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Research Article

The Experience of Paid Family-Care Workers of People with Dementia in South Korea



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ABSTRACT

Purpose: The South Korean government introduced the universal long-term care insurance program in 2008 that created a new employment category of "paid family-care worker" to assist the elderly with chronic illnesses including dementia. The aim of this study was to understand the lived experience of paid family-care workers of people with dementia in South Korea.

Methods: The study was a qualitative research design underpinned by interpretive description principles involving eight paid family-care workers. The participants were recruited by attaching the advertisement flyer in a notice board of an educational facility for paid family-care workers.

Results: Paid family-care workers struggled to manage the behavioral and psychological symptoms of their care recipients. Their workloads created physical, emotional, social, and financial burdens. However, the care-giving activities were encouraged through their sense of responsibility, filial piety, and personal religious beliefs. Financial subsidies from the government and help received from others were also identified as encouragements. The education course provided to them assisted them to improve their dementia-care capabilities.

Conclusion: Understanding paid family-care workers' lived experience in dementia care in South Korea assists with the identification of their educational needs and level of support they require to improve dementia care in the home care environment. A number of suggestions are made to increase paid family-care workers' knowledge, clinical skills, and job satisfaction to reduce their burdens and work-related incidents, such as challenging behaviors from those being cared for.

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Introduction

South Korea has a rapidly increasing aging population. The proportion of people aged 65 years or above has increased from 2.9% in 1960 to 7.3% in 2000 and is expected to reach 14% by 2018 [1]. At the same time, the population of people with dementia is also on the increase, with 9% of the elderly population being diagnosed with the disease in 2012, and the number of people living with dementia is estimated to increase to more than 2 million by 2041 [2]. Unlike Western developed countries that have had a well-developed long-term care (LTC) to respond to significant demographic and social changes related to an aging population in the 20th century [3], LTC in Asian countries, including South Korea, is still in its infant stage and needs to be advanced [4]. In recent years, South Korea is making fast progress toward an LTC system that is

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responsive to the cultural values for home-based care for older people [5]. Government subsidizing family-care workers to enable older people living at home and being cared for by family members is one of the examples of culturally responsive LTC policy. However, since the implementation of this initiative in 2008, little is known about this specific group of workforce in the LTC, particularly those who care for people with dementia, a most challenging area in the LTC. Studies on this group of workforce are much needed to inform evidence-based dementia-care policy and practice.

Traditionally, families play a key role in elderly care in South Korea because culturally sensitive strategy is a factor in the decision to place a family member(s) with dementia in a facility or not [6]. South Koreans have a strong tendency to support parents with dementia to live in the home setting [6] as the harmony of the family is paramount in the country. Therefore, it is expected that adult children become their parents' guardians in South Korea [6]. With regard to cultural background, informal family carers have been common in South Korea. When the long-term care insurance (LTCI) commenced in 2008, an assessment tool with 52 questions was developed to measure what help older people with chronic

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illness(es) require. Older people who reach at least 55 of 100 points are eligible to receive the benefits of the LTCI [5] (see Table 1). With this assessment approach, older people with mild dementia would not become a home-care recipient as the physical functioning of this group was assessed as "independent". On the recognition that behaviors and psychological symptoms of dementia (BPSD) are significantly associated with higher levels of care-giving burden, the South Korean government decided to provide persons with dementia with bonus scores from May 2011 [7].

The LTCI scheme in South Korea is strictly limited to cash benefits for the elderly with chronic illness(es) by law [5]. It can only be offered in exceptional cases, such as when people live in rural areas or remote islands which do not have any service infrastructure [8]. Therefore, most LTCI users need to choose between using the residential care or the home-care service [9]. As mentioned earlier, elderly in South Korea prefer to live in their own homes rather than being placed in a care facility due to the cultural sensibility. Therefore, there will be an increased need for family carers to take on the primary care responsibilities.

