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## SEARCH STRATEGY

Set No.	Searched for	Databases	Results
S1	Asian Nursing Research	Ebook Central, Public Health Database, Publicly Available Content Database	58472*

\* Duplicates are removed from your search, but included in your result count.

# Experiences of Body Image Changes in Chinese Patients Living with Inflammatory Bowel Disease: A Descriptive Qualitative Study

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## ABSTRACT (ENGLISH)

### Purpose

Body image changes are common among patients living with inflammatory bowel disease (IBD) because of the illness and related treatments. Currently, there is little known about how those patients experience and perceive their altered body image in the literature. The aim of this study was to explore the experiences of body image changes in patients with IBD in China and to describe how those changes influence patients' perception of body and self.

### Methods

This study used a descriptive qualitative approach. A total of 16 participants from three tertiary hospitals in southeast China were recruited through purposive sampling combined with maximum variation strategy. Data were collected through semistructured interviews and analyzed using conventional content analysis method.

### Results

The following six themes were extracted: (1) "being a constrained person," (2) "being a flawed person," (3) "being a disliked person," (4) "being an alienated person," (5) "being a reconciled person," and (6) "being a blessed person."

### Conclusion

With the diagnosis of IBD and its side effects of treatments, patients' life changed significantly and they were struggling to reinterpret their body and self. As a result, negative self-evaluations and/or positive self-evaluations towards themselves generated. Further studies are required to explore the underlying mechanism and related influencing factors about how those different images were produced.

## FULL TEXT

### Introduction

Inflammatory bowel disease (IBD) is a chronic gastrointestinal disorder with unknown etiology and characterized by an unpredictable course between flare-up and remission. It mainly includes the following two types: Crohn's disease (CD) and ulcerative colitis (UC). In 2017, there were 6.8 million people suffering from IBD globally [<sup>1</sup>]. The highest reported incidence of UC and CD were in Europe (57.9 and 15.4 per 100,000 people-year, respectively), North America (23.1 and 23.8 per 100,000 people-year, respectively), and Australia (17.4 and 29.3 per 100,000 people-year, respectively) [<sup>2</sup>]. Since 1990, the incidence has been rising in newly industrialized countries of Asia, Africa, and South America, where their societies have become more westernized [<sup>2</sup>]. As reported, the annual incidence increased 11.1% for CD and 14.9% for UC in Brazil [<sup>2</sup>], and the estimated incidence of IBD in China increased from 0.068 per 100,000 in 1998 to 3.44 per 100,000 in 2013 [<sup>3</sup>]. At the turn of the 21<sup>st</sup> century, IBD has emerged as a worldwide public health challenge.

Although IBD can occur at any age, people are frequently diagnosed between the ages of 20 and 24 years, a time

when they usually increase their awareness on weight, body shape, physical function, and intimate relationships [4]. As described in the literature [5-9], both IBD and its related treatments can dramatically change patients' body. Patients with active disease may experience many symptoms, such as abdominal pain, rectal bleeding, fecal incontinence, disfiguring fistulas, loss of energy [9], as well as delayed growth [6] and sexual dysfunction [8]. Extraintestinal manifestations mainly involve eyes (episcleritis), joints (peripheral and axial arthropathies), and skin (erythema nodosum) [7]. In addition, bodily changes brought by treatments include moon face and weight gain because of the side effects of steroid, scars, and stomas because of undergoing surgical treatment [5], and a distorted image due to nasogastric feeding [5].

Body image refers to an individual's overall sense of their physical appearance and body function [10]. A person's body image forms during adolescence and young adulthood and remains fluid throughout adult life [4]. Body image has a significant influence on personal relationships and social interactions. A negative body image is associated with social anxiety, depressive symptoms, and low self-esteem [4, 5, 11]. Quantitative studies from Western (the USA and Ireland) and Asian (Korea and China) countries have consistently indicated that body image changes are common phenomena in patients with IBD (a prevalence of a negative body image ranged from 21.0% to 81.0%) [11] and are associated with significant psychological dysfunction and impaired quality of life [4, 5, 11]. Currently, there has been relatively little literature published on the experiences of body image changes among patients with IBD. By gaining valuable insight and understanding of these experiences, health care providers can not only provide better patient-centered care, but also find new directions for relevant future researches. Hence, the aim of this study was to explore the experiences of body image changes in patients living with IBD in China and also to describe how those changes influence patients' perception of body and self. In line with the research objective which is to provide direct descriptions of experiences of body image changes among patients with IBD, rather than reveal the essence of lived experience (phenomenology) or generate a theory (grounded theory) of this phenomenon [12-14], a descriptive qualitative approach was adopted in this study.

### **Methods Study design**

The descriptive qualitative approach is based on the general tenets of naturalistic inquiry, which has no prior commitment to any theoretical view of a target event. It states that realities need to be understood within contexts and time [15]. The aim of this qualitative approach is less theory-driven [12, 16-18] but to offer a comprehensive summary or straight description of an event or an experience [12, 16-18]. This design differs from descriptive phenomenological approach in many aspects, such as the latter is grounded in a phenomenological philosophy (phenomenological reduction, bracketing, lifeworld), seeking to discover the essence and meanings of lived experience or describing the essential structure of the phenomenon, and providing a deep description which clearly shows the web of relationships and meanings that exist among the lifeworld features of the phenomenon [12, 17].

### **Setting and samples**

Purposive sampling combined with maximum variation strategy was used to identify and select information-rich participants related to the research phenomenon [19]. Maximum variation was achieved in terms of participants' gender, education level, occupation, duration of illness, disease activity indices, and treatment methods, respectively. The participants were recruited from outpatient departments and inpatient departments of three large university-affiliated tertiary hospitals in Hangzhou and Shaoxing, two major cities in Zhejiang Province, southeast China. The inclusion criteria were as follows: (1) diagnosis of IBD according to the Chinese Society of Gastroenterology criteria released in 2012 [20]; (2) age of 18 years or older; and (3) willing to participate in the study. Participants were excluded if they were pregnant or had other diseases or health conditions, which might affect an individual's body image (such as systemic lupus erythematosus and visible physical disabilities). Purposive sampling continued until thematic saturation was reached during data analysis.

Two researchers (JR and LW) approached eligible patients separately in the outpatient department and ward for recruiting participants. They provided a comprehensive explanation of this study and invited these patients to participate in a face-to-face interview orally. A total of 18 patients met the inclusion criteria, two women declined because of no interest and time conflict. Among the 16 participants, eight had established good relationships with

the researcher (LW) who engaged in IBD patient education activities as a student volunteer before study commencement. This rapport building facilitated those patients' study participation.

### **Ethical considerations**

Approval of this study was granted by the Research Ethics Committee of Zhejiang Chinese Medical University (Approval no. 20200924-1). All participants were informed about the purpose of the study. No researchers were staff from the three tertiary hospitals, and therefore no participants were coerced to join in this study because of concern about their treatments and nursing care. Participants were told that they could refuse to answer any questions during the interview or withdraw the interview at any time without penalty. A written informed consent was obtained before each interview. The confidentiality of research data was assured.

### **Data collection**

Data were collected from May 2017 to July 2019 through audio-recorded, face-to-face, semi-structured interviews. The time and places of interviews were determined by the participants' preference. The interview settings included wards, restaurants, coffee shops, clinics, patients' homes, patient's shop, a park, and patient's car. Chinese was the interview language. All interviews were conducted by a female postgraduate nursing student (LW) with the guidance of her master tutor (YZ). LW had some previous experience in descriptive qualitative research from reading literature, taking courses, and undertaking two previous studies using this approach. YZ is a female PhD qualitative nursing expert who work at a school of nursing and had published several peer-reviewed qualitative papers before this study.

Before the interview, potential participants were told that the researcher was interested to know their illness experience for her master thesis project. Initially, an interview guide was developed based on clinical experience, literature review, and expert consultation. An open question, "please tell me your illness experiences of living with IBD?" was asked first. If the participant mentioned something related to body image, the following questions on the interview guide were asked further: (1) Please tell me how your body image, such as physical appearance/physical function/body structure, have changed since the diagnosis of IBD? (2) What are your thoughts/feelings/perceptions when you recognized the changes? (3) How did the changes influence your daily lives? (4) How did the changes influence your perception of yourself?

During the interview, the researcher remained neutral and avoided making any judgment on the interview contents. Probing questions were asked to clarify the participants' responses and redirect discussions when necessary. Field notes were written after each interview to record the details of interactions, observations, interview environment, and relevant nonverbal communications of the participants. The length of the 16 interviews varied between 32 and 149 minutes, with a mean of 71 minutes. The participant's spouse was present during two interviews.

### **Data analysis**

Shortly after each interview, the audio recording was transcribed verbatim. Data analysis proceeded concurrently with data collection using conventional content analysis method [21]. LW, along with a female clinical nurse who has a master degree in nursing and some descriptive qualitative research experience (JR), analyzed the data at each time point. Meanwhile, a qualitative nursing expert (YZ) reviewed the research process regularly and provided guidance to enhance the analysis quality. Chinese was the language used for coding and the quotes and themes were translated into English for writing the report.

First, the two coders (JR and LW) read the transcription and field note of each participant's interview several times to immerse themselves in the data and obtain an overall understanding of the participant's interview and experiences. Then, the coders manually coded the transcripts line-by-line independently to identify any narrative data that were related to the experiences of body image changes of participants. Subsequently, the two coders discussed and compared their coding of each transcript until a consensus on codes and coding definitions was reached. Then, the coders grouped the coding units based on shared characteristics and presented the experiences of the participants in a more abstract way. Finally, similar coding units with a higher abstraction level were extracted and clustered into subthemes and themes through an interactive and inductive process. Saturation for the analysis was deemed to be met after the 12<sup>th</sup> interview when the three researchers noted repetition in participants' responses and saw that no

new subthemes or themes related to the experiences of body image changes were emerged [22]. Another four interviews were conducted to further confirm saturation.

## **Rigor**

Several strategies were used to maintain rigor in this study [13, 18, 23]. Firstly, authenticity was obtained by encouraging participants to speak freely based on an establishment of a trusting relationship between the researcher and eight participants [13]. This rapport building increased the researcher's chance of hearing the "true story." Secondly, credibility was established through peer debriefing, in which the researchers consulted with each other to address any disagreement or ambiguities on methodological issues or data analysis [18, 23]. For example, LW analyzed data together with JR, who was not involved in the interview process to get a fresh perspective, and discussed data collection and data analysis regularly with a qualitative research expert (YZ). Thirdly, criticality and integrity were achieved by critically appraising each research decision and actively writing reflective journals throughout the study [13, 18]. For example, LW wrote down her assumptions and thoughts about the research topic before data collection; wrote down her preconceived knowledge and perceptions about the eight participants with whom she had established a good relationship before interview. To reduce her bias, she reminded herself constantly to remain open during the interview process and encouraged the participants to articulate as much as possible, listened actively so as to get the perspective from the participants. She also self-reflected how her researcher role (single, young female with some relevant clinical experience) might influence the interviews. These reflexive strategies helped researchers to see the research phenomenon with "fresh eyes." In addition, to confirm whether the subthemes and themes extracted from the data reflected participants' experiences well, member checking was used [13]. Four participants were involved in this process.

## **Results**

The demographics and clinical characteristics of the study participants ( $N = 16$ ) are provided in <sup>Table 1</sup>. The participants (6 with UC and 10 with CD) comprised eight men and eight women with an average age of 34 years, ranging from 21 to 58 years. Regarding education, most participants had completed secondary education (7) and tertiary or above education (7), and two participants had primary or less education. Ten participants were married and six were single. Most participants (11) were employed, four were unemployed, and one was retired. The median duration of illness was 87 months (range from 4 to 300 months).

Six themes and 14 subthemes were emerged from data analysis (see <sup>Table 2</sup>). These themes were presented as following: (1) "being a constrained person," (2) "being a flawed person," (3) "being a disliked person," (4) "being an alienated person," (5) "being a reconciled person," and (6) "being a blessed person."

### **Being a constrained person**

Body structure and body function of many participants were affected severely because of unpredictable disease symptoms and side effects of related treatments. It not only influences significantly on patients' daily life, but also their personal development. Most participants developed strong feelings of being controlled by illness, which made them feel powerless and helpless sometimes.

#### **1. My life being limited**

Participants' diet, daily activities, and sexual lives were constricted more or less because of suffering from IBD. Eating nutrient-rich and tasty food was not only seen as a mean of absorbing essential nutrients, but also regarded as an enjoyable experience. Nevertheless, nearly all the participants limited their intake of a certain food or several kinds of food to some extent to prevent disease flare-ups. One female participant said, "We local residents are crazy about chili peppers! Nearly every meal I ate was spicy. However, I was struggling not to eat spicy food anymore due to potential risk of disease relapse. I really missed my favorite food!" (P8)

Participants' daily activities were significantly restricted because of their shrinking activity space. Many of them chose to stay at home or only went to some places nearby instead of going out freely or traveling to some regions far from where they lived. There were some factors attributing to this phenomenon, such as afraid of being infected,

worrying about an urgent need to use a toilet but without one available nearby, and concerning about their altered physical appearances (e.g., carrying nasogastric feeding tube) being seen by others in public. One participant said the following:

"I must stay somewhere easily accessible to a toilet at any time. I feel anxious if going to places more than 5 kilometers away from my place, because I am not familiar with the toilet location there." (P11)

Sex is crucial in a marriage relationship. Engaging in sexual activity can bring instant emotional and physical satisfaction, and also create a broader sense of intimacy in a loving relationship. Four married participants, two women and two men, mentioned that their sexual drive declined, sexual function diminished (e.g., erectile dysfunction) and sexual activities decreased after diagnosis and receiving treatments. This was particularly common when the disease was active, when patients were affected by adverse effects of treatments (e.g., fatigue), or experiencing inconvenience resulting from treatments (e.g., receiving nasogastric feeding at home or having an ostomy). As a 35-year-old participant with CD said, "I had low sexual desire after diagnosis. I found it boring, while my husband wanted to have sex often. I refused him sometimes, and he was really disappointed! I had no way but to agree with him." (P1)

#### 1. My development being influenced

A few participants recalled that they were unable to attend school regularly as other healthy students did because of moderate or severe disease symptoms (e.g., abdominal pain, persistent diarrhea, bloody stool, and worsening arthritis). The time they used to spend on study have been used for visiting doctors on a regular basis or staying at hospitals for treatment. One participant mentioned that her learning efficiency decreased significantly. She found it difficult for her to concentrate on study and complete assignments within deadlines as before because of numerous sick leaves from school, which lead to her poor academic performance. As she stated, "I used to be a top-student at school. However, could you believe that I turned into an academically poor student in high school, just as a result of frequent sick leaves?" (P7)

Not only their academic performance, but also their career development was influenced. Appropriate jobs for patients were much less than for healthy people because of this unpredictable lifelong illness. One man with UC stated with regret:

"China's housing market developed rapidly in 2007 and 2008, and many people made millions or even billions from this industry at that time. I felt disappointed to miss such a great opportunity to make a fortune only because of my frequent diarrhea with blood." (P5)

Almost all the employed participants mentioned that their promotion opportunities were rare. This was because they need to put their health needs as priority rather than working hard to get promoted as most of their colleagues do. In those participants' eyes, if they wanted bright career prospects and were eager to get promotion in a short term in this super-competitive society, they had to do something to please their supervisors. However, these behaviors may be harmful to their health, such as consuming ready meals on a regular basis to save time, staying up late to complete work assignments to meet deadlines, attending business lunch or dinner often to build and maintain a network with clients, and going on long business trips frequently. One participant who was a game designer mentioned, "Your career advancement was restricted by your disease. You were still able to work, but the extent you devoted to your work was controlled significantly." (P8)

#### **Being a flawed person**

As time went by, patients gradually realized that they were different from who they were before the illness and were also distinct from other healthy people around. They evaluated themselves as flawed persons because of their



imperfect bodies and tried to conceal these flaws so as to be perceived as normal by others.

#### 1. My body having flaws

All participants mentioned that their physical appearances have changed in different degrees because of illness and treatment, such as pale skin, rapid and dramatic weight loss, unexpected emaciation, hair loss, fistula, slow growth, and moon face (a rounded appearance). Half participants indicated that they lost control of their bowels when the disease was active. That means they had an urgent need to go to the toilet to defecate or there was an accidental leakage of stool or gas. A 29-year-old participant with CD described, "(I have) urgent diarrhea like running water from a broken water tap. It was almost impossible to control it right away." (P3)

Living with this long-term illness, IBD patients need to receive continuous treatments to induce and maintain remission. Some participants described themselves as machines, which were unable to operate independently. What is more, a few participants even equated themselves to those individuals with obvious disabilities such as amputations, despite the fact that IBD is invisible illness in most cases. One participant said, "I am the kind of person who lives with UC. This is just similar to the type of person who is dumb or an individual without arms or legs." (P5) As the disease progressed, some patients with severe disease may need operations such as bowel resection. Several participants metaphorized their bodies as machines and their organs and tissues as components and parts of these artificial things. When one or several parts were removed, those participants generated a sense of defectiveness. This negative feeling was much stronger among those patients who had undergone surgeries more than once. As indicated by one participant, "I was just like a person with a disability. You know, a part of my large intestine has been removed ." (P10)

#### 1. Trying to conceal the flaws

To reduce their feelings of being different from others, some patients used several strategies to conceal their flaws (IBD patient identity and their changed body images) when being exposed to people who were not informed about their illness.

Some participants wear large sunglasses to make their moon face look slimmer and brighter, or put on some makeup to cover acne due to moon face when going out. For others who were with the presence of nasogastric tubes in their noses, they chose to wear a face mask or let their hairs down to cover their "monster" appearance if they wanted to go out during the day or chose directly to go out at night. As one female participant noted, "I didn't want people on the street to see me as an animal because of this feeding tube. Hence, I always went out at night rather than daytime." (P3)

A few participants had several surgical scars on their bodies (e.g., abdominal scars). To hide this ugly image, one young male with CD said, "I chose to take a shower at a separated bathroom rather than go to public bathrooms as before." (P6)

It was not easy to cover patients' flaws. Although aforementioned strategies were adopted, two participants still indicated that some people around them could recognize their patient identity and guess that they were sick individuals because of their visibly unhealthy physical appearances (e.g., very thin, bloodless face, and weakness). As one participant revealed, "When my friends saw me, they asked me whether I was ill or not. I said that I was fine. However, they said 'you were so skinny and weak! You must be sick'." (P1)

#### **Being a disliked person**

This theme has two aspects. The first one is that those patients disgusted themselves; the other is that they were disliked by some people around them because of their patient identity or patients believed that others would dislike them if their patient identity was revealed. This perception was based on past experiences of patients or individuals

with the same diagnoses, or their imaginations.

