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# Qualitative exploration of the experiences of informal care-givers for dependent older adults in Mexico City

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## Abstract

Population ageing and increasing prevalence of chronic diseases and their consequences, changes in family structure and a decrease in the potential pool of family care, increase the need for formal long-term care for older adults in Mexico, and the need to understand the experiences of informal care-givers and how this impacts their social, family and personal conditions. This study investigates the experience of informal care-givers of dependent older adults using a cross-sectional qualitative study with an ethnographic focus. Thematic analysis was performed. The study comprised 48 semi-structured interviews with care-givers of dependent older adults who are beneficiaries of an in-home medical programme in Mexico City. The average age of care-givers was 54.7 years (standard deviation = 13.1, range = 24–86) and 75 per cent (36) were women. Results show care-giving experiences are diverse and complex, and profoundly affect the care-giver's life in terms of emotional burden, health deterioration and adverse life conditions due to economic deprivation. They also revealed key aspects such as the need to improve communication between care-givers and health-care personnel, the need for training about specific care needs and opportunity costs incurred. This information can serve as a basis for generating support strategies that may be integrated into the in-home programme. It is essential to promote actions that consider the 'dependent older adult–informal care-giver' dyad, and that aim to reduce the care-giving burden.

**Keywords:** long-term care; informal care-giver; older adult; ethnographic analysis; Mexico City

## Introduction

In the context of an ageing population and increasing chronic diseases and its consequences, long-term care represents a challenge for supporting and caring for older persons due to their loss of capabilities (World Health Organization (WHO) 2015a). Long-term care refers to support and care activities that may be

provided formally (services offering personal and health care in the home or in specialised institutions) or informally (family or other persons close to the older adult, such as neighbours or friends) to ensure that a person who is not completely capable of self-care, and consequently is dependent on others to perform daily activities, maintains the highest possible quality of life, independence, autonomy, participation, personal fulfillment and dignity according to their preferences (Organisation for Economic Co-operation and Development (OECD) 2005; WHO 2000).

Informal care by family members of an older adult is the most common form of long-term care and, on occasion, acts as a substitute for or complement to formal health-care systems (Greene 1983; Pezzin, Kemper and Reschovsky 1996; Tennstedt, Crawford and McKinlay 1993). Informal care of older adults, by its very nature, has implications that are personal, public and social (National Academies of Sciences, Engineering, and Medicine 2016). Various studies have demonstrated that informal care-givers provide the majority of assistance for dependent older adults so that they can perform their daily activities and also support activities related to health care, such as doctor visits, medical decisions and health-care tasks in the home (Institute of Medicine 2008; Wolff *et al.* 2016). Women perform the largest part of this care, a condition that has been reported even in countries that provide formal long-term care services for their populations (La Parra 2001; Pickard 2001; Pickard *et al.* 2000; Tomassini *et al.* 2004; Vaquiro and Stieповich 2010; Wittenberg *et al.* 1998). This last aspect implies that women who provide care face work overload, deterioration of health, fewer social activities, and very high economic and opportunity costs (National Academies of Sciences, Engineering, and Medicine 2016; Williams *et al.* 2016). Factors that affect the provision of informal care include the availability of formal care either at home or in institutions, the availability of other potential care-givers within the household, as well as competing responsibilities of care-givers such as care for small children, flexibility of working hours and the severity of the care needs.

Despite this evidence, few studies have considered informal care as a fundamental component of health-care systems (National Academies of Sciences, Engineering, and Medicine 2016), a fact that should be reconsidered given that the population growth of older adults and the financial difficulties of health-care systems and of public social services are causing some countries to cut formal long-term care programmes and are increasingly shifting this responsibility on to family members or other people close to older adults (Williams *et al.* 2016).

Previous studies have identified negative effects on informal care-givers related to providing care, such as a higher probability of suffering stress, anxiety, depression, social isolation, physical exhaustion, lack of attention to one's own health and financial burden that, on occasion, lead to catastrophic expenditures (Baptista *et al.* 2012; OECD 2011; Schulz and Sherwood 2008; Smith *et al.* 2014; Wolff *et al.* 2016). Additionally, care-givers commonly perceive a need to reduce their work hours or quit working completely due to the responsibilities of care (Chadiha *et al.* 2004; Grunfeld *et al.* 2004; Sawatzky and Fowler-Kerry 2003; Schultz and Sherwood 2008; Wiener 2003). Other conditions that have been identified as risks to the physical and mental health of informal care-givers include having to perform greater physical efforts without the support of other family members

and friends, in addition to a lack of medical knowledge and/or training to perform care-related activities (Sawatzky and Fowler-Kerry 2003).

In the literature about this topic, it is mentioned that informal care-givers encounter obstacles to meeting the needs of older adults adequately, which have been attributed to a scarcity or absence of training, lack of economic and social resources, and the complexity of the health-care system with which care-givers must interact to fulfil the various roles they must perform (Wolff *et al.* 2016).

