

## **Exploring the Experiences of Home Caregivers for Elderly People in Qatar**

### **Executive summary**

The past few decades have shown profound demographic changes in Qatar which have led to a slow increase in the proportion of older people and will inevitably place heavy burdens on families who assumed the responsibility in providing care for its older members. Research on elderly caregiving and the challenges that face family member caregivers in Qatar and the Arab world is limited.

The improved economic situation and standards of living that began around the 1950s have led to many structural changes in the Arab world, including significant decreases in morbidity, mortality, and fertility rates (United Nations 2012). As a result, the age demographic in Qatar and other countries in the region have significantly changed. For example, there has been a rapid increase in the number of people aged 25-64 years of age. These changes have led to individuals living much longer. Today, there are a significant number of Qataris (10,756) and non-Qataris living in Qatar (18,070) above the age of 60 (Qatar Statistics Authority, 2010). The age group of 65-69 according to 2010 census was 2,685 Qatari and 3,769 non-Qatari, for the group age 70-74 it was 2,032 Qatari and 1,605 non-Qatari and finally above 75+ it was 2,630 Qatari and 1,096 non-Qatari (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.

In the Gulf region, there is some indication that the prevalence of physical and chronic illness (e.g. diabetes, cardiovascular disease, and cancer) is greater among elderly living at home than their institutionalized counterparts (Al-Nassir & Al-Haddad, 1999). That is why this current study is important to investigate the home care sector, specifically caregivers.

Family members are the most common providers of care for older persons requiring care in the home. Recent societal changes, however, have caused increased pressures on family members who are responsible for the care of older persons. Studies showed that the increasing participation of women in the workforce is a factor that significantly impacts the needs of the family in caring for elderly family members (see Schoendelder et al 2000, Dwyer & Coward 1991), Qatar is no exception. Although, extended families are common and filial responsibility is highly valued in Qatar, family members who care for older persons might experience significant strain that potentially compromise the quality of life of older adults and the caregivers. Thus, the objective of the report is to investigate the experiences of Qatari and non-Qatari caregivers in Qatar who provide care for older family members. We focused on the stress and burdens of caregiving, coping strategies of caregivers, and the benefits caregivers garner from caregiving.

We conducted an in-depth interview with 22 Qatar and non-Qatar male and female caregivers caring for their elderly family members in Doha. Five men and seventeen women were

interviewed. The age of the caregivers ranged between 20-50 years old. Most of the care recipients were parents to the caregivers and majority of the elderly people (18) suffered from diabetes, hypertension, while some complained from heart problems and dementia. There were some cases where the elderly parent was experiencing co-morbidities and long term complications and disability, such as dementia. The age of the care-receivers ranged from 65-80 years.

Our analysis revealed four major ideas:

### **Division of Labor for Caregiver**

The data revealed that caregiving for older family members is mostly carried for by family members and in most cases performed by women. Some family members found themselves involved in caregiving by default- as circumstances in the family made them become caregivers to the elderly family members such as single or divorced women living with the elderly person. In this report we differentiated between the primary caregiver (direct caregiving) and secondary caregivers (indirect caregiving).

The process of caregiving is complex and demanding for the caregiver. It is composed of not only Instrumental Activities Daily Living (IADL) and Activities Daily Living (ADL) but other factors such as emotional support, dependency and sensitivity issues was revealed from the data and the caregiver has to take into consideration. Direct caregiving included ADL, such as bathing, dressing, grooming, mouth care, toileting, transferring bed/chair, walking, climbing, eating. IADL included shopping, cooking, managing medications, using the phone or computer, doing housework, doing laundry, driving or using transportation, managing finances, coping with illness behaviors, communicating with and navigating the health care and social services systems, protective actions that caregivers to take to ensure the old person safety and well-being

Female caregivers were diverse in terms of marital status and included women who were married (5 females), divorced (1 female), single (11 females). However, 15 out of the 22 primary caregivers were married, single or divorced women who perform direct caregiving. Five males (2 single) and (3 married) performed direct caregiving.

The caregivers particularly women face social constraints in taking care of their elderly fathers such as assisting in walking, staying with their fathers in the hospital, access to men's section during routine check-ups at the hospital. This is a constraint which frustrates the caregiver in taking care of their elderly family member which can cause stress and anger

Secondary caregivers mainly perform duties and activities similar to the primary caregivers but they tend to spend less time with the elderly person. They mainly assist the primary caregiver in ADL and IADL functions; assist in health issues for the old person if needed. Most of the secondary caregivers were siblings or grandchildren (two females) which raises the concept of intergenerational relationships between elderly family members and grandchildren

Emotional support is an important issue within the caregiving process. Most of the caregivers interviewed showed emotional support towards their care recipients and emphasized that it enriches the quality of life of the care receiver as well as themselves – constituting one of the

major positives of caregiving. This emotional exchange both influenced the relation and quality between the caregiver and care receiver. The findings showed that emotional care is important to the caregiving context and related to the instrumental aid given to dependent family members.

