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ARTICLE

Cognitive status, psychological state and needs of caregivers for elderly patients with home-induced pressure injuries: a qualitative study

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Abstract

Aims/Background Pressure injury stands as a global healthcare concern, primarily affecting elderly individuals. As the ageing of the global population shows no signs of slowing down, both society and the families of the affected individuals continue to bear the brunt of the consequences of pressure injuries. The majority of pressure injury cases are managed at home, and the occurrence and progression of pressure injuries in the elderly are closely associated with informal caregivers. This study aims to qualitatively explore the cognitive status of caregivers for elderly patients with home-induced pressure injuries, as well as their psychological state and needs during the caregiving process.

Methods This research is qualitative, descriptive, and phenomenological in nature. A purposive sampling method was used. Eighteen caregivers of elderly patients with pressure injuries were selected from Jiangnan University Medical Centre as interviewees from June 2023 to August 2023. Semi-structured interviews were utilised to collect data regarding the caregivers' cognition, psychological state, and care-related needs while caring for elderly patients with home-induced pressure injuries. The data were then organised and analysed using Colaizzi's phenomenological analysis method and NVivo 11.0.

Results Through the analysis of interview data from caregivers of elderly patients with home-induced pressure injuries, three main themes and nine subthemes were identified. The data analysis also revealed that the caregivers surveyed lacked the crucial awareness of preventing pressure injuries and that their caregiving practices were not up to standards. During the caregiving process, they were challenged with substantial stress while also experiencing negative emotions such as anxiety or depression. They had a strong desire for persistent medical support to alleviate the psychological and emotional challenges.

Conclusion The findings of this study establish a collaborative relationship network among the hospitals, family, medical staff, and caregivers in the management of pressure injuries, but with a special attention to the caregivers' needs for disease-related knowledge and psychophysical support. Such relationships streamline communication between medical staff, patients, and their caregivers, facilitating the adoption of active and correct methods by caregivers to prevent and care for pressure injuries. This can positively impact the quality of care for pressure injuries, further improving the life quality of patients and their caregivers, controlling the incidence of pressure injuries, and reducing readmission rates.

Key words: Cognition; Elderly; Home caregivers; Pressure injury

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Introduction

Pressure injury (PI) (The International Guideline, 2019) is a localised damage to the skin and/or subcutaneous tissue caused by pressure, or a combination of pressure and shear force. Pressure injuries typically occur over bony prominences, but they may also be induced by medical devices or other objects (The International Guideline, 2019). The prevalence of PI in individuals over 70 years old is as high as 70% (Tong et al, 2016), making the elderly population a high-risk group for pressure injuries (Mervis and Phillips, 2019). Studies indicate that the global prevalence of pressure injuries ranges approximately from 6% to 18.5% (Tubaishat et al, 2018). In the United States, about 1.7 million people develop

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pressure injuries annually (Peterson et al, 2013), while the overall prevalence of PI in Europe stands at 13.7% (Moore et al, 2019). In China, the incidence rate of bedsores in hospitalised patients is 1.57%, while elderly patients and long-term bedridden elderly patients account for incidence rates of 3.34% and 25.7%, respectively (Ying, 2017). Pressure injuries are chronic wounds and have been listed as one of the five common issues endangering patients' health worldwide (Tannen et al, 2008). Although many clinical treatment methods are available, most of them remains suboptimal in efficacy and time-consuming (Boyko et al, 2018). It is estimated that the annual cost of care for pressure injuries is approximately over USD 10 billion (National Pressure Ulcer Advisory Panel, 2014), with the cost of preventing pressure injuries ranging between 2.6 and 87.6 Euros (Demarré et al, 2015), imposing a significant economic burden on society, healthcare systems, and families.

The current primary treatment methods for pressure injuries include reducing the source of pressure, debridement, controlling infection, and suitable dressings, with reconstructive surgery considered for more severe cases (Boyko et al, 2018). Studies have shown that stage I pressure injuries can generally heal within 6 months, with healing rates for stages II, III, and IV at 69%, 41%, and 21%, respectively (Guest et al, 2018). Treating PI is a challenging endeavour, often culminating with not ideal outcomes. This is especially true for the elderly, who may have more lax skin, reduced compressive strength and tolerance (Dyer and Miller, 2018), and may also suffer from multiple underlying diseases, making them particularly susceptible to pressure injuries (Parnham et al, 2015). Moreover, PI in elderly patients pose huge difficulty for treatment and may deteriorate to more severe stages. Additionally, research indicates that the majority of pressure injuries are cared for at home (Santos DIFA, 2008), with the incidence rate of pressure injuries in long-term bedridden patients at home ranging from 20% to 50% (Dong-Mei et al, 2011). Therefore, elderly patients with home-induced pressure injuries represent a population that warrants significant attention.