Under this policy, a family member may be a "paid family-care worker" if they satisfy the following conditions [5]:

- Being a spouse, brother or sister, son or daughter, son-in-law or daughter-in-law, brother-in-law or sister-in-law, or a stepson or stepdaughter of the person affected;
- (2) In possession of a personal care worker license obtained through 240 hours of training and achieving satisfactory results in a national qualification examination; and
- (3) Not working full-time elsewhere.

There was a lack of infrastructure to support family carers when the government introduced the LTCI in South Korea [4]. Japan brought in LTCI when they had built infrastructure at each local level, whereas the government of South Korea commenced the LTCI without setting up infrastructure [4,10]. Therefore, the government had to institute infrastructure and the LTCI at the same time in South Korea. Because the LTCI scheme required a number of care workers immediately, the training period had to be kept short [4]. The required 240-hour training for a care worker is viewed as insufficient and too short to learn to become a formal carer in the placement [5]. It is reported that care workers in Japan have to undergo training of more than 1,800 hours to receive their certificate [10]. In comparison, the short training period may give the impression that care work for elderly in South Korea might be unprofessional and of a low quality [4]. In addition to a short

training period, there is a traditional thought that women have the capacity to provide home care as they are naturally suited to care work through their mothering experiences and their innate knowledge and skills associated with being a female [11]. This cultural belief may influence the government in establishing a comprehensive education program for care workers.

Care workers, especially those who work at home such as paid family-care workers in dementia care, may encounter different challenges and have specific needs for support to sustain their role in the LTC. There have been a number of studies about paid and unpaid care workers of people with dementia [6,7,12–15]. However, research on people working under the LTCI scheme in South Korea, specifically paid family-care workers, is scarce.

Methods

Research design

Interpretive description described by Thorne [16] was used as a methodology to address the aim of the study. The philosophical framework of interpretive description assumes that absolute and wholly objective knowledge is unattainable through empirical analysis. Basically, the researcher and the participants together construct understanding [17]. Therefore, the inquiry and the object of inquiry interact to influence one another and are inseparable [16]. Another purpose of interpretive description aims to capture themes and patterns within subjective perceptions and to generate research evidence to inform practice [16].

In this study, Interpretive Description guided the development of a coherent logic and structure that enabled or inhibited dementia care giving and for illustrating changes needed to improve services and support in ways that are realistic and practical [17]. In addition, Interpretive Description allowed researchers to work with participants to share their social worlds and construct their care-giving experience [17].

Setting and sample

Paid family-care workers who had been caring for a relative with dementia for at least one month were recruited to the study. To meet the selection criteria, family-care workers were required to have had formal education that included clinical placements and who were in possession of the care worker's license. They were also required to have been caring for a relative with dementia at home for at least one month. The advertisement flyer was attached to a

Table 1 Assessment Questionnaire.

Domain (Number of questions)	Item	Response option
Activities of daily living (12)	Dressing, washing face, brushing teeth, bathing, eating, turning in bed, sitting up in bed, transferring from bed to chair, moving out of room, toileting, bowel control, and bladder control	Independent Partially dependent Fully dependent
Cognitive function (7)	Short-term memory, remembering dates, places, and date of birth, understanding instructions, judgment, and communication	Yes/No
Problem behaviors (14)	Feeling persecuted, visual or auditory hallucination, depressed mood, reversal of day and night, resisting advice or care, restlessness, being lost, verbal or physical violence, trying to go out alone, destroying items, meaningless behavior, hiding money or items, dressing inappropriately, and unsanitary behavior	Yes/No
Nursing care needs (9)	Tracheostomy care, suction, oxygen therapy, sore care, tube feeding, pain control, urine catheter care, colostomy care, dialysis care	Yes/No
Rehabilitation needs (10)	Motor disturbance in the right arm, left arm, right leg, left leg and limitation of movement in joints in the shoulder, elbow, wrist, hip, knee, and ankle	Not disabled Partially disabled Disabled No limitation Limitation of one joint Limitation of both joints

notice board of an educational facility that provided ongoing training for experienced care workers. The potential participants showed their willingness to participate by contacting the researcher and were allowed to choose the place and time for the interview. All eight participants preferred their own place, and the interview with each participant occurred only once taking up to one hour.

