

Research paper

Bearing witness to life narratives: Iranian immigrant experiences of taking care of a family member with dementia

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What is known on this subject

- Taking care of a person with dementia is one of the most challenging experiences of caregiving, and decreases caregivers' well-being and quality of life.
- Few studies have focused on dementia caregivers from culturally and linguistically diverse backgrounds.
- Caregivers who reside with a person with dementia have an essential role in allowing dementia patients to remain in their own homes rather than being moved to institutions.

What this paper adds

- It provides an insight into how family caregivers of people with dementia who have an Iranian immigrant background experience dementia.
- It increases our understanding of how the caregiving role provides a basis for constructing life meanings, and focuses on positive aspects of caregiving.
- It offers perspectives from family caregivers who may experience fulfilment as a result of providing care for their family members with dementia.
- It discusses the impact on family caregivers of not being recognised by a family member with dementia.

ABSTRACT

Caring for a person with dementia is one of the most devastating and challenging experiences that caregivers have to face. Many studies indicate that the experience of caregiving reflects cultural care values and beliefs. Even though dementia caregiving is the most frequently studied type of care as reflected in the literature, few studies have focused on dementia caregivers from culturally and linguistically diverse

backgrounds. The purpose of this study was to explore Iranian immigrant experiences of taking care of a family member with dementia.

An interpretive phenomenological approach was employed to investigate the experiences of ten Iranian family caregivers, each caring for a family member with dementia and living in Sweden. Caregivers were recruited through purposeful sampling and took part in

semi-structured interviews. All of the individuals who were contacted participated in the study. The participants included seven women and three men, ranging in age from 40 to 65 years, from different cities. They had all lived in Sweden for at least 20 years. Two caregivers were married to people with dementia, and eight were caring for parents with dementia. Data analysis was guided by Benner's interpretive phenomenology and revealed three key themes, namely caring as an experience of fulfilment, admitting the diagnosis of dementia, and the shock of not being recognised

by their family members with dementia. Positive aspects of caregiving should be recognised and supported in order to facilitate the maintaining of caregivers' involvement. The positive experiences of caregiving could help to alleviate the problems that are experienced by the caregivers of people with dementia.

Keywords: dementia, family caregivers, immigrants, interpretive phenomenology, Iranian immigrants

Introduction

It is commonly stated in the literature on caregiving and dementia that caring for a person with dementia is one of the most devastating and demanding responsibilities that caregivers can experience (Butcher *et al*, 2001). Looking after someone with dementia significantly decreases the well-being and quality of life of the caregiver (Carers UK, 2004; Milne and Chryssanthopoulou, 2005). The burden of caring for individuals with dementia has been reported to be greater than that of caring for people with other chronic conditions (Conde Sala, 1998; Ericson *et al*, 2001). The fact that as many as 80% of individuals with dementia are cared for in their homes by family members (Haley, 1997) highlights the importance of family caregiving issues. Caregivers who reside with a family member who has dementia have an essential role in allowing dementia patients to remain in their own homes rather than being moved to institutions (Schneider *et al*, 1999).

Relatives approach the caregiving needs of their dependent family members with dementia in different ways. While some care for their loved ones at home, regarding institutionalisation as stigmatising, others arrange for their family member to receive care in a nursing home. A variety of different reasons have been cited to explain why people respond as they do to relatives' caregiving needs, ranging from cultural issues such as children's obligation to take care of their parents (Park and Chesla, 2007), to identifying caregiving as an expected family role (Wallhagen and Yamamoto-Mitani, 2006), and practical concerns such as utilising the available resources in society in order to be able to perform other roles, and identifying caregiving as an unexpected career (Aneshensel, 1995). Caregiving can be a positive experience (McIntyre, 2003; Tarlow *et al*, 2004; Carbonneau *et al*, 2010) or a negative one (Etters *et al*, 2008; Takai *et al*, 2009). Increasingly, researchers have pointed to a growing

need to qualitatively explore why some of those who care for relatives regard the quality of the caregiving experience as poor, while others derive positive benefits from it (Fox *et al*, 1999; Hinton, 2002; Milne and Chryssanthopoulou, 2005). This paper presents the findings from a study designed to explore caregivers' experiences with particular reference to those belonging to a minority ethnic group.