Like in other countries, the population of Mexico is ageing rapidly. In 2015, 10 per cent of the total population were older adults or, as defined by the Mexican Law on the Rights of Older Adults, 60 years or older (Diario Oficial de la Federación 2002), in this age group. It is estimated that this will increase to 15 and 21 per cent in 2030 and 2050, respectively (Consejo Nacional de Población 2017). Life expectancy at birth in 2015 reached 75 years (Consejo Nacional de Población 2017); however, five million older adults have some disability, and of these, more than 500,000 are dependent on others to perform daily activities (Gutiérrez-Robledo *et al.* 2012). Family structure in Mexico has also been deeply modified by the decrease in fertility. In the period 1970–2015, the average household size decreased from 4.9 to 3.7 members on average (Consejo Nacional de Población 2009), generating a diminishing density of family networks (Quilodrán 2010). Regarding living arrangements, on the one hand, the majority of older adults live at home in extended households where they co-reside with their spouse or partner, adult children, grandchildren or other close relatives. On the other hand, single-headed households among older adults have steadily increased, most notably, the percentage of those 80 years and older living alone which in 2010 was 15 per cent, up from 12 per cent in 2000 (Wong, Gonzalez and Lopez-Ortega 2014).

Mexico City is one of the federal bodies with the highest proportion of older adults in the country: in 2015, 13.4 per cent of its total population was 60 years or older, and it is estimated that by 2030, this age cohort will account for 20 per cent of the total population. According to data from the 2010 Population and Housing Census, 29 per cent of the older-adult population of Mexico City had at least one type of disability (Instituto Nacional de Estadística y Geografía 2010).

Despite the accelerated ageing of the Mexican population, social and public health services for the older adults are scarce, and there is no specific long-term care programme that supports people with disabilities or informal care-givers. Within the Mexican context, family care responds to strong familial obligations, however, social and economic conditions are affecting traditional social norms. Results from a national survey show that while children declare strong willingness to care for their parents, when asked how much they are able to follow through on taking up care-giving activities, they feel that currently children care for their parents less than they did so in the past (López-Ortega and Gutiérrez-Robledo 2015).

Owing to increased demand for medical care for chronic and degenerative diseases and to demographic and epidemiological changes, the Health Department of Mexico City has developed an in-home care programme to guarantee effective no-cost access to health care for people whose health and economic situations prevent them from travelling to a medical facility or otherwise accessing medical services. This programme's objective is to provide medical care to vulnerable populations with complex health-care needs, primarily older adults, persons with

disabilities and the terminally ill. The services provided by this programme are detection and care for chronic diseases, podiatry care, palliative care, dental care, medication delivery, laboratory tests, hearing checks and diagnostics, patient and family education regarding ailments, and general care. To accomplish these activities, a health-care team composed of doctors, nurses, social workers, psychologists and dentists make periodic visits (once per month) to the beneficiary's home (Secretaría de Salud de la Ciudad de México 2017).

Given the impact of an ageing population and the need to provide informal care in the home, it is vital to understand better who is providing informal care and what their conditions are. The research questions that arise are: Who are these care-givers, and what activities do they perform? How and under what circumstances do they care for an older person? What are their needs and challenges in providing care? What effect does care have on their lives and their health?

To answer these questions, the aim of this study was to explore the experiences of informal care-givers regarding the dynamics of care for dependent older adults who participate in the Mexico City Health Department's public programme of in-home medical visits.

## Methods

### *Data collection*

The study comprised semi-structured interviews with informal care-givers of older adults ( $\geq 60$  years of age) dependent on care. In the present work, 'care-giver' refers to a family member, friend or neighbour who offers assistance at no cost to a person with a chronic or debilitating disease (Family Caregiver Alliance 2006). A person was considered care-dependent when the older adult's functional capacity was such that they could no longer perform their daily activities without help (WHO 2015a).

A cross-sectional qualitative study with an ethnographic focus was performed. The ethnographic focus was chosen given that qualitative methods focus on the daily lives of people, used experiences and perceptions (Hammersley and Atkinson 1995). On the other hand, ethnography allows comprehension of social phenomena from the perspective of their protagonists and does not impose the researchers' logic in the interpreting of observed realities, while allowing perception of situations in the environment of the participants that go beyond discourse (Guber 2001).

The semi-structured interviews were performed between October 2014 and March 2015, based on a guide previously developed by the research team, which was adjusted according to the results of a pilot test of six interviews with informal care-givers at one of the health-care centres included in the study. The interview consisted of open-ended questions aimed at understanding the lived experiences of care-givers in terms of their responsibility in the provision of informal care to dependent older adults. The interviews were complemented with observations of the environment and of the relation of participants to the older adult and other family members, which were recorded in field journals. The average duration of each interview was one and a half hours (range = 45–200 minutes), all were recorded and each was assigned a code to guarantee anonymity.

### Sample size

A convenience sample was taken from three health-care centres belonging to the Mexico City Health Services System located in three health jurisdictions, out of a total of 16, and in which the Mexico City Health Department's in-home care programme currently operates. These are primary care units with an emphasis on preventive care and health promotion that cater to all residents in the city that are not affiliated to one of the social security institutions. Services are free at the point of service delivery.

