

pISSN: 1976-1317 eISSN: 2093-7482

VOLUME 13 | NUMBER 2 | MAY 2019

# ASIAN NURSING RESEARCH

Eui Geum Oh, PhD, RN, FAAN  
Editor-in-Chief



Korean Society of  
Nursing Science

Currently indexed in SCIE, SSCI and SBS  
<http://www.asian-nursingresearch.com>



This journal was supported by the Korean Federation of Science and Technology Societies Grant  
Sponsored by Korean Government (Ministry of Education)



## Research Article

# Combating with Compassion Fatigue: The Perspective of Family Caregivers of People with Schizophrenia



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## ARTICLE INFO

## Article history:

Received 20 January 2022

Received in revised form

14 September 2022

Accepted 22 September 2022

## Keywords:

caregivers

compassion fatigue

grounded theory

schizophrenia

## SUMMARY

**Purpose:** The purpose of this study was to explore the coping processes used by family caregivers of individuals with schizophrenia to deal with compassion fatigue (CF).

**Methods:** Grounded theory was used in this study. For recruitment, purposive and theoretical samplings were used to recruit participants. Data were collected from 29 family caregivers through in-depth interviews and field notes. Data were analyzed using constant and comparative methods.

**Results:** The study revealed a core process for dealing with CF as “Combating with compassion fatigue” that comprised three dynamic phases: strengthening attachment with the care recipient to increase willpower, learning how to deal with the illness, and self-empowerment to fight to the physical and mental fatigue.

**Conclusions:** Family caregivers of people with a diagnosis of schizophrenia use various strategies to fight to CF. These combine the past experiences of strategies that work and new approaches. Our research will allow mental health professionals to provide basic strategies to family caregivers of people with a diagnosis of schizophrenia to help them to cope with CF.

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## Introduction

Schizophrenia is a chronic condition, and a large group of disorders fall within the schizophrenia spectrum; these are characterized by the disturbances of thought, mood, and behavior [1]. Schizophrenic individuals may exhibit strange behaviors and delusional beliefs, and often experience hallucinations [2]. While schizophrenia can be controlled with medication, the majority of sufferers experience relapse [3,4]. Family caregivers have limitations in caring for schizophrenic patients at home, which include lack of understanding about schizophrenia and its treatment, and communication with health professionals. In addition, family caregivers have poor assessment follow-up and guidance for medication compliance with respect to their schizophrenic patients

[5,6]. Those limitations can cause the family caregivers to feel overburdened and overwhelmed and to experience stress, health problems, and a deterioration in quality of life [3,7,8].

Caregiving, whether it is over a long period or for an individual with an acute or severe illness, can lead to compassion fatigue (CF). CF occurs when the caregiver experiences strong empathy with his or her charge, resulting in a deep psychological response that may progress to physical, mental, social, or spiritual exhaustion [9]. Previous studies have demonstrated the prevalence of CF among family caregivers [9–11]. CF manifests a range of emotions and behaviors, including helplessness, disappointment, stress, a feeling of endless hard work, guilt, uncertainty, social isolation, dissatisfaction, and reduced ability [10]. CF is also seen in professional caregivers such as primary care nurses in long-term care situations like mental health or cancer care [9,12–15]. It has been found that patients' suffering can affect caregivers despite their professional health backgrounds and the requisite ability to provide high-quality care.

Previous research on CF has primarily been conducted in the context of professional health care provision [15–17,19]. However, a few studies have focused on CF among family caregivers [10,11,18]. For instance, a literature review on CF in family caregivers by Blair and Perry [10] showed that most family caregivers feel a strong

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<https://doi.org/10.1016/j.anr.2022.09.001>

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duty of care due to their emotional attachment to their care recipient and gain satisfaction from providing this care. However, caregivers also experience feelings of guilt, helplessness, disappointment, uncertainty, and dissatisfaction in the face of the ongoing and extensive needs of the care recipient. Day and Anderson [20] reviewed the literature on CF among family caregivers of individuals with dementia. The results revealed that most caregivers experience CF, and this manifests in the feelings of disappointment, helplessness, and a lack of interest and positive intentions toward their charges. This ultimately results in the avoidance of caregiving duties of the family caregivers.

Previous research has also found that family caregivers experience problems such as depression, stress, feeling overburdened, impaired relationships with other persons, and health problems. Those problems also lead to poor care provision or the termination of caregiving [10,11,20]. In addition, a qualitative study revealed that family caregivers of schizophrenic patients experienced CF, the characteristics of which include living with stress for long periods, physical, or mental exhaustion or both, being disheartened, anxiety and uncertainty, and having difficulty sleeping [21]. No effective ways of coping among family caregivers have yet been found. Nurses need to be attentive to the needs of family caregivers. Hence, there is a growing need to identify strategies that will help family caregivers to mitigate the negative effects and cope with CF.

There is little known about such strategies for coping with CF, especially among family caregivers of people with a diagnosis of schizophrenia in Thailand. In view of this lack of basic knowledge, this study aims to explore the coping processes used by family caregivers of individuals with schizophrenia to deal with CF. The findings can benefit health professionals, provide effective intervention to reduce or prevent CF in family caregivers of people with schizophrenia. Our findings can also potentially be used to improve and expand mental health services that assist family caregivers in the ongoing provision of care to family members with schizophrenia. The authors hope the findings will also be beneficial for international readers who hope to learn more about coping with CF in family caregivers.

## Methods

This paper is a part of a larger research project entitled “Coping with compassion fatigue among family caregivers of persons with schizophrenia” that comprises two sub-studies. The first sub-study is “Compassion fatigue among family caregivers of schizophrenic patients” [21]. This current study was the second sub-study that uses grounded theory to explore how family caregivers deal with CF. The main purpose of grounded theory is to explore basic processes and generate theory from real-world situations and the perspectives of members of a given society. Grounded theory methodology explores the richness of human experience to generate and develop substantive theories. The approach allowed the researchers to explore, conceptualize, and generate substantive knowledge concerning the dealing with CF among family caregivers of persons with schizophrenia. The theories that emerge from such research in nursing frequently focus on behavioral concepts such as caring, coping, and parenting. In addition, these theories are helpful in their application to nursing practice [22,23].

### Participants and ethical issue

The study was approved by the Research Ethics Review Committee for Research Involving Human Research Participants, Group 1. Chulalongkorn University (Approval no. 106.1/63). Approval was received before data collection began. Measures were taken to protect the anonymity of participants. Further, all participants who had experienced CF were made aware of their right to withdraw from the study at any time, and informed consent was obtained. The

participants were selected using purposive and theoretical sampling to ensure complete and reliable data. The inclusion criteria were (1) the participants must be primary caregivers who provide care for schizophrenic patients over 20 years of age; (2) the participants must be family members (not hired for caregiving) with the main duties of looking after schizophrenic patients directly for at least two or more years without receiving any compensation; (3) the participants could explain their experience of coping with CF due to caring for schizophrenic patients; (4) they were able to communicate through Thai language their willingness to participate in this research. The first author conducted interviews in a private room of each hospital. Data saturation was reached at 29 interviews. All of the participants (24 females and 5 males) were interviewed about the strategies they use to cope with CF. The mean age of the participants was 51.5 years; 21 participants were married; 16 participants were educated to primary school level, and some participants had no formal education. The length of time 12 participants had been caring for a relative with schizophrenia ranged from 2 to 5 years, and 13 participants were mothers of the patients. Other demographic details were also presented in the first sub-study [21].

### Data collection

Data collection took place at a psychiatric hospital and a general hospital from August to December, 2020. Data were collected using in-depth interviews with 29 family caregivers who met the inclusion criteria. In order to maintain consistency, only the first author, who had more experience in in-depth interviewing in qualitative research, conducted the interviews with the participants after written consent was obtained. The first author used open-ended questions to encourage participants to share their experiences of coping with CF in the course of caring for their patients. The major questions used for gaining data with the family caregivers were how did you provide caregiving with schizophrenic patients at home? and how did you deal with your CF that was happening such as stress, physical, and mental exhaustion, being disheartened, anxiety, and uncertainty? The question was designed to invite the informants to answer freely and provide as many details as possible. During the interviews, the interviewer also mainly used layperson’s language and empathic expressions in order to build rapport, trust, and to stimulate the participants to speak about their experiences of coping with CF. The duration of each interview was approximately 60 minutes. All interviews were audio-recorded and transcribed before data analysis. Field notes were also taken about facial expressions, tones of voice, and posture of the participants. Other details of data collection were explained in the first sub-study [21].

### Data analysis

Data analysis using constant comparative method [24] was carried out alongside data collection during the research process. Data analysis comprised three stages. The first stage was open coding, in which the first and the second author independently read the transcribed conversations with each participant thoroughly and repeatedly. They then produced substantive theory code for each conversation. This incorporated consideration of the types of situations, activities, and behaviors were described by participants. Simultaneously, the authors compared the data relating to each situation, activity, and behavior extensively and developed categories for each type. The second stage of data analysis was selective coding. During this stage, the previously defined substantive codes were reduced to obtain variables or recurring issues and identify major categories through coded information classification. Those conversational units with the same

or similar meaning were classified into the same group. Subsequently, the authors named all of the categories and sub-categories. The third stage was theoretical coding. The authors mutually agreed upon the relationships between categories and sub-categories, and these were then linked with theoretical codes to map the social process of coping with CF in family caregivers of people with schizophrenia.

#### Trustworthiness

Regarding grounded theory, Glaser and Strauss [22] stated that the proper criteria for judging the credibility, fittingness, and stability of findings are based on flexible research. The credibility was evaluated through the vividness and faithfulness of the description of a phenomenon of coping with CF such as triangulation-method triangulation-in this study, selecting the appropriate participants who had the ability to tell their CF during care for people with schizophrenia. Semi-structured interviews and field notes were conducted by only the first author. The authors' background in qualitative research helped her to provide details and thick description to increase transferability. Then, peer debriefing with co-author and audit trail were employed to enhance stability of finding.

## Results

### Combating with CF

The core process with which family caregivers cope with CF while providing care for individuals with severe mental illness was found that was called "Combating with compassion fatigue." The process was comprised of strengthening attachment to the care recipient to increase willpower, learning how to deal with the illness, and self-empowerment to fight the physical and mental fatigue.

#### Category 1: strengthening attachment to the care recipient to increase willpower

Family caregivers strengthen attachments with care recipients to increase their willpower using three strategies: recognizing the care recipient as a good person to increase willpower, maintaining love and sympathy, and engaging in shared activities with the care recipient. The strategies helped caregivers to maintain their desire to care for the care recipients. Three sub-categories were identified, as follows.

#### Recognizing the care recipient as a good person

Most participants believed their care recipient to be a good person. The believe liked this could help them to have more power and encouragement. The participants shared positive behaviors they had seen in their care recipient such as abstaining from cigarettes and alcohol, doing the housework, and going to the temple to do good things. Other care recipients helped with home maintenance and repairs and worked to earn money. The good nature of a care recipient encouraged their caregiver to continue providing care despite physical and psychological exhaustion. Participants said:

*"He still has auditory hallucinations. He always tells me about that. However, he does not use cigarettes or alcohol. Besides, he is a good person. He likes to go to the temple to make merit every week. He helps me to do housework. He cooks and cleans the house."* (P 29)

*"He is a good guy. He takes care of his father and mother in everything. He buys food for his mother and father. He reconstructed the house. Before he was diagnosed with schizophrenia, he*

*worked to earn money to help the family with things such as paying for a car. I understand his illness."* (P 12)

Recognizing the care recipient as a good person was an important strategy with which the participants strengthened their connection with the care recipients. The participants had positive thinking by acknowledging of the goodness of the care recipient invited them to be willing to continue caring.

#### Maintaining love and sympathy

In caring for people with a diagnosis of schizophrenia for a long period, the participants experienced physical and mental exhaustion. However, they continued providing care because of their love and sympathy for the care recipients. Many of the participants would remind themselves that they love their care recipient. Care recipients are often a significant other, child or close family member of the caregiver. They expressed their love to the care recipients verbally but also non-verbally through their caregiving. Despite not knowing when the care recipients would recover from their illness, the participants understood that they must be patient and provide indefinite ongoing care. The participants said:

*"I could say that I am very physically and mentally exhausted. I tell myself that he is my son. I love him. I must fight. If I do not, who will care for my son? I also work so hard every day to earn money and buy food. I prepare food for the patient when he cannot do it for himself. When I take a break at noon, I come back home to care for him."* (P 24)

*"I was very tired. But I do it because I love her. I tell myself that she is my wife. I love her so much; I would do anything for her. I want her to get better. She might not do any work. It's alright by me. I am always ready to care for her. She might do many things when she is better."* (P 2)

#### Engaging in shared activities

Engaging in activities together was another method used to strengthen the bond between caregivers and the individual for whom they cared. Most participants said that they invite the care recipients to join in activities with them such as going to the temple and going on weekend trips. The participants also found that shared activities were a good way to allow them to engage more as a family. In addition, activities with the care recipients could be a source of relaxation for both. One of the participants said:

*"Usually, our family likes to do activities together such as making merit, meditation, and travelling. One day, I went to a temple in another province. I invited him and my husband. We took meditation. I think that it's helped us relax. I like to invite him to activities. We are comfortable doing that."* (P 5)

Another participant shared their feelings of love and sympathy for their son with schizophrenic. The participant encouraged their son to do exercise and housework every day.

*"I live alone with my son who was ill. We do not have any relatives. I love him and sympathize. I often invite him to exercise with me. Some days, I invite; some days the patient invites me. I am very happy, comfortable, and more bonding. I felt that. I want him to get well."* (P 26)

Strengthening the attachment to the care recipient to increase willpower was seen as a good way to cope with CF. When the participants felt physical or mental exhaustion or were otherwise suffering, they would recall nice experiences and their positive

relationship with the care recipient. Their love and sympathy helped to maintain good feelings and a willingness to continue caring for the care recipients. Later, the participants' CF could be decreased.

#### Category 2: learning how to deal with the patient's illness

Learning how to deal with the patient's illness was the second stage of the coping process. The participants not only provided love and sympathy to their care recipients but also tried to learn how to deal with them. This way helped the participants to be able to care for and manage the patient's illness. One important thing that associated with CF was lack of knowledge to care for the schizophrenic patient. This was achieved in two ways: understanding the care recipient's conditions and finding information about caring for them. Learning care strategies improved participants' competence at care provision. It also increased the participants' well-being and decreased the caregiving burden as well as CF. Two sub-categories were identified, as follows.

##### Understanding the condition

Understanding the care recipient's disturbance was a further strategy that the participants used to deal with the care recipients' illness. The understanding also helped the participants to have more power and confidence to provide continuous care. The participants used various self-devised strategies to achieve this, including observing the care recipient's symptoms, the effects of the medicine, and other behaviors. Learning by observation improved understanding of the illness and how to care for their charges. As one participant said,

*"I live with my ill brother, so I have time to observe his symptoms. In the beginning, I did not know or understand what was happening to my brother. After a while, I began to know what the patient needed. For instance, I tactfully monitor his symptoms and delusions. I know that it's not real. The delusions are a symptom." (P 18)*

Another method used to improve understanding of the illness of the participants was to ask the care recipient about their symptoms and experiences. The questions asked by the participants primarily focused on the medicine and its side effects. One participant said,

*"I always ask him about taking medicine. I remind him to take medicine. I knew that if I don't ask, he won't take it. I asked him about the side effects and it helped me understand why would want to remain abnormal. It is because of the side effects of the medicine." (P 9)*

##### Finding information about caring for people with schizophrenia

Finding information about caring for schizophrenia was a strategy used by the participants to learn how to deal with the condition. Most of the participants had sought knowledge about schizophrenia and how to care for schizophrenic people by asking mental health nurses. Family caregivers had telephone numbers for the mental health nurses involved in their relatives' treatment. They called the nurses to talk about the care recipients' symptoms and disturbances, how to deal with refusal to take medication, and how to manage the care recipient's behaviors. They also discussed health outcomes. Receiving such information helped the participants to learn how to care for their care recipients appropriately. The participants said:

*"I called the nurse and asked her what to do when the patient forgot to take their medicine. The nurse was very nice and kind to me and the patient." (P 20)*

*"Sometimes, he has delusions. he walks around the home and runs away from home. I did not know what to do so I called the nurse. I asked the nurse what to do, how to care for the patient. The nurse gave me some preliminary advice and then she came to my home." (P 14)*

The participants used understanding the care recipient's disturbances and finding care information to improve their ability to deal with the care recipient's illness. After the participants could provide effective care for their care recipient to be better, the participants would be fine as well. This was found to be a good way of helping the participants to cope with CF.

#### Category 3: Self-empowerment to fight the physical and mental fatigue

The participants used self-empowerment to cope with CF. This was achieved using three strategies: maintaining hope the care recipient will get better, believing that the caregiving is their responsibility, and finding ways to release stress. These strategies gave the participants strength and confidence, and strengthened their resolve to continue caring for the care recipients. Three sub-categories were identified, as follows.

##### Maintaining hope that the care recipient will get well

Maintaining hope that the care recipient will get well was a strategy used for personal empowerment by the caregivers in this study. Most participants expressed this hope and said that their hope increased when the care recipients' symptoms lessened. This reduction of psychotic symptoms in the care recipient gave participants more energy to care for their relatives with schizophrenia. One participant said:

*"I hope that he keeps doing well. In the beginning, he could not stop smoking and drinking alcohol. He often went out drinking with his friends. Then, he had active symptoms many times. However, he went to see the doctor and took the medicine he was prescribed. He got better and stopped having psychotic symptoms; This makes me hope that he will get better again and then I feel more able to care for him." (P 25)*

Another participant talked about their care recipients increased ability to undertake tasks and activities such as housework. The participant felt good and was optimistic about the care recipient's improved condition. The participants said:

*"I told the patient to do housework. He can do it by himself and when I saw that, I felt so good and I thought that he will be better or recovered from the disease soon. I understand him. I also sympathize with him. He might feel lonely. I hope that he will get better." (P 27)*

##### Believing that the caregiving is a responsibility

Another strategy used for empowerment was to regard caring for the care recipient was as a responsibility. The participants would often tell themselves that caring for the care recipients was an important duty. This was particularly so because of their close familial relationships with the care recipients. When participants found themselves physically and mentally exhausted, they would remind themselves of the importance of their responsibility and feel empowered to continue caregiving. The participants said:

*"I must care for him. If I did not, no one would care for him. He is my only brother. I take him to the hospital. I must. When I think like that it gives me the strength to keep caring for him." (P 29)*

*"I am so tired. But I must be patient and fight for our family. she is my mother. I must care for her. I am her son. It is a responsibility that I must uphold. Sometimes, I go out to relax for a few hours. I come home because I must make sure my mom takes her medicine. I want to see my family members happy." (P 4)*

#### Finding ways to release CF

Another means participants used to cope with CF was to find the outlets for CF release. Methods used to achieve this included spending time with other people, spending time working hard, undertaking regular religious activities, and engaging in exercise and hobbies. These strategies that could help the participants to decrease the CF were identified, as follows.

#### Spending time with other people

Most participants had found positive ways to relieve stress. Stress as a characteristic of CF happening with the participants. The participants used time with other people such as family members and friends to talk about the care recipients' illness and treatments and about methods of caregiving. After talking with others, they felt more able to provide care, more relaxed, and less stressed and anxious. One of the participants said:

*"When I am stressed, I go out to talk with my friends. We talk about the patient behaviors and drink alcohol. My friends, they always listen to me. I need to do this because I am so stressed. My friends also find jobs for me. So, I feel better and get the jobs." (P 4)*

#### Hard work

Participants spent time working hard to forget distresses from CF. Bussing themselves with jobs provided a distraction from tension or suffering. Participants found that they enjoyed doing the jobs and forgot their troubles.

*"Sometimes, I am exhausted. I am disheartened because I care for the patient alone. I also have difficulty sleeping. I must do more jobs to forget things. I do housework such as cooking, washing clothes, and cleaning the house. I am then comfortable and can carry on." (P 26)*

#### Religious activities

Undertaking religious activities in daily life was another strategy that helped the participants to let go, relax, and increase their understanding of life. The participants could let negative consequences due to CF. The religious activities that participants incorporated into their daily lives included chanting, meditation, and good works. Some participants practiced dharma through acts such as offering food to monks each morning. One participant said:

*"I practice dharma every day. I liked to give alms to the monks in the morning. I do this every day. I invite my son who was ill to do it with me. Sometimes, he does but sometimes does not. I meditate every week, which helps me to feel better. Sometimes, I am so stressed and this makes it better." (P 23)*

#### Exercise and hobbies

The participants accepted that caring for the care recipients could be hard. They engaged in exercise and hobbies such as gardening, jogging, and walking to help themselves to relax and unwind and relieve stress. One participant said:

*"I am very tired. I tell myself that I must fight. When I have a little time, I walk or jog around my home, which helps me to feel better. I invite him to exercise, but he does not like to." (P 11)*

In this study, coping with CF was found to be a basic process that occurred between family caregivers and care recipients. It is also a dynamic process. The participants strengthened their attachment with the care recipient to increase willpower in providing care by using three sub-strategies: recognizing the care recipient as a good person, maintaining love and sympathy, and sharing activities with the care recipient. At the same time, the participants used the strategy of learning how to deal with the care recipient's illness through understanding the care recipient's disturbances and finding information about caring for people with a diagnosis of schizophrenia. This phase, the participants could improve their ability to deal with the care recipient's illness. The participants also used another strategy of self-empowerment to fight the physical and mental fatigue, with three sub-strategies: maintaining hope that the care recipient will get well and regarding caregiving as an important responsibility, and finding positive outlets for CF release. When the time passed, the participants can move back and forth to use the strategy of strengthening attachment with the care recipient to increase willpower or finding ways to deal with the care recipient's illness again. The relationships between the three phases can be conceptualized as circular and iterative, as shown in [Figure 1](#).

## Discussion

Schizophrenia is recognized as a severe mental illness requiring long-term treatment need [25]. Taking care of a schizophrenic family member can be a tremendous burden upon the caregiver who must deal with stigma, misunderstanding, damaged and disturbed relationships, negative effects on their own mental health, and difficulty coping [26–28]. The resulting CF can cause health problems and a reduced quality of life of family caregivers [3,7]. Our findings highlight the strategies used by family caregivers to cope with CF that were called "Combating with compassion fatigue". These strategies comprise three stages: strengthening attachment with the care recipient to increase willpower, learning how to deal with the care recipients' illness, and self-empowerment to fight to the physical and mental fatigue. Lazarus and Folkman [29] have defined coping as a process that uses cognition, decision making, planning, and support-seeking to manage problems and life. Our participants availed themselves of both emotion and problem-focused coping strategies.

Emotion-focused coping strategies included recognizing the care recipients as good people, maintaining love and sympathy, sharing activities with the care recipient. These strategies manage and minimize negative emotions and maximize positive emotions [29]. Strengthening attachments helped the participants to communicate and have more positive relationships with the care recipients. They also encouraged participants to continued caregiving and improved overall well-being. A strong attachment to the care recipient helped our participants to cope with the negative emotion that are manifestations of CF. This finding also is consistent with a study by Blair and Perry [10] that revealed the family caregivers feel a strong duty of care due to their emotional attachment to the care recipient. Besides, the family caregivers gain satisfaction from providing this care.

The participants also used problem-focused coping strategies to fight to the CF. These focused on looking for ways to manage the care recipient's illness. This was achieved through understanding the care recipients' disturbances and finding information about

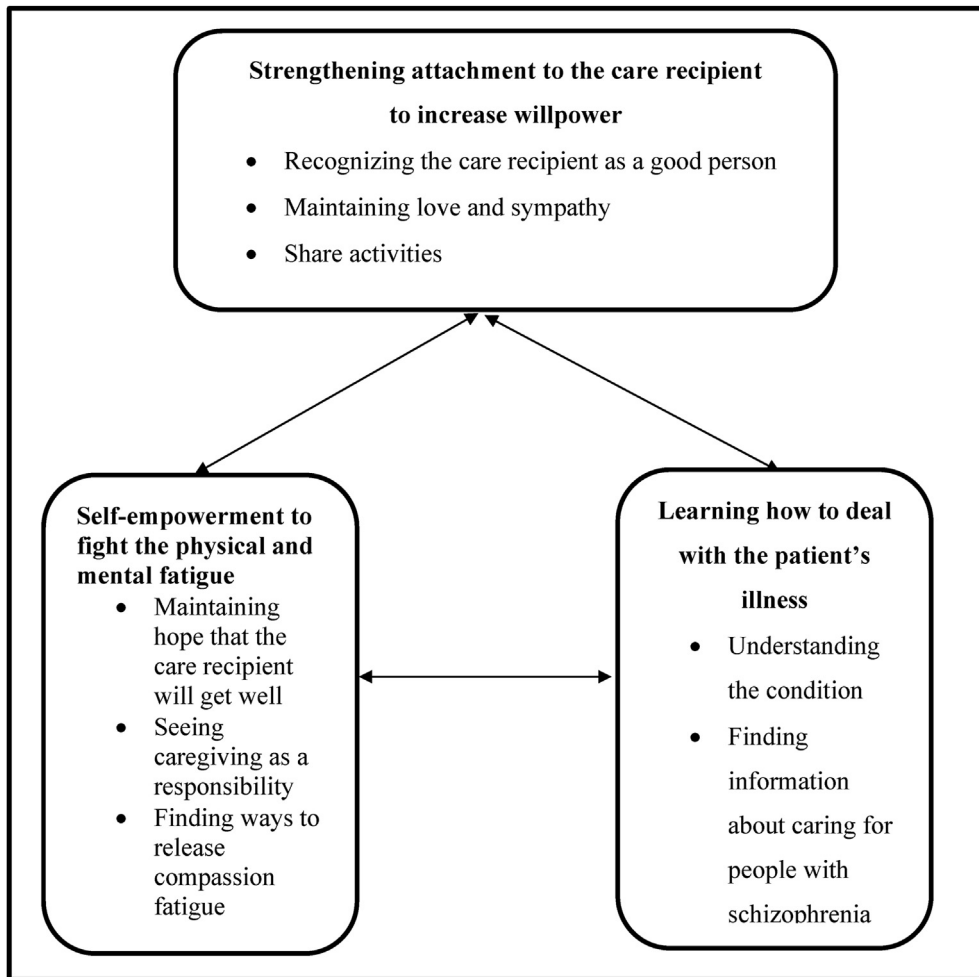


Figure 1. Combating with Compassion Fatigue among Family Caregivers.

caring for people with schizophrenia. Sub-strategies of this included observation of the care recipients' symptoms, other behaviors, and their medicine and its effects to increase their understanding. This is regarded as part of the role of a family caregiver [30]. The participants sought ways to manage the problem inherent in caring for their charges and dealing with their care recipients' active symptoms. Thus, some participants took their lead from health professionals through informal health assessment and data analysis that informed their caring activities. These problem-focused coping strategies and autodidactic processes helped to build the caregivers' knowledge about the illness and caregiving skills, leaving them better equipped to cope with the caregiving burden [31,32].

