

Fears come true: the experiences of older care recipients and their family members of live-in foreign home care workers

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ABSTRACT

Background: Foreign home care services provided to frail older adults by individuals from the developing world are a global phenomenon. This study evaluated the challenges associated with live-in foreign home care from the perspective of older care recipients and their family members.

Methods: Qualitative interviews were conducted with 23 family members and seven older care recipients. Interviews were analyzed thematically.

Results: Three main themes were identified: (i) the intense *fears* associated with witnessing the decline of the older care recipient and the subsequent employment of a foreign home care worker; (ii) *actual negative experiences* within this caregiving setting; and (iii) the ways in which family members and older care recipients *coped* with these challenging experiences.

Conclusions: The key to this caregiving arrangement is the establishment of trust. Yet, many care recipients experienced violations of trust that resulted in abuse and neglect, which served to further intensify fears and concerns about this caregiving arrangement. The same coping methods used to maintain this arrangement, despite fears and concerns, are the ones responsible for maintaining the older care recipient in an abusive situation.

Key words: abuse, neglect, domestic care, globalization, long-term care, frailty

Introduction

This study addresses a global social phenomenon of workers from the developing world, who provide care to more affluent, yet frail individuals from the developed world (Yeoh *et al.*, 1999; Ehrenreich and Hochschild, 2000). The shortage of available family members as carers is due to many demographic changes that have been taking place in Western society over the past decades. These include the increase in longevity, the decrease in childbirth, the fragmentation and nuclearization of the family system, and the entrance of women into the workforce (Popenoe, 1993). The shortage of family members as caregivers, the low status assigned to caregiving in many Western countries (Feldbaum and Feldbaum, 1981), the low financial costs associated with home care relative to institutional care (Aronson and Neysmith, 1996), and the wishes of many older adults to stay in their home environment as long as they possibly can (Keysor

et al., 1999) are all responsible for the increasing popularity of utilizing foreign home care worldwide.

In Israel, there are 54,000 documented foreign home care workers and at least 40,000 undocumented workers (Nathan, 2008). Because only the most impaired individuals are eligible for a foreign home care worker, almost all live-in home care services are provided by foreign workers, who provide round the clock personal care, such as assistance in grooming or feeding. The majority of these workers are from the Philippines, but others come from India, Nepal, Sri Lanka, Romania, Moldavia and Hungary. These workers are not considered as immigrants as their stay in the country is temporary and they are expected to leave the country after several years or when their care recipient dies. In order to ensure that their stay in the country is limited, workers are not allowed to bring their family members with them and their prospects of becoming Israeli citizens are almost non-existent. Further, the Israeli government is actively seeking to restrict the number of foreign workers in the country (Borowski and Yanay, 1997). Nonetheless, the number of foreign home care workers has been steadily increasing because

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permits are given based on need, which continues to increase with the aging of the Israeli population (Heller, 2003; Klein-Zeevi, 2003).

Despite the fact that this global phenomenon is prevalent in many Western societies, the research on the topic is scarce. The limited research available suggests that workers are often treated as invisible carers, whose work is acknowledged only when problems arise (Ehrenreich and Hochschild, 2000). Though the salary of the workers in the host culture is substantially higher than their salary in their home country, their status is lower, as they capture positions that are not wanted by the citizens of the host culture (Raijman *et al.*, 2003). Research has also shown that workers are often exposed to high levels of abuse and negative working conditions because of the nature of their work behind closed doors, within the private realm of someone else's home (Denton *et al.*, 2002a; 2002b; Neysmith and Aronson, 1997; Ayalon, 2009a).

