



معهد الدوحة الدولي للأسرة
Doha International Family Institute

البحوث لدعم السياسات الأسرية
Research to advance family policies

عضو في مؤسسة قطر
Member of Qatar Foundation

Family Home Caregivers for Elderly People in Qatar



FAMILY HOME CAREGIVERS FOR ELDERLY PEOPLE IN QATAR



DIFI

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DOHA INTERNATIONAL FAMILY INSTITUTE

The Doha International Family Institute (DIFI), a member of Qatar Foundation for Education, Science and Community Development (QF), was established in 2006. The Institute works to strengthen the family through the development and dissemination of high-quality research on Arab families, encouraging knowledge exchange on issues relevant to the family and making the family a priority to policy makers through advocacy and outreach at the national, regional and international levels. Among the Institute's most important initiatives are the Annual Conference on the Family and the OSRA Research Grant in collaboration with the Qatar National Research Fund, an annual research grant which encourages research related to the Arab family and family policy. The Institute has special consultative status with the United Nations Economic and Social Council (ECOSOC).

To know more about the Doha International Family Institute, please visit www.difi.org.qa.

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EXECUTIVE SUMMARY

Over the past few decades, Qatar has witnessed profound demographic changes leading to a slowly increasing population of older adults. Inevitably, this trend will place heavy burdens on many families in Qatar as they assume responsibility for elderly care.

Improved economic conditions and standards of living that began around the 1950s have resulted in many structural changes in the Arab world, including significant decreases in morbidity, mortality, and fertility rates (United Nations, 2012). This has significantly altered the age demographic in Qatar and other countries in the region where individuals are living much longer, and the number of people aged 25–64 years have increased. Today, there are a significant number of Qataris (10,756) and non-Qataris living in Qatar (18,070) above the age of 60. According to the 2010 census, there were 2,685 Qataris and 3,769 non-Qataris in the 65–69 age group, 2,032 Qataris and 1,605 non-Qataris in the 70–74 age group, and 2,630 Qataris and 1,096 non-Qataris over 75 years of age (Qatar Statistics Authority, 2010). Furthermore, the average life expectancy in Qatar is 79.4 (United Nations, 2012), suggesting that the number of older persons in Qatar is on the rise.

Family members are the most common providers of home eldercare. However, recent societal changes have multiplied the pressures faced by family members who are responsible for such care. For example, studies have shown that increased participation of women in the workforce is one factor that significantly impacts the needs of families who care for an elderly member (Schoenfelder, Swanson, Pringle, Meridean, & Johnson, 2000; Dwyer & Coward, 1991). Qatar is no exception. Although extended families are common and filial responsibility is highly valued in Qatar, family eldercare providers might be dealing with significant strain that has the potential to compromise both their own quality of life and that of their elderly relatives. Despite these changes, research on elderly caregiving and the challenges of family elder caregivers in Qatar and the Arab world remains limited. Thus, the objective of the report is to investigate the experiences of elder caregivers in Qatar with a particular focus on the stress and burdens of caregiving, the coping strategies of caregivers, and the benefits garnered from their caregiving.

We conducted in-depth interviews with 22 elder caregivers in Doha including both Qatari and non-Qatari, and male (five) and female (17) with ages ranging between 20 and 50 years. Most of the care recipients were parents (18) ranging from 65 to 80 year olds who suffered from diabetes and/or hypertension with some complaining of heart problems and/or dementia. There were some cases where the elderly parent was experiencing co-morbidities and long-term complications and disabilities (e.g. dementia).

Our analysis revealed four major areas:

Division of Caregiver Labor

The data revealed that elder caregiving is mostly provided by female family members. Some family members, such as single or divorced women living in the same home, found themselves involved in caregiving by default due to family circumstances. However, female caregivers varied by marital status, including those who were married (five), divorced (one), and single (11). While females formed the majority of primary caregivers (15), five males (two single and three married) also performed direct caregiving. All these caregivers face a number of social constraints while providing eldercare, particularly the women.

In this report, we differentiated between primary caregivers (direct caregiving) and secondary caregivers (indirect caregiving). Primary caregiving included Activities of Daily Living (ADL), such as bathing, dressing, grooming, and oral hygiene, toileting, transferring to bed/chair, walking, climbing, and feeding. Instrumental Activities of Daily Living (IADL) included shopping, cooking, managing medications, using the phone or computer, doing housework, doing laundry, driving or using transportation, managing finances and social services systems, and assuming protective actions to ensure the safety and well-being of the elderly family member. Secondary caregivers performed duties and activities similar to primary caregivers but tended to spend less time with the elderly person, mainly assisting the primary caregiver in ADL and IADL functions or providing assistance with the health issues of the elderly person, if needed.

In addition, caregivers had to take into consideration other factors during the caregiving process, such as showing emotional support and demonstrating sensitivity while understanding the dependency of their elderly family member. Their emotional support of their care recipients enriched the quality of life of both the care receiver as well as themselves, constituting one of the major positives of caregiving. Also, dependency was an issue of importance in the life of the elderly person who was mainly dependent on their caregivers, whether male or female, and felt a sense of insecurity when these caregivers were away from them. Another issue that emerged in the caregiving process was the importance of demonstrating sensitivity to the needs and desires of the elderly family member. Meeting the care recipient's emotional needs and respecting or deferring to the wishes and desires of the elderly person might be demanding, and in some cases, too much to bear.

The nine employed or studying women, whether single, married or divorced, had become responsible for doubled workloads as they performed the duties of caregiving in addition to their paid job duties outside the house. The caregiving activities that employed women performed after their work duties continued into what is traditionally thought of as a **“second or third shift”**, negatively impacting both the health and job performance of the caregivers as witnessed by their reports of increased absenteeism, extra distractions at work, more physical health problems and loss of career advancement prospects.

Challenges of Caregiving

Stress and burdens are the main factors impacting caregiver health. Many described stress as a loss of control of temper, patience and tolerance while some expressed a sense of burden, feelings of anger and signs of bodily wear and tear. They also revealed the number of demands placed on them that made caregiving particularly challenging, explaining the higher the time demand, the higher the threat for disrupted schedules and loss of physical strength.

Stress impacts caregivers because these individuals end up with very limited or no time for personal pursuits either due to limited social support from other family members or isolation. As the caregiving intensifies over time, they face new responsibilities and difficulties which increase risks to their health. Caregivers raised concern about their ability to provide sustained, long-term care as most described feeling exhausted, depressed, and fatigued due to sleep loss, all of which contributed to an increase in stress levels and failing health. They also revealed feeling deprived due to limited resources, lack of support, loss of personal time and pleasure. Almost all of the caregivers expressed the need for more easily accessible avenues of formal help and assistance in the long run. For many of the participants, the aforementioned practical help was related to the challenges of transporting the elderly person to medical appointments.

Coping Strategies

The coping strategy of caregivers differed from one person to another depending on the amount of time spent with the recipient. Some caregivers coped with frustration by reminding themselves that they were doing a good job. They referred frequently to their faith, indicating that they were given this responsibility based upon their capability to positively impact the life of their elderly family member. In most cases, the caregiver relied on spiritual support to boost their patience and kindness while caregiving. Some remained optimistic and attempted to convey this hopefulness to the care recipient, stressing the importance of a positive outlook and a firm belief in their ability to fulfill the responsibility entrusted to them.

Some of their coping strategies for stress and fatigue were to have “**time-outs**”—taking brief periods of time away from their caregiving roles to talk with friends or pray. Other strategies included going out with friends and relatives or talking about their problems with others. Some also exercised to alleviate the stresses of caregiving.

Joy and Happiness from Caregiving

Although caregiving is a demanding job, the caregivers also experienced a joyful side of their caregiving role. The praise and appreciation of the care recipient served as a source of motivation. Particularly for primary caregivers, this appreciation coupled with their sense of responsibility reinforced their feelings of obligation and duty towards their elderly family member and renewed their will to continue.

The majority of caregivers felt a sense of happiness when they saw their elderly family members happy, smiling and comfortable. Most also learned how to be patient and tolerant during the difficult and complicated circumstances of caregiving. Love and filial duty were significant motivators and existing sources of joy and rewards, strengthening the altruistic values of the caregivers.

What Do Caregivers Want?

- Caregivers reported a need for professional guidance and counseling on how to care for elderly family members, specifically in regards to administering medication, home visits, monitoring and following up with the caregiver on the health of the care recipient.
- Caregivers want healthcare providers to cooperate with them and support them by providing the necessary knowledge and skills needed to maintain high quality care in both nutrition and first aid.
- Caregivers want to attend training sessions on communication skills and problem-solving techniques, such as tolerance and patience, when working with the care recipient. This should be tailored to the specific condition and disease of the recipient.

Suggested Interventions and Policy Implications

- Psychoeducational interventions, which are structured programs that provide information about the care recipient's disease and the caregiving process in addition to resources, services, training for caregivers to respond effectively.
- Support group interventions, which involve expanding the caregiver's support network by including them in professional support groups that provide a place for discussing the problems, successes and feelings related to caregiving.
- Multicomponent interventions, which include a combination of educational interventions, support networks, psychotherapy and respite.
- Formal support programs, such as homecare visits and social activities for caregivers and care receivers, need to be maximized and intensified, particularly in the direct aftermath of a care recipient's debilitating event and then, sustained throughout the caregiving process.
- All supportive programs should enhance the roles of women as they represent the majority of home providers of eldercare.

CHAPTER ONE: EXPLORING THE EXPERIENCES OF HOME CAREGIVERS IN QATAR

Prior to the research reported here, caregiving for the elderly in Qatar had yet to be studied. This topic is of the utmost importance since the family as a social institution is thought to be the cornerstone of society in Qatar. Also, the family is of particular importance for older individuals, especially when their physical and/or mental health declines and they can no longer function independently. Once this happens, it is often members of the family (e.g. a spouse or child) who become informal caregivers for the elderly person or persons requiring support.

1.1. Why Caregiving and Why Now?

The age demographic in Qatar, like other countries in the region and around the world, has significantly changed. For instance, there has been a rapid increase in the number of people aged 25–64 years. In addition, advances in healthcare and a changing socio-economic demographic has led to a longer life expectancy and an increase in the number of adults over the age of 60. In 2010, the number of Qataris and non-Qataris above the age of 60 was estimated to be 10,756 and 18,030 respectively (Qatar Statistics Authority, 2010). Furthermore, because the average life expectancy in Qatar is nearly 80 years of age (United Nations, 2012), most individuals in Qatar can expect to reach old age, suggesting that the number of elderly persons in Qatar will only rise. In fact, Qatar is one of the fastest aging countries in the Middle East (Saxena, 2008).

The process of caregiving for elderly persons is a complex issue. Caregivers are often required to gain specialized knowledge unique to the needs of the care recipient. In addition, they often have to meet with healthcare professionals during different stages of the caregiving process (Given, Sherwoon, & Given, 2008; Given, Given, & Kozachik, 2001; Northouse, Mood, Templin, Mellon, & George, 2000).

Internationally, there is an abundance of social research on the experiences of elder caregivers. However, there has been no research conducted in Qatar, and only a few studies on the elderly in the Arab region. This research gap is especially problematic since reports suggest that there are concerning problems in eldercare in the Arab world including the presence of neglect, abuse or violence and a lack of support for caregivers (ESCWA, 2013). This begs the question: how can we better meet the needs of all segments of the elderly population in Qatar who require informal care from family members? This report was designed to qualitatively explore the experiences of family elder caregivers in Qatar by utilizing a qualitative descriptive design in order to establish the initial understanding required to guide a formal program of research into this growing family phenomenon in Qatar that is currently is poorly understood.

The findings from this study draw attention to the stresses and burdens of elder caregivers and provide insight into their coping strategies. It also begins to shed light on the type of resources that would benefit caregivers. In addition, we move beyond the one-dimensional focus of caregiving literature by also examining some of the positive

aspects or joys of caregiving. As such, this report focuses on the lived experiences of caregivers and the positive and negative consequences that the experience of providing home eldercare has on the lives of caregivers.

This report adds important knowledge to the literature by exploring caregiving in the unique cultural context of Qatar, and is likely to have a broader relevance to the Arab region as a whole. The findings reported here on the lived experiences of caregivers in Qatar provide a solid base for policy makers to consider as they develop or modify policies and practices expected to better assist caregivers. The insights from this research may also inform systems of care, to allow them to anticipate issues and respond to the vulnerability of elderly people thereby ensuring their physical and social needs are met with humane compassion. This research contributes to the development and modification of policies and practices to better serve care receivers and better assist caregivers and healthcare workers that interface with caregivers and their loved ones, therefore increasing the quality of care and positive health outcomes for both caregivers and care recipients. In addition, the findings of this report address components of the Qatar National Research Strategy (QNRS) of 2012; Qatar National Vision 2030 and Qatar National Development Strategy 2011–2016 (QNDS 2011–2016, 2011). This research is aligned with and facilitates the achievement of the goals set in the QNRS, specifically those outlined under the **“health pillar”** and the **“social sciences, arts and humanities pillar”**.