#### 1. Having a dirty image

Some participants evaluated themselves as an unclean and unhygienic person. This opinion attributed to these following factors. Three participants had recurrent anal leakage with foul-smelling mucus from the anus. Three UC and two CD participants stained their underwear more than once because of urgent watery stools. Furthermore, two participants felt very disgusted when they saw their pink or red intestines, heard embarrassing noises from stoma (such as squeaks, pops, and gurgles) and observed soft or watery stools or intestinal mucus draining directly from their transparent ostomy bags. As one participant mentioned, "I was definitely the kind of person who was not clean!!! I couldn't accept myself to be a person who had intermittent pus-like liquid from the anus and also had a terrible fishy smell." (P6)

Some participants cared much about others' perceptions. They were so afraid to be regarded as abnormal persons or someone paying little attention to personal hygiene because of above reasons. The sense of worry was particularly strong when patients were in public and (or) their diseases were active. For instance, one participant mentioned:

"When I passed wind, my underwear, even over-trousers, was soiled and became wet due to watery stools. I was really worried that it might be seen by my colleagues ...I carried clean underwear with me anytime, so I could change my stained one immediately if something embarrassing occurred." (P4)

#### 1. Being a useless person

Some IBD patients disliked themselves and evaluated themselves as useless persons. Nearly half of the participants in this study, especially those young and middle-aged with severe disease, felt inferior and worthless to varying degrees. Before diagnosis, they played the role of breadwinners of their family and (or) took well care of their children and parents. However, with the persistent disease or recurrent relapse, what they could do at the moment was to receive constant care and financial support from their family members, meanwhile let their children to be looked after by their caregivers. They found it difficult for them to return their caregivers' kindness. A male participant with CD felt very worthless, guilty, and regarded himself as a burden to his family. As he said, "I was worthless and a burden to my family! I was unable to make money now because of the severe disease but needed my caregivers to give me continuous financial support." (P9)

Some participants mentioned that some neighbors often gossiped them behind their backs. In those people's eyes, these participants were worthless. It was a waste of time and money to raise up a child with an illness, because their family was hard to be prosperous anymore because of this rare, expensive, and long-term illness. As a single female participant stated, "In my neighbors' mind, I was a 'bottomless pit' of my family because of this lifelong illness and related costly treatments. They gossiped that my family was hard to be rich anymore." (P13)

#### **Being an alienated person**

Compared with some common chronic diseases in China, such as heart disease or diabetes, IBD was relatively rare and often misinterpreted by the public. Besides, people with IBD were also hard to be understood and accepted by society. Those factors made IBD patients felt alienated from others.

#### 1. Being not understood

Some participants reported that IBD was often misunderstood by the public, regarding it either as a mild disease (e.g., enterogastritis) or a serious, life-threatening illness (e.g., green cancer). As a woman participant indicated, "From my friends' perspectives, UC was equal to a mild form of enterogastritis, which was a common thing in every

individual's daily life. No big deal!" (P8)

Two participants attempted to introduce IBD to others, but they felt confused about how to illustrate this illness appropriately and scientifically. It was particularly difficult if the disease affected their private parts, such as the anus or vaginal area. As one young male participant mentioned, "My disorder involved my anus; I was too embarrassed to mention it!" (P6)

Some participants said that they found it almost impossible for their intimate others to stand in their shoes to understand their illness experiences, despite of having been informed of IBD. As one young participant with CD complained, "Those who are not in my position couldn't completely understand my experiences, even my fiancée." (P15)

#### 1. Being not accepted

Some participants mentioned that they experienced employment discrimination (e.g., being treated differently) and workplace discrimination (e.g., unfair dismissal) because of this medical condition and potential risk of reducing their productivity. One participant aged 29 years stated angrily:

"At the job interview, the employer was satisfied with me and interested in hiring me. Then, I told him the truth that I had a kind of chronic illness similar to hypertension, which only needs to take medicines every day. He changed his mind quickly, rejected me at once and said, 'This job is really exhausting, it is not suitable for you. You are ill, so you should take care of your body first'. I felt very gloomy and cried on my way home that day." (P3)

Not only unaccepted by job recruiters and employers, patients with IBD were also at a disadvantage when it comes to looking for a potential life partner. This is related to their incurable chronic illness and decreased physical attractiveness. The latter one included a moon face, a bony appearance, having a stoma bag temporarily or permanently, and/or short stature because of delayed development and stunted growth. Some participants said with certainty that almost no one would accept them as potential life partners. As one young male participant said the following:

"It was understandable that nearly no one wanted to go on a date and get married to an IBD patient. After all, looking for a life partner with a life-long illness would bring huge psychological pressure to healthy people." (P6)

#### **Being a reconciled person**

Since the diagnosis, all IBD patients had to live with the illness in their life and learned how to reconcile with it. The reconciliation process consists of three aspects: "accepting the illness," "downplaying the patient identity," and "making friends with the illness."

#### 1. Accepting the illness

Some participants realized that the diagnosis of IBD was an established and unchangeable fact. They had no other options but to acknowledge it. As one male participant mentioned, "It is a fact that I have been diagnosed with CD. There were no other choices for me, only to accept the disease gradually." (P6)

In contrast to those individuals with malignant diseases, some participants felt fortunate and accepted the illness easier. After all, what they suffered from was only one type of chronic diseases. Those participants realized that they should still be hopeful for their future rather than taking the illness as something holding them back from their dream life. As one male participant said, "CD belongs to a kind of chronic illness, not the category of cancer. I believed that new drugs will be developed with the help of future cutting-edge technologies and this disease could be cured someday." (P14)

Some participants accepted treatments and faced related potential side effects with courage, such as altered appearances. This embodied the participants' confidence for the future, and also manifested their strong sense of

responsibility for their significant others. As a male participant with CD said, "If you lost confidence in life and gave up on yourself just because of having a stoma bag, this was totally irresponsible for your entire family!!!" (P9)

#### 1. Downplaying the patient identity

Although accepting the fact of being ill, a few participants indicated that it was not beneficial for them to worry about their health condition throughout the day, which only resulted in aggravation of their illness and affecting their mood. By contrast, they tried to live a life neglecting their illness, especially during periods of remission when they felt that they were as same as "normal people." As one participant mentioned, "I often forgot that I was a CD patient. If I worried about my illness all day long and did nothing, there was no doubt that my health condition would become worse in such a negative emotional state!" (P7)

Indeed, with increasing disease knowledge and self-management experience, some participants were able to deal with uncomfortable symptoms properly and with great ease. Instead of feeling anxious, confused, and not knowing what to do as before, some participants treated the disease recurrence in a calm way.

"I was not afraid of diarrhea now. If the disease relapses, I just stay at home and evaluate the disease symptoms calmly. If it gets worse, I will see a doctor soon." (P12)

Many participants were struggling to maintain their previous normal identity and forgot about their illness. However, it was not easy for them to downplay their patient identity. Frequent inquiries related to the illness from the family members, relatives or intimate others reminded them the fact of being ill from time to time.

"I recovered well after surgery. However, my fiancée often asked me whether I felt pain or whether the disease had flared up. I didn't want her to label me as a patient, always asking me something like this!" (P15)

#### 1. Making friends with the illness

UC and CD were idiopathic relapsing, chronic illness, which need to be handled for life time. The relationship between patients and illness itself would influence patients' quality of life in a large degree. Many participants were willing to take IBD as friends, that means they were trying to establish a harmonious relationship with illness and live peacefully with it in life.

In their life, the participants attempted to meet their bodies' needs based on disease management rather than going to extremes, such as overwhelmingly worrying about illness or ignoring their patient identity completely. Those extremes were not good to maintain a healthy, long-term relationship with IBD, which might lead to psychological issues and/or make disease worse. As one participant stated, "You should make friends with your illness and get along well with it. Be good and nice to it; Eating carefully, but not worrying all day about whether it would prompt a disease relapse or not." (P5)

Three participants, who were in persistent active disease, felt that there was little hope for controlling the disease. As far as they were concerned, what they longed for was to build and maintain a peaceful relationship with this active illness. As one of the participants said, "My disease was severe and active for a long time. It was hard to be controlled. What I really needed now was how to get along well with CD." (P3)

#### **Being a blessed person**

As the old saying goes, everything in life is a double-edged sword. Living with a chronic disease sometimes is a blessing in disguise. Half of the participants gradually realized the positive sides of suffering from IBD. They mentioned this and described themselves as someone blessed by the illness.

#### 1. Becoming more beautiful

In contemporary Chinese society, a slim figure was considered as a symbol of beauty. Many young females tried hard to keep slim by strict weight management. It requires a lot of patience and much perseverance. Two participants, who were obese previously but lost a few pounds after illness, mentioned that they felt happy because they became more attractive as a result of UC.

"I was discharged from hospital that day. On my way home with my husband, I suddenly realized that I lost weight and became slim. I had a small waist that I didn't have before. I was so happy!" (P11)

"I was a little overweight and had a big face before illness, but I got slim now. In my friends' mind, I became more charming after suffering from the illness." (P2)

#### 1. Paying attention to health

Many young participants work extremely hard to pursue material wealth and higher position, which caused physical exhaustion. After diagnosis, they became aware of the importance of health and gave priority to it in their life. One young female said, "Since diagnosis, I realized that comparing to my health, how much I earned was not an important thing." (P2)

Some participants considered they would live longer than some healthy people, because they paid more attention to health. As one participant mentioned, "Maybe we would have a longer expectancy than some healthy people. Because we focused on our health and took care of our bodies because of IBD, whereas they just took health for granted and didn't emphasize it." (P3)

#### 1. Improving character

There were hardships, struggling, difficulties, and challenges while living with illness. Some participants tried to self-motivate and persuade themselves to be persistent, and they became stronger as a result. Some others realized that hardships such as suffering from illness is a normal part in each individual's daily life. They became calmer than before when facing a difficulty in life.

"Now I stayed calm during difficult times in my life rather than being anxious like what I did at the initial stage of disease diagnosis. To be honest, my inner world has become rich through illness experience." (P16)

Some participants became more understanding, thoughtful, helpful, and kind to others after going through the illness. One participant even mentioned that she became kinder to living creatures, including those she did not like previously.

"I definitely became kinder. For example, I tried to do something good to return society like protecting animals ...Before diagnosis, I was kind of selfish and just thought that preserving animals was none of my business." (P13)

Three participants boost their confidence and self-esteem after illness and cared less about the gossips of others nearby (e.g., neighbors, colleagues). Meanwhile, they did not compare themselves with others anymore. As one participant stated, "I have a peaceful mind now. I cared too much about what other people thought about me before illness, but now I think it doesn't matter. Just let them say what they want." (P3)

## Discussion

This qualitative study provides new sights into the experiences of body image changes in Chinese patients living with IBD. Chronic illness assaults the body and threatens the integrity of self [14]. According to the self-discrepancy theory [26], perceiving a discrepancy between one's actual self and one's ideal self (actual-ideal discrepancy) or ought self (actual-ought discrepancy) could elicit negative evaluations, which cause depression or agitation. The gaps between these selves due to impaired body images also occurred in patients with IBD in the present study. Multiple uncontrollable bodily changes and losses intensified feelings of separation from patients' past familiar body [14]. The body once patients taking for granted as a possession to control was out of control and it is difficult for

patients to be a master of their own life. The huge psychological gap between the past self and the present self brought negative emotions like disappointment and powerlessness, and patients describe themselves as “being a constrained person.” This theme was supported by previous studies [9, 27, 28], such as “loss of control over your body” among IBD patients from the UK [9], “the bowels rules life” and “losing bowl control” among Swedish IBD patients [27], and “perceived losses due to CD” (e.g., barriers to certain jobs or academic qualifications) among Spanish CD patients [28]. In agreement with a qualitative systematic review, most IBD patients chose to stay at home when lost control over their body [9]. Giving up the idea of having children or only having a small family because of complications experienced during pregnancy with the first child, also reflected how those patients' body were controlled by IBD [28]. We did not find this limitation in our study. It might be because most participants were parents in that study [28] or because of different childbearing policies in Spain (a pronatalist policy) [29] and Mainland China (a long-term one-child policy and two-child policy since 2016) [30].

Body image and self-perception were contextual, dynamic, and social [31]. An individual's perception of self was related to the context of body image [26]. Bodily changes made Chinese patients reassess who they were and compare their present body with their past body and/or other healthy person's body. The person is now flawed and disliked, and the unfamiliar body is physically imperfect, becoming a symbol of sickness, an embodiment of a dirty image, and an expression of worthlessness. Similar views were identified as “the grotesque body” in an autoethnography study about IBD patients [32], “living in a flawed body” in a systematic review regarding IBD patients [9], “I am dirty or weird” in a phenomenological study among CD patients [28], and “I made one hell of a stink” as well as “having a body that smells” in two IBD studies using rhetorical discourse analysis and the critical incident technique, respectively [27, 33]. It was reported that two-thirds of Australian IBD patients perceived a negative body image [8]. Similar strategies, such as always carrying a change of underwear in a bag or even wearing sanitary protection, was also adopted by Swedish IBD patients [27]. In addition, using a cognitive defusion intervention, a core component of Acceptance and Commitment Therapy, might be a way to mitigate body image dissatisfaction [34].

Unlike many Western countries with an individualist culture, China is a country with a collectivist culture and “group orientation,” which is characterized by greater orientation toward ingroups (e.g., family, friends, or coworkers) than toward outgroups (e.g., that is, all other people), and an emphasis on individuals' connectedness and cohesiveness to the ingroups [35]. Some Spanish CD patients perceived a level of rejection from the general population [28], which is in line with “being an alienated person” in the present study. Influenced by a collectivist culture, the desire to be understood and accepted by others, especially by members of the ingroups, might be much stronger in Chinese IBD patients. The subcategory “pursuing a sense of belonging” in a constructivist ground theory among Chinese CD patients also supported this argument [5].

The subtheme “being not understood” was also found in previous studies [9, 33, 36]. One woman in Pihl Lesnovska et al's study expressed that the invisibility of IBD would contribute to the sense of not being believed when denied permission to use the toilet [27]. This phenomenon was probably associated with limited knowledge about IBD by the public and inaccurate media report. In agreement with our results, lack of understanding and public awareness in relation to IBD have been reported in earlier studies [9, 37]. A public awareness campaign is recommended to encourage more open discussion and promote better knowledge of IBD [37].

The subtheme “being not accepted” might be related to patients' work disability and Chinese individuals' attitudes toward love and marriage. Work disability is an important but often neglected issue for IBD patients. According to Büsch et al [38] and Mandel et al [39], 9–25.9% IBD patients suffered from absenteeism, leading to a 28.0% loss of work productivity, and 19–22.0% of IBD patients were no longer work because of disease activity. Pihl Lesnovska et al [27] reported that being unable to meet own and others' expectations, such as performing duties at work, became

critical incidents in patients' life. Another two challenges were difficult to find the right words to explain absences from work [40] and feeling pressure to make special efforts to prove that they were not held back by IBD in the workplace [36]. In the present study, taking the potential loss of productivity into consideration, some employers rejected or fired the participants, which posed a threat to their psychological well-being and also standards of living. There are different marriage customs around the globe because of different cultural background [41]. In Western countries, such as the United States, love is a priority in marriage and Americans admire a marriage, which is a direct result of love instead of family interests [41]. In China, a marriage is more than just a bond between two people, but an establishment of a relationship between two families. Influenced deeply by Confucianism, the cornerstone of traditional Chinese culture, even in modern society, the main intention of marriage is still to get offspring and benefits for the family [41]. Most Chinese marriage is well-matched in the socioeconomic position [41]. That means "love" might not be the prerequisite when picking potential life partner in China, but other social and economic advantages matter [42]. However, to pick an unhealthy marriage partner with lifelong illness means continuous treatments cost, increased risk of infertility, having an unhealthy child, "low-quality" sexual life, as well as an uncertain and unstable life. These interpretations explained why Chinese patients were usually unaccepted by healthy individuals while looking for a potential partner.

Under the subtheme "accepting the illness," we noted that some participants did not give up but faced the illness bravely because of their strong responsibility for family. Family is a key part of East civilization and a whole family is valued by most Chinese people [41]. It indicates that health care providers could try to help newly diagnosed Chinese patients with IBD to accept illness sooner by emphasizing the meaning and significance of family. The subtheme "making friends with the illness" reflected a good result of negotiation between patients' past self and present self. Accepting the body changes and acknowledging the inability to control the changes made patients perceive illness from a different perspective. Influenced by this coping strategy, illness was integrated as a part of patients, and it was treated as a friend rather than a foe. Some participants in Spain also transformed their chronic condition (CD) into a natural part of their lives until becoming part of it [28]. According to Breakwell's "identity process theory," patients' new identity (such as "normal people") was developed by a dynamic process of assimilation–accommodation [31]. This was also a manifestation of regaining normality process of IBD patients in China [5].

The theme "being a blessed person" revealed those patients' positive outlook on life, new meaning ascribed to illness, and also functioned as a self-protection strategy to gain psychological comfort. In agreement with our findings, several studies have reported that people with IBD maintained positive attitude (e.g., valuing things I did not realize before illness), became more compassionate, being more resilient (e.g., developing a struggling spirit), and made small changes to become a healthier person (e.g., life being a little more organized in relation to food and sleeping habits) [28, 36, 43]. Inconsistent with an earlier study by Purc-Stephenson et al [43], our participants did not mention about spiritual growth, such as engaging in prayer to a greater extent since diagnosis. This was probably linked with different status of religious belief in Western countries and China. More than 60.0% people in Canada and 70.0% in the United States were Christians [44, 45], while more than 70.0% people in China were nonreligious [46]. The subtheme "becoming more beautiful" was an interesting finding in this study. This was related to social contexts and values of Chinese modern society about female body image. The body was an expression of one's identity. Influenced by traditional media, a desire to be thin and light-skinned, a typical Asian perfectionism, is deeply rooted in Chinese female individuals [47]. Suffering from disease sometimes narrowed the gap between their actual self and their ideal self for some patients regarding their body shape. Nurses could help patients to realize this advantage from illness, so as to promote their psychological well-being and create harmonious relationship between illness and

self.

### **Study limitation**

There are several limitations to this study. First, we did not achieve maximum variation for sampling in terms of marital status, age, and place of residence. Current sample was composed of single and married participants, and most were relatively young and all were from Zhejiang Province, southeast China. Perhaps, had there been additional divorced participants, particularly those whose marriage were broken down mainly due to IBD, or more individuals who are old and individuals from other regions of China, other themes might be revealed. Second, for practical reasons, some participants chose to be interviewed at places such as restaurants or coffee shops. Those settings were not ideal for interviews because of the presence of some noises and the perception that other strangers could hear the interview. All these might inhibit participants' expression. Third, a spouse was present at two of the interviews, which might have affected the participants' openness and truthfulness. These factors should be considered when interpreting this study's findings.

### **Implications for nursing practice, education, and research**

Nurses and other health care professionals should understand and pay much attention to the psychosocial difficulties and stresses that patients faced because of body image changes after diagnosis and its related treatments. Nurses, together with specialized psychologists, could design some psychosocial interventions to help patients to cope with appearance changes. As disseminators of health information, nurses should also help the public to gain scientific and reasonable knowledge about IBD through media, such as IBD belonging to chronic illness and the reasons for body image changes of patients. Information about potential body image changes needs to be informed to patients by nurses, especially for those newly diagnosed patients, to help them form more reasonable ideal self after illness and reduce the potential actual–ideal discrepancy. In addition, nurses should also help patients gain knowledge about worker rights and entitlements, realize the importance of workplace culture and policies supportive of accommodations, communicate with their employers when they are unable to work because of illness if necessary [<sup>40</sup>], and provide guidance for patients to deal with situations of job application discrimination and workplace discrimination. Last but not least, some positive body image evaluations were also generated in this study. Further studies need to explore the underlying mechanism of this process and reveal its related influencing factors.

### **Conclusion**

This study contributes new knowledge to the understanding of experiences of body image changes in Chinese patients living with IBD. With the diagnosis of IBD and its side effects of treatments, the individual's life and appearance were changed significantly. It was a tough process for them to reinterpret and acknowledge their altered identity and self, which generated negative self-evaluations like low-esteem.

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### **Conflict of interest**

The authors declare there are no conflicts of interest.