Interestingly, even less attention has been given to the experience of the older care recipients and their family members within this caregiving arrangement. As already noted, a few studies have documented a strong preference of older adults and their family members for home care rather than institutional care (Keysor *et al.*, 1999). Others, on the other hand, have documented some of the challenges associated with such care; these studies have identified the active negotiation of space and boundaries within such an intense work/home situation as a major challenge (Martin-Matthews, 2007), while others have explored the issue of establishing trust within such an arrangement (Porter, 2005; Porter *et al.*, 2005). The few epidemiological studies conducted have shown that the rates of abuse and neglect under the home care system are similar to the rates in the general population of older adults (Cooper *et al.*, 2006; Ogioni *et al.*, 2007; Laumann *et al.*, 2008).

Although informative, the majority of this research has focused on the variety of home care services (e.g. social work, health services, etc.) rather than on live-in round-the-clock personal care and, more specifically, on foreign home care workers, who come from the developing world to provide care to frail individuals in the developed world. The Israeli case is unique because the most intimate care is provided for money by a complete stranger, who comes from a different cultural and religious background and likely holds many beliefs and attitudes that are at odds with the beliefs and attitudes held by the care recipient and their family members. Furthermore, current policy that allows only the most impaired individuals to hire a foreign home care worker and regards the worker as part of a temporary workforce with almost no

prospects of becoming an Israeli citizen places both care recipient and worker alike in inferior positions and intensifies the interdependence between the involved parties. The intensity of this caregiving arrangement is further reinforced by the fact that it takes place round the clock, in the private realm, behind closed doors and with only minimal supervision. Given these unique characteristics and the popularity of foreign home care worldwide, there is clearly a need to evaluate it further. The present study focuses on the challenges associated with foreign home care from the perspective of older care recipients and their family members.

Methods

Sample

Inclusion criteria for this study were (a) being a family member of a person aged 60 years or more who receives round the clock home care services by a Filipino home care worker (both adult children and spouses who defined themselves as the primary caregiver were included under this criterion); or (b) being an adult aged 60 years or more, who receives round-the-clock home care services from a Filipino home care worker. Care recipients with severe cognitive or physical limitations were not interviewed. The study was limited to Filipino home care workers because this is the largest group of foreign home care workers in Israel. Participants were approached in adult day care centers, social services centers, at neighborhood events, and similar settings. A convenience sample was used in order to reach maximum variations in gender and geographical location.

Overall, 23 interviews with family members of older adults cared for by a Filipino home care worker were conducted. Their ages ranged from 38 to 84, and the majority of these primary family caregivers were women (12), with most being daughters (10). Of the five spouse caregivers, two were wives. In the majority of cases, the care recipient was a female (12). Whereas spouses shared a residency with the care recipient, none of the adult children shared a residency with the care recipient.

A total of seven care recipients were interviewed for this study. Of these, four were male and their ages ranged from 74 to 94. The length of time in receipt of foreign home care services varied from several months to 12 years. All care recipients were completely impaired in their activities of daily living as this is the major eligibility criterion for hiring a foreign home care worker in Israel. The majority lived with a partner (5) and all had less than 12 years of school. The majority of foreign home

care workers who provided care to these seven care recipients were female (5).

Procedure

This study was approved by the institutional review board of Bar Ilan University. All interviews were conducted by experienced qualitative interviewers. Questions encompassed the decision to hire a foreign home care worker, changes that took place following the arrival of the foreign home care worker, similarities and differences between a foreign home care worker and an Israeli worker, and beliefs about the appropriate person to provide care to older adults. Questions were further modified based on feedback from initial interviews. Interviewers were instructed to use a funnel approach, starting with broad questions which then became more specific. Interviews lasted between one to three hours.