1.2. Background

The prevalence of physical, cognitive, and chronic disabilities increases as the population ages (Chappell, McDonald, & Stones, 2007; ESCWA, 2013). In the Gulf region, there is some indication that the prevalence of physical and chronic disabilities (e.g. diabetes, cardiovascular disease, and cancer) are greater in the elderly receiving homecare than in their institutionalized counterparts (Al-Nassir & Al-Haddad, 1999). However, the rate of cognitive impairment in non-institutionalized elderly in Qatar is comparable to rates in the United Kingdom (ESCWA, 2013; Ghubash, El-Rufaie, Zoubeidi, Al-Shboul, & Sabri, 2004).

Family members are the most common providers of home eldercare (ESCWA, 2013). However, recent societal changes have increased the level of pressure placed on family members who are responsible for the care of elderly family members. While extended families are the norm and filial responsibility is highly valued in Qatar, our findings indicate that family elder caregivers experience significant stress, which can negatively impact both the quality of life of the elderly and their families. This is particularly relevant for women, who are the primary elder caregivers in Arab societies (Given et al., 2008).

1.3. Objectives of the Study

The focused objectives of this study were to:

1. **Gain a better understanding of the experiences of caregivers providing home-care for elderly family members in Qatar.**
2. **Investigate the perspectives of caregivers on their needs, and the strengths and weaknesses in current services and support available in Qatar.**
3. **Propose policy and practice recommendations based on the findings of this study.**

The method used in this report was a qualitative description research design utilizing in-depth interviews with open-ended questions. More details on the methods and limitations of the study are available in the Appendices.

CHAPTER TWO: ROLES AND RESPONSIBILITIES OF FAMILY CAREGIVERS IN QATAR: MAIN ISSUES

“I help my father with medications, follow-up with doctors’ appointments. I take him shopping as he likes to go shopping to buy groceries . . . If he wants to visit friends and relatives, I take him.” (Dream, non-Qatari caregiver in her 30s)

It is well established in Qatar that the family is the main care provider for its elderly members. Studies show that the family is particularly important for the elderly, especially when they begin requiring assistance due to the effects of debilitating chronic conditions and diseases such as severe arthritis, disability, significant sensory loss, Parkinson’s disease, Alzheimer’s disease, or increased frailty (Walker, Clara, Pratt, & Lindy, 1995). In our study, eldercare in its many forms was found to be mostly carried out by relatives. This chapter focuses on the different types of work described by participants as associated with their roles as caregivers.

2.1. Division of Labor: Roles and Responsibilities

There is a large body of international literature that discusses common trends in a gendered division of labor for caregivers (Lin, Holly, & Hsueh-Sheng, 2012; Neal, Berit, & Marjorie, 1997; Piercy, 1998; Singleton, 2000; Stein, Virginia, Marcia, Michelle, Andrew, & Thomas, 1998; Teschendorf & Carolyn, 2007; Walker et al., 1995). Our data supported that the division of labor by gender is a factor in the caregiving process. While there were clear exceptions, it is primarily women looking after the elderly.

Our findings are also in agreement with previous international studies that found that even when an extended network of caregivers is present, there is often one primary caregiver who is involved directly with Activities of Daily Living (ADL) (Messeccar, 2012; Capezuti, Deanne, Mathy, & Terry, 2008). These include day-to-day assistance with activities such as bathing, eating, dressing, mobility, transferring from one place to another, and using the toilet. Illness related care extends beyond this basic physical work and includes carrying out treatments, performing medical or nursing procedures, coping with the behaviors associated with illness such as cognitive impairments, liaising with health professionals, and navigating the healthcare and social services systems. Many of these are protective actions that caregivers take to ensure the elderly person’s safety and well-being (Bowers, 1987; Messeccar, 2012; Schumacher, Barbara, Patricia, Mildred, Faith, & Sangeeta, 2008; and Smith, 1994). Other Instrumental Activities of Daily Living (IADL) including meal preparation, grocery shopping, housework, making phone calls, income generation and money management also contribute to the well-being of the recipient of home eldercare and should not be underestimated.

In the literature, the roles of the caregiver have been classified based on the person who handles the major responsibilities (primary caregiver) versus those who are categorized as having only supportive roles (secondary caregivers). According to

Messecar (2012), females and spouses are most likely to assume the primary caregiving role, whereas adult children are more likely to be secondary caregivers (p. 130). However, our data did not fit easily into the demographics described in the literature. Many of the primary caregivers in our study did not have a spousal relationship with their elderly relative but were instead their adult sons and daughters. Moreover, while the literature describes the categories of support provided by caregivers into the distinct realms of ADL (illness related, personal care, etc.) and IADLs (other instrumental support to maintain the home) as a conceptual framework through which to describe their roles and responsibilities, our qualitative data unearthed much more nuanced negotiations, dependencies and interdependencies among family members that were directed towards ensuring elderly relatives felt loved and enjoyed a good quality of life.

In our small group of participants, there was a predominance of women identified as primary caregivers. Sixty-three percent of the primary caregivers interviewed were single women (e.g. either never married or had been divorced) who provided care for their elderly parents. Among them was Noor, a single 30-year-old Qatari woman who was both employed full-time outside the house and also responsible for the care of her father and mother, who were both in their 60s. Noor's father was afflicted by several chronic illnesses that led to limited vision while her mother suffered from diabetes, hypertension, and other health issues, including a wound that needed continuous cleaning. Noor reported having to negotiate with her employer to get permission to attend medical appointments with her father or mother. Although she has brothers and sisters, all but her youngest brother, in his 20s, are married and live in their own homes. While the youngest brother lives with Noor and her parents, he is not closely involved in their day-to-day care. Noor described her daily routine as follows:

I wake up every morning, I prepare their breakfast. My mother wakes up at 5 a.m. I give breakfast to my father and mother, I give them their medication and then I go to work. I tell the housemaid to give them juice at 11 a.m. and to check their sugar levels. In the afternoon when I come back, I check that they have taken their medications and I prepare the medications for the rest of the day or the next day. When I come back from work at 3 p.m., I prepare their lunch and then I sit with them for the rest of the day, giving them their medications and tending to any other issues that they have. Every two days, we need to check their feet and clean them. Sometimes the housemaid does it but normally I do, I wash their feet. I check what is missing in the house in terms of food or other things that need to be done.

She went on to explain the following:

The housemaid helps me with the cleaning of the house and looking after my parents when I am at work, but sometimes when you do not have a good housemaid, you get scared. And I tend to leave work and take permission to go back home and look after my parents because no one will look after them. My single younger brother works, and my other sisters and brothers all have their own lives and responsibilities. So I have a hard time when I do not have a good housemaid as everything is on me.

Noor's experience corresponds to what has been written in the literature and fits within the international demographic of women who function in a caregiving role for a parent in need of assistance (Brody, 1990; Cantor, 1983; Singleton, 2000). Noor describes that she takes care of her parents' practical needs while her other siblings are involved in the social aspects of her aging parents' well-being. It became clear through speaking to Noor that she bears the responsibility of the day-to-day worries and navigating her parents' medications, their need for regular snacks and the support they need due to their disabilities and health conditions in addition to supervising the migrant housemaids¹ whom she finds difficult to trust.

This gendered responsibility for the recipient's care is discussed by Schoenfelder et al. (2000) who document gender differences in the caregiving tasks being carried out. They identified wives, daughters, and daughters-in-law as those who provide the bulk of the personal care for the elderly family member. In Schoenfelder's study, husbands and sons were noted as monitoring the care of elderly relatives from a distance. Most often living separately from the aging relative, they were seen to intervene and offer advice or directions by telephone or during visits (Dwyer & Coward, 1991).

Another caregiver we interviewed was Green, a 45-year-old single Palestinian woman. She described her daily activity of caregiving for her parents as complex and demanding, in particular for her father who is in his 70s, is confined to a wheelchair, and suffers from heart block, anemia and hearing loss. Green is trained in the field of medicine but is not currently practicing. She and her family have lived in Qatar for more than 20 years. Since her father's retirement, she has increasingly taken on the responsibility of her parents. Her brothers are married and living in separate houses while her sisters are unmarried but have full-time jobs, which leaves Green alone to take care of her parents. Her mother is fairly independent with ADL but needs Green's assistance with some other things. Green describes her daily activity with her father, quoted at length below:

I take care of my father. I give [him] food regularly. He takes warfarin because he has atrial fibrillation and this has to be taken at sunset. I have to check with him at 6 p.m. if he took his warfarin or not. I tell my mother to keep his food ready in case his blood fluidity increases or decreases because it can cause clots or bleeding. I bathe my father as he cannot bathe himself. Sometimes my mother helps but most of the time I do it. I know all his medication. I give him his medication every day and if there are doctors' appointments, I go with him. I help him go to the bathroom and take short walks around the house because he cannot walk for long distances. When I go with him to the doctor, I follow up on his medications, buy them and finish all the necessary paperwork. And then we go back home.

If he gets sick and has to stay in the hospital, I am the one who stays with him. This has happened several times and I had to stay the night with him in the male ward, which was uncomfortable for me as it is not allowed for women to stay in the male ward but he wanted me to stay with him. ... Besides that, I do the shopping [and]

¹ Refer to chapter 3 for additional information on migrant domestic workers (housemaids).

other things for the house. My mother cooks but I help her with the cooking as sometimes she cannot.

We have a housemaid who cleans and washes but does not prepare food. I or my mother prepare my father's food because my father needs to follow a certain diet as recommended by his doctors to restore his health ... My siblings help, mostly my sisters when I want to sleep, they look after him, but my brothers, although I have one brother [who works in the medical field], he just advises us on the medications, and visits us on weekends because he is busy most of the time with his family and work.

Green's description of her responsibilities reflect a multifaceted, carefully balanced daily routine wherein she is the central figure responsible for her parents' health. It is apparent that she has developed knowledge about the complexities of atrial fibrillation and blood thinners, and that she is cognizant of the dietary monitoring that is required to ensure that her father's coagulation time remains stable. Managing coagulation times is complex. If it is not carefully maintained, Green's father is at risk of developing bruising and bleeding. This knowledge about diet and medications is combined with knowledge about bathing, toileting and maintaining his physical endurance. Through Green's description, the caregiver's role for coordinating care is obvious as she discusses how she navigates his medical appointments, pharmacy needs and intermittent hospitalizations.

May, a single Qatari female in her 50s, employed part-time, takes care of her 70-year-old mother who suffers from breast cancer and has a complex health history. For the past four years, May has been fully responsible for her mother as well as all the housework. While she has siblings, some of whom are unmarried and live at home while others are married and live separately, May considers herself the primary caregiver. She describes her mother's health challenges and the care that her mother requires as follows:

Over the past seven years, my mother has undergone four major operations ... All these operations have made my mother frail and sick, needing assistance from me. I take care of my mother because my sisters are all married, and after each operation she needs time to recover and rehabilitate. So, the entire time that she stays in the hospital, I am the one who accompanies her. I am one hundred percent responsible for the shopping, cooking, managing medications, doing housework, managing finances and paying bills. I assist my mother with other personal activities such as bathing, dressing, toileting, walking, eating, and transferring beds, particularly after surgery. My mother was completely dependent on me to handle these tasks immediately after her surgeries. Since her recovery she manages by herself but needs supervision and assistance.

The descriptions that Noor, Green and May have provided about their roles in their families, their primary role in caregiving, and the secondary contributions of

siblings are similar to other caregivers in this study. The work of caregiving is complex and includes multiple work processes. Furthermore, while siblings share some of the caregiving responsibilities, it is seldom shared “**equally**”. Below, we provide a more in-depth look into the complex work of caregiving made visible by talking to our participants.

2.2. Indirect Caregiving/Secondary Caregivers

According to the literature, secondary caregiving has some similarities to the work of the primary caregiver. However, often the day-to-day contributions are intermittent because secondary caregivers are involved in full-time employment or they live at a distance from the home of the dependent elder (Philips, 1989). According to Swanson, Deborah, Janet, Marion, and Meridean (1997), and, more recently, Lee, Yiin, Lu, and Chao (2015), the roles and responsibilities of the secondary caregiver are often critical to the well-being of the dependent elder. In some cases, the role of the secondary caregiver is to provide respite for the primary caregiver. In this regard, secondary caregivers may assist with ADL and IADL. Secondary caregivers also display skills in overseeing needed services and know the healthcare professionals involved in their relative’s care and can coordinate with them. Also, they are able to monitor the elderly relative, recognizing changes in their health status, reporting problems, and contributing to problem solving within the caregiving situation. This ability to confidently confront potential or actual problems related to the provision of care is important and demonstrates the secondary caregivers’ competent role.

Most of the primary caregivers interviewed, reported getting assistance from other family members although the amount and quality of that assistance varied. Some of the research participants received regular assistance from their siblings who live away from them. This was often in the form of regular visits when the siblings would join the primary caregiver for evening meals or family social time.

Another important source of secondary caregiving was from housemaids, present in the homes of all but one of our participants. Indeed, there were many aspects to this participant’s experience that stood out from the data. This young man, Mo (non-Qatari), was the primary caregiver for his severely disabled father who was bedridden following a major stroke². Our participants indicated that most of their housemaids were only involved in the IADL. Although the data revealed minimal details about the day-to-day responsibilities of the housemaids, the participants indicated that housemaids were essential to the primary caregivers’ capacity to provide care.