Dependency is an issue of importance in the life of the elderly person. The elderly people were mainly dependent on their caregivers whether males or females and felt a sense of insecurity when their caregivers are away from them. The concern for maintaining the older person autonomy for as long as possible was one of the issues that some of the caregivers mentioned

Sensitivity to the needs and desires of the older family member emerged in the caregiving process. Meeting the care recipients emotional needs and respecting or deferring to the wishes and desires of the older person is intolerable and demanding.

Employed or studying single, married or divorced women (9 females) have double tasks to perform beside their employed job. The activities that employed women caregivers perform after their duty work can continue what is traditionally thought of as the “second or third shift” which had an impact on the health and job performance of the caregiver. In addition employed caregivers, report more absenteeism, more distractions at work, more physical health problems and loss of career advancement.

### **Impact of caregiving on the caregiver:**

Stress and burden are the main factors that impact the health of the caregivers. Caregivers talked about stress as loss of control of temper, patience and tolerance and some expressed a sense of burden, anger and a state of wear and tear on the body. The caregivers also revealed the amount of demand exerted on them and explained time spent in caregiving tasks which showed that the higher the demand the higher the threat, disrupted schedules and loss of physical strength. Caregivers indicated that disrupted schedules and loss of physical strength made caregiving particularly challenging.

Stress has impact on the health of the caregiver as the caregiver ends up with limited or no time for personal pursuits either because limited social support from the other family members or isolation. As the caregiving grow in intensity over time, new responsibilities and difficulties faces the caregiver, increasing the risks to caregiver’s health. This issue raised concern about the capacity to sustain the care they provided. Most of the caregivers described feeling exhausted, depressed, blaming fatigue on sleep loss, which are all stressful issues that shows that their health is failing. They also described feeling deprived due to limited resources, lack of support, loss of personal time and pleasure which they are missing. Almost all the caregivers expressed the need for more easily accessible formal help and assistance in the long run. For many of the participants the pragmatic help they identified related to challenges they faced when they were transporting the elderly person to medical appointments.

### **Coping strategies:**

The coping strategy for the caregivers differs from one person to another and on the amount of time spent with the care recipient. Some caregivers who are affected with frustration suggested their method of coping was to remind themselves that they were doing a good job. They refer

frequently to their faith, indicating that they were given this responsibility because they are capable of doing a positive impact on the life of the older person. In most of the cases, the caregiver refers to spiritual support to give them a boost in caregiving process and help them to be patient and kind in their role as caregiver. Some remained optimistic and attempted to convey this hopefulness to the care recipient. They spoke about the importance of being positive and the belief that they could bear the responsibility and trust vested in them.

Some of their coping strategies when they feel stressed or tired from the caregiving process are to take “time-outs” – taking brief time away from their caregiving roles talking to friends, praying. Other strategies included going out with friends and relatives and talking about their problems to other people. Some also exercised to help them in coping with stresses of caregiving.

### **Joy and happiness of caregiving**

Beside the demanding job of caregiving, caregivers also experience a joyful side of their caregiving role. The praise and appreciation from the caregiver gives them a motivation towards the caregiving process. The feeling and sense of responsibility in particular for the primary caregivers gives them sense of obligation and duty towards their elderly person. This gives them a boost towards continuing life. The majority of the caregivers felt a sense of happiness when they see their elderly persons happy, smiling and comfortable. Most of the caregivers learned how to be patient and tolerant to the situation an issue which is hard to get in such circumstances. Love and filial duty were significant motivators and concurrent sources of joy in relation to the rewards caregivers achieved within their altruistic values.

### **What Caregivers Want?**

- Caregivers wanted guidance, counseling and direction from health care providers in how to take care of the old person in administering medication, home visits, monitoring and follow up with the caregiver on the health of the old person.
- Health care providers to cooperate with the family caregivers supporting them and providing them with the appropriate knowledge and skills in order to achieve high quality of care in nutrition and first aid.
- Caregivers wanted sessions on communication skills and problem solving with the care recipient in problem solving, tolerance, patience. This is because it depends on the old person condition and what disease they have.

### **Interventions and policy implications**

- Psychoeducational interventions which is a structured program which provide information about the care receiver’s disease, process, resources and services and training caregivers to respond effectively.
- Support groups interventions which involves supportive and professional groups to discuss problems, successes and feeling regarding caregiving
- Multicomponent intervention which involves combination of educational interventions, support, psychotherapy and respite.

- Formal supports programs such as home care visits, social activities for the caregivers and care receivers needs to be maximized in following the acute event that leads to caregiving and sustained throughout the caregiving process.
- All supportive programs should enhance the role of women as they are the main home caregivers taking care of elderly people.