Analysis

The interview transcripts were analyzed by three independent raters, all experienced in qualitative research. One of the raters was blinded to the research question and study rationale. We coded data categories in stages, with each stage representing a more complex conceptual level (Strauss and Corbin, 1998). Each interview was first coded thematically for major content areas. Next, commonalities and differences across interviews were evaluated and themes were regrouped to represent major content areas that received considerable attention across participants. Data were not forced into preconceived themes but instead an open coding approach was employed, so that interview data guided the creation of the categories (Cresswell, 2003). In searching for inter-theme consistencies and contradictions, descriptive and then interpretive categories were created to represent interview data. The final stage was selective coding which involved the identification of core categories to create a story line (Strauss and Corbin, 1998). These categories were subsequently integrated with relevant literature. We maintained an audit trail (Rodgers and Cowles, 1993) by recording the data analysis process and keeping records of all stages of the analysis. Owing to the large volume of complex data, this paper focuses on major themes concerning the challenges associated with this caregiving arrangement as identified by the family members and older care recipients. Some of the advantages associated with this caregiving arrangement are discussed in great detail elsewhere (Ayalon, 2009; Ayalon *et al.*, 2008). To establish the rigor of the study, several interviews were analyzed independently by different raters and disagreements

were discussed. Portions of the findings have been presented at several scientific meetings and the feedback of researchers and clinicians who work with the study population has been incorporated.

Results

Three main themes were evident from interviews with family members and older adults. The first concerns the intense *fears* associated with witnessing the decline of the older care recipient and the subsequent employment of a foreign home care worker. The second theme concerns *actual negative experiences* within this caregiving setting. The third theme addresses the ways in which family members and older adults *cope* with these challenges and negative experiences. I present the views of family members and older care recipients together, and note the unique views that are characteristic of only one of the groups.

Fears

A major fear expressed by both older adults and their family members concerned *having a stranger in the house*. For some, this fear was so pervasive that they were hardly able to express in words the specific concerns they had about having a live-in foreign home care worker, whereas others were able to put into words some of their concerns. These included the natural fears concerning *invasion of one's privacy* and the potential *changes in routine*, while others expressed much deeper concerns, such as *potential violation of trust*, threats of *physical, financial, or emotional abuse*, and an intense fear of *neglect or abandonment* of the older care recipient by the foreign home care worker. Interestingly, many of these fears remained strong despite many years of care by the same foreign home care worker.

One daughter of an older care recipient stated: “She [older care recipient] *disagreed, she did not want a live-in foreign home care worker, it seemed strange to her, that a worker would be with her at home.*”

An older care recipient declared vividly that: “*It is important for me that the worker will respect me and speak nicely to me. I have heard stories about workers who hit the older adults they take care of . . . People have problems with these workers . . . there are arguments. Not every thing goes smoothly.*”

Another major fear expressed primarily by family members was the fear of *losing independence*. Independence was portrayed not only in *functional* terms, but also in *financial*, and *respect/authority* terms. Many family members who have witnessed the physical and cognitive decline of their loved ones, the financial burden associated with these declines, and the subsequent loss of authority and

respect around the house expressed great fears of experiencing similar declines in the future. Many of them expressed the hope that they would not end up in a similar situation. These fears, inevitably, brought up the question of “*who will take care of me?*” as many family members could not imagine that they would enjoy the same level of care as the care they currently provide to their love ones.

As stated by an adult daughter: “*I hope God will take me young. A car accident . . . I want to die at once. As great as my kids are, even today when I say that I need medicine, they respond that they don’t have enough time, ‘not today, I can’t do this,’ I do not ask anything from any one, just from him (God), I do.*”

Fears come true

The fears concerning a live-in foreign home care worker expressed by family members and care recipients came true, at least for some of the interviewees. Many reported an *invasion of privacy* that required *major changes in their routines*, whereas others reported the *violation of their trust* resulting in *exposure to abuse, neglect, and abandonment*.

The most common type of abuse reported was *financial*. In most cases, financial abuse was performed through partial cooperation of the older care recipient, who was physically and emotionally dependent upon the live-in foreign home care worker. Apparently, many older care recipients were willing to give substantial amounts of money to the home care worker in order to prevent real or imagined abandonment and in order to continue and experience an emotional bond with the worker.