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No.	Gender	Age (yrs)	Marital status	Education level	Occupation	Disease type	Duration of illness (months)	Disease activity indices	Current treatment
1	Women	35	Married	Primary or less	Unemployed	CD	53	2	Immunosuppressive medications + surgery + nutritional support
2	Women	26	Married	Tertiary or above	Librarian	UC	26	4	Immunosuppressive medications + anti-inflammatory drugs
3	Women	29	Single	Tertiary or above	Unemployed	CD	48	8	Immunosuppressive medications + anti-inflammatory drugs + surgery + nutritional support
4	Men	41	Married	Secondary	Manufacturing worker	CD	252	8	Immunosuppressive medications + surgery + nutritional support
5	Men	36	Married	Secondary	Self-employed entrepreneur	UC	91	5	Immunosuppressive medications + anti-inflammatory drugs
6	Men	24	Single	Tertiary or above	Interior decorator	CD	42	3	Immunosuppressive medications + surgery
7	Women	29	Married	Secondary	Self-employed entrepreneur	CD	300	3	Immunosuppressive medications
8	Women	27	Single	Tertiary or above	Game designer	UC	26	2	Anti-inflammatory drug
9	Men	33	Married	Secondary	Unemployed	CD	140	2	Immunosuppressive medications + anti-inflammatory drugs + surgery + nutritional support

10	Men	53	Married	Primary or less	Storekeeper	UC	15	6	Traditional Chinese medicine + surgery + nutritional support
11	Women	39	Married	Secondary	Self-employed entrepreneur	UC	39	7	Surgery
12	Women	58	Married	Secondary	Retired	UC	196	2	Immunosuppressive medications + anti-inflammatory drugs
13	Women	21	Single	Secondary	Interior designer	CD	19	1	Immunosuppressive medications
14	Men	32	Married	Tertiary or above	Media worker	CD	4	1	Immunosuppressive medications
15	Men	29	Single	Tertiary or above	Unemployed	CD	115	7	Immunosuppressive medications + surgery
16	Men	24	Single	Tertiary or above	Makeup designer	CD	22	2	Immunosuppressive medications

Themes	Subthemes
Being a constrained person	1. My life being limited
	2. My development being influenced
Being a flawed person	1. My body having flaws
	2. Trying to conceal the flaws
Being a disliked person	1. Having a dirty image
	2. Being a useless person

Being an alienated person	1. Being not understood
	2. Being not accepted
Being a reconciled person	1. Accepting the illness
	2. Downplaying the patient identity
	3. Making friends with the illness
Being a blessed person	1. Becoming more beautiful
	2. Paying attention to health
	3. Improving character

## DETAILS

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# Risk Factors for Work-Related Musculoskeletal Disorders Among Intensive Care Unit Nurses in China: A Structural Equation Model Approach

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[ProQuest document link](#)

## ABSTRACT (ENGLISH)

### Summary Purpose

This study explored the direct and indirect effects of risk factors of work-related musculoskeletal disorders (WRMDs) in nurses working in intensive care units (ICUs).

### Methods

A cross-sectional study design was used. ICU nurses from 28 tertiary hospitals in the Hunan and Guangdong

provinces participated in a survey conducted via a self-reported online questionnaire. A structural equation model was used to fit the data and to evaluate associations among WRMDs and risk factors.

## Results

Valid questionnaire samples were submitted by 984 ICU nurses. The prevalence of WRMDs within the previous year among ICU nurses was 96.8%. A valid structural equation model was constructed, and a good fit was shown: Chi-square value/degrees of freedom = 2.248; comparative fit index = .931; normal fit index = .905; goodness-of-fit index = .978; adjusted goodness-of-fit index = .966; and root mean square error of approximation = .036. All regression coefficients for direct effect reached significant levels (critical ratio > 1.96 and  $p < .05$ ). In the structural equation model, the occurrence of WRMDs was directly affected by the following: physical factors, risk perception, and job stress. Physical factors and a safe environment indirectly affected WRMDs through risk perception and job stress. The strongest correlations with WRMDs were physical factors.

## Conclusion

The model provided a new perspective for understanding the associations among physical factors, workplace safety environment, risk perception, job stress, and WRMDs. To improve the practice setting of the ICU, efforts should be made to help prevent WRMDs from physical, psychosocial, and environmental factors.

## FULL TEXT

### Introduction

Work-related musculoskeletal disorders (WRMDs) encompass a wide range of dysfunctions that occur at the job site, affecting the muscles, nerves, joints, tendons, cartilage, and intervertebral discs [1]. In particular, WRMDs most often affect the low back, neck, and shoulder. These disorders rarely threaten mortality, but do result in work absence and financial burdens [2, 3]. For nurses, WRMDs are a major occupational health problem that may even occur in the first year of work, contributing to lost labor time or seeking other employment [3]. In a survey of 43,000 registered nurses in 5 countries, 17–39.0% nurses intended to leave their job owing to WRMDs [4].

The prevalence of WRMDs in nurses of different countries varies owing to differences in the nature of the work and facilities [5]; rates include 69.0% in California [6], 80.8% in Uganda [7], and 91.9% in Japan [8]. Among nurses in China, the prevalence of WRMDs ranges from 56.0% to 92.0% [9]. Many factors affect the occurrence of WRMDs among nurses—individual, physical, organizational, or environmental factors [2, 10]. Some researchers have proposed theoretical models of risk factors of WRMDs, such as the conceptual model for the development of WRMDs proposed by the National Institute for Occupational Safety and Health in 2001 [11] and the conceptual framework of WRMDs proposed by Lee et al. [12]. In both of these theoretical models, the occurrence of WRMDs is affected by multiple factors that alter the biomechanics of the body. Although the understanding of the risk factors of WRMDs has increased, more evidence is needed with regard to how these risk factors directly or indirectly affect WRMDs. Efforts to link various risk factors should be pursued to understand better the pathways of injury and take preventive measures.

An intensive care unit (ICU) is a department dedicated to the care of severely ill patients [13]. Patients in ICUs usually have poor ability to care for themselves and are severely weak. Their safety of life is always threatened. Nurses in the ICU daily conduct multiple procedures such as infusion, oral care, and airway management, and frequent night shifts and staff shortages place nurses in a long-term stressful working environment [14]. More than nurses in other units, ICU nurses are required to depend on their physical strength and mental stability [15, 16]. In China, WRMDs are very common among ICU nurses, with a prevalence of 95–98.0% [17]; among all nurses, those in the ICU experience the greatest leave or transfer owing to WRMDs [6, 18]. However, few studies have investigated the risk factors of WRMDs that are specific to ICU nurses in China as this group has been given little focused attention. In addition, previous studies on WRMDs in ICU nurses have rarely explored how the various risk factors influence one another. Identifying the risk factors of WRMDs and how they interrelate may help us develop tailored prevention strategies and ensure the stability of ICU teams.

The present study relied on the conceptual framework of WRMDs proposed by Lee et al. [12] (Figure 1). The framework presents the major risk factors of WRMDs as they relate to demographics (e.g., age, gender, and education), job

characteristics (job title, shift, work hours), and physical, psychosocial, and workplace organizational factors. Physical factors refer to the physical workload such as force, posture, and repetition. Psychosocial factors include the job stress caused by an imbalance between high effort and low reward [<sup>19, 20</sup>]. Workplace organizational factors affect how employees perceive workplace or organizational safety. Some studies confirm that WRMDs are associated with physical and psychosocial factors [<sup>21, 22</sup>]. The climate of workplace safety is also associated with WRMDs [<sup>23</sup>]. These risk factors may directly or indirectly affect the occurrence of WRMDs through risk perception and work behavior. The occurrence of WRMDs, in turn, may also affect the perception of risk and work behavior. Altogether, these factors are mediated by internal biomechanical strain, physiological response, and psychological stress.

The purpose of this study was to identify risk factors of WRMDs among ICU nurses in China and how physical factors, psychosocial factors, workplace organizational factors, risk perception, and WRMDs are interrelated. A structural equation model approach was used to explore the direct and indirect effects of risk factors of WRMDs.

### **Methods Study design**

The study used a descriptive, cross-sectional design and a self-reported online questionnaire to identify the risk factors that affect WRMDs among ICU nurses in China.

### **Setting and sample**

The study was conducted at 28 mixed ICUs (i.e., with patients transferred from other various departments) in 28 tertiary hospitals in Hunan Province and Guangdong Province, China. As per inclusion criteria, participants were registered nurses directly engaged in the care of patients in their daily work and who had been working for more than 1 year. Nurses who performed only administrative work (i.e., not involved directly in patient care) were excluded.

The researcher first collected a list of tertiary hospitals in the Hunan and Guangdong provinces by consulting the websites of provincial health commissions and determined whether they were tertiary hospitals. Second, the nursing directors and head nurses of mixed ICUs were contacted by telephone to introduce the purpose and method of the study and to invite them to participate in the survey. With the consent of nursing directors and head nurses, researchers introduced the purpose of the study and the method of participation to ICU nurses, face-to-face, at a meeting organized by head nurses.

Altogether, 1412 ICU nurses were invited to participate in the survey, of which 1018 participated (response rate = 72.1%). Of these 1018 ICU nurses, 34 were excluded because they had worked for less than 1 year ( $n = 24$ ) or were not employed in serving hospitals ( $n = 8$ ). In addition, 2 nurses were excluded because they answered that they had experienced WRMDs in the previous year, but did not identify any specific WRMDs in a separate question. Finally, 984 ICU nurses were included in the present data analysis.

### **Ethical consideration**

Before commencing the study, the Research Ethics Committee of behavioral and nursing research in School of Nursing of CSU approved all the research procedures (Approval no. 2017025). Subsequent to this approval, informed consent was obtained from the participating chief managers of the hospital nursing departments, the head nurses of the ICUs, and the ICU nurses. All the personal data were treated confidentially and anonymously and will never be used for any purpose other than this research.

### **Measurements Demographic characteristics**

The basic demographic characteristics of the participants included the hospital type where they worked, gender, age, marital status, job title, education, years of employment in the ICU, and whether the nurse exercised.

### **Physical factors**

As a latent variable, physical factors were judged as per 2 observation variables: frequency of patient handling (6 items) and physical workload (9 items). These were measured using the Nursing Physical Factors Evaluation Questionnaire, developed by the author based on the relevant literature [<sup>24</sup>] and consultation with 2 work-related musculoskeletal and 1 ergonomics experts, each of whom have more than 10 years of experience in work-related musculoskeletal research. All items were answered on a 5-point Likert scale (0 = never to 4 = very often), and the

final score was the total score of the 15 items.

The frequency of handling patients was reported as per the following 6 means: manual lift or transfer; lifting device; sling or sheet; hands to tightly grip a belt or article of clothing to pull, lift, or reposition; transfer of patients who cannot bear weight with the help of a coworker and without equipment; and lifting or moving a patient using just one side of the nurse's body. The physical workload was measured based on whether nurses were required to do any of the following 9 items: keep their hands above the shoulders; stand, sit, continuously bend or turn, or hold the neck forward or back for a long time; perform the same action repeatedly; carry or transfer goods weighing 10 to 20 kg, or >20 kg; or work that required maximum strength for a short time. The final score was the sum of the 15 items, wherein higher scores indicated greater ergonomic risk. The scale had good reliability and validity: the item- and scale-level validity indexes for content were 1 and .87, respectively. The Cronbach's  $\alpha$  was .76 in the survey sample.

### **Psychosocial factors**

Psychosocial factors were measured using the Chinese version of the Effort–Reward Imbalance scale, comprising effort (6 items), reward (11 items), and overcommitment (6 items) [25]. Each item used a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree).

High effort with low reward leads to an effort–reward imbalance, which can cause job stress. Based on the aim of the study, we chose job stress as the only observation variable for effort–reward imbalance to represent work pressures of nurses that are due to an effort–reward imbalance. Job stress was calculated by dividing the effort score by the reward score and multiplying by a correction factor (.55) to account for the difference in the number of items. A higher ratio indicated greater job stress. Yu [26] used confirmatory factor analysis to test the validity of the scale, and the results showed that the model fit well. The Cronbach's  $\alpha$  for each subscale was .88, .86, and .92.

### **Workplace safety environment**

The workplace safety environment was measured using the Chinese version of the Hospital Safety Climate Questionnaire [27], modified slightly to fit the context of this study. The questionnaire measured the perception of workplace or organizational safety. The main areas included management support (6 items), barriers and conflict (6 items), and feedback and training (9 items). A 5-point Likert scale (1 = strongly agree to 5 = strongly disagree) was used to evaluate the perception of safety in the workplace environment. The score was calculated as the sum of the items. Lower scores indicated a perception of a safer environment. Xu et al. [27] reported acceptable reliability and validity of the scale: the item-level validity indexes for content were .90–1, and the scale-level validity indexes for content were .95. In the present study, the Cronbach's  $\alpha$  for each subscale ranged from .87 to .92, and the Cronbach's  $\alpha$  for the scale was .94.

### **Risk perception**

Risk perception had 2 observation variables: perception of risk to self (4 items) and perception of risk to others (4 items). These were measured using the Risk Perception of Musculoskeletal Injury (RPMI) scale developed by Lee et al. [12]. After obtaining the author's permission, the Chinese version of the RPMI scale was translated from English to Chinese and then back translated to ensure accuracy and was adjusted for cultural differences.

The 8-item Chinese version of the RPMI scale asked about experiencing WRMDs within the last year, in the following 4 categories: nursing work in general, work tasks not related to patient handling, patient handling tasks performed manually, and patient handling tasks performed using a mechanical lifting device. The respondents were asked to estimate the risk to themselves or to other nurses in their units. A 6-point Likert scale (1 = extremely unlikely to 6 = extremely likely) was used. The score was calculated as the mean of the 8 items. Lee et al. [12] reported satisfactory convergent and discriminant validity of the RPMI scale. In the present study, the Cronbach's  $\alpha$  for subscales was .72 and .76, and the Cronbach's  $\alpha$  for the scale was .78.

### **Work-related musculoskeletal symptoms**

Symptoms of WRMDs were measured using the Chinese version of the Nordic Musculoskeletal Questionnaire [28]. Self-reports of nurses were used. We asked nurses to indicate whether they experienced symptoms among 9 different body regions in the last year and to place a checkmark at the affected areas. A diagram of the body was included. None or multiple checkmarks were allowed. One or more affected regions that were checked indicated that

the nurse had WRMDs within the previous year. The prevalence of WRMDs was computed by dividing the number of nurses with WRMDs by the total number of nurses. The participant also provided details of whether they took sick leave or sought medical advice.

We performed a confirmatory analysis of factors for the WRMD measurement model. The result showed that 6 items (neck, shoulder, upper back, wrist, low back, and knee pain) achieved factor loadings  $>0.3$ ; other parts of the affected regions achieved factor loadings

**Data collection**  
Data collection via an online questionnaire was conducted from July to September in 2017 and from January to March in 2018. The online questionnaire was developed using SoJump software (SoJump, Hu Xiao, China). The software generated an online link and a 2-dimensional image code. The image was scanned using the WeChat application on a mobile device, to access and complete the questionnaire.

The online questionnaire comprised 2 parts. The first part consisted of informed consent. If nurses were willing to participate in the study, they completed the succeeding questionnaire, but if not, the nurse closed the application. The second part was the questionnaire itself. The questionnaire was designed so that each nurse could save it partially completed, to finish later. They had 2 weeks to complete the questionnaire.

On completion, the online questionnaire data were collected in SoJump software. Each WeChat application was linked to a mobile phone account, and each account was limited to only one completion of the questionnaire. Mandatory fields were included to prevent incomplete questionnaires. As an incentive, all respondents who completed the questionnaire received ¥1.00 Yuan (about USD 0.15) via the WeChat mobile payment red envelope function.

### **Data analysis**

The analysis of data was conducted using SPSS 19.0 (IBM Corp., Armonk, NY, USA) and AMOS 21.0 software. Descriptive statistics were performed to summarize the demographic characteristics of the participants and the prevalence of WRMDs within the previous year.

The proposed hypothetical model was based on the conceptual framework of WRMDs proposed by Lee et al. [12]. The hypothetical model comprised physical factors, effort–reward imbalance, and safe environment as exogenous latent variables; risk perception as a mediation latent variable; and WRMDs as the endogenous dependent variable. Confirmatory factor analyses were performed for the items of latent constructs to confirm the validity of the scale and the hypothetical model.

We used AMOS 21.0 for the structural equation model analysis to assess the associations among observed and latent variables. The variables did not conform to the multivariate normal distribution. The generalized least squares method was used for parameter estimation. The fitness of the model was assessed using 6 indices [29]. These included the Chi-square value divided by the relevant degrees of freedom, with a value between 1 and 3. In addition, there were indices for comparative fit index, normal fit index, goodness-of-fit index, and adjusted goodness-of-fit index ( $>.90$ ) and the root mean square error of approximation (1.96 for a variable and  $p$  value

The hypothetical model originally proposed did not fit well because the model fitting indices did not meet the aforementioned fitting standards. We appropriately modified the hypothetical model as per the relevant literature and the modification indices provided by AMOS software. When all model fitting indices met the fitting standard, no modification index was suggested, and all regression coefficients for direct effect reached significant levels (CR  $>1.96$  and  $p$

### **Results Demographic characteristics**

All 984 of the ICU nurses who completed the survey were employed in public hospitals (Table 1). Most nurses were young, with a mean age of 29 years. Of the 984 nurses, 893 (90.8%) were women, 351 (35.7%) were married, and 865 (86.8%) had attained a bachelor's degree or higher. The average duration of employment was 8 years. Most (870, or 88.4%) did not exercise often (i.e., 88.0% exercised less than 6 times per month).

### **Prevalence of WRMDs among ICU nurses**

The prevalence of WRMD symptoms in the study population within the previous year was 96.8%. The highest rates of reported WRMDs were low back pain (80.5%), followed by neck pain (79.0%) and shoulder pain (70.4%). The prevalence of single-site WRMDs was 12.4%; 2 or more sites had a prevalence of 87.6% (data not shown).



## Structural equation modeling analyses

The final structural equation model consisted of exogenous physical factors, job stress, safe environment, risk perception, and endogenous WRMDs. A good fit was demonstrated: Chi-square value/degrees of freedom = 2.248, comparative fit index = .931, normal fit index = .905, goodness-of-fit index = .978, adjusted goodness-of-fit index = .966, and root mean square error of approximation = .036. The final structural model is shown in [Figure 2](#). The factor loading, from the latent constructs to the observable, revealed the weighting of the observable variables that set the latent construct.

The paths of standardized regression coefficients showed the extent to which physical factors, job stress, safe environment, risk perception, and endogenous WRMDs correlate ([Table 2](#)). The CR for all variables was  $>1.96$ , and the *P* value was

The standardized direct and indirect effects of WRMDs are reported in [Table 3](#). Physical factors had the greatest accumulated total effect on WRMDs, both directly and indirectly via risk perception, safe environment, and job stress. A safe environment had an indirect effect on WRMDs through risk perception and job stress. Risk perception had the second greatest effect on WRMDs. There was a direct link between risk perception and WRMDs and between job stress and WRMDs.

## Discussion

Many studies have focused on the risk factors and the prevalence of WRMDs using a cross-sectional design [[30](#), [31](#)], but cross-sectional studies cannot determine either a causal association or the direction of associations among variables. The present study used a structural equation model, and a complex of interassociations was found among physical factors, job stress, safe environment, risk perception, and the symptoms of WRMDs in nurses working in the ICU. We conclude that mechanisms that affect the occurrence of WRMDs in this occupation are both direct and indirect.

The associations among risk factors in the final structural equation model were partly consistent with the conceptual framework of WRMDs proposed by Lee et al. [[12](#)] in 2013. In the present study, physical factors directly and indirectly affected WRMDs through the risk perception by nurses, and a safe environment also indirectly affected WRMDs through the lens of risk perception. The correlation between these risk factors and WRMDs has been demonstrated in previous studies [[32](#), [33](#)].

