Development of a Self-Management Scale for Patients with Liver Cirrhosis

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Development of a Self-Management Scale for Patients with Liver Cirrhosis

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You will show me the path that leads to life; your presence falls me with joy and brings me pleasure forever. Pslms 16:11
God is always at work in you to make you willing and able to obey his own purpose. Philippians 2:13
I praise God for always being with me.

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ABSTRACT

Development of a Self-Management Scale
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Introduction: Liver cirrhosis comprises one of the representative chronic liver diseases, being known as a disease with fatal complications. Although mortality is reducing with the development of medications that treat the causes of liver disease, the incidence of liver cirrhosis is still increasing. Furthermore, during the transition from the compensation stage to the decompensation stage, liver cirrhosis can lead to severe and potentially life-threatening complications. Self-management is a form of an active patient participant, and it is important for patients with liver cirrhosis to maintain and improve their lives, health, and well-being. However, there was a lack of scales to assess the comprehensive aspects of self-management among patients with liver cirrhosis. The purpose of this study was to develop and validate a self-management scale for patients

with liver cirrhosis for measuring the self-management level.

Methods: The present methodological study was conducted in two phases consisting of eight stages based on the process of scale development by DeVellis using the data from cirrhotic patients at a tertiary hospital in Seoul. In the development phase, the initial items were derived from a literature review and in-depth interviews with 10 individuals with cirrhosis. The content was validated by 10 experts and a preliminary survey of 20 patients was conducted between June and July 2020 from the outpatient clinic of the hospital. In the evaluation phase, 169 outpatients for exploratory factor analysis and 126 patients in the online survey for confirmatory factor analysis participated for the construct validation. Reliability test was conducted using Cronbach's alpha coefficient and concurrent validation was performed to assess the correlation between the developed self-management scale and the Chronic Disease Self-Efficacy Scale.

Results: Among a total of 33 items on the preliminary scale, 25 items were selected during item analysis. Five factors with 21 items were extracted with 61.1% of the total variance in exploratory factor analysis from the data of 169 patients with liver cirrhosis: symptom management (6 items), liver cirrhosis-specific lifestyle management (5 items), general lifestyle management (4 items), medical treatment compliance (3 items), and family support (3 items). The model of the final self-management scale with 21 items was analyzed using confirmatory factor analysis with the data from 126 patients, and the model fit was confirmed to be a good with a root mean square error of approximation (RMSEA) of 0.059 and a standardized root mean square residual (SRMR) of 0.070. The

correlation coefficients between factors ranged from 0.33 to 0.58. The concurrent validity of the proposed scale was confirmed via the correlation with the Chronic Disease Self-Efficacy Scale (r=0.47, p<.01). The scale had a Cronbach's α value of 0.90, thus confirming its reliability.

Conclusions: The self-management scale for patients with liver cirrhosis consisted of five factors with 21 items, with scoring based on a 5-point Likert scale. The results of this study indicate that the proposed self-management scale for the patients is valid and reliable. This scale will be useful for identifying the self-management level of patients with liver cirrhosis and developing strategies to improve the self-management behaviors of this population.

Keywords: liver cirrhosis, self-management, scale development, content validity, construct validity, exploratory factor analysis, confirmatory factor analysis.

I. INTRODUCTION

1.1. Background

Liver cirrhosis comprises one of the representative chronic liver diseases, being known as a disease with fatal complications. According to a 2019 report by the National Statistical Office, chronic liver disease ranks eighth among the top 10 causes of death in Korea, with a mortality rate of 12.7 per million persons (Korean Statistical Information Service, 2020). More than 1 million people worldwide die from cirrhosis every year; however, in Asia, vaccination against hepatitis—one of the major causes of cirrhosis—has contributed to decreasing the mortality rate of this condition. Nevertheless, the incidence of liver cirrhosis has continued to increase in Korea from 20.4% in 2000 to 22.9% in 2015 (Wong et al., 2019). This rising incidence rate has led to an increase in the occurrence of disability and use of health services. In particular, liver cirrhosis occurs more frequently among middle-aged men in their 40s and 50s who are socially and economically active, and the disease burden is thus increasing (Mokdad et al., 2014).

Liver cirrhosis includes asymptomatic compensated cirrhosis and decompensated cirrhosis with one or more complications. In early liver cirrhosis, most patients are asymptomatic and compensated, but as it progresses, physical symptoms, such as fatigue, and mental symptoms, such as depression and sleep disturbances as well as deterioration

of liver function, cause edema and ascites, bleeding gastroesophageal varices, and hepatic coma (Flamm, 2018). This leads to decompensated cirrhosis with several complications. Once complications begin to occur, the prognosis is poor, with a four-year survival rate of approximately 20−40% (Eun, 2019). To reduce the incidence of serious complications and mortality, it is necessary to slow the progression of the disease, prevent the occurrence of symptoms, and manage complications through an active treatment for the causes of cirrhosis (Lee, 2012).

With chronic disease progression, the self-management of patient is considered important for disease management. Self-management is a practical act of performing desirable behaviors according to one's beliefs to maintain and promote one's life, health, and wellbeing while voluntarily taking responsibility for one's own health (Orem et al., 2001). Hospital visits, regular checkups, and management of complications have previously been considered important for the management of cirrhosis (Jung & Min, 2007). In previous study, active treatments of underlying disease and self-management were emphasized as important management strategies for liver cirrhosis to prevent the progression to liver fibrosis (Chirapongsathorn et al., 2016). However, despite the importance of self-management, patients with liver cirrhosis face several problems, such as difficulties regarding abstinence and nutritional imbalances due to lack of awareness or knowledge of the disease severity (Kim, 2017; Park & Shin, 2017). There have been many cases of readmission to the hospital due to complications from lack of management (Jung & Min, 2007; Lim & Choi, 1996). These studies have shown that self-management

among patients with liver cirrhosis is not properly implemented; thus, it is necessary to evaluate the level of self-management among patients.

To date, there has been no scale in Korea developed target patients with liver cirrhosis to measure their level of the self-management. The existing scales for patients with liver cirrhosis has been used by modifying and revised the scale developed for different diseases to comprise items related to the prevention and treatment of liver cirrhosis (Kim, 2003; Yoon & Min, 2016). However, such instruments have not been adequately validated; by modifying the measurements developed for patients with other chronic diseases, there are limitations to assessing the states of liver cirrhosis or symptom-specific management of patients with liver cirrhosis beyond general self-management. In addition, there is a disadvantage in that self-management of patients with liver cirrhosis is focused only on the individual dimension. A self-management scale for patients with liver cirrhosis was developed overseas by Wang and colleagues in 2015; however, the self-management behavior measurement items are somewhat overlapping, and there is only one question regarding family support that inquiries about whether the patient communicates with family or friends. Furthermore, since the scale was developed in a different cultural environment, there is a limit to its use in Korean patients, and it has not yet been widely used.

Self-management behavior is believed to be facilitated through interactions with the family and support systems, as suggested by the Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin, 2009). Family support is a factor that promotes

treatment implementation and self-efficacy among patients with chronic diseases such as liver cirrhosis (Oh & Lim, 2005). In diabetic patients, family support was found to decrease the risk of complications and to have a positive effect on self-efficacy, diet, and exercise behavior (Pamungkas et al., 2017). Therefore, it is necessary to develop an instrument that can comprehensively measure the level of self-management that reflects not only personal aspects but also social interactions, such as family support, in the self-management process.

Therefore, this study comprehensively identified the self-management behavior of patients with liver cirrhosis in Korean including lifestyle modification, medical treatment adherence, symptom monitoring, prevention of complication, and family support. A systematic scale with verified reliability and validity also needs to be developed to evaluated self-management among patients with liver cirrhosis and nursing interventions. For this purpose, we intend to contribute to nursing practice and research regarding the care for patients with liver cirrhosis.

1.2. Purpose

This study aimed to develop an instrument that can comprehensively measure the level of self-management in patients with liver cirrhosis. Its specific objectives are as follows:

1) Identify the components of self-management in patients with liver cirrhosis.
2) Develop a scale to assess self-management among patients with liver cirrhosis.
3) Evaluate the validity and reliability of the developed scale for assessing self-management among patients with liver cirrhosis.

1.3. Definitions

1.3.1. Patient with liver cirrhosis

- Theoretical definition: Liver cirrhosis represents a state in which hepatitis caused by hepatitis virus or alcohol consumption continues for a long period of time, causing hepatocytes destruction, fibrosis, and regenerative nodules, resulting in gradual functional decline (Korean Liver Society, 2019).
- Operational definition: In this study, a patient with liver cirrhosis refers to a patient diagnosed with liver cirrhosis histologically by liver biopsy, or was shown clinical

findings as follows: 1) platelet count < 150,000 /μL and ultrasonographic findings suggestive of cirrhosis, including a blunted, nodular liver edge accompanied by splenomegaly (≥ 12cm); and/or 2) esophageal or gastric varices (Kim et al., 2022).

1.3.2. Self-management

- Theoretical definition: Self-management is an activity that each individual performs on his or her own to maintain the life, health, and wellbeing (Orem, 2001).
- Operational definition: In this study, self-management refers to the score measured by the self-management scale developed in this study to assess patient self-management related to the treatment and prevention of liver cirrhosis and disease management in daily life.

II. LITERATURE REVIEW

This study aims to develop a self-management scale for patients with liver cirrhosis and to describe the characteristics of self-management related to health conditions, individual circumstances, behaviors, and facilitators in daily life. In this section, the health problems associated liver cirrhosis and the existing self-management scale for patients with liver cirrhosis will be reviewed to identify the attributes of self-management in the patients with cirrhosis and build the scale structure.

2.1. Health problems of patients with liver cirrhosis

Liver cirrhosis refers to a condition in which liver function deteriorates gradually as fibrosis progresses and regenerative nodules form due to damaged hepatocytes (Jang, 2019). Liver cirrhosis is generally the last stage of liver damage in chronic liver disease, and the causes include alcohol, chronic hepatitis B and C infections, nonalcoholic fatty liver disease, hemochromatosis, genetic diseases such as Wilson's disease, primary biliary cirrhosis or cholangitis, and autoimmune hepatitis (Naveau, Perlemuter, & Balian, 2005). In Western countries, liver cirrhosis is mainly caused by alcohol consumption or chronic hepatitis C infection, while chronic hepatitis B infection is the main cause in the Asia-Pacific region (Liaw et al., 2008). In Korea, 70–80% of liver cirrhosis cases are caused by

hepatitis B virus infection, 10–15% by hepatitis C virus infection, and the remaining 10–15% by excessive alcohol consumption and other diseases (Korean Liver Society, 2019).

Most chronic liver diseases are asymptomatic, but after progressing to cirrhosis, various complications, such as ascites, varix bleeding, and hepatic coma, can occur. Compensated cirrhosis is a condition in which cirrhosis is present without complications or no clinical symptoms; in contrast, decompensated cirrhosis involves one or more associated complications (Jang, 2019; Lee, 2012). Proper management and treatment of complications that may occur during liver cirrhosis is important since patient pain may be aggravated with the experience of various symptoms. The Child-Pugh classification system is used to classify the severity of cirrhosis; this system was initially designed to predict postoperative mortality in patients with liver cirrhosis (Child & Turcott, 1964). However, it is now used to assess the overall prognosis of patients with cirrhosis. The Child-Pugh classification system represents the sum of scores rated from 1–3 for bilirubin, albumin, prothrombin time, ascites, and hepatic coma. A score of 5–6 is defined as Child-Pugh A; a score of 7–9 is defined as Child-Pugh B; and a score of 10 or higher is defined as Child-Pugh C. Child-Pugh A is classified as compensable cirrhosis, while Child-Pugh B and C are classified as decompensated cirrhosis (Durand & Valla, 2008).

The most common complication of cirrhosis is ascites. As cirrhosis progresses, the blood flow in the portal vein is impaired, and the portal pressure rises. If ascites recurs despite treatment, the prognosis is poor. Ascites may occur in severe cases, such as cases of spontaneous bacterial peritonitis or hepatorenal syndrome. To treat ascites, salt

restriction is important to maintain sodium balance in the body; thus, a low-sodium diet or diuretics should be implemented to control edema and weight. Varicose vein are another complications caused by elevated portal pressure and are experienced in approximately 40% of patients with compensated cirrhosis 70–80% of those with decompensated cirrhosis. Varicose veins are reported to develop or worsen in approximately 7% of patients every year (European Association for The Study of the Liver, 2018). Varicose veins often occur in the esophagus or stomach, and in severe cases, they can rupture and cause large-volume hemorrhage. Once bleeding occurs, the risks of re-bleeding and mortality increases (Lo et al., 2009). Since varicose veins appear as a result of increased portal pressure, beta-blockers may be used to reduce portal pressure, depending on the patient's bleeding risk. Hepatic coma is a complication of cirrhosis in which loss of consciousness, disorientation, and psychiatric changes occur. In the early stages, sleep disorders, changes in sleep patterns, and personality and mood disorders may appear, following various symptoms, including confusion and coma (Lee, 2012). Treatment for hepatic coma involves the identification and correction of triggers, and supportive care is used to prevent secondary bodily damage, such as falls and pneumonia due to changes in consciousness or disability. The survival rate after one year of hepatic coma is 42%; since the severity of the first episode of hepatic coma is related to the prognosis, liver transplantation is sometimes considered in severe cases of hepatic coma (Vilstrup et al., 2014). The treatment of liver cirrhosis does not traditionally imply a complete cure, but the main aim is to prevent the disease from worsening without causing

symptoms while treating and preventing complications. However, in recent years, the focus has changed to preventing the progression of cirrhosis or treating liver fibrosis by healing the factors that cause cirrhosis (Jang, 2019). Therefore, for the treatment of liver cirrhosis, along with taking antiviral medication s to treat the cause, improving in one's lifestyle, such as through weight loss, abstinence from alcohol, diet, and exercise, is considered important.

2.2. Self-management among patients with liver cirrhosis

As the number of chronic diseases increases, it has become difficult to achieve clinical treatment results by performing traditional and direct nursing or by providing nursing care that meets patient needs. Self-management involves a process of increasing an individual's potential to maintain health to effectively function through personal accountability for disease prevention and health promotion (Noris, 1979). Levin (1981) viewed self-care as the act of performing activities in daily life and said that it is important to acquire knowledge to promote it. He also emphasized that the goal should be aimed at returning the patient to an independent state.

The term self-management is mainly used with regard to chronic diseases and special health conditions, such as diabetes, hypertension, asthma, and epilepsy (Balduino et al., 2013; Mammen & Rhee, 2012; Schilling et al., 2002; Unger & Buelow, 2009). However, self-care, self-care management, treatment management, and disease

management are used interchangeably (Matarese et al., 2018). Similar terms include self-monitoring, compliance, and adherence, while the term self-care is used considerably in the nursing literature; self-management is used more frequently in the medical literature (Balduino et al., 2013). Attributes of self-care refer to the physical, mental, social, and spiritual behaviors that an individual acquires and consciously performs, including universal needs, purposes, and behavioral capacities focused on health issues, morbidities, and processes that lead to health and wellbeing. In such self-management, information and knowledge, self-efficacy, motivation, and social support are leading factors; in particular, individuals learn responsibility for disease management from their parents during childhood, which is affected by their developmental stage (Mammen & Rhee, 2012; Miller et al., 2015).

Previous studies have shown that areas of self-management for patients with liver cirrhosis include diet, stability and activity, hospital visits and regular clinical examination, and prevention and observation of complications (Lee & Lee, 1997). In the past, due to the perception that hepatocellular damage is irreversible, regular check-ups, medication, or medical treatment were considered important for managing complications or implementing treatment. As several studies have recently reported that the damage to liver cells is reversible (Campana & Iredale, 2017; Pellicoro et al., 2012; Seki & Brenner, 2015), the management of liver cirrhosis by patients themselves is becoming more important.

However, due to the lack of awareness, knowledge, and motivation for management

according to the characteristics of liver cirrhosis, which mainly occur in men who are economically and socially responsible, steady therapeutic compliance is not achieved, and self-management of liver cirrhosis is not properly implemented. Therefore, repeated hospitalization is common due to failure of symptom management, and complications occur frequently due to inadequate nutritional status and failure to abstain from alcohol consumption (Lim & Choi, 1996; Jung & Min, 2007). Tapper and Volt (2017) suggested strategies for reduction of 30-day re-admission, morbidity, mortality, and financial burden on the health system, and one of those was improving the knowledge of patients with liver cirrhosis (Tapper & Volt, 2017).

To improve self-management among patients with liver cirrhosis, it is most important to identify the factors that influenced its implementation. Kim and Na (2017) found that self-efficacy, disease severity, age, and gender influence self-management implementation in 160 patients with liver cirrhosis. Recently, Yoon and Eun (2020) analyzed the factors affecting readmission in 75 hospitalized patients with cirrhosis and found that alcohol consumption within a month after discharge and the presence or absence of complications were the main associated factors. In a study by Jung and Min (2007) targeting patients with liver cirrhosis, they found that the higher the self-nursing performance was, the lower the experience of disease-related symptoms; and the lower the symptom experience was, the better the disease state. In a study by Seo and Do (2015), the results showed that the higher the social support was, the less frequent the drinking behavior in patients with liver cirrhosis

As mentioned above, past literature related to self-management considered self-management to be a series of activities through which an individual with health problems solves these problems while being in social relationships, and this includes a healthy lifestyle. Self-management also involves requesting professional help for the maintenance and treatment of diseases, management and prevention of symptoms, and resolution of health problems. To maintain the functional status of patients with liver cirrhosis through such self-management and ultimately improve their survival rate through appropriate symptom management, it is necessary to accurately assess the level of implementation of self-management

2.3. Self-management scale for patients with liver cirrhosis

To date, the scales used to measure self-management among patients with liver cirrhosis have mainly focused on their actions for disease management. However, since patients with chronic disease must perform health behaviors for disease care in their daily lives, it is necessary to consider factors that affect self-management to accurately measure self-management.

Considering the scales used to measure self-management among patients with liver cirrhosis in previous studies, no self-management scale has been developed to target patients with liver cirrhosis in Korea. Kim (2003) modified a scale that Kim developed to measure self-management among patients with hepatitis B in 1989, and Um modified this

scale in 1998 to identify the effect of family support on self-care and disease status. Yoon (2018) used the scale modified by Kim (2003) to identify the relationships between self-care for patients with liver cirrhosis and fatigue, depression, and sleep disorders. The scale developed by Kim (1989) was divided into subdomains of diet, stability, and activity, hospital visits and regular checkups, and prevention and observation of complications, which consisted of 71 items. Yoon & Min (2016) added a subdomain of regular medication administration to this scale and added one separate question for this domain. Furthermore, items related to alcohol consumption were separated, and self-management among patients with liver cirrhosis was measured with 16 items. However, these scales did not reflect the importance of family or social support in performing self-management in daily life; thus, they are insufficient in comprehensively measuring the level of self-management that matches the actual daily lives of patients with cirrhosis. In addition, the original scale (Kim, 1989) only verified content validity, and it was modified and implemented without appropriate validity or reliability testing.

In foreign countries, many self-management scales for chronic diseases are being developed. In particular, self-management scales for chronic diseases such as diabetes and hypertension that consider the characteristics of these diseases have been developed and used in many studies; studies comparing and evaluating these scales are being actively conducted (Lu et al., 2016; Sedlar et al., 2017). On the other hand, scales for assessing the level of self-management among patients with cirrhosis are lacking. Among the recently developed scales to evaluate the level of self-management among patients

with cirrhosis, there is the Self-management Behavior Scale developed by Wang et al. (2015). This instrument consists of 24 questions and four subdomains of diet, daily life, medication, and disease management of patients with cirrhosis. However, in this scale, only one item assesses the relationship of the patient with his or her family or the social support environment, which is crucial for facilitating self-management behaviors. There is also a limitation in terms of some overlapping parts between the items of diet and daily life. Since the patient's circumstances and context are important factors for evaluating self-management behaviors, it seems inappropriate to use scales that developed and validated in other cultures.

As a result of exploring the existing self-management scales for patients with liver cirrhosis developed, it is necessary to include the relationship between the self-management behaviors of patients and their families or social support system and to consider disease specificities when developing a self-management scale. Therefore, a self-management scale should be developed by evaluating its validity and reliability to effectively measure the self-management behaviors of patients with liver cirrhosis.

III. CONCEPTUAL FRAMEWORK

This study intended to elucidate the factors to be included in a self-management instrument for patients with liver cirrhosis based on the IFSMT by Ryan and Sawin (2009). The IFSMT is a mid-range nursing theory, in managing the health problems of chronically ill patients, when a subject with health problems performs self-management behaviors, an intervention including his or her family can be provided to achieve effective health outcomes (Ryan & Sawin, 2009). The family is not limited to the biological family but may involve the cooperation of health professionals for individuals performing self-management. In this theory, self-management consists of the dimensions of context, process, and outcomes, which include complex and dynamic phenomena (Fawcett et al., 2001) (Figure 1).

The situational dimension consists of risk and protective factors, which include factors for each disease state, physical and social environment, and individual and family characteristics (Schilling et al., 2002). The factors for each disease state are the pathological, structural, or functional characteristics of the disease state, the quantity and forms of behavior necessary for treatment or self-management, and the prevention of the state affecting the essence. Environmental factors include physical and social factors, such as healthcare providers or backgrounds and migration to other neighborhoods, work, school culture, or society. Individual and family trait factors refer to their direct

characteristics, such as developmental stage, perspective, literacy, and information processing or receptive ability. These situational factors directly affect health outcomes and the relationship between individuals and families in the process of self-management.

