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Beliefs and practices regarding Alzheimer's disease and related dementias among Filipino home care workers in Israel

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Background: In the past few decades, foreign home care to frail older adults has become a common alternative to family care in many developed countries. Whereas Alzheimer's disease and related dementias (ADRD) are common conditions in this population of frail older adults, little is known about the beliefs of foreign home care workers about ADRD or about their practices.
Methods: A mixed-methods design was conducted in 2006–2007 in Israel. The study included a survey of beliefs about ADRD completed by 184 Filipino home care workers and qualitative interviews with 29 Filipino home care workers.
Results: On seven of the 14 belief items, more than 30% of the workers were in discordance with scientific view about ADRD. Those workers who were not informed about the care recipient's medical conditions were more likely to report beliefs that were inconsistent with current scientific knowledge. In qualitative interviews, Filipino home care workers reported using intuitively behavioral techniques when caring for older adults with ADRD.
Conclusions: Despite the fact that some of the workers' beliefs are inconsistent with current scientific view, their actual intuitive practices are consistent with the scientific paradigm. Specific emphasis has to be placed on encouraging workers' intuitive approach to ADRD and providing workers with ample information about the medical conditions and needs of the care recipient.

Keywords: knowledge; attitudes; migrant workers; dementia; cross-cultural; formal caregiving; domestic care

Introduction

In the past few decades, foreign home care[1] to older adults has become a common alternative to family care in many developed countries (Ehrenreich & Hochschild, 2000; Yeoh, Huang, & Gonzalez, 1999). The increasing prevalence of foreign home care has been attributed to the entrance of women into the workforce, the fragmentation of the family system, and the low status associated with caregiving in Western society (Ehrenreich & Hochschild, 2000; Popenoe, 1993). Financial forces also encourage foreign home care, as it is substantially cheaper than institutional care (Heller, 2003). In addition, many developing countries encourage migration because workers (primarily women) tend to send their income back to their country of origin. In fact, in some developing countries, such as the Philippines, care providers have become the number one commodity of export with almost half the population in the Philippines being sustained by money sent back home from oversees (Mission, 1998). Another reason for the increasing prevalence of home care is that it usually reflects the preferences of older adults and their family members to stay in their home environment as long as possible (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004; Keysor, Desai, & Mutran, 1999).

In Israel, the majority of older adults are cared for at their homes with only 4% being cared in institutions (Heller, 2003). Whereas Israelis usually provide hourly personal home care, almost all around-the-clock personal home care is provided by live-in foreign workers (Heller, 2003). Currently, there are approximately 38,000 documented foreign home care workers and according to some estimates another 30,000 undocumented foreign home care workers in Israel. The majority of workers are from the Philippines (about 70%), but workers from Nepal, India and Eastern Europe also are represented (Heller, 2003).

In order to be eligible for a foreign home care worker, the older adult has to live in the community and to demonstrate significant impairment in activities of daily living. Once impairment is determined, permission to employ a foreign home care worker is issued. The Israeli government partially subsidises home care services and regulates employment through private nursing agencies. These agencies are in charge of bringing the workers into the country and matching the foreign home care worker to the older adult. The nursing agencies also are in charge of supervising this caregiving arrangement and of assuring the welfare of the older adult (Weisblay, 2005). Whereas some training is usually provided to foreign workers prior to their arrival in the country and during their initial working period, this training is variable and is not monitored systematically (Ayalon, Kaniel, Rosenbers, 2008).

As stated above, in Israel, in order to be eligible to take a foreign home care worker, the older care

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recipient has to be severely impaired in activities of daily living (Heller, 2003). Consistently, the international literature has shown that home care recipients often are both cognitively and physically impaired (Hawranik & Strain, 2001), with cognitive impairment of care recipients being most often cited as a challenge faced by home care workers (Soini & Valimaki, 2002). Nonetheless, no clear statistics are available regarding the cognitive and mental functioning of older home care recipients in Israel.

Despite the increasing prevalence of foreign home care in the developed world (Brush & Vasupuram, 2006; Chang, 2000; Martineau & Willetts, 2006; Salazar Parrenas, 2001; Yeoh et al., 1999), little is known about foreign home care workers' beliefs and attitudes towards Alzheimer's disease and related dementias (ADRD) or about their actual practices with older adults with ADRD. Because these workers have limited prior training in aging-related issues, yet provide the majority of around-the-clock personal care, their opinions and practices are particularly relevant. The fact that these workers come from a different cultural background and are likely to hold beliefs and attitudes that are different from the majority culture reemphasizes the importance of evaluating their beliefs.