Self-empowerment to fight the physical and mental fatigue was another way that was performed by participants. Taking care of the afflicted family member for long periods at home impacted the participants' physical and psychological health and quality of life. The less able the caregiver felt, the greater the negative effects and CF [5,9,33]. The participants described methods they used for self-empowerment while providing care to fight to their physical and mental fatigue. These included maintaining the belief that the care recipient was a good person and the use of distracting activities. The strategies used demonstrate that the participants engaged in cognitive self-adjustment. Participants also made emotional adjustments such as spending time with friends, meditation, doing good works, exercise, and hobbies. They also attempted to modify their daily routines to allow for their caregiving duties. These

strategies gave the participants more energy to continue caring for the care recipients. Previous research with primary caregivers of elderly individuals with dementia showed a similar self-empowerment, that including enhancement of care ability, emotional management, and life management [33].

#### Limitations

In this qualitative study focused on an in-depth exploration of the experiences of a small sample of family caregivers of people with a diagnosis of schizophrenia and only two hospitals. It may therefore not be generalizable to family caregiving with other types of care recipients.

#### Conclusions

Caring for schizophrenic patients can be difficult for family caregivers. The family caregivers who participated in this study used numerous strategies to cope with CF. We found that the family caregivers of schizophrenic patients in Thailand engaged in a specific coping process. The findings can be used to provide guidelines for family caregivers who are suffering from CF. Health care professionals, including mental health nurses and psychologists can apply this coping process to family caregivers with CF. Each stage of the process can be adapted for greater efficacy and flexibility. In addition, the process can be applied to help family caregivers who dealing with patients with aggressive behaviors or poor medication

adherence. Mental health policymakers may consider our findings as a foundation upon which to build strategies that empower family caregivers via mental health facilities. Further research should look for factors influencing to CF among family caregivers. In addition, the effective interventions should be developed.

### Data availability statement

The data that support the findings of this research are available from the corresponding author upon reasonable request.

### Ethical statement

This research received ethical approval from the Office of the Research Ethics Review Committee for Research Involving Human Subjects: The First Allied Academic Group in Health Sciences, Chulalongkorn University. The research project number is 106.1/63.

### Author contributions

Data were collected and analyzed, and the manuscript was written, by RU and WS.

### Conflict of interest

The authors have no conflict of interest to declare.

### Acknowledgments

The authors are especially grateful to the family caregivers who participated in this study. This work was supported by the Thailand Science Research and Innovation Fund Chulalongkorn University (CU\_FRB640001\_36\_2); (CUFRB65\_soc(4)\_004\_27\_04); and Thinking and Disposition STAR Research (TDSR) group, Faculty of Education, Ratchadapiseksompoch Fund (social science) (STF 6500227001-1).

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## Research Article

# Roles and Effects of Peer Recovery Coach Intervention in the Field of Substance Abuse: An Integrative Literature Review



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## ARTICLE INFO

## Article history:

Received 28 April 2022

Received in revised form

1 October 2022

Accepted 5 October 2022

## Keywords:

Substance-related disorders

Mental health recovery

Psychosocial intervention

## SUMMARY

**Purpose:** There are ongoing public initiatives to help substance abusers by involving peer recovery coaches (PRCs) in the field of substance abuse worldwide. This study examines the contents and delivery methods of PRC intervention programs and their effects from the participants' standpoint.

**Methods:** An integrative literature search was conducted in seven electronic databases using English and Korean search terms. Two researchers independently reviewed the extracted papers and rated their quality based on predetermined inclusion and exclusion criteria, resulting in the selection of nine papers. **Results:** Research on PRC participation in substance abuse treatment were predominantly US-based, and all articles derived were quantitative studies. The main roles of PRCs included liaising between treatment and community resources, assisting with stress management and coping skills, counseling and case management, and recovery and recurrence prevention education. In addition, the PRC-delivered intervention was tested with various outcome variables. It reduced participants' substance use and enhanced their treatment adherence rates, self-efficacy, quality of life, and stress control.

**Conclusions:** This study confirmed the need to extend existing studies by testing the effects of PRC-delivered intervention through multidisciplinary efforts in more regions and establishing PRCs' role definition and concretization. The results of this study will serve as significant basic data in developing and applying for nursing intervention programs with PRCs in clinical and community nursing settings in the future.

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## Introduction

Substance use disorder (SUD) refers to an individual's continuous substance use despite its negative consequences [1]. As of 2019, more than 2.0% of the world's population was dependent on alcohol or illegal drugs [2], and 11.7% of US adolescents and adults (aged  $\geq 12$  years) use illegal drugs [3]. Furthermore, as of 2021, arrests for drug offenses reached 16,153 cases [4]. SUD is characterized by losing control of substance use, physical dependence, social problems, and hazardous use [1]. It causes health problems and social and school maladaptation in adolescents [5] and a high relapse rate and has a difficult recovery process [6]. Recovering

from addiction is a continuous process of developing a healthy and productive life by overcoming various life problems, rather than simply a cessation of addictive substances or returning to the state before addiction [7]. Hence, SUD is treated as a chronic disease [8] and necessitates continuous community-level management.

A variety of community-level health services have been developed and implemented to prevent the relapse of SUD. After adopting the chronic disease concept of SUD management, more emphasis has been placed on substance abuse recovery support programs delivered by peer recovery coaches (PRCs) [9]. PRCs are experts and mentors specifically trained to help individuals successfully recover from SUD by leveraging their own experience of recovery from SUD and other mental illnesses [10,11]. PRCs provide a wide variety of services, such as instilling hope for recovery in people with similar experiences, accompanying them through the recovery process, setting recovery goals, supporting the roadmap development process, and helping to gain access to necessary resources [11]. Such activities of PRCs not only help the addicts recover but also help them maintain their own recovery [12]. PRCs

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<https://doi.org/10.1016/j.anr.2022.10.001>

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provide services in various formats, including one-on-one and group sessions [13,14]. These services can be delivered to different groups in various settings such as churches, prisons/jails, probation/parole programs, HIV/AIDS and other social service centers, and substance abuse and mental health treatment facilities [15].

According to the related literature, PRC programs enhance self-esteem and self-confidence [16], improve self-control [17], increase self-care participation, reduce symptoms of mental disorders and hospital admission rates [17], and increase social function participation [18]. However, these studies explore the effects of PRC programs on patients with mental disorders, with only a few studies evaluating the effects of PRC programs on SUD patients. Furthermore, the existing PRC-related literature covers either alcohol or substance abuse [9], and literature review studies lack systematic frameworks [19], conducting reviews of therapeutic interventions other than PRC programs. Given this background, this study examines the effects of PRC programs applied to SUD patients by comprehensively reviewing papers on PRC programs applied to SUD patients thus far. The integrative review performed in this study can serve as a meaningful basis for providing the rationale and direction for nursing intervention programs with PRCs for SUD patients in clinical and community settings.

## Methods

### Study aims

To provide the basic information for the development of nursing interventions with PRCs, this study identified the roles of PRCs in program operation and analyzed the main contents, operation methods, and effects of the programs with PRCs.

### Research design

This integrative literature review was conducted according to the five steps of Whittemore and Knaff's integrative literature review model: specifying the research question, searching the literature, evaluating the literature, analyzing the literature, and presenting the results [20].

### Research question

The PICO (population, intervention, control, and outcomes) of this study was as follows: P: SUD patients, I: PRC interventions, C: none, O: effects of peer support interventions. The research question of this study is, "What are the attributes and effects of PRC intervention for SUD patients?"

### Literature search

Two independent researchers performed the entire literature selection process, and differences of opinion were resolved through a consensus reached in research team meetings. First, before the literature search, the research team set literature selection criteria based on coordinated opinions. Inclusion criteria were (1) articles related to the effects of PRC programs on SUD patients, (2) articles sharing full-text access, and (3) articles published in Korean or in English until March 25, 2022. Exclusion criteria were (1) articles on non-PRC interventions (e.g., pharmacotherapy); (2) dissertations, letters to the editor, conference presentation papers, and reviews; and (3) articles that have not been published in Korean and English. Two independent researchers conducted the literature search from March 25 to April 5, 2022. In South Korea, PRCs are also working, and there was a possibility that published Korean papers about the effects of their participation existed. Therefore, the articles searched

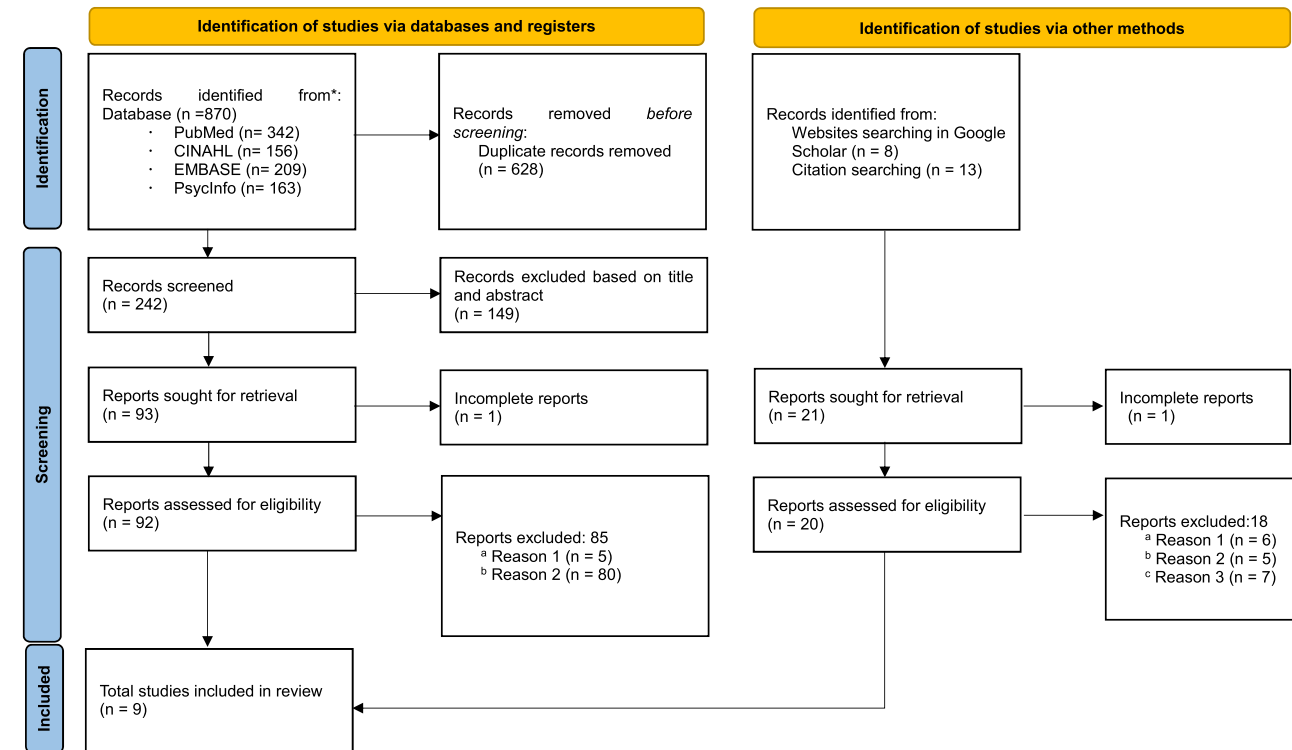
were related to PRC interventions (programs) for SUD patients and published in Korean and English academic journals. Seven databases were searched: three Korean (Research Information Sharing Service [RISS], Korean studies Information Service System [KISS], and Data Base Periodical Information Academic [DBpia]) and four international (CINAHL [Cumulative Index to Nursing & Allied Health Literature], EMBASE, PubMed, and PsycINFO). Search terms were selected based primarily on the Medical Subject Headings (MeSH) and on English titles and keywords of previous studies to find out the most frequently occurring keywords. As a result, the following search formula was established: ("Substance-Related Disorders" OR "Substance Related Disorder" OR "Substance Abuse\*" OR "Substance Dependence" OR "Substance Addiction" OR "Substance Use Disorder") AND ("Consumer Provider" OR "Addiction Recovery Counselor" OR "Recovery Activist" OR "Peer Recovery Coach" OR "Peer Support" OR "Peer Recovery Specialist") AND (Program OR Intervention) (Supplementary file 1). Therefore, databases such as CINAHL, EMBASE, PubMed, and PsycINFO were searched using the search formula, and all cases for each combination of terms were substituted and correspondingly searched in the Korean databases. The articles retrieved from the databases were cataloged using the bibliographic management software (EndNote 20.2.1) and then reviewed and classified. No eligible article was found in the Korean databases, and the 870 English articles found in the international databases underwent the following screening process: First, 628 articles were extracted after removing duplicates. Second, in the review of titles and abstracts, 149 articles that did not meet the selection criteria were removed, leaving 93 articles. Third, an article that was not full text was deleted from the full-text review. Fourth, through the researcher's meeting, five articles in which participants were not SUD patients or had other mental disorders other than SUD were excluded, along with 80 articles that did not perform peer support intervention. Furthermore, 13 additional articles were searched for relevant literature during the full-text review, and eight articles were additionally analyzed through a search in Google Scholar. After removing one non-full-text article, six not including SUD patients, five without peer support intervention, and seven review articles not for intervention studies were removed. Finally, nine articles were selected for analysis at the researcher's meeting (Figure 1).

### Quality evaluation of the literature

The selected papers went through quality evaluation based on the Joanna Briggs Institute (JBI) checklists, which were separately applied to randomized clinical trials [21], quasi-experimental trials [22], and cohort studies [23]. The number of items and their contents of the JBI questions were applied differently depending on the study design, and each checklist is presented in Supplementary files 2–4. Each item is structured to be answered with "yes" (Y), "no" (N), "unclear" (UC), or "not applicable" (N/A). "Yes" indicated that the JBI quality evaluation standard was met. When evaluating the quality of articles using the JBI Quality Assessment Checklist, two researchers separately evaluated and compared them. In the case of disagreements, they were jointly evaluated by these researchers to reach a consensus. Table 1 presents the quality evaluation results for the nine articles selected.

### Analysis of the literature

The general characteristics of the selected articles were analyzed in the order of the country of study, year of publication, and research design and the PRC programs applied to SUD patients in the order of the program participants, type, content, results, and effects. Two independent researchers analyzed the literature. They



<sup>a</sup> Reason 1: The subjects were non-SUD patients (PRCs or experts) or SUD patients comorbid with other mental illnesses.  
<sup>b</sup> Reason 2: The studies did not involve peer support intervention or peer support was not the main program topic.  
<sup>c</sup> Reason 3: The papers were literature reviews or peer-reviewed articles.

Figure 1. PRISMA 2020 Flowchart of Study Selection.

reviewed the entire literature independently of each other and integrated their analysis results. Differing opinions were resolved through intensive discussions and reviews until a consensus was reached.

Presenting the results

Nine studies were included in this study, and their results are presented in the following section. The results of the integrative literature review are presented in the order of the general characteristics of the literature, the contents and implementation formats of the PRC programs, the role of the PRC, and the effects of the PRC programs.

Ethical considerations

This study was approved by the Institutional Review Board of G University (IRB No. GIRB-G221\*\*24).

Results

General characteristics of the literature

Table 2 outlines the general characteristics of the selected articles. All nine selected articles for analysis were US studies published in 1985 (1 article) and between 2008 and 2021 (8 articles). Randomized clinical trial was the most common research design

Table 1 JBI Critical Appraisal of Included Studies by Research Design.

Design/citation	Critical appraisal												
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13
<b>RCTs</b>													
Kirmil-Gray et al. (1985)	Y	Y	Y	Y	UC	Y	Y	Y	Y	Y	Y	Y	Y
Winhusen et al. (2020)	Y	Y	Y	UC	UC	Y	Y	Y	Y	Y	Y	Y	Y
Belenko et al. (2021)	Y	Y	Y	Y	UC	Y	Y	Y	Y	Y	Y	Y	Y
Ray et al. (2021)	Y	Y	Y	Y	UC	Y	Y	Y	Y	Y	Y	Y	Y
<b>Quasi-experimental studies</b>													
Ashford et al. (2019)	Y	N/A	N/A	N/A	Y	UC	Y	Y	Y	–	–	–	–
Cos et al. (2019)	Y	Y	N/A	N/A	Y	Y	N/A	Y	Y	–	–	–	–
<b>Cohort studies</b>													
Blondell et al. (2008)	Y	Y	Y	UC	UC	Y	Y	Y	Y	UC	Y	–	–
James et al. (2014)	Y	Y	Y	Y	Y	Y	Y	Y	Y	UC	Y	–	–
Mills Huffnagle et al. (2021)	Y	Y	Y	Y	Y	Y	Y	UC	UC	UC	Y	–	–

Note. N = no; N/A = not applicable; RCT = randomized controlled trial; UC = unclear; Y = yes.

**Table 2** General Characteristics of the Reviewed Articles (n = 9).

Category	Content	n	%
Country	USA	9	100
Published year	1985	1	11.1
	2008	1	11.1
	2014	1	11.1
	2019	2	22.2
	2020	1	11.1
Research design	2021	3	33.4
	RCT	4	44.5
	Quasi-experimental study	2	22.2
	Cohort study	3	33.3

Note. RCT = randomized controlled trial.

(n = 4, 44.5%), followed by cohort study (n = 3, 33.3%) and quasi-experimental study (n = 2, 22.2%). The effects of the programs applied in these articles were identified by comparing pretest-posttest design or cohort groups.

#### PRC program contents and implementation formats

Table 3 presents the PRC program types provided in each of the nine selected articles. The PRC programs were provided in face-to-face (offline) and contact-free (phone/messaging) formats. Four programs [24–26] used only face-to-face format, and four programs [28–31] used both formats. Only one program [32] exclusively used the contact-free format, which included phone calls, text messages, and email. A PRC ran one program [27], and two or more PRCs were involved in five studies. Each session ranged between 20 and 120 minutes, and the program applied in Ray et al. [27] was flexibly operated based on the participants' needs or preferences.

#### PRC's role

The roles played by PRCs in program operation were derived as follows. First, they recommended participation in a therapy program for SUD patients to be treated by specialists or encouraged attendance in a therapeutic intervention [25,28,29,31,32]. That is, they played the role of “navigator” for patients in their combat against SUD, enhancing their motivation for alcohol and drug abstinence and encouraging them to participate in self-help groups and therapeutic intervention programs. Second, they helped SUD patients better manage their stress [26] and control substance use by guiding them through practicing effective coping strategies in their living environment. Third, they sought to prevent substance abuse and relapse by providing SUD patients with emotional support [24], counseling, and case management services [27,31]. Fourth, they educated SUD patients about SUD recovery and recurrence prevention, explored community resources to help them with rehabilitation, and encouraged them to achieve their goals [30].

#### Effects of PRC programs

The variables used to identify the effects of PRC intervention were the extent of using substances such as alcohol and drugs [26–29,31,32], program participation rate [24,25,28–31], therapy motivation [27], self-efficacy [26,27], quality of life [28], stress [26], alcohol and drug abstinence [24], and the number of intensive care unit admissions due to substance use [29].

Table 3 presents the outcomes of PRC programs. Their effects can be summarized as follows. First, PRC programs had a positive

effect on reducing substance abuse. PRC intervention significantly impacted opioid overdose and regular intake of alcohol and substances and positively affected adherence to 7-day abstinence after discharge [24,28,29,32]. In some studies, however, the effect of reducing alcohol and illicit drug abuse declined over time, from 30.0% at the baseline to 16.0% over 6 months [27]. However, no statistical evidence was presented regarding the level of substance use reduction [32]. Second, PRC programs enhanced the treatment adherence rate. SUD patients made efforts for treatment by attending self-help programs or complying with rehabilitation programs [24]. SUD patients adhered more to treatment participation from referral to treatment. They also completed their treatment plans and did not miss treatment sessions [25]. Furthermore, they readily attended medical appointments [30], drug court engagement [31], and showed higher motivation for treatment [27]. However, statistically significant improvements could not be maintained [30]. Third, PRC programs effectively increased self-efficacy [26,27] immediately after the program and at the 1-year follow-up. Fourth, PRC programs improved the quality of life [28]. Fifth, they also positively affected stress control [24].

#### Discussion

This study was conducted to provide useful data for developing and applying PRC-delivered programs for SUD patients in South Korea and abroad by examining their contents, methods, and effects.

No Korean studies were encountered in the literature search for articles analyzing the effects of PRC programs, and foreign studies derived were predominantly US studies. Regarding research design, they were all quantitative studies. In South Korea, there are a few studies on PRC-delivered intervention in the field of social welfare. However, their focus was on the standpoints of PRCs or practitioners, and the research itself is in its incipient stage [33–35]. This may be attributable to a complex interaction of multiple factors associated with the immature PRC business model, such as a lack of PRC's role definition, unstructured work profile [36,37], distrust in the professionalism associated with the involvement of ex-addicts, and insufficient financial support [12]. Some qualitative studies aim to confirm the effectiveness of PRC participation in SUD. However, they revolve around interviews with practitioners or PRCs, not with SUD patients [38,39]. Given the importance of in-depth exploration and understanding of the changes and effects experienced firsthand by SUD patients, it is necessary to conduct further qualitative research to confirm the effects of PRC programs from the standpoint of SUD patients.