To select care-givers, the registry of beneficiaries of the in-home care programme was used from each of the chosen health-care centres that met the inclusion criteria: an unremunerated informal care-giver  $\geq 18$  years old who provides assistance to an older adult ( $\geq 60$  years of age) who is dependent in their activities of daily living, such as personal care, dressing, hygiene, walking and getting into and out of bed, and their instrumental activities of daily living, such as using transportation, buying and preparing food, administering medications and managing money, for a period longer than six months and who lives in the community. A person was considered care-dependent when the older adult's functional capacity was such that they could no longer perform their daily activities without help (WHO 2015a). Specifically, as part of the in-home care programme, functional ability is measured using the Barthel Index and individuals with scores of 0–20 points (totally dependent) or 21–60 (severely dependent) are included in the programme.

A health-care professional from the in-home care programme team contacted the selected care-givers. After an informed-consent letter was signed, two researchers from the area of collective health (GRL) and anthropology (GJN), who were previously trained and standardised, independently performed interviews in the home of the older adult receiving care and took field notes, which complemented the information from the interviews and recorded situations not reflected in the discussions with interviewees (e.g. family and housing environments). Researchers conducted interviews with the care-giver and the care recipient separately. The different backgrounds of the researchers allowed them to achieve a comprehensive perception of the experience of care and family context and dynamics of the visited homes. An ethnographic perspective enabled them to expand in the subjective experiences of interviewees while being respectful and making no judgements.

### Data analysis

Each interview recording was transcribed verbatim upon conclusion of each interview. Subsequently, the principal researcher reviewed each interview within two weeks of the date of the interview. The transcripts were encoded using thematic analysis (Braun and Clarke 2006; Guest, MacQueen and Namey 2012). In this study, the themes established were defined according to the project objectives, and emergent themes were identified during the transcription and reading of interviews. Three authors (GRL, LOM and GJN) were familiarised with the verbatim transcripts, and subsequently, each one independently encoded the narratives inductively and, from this encoding, defined a set of themes and performed a review of those they considered most relevant to achieving the research objective. Next, the themes were reviewed by the entire research team. The software package Atlas.ti version 7 was used for the encoding and analysis of information.

### **Ethical considerations**

The study was approved by the Ethics and Research Committees of the National Institute of Geriatrics (Registry: SiRES-DI-JEDDS-001/14). Participation was voluntary and was based on confidentiality and anonymity. All participants signed a letter of informed consent.

### **Results**

Of the 223 dependent patients enrolled in the in-home care programme, 78.9 per cent were older adults ( $\geq 60$  years old). From this sub-group, 48 informal care-givers were invited to participate in the interviews (16 per health-care centre). The social context in which the participants lived was characterised as urban and exhibiting high levels of poverty, insecurity and weak social-support networks. Based on the researcher's observation and field notes, it was evident that the social environment and housing were characterised by poor physical access such as steep roads, roads in bad conditions, lack of pavements or lack of public transport. These conditions pose additional strains to the daily care-giving experience by making daily tasks such as buying medicines or food and attending medical appointments, among others, very hard to accomplish and, thereby, an exhausting experience for both the care-givers and the dependent older adults.

Demographic characteristics of participants are presented in [Table 1](#). The majority of care-givers were female (75%), the average age of participants was 54.7 (standard deviation = 13.1) years, 52.1 per cent had basic education (elementary and middle school) and 43.8 per cent had partners; however, the majority of men were single or divorced. Regarding the activities performed by the interviewees, in addition to caring for the older adult, 62.5 per cent performed domestic work and 33.3 per cent had some type of informal economic activity. Approximately 70 per cent perceived their health status as regular or poor and reported various illnesses, such as diabetes, hypertension, muscle pain and depression, among others. The care-givers were mainly children or current partners of the older adult. They dedicated on average ten hours per day to provision of care for the older adult, in addition to performing other domestic and extra-domestic activities as circumstances permitted. Out of all care-givers, 79.2 per cent had been performing these activities for more than three years, and 60.4 per cent reported having support from other family members in performing care for the older adult.

In the analysis of the interviews, four themes were identified that encompassed the general findings of the study:

- Theme 1: Beginning of care and decision to become a care-giver (the factors and reasons for assuming care of a dependent older adult were analysed).
- Theme 2: Difficulties in providing care (care-giver knowledge and information needs were addressed).
- Theme 3: Opportunity costs and impact of care on the personal and social life of the care-giver (the experience of care and negative effects were analysed).
- Theme 4: Feelings regarding the older adult and the task of care-giving (these were evaluated as a function of the first three themes).