Study aims

The goals of the present study were three-fold: (a) to obtain preliminary information about foreign home care workers' beliefs about ADRD (a highly prevalent condition in this vulnerable population of older adults); (b) to identify the groups most at need for further ADRD training by evaluating sociodemographic correlates of beliefs about ADRD, such as acculturation and home care experience; and (c) to describe the subjective experiences of foreign home care workers who work with older adults with ADRD.

Based on past research that has shown that ethnic minorities (Ayalon & Areán, 2004) and paraprofessional nursing care workers (e.g. certified nurse's aides, nurse's assistants; Ayalon, Areán, Bornfeld, & Bird, 2008) tend to hold beliefs and attitudes that are in disagreement with current scientific knowledge, I expected foreign home care workers to hold beliefs about ADRD that are divergent from current scientific view. I further expected less acculturated foreign home care workers to report views that are more divergent from current scientific view. Finally, similarly to findings of Ladson and Levkoff (1999) that have shown a tendency of ethnic minorities to report normalizing beliefs about ADRD, I expected foreign home care workers to normalize ADRD during interviews.

This study is important because it is the first to evaluate beliefs about ADRD in foreign home care workers. Given the every day contact many foreign home care workers have with these conditions, evaluating their beliefs and attitudes is the first step in developing training programs for these workers. The use of both quantitative and qualitative methodologies allows for additional information not only about workers' beliefs but also about their actual practice. This study is limited to Filipino home care workers because this is the largest community of foreign home care workers in Israel.

Methods

Phase I: Quantitative survey

This study was approved by the institutional review board of Bar Ilan University. All participants signed an informed consent prior to participating in the study. For the *quantitative survey phase*, participants were recruited in a variety of locales commonly attended by foreign workers including home care agencies, human rights organizations, public parks, Tel Aviv central bus station, and by other snow balling techniques. All Filipino home care workers who provided around-the-clock care to a person 60 years and older were eligible to participate in this study.

Sample characteristics

Overall, 184 Filipino home care workers completed the beliefs and attitudes questionnaire. Mean age was 36.3 (SD = 8.3). The majority were not married (55.4%), female (83.7%) and had at least some college or trade school education (69.1%). The majority of participants identified their profession in the Philippines as 'other' (39.5%); yet 15.2% self-identified as teachers, 2.7% self identified as nurses, 3.5% self identified as being in business and 3.9% self-identified as physical therapists. The majority of foreign home care workers indicated that they had been in Israel between 1 and 5 years (70.7%) and had worked as home care workers for between 1 and 5 years (70.7%). Overall, 16.3% reported that they had never been informed about the medical conditions of the care recipient.

Measures

All measures were available in English and Tagalog to accommodate to workers' preferences.

Knowledge about Alzheimer's disease and related disorders. This measure was adapted for use in the present study based on an existing questionnaire previously used with ethnic minorities (Ayalon & Areán, 2004) and paraprofessional nursing care staff (Ayalon et al., 2008). The questionnaire was further revised based on feedback from foreign home care workers, human rights organizations, and the Filipino consulate in Israel. The questionnaire has 14 items. Two items concern the presentation of ADRD, e.g. 'in people over 75, forgetfulness is a sign of dementia'. Six items concern the etiology of ADRD, e.g. 'If your

family member has Alzheimer's disease, you also are going to have Alzheimer's disease (Alzheimer's disease is inherited)'. Six items concern treatments of ADRD and agitation, e.g. 'You should never touch an older person who is agitated (yells, curses or paces aimlessly)'. Scores range from 0 to 14, with a higher score representing knowledge that is more consistent with the current scientific view. In this study, internal consistency was 0.58.

Sociodemographic variables. Age, gender, education, years in the country, number of years as a home care worker and knowledge of care recipient's condition were gathered based on self-report.

Analysis

Descriptive statistics were first obtained to characterize the sample. Then correlation analyses were run between all sociodemographic variables in order to rule out multicollinearity. Next, a regression analysis was conducted with knowledge of ADRD as an outcome and all sociodemographic variables as potential predictors.