Regarding program delivery methods, PRC participation programs were mostly provided using hybrid formats of face-to-face and contact-free methods. The main reasons for adopting a contact-free approach by extending the existing face-to-face method include providing convenience and flexibility to compensate for accessibility constraints and mitigating the problems of shame and stigma by ensuring the participants' anonymity [40–42]. The recent difficulties encountered due to social distancing measures to cope with the COVID-19 pandemic led to temporary suspension or delay of SUD services and subsequent increases in relapse risk [40,43]. This highlighted the need to develop efficient contact-free SUD intervention programs, including PRC participation programs, in preparation for the current and future pandemics. Along with the diversification of program delivery methods, the involvement of two or more PRCs was advantageous over a single PRC participation. The substance abuse recovery process is self-directed, and each individual recovering from substance abuse is exposed to a unique experience of the withdrawal process. Therefore, it is necessary to adopt an approach

**Table 3** Summary of PRC-Delivered Program for SUD Patients.

Authors (yr)	Participants				Program type	Program contents	Significant outcomes				
	Exp. group		Ctr. group								
	n	Mean age (yr)	n	Mean age (yr)							
					Contact method	No. of PRCs	No. of sessions	Time per session	Periods (wk/mo)		
Kirmil-Gray et al. (1985)	6	48.00	6	52.00	Face-to-face	2	12	120 mins	12 wk	(1) Providing daytime stress treatment: merged the brief consultation treatment with direct instruction in specific skills to reduce physical tension and review mental arousal and group meetings and peer support for behavior change. (2) (a) Relaxation exercise: 10–15 mins. (3) (b) Reported on the quality of sleep, medication use, and homework completed during the previous week. (4) (c) New skills were presented followed by exercises that required participants to apply these skills to situations in their own lives (5) (d) Assignments to try out new skills in everyday situations during the coming week	All-night home polysomnographic recordings: (1) Latency to sleep onset ( $p = .04$ ) (2) Total wake time ( $p = .04$ ) (3) Sleep efficiency ( $p = .04$ ) (4) Total dark time ( $p = .04$ ) Self-efficacy: Limit early awakenings ( $p < .01$ ) Stress: Novaco Anger Scale ( $p = .04$ )
Blondell et al. (2008)	20	40.00	99	38.00	Face-to-face	2	N/A	30–60 mins	N/A	Providing emotional support to patients hospitalized for detoxification To enhance the patient's motivation to maintain abstinence To encourage the patient to attend meetings of self-help groups and initiate professional chemical dependency treatment after hospital discharge Explain involvement in self-help programs.	Abstinent for 7 days after discharge ( $p = .06$ ) Initiated rehabilitation services ( $p = .06$ ) Attended self-help program meeting ( $p = .05$ )
James et al. (2014)	681	28.63	681	28.57	Face-to-face	N/A	N/A	N/A	N/A	Providing outreach and engagement to parents recently referred to the program Served as “navigators” as the preferred parents initiated treatment for substance use disorders	Days from referral to assessment ( $p < .01$ ) Days from referral to first service ( $p < .01$ ) Completed treatment plan ( $p < .01$ ) Other reasons for closure ( $p < .01$ ) Discontinued participation ( $p < .01$ )
Ashford et al. (2019)	205	39.94	N/A	N/A	Face-to-face, phone call, text message	N/A	N/A	N/A	N/A	Referrals to a distinct level of care (e.g., withdrawal management, inpatient residential rehabilitation, recovery residence) Community-based referrals (e.g., mutual-aid support groups)	Multiple peer specialist engagements and regular alcohol use were significant Response to initial peer engagement and substances regularly used were significant
Cos et al. (2019)	350	47.30	N/A	N/A	Face-to-face, phone call	3	N/A	N/A	9 mo	To connect new patients to the FQHC and the peer specialist program included street outreach in high drug use locations, presentations at local shelters, recovery homes, and intensive outpatient treatment programs Conducted via phone and in-person visits to connect with clinic patients who had not contacted the medical clinic or peers in over 3 mo	Substance use outcomes Care and service utilization outcomes Behavioral health outcomes Quality of life, criminal justice system involvement, and infectious disease outcomes

Winhusen et al. (2020)	23	40.30	21	38.00	Phone call	4	N/A	20 mins	N/A	Encouraging participants to enroll in MOUD	Self-reported opioid overdose ( $p = .03$ )
Mills Huffnagle et al. (2021)	47	35.00	230	37.60	Face-to-face, phone call, text message, email	N/A	Weekly, gradually increasing or decreasing touchpoints as stages of recovery ( $M \pm SD = 14.0 \pm 18.2$ )	N/A	N/A	Providing education related to substance use disorder and the recovery process Development of long-term sustainable recovery through community resources Navigation through managed care systems Connections to appropriate resources Modeling a recovery lifestyle Empathizing with cravings to use or a return to use Developing use prevention plans Empowering participants to succeed in their identified goals	Medical appointments ( $p = .02$ )
Belenko et al. (2021)	39	28.20	37	26.70	Face-to-face, phone call	3		N/A	9 mo	Encourage participation in rehabilitation and treatment. PRC to have their first face-to-face contact with their client within five business days of the initial contact, followed by a minimum of three face-to-face meetings and one phone contact each month	Drug court engagement ( $p = .02$ )
Ray et al. (2021)	46	39.00	54	38.50	Face-to-face	1		Individualized based on client needs and preferences	12 mo	Offer guidance, support, and coordination of treatment services \$700 voucher support to cover the cost of the additional flexible recovery support services Substance use counseling and case management services	Treatment motivation (external motivation) after 6 mo ( $p = .04$ ) Self-efficacy after 12 mo ( $p = .03$ ) Alcohol or illegal drugs use decreased from 30% at baseline to 16% at 6 mo, which is not statistically significant

Note. Ctr = control; Exp = experimental; FQHC = federally qualified health center; M = mean; Mo = months; PRC = peer recovery coach; SD = standard deviation; Wk = weeks; yr = years.

emphasizing the pursuit of a personal agenda in conducting PRC programs [9,12]. For example, each US state has its coherent system of training and certifying PRCs [19], and a similar system is being adopted in South Korea [35]. In this context, particular care should be given to the coherency of the PRC education system to avoid confusion in defining PRC's roles, qualifications, and competency areas due to interregional and international differences.

This study confirms various roles of PRCs in preventing SUD relapse and recovery from SUD. This finding is supported by previous studies that report that PRCs can help SUD patients through their roles as emotional supporters, information providers, educators, liaisons between treatment and resources, role models, and mentors [39,44–46]. Furthermore, PRCs have experienced addiction problems themselves and continue to make efforts to prevent recurrence and maintain recovery in daily living. Therefore, this is a great strength in assuming their roles by providing SUD patients with efficient and concrete coping strategies based on an in-depth understanding of their situations [47]. However, the PRC model is faced with challenges such as role definition, personnel recruitment, and fundraising necessary for PRCs' activities at home and abroad [46,48]. For PRCs to act as an entity providing practical help to SUD patients by leveraging their strengths, it is necessary to establish a concrete and consistent role definition, policy approach, and multidisciplinary cooperation, including nursing.

In the articles reviewed, the effects of the programs provided with PRC involvement were evaluated through various outcome variables. Previous studies reported positive effects of PRC involvement in reducing participants' substance use [9,49] and enhancing the referral to treatment, self-efficacy [50,51], stress control [50], and quality of life [50,52]. However, there are also reports of contrary effects in different PRC participation studies, such as no significant difference in the participants' quality of life [53]. Some of the articles analyzed in this study reported no significant differences in the reduction of substance use or maintenance of treatment [27,30,32] and decrease in the effects [27]. Based on these discrepancies, we additionally attempted to perform the meta-analysis (Supplementary file 5) for three outcome variables (substance use, treatment participation rate, and self-efficacy) common to two papers, all three outcome variables had  $I^2$  values of 70 or higher, indicating that they were not homogeneous. In the analysis for effect size (effect size [95% confidence interval]), "reducing substance abuse" was found to be insignificant (1.03 [0.09, 12.44]). This might be because two studies reporting contradictory results were included in the analysis. Contrarily, "treatment participation rate" and "self-efficacy" were significant (4.51 [1.29–7.74] and 3.29 [1.11–5.48], respectively), and these can be interpreted that the PRC programs have the significant effects on "treatment participation rate" and "self-efficacy" for SUD subjects. However, the test included only the studies that presented all the necessary data for meta-analysis, so only some papers were analyzed (2 papers per each variable). Therefore, the meta-analysis results are likely biased. The research on PRC involvement programs is in a nascent stage and are few relevant studies. In addition, the outcome variables and methods applied to verify the effects of the programs are diverse. Based on the results of this study, follow-up studies applying meta-analysis are proposed to analyze the systematic and quantitative effects of the programs if more papers on the same topic are published in the future. In addition, depending on the existence of heterogeneity, analyzing the causes of the heterogeneity such as subgroup analysis and meta-regression would be needed.

Given the complexity of personal problems associated with substance abuse, various approaches are required to address SUD patients' recovery [54]. For evidence-based interventions with proven efficacy in substance abuse, including PRC involvement,

to be actively used, interdisciplinary endeavors and cooperation are required in clinical and community nursing settings. A previous study identified the negative attitudes of mental health experts as one of the major barriers to PRC involvement [12]. Nurses are in an ideal position to provide leadership in promoting the roles of PRCs in the clinical and community settings [12]; therefore, these barriers should be addressed by concerted efforts to verify the efficacy and improve the perceptions of PRCs' activities in the nursing arena. Development and application of nursing intervention programs with PRCs involvement based on PRC's activities and empirical research results will improve participants' mental health, diversify the approach in the related nursing practice in Korea, and improve the competency of nursing practitioners.

This study provides basic data and a rationale for developing nursing interventions that can create synergy effects with PRCs by presenting results regarding the contents, methods, and effects of PRC involvement in programs in the substance abuse fields. The results of therapeutic use of the lived experiences of PRCs related to relapse prevention and recovery maintenance provide opportunities for nursing students to understand addicts in greater depth; in addition, meaningful information can be provided for the students to plan nursing interventions and educational programs with PRCs. By identifying the roles of PRCs and examining the effectiveness of the PRC involvement programs, it is also possible to reduce prejudice and promote understanding by health professionals.

Despite the significance of this study, there are also limitations. First, the articles selected for analysis are regionally concentrated in a specific country, which affects the generalizability of the results drawn in this study in applying them to the entire SUD patients participating in PRC-delivered intervention programs. Second, by analyzing the effects of PRC programs from the standpoint of SUD patients, the perspectives of practitioners and PRCs involved could not be considered. Therefore, an integrative analysis of the effects of PRC participation programs in different fields is necessary to expand the research scope.

## Conclusions

This study was conducted to identify the main contents, methods, and effects of the PRC-delivered intervention in the field of substance abuse from the participants' standpoint through an integrative literature review. This literature analysis confirmed the need to conduct research in different countries using various research designs to address the problems of regional concentration of research activities in the US and the methodological predominance of quantitative research. It was also found that face-to-face and contact-free intervention programs used a wide range of contents and approaches to the treatment of and recovery from substance abuse in addressing the complexity of substance abuse issues, which may serve as basic data useful in preparing for the current and future pandemics. In addition, PRCs' roles in linking treatment and resources, stress management and coping, emotional support, counseling, and case management, and PRCs' positive influence reduced substance use and improved participants' referral rates to treatment and psychosocial help. These research findings are expected to provide important primary data and guidelines for developing and implementing intervention programs with PRC involvement in clinical and community nursing settings in the future. Specifically, they might also present the necessary direction and rationale for attempting continuous changes in South Korea, which is in its incipient stage of research on examining the application and efficacy of PRC participation programs.



## Conflict of interest

The authors declare no conflict of interest.

## Acknowledgments

This research was supported by the National Research Foundation of Korea (NRF) grant funded by the Korea government (MSIT) (Reference number: NRF-2021R1G1A1094282).

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## Research Article

# Development and Evaluation of a Mobile Web-based Food Allergy and Anaphylaxis Management Educational Program for Parents of School-aged Children with Food Allergy: A Randomized Controlled Trial

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## ARTICLE INFO

## Article history:

Received 16 November 2021

Received in revised form

7 October 2022

Accepted 25 October 2022

## Keywords:

food allergy

health behavior

internet-based intervention

parents

## SUMMARY

**Purpose:** This study aimed to develop a mobile web-based food allergy (FA) and anaphylaxis management educational program for parents of school-aged children with food allergies and evaluate its effectiveness.

**Methods:** A mobile program was developed based on a web-based teaching-learning system model. Its effectiveness was subsequently evaluated using a parallel, randomized controlled pre- and post-test design. This study included 73 parents of school-aged children with food allergies. These parents were randomly assigned to either the experimental (n = 37) or control (n = 36) groups. The experimental group participated in a 2-week mobile web-based educational program that covered major topics in FA and anaphylaxis management. These topics included an understanding of food allergies and anaphylaxis, learning techniques for using an epinephrine auto-injector, and developing an emergency action plan. An educational booklet was provided to the control group. Participants completed a pre-test and two post-test questionnaires to evaluate the impact of the program. The assessment tools were the Food Allergy Knowledge Test, Food Allergy Self-Efficacy for Parents, and Food Management and Adaptation Scale. The data were analyzed using descriptive statistics, a test of homogeneity for the pre-test, an independent t-test, and repeated measures ANOVA.

**Results:** The experimental group experienced greater improvement in the knowledge of FA (post-intervention t = 14.51, p < .001; 2 weeks post-intervention, t = 16.15, p < .001), FA self-efficacy (post-intervention t = 77.99, p < .001; 2 weeks post-intervention, t = 76.09, p < .001), and practice behavior in FA management (post-intervention t = 28.10, p < .001; 2 weeks post-intervention, t = 27.98, p < .001) after web-based FA education.

**Conclusion:** This study revealed improvements in the knowledge, self-efficacy, and practice behaviors of parents regarding FA and anaphylaxis management. Therefore, the mobile web-based educational program can contribute to the effective management of food allergies and anaphylaxis for parents of school-aged children. CRIS registration: KCT0007491.

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## Introduction

Food allergy (FA) is an abnormal immune response of the body to otherwise harmless food. FA reactions mediated by immunoglobulin E (IgE) can cause hives, breathing difficulties, and gastrointestinal

symptoms. Furthermore, FA symptoms can range from mild to severe, and in rare cases, lead to anaphylaxis, which is potentially fatal [1–4]. There is an increasing number of these severe and potentially life-threatening allergic reactions (anaphylaxis) in children [5–9].

FA is estimated to affect 2–10.0% of the population, with higher rates among school-aged children than among adults [6,7]. In South Korea, the prevalence of diagnosed FA in school-aged children was 4.6%, 5.2%, 6.4%, 5.5%, and 6.6% in 1995, 2000, 2005, 2008, and 2012, respectively [8,9]. The prevalence of immediate-type FA among school-aged children was found to be 5.3%, with hen's egg, cow's milk, peanuts, tree nuts, wheat, and seafood as the leading causes of this reaction [2,10,11]. With the increasing prevalence of FA over the

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<https://doi.org/10.1016/j.anr.2022.10.002>

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last two decades, the care of school-aged children with life-threatening allergies has become a major challenge for parents. Moreover, food-induced anaphylaxis data revealed that 30.0% of anaphylactic reactions occur in schools [12].

There is no known cure for FA. Therefore, strict avoidance of food allergens and early recognition and management of allergic reactions are important measures for the prevention of serious health consequences [9,13]. Childhood FA has a wide-ranging effect on parental quality of life; it creates a burden for meal preparation, social activity limitations due to dietary restrictions, anxiety over unintentional exposure, fear of leaving the child in the care of others, and life-threatening allergic reactions [14,15]. Although FA and food-induced anaphylaxis practice guidelines with comprehensive education have been proposed for parents, parents often experience a high degree of anxiety when their child is diagnosed with FA. Parents also report a fear of handing over the main responsibility for allergen avoidance to their children [14].

School-aged children require care that promotes a healthy lifestyle and well-being, including a positive sense of self and the ability to cope with stressful situations [15]. Parents are an essential resource for children to manage their health and behavior. Thus, parenting knowledge, attitudes, and practices are associated with positive parent-child interactions and healthy development in children [16]. Although the risk of anaphylaxis is low, it can occur after the consumption of certain foods at home, school, and in public places. In South Korea, 74.7% of life-threatening allergies among school-aged children are related to food-induced anaphylaxis [9]. Therefore, parents and caregivers should be aware of FA management, the risk of life-threatening allergies, and timely responses [17]. In this context, various interventions have been developed worldwide to evaluate the effectiveness of improving FA management and supporting the quality of life for families [17]. Some interventions designed to improve parental knowledge and self-efficacy in managing and coping with FA management enhance their ability to respond more effectively to their child's risk-related episodes and promote allergy management throughout their daily lives [18]. These studies improve parental knowledge and confidence in allergy management. However, they require actual allergy management practices (e.g., label reading, cross-contamination, and auto-injector administration) that may not be available in all treatment settings. To establish actual management practices, education should encourage voluntary reporting and practice through ongoing interactive online learning rather than in a single course [18]. In addition, interventions are diverse and have yet to achieve the desired effect on different outcome measures. Therefore, the optimal format, as well as evidence-based content and a combination of intervention components, requires further investigation [14].

In South Korea, increasing interest in FA and anaphylaxis has led to extensive research on their mechanism, diagnosis, and treatment [12]. However, developing evidence-based guidelines, including standard educational protocols that can improve both the quality of care and patient outcomes, is equally critical [19]. In response, the South Korea Center for Disease Control and Prevention (KCDC) has published and distributed guidelines for the management of food allergies and anaphylactic reactions in preschools, schools, and public places in accordance with evidence-based research since 2013 [20]. These guidelines seek to effectively provide care to children with known FA and enable the recognition of symptoms of allergic reactions in both diagnosed and undiagnosed children to foster timely responses to emergency needs [21]. Previous studies have demonstrated the necessity of developing a parent education program that facilitates the communication of practical information and uses credible educational resources to support effective allergy management [18,22]. Because parents of children with food allergies tend to make childcare and school decisions based on their

knowledge [22], they need an educational program that follows evidence-based guidelines to make informed decisions about school and social activities [23].

There has been an increase in the number of parents working fulltime in recent years, making face-to-face education challenging [24]. Online learning interventions provide an opportunity to facilitate distance education [25]. Most of these methods use an internet-connected network that enables regular and reliable availability of information and offers learner-centered interventions using audio, video, and text to communicate with learners [26,27]. This can help create a collaborative and interactive nursing intervention environment where learners can be engaged, provide immediate feedback, and ask questions [28]. In addition, online learning interventions are more cost-effective than traditional lectures and can maintain anonymity and privacy [29].

This study aimed to develop and verify the effectiveness of a mobile web-based FA and anaphylaxis management educational program for parents. The educational content, both for the experimental group that participated in the online learning program and the control group that received a booklet, is based on KCDC guidelines. The study hypothesis was as follows: the parents who participated in the intervention (online learning group) would have increased knowledge, self-efficacy, and improved practice behavior compared to that in the control group (booklet distribution group).

## Methods

### Study design

This study describes the development process of a mobile web-based FA and anaphylaxis management educational program. Furthermore, it evaluates the effectiveness of online learning among parents of school-aged children with food allergies using a parallel, randomized controlled pre- and post-test design. This study was registered at [cris.nih.go.kr](http://cris.nih.go.kr) (KCT0007491).

### Development process of a mobile web-based FA and anaphylaxis management educational program.

In this study, a mobile web-based educational program was developed based on Jung's [30] web-based teaching-learning system model. The five-stage process involved analysis, design, development, application, and evaluation. In the first stage, we analyzed the KCDC guidelines, literature, user needs assessment, and conducted expert interviews. In the design stage, we established learning objectives, educational content, and user-friendly web design. We collaborated with web development experts for mobile web-based program development during the third stage. In the application and evaluation stages, an operating web server was created, evaluation by an expert and a user were performed, and the mobile web-based educational program was modified and updated accordingly.

### Evaluating the mobile web-based FA and anaphylaxis management educational program.

### Setting and samples

A total of 73 participants (experimental group, 37; control group, 36) were included in this study. Parents of school-aged children with FA from the Atopy Education Information Center in South Korea were invited to participate in the study. The inclusion criteria were as follows: (1) parents of children who had been diagnosed with FA, who voluntarily agreed to participate; (2) parents of children between 6 and 12 years of age; and (3) parents who could access the internet through desktop computers, tablets, or mobile devices.

The sample size needed for repeated-measures analysis of variance (ANOVA) was calculated using G\*Power 3.1 [31]. A total sample size of 44 participants (22 in each group) was required for a significance level ( $\alpha$ ) of .05, power of .95, medium effect size ( $f^2$ ) of 0.25, correlation among repeated measures of .05, and two groups across the three measurements. We used an effect size of 0.25 based on a prior study [28], wherein the medium effect size of a web-based educational program and a power of .95 were used to obtain a larger sample that supports the hypothesis. Considering the drop-off rate, we recruited 80 participants and randomly assigned them to the experimental and control groups, with 40 participants in each group. A research assistant, who was not involved in the study, independently conducted randomization using an allocation program ([www.randomizer.org](http://www.randomizer.org)). The participants were placed into the experimental and control groups using an opaque sealed envelope. Participants were blinded to the allocation to prevent the discovery of their assigned study group. After excluding participants who were not involved in the program ( $n = 2$ ) or had incomplete data for the post-test ( $n = 5$ ), data from 73 participants (37 experimental and 36 control) were included in the final analysis (Figure 1).

*Ethical consideration*

This study was approved by the Institutional Review Board of Sahmyook University, South Korea (IRB NO:2-7001793-AB-N-0120180V80HR). Participants received information on the eligibility

criteria, purpose, and procedures of the study. Furthermore, eligible participants signed informed consent and were assured of confidentiality. Participants could also voluntarily withdraw without any adverse consequences. All participants were provided a small compensation (a skin moisturizing kit). After collecting the post-test data, access to the mobile web-based educational program was provided to participants in the control group.

*Measurements*

FA knowledge, self-efficacy, and practice behavior in FA management were assessed using questionnaires. The questionnaires were translated by an English translator using a translation and back-translation procedure following permission from the author. The content was verified by three pediatric allergists, three nursing professors, one nurse, and one dietitian. The content validity index (CVI) was calculated using the proportion of items, where experts gave three or four points on a four-point scale (four points for ‘very appropriate’ and one point for ‘not at all appropriate’) [32]. When the CVI was .80 or higher, it was determined that the content validity was secured [32].

*FA knowledge*

FA knowledge was assessed using the Food Allergy Knowledge Test (FAKT) developed by Hahn [33]. Four items with CVI scores

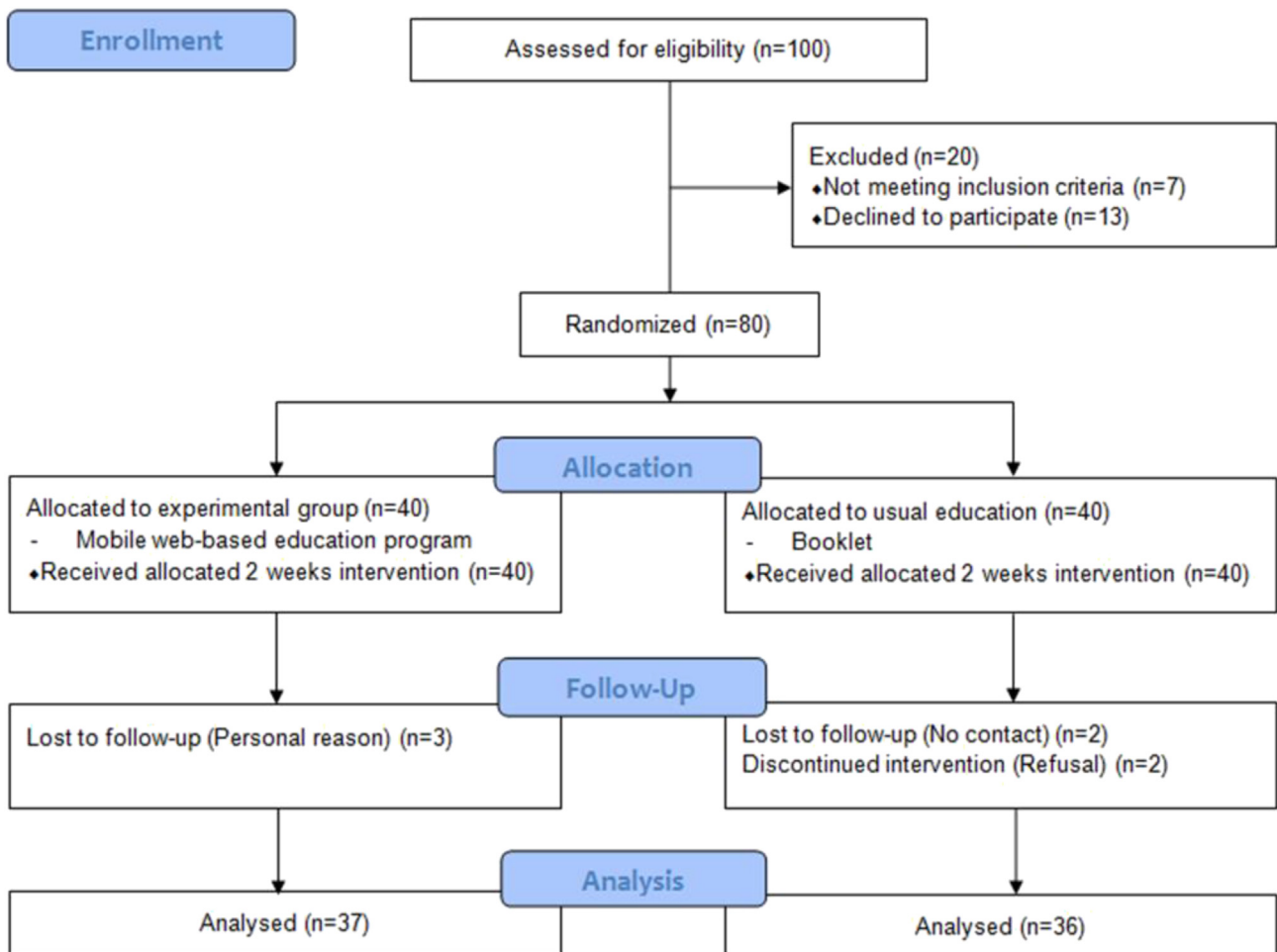


Figure 1. Participant Flowchart.

lower than .80 were eliminated in the FA knowledge scale. This tool consists of 53 questions that address the following: food avoidance (7), knowledge of FA (6), using an EpiPen (13), understanding anaphylactic shock (4), and symptoms (23). “One” point was given for a correct answer and “zero” for an incorrect or unknown answer. The maximum total score is 53 points, with a higher score indicating higher FA knowledge. A previous study reported its initial development with a Cronbach's  $\alpha$  of .86 [33]. In this study, the Cronbach's  $\alpha$  was .95. We obtained permission from the author to use FAKT.

#### *Self-efficacy in FA management*

Self-efficacy in FA management was assessed using the Food Allergy Self-Efficacy for Parents (FASE-P), which was developed by Knibb et al. [34]. This tool consists of 22 items: six on managing social activities, seven on precaution and prevention, three on allergy treatment, three on food allergen identification, and three on seeking information about FA. CVI values for each item ranged from .88 to 1.00. Moreover, questions were rated on a 10-Likert scale (0 = not at all to 10 = very much so). The total maximum score was 220 points, with higher scores indicating higher self-efficacy confidence. In a previous similar study, the Cronbach's  $\alpha$  was .88 [34]. The reliability of the instrument was indicated by a Cronbach's  $\alpha$  of .97. We obtained permission from the author to use FASE-P.

#### *Practice behavior in FA management*

Practice behavior in FA management was assessed using the Food Management and Adaptation Scale (FAMAS). This tool was developed by Klinnet et al. [35] and consists of 11 items: 10 on FA management and 1 on balanced integration. Each item had a CVI value ranging from .88 to 1.00. Questions were rated on a nine-Likert scale (one = not at all to nine = very much so). The maximum total score was 99 points, with a higher score indicating more positive practice behavior. In a previous study, Cronbach's  $\alpha$  ranged from .91 to .98 [35]. Here, Cronbach's  $\alpha$  was .95. Permission to use this tool was obtained from the authors.

