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## Research Article

# The Lived Experience of Frailty in Patients Aged 60 Years and Older with Heart Failure: A Qualitative Study



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## SUMMARY

**Purpose:** The prevalence of frailty among patients with heart failure is about 45%. Frailty may result in patients' functional decline, falls, disability, and decreased quality of life. Qualitative studies can explore older patients' perceptions of frailty and help patients cope with it. However, a qualitative approach that explores the experience of frailty in older patients living with heart failure is lacking. This study aimed to explore the lived experience of frailty in older patients with heart failure.

**Methods:** This qualitative study applies Giorgi's phenomenological method. Data were collected from October 2019 to August 2020. Thirteen older patients with heart failure aged at least 60 years were recruited using purposive sampling from a medical center in Taiwan. The participants participated in an in-depth interview using a semistructured interview guide.

**Results:** Seven themes were identified: "being reborn at the end of the road but having difficulty recovering", "living with a disease with an ineffable feeling", "feeling like being drained: physical weakness and a dysfunctional body", "struggling with impaired physical mobility and facing unexpected events", "suffering from mental exhaustion", "receiving care from loved ones", and "turning over a new leaf".

**Conclusions:** Frailty in older patients with heart failure was obscure and difficult to describe. Frailty could be improved by medical intervention, self-management, and social support but was difficult to reverse. Patients with heart failure should be evaluated for frailty using multidimensional assessment tools at first diagnosis and provided frailty-related information so that patients have proper insight into their disease as early as possible.

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## Introduction

Frailty is defined as a multidimensional and dynamic syndrome involving physiological, psychological, and social environmental aspects [1]. During aging, the decline in physiological reserve capacity reduces an individual's ability to resist stressors and recover from stressful events, resulting in functional decline, falls, disability, increased demand for medical care, decreased quality of life, and eventually even death [2,3]. Physical frailty is caused by skeletal and muscular changes resulting from disease and aging and chronic malnutrition resulting from neuroendocrine disorders, which lead to sarcopenia [4]. Sarcopenia reduces muscle strength,

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maximum oxygen consumption, and the resting metabolic rate, leading to a lower walking speed, reduced physical activity, and decreased total energy expenditure; sarcopenia renders individuals incapacitated and dependent on others in activities of daily living (ADLs), forming a vicious cycle. Fried et al. defined frailty as a clinical symptom in which three or more of the following criteria were present: unintentional weight loss, self-reported exhaustion, weakness (grip strength), slow walking speed, and low physical activity [4]. The authors found that the prevalence of frailty in the community-dwelling population was 6.9% [4].

The risk of frailty among patients with heart failure is six times higher than that among older people [5]. The prevalence of frailty among people who have heart failure is approximately 45% [6]. Among people who have heart failure, approximately 20% have sarcopenia and 10% have cardiac cachexia [7]. When an excessive loss of skeletal muscle and adipose tissue causes cardiac cachexia, patients experience unexpected weight loss, a decline in muscle strength, fatigue, loss of appetite, an abnormal inflammation index, an abnormal serum albumin value and anemia, making patients frail and decreasing their mobility [8]. Frailty is a dynamic condition that changes with the patient's health condition and can be either reversible or irreversible in patients with heart failure. A failure to cope with internal and external stressors can worsen frailty and exacerbate illness in patients with heart failure, leading to hospitalization, disability, institutionalization, and mortality [5,9]. Therefore, the care of patients with heart failure should also involve evaluating and managing frailty and its related factors to prevent patients from experiencing adverse consequences.

Previous research on frailty has focused mostly on older people. These studies found that physical frailty caused older people to have difficulty walking and to be afraid of falling, caused weight loss, decreased their visual acuity, and caused them to become socially isolated, while psychological and cognitive frailty mostly manifested as amnesia, a decreased ability to concentrate, and memory decline [1,10]. In addition, older adults held negative thoughts and attitudes toward frailty; they considered frailty a derogatory term and felt that they had lost control and had no ability to adapt to stress [1,11]. Some older adults attributed their frailty to age, mobility limitations, and poor health, while some older adults did not identify themselves as frail even if they had mobility limitations and poor health. Additionally, the recognition of frailty can be challenging in individuals with heart failure, as these two conditions share similar pathogenic mechanisms, symptoms, and prognoses [6,12]. Therefore, understanding patients' perception of and lived experience with frailty is a pivotal step in helping patients cope with frailty.

However, existing qualitative studies have focused mostly on the lived experience of older people living with frailty [1,10,13,14]. The lived experience of patients who have heart failure living with frailty has been relatively unexplored. Hence, researchers have suggested that future research should be conducted from the perspective of heart failure (HF) patients and expanded to include patients' opinions toward frailty to fill the current research gap [6,12]. Therefore, the aim of this study is to investigate the lived experience of frailty in older patients with heart failure, including their perceptions of both heart failure and frailty, as well as their coping strategies. Qualitative research methodologies will be utilized to achieve these objectives.

## Methods

### Design

This study used a qualitative research design that applies Giorgi's phenomenological method to in-depth interviews [15].

### Setting and participants

Study subjects were recruited from the cardiology outpatient clinic of a medical center in Taiwan. Purposive sampling was used, and a wide range of demographic characteristics were secured to facilitate sufficient data richness. The inclusion criteria were as follows: each patient (1) was diagnosed with heart failure by a cardiologist (ICD-509, 5020); (2) was at least 60 years of age; (3) had a stable disease condition identified by a cardiologist; (4) had a clear consciousness, could express himself or herself, and could communicate in Mandarin Chinese or Taigi; (5) had normal cognitive function. We included participants aged 60 years and above because the mean age of patients with heart failure in Taiwan is over 60 years. Cognitive function was evaluated using the Short Portable Mental Status Questionnaire (SPMSQ) and considered normal for participants with an elementary school education and who answered only 0–2 questions incorrectly [16]. Patients whose SPMSQ score >2 were excluded because we wanted to explore the essence of frailty specific to the heart failure condition, rather than the influence of any other major contributing factor.

During the study period from October 2019 to August 2020, 16 patients with heart failure were eligible for inclusion in this study. Three of the patients felt that too much effort would be involved; therefore, they refused to be interviewed. Finally, 13 patients were willing to participate in an in-depth interview.

### Data collection

This study was approved by the Institutional Review Board of the Wu Ho-Su Memorial hospital (Approval no. 20181204R). After being introduced by the cardiologist, the researcher (first author) contacted and built a trusting relationship with the participants before conducting the interviews to facilitate the participants' expression of their feelings. The researcher explained the purpose and procedures of the study to the participants and obtained signed consent forms from them. The researcher collected general information, such as age, gender, marital status, educational level, religion, residence status, work status, and financial status, through a personal information sheet. Additionally, disease-related information such as the duration of heart failure, current comorbidities, medication use, number of hospitalizations, surgical history, history of falls, overall daily functioning, disease severity, and left ventricular ejection fraction (LVEF), was obtained by the researcher from the electronic medical records. All participants were evaluated for cognitive function using the SPMSQ and then participated in an in-depth interview. All semistructured interviews were conducted by the first author, who is a registered nurse who had completed a qualitative research and phenomenology course, had previously participated in research projects related to heart disease, and had experience providing care to patients with heart disease. The interviews were one-on-one and conducted in a quiet and private space in the outpatient clinic or the participant's home. The investigator followed interview guidelines to assist the interviewee in recalling their experience with frailty. The interview guidelines were developed by the research team based on a literature review, researchers' practical experience and qualitative experts' suggestions (Table 1). All interviews lasted 45 to 60 minutes and were audio recorded in their entirety.

### Data analysis

The data were analyzed using Giorgi's [15] four-step method: (1) the entire written account was read for a sense of the whole; (2) meaning units were identified and delineated; (3) the meaning units were transformed into psychologically sensitive statements of their lived meanings; (4) a general psychological structure of the

**Table 1** Interview Guidelines.

1. Opening: How do you feel about your health since you had heart issues?
2. Main questions:
(1) In your own words, how would you define frailty?
(2) Do you perceive yourself as being frail?
2-1 Questions for participants with frailty:
2-1-1 What symptoms or discomforts make you think you have frailty?
2-1-2 In your opinion, why do you have frailty? (What are the causes of your frailty?)
2-1-3 What problems have frailty caused in your life?
2-1-4 How do you cope with your frailty? (What have you done to improve your frailty?)
2-2 Questions for participants without frailty:
2-2-1 Why do you think you do not have frailty?
2-2-2 In your opinion, what are the symptoms of frailty?
2-2-3 In your opinion, why does a person become frail? (What are the causes of frailty?)
2-2-4 What disturbances and impacts can frailty cause in a person's life?
2-2-5 How can frailty be prevented or improved?
3. Ending: Are there other experiences we have not mentioned in the interview but you want to share? In your opinion, is there anything else related to the topic of this interview or the lived experience of heart failure patients with frailty that should be further discussed in detail?

experience was synthesized. Both the first author and corresponding author involve in the data analysis process. First, the first author of this paper transcribed verbatim the full audio-recorded interview data into transcripts. Then, the first author read the transcripts at least twice prior to data analysis. The meaning units were delineated from the interview data and transformed to generate subthemes and themes. The corresponding author also independently reviewed and transformed the data. Data collection and analysis continued until the point of data saturation. Ultimately, seven themes were determined after discussion and modification by two researchers.

Lincoln and Guba's criteria were adopted to ensure the rigor of the study findings [17]. To ensure credibility, the first author invited participants to review whether the analysis results truly reflected their life experience and received peer reviews from qualitative research experts. To improve transferability, in-depth interviews were conducted using open-ended questions, and participants with different characteristics were selected by purposive sampling to increase data diversity and abundance. To ensure dependability, the data analysis process was recorded and documented in detail and reviewed by experts for its appropriateness of classification. To ensure confirmability, the researchers constantly reviewed and clearly documented the transformation and classification process for the raw data.

**Table 2** Characteristics of the Participants.

No.	Age	Gender	Marital status	Educational level	Living with whom	Financial status	HF duration (year)	NYHA	EF (%)	Overall ADLs functioning
A	78	Women	Widowed	Elementary school	Foreign domestic worker	Average	1.08	II	59	Slightly dependent
B	65	Men	Separated	Associate degree	Family member(s)	Average	6.58	II	32.6	Completely independent
C	86	Men	Married	High school	Family member(s)	Well-off	0.08	II	64	Completely independent
D	79	Women	Married	Elementary school	Family member(s)	Average	3.67	III	44	Completely dependent
E	60	Men	Married	Middle school	Family member(s)	Wealthy	2.17	II	38	Completely independent
F	66	Women	Married	High school	Family member(s)	Well-off	0.58	II	52	Completely independent
G	84	Men	Married	Elementary school	Family member(s)	Average	5.17	III	79	Slightly dependent
H	62	Women	Married	Elementary school	Family member(s)	Well-off	4.92	II	20	Completely independent
I	86	Women	Widowed	High school	Family member(s)	Wealthy	4.17	II	72	Moderately dependent
J	68	Men	Married	Elementary school	Family member(s)	Average	7.50	III	60	Slightly dependent
K	82	Men	Married	Elementary school	Family member(s)	Well-off	12.75	II	58	Completely independent
L	92	Men	Married	High school	Family member(s)	Well-off	5.58	II	50	Completely independent
M	78	Men	Married	Elementary school	Family member(s)	Average	3.08	II	62	Completely independent

ADLs= activities of daily living; HF= heart failure; LVEF= left ventricular ejection fraction; NYHA= New York Heart Association functional class.

## Results

### Characteristics of the participants

The average age of the 13 participants (coded A to M) was 75.84 years (between 60 and 92 years). Most participants were males ( $n = 8$ ), were married ( $n = 10$ ), were living with family ( $n = 12$ ), had received only an elementary school education ( $n = 7$ ), and were completely independent regarding ADLs ( $n = 8$ ); additionally, the plurality of participants had an average financial status ( $n = 6$ ). The average duration of heart failure was 4.41 years (between 0.08 and 12.75 years), and most patients were classified as New York Heart Association (NYHA) functional class II ( $n = 10$ ). The LVEF was 53.1% on average (Table 2). According to participants' responses to the interview questions, when asked "Do you perceive yourself as being frail?", 10 participants described themselves as having frailty. The remaining three patients' family members also believe that these patients are experiencing frailty.

### Themes

Seven themes were extracted (Table 3): (1) being reborn at the end of the road but having difficulty recovering, (2) living with a disease with an ineffable feeling, (3) feeling like being drained: physical weakness and a dysfunctional body, (4) struggling with impaired physical mobility and facing unexpected events, (5) suffering from mental exhaustion, (6) receiving care from loved ones, and (7) turning over a new leaf.

Overall, the results showed that frailty in people who have heart failure was obscure and difficult to describe (**living with a disease with an ineffable feeling**). In patients who had poor overall health that leads to dependence or death (**feeling like being drained: physical weakness and a dysfunctional body**), any change could easily disrupt the balance of physiological and adaptive functioning, affecting physical functioning and psychological cognition (**struggling with impaired physical mobility and facing unexpected events; suffering from mental exhaustion**). Under such circumstances, the power that enabled the patients with heart failure to hold themselves together came from self-management (**turning over a new leaf**) and support from healthcare workers, family members, friends, and the social environment (**receiving care from loved ones**). Although the frailty state of patients with heart failure could be maintained or improved by the approaches above, a full recovery was difficult (**being reborn at the end of the road but having difficulty recovering**) (Figure 1). Table 3 shows the themes, subthemes, and quotes from the interviews.

**Table 3** Themes, Subthemes, and Quotes from the Interviews.

Theme/subtheme	Quotes from the interviews
<b>Theme 1 Being reborn at the end of the road but having difficulty recovering</b>	
Aging	"Doing things by myself when I was young and watching television at home when I got old. This is aging, a natural phenomenon." (Participant L)
Feeling weak and powerless despite a strong will	"Frailty is just feeling weak, powerless, not in a good physical condition. I must use a wheelchair ... I need my husband to buy food for me, and he accompanies me to dialysis 3 days a week ... I cannot do anything without my crutch." (Participants D) "Frailty is a sense of feeling weak, having no energy, having a hard time breathing, becoming very tired after only 2-3 hours of shopping, having a weak heart and weak lungs, having no energy to chew food, having a poor appetite, having trouble falling asleep, being very tired, and having low sleep quality." (Participant H)
Difficult to recover although there is a slim hope	"I do feel better, but it is impossible to completely recover. Now, I must eat some food to improve my physical strength before exercise. It works a little bit, but I still feel weak. I was thinking about taking Ensure (supplement), but it won't make me jump higher ... (Frailty) just cannot be cured by doctors and have a full recovery of energy like some other diseases." (Participant B)
<b>Theme 2 Living with a disease with an ineffable feeling</b>	
Living with a disease and feeling different than others	"(Thinking) ... I don't know what has changed about me; I cannot tell because I am living with the disease and got used to it." (Participant J)
Lacking recognition of frailty	"I don't understand. Do you think I am frail? Is this called frailty?" (Participant I) "What is frailty? I didn't have much education, so I don't understand this term." (Participant J)
<b>Theme 3 Feeling like being drained: Physical weakness and a dysfunctional body</b>	
Age-related changes in physiological functioning	"I have anemia and have had knee replacements. I have kidney disease and need dialysis. I can only eat beef that is cooked for a long time until it turns into liquid//I have become so thin after being frail that all my skirts are too loose to wear ... My weight is only 39 kg ... everybody says that I am too thin, but I can't gain weight no matter how much I eat." (Participant G)
Being affected by comorbidities	"Lower back pain can never improve no matter which doctor you see (shaking head). The ophthalmologists said they can't treat my poor vision. I have been suffering from tinnitus and dizziness, which also can't be treated//I am short of breath even when I walk only several steps, and exercise can be unbearable ... I would be tired and go to bed before finishing my meal ... I would sit on my butt and slide down when I try to walk down the steps because my legs are so weak ... feel dizzy 24 hours a day ... My doctor told me not to drink too much water, but then, I am often constipated, so I must use full strength to poop ... I have a poor appetite, which makes me frail because I eat too little ... I wake up after less than 2 hours of sleep, and even sleeping pills don't work//It is painful (pointing at the shoulders)! I feel pinching pain if I try to move them. I cannot work on my feet. I must use a crutch and walk very slowly because of pain. I feel pain if I walk too far ... I feel visceral pain every time I get dialysis ... I have a horrible headache like there is a fight in my head." (Participant J)
Poor self-management	"I am living in the moment with no thought to the future. I don't want to take too many medications since they don't work anyway." (Participant B)
Poor socioeconomic conditions	"I am slowly losing my physical strength because I exercise less after I retired....my appetite is getting bad, too//I don't have any retirement pension. Therefore, I live day by day with the necessities." (Participant C)
Managing with a dysfunctional body	"I have fallen several times already//I could not walk downstairs and didn't go out for a week//I don't have other choices. I need other people's help for everything, including cooking food, serving me food, helping me take a bath.... I have to bring my crutch even when I go to hospital.... My life is all about dialysis because I won't survive without dialysis//If it is time for me to die, just let me go. I told my wife that I definitely don't want CPR and life support. It is meaningless to keep me alive like that....Let my death be natural.... Leaving without CPR is better.... If our government allows euthanasia like other countries, I will definitely apply for it." (Participant J)
<b>Theme 4 Struggling with impaired physical mobility and facing unexpected events</b>	
Reduced physical activity and mobility	"My feet become numb when walking. I will lose feeling from here (pointing at the legs) to here (pointing at the knee) after walking just 100 meters, and then my feet can no longer move." (Participant L)
Deteriorated mobility	"My weak and thin legs have only bones left without muscle. I cannot make a three-point shot even with a very light ball. Even though I use all my strength to kick a ball, the ball will not reach the gate. My muscle strength is gone//I won't be able to stand and will fall if I try to jump down from bed. I don't feel like I can keep my feet firmly on the ground when running. My arms and legs are sore, so I cannot run fast. I used to do pushups before going to bed, but now I won't be able to get up if I lie down." (Participant B)
Medication-, treatment-, and surgery-related medical interventions	"Drugs would weaken the functioning of the body.... Surgery made my whole body powerless. My body was cut open, making my Qi leak out a lot. Since then, my health has worsened badly, and I feel very weak." (Participants B)
Physiological parameters, events, changes in the amount of physical activity, and stressors	"I don't feel well, and my eyes sting when my blood sugar level and blood pressure are high. I feel so horrible when my blood sugar level becomes very high//Herpes made me uncomfortable. I have been losing weight.... Getting a cold makes me not to feel well//I feel uncomfortable with my heart if I don't go out and don't exercise for 2 to 3 days (tapping the chest) ... If I don't walk, I feel horrible and feel bloated. It is good to take walks." (Participant A)
<b>Theme 5 Suffering from mental exhaustion</b>	
Psychological suffering caused by physical suffering	"I am living in fear of the onset of the disease. I am afraid of chest pain when I am short of breath." (Participant M)
Suffering from negative emotions	"A bad mood can cause frailty. I can't go out because I don't feel well and have no energy, which upsets me." (Participant D)
Suffering because of feeling hopeless	"I no longer have any expectation.... I don't care about anything, don't believe the future can be good. What can a good future bring to me? There is no hope that my body can become as strong as before.... I have lost hope and ambition.... I used to be willing to fight//It is better to ignore the

Table 3 (continued)

Theme/subtheme	Quotes from the interviews
Being distressed by impaired cognitive function	disease, so I don't think too much.... I often try to get relief by smoking cigarettes. I would smoke all day." (Participant B) "I hate to see myself in a mirror//I feel it is better to die, but it is not easy to die .... If I go out tonight and meet somebody who gives me some poison, I will eat it because I truly feel miserable and want to die! I now understand why people jump from buildings and kill themselves when they get sick and don't want to live anymore." (Participant F) "There was a period I lost my memory and forgot everything.... My memory gradually came back a half year later//I have to rely on GPS to drive. I don't read GPS well, and I don't drive as well as I used to. I couldn't reverse my car smoothly and properly several times." (Participant E)
<b>Theme 6 Receiving care from loved ones</b>	
Family's help	"Everybody in my family visited me when I was in the hospital for surgery .... Everybody was happy because they came back once a month.... My son will handle everything for me if I tell him.... If I am picky with food and refuse to eat, my family will tell me I can't do that." (Participant A)
Friends' companionship	"Many friends came to see me and care about me. My friends will order food and send food to my house whenever I ask." (Participant F)
Healthcare workers' guidance	"Since my doctor told me not to eat hotpot, I have never touched hotpot//I returned to normal by taking only four little pills.... After seeing the chief physician, now I can fall to sleep immediately after I lie down .... I am lucky to have good doctors behind me. They saved my life so I can continue to live." (Participants F)
<b>Theme 7 Turning over a new leaf</b>	
Breaking free of restraints and protecting the body	"I play ball every day. It is important to properly use physical strength .... I paid attention to food and exercise. It is unnecessary to ask for help for everything. I try to handle things by myself//If possible, I would rather take drugs and avoid surgery. I thought about lifting dumbbells and barbells like before, but it is difficult to even hold a ball with my hands. Therefore, I am kind of passive." (Participant B)
Self-monitoring and self-management	"Medications prescribed in the hospital are good. Why would I take other drugs? I take Wakamoto [a gastrointestinal remedy] if I have a bowel issue//I don't drink too much soup ... eat vegetables, egg, and meat//I stand up for a half hour at home.... I go out and get some sunshine if I feel okay." (Participant J)
Getting help from others and calming the mind	"Vitamins work very well. I feel good if I take them every day and feel down if I stop taking them//I pray to Avalokiteshvara to save me from suffering and distress. I hope this will make me get well soon. My pet's companionship gave me lots of relief.... I rewarded myself by having a good meal. I was relaxed and happy.... My expectations have changed. I am happy that I am alive. I don't want more as long as I am still alive." (Participants B)
Locking oneself up	"It is no use to tell other people. Talking about this just adds to the pain. I don't want to bring more trouble to young people because I need to go out.... I will take whatever other family members give me." (Participant A)
Adaptation to living conditions	"I can do more exercise and don't get tired if the air quality is good. If the air quality is not good, I can only sit there and wear my oxygen device ... //(I have to climb downstairs if I go to the first floor from the second floor in my house) I am too lazy to go downstairs ... too hard to breathe." (Participant A)

CPR= cardiopulmonary resuscitation; GPS= global positional system.

### Theme 1: being reborn at the end of the road but having difficulty recovering

Frailty was seen by people who have heart failure as a natural part of aging. Patients believed that frailty was caused by a gradual decline in physiological, psychological, and ADL functioning. Disturbed by physiological symptoms, such as difficulty breathing, fatigue, weakness, poor appetite, dizziness, sleep problems, heart discomfort, edema, and nocturia, the participants could not perform ADLs as well as before their diagnosis, feeling powerless despite their strong will. ADLs were affected by a decline in physiological functioning, leading to dependence on assistive devices or the assistance of others to complete ADLs. Furthermore, the participants were distressed psychologically with negative emotions. Frailty might be improved by self-management with drugs and diet as well as medical interventions, but a full recovery was difficult (Participant B, D, H, L in Table 3).