The process dimension is based on the health behavior change theory, self-regulation theory, social support theory, and chronic disease-related research (Medicine et al., 2001). Individuals are more likely to engage in appropriate health behaviors if they accept sustainable health beliefs, develop the ability to change their health behaviors, and experience social facilitation for preventive health behaviors. As factors associated with the process, knowledge, and beliefs affect self-efficacy, health outcome expectations, and goal agreement. Self-regulation is a process by which health behaviors change, and includes behaviors such as goal setting, self-monitoring, reflective thinking, and decision-making. Social facilitation includes the concept of social support and cooperation that occurs among individuals, families, and health professionals.

There are short-term and long-term outcomes in the outcome dimension. Short-term outcomes refer to actual behaviors that involve following self-management for a condition, such as risk or transition, along with symptom management or medication usage. This includes expenses incurred due to the use of health services. Long-term outcomes are related to the successful achievement of short-term outcomes and include health status, quality of life, perceived well-being, and health services costs.

As described above, the IFSMT is different from the existing self-management theories in chronic disease management that explain health behaviors at the level of an

individual who performed health behaviors; it assumes on the premise of combining the individual and his or her family. Self-management is described as a process of changing positive health behaviors amid this influence.

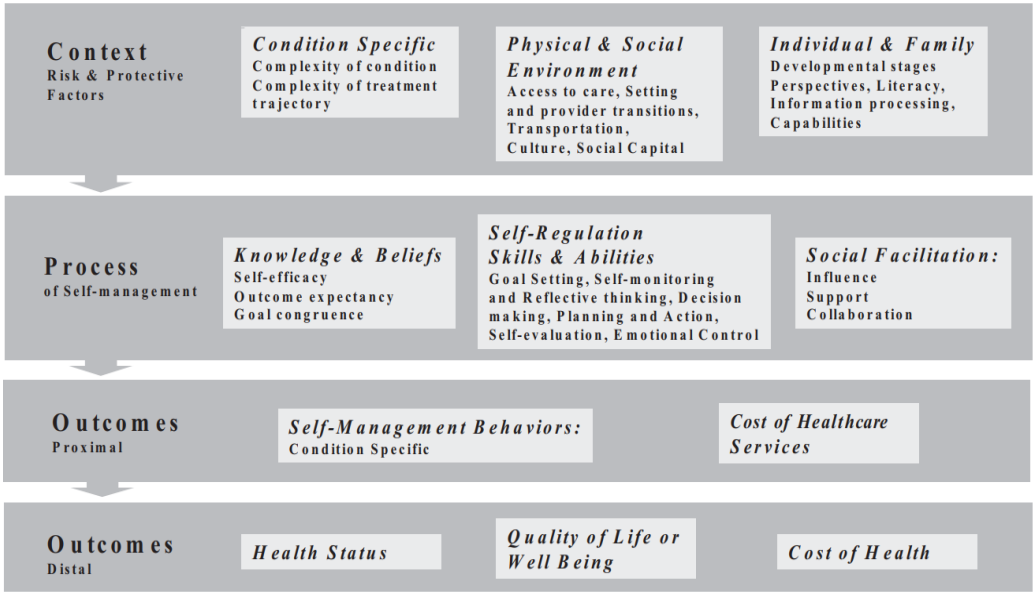


Figure 1. Individual and Family Self-Management Theory

The IFSMT model is valuable for describing the relationship between individuals and families in performing self-management behaviors among patients with liver cirrhosis. This study focused on the process dimension in the IFSMT model, and the key concepts and constructs have been adapted to explain the actions regarding self-management among this population in their relationships with families or caregivers (Figure 2). Self-management among patients with liver cirrhosis is mainly related to

activities in various aspects, such as daily life management, treatment compliance, symptom management and monitoring, and prevention behaviors in each individual's context. In the IFSMT model, the factors in the process dimension influenced by various individual contexts interact with each other and lead to practical behaviors, which lead to the proximal and distal outcomes of self-management. In addition, the model shows the interactions between patients and their families and the process by which the self-management behaviors take occur. Therefore, this study was based on the IFSMT model to elucidate self-management among patients with liver cirrhosis and to identify the components of self-management. Ultimately, a scale to measure self-management among patients with liver cirrhosis was developed based on the results.

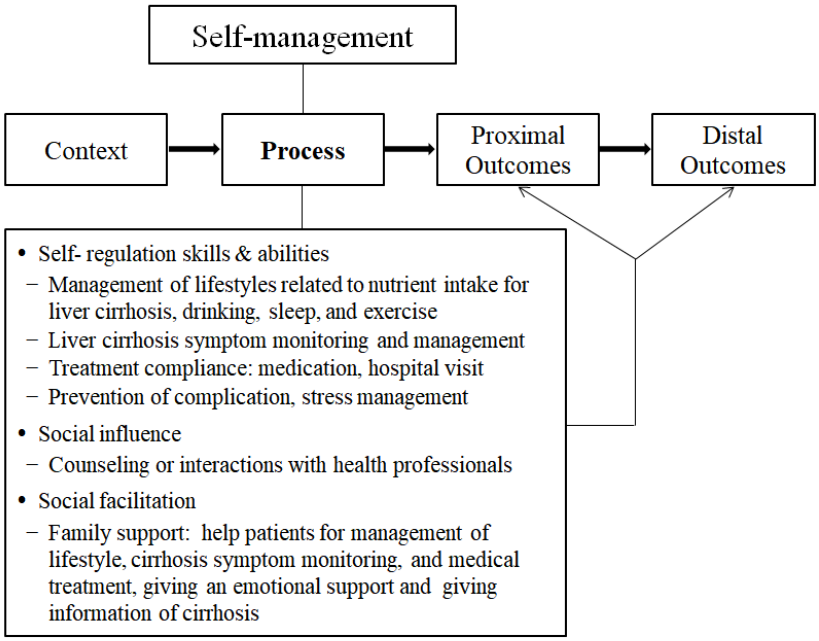


Figure 2. Conceptual framework of self-management among patients with liver cirrhosis

IV. METHODS

4.1. Study design

This was a methodological study conducted to develop and validate a scale that measures the level of self-management among patients with liver cirrhosis. This was developed based on the process suggested by DeVellis (2016). It consists of two phases: the development phase includes five steps and the evaluation phase includes three steps. The methods and procedures used in each step in the development process are presented in Figure 3.

In the development phase, the components of self-management among patients with liver cirrhosis were derived by reviewing the prior literature and clinical guidelines. The suitability of the contents in the field was confirmed and supplemented through in-depth interviews with patients with cirrhosis. After determining the measurement format, the preliminary items of the self-management scale for patients with liver cirrhosis were evaluated for content validity by experts. A pilot test of the items was performed with the patients. In the evaluation phase, the preliminary items were administered to patients with liver cirrhosis and evaluated for construct validity and reliability. Based on the results, the items included on this self-management scale for patients with liver cirrhosis were optimized.

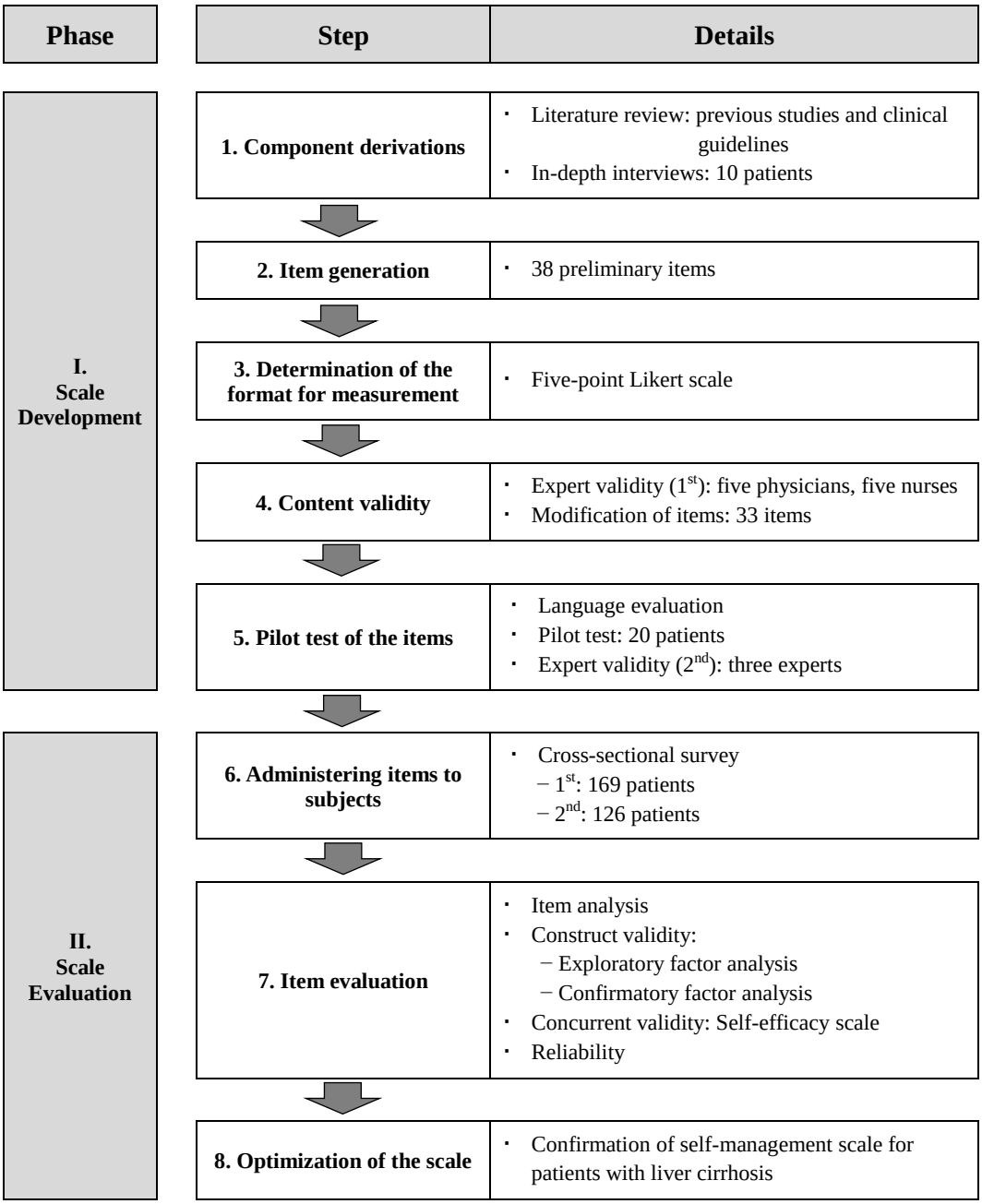


Figure 3. Development process for the self-management scale

4.2. Study procedures: Phase I - Scale development

4.2.1. Step 1: Derivation of the components of self-management among patients with liver cirrhosis

To identify the components of self-management, past literature and clinical guidelines were reviewed, and in-depth interviews of 10 patients with liver cirrhosis were conducted to confirm the field suitability of the extracted contents.

4.2.1.1. Literature review

A literature review was conducted to extract the factors and items involved in self-management among patients with liver cirrhosis. The literature was searched using four databases (Pubmed, CINAHL, Cochrane, and Embase) for foreign articles. To identify the domestic self-management scales for liver cirrhosis, one database (Research Information Sharing Service [RISS]) was used additionally. This review searched for all studies that targeting patients with liver cirrhosis. The search terms were (“liver cirrhosis” or “hepatic cirrhosis”) AND (“self-care” or “self-management”). All studies measuring self-management among patients with liver cirrhosis were included without restrictions on study design and publication year, and factors and items related to self-management were extracted from the included studies. Studies met the following criteria were considered for inclusion in this review: (1) studies involving all adults (aged 18 years and older)

diagnosed with liver cirrhosis; (2) studies that researched factors related to self-management; and (3) no limitations on outcomes. The exclusion criteria were as follows: (1) patients with liver cirrhosis were not the main participants; (2) liver cirrhosis was not the primary diagnosis; and (3) the studies were not written in English or Korean.

Studies identified according to the selection and exclusion criteria were imported and compiled into reference management software (Endnote X9.2) for selection. For the initial search, after removing duplicates, the titles and abstracts of the studies identified from four electronic databases were screened using eligibility assessment lists. All the remaining studies were reviewed for the study type, and the full texts of potentially relevant articles were retrieved.

4.2.1.2. In-depth interviews

In-depth interviews were conducted to elucidate the experiences and meanings of self-management for these patients and to confirm or revise the components of self-management among patients with liver cirrhosis extracted based on the literature review.

Participants were outpatients diagnosed with liver cirrhosis in the gastroenterology clinic of S hospital in Seoul. The inclusion criteria for the participants were as follows: (1) adults older than 20 years of age who were conscious and able to communicate; (2) patients diagnosed with liver cirrhosis for more than six months; and (3) patients who understood the purpose of the research and agreed to participate in the interview. Patients with the following criteria were excluded: those with cognitive impairment due to

dementia or hepatic encephalopathy and those who were being treated for liver cancer or other advanced cancer.

The in-depth interviews were conducted by a researcher to explore patient experiences with managing liver cirrhosis using semi-structured open-ended questions according to the purpose of the study; these included questions about management in daily life, clinical experience, and family relationships (Table 1). The questions were reviewed by a professor of nursing who had experience in interviewing and advised on the conduct of the interview.

Table 1. The in-depth interview questions

Type	Question
Introduction	1. How did you feel when you were first diagnosed with liver cirrhosis?
Transition	2. After being diagnosed with liver cirrhosis, what changes did you experience compared with before?
Main	3-1. Which of the symptoms or signs you experience with liver cirrhosis is the most difficult? How do you deal with it?
	3-2. What do you know about how to manage liver cirrhosis, and which parts of it do you think are important?
	3-3. Is there anyone who can help you manage liver cirrhosis? If so, who is that person, and what kind of help are you getting from that person?
Wrap-up	4. Please tell us how you continue to manage liver cirrhosis and share your advice for managing other patients with liver cirrhosis.

A convenience sample of 10 participants was interviewed face to face or by phone from May to June 2022, and all interviews were audio recorded. The average time for each interview was approximately 40−60 minutes; some interviews took more time based on the participant's speaking style and experience. During the interview, the researcher of this study wrote field notes and asked probing questions based on the information provided by the participants.

After completing the interviews, data from field notes and interview records were transcribed and summarized by the researcher in this study. Data were analyzed to describe patients' experience of self-management regarding liver cirrhosis and to derive the factors and components of self-management.

4.2.2. Step 2: Item generation

The preliminary items of the self-management scale for patients with liver cirrhosis were extracted from the literature review and in-depth interviews. Each item of the scale was developed considering its readability and accuracy, and terms with several meanings or situations were not included (DeVellis, 2016).

4.2.3. Step 3: Determination of the format for measurement

The developed scale of this study was determined to use a 5-point Likert scale for scoring each item. Likert scale is generally used to measure psychometric variables such

as opinions, beliefs, and attitudes. The 5-point Likert scale has an interval scale with a midpoint, and it allows respondents to express their true neutral or indifferent opinion when they are familiar with a topic. Therefore, this study selected the 5-point Likert scale for response of each item to improve clarity and reliability of survey items respondents tends to select a midpoint when they are uncertain about the meaning of the items (Chyung et al., 2017). In this scale, items were scored using a five-scale: “always” was scored as 5 points, “almost” was scored as 4 points, “average” was scored as 3 points, “almost not” was scored as 2 points, and “not at all” was scored as 1 point.

4.2.4. Step 4: Content validity

Content validity is the process of evaluating whether a scale contains the content related to the concept being measured. In this study, it was calculated by content validity index (CVI), and the number of experts needed to appropriately assess content validity is 3−10 (Lynn, 1986). The experts group in this study consisted of five physicians and five nurses with more than five years of experiences in the relevant field. Response to each item’s adequacy was provided on a four-point Likert scale ranging from 1 (not at all) to 4 (very much). The items with a score of 0.8 or higher were selected by calculating the ratio of experts who scored 3 or 4 points to the total number of experts.

4.2.5. Step 5: Pilot test of the preliminary items

4.2.5.1. Language evaluation

To assess the language accuracy and readability of the preliminary items, a Korean language specialist with a doctoral degree reviewed the items for grammar, word order, and ambiguity.

4.2.5.2. Pilot test of the preliminary items

As a result of the content validity test, the preliminary items of the self-management scale were evaluated for any issues with the understanding of each item, the clarity of the language including the adequacy of the number of items and item length, and the response time required to complete the scale to improve respondent understanding of the contents by 20 patients with liver cirrhosis. The eligibility criteria for the participants were the same as those used for the in-depth interviews. Participants responded regarding the degree of understanding of each item on a five-point Likert scale: 1=very difficult, 2=difficult, 3=moderate, 4=easy, and 5=very easy. According to the results, the items were revised to be more readable and understandable. After pilot test, the final items were evaluated for the contents with three of experts participated in the content validity.

4.3. Study procedures: Phase II - Scale evaluation

4.3.1. Step 6: Administration of the scale to the subjects

This step involved the process of a survey applying the initial self-management scale to patients with cirrhosis to evaluate construct validity.

Participants were recruited from July 20 to October 22, 2022. A sample for factor analysis is considered adequate if it includes at least five times the number of items on the scale (Tabachnick & Fidell, 2013). For exploratory factor analysis (EFA), participants who were diagnosed with liver cirrhosis including 171 outpatients from the gastroenterology clinic at S hospital in Seoul were recruited. A total of 205 patients registered in online communities providing information related to liver diseases were recruited for confirmatory factor analysis (CFA) because of the difficulty in considering each patient's follow-up period at the clinic (most commonly, 3–6 months). All 376 patients participated in the survey, and eligible data from 169 patients for EFA and 126 patients for CFA were analyzed excluding incomplete data (two patients' data from the clinic) and redundant participation data (79 patients' data from online).

The inclusion criteria for the participants were as follows: (1) adults older than 20 years of age who were conscious and able to communicate; (2) patients diagnosed with liver cirrhosis for more than six months; and (3) patients who understood the purpose of the research and agreed to participate in the interviews.

Patients with the following criteria were excluded: Patients with cognitive

impairment due to dementia or hepatic encephalopathy and those who were being treated with liver cancer or other advanced cancer. In addition, patients from the online community were recruited using questions regarding the exclusion criteria that could be selected to automatically excluded the subject, if the answer was ‘yes’.

4.3.2. Step 7: Evaluation of the items

4.3.2.1. Item analysis

For item analysis, descriptive statistics including the mean, standard deviation, skewness, and kurtosis were evaluated. Kline (2011) suggested that item analysis is possible when the absolute value of skewness is three or less and the absolute value of kurtosis is seven or less. The normality of each item was evaluated based on these criteria. The average correlation and inter-item correlation value was analyzed to evaluate the redundancy of each item and the relationship with the scale. The rule of thumb is that items that correlate below 0.3 are not sufficiently related to the measure and items and that correlate over 0.7 are redundant (Gharaibeh, 2017). The corrected item-total score correlation coefficient was calculated to determine the relevance of each item. Items with coefficients greater than 0.30 were suitable (Tabachnick & Fidell, 2007). In this study, items with a coefficient less than 0.40 were excluded from the preliminary scale.

4.3.2.2. Construct validity: exploratory factor analysis (EFA)

EFA is a method of estimating factors or concepts to determine whether latent factors are appropriate based on data when there are no existing instruments or hypotheses for latent factors. To determine whether the items selected through item analysis are suitable for factor analysis, the Kaise-Meyer-Olkin (KMO) test and Bartlett's Test of Sphericity were performed. The KMO value indicates the adequacy of the sample and the degree to which the correlation between variables is explained by other variables. If this value is close to one, this indicates that the data are suitable for use in factor analysis. In general, if it is 0.5 or more, the data are suitable for factor analysis. A value greater than 0.9 is considered as excellent; those between 0.80–0.89 as valuable; 0.70–0.79 as intermediate; and 0.6–0.69 as normal. Bartlett's Sphericity test is confirmed if the *p*–value is less than .05, and the factors are valid for factor analysis.

To extract the factors of the scale, principal component analysis (PCA) with oblique rotation (Promax) was performed. Kaiser (1974) explained that the eigenvalue of the sample correlation matrix should be 1.0 or more to determine the number of factors, indicating that one factor explains the variance of one or more variables.

In factor analysis, items with factor loading values of 0.3 or higher in absolute value are suitable (Seong, 2014). In this study, items with factor loading values of 0.4 or higher were selected.

4.3.2.3. Construct validity: confirmatory factor analysis (CFA)

The items extracted from the result of EFA were evaluated to confirm the fit of the model by CFA. Based on the five-factor structure and 22-item scale model in the present study, the fit indices and its acceptable threshold value are as follows: the Comparative Fitness Index (CFI) and Tucker-Lewis Index (TLI) with a value of 0.9 or more; the Root Mean Square Error of Approximation (RMSEA) with a value of 0.08 or less; the probability RMSEA with the desired value of more than 0.05; and the standardized root mean square (SRMR) with a desired value of less than 0.08 (Hair, 2010).

4.3.2.4. Concurrent validity

The concurrency validity of the developed scale was evaluated according to its correlation with the self-efficacy of patients with liver cirrhosis. In previous studies, the self-management of chronic diseases had significant positive correlations with self-efficacy. Therefore, it was judged appropriate to use the self-efficacy scale to evaluate the concurrent validity of this scale. To measure self-efficacy, the Chronic Disease Self-Efficacy Scale-Korean Version (CDSES-K) developed by Lorig et al. (1996) and modified by Kim et al. (2012) was used. This scale consists of 32 questions answered on a 10-point Likert scale ranging from 1 (cannot do it at all) to 10 (can do it very well), and Cronbach's α for the Korean scale was 0.93. In this study, the reliability was 0.97.

4.3.2.5. Reliability

The reliability coefficient (Cronbach's α) was calculated to evaluate how consistent all the items of the instrument developed in this study were and to measure the construct (Gray, Grove, & Sutherland, 2017).

4.3.3. Step 8: Optimization of the scale

The self-management scale for patients with liver cirrhosis was optimized based on the results of the validity and reliability testing.