Risk perception is a relatively new variable that has been recognized as important in a number of studies of behavioral theory [[34](#)]. Adequate perception of occupational risk can be a motivator for adopting healthy behaviors [[35](#), [36](#)]. As a variable with an indirect effect, perception of risk is meaningful and can be regulated. Hospital executives can improve risk awareness of WRMDs through education and skill training and thereby reduce the occurrence of WRMDs [[37](#)].

We also found that physical factors and a safe environment may affect WRMDs through job stress. The association was not included in the conceptual framework of WRMDs proposed by Lee et al. [[12](#)], which may be due to the difference in study groups and statistical methods. Single-factor analysis can indicate a correlation, but cannot differentiate direct or indirect effect [[38](#)]. Some studies had shown an association between job stress and WRMDs [[20](#), [39](#)], but Koch et al. [[19](#)] in a systematic review were unable to confirm an association between effort–reward imbalance and WRMDs. The present study indicated that the effect of job stress in the occurrence of WRMDs was indirect and small. This may be because nurses working in tertiary hospitals in China are relatively well paid, and therefore, the effort–reward imbalance is small and has little mediating effect [[20](#)]. This new finding needs verification in a future study.

In the present study, physical factors could directly affect the occurrence of WRMDs or indirectly affect the occurrence of WRMDs through risk perception, job stress, and safe environment. Previous studies have shown that nurses who were subjected to high physical demands were more likely to report WRMDs [[40](#), [41](#)], and the present study corroborates this. It may be that the indirect effect of physical factors on WRMDs is because nurses exposed to high physical demands are more likely to have a heightened awareness of the risk of injuries and report worse symptoms. Landry [[42](#)] also found that the physical workload was associated with the perception of risk of injuries.

Few studies have considered the perception of risk or job stress as influencing factors, and an indirect effect of the effort–reward ratio on WRMDs has not been reported.

In the present study, the presence of a safe environment indirectly affected the occurrence of WRMDs through risk perception. The workplace environment has a significant role in the health and safety of workers [43, 44]. A poor workplace environment is not enough to affect the occurrence of WRMDs directly, but mainly depends on the nurses' individual perception and behaviors to protect their safety [45]. In the safety culture of tertiary hospitals in China, nurses lack awareness of the cumulative damage caused by WRMDs [27], so individual risk perception may play a regulatory role between the environment and WRMDs. An unsafe workplace environment may negatively (e.g., by reducing the ability to work or adding incentive to change jobs) or positively (by requesting a safe work environment) influence nurses. Either way, organizational efforts should ensure a safe work environment by establishing a healthy hospital safety culture and improve risk consciousness [46].

Based on the conceptual framework of WRMDs, we considered that the structural equation model might be complex and more parameters may need to be estimated, and we used a large sample [29]. In general, model fitting is difficult to achieve with large sample sizes because of the larger covariance. In the present study, the fit of the model is good. In addition, the response rate from each hospital was very good. However, there are also several limitations with regard to the data set. First, all measurements depended on the nurses' self-reports, and the study findings may have been affected by information bias from recall errors. Second, the structural validity of the questionnaire was not analyzed as 4 of the questionnaires had been validated in previous studies. Finally, our study only collected data from ICU nurses in Chinese tertiary hospitals and might not be representative of ICU nurses in other settings.

In addition, although this is a multicenter study, we tried to ensure the homogeneity of the samples. First, all the 28 hospitals are public tertiary hospitals. In China, tertiary hospitals are unified by a standard qualification evaluation. Second, all the ICUs are mixed ICUs, with the same basic configuration, work scheduling (8-hour shifts), and nurse-to-patient ratio (based on the staffing standards, an average of 2.5 to 3 nurses care for each patient). Third, none of the participating hospitals had large patient-moving equipment or participated in an intervention study to reduce WRMDs.

## **Conclusion**

Structural equation modeling was a useful method to reveal associations among risk factors and WRMDs in ICU nurses. The results provide evidence of associations among physical factors, job stress, safe environment, risk perception, and WRMDs. Nurses' risk perception and job stress act as mediators between physical factors and safe environment and WRMDs. To improve the practice setting of the ICU, nurses, head nurses, and chief managers of hospitals should make efforts to reduce the prevalence of WRMDs. As individuals, nurses should improve their risk perception of WRMDs by actively training in appropriate patient transfers and movement. Head nurses must know to provide nurses with theoretical knowledge and practical training in WRMDs, and equipment and ICU layouts should be reasonably arranged to create a safer working environment, reducing the job stress of nurses. Hospital chief managers should attach importance to the high probability of WRMDs experienced by ICU nurses, ensure nursing manpower allocation in ICUs, and strive to provide the relevant equipment for patient handling. These efforts would contribute to a healthy and stable ICU nursing team. Future research is needed to develop a specialized program that focuses on the risk factors that affect WRMDs in ICU nurses, a multidimensional intervention that includes risk perception, physical and psychosocial factors, and environmental factors.

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## **Author contributions**

S.Y. participated in the study design and data collection and was a major contributor in writing the manuscript. L.L. helped draft the manuscript and participated in the analysis of the structural equation model. L.W. and J.Z. participated in data collection. Y.L. participated in study design and contacted the participating hospitals. All authors read and approved the final manuscript.

## **Conflict of interests**

All authors declare that they have no conflicts of interests.

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Variable		Mean ± SD or n (%)
Age, yrs		29.26 ± 4.71
ICU employment, yrs		7.82 ± 5.26
Hospital type	Public	984 (100)
Other	0 (0)	Gender
Women	893 (90.8)	Men
91 (9.2)	Marital status	Married
351 (35.7)	Unmarried	633 (64.3)
Job title	Nurse	719 (73.1)
Senior nurse <sup>a</sup>	265 (20.9)	Education
Junior college <sup>b</sup>	130 (13.2)	Bachelor
828 (84.2)	Master or doctoral	26 (2.6)
Exercise	1–2 times a month	443 (45.0)
3–5 times a month	427 (43.4)	≥6 times a month

Variable 1	Variable 2	Final model				
Estimate	SE	β	CR	P	Risk perception	Physical factors

0.838	0.074	0.502	11.336	<.001	Safe environment	Physical factors
0.515	0.088	0.324	5.873	<.001	Job stress	Physical factors
-0.057	0.013	-0.175	-4.253	<.001	Job stress	Safe environment
-0.023	0.008	-0.113	-2.978	.003	Risk perception	Safe environment
0.014	0.042	0.134	3.364	<.001	WRMDs	Physical factors
0.093	0.021	0.358	4.480	<.001	WRMDs	Risk perception
0.024	0.008	0.152	2.802	.005	WRMDs	Job stress

Variable	Effect	Physical factors	Risk perception	Safe environment	Job stress
Risk perception	Total	0.546	—	0.134	—
Direct	0.503	—	0.134	—	Indirect
0.043	—	—	—	Safe environment	Total
0.324	—	—	—	Direct	0.324
—	—	—	Indirect	—	—
—	—	Job stress	Total	-0.211	—
-0.113	—	Direct	-0.174	—	-0.113
—	Indirect	-0.037	—	—	—

WRMDs	Total	0.417	0.152	-0.008	0.112
Direct	0.358	0.152	—	0.112	Indirect

## DETAILS

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# A New Self-management Scale with a Hierarchical Structure for Patients with Type 2 Diabetes

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[ProQuest document link](#)

## ABSTRACT (ENGLISH)

### SummaryPurpose

The aims of this study were to develop a new instrument for measuring self-management with a hierarchical structure [the Diabetes Self-Management Scale (DSMS)] in patients with type 2 diabetes, and evaluate its psychometric properties.

### Method

The DSMS instrument was developed in three phases: (1) conceptualization and item generation; (2) content validity and pilot testing; and (3) field testing of its psychometric properties. A convenience sample of 473 participants was recruited in three university hospitals and one regional health center, South Korea.

### Results

Exploratory and confirmatory factor analyses yielded two second-order component models explaining the common variance among six first-order factors. Principal axis factoring with a varimax rotation accounted for 60.88% of the variance. Confirmatory factor analysis of the hierarchical structure revealed the following fit indices:  $\chi^2/df = 1.373$ , standardized root-mean-square residual = .050, goodness-of-fit index = .935, incremental fit index = .975, comparative fit index = .974, and root-mean-square error of approximation = .039. All Cronbach'  $\alpha$  values for internal

consistency exceeded the criterion of .70. All of the intraclass correlation coefficients for test–retest reliability exceeded .70 except that for the taking-medication subscale. The components of the DSMS were moderately correlated with the comparator measures of self-efficacy and health literacy administered for convergent validity.

### Conclusion

The DSMS is a new instrument for measuring the complex nature of self-management in patients with type 2 diabetes, comprising 17 items scored on a five-point Likert scale. The DSMS exhibits satisfactory psychometric properties for five reliability and validity metrics, and so is a suitable instrument to apply in both research and clinical practices.

## FULL TEXT

### DETAILS

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# The Use of Modified Mindfulness-Based Stress Reduction and Mindfulness-Based Cognitive Therapy Program for Family Caregivers of People Living with Dementia: A Feasibility Study

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[ProQuest document link](#)

## ABSTRACT (ENGLISH)

### Purpose

The aim of this study was to investigate the feasibility and preliminary efficacy of a modified mindfulness-based stress reduction (MBSR) program and mindfulness-based cognitive therapy (MBCT) program for reducing the stress, depressive symptoms, and subjective burden of family caregivers of people with dementia (PWD).

### Methods

A prospective, parallel-group, randomized controlled trial design was adopted. Fifty-seven participants were recruited from the community and randomized into either the modified MBSR group (n = 27) or modified MBCT group (n = 26), receiving seven face-to-face intervention sessions for more than 16 weeks. Various psychological outcomes were measured at baseline (T0), immediately after intervention (T1), and at the 3-month follow-up (T2).

### Results



Both interventions were found to be feasible in view of the high attendance (more than 70.0%) and low attrition (3.8%) rates. The mixed analysis of variance (ANOVA) results showed positive within-group effects on perceived stress ( $p = .030$ , Cohen's  $d = 0.54$ ), depressive symptoms ( $p = .002$ , Cohen's  $d = 0.77$ ), and subjective caregiver burden ( $p < .001$ , Cohen's  $d = 1.12$ ) in both interventions across the time points, whereas the modified MBCT had a larger effect on stress reduction, compared with the modified MBSR ( $p = .019$ ).

### Conclusion

Both the modified MBSR and MBCT are acceptable to family caregivers of PWD. Their preliminary effects were improvements in stress, depressive symptoms, and subjective burden. The modified MBCT may be more suitable for caregivers of PWD than the MBSR. A future clinical trial is needed to confirm their effectiveness in improving the psychological well-being of caregivers of PWD.

## FULL TEXT

### Introduction

Dementia is a neurocognitive degenerative disease with no known cure. As the disease progresses, the cognitive function and self-care ability of people with dementia (PWD) gradually declines. Family caregivers are usually the backbone of informal care. The demanding caregiving tasks that are involved always create a high level of stress and burden on family caregivers, which negatively affects their physical and psychological health [1]. Compared with other caregivers, caregivers of PWD have higher rates of depression and anxiety [2], and poorer physical morbidity [3]. Around 70.0% of caregivers of PWD have reported various degrees of psychological distress [1] and a higher rate of health-care utilization [4]. Providing support for family caregivers is important to maintain their continued ability to care for their relative with dementia and prevent the latter's premature institutionalization [5].

Researchers are keen to develop interventions to reduce the perceived stress of caregivers of PWD and improve their well-being. Such interventions have included case management, cognitive stimulation, cognitive and behavioral interventions, education, physical activity interventions, psychosocial support, relaxation, respite, and skill-building [6]. Although most psychosocial interventions appear to be effective at reducing caregiver stress and psychological morbidity [7-9], the treatment effect sizes have been relatively small and inconsistent [10].

Mindfulness-based interventions (MBIs) have been broadly used to reduce stress and emotional problems in both healthy individuals and caregivers of people with chronic conditions, as well as to improve mental health and well-being in general, with consistent and promising results [11, 12]. MBIs help participants to focus on the experience of the present moment and adopt an orientation of openness and acceptance toward their experience [13]. Through practising the meditation exercises in the MBI, improvements were observed in trait mindfulness (a keen awareness and attention to our thoughts and feelings in the present moment), cognitive reactivity, and emotional reactivity, leading to insight and a nonreactive acceptance of one's experience, which in turn eventually led to positive psychological outcomes [11]. In recent years, MBIs are increasingly being used to reduce stress in caregivers of PWD. However, a Cochrane Review reported that the existing evidence found in the majority of prior trials is of low to very low quality and that the risk of bias is high (e.g., performance bias, detection bias) [14], which may hinder the use of MBIs in clinical practice. In addition, different forms of MBIs were adopted in previous studies. It is therefore important to find an appropriate modality of MBIs for caregivers of PWD before conducting a more rigorous clinical trial to test its effectiveness.

The most popular types of MBIs are mindfulness-based stress reduction (MBSR) and mindfulness-based cognitive therapy (MBCT). MBSR was used as early as 1979 as a training vehicle to relieve pain and distress in the general population with chronic health problems [11]. Later, it was integrated with cognitive theory and cognitive behavioral therapy to create MBCT and used for preventing the relapse or reoccurrence of depression in people who had been diagnosed with that ailment [11]. Both types of interventions have been preliminarily tested with caregivers in separate studies and found to be effective at reducing stress and promoting well-being [15-17]. In the MBSR, caregivers learn about how to adopt mindfulness to respond to the stressors of caregiving. In the MBCT, caregivers learn more about how to disengage with their negative thinking patterns through mindfulness and CBT techniques.

Although the programmes appear to be very similar in structure and content, it is not known which intervention is more suitable. Because family caregivers are a nonclinical population, MBSR would be an appropriate approach [18]. However, several studies have indicated that the majority of family caregivers of PWD experience depressive symptoms resulting from repeatedly thinking about the unpredictable progress of the disease and the symptoms of the PWD [19]. Family caregivers of PWD always report higher levels of stress than the family caregivers of people with other chronic diseases [20]. The MBCT, which targets ruminative thoughts, may be more suitable for family caregivers of PWD.

In a meta-analysis of five studies, the stress levels of caregivers of PWD were found to have dropped significantly after either MBSR or MBCT, which had a moderate effect size [14]. The review also showed that the long duration and highly intensive training involved in MBCT and MBSR often results in a high attrition rate, which justifies the need for modifications to be made to the protocols to meet the needs of caregivers. Moreover, using MBIs to support caregivers of PWD is a relatively novel approach, especially among Asian populations. Therefore, this study adopted the modified version of the MBSR and MBCT protocols and tested them on family caregivers of PWD in the local context.

### **Purpose of this study**

The aim of this study was to (1) investigate the feasibility of implementing the modified MBSR and modified MBCT protocols on family caregivers of PWD; and (2) explore and compare the preliminary efficacy of the two interventions in improving the psychological symptoms of the caregivers, namely, perceived stress, depressive symptoms, and subjective caregiver burden.

### **Methods Design**

This study is a two-arm randomized controlled trial with an allocation ratio of 1:1. It was undertaken between February 2016 and May 2017 in the Hong Kong SAR, China [ClinicalTrials.gov Identifier: NCT02667782].

### **Participants**

The participants were family caregivers of PWD. Convenience sampling was adopted to recruit family caregivers from two elderly centers in Hong Kong that provide dementia services. The inclusion and exclusion criteria were drawn from the standard practice guideline of the MBSR program published by the Center of Mindfulness, University of Massachusetts Medical School [21]. The criteria for participation included the following: (a) being 18 years or older; (b) being the primary family caregiver of an individual with a confirmed medical diagnosis of dementia who is residing in the community; and (c) having provided care for at least three months before recruitment. In this study, a primary caregiver is defined as an unpaid individual who has a significant personal relationship with the person with whom he/she is living and who assists that person with the activities of daily living. The participants excluded were those with (a) acute mental disorders; (b) serious or chronic pain and/or a physical disease such as cancer and cardiovascular disease in an acute phase; and/or (c) those who had participated in any MBI, cognitive therapy, or structured psychosocial intervention in the six months before recruitment. Verification of eligibility was conducted individually before the signing of the consent to participate form.

### **Sample size**

For feasibility studies, it may not be possible to produce a formal calculation of sample size. However, minimum sample sizes of between 24 and 50 have been recommended [22, 23]. Therefore, in this study, a minimum sample size of 50 was required, although 53 caregivers were ultimately recruited.

### **Interventions (modified MBSR and modified MBCT)**

To improve the adherence of family caregivers to the MBSR and MBCT programmes, we made the following changes to the MBSR and MBCT protocols by (1) integrating the content of some sessions to shorten the face-to-face training, (2) providing telephone follow-ups to monitor their progress and adherence to the practice of mindfulness and; (3) extending the last three sessions from weekly to biweekly to help the participants develop a habit of practising mindfulness on a daily basis. The modifications to the protocols were based on recommendations from previous studies [24-29]. The protocols were then reviewed by a panel of experts consisting of mindfulness interventionists, registered nurses experienced in dementia care, and a clinical psychologist. Details of the

modifications and the rationales for them can be found in our recent publications [24].

Both intervention programmes lasted for 16 weeks and consisted of seven 2.5-hour face-to-face group-based training sessions. In the first month, the participants took part in four weekly sessions, followed by three monthly sessions. In between the three monthly sessions, three trained research assistants with nursing backgrounds provided biweekly 15-minute telephone follow-ups (a total of three times) to encourage and advise the participants and to ensure fidelity to the intervention. A certified cognitive therapist, who was also a mental health nurse and a mindfulness teacher with more than 10 years of experience, delivered both interventions. An audio CD of recordings of mindfulness exercises was also provided to all participants.

Although the class structure and mode of delivery were similar in both groups, the two protocols differed slightly in content within each session. In the modified MBCT, a greater focus was placed on addressing low moods and negative thoughts to help the participants gain experience in recognizing emotional symptoms and become confident in responding skillfully early in the program [30]. By contrast, in the MBSR, minus the CBT component, psychoeducation was adopted to help the participants understand their habitual reactions to stress and teach them how to adopt the skill of mindfulness to respond nonjudgementally to stressors [11]. Details about the contents of the programmes and the differences between them are listed in Table 1 (the modified MBSR and MBCT protocols).

### **Measurements**

Demographic data were collected at baseline before randomization, including data on age, gender, level of education, marital status, household income, relationship with the person living with dementia, and the number of hours spent in providing care.

### **Feasibility assessment**

To assess the feasibility of the interventions, we collected information about recruitment, attendance, and completion rates in the face-to-face intervention sessions, and asked the therapist to report any adverse reactions during those sessions. Some potential adverse effects reported in previous studies include transient negative emotions reported by the caregivers, and muscle or joint pain after practising mindful yoga [31].

### **Efficacy**

To explore the efficacy of the two interventions, psychological outcomes were measured at baseline before randomization (T0), immediately postintervention (T1), and three months after the intervention (T2). The primary psychological outcome was the participants' perceived stress. Secondary psychological outcomes were depressive symptoms and subjective caregiver burden, which have been found to be related to MBIs [15, 32]. We also examined trait mindfulness as a process indicator, as it had been identified in previous studies as an indicator of the participants' mastery of mindfulness skills [11]. Trait mindfulness refers to a state of keen awareness and attention to our thoughts and feelings in the present moment [33].

