuk Lee			X	Nursing Home
Seungil Im		X (1 <sup>st</sup> Grade)		In-Home
Seonghyeok Park	X			In-Home
Jeonghyeok Lee				In-Home
Woojin Kim		X (1 <sup>st</sup> Grade)		In-Home
Seongjin Noh				Nursing Home
Seongmin Kim				In-Home
Wooseong Kam		X (2 <sup>nd</sup> Grade)		In-Home
Jeongmin Hwang	X			
Seungchan Yu		X (1 <sup>st</sup> Grade)		Nursing Home
Jeonghwan Ahn		X (3 <sup>rd</sup> Grade)		

<sup>a</sup> Pseudonyms are used for all participants.

## Interviews

In-depth, semi-structured interviews were conducted with 23 older husband caregivers from May 20 to July 22, 2009. In a phenomenological study, in-depth interviewing is one of the main sources for lived-experience material in that it allows the researcher to enter the private

spheres of an individual's experience and to learn his thoughts, feelings, and intentions (Daly, 1992; van Manen, 1990). Asking all participants the same questions by using an interview guide but maintaining a flexible order, helps to maintain a focus on the research questions and simultaneously allows for the flexibility to arrange further questions determined by participants' responses (Daly, 2007). After the first interview, a set of guiding questions was modified (Daly, 2007). For example, difficulties of fulfilling the caregiver role were subdivided into two levels of difficulties: on the transition to caregiving and after the transition to caregiving. Changes in the marital and parent-children relationship were also subdivided into two levels of changes between on and after entry into caregiving. Older husbands' health status and self-care were added into the interview guide. This format was used to ensure that the same information was covered in each interview and to obtain unexpected findings. The interview guide (Appendix A) consisted of the following topics: transition to spousal caregiving, changes in the caregiver role, changes in interpersonal relationships, changes in work, family, and personal life, informal and formal assistances, end of caregiving, changes in position within Korean society and the culture of caregiving, aging experience, plans for old age, and end-of-life issues.

The interviews lasted from one to three hours. All interviews took place in a comfortable and convenient site that participants chose (e.g., participant's homes, coffee shops, day care centers, hospitals, and senior welfare centers). If there was not any backup caregiver in the in-home or hospital care setting, participants' wives accompanied them during the interview; sometimes, a participant was distracted by the spouse's interruption or help-request. Before the interview, consent forms were given to the participants to inform them of their rights; including that they could stop the interview or withdraw from the study and that they could refuse to answer any question (see Appendix B). They were asked to sign two consent forms, one of



which they would keep and the other was returned to me. I am a native Korean speaker so all interviews were conducted in the Korean language and were digitally recorded with permission from the participants. I kept field notes on participants' nonverbal behaviors, the settings, and other observations.

### **Data Analysis**

Translation between English and non-English language is a challenge in retaining the meanings and nuances of the original data in cross-cultural research (Hurv & Kim, 1984). Kim (2001a) argued that translating only significant parts into English after the analysis of the original non-English transcript is the better strategy for keeping the authentic meanings and nuances, rather than analyzing after transcribing whole interviews into English. Thus, the interviews were transcribed verbatim with field notes and analyzed in Korea. Subsequently, significant parts of transcribed materials were translated into English with translated meanings checked and confirmed using back translation.

The goal of phenomenological research is to clarify what appears to participants and to unfold the essential features and meanings of a phenomenon (Kvale, 1996). Phenomenological analysis begins with a rich, full description of lived experience, provided by the participants (Daly, 2007). To see the world through the participants' lens, a researcher is required to set aside any prejudgment, preconception, and biases regarding the phenomenon being investigated (Daly, 2007; Hycner, 1985). Phenomenological analysis is a process of maintaining 'fidelity to the phenomenon' as it is lived (Colaizzi, 1978; Kvale, 1996).

Data analysis in this study was grounded in a synthesis of Giorgi's (1975) phenomenological method and the Stevick-Colaizzi-Keen method, modified by Moustakas (Moustakas, 1994). First, suspending my interpretations and meanings as much as possible, I

carefully read and re-read the transcripts a number of times to get a sense of the whole and to dwell with the participants' experiences. After finding significant statements about the participants' experiences of caregiving, I developed a list of statements, which were treated as if they had equal weight, to identify repetitive or overlapping statements. The statements were grouped into 'meaning units' of the experience, followed by linking and clustering them into themes. Each unit and theme was coded by open coding, the process of identifying the themes or concepts emerging from the raw data (Strauss & Corbin, 1990). The entire coding process was conducted using ATLAS.ti 5.2 software program. I described what the participants experienced with the phenomenon (textual description of experience) and how the experience happened (structural description of experience) and then incorporated the textual and structural descriptions to represent the meanings and essences of the experience. The descriptive summary for each participant's interview was also created for each older husband to provide a sense of the whole and the context for the emergence of meaning units and themes.

### **Trustworthiness**

In qualitative research, the concepts of validity and reliability cannot be approached in the same way as in positivist research (Shenton, 2004). Qualitative researchers have attempted to deal with the issues of validity and reliability using different terminology and approaches that could provide distance from the positivist paradigm. Lincoln and Guba (1985) proposed four criteria that should be considered by qualitative researchers to establish a trustworthy study: credibility, transferability, dependability, and confirmability. However, Lincoln and Guba's constructs correspond to the criteria employed by positivist investigators in presenting similar issues: credibility-internal validity, transferability-external validity, dependability-reliability, and

confirmability-objectivity (Shento, 2004). Thus, the discussion of these issues in this study is considered in the traditional language of validity and reliability, not in Lincoln and Guba's terms.

From a phenomenological perspective, the issues of validity and reliability are the potential dilemma if the researcher needs to remove subjectivity and to establish an equivalence of measurement, as the process of improving the power of positivist research (Giorgi, 2002; Seamon, 2000). The validity question arises with respect to phenomenological description and interpretation of the participants' lived experience. In a phenomenological inquiry, researcher subjectivity is inevitably implicated in research (Giorgi, 1994; Priest, 2002; Seamon, 2000). Giorgi (1994, 2002) argued that, within phenomenology, the elimination of subjectivity is not a solution because all knowledge is correlated with subjectivity and what matters is how a conscious subject is present to an event or thing in the world. Rather, for the researcher, it is necessary to be aware of one's own subjectivity and to be conscious of the potential impact on research process and interpretation (Finlay, 2008; Giorgi, 2002; Maxwell, 2005). Researcher self-reflection and self-knowledge, as a critical step of the research process, help to separate out preexisting biases, interests, and assumptions from the participants' description of lived experience and to gaze at their experiences in a fresh way (Finlay, 2009). In addition, because the influence of the researcher on the participant in the interview situation become a potential threat to the validity of qualitative research, the researcher, during the interview, needs to avoid being preoccupied with one's own emotions, theoretical thoughts, and experience and to focus on the participant and the phenomenon in its appearing (Finlay, 2009; Maxwell, 2005). To enhance the validity of this study, I acknowledged and addressed my biases, assumptions, thoughts, and experiences as a researcher, enabling me "to better understand how the data might have been interpreted in the manner in which they were" (Merriam, 1995, p. 55).

The issue of reliability in phenomenological research is concerned with *interpretive appropriateness* referring to “an accurate fit between experience and language, between what we know as individuals in our own lives versus how that knowledge can be accurately placed theoretically” (Seamon, 2000, p. 169). Reliability from a phenomenological perspective is not defined as equivalence of measurements based on a predetermined scale or standard separate from the understanding and experience of the researcher (Merriam, 1995; Seamon, 2000). However, if measurement is applied to the description of qualitative research, the criterion for agreement regarding equivalence of descriptions cannot be clearly defined and the required equivalence is difficult to establish (Seamon, 2000). As a way to consider the issue of reliability of phenomenological research, Churchill and colleagues (1998) highlighted that there are both same and different interpretations of data among researchers because human interpretation is always partial. It is necessary to consider the issue of reliability in broad terms: interpretative possibilities open to another position as well as same viewpoints regarding the original description of a phenomenon (Giorgi, 1975; Seamon, 2000). The criterion for reliability is not whether other researchers can equally interpret the original description of lived experience with the same phenomenon from the same people, but whether the first-person interpretation can be accepted as the first person’s interpretation and conclusion (Seamon, 2000). Clear, vivid interpretive and reflective processing of the data collected as well as full, rich description of the phenomenon from the participants’ perspectives ensure greater reliability in phenomenological research (Merriam, 1995). In addition, peer/colleague examination (Merriam, 1995) was used as a strategy for enhancing trustworthiness in this study. It provides the researcher with a check for the plausibility of emerging findings and interpretation. I discussed the methods and the findings with the major professor, whose specialty is qualitative methodology and gerontology.

### **Subjectivity Statement**

Observing the aging process of my parents, I became interested in the topic of “being old.” One year later, my father was diagnosed with terminal colorectal cancer. After acknowledging his medical diagnosis and surgery, I returned to my homeland, South Korea, and stayed with my family for about four months. At that time, I took primary responsibility for taking care of my father. Usually, I provided assistance with IADLs to him. After the acquisition of the caregiver role, his frequent hospitalizations restricted my life into the caregiving situation. When he was hospitalized for chemotherapy, I observed many other patients struggling with cancer or other illness and their family caregivers in the hospital. Watching my father and family, as well as other patients and their families, surviving in the new world of illness and caregiving, my research interests focused on family caregiving for the elderly. After coming back to my doctoral program, I began to review the literature regarding eldercare and family caregiving and learned about family caregivers’ experiences. I was looking for research opportunities and the major professor invited me to work with her in analyzing the data about family caregivers’ experiences providing home-based care in Georgia. I believe that the topic, family caregiving for the elderly, seemed applicable to my life, as a child caregiver and a researcher in eldercare. In the discussion of family responsibility for eldercare by the rapid growth of older population and the dramatic decrease in the number of children in South Korea, I became deeply reflective and interested in the role of Korean older husbands in eldercare. I faced the marginalization of older husband caregivers in the social, scholarly discussion of eldercare. Often, their care work was undervalued. Sometimes, I observed the older husband caregivers were portrayed as unfamiliar figures in the Mass Media. There are many questions about older husband caregivers left unanswered. The mingling of my personal experience with my research interest, knowledge, and

experience leaves me with the persistent urge to know how older husband caregivers became spouse caregivers and reshaped self-concept as primary family caregivers in Korean society.

From my personal experience and theoretical/empirical knowledge, I believe the lived experiences of older husband caregivers providing spousal care are not only similar to female caregivers' ones, including mine, but different from. In addition, I believe that, beyond gender and Confucian patriarchy discourses in Korean society, older husbands searched their own meanings of the caregiver role and established the unique world of caregiving. In this sense, this research may have been beneficial to participants because it may have given an opportunity to reflect on the meanings of their roles and relationships in their lives after the transition to caregiving. One of my challenges throughout this research was to bracket my personal experience and pre-existing thoughts and theoretical belief in approaching and understanding participants' experience as they view it. I tried to position myself outside the lived world of older husband caregivers in the process of understanding and interpreting their lived experiences.

### **Ethical Consideration**

Ethical issues were taken into consideration through this research study because the participants' disclosure of very personal, private information is sometimes inevitable in qualitative research. As the first step of ethical consideration, approval from the University of Georgia Institutional Review Board (IRB) was obtained prior to beginning the study. By fully explaining the research topics and my intention of conducting the interview both verbally and in a written consent form, I assured the participants that participation was entirely voluntary and that they had the unquestionable right to refuse to answer any question and to stop the interview at any time. Each participant was required to sign a consent form after reaffirming his agreement to participate. The consent form included researchers' information, such as address, phone

number, and email address, which the participants could contact if they had any question about the interview, if they decided to withdraw from the interview, or if they requested the data be erased and not used in the study. To protect the confidentiality of the participants, I concealed each participant's identifiable information in the transcripts, the field notes, and the final written work through the use of pseudonyms. The interview data were stored in the digital audio file during the transcription process. After transcription, the audio data were erased.

## CHAPTER 5

### FINDINGS AND DISCUSSION

The purpose of this study was to understand how older husbands become spousal caregivers in South Korea. The narratives of older husbands reveal ‘being a spousal caregiver’ in later life is an ongoing, dynamic process of adjusting to continuously emerging changes within a diversity of contexts and developing their own strategies for managing changes and difficulties in relative to spousal caregiving. Findings in the first section outline how older husbands assumed primary or sole responsibility for taking care of their spouses. In the second section, after the transition to caregiving, the lived experiences of older husbands are depicted in how they confronted changes emerging from the multiple, intertwined contexts and in developing their own strategies for managing them to enhance their caregiving capabilities and the quality of care.

#### **Transitioning to Spousal Caregiving**

The following pages are the narratives of older husbands describing, in their own voices, how they became primarily or solely responsible for taking care of their spouses with illness or impairment. There was a diversity of scenarios for entering into the caregiving sphere and becoming a primary family caregiver in later life. However, over half of these older husbands unexpectedly took on the new role of caregiver in cases of the sudden occurrence of their spouses’ illness or injury or the rapid progression of illness. As spouses’ diseases gradually progressed, the husbands met the increasing care needs of their spouses. They often were



oblivious to the actual entry into spousal caregiving; consequently, ‘becoming a caregiver’ was an ongoing process of adjusting to escalating demands for spousal caregiving.

### **Sudden and/or Repeated Transition into Spousal Caregiving**

Fifteen husbands, as primary caregivers, took on new and unexpected caregiving roles that occurred with the onset of their spouses’ health problems. Suddenly, the provision of care to the wife became a pivotal and overriding role in their daily routine. However, two husbands, 71-year-old Seungil Im and 79-year-old Jeonghyeok Lee, became involved in the care of their ill spouses after illness onset. Because his wife suffered with moderate functional limitations after a brain hemorrhage, Seungil Im had been forced to return from Japan, where he was employed as a construction worker, in order to carry out caregiving duties. Two years later, after the occurrence of her brain hemorrhage, he had to leave for home to take care of his wife. Jeonghyeok Lee had, within the two months prior to our interview, taken a primary responsibility for fulfilling the duty of providing care to his wife in order to relieve his daughter who had taken care of his wife immediately after her hospitalization. The abrupt shift of husbands’ positions to care providers in everyday life mainly arose from a rapid deterioration of chronic disease (e.g., diabetes and back pains), injury or accident (e.g., fracture following fall or collapse and head injury after concussion), stroke, acute illness (e.g., gallstone and shingles), and cancer diagnosis (see Table 5-1). To satisfy emerging care needs of the spouses who became suddenly impaired functionally and/or cognitively, older husbands began to provide help with Activities of Daily Living (ADLs), including basic self-care tasks including eating, bathing, toileting, walking, or dressing (Cavanaugh & Blanchard-Fields, 2006, p. 105), and/or Instrumental Activities of Daily Living (IADLs), defined as actions entailing some intellectual competence and planning and constituting various tasks (Cavanaugh & Blanchard-Fields, 2006, pp. 105-106), to their spouses

and unquestioningly adopted the caregiving role. Even after their initial entry into the caregiving role, several husband caregivers transitioned back and forth between caregiving and not caregiving. For example, 68-year-old Kyeongwook Kim and 72-year-old Seongmin Kim both experienced recurrent transitions to spousal caregiving to take care of their wives who repeatedly drifted in and out of a series of illnesses or injuries. Five times over a two-year period, Kyeongwook Kim intermittently engaged in caregiving responsibilities for his wife who suffered from a series of multiple illness and injuries (i.e., fractured toe, high fever, back pains, femoral fracture, and car accident). Seongmin Kim also had to become re-involved in caregiving activities when his wife's femur was broken again after functional recovery from the first femoral fracture. In older husbands' lives, this sudden and unforeseen transition to spousal caregiving brought about rapid changes in their roles and relationships both inside and outside the caregiving milieu.

Table 5-1. Major Illnesses Contributing to the Sudden Transition to Spousal Caregiving

The onset of spouse's illness (N)	Husband caregiver
Rapid deterioration of chronic disease (2)	
Back pains	Sunbeom Park
Vision problem/loss as diabetes complications	Seungchan Yu
Injury (4)	
Toe fracture	Kyeongwook Kim
Head injury (Post-concussion)	Changsu Yu
Femoral fracture	Woojin Kim, Seongmin Kim
Stroke (5)	
Brain hemorrhage	Seungil Im
Stroke	Yoonseok Lee, Hyungwoo Yu, Kisang

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Kwon, Euihan Kim

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Acute illness(2)

Gallstone

Jeonghyeok Lee

Shingles

Jeongmin Hwang

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Cancer diagnosis (2)

Stomach cancer

Sanggyu Cho

Lung cancer

Wooseong Kam

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### **Unapparent and Ongoing Transition into Spousal Caregiving**

Eight older husbands (i.e., seven Alzheimer's or dementia caregivers and one diabetes caregiver), whose spouses' functional and/or cognitive conditions gradually deteriorated, experienced an unrealized but ongoing transition into spousal caregiving over a relatively long period of time. In the early stages of the spouses' illnesses such as Alzheimer's disease, dementia, and diabetes, older husbands did not notice their wives' initial symptoms. When a husband noticed a wife's slight change in functional and/or cognitive activity, he attributed that change as simply a sign of 'being old.' These husbands did not acknowledge the spouses' behavioral and cognitive changes and assumed that their spouses had acquired some geriatric-related disease. For example, older husbands who took care of their spouses with Alzheimer's disease or other dementia viewed wives' frequent forgetfulness as a normal feature of 'getting old', not an initial sign of Alzheimer's disease or dementia. As the loss of wives' cognitive and functional abilities occurred gradually, husbands naturally and increasingly helped their spouses to perform daily activities. Consequently, they participated in caregiving activities without realizing that what they were doing was, indeed, caregiving; instead, it was simply providing help. The beginning of

the transition to spousal caregiving was unclear. With the progression of Alzheimer's disease or dementia into mild to moderate stages or the rapid deterioration of diabetes, increases in wives' cognitive and/or physical disabilities led older husbands to unquestionably accept them as noticeable and visible signs of disease and to attempt to ask medical help for disease diagnosis. After the diagnosis of wives' illnesses, they kept performing their caregiving duties and eventually, they officially become spousal caregivers.

### **Acclimating to Caregiver Role**

After entry into spousal caregiving, older husbands were continuously required to recognize changing responsibilities and tasks in caring for their spouses and to adjust to these changes. Upon the transition to caregiving, husband caregivers adjusted to various changes emerging from the occurrence of spouses' illnesses or injuries or the progression of spouses' illnesses. As spouses' health problems deteriorated, however, older husbands adapted to ongoing emerging changes inside and outside the caregiving and actively managed them to refashion the better caregiving situations.

### **Emerging Tasks and Expanding Family Roles**

Knowing spouses' health problems and adopting a caregiver role, older husbands found themselves in a new, unfamiliar life situation, primarily in caregiving and family contexts. They experienced sudden, unforeseen changes in their tasks and responsibilities. On the transition to spousal caregiving, their new caregiving tasks and duties and the changed familial role became the major changes that they were obligated to manage.

### **Learning about wives' illnesses and medical care.**

After either the sudden or gradual emergence of spouses' problematic changes in health status, older husbands became primarily concerned about wives' health problems and medical

treatments. Through relatively long-term observation or medical diagnosis, they were educated about their spouses' illness and its changes over the course of the illness. One respondent, 73-year-old Sanggyu Cho, whose wife was diagnosed with stomach cancer in 2009, described how he accidentally discovered that his wife's physical and psychological changes, such as sudden weight loss, indigestion, and the feeling of anxiety, were caused by stomach cancer, not eating disorders.

Losing her weight. ... And, feeling anxious. She was emotionally unstable. We just thought that it was because of stomach problem. ... Two years ago, she had regular health checks. Endoscopy hadn't found anything. But, after medical tests such as blood tests, CT scanning, and endoscopy [this time], she was diagnosed with stomach cancer. She was in early stage, so she would be fine after receiving medical treatment.

Learning about his wife's illness and medical care led him to become involved in spousal caregiving. Through the medical diagnosis of cancer, he became medically knowledgeable about his wife's condition, illness, and treatment. Moreover, he became perceptive to her current needs in medical care. Simultaneously, it was important for him to identify the possibility of her recovery and to anticipate his wife's needs and the caregiver demands he would face in providing medical and spousal care. Knowing was the beginning of and the prerequisite for providing proper care to his wife. Although Sipes (2005) reported on men's provision of care to gay partners, these findings are similar in that older husbands recognized that learning their wives' diagnoses was the beginning of their acknowledged role as caregiver. Similarly, 82-year-old Daeman Kang expressed his experience of an unapparent entry into spousal caregiving occurring with 'being gradually aware' of problematic changes in his wife's cognitive function.

She had made soybean paste and soy sauce herself. One day, making soybean paste, she added salt. But, she thought she didn't, so she added salt again. It didn't taste as good as it used to. It was too salty. Eating the salty soybean paste, I asked her why it was salty. She said she probably added salt twice. But, one year later, she didn't recognize if she added salt or not. She became increasingly forgetful. ... I took her to a hospital. She got some medical tests, but they didn't find anything. A year later, she had a medical test. We knew her brain function deteriorated.

His observation of her gradually altered behaviors in daily life led to his growing suspicion of her cognitive impairment. However, he could not recognize the cause of her problematic changes or dementia nor did he understand this unfamiliar, odd situation. Thus, although he provided assistance to his wife, he did not perceive her as a patient who needed medical care until the actual medical diagnosis of her dementia. He was an incomplete caregiver in that he did not fully identify himself as a caregiver meeting the demands of her care needs. The gradual deterioration of her cognitive function brought about the delayed awareness of himself as a spousal caregiver. This is similar to the positionality discussed by O'Connor (2007) in that husband caregivers first had to position themselves within the tasks of caregiving before they could identify as "caregivers." After his wife's medical examination, Daeman Kang was clearly aware of her cognitive ability and his caregiving responsibilities; thus, he came to expect potential changes in her functional status and acknowledged his longer-term caregiving tasks and duties as the illness progresses. Learning a medical diagnosis served to answer older husbands' questions about spouses' illness and the possibility of cure. In particular, it helped them identify their caregiving duties as the beginning of their roles as caregivers.

In addition, a chronic illness, which persisted or progressed without proper treatment, impinged on an immediate and appropriate medical treatment for the acute illness during the transition to spousal caregiving. Sometimes current health problems were exacerbated because of the co-morbidity of a chronic disease. For example, 71-year-old Woojin Kim described that he recognized the existence of diabetes at the time of her treatment for her femoral fracture. He became aware of the difficulty she had scheduling her femoral surgery because of her undiagnosed diabetes.

Not recognizing her own femur was broken, she was lying all day. At night, she suffered in agonies of pain. ... I called 119. After taking X-ray, we knew her thigh bone was fractured. She needed to receive treatment but she couldn't because of her high blood sugar level. Her doctor said she could have a surgery only after her blood sugar level fell. So, she couldn't have the surgery for one month. We didn't know she got diabetes.

Learning about his wife's current health status included the process of gaining medical knowledge about her chronic, previously unacknowledged, illness as well as her more currently emerging illness or injury. It enabled him to realize the seriousness of his wife's current health problem due to the unrecognized diabetes. For him as a beginning caregiver, it formed the basis of developing capability to make sense of the illness' progression and its treatment process. This allowed him to better manage emerging changes and more effectively handle problems he encountered in caregiving. For older husbands, such as the husbands described here, on the occurrence of spouses' illnesses or injuries, grasping the causes of health problems, including both current and unacknowledged illness, and treatment processes became the first step toward their own lives as spousal caregivers. Knowing spouses' health statuses, which were related to

the awareness of their caregiving responsibilities and requirements and to the anticipation of subsequent progression of spouses' illnesses, helped husbands cope with changes and challenges resulting from the onset of their spouses' health problems. Although Parsons (1997) researched exclusively about caring for a family member with Alzheimer's disease, husband caregivers in South Korea experienced a similar transition to caregiving.

### **Performing ADL/IADL tasks.**

After taking care of spouses with illnesses or impairments, older husbands began to engage in various caregiving tasks that they had not performed before. For the spouses with ADL and/or IADL difficulties, husbands permanently or sporadically provided assistance with everyday activities and engaged in household tasks that the wives had previously performed. The range and intensity of caregiving tasks greatly varied depending on the spouses' ADL/IADL limitations. Performance of extensive caregiving tasks was accepted as new but crucial duties and responsibilities in the daily life. For example, 62-year-old Kyeongwoo Kim commented on new tasks that he carried out for his wife who suffered from physical impairment after a femoral fracture. He said:

There were lots of small things. If she felt uncomfortable during lying down and she wanted to sit up in bed, I had to help her. And, if she got thirsty, I had to bring water to her. If she wanted something to eat or she needed something, I had to pick it up. Lots of things. Small things. If she needed facial tissues, I had to bring them to her. If she needed a cold wet towel, I had to. And, I had to wipe her feet and hands with a wet towel. There were lots of things.

The beginning of his caregiving experience was from providing physical help to his wife who became suddenly impaired. New daily tasks were identified through the attempt to meet the



wife's needs. He provided constant, hands-on care. These tasks were unquestioning and intuitive responses to his wife's ADL care needs. The tasks taken on by the husbands in this study are similar to those previously described as done by those who were unprepared and whose work was unacknowledged (Ward-Griffin, 2001). Similarly, 75-year-old Hyungwoo Yu also talked about new caregiving tasks that he carried out for his wife with ADL/IADL difficulties after she fractured her wrist. His account also highlighted that his tasks focused more on ADL and IADL assistance.

One wrist knitted, but the other didn't properly. Her hand became weak and numb. She can't use chopsticks well. She uses a fork and spoon to eat. She is unable to use her hands. But, she can eat, go to the toilet. These are the only things that she can do. I have to do others for her. I have to give her insulin shots because she has diabetes. I have to remind her to take medicines. If I don't, she won't take. She can't dial the right telephone number. So, she can't call at all. I have to dial it for her.

After the abrupt loss of his wife's functional autonomy, he suddenly was confronted with extensive, intensive caregiving tasks and activities in that he had to become her extra hand assisting her in performing former daily activities. He was unexpectedly forced to commit to ADL and IADL care, including washing, dressing, dialing the phone, injecting insulin, and taking medicines. In addition, he lived only with his wife so he became solely responsible for performing these tasks and duties. After the transition to caregiving, performing these caregiving tasks became a significant, core part of his daily activities and life. It also led to significant and sudden changes in their daily routines.

