RECONCILING WORK AND ELDERCARE

Caregiving men of Alzheimer’s disease sufferers in Nuevo León (Mexico): experiences and meanings

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Abstract
Despite their invaluable contribution to health care, men who fulfill the social role of primary caregivers at an older age represent an understudied group in the state of Nuevo León (Mexico), and elsewhere. Ongoing demographic and epidemiological changes point to a graying population, an increase of disabling chronic and degenerative diseases, and functional limitations linked to a decline in self-reliance. The latter leads to further dependence on assistance which is predominantly home based. This article investigates the lived experiences of caregiving men providing care to their elderly relatives who have Alzheimer’s disease (AD). After obtaining verbal informed consent, face-to-face, in-depth interviews were carried out in the natural environment with a convenience sample of 58 spouses and sons. Absenteeism was a common occurrence among those who were still involved in the labor force; however, the ways it was handled differed according to the sector of the economy (formal vs. informal) the participant contributed to. Assistance provided by AD support groups, the availability and use of paid helpers, immediate and extended family, and making adjustments to daily routines to accommodate work schedules contributed to easing the burden of care. However, medical expenses put a strain on caregiver finances, and complaints about the costs of medications were consistent among employed and retired caregivers. A mix of positive and negative aspects inherent to this dyadic process was revealed along with trajectories of elder caregiving that were not always unilinear. Relationships of reciprocity, dependence and interdependence, and strengthened family bonds were salient. These findings are discussed in light of existentialist and humanistic theoretical frameworks on social integration and needs, with their propensity for emphasizing cognitive benefits, and the related meanings to individuals. The findings imply that concerted policy making in public health, labor, and social sectors, to provide timely recognition and support to caregivers, is needed as a proactive approach to lightening the burden of elder caregiving.

Keywords: Neuro-degenerative disorder; elder caregiving; social roles; under researched group; Mexico

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In Mexico, besides emigration to the United States (Instituto Nacional de Estadística Geografía e Informática [INEGI], 2005), demographic aging is explained by the combined effect of mortality and birth decline which accompanies epidemiological transition (Zuñiga, García, & Partida, 2003). In the northeastern state of Nuevo León, a more industrialized state than those located in the south and center of the country, longevity is a noticeable feature, with an average life expectancy at birth of 75 years for men and 79 years for women (Gobierno de Nuevo León, 2008). Age is a risk factor consistently associated with Alzheimer's disease (AD), a neuro-degenerative condition which slowly progresses to senile dementia (Lindsay et al., 2002).

AD has three stages—early, middle, and late—and each stage is accompanied by a series of changes in the patient over time. They encompass deteriorations related to personality and behavioral changes, troubles with communication (language is impaired with aphasia, apraxia, and agnosia), swallowing food, control of bodily functions, disturbed sleep, memory loss, and other impairments (Hubbell & Hubbell, 2002; Zanni & Wick, 2007).

In the United States, AD patients represent about 10% of the population aged 65 or older. The number of informal carers of these patients is estimated at more than 3 million persons who are also caring for almost 50% of those aged 85 years and older (Arehart-Treichel, 2008; Donelan et al., 2002; Hubbell & Hubbell, 2002). In Mexico, where estimates of AD are less accurate, there are about 350 geriatricians for a population of about 8.2 million older adults. This ratio implies an extension of the informal care system and highlights the potential for societal and family tensions that can result from the proliferation of informal care (Montgomery, Gonyea, & Hooyman, 1985; Tennesdett & Mckinlay, 1989).

Tensions are felt at an economic level. Nationwide data on economic productivity and caregiving in Mexico are not as easily available as is the case in other countries such as the United States. In the United States, annual losses for the business sector in relation to employees' need to care for loved ones aged 50 years and older are estimated at as much as $US34 billion. Health care costs for the employers of caregivers are 8% higher than employers of non-caregivers with $US13.4 billion per year (Caregiver Action Network, 2010). A recent study conducted among caregivers in Mexico City on differences in the economic burden associated with the hospitalization of older adults (in a geriatric unit and internal medicine ward), focused on out-of-pocket expenses, non-medical out-of-pocket expenses, and indirect costs (López-Ortega, García-Peña, Granados-García, García-González, & Pérez-Zepeda, 2013). Transportation and medications were the most common expenses, and the indirect costs consisted of 4.12 days (as mean numbers of days) of lost income. Parking and food represented other costs for the family caregiver staying with the elderly patient.

A review of the economic disadvantage of caregiving in the context of Mexico is problematic as reliable estimates of the benefits of unpaid caregiving for the nation’s economy and/or the negative effects of unpaid caregiving on caregivers’ capacity to maintain paid employment are not available. It is important to note that in Mexico even when paid
employment is maintained, salaries in general are low and have been losing their purchasing power. An increase in minimum wages is not expected to make a significant difference. A recent study in India found that informal caregiving lead to substantial economic disadvantage since caregivers reduced their working hours or stopped working without receiving any form of allowance. A combination of reduced family income with medical care cost increases impoverishment in low-income households (Shaji & Reddy, 2012).

Other tensions relate to the health impact of informal caregiving. Full-time commitment to an AD patient is associated with social isolation and burnout of the primary carers, and ruptures in routine family life (Fuller-Jonap & Haley, 1995; Harris, 1993; Hubbell & Hubbell, 2002; Perel, 1998; Psychiatric News, 2008). Mortality, higher rates of depression, and physical health problems due to caregiving roles are more often associated with AD than other diseases (Arehart-Treichel, 2008; Tremont, 2011; Christakis & Allison, 2006).