Caregiving among minority ethnic groups

Although many studies indicate that the experience of caregiving is deeply cultural (Chee and Levkoff, 2001; Hinton, 2002; Yen *et al*, 2010), we know little about the culturally related issues surrounding caregiving. Even though dementia caregiving is the most frequently studied type of care represented in the literature, few studies have focused on the experiences of those caring for patients from immigrant groups. There are studies on caregiving that address 'Asian' family caregivers' experiences, but which appear to mask considerable heterogeneity and diversities among them. We should also bear in mind that the term 'Asian' has different meanings in different contexts. Furthermore, these studies mostly related to East Asian countries, such as China and Korea (Park and Chesla, 2007), and very few of them included any data from countries in the Middle East, such as Iran.

Given the critical need to reduce ethnic health disparities among older adults, the participation of people with immigrant backgrounds in research studies is considered crucial (Nápoles-Springer *et al*, 2000; Zambrana and Carter-Pokras, 2001). Gerontologists, researchers, care providers and policy makers have been encouraged to pay greater attention to the diversity and needs of communities of immigrants as they age (Salari, 2002).

In Sweden, almost 13% of the population aged over 65 years is of foreign origin (Statistics Sweden, 2005), and in 2007, Iranian immigrants accounted for 0.62% of Sweden's population. These figures have implications for the planning and provision of health and elderly care programmes, and in particular for family-based care for elderly people with dementia (Aranda and Knight, 1997; Gallagher-Thompson *et al*, 2000). The study reported here focused on caregiving from the perspective of Iranian people living in Sweden and looking after a family member with dementia.

Methodology

Research design

The study was designed and carried out using an interpretive phenomenological approach (Heidegger, 1972; Benner and Wrubel, 1989; Benner, 1994). The phenomenological approach attempts to describe human experiences within the complexity of their contexts (Morse, 1994). According to Valle and King (1978), phenomenologically oriented research answers questions such as 'What is the phenomenon that is experienced and lived?', 'What is its structure?' and 'Which commonalities exist among the many diverse appearances of the phenomenon?' According to the interpretive phenomenological perspective of Benner (1994), people experience their world 'through their embodied intelligence, their skillful habitual bodies, background meanings, and concerns and understandings of the situation' (Emami *et al*, 2000, p. 6). From this viewpoint, the investigators aimed to gain a deeper understanding of the participants' experiences of caring for their relatives with dementia through their descriptions of and reflections on having a relative with dementia, which offered a window into their life worlds.

Method and data collection

Semi-structured interviews were conducted to investigate the Iranian immigrant family caregivers' experiences of taking care of a family member with dementia (see Box 1). The interviews were conducted in Persian, which was the first language of all of the participants as well as that of the first author, who conducted the interviews, and three of the co-authors, who reviewed and co-analysed the data. The interviews took place either in the participants' homes or in care centres, depending on personal preferences. Each interview session lasted between 1 and 3 hours. All of the interviews were audio recorded.

Analysis of data

All of the interviews were transcribed verbatim. Summaries were written for each interview in English, and two interviews were translated in full so that they could be analysed by the second author, who did not speak Persian. All of the authors were fluent in English, which enabled them to discuss their analyses with each other.

The transcriptions were compared with the recorded interviews for accuracy. All transcriptions were carefully read in order to gain an impression of each of them and an overall understanding of the interview. The overall impressions of each caregiver's experiences were noted. The text of each interview was then read, word by word, once more and interpretation of significant statements was formulated. Interpretation of the interviews moved back and forth between the whole and parts to allow understanding, comparison and critical reflection on the text. Each participant's transcript was analysed in order to identify themes. All of the analyses were compared and contrasted with the previous and following ones. Clusters of themes from the aggregated formulated interpretations were organised and referred back to each original description for validation. The results were integrated to yield an exhaustive description of the study phenomenon.

To ensure rigour of the data analysis, the investigators utilised prolonged engagement with the data to understand the patterns and meanings. Sharing the

Box 1 Main questions asked during interviews

- What comes into your mind when you think about dementia?
- What is it like to live with a relative with dementia?
- What is it like to care for a relative with dementia?
- What changes have occurred in your life due to having and/or taking care of a relative with dementia?
- Describe some concrete situations in this regard.
- What kind of problems do you have in caring for your relative?

Additional probing questions were included as appropriate.

emerging results with other researchers in research seminars created external checks which helped to clarify less obvious points and blind spots. As all four co-researchers were involved in drawing conclusions from the data, an audit trail for the data was created, which included investigator responsiveness (see Box 2). Moreover, the investigators were aware of verification in the process of conducting the research. Finally, data were systematically checked, focus was maintained, and the fit of data and the conceptual work of analysis and interpretation were monitored and confirmed continually (Morse *et al*, 2002).