As stated by an adult daughter: “*After three months we realized that something was not right, and it looked as if she [the worker] was abusing his [care recipient’s] situation. First, there was the financial abuse. Even though, I was the one in charge of all the financial arrangements, she kept asking him for more and more, and it seemed manipulative.*”

Physical and emotional abuse by the foreign home care worker were reported much less frequently and, in fact, family members often admitted to being emotionally abusive while commending the foreign home care worker’s patience and respect for the older adult.

One adult daughter noted: “*I try to think, how I deal with my mother’s mood swings, with her craziness. Today I take it silently, but I used to get really mad, and the worker used to calm me down. She [worker] knows how to accept this. My mother would yell at her and misbehave, and she would continue dressing her up, not fighting, not arguing, maybe because emotionally, she [worker] is less attached to my mother. So, she can accept this, she does not fight with her as I do.*”

Neglect was another common theme expressed by both older care recipients and their family members. Interestingly, in most interviews, neglect was portrayed in “gray colors” and there was an equivocal judgment assigned to it. According to some, neglect was performed unintentionally; as in the case of a foreign home care worker who could not learn how to manage her older care recipient’s medical regime, whereas others expressed their empathy and understanding for the worker’s neglectful behavior. However, others reported neglect that could not be viewed equivocally.

As noted by an adult son, “*He [worker] does not neglect my mother’s care because he does not see things, but I do have to tell him more often, ‘don’t do this, do that, make sure this is clean, or throw away the trash,’ the former worker used to do these things without us telling him.*”

Abandonment by the foreign home care worker was a common experience reported in many of the interviews. At times, abandonment was in the form of neglect, as in the case of a worker who took a few hours off without telling the family members; at other times, the abandonment was final, as in the case of a worker who left the care recipient for a better job.

Not liking the worker or not *getting along* with the worker was a theme evident primarily in interviews with older care recipients, who tended to place a greater emphasis on the emotional and social aspects of the job than on its physical aspects.

One older care recipient noted: “*They [family members] were impressed with how she [worker] speaks Hebrew. But, I didn’t want her, didn’t like her. She took care of my husband, but when he died I wanted some one else, I just didn’t like her.*”

Ways of coping

Family members and older adults alike engaged in a variety of coping methods in an attempt to ease their fears of this caregiving arrangement and to continue the arrangement even in the face of challenges. A major coping mechanism was the belief that foreign home care was *the best option*. To support their decision, family members and older care recipients alike emphasized their *concerns about nursing homes* as representing the worst alternative. Further, many expressed explicit distinctions between the different options of home care, arguing that *there is a way to tell the difference between a good worker and a bad one*.

As noted by an adult daughter, “*I knew I would not hospitalize daddy in an institution. There was no need. I mean, there was mother, there was money, there was an apartment . . . It was clear that daddy would never end up in an institution.*”

Others stated that they did not wish to *rock the boat* and preferred to *look at the bright side* of this caregiving arrangement because a *different worker may even be worse*. Interestingly, even family members and care recipients who were subject to severe financial abuse still reported their ambivalence about breaking the relationship with the abusive worker, pointing out some of the *strengths of the worker*.

An older care recipient commented: “*I cannot say he is not doing what he is supposed to . . . Of course, I can criticize him, but this will be nitpicking, if it were up to me, I would have replaced him by now, but my wife says, ‘we have known him for several years, we have educated him, we know what to expect of him . . .’*”

Giving extras was another very common theme expressed by both older care recipients and their family members. As already noted, at times “giving extra” was so substantial that it took the form of financial abuse, whereas at other times, family members and older care recipients alike did not regard giving extras as abusive – they reported giving gifts, extra money, extra food, and extra benefits in order to “please” the worker and to prevent an imagined or real abandonment.