AD, like many developmental diseases and disorders requires many hours of care. According to a recent study from Canada, these are diseases and disorders for which 51% of caregivers spend at least 10 hours weekly providing help (Sinha, 2013). Irritability, nervousness, anxiety, and depression are related to the number of hours per week of care provision and are manifestations of the stress and burden associated with the responsibility. The number of activities (i.e. too many tasks) undertaken by caregivers who may be ill-equipped to take on these responsibilities has been considered a major source of stress (Schulz & Martire, 2004; Navaie-Waliser et al., 2002).

If the greater negative impacts of AD caregiving have been well described (Feinberg, Reinhard, Houser, & Choula, 2011; Schulz & Sherwood, 2008), it is also worthy to mention the existence of conflicting data. A comparative study of caregivers and non-caregivers found that caregivers rated their health better, and did not report more depressive symptoms or social isolation, which suggested that caregiving per se does not lead to symptoms of depression, poor health, or social isolation (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Also well documented are positive coping mechanisms that mitigate negative effects on the caregiver. One such mechanism is the support provided by social ties. The pioneering work by Durkheim (1951) established the importance of social structure and norms in protecting and regulating behavior. Since then, many studies on social integration and its impact on health and mortality have been undertaken (e.g. Christakis & Fowler, 2007; Holt-Lundstad, Smith, & Layton, 2010; House, Robbins, & Metzner, 1982).

The interchangeable use of the terms social integration, social ties, social networks, and social engagement is common in the research literature on social relationships and affiliation. Social integration and social networks as opposed to social isolation or non-supportive social interactions are often associated with better health outcomes (Cannuscio et al., 2004). In a study of social ties and health, the quality of existing ties was highlighted as an influence on the health benefits provided by social integration (Seeman, 1996). Along with social networks and social participation, trust and reciprocity are components of social capital (Abbot & Freeth, 2008), an
intangible asset with influences on health (Berry & Welsh, 2010; Hsieh, 2008).

Male caregivers are underrepresented in research studies on informal caregiving, in comparison to female caregivers. Such a discrepancy has been attributed to a scientific production for and by women (Cahill, 2000; Paul, 1999). Since the 1980s, however, there has been an emerging research literature which compared men and women in this social role and differentiated them in terms of motivation (Finch & Mason, 1993; Mathew, Mattocks, & Slatt, 1990), likelihood of depression, feelings of guilt (Kaye & Applegate, 1990), performance of duties (Harris, 1993; Miller, 1990; Ungerson, 1983), formal and informal service utilization, and help and support networks (Johnson, 1983; Stoller & Cutler, 1992; Zarit, Todd, & Zarit, 1986).

Recently, it was noted that in the United States 41% informal caregivers of AD patients were males (Psychiatric News, 2008). In the United Kingdom, a population-based study of informal carers which revealed a systematic link with both age and gender, showed a reversed pattern in later life (70 years of age and older) with a higher proportion of male carers and greater time commitment to caregiving among males (Dahlberg, Demack, & Bambra, 2007). In a similar vein, it was found in Spain that female caregivers are at a higher risk of poorer health due to a greater intensity of caregiver burden, but as men’s caregiving burden increases, gender inequalities decrease or invert (Larrañaga et al., 2008).

While the lack of visibility of male participants in caregiver research is now recognized (Houde, 2002), exploring the commitment to fulfilling a caregiving role among this understudied group is of particular concern for this research. Beyond normative gender roles, what can we learn about their lived experience and the meanings they ascribe to it? In seeking such knowledge, their narratives are essential.

In the context of Mexico, characterized by persistent social inequalities, and an aging population, neglecting this group of male caregivers (often labor force participants or retired workers), reflects a narrow approach to the long-term care and quality of life of care recipients. The objective of this article is to examine male caregiving experiences, and the meanings ascribed to providing care for their elderly relatives who are AD sufferers.

**METHODS**

**The qualitative approach**

Fieldwork, the main component of the empirical research carried out, consisted of two main phases. The first phase was a necessary immersion in support groups of family carers of AD patients for a period of approximately 3 years. These are self-help groups located in Monterrey and its metropolitan area, led by geriatricians who share their time and provide their expertise. They offer many benefits to participants by educating them about the disease.

In addition to becoming more familiar with the dynamics of these support groups, immersion facilitated the proposed research. The second phase consisted of accessing study participants in their natural life context.
Recruitment and sampling

The inclusion criteria were being male, and having a major role in the care provision of a parent who is or was an AD sufferer. The family caregiving experience could be ongoing or prior to the initiation of the study at the local Association of AD in Monterrey, the capital city of the state of Nuevo León. The period covering the admission of the patient to a hospice was excluded. A total of 34 participants were recruited from the AD support groups. Using a snowball technique, the size of the convenience sample was increased. Some study participants helped to locate other family caregivers who were no longer attending the support groups. The final sample was $n = 58$.

Data collection and analysis

Interviewing

In order to collect primary data, individual semi-structured face-to-face interviews, conducted in Spanish, took place at the homes of the study participants in Monterrey and its outskirts. The interviews were undertaken during two to five visits, varying between 2 and 4 hours each, depending on the availability of the interviewees. Two respondents were interviewed at their office for convenience. All appeared to feel comfortable and safe in an interview environment familiar to them, and spoke openly.

Interview questions were worded to obtain answers relevant to the research questions and objectives. Pretesting of questions was undertaken to check the relevance of some of the research themes and key words. Semi-structured interviews were used as they are more likely to yield in-depth and comprehensive information about lived experiences. All the interviews were audiotaped.

