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Experiences of non-family paid helpers providing palliative care to stroke patients: The toll of professional informal caregiving in a job lacking recognition

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Abstract

Background

Employing non-family paid helpers has become a prevalent practice across North America, Europe, and Asia, which families adopt to alleviate the stroke care burden, allowing family to take a break from their obligations and perform other social activities. However, paid helpers' experiences of providing palliative care to stroke patients is under-explored. This study aimed to explore the caregiving experiences of non-family paid helpers providing palliative care to stroke patients.

Method

A qualitative descriptive study was undertaken using semi-structured in-depth interviews. Thematic analysis was used for data analysis.

Results

Seventeen participants (mean age: 51.23 years) were included, predominantly being female (88%), and their caregiving experiences with patients ranged from four to 26 years. Participants shared that monetary compensation offset the exhaustion, familial and health sacrifices of palliative caregiving. They emphasized emotional self-management through accepting and coping or avoiding and distancing, and appreciated rewarding appraisals from stroke patients and family members. They also expressed a lack of recognition from the public, being invisible to the healthcare system/professionals, and insecurity in employment rights.

Conclusions

Findings support the need for governmental initiatives to subsidize families in employing helpers to provide palliative care. Helpers perceived monetary compensation and a reciprocal caregiving relationship as the primary motives for providing care. Public recognition of this role as a helper in caregiving, contractual employment rights, and being recognized by the healthcare system and healthcare professionals are considerations in promoting quality care and alleviating a health care burden. The findings may contribute to further understanding of the experiences of non-family paid helpers in a job lacking recognition when delivering palliative care in a hospital for stroke patients. Evidence-based interventions that enhance reciprocity and recognition should be considered as part of the global initiatives to support paid helpers in palliative care.

Keywords: Caregiving, experiences, employed, stroke, monetary compensation

Introduction

Stroke is the interruption of blood perfusion to the brain, which causes brain tissue damage and related function abnormality or even death.[2,3] Stroke is one of the leading causes of long-term disability as survivors above 65 years of age often experience severe consequences; about two-thirds of survivors had hemiparesis, and more than half had impaired mobility and dependence in activities of daily living.[4,5] The World Health Organization (WHO) has reported that about 15 million cases of stroke occur annually, with one-third of victims being left permanently disabled, making informal caregivers the backbone of caregiving support.[6]

The devastating effects of the illness may make family members, the primary source of support, unable to meet the extensive hands-on needs of their patients and consequently pay for caregivers.[7,8] Along with patients' deteriorating function, family size shrinking, and family members continuing to engage in the workforce, reliance on non-family paid helpers has increased across North America, Europe, and Asia.[9,10] Employed non-family paid helpers are defined as people (i.e., domestic helper, hospital-based helper) who are employed by patients/relatives for contracted caregiving.[11] Employing non-family paid helpers has become a prevalent practice that families adopt to alleviate the caregiving burden, allowing them to perform other social roles (i.e., employment) and partially fulfill family obligations.[12] Although hiring helpers has its costs, family members reported a reduced financial burden for them to remain employed.[9] Thus, government officials have increasingly recognized non-family paid helpers. For example, in Europe, the United Kingdom has defined caregivers as both under a contract or voluntary work[13] and implemented schemes to support hiring helpers, such as providing an Attendance Allowance.[14] Likewise in Asia, the Singapore government implemented Foreign Domestic Worker Levy Relief [15] to subsidize hiring non-family paid helpers. In the United States, the Standard Occupational Classification system considered non-family paid helpers responsible for daily personal care (e.g., bathing and toileting), housekeeping (e.g., laundry), grocery shopping, preparing meals, arranging transportation to visit doctors, giving medicine, and enhancing social networks.[16]

Meanwhile, the challenges and mental distress of paid helpers were increasingly being recognized. They are the conduit between patients and the healthcare system such that the well-being of the non-family paid helpers determines the health condition and disease trajectory of patients.[11,17] Non-family paid helpers are monitored and supervised by healthcare professionals or family members in providing bedside personal care.[19] However, these helpers are poorly appreciated at an institutional and societal level, as most of them were previously laid-off workers or rural-urban migrant workers having a poor education background and are currently assuming personal care duty with minimal professional knowledge and skill.[21] One cross-sectional study investigated the mental well-being of non-family paid helpers who provided care in the hospital in Mainland China and observed a significant caregiving burden from multiple aspects (i.e., physical and emotional care), with 25.9% of helpers showing signs of depression.[11] They were also reported to experience significant psychological disorders and work pressure caused by sleep disturbances, unstable income, and a lack of social respect and support.[11]