### **The primary psychological outcome Perceived stress**

Perceived stress was assessed using the Chinese version of the Perceived Stress Scale (PSS) [34]. This is a 14-item, self-reported scale that is used to evaluate the degree to which individuals appraise situations in their lives as stressful in the previous month, using a 5-point Likert scale (0 = never to 4 = very often). The total score ranges from zero to 56, with higher scores indicating greater perceived stress. The Chinese version of the PSS was tested in the community, with 500 adults receiving mindfulness interventions. A factor analysis revealed that the scale contains two factors (namely, positive and negative factors), with a factor loading ranging from .26 to .78 and a Cronbach's  $\alpha$  of between .76 and .83. The test-retest reliability coefficient was .85. These results support the view that the scale is a reliable and valid instrument [35].

### **Secondary psychological outcomes The depressive symptoms**

The depressive symptoms of the participants were measured using the Chinese version of the Center of Epidemiological Studies – Depression Scale (CES-D) [34]. The scale has 20 items, which measure an individual's depressive symptoms over the past week on a 4-point Likert scale (0 = rarely to 3 = almost all the time). The total score ranges from zero to 60, with higher scores indicating higher levels of depression. The Chinese version of the CESD was tested in the community with 3,686 Chinese adults attending primary care services (Chin et al [36]). A

factor analysis revealed that the instrument contains four factors (namely, depressed affect, positive affect, somatic and retarded activity, and interpersonal problems) with a factor loading ranging from .12 to .88. The results showed acceptable levels of psychometric properties, which include an intraclass correlation coefficient of .91 and an internal consistency for general depression figure of 0.85.

### **Subjective caregiver burden**

This was assessed using the Chinese version of the Zarit Burden Interview (ZBI) [37]. For each of the 22 items, the participants were asked to indicate their level of caregiving distress on a 5-point Likert scale (0 = never to 4 = nearly always). Higher total scores indicate a greater caregiver burden. This instrument demonstrated a high intraclass correlation coefficient of .99 and a split-half correlation coefficient of .81 [37]. The correlation between the ZBI and the General Health Questionnaire was .59 and between the ZBI and the Activity Survey was .57. This supports the view that the scale is a reliable and valid instrument [37].

### **Process indicator Trait mindfulness**

This was assessed using the Chinese version of the Five Facet Mindfulness Questionnaire – Short Form (FFMQ-SF) [38]. The FFMQ-SF consists of 20 items in five domains, namely: observing (4 items), describing (4 items), nonjudging of experience (4 items), acting with awareness (4 items), and nonreactivity to inner experience (4 items). The participants were asked to rate these items on a 5-point Likert scale (1 = never to 5 = very often). A higher total score (ranging from 20 to 100) reflects a higher level of trait mindfulness, which could support their mastery of the mindfulness skills, resulting in an increase in trait mindfulness. The Chinese version of the FFMQ was tested among Chinese adults in the community (n = 230) and among adult and clinical patients with significant psychological distress (n = 156) (Hou et al [39]). Internal consistency was high in five subscales: nonreactivity = .75, observing = .83, acting with awareness = .87, nonjudging = .87, and describing = .91. The results showed good test–retest reliability (.88) and a high level of internal consistency of .83 in the community sample and .80 in the clinical sample). This supports the view that the scale is a reliable and valid instrument.

### **Randomization and blinding**

Those who met the criteria for eligibility and provided informed consent were randomly allocated into either the modified MBSR group or the modified MBCT group by block randomization (with a block size of six) and computer-generated random numbers. An independent researcher who was not involved in collecting or entering the data or delivering the interventions conducted the randomization. The group assignments were concealed from the other researchers and staff members of the center (with the exception of the therapist) until the data collection process was complete.

### **Ethical considerations**

Ethical approval for the study was received from the HongKong Polytechnic University (Approval no. HSEARS20151213002-01). The research team explained to the potential participants the nature of a randomized controlled trial and their rights as research participants, before asking them to voluntarily sign the informed consent forms.

### **Data analysis**

Quantitative data were entered, managed, and analyzed using SPSS AMOS 23.0 (IBM Corp., Armonk, NY, USA). To determine the feasibility of the interventions (objective 1), the recruitment, attendance, and completion rates of the two programmes were descriptively reported in percentage and mean (standard deviation) terms, where appropriate. To explore and compare the efficacy of the two interventions (objective 2), mixed analysis of variance (ANOVA) was conducted to examine the change in psychological outcomes and trait mindfulness across time points in the two groups. All of the participants were included in the final analysis based on an intention-to-treat principle. Missing data were replaced using the last observation carried forward method. To assess homogeneity between the two groups, an independent t-test (as the data were found to be normally distributed) and a chi-square test were used for continuous and categorical baseline data, respectively. Preliminary statistical assumptions were tested, and no violations were noted on normality, linearity, univariate and multivariate outliers, the homogeneity of the variance–covariance matrices, and multicollinearity. Because there were three time points of measurement in this

study, a Helmert contrast test was performed to examine which pairs of time points (i.e., T0-T1, T0-T2, T1-T2) showed differences if there was a significant group × time interaction effect. To further investigate changes in the outcomes of two individual groups between time points, a pairwise comparison with a Bonferroni adjustment was conducted. All of the participants were included in the final analysis based on the intention-to-treat principle involving 27 caregivers in the MBSR group and 26 caregivers in the MBCT group.

### **Results Participant characteristics**

Ninety-seven family caregivers showed an interest in joining this study. Of these, 80 met the sample selection criteria and 53 agreed to take part in the study (please refer to the Consolidated Standards of Reporting Trial flow chart in <sup>Figure 1</sup>). The participants were randomly allocated into either the modified MBSR group (n = 27) or the modified MBCT (n = 26) group. Their demographic and clinical characteristics are summarized in <sup>Table 2</sup>. All of the participants were Chinese (100%) and the majority were female (86.8%). Their mean age was 56 (SD = 9.26) years. Most of the participants were the adult children of PWD for whom they were the caregivers (71.7%). The average duration of cognitive impairment in the PWD was 71.1 (SD = 59.96) months, whereas the average duration of caregiving was 8.72 (SD = 10.56) years. No significant differences were found between the two groups in any of the demographic and clinical characteristics at baseline.

### **Feasibility of the interventions Recruitment**

Two day-care centers for the elderly that were known to the research team were invited to participate in this project. A public seminar and seven briefing sessions were organized at the University and at the day-care centers for the elderly to introduce the MBI, as well as to attract potential participants to this project. A total of 253 people attended the public seminar and briefing sessions. Ninety-seven caregivers were eligible to participate in this study, and 53 agreed to do so. The recruitment rate was 54.6%.

### **Attendance**

The mean attendance rate of the 10-week training sessions was 73.5% (SD = 28.48) for the modified MBSR group and 82.4% (SD = 20.32) for modified MBCT group. There was no significant difference in attendance rate between the two groups ( $p = .197$ ).

### **Completion**

The overall dropout rate was 3.8%. The completion rate (defined as having attended 80% or more of the sessions) was 63.0% (n = 17) for the modified MBSR group and 69.2% (n = 18) for the modified MBCT group. There was no significant difference between the two groups in completion rate ( $p = .610$ ).

### **Adverse reactions**

No adverse events were reported in any of the mindfulness sessions, indicating that both modified interventions are safe.

### **Preliminary efficacy**

Mixed ANOVA were conducted for all outcomes, and the results are given in <sup>Table 3</sup>. Significant time effects were found in all of the outcomes, including perceived stress ( $p = .030$ , Cohen's  $d = 0.54$ ), depressive symptoms ( $p = .002$ , Cohen's  $d = 0.77$ ), and subjective caregiver burden ( $p = 1.12$ ) at the three-month follow-up (T2). A significant interaction effect (group × time) was found only for stress ( $p = .019$ , Cohen's  $d = 0.63$ ).

A Helmert's contrast test found significant improvements in the following: (1) stress at both T0-T1 and T0-T2 (mean difference = 1.74 and 1.98, standard error [SE] = 0.78 and 0.91, respectively); (2) depression at both T0-T1 and T0-T2 (mean difference = 3.61 and 4.05, SE = 1.27 and 1.27, respectively); and (3) burden at both T0-T1 and T0-T2 (mean difference = 5.65 and 7.40, SE = 1.47 and 1.55, respectively). There was no significant change between T1 and T2 in any of the psychological outcomes.

In the pairwise comparison of the outcomes of the two groups between time points, the results showed that the modified MBSR group showed significant improvement from T0 to T1 in burden (mean difference = 5.41, SE = 1.73,  $p = .013$ ), whereas the modified MBCT group showed significant improvement from T0 to T1 in stress (mean difference = 3.19, SE = 1.14,  $p = .030$ ) and significant improvement from T1 to T2 in burden (mean difference = 5.19, SE = 1.68,  $p = .014$ ). There were no significant differences in other outcomes in other time point

comparisons. The results are tabulated in <sup>Table 4</sup>.

### Trait mindfulness

The mixed ANOVA results showed that there was a significant time effect on mindfulness from T0 to T2 [ $F(2, 135) = 3.70, p = .040, \text{partial } \eta^2 = .07$ ]. The results of the Helmert's contrast test indicated that the trait mindfulness of the participants improved significantly at both T0-T1 and T0-T2 (mean difference = 2.43 and 2.50, SE = 1.16 and 1.22, respectively), but that there were no significant changes from T1 to T2.

### Discussion

To the best of our knowledge, this is the first study to investigate the feasibility of two types of MBI, namely modified MBSR and modified MBCT, for improving the perceived stress and other psychological outcomes of caregivers of PWD; and to provide preliminary evidence of which intervention appears to be more effective. Our findings suggest that, given the good attendance rates, the modified MBSR and modified MBCT interventions are both feasible for use among family caregivers of PWD. In addition, a statistically significant increase in trait mindfulness in both the MBSR and MBCT groups demonstrated that our modified MBSR and MBCT protocols are effective at developing a mindful attitude in family caregivers. There were no reported adverse events during the mindfulness sessions. Comparing the effect between the two interventions, MBCT was found to be more effective at reducing stress, with a similar improvement being observed in other outcomes including burden and depression.

This study reported a low dropout rate of 3.8%. Compared with a recent systematic review of the implementation of MBIs on family caregivers of PWD [<sup>39</sup>], which included four RCTs ( $n = 168$ ) with attrition rates ranging from 10.3% to 17.2%, our study demonstrated the lowest attrition rate. We believe that the low attrition rate may be attributed to our modified protocol, in which we provided biweekly telephone follow-ups, reduced the number of face-to-face sessions from eight to seven, and abridged the whole-day retreat. Despite reducing the number of sessions, a significant increase in trait mindfulness was also identified immediately after the MBI. A study with a similar number of sessions also demonstrated a moderate to large effect size on psychological outcomes [<sup>25</sup>]. These outcomes support the argument that our modified interventions are sufficient to reduce the stress of caregivers of PWD.

Our findings showed that both modified protocols were effective at reducing the level of perceived stress, depressive symptoms, and subjective caregiver burden, and that the effects lasted for at least three months after intervention. MBSR is widely used in nonclinical populations (e.g., health professionals and family caregivers), whereas MBCT is usually used in clinical settings (e.g., among people with recurrent depression or other mental illnesses). There are no standard guidelines for recommending either protocol to family caregivers of PWD [<sup>40</sup>]. In MBCT, techniques from cognitive behavioral therapy are used to promote greater awareness of depressive thought patterns. In the program, mindfulness practices are used to help participants to disengage from negative thinking. In fact, the prevalence of depression and psychological distress is high in family caregivers of PWD (ranging from 45.0% to 85.0%) resulting from recurrent negative thoughts about caregiving [<sup>41, 42</sup>]. Compared with MBSR, which uses psychoeducation to help participants recognize habitual, unhelpful reactions to difficulties, MBCT may be more helpful to family caregivers. A significant interaction effect (group  $\times$  time) was found in the caregivers' stress, indicating that the modified MBCT has a larger effect on reducing stress than the modified MBSR program. Similar findings were also shown in a study in which 33 patients with comorbid depression and cardiovascular disease were randomized into three groups receiving adapted MBCT, MBSR, or the usual care [<sup>43</sup>]. Greater improvements in psychological outcomes and higher acceptability and engagement were found in the adapted MBCT group than in the MBSR group and the usual care control group. The adapted MBCT focused more on depression-specific mechanisms, including rumination about the causes of disease, and the meanings and consequences of low mood, which would be more suitable for people with ruminative thoughts. Rumination refers to the focusing of attention on and the repetition of the same thoughts about various aspects of situations that are upsetting. It is a common symptom in family caregivers of PWD, who are highly stressed as a result of their negative thoughts about the progression of their relative's disease and their own caregiving tasks [<sup>44</sup>]. This rumination aggravates the chronic stress that caregivers feel through a prolonged pattern of negative thinking [<sup>45</sup>]. This may explain why MBCT could have a larger effect on reducing stress than MBSR. Caregivers with more of a tendency to ruminate have higher levels of depression and anxiety, and lower levels of

satisfaction with life [44, 45]. Compared with MBSR, MBCT focuses more on negative thoughts and thus may be a better modality for improving the psychological health of caregivers of PWD. Given the small sample in this feasibility study, it is suggested that future randomized controlled trials with appropriate sample sizes be conducted to compare the effect between MBSR and MBCT in improving various psychological outcomes of caregivers. Both MBSR and MBCT require the practise at home of mindfulness skills, the duration of which has been associated with beneficial effects [18]. However, some participants reported having difficulty finding the time to practise the 45-minute body scanning exercise. The 45-minute body scan is regarded as a major component of the original MBSR and MBCT protocols [11, 13]. A body scan directs a caregiver's attention to the present moment through observations of one's breath and bodily sensations, while becoming aware of, and accepting without judgment, any thoughts and feelings that arise [13]. In the past few decades, several brief versions of the scan have been developed, ranging in duration from 10 to 30 minutes [46, 47]. The UCLA Mindful Awareness Research Center has also developed a 13-minute version of the body scanning technique [48]. Caregivers are busy people and may find it difficult to comply with the intervention. It is important to design interventions that consume less time but are effective. Because there are different brief versions of the mindfulness-based body scan, to increase compliance it is suggested that further research be conducted to compare the effects of the 45-minute body scan technique and the brief versions. Apart from the scan, both modified protocols involved other mindfulness activities, such as mindful eating, mindful walking, and sitting meditation, to help the participants develop a mindful attitude. We evaluated the caregivers' trait mindfulness. The statistical analysis revealed that the improvement in trait mindfulness was statistically significant. Although our findings suggest that the modified MBCT is more effective at reducing stress than the MBSR, the qualifications of the interventionist have to be considered when advising caregivers of PWD. A UK survey of 103 MBCT interventionists providing MBCT under the National Health Service found that over 67.0% of them indicated that they had received insufficient training in delivering MBCT, and 54.0% had not undertaken formal postgraduate training in MBCT. Keeping in good practice in the coaching of mindfulness through formal training, continuing education, and supervision is important in controlling and maximizing the effects of the intervention [49].

### **Limitations and suggestions**

This study is not without limitations. First, the cognitive status or behavioral symptoms of the PWD who were being cared for by the caregiver participants were not measured. These are major stressors for caregivers [50], which might have affected the results. Similarly, the positive effects of the interventions on psychological symptoms (i.e., perceived stress, depressive symptoms, and subjective caregiver burden) might have been mediated by other factors. Examples of such factors are repetitive negative thinking, self-compassion, cognitive and emotional reactivity, and psychological flexibility [11]. Second, we did not precisely monitor the number of hours in which the participants were engaged in the daily practise of mindfulness during and after the program. During the telephone follow-ups, we asked the participants about their home practise but did not quantify the data so that it could be used for analysis. This information would be useful in understanding the participants' adherence to the mindfulness-based intervention protocol and in examining the relationship among adherence, the level of mastery of mindfulness, and the outcomes of the study. Finally, this study did not have a no-treatment control group, which potentially weakens its internal validity.

### **Implications for future study**

Based on the results of this feasibility study, several recommendations can be made for the main study. First, the results of the feasibility suggested that the MBCT would be a better modality of MBI for the family caregivers of PWD, compared with the MBSR. The MBCT should be adopted in a future study and its effectiveness on reducing stress in family caregivers of PWD investigated using larger samples and a control group. Second, the pattern and duration of the MBCT protocol could be further revised in the later study to further raise the completion rate to yield positive health outcomes. In addition, the majority of family caregivers commented that the interval between the last three sessions (one month) was too long. They could not immediately ask the therapist questions when they encountered problems while practising the protocol but needed to wait for the next monthly session. Consideration should be given in a future study to adding several more telephone follow-up sessions to monitor their progress and

address their concerns. Finally, the relationship between the trait mindfulness and the psychological outcomes of the family caregivers should be investigated in a future study. In this feasibility study, the family caregivers experienced a significant increase in their trait mindfulness after attending the MBSR or MBCT program. However, whether the improvement in their psychological outcomes was related to the increase in their trait mindfulness is unknown and should be addressed in a future study.

**Conclusion**

Despite the aforementioned limitations, the findings of this study suggest that both the modified MBSR and modified MBCT are feasible for use among family caregivers of PWD, and that the modified MBCT may be more suitable for caregivers of PWD than the MBSR. These protocols can be further tested and compared with treatment as usual to confirm their effectiveness in this population.

**Conflict of interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Modified MBSR Program			Modified MBCT Program		
Session	Theme	Description and activities	Session	Theme	Description and activities
S1	Awakening to automatic pilot	Mindful awareness by paying attention, on purpose, in the present moment, nonjudgementally. Activities: Raisin-eating meditation; abdominal breathing; body scan.	S1	Waking up from automatic pilot	Emphasis on our minds being taken over by the doing mode – the automatic pilot, then to the driven-doing mode – the rumination. Activities: Raisin-eating meditation; body scan.