According to the Qatar Statistics Authority (2012), the number of domestic housemaids was 90,361 females and 49,543 males adding to 139,904 out of a total population of 1,341,193 in 2012. In 2014, the number increased to 154,000 domestic housemaids (Ministry of Development Planning and Statistics, 2014). Beyond the

² In keeping with qualitative approaches, we consider this exceptional case as important data. In qualitative research, “outliers” are not discarded or statistically adjusted. They provide useful insight into how to develop policies that can accommodate all the varied exceptions that constitute the “real world” of, in this case, family caregivers.

support by housemaids for the primary caregiver, they also emerged as critically important contributors to the quality of life of the whole family. We discovered that housemaids typically bear responsibility for housecleaning and laundry with some assisting with food preparation. In some families (Bless, Amna and Hope's), the housemaid was more closely connected to the physical care of the elderly person, helping with lifting, dressing or bathing. However, most cases emphasized that medications were not given by the housemaid, but this was instead the sole responsibility of the primary caregiver. In the rare cases when the housemaid administered medications, the primary caregiver provided detailed directions and careful planning, relinquishing only the administration of the medication to the housemaid, not its scheduling or preparation.

The other exception relating to secondary caregivers was in the situation of Blue, a Sudanese man, who hired a specialized nurse to provide care for his father who had suffered a stroke. Blue's father is paralyzed, suffering from intermittent confusion accompanied by agitation and occasional physical aggression. The nurse was involved in assisting Blue's paralyzed father to bathe and dress. The nurse, also male, could physically lift Blue's father into a chair. However, as with the other families, Blue, a trained healthcare professional himself, maintained responsibility for his father's medications even with the availability of a trained nurse. In Blue's household as well, his mother prepared food for his father. Blue identified himself as the primary caregiver for his father indicating that he **“trained and trusted the nurse.”** He added: **“[The nurse] is here for three years so he knows everything. So, when I leave the house for any reason, I am confident and comfortable that he is there.”**

2.3. Practical, Social and Emotional Aspects of Being a Primary Caregiver

2.3.1. Feelings of responsibility

Fears about leaving the dependent elder were expressed by several of our study participants. There seemed to be an underlying specter of worry if the primary caregiver had to leave the house. All of the primary caregivers developed complex systems to address this worry. Mobile phones appeared to be an indispensable tool for communication among primary and secondary caregivers and seemed to facilitate primary caregivers' capacity to carry out activities outside their house. This was especially the case for the participants who left home for employment or to attend university.

All the caregivers expressed a pervasive high level of worry and concern for their elderly family member accompanied by strong feelings of personal responsibility. For some, this extended to ongoing worries about **“something happening”** and their expressed sense of guilt and failure if they were to be away when they were needed. Even when other family members lived in the house and had close knowledge of the complexity of the caregiving work, the primary caregivers seemed to bear primary worry. They told us the other family members did not seem burdened by the weight of responsibility, nor by the worries and tensions that the primary caregivers experienced. This too seemed gendered, particularly with sons (the caregivers' brothers) living in the same house.

2.3.2. Dependency on the caregiver

The level of dependency of the elderly person is intricately related to this sense of worry. Even when the elderly parents were physically able (as with Mo, Bless and Hope's), the sense of responsibility for issues such as proper diabetes management in order to decrease the risk of diabetic emergencies, such as a hypoglycemic coma, established critical dependency on the primary caregiver. In cases such as Mo's where his father depended on him for every trip to the toilet, this sense of responsibility and worry was greatly magnified. All of the elderly people cared for by the participants of this study were dependent on their primary caregivers.

They were dependent for shopping, transportation to and from medical appointments, and even a feeling of social inclusion, allowing them to feel loved and wanted, not isolated. These sorts of dependencies accompanied the other features of ADL and IADL activities. Although we did not measure the amount of time the caregivers spent in providing care, the descriptions revealed that their caregiving role absorbed a lot of time each day. Even when caregivers were not directly absorbed in ADL or IADL, there was a mental energy that linked the caregivers to the care recipients.

We noted that the daughters who resided with their elderly family members in the same house described spending a lot of time each day helping and assisting them with their activities³. There was also a thread in the data that indicated that the elderly person expected a high level of commitment from their daughters—perhaps more than from their sons who, even if sons were identified as the primary caregiver for a highly dependent elder, seemed to have more leniency to pursue interests outside the home. For example, Blue, who attended university full-time despite being the primary caregiver for his bedridden, severely disabled father.

2.3.3. Emotional care

The caregivers negotiated a variety of ways to provide for their relatives' emotional needs. They described how providing ongoing emotional support while facing fatigue and the high expectations of the care recipient was a difficult emotional terrain to navigate. All of the caregivers in the study mentioned the ways they showed patience, respect, and dignity. Noor talked about how she returned home from work to spend the afternoon and evening with her mother, trying to **“make up”** for the isolation she knows her mother experiences when she is not around. She described the day-to-day irritations that she and her mother experience together but emphasized how she sees it as her duty to always obey her mother and consistently provide for her wants and needs after returning home from her paid job. Participants Dream and Mony revealed how they prioritized time with their fathers in order to give them emotional support and comfort, consistently focusing their attention on reducing their fathers' sense of loneliness or depression. These types of emotional exchanges influenced the relationship between the caregiver and care recipient and seemed to contribute to overall improvements in their quality of life. These caregiving efforts directed towards

³ These women caregivers seemed at high risk of feeling isolated and losing a sense of community, a finding that we discuss later in this report.

sensitively expressing love and respect seemed to contribute to a rich sense of reward for the caregivers. Even in the face of irritation, frustration and annoyance that is inevitably a part of the caregiving experience, the caregivers maintained the value of patience, providing an emotional climate that demonstrated care and upheld dignity.

These findings are supported by research that has shown that socioemotional care is important to the caregiving context and is closely related to the instrumental aid given to dependent family members (Walker et al., 1995, p. 404). Indeed, a strong theme in most of the interviews was the attention that caregivers pay to the emotions of their elderly relatives and their thoughtful interactions with them. The caregivers' focus on the emotional well-being of their elderly relatives is an important finding of this preliminary descriptive study that suggests that the current norm in Qatar of the family as the main social institution for elderly care is an important value to promote and support, and an important differentiation between elderly care in other cultures where the cultural norm accepts **"care homes"**.

2.3.4. Emotional energy directed towards inclusion

Within the caregiving roles and responsibilities, an important issue of emotional care was the inclusion of the elderly person. All the participants expressed that they try their best to include their elderly relatives in their lives in a variety of ways regardless of the level of their functional impairment. This goal of the caregivers had nuanced differences in how they discussed emotional support. The caregiving efforts directed towards inclusion were focused on ensuring that the elderly relative felt needed and knew they were a valuable contributor to family life. Bless, for example, explained how she goes **"out with my father for walks, and on Fridays the rest of my siblings join us with their children and it makes my father happy"**. Blue also explained how he includes his father in his family life:

In the afternoon, we take our father to sit in the garden and the rest of our siblings or friends come and visit us to chat with him. This entertains him and makes him happy. I keep talking to him about our family and news of the world to engage him in conversations and discussions with me. Sometimes it is not easy to keep talking but we do our best.

Abu Ali also engages his father although he works full time, comes home late and does not find time to stay long with his father. He said:

I feel that he gets upset when I tell him that I am going to sleep or check on my children. So, I try not to upset him by laughing or staying for some time ... I bring my children to play with him and entertain him ...

Inclusion of the elderly relative within the family increases their quality of life and sustains their health; the more an elderly person is involved in the family, the more she/he feels integrated, which appears to have positive health benefits (Piercy, 1998). This

was clear in the case of Blue when he explained that including his father in his family life makes him “happy”.

2.3.5. Emotional energy directed towards responding with sensitivity

Being sensitive to the needs and desires of elderly family members is a factor that caregivers believe is an important part of their role. Some of the caregivers likened their elderly relatives to the younger members of the family, noting that like children who are tender, fragile and vulnerable, elderly people need similar support, affection and care. However, they were also sensitive to the wisdom and independence that come with age and to issues of autonomy and control. For example, they tried to make sure that the household affairs were maintained in a similar way to how their elderly parents “ran things” prior to becoming dependent.

Um Ibrahim, a single Qatari female in her 40s who was the primary caretaker for her aging mother, described how “my mother sometimes likes to cook although we have two housemaids, but my mother is the one who supervises the cooking. This keeps her busy during the day”. Here, Um Ibrahim was being respectful of her mother’s many years of culinary expertise and created a safe environment for her mother to continue to be active in the kitchen. Jamie, also a single woman, said: “I love my father very much and since we are a big family and have kids, every time my father comes from outside, I make sure that his room is clean before he enters. I put everything in order just to make him happy.” These descriptions reflect that caregivers cared about sensitive issues that might disturb their elderly relatives. For example, Jamie cares about keeping her father’s room clean and tidy as she understands this makes him happy as he likes a clean place.

Sensitivity to and respect for the wishes of the elderly relative was also encountered. Karkar, a single Qatari woman in her 40s taking care of her mother and grandmother, mentioned:

My siblings and I try to arrange programs for both my mother and grandmother. For my grandmother, she likes to go to the farm, so we take her twice a month. She also likes fishing so we arrange a boat for her as she likes going to the sea a lot.

May who takes care of her mother said: “My mother does not like for me to travel. When I tell her that I am traveling and I feel that she will not accept it, I cancel. I do not like to upset her.”

Being sensitive and considerate to the requests of the elderly relative is an important part of the caregiving process and generates a mutualistic relationship.

Sometimes responding sensitively means being highly attuned to predicting the demands of the energy reserves of the care recipient. For example, Hope, a female caregiver taking care of her mother, said:

Waiting at the clinic is unbearable for my mother. She needs to go to the bathroom frequently as she takes diuretic pills. So, on the day we are going to the clinic, I stop the pills although stopping the pills make her feet swell which is not good for her. But I have no choice.

Hope is closely in tune with her mother's medication regimen and its effects on her day-to-day life.

All the people interviewed expressed a desire to respect the wishes of their elderly relatives. They expressed fulfillment in their caregiving role when the elderly relative was integrated and not isolated or lonely. While this became more difficult as cognitive or physical debility increased, all the caregivers described ongoing efforts to engage their elderly relatives as much as possible and support their participation in the daily activities of home life. By doing so, the caregivers believed that the elderly person would experience less frustration and their quality of life would be enriched.

2.4. Planning and Problem Solving

Due to the sensitive emotional care that the caregivers must provide under demanding circumstances, they develop action plans and embark on problem solving that may, in turn, create unintended feelings of anxiety. For example, Hope's ad hoc decision to not administer the diuretic (water pill) on the morning of medical appointments reflects her sensitivity to the anxiety that is created when her mother experiences the need to urinate while waiting for her doctor's appointment. However, this sort of planning and decision making can create added stress as they require family caregivers like Hope to make medical decisions for which they feel unqualified. She herself expressed misgivings related to the limited options available when she is sensitively working to support her mother's well-being.

Noor, who is employed while serving as the primary caregiver for her parents narrated a similar tale. She said, **"I work full time and if I am late to work, I ask the housemaid to give my parents their food and juice but not medication. I usually prepare their food before I leave for work so I plan ahead."**

Caregivers need to plan ahead and follow up on it to cope with certain circumstances in the caregiving process as planning an action or solving a foreseeable problem helps reduce the cause of the stressor. Mo, who is a male student taking care of his father, said: **"I feel stressed when exams are nearing but I arrange with my siblings to take care of my father."** When some caregivers find that a stressful event is approaching, they seek the help of others within the family who may solve their problems. The caregivers in this study managed to find solutions for their stressful events by either planning ahead to alleviate stress or coming up with different solutions to the problem.

2.4.1. Time management

Another skill caregivers tackle is time management. However, this is challenging for caregivers as they need to manage their time to meet their own needs and those of

the care recipients. For example, most of the caregivers in this study complained about the long hours spent waiting at the clinic or hospital. Hope emphasized this and said,

When we have an appointment for my mother at the hospital, we have to leave the house three hours before the appointment in order to avoid traffic jams and find a parking spot. Although there are parking spots for the disabled, these are always occupied. By leaving early, we arrive on time but still have to wait in the waiting room until we see the doctor.

Bless had a similar story to tell:

We have to leave the house early to avoid traffic and find a parking spot ... My father does not like to sit in a wheelchair so I hold his hand and walk with him to show him the way, which takes time ... I have to keep all of this in mind to be on time for the doctor.

2.4.2. Environmental quality

The caregivers we interviewed cared about the quality of the environment surrounding their elderly relatives. This concern for the environment was not only for its comfort and aesthetics but also for protection and security. The caregivers assumed responsibility for the quality of the environment although the financial resources for providing a comfortable and safe environment were often shared. In fact, the financial contributions required to run a house may well be a major contribution of the secondary caregivers. This is a gap in our data in so far as we did not explore in depth the economic resources required to support home caregivers, nor did we ask about who the primary financial contributor to the house⁴ was.