Similarly, 67-year-old Seungchan Yu stressed responsibilities for personal care as a new, primary caregiving task of taking care of his wife who had lost her functional capability after the rapid progression of diabetes in 2004. He said,

I had to help her sitting up or lying in bed. When she wanted to go to toilet, I let her sit on the toilet. After her bowel movement, I had to wipe her bottom. I got her to clean with water.... I used to carry water in a washbowl. After wetting a hand towel, I wiped her bottom.

The loss of her eyesight after an ophthalmic surgery led her to increase her physical and behavioral dependency in daily life; encompassing increasing caregiving demands. His narratives show his new caregiving tasks (toileting and washing) after his wife's severe vision problems caused her to lose functional autonomy and independence in everyday activities. The provision of personal, hands-on care became a sudden, new obligation to his wife. Personal care tasks reflected his obligatory attempts to meet her personal hygiene needs with little hesitancy and to adapt to the unfamiliar caregiving situation that had not been considered previously. This is similar to the acceptance of caregiving tasks described by Russell (2007). For older husbands who adopted caregiving responsibilities for their physically and/or cognitively impaired spouses, the provision of ADL and/or IADL care was a sudden but natural response to spouses' needs. In their new lives as a primary spousal caregiver, these caregiving tasks were viewed as unfamiliar but inevitable, they were taken-for-granted, but were not viewed as problematic.

### **Maintaining husband's family roles.**

Mostly, older husbands and their spouses had followed strict gendered norms in their marriages. Husbands, as primary breadwinners, had been financially responsible for the family. Their marital systems were disrupted after the onset of spouses' illness or injury. However, most

older husbands still felt a strong sense of financial responsibility for taking care of their wives. Even though they were retired before entry into caregiving, their financial and real assets (e.g., pension, savings, and real estate), rather than economic activities, were crucial resources enabling them to fulfill the breadwinner role in caring for their wives. As 75-year-old Hyungwoo Yu, who was taking care of his wife with functional difficulties after wrist fractures, stated:

Financially and physically..., I didn't need help. I didn't want. I thought I would take care of her until the day I could not. So far, I've been financially responsible.

I've never asked my children for money. I've lived on my own with mine.

Financially, I've never burdened them. I've lived on my own, so far.

Even after the provision of ADL and IADL care became an essential part of his daily routine, he did not participate in economic activities but still felt financially responsible for spousal caregiving. Unquestionably, he did not expect financial support from his adult children because, with his sufficient financial assets, he was able to fulfill the primary breadwinner role in spousal caregiving. He viewed his financial capability as a critical component of becoming a spousal caregiver. In addition, his financial responsibility for caregiving was accepted as an extension of the breadwinner role that was undertaken by him previously. In the caregiving situation, it led to maintenance of his marital role. Caring for his wife with Alzheimer's disease, 79-year-old Kangho Park described a similar experience of continuing his breadwinner role in caregiving.

When I was 60..., I began to take care of her. At that time, I had the power of protecting and caring for her even though I was employed. ... I said to my children, "Live well with your own family and don't worry about your mom. I

will take on all financial burden of mom's treatment. I will do everything. Never visit."

After the transition to caregiving, he was able to keep his full-time job because of his wife's slight functional and cognitive impairments; thus, maintaining his financial ability to cover all care-related costs. His ability to afford costs associated with caregiving strengthened a sense of fulfilling financial obligations to his wife. Even in the caregiving setting, his breadwinner role continued. The opposite pattern was found with 73-year-old Changsu Yu who, on entry into caregiving, had to leave the work setting to take primary responsibility for his wife. Yet, after the loss of family income, his ability to provide financially for his family was sustained by the disposition of real estate.

I owned an apartment. And, I also owned lands in the country. After my wife became sick..., my apartment's gone. I sold it to treat her. We bought the apartment with a bank loan. We had repaid the home loan. But, after she became sick, I couldn't make money and neither could she. It was tough to handle the load. So, I sold the apartment. Our house's gone. And, we had to sell some land.

When his wife had a head injury after a concussion, he had to take sole care of her because his children were unable to share caregiving responsibility. After he quit work as an apartment guard due to the competing demands of employment and caregiving, he experienced a shift from the workplace field to the family caregiving field. However, on the transition to spousal caregiving, despite the sudden loss of stable economic resources, he felt strongly the need to be financially responsible for spousal caregiving as well as the financial responsibilities of the household as he had been the primary breadwinner of the family. The expenses of health care were covered by selling his apartment and real estate. In addition, often, his couple had to

move to cheaper houses for rent. Because caregiving imposes greater financial demands over time, it was not possible for him to seek re-employment; therefore, limited financial resources were a major obstacle to maintaining his financial capability. In the future, if he could not rely on financial support from his children or public assistance programs, he may be placed in a financially vulnerable situation. Like Changsu Yu, those older husbands who did not have sufficient financial resources or had lost stable economic sources were unable to maintain the breadwinning status in the family while operating within caregiving spheres; thus, increasing their financial strains and economic hardships in the caregiving situations.

### **Taking over wives' family roles.**

Before the onset of illness or injury, wives had primary responsibility for household management. However, with the onset of illness or disability, wives' difficulties of fulfilling their duties marked changes in their relationships, particularly their marital functions. On entry into spousal caregiving, to survive as marital units, older husbands were required to take over everyday tasks that previously had been handled each day by their wives (such as meal preparation, cooking, laundry, cleaning, grocery shopping, and financial management). It appeared that most older husbands faced challenges in carrying out these household tasks because of their inexperience. A remarkably changed marital role meant a shift from a mutual marital relationship to a unidirectional relationship. This finding supports research previously done by Sandberg and Eriksson (2007) (Sandberg & Eriksson, 2007). Seventy-two-year-old Seongmin Kim described the daily household tasks that he had to take over after his wife's hospitalization.

After she got out of the hospital, I had to do everything. From meals. All money matters. I had to do everything. I had to go to the bank. I did everything. A cook.

I've been a cook. First time, I got annoyed to do kitchen work. How to cook rice?

I had never cooked. (Laughing) I couldn't cook.

When she returned home after completing a long-term hospitalization, her ADL and IADL limitations led him to experience larger changes in the division of duties in the marital relationship. Because his wife was unable to fulfill household responsibilities like she used to do, he had to perform all kinds of household tasks that were previously her responsibility. To fill in her vacant position in the family sphere, he began to participate in household management. Taking over her household responsibility was his response to a shifting balance in the marital functioning. He indicated that this taking over of her tasks was unavoidable and significantly increased his duties as he transitioned to caregiving. Household-related activities and responsibilities were a large challenge as he acclimated to his new role and created a dramatic change in his family life. These changes are similar to shifts in marital relationships described by other researchers (Calasanti & Bowen, 2006; Choi & Eun, 2000; Sandberg & Eriksson, 2007). These new tasks were also a potentially ongoing source of stress until he became familiar with them. The stress he reported is not unlike the findings of Calasanti and Bowen (2006). Similarly, the accounts of 63-year-old Euihan Kim, whose wife became disabled after a stroke, showed his experience of taking over household tasks as a sudden extension of his family role and an unexpected shift of his primary role sphere to the home setting. He stated,

After she was sick, I learned where a kitchen was and where kitchen stuff was in the kitchen. Before that, I didn't do anything at home. Just, when I felt bored, I helped her doing the laundry, cleaning a duvet. Before that, I had never thought of doing housework. She couldn't do that after she was sick, so I had to do.

He suddenly began to carry out all her tasks without the necessary knowledge and skills. The domestic sphere became a core place for him. These changes in his duties created a gap between past and present marital relationships and an unforeseen, unfamiliar rearrangement of marital roles in his life. In addition, his cooperative relationship with his wife was changed to a one-way caring relationship within the family system (Sandberg & Eriksson, 2007). However, the greatly increased marital duties were an inevitable way of adapting to the irreversible loss of balance in marital functioning.

### **Rearranging marital role and responsibility.**

After the occurrence of the spouses' illnesses or injuries, their functional limitations led to the absence of their marital role in the family that necessitated rearranging marital unions. Oftentimes, this rearrangement was temporary or transient. At other times, the rearrangement of marital roles was permanent. Older husbands began to fill in the loss of wifely role in the marital system in order to maintain the husband-wife relationship as a unity in the family. This rearrangement meant that husbands took over their spouses' responsibilities and duties. Even after the transition to caregiving, as the spouses' health status changed, marital roles were flexibly, continuously reorganized, depending on the spouses' cognitive and/or physical function. However, the absence of the wife's role in marital practice did not mean the loss of marital identity of the spouses giving and receiving family care. Rather, similar to research done by Lewis (1998), the spouses, who obtained a new status of "care recipient" in the caregiving situation, still identified themselves as "wife." Their husbands also labeled the spouses as "wife." That is, in the family, a care receiver-caregiver relationship was a continuum of wife-husband relationship even in situations involving long-term care. It represented changes in marital roles, not in marital positions.

As a part of the marital union, the spouses with functional limitations could not fulfill household duties, as their previous role responsibilities, but indirectly participated in marital practice through establishing cooperative relationships with older husbands. Within the reorganized marital system, spouses supported older husbands who experienced role insufficiency in performing new tasks. Thus, the marital relationship was characterized as complementary even in the caregiving situation. Seventy-three-year-old Sanggyu Cho's narratives indicated how he and his wife changed the arrangement of marital duties after her operation for stomach cancer.

We always have discussed everything. But, we strictly divided up responsibilities.

I took 100% responsibility for outside the house. She was responsible for inside the house. But, after it [her stomach cancer] happened, I've taken more responsibility. I became responsible for my outside work and took over half her responsibilities.

His wife, who became physically weak and was taking warfarin after the stomach cancer surgery, was unable to fully carry out household tasks for which she had sole responsibility. Her difficulties of managing household tasks created something of a vacancy of her role in the family; thus, reorganizing marital roles in the family became necessary. He had to take over half of her household duties (e.g., cooking, meal preparation, and dishwashing), as well as his primary breadwinning responsibility. They had to sustain the altered marital system until, after complete recovery, she could return to her former role. In addition, he planned to gradually give back the household duties to her during her recovery process. The arrangement of marital roles represented the flexible, mutual, complementary aspects of the marital union in the family.



Hyungwoo Yu, aged 75, also commented on the reorganized division of household labor after his wife began to collapse as a result of brain surgery sequela.

[After she collapsed in 2007] I took all responsibility. Before she collapsed, I had helped her. But, after that, I have done 100%. .... I did laundry. She cooked rice, .... I didn't cook. But, after she collapsed... on June 6, 2007. From 7th, I took over hers. 100% was my responsibility.

He and his wife completely and permanently changed roles within the marriage. Her limitations in IADLs and a sudden, unpredictable recurrence of collapse led her to stand back from her household duties. Simultaneously, he suddenly had to fill in the loss of the wifely role in marital practice. His marital role was expanded in the marital system. Although the shift of all her marital role duties to him caused the loss of role balance between the couple, their positions as wife and husbands in the marital relationship continued.

Even though older husbands took over the spouses' marital duties or responsibilities for household management, they built a complementary relationship as husbands executed household tasks. When husband caregivers had difficulties carrying out domestic tasks, their wives provided instruction or supervision. Sixty-seven-year-old Kihyeong Hong's comments indicated his complementary interactions with his wife in his performance of housework tasks after he took over her household duties.

She likes doenjang jjigae [Soybean paste stew in Korean]. I stirred to dissolve one or two spoons of soybean paste, cut and added chili pepper, green onion, garlic, and dried anchovies. Ah, I added ugeoji [outer leaves of a cabbage or other greens in Korean]. And then, I showed jjigae and asked her, "Honey, it's okay?"

(Laughing) She said, “It’s good, but you need to add more water.” And, I added water.

With the progression of her multiple illnesses, including diabetes complications, back pains, teeth programs, cataracts, and urination problems, her functional impairment worsened and thus, the time spent in bed increased. As a consequence, he took on her responsibility for household management. Because he was not accustomed to doing housework, particularly cooking, he often asked her if the work he was doing was correct. Her instruction or supervision was a complement to his performance of the household role. In the marital system, his wife’s functional impairment brought about imbalance in marital roles. Yet, through the process of reorganizing marital roles and building a complementary relationship in marital practice, the disrupted marital system was re-established into a new stable, workable marital system.

#### **Extension of marital duty.**

Older husbands felt obligated to take care of their wives and unquestionably accepted the caregiver role as an extension of the marital role. Regardless of their feelings or attitudes toward their spouses, husbands’ strong feelings of marital responsibility were deeply rooted in their marital relations. Marital responsibility was a major motivation for entering into spousal caregiving. These findings are analogous to research reported by Lee (2005), Lee and Kim (2009), Lewis (1998), Miller (1996), Milne and Hatzidimitriadou (2003), O’Connor (1999), Ribeiro and Paúl (2008), and Ross (1991). Seventy-three-year-old Changsu Yu’s narratives clearly represented his decision to take sole responsibility for caring for his wife who had a concussion in 1996.

[After she fell down] I was so shocked. It was because she had never taken a cold.

After a head injury, it was so preposterous! But, I can't help it because she is my wife. So, after I quickly composed myself, I started caring for her actively.

'Caring for an elderly person' in the family was accepted as a marital obligation, not as a filial obligation. Despite having adult children, he decided not to share caregiving responsibility with them. He became a sole caregiver just because he was her husband. 'Becoming a caregiver' meant that he began to commit to the marital role as husband in a new, unfamiliar situation although features of the marital role would be altered. Woojin Kim, aged 71, also highlighted the caregiver role as the fulfillment of marital obligation.

Because we got married and had our children, we had lived together just as the couple. I was not deeply attached to my wife. We were a married couple only in name. So, after she was ill..., she was my wife, so.... And, I thought I would do what I had to do. I would do the best I could. It was not because I loved her, but because we got married and had kids and she was my wife. We've lived together..., so I became responsible for her.

A married couple was obligated to fulfill the socially, culturally shared role expectations, like "living together, having and raising children, and maintaining the family." Role responsibility or duty was the most important component of his marital and familial life. Thus, the marital relationship with his wife could be explained by responsibility associated with the marriage vows, not by love. Unlike the study done by Ribeiro and Paúl (2008), rather than marital affection, marital loyalty was the motivating factor in his journey of spousal caregiving. This is analogous to research reported by Lee and Kim (2009) and Miller (1996).

In addition, as Miller (1996) and Ribeiro and Paúl (2008) noted, marital affection and fidelity promoted older husbands' motivation to "become a spouse caregiver." The occurrence of wives' illnesses or injuries became a heartbreak to older husbands. The couples strongly emotionally attached to each other were reluctant to endow others with caregiving responsibility. From their deep feelings of marital love, husbands were willing to take responsibility for caring for their wives. Jeongmin Hwang, aged 79, demonstrated his strong marital affection as a determinant in becoming her caregiver after his wife developed shingles.

We are inseparable. We can't be separable from each other. Honestly speaking, we are deeply attached to each other. So, we can't be separable. It is love..., and loyalty. I can't allow others to care for her. I thought, 'whatever I do, I will be next to her and take care of her.' I can't let others to do it.

This couple unquestionably accepted caring for the loved one as his responsibility and duty in the marital life. The caregiver role was a continuum of marital love and fidelity as well as marital duty. After the onset of her disease, this couple obtained new positions as care recipient and caregiver within an unfamiliar circumstance. However, their marital status as husband and wife was continuous and central in his life.

Mostly, older husbands' family roles were expanded after taking over the spouses' household responsibilities. However, some older husbands also had to take over the spouses' family responsibilities, which were not socially expected as a normal role obligation of older husbands in later life. Usually, on the transition to spousal caregiving, older husbands also adopted primary responsibility for rearing grandchildren in the case of divorced or lost children. The narrative of 63-year-old Euihan Kim provides insight into this shift in responsibilities:

Getting up at 6:30am, I help the eldest grandchild to urinate. For about two hours, I lay down. I get up at 8 am again. I wake up my grandchildren, wash their faces, and dress them. I get them ready for kindergarten because a kindergarten bus is coming at 8:30am. After sending them to kindergarten, I clean the house, put away beddings. It is around 9am. If there isn't any cooked rice in the rice cooker, I have to cook rice. When they come home from kindergarten at 6pm, I have to wash their hands, to give dinner to them, and to bathe them. It becomes about 8pm.

His wife's stroke led him to suddenly, unexpectedly take heavy responsibilities for the extended family roles as well as spousal caregiving. After entering into the caregiving world, he took on triple roles of caring for his wife, managing household activities, and raising his grandchildren as part of his home-based caregiving responsibilities. In particular, nurturing grandchildren, which was his wife's previous major duty for their divorced son, was an unexpected but inevitable role in his life. On the transition to caregiving, his lack of knowledge and skills in relation to these new role tasks led to a challenge for smoothly accomplishing such complex work that he had not noticed being done by his wife prior to her illness. The addition of the "wifely" responsibilities he took on and the spousal caregiver role he assumed resulted in an ever-heavier workload.

Acquiring new duties for household, familial, and caregiving activities as part of the transition to spousal caregiving, older husbands began to play two crucial roles. One was taking over the responsibilities usually associated with a housewife or grandmother, protecting and caring for the family. At the same time, he was a caregiver providing care to his wife. Suddenly increased role duties emerged while he was acclimating to and managing new multiple tasks.

Interestingly, in home-based caregiving, household and familial activities were viewed as a separate matter from caregiving activities in that the former was derived from wives' family roles.

### **Changing attitudes toward wife.**

Older husbands often experienced changes in emotional feelings and attitudes toward their spouses as the husbands transitioned to the caregiver role. Although Lee (2005) reported on changes in husband caregivers' attitudes toward their wives with Alzheimer's disease, these findings add to the knowledge gained from Lee's study in that, observing the spouses suffering from illnesses, most of older husbands felt pity for them. In addition, they showed their gratitude to their spouses who had sacrificed everything for their families. Kangho Park, age 79 years, acknowledged his growing sorrow and sympathy associated with the completely changed appearance and personality of his beloved wife with the progression of her Alzheimer's disease.

She was smart and beautiful.... She is 164 [cm] tall. She was not short in her generation. She was slim, white faced, and beautiful. What happened to her? After having Alzheimer's disease, she lost her memory and personality. How miserable it was. I felt pity for her. My heart hurt to see her.

He highlighted that as her Alzheimer's disease developed, he had to observe how she gradually changed in appearance and personality. He recognized the wife he had known in earlier years of their marriage was gradually disappearing from their marital life. These changes hurt his feelings. At the same time, he felt pity for his wife as she succumbed to Alzheimer's disease. Although his ill wife still existed within the caregiving situation, the wife he remembered as wise and beautiful no longer existed. Similar to research done by Lewis (1998), the loss of his wife, with their shared history, fueled his sadness and emotional pain as he

provided her with long-term care. Their marital life was dramatically changed as he experienced a discontinuity of emotional interaction with her.

Many older husbands often expressed a feeling of appreciation or thankfulness, as well as pity and sorrow, when discussing their wives. Mostly, their wives were evaluated as good wives and mothers, who had devoted much of their lives to children and husband. Older husbands complimented their wives on their household roles and showed their deep gratitude to their spouses who had sacrificed their lives for the family. It was only after the spouses were ill that husbands realized how precious their wives were in the marital or familial life. Eighty-two-year-old Daeman Kang's comments showed his thankfulness to his wife who currently suffered from Alzheimer's disease.

I had depended on my wife. She made sacrifices for [her] husband. Now, I know she had made me a priority, had dedicated to me, and had served me. Sincerely, I'm grateful to her. Compared with her, I have not done anything to her. When I think, in her later years..., she has such a serious disease, I'm sorry and pity for her.

After caring for his wife with Alzheimer's disease, he retrospectively recognized his wife's wholehearted support and sacrifice for him in their former marital life. He greatly felt the loss of his wife in the current relational aspect of their marriage. Simultaneously, he regretted that he had been a poor and inattentive husband to her. He expressed mixed feelings toward his wife, that is, he felt both sorry for and thankful for her. He switched location in the marital relationship, from a position of receiving care and support to a position of providing care and support. This switch made him understand his wife's role responsibility or duty in the former

family and marital structure and, as a consequence, he experienced changes in his attitudes toward his wife.

A few older husbands, who had unsatisfactory marital relations before the occurrence of their spouses' illness or injury, showed ambivalent feelings toward their wives in the caregiving setting. They continued to feel dissatisfied with their spouse and felt pity for them as well. Sixty-seven-year-old Seungchan Yu said,

She had neglected me and our children. So, I really hated her and ignored her, too.

After taking care of her..., sometimes, when I got upset, I yelled and swore at her.

Other times, I felt pity for her. A pity for her. If I don't feel pity, I won't be a human. I had hated her..., entirely hated her. But, when seeing her not recognize even faces, I feel pity for her.

He did not have any memory of being cared and supported by his wife in the marital and family life. Rather, instead of her performing as a housewife and mother, he had to perform household and familial tasks. His marital and family life had been unhappy and unsatisfactory. His unhappy marriage had increased his negative, hostile feelings to his wife. After she suffered from diabetes complications, a sense of marital obligation and humanity led him to begin taking care of her. He experienced the mixed feelings toward her even as he was caring for her. As a husband, he hated his wife yet, simultaneously, as a human being, he felt compassion and pity for her as she became severely impaired. Marital dissatisfaction and conflict were ongoing emotional and relational issues for some husband caregivers, even in the caregiving environment. At the onset of their spouses' illness or injury, they took primary responsibility for taking care of their wives but they still were dissatisfied with both the caregiver life and the marital life. They thought the caregiver role amplified the feelings of regret in their marriages and of dissatisfaction



with their current lives. Sixty-seven-year-old Seungchan Yu stated that, in his current life, all his unhappiness originated from marriage.

Looking back now, I don't know why I didn't divorce. Now, I'm bitterly regretting. I didn't beat her up and left her to do whatever she wanted. I didn't care if she got crazy or not. I didn't care if she went out with her friends or not. I had just kept my eyes ahead and had focused on my work. In some ways, I think I'm very good-hearted. So, consequently, I become unhappy.

From 2004, as a husband's duty, he began to be responsible for providing care to his wife who had suddenly become sick. However, he assertively stated that he did not have any affection toward his wife. He stated that, marital duty, not marital affection, was why he took on the caregiver role. Provision of spousal care was accepted as his unwanted but socially unavoidable duty. In this sense, when he got upset or annoyed in performing caregiving tasks, he regretted he had not divorced his wife. In addition, he strongly believed that his marriage caused the current stress and anger in the caregiving situation. The feeling of unhappiness and dissatisfaction in spousal care was a continuation of his unhappy marriage.

### **Changing marital relationships.**

After the occurrence of spouse's health problems, husband-wife relationships changed to caregiver-care receiver relationships in the family as well as in the caregiving situation. The altered relationship contributed to changes in the quality of their emotional relationship. In the caregiving environment, husband-wife interaction led to strengthen or weaken their emotional tie. Mostly, through the process of enduring caregiving-caused hardships together, older husbands and their wives experienced deeper marital intimacy and affection and developed a sense of partnership in the caregiving setting. In addition, they increasingly became emotionally

interdependent. Having taken care of his wife suffering from back pains for 10 years, 77-year-old Sungbeom Park stated the caregiver-care recipient relationship brought them emotionally closer to each other.

Without me, she can't live. After she was ill, we became closer together. I try to console her more. And, I often say to her, "Honey, don't worry. I will be with you forever." We got much closer together than before. She always relies on me. Is there anyone better than me? I'm the best person she can depend on. Whom can an old person rely on and speak a word to?

After their children got married, they continued to live together in their own home. He said they had always been affectionate with each other and had been known to be lovebirds. After her back pains were recurrent 10 years ago, the new caregiver-care recipient relationship in marriage has strengthened their emotional bond. Their couple became more affectionate, interdependent with each other through the process of providing and receiving support and assistance with everyday activities. They became the most trustworthy, comfortable person to each other in any situation. This couple became reluctant to receive outside support or care for the wife. The caregiver-receiver relationship made their marital relationship stronger and more central in the emotional and physical spheres of life. Seventy-five-year-old Kisang Kwon also remarked on increases in his marital happiness or satisfaction in the caregiving situation.

I often think, 'Ah~, I'm very blessed.' Because she is alive, I can take care of her. If she is not, can I care for her? She is alive, so I'm very happy. Just, I'm happy because we are together. Just, I'm happy.

From 2001, his wife has suffered from a series of illnesses and injuries (e.g., stroke, rib fracture, back injury, and sacral fracture). He was thankful that she survived despite the

unceasing occurrences of health problems. In addition, he was satisfied that, even though she could not fulfill wifely duties like before, she has been with him and he has taken care of her for a long time. The symbolic and physical existence of his wife improved his feelings of belonging, happiness, and satisfaction in his marriage during his provision of long-term care to his wife. In addition, she occupied a large, central part of his life. In the caregiving process, her illnesses and disabilities heavily increased marital interdependence and emotional attachment.

For some older husbands, their wives became the will to live in their lives. Husbands assertively said that, if their wives would pass away, they do not need to live alone. The spouses' death was viewed as the end of both their lives. Sometimes, extreme marital interdependence led some older husbands not to take care of themselves in order to face the end of their lives with their loved ones. Seventy-nine-year-old Jeongmin Hwang's narratives poignantly indicated that his wife was the meaning of his life.

I have a little bit stomach trouble. Others told me to see a doctor, but I won't. This is because, honestly saying, I will follow her..., if she pass away. I will follow her.

I think I will suicide. What is the use of only me being healthy?

After one of two sons died and the other ran away from home, only the couple was left as the remnants of previous family life. The loss of their sons made them more interdependent in the marital life. Indeed, after she became sick, a new bond of caregiver-care recipient has strengthened physical and emotional inter-reliance in their everyday lives. This couple became emotionally and physically inseparable. Rather than focusing on himself, his wife became central to his life. Thus, his wife's health, not his own health, was the only concern in his life. Recently, as she has seriously deteriorated, he began to think she was near the end of life. It also meant there was not much time left to live in his life because his life without her was meaningless.

### **Establishing supportive relationship with adult children.**

Most adult children did not share primary responsibility for performing caregiving tasks; instead, they supported their fathers' caregiver role in various ways, such as with financial, instrumental, and emotional support. Much like other studies by Adams (2006), Lee (2005), Miller (1990a), Russell (2004), and Sanders (2007), for the older husbands in this study, adult children became the most important informal support network in long-term care. Alternately, when older husbands were not available for carrying out caregiving duties (such as when husbands had their own doctor's appointments), adult children supported their fathers as backup caregivers. Adult children also were likely to provide emotional support to their parents through telephone calls or visiting, particularly when their mothers were suffering from an illness. Adult children's support was critical to lessen husband caregivers' stress or burden, enhance their caregiving capabilities, and improve the quality of care. Seventy-five year-old Kisang Kwon, who has taken care of his wife because of a series of illnesses that began in 2001, remarked on the importance of financial support from his sons for his pocket money and the feeling of thankfulness to them.