Phase II: Qualitative research

Participants in this phase were not the same ones who participated in the quantitative phase. Participants were recruited through nursing agencies and adult day care centers. Overall, 29 Filipino home care workers were interviewed. Seven of the Filipino home care workers were interviewed during in-depth individual interviews. In addition, three focus groups of two to 11 participants were conducted. The majority of Filipino home care workers were female (82%). They ranged in age from 18 to 56. Number of years in Israel ranged from several months to 11 years. All had experience working with older adults with ADRD either in their present position (96% workers) or in the past (3%).

Procedure of qualitative phase

All interviews were conducted by experienced Israeli interviewers. Interviews were conducted in either English or Hebrew (two of the interviews). Foreign home care workers were asked about their decision to come to Israel, challenges and advantages associated with their work, and their beliefs about appropriate care to the elderly. Workers were also asked about their experience working with older adults with ADRD and specific challenges associated with such work. Questions were further modified based on feedback from initial interviews. Interviewers were instructed to use a funnel approach, starting from broad questions followed by more specific ones. Interviews lasted approximately 1–2 h. Notes were taken during interviews. In addition, all interviews were tape-recorded and transcribed verbatim with the exception of one focus group that was not tape-recorded due to a technical glitch.

Analysis of qualitative data

Three independent raters, all experienced in qualitative research, analyzed the interviews. 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 & 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 area 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 (Creswell, 1998). Searching for intertheme consistencies and contradictions, descriptive and then interpretive categories were created to represent interview data. The final stage was selective coding, which involves the identification of core categories to create a story line (Strauss & Corbin, 1998). These categories were subsequently integrated with relevant literature. We maintained an audit trail (Rodgers & Cowles, 1993) by recording the data analysis process and keeping records of all stages of analysis. Owing to the large volume of complex data, this paper focuses on major themes related to providing care to older adults with ADRD.

To establish the rigor of the study and assure its conformability (Guba & Lincoln, 1989), different raters analyzed interviews independently and disagreements were discussed. Portions of the findings were presented at several scientific meetings and the feedback of researchers and clinicians who work with this study population was incorporated. A limited member check was also conducted by incorporating the feedback of several participants at different stages of the study. Finally, the use of mixed-methods and the integration of data from two different data sources allows for triangulation (i.e. a common method used in qualitative research for confirmation and generalization; Creswell & Miller, 2000) of the findings.

Results

Beliefs about Alzheimer's disease and related dementias

On seven items, more than 30% of the workers reported beliefs that were discordant from the majority culture. For example, 33% of the workers believed that agitated older adults try to annoy their caregivers on purpose, 60% believed that it is better not to involve family members when the care recipient is agitated, 56% believed that sedatives are the only effective treatment for agitation, 56% believed that agitated older adults do not like to be talked to, 70% believed

Table 1. Foreign home care workers' beliefs about Alzheimer's disease and related dementias ($n = 184$).

	Item	Response *n* (%)
1.	The major symptom of Alzheimer's disease is memory loss. (True)[a]	10 (5.4%)
2.	Older adults who are agitated (e.g. shout, wander around, yell, curse or pace aimlessly) usually try, on purpose, to annoy their caregivers and family members. (False)	60 (32.6%)
3.	In people over 75, forgetfulness is a sign of Alzheimer's disease. (False)	129 (70.1%)
4.	Alzheimer's disease is often a punishment for past behaviors. (False)	50 (27.2%)
5.	It is normal to have Alzheimer's disease, as you get older. (False)	94 (51.1%)
6.	It is better not to be next to people with Alzheimer's disease, because it is contagious. (False)	35 (19.0%)
7.	If your family member has Alzheimer's disease, you also are going to have Alzheimer's disease (Alzheimer's disease is inherited). (False)	42 (22.8%)
8.	In my native country, older adults do not suffer from Alzheimer's disease. (False)	53 (28.3%)
9.	When an older adult is agitated (e.g. starts yelling, cursing or pacing aimlessly), it is better not to involve his or her family members because it would cause trouble. (False)	109 (59.2%)
10.	Sedatives are the only effective treatment for older adults who are agitated (e.g. yell, curse or pace aimlessly). (False)	104 (56.5%)
11.	Physical restrains are the only effective treatment for older adults who are agitated (e.g. yell, curse or pace aimlessly). (False)	54 (29.3%)
12.	When older adults are agitated (yell, curse, or pace aimlessly), they do not like to be talked to. (False)	103 (56.0%)
13.	You should never touch an older person who is agitated (yells, curses or paces aimlessly). (False)	50 (27.2%)
14.	People with Alzheimer's disease need constant supervision. (False)	152 (82.6%)

[a] True/false response in parentheses represents beliefs that are inconsistent with the majority in Western society.

that forgetfulness was a sign of ADRD, 51% believed that it was normal to have ADRD as you get older and 83% believed that individuals with ADRD need constant supervision (see Table 1).

