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

#### Prepared by:

Dr. Azza Abdelmoneium, PhD – Doha International Family Institute

Dr. Michael Corman, PhD – Queens University Belfast

Dr. Janet Rankin, PhD – University of Calgary in Qatar

## Outline

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## INTRODUCTION

- The centrality of families in Qatar
- Particularly important in old age



### RATIONALE

## Demographic transition in Qatar Population aging and People are living longer

- Total population 2.28 million
- Increased life expectancy
  - **○**Males 77.7
  - ©Females 79.4.
- Decline in fertility rate (less people having children)
- The proportion of elderly increasing
  - 7.8% of the total population in 2035 (projected)
- Roughly 30,0000 elderly Qataris and of non-Qataris

This number WILL increase!

## PURPOSE OF RESEARCH

- To understand the stresses and benefits of caregiving, and the coping strategies and resources used by family caregivers
- To understand the experiences of these caregivers

## **RESEARCH QUESTIONS**

- OWhat are the experiences of family caregivers in Qatar caring for their elderly persons in the home?
- What is their understanding of the stresses and benefits of caregiving and the different coping strategies and resources available for family caregivers in Qatar?

## WHAT? (IMPLICATIONS)

- O How can we better meet the needs of an aging society?
  - We must develop policy that reflects the experience of growing old in Qatar and assist those who provide care to elderly persons
  - This segment of the population has yet to be investigated in Qatar and the Arab Region
- It is about the quality of life and well-being of both caregivers and care-receivers.

## THEORETICAL FRAMEWORKS

- The stress-process model (Pearlin et al., 1990):
  - Focuses on how people give meaning to caregiving
    - How stress is a social process
- ✓ Stress-coping process model (Lazarus and Folkman, 1984; Folkman, 1997)
  - Focuses on how caregivers cope with the demands of caregiving
- There is scope for examining the positives of caregiving (Corman, 2009)

### **METHODOLOGY**

- Qualitative descriptive design (Sandelowski, 2000)
- In-depth interviews with 22 Qatari and non-Qatari residents
   Focus of interview
- Qualitative Content Analysis:

Qualitative content analysis . . . is oriented toward summarizing the informational contents of that data . . . Qualitative content analysis is similarly reflexive and interactive as researchers continuously modify their treatment of data to accommodate new data and new insights about those data. (Sandelowski, 2000, p. 338)

### **PARTICIPANTS**

	Male	Female
Number of Participants	5	17
Marital status	3 married 2 single	1 divorced , 4 married, 12 single
Nationality	5 non-Qatari	10 Qatari, 7 non-Qatari
Age	20-50 years	20-50 years
Work status	1 student 4 employee	2 students, 6 employee, 9 unemployed



### **FINDINGS**

- The work of caregiving
- Stressors and burdens of caregiving
- **©**Coping strategies
- The positives of caregiving

## THE WORK OF CAREGIVING

**Primary/direct family Caregivers** 

I help my father with medications [and] follow up with doctor appointments. I take him shopping as he likes to go shopping to buy groceries . . . If he want to visit friends and relatives I take him



### THE WORK OF CAREGIVING

### Indirect/secondary caregiving

- Assistance from other family members
- Foreign domestic caregivers ("Maids")

I prepare his breakfast and I give him his medication . . . If I'm not able to be at home, then I call mother who will prepare the medication for him.



## THE WORK OF CAREGIVING - GENDER

- Primary caregivers typically (but not always) women
- The majority of female caregivers were single or divorced (daughters who either never married or divorced) who provided most of the care for their parents.
- Many caregivers had a double shift (paid and unpaid work)

## THE WORK OF CAREGIVING-Example

Noor is a Qatari single woman in her 30s who was employed full-time outside the home and was also responsible for her father (almost 70 years old) and her mother (aged in her 60s). Noor's father has diabetes, hypertension and limited vision due to diabetic retinopathy. Her mother also has diabetes, hypertension, rheumatism and other health issues such as fungus on her foot which needs continuous cleaning. Noor reported that she had 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 one are married and live in their own homes. Noor's youngest brother in his 20s and lives with Noor and her parents but he is not closely involved in the day to day care.

# THE WORK OF CAREGIVING - EXAMPLE

I wake up every morning, I prepare their breakfast. My mother wakes up at five. I give breakfast for 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 and check their sugar level. In the afternoon when I come back I check that they had their medications and I prepare the medications for the rest of the day or the second day. When I come back from work at 3pm I prepare their lunch and then I sit with them for the rest of the day and give them their medications and any other issues that they need. Every two days we need to check their foot and clean it. Sometimes the housemaid does it but normally I do it. I wash their feet I check what is missing in the house in terms of food or other things that needs to be done.

## THE WORK OF CAREGIVING - EMOTIONAL SUPPORT

- Most caregivers provided emotional support towards care recipients.
  - I always chat with my father
  - I sit with my father everyday
- It enriches the quality of life of the caregiver and care receiver
  - •A positive of caregiving.
- Most described having good relations with the care recipients.