If I can go out, I can make even pocket money. I can't go out, so I can't help relying on my son. I know my children financially have a hard time. But, they give my pocket money and cover her hospital and medicine costs. It costs too much, every month. ... If they don't support, I can't afford to pay. I ask them about medicine and hospital costs, fare, and others. Then, they give money.

Caring for his wife with functional limitations led to restrict his participation in outside or work-related activities. He felt burdened to handle her hospital and medicine costs by himself because of the loss of financial sources after leaving the workplace. To keep the caregiving role,

he needed to receive financial support. As Silverstein, Gans, and Yang (2006) and Zhan and Montgomery (2003) noted, his children were the only resource on which he could be financially reliant for care-related expenses. Particularly, his sons covered all her medical care expenses and his necessary expenses for caregiving; thus, lightening his financial burden of caregiving. However, he felt sorry for imposing a heavy burden on them because he knew his children tried to support their parent despite economic difficulties.

Sometimes adult children, particularly daughters-in-law or daughters, provided secondary or back-up care to their mothers or mothers-in-law for a short time. Adult children were the most comfortable person older husbands could ask for urgent help. Seventy-nine year-old Kangho Park stated that, during his work hours, his daughters-in-law often visited his house to check their mother-in-law's condition.

During the middle stage, daughters-in-law lived near me. So, they stopped by for checking if she was fine or had lunch. And, once every four days, she defecated. When it became the day she defecated, she visited home to take care of her stools. So, I could handle work and caregiving. After leaving the office at 5pm, I took care of her.

In the middle stage of Alzheimer's disease, while he was at work, he used to let his wife stay home alone. Even though she was able to stay home alone without trouble of wandering or being lost, he was concerned about his wife's meals and defecation because he could not leave his office during his working hours. He needed daytime help with a few of her everyday activities. Because his work prevented him from carrying out caregiving tasks, daughters-in-law who lived nearby became secondary caregivers for daytime care. After receiving daughters-in-law's assistance once every four days, he felt less burdened to juggle the demands of work and

caregiving. In addition, their instrumental assistance helped relieve some of his worries about his wife during his working hours. He established a support relationship with his adult children, particularly his daughters-in-law so they could fill the gap in his role performance. Family collaboration became a critical component of a secure, appropriate caregiving situation for his wife. Similarly, 75-year-old Hyungwoo Yu commented on daughters or daughters-in-law's assistance in personal care, "I can't take her to a public bath. She can't get into the bath by herself. Without children's help, she can't do. So, daughters or daughters-in-law help her go to the public bath." As backup caregivers, his children willingly went to a public bath with her and helped her bathe. Children's support led to decreases in his burden or stress regarding her bathing in a public bath. In addition, similar to the research done by Miller and Guo (2000), adult children provided a diversity of instrumental assistances, usually in response to older husbands' requests. They unquestionably supported their father during urgent needs for long-term care assistance.

Adult children also strengthen emotional bonds with their ill mothers through frequent phone calls and visits. Many old husbands also asked adult children for help in making their wives feel more emotionally supported from adult children rather than for only providing instrumental tasks. Husband caregivers expected that children's emotional support would contribute to improve their mothers' emotional stability and to encourage her in the disease process. Seventy-three year-old Sanggyu Cho's comments showed his expectation of adult children's role in the caregiving circumstance.

Rather than cooking, their visiting and talking with her help her become psychologically stable. Because she only stayed at home, I think she can feel lonely now. When she was healthy, she could focus on her work or go out. But,

now, she has nothing to do. So, children often visit and talk with her.

Grandchildren also visit. I think they work for her recovery as well as psychological stability.

After his wife was diagnosed with early stage stomach cancer, she became disappointed and frustrated even though her doctor told she would fully recover her health after surgery and medical treatment. He thought it was urgent to encourage her to manage emotional difficulties. He stated that he felt perfectly capable of providing ADL and IADL care to her but his emotional support was insufficient to maintain her emotional stability. He needed his adult children's assistance with meeting her emotional needs and improving her positive attitude toward her illness and medical treatment. Adult children and grandchildren willingly accepted his request for emotional support and thus, often spent a lot of time with her encouraging her in her struggles with stomach cancer. Because of their emotional support, she began to regain emotional stability and to be motivated to recover her health.

#### **Extension of parental role.**

At the onset of the spouses' illness or injury, older husbands were worried that their married children's work and family life might be disturbed by their involvements in caregiving. In particular, in the caregiving situation that they could not expect their spouses' rapid recovery from physical and/or mental illness, they decided to sacrifice themselves for their children's life; consequently, they took sole responsibility for caregiving. It was their duty as a parent to fully support children's happiness and well-being. It reflected unidirectional parental affection to children in Korean society. These findings are analogous to Korean research reported by Lee (2005) and Lee and Kim (2009). 79-year-old Kangho Park's comments showed his parental

consideration for his three sons and daughters-in-law in determining who was a primary caregiver.

If one person sacrifices or becomes a victim to the bad thing, the whole family could be relieved. It can make people around me at ease. If I don't accept it, all my three sons and their wives will get worried or anxious, won't they? When I was solely responsible for it, I thought all would be peaceful and comfortable. So, after I did, our life became peaceful.

In the face of need for providing family care to his wife with Alzheimer's disease, his family had to manage a key issue emerging from the occurrence of her disease, "Who would take care of her?" However, because Alzheimer's disease required increasing, ongoing demands of care work, he did not want all family members to suffer from her chronic disease and family responsibilities for long-term care. He felt it was inefficient to let his children share caregiving duties with him because the shared responsibility for long-term care would interfere with their current family and work duties. For children's life, he, as a parent, took sole responsibility for taking care of his wife and did not allow his children to involve in caregiving. His sacrifice originated from his parental caring and consideration. It reflected his parental responsibility for protecting his children's lives, not being disturbed by shared caregiving responsibility. 73 aged Changsu Yu's narratives also indicated his anxiety about children's work and familial life in family caregiving.

When my wife was in the hospital, I thought they should work to live their wife and children. So, I said to them, "It won't be done in one or two days. So, we can't be together here anymore. Go home. I will take care of her." Since then, I've taken all responsibility.



His wife's physical and cognitive impairments after head injury reflected the permanent loss of her physical independence and autonomy. Until the uncertain end of her life, a primary caregiver was required to continuously provide full-time, intensive care to his wife with functional limitation. In addition, the caregiver duties or responsibilities would change all aspects of the caregiver's life in that the caregiving demands were incompatible with the demands of non-care work. In this sense, after observing that his children's work and family lives were disrupted by their caregiving performance during the first few days of hospital care after her head injury, he, as a parent, became hurting from children's entry into this uncertain, hopeless situation. He desired that his children's lives would not be impeded nor felt burdened by filial obligations in long-term care. For his children, he took sole responsibility for taking care of his wife. Because, for him as a parent, children's happiness and success were the top priority rather than his couple's ones, "becoming a primary caregiver" was a choice for his children's lives. Finally, his caregiving responsibility was an extension of parental role.

### **Separating from adult children's lives.**

One consequence of the caregiving setting was emotional and/or physical separation from adult children's lives. Oftentimes, older husbands kept their physical and/or emotional distance from their children in the caregiving circumstances so as not to burden their children or impinge on children's work and family life because of caregiving tasks or responsibilities. Even though many adult children wanted to share caregiving responsibility with their father, husband caregivers rejected their participation or assistance. In addition, as Lee (2005) asserted, marital obligations were strong motivations for husband caregivers. Older husbands in this study often informed their children that caring for the spouses was their own responsibility. Similar also to research done by Adams (2006), Lee (2005), Miller (1990a), and Sanders (2007), these older

husbands did not expect support from adult children, who had difficulty supporting their parents or were indifferent to the older parents. In this sense, the caregiving circumstance became an emotionally and physically private space for older husbands and their spouses with no room in that space for adult children. Sometimes this separation led couples to feel socially isolated in the caregiving setting. Seventy-nine year-old Kangho Park's narratives reveal his efforts in preventing his children from becoming involved in caregiving.

Seriously, I've said to children, "I don't need your help. I will take care of her. So, you just sometimes visit to see her. I mean it from the bottom of my heart." They wanted to come, but I didn't allow. But, daughters-in-law visited with some foods. Three daughters-in-law. I didn't make the situation they couldn't sleep and experience some problems in their lives, in their businesses, or others even though they might not be comfortable because their mother was bedridden for a long time.

He took full responsibility for taking care of his wife with Alzheimer's disease for 17 years. His emotional and spatial separation from his children reflected parental affection toward their children. He did not try to bring them into this stressful, tough situation because he did not want them to suffer from the stress and burden of long-term parental care. As their parent, he expressed his strong desire that his children could concentrate on their own work and family without being disturbed by caregiver duties and activities. Comments made by 73-year-old Changsu Yu's also showed a similar attitude toward his children, he stated, "I didn't want to emotionally burden them. So, I've tried to handle everything. I didn't say to them. I didn't tell them about her illness. I never say. I don't say to them yet." He just accepted spousal caregiving as his inevitably being his responsibility. His choice of 'becoming the primary caregiver' was as much for his children's protection as it was for his wife's care. Because of his decision, there

was a physically and emotionally rigid and impermeable boundary surrounding the caregiving situation, a boundary that adult children could not bridge.

Several older husbands experienced increasing emotional or physical distance from their children after their transition to caregiving. This was especially apparent when adult children lived long distance away from them, suffered from financial difficulties, or prioritized their own work and family over parents. This finding is similar to findings reported by Adams (2006), Lee (2005), and Miller (1990a) noted. Even though they felt disappointed with their children, they understood children's situation and did not expect their assistance. One husband in this situation, 73-year-old Changsu Yu, stated that he fully understood why his children could not visit his home after his wife became ill.

My daughter doesn't visit because she can't take care of her and can't afford to support us. ... Among my children..., there is no child who can support us. And, there is no one who can care for her.... I think, from their views, if they can support us, they can visit to see her. But, because they can't support, they can't come. I'm not disappointed. I understand them.

Since his son-in-law passed away, his daughter has struggled with a severe financial hardship. Other children also had economic difficulties after business failures or job losses. Because it is a strong cultural norm in South Korea for children to support their aging parents, he thought that they could neither be in touch with him nor visit his home to see their mother in sickness because they were ashamed to face their parents. As a parent, he understood his children's situation and feelings and accepted the severance of family bonds. The caregiving setting became a socially isolated or private site only for his couple without any interaction with

adult children. A similar type of situation affected 72-year-old Seongmin Kim and his wife. He also understood his children's difficulties in visiting and caring for their mother.

We have children, but.... They just visit to see their sick mom. That's all. I understand them because they have to live their own lives. My daughter lives with her parents-in-law in Cheonan. It is not easy to visit to see her. So, I can't ask her for help.

After his children got married, they moved out of Incheon. In their own busy family and work life, they were often unable to participate in caregiving or to visit parents' home. His daughter raised her children and lived with and supported her parents-in-law in a distant province so it was even very difficult for her to come to Incheon. As Lee et al. (1993) noted, for his daughter, geographic distance was an obstacle to support her father who took care of her mother. He understood their busy situations and thus, was not disappointed with them. As a parent, he did not want to burden them. Without children to rely on for any form of care, he took full responsibility for taking care of his wife. Protecting children's lives was accepted as a parental duty. Older husbands in similar situations just adapted to the ongoing social isolation.

### **Changing relationships with adult children.**

Not all older husbands reported the type of isolation described in the preceding narratives, for some, family relationships were re-established as supportive bonds between older husbands and their adult children. Such rebuilt relationships contributed to positive changes in older husbands' attitudes toward their children and strengthened emotional bonds with them. First, older husbands, who received support from their children, emphasized that they became more intimate with their children through the shared struggles with caregiving hardships. In addition, family relationships were strengthened on mutual trust and support. As 68-year-old Kyeongwoo

Kim's comments clearly showed, increasing family cohesion and supportive interactions aided in the caregiving circumstance.

After she was ill, we've paid all attention to her. So, my children often call each other to talk about their mom. If there is something wrong with her, younger sister immediately call her elder sister. We often call each other and share everything about her. I think our cohesion has been strengthened. And, we are always anxious about her. So, we often call each other and ask about her condition.

The pattern or style of family communication and interaction positively and organically changed in response to this wife's caregiving needs. All family members shared patient-related information and knowledge through frequent cooperative communications. Frequent family interactions helped enhance family capability to provide better, proper care. Collaborative caregiving strengthened family functioning and cohesion among family members. Similarly, 75-year-old Kisang Kwon also commented on increasing intimacy and trust among family members after his wife became ill.

Adult children always follow me and never disagree with me. And, they always try to give me whatever I ask. They are very filial children. (Laughing) After she was sick, I become much intimate with them. ... We share everything without hiding. And, they try to support me. They trust me. And, I also trust them.

After her stroke in 2001, he has taken primary responsibility for his wife's care and has become financially dependent on his adult children. Despite their own difficulties, his children enacted filial behaviors to financially and emotionally support their parents in the caregiving situation. He reported that he felt thankful for their support and was proud to have such filial children. He underscored that the supportive interaction and communication with children led to

enhance emotional closeness and mutual trust among family members. He was consoled by his children's filial piety.

However, when adult children neglected parents' stress and pains or did not support their parents, some husband caregivers expressed a sense of disappointment and frustration in the relationship with adult children. They felt alone in the family and felt isolated in the caregiving circumstance. As 77-year-old Sungbeom Park pointed out, he became disappointed with his sons who did not go to the hospital to see their mother.

I yelled at children, "Are you her children? Without her, you can't exist. You have to feel pity for her. Without your mom, can you be born? You have to respect her all the time. If you don't respect her, you're not human beings." They have to visit to see her every day, but they don't. They always say it is hard to live. I tell them it is your business.

His son's undutiful behavior and attitude made him feel disappointed and dissatisfied with his children. He felt that, without children's care and support, he and his wife became confined to the caregiving setting and felt socially isolated. Conflict with his son was also apparent in 67-year-old Seungchan Yu's narratives.

I think my son has to understand me, but he doesn't. Sometimes, I say to him, "I will live recklessly, and I will die." I'm not happy. He isn't an unfilial son, but he doesn't support me. Sometimes, I feel doubts about my life. I don't know why I have to live. For example, if I pour out my sufferings to him, I expect him to say, "Dad, don't worry. I'll take care of you as much as I can." But, he doesn't console me. Rather, he says to me, "I feel tough, too." I become disappointed more.

His son's physical and emotional severance aggravated his feelings of fatigue or isolation and increased caregiver distress. The absence of social outlets for emotional difficulties led to weaken his inner strength or power and to deteriorate his mental health or emotional state; consequently, reducing his caregiver capability in long-term care.

As these narratives show, strong notions of filial piety influence relationships between parents and adult children. For some older husbands, the cultural norm of protecting ones children took precedence over norms associated with the filial obligation for adult children to provide care. The dissonance between these two South Korean norms led several older husbands to experience a sense of isolation within the caregiving environment.

### **Evolving Caregiver Role**

After the transition to caregiving, the caregiving role constantly changed and the spouses' condition and health status changed. Older husbands continuously had to manage care-related changes that occurred in response to wives' progressive illness or disability. In addition, to improve their caregiving capability and to provide better and appropriate care to the spouse, older husbands developed their own strategies for adapting to these changes and rearranging the caregiving contexts. The following paragraphs illustrate many of these adaptations.

#### **Managing outside the caregiver role.**

Caring for the spouse with limitations in everyday competences led older husbands to downsize their geographic, social, and emotional spheres of everyday life after entry into spousal caregiving. This is similar to the geographic spheres described by Wiles (2003). For older husbands who were physically and emotionally overwhelmed by their caregiving responsibility, it was not easy to leave their spouses with functional and/or cognitive impairments in that they had to pay continuous, careful attention to changes in their spouses' health and to immediately

satisfy their spouses' new or increasing needs. After becoming a spousal caregiver, they kept spending most of their time being with their spouses in the house or in the hospital. Feeling trapped in the caregiver role, they realized that caregiving activities were incompatible with previous social or work activities. In the ongoing restricted situation, in which outside activities interfered with caregiving activities, handling two conflicting settings remained as an unfinished challenge in spousal caregiving. For older husbands, it was crucial that they devote themselves to spousal caregiving and in order to alleviate the stress of disharmony between activities and responsibilities inside and outside the caregiving sphere. After 72-year-old Seongmin Kim's wife became severely physically impaired after the second femoral fracture, he was overburdened by the double responsibility for caregiving and work. His narratives illustrated his experience of balancing between work and caregiving demands.

I work every other day. One day, I can take care of her. But, next day, I have to be at work all day. I couldn't handle this situation. Hiring a paid caregiver was expensive. It was 50,000won a day. But, I had to hire a paid caregiver. In a hospital, the paid caregiver took care of her for two years.

Because his hospitalized wife needed constant care because of her severe functional impairment, the greatly increasing demands of caregiving emerged as a challenge in balancing the duties of two seemingly incompatible roles (Stone et al., 1987). It meant that his risk for burden increased in response to his changed situation. He recognized that the caregiving demands exceeded his physical and emotional ability; thus, he acknowledged the need for formal help. Finally, to manage the conflict between work and caregiver roles, he decided to hire a paid caregiver to decrease his feeling of burden in fulfilling dual responsibilities. Using formal care was a choice he made in order to lessen his caregiving burden and stress and simultaneously, to



maintain his caregiver role. Even after using formal care, however, he could not fully relieve the caregiver burden he felt during his work hours. His constant worry about her led him to frequently call her to check on her condition. He said, “Working in an office, I can’t take care of her. So, I often have to call her. I often called to her until my cellphone battery died.” He experienced psychological spillover from the caregiver role to the work role. He could not concentrate on his work because of his excessively frequent phone calls to his wife. Those calls lessened his anxiety or worry about her when he could not be directly involved in spousal caregiving.

Unlike Seongmin Kim, 68-year-old Kyeongwoo Kim, who took care of his wife with functional impairment after frequent injuries, reduced his activities and responsibilities outside caregiving to alleviate the stress from the conflict between work and caregiver roles. He said,

When she was healthy, I was busy. After my classes, I had to meet lots of people, had lots of meetings..., I participated in various activities with friends. But..., I cut out all but the most important activities. I had to cut out. Having some time, I had to get back home or go to the hospital.

Kyeongwoo Kim felt burdened by the incompatibility between caregiving and working as he struggled to meet the increased needs of his wife. The provision of ADL care brought about his restricted activities and life. However, because caregiving responsibilities became a high priority in his life, he rearranged his work and social schedules to allocate his limited time to caregiving more than to working. He reduced his work duties to a minimum and gave up most of social activities. In particular, for him, the flexible work situation was a resource to enhance the capability to reschedule work-related tasks and to manage caregiving and work demands when confronted with growing caregiving duties. Lapierre and Allen (2006) found a similar pattern of

caregivers juggling work and caregiving duties. After his wife suddenly and frequently collapsed as a symptom of post-surgical sequela, 75-year-old Hyungwoo Yu also demonstrated that, because of the difficulties of participating in activities outside caregiving, he had to give up religious activities for the caregiver role.

I quit Legion meetings, which I had attended for 19 years. In the evening, it took two or three hours to attend Mass and Legion meeting. I got anxious. So, I quit the meeting. Every Friday, I went to elderly school. But, I quit, too. I couldn't be there for three hours because I got worried about her. ... And, I had been on the church board of funeral services for 10 years. I couldn't volunteer for Legion of Mary and funeral service commission, either.

After brain surgery for a cerebral infarction in July 2006, his wife's repeated losses of consciousness became a primary anxiety and fear for him in spousal caregiving. Her recurrent blackouts prevented him from leaving her alone in the house. His anxiety about her relapse and her physical functional limitations hampered his participation in religious activities, in which he had passionately been involved for a long time. He was physically and emotionally imprisoned into the home in which spousal caregiving occurred (Ducharme, Lévesque, Lachance, et al., 2007). In prioritizing care for his wife, he sacrificed his personal and religious life because it was conflicting with his caregiver life. Taking care of his wife led him to lose control of activities not related to caregiving and to detach from the outside world outside. His restricted activities became a major change in his life after the transition to caregiving but were accepted as an inevitable, natural outcome of the caregiver role.

Older husbands, who could not be away from the caregiving setting for a substantial amount of time, sometimes confronted a challenge of dealing with important and inevitable

errands outside the caregiving situation. They attempted to rearrange caregiving tasks on a schedule to make time available for outside errands. However, very limited time was available for running errands not related to caregiving. Thus, considering spatial and temporal availability, they screened, prioritized, and limited their outside tasks. They only left the caregiving setting for outside tasks that could be handled within the neighborhood or the district. Seventy-three-year-old Changsu Yu's narratives showed his own strategy for running outside errands in the restricted setting of spousal caregiving.

In the afternoon, she is lying down here [the living room floor] or is in bed. There are some personal errands I have to run. She can't sit up on her own, so I can go outdoors on a ride for a while. For example, personal errands like paying taxes, buying her diapers. For a while, I ride a bike to the market or to the clinic.

Before she became bedridden, he paid continuous attention to his wife with Alzheimer's disease because he had to manage her behavioral problems, such as wandering, hallucinations, and aggression. He could not leave her alone for outside errands. However, after she became completely bedridden, he did not need to care for her around the clock and was able to spend brief periods of time away. The complete loss of her independence and autonomy allowed him to establish a routine schedule dealing with the restrictions and necessities in the caregiving situation.

Sometimes, the usage of formal care became an opportunity for completing non-care related tasks outside the caregiving situation. While wives received formal care, such as in-home care service from long-term care insurance and adult day care service, older husbands spent their limited time away engaged in vital activities outside of caregiving. They had to practice careful time management so they could return to the caregiving environment before care services were

finished. Seventy-three-year-old Changsu Yu's comments clearly showed that he could fulfill important responsibilities outside the home while a long-term care worker took care of his wife.

When the inevitable happens..., like relatives' weddings, a family bereavement....

I should attend. In the morning, the long-term care worker comes to care for her.

While the worker takes care of her, I do. But, I have to get back immediately.

After he took care of his wife with functional and cognitive disability after a head injury, he accepted participation in interpersonal activities as a challenge. Because he could not easily commit social and familial responsibilities outside the caregiving sphere, he attended only the most important family occasions (e.g., weddings and funerals) that were perceived as fundamental duties in interpersonal relationships. Fortunately, long-term care service was the only time that he felt physically and emotionally relieved from caregiver burden. The services provided by the service contributed to lessen his burden of fulfilling the minimum social, kinship duties as a social member. But, within four hours, he had to come back to caregiving activities after fulfilling social or family duties.

### **Managing within the caregiving role.**

As the spouse's conditions deteriorated or improved, her functional ability also changed. In caring for the spouses, older husbands, as primary caregivers, needed to pay constant attention to their spouses to identify and to properly respond to their changing care needs. As their primary duties of providing appropriate and better care to the spouse, husband caregivers continuously recognized changes in the spouses' symptoms or health conditions and repeatedly modified their own strategies for taking care of their spouses.

***Managing wives' symptoms.***

As the spouses' diseases progressed, older husbands detected various functional capabilities and performances in their wives. Particularly, the spouses' problematic behaviors, caused by progressive cognitive deterioration, became a major concern to husband caregivers in that these functional changes or behavioral disturbances as strong threats to their safeties. It meant husbands were required to monitor and supervise spouses' activities and behaviors. They built an optimal coping strategy for managing both behavioral problems and their own reactions to spouses' dysfunctional behaviors. For example, after observing the emergence of his wife's Alzheimer-related hallucinations and aggression, 79-year-old Kangho Park described how he handled these behavioral disturbances in caring for her.

Her symptoms became progressively worse. Seeing herself on a screen, she thought to see a monster. And, she used to hit a TV screen and glasses. Seeing her face..., she screamed a ghost showed up and then, she began to hit. If I turned on the TV, she said she heard ghost voices from the TV and yelled at me to turn off the TV right now. So, I put papers on all windows. I made her not to see her face again. And, the TV was always turned off.

Her dysfunctional changes, as a potential threat to both their safeties and emotional states, influenced the quality of their lives. The home setting became a worrisome and unsafe place. After acknowledging her behaviors were progressive symptoms of Alzheimer's disease, he attempted to reduce her violence. He modified the physical environment for her safety and comfort as his strategy for coping with increasingly unusual changes in her behaviors. Seventy-six-year-old Taeseob Choi also remarked on the experience of handling his wife's cognitive impairments associated with Alzheimer's disease.

I don't give a house key to her. If I give it to her, she will lose the key within a month. She is asking for a new key. It's not difficult to give a new key. But, she will lose it again. She spins the key and then throws it away. Whenever I asked her about the key, she just said, "Ah...." ... We had a cordless phone. It worked away from 50m. My daughter sent the cordless phone from USA. One day, I couldn't find the phone anywhere. (Laughing) It was in the refrigerator. So, I felt I should change to a corded phone.

With the progression of her Alzheimer's disease, frequent losses or misplacements of familiar objects, like keys and the cordless phone, emerged as visible changes. However, at first, he did not realize that these were symptoms of her disease. Because he did not recognize the relationship, he was unable to appropriately respond to her changed behaviors. Even after realizing that it was common for people with Alzheimer's disease to lose the ability to manage personal belongings and to properly use daily commodities, managing her memory loss became a primary area of struggling with the endless repetition of her problematic behaviors. Her behaviors caused him difficulty in caring for her until he came up with a solution. In dealing with her cognitive impairments, he used a restrictive strategy (such as banning her from having a key or changing the cordless phone to the corded one), not a coercive strategy because of communication difficulties with her.

Sometimes, because a spouse's functional impairment could threaten their own or others' safety, husband caregivers tried to avoid a potentially high-risk situation, particularly the risk of fire hazard. In older husbands' narratives, fire-safety appeared as one of the most significant worries in caring for their cognitively-impaired spouses. Fire-safety was an issue expressed by 75-year-old Hyungwoo Yu, whose wife suffered from frequent forgetfulness after brain surgery,

Almost, she lost her memory. Forgetting is very dangerous. So, I can't go anywhere. When I leave home, I get so anxious. When I'm at home, I always keep her away from fire. If I don't, a fire can break out. At home, I always let her not to turn on the stove in the kitchen. And, she has the fear of fire. While I'm away, she can't heat up anything. So, after I come home, I heat up instead of her.