4.4. Data analysis

Data collected to assess the validity and reliability of the developed scale were analyzed using SPSS for Windows version 25.0 and Mplus 8.0 software. The specific methods are as follows:

A. The general characteristics of the study participants were calculated using percentages, frequencies, mean, and standard deviation.

B. The content validity of preliminary items was assessed by an expert group using the CVI.

C. The construct validity of the scale was evaluated by item analysis, EFA, and CFA.

- An analysis of the preliminary items was performed, and items with an item-total correlation coefficient of 0.4 or higher were selected.

- The adequacy of data collected in this study for EFA was tested by the KMO test and Bartlett's Sphericity test. The factors of the self-management scale for patients with liver cirrhosis were extracted using PCA with Promax rotation. Items with eigenvalues of 1.0 or more and factor loadings of 0.4 or more were selected as criteria for extracting appropriate factors in the PCA.
- Statistical analysis for CFA was conducted using Mplus 8.0 software.
- The concurrent validity of the scale was evaluated using the correlation coefficients between the self-management scale developed in this study and the self-efficacy scale.
- The reliability of the scale was calculated by Cronbach's α.

4.5. Ethical considerations

This study was approved by the Institutional Review Board of Yonsei University Health system prior to data collection (No: 2021-2991-003, Appendix 1). When conducting interviews and surveys, data were collected from those who understood the study purpose and agreed to participate voluntarily. Information about the research was provided with a verbal explanation about the purpose and process of the study, and the participants were informed in advance that no harm would occur and that confidentiality would be maintained. In addition, after explaining that participation could be withdrawn according to each participant's will and that there would be no disadvantages in the case of withdrawal, the research consent form was signed, and the research proceeded.

V. RESULTS

5.1. Phase I - Scale development

5.1.1. Step 1: Derivation of the components of self-management among patients with liver cirrhosis

The components of self-management in patients with liver cirrhosis were extracted by conducting a literature review and confirmed by conducting in-depth interviews with the patients in the clinical field.

5.1.1.1. Literature review

A. Study selection

In the foreign literature, a total of 2,943 articles were retrieved using the search method in this study. After removing duplicates, 2,724 records were retained, and 2,693 articles with ineligible titles and abstracts were excluded. Consequently, 31 articles were evaluated for full-text review. Among them, 17 studies (11 studies that did not measure self-management as a main variable, three studies with an improper study population, two studies that were a protocol study and one unoriginal research) were excluded. Finally, 14 studies (Beg et al., 2016; Fagerström & Frisman, 2017; Ignatiev et al., 2021; Kim & Park, 2020; Mansouri et al., 2017; Ramachandran et al., 2021; Saleh et al., 2021; Stelmach et

al., 2021; Valery et al., 2017; Volk et al., 2013; Qian Wang et al., 2015; Wigg et al., 2013; Zandi et al., 2005; Yoon, 2018) from the foreign literature were included for review. The selection process of the studies is shown in Figure 4.

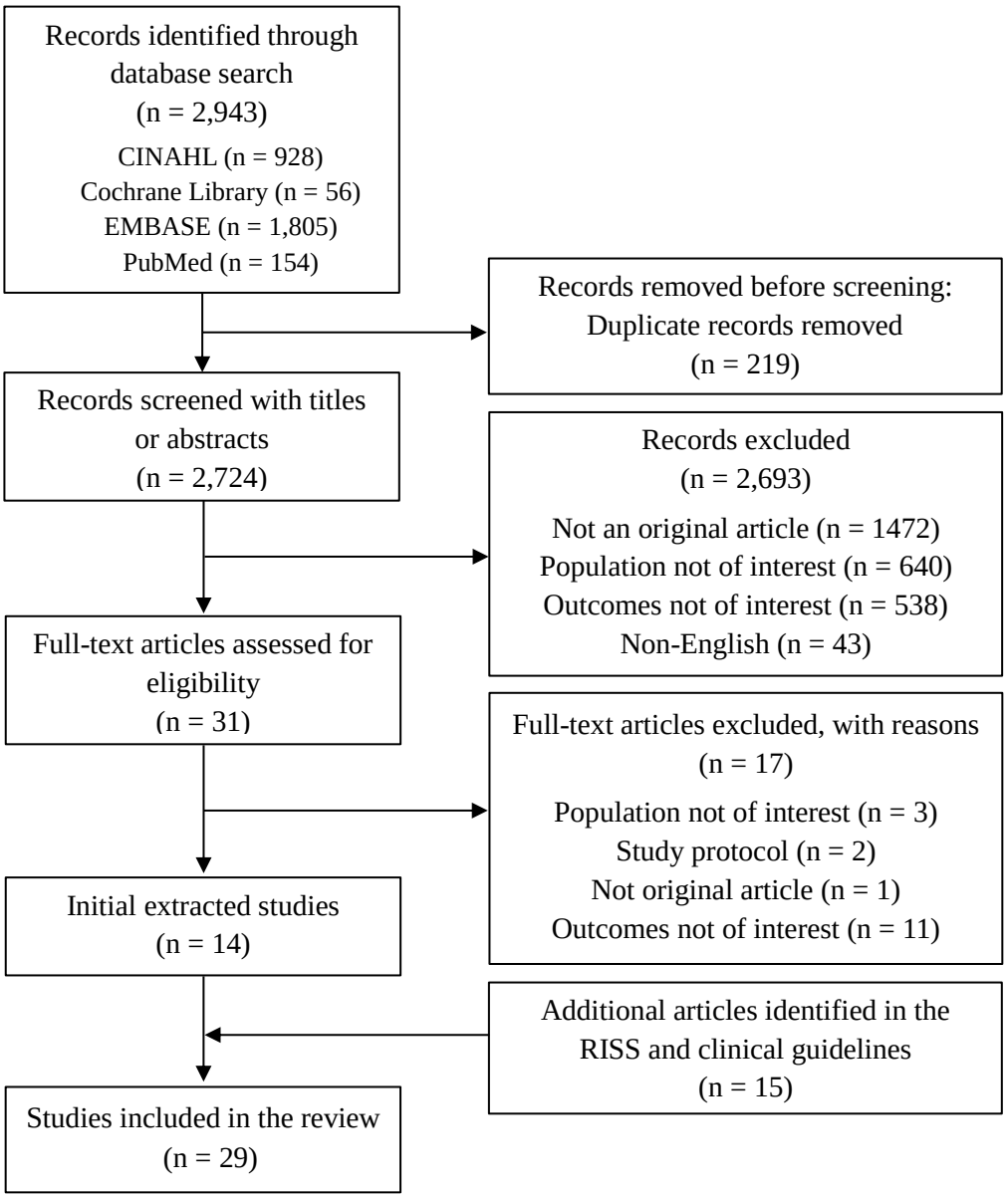


Figure 4. Process of study selection

Fourteen additional studies were extracted from the RISS database in domestic studies (published articles or thesis) and a clinical guideline regarding the management of liver cirrhosis (Lai et al., 2021). For the literature review in this study, 29 studies were included and reviewed (Appendix 2).

B. Results of the literature review

The concept to be measured of this study is self-management among patients with liver cirrhosis. The identified components of self-management in patients with liver cirrhosis are presented in Table 2.

The domains of self-management in patients with liver cirrhosis were diet management, lifestyle management, medical treatment compliance, and symptom management and monitoring.

Dietary management was confirmed as a subdomain of self-management in patients with liver cirrhosis through the literature review. The contents of this subdomain were regular diet, adequate amount of food intake or consumption of small amounts frequently, adequate protein intake, avoidance consumption of contaminated or raw food, and eating soft foods. Among these, regular diet and sufficient nutrition intake were found not only in previous studies but also in clinical guidelines; therefore, they were considered essential items for patients to self-manage liver cirrhosis.

Table 2. Components of self-management in patients with liver cirrhosis

Domain	Content	Study
Diet management	・ Regular diet	A1,3,4,7,8/ B1,2,3,8,12,13/ C
	・ Adequate amount of food	A14/ C
	・ Consumption of small amounts frequently	C
	・ Adequate intake of protein (1.2−1.5g/kg/d)	A1,3,4,7,8/ B1,2,3,8,9,13/ C
	・ Limit consumption of contaminated or raw foods	A13/ B3,8,9,13
	・ Consumption of soft foods rather than coarse foods	A4/ B3,8,9,13
Lifestyle management	・ Sufficient rest when tired.	A1,6,14/ B1,2,3,8,9,12
	・ Sufficient sleep at a set time each day	A4,9/ B1,2,3,8,9,12
	・ Avoidance of alcohol consumption	A5,8,10/ B1,2,3,8,9,12,13/ C
	・ Regular exercise	A4,6,8,10/ B3,8,9,12/ C
Medical treatment compliance	・ Attendance at regular hospital visits on a set date	A6,10,13/ B1,2,3,8,9,13
	・ Performance of regularly prescribed tests	A2,3,4/ B3,8,9,13
	・ Regular consumption of prescribed medications according to dosage	A2,3,5,11,14/ B3,8,9,13
	・ Consultation with a healthcare provider about over-the-counter medications	A4,5,6/ B3,8,9,13
	・ Consumption of only nutritional supplements approved by a doctor	A4,5,6/ B3,8,9,13
	・ Hospital visitation if symptoms of liver cirrhosis occur	A4,9,12,14
Symptom management and monitoring	・ Regular measurement of body weight or abdominal circumference to monitor for ascites or edema	A2,3,4,11/ B3,8,9,13
	・ Limitation salt intake in the case of ascites	A2,4,9,12/ C
	・ Us of a soft toothbrush to prevent bleeding gums	A4,5/ B2,3,7,10
	・ Consumption of soft foods to prevent varix bleeding in the esophagus or stomach	A4,5/ B3,8,9,13
	・ Application of prescribed lotions or use of loose clothing for dry or itchy skin	A1,4,9,14/ B3,8,9,13
	・ Ensure smooth bowel movements to prevent complications	A2,5,6/ B3,8,9,12
	・ Regular monitoring for blood in the stool	A4,5

Note. The list of studies included in review is presented in Appendix 2.

Lifestyle management such as fatigue, sleep, alcohol consumption, and exercise was identified as a domain of self-management in patients with liver cirrhosis. Fatigue is explained as high level of tiredness or physical discomfort, and it is a common problem in liver cirrhosis. Moreover, as other components of self-management, sleep, alcohol consumption, and exercise were also measured in many domestic and foreign studies.

To manage of liver cirrhosis, regular hospital visits and examinations, medication administration, consultation with healthcare providers about taking medications and supplements, and symptom changes were measured to identify the self-management level of patients. Therefore, with these components, the domain of medical treatment compliance was extracted as a factor of self-management necessary for continuous monitoring.

During the progression of liver cirrhosis, many symptoms and complications can occur. Items related to monitoring or management of body weight, ascites, bleeding tendencies, dry or itchy skin, and bowel movements were identified in previous studies. These items were included in the subdomain of symptom management and monitoring in cirrhosis management.

5.1.1.1. In-depth interviews

In-depth interviews were conducted with patients with liver cirrhosis to confirm and refine the domains and components of self-management for liver cirrhosis identified through the literature review in the field.

A. General characteristics of participants in the in-depth interviews

Participants of the in-depth interviews included 10 patients with liver cirrhosis (Table 3). Among them, six (60%) were male, and the mean age was 53.5 years (range: 36-76 years old). Four participants were patients with decompensated cirrhosis, and the mean period of treatment was 7.4 years (range: 0.5−23 years). Six participants were married and nine were living with their parents, spouse, children, or siblings.

Table 3. General characteristics of participants

ID	Sex	Age (years)	Type	Treatment duration (years)	Marital status	Living with
1	Female	75	Compensated	5 y	Married	Spouse
2	Female	76	Compensated	0.5 y	Married	Child
3	Male	36	Decompensated	3 y	Unmarried	Parents
4	Male	65	Compensated	8 y	Married	Spouse
5	Female	70	Compensated	18 y	Married	Spouse
6	Male	54	Decompensated	5 y	Divorced	Alone
7	Female	54	Compensated	4 y	Married	Spouse and children
8	Male	54	Decompensated	5 y	Unmarried	Sister
9	Male	54	Decompensated	2 y	Divorced	Mother and children
10	Male	51	Compensated	23 y	Married	Spouse and children

B. Results of in-depth interviews

A total of six categories and 26 subcategories were identified from the interviews.

a. Diet management

To manage liver cirrhosis, patients tried to eat more regularly than before diagnosis of liver cirrhosis, and they ate frequently in small amount of food in case of ascites or nausea. Patients tried to eat cooked food rather than raw to prevent infection, and to consume enough protein and water to manage liver cirrhosis. And they tried to choose their favorite foods while were simultaneously good for liver cirrhosis and to manage themselves what they eat for them, and avoided salty or spicy foods.

▪ Trying to more regularly consume foods for liver cirrhosis than before a diagnosis of cirrhosis

"I eat regularly and eat fruits and vegetables regardless of what they are because of the management of cirrhosis." (4)

"I only eat two meals a day, lunch and dinner, because I don't have much. But I eat at a regular time." (7)

"I try to avoid spicy and salty foods and eating them regularly." (9)

"In the past, I used to skip meals while working, but now I try to eat something on time even if I have time." (4)

▪ Eating small amounts frequently because of ascites or nausea

"Since I have ascites, the amount of food I eat has decreased, so I tend to share it little by little and eat it often." (6)

"I sometimes overeat because I am gluttonous, but I try to eat a small amount because I feel a little nauseous." (9)

▪ Avoiding raw food and trying to eat cooked food as much as possible

"After being diagnosed with cirrhosis, the doctor told me not to eat raw food, so I don't eat it anymore; but, if possible, I eat it cooked." (1)

"I used to love raw fish. But I don't eat it anymore. Doctors told me not to eat it." (2)

"My doctor told me not to eat sashimi because of getting infected, so I don't eat it anymore even if anyone gives it to me. I try to avoid it just in case." (5)

▪ Trying to eat protein well for treatment as recommended by the doctor

"I try to eat meat when I'm having a hard time. I don't really like meat, but the doctor told me to eat it well."(5)

"The doctor said I should eat protein, but I don't like meat, so I'm eating protein powder instead." (8)

"I'm trying to eat protein because I need to eat it well, but I can't eat a lot because I had intestinal surgery." (8)

▪ Trying to drink water sufficiently

"My skin is getting drier and itchy, I drink more water." (3)

"My skin is dry, so I try to drink a lot of water" (6)

▪ Finding food that is good for the liver that I enjoy eating

"I try to find food that doesn't strain my liver and that I like." (3)

"Even if there's only one side dish, I make it so that it's not salty. The food that I buy

outside is salty and spicy, so I thought it would be bad...” (6)

“After being diagnosed with cirrhosis, I tend to check if the food is good for the liver and eat it.” (7)

▪ Avoiding salty or spicy foods and overeating after being diagnosed with cirrhosis and drinking less water and eating less food because of ascites

“Before, I used to eat anything and buy it, but now I avoid stimulating foods like salty and spicy foods because they are not good for cirrhosis.” (9)

“The doctor told me not to overeat.” (5)

“As I have ascites, the amount of food and water I consume has decreased.” (8)

▪ Caring about what I eat myself

“After I was diagnosed with cirrhosis, I focused on eating on my own.” (6)

“I try not to make the food salty or spicy...because no one else cares about me or about these things; I take care of myself.” (7)

b. Lifestyle management

Patients felt more fatigue than before the diagnosis of liver cirrhosis, so they would rest if possible even when working, and try to get enough sleep. They thought abstinence from alcohol was important for the treatment of liver cirrhosis, and they tried not to drink alcohol and exercise regularly in daily life.

▪ Feeling more tired than before and resting even while working

“I feel tired earlier than before, and I have to lie down right away if I'm tired. That's how it gets better.” (1)

"I can't work for a long time because I'm tired. I'm lying down after doing a little bit and I'm lying down. So, things are a little slow." (5)

"I have cirrhosis and diabetes, so I get sleepy when I'm tired or low on sugar, but I sleep at that time." (8)

"I didn't have any other symptoms when I was first diagnosed with cirrhosis, but I felt a lot of fatigue. I still feel tired, but then I just rest." (10)

▪ Avoiding alcohol consumption because abstinence is important for the treatment of cirrhosis

"I don't know much about cirrhosis, but I know it gets worse when I drink. I don't drink at all." (2)

"I couldn't sleep at night, so I started drinking and became an alcoholic. Once I drink, I keep drinking, so I received treatment to help me not to drink." (3)

"I think abstinence from alcohol is the most important thing for cirrhosis. There are times when I still think of alcohol, but when I really want to drink, I drink a can of beer and don't drink more than that." (7)

"I used to meet my friends and drink a lot. But I can't drink now, so I just don't meet my friends. If I don't drink when I meet my friend, I have to explain. It's annoying, so I don't meet him." (8)

▪ Trying to sleep well because of feeling tired more easily than before

"I get tired easily, so I try to sleep well on purpose" (5)

"I can't sleep well because I'm sensitive. My sleeping hours are irregular, and I'm

tired because I can't sleep for a long time even if I fall asleep." (7)

"It's been a while since I was diagnosed, so I try to sleep 6−7 hours a day. I think it's become a habit because I go to work and feel tired more easily than others." (10)

▪ Trying to exercise regularly

"I can't exercise well because of my ascites, but if I still walk for about 20 minutes at least inside the house, and if I can't, I lie down and lift my legs up and down." (5)

"I've been exercising since I was diagnosed with diabetes. After eating, I go to the park and walk. My sister nags me to leave if I don't go out, so I just come out to exercise when I eat." (8)

"I think exercise is the second most important thing in liver cirrhosis management after abstinence. I purposely go around the company building for about an hour after lunch so that I don't miss exercising. I go hiking on the weekend." (10)

c. Medical treatment compliance

Patients underwent regular hospital treatment and examinations for the management of liver cirrhosis. They tried to take the prescribed medication well and checked with the physicians when taking not prescribed medications or nutritional supplements. They knew that they have to visit the hospital when new symptoms developed or when symptoms worsened.

▪ Visiting the hospital regularly because it is the most important factor for treatment

"I have cirrhosis because of hepatitis, so I'm taking medicine well. That's why I go to

the hospital all the time." (5)

"When I get home from the hospital, I always write down the next visit date on the calendar because I can't skip it, and I don't want to forget." (1)

"I need to see a doctor to get treatment. I think a hospital visit for treatment is the most important thing." (2, 4, 6, 9, 10)

▪ Receiving an examination regularly as prescribed for treatment

"I go to the hospital every three months for a blood test. That way, I can check if my condition is better." (3, 5)

"There are times when I postpone my treatment schedule because I can't get a test, but I have to keep taking medicine, so I do a blood test or anything. I think it's an important part of management." (8, 10)

▪ Taking medicines as prescribed without missing a dose

"I've experienced hospitalization because I didn't listen to the doctor a few times, and I make sure to take the prescribed medicine without missing it." (3)

"I only take the medicine prescribed by the doctor, but I don't take anything else. " (4, 8, 9)

"I heard that the best solution is to take the medicine prescribed by the doctor for the liver." (7)

"For liver cirrhosis management, I only take the medicine for hyperlipidemia, Urusa, and gastrointestinal medicine prescribed by the doctor. It's the most important thing to treat." (8)

▪ Asking a medical doctor prior to taking non-prescribed medications or nutritional supplements

"People around me tell me to take oriental medicine because it's good, but I don't even look at it. I asked the doctor a few times about the medicine, and he said it could be wrong." (3)

"Without realizing it, maybe it's because the teacher says it often, but I think I shouldn't take any medicine, so I don't take it, except what I've been prescribed. Even if people around me say it's good." (5)

"I usually don't take nutritional supplements. But, I eat red ginseng, and I asked the doctor about taking it first, and he said it was okay, so I'm only eating it." (6)

"No matter how good the liver is, I don't eat it without checking with a doctor or a pharmacist. I only eat what he or she said is okay when I ask the doctor about it. What if it goes wrong?" (7)

"At first, when I got sick, I ate it to live something that was good for my body, but now I know I don't need it after hearing it from the doctor, so I don't eat it anymore." (8)

▪ Visiting the hospital when new symptoms develop or existing symptoms worsen

"Sometimes, if I gain weight and feel a little stuffy breathing, I go to a hospital near your house and check if I have more ascites because my house is far from here (Severance hospital). Then, the doctor will tell me to go here or if I'm okay." (5)

"I get a little tired when I have more ascites. I can't walk and exercise. Then I tell my mother that we should go to the hospital together." (9)

"Last time, I was hospitalized for hepatic coma, but I couldn't do anything because my body was weak. I didn't know if I should go to the hospital or not. That's a tough situation." (9)

d. Symptom management and monitoring

Patients with liver cirrhosis measured body weight regularly for monitoring their conditions, and if they have ascites, they tried to reduce intake of salt or water in management of liver cirrhosis. Moreover, they checked the stool when defecating to monitor bleeding sign.

▪ Measuring body weight regularly and monitoring for any bodily changes

"I was told by the hospital to check my weight every day, so I weigh myself after going to the bathroom every morning." (2)

"I check my weight every day while exercising. So I know that there is a change of 1-2 kilograms, but there is no change beyond that." (4)

"I weigh myself every day." (5, 6, 7, 9)

"I check my weight every day and know that if I gain weight, I get more ascites, so I go to the hospital and get diuretics and paracentesis." (9)

▪ Reducing salt and water intake for ascites management

"I think it's harder because there's a lot of ascites. I can't eat salty food, so I can't eat more if I season less...(Omitted)…I drink less water on purpose because I feel full and out of breath. And I don't eat it because it makes more ascites." (6)

"Because my mother cooks for me... My mom makes it bland because of me. But I

don't really drink water either. I think the water alone fills me with more ascites." (9)

▪ Monitoring the stool for bleeding after each defecation

"I've been recording the number and thickness of my stool on paper for a long time, so I've been monitoring it well." (2)

"I have been hospitalized for bloody stool, so I always check my stool. I remember that time being so hard." (3)

"I defecate several times every day because of cirrhosis and colon surgery, and I know about it every time; I check my bowel movements every time. Blood shouldn't come out of my stool." (8)

d. Family support

Patients felt that they managed liver cirrhosis mostly alone, but they found that their families helped them avoid drinking alcohol and take their medications well in daily life. Additionally, they said that their families help them with hospital visits eat healthy food. Patients said that their families gave them information related to liver cirrhosis if they have, and that they support them emotionally.