**Table 1.** General characteristics of care-givers for dependent older adults

Characteristics	Female		Male		Total	
	N	%	N	%	N	%
	36	75	12	25	48	100
Mean age (SD)	54.0 (13.5)		56.7 (11.9)		54.7 (13.1)	
Education:						
Basic education (<10 years)	19	52.8	6	50.0	25	52.1
Advanced secondary and higher education (≥10 years)	17	47.2	6	50.0	23	47.9
Marital status:						
Married/partnered	19	52.8	2	16.7	21	43.8
Single	9	25.0	8	66.7	17	35.4
Widow/er	6	16.7	0	0	6	12.5
Divorced/separated	2	5.6	2	16.7	4	8.3
Other occupation beyond care for older adult:						
Domestic worker	23	63.9	7	58.3	30	62.5
Self-employed	12	33.3	4	33.3	16	33.3
Paid worker	1	2.8	1	8.3	2	4.2
Self-perception of health status:						
Good	12	33.3	3	25.0	15	31.3
Normal	15	41.7	4	33.3	19	39.6
Poor	9	25.0	5	41.7	14	29.2
Relationship with the older adult:						
Child	22	61.1	6	50.0	28	58.3
Spouse/partner	5	13.9	2	16.7	7	14.6
Sibling	3	8.3	2	16.7	5	10.4
Other	6	16.7	2	16.7	8	16.7
Median hours dedicated to care-giving per day (minimum–maximum):						
>5–8	17	47.2	6	50.0	23	47.9
>8–12	13	36.1	3	25.0	16	33.3
>12	6	16.7	3	25.0	9	18.8
Length of time giving care:						
≥6–12 months	4	11.1	0	0	4	8.3
>1–<3 years	5	13.9	1	8.3	6	12.5
≥3 years	27	75.0	11	91.7	38	79.2
Has support of another family member for care of the older adult:						
Yes	22	61.1	7	58.3	29	60.4
No	14	38.9	5	41.7	19	39.6

Notes: N = 48. SD: standard deviation.

**Theme 1: Beginning of care and decision to become a care-giver**

The answers from the participants suggest that families are not prepared to care for an older adult who cannot live independently, and the decision to become a care-giver for a dependent older adult depends on multiple personal, economic and circumstantial factors that interact with family structure, dynamic and history. In some cases, the beginning of care arises suddenly owing to a rapid decline in the health of the older adult, mainly as a result of a surgical intervention or a fall:

I assumed care for my husband because one day I came home and found him on the floor. Poor man, there was sand and he fell and couldn't stand up. (HCC3:7)

One daughter commented:

It was the circumstances, in other words, one doesn't decide, I'm going to take care of my parents. My mom started having problems with glaucoma ... my dad got sick and my mom's health started to decline, because when my dad was sick I took care of him at night and she took care of him during the day ... But there are situations, there are events where you have to decide in the moment. (HCC1:16)

In other cases, the need for care was a gradual process and was associated with declining health or the ageing process of the older adult. For example, one son commented:

...after her operation, my mom continued cooking, washing clothes, but recently over the last ten years, my activities in supporting her were increasing a bit more according to her age and her ailments, which had been progressing, and over the last five years, my care-giving has increased much more. (HCC1:10)

In the decision to provide care, personal, marital or filial responsibility has a heavy moral or social type of obligation. In the case of spouses who assume care for their partner, one can appreciate a heavy moral weight regarding the work of caring: 'he is my husband, and I feel responsible for him' (HCC2:11). Another woman commented that although in the past, she had lived through situations of domestic violence, she cared for her spouse 'because there was no one to support him, to help him' (HCC2:10). Although they no longer live together, social duty (HCC3:09) is a key element in assuming care:

...he had no one to care for him, his relatives and siblings have their obligations, and so they passed it on to me because I'm his wife and I have to care for him. (HCC1:07)

In the case of daughters, filial responsibility was more notable as a determining factor in the decision to provide care:



...the love I have for my father, and I know that he needs me right now, and if they were there for me in my childhood, cared for me, then now I give back in some way what they did for me. (HCC1:08)

I feel that as a daughter, it is my responsibility. (HCC1:13)

In the case of male children, filial obligation dissipates and the economic dependence of the care-giver had greater significance. For example, one son commented, 'well now I am with her, I had my own house but since I separated, I came here with her' (HCC2:04). Similarly, another of the interviewees commented, 'she depends on me, I depend on her' (HCC1:03).

Another factor that influences whether a son becomes a care-giver is co-residency; some children mentioned that the decision was related to living in the house of the older adult because of being a single mother (HCC1:11), never having left their parents' home (HCC2:12; HCC3:10) or being out of work (HCC2:07; HCC2:08). Additionally, siblings believe that the child who is in the home should take charge of the older adult (HCC3:08), as noted by one care-giving son:

...since they all began getting married, they all grabbed their partners, built their families and forgot about mom; time passed, and so because of health problems, I stayed with my mom, and as I stayed, everyone stepped aside and I had to care for her. (HCC1:10)

Family structure and dynamics are other factors that intervene and can result in family members other than the spouse or children assuming care for an older adult. A woman who cares for her sister noted:

...the three of us came together, as she was also widowed, so then we came to live here, and now that she has this illness, one supports her' (HCC1:12)

When there are no children, other family members assume care of the older adult. For example, a cousin commented:

She didn't have any other family, her mother died, her father too, and she had no one to care for her, she's my cousin and like a sister, and I had the need to see to her. (HCC3:12)

On the other hand, when the children are unwilling or unable to take charge of their older parents, it is the siblings or daughters-in-law of the older adult who generally assume care: 'my father-in-law died, and there was no one who could take care of him' (HCC2:03). The brother of an older adult mentioned, 'Of his four children, none of them wants to know anything about him, and they tell me this plainly' (HCC1:15). Another interviewee expresses that he cares for his brother

because there is no one to care for him; my nephew is a reporter and has to be at work, and as I explained, we are alone, I had to assume care mostly because he is alone. (HCC1:04)