Examples of open-ended questions asked were: What do you do as a primary caregiver? How do you assess the levels of difficulty of your caregiving tasks? What do you like and dislike about it? What motivated you to commit to such a role? What does it mean to you to play such a role? What have you been through as a male primary caregiver? What did you learn from it? How do you or did you find the overall experience? Open-ended questions were preceded by closed ones in order to obtain information on the demographic characteristics of study participants. The number of hours dedicated to caregiving was computed to assess its intensity. Its extent was also assessed by asking questions about the duration of the caregiving role. However, in accordance with the qualitative nature of the research, evidence on the amount of time devoted to eldercare is not reported here.

Data analysis

Data analysis was undertaken of all the audiotaped interviews looking for similarities, differences, and inconsistencies in data drawn from the respondents. A prior step was to ensure completeness of the original transcripts. Coherence between the data collected and the transcripts is an important step in ensuring reliable conclusions regarding the research questions are derived from the data.

Key themes emerging from the verbatim transcriptions were assembled for optimizing thematic analyses. The key themes were: coping strategies/reliance...
on external help; contradictory emotions of the eldercare work performed; family bonds, dependence/interdependence; reciprocal care, sense of rightness, and esteem as meanings ascribed to caregiving; achieving the personal value of being helpful, supportive; and feelings about successes and failures.

More specifically, raw data derived from open-ended questions were classified into themes and subthemes. After a thorough review, they were examined through a fine-grained procedure in order to identify similarities and were then codified (open coding). After assigning code labels, detailed descriptions fitting a specific theme and their meanings were extracted. Categories and subcategories were formed and compared from the narratives to obtain storylines, to highlight interconnections and discrepancies, and to refine the categories during the process. After continuous review of verbatim transcripts, a further expansion of codes, comparing raw data gathered during the AD support groups’ sessions with data which emerged from the interviews, and following sorting of the data, a theoretical saturation was reached.

Short excerpts, rather than lengthy answers, are used as illustrations. In doing so, individual excerpts do not lose their unique qualitative distinction to illustrate the findings. The original direct quotations in Spanish are translated into English. Data collection and analysis were completed extensively over a period of 10 years (since 2003) by the author as a primary investigator. Due to the qualitative nature of the study, findings are not generalizable beyond the sample.

Research ethics
Informed and free verbal consent was obtained from study participants at the first phase of fieldwork and then again prior to collecting data. Participants were informed about the objectives of the study and agreed to be interviewed at their own residence, except for cases where access to public transportation was difficult. Numbers were used to match identification on the interview files and transcripts, in order to maintain anonymity. None of the participants received any payment. No formal ethical approval was required or granted for this study since it was deemed not to pose any threat to participants.

RESULTS
Taking on the caregiving role
The decision to fulfill the role of primary caregiver was either made individually, or was the outcome of a family consensus. In Mexico, the law protects against elder neglect and can be enforced in cases where adult children are reluctant to provide for the needs of their frail, ill, or disabled parents. None of the participants indicated they were unwilling to provide care or felt pressured or forced to undertake the caregiving role. These men provided unpaid preventive, supervisory, and instrumental care to a parent (more often a father) or a spouse (wife) since the onset of the disease. They provided care more often in their own home with most of the primary care recipients living with them. The amount of time—an average of 20 hours weekly—dedicated to the
AD patient increased according to the progression of the disease. Being self-employed offered the advantage of more flexible working hours and a larger amount of time to spend with the care recipient. When care for the entire day was required, the carers sought additional help within the family or externally. Care recipients needed help for tasks such as cooking and often for personal care (bathing, dressing).

The primary caregivers were married older adults with children, with the exception of one participant. Their educational achievement ranged from basic and middle (primary and secondary school) to vocational training, and tertiary or advanced levels (college/university), with some holding professional degrees. Their monthly income was either derived from both formal and informal economic activities, or an old age pension, or an early retirement pension. Most were beneficiaries of health insurance, usually from the Mexican Institute for Social Security (Instituto Mexicano de Seguro Social/IMSS), which covers both the primary caregiver and their family. Participants had no previous caregiving experience. The duration of care provision varied between 6 months and 8 years.

**Facing and managing double work: care and employment**

In Mexico, delaying retirement is a practice which is not as common as it is in Europe and other developed nations, and successfully working octogenarians are more the exception than the rule. However, despite decreased labor participation in old age, the conflict between caregiving and work demands was present among study participants. In addressing how the related tensions were dealt with, a typology of workers linked to varying working conditions emerges (formally employed versus informally employed).

When they are still engaged formally in the labor force, caregivers can often be absent due to their caregiving responsibilities and this in turn can result in lower productivity. Those who are formally employed and work full-time are entitled to a definite number of hours of absence and paid vacation on a yearly basis. Therefore, missing work fits within what is permitted. Exceeding the limit puts them at risk for being lawfully fired. Once the limit is reached, they have no alternative than to seek permission from their employer to leave work early in order to meet demands related to their caregiving role. For those who are not formally employed, taking time off for caregiving duties can be easier. In the informal sector of the economy where it is easier for the elderly to get unskilled jobs and other income-generating opportunities, scheduling is flexible. As some participants noted, they did not have the constraint of justifying their absence:

[I do not have to hand in any medical proof].

[I do not have to check time cards].

Nonetheless, in both employment situations, absenteeism among caregivers is a common occurrence along with the care decision to seek help inside and outside their family circle. This kind of assistance coupled with optimizing and adapting non-working hours to some caregiving activities, allowed a better balance between both responsibilities to be reached.
As a result, the care recipient was never left unattended:

[There is always someone at home ... We made some adjustments to our working time and school schedule ... This is how we arranged it with my daughters and nieces].