The continual ageing of the global population and the increasing prevalence and complexity of chronic diseases have spurred on the rise of PI incidence, which translates to increased economic and caregiving burden on families of affected individuals. Caregivers are entrusted with a tremendous responsibility (Dongmei, 2011; Downie et al, 2013; Lili, 2013; Lechner et al, 2021) in caring for the bedridden or wheelchair-bound elderly who are unable to care for themselves. This particular group of elderly individuals are more susceptible to pressure injuries due to their limited movement capability for reducing pressure. Hibbs indicated that 95% of PI cases are preventable (Downie et al, 2013). Therefore, caregivers play a crucial role in preventing pressure injuries, promptly identifying them, and implementing effective interventions to prevent the injuries from progressing to more severe stages (Lechner et al, 2021). Consequently, the attitudes of caregivers have a significant influence on the occurrence and severity of pressure injuries—a topic deserving of more in-depth study.

As the ageing problems in the Chinese population show no signs of slowing down (National Bureau of Statistics, 2011), and considering that the elderly population is a high-risk group for pressure injuries (Mervis and Phillips, 2019), complications arising from old age, disability, and dementia, coupled with limited caregiving capabilities, may prevent effective prevention and timely medical consultation. This often leads to the progression of pressure injuries to more severe stages, during which the injuries would become more difficult to heal. The PI care largely hinges on the participation and effective collaboration of caregivers, which is crucial for the efficient prevention and treatment of pressure injuries. To better understand and analyse the cognition, psychological state, and practical needs of caregivers for elderly patients with home-induced pressure injuries, this qualitative study aimed to provide a theoretical basis and reference for strengthening the prevention and care of pressure injuries among bedridden elderly at home, improving caregivers' attitudes, enhancing the quality of care for PI, further improving the life quality of patients and their caregivers, optimising the management of pressure injuries, contributing to the control of pressure injuries acquired outside the hospital, and reducing readmission rates.

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Methods

To ensure that the interviews remain focused on the topic and needs while conducting more in-depth analysis of participants' information, and to allow participants sufficient freedom to express themselves, this study employed semi-structured interviews for data collection. In accordance with the research objectives and content, a preliminary interview outline was developed after evaluating the content's validity and consulting with experts for discussion and revision. We then conducted pre-interviews with caregivers of elderly patients with pressure injuries to find out whether they could understand the questions and how they felt about the caregiving process. Based on the feedback, the research design was refined through finalisation of the formal interview outline, which is shown in Table 1.

Six nursing experts were invited to assess content validity in this study. These experts were requested to provide basic information and complete authority level surveys, and to evaluate the relevance of each item in the initial questionnaire to the respective content dimensions. A four-point Likert scale was employed (1=highly irrelevant; 2=irrelevant; 3=relevant; 4=highly relevant). All six experts returned the questionnaires (100% response rate). Multiple experts provided suggestions for modifications and additional indicators, showcasing their high-level enthusiasm for this research.

The authority level of the experts is represented by the authority coefficient (Cr). It is calculated based on the expert's judgment basis (Ca) and the expert's familiarity with the issue (Cs). The formula is given by $Cr=(Ca + Cs)/2$. A coefficient not less than 0.70 represents acceptable credibility, signifying reliable study results (Luo et al, 2021). Details on the basic information of the experts and their authority levels are shown in Tables 2–4. This study obtained the judgment basis from experts through theoretical analysis, practical experience, references to domestic and international literature, and subjective feelings. The calculated values are: $Ca=0.92$, $Cs=0.87$; therefore, $Cr=0.90$. As this is not less than 0.70, the evaluation results are deemed reliable.

Literature suggests that before calculating the content validity index (CVI), interrater agreement (IR) should be computed. This is done by summing the number of items in the expert panel survey that are rated as 1 or 2 and those rated as 3 or 4, and then dividing by the total number of items, and those no less than 0.70 are considered good interrater agreement, allowing further calculation of the CVI (Davis, 1992; Polit and Beck, 2006). Before calculating the CVI, the IR was determined to be 0.86. Since it is not less than 0.70,

Table 1. Interview outline for caregivers of elderly patients with pressure injuries (For the convenience of interviewees, questions regarding pressure injuries have been posed using the terms 'pressure ulcers/ bedsores'.)

Interview outline
A1: What do you know about pressure ulcers/bedsores? Where did you learn about them?
A2: In your opinion, under what circumstances pressure ulcers/bedsores are more likely to occur? How should they be prevented?
A3: When did you realise the need to seek information about pressure ulcers/bedsores? Can you describe the potential harm caused by them?
B1: How do you feel about preventing or treating pressure ulcers/bedsores?
B2: In your opinion, what part of the caregiving process is the most challenging or difficult?
C1: During the hospital stay of the person you're caring for, what support do you believe is needed from medical staff?
C2: Do you think the current channels of information and contents are sufficient for effective prevention of pressure ulcers/bedsores in daily care? If not, what aspects need improvements?
C3: What further assistance do you believe is necessary for better prevention and treatment of pressure ulcers/bedsores?