### **Theme 2: Difficulties in providing care**

The majority of care-givers had no experience in caring for a dependent older adult and did not have information regarding management of their illnesses. Care involves not only helping with basic and instrumental activities but also providing medical, pharmacological, rehabilitation and emotional care, and taking medical decisions. One participant mentioned,

...really, I do nearly everything for him, I have to tend his bed, I help him to bathe, to dress, I give him his medications, I prepare his food. (HCC1:13)

The activities informal care-givers perform are numerous and depend on the illness and degree of disability of the older adult:

I help her with everything, I bathe her, I check her sugar, blood pressure, if the catheter comes out I replace it, I feed her, give her medication. (HCC2:06)

In this sense, unfamiliarity with care work generates fear and worry in the care-giver as they perceive their lack of training as increasing their chances of not providing appropriate care or unintentionally harming them, affecting the older adult's health (HCC1:01; HCC2:08).

Differences between men and women were found in the challenges that care-giving presents. Men who provide care expressed greater difficulties than women because they needed to learn to prepare food, wash clothes and do other work that was traditionally performed by women in their families. In this regard, one son commented:

...with time I said to my mom, show me how to make food because there will come a day when I will have to make some eggs, a stew, and that's how it's happened; these days I have to make food for her, feed her and wash all her clothes for her. (HCC1:10)

One activity that proves difficult for care-givers, especially for male children and older care-givers, is assistance with bathing and hygiene because they consider it a sensitive, strenuous and embarrassing task for which they have received no type of training (HCC1:10; HCC1:13; HCC2:02; HCC2:04; HCC2:10). On this point, one care-giving son commented, 'I don't bathe her, it shames her a lot, and I have to call on other people, on my sister-in-law or on nieces so they may bathe her' (HCC2:21); one 77-year-old care-giver said, 'bathing her [the older adult], this is the hardest problem' (HCC1:12). As a result, bathing becomes a sporadic activity for the older adult that can occur as rarely as once per week or month or whenever another family member can help.

Another situation experienced as a problem in care-giving is the management of faecal and urinary incontinence in the older adult. Environmental conditions (physical obstacles in the house when going to the bathroom), lack of resources (such as disposable pads, urinals and catheters) and lack of information about this topic affect care activities and generate great physical and emotional impacts on the care-giver and distress in the older adult, in addition to conflicting relations, especially when the care-giver does not know that incontinence is a health problem (HCC2:11; HCC3:12; HCC3:13). Similarly, when disability is severe and the older adult requires assistance with mobility, lack of knowledge about the manners in which the person should be moved can result in injuries to the older adult (HCC2:08) or the care-giver (HCC3:13). Among bedbound older adults or those with incontinence, it was frequent to find injuries, excoriations or ulcers on their bodies as a result of the care-giver's lack of knowledge regarding managing this type of situation.

The in-home care programme is perceived by informal care-givers as a resource through which they may receive advice and training to care for the older adult. In this regard, one of them commented:

When the doctor comes, well they give me advice, they tell me to have a lot of patience and how I should give medications ... still, I believe that doctors should tell us how to treat a person in their old age, this would definitely help us. (HCC1:13)

Additionally, it is recognised that the terms that health-care personnel use are complex, and the information provided is often insufficient. Regarding this situation, one care-giver said:

I don't understand them, not even what they write ... they send us to get a test, and they don't explain to us what it's about. (HCC1:15)

According to the care-givers, health-care professionals do not have sufficient time to provide information about the evolution and management of disease, something that could contribute positively to the daily work of caring for a dependent adult. Additionally, care-givers perceive a lack of comprehension on the part of health-care professionals about the impact that the older adult's illness has on the life of the care-giver and their family.

Given the various difficulties that care-givers face and the lack of counselling on the part of health-care professionals from the medical-visit programme, some care-givers seek appropriate information about managing the older adult's illness through courses (HCC2:05), the internet (HCC3:13), printed materials (HCC3:03) or questioning those they believe may be able to help them. On this point, one care-giver comments:

Last year, I asked for ambulance support to transport my mother-in-law to the hospital because she was convulsing, and my mother-in-law has a prosthesis on her right shoulder, causing a lot of pain to her arm, and so the paramedic realised the situation and told me what I had to do so it wouldn't hurt her. (HCC2:06)

**Theme 3: Opportunity costs and impact of care on the personal and social life of the care-giver**

Caring for a dependent older adult changes various areas of the care-giver's life. In general, the repercussions tend to be negatively associated with work status, economics, leisure, family and social relationships, and the physical and mental health of the care-givers. Some care-givers must quit work or pursue informal jobs that allow them to have flexible schedules to be able to care for the older adult. One care-giver related:

...I used to work in a bar, I was a bartender, and now, I don't work because I'm here with him, since I left we have had to take him to the hospital because they put in a catheter, and every month we have to take him back so they can change it. (HCC1:04)

One of the interviewees (HCC1:08) worked in an institution but now sells breakfast in the mornings outside her daughter's school so that she can provide care to her parents. Informal jobs allow flexible schedules but jeopardise the economic and working conditions of care-givers, as one of the participants noted:

I can't have regular work, that is to say, I put up my food stand, but when she takes ill, everything closes down. (HCC2:06)