S2	Body–mind connectedness	<p>Perception and creative responding by experiencing how to perceive pain, illness, and the stresses and pressures in life.</p> <p>Emphasizing the principle that it is not the stressors themselves but how they are to be handled and the level of commitment.</p> <p>Activities: Guided body scan; mindful yoga; guided sitting meditation with awareness of breathing.</p>	S 2	Knowing in the awareness	<p>Experiencing the doing mode so that we know about our experience through thought, and the knowing in the awareness through direct experience.</p> <p>Activities: Thoughts &amp; feelings exercises; body scan; brief mindfulness of breathing.</p>
S3	Pleasantness/Unpleasantness and body–mind in the present moment	<p>Emphasis on gentleness, nonjudgement, curiosity, respect for current physical limits and non-striving.</p> <p>Noticing the tendency to label events as pleasant or unpleasant.</p> <p>Activities: Walking meditation; mindful yoga.</p>	S 3	Living in the present	<p>Learning to disengage from unhelpful and unintended mental time travel and to gather and settle scattered minds.</p> <p>Activities: Focus on unpleasant experiences exercises; practise seeing/hearing; sitting with breath and body and responding to painful sensations; 3-minute breathing space; combining stretching and breath meditation; mindful movement.</p>

S4	Stress and body–mind reactions	<p>Emphasis on the development of concentration, openness to the full range of experiences, and a more flexible capacity for attention.</p> <p>Learning new ways to reduce the negative effects of stress reactivity and developing effective ways of responding positively to stressful situations.</p> <p>Highlighting the conditioned patterns of stress reaction – fight and flight reactivity.</p> <p>Activities: Mindful yoga; sitting meditation with a focus on breathing, body sensations, and the whole body; choiceless awareness/open presence.</p>	S 4	Recognizing aversion & allowing	<p>Emphasis on turning to face, investigate, and recognize unpleasant feelings and reactions to them so that they can be held in awareness and met with a conscious response rather than an automatic reaction.</p> <p>Allowing difficult feelings, thoughts, sensations, and inner experiences to be held in awareness and to be just as they already are.</p> <p>Activities: Defining the territory of depression exercise; sitting with breath, body, sounds, thoughts, open awareness; 3-minute breathing space (regular); mindful walking; expanded breathing space.</p>
S5	Dancing with difficulties	<p>Emphasis on the attentiveness to perception and appraisal in difficult moments.</p> <p>Exploring the effect of emotional reactivity in health and illness.</p> <p>Activities: Mindful yoga; sitting meditation with choiceless awareness; speaking and listening exercise.</p>	S 5	Thoughts are not facts	<p>Highlighting how moods and feelings shape the frame of mind, which is constantly making meaning out of what is actually there in the world.</p> <p>Activities: Moods, thoughts, and alternative viewpoints exercise relating to distress in taking care of demented people; sitting with breath, body, and difficulty; 3-minute breathing space (responsive).</p>
S6	Living moment to moment	<p>Developing a greater awareness of interpersonal communication patterns particularly under situations of acute and chronic stress in order to cultivate the capacity for rapid recovery.</p> <p>Activities: Changing seat exercise; sitting meditation with choiceless awareness; speaking and listening exercise.</p>	S 6	Kindness – the healing power	<p>Engaging in mastery or pleasurable activities as an act of kindness to oneself – changing what to do can change how to feel.</p> <p>Activities: Activity and mood exercise; identifying habitual emotional reactions to difficulties; sitting with breath, body, sounds, thoughts, choiceless awareness; 3-minute breathing space (responsive).</p>

S7	Formal and informal mindfulness in life	<p>Integrating the practise of mindfulness into daily life and identifying adaptive and self-limiting lifestyle choices.</p> <p>Maintaining momentum in the practise of mindfulness and reviewing related support to help integrate the learning over time.</p> <p>Activities: Body scan; mindful yoga; sitting meditation; life nourishment.</p>	S7	<p>Mindfulness in the caregiver's life</p> <p>Reflecting on what one has experienced, learned, and values most and how to integrate all this into the caregiver's life.</p> <p>Consolidating the aims of MBCT in terms of recognizing habitual patterns of mind and cultivating a new way of being.</p> <p>Activities: Looking forward exercise; preparing for the future exercise; body scan; 3-minute breathing space (responsive).</p>
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Variable	Total (n = 53)	Modified MBSR (n = 27)	Modified MBCT (n = 26)	Test value <sup>†</sup>	p value
n (%)	n (%)	n (%)	$\chi^2$	Gender	
		0.21	.649	Women	46 (86.8)
24 (88.9)	22 (84.6)			Men	7 (13.2)
3 (11.1)	4 (15.4)			Educational level	
		1.49	.475	Primary	7 (13.2)
5 (18.5)	2 (7.7)			Secondary	18 (34.0)
8 (29.6)	10 (38.5)			Tertiary or university	28 (52.8)

14 (51.9)	14 (53.8)			Income per month (HKD\$) <sup>‡</sup>	
		9.35	.229	Less than \$2000	16 (30.2)
7 (25.9)	9 (34.6)			\$2000 - \$9999	12 (22.6)
7 (25.9)	5 (19.2)			\$10000 - \$19999	8 (15.1)
3 (11.1)	5 (19.2)			More than \$20000	17 (32.1)
10 (37.0)	7 (26.9)			Relationship with the PWD	
		3.65	.724	Spouse	4 (7.5)
3 (11.1)	1 (3.8)			Parent	39 (73.6)
20 (74.1)	19 (73.1)			Grandparent	3 (5.7)
2 (7.4)	1 (3.8)			Parent-in-law	5 (9.4)
2 (7.4)	3 (11.5)			Other (e.g., sibling)	2 (3.8)

0 (0.0)	2 (7.7)			Number of participants attending ≥ 80% of sessions	35 (66.0)
17 (63.0)	18 (69.2)	0.23	.630		Mean (SD)
Mean (SD)	Mean (SD)	t score	p value	Age	56.00 (9.26)
56.74 (9.49)	55.20 (9.12)	0.60	.554	Mean duration of cognitive impairment (month)	71.09 (59.96)
84.63 (65.61)	55.4 (52.97)	1.71	.094	Mean duration of providing care to PWD (year)	8.71 (10.56)
9.43 (10.11)	9.57 (11.16)	0.50	.623	Attendance rate (%)	77.90 (24.99)
73.55 (28.45)	82.42 (20.32)	-1.30	.197	PSS total score	26.00 (6.24)
24.63 (5.94)	27.42 (6.34)	-0.84	.403	CESD total score	17.87 (9.50)
17.15 (10.25)	18.62 (8.79)	-0.12	.912	ZBI total score	40.02 (13.95)

38.48 (13.04)	41.62 (14.92)	-0.43	.672	FFMQ-SF total score	62.96 (10.35)
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	Modified MBSR (n = 27)						Modified MBCT (n = 26)						Time effect	Group effect	Group × time
	T0		T1		T2		T0		T1		T2				
Instrument	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	p value (Cohen's d)		
PSS	24.63	5.94	24.85	5.68	24.70	4.79	27.42	6.34	23.73	4.50	23.38	6.17	.030* (0.54)	.927 (<0.001)	.019* (0.63)
CES-D	17.15	10.25	14.81	8.95	14.59	8.55	18.62	8.79	13.73	7.61	13.08	7.36	.002* (0.77)	.852 (0.06)	.345 (0.29)
ZBI	38.48	13.04	33.07	11.93	33.37	15.31	41.62	14.92	35.73	10.67	31.92	11.62	<.001*** (1.12)	.656 (0.13)	.186 (0.35)
FFMQ-SF	63.33	10.94	64.88	8.63	65.48	8.97	60.26	9.90	65.88	8.03	65.42	9.03	.041* (0.53)	.979 (<0.001)	.646 (0.20)

Outcome variable	Time points	Mean difference	SE		p value <sup>†</sup>	95% CI
PSS total score						
Modified MBSR	T0-T1	-0.41		0.73	1.000	-2.27-1.46
	T1-T2	0.33		0.82	1.000	-1.76-2.43
		-0.07		0.93	1.000	-2.44-2.30
					Modified MBCT	T0-T1

3.19		1.14		.030*	0.26–6.1 3	T1–T2	0.73
	1.01		1.000	-1.87– 3.33	T0–T2	3.92	
1.59		.061	-0.015 –7.99	CESD total score			
Modified MBSR	T0–T1	2.33		1.83		.637	-2.34–7.00
T1–T2	0.22		0.82		1.000	-1.87–2.31	T0–T2
2.56		1.73		.452	-1.86–6. 97	Modified MBCT	T0–T1
3.73		2.13		.276	-1.74–9. 20	T1–T2	0.42
	0.99		1.000	-2.10– 2.95	T0–T2	4.15	
2.31		.253	-1.78– 10.08	ZBI total score			
Modified MBSR	T0–T1	5.41		1.73		.013*	0.99–9.82
T1–T2	-0.30		1.44		1.000	-3.98–3.38	T0–T2
5.11		2.11		.068	-0.28–1 0.51	Modified MBCT	T0–T1
4.46		2.84		.385	-2.82–1 1.74	T1–T2	5.19
	1.68		.014*	0.89–9 .49	T0–T2	9.65	
2.28		.001	3.80–1 5.51	FFMQ–SF total score			
Modified MBSR	T0–T1	-1.56		1.37		.797	-5.06–1.94
T1–T2	-0.59		1.09		1.000	-3.39–2.20	T0–T2

-2.15		1.43		.435	-5.81-1.51	Modified MBCT	T0-T1
-5.81		2.82		.149	-13.03-1.42	T1-T2	1.00
	1.08		1.000	-1.78-3.78	T0-T2	-4.81	

## DETAILS

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# The Relationship Among Rumination, Coping Strategies, and Subjective Well-being in Chinese Patients With Breast Cancer: A Cross-sectional study

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## ABSTRACT (ENGLISH)

### SummaryPurpose

To investigate the relationship between rumination, coping strategies, and subjective well-being (SWB) and test the mediating effects of coping strategies on rumination and SWB in patients with breast cancer (BC).

### Methods

This cross-sectional study assessed rumination, coping strategies, and SWB using the General Well-being Schedule, the Chinese Event-Related Rumination Inventory, and the Medical Coping Modes Questionnaire in BC patients admitted to a tertiary general hospital in China.

### Results

SWB was positively associated with the total score for rumination ( $r = .32, p < .01$ ), deliberate rumination ( $r = .75, p < .01$ ), and confrontation ( $r = .58, p < .01$ ). The relationship between rumination and SWB was mediated by confrontation (indirect effect = .74).

### Conclusion

BC diagnosis can affect patient's SWB. These findings indicate that rumination and confrontation have direct and

indirect effects on SWB. Therefore, psychological interventions focused on improving coping may increase SWB. Notwithstanding, larger longitudinal studies are needed to further examine the relationship between cognitive processes, coping strategies, and SWB.

## FULL TEXT

## DETAILS

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# The Sexual Risk Behaviors of Middle School Students According to School Nurse Placement Levels in Korea

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## ABSTRACT (ENGLISH)

### Purpose

This study aimed to provide basic data for the future development of school-based sexuality education and school nurse placement policies by examining the sexuality education experience in middle schools according to levels of school nurse placement and identifying factors influencing on adolescent sexual risk behaviors.

### Methods

This study examined data from the 2018 14th Korean Youth Risk Behavior Survey. The raw data from 30,229 middle school students enrolled in 400 schools were analyzed using descriptive statistics, Chi-square test, independent *t* test, and complex sample logistic regression analysis.

### Results

It is found that, in Korea, school nurse placement rates varied by region from 37.9% to 114.8%, resulting in different levels of sexuality and alcohol prevention education ( $p < .001$ ). Sexuality and alcohol prevention education lowered the likelihood of sexual risk behaviors by 0.54 and 0.87 times, respectively. The experience of drinking alcohol increased a student's likelihood of committing sexual risk behaviors by 4.40 and 3.57 times, respectively, whereas the experience of using a drug increased the risk by 9.42 and 5.00 times, respectively. Personal factors (e.g., gender and academic achievement) and socioenvironmental factors (e.g., school type and perceived economic status) were also found to influence on the sexual risk behaviors of adolescents, although, not to the same degree as sexuality education or health risk behaviors.

### Conclusion

To protect students' sex-related health equity, more elaborate support policies are needed to ensure adequate placement of school nurses able to provide professional sexuality and related health education.

## FULL TEXT

### DETAILS

<b>Subject:</b>	Child development; Sexual behavior; Sexual intercourse; Health education; Sexuality; School nurses; Alcohol; Middle school students; Disease prevention; Middle schools; Secondary schools; Influence; Secondary school students; Nurses; Teenagers; Disease control; Medical research
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# Effects of a Death Education Intervention for Older People with Chronic Disease and Family Caregivers: A Quasi-Experimental Study

Chen, Weilin; Ma, Hongmei; Wang, Xiao; Chen, Jiaojiao

[ProQuest document link](#)

## ABSTRACT (ENGLISH)

### SummaryPurpose

To investigate the effectiveness of a structured death education program for older adults with chronic illness and their family caregivers.

### Methods

This study adopted two-group, nonrandomized quasi-experimental design. Patient-caregiver dyads in the intervention group ( $N = 40$  dyads) engaged in the death education program at the bedside once a week for 5 weeks, and were compared with participants ( $N = 40$  dyads) in the control group who received usual health education. The program consisted of five sessions based on the Interaction Model of Client Health Behavior. Death attitude, death competence, well-being, family function, and satisfaction were measured at baseline (T0), immediately after the intervention (T1), and 1 month later (T2). Data collection was conducted from July 30, 2019, to December 30, 2019.

### Results

The intention-to-treat analysis of between groups at 1-month follow-up revealed that the intervention group had greater decreases in the fear of death ( $p=.002$ , 95% CI -2.53, -0.47;  $p<.001$ , 95% CI -3.61, -1.65) and death avoidance ( $p<.001$ , 95% CI -3.46, -1.84;  $p<.001$ , 95% CI -3.89, -2.43), had greater increases in the neutral acceptance ( $p=.032$ , 95% CI 0.05, 1.38;  $p<.001$ , 95% CI 0.99, 2.56) and death competence ( $p<.001$ , 95% CI 4.10, 8.01;  $p<.001$ , 95% CI 7.80, 12.11) in patients and caregivers, respectively. There were significant intergroup differences over time for patient well-being of ( $p<.001$ , 95% CI 3.06, 9.74) and satisfaction of ( $p<.001$ , 95% CI 2.01, 4.59). Results were consistent with the results from the sensitivity analysis.

### Conclusion

This study demonstrated the feasibility and benefits of death education in hospitals and provided an implementation plan for nursing professionals. Nurses should consider providing death education for older adults with chronic diseases and their families to promote the development of palliative care and the quality of end-of-life.

## FULL TEXT

### Introduction

Death is an inevitable process of life for each individual. Death education refers to a series of educational activities to help people develop the knowledge, attitudes, and skills related to dying, death, and bereavement [1].

Globally, deaths from chronic noncommunicable diseases accounted for 71.0% of all deaths. Of these, 58.0% occurred in older adults aged 70 years and above [2]. In recent decades, the major causes of death have been shifted from acute and infectious diseases to chronic noncommunicable diseases, which provides people the time to discuss and prepare for death [3].

However, the awareness and action of death preparation and discussion among patients with chronic illness and their families are insufficient. Although more patients may benefit from palliative care in the future [4], their cognition and understanding of palliative care remain limited. In a recent survey [5], less than half of the patients reported being aware of palliative care. Consequently, death-related communications are often avoided in families and make people feel upset or discomfort [6,7]. The role of the family is too crucial to be replaced or ignored during end-of-life care [8]. Most family members make end-of-life care decisions relying on their personal experiences and opinions instead of patients' preferences [9]. A nationwide survey in Japan indicated that one-third of bereaved families of cancer patients regretted not adequately talking with patients about their death [10]. The lack of death-related awareness and action may lead to more aggressive end-of-life care, worse patients' quality of life, and worse bereavement adjustment [11-13]. It is worth noting that the older adult often suffer from functional disorders due to chronic diseases or aging, which may affect the achievement of optimal care goals [14,15]. For example, when the cognitive function of older adults declines, medical decision-making will become very difficult for them [16]. Therefore, older adults with chronic illness and their families need to be given the necessary death education before severe dysfunction occurs.

To implement death education for patients and families in clinical practice is challenging in some societies. At present, death education undertaken within clinical settings is informal and sometimes simply occurs during end-of-life care [17]. Conversing over death or death-related issues is negative or sensitive in the Chinese and other Asian cultures [18]. Influenced by traditional culture, Chinese people generally avoid talking about death because they believe conversations about death are unlucky [19]. The phenomenon is even more pronounced in hospitals. Many families want to "protect" patients so that they refuse to tell patients the truth about diagnosis or prognosis [20]. In this case, openly talking about death is not easy for medical professionals, patients, and families. Despite people's vulnerability in discussing death, cultural beliefs such as belief in the afterlife and emphasis on funeral rites in Chinese culture may be a reasonable basis for promoting the discussion of death [21]. These cultural characteristics should be considered in death education for patients and their families.

Presently, the education objects of formal death education programs or courses are mainly students, health care staff, and the general public [22]. For older adults, previous death education studies [23,24] were carried out in the communities. These educational interventions enhanced knowledge about end-of-life care among older adults, particularly the knowledge about medical care preferences, including advance directives [24]. Meanwhile, they provided opportunities for the older adult to express end-of-life thoughts and facilitate communicating end-of-life issues with family members and health care professionals [23,24]. So far, little research has been conducted on death education for patients in the hospitals. To the best of our knowledge, only two studies have examined the effect of properly designed death education in clinical settings [25,26]. A randomized controlled trial by Kim et al [25] found that breast cancer patients who received death education showed a lower level of fear of death, a higher level of hope, and spiritual well-being compared with those who received usual care. Pui-Yu Leung et al [26] reported positive changes in a quasi-experimental study that concentrated on death preparation and life meaning for patients with chronic diseases. Nevertheless, family caregivers were failed to engage in these two studies.

In this study, we explored the potential benefits of a death education program for older adults with chronic illness and their family caregivers. Framed by the Interaction Model of Client Health Behavior (IMCHB) [27], the program was designed to be attractive and interactive through full contents and various tools.

## **Aims and hypotheses**

The aim of this study is to evaluate the effectiveness of the death education program for older people with chronic illness and their family caregivers. We considered the following two primary research questions: (1) Does the death education program have a positive effect on death attitude and death competence among older people with chronic illness and their family caregivers compared with health education as usual? (2) Does the death education program improve well-being, family function, and satisfaction among older people with chronic illness compared with health education as usual? We hypothesized that the death education program would promote positive changes in death attitude and death competence for older people with chronic illness and their family caregivers. Moreover, we hypothesized that the program would lead to an improvement in patient well-being, family function, and patient satisfaction.

## **Methods Study design**

This study was a quasi-experimental study with single blind (evaluator and statistician).

## **Setting and sample**

Older people and their family caregivers were recruited from four wards of the department of geriatrics at a level A tertiary general hospital in Wuhan, China. Convenience sampling was used to obtain samples. The sample size was calculated using the G\*Power 3.1.9.2 program, University of Kiel, Germany. The required sample for each group was 33 (the total sample was 66) for a repeated measures analysis of variance, which could achieve 80.0% power and an effect size of 0.25 at a 5.0% level of significance. We considered the 20.0% lost to follow-up rate, 80 dyads of participants were recruited, 40 dyads in the intervention group and 40 dyads in the control group. Each dyad includes patient and one of their family caregivers.

Inclusion criteria for patients were as follows: (1) age  $\geq$  70 years; (2) suffering from one or more chronic diseases, meeting the International Classification of Diseases, Eleventh Revision criteria of corresponding chronic diseases; (3) a life expectancy of more than 6 months estimated by a primary doctor; (4) having at least one family member as the primary caregiver; (5) permanent resident in the urban area of Wuhan; and (6) consent to participate in the study.

Exclusion criteria for patients were as follows: (1) unconsciousness; (2) in the aggravating or terminal stage of the disease; (3) have significant visual, auditory, cognitive impairment, or cannot communicate well; (4) have a mental disorder or cannot cooperate with the researcher; and (5) participating in or having participated in a similar study in the past 6 months.

Inclusion criteria for family caregivers were as follows: (1) age  $\geq$  18 years; (2) one of the primary family caregivers of the patient (living with the patient or visiting the patient at least twice a week in the past month); and (3) consent to participate in the study.

Exclusion criteria for family caregivers were as follows: (1) have significant visual, auditory, cognitive impairment, or cannot communicate well; (2) have a mental disorder and cannot cooperate with the researcher; (3) hospitalized patients during the study period; and (4) participating in or have participated in a similar study in the past 6 months.

## **Ethical consideration**

The study protocol was reviewed and approved by Chinese Ethics Committee of Registering Clinical Trials (Approval no. ChiECRCT20190101). Before the implementation of the study, written informed consents were obtained from all the participants.

## **Measurements Sociodemographic and medical information**

Participants sociodemographic items (e.g., gender, age, and religion) were included in the baseline questionnaires and completed through face-to-face interviews. Patients' medical data were collected from their electronic medical records.

## **Primary outcomes Death attitude**

Death attitude was assessed by the Chinese version of Death Attitude Profile-Revised (DAP-R). DAP-R was developed by Wong, Reker, and Gesser [<sup>28</sup>]. It comprises of several statements related to different attitudes toward death. For example, *Death is neither good nor bad*. The scale has five dimensions: fear of death, death

avoidance, neutral acceptance, approach acceptance, and escape acceptance. There are 25 items in the Chinese version, and five items are generated for each dimension. Each item is rated on a five-point Likert scale from 1 (=strongly disagree) to 5 (=strongly agree). The death attitude of the subjects was judged by the score of each dimension. The higher the score, the more positive or the more negative death attitude. The Cronbach's  $\alpha$  and the split-half coefficient for the whole scale were both .84 [29]. In the present study, Cronbach's  $\alpha$  was .81.