In particular, the elderly person's safety represents a worry that was carefully considered by the caregiver. For example, Bless, a Qatari woman in her 40s who had been taking care of her blind father in his 70s for several years, worries about her father's safety as he adapts to his vision loss. He has now been totally blind for two years. She also manages the medical care of his diabetes and hypertension. For Bless to maintain a comfortable and protective environment in the house, she prepared a room that catered to his unique needs:

In the bathroom, we have a special shower chair in the bath for my father to sit on. I arranged a wheelchair ramp for outside access. The room downstairs that I am preparing for him is equipped for a disabled person with a chair, a bed, and an exercise machine. I or my housemaid give him his massages and do nail treatment, and hair dressing. He likes to listen to the news so I always have the news channel on, on the

⁴ We considered including this line of questioning in our study design but decided that it may be too sensitive. Once we conducted the interviews, we discovered our participants were very open and candid and that this line of questioning would be entirely appropriate in the design of follow-up research.

TV at a loud volume so he can hear the news. And sometimes if there is something important that he has missed then I tell him about it. I try to make things in the house easily accessible for him, and to know his whereabouts. This is important because my father used to be an independent person. And now after he has lost his sight, I do not want him to feel that he has lost his independence. I try to make everything in the house comfortable for him.

This situation is quite similar to that of Blue's, who is a male caregiver in his 30s taking care of his paralyzed father for the past eight years. Blue explained:

Since my father was paralyzed, we have provided him a comfortable medical bed with a medical mattress that helps him sleep and avoid any bed injuries. We also have a wheelchair for him and we arranged for his bathroom to have all the handles that a disabled person needs.

All of the participants in this study initiated a discussion about the safety and security of their elderly relatives. Preventing falls and avoiding medical complications were a key focus of the caregivers' concern. The caregivers noted that their environment had to be comfortable and safe. They also noted that their caregiving work was easier when they had the right equipment and the house was laid out in a way that was conducive to physical care. Keeping their elderly relative safe also included the issue of caregivers being available to address the needs of the elderly relative 24 hours a day. It was in these discussions that the ambivalence of caregivers about housemaids arose. There was a theme in the data that indicated that it was difficult for the primary caregivers to **"trust"** housemaids. This was likely related to language barriers or lack of experience in providing personal care⁵. Also, the transient nature of the migrant domestic labor force seemed to be a factor in the caregivers' feelings of mistrust. The high turnover among housemaids also caused the caregivers to make difficult decisions regarding leaving the elderly relative **"alone"** with a housemaid, which, in turn, created issues of isolation among caregivers who did not have **"respite"** from their responsibilities as they worried that secondary caregivers did not have the knowledge or skills to adequately respond to **"safety"** issues that may arise in their absence (such as hypoglycemia, falls, periods of confusion, and so forth).

2.5. Summary of the Roles and Responsibilities of Caregivers

When caregiving roles are well established, they can be taken for granted. However, we suggest that the amount of care provided to aging family members may have policy implications. In Qatar, the social structure, including the government, employers and health insurers', places limitations on the availability of formal help, which have considerable implications for the informal or unpaid caregiving labor of women

⁵ Further investigation into the issues of migrant domestic labor as they relate to care of the elderly in Qatar is an important topic for future research.

(or, in the case of domestic workers, low paid). This is a particular challenge for poor and working-class families who are unable to purchase formal care. The situation gets worse for non-Qatari caregivers as they do not get any formal assistance from the government beyond subsidized medications. Although better off, the social assistance provided to Qatari nationals also has its limitations.

Cultural gender norms play a major role in the experiences of family caregivers. Men are often viewed as being responsible for the financial security of the household and caregiving is primarily seen as natural to women. Although several of the primary women caregivers we interviewed were employed outside the house, their income did not seem to be the main household income. These culturally accepted gender roles seem to justify men's limited involvement, which was particularly evident for both Green and May whose brothers did not contribute significantly to caregiving duties. This finding is not unique to Qatar. Our small study did, however, uncover a notable exception: the dedicated work of a young male nursing student, Mo, who was the primary caregiver for his severely disabled father, indicating in his interview that part of his motivation to seek a professional nursing education was to be able to care for his father more effectively. There was substantial data revealing frequent family gatherings as well. In contrast to the published literature, the strong themes of roles and responsibilities and gender in our data seem a unique finding related to these family caregiving experiences.

CHAPTER THREE: THE STRESSES OF CAREGIVING

The participant interviews have painted a complex picture of caregiving and the demands that it places on caregivers. This suggests that the concept of providing care to elderly relatives is alive or on-the-move because it varies from person to person depending on the context in which the caregiving occurs, and the type of caregiving work involved. Also, the responsibilities of caregivers vary greatly depending on the needs of the care recipient and a multiplicity of other interfacing factors. Furthermore, this caregiving process evolves over time. Hence, this chapter focuses on the stresses of caregiving and more specifically, the antecedents to stress (stressors) and the burdens (stressor-outcomes or stress) reported by the participants linked to their caregiving experiences. It is important to note that the stressors and stress discussed do not occur in isolation. Rather, they can co-occur and interface with each other in complex ways.

3.1. Work Processes and Stress

Many caregivers described stress as arising from demands directly involved in caregiving. Mo discussed how stress emerged from the duties required to take care of the recipient and the physical environment in which this task occurred. He gave an example of giving his father a bath and how this task was made difficult by the physical structure of the bathroom that both he and his father had available to them. In this case, the space and place where caregiving occurs impact the experience of providing care and stresses result from the caregiving activity. Others described how providing medical care to their loved ones was a source of stress. Noor discussed how giving **“injections”** to her loved one was stressful because she worried that he **“suffered.”** As a result of this concern, Noor described **“feeling afraid to give the injection,”** and with no other support available to assist her in this caregiving requirement—**“my mother cannot ... she has neurological problems ...”**—the sole responsibility fell on her. Another similar stress was described by Salma who explained that not knowing how to provide the needed medical care was a source of stress.

3.2. Demanding Behaviors of Care Recipients

Other caregivers discussed the demanding behaviors of their loved ones as a source of stress. Blue mentioned how he experienced stress due to a combination of demanding behaviors from his father including how he would get **“very agitated”** and have **“mood swing”** which Blue found difficult to handle. He described how his father would sometimes **“shout”** at people and **“may say something not nice”**. Other times, he explained that his father would become **“violent—he uses his hand,”** which he found particularly **“stressful”**. Blue attributed this behavior to the fact that his father had a stroke and this contrasted with his past behavior prior to the stroke when **“he used to be a very gentle and nice person.”** The stress associated with these behaviors appeared to intensify at nighttime **“for somebody who is sleeping in the house.”** Nevertheless, such demanding behaviors **“affect everybody, even his friends”**.

Another demanding behavior was described by Abu Ali, who discussed the demanding task of getting his father to eat healthy food:

Regarding food, he likes foods with high amounts of sugar like dates, chocolates and sweet pastries. We always keep telling him ‘no, that is not good for you’ and he feels upset to the point ... [where] he just eats it regardless of anything. For example, he doesn’t like diet sugar and he takes white sugar in a bowl and keeps it in his room too. When I see him, I don’t like to take it from him, so I leave it. I put the dates and chocolate on the table and he eats them and he uses the sugar ... If there is awareness in such situations, it would be great.

Such persistent behaviors were also described by Karkar, who explained that **“we suffer with my grandmother”** and mother because **“they do what they like”**.

Karkar: They are not convinced. My mother and my grandmother will not be convinced, not at all, but they do what they like.

Interviewer: Even if this can harm their health?

Participant: Yes. They do it. Even if we say to them: ‘Be careful when eating nuts or drinking tea.’ When we are around, they intentionally eat nuts and drink tea ... They know it harms them, but they are still doing it, yes. This is the mentality I am talking about.

Karkar described such behaviors as being **“closed-minded,”** and because of this close-mindedness, **“it sometimes reaches the point of fighting”** when she tried to get her mother and grandmother to listen. As a result of these behaviors, she described getting **“upset”**. Such demanding behaviors faced by Abu Ali, Blue and Karkar represented some of the challenges they experienced in getting their loved one to eat healthily and comply with their medication regimen. Abu Ali suggested that providing more information to caregivers in this area — raising **“awareness in such situations”** — would be beneficial.

Other demanding behaviors were described by Amal, who explained that her mother **“talk[s] too much ... sometimes I feel annoyed, because she talks too much.”** As such, the continuous talking combined with her inability to talk to her mother about her own family **“pressures”** acted as a source of stress.

3.3. Isolation

Many caregivers described isolation as an antecedent to the loneliness resulting from their caregiving demands. Halom, for instance, described a **“lack of social contact”** as a stress factor, mentioning the following:

Lack of social contact. Lack of contact with people my own age. The people we used to know have left, because Qatar is not a country that allows immigration. When you get old or you resign from your job, you leave. The people who are now coming belong to our children's generation.

Halom explained how being isolated contrasted with how she used to **“travel quite a bit”** with her partner. She contrasted this to now where **“I don't want to leave my husband. Unless another family member—either our daughter or my husband's sister—can come over ...”**

Blue described a process that occurred over time whereby his social relationships began to change due to the demands of caregiving. This was precipitated by taking time off from his paid job:

I quit my job for nearly two or three years. I just quit it and socially we are ok, but also it affects our ... people used to call us, people used to visit us, but on the other hand some of the people expect you to visit them back if something happens to them. I see, right now, my relationships with my friends, the closest ones still care, but I don't see them regularly, but we talk to each other. But it is ok because they understand the situation. Other people do not understand the situation. For example, if I want to go out of the house, I just go ... in the night or when it is an emergency, I have limited hours to interact with my friends.

Blue did not talk about isolation per se but, rather, described a process whereby his relationships with his friends were modified or fluctuated based on his caregiving responsibilities.

3.4. Being Absent

Many caregivers describe being absent from home as a stressor. Jigi illustrated this concern when she explained how she worried about her mother's well-being when she was not present to provide care. She worried about her mother **“fall[ing] down”** when **“no one is with her at home.”** She went on to explain how the stress of not being present is **“the main problem that I have”**. While she tried to mitigate this stress by **“calling her every hour,”** this solution did not always work: **“Maybe she is asleep ... I wish I had someone to help right now just to keep an eye on her”**.

Mony expressed similar sentiments. She explained how when she was away from her mother and father, **“my mind was [still] with them”**. She said that even when she was away from her parents, she worried about the care they were receiving:

For example, I'm at the university, but my mind is with them. I'm sure that there is one person at home there taking care of them, still, I'm worried about what they are doing and who will care for them. Because my sister and I are at the university, my brothers care for my father and mother but not as much as we do.

Not being present at home was a stressor for Mony, stemming from her concerns about the quality of care her parents were receiving when she was not there. Yet, she also expressed how competing demands, such as those from being a university student, compounded this stressor. Being absent from home acted as a stressor for many participants as it represented a discontinuity in their caregiving work. The time spent by caregivers outside the house and away from their elderly relatives resulted in feelings of worry and guilt for some.

3.5. Financial Stressors

Other stressors discussed by participants included finances. Abu Ali, for instance, discussed how providing **“treatments”** for his father were **“expensive as he is not a resident.”** Others, like Green, explained how medication costs were **“expensive.”** While some medications were costlier than others, she elucidated, **“The bill sometimes reaches around 300 Qatari Riyal,”** and because her **“father is retired, mother [is] not working, [and] I am the eldest”**, such financial stressors were particularly problematic. Green also explained how it was not just the medication expenses that were stressful, she explained there were costs associated with going to his appointment for **“blood injections”** and getting his medication—**“400 [Qatari Riyal] per month for taxis, only for taxis, besides medication”**. Others, like Karkar, explained that traveling with her mother puts her in a positive **“mood”**. However, travel costs are difficult for her to **“handle”**.

3.6. External Stressors

3.6.1. Formal support

Some caregivers described how external stressors (stressors occurring outside of direct caregiving responsibilities) acted as sources of stress. Halom described, for instance, the stress of the possibility of **“losing the support”** that is currently being provided by her husband's former employer.

That gives me sleepless nights, yes. Because although I was told, ‘Don't worry, everything will continue exactly the same way,’ but the people who are in charge now may change. You see, it's also a different generation of Qatar. They might have different ideas. They might have ideological ideas of a knowledge-based society. A business-based society might take over one day, and then I don't know whether we would still be supported. But for the time being, it's okay.

Halom explained her husband receives support from her husband's former employer through a third-party insurance company for healthcare services that supplemented the healthcare services offered by the State. She explained that the possibility of losing this support **"gives me sleepless nights"**, even though she has been reassured by her husband's former employer that **"everything will continue exactly the same way"**. Despite this reassurance, she is worried about the possibility that things **"may change"** when **"a different generation"** with **"different ideas"** takes over. This particular stress points to the inadequacies of the current organizational structure of the healthcare system in Qatar.

Dream described a complex mix of stressors that greatly impacted her after her father was admitted to the hospital after an acute event—a cardiac arrest requiring surgery. She described how she was the main person staying with her father at the hospital. While she was at the hospital, she described two primary stressors: serving as the primary caregiver and staying with her father at the hospital with little to no relief while he recovered from surgery; and additional demands placed upon her by hospital staff due to her medical background.