However, no empirical study explored perspectives of paid helpers for palliative stage stroke patients whose caregiving task can be fluctuating and demanding subject to the severity of brain damage.[8] For most palliative stage stroke cases, helpers are expected to provide 24-hour day bedside care, including daily personal care (e.g., bathing, cleaning urine/excrement, feeding, and making the bed), facilitating communication, and offering patients emotional support.[11,20] Like other paid caregivers, they could also experience significant psychological disorders and work pressure related sleep disturbances, unstable income, and a lack of social respect and support.[11]

This is in concordance with the well-documented caregiving burden and efforts to reduce such burdens,[24] while research on understanding the lived experience and positive aspects remains unexplored. Considering the responsibilities that non-family paid helpers are being given, this study aimed to explore and describe the caregiving experiences of non-family paid helpers caring for palliative stage stroke patients.

Methods

Design

Qualitative description employing in-depth, semi-structured face-to-face interviews was undertaken to explore participants' constructed experiences of providing palliative care to stroke patients.[25] Qualitative description draws from the general tenets of naturalistic inquiry with the researcher staying close to the data to provide a rich, detailed description of an experience.[26] Considering that the current study sought to explore and describe caregiving experiences, qualitative description was considered a good fit. The study has been reported following the Consolidated Criteria for Reporting Qualitative Research guidelines.[27]

Setting and population

The study was conducted in a first-rank tertiary hospital in Guangdong, China. Non-family paid helpers from the geriatric unit of one major hospital who provided palliative care to patients following severe stroke were recruited. Helpers with past experience in caring for persons needing extensive assistance with activities of daily living, providing palliative care for stroke patients for more than one month, providing full-time care activities at the bedside (>40 hours per week), and being employed to provide care were recruited. Helpers should have provided care to stroke survivors with moderate to high levels of dependency (Barthel index ≤59), which is recommended as operational definition for palliative care of stroke patients.[28,29] To maximize variability, helpers with different socio-demographic characteristics (sex, age, caring duration, and past caregiving experiences) and taking care of patients with varying socio-demographic and clinical characteristics were recruited. Due to the lack of legislation or regulations for hiring of helpers, this study recruited non-family paid helpers based on actual employer-employee payment relationships (with or without a written contract).

Sampling, sample size and data collection

Participants were recruited using purposive sampling, allowing for choosing individuals who had rich caregiving experiences with stroke patients for an in-depth interview. Helpers (non-family, paid) were introduced to the study and provided an oral explanation of its purpose. They were given an information sheet describing the study, its purpose, the researchers, permission, and extent of participation, rights and method of contact. Helpers were, encouraged to ask questions and invited to participate. Written informed consent was obtained before data collection. A researcher-designed socio-demographic questionnaire was used to collect data regarding participants' age, sex, marital status, education, years of work as a helper and duration of care for current stroke patients.

After reviewing the patient's health records, the researcher obtained information on patient's age, sex, marital status, education level, and diagnosis was collected. The patient's level of activities of daily living was identified using the Barthel Index (reference needed here). This was completed by a geriatric nurse with extensive training and clinical experience.

Semi-structured individual in-depth interviews were conducted and audio-recorded using an interview guide with probes (Table 1). The guide was developed by the researchers based on previous clinical interactions with non-family paid helpers regarding how their family life was affected by their caregiving experiences. The researchers used both sociodemographic data and open-ended questions to explore their working background, working experiences, schedules, and the impact of caregiving on their personal life. All interviews were conducted in a private room on the unit where the helper was providing care, by the lead researcher, a doctorally prepared nurse with extensive experience working with stroke patients and caregivers and in using qualitative interview techniques. Each interview lasted 30 to 60 minutes scheduled during a patient's rest period to reduce interruption; and a nursing assistant was assigned to check on the patient every 15 minutes during the interview. Field notes and observations were made throughout the interview sessions. Transcripts were returned to participants for accuracy checks, with 15 confirming content, and two providing second brief interviews for clarifications. Sample size determination was guided by the data saturation principle and was attained with the fifteenth interview and confirmed with two additional interviews.[30] Thus, a total of 17 non-family paid helpers participated in the study.