### **Death competence**

Death competence was measured using Bugen's Coping with Death Scale (CDS). CDS was a useful tool to evaluate the effect of death education [28]. The scale contains 30 items, for example, *I can express my fears about dying*. It is measured using a seven-point Likert scale, ranging from "strongly agree" (7 points) to "strongly disagree" (1 point). The total score of the scale is 30–210, with higher scores indicating higher death competence. The CDS has been validated in Chinese, and Cronbach's  $\alpha$  was .92 [30]. It had a Cronbach's  $\alpha$  of .88 in the current sample.

### **Secondary outcomes Well-being**

The Chinese language version of the World Health Organization (WHO) (Five) Well-being Index (WHO-5) was used to assess patient well-being. The WHO-5 is one of the most widely used questionnaires assessing subjective psychological well-being [31]. It consists of the following five questions: (1) *I have felt cheerful and in good spirits*, (2) *I have felt calm and relaxed*, (3) *I have felt active and vigorous*, (4) *I woke up feeling fresh and rested*, and (5) *My daily life has been filled with things that interest me*. Patients are asked to report how they have been feeling over the past 2 weeks on a six-point scale ranging from "all of the time" (5 points) to "at no time" (0). The raw score ranges from 0 to 25, with higher scores mean better well-being. The percentage score (the raw score is multiplied by 4) is used to monitor possible changes in well-being. The internal consistency of the scale was Cronbach's  $\alpha$  = .89 in Chinese patients with chronic illness [32] and Cronbach's  $\alpha$  = .91 in this sample.

### **Family function**

The family function was evaluated using the Family APGAR. Family APGAR is a questionnaire to measure patients' satisfaction with family function [33]. The following five components of family function are considered: adaptation, partnership, growth, affection, and resolve. There are five questions in the questionnaire, for example, *I am satisfied with the help that I receive from my family when something is troubling me*. Each question is scored by a three-point response option from "almost always" (2 points) to "hardly ever" (0). The total score ranges from 0 to 10 with the following cut-off points: 0–3 suggests a severely dysfunctional family, 4–6 suggests a moderately dysfunctional family, and 7–10 suggests a highly functional family. The Family APGAR has been validated with good reliability and validity in Chinese families, and Cronbach's  $\alpha$  = .73 [34]. The Cronbach's  $\alpha$  was .75 in the current sample.

### **Satisfaction**

Patient satisfaction was assessed by the Client Satisfaction Tool (CST) developed by Bear and Bowers [35]. The CST is based on the IMCHB. There are six domains in this tool, which are as follows: affective support, health information, decisional control, technical competencies, accessibility, and overall satisfaction. The CST includes 12 items, for example, *I got my questions answered in an individual way*. It is measured using the five-point Likert scale, ranging from 1 (=strongly disagree) to 5 (=strongly agree). The total range of responses possible is 12–60, with higher scores indicating higher satisfaction. The Chinese version of the CST [36] is a 12-item, self-report inventory that has shown good reliability and validity (Cronbach's  $\alpha$  = .94). It had a Cronbach's  $\alpha$  of .89 for the current sample.

### **Procedure**

The trial was completed between January 2019 and December 2019. Data collection was conducted from July 30, 2019, to December 30, 2019. After screening the participants based on inclusion and exclusion criteria, eligible patient–caregiver dyads were assigned to the intervention group or control group according to the ward where the patients lived. The patients in the first and second wards of the department of geriatrics were the intervention group, and the patients in the third and fourth wards were the control group. Randomization could not be performed because of potential data contamination. Both groups received health education as usual. The intervention group also received a death education provided by researchers. At baseline (T0), participants' sociodemographic and patients' medical records were collected. Death attitude and death competence of patients and caregivers, patient



well-being, family function, and patient satisfaction were assessed at baseline (T0), immediately after the intervention (T1), and 1-month follow-up (T2). Most patients spent more than a month in the hospital. If the patients were discharged during the follow-up investigation, T2 would be completed by telephone. Data collector was a research assistant who was blinded to the participants' study condition. When data collection has been completed, all participants received a small gift.

### **Intervention group**

The death education intervention drew on the IMCHB developed by Cox [27]. The model is composed of the following three conceptual categories: client singularity, client–professional interaction, and health outcome. Client singularity includes background variables composed of demographic characteristics, social influence, previous health care experience and environmental resources, as well as dynamic variables composed of intrinsic motivation, cognitive appraisal, and affective response. There are four components to client–professional interaction, which are as follows: affective support, health information, decisional control, and technical competencies. The elements of health outcome are utilization of health care services, clinical health status indicators, severity of health care problems, adherence to the recommended care regimen, and satisfaction with care. Client–professional interaction has a considerable impact on client health care behavior [37]. In the present study, the information related to participants' singularity were collected during baseline assessment. Death attitude, death competence, well-being, family function (health status), and satisfaction (satisfaction with care) were included as health outcome variables. The death education program was developed based on the four elements of client–professional interaction to provide comprehensive education and increase patient engagement. In this program, affective support meant supporting the feelings and emotions of patients and family caregivers, such as assisting the patient in expressing gratitude and regret. Health information referred to knowledge related to dying, death, and bereavement, such as the nature of death and the manifestation of near-death. Decisional control was regarded as helping patients to understand their rights and options before death, encouraging patients to participate in end-of-life decision-making and improving patients' participation and autonomy. Technical competence referred to teaching patients and family caregivers the skills to deal with death-related issues, such as caring for dying patients and coping with grief. See <sup>Table 1</sup> for the main contents of the death education program.

From the second to the fifth session, researchers used tools to activate death discussion and increase interaction. For instance, the research team created a life map to depict the different stages of life. Patient–caregiver dyads were required to work together and complete the patient's life map. Besides, the researchers made a conversation game on a game production website and featured an old couple discussing the death of a friend. The text was inserted for interaction, such as “if you were asked to write a sentence as an epitaph, how would you write it?” Educational booklet, letter paper, and thanks card were also used.

The death education program was first drafted by the research team with reference to *Death Education* [38] and *End-of-Life Care A Practical Guide* [39]. After that, it was revised by referring to the opinions of the expert group. The expert group consisted of two professors of geriatric nursing, one professor of gerontology, one head nurse of geriatrics, and one professor of psychology. Before the formal study began, we applied the plan to three groups of older people with chronic diseases and their families, consulted them for revisions and determined the final program. Patient–caregiver dyads in the intervention group would engage in the death education program at the bedside at an agreed time. The program was once a week, 1.5–2 h each time, for 5 weeks. Before the first session, researchers negotiated a schedule with the patients and family caregivers to ensure that the program could be completed face-to-face in the ward. One day before the start of each session, participants were notified by phone.

The death education providers comprised three nurses. One nurse with more than 20 years of geriatric nursing experience was one of the researchers in the study. Two nurses with 2 years of geriatric nursing experience worked in the geriatrics department. All of them had competent communication skills and had attended the death education training course in the past year. The research team developed an instruction manual for the implementation of the death education program and conducted unified training for them. Each session in the program was carried out by them as an education team.

## Control group

The control group received health education provided by their nurses as usual. The health education was conducted during the period of hospitalization, both patients and family caregivers were asked to participate. It was held in five sessions of at least 30 min each. The contents included an explanation of disease-related knowledge, as well as education on medication, health behavior, and psychology. After the completion of data collection, the control group received the death education program to extend them the same potential benefits of the program.

## Data analysis

Continuous data were summarized by the mean and standard deviation (SD), whereas categorical data were described by number (*n*) and percentage (%). The characteristics at baseline were compared using either a *t* test or Chi-square test. Death attitude, death competence, well-being, family function, and satisfaction in the intervention and control groups were analyzed using repeated measures analysis of variance and Bonferroni *post hoc* analysis. The intention-to-treat (ITT) analysis was performed to deal with the loss of follow-up of the participants. The missing values were replaced by carrying forward the last observation. A sensitivity analysis including only complete cases was also performed to test how robust these results were. A *p* > .05. All statistical analyses were performed using SPSS AMOS 20.0 (IBM Corp., Armonk, NY, USA).

## Results Demographic characteristics

The total number of eligible participants was 94 dyads, 80 dyads consented to participate. However, four dyads in two groups withdrew or lost to follow-up. Thus, 38 dyads in each group completed the study, and data are presented for 80 dyads following the ITT analysis principle. <sup>Figure 1</sup> shows a flow chart of participant recruitment in the study. <sup>Table 2</sup> provides the demographic information and baseline variables of all participants. In the intervention group, the mean (SD) age of the patients was 78.18 (5.97) years with 55.0% being males, married (70.0%) and religious (22.5%). 40% of patients had at least college education, and most of the patients (67.5%) had monthly income more than 3,000 yuan. 62.5% of them had hypertension, half of them had diabetes, 40.0% of them had cerebrovascular disease, 20.0% of them had Ischemic heart disease (IHD), 15.0% of them had Chronic obstructive pulmonary disease (COPD), and 62.5% of them had cancer. In the control group, the mean (SD) age of the patients was 79.15 (6.24) years with 52.5% being males, married (60.0%) and religious (20.0%). 57.5% of patients had at least college education, and 52.5% of the patients had monthly income more than 3,000 yuan. 67.5% of them had hypertension, 37.5% of them had diabetes, 27.5% of them had cerebrovascular disease, 20.0% of them had Ischemic heart disease (IHD), 20.0% of them had Chronic obstructive pulmonary disease (COPD), and 42.5% of them had cancer. Most of the caregivers in the intervention group had at least college education (70.0%) and had monthly income more than 3,000 yuan (62.5%). 42.5% of them were spouses of patients, and 42.5% were children of patients. More than half of the caregivers in the control group had at least college education (52.5%) and had monthly income more than 3,000 yuan (52.5%). 30.0% of them were spouses of patients, and 52.5% were children of patients. The two groups were similar for demographic variables (all *p* > .05). There were no significant differences between groups at baseline (all *p* > .05) indicating all outcome measures comparable.

## Primary outcomes

<sup>Table 3</sup> shows data for scores of each dimension of the DAP-R and CDS total scores at baseline (T0), immediately after the intervention (T1), and 1 month later (T2). For patients, the intergroup analysis at the final follow-up assessment showed that the intervention group had greater decreases in the fear of death (*p* = .002, 95% CI -2.53, -0.47) and death avoidance (*p* = .032, 95% CI 0.05, 1.38) and death competence (*p* = .002) and 1.15 (*p* = .001) at T1 and T2, respectively. Patient neutral acceptance in the intervention group increased significantly by 1.20 (*p* = .003) and 2.20 (*p* = .001) at T1 and T2, respectively.

For caregivers, the ITT analysis of between groups at T1 and T2 revealed that the intervention group had greater decreases in the fear of death (both *p* = .002, *p* = .008, *p* = .001 for neutral acceptance at T1). In contrast, the same parameters did not show meaningful positive changes in the control group.

## Secondary outcomes

<sup>Table 4</sup> provides the means changes for patient well-being, family function, and patient satisfaction. There were

significant intergroup differences over time for patient's well-being of 6.40 (3.06, 9.74) and satisfaction of 3.30 (2.01, 4.59), with both  $p = .023$  and 9.68 ( $p = .001$ ), and in satisfaction by 4.73 ( $p = .002$ ). However, no positive changes were detected for family function in the control group.

## Discussion

The results of this study indicated that the death education program promoted the transition of death attitude from death avoidance to neutral acceptance, and improved death competence among older people with chronic illness and their family caregivers, which confirmed the first hypothesis. The second hypothesis was partially verified. The death education program significantly improved patient's well-being and satisfaction. Although family function in the intervention group increased after the intervention, the differences were not statistically significant compared with the control group.

Consistent with previous reports [<sup>25, 26</sup>], our results also demonstrated that death education improved death attitude, especially reducing fear of death and death avoidance. In the present study, the reduction of fear of death may be related to the affective support and health information provided by the death education program. Emotional attention and support to the older adult are essential in the patient engagement interventions [<sup>41</sup>]. The program encouraged participants to express emotions related to death, and fear may be alleviated to some extent during the process of expression and outpouring. Furthermore, it offered participants with knowledge and information about dying, death, and bereavement, such as management of pain and other symptoms, which may remove some worries and uncertainties [<sup>42</sup>]. Through the guidance of the education team, participants can face up to the topic of death and take part in the interactions. Then, the level of death avoidance became lower. Kim et al [<sup>25</sup>] also suggested that death education provides an opportunity for families to discuss death openly. Although most of the Chinese people tend to avoid talking about death in their lives, they have a cultural belief in the afterlife and an expectation of a good death, which might be a sound basis for a discussion about death [<sup>19</sup>].

To date, limited research has examined death competence in patients and caregivers. Thus, few comparisons of this trial to prior study can be made. Death competence is defined as a range of human skills, belief, and attitude in coping with death-related issues [<sup>28</sup>]. The practical skills involved in the death education program may improve the death competence, such as caring for dying patients, alleviating sadness, and maintaining family function. The present study found that the participants showed great interest in the practical part of the content, which was congruent with the previous study [<sup>22</sup>]. Knowledge and skills that were closely related to the actual lives of patients and their families were in high demand. Therefore, death education should not only talk about life and death but also teach people practical methods to deal with death-related events.

Our hypothesis that patients would report improved family function was not supported. This is perhaps not unexpected, given the intervention was too short to improve family function significantly. In contrast, baseline scores of family function were high in the current sample, with mean scores around 7 of 10, potentially leaving little room for change in response to the intervention. However, the program significantly improved patient's well-being and satisfaction. In the current hospital settings, health care professionals rarely discuss death-related issues with older adults with chronic diseases directly. During the intervention, we found that most older adults were interested in discussing death-related issues and were willing to express their opinions.

Nurse-patient-family interaction was vital in the death education program. First, nurses developed a trusting relationship with patients and their family caregivers to communicate sensitive topics. Nurses are usually professional caregivers who have the most contact with patients and their families in hospital; therefore, they are relatively easy to establish a good relationship with patients and their families. Only on the premise of mutual trust, patients and their families are willing to discuss the topics related to the death they usually try to avoid and express their inner thoughts [<sup>43, 44</sup>]. Second, the interaction between patients and their family caregivers was not negligible. In this program, each session is jointly completed by the patient and family caregivers, which may enhance mutual understanding. Such finding is in line with the literature, in that family involvement in life review can promote an intimate relationship [<sup>45</sup>].

The death education program changed the traditional didactic death education and encouraged patients and family

caregivers to participate in death education activities actively. We adopted interesting and appropriate interactive tools to achieve better interaction. First, using tools could motivate individuals to engage in conversations about end-of-life issues in a relatively pleasant way. Certain tools have the potential to facilitate smoother discussion in this matter [46-48]. Second, some tools (e.g., thanks card) helped patients express emotions indirectly, which conformed to the implicit characteristics of Chinese [23]. Finally, the design and application of these tools thoroughly considered the applicability of objects and clinical settings. For example, words and pictures that may cause discomfort were avoided in the game and booklet. The educator should be sensitive in using the words “dying,” “death,” and should accept the participants avoiding these words in the conversation [8].

### **Limitations**

This study has several limitations that warrant attention. First, the sample contained a smaller representation of individuals with lower income. Future efforts would do well to intentionally expand participation from more diverse segments of society to ensure those with lower income and fewer resources also have this opportunity. Second, the inclusion of older adults with a variety of chronic diseases may confound the findings of the study. It is recommended that the diagnosis-specific sample can be used in future studies. Third, all the outcomes were assessed subjectively by the participants without the use of objective measurement tools. Further research on objective assessment tools for the effects of death education is needed. Alternatively, combining objective data, such as the utilization rate of hospice services, to analyze the effect of death education from an objective perspective. Finally, no nursing fee was set in this study, and the nursing fee of death education needs to be further clarified.

### **Implications for nursing practice**

The structured death education program is feasible and beneficial in older adults with chronic illness and their family caregivers. Nurses should consider facing death-related concerns of patients and their families in clinical practice and implement interactive death education based on establishing mutual trust. The use of interactive tools in death education contributes to stimulate the participation of patients and their families and to initiate death discussion. For patients and family caregivers who have negative views of death, nurses' aged care experience, communication skills, as well as making full use of interactive tools are important. For instance, in the session of life review, the life map is used to adequately stimulate patients' enthusiasm for participation and guide patients to think and tell about their life experience. Also, nurses should be sensitive to the use of words such as death and terminal illness, and should accept patients to avoid using these words. This approach does not prevent us from conveying death education information to older people and their families.

### **Conclusion**

In conclusion, this study presents a systematic and structured death education program for older people and their family caregivers. The program included affective support, health information, decisional control, and technical competence. Some tools were used to promote engagement and interaction. We found that the death education program improved death attitude, death competence, and patient satisfaction. The nurse should consider providing death education to facilitate death discussion and preparation in patients and families.

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### **Conflict of interest**

None.