Changes in work status have an impact on the economic situation of the care-giver and their family, on some occasions causing a lack of food and payment for basic services, such as water, electricity or gas. One of the participants (HCC1:09) worked in shoe repair but, as his wife's illness progressed, had to quit his job and completely lost the possibility of income. One care-giver commented, 'we are now very limited, our lifestyle changed radically' (HCC2:05). In general terms, the incomes of these families were greatly affected, and in the majority of cases, the family income was reduced to only the older adult's income, which generally comes from pensions or government support. In this regard, one care-giver commented:

...now we are lacking money. Before [the care-giving experience], we had money as we were merchants, but now we only have what the government gives us, and here we are, waiting to go and collect every two months. (HCC3:16)

Leisure time for care-givers was very much reduced and often non-existent. One care-giver mentioned:

...sometimes I want to go out somewhere and I can't because there are things to do, I have to give her food, give her medicine, give her insulin... (HCC1:02)

When asked if she did things other than care for the older adult, one care-giver responded:

I don't go anywhere because she gets angry, she doesn't let me take vacations or anything, and then later wants to go with me. I tell her no, and God forgive me, but I fought with her all week and still took her with me, so because of all this, it's better if I stay home with her, not even go back to my house, I want to be alone with my family, but I can't. (HCC2:12)

Similarly, care-givers' family and social relationships change owing to the responsibilities of care-giving, with particular detriment to the relationships with the care-giver's partner or children. One care-giving daughter (HCC1:07) said that she gave up going out with her children as a result of her father's disability and the absence of modes of transport to move about with him. Another daughter mentioned:

...there are many care needs, in fact, I can't easily go out with my husband because I have to be available for him [referring to her father], so that he won't have a fall. (HCC1:13)

Social life is also affected when care-givers give up going out with their friends in favour of caring for the older person (HCC1:09; HCC2:05; HCC3:11). One consequence of this situation is that care-givers end up losing their social and support networks, which results in greater isolation for both the care-giver and the older adult.

The impact of care-giving is also reflected in the physical and mental health of informal care-givers. The responsibility of caring for a dependent older adult involves a high burden and dedication of time, which lead to stress, the care-givers not being able to attend to their own health problems and resulting illness. Some care-givers prioritise care over attending to their own health. On this point, one hypertensive care-giver commented:

I'm very uncertain about my health because first I give attention to those who need me and I come last, so there are times I say, my health is going to come first, but if my father seems ill, I see to him first. (HCC3:17)

Among the main physical health problems, care-givers reported gastrointestinal illnesses, diabetes, hypertension, musculoskeletal and vision problems, in addition to the presence of pain. In some cases, care-givers reported receiving treatment for control of their illness. Oral health is a common problem, although it is not recognised as such, and the majority of informal care-givers receive no treatment.

Care-givers also mentioned having problems with anxiety and depression, especially in cases in which the older adults had greater dependence and care-givers had less family support and insufficient economic resources (HCC1:05; HCC1:09; HCC1:13; HCC2:01; HCC2:12; HCC3:02). The idea of suicide was expressed by some care-givers, mainly in the case of men (HCC1:05; HCC1:09; HCC2:11). Doctors who visit the homes of older adults have recommended that care-givers seek psychological care; however, some of them do not do this owing to time constraints (HCC1:04; HCC2:01), and others who went to a psychologist mentioned that their experience was unpleasant because the professional did not understand

the reality of people who dedicate their lives fully to the care of an older adult (HCC1:05; HCC1:09).

In general terms, care-givers do not attend to their own health needs because of economic problems, lack of family support or absence of support networks, lack of time, problems associated with public health services related to long wait times and lack of psychological-support personnel; these factors are interrelated with the consequences of their emotional situation.

#### **Theme 4: Feelings about the older adult and the work of care-giving**

Among the care-givers interviewed, the feelings that predominated were associated with fear, distress, hopelessness, powerlessness, guilt, anger, exhaustion and isolation. The physical, cognitive and behavioural deterioration of the older adult are aspects that complicate care in daily life and that generate a multiplicity of feelings in care-givers. Similarly, care-related issues such as lack of information, lack of knowledge of the illness, lack of economic, family and social support, isolation, family conflicts, and histories have an impact. Filial responsibility is such that some care-givers feel a moral duty to care for their older parents, which can result in the expression of feelings of guilt. In this regard, one of the interviewees said that she prefers to care for her mother and fight with her in the present rather than have regrets in the future, 'because later the family makes us feel guilty' (HCC1:16). For various socio-economic (*e.g.* unemployment, informal work and highly marginalised contexts), family (*e.g.* lack of care networks and concentration of care-giving in one individual), cultural (*e.g.* ideas and expectations of family and gender roles) and individual (*e.g.* personal aspirations) reasons, care-giving generates additional burdens and negative emotions in the care-givers. Grappling with the contradiction represented by this filial responsibility, cultural norms and lack of formal support can have disruptive effects on the mental health of care-givers.