Ethical considerations

The Social and Behavioral Research Ethics Committee of Flinders University approved the study (Approval no. 6468). Written permission for distributing a flyer was given by the educational facility. Participants were recruited by distributing invitations through the education center, and the respondents who gave informed consent participated in a face-to-face audio-taped interview. The participants were given a participant information sheet and a list of semi-structured questions for the interview, and they signed an informed consent before the interview. Any information from the participants was treated in the strictest confidence, and the participants are not individually identifiable in the resultant thesis with the use of pseudonyms to maintain anonymity.

Data collection

Objective

Semi-structured questions based on a literature review guided the interviews to gather information from the participants. This interview schedule asked for demographic information and a number of open-ended questions under the objectives of the study. The open-ended questions were focused on paid family-care workers' motivations, barriers, and the factors supporting them to promote their care-giving activities (see Table 2). Further probing questions were asked to elicit more information from participants.

One-to-one interviews with eight paid family-care workers who cared for a person with dementia were demonstrated to collect the data. Each interview lasted up to 60 minutes which included the questions about demographic information of the person with dementia and their paid family-care workers. All the interviews were

Interview questions

What do you do when this happens?

 $\textbf{Table 2} \ \ \textit{Objectives and Open Ended Interview Questions}.$

Objective 1 What do you know about dementia? What are the motives of family Where did you get the information members to become paid about being a paid family-care family-care workers worker? for people with dementia? Why did you become a paid family-care worker? Objective 2 What helps you caring for people What are the factors supporting paid with dementia? family-care workers that are What support can improve your enabling of your caring? caring activities? Can you describe the support you get from your family or friends if any? Objective 3 What problems do the What are barriers affecting their dementia-impaired people have caring role? that affect your caring? What kinds of care activities are typically required? Can you tell me about their self-ability for activities of daily living such as their nutrition, mobilizing, socializing, communication and hygiene? Are there any behavior problems and can you describe the problems you have associated with this?

audio recorded, and the audio-taped data were translated and transcribed verbatim for analysis.

Data analysis

The data analysis process in this study was conducted following Clarke and Braun's guidelines [18] as outlined in six steps: (1) becoming familiar with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing the themes; (5) defining and naming the themes, and (6) producing the report. The eight interviews were transcribed and read several times as a whole to become familiar with all the data. This proceeded to creating initial codes depending on each classification. Coding clusters were then determined to develop the emerging themes, and these were reviewed a number of times leading to saturation. After this procedure, the themes were defined, described, interpreted, and examples given.

Four criteria of trustworthiness were applied to improve the qualitative strand, namely: credibility, transferability, dependability, and confirmability. These are fundamental to the development of standards that are used to evaluate qualitative inquiry [19]. To ensure credibility, all the interviews were recorded, and the audio-taped data were transcribed verbatim. As well, quotes were used as examples that were the participants' own words. Transferability refers to the generalizability of the inquiry [20]. As caring for a person with dementia is a common role of the family, these findings may be transferrable to other paid care workers in the South Korean context. Dependability describes the researcher's responsibility to ensure that every part of the research is transparent and methodical [20], as well as logical, traceable, and clearly documented [21]. All the procedures for the data collection and interpretation were well documented to enhance dependability. Confirmability is concerned with establishing that the interpretations of the data and the research findings are derived from the data, rather than from the researcher's perspective [20]. In this study, the collected interview data were accurately transcribed, translated into English, and interpreted by the researchers. In addition, the audiotapes, transcripts, and the analyzed data were securely stored to confirm any procedures undertaken.