### Theme 2: living with a disease with an ineffable feeling

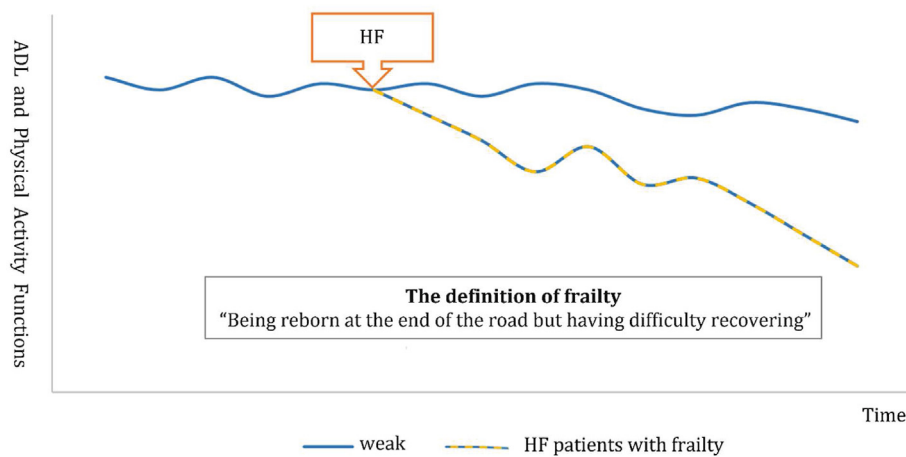
People who have heart failure were generally accustomed to the changes resulting from the decline in heart function and believed that they were not significantly different from their past selves; therefore, they did not readily acknowledge that they had become frail. In addition, they often lacked an understanding of the

definition of frailty; thus, it was difficult for patients with heart failure to describe their frailty. Many patients with heart failure felt that understanding the concept of frailty was too difficult for them. Some patients experienced difficulties in comprehending the concept of frailty during interviews. Patients with heart failure gradually adapt to the changes induced by their disease over time, leading to a lower sensitivity to frailty-related symptoms. However, those close to the patients, such as family members or caregivers, may be more likely to recognize signs of frailty and related changes in these individuals (Participants I and J in Table 3).

### Theme 3: feeling like being drained: physical weakness and a dysfunctional body

Internal and external stressors were not the direct factors causing the collapse of people who have heart failure; instead, their overall health status plays a crucial role in determining their collapse. Patients with heart failure gradually felt frail once the "foundation" of the body eroded. People who have heart failure are at a higher risk of developing frailty due to age-related declines in physiological functioning and the presence of multiple co-existing diseases. The symptoms experienced by patients with heart failure are often uncomfortable, severe, and difficult to manage, causing significant suffering. These symptoms can be divided into heart failure-related symptoms (e.g., difficulty breathing, fatigue,

## A. Definition of frailty



## B. Frailty in heart failure patients

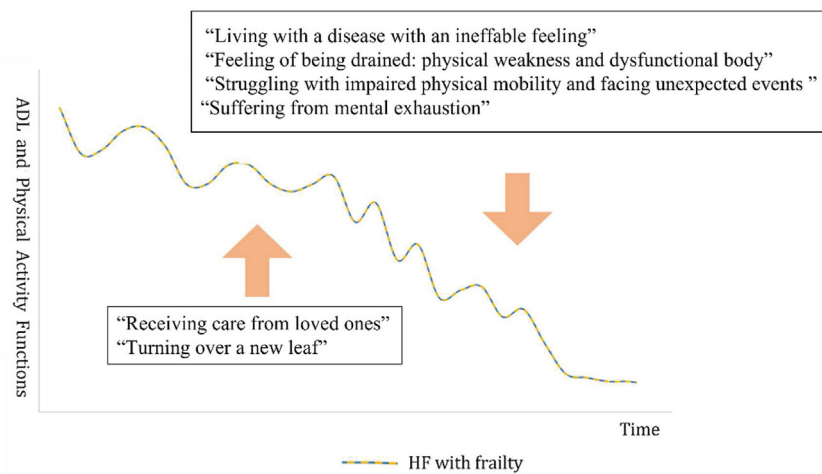


Figure 1. Experience of Frailty in Patients with Heart Failure.

weakness, poor appetite, dizziness, sleep problems, chest pain, edema, and nocturia) and non-heart failure-related symptoms (e.g., pain). Long-term discomfort makes patients feel frail (Participants G and J in Table 3).

People who have heart failure are at a higher risk of developing frailty if they do not perform self-management well. For example, excessively relying on others causes patients to have less of a chance to actively participate in their own care, have poor dietary self-management (e.g., imbalanced diet and lack of knowledge of diet for heart failure), non-adherence to medications, and poor lifestyle habits (e.g., smoking and lack of regular exercise). Socioeconomic conditions, such as work hour flexibility, retirement, and financial status, also affected frailty status (Participants B and C in Table 3).

Frailty will eventually make patients too weak to handle any life changes; as a result, a small event may lead to a decline in overall health, causing patients to stay at home and gradually become dependent. In addition, patients live in fear of death because they realize their life will not last long; however, they still want to tell other people that they want the end of life to be good—this is their most notable desire (Participant J in Table 3).

#### Theme 4: struggling with impaired physical mobility and facing unexpected events

People who have heart failure believed that decreased physical activity and declining physical functioning limited their mobility and caused frailty. Patients' activity intolerance and fear of falling led to a sedentary lifestyle with a substantial amount of sitting and lying down, causing patients to become frail. Frailty is also associated with decreased muscle function and poor physical functional performance. Muscle functional decline manifests as reduced muscle volume and decreased muscle strength and endurance. Poor physical functional performance is characterized by unsteadiness while standing and walking, a slow walking speed, a short walking distance, and difficulties in completing activities that could be easily completed in the past (Participant B and L in Table 3).

In patients with heart failure, sudden events or changes can disrupt the stable state and lead to significant declines in overall health, ultimately resulting in frailty. The occurrence of frailty was related to medical interventions. For example, the effects and side

effects of drugs, adjustments of medications, or hospitalization for surgery or other treatments exacerbated frailty. Additionally, frailty was related to unstable physiological parameters, unexpected events (e.g., getting a cold or falling), an increase or decrease in physical activity, and stress (Participants A and B in Table 3).

#### *Theme 5: suffering from mental exhaustion*

People who have heart failure described that physical discomfort can cause mental exhaustion, negative emotions, and even desperation because patients feel hopeless and give up on themselves. In addition, a decline in cognitive functioning affects daily living and self-care, causing patients to suffer. Hence, suffering from mental exhaustion is a risk factor for frailty.

The changes in physiological functioning caused patients with heart failure to worry constantly that their body would suffer more if another unexpected event occurred. Facing the unknown and uncertainty is a type of mental suffering. Common negative emotions were frustration and depression. For example, the patients were frustrated about their poor health, about the trouble and burden they might bring to others, and about their family; consequently, they became worried and upset (Participant D and M in Table 3).

The patients suffered from uncertainty about the future and hopelessness because their overall functioning had gradually weakened, and there was no effective way to improve or control the weakening. The patients lost the willpower to fight against the disease and had negative self-evaluations because the gap between expectations and reality had made them lose hope and give up on themselves. Due to frailty-caused physical discomfort, the patients felt that their life was miserable and that it was better to die than to live (Participants B and F in Table 3).

Cognitive decline made self-care and daily life difficult, thereby accelerating the decline. Cognitive decline commonly manifests as a decline in memory, language function (difficulty in comprehension, expression, and naming), the ability to make decisions, and executive function (Participant E in Table 3).

#### *Theme 6: receiving care from loved ones*

People who have heart failure realized that it was difficult to handle frailty by themselves, and therefore, support from loved ones and health care providers was important. However, the effort from family can be both positive and negative. Family support can help patients fight frailty. Providing caring and companionship, assisting with daily care tasks, and offering reminders and suggestions related to medical care can be beneficial to patients with heart failure, especially when provided by family members. However, an insufficiency of caring knowledge and ability by family members may generate negative outcomes. For example, the family's misconception that the patient should not eat too much or eat meat might cause dietary protein insufficiency. Therefore, a lack of knowledge regarding care is a risk factor for frailty. Additionally, to prevent their loved ones from sustaining further injuries or experiencing additional pressure, family members of patients with heart failure may become overly protective and inadvertently deprive the patients of the opportunity to perform ADLs independently, thereby increasing their risk of developing frailty (Participant A in Table 3).

Thorough communication and explanations by healthcare providers can eliminate the confusion of patients regarding the disease, medication, and treatment of heart failure. An insufficiency of instructions specifically regarding a patient's condition might increase the risk of the patient becoming frail. Proper treatment that can effectively control the symptoms of and discomfort in patients with heart failure can reduce the risk of developing frailty (Participant F in Table 3).

#### *Theme 7: turning over a new leaf*

People who have heart failure can develop new lifestyles to cope with heart failure-related frailty. The coping strategies include positive and negative strategies. Some patients were motivated to break free from the current restraints when they were in a frail state. For example, they developed a stronger desire to pursue their goals; because they did not want to become a burden to other people, they did everything by themselves and worked hard to be independent; additionally, they took measures to protect their body, such as by keeping warm, avoiding unnecessary injury, and decreasing physical activity, to minimize their risk of frailty (Participant B in Table 3).

People who have heart failure coped with frailty-related changes through self-management, such as cooperating with health care providers to take medications and receive treatment, monitoring and treating discomfort, managing their diet, managing physical activity, and maintaining ADLs as much as possible. Assistance of others could effectively maintain or improve frailty. Discussing the disease with health care providers, finding traditional Chinese medicines or dietary supplements as a substitute treatment, blending into society again, and keeping a peaceful mind (e.g., through religion, by emotional adjustment, and by being open-minded rather than stubborn) can reduce the emotional changes brought by frailty (Participant B and J in Table 3). Some patients with heart failure took negative strategies to cope with frailty. To reduce the burden on caregivers, these patients cooperated with other people in all aspects of life and hid their true feelings, or they treated other people with a grumpy or indifferent attitude and became homebound to avoid being seen by others (Participant A in Table 3).

## **Discussion**

As shown in previous studies, heart-failure-related frailty is a multidimensional and multisystem syndrome that often occurs in older people who have heart failure and causes functional decline and adverse clinical consequences [18]. However, a systematic review of 26 studies including 6896 people who have heart failure found that frailty is not just an aging-related syndrome in people who have heart failure; instead, it may also involve functional decline in other domains [6]. Our study found that individuals with heart failure had difficulty acknowledging the presence of frailty and describing their experience with frailty. This difficulty was particularly pronounced in participants with limited knowledge about frailty, those experiencing symptoms associated with heart failure, those with an elementary school education, those classified as NYHA class II, and those with a LVEF greater than or equal to 50%. Our findings are consistent with a previous study [19]. Furthermore, people who have heart failure were found to hold a negative stereotyped opinion about frailty, as evidenced by the fact that the patients often used “that” and “like that” to avoid directly using the word “frailty.” This finding is similar to the results reported by previous studies [20,21].

Due to the normalization and coexistence of symptoms of heart failure, individuals with heart failure may have difficulty recognizing the presence of frailty, which can make frailty difficult to articulate or express for some patients with heart failure. Individuals with heart failure often have poor overall health, and as a result, any change can easily disrupt the delicate balance of their physiological and adaptive functioning. This disruption can affect their physical functioning and cognitive processes, potentially leading to a gradual decline in their overall health. Ultimately, this decline can increase their dependence on others or even result in death. Under such circumstances, self-management of heart failure symptoms and patient adherence to



medical treatment are critical factors that enable patients to maintain their health. However, completely reversing frailty can be challenging. Therefore, it is suggested that cardiovascular nurses provide patient education on the concept of frailty and its connection to heart failure. They should also emphasize the crucial role of symptom management, medication adherence, and lifestyle modifications in preventing frailty, especially for patients with lower educational levels or mild disease severity.

Based on the findings of this study, the factors influencing frailty can be divided into six dimensions: basic attributes, physiology, sources of internal and external stress, ADL functioning and mobility, psychological cognition, and social environment. With aging and declining overall health in people who have heart failure, sudden events may bring significant changes, leading to the deterioration of overall health conditions, functional decline in physical activity and daily life, psychological suffering, and cognitive decline. As a result, patients gradually lose their ability to interact and establish a good relationship with others, making them frail. However, support from the social environment (e.g., medical personnel, family, friends, and policies) is an important factor that reduces the risk of frailty [20]. It is recommended that nurses conduct a comprehensive assessment of frailty and its contributing factors in heart failure patients, and provide tailored nursing interventions, including patient education and necessary support. Moreover, educating family members about frailty-related issues can help patients in self-managing heart failure symptoms and coping with internal and external stressors, thereby preventing the development of frailty.

Frailty can cause a decline in overall health among people who have heart failure, leading to a series of adverse effects. These effects may include frequent hospital visits, an increased risk of injury, longer recovery times, a greater burden on family caregivers, difficulty maintaining employment and earning income, and a decreased quality of life. Furthermore, frailty causes patients to gradually become dependent and even cause death [22]. Being frail caused people who have heart failure to realize that they were getting close to death and living under the threat of death. This result was consistent with the results of a qualitative meta-analysis [23], i.e., heart failure makes the prediction of physical changes difficult and brings uncertainty to the life of patients. In addition, frailty may activate proinflammatory pathways and reshape the structure of ion channels in the heart, resulting in heart rhythm disturbances due to abnormal cardiac depolarization and conduction. Consequently, people who have heart failure living with frailty are prone to arrhythmia and sudden cardiac death [24]. Therefore, it is important for frail people who have heart failure to discuss end-of-life care and prepare a medical care plan as early as possible. However, previous studies found that most people who have heart failure did not participate in end-of-life healthcare discussions with their families and healthcare providers, and the percentage of patients who utilized hospice palliative care was lower than that of cancer patients [25,26]. These findings suggest that healthcare providers should engage in discussions on palliative care and death-related topics with individuals who have heart failure.

People who have heart failure may develop new lifestyles to cope with frailty. Three types of coping strategies were found in our study: problem-focused coping, emotion-focused coping, and avoidance coping. Problem-focused coping involves solving the problem; this strategy is reflected in our study as “breaking free of restraints,” “protecting the body,” and “self-monitoring and management”. Emotion-focused coping involves reducing emotions caused by stress. This type of response is reflected in our study as “calming the mind” and “locking oneself up”. However, some patients who employ this strategy might have increased stress. Avoidance coping involves avoidance and distancing oneself from stressful situations,

e.g., distracting oneself with help from other people or by doing other things. This strategy is reflected in our study as “getting help from others.” However, the participants in our study did not report the use of avoidance coping strategies—distractions, such as eating one’s favorite foods, shopping, or watching TV. Socializing is tremendously troublesome for people who have heart failure as they are restrained by the decline in physical functioning and increase in dependence in ADLs. As a result, individuals with heart failure may have limited interests, which could explain why none of the participants in our study used distraction as a coping mechanism for frailty. Emotion-focused and problem-focused coping were negatively correlated with a sense of coherence and the mental quality of life [27]. Most of the participants in our study were living with family; therefore, we believed that they received sufficient support from family members. In addition, this study did not enroll any patients with psychological and emotional disorders. Therefore, most of the participants in our study had positive coping styles when handling the impact of frailty. These findings suggest that nursing care should incorporate the assessment of patients’ coping strategies and their adjustment to heart failure or frailty in order to enhance their mental quality of life.

Our findings further emphasize the significance of fortifying the heart failure case management system and promoting transdisciplinary collaboration in the care of patients with heart failure. A heart failure case manager provides personalized disease education, ongoing support, and follow-up and facilitates coordination with other healthcare providers to form a comprehensive care team. At the first diagnosis of heart failure, patients should be properly educated that frailty is not only an aging phenomenon but also related to functional decline in all domains as a result of the decline in heart function. The causes, prevention methods, and prognosis of frailty should be explained as soon as possible to help each patient gain a correct understanding of the disease and insight. In addition, the frailty status of each patient should be assessed regularly using the assessment tools with different dimensions so that an individualized care plan can be developed in a timely manner. The content of patient education may cover how to monitor medication and side effects, how to achieve a balanced diet, how to manage comorbidities and symptoms, physical activity, positive coping strategies for stress, and death-related topics at the end stage of the disease. Primary caregivers should be included in health education to improve their care knowledge and skills, provide continuous mental support, and correct their misconceptions if necessary, such as overprotection, which can accelerate frailty.

#### *Limitations*

This study included people who have heart failure and were 60 years old or over with low educational levels. Most participants were classified as NYHA class II and were mostly completely independent regarding daily living. Due to a lack of interviews with primary caregivers and the absence of observational methods, objective data on patients with a poor perception of discomfort were not obtained to explore the actual life experiences of individuals with frailty. Future research on heart failure should consider patients who are classified as NYHA class III/IV and are dependent regarding daily living. To minimize memory errors, inclusion criteria of participants should be those who have been diagnosed with heart failure for a certain period and have experienced frailty or been hospitalized recently. The educational level of patients and their ability to perceive heart failure symptoms, which affect their ability to understand frailty, should also be considered. In addition, primary caregivers should be included and interviewed. Furthermore, observational methods can be jointly used to increase the overall understanding of frailty.

## Conclusions

Frailty is often difficult for older patients with heart failure to describe or understand, particularly those with limited knowledge about frailty, lower education levels, or mild disease severity or symptoms. Many patients perceive frailty as a natural part of aging, caused by a gradual decline in physiological, psychological, and ADL functioning. Frailty is associated with overall health status, heart failure symptoms, sources of internal and external stress, and family support. Medical intervention, self-management, and social support can improve frailty, but it is difficult to reverse. Therefore, early detection of frailty is crucial for patients with heart failure, and multidimensional assessment tools should be used to evaluate frailty at first diagnosis. Providing frailty-related information early can help patients to better understand their disease and the concept of frailty. Further research is needed to identify suitable interventions for preventing and improving frailty in patients with heart failure living with frailty, ultimately promoting their quality of life.

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## Ethical approval

This study was approved by the Institutional Review Board of Shin Kong Wu Ho-Su Memorial Hospital, Taipei, Taiwan, R.O.C (20181204R).

## Authors contributions

Conception and design: HS, HFH, MHL, AFC; acquisition of data: HS, HFH, SPH, YCC; analysis and interpretation of data: HS, HFH, MHL, YCC, AFC; manuscript drafting: HS, AFC; manuscript revision and final approval of the version to be published: HS, HFH, SPH, MHL, YCC, AFC.

## Conflict of interest

None.

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## Research Article

## Development and Psychometric Evaluation of the Career Growth Scale for Nurses

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## SUMMARY

**Purpose:** The purpose of this study was to develop the career growth scale for nurses (CGSN) and evaluate its psychometric properties.**Methods:** This study was conducted in four phases: (1) creating a pool of potential items through a qualitative design; (2) developing a preliminary scale using a modified two-round Delphi process; (3) refining the preliminary scale to finalize the scale using a cross-sectional survey; and (4) evaluating the psychometric properties of the final scale using another cross-sectional survey. A sample of 858 registered nurses from 12 general hospitals was recruited for this study.**Results:** The final scale consisted of 17 items categorized into three factors: career goal progress, professional ability and attribute improvement, and career promotion and prestige increase. The three factors accounted for 75.4% of the observed variance in career growth. The overall Cronbach's  $\alpha$  was .96, and the intraclass correlation coefficient was .92. The content validity index was .97. Confirmatory factor analysis showed acceptable model fitness.**Conclusions:** These results showed that the CGSN has good psychometric properties and can be used to evaluate specific career growth among nurses. This new instrument can further help nurse managers and clinical nurses themselves assess career growth and identify unsatisfactory aspects of growth, thereby designing tailored training programs and evaluating the effectiveness of such interventions.© 2023 Korean Society of Nursing Science. Published by Elsevier BV. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

## Introduction

Career growth has proven to be an important construct since it shows significant predictive value for nurses' intentions to leave [1–3]. Satisfactory career growth has a wide range of positive effects on both organizations (e.g., retaining talented employees [4,5]) and individuals (e.g., improving organizational commitment [6], job satisfaction [7], and innovative behavior [8]). As boundaryless career time comes, employees are increasingly valuing their own career growth such as skill and ability development [9]. Thus, organizations must increasingly think of new ways to

promote employees' career growth. The basis for accelerating career growth is to evaluate it comprehensively and precisely.

Over the past decades, career growth has been deeply explored in various disciplines [10,11], such as business, higher education, and corporate companies, yet career growth in the field of nursing is relatively limited. Career growth is a specific concept that is distinct from other similar concepts (e.g., career success) since the former concerns the process of growth and development within the present organization, while the latter emphasizes the results of effort and accumulation across one's entire career [4,6]. Broadly defined, career growth refers to individuals' perceptions of the opportunities for development and advancement within an organization [6,10]. Weng et al. [10] argued that career growth is a function of one's own efforts in pursuing development (e.g., skill improvement) as well as the organization's efforts in rewarding an individual's efforts (e.g., hierarchical advancement). Recent research has shown that individuals' perceptions of career growth in the nursing context [12] are different from those of nonhealth-related careers (e.g., business) [4]. Nurses tend to value clinical competence, knowledge, and

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patient-centered care, while employees who work in nonhealth-related careers prefer to pursue a hierarchical status and high income [12]. As such, career growth is a multidimensional construct that varies in different work contexts [4].

To date, existing instruments measuring career growth have been developed outside of the nursing discipline (e.g., business). For example, Bedeian et al. [13] used two items to evaluate an individual’s career growth (i.e., “I feel that my present job will lead to future attainment of my career goals” and “My present job is relevant to the growth and development in my career”). Weng and Xi [14] developed a 15-item career growth scale with four dimensions (i.e., career goal progress, professional ability development, promotion speed, and remuneration growth) to measure employees’ career growth in enterprises. Liu et al. used this scale [14] to measure nurses’ career growth and showed acceptable validity and reliability. Despite this, the scale was developed in the context of the enterprise, and thus, some specific aspects among nurses may be ignored, such as professional identity development. Empirical research has shown that professional identity development is a nurse-specific symbol of career growth [12]. Moreover, career growth is a value-driven concept that varies in different sociocultural and work contexts [15]. Therefore, it is of great significance to develop a new scale to measure nurses’ career growth based on the nurse-specific context. A validated and reliable career growth scale for nurses can contribute to establishing fundamental data to guide specific intervention programs and quantitatively assess the effectiveness of related training programs.

The first step in developing a new scale is to define the concept that will be measured. We previously developed a conceptual framework for nurse career growth and found that nurses’ career growth consists of five components: career promotion, career goal progress, professional ability and quality improvement, professional identity development, and an increase in personal prestige [12]. This framework indicated that the essence of nurse career growth was a series of changes in work, especially positive changes [12]. In other words, nurse career growth shows a process characteristic. Based on the conceptual framework of nurse career growth [12] and previous studies [6,14], the nurses’ career growth in this study is defined as a series of positive changes in work that include career promotion, career goal progress, professional ability and quality improvement, professional identity development, and an increase in personal prestige.

The purposes of the present study were to develop the career growth scale for nurses (CGSN) to assess nurses’ career growth and to evaluate the reliability and validity of the CGSN for Chinese nurses.