#### *Data collection and procedure*

Measurements were performed at baseline, post-intervention, and 2 weeks post-intervention at the Atopy Education Information Center, Seoul city. Data from the pre-test were collected from patients who visited the center, met the selection criteria, and signed an informed consent form agreeing to participate in the study. To prevent contamination, control group data were collected from October to November 2018, and experimental data were collected from November to December 2018. To protect the personal information of participants, members were granted access by the researcher as a program system administrator when registering on the site. After approval, security was maintained to prevent the exposure of personal information and content. A questionnaire was allotted by a researcher for assessment, whereas the pre- and post-tests were conducted by a researcher who was unaware of the group assignment. The researcher monitored learning history after registering to check the learning process of the experimental group.

For the control group, a small booklet titled “FA and anaphylaxis management” was created and distributed. A mobile text message was sent to remind participants to read the booklet twice a week for 2 weeks. Next, a follow-up survey was conducted immediately post-intervention (booklet distribution) and 2 weeks post-intervention. A previous study showed that the 2-week intervention period of transformation into practice was related to knowledge and self-efficacy [36].

For the experimental group, the mobile web-based educational program for FA and anaphylaxis management was delivered for 2 weeks, five times per week, for approximately 45 min/day (Table 1). The experimental group could access the website and listen to the lecture any time during the 2 weeks.

#### *Statistical analyses*

All statistical analyses were performed using SPSS (version 21.0; IBM Corp., Armonk, NY, USA). The general characteristics of participants were calculated using the frequency, percentage, mean, and standard deviation. The between-group homogeneity of the dependent variables was analyzed using the Chi-square, Fisher's exact, and independent t-tests. Moreover, FA knowledge, self-efficacy, and practice behavior in the FA management of the intervention time or between groups were analyzed using repeated-measures ANOVA and independent t-test. Five incomplete data points were excluded from the analysis. Therefore, there were no missing values. The assumptions of normality and homogeneity of variance for the study variables were checked for normality (skewness, 0.89–2.22; kurtosis, 1.58–4.31), Leven's statistics for homogeneity of variance in FA knowledge (0.55,  $p = .460$ ), self-efficacy (2.89,  $p = .093$ ), and practice behavior (0.00,  $p = .991$ ). Finally, the Greenhouse–Geisser value was used because the assumption of sphericity was not met (FA knowledge:  $W = 0.12$ ,  $p < .001$ ; self-efficacy:  $W = 0.02$ ,  $p < .001$ ; practice behavior:  $W = 0.07$ ,  $p < .001$ ).

## **Results**

### *Development of a mobile web-based FA and anaphylaxis management educational program*

We reviewed the KCDC guidelines to determine the recommended curriculum and educational content. To discuss educational program needs and preferences of parents, we conducted focus group discussions through semi-structured interviews with parents of school-aged children, who have previously been diagnosed with FA and have been administered an epinephrine auto-injector. Interviews were conducted with FA experts, including a dietitian, two nurses, and two allergists. In addition, the scope and content of the learning material contained on the website were evaluated in relation to FA-related information available on the Ministry of Food and Drug Safety website. Integration of the findings from this stage helped us plan the content of the educational program. The survey revealed that the desired educational content included four main topics: understanding FA, anaphylaxis, techniques for using an epinephrine auto-injector, and emergency action plans.

Two web designers and the researcher designed the webpages during the design stage. There were four headings on the main screen: FA, anaphylaxis, epinephrine auto-injector, and emergency action plan. FA-related website links were also provided to access additional information. To create a user-friendly website, a responsive web design (RWD) that gives every user a flawless online experience was implemented [29]. The menus were well-positioned on the top left corner of the site to help users identify the educational content. Icons designed to enhance the aesthetic appeal of educational content, as well as updated information and notification services, were provided in real time to enable users to regularly interact with the content.

In the development stage, the interactive mobile web educational program was developed through a storyboard that provided details of an entire website to make lessons more meaningful and interesting. The curriculum consisted of 4 sessions (themes) and 23

**Table 1** The Contents of Mobile Web-based Food Allergy Management Education Program.

Session/theme	Day	Program contents	Time (min)	Method
1. Food allergy general knowledge and management	1	Program instruction	5	Online lecture (PPT, audio, video) Formative evaluation
		The comparison of food allergy, food intolerance, and food poisoning/review/quiz and feedback	10/2/3	
		The signs and symptoms of an allergic reaction and risk factors/review/quiz and feedback	10/2/3	
	2	Q & A and discussion	10	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Food allergen according to age (preschool, elementary, high school level)/review/quiz and feedback	10/2/5	
	3	Know which food allergens commonly cross-react/review/quiz and feedback	10/2/5	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Q & A and discussion	15	
		Prevalence of food allergy according to age/review/quiz and feedback	5/2/3	
	4	The relationship between atopic dermatitis and food allergy/review/quiz and feedback	5/2/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		The importance of diagnosis and the principles of treatment/review/quiz and feedback	/2/3	
		Q & A and discussion	15	
		Be aware of food avoidance, food cross-contamination, food label/review/quiz and feedback	6/2/3	
	5	How to prepare safe meals/review/quiz and feedback	6/2/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Cookware and kitchenware quality management/review/quiz and feedback	6/2/3	
		Q & A and discussion	15	
2. Anaphylaxis general knowledge and management	6	Well-balanced diet through a nutritious alternative/review/quiz and feedback	10/2/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Coordinate local community support (home, playgroup, schools)/review/quiz and feedback	10/2/3	
	7	Q & A and discussion	15	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Understanding the mechanisms of anaphylaxis/review/quiz and feedback	10/2/3	
		Identify precipitating causes initiate relevant investigations/review/quiz and feedback	10/2/3	
	8	The critical signs and symptoms suggestive of anaphylaxis/review/quiz and feedback	15	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Q & A and discussion	15	
		The common and uncommon foods that trigger hypersensitivity reactions/review/quiz and feedback	5/2/3	
		Management and treatment/review/quiz and feedback	6/2/3	
	9	The importance of prescription epinephrine auto-injectors and how to use correctly /review/quiz and feedback	7/2/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
Q & A and discussion		15		
3. Epinephrine auto-injector	9	How to undertake emergency management of anaphylaxis/review/quiz and feedback	5/2/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Considerations and management for eating out, social activities, daily life/review/quiz and feedback	5/2/3	
4. Anaphylaxis emergency action	10	Prevention and precaution at home and in schools/review/quiz and feedback	6/2/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Q & A and discussion	15	
3. Epinephrine auto-injector	9	How to properly use and practice epinephrine auto-injector in the event of a severe allergic reaction/review/quiz and feedback	17/5/3	Online participation (webinar) Online lecture (PPT, audio, video) Formative evaluation
		Q & A and discussion	20	
4. Anaphylaxis emergency action	10	Information on steps to take during and after an allergic emergency/review/quiz and feedback	17/5/3	Online participation (webinar)/ demonstration Online lecture (PPT, audio, video) Formative evaluation
		Q & A and discussion	20	

topics (Table 1). The duration of each session was approximately 30 min through teaching–learning materials (PowerPoint, audio, or video), which offered the main lecture on the topic (Table 1). The review, quiz, and feedback with 1:1 coaching were provided for 5 min at the end of each topic to encourage continuity of learning. The interactive online discussion held through a webinar lasted for approximately 10–15 min. This discussion was held to enhance the ability of users to understand educational content. Before the class, the program information and schedule were shown on the bulletin board. To support autonomous learning, a question-and-answer (Q & A) session was conducted through the website and mobile text. A

total of 86 storyboards were converted to a booklet PDF format that was uploaded on the website.

During the application stage, the mobile web-based educational program, termed “FA and anaphylaxis management,” was implemented in the experimental group after validation by seven experts. The criteria for evaluating the educational curriculum included its comprehensiveness, alignment with the standard, consistency with objectives, relevance, efficacy, effectiveness, reliability, impact, and sustainability. The results for evaluating the website (1–4 points) were accuracy (4 points), objectivity (4 points), currency (4 points), authority (3.8 points), and coverage



(3.6 points). All parents, who completed the mobile web-based educational program, reported on system efficacy (3.9 points), system convenience (3.8 points), design (3.8 points), reliability of information (3.8 points), and usefulness of information (3.8 points).

#### Effectiveness of the mobile web-based intervention

##### Participant characteristics and homogeneity tests

A total of 73 parents of children with FA participated in this study, with 37 parents randomized to the experimental group and 36 to the control group. As indicated in Table 2, no significant differences in characteristics were found between the two groups. The mean age of participants was  $38.00 \pm 0.11$  years in the experimental group and  $37.81 \pm 1.37$  years in the control group. In both groups, most participants were mothers (experimental group, 83.3%; control group, 75.0%). The children included 42 boys (57.5%) and 31 girls (42.5%) with FA. The mean age of children whose parents were assigned to the experimental group was  $8.73 \pm 2.19$  years, whereas that of children whose parents were assigned to the control group was  $8.08 \pm 2.35$  years. The products most frequently responsible for reactions were milk (experimental group, 54.1%; control group, 38.9%), eggs (experimental group, 21.6%; control group, 22.2%), nuts (experimental group, 10.8%; control group, 19.4%), wheat (experimental group, 10.8%; control group, 16.7%), and shellfish (experimental group, 2.8%; control group, 2.8%). In the homogeneity test, no significant differences were found in FA knowledge ( $t = -0.84, p = .405$ ), self-efficacy ( $t = -0.51, p = .610$ ), and practice behavior in FA management ( $t = -1.41, p = .163$ ) between the two groups at baseline.

##### Hypothesis verification

**FA knowledge:** A significant difference was found in the interaction between the groups and time (time:  $F = 576.73, p < .001$ ; groups:  $F = 68.97, p < .001$ , time by group:  $F = 124.63, p < .001$ )

(Table 3) (Figure 2A). The mean and estimated mean are the same when rounded to the third digit after the decimal point. Therefore, the estimated mean is not indicated in Table 3. The experimental group showed significantly greater improvement in knowledge scores than by the control group both at the post-intervention ( $t = 14.81, p < .001$ ) and 2-week follow-up ( $t = 16.15, p < .001$ ). The mean scores for FA knowledge from baseline to post-intervention and 2-week follow-ups were 13.05, 49.73, and 49.16, respectively, in the experimental group and 15.25, 30.89, and 26.41 in the control group. The FA knowledge scores were significantly different between the post-intervention and 2-week follow-up in both the experimental ( $t = 3.60, p = .001$ ) and control groups ( $t = 9.24, p < .001$ ). These results support our hypothesis.

**Self-efficacy in FA management:** A significant difference was found in the interaction between the groups and time (time:  $F = 7308.92, p < .001$ ; groups:  $F = 166.74, p < .001$ , time by group:  $F = 625.21, p < .001$ ) (Table 3; Figure 2B). The experimental group showed significantly greater improvement in self-efficacy scores than the control group at both the post-intervention ( $t = 18.64, p < .001$ ) and 2-week follow-up ( $t = 18.38, p < .001$ ). In the experimental group, the mean scores for self-efficacy from baseline to post-intervention and 2-week follow-ups were 2.55, 8.24, and 8.21, respectively. In contrast, these scores were 2.62, 5.72, and 5.73 in the control group. The self-efficacy scores were significantly different between the post-intervention and 2-week follow-up in the experimental group ( $t = 3.90, p < .001$ ), but there was no significant difference in the control group ( $t = -1.22, p = .230$ ). These results support our hypothesis.

**Practice behavior in FA management:** A significant difference was found in the interaction between the groups and time (time:  $F = 5411.80, p < .001$ ; groups:  $F = 386.53, p < .001$ , time by group:  $F = 1285.84, p < .001$ ) (Table 3; Figure 2C). The experimental group showed significantly greater improvement in practice behavior scores than the control group at both the post-intervention

**Table 2** Homogeneity Test of General Characteristic between Experimental and Control Groups at Baseline ( $N = 73$ ).

Characteristics		Categories	Total (n = 73) n (%)	Exp. (n = 37) n (%)	Cont. (n = 36) n (%)	$\chi^2$ or t	P
Parents	Age (M± SD)			38.00 ± 0.11	37.81 ± 1.37	0.67	.506
	Gender	Women	58 (79.5)	31 (83.8)	27 (75.0)	0.86	.353
		Men	15 (20.5)	6 (16.2)	9 (25.0)		
	Education	≤ High school	12 (16.4)	7 (18.9)	5 (13.9)	0.37	.562
		≥ college	61 (83.6)	30 (81.1)	31 (86.1)		
	Work	Two-income family	29 (39.7)	14 (37.8)	15 (41.7)	0.11	.74
Single-income family		44 (60.3)	23 (62.2)	21 (58.3)			
Education experience of food allergy	Yes	9 (12.3)	5 (13.5)	4 (11.1)		.999†	
	No	64 (87.7)	32 (86.5)	32 (88.8)			
Child	Age (M± SD)			8.73 ± 2.19	8.08 ± 2.35	1.21	.230
	Gender	Boy	31 (42.5)	18 (48.6)	13 (36.1)	1.17	.279
		Girl	42 (57.5)	19 (51.4)	23 (63.9)		
	Allergen(s)	Egg	16 (21.9)	8 (21.6)	8 (22.2)	2.26	.687
		Peanuts	11 (15.1)	4 (10.8)	7 (19.4)		
		Wheat	10 (13.7)	4 (10.8)	6 (16.7)		
		Shellfish	2 (2.7)	1 (2.8)	1 (2.8)		
	Symptoms	Milk	34 (46.6)	20 (54.1)	14 (38.9)		
		Urticaria	50 (65.8)	26 (70.3)	24 (66.7)	4.67	.457
		Diarrhea	9 (1.3)	6 (16.2)	3 (8.3)		
		Lip swelling	11 (16.4)	4 (10.8)	7 (19.4)		
	Difficulty breathing		5 (8.3)	2 (5.4)	3 (8.4)		
		Yes	7 (9.6)	4 (10.8)	3 (8.3)	0.13	.719
		No	66 (90.4)	33 (89.2)	33 (91.7)		
	History of epinephrine injection	Yes	2 (28.6)	1 (25.0)	1 (33.3)	0.06	.809
No		5 (71.4)	3 (75.0)	2 (66.7)			
History of emergency department visit	Yes	7 (9.6)	4 (10.8)	3 (8.3)	0.13	.719	
	No	66 (90.4)	33 (89.2)	33 (91.7)			

Note: Exp. = experimental group; Cont. = control group; M±SD = mean ± standard deviation.

†Fisher's exact test.

**Table 3** Comparison of Knowledge, Self-efficacy, and Practice Behavior between Experimental and Control Group (N = 73).

Variable	Pre-test		Post-test 1		Post-test 2		Post 1-pre		Post 2-pre		Post 2-post 1		Sources	F(p)
	M <sup>a</sup> ± SD (SE)	t(p)	M <sup>a</sup> ± SD (SE)	t(p)	M <sup>a</sup> ± SD (SE)	t(p)	t(p)	t(p)	t(p)	t(p)				
<b>Knowledge</b>														
Exp. (n = 37)	13.05 ± 11.79 (1.84)		49.73 ± 1.56 (0.88)		49.16 ± 1.70 (0.98)		19.64 (<.001)		19.48 (<.001)		3.60 (.001)		Time	576.73 (<.001)
Cont. (n = 36)	15.25 ± 10.60 (1.87)		30.89 ± 7.47 (0.89)		26.42 ± 8.28 (0.99)		16.9 (<.001)		15.08 (<.001)		9.24 (<.001)		Group	68.97 (<.001)
t(p)			14.81 (<.001)		16.15 (<.001)								Time × Group	124.63 (<.001)
<b>Self-efficacy</b>														
Exp. (n = 37)	2.55 ± 0.55 (0.10)		8.24 ± 0.51 (0.10)		8.21 ± 0.52 (0.10)		77.99 (<.001)		76.09 (<.001)		3.90 (<.001)		Time	7308.92 (<.001)
Cont. (n = 36)	2.62 ± 0.63 (0.10)		5.72 ± 0.64 (0.10)		5.73 ± 0.63 (0.10)		42.90 (<.001)		44.33 (<.001)		-1.22 (.230)		Group	166.748 (<.001)
t(p)			18.64 (<.001)		18.38 (<.001)								Time × Group	625.21 (<.001)
<b>Practice behavior</b>														
Exp. (n = 37)	2.38 ± .61 (0.09)		8.27 ± .50 (0.09)		8.27 ± .50 (0.09)		72.26 (<.001)		72.26 (<.001)		.00 (.999)		Time	5411.80 (<.001)
Cont. (n = 36)	2.56 ± .52 (0.10)		4.60 ± .61 (0.09)		4.59 ± .62 (0.09)		30.28 (<.001)		28.68 (<.001)		.92 (.373)		Group	386.53 (<.001)
t(p)			28.10 (<.001)		27.98 (<.001)								Time × Group	1285.84 (<.001)

Note: Exp. = experimental group; Cont. = control group; FA = food allergy; M<sup>a</sup>±SD = mean ± standard deviation; SE = standard error.

<sup>a</sup> Estimated mean and mean are the same when rounded to the third digit after the decimal point.

( $t = 28.10, p < .001$ ) and 2-week follow-ups ( $t = 27.98, p < .001$ ). The mean scores for practice behavior from baseline to post-intervention and 2-week follow-ups were 2.38, 8.27, and 8.27, respectively, in the experimental group and 2.56, 4.60, and 4.59 in the control group. The practice behavior scores in both the experimental group ( $t = 0.00, p = .999$ ) and the control group ( $t = 0.92, p = 0.373$ ) did not show significant differences between the post-intervention and 2-week follow-up. These results support our hypothesis.

## Discussion

### Development of a mobile web-based FA and anaphylaxis management educational program

School-aged children with FA and their parents have first-hand experience with allergic reactions and should be involved in school decisions [37]. Web-enabled devices, such as smartphones, tablets, and laptops, have evolved into essential tools for education, communication, and information [26]. The findings of this study suggest that online learning is more effective than open lectures for the self-management of FA [35]. This evaluation of online learning content showed that RWD, offering a seamless experience on any device, has been recommended because all users have access to all digital devices [29]. RWD enables the design of sites for different device types, making maintenance easier over time for learners. However, communication and human contact between learners and educators are difficult to facilitate [38]. Therefore, effective development of educational methods requires the design of online discussions that offer a tool through which learners can actively participate in a more meaningful manner than in face-to-face instructional teaching [27]. The participants acknowledged that the learning process was improved by reflecting on their knowledge and establishing learning strategies with practice through 1:1 coaching and online discussion. However, some participants were not motivated to practice. Therefore, adding coaching to promote self-reflection and facilitate encouragement may be helpful in future educational programs.

In this study, online course time was approximately 45 min as a relative learning time for promoting the development of the parental awareness program to care for children with food allergies [36]. In a previous study, learners were able to learn various educational strategies and skills through repetition and effective communication [28]. Therefore, the online learning program in this study emphasizes competency reinforcement and problem-solving ability through repetition. It provided effective online communication approaches, such as quizzes and feedback, update and notification services, and Q & A sessions. Repetition in learning, both direct and indirect, is thought to influence the ability of participants to identify the problem and practice the best solutions in their social activities.

### Effectiveness of the mobile web-based intervention

Parenting knowledge, self-efficacy, and practice behavior are associated with positive parent–child interactions and healthy development of school-aged children [39]. The study showed that a mobile web-based intervention significantly improved parental knowledge, self-efficacy, and practice behavior regarding FA and anaphylaxis management compared to the control group [40]. This finding is consistent with those of other studies [28], which showed that an educational intervention positively influenced practice behavior, along with the level of parent knowledge and self-efficacy. These results indicate that mobile web-based education and online learning can improve the practice behavior of

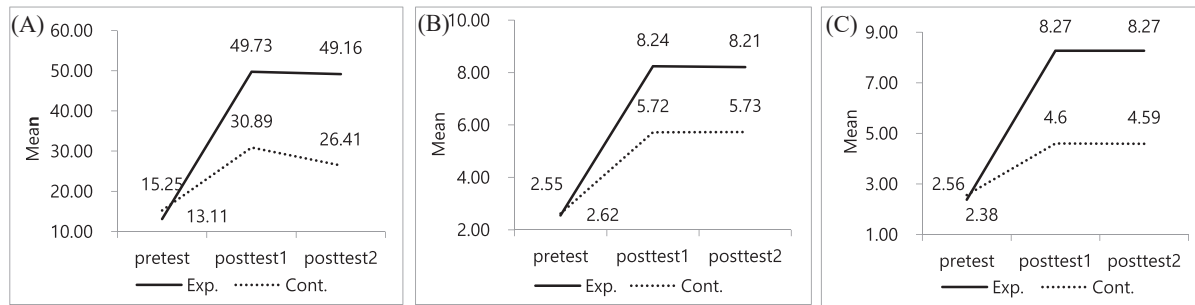


Figure 2. The Effects of Mobile Web-based Educational Program on Knowledge, Self-efficacy, and Practice Behavior from Baseline to Follow-up. (A) The Effects of Mobile Web-based Program on Knowledge. (B) The Effects of Mobile Web-based Program on Self-efficacy. (C) The Effects of Mobile Web-based Program on Practice Behavior

parents. This suggests that online learning platforms are suitable for people with limited time.

In this study, the knowledge of FA management in the experimental group was significantly higher than that in the control group after a 2-week intervention. This supports the suggestion that online education is more beneficial than traditional face-to-face education [41]. Our findings demonstrate the necessity of considering the impact of variables, such as participant characteristics and educational topics, on the effectiveness of the educational method when approaching learning design [23]. We designed the FA management and anaphylaxis management curriculum based on guidelines, which comprised an initial assessment of parental needs and preferences via focus groups, criteria established by the KCDC, and drafting via expert interviews and website surveys. The topics of the education module that were determined to be key for successful management included FA epidemiology, clinical manifestations, diagnosis and treatment, food avoidance, symptoms, epinephrine auto-injector, anaphylaxis, emergencies, labeling, and accidental exposure prevention. The module was also designed as an RWD with screens optimized for a wide variety of devices that use the internet, from mobile devices to desktops. Therefore, accessibility and utilization enabled participation in training without interruption.

There was a statistically significant increase in the self-efficacy score in FA and anaphylaxis management of the experimental group compared to that of the control group. Web-based self-management significantly increased self-efficacy in FA management education compared to face-to-face learning [36]. However, no significant difference was observed in self-efficacy between online-based FA management school nurse education and face-to-face intervention [42]. Repeated education and encouragement are required to improve self-efficacy in education [33]. Therefore, parents were instructed to participate in a 25-min online lesson with attractive teaching materials (PowerPoint, audio, and video) to motivate self-efficacy. Moreover, a 5-min review, quiz, and feedback (1:1 coaching) encouraged in-depth knowledge. The educational material could be accessed with no or limited restrictions at any time to promote greater confidence in the parents' ability to respond effectively. Most parents reported spending over 1 h connecting to the program every day via internet-connected devices during the online intervention.

Practice behavior in FA management in the experimental group showed a significant difference in scores compared to that in the control group after the mobile web-based intervention. This result, although obtained from a single-group study design, partially supports the finding of a previous study. The practice behavior of adolescents aged 13–17 years, who were diagnosed with FA and prescribed an epinephrine auto-injector, was significantly

increased after the intervention compared to that before the intervention. In that study, the researchers set up the action and timeframe in which they measured practice behavior [43]. Here, we used a questionnaire to measure the willingness to change attitude and behavior with confidence in practice, rather than frequency and rate recording. As some parents of school-going children are not aware of their responsibility for childcare, a network that supports communication and feedback and promotes cooperation between the school and healthcare providers is necessary [44]. In this study, online interventions directed at parents addressed behavior change by sharing information about target problem-solving skills through online discussions, Q&A, and individual feedback. In particular, interactive online discussions (webinars) influenced user motivation to gain confidence in childcare and encouraged more time to reflect on and contribute to thoughtful interactions. However, some participants expressed that their interactive communication was insufficient. Therefore, future programs should be developed to enhance their own practices with confidence as a learning strategy.

In this study, the experimental group showed significantly improved knowledge, self-efficacy, and practice behavior in FA and anaphylaxis management compared to that by the control group, indicating the effectiveness of mobile web-based education. This could contribute to the creation of FA and anaphylaxis management in schools, healthcare facilities, and the public. Further, it could be achieved by developing more dynamic, interesting, and interactive mobile web-based learning content and establishing an online educational platform for the parents of school-aged children. In addition, the collaboration between parents, schools, and healthcare providers can facilitate better communication and foster similar expectations. Therefore, assessing the effectiveness of FA management for schools and clinical nurses is suggested.

The FA knowledge and self-efficacy of the 2-week follow-up were significantly decreased compared to the post-intervention. It is essential to help parents maintain continuity of learning that ultimately improves practice behavior at a high risk of life-threatening allergies. It is not easy to maintain the continuity of learning with time, owing to decreased memory activation. Therefore, repetitive learning is vital for the enhancement and sustenance of education effects over a long time [45]. However, previous studies did not confirm the continuity of learning related to the subject of this study. As cognitive knowledge and self-efficacy are significant factors influencing practice behavior [15], ensuring continuity of learning with available resources is imperative. Therefore, exploring the effect of educational resources and the interval of repetitive learning on sustaining the continuity of FA and anaphylaxis management education is necessary in the future.

## Limitation

This study has some limitations. First, our sample population comprised parents who had basic internet and computer knowledge, with most children already being treated by an allergist. Therefore, the participants were likely to be more knowledgeable about FA than the general population. Second, because practice behavior in FA management was identified based on the subjective reports of participants in this study, the degree of FA management should be measured and compared with objective indicators in the future.