Results

One male and seven female paid family-care workers were recruited for this study. The participants comprised three daughters, three daughters-in-laws, one wife, and one husband of the persons with dementia. The age ranges were varies from 46 to 73, and the longest and the shortest working experiences as a paid family-care worker was 60 months and a month, respectively. They were usually working 5 hours to 12 hours a day. The demographic information of the paid family-care workers is summarized in Table 3.

Four major themes emerged following the six-step thematic analysis described previously and relate to the paid family-care workers' experiences.

- · Managing BPSD of dementia
- Other hindrances
- Encouragements
- Education

As detailed below, analysis of the interviews' data demonstrated how paid family-care workers managed dementia behaviors, any care-giving hindrances, and encouragements which affected the quality of their care-giving activities and paid family-care workers' understanding of dementia and their educational training.

Table 3 Demographic Data of the Participants.

	No	Pseudonyms	Gender	Age (yr)	Relationship with the person with dementia	Work experience as a PCW (mo)	Work (hr/day)
Ī	1	Eunmi	F	58	Daughter	60	5
	2	Chulsu	M	73	Husband	1	14
	3	Mijin	F	62	Daughter-in-law	8	10
	4	Jinah	F	57	Wife	9	12
	5	Namhee	F	46	Daughter	4	8.5
	6	Misun	F	56	Daughter	12	8
	7	Sojung	F	48	Daughter-in-law	24	8
	8	Gyungran	F	55	Daughter-in-law	4	7

PCW = personal care worker.

Managing BPSD of dementia

Problem behaviors, such as aggression, were identified as a major concern contributing to care-giving burden. The participants in the present study also stated that dealing with the symptoms of the care recipients' cognitive impairment was a significant issue.

In addition, managing care recipients' problem behaviors and helping with activities of daily living (ADL) were frequently mentioned as sources of objective burden by participants. All participants had a limited understanding of dementia as one of the paid family-care workers stated "... My dad is asking the same questions again and again. Even though I am his daughter, repeating the same answers every day makes me upset and tired. Sometimes, I even want to escape from this situation" (Eunmi).

This example showed that the participant reacted to BPSD with emotion, rather than workable solutions due to lack of knowledge of causes and triggers of repeating behavior.

When paid family-care workers had a lack of understanding of the disease, it may have triggered more problematic behavior or delayed the appropriate treatment, as a participant stated "She does not directly ask me to bring the money back, but just swears at me. (When she does that), I swear back to her" (Sojung).

Other paid family-care workers stated their thoughts and simple solutions when they interacted with the person with dementia in the following excerpts: "When I sing a hymn, she (my mom) seems to be back in normal ... Only the God can cure her disease" (Namhee).

"She worries about one of her kids whose business failed. However, this happened many years ago, and she still worries a lot. In fact, she is very old, and there is nothing she can do about it, but she did not even sleep properly and talks to me without making sense. I think this shows how great the parent's love is" (Misun).

The findings demonstrated that paid family-care workers generally thought about BPSD experiencing high levels of stress. The way they responded to BPSD may also deteriorate the BPSD. None of participants were able to describe that they had strategies to prevent BPSD.

Other hindrances

Physical, financial, emotional, and social hindrances were identified throughout the interviews. One of the paid family-care workers demonstrated how she obtained physical illness as she stated "I have physical illnesses. Especially, I have very bad finger joints because I am working too hard to look after people with dementia. I think when I showered them, I hurt myself. As I do work for other people with dementia as well as my dad, all my joints are not good. Also, I often lift them up by using my body so my elbows are very sore" (Eunmi).

Paid family-care workers stated that their care recipients have high-care demands although they were permitted to receive home care by law. Back problems were the most common ailments reported, as well as sore fingers, elbows, shoulders, and knees. These locations of the pain supported that the paid family-care workers may not have enough manual handling training.