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Table 2. Basic information of experts

Expert ID	Education	Major	Title	Department	Position	Servicing tenure (Year)
A	Bachelor's	Nursing	Deputy chief nurse	Neurosurgery	Head nurse	24
B	Bachelor's	Nursing	Chief nurse	Hepatobiliary and pancreatic surgery	-	22
C	Bachelor's	Nursing	Deputy chief nurse	Intensive care	Deputy head nurse	13
D	Bachelor's	Wound care	Deputy chief nurse	Wound ostomy clinic	Deputy head nurse	35
E	Bachelor's	Nursing	Deputy chief nurse	Neurosurgery	Head nurse	27
F	Bachelor's	Wound care	Deputy chief nurse	Wound ostomy clinic	Head nurse	19

Table 3. Experts' judgment basis

	Number (assigned value)		
Judgment basis (Ca)	Large	Medium	Small
Theoretical analysis	5 (0.4)	1 (0.3)	0 (0.2)
Practical experience	4 (0.3)	2 (0.2)	0 (0.1)
Relevance to domestic/international literature	4 (0.2)	2 (0.1)	0 (0.1)
Subjective feelings	2 (0.1)	2 (0.1)	2 (0.1)

Table 4. Experts' familiarity level

	Number (assigned value)				
Familiarity level (Cs)	Very familiar	Familiar	Average	Unfamiliar	Very unfamiliar
	2 (1)	4 (0.8)	0 (0.6)	0 (0.4)	0 (0.2)

we considered that the agreement between the evaluators was good. We further calculated the CVI (Lynn, 1986; Polit and Beck, 2006; Shi et al, 2012). In this study, we designed an interview outline for caregivers of elderly patients with pressure injuries (pressure sores) that includes seven items. Experts A to F were asked to evaluate the CVI, as detailed in Table 5.

Upon calculation, the item-level CVIs (I-CVIs) of this study ranged from 0.83 to 1.00, not less than 0.78 (Lynn, 1986; Wu, 2010). Adjustments were made for the Chance Agreement, and the resulting Kappa values ranged from 0.82 to 1.00, which were considered excellent as they were not less than 0.74 (Polit et al, 2007; Shi et al, 2012). The average scale-level CVI (S-CVI/Ave) was 0.98, not less than 0.90 (Polit et al, 2007; Wu, 2010). These results reflected that the content validity of the questionnaire was deemed satisfactory.

Participants and study settings

We adopted the purposive sampling method, selecting participants (caregivers) based on the diversity principle in terms of age, gender, educational level, profession, relationship with the patient, caregiving duration, financial status, etc., to glean the highest possible amount of information and increase the representativeness of the sample.

The caregivers of elderly patients with home-induced pressure injuries were recruited as interviewees at Jiangnan University Medical Centre from June to August 2023. The

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Table 5. Evaluation table for interview outline of caregivers for elderly patients with pressure injuries

Items	Expert score						Number of experts scoring 3 or 4	I-CVI	P_C	Kappa value
	A	B	C	D	E	F				
A1	4	4	4	4	4	4	6	1.00	0.016	1.00
A2	4	4	4	4	4	4	6	1.00	0.016	1.00
A3	4	3	4	4	4	3	6	1.00	0.016	1.00
B1	3	4	4	4	4	4	6	1.00	0.016	1.00
B2	3	4	4	4	4	4	6	1.00	0.016	1.00
C1	4	3	2	4	4	4	5	0.83	0.094	0.82
C2	3	3	4	4	4	4	6	1.00	0.016	1.00

The I-CVI (item-level CVI) is calculated based on individual items, with the formula for I-CVI being the number of experts who gave a score of 3 or 4 in the expert consultation form divided by the total number of experts participating in this evaluation; P_C stands for the probability of random consistency.

sample size for this study was determined based on when information saturation was reached, ultimately including 18 interviewees.

The inclusion criteria for this study are two-fold, and designed based on the characteristics of both patients and caregivers. On the dimension of patients, the inclusion criteria include the following: (i) Having home-induced pressure injuries; (ii) Being aged ≥60; and (iii) Being required to be temporarily or long-term bedridden/wheelchair-bound for various reasons. On the dimension of caregivers, the inclusion criteria include the following: (i) Having full understanding of the patient's medical condition; (ii) Being aged ≥18; (iii) Possessing clear consciousness and normal communication abilities, with clear understanding of the questionnaire content; (iv) Agreed to participate in this research by giving informed consent.

Exclusion criteria: (1) Patients: (i) Those with pressure injuries from non-home environments like nursing homes or rehabilitation centres; (ii) Fully mobile; (iii) Unable to cooperate with the research content. (2) Caregivers: (i) Those with language expression barriers; (ii) Those who interrupt the research process for various reasons; (iii) Unable to cooperate with the research content.

Study procedures

Before the formal interview, the purpose and content of the study were explained to the participants. Each interview was recorded. Participants were asked to give their informed consent in writing. The interviews were conducted one-on-one, following a pre-prepared outline. Participants were encouraged to express genuine feelings and thoughts, avoiding suggestive or leading questions. Observations of non-verbal cues (such as facial expressions, gestures, tone, etc.) were noted. Each interview lasted between 30 to 60 minutes.

Quality control

Before the study, we had mastered the research methods and interview techniques through systematic theoretical and practical learning. These methods equipped us with the ability to solicit genuine feelings and thoughts from the interviewees during the process by gaining a full understanding of the interviewees' profile and personality and establishing a strong trust relationship with them.