## Conclusion

The mobile web-based FA and anaphylaxis management educational program improved parental knowledge, self-efficacy, and practice behavior regarding FA and anaphylaxis management after program completion. The curriculum consisted of 4 sessions (themes) and 23 topics. During the sessions, teaching–learning materials (PowerPoint, audio, and video), interactive online discussions (webinar), quizzes, and feedback (1:1 coaching) were utilized. Update and notification services were provided after the lesson to encourage continuity of learning. In addition, a Q&A session was conducted via a website and mobile text to support autonomous learning. This program can be used to deepen the knowledge of parents and improve self-efficacy and practice behaviors regarding FA and anaphylactic management. Therefore, the results of this study provide an innovative and important contribution to learner-centered education, which can be achieved by extending nursing care. To demonstrate the effectiveness of the mobile web-based educational program for several participants in various settings, long-term follow-up studies in different clinical settings are recommended.

## Conflict of interest

The authors declare no conflict of interest

## Acknowledgment

This article is a revision of the first author Kwen Hwayoung's doctoral dissertation from Sahmyook University.

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## Research Article

## Effect of a Nursing Comprehensive Skill Training Course (NCST-C) on Nursing Students' Metacognitive Awareness: A Quasi-experimental Study

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## ARTICLE INFO

## Article history:

Received 21 July 2022

Received in revised form

20 October 2022

Accepted 25 October 2022

## Keywords:

metacognitive awareness  
nursing students

## SUMMARY

**Purpose:** This study explored the effect of a nursing comprehensive skill training course (NCST-C) on the metacognitive awareness of nursing students to provide a scientific foundation for improving metacognitive awareness.

**Methods:** This study used a quasi-experimental two-group matched pretest, post-test, and follow-up test. Ninety-six junior nursing students were recruited using convenience sampling and assigned to two groups by drawing lots with odd and even numbers in a nursing school at Huzhou University. The control group received a traditional skill-training course. The intervention group received NCST-C. Nursing students' metacognitive awareness inventory (MAI) was evaluated at the baseline, 16-week, and 20-week follow-up points. A repeated-measures analysis of variance and a simple effect test was used to compare each outcome measure of the two groups three times.

**Results:** The NCST-C resulted in greater benefits for nursing students' metacognitive awareness as well as various dimensions (knowledge of cognition and regulation of cognition) in the intervention group. Combined with a simple effects test, the MAI and dimension scores of those in the intervention group significantly improved at 16 weeks after the baseline ( $F = 9.78-44.03$ ; all  $ps < .01$ ). The sustainable effect of NCST-C lasted 1 month after the intervention ( $F = 14.24-62.36$ ;  $ps < .01$ ), reaching statistical significance ( $p < .05$ ).

**Conclusions:** The NCST-C effectively developed metacognitive awareness among nursing students. Its design provides a new type of experimental course for improving metacognitive awareness.

**Trial registration:** [chictr.org.cn](http://chictr.org.cn): ChiCTR2200057910. First registration date: 1/11/2020.

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## Introduction

Rapid developments in science and technology have had positive effects on the quality of education [1]. Online courses have facilitated student-centered education and the innovative development of diversified teaching models [2]. Construction of online courses is both a challenge and an opportunity. Research shows that the construction and implementation of online courses cannot meet the

needs of contemporary students' learning, and students call for returning to classroom learning [3]. The view that high-quality resource construction of online courses and free learning environment beyond space are auxiliary carriers of classroom teaching has been recognized by scholars [4]. Therefore, exploring the design of online and offline hybrid courses, integrating the advantages of on-line platforms and the original motivation of classroom teaching is the focus of research to adapt to social and professional development. Recent study has shown that these all require the drive of students' metacognitive awareness [5].

Metacognitive awareness includes knowledge of cognition and regulation of cognition, it has been defined as the ability to reflect upon, understand, and control one's learning [6]. Knowledge of cognition can help students recognize their strengths and weaknesses, and then affects learning motivation and interest [7]. Regulation of cognition includes planning, implementing,

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<https://doi.org/10.1016/j.anr.2022.10.003>

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monitoring, debugging, and evaluating strategies and it is a trigger for evaluating and adjusting students' learning strategies [4,8]. Knowledge of cognition and regulation of cognition are interrelated, but not simply compensatory [9]. Studies show that students with higher knowledge of cognition have shown better test performance. However, if their regulation of cognition ability decreases, students will show unreasonable planning and self-debugging, thus affecting their exam results [10,11]. Recent studies have shown that metacognitive awareness contributes to the development of critical thinking and positive learning [12,13]. Students with low metacognitive awareness often adopt ineffective learning strategies and fail to use critical thinking or to develop practical skills to overcome learning challenges [14]. Therefore, focusing on metacognitive awareness as a means to adjust learning motivation, positive learning ability, and professional thinking can be considered important for improving the quality of nursing education.

Evidence suggests that active learning can improve students' metacognitive awareness [15,16]. Active learning is defined as a process in which learners play an energetic and dynamic role in their education [17]. Examples of active learning modes include mixed online and offline teaching modes and cooperative learning [18]. Mixed online–offline teaching modes involve multi-spatial teacher–student interaction. Here, teachers need to design online teaching content and methods while also designing offline classroom teaching methods and content [19,20]. Studies have suggested that the design of the teaching method before, during, and after class is the key content of hybrid online–offline teaching [20]. Cooperative group learning is another online–offline teaching mode that can promote learning interaction and knowledge exchange among students [21]. Research has shown that the instructional design of cooperative group learning is an important technical aspect of successful teaching [22,23]. Thus, whether cooperative group learning in mixed online–offline teaching can successfully replace traditional teaching depends on the course content and the feasibility of the teaching design.

Undergraduate nursing education in China has been subject-oriented, with a strong emphasis on theoretical knowledge and technical competence [24]. Mixed online–offline teaching with cooperative group learning has been found to achieve good results in nursing theory courses but not research in skill training courses [25,26]. Previous studies have shown that mixed online–offline and cooperative group learning needs to be guided by case problems, the integration of diversified teaching methods, and scientifically feasible teaching design [27]. Research suggests that undergraduate nursing education should focus on the high-level development of skill training content and assessment courses [28]. Therefore, this study aimed to develop students' metacognitive awareness by using online–offline teaching and cooperative group learning that integrated experimental technology curriculum content and a multi-station nursing skill examination design.

In 2021, China's National Nursing Skills Competition adopted a new form of multi-station nursing skill examination (Ministry of Education of China). This consists of both personal operation and team cooperation. The number of test stations can be set to three or eight. Starting from the first test station, each student conducts nursing assessment, preparation, planning, and integration using an advanced simulation model to implement individual or team skill operations [29,30]. Each station requires 6 or 10 min to complete all case operations. Scoring is done using a combination of computer scoring and manual scoring. Multi-station nursing skill examination establishes higher standards for nursing students' skill operation accuracy.

A comprehensive course can move beyond existing traditional disciplinary frameworks, re-integrate internally related content, and form new courses [31]. For this study, we constructed a

comprehensive nursing skill training course, which includes integrated medicine nursing, surgical nursing, and emergency and critical care experimental content, design online–offline teaching model, use cooperative group learning methods, design multi-station skill assessment examination to evaluate the course's effect on students' metacognitive awareness.

We hypothesized that nursing students who participated in the NCST-C would have a better performance on metacognitive awareness than the control group. We further hypothesized that there were differences in short-term and long-term effect outcomes between a tailored integrated nursing comprehensive skill training course intervention and traditional teaching skill training course.

## Materials and methods

### Study design

This study used a two-group matched pretest, post-test, and follow-up test designs which utilized a quasi-experimental study.

### Ethical considerations

Huzhou University's Ethics Committee review board approved our study (no. 202012-JG01), and the study complied with the Declaration of Helsinki. All participants were informed of the study's objectives, procedures, and potential risks, and informed that they have the right to withdraw at any time. Written consent was obtained from the participants.

### Sample and setting

The participants were recruited from junior-year nursing students at Huzhou University, Zhejiang Province, China. G\*Power 3.1 was used for sample size calculations. Repeated-measures analysis of variance (ANOVA) was selected, there were three measurements and two groups. With a power (1- $\beta$ ) of .80 tests, the effect size was .25, error probability value was .05. Based on per-experimental data, we established a correlation among the repeated measures of .50. Consequently, the total sample consisted of 96 people, 48 in the experimental group and 48 in the control group.

The inclusion criteria were as follows: (1) nursing students in the second semester of the third year in University; (2) voluntary course selection; (3) informed consent, willing to cooperate. The exclusion criteria were as follows: (1) not interested and (2) research objects who are participating in other teaching reform.

### Sampling and recruitment method

Our research team conducted publicity and knowledge lectures on the curriculum teaching reform project among the nursing students in the third year of the University. According to the interests and with informed consent, the students were recruited in the form of voluntary registration. After that, nursing students applied to join through the curriculum registration network system. The computer randomly assigned the students to the experimental group and control group according to cardinal and even number of the submission system sequence. Students participating in the project will be taught in an independent laboratory. The nursing students in the experimental group joined the online course platform through personal application and the course administrator agree. According to the principle of equality, nursing students in the control group were informed that after the course was completed, they would join the course platform and learn freely.



Intervention

Control group

Traditional teaching skill training course methods comprised a total of 64 class hours, offline teaching in the laboratory. Curriculum content included 27 items single experiment technology. Part of the content as shown in Figure 1, course chapter content included basic nursing experiment technology, internal nursing experimental technology, surgical nursing experimental technology, and experimental techniques of emergency nursing. Teaching method and assessment were based on teacher demonstration, students practice by themselves, and one-way technical examination. Teaching organization was under the guidance of two teachers, a total of 16 weeks of course teaching was completed in the form of classroom teaching (Figure 2).

Intervention group

(1) Curriculum content

According to the independence and team-based nature of the technology application, the integrated nursing experiment technology included 30 items, as shown in Figure 1.

(2) Curriculum design

The curriculum involved a three-module, mixed online–offline teaching mode. It comprised a total of 64 class hours: 16 h online and 48 offline. One class “hour” was 45 min. Module one, during the first week, included 2 h online and 2 h offline; it covered the curriculum introduction and learning method training. Module two lasted 12 weeks, with a unit module every 2 weeks (2 h online, 6 h offline), for a total of six unit modules. This covered online problem-

oriented self-learning skills, classroom guidance and training skills, and multi-station examination. Module three (3 weeks; 2 h online and 10 h offline) covered online team skill self-learning, in-classroom multi-station examination guidance and exercises, team multi-station examination, and a nursing practice module.

(3) Teaching method

Online teaching adopted a task-oriented approach that included 1 h of video learning, 15 min of online practice, 10 min of discussion and interaction, and 1000 words of operation process writing. Offline teaching adopted cooperative group learning methods, including group scenario simulation, and group discussion. After class, students completed post-learning tasks on the online teaching platform.

(4) Teaching organization

Online teaching was organized and managed by a teacher, who would post online videos, tasks, assignments, and interactions. In-class teaching used the form of cooperative group learning. First, before class started, students were randomly divided into four groups of 12. Second, matching of teachers and student groups was determined by lottery for each lesson. All four teachers conducted collective lesson preparation and training before class.

(5) Course assessment

Course assessment adopted a combined online–offline form. The curriculum design included 30 learning tasks, seven multi-station nursing skill examinations, and three nursing practices. Based on the tasks published online, online course assessment involved calculating a total score using a big data platform. Offline

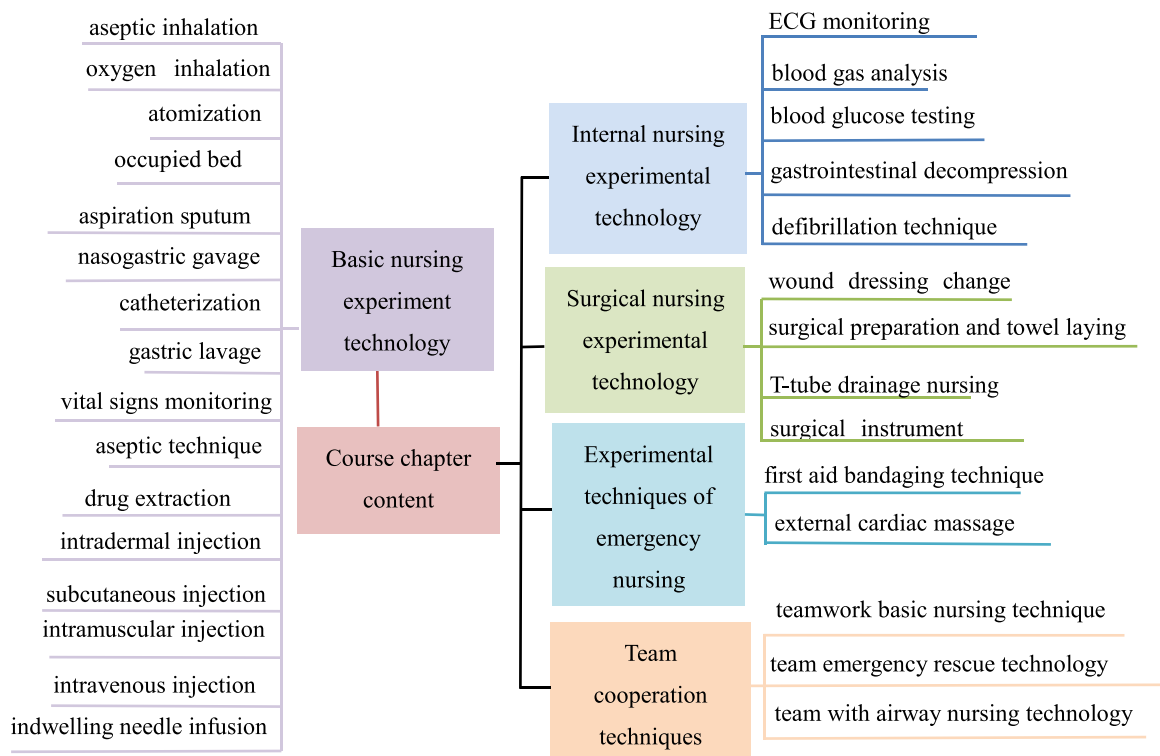


Figure 1. Nursing Comprehensive Skill Training (NCST-C) Curriculum Content.

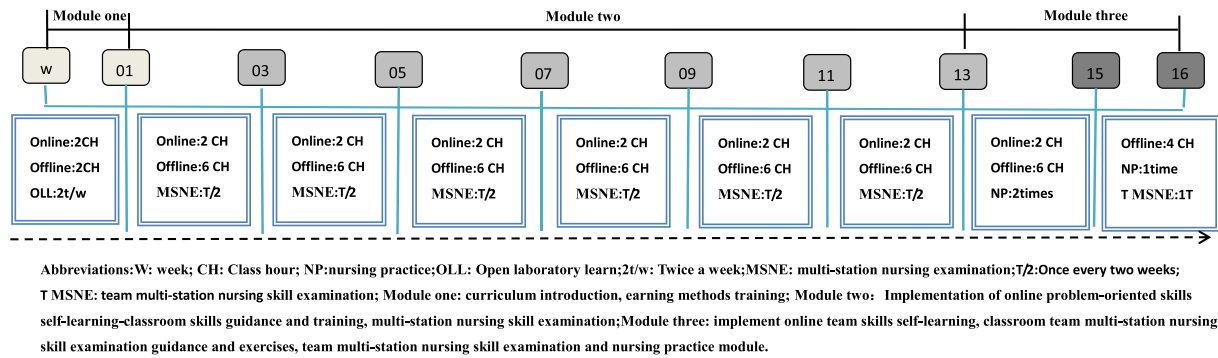


Figure 2. Online and Offline Mixed Curriculum Design.

course assessment involved the skill learning and multi-station assessment of teams and individuals. Each multi-station examination included three stations, individual examinations were 6 min per station, and team examinations were 10 min per station.

### Instruments

#### Demographic information

General demographic information was collected, including age, gender, only child or not, and family location.

#### Metacognitive awareness inventory

Metacognitive awareness inventory (MAI) consists of knowledge of cognition (17 items) and regulation of cognition (35 items), a total of 52 items [7]. Knowledge of cognition includes declarative knowledge, procedural knowledge, and conditional knowledge. Regulation of cognition includes planning, information management, monitoring, debugging, and evaluation. Each item is scored on a 5-point Likert scale. Total scores ranged from 52 to 260. The higher the score, the stronger the metacognitive awareness. To revise the MAI for nursing students in China, we carried out translation, back translation, expert consultation, and exploratory factor analysis (EFA). The Cronbach's  $\alpha$  of the scales and subscales were .96 and .87–.99, respectively. The KMO measure was computed to be .84, the C-WAI (52 items) had a eight-factor solution, accounting for 89.4% of the total variance, and the content validity index at the scale level (S-CVI) was .912. The questionnaire was demonstrated good reliability and validity. Our study used the total scale on knowledge of cognition comprehensively observe the changes of metacognitive knowledge.

#### Data collection

Data collection were conducted at 3 time intervals, which were evaluated at the baseline (T0), 16-week (T1), and 20-week follow-up points (T2). No nursing student dropouts during the experiment. All investigators participated in one-day training before the survey, they were independent of the research team. The same investigators completed the collection, inspection, and analysis of the scales, with a recovery rate of 100%.

#### Statistical analysis

SPSS 21.0 was used for data analysis. Descriptive analysis was used to describe the collected demographic data, normal distribution, and MAI scores at T<sub>0</sub>, T<sub>1</sub>, and T<sub>2</sub>. A repeated-measures analysis of variance was used to compare the MAI between the two groups.

The statistical significance was established at  $p$ -value less than 0.05. Cohen's  $d$  was used to calculate the effect sizes post-intervention, mainly using the mean and combined standard deviation of the conditional measures (less than 0.33 was small, 0.33–0.55 moderate, and 0.56–1.2 large) [31].

### Results

#### Participant characteristics

Participants' mean age was  $21.07 \pm 1.03$  years. Table 1 shows that there were no significant differences in demographic information between the two groups of students ( $p > .05$ ).

#### Intervention efficacy

The data of the intervention group and the control group were normally distributed ( $p > .05$ ). Table 2 shows that the results of metacognitive awareness and subcategory measures of Mauchly's identity matrix test showed significant ( $X^2_{(2, 96)} = 5.02-95.34$ ; all  $ps < .01$ ). Metacognitive awareness and subcategory measures were found significant interaction effects ( $F_{(2, 96)} = 11.43-50.30$ ; all  $ps < .01$ ). Also, a statistically significant main effect for the group factor was observed for debugging ( $F_{(1, 48)} = 4.93, p = .032$ ) and evaluation ( $F_{(1, 48)} = 9.60, p = .013$ ). Significant group factors were found for other subcategory outcome measures ( $F_{(1, 48)} = 14.87-23.10$ ; all  $ps < .01$ ). Meanwhile, a statistically significant main effect for the time factor was observed ( $F_{(2, 96)} = 15.52-64.20$ ; all  $ps < .01$ ) for metacognitive awareness and the subcategory outcome measures.

Table 1 Sociodemographic Characteristics of Participants in the Two Groups.

Sociodemographic characteristics	Invention Group (n = 48)	Control Group (n = 48)	T or Chi square	p
Age, mean (SD)	21.20 ± 1.60	20.99 ± 1.01	0.77	.444
Gender, n (%)			0.33	.563
Men	6 (12.5)	8 (16.6)		
Women	42 (87.5)	40 (83.4)		
An only child in a family, n (%)			0.42	.838
Yes	25 (52.1)	26 (54.2)		
No	23 (47.9)	22 (45.8)		
Family location, n (%)			0.04	.838
Rural area	24 (50.0)	23 (47.9)		
Town	24 (50.0)	25 (52.1)		

Notes: SD = standard deviation.

**Table 2** Impact of the Intervention on Metacognitive Awareness Outcome Measures at Three Time-points (Group  $\times$  Time) test ( $N = 96$ ).

Outcome measures	Measure Time			Mauchly's identity test		Group Factor		Time Factor		Interaction Effect	
	T0 (Mean T SD)	T1 (Mean T SD)	T2 (Mean T SD)	$X^2$	$p$	F	$p$	F	$p$	F	$p$
Metacognitive knowledge											
Experimental group (G1)	66.56 $\pm$ 6.40	74.46 $\pm$ 6.90	74.95 $\pm$ 5.80	17.89	.000	17.30	.000	59.12	.000	47.09	.000
Control group (G2)	67.00 $\pm$ 7.18	67.75 $\pm$ 5.11	67.23 $\pm$ 4.64	95.34	.000						
Regulation of cognition						20.81	.000	49.36	.000	34.86	.000
Experimental group (G1)	130.92 $\pm$ 29.86	165.23 $\pm$ 29.08	167.50 $\pm$ 24.29	17.89	.000						
Control group (G2)	132.73 $\pm$ 34.43	135.63 $\pm$ 29.06	136.77 $\pm$ 22.47	5.02	.000						
Planning						15.86	.000	57.89	.000	44.82	.000
Experimental group (G1)	26.58 $\pm$ 5.91	33.77 $\pm$ 5.36	34.54 $\pm$ 4.81	18.69	.000						
Control group (G2)	27.06 $\pm$ 7.04	27.79 $\pm$ 5.97	27.37 $\pm$ 5.08	44.69	.000						
Information management						21.11	.000	93.17	.000	46.19	.000
Experimental group (G1)	37.50 $\pm$ 5.80	45.97 $\pm$ 6.17	46.16 $\pm$ 4.99	9.90	.007						
Control group (G2)	37.10 $\pm$ 6.99	39.29 $\pm$ 5.13	39.12 $\pm$ 4.76	30.82	.000						
Monitoring						23.10	.000	64.20	.000	50.30	.000
Experimental group (G1)	26.56 $\pm$ 5.81	34.94 $\pm$ 6.07	35.35 $\pm$ 4.96	9.95	.007						
Control group (G2)	27.00 $\pm$ 7.18	27.31 $\pm$ 5.15	27.71 $\pm$ 4.51	67.07	.000						
Debugging						4.93	.032	30.80	.000	11.43	.000
Experimental group (G1)	18.58 $\pm$ 6.35	23.91 $\pm$ 6.17	24.31 $\pm$ 4.96	17.14	.000						
Control group (G2)	19.12 $\pm$ 6.89	20.29 $\pm$ 5.14	20.62 $\pm$ 4.60	65.46	.000						
Evaluation						9.60	.013	15.52	.000	13.80	.000
Experimental group (G1)	21.68 $\pm$ 6.37	26.62 $\pm$ 6.09	27.12 $\pm$ 5.41	16.87	.000						
Control group (G2)	21.91 $\pm$ 7.45	22.25 $\pm$ 4.96	21.93 $\pm$ 4.16	59.26	.000						
Metacognitive awareness						14.87	.000	53.80	.000	32.90	.000
Experimental group (G1)	197.48 $\pm$ 36.05	239.69 $\pm$ 35.48	242.64 $\pm$ 29.18	18.89	.000						
Control group (G2)	199.21 $\pm$ 42.72	204.69 $\pm$ 30.98	204.48 $\pm$ 27.05	87.72	.000						

Notes: T0, baseline; T1, post-intervention (16 weeks after baseline); T2, 1-month follow-up (20 weeks after baseline);  $p$  value .000 -mean "<.001".

### Simple effect test on interaction effects for metacognitive awareness

Table 3 shows that at the T<sub>0</sub> level, the group factor had no effects on metacognitive awareness and subcategory outcome measures ( $F_{(2, 96)} = 0.01$ – $0.16$ ; all  $ps > .05$ ). This means that there were no significant differences between the two groups at the baseline. At the T<sub>1</sub> level, two groups had significant effects on metacognitive awareness and the subcategory outcome measures ( $F_{(2, 96)} = 9.78$ – $44.03$ ; all  $ps < .01$ ). This means that 16-week NCST-C intervention has significant effect on metacognitive awareness. At the T<sub>2</sub> level, two groups had significant effects on metacognitive awareness and the subcategory outcome measures ( $F_{(1, 48)} = 14.24$ – $62.36$ ; all  $ps < .01$ ). This means that on the metacognitive awareness and subcategory outcome measures, the NCST-C intervention effect persisted for 1 month. In addition, from post-intervention to follow-up, the intervention group had a higher effect size than the control group (Cohen's  $d > 0.56$ ).

Each group was compared at three time points as seen in Table 3. The intervention group results revealed that before and after the intervention for all outcome measures had statistically significant differences ( $F_{(1, 48)} = 17.83$ – $79.85$ ; all  $ps < .01$ ). Metacognitive awareness and subcategory outcome measures effect sizes at post-intervention (Cohen's  $d = -1.41$  to  $0.37$ ) and follow-up (Cohen's  $d = -1.63$  to  $0.40$ ) were higher than baseline measures in the intervention group. However, metacognitive awareness and subcategory outcome measures in the control group showed that a change trend was not obvious at three time points, and there were no statistically significant differences on follow-up and post-intervention ( $F_{(1, 48)} = 0.24$ – $2.87$ ; all  $ps > .05$ ).

### Discussion

This study found that nursing students' metacognitive awareness significantly improved in the intervention group, but there was no statistically significant difference in the control group. This indicates that traditional skill training courses do not cultivate students' metacognitive awareness. The intervention group results,

meanwhile, showed that the NCST-C could improve metacognitive awareness. This may be partially attributable to our study's three-module online–offline design and multi-station examination design [32]. Mansueto's research emphasizes that a maximum learning effect occurs when individuals are reinforced metacognitive beliefs and receive timely feedback [33]. NCST-C provides periodic feedback in the three dimensions of online data feedback, classroom skill examination, and practical service testing. Students can observe their performance in real time, gaining a sense of satisfaction and accomplishment, which can stimulate internal learning motivation and affect metacognitive awareness [34].