**Methods**

*Design*

This scale development and validation study was performed in four phases (Figure 1) following DeVellis’s recommendation [16]: (1) establishing a pool of potential items and response scales; (2)

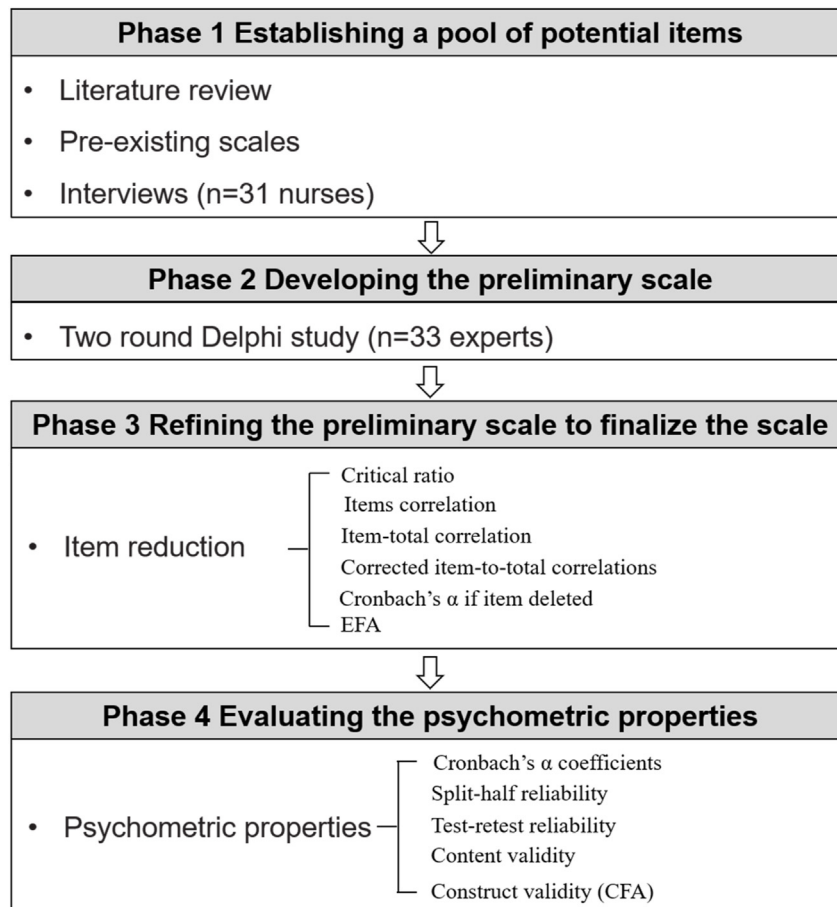


Figure 1. Phases in the Development and Validation of the Scale. Note: EFA = exploratory factor analysis; CFA = confirmatory factor analysis.

developing the preliminary scale using a Delphi survey; (3) performing item reduction to refine the scale; and (4) ensuring the structural validity and reliability of the final scale. This study was performed in accordance with the Strengthening the Reporting of Observational studies in Epidemiology (STROBE) guidelines.

#### Phase 1: Establishing a pool of potential items

The potential items on the scale were generated based on three sources: 1) a comprehensive literature review of career growth; 2) preexisting career growth models and available scales related to career growth [14]; and 3) findings from a qualitative study [12] that explored nurses' perspectives on career growth and identified the conceptual framework.

For the existing models and available scales, the career growth scale developed by Weng and Xi [14] provided important guidance to generate initial items because this scale was developed in Chinese culture and has been widely applied in other cultures [17,18], showing good reliability and validity. This model demonstrates that career growth contains four aspects, namely, career goal progress, professional ability development, promotion speed, and remuneration growth [14]. For our previous qualitative study, thirty-one nurses from 18 hospitals in China were purposefully selected to participate in individual semistructured face-to-face interviews to explore their experiences and perceptions of career growth. The participants' inclusion criteria were as follows: (a) registered nurses; and (b) willingness to participate in the study. Nurses who were on holidays, maternity leave, or sick leave during the interview period were excluded. A semistructured interview guide was used to direct conversations toward the research topic, for example, "How do you experience or perceive career growth?" The average duration of the interview was 43 min. The transcripts were reviewed and analyzed by two researchers using deductive content analysis. Finally, we developed a conceptual framework of nurses' career growth and found that nurses' career growth included five dimensions: career promotion, career goal progress, professional ability and quality improvement, professional identity development, and an increase in personal prestige (Figure 2) (more details of this qualitative study are reported elsewhere [12]).

By comparing, contrasting, and combining [16] the results derived from the literature review, the career growth model in enterprises [14], and our previous results of nurses' career growth model [12], the item pool for the CGSN was generated with 56 items categorized into six dimensions (i.e., career promotion, career goal progress, professional ability improvement, professional quality improvement, professional identity development, and increase in personal prestige). DeVellis [16] recommended that the number of preliminary items be approximately 3–4 times the finalized scale. The finalized scale consisted of 17 items, indicating that 56 preliminary items were appropriate. Respondents were required to report how much they agree with the different aspects

of career growth by using a 5-point Likert-type response format for each item (1 = strongly disagree, 5 = strongly agree).

#### Phase 2: Preliminary scale – Delphi Process

To assess whether the items generated could actually measure the domain of interest, the modified Delphi process was performed by e-mail. A panel of qualified experts was purposefully selected at the national level according to their experience and professional titles. The criteria for choosing experts included the following: (1) nursing administration practice or research experience for more than ten years; (2) professor or associate professor; (3) familiarity with nurses' management; and (4) volunteering to participate in this study. Based on the current research topic and research guidelines for the Delphi method [19], thirty-three experts from 16 hospitals and 17 colleges across 24 provinces in China were selected to verify the potential items and dimensions. The characteristics of the experts are presented in Supplemental Table S1.

Experts were asked to assess whether the dimensions and items were relevant, clear, and essential using a five-point scale ranging from 1 (not relevant) to 5 (highly relevant). Moreover, we provided the possibility for the panelists to make comments on each item and to suggest new items. After two rounds, consensus was achieved; that is, at least 80.0% of the panelists generally agreed with the content of the scale [20]. All experts completed two rounds of consultation, and the expert authoritative coefficient was .87. The rejection criteria for items were set as relevancy less than 4 or coefficient of variation greater than .25 [21]. Item content validity indexes (I-CVIs) were computed by totaling the number of experts rating either 4 (relevant) or 5 (highly relevant) and then dividing by the total number of experts. Items with I-CVIs lower than .80 were deleted or revised [22]. According to the results of expert consultation, two items were removed for their lower value of I-CVIs (value < .80), fifteen items were deleted due to close and/or overlapping meanings, four items were supplemented, and six items were revised slightly for wording ambiguities. Thus, the preliminary 43-item CGSN with six dimensions was designed.

#### Phase 3: Refining the preliminary scale to finalize the scale

Following DeVellis's suggestions, item reduction was performed to refine the preliminary scale through field testing. An online cross-sectional study was conducted in Sichuan Province, China. The participants were 429 nurses working in six general hospitals (Table 1). Nurses who had worked in the current hospitals for more than 6 months and volunteered to participate in this study were included. Those who were on maternity or sick leave were excluded. The sample size for factor analysis was calculated using a subject-to-item ratio of 5:1 to 10:1 [23]. Thus, a sample of 429 was sufficient. Stratified sampling procedures were used to recruit participants based on geographical region and hospital size (beds



Figure 2. Conceptual Framework of Nurse Career Growth.

**Table 1** Demographics of the Participants in Phase 3 and Phase 4.

Variable	Frequency (percentage, %)	
	Piloting the scale (n = 429)	Validating the scale (n = 429)
Gender		
Men	17 (4.0)	20 (4.7)
Women	412 (96.0)	409 (95.3)
Age (years), Mean (SD)	31.22 (7.12)	31.32 (6.97)
<30	213 (49.7)	187 (43.6)
30–40	167 (38.9)	200 (46.6)
41–50	39 (9.1)	35 (8.2)
>50	10 (2.3)	7 (1.6)
Marital status		
Single	142 (33.1)	147 (34.3)
Married	287 (66.9)	282 (65.7)
Years in nursing practice, Mean (SD)	9.76 (7.85)	9.86 (7.40)
≤5	151 (35.2)	140 (32.6)
6–10	141 (32.9)	139 (32.4)
11–15	57 (13.3)	69 (16.1)
16–20	33 (7.7)	40 (9.3)
>20	47 (11.0)	41 (9.6)
Education		
Secondary diploma	7 (1.6)	10 (2.3)
Advanced diploma	159 (37.1)	151 (35.2)
Bachelor's degree	257 (59.9)	261 (60.8)
Master's degree or higher	6 (1.4)	7 (1.6)
Professional title		
Junior	319 (74.4)	309 (72.0)
Intermediate	89 (20.7)	96 (22.4)
Senior	21 (4.9)	24 (5.6)
Hospital size		
Beds <500	182 (42.4)	176 (41.0)
Beds ≥500	247 (57.6)	253 (59.0)

Note. SD = standard deviation.

≥500 or beds <500). Participants were asked to complete the 43-item CGSN developed in the second phase of the study. Words were modified according to the participants' responses. After this phase, a 17-item final CGSN, including three dimensions (i.e., career goal progress, professional ability and attribute improvement, and career promotion and prestige increase), was developed.

#### Phase 4: Evaluating the psychometric properties of the scale

Another cross-sectional online survey was performed after phase 3 to evaluate the psychometric properties of the final scale. The sample size of this phase was calculated according to confirmatory factor analysis (CFA). A minimum sample size for 200 is recommended for the CFA [24]. We recruited 429 nurses working in six other general hospitals (Table 1) and asked them to complete the final 17-item CGSN. The inclusion criteria and exclusion criteria were consistent with those in Phase 3. Among the 429 nurses, 83 participated in this survey were resurveyed after a 2-week interval [25]. The content validity of the scale was tested by the I-CVI and the scale-level content validity indexes (S-CVI) using the expert panel review in Phase 2.

#### Data collection

The data were collected between November 2020 and January 2021. The questionnaire link was generated on the questionnaire star™ platform and could be distributed through WeChat and e-mail. Prior to data collection, the research team contacted the directors of nursing in each hospital to explain the study and obtain approval for recruitment and data collection in their respective care units. Following the approval of each director of nursing, researchers distributed the questionnaire link to potential participants via WeChat. The study information (i.e., study purpose, use of

data, and anonymity) was presented on the first page of the questionnaires. Nurses who were willing to participate in the study must click a box indicating informed consent before they can enter the questionnaires. Completed questionnaires were returned to questionnaire star, and the data could only be accessed by researchers. A reminder message was sent out two weeks after questionnaire distribution.

#### Data analysis

Demographic characteristics were analyzed using descriptive statistics. Several tests were performed to reduce the number of items based on DeVellis's recommendation [16]. The following principles guided the item reduction process: 1) items with low critical ratios (i.e., t test of significance of difference between the first 27.0% and the last 27.0% of the total score of the scale,  $p > .050$  or  $t \leq 3.00$ ) were removed [26]; 2) items with strong correlations (Pearson's  $r > .80$ ) were not remained together to avoid redundancy [27]; 3) items were considered for deletion when the item-total correlation was lower than .50 [28] or the corrected item-to-total correlations were lower than .40 [29]; and 4) an increase in Cronbach's  $\alpha$  if an item is deleted indicates that the items poorly contribute to Cronbach's  $\alpha$  value and should be removed [29]. Importantly, item reduction was based not only on those statistical results but also on the practical meaning of the item (e.g., item redundancy, item equivocality, and conceptual fitness). Exploratory factor analysis (EFA) with principal component analysis and varimax rotation methods [30] was conducted to undertake further item reduction and identify the underlying factor structure of the CGSN. The number of extraction factors was identified by the following strategies: 1) the number of factors with eigenvalues  $>1$ ; 2) examining the scree plot to determine the number of factors; 3) factor loading  $\geq .50$  [31]; and 4) interpretability of the overall factors  $>50.0\%$ . Bartlett's sphericity test and Kaiser–Meyer–Olkin test were performed to determine the suitability of factor analysis before EFA.

Reliability was evaluated by Cronbach's  $\alpha$  coefficients, MacDonal's omega, and two-week test-retest reliability. A Cronbach's  $\alpha$  coefficient, MacDonal's omega, and test-retest reliability higher than .70 were considered satisfactory [32]. Two-week test-retest reliability was identified using the intraclass correlation coefficient (ICC). Validity was assessed through content validity, construct validity, and discriminant validity. Content validity was identified by computing the CVI at both the I-CVI and S-CVI. Construct validity was ascertained through CFA. Adequate model fit was evaluated by the following indexes [26]:  $\chi^2/df < 5$ , root mean square error of approximation (RMSEA)  $< .08$ , standardized root mean square (SRMR)  $< .05$ , comparative fit index (CFI)  $< .90$ , incremental fit index (IFI)  $< .90$ , and Tucker–Lewis Index (TLI)  $< .90$ . Mardia's normalized estimate of multivariate kurtosis was used to test the multivariate normality for CFA. If Mardia's coefficients for multivariate kurtosis were  $>5$ , it indicates significant multivariate non-normality in the data [33]. Then, a bootstrapping procedure was performed on 1000 samples using the maximum likelihood estimator to adjust the model fit and parameter estimates to accommodate multivariate nonnormality [34]. Distinctness between factors (subscales) was examined by calculating the heterotrait–monotrait (HTMT) ratio [35]. An HTMT ratio  $< .85$  indicated good discriminant validity between factors [36]. Data analyses were performed using SPSS Version 26.0 (IBM Corp., Armonk, NY, USA) and Amos Version 23.0.

#### Ethical considerations

The study was approved by the Ethical Committee of Sichuan University (No. 2019-949). All participants were informed about

the purpose of the study, and written informed consent was obtained from them. Participation was voluntary, and they could withdraw at any time without any penalty.

## Results

### Sample characteristics

A total of 858 nurses participated in this study. The characteristics of the participants are presented in [Table 1](#).

### Item reduction and EFA

The critical ratio ranged from 19.97 to 31.63 with a  $p < .050$ . The item-total correlation for all items was higher than .50 [28]. The corrected item-to-total correlations of each item were higher than .45, and the Cronbach's  $\alpha$  if the item was deleted did not increase, indicating that all items contributed to the Cronbach's  $\alpha$  value [29] ([Supplemental Table S2](#)). Twelve items were removed since the correlation coefficient between items was higher than .80 [16], leaving 31 items for EFA.

The Kaiser–Meyer–Olkin value was .95, and Bartlett's sphericity value was also statistically significant ( $\chi^2 = 6822.96$ ,  $p < .001$ ), indicating that the sample was suitable to perform factor analysis [26]. Fourteen items were removed due to a factor loading lower than .50, and their meaning could be captured by the retained items. Of the six components in the preliminary scale, professional ability improvement, professional quality improvement, and professional identity development were combined into one factor and renamed “professional ability and attribute improvement” (factor 1); career promotion and an increase in personal prestige were also combined into one factor and renamed “career promotion and prestige increase” (factor 2); and the initial dimension of career goal progress remained (factor 3). Finally, three factors emerged from the remaining 17 items, explaining 75.4% of the total variance. The results of exploratory factor analysis are shown in [Table 2](#).

The final CGSN included 17 items measuring three dimensions of nurses' career growth: professional ability and attribute improvement (7 items), career promotion and prestige increase (6 items), and career goal progress (4 items). All items were scored using a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree) that evaluates the extent to which nurses perceive the process of career growth.

### Psychometric properties of the CGSN

#### Reliability

The Cronbach's  $\alpha$  of the total scale was .96 and that of each dimension ranged from .91 to .96; the MacDonald's omega of the total scale was .97 and that of each dimension ranged from .93 to .97; the two-week ICC of the total scale was .92 and that of each dimension ranged from .80 to .85. These results showed suitable stability on the scale.

#### Structural validity

The I-CVI ranged from .91 to 1.00, and the overall S-CVI was .97, indicating good content validity of the scale [37]. The construct validity was determined by CFA ([Figure 3](#)). Mardia's normalized estimate of multivariate kurtosis was 117.01, indicating significant multivariate nonnormality in the data. Hence, a bootstrapping procedure was performed on 1000 samples. The standardized factor loadings ranged from .72 to .96 and were statistically significant. The goodness of fit of the three-factor model was

**Table 2** Factor Loading of the Career Growth Scale for Nurses (CGSN) Using Exploratory Factor Analysis.

Items	Factor 1	Factor 2	Factor 3	Commonalities
<b>Factor 1: Professional ability and attribute improvement</b>				
8. At work, my sense of responsibility is getting stronger and stronger.	.80	.32	.21	.79
10. At work, I gradually realize my role and can better adapt to it.	.77	.38	.29	.82
11. I gradually realize the importance of nursing.	.73	.33	.25	.70
6. My communication skills are getting better and better.	.69	.25	.44	.74
7. I increasingly stand at the patient's point of view.	.68	.37	.34	.71
5. My competence is improving.	.64	.29	.48	.72
9. At work, my ability to control emotions is gradually improved.	.62	.28	.36	.59
<b>Factor 2: Career promotion and prestige increase</b>				
14. I gradually take on more important tasks in my organization.	.23	.77	.37	.77
15. I gradually upgrade my education level or have obtained the highest degree in my major.	.31	.75	.16	.69
12. My promotion is on time according to the promotion ladder of the current organization.	.40	.73	.20	.72
13. My role is gradually extended, such as being a manager, a clinical nurse specialist or a teacher.	.38	.70	.20	.67
16. My salary is growing in my present organization.	.19	.70	.45	.72
17. My prestige is increasing because of my work ability or achievements.	.36	.65	.34	.66
<b>Factor 3: Career goal progress</b>				
2. I gradually make plans practically to achieve my goals.	.32	.31	.84	.91
1. I gradually set my career goals clearly.	.34	.29	.83	.88
4. My efforts move me closer to my career goals.	.34	.27	.81	.85
3. I gradually carry out my plans conscientiously.	.34	.31	.81	.86
Eigenvalue <sup>a</sup>	4.57	4.13	4.11	
Explained variance (%)	26.9	24.3	24.2	
Cumulative variance (%)	26.9	51.2	75.4	

Note. Factor loadings exceeding .50 are in boldface. The items were translated from Chinese to English for international publication.

<sup>a</sup> Rotated eigenvalues.

satisfactory:  $\chi^2/df = 3.43$ , RMSEA = .07, SRMR = .04, CFI = .96, IFI = .96, TLI = .95. The HTMT ratio ranged between 0.70 and 0.79, indicating an acceptable value [36].



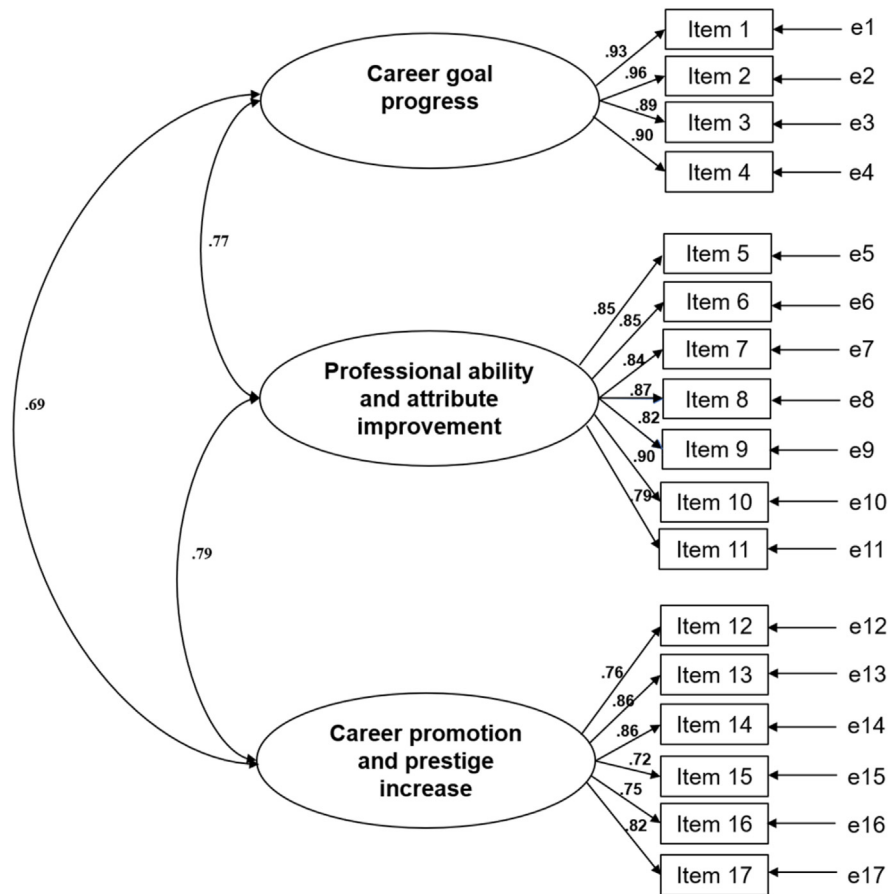


Figure 3. Confirmatory Factor Analysis of the Career Growth Scale for Nurses.

**Discussion**

In this study, we developed a new instrument to measure career growth for nurses and further examined its validity and reliability. The items of this instrument were designed based on a qualitative descriptive study in the context of nursing, a thorough international literature review, and the conceptual framework of career growth. The final scale has 17 items in three factors with acceptable model fitness. All results show that the CGSN has good psychometric properties. To the best of our knowledge, this is the first study attempting to develop an instrument for measuring career growth in a nurse-specific context, helping to enrich and facilitate the accurate assessment of career growth for nurses.

All three factors (i.e., career goal progress, professional ability and attribute improvement, and career promotion and prestige increase) of the CGSN accounted for 75.4% of the total observed variance, indicating that this scale captured comprehensive aspects of nurses' career growth. This finding is consistent with previous studies showing that the notion of career growth is a multidimensional concept [6,10]. Weng and Xi [14] suggested that employee career growth could be captured by four factors, including career goal progress, professional ability development, promotion speed, and remuneration growth. Weer [11] proposed that career growth consists of two components or indicators: structural advancement (e.g., hierarchical advancement) and content advancement (e.g., on-the-job experiences). The CGSN added several components or items (e.g., professional attribute improvement and prestige increase). The reason why the dimensions or

items in our study differ from those in previous studies may be due to the different work contexts in nursing.

Regarding the components of this instrument in comparison to other instruments [11,14], the CGSN further assessed nurse-specific perceptions. None of the existing career growth scales included components related to professional attribute improvement, for instance, adaptability, conscientiousness, and professional identity, but this component was very important for nurses when they mentioned career growth [38]. The CGSN included professional attribute improvement and disclosed an inclusive picture of nurses' career growth. Furthermore, remuneration was one item rather than a dimension since income was not the main indicator of career development among nurses [12,39]. During the early stage of scale development, six dimensions were identified according to the conceptual framework of career growth proposed by Weng and Xi [14] and previous results of interviews [12]; however, factor analysis subsequently identified only three dimensions. This result confirmed that career growth for nurses had several differences from other disciplines (e.g., business and management).

The *professional ability and attribute improvement* dimension consists of seven items. It reveals improvements in ability, professional quality, and professional identity [12]. Weng's [10] career growth scale also included the component of ability; however, the ability in that scale was generic and mainly referred to knowledge and skills. In our study, abilities were concretized on the CGSN. "Ability" in the present study refers to the comprehensive nursing abilities needed in different nursing practice fields, for instance, clinical skills, communication skills, and knowledge-based

intuition. Thus, the meaning of “ability” in our study was slightly different from Benner’s theory [40], which regarded “ability” as being skilled in clinical practice. Moreover, this dimension contains professional attribute improvement (e.g., emotional self-control, adaptability), and this aspect has not yet been included in other career growth scales. Past studies [39] indicated that positive professional attributes were considered fundamental elements for making progress and providing high-quality care. As described in the previous literature [41], professional identity was defined by professionals’ knowledge, skills, attitudes, and values. Therefore, it is reasonable to integrate professional identity, ability, and professional quality (e.g., responsibility, emotional self-control, and stress response) [12] into one factor.

The *career promotion and prestige increase* dimension consists of six items. It refers to the nature of an individual’s promotion to higher positions, increased responsibilities via hierarchical advancement, and increased prestige [12,14]. This dimension presents the external characteristic of career growth and can be directly observed, reflecting organizations’ efforts to reward nurses’ efforts. Professional title promotion, education upgrades, and income growth are also included in addition to position promotion, as these indicators can be clearly observed by others. This factor is similar to the findings of previous work by Weng et al. [4], whereby climbing the hierarchical ladder and increasing remuneration were the main components of career growth for employees in enterprises. We further replenished the prestige increase and education upgrades in this study.