Family conflicts (between spouses, between children and parents, and between siblings) were also a constant in the lives of interviewed care-givers. For spouses, especially when the woman is the care-giver, domestic violence suffered in the past often influences the care she provides to the older spouse and her relationship with him (HCC2:10; HCC3:09). One wife commented:

I suffered a lot with him, he mistreated me, he beat me, so I take care of him but now we argue a lot, quite a lot. (HCC2:10)

In turn, conflicts between children and parents in some cases are related to unresolved problems from the past (HCC1:05; HCC2:07; HCC3:15). Economic situations are also a trigger for conflict; one of the interviewees admitted that she shouts at her parents in moments of desperation, when she feels she reaches a 'limit' in which 'everything comes together, all at once I don't have the money, and I have all the responsibility and I am already drained' (HCC2:08). The exhaustion caused by the care-giving itself and the scant support from siblings also leads to conflicts. One care-giver in charge of her mother said that she would like her siblings to take care of the older adult 'even for just one week and they will see how my mom actually is' because 'they don't put themselves in another's shoes,

because there are many responsibilities and disagreements' (HCC2:07). However, on occasion, the negative feelings associated with care-giving are associated not only with conflicts but also with the emotional impact of watching the older adult ageing. In this regard, one care-giver mentioned feeling

...despair at the way the world closes down on me as I watch her suffer with her pain, I have a breakdown to see her this way, what can I do, what can I do to help take away her pain, I need to control myself because there is no way out, other than control yourself and struggle with the illness. (HCC1:03)

For various care-givers, assuming this role represents an abandonment of projects and personal activities, which is also a factor in frustration, anger and sadness. Caring for an older adult can postpone or end expectations and ideas that care-givers have for their lives; on this point, one care-giver noted that

I never imagined myself having my mom here, any normal woman marries, [has] her daughters, her sons. (HCC1:05)

Another care-giver affirmed that she does not like fulfilling this role because

I really liked going to work and now that [my life] is cut short ... I had a very active social life and now that's gone, and it weighs on me. (HCC2:07)

Lack of care-giver training is another factor that generates fear and guilt. Situations such as domestic accidents (HCC2:09) and care-givers feeling that they cannot or do not know how to attend to the older adult adequately (HCC2:12) were noted as causes of feelings of guilt and hopelessness.

The interviewed care-givers were observed to be affected by emotional and attitudinal changes in the older adult and felt frustration when they observed that the older adult did not co-operate or did not comply with the recommendations for taking care of their health. The care-giver for an older diabetic adult with right-leg and finger amputations commented on her desperation: 'she does many foolish things, things she mustn't do' (HCC2:08). Various care-givers spoke of a need for the older adult to 'commit' to their own treatment and of discouragement from feeling their lack of collaboration (HCC3:13). Another care-giver (HCC2:05) related that for her, it is very frustrating to be unable to break the older adult out of the passivity in which she finds her. These emotions generate changes in the care-givers themselves; on this note, one care-giver commented:

My character is changing, I feel like before I was much more approachable, patient and everything, and now with so much responsibility, there comes a time when I go out of my mind. (HCC2:07)

Feelings of hopelessness lead many care-givers to think of institutionalising the older adult or, in more extreme cases, to desire their death. In this regard, one care-giver commented:

Often in my thoughts I have said ‘God take him’ because of his fighting, but later I reflect and when I go to church and say, Lord, forgive me for my thoughts, you know I try to give everything I am able to give, help me and forgive me for these thoughts. (HCC1:04)

In other cases, the weight of these negative feelings is so great that care-givers come to wish for their own death or to conceive of the care as a punishment (HCC2:11). Weeping was a constant during the interviews.

Nevertheless, other care-givers interviewed recounted positive feelings when they realise the older adult co-operates in their treatment and maintains their desire to live (HCC1:11) or when they feel that they are learning something about the situation (HCC2:05). Likewise, having living older relatives despite their age was recognised by some care-givers as a rewarding aspect (HCC3:11).

## Discussion

Consistent with previous studies (Wolff and Spillman 2014), one of the most relevant findings of this study is the high time demand for care in light of precarious health conditions and the presence of disability in the older adults. Another important result is that although characteristics of the care-givers interviewed were diverse regarding sex, relationship to care recipient, educational level, occupation and capacity to provide care, as well as the health conditions of the dependent older adults, some common aspects were identified. One of these commonalities was the fact that the care-givers were not prepared to attend to the dependent older adult, which is exacerbated when care responsibilities begin suddenly, an aspect that has been documented previously in the literature (Williams *et al.* 2016). Moreover, it was observed that when care-givers did not freely choose the role of care-giver, this negatively influenced the experience of caring. Even though moral or social obligations are felt by children and spouses, over time, the experience of care generates instability in the conditions of a care-giver’s life and various emotions, such as frustration.

These results reveal an urgent need to create long-term care systems in Mexico, as suggested by the WHO (2015a, 2015b). It is important for these systems to include formal in-home support services, adult day-care or respite services, primarily in cases in which the care-giver is an older adult with health problems, when no family care-giver is available, when care-givers do not have sufficient economic resources or when care-givers lack support networks that would allow them to continue working.