The intervention group had a significant improvement in its knowledge of cognition scores at 16 weeks compared with the control group. This improvement was long-lasting (over 1 month; Cohen's  $d = 1.31$ ) and almost identical to what Gholami found in problem-based learning intervention [35]. Studies on metacognition have shown a positive relationship between students' knowledge of cognition and their problem-solving ability, in this regard, case-based blended learning modules can act as a catalyst for improving the knowledge of cognition in nursing students [21]. Adding case questions to the NCST-C individual and team examinations is the key point to improve the knowledge of cognition on nursing students in this study. A recent study showed that guided reciprocal peer questioning improved nursing students' knowledge of cognition [16]. This is similar to our study in that NCST-C stimulated students to think about how to use online learning resources and cooperative group learning, adapt to a new type of examination, and smoothly complete the cooperative group experimental course. This process promotes the accumulation of declarative, procedural, and conditional knowledge contained in knowledge of cognition.

The intervention group showed a significant improvement in the regulation of cognition scores compared with the control group. This included improvements in students' planning, information management, monitoring, debugging, and evaluation abilities. This could be because metacognitive awareness is a multi-dimensional process that involves individual awareness in recalling and

Table 3 Results of Simple Effects of Interaction Effects on All Outcomes.

Source of variation	Metacognitive knowledge		Metacognitive regulation		Planning		Information management		Monitoring		Debugging		Evaluation		Metacognitive awareness						
	F	Cohen's d	F	Cohen's d	F	Cohen's d	F	Cohen's d	F	Cohen's d	F	Cohen's d	F	Cohen's d	F	Cohen's d					
G WITHIN T0	0.01	.753	-0.06	-0.06	0.13	.722	-0.07	0.06	0.11	.743	-0.07	0.16	.694	-0.08	0.03	.875	-0.79	0.04	.831	-0.04	
G WITHIN T1	29.28	.000	1.11	1.02	26.62	.000	1.05	33.36	.000	1.17	44.03	.000	1.36	9.78	.000	0.64	14.88	.000	0.78	26.51	.000
G WITHIN T2	51.95	.000	1.47	1.31	50.22	.000	1.45	49.99	.000	1.44	62.36	.000	1.61	14.24	.000	0.77	27.72	.000	1.07	44.16	.000
T WITHIN G1	63.54	.000	-	-	63.31	.000	-	79.85	.000	-	73.86	.000	-	24.69	.000	-	17.83	.000	-	51.34	.000
G1 (T0 v. T1)	-0.37	-	-1.16	-	-	-	-1.27	-	-1.41	-	-1.41	-	-0.85	-	-	-	-0.79	-	-	-	-1.18
G1 (T0 v. T2)	-0.40	-	-1.34	-	-	-	-1.48	-	-1.60	-	-1.63	-	-1.01	-	-	-	-0.92	-	-	-	-1.38
G1 (T1 v. T2)	-0.08	-	-0.08	-	-	-	-0.15	-	-0.03	-	-0.07	-	-0.07	-	-	-	-0.09	-	-	-	-0.09
T WITHIN G2	1.30	.282	-	-	1.05	.352	-	2.87	.064	-	0.59	.562	-	1.64	.202	-	0.24	.781	-	0.81	.448
G2 (T0 v. T1)	-0.12	-	-0.09	-	-	-	-0.11	-	-0.32	-	-0.05	-	-0.19	-	-	-	-0.05	-	-	-	-0.15
G2 (T0 v. T2)	-0.04	-	-0.14	-	-	-	-0.05	-	-0.31	-	-0.12	-	-0.26	-	-	-	-0.01	-	-	-	-0.14
G2 (T1 v. T2)	0.11	.000	-0.04	-	0.08	.008	-	0.03	.003	-	-0.08	-	-0.07	-	-	-	0.07	.007	-	0.07	.001

Notes: G, group; G1, Experimental group; G2, Control group; T, time point; T0, baseline; T1, post-intervention (16 weeks after baseline); T2, 1-month follow-up (20 weeks after baseline).

thinking about information and transforming it into behavior [36]. Previous research has shown that more examination setting and team-based learning can improve students' information, time management skills, and enhances students' metacognitive awareness [37]. The NCST-C focused on multi-station nursing skill examination, cooperative group learning, and experiential online resources. The classroom teaching component focused on group teaching, which inspires students to use teamwork to solve problems together. These placed higher requirements on students' planning, information management, team monitoring, and self-debugging abilities. In addition, developing such capabilities would likely take 16 weeks in a university learning environment, which the NCST-C can achieve. The results of the one-month follow-up showed that these abilities were maintained.

The students' adherence rates and open-ended comments indicated that the NCST-C was well-planned, flexible, and acceptable, and students appreciated the teaching and learning environment. The adherence rate of the intervention group was 100%. Our approach was acceptable to the nursing students because it fits in with the current Chinese culture and educational development. First, this high adherence rate may be attributable to the integrated learning and teaching methods. Module one mainly covered learning and teaching methods content, and students were familiarized with the new curriculum and learning forms [38]. Second, we use cooperative group learning methods, integrate experimental content design online–offline teaching mode, and use individual and team multi-station skill assessment were key to controlling teaching quality and enhancing students' interest in learning [12]. The smooth implementation of the NCST-C can also be attributed to the efforts of our course team teachers to course resources and provide professional guidance.

### Limitations

Due to time and conditions limitation, our study has some limitations. First, this was a quasi-experimental study and administered in only one school. The limitations of this design include its small sample size, potential desirability bias, selection bias, and limited external validity. Future studies should be tested in other schools and explore the effects of NCST-C using larger and more diverse samples. Second, self-reported questionnaires have inherent limitations, inability to deeply analyze the emotional experience of participating in the course. Future studies should consider adding qualitative interviews to explore students' subjective feelings about participating in a course. Third, given the positive effects on the metacognitive awareness and 1 month long-term effects, future studies could examine its effects on other aspects and explored beyond 1 month long-term effects.

### Conclusion

This study demonstrated that the NCST-C effectively developed metacognitive awareness among nursing students. Its design provides a new type of experimental course for improving metacognitive awareness. We hope the findings can specifically inform multi-dimensional structural design in nursing curricula reform while providing a practical basis for nursing curricula development.

### Contributions

Shasha Li: conceiving, designing the study and writing the paper. Minerva de Ala: design direction. Dandan Mao: data survey and analyzing the data. Afeng Wang and Congwen Wu: implementation of teaching. The authors gave final approval of the version to be published.

## Funding

The study was funded by Ministry of Education Industry-University Cooperation Collaborative Education Project, China (No. 220605634075052). Ministry of Education Humanities and Social Sciences Research Youth Fund Project, China (No. 17YJCZH092).

## Conflict of interest

The authors declare that they have no conflicts of interest.

## Acknowledgments

We thank all of the students and teacher who participated in this study.

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## Research Article

# School Nurse–Parent Partnership in School Health Care for Children with Type 1 Diabetes: A Hybrid Method Concept Analysis



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## ARTICLE INFO

## Article history:

Received 27 June 2022

Received in revised form

31 October 2022

Accepted 1 November 2022

## Keywords:

diabetes mellitus type 1

mothers

school health services

students

## SUMMARY

**Purpose:** To define school nurse–parent partnerships in school health care for children with type 1 diabetes (T1D) and determine its attributes using a hybrid model.

**Methods:** This method involves a three-phase process: theoretical, fieldwork, and analytical. A literature review was conducted during the theoretical phase. A literature search of articles from January 1991 to February 2020 was conducted using relevant electronic databases. Eighty-three articles that met the inclusion criteria were completely read. Fieldwork data were collected through individual interviews from February to July 2019 in South Korea. In the fieldwork phase, interviews were conducted individually with 22 mothers of students with T1D and 20 school nurses recruited by purposeful sampling. Inductive content analysis was conducted. The findings from the theoretical phase were integrated with those from the fieldwork phase, and the final concept was derived.

**Results:** School nurse–parent partnership in school health care for children with T1D has been defined as an interactive process of maintaining a balanced responsibility and providing tailored care to meet needs by establishing trusting relationships and communicating transparently and openly. This analysis yielded four attributes: trusting relationships, transparent and open communication, balanced responsibility, and providing tailored care to meet needs—this entails providing nursing actions by advocating for students and performing a negotiated role together or individually for student and family.

**Conclusion:** The findings of this study add to the importance of an attribute of balancing responsibility for partnership in school health care. The results show that this partnership could contribute to the development of a scale, theory, and nursing intervention in school health care for children with T1D.

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## Introduction

In the USA, approximately 40.0% of school-age children and adolescents are reported to have one or more chronic conditions, such as asthma, obesity, or diabetes. The health care needs of children and adolescents with such chronic diseases include the daily management of the disease and the resolution of potential emergencies [1]. To increase the independence and self-management of school-aged children and adolescents with chronic diseases, care coordination through partnerships between

families and school nurses is essential [2]. Family engagement in school is key to the health care of school-aged children and adolescents with chronic disease, which can help their successful transition into independent young adults [3]. The Centers for Disease Control and Prevention (CDC) presents family engagement as an important component of the whole-school, whole-community, and whole-child models to address health problems in the school setting [4].

Currently, school-based interventions for children with chronic conditions have been implemented [5], and type 1 diabetes (T1D) self-management has become much easier with the introduction of advances in technology, such as continuous glucose monitoring or artificial pancreas system [6]. However, it is not known whether the development of school-based interventions or technologies using devices has strengthened collaboration between each party or reduced the need for collaboration. Moreover, the ratio of school nurses to students is correlated with the HbA1c of students with

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<https://doi.org/10.1016/j.anr.2022.11.001>

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T1D. This finding suggests that this change in the level of collaboration may be applied in the calculation of the ideal staffing level of school nurses [7]; however, there is currently no scale to measure it, and above all, no concept analysis has been conducted. Several scales applied concepts regarding partnership have been developed in children's hospital and long-term care facility settings; however, it has not been revealed whether the conceptual attributes of partnership in school health care are the same as that in these settings or if it includes other attributes.

## Background

The most common health conditions requiring school health care were asthma, attention deficit disorder/attention deficit hyperactivity disorder, and severe allergies, but the most common health care procedure by school nurses was related to all diabetes care, such as glucose monitoring, insulin injections, and glucagon injection in the USA [5]. The previous study noted that there was an increase in blood glucose monitoring and insulin injections and decrease in nebulizer treatment and oxygen saturation checks during care by the school nurse. This result is consistent with research on the increase in T1D in the USA; the estimated T1D prevalence per 1000 youths for those 19 years or younger increased significantly from 1.48 in 2001 to 2.15 in 2017 [8]. In a review study on the perception of school health care among parents of children with chronic diseases from 2010 to 2020, 60.0% were identified related to diabetes, which was twice as high as asthma [9]. Otherwise, in a national survey on confidence in school health care, 42.0% of school nurses reported that they were confident in diabetes management, which was lower than in the case of anaphylaxis (82.0%), asthma (73.0%), eczema (57.0%), and epilepsy (58.0%) [10]. These results suggest that diabetes is one of the health problems that should be preferentially dealt with in school health care. Additionally, mothers are the primary caregivers for children with T1D, and only 5.0% of children had a father or grandparent as the primary caregiver [11]. In addition, compared to fathers, mothers of children with T1D reported significantly greater parenting stress [12], perceived burden, and emotional distress [13].

In school, children with T1D not only need skills but also the ability to make decisions about the need for tests and medications and dosing for proper blood sugar control, but school-aged children are far from perfect. A previous study of students aged 6 to 9 (1<sup>st</sup> to 3<sup>rd</sup> grades) reported that parents frequently received calls from the school or were requested to visit school [14]. Furthermore, 56.5% of children aged 6 to 9 required assistance in administering insulin injections; even 15.6% of older children (aged 10 to 12) did not have the skills to determine the type and dose of insulin [15]. Even if adolescents have self-medication skills, it does not mean that they do not need help in acquiring information about medication. Only 8–9.0% of adolescents aged 13 to 15 with diabetes needed help with self-care at school [16], but 36.5% of adolescents obtained information about self-medication from their parents [17].

In 2016, the National Association of School Nurses (NASN) released “21<sup>st</sup> Century School Nursing Practice,” a new framework moving beyond basic care management to a systems-level approach for delivery of school health care [18]. A key element in the application of this framework is care coordination, including direct treatment and communication throughout the system. Care coordination includes case management, chronic disease management, collaborative communication, direct care, education, interdisciplinary teams, motivational interviewing/counseling, nursing delegation, student care plans, student-centered care, student self-empowerment, and transitioning planning [19].

Students' health status has a positive correlation with academic achievement and lifelong well-being [20,21]. School nurses, who

occupy the largest portion of school health services, have a direct and lasting relationship with students. School health care is team-based care that works collaboratively with patients, family caregivers, school nurses, and primary and community health care providers [22]. Specifically, school-based intervention for children with chronic diseases emphasizes the partnership with the school nurse or child/youth and family [23].

Similarly, the partnership between family and the school nurse is emphasized in school health care for children with T1D; however, both parents and school nurses recognized various interpersonal obstacles pertaining to school health care for children with chronic diseases [9,24]. Although advances in technology for children with chronic diseases have recently been developed, there is no quantitative comparative study on how these developments affected the collaboration between families and schools in school health [25]. A scale examining partnerships with pediatric nurses in hospital settings has been developed [26]; however, a concept analysis of partnerships in the context of school health care has not been conducted. It is necessary to analyze the concept and develop scales for partnership with families in school-based care.

Partnerships in child care are different from partnerships with patients or clients as they include parental participation and parents as experts regarding the developmental aspects and health statuses of children [3,27]. Family-centered care (FCC) is used as a surrogate term for partnership in care and its attributes, including parental participation in care, development of a respectful and trusting partnership, and information sharing [28].

To improve the quality of school health care for students with chronic conditions, it is necessary to identify commonalities and differences between the ambiguous concepts of partnerships between school nurses and parents in school health care settings and clarify conceptual attributes. Concept analysis promotes understanding of a specific phenomenon with a concept that is poorly defined or has inconsistencies between the definition and its use in research, which aims to clarify, recognize, and define [29]. In a hybrid model of concept development, analysis from the literature review is closely integrated with the empirical data collected in the clinical setting and precedes the measurement of a concept [30]. The school nurse–parent partnership in school health care for managing T1D can provide a theoretical basis and an understanding of key elements to develop a scale and school-based intervention. This concept analysis aims to evaluate the school nurse–parent partnerships using a hybrid model.

## Methods

This study analyzed the concept of school nurse–parent partnerships in school health care for children with T1D using a hybrid model. This method involves a three-phase process: theoretical, fieldwork, and analytical.

### *Theoretical phase*

A literature review was conducted during the theoretical phase. The keywords and synonyms related to “school nurse,” “family,” and “partnership” were used, employing four databases—PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature, and Web of Science (supplementary file). The inclusion criteria were as follows: (1) published in English, (2) peer-reviewed articles published from the beginning of database until February 2020, and (3) primary reviews and descriptive studies, including attributes of partnership in school health care. Of the total 704 articles initially obtained from the search, the titles and abstracts of 432 studies were reviewed after the duplicates were deleted. Eighty-three



articles that met the inclusion criteria were completely read. Finally, 19 articles were selected for the analytical phase (Figure 1, Table 1).

The literature was reviewed as follows: What is the nature of the partnership between school nurses and families of children with T1D? How has the partnership been defined? How has the partnership been conceptualized? How has the partnership been measured? For data analysis, the authors repeatedly read the selected articles to extract relevant meaning units, which were coded. Codes were identified and classified, which were integrated as subcategories and categorized.

#### Fieldwork phase

In the fieldwork stage, in-depth interviews were conducted with 22 mothers of students with T1D and 20 school nurses (Table 2). The inclusion criteria were mothers who had: (1) children with T1D, (2) children aged between 6 and 12 (primary school age), and (3) children who experienced school health care for one year after the first diagnosis. The inclusion criteria of school nurses were as follows: (1) more than one year of experience. Purposeful sampling was used to recruit participants through an online self-help

group of parents of children with T1D and school nurse groups in two districts in South Korea. Those who voluntarily agreed to participate in the interview following the introduction of the purpose, process, and implications of this study were selected. The participants were sampled until the responses to the interview questions reached saturation and no new codes emerged, and then data collection was terminated [31].

The individual interviews were conducted between February and July 2019, in consideration of the participant's preferred schedule (school nurse: 5 months; parents: 4 months), mainly at the participants' home. However, if this was unfeasible, a rented private space near the home was used temporarily to conduct interviews. Interviews with parents and school nurses lasted for  $57.64 \pm 11.74$  and  $53.33 \pm 20.55$  minutes, respectively. The interviews were based on a semi-structured interview guide. The interview questions included experiences of cooperating with the parents or school nurses and perceived components of partnership. The interviews were recorded and transcribed. Inductive content analysis was conducted [32].

The collected data were analyzed according to the inductive approach to qualitative content analysis procedures suggested by

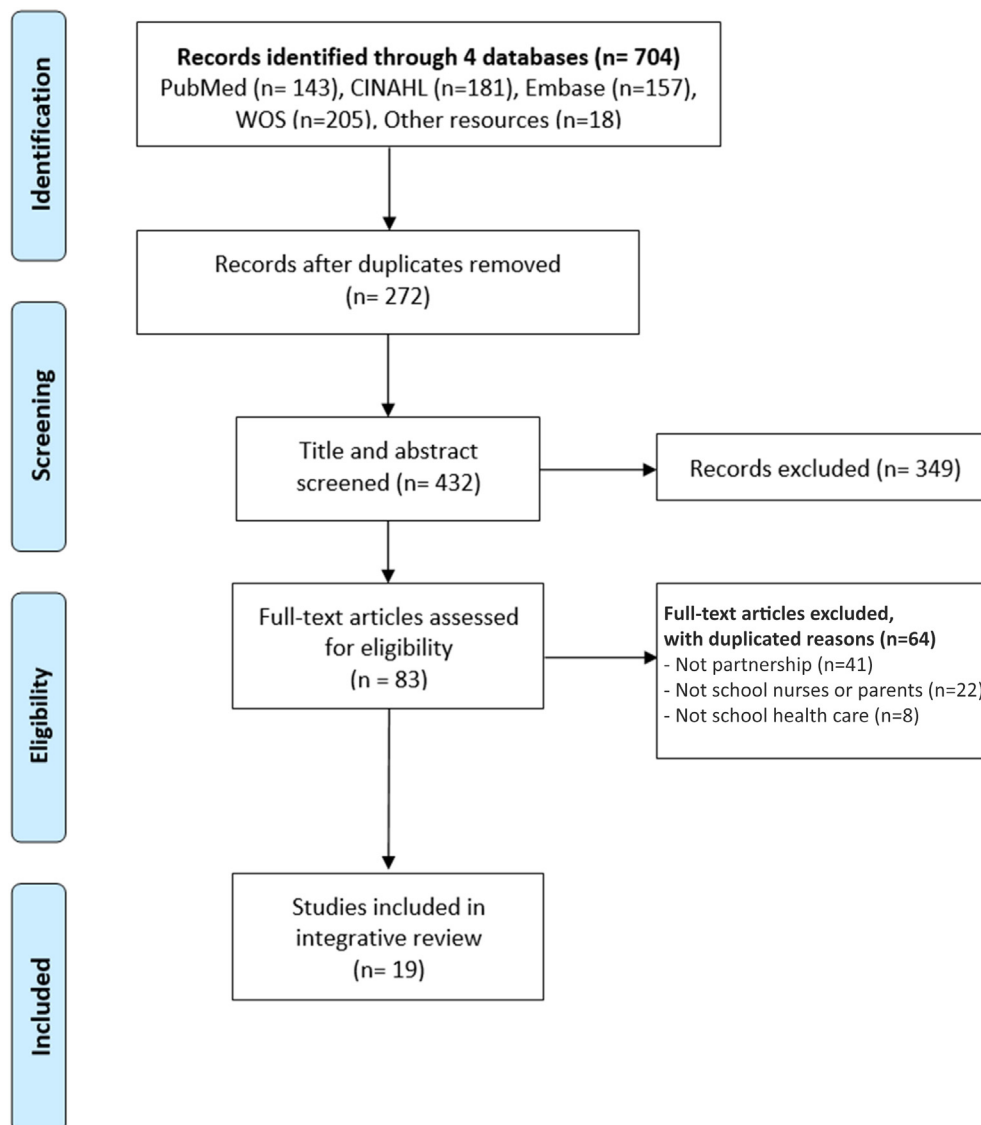


Figure 1. Theoretical Phase: PRISMA Flowchart.

**Table 1** Literature Reviewed in the Theoretical Phase.

Author (Published year)	Subcategories	Attributes
Mäenpää, Paavilainen, & Åstedt-Kurki (2013) Maenpaa & Astedt-Kurki (2008a) Erickson, Splett, Mullett, Jensen, et al. (2006) Rouse (2012)	Respect	Building a rapport
Maenpaa & Astedt-Kurki (2008a) Erickson, Splett, Mullett, Jensen, et al. (2006) Murdock, Robinson, Adams, Berz, & Rollock (2009) Maenpaa & Astedt-Kurki (2008a) Rouse (2012)	Trust and confidence	
Murdock, Robinson, Adams, Berz, & Rollock (2009) Maenpaa & Astedt-Kurki (2008a) Guilday (2014)	Familiarity Reciprocity Contact availability	Transparent and open communication
Maenpaa & Astedt-Kurki (2008a) Guilday (2014) Erickson, Splett, Mullett, & Heiman (2006) Mäenpää, Paavilainen, & Åstedt-Kurki (2013) Kakumanu, Antos, & Lemanske (2017) Maenpaa & Astedt-Kurki (2008a) Maenpaa & Astedt-Kurki (2008b) Bullard, McAlister, & Chilton (2020) Lavalle (2002)	Honesty, openness, confidentiality Open and effective communication	
Erickson, Splett, Mullett, Jensen, et al. (2006) Rouse (2012) Mäenpää, Paavilainen, & Åstedt-Kurki (2013) Lavalle (2002) Holmström, Häggström, & Söderberg (2018)	Mutually exchange information about the children's health status	
CDA (1999) Lavalle (2002) Mäenpää, Paavilainen, & Åstedt-Kurki (2013) Maenpaa & Astedt-Kurki (2008b) Guilday (2014) AADE (2016)	Problem-based communication Assessing the needs of the parent Responsiveness to individual needs of students and parents Agreements on addressing the situation Clarifying the roles and responsibilities of school nurses and parents in school health care Understanding the roles and responsibility of the team Assessing, knowing, and monitoring children's health	Negotiation Clear role delineation
Jackson & Albanese-O'Neill (2016) Strawhacker (2001) NASN (2016) Mäenpää, Paavilainen, & Åstedt-Kurki (2013) Mäenpää, Paavilainen, & Åstedt-Kurki (2013) NASN (2016) Kakumanu, Antos, & Lemanske (2017) Lavalle (2002) AADE (2016)	Supporting self-care practices: teaching skills, sharing knowledge, and empowerment	
Bobo, Kaup, McCarty, & Carlson (2011) Murdock, Robinson, Adams, Berz, & Rollock (2009) Rouse (2012)	Respect for child's privacy in decision-making Helping with problematic situations Implementing management plans	
Kakumanu, Antos, & Lemanske (2017) Bobo, Kaup, McCarty, & Carlson (2011) Kakumanu, Antos, & Lemanske (2017) Maenpaa & Astedt-Kurki (2008b) Bobo, Kaup, McCarty, & Carlson (2011) Erickson, Splett, Mullett, & Heiman (2006) Maenpaa & Astedt-Kurki (2008a) Freeman (2011)	Parental participation in care	
	Ensuring safety Applying flexible rules within the school Enhancing school staff awareness and education Understanding the family situation	Advocating Empowering parents
	Supporting the family to care for themselves Enhancing parental resources, and linking resources	

Note: NASN = National Association of School Nurses; AADE = American Association of Diabetes Educators; CDA = Canadian Diabetes Association.

Elo and Kyngäs, comprising open coding, coding sheets, grouping, categorization, and abstraction [33]. For data analysis, the researchers read the transcripts repeatedly to find important sentences or phrases, grasped the meaning, and created codes. The codes, subcategories, and categories were developed using the NVivo (Release 1.5.1) [34]. Meaningful units and initial codes were extracted through repetitive line-by-line reading. Similar codes were formulated and grouped into subcategories, and categories were formed by integrating them. Conflicting opinions were discussed until a consensus was reached.

#### Analytical phase

After extracting the categories regarding school nurse–parent partnership in school health care for children with T1D in the theoretical phase, the categories at the theoretical level were compared and contrasted with those at the field level. The findings from the theoretical phase were integrated with those from field-work phase, and the concept regarding school nurse–parent partnership in school health care was expanded, and consequently, the final concept was derived.

**Table 2** Characteristics of the Participants (N = 42).

Characteristics	Categories	n (%) or M±SD
Parent (n = 22)		
Gender	Female	22 (100.0)
	Male	0 (0.0)
Age (years)		42.77 ± 3.94
Education	High school	5 (22.7)
	Bachelor's degree	11 (50.0)
	≥ Master's degree	6 (27.3)
Employed	No	9 (40.9)
	Yes	13 (59.1)
Child's age (years)		11.00 ± 1.72
Duration of disease onset (months)		36.00 ± 27.30
Child's school type	Public	21 (95.5)
	Private	1 (4.5)
School nurse (n = 20)		
Age (years)		47.60 ± 7.26
Career as school nurse (months)		210.05 ± 109.61
Education	Bachelor's degree	15 (75.0)
	Master's degree	5 (25.0)

### Ethical considerations

This study was approved by the Institutional Human Research Board (IRB No. 1041386-202101-HR-75-01). Interviews were conducted after the approval of IRB on qualitative research through interviews with school nurses and mothers (IRB No. DHUMC-D-19001-PRO-01 and DHUMC-D-19002-PRO-01). Participants who voluntarily consented to participate in the qualitative phase through interviews were included.