[I manage to wake up when my wife is no longer asleep] ...

[I had to make some adjustments to my eating time] ... [...] I eat on our way to the doctor's appointment].

The work situations of some of the caregiving men were derived and summarized from the conversational interviews. When they have an employer, salespersons are paid on a commission basis, or receive a basic salary in addition to commissions depending on the kind and size of company they are involved with. Salary deductions are made for unjustified absences, and there is a limit for the number of justified absences. Absenteeism implies decreased sales, which means less productivity, and, thus, less commission. Productivity at work is key to being promoted and could give an edge in salary negotiations. A street vendor retailing food or non-food items on his own account is not concerned with promotions but remains vulnerable to the consequences of absenteeism for his sustenance. The dilemma was stated like this:

[I need my business to take care of my beloved wife. That's not easy ... I cannot neglect my woman either. She needs me ... It is about to provide for both, otherwise how can we live?].

A solution is to make the most of the law of supply and demand. Hence, labor-intensive periods of time become a higher priority when people are willing and able to spend:

[When they get their bonus at the end of the year, or for some celebrations, they buy and buy, they are unstoppable. This is when I cannot skip. I have to work more during these favorable sale seasons and make more profit because after that, comes the post-holiday budget crunch and people watch their money].

For unpaid workers, such as volunteer packers in supermarkets, parking attendants, and gardeners, going in late and workplace adjustments are self-managed. They only receive gratuities, not wages, and are not entitled to any employment benefits. Unlike workers who are formal employees, they do not have to seek permission from an employer. However, though income is unstable, the amount of money they make represents a cash inflow which can be reduced each time they have to stop working owing to caregiving duties. Therefore, when absenteeism becomes excessive, their means of livelihood are under threat.

Being away from work due to caregiving constraints, or physical fatigue, is not easily avoidable, and it contributes to depressed earnings. In some cases, for those primary caregivers who are retired and live strictly off their old age pension or retirement savings, a consensus is reached within the family to provide them with some financial support:

[I am a pensioner ... you know how it is (referring to the amount), it is not sufficient to cover the spending] ...

[Everyone's contribution is very important ... He is our father anyway].
Impacts of the caregiving experience

Learning opportunity

Fulfilling the role of primary family caregiver has a range of repercussions. The felt and expressed impacts are both negative and positive. Attending the AD support groups is beneficial in terms of acquiring new knowledge. In addition, these primary caregivers make individual efforts to research into AD. Education matters to most of them, and curiosity to deepen their knowledge of the disease is a strong motivation. For some, their knowledge is enhanced through reading specialized literature:

[I read magazines and books ... I look for information in newspapers’ articles, journals, self-help groups.]

Another important aspect is the creation of the local Alzheimer’s Association and activities associated with related membership. It has a positive impact by providing the opportunity to participate in national and international scientific and professional meetings (seminars, conferences, symposia) about the disease.

Most study participants found the experience of caring invaluable, because the regular closeness to the patient strengthened already existing bonds. Being committed to a parent in need of care, be it for solidarity, reciprocity or any other reasons, generated a feeling of satisfaction in some. In their own words:

[He is my father, I am his own blood ... He has taken care of me since my early childhood ... He would have done so for me ... we have to help each other ...].

Alluding to his spouse, a study participant said:

[I had to do it for her. It was the right thing to do].

Struggling to have the care recipient take their prescription medicines was considered a learning experience. The role played in keeping the AD patient in their home environment with people family members, and delaying institutional placement, were felt and stated as positive outcomes. There was a lack of reliance on nursing homes.

Patients’ cooperative behavior

Observing the care recipient not only complying with exercise routines specifically designed to promote their physical and mental activities, but also witnessing that they were enjoying them, was a great source of satisfaction among the caregiving men. Other positive feelings expressed were related to changes in the patients’ appetite, and acceptance of medications. For some of these caregivers, to see their relatives making efforts to chew their food properly, or eating with more appetite and even making eye contact more frequently, was personally satisfying.

Realizing that patience during mealtimes, or reading to or taking the care recipient on a walk was not benefited the care recipient provided the participants with a sense of accomplishment they found difficult to express. There was a feeling of accomplishment for having been helpful at improving, to some extent, the quality of life for their family member suffering from a particularly complex health condition. In their own terms:

[There is such a great feeling of satisfaction, something inside, an unspeakable huge joy] ...
The satisfaction of accomplishment creates a great feeling which motivates one to do more and more.

These occasions give the participant much needed hope, boosts their faith, and helps to overcome some fears.

These sudden changes create a feeling of happiness. The truth is, a lot of happiness. It can be compared to a ray of sunshine. When that happens, I wish it never ends ...]

[I even scream, and I say oh dear lord, if you could stop the time ... I wish I had magical powers to make the moment last forever ...]

Maintaining and strengthening the family bond

Striving to converse with the AD patient despite an impaired ability to communicate can often seem unproductive. However, interactions with the care recipient, such as moving them around in a wheelchair, administering their medications, and providing gentle massages, create opportunities to spend some quality time together, and to enjoy more closeness with their family member. These are considered positive experiences with great impact because committing to a sick elderly relative, and especially a loved one, represents another way of transmitting family values to the younger family members and thus, perpetuates traditions of mutual care:

[We have some values to teach to the youngest ones ... This is how one learns, so that we do not lose our traditions of solidarity and support].