Increasing frequent forgetfulness led her to feel less confident in her performance of daily activities, particularly using a gas stove for cooking. Also, he got seriously worried about being a fire hazard in moments of her forgetfulness. He, as one of his primary caregiving tasks, needed to alleviate her fear of fire and to protect her from the fire hazard in the home setting, in particular in the kitchen. His concern for fire safety restricted her mobility and activity in the house and simultaneously, his activities outside the caregiving. To avoid all fire hazards, he restricted her access to the gas stove. Instead, only he used the stove for cooking or warming up her foods; thus, paying constant, careful attention to her and spending most of his time with her in the house. The increasing cognitive impairments of spouses over time led to dysfunctional, problematic behaviors that endangered the personal safety of themselves and their husbands. Husbands needed to continuously monitor or manage spouses' activities or behaviors. Simultaneously, endless demands generated by spouses' cognitive status and behavioral problems, which were emphasized as a primary stressor in the research on male caregivers in eldercare (Croog et al., 2001; Ducharme, Lévesque, Zarit, et al., 2007; Pearlin, Mullan, Semple, & Skaff, 1990; Roland, Jenkins, & Johnson, 2010), became the potential caregiving burden and difficulty experienced by these older husbands in long-term care.

***Managing wives' food and diet.***

In taking care of spouses who experienced changes in gastrointestinal function or who needed to avoid symptom-provoking foods, dietary management became a key caregiving task for older husbands. Keeping appropriate food and nutrition was critical to maintain the spouses' health and to manage their illnesses. To meet their spouses' dietary requirements, older husbands built various dietary strategies, such as setting up eating plans or schedules, changing food texture and feeding style, and making dietary instructions. Sanggyu Cho, aged 73, referred to his dietary strategy for helping the return of his wife's gastrointestinal function after surgery for stomach cancer.

She has stomach cancer, so she needs to eat six meals a day. She eats each meal twice. And then, she eats snacks twice or three times. For the first month after the surgery.... I designed an eating schedule for her. I made a schedule time table. And, I've given her meals according to the schedule.

His daily schedule and activities were arranged to fit her dietary schedule. Because his daily life was mostly occupied by managing her eating schedule and pattern, his activities became very restricted. However, he readily accepted meal management as the most important caregiving task until the recovery of her digestive function. He also expected that, as her digestive ability gradually improved, the time and effort he devoted to preparing her meals and snacks would decrease. Similarly, 80-year-old Jeonghwan Ahn described his experience of modifying food texture to cope with declines in his wife's digestive capability after she was bedridden because of vertigo and depression. He said,

Until two months ago, she could eat a rice meal. But, now, she can't eat the rice meal. I've prepared gruel for her. ... And, she drinks milk. The doctor said milk is



very nutritious food and drinking plenty of milk is good for her. So, I let her to drink milk, tomato juice.

Two months ago, she became suddenly unable to swallow solid foods. For her eating problems, he had to replace solid foods with semi-liquid food that was easier for her to swallow and eat. However, he was concerned about insufficient nutrient intake and potential nutritional vulnerability. He searched dietary information or asked her doctors about dietary care for his wife. To achieve nutritional benefits, he also prepared liquid foods, such as milk and tomato juice, as nutritional supplements. After the sudden deterioration of her digestive function, preparing appropriately nourishing food fitting to her digestive ability and maintaining her nutritional balance and physical vigor were perceived as his key caregiving tasks. He made great effort in the management of her dietary intake. However, her increasingly worsening digestive ability meant the decline of her physical health and the loss of her ability to struggle with her diseases. Consequently, he increasingly worried and was anxious about her health and dietary intake. Thus, serving digestible, nutritious foods was his ongoing key concern and caregiving task in caring for her.

Sometimes, dietary management was associated with avoiding some foods that provoked the spouse's symptoms. Husbands restricted spouses' access to foods causing symptoms even though such a restriction caused conflict with them. Or, the spouses were given an immediate intake of prepared emergency foods when their symptoms suddenly got worse. Seventy-two-year-old Seongmin Kim, who was taking care of his wife with diabetes, described his restrictions on her dietary habits to prevent diabetic deterioration.

I don't allow her to eat salty food. There are many foods diabetic person can't enjoy. Simply talking, she can't eat sugar-containing..., sugar-rich foods. I've

never allowed her to eat [those foods]. But, she likes them. When I don't allow her to eat, she gets irritated. I coax her not to eat them.

He was deeply concerned about the development and progression of her diabetic complications because she had suffered from femoral fractures that did not heal properly, as diabetic complications, three times. To avoid the subsequent occurrence of fractures, he tried to strictly limit salty and sugar-rich foods, her preferred foods, which could accelerate the deterioration of diabetes. He knew it was not easy to control her dietary needs but it was necessary to prevent further deterioration. Even though his strict restriction on her eating habits brought about her discomfort, dissatisfaction, and marital conflict, he could not allow her to eat her favorite foods. In addition, for his wife suffering from frequent hypoglycemia, he had to prepare emergency foods, such as chocolates, sugars, and candies, and always reminded her of his dietary instructions. He said,

Her blood sugar often gets too low. So, for her hypoglycemia, I've prepared chocolates, sugars, and candies at home. If she calls me when her blood sugar becomes low, I tell her to eat chocolates right now. And then, add sugar into water and drink. I always tell her, when she gets hungry, to drink a cup of milk before eating a meal. It works for hypoglycemia.

Being at work, he always got anxious about potential threat to hypoglycemia because she was alone in the house. For this urgent setting, he prepared sweets, which she could eat immediately. He drew up guidelines on sudden hypoglycemia and pre-meal habits for her. His key caregiving task, in addition to helping her effectively and immediately handle risky situations, was to remind her to follow the dietary instructions. He stated that putting his constant efforts into dietary management was successful in maintaining her normal blood sugar levels. He

emphasized that the management of dietary intake was very satisfactory. Just as described by Ducharme, Lévesque, Zarit, Lachance, and Giroux (2007), after successfully dealing with the emerging caregiving demands, he experienced increasing self-efficacy as a spouse caregiver. For older husbands, dietary management was an essential task to improve or maintain the spouse's physical strength and health in long-term care. They expected the provision of better or appropriate foods would help their wives struggling with their chronic diseases for survival.

***Maintaining wives' physical vigor and health.***

With the progression of the spouse's illness and/or disability for long periods of time, decreasing physical vigor and health was an emerging critical concern in long-term care. Older husbands thought that maintaining physical strength was a prerequisite for their spouses' long-term survival and tried to maintain or improve their wives' physical vigor and health through light workouts or dietary supplements. For example, 79-year-old Kangho Park expressed his belief that light workouts would be helpful for his wife who had Alzheimer's disease so she could physically endure disease-caused hardships.

I wanted her to live one more day. I thought, first of all, she had to be physically healthy. So, from 1990, I used to go for a walk with her in the park near my house. We used to take a turn in the park.

He asserted that good physical strength and health has been beneficial to her 17-year survival of Alzheimer's disease. Workouts were viewed as a way of enhancing bodily vigor and physical health. As her Alzheimer's disease progressed, he designed an appropriate physical activity program for her physical and functional status. For example, after he began to care for her, he kept walking around the park with her every day until she had difficulties walking and moving. After she became moderately to severely physically impaired, keeping regular light

exercise became useless and inappropriate. Thus, he had to seek another way of maintaining her physical vigor. He described a new strategy for sustaining physical strength. “Changing her diaper in the evening, I made her be on her foot and then, changed her diaper. I thought it would be good for her health rather than changing the diaper while she lay down. I thought it would be a way of building her leg strength.” Instead of everyday walking around the park, very simple and low-intensity physical activities were needed to maintain her physical health. He thought that changing her diapers while standing was a proper activity.

Sometimes, nutritional supplements were perceived as another way of improving or sustaining a wife’s physical vigor and strength in long-term care. Seventy-seven-year-old Yoonseok Lee’s comments showed his desire that supplements, such as Chinese herbal medicines, IV injections, and red ginseng, would help the maintenance of his wife’s physical strength.

I had bought 300,000-won [about 264 US dollars] Chinese herbal medicines for her. I wished she would recover her strength soon. Getting an IV injection worked for only a few days. They didn’t work. Red ginseng. It worked for her. She has taken red ginseng. If she doesn’t take tonics, she becomes physically weak. After having a crap, I’m worried if she will plop down, not stand up. I’ve given her tonics to keep her strength.

His wife’s ongoing physical weakness and health deterioration, after the development of subsequent illnesses for 19 years, led to increases in her physical needs. He, who was in his 70’s, felt physically burdened to provide IADL and ADL care to her. In addition, similar to research done by Pearlin, Mullan, Semple, and Skaff (1990) and O’Brien (1993), the continuous deterioration of her physical functioning enlarged his worry about increasing caregiving burden

and difficulty over time. He expected that taking supplements, such as Chinese herbal medicines, IV injection, and red ginseng, was beneficial to sustain her physical strength and slow down the progression of functional limitations; thus, lessening his physical demands of care and enhancing her ability to struggle with chronic health problems. He was satisfied with the benefits of supplements, in that she was not severely disabled but could survive from her various illnesses for 19 years.

***Managing hygienic condition.***

Older husbands, whose spouses became bedridden after the progression of ADL/IADL disability over time, became concerned about a threat of poor personal hygiene to the spouses' health and well-being. Husbands tried to maintain the cleanliness of their bedridden wives to prevent life-threatening conditions through frequently checking their hygienic condition and washing, bathing, and drying them. Managing a wife's personal hygiene became a crucial task of caring for the spouse who became severely physically and/or cognitively impaired. Seungchan Yu, 67 years old, commented on his experiences and feelings associated with bathing his long-term bedridden wife to maintain her cleanliness.

If she is really dirty, it's not good for her. Twice a week, I bathed her. I did that all alone. It was so tough. Who can do that.? No man will do that. No man is willing to do. I couldn't stand dirty nor let her dirty. It bothered me, but I had to wash and bathe her.

After his wife was confined to bed due to the development of her diabetes complications, she became very vulnerable to bedsores and other health risks. The maintenance of her physical cleanliness and low risk of bedsores became one of his primary caregiving tasks. He relatively often bathed her to keep good personal hygiene of his wife. However, this responsibility was

unfamiliar or at least uncomfortable, sometimes inducing annoyance. Just as described by Russel (2007a), he perceived that the demands of personal care made him reach a point beyond what was considered to be baseline as a man because bodily care placed him in a situation challenging traditional notions of work and gender. The provision of personal care, which was not associated with men's work, was a new, extraordinary attempt to adapt outside the normative realm of men's work in a man's life. In addition, because of the loss of her functional independence, personal care became a physically demanding work for him. Thus, his responsibility for managing personal hygiene brought about emotional and physical strains.

In long-term care for their bedridden spouses, because older husbands were commonly concerned about the development of pressure sores threatening spouses' health or lives, they developed their own strategies for reducing the high risks for the occurrence of bedsores. For example, 79-year-old Kangho Park, whose wife had moderate to severe Alzheimer's disease, became physically and cognitively impaired, underscored the danger of developing bedsores and described his techniques of avoiding bedsores.

After bedsores had developed before, I often cleaned and dried her back. I learned she shouldn't be bedridden for a few hours. Every two hours, I had to change her position. And then, I often checked if her bedding was dirty or not. When I found stains or fecal stains on her bedding, I changed it at once and washed it.

At the beginning of spousal caregiving, he, who lacked knowledge about and preparedness for bedsores, did not recognize her recurring bedsores as serious enough to cause a life-threatening situation. In medical treatment of her bedsores, he became aware of the danger of getting bedsores and obtained skills about decreasing their likelihood. To avoid recurrence of bedsores, he created his own strategy for maintaining her cleanliness and hygiene, such as

frequently washing and drying her, checking her bedding, and changing her position at regular intervals. These tasks became a primary daily routine for taking care of his wife. Such ongoing effort was helpful for effectively preventing bedsores. Similarly, 80-year-old Jeonghwan Ahn illustrated his own strategy for keeping his bedridden wife from the occurrence of bedsores.

I learned, if her clothes become wet from sweat, it would be seriously bad on her back. So, I bought four [ramie] clothes. With them, I changed her clothes. They are really great. The [ramie] clothes don't cling to her body. If they are hanged out, they dry quickly. These days, she is sweating too much. So, I change her clothes four times a day. It doesn't take long to dry them. After changing, I immediately wash and dry it.

He got anxious about the likelihood of occurring pressure sores to his wife who stayed asleep in bed most of the day and sweated a lot during sleeping. In a certificate program for long-term care worker, he acknowledged the danger of bedsores and was trained to manage personal hygiene care. Based on the knowledge and skills, he also developed a strategy for reducing the development of bedsores. Ramie clothing became a usual means for avoiding the threat to bedsores. It was helpful for keeping her body and bedding clean and dry all the time; thus alleviating his worry about the risk for bedsores. He was very satisfied with the usage of ramie clothes in performing his daily tasks of managing her personal hygiene, as one of his important caregiving duties, and in protecting her from increasing health risks following bedsores.

### ***Using assistive equipment.***

As the spouses' functional impairments worsened, they became increasingly dependent on their primary caregivers, their husbands, in daily life. The spouses' functional deterioration led to increasing the physical demands of caregiving upon their husbands, pushing them to reach

the limits of their physical capabilities. To preserve their own competences as the primary caregivers, husbands used a diversity of assistive equipment (e.g., wheelchairs, electronic mobility scooter, cane, body support straps, grab bars, ID necklace, and so on). The use of these assistive devices enabled care-receiving spouses to retain functional independence and husband caregivers to lessen their daily caregiver workloads. Seventy-five-year-old Kisang Kwon, who was providing care to his wife with cognitive and physical impairments after a stroke, illustrated the experience of using an electronic mobility scooter to meet her mobility needs.

She used the [electric mobility] scooter for moving around. I taught her how to operate it. How to drive forward or backward. How to drive fast or slowly. She was smart, so she learned and operated it well under my instructions. She was able to go out on her electric scooter. I always walked behind her. The scooter was equipped with a basket, so we could go grocery shopping.

Physical functional limitations led her to experience walking difficulties. After staying home most of the day, she got disappointed and depressed with her restricted activities outside the caregiving setting. Seeking a way of reducing her stress of the restricted mobility, he arranged for electric mobility scooter service for the disabled. Because the service was perceived as useful for his wife, he immediately applied to it. After having an electronic mobility scooter, even without his IADL assistance, she could go anywhere she wanted, like grocery shopping. The usage of a mobility aid contributed to enhance her performance and independence in ADLs and IADLs. In addition, his physical demands of IADL care reduced. Both his wife and he were satisfied with the mobility aid changing their lifestyles and the quality of life.

Older husbands, who cared for the spouses with severe functional impairments, strategically used various assistive devices to enhance their caregiving capabilities and at the



same time, reduce their physical workloads. The husband caregivers expected that the use of assistive aids helped relieving their physical burdens of caregiving and protecting their physically-disabled spouses from collateral risks of injury. The narratives of 67-year-old Seungchan Yu showed the benefits of using assistance equipment when he performed ADL tasks for his wife with severe limitation in ADLs.

She couldn't walk without help. Holding her in my arms, I had to take her to bathroom. Sitting on the toilet, she often fell. I set two wire loops on the wall behind the toilet. I tied a cotton strap to each loop. Like wearing a backpack over the shoulder, I let her wear the straps. It helped her not fall again.

In taking care of his wife whose functional independence or autonomy was lost, toileting was very intensive and physically-demanding work. In addition, he was concerned that she was at high risk for injury during toileting because it was impossible for his wife who lost control of her body to sit on the toilet seat without other's help. He had to search a way of helping her with her ADL disability, in particular her sitting imbalance. Body support straps were a means designed to reduce the risk of injury and to improve his ability to carry out ADL tasks. The straps improved her activities of everyday life and simultaneously, lessened his burden of ADL care and his worry about her safety.

Some older husbands used assistive devices to effectively manage physical and time burdens of caregiving and to improve their own well-being. For example, 80-year-old Jeonghwan Ahn, whose wife was physically limited because of severe dizziness, pointed out the usage of a toileting button, which was installed near her bed, to lighten his caregiving workload at night. His accounts follow: "At night, she has to go to the bathroom four times. So, I can't sleep. I made a button on her bed. When she wants to go to the bathroom, she pushes the button.

And, I take her to the bathroom.” Every night, she needed her husband’s assistance with toileting several times. Her frequent toiletings disturbed his sleep. In addition, he, who slept in a separate room, could only reach a light sleep so he could quickly notice the unforeseen, irregular needs of her toileting. Increasing fatigue and burden caused by the lack of sleep undermined his health and the quality of life as well as his caregiving capabilities. He installed a button, which she could push when she needed his help with toileting, on her bed to lessen his strain of toileting assistance through the night. It meant he became able to relax and sleep until she pressed the button. The toileting button contributed to his ability to fall asleep and to boost his energy, even if only for a while. He was satisfied with the night button in that it could enhance his ability for night care and he felt less burdened or strained.

***Continuously monitoring wives’ conditions.***

In caring for spouses after the transition to caregiving, most older husbands continuously observed sudden or rapid deterioration of the spouses’ health status. As a primary caregiver, husbands were required to instantly, effectively manage the urgent setting inducing the threat to wives’ safety and well-being. Therefore, they were always concerned about an emerging risky condition caused by sudden deterioration and continuously took notice of their wives’ behavioral functions or health conditions. In particular, when the spouses were sleeping at night or stayed home alone, husbands constantly, frequently monitored their wives’ conditions, as 79-year-old Kangho Park illustrated. When he took care of his wife with final-stage Alzheimer’s disease, he had to frequently check her night sleep to identify if she was okay or not.

I put the folding bed next to her bed. At night, I slept in the folding bed. Several times, I woke up for checking if she was saying strange things or she was fine.

After I identified she was okay, I fell asleep again.

As she reached the final stage of Alzheimer's disease, her health and functional performance severely deteriorated. He began to worry about an escalating possibility of an urgent situation. His anxiety about the loss of his wife became a key stress or challenge in long-term care. Jansson, Nordberg, and Grafström (2001) also discussed caring activities performed by husband caregivers as well as female caregivers in dementia care. The accounts of Kangho Park were similar in that a strong feeling of fear led him to continuously monitor her health status with his full attention, even through the night. He focused on the loss of his wife that might occur as an outcome of Alzheimer's disease. Therefore, he became increasingly physically and emotionally submerged in the care relationship with his wife and the overall caregiving environment. Constant monitoring was his own strategy for lessening his anxious or fearful state through ascertaining her status.

### **Emotional care.**

Older husbands often saw their spouses get disappointed and feel depressed or frustrated with their restricted mobility in long-term care. Or, they observed that, with the progression of cognitive impairment, their spouses became aggressive, agitated, hostile, or impulsive. Dealing with changes in the spouses' feelings or personality was accepted as a crucial caregiving task that they should perform. They tried to help their wives being comfortable and calm in the caregiving situation. For older husbands, managing wives' emotional state became one of significant caregiving tasks. For example, they were empathetic toward the spouse, who suffered from illness or functional limitations, or searched for ways of pleasing and encouraging them. To reduce the spouses' problem behavior (e.g., aggression, hostility, impulsivity, and so on), they tried to keep them calm all the time and simultaneously, not to stir up their dysfunctional feelings. As Ciambrone and Allen (2002) and Lichtman, Taylor, and Wood (1987) noted, emotional

supports provided by husbands appeared critical, as a powerful influence to enhance their spouses' internal strength or psychological well-being in long-term care. Seventy-seven-year-old Sungbeom Park, who has provided care to his wife suffering from back pain for 10 years, referred to his constant effort to reduce her excessive worry about mobility disability following the third disc surgery.

I always tell her, "Stop worrying. Stop worrying, and you will get well." I always say, "If you're always worried, you can't get well. Stop worrying. You believe you can get well."

After she began to suffer from recurrent low back pain 10 years ago, she underwent disc surgery three times. She relieved her back pain and got back to her everyday life after hospitalization for about two weeks after two previous surgeries. However, after having the third surgery three months ago, she became unable to move her body and had to be bedridden. Her long-term bedridden situation made her become terribly worried that she might be permanently disabled. He was also worried about her situation, but he, as a primary caregiver, had to positively respond to this situation. In addition, he believed that the provision of comfort and offering hope to her would be helpful to improve her motivation to get better quickly. Hiding his own worry or anxiety, he always encouraged his wife to overcome the current difficulty. In addition, he attempted to divert her excessive attention from her suffering or pains. This was accepted as a vital role of fully understanding and interpreting the feeling of his frustrated wife and of providing appropriate emotional response to her. Similarly, 68-year-old Kyeongwoo Kim encouraged his wife, who was intimidated by a series of injuries and illnesses (e.g., toe fracture, high fever, back pain, femoral fracture, and neck pain) for two years, to relieve her pain and emotional distress. Whenever she expressed her psychological distress or suffering, he instilled

hope for recovery into her with the following words, “Having physical therapy, you’ll get better. Time is a great healer.”

For some older husbands, affective expression, as well as verbal encouragement, were key means of lowering the spouse’s anxiety and distress and of pleasing or cheering the wife. For instance, Jeonghwan Ahn, aged 80, stated that, after his wife became ill, he has expressed more affection toward her, so as not to get disheartened by her changed life.

I still kiss her morning and evening. And, she likes. Is a patient dissatisfied, isn’t she? Think about it. She will think, if I’m healthy, I won’t be neglected. But, I think, because she’s sick and bedridden, she might feel slighted now. To make her not to feel slighted, I kiss and bathe her. She likes so much. And, she says, “thank you.”

After, with the gradual progression of vertigo, depression, and Alzheimer’s disease for two years, his wife became severely physically impaired, he supposed she might have internalized herself as insignificant and worthless because she became unhealthy and dysfunctional. However, as Lewis (1998) noted, contrary to her thought, because she was his wife even in sickness, she was still very precious to him. He wanted her feel loved and have good self-worth and showed his love to her through performing intimate tasks, such as kissing and bathing her. In addition, similar to research done by Calasanti and Bowen (2006), his narratives showed that feeling loved would be helpful for encouraging her to preserve her sense of herself as wife or woman and for improving her internal strength and psychological well-being in struggling with her illnesses and functional limitation. His efforts contributed to satisfy her and consequently, to boost her self-esteem in sickness. Beyond marital affection, expressing his love to her along with emotional support was perceived as one of his significant caregiving

tasks. He unquestionably considered that, as the primary caregiver, he was required to understand his wife's emotional state and to enhance her positive attitudes toward her illness and condition. Kihyeong Hong, aged 67, remarked on his attempt to encourage his wife, who was demoralized by her mobility limitations, through preparing her favorite foods.

I always ask her if there is something she wants to eat. If she wants to eat some bread, I buy her it. At the market, I buy Oiji [Korean pickled cucumbers] for her side dish. Buying Ugeoji [outer leaves of a cabbage or other greens in Korean], I make her Ugeoji-Doenjangguk [Korean soybean paste soup]. I should try to make the sick person feel satisfied.

After the development of back pain and diabetes complications, she suffered from various health problems (e.g., diabetic foot syndrome, back pain, teeth problem, cataract, and urination problem), which impaired her mobility and everyday performance. His physically impaired wife spent all day lying in bed watching TV. He began to worry that her restricted mobility made her discouraged and depressed. Even though he wanted to take her outside for some fresh air, he could not put his plan in practice because she had difficulty walking even short distance due to foot sores and back pain. Instead, he decided to prepare her favorite foods, such as Oiji and Ugeoji-Doenjangguk. Her favorite foods, as a sort of refreshment, were expected to diminish her sense of illness and to encourage her in her sickness. In addition, the provision of her favorite foods reflected his empathy for her, as a requisite for emotional care.

For older husbands who took care of their cognitively impaired spouses, coping with spouses' dysfunctional and maladaptive emotions became a key task in long-term care. After acknowledging the care recipients who were unable to self-regulate emotions, husbands tried to avoid a situation triggering their maladaptive emotions and behaviors. Seventy-nine-year-old

Kangho Park, who had taken care of his wife with Alzheimer's disease, commented on his strategy for handling her affective disorder.

She had Alzheimer's disease. I read books about Alzheimer's disease. The books said, "Don't argue with Alzheimer's patients. Make them comfortable." I learned some tips. After that, if she made a mistake, I would say to her, "It's okay. Don't worry." She became in good mood, didn't get mad, and didn't cry.

After he had acquired information about the changes in Alzheimer's patients' functioning over time, he was not distressed or perplexed at mistakes made by his wife because her aggressive or disruptive behaviors potentially endangered personal safety of his wife or him. Rather, he was aware that it was not necessary to point out her mistakes and to attempt to rectify them; instead, he built his own strategy for avoiding conflict with her and not making her agitated or upset. It was very powerful to manage his wife's emotional state. His effort to maintain her emotional stability was recognized as a vital task to enhance her emotional well-being and not to increase unnecessary conflict and trouble in the caregiving environment. Controlling her emotions or feelings became critical in taking care of his wife while considering her safety or psychological well-being.

### **Managing financial matters.**

The long-term progression of spouses' functional limitations or frequent recurrences of their illnesses led to increased financial demands for medical care or caregiving and simultaneously, to greatly restrict husband caregivers' activities and lives. It meant older husbands, in particular those who wanted to re-participate in the labor force for acquiring economic resources, lost an opportunity for re-employment because of their wives' long-term care needs. Most older husbands, who had difficulties receiving financial assistance or returning

to the workplace because of chronological age or the caregiver role, confronted a challenge of managing financial issues resulting from limited economic resources. Within the restricted financial environments, they built their own strategy for dealing with economic adversity. For example, they eliminated relatively unnecessary costs from living or caregiving expenses or received public assistance for medical care. Seventy-three-year-old Changsu Yu, a receipt of the National Basic Livelihood Security (NBLs) benefits, referred to his strict financial planning and expenses to effectively manage livelihood allowance from the NBLs program in the caregiving environment.

After receiving livelihood benefits [from the National Basic Livelihood Security program], I withdraw money to fit my budget for planned necessary expenditure.