▪ Feeling like I manage liver cirrhosis mostly on my own, without help

"Even if my husband lives with me, he doesn't take care of me and I take care of it myself." (1)

"I didn't even talk about cirrhosis in case my son was worried. I can still take care of it by myself."(2)

"There was no one around me who was familiar with cirrhosis, so there was no one who helped me with how to manage it. I'm just doing it by myself." (3)

▪ Receiving assistance to sleep regularly and avoiding drinking alcohol in daily life

"My sister tries to help me sleep regularly. I've had bowel surgery, so I have to wake up often because I have bowel movements all the time, but when I go to bed, my sister keeps quiet." (8)

"I have symptoms of hepatic coma, so I try not to drink alcohol even if I'm alone because my mother and daughter are worried a lot." (9)

"My wife told me not to drink alcohol so many times in the past, so I don't drink anymore because I think of my wife even when I go to a company dinner." (10)

▪ Receiving monitoring by a family member regarding regular medication usages or receiving hospital treatments, and being provided with accompaniment to hospital visits

"After having cirrhosis, my husband doesn't, and my son often asks about my medical treatment and taking medicine. Maybe he's taking care of me because he's worried about his mother." (7)

"My mother helps me come to the hospital. Come to the hospital with me." (9)

▪ Receiving help from a family member with monitoring regular consumption of medications or health supplements

"My daughter sometimes sends me good things like Gongjindang. Then I check if it's good for my liver and eat it if it's necessary." (2)

"My husband doesn't do much to help me. Come to think of it, he always pours warm water into a cup for me to take medicine in the morning. And he asks me if I took medicine later. He does take care of me."(5)

"My sister knows about nutritional supplements such as Lactobacillus and vitamins. She knows what's good and bad for the liver, so she takes care of me if I need it." (8)

"When I get the medicine, my mother keeps it in the medicine container by day of the week. Then, I'll take it." (9)

▪ Receiving healthy food from a family member

"I live alone, so I do most of things alone, but my cousin lives nearby, and sometimes she makes kimchi and other foods for me. My sister cares about me because my liver also is not good"(6)

"My sister nags me and takes care of me when I eat. Whenever I go to meet my friend, she always tells me not to drink. She made side dishes for me. She purposely takes care of all the vegetables and protein for me." (8)

"My wife is working, but she's a nurse, so she usually takes care of food. I have no problems with my social life, so I do most of the things on my own, but my wife is in charge of eating." (10)

▪ Receiving information from a family member related to the management of liver cirrhosis

"My daughter doesn't live with me, but she calls me often and tells me what's good or bad."(8)

"My sister works at a hospital, so if she hears anything from the hospital or meets some patients like me, she comes and tells me what I need. I'm very thankful for that."(8)

▪ Receiving emotional support or strength from a family member while receiving treatment

"When I talk to my parents, I feel like the lump in my chest is loosened a little bit. So I also tell other patients that if they are having a hard time while getting treatment, it's good for them to talk to their families a lot and get treatment together."(3)

"I take care of most of things by myself. My husband doesn't do much for me, but he just eats and talks with me and works in the garden. That gives me a lot of strength." (5)

"I'm not married. By the way, after being hospitalized for surgery and treatment, I feel psychologically stable that someone is just around me. That's something that a doctor or a hospital can't do for me."(8)

5.1.2. Step 2: Item generation

The preliminary 38 items included in the self-management scale were identified based on the final constituent factors and contents derived from the summaries of the theoretical considerations of the literature review and field suitability verification via in-depth interviews.

Among the components of self-management among patients with liver cirrhosis,

dietary management (13 items), lifestyle management (5 items), medical treatment implementation (6 items), symptom management and monitoring (7 items), and family support (7 items) were identified (Table 4).

Table 4. Preliminary items of the self-management scale for patients with liver cirrhosis

Domain	Preliminary items
Diet management (13 items)	1. I eat meals regularly.
	2. I eat small amounts of food frequently.
	3. I eat cooked food rather than contaminated or raw food.
	4. I eat 2−3 pieces of meat, fish, tofu, eggs, seafood, etc., that are the size of a table tennis ball for each meal.
	5. I eat enough at every meal, and I have not lost weight.
	6. I have a late evening snack and breakfast to prevent having an empty stomach for a long time.
	7. I eat foods containing fiber, such as vegetables and fruits for smooth bowel movements.
	8. I drink at least eight glasses of water per day (or the recommended amount).
	9. I limit intake of stimulating foods (coffee, tea, etc.).
	10. I do not overeat.
	11. I cook food for myself.
	12. I eat food knowing about the food's pros and cons.
	13. I can find my favorite food without any harm to the liver.
Lifestyle management (5 items)	14. I rest sufficiently when I feel tired.
	15. I get enough sleep at a regular time every day.
	16. I do not drink alcohol to manage liver cirrhosis.
	17. I exercise regularly.
	18. When I feel stressed or uncomfortable, I look for ways to relieve it.
Medical treatment compliance (6 items)	19. I visit the hospital regularly as scheduled for the management of liver cirrhosis.
	20. I regularly undergo the prescribed tests to manage liver cirrhosis.
	21. I take the prescribed medication according to the dosing schedule.
	22. I consult with my medical doctor about taking over-the-count

	medication.
	23. I only take supplements that have been approved by the physician.
	24. If any symptom of liver cirrhosis occurs, I visit the hospital as necessary.
Symptom management and monitoring (7 items)	25. I regularly measure my weight and abdominal circumference to monitor ascites or edema.
	26. If I have ascites, I limit my salt intake.
	27. I use a soft toothbrush to prevent bleeding gums.
	28. I eat soft foods to prevent variceal bleeding in the esophagus or stomach.
	29. I apply the lotion prescribed for dry or itchy skin or wear loose clothing.
	30. I check for blood in my stool when defecating.
	31. When I have ascites, I reduce my water intake.
Family support (7 items)	32. I mostly manage my cirrhosis alone. (If you answered “yes,” please answer the following questions while thinking of those who can help you in any way.)
	33. My family (or caregiver) helps me my lifestyle management related to liver cirrhosis.
	34. My family (or caregiver) accompanies me to the scheduled cirrhosis consultations and treatments.
	35. My family (or caregiver) helps me safely take my prescribed medications and the permitted dietary supplements.
	36. My family (or caregiver) helps me with dietary management related to liver cirrhosis, such as regular meals and food types.
	37. My family (or caregiver) gives me informs about liver cirrhosis.
	38. My family (or caregiver) provides emotional support to help me manage liver cirrhosis.

5.1.3. Step 3: Determination of the format for measurement

For the proposed scale in this study, a five-point Likert scale selected to evaluate each item, and the scoring method of the scale was as follows: “always” was scored as 5 points, “almost” was scored as 4 points, “average” was scored as 3 points, “almost not” was scored as 2 points, and “not at all” was scored as 1 point.

5.1.4. Step 4: Content validity

The content validity of the scale was assessed by 10 experts who had experience in the treatment, nursing, and education of patients with liver cirrhosis. The experts consisted of five clinicians and five nurses with an average clinical experience of 9.1 years. According to the criteria suggested by Lynn (1986), the number of experts that scored three or four points for each item was divided by the total number of experts, and items with a score of 0.80 or higher were selected. The items were revised and supplemented according to the experts’ opinions of some items, and the results are presented in Appendix 3. A total of five items were deleted, including items 2, 8, 9, 11, and 13. In addition, item 28 was deleted because it conflicted with item 7 and was not essential. The CVI for both items 4 and 6 was 0.70; however, these items were revised and kept based on the clinical guidelines and the researcher’s judgment that they are important items related to sarcopenia, which can occur in patients with liver cirrhosis. The CVI was 0.80 or higher, but three items (12, 30, and 38) were revised according to

the opinions of the experts and the judgment of the researcher. Furthermore, one item related to the family's perception of the patient's mental status was added according to the experts' opinions. The final items of scale included a total of 33 items.

5.1.5. Step 5: Pilot test of the preliminary items

5.1.5.1. Language evaluation

Before the preliminary test, the items were evaluated by a Korean language specialist to review the grammar, character length, and readability. Except for 11 items among all of the evaluated items, the arrangement of words or conjunctions was modified to improve readability, whereas 22 items were deemed sufficiently clear and thus required no additional changes (Appendix 4).

5.1.5.2. Pilot test of the preliminary items

After the language evaluation, the preliminary 33 items were evaluated on 20 patients with liver cirrhosis (Appendix 5). The response time required for the scale, the degree of understanding of each item, adequacy of the number of item, and appropriateness of the item length were evaluated, and the results are summarized in Table 5. The average response time for all items was 7.5 (SD: 3.10) minutes, and the mean score for the understanding level was 4.2 (SD: 0.69). The scores for the adequacy of the number of items and the appropriateness of item length were 4.0 (SD: 0.76) and 4.1

(SD: 0.61), respectively. As a result, there was no item revised, and all items of the scale were finally validated by three experts for scale evaluation.

Table 5. Results of the pilot test (*N* = 20)

Variable	Mean ± SD	Range
Response time (minute)	7.5 ± 3.10	–
Understanding	4.2 ± 0.69	1–5
Number of items	4.0 ± 0.76	1–5
Length of items	4.1 ± 0.61	1–5

5.2. Phase II - Scale evaluation

5.2.1. Step 6: Administrating the items to subjects

The general characteristics of participants were shown in Table 6. Males accounted for 58.6% were male, whereas 41.4% were female. The mean age was 63.0 years old, and 69.8% of the participants were married. Regarding their socioeconomic characteristics, 76.0% had an education level above high school and 39.5% had an average monthly income of four million won or more. The average duration of cirrhosis treatment was 4.3 years (range: 0.5–18 years) and 26.6% of patients experienced one or more complications.

Table 6. General characteristics of participants in exploratory factor analysis (*N*=169)

Variable	Category	n (%) or Mean ± SD
Demographics		
Sex	Male	99 (58.6)
	Female	70 (41.4)
Age		63.0 ± 12.84
Marital status	Single	17 (10.1)
	Married	118 (69.8)
	Bereaved/Divorced/Separate	31 (18.3)
	Others	3 (1.8)
Education	≤ Middle school	40 (24.0)
	> Middle school, ≤ College	121 (72.4)
	> Graduate school	6 (3.6)
Job	Yes	85 (50.6)
House income	≤ 200	60 (35.9)
(million, KRW)	> 200, ≤ 400	41 (24.6)
	> 400, ≤ 600	42 (25.1)
	> 600	24 (14.4)
Health-related		
Drinking	Yes	38 (22.6)
Sleep sufficiency	Yes	92 (54.8)
Treatment duration (years)		4.3 ± 4.55
Comorbidities*	Yes	119 (70.4)
	Hypertension	73 (43.2)
	Diabetes	55 (32.5)
	Others	39 (23.1)
Complications*	Yes	45 (26.6)
	Ascites	29 (17.2)
	Hepatic encephalopathy	4 (2.4)
	Bleeding	15 (8.9)
	Malnutrition	11 (6.5)

Note. * = Multi-response.

5.2.2. Step 7: Item evaluation

5.2.2.1. Item analysis

The mean, standard deviation, skewness, and kurtosis of each item were assessed to determine whether the collected data were suitable for factor analysis (Appendix 6). Skewness and kurtosis values that did not exceed the absolute value of 2 were considered within the suitable range for the assumption of normality. The mean score of the 33 preliminary items was 3.6 (SD: 0.61), ranged 2.9–4.5. The ranges of skewness and kurtosis were 0.04–1.47 and 0.02–5.17, respectively. Of the 33 items, items 14 (kurtosis: 4.75), 15 (kurtosis: 5.17), and 19 (kurtosis: 2.01) had a higher kurtosis value than the absolute value of 2. However, it is possible that the absolute value of kurtosis for factor analysis is 7 or less. Therefore, all items of the preliminary scale including these 3 items were maintained for analysis.

The average correlation value of each item with the other items on the scale ranged from 0.142 to 0.383 (Appendix 7). The value of items 4 and 26 were lower than 0.2. In the inter-item correlation analysis, ten items (14, 15, 16, 27, 28, 29, 30, 31, 32, and 33) were strongly correlated with other several items, with the values above 0.7 (Appendix 8). Among these items, the meaning of item 15 was judged to be included in that of item 14 because most patients received not only treatment but also prescribed clinical examinations when they visit the hospital. Items 28, 29, 30, and 32 were considered that the meanings were included in item 27 that measures family assistance related to lifestyle management. Therefore, items 15, 28, 29, 30, and 32 were deleted due to the redundancy

of the items' characteristics. The item-total correlation coefficient of the 33 items ranged from 0.257 to 0.709, and the coefficients of items 4, 7, and item 26 were lower than 0.4. Therefore, eight items (4, 7, 15, 26, 28, 29, 30, and 32) were deleted, and a total of 25 items in the scale showed satisfactory coefficients of average inter-item correlations (range: 0.248–0.347) and corrected item-total correlations (range: 0.425–0.617).

5.2.2.2. Construct validity: exploratory factor analysis (EFA)

Based on the results of the item analysis, an EFA was performed on 25 items. Data from all 169 participants in this study were used for EFA. KMO and Bartlett's Test of Sphericity were used to test the suitability of the collected data (Table 7). The result of KMO was 0.851, indicating that the sample size used for the current study was more than adequate. The result of Bartlett's Test of Sphericity was significant (1796.2, p <.001). Therefore, the data were suitable for factor analysis.

A principle component extraction with promax rotation for the EFA was used to establish the construct validity of the 25 items. The commonality is recommended to be 0.4 or more, which is evaluated as an item with significant explanatory power (Costello & Osborne, 2005). The commonalities of all items ranged from 0.381 to 0.802 (Appendix 9).

Table 7. Result of Kaise-Meyer-Olkin test and Bartlett's Test of Sphericity

Kaise-Meyer-Olkin measure of sampling adequacy		0.851
Bartlett's Test of Sphericity	Approximate $\chi 2$	1796.206
	df	300
	p	< .001

Five factors were extracted by fixing a number of factors and the cumulative explanatory power was 57.1%. The commonalities of items 8 and 13 (0.381 and 0.388, respectively) were lower than the recommended values of 0.4.

The factor loadings of items 8, 13, and 17 in the structure matrix were between 0.3 and 0.6. However, the pattern coefficients of the items were lower than 0.4. Item 18 exhibited cross-loading in two factors with pattern coefficients of 0.601 and 0.326, but the item in the structure matrix was cross-loaded with the differences between factors of less than < 0.2 in three factors, meaning that the item is not appropriate to explain a factor. Therefore, these four items (8, 13, 17, and 18) were deleted. Items 9, 11, 22, and 23 showed cross-loading with differences of less than 0.2 in two factors, but they were kept because they were deemed essential items for the self-management of liver cirrhosis. Items 19, 20, and 27 exhibited cross-loadings in three factors in the structure matrix reflecting the correlations between factors. However, these items were kept in the scale because the differences between the factor loadings of each item exceeded 0.2 and each item belonged to one factor in the pattern matrix.

Finally, five factors with 21 items were extracted for the self-management of patients with liver cirrhosis (Table 8). All items were deemed suitable based on a corrected item-total correlation coefficient values of 0.4 or more. The commonalities of all items were 0.4 or more, ranging from 0.489 to 0.817. The cumulative explanatory power of the five factors was 61.1%, which satisfied the >50% explanatory power criterion (Hair, Black, Babin, & Anderson, 2009).

Table 8. The results of exploratory factor analysis (N = 169)

Factor	Item	Commonality	Factor*				
			1	2	3	4	5
Symptom management	25	0.587	**0.783**	−0.106	0.076	0.064	−0.072
	20	0.575	**0.645**	−0.019	0.191	−0.074	0.134
	24	0.489	**0.634**	0.039	0.038	0.089	−0.026
	21	0.546	**0.614**	0.027	0.161	0.039	0.050
	23	0.613	**0.569**	0.458	−0.283	−0.037	−0.077
	22	0.499	**0.482**	0.358	−0.219	0.061	0.000
Liver cirrhosis specific lifestyle management	5	0.579	0.044	**0.781**	0.012	−0.124	−0.004
	6	0.565	0.032	**0.706**	−0.027	0.040	0.042
	2	0.521	0.054	**0.663**	0.181	−0.078	−0.014
	11	0.551	−0.105	**0.548**	0.431	0.170	−0.194
	9	0.583	−0.156	**0.520**	−0.022	0.122	0.404
Medical treatment compliance	14	0.798	0.001	0.058	**0.896**	−0.022	−0.039
	16	0.817	0.044	0.015	**0.879**	0.006	0.012
	19	0.486	0.281	−0.041	**0.498**	−0.050	0.166
Family support	33	0.800	−0.084	0.034	−0.005	**0.926**	−0.031
	31	0.789	0.164	−0.078	0.008	**0.860**	−0.077
	27	0.768	0.101	−0.046	−0.026	**0.793**	0.142
General lifestyle management	12	0.623	0.124	−0.283	−0.038	0.055	**0.814**
	3	0.575	0.056	0.147	−0.003	−0.223	**0.718**
	10	0.572	−0.173	0.190	−0.073	0.131	**0.694**
	1	0.493	−0.021	0.072	0.195	0.032	**0.570**
Eigen value			7.0	1.7	1.6	1.3	1.2
Variance (%)			33.5	8.2	7.6	6.1	5.7
Cumulative variance (%)			33.5	41.7	49.3	55.4	61.1

Note. *: Factors in pattern matrix.

A. Naming of factors

As a result of the EFA of the self-management scale for patients with liver cirrhosis, five identified factors with 21 items were named as follows.

The first factor consisted of 6 items (20, 21, 22, 23, 24, and 25) and was named 'symptom management,' accounting for 7.0% of the total variance. This factor consists of items related to the management of ascites, gum and gastrointestinal bleeding, and dry skin, which are common symptoms or complications of liver cirrhosis.

The second factor is 'liver cirrhosis specific lifestyle management' with 5 items (2, 5, 6, 9, and 11), accounting for 1.7% of the total variance. The factor includes essential items for the treatment of liver cirrhosis related to preventing infection, sarcopenia, constipation, fatigue, and alcohol intake, all of which should be managed in daily life.

The third factor consists of 3 items (14, 16, and 19), and was named 'medical treatment compliance,' accounting for 1.6% of the total variance. The items of this factor measure the patient's adherence to regular hospital visits and prescribed medication administration, which is essential for the treatment and management of liver cirrhosis. Additionally, item 19 measures the willingness of the patient visit the hospital for examination when the conditions or symptoms related to liver cirrhosis change.

The fourth factor includes three items (27, 31, and 33), accounting for 1.3% of the total variance. Item 27 measures the families' participation in the patient's management of liver cirrhosis in daily life, whereas item 31 evaluates the family member's awareness of the patient's state of consciousness and the changes that may occur depending on the

complications of liver cirrhosis. Therefore, the factor was labeled as ‘family support,’ which plays an important role in facilitating patients to improve self-management behavior.

The fifth factor contained items 1, 3, 10, and 12. The factor accounts for 1.2% of the total variance and consists of items measuring the management of regular meals, protein intake, sleep and exercise as general disease management strategies.

B. Correlation between five factors

The correlation between the five factors is shown in Table 9. A correlation analysis between factors was to determine whether the five factors extracted from factor analysis were distinguished and explained by the items constituting each factor. The correlation coefficients ranged from 0.33 to 0.58. The discriminant validity of each factor can be judged as another factor if the correlation coefficient between factors is less than 0.85. In this regard, the five factors of this scale were considered factors with distinguishing characteristics.

Table 9. Correlation matrix between five factors

Factor	1	2	3	4	5
1. Symptom management	−				
2. Liver cirrhosis specific lifestyle management	0.58**	−			
3. Medical treatment compliance	0.44**	0.45**	−		
4. Family support	0.51**	0.42**	0.33**	−	
5. General lifestyle management	0.48**	0.51**	0.43**	0.36**	−

Note. **: Correlation is significant at the .01 level (2-tailed).

5.2.2.3. Construct validity: confirmatory factor analysis (CFA)

The data of 126 patients were included for CFA. Table 10 shows the general characteristics of the participants. Among the participants, 52.4% were male and 61.1% were married. The mean age was 44.4 years. Almost 90% of all participants had an education level above high school, and 40.5% had an average monthly income of four million won or more. The average duration of cirrhosis treatment was 2.6 years (range: 0.5–18 years), and 57.9% patients had experienced one or more complications.

Table 10. General characteristics of participants in confirmatory factor analysis (*N*=126)

Variable	Category	n (%) or Mean ± SD
Demographics		
Sex	Male	66 (52.4)
	Female	60 (47.6)
Age		44.4 ± 8.86
Marital status	Single	40 (31.7)
	Married	77 (61.1)
	Bereaved/divorced/separate	6 (4.8)
	No response	3 (2.4)
Education	≤ Middle school	3 (2.4)
	High school	24 (19.1)
	> College	88 (69.8)
	No response	11 (8.7)
Job	Yes	88 (69.8)
House income (million, KRW)	≤ 200	24 (19.1)
	> 200, ≤ 400	51 (40.5)
	> 400, ≤ 600	35 (27.8)
	> 600	16 (12.7)
Health-related		
Drinking	Yes	21 (16.7)
Sleep sufficiency	Yes	68 (54.0)
Treatment duration (years)		2.6 ± 2.99
Comorbidities*	Yes	37 (29.4)
	Hypertension	22 (17.5)
	Diabetes	6 (4.8)
	Others	8 (6.3)
Complications*	Yes	73 (57.9)
	Ascites	23 (18.3)
	Hepatic encephalopathy	16 (12.7)
	Bleeding	22 (17.5)
	Malnutrition	27 (21.4)

Note. * = Multi-response.