As noted by an adult daughter: “*I always give him [worker] money, every weekend. We know what his expenses are, but I never leave him the exact amount, I always give him extra and I never check or ask . . . And sometimes, I give him aftershave or other gifts. He [care recipient] really wants to spoil him [worker]. My dad has diabetes, so he cannot eat candies, but he keeps buying the worker candies instead . . .*”

A coping mechanism evident only in interviews with older care recipients was *active surrender* to the worker. In many interviews, older adults reported great efforts to please the worker, even at the expense of their own needs. In other interviews, fear of the worker was so evident that many older care recipients had asked to meet on the worker’s day off in order to discuss their experiences. Even so, they continued to whisper their experiences in fear, despite the worker not being present in the house.

As noted by an older care recipient, “*I do not wish to talk, because he [worker] understands every thing. As if I am talking behind his back, but I could have said many things about him . . .*”

The belief that “*this is the dementia*” was a mechanism of denial employed by many family members. At times, it was the person with the dementia who sensed the abuse or the inappropriate treatment long before anyone else in the family noticed; furthermore, the person with the dementia often pointed out problems that were never corroborated as it was difficult to test the word of the older care recipient with dementia against the word of the foreign home care worker.

One adult daughter noted: “*The only one who saw this was my mother, because she lived in the house. She said she [worker] was manipulative, she was stealing from them . . . and this was the case, but we did not want to see this, because we were happy that there was some one taking care of our father, making our father happy . . .*”

Active watching and *taking over* some of the caregiving tasks was discussed by family members. Apparently, when family members sensed a potential threat to the care recipient, they tended to respond by monitoring more closely the care provided to their loved one. When the threat for financial abuse was evident, family members tended to take over more responsibilities and to limit the control of the care recipient and the worker. In addition, they tended actively to hide information from the foreign home care worker.

As described by an adult daughter: “*I even thought about placing a hidden camera, I used to come, stand by the door, take the stairs, not the elevator, wait for 20 minutes or so to hear what’s going on around the house, ask neighbors . . .*”

Finally, in order to cope with their intense fear of future loss of their own independence in the perceived absence of family members to provide them with similar quality care as the care currently provided to their loved ones, many family members reported *active preparation* for such a future. For some, taking care of their loved ones now served as a “*guarantee*” that in the future, their children, who have watched and learned, will do the same. Others stated that they have already made plans for *an institution*, in order not to test the ability of their family members to care for them, whereas others expressed active *suicidal ideation*, if or when they become functionally dependent.

Discussion

The present study provides a unique view into some of the challenges and negative aspects of this popular caregiving arrangement involving foreign home care workers, frail older adults, and their family members. Whereas the focus of this paper is on some of the challenges associated with this caregiving arrangement, it is important to note that this arrangement has many positive aspects, which account for its increasing popularity. These have been outlined in great detail in past research (Ayalon, 2009b; Ayalon *et al.*, 2008). It also is important to note that this caregiving arrangement is challenging not only for the care recipients and their family members, but also for the foreign home care workers themselves, who are often exposed to inhumane working conditions and abuse (Denton

et al., 2002a; 2002b; Ayalon, 2009). Nonetheless, in this paper, I selectively outline those challenges discussed by older care recipients and their family members.

Similar to past research (Porter, 2005; Porter *et al.*, 2005), this study demonstrates that a major challenge associated with this particular caregiving arrangement is the establishment of trust. As already noted, this caregiving arrangement places both foreign home care workers and older care recipients in a fragile and interdependent position. Such an arrangement cannot be maintained in a contractual, business-like way but has to rely on trust, intimacy, and emotional and social connectedness. Nonetheless, given the unique characteristics of this arrangement, the establishment of trust is often very difficult. Family members and older adults alike experience intense fears of abuse and neglect of all types. The fact that so many older adults and family members reported actual exposure to violations of trust, neglect or even abuse by a foreign home care worker further intensifies the worries that family members and older care recipients share about this caregiving arrangement.