Recruitment of participants

Participants were recruited to the study on the basis of purposeful sampling (Morse, 1994). The main inclusion criteria were that candidates should be Iranian immigrants living in Sweden, primary caregivers for relatives with dementia, and be able and willing to talk about their experiences. In addition, the relatives with dementia should have been diagnosed at least one year prior to the interview session.

The initial plan was to recruit the potential participants from Stockholm, but there were too few patients residing in that city. Therefore, the first author contacted specialised care centres for dementia patients in different cities in Sweden. Staff at these centres made the first approach to family caregivers to ask them if they would like to participate in the study. All of those who were contacted agreed to participate. The first author then contacted each participant directly to give them more information about the study and to schedule an appointment for conducting the interview.

Ten family caregivers of Iranian immigrants who suffered from dementia participated in the study. The group included seven women and three men, ranging

in age from 40 to 65 years, from different Swedish cities. All of the caregivers had been living in Sweden for at least 20 years. Two respondents were married to people with dementia, and eight were caring for parents with dementia. In each case the family member with dementia had been diagnosed two to eight years prior to the study.

Ethical considerations

Throughout the research process, the investigators strived to adhere to the ethical principles set out in the Helsinki Declaration (World Medical Association, 2008). The study was approved by the Karolinska Institute's Regional Ethical Research Committee. Information about the study was provided by the first author orally and in writing, in Persian, for all of the participants. In addition, Swedish and English versions were prepared, to be used if necessary. All of the participants expressed a preference for using the Persian language. The information consisted of the study's aim and the method of data collection used. Participants were also informed that participation was voluntary, and that they could withdraw at any time without the need to explain their reasons for this. All of the participants gave their oral consent, which was documented. The researcher did not consider it necessary to use signed consent forms in this particular study, as it has been reported that Iranian immigrants in Sweden are reluctant to have any contact with the authorities (Emami, 2000).

During data collection, the researcher made every possible effort to detect non-verbal signs that indicated a desire to withdraw from the interviews. All of the participants were assured of confidentiality, and the analysis was performed with the aim of maintaining the anonymity of all those who took part in the study. The recorded audio files were kept in a secure

Box 2 The audit trail and investigator responsiveness

The audit trail was developed by:

- recording all of the interviews
- verbatim transcription
- writing down the analysis process
- recording the progress of developing the final results.

Investigator responsiveness was noted as a part of this trail by:

- listening to the data
- the ability to abstract, synthesise or move beyond the technicalities of data coding
- trying not to work deductively from previously held assumptions or a theoretical framework
- using instructions strategically in decision making, rather than in a rote fashion
- methodological coherence
- sampling adequacy
- peer debriefing.

cabinet, and the transcripts of interviews were coded by numbers which could only be accessed by the first author.

Findings

All of the participants wanted to explain what caregiving meant for them rather than talk about the day-to-day care activities in which they engaged, even when they were asked directly about these activities. All of the caregivers were living with their family member with dementia. Seven had moved to live with them, and the rest were already living in the same house. Two participants chose to stop working in order to be able to spend more time with their family member with dementia. One participant was divorced because his wife was unable to cope with the situation, and three participants decided not to engage in long-term personal relationships because of their responsibilities. The participants described their caregiving as a fulfilling experience, and referred to the positive aspects of being the main caregiver for their family member with dementia. They explained how they struggled to acknowledge that their loved one had dementia, and how it took a long time for them to accept the diagnosis. The turning point was the shocking experience of not being recognised by their spouse or parent.

Caring as an experience of fulfilment

Many of the Iranian immigrant family caregivers, especially the children of parents with dementia, found caring for their family members to be a fulfilling experience that brought them a high level of satisfaction and raised their self-esteem. The experience of 'giving something and getting more back', as one participant suggested, came from having the responsibility of providing care for their loved one, making life meaningful and more alive. They looked upon their activities as a way to compensate for what their relative had done for them during other stages of their life, such as during childhood, or during particular hardships, such as those that forced them to leave their homeland and move to a faraway country. Some considered their caregiving activities to be a normal part of life, and as something they were pleased to do. Providing care was a rewarding activity in itself, and they were satisfied and happy with its outcomes. Even when the family member with dementia was no longer able to recognise them, they continued to take good care of them.

Perhaps the outsider couldn't see how I am enjoying myself when I see how comfortable she [his mother] is after taking her to the toilet, I am looking at her and my

body is filled with energy, relaxation and satisfaction. If someone can be happy with his life, it's a great fortune.