The results highlight important gender differences in the provision of care, in that male care-givers reported more barriers to satisfying needs and to improving the health care of the older adult for whom they care. This result is related to others reported previously in which differences in the impact of care on the health of a dependent adult depended on the care-giver’s sex, where a lower probability of the older adult dying was observed for adults cared for by a daughter. The authors of this study suggest that the impact of gender differences on the health of an older adult may be due to daughters providing higher quantity and quality of care than sons (Trujillo *et al.* 2012). However, as was found in this study and as has been suggested in other studies, men interviewed experienced more difficulties in providing



care due to cultural aspects and to traditional gender roles in their social environments, which impacts their ability to provide care (Williams *et al.* 2016). The results of the present study suggest the importance of analysing the care-giving experience from a gender perspective, which would aid in better understanding the impact of care on care-givers and on the receivers of care.

This analysis revealed that the health education and orientation provided to the patient and family regarding illness and general care by the in-home care programme is insufficient because many of the care-givers reported a need to receive training and advice regarding managing the older adult's illness. Interviewed care-givers not only provided support for the older adult in basic and instrumental activities of daily living but also, in the majority of cases, had to perform treatments, therapies or rehabilitative exercises. Results from previous studies suggest that interventions directed to informal care-givers significantly improve the quality of care provided, in addition to the wellbeing and quality of life of the care-giver and the older adult for whom they care (National Academies of Sciences, Engineering, and Medicine 2016) and, therefore, implementation of such strategies is also recommended.

In the literature, it has been documented that informal care-givers face economic problems and deteriorating physical and mental health (Sawatzky and Fowler-Kerry 2003; Smith *et al.* 2014; Williams *et al.* 2016). These conditions were observed in this study and were more apparent in care-givers who lived in the same dwelling as the older adult, who dedicated more hours to care, who did not engage in activities outside the home, who did not have support networks, who had to quit a job to dedicate themselves to care-giving, who did not have their own incomes, and who expressed experiencing present and past family conflicts. The study revealed a need to analyse the type of relationship the care-giver establishes with the person receiving care because the pre-existence of conflicting relationships negatively affects the manner in which care is provided.

In addition to conflicts between the care-giver and older adult and between siblings, which have already been documented (Williams *et al.* 2016), also evident in the present work were conflicts that care-givers have with other family members due to the time they dedicate to caring for the older adult. Regarding the economic situation, it was also noted that some of the care-givers had to meet the economic needs of the older adult in addition to their own economic needs. In contrast to the situation in some high-income countries where care-givers have access to public programmes that may allow them to balance remunerated work and provision of care (Williams *et al.* 2016), the present study demonstrated that care-givers interviewed in Mexico City often had to quit working or take on informal work to provide care for the older adult, mainly due to the absence of flexible employment policies, the number of hours they dedicate to care-giving and lack of support networks. As has been documented in other studies, financial difficulties add a greater burden to informal care (Williams *et al.* 2016).

One of the findings of the study is the clear burnout and overload expressed by the majority of informal care-givers. This is evidenced by the lack of care for their own health, the existence of conflicting relationships (care-giver-older adult), and the presence of feelings of anguish, guilt, anger, exhaustion and isolation. This burden of the informal care-giver is a recurring theme in the literature (Baptista *et al.* 2012). Still, analysis of the care experience that accounts for this overburden is

enriched by the recognition of other factors associated with the family and social contexts of individuals involved, such as the absence of robust and co-ordinated health and social services, in addition to public policies that could ensure quality of life for the care-giver and older adult. Accordingly, this suggests a need to create public policies oriented towards 'caring for the care-giver', for which an opportunity exists in the in-home care programme to include actions directed at the physical and mental health of informal care-givers, which in theory will have a favourable impact in the form of better care for the older adults for whom informal care-givers are responsible.

The rich descriptive information obtained in this study provided useful insights into this group's care-giving experiences. However, in interpreting the results, some limitations should be acknowledged. This study interviewed care-givers that represent a particular group by being care-givers of dependent older adults who are beneficiaries of an in-home medical visits programme, and as such have at least some contact with health professionals that other care-givers lack. Further, the context where these dependent older adults and their care-givers live is characterised by large urban settings exposed to economic hardship and poor physical access that impact the care-giving experience in specific ways. Therefore, results may not be generalised to all care-givers in Mexico City or those in less urban areas in the country. Future research could consider a more diverse population by including care-givers who are not in contact with the in-home care programme, and care-givers from other socio-economic levels and from less urban settings.

## Conclusion

Family care-giving is increasingly complicated due to higher prevalence of chronic illnesses and disability, an increase in duration, intensity and load of care, increasing financial costs associated with informal care-giving and the significant decrease of remunerated formal care (Family Caregiver Alliance 2006). In this sense, participation of informal care-givers is highly relevant in achieving the rehabilitation, health preservation, maintaining quality of life and social participation of older adults. However, regardless of the fundamental role informal care-givers play, this study shows the diverse problems associated with providing such care, such as lack of information on care needed, high opportunity costs, high impact on personal and social life, as well as negative emotions and feelings about their care responsibilities. This situation makes evident the urgent need to generate strategies that satisfy the needs of care-givers within the health-care system, and the development of psycho-social interventions and coping strategies that take into account socio-economic characteristics and individual resources of care-givers so that they can be integrated into current programmes such as the Mexico City Health Department's in-home care programme. It seems urgent that decision makers understand and acknowledge the relevance of further developing public policies with a gender perspective within a system of long-term care where support for informal care-givers of disabled older adults is one of the central strategies.

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