### Rigor

Field notes were taken for rich descriptions. Member checks, peer debriefing, and referential adequacy were conducted for credibility [35]. Credibility, which is equivalent to internal validity in quantitative research, is an evaluation of whether the analyzed results are reasonably derived from the data obtained from the participant and whether the participant's original point of view is accurately interpreted [36]. Member checking includes systematic feedback from participants on data, categories, interpretations, and research conclusions to reduce the risk of misinterpretation [37]. There was no significantly meaningful change in interpretation and categories by member checking. Peer debriefing is a kind of external evaluation regarding the research process by peer researchers [37].

## Results

### Theoretical phase

#### Dictionary definition of partnership

A partnership is defined as a relationship between individuals or groups characterized by mutual cooperation and responsibility to achieve a specific goal [38].

#### Attributes of partnership from other disciplines

Partnerships have been used in a variety of areas, including business and administration, public service, education, health, and social care. Its dimensions in business and administration include commitment, coordination, interdependence, and trust [39]. In the public service context, the partnership includes sharing power, work, support, and/or information with others in the achievement of joint goals and/or mutual benefit [40]. Partnerships with family have been used extensively in education. Its dimensions include commitment, respect, communication, and professional

competence [41]. Staff or families are required to have capacities, such as capabilities (skills and knowledge), connections (networks), cognition (belief, values), and confidence (self-efficacy) [42].

#### Attributes of partnership in nursing

The nature of partnerships with a client in the health field reflects its attributes in nursing. This relationship has the characteristics of a working alliance [43]. In the health visiting context, attributes include a genuine and trusting relationship, honest and open communication and listening, praise and encouragement, reciprocity, empathy, sharing and respect for the other's expertise, working together with negotiation of goals, plans and boundaries, participation and involvement, support and advocacy, information giving, and enabling choice and equity [44].

Common key attributes of partnership in nursing are information sharing, participation, collaboration, power sharing, and negotiation [45,46]. Partnership in caring for the accident and emergency environment included three attributes, namely negotiation and equality of care, parents as equal partners, and shifting of care responsibility [47]. Partnership within the relationship between health care providers and patients included eight attributes: shared decision-making, relationship, professional competence, shared knowledge, autonomy, communication, participation, and shared power [46].

Partnerships in children's health care include understanding children's health issues in a family and respecting them as experts [48]. Partnerships with parents include assessing their as well as their children's needs, sharing care with families, encouraging parental involvement, keeping them informed, and respecting, empowering, and collaborating with them [49]. Pediatric nurse–parent partnership included seven attributes—reciprocity, professional knowledge and skills, sensitivity, collaboration, communication, shared information, and cautiousness [26].

#### Definition of partnership in school health care

Partnership in school health care is intended to form a supportive circle for children in collaboration with health care faculty in schools and the community [50]. It was defined as collaboratively looking for opportunities to teach skills, sharing disease knowledge, and providing support to empower students toward self-management [51]. Kakumanu et al (2017) defined partnerships in school health care for children with chronic diseases as shaping a child-centered supportive circle, comprising clinicians, school nurses, and families around children with chronic disease [52].

In the theoretical phase of this study, seven attributes were identified: building a rapport, transparent and open communication, negotiation, clear role delineation, using the nursing process, advocating, and empowering parents.

#### Fieldwork phase

In this phase, primary codes were extracted and grouped into attributes of school nurse–parent partnership in school health care for children with T1D.

#### Attributes

The extracted attributes were classified into 7 categories, 23 subcategories, and 222 codes (102 of parents and 120 of school nurses). The fieldwork phase analysis results were identified with seven attributes similar to those of the theoretical phase: (1) respectable and reciprocal relationship, (2) sharing health information, (3) mutual agreement on the roles of each party, (4) shared responsibility, (5) providing personalized care, (6) protection from discrimination, and (7) empowering parents.

### (1) Respectable and reciprocal relationship

Participants recognized “respectable and reciprocal relationship” as a subcategory of reciprocity, mutual respect, trust, cautiousness, and politeness as important attributes of partnership in school health care. Most parents and school nurses recognized the importance of trust and respect for each other. In particular, it was not an effort by one party, but reciprocal features were emphasized. They said that it was necessary for parents to trust the school nurse as the sole health care professional in school, and for the school nurse to recognize the parent as another expert in the health care area. They also said that the rapport formed through this was a way to make cooperation easier. In this process, they pointed out the importance of each other's cautiousness and respectful attitude.

*“The school nurse should respect parents, and it would be inappropriate to teach children's parents.” [school nurse4] “I believe that a little politeness between the school nurse and parents and caution during the introduction are needed.” [parent8] “There's a great difference between saying ‘I'm worried about my child's situation’ and asking, ‘If something happens to my child, will the school nurse take responsibility? Isn't that what they have to do?’” [school nurse13].*

### (2) Sharing health information

Both parties shared students' health information and opinions to solve students' health conditions. For this, participants had periodic contact between themselves and exchanged information for the child's condition. They recognized that timely contact and regular meetings were needed, rather than frequent meetings or contacts, due to the time limitations of either parents at work or the school nurse. Parents informed the health status of their children to the school nurse in detail so that the school nurse could prepare and respond in advance. The school nurse also informed parents of students' health problems at school so that the parents could receive active treatment at a hospital or discuss any problem with the parents to immediately solve it.

*“A connection is needed, whereby we can send and receive short text messages about the child's condition when the child goes to school sick.” [parent9] “When we talk, the school nurse tells me to solve things I did not think of.” [parent17] “I am in touch to see how I can keep this child healthy by sharing opinions.” [school nurse12]*

### (3) Mutual agreement on the roles of each party

The subcategories of the third attribute, mutual agreement on the roles of each party, included verifying needs and requests, and compromising. It means that the school nurse verifies what kind of demands the parents had from school health care, and the parents also request to learn about the kinds of school health care that they want from the school nurse. In this process, as parents are in the position to request the school nurse for specific roles, and the school nurse is in a position to receive requests from the parents, it is important to find a midpoint between each other's needs so that both the mother's needs and the school nurse's work situation can be considered simultaneously. In other words, while parents should not make unreasonable demands from the school nurse beyond the legal scope, school nurses too should consider the situation of the student's family and try to find ways and means to help parents as much as possible rather than drawing a clear line on parental requests.

*“I told the school nurse that I should be able to call you if the pump is clogged, or the machine is malfunctioning.” [parent15] “It would*

*be good to have an in-depth discussion about the child, and the school nurse would like to talk about their position and what school nurse can and cannot do. First, I would request you to help as much as possible regarding childcare.” [parent11] “I think it is right to open up gradually while communicating with the mother because they [mothers and school nurses] have different expectations for each role.” [school nurse3] “We have to find the center point among the needs of the school nurse and parents.” [school nurse5].*

### (4) Shared responsibility

Shared responsibility includes three subcategories: mutual understanding, shared duties, and working together. It means that school nurses and parents faithfully share responsibility to achieve the common goal of optimal health outcomes for students. For this, parents and school nurses need to know the scope of each other's roles well and to have agreed role descriptions for specific situations. There is no written agreement on the roles of each, but the roles that each of them plays individually or together are partly subdivided.

*“The school nurse works with me to adjust the insulin amount to match the child's blood sugar.” [parent3] “First, I think we should know each other well... about the extent of demands and how the school nurse can help.” [parent8] “We need to properly determine what we can do together and individually.” [school nurse12].*

### (5) Providing personalized care

This refers to taking an interest in students' health care and providing supportive care and includes providing personalized care to meet the students' individual needs. The attributes are educating and strengthening students' self-care, counseling and psychological care, providing nursing interventions, and parental participation in care. Both parents and school nurses said that it was necessary to educate students so that they can take care of themselves from an early age. In addition, parents and school nurses each perform their own negotiated tasks; the school nurse performs health care for children with chronic diseases in addition to basic tasks, and parents participated in school health care as the school nurse could not fulfill the tasks of their own volition.

*“We need to work with the school nurse and parents to make the child independent.” [school nurse16] “This should be tailored to the child's characteristics.” [parent10] “I tried to apply the nebulizer because of the difficulties of peer problems other than the health of the child.” [school nurse18] “These things cheer up the child. First, I can take good care of their physical health. Although I do not want the school nurse to do a great deal, I want them to provide the best possible care and psychological support.” [parent9].*

### (6) Protection from discrimination

This category is to protect a student's illness from becoming a weakness and help the student be considered a regular student by school staff and peers. Parents want their children to experience a normal school life without discrimination through effective disease management rather than receiving special treatment at school. The participants recognized the need to protect privacy so that the child's disease does not become a weakness at school, to consider the students for effective disease management, and to give the child as much attention as desired.

*“I think school nurse should protect children's own rules.” [school nurse20] “I'm just trying to be a guard on the kid so she won't be withdrawn in school.” [parent3] “I think it's a concern for a child*

who needs care.” [school nurse6] “I hope school nurses would raise awareness about diseases among their peers.” [parent13] “I made it easy for my child to rest in the health room and then go back to the classroom.” [school nurse3].

#### (7) Empowering parents

Participants state that supporting parents and linking them with the resources they need is important. They believed it was important to advocate for parents with relevant resources. Some school nurses perceived cooperation with parents as providing a counseling program for parents to resolve their psychological distress or introducing financial support through national funding programs.

“The school nurse told me about the funding project supported by the government.” [parent2] “I am working on paperwork to ensure that the child can receive medical help.” [school nurse6].

#### Final analytical phase

The school nurse–parent partnership in school health care for T1D was analyzed in the final analytical phase. In this, attributes were confirmed by a comparative analysis of the theoretical phase results and fieldwork phase results.

School nurse–parent partnership in school health care for children with T1D has been defined as an interactive process of maintaining a balanced responsibility and providing tailored care to meet needs by establishing trusting relationships and communicating transparently and openly.

The four attributes of school nurse–parent partnership in school health care for T1D are as follows: (1) trusting relationships: this refers to establishing mutually trusting and respectful relationships between the school nurse and parents, (2) transparent and open communication: this means communicating openly and consistently to share and solve students' health problems, (3) balanced responsibility: this means compromising each other's needs, sharing roles, and working together to pursue a common goal, and (4) providing tailored cares to meet needs: this means providing nursing actions through advocating students and performing a negotiated role together or individually for student and family (Figure 2).

#### Discussion

The purpose of this concept analysis was to analyze the school nurse–parent partnership in school health care for T1D using the hybrid model. In this study, four attributes (trusting relationship, transparent and open communication, balanced responsibility, and providing tailored care to meet needs) of this partnership were derived. Previous literature regarding partnership in school health care related to asthma found the attributes of forming supportive relationships and communication, which were similar to those found in this study; however, attributes like implementation according to an action plan and assessment of asthma-triggering factors differed from this study [52].

In a previous concept synthesis regarding FCC and partnership in care for children with chronic disease, the domains were similar to this study and included the following: valuing parents' expertise and knowledge about their child; forming a trusting relationship with the child and family; and facilitating the child and family to participate in care delivery through negotiation, empowerment, and shared goal setting [53]. However, the differences between attributes in this synthesis and the current study is that the provision of specific services in FCC, such as providing support to patients and families, providing special knowledge to parents, facilitating parental involvement, and involving parents in care rounds, participation in care, and specific roles [27,53,54], is more pronounced. The attributes extracted in this study had a larger emphasis on the reciprocity, such as “mutual exchange of information” and “mutual agreement,” of partnership than those of FCC [53]. As T1D often affects children from early childhood [55,56], the participants perceived that parents were already experts in their child's care; hence, the provision of special knowledge by school nurses or the dependence on the school nurse for specific care may have been found to a lesser extent in this study.

Relationship is an attribute that accounts for the largest proportion of partnership attributes [46]. In the present study, establishing a trusting relationship is similar to reciprocity [26] and relationship [57] derived as an attribute in other conceptual analysis studies on partnership. This means that parents and school nurses have mutual respect and trust to achieve a common goal. Respect has been recognized as an attribute of FCC for children with chronic disease, a counterparty to valued contributors. Trust to

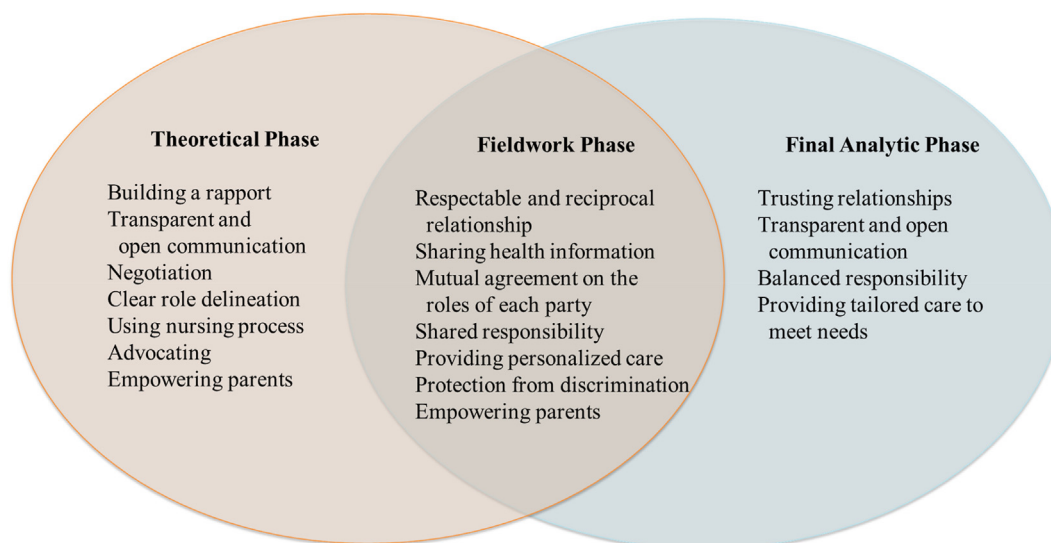


Figure 2. Concept of School Nurse–Parent Partnership in School Health Care for Children with Type 1 Diabetes.

support children's interests is another attribute of FCC [58]. Establishing trusting relationships is a theme to facilitate in a challenging context for youth with T1D [59]. Building rapport, developing trust, and increasing familiarity are needed to facilitate communication with children when there is low utilization of school-based health services [60]. Parents and school nurses emphasized reciprocity in mutual collaboration [61].

Communication is an attribute equally mentioned in the extant literature [26,46]. Communication between parents and school personnel is essential for establishing individualized care plans in school health care for students with T1D [62]. When a child has a specific health problem, parents sometimes hide the disease [63]. Therefore, honest and open communication has been emphasized in the literature [64,65], and "open" has been included as it becomes a channel through which information is regularly exchanged in this study. Specifically, parents, school nurses, and primary care providers (PCP) should cooperate in school health care for chronic diseases [66]. However, if PCPs have not been involved in school health care, it may be important to closely communicate and cooperate with parents and school nurses for decision-making to solve children's health problems. It is necessary for the school nurse and parents to set a common goal that can bring the most desirable results to students [67,68]. Moreover, school nurses can bridge the gap as a stepping stone through communication between teachers, students, and parents and can mediate relational conflicts among them.

Partnership between parents and pediatric nurses in hospitals did not have attributes, such as negotiation or shared responsibility, because the given responsibilities of staff nurses were clear, and nurses would not feel like sharing their assigned roles [26]. Balanced responsibility was a unique concept in partnership for school health care with unclear responsibilities. Compared with another conceptual analysis study in partnership between staff and family in a long-term care facility, it is similar to the inclusion of negotiation and shared responsibility [57]. Role negotiation is a tenet concept for partnership between health professionals and the family in child health nursing [69]. Parents with knowledge and experience of chronic disease could negotiate appropriate support to achieve collaborative care [70]; participants in this study also seemed to seek balanced roles in school health care through effective communication. Effective negotiation needs a clear delineation of roles and mutual agreement of participation in care [71]. In the USA, a care or action plan in school is written in collaboration with the parent and the school, and is based on, and consistent with, the written school-based medical management plan [72]. This is also related to clear role delineation and is distinguished from the attributes of other partnerships by understanding the responsibilities of the role according to consensus. However, in cases where there are no legal standards or guidelines for the scope of practice, such as injections and blood sugar tests, although parents make such requests, school nurses either accept or reject them. When both demands did not find a balance or a midpoint, the subjects eventually perceived a lack of cooperation, and either the school nurse or parents, mostly mothers, had no choice but to take care of the child. Hence, these problems resulted in parental dissatisfaction with school health care as a consequence in the analysis of this study. Conversely, the consequences also revealed that mothers who found a compromise and shared duties with the school nurse expressed satisfaction with the school health care. Regarding a school health environment where there is no action plan for institutional reasons, specifying and documenting role responsibilities may help improve the partnership.

The final attribute is providing tailored care to meet needs. For the students' optimal health outcomes, it means providing care that meets the needs of students by planning or teaching skills to

perform self-care, performing negotiated roles, and advocating for students. This includes what a school health professional implements according to an action plan for a child with diabetes [52]. In the USA, school nurses are responsible for coordinating and overseeing medical management and safety during school hours and all school-sponsored activities [72]. They play an important role, including direct care such as testing and medication administration, education for stakeholders, and organization of care for children with chronic disease [73]. The scope of direct practice of school nurse could be limited because of legal limitations and the absence of a similar action plan [24]. The administration of medication and blood sugar testing depended heavily on parental care in this study, which is similar to the literature from some countries [14,74]. To supplement this, school nurses in this study particularly emphasized the cooperative role of self-care for children. Supporting students' self-care is an important attribute of partnership on the trajectory to self-management, which includes teaching skills, sharing knowledge, and providing support to empower students on the trajectory of self-management [14,51]. In advocating, mothers in this study wanted them to participate in school activities like other children without discrimination and socialize with their peers without isolation rather than receiving extra special school services. They also wanted to be a pioneer in peer education and awareness improvement by school nurses so that their children's diseases would not be stigmatized. This finding is consistent with that of parents of children with T1D perceiving stigma surrounding T1D [75] and adolescents with T1D perceiving stigma of varying severity as a social barrier for self-care [76] in other studies. In this context, the school nurse should continuously strive for knowledge and skills for the well-being of students by providing tailored care and playing the role of an advocate.

The implications of this study are as follows: first, the attributes identified through this study can be linked to further nursing research, including scale development, and contribute to the development of practical theory [29]. Second, nursing intervention can be developed to promote partnership in school health care for school nurses and parents based on these attributes in the nursing education area. Third, a scale based on this concept can contribute to further quantitative research on the effect of the level of partnership between school nurses and parents with children with chronic diseases on the perception of school nurse, students' health outcomes, school nurse-to-student ratios, and parental satisfaction in school health care, which can contribute to the policy development of school health care. This study has some limitations. The participants' interviews in the qualitative study were conducted in one country. Moreover, interviewees in the field phase were limited to mothers of children with T1D among chronic diseases. Therefore, it is necessary to compare the results of studies conducted in various countries with those of parents of children with various chronic diseases.

## Conclusion

The partnership between school nurses and parents is a prerequisite for providing high-quality school health care to students with T1D. However, there is limited understanding of the school health care setting because of the multidimensional properties of the concept and the diversity of the contexts in which the concept is used. The concept analysis in this study highlights the importance of trusting relationships, transparent and open communication, balanced responsibility, and providing tailored care to meet needs in partnership with the school nurse and parent. Based on the definition and attributes of school nurse–parent partnership identified through the results, it can be used as basic data for future

scale development and various intervention programs for school nurses and parents.

### Funding information

This work was supported by the National Research Foundation of Korea (NRF) funded by the Korea government Ministry of Science and ICT (MSIT) (NRF-2018R1C1B5086063).

### Ethics approval

This study was approved by the Institutional Review Board at the Pukyong National University (1041386-202101-HR-75-01).

### Data availability

The datasets analyzed during the current study are not publicly available due to ethical restrictions but are available from the corresponding author on reasonable request.

### Conflict of interest

There are no conflicts of interest to declare.

### Acknowledgments

Authors would like to express our deepest gratitude to the mothers of SugarTree and school nurses who sincerely participated in the interview.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.anr.2022.11.001>.

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## Review Article

## Prevalence and Risk Factors of Postdialysis Fatigue in Patients Under Maintenance Hemodialysis: A Systematic Review and Meta-Analysis

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## ARTICLE INFO

## Article history:

Received 8 June 2022

Received in revised form

20 November 2022

Accepted 21 November 2022

## Keywords:

Fatigue

Meta-analysis

Prevalence

Risk factors

## SUMMARY

**Purpose:** Despite the high prevalence of postdialysis fatigue (PDF) in maintenance hemodialysis patients, no meta-analysis on the prevalence and risk factors of PDF has yet been published. This study aimed to identify the prevalence of PDF and explore its related factors.

**Methods:** PubMed, Embase, CENTRAL, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the four Chinese databases (National Knowledge Infrastructure [CNKI], Chinese Biomedical Literature database [SinoMed], Wanfang Digital Periodicals [WANFANG], and Chinese Science and Technology Periodicals [VIP] database) were searched from inception up to July 2022. This study was performed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines. The articles were independently searched by two reviewers, and the relevant data were extracted. The Agency for Healthcare Research and Quality was used to assess the quality of the included studies.

**Results:** Thirteen articles with 2,118 participants were included. The pooled prevalence was 60.0%. The meta-analysis results revealed that the ultrafiltration volume, mean arterial pressure after dialysis, and good sleep quality were potentially associated with PDF, whereas only good sleep quality (odds ratio 0.24, 95% confidence interval 0.19–0.30) was significantly associated with PDF.

**Conclusion:** PDF is common in maintenance hemodialysis patients, which is related to the ultrafiltration volume, sleep quality, and mean arterial pressure after dialysis. However, the mechanism underlying the risk factors and PDF remains unknown. Further research is warranted to investigate the risk factors, intervention, treatment, and mechanism in maintenance hemodialysis patients.

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## Introduction

End-stage renal disease (ESRD) refers to the inability of the kidneys to maintain fluid, electrolyte, and waste balance in the

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body and is a major public health challenge around the world [1]. More than 2 million patients with ESRD require dialysis to survive [2], and maintenance hemodialysis (MHD) is the main method of renal replacement therapy. One of the most frequent side effects of MHD is postdialysis fatigue (PDF). PDF is defined as a feeling of exhaustion requiring rest or sleep for relief [3]. Patients with PDF may need more than 2 hours of sleep or rest to recuperate from dialysis [4], hindering the treatment compliance of dialysis patients. It is a pervasive and debilitating condition that adversely affects the quality of life [5]. In addition, PDF may be associated with functional disability, cardiac ischemia occurrence, and an increased risk of mortality [6,7]. Chronic fatigue (not specified as PDF) may be a contributing factor to cardiovascular events and overall mortality [8,9]. Although chronic fatigue is associated with a high rate of morbidity and mortality among patients with ESRD, prevalence and risk factors for PDF have not been identified yet.

<https://doi.org/10.1016/j.anr.2022.11.002>

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The prevalence of PDF ranges between 42.9% and 80.0% [10,11]. Several factors may explain the variation in PDF prevalence. First of all, various scales are used to evaluate the symptoms and severity of PDF, such as the revised Piper fatigue scale (RPFS), Chalder fatigue questionnaire, postdialysis fatigue self-assessment scale (PDF scale), and self-designed questionnaires based on time, frequency, and intensity. Therefore, the sensitivity and specificity of the scales are different. Second, methodological differences, such as sampling strategy, may affect the estimates of prevalence. In addition, PDF is considered to be chronic fatigue by health care providers, which may be a key point in explaining the lack of attention in hospitals. Moreover, the lack of acknowledgment of the risk factors of PDF may be attributed to the lack of awareness of this symptom, and some risk factors for PDF remain contradictory. For example, the study by Wang et al. supported an association between PDF and C-reactive protein [12], whereas others did not [13]. Zeng et al. reported an association between PDF and mean arterial pressure after dialysis [13], which was contradicted by another study [14]. Meanwhile, ultrafiltration volume, serum sodium, lactic acid, and dialysis complications were also found to be associated with PDF, but the results are discrepant and inconclusive.

There is no worldwide consensus regarding the prevalence and risk factors of PDF. A previous summarized the estimated prevalence of PDF at 51.0–86.0% [15], but only included three articles without quantitative analysis. Therefore, a systematic review and meta-analysis were performed to synthesize the prevalence and risk factors of PDF to provide better guidance to health care workers.

## Methods

### Design

The review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines. The detailed study protocol can be found on the PROSPERO website under the registration number CRD42022309395.

### Search methods

Nine databases were comprehensively searched from inception to July 2022, including PubMed, Embase, CENTRAL, Web of Science, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and the four Chinese databases (National Knowledge Infrastructure [CNKI], Chinese Biomedical Literatures database [SinoMed], Wanfang Digital Periodicals [WANFANG] and Chinese Science and Technology Periodicals [VIP] database). Combinations of MeSH terms, Emtree synonyms, and free words were used in the literature search. The search terms comprised kidney failure, hemodialysis, renal dialysis, blood dialysis, blood purification, dialysis, maintenance hemodialysis, maintained hemodialysis, MHD, continuous renal replacement therapy, extracorporeal dialysis, fatigue, weary, exhausted, and PDF. Furthermore, no restrictions were placed on the date, country, publication status, or year of publication, but the languages were restricted to English and Chinese. The details of the search strategy are outlined in [Appendix 1](#). In addition, grey literature and the reference lists included in the identified articles were manually searched.