Deterioration in the patient’s health makes it more difficult to provide the needed care at home. Ideally the goal is to delay or slow the advance of the disease, by maintaining the connections within the dyadic process of care. Being successful at fulfilling the caregiving role means having the AD patient at home for the longest period of time possible, minimizing the pain of separation, delaying institutionalization, and strengthening parental bonds.

Health aspects

Primary carers of AD sufferers reported negative impacts on both their physical and emotional health. Often the care recipient cannot remain unattended because of the possibility of accidents if left alone. For instance, one study participant commented that his spouse had lost her thermal and touch sensitivity. Because of her reduced sensory acuity, she was unable to clearly distinguish between hot and cold. Consequently, she was often at risk for accidents and injury and had had a number of incidents with hot water that resulted in first degree burns.

AD patients can be very active and restless. This requires continual vigilance on behalf of the carer, and thus considerable energy expenditure. More intense supervision is required when the care recipient is reluctant to eat, or tries to avoid medications (e.g. hiding pills under their tongue and later throwing them away). Physical fatigue is a recurring symptom for the participants. The health of the care recipient and the family caregiver are interrelated in various ways. A case of herniated disk was reported by a primary carer whose father was lacking balance and was heavier than him. He had to carry him on a regular
basis, and this resulted in deterioration in his own physical health.

The physical state of health of the AD care recipient is also related to the emotional health of the primary caregivers. One of the participants reported being deeply distressed in relation to a fall his spouse had on the stairs in their home which resulted in head injury. Respondents made comments about anxiety, lack of sleep, or disturbed sleep from being worried about the care recipient’s state of health, and functional impairments. The following case study provides an illustration of the emotional health of a study participant impacted by the change over time in his wife, a talented cook.

**Case study: a queen of the kitchen**

Doña XY, native from another state of the Mexican republic, was married to male caregiver Z for many years (they had adult children and grandchildren), when she fell sick and later was diagnosed with AD. Among many qualities she had, she was an excellent cook. Not only was her husband Z very proud of her, but he felt very lucky and blessed. She used to cater for them with a variety of dishes derived from recipes typical from her coastal hometown. According to Z, his wife could cook for several months without repeating a dish and they were never bored eating at home. On the contrary, it was always a delight. With the progression of the disease, a change in her cooking dexterity became quickly noticeable which came as a complete shock to Z. Though knowledgeable of the changes an AD patient is expected to go through (e.g. long-term / procedural memory loss, reduced time reaction), he found it difficult to adjust to the reality, and it affected him emotionally. Realizing what was happening to Z felt like a bitter blow. It was disheartening to see that the “queen of the kitchen” no longer remembered how to prepare a meal. She could not even move around comfortably in the kitchen where she used to be so happy.

**Unhealthy finances**

The emotional health of the primary caregivers was also affected by the burden of their responsibility for their financial situation. For instance, the cost of disposable diapers is felt when they need to be purchased on a regular basis. Even though the AD patient and the primary caregiver are insured by the IMSS which provides some entitlements, it does not fully cover all the costs involved. It is a cause for concern, because some medications are very expensive and unaffordable to those with lower incomes. Primary caregivers are worried by how expensive the prescription drugs are and how long they last. A respondent expressed his concern for the financial burden as follows:

> [Medications are very expensive and many are not covered by the insurance (IMSS). Besides, they do not last … All this hits one’s wallet].

**Time, personal and social life**

Committing to the caregiving role is at the expense of private and leisure time given to other activities such as the practice of a favorite instrument, a hobby with friends, or work on a personal project. Time is a precious resource and providing care can undermine social life. Social relations with relatives and
friends change over the course of time. Social isolation may result when friends and other relatives find it difficult to visit the care recipient, owing to noticeable deteriorations and transformations in their physical appearance. The way the social life of the primary carers is impacted is reflected in statements such as:

[I withdrew from my buddies, get together] …

[I no longer go to parties, wedding celebrations either] …

[Less get together with family members ... They no longer invite you, and they no longer pay you a visit for the pity to see her (the AD sufferer) the way she is, slimming down, emaciated ...].

Despite an improved knowledge of the disease and a better understanding of the patient’s behavior, some of the caregiving men lost their patience and became irritated with the care recipient. A loss of appetite and self-neglect are some of the potential outcomes for care providers who fall into a state of depression. For some, their rest time is insufficient, and it impacts their mood at work. Many have never considered seeking professional help (i.e. mental health services). This reluctance is not due to scarcity of time or lack of money, rather these kinds of services are seen as associated with dementia, or other mental illnesses. The end of the caregiving role creates ambivalent feelings and emotions, stemming from relief to emotional distress and sadness.

A non-lineal provision of informal care

The shift from informal elder care to institutional placement is a classic lineal sequence, when the informal caregiver is no longer able to fully undertake caregiving responsibilities, and seeking professional help becomes unavoidable. However, “anticipatory caregiving” (Bowers, 1987) which is by adult children does not end with the institutional placement of the AD patient. Some of the study participants reported that their care recipient transitioned back and forth between a nursing home and their home.

Visits to the care recipient in residential care provide the opportunity to see for themselves how their family member was adjusting to their new residence. Those who decided to withdraw their relative from a nursing home often reported they had detected neglect and observed that the patient’s situation was worsening:

[She had a private room and people of her age to keep her company, but what kind of attention was she given? She did not even eat.] …

[What kind of care is that? Having my dad bedbound whilst he is still able to move around, and eating only jello. They said it was for his safety ... He looked like a skeleton] …

[... Only checking from time to time her body temperature and her blood pressure ... That was all! Almost nothing was done about her personal hygiene ...].