(Middle-aged man who was caring for his mother)

The only life that is meaningless to continue is a life without love. People who don't feel happy and fortunate are those who live without love. I don't have a meaningless life. It's a life which is founded on love, and this is what is important for me. Before she got the disease, I couldn't imagine how important and crucial [love] is in my life, but then I discovered that it's the most important thing.

(Male caregiver in late middle age who was caring for his mother)

It's a practice of patience, a way to understand her better, what it was like for her to take care of me [in childhood].

(Middle-aged female caregiver who was caring for her mother)

Admitting the diagnosis of dementia

Most of the participants hoped that their genuine and diligent efforts would contribute to decreasing the signs and symptoms of the disease, as well as its progress. They believed that they were taking care of their relative with dementia in order to help them to get better. This hope motivated their caregiving activities. Thus, especially in the beginning, it was difficult for them to admit that their family member had dementia, as this meant that they had to acknowledge that there was not much hope of recovery. Doubting their relative's diagnosis or the prescribed treatment helped the participants to keep their hope alive and reinforced their belief that they could help the relative. Many of them expressed deep suspicions about the healthcare services when they were informed about the disease prognosis. They kept hoping that the healthcare providers had failed to recognise that there was a difference between their relative's disease and that of others who actually had dementia. At this stage they believed that they could overcome the disease by providing excellent care and support. The occurrence of memory fluctuations, where the person with dementia oscillated between being normal and being cognitively impaired, gave the caregivers hope that recovery might take place. When the symptoms became more obvious and severe, the caregivers became increasingly less suspicious about the accuracy of the diagnosis.

Different experiences were described by the participants who were caring for their father and those who were caring for their mother. Those who were caring for their father were fearful about the parent's future as the disease progressed, and expressed much worry and anxiety about this. In contrast, those who were caring for their mother mostly spoke about how they could make their parent comfortable at the present time. The experiences of caregivers who were married to a person

with dementia differed from those who were caring for a parent with dementia. Children of people with dementia expressed a sense of just being happy to fulfil their caregiving tasks, and being able to repay their parents for the care they had themselves received. Married partners, in contrast, felt restricted and victimised, and talked about their own needs as well.

We still aren't sure whether he has dementia or not, sometimes his memory is perfect. I think that these symptoms are periodical. I am trying to read a lot to understand it thoroughly. I think when he had his heart operated on, something happened to him that doesn't have any association with dementia.

(Middle-aged female caregiver who was caring for her father)

Ask me how much I can admit to her illness, not if I have accepted it.

(Male caregiver in late middle age who was caring for his mother)

My mother is like a flower, you are taking very good care of it every day, watering it, doing all you can for it, but you see it withers more and more, every day, nonetheless. This is very heavy to bear ... like a tree which buds, blooms, bears fruit, but what about a tree which is going to dry up, and wither day by day?

(Middle-aged man who was caring for his mother)

The shock of not being recognised by family members with dementia

The most difficult moment for most participants was when their loved one no longer recognised them as their child or marriage partner. For most participants this marked the point at which they had to accept the diagnosis of dementia. They pointed out that it was much easier to tolerate the aggression toward all other people in their extended family, the anger, suspicions, memory loss, jealousy, impatience, and inability to meet their basic needs. However, discovering that the person with dementia could not recognise them was a very traumatic experience for the participants.

It wasn't terribly shocking to hear that your mother had dementia. The shock comes when she can't recognise you any more. You can't accept, it, not at all. ... Even when you do accept it, it just helps a little, and the situation remains hard and painful for ever.

(Middle-aged man who was caring for his mother)

Now [when his mother could no longer recognise him after 6 years of dementia] I am trying to getting used to the situation, reducing the time I am spending with her. She has forgotten me almost. I shall accept that she is ill.

(Male caregiver in late middle age who was caring for his mother)

I couldn't bear to realise my father has lower tolerance for his child [herself].

(Middle-aged woman who was caring for her father)

Discussion

The participants expressed great willingness to continue to care for their family members. They were happy that what they were doing could contribute to prolonging and increasing the quality of their loved one's life. The responsibility of being the primary caregiver for their family member with dementia seemed to be the signifier for their life, but because they devoted their life to taking care of their relative with dementia, it was not easy to accept that their loved one could forget them as easily as they seemed to forget who others were. In fact, not being recognised by the person they were caring for meant a great deal to the Iranian caregivers who participated in the study. It threatened the image they had of themselves as the person who was closest to and most caring towards the relative with dementia, and the one whose genuine efforts would be acknowledged and recognised in some way by the recipient of care.