The interview outline was designed based on relevant literature and tailored to the research objectives and content. After consultations with experts and preliminary interviews, the outline had undergone multiple discussions, revisions, and continuous refinement.

Interviews were conducted in a quiet and comfortable site to ensure there were no interruptions. Equipment was checked beforehand to ensure it was functioning properly and the battery could last for the entire session. Throughout the interview, the non-verbal reactions of the participants were closely observed, with timely notations made. Leading

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or suggestive questions were avoided. Appropriate interview techniques, such as probing and repeating, were employed to accurately understand the verbal accounts given by the interviewees.

Two researchers were designated to transcribe the recordings verbatim. The analysis was constantly compared with the original data. Upon completion, the transcripts were checked against the recordings listened to ensure accuracy and credibility. Finally, the results of the analysis were sent to the participants to verify the authenticity of the content.

Ethical principles

This study followed the principles of informed consent, confidentiality, beneficence, and non-maleficence and has been approved by the Ethics Committee of Jiangnan University Medical Centre (Approval number: 2024-Y-15). Before the interview, the researchers provided the interviewees with a detailed explanation of the purpose and content of the study, reminding them that the entire interview would be recorded and guaranteeing that the interview would not elicit risks or discomforts. Informed consent was obtained from the interviewees, who then signed a consent form. Interviewees were informed that they reserved the right not to participate in the study or to withdraw from the study any time they wished. All personal and confidential information would remain confidential, with access granted only to the research team, and their personal details would not be disclosed.

Data analysis

Within 24 hours of each interview, the recordings were transcribed verbatim by two researchers. Non-verbal responses and general information about the interviewee were noted. The interview data was processed using NVivo 11.0 (Net Number Era Technology Co., Ltd., Beijing, China), which was downloaded from the official Nvivo website. Data was analysed using Colaizzi's phenomenological method in seven steps (Coates, 2004; Li, 2012):

(i) Carefully read all interview materials.
(ii) Read the interview data verbatim, marking important words and sentences that appear repeatedly and are related to the research question.
(iii) Construct/code meanings for recurring views, forming meaning units. In this study, we identified a total of 87 significant statements and transferred them into another table, after which they were repeatedly deliberated and inducted to form 26 meaning units. They were then checked and agreed upon by two researchers.
(iv) Two researchers then deliberated, reflected upon, and imagined all meaning units, referring to each significant original statement, and collated the encoded views into embryonic themes.
(v) Each embryonic theme produced was defined and described, and some typical original statements were extracted for each theme description.
(vi) Similar embryonic themes and their descriptions were compared repeatedly, inducing the common views constituting the phenomenon for theme summarisation. A total of three themes and nine subthemes were ultimately formed.
(vii) The resulting themes and subthemes were returned to the study participants for validation. They were asked if their true experiences were captured, ensuring the accuracy and authenticity of the results.

Results

In this study, interviews were conducted with 18 caregivers of elderly patients who suffered from home-induced pressure injuries. The caregivers were coded from C1 to C18. Detailed demographic information about the caregivers is given in Table 6. A total of three themes and nine sub-themes were ultimately distilled from the caregiver interviews. The themes and sub-themes are specified in Figure 1.

Theme 1: Caregivers' knowledge deficiencies

Sub-theme 1: Vague and fragmented understanding

Caregivers have very limited knowledge about pressure injuries. About 90% (89%) of the caregivers are only able to mention that such injuries might occur if someone is bedridden

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Table 6. General information of caregivers (n=18)										
Serial number	**Gender**	**Age (years)**	**Ethnicity**	**Place of residence**	**Education level**	**Employment status**	**Relationship with patient**	**Daily care hours provided by caregiver (hours)**	**Serving tenure as a caregiver (years)**	**Average monthly household income (yuan)**
C1	Female	45–59	Chinese	Town	Junior College or Bachelor's Degree	Retired	Children	6–12	<1	5000–10,000
C2	Male	45–59	Chinese	Town	Junior College or Bachelor's Degree	Employed	Children's spouse	6–12	1–3	5000–10,000
C3	Male	45–59	Chinese	Countryside	Middle school	Unemployed	Spouse	12–24	1–3	<3000
C4	Female	60–74	Chinese	Town	Middle school	Retired	Spouse	12–24	3–5	3000–5000
C5	Female	60–74	Chinese	Town	Middle school	Retired	Children	12–24	5–10	3000–5000
C6	Female	60–74	Chinese	Town	High School or Vocational School	Retired	Children's spouse	12–24	5–10	3000–5000
C7	Female	60–74	Chinese	Countryside	Elementary School	Employed	Nanny	12–24	3–5	5000–10,000
C8	Male	45–59	Chinese	Town	Middle School	Unemployed	Children	12–24	<1	<3000
C9	Female	60–74	Chinese	Town	Middle School	Retired	Spouse	12–24	1–3	<3000
C10	Female	45–59	Chinese	Town	Middle School	Retired	Children	12–24	3–5	3000–5000
C11	Female	60–74	Chinese	Town	High School or Vocational School	Retired	Children	12–24	1–3	<3000
C12	Female	75–89	Chinese	Countryside	No Formal Education	Retired	Spouse	12–24	5–10	<3000
C13	Female	45–59	Chinese	Town	Junior College or Bachelor's Degree	Employed	Children	<3	<1	5000–10,000
C14	Female	45–59	Chinese	Town	Middle School	Employed	Children	6–12	5–10	3000–5000
C15	Female	75–89	Chinese	Town	Middle School	Retired	Spouse	12–24	3–5	<3000
C16	Female	75–89	Chinese	Town	Middle School	Retired	Spouse	3–6	<1	<3000
C17	Female	75–89	Chinese	Town	High School or Vocational School	Retired	Spouse	6–12	<1	<3000
C18	Female	60–74	Chinese	Town	Middle School	Retired	Older sister	12–24	<1	<3000