In terms of their payment, paid family-care workers get paid for 60–90 minutes a day, but the participants stated that they work more hours than paid hours, and the income is too low for it to be their main job. The participants stated in following excerpts: "I have 90 minutes a day to get paid, and it is absolutely not enough for living" (Chulsu).

"In fact, I spend a large amount of time with my dad, and I do so much care for him. ... I believe that I should receive the money for every single hour I spend with my dad. If I work somewhere else rather than my dad, I would make better money for sure. Even if I may need someone to look after my dad, I still save better money. That is why I am saying the government treats me unfairly" (Eunmi).

"As my dad is not able to swallow solid food, I always need to prepare porridge with potato, mushroom, etc. All the fresh ingredients are so much expensive. I sometimes only give him soft cake with yogurt. I think it has enough nutrients. There is nothing much I can do about. All my income goes to his food anyway" (Eunmi).

Aforementioned examples showed that low income may decrease the workers' motivation to work and would affect the quality of the care as paid family-care workers found difficulties to provide sufficient necessities. According to one of the above excerpts, in addition, it is curious that whether home care recipients get enough nutrition or not. The diet plan was made by the paid family-care worker alone, and it can cause malnutrition in the care recipients. Moreover, some paid family-care workers were unable to supply essential equipment for the decent care giving or care recipients' favorite activities, as a paid family care worker stated "My mom loves going to her hairdresser. Taking her to the hairdresser is the only thing that can make her sing. If I had enough money, I would be able to afford it more often" (Gyungran).

"As you can see by my dad's place, he only has this one room. So, when it is winter, I cannot even get him to reach the tap water because he has to be outside of his place and it will be too cold for him. I can only give him a sponge with hot water" (Eunmi).

Paid family-care workers' financial ability may relate to the quality of care for the care recipients and the care workers' workload. Some paid family-care workers may require physical help or equipment to care for persons with severe dementia or comorbidities. Paid family-care workers stated in following excerpts "A volunteer comes to help me with showering my wife; however, the frequency is not enough as she requires a shower every day" (Chulsu).

"She (my mom) is not able to walk or stand up by herself after the stroke. She needs suppositories every second day and I prefer to give her wash or shower after her bowel movement. I have to use my whole body to stand her up and drag her to the bath room" (Namhee).

Because the government of South Korea permitted people with severe illness(es) to access home care, extra physical help such as volunteers or other family members may be necessary for some paid family-care workers. They also expressed significant emotional distress, as one participant stated:

"Sometimes, I experience emotional difficulties as I am living with my mom at the same place. I mean, the status of emotions cannot be the same every day. As a human, care-giving activities are not joyful work. Sometimes, I feel angry. Hence, sometimes I expose these feelings (to my mother)" (Misun).

Paid family-care workers, especially those living with their care recipients in the same household, stated they had a lack of personal

space, and this created emotional distress as it was an all day work, and they could not have a break. Consequently, the paid family-care workers may be socially isolated as a participant described:

"... I cannot get involved in any social activities. I cannot attend social meetings. Especially, traveling is impossible for me, as I have to go to my dad's place every day. As I am human, I feel angry about it sometimes" (Eunmi).

"I am with my wife for 24 hours a day as she does not know where she is going and what she is doing. As my friends do not like to have my wife at their place, I have given up going out. I cannot leave my wife alone even a second" (Chulsu).

Those excerpts showed that paid family-care workers were emotional with their situation. When paid family-care workers strongly committed to work, the situation may have created a conflict between the care workers and the care recipients.

The results clearly indicated that paid family-care workers suffered from various burdens, including physical, financial, emotional, and social aspects. Especially, paid family-care workers experienced additional burden when the place to provide care was not fully equipped or the care recipients require more than one person's assistance. The relationship between emotional difficulties, financial hardship, social isolation, and physical burden affected care-giving activities according to the participants.