The present study can be compared with a similar study of Swedish family caregivers in rural and urban areas of Sweden (Ehrlich *et al*, in preparation), which showed that the family members, especially marriage partners, would like to continue to care for their loved one with dementia. Other studies, such as that by Spitznagel *et al* (2006), reported that in contrast to marriage partners, the children of people with dementia were unwilling to continue to act as caregivers for their parents as the disease progressed, and preferred to institutionalise them. This was in stark contrast to the participants in our study, who chose to care full-time for their parents even though qualified formal care was available.

A study of healthy elderly Iranian immigrants in Sweden (Emami and Ekman, 1998) showed that they experienced disappointment in their children, who had adopted the individual-centred western morality of their new homeland. It may be that the participants in the study described in this paper expressed satisfaction with caregiving because this allowed them to compensate for the suffering that their parents experienced because of them. If their parents suffered as a result of their children's special circumstances, being forced to emigrate and much more, the onset of dementia meant that the children suffered with them and accompanied them on their journey. In fact their parents' dementia offered them a last opportunity to satisfy them and fulfil the cultural responsibilities that their elderly family members expected them to take

on. The participants hoped that their loved ones could appreciate their efforts.

Caregiving for people with dementia is carried out more often by the marriage partner than by other family members (Etters *et al*, 2008), and a significant association has been reported between caregiving at a younger age and carer burden (Spitznagel *et al*, 2006). However, in the present study, those caring for parents with dementia expressed satisfaction and fulfillment with regard to being the primary caregiver. This illustrates the importance of a wider frame of reference when conducting research, and the need to take into account the culture, life course and history of the participants. Moreover, people's cultural norms and characteristics undergo many changes during the course of their life, and therefore the specific context within which care is provided should not be overlooked (Jefferys, 1996).

During the interviews, participants shared very detailed stories about their life as caregivers for their loved ones with dementia. They were very eager to describe their experiences in detail. According to Hannah Arendt (1993, p. 238), 'It exists to the extent that it is spoken out, even if it occurs in the domain of privacy'. Arendt argues that memory is conjured essentially in order to address another, to impress upon a listener, or to appeal to a community. Therefore to testify is not merely to narrate, but also to commit oneself and to commit the narrative to others – to take responsibility (Felman, 1992, p. 204). All of the participants' efforts to make sacrifices in their own lives served to give the private story of their relative with dementia a general validity. Their caregiving world could become meaningful and worthy of admiration if it was confirmed and recognised by someone else. At the same time, the family caregivers who participated in the study were also bearing witness to the lives of their family members with dementia, chronicling their struggles as they witnessed them. Their testimonies included references not only to friends and relatives, but also to their entire social network, including healthcare professionals and the interviewer, as they signified their own acts in the eyes of anyone who might bear witness to their experiences. In addition to this need to have their acts witnessed, there may be an alternative explanation for the detailed descriptions these caregivers shared, which is related to methodology. Their eagerness could be related to the fact that the interviewer was from the same culture, and through her they could confirm that they were fulfilling their duties and 'paying back', as is expected according to Persian cultural values. However, Ahmadi (2003) argues that, for Iranian immigrants in Sweden, personal desires and life projects are of central importance, so in future they may be much less faithful to the collective cultural values of their homeland.

Nevertheless, the study showed that Iranian social values appear to guide the caregiving activities of

family caregivers, in a similar manner to that in which filial piety values have been shown to play a role in East Asian countries (Sung, 1998; Park and Chesla, 2007). The core concept of filial piety, which is a social norm, is to fulfil one's obligations to one's parents (Levande *et al*, 2000). To do so is considered natural to human nature in these contexts (Sung, 1998). This sentiment was expressed similarly by the participants in our study, but was grounded in other motivations as well.

Svanström and Dahlberg (2004) found that the relatives of people with dementia experienced a new life, but one with unknown meaning, which contributed to a feeling of uncertainty that left them in a quandary. The present study showed how meaningful this new life could be for some family caregivers. Being responsible demands hard work but gives our lives a hitherto unknown content and meaning (Lögstrup, 1992). As dementia progressed and the study participants became more involved in caring for their relatives with dementia, they in turn developed different views on life, with new qualities that had not existed previously. The satisfactory experience of caring seems to be conditioned by cultural living and beliefs. Being the primary caregiver for their close relatives had brought these men and women a sense of satisfaction and importance.