According to one respondent, his spouse became more unwell due to generalized neglect at an expensive residence:

[... As a result of an overall neglect, my wife got sicker. Therefore, we decided to take our patient back home. In her own home, living conditions are better and
besides, she is surrounded with love. That was a family decision].

Some participants reached the conclusion that their relatives were not receiving proper assistance:

[What are the good things they are giving them? Afternoon snacks? They think they are smarter. All the old people get it. How about their health? This is the most important] . . .

[There are places where the patient is so neglected that they get even worse, as people use to say from Guatemala to Guatepeor . . . What only does matter to them is making money . . . I had to take my mom out of there and have her here again in my house which is her home too]

Perceived or real, the thought that their relative was not in good hands had an impact on their own emotional stability:

[It was hard to sleep knowing that dad was not in good hands. This was the rationale to have him back at home.]

Finding they had paid for a disappointing service and had to rely on law enforcement for any remedial action was also raised:

[What is the point about pressing charges against them? Impunity is common here.] A related comment was the following:

[What can be done against these people? Jeez! They have the levers. The press comes, the place gets formally closed, and the next day it reopens and that’s it. The best thing to do was to take my dad back home meanwhile we could find a more reliable residence.]

**DISCUSSION**

Identity building and meanings of multifaceted caregiving experiences

Through their narratives, male caregivers of a relative with AD reported a range of experiences lived over time while fulfilling a social role which led them to build an identity as caregivers. The concepts of social roles, identities, and meaningful existence (Thoits, 1983) provide insight into these research findings. The fulfillment of a social role operates as a self-esteem enhancer when expectations are met. Social roles, from an existentialist perspective, enable people to build an identity in relation to role expectations and an accumulation of these role-identities provides meaning to their existence.

By committing to their caregiving role, these men are meeting what is expected of them—an appropriate behavior—and this gives their life purpose. The resulting enhanced self-esteem, along with the sense of rightness (“it was the right thing do”) may motivate them to continue despite the increased challenges they face with the progression of the disease. Applying the identity accumulation hypothesis (Thoits, 1983) suggests, from a cognitive standpoint, that their caregiving role is a positive behavior which makes their existence meaningful.

A caregiving commitment creates a meaningful role identity, and it reveals relationships of interdependence with the AD patient as a spouse, a father—relationships of trust and reciprocity (“He would have done that for me”). Along with the awareness that the care recipient needs them to fulfill the caregiving role, self-worth is experienced through being able to give something of
value back, to pay forward. In a recent study, a strong sense of duty among sons was highlighted as a motivation to provide care (Mc Donnell & Ryan, 2013).

The strengthening of bonds between spouses, fathers, and sons was a positive outcome which coexists with the negative outcomes associated with the caregiving burden as previously addressed. Statements such as: “It was very tough sometimes, but I have no regret . . . . I had to be there, and I am glad about it . . . . Looking back, I would not change anything,” may seem paradoxical. However, in a previous study where male and female caregivers were compared on their satisfaction with the caregiving situation, satisfaction scores where higher among men. In contrast to female caregivers, male caregivers found the experience rewarding, experiencing personal growth and a broadening of their horizons (Ekwall & Hallberg, 2007). This personal growth or “benefit finding” in caregiving has been related to increased meaning and positive coping with distress (Haley, LaMonde, Han, Burton, & Schonwetter, 2003).

A humanistic perspective on needs

Maslow’s theory of human motivation which establishes a hierarchy of needs (Maslow, 1968) provides a relevant framework for a discussion of the findings. Esteem needs located at a higher-level need (the fourth level) in the hierarchy of needs, are related to self-esteem and personal worth and account for motivating behavior. In the present study, striving to gain further knowledge about AD, undertaken by some caregivers, may not be as visible or noticeable as instrumental care, but is reflective of a sense of purpose. Being better informed about the disease is likely to better equip them to fulfill their role as caregiver, and to satisfy their esteem needs which are linked to mastery. Though intangible, learning for more mastery denotes motivation and determination for genuine improvement in care provision, rather than the pursuit of a personal goal (e.g. a degree for career development) and reflects commitment and dedication to the social role of caregiver.

Although providing care was seen as challenging for some caregiving men, there was also a sense of esteem derived from the value of the help they provided to the AD patient. Evidence gathered supports the notion that these male caregivers are investing time and effort into the higher-level need of esteem. As none of the caregivers were entitled to a carer’s allowance, expectations of a financial benefit can be discarded. The care work they undertook for a relative involved conflicting emotions, suffering, and was a challenging and demanding long-term commitment. Purpose was a key element in the motivation to commit to the caregiving role, however perseverance was also an essential factor in maintaining that commitment.

The social role assumed is not merely that of a caregiver, but of a primary caregiver which implies greater responsibility, involves decision making, may require a given profile and status, and qualities that inspire trust and respect. For some, the acceptance of the role of primary caregiver occurred after reaching a consensus within the family of the AD patient, whilst for some the decision was made individually. Fulfilling the caregiving role, especially when the decision is made via family consensus,
could be seen as a form of recognition within the family circle.