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Session	Theme	Contents	IMCHB subdomain	Tools	Methods	Duration (min)
1	Pretest	Demographic characteristics Death attitude, death competence, well-being, family function, satisfaction	Client singularity	Questionnaires and scales	-	45
Introduction	Self-introduction Program introduction Communicate with patient and family caregiver, and build a good relationship	-	Group discussion and sharing	45	2	Life review
Fill in the life map with important moments in lives Review different life stages, share happiness and regret, understand the meaning of life	Affective support	Life map	Group discussion and sharing	90	3	Death discussion
The nature of death and manifestations of dying	Health information	Conversation game	Lecture	20	Family function maintenance	Technical competencies
	Demonstration and practice	50	Skills coping with sadness and loss			

	Write an epitaph	Decisional control			25	Discuss funeral affairs
Affective support		Group discussion and sharing	25	4	Dying well	The meaning of good death Death preparation Palliative care
Health information	Educational booklet	Lecture	45	Caring for dying people	Technical competencies	

Demonstration and practice	45	5	Embrace life	Review previous sessions Express thoughts about life and death Patient and family caregiver write thanks cards to each other Patient and family caregiver take photos together	Affective support	Letter paper and thanks card
Group discussion and sharing	45	Patient writes a planning letter for future	Decisional control		Demonstration and practice	30

Characteristics/variables	Patients (n = 80)		t test/ $\chi^2$ p	Caregivers (n = 80)		t test/ $\chi^2$ p
IG	CG	IG	CG	Gender, n (%)		
Men	22 (55.0)	21 (52.5)	.823	17 (42.5)	24 (60.0)	.117
Women	18 (45.0)	19 (47.5)		23 (57.5)	16 (40.0)	
Age (yrs)						
Mean (SD)	78.18 (5.97)	79.15 (6.24)	.477	51.75 (19.00)	51.30 (16.83)	.911

Range	70–88	71–94		19–87	21–82	
Religion, n (%)						
Yes	9 (22.5)	8 (20.0)	.785	5 (12.5)	5 (12.5)	<.99 9
No	31 (77.5)	32 (80.0)		35 (87.5)	35 (87.5)	
Education, n (%)						
≤High school	24 (60.0)	17 (42.5)	.117	12 (30.0)	19 (47.5)	.108
≥College	16 (40.0)	23 (57.5)		28 (70.0)	21 (52.5)	
Monthly income (yuan), n (%)						
<1500	5 (12.5)	6 (15.0)	.362	4 (10.0)	4 (10.0)	.618
1500–3000	8 (20.0)	13 (32.5)		11 (27.5)	15 (37.5)	
>3000	27 (67.5)	21 (52.5)		25 (62.5)	21 (52.5)	
Marital status, n (%)						
Married	28 (70.0)	24 (60.0)	.348	28 (70.0)	32 (80.0)	.302
Single/divorced/widowed	12 (30.0)	16 (40.0)		12 (30.0)	8 (20.0)	
Living status, n (%)						
Alone	4 (10.0)	11 (27.5)	.101	–	–	–
Spouse	27 (67.5)	24 (60.0)		–	–	
Children	9 (22.5)	5 (12.5)		–	–	
Chronic diseases, n (%)						
Hypertension	25 (62.5)	27 (67.5)	.639	–	–	–
Diabetes	20 (50.0)	15 (37.5)	.260	–	–	–
Cerebrovascular disease	16 (40.0)	11 (27.5)	.237	–	–	–



IHD	8 (20.0)	8 (20.0)	<.999	–	–	–
COPD	6 (15.0)	8 (20.0)	.556	–	–	–
Cancer	25 (62.5)	17 (42.5)	.073	–	–	–
Other	12 (30.0)	7 (17.5)	.189	–	–	–
Year since diagnosis						
Mean (SD)	4.88 (2.55)	5.73 (2.81)	.161	–	–	–
Range	1–11	1–10		–	–	
Caregiver relationship to the patient, n (%)						
Spouse	–	–	–	17 (42.5)	12 (30.0)	.507
Children	–	–		17 (42.5)	21 (52.5)	
Other family member	–	–		6 (15.0)	7 (17.5)	
Fear of death	15.55 (5.33)	15.40 (4.81)	.895	17.03 (4.77)	16.15 (4.35)	.394
Death avoidance	18.68 (2.83)	18.45 (3.06)	.734	19.93 (2.44)	18.75 (2.87)	.052
Neutral acceptance	17.43 (3.55)	18.00 (3.47)	.466	16.18 (3.56)	17.48 (3.61)	.109
Approach acceptance	10.03 (3.89)	10.75 (3.79)	.401	9.60 (3.05)	10.18 (3.24)	.417
Escape acceptance	15.13 (3.83)	14.63 (4.04)	.572	15.40 (3.66)	14.80 (3.67)	.465
Death competence	110.15 (11.73)	110.60 (11.86)	.865	104.05 (9.81)	105.63(10.56)	.492
Well-being	56.80 (13.41)	59.00 (13.78)	.471	–	–	–
Family function	6.70 (1.59)	6.98 (1.70)	.457	–	–	–

Satisfaction	43.63 (6.55)	45.85 (5.70)	.109	-	-	-
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Outcome	IG			CG			Mean difference (95%CI) between groups <sup>b</sup> × time						
Mean change (95%CI) from baseline				Mean change (95%CI) from baseline			T1	p	T2	p	T1	p	
T2	p	T1	p	T2	p	Partial η <sup>2</sup>	Patients (n = 80)						
Fear of death	-1.83 (-2.76, -0.89) <sup>a</sup>	<.001	-4.33 (-5.77, -2.88) <sup>a</sup>	<.001	0.55 (-0.77, 1.87)	.914	1.33 (-0.20, 2.85)	.06	-0.64 (-1.43, 0.15)	.57	-1.50 (-2.53, -0.47) <sup>b</sup>	.002	.32
Death avoidance	-2.78 (-4.02, -1.53) <sup>a</sup>	<.001	-6.45 (-7.95, -4.95) <sup>a</sup>	<.001	0.95 (0.31, 1.59) <sup>a</sup>	.022	1.15 (0.43, 1.87) <sup>a</sup>	.01	-0.91 (-1.60, -0.23) <sup>b</sup>	.05	-2.65 (-3.46, -1.84) <sup>b</sup>	<.001	.52
Neutral acceptance	1.20 (0.35, 2.06) <sup>a</sup>	.003	2.20 (1.09, 3.31) <sup>a</sup>	<.001	-0.18 (-0.55, 0.20)	.765	-0.78 (-1.57, 0.02)	.08	0.51 (0.06, 0.97) <sup>b</sup>	.03	0.71 (0.05, 1.38) <sup>b</sup>	.002	.21
Approach acceptance	0.33 (-0.12, 0.77)	.221	0.73 (-0.03, 1.48)	.063	0.18 (-0.45, 0.80)	.100	0.08 (-0.62, 0.77)	.00	0.25 (-0.13, 0.63)	.321	0.40 (-0.10, 0.90)	.165	.03

Escape acceptance	1.30 (-0.32, 2.92)	.156	1.20 (-0.49, 2.89)	.252	0.03 (-0.67, 0.72)	.150	0.48 (-0.43, 1.38)	.590	0.66 (-0.20, 1.53)	.193	0.84 (-0.10, 1.78)	.096	.02
Death competence	8.13 (5.47, 10.78) <sup>a</sup>	<.001	11.10 (7.80, 14.40) <sup>a</sup>	<.001	0.00 (-1.53, 1.53)	.150	1.00 (-1.25, 3.25)	.82	4.06 (2.56, 5.56) <sup>b</sup>	<.001	6.05 (4.10, 8.01) <sup>b</sup>	<.001	.23
Caregivers (n = 80)													
Fear of death	-2.98 (-4.08, -1.87) <sup>a</sup>	<.001	-5.90 (-7.37, -4.43) <sup>a</sup>	<.001	0.08 (-1.22, 1.37)	.150	0.65 (-0.71, 2.01)	.714	-1.45 (-2.28, -0.62) <sup>b</sup>	<.001	-2.63 (-3.61, -1.65) <sup>b</sup>	<.001	.37
Death avoidance	-3.05 (-4.26, -1.84) <sup>a</sup>	<.001	-7.10 (-8.29, -5.91) <sup>a</sup>	<.001	0.90 (-0.00, 1.80)	.051	0.78 (-0.12, 1.67)	.111	-1.08 (-1.81, -0.34) <sup>b</sup>	.002	-3.16 (-3.89, -2.43) <sup>b</sup>	<.001	.54
Neutral acceptance	1.58 (0.60, 2.55) <sup>a</sup>	.001	3.73 (2.43, 5.02) <sup>a</sup>	<.001	-0.10 (-0.78, 0.58)	.150	-0.18 (-1.12, 0.77)	.100	0.74 (0.16, 1.32) <sup>b</sup>	.008	1.78 (0.99, 2.56) <sup>b</sup>	<.001	.25
Approach acceptance	0.55 (-0.06, 1.16)	.087	0.68 (0.03, 1.32) <sup>a</sup>	.039	0.13 (-0.38, 0.63)	.150	-0.30 (-1.03, 0.43)	.939	0.34 (-0.05, 0.72)	.105	0.19 (-0.29, 0.67)	1.00	.05
Escape acceptance	-0.13 (-0.88, 0.63)	.100	-0.35 (-1.63, 0.93)	.100	-0.03 (-0.62, 0.57)	.150	-0.15 (-0.85, 0.55)	.100	-0.08 (-0.54, 0.39)	.100	-0.25 (-0.97, 0.47)	1.00	.00

Death competence	9.88 (7.51, 12.24) <sup>a</sup>	< .0001	18.30 (14.78, 21.82) <sup>a</sup>	< .0001	0.73 (-0.88, 2.33)	.792	1.80 (-0.49, 4.09)	.170	5.30 (3.91, 6.70) <sup>b</sup>	< .0001	10.05 (7.80, 12.11) <sup>b</sup>	<.001	.45
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Outcome	IG			CG			Mean difference (95% CI) between groups <sup>b</sup> × time						
	Mean change (95% CI) from baseline			Mean change (95% CI) from baseline			T1	p	T2	p	T1	p	
T2	p	T1	p	T2	p	Partia l n	Patients (n = 80)						
Well-being	8.78 (0.98, 16.57) <sup>a</sup>	.023	9.68 (3.67, 15.68) <sup>a</sup>	.001	3.73 (0.62, 6.83) <sup>a</sup>	.014	3.13 (-0.15, 6.40)	.065	6.25 (2.15, 10.35) <sup>b</sup>	.001	6.40 (3.06, 9.74) <sup>b</sup>	<.001	.04
Family function	0.25 (0.09, 0.59)	.230	0.68 (0.22, 1.13) <sup>a</sup>	.002	-0.13 (-0.31, 0.06)	.288	-0.23 (-0.44, -0.02) <sup>a</sup>	.032	0.06 (-0.13, 0.25)	.100	0.23 (-0.02, 0.47)	.079	.15
Satisfaction	4.73 (2.32, 7.13) <sup>a</sup>	<.001	6.53 (4.07, 8.98) <sup>a</sup>	<.001	0.08 (-0.73, 0.88)	.100	0.08 (-0.89, 1.04)	.100	2.40 (1.16, 3.64) <sup>b</sup>	<.001	3.30 (2.01, 4.59) <sup>b</sup>	<.001	.25

## DETAILS

### Subject:

Culture; Health education; Health care; Mental disorders; Sociodemographics; Chronic illnesses; Palliative care; Likert scale; Older people; Cognitive ability; Caregivers; Attitudes; Professional ethics; Adults; Patient satisfaction; Medical research

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# Understanding Taiwanese Women's Decisional Experiences Regarding Prenatal Screening Procedures And Diagnostics: A Phenomenological Study

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[ProQuest document link](#)

## ABSTRACT (ENGLISH)

Abstract

### Purpose

This study sought to understand Taiwanese women's decisional experiences regarding prenatal screening procedures and diagnostics.

### Methods

A hermeneutic phenomenological design guided semistructured interviews with 33 women who were 36 weeks pregnant. Data were collected between February and October 2016. Verbatim transcripts were analyzed following hermeneutic circle to cocreate an understanding of Taiwanese women's decision-making in prenatal screening and diagnostics.

### Results

Women's existential experiences were derived from their decision-making process on prenatal screening procedures and diagnostics for chromosomal aneuploidy. These decisional experiences were captured by four theme clusters and eight themes, which were inductively derived from 16 meaning units: (1) accessing health information; (2) considering what was best for my baby; (3) considering family finance; and (4) feeling anxiety posttest.

### Conclusion

Participants made informed choices on several prenatal screening procedures, ostensibly, based on their personal values and considerations. During the decision-making process, often-cited benefits of genetic screenings were emphasized, but test limitations were often unheeded. A fundamental need for supportive information in decision making was further identified with recommended strategies. Hence, a revision of traditional genetic counseling approaches is recommended. As genomics technologies are increasingly available during antenatal services, women should be sufficiently educated about them to support decision making.

## FULL TEXT

## DETAILS

**Subject:** Research methodology; Womens health; Phenomenology; Childbirth &labor; Genetics; Decision making; Hospitals; Pregnancy; Data collection; Data analysis; Industrialized nations; Dialectics; Amniocentesis; Interviews; Ultrasonic imaging; Postpartum period; Prenatal care; Medical research; Clinical decision making; Qualitative research; Medical diagnosis

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# The Effectiveness of Dignity Therapy as Applied to End-of-Life Patients with Cancer in Taiwan: A Quasi-Experimental Study

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[ProQuest document link](#)

## ABSTRACT (ENGLISH)

### Purpose

The aim of the study was to determine the effectiveness of dignity therapy for end-of-life patients with cancer.

### Methods

This study used a quasi-experimental study design with a nonrandomized controlled trial. Dignity therapy was used as an intervention in the experimental group, and general visit was used in the control group. Thirty end-of-life patients with cancer were recruited, with 16 in the experimental group and 14 in the control group. Outcome variables were the participants' dignity, demoralization, and depression. Measurements were taken at the following time points: pre-test (before intervention), post-test 1 (the 7th day), and post-test 2 (the 14th day). The effectiveness of the intervention in the two groups was analyzed using the generalized estimating equation, with the  $p$  value set to be less than .05.

### Results

After dignity therapy, the end-of-life patients with cancer reflected increased dignity significantly [ $\beta = -37.08$ , standard error (SE) = 7.43, Wald  $\chi^2 = 24.94$ ,  $p < .001$ ], whereas demoralization ( $\beta = -39.55$ , SE = 6.42, Wald  $\chi^2 = 37.95$ ,  $p < .001$ ) and depression ( $\beta = -12.01$ , SE = 2.17, Wald  $\chi^2 = 30.71$ ,  $p < .001$ ) were both reduced significantly.

### Conclusion

Clinical nurses could be adopting dignity therapy to relieve psychological distress and improve spiritual need in end-of-life patients with cancer. Future studies might be expanded to looking at patients vis-à-vis end-of-life patients without cancer to improve their psychological distress. These results provide reference data for the care of end-of-life patients with cancer for nursing professionals.

## FULL TEXT

## DETAILS

### Subject:

Cancer; Patients; Palliative care; Therapists; Therapy; Nursing; Questionnaires; Medical research; Mental depression; Anxiety



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## Bibliography

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Ruan, J., Wu, L., & Zhou, Y. (2020). Experiences of body image changes in chinese patients living with inflammatory bowel disease: A descriptive qualitative study. *Asian Nursing Research*, 14(4), 196-205. doi:<https://doi.org/10.1016/j.anr.2020.07.006>

**Purpose**Body image changes are common among patients living with inflammatory bowel disease (IBD) because of the illness and related treatments. Currently, there is little known about how those patients experience and perceive their altered body image in the literature. The aim of this study was to explore the experiences of body image changes in patients with IBD in China and to describe how those changes influence patients' perception of body and self.  
**Methods**This study used a descriptive qualitative approach. A total of 16 participants from three tertiary hospitals in southeast China were recruited through purposive sampling combined with maximum variation strategy. Data were collected through semistructured interviews and analyzed using conventional content analysis method.  
**Results**The following six themes were extracted: (1) "being a constrained person," (2) "being a flawed person," (3) "being a disliked person," (4) "being an alienated person," (5) "being a reconciled person," and (6) "being a blessed person."  
**Conclusion**With the diagnosis of IBD and its side effects of treatments, patients' life changed significantly and they were struggling to reinterpret their body and self. As a result, negative self-evaluations and/or positive self-evaluations towards themselves generated. Further studies are required to explore the underlying mechanism and related influencing factors about how those different images were produced.

Yang, S., Li, L., Wang, L., Zeng, J., & Li, Y. (2020). Risk factors for work-related musculoskeletal disorders among intensive care unit nurses in china: A structural equation model approach. *Asian Nursing Research*, 14(4), 241-248. doi:<https://doi.org/10.1016/j.anr.2020.08.004>

**SummaryPurpose**This study explored the direct and indirect effects of risk factors of work-related musculoskeletal disorders (WRMDs) in nurses working in intensive care units (ICUs).  
**Methods**A cross-sectional study design was used. ICU nurses from 28 tertiary hospitals in the Hunan and Guangdong provinces participated in a survey conducted via a self-reported online questionnaire. A structural equation model was used to fit the data and to evaluate associations among WRMDs and risk factors.  
**Results**Valid questionnaire samples were submitted by 984 ICU nurses. The prevalence of WRMDs within the previous year among ICU nurses was 96.8%. A valid structural equation model was constructed, and a good fit was shown: Chi-square value/degrees of freedom = 2.248; comparative fit index = .931; normal fit index = .905; goodness-of-fit index = .978; adjusted goodness-of-fit index = .966; and root mean square error of approximation = .036. All regression coefficients for direct effect reached significant levels (critical ratio > 1.96 and  $p < .05$ ). In the structural equation model, the occurrence of WRMDs was directly affected by the following: physical factors, risk perception, and job stress. Physical factors and a safe environment indirectly affected WRMDs through risk perception and job stress. The strongest correlations with WRMDs were physical factors.  
**Conclusion**The model provided a new perspective for understanding the associations among physical factors, workplace safety environment, risk perception, job stress, and WRMDs. To improve the practice setting of the ICU, efforts should be made to help prevent WRMDs from physical, psychosocial, and environmental factors.

Eun-Hyun, L., Young, W. L., Chae, D., Kwan-Woo, L., Jin, O. C., Hong, S., . . . Kang, E. H. (2020). A new self-management scale with a hierarchical structure for patients with type 2 diabetes. *Asian Nursing Research*, 14(4), 249-256. doi:<https://doi.org/10.1016/j.anr.2020.08.003>

**SummaryPurpose**The aims of this study were to develop a new instrument for measuring self-management with a hierarchical structure the Diabetes Self-Management Scale (DSMS)] in patients with type 2 diabetes, and evaluate its psychometric properties.  
**Method**The DSMS instrument was developed in three phases: (1) conceptualization and item generation; (2) content validity and pilot testing; and (3) field testing of its psychometric properties. A convenience sample of 473 participants was recruited in three university hospitals and one regional health center, South Korea.  
**Results**Exploratory and confirmatory factor analyses yielded two second-order component models explaining the common variance among six first-order factors. Principal axis factoring with a varimax rotation

accounted for 60.88% of the variance. Confirmatory factor analysis of the hierarchical structure revealed the following fit indices:  $\chi^2/df = 1.373$ , standardized root-mean-square residual = .050, goodness-of-fit index = .935, incremental fit index = .975, comparative fit index = .974, and root-mean-square error of approximation = .039. All Cronbach'  $\alpha$  values for internal consistency exceeded the criterion of .70. All of the intraclass correlation coefficients for test-retest reliability exceeded .70 except that for the taking-medication subscale. The components of the DSMS were moderately correlated with the comparator measures of self-efficacy and health literacy administered for convergent validity. Conclusion The DSMS is a new instrument for measuring the complex nature of self-management in patients with type 2 diabetes, comprising 17 items scored on a five-point Likert scale. The DSMS exhibits satisfactory psychometric properties for five reliability and validity metrics, and so is a suitable instrument to apply in both research and clinical practices.

Daphne Sze, K. C., Patrick Pui, K. K., Jones, C., Davies, N., Moyle, W., Wai, T. C., . . . Lai, C. K. Y. (2020). The use of modified mindfulness-based stress reduction and mindfulness-based cognitive therapy Program for family caregivers of people living with dementia: A feasibility study. *Asian Nursing Research*, 14(4), 221-230. doi:<https://doi.org/10.1016/j.anr.2020.08.009>

Purpose The aim of this study was to investigate the feasibility and preliminary efficacy of a modified mindfulness-based stress reduction (MBSR) program and mindfulness-based cognitive therapy (MBCT) program for reducing the stress, depressive symptoms, and subjective burden of family caregivers of people with dementia (PWD). Methods A prospective, parallel-group, randomized controlled trial design was adopted. Fifty-seven participants were recruited from the community and randomized into either the modified MBSR group (n = 27) or modified MBCT group (n = 26), receiving seven face-to-face intervention sessions for more than 16 weeks. Various psychological outcomes were measured at baseline (T0), immediately after intervention (T1), and at the 3-month follow-up (T2). Results Both interventions were found to be feasible in view of the high attendance (more than 70.0%) and low attrition (3.8%) rates. The mixed analysis of variance (ANOVA) results showed positive within-group effects on perceived stress (p = .030, Cohen's d = 0.54), depressive symptoms (p = .002, Cohen's d = 0.77), and subjective caregiver burden (p < .001, Cohen's d = 1.12) in both interventions across the time points, whereas the modified MBCT had a larger effect on stress reduction, compared with the modified MBSR (p = .019). Conclusion Both the modified MBSR and MBCT are acceptable to family caregivers of PWD. Their preliminary effects were improvements in stress, depressive symptoms, and subjective burden. The modified MBCT may be more suitable for caregivers of PWD than the MBSR. A future clinical trial is needed to confirm their effectiveness in improving the psychological well-being of caregivers of PWD.

Liu, Y., Tong-tong, J., & Tie-ying Shi. (2020). The relationship among rumination, coping strategies, and subjective well-being in chinese patients with breast cancer: A cross-sectional study. *Asian Nursing Research*, 14(4), 206-211. doi:<https://doi.org/10.1016/j.anr.2020.07.005>

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