It is not to spend money unnecessarily. Only for taxes, her diapers, and living costs. I always planned how to spend for them. Even though I want to spend, I can't. (Laughing)

He was unable to leave his wife home alone for work and did not receive financial support from his children; therefore, livelihood benefits from the NBLs program were his only financial resource. However, because the NBLs program is designed to secure minimum standards of living to beneficiaries, he always experienced financial burden of managing the restricted fund that did not to meet all his financial needs. It became a primary challenge in daily life. His monthly expense plan was his strategy for living with the minimum cost of living and dealing with limited financial resources. In addition, the spending plan was used to control purchases of relatively unneeded items. The accounts of 67-year-old Kihyeong Hong, a beneficiary of the National Basic Livelihood Security (NBLs) benefits, also showed his own strategy for lowering living expenses. He said, "At a vegetable store, there are vegetables in



baskets, not ones displayed on the shelves. Vegetables in the baskets have a few flaws. So, they are a little bit cheap. Five or six for 2,000 won. I usually buy them.” He tried to buy his wife with diabetes vegetables, which was helpful for improving her health. However, he always felt financially burdened to buy vegetables. Restricted funds from the livelihood benefits always led him to search out cheaper vegetables, flawed ones rather than fresh ones. Buying these vegetables was an effective way of reducing the costs of necessities. It was helpful for satisfying his needs of saving money and providing nutritious food to his wife.

In addition, the continued progression of the spouses’ disease or disorder contributed to increasing demands for medical care to retard their deterioration or to improve their health. However, older husbands, with relatively few financial resources, felt burdened by growing medical costs. Because of the inevitable, constant needs of medical care, husband caregivers looked for free or subsidized medical services to lessen their financial burden. Sixty-seven-year-old Seungchan Yu, who had financial difficulty supporting his wife’s dialysis, illustrated his psychological relief from financial burden on dialysis costs.

I couldn’t afford the medical bills. And I almost used up my money. Losing money, I was scared I might sell this apartment. One day, on my way to the park, I saw ‘Free dialysis center.’ I learned it was the first center offering free dialysis in Incheon. It was free dialysis service. ... The next day, she began to get free dialysis. So, I was a little bit relieved.

After the sudden deterioration of her kidney function, she had been hospitalized for receiving dialysis treatment three times a week for a while. Because the cost of kidney dialysis treatment was about 80,000 won (about 70 US dollars), he had to pay 240,000 won (about 211 US dollars) for her dialysis treatment every week. However, his retirement allowance and

savings had barely covered living and caregiving expenses, so he began to psychologically and financially suffer from the new expenses associated with dialysis treatment in caring for his wife. Fortunately, he found a dialysis center that provided free dialysis treatment for outpatients and began to use the center. It contributed to a decrease in his financial strain for her medical care. Later, when she no longer received free dialysis service from the center after she was hospitalized again, he became stressed over covering for the dialysis costs. Supporting the costs of dialysis service became a large challenge again. From other family caregivers in the patient room, he obtained information about disability benefits whose beneficiaries could receive subsidized dialysis treatment. After he applied to the disability benefits, she became a recipient of the disability benefit and received free dialysis again. Again, he began to feel relief from the financial burden of her dialysis treatment.

### **Seeking information.**

After the transition to spousal caregiving, older husbands confronted a lot of ongoing changes in their spouses' symptoms and health status conditions in long-term care. Simultaneously, they, as primary caregivers, were continuously required to gain knowledge about their spouses' disease process and medical care to understand the emerging needs of the spouses' and to better or effectively cope with the changes in their health status. As Lee (2005) noted, to appropriately complete their caregiving responsibilities, they constantly sought all information about illness, caregiving, and care-related services through various resources. First, asking outside people (e.g., friends, neighbors, and community people) was often used to satisfy their information needs. They asked people around them about their direct or indirect experience in relative to illness and medical care. For 72-year-old Seongmin Kim, his friends, particularly ones with diabetes, became a good source of diabetes-associated information. He said,

I have some friends suffering from diabetes. Meeting them, I often ask for details.

What's your blood sugar level? What is different between high and low blood sugar levels? I often ask. I ask about how to live, what to eat, what to control, and.... I often ask.

In caring for his wife with diabetes, he collected diabetes-related information from his friends who have struggled with the same disease. In this way, he acquired an overall understanding of diabetes symptoms and diabetes management skills (e.g., diet and exercise). Simultaneously, all their experiences of fighting against diabetes became critical, valuable guidelines to design his own caregiving strategy for managing diabetes and improving his wife's life with diabetes. Sixty-seven-year-old Kihyeong Hong's narratives highlighted his reliance as a primary source of information about illness and medical care on community people he usually met in the welfare center and the park.

I know an old woman who comes to the welfare center for lunch. I asked her about my wife's illness [back pain]. She recommended a hospital. She said if my wife got a shot, she would get better. So, we went to the hospital and she got a shot. Many elders came to the welfare center for lunch. I asked them because the elders have more experience than me. They said diabetes patients would die because of diabetes complications.

Because several elderly people he met had lots of experience in various areas of life, he expected he could obtain helpful or useful information about illnesses and medical care from their knowledge and experience. Therefore, he often asked them about his wife's illnesses, usually diabetes and back pain, and carefully listened to their accounts of disease progression and medical treatment. Based on the knowledge and information he gained from these

interactions, he often made a decision regarding his wife's medical treatment. However, he fully relied on them as a primary source of information, rather than medical professionals, in that he had easy access to elderly acquaintances within the community. Yet, he did not identify the potential for harm from inaccurate, unreliable information obtained from community people in understanding her disease process and deciding medical care.

Besides human resources, diverse types of information resources were used to improve husband caregivers' understanding of caregiving and care-related contexts. For example, a public lecture, which was designed to provide information about a specific illness or disease, was an accepted opportunity for gaining valuable knowledge on their spouses' health problems. Seventy-nine-year-old Kangho Park's accounts showed his experience of gaining in-depth knowledge of his wife's disease through attending public lectures on Alzheimer's disease and asking the lecturer questions. He stated, "Public lecture on Alzheimer's disease.... I attended the lecture. After the lecture, I asked the doctor my questions and listened to his answers." To meet his information needs, he was actively dependent on Alzheimer's- or dementia-related professionals' knowledge or opinion. Such professional information became the basis of his caregiving capability to provide appropriate, better care to his wife.

For some older husbands, particularly ones with restricted access to external resources, newspapers or newsletters were used as a major means of obtaining information about caregiving and social service programs. Changsu Yu, aged 73, underscored the importance of newspaper and newsletters as the only route for gaining access to outside information about social service programs for informal care or public assistance.

Reading the newspaper, I found an article about the adult day care center run by the Red Cross. The article said, the center was very well-received. I knew, in my

gu [borough], there is an adult day care center. I got information about who can use the adult day care center. And, I asked the public health center about the center. I usually stay home and can't get around outside. I get all information from the newspaper.

Because he needed to pay constant attention to his wife because of her cognitive declines, leaving her home alone was a large challenge in his caregiving life. His restricted activity was a considerable obstacle in seeking useful information outside the caregiving situation. He had to seek another way of accessing care-related information. A newspaper, which was delivered to his home every day, became a good resource to satisfy his informational needs. He learned about new welfare policies and social services by reading the newspaper, and thus became well informed about them. In addition, the disability newspaper and 'Gu' [borough] newsletters were key information resources that led him to disability benefits and social service programs. Home-delivered resources contributed to improve his caregiving knowledge and ability in managing the family caregiving milieu both inside and outside the home for his wife.

### **Learning caregiving skills.**

Older husbands continuously confronted a challenge of recognizing changes in spouses' functional and/or cognitive status and were forced to manage these changes in order to provide proper care to their wives. However, because they have never been professionally trained as a caregiver, it was not easy for these husband caregivers to effectively and immediately provide appropriate care that addresses the wives' symptoms. As spouses' health conditions deteriorated, husband caregivers showed a desire to enhance their caregiving abilities. Acquisition of caregiving skills and techniques was viewed as a vital component for creating a better caregiving environment for the spouse. By creating a better caregiving environment, their own caregiver

burden and stress were reduced. A skilled caregiver or professional, when one was available, became a good tutor for husband caregivers who desired to enhance their caregiving competences for mastering caregiving-related knowledge and skills. Older husbands carefully observed how the professional or skilled caregiver provided essential help with ADLs and IADLs to patients with cognitive and/or functional impairment in order to learn caregiving skills. Sometimes, husbands were directly taught practical caregiving tips so they could more effectively respond to increasing care demands and to properly control their spouses' behavioral problems. Seventy-five-year-old Kisang Kwon, who was taking care of his wife with ADL limitations, commented on his lack of patient-handling techniques and his effort to learn from formal caregivers how to carry out patient-handling tasks.

When I didn't know how to do, I asked the caregivers. I asked about how to do.

They were already trained. I didn't receive education. I wasn't trained to take care of patients. Whenever I saw very experienced caregivers, I asked them about caregiving skills. They taught me how to lift patients up in bed. They taught me everything. ... I learned a lot.

After his wife was hospitalized after a sacral fracture, she needed physical help to perform ADL. Moving and lifting his immobile wife became a key caregiving tasks during her hospitalization. As an untrained, inexperienced caregiver, he recognized his lack of knowledge and skill in properly, safely transferring a physically impaired person. The lack of patient-handling skills increased his emotional and physical burden of providing ADL care to his wife while she was in the hospital. Formal caregivers who took care of his wife and other patients in the same room became his supervisor, training him as a skillful caregiver through their knowledge and experience. After short-term, intensive coaching, he changed from being an

unskilled caregiver to a proficient caregiver. In addition, learning effective, useful caregiving skills boosted his self-efficacy as a caregiver.

While providing care to spouses with cognitive deterioration, husband caregivers were likely to confront trouble in understanding and dealing with spouse's unusual behaviors. Husbands' incapability in effectively handle the spouses' challenging behaviors amplified caregiver burden or stress. For husband caregivers, new caregiving knowledge and skills were needed to respond to and cope with changes in their wives' behavior and personality. Kangho Park, aged 79, explained how he acquired technical skills for making a dementia patient calm and comfortable when the dementia patient became aggressive or violent.

The nurse manager knew Alzheimer's patients' characteristics well, understood them, and took care of them well. When I took her to the adult day care center, the nurse manager said 'hi' to her. My wife swore to the nurse manager. Others were surprised. The nurse manager told a staff, "Please, bring sugar water." And, she gave sugar water to my wife. She asked my wife, "Is it good?" My wife replied, "Yes, it's good." I learned how to control patients. 'When the patient swears, I just have to laugh. The patient likes sugar, so give her sugar water.' I learned.

As his wife's Alzheimer's disease worsened, he began to observe her increasingly inappropriate behavior and personality. The lack of knowledge and skills for helping a frantic patient calm down often led him to feel that it was very difficult to control her aggressive behaviors, such as cursing and yelling. He felt that managing her disruptive behaviors was beyond his control. The nurse manager, who had worked for a long time in the adult day care center with people with Alzheimer's disease and other forms of dementia, became like a caregiving manual for inexperienced caregivers. The nurse manager's competence in soothing

the patients and managing their problem behaviors were important, necessary caregiving skills that he had to learn. Observation of the manager's skills or techniques helped improve his understanding of his wife's challenging behavior and personality and in developing his own strategy for dealing with the problematic behaviors. He began to feel less burdened to take care for his wife.

Older husbands, who had to take responsibility for carrying out both day-to-day housework and caregiving tasks after the transition to spousal caregiving, learned tips to effectively deal with conflicting housework and caregiving duties when confronting with the increasing demands of caregiving as spouses' physical and/or mental impairments progressed. As 73-year-old Changsu Yu said,

After she was sick, I had to do everything. I had to cook side dishes..., and had to cook rice. Long-term care worker advised me to cook during the day because I had to bathe her and to move her into the room in the evening. She said I was too busy caring for her at night and recommended to do housework during the day. So, I cook side dishes and rice by day.

After his wife's functional status severely deteriorated, his temporal and physical demands for caring increased. In particular, her functional impairment lengthened the time required to bathe her and to prepare her for sleeping every evening. The demands of ADL care were conflicting every evening with the demands of household tasks, particularly cooking dinner and preparing the next day's meals. Thus, the dual responsibilities for housework and personal care at night gradually became a challenge beyond his ability. He did not initially recognize the need for re-arranging the conflicting tasks and increasingly felt exhausted from the tasks he needed to accomplish at night. Because a long-term care worker provided in-home care service



for several months, she knew his caregiving situation and coached him on the management of the incompatible demands of ADL care and housework. He re-allocated time spent on household and caregiving responsibilities. The worker's coaching was useful for improving his management ability and lowering his burden of dealing with these dual responsibilities. Moreover, it enhanced the quality of both his daily life and his caregiving through lessening his fatigue in the evening.

### **Using formal care.**

Caring for the spouses with chronic illness or long-term impairment was threatening older husbands' physical and/or mental health. Similar to research done by Coe and Neufeld (1999) and Parsons (1997), older husbands sought formal assistance to lighten caregiver burnout and to regain strength in their caregiver ability for providing long-term care. The use of formal care services buffered the negative effect on husbands' health and well-being and provided them with an emotional outlet. Hiring a paid caregiver or using care-related facilities was a primary source of formal assistance and for providing relief from caregiving to husband caregivers.

Seventy-five-year-old Hyungwoo Yu, who became exhausted because of intensive demands of caregiving, stated his intention to hire a paid caregiver who would then take care of his hospitalized wife instead of him.

I was so exhausted, so I hired a paid caregiver. For 45 days, the caregiver took care of her. In August 2007. I went back and forth from home to hospital..., every day. I slept at home. Getting up in the morning, first..., I called [to the caregiver] and asked about her condition. Every day, I went to hospital. The caregiver was there..., through the night. I went to hospital in the morning and came home in the afternoon.

After his wife broke both her arms, she needed 24-hour assistance with ADLs while in a hospital. Suddenly increased demands of caregiving made him, who had sole responsibility for caregiving, feel severely fatigued and both physically and emotionally exhausted.

The arduous caregiving duties were nearly beyond his capabilities. Finally, the need for formal assistance led him to hire a paid caregiver. The hired caregiver took sole responsibility for intensive care. The use of a paid caregiver during her hospitalization helped relieve the caregiver burden threatening his health and well-being. In addition, he became assured and satisfied that formal care provided by the hired caregiver was beneficial to wife's recovery and well-being. Also, 72-year-old Seongmin Kim, whose wife was hospitalized for two years after a femoral fracture, hired a paid caregiver because of his difficulties in balancing between his work and caregiving responsibilities.

After the surgery, she became hospitalized. The hardest thing was.... Because I was employed..., one day, I could take care of her and, the next day, I had to be in the office all day. I couldn't handle those. So, I hired a carer.... For about two years.

During hospitalization, his wife became severely physically limited and had to receive 24-hour care. However, because he had to work every other day, he could not meet her needs for full-time care on a workday. Handling the incompatible responsibilities for working and caregiving became a large challenge to him as a caregiver as well as an employee. Such difficulty of juggling work and caregiving demands made him seek the assistance of a formal caregiver during her long-term hospital care. A hired caregiver took care of his wife for two years. As a supportive caregiver, he often helped the paid caregiver by providing heavy physical or personal care even on a workday, whenever the caregiver requested his assistance, as well as

on a day off work. In long-term hospital care, his reliance on the paid caregiver's assistance contributed to relieve his emotional and physical strain that was caused by the conflicting association between work and caregiving duties.

The progressive deterioration in spouses' cognitive and/or functional state led older husbands to face difficulties of managing the ongoing, increasing demands of spousal care. Sometimes, husband caregivers reached the limit of their capability and tolerance in the caregiving environment. Husbands, who felt they could not continue the caregiver role, began to consider alternative caregiving arrangements for providing secure, better care to their spouses while simultaneously reducing the caregiver burden they were experiencing. Institutionalization of spouses into health care-related facilities was considered as their final choice; consequently, ending the journey of spousal caregiving. Seventy-three year-old Changsu Yu, who cared for his wife with severe cognitive impairment caused by head injury and dementia, explained the reason for placing her in nursing home.

My wife swore to me. She just shouted abuse toward me. For haircut, I took her to a salon. She frantically just threw everything she could get her hands on. While I held on her sitting with her back toward the mirror, a hairstylist cut her hair. The hairstylist was so shocked. I couldn't control her. It was really tough to manage her. I was so exhausted. So, I sent her to a nursing home.

As her cognitive deterioration progressed, she frequently exhibited abrupt mood changes and dysfunctional behaviors. He increasingly felt burdened in managing her aggressive or violent behaviors that were threatening the personal safety of her or others, particularly in public places. Going out with her was perceived as an especially stressful experience for him. Gradually, he felt it was coming to the point where he reached his limit in the caregiving situation. Finally, he

made the decision to institutionalize her in a nursing home so that for both her and his qualities of life were improved. However, she maladjusted to the nursing home, refusing to eat or drink, so he had to bring her to home.

Some older husbands' desires to improve their spouses' functional and emotional states led them to consider the use of non-residential facilities, like an adult day care center. Husbands believed that the use of care-related facilities was beneficial to their spouses in that the participation in various activities was helpful for enhancing spouses' mood and reducing their disruptive behaviors. As 79-year-old Kangho Park, who had taken care of his wife with Alzheimer's disease, said,

I thought that conversation with several people would be good for her. She was a patient, but it seemed it was not good to stay home. So, in the morning, I used to drive her [to the adult day center]. At 4 pm, I used to pick her up. From 10 am to 4 pm.

Taking care of his wife with Alzheimer's disease, he always tried to arrange a better caregiving setting for her physical and mental health. He expected mingling with those with the same disease in an adult day center, rather than staying home all day, would be helpful for increasing her physical and intellectual activities. In addition, it would provide a positive impetus to maintain or improve her cognitive and functional performance. He was satisfied that she had received the benefits of adult day care services and thought that the service was helpful in delaying the progression of her Alzheimer's disease. Moreover, while she was cared for in the adult day care center, he was physically and emotionally relieved from the primary caregiver role. The service changed the quality of life for both his wife and him.

### **Receiving social welfare benefits.**

After the onset of spouses' health problems, older husbands and their spouses underwent changes in their social, economic, and/or health status within Korean society. These couples often shifted into a socioeconomically disadvantaged group who needed social protection and support with spousal caregiving. These couples became beneficiaries of social welfare programs that could meet their basic life needs in the caregiving environment. The social welfare services, which older husbands and their spouses received after entry into caregiving in Korean society, were usually Disability benefits, the National Basic Livelihood Security (NBLs) program, and the Elderly Long-Term Care Insurance. For example, after the physically or intellectually disabled spouses qualified for social welfare benefits for the disabled, they began to receive a variety of disability benefits, such as disability allowance, free or subsidized medical care, and support service for equipment and assistive devices for the disabled (Ministry of Health & Welfare, 2012b). Seventy-five year-old Kisang Kwon remarked on his satisfaction with the call taxi service for persons with disability, as one of the disability benefits, they attained in 2002.

We can receive the call taxi service for the disabled. I'm really thankful. Calling for the taxi, it arrives in one and a half or an hour. We say we need to go to hospital or anywhere, the taxi brings us. If we take a taxi, it's about 4,000 won. But, if we take the call taxi, it's 1,800 won. It's really cheap. Her wheelchair is lifted into and out the taxi. It's so comfortable.

When he went to hospital or anywhere using public transportation that was not equipped for disabled people, transporting his wife in her wheelchair was a stressful challenge for both of them. It took too long to arrive at their destination by public transit. Once she reached the level of disability to qualify for the call taxi, he was very satisfied with the call taxi service for the

disabled. The taxi for the disabled was inexpensive and was designed for wheelchair users allowing them to easily get on and off it. This service reduced their physical and emotional burden of going outside and increased the extent of their geographic mobility. Seventy-one year-old Woojin Kim also referred to free medical care as disability benefits.

A visiting nurse comes once a week. When her condition gets worse, she visits twice a week. Nowadays, her condition has deteriorated, so I asked her to visit three times a week. Now, public health center covers the cost of this service because she received first-degree disability status.

After his wife became bedridden, she received visiting nurse services for four years for bedsore care and medical checkups (e.g., blood pressure and blood sugar testing). He stated that, after the policy of the visiting nurse service was recently changed, she began to receive free service because of her level of disability status. Once she reached the most disabled status, he could request additional services for treating her progressive bedsores without incurring a financial burden. This visiting nurse service contributed to lessen his financial and practical demands of managing her bedsores. He was satisfied with the changed policy for home delivery of medical services in caring for his wife.

Mostly, after older husbands took a primary responsibility for spousal caregiving, their restricted life prevented them from seeking re-employment. Over time, some older husbands, who had relied on their personal financial resources for caregiving without any financial support from adult children or others, began to experience financial hardships because of depleting personal financial resources. For them, the National Basic Livelihood Security (NBLs) program, which supports the livelihood of low-income families whose income is less than minimum cost of life (Ministry of Health & Welfare, 2012a), became a crucial source of financial assistance.

After becoming a receipt of the NBLS program, they usually received compensation for livelihood and self-sufficiency expenses, medical care, and funeral benefits. Changsu Yu, age 73, said,

The doctor assessed her as first-degree intellectual disability. After the diagnosis of intellectual disability and disability registration, I couldn't go outside because of her. There was no way to make money. My children were unable to support us. My son left his home. We lost him. So, I went to the Social Welfare Division. We became a beneficiary of the Basic Livelihood Security program.

After he quit his job to take care of his wife with brain injury following a concussion in 1996, his financial burden increased over time. However, to cover all costs of medical treatment, caregiving, and living, he could not expect financial support from his children because they also were suffering from financial difficulties. Economic hardship became a primary concern in his caregiving environment. Without any financial help from outside, he could not keep his caregiver duties and livelihood. He reached financial difficulties such that caregiving and livelihood could not be maintained. In family economic adversity, the NBLS program was the only way for obtaining a stable financial source. After becoming a receipt of the NBLS program, the NBLS benefits contributed to alleviate his financial strain in long-term care. Even though it was not sufficient for all his financial needs, he did not need to return to the workplace. Along with the relief from severe financial burden, his wife also could receive free or subsidized benefits of medical care or adult day care service. For this couple, NBLS benefit was a vital social resource for public support and protection.

Entitlement to the NBLS program helped older husbands obtain unofficial or extra public assistance provided by community-based institutions, such as a social welfare center, a senior

welfare center, and church. Seventy-three year-old Changsu Yu stated that, because he was a beneficiary of the NBLS program, he became eligible to receive free foods from the food bank and free clothes from the social welfare center.

Did you see the supermarket [the Food Bank in the Social Welfare Center]?

[Interviewer: What can you get there?] Soy sauce, doenjang [Korean soybean paste], cooking oil, ramen, and others. I got free foods. Ah~, I got free ramen, bread, and big size beverage! Sometimes, I got socks, shoes, and clothes. I also received several pants.

To obtain qualification to use the food bank, it was necessary to submit certified copies of residence register and Basic Livelihood Security. Receiving free food and clothes contributed to reduce their spending in that NBLS allowance was a very limited fund that helped maintain this couple's living and caregiving expenses. The food bank service was very helpful for lightening the financial burden and relieving stress in long-term care. He was satisfied with and felt thankful for the food bank service.

After the introduction of new social insurance for long-term care in July 2008, 13 wives became recipients of long-term care services. The social insurance for long-term care became a key public assistance for husband caregivers in that it did not require a strict qualification to receive the benefits. It was a new social welfare program providing two types of care services, in-home care and nursing home care, to all those over age 65 and to younger people with geriatric disease (Kwon, 2009; Ministry of Health & Welfare, 2011). Beneficiaries received long-term care services at relatively low cost because of a government subsidy. Of 13 older husbands, 10 informants began to receive formal assistance with caregiving tasks from a registered long-term care worker for three or four hours a day. Three husbands got relief from



the practical demands of caregiving after placing their spouses in a nursing home. Seventy-one year-old Woojin Kim's narratives demonstrated how his wife became a recipient of the national insurance for long-term care.

Probably, in winter or fall. Someone visited my home and told about this service.

Before that, I didn't know this program. Looking for patients, a long-term worker heard about my wife from a neighbor. So, the worker visited my home. She explained long-term care insurance and asked for applying. After applying to that, the National Health Insurance Corporation assessed her status.

After the evaluation of her eligibility for long-term care insurance, her social status was officially changed to an older woman with functional limitation in need of care and she became a beneficiary of in-home care service from the new insurance program. During the weekdays, two registered workers carried out caregiving and housework tasks for two hours in the morning and afternoon. His caregiving responsibility was shared with the long-term care workers for four hours a day. After receiving in-home care service, he could get short-term relief from the primary caregiver role and it allowed him to make important changes in his daily home-based caregiving routine. Sixty-seven year-old Seungchan Yu stated that he could consider his wife's nursing home placement because the cost of her nursing home care was partially covered by the elderly long-term care insurance. These social welfare benefits contributed to alleviate his financial burden of using a residential facility. He said,

A neighbor told me that the long-term care insurance became effective last year.

She recommended me to apply to it at the National Health Insurance Corporation.

So, I applied. A health center staff visited home and assessed her status. And then, she became a beneficiary. So, I could send her to a nursing home.

After his wife attained the second long-term care grade, which was assessed as a person having a significant need for others' help in daily life (Ministry of Health & Welfare, 2011), she became eligible for nursing home care service. His chronic fatigue and burnout associated with her long-term care led him to make up his mind to place her in a nursing home. After her institutionalization, practical demands of spousal care decreased. In addition, he could return to the workplace, an important step because he needed to partially support the cost of her nursing home care. He was satisfied with the changes in his life for relieving caregiver burden and bringing his personal life back.

### **Handling Caregiver Burden and Stress**

Caring for the spouses led husband caregivers to meet the changing, increasing needs for spousal care and to increasingly get absorbed into the caregiver role over time. In long-term care, the expanding, changing demands of spousal caregiving augmented husband caregivers' burden and stress, threatening their physical and mental health. However, to continue the caregiver role, they constantly managed the negative impact on their health and well-being in diverse ways. This section discusses the ways in which husband caregivers dealt with caregiver burden and stress they experienced as they performed care work.

#### **Venting.**

When husband caregivers got emotionally or psychologically distressed by their caregiving tasks or situations, some husbands vented negative emotions, such as outrage and annoyance. Repression of negative feelings was perceived to negatively affect their health. In a stressful situation of caregiving, they were not reluctant to express their complaints or annoyance toward their wives. Moreover, they showed a strong belief that venting was helpful for enduring the stressful and painful situation. For example, 62-year-old Wooseong Kam, who took care of

his wife suffering from lung cancer and dementia, explained the reason for his emotional release in the caregiving situation.

I cook for her, but she doesn't eat anything. So, I just get mad. I'm very short tempered. If I have to suppress my anger, I will die. So, I just get angry with her. I show my temper to her. It helps relieving my stress. If she pees, I yelled at her.