## THE WORK OF CAREGIVING – DEPENDENCY

- Care recipients depend on the caregiver
- Sense of insecurity when the caregiver is away
- Continuous care is needed from the caregiver
  - Caregiving from afar

## THE WORK OF CAREGIVING - SENSITIVITY

- Caregivers were sensitive to the needs and desires of the care recipient
  - Maintaining autonomy
  - Respecting the wishes and desires of the old person

My mother sometimes likes to cook alone although we have housemaid but she is the one who supervises the cooking and this make her busy.

Me and my siblings try to arrange programs for both my mother and grandmother. My grandmother likes to go to the farm and likes fishing so we arrange for her a boat as she likes going to the sea a lot.

#### **EMPLOYED and STUDENT CAREGIVERS**

#### Have double tasks to perform beside their employed job

I take permission from my office to take her to the appointment. I try to do that as much as I can. If the appointment [is] at evening, then I can take her, but her specialists work at morning, so I have to take this permission to take her there.

I care for my father and responsible for his bathing, medicine, food etc., but because of his sickness he goes to the bathroom a lot. He calls me when I am in the lecture at the university saying that he want to go the bathroom. My mother cannot take him to the bathroom and we cannot afford for a maid and my other siblings are not at home and work far away so I have to leave the lecture to go to the house and by the time I return to the university the lecture has finished . . . It stresses me most when I have final exams as I feel stressed and I need to pay attention to my studies.

#### SECONDARY/INDIRECT CAREGIVERS

- Spend less time with the elderly person
- **CAssist with ADL and IADL** functions
- OMost of the secondary caregivers in the cases were siblings or grandchildren

#### IMPACT OF CAREGIVING ON CAREGIVER

### Stressors (antecedents to stress):

Demanding behaviours, not being present, hands on care, isolation, financial costs associated with caregiving, formal services, and other unique stressors

#### **OBurdens:**

Guilt, loneliness, loss of control, exhaustion

# STRESS CHALLENGES case study

- I do not know what to do with my mother and grandmother, they are very stubborn, they have high sugar and hypertension, they do not follow any diet and refuse to obey to doctor's instruction. They were hospitalized several times and when we speak to them they refuse to listen. This stresses me as I work full time and always worried that something happens to them while am work... my other siblings are busy with school and I am the only one who can escort them to the hospital if they have appointments etc.
- O I am responsible for my father all my sisters and brothers are married and living on their own. I am not married and has no life except my father. I feed him, bath him. All I have to do by myself but sometimes the maid assists me. I feel pressure because I have to be with him all the time, none of my brothers assist me. Only Fridays they come to visit him, but I take him to the doctor, give his medication, travel with him etc. This is a big responsibility for me and I feel stressed and nervous. Sometimes I do not like to talk but I have to talk to him, as I feel guilty if I leave him not talking or sitting doing nothing. He lost his sight and that made him lonely and sad.

## STRESS CHALLENGES Stressors

#### **OHands on care:**

Giving "injections" and worrying that her loved one "suffered."

#### **Isolation:**

Lack of social contact. Lack of contact to people my own age. The people we used to know they have left, because Qatar is not an immigration country. When you get old, or you finish your job, you leave. The people who are now coming are the generation of our children.

## STRESS CHALLENGES Stressors continued

#### Not being present:

- "My mind was [still] for them."
- Worrying about her loved one "fall[ing] down" when "no one is with her at home." Not being present is "the main problem that I have."

#### Demanding Behaviours:

- "Very agitated"
- "Mood swings"
- "He will take the medication according to himself."
- "Talk[ing] too much . . . sometimes I feel annoyed, because she talks too much."

#### Financial Stressors:

- "Treatments" for his father[?] were "expensive as he is not a resident."
- ▼ Traveling costs "400[Qatari Riyal] per month for taxi, only for taxi, beside medication."

## STRESS CHALLENGES External Stressors

#### Formal Supports:

- The potential of losing supports "gives me sleepless nights"
- Hospital staff placing additional responsibilities on medically trained caregivers
- Medical staff "made us very confused"
- One doctor told her don't eat anything with green color. Another doctor tells her you can eat but with certain quantity. So how do I know what is the right one? This is the problem."
- "Why are you discharging the patient early?"
- Waiting

#### Traffic:

"When you take him to the hospital, you're suffering starts since you go out of the house."

## STRESS CHALLENGES Unique Stressors

### **♥** Stigma:

Many "people are looking at him."

### Why Did Illness Occur?

"I cannot see what he did in the past, just I see the good things maybe . . . I don't know because the God do this one, why there is no way to treat him."

## Gender and Cultural Expectations:

"Where did I spend the night? It was in [the] men's section. They are all men. That was the problem."

## STRESS CHALLENGES Burdens (Negative Outcomes) of Caregiving

- Exhaustion
- **G**Guilt
- **U**Loneliness
- CLow levels of focus of control (lack of controllability

### Coping

How do caregivers deal or cope with the demands of caregiving?