CFA was performed with 126 patients with liver cirrhosis to verify the construct validity of the developed self-management scale, and the relationships between latent variables and the items extracted by EFA were evaluated. The fit indices of the measurement models are summarized in Table 11. The Chi-square value was 258.3 (df = 179, p < .001), indicating that the model was not suitable. However, the Chi-square test is affected by the degrees of freedom. Therefore, the fit of the model was assessed based on the value obtained by dividing the Chi-square by the degrees of freedom (CMIN), and the model was considered suitable because the resulting value (1.44) was lower than 3 (Kline, 1998). Additionally, this study evaluated the absolute fit index of RMSEA, SRMR, probability RMSEA, CFI, and TLI. RMSEA (0.059) and SRMR (0.070) satisfied the acceptable values and therefore the measurement model fit was considered good. The probability RMSEA (0.171), CFI (0.885), and TLI (0.864) did not satisfy the acceptable values. Therefore, the model showed a good fit with the data (CMIN/df = 1.44, RMSEA = 0.059, SRMR = 0.070)(Figure 5).

Table 11. Results of confirmatory factor analysis (N = 126)

	RMSEA (90% CI)	Probability RMSEA	SRMR	CFI	TLI
Model	**0.059 (0.042–0.075)**	0.171	**0.070**	0.885	0.864
Reference	< 0.08	≤ 0.05	< 0.08	> 0.9	> 0.9

Note. CI = confidence interval.

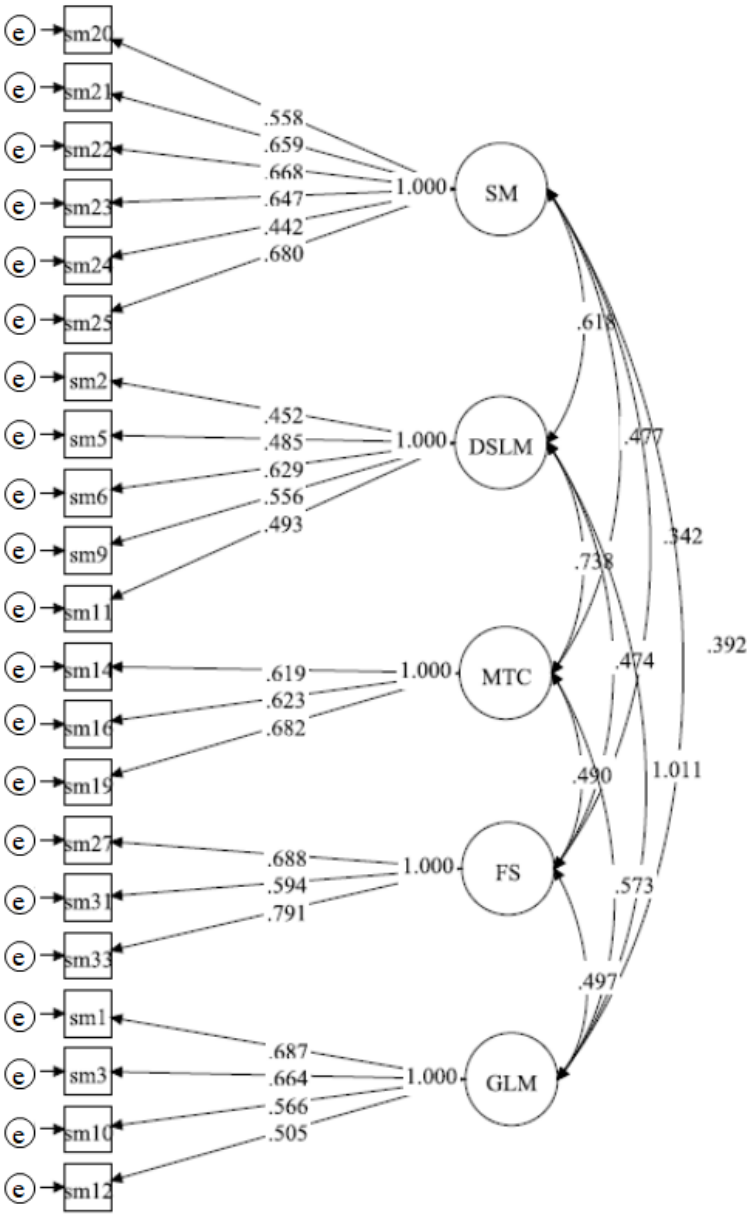


Figure 5. The model of the self-management scale for patients with liver cirrhosis

Note. SM=symptom management; DSLM=disease specific-lifestyle management; MTC=medical treatment compliance; FS=family support; GLM=general lifestyle management.

5.2.2.4. Concurrent validity

The concurrent validity was assessed to confirm the correlation between the self-management scale developed in this study and the Chronic Disease Self-Efficacy Scale (i.e., a previously developed and well-acknowledged scale). The correlation coefficient between the scale developed in this study and the self-efficacy scale was 0.47 (p<.01), and there was a statistically significant positive correlation between the two scales.

5.2.2.5. Reliability

The developed scale had a Cronbach's α value of 0.90, thus confirming the reliability of the proposed scale. For each factor, the Cronbach's α values of symptom management, liver cirrhosis-specific lifestyle management, and medical treatment compliance were 0.80, 0.76, and 0.73, respectively. The values of family support and general lifestyle management were 0.86 and 0.71, respectively (Table 12). The Cronbach's α for each factor were above the value of 0.7. Therefore, the reliability of the developed self-management scale was deemed suitable.

Table 12. Reliability of the self-management scale for patients with liver cirrhosis

Factor	Number of item	Cronbach's α
1. Symptom management	6	0.80
2. Liver cirrhosis specific lifestyle management	5	0.76
3. Medical treatment compliance	3	0.73
4. Family support	3	0.86
5. General lifestyle management	4	0.71
Overall	21	0.90

5.2.3. Step 8: Optimization of the scale

As described above, the validity and reliability of the proposed scale were evaluated to determine the construct of the final self-management scale of patients with liver cirrhosis (Table 13). The final scale consisted of a total of 21 items, including of 6 items for symptom management, 5 items for liver cirrhosis-specific lifestyle management, 4 items for general lifestyle management, 3 items for medical treatment compliance, and 3 items for family support. The Korean version of this scale is presented in appendix 12. Each item is scored using a 5-point Likert scale, rated on a scale of 1 point for “not at all” to 5 points for “always”. The total score ranges from 21 to 105 points.

Table 13. The final version of the self-management scale for patients with liver cirrhosis (21 items)

Domain (Number of item)	Item	Not at all ⟷ Always				
Symptom management (6)	1. I regularly measure body weight (or abdominal circumference) to monitor the occurrence of ascites or edema.	1	2	3	4	5
	2. If I have ascites, I limit my salt intake.	1	2	3	4	5
	3. I use a soft toothbrush to prevent bleeding of gums.	1	2	3	4	5
	4. I wear loose clothing or apply the lotion prescribed for dry or itchy skin.	1	2	3	4	5
	5. I check for blood in the stool when defecating.	1	2	3	4	5
	6. When I have ascites, I reduce my water intake.	1	2	3	4	5
Liver cirrhosis-specific lifestyle management (5)	7. I avoid raw and contaminated food and eat cooked food.	1	2	3	4	5
	8. I eat small amounts of food frequently, every 3−4 hours.	1	2	3	4	5
	9. I eat foods with fiber, such as vegetables and fruits to facilitate bowel movements.	1	2	3	4	5
	10. I get enough rest when I feel tired.	1	2	3	4	5
	11. I do not drink alcohol.	1	2	3	4	5
General lifestyle management (4)	12. I eat a meal regularly.	1	2	3	4	5
	13. I eat 2−3 pieces of meat, fish, tofu, eggs, seafood, etc., that are the size of a table tennis ball for each meal.	1	2	3	4	5
	14. I get enough sleep every day.	1	2	3	4	5
	15. I exercise regularly.	1	2	3	4	5
Medical treatment compliance (3)	16. I visit the hospital regularly as scheduled for the management of liver cirrhosis.	1	2	3	4	5
	17. I take the prescribed medication according to the purpose and dosage.	1	2	3	4	5
	18. When I have physical changes related to liver cirrhosis, I go to the hospital.	1	2	3	4	5
Family support (3)	19. My family (or caregiver) helps me manage my daily life related to liver cirrhosis.	1	2	3	4	5
	20. My family can perceive my state of consciousness in relation to liver cirrhosis.	1	2	3	4	5
	21. I am supported emotionally by my family.	1	2	3	4	5

VI. DISCUSSION

This study was conducted to identify the factors of self-management in patients with liver cirrhosis and to develop and evaluate the validity and reliability of a unique self-management scale to quantify self-management. Previous self-management scales were obtained by modifying scales that were developed for patients with other diseases, and the validity of these previous scales were not evaluated adequately for use in patients with liver cirrhosis. In this section, the development and evaluation of the self-management scale that was developed in this study have been discussed.

6.1. Development of a self-management scale for patients with liver cirrhosis

The self-management scale for patients with liver cirrhosis was developed systematically by following the scale development process propounded by DeVellis (2016). This study explored the components of the self-management based on the Individual and Family Self-Management Theory for the development of the self-management scale for patients with liver cirrhosis (Ryan & Sawin, 2009), specially while focusing on the process of self-management in the abovementioned theory as a

framework. Based on this framework, the components of the self-management scale were extracted from the literature and in-depth interviews with patients with liver cirrhosis were conducted to obtain practical evidence of self-management behaviors.

The results of the literature review and in-depth interviews that targeted patients with compensated and decompensated liver cirrhosis states reflected the characteristics of self-management and included the overall daily life behaviors related to the self-management of liver cirrhosis. Especially, the in-depth interviews were useful to understand the self-management of patients with liver cirrhosis and identify the actual behaviors and circumstances of the patients (Legard et al., 2003). This is a meaningful part of the current study as the existing self-management scales (Kim, 2003; Park & Shin, 2017; Yun, 2018) have been obtained by modifying or revising scales that has been developed for patients with other diseases. The self-management scale that has been developed in this study will be able to more practically measure the self-management level of patients with liver cirrhosis.

Furthermore, based on the results of the in-depth interview, 5 categories (diet management, lifestyle management, medical treatment compliance, symptom monitoring and management, and family support) and 26 subcategories were identified. Among these categories, family support was identified as one of the categories of self-management, although this factor was not included in previous self-management scales, which have included only the following factors: diet, rest and activity, hospital visit, prevention of complications, symptom monitoring, and medication administration (Kim, 2003; Park &

Shin, 2017; Yoon & Eun, 2020). Wang and the colleagues (2015) developed the self-management scale for patients with liver cirrhosis that includes the four factors of dietary, daily life, medication, and illness monitoring. Related to support for patients, there was only one item included in the factor of daily life, “You are able to active communicate with family members, relatives, and family.” The components in family support of this study were related to the help from family members to enable the patient’s self-management behaviors in daily life, such as regular hospital visits and examinations, taking medications and health supplements, regular food intake, sharing information on liver cirrhosis, and emotional support. Therefore, the derivation of family support as a domain in the proposed scale is one of the major contributions of this study in that, unlike the existing scales that measure self-management only in the personal aspects of the patients, this novel scale reflects the factors from the patient's context as well.

6.2. Evaluation of a self-management scale for patients with liver cirrhosis

In the current study, the items of the preliminary scale were evaluated using statistical analysis based on the values of average correlation and the inter-item correlation of each item during the item analysis (Gharaibeh et al., 2017). With this process, the items of the scale could be further refined by identifying items with

redundant characteristics, extracted from the literature review and in-depth interviews, as well as by deleting unnecessary items. The item analysis in this study is meaningful in that most of the existing scales did not evaluate the items statistically, and even those that did, evaluated only the content validity (Bae & Suh, 2001; Yoon, 2018). However, further research is necessary to confirm whether there are any items that are essential for self-management from among the items that were deleted during the analysis.

The proposed scale that was constructed with the 5 factors extracted from the EFA had a cumulative variance of 61.1%. Thus 5 factors adequately explain the self-management of patients with cirrhosis without being biased toward a specific factor, as each factor accounts for less than the standard value of 40%. Therefore, when compared to the variance of 58.1% in the chronic hepatitis B self-management scale and 57.0 % in liver cirrhosis self-management scale, the explanatory variance of this scale is considered appropriate (Kong et al., 2018; Wang et al., 2015). Furthermore, confirmatory factor analysis was conducted to confirm the suitability of the item composition of the developed scale and to verify the validity of the construct. In the model fit evaluation for five factors with 21 items, the CMIN/*df*, RMSEA, and SRMR satisfied the acceptance criteria. Confirmatory factor analysis has not been conducted for the existing scales and, therefore, a comparison is not possible. However, in this study, exploratory factor analysis and confirmatory factor analysis were performed, and this scale constitutes a scale that has an appropriate construct validity to measure the self-management of patients with liver cirrhosis and can be used in future studies to measure the self-management level of

patients with liver cirrhosis.

In this study, the concurrent validity was verified. Since there is currently no gold standard for measuring self-management in patients with cirrhosis, this study assessed the correlation between the proposed scale and self-efficacy scale for the validity. Self-efficacy was known as a predictor of health behavior (Bandura, 1997), and has been significantly correlated with the level of self-management among patients with chronic diseases (Lo et al., 2015; Yoo et al., 2011). The significant positive correlation of the proposed scale with the self-efficacy scale suggests that this scale is appropriate for measuring self-management. Moreover, the reliability index was 0.90, indicating high reliability, and that of each factor ranged from 0.71 to 0.86. Thus, the result was in a reliable range, and has similar reliability as the self-care scales for diabetes (Lu et al., 2016). Therefore, the concurrent validity, reliability, and construct validity of the scale that was developed in this study were assessed and the scale was validated as a scale to measure the self-management of patients with liver cirrhosis.

6.3. Components of the self-management scale for patients with liver cirrhosis

To assess the self-management of patients with liver cirrhosis, this study was conducted to develop the self-management scale, and 5 factors with 21 items (symptom

management, liver cirrhosis-specific lifestyle management, general lifestyle management, medical treatment compliance, and family support) were extracted after validation.

The first factor, “symptom management,” comprises 6 items involving the monitoring of weight change and management liver cirrhosis-induced of ascites, dry skin, and bleeding. Body weight is not only a basic parameter for health monitoring in patients with liver cirrhosis, but also is an essential indicator for detecting the occurrence of symptoms or monitoring changes in symptoms (Smith et al., 2019). Additionally, ascites, dry skin, and bleeding are symptoms that occur relatively early. Particularly, ascites or bleeding are related to the progression of liver cirrhosis (Chawla & Bodh, 2015), and therefore early management and treatment are considered important when these symptoms are present. Items associated with the management of these symptoms have been included in the scales that were used in previous studies as well (Kim & Na, 2017; Kim, 2003). Furthermore, these items were maintained during the process of item development and validity evaluation in this study which thus confirm that these items are an essential part of the management of patients with liver cirrhosis.

The second factor, “liver cirrhosis-specific lifestyle management,” consists of 5 items. During the development process of the initial items, the items 2, 5, and 6, which belonged to the subdomain of dietary management, and items 9 and 11, which were included in the subdomain of lifestyle management, were grouped under this second factor. “Avoiding raw or contaminated food and eating cooked food,” “eating small amounts of food frequently every 3−4 hours,” and “eating fibrous food for smooth bowel

movements" are management items that can prevent infection, sarcopenia, and hepatic coma in patients with cirrhosis. Furthermore, fatigue, a common complaint among patients with liver cirrhosis (Swain & Jones, 2019), and alcohol consumption are both related to the symptoms, progression, and prognosis of liver cirrhosis and are considered essential items for the management of liver cirrhosis (Lackner et al., 2017). However, although items related to cooked food intake, fibrous food intake, fatigue, and drinking were included in the previously used scales, the item of "frequent intake of small amounts of food" was not included in those scales and was therefore extracted through a literature review. The frequent intake of small amounts of food can prevent sarcopenia during fasting that is a common symptom of liver cirrhosis, and recent clinical guidelines have highlighted the importance of food ration management according to the results of several studies (Dasarathy & Merli, 2016; Ebadi et al., 2019; Hey et al., 2021).

The third factor is "general lifestyle management," which measures health behaviors related to self-management in daily life for most patients with liver cirrhosis and consists of 4 items. This factor included items associated with regular meals, sufficient protein intake, sleep, and regular exercise. However, the previous scales measured activities within a range that does not strain the body, whereas this study considered regular exercise. As suggested in the guidelines and previous studies on liver cirrhosis, appropriate exercise according to the health condition is recommended for patients as a crucial health behavior to prevent sarcopenia or strengthen muscles (Duarte-Rojo et al., 2018; Duarte-Rojo et al., 2018; Kappus et al., 2016). Moreover, as suggested from the

results of in-depth interviews, some of the participants of this study were aware of the importance of exercise and continued to exercise regularly.

The fourth factor, “medical treatment compliance,” refers to regular visits to the hospital for liver cirrhosis management, taking medications as prescribed, and visiting the hospital when needed according to changes in symptoms. Regular hospital check-ups and medication administration are measured for self-management in previous scales (Kim & Na, 2017; Kim, 2003). However, the present study evaluated whether the patients were aware of changes in their health status in daily life and considered seeking medical attention according to these changes as part of their cirrhosis management. This is one of the most significant differences of this new scale as compared to previous scales.

The fifth factor, “family support,” consisted of 3 items and was developed as a subdomain to measure the self-management of patients with liver cirrhosis. With the recent increase in incidence of chronic diseases, there has been an emphasis on self-management and influence of family members on the patients’ wellbeing because the individual context of each patient can positively influence their self-management behaviors (Peñarrieta et al., 2015; Ravi et al., 2018). This study differs from other scales in that it accounts for family support as a factor for measuring the patient's self-management level. The initial items of family support included 7 items. Among them, 3 items were retained for assessing family support, after deleting some items during the process of scale evaluation after considering redundancies in the characteristics of each item and the inter-item correlations. A larger number of items can increase the reliability

of a factor, and at least three items per factor was recommended (Tabachnick & Fidell, 2013). Including family support as a factor that influences patient compliance allows a more comprehensive assessment of the self-management level of patients with liver cirrhosis. This suggests that the proposed scale in this study has a significant meaning that is markedly different from that of the existing scales.

6.4. Significance of the study

6.4.1. Nursing theory

This study developed a scale based on the various factors that influence the self-management of liver cirrhosis including the patient's knowledge of the disease, management skill and ability, and family as a social facilitator during the process of self-management behaviors in daily life based on the Individual and Family Self-Management Theory. Furthermore, the scale was developed by reflecting the results from in-depth interviews with patients on self-management of liver cirrhosis in Korea. This novel scale could contribute to the development of nursing theories by being incorporated into studies to identify the factors that influence the self-management behaviors of patients with liver cirrhosis and the relationship between them.

6.4.2. Nursing research

The current study is a methodological study to develop a self-management scale and evaluate its validity. The steps taken to conduct this study were based on the method for scale development, and therefore the developed scale can be used as a basis for the development of other self-management scales in patient care. Furthermore, the proposed scale enabled the measurement of the level of self-management of the patients and reflected the characteristics of patients with liver cirrhosis. The present study also assessed the validity and reliability of the proposed scale, thus providing reliable indicators for measuring the effectiveness of nursing interventions, which can improve the self-management level of patients with liver cirrhosis.

6.4.3. Nursing practice

This study developed and validated the first self-management scale for patients with liver cirrhosis. This scale can be used to measure the self-management of patients with liver cirrhosis more consistently and provides a more objective means to assess the behaviors of the patients than scales borrowed and modified from other diseases. Additionally, this scale can be used as s basis to evaluate the self-management level of patients with liver cirrhosis and develop effective interventions for patients in daily life and personalized nursing intervention strategies.

6.5. Limitation

Although the proposed scale was validated and was found to be highly reliable, this study had some limitations. First, the participants of this study were recruited using convenience sampling, and therefore our study cannot be considered representative of all patients with liver cirrhosis in Korea. Thus the results of this study must be interpreted with caution and generalizations must be avoided.

Furthermore, the scale measures various aspects of self-management in patients with liver cirrhosis, but it is a self-reported questionnaire, and responses may be subjective or may not reflect all actual self-management behaviors. Therefore, the results of the scale proposed herein should be interpreted carefully.

6.6. Suggestions for future studies

This study developed and validated a self-management scale for patients with liver cirrhosis. The following suggestions are proposed for future studies. First, the current study was conducted using the convenience sampling method. However, future studies should evaluated the validity and reliability of this scale in a variety of conditions according to the size of the medical center, region, treatment period, and physical condition of the patient. Second, the scale developed in this study could be used in future research to identify the factors affecting the self-management and develop strategies to improve the self-management level of patients with liver cirrhosis.

VII. CONCLUSIONS

This study was conducted to develop and evaluate the validity and reliability of a self-management scale for patients with liver cirrhosis. The scale was a self-reported questionnaire consisting of five factors with 21 items and was scored using a 5-point Likert scale. The five factors and their respective number of items were symptom management (6 items), liver cirrhosis-specific lifestyle management (5 items), general lifestyle management (4 items), medical treatment compliance (3 items), and family support (3 items). The proposed self-management scale in this study would be useful for identifying the self-management level of patients with liver cirrhosis and could contribute to the development of tailored interventions to improve the self-management behaviors of this population. Consequently, these approaches using this scale will enhance health outcomes in clinical settings.