### Inclusion and exclusion criteria

The inclusion criteria were as follows: (1) observational studies; (2) study subjects were adult patients receiving MHD with dialysis duration of more than 3 months, as most of the symptoms of ESRD have been treated and alleviated, to rule out the influence of chronic fatigue state caused by ESRD; (3) specific diagnostic criteria for

detecting PDF were available (including scales or dialysis recovery time [DRT]); (4) prevalence or risk factors of PDF were reported. The exclusion criteria were as follows: (1) the studies were not published in English or Chinese language; (2) duplicate studies; (3) no eligible data for extraction; and (4) low-quality studies.

### Quality appraisal

Two reviewers (Y.Q. and W.C.X.) independently identified the relevant studies, and any discrepancy relating to the quality of studies was resolved by a third reviewer (B.D.X. or G.J.). The tool of the National Center for Biotechnology Information (US), recommended by the Agency for Healthcare Research and Quality (AHRQ), was used to evaluate the quality of the included studies. The AHRQ includes a total of 11 items with the options “Yes (1 point),” “No (0 point),” and “Unclear (0 point).” According to the score, 0–3 points are regarded as low quality, 4–7 points indicate medium quality, and 8–11 points are considered high quality [16].

### Study selection and data extraction

Strictly following the inclusion and exclusion criteria, two reviewers (Y.Q. and W.C.X.) retrieved and reviewed full-text articles after scrutinizing the titles and abstracts of all articles independently. Every article was independently evaluated by the two reviewers for inclusion in this systematic review and meta-analysis. Any discrepancies relating to article inclusion were resolved by discussion with a third reviewer (B.D.X. or G.J.) to reach a consensus. Data extraction was also performed by two independent reviewers (Y.Q. and W.C.X.). The data from the studies included in the systematic review were the name of the first author, publication year, survey time, country, sample size, age of participants, duration of dialysis, diagnostic criteria, prevalence of PDF, and risk factors.

### Synthesis

Stata 15.0 software (Stata Corporation, College Station, Texas, USA) was used for data analysis. The inverse variance method was adopted to estimate the overall prevalence and 95.0% confidence intervals (CIs). The heterogeneity of the included studies was examined by Cochrane's  $Q$  statistic and  $I^2$  statistic. Pooled prevalence and 95.0% CIs for PDF were calculated using a random effects model or a fixed effects model according to the heterogeneity of results. If no statistical heterogeneity was observed among the results ( $p > 0.05$ ,  $I^2 < 50.0\%$ ), the fixed effects model was used for meta-analysis. In contrast, if statistical heterogeneity was identified, the source of heterogeneity would be further analyzed, and a random effects model was used for meta-analysis. A meta-regression analysis was performed to assess the potential effect of important covariates that may lead to heterogeneity. Significant clinical heterogeneity was evaluated by subgroup analysis or a leave-one-out method by iteratively removing the included study. A sensitivity analysis was also performed to estimate the stability of the results. In addition, the proportions of patients diagnosed with the symptoms were retrieved from all included studies to assess the pooled prevalence of PDF. The odds ratios (ORs) and associated 95% CIs were used to assess the risk factors of PDF. Meanwhile, funnel plots, Begg's test, and Egger's test were used to detect publication bias.

## Results

### Search outcomes

A total of 3055 articles were identified from our search strategy. After removing 872 duplicates, 2100 articles were excluded, as the

titles and abstracts were not relevant to this study, and the full text of 83 articles was reviewed. Finally, 13 articles were included in the systematic review and meta-analysis.

#### Characteristics of the included studies

A total of 2118 participants were included in the 13 cross-sectional studies. Most articles (11/13) were published in the past 5 years, of which most (8/13) were conducted in China, with two in America, two in Italy, and one in Japan. The characteristics of the included studies are summarized in Table 1.

#### Risk of bias within studies

Thirteen studies were evaluated by AHRQ. There were eight high-quality studies with a score ranging between 8 and 9 points and five middle-quality studies with scores of 6–7 points. The details of the quality assessment are presented in Table 2.

#### Prevalence of PDF

In total, 13 of the included studies reported the prevalence of PDF. The prevalence of PDF ranged from 42.9% to 80.8%, irrespective of the PDF assessment method. The pooled prevalence of PDF was estimated to be 60.0% (95% CI: 53.0%, 66.0%,  $I^2 = 89.3%$ ,  $p < 0.0001$ ).

#### Meta-regression analyses

The sample size, publication year, survey time, gender ratio, literature quality score, scale, country, and duration of dialysis were chosen as covariates. However, the regression coefficients of the above covariates showed no statistically significant difference between the intervention effect of each subgroup and the designated reference subgroup ( $p > 0.05$ ; Table 3).

#### Subgroup analyses

Subgroup analyses were performed according to the PDF degree (mild, moderate, or severe) as determined by the scale score or DRT. The RPFS classification is based on the total score of each item added together: 0 = no fatigue, 1–3 = mild fatigue, 4–6 = moderate fatigue, and 7–10 = severe fatigue. The Chalder fatigue questionnaire classification is based on the interquartile range score: < 13 = no fatigue, 13–16 = mild fatigue, 17–22 = moderate fatigue, and  $\geq 23$  = severe fatigue. For DRT, PDF lasting >2 h after dialysis was defined as severe PDF, and <2 h was defined as mild PDF. The estimated pooled prevalence of mild, moderate, and severe PDF was 28.0%, 32.2%, and 20.2%, respectively. Sensitivity analysis was conducted due to the statistical heterogeneity of moderate and severe PDF ( $I^2 = 84.1%$ ,  $I^2 = 92.8%$ ). As for severe PDF, the study by Li et al. [16] might be a source of heterogeneity because the heterogeneity was reduced after excluding the study, with  $I^2$  decreasing

**Table 1** Characteristics of the Included Studies.

First author (year)	Country	Survey time	Sample size, No. (M/W)	Age (mean $\pm$ SD)	Duration of dialysis	Diagnostic criteria	Prevalence (%)	Risk factors
							PDF	
Wang 2021 [12]	China	2018.10–2019.10	280 (178/102)	46.8 $\pm$ 7.2	> 6 mo	CFQ	54.4	CRP, triacylglycerol, diastolic blood pressure after dialysis
Gordon 2011 [11]	America	NR	58 (38/20)	56.87 $\pm$ 14.54	$\geq 3$ mo	Questionnaire developed by Sklar	80.8	The average daily physical activity, dialysis vintage
Zhuang 2018 [14]	China	2016.12–2017.6	109 (75/34)	53.41 $\pm$ 10.25	$\geq 3$ mo	Self-designed questionnaire	71.7	NR
Mao 2021 [17]	China	2018.7–2020.7	120 (73/47)	52.75 $\pm$ 7.85	$\geq 3$ mo	RPFS	55.8	Sleep quality, ultrafiltration volume, serum calcium, mean arterial pressure after dialysis, higher interdialytic weight gain, recovery time
Zeng 2020 [13]	China	2018.12–2019.2	70 (45/25)	54.32 $\pm$ 11.61	$\geq 3$ mo	RPFS	78.6	Ultrafiltration volume, sleep quality, mean arterial pressure after dialysis
Li 2018 [18]	China	2017.5–2017.6	148 (84/64)	NR	$\geq 3$ mo	RPFS	54.7	Age, ultrafiltration volume, dialysis complications, hemoglobin, dialysis course
Lin 2019 [19]	China	2017.05–2018.04	65 (48/17)	49.20 $\pm$ 5.03	$\geq 24$ mo	FAI	43.1	Hemodialysis duration, ultrafiltration volume, dialysis complications
Bossola 2018 [5]	Italy	NR	271	NR	$\geq 12$ mo	SF-36 Vitality Subscale	60.5	Activity daily living
Sklar 1996 [3]	America	1995.06–1995.08	85 (50/35)	NR	$\geq 3$ mo	Self-designed questionnaire	50.6	NR
Kodama 2020 [10]	Japan	2016.06–2016.11	126 (85/41)	NR	$\geq 3$ mo	PDF scale	42.9	NR
Zu 2020 [20]	China	2018.03–2019.03	115 (59/56)	54.50 $\pm$ 12.76	$\geq 6$ mo	DRT	60.0	IDH, postdialysis Na, lactic acid, Charlson comorbidity index, ultrafiltration rate
Jiang 2022 [21]	China	2019.12	626 (385/241)	56.1 $\pm$ 12.9	$\geq 3$ mo	Self-designed questionnaire	55.5	HAMA score, HAMD score, ultrafiltration volume
Brys 2020 [22]	Italy	2017.01–2017.12	45 (29/16)	NR	$\geq 12$ mo	Questionnaire developed by Sklar	74.0	IL-10 levels before dialysis

Note. CFQ = Chalder Fatigue Questionnaire; CRP = C-reactive protein; FAI = Fatigue Assessment Instrument; HAMA = Hamilton Anxiety Scale; HAMD = Hamilton Depression Scale; IDH = intradialytic hypotension; IL = interleukin; M/W = men/women; NR = not reported; PDF = postdialysis fatigue; RPFS = Revised Piper Fatigue Scale; SD = standard deviation; Y = year.

**Table 2** AHRQ Critical Appraisal Checklist Applied for Included Studies in the Systematic Review.

Author (year)	Q <sub>1</sub>	Q <sub>2</sub>	Q <sub>3</sub>	Q <sub>4</sub>	Q <sub>5</sub>	Q <sub>6</sub>	Q <sub>7</sub>	Q <sub>8</sub>	Q <sub>9</sub>	Q <sub>10</sub>	Q <sub>11</sub>	Score	Quality of study
Wang (2021)	Y	Y	Y	Y	U	Y	Y	Y	N	Y	N	8	High
Gordon (2011)	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	N	9	High
Zhuang (2018)	Y	Y	Y	Y	U	N	N	Y	N	Y	N	6	Middle
Mao (2021)	Y	Y	Y	Y	U	Y	N	Y	N	Y	N	7	Middle
Zeng (2020)	Y	Y	Y	Y	U	Y	N	Y	N	Y	N	7	Middle
Li (2018)	Y	Y	Y	Y	U	Y	N	Y	Y	Y	N	8	High
Lin (2019)	Y	Y	Y	Y	U	Y	N	Y	N	Y	N	7	Middle
Bossola (2018)	Y	Y	Y	Y	U	Y	Y	Y	N	Y	N	8	High
Sklar (1996)	Y	Y	Y	Y	U	Y	Y	N	N	Y	Y	8	High
Kodama (2020)	Y	Y	Y	Y	U	Y	Y	Y	Y	Y	N	9	High
Zu (2020)	Y	Y	Y	Y	U	Y	Y	Y	N	Y	N	8	High
Jiang (2022)	Y	Y	Y	Y	U	Y	N	Y	Y	Y	N	7	Middle
Brys (2020)	Y	Y	Y	Y	U	Y	N	Y	Y	Y	N	8	High

Note. Q<sub>1</sub> = Define the source of information (survey, record review); Q<sub>2</sub> = List inclusion and exclusion criteria for exposed and unexposed subjects (cases and controls) or refer to previous publications; Q<sub>3</sub> = Indicate period used for identifying patients.; Q<sub>4</sub> = Indicate whether or not subjects were consecutive if not population-based; Q<sub>5</sub> = Indicate if evaluators of subjective components of study were masked to other aspects of the status of the participants; Q<sub>6</sub> = Describe any assessments undertaken for quality assurance purposes (e.g., test/retest of primary outcome measurements); Q<sub>7</sub> = Explain any patient exclusions from analysis; Q<sub>8</sub> = Describe how confounding was assessed and/or controlled; Q<sub>9</sub> = If applicable, explain how missing data were handled in the analysis; Q<sub>10</sub> = Summarize patient response rates and completeness of data collection; Q<sub>11</sub> = Clarify what follow-up, if any, was expected and the percentage of patients for which incomplete data or follow-up was obtained.  
N = No; U = Unclear; Y = Yes.

**Table 3** Meta-Regression Analyses Results.

Covariate	β	95% CI	p
Sample size	-0.000	-0.001 to 0.000	0.363
Publication year	-0.025	-0.248 to 0.198	0.863
Survey time	-0.020	-0.052 to 0.012	0.193
Men to women ratio	-0.000	-0.001 to 0.000	0.808
Score	-0.018	-0.160 to 0.197	0.824
Scale	-0.014	-0.048 to 0.021	0.397
Country			
America	0.025	0.751 to 1.400	0.861
China	0.918	0.718 to 1.173	0.449
Italy	0.791	0.542 to 1.154	0.194
Duration of dialysis	0.026	-0.070 to 0.768	0.560

Note. CI = confidence interval.

from 92.8% to 76.9%. The disparity in dialysis frequency may be attributed to the heterogeneity of severe PD.

The estimates of pooled prevalence of RPFS, based on the questionnaire developed by Sklar and other PDF scales, were 60.3%, 70.1%, and 53.1%, respectively. Due to the high statistical heterogeneity ( $I^2 = 87.8\%$ ,  $I^2 = 92.1\%$ ,  $I^2 = 86.7\%$ ), sensitivity analysis was adopted. Heterogeneity in the scale of RPFS was significantly reduced from 87.8% to 0.0% when Zeng's study [11] was eliminated, possibly because patients with severe trauma within 1 month were excluded in Zeng's study, resulting in a lower total score on the behavioral/severity dimension of the scale. As for the questionnaire developed by Sklar [3], the heterogeneity was decreased from 92.1% to 61.4% after excluding the study by Sklar et al [10]. The heterogeneity may result from different dialysis methods (conventional dialysis with hollow fiber dialyzers vs. central venous catheterization).

Subgroup analyses were conducted based on the survey time before and after 2016, as fatigue was identified as a core prognostic outcome in 2016. The estimated pooled prevalence of PDF was 59.1% before 2016 and 45.9% after 2016, with a statistical heterogeneity of 86.1% and 18.3%, respectively. Subgroup analyses of the PDF are displayed in Table 4.

**Risk factors**

In total, 26 potential risk factors related to PDF were identified, including C-reactive protein, triacylglycerol, diastolic blood pressure after dialysis, the average daily physical activity, dialysis vintage, sleep quality, ultrafiltration volume, serum calcium, mean

**Table 4** Subgroup Analyses of the PDF.

Subgroup	Number of studies	Results of heterogeneity		Effect model	Prevalence (%; 95% CI)
		$I^2$ , %	p		
PDF degree					
Mild	4	0	0.526	Fixed	28.0 (23.9–32.1)
Moderate	3	84.1	<0.001	Random	32.2 (19.8–44.5)
Severe	4	92.8	<0.001	Random	20.2 (7.4–33.1)
Scales for PDF					
RPFS	3	87.8	<0.001	Random	60.3 (55.1–65.4)
Questionnaire developed by Sklar	3	92.1	<0.001	Random	70.1 (48.1–92.2)
Other PDF scale	6	86.7	<0.001	Random	53.1 (45.6–60.6)
Survey time					
The years before 2016	2	86.1	<0.001	Random	59.1 (52.2–66.1)
The years after 2016	9	18.3	0.269	Fixed	45.9 (39.2–52.6)
Region					
Asia	9	86.5	<0.001	Random	56.1 (49.2–62.9)
Non-Asia	4	90.8	<0.001	Random	67.6 (52.6–82.6)

Note. CI = confidence interval; PDF = postdialysis fatigue.

arterial pressure after dialysis, higher interdialytic weight gain, DRT, sleep quality, age, dialysis complications, hemoglobin, dialysis course, hemodialysis duration, activity daily living, intra-dialytic hypotension, postdialysis Na, lactic acid, Charlson comorbidity index, ultrafiltration rate, Hamilton Anxiety Scale score, Hamilton depression scale score, and interleukin-10 levels before dialysis. However, among them, only ultrafiltration volume, sleep quality, and mean arterial pressure after dialysis have sufficient data and could be synthesized. In the analysis of sleep quality and mean arterial pressure after dialysis, a fixed effects model was used, as no statistically significant heterogeneity was observed. While the statistical heterogeneity of ultrafiltration volume was observed, thus a random effects model was used. Sensitivity analysis was performed to explore the source of heterogeneity. After excluding the study by Lin et al,<sup>19</sup> the heterogeneity was reduced from 99.0% to 72.0%, which may be attributed to the inclusion of patients with MHD with coronary heart disease (Table 5).

**Sensitivity analysis/publication bias**

Sensitivity analysis suggested that the meta-analysis results were relatively stable. Funnel plots and Egger's test were used to

**Table 5** Pooled Risk Factors of PDF.

Risk factors	Number of included studies	Results of heterogeneity		Effect model	Results of meta-analysis	
		<i>p</i>	<i>I</i> <sup>2</sup> (%)		OR (95% CI)	<i>p</i>
Ultrafiltration volume	5	<0.001	99.0	Random	2.93 (0.83–10.40) = 0.10	
Sleep quality	2	= 0.99	0.0	Fixed	0.24 (0.19–0.30) <0.001	
Mean arterial pressure after dialysis	2	= 0.55	0.0	Fixed	0.96 (0.93–1.00) = 0.03	

Note. CI = confidence interval; OR = odds ratio; PDF = postdialysis fatigue.

evaluate publication bias. The funnel plot showed no publication bias, whereas the results of Begg's test ( $Z = 0.583$ ) and Egger's test ( $p = 0.378$ ) indicated a low risk of publication bias in this analysis.

## Discussion

This study included 13 studies with 2,118 patients. Regarding the quality of the included studies, the AHRQ scores ranged from 5 to 6, indicating a moderate or higher level of quality. Meta-regression analyses showed no statistically significant difference among the covariates of sample size, publication year, survey time, gender ratio, the literature quality score, scale, country, and duration of dialysis. However, the heterogeneity was significantly reduced in the subgroup analysis by PDF degree, scales for PDF assessment, and survey time, suggesting that the above factors may introduce heterogeneity. The pooled prevalence of PDF was 60.0%, which is lower than the systematic review published in 2018 [23]. This discrepancy might be attributed to our strict inclusion and exclusion criteria, whereas the other's subjects included a wider range of chronic fatigue participants. Furthermore, PDF is largely ignored in the clinical setting, and there are few effective therapies for PDF. The symptom has not been explored in other regions than China, Japan, America, and Italy. Future research should be conducted in countries that lack data on the prevalence of PDF.

This study demonstrated a difference between the pooled prevalence of PDF and the degree of fatigue. Moderate PDF was more prevalent than mild or severe PDF, which is consistent with other research results [24]. This finding may be related to the following two factors. On the one hand, the lack of recognition of PDF may result in overlooking PDF. Mild PDF could be ignored, whereas severe PDF could be mistaken for chronic fatigue by health care workers. On the other hand, some of the fatigue scales are not specific for PDF, and the limited sensitivity reduces the detection of mild PDF. Therefore, health care workers should pay more attention to PDF and their treatment. Future studies should lead to the development of different therapies for PDF.

Among the included studies, nine different scales were used to measure PDF, and the distinct instruments may limit the internal validity of this study [25]. Among the nine scales, only the PDF scale was designed for PDF in hemodialysis patients, showing good reliability and validity [10]. However, the new assessment scale was first applied in 2020 and needs further verification. RPFs was the most frequently used tool, but it was designed for cancer-related fatigue, yielding a lower prevalence of PDF (60.3%). The first used tool was the questionnaire developed by Sklar. The fatigue index considers the duration, frequency, and intensity of PDF, but its sensitivity and specificity have not been evaluated [3]. Fatigue Assessment Instrument has high internal consistency and good concurrent and discriminant validity and can distinguish the fatigue of healthy people from the fatigue from hemodialysis and different diseases [26]. Currently, there is no international

consensus to measure PDF, so a multidisciplinary collaboration is recommended. Health care workers and researchers should work together to agree on the use of a dedicated scale to assess PDF to improve clinical treatment.

The prevalence of PDF has varied over time. In November 2016, the standardized outcomes in nephrology-hemodialysis Fatigue Consensus Workshop identified fatigue as a core prognostic outcome [27]. Although the number of studies on chronic fatigue has increased year by year, few studies focused on PDF. Patients suffering from PDF received prompt treatment although the symptom was mistaken for chronic fatigue. In the last 5 years, a growing number of studies have investigated PDF, increasing its awareness among health care workers. Furthermore, the symptom of PDF in some patients is prevented before occurring, which may explain the higher prevalence of PDF after 2016 compared with before 2016. ERS is a global public health problem, and this study suggests a higher estimated pooled prevalence of PDF in non-Asian countries than in Asia. This difference in prevalence may be attributed to the particularly high prevalence of kidney disease in Asia. With the increased awareness of the symptom of PDF among health care staff, effective measures were taken as soon as possible. An international survey indicated that 68.0% of patients reported taking longer than 2 hours to recover from a dialysis session, with 27.0% taking more than 6 hours [28]. Therefore, it is important to improve the awareness and knowledge of PDF in non-Asian countries.

Sleep quality was significantly associated with PDF. Among MHD patients, the majority (68.1%) were poor sleepers [29], which might be because MHD patients generally need lifelong treatment, and the relatively high treatment cost brings a considerable economic burden to the patients and their families. Therefore, MHD patients are likely to experience negative emotions, resulting in sleep disorders and poor sleep quality. Thus, health care workers should provide patients with a quiet and comfortable treatment environment during dialysis, fully assess the patient's psychological state, and carry out a personalized psychological intervention.

This study identified the mean arterial pressure after dialysis as a risk factor for PDF. Previous studies reported that low blood pressure was significantly associated with longer recovery time [30]. Lower mean arterial pressure after dialysis leads to hypoperfusion of vital organs and affects the recovery time of the brain and heart, prolonging the recovery time of fatigue after dialysis. In addition, cold dialysis was found to relieve the symptom of fatigue [31], as it possibly improves hemodynamic stability and systolic blood pressure [32]. Therefore, monitoring the blood pressure of patients during dialysis and actively preventing and treating severe hypotension may alleviate fatigue after dialysis.

Some studies have demonstrated the relationship between ultrafiltration volume and PDF. First, ultrafiltration volume overload is usually caused by an excessive increase in body weight during dialysis, which increases extracellular water, impairing cardiac and respiratory function, and providing a physiological basis for PDF [33]. Moreover, excessive ultrafiltration increases the changes in plasma and intracellular fluid movement during dialysis and increases the risk of dialysis-related hypotension [34]. Therefore, the water intake should be appropriately reduced during dialysis treatment to effectively reduce the impact of PDF on life.

To our knowledge, this study was the first systematic review and meta-analysis to analyze the pooled prevalence and risk factors of PDF. This study may enhance health care workers' understanding of PDF, promoting its prevention, assessment, diagnosis, treatment, and monitoring. Overall, one of this study's strengths is the thorough literature search across nine electronic databases to limit the risk of missing research. Moreover, the quality of included studies

was high or moderate. Meta-regression, subgroup analyses, and sensitivity analyses were performed to explore the possible reasons for heterogeneity. However, the limitations of this study should also be acknowledged. First, the included studies adopted different scales for PDF, which affected the internal validity of this study. Second, the risk factors available from each study were inconsistent, so some risk factors for PDF could not be analyzed in depth. Meanwhile, the association between PDF and cardiovascular events, stroke, and mortality, and the potential possible effect of racial disparities could not be explored due to the limited number of studies. Our team aims to carry out relevant original studies in the future. Third, the included studies were conducted mainly in China, possibly raising bias. Finally, relatively high heterogeneity was observed, and the results require cautious interpretation.

### Clinical implications

This study has demonstrated the prevalence of PDF and its related factors. Exploring the prevalence and risk factors of PDF can provide an up-to-date theoretical basis for the management of maintenance hemodialysis patients. Most significantly, this study emphasizes the importance of PDF.

### Conclusion

We found a pooled prevalence of PDF of 60.0%. With such a high prevalence, health care workers should pay more attention to PDF. Ultrafiltration volume, sleep quality, and mean arterial pressure after dialysis are related to PDF. These findings suggest that future research with a large overall sample should be conducted to determine which risk factors most strongly affect the symptom of PDF, its underlying mechanism, and the most effective treatments.

### Conflict of interest

None.

### Ethics approval statement

This is not a clinical trial; this study did not require the approval of an Ethics Committee because it is based entirely on previously published studies.

### Patient consent statement

As it is based entirely on previously published studies, this study did not require the approval of patients. In addition, we have asked the authors of including studies for permission to cite data.

### Clinical trial registration

As it is based entirely on previously published studies, this study protocol has registered on the PROSPERO website (CRD42022309395).

### Acknowledgments

None.

### Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.anr.2022.11.002>.

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At the conclusion of Volume 16 of the Asian Nursing Research, the Editors wish to express gratitude and appreciation for the support of so many colleagues who have dedicated their time for ANR this year. They evaluated the research that was submitted to the journal and shared their insights about the papers' strengths and weaknesses. This enabled us to make the right decisions and it helped our authors to further improve their work. At the end of this year, we would like to take an opportunity to openly acknowledge all those reviewers who have contributed to the journal's success. Their names of those who completed one or more reviews between January 1st, 2022 and November 30th, 2022 are listed as below. We would like to warmly thank them for their hard work and dedication and would like to extend a special thanks to those who completed their reviews on time as good and timely peer review is absolutely essential for the success of the ANR.

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Song, Junah	Tungpunkom, Patraporn	Xu, Cuiping	Zhang, Yanjie
Song, Mi Ryeong	Tutton, Elizabeth	Xu, Cuirong	Zhang, Yuxia
Song, Rhayun	Uğraş, Gülay Altun	Xu, Dongjuan	Zhou, Yunxian
Song, Yeongsuk	Uhrenfeldt, Lisbeth	Yada, Hironori	Zhu, Lingyan
Song, Youngshin	Um, Youn-Joo	Yaman Aktaş, Yeşim	Zillich, Alan J.
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