Encouragements

Despite the aforementioned burdens, the paid family-care workers still maintained their work and care-giving activities. The participants received support from the South Korean government, relatives, and neighbors. The types of encouragement were varied, including financial assistance, physical help, and emotional support.

The payment was one of the financial encouragements often mentioned by paid family-care workers. As mentioned Other hindrances although the participants were all dissatisfied with the little amount of payment from the government, they still appreciated the fact that they were at least paid, as a paid family-care worker stated "It is good to receive money for looking after my parents" (Misun).

Although caring for relatives with dementia was the participants' formal job, they still required personal leave. Paid family-care workers appreciated being relieved from their duty by someone, and this was one of the most common types of encouragements as reported by all participants. Two participants stated that

" ... My neighbors are so good, especially, the lady who lives next door. I could not keep doing this job, if I did not have her. She does drop into my place to talk to my mom (with dementia), when I am busy with doing something else" (Gyungran).

"I can call my sister to come over my place. So, she can look after my mom when I have important appointments. I am so glad that I have sisters to help me. But I come back home as soon as possible, as I am the one who get paid for the job" (Misun).

Such help not only encouraged the paid family-care workers but also may have assisted them to continue doing the job.

Some statements showed that they were not only working for the money but also caring because of filial piety duty or love, as described in the following: "I am looking after her because she is my mom" (Misun).

"Parents have fed their children from even their mouths, so it is the children's turn to pay back" (Eunmi).

"I know if I work in some other places as a personal care worker, I can make better money, but I still want to look after my mother-in-law" (Mijin).

In some cases, the care workers' personal religion also motivated them to care and work for their loved one, as a paid family-

care worker stated: "If I think that she (my mom) can go to heaven (with my efforts of praying), there is no stress at all" (Namhee).

The findings demonstrated that paid family-care workers were pleased to receive the payment from the government. In addition, their care-giving activities also would be prompted by filial piety and personal religious beliefs.

Education

According to the law, care workers need to complete training and achieve satisfactory results in the national qualification examination. During the interviews for this study, paid family-care workers generally had positive thought about the training program, as a participant stated: "The education helped me a lot. It made me be able to see my husband as a patient" (Jinah).

Although the participants were appreciated with the education given to them, the entire course may not be adequate. A participant mentioned that "What I usually did during my clinical placement in a hospital is cleaning the windows. That was what the nurses asked me to do it" (Gyungran).

The statement showed that paid family-care workers were dissatisfied with clinical placement as there is lack of chances to learn. In addition, clinical placement was the first experience for most participants seeing how residential aged care facilities work for people with dementia. The experience can be a negative aspect of residential care, as a participant stated

"As I went through the clinical placement, I know what is going on there. Because of the number of patients in a facility is huge, staff cannot be good (friendly) to everyone. I am sure that staff members in a facility would not accept my mother-in-law's personal character. She is especially very fussy about food, so I always prefer to cook what she wants to eat. I reckon she won't be able to survive in a facility at all" (Mijin).

The major findings were summarized under four categories. First, paid family-care workers struggled with the BPSD of the persons with dementia due to their lack of understanding of dementia. Second, paid family-care workers experienced a higher level of physical, emotional, financial, and social burden. This finding reflected their insufficient payment, the severity of the care recipients' illness, and inadequate environment for care giving. Third, paid family-care workers were motivated to work better because of the fact that they receive payment and for filial piety and religion. Last, the education to become a paid family-care worker increased their understanding of dementia. However, low quality of clinical placement was identified.

Discussion

Behavioral and psychological symptoms of dementia include verbal and physical aggression, agitation, psychotic symptoms (e.g., hallucinations and delusions), sleep disturbances, depression, oppositional behaviors, and wandering [22]. Paid family-care workers in this study mentioned that their care recipients had more than one of the aforementioned symptoms. It is strongly suggested in the literature that carers' direct, clear, and nonthreatening language is the most appropriate and effective way to approach people with dementia and to prevent BPSD [23]. Paid family-care workers need to be equipped with knowledge and skills through education and training to manage BPSD [23]. Poor behavior management skills such as using swearing words to the care recipient were identified in the study and were related to subjective burden. The finding supported previous studies that lack of understanding of dementia among care workers was associated with higher levels of distress and caregiver burden [23].