The expressed life world of the Iranian immigrant family members can also be understood using Levinas' philosophy (1987). Levinas argued that 'the face-to-face encounter with the "Other" is ethical, as it may allow us to see the vulnerability and mortality of the "Other", which may then result in feeling obliged to respond or to take responsibility for the "Other"' (Röing *et al*, 2008). In this context, compassion can be seen as an imperative manifestation of life (Lögstrup, 1992). It is assumed that an ethical demand is implied in an encounter with a person in need of help. We shall continue to experience a never-ending sense of guilt if we do not care for the people who need our help. In this study, the participants carried out major acts of compassion, accompanied by a willingness to make some sacrifices as they went out of their way to help others (Thomasma and Kushner, 1995). Many of the men and women had made huge changes in their personal lives in order to care for their partner or parent as they wished. Moreover, they regarded these lifestyle alterations as a natural part of life, and not as a sacrifice. This attitude has also been noted in studies examining the experiences of close relatives living with a person with a serious chronic illness (Öhman and Söderberg, 2004). Compassion generates a profound responsiveness to those who call for help – an illustration of mercy if you will (Oreopoulos, 2001). It calls upon us to help the others even when this means sacrifice, inconvenience and denial of personal interests (Dougherty and Purtilo, 1995). Levinas regards mercy as a way of:

being for the other first. Once we have escaped the centrifugal pull of our own identity, needs, interests and values we can then plot a new trajectory towards the other. No more am I driven by my personal agenda but I act for the sake of the others.

(Dixon, 1997, p. 299)

According to Levinas, people who are responsible for others become more ethical individuals as they get close to the other person. He states that this makes us 'hostages', who cannot take for granted our own freedom to act in these kinds of relationships (Öhman and Söderberg, 2004). The participants described with strong feeling their great efforts to comfort their relatives with dementia. Levinas (1990, p. 83) described the relationship among human beings as a parental relationship. Regarding the other person as one's child involves establishing what he called 'beyond the possible', which makes one able to see the other's possibilities as one's own.

One might have expected the participants in this study to raise issues related to spirituality and/or religion, but this was not the case. Our methodological approach was such that we posed open-ended questions and followed these up with probing when necessary. Consequently, the participants only talked about their situation in terms of what they felt were important aspects to discuss, and the subject of spirituality and/or religion was not raised spontaneously. Ahmadi (2003) has suggested one reason why this aspect does not appear to be central to the participants' experiences. He argues that many Iranian immigrants in Sweden are trying to live a secularised life, or had already embraced liberal values before emigrating to Sweden. Ahmadi (2003) reports the importance of self-desires, goals and personal life as central issues for Iranian immigrants in Sweden which contributed to their choosing Sweden as their new homeland. If this is the case, the participants in this study may quite simply have not discussed spirituality/religious issues because these were not relevant to them. However, because we did not ask our participants specific questions about the role of religion/spirituality in the caregiving experience, this suggested explanation can be neither confirmed nor disproved.

Implications for clinical practice

Knowledge of this special and close relationship between the Iranian immigrant family caregivers in this study and their relatives with dementia, as well as what this relationship actually means for them, may contribute to a better understanding of the phenomenon of family caregivers' experiences. For example, it suggests to healthcare providers that the caregivers'

experiences may differ from what might be assumed to be the usual responses. Given that good nursing practice requires one to see the unique person who is being cared for, this study suggests that it might be necessary to tailor clinical practice to the different subjective views of caregivers in different contexts.

The multi-dimensional impact of ethnicity, culture and life experiences on caregiving behaviours needs to be considered more carefully. Family caregivers other than marriage partners are increasingly assuming caregiving responsibilities (Etters *et al*, 2008). Studying the experiences of these other types of groups as they perform such roles, and learning more about their perceptions, could yield interesting findings. Further knowledge about the factors that mediate whether or not caregiving in various settings will lead to perceived positive or negative consequences for the caregiver, especially with regard to caring for people with dementia, would be invaluable. Unfortunately, the current approaches to research in these areas tend to be narrow and to overlook possible cultural conditions, thus hampering a better understanding.

Conclusion

This paper calls for research to pay specific attention to and reflect upon the caregiving experiences of different social groups who are supporting chronically ill patients. A better understanding of the new life world of healthcare clients could assist significantly in the design of more appropriate healthcare supports, and in increasing well-being and quality of life while avoiding stereotyping with regard to the provision of care.

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CONFLICTS OF INTEREST

None.

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