Data analysis

Data were analyzed using thematic analysis. Audio recordings were transcribed verbatim into Simplified Chinese (Mandarin) and reviewed against the original audio recordings and field notes for accuracy. Transcripts were reviewed and translated into English by two researchers who are fluent in both languages. A third researcher who is also fluent in both languages facilitated a discussion if there was a disagreement between the initial translators. Two researchers read and re-read the transcripts independently and created codes for the same five transcripts and met jointly to discuss a common code book. They continued to code the transcripts independently and compared and contrasted the coding schema to identify new codes iteratively. Ultimately, a consensus-based codebook was generated through team discussion and consultation.[25] These codes were applied to two randomly selected transcripts. Iterative process and team consultation ensured consistency in the data analysis and enhanced a thorough understanding of the perspectives in each interview. Using the finalized codebook, transcripts were analyzed for patterns in NVIVO software (version 12.0). Codes with similar meanings or conceptually related were assembled to form subthemes. Using iterative inductive and deductive grouping of the subthemes, the main themes emerged.

Methodological rigor/ trustworthiness

Several strategies were used to ensure the trustworthiness of the findings congruent with Lincoln and Guba's framework.[31] Credibility was established through appropriate data curation, accompanied by ongoing quality checks before the coding began. Probes and prompts were also used throughout the interviews to obtain rich data regarding caregiving experiences. All researchers were involved in coding, and group discussions were employed to maximize the accuracy of data analysis. Dependability was achieved by using a piloted interview guide which enabled the interviewers to ask the same questions of all participants. Confirmability of findings was achieved by sending transcripts to the participants for validation before the coding began, which is in line with Guba's constructs.[32] Researchers used an audit trail to document the step-by-step process of the data analysis to allow reflective consideration of their personal biases and research procedures to enhance dependability and confirmability. This approach also enhances transferability as readers are able to ascertain which aspects of the study are applicable to their setting. In addition, recruiting non-family paid helpers having different socio-demographic backgrounds, caregiving experiences, and care for diversified care-dependencies supported the transferability of findings.

Results

Participants' characteristics

A total of 17 participants were recruited in the study. All were adults (mean age in years=51.2, SD=4.3), most were female (88%), and all were married. The majority had a secondary level education (n=12), while the rest had primary school education. The participants had been working as helpers for a mean of 12.8 years (SD=18.3), and the caregiving duration for the current palliative stage stroke patients ranged from one month to three years. Helpers cared for one patient for an entire day (24 hours standby). Patients were older adults (mean age in years=88.8, SD=3.7), the majority were male (64.47%), 57.8% were married, and 41.2% were widowed. The stroke patients needed assistance in all areas of activities of daily living; all were unable to speak due to their stroke or subsequent tracheal intubation (n=2), eleven had co-morbidities of heart disease, five with diabetes, and seven had dementia.

Themes and subthemes

The study findings generated four themes and nine subthemes describing the helpers' experiences of stroke palliative caregiving. These themes are broadly dichotomized into positive and negative experiences. Positive experiences motivated non-family paid helpers to remain in their arrangement due to dedication, and included monetary compensation for their work to offset their personal burdens in caregiving, emotional self-management, and rewarding appraisals of the caregiving relationship. In contrast, negative experiences focused on the lack of recognition by the public and the healthcare system and was reflected in caregivers' insecurity related to employment rights. A detailed description of the themes and subthemes are presented in Table 2.

Monetary compensation offsets caregiving burden

This theme describes the struggle between the extensive caregiving demands of the patients and the sacrifices of the helpers, including exhaustion and personal health issues. Helpers remained in their current employment situation by acknowledging that payment was compensation for their efforts to provide diligent care.

Monetary compensation offsets exhaustion in providing care

Participants unanimously shared the demanding nature of stroke palliative care in helping their clients participate in activities of daily living (i.e., personal hygiene, dressing, feeding, and toileting). They emphasized the exhaustion generated from frequent contact with bodily secretions, vigilant awareness of their personal health and safety concerns as well as those of their clients, emotional fatigue, and how monetary compensation stimulated their performance as a caregiver. They compared their current job to other occupations they could find and considered that the salary was appropriate to their efforts. A sense of obligation to provide patients with care and diligence was identical to any other occupation that requires commitment.