REFERENCE

Bae, H. O. & Suh, S. R. (2001). Effect of structured information provided on knowledge and self-care behavior of liver cirrhosis patients. *Korean Society of Adult Nursing*. *13*(3). 476−485.

Balduino, A. d. F. A., Mantovani, M. d. F., Lacerda, M. R., & Meier, M. J. (2013). Conceptual self-management analysis of hypertensive individuals. *Revista gaucha de enfermagem, 34*, 37−44.

Bandura, A. (1997).*Self-efficacy: The exercise of control*. New York: W.H. Free-man.

Beg, S., Curtis, S., & Shariff, M. (2016). Patient education and its effect on self-management in cirrhosis: a pilot study. *European Journal of Gastroenterology & Hepatology, 28*(5), 582−587.

Campana, L., & Iredale, J. P. (2017). Regression of liver fibrosis. *Seminars in liver disease, 15*(1), 1−10.

Chawla, Y., & Bodh, V. (2015). Clinical clues to the diagnosis of cirrhosis. *Cirrhosis: A practical guide to management*, 1−11.

Chirapongsathorn, S., Talwalkar, J. A., & Kamath, P. S. (2016). Readmission in cirrhosis: a growing problem. *Current treatment options in gastroenterology, 14*(2), 236−246.

Chyung, S. Y., Roberts, K., Swanson, I., & Hankinson, A. (2017). Evidence-based survey design: The use of a midpoint on the Likert scale. *Performance Improvement, 56*(10), 15−23.

Costello, A. B., & Osborne, J. (2005). Best practices in exploratory factor analysis: Four recommendations for getting the most from your analysis. *Practical assessment, research, and evaluation, 10*(1), 7.

Dasarathy, S., & Merli, M. (2016). Sarcopenia from mechanism to diagnosis and

treatment in liver disease. *Journal of hepatology, 65*(6), 1232−1244.

DeVellis, R. F. (2016). *Scale development: Theory and applications* (Vol. 26). Sage publications.

Duarte-Rojo, A., Ruiz-Margáin, A., Montaño-Loza, A. J., Macías-Rodríguez, R. U., Ferrando, A., & Kim, W. R. (2018). Exercise and physical activity for patients with end-stage liver disease: improving functional status and sarcopenia while on the transplant waiting list. *Liver Transplantation, 24*(1), 122-139.

Durand, F., & Valla, D. (2008). Assessment of prognosis of cirrhosis. *Seminars in liver disease. 28*(1), 110−122.

Ebadi, M., Bhanji, R. A., Mazurak, V. C., & Montano-Loza, A. J. (2019). Sarcopenia in cirrhosis: from pathogenesis to interventions. *Journal of gastroenterology, 54*(10), 845−859.

European Association for The Study of the Liver. (2018). EASL Clinical Practice Guidelines for the management of patients with decompensated cirrhosis. Journal of hepatology, 69(2), 406−460.

Fagerström, C., & Frisman, G. H. (2017). Living with liver cirrhosis: a vulnerable life. *Gastroenterology Nursing, 40*(1), 38−46.

Fawcett, J., Watson, J., Neuman, B., Walker, P. H., & Fitzpatrick, J. J. (2001). On nursing theories and evidence. *J Nurs Scholarsh, 33*(2), 115−119. https://doi.org/10.1111/j.1547-5069.2001.00115.x

Flamm, S. L. (2018). Complications of cirrhosis in primary care: recognition and management of hepatic encephalopathy. *The American journal of the medical sciences, 356*(3), 296−303.

Gharaibeh, B., Al-Smadi, A. M., & Boyle, D. (2017). Psychometric properties and characteristics of the Diabetes Self Management Scale. *International journal of nursing sciences, 4*(3), 252−259.

Hair, J. F., Black. W. C., Babin. B. J., & Anderson, R. E. (2010). *Multivariate Data Analysis*. 7th ed. In. Pearson Prentice Hall. New Jersey.

Hair, J. F., Black, W. C., Babin, B. J., Anderson, R. E., & Tatham, R. L. (2009). Análise multivariada de dados. *Bookman editora*.

Hey, P., Gow, P., Testro, A. G., Apostolov, R., Chapman, B., & Sinclair, M. (2021). Nutraceuticals for the treatment of sarcopenia in chronic liver disease. *Clinical nutrition ESPEN, 41*, 13−22.

Ignatiev, E., Samardzija, M. K., Paul, S., Vuckovic, K. M., & Lockwood, M. B. (2021). Standardized patient education for decompensated cirrhotic patients and impact on clinician satisfaction. *Gastroenterology Nursing, 44*(4), 233−239.

Heo, J. (2013). Amos Structural Equation Model: Basics. Seoul: Hannara Academy.

Jang, E. S. (2019). Introduction of the 2019 revised Korean Liver Society guidelines for liver cirrhosis: varicose veins, hepatic encephalopathy and related complications. *Korean J Gastroenterol, 74*(5), 274-280

Jun, D. W., Tak, W. Y., Bae, S. H., & Lee, Y. J. (2012). Recent trends in the treatment of chronic hepatitis C. *Korean J Hepatol, 18*(1), 22−28. https://doi.org/10.3350/kjhep.2012.18.1.22

Jung, K. S., & Min, H. S. (2007). The relations among self-care, symptom experiences, and disease status of the patient with liver cirrhosis. *Korean Journal of Adult Nursing, 19*(2), 318−328.

Kaiser, H. F. (1974). An index of factorial simplicity. *Psychometrika, 39*(1), 31−36.

Kappus, M. R., Mendoza, M. S., Nguyen, D., Medici, V., & McClave, S. A. (2016). Sarcopenia in patients with chronic liver disease: can it be altered by diet and exercise? *Current gastroenterology reports, 18*(8), 1-7.

Kim, C. J., Chae, S. M., & Yoo, H. (2012). Psychometric testing of the Chronic Disease Self-Efficacy Scale-Korean Version (CDSES-K). *J Transcult Nurs, 23*(2), 173−180. https://doi.org/10.1177/1043659611434059

Kim, E. K., & Park, H. (2020). Predictors of Emergency Room Admission in Patients With Liver Cirrhosis: A Prospective, Descriptive Study. *Gastroenterology Nursing, 43*(1), 65−75.

Kim, M. K. & Na, H. J. (2017). Influencing factors on the implementation of self-care in cirrhosis patients. *Journal of Muscular and Joint Health, 24*(1), 47−55.

Kim, M. N., Kim, B. K., Roh, Y. H., Choi, N. R., Yu, S. J., & Kim, S. U. (2022). *Comparable Efficacy Between Ongoing Versus Initiation of Antiviral Therapy at Treatment for HBV-related Hepatocellular Carcinoma*. Clinical Gastroenterology and Hepatology.

Kim, N. (2003). The influence of family support on self-care and disease status of the patient with liver cirrhosis. Unpublished master's thesis, Ewha Womans University, Seoul.

Kim, S. (1989). Hepatitis B Therapeutic Relationship with the Knowledge and Implementation of the Family Support and to Recognize Hepatitis. Master's Thesis, Yeonsei University, Seoul.

Kline, R. (1998). *Priciples dind Dracices of Sirlicird edidion hodeling.* New York: Guilford.

Kline, R. B. (2011). *Convergence of structural equation modeling and multilevel modeling*. 3rd ed. New York: Guilford Press.

Kong, L. N., Zhu, W. F., He, S., Wang, T., & Guo, Y. (2018). Development and preliminary validation of the chronic hepatitis B self-management scale. *Applied Nursing Research, 41*, 46−51.

Lackner, C., Spindelboeck, W., Haybaeck, J., Douschan, P., Rainer, F., Terracciano, L., Haas, J., Berghold, A., Bataller, R., & Stauber, R. E. (2017). Histological parameters and alcohol abstinence determine long-term prognosis in patients with alcoholic liver disease. *Journal of hepatology, 66*(3), 610−618.

Lai, J. C., Tandon, P., Bernal, W., Tapper, E. B., Ekong, U., Dasarathy, S., & Carey, E. J. (2021). Malnutrition, frailty, and sarcopenia in patients with cirrhosis: 2021 practice guidance by the American Association for the Study of Liver Diseases. *Hepatology, 74*(3), 1611−1644.

Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. *Qualitative research*

practice: A guide for social science students and researchers, 6(1), 138−169.

Lee, H. J., & Lee, H. R. (1997). The effect of structured patient education on knowledge and activity performance on early rehabilitation of stroke patients. The effect of structured patient education on knowledge and activity performance on early rehabilitation of stroke patients. *Journal of Korean Academy of Nursing, 27*(1), 109−119.

Liaw, Y. F., Leung, N., Kao, J. H., Piratvisuth, T., Gane, E., Han, K. H., Guan, R., Lau, G. K., Locarnini, S., & Chronic Hepatitis, B. G. W. P. o. t. A.-P. A. f. t. S. o. t. L. (2008). Asian-Pacific consensus statement on the management of chronic hepatitis B: a 2008 update. *Hepatol Int, 2*(3), 263−283. https://doi.org/10.1007/s12072-008-9080-3

Lim, S., & Choi, K. (1996). A study on experiences of patients with liver cirrhosis and spouses. *Korean Journal of Adult Nursing*, 8(2), 309−323.

Liver, E. A. f. T. S. o. t. (2018). EASL Clinical Practice Guidelines for the management of patients with decompensated cirrhosis. *Journal of hepatology, 69*(2), 406−460.

Lo, G. H., Chen, W. C., Chan, H. H., Tsai, W. L., Hsu, P. I., Lin, C. K., Chen, T. A., & Lai, K. H. (2009). A randomized, controlled trial of banding ligation plus drug therapy versus drug therapy alone in the prevention of esophageal variceal rebleeding. *Journal of gastroenterology and hepatology, 24*(6), 982−987.

Lo, S. W. S., Chair, S. Y., & Lee, F. K. (2015). Factors associated with health-promoting behavior of people with or at high risk of metabolic syndrome: based on the health belief model. *Applied Nursing Research*, *28*(2), 197−201.

Lorig, K., Stewart, A., Ritter, P., Gonzalez, V., Lynch, J., & Laurent, D. (1996). *Outcome measures for health education and other health care interventions*. Sage.

Lu, Y., Xu, J., Zhao, W., & Han, H.-R. (2016). Measuring self-care in persons with type 2 diabetes: a systematic review. *Evaluation & the Health Professions, 39*(2), 131−184.

Lynn, M. R. (1986). *Determination and quantification of content validity*. Nursing

research.

Mammen, J., & Rhee, H. (2012). Adolescent asthma self-management: a concept analysis and operational definition. *Pediatric allergy, immunology, and pulmonology*, *25*(4), 180−189.

Mansouri, P., Ghadami, M., Najafi, S. S., & Yektatalab, S. (2017). The effect of self-management training on self-efficacy of cirrhotic patients referring to transplantation Center of Nemazee Hospital: A randomized controlled clinical trial. *International journal of community based nursing and midwifery*, *5*(3), 256.

Matarese, M., Lommi, M., De Marinis, M. G., & Riegel, B. (2018). A Systematic Review and Integration of Concept Analyses of Self-Care and Related Concepts. *J Nurs Scholarsh*, *50*(3), 296-305. https://doi.org/10.1111/jnu.12385

Medicine, I. o., Health, I. o. M. C. o., Medicine, I. o., Health, D. C. o., Practice, Neuroscience, P. B. o., Health, B., Staff, I. o. M., Neuroscience, B. o., & Health, B. (2001). *Health and behavior: The interplay of biological, behavioral, and societal influences.* National Academies Press.

Miller, W. R., Lasiter, S., Ellis, R. B., & Buelow, J. M. (2015). Chronic disease self-management: a hybrid concept analysis. *Nursing outlook*, 63(2), 154−161.

Mokdad, A. A., Lopez, A. D., Shahraz, S., Lozano, R., Mokdad, A. H., Stanaway, J., Murray, C. J., & Naghavi, M. (2014). Liver cirrhosis mortality in 187 countries between 1980 and 2010: a systematic analysis. *BMC Med*, *12*, 145. https://doi.org/10.1186/s12916-014-0145-y

Naveau, S., Perlemuter, G., & Balian, A. (2005). [Epidemiology and natural history of cirrhosis]. *Rev Prat*, *55*(14), 1527−1532. https://www.ncbi.nlm.nih.gov/pubmed/16255293

Norris, C. M. (1979). Self-care. *The American journal of nursing*, 486−489.

Oh, J. H., & Lim, N.-Y. (2005). A study on the relationships between family support, self-efficacy, and compliance in chronic arthritis. *Journal of muscle and joint health*, *12*(1), 28−38.

Orem, D. E., Taylor, S. G., & Repenning, K. M. (2001). *Nursing concepts of practice*. Mosby, St. Louis.

Pamungkas, R. A., Chamroonsawasdi, K., &Vatanasomboon, P. (2017). A systematic review: family support integrated with diabetes self-management among uncontrolled type II diabetes mellitus patients. *Behavioral Sciences, 7*(3), 62.

Park, H., & Shin, Y. (2017). Factors related self-care behavior among patients with liver cirrhosis: focusing on disease knowledge and family support. *Journal of the Korea* Academia-Industrial cooperation Society, 18(5), 647−656.

Pellicoro, A., Ramachandran, P., & Iredale, J. P. (2012). Reversibility of liver fibrosis. *Fibrogenesis & tissue repair, 5*(1), 1−4.

Peñarrieta, M. I., Flores-Barrios, F., Gutiérrez-Gómez, T., Piñones-Martínez, S., Resendiz-Gonzalez, E., & Quintero-Valle, L. M. (2015). Self-management and family support in chronic diseases. *J Nurs Educ Pract, 5*(11), 73−80.

Ramachandran, J., Smith, D., Woodman, R., Muller, K., Wundke, R., McCormick, R., Kaambwa, B., & Wigg, A. (2021). Psychometric validation of the Partners in Health scale as a self-management tool in patients with liver cirrhosis. *Internal Medicine Journal, 51*(12), 2104−2110.

Ravi, S., Kumar, S., & Gopichandran, V. (2018). Do supportive family behaviors promote diabetes self-management in resource limited urban settings? A cross sectional study. *BMC Public Health, 18*(1), 1−9.

Ryan, P., & Sawin, K. J. (2009). The Individual and Family Self-Management Theory: background and perspectives on context, process, and outcomes. *Nurs Outlook, 57*(4), 217−225 e216. https://doi.org/10.1016/j.outlook.2008.10.004

Saleh, Z. M., Bloom, P. P., Grzyb, K., & Tapper, E. B. (2021). How do patients with cirrhosis and their caregivers learn about and manage their health? A review and qualitative study. *Hepatology communications, 5*(2), 168−176.

Schilling, L. S., Grey, M., & Knafl, K. A. (2002). The concept of self-management of type 1 diabetes in children and adolescents: an evolutionary concept analysis.

Journal of advanced nursing, 37(1), 87−99.

Seki, E., & Brenner, D. A. (2015). Recent advancement of molecular mechanisms of liver fibrosis. *Journal of Hepato-Biliary-Pancreatic Sciences, 22*(7), 512−518.

Seo, Y. S, & Do, E. S. (2015). Aspects of Convergence of Alcohol-Related Variables-Drinking Behavior and Disease-Related Variables in Patients with Liver Cirrhosis. *Digital Convergence Research, 13*(7), 249−258.

Smith, A., Baumgartner, K., & Bositis, C. (2019). Cirrhosis: diagnosis and management. *American family physician, 100*(12), 759−770.

Statistical Korea. (2020). *The Causes of Death Statistics in 2019 in the Republic of Korea*. Daejeon: Statistics Korea.

Stelmach, M., de Almeida Medeiros, K. A., Carvalho, B. J., Pipek, L. Z., de Mesquita, G. H. A., Nii, F., Martines, D. R., Iuamoto, L. R., D'Albuquerque, L. A. C., & Meyer, A. (2021). Instrument to evaluate the knowledge of patient with cirrhosis on his disease: construction and validity. *BMC gastroenterology, 21*(1), 1−7.

Swain, M. G., & Jones, D. E. (2019). Fatigue in chronic liver disease: New insights and therapeutic approaches. *Liver International, 39*(1), 6−19.

Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6th ed.). Boston, MA: Pearson Education.

Tapper, E. B., & Volk, M. (2017). Strategies to reduce 30-day readmissions in patients with cirrhosis. *Current gastroenterology reports, 19*(1), 1−7.

Unger, W. R., & Buelow, J. M. (2009). Hybrid concept analysis of self-management in adults newly diagnosed with epilepsy. *Epilepsy & Behavior, 14*(1), 89−95.

Valery, P. C., Clark, P. J., McPhail, S. M., Rahman, T., Hayward, K., Martin, J., Horsfall, L., Volk, M. L., Skoien, R., & Powell, E. (2017). Exploratory study into the unmet supportive needs of people diagnosed with cirrhosis in Queensland, Australia. *Internal Medicine Journal, 47*(4), 429−435.

Vilstrup, H., Amodio, P., Bajaj, J., Cordoba, J., Ferenci, P., Mullen, K. D., Weissenborn, K., & Wong, P. (2014). Hepatic encephalopathy in chronic liver disease: 2014

Practice.

Volk, M. L., Fisher, N., & Fontana, R. J. (2013). Patient knowledge about disease self-management in cirrhosis. *The American journal of gastroenterology*, *108*(3).

Wang, Q., Wang, Y., Gao, J., Han, J.-T., & Li, Y.-P. (2015). Development of a self-management behaviour scale for liver cirrhosis. *International Journal of Nursing Sciences*, *2*(1), 73−79.

Wigg, A. J., McCormick, R., Wundke, R., & Woodman, R. J. (2013). Efficacy of a chronic disease management model for patients with chronic liver failure. *Clinical Gastroenterology and Hepatology*, *11*(7), 850−858. e854.

Williams & W. P. (2011). *Handbook of innovation in social research methods.* (pp. 562–589). London: Sage.

Wong, M. C. S., Huang, J. L. W., George, J., Huang, J., Leung, C., Eslam, M., Chan, H. L. Y., & Ng, S. C. (2019). The changing epidemiology of liver diseases in the Asia-Pacific region. *Nat Rev Gastroenterol Hepatol*, *16*(1), 57−73.

Woo. J. P. (2012). *Structural equation model concept and understanding*. Seoul; Ha Na-rae Academy.

Yang, J. H. (2011). Factors influencing self-management compliance of patients with chronic hepatitis B. *Journal of Korean Academy of Fundamentals of Nursing*, *18*(4), 520−528.

Yoo, H., Kim, C. J., Jang, Y., & You, M. A. (2011). Self-efficacy associated with self-management behaviours and health status of South Koreans with chronic diseases. *International journal of nursing practice*, *17*(6), 599−606.

Yoon, M. J., & Min, H. S. (2016). Development and application of autonomy support program for patients with liver cirrhosis: based on self-determination theory. Korean Society of Nursing Science Conference, 339−339.

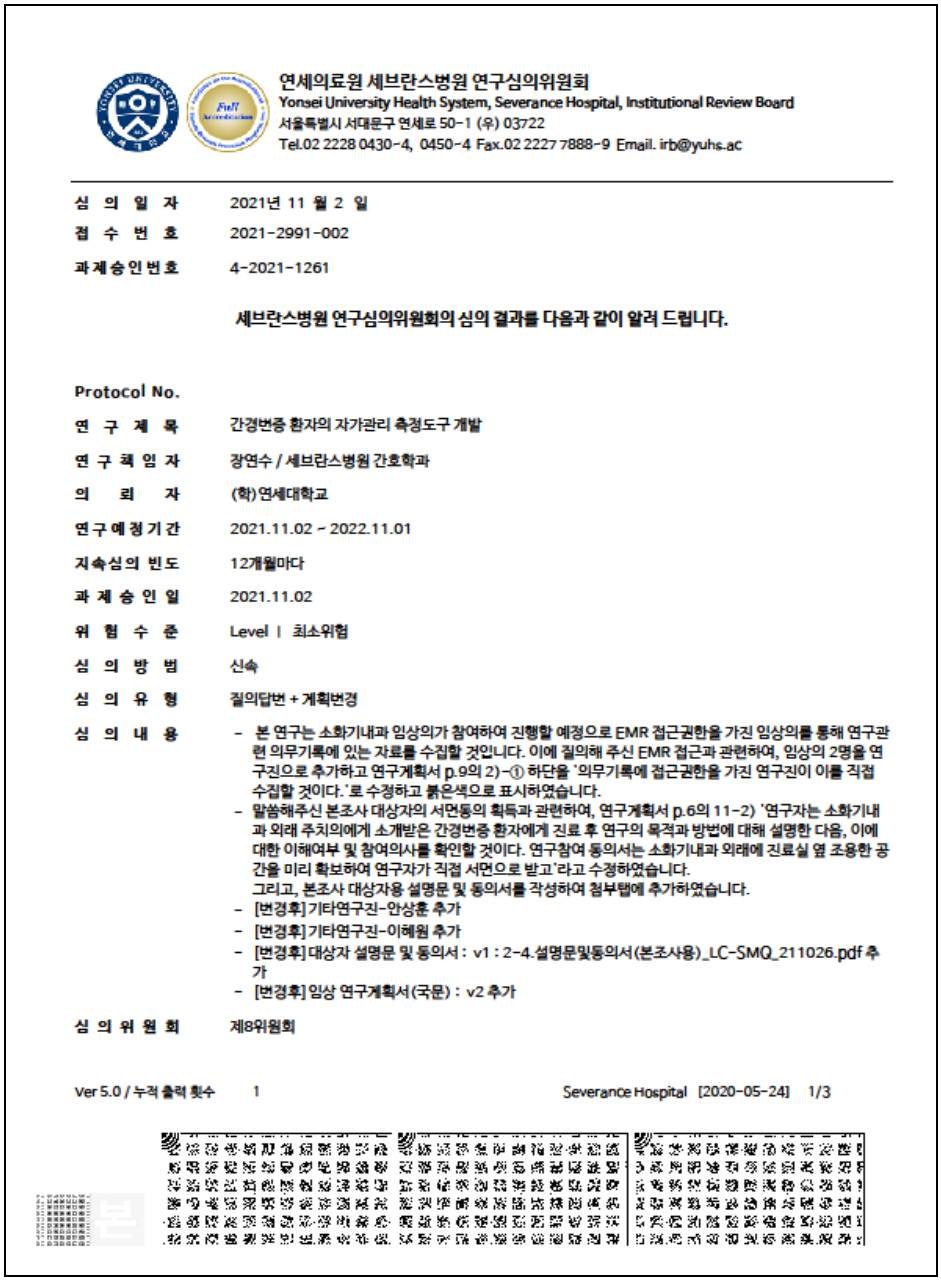
Yoon, M. R., & Eun, E. Y. (2020). Factors influencing the readmission experience of patients with cirrhosis. *Journal of the Korean Society of Industrial-Academic Technology*, *21*(5), 111−120.