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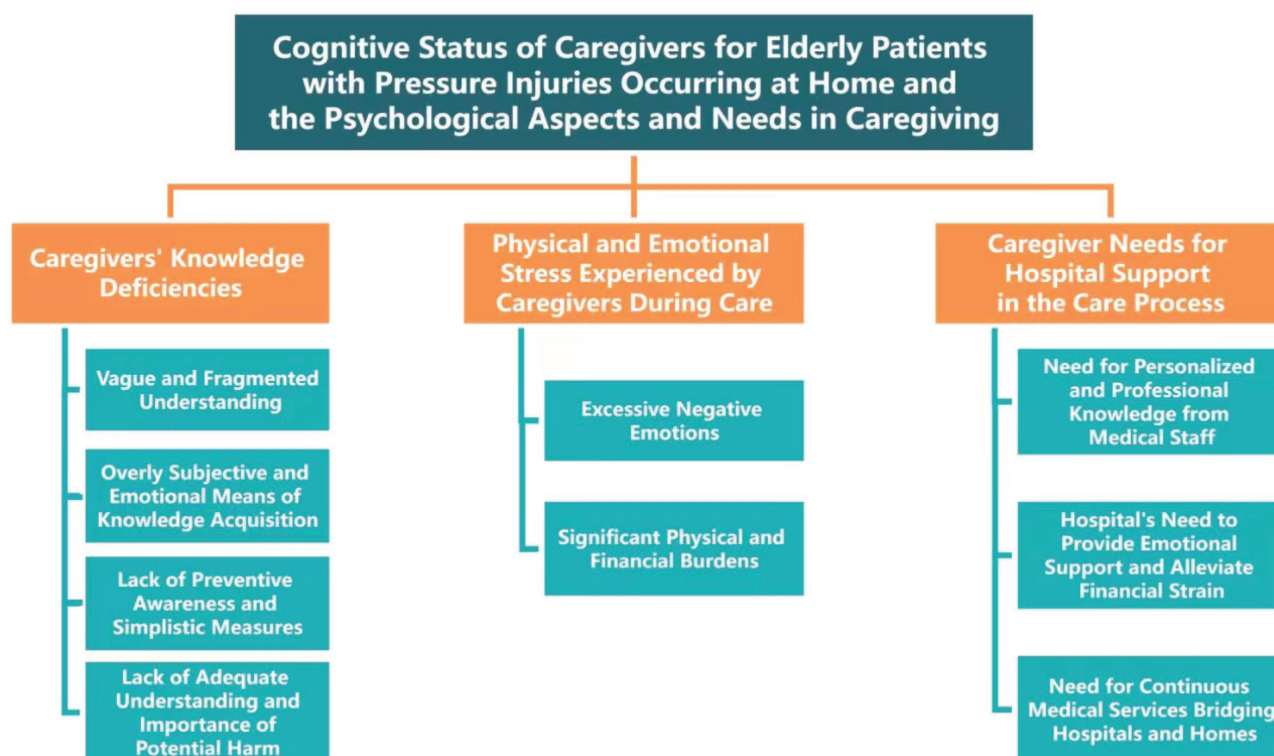

Figure 1. Themes and sub-themes. Illustration made with Lucidchart.

and unable to take care of themselves for an extended period. For example, C2 stated: 'If one lies in the same position without moving, or stays there for a long time, bedsores can form.' Additionally, some caregivers admitted they did not have a good understanding of pressure injuries, or even if they did, they do not seem to know everything about it. C8 said: 'I don't really understand bedsores, I'm not familiar with them (frowning).' C4 revealed: 'I didn't know about it before. After my mother fell ill and was bedridden in the hospital, I became somewhat aware of it (pressure injuries), but it's still not very clear (bitter smile).'

Sub-theme 2: Overly subjective and emotional means of knowledge acquisition

About three quarters (78%) of the caregivers derived their understanding about pressure injuries from personal experience. Some learned about the illness through the Internet, from others such as peers with similar experiences, or after consulting 'barefoot doctors' (a colloquial term in China referring to non-professional or semi-professional health workers). For example, C1 said: 'After my mother got sick, I asked my friends, searched online, consulted my peers, and even consulted traditional Chinese medicine practitioners.' C11 shared: 'It's all based on what I've seen and heard from others.' Only a few caregivers sought information from professional medical workers. For instance, C3 mentioned: 'I learned about it from a nurse.'