> *Today I have cleaned his poop three times, wiping and cleaning. The room smelled, and I felt too disgusted to eat. It's very exhausting. I have to tie him; otherwise, he would beat me, and the dirt would be everywhere……I thought about quitting, many times, but thought about the payment. I have to tell myself so. (P13)*
>
> *Always stay vigilant. Her face suddenly became pale when sitting up; her blood pressure dropped to 30 (mmHg). I have no choice but to earn a living. (P4)*
>
> *It's a difficult job, but it pays better than being a factory worker or a cleaning lady. (P11)*

Some participants expressed that the monetary compensation aroused empathy toward the family members of the stroke patients when considering the substantial financial expense of health care and hiring caregivers, along with the emotional distress.

> *It's OK. Her daughter pays for me and some medical expenses like albumin (infusion). The worrying and expenses burden for her is no less than mine. (P4)*

Monetary compensation reimburses for familial and health sacrifices

The non-family paid helpers consistently shared that a 24 hour/day position due to the severity of the patient's illness and a lack of additional caregivers, did not allow them to have a personal life. Some also described their family's sacrifices or personal health sacrifices they had made to meet palliative care demands, and they perceived monetary compensation as a reward to earn a salary for their family and generate self-value. They rendered this position as a helper as part of weathering the stress in life.

> *My family has been wrenched apart by this caregiver job (sob). For years, I have been caring for the patient every single day. My husband and children are elsewhere. My house is collapsing and no one is there. (P4)*
>
> *Several times when I transferred her, I almost fell. It causes me pain as I have kidney stones. But I stayed—day in and day out, year in and year out. I supported my kids' school and built a house in my hometown. Caregiving is stressful, so is life. (P1)*

Emotional self-management

The caregivers shared a variety of emotional self-management strategies they used when providing palliative care for patients with a severe medical condition or who manifested emotional problems. Emotional self-management is perceived as crucial for them to continue their role for the patient and for themselves. Two self-management approaches were identified as some participants shared they used an accepting and coping approach while others used an avoiding and distancing approach.

Accepting and coping

Accepting and coping with heavy caregiving duties and patients' emotional problems were the main strategies shared by the helpers, which enabled them to be more patient, sensitive to the needs of the patients, and resilient through the caregiving journey. They recalled emotional crisis of the patients in the past and mentioned how their conscience as a caregiver enabled them to patiently accept the patients' negative emotions and deliver care gradually, in a calm and caring manner.

They also described using comforting skills more frequently, such as calming down, thinking positively, and positive distractions based on their understanding of the patients.

> *There was one time, I was giving her massage for skin care; she accused me of beating her. I said 'yes, I did' and continued. She would also complain to her family. I still do what I should do, cheering her up by taking her out for a walk after she calms down. It takes patience and caring over time. How others evaluate me is secondary, I need to trust myself and face my own standard. (P3)*
>
> *I would give us some time and space. If she is angry, let her calm down. I would think about the good memories we share and distract her with a walk after she became peaceful. It's harder for them to be happy in this situation. Initially, I reacted to their negativity, but gradually, I understand more. Better for both of us, isn't it? (P 12)*

Avoiding and distancing

Some shared a more passive approach to coping with patients' emotions by distancing and avoiding the patients' negative emotions to prevent themselves from being emotionally drained. In using this approach, they tried to disassociate their feelings with the negative emotions of the patients and to create space for recuperation.

> *I tried not to talk. She sometimes took the hospital as her home and would fetch her stuff. I told her this was the hospital, not home, she did not believe it. She was unhappy; then she went crazy. She goes crazy easily. Even I tried to comfort her by saying, take a good rest. She used to accuse me of saying bad things about her (annoyed). (P1)*

Sometimes the two approaches were interwoven and were reported by the same caregivers during different phases of their caregiving or based on the condition of the patient.