Findings confirmed the previous study that care workers' physical and mental health would be deteriorated when they experienced high levels of caregiver burden [12]. The previous study stated that the effects of physical exertion lead to muscle strain, skeletal injuries, aggravation of chronic illnesses such as arthritis, and other sources of physical discomfort and pain [12]. Paid family-care workers expressed being mentally distressed, and this can lead to depressive symptoms caused by their care recipients' problem behaviors [12]. Hence, the concept of "person-centered care" was introduced to prevent behaviors from occurring in the first place and to manage BPSD effectively [24]. "Person-centeredness" is an acknowledgment that the individual is a person who can experience life and relationship, despite having a progressive disease [24]. In fact, the paid family-care workers in the study were partly demonstrating person-centered care by giving care recipients chances to choose what they desire to eat or offering care recipients' preferred activities [25]. However, there lacked understanding of the whole concept of person-centered care. Therefore, sufficient education sessions are required to develop paid family-care workers' understanding about person-centered care.

Some factors contributed to the high level of burden in paid family-care workers in this study. First, home care may be not suitable for some people with dementia. In fact, some care recipients in this study may require more than one care worker to assist due to a high level of dependence. As the government of South Korea permits moderate to very severe stages of elderly with chronic illness(es) to use home care [9], paid family-care workers' physical workload can be heavy. Second, paid family-care workers had not been given appropriate care plans in terms of their care recipients' food and fluid tolerance, mobility, and ADL dependence. Especially, assessing the ADL dependence of persons with dementia is important to ensure both care workers' and care recipients' safety [26]. Therefore, nonexistent care plans would increase paid familycare workers' physical burden. Third, paid family-care workers had not been taught about manual handing skills. Because some care recipients have poor mobility due to their severe stage of dementia or comorbidity, this inappropriate manual handling was a risk for the paid family-care worker and the person with dementia.

Paid family-care workers in the study were also enduring financial difficulties. Financial burden for family-care workers is a quite common phenomenon [27]. However, paid family-care workers in South Korea are prohibited to have other full-time work by law [5]. Therefore, the financial aid they were currently receiving may need to be adjusted.

In addition, paid family-care workers were often isolated from their social activities due to lack of time to be alone. The main reason was the demand for vigilance and the constant care required without respite. This is a quite common issue in South Korea as there are only limited numbers of aged care facilities with respite available [28].

Paid family-care workers had their own strong reasons to take care of their family member with dementia, and these reasons helped them to be motivated to work. Some paid family-care workers who had positive relationship with their care recipients had less complaint about this burden. The literature supports that distant relationships can be a cause for paid family-care workers' psychological distress [13]. Therefore, the quality of the previous relationship may increase or decrease paid family-care workers' burden. Filial piety was another coping skill for paid family-care workers. The obligation of filial piety was accompanied by reciprocity, so that adult children's care giving was a form of repayment [14]. Furthermore, adult children's truthful filial piety develops a strong resilience, and people with high filial responsibility have a lower care-giving burden [15]. Hence, the strength of each person's filial piety acted as a coping mechanism for adult children care workers to reduce their care-giving burden.