Sub-theme 3: Lack of preventive awareness and simplistic measures

Ninety-four percent of the caregivers expressed that they only started actively seeking information about and paying attention to pressure injuries after encountering this condition while providing care or because of past caregiving experiences. For example, C4 shared: 'I wasn't aware (of pressure injuries) initially. But after my mother got sick and had such injuries in the hospital, I often tried to learn more about it.' C10 mentioned: 'After having two senior members in my family suffering from pressure injuries, I'm forced to understand

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more about it.' Some caregivers also noted that the pressure injuries were only discovered in the patients after hospitalisation. C14 recalled: 'I realised my father was grappling with PI when he was hospitalised as his skin was decaying and ruptured.' Furthermore, most caregivers believe that measures such as turning the patient over in bed, maintaining skin hygiene, or applying ointment can prevent the occurrence of pressure injuries. For example, C6 said: 'One needs to change diapers frequently to keep it dry. Another key to prevention is to frequently turn them over and shift their position.' Some caregivers also indicated that only an air cushion bed can prevent its occurrence. As C10 emphasised: 'Pressure ulcers can only be prevented by using an air cushion bed. This is the only method; only this is effective (tone-strengthening).'

Sub-theme 4: Lack of adequate understanding and importance of potential harm

Regarding the possible harm of pressure injuries, 67% of caregivers expressed a lack of understanding. However, 89% were not clear about the specific dangers, only assuming it might cause pain, lead to infections, or affect overall health. For instance, C18 noted: 'I'm not clear about the harm of pressure injuries.' C2 stated: 'It will hurt; pressure injuries can lead to severe consequences.' C6 mentioned: 'The harm of pressure ulcers is that the patients may get infected.' C10 reflected: 'It might impact the elderly's health and lifespan.' Some caregivers believe that minor pressure injuries can be managed with frequent turning, while severe cases require professional help. C2 elaborated that 'if the PI is severe, measures should be taken, and help should be sought from professionals; if it's not severe, turn them over frequently.'

Theme 2: Physical and emotional stress experienced by caregivers during care

Sub-theme 1: Excessive negative emotions

Almost three quarters (72%) of the caregivers expressed feelings of tension and anxiety during the caregiving process for patients with pressure injuries. They are unsure about how to deal with the situation and are concerned about unsuccessful treatments. For example, C6 shared: 'When I initially didn't understand much about pressure injuries, I felt a bit tense because I didn't know how to deal with it.' C3 expressed: 'Knowing that (the patient) has this condition, I'm always worried it won't heal. I'm also worried he might pass away; it's… distressing.' Sixty-one percent of the caregivers also expressed feeling a great deal of pressure. C1 remarked that 'if we, as family members, can't provide proper care to treat pressure ulcer, it feels like we're not being filial enough.' A big majority of the caregivers (83%) also expressed distress due to their work commitments, which prevented them from providing constant care. As C12 said with a frown: 'I'm busy with work and can't be by (the patient's) side all the time. My mother, at times, is not strong or healthy to tend to (the patient) constantly, causing me a lot of trouble.'

Sub-theme 2: Significant physical and financial burdens

A quarter of the caregivers (28%) expressed that they themselves are of advanced age and suffer from various ailments. During the caregiving process for pressure injuries, they often find themselves physically exhausted and overwhelmed. For instance, C10 remarked, 'When someone has pressure sores, the caregiving process becomes more laborious (for me). Roughly, I have to turn them every 3 hours at home, even in the middle of the night. It's quite a strain.' Furthermore, 56% of caregivers believe that pressure injuries bring a significant burden to the family both emotionally and financially. C9 mentioned, 'Pressure sores weigh heavily on our family. Now, he (the patient) is bedridden and immobile. I am the one handling every aspect of the care process!' C15 asserted, 'The financial burden is immense. Both my daughters are not nearby, and I am struggling with my own health issues.'

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Theme 3: The Caregivers need hospital support in the care process

Sub-theme 1: Need for personalised and professional knowledge from medical staff

Many caregivers (94%) expressed the desire for professional insights into PI management from medical staff and guidance tailored to each patient's unique condition. C1 stated, 'We wish they (medical staff) could offer more knowledge about caregiving, (in particular) more guidance.' C12 suggested, 'I hope the hospital could cater to the unique condition of each individual and periodically try to provide us with relevant knowledge.'

Sub-theme 2: Hospital's need to provide emotional support and alleviate financial strain

Eighty-nine percent of the caregivers hope that medical personnel can offer more attention and assistance. C10 said, 'I hope they (can) pay more attention to us, and, for instance, often share things we should be mindful of.' About three quarters of the caregivers (78%) also felt that the cost of treating pressure injuries is high. They hope that the patients can be reimbursed through medical insurance, and that medical staff can suggest more cost-effective options. C14 shared, 'Since he (the patient) is bedridden and elderly, you never know how long he'll live. These things (dressings) need frequent replacements, which are costly. I wish medical insurance could cover some of it or perhaps there are better, more cost-effective recommendations.' Additionally, caregivers recommend that physicians prescribe pressure-reducing dressings that are easily available. C1 expressed, 'To treat these pressure sores, I hope the hospital prepares whatever dressing we need, or at least the hospital's pharmacy store should have enough stocks. Currently, many dressings are unavailable.'