*Career goal progress* consists of four items. It represents nurses’ efforts to set career goals and achieve them. From the beginning of the career growth instruments developed, career goals were considered a crucial component of career growth [14]. Bedeian et al. [13] and Chay et al. [42] only used career goal progress to evaluate individuals’ career growth. Previous scales measuring career growth in enterprises also included the component of career goals [14]. Our study confirmed these findings and further added items regarding setting goals for improvement.

The results of reliability tests demonstrated that the CGSN was an overall reliable instrument since the Cronbach’s alpha internal consistency coefficient, MacDonald’s omega, and ICC were far higher than the acceptable coefficient of 0.70 [43]. Compared with the study by Weng [14] and Weer [11], the Cronbach’s alpha internal consistency coefficient of the CGSN is slightly higher, indicating a high degree of usability of the scale we developed. The satisfactory ICC demonstrated that the scale maintained stability over time [43]. The content validity index showed that the scale had high content validity. However, previous studies on career growth scales [11,14] have rarely reported content validity and test–retest reliability. Of the CFA results for evaluating construct validity, the standardized loading of each item underlying the corresponding dimension was higher than 0.7 [26], and the model fit indexes met the recommended criteria; thus, the structure of the CGSN and empirical data were well consistent. Furthermore, the results of the HTMT ratio indicated that the items under each factor of the CGSN are different from the items under the other factors [44]. In summary, the CGSN is a valid and reliable instrument for comprehensively measuring nurses’ career growth.

### Limitations

There are several limitations when interpreting the CGSN. This study did not provide a cut-off score for career growth. The perceptions of career growth vary by individual [12], and thus, it is difficult to conclude that a nurse with a low CGSN means no growth. Career growth depends on the nurses rather than the tool used. Furthermore, this new tool was developed to quantify career

growth as perceived by nurses themselves and not by their leaders. Nurses may tend to answer the questions in accordance with social desirability instead of their true feelings [45]. Future research could revise this scale to serve as a tool for leaders to evaluate the career growth of subordinates. In addition, career growth emphasizes the process of growth [4]; thus, longitudinal studies are needed to further validate the CGSN. Finally, it is recommended for further studies to test other psychometric properties of the scale such as convergent validity, discriminant validity, criterion validity, known-group validity, and responsiveness.

### Implications for practice

Satisfactory career growth has benefits for both organizations and individuals. Accurately evaluating career growth among nurses is the premise for developing intervention strategies to promote career growth. The newly developed scale can be used to determine the extent of career growth nurses experience in their careers. This scale may be a potential reference for use by clinical nurses themselves and nurse managers to better understand career growth within their organizations, further identify unmet aspects of growth, and determine influencing factors. The CGSN can also be used when designing career development training sessions and can help nurse managers draw up plans for removing obstacles to career growth. This scale can also aid in self-appraisal and identifying personal career growth to promote personal and professional development. Moreover, the CGSN can also work as an alternative instrument to compare different career mapping programs and then help select the most cost-effective interventions.

### Conclusion

This study presents a newly developed scale to assess career growth among nurses. This scale was designed and developed based on an extensive literature search, a review of an existing career growth tool, and a previous conceptual framework. The instrument consists of 17 items categorized into three factors that comprehensively reflect nurses’ career growth, showing good reliability and validity. Thus, this new scale can be used to effectively measure career growth for nurses.

### Data statement

Data are available on request from the corresponding author.

### Conflict of interest

The authors have no conflicts of interest to report.

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### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.anr.2023.08.001>.

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## Research Article

# The Expectations and Acceptability of a Smart Nursing Home Model Among Chinese Older Adults and Family Members: A Qualitative Study



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## SUMMARY

**Purpose:** This study aims to explore the expectations and acceptability of a smart nursing home model among Chinese older adults and their family members based on a scoping review that defines the concept of smart nursing homes.

**Methods:** A qualitative case study was employed for this research. Semi-structured, in-depth interviews and focus group discussions were conducted on WeChat. Participants were purposively sampled through snowball sampling in Hainan and Dalian, China. A total of 28 older adults aged 60–75 and six adult children were interviewed until data saturation was achieved, followed by a thematic analysis.

**Results:** The expectations of smart nursing homes include: 1) quality of care supported by governments and societies; 2) smart technology applications; 3) the presence of a skilled healthcare professional team; 4) access to and scope of basic medical services; and 5) integration of medical services. The acceptability of smart nursing homes included factors such as stakeholders' perceived efficaciousness, usability, and collateral damages of using smart technologies, and the coping process of adoption was influenced by factors such as age, economic status, health status, education, and openness to smart technologies among older adults.

**Conclusions:** Chinese older adults and their family members have a positive perception of the smart nursing home model. The qualitative evidence regarding their expectations and acceptability of smart nursing homes contributes valuable insights for a wide range of stakeholders involved in the planning and implementation of smart nursing homes.

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## Introduction

Longer life expectancy has accelerated China's transition into a super-aged society [1]. The population aged  $\geq 60$  years old in China has increased from 18.7% in 2020 to 18.9% in 2021 [2]. Despite being

home to the largest population of dementia patients worldwide, China has implemented a policy to expand long-term care facilities for older adults aged  $\geq 65$  years old. However, the majority of older adults with dementia still receive care at home [3]. The concept of 'aging in place' has become challenging due to the one-child policy, which has resulted in a 'sandwich' generation responsible for caring for their children, parents, and even grandparents simultaneously [4]. Consequently, many Chinese older adults are seeking nursing homes as alternative options for continuous care [5]. However, nursing homes in China are typically driven by policies rather than demands, resulting in a quality of care that often fails to meet the needs of older adults, including access to trained

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caregivers and health monitoring and assessment [6]. In 2014, the Chinese Ministry of Civil Affairs launched the ‘Smart Internet of Things Pilot Project’ to encourage and financially support smart solutions for health monitoring, fall protection, activity analysis, and disease prediction for older adults, aiming to improve the quality of care and enhance their quality of life [7]. Furthermore, at the 18th National Congress of the Communist Party of China, the central government emphasized the exploration of an innovative model for senior care that relies on institutional care and integrates medical services with smart technologies to meet the healthcare needs of older adults [8].

Based on a comprehensive scoping review of the literature, consisting of 164 journal articles and 13 website documents [9], we established a clear definition of smart nursing homes and identified the feasible smart technologies that could be implemented in nursing home settings. The smart nursing home model was defined as ‘an evidence-based care model that integrates the Internet of Things (IoT), digital health, information management system (IMS), big data, artificial intelligence (AI), computing, and cloud computing technologies [9]. This model aims to provide effective, efficient, and person-centered care by enabling continuous monitoring of older adults, facilitating efficient communication among care providers, and integrating with external medical resources such as hospitals and remote medical specialists. The ultimate goal is to enhance the quality of care and ensure stakeholders’ satisfaction. Smart nursing homes create a safe and affordable environment that attends to older adults’ healthcare needs promptly and consistently, thereby improving their quality of life.

The study reported the expectations and possibly unmet needs of older adults for a ubiquitous healthcare service system, including various aspects such as health monitoring, health report generation, call-out services, referral services, and personalized treatment [10]. Previous research has demonstrated the potential benefits of nursing homes that utilize smart technologies and integrated medical services, as they can improve the efficiency of nursing services and enhance the effectiveness of medical care for both residents and healthcare professionals (HCPs) [11,12]. For example, the implementation of teleconsultations through videoconferencing has proven valuable in overcoming the lack of local medical resources, increasing healthcare accessibility for residents, and facilitating remote consultations with specialists. Additionally, the use of sensors to capture various data, such as motion and heartbeats, has enabled nursing homes to accommodate a larger number of residents and provide more tailored care [13]. However, older adults commonly exhibit negative attitudes toward technologies, perceiving them as useless, difficult to use, costly, and requiring training [14]. These negative attitudes can potentially hinder the development and evaluation of smart nursing homes with a defined service scope, particularly when considering the perceptions of older adults [9]. Therefore, it is crucial to gain an understanding of the expectations and acceptability of the smart nursing home model among Chinese older adults and their family members. This understanding will facilitate the design of a survey tool to confirm the expectations and acceptability of smart nursing homes among a larger population. It will also assist in the development of feasible, affordable, and person-centered smart nursing homes that can better meet the needs of older adults in the future.

### Study questions and objectives

With a clear concept of smart nursing homes captured from our scoping review [9], the following research questions were formulated: 1) What are the expectations of smart nursing homes among Chinese older adults? 2) Will the older adults and their family members accept, and how will they receive an evidence-based

smart nursing home model? The present study aims to explore the perceptions of mainland Chinese older adults and their family members to answer the research questions. The study objectives are set out as follows:

1. To explore the expectations of smart nursing homes among mainland Chinese older adults and their family members.
2. To explore the acceptability of an evidence-based smart nursing home model among mainland Chinese older adults and their family members.

### Methods

Qualitative research was conducted, and thematic analysis was guided by the theoretical model of smart technology adoption behaviors of older consumers [15] and a scoping review [9]. There were five full-time researchers with doctoral degrees involved in this study as investigators. The investigators (YYZ and JS) were trained in qualitative research to conduct field interviews during the interview and data coding in the analysis process. Other investigators in the research team, including a family physician with an interest in gerontology and an expert in qualitative study (SGS), a family physician and methodologist (BHC), and a gerontechnology engineer (FZR), participated in the coding and data analysis process.

### Ethical consideration

Ethical approvals for this study were obtained from the Ethics Committee for Research Involving Human Subjects, Universiti Putra Malaysia, Malaysia (UPM/TNCPI/RMC/JKEUPM/1.4.18.2, 28/11/2020) and Hainan Medical University, China (YLIJ-2020-021, 03/09/2020). An honorarium of 100–200 CNY (15–30 USD) was transferred online to the participants via WeChat wallet, or ‘rad bag’ at the end of the data collection.

### Theoretical framework

The theoretical model of smart technology adoption behaviors of older consumers by Golant (2017) was adopted to guide the analysis and interpretation of the qualitative data [15]. Based on other technology acceptance models, such as the technology acceptance model (TAM), unified theory of acceptance, and use of technology models (UTAUT and UTAUT2), Golant’s (2017) theoretical model could be more relevantly applied to understand the appraisal process when older consumers adopt smart technologies as an alternative solution if they have expectations in healthcare aspects of smart nursing homes. When these expectations are not met, they can also be perceived as unmet needs [16]. The coping process of smart technology adoption includes information and technology appraisals. The older adults’ experiences of using smart technologies (internal information) and the persuasiveness of external information such as persuasion from family members, friends, or HCPs who perceive the benefits of using smart technologies, may influence this coping process. After the appraisals of perceived efficaciousness, usability, and collateral damages of technologies, the older adults would then decide whether to adopt the ‘smart’ nursing homes or not (Figure 1). It has been noted that expectations are a determinant of acceptability if the concept of smart nursing homes meets the stakeholders’ expectations [17]. In this study, the explored expectations refer to the desires or wants of consumers regarding what they feel a smart nursing home should offer [18]. At the same time, acceptability is the intention to use or willingness to adopt a smart nursing home [19]. In addition, the expectations and acceptability of smart nursing home stakeholders,

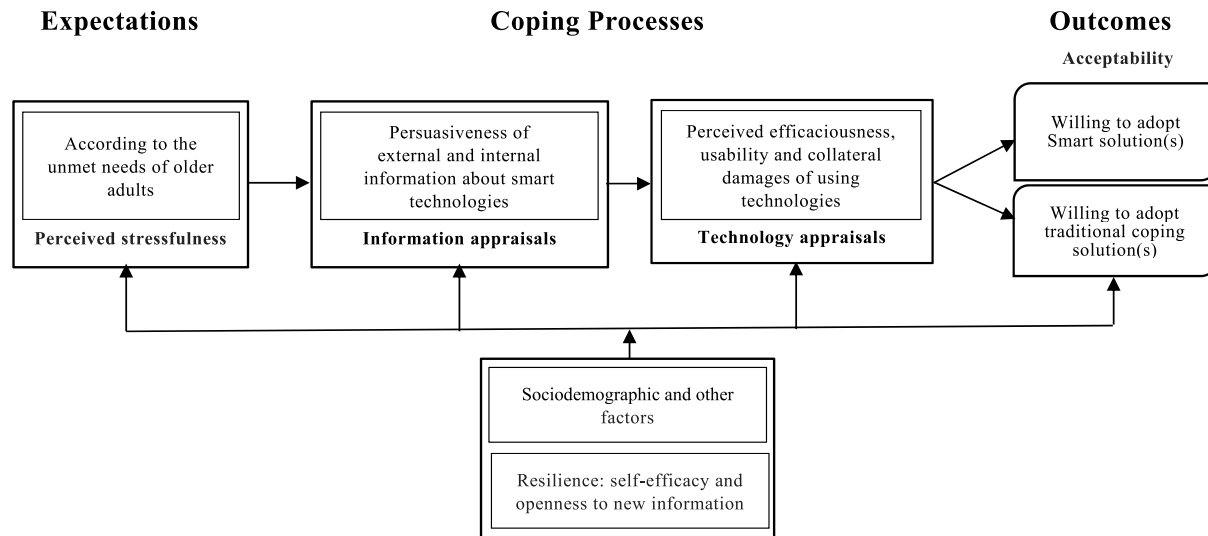


Figure 1. The Theoretical Model of Smart Technology Adoption Behaviors by Older Consumers.

especially older adults, will also be affected by sociodemographic factors such as health status (severity of illness) and their resilience to new information [9].

#### Participants

Consistent with the research population outlined in our scoping review [9], the recruitment of participants on Hainan Island and Dalian adhered to the following inclusion criteria: 1) residents or migrants aged 60–75 years old with or without chronic diseases; and 2) those who have fewer children or no children available to provide care such as adult children working in other cities, living abroad, or occupied with work commitments. Older adults who experienced communication difficulties due to dysphasia or cognitive disorders were excluded. Given that decisions regarding nursing home admission primarily rest with family members, particularly adult children [20], the inclusion criteria for family members focused on adult children of the eligible older adults.

#### Study setting

We recruited a diverse group of eligible participants with varied sociodemographic characteristics from two sites spanning three cities: Haikou and Dongfang on Hainan Island (located in South China) and Dalian (situated in Northeast China). Hainan Island is recognized as one of the most desirable cities for older adults, attracting 1.64 million individuals from 27 provinces in China to spend their winters there [21]. Similarly, Dalian is renowned as an eco-friendly and livable city in Northeast China, attracting older adults from various provinces to settle down or reside in nursing homes after retirement [22].

#### Data collection

The data collection for this study took place from February 2021 to April 2021. The investigator (YYZ) recruited participants in Dalian and Dongfang, Hainan, while the co-investigator (JS) and the Hainan Longevity Association recruited eligible participants in Haikou, Hainan. Semi-structured interviews were conducted with mainland Chinese older adults and family members of eligible older adults. Due to travel restrictions caused by the COVID-19 pandemic, all interviews were conducted using WeChat, a popular

communication app in China. The snowball sampling method was employed to recruit purposive samples [23]. Study information with the investigator's contact was shared within older adult communities through WeChat groups, facilitated by two contact persons. The investigator (YYZ) contacted all potential interview candidates, explained the study's purpose, and confirmed their willingness to participate. Three candidates dropped out due to personal schedule conflicts. Data collection utilized two methods, including in-depth interviews and focus group discussions with 4–5 participants per session. Participants were consulted regarding their preferred interview methods and times. Figure 2 illustrates the entire data collection process, from participant identification to data analysis, at the two research sites.

Before the interviews, the investigator (YYZ) provided a concise description of the concept of smart nursing homes [9]. For example, smart nursing homes are transforming senior care by integrating the healthcare needs of older adults with information technologies. This model emphasizes effectiveness and efficiency to deliver comprehensive and personalized care in a secure and relatively independent environment. Family members can remotely monitor their loved ones' daily lives and access their health information using smartphones. The care model also incorporates external medical resources such as remote consultations and smartphone-based care or disease management. Smart technologies, including sensors embedded in furniture, mattresses, and clothing, enable the collection and analysis of vital signs, body temperature, and sleep patterns. Behavior data analysis can help predict falls and track patients with dementia. Additionally, technologies like AI and cloud computing assist in processing and analyzing large datasets to promptly and accurately identify changes in the health of older residents. Digital health records are employed to support treatment planning and decision-making.

Participants were provided with the respondent's information sheet and informed consent form and agreement was obtained through verbal confirmation or written messages on WeChat. Sociodemographic information, including age, education, occupation, income, insurance, and health status, was collected from the participants. An interview guide consisting of open-ended questions and probes (see supplementary file 1) was developed based on the scoping review conducted for this study [9]. A pilot test was conducted with two older adults to assess the feasibility of the research methods and procedures. All interviews were conducted

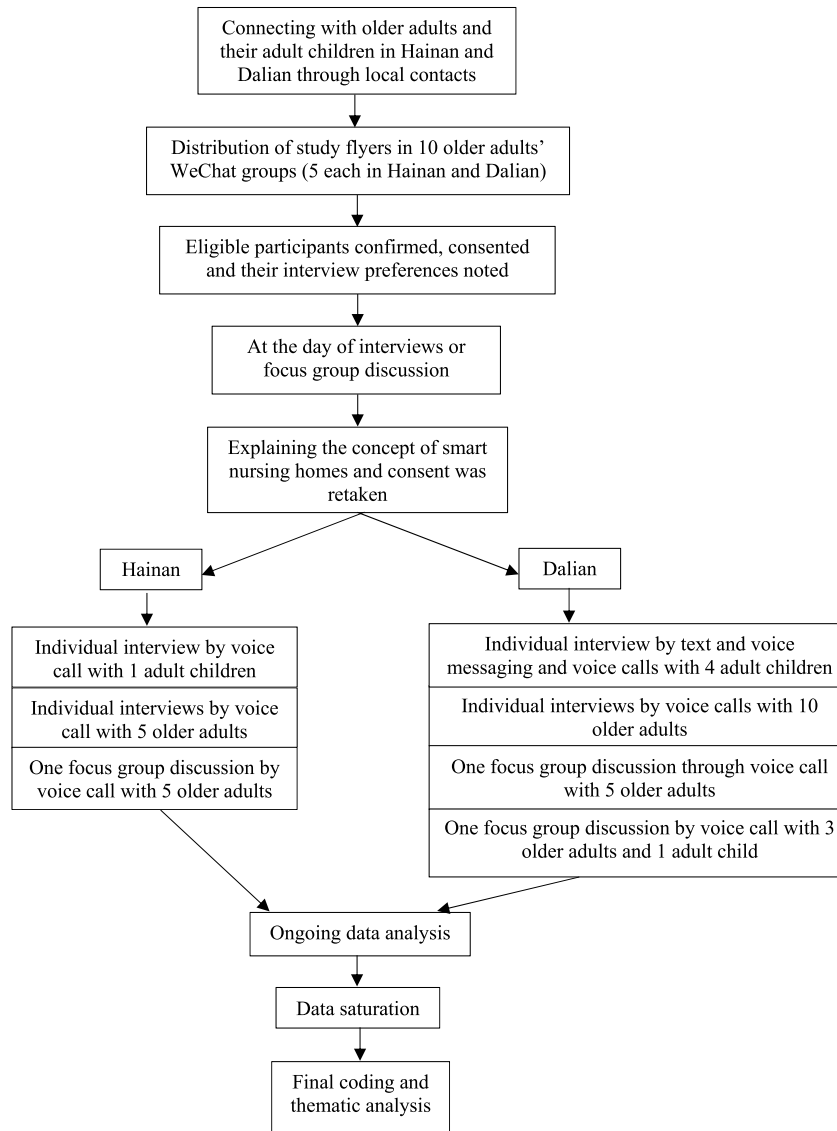


Figure 2. The Process of Sampling and Data Collection in a Qualitative Study.

in Chinese, audio-recorded, and supplemented with detailed field notes. Participants were encouraged to contact the investigator (YYZ) for further information or to provide additional comments on the topic. Recruitment of participants continued until data saturation was achieved, followed by conducting a thematic analysis.

To ensure the trustworthiness of the study, semi-structured in-depth interviews and focus group discussions were utilized for data collection. Member checking was performed, and five investigators were involved in data auditing, analysis, and coding discussions to validate the findings [24]. The study protocol, which outlines the research methodology and objectives in detail, has been published elsewhere [25].

### Analysis

The Framework Method [26], which employs both inductive and deductive approaches, was utilized to analyze the textual data in six steps. The data were coded and categorized into themes [27]. One investigator (YYZ) transcribed all audio-recorded interviews verbatim, while voice messages were automatically converted into texts using WeChat. Another investigator (JS)

reviewed and corrected the transcriptions. Relevant audio recordings and primary findings were shared with the participants who were interviewed via voice calls, and the transcripts were sent to the four key participants for member checking. Two participants responded and provided contact information for two nursing homes in Dalian using smart technologies. However, no additional comments on the interview questions were received from the other participants.

One investigator (YYZ) translated the Chinese transcripts into English, which were then reviewed by two other investigators (JS and BHC). Prior to translation, data preparation involved consolidating different Chinese terms with similar meanings. For example, the terms 'Zhi Neng' and 'Zhi Hui', commonly used in Chinese to describe 'smartness' such as smart technologies or smart homes, were merged into a single term and translated as 'smart' in English. The translation process consisted of three steps to ensure accuracy: 1) the online platform 'DeepL Translator' was utilized to aid in converting Chinese into English; 2) the investigator (YYZ) refined the accuracy of the Chinese transcripts by correcting and revising them based on context and local dialect, addressing any identified inaccuracies or incomplete language; and 3) the other two



investigators (JS and BHC) conducted a double-check of the translation in the quotation tables.

The analysis process involved six steps: 1) three investigators (YYZ, JS, and BHC) repeatedly read each transcript in Chinese to familiarize themselves with the entire dataset; 2) the investigator (YYZ) assigned preliminary codes and themes based on the recurring terms within the same clusters, using generalizability, relevance, and high-quality data from the quotations and contextual information. The other two investigators (JS and SGS) independently reviewed the Chinese and English transcripts and code sheets to ensure coding agreement; 3) codes were applied and categorized according to the theoretical model [15] and the scoping review [9]; 4) the data extraction and analysis process involved multiple rounds of coding and subsequent discussions among all investigators. The coding categories were defined and refined until consensus was reached among at least three of the five investigators in the research team; 5) codes and quotations presented in quotation tables with accompanying explanations; 6) the results of this qualitative study were interpreted and reported following the checklists of the standards for reporting qualitative research [28] and the consolidated criteria for reporting qualitative research [29] to address the research questions and objectives (see Supplementary file 6). Data saturation was deemed achieved when no new patterns related to the expectations and acceptability of smart nursing homes emerged [25]. Audit trails by other research members (BHC and FZR) enhanced confirmability throughout the process [30]. The data were organized and analyzed using ATLAS.ti8 software.