Her suffering and eating difficulties often made him feel frustrated and distressed. Even though he understood her pains and difficulties in the current situation, it was tough for him to intentionally suppress or minimize negative emotions. Instead, he outwardly expressed his resentment or discomfort. He thought that the control of negative emotions became an additional emotional strain in the caregiving situation. Moreover, he was at high risk for physical and emotional problems in that there were no channels for buffering his caregiver burden and stress in the restricted life he led after his transition to caregiving. Instead of hiding or repressing his emotional strain or stress, venting his negative emotions was his own strategy for protecting himself from the stressful, frustrating caregiving situation and continuing the caregiver role. Also, 67-year-old Seungchan Yu stated that he expressed his resentment toward his wife through swearing and yelling at her when he had a conflict with her over the issue of drinking water.

She used to insist on drinking water. We got into a huge argument over water. I got upset and swore to her. I yelled, "Drinking water is harmful to you. Why do you keep asking for water?" She is very stubborn, extremely stubborn. She had never given up things she wanted. Until she could not drink, she kept insisting. So, we had a huge argument.

During dialysis treatment, she had a restriction on the amount of daily water intake. But, because she did not care about the restriction, he had to control her insistence on drinking extra

water. Whenever she was restrained from drinking water, he began to violently argue with her. It became a considerably stressful situation arousing his resentment or irritation toward her. He was unable to control her needs and behaviors and simultaneously, he was unable to self-regulate his anger and stress. When realizing he reached the limits of his patience, he just released a sense of discomfort with the conflict with her in the form of extreme anger. It was a means to survive in the terribly stressful situation and to maintain his caregiving duties and responsibilities.

Sometimes, in the caregiving situation, caregivers' emotional crisis led their spouses to be vulnerable to verbal and/or physical abuse of husband caregivers. In the research on husbands' potentially harmful behavior in spousal caregiving (Beach et al., 2005; Lee & Kolomer, 2005; Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001), severe caregiver stress sometimes turned into an explosively violent situation by husband caregivers' harmful behaviors against their wives. In spousal caregiving, the wives with cognitive and/or functional limitations or with difficulties of communication with their caregivers are at high risk for being abused. When being asked about the caregiver burden or stress, 67-year-old Byeonguk Lee confessed that, when getting distressed to see his wife have troubles eating, he cursed her out, "You would rather die...." He understood her suffering but he could not control his anger or frustration. Sometimes, she was verbally abused by him. However, his violence hurt both his and her feelings and increased his sorrow and guilt for her. And, the interviewer observed evidences of domestic violence in an interviewee's house. Before visiting 71-year-old Seungil Im's home for interviewing, a manager and a long-term care worker of the senior welfare center, that have provided in-home care to his wife and introduced him as an interviewee, briefly explained their familial and caregiving situation. They showed a sense of anxiety about his frequent physical violence toward his wife. The day before interviewing, the

long-term care worker witnessed that her face, particularly around her eyes, was bruised when the worker came to his home for in-home care service. The long-term care worker stated that his wife's eating disorder and continuous diarrhea over the weekend made him get very distressed and upset and punch her on the face before the worker arrived. Visiting his home with the long-term care worker, I greeted his wife and noticed her severely bruised face. However, when he was asked about how to deal with his caregiver stress, he never mentioned his violent and abusive behavior toward her. For some older husbands, venting was an often-used means of maintaining their mental health or self-regulating a stressful state. However, it sometimes made their wives become at risk of becoming a victim of family violence. In particular, because spousal caregiving occurred in the private and unopened home setting, violent and dangerous situation would be not easily exposed to outsiders.

### **Self-control.**

As husband caregivers became increasingly overwhelmed with ongoing challenges of caregiving, they found it was vital to develop inner strengths that enabled them to better accept their situation and to cope with the stress of everyday life in the caregiving environment. Deeper inner strength contributed to reduce their emotional suffering and burden and thus, to improve their attitudes toward themselves, their spouses, and the caregiver role. Similar to research done by Calasanti and King (2007) and Ribeiro and Paúl (2008), they enhanced their own emotional strength and resilience through their effort to find relatively positive aspects of caregiving or to change their views on caregiving. Sixty-eight year-old Kyeongwoo Kim stated he tried to endure stress and frustration from caregiving through comparing himself to persons in a much tougher situation.

Absolutely, it's tough. When I become exhausted or get irritated, I try to think positively. I always try to think about people in worse situations than me. Then, I feel better. And, in hospitals, I saw lots of patients and thought about patients in more painful situations. I thought her injuries weren't too bad.

During the past two years, frequent injuries and illnesses of his wife (e.g., toe fracture, high fever, back pains, femoral fracture, and car accident) led him to become intensively nervous about her potential risks and to become too exhausted by his repeated entries into caregiving. As a strategy for alleviating his emotional suffering and fatigue, comparing with persons in a more difficult and painful situation was helpful for changing his view and mind on the stressful, frustrating situation. That offered an opportunity for objectively viewing his situation. He realized that he was in a much better, hopeful situation in that, despite a series of illness and injuries, his wife has gradually recovered.

Auto-suggestion was another key coping strategy for improving inner power of enduring stress and frustration in long-term care. Husbands constantly reminded themselves of attitudes and thoughts that they needed to be willing to perform caregiving tasks or to internalize their caregiving duties as normal daily routine, not as stressful tasks. Seventy-three year-old Changsu Yu also referred to his way of auto-suggesting to overcome difficulties in performing ADL care tasks, particularly dealing with incontinence.

She had watery stools. At first, I couldn't eat anything. Even now, I sometimes can't eat. But, now, if she has watery stools, I can't smell that. I got used to it. I changed my mind. 'If I think of it as dirty, I can't take care of her. It's just my daily life. So, undressing her, bathing her, and getting her dressed are just my daily routine, my daily life.' I completely changed my mind last year.

Dealing with his wife's watery stools was one of the toughest caregiving tasks for him. However, he figured out that it was needed to accept all caregiving tasks, including relatively dirty tasks, as his unavoidable duty and willingly take on that burden in daily tasks of routine care. After changing his mind on carrying out tough or dirty care tasks, his inner ability was improved as much as possible and he was more able to endure or reduce stress from the provision of ADL care. Similarly, 82-year-old Seongjin Noh, who has taken care of his wife with Alzheimer's disease for over 10 years, commented on his auto-suggestion to maintain the caregiver role and to manage chronic caregiver stress and frustration.

If she is mentally healthy, I can get upset at her. But, she isn't, so it's useless. I keep 'Moo (無)' [Moo (無) - 'nothing' in Korean (Chinese)] in my mind. I have three 'Moo (無).' There are no myself, no wife, and no child. I don't go to get some fresh air. I don't need to get angry.

Management of behavioral and functional symptoms in his wife with Alzheimer's disease often caused his emotional crisis, such as emotional exhaustion or agitation. However, he recognized that his anger or resentment was a meaningless response to her behavior in the caregiving environment. Keeping three 'Moo (無)' in his mind was his strategy for self-framing his position in the caregiving situation and protecting himself from emotional burnout. In the caregiving situation, he thought that he, as husband and father, no longer existed. Instead, there was just a caregiver. In his life, which was wholly occupied with the caregiver duties, he tried to empty his mind of all thoughts unrelated to caregiving to concentrate only on the caregiver role. It helped him patiently endure everything emerging from caregiving.

### **Self-care.**

Devoting his time and energy to the caregiver role, older husbands were unlikely to take care of themselves because they were relatively much healthier than their spouses. As Gallant and Connell (1998) noted, though, over time husband caregivers became aware of diminishing physical strength and deteriorating health, such as fatigue, weight loss, and malnutrition. Some husbands felt it was necessary to maintain or improve their own emotional and physical health for the caregiver role. Proper nutrition, eating well, and exercise were their primary self-care behaviors to promote health and vigor. Seventy-one-year-old Woojin Kim commented on his rapid weight loss that occurred in response to the demands of intensive caregiving following his wife's femoral fracture and diabetes progression. The following narrative addresses his attempt to recover his lost weight. He said, "I lost 7kg. I thought I should change. So, just, just..., I began eating. Intentionally, I ate a lot of food to maintain my weight." Because of the deterioration of her kidney function and recurrence of bedsores, she was often hospitalized. Her frequent hospital treatments led him to become overloaded with repeatedly increasing demands from dual responsibilities for her hospital care and household management. His severe fatigue and poor self-care led to rapid weight loss, threatening his health and interfering with his caregiving ability. After recognizing self-care as a requisite for caregiving capability, he began to pay attention to his own health and to manage his own physical health and strength.

The deterioration of spouses' functional capability contributed to increase their physical dependence on their primary caregivers. Simultaneously, older husbands were forced to perform strength-demanding tasks and activities, such as lifting, moving, and bathing. Husband caregivers faced a challenge of maintaining or improving their physical strength to manage physically heavy demands of caregiving. To cope with increasing physical workloads, some



husbands started exercising regularly, even if only for a little while. Seventy-three-year-old Changsu Yu's narratives indicated regular light workout as his strategy for keeping physical vigor in long-term care.

In the house, in the room..., not to become physically exhausted, I've done light workout. Can you see the weights next to the bed? (Laughing) After she falls asleep, I lift the weights or do push-ups. At night, I work out alone. To take care of her, I don't have to become weak. Always..., I should keep healthy to care for her well. So, I don't smoke and drink. I don't skip meals.

After his wife became physically and intellectually disabled, caring for her (e.g., such as bathing, moving, and lifting her) required greater physical vigor or strength. Becoming physically drained was perceived as an obstacle in fulfilling his primary responsibility for spousal caregiving. He chose indoor exercise (e.g., lifting weights and push-ups) as a strategy for improving physical strength in his restricted life situation. In addition, adding healthy behaviors, including not smoking or drinking alcohol, was another strategy for maintaining his functional health. For him, self-care was a critical component of his ability to provide long-term care.

### **Self-distraction.**

Caring for spouses with moderate or severe cognitive and functional impairments mostly led to restrict the range of husband caregivers' activities to inside the home. Even though husbands did not need to provide care to their wives around the clock, they had to be on standby in the house for immediate responses to spouses' needs or urgent situations. Standing by in the house was an extension of the caregiver duty but was also a caregiver stressor aggravating the feeling of imprisonment. In keeping with research done by Calasanti and King (2007), husband caregivers, who were embedded in a stressful caregiving situation, tried to get busy with

distracting indoor activities even for a little while. Changsu Yu, aged 73, referred to some activities helpful for forgetting emotional pain and caregiver burden for a moment.

Reading the Bible, reading others..., reading a newspaper, I keep reading something. If possible, I try to focus on others. Doing the laundry. ... Knowing she pees or poops, I immediately wash her clothes. They won't smell bad. And, I should do anything. Even at that moment I focus on something, I can forget about caregiving.

In taking care of his wife with severe cognitive and function limitations, it was unthinkable that he could leave her home alone. Within the very restricted space, repeated daily caregiving routines made him become physically and emotionally exhausted. His constant attempt to search for distracting activities, such as reading the Bible or newspapers and doing household chores, reflected his desire to relieve caregiver burden or stress even for a moment. For him, these activities were a useful means of controlling his own emotion and forgetting caregiver stress for a little while.

Since his wife became bedridden after femoral fracture and diabetes progression, 71-year-old Woojin remarked on the changed lifestyle and his own strategy for adjusting to his changed life in home-based caregiving. He said,

If she isn't ill, I wouldn't do this. I would go around the outside. But, I can't now. So, I began doing Photoshop. It's fun. So, usually, I do Photoshop. And, I'm running a blog for my wife. Is my wife a patient, isn't she? ... I made her blog and, instead of her, I've run her blog.

Entry into spousal caregiving was an unexpected, sudden event changing his personal and social lives. It meant that, on the transition to caregiving, he had to give up his former social and

leisure activities and to adjust to the changed situation. After accepting the caregiver role as an inevitable obligation to his wife, he quickly adapted to his new life. His geographic mobility became limited to inside house because he had to stay home for providing personal care (e.g., changing diapers, bathing, feeding, and checking her condition) and bedsores care. He began to learn how to use Photoshop and to blog as a strategy for dealing with his monotonously repetitive daily life and socially restricted life. Photoshop and blogging, which he could do with a computer in the house, became his major activities that enabled him to refresh himself within his restricted life. The activities helped him to forget his caregiver role until the time when he had to provide care and to lower his stress and frustration from the caregiving situation.

#### **Short-term escape from caregiving.**

When older husbands reached the limit of their patience in the face of caregiver stress, they left the caregiving situation for a short time to self-regulate their negative emotional state or to avoid a larger conflict. They looked for some places where they could spend some time alone or without their spouses. Although Calasanti and King (2007) reported long-distance trips as well as short-term outdoor activities as husband caregivers' strategy for dealing with caregiver stress, for most older husbands in this study, sporadic, short-term relief from a stressful caregiving situation, not long-distance travel or long-term relief, contributed toward soothing themselves at some places within the neighborhood or community for a few hours. Sixty-seven year-old Seungchan Yu stated that, when he suddenly got upset or was going to burst out because of his wife's stubbornness, he rode his motorcycle to a park to escape from the stressful setting and to calm himself down.

When she kept on insisting, I usually endured her. But, sometimes, I couldn't stand anymore. When I was gonna burst out..., I had a motorcycle. It's in the

underground parking lot. ... I got angry and couldn't stand in the house. So, I used to ride my motorcycle to the park and to stay there for two hours. In the park, there is a lake. And, there are wild ducks on the lake. After taking a turn around the lake, I used to go back home.

As previously mentioned, in caring for his wife (a kidney dialysis patient), he needed to control the amount of water she took in daily. But, it was not easy for him to restrain her from drinking water excessively. When she insisted on drinking excess water, he often argued with her and, sometimes, he became enraged. He knew that, if he kept staying home with her, he could not avoid the risk of their aggravating conflict and his violent outbursts. Keeping away from this situation for about two hours was his strategy for avoiding the potentially risky situation. It was helpful for self-controlling his emotional state and re-gathering strength and energy to continue the caregiver role. Short-term escape became a useful means of coping with his excessive stress and anger in long-term care. Seventy-six-year-old Taeseob Choi also described that, when he suddenly got distressed and angry at caring for his wife with Alzheimer's disease, he went to a quiet coffee shop. For him, spending some time in the coffee shop was the way of managing his own emotional state, 'I don't have to get upset. Leave the past in the past. Don't think about the past. It's irretrievable.'

Some husbands, who took care of their spouses with slight or moderate ADL and/or IADL limitations, felt relatively less burdened with leaving their spouses home alone for a little while. To lessen their chronic distress and enhance their emotional well-being, husband caregivers often spent a few hours outside for themselves. For example, husband caregivers went to a social welfare center for a free lunch program, to the park for talking with others, or drank around the house. However, because of the geographically restricted mobility of older husbands,

they usually stayed within the neighbor or community. Seventy-five-year-old Hyungwoo Yu commented on his short outings for drinking, “My wife is bedridden most of the time. Her back hurts, so she usually is lying. During the day, while she is bedridden, I sometimes go outside. Going downstairs, I have a drink and come back.” For four years, in caring for his wife with limitations in IADL activities, it was not necessary for him to provide full-time care. However, he, as the primary caregiver, had become nervous because of the sudden, unforeseen reoccurrence of her collapse and injury. In long-term care, self-controlling his emotional exhaustion became a challenge of fulfilling caregiving responsibilities and a component of maintaining his caregiving capability. He needed a healthy outlet for chronic caregiver distress in the restricted life situation. Spending a few hours alone outside helped him regularly relieve chronic caregiver stress and restore energy and vigor. Enjoying light drinking or going to the park in the neighborhood was the reason that he could sustain caregiving activities for a long time.

Contrary to husband caregivers who left the caregiving environment only for a few hours, 62-year-old Wooseong Kam spent every weekend alone in his own space to take a respite from his weekday care work. For him, staying in a rural house over the weekend was a reward for taking sole responsibility for his wife’s care. He said,

Every weekend, I escape from home. I have a place to go. My own house is in a rural area. After telling my children to be with your mom, I go to my rural house.

It’s my vacation. If there is no traffic jam, it will take two hours to get there.

Weeding, I pull out the weeds. I sometimes take a break.

Weekday caregiving was accepted as his inevitable obligation because his children were fully-employed workers. However, he highlighted that weekend caregiving was fully their filial

obligations. Instead, he escaped from the caregiver role on the weekend because he felt that he deserved a rest for his performance of caregiving activities on weekdays. Having his private time and space was helpful for alleviating the stress and burden of weekday caregiving and recharging energy and internal strength for the next week of caregiving. For him, this regular respite from caregiving duties was his own strategy for coping with chronic, intensive caregiver distress and for continuing his caregiving role in his wife's long-term care.

### **Negative coping through smoking and/or alcohol use.**

Some older husbands smoked cigarettes or drank alcohol to control their own emotions caused by feeling stressful or agitated in the caregiving situation. The more stressful they felt, the more cigarettes and/or alcohol they used. The use of cigarettes and/or alcohol as an outlet for caregiver anger or stress was also one of health behavior changes in the caregiver stress process of both wife and husband caregivers in research done by Gallant and Connell (1998). Use of these substances was not uncommon among the participants of this study. For example, 71-year-old Seungil Im described that, when he got upset, drinking alcohol was helpful for easing his emotional pain and for forgetting his caregiver stress or burden.

If I get really angry, in the house..., I drink. .... At the pier near my home, there are lots of sushi restaurants. When ships arrive, I head out for buying fish. I like the broiled fish and maeuntang [hot spicy fish soup in Korean]. Buying fish, I drink. If I drink a bottle of soju [a kind of Korean alcohol], I can sleep well. I just black out.

In particular, when he got furiously angry, getting drunk was his only means of release from his extreme caregiver burden and for forgetting his suffering and tragedy even for a while. Financial hardship and caregiving were a key stressor in his current caregiving situation. He

often got distressed or agitated with his caregiver duties and financial stress. Drinking was an unhealthy coping strategy to temporarily avoid the stressful, frustrating situation in long-term care.

Smoking cigarettes was another unhealthy strategy for buffering caregiver stress and burden. In stressful caregiving situations, some husband caregivers showed heavy reliance on the use of cigarettes for stress relief. Kihyeong Hong (age 67) commented on his increased use of cigarettes as he became emotionally tired or weak.

Emotionally, I'm getting weaker. I try to become strong, but.... I just smoke the innocent cigarette. I wasn't a heavy smoker. Smoking cigarettes doesn't agree with me.... I smoked a pack of cigarettes for about one week or 10 days. But, nowadays, I smoke more. A pack of cigarettes for three days.

As wife's diabetes complications deteriorated to the point that she often complained of having unbearable pains from various health problems, such as diabetic foot syndrome, back pains, teeth problems, and urination problems. Her rapid deterioration made him feel more anxious and distressed. Sometimes, he feared that he might lose his wife. Recently, the number of cigarettes smoked daily increased, from two to six or seven cigarettes a day. Even though he knew it was harmful to his health and he stated that he could not stop or reduce smoking cigarettes. He felt comforted by cigarettes. For him, smoking cigarettes was the only way of soothing his increasing stress and worry. Smoking and/or drinking were an unhealthy behavior pattern for managing the increasing, ongoing exhaustion and fatigue in long-term care. Through relying on alcohol and/or cigarettes, some older husbands gained emotional relief from their caregiver burden or stress. However, heavy reliance on drinking and/or smoking potentially

increased their risk for the deterioration of their own health and internal strength, lowering the quality of spousal care.

**Positive coping through religious faith/spirituality.**

Spirituality or religiousness became a key coping resource for several older husbands in this long-term spousal care study. As Lee (2005) and Stolley and Chohan (2005) noted, a sense of spirituality or religiousness contributed to the positive experiences of husband caregivers. Those with a strong sense of spirituality or religiousness appraised the caregiving situation as manageable and found positive meanings in the caregiving situation. Spirituality or religiousness was critical to alleviating husbands' negative emotional responses and to improving inner power or strength when they faced stressful or painful situations. However, because of their restricted activities, older husbands also showed passive religious behaviors (e.g., such as praying, singing hymns, and reading the Bible) to seek religious consolations in spousal caregiving. These religious activities strengthen their belief that they would be fairly rewarded for the caregiver role after their deaths. Seventy-three-year-old Changsu Yu, who took care of his wife with severe cognitive and functional impairments, stated that singing along with hymns was helpful for coping with the increasing stress of caregiving.

Under the television..., there is a portable cassette player. Every day, putting it here, I sing the hymns with her day and night. I sing the hymns to forget even for a while and to get rid of stress. Like a thoughtless person, I clap and sing along with the playing hymns. Others may be wondering what I am so happy about.

After the entry into spousal caregiving, it was difficult for him to go to church because of his time restrictions. Instead, singing hymns with his wife became a major religious practice. Clapping and singing the hymns contributed to his experience of



lightening emotional exhaustion and forgetting his worry and emotional pains while providing his wife with long-term care. In addition, his emotional suffering felt consoled by the hymn lyrics and his belief about God. Therefore, whenever he had free time or felt extremely drained emotionally and/or physically, he passionately clapped and sang hymns. These religious activities became his coping resource for receiving consolation and for enduring the chronic stress and burnout of caregiving.

Reliance on religious or spiritual beliefs contributed to improve personal control and inner power for managing the caregiving situation. Seongjin Noh, aged 82, commented on the effects of spiritual or religious beliefs on his attitude toward the difficulties of caregiving.

After having stools, she always touched them. I had to wash her hands and her clothes. I got upset. But, what to do? It was no use of scolding her for her behavior. I thought it was what God gave me. James 1 says, “In all tests, endure, be humble, love, and like. Be patient through hardships. Victory comes through hardships. I will record everything.” Believing the words, I hand-washed her clothes and hung them out to dry.

While he changed his diapers and dealt with her stools after her fecal incontinence, it was difficult to restrain her from touching her stools. Her uncontrollable behavior often made him get mad or enraged at her. But, rather than scolding her, he self-regulated the feeling of resentment or anger with his belief about God. Religious words were helpful for managing his negative emotions and finding positive meaning of his caregiving activities. Caregiving difficulties were accepted as a kind of test provided by God. In addition, he strongly believed that God would give him a valuable reward for this adversity at the end of the journey of caregiving or life. His

religious beliefs and activities influenced his attitude and response toward his wife and the caregiving situation. Thus, for him, religiousness or spirituality was an inner power providing guidance on the caregiving trajectory and helping him preserve the caregiver role.

### **Positive coping through social activities.**

Over time, increasing caregiving activities and responsibilities have severely restricted older husbands' social lives. Emotional and physical absorption into spousal caregiving led them to give up many social or sport activities, such as meeting friends, tennis club, hiking club, and volunteering. However, as Calasanti and King (2007) noted, some husbands experienced a sense of emotional relief through regularly and actively engaging in social or recreational activities. Instead, the older husband caregivers in this study kept minimal social activities or reduced the frequency of participation in social meetings to avoid interfering with their care work. After entry into spousal caregiving, for example, 75-year-old Hyungwoo Yu referred to the only social meeting that he kept attending in his restricted life.

Sometimes, I have lunch with church friends. We meet once or twice a week.

Every Sunday, after Mass, we have lunch together. I can't often meet them.

Just..., every Sunday, regularly, I meet them.

After he took responsibility for caring for his wife with physical functional limitations, he had to give up various church activities (e.g., the Legion and the church board of funeral services), which he had participated in for over 10 years. However, he could not give up a lunch meeting with his church friends. Instead, having lunch with them once or twice a week provided him with solace and refreshed his energy for caregiving. Having lunch together for one or two hours gave him a valuable respite from his caregiving responsibilities. He kept this lunch meeting as the only outlet for his chronic caregiver stress or burden. Sixty-two-year-old

Wooseong Kam also mentioned that, after caring for his wife with cognitive and physical impairments, he could no longer go hiking every weekend with friends. His narrative revealed his restricted leisure activity: “I go hiking with friends. [After she was ill] Once a month. My friends go hiking once a week, but I can do once a month.” He greatly reduced the frequency of joining his friends in the hiking club. However, occasional participations in hiking provided an opportunity for stepping away from home-based caregiving for a while and replenishing his depleted physical and emotional energy. Even though he was unable to remain involve in leisure activities as much as before, he was satisfied with infrequent opportunities for relieving caregiver burden and strain. It was his strategy for managing his chronic emotional and physical state in spousal caregiving.

A few husband caregivers intentionally tried to actively participate in outside activities. During the time when they did not need to provide practical care to their spouses, they intentionally got busy with social activities outside the caregiving environment to dramatically reduce their worries over their spouses. They believed that excessive worry or anxiety sometimes made them feel more discouraged or stressful in caregiving situations, further augmenting their caregiver distress. The involvement in non-care-related activities was a strategy for preventing unnecessary anxieties or tensions and improving caregiving capability. For example, 80-year-old Jeonghwan Ahn explained why he focused on volunteering activities during the time when he did not perform caregiving.

I’ve volunteered. When I’m busy, time goes so quickly. The more time I have, the more worried I become. If I sit alone with absent mindness, I get more and more worried. So, I always look for things to do. Volunteering. I’ve found volunteer opportunities.

Because his wife spent most of the day asleep due to severe vertigo, depression, and Alzheimer's disease, he felt relatively less burdened to stay outside the home for a while. Instead of unnecessarily staying home without any need to perform caregiving tasks, he tried to go out for volunteering or social activities. Successfully managing volunteering or social activities provided an opportunity for buffering caregiver distress and for re-affirming his confidence or self-efficacy. As Ducharme et al. (2007) noted, self-efficacy, which also is discussed as an internal resource by Bandura (1982), was critical to husband caregivers' health and internal strength in long-term care. Enhancing a sense of self-efficacy from volunteer accomplishments lightened the effects of several primary stressors in caregiving situations and simultaneously, strengthened his inner vigor or power as a caregiver. Thus, volunteering was a strategy for improving his responses to changing caregiving environment and the quality of spousal care.