Other fears, expressed primarily by family members of older care recipients, were associated with their experience as caregivers of frail older adults, who have witnessed the decline of their loved ones and the extreme burden this has placed upon the family even when significant assistance in the form of a live-in home care worker was available. These experiences have led many family caregivers to question the ability of their own family members to care for them in the future. Many expressed their fears and concerns that no one would be around to provide them with the intensity of care that is required of family members even under the live-in round-the-clock system. Hence, even though family members chose foreign home care for their loved ones, believing this was the best alternative, many did not view it as a feasible alternative for themselves in the future.

In almost all interviews, interviewees reported exposure to at least some negative experiences, with violation of trust, financial abuse, and neglect being the most common themes reported, and experiences of abandonment and physical and emotional abuse also being reported. Nevertheless, many viewed these negative experiences at least somewhat equivocally. For instance, some family members justified emotionally abusive behaviors by stating that they would have behaved the same or even worse, whereas others justified abusive experiences by pointing to some of the positive aspects of the caregiving arrangement and the drawbacks associated with making changes to this arrangement. Furthermore, many interviewees

found it difficult to draw the line between giving the worker extra financial support in order to assure his or her services and being financial abused by the worker. Hence, the same coping mechanisms that help family members and older care recipients accept this caregiving arrangement are the ones responsible for maintaining older adults in abusive relationships.

This study has some limitations that should be noted. Only a small proportion of the care recipients were interviewed because the majority were cognitively and physically impaired and unable to participate in such an interview. In addition, as already noted, this study selectively addressed the challenges associated with this caregiving arrangement and did not emphasize many of the strengths. Further, the study focused solely on care by Filipino home care workers, because this is the largest group of foreign home care workers in the country. Thus, the experiences of individuals cared for by foreign workers from other destinations are not discussed because these might be very different. The study is also limited by not integrating the experiences of family members and care recipients with the experiences of the Filipino home care workers. I decided against such integration because the experiences of Filipino home care workers were so different from the experiences of the other two stakeholders. Nonetheless, as already noted, another paper is completely dedicated to the main themes identified in interviews with Filipino home care workers (see Ayalon, 2009). Finally, some may argue that this study may be non-representative of the general population because of the reliance on a small non-representative sample size and lack of standardized measures. Nonetheless, it is important to note that the purpose of qualitative research is not to generalize or represent the entire study population, but rather to provide an in-depth understanding into a social phenomenon. For this purpose, participants are purposively sampled to maximize variations in opinions and attitudes (Patton, 1997). In addition, the questions are only semi-structured because their purpose is to represent the subjective views of respondents as accurately as possible. Similarly, coding of qualitative data is by nature subjective. However, to systematize the process, data were coded by several different coders and only themes that emerged across interviews were presented.

Implications for research and practice

The study shows that both older care recipients and their family members experience many challenges under the live-in foreign home care system. Interestingly, exactly the same coping mechanisms that allow them to maintain this arrangement

despite its limitations are the ones that also maintain elder abuse and neglect. Hence, older care recipients and family members under the live-in foreign home care system could benefit from further education about what constitutes elder abuse and neglect and what to do when it is detected. The finding that financial abuse and neglect were the most frequent themes reported is not surprising as most foreign home care workers receive salaries that are below or on a par with the minimum wage. These workers are also given very little time off work (Ayalon, 2009a). Hence, it is possible that their current working conditions precipitate some of the negative behaviors reported in the present study. Improvement in their working conditions might therefore result in a subsequent improvement in the care they provide.

A major fear reported primarily by family members was the fear of their own future as frail care recipients. Many were unable to conceive that such a care option would be available to them, requiring as it does such an intense involvement of family members. Hence, it is clear that further support of family members is needed in order to ease the burden associated with caregiving even under the live-in foreign home care system. It also is important to continue and evaluate whether round-the-clock home care remains applicable for future generations of older adults, who may enjoy less cohesive familial support. Finally, further epidemiological research concerning elder abuse and neglect under the live-in foreign home care system is needed in order to obtain a more thorough understanding of this phenomenon.

Conflict of interest

None.

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