## Results

A total of 34 participants, consisting of 28 older adults (12 men and 16 women) and 6 adult children of eligible older adults (2 men and 4 women), were recruited for the study. Twenty in-depth interviews and three focus groups were conducted as planned, utilizing voice calls, voice messages, or text messages on WeChat. Data analysis was underway during this process, and data saturation was achieved after 30 interviews. Subsequently, we conducted four additional interviews to ensure that no new codes emerged [31]. The average age of the recruited older adults was 67 years old. Eleven of them (39.3%) self-reported that they were living with a variety of chronic diseases, such as hypertension, respiratory diseases, diabetes mellitus, and chronic pain. All older adults interviewed owned health insurance. Regarding educational attainment, 15 older adults had university degrees (53.6%), 8 had high school degrees (28.6%), 2 had junior school degrees (7.1%), and 3 had primary school degrees (10.7%). Nineteen (67.9%) had pensions or income ranging from 2000–4000 CNY (295–590 USD). In compliance with the population control policy, 19 (67.9%) of the older adults had only one child. Meanwhile, 22 (78.6%) of them lived with their spouses or partners, and 6 (21.4%) lived alone. The six adult children of the eligible older adults were aged between 39 and 44 years old. Table 1 demonstrates the participants' socio-demographic categories, and supplementary file 2 presents the profiles of the participants. Each in-depth interview conducted via voice call took between 17 and 70 minutes, and the focus group discussions lasted between 30 and 70 minutes. Interviews conducted through voice message or text message took up to 2 hours. All participants expressed great interest in the smart nursing home model.

### The expectations of smart nursing homes

The codes presenting the participants' expectations of smart nursing homes were as follows: 1) quality of care supported by governments and societies; 2) smart technology applications; 3)

**Table 1** Sociodemographic Categories of the Participants.

Older adults	In-depth interviews, n (%)	Focus groups, n (%)	Total, n (%)
<b>Total</b>	15 (53.6)	13 (46.4)	28 (100.0)
<b>All sites</b>			
Dalian	10 (55.6)	8 (44.4)	18 (64.3)
Hainan	5 (50.0)	5 (50.0)	10 (35.7)
<b>Age</b>			
60–64 years old	1 (14.3)	6 (85.7)	7 (25.0)
65–70 years old	12 (75.0)	4 (25.0)	16 (57.1)
71–75 years old	2 (40.0)	3 (60.0)	5 (17.9)
<b>Gender</b>			
Man	7 (58.3)	5 (41.7)	12 (42.9)
Woman	8 (50.0)	8 (50.0)	16 (57.1)
<b>Level of Education</b>			
Primary school	0 (0.0)	3 (100.0)	3 (10.7)
Junior high School	1 (50.0)	1 (50.0)	2 (7.1)
High school	4 (50.0)	4 (50.0)	8 (28.6)
Bachelor	10 (60.0)	5 (40.0)	15 (53.6)
<b>Income/Amount (RMB)</b>			
>4000	6 (75.0)	2 (25.0)	8 (28.6)
2000–4000	9 (47.4)	10 (52.6)	19 (67.9)
<2000	0 (0.0)	1 (100.0)	1 (3.5)
<b>Health insurance</b>			
Yes	15 (53.6)	13 (46.4)	28 (100.0)
No	0 (0.0)	0 (0.0)	0 (0.0)
<b>Number of child</b>			
1 child	13 (68.4)	6 (31.6)	19 (67.9)
2 children	2 (22.2)	7 (77.8)	9 (32.1)
<b>Living with</b>			
Spouses or partners	13 (59.1)	9 (40.9)	22 (78.6)
Alone	2 (33.3)	4 (66.7)	6 (21.4)
<b>Health status</b>			
Healthy	9 (52.9)	8 (47.1)	17 (60.7)
One or one more chronic disease	6 (54.5)	5 (45.5)	11 (39.3)
<b>Family members</b>			
<b>Total</b>	5 (83.3)	1 (16.7)	6 (100)
<b>All sites</b>			
Dalian	4 (80.0)	1 (20.0)	5 (83.3)
Hainan	1 (100.0)	0 (0.0)	1 (16.7)
<b>Gender</b>			
Man	2 (100.0)	0 (0.0)	2 (33.3)
Woman	3 (75.0)	1 (25.0)	4 (66.7)

the presence of a skilled HCP team; 4) access and scope of basic medical services; and 5) integration of medical services. Table 2 presents the codes, and the quotations of their expectations are in supplementary file 3.

### Code 1: Quality of care supported by governments and societies

The Chinese government plays a significant role in implementing and funding nursing homes across the country. Due to the one-child policy initiated by the central government in the 1970s, older adults expected the government to consider their healthcare demands. Meanwhile, they believed that the government could lead the implementation of smart nursing homes. Meanwhile, older adults realized that other resources from society, such as communities, could support and roll up nursing homes. The cooperation of social and government support was seen as crucial for the current healthcare system to ensure patients quality of life. Additionally, a clear managerial and responsible mechanism, along with effective communication in the healthcare system, were required by older adults and their family members to ensure the quality of care. These expectations on mechanisms include the responsibility of making medication decisions for the older residents who do not have a guardian and an efficient communication system among stakeholders such as the communication between HCPs and

**Table 2** The Expectations of Smart Nursing Homes among Chinese Older Adults and their Family Members.

Sub-codes (Number of the participants commented)	Codes	Description
<ul style="list-style-type: none"> <li>Government support (17.9%, 5 OA<sup>a</sup>)</li> <li>Trust in the government (17.9%, 5 OA; 16.6%, 1 FM)</li> <li>Social support (3.6%, 1 OA)</li> <li>The cooperation of society and government (7.1%, 2 OA)</li> <li>Assurance of quality of life (7.1%, 2 OA; 16.7%, 1 FM<sup>b</sup>)</li> <li>Having a clear managerial and responsible mechanism (3.6%, 1 OA)</li> <li>Effective communication (14.3%, 4 OA; 16.7%, 1 FM)</li> <li>Improving the accuracy of clinical practice through advanced technologies (10.7%, 3 OA; 16.7%, 1 FM)</li> <li>Improving quality of care through advanced technologies (3.6%, 1 OA)</li> <li>Need more portable and smart devices to meet the medical demands of older adults (3.6%, 1 OA; 16.7%, 1 FM)</li> <li>Use of smart technologies and devices in monitoring the health status and safety of older adults (60.7%, 17 OA; 66.7%, 4 FM)</li> <li>Risk prediction and health management (25.0%, 7 OA; 33.3%, 2 FM)</li> <li>Solution for emergency and first aid (25.0%, 7 OA; 50.0%, 3 FM)</li> <li>Establishing an electronic health record (3.6%, 1 OA; 16.7%, 1 FM)</li> <li>Customized care services (50.0%, 14 OA; 33.3%, 2 FM)</li> <li>Provide medical services by healthcare professionals (32.1%, 9 OA)</li> <li>Need general practitioners (21.4%, 6 OA)</li> <li>Need specialists (7.1%, 2 OA)</li> <li>Need trained nurses and skilled caregivers (32.1%, 9 OA; 16.7%, 1 FM)</li> <li>NH<sup>c</sup> has the function of nursing care and medical treatment (21.4%, 6 OA)</li> <li>NH is built with a hospital (7.1%, 2 OA; 16.7%, 1 FM)</li> <li>NH is near a hospital (7.1%, 2 OA; 33.3%, 2 FM)</li> <li>NH provides basic medical service (7.1%, 2 OA; 33.3%, 2 FM)</li> <li>Major and emerging diseases are treated at hospitals, and chronic diseases are managed at NHs (28.6%, 8 OA; 50.0%, 3 FM)</li> <li>Rehabilitation services (3.6%, 1 OA; 16.7%, 1 FM)</li> <li>Mental and psychological wellbeing (3.6%, 1 OA; 33.3%, 2 FM)</li> <li>Integrating medical services from remote hospitals (50.0%, 14 OA; 66.7%, 4 FM)</li> <li>Seamless real-time integration between smart nursing homes and remote medical institutions (10.7%, 3 OA)</li> <li>Integrating with remote doctors (10.7%, 3 OA; 16.7%, 1 FM)</li> </ul>	<p>Quality of care supported by governments and societies</p> <p>Smart technology applications</p> <p>The presence of a skilled healthcare professional team</p> <p>Access and scope of basic medical services</p> <p>Integration of medical services</p>	<p>Chinese nursing homes are typically driven by policies rather than demand, which often results in a quality of care that fails to meet the unmet needs of older adults and their families, including access to trained caregivers, health monitoring, and assessment. Therefore, social and government support is necessary and crucial to ensure the quality of care and the future feasibility of implementing smart nursing homes.</p> <p>Improving the quality of care and the accuracy of clinical practice by using effective and efficient smart solutions.</p> <p>Healthcare professionals, in particular general practitioners, medical specialists, trained nurses, and skilled caregivers, are expected to be available in nursing homes to provide medical services.</p> <p>A smart nursing home is expected to integrate nursing care and medical treatment to provide quality services. Such a nursing home should be built in or near a hospital to provide basic medical services. It should be able to manage chronic diseases, offer rehabilitation services, and provide programs for mental and psychological well-being. Major and emerging diseases should be treated at hospitals. This healthcare delivery model is essential for meeting the expectations of older adults and improving their overall health outcomes.</p> <p>Integrating medical services from remote hospitals or remote doctors can overcome the shortage of medical resources in some rural regions and reduce unnecessary hospitalization. The integration of medical services may also facilitate seamless real-time integration between smart nursing homes and remote medical institutions.</p>

<sup>a</sup> OA = Mentioned frequency from older adults (total 28 older adults).

<sup>b</sup> FM = Mentioned frequency from family members (total 6 family members).

<sup>c</sup> NH = Nursing home.

older residents, nursing homes and family members, and nursing homes and healthcare decision-makers.

*'I hope the government can run the nursing homes. We contributed to the country when we were young, so when we are old, our children are not around; some older adults do not even have children or their children have died; the older parents are still alive; the government should take responsibility to lead the management for this.'* (DL04, woman, 71 years old)

*'I still emphasize that the technology will be a guarantee, and it will be done well when the government and society work together.'* (DL01, man, 70 years old)

#### Code 2: Smart technology applications

Participants expressed their aspiration for the utilization of smart technologies in nursing homes. Particularly, they envisioned the application of technologies like AI to enhance the precision of clinical practices and improve the overall quality of care. Older adults demonstrated a preference for portable and smart devices. Furthermore, they emphasized the significance of effective and

efficient smart technologies in facilitating their activities of daily living. Examples included using smart devices to monitor health status and safety, predict health-related risks, provide emergency services, establish electronic health records, and deliver personalized care services.

*'We need more equipment, electronic products, monitoring devices, etc. These automatic monitoring devices can be effective, timely, and sensitive to identify the problems of older adults.'* (DL01, man, 70 years old)

*'The medical equipment in nursing homes should not be outdated, and it should be regularly maintained. If the equipment does not work properly, the monitoring of the older adults may not be accurate.'* (FGD 2.1, woman, 64 years old)

#### Code 3: The presence of a skilled HCP team

Participants expressed expectations for a proficient HCP team to deliver medical services within smart nursing homes. This team would ideally consist of general practitioners, medical specialists, trained nurses, and skilled caregivers.

**Table 3** The Stakeholders' Acceptability.

Sub-codes (Number of the participants commented)	Codes	Description	Themes
<ul style="list-style-type: none"> <li>Usefulness (32.1%, 9 OA<sup>a</sup>; 50.0%, 3 FM<sup>b</sup>)</li> <li>A better solution for geriatric care (3.6%, 1 OA)</li> <li>Improvement of quality of care (3.6%, 1 OA; 16.7%, 1 FM)</li> <li>Assurance of quality of life (10.7%, 3 OA)</li> </ul>	Perceived efficaciousness	The perceived efficaciousness of smart nursing homes, including the usefulness of smart technologies, the perceived superiority of smart nursing homes as a better solution compared to traditional nursing homes or home-based care, improvements in the quality of care, and the assurance of a better quality of life, are associated with the acceptability of smart nursing homes.	Technology appraisals
<ul style="list-style-type: none"> <li>Necessity for care (67.9%, 19 OA; 50.0%, 3 FM)</li> <li>Ease of use (17.9%, 5 OA; 33.3%, 2 FM)</li> <li>User-friendliness (3.6%, 1 OA; 16.7%, 1 FM)</li> <li>Convenience (21.4%, 6 OA; 50.0%, 3 FM)</li> <li>Affordability (75.0%, 21 OA; 83.3%, 5 FM)</li> <li>Cost effectiveness (emerging code) (10.7%, 3 OA; 33.3%, 2 FM)</li> <li>Safety of technology (emerging code) (7.1%, 2 OA)</li> <li>Psychological pressure of using smart devices (3.6%, 1 OA)</li> </ul>	Perceived usability (positive)	The perceived positive usability is associated with the acceptability of smart nursing homes, which includes factors such as the necessity for care, ease of use, user friendliness, convenience, affordability, cost effectiveness, and safety of the technology.	
<ul style="list-style-type: none"> <li>Unaffordability (32.1%, 9 OA; 33.3%, 2 FM)</li> <li>The burden of extra cost (10.7%, 3 OA; 33.3%, 2 FM)</li> <li>Overall concern of the technologies (25.0%, 7 OA; 83.3%, 5 FM)</li> <li>Privacy exposure (7.1%, 2 OA; 16.7%, 1 FM)</li> </ul>	Perceived usability (negative)	A negative perception toward the usability of smart solution.	
<ul style="list-style-type: none"> <li>Persuasiveness of external information from the media (3.6%, 1 OA; 33.3%, 2 FM)</li> <li>Persuasiveness of external information from friends and other peers (10.7%, 3 OA; 16.7%, 1 FM)</li> <li>Persuasiveness of external information from children or family members (14.3%, 4 OA; 33.3%, 2 FM)</li> <li>Persuasiveness of external information from doctors (10.7%, 3 OA; 16.7%, 1 FM)</li> </ul>	Perceived collateral damages	The concerns about adopting smart solutions are associated with the unintended and harmful effects of using technologies, which will result in negative user adoption. These concerns include the safety of using technologies and assaults on their lifestyles.	Information appraisals
<ul style="list-style-type: none"> <li>Persuasiveness of external information from the media (3.6%, 1 OA; 33.3%, 2 FM)</li> <li>Persuasiveness of external information from friends and other peers (10.7%, 3 OA; 16.7%, 1 FM)</li> <li>Persuasiveness of external information from children or family members (14.3%, 4 OA; 33.3%, 2 FM)</li> <li>Persuasiveness of external information from doctors (10.7%, 3 OA; 16.7%, 1 FM)</li> <li>User experience of benefits from using a new technology (3.6%, 1 OA; 50.0%, 3 FM)</li> </ul>	Persuasiveness of external information	The external information that influences the user accountability of smart solutions is received from healthcare professionals, friends, family members, and media sources.	
<ul style="list-style-type: none"> <li>Would like to pay more for a better service (10.7%, 3 OA; 16.7%, 1 FM)</li> <li>No more medical needs with younger age (7.1%, 2 OA)</li> <li>The accountability depends on the level of education (14.3%, 4 OA)</li> <li>The older adults with lower education have fewer demands (3.6%, 1 OA)</li> </ul>	Persuasiveness of internal information	People acquire information from their past experiences and the achievement of outcomes that satisfy them.	Attributes of older adults
<ul style="list-style-type: none"> <li>Seeking a new solution because of the poor health status (28.6%, 8 OA)</li> <li>No more need because of a good health status (21.4%, 6 OA; 16.7%, 1 FM)</li> <li>Openness to new technology (28.6%, 8 OA)</li> <li>Self-efficacy with new technology (7.1%, 2 OA)</li> </ul>	Severity of illness	The demographic characteristics of older adults such as their health status, educational attainment, and resilience to new technology, are determinants of smart nursing home adoption.	
	Great resilience		

<sup>a</sup> OA = Mentioned frequency from older adults (total 28 older adults).

<sup>b</sup> FM = Mentioned frequency from family members (total 6 family members).

*'I think there should be such a medical facility in the nursing homes. A nursing home must be a medical institution that serves everyone, including older adults. If the older adults are not feeling well, they can go to the medical room within the nursing home to get a checkup.'* (DL04, woman, 71 years old)

*'It (smart nursing homes) should include professionals who can operate smart devices and trained nurses. This is necessary.'* (DLFM13, family member, woman)

#### Code 4: Access and scope of basic medical services

Participants expected a smart nursing home that integrated nursing care and medical treatment to deliver high-quality services. They emphasized the importance of establishing these

nursing homes in proximity to or in collaboration with hospitals to ensure access to essential medical services. Additionally, participants highlighted the necessity for these nursing homes to effectively manage chronic diseases, offer comprehensive rehabilitation services, and provide programs aimed at promoting mental and psychological well-being. It was acknowledged that major and emerging diseases should be primarily treated at hospitals. The implementation of this healthcare delivery model is deemed crucial in meeting the expectations of older adults and enhancing their overall health outcomes.

*'It will be fine if a hospital is near the nursing home. There is no need for both facilities to be together; just a hospital near the nursing home. It's fine; it's convenient to go.'* (FGD 2.1, woman, 64 years old)

*'Firstly, we hope that the nursing home will carry out a preliminary diagnosis. Chronic diseases can be treated within the nursing home, but for many emerging cases, they must be treated in a hospital.'* (DLFM11, woman, family member)

*'I am concerned about the mental health of the older adults, the care for their moods, and the care for their end-of-life. Are there any services focusing on these aspects?'* (FGD 2.4, woman, family member)

#### Code 5: Integration of medical services

Participants remarked that the integration of medical services, including those provided by remote hospitals or remote doctors, could effectively address the shortage of medical resources in some rural areas and reduce instances of unnecessary hospitalization. Moreover, the integration of medical services was viewed as a means to facilitate seamless real-time coordination between smart nursing homes and remote medical institutions, particularly in emergency situations such as the transfer of older adults to a hospital.

*'This is the right solution, and it should be completed such as through the use of remote diagnosis, telemedicine, etc. Through the remote digital transmission, doctors at a remote hospital can analyze the data and confirm the diagnosis. I think this is very necessary.'* (DL05, man, 68 years old)

#### The acceptability of smart nursing homes

Table 3 provides an overview of the codes related to acceptability, while supplementary file 4 contains the corresponding quotations. The process of coping with and making decisions regarding the adoption of smart nursing homes is influenced by technology and information appraisals. Within the coping process, the acceptability of smart nursing homes for older adults and their family members is determined by their perceived efficaciousness, usability (either positive or negative), and potential collateral damages of smart technologies. Notably, attributes of older adults such as age, economic status, health status, educational attainment, and openness to smart technologies, have been observed to be associated with the acceptability of smart nursing homes.

#### Theme 1: Technology appraisals

##### Code 1: Perceived efficaciousness

The acceptability of smart nursing homes among older adults and their family members is closely linked to their perceived efficacy. The perceived efficaciousness of smart nursing homes encompasses several categories, including the usefulness of smart technologies, the perceived superiority of smart nursing homes as compared to traditional nursing homes or home-based care, improvements in the quality of care, and the assurance of a better quality of life. Among these categories, the usefulness of smart technologies was mentioned most frequently by participants. Furthermore, older adults and their family members expressed a willingness to pay for smart nursing homes if they offer quality nursing care that ensures a good quality of life.

*'They (the older adults) will be interested in these technologies, the new technologies in nursing home, such as body sensors that could help the older adults to know that they are healthy or having any problems; it is useful to their health.'* (DLFM02, family member, woman)

*'The care in a smart nursing home is better than the care provided by their children ... Smart nursing homes are able to serve well. I would rather spend money on these services than go to a traditional nursing home where I have to find doctors on my own. It's a waste of time.'* (DL05, man, 68 years old)

##### Code 2: Perceived positive usability

The older adults expressed their willingness to adopt smart nursing homes if they were deemed necessary for their care or health. Additionally, factors such as ease of use, user friendliness, and convenience were identified as enhancing the acceptability of smart nursing homes. Notably, affordability emerged as a critical determinant of acceptability. Participants generally agreed that the monthly charges for smart nursing homes should not exceed their income or pensions. However, some individuals were willing to accept slightly higher charges to get better services. Moreover, cost-effectiveness and technology safety were identified as emerging codes that positively influenced the acceptability of smart nursing homes. Cost-effectiveness entails comparing the benefits and outcomes of different strategies or interventions, even if they involve higher costs [32]. In this study, a comparison was made between smart nursing homes and traditional ones, or between services provided by the public and private sectors, to assess which approach was more cost-effective. The certification of technological safety was regarded as a necessary requirement.

*'If I have a disease and I have to use this device, then I have to accept it, and I won't even consider the price. Because without this device, my life is probably threatened. If it is a must, then it must be used. If it (disease) is life-threatening, then it must be used.'* (HN05, man, 67 years old)

*'As an older adult with demands, I will specifically evaluate what kind of services the nursing home can provide, and of course I will also compare the services; for example, who will provide me with a better quality of care and affordable services? I will use their services.'* (DL05, man, 68 years old)

##### Code 3: Perceived negative usability

Participants highlighted that their perceived negative usability of smart nursing homes was associated with psychological pressures. Moreover, unaffordability was identified as a significant factor negatively impacting the acceptability of smart nursing homes. Additionally, participants expressed concerns regarding the potential higher costs of medication and treatment within smart nursing homes compared to hospitals, which may offer more specialized medical services.

*'The older person, some patients, they don't like these things, why? Because when you give them these devices, they feel that they are almost dying; it is psychological pressure; this kind of monitoring is not acceptable.'* (DL08, man, 68 years old)

*'The services provided in a nursing home are hardly to the standard of a specialist hospital or a first-class hospital. If it does, as you can imagine, the cost of a nursing home is much higher than a hospital.'* (HNF02, man, family member)

##### Code 4: Perceived collateral damages

Perceived collateral damages encompass concerns related to the feasibility and reliability of technology, as well as potential medical risks such as electricity leaks and the absence of standardized supervision in the services provided by smart nursing homes. These

concerns can negatively impact the willingness of older adults to adopt smart nursing homes. With regard to privacy exposure, only three participants expressed concerns about this issue. For example, they voiced worries about being monitored 24 hours a day (DL08, man, 68 years old) or being monitored in all their activities (HN04, man, 65 years old). On the other hand, other participants indicated that Chinese older adults generally exhibit less concern for privacy compared to Western individuals or younger generations (DL07, woman, 65 years old; DL05, man, 68 years old; HN05, man, 67 years old).

### Theme 2: Information appraisals

Older adults' appraisal process for adopting smart nursing homes was influenced by their past experiences (code 1: internal information), specifically their perceived benefits of using smart technologies. These perceived benefits were often derived from external resources (code 2: external information), including the public media, friends, family members, and HCPs. These external information sources played a persuasive role, influencing older adults' awareness and consideration of adopting smart nursing homes.

*'About using the new devices, I think it's better to listen to family members and friends, the media, and doctors who might have preconceptions. If it's explained by friends or family members, they've all had personal experiences.'* (FGH 3.1, man, 65 years old)

### Theme 3: Attributes of older adults to the acceptability of smart nursing homes

Five codes were observed to be associated with the attributes of older adults, namely economic status, age, health status (severity of illness), educational attainment, and resilience toward smart technologies such as openness to new technology. Participants with a higher economic status expressed a willingness to pay more in order to meet their demands for better services in nursing homes. Younger or healthier older adults were less inclined to consider moving to a traditional nursing home for continuous care in comparison to older adults with poorer health status. Conversely, older adults living with chronic diseases demonstrated greater resilience toward smart nursing homes. Moreover, older adults with an openness to new technologies and those with higher educational attainment exhibited higher levels of acceptability toward smart nursing homes.

Supplementary file 5 provides an illustration of the coping processes of Chinese older adults in relation to the acceptability of smart nursing homes.

## Discussion

To the best of our knowledge, this study represents the first qualitative exploration providing an in-depth insight into the expectations and acceptability of smart nursing homes among mainland Chinese older adults and their family members. The significance of this study lies in its focused exploration of the expectations and acceptability of smart nursing homes, which were succinctly defined based on the literature, among both older adults and their family members. It provides insight into the important and quality factors that are expected, as well as the coping process involved in accepting the possibility of moving to smart nursing homes. The study is anchored in the concept of smart nursing homes, which are equipped with feasible technologies and integrated with medical services, as identified through a scoping review conducted prior to this qualitative investigation

[9]. Notably, all participants positively accepted the smart nursing home model.