First, she described how she experienced a lack of sleep due to staying with her father at the hospital. While she tried to explain to family members that she needed support because, **"I cannot stay at the hospital all the time, I need somebody to take shifts so that I can rest"**, her family was under the misconception that **"I am sleeping"** at the hospital. In talking about this experience, she was adamant that **"I was not sleeping"** and noted that **"this is huge pressure I felt in my life"** because of other external demands like going to school. Stress here resulted from not only having to come to terms with her father's illness and providing him with support, but also having to look after him in a way that is typically done by doctors and nurses.

Some caregivers questioned the quality of care their loved ones were receiving in hospital. Amal described how the hospital that provided care to her loved one **"didn't treat him well."** For Dream, concerns arose about the quality of care her father was receiving. This came to the forefront when she spoke about her father being discharged from the hospital. She felt as though **"he need[ed] to stay longer at the hospital. And four days after surgery, they discharged him. I felt like, 'This is a heart surgery. Why are you discharging the patient early?'"** In addition to this stressor, Dream began **"blaming"** herself for not being able to take care of her father.

Other examples of formal services and support being a source of stress were given by Salma. Salma described getting contradictory information from medical professionals about what she should feed her loved one: **"One doctor tells her 'don't eat anything green'. Another doctor tells her 'you can eat it but in certain quantities'. So how do I know which is right? This is the problem."**

3.6.2. External demands

Others like Mo described how demands unrelated to caregiving acted as a stressor. He expressed, for instance, how he felt guilty that he was not providing his father with the **"right care"** due to **"other stressors affecting me"**. He explained how the demands of being a student interfered with the demands of being his father's caregiver:

Sometimes he called me in the middle of a lecture. I went out of the classroom and when I answered the phone, he is like, 'I want to go to bathroom now'. I don't know what to do in this situation. Sometimes I ignore the lecture and go back home, help him go to the bathroom and then come back to the university and the lecture is almost over. Sometimes I [do not] see the point in going back to the university, so I stay at home. That's affecting my grade, affecting my performance ... I feel bad because I missed the lecture at the university ... Yeah, it's really stressful.

The stress Mo spoke of was in part due to the complexities of having to navigate between being a student and being “on-call,” so to speak, to provide care to his father. Furthermore, it appeared that there was also stress derived from Mo’s daily routines being interrupted by the needs of his father.

We can see in Mo and Abu Ali’s cases that there is tension between the desires of these caregivers to fulfill the desires of their loved ones and to juggle external demands placed upon them.

3.6.3. Visa issues

Some caregivers discussed visa issues as a stressor. Jigi explained how she experienced difficulty getting a visa for her mother to be allowed to stay in Qatar. She explained how she not only had difficulty sponsoring her mother but once her mother turned 60, additional obstacles emerged. This is because, according to Jigi, “after 60, they normally don't give you a visa”. Jigi explained the complicated visits of her brother to the “labor court” in order to make a case for their mother to stay in Qatar.

Moreover, visa issues acted as a stressor for caregivers also by adding to the costs associated with caregiving, as visa issues made it challenging for caregivers to access services and other forms of support for their loved ones. Some caregivers spoke about how visa issues acted as an obstacle that kept them from hiring additional support (e.g. nurse) for their loved ones.

3.6.4. Traffic

Many caregivers discussed more pragmatic stresses associated with going to the hospital. Hope described these challenges as follows:

When you take him to the hospital, your suffering starts from the time you leave the house. When you reach the hospital, you do not find space to park the car. My mother has a [disabled] sticker yet I can't find parking easily. The parking [is] used [by people who have] no sticker. There is a lack of awareness. Here, the pressure begins to build, so I have to go as early as possible to avoid traffic and to find a parking spot.

In addition to traffic and parking challenges experienced by individuals going to medical appointments, Hope discussed additional stressors including difficulties setting up appointments to see the doctor, the sometimes extended waiting time (e.g. two hours) after they arrive to a scheduled appointment, and other instances when they arrived for an appointment to find out that **“the doctor [is] not working today”**:

Last Monday, we went to two appointments [at two different hospitals]. We had two appointments. I was exhausted physically. The doctor told me to take her to the Emergency Unit at noon for the x-ray required and he said ‘I will call the doctor because this is an urgent case.’ I went home, took [a] shower and had lunch and I didn’t get to rest. I went back to the hospital. I went during rush hour and it took me almost one hour to reach the hospital. I was driving around the Emergency Unit as there were no available parking spots ... I went around for more than an hour and a half to find out in the end that the ‘doctor [is] not working today.’

Noor expressed similar sentiments when she discussed the stress associated with waiting for formal services and support (e.g. medical and pharmaceutical services). She described the following:

When we go to the hospital, we feel worried ... Because of the waiting list, I have to be patient but we get tired with more and more waiting. When I go with my mother, we wait outside longer than we spend inside with the doctor. She goes back exhausted with swollen eyes and hands. There is a wait for the medication [to be filled by the pharmacy]. Another hour for the medication. All this time waiting makes her tired. I am forced to take her to a private hospital instead of taking her to the government hospital. I buy the medication, paying from my pocket, it is better than waiting. We suffer from this, no flexibility and difficult dealings.

The stresses associated with waiting for extended periods of time not only impact the caregiver but, as exemplified by Noor, also have an impact on the care recipients. Extended waiting resulted in their exhaustion and potentially exacerbated other physical ailments too (e.g. swollen legs and feet).

3.7. Other Stressors

One caregiver discussed the stigma associated with caregiving. Mony explained how when she takes her father out in public, many **“people stare at him”**. She hinted that this caused her embarrassment—**“I don’t want anyone to see my father in a wheelchair”**. Another unique stressor Mony mentioned was related to her not understanding why her father became ill in the first place. She attempted to understand why he became ill through a religious lens—**“I cannot see what he did in the past, I just see the good things maybe ... I don’t know because God did this, why isn’t there a way to treat him.”** For Mony, her stress was linked with her fear of losing her father

as she was concerned that her father was “get[ting] worse, worse, [and] worse,” and she did not know why.

A few participants discussed experiencing stress when gender-specific cultural norms and expectations were not met or were eroded. For Green, this occurred in the hospital when she was in the “male” ward of the hospital caring for her father. She described how she had been “afraid” that her father had a serious heart infection due to a recent surgery. While waiting to find out the results of a “culture,” she decided to “**spend the night with my father [at the hospital] because I am the eldest daughter**”. However, as many of the hospital facilities in Qatar are gender specific (e.g. with separate male and female wards), she noted, “**where did I spend the night? It was in [the] men’s ward. They were all men. That was the problem**”.

3.8. Stressor-Outcomes – Stress

The last section of this chapter focuses on the burdens, stressor outcomes, or stresses of caregiving that resulted from the stressors in the aforementioned section. Our data revealed that family caregivers in Qatar are positioned to shoulder complex caregiving responsibilities for seriously compromised elderly loved ones for a period of several years.⁶ The combination of complex eldercare, demands of paid employment, increasing economic pressures, and the physical and emotional toll of long-term caregiving can have a serious impact on the health of caregivers. Our data suggests that health impacts are increased when the caregiving extends for years and is accompanied by the steady deterioration of the elderly relative’s independence in terms of activities of daily living. And, when resources for outside help are limited, then the deleterious impact on the caregiver are magnified.

The work of the caregiver can become medically complex and require in-depth knowledge of chronic disease management, which increases the stress and worry that accompany their caregiving responsibilities. Our data analysis examines caregiver perceptions of the physical and psychological impact of caregiving. In particular, we look at the psychological issues related to caregiver stress due to the lack of supportive resources and the emotions (such as guilt and anger) experienced by our participants. We also note risks to physical health which include fatigue, disturbed sleep, and the headaches and pain from which some of our respondents suffer. Thus, this section analyses the challenges to the psychological and physical health that have an impact on the well-being of caregivers.

The caregivers in our study expressed several issues that led to stress, which had negative psychological impacts over time. Those issues were related with how to handle emotions of guilt and anger, and how to manage the limited resources and pressures that ensued from juggling many demands in their limited time. We found that these issues are circular in so far as feelings of anger produce feelings of guilt. Similarly, the

⁶ The caregivers in our study, on average, had been providing care for six years. Qualitatively, our informants indicated that caregiving became more complex and the issues we described in this chapter intensified as the older person became physically more dependent and/or more cognitively impaired.

employment necessary to meet the economic needs of the household reduces time available for caregiving. Thus, the issues that impact the psychological well-being of caregivers overlap with each other and create a situation of tenuous stability whereby any unexpected event can overwhelm the caregiver's capacity to respond and can create ineffective coping.

Our data revealed that stress was experienced by all the caregivers we interviewed here in Qatar. It was our impression that for some of the caregivers, the stress was serious and ongoing, and that it placed the caregivers' psychological and physical health at risk, as previously indicated in the literature (Cohen, Tom, & Robin, 1983; Pearlin, Mullan, Semple, & Skaff, 1990; Schumacher et al., 2008). That said, stress was experienced differently by the 22 participants and was highly dependent on the circumstances of the caregiver and care recipient. We outline below the burdens of caregiving reported by participants.

3.8.1. Guilt

Guilt arose as a sense of inadequacy, expressed as not being able to do enough or the inability to attend to the entire family. This arose due to personal issues related to conflicting demands from other people, such as employees, children or other relatives. Some of the research participants felt guilty for not giving more support to their loved one. They felt guilty for not spending more time or being unable to provide more financial support for equipment needed. Other sources of guilt surfaced when the caregiver felt that they had not responded well to a situation, such as those times when tempers flared and voices were raised, or when they had not shown their elderly relative respect.

Employed participants were subject to other sources of guilt. They felt guilty for not being able to achieve a good work-life balance. They also felt guilty when their paid work interfered with their desire to care for their elderly relative. They felt guilt about their performance at work as well, worrying about the lack of attention to their job, or the amount of time that was required away from work in order to meet their home caregiving obligations. Guilt and the duty of caregiving were intimately connected, even consuming and overpowering for some participants. They were overwhelmed by their inability to finish tasks, experiencing limited control over the demands placed on them in relation to time and people. They experienced ongoing guilt, never quite measuring up to the expectations they had for themselves.

Jigi described how taking care of her mother resulted in such guilt: **“My mother lives with me and I have to take care of her when I come home from work, and take care of my kids and husband. Sometimes I feel too tired and feel guilty that I am not spending much time with her.”**

3.8.2. Anger

A number of our participants expressed times when they experienced strong feelings of anger and described how they occasionally cursed, yelled, became irritated and/or withdrew. Caregiver anger was linked to feeling out of control, overwhelmed,

anxious, scared, tired or stressed. Some caregivers expressed anger towards other family members who they judged were not helping enough. They viewed this as unfair. Similar to the feelings of guilt described above, some caregivers became angry at themselves for not doing more.

For instance, Karkar said: **“I feel nervous and angry when they do not take their medications and follow the doctor’s instructions. This frustrates me and I get angry and end the discussion with a fight”**. Others like Adil gave another example of anger arising from caregiving: **“One day I came from work and was tired, and my mother said she wanted additional things from the shop, I raised my voice and got angry that I just came and feel tired as when I had been there at the shop, she had been talking to me on the phone, but she hadn’t requested these additional things. ...”**

3.8.3. Sadness

Some of the caregivers expressed deep sadness about being witnesses to the rapid or slow decline of their relative. Blue explained how he had to **“leave my job for two years to take care of my father who was paralyzed and could not move. It was a very hard time for me and hard to accept the sudden illness experienced by my father. Suddenly, he had a stroke and was not moving or talking”**. For many caregivers, the changes brought on by their loved one’s illness resulted in a profound sadness that was concomitant with coming to terms with the life-changing effects on their loved one and family.

3.8.4. Frustration

The participants in this report described strong feelings of frustration. These feelings were most often elicited in relation to access to services, the obstacles that were faced in supporting ADL with inadequate equipment, or the demands of physically taking care of their elderly relative. Indeed, a caregiver may have too much to do and no time in which to do it or may feel unappreciated. According to Lazarus’ (1993) theory of stress, frustration often arises out of trying to change an uncontrollable circumstance.

Bless gave an example of this frustration when she disclosed the following:

I feel frustrated when parking the car for the past two years now. The parking spot exists but if you want to park your car, you find there is another car parked there. Another frustrating issue is the waiting time in the clinic to see the doctor. The waiting time is long, and my father is diabetic and cannot stay long. He gets frustrated and keeps asking me, ‘When am I going to see the doctor?’. He becomes impatient.

3.8.5. Isolation and loneliness

Studies have shown that increased demands on the caregiver to take care of the elderly person can decrease the caregiver’s quality of life and enjoyment

(White, Lauzon, Yaffe, & Wood-Dauphinee, 2004). This was consistent with our data⁷ as many caregivers reported a decreased enjoyment of life due to their caregiving responsibilities. Many of the caregivers we spoke to stated that the time needed for caregiving took away from the time needed to care for their families or themselves, in addition to resulting in less time to socialize and limited recreational activities to partake in. In turn, these realities of caregiving diminished their quality of life. An important finding of this study is that caregivers expressed feelings of isolation stemming from a loss of social networks due to decreased leisure time.