Correlates of beliefs about Alzheimer's disease and related disorders

There was multicollinearity between number of years in Israel and number of years as a home care worker ($r = 0.91, p < 0.001$). Hence, only number of years as a home care worker was included in the regression analysis. In multivariate analysis, the only significant variable was whether or not one was informed about the medical conditions of the care recipient ($\beta = 1.5, \mathrm{SE} = 0.5, p = 0.005$). However, the overall multivariate model was not significant, $R^2 = 0.10$, $p = 0.19$, suggesting that the variables evaluated in this multivariate model are poor predictors overall.

Qualitative findings

Based on qualitative findings, three main themes were identified related to caring for older adults with ADRD. These included (a) the nature of ADRD, (b) challenges and advantages associated with caring for older adults with ADRD and (c) clinical practices employed in the care of older adults with ADRD. Below, these three themes are supported with direct quotes from interview data.

The nature of Alzheimer's disease and related dementias

In general, Filipino home care workers were knowledgeable about signs and symptoms of ADRD. Memory loss and forgetfulness were the main symptoms mentioned when talking about care recipient/s who suffer from ADRD. Foreign home care workers also acknowledged personality changes that accompany ADRD as well as thought difficulties. Many workers acknowledged the progressive nature of ADRD and expressed an expectation that the care recipient's condition would eventually worsen.

> If some one has AD, this person forgets all the time. Every minute, second . . . all the time.

Challenges associated with caring for older adults with Alzheimer's disease and related dementias

Many workers stated that they were not aware of ADRD prior to coming to Israel, because older adults in the Philippines do not live to old age and because they had no prior experience caring for older adults in the Philippines. Hence, lack of knowledge and prior experience affected their ability to care for older adults with ADRD in Israel. Others emphasized the physical difficulties associated with caring for older adults with ADRD. The need for constant supervision of the care recipient was portrayed as a major challenge. These difficulties often were exacerbated by the need to stay awake at night due to sleep disturbances of the care recipient. Emotionally, caring for an older adult with ADRD also was described as a challenge. Even those Filipino home care workers who acknowledged the fact that the cognitive impairments of the care recipient had impacted his or her functioning still reported being emotionally hurt as a result of care recipient's attitudes. Watching the physical and mental deterioration of the care recipient was described as challenging, frustrating, and at times embarrassing, as if workers were in charge of the overall well-being of their care recipient.

> Lately, things have been terrible, she forgets everything, even the name of the children and sometimes she is doing something and she is saying something else... So it's very hard to work with her and to be patient because we know already that no one can be patient all the time.

Clinical practice

Workers emphasized emotional aspects of care that have helped them in their work with older adults with ADRD; caring with love, compassion, empathy and patience were often mentioned as tools that workers used in order to adjust to the difficult behavioral manifestations of the care recipients. Employing behavioral techniques, such as going with the 'flow', instead of arguing or attempting to correct, were other methods workers successfully used when working with older adults with ADRD.

> The Saba (Hebrew word for grandfather), he already doesn't remember anything, every time, every night he asks: 'what day is it today, what day is coming tomorrow? What's now?' Every night like this. Every shabat (Hebrew word for Saturday) he wants to go to Beit kneset (Hebrew word for synagogue) very early in the morning and because he doesn't know the days he wakes up very early in the morning, so every night I tell him, 'tomorrow is Monday don't wake up early'.

Discussion

The present study is unique because it evaluates beliefs and practices related to ADRD in foreign home care workers, a group that has largely been neglected in gerontological research. Despite the increase use of foreign home care worldwide, this group of foreign home care workers has received only minimal research attention. Given the increasingly important role foreign home care workers play in the care of older adults worldwide and the fact that the majority of these care recipients present with ADRD and cognitive impairments, it is particularly important to evaluate foreign home care workers' beliefs and practices.