**Changes in social networks and continuity in caregiving commitment**

Social support, social ties, and networks of relationships, whose protective impact against the effects of negative life events and challenging situations has been widely accepted, are not always stable. Over time these ties are subject to change and may increase, loosen, or reduce (Berkman & Syme, 1979). Social isolation was highlighted as an important factor in this study, and this was not solely attributable to caregiving responsibilities. The withdrawal of friends, and even some family members, due to the presence of the AD patient, especially their changing demeanor (e.g. losing lots of weight, frailty) was also stressed. However, the shrinking of supportive social ties did not seem to be a deterrent to committing to the caregiving role. Care work is also an act of love, and even when the AD patient is no longer at home, an emotional connection remains. The feelings of disappointment, and dissatisfaction expressed by some of the study participants about the institutional care provided to the AD patient, suggests that comprehensive and compassionate care is important to them. Having the care recipient return to them at home reveals that placement is not always unilineal and not necessarily a means for overburdened caregivers to be free of the challenging caregiving role. In addition to suggesting that the family bond does not weaken with physical distance, continuing to commit to the social role of caregiver is a reflection of the moral meaning of compassion. Finally and most importantly, evidence suggests that institutional placement was not seen as a preferred option to ease the tensions between elder caregiving and work.

**Shared concerns of the caregivers: economic impact and lack of formal help**

Employment has been conceptualized as a predisposing characteristic of health services use in a well-known behavioral model (Andersen, 1995; Andersen & Newman, 1973). A study of caregiver labor participation and caregiving activities conducted in California showed that employed caregivers were more likely to use caregiver support services than their non-employed caregiver counterparts (Scharlach, Gustavson, & Dal Santo, 2007). In the state of Nuevo León where the present study was conducted, housekeeping and personal care services are not expensive as much of this labor market is made up of migrant workers from less wealthy states, willing to accept lower wages.

Even though participation in the paid workforce can make a difference in hiring professional help to assist with care, it does not resolve the issue of the financial strain associated with informal caregiving. Related out-of-pocket expenses have been found to have an impact on income and personal savings of caregivers (Keating, Lero, Fast, Lucas, & Eales, 2013). In the present study, participants complained about medical and non-medical expenses such as the costs of some prescribed medicines, and the regular purchase of disposable diapers. Many found them to be a heavy economic burden.

Financial pressure is one of the 15 stressors frequently identified in the
research literature on depression and stress among family carers (Zarit et al. 2007). In social democracies, such as Canada, informal and formal help to family caregivers coexists. This is attributable to government programs and federal tax credits allocated under the application of specific criteria that determines the level of caregiving burden. In the present study, participants did not mention these kinds of formal help at any level of government (municipal, state, federal) as a potential source to ease their financial burden.

A shared feature of the caregivers: participation to the AD support groups

AD support groups for family carers are not-for-profit groups that allow participants to listen to first-hand testimonies, and share the uniqueness of their caregiving experiences (Azoh, 2002). Participating in these support groups helps caregivers in getting prepared for the task at hand, being aware that they are not alone, and at the same time decreasing social isolation. The use of support groups is likely to be beneficial among support group participants. Seeking professional help through these groups was a predominant coping strategy among the primary male caregivers of this study, regardless of their employment status. Spending time in AD support groups increased participants’ opportunities for social contacts. The caregiving men were able to avail themselves of this resource due to the availability of home help to perform some of the instrumental care at an affordable cost. This could explain why house cleaning, food provision, meal planning and preparation were not major issues among the participants. Being skilled in time management and the user-friendly opening hours of the support groups also allowed the caregivers to participate in the groups more easily.

Participation in the AD support groups, enabled by access to additional home help, demonstrates participants’ willingness to get better at doing what they do. Being better informed and prepared could, to some extent, ease their fears about what they are undertaking, making them less worried at home and at work. The availability and use of paid care providers and extended family is likely to play an important role in balancing the burden of the primary caregivers working full-time outside of their home.

Study limitations

This study of male experiences of informal eldercare is not without limitations. The main issues are in relation to sampling procedure and sample size. The sample was not randomly selected nor broadly representative of male caregivers. An important limitation related to the representativeness issue is the inherent shortcomings of clinical samples, as opposed to population-based samples, thereby limiting the generalizability of findings. There is no doubt that a recruitment of caregivers in the wider community as a source could have resulted, to some extent, in different findings. For example, more variability in their lived experiences could have been yielded, since they may not utilize some services such as the AD support groups, and consequently may be less informed and prepared for the caregiving role. However, undertaking this type of qualitative
research requires cultivating relationships, and building trust, prior to collecting in-depth data. Entering the field is key to this aspect of the research process and attending the AD support groups provided some degree of acceptance which, among other factors, takes time to achieve.

Knowing that gender roles are socially constructed, addressing the presence of men in the caregiving arena is a challenge for the researcher. Despite obtaining informed consent from a sample of caregiving men, a lack of trust could have led to greater reservation about their lived experiences, their social supports and networks, and a denial of some feelings and emotions, or a controlled expressivity, in accordance with their masculinities.

An additional critical perspective

Comments offered by some of the study participants suggested that more male primary caregivers exist, but not all attend support groups. The reasons mentioned were that men are more reserved and less inclined to seek informal help or ask for formal help and support. Doing so may be seen to equate to being needy and dependent, and lacking in self-respect. The informal care of a relative with AD or any other dementia may still be considered by many as a private matter. Reluctance of older men to seek help has also been noted before (Calasanti, 2004).

In addition, social acceptance bias must be taken into account in interpreting the current findings. The veracity of some answers may be questioned as some participants may have provided socially acceptable responses rather than risk creating a bad impression. However, the way the data were collected (e.g. collective interviews; focus groups) may have reduced the tendency to conform to the group. In addition, the extended contact of the researcher with the caregivers provided the opportunity to become more familiar with the participants and the way they expressed their feelings. For instance, when some participants felt upset, it was often more about another family member’s behavior rather than the AD patient they were taking care of. Being a family affair (un asunto familiar), the financial contribution of direct relatives (e.g. children of the AD patients) is often sought which can cause family tensions.