May provided an example of isolation and loneliness when she explained how she **“Come[s] from work and take[s] care of my mother’s medications and if she needs anything, I do it for her. I do not have the time to socialize or go out with friends because if I leave the house (after work), my mother gets upset ...”** Abu Ali expressed similar sentiments when he revealed: **“I work full time and am married with children. My father stays with us but when I come home late, sometimes not before 6 p.m., I have to strike a balance between my family and him. I sit with him for some time and then have to check on my children and stay with them before they go to sleep. He gets upset but I feel tired by the end of the day as time is too short to do everything.”**

3.9. Health Challenges and Stress

The demands of caregiving also impact the physiological health of the caregiver. Participants reported feelings of fatigue, sleepless nights and headaches/pains. They also raised concerns about their capacity to sustain care over time. These physical challenges were reported to be the most severe when their elderly relative was experiencing a serious illness or recovering from surgery. In such situations, the caregiver exerts more effort and energy to take care of the elderly person, which leads to overall fatigue, and undermines the caregiver’s own health. We found the three physical health challenges that emerged from the interviews were fatigue, disturbed sleep, and headaches.

Mony, for example, described sleep disturbances and having **“too much pressure”** from caregiving and other aspects of her life as taking a physical toll on her health. She reported the following:

I was 17 years old when my mom got coronary artery disease. She had severe pain in her chest. She was at Hamad Hospital and wasn’t aware of her diagnosis. I stayed with my mom and did not sleep that whole night. It was very stressful because it was the first time it happened to our family and later she had to go to Iran for surgery. I felt alone and I did not speak to anyone because I was thinking about my mom. The same thing happened to my father and he had to have surgery ... these circumstances made me forfeit my university studies because of too much stress and too much pressure.

⁷ However, our data also demonstrated that there are many positive effects that caregivers experience related to the maintenance of loving relationships and a sense of being a good person and doing the right thing that for many translated into a sense of spiritual reward and confirmation of faith.

Dream provided another example of the complexity of exhaustion that arose from both the caregiving and external demands placed on her: **“Sometimes my mother will say, ‘Come and help us,’ when I am in the middle of giving the kids a bath. Or I’m helping them with dinner, so I need to feed them. So I tell her, ‘I’m experiencing pressure from my studies and I’m tired from work and you are asking me to help you’ ...”**

Lastly, caregivers in our study reported stress-induced headaches and migraines. Hope explained she not only feels **“physically tired, exhausted and pain in my body”** resulting from the demands of caregiving but she sometimes suffers from **“headaches”**. She went on to explain:

Waiting too long at the hospital is frustrating and makes me stressed ... I take care of my mother and my suffering starts when she has an appointment at the hospital. This is because the traffic is bad on the way to the hospital and I do not find parking when I arrive at the hospital. After that, when we reach the clinic, there are always patients ahead of us and my mother is in a wheelchair so she cannot wait long but they do not give priority to the elderly. Also, she needs to go to the bathroom and on the day of the hospital appointment, I stop her diuretic pills, which is not good because her legs become swollen. ... I feel impatient but I try not to show her my impatience. By the time we finish and go home, I am physically tired, exhausted and have pain in my body. Sometimes I suffer from headaches. Waiting too long at the hospital is frustrating and makes me stressed.

3.10. Conclusion

This chapter reported on the stressors and burdens of caregiving. Caregiving can place a multiplicity of demands on caregivers, which can impact the psychological and physical health of participants. The majority of the caregivers interviewed stated that the time spent caregiving took away from time to care for their families or themselves, thus allowing less time to socialize with friends and families or for recreational activities. This along with feelings of isolation at times negatively affects their quality of life.

This chapter highlighted the impact of caregiving on the caregiver’s health and described what caregivers experienced during the process of caregiving that can affect their psychological and physical health. In other words, we focused on the different types of psychological and physiological tolls that caregiving can place on caregivers, and the antecedents to these tolls. While all caregivers were able to discuss many different stressors and burdens of caregiving, most seemed to be coping well (Chappell et al., 2008). The chapter that follows focuses on the different coping strategies and resources employed by caregivers to cope with these demands. We also focus on the other side of caregiving, its positives.

CHAPTER FOUR: COPING AND THE POSITIVES OF CAREGIVING

Family home caregivers play an important role in the health and quality of life of elderly people. In particular, chronically ill elderly people are dependent upon family caregivers to carry out everyday activities. The previous chapters explained the role of caregivers (chapter 2) and the stressors associated with caregiving and their impact on the health of caregivers (chapter 3). Overall, caregivers experienced stress and expressed a need for informal and formal support services for them and their loved ones.

Despite the demands of caregiving explored in the previous chapter, most appeared to be coping well. This finding is aligned with other research that suggests that the majority of caregivers **“do not emerge as overburdened and unable to cope”**. This chapter explores the coping strategies and resources utilized by caregivers to deal with the demands of caregiving. We also report on the positives of caregiving. The focus of this chapter is aligned with Chappell and colleagues’ (2008) call for more research that focuses on **“the positive consequences of caregiving and the beneficial coping skills of caregivers”** (Chappell et al., 2008, p. 321).

4.1. Coping

When asked about whether or not he has a difficult time coping, one of the informants, Adil, responded passionately:

No, not at all. I have been asked a similar question about how I go to work and take care of my mother and take her to hospital appointments. I said if need be, I will resign from my job, ignore every personal issue and sit at my mother’s feet. And I don’t want a salary or need work, all I need is to be near my mother. This is the most important thing in my life. I don’t think there is a person who can love me the way she loves me. She is my mother. I have never loved someone like I have loved her. I don’t call it a service but my duty. This is my duty to my mother. If I am not able to give her all of that, to whom should I give it then? If you don’t care for your mother and father, you will not give good care to anyone else and you can’t trust them. Do I have pressures? No, no way. This is the thing that I love most.

How caregivers in this study coped with the demands of caregiving were diverse and varied depending on the context in which coping occurred. Furthermore, caregivers often deployed multiple strategies and accessed multiple resources in order to cope. The strategies discussed below include withdrawal, avoidance coping, giving in, being active, and religion. In addition to the different types of coping strategies, caregivers utilized a variety of formal and informal forms of support. With that said, it is important to note that the use of the word **“coping”** did not resonate with some caregivers. In the quote at the beginning of this section, Adil describes a much more complex worldview that is not captured in the word **“coping”**.

4.2. Withdrawal

Some caregivers described withdrawing from stressful encounters or contexts as a way of managing the demands of caregiving. Blue, for example, described going out **“to the front yard”** for a break when her father’s demanding behavior became challenging. Also, Halom described how withdrawing to a place of solitude facilitated her coping. She explained how she withdrew to **“my bedroom, sitting room with the TV, and then to the library, my desktop, the computer”**. She described this area as **“my world”** where she could **“withdraw”**. She went on to explain how this alleviates her stress that is caused by her duty managing a team of caregivers: **“So stress for me comes from being very active during the day, so relaxing in the evening helps with not feeling too sorry for myself.”** For Jigi, a form of withdrawal included listening to music. **“When I turn the music on my mum knows that I am angry so she ignores me until I calm down. Music helps a lot.”**

4.3. Avoidance Coping

Another coping strategy of caregivers was avoidance coping, where they tried to avoid thinking about a particularly stressful issue or tried to avoid a particular problem. Noor gave an example of how she would avoid going to hospital appointments because of the stress of waiting for formal services and support.

Other caregivers described how they avoided thinking about stressor situations as a method of coping. Halom, for instance, described how she copes with the fear of losing financial support to care for her husband:

I give it a bit of thought, and then I just try to distract myself. I read or I watch television. I must say the distraction has helped me through difficult periods in our life ... The minute I think too much about it, I can’t cope, I can’t function. So I shut it out. And I just continue on with what is demanded of me.

It is important to note that distraction or avoidance coping does not address the underlying problem causing the stress. As a result, such coping strategies, while working in the short-term, might have limited long-term benefits. Dream illustrated the problematic nature of this type of coping when she explained how she suppresses herself and compartmentalizes caregiving work with other demands placed on her.

I suppress myself like when I’m at the hospital. I am there for my dad. When I go to the university, it’s for university to finish things. But if I’m telling you that I have gotten over it from that point on—no, sometimes I’m still feeling it, yeah.

Dream went on to explain how this type of coping strategy allows her to **“cope for the moment,”** but such coping only has a short-term impact; she said: **“Yeah, I coped for the moment, but still for the ... I feel like, one day I am sitting and memorizing**

everything [for school] and I find myself still teary eyed about the things that happened to me.”

Whereas withdrawing to a place of solitude could be viewed as a way of receiving respite from caregiving, avoidance coping on the other hand represented short-term moments of relief that did not address the causes of the stress.

4.4. Giving In

While some caregivers described withdrawing as a coping strategy, others described giving in as a strategy to mediate stressful events. Abu Ali, for example, described a sort of acquiescence coping where he agreed to give in to the wishes of his father when, for example, **“he gets upset”** about being told what to eat. **“‘Don’t tell me what to eat’ he sometimes tells me”**. He went on to explain how he will often cope by saying to his father, **“As you like. This is your house ...”**

4.5. Being Proactive

Demonstrating the complexity of coping, many caregivers discussed using a combination of coping styles and resources. For example, although Amal described how she copes by thinking positively and **“controlling”** her mind, she also described being an active problem solver to cope with the stresses of caregiving. **“From my side, I try to solve it. I don’t like to live with a problem. I prefer to find a solution and enjoy searching for the solution, but I don’t like to live with the problem.”**

Other forms of being proactive as a coping strategy included exercising. Dream discussed how exercising had a positive mental impact on her. She explained that when she goes to the gym, it makes her feel **“relaxed”**. Listening to her was especially poignant as she contrasted her stress levels after she has a chance to exercise to times when she is unable to go to the gym.

Being proactive for these caregivers contrasted significantly with avoidance coping; whereas the latter is geared towards avoiding a problem or coping with it on a short-term basis, being proactive as a coping strategy appeared to be aimed at addressing the stressor and thus, mitigating its effects.

Lastly, some caregivers explained how they coped by actively staying in constant communication with their loved ones when they were not present at home. For example, because there was no one at her place to assist her mother in her absence, Jigi coped by phoning her mother constantly to check up on her. This was particularly vital for Jigi as she was concerned that something could happen to her mother when **“her sugar level goes down”**.

[I] wish that I had someone to help right now just to keep an eye on her. What if she falls down and no one is with her at home? This is the time when you need someone to help. So, the problem is I keep calling her every hour but maybe she is asleep, so this again disturbs her.

Constantly staying in contact with her loved one reduced Jigi's fear of something bad happening to her. Furthermore, actively staying in constant communication with her mother allowed Jigi to give care from afar.

4.6. Religion

Caregivers also discussed how they drew strength from their religious beliefs to cope with the demands of caregiving. Dream described how she turned to religion to cope in light of her limited network of social support. She explained how turning to Allah “really worked”:

I told [my friend], ‘I don’t know where to go.’ I was telling her, ‘I feel I’m lost, I don’t know what to do.’ Then she told me, ‘You just go back to Allah and pray to God.’ She said, ‘Forget about everything ... We came from and were created by Allah, so go back to Allah and pray. The more prayers you perform, the more relaxed you will be.

In responding to a question asking Noor how she copes with the demands of caregiving, she responded saying: **“I don’t (laughs). Praying and reading the Qur’an. Life goes on. I sometimes go to the mall, go shopping, and go to the shop for my personal needs. I relieve my stress that way.”**

For many participants, religiosity played a central role in not only how they gave meaning to caregiving but also how they attempted to cope with the demands of caregiving.

4.7. Social Support

In addition to using a multiplicity of strategies, caregivers spoke about the different types of formal and informal support they rely on. Social support is viewed here as a potential coping resource that caregivers access in order to cope with the demands of caregiving. It is important to note that the word social support is a complex term that has been used in different ways in different research (Chappell et al., 2008). Here, social support is conceptualized as having a positive, negative, or neutral impact on a caregiver's stress-coping process depending on how the caregiver gives meaning to the support. For example, we saw in the previous chapter that a major stressor for caregivers was the formal support system. Caregiver appraisal of the social support they receive determines the impact of that form of support on their stress-coping process; if social support is assessed in a negative light, it will likely impact their stress-coping process in a problematic way.

This section is separated into two parts: informal and formal support. Formal support refers to paid assistance given to an individual by a group or agency. In contrast, informal support can be defined as unpaid assistance, usually from family, friends and neighbors (Pearlin et al., 1990). In this section, we also discuss the work of foreign domestic caregivers, known colloquially as “maids” or “housemaids”, as a form of

support used by caregivers to cope. Our discussion of foreign domestic caregivers blurs the line between formal and informal support. On the one hand, foreign domestic caregivers are a paid support. Yet, on the other hand, they can also be viewed as an informal support as their work is undervalued and poorly understood; they lack the specific training characteristics of paid support, and their role lacks institutional recognition. In fact, as we saw, many foreign domestic caregivers were not only central to the process of coping for both Qatari and non-Qatari caregivers, but these individuals also acted as caregivers for the elderly person.