- Positive Thinking
- Withdrawing
- Being active
- **Giving in**
- Social support Talking to others
- Religiosity
- Formal Supports
  - Nursing Support
  - Foreign Domestic caregivers ("maids")

## **Coping – Positive Thinking**

#### Positive Thinking:

The actual caregiving, I don't find stressful. I find much more stressful how our life has been turned upside down, to come to terms with that. Fortunately, I am a person who benefits from positive aspects, even after a negative event. I seem to forget that and always learn something positive. I manage by just, how should I say, not dwelling on our bad luck. I'm functioning. As long as there are challenges, practical challenges I have to cope with, I function and I don't go into emotional stress or I don't allow myself to get upset. It's futile, it uses up my energy. Instead I put myself to use.

## **Coping – Being Active**

#### Being Active (Actively trying to manage stress and being physically active):

From my side, I try to solve it. I don't like to live within a problem. I prefer to find a solution and enjoy search for the solution, but I don't like to live within the problem.

[Going to the gym makes me feel] relaxed because I'm really feeling the stress because now six month I'm not going my gym. So because of the study, I cannot even go one hour . . . With my exams, with the lot of stress I'm feeling, with exercise, it will be less stressed with me. I'm expressing myself out with the stress.

## Coping – Religion

#### Religion:

The thing I told [my friend], 'I don't know where to go.' I was telling her, 'I'm feeling I'm lost. I don't know what to do.' Then she told me, 'You just go back to Allah and pray for God.' She said, 'Forget about everything'... We came and created by Allah, so go back for Allah and pray. The more pray you will do, the more relaxed you will be.' And really, the moment I tried and, yeah, I was crying, but I became calm more. That thing really worked. I still thank her for that because she is the one only who told me . . .

## Coping – Foreign Domestic Caregivers ("Maids)

#### Foreign Domestic Caregivers:

... when his blood sugar decreased. I went to the work and my mother wasn't there and I saw him little bit tired. He always sits in the hall but he didn't come to the hall for few days. When I asked him what is wrong he told me "nothing wrong." That day the housemaid called me while I was in the office that my father is not well and she is scared . . . I told the housemaid to [get some help from another individual in the house].

Comes and talks to him" when she is not present and will often "sit and entertain and talk to him" when she is "out shopping or upstairs answer[ing] emails or something . . . It works like in a big family.

## Coping – Foreign Domestic Caregivers ("Maids)

### Foreign Domestic Caregivers

Similarly, Amna's domestic support "gives her the medication . . . puts the drops in her eyes," and "sleeps with" her loved one. In addition to this, Amna described her housemaid as being *standing ready*, so to speak; "if she wants anything, she will tell the housemaid."

#### **©** Future Research!

## **POSITIVES OF CAREGIVING**

#### While caregivers described caregiving as demanding, many also discussed the positive aspects of caregiving.

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

That's why I went when he was still in hospital. I went in the morning and I stayed the whole day because I wanted to make sure, first of all, that things are going well – done well. And also, I wanted to see his improvement and now, I find, I enjoy having him, I enjoy very much being able to care for him at home, because I'm, I see also the improvement and it's a reward too.

## **POSITIVES OF CAREGIVING**

Actually, for me, the good thing, I felt like I start knowing my father more. Because even though I used to, in some way when I was working, I used to tell him about the pressure of work, whatever that happened to me. He would tell me, like I used to have this . . . So he sharing with me where he used to, because my father worked at [a company in Qatar].

Yeah, actually all of us we felt attachment after my father sickness. I felt like all my brothers and sisters, even my sister in [another Gulf country] she came. All of us were there. That time really it was a good moment for me. Even my dad, he was really . . . after the surgery, but it was being the whole family together. I am feeling there is moments you should be with your families. That's the joy for me actually.

# SUMMARY – STRESS, COPING, AND JOYS

- Individuals experience multiple stressors throughout their experiences of caregiving
- Activates coping processes to mediate the impacts of stress.
  - Some cope better than others (most appear to be coping well)
  - We must meet the needs of those who are and are not coping well
    - Identify those who are not coping well
- Faith and religion play a role in the coping strategy
- Despite the demands of caregiving, all caregivers described positives of caregiving

#### **SUGGESTIONS FROM CAREGIVERS**

Have patience

If they didn't catch what you're saying don't ignore them . . . repeat it once or twice till they got it.

The one who's caregiver, he needs somebody to talk with him really.

I sometimes say she is not only my mother; she is the mother of all.

If you don't take care of yourself, who would take care of you?

Don't treat them like children. Don't forget they have their own character, their own personality.

... But I treat my mother like a child...

First of all they need to learn to listen and to pay attention to what [the care-receiver wants].

## INTERVENTIONS AND POLICY IMPLICATIONS

- **©** Formal Services:
  - Support groups
  - **O** Home Care
  - **©** Respite services
  - Educational services
    - Individualized educational programs
  - Access to health care
- Informal Supports
  - Support groups
- **©** Financial assistance

# IMPLICATIONS FOR FUTURE RESEARCH

- In-depth on the role of caregivers and care receivers in Qatar including quantitative survey.
- Research on the health services for the elderly people in Qatar and Arab countries
- Foreign Domestic Caregivers
- Religion and caregiving
- Research on the role of caregivers in other Arab countries

# Thank you