Referring to the expectation code concerning the 'quality of care supported by governments and societies', a previous study revealed that 80% of Chinese older adults expected the government to develop an efficient and sustainable system for senior care, regulate services, and make nursing home costs affordable [33]. Unlike other developed countries, the current multi-level insurance scheme in China does not cover the costs of senior care and medical services in nursing homes [34]. Interviewed older adults expressed their hope that the government could establish and implement affordable smart nursing homes to ensure both the quality of care and their quality of life. Older adults may perceive public smart nursing homes as affordable since they believe that public nursing homes should serve as many older adults as possible, while private nursing homes are expected to be driven by profit motives [35]. In line with the codes 'presence of a skilled HCP team' and 'access and scope of basic medical services', previous research on expectations of traditional nursing home services reported similar demands, indicating that Chinese older adults require professional staff and medical services to offer timely clinical consultation, regular physical examinations, chronic disease management, rehabilitation, and emergency aid [5]. However, providing medical services within nursing homes might not be feasible in China due to a shortage of healthcare HCPs and the potential risks of legal disputes related to medication [36]. Furthermore, the code 'smart technology applications' in the present study reflected older adults' specific expectation that the quality of nursing care and medical-related services would improve in smart nursing homes through the use of smart technologies. Older adults particularly anticipated ambient assisted living technologies that could monitor their physical activities such as walking patterns, sleep quality, real-time location, and fall detection [37]. Therefore, it should be noted that building automated environments in nursing homes such as collecting data using sensors and detecting anomalies in older adults' behavior, may not be completely achieved due to the heterogeneity of devices and manufacturers that utilize different communication protocols [38]. Moreover, the application of smart technology such as wearable devices and installed sensors, may result in additional costs for patients and nursing home operators [39]. In a previous study, the expectation of integrating medical services through a partnership between a nursing home and a remotely located large hospital was commonly expressed by Chinese older adults [5], particularly for a cost-effective service that could reduce unnecessary hospitalization [40]. Similar findings were observed in our present study.

Based on Golant's theoretical framework, the coping process of adopting smart nursing homes among Chinese older adults and their family members was categorized to help understand their acceptability. A previous literature review [41] identified 36 factors influencing the acceptability of digital technology assisting in health monitoring and daily activities among home-based older adults, which are similar to our present study. For example, the perceived positive features of technology such as safety, benefits of using technology, the presence of a real need for technology, and influence by other people, determined the adoption of technology. In contrast, the factors of adoption concern and the intended damages of using technologies were negatively associated with adoption. It is noted that the coping processes of acceptability for technology in smart nursing homes and home-based care settings are similar among older adults. It should be noted that the affordability of smart nursing homes was most frequently mentioned by participants in the present study regarding their perceived usability. Smart nursing homes would be better accepted if the monthly cost was not more than that charged by traditional nursing homes.

This budget requirement is consistent with a previous study regarding smart technologies used in European nursing homes [42]. Another study conducted among Chinese nursing homes elicited that residents with chronic diseases were willing to pay an additional cost of between \$70 and \$285 per year for customized care services using smart technologies such as abnormal event monitoring and consultation with a remote physician [43]. In our present study, we observed that participants with a better economic status were willing to pay more for better care services in smart nursing homes to meet their care demands.

The strength of this study lies in the inclusion of interviews with a diverse group of older adults residing in Hainan and Dalian who originate from various regions across China. By selecting research sites in these locations, data were collected from respondents with diverse backgrounds, allowing for representation of the aging Chinese population. Additionally, the development of the smart nursing home model and the semi-structured interview guide were based on a rigorous scoping review that provided robust qualitative evidence [9]. To ensure adequate preparation, the concept of smart nursing homes was introduced to participants prior to the interviews. Trustworthiness in the qualitative study was addressed through several strategies. These included utilizing in-depth interviews and focus group discussions as distinct data collection methods, incorporating follow-up questions to gather additional information, encouraging participants to provide supplementary data after the interviews, and involving multiple investigators in the data collection, audit trail, data analysis, and result interpretation processes.

However, this study does have several limitations. Firstly, the sociodemographic characteristics of the sample were not evenly distributed. The majority of the recruited older adults were between the ages of 65 and 70, and half of the participants had tertiary education (bachelor's degrees). Additionally, only a small proportion (3/28, 10.7%) of the samples were recruited from rural areas, which may have influenced their responses to the open-ended questions. It is possible that higher-educated and younger-aged older adults may have displayed greater acceptability toward smart nursing homes. Furthermore, older adults with more challenging socioeconomic backgrounds might not have been available or able to participate, leading to a potentially incomplete understanding of perceptions surrounding smart nursing homes. The snowball sampling process may have introduced bias, as participants could have referred friends who shared similar opinions about nursing home admission and perspectives on smart nursing homes. The use of virtual interviews such as those conducted on WeChat, may have limited the participation of older adults without internet access or made some participants who were unfamiliar with technology feel more nervous when answering questions compared to face-to-face interviews [44]. Additionally, participants were unable to answer open-ended questions related to the acceptability of smart nursing homes as a whole because there was still no actual smart nursing home that they could use as a reference. However, their willingness to adopt smart nursing homes and their experiences with adopting smart technology did influence their responses to the open-ended questions.

To gain a more comprehensive understanding of the perception of smart nursing homes, future studies should consider recruiting a more diverse range of participants, including older adults residing in rural areas. Face-to-face interviews could be employed to facilitate in-depth discussions and gather more nuanced insights. It would also be valuable to include participants with prior experience using smart technologies in nursing homes, as their input could provide more precise and detailed responses to open-ended questions. Furthermore, future implementations of smart nursing homes should take into account the specific demands expressed by

older adults and their family members. For example, a significant proportion of participants expressed expectations related to the use of smart technologies for monitoring older residents, the integration of medical services from remote hospitals, customized care services, addressing health emergencies, and providing rehabilitation services for chronic diseases. On the other hand, fewer participants mentioned the establishment of electronic health records and the addressing of mental wellbeing, which may not be considered major codes. However, these perspectives still provide valuable insights that contribute to an overall understanding of older adults' healthcare demands.

## Conclusions

The smart nursing home model was both expected and accepted by Chinese older adults and their family members. They expected that smart nursing homes would provide basic medical services, be operated by a skilled team of people, including trained HCPs, and integrate medical services to ensure a higher quality of nursing care. The effective and efficient use of technologies in assisting the activities of daily living for older adults in smart nursing homes was emphasized. Furthermore, older adults expected the Chinese government and other social sectors to implement smart nursing homes and ensure the quality of care. It is important to note that the acceptability of smart nursing homes among Chinese older adults relates to perceived efficaciousness, usability, and the collateral damages of using technologies. Their personal experiences with technology and the influence of external information from family members and the media can also shape their acceptability. Additionally, older adults' economic status, age, health status, educational attainment, and resilience toward smart technology may impact their acceptability of smart nursing homes.

Given that the implementation of smart nursing homes involves multiple disciplines, including health sciences, computer sciences, engineering, and business administration, successful implementation will require collaboration among multidisciplinary teams. The qualitative evidence from this study holds relevance for a wide range of stakeholders, including older adults, family members, healthcare providers, nursing home staff, technology vendors and developers, regulatory agencies, and insurance providers. The findings have the potential to be applicable in other developed and developing countries.

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## Data availability statement

The authors confirm that the data supporting the findings of this qualitative study are available within the article and its supplementary files.

## Conflict of interest

The authors have no conflicts of interest to disclose.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.anr.2023.08.002>.

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## Review Article

## Exploring the Barriers and Coping Strategies Faced by Male Nursing Students in Japanese Nursing Education

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## SUMMARY

**Purpose:** Nursing is traditionally considered a female profession, and male nursing students face gender stereotype barriers. Most studies of male nursing students in Japan focus on their learning experiences in maternal nursing, and little is known about the experiences of male nursing students in their usual learning environment. Therefore, the purpose of this study is to explore the barriers and coping strategies of Japanese male nursing students in nursing education, including classroom and practical training.

**Methods:** A qualitative descriptive design was used to study 20 male nursing students from eight Japanese universities. Purposive sampling using the snowball method was used to recruit participants. Semistructured interviews were used to gather data about the participants' thoughts and experiences in nursing education. All interview data were analyzed using thematic analysis.

**Results:** Four themes emerged from the data: (1) nursing choices of own volition; (2) loneliness due to the female-dominated environment and marginalization; (3) dealing with barriers and seeking support; and (4) positive experiences in nursing education. Male nursing students face barriers such as loneliness and feelings of alienation. Family support, mutual support among male nursing students, and the presence of role models were factors that addressed these barriers and positively influenced career choice.

**Conclusions:** This research suggests that nursing educators need to understand the barriers faced by male nursing students and provide a gender-neutral learning environment for all students.

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## Introduction

In recent years, a shortage of nurses has become a problem worldwide [1,2]. This has been attributed to both the small number of individuals, especially men, who view nursing as an ideal profession and the increasing turnover rates [3]. A possible contributing factor is that nursing is traditionally regarded as a woman's profession. Its origins are attributed to Florence Nightingale, who laid the foundation for today's nursing, where women supported

male soldiers [4]. Men's reluctant entry into nursing is shaped by these social and gender stereotypes [5].

Male nurses are considered an untapped human healthcare resource and can contribute to increasing the nursing workforce [6]. It is also believed that the entry of men into nursing can contribute to the quality of nursing care, such as higher technical skills in intensive care units and operating rooms, quicker decision making, and greater physical strength compared to female nurses [7,8]. Furthermore, it is believed that the increase in male nurses can diversify the medical and nursing field [9]. However, men entering nursing face barriers due to gender stereotyping, such as being questioned about their sexuality, being refused the opportunity to care or escort female patients, and fear of sexual harassment from other staff [10,11].

Over the past few decades, the number of male nurses in Japan has gradually increased. However, of the total number of nurses,

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only 8.1% are male [12]. The importance of increasing the number of male nursing students and nurses has been widely discussed alongside the need to identify factors related to retention and the creation of a conducive cultural and social environment [13]. Entering nursing school is the first professional experience for men. The fact that the curriculum is geared toward women and that many textbooks depict female nurses leads to confusion about gender roles in the profession, and higher dropout rates have been reported for male nursing students [14,15].

Clinical practice in maternity has been studied extensively around the world because the stereotypes of male nursing students are most pronounced [16]. Most studies on Japanese male students' experiences and barriers in nursing education have also focused on practical training in maternal nursing [17,18]. However, gender differentiation and traditional masculinity have a pronounced impact on male nursing students not only in maternal nursing practice but also in their everyday classroom life [16]. Few studies have explored the experiences of male nursing students in these classrooms. Male nursing students' experiences of learning and interacting with others in the classroom and in clinical practice have a significant impact on their perceptions of the profession and their future career decisions [3]. In this context, it is important to comprehensively identify the barriers and coping strategies faced by male nursing students in their education to improve their learning environment. Therefore, the purpose of this study is to explore the barriers and coping strategies of Japanese male nursing students in nursing education, including classroom and practical training.

## Methods

### Study design

A qualitative descriptive study [19] was used to gather the barriers and coping strategies of Japanese male nursing students in a female-dominated learning environment. The study was conducted from May to July 2021.

### Participants

Twenty male nursing students enrolled in four-year undergraduate nursing degree programs from eight universities in Hokkaido, Japan, participated in the study. Participants were recruited by the purposive sampling using the snowball method. Sample enrollment continued until data saturation was reached. Twenty interviews were deemed saturated because no new themes were discovered by researchers, although the number of variations included in the themes increased [40]. In this regard, the authors reached consensus that collecting further data would offer no further new information regarding the barriers and coping strategies of male nursing students. The inclusion criterion for the participants was male students currently enrolled in nursing school, with no prior work experience and being placed in a female-majority environment for the first time.

### Data collection and analysis

An interview guide was developed based on previous studies [3,20] regarding perception, barriers, and coping strategies in nursing education. Two researchers conducted semistructured interviews with each participant using the online video-calling platform Zoom. Each interview lasted 30–60 minutes and was conducted in Japanese with two researchers and one participant. The following five questions were asked:

1. What motivated you to pursue nursing?
2. How did your family/friends/peers respond to your decision to study nursing?
3. Please share your experiences of being a nursing student.
4. Describe the barriers or challenges you encountered in your classroom and clinical placement.
5. How did you manage the barriers or challenges you encountered?

Additional questions such as “How did that make you feel?” and “What do you think about that?” were also asked, depending on the situation, to clarify and elaborate on the participants' responses.

The interviews were recorded and transcribed verbatim. To ensure the reliability of the verbatim transcripts, the two researchers who conducted the interviews independently checked all verbatim transcripts for accuracy. MAXQDA software version 2020 (The Art of Data Analysis) was used for the analysis of interviews. The transcripts were coded and categorized using the six-step thematic analysis [19]. Six steps were followed, including the following: (1) familiarizing oneself with the data; (2) generating codes; (3) constructing themes; (4) reviewing potential themes; (5) defining and naming themes; and (6) producing the report. Similar codes with the same meaning were combined to create subthemes, and finally similar subthemes were combined to identify common themes. In this process, all authors examined the common themes and subthemes until reaching the consensus. All analyses were conducted using qualitative data analysis software. The consolidated criteria for reporting research (COREQ) checklist was used to ensure quality reporting in the study [21].

### Rigor

In analyzing the data, efforts were made to ensure rigor from four perspectives: credibility, confirmability, dependability, and transferability [22]. Credibility was ensured by the two researchers present in a particular interview coding the recorded data for it and checking it with MAXQDA2020 (The Art of Data Analysis) software. Data were represented as accurately as possible, and verbatim quotes were included in abundance. Confirmability was established by describing the decision process using the six-step thematic analysis developed by Braun and Clarke [19]. Dependability was obtained by having two researchers independently code the data and compare all codes; any discrepancies in the two researchers' codes were discussed with a third researcher familiar with qualitative research to reach a consensus. Transferability was discussed in terms of the extent to which the results of this study could be applied by describing them in detail. In addition, to ensure reflexivity, the interviewer's gender and position may influence the interviewee on topics experienced uniquely by male nursing students, such as barriers due to gender. Therefore, interviews were conducted by the first author, a male graduate student in a master's program who is the same age as the participants and has a nursing license, and the second author, a current male nursing student. In addition, a personal relationship was established through social networking and e-mail contact prior to the interviews, making it comfortable for the interviewees to confide in each other about private topics, such as barriers.

### Ethical consideration

This study was conducted with the approval of the Ethical Review Committee of the Faculty of Health Sciences, Hokkaido University (approval no. 20-74). Information that could potentially identify the participants was removed and anonymized. The purpose of the study was explained to the participants, and they were

assured that withdrawal from or nonparticipation in the study would not affect them negatively. Written consent was obtained from all participants, with additional consent being sought from parents for participants who were minors (younger than 20 years).

## Results

Twenty male nursing students aged 19–25 years (mean  $20.80 \pm 1.33$ ) participated in this study. All participants were majoring in nursing at a university (Table 1). Through analysis of the interview data, four themes with 11 subthemes and 531 codes emerged. The themes and subthemes are listed in Table 2: (1) nursing choices of own volition; (2) loneliness due to the female-dominated environment and marginalization; (3) dealing with barriers and seeking support; and (4) positive experiences in nursing education. Male nursing students face barriers such as loneliness and feelings of alienation. Family support, mutual support among male nursing students, and the presence of role models were factors that addressed these barriers and positively influenced career choice. These themes and subthemes are discussed in depth in the following sections.

### 1. Nursing choices of own volition

Most of the participants ( $n = 19, 95.0\%$ ) decided to study nursing of their own volition. Except for the individual personality aptitudes of the participants, none of the family members or friends reacted negatively to their decision to enter nursing school because of their gender.

#### 1.1. Attractiveness of nurses

Many participants cited the emotional care and communication with patients that nurses provide as a factor in this decision.

*No one was against it at all, and my mother was like, “Maybe (nursing) is right for you.” My friends were also involved with me regularly, and they saw my personality and internal aspects, and they told me I was suited to be a nurse. My high school teacher also told me that I should do a job that would help people. I have never had any opposition. (Participant A)*

*When I went to visit a patient, I saw a male nurse and thought it was a very cool job for me, so I started to aspire to be a nurse because of that admiration. (Participant J)*

#### 1.2. Interest by hospitalization experience

Other reasons given included the experience of being hospitalized themselves or seeing a family member hospitalized attracted them to the nursing profession, leading to an increase in their interest in the medical field.

*The reason I wanted to become a nurse was that my grandmother had malignant lymphoma and she died after about two months in*

**Table 1** Characteristics of the Participants ( $N = 20$ ).

		M $\pm$ SD or N (%)
Age		20.80 $\pm$ 1.33
Marital status	Single	20 (100)
	Married	0 (0)
Grade in school	Freshman	2 (10)
	Sophomore	2 (10)
	Junior	7 (35)
	Senior	9 (45)

**Table 2** Themes and Subthemes of Educational Experiences and Barriers of Male Nursing Students.

Themes	Subthemes
1 Nursing choices of own volition	1.1 Attractiveness of nurses 1.2 Interest by hospitalization experience 1.3 Family members of nurses
2 Loneliness due to the female-dominated environment and marginalization	2.1 Heterogeneous due to being a minority 2.2 Impact of gender on learning 2.3 Male students' own perceptions of male nurses
3 Dealing with barriers and seeking support	3.1 How to cope with barriers alone 3.2 Support for male students at the organizational and social levels
4 Positive experiences in nursing education	4.1 Strong bonds between men 4.2 Easy to get a good evaluation 4.3 Contact with role models

*the hospital. At that time, I was only able to go to the hospital and visit her. My grandmother suffered and died without my being able to provide emotional support or help. I would like to become a nurse because I want to repay my grandmother and I don't want everyone to feel helpless. (Participant E)*

#### 1.3. Family members of nurses

Having a family member or relative who is a nurse also had a significant impact on their perceptions of nursing.

*I heard about my sister being a nurse and it sounded like a lot of work, but she said she found it very rewarding. I have always been interested in humanistic work and hospitals, so when I heard my sister's story, I knew that this was the direction I wanted to go. Even now, I can ask questions I don't understand on SNS (Social Networking Services), and that aspect is also very helpful, and I hear a lot of helpful things. (Participant Q)*

### 2. Loneliness due to the female-dominated environment and marginalization

As the participants went through their nursing education, they felt that there is still a social perception that nursing is a female profession. In addition to the fact that male students are a minority, this is an experience that participants described as inconvenient for men due to the nature of nursing.

#### 2.1. Heterogeneous due to being a minority

Male students reported that textbooks and other educational material are made based on the conventional stereotype that the job of nurse is for women, which led to ambivalence among men to become a nurse. Participants also reported that they needed to defer to their female classmates and felt uncomfortable in a female-dominated environment. In addition, male students were often isolated in group work and felt uncomfortable being forced into the role of group leader or presenter. This small decision-making authority is a problem unique to male students as a minority. Male students also had problems during their interactions with faculty. They mentioned that many male students are singled out by faculty members during class and are the focus of attention.

*In nursing books and textbooks, the word “kangofu (= traditional Japanese way of referring to female nurses)” is still used, and I often wonder if I am allowed to become a nurse. (Participant E)*

*In group activities, when the ratio was one male to five females, I tended to be made the leader, or perhaps it was an unspoken*

agreement, and I didn't like it that way. I don't dislike being a leader, but I don't like the fact that it's like a half-mandate. (Participant B)

I get a lot of nominations from teachers. I'm often asked when a teacher wants to ask someone's opinion and is not sure who to nominate, "Mr. A." So, I wish teachers would stop doing that. I would like you to nominate everyone in the class equally. (Participant A)

## 2.2. Impact of gender on learning

In their practical training, the patients they came in contact with, especially in maternal nursing, were resistant to receiving physical care from male nursing students, which prevented the nursing students from gaining satisfactory practice experience. Participants also reported that they themselves were afraid and confused when touching female students and female patients, and could not fully concentrate on their nursing care.

I had an in-class practical training to move a patient who was lying on the bed, and the patient was played by a female classmate. At that time, I wondered if it would be okay for me to do it. I wondered if it was okay if I touched her. But if I think like that, she will feel my anxiety. I try not to think that way. (Participant D)

The patient I was in charge of was an elderly woman, and I was supposed to give her a shower bath or clean and wipe her down. However, she refused because she was still embarrassed to be seen with a man in those situations. There were three of my classmates, including myself, who went to the same hospital, and the other two were girls, and they had experienced showering and wiping, but I had to wait at the nurses' station. (Participant G)

I had learned many things in class, such as breastfeeding and other things (about maternal nursing), but when I observed the patients, they rejected the idea of having a male student come in. It was more of a sad feeling than a stressful one. (Participant S)

## 2.3. Male students' own perceptions of male nurses

Participants felt that compared to female students, they had a disadvantageous image of their gender in terms of cleanliness and politeness. They also had a stereotype that women are better than men at providing emotional care, which is the most important nursing role. They feared that the nursing role is closely associated with feminine traits and hence men in nursing are a mismatch.

In the end, there is nothing we can do about it, but I think what makes women better is their cleanliness and politeness. In fact, from the patient's point of view, the first impression of a nurse is very important. (Participant B)

There are few men who clean toilets as a job. Men do not clean women's toilets, but women have the power to be tolerated, just as women can clean men's toilets. In the construction field, there are more men because they have more power, and in the same way, women's ability to be tolerated is a value in itself. I think this applies to nurses as well. (Participant M)

## 3. Dealing with barriers and seeking support

As noted earlier, male nursing students face a variety of barriers, but they are taking their educational courses while coping with the barriers. However, they are not yet satisfied, and the participants mentioned regarding the support they seek.

### 3.1. How to cope with barriers alone

Many participants coped by sharing their problems and stress with male peers, seniors, and juniors who were going through the same experiences. Furthermore, it was mentioned that the spread of social networking services (SNS) has connected those with the same problem not just within one school but across the country. In addition, some participants reported that SNS reduces the gap between male and female students. However, they were prepared for the small daily gender barriers, such as rejection from female patients and interactions with female classmates, even before they entered the program, and dealt with them by giving up halfway through.

There are many nursing students on the Internet and on Twitter. I have a separate account, independent of my private one, where I consult with nursing students all over the country. I think I used the Internet very well to relieve stress. I was able to talk about anything without worrying too much about the environment in which I normally live, and I think it was great that I was able to talk to people regardless of gender. (Participant I)

There are so many things I can't control, but I knew it would be hard anyway, so I try not to think about it too much, I just bear it in mindlessness. (Participant Q)

### 3.2. Support for male students at the organizational and social levels

Although participants are coping with barriers, they mentioned that there are limits to what individuals can do on their own. As support is needed, many participants expressed a desire for public outreach, such as promoting the benefits of male nurses and dispelling the image of a female-dominated profession. As support for future concerns, seeking contact with male nurses was mentioned. In particular, they requested an increase in the number of male faculty, as they would be the most accessible resource to consult.

In the past, male nurses were viewed by the public as being unfit or strange, but I think that has improved in recent years. However, I strongly feel that it is still insufficient. I think it will be easier for men who want to become nurses, including myself, if the recognition that male nurses are commonplace spreads. (Participant F)

There are a few men in the nursing faculty, but I think it would be a good idea to have a few more. It would be easier to consult with them. I don't think many people know male nurses. Therefore, I think that the most accessible people to consult from the standpoint of male nurses are the teachers. If we increase the number of male faculty members, they can provide mental health care for male students. (Participant G)

## 4. Positive experiences in nursing education

Participants stated that while male nursing students have many difficulties in education, advantages also exist.