#### **Fate.**

'Becoming a spouse caregiver' was viewed as an unexpected but inevitable life event in the later life. Similar to research done by Lee and Kim (2009), without question, these older husbands naturally accepted the caregiver role for their spouses as their fate. On the transition to caregiving, they were not disappointed with their changed roles and statuses. In addition, they perceived these changes as already-happened events against their will and as an unfavorable but unavoidable destiny in the current life. Thus, they could adjust to the suddenly changed duties. Sixty-eight-year-old Kyeongwoo Kim's narratives clearly represented his acceptance of the caregiver role as a fate, "Already..., the fate began. It was inevitable. I just accepted. I couldn't think about other things." After his wife's toe was fractured in spring 2007, his caregiving life started. In 'becoming a spouse caregiver,' his choice did not matter. The caregiver role was what he had to do and he could not withdraw from it. It was an unavoidable or inevitable change in his

life. Yoonseok Lee, aged 77, also described entry into caregiving as his accepted fate. He said, “Of course, I should. I thought it as my fate. I thought I should do. So, I took responsibility for caring. I was not disappointed with it.” He had to take primary responsibility for caring for his wife after her stroke 19 years earlier. He just tried to quickly acclimate himself to his fate of a new, unfamiliar circumstance.

**As person living in unexpected life.**

The transition to caregiving after the onset of the spouse’s illness or injury was an unexpected and sudden life event shaking older husbands’ life completely. Their current lives, as spouse caregivers, were totally different from the future life that they had expected before the entry into caregiving. To the unforeseen changes in the unanticipated setting, they reset their future plans or abandoned their hopes or plans for the future. Sixty-eight-year-old Kyeongwoo Kim’s comments indicated his adaptation to the changed current life through accepting the caregiver role as his fate and finding positive aspects of unexpected or unhappy life.

I think it’s my fate, always. In the words of the old saying, there is ‘one consolation in sadness.’ So, I think about the worst accidents and incidents. And, I often think, ‘Ah, we’re lucky. It’s not too bad for us.’ In the hospital, I saw many seriously ill patients and disabled ones. Mentally, they feel very painful.

Comparing with them, we’re not too bad.

Over the past two years, frequent injuries of his wife have suddenly, fairly changed his daily life. To care for his wife with functional impairment, he had to give up most of his social and work activities and then, to devote most of his energy and time to a new role, the caregiver role. It clearly was a disappointing but unavoidable change in his life. To adjust to these changes, he accepted the changed life as his fate. However, contrary to other patients suffering from

chronic disease or permanent disability, because his wife could recover her health completely, he tried to view positive aspects of caregiving situation and his caregiving performance. That is, he expected that, if another injury or illness would not occur in her wife, his caregiving trajectory would be completed. His expectation of returning to his former life after her complete recovery made him feel hopeful in the current situation and endure the stress and burden of caregiving.

However, unlike a few husbands whose spouses had the potential for recovery from illness or injury, most older husbands underscored that caring for their wives with progressive deterioration or impairment was ongoing, limitless duties or responsibility in the rest of their life. Over time, they felt that their hopes for returning to the former life or the planned future were fading. Mostly, before the transition to caregiving, they had expected the future as a new period of their life separate from the previous period. In the future, they anticipated to accomplish all role responsibilities which they, such as a worker, father, husband, and adult son, have undertaken in the past and present and to relieve socially-assigned role duties and obligations. In addition, in the future, they had dreamed of plans and activities only for themselves and their spouses, such as traveling, farming, and living in a rural area. However, after the entry into spousal caregiving, they could not keep the plans for the future anymore. Their future plans became unrealizable and absurd in the caregiving situation until their spouse's death or institutionalization because they physically, psychologically became trapped by the caregiving environment. Sixty-seven-year-old Seungchan Yu remarked on his adaptation to the changed life after the entry into caregiving.

My dream was gone. All my plans were gone. The only plan is..., living in this house all my life. And, I want not to be sick and to live healthy day by day..., I want to live without worry.

Before her diabetes progressed, he dreamed his later life would be spent in a rural area. After retiring and selling his apartment, he planned to move into the country and to spend the remaining time left to live farming or enjoying nature. However, after a series of his wife's multiple illnesses (e.g., cataract, vision loss, kidney dysfunction, toe gangrene, and bedsores), he lost his future dream, the later life in a rural area. Instead, seeing his wife suffering from multiple illnesses and caring for her, he highly realized the significance of physical and mental health in old age. That is, loss of health would bring about declines in physical activities and functional independence, worsening the quality of life and well-being in the later life. He hoped he would maintain physical and mental health in old age and would keep functional independence until the end of life. His future plan was changed, from 'comfortable and leisurely life in a country' to 'healthy aging.' In the present, he tried to regularly exercise to stay healthy. However, after losing their plans for the future, some husbands fell into despair and lived from day to day without any expectation or hope. Sixty-three-year-old Euihan Kim's comments clearly showed the feeling of desperation and helplessness in the caregiving situation.

At that time, I thought about going down to the country. Before she became ill, I put my house up for sale..., to live in the country after selling it. After putting it up for sale, she became ill. Everything has gone. I thought this was all my fortunes and my luck was over. I got so desperate. And, I've just lived and endured..., day after day. When the morning comes, I think its morning. I just live. I have no joy and pleasure in my life. Nothing in my life.

Just before taking all responsibility for caring for his wife, he prepared for carrying out his plan for old age, spending the rest of his life living in a rural area. However, the occurrence of her stroke made his plan in vain. To take care of his wife with functional impairment, he could

not leave Incheon for the country. After his life was fully occupied by endless caregiving duties and care-caused unhappiness, he had to give up his future plan. He got frustrated and hopeless. And, he threw himself away to despair. Enduring his desperate life was the only thing that he could do in the present and future. After losing the will to live, he viewed his current and future times as the hopeless or desperate life.

**As person living in gendered world.**

The entry into spousal caregiving led older husbands to experience crossing a gender boundary. The caregiver role was recognized as women's work through observing female domination in the caregiving setting. They figured out that they performed gender-sensitive caregiving tasks, which were alien to the cultural notions of masculinity, in the caregiving situation. Similar to research done by Calasanti and Bowen (2006) and Davidson, Arber, and Ginn (2000), on the transition to caregiving, they shifted from the man's sphere to the woman's one. For some older husbands, even though eldercare was considered as daughters-in-law's filial obligation, the absence of daughter-in-law caregivers forced them to involuntarily become a spouse caregiver. Sixty-three-year-old Euihan Kim's narratives showed his experience of involving in the gendered caregiving.

If I have a daughter-in-law, it will be different from now. I can go to work. It might be just my thought, but I can still earn about 2,000,000 won a month. Why? It is because I have skills. If have a daughter-in-law, I can earn enough money to support a family of five. I still have a mind to work. But, when my friend asked me for helping him, I refused the offer.

After his wife had stroke in 2006, he took primary responsibility for his wife with functional impairment. He stated, if he had a daughter-in-law at the onset of her stroke, he would



not become a primary caregiver because his daughter-in-law was socially obligated to take primary responsibility for caregiving. However, the absence of a daughter-in-law in the family led him to take over the caregiver role after leaving the workplace. For him, the involvement in caregiving was considered as experience of traversing the gender boundary in that he had to take on daughter-in-law's obligation after giving up his role as a man. His desire to return the masculine domain was conflicting with his current caregiving responsibility in the caregiving setting. Despite several opportunities for coming back to the workplace, he had to give up the involvement in breadwinning activities and to stay in the feminine field for his obligation to spousal caregiving. In the caregiving environment, he viewed himself as a man who was performing women-oriented tasks, not men-oriented ones.

Despite a gendered sense of caregiving, most older husbands were not reluctant to carry out feminine activities for spousal caregiving. Similar to research done by Calasanti and King (2007), Hirsch and Newman (1995), Lee and Kim (2009), Miller (1996), and Ribeiro et al. (2007), after the transition to caregiving, older husbands experienced the gendered nature of caregiving but developed their own meanings of the caregiver role beyond traditional gender role ideology in caregiving. In this sense, commitment to the caregiver role was unquestionably viewed as an extension of marital obligation in caring for an ill spouse, not as a challenge of adjusting to feminine-typed tasks. For them, gender was not a critical issue which they had to consider in spousal caregiving. Seventy-five-year-old Hyungwoo Yu emphasized the unclear gender boundary in the marital relation and the insignificance of gender in spousal caregiving.

Sometimes, despite women's work, man can do it, too. And, man has to do. There is nothing to divide between woman and man. Especially, in the marital relation.

It doesn't matter whether a patient is man or woman. I feel it doesn't matter. But,

caring for a wife doesn't look good to others. But I don't care how they think. I can care for her, and I have to do. So, I don't need to be afraid of others' eyes.

Before his wife became functionally limited after head injury, by the strict gendered division of labor in the marital relation, he had played primary role in breadwinning function whereas his wife had done in household management. However, after his wife became a care receiver, he took primary responsibility for performing caregiving activities as well as household ones. Although, through observing female domination of caregiving, he knew his caregiving duties were socially recognized as women's work, gender was not accepted as an important matter in committing to the caregiver role. He thought that the gender-based division of labor was available only when this couple was physically and mentally healthy and independent. When a spouse became functionally impaired and needed help with everyday activities, the gender role became unmeaningful in the marital functioning system. That is, caring for the spouse with illness or disability took precedence over the gender-based division of family work. In the caregiving situation, gender did not exist in their relationship. He thought that he, as a husband, performed household tasks instead of his ill wife and cared for her with functional limitation. He was in the female-dominated field but he was not affected by gender issue in carrying out caregiving tasks. In this sense, he was not afraid of socially-gendered view on his caregiving participation. His caregiving activities just were a continuum of marital practices in the caregiving situation and were a strategy for returning the imbalanced marital system into equilibrium through filling in the absence of wifely role. Woojin Kim, aged 71, also remarked on the insignificant effect of gender on his involvement in household activities.

As a man, do I feel hard? No, I don't. If I had known I would care for her like now, I had better have done kitchen work. I saw some men helped their wife and

worked together in the kitchen. But, I had never done. (Laughing) I had never gone near the kitchen.

Before the entry into caregiving, he was also just a typical Korean man who thought household tasks were wife's primary obligation. However, after the entry into caregiving, instead of his wife with functional and cognitive impairments, like Hyungwoo, he began to carry out her housework tasks. In the caregiving setting, he viewed himself as a husband performing housework duties instead of wife, not as a man carrying out feminine tasks. In the domestic domain, caregiving duties were viewed as gender-neutral. The performance of caregiving tasks was accepted as marital practice, not as women's work, and did not affect his gender identity and attitude.

Older husbands did not recognize their gender identities, 'being a man,' in carrying out caregiving tasks, in particular in the domestic or private sphere. However, in the female-dominated setting, they realized their caregiver roles were inconsistent with their own sense of gender identity. Social identification of his gender in the female-dominated context, like a hospital or a park, sometimes made husband caregivers feel distressed or discomfited. Sixty-seven-year-old Seungchan Yu's comments clearly revealed the feeling of discomfort or shame in performing caregiving tasks in front of other female caregivers and care recipients.

[In the patient's room] I got uncomfortable with..., changing her diapers. When I was changing her diapers, women stared at me..., because a man was changing a diaper. When they stared at me, I felt so guilty. That was the hardest thing. Not a woman, a man changes a diaper and wipe..., so it was so hard. At that time, there was no bed screen.

When his wife was hospitalized, he had to stay with her in the patient's room and assisted with personal care for his wife suffering from severe physical limitation. However, the fulfillment of caregiving demands in the patient's room, which was filled with female caregivers and patients, were his great hardship. Within the female-dominated circumstance, all eyes were centered on a male caregiver providing care to a female patient. In particular, providing personal, bodily care, he felt that all patients and their caregivers were looking at all his behavior and that he was perceived as a strange or odd man to them, not as her husband. He experienced people looked strangely at him or did not understand his caregiving participation in that his care work was against social norm or expectation about gender role. He recognized his gender identity, 'being a man' within the feminine domain. Caregiving performance in the public setting made him feel guilty or shameful because he socially deviated from normal rule or image of masculine work.

### **Social Identity as Caregiver**

Older husbands' awareness of themselves as a caregiver occurred both inside and outside the caregiving situation (O'Connor, 1999, 2007; Ribeiro et al., 2007). Husbands identified with social recognition, such as the response or feedback from others outside the caregiving, as well as self-references. Ribeiro et al. (2007) stressed that social visibility of older husbands as "caregiver" was related to "being against the mainstream" in the public arena of caregiving.

### **Uncommon or unusual man.**

Older husbands, who were taking care of their wives, were socially portrayed as an unfamiliar old man or husband because of the socially scarce observation of male caregivers, particularly husband caregivers, in Korean society. Their caregiving performances were recognized as incredible or unusual because daughter-in-law or wife was socially expected to

take on the caregiver role in Korean society. Some people showed their indiscriminate praises and respects for the rare husband caregivers, whereas others did not understand their participation in spousal caregiving. Seventy-nine-year-old Kangho Park's narratives obviously displayed social attitudes toward him as being deserved to be praised or respected.

I hear, "There is no one like you in the world." I don't know if it is good or not.

People say it to me. ... I know, because other husbands are only at work, they say to their children, "While I'm working, how can I take care of your mother? Take care of your mom." Other men just support [with] money. They will think they fulfill all their responsibility. And, married daughters ask their sister-in-law for taking care of their mom well. However, they don't know much about her caring. So, they bring their mom their home. But, three days later, they bring mom back to the sister-in-law's home. They, who had such an experience, say to me, "Wow, you're better than average. Your caring is great. You're great."

Members of Alzheimer's family caregiver support group often admired him for what he has done as a caregiver, moreover a male caregiver, because they knew how difficult or stressful it was to care for a person with Alzheimer's disease. Taking sole responsibility for care instead of his daughters-in-law, he was accepted as atypical man, compared with other older men in the Korean caregiving culture. In addition, he was viewed as an uncommon but great man or husband in Korean society. He socially became respected or acclaimed in the gendered world of caregiving. However, in a difference sense, he was unwelcomed to older husbands because of his different life pathway from typical Korean older men's. For example, 79-year-old Kangho Park said,

Some say, “It’s your destiny. If I were you, I couldn’t do that.” Some ask me, “Is there no one taking care of her?” But, I can’t agree with them because a husband should take care of his wife.

Within the Korean caregiving context, like Kangho Park, he was also just an odd man who unnecessarily participated in spousal caregiving, instead of his three children. His voluntary choice of the new life as spousal caregiver reflected the unconventionality of his role as a man performing daughter-in-law’s role. However, despite their unwelcome or odd views on his caregiving activities, he unquestionably accepted his caregiving responsibilities as a part of marital duties and did not care about their attitudes.

**Poor or unfortunate old man.**

Sometimes, older husbands were socially considered as a poor or unfortunate old man who suffered from unforeseen misfortune or affliction, such as their spouses’ illness and their caregiving involvement, in the later life. They often faced sympathetic attitudes and behavior of people toward them. For example, 63-year-old Euihan Kim referred to social pity or sympathy for him after taking care of his wife after stroke.

Going to my hometown, many said I had a hard time taking care of my wife. My aunt is still alive. Perhaps, she is..., about 70. She often says to me, “Why?” She feels pity for me because I have suffered in my later years. And, she says that, in old days, I might die at my age.

Whenever he visited his hometown, his countrymen, particularly his aunt, felt sorry or sympathy for him who took care of his wife with functional impairment. Because, for men, the transition to caregiving was not socially a normal, expected life event in later life (Ribeiro et al., 2007), his caregiving performance was viewed just as abnormal duties and simultaneously,

sudden adversity in the later life. Through external feedback or response to his caregiver role, he identified social recognition of him as a poor or pitiful old man who should carry out misfortune or unanticipated duties in Korean society. Kangho Park, age 79, also commented on his experience of receiving sympathy from others and his responses to social views.

Many people feel pity and sympathy for me. They always have sympathy for me because of my wife. I see that look in their eyes. They tell to me. Well, if I often receive their consolation, I might get distressed. But, sometimes, I felt thankful for them because they gave the credit for me.

It was a pity that his wife had Alzheimer's disease and he should care for her in the later life in that Alzheimer's disease care was considerably burdensome and stressful for a caregiver. Always, he felt pitied and solaced by people. Their words of consolation and sympathy reflected his social position or visibility; he was a poor man or husband suffering from his wife's illness and caregiving. Frequent sympathetic views made him feel distressed or discomforted, but he sometimes became comforted and supported.

### **Faithful or good husband.**

Husband caregivers also were socially depicted as faithful or good husbands who took care of their ill spouses. Their caregiving performance was social interpreted as marital affection or fidelity toward the spouse. In addition, often, they were socially praised for their long-term commitment and devotion to spousal caregiving. Seventy-five-year-old Kisang Kwon's accounts evidently identified his social reputation as a faithful or loyal husband who became willingly responsible for a wife in need of help and care.

Neighbors say I'm really loyal. (Laughing) Sometimes, I get upset. It's natural to take around an ill person. Walking and holding with her is fidelity? Sometimes, I become upset but sometimes, I just say we are loyal to each other.

After his wife became physically impaired after a stroke, caring for an ill family member was accepted as his natural duty and responsibility. However, contrary to his caregiving motivation, he was often considered as loyal or faithful to his wife. Or, seeing this couple going around together, people acclaimed for their marital closeness and intimacy. However, he emphasized that his social honor just resulted from a social overvaluation of his behavior of providing assistance with ADLs. Sometimes, this social view made him feel uncomfortable or burdened. Seventy-five-year-old Hyungwoo Yu also referred to social misunderstanding of the relationship with his wife in the caregiving situation.

Many say I love my wife. And, they say, even though she is ill, she is blessed.

(Laughing) Even though she is suffering for her illness, she is blessed because she meets a nice man. They have pity for me. Sometimes, I get upset but it's my duty.

After the occurrence of her stroke in 2006, he has provided care to his wife with functional impairment. He just recognized caregiving performance as an extension of marital duty rather than marital affection. However, people thought he has cared for his wife because he loved her. In addition, even though his wife suffered with limitations in everyday activities, she became the object of social envy in that she was fully loved. He stressed that the socially-constructed image of this couple was far from the truth because his caregiving activities was to meet her needs of help with ADLs. His social reputation as a good husband sometimes made him feel uneasy.



## CHAPTER 6

### CONCLUSION

The present study adds to the body of existing research identifying the complex world of male caregivers in eldercare by offering in-depth accounts of older husbands' experience of fulfilling the caregiving role. While some findings of this study are consistent with previous studies, other findings reveal that there are many gaps in our theoretical, empirical knowledge surrounding the lived experience of "being an older husband caregiver." The coexistence of different phenomena regarding older husband caregivers is attributed to gender role stereotyping. In the previous and current discussions of caregiving, gender is an important issue that has to be considered to understand the social, cultural scripts of caregiving activities (Miller, 1996). In social and cultural scripts, caregiving is highlighted as a gender-linked experience. Men's caregiving is often understood through comparisons to female gender roles. Male caregivers are underrepresented in studies of caregiver's behaviors and outcomes, compared with female caregivers (e.g., Alexander & Wilz, 2010; Allen et al., 1999; Bookwala & Schulz, 1998, 2000; Chappell & Kuehne, 1998). Male caregivers often are portrayed as invisible, less vulnerable caregivers.

However, as Gerstel and Gallagher (2001), Lee (2005), Miller (1996), Ribeiro and Pául (2008), and Russell (2007a) noted, the experience of older husband caregivers caring for their spouses cannot be explained by gender-role or Confucian patriarchal ideologies. In the lived experience of older husband caregivers, they view spousal caregiving as a normative experience in that the caregiver role is an extension of marital roles and a continuum of marital relationships.

In caring for their wives, older husbands, as primary caregivers, carry out a variety of caregiving tasks, including household, hands-on personal caregiving and emotional tasks as well as instrumental and financial tasks. Contrary to the theoretical, empirical knowledge of caregiving, gender or patriarchal scripts do not exist in the motivation and activities of older husband caregivers in Korean society.

Because this is a phenomenological study, the integrative theoretical framework emerged and is shaped to develop a broad, contextual, dynamic view of an ongoing trajectory of being a husband caregiver in old age within multidimensional contexts through a synthesis of the following theories and perspectives: social constructionist perspectives, political economy of aging, and the life course perspective (See Figure 1). This diagram, entitled “the trajectory of spousal caregiving in older men’s life,” shows the caregiving pathway for older husbands after the transition to spousal caregiving. It displays the dynamic, ongoing process of constructing the trajectory within the socio-cultural and economic political contexts of caregiving. The square represents the pre-existing circumstances of caregiving: the sociocultural context and the social political context. After the transition to caregiving, older husbands experienced the influence of the pre-existing caregiving milieus (e.g., social stereotype, family norms, Confucian values, gender norms, social welfare policy, and social & health services) on their caregiving activities and their caregiving circumstance. For example, social stereotype of and attitude toward their caregiving performances affected older husbands’ reconstructions of meaning and self-concept in providing spousal care. In the political economic context, the acquisition of new statuses, family caregiver and care recipient, includes changes in social positions; becoming eligible for several social services and programs regarding caregiving and health care. In the diagram, as wife’s health status changes, the ongoing process of changing husband’s caregiving role and spousal

care setting with the multiple, intertwined contexts (e.g., familial, work, interpersonal, social, community contexts) is depicted within the sociocultural and economic political cultures of caregiving. Changing cylinders, that are continuously shrinking or expanding, represented outcomes of older husbands' adaptation to changes and management of their role duties and relationships in diverse contexts as well as the caregiving situation, under consideration of choices and constraints.

Three theories emerged from the understanding of older husbands' experiences of "being a spouse caregiver" in a diversity of contexts. First, both social constructionism and political economy of aging highlight the influence of pre-existing, dominant cultures of caregiving on older husbands' experience of spousal caregiving. These two theoretical foundations reveal the creation of husband caregivers own meanings of and attitudes toward caregiving. The life course perspective makes visible how, after the transition to spousal caregiving, older husbands continuously adjusted to changes in their roles and relationships within micro- and macro social contexts and, at the same time, rearranged role duties and interpersonal bonds inside and outside caregiving circumstance to enhance their strength or ability for caregiving performance. The following paragraphs provide a more thorough discussion of the theories that emerged and were combined to gain a deeper understanding of older husbands' experiences.

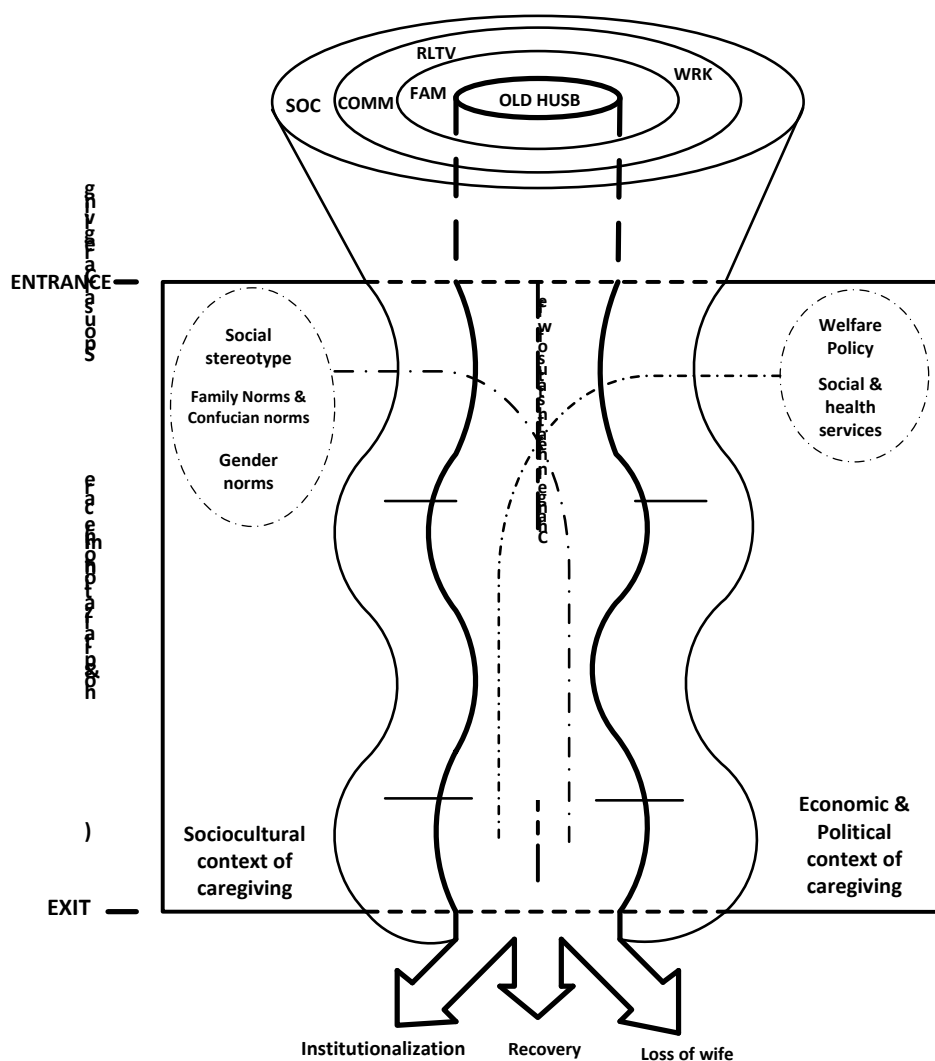


Figure 1. The Trajectory of Spousal Caregiving in Older Men's Life

### Social Constructionist Perspectives

Social constructionism is one of the most frequently employed perspectives in social sciences focusing on human agency and social behavior in everyday life (Bengtson, Burgess, & Parrott, 1997). Being strongly rooted in a belief that all reality is not a naturally given thing but a socially constructed one (Crotty, 1998; Daly, 2007), social constructionist perspective underlines the dialectic interaction between human beings and society in constructing meaning and knowledge (Berger & Luckmann, 1966; Crotty, 1998). According to social constructionism, all

ways in which we commonly understand the world are not derived from the nature of the world (Berger & Luckmann, 1966; Burr, 2003). Instead, it is argued that our knowledge of the world is the product of interactions or communications between people taking place within the shared systems of intelligibility in society (Berger & Luckmann, 1966; Burr, 2003; Schwandt, 1994). The knowledge is also continually transmitted from a generation to another (Berger & Luckmann, 1966). Culture is seen as a set of shared symbols, meanings, and perspectives, which are constructed, sustained, and reproduced through social practices of people, and as a source of directing their identities and behaviors and organizing their experiences in a meaningful fashion (Berger & Luckmann, 1966; Crotty, 1998; Gubrium & Holstein, 1999). Social constructionist theories provide insight into the understanding of the way that ordinary people participate in their everyday lives and simultaneously, that they construct and maintain social meanings of their lived experience for themselves and others in society (Bengtson et al., 1997).