4.8. Informal Support (Familial Support)

Caregivers utilized a variety of informal support. Dream described how she manages the demands of caregiving by depending on familial support in times of need. She said when she needed to study for exams at school, she would call her brother; stating that: **“Sometimes, I get really tired. I call my brother to stay at home for this period of time, for a week during my final exams, because I know that I will keep myself busy with studying. We manage it.”**

Others like Mony described how she seeks support from her sister during demanding times; she said: **“I have my sister. So, we support each other. If for example, I have a midterm, I stay in my room, and say, ‘Could you take care of them?’ She says, ‘Yes, I will stay with them.’”**

Some caregivers described how they sought out informal support from other family members during times of need. Such forms of social support provided caregivers with the autonomy to continue in their other roles or fulfill other responsibilities.

Informal support also acted as a coping strategy as they allowed individuals to talk with others about the demands of caregiving.

4.9. Paid Support

Many caregivers spoke about the different forms of paid support accessed by them to cope with the demands of caregiving. As seen in the previous chapter, many caregivers accessed support provided by the State of Qatar in the form of hospital services, which for some was also a source of stress. However, for many caregivers, formal (paid) support was central to their caregiving experience and to the stress-coping process. Some caregivers used specially trained individuals to assist them in providing care to their loved one while others described using foreign domestic caregivers with less or no formal training to assist with caregiving. Halom described having access to formally trained nurses to provide 24-hour support to her husband. She represented the most privileged side of the continuum in terms of having access to ‘insurance’ from her husband’s employer that paid for this support. This support was connected to her husband’s occupational status where his occupational prestige, as describe by Halom, resulted in his employer still **“supporting us”** despite her husband no longer working.

Halom specifically referred to how having paid support—**“my team”**—assisted her

with the demands of providing **“hands-on care”** for her husband. For Halom, having paid support allowed her to continue in her caregiving role as a **“manager”** of the care **“team”**.

4.10. Foreign Domestic Caregivers

Abu Ali said, **“The other day the housemaid called me while I was in the office saying my father was not well and she was scared ... I told the housemaid to [get some help from another individual in the house] until I reached home.”**

The quote above exemplifies some of the work of foreign domestic caregivers. Most of the individuals we interviewed had a foreign domestic caregiver, who was not only present but central to the caregiving process. While reports from some of the participants suggested that the role of these caregivers was more behind-the-scenes (e.g. cleaning and handling food preparation), other caregivers spoke about how their foreign domestic caregiver was central to their well-being and the well-being of the care recipient. In Abu Ali’s case quoted above, you can see that the housemaid was standing ready so to speak to assist in caregiving or managing the work of other caregivers; had she not notified Abu Ali that something was wrong with his father, his father’s condition might not have been treated in a timely manner. Other caregivers expressed similar sentiments with Amna describing her housemaid as also standing ready—**“if she wants anything, she will tell the housemaid.”**

In addition, Abu Ali explained how the housemaid played an important role, not only in his caregiving duties, but also in the care provided to his loved one. This became clear when Abu Ali spoke about the important work of dispensing medication:

Abu Ali: I put them weekly in the box. The housemaid puts the pills on a small plate when she gives him dinner and then she gives him the plate.

Interviewer: So the housemaid is the one who observes that?

Abu Ali: Yes, she transfers the pills. I put the medication weekly in the box. Even when I go out in the evening, the housemaid knows when the box will be empty of pills and she tells me, “the box is almost empty or the box is empty,” so I refill it. If I am at home, I give him the pills. And if am not there, she gives him the pills.

In addition to dispensing medication, Abu Ali’s maid **“prepares his food according to my mother’s orders”** based on family preferences. In describing the importance of his maid as a source of support, he said, **“Thank God we have a housemaid.”**

Halom also demonstrated the importance of this type of support. In addition to 24-hour nursing support, she also had a **“housekeeper, who’s been with us now for eight years; they’ve been with us from day one”**. In terms of her housekeeper, Halom said she gave a hand in the various aspects of providing care to her loved one. She explained how the housekeeper assists with household tasks like laundry and preparing food for the nurses when it is mealtime as well as assisting in the direct care provided for her

husband. Halom explained, for instance, how her housekeeper **“comes and talks to him”** when she is not present and will often provide her husband with companionship and support when the nurses are **“helping and handling him”**. Lastly, she described how the housekeeper will **“sit and entertain and talk to him”** when she is **“out shopping or upstairs answer[ing] emails or something”**. Through this example we see the housekeeper was central to Halom’s caregiving experience and likely allowed for her to take respite from the demands of caregiving. In fact, Halom described her support staff as if they were part of the family—**“It works like one big family”**.

Dream also talked about how her maid was a significant source of support. In addition to providing meals for her father—**“she will prepare breakfast, meals and everything for him”**—and assist in her father’s shopping. She was relied on for other things including watching the children in the house, which allowed Dream the opportunity to provide care to her father. In other words, the maid facilitated caregiving for Dream’s elderly father as the maid took over some of Dream’s childcare responsibilities.

While many caregivers described how maids provided them with much needed support, other caregivers described how there was still work involved in having a foreign support worker. Noor described how **“even if I have housemaid, I will check everything. What is missing? What is required and the typical household duties?”** What these diverse experiences of having a foreign domestic caregiver suggest is that there are a multiplicity of factors to consider when looking at the role of foreign domestic caregivers in the caregiving process. Similar to other forms of social support, how individuals give meaning to these support outlets matter in determining their adaptive function. In addition to further examining the work of foreign domestic caregivers, we must also empirically explore how individuals give meaning to the utilization of foreign domestic caregivers and, in turn, how such caregivers are treated and conceptualized as part of **“the family”** or not.

4.11. The Positives of Caregiving

Despite the demands of caregiving and the correlating stressors and burdens described in the previous chapters, caregivers described various positives or joys of caregiving. As Corman (2009) explains, the positives or joys of caregiving can be defined as **“experiences or events that caregivers appraise as positive and sometimes joyous. It is important to note that if this definition seems ambiguous, it is because the positives of caregiving remain relatively uncharted, lacking conceptual clarification.”**

The positives of caregiving for many caregivers involved spending time together with their loved ones despite the demands of caregiving. Halom described the joys of spending time with her husband. She explained how **“having him near me [and] being able to regulate our life”** is something that brought joy to her life, despite the demands stemming from the changes brought on by her husband’s illness. She gave an example of providing lunch for her husband: **“When I ask him, ‘Did you enjoy your lunch?’ and he says, ‘Yes.’ It’s our life together.”** Furthermore, there is joy in spending time together interfaced with the joy of maintaining autonomy and regularity as described by Halom:

And the fact that I can run our own household, determine the schedule, the meals, the activities, I find very positive ... I find the fact that we can continue, in the same house and more or less lead the same life, except that my husband is handicapped and needs help, is positive.

It was a combination of spending time together with her autonomy to hold on to and reproduce remnants of **“the same life”** from prior to the illness that **“keeps me going”**.

Abu Ali described a combination of joys that resulted from spending time together with his father and doing things for him that made him happy:

Being good with him, I sometimes do simple things but their effects were satisfying to him. Every time I clean him and dress him ... ‘God bless you’, he keeps saying that every time I wash him. Although it is a simple thing you do, the impact is great ... Every time he goes out, I put cream on his hands and I cut his nails, he is satisfied.

For Abu Ali, life satisfaction stemmed from these times spent together and the joys he gained from the gratefulness expressed to him by his father for his care. Others like Amal also took pride in providing care to her loved ones. This sense of pride was a source of joy as shown when she said: **“I feel glad when my father and my mother ask me to do something for them ... I feel happy when I make them happy. I always try to make them happy, I am happy because of their happiness.”**

Other caregivers described a process of getting to know their loved ones in a different light as a result of their caregiving responsibilities. Dream’s comments elucidated this:

For me, the good thing is that I felt like I started to get to know my father better ... When I was working, I used to tell him about the pressure of work and what happened to me. He would say, ‘I used to experience this’ ... So he was sharing with me what he used to do, because my father worked at [a company in Qatar].

For Dream, **“sharing with us the stories of his life”** was a significant positive of caregiving—**“he’s passing on ... knowledge to you”**—and something she may not have had a chance to learn about without this experience. Because of these caregiving experiences and the positives of caregiving, she notes that **“somehow I’m feel like I know my father better”**. In addition to learning more about her father, she **“learned a lot”** from her caregiving responsibilities. As such, caregiving provided Dream with a new outlook on life. For instance, she explained, that prior to caregiving, **“I used to care only about my clothes and myself”**. Because of her caregiving experience, she found that **“I’ve somehow learned how to deal with people better”**. Also, Mony expressed similar sentiments of a changing perception of self when she described becoming a **“more responsible”** and **“smarter”** person due to caregiving.

Lastly, some caregivers infused religious understandings of caregiving with the positives of caregiving. Mardi described getting joy from caregiving because in his view, one's **"mother is one door to heaven"**. There is a saying in Islam that **"heaven is beneath your mother's feet"** that reinforces the more you take care of your parents, the greater your reward in heaven. Honoring one's parents is called for and emphasized in Islam, as noted in this quote from Mardi. For Mardi **"there is no feeling better than [caregiving]"**. May used similar religious beliefs when she explained that providing care results in a **"blessing"** understood as a **"pleasure to serve. It erases sin"**. For some caregivers, a sense of responsibility framed their desire to provide care for their loved ones.

4.12. Conclusion

This chapter described the different coping strategies and resources caregivers used to mitigate and moderate the demands of caregiving. In this chapter, we also discussed the more positive side of the caregiving experience and documented how caregiving had a positive impact on caregivers despite the demands associated with it.

CHAPTER FIVE: WAY FORWARD: INTERVENTIONS AND POLICY IMPLICATIONS

The past chapters explained the role of caregivers in Qatar including the stresses experienced by them and the coping strategies that they employ during the caregiving process. This chapter will describe what the caregivers need to facilitate caregiving for their elderly relatives in addition to some suggested implications for the implementation of needed policies.

5.1. What Caregivers Want: Interventions

5.1.1. Educational programs

Some people struggle with finding activities that engage and entertain their elderly relatives as expressed by Halom:

Sometimes I feel I would like to have more ideas on how to entertain him—the practical side, I’m managing very well ... Brian and Julie, you know, they’re young. They know how to handle these electronic devices very well. They get interested in things so I have to ask them for help. On the other hand, instead of using early learning material, which was developed for children, I also thought, ‘No’. Because one day, when we did find some things to pair off, socks and shoes, lots of cards—games you might play with your children—he looked at me. He couldn’t manage well physically, he looked at me and said ‘You think I’m stupid?’ I said ‘No darling of course not, but we have to exercise your hand’. I do this to see his mental progress to see if it is faster than his physical progress.

5.1.2. Support groups

Family caregivers reported feeling isolated and lonely. They **“often invest a lot of personal time, emotion, and money providing care so they find it difficult to share caregiving or turn it over to paid caregivers. They see caregiving to be turned over to nurses as a failure on their part”** (Mezey, Miller, & Lori, 1999, p. 49). Caregivers need social support groups where they can express their feelings and share their caregiving experiences. They need infrastructure that provides a way for them to network with people who are encountering similar stresses and rewards.

Caregivers reported that they need to seek help and support from others, as with Dream who said:

It’s one thing being a caregiver, but he needs somebody to talk with him ... What I learned is yes, I feel it puts pressure on me but I start talking with and engaging my brother and sister. I will tell them, ‘It’s your turn to take my father. It’s your turn to do this’ ... I split the work ... If you’re not feeling good ... if you don’t take care of yourself, who will take care of you? This is the thing. You should take care of

yourself and split work among your family. Don't take the whole load upon yourself. And sometimes you will be angry with your brother and your sister even, about why are they not there ... So don't put pressure on yourself as a caregiver.

5.1.3. Religion

The participants we interviewed were connected by a strong sense of Islam and the prayerful life that it embodies. Research shows that spiritual support boosts caregiver attitude and enhances the performance of the caregiver. Spiritual support can provide strength, hope and meaning to the caregiver, especially in cases where the care recipient suffers from a severe illness (Swanson et al., 1997). The caregivers mentioned that it is important to talk to their elderly relatives using stories or quotes from the Hadith (sayings of our Prophet Muhammad PBUH).

This research suggests that Islam and the mosque community may provide more formal support for caregivers and could offer additional resources that enhance both the sense of well-being of caregivers and care receivers.

5.1.4. Strategies for being patient

Be patient:

- **“Have patience.”** (Abu Ali)
- **“The most important thing is that you are patient with them.”** (Dream)
- **“Second thing, be patient. If they didn't catch what you're saying, don't ignore them ... repeat it once or twice till they get it.”** (Um Ibrahim)

Patience is an important quality that caregivers emphasize, particularly as the demands of the elderly relative increase.

Caregivers expressed that they do not know how to handle the expressed and explicit needs of the care recipient. Research has demonstrated that: **“from time spent in caregiving tasks, amount of assistance provided etc. ... that the higher the level of demand, the higher the threat and loss appraisals, disrupted schedules and loss of physical strength, role overload, role captivity and loss of intimate exchange”** (Schumacher et al., 2008, p. 50). The findings from this research suggest that a formal system directed towards **“checking in”** with caregivers to assess and respond to stressful caregiving demands would provide a safety net for when these demands begin to overtake available resources.