### 4.1. Strong bonds between men

Most participants were able to form strong connections with other male students because they were in the minority. These connections were not limited to the same grade level. As one participant noted, "There are not many male nursing students, so it was nice to be able to get to know each other so well because we are among the few" (Participant S).

*When I first entered the school, I was treated very well by the seniors. There has always been a group of male students called the “Nurse Men,” who have, as a tradition, taken over the textbooks every year and set up a store at the school festival with only male nursing students. (Participant F )*

#### 4.2. Easy to get a good evaluation

Some of the participants also noted that they received more attention from their clinical nurse supervisors in hospital training and classroom teachers than female students, and reported that they tended to receive better feedback than female students. Participant B expressed that he sometimes did not like the attention, but that he benefited more from it.

*The good thing is that at school, on the other hand, because there are so few [boys], if you do something bad or good, it catches the attention of the teachers. Immediately. But because of that, they pay attention to me, so I am happy that they depend on me every time I do something, and sometimes I am not so happy. But I am quite grateful to be recognized by the teachers, and in that aspect, I think it is better to be a boy. ( Participant B )*

#### 4.3. Contact with role models

Before entering the program and before meeting male nurses who actually work there, many participants were concerned about their future due to an image of male nurses as only being in charge of heavy lifting, and a lack of information about male nurses, such as not understanding the role of male nurses compared to that of female nurses. However, unlike other majors, nursing education allows students to go to the actual workplace, where they can also make contact with expert male nurses who have established themselves in the field. Participants felt that by having male nurses as role models, that men can also be excellent nurses and have fulfilling careers.

*When my grandfather was hospitalized, there was a male nurse who was about 40 years old, and I was surprised at how cool he was and that there were men who were also active in this field. I had heard that men did all the heavy lifting, so I was worried about that, but I thought he was a shining example of a medical professional. I wanted to follow him closely to see what kind of work he does. (Participant L )*

## Discussion

In this research, four themes emerged: (1) nursing choices of own volition; (2) loneliness due to the female-dominated environment and marginalization; (3) dealing with barriers and seeking support; and (4) positive experiences in nursing education.

For men to choose nursing as a career, it is important to develop interventions such as textbooks and materials that offer gender-based information. However, it is crucial to change the gender-based stereotypes toward the job of nurse as a fundamental solution. Although the idea that men can become nurses is gradually being accepted, the perception of a feminine profession remains, and men rarely choose nursing without resistance [23]. Nevertheless, most participants in this study chose to enroll in nursing school, and gender had no bearing on their family and friends' support. Factors that contributed to their self-determined decision were their perception of male nurses and the understanding of their families. Seeing male nurses working in practice is said to be a factor in recognizing that men can be active in the nursing field and considering nursing as a career option [3]. Family members are

likely to be the closest supporters in career choices [24], and family understanding is likely to play an important role in men's choice of a career in nursing. In particular, having a nurse in the family is likely to make them more understanding of men becoming nurses and may be a factor in supporting their career choice [6]. The participants in this study were also consistent with the findings of Rajacich et al [6]. These findings suggest that more opportunities for men to become aware of nursing and an environment in which those around them recognize nurses regardless of gender will expand the numbers opting for this career.

However, male nursing students report that barriers exist after enrollment, including uncomfortable feelings of being a minority and stress in caring for female classmates. In general, during education, nursing students feel burdened by the amount of practical training and assignments [25–27]. In terms of discomfort, a strong sense of peer pressure from female students was cited as a factor in male students lacking in decision-making authority. In addition, many participants experienced a tendency for men to assume roles because of their gender since they may be the only male among the female students during group activities. These experiences may cause loneliness and act as a barrier in the learning environment [14]. Furthermore, male nursing students tend to receive more distinction and attention from nursing educators than is necessary [20,28]. Participants complained of being segregated by gender, even in group activities that do not require gender sensitivity, and of teachers specifically singling out and focusing on male students. This emphasis on “male” nursing students may lead to excessive pressure to attract attention and excel academically. Thus, there is a need to create an environment in which they can focus on their studies, as they face not only stress related to learning but also barriers unique to being male.

The traditional stereotype of nursing as a feminine profession is a factor that marginalizes male nursing students. Although male nursing students in Japan are prohibited from becoming midwives, their educational curriculum requires them to experience practical training in the area of maternal nursing. Gao et al. and Zhang et al. reported that male nurses experience rejection from female patients for physical care [9,29], but even the participants in this study, who were students, experienced rejection from patients when providing gender-sensitive care, especially in maternal nursing practice, which is in any case not useful for the future. Participants described giving up and enduring as a way of coping with barriers. Traditional masculinity is reported to be “reluctant to ask for help” and “willing to endure physical pain and discomfort” [30]. This masculine image may be the reason why male students choose the coping behavior of enduring. However, enduring does not lead to a fundamental solution and may lead to retirement when the stress becomes unbearable. In addition, faculty members are also confused by the treatment of male students [10], so nursing education should first work to create an equal learning environment between male and female students and to improve the position of male students.

In Japan, female nurses were called “kangofu” until 2002, after which the gender-neutral term “kangoshi” was introduced. However, textbooks also continue to include descriptions of female nurses and the traditional term “kangofu.” This background of language and culture that has distinguished nurses as women and the perception that the nursing education curriculum is geared toward women may contribute to feelings of marginalization in the nursing field. Gender role consciousness has been reported to correlate with burnout and negatively influence nurses' willingness to continue working [31]. Several participants also noted that while male strength is an advantage, the image of cleanliness and politeness that women have is more advantageous as nurses. In Japan, men have traditionally been assigned to psychiatric and

emergency wards [32], which may imply that male strength is the only attribute required for nursing and that there are fewer opportunities for men to play an active role. Male nursing students who aspire to the profession because they are attracted to mental health care and communication with patients may feel that this role is primarily for women and may mistakenly believe that they can only be active in certain fields, leading to career uncertainty due to the gap between their ideal future and reality [33]. The above feelings of marginalization and anxiety about their own careers are thought to be the cause of male nursing students dropping out of school [34].

Male nursing students perceived the stress of a female-dominated environment and the recognition of their male role as barriers, but they coped with these barriers by engaging with other male nursing students who were going through the same experiences. At several of the participants' universities, they formed communities not only with their peers but also with male seniors and juniors, creating a system of support among themselves despite being in the minority. In addition, the widespread use of SNS has helped against barriers by making it easier to connect with others in the same situation, by being able to join multiple communities of male nursing students and confiding in them about their experiences with the ease of anonymous participation. Support and encouragement among peers using SNS may be the most effective support for male nursing students in the future, a new finding of this study. In the United States, the American Assembly for Men in Nursing (AAMN) is an organization that has established chapters at colleges across the country to provide peer support among male nursing students [35]. In a previous study in China, establishing an alliance of male nursing students was found to help create a supportive environment for men [36]. This sense of connection and shared experiences among male nursing students may alleviate feelings of loneliness and marginalization. The opportunity to interact not only within the same school but also with male nursing students from other schools through SNS is considered an effective means of addressing barriers, especially in schools with a small number of male students.

In addition to the barriers that male nursing students currently face, they also had concerns about their future careers, but consistent with the findings of the literature review by MacWilliams [37], the presence of role models proved to be a factor in alleviating their anxiety. Men who aspire to become nurses have concerns regarding their masculinity and sexuality and feel more anxious about their career choices [10]. Exposure to actual male nurses working in the field provides an opportunity for them to recognize the role of men in nursing and to have a clear vision of their future [3]. Participants in this study also found that the presence of role models was a factor in their choice of nursing career and a factor in reducing their anxiety about the future. Role models include working male nurses and male nursing faculty who interact with them at school [38]. Therefore, it is necessary to establish a framework in which male faculty can consult with and support male students.

For male nursing students to continue their studies and remain in the profession, the cultural and social environment needs to be improved. Participants desired broader social awareness of men in nursing and more opportunities to see male nurses in action. It is the responsibility of the education system to correct the stereotype of nursing as a feminine profession and to make society aware of men in nursing [13]. It is reported that male students fear that they will be perceived as unmanly for choosing to become a nurse [23]. The ideal state of nursing education is to instruct all students in interpersonal care [6], and allow them to feel comfortable and grow as professionals, regardless of gender [39]. Barriers faced by male

nursing students in nursing education were related to their studies, practice as nursing students, and those specific to being male, such as social stigma and gender roles. These results suggest that nursing educators need to understand the barriers faced by male nursing students and support them with strategies to improve the learning environment.

### Limitations

Since this study used snowball sampling, it may not be a valid representation of the population. In addition, information on barriers was likely limited because the study did not consider the participants' family environment or academic performance. Therefore, it is difficult to determine the presence or absence of effects due to them in this study. Participants were recruited from eight universities, rather than one, to ensure that the sample was as representative as possible.

### Conclusion

The results of this study indicated that male nursing students face barriers in nursing education, such as loneliness due to the female-dominated environment and marginalization due to the perceived feminine nature of the profession. Family support, mutual support among male nursing students, and the presence of role models helped male students cope with these barriers and served as positive factors in their career choices. Findings emphasize the importance of nurse educators understanding the barriers faced by male students and working to mentor nursing students. Educators must also work to correct gender bias and create an environment in which male nursing students can concentrate on their academics.

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### Conflicts of interest

The authors have no conflict of interest to disclose.

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## Research Article

## Phenomenological Study on the Lived Experiences of Mothers Caring for Their Pubescent Children with Developmental Disabilities



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## SUMMARY

**Purpose:** This phenomenological study explored and revealed the mothers' lived experiences of caring for pubescent children with developmental disabilities (DDs) in Korea.

**Methods:** Data were collected from semistructured individual in-depth interviews with nine mothers. This study adopted Giorgi's phenomenological analysis, through which a general structure of mothers' caregiving experiences with their pubescent adolescents with DDs was formulated.

**Results:** The lived experiences of mothers caring for pubescent children with DDs were clustered into four themes and nine subthemes from 19 meaning units: (1) not being allowed to take delight in child's growth due to unbalanced growth pace; (2) feeling marginalized along with the disabled child; (3) feeling like being kicked out of society slowly and permanently; and (4) rearrangement of care direction and purpose.

**Conclusions:** This qualitative study captured vivid experiences of mothers who care for pubescent children with DDs by illustrating these mothers' detailed physical, emotional, and relational difficulties in their caring. Most importantly, this study found that it is puberty that these mothers come to clearly understand that their children and their disabilities are inseparable and change the purpose and direction of childcare. The findings of this study can help health professionals better understand that these mothers are in urgent need for emotional support and need to be included in nursing care. And this study can be used as base data for increasing disability awareness for both healthcare workers and public in general.

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## Introduction

Developmental disabilities (DDs) are disorders characterized by delays in one or multiple developmental domains, such as learning, behavior, language, social-emotional skills, and self-care [1]. According to the Korean Act on Guarantee of Rights of and Support for Persons with Developmental Disabilities, people with DDs are those with autism spectrum disorder (ASD), people with intellectual disabilities (IDs), and individuals who need help from others to lead their lives because they lack the ability to perform daily tasks or engage in social life on their own due to the absence or delay of typical development (TD) [2]. The prevalence of DDs is globally increasing with the United States of America showing significant increase from 5.76% to 6.99% during 2014 to 2016 [1], and South Korea showing the increase of the number of registered people with

DDs from 2.34 million in 2015 to 2.52 million in 2021. Among age groups, children under 10 years old, and from 10 to 20 years old consists respectively 7.4%, and 17.3% of the whole DDs population in South Korea [3].

Adolescents undergo puberty which is an integrative transitional period when boys and girls show distinct and rapid sexual maturation, physical and emotional changes [4]. All these personal, biological, sexual, and social changes during this transitional period are significant for any child but are of greater significance for caregivers because children with DDs depend on their caregivers for most of their daily life activities. According to many previous studies, most people with DDs are looked after by their families, usually their mothers, with studies finding similar trends in many countries [5–8] and mothers of children with IDs regard caregiving as their unavoidable responsibility [9].

However, there have been reports about negative effects of taking this responsibility of caring children with DDs on mothers' lives. Mothers of adolescents with DDs are reported to experience higher levels of caregiver stress than mothers of adolescents with TD [10], higher level of depression and somatization than those of TD children [11], and had increased burden of managing their

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children's health care needs [12]. In addition, mothers of children with DDs displayed more marital problems and family dysfunctions than those of TD children [5]. And older mothers with adolescent children with DDs are more likely to be stressed than similarly aged mothers of children with TD [10].

The above findings allow the glimpse of how mothers are affected by the need to address changes in their pubescent children. To note is the Korean media report of a mother who took her own life and that of her adolescent child with DDs, leaving a suicide note of despair, frustration, and hopelessness of caring her child with DDs [13]. Given the extensive time that mothers spend taking care of their adolescent children with DDs from birth, as well as them being middle-aged, these mothers' health and quality of life need to be included in nursing attention because caregivers' health and quality of life affect the child's quality of life. However, there is little detailed information available with regards to the impact of the transition of child with DDs on mothers, and many aspects of caregivers' burden to adapt to physical, sexual, emotional, and behavioral changes in her child remain poorly understood.

Therefore, the present study aims to explore mothers' lived experiences of caring for their pubescent children with DDs. The result of this research will increase knowledge about the lived experiences of these mothers in childcaring and provide anticipatory guidance to help those who is taking care of younger child with DDs prepare their child's puberty.

## Methods

### Study design

This descriptive phenomenological study, which adopts Giorgi's phenomenological approach [14], aimed to understand the essential structure of the lived experiences of mothers who care for their pubescent children with DDs, the most common developmental disability being intellectual disability. Following Husserl's stance that nothing must be added or subtracted from what is presented to gain an understanding of experience just as it is experienced, Giorgi emphasized the phenomenological reduction, which implies bracketing past knowledge about the phenomenon encountered [15]. The research questions were "What are the mothers' lived experiences of caring for their pubescent children with DDs?"

### Participants

The participants were selected through purposeful sampling to collect information-rich cases [16]. Recruitment was done with the help of: (1) a neurologist at a university hospital in Daegu, a southern metropolitan city in South Korea; (2) leaders of the

Parents Association of Children with Disabilities; and (3) a long-time friend who cares for a child with DDs. The investigator met with these people separately and explained the research purpose and process as well as presented them the study advertisement. These people recruited participants candidates, and if participants candidates agreed to participate in the interview, phone number was given to the primary investigator, in turn made a brief phone interview to check if the participants candidates meet the inclusion criteria and information-rich cases.

The criteria for participation were as follows: (1) mothers who have been caring for children with DDs aged 13–18 years (1<sup>st</sup> grade of middle school through 3<sup>rd</sup> grade of high school) who went through puberty or are in puberty; (2) lacking any psychological disorders; (3) able to read and communicate; and (4) have willingness to share their experience. Table 1 shows the demographic details of the participants and their children.

### Ethical considerations

The study was approved by the Institutional Review Board of the Kyungpook National University (IRB No. KNU-2018-0186). Before data collection, the participants were informed of the study purpose and process and of their right to voluntary withdrawal from the study, privacy, confidentiality, and anonymity. Each participant consented to participate in the study either by filling out the consent form (in the case of face-to-face interviews) or by verbally expressing their voluntary participation in the study (in the case of telephone interviews).

### Data collection

The participants, who were Korean mothers caring for adolescents with DDs in puberty, were selected between December 2018 and February 2021. It took 27-month period in participant recruiting due to social distancing during the coronavirus disease 2019 (COVID-19) pandemic. Purposeful sampling was used to collect information-rich cases [16]. After obtaining their written or verbal consent, each participant completed a brief questionnaire about their demographics including their children's. Qualitative data were obtained from in-depth interviews with nine mothers until no new themes emerged. All interviews were conducted by the primary investigator who has been conducting qualitative research mostly as a primary investigator for almost 10 years, thus, having ample knowledge and skills to conduct interviews for qualitative research to elicit rich information from the participants. The interviews were conducted individually at mutually agreed times and in private places such as participant's home or researcher's office, and no one else was present beside the participant and researcher to conduct

**Table 1** Characteristics of Mothers and Pubescent Adolescents with Developmental Disabilities (N = 9).

No.	Mother				Child					
	Age (years)	Education	Marital status	Employment	Age (years)	Gender	Disability type	Disability grade	Medical condition	Medication due to behavior problems
1	49	University	Married	No	19	Boy	ID	1	None	O
2	51	University	Married	No	16	Boy	ID	1	Epilepsy	O
3	45	University	Married	No	16	Boy	ID	1	None	O
4	45	University	Married	No	18	Boy	ID	1	CMT	O
5	47	University	Married	No	18	Girl	ID	2	None	O
6	44	University	Married	No	16	Girl	ID	1	None	O
7	49	High school	Married	No	16	Girl	ID	2	Epilepsy	X
8	45	High school	Divorced	Part-time	16	Girl	ID	1	Epilepsy	O
9	50	High school	Married	No	19	Girl	ID with DS	2	Epilepsy	O

CMT = Charcot–Marie–Tooth disease; DS = Down syndrome; ID = intellectual disability.  
Disability grade = Grade 1: IQ < 35, Grade 2: 35 ≤ IQ < 50, Grade 3: 50 ≤ IQ < 70.

the interview without bothering. All interviews were headed by the principal investigator, who has ample experience in conducting interviews for qualitative research. The first four participants participated in face-to-face interviews during school hours whereas the others participated in telephonic interviews because of the COVID-19 pandemic and were conducted on late nights when the children were asleep to ensure the children's safety.

The interviews began with open ended questions to obtain more descriptive information. The main question was "What is your experience of caring for a child with developmental disability in puberty? Facilitative questions were also asked, such as "Could you explain it in detail?" "Could you give me an example?" and "How do you feel about this change?" based on the phrases and words used by the interviewee. Keeping in mind of the concept of phenomenological reduction [16], the investigator recognized their own initial assumptions about the phenomena (for example, the changes taking place in a pubescent child with DDs surely affect caregivers negatively, and these caregivers would experience distinct hardships in caregiving) throughout data collection and analysis and tried to remain open to the phenomenon itself to avoid going beyond the data.

During the interviews, the investigator tried to establish rapport with the participants by showing empathy in a manner that did not undermine neutrality to their experiences [16]. The interviews lasted from under 10 minutes to 2 hours. The investigator conducted a follow-up telephone conversation with four participants to clarify the interview data. All interviews were conducted in Korean, audio recorded with the participants' consent, and transcribed verbatim in Korean as soon as possible. After the interviews, all participants were given incentives. All recorded and transcribed data were kept safe in a password protected computer or a locked filing cabinet. The findings were then translated into English by the professional translators and checked by the author, and later reviewed and edited by a native English speaker.

#### Data analysis

The principal investigator, who has a doctorate with a specialty in qualitative research, has published several qualitative studies in academic journals and has been teaching qualitative research methods at an academic institution. The investigator has also been interested in the current phenomenon through interactions with a friend who looks after an adolescent child with DDs.

Data were analyzed following Giorgi's descriptive phenomenological method [14]. After reading the transcript to gain a general impression of the participants' caring experiences, the investigator identified phrases and sentences regarded as meaningful for such experiences and converted them into phenomenologically sensitive terms. Focal meanings were synthesized and categorized into themes to reflect each participant's perspective, and finally, the general meaning of the participants' caring experiences was synthesized and described. Participant specific concepts were eliminated, and common meanings were left to form the general structural description. The findings were translated by professional translators and the primary investigator checked the accuracy of the translation of the transcript verbatim in Korean to English. After that, the translated manuscript was checked and reviewed by a professional native English editor.

#### Methodological rigor

To promote rigor, this study employed Guba and Lincoln's four criteria of trustworthiness [17]: truth value (credibility), applicability (transferability), consistency (dependability), and neutrality (confirmability). In the selection process, purposeful sampling was

done to obtain information-rich cases and face to face or phone interviews with open ended questions were held to ensure truth value. Additionally, member checks were performed by the participants to confirm that the interpretations coincided with their experiences, and a peer review was conducted by a nursing scholar with qualitative research experience to ensure the certainty of the interpretations. To ensure applicability, data were collected through purposeful sampling, and the author presented detailed descriptions of the general characteristics of each participant and their respective child. To achieve consistency, Giorgi's analytic steps were closely followed, all research procedures carefully documented, and participants' vivid statements for each theme presented. To ensure neutrality, the author read the transcripts multiple times in the process of analysis and went back to the raw data with each finding so that the findings are grounded in the data. In addition, the author made a conscious effort to minimize the degree and incidence of the researcher bias in the whole process of the study.

## Results

### *Transformed meaning units from raw data and structuralized participant experience*

This study extracted and converted 19 meaning units from the raw data; the converted meaning units were merged into nine subthemes and four themes representing the fundamental components of the participants' experiences (Table 2).

#### *Theme One: Not being allowed to take delight in child's growth due to unbalanced growth pace*

This theme is about the participants' experiences of caring related to the pubescent children's unbalanced physical, sexual, emotional and behavioral changes.

#### *Subtheme One: Child's physical growth spurt adding much more burden than enough*

A child who hits puberty grows rapidly, showing no promise of becoming independent. The mothers are perplexed and bewildered when their children still act like toddlers despite their size. A child's fast-growing body adds burden to the mothers' daily tasks. After a child reaches puberty, their personal hygiene becomes a more serious issue. Mothers' daily tasks, such as cleaning and brushing the child, become challenging as the child's stubbornness grows along with their body. This makes mothers constantly feel inadequate, and take child's growth spurt not a pleasure but another burden.

*At a supermarket, he tries to get in a cart that is too small for him. He's all grown now, and I didn't know that only his body would grow like this. He used to have that baby like smell, but not now. He doesn't know how to keep his body clean. I have to clean him every day. Whenever I clean him and brush his teeth, it is like fighting a battle. (Participant 2 having a 16-year-old boy with intellectual disability [ID] and epilepsy)*

*I would be satisfied just if she wipes after a bowel movement, changes the sanitary pad, takes a shower, and washes her hair by herself. It was not that difficult for me to clean her body before, but, these days, I feel really tired after I have her cleaned because only her body has grown. (Participant 6 having a 16-year-old girl with ID)*

The child's rapid physical growth increases their mothers' concerns about their health issues. Mothers who raise children with

**Table 2** Themes and Subthemes that Build the General Structure of the Lived Caring Experiences of Mothers of Pubescent Children with Developmental Disabilities.

Themes	Subthemes	Meaning Units
Not being allowed to take delight in child's growth due to unbalanced growth pace	- Child's physical growth spurt adding much more burden than enough	- Child's fast-growing body taken as a burden - Becoming sensitive about child's health issues including obesity - Health professionals not welcoming pubescent with DD
Feeling marginalized along with the disabled child	- Perplexed by the unexpected and unwelcome child's sexual growth - Feeling loss of control and words toward child's mood swings and violent tendencies	- Manifestation of child's sexual desire: an unwelcome surprise - Anxiety about the child becoming the victim or aggressor of sexual abuse - Frustration with unexpected violence and stubbornness of the child - Stifled by the child's restricted verbal expression
Feeling like being kicked out of society slowly and permanently	- Becoming a nuisance with the child to the world - Bearing burdens by themselves without rest and support	- Subjected to cold glares along with the child - Feeling small and inferior as mother of disabled child - Increasingly becoming the only caregiver - Realizing the limitation of professional help
Rearrangement of care direction and priority	- Feeling like losing a foothold in society tied up with the child - Realizing that time won't heal the problem	- No comfortable place to stay and to go to -Gloomy outlook after the child's school graduation - Child progress seems to disappear - Enduring the intolerable present with no end in sight - Realizing that disability is not something that can be healed - Accepting that the child's disabilities are a part of them - Ensuring a safe nest for the child - Realizing the importance of a policy assisted support system and the need for team work
	- Realizing disability is inseparable from the child - Preventing the worst scenario from becoming the dreaded reality	

underlying diseases are worried that hormonal changes may exacerbate those conditions whereas those whose children have no apparent illnesses are highly anxious about the possibility of their child contracting new diseases. Among other health worries, mothers become very concerned about the child's possible obesity, which could bring about health risks for the child. Furthermore, access to hospital services has become more difficult. Their children strongly resist whatever they perceive as strange, which makes medical checkups an arduous process.