Sub-theme 3: Need for continuous medical services bridging hospitals and homes

The majority of caregivers (83%) expressed the desire for continued assistance from professionals after the patient is discharged. They wish that the hospital could regularly follow up and provide guidance on the treatment of pressure injuries. C12 stated, 'After my father was discharged, there should certainly be regular follow-ups from the hospital, but this seems to be lacking.' C16 added, 'Now, the patient is about to be discharged. In that case, there might not be any professional assistance; upon discharge, there's no one to consult.' Moreover, 67% of caregivers mentioned that compared to community services, they prefer to receive assistance from the hospital. They hold the opinion that hospital staff is more trustable given their authoritative and professional stanidng. C14 remarked, 'Currently, I mostly follow the hospital's advice. You can't count on the community; it's not very professional. It's better to go to city-level major hospitals because I trust the nurses there more.'

Discussion

Enhancing awareness and strengthening care capacity

The elderly population emerges as a high-risk group for pressure injuries3. Requiring temporary or long-term bed rest, and having multiple underlying diseases that render the patients less independent, are factors underscoring the importance of caregivers in preventing and treating pressure injuries. This study reveals that the caregivers of elderly patients who suffered home-induced pressure injuries have a weak and quite vague understanding of pressure injuries. Their knowledge regarding the related concepts, risk factors, preventive measures, and potential harm is lacking and not comprehensive. Moreover, they were flippant about the management of PI. Among them, five caregivers lacked knowledge related to pressure injuries, and all of these five caregivers had only attended middle school. Additionally, the caregivers gain an understanding of pressure injuries mainly from past experiences, the internet, interacting with other patients, listening to others' experiences,

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and advice from unlicensed doctors. Some caregivers commented that they were constantly trying different approaches to deepen their understanding of this illness, but remained ambiguous about the veracity of the information collected. These findings are consistent with the research results of Tharu et al (2022), Sharma et al (2013), Mersal (2014).

This lack of understanding about PI among the caregivers highlights the need for offering professional medical education to about pressure injuries caregivers during treatment process, to raise their awareness about prevention and treatment, enabling them to understand and master the correct related knowledge. Furthermore, given the differences in caregivers' education levels, comprehension skills, and past experiences in managing pressure injuries, medical staff should provide targeted instructions and demonstrations. Additionally, they should point out any inappropriate conduct promptly and continuously to strengthen the caregivers' capacity and education in caregiving.

Offering holistic medical services for physical and mental wellbeing

This study found that caregivers, in the process of caring for elderly patients with pressure injuries, experienced negative emotions such as anxiety, tension, depression, and sadness, along with significant financial stress. Among the 18 caregivers, 12 of them provided care all day long, 12 had been providing care for over a year, and 9 caregivers had a household average monthly income of less than 3000 yuan. Some caregivers also expressed a strong sense of uncertainty about the disease. A past study has shown that caregivers tend to experience negative emotions when caring for patients dependent on caregivers (Rodrigues et al, 2015). Furthermore, the psychological burden on the caregiver grows with the patient's dependence. However, such emotions can be alleviated when more medical attention is diverted to improving the psychological and physical stresses of caregivers.

Therefore, medical professionals should offer timely psychological support and counselling, as well as fully understand the needs of each caregiver to provide the most appropriate, targeted treatment. This approach aims to offer caregivers comprehensive care services for both physical and mental well-being. It is also vital to promptly provide caregivers with professional knowledge and treatment information related to pressure injuries, discuss and make decisions together, and encourage caregivers to participate in the care of pressure injuries. This involvement can lead to positive experiences, mitigating the negative emotions produced during caregiving. Additionally, aside from the support and assistance afforded by medical staff, physical and psychological support from secondary caregivers (such as other family members, friends, neighbours, etc.) is also needed to reduce the psychological and physical stresses caregivers experience during the caregiving process (Pimenta et al, 2009).

Studies have shown that the treatment costs for pressure injuries are high and show an ever-increasing trend (Nussbaum et al, 2018). However, at present, medical avenues available for treating pressure injuries are scarce. Therefore, how to better prevent pressure injuries should be a focal point in treatment and disease management for both hospitals and home caregivers (Padula et al, 2011; He and Shen, 2017). In addition, it is also anticipated that the government would roll out relevant policies beneficial for pressure injuries and ensure the persistent availability of high-quality medical supplies for PI that are reimbursable within the breadth of medical insurance.