The low quality of the educational program for paid family-care workers was identified. In the course, the clinical placement is a compulsory aspect of becoming a paid family-care worker. It has been reported that staff members in residential aged care facilities lacked the necessary knowledge and skills to provide appropriate care for the frail elderly [29]. This would be a reason for the paid family-care workers showing their disappointment with their experience of the clinical placement. In addition, undergraduate nursing students often reported that clinical placements in aged care were unsatisfactory due to the staff members' lack of core nursing skills and the poor environment in these facilities [30]. The findings of this study are consistent with what the previous studies reported as paid family-care workers evaluated the quality of the care in the facility in which they had worked for their clinical placement as being unsatisfactory and this, in turn, made them doubt whether the facility could provide quality care for their family member with dementia. Furthermore, this could be one of the main reasons why people in South Korea prefer to have their family members with dementia living at home. Furthermore, a lack of theory provided on person-centered care and how to interact with a person with dementia was evident in some of the interviews. The factors aforementioned suggest that it is unrealistic to expect the sustainability of paid family-care workers' role without adequate preparation, training, education, regulation, and support.

Limitations of the study

Several limitations have been identified in this study. First, because only eight participants were recruited for the study, it may be difficult to generalize. However, the study explored the experiences of paid family-care workers by using a qualitative method which allowed for a small number of participants, and the findings may be transferable to other care workers. Second, the research sample failed to have gender variety. There is only one male paid family-care worker recruited, whereas seven female paid familycare workers took part. Therefore, the study was not able to compare the experiences between both gender groups. Third, the researcher acknowledged that some of the participants had only a short experience of working under the LTCI. Finally, the participants were recruited through a single educational institution. As a result, all the participants received similar training and were from a single city in South Korea. Paid family-care workers living in other cities may have different experiences.

Interpretive description in this study produced practice-relevant findings revealing how the home care system works as part of the LTCI scheme in South Korea through the voices of paid familycare workers themselves. In summary, greater efforts need to be made by education providers and the South Korean government for additional support for paid family-care workers caring for someone with dementia. The burdens identified included physical, financial. and emotional burdens that required further support. Providing education programs and care strategies, setting up adequate payment rates, and providing regular, clear, follow-up appraisal programs are strongly suggested to increase paid family-care workers' satisfaction and to prevent their own health from deterioration. Therefore, individual paid family-care workers, education institutions, health-care professionals, and the government need to work together to improve the LTCI scheme for persons with dementia and their paid family-care workers.

Conclusion

The findings of this study can be used to develop this workforce stream in the LTCI scheme system to improve quality of dementia care in community care settings. First, the education and training providers need to incorporate person-centered dementia care, how to interact with a person with dementia, and paid family-care workers' safety, including manual handling. Appropriate communication skills and person-centered interactions should also be taught in the educational program to prevent and manage behaviors. As noneffective communication was shown in the findings, family-care workers need to learn about the effects of positive and negative forms of communication and the skills to demonstrate effective ways of communicating with a person who has dementia. In addition, the study reported that many care workers were unsatisfied with their clinical placement experiences, and the education providers need to closely supervise whether the aged care facilities provided a positive educational environment.

Second, paid family-care workers require further education and understanding of dementia and also supported in reporting their care recipients' deterioration to health-care professionals. They should also be able to find support for any stress experienced and have an option of respite when needed.

Third, assessment should extend beyond the functional ability of a person with dementia also to his or her living environment that directly affects the quality of care that is to be provided. Effective communication and information sharing could be established between the users of the LTCI scheme and the policy department to ensure paid family-care workers' and care recipients' accessed information about the available government services and support. In addition, the payment of paid family-care workers needs to be reviewed to relieve them from their financial burden, which will in turn promote better quality care.

Finally, health-care professionals have a responsibility to supervise, educate, and support paid family-care workers and to advocate for changes to improve the long-term care system in South Korea. Setting up appropriate protocols and procedural guidelines and providing person-centered care plans are recommended.

A national survey of paid family-care workers' experiences in South Korea is suggested. As this study was conducted in a single city, a national survey would assist with generalizing the findings. In addition, the findings of this study included the positive and negative effects of the LTCI. As dementia is not only a chronic elderly disease, exploring the experiences of the LTCI users is recommended to understand the general advantages and disadvantages of the scheme.

Conflicts of interest

The authors declare there are no conflicts of interest.

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