> *I tried my best to make her comfortable. Sensitive and caring. She is gentle. One (a former patient) died, but (his/her) harshness is still alive who said nothing except to complain to others (about me). I can only mute myself. (P4)*

Rewarding appraisals from the caregiving relationship

A rewarding appraisal from the stroke patients

The non-family paid helpers appreciated the emotional attachment expressed by the stroke patients which was demonstrated in various ways such as reliance, trust, caring and familial love. Such emotional attachment was considered as a sign of acceptance and reward for assuming a palliative caregiving role.

> *If you do well and take good care of him (patient), he will feel comfortable, and his family will believe in you, right? This is one (principle). It is useless for him not to accept you. (P17)*

Some caregivers shared being a de facto family member of the patient:

> *She would look around and check on me before sleep. She wanted to feed me when I fed her. I felt happy as if she was my mom. Very warm. (P7)*

Rewarding appraisal from family members

The rewarding appraisals also involved family members. Helpers appreciated the acknowledgement and gratitude received from them. Appraisals from family members were considered crucial to their dual roles: helper and employee. Recognition from family caregivers who shared similar concerns about maximizing their family member's health was perceived by the non-family paid helpers as emotional comfort. Recognition by the family caregivers as employers was considered as an affirmation of the helpers' work performance and efforts.

> *She (patient's daughter) held my hand and said, I do not know how she would be without you. Thank you; I still have a mom. My heart is comfortable (smile). (P3)*

Such rewarding appraisals and collegial relationships established with the stroke patients (including their family members) are described as beneficial to all parties involved in patient care.

> *The family members respect me. I instinctively respect them. It's healthy for everyone. (P11)*

Lack of recognition

From the public

All participants regarded being employed as a helper providing palliative care was a job that required hard work and honesty and required recognition accordingly. They believed that their job offered an option for family caregivers to balance their caregiving and employment and reduce the workload of the healthcare professionals in terms of providing personal care and close monitoring. They, however, unanimously stated negative and hurtful experiences when being labeled as 'someone who wipes the butt' or 'low-level labor'. They felt it was unfair to use such labeling considering the commitment and altruistic attributes of their caregiving duties and the universal human needs for respect instead of enduring stigma as hard-working individuals.

> *The family needs us. Everyone is busy working. If not us, who provides care? Doctors and nurses need us. We are experienced helpers with good physical strength. We can transfer (patients), do personal care and monitor urgent situations. (P4)*
> *Some people would consider us as 'someone who wipes the butt' (bitter smile). (P17)*
> *In our society, every job needs people to do it. No matter how dirty and tiring. Besides, we are doing good deeds to support other people's lives. (P2)*

Invisible to the healthcare system and healthcare professionals

Non-family paid helpers shared that their status of invisibility and coming from a lower socio-economic background was fitting for someone who was willing to tolerate heavy, tedious work and unsanitary conditions. Because of this, they described being invisible in the hospital and the healthcare system, physically and professionally.

> *Low-class labor. Less-educated and middle-aged women are the preferred caregivers in the job market because we can do heavy and dirty caregiving work for years. We don't complain, and we are silent. (P16)*

Helpers described how they should be invisible and their personal belongings (i.e., mattress) had to be hidden:

> *I stayed in the hospital 24 hours a day but had to keep all my belongings invisible. No space for me. Because if I can put my belongings properly, the caregiving would be more convenient. (P3)*

The lack of recognition is also described as 'who am I' to be involved in the decision-making or health dialogue of the patients. Participants shared the dilemma of being the person closest to and knowledgeable about the patients without having a voice beyond caring for the physical aspects.

> *He looked at me and begged for mercy not to insert the tube. My heart felt painful. I pity him. But what can I do?* (Sob) *(P12)*
> *Family members are good. We are good in a different way, 24-hour stay together, the bond. But the family won't be happy to think we are the closest. The doctors and nurses only asked us things like about pee and poo. (P15)*

Insecurity in employment status

When being asked about desired support, the participants shared uncertainty and reservations as they did not want to be perceived as 'demanding'. After probing, some participants shared feelings of insecurity and vulnerability regarding their employment and salary, regulated by mutual agreement between the family members and the helpers. There was concern expressed about the need for a more formal agreement/contract, an annual leave policy, sick leave and remuneration for working public holidays.