Similarly to past research, Filipino home care workers reported both stigmatizing and normalizing views of ADRD (Ladson & Levkoff, 1999; Ayalon & Areán, 2004). For example, whereas over 30% of the sample reported that agitated individuals who annoy their care givers do so on purpose, more than 50% stated that it was normal to have ADRD as you get older. Based on interview data, it is apparent that many Filipino home care workers have had very limited prior experience with older adults and/or with ADRD both because of lower life expectancy in the Philippines and because of lack of prior caregiving experience. Hence, it is not surprising that workers employ both stigmatizing and normalizing views when adjusting to their first encounters with older adults with ADRD and with the Israeli society at large. Furthermore, the fact that care recipients come from a very different culture could potentially explain these stigmatizing views, whereas the fact that almost all Filipinos in Israel work as home care workers and provide care to impaired older adults could explain the normalization of ADRD among Filipino home care workers in Israel.

One of the most notable finding was that many Filipino home care workers reported effectively using behavioral techniques intuitively when working with older adults with ADRD. These techniques stand in accordance with restraint-free environment approach that is currently supported by research (Ayalon, Gum, Feliciano, & Areán, 2006; Strumpf, Robinson, Wagner, & Evans, 1998). This approach views physical and chemical restraint as unethical and often ineffective, resulting in drug-to-drug interactions, side effects and an increased risk of falls (Gatz, 2000; Levine, Marchello, & Totolos, 1995). The restraint-free-environment approach argues that many problem behaviors of older adults are due to lack of social stimulation and, therefore, further contact with the agitated individual is prescribed. Whereas an increase in social and emotional contact in response to problem behaviors was reported in qualitative interviews, consistently with past survey research on paraprofessional workers (Ayalon et al., 2008), 56% of the sample thought that agitated older adults do not like to be talked to and more than 50% of the sample believed that sedatives are the only effective treatment for agitation. This demonstrates a distinction between intuitive clinical practice reported in qualitative interviews and attitudes and beliefs reported in the survey. Interventions geared towards Filipino home care workers should encourage and support their intuitive reasoning about caregiving to older adults with ADRD.

Overall, 60% of the sample believed that it is better not to involve family members when the older adult is agitated. This stands in clear contrast to the restraint-free-environment approach that views the family as a major source of information about the older adult. Similarly, 86% of the sample believed that older adults with ADRD need constant supervision. In the context of home care, however, where workers are expected to provide around-the-clock care to the most impaired older adults, these beliefs are reasonable. Furthermore, past research has shown that family members of older adults tend to leave personal, emotional and social care in the hands of care recipients and view their own role as mainly managerial (Ayalon, under review).

The only significant predictor of beliefs about ADRD was whether or not the Filipino home care worker was informed about the condition of the care recipient. This finding underscores the importance of sharing medical information about the care recipient with the home care worker. This is particularly important in the case of around-the-clock home care workers who literally provide all personal care and often social and emotional care as well. In addition, informing the home care worker about additional details related to the care recipient, such as care

recipient's likes and dislikes or personal history may also be of utmost importance (Ayalon et al., 2008).

The present study does is not without limitations. First, this is a convenience sample and no data on refusal rate is available. However, because about 50% of the foreign home care workers in Israel are undocumented, it is impossible to obtain a representative sample of this population. Second, this is a cross-sectional study that does not allow for inferences about cause and effect. Third, whether or not workers provided care to a care recipient with ADRD was not evaluated in the survey phase. Hence, it is likely that a small portion of foreign home care workers never worked with older adults with ADRD. Fourth, further research comparing the views of Filipino home care workers about ADRD and agitation to the majority view in Israel could provide a more refined context to evaluate the findings. In addition, future research will benefit from including the voices of care recipients and their experiences regarding foreign home care. Finally, although many foreign workers work as nurses or provide care in institutions worldwide (Aiken, 2007), the Israeli government limits their employment to the home care industry and as a result, this paper is focused only on foreign home care workers.

Nonetheless, this study is important for several reasons. First, this study sheds light on a phenomenon that is expected to increase in future years. Second, this is the first study to evaluate beliefs of foreign home care workers about ADRD, conditions that are highly prevalent among home care recipients. Using both quantitative and qualitative methodologies, the study is better equipped to identify and explain contradictions between workers' beliefs and actual practice. Results suggest that specific emphasis has to be placed on encouraging workers' intuitive approach to ADRD and providing workers with ample information about the medical conditions and needs of the care recipient.

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There is no conflict of interest to declare.

Note

1. Foreign home care is a direct translation from Hebrew. This term is used because it conveys information about the status of these workers in Israel.

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