A few research participants reported that some of their relatives were not supportive at all, did not have enough understanding of the disease, and were prompt at fueling family conflicts with complaints such as: “Why isn’t s/he [the AD patient] improving?” or “Why going through so much hardship if s/he [the AD patient] is going to die anyway?” It suggests that in the context of Mexico, the extended family is also important when it comes to addressing the economic aspects of care such as income loss or cash inflow/outflow, along with the impact of reduced working hours, earnings, and spending of the primary caregivers.

CONCLUSION

This study examined elder caregiving experiences among men in the context of Nuevo León, in Mexico, on the basis of first-person accounts that outlined both positive and negative aspects of caregiving roles, and the coping strategies
used by carers. The findings highlight the patience and dedication of men in a non-traditional social role, and their role providing a better quality of life for care recipients in an aging context. Informal care provision was associated with unseen gains, intrinsic rewards, costs, difficulties, and sacrifices.

On the one hand, the caregiving role provides opportunities for human contact through companionship and a greater sense of connectedness to the patient. Committing to the caregiving role not only sustains the role identity but also has a moral meaning. Above and beyond the moral obligation and/or norm of reciprocity, giving something back is a way of cultivating altruism and increasing selflessness. In this dyadic relationship, the safety needs (love and protection) of the care receiver and the esteem needs of the caregiver are two needs that can be met simultaneously.

Eldercare is also experienced as an expression of solidarity and gratitude. Gratitude itself is a positive emotion and as such, it should be considered as a protective factor to investigate. Knowledge and skills acquired about AD and how to handle the patient are valuable gains. The opportunity for enriching oneself through caregiving activities and related sacrifices creates a feeling of well-being which is intangible.

On the other hand, physical, emotional, and financial exhaustion, and related family conflicts are considerable parts of participants’ caregiving experiences. Caregivers showed greatest concerns about the economic costs associated with their social role. Insufficient income to meet the costs of such necessities as diapers and pharmaceuticals represents a significant hardship for those with lower buying power. The availability of medical insurance schemes is not sufficient to cover some costs related to the care of the AD patients. The expenses incurred for expensive prescription medicines are not refundable, and the financially fragile and distressed, in particular, would benefit to improvements in how these medicines are funded.

Besides the participation of caregivers in the support groups, which is to be encouraged, participants expressed their enthusiasm for providing the best possible care to the AD sufferer. The financial impact of providing informal care is not conducive to enhancing the motivation and commitment of caregivers, regardless of gender or employment status. The combination of financial hardship, loneliness, and little to no hope of receiving financial incentives from the government places considerable strain on the primary caregiver. In this context, the role of the family network is important in supplying caregivers with much needed supports.

In Mexico, a country with policies that favor aging in place, demographic aging will result in an increase in the number of older adults that require some form of care and support. This situation of epidemiological change will require a further mobilization of diverse resources and state interventions to alleviate some of the burden of caregiving among patients’ families. Geriatricians, who are very few in number in Mexico and particularly in Nuevo León, along with the local Association of AD, have been making a significant and considerable contribution through their commitment to supporting family members. Such an example is not only to be acknowledged but also emulated and replicated nationwide.
Policy and research implications

In the future, Mexico, as a member of the Organization for Economic Co-operation and Development (OECD), may opt for introducing delayed retirement such as many of its European counterparts have done. When and if this happens, labor policies should consider addressing eldercare responsibilities and demands if the country is to adapt to the new realities of an aging population. This implies partnerships with the health care sector and employers in assessing and accommodating workplace practices to suit the needs of workers committed to elder caregiving.

Central to these adaptative measures is the supply of flexible work practices such as flexitime, part-time work, and shifts. There is evidence that practices that allow individuals to balance their work and other aspects of their lives have benefits for the employee and the employer (e.g. Kim, Ingersoll-Dayton, & Kwak, 2011). Implementing awareness-related activities, including a national month or day honoring those involved in caregiving, is important.

Further knowledge on this understudied group of male caregivers in the state of Nuevo León, and in Mexico as a whole, is needed. Informal caregiving is an overlooked activity which brings with it a number of occupational hazards and a range of unmet needs that need further investigation. Further research on its contribution to delaying institutional placement is also encouraged. The present study would be complemented with quantitative approaches that investigate the prevalence of caregivers and their characteristics, the financial consequences associated with informal caregiving responsibilities, and projecting the future needs of caregivers through surveys and economic studies. Data derived from a variety of research designs would be relevant to inform programmatic planning, and policy making.

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Notes

1. Stage 1 (mild) may last between 2 and 4 years; stage 2 (moderate) may last between 2 and 10 years; and stage 3, (severe), may last between 1 and 3 and more years. The patient may remain affected for more than 20 years following a positive diagnostic (Hubbell & Hubbell, 2002).
2. A caregiver is “Anybody who provides unpaid or arranges for paid or unpaid help to a relative or friend because they have an illness or disability that leaves them unable to do some things for themselves or because they are getting older” (National Alliance for Caregiving/NIH Senior Health, 2011).
3. Updated data on minimum wages by the Comisión Nacional de Salarios Míminos apply to the year 2013 (http://www.conasami.gob.mx website) according to the geographic areas in the country. Area A: 64.76 pesos daily; Area B: 61.38 pesos daily. The value of the peso varies on a daily basis, for example, it could be between 5$-6$USD.
4. Interview themes were numerous, encompassing the whole caregiving experience (how the caregiving decision was made, intensity, financial means, unmet needs and coping strategies, social network), balancing caregiving activities and employment (employment status and sector of

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employment full-time, part-time; formal, informal), challenges/discomfort, and other aspects related to eldercare.

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