Applying the social constructionist perspective to caregiving has illuminated social representations of caregiving in a monolithic term of female gender, regardless of cultural context. In the research on male caregivers as well as female caregivers in eldercare, the gendered nature and patterns of caregiving are considered as an extension of the social, cultural definitions of gender-appropriate behavior to eldercare and experience of providing eldercare is invariably discussed through a feminine lens (Brody, 1981; Calasanti & King, 2007; Davidson et al., 2000; Russell, 2007a). The dominant culture of caregiving does not allow alternative explanations or meanings of caregiving and male caregivers, who are marginalized or isolated in the discussion of eldercare, are resisting collective notions of caregiving and are developing their own subculture of caregiving. Social constructionist perspectives highlight the existence of subcultures which are socially constructed by various criteria, such as gender, class, age, race,

and so on, and the emergence of a particular perspective and meaning related to each subculture's social interests (Berger & Luckmann, 1966). Thus, in this study, social constructionist approach to caregiving offers the researcher one tool for understanding how the meaning and experience of caregiving is shaped by cultural and social systems and simultaneously, for describing how older husband caregivers live within the caregiver role using socially shared notions of caregiving and develop new meanings of and attitudes toward caregiving. It provides a new, positive way to understand older husbands' participation in spousal caregiving and to conceptualize and actualize the experience of men's caregiving. In this study, older husbands perceived "caring for an older adult" as the primary obligation of daughters-in-law or women's work in Korean society but stressed their own motivations for transitioning into eldercare, such as the extension of marital duties or parental role, against socially, culturally shared belief and expectation. In addition, older husband caregivers constructed their own meanings of spousal care, such as husbands, parents, and persons living in the gendered world, the unexpected life, or the fated life. Social constructionism provides a way to understand the shared meanings of caregiving; however, it does not provide a suitable lens for understanding the influence of external pressures that influence internal processes. Therefore, it was also necessary to include concepts from the Political Economy Perspective of Aging.

### **Political Economy Perspective of Aging**

Political economy perspective is more specific to aging research and is one of the most utilized theoretical frameworks in social gerontology (Bengtson et al., 1997; Minkler & Estes, 1984; Quadagno & Reid, 1999). Political economy perspective emphasizes the understanding of life experience within socio-economic and political structures, which differentially allocate social resources and privileges by age, gender, class, or race/ethnicity (Bengtson et al., 1997;

Estes, Swan, & Gerard, 1982; Quadagno & Reid, 1999). This perspective, which originated from the theories of Karl Marx and Max Weber, posits that an individual's socio-economic and political status, as a critical determinant of social distribution of resources, benefits, and power, affects one's life chances, opportunities, and resources throughout the life span (Minkler, 1984; Walker, 1981).

In gerontological research, applying political economy perspective starts from the social definition of 'aging' as a problematic status in medical and resource terms (Estes, 1979; Estes & Binney, 1989; Phillipson, 1998; Walker, 1981). The inevitable process of sickness and/or retirement in old age leads the elderly to be apart from the productive process and from society and to then be classified into a group which is frail, powerless, unproductive, and/or dependent in social and economic spheres (Estes, Swan, & Gerard, 1984; Walker, 1981). Elderhood or aging is expressed as being in disadvantaged or marginalized positions with smaller resources and power in the social structure (Estes et al., 1982; Hockey & James, 1993; Irwin, 1999). Social and economic status of older people determines how they are treated and how resources and power are reallocated to protect them against potential risks and disadvantages in the unequal social, economic, and political system (Minkler, 1984; Quadagno & Reid, 1999). Social policies for the elderly are a reflection of a society's values and attitudes toward the older population and a social mechanism for the redistribution of resources and benefits to enhance their status (Ashcroft, 2010; Quadagno & Reid, 1999). From a political economy perspective of aging, the experience of aging and old age is shaped by attitudes and policies which are constructed within the socio-economic and political realm (Bengtson et al., 1997; Irwin, 1999; Walker, 1981).

With the increased longevity for older adults with disability and/or chronic illness as well as the expansion of the older population, social attitudes and responses to elders' needs are

related to attitudes toward health care, long-term care, and social assistance in eldercare (Svallfors, 2008). The interplay between economic and political forces influences social attitudes toward inequality in the distribution of resources and services in eldercare and the extent of public responsibility for caregiving (Ashcroft, 2010). It is important to establish a social orientation to welfare provision and to develop care-related policies and services affecting individual's experiences of chronic disability and/or illness or long-term care. Political economy perspective may be expected to offer a lens for identifying and acknowledging systemic and structural forces that shape an eldercare environment in Korean society and acknowledging older husbands' position as a primary caregiver in the social, economic, and political context of eldercare. However, to more fully understand the agency exhibited by older husband caregivers, it also was important to consider the dynamic context of the life course.

### **Life Course Perspective**

A life course perspective provides a useful lens viewing caregiving as the dynamic of multiple, interdependent pathways within temporal and social-structural contexts (Evans, Crogan, Belyea, & Coon, 2009; Moen, Robison, & Dempster-McClain, 1995). It also addresses the process of stability and change in caregiving experience over time through individual adaptations and choices (Evans et al., 2009). The life course perspective highlights the importance of time, context, process, and meaning on individual development and lives and proposes major concepts and themes designed to elucidate multiple, dynamic features of the life course at micro- and macrosocial levels, including trajectory, transitions, turning points, cohorts, interplay of human lives and historical time, timing of lives, linked lives, and human agency (Bengtson & Allen, 1993; Elder, 1985, 1994; Elder & Johnson, 2003).



Some researchers stressed that caregiver role acquisition leads to significant changes in responsibilities of existing roles, such as social, work, and family roles, and asserted that becoming a family caregiver is a life course transition (Choi & Marks, 2006; Evans et al., 2009; Kramer & Lambert, 1999; Marks et al., 2002; Moen & Robinson, 1994; Moen et al., 1995). Transition to caregiving represents a new phase of life; that is, the caregiving trajectory, begins and also includes a variety of changes in multiple, interlocking trajectories of which individual lives are comprised, such as family life, work, education, and other trajectories (Evans et al., 2009; Kramer & Lambert, 1999; Marks et al., 2002). Accepting primary responsibility for caregiving becomes a turning point in personal life in that it contributes to unusual, unexpected role changes at any stage of the life course and key life changes or discontinuities modifying one's own life (Evans et al., 2009).

Caregiving status includes physical and emotional burdens and increased stress, which are constantly faced in the ongoing caregiving trajectory (Kramer & Lambert, 1999; Marks et al., 2002), even though it became an opportunity for personal growth (Kaye & Applegate, 1990; Ribeiro & Pául, 2008). Caregiver's burden and resilience are influenced by advantages or disadvantages of personal resources or socioeconomic status and by sociocultural definitions and norms on gender role (Evans et al., 2009; Moen et al., 1995). The life course perspective emphasizes that the life course is a partial product of human choices and actions within sociostructural and historical opportunities and constraints (Elder, 1994). Caregivers, particularly older husbands, develop their own adaptive strategies as responses to changing demands and burdens in multiple circumstances including caregiving and to the discordance of their caregiving commitments with sociocultural expectations on caregiving and gender role (Evans et al., 2009; Kramer & Lambert, 1999; Marks et al., 2002). In the caregiving trajectory, caregivers

employ human agency for rearranging personal power and coping with difficulties and are not passive victims. The reorganized networks of relationships and social worlds after the transition to caregiving may be important resources as social support strengthening caregivers' performances despite restrictions in their social activities and lives (Kramer & Lambert, 1999; Moen et al., 1995).

The life course perspective encourages researchers to view caregiving as the dynamic, complex, ongoing process of adapting to simultaneous changes in multiple domains and refashioning the course of life and caregiving, not as a static life event. It provides a way to explain older husbands' experiences of caregiving beyond a simplistic, deterministic perspective. This combination of theoretical perspectives provides the foundation for understanding the phenomenological narratives of the older husbands represented in this dissertation.

The experience of "being an older husband caregiver" presents a dynamic, ongoing process of adjusting to and managing a diversity of changes emerging from multiple contexts in which husband caregivers are embedded. This process is diagramed in the theoretical model previously displayed. Spousal caregiving is not static but is constantly changing. Moreover, caregiving is not a monolithic context. It is an integrated unit that is composed of interrelated, intertwined contexts, such as the caregiving setting and familial, work, community, social, cultural, economic, and political contexts. At the beginning of the caregiving trajectory, the transition to caregiving that older husbands experience as they acquire "caregiver status" may be sudden or gradual. However, it is often not readily apparent to the husbands and often depends on the onset or progression of spouses' illnesses or disabilities. Even though the caregiver role is an unexpected change, many husbands accepted it as an inevitable change in later life. This transition brings about changes in role responsibilities or duties as a husband- caregiver. Changes

in husbands' lives continued even after the entry into spousal caregiving. Older husbands undergo changes in caregiving, marital duties, and marital relationships. They also experience changes in social networks, including adult children, friends, religious people, neighbors, relatives, co-workers, community people, informal care, formal care, social/public assistance, and medical professionals. These changes in various contexts affect older husbands' abilities, behaviors, and attitudes in fulfilling the caregiver role. However, they not only adjust to these changes but manage them to improve the caregiving setting or improve their inner strengths and capabilities as older husband caregivers.

In previous research on the outcomes of caregiving (e.g., Alexander & Wilz, 2010; Ashley & Kleinpeter, 2002; Fitting et al., 1986; Miller, 1990b), female caregivers are shown to be more vulnerable than male caregivers to negative outcomes, such as depression, psychological distress, and anxiety. However, in this study, older husbands' participation in spousal caregiving caused diverse challenges in multiple contexts. Older husbands were at high risk for negative impacts on their health and well-being in various situations, such as acclimating to new tasks and roles, financial burdens, spouse's deterioration because of illness or disability, restricted activities, and emotional or physical distance from adult children, friends, and relatives. In the caregiving life, time and geographic restrictions become primary stressors in that a husband's restricted life is related to shrinking social networks, difficult access to outside support, and the loss of opportunities for re-employment.

Older husbands identify themselves as a spousal caregiver by personal or social recognition (O'Connor, 2007; Ribeiro & Pául, 2008; Ribeiro et al., 2007). However, the meaning of "being an older husband caregiver" varies according to their location and status. That is, "being a caregiver" is very situational and relational. For example, "being a caregiver" meant a

husband caring for the wife in the marital context or an unusual husband or older man caring for his wife.

### **Limitations of the Study**

The findings of this study reflect how older husbands adjust to and manage changes in multiple contexts while caring for their wives. Many have refashioned themselves as a spouse caregiver in later life in Korean society. The study provides a new viewpoint on caregiving as a dynamic, ongoing process in multiple, intertwined contexts. The findings are limited, however, to a non-random, small sample size of 23 older husband caregivers. Such a small sample size brings generalizability into question even though participants represent a wide range of socioeconomic statuses and, among the spouses, a variety of health conditions. In addition, this study is the first attempt to focus on the ongoing process of being a husband caregiver in various contexts in Korean society. This issue should be further investigated using a larger sample with older husband caregivers with similar backgrounds.

Another limitation comes from its cross-sectional design. This study is to explore the caregiving trajectory of older husbands in Korean society. The data from in-depth interviews reflects their life histories regarding spousal caregiving and life trajectories through their retrospective narratives. Caring is a stressful, time-intensive, and emotional experience for older husbands. During interviews, they were likely to face sensitive and private issues that revealed their vulnerabilities. Some older husbands may not feel comfortable discussing these issues with a much younger single woman interviewer. It is not easy for older husbands, who provide full-time, intensive care to their wives to be interviewed for 2 or 3 hours. Therefore, these one-time interviews with them may not be enough to understand their life histories and caregiving trajectories.

### **Implications for Future Research**

The purpose of this study was to understand the experience of ‘being a husband caregiver’ in later life. Based on the findings of this qualitative study, the present study provides some implications for future research. This study adds to the current literature on how older men become spouse caregivers for their wives. The findings of this study identify many gaps in the theoretical, empirical knowledge related to older husbands participating in spousal caregiving. It reflected that older husbands’ experiences of caring for their wives is understood and interpreted through gender-sensitive perspectives. The gender-based approach to caregiving reflects notions of traditional gender roles or cultural notions of Confucian patriarchy in Asian countries. In this study, older husband caregivers, as primary caregivers, perceive their caregiving duties or responsibilities beyond the notions of gender roles or Confucian patriarchy. It meant that the transcultural underrepresentation of male caregivers in informal care or eldercare cannot be explained only by marital obligations or love without considering the gender- and culture-linked theories. Therefore, a new approach combining gender/culture-based perspective and marital obligation/affection is needed to understand older husbands’ experience of spousal care. To explore the influence of gender roles or Confucian patriarchal ideology, it is beneficial to conduct research comparing various older husband subgroups’ beliefs and attitudes toward spousal care: the primary older husband caregiver, the secondary husband caregiver, financial supporter, older husbands using formal care (in-home carer or institutionalization), and husbands as non-caregivers.

The research on male caregivers in eldercare focuses on performance of new caregiving duties and tasks as women’s work, outcomes of caregiving activities, and strategies for coping with negative outcomes or caregiving difficulties (Black et al., 2008; Calasanti & Bowen, 2006;

Ducharme, Lévesque, Zarit, et al., 2007; Gallant & Connell, 1998). It reflects a limited perspective on their caregiving experiences through paying attention to some aspects of the complex world of older husband caregivers while ignoring others. The findings of the present study reveal that the experiences of older husbands caring for their wives is a complex, dynamic, ongoing process of adapting to and managing various changes that continuously occur in interrelated, intertwined contexts. It is important to explore and understand the experience of being an older husband from a broad, multidimensional perspective. This study explores changes in multiple, intertwined contexts and husbands' strategies for coping with these changes. For example, when older husbands' social networks are understood, it is important to consider changes in all potential social networks in the caregiving situation, such as shrinking networks (e.g., relatives, friends, and religious people) and emerging networks (e.g., medical professionals, formal care, other patients and their caregivers, and community people). Simultaneously, it is necessary to view older husbands as an agent managing or modifying physical, emotional, and relational settings for improving their caregiving abilities and the quality of care, not as a passive being adjusting to changes or difficulties.

### **Implications for Practice and Policy**

This study clearly demonstrates restricted activities as a primary change or challenge in the husband caregiver's life. This reflects that time or geographic restrictions caused the loss of social resources through losing social ties or though difficulties accessing to the world outside caregiving. Social or public assistance services or programs are oriented to an outward approach, not the inward approach. That is, when caregivers and their care recipients need help or assistance, they have to contact or visit an agency or institution to seek or ask for help. In the restricted life, because older husbands are likely to have limited or difficult access to information,

interpersonal resources, social support services or programs need an inward approach. For example, there are various channels (e.g., hotline, regular contact or visiting to the past and current service users, newsletter delivery, online contact line, and others) that could be used to reach older husband caregivers who may be seeking help within the caregiving sphere.

From the narratives of older husband caregivers in this study, taking sole responsibility for spousal caregiving reflects the loss of opportunities for returning the workplace. Over time, older husbands, who do not have stable economic sources or sufficient financial resources, are likely to feel burdened by increasing expenses of living, caregiving, and health care. However, if older husband caregivers, who often feel physically trapped by the caregiver role, are not eligible for public programs for financial assistance (e.g., National Basic Livelihood Security program) and do not have informal financial support, they became more vulnerable to financial adversity in the caregiving situation. A social support service for working male caregivers (e.g., short-term respite or day care program with flexible care hours) that helps older husbands return the workplace might allow them to gain a stable economic source.

While caring for their wives with moderate or severe cognitive and/or functional limitations, older husbands cannot take care of themselves because they have to provide full-time, intensive care. In addition, because older husband caregivers also potentially experience health decline or loss as they age, they need to manage their physical and mental health. In Korean society, social support services or programs for long-term care focus on providing instrumental assistance. That is, it is patient-centered program (Ministry of Health & Welfare, 2011). Instead, a social service or program needs to include caregiver support services (e.g., nutrition management, exercise program, or counseling) as well as the patient-based services.

Finally, in the study, two care recipients were vulnerable to verbal or physical abuse in a situation that their caregiving husbands exhibited extreme stress responses. In particular, even though the in-home worker and the agency for in-home care observed signs of spousal abuse, bruises on the face of Seungil's wife, and recognized she was always at high risk for physical abuse, they did not respond to warning signs of elder abuse. Because social service for in-home care focused on the provision of ADL and IADL care to support primary family caregiver's role duties and activities, it is not easy for paid caregivers, in-home workers, or in-home care agencies to actively, properly intervene in situations in which care receivers fall victims to abuse, without any law on or social intervention programs for elder abuse in home-based caregiving. The harm of care recipients in vulnerable position is likely to be neglected in the domestic sphere. In Korean society, it is necessary to develop an effective law and social intervention system that help preventing elder abuse and improve the quality of care in home-based caregiving. First of all, it is essential that, as mandatory duties, all professionals (e.g., paid caregiver, in-home care workers, in-home care agencies, and home-visiting nurses), who engage in home-based caregiving, watch for suspected signs of elder abuse and report them to the local domestic violence-related agency or law enforcement agencies. The certificate program for In-home care workers is required to train attendees to detect the presence of abuse signs and to respond to the suspected abuses, as well as to perform caregiving tasks.



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## APPENDICES

### Appendix A: Interview Guide

**Name/Age:**

#### **I. CAREGIVING EXPERIENCE**

##### **1. Transition To Spousal Caregiving (Onset Of Wife's Illness Or Disability)**

- a) Onset of wife's illness: cause of wife's health problem, wife's health & functional condition, medical diagnosis & treatment, the time or wife/interviewee age, selection of primary caregiver
- b) Transition to caregiving: the time or wife/interviewee age, caregiving motivation, caregiving tasks & duties, significant/meaningful changes in daily life (e.g., the family, work, others), caregiving stress & burden
- c) Wife's illness trajectory: Health status before and after becoming a care recipient
- d) Caregiving trajectory: length, beginning-ending

##### **2. Changes In The Caregiver Role (Post-Transition To Caregiving)**

- a) Wife's illness trajectory: health and functional/cognitive condition (wife's need of care), health care, formal care, care-related social welfare benefits
- b) Caregiving trajectory: caregiving tasks & duties, caregiver stress & burden, caregiver health, daily routine, informal & formal assistance
- c) Changes in roles & activities in the personal, familial, work, and social life
- d) Coping strategies

##### **3. Changes In Interpersonal Relationship (Pre-Transition Vs. Post-Transition)**

- a) Changes in marital relations: role duties, relationship, & attitudes

- b) Changes in relationships with adult children: caregiving involvement, support, interaction/communication, emotional/physical distances, attitudes
- c) Changes in social relationships with relatives, friends, co-workers, neighbors/community people, region-related people, and others: contact, interaction/communication, support, emotional/physical distances, attitudes

#### **4. End Of Caregiving (If Not Provide Care Anymore)**

- a) Reason of completing caregiving
- b) Changes in daily routine
- c) Feelings/attitudes after end of caregiving – individual, familial, social, and other parts

#### **5. The Culture Of Caregiving**

- a) Gender issues in caregiving: female-dominated context, stereotype/prejudice
- b) Disclosure of caregiving situation
- c) Social image & reputation of interviewee as caregiver

## **II. Aging experience**

### **1. Aging Experience**

- a) Transition to old age
- b) Experience of being old
- c) Good aging

### **2. Planning In The Later Life**

- a) Plans for old age before transition to caregiving
- b) Plans for old age after transition to caregiving
- c) Plans for old age after termination of caregiving

**3. End-Of-Life Issues**

- a) Remaining life expectancy
- b) Preparation for end-of-life
- c) Attitude toward dying/death
- d) Good dying/death

## **Appendix B: Consent Form**

### **CONSENT TO PARTICIPATE IN A RESEARCH STUDY**

#### **Older men's experience on spousal caregiving in Korea**

You are being asked to take part in a research study entitled "Older men's experience on spouse caregiving in Korea," which is being conducted by professor Denise C. Lewis, Ph. D., Department of Child and Family Development, University of Georgia, 1-XXX-XXX-XXXX, and Ms. Won Jee Cho, Department of Child and Family Development, University of Georgia, 82-XX-XXX-XXXX. You do not have to take part in this study, and that you can refuse to participate or stop taking part in the study at any time without giving any reason, and without penalty or loss of benefits to which you are otherwise entitled. You can ask to have information that can be identified as yours returned to you, removed from the research records, or destroyed.

The reason for this study is to better understand older men's experience in providing care for their wives and changes in attitudes and feelings concerning being a caregiver in later life within the Korean culture. By doing this study, the researchers hope to be more aware about the association between spousal caregiving and older men's lives and aging processes. The findings of the study may prove useful for developing culturally sensitive programs for older male caregivers that can be helpful for enhancing their strength to adjust and manage their caregiving tasks and their later life.

To be included in this study, you must currently provide or have previously provided care for your ill or disabled wife while in your 60's or older and must be available in South Korea. You will be asked questions about your experiences and feelings related to caring for your ill or disabled wife, experiences and feelings in the aging process, and demographics.

The research procedures will be conducted in your home. Researchers will make written notes during your interviews. We will record information from you with a digital voice recorder. The interview will take approximately one to three hours. You will receive no other compensation and no payment for your participation in this study.

To the best of our knowledge, the information you will be talking about with us creates no more risk of harm or discomfort than you would experience when talking to some friend or family member about your daily life and the aging process.

Your information will be combined with information from other people taking part in the study. You will not be identified in the written materials for the study. Your name and information will be stored in separate locked places. Audio-recorded files will be deleted after transcription is complete. We will make every effort to prevent anyone who is not on the research team from identifying you as a participant.

If you decide to take part in the study you still have the right to decide at any time that you no longer want to continue. You will receive no penalty if you decide to stop participating in the study.

Before you decide whether to accept this invitation to take part in the study, please ask any question that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Denise C. Lewis at 1-XXX-XXX-XXXX, or you may contact Won Jee Cho at 82-XX-XXX-XXXX.

***Your signature below indicates that Dr. Lewis or Ms. Won Jee Cho have answered all of your questions to your satisfaction and that you consent to volunteer for this study. You have been given a copy of this form.***

**Please sign both copies, keep one and return one to the researcher.**

***Additional questions or problems regarding your rights as a research participant should be addressed to The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address [IRB@uga.edu](mailto:IRB@uga.edu)***

Denise C. Lewis, Ph.D.  
Child and Family Development  
University of Georgia  
(Office) 1-XXX-XXX-XXXX

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Won Jee Cho

\_\_\_\_\_

Child and Family Development

Signature

Date

University of Georgia  
(Cell) 82-XX-XXX-XXXX

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Printed name of participants

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Signature

---

Date



## 1. 연구 참여 동의서

### 노년기의 아픈 아내를 돌보는 남편의 돌봄 경험

University of Georgia 의 아동가족학과 소속인 Dr. Lewis (1-XXX-XXX-XXXX)와 조원지 (1-XX-XXX-XXXX)가 진행하는 “노년기의 아픈 아내를 돌보는 남편의 돌봄 경험” 연구에 참여 부탁드립니다. 이 연구 참여는 어떠한 의무나 강요에 의한 것이 아니라, 본인의 참여의사가 가장 중요하기 때문에, 참여 중간에 어떠한 제약없이 중단할 수 있으며, 본인과 관련된 그리고 제공한 정보 모두를 폐기 또는 회수할 수 있도록 요구할 수 있습니다.

본 연구의 목적은 노년기의 아픈 부인을 돌보는 남편들의 돌봄 경험에 대해 알기 위한 것입니다. 이 연구를 통해 우리는 남성들의 부인 돌봄 경험과 노화과정과의 관계를 이해하는데 중요한 정보를 얻을 것으로 기대합니다. 또한 부인을 돌보는 남편들이 경험할 수 있는 어려움을 극복하고, 노년기 삶의 질을 향상시키기 위한 프로그램을 개발하는데 가치있는 자료로 사용되길 기대하고 있습니다.

60 세 이후 아픈 또는 거동이 불편한 부인을 현재 돌보고 있거나 과거에 돌봄 경험이 있고 한국에 거주하는 60 세 이상 연령이신 누구나 참여가능합니다. 인터뷰 중에 부인을 돌봄 경험, 자신의 나이들의 경험, 그리고 가족에 관한 일반적인 정보를 여쭙보려 합니다.

인터뷰는 참여자의 집을 방문하여 진행될 것이며, 연구자는 인터뷰 중간중간 연구에 도움이 될 만한 정보들을 기록하게 될 것입니다. 인터뷰는 한 시간에서 세시간 정도 진행되는 동안, 참여자의 인터뷰는 디지털 녹음기로 녹음이 될 것입니다. 이 연구 참여를 통해 어떠한 보상이나 참여에 따른 비용은 제공되지 않을 것입니다.

인터뷰하는 동안 본인이 제공하는 이야기로 인하여 어떠한 불편함을 경험하지 않을 것입니다.

인터뷰에서의 이야기는 본 연구에 참여한 다른 참여자의 이야기들과 함께 사용될 것입니다. 그러나 연구결과를 발표하는 어떠한 출판물에서도 참가자의 정보가 노출되지 않게 될 것입니다. 본인의 성명과 정보는 잠금 장치가 된 다른 장소에 각각 보관될 것입니다. 녹음된 인터뷰의 필사(口口)가 끝나면 귀하의 녹음된 파일은 삭제될 것입니다. 또한 참여자의 정보는 본 연구와 관련없는 이들의 접근이 불가능하도록 최대한의 노력을 기울일 것입니다.

만약 언제든지 더 이상 연구에 참여하고 싶지 않을 때, 어떠한 제약없이 인터뷰를 중단할 수 있습니다. 또한 Dr. Lewis 와 조원지는 참여자의 정보가 연구와 관련이 없을 때 중단할 수 있습니다.

참여를 결정하기 전, 어떠한 문의 사항이 있으면 질문해 주십시오. 이후에 연구에 관련한 문의사항이 생기면, 연구자 Dr. Lewis (1-XXX-XXX-XXXX, dlewis@fcs.uga.edu)와 조원지 (82-XX-XXX-XXXX, [wonjee@gmail.com](mailto:wonjee@gmail.com) or [wonjee@uga.edu](mailto:wonjee@uga.edu))에게 연락하시길 바랍니다.

두 장의 동의서 모두에 서명해 주시길 바랍니다. 한 장의 동의서는 참여자를 위한 것이며, 다른 한 장은 연구자를 위한 것입니다.

연구 참여자로서의 권리에 관련한 추가적인 의문 사항 또는 문제는 ***The Chairperson, Institutional Review Board, University of Georgia, 612 Boyd Graduate Studies Research Center,***

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