> *We are not qualified to ask for support. If that's the case, we can't do the job. We just need to do our own thing. How dare we ask for things, just do our own duty. (P 16)*
> *There is no annual leave or holiday. I had to leave for four days and asked my friend to take care of my patient. I employed my friend in advance but only reimbursed half from my employer (cry). I felt so inferior. (P12)*

Discussion

This study explored the experiences of non-family paid helpers in China who provide palliative care for stroke patients regarding every aspect of their patients' daily lives and the negative consequences on the helpers' physical, psychological and social well-being. Concurrently, monetary compensation, the rewarding appraisal from the emotional bond established through caregiving, and the need for recognition were identified. Their lack of recognition was stated as inadequate recognition by the public, the insecurity of employment status, being invisible in the healthcare system, and lack of involvement in any decision-making regardless of engagement in the patients' everyday lives.

Unlike family members who are assuming caregiving roles driven by familial obligation (i.e., marital obligation, filial piety) and societal expectations,[8] non-family paid helpers reported caregiving responsibility driven by monetary rewards and a sense of reciprocity. Literature has reported that receiving monetary support to assume familial obligations is a critical motive in caregiving and raised the concerns of monetizing the caregiving relationship.[33,34] The helpers in this study shared that their salary does not monetize the relationship; rather, it functions as a great incentive for them to endure the many challenges. Monetary benefits encouraged them to provide quality care to preclude patients from dying in poor care environments and subsequent job loss, which may affirm the governments' initiatives in subsidizing family members to hire helpers.[34] However, such commitment may prohibit helpers from taking good care of themselves or going on a break, as the ethical responsibility and delicate caregiving are infinite for stroke survivors.[24,35] This creates a conflict in that 24 hours/day of caregiving gives helpers no opportunity to fulfill other life priorities, such as their own familial obligations.[35] The tears and desperation of participants in this study revealed the overwhelming status quo of caregiving to stroke patients. Therefore, this raises the issue of the need for contracts to regulate work hours and conditions to prevent exhaustion and over-use and abuse of helpers.

Despite the heavy care burden and demand, reciprocity was identified in helpers' sharing their positive coping mechanisms and personal gains, including emotional self-management and a sense of reward. This is different from the literature suggesting economically motivated helpers will take shortcuts, seriously jeopardizing the quality of care.[36] One possible explanation is that long-term one-on-one palliative care allows helpers to unbundle caregiving procedures into discreet and personalized care, which creates affective ties between helpers and stroke patients.[37] Helpers in the current study appreciated the relationship with patients regarding an enduring intimacy as part of a familial experience, accommodating the functional and cognitive deterioration that occurred in the palliative stage. Helpers shared that they learned to become more 'patient and caring' and 'emotionally intelligent' in meaningful caregiving relationships.[3839] Such positive perspectives may be explained by the 'broaden-and-build' theory that positive experiences may contribute to adaptive coping and an increased sense of mastery while negative feelings narrow the attention field and hinder practical strategies for caregiving.[40] Participants considered caregiving as a life occupation; developing positive coping and emotional intelligence is essential for role identity and efficient functioning as a caregiver. In contrast, negative emotional reactions were also identified by participants, such as distancing themselves from stroke patients and ignoring the mental health aspects.[41] Negative emotions as a result of caregiving were also reported in a previous study indicating prevalent mental distress among non-family paid helpers, which may lead to poor care quality or even psychological abuse of older adults (i.e., ignorance, coldness).[11] Thus, it is imperative for the healthcare system to launch training and psychosocial support programs for non-family paid helpers to mitigate the distress from managing patients' disabilities and agitation.

Findings suggested that recognizing non-family paid helpers is imperative to improve workforce planning and enhance reciprocity for the demanding palliative care. This is in concordance with a large-scale longitudinal study in Canada showing workforce shortages as paid helpers are experiencing exhaustion, burnout and deconditioning in the quality of work-life.[42] It is worth noting that research studies, the national elderly care plan, and news reports in China consistently emphasize the foreseeable staffing shortage of non-family paid helpers.[182343] Local governments should respond to the State Council’s direction, including initiating financial support/subsidies to promote training and certification for the paid helper workforce in China. This way the paid helpers can be better prepared to deliver care in various settings (e.g., hospitals, nursing homes, communities) for people with varying care-dependency levels and to break the stereotype that paid helpers are exclusively middle-aged or older females with low socioeconomic status and minimal job options other than caregiving.[11] These findings supported international policy initiatives that set as top priority for action the need for recognition and respect towards caregivers.[44] To enhance recognition at the policy level, the operation and promotion of standardized employment contracts, for example, regulating roles, benefits, and annual leave, may be needed to protect the interest of both the employer and employee.[45] In addition, emerging literature advocated the positive appraisal arising from caregiving where skill mastery and affective ties can be fostered by witnessing suffering, being exposed to a caring environment, and establishing a reciprocal relationship.[24,46] Building an emotional bond and rewarding appraisal from patients and family through enhancing their comfort and actualizing their identity as a helper fosters the continuation of the reciprocal cycle.