Enhancing the support system to fulfil the caregiving needs

This study revealed that 15 caregivers expressed a desire for healthcare professionals to offer personalised and professional guidance and support concerning pressure injuries during patients' stay at the hospitals. Previous study indicates the vast challenges faced by caregivers when caring for patients with pressure injuries. Before formulating caregiving plans, it is essential for caregivers to clearly understand the kind of support and assistance they require (Haesler et al, 2022). Therefore, upon a patient's admission, nurses should fully comprehend the patient's background and actively communicate with their caregivers, inquiring about their needs. Caregivers should receive one-on-one educational sessions on pressure injuries, tailored to their specific situation, and be provided with handbooks consisting of essential guides and information. Additionally, for the technical care procedures for pressure injuries, caregivers can be educated through demonstrations, instructional

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videos, and other means to learn the correct care methods. This will help prevent improper practices, such as dragging patients during turning or massaging reddened areas.

Ageing exacerbates the fragility of human skin and decreases its ability to withstand pressure (Dyer and Miller, 2018). The existence of underlying diseases and other factors further complicate the illness, prolonging the healing process of pressure injuries 42 or increasing the likelihood of its recurrence. Thus, after discharge, caregivers take over the responsibility to care for patients and prevent the occurrence of pressure injuries. This study shows that five caregivers expressed concerns about their inability to provide professional care to the PI post-discharge and hoped to continue receiving expert assistance from the hospital staff. Additionally, 14 caregivers stated that they preferred hospital assistance over aid from the community or other medical institutions, because they believe that hospital staff is more professional. Before discharging patients, healthcare providers should inform caregivers in detail about the treatment and care procedures needed for pressure injuries and provide thorough health education. Furthermore, hospitals should establish a routine hospital-home medical service for patients with pressure injuries, scheduling regular follow-ups, notifying patients and caregivers about check-ups through calls or text messages, and expanding online consultation services to readily address the challenges of caregivers and offer professional guidance.

For bedridden elderly, caregivers' attitudes play a significant role in their treatment. Understanding the actual needs of caregivers during the caregiving process and prompting a collaboration between caregivers and medical staff are crucial for preventing and treating pressure injuries (García-Sánchez et al, 2019). Based on the results of this study, most families, due to a lack of attention to pressure injuries, do not seek timely medical help for elderly individuals suffering from such injuries but rather choose to deal with it according to their own experience. Professional help and guidance come to the caregivers only when the patients are admitted to the hospital due to other diseases. While the patients are hospitalised, caregivers get to learn about professional treatment and care related to pressure injuries and recognise the dangers associated with them. Upon discharge, it is common for most caregivers to express the urgent need for continuous help and guidance from the hospital staff.

Limitation

The current research is a qualitative study of a limited sample size, focusing exclusively on elderly patients with PI under home care. Future research should consider cross-sectional study design, employing a larger sample with a wide and diverse coverage of patients to address the existing gaps. Such a study design improvement would offer a more comprehensive reference for the development of a PI prevention plan tailored to bedridden elderly individuals under home care.

Conclusion

The results of this study show that caregivers lack the awareness of PI prevention and the appropriate caregiving attitudes. The caregiving process puts them under significant stress and negative emotions such as anxiety or depression. Many caregivers also expressed that they desire practical support from hospitals and other relevant entities in the management of pressure injuries. By enhancing the collaboration between hospitals and families, medical staff, and caregivers in the management of pressure injuries, we aim to improve the quality of care for PI wounds, further enhance the quality of life for patients and their caregivers, optimise the management of pressure injuries, lower the incidence of pressure injuries, and reduce the rate of rehospitalization.

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Key points

- This qualitative study aims to understand and explore the perceptions of caregivers of elderly patients who have developed pressure injuries at home, as well as their psychological state and needs during the caregiving process.
- Research reveals deficiencies in caregivers' awareness, significant psychophysical stress during care, and the need for supportive expectations from hospitals.
- Deficiencies in caregivers' awareness include vague and one-sided understanding, overly subjective and emotional approaches to understanding, weak preventive awareness with simplistic measures, and a lack of sufficient knowledge and importance placed on the harms.
- The psychophysical stress includes excessive negative emotions, and significant physical and financial burdens.
- Caregivers' expectations for hospital support during the care process include the need for personalised and professional nursing knowledge from medical staff, psychological and financial support from hospitals, and the demand for continuous medical services between hospitals and families.
- This suggests the importance of viewing the hospital-family/medical staff-caregiver dynamic as a collaborative entity in the management of pressure injuries, enhancing caregivers' ability to care for pressure injuries at home, focusing on caregivers' needs for disease-related knowledge and psychophysical support, promoting communication between medical staff and caregivers, and encouraging positive, correct, and effective care behaviours.

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Availability of data and materials

All data included in this study are available upon request by contact with the corresponding author.

Author contributions

Study concept: JQS and PY; data curation: LLZ and XJL; writing and original draft: JQS and LLZ; writing, review and editing: XJL. All authors contributed to important editorial changes in the manuscript. All authors read and approved the final manuscript. All authors have participated sufficiently in the work and agreed to be accountable for all aspects of the work.

Ethics approval and consent to participate

This study followed the principles of informed consent, confidentiality, beneficence, and non-maleficence and has been approved by the Ethics Committee of Jiangnan University Medical Centre (Approval number: 2024-Y-15).

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Conflict of interest

The authors declare that they have no conflicts of interest.

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