Yun, S. A. (2018). The relationship between fatigue, depression, sleep disorder and self-care practice in patients with live cirrhosis. Master's thesis, Yonsei University, Seoul.

Zandi, M., Adib-Hajbagheri, M., Memarian, R., Nejhad, A. K., & Alavian, S. M. (2005). Effects of a self-care program on quality of life of cirrhotic patients referring to Tehran Hepatitis Center. *Health and quality of life outcomes, 3*(1), 1−8.

APPENDICES

Appendix 1. Approval from the institutional review board



연세의료원 세브란스병원 연구심의위원회
Yonsei University Health System, Severance Hospital, Institutional Review Board
서울특별시 서대문구 연세로 50-1 (우) 03722
Tel.02 2228 0430-4, 0450-4 Fax.02 2227 7888-9 Email. irb@yuhs.ac

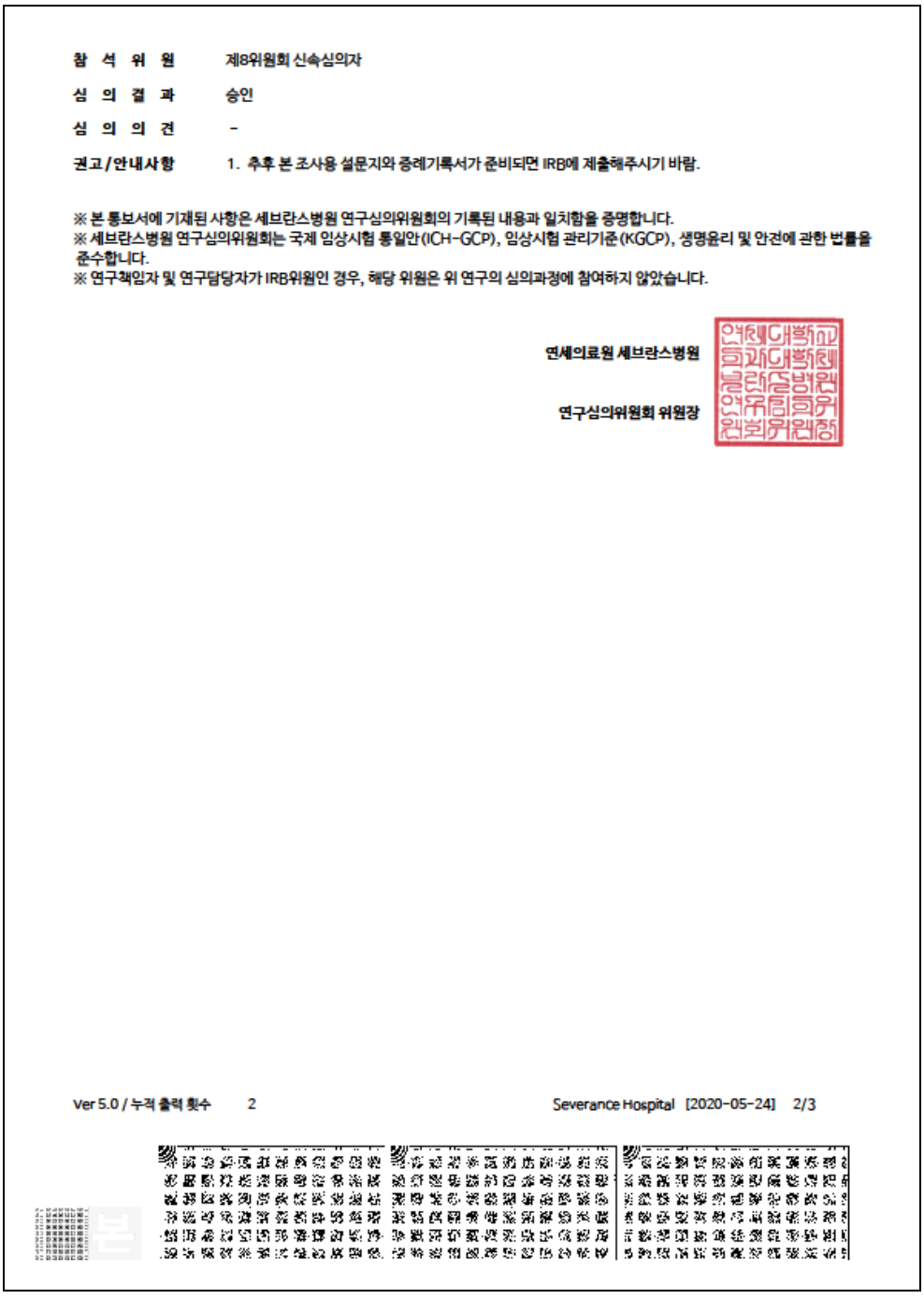
심 의 일 자	2021년 11 월 2 일
접 수 번 호	2021-2991-002
과제승인번호	4-2021-1261

세브란스병원 연구심의위원회의 심의 결과를 다음과 같이 알려 드립니다.

Protocol No.	
연 구 제 목	간경변증 환자의 자가관리 측정도구 개발
연 구 책 임 자	장연수 / 세브란스병원 간호학과
의 뢰 자	(학)연세대학교
연구예정기간	2021.11.02 ~ 2022.11.01
지속심의 빈도	12개월마다
과 제 승 인 일	2021.11.02
위 험 수 준	Level I 최소위험
심 의 방 법	신속
심 의 유 형	질의답변 + 계획변경
심 의 내 용	- 본 연구는 소화기내과 임상의가 참여하여 진행할 예정으로 EMR 접근권한을 가진 임상의를 통해 연구관련 의무기록에 있는 자료를 수집할 것입니다. 이에 질의해 주신 EMR 접근과 관련하여, 임상의 2명을 연구진으로 추가하고 연구계획서 p.9의 2)-① 하단을 '의무기록에 접근권한을 가진 연구진이 이를 직접 수집할 것이다.'로 수정하고 붉은색으로 표시하였습니다. - 말씀해주신 본조사 대상자의 서면동의 획득과 관련하여, 연구계획서 p.6의 11-2) '연구자는 소화기내과 외래 주치의에게 소개받은 간경변증 환자에게 진료 후 연구의 목적과 방법에 대해 설명한 다음, 이에 대한 이해여부 및 참여의사를 확인할 것이다. 연구참여 동의서는 소화기내과 외래에 진료실 옆 조용한 공간을 미리 확보하여 연구자가 직접 서면으로 받고'라고 수정하였습니다. 그리고, 본조사 대상자용 설명문 및 동의서를 작성하여 첨부탭에 추가하였습니다. - [번경후] 기타연구진-안상훈 추가 - [번경후] 기타연구진-이혜원 추가 - [번경후] 대상자 설명문 및 동의서 : v1 : 2-4.설명문및동의서(본조사용)_LC-SMQ_211026.pdf 추가 - [번경후] 임상 연구계획서(국문) : v2 추가
심 의 위 원 회	제8위원회

Ver 5.0 / 누적 출력 횟수 1 Severance Hospital [2020-05-24] 1/3

Appendix 1. Approval from the institutional board (continued)



참 석 위 원 제8위원회 신속심의자

심 의 결 과 승인

심 의 의 견 -

권고/안내사항 1. 추후 본 조사용 설문지와 증례기록서가 준비되면 IRB에 제출해주시기 바람.

※ 본 통보서에 기재된 사항은 세브란스병원 연구심의위원회의 기록된 내용과 일치함을 증명합니다.
※ 세브란스병원 연구심의위원회는 국제 임상시험 통일안(ICH-GCP), 임상시험 관리기준(KGCP), 생명윤리 및 안전에 관한 법률을 준수합니다.
※ 연구책임자 및 연구담당자가 IRB위원인 경우, 해당 위원은 위 연구의 심의과정에 참여하지 않았습니다.

연세의료원 세브란스병원

연구심의위원회 위원장

Ver 5.0 / 누적 출력 횟수 2

Severance Hospital [2020-05-24] 2/3

Appendix 2. Studies included in literature review (*N*=29)

N	Author	Year	Title
A1	Zandi et al.	2005	Effects of a self-care program on quality of life of cirrhotic patients referring to Tehran Hepatitis Center
A2	Volk et al.	2013	Patient knowledge about disease self-management in cirrhosis
A3	Wigg et al.	2013	Efficacy of a chronic disease management model for patients with chronic liver failure
A4	Wang et al.	2015	Development of a self-management behaviour scale for liver cirrhosis
A5	Beg et al.	2016	Patient education and its effect on self-management in cirrhosis
A6	Fagerström et al.	2017	Living With Liver Cirrhosis: A Vulnerable Life
A7	Mansouri et al.	2017	The effect of Self-Management Training on Self-Efficacy of Cirrhotic Patients Referring to Transplantation Center of Nemazee Hospital
A8	Valery et al.	2017	Exploratory study into the unmet supportive needs of people diagnosed with cirrhosis in Queensland, Australia
A9	Dong et al.	2020	Self-Management Behaviors Among Patients With Liver Cirrhosis in Shanghai, China: A Cross-Sectional Study
A10	Kim et al.	2020	Predictors of Emergency Room Admission in Patients With Liver Cirrhosis: A Prospective, Descriptive Study
A11	Ramachandran et al.	2020	Psychometric validation of the Partners in Health scale as a self-management tool in patients with liver cirrhosis
A12	Ignatiev et al.	2021	Standardized Patient Education for Decompensated Cirrhotic Patients and Impact on Clinician Satisfaction

Appendix 2. Studies included in literature review (continued)

N	Author	Year	Title
A13	Saleh et al.	2021	How Do Patients With Cirrhosis and Their Caregivers Learn About and Manage Their Health? A Review and Qualitative Study
A14	Stelmach et al.	2021	Instrument to evaluate the knowledge of patient with cirrhosis on his disease: construction and validity
B1	배희옥 외1	2001	구조화된 정보제공이 간경변증 환자의 지식과 자가간호 수행에 미치는 효과
B2	허정은	2003	가족참여 환자교육이 간경변증 환자의 지식과 자가간호 수행에 미치는 영향
B3	김남영	2003	가족지지가 간경변증 환자의 자가간호와 질병상태에 미치는 영향
B4	안수옥	2005	간경변증 환자의 자가 간호 수행 유형과 자가 간호 수행 관련 요인에 관한 연구
B5	정경선 외2	2007	구조화된 정보제공이 간경변증 환자의 자가간호 지식과 자가간호 수행, 기능상태에 미치는 영향
B6	정경선 외1	2007	간경변증 환자의 자가간호수행과 증상경험 및 질병상태와의 관계
B7	박서희 외1	2013	만성 간질환 환자의 삶의 질 영향요인
B8	양선희	2014	간경변 환자의 자가간호행위와 퇴원교육요구도 분석
B9	윤미정 외1	2016	간경변증 환자의 자율성지지 프로그램 개발 및 적용 : 자기결정성이론을 기반으로
B10	박해진 외1	2017	간경변증 환자의 자가간호 행동 관련 요인: 질병 지식과 가족지지를 중심으로
B11	김미경 외1	2017	간경변증 환자의 자가간호 이행에 미치는 영향요인
B12	윤미정	2018	간경변증 환자의 자가간호이행 관련 요인: 증상경험, 지각된 건강상태 및 질병상태를 중심으로
B13	윤선아	2018	간경변증 환자의 피로, 우울, 수면장애와 자가간호 수행 간의 관계
B14	윤미림 외1	2020	간경변증 환자의 재입원 경험에 영향을 미치는 요인
C1	Lai et al.	2021	Malnutrition, frailty, and sarcopenia in patients with cirrhosis: 2021 practice guidance by the American Association for the Study of Liver Diseases

Appendix 2. Studies included in literature review (continued)

N	Reference
A1	Zandi, M., Adib-Hajbagheri, M., Memarian, R., Nejhad, A. K., & Alavian, S. M. (2005). Effects of a self-care program on quality of life of cirrhotic patients referring to Tehran Hepatitis Center. *Health and quality of life outcomes*, *3*(1), 1-8.
A2	Volk, M. L., Fisher, N., & Fontana, R. J. (2013). Patient knowledge about disease self-management in cirrhosis. *The American journal of gastroenterology*, *108*(3).
A3	Wigg, A. J., McCormick, R., Wundke, R., & Woodman, R. J. (2013). Efficacy of a chronic disease management model for patients with chronic liver failure. *Clinical Gastroenterology and Hepatology*, *11*(7), 850-858.
A4	Wang, Q., Wang, Y., Gao, J., Han, J. T., & Li, Y. P. (2015). Development of a self-management behaviour scale for liver cirrhosis. *International Journal of Nursing Sciences*, *2*(1), 73-79.
A5	Beg, S., Curtis, S., & Shariff, M. (2016). Patient education and its effect on self-management in cirrhosis: a pilot study. *European Journal of Gastroenterology & Hepatology*, *28*(5), 582-587.
A6	Fagerström, C., & Frisman, G. H. (2017). Living with liver cirrhosis: a vulnerable life. *Gastroenterology Nursing*, *40*(1), 38-46.
A7	Mansouri, P., Ghadami, M., Najafi, S. S., & Yektatalab, S. (2017). The effect of self-management training on self-efficacy of cirrhotic patients referring to transplantation Center of Nemazee Hospital: A randomized controlled clinical trial. *International journal of community based nursing and midwifery*, *5*(3), 256.
A8	Valery, P. C., Clark, P. J., McPhail, S. M., Rahman, T., Hayward, K., Martin, J., & Powell, E. (2017). Exploratory study into the unmet supportive needs of people diagnosed with cirrhosis in Queensland, Australia. *Internal medicine journal*, *47*(4), 429-435.
A9	Dong, N., Chen, W. T., Bao, M., Lu, Y., Qian, Y., & Lu, H. (2020). Self-management behaviors among patients with liver cirrhosis in Shanghai, China: a cross-sectional study. *Clinical nursing research*, *29*(7), 448-459.
A10	Predictors of Emergency Room Admission in Patients With Liver Cirrhosis: A Prospective, Descriptive Study
A11	Ramachandran, J., Smith, D., Woodman, R., Muller, K., Wundke, R., McCormick, R., & Wigg, A. (2021). Psychometric validation of the Partners in Health scale as a self-management tool in patients with liver cirrhosis. *Internal Medicine Journal*, *51*(12), 2104-2110.
A12	Ignatiev, E., Samardzija, M. K., Paul, S., Vuckovic, K. M., & Lockwood, M. B. (2021). Standardized patient education for decompensated cirrhotic patients and impact on clinician satisfaction. *Gastroenterology Nursing*, *44*(4), 233-239.

N	Reference
A13	Saleh, Z. M., Bloom, P. P., Grzyb, K., & Tapper, E. B. (2021). How do patients with cirrhosis and their caregivers learn about and manage their health? A review and qualitative study. *Hepatology communications*, *5*(2), 168-176.
A14	Stelmach, M., de Almeida Medeiros, K. A., Carvalho, B. J., Pipek, L. Z., de Mesquita, G. H. A., Nii, F., ... & Andraus, W. (2021). Instrument to evaluate the knowledge of patient with cirrhosis on his disease: construction and validity. *BMC gastroenterology*, *21*(1), 1-7.
B1	배희옥, & 서순림. (2001). 구조화된 정보제공이 간경변증 환자의 지식과 자가간호 수행에 미치는 효과. *성인간호학회지*, *13*(3), 476-485.
B2	허정은. (2003). 가족참여 환자교육이 간경변증 환자의 지식과 자가간호 수행에 미치는 영향.
B3	김남영. (2003). 가족지지가 간경변증 환자의 자가간호와 질병상태에 미치는 영향.
B4	안수옥. (2005). 간경변증 환자의 자가 간호 수행 유형과 자가간호 수행 관련 요인에 관한 연구. [석사학위논문, 고려대학교 교육대학원]
B5	정경선, 민혜숙, & 송영선. (2007). 구조화된 정보제공이 간경변증 환자의 자가간호 지식과 자가간호 수행, 기능상태에 미치는 영향. *재활간호학회지*, *10*(1), 29-36.
B6	정경선, & 민혜숙. (2007). 간경변증 환자의 자가간호수행과 증상경험 및 질병상태와의 관계. *성인간호학회지*, *19*(2), 318-328.
B7	박서희, & 양진향. (2013). 만성 간질환 환자의 삶의 질 영향요인. *Journal of The Korean Data Analysis Society*, *15*(1), 223-236.
B8	양선희. (2014). *간경변 환자의 자가간호행위와 퇴원교육요구도 분석*. [석사학위논문, 인하대학교]
B9	윤미정, & 민혜숙. (2016). 간경변증 환자의 자율성지지 프로그램 개발 및 적용: 자기결정성이론을 기반으로. *한국간호과학회 학술대회*, 339-339.
B10	박해진, & 신영희. (2017). 간경변증 환자의 자가간호 행동 관련 요인: 질병 지식과 가족지지를 중심으로. *한국산학기술학회. 18*(5), 647-656.
B11	김미경, & 나현주. (2017). 간경변증 환자의 자가간호 이행에 미치는 영향요인. *근관절건강학회지*, *24*(1), 47-55.
B12	윤미정. (2018). 간경변증 환자의 자가간호이행 관련 요인: 증상경험, 지각된 건강상태 및 질병상태를 중심으로. *기본간호학회지*, *25*(3), 165-175.
B13	윤선아. (2018). *간경변증 환자의 피로, 우울, 수면장애와 자가 간호 수행간의 관계*. [석사학위논문, 연세대학교].
B14	윤미림, & 은영. (2020). 간경변증 환자의 재입원 경험에 영향을 미치는 요인. *한국산학기술학회 논문지*, *21*(5), 111-120.
C1	Lai, J. C., Tandon, P., Bernal, W., Tapper, E. B., Ekong, U., Dasarathy, S., & Carey, E. J. (2021). Malnutrition, frailty, and sarcopenia in patients with cirrhosis: 2021 practice guidance by the American Association for the Study of Liver Diseases. *Hepatology*, *74*(3), 1611-44.