The lack of recognition and invisible status of non-family paid helpers may reflect the broader lack of recognition for caregivers. In agreement with the literature, stroke palliative care is burdensome and long-lasting, and there is a scarce system- and policy-level to support caregivers.[24] The lack of involvement in health dialogue can also be reflected by the fact that even family members of stroke patients reported inadequate information and involvement in health dialogue.[47] Disjointed stroke palliative care was reflected by the participants' narration that there is a lack of conversation engaging full-time non-family paid helpers who have the best knowledge of their patients which can preclude holistic care. It is important to promote collaboration between healthcare professionals, family members, and caregivers, where the full-time caregiver, even by contractual obligation, is involved in caregiving and planning, recognizing their knowledge of their patients.

Implications

The current study suggests that non-family paid helpers providing palliative care of stroke patients experienced onerous physical, psychological and societal burdens and developed internal coping mechanisms to build reciprocal caregiving relationships. Findings affirmed that hiring helpers is both practical and reciprocal, considering the monetary compensation and reciprocity that motivates quality care. Public recognition of non-family paid helpers should be promoted to foster a nurturing environment to improve the helpers' well-being and care quality. Development of a contract is needed for regulating work hours and work conditions to prevent exhaustion and exploitation of non-family paid helpers. The healthcare system should provide training and counseling to the helpers to mitigate the distress related to managing palliative stage stroke patients' disabilities and agitation. Healthcare professionals should consider harnessing the helpers' knowledge of their patients by involving them in health conversations. Given the diversified comorbidities of the patients, this study's findings and recommendations would apply to paid helpers for older adults with other conditions that require hospice care.

Conclusion

The high palliative care burden resulting from non-family paid helpers meeting patients' physical needs and high levels of dependency is comparable to that of family members. Monetary compensation and reciprocity in caregiving relationships identified by the helpers affirmed the importance of governmental initiatives in subsidizing family members to hire helpers to alleviate the palliative caregiving burden. Recognition from the public about the responsibilities of a non-family paid helper, employment rights bound by contract, being visible within the healthcare system and by healthcare professionals should be considered to foster quality care and alleviate care burden. It is crucial to offer non-family paid helpers training and counseling to assist them in mitigating distress while managing stroke patients' disabilities and altered mental status.

Authors' Note

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Competing interests

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Declaration of Conflicting Interests

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Availability of data and material

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Table 1: Interview questions

Questions
• Please share your experiences of working as a hired caregiver for stroke patients. (What's your role/duty? What do you think of your role?)
• How did working as a caregiver influence you? (Yourself? Your family?)
• Can you share a challenging experience of being a hired caregiver for stroke patients? (What happened? Who was there? What did you/others say and do? How do you cope with such a situation? How do you feel about it?)
• Can you share a rewarding experience of working as a hired caregiver for stroke patients? (What happened? Who was there? What did you/others say and do? What contributed to such achievement? How do you feel about it?)
• What do you think of your job as a caregiver?
• What would be your suggestions in order to support your caregiving to the patients?
• How are you feeling now (at the end of the interview to assess if counselling is needed)

Table 2: Themes and subthemes

Themes	**Subthemes**
Monetary compensation offsets caregiving burden	Monetary compensation offsets the exhaustion in providing care
	Monetary compensation reimburses for familial and health sacrifices
Emotional self-management	Accepting and coping
	Avoiding and distancing
Rewarding appraisals from the caregiving relationship	A rewarding appraisal from the stroke patients
	A rewarding appraisal from the family members
Lack of recognition	From the public
	Invisible to the healthcare system and healthcare professionals
	Insecurity in employment rights