5.1.5. Preparedness

Another important issue mentioned by most of the participants in this study is that caregivers should be prepared and always listen to the care recipient in order to fulfill their caregiving responsibilities. Um Ibrahim said: **“First of all, they need to learn to listen and to pay attention to what [the care recipient wants]”**.

Feeling competent and prepared to respond to the complex needs of elderly care was a strong theme in the research. Preparedness was a need expressed by the caregivers. However, it has received the least attention in the research on caregiving in Qatar.

By domains, the authors mean providing physical care, emotional support, setting up in-home support services, and dealing with the stress of caregiving. Also, the caregivers in this study revealed that they need to be better prepared to provide nursing care. Learning how to provide for the physical needs of a dependent person may seem simple but professional nurses study for four years to hone their skills. For instance, while caring for the elderly they learn how to assess swallowing to prevent choking, how to communicate with people with cognitive impairment, how to move and position people to prevent skin sores, how to support people to maintain muscle tone, how to cope with nighttime confusion (known as “**sundowning**” syndrome; Fisher Center for Alzheimer’s Research Foundation, 2017), respond to visual and hearing deficits and so forth. There is a serious gap in this sort of knowledge among family caregivers in Qatar. Moreover, there are other skills related to communication such as how to control one’s nerves to avoid getting angry in circumstances such as those described by Amal.

Family caregivers are involved in intensely personal relationships with their elderly relatives that interject a layer of emotion into their reactions that paid caregivers may not experience. These sorts of communication challenges intensify with increased needs/demands. Another important issue emerged from the data as Halom mentioned, that it is important for the caregiver to know how to treat their elderly relative:

Don’t treat them like children. Don’t forget they have their own character, their own personality. Because I find sometimes people deal with the handicapped or people who need care as if they are entirely helpless. They are not entirely helpless. Try to find out how much help they actually need and don’t go beyond that. For instance, when we put on him these disposable bibs, I never talk about bibs, because babies wear bibs. It’s a serviette. Try to keep it at an adult level, a respectful adult level.

It has been noted in prior research that caregivers do not have the necessary skills and knowledge to provide sustained care for a person with chronic illness or frail older persons, in particular elderly persons who have multiple conditions, such as the non-communicable diseases mentioned above requiring treatment protocols (Given et al., 2008; Given et al., 2001; Northouse et al., 2000).

Most prior studies do not organize or classify interventions according to caregiver tasks or the knowledge and skills they require. Nonetheless, a level of competency that includes knowledge of chronic illnesses and the nursing knowledge required to implement and monitor medical interventions is vital in the planning and implementation of the healthcare that has been entrusted to family caregivers to provide. In light of this reality, recent research has suggested that family caregivers require both knowledge and skill to provide the necessary care and to reduce their own stress levels (Abdelmoneium & Alharahsheh, 2016; Given, 2008; Farran, Gilley, McCann, Bienias, Lindeman, & Evans, 2007; Schumacher et al., 2000; Bakas, Austin, Jessup, Williams, & Oberst, 2004). For example, Abu Ali mentioned that he needs more nutritional knowledge as his father is diabetic.

Schumacher and others (2008) defined family caregiving skills as **“the ability to engage effectively and smoothly in nine care processes requiring psychomotor, cognitive and psychological skills”**. (P. 191–192) Caregivers should receive guidance, counselling and direction from health clinicians and rehearse what they learn in order to take appropriate action with their family members. Over time, caregivers can develop their skills (Given et al., 2008). The core skills to which Schumacher refers include monitoring, interpreting, making decisions, taking actions, adjusting to changing needs, comforting with hands-on care, accessing resources, working with the sick persons and negotiating the healthcare system (Schumacher et al, 2000; Given et al., 2008). The key is to not only ensure that the elderly person’s highest level of well-being is maintained, but also to prevent complications and avoid costly hospital admissions.

To this end, caregivers need to learn to perform complex nursing tasks— medication administration, injections, wound care, nutritional support, passive and active exercise. Caregivers handle devices such as lifts, wheelchairs and bathroom chairs. They also manage oxygen. Also, one of the most demanding aspects of elderly decline for caregivers is incontinence support (which creates large amounts of laundry and is physically demanding to address). They need to manage the household as well, in order to monitor the elderly person, make decisions, solve problems, provide emotional support, and coordinate care among the various physiotherapists, nutritionists, occupational therapists, pharmacists, social workers and medical doctors involved in the elderly person’s financial affairs, illnesses and deficits.

Caregivers also provide custodial care, transportation, and advocacy. All this complex work is time consuming. It is all critically important to the well-being of the care recipient. The caregivers in this study emphasized that they need access to knowledge and guidance to learn the delicate and complex skills of eldercare. This demand increases as the treatment changes, or the disease progresses, or the elderly person’s functional or cognitive capacity deteriorates. Each stage requires different skills, a different set of knowledge and resources. Professional nurses are needed to liaise with the medical doctors and to support, reassess and adapt the capabilities of the caregivers in order to ensure the home-care is being well managed and that caregivers are also being looked after.

It is true that most interventions provide basic written materials that inform caregivers about the expected course of illness and treatment plans. Yet, competent nursing care is much more than this, and family caregivers need support to learn about and implement the patient’s plan of care.

5.2. Communication Strategies

One of the important challenges faced by family caregivers is effective communication. Corcoran (2003) defined communication as **“a complex interaction that requires adequate production, transmission and reception of information. Many factors can work to impede communication and lead to frustration, wasted effort, resistance to care or an unsafe situation”** (p. 12). Communication involves **“sending, receiving, understanding and utilizing information. Attitudes, feelings, and behaviors can cause breakdowns in communication between people of different generations.**

Miscommunication can cause people to respond or react negatively” (University of Cincinnati College of Nursing, 2011, p. 2). As Um Ibrahim mentioned above, it is important for caregivers to learn to listen to their elderly relative.

The caregivers in our study indicated that communication with the elderly relative could be a source of tension. The tension arose not only because the elderly relative had impaired communication but also because of the ordinary friction that can arise when people are sharing a house. Home caregivers could be supported in this regard. They could be taught about how to adapt to deafness, how to listen and better understand what the elderly person is saying. There are specific skills to take into consideration to effectively communicate with mild cognitive or sensory impairment—such as speaking slowly, adapting the pitch of the voice, avoiding complex medical terminology, using hand gestures and facial animation, communicating with simple pictures, and so forth. When basic communication is improved, frustration is also kept to a minimum. These issues are rarely discussed or implemented with maximum effectiveness among family home caregivers (Kozier, Harvey, & Morgan-Samuel, 2011, p. 74). For communication to be effective, home caregivers need to be aware of age-related issues, such as hearing impairment, deteriorating sight, poor memory, and the inability to read or understand. Other issues might include the type of information being shared, understanding of an issue or topic, the environment and personal style such as the use of body language, tone of voice, words chosen, speaking style, etc. (University of Cincinnati College of Nursing, 2011). As May said:

I wish I could talk in a calm way; I talk in an irritated fashion and I try not to, I have this difficulty when taking care of my mother. I did not have this problem when I was taking care of my father but with my mother, because she is not an easy-going person, I talk in an irritated manner.

There are special communication techniques related to conditions and diseases. For example, communicating with an elderly person who has dementia is different from one with impaired hearing or with Alzheimer’s. In particular, there is good science that identifies how to enhance the well-being of people with serious short-term memory impairment and how to minimize agitation and aggression in people with Alzheimer’s disease. Family caregivers need to know the skills needed to communicate with an elderly person, and research has shown that there are many guidelines and tools of communication between the caregiver and the elderly person (Abdelmoneium & Al Harasheh, 2016).

5.3. Recommendations and Policy Implications

5.3.1. Formal support groups:

- Healthcare providers should be tasked with facilitating family support groups. In the facilitator role, they should consult with family caregivers and consider them as “experts” in care. This positioning will establish the respect caregivers need to feel supported. It represents a collaborative way to provide caregivers with the appropriate knowledge and skills in order to achieve high-quality care.

Members of the group can share “insider knowledge” about how to navigate the healthcare system and provide each other with their insights on eldercare. Healthcare providers could contribute their knowledge and resources to help family caregivers solve problems and to enhance communication skills. Facilitating support groups in Qatar would require insight into cultural and ethnic differences. Formal interventions from the health providers are needed to achieve optimal clinical outcomes.

- Educational interventions which involve structured programs directed towards providing both basic and advanced information about the disease process, resources and services specific to the care recipient. During the educational intervention, caregivers would receive training in how to respond effectively to disease-related problems such as stroke management, diabetes management, cardiac and blood pressure control, memory and behavior problems, depression and anger. Lectures, group discussions, and written materials developed by a trained leader would be the foundation of this sort of education (Capezuti et al., 2008, p. 137).
- Home care visits focused on building rapport among participants and creating a space in which to discuss problems, successes, and feelings regarding caregiving would address some elements of caregiver isolation. It would also provide a practical resource and address caregiver feelings of being overwhelmed with the physical demands of care. Homecare services should include respite services to provide the caregiver with worry-free personal time and a proper opportunity to distance themselves from the day-to-day frustrations.
- Psycho educational skills (and possibly even psychotherapy) should be made available to those caregivers who show serious psychological strain. These sorts of support could build caregiver insight to support their role. It could also support caregivers by establishing interventions that include information about the care needed by the recipient and how to deal with change, manage competing responsibilities and temper feelings of resentment, hopelessness and loss.

5.3.2. Informal support groups

- Informal support group interventions facilitated by non-professionals would provide another venue for caregivers to discuss problems, successes and their feelings.

5.3.3. Financial assistance

- The creation of a database for caregivers who are in need of financial assistance, in particular non-Qataris residing in Qatar after the age of 60+, would help alleviate the demands placed on this segment of caregivers.

All recommendations should enhance the role of women as they are the main home elder caregivers.

APPENDIX A

METHODS

This research employed a phenomenological qualitative descriptive design geared towards gaining an understanding of the experiences of family caregivers. Interested in the qualitative and contextual complexity of the issue, we focused on participant views (Creswell, 2003) of caregiving experiences. In the context of this study, the goal was to shed light on the private realm of family life in a respectful way in order to gain insight into the complicated nature of the lived experiences of caregivers, and to identify how their family caregiving role could be supported and enhanced. This study used an inductive approach to generating knowledge through in-depth interviews, which were used to identify patterns based on the experiences of participants (Rudestam & Newton, 2001). Utilizing qualitative, semi-structured interviews with open-ended questions, we successfully elicited data that allowed the researchers to identify themes related to the stressors, benefits, coping strategies and resources of participants. This study was informed by the theoretical framework of the stress process and coping-process models of Pearlin et al. (1990) and Lazarus and Folkman (1984).

The following inclusion criteria was used in this study: 1) live in Qatar; 2) self-identify as full-time or part-time caregivers; 3) care for family members who are aged 65+; 4) speak English and/or Arabic; and 5) reside in Doha, Qatar. We recruited participants by using posters, word of mouth, and through a presentation given at the Doha International Family Institute.

We recruited 22 participants who met the inclusion criteria. The study underwent ethical review by the Conjoint Health Research Ethics Board at the University of Calgary and at Qatar Foundation. Among the 22 participants, five were male and 17 were female. Of the 17 females, ten were Qatari nationals and seven were non-Qatari long-term residents. The five males were all non-Qatari nationals who were also long-term residents. The age range was 20–50 years. Most caregivers considered themselves the primary caregiver although discerning between the role of primary or secondary caregiving was sometimes difficult because caregiving was organized through complex sharing of responsibilities. Out of the 22 participants, 11 were employed or were attending post-secondary education either on a full or part-time basis.

APPENDIX B

LIMITATIONS OF THE STUDY

As an exploratory study this research has advantages and limitations. The study does provide a preliminary view into the experiences of family caregivers in Qatar. However, there were limitations on the data. Conducting interviews in people's mother tongue made it easier to communicate with the participants. However, as the interviews were translated into English and the analysis was also conducted in English, we recognize this limitation. Conducting 22 interviews is considered a large data source in qualitative research. As such, the number of interviews and the diversity of the participants also mitigated the limitations generated by translation.

Another limitation to this study relates to the willingness of participants to voluntarily participate in the project. Some people were referred to by word of mouth and did not consent to be interviewed despite indicating a strong interest in the study. This limited the depth of our descriptive themes.

We are confident that the themes we have identified are representative of lived experiences of caregivers in Doha in so far as we adhered closely to the Critical Appraisal Skills Program (CASP) for qualitative research and appraising evidence in the design and implementation of research⁸. As in most qualitative work, which focuses on local/personal experiences in a particular context, generalizability is not an expected attribute. This limits the value of this small study in regard to its contribution to policy. Nonetheless, with the rising trend of meta-analysis, the research conducted in Doha **"adds up"** to a significant contribution when the findings from this research are placed into the broad context of what is known internationally about caregiving experiences, a significant contribution that can be considered carefully when making policy decisions on how to provide adequate resources and support to family caregivers in Qatar.

⁸ <http://www.casp-uk.net/>

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