*After she had her first period, she has a seizure two to three times before her period begins. I can't sleep when she nears her period because of anxiety. When injecting a needle, I am thrown off when she pushes me. When she was little, medical treatment was not a big deal, but now going to the hospital is just too much. (Participant 8 having a 16-year-old girl with ID and epilepsy)*

*My child should not grow anymore. He cannot control his diet, nor does he exercise for himself. He used to be skinny, and then, things changed. I give him small portions, even though it aches my heart. I control his diet, because a bigger body, especially obese body would work badly for him by bringing new health issues. (Participant 1 having a 19-year-old boy with ID)*

What increases the mothers' concerns about their child's health issues in this period is that mothers cannot help but endure the obvious reluctance of some healthcare professionals to examine the child.

*We can't go to most regular hospitals. Some doctors are downright unwelcoming. Even when the doctor is fine, I see hospital staff looking at us like, 'Why can't you go to another hospital?' (Participant 4 having an 18-year-old boy with ID and Charcot-Marie-Tooth[CMT])*

#### *Subtheme Two: Perplexed by the unexpected and unwelcome child's sexual growth*

The participants felt perplexed when they found out that their "baby like" adolescent child expressed sexual desire, which came as an unexpected and unwelcome big surprise. For these mothers, the development of secondary sexual characteristics which are a clear sign of child's growth into adulthood meant not something to celebrate, but just a further inconvenience and more things to focus

on. Even worse, finding support which is specific to their children was not easy.

*When I first saw my son masturbating, I was so shocked and didn't know what to do. I thought something might come up as he hit puberty, but I didn't think about it too much because he was still 'a little baby' to me. I was desperately looking for help, but most sex education is designed for typically developing children. When my boy was little, I took him with me into the women's room, but now I can't. I feel miserable because something that should be celebrated is a burden to me. (Participant 3 having a 16-year-old-boy with ID)*

In addition, mothers are highly anxious that their children may behave in a socially inappropriate manner and might be involved with sexual crimes. Mothers with boys are worried that their children may be accused of sexual crimes, while mothers with girls are anxious that their children may fall victim to unfortunate incidents which may lead to devastating consequences. Thus, continue the days of up-close and constant surveillance to protect their child from sexual abuse.

*I've heard stories about sexual problems experienced by other mothers raising children with DDs. Those stories were frightening. I saw so many cases of taking off trousers in public or chasing after women. I am so afraid of sexual problems happening. (Participant 3 having a 16-year-old-boy with ID)*

*As body matures kids touch their body, but they do it when others are not around, but children like my kid touch their genitals like it's nothing in front of others. I worry when her period comes late because you never know what will happen. She can't express herself, which is why I become anxious when she is not around. (Participant 9 having a 19-year-old girl with ID, Down Syndrome, and epilepsy)*

#### *Subtheme Three: Feeling loss of control and words toward child's mood swings and violent tendencies*

The children used to be docile, but since they reached puberty, the level of defiance and violence of adolescents with DDs has well exceeded what their mothers could have predicted and was beyond their coping abilities for most participants. Eight participants had their children take drugs to control their violent behaviors. The

participants felt betrayed, hopeless, miserable, and frustrated to no end and at the same time were afraid that these socially unacceptable behaviors may put their child's life out of society's favor.

*I heard a lot about mothers getting beaten by their kids, but I never thought that would be my reality. It was just a shock, I felt like I got terrorized. When he attacked me, there was nothing I could do to make him subdue. I don't have any clue about his abrupt violent behavior. Is this violence the reward I get for the past years of sacrifice to take care of him? I thought about jumping off somewhere every time I drove the car to the school. And, you know, the combination of disability and violence, no way! (Participant 4 having an 18-year-old boy with ID and CMT)*

What's even worse is that the participants had to deal with their children's defiance every day without a clue as to what the children were thinking because of their limited verbal communication ability. Mothers got frustrated because their words do not have any effect on the child. And Mothers feel sorry for their children, guessing that their violent episodes might result from the limited ability to express their inner changes and pain with words. The child's limited verbal expressions make it harder for mothers to read the child's mind, to cope with child's mood swings and violence.

*She used to be so calm. Now, she gets upset every time something does not go her way. I don't know what to do for her, and I don't know what has got into her. Unlike other kids, my child cannot let out her suppressed adolescent feelings by sharing them with her friends. She can neither express her feelings nor interact with the ones who would empathize with her. (Participant 7 having a 16-year-old-girl with ID and epilepsy)*

#### *Theme Two: Feeling marginalized along with disabled child*

This theme is about the participants' relationship with self and others experienced by pubescent with DDs caring.

##### *Subtheme One: Becoming a nuisance with the child to the world*

Since entering adolescence, the children's disabilities became more apparent, and they seemed to lose their charm that they had as little ones. Mothers feel that their children draw more attention from others than they used to. The participants realized that the sympathetic gaze during the child's younger days has been replaced by cold stares of uneasiness and rejection. The participants reported feeling frustrated and embarrassed when other people glare at them and their children, especially when some people cringe upon seeing their children.

*When she was little, people seemed to accept her as a little cute girl; however, these days, I feel like people look at us and say, "She's all grown up. How can she do that?" I may have been more depressed because of the look that people gave us. After she entered middle school, she became louder and had more episodes of abnormal behaviors. And I had to deal with more people staring at us. It was so frustrating. (Participant 9 having a 19-year-old girl with ID, Down Syndrome, and epilepsy)*

The participants said they hated the feeling of being a nuisance to others and situations where they felt guilty and inferior even when they had done nothing wrong. Since the child got into puberty, mothers found themselves increasingly distant from others and feeling small.

*He repeatedly throws a fit, and I apologize every time he misbehaves. He just does without considering the consequences of his*

*misbehavior, and I keep saying sorry to others instead of him. One day I asked myself, "What did I do so wrong to say sorry all the time?" I feel that I, with my child, am nothing but a nuisance to the world. I feel like I'm becoming inferior, and I rarely meet people. (Participant 2 having a 16-year-old boy with ID and epilepsy)*

##### *Subtheme Two: Bearing burdens alone without rest and support*

The participants found the care burden increasingly being put only on their shoulders, and they reported feeling despair about having no one to count on. Activity helpers sent by the government would shake their heads in refusal upon seeing the grown up child. If the mothers could count on their spouses for help, things would be easier. However, most of the participants feel that their spouses believed that taking care of the children is solely a mother's responsibility. Some would even disparage the mothers' efforts, adding to the mothers' resentment and anger.

*My boy is 180 cm tall, and he acts like 5 to 6-year old. Most helpers run away finding that the child they should help is not a little one, but almost a fully grown adolescent. An activity helper, who had taken care of him since the boy was little, stopped showing up one day after being hit by him. I must go through with it alone. When the boy was little, it was okay. I could control him, and get help from activity helpers. But not now. It was unbearable because there was no end in sight and no one to help me. It's my duty, I know, to take care of him, but I also need a break. (Participant 4 having an 18-year-old boy with ID and CMT)*

*My husband insists on taking the kid outside because she still looks like a baby to him. However, outside, he doesn't take care of her once she starts to act out. One day, I told my husband that I am tired of dealing with her. And he said, "How can this be so difficult? Other moms raise kids worse than her, and they have jobs, too." (Participant 6 having a 16-year-old girl with ID)*

These difficulties are compounded by the perceived limitation of professional help. The participants approach doctors or teachers hoping for solutions to their problems. However, they are often disappointed to realize that even professionals could not help them find a way out of their hardship.

*The psychiatrist just told me, "Don't think about like that." I paid good money for the session, but it did not help me at all. Hospitals always end up proposing drug treatment .... Some teachers resent us, saying they are stressed out by our children. Such struggle peaks during this period. But we can't complain. What could mothers complain about when the teachers take care of their children? (Participant 3 having a 16-year-old-boy with ID)*

In contrast, a mother reported that a teacher who had experience with adolescents with DDs gave her advice that helped her persevere and guided her on how to approach the problem.

*My son's teacher told me, "All kids are like that when they hit puberty. Things will get better. He is just trying to tell you he is going through tough times." After the talk, I thought, Ah, it is puberty. That is what it was. (Participant 1 having a 19-year-old boy with ID)*

##### *Theme Three: Feeling like being kicked out of society slowly and forever*

This theme is about the participants' perception about space and time regarding pubescent with DDs caring.

*Subtheme One: Feeling like losing foothold in society being tied up with the child*

After several episodes of struggling with their children's stubbornness and rebellion in a public space, thus receiving other people's disapproving stares, the mothers reported feeling reluctant to go out with their children and avoiding crowded places. There are little things mothers can do about the child's aggressiveness that manifests itself regardless of time and place. Participants said nowhere is comfortable to stay and go with their respective child.

*I stopped him from pushing elevator buttons, and he began to throw a feat. These things happen repeatedly, and I'm afraid of going out with him. I don't feel comfortable even visiting my parent's house. I just have to stay home with him. What's even worse is that I don't feel comfortable even at my own house. His mood fluctuates, and he keeps crying and screaming, lying on the floor. Since puberty, his voices got louder and I worry about noises between floors. (Participant 2 having a 16-year-old boy with ID and epilepsy)*

After graduation, children with DDs will have nowhere to go in this society, and they have to sit at home all day long, which means their mothers have no choice but to be with them all the time. Mothers said they feel nauseous just by the thought of sharing the same space with them all the time. As the children slowly lose their foothold in society, participants feel that they also lose their place in society along with their respective child.

*High school graduation is a big issue for mothers of adolescent children with DDs. School is the only place where he can interact with people other than family members. There are so many 'people with DDs who live in their own home or with their family', and we, mothers, really hate hearing this term. If my boy had nowhere to go and stayed at home 24 by 7, I would be a prisoner at home with him, and I feel suffocated whenever I think about it. I love my boy, but that's the most dreadful feature of life. (Participant 4 having an 18-year-old boy with ID and CMT)*

*Subtheme Two: Realizing that time won't heal the problem*

Participants confessed that puberty of children with DDs is the toughest time for mothers to stand strong in child caring because children with DDs show behaviors that strongly indicate regression. Participants tried everything to teach their children letters, how to hold tableware properly, etc., and the children started showing progress very slowly. But since puberty arrived, it was just like a tower built with hard work collapsing in a second. Mothers realize that enduring the intolerably endless present results in an even more depressing future without any glimpse of hope. And they have no choice but to wait.

*Ever since my boy was diagnosed, it has never been easy. When he was little, I vaguely thought that things would be better sometime in the future, and I poured out all my energy to help him hoping that he would improve. However, my boy shows no improvement in sight, and I'm in my late 40s losing strength every day. How long should I keep doing this? I feel like going in an endless loop without being able to escape. Time doesn't bring any progress, it's not on my side. (Participant 2 having a 16-year-old boy with ID and epilepsy)*

*Theme Four: Rearrangement of care direction and priority*

This theme is about the participants' change of care purpose, realizing that their child's developmental disabilities are not something to be healed.

*Subtheme One: Realizing disabilities are inseparable from the child*

It was not until the onset of puberty that participants came to understand that their children and their disabilities are inseparable. All except one participant confessed that they used to rely on the Korean saying "sincerity moves heaven" and hoped for their children's normal growth. However, the participants realized there are things in life on which sincerity has no effect, and they must accept the limitations to their children's development. The hope that the children would be able to catch up and their disabilities would be cured was replaced by the unshakable realization that "this is it."

*I found out that every effort for the past 10 years to make him a "typically developing child" was collapsing like the Babel Tower since he entered puberty. I came to realize that disability is not something that can be cured. I expected sunny days to come if I tried my best; however, I face this dark, gloomy reality. (Participant 3 having a 16-year-old-boy with ID)*

*When other mothers said their children with DDs can't do things on their own, I nodded in front of them but, on the inside, I thought my kid would be different. Now, I know this is as far as he goes. It took me a long time to accept that his disabilities are a part of him. I had been obsessed with curing his disabilities as if they were some diseases. (Participant 2 having a 16-year-old boy with ID and epilepsy)*

*Subtheme Two: Preventing the worst scenario from becoming the reality*

The mothers have realized that their children's future, as well as their own, are even more dismal. The child will be left alone in this world in the end and will still be unable to do anything by themselves, with no safe place to stay or someone close to take care of them. Most participants admitted thinking about taking out their own lives along with their children's, overwhelmed with their lives that show no sign of improvement.

*I can't imagine life being any more difficult than this. It's terrifying and I want to run away. But I have to take the burden. When I die, I should take my kid along with me. Without me, he will be tied up with a steel chain and beaten to death. The life of disabled kids on the news is his future. Puberty is difficult even for mothers of typically developing children, but for kids like mine, even when it's over, they will not be normal. So, the pain remains. (Participant 3 having a 16-year-old-boy with ID)*

The participants were overwhelmed with the realization that even their best efforts and lifelong caregiving would lead to nothing. Their caregiving focus shifted from curing the disability to preparing a safe place for the child to live in. And preparation for their child's socialization became the most important thing in childcare for mothers, and they felt pressured to teach the children how to at least maintain personal hygiene. Moreover, going through

this toughest time of child caring, the mothers realized that individual efforts do not provide solutions to the child's and their own future, thus realizing the importance of mothers' team work. And they opened their eyes to the need for policy assisted support system that guarantees the safety of those with DDs.

*I paid every effort to help my daughter learn ABCs, but now, the focus is not reading and writing. They say institutions accept people only in good conditions. I have to prepare her for her life at an institution so that she can live there without being hated by others after I'm gone. (Participant 6 having a 16-year-old girl with ID)*

*I have focused on "curing" my boy's disability, but going through his puberty, I realized the need for systematic support for people like us. I would feel much more at ease if my boy had a definite safe place to go after graduation and if the government had such a system. And, mothers like us should not be left alone taking all the burden of caring for child with DDs. If it continues as it is, you would hear a lot more tragic media reports of suicide of mothers like the recent one. (Participant 4 having an 18-year-old boy with ID and CMT)*

## Discussion

Changes of puberty in child may influence even the life of mothers of typical development (TD) child; however, by this period, mothers of TD child would not consider the maintenance of kids' hygiene as a matter of their concern. However, the participants of current study still take the responsibility of personal hygiene of almost fully-grown child with DDs, thus physically become exhausted. This finding would be a clear detail of previous research [10], which reported that caregivers of special needs children are under high physical burden. What's even worse is they don't have any support resources to utilize in this tough period of childcare. Considering most participants are in late 40s, this daily task must be a tough routine for them. Furthermore, the finding that participants couldn't get help even from government paid activity helpers due to the child's grown body and problematic behaviors accentuate the physical difficulty of caring pubescent children with DDs. Therefore, ways to lower physical burden of these mothers should be implemented. For example, training and deploying helpers with knowledge and skill to deal with pubescent children with DDs would be effective in alleviating these mothers' physical burden.

Concerns about health issues of children with DDs including obesity were high among the participants. Obesity in childhood is linked with numerous undesirable medical conditions along with negative social consequences [18], and previous research reported that youth with autism spectrum disorder had significantly higher odds of overweight and obesity compared with TD youth [19]. Therefore, health management, including weight control of adolescents with DDs, should be dealt with by health professionals. However, this research reveals that health professionals' negative attitude toward pubescent children with DDs works as barriers to utilization of healthcare facilities, resulting in the participants' increased anxiety about their children's health concerns. Health professionals' attitudes have significant impact on comfort and compliance of people with DDs and their caregivers [20], but it is reported that healthcare professionals lack the practical ability, knowledge, and skills to treat adolescents with ID [21]. Therefore, disability awareness education aiming to increase understanding and empathetic attitude need to be inculcated in the early healthcare education. In addition, nursing education and intervention focusing on health maintenance of pubescent children with DDs, including nutrition, exercise, and medical consequences of obesity should be delivered to caregivers of adolescents with DDs.

Participants of current study expressed feelings of shock, embarrassment, anxiety, despair, and frustration facing their child's socially unacceptable behaviors, which turn out to be a new burden mothers get in this transitional period of child's growth. This finding is consistent with previous studies reporting that inappropriate sexual behaviors of child with ID was a top stressor for mothers [22], and behaviors and emotional issues of children with DDs are crucial factors affecting mothers' anxiety, depression, and parenting stress [23,24]. Current study shows that mothers are in great needs of sexuality education, knowledge, and communication support to effectively deal with sexual, behavioral, and emotional changes of their child. Previous study [25] also reports that mothers of ID children want to provide sexuality education which is specific for the child with special needs themselves, and they need assistance of professionals for skill and knowledge. Furthermore, the participants require substantial communication support in coping with their child's mood swings and violent tendencies. The existence of coping strategies reduces parenting stress induced by the symptoms and behavioral issues of child with DDs [26]. Therefore, nursing intervention such as tailored sex education programs for children with DDs and their caregivers, and practical communication support should be developed and implemented.

Current study shows that caring pubescent children with DDs has great ramification on mothers' social connections, relationship with others and even on identity. Disability related stigma and social burden on people with DDs and caregivers seem to be similar regardless of culture difference; Caregivers of children with ID in China refrain from visiting public places to avoid discrimination [9], and caregivers of preschoolers with Autism Spectrum Disorder in Greece report that their inner self has changed due to stigma related with DDs [27]. However, participants of current study reported that their feelings of crisis, stigma, isolation, and inferiority dramatically increased since their children with DDs entered puberty, which maybe the result of getting more attention from others. According to previous research [28], collaboration between professionals and caregivers reduces the feeling of stigmatization and improves the quality of life for both the disabled adolescents and their families. Therefore, support programs to help these mothers and to bring about changes in public attitudes toward people with disabilities and their families should be developed and applied.

The current study revealed the absence of assistance and participants becoming the only caregiver in this tough period of childcare. Most participants reported receiving no help from their spouses, which is consistent with studies conducted in Hong Kong and India [29,30], where the patriarchal social structure is still influential as in Korean society. Notably, the lack of paternal involvement in the care of children with DDs is also seen in the USA according to previous study [31]. Given the traditional Korean parenting roles in which mothers take the most responsibility in child rearing, fathers' lack of involvement in child care is no surprise. However, spousal support is crucial in relieving mothers' strain and lightening the burdens of caregivers of children with DDs [32]. Therefore, education aimed at increasing fathers' understanding of the changes experienced by their pubescent children with DDs and, most of all, their earlier involvement and participation in childcare must be delivered.

Most participants showed serious emotional difficulties, facing their child's regression and gloomy outlook ahead of them. Previous study [33] reported that both anxiety and depressions are extremely common in parents, especially mothers, of adolescent with ID, and their level of anxiety and depression is high enough requiring intervention. To note is that most participants of the current study mentioned "taking their lives with their children",

which recalls recent tragedies in which the mother of an adolescent with DDs found dead along with the child [13], and the family of a child with DDs attempted suicide along with the child [34]; These tragic stories demonstrate the urgency of emotional support for caregivers of child with DDs. Emotional support is crucial to prevent tragic news reports such as suicide from being repeated. Therefore, mothers of adolescent children with DDs need to be screened regularly and receive timely treatment if they are found to require psychiatric assistance. Professionals across different disciplines must collaborate to develop and implement various forms of psychological intervention and education that will alleviate these mothers' emotional burden.

The research reveals that it was not until the onset of puberty that the participants realize that the children and their disabilities are inseparable, and their anxiety for their child's future has become unbearable. While mothers engage in fierce competition to let their children enter prestigious universities in Korean society [35], participants of current study were extremely anxious about the basic safety needs of their children not being met. As for future planning among families of children with ID/dDDs, it seems that the situation doesn't show the difference between countries; Systematic review on future planning of families with ID/DDs children which contains researches mostly conducted in western countries also reported that few families have future plans for their ID/DDs children [36], and aging parent caregivers of adult children with ID still suffer from intolerable uncertainty about their child's future life because of having no guarantee of safe and comprehensive care [37]. While it would be ideal for adolescents and adults with DDs to be cared for by their families in their home environment, mother caregivers in Korea should not shoulder all the caregiving responsibility. Policymakers must pay attention to a recent event in which parents of children with DDs held a ceremony where they shaved their hair asking for the establishment of a 24-hour support system [38], which highlights caregivers' frustration with lifetime caregiving. The local government could provide policy-based support, for example, through community based safe group home services. And health professionals should help these mothers organize advocacy groups for themselves which could give practical advice from firsthand experience to help with each other, and let newly diagnosed mothers prepare for this period of child caring from a long-term perspective.

This study is conducted phenomenologically, utilizing phenomenological reduction [15] to achieve the purpose of the study, which is to understand the lived experience of caregiving in mothers of pubescent children with DDs; the investigator tried to suspend attitudes, beliefs and suppositions, and minimize the influence of researcher on the interview and data analysis so that the participants' experiences can be encountered freshly and described just as they are experienced. The essence of caring pubescent children with DDs found through the imaginative variation is that while suffering unbearable physical, emotional, and relational difficulties by taking care of their pubescent children with DDs, participants of this study clearly realized that their children and their disabilities are inseparable, and they changed the purpose and direction of childcare.

## Conclusion

This phenomenological study explored and revealed the caring experiences of mothers of pubescent children with DDs. Its findings provide deeper understanding on these mothers' caring experiences and ample evidence for developing and implementing practical policies and education programs for such mothers.

This study found that the mothers suffered physical, emotional, and relational difficulties going through puberty of their children with DDs, and it is with the onset of puberty that these mothers

come to clearly understand that their children and their disabilities are inseparable, and change the purpose and direction of childcare. Most of all, this research showed clearly that there is urgent need for emotional support for these mothers.

Based on the study findings, here are some suggestions. First, health professionals should provide services with a warm and empathetic stance, and implement and provide tailored sexuality education program for pubescent children with DDs and caregivers. In addition, disability awareness education for healthcare workers, including medical and nursing students, should be given along with the efforts to change the public attitude toward disabled people and their caregivers. Second, multidisciplinary cooperation is needed to devise policies to alleviate these mothers' anxiety about their children's future life, and to build a safe social network to share caregiving responsibilities for individuals who need help.

This qualitative study which collected data through semi-structured individual interviews has its strength in capturing vivid experiences of the participants, which could not be achieved by quantitative research. However, due to purposive sampling, and with a sample size of nine mothers, the result should not be interpreted as representing all caregivers of adolescent children with DDs in South Korea. In addition, the way of interviewing may have affected the findings.

## Permission of instruments used in the study

N/A.

## Dissertation

N/A.

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## Authorship criteria and Responsibility

Study conceptualization; data collection; data curation and management; methodology; analysis and interpretation of the data; resources; investigation; writing original draft, review and editing of the manuscript; validation, funding acquisition, supervision by Woo Joung Joung.

## Ethical statement

This study was approved by The Institutional Review Board of Kyungpook National University (approval no. KNU-2018-0186). All participants provided written (in the case of face-to-face interviews) or voice (in the case of telephone interviews) informed consent prior to participation in the study.

## Conflict of interest

There is no conflict of interest.

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