Appendix 3. Result of content validity

문항 초안	I-CVI	수정여부	비고
식이관리			
1. 나는 식사를 규칙적으로 한다.	1.00	유지	
2. 나는 소량의 음식을 자주 섭취한다.	0.60	삭제	6 번과 같은 맥락의 문항
3. 나는 오염되거나 날 것보다는 익힌 음식을 먹는다.	0.90	유지	
4. 나는 매 끼니마다 고기, 생선, 두부, 계란, 해산물 등을 탁구공 크기로 2-3 개 크기 내외 정도 섭취하고 있다. → 나는 매 끼니마다 고기, 생선, 두부, 계란, 해산물 등을 탁구공 크기(1 개: 8g 정도)로 2-3 개 크기 내외 정도 섭취한다.	0.70	수정,유지	근소실 예방 위한 문항이므로 유지.
5. 나는 매끼 충분한 식사를 하고 있으며, 체중감소가 없다. → 나는 매끼 충분한 식사를 하고 있다.	0.80	수정,유지	
6. 나는 긴 공복시간을 예방하기 위해 늦은 저녁 간식과 아침 식사를 한다. → 긴 공복시간은 근육을 감소시킬 수 있으므로 3-4 시간 간격으로 음식을 소량씩 자주 섭취한다..	0.70	수정,유지	근소실 예방을 위한 중요문항.
7. 나는 원활한 배변을 위해 채소나 과일 등의 섬유질을 섭취한다.	0.90	유지	
8. 나는 하루에 8 잔 이상(혹은 권고 받은 양)의 물을 마신다. (성인기준: 하루 8 잔 이상)	0.60	삭제	
9. 나는 자극적인 음식(커피, 차 등)을 제한하여 섭취한다.	0.60	삭제	
10. 나는 과식을 하지 않는다.	1.00	유지	
11. 나는 스스로 음식을 챙겨 먹는다.	0.70	삭제	
12. 나는 음식의 장단점을 알고 섭취한다. → 나는 음식을 섭취할 때, 간경변에 좋은지 나쁜지를 알아보고 섭취한다.	0.90	수정,유지	
13. 나는 간에 해가 없으면서 내가 좋아하는 음식을 찾을 수 있다.	0.70	삭제	
일상생활관리			
14. 나는 피로가 느껴지면 충분히 쉰다.	1.00	유지	
15. 나는 잠을 매일 일정한 시간에 충분히 잔다.	1.00	유지	

16. 나는 간경변증 관리를 위해 술을 마시지 않는다. → 나는 술을 마시지 않는다.	1.00	유지	
17. 나는 규칙적으로 운동을 한다.	1.00	유지	
18. 나는 스트레스나 불편한 감정이 생겼을 때, 이를 완화할 수 있는 방법을 찾는다.	0.90	유지	
의학적치료이행			
19. 나는 간경변증 관리를 위해 정해진 날짜에 정기적으로 병원을 방문한다.	1.00	유지	
20. 나는 간경변증 관리를 위해 정기적으로 처방받은 검사를 받는다.	1.00	유지	
22. 나는 처방받지 않는 약물의 복용에 대해 의료진과 상의한다.	1.00	유지	
23. 나는 의사가 허용한 영양제만 복용한다.	1.00	유지	
24. 나는 간경변증의 증상이 발생했을 경우, 필요시 병원진료를 받는다. → 나는 간경변증과 관련된 신체적 변화가 생겼을 때, 병원진료를 받는다.	0.90	유지	
증상관리 및 모니터링			
25. 나는 복수나 부종을 모니터링하기 위해 규칙적으로 체중과 복부둘레를 측정한다.	1.00	유지	
26. 나는 복수가 발생했을 경우 염분을 제한하여 섭취한다.	1.00	유지	
27. 나는 잇몸출혈을 예방하기 위해 부드러운 칫솔을 사용한다.	0.90	유지	
28. 나는 식도나 위에 정맥류 출혈을 에방하기 위해 부드러운 음식을 섭취한다.	1.00	삭제	
29. 나는 건조하거나 가려운 피부관리를 위해 처방된 로션을 바르거나 헐렁한 옷을 입는다.	0.90	유지	
30. 나는 배변시 혈변이 있는지를 확인한다. → 나는 배변시 혈변(붉은색 혹은 검은색)이 있는지를 확인한다.	1.00	수정,유지	
31. 나는 복수가 차면 물 섭취양을 줄인다.	1.00	유지	
가족지지			
32 나는 주로 혼자 간경변증을 관리를 한다. (그렇다'라고 대답한 경우, 조금이라도 도움을 주는 사람을 떠올리고 다음 문항들에 답해주세요.)	1.00	유지	

33. 나의 가족(혈연 혹은 돌봄을 제공해주는 사람)은 간경변증과 관련된 일상생활 관리를 도와준다.	1.00	유지	
34. 나의 가족은 예정된 시간에 간경변증 진료와 치료 받는 것을 도와준다.	1.00	유지	
35. 나의 가족은 처방된 약물이나 허용된 건강보조제를 안전하게 복용할 수 있도록 도와준다.	1.00	유지	
36. 나의 가족은 규칙적인 식사나 음식의 종류과 같이 간경변증과 관련된 식이관리를 도와준다.	1.00	유지	
37. 나의 가족은 간경변증과 관련된 나의 의식상태를 확인할 수 있다.	–		전문가 피드백으로 추가
38. 나의 가족은 간경변증 관리에 대한 정보를 나에게 알려준다. → 나의 가족은 간경변증 관리에 대한 정보가 있으면 나에게 알려준다.	1.00	수정,유지	
39. 나의 가족은 간경변증 관리에 있어 정서적으로 지지가 된다. → 나의 가족은 내가 간경변증을 관리함에 있어 정서적으로 지지가 된다.	1.00	수정,유지	

Appendix 4. Result of language evaluation

문 항	
어휘 검정 전	어휘 검정 후
1. 나는 식사를 규칙적으로 한다.	1. 나는 식사를 규칙적으로 한다.
2. 나는 오염되거나 날 것보다는 익힌 음식을 먹는다.	2. 나는 날 것이나 오염된 음식을 피하고 익힌 음식을 먹는다.
3. 나는 매끼니마다 고기, 생선, 두부, 계란, 해산물 등을 탁구공 크기(1개: 8g정도)로 2-3개 크기 내외 정도 섭취한다.	3. 나는 매 끼니마다 고기, 생선, 두부, 계란, 해산물 등의 음식을 탁구공 (8g정도) 2-3개 정도의 크기로 섭취한다.
4. 나는 매끼 충분한 식사를 하고 있다.	4. 나는 매 끼니 충분한 양의 식사를 하고 있다.
5. 긴 공복시간은 근육량을 감소시킬 수 있으므로 3-4 시간 간격으로 음식을 소량씩 자주 섭취한다.	5. 공복이 길면 근육량이 감소될 수 있으므로 나는 3-4시간 간격으로 소량의 음식을 자주 섭취한다.
6. 나는 원활한 배변을 위해 채소나 과일 등의 섬유질을 섭취한다.	6. 나는 배변을 원활하게 하기 위해 채소나 과일 등 섬유질이 있는 음식을 섭취한다.
7. 나는 과식을 하지 않는다.	7. 나는 과식을 하지 않는다.
8. 나는 음식을 섭취할 때, 간경변증에 좋은지 나쁜지를 알아보고 섭취한다.	8. 나는 음식을 섭취할 때 그것이 간경변증에 영향을 주는지 알아본 후 섭취한다.
9. 나는 피로가 느껴지면 충분히 쉰다.	9. 나는 피로가 느껴지면 충분히 쉰다.
10. 나는 잠을 매일 일정한 시간에 충분히 잔다.	10. 나는 매일 충분히 잔다.
11. 나는 술을 마시지 않는다.	11. 나는 술을 마시지 않는다.
12. 나는 규칙적으로 운동을 한다.	12. 나는 규칙적으로 운동을 한다.
13. 나는 스트레스나 불편한 감정이 생겼을 때, 이를 해결할 수 있는 방법을 찾는다.	13. 나는 스트레스나 불편한 감정이 생겼을 때, 그것을 해결하고자 한다.
14. 나는 간경변증 관리를 위해 정해진 날짜에 정기적으로 병원을 방문한다.	14. 나는 간경변증 관리를 위해 정해진 날짜를 지켜 정기적으로 병원 진료를 받는다.
15. 나는 간경변증 관리를 위해 정기적으로 처방받은 검사를 받는다.	15. 나는 간경변증 관리를 위해 처방에 따라 정기적으로 검사를 받는다.
16. 나는 처방받은 약물의 투여목적과 용량에 맞게 복용한다.	16. 나는 처방받은 약물을 투여 목적과 용량에 맞게 복용한다.
17. 나는 처방받지 않는 약물의 복용에 대해 의료진과 상의한다.	17. 나는 처방받지 않은 약물의 복용에 대해 의료진과 상의한다.
18. 나는 의사가 허용한 영양제만 복용한다.	18. 나는 의사가 허용한 영양제만 복용한다.
19. 나는 간경변증과 관련된 신체적 변화가 생겼을 때, 병원진료를 받는다.	19. 나는 간경변증과 관련된 신체적 변화가 생겼을 때, 병원 진료를 받는다.

20. 나는 복수나 부종을 모니터링하기 위해 규칙적으로 체중과 복부둘레를 측정한다.	20. 나는 복수나 부종의 발생을 모니터링하기 위해 규칙적으로 체중(혹은 복부둘레)을 측정한다.
21. 나는 복수가 발생할 경우, 염분제한이 필요하다는 것을 알고 있다.	21. 나는 복수가 차면 염분을 제한하여 섭취하도록 한다.
22. 나는 잇몸출혈을 예방하기 위해 부드러운 칫솔을 사용한다.	22. 나는 잇몸출혈을 예방하기 위해 부드러운 칫솔모를 사용한다.
23. 나는 건조하거나 가려운 피부관리를 위해 처방된 로션을 바르거나 헐렁한 옷을 입는다.	23. 나는 건조하거나 가려운 피부관리를 위해 옷을 헐렁하게 입거나 처방된 로션을 바른다.
24. 나는 배변시 혈변(붉은색 혹은 검은색)이 있는지를 확인한다.	24. 나는 배변 시 혈변(붉은색 혹은 검은색)이 있는지를 확인한다.
25. 나는 복수가 차면 물 섭취량을 줄인다.	25. 나는 복수가 차면 물 섭취량을 줄인다.
26. 나는 주로 혼자 간경변증을 관리를 한다.	26. 나는 간경변증을 대부분 혼자 관리한다.
'가족' 은 혈연 혹은 돌봄을 제공해주는 사람입니다. 26번에서 '그렇다' 혹은 '매우 그렇다'고 대답한 경우에도, 최소한의 도움을 주는 사람을 떠올리며 27-33번 문항에 답해 주세요.	
27. 나의 가족은 간경변증과 관련된 일상생활 관리를 도와준다.	27. 나의 가족은 간경변증과 관련된 일상 생활 관리에 도움을 준다.
28. 나의 가족은 예정된 시간에 간경변증 진료와 치료받는 것을 도와준다.	28. 나의 가족은 예정된 시간에 간경변증 진료와 치료를 받을 수 있도록 도움을 준다.
29. 나의 가족은 처방된 약물이나 허용된 건강보조제를 안전하게 복용할 수 있도록 도와준다.	29. 나의 가족은 처방된 약물이나 허용된 건강보조제를 안전하게 복용할 수 있도록 도움을 준다.
30. 나의 가족은 규칙적인 식사나 음식의 종류와 같이 간경변증과 관련된 식이관리를 도와준다..	30. 나의 가족은 간경변증과 관련된 식이 관리에 도움을 준다..
31. 나의 가족은 간경변증과 관련된 나의 의식상태를 확인할 수 있다.	31. 나의 가족은 간경변증과 관련하여 나의 의식상태를 인지할 수 있다.
32. 나의 가족은 간경변증 관리에 대한 정보가 있으면 나에게 알려준다.	32. 나의 가족은 간경변증 관리와 관련된 정보가 있으면 나에게 알려준다.
33. 나의 가족은 나에게 정서적으로 지지가 된다.	33. 나는 나의 가족을 통해 정서적으로 지지를 받는다.

Appendix 5. Preliminary 33 items

초기 도구의 문항
1. 나는 식사를 규칙적으로 한다.
2. 나는 날 것이나 오염된 음식을 피하고 익힌 음식을 먹는다.
3. 나는 매 끼니마다 고기, 생선, 두부, 계란, 해산물 등을 탁구공(8g정도) 2-3개 정도의 크기로 섭취한다.
4. 나는 매 끼니 충분한 양의 식사를 하고 있다.
5. 공복이 길면 근육량이 감소될 수 있으므로 나는 3-4시간 간격으로 소량의 음식을 자주 섭취한다.
6. 나는 배변을 원활하게 하기 위해 채소나 과일 등의 섬유질이 있는 음식을 섭취한다.
7. 나는 과식을 하지 않는다.
8. 나는 음식을 섭취할 때 그것이 간경변증에 영향을 주는지 알아본 후 섭취한다.
9. 나는 피로가 느껴지면 충분히 쉰다.
10. 나는 매일 충분히 잔다.
11. 나는 술을 마시지 않는다.
12. 나는 규칙적으로 운동을 한다.
13. 나는 스트레스나 불편한 감정이 생겼을 때, 그것을 해결하고자 한다.
14. 나는 간경변증 관리를 위해 정해진 날짜를 지켜 정기적으로 병원 진료를 받는다.
15. 나는 간경변증 관리를 위해 처방에 따라 정기적으로 검사를 받는다.
16. 나는 처방 받은 약물을 투여 목적과 용량에 맞게 복용한다.
17. 나는 처방 받지 않은 약물의 복용에 대해 의료진과 상의한다.
18. 나는 의사가 허용한 영양제만 복용한다.
19. 나는 간경변증과 관련된 신체적 변화가 생겼을 때, 병원 진료를 받는다.
20. 나는 복수나 부종의 발생을 모니터링하기 위해 규칙적으로 체중(혹은 복부둘레)을 측정한다.
21. 나는 복수가 차면 염분을 제한하여 섭취하고자 한다.
22. 나는 잇몸 출혈을 예방하기 위해 부드러운 칫솔을 사용한다.
23. 나는 건조하거나 가려운 피부관리를 위해 옷을 헐렁하게 입거나 처방된 로션을 바른다.
24. 나는 배변 시 혈변(붉은색 혹은 검은색)이 있는지를 확인한다.
25. 나는 복수가 차면 물 섭취량을 줄인다.
26. 나는 간경변증을 대부분 혼자 관리한다. ('그렇다'고 대답한 경우, 조금이라도 도움을 주는 사람을 떠올려 다음 문항들에 답해 주세요.)

27. 나의 가족(혈연 혹은 돌봄을 제공해주는 사람)은 간경변증과 관련된 일상생활 관리에 도움을 준다.
28. 나의 가족은 예정된 시간에 간경변증 진료와 치료를 받을 수 있도록 도와준다.
29. 나의 가족은 처방된 약물이나 허용된 건강보조제를 안전하게 복용할 수 있도록 도움을 준다.
30. 나의 가족은 간경변증과 관련된 식이 관리에 도움을 준다.
31. 나의 가족은 간경변증과 관련하여 나의 의식상태를 인지할 수 있다.
32. 나의 가족은 간경변증 관리에 대한 정보가 있으면 나에게 알려준다.
33. 나는 나의 가족을 통해 정서적으로 지지를 받는다.

Appendix 6. Descriptive statistics of 33 items (N = 169)

Item	Mean	SD	Skewness	Kurtosis
1	3.5	1.02	−0.23	−0.57
2	3.9	0.97	−0.79	0.27
3	3.0	1.05	0.41	−0.51
4	3.5	0.97	−0.26	−0.45
5	2.9	1.06	0.37	−0.54
6	3.5	1.01	−0.43	−0.27
7	3.6	0.94	−0.30	−0.24
8	2.9	1.20	0.17	−1.00
9	3.6	0.92	−0.36	0.04
10	3.2	1.06	−0.09	−0.65
11	3.8	1.29	−0.72	−0.77
12	3.2	1.12	0.04	−0.86
13	3.5	0.94	−0.53	0.17
14	4.5	0.64	−1.43	**4.75**
15	4.5	0.63	−1.47	**5.17**
16	4.4	0.64	−0.86	0.99
17	3.9	1.05	−1.01	0.54
18	3.9	1.14	−0.89	−0.10
19	4.1	0.84	−1.21	**2.01**
20	3.3	1.21	−0.18	−1.00
21	3.3	1.26	−0.27	−1.01
22	3.6	1.02	−0.64	−0.02
23	3.4	1.18	−0.33	−0.82
24	3.7	1.17	−0.83	−0.17
25	3.3	1.29	−0.31	−0.95
26	3.5	1.20	−0.63	−0.48
27	3.7	1.15	−0.74	−0.24
28	3.9	1.10	−1.24	1.07
29	3.8	1.11	−1.01	0.45
30	3.6	1.17	−0.59	−0.48
31	3.6	1.13	−0.67	−0.25
32	3.6	1.12	−0.72	−0.08
33	3.8	1.11	−0.97	0.49

Appendix 7. The results of correlations between items (N = 169)

Item	Average correlation	Item-total correlation
1	0.296	0.526
2	0.276	0.495
3	0.251	0.444
4	**0.177**	**0.305**
5	0.254	0.456
6	0.293	0.532
7	0.205	**0.363**
8	0.290	0.522
9	0.307	0.558
10	0.265	0.478
11	0.268	0.470
12	0.243	0.438
13	0.292	0.534
14	0.285	0.484
15	0.285	0.484
16	0.307	0.530
17	0.281	0.501
18	0.231	0.405
19	0.289	0.509
20	0.328	0.592
21	0.330	0.603
22	0.272	0.500
23	0.259	0.481
24	0.294	0.540
25	0.288	0.530
26	**0.142**	**0.257**
27	0.371	0.689
28	0.383	0.709
29	0.303	0.560
30	0.345	0.639
31	0.342	0.639
32	0.295	0.551
33	0.308	0.571

Appendix 8. The items with strong correlation (N = 169)

Item	Number of strong correlation	Correlating items	Correlation coefficient
14	2	15, 16	0.963, 0.776
15	2	14, 16	0.963, 0.754
16	2	14, 15	0.776, 0.754
27	3	28, 30, 32	0.790, 0.749, 0.763
28	3	27, 30, 33	0.790, 0.708, 0.708
29	2	30, 31	0.720, 0.749
30	5	27, 28, 29, 31, 32	0.749, 0.708, 0.720, 0.785, 0.752
31	2	29, 30	0.749, 0.785
32	2	27, 30	0.763, 0.752
33	1	28	0.708

Appendix 9. The results of exploratory factor analysis (N =169)

Item	Commonality	Factor				
		1	2	3	4	5
1	0.486	−0.082	0.073	0.197	0.584	0.062
2	0.532	0.066	0.672	0.213	−0.003	−0.101
3	0.564	0.003	0.151	−0.031	0.744	−0.203
5	0.571	0.102	0.743	0.029	0.044	−0.161
6	0.582	0.098	0.679	−0.028	0.096	0.001
8	0.381	0.349	0.111	0.040	0.268	−0.004
9	0.566	−0.099	0.444	−0.006	0.491	0.066
10	0.552	−0.184	0.147	−0.064	0.746	0.107
11	0.558	−0.089	0.546	0.481	−0.174	0.150
12	0.534	0.030	−0.194	−0.108	0.764	0.126
13	0.388	0.353	0.194	−0.050	0.084	0.204
14	0.777	−0.062	0.140	0.903	−0.088	0.017
16	0.802	−0.015	0.080	0.883	−0.023	0.043
17	0.488	0.320	−0.190	0.316	0.297	0.020
18	0.588	0.601	−0.248	0.326	0.131	−0.238
19	0.493	0.317	−0.029	0.466	0.104	−0.034
20	0.543	0.637	0.036	0.116	0.062	−0.016
21	0.512	0.589	0.085	0.115	−0.022	0.094
22	0.482	0.473	0.369	−0.234	−0.028	0.099
23	0.593	0.702	0.346	−0.280	−0.065	−0.082
24	0.418	0.554	0.121	0.018	−0.096	0.146
25	0.541	0.775	−0.028	0.025	−0.196	0.111
27	0.763	0.094	−0.075	−0.009	0.161	0.794
31	0.776	0.204	−0.119	0.017	−0.059	0.843
33	0.779	−0.077	−0.016	0.040	0.014	0.904
Eigen value		8.1	1.9	1.6	1.3	1.3
Variance (%)		32.6	7.6	6.4	5.3	5.2
Cumulative variance (%)		32.6	40.2	46.6	51.9	57.1

Appendix 10. Informed consent form of main survey for scale evaluation

대 상 자 설 명 문 (환자용)

연구 제목 : **간경변증 환자의 자가관리 측정도구 개발**

연구 책임자 : 연세대학교 간호대학 교수 장 연 수

이 설명문은 본 연구에 대한 귀하의 이해를 돕기 위해 마련된 것이고, 이 연구에 대한 자세한 내용을 담고 있으니 이 설명문을 읽고 충분히 이해하고 생각하신 후에 참여 여부를 결정해주시기 바랍니다. 본 연구의 목적은 간경변증 환자가 일상생활에서 자신의 질환을 얼마나 잘 관리하는지 확인하기 위한 탐색적 연구로 참여자들의 간경변증을 경험해가고 있는지를 탐색하여 어떻게 간경변증을 관리해가는지를 이해하기 위한 목적에서 이루어지는 것입니다. 귀하께서 자발적으로 참여에 동의하여 동의서를 작성하시는 경우에 연구에 참여하실 수 있으며 참여하지 않기로 결정하더라도 어떠한 불이익도 없을 것입니다.

1. 연구의 배경과 목적

간경변증은 대표적인 만성 간질환 중의 하나이며 치명적인 합병증을 가진 질환으로 알려져 있습니다. 간경변증의 원인은 만성 B 형, C 형 간염이나 알코올성 간염 등과 같은 만성질환이 대표적이며 간조직의 반복적인 염증반응과 섬유화로 인한 간 경화로 간 기능이 저하된 상태입니다. 초기 간경변증에서는 증상이 없는 경우가 대부분이지만, 합병증이 한번 발생하면 환자들의 예후는 불량해질 수 있어 심각한 합병증의 발생을 줄이기 위해서는 적극적인 치료로 질병의 진행을 늦추고 증상발생의 예방과 합병증을 관리하는 것이 필요합니다. 그리고, 대부분의 간경변증은 완치가 불가능하기 때문에 일상생활에서 환자들이 자신의 질병을 스스로 관리해 나가는 것이 무엇보다 중요합니다.

자가관리는 만성질환이 증가됨에 따라 환자들의 질병관리를 위해 중요하게 여겨지고 있습니다. 자가관리는 자신의 생명, 건강, 안녕을 유지하고 증진하기 위해 자신의 신념을 수행하는 실제적인 행위이며, 자신의 건강에 대한 책임을 가지고 이를 위한 바람직한 행동을 자발적으로 해나가는 것입니다. 기존에 간경변증 관리를 위해서는 병원방문 및 정기검진, 합병증 관리가 중요하게 여겨져 왔으나, 간경변증에 대한 인식이나 지식부족으로 인해 금주의 어려움과 영양불균형 등의 문제가 있으며, 규칙적인 관리부족으로 인한 합병증 발생으로 병원에 재입원하는 경우가 많다고 보고되고 있습니다. 이러한 결과들은 간경변증 환자들의 자가관리가 적절하게 이루어지지 못하고 있음을 보여주는 것으로서,

Appendix 10. Informed consent form of main survey for scale evaluation (continued)

간경변증 환자의 자가관리를 평가하여 그 수준을 파악하는 것이 중요함을 알 수 있습니다. 이에 본 연구에서는 간경변증 환자들의 자가관리 도구를 개발하기 위하여 간경변증 자가관리에 대한 환자와 그 보호자의 자가관리 경험을 탐색하고 이를 바탕으로 자가관리의 중요한 요소들을 확인하고자 합니다.

2. 연구에 참여하는 대상자의 수, 기간과 장소

본 연구는 연세대학교 세브란스병원 소화기내과 외래에서 추적관찰하고 있는 간경변증 환자들 중에서 본 연구의 선정기준에 부합하고 본 연구의 목적을 이해하여 참여에 동의하는 환자들 10 명과 그 보호자가 참여할 것입니다. 귀하께서 연구참여에 동의하실 경우, 연구윤리심의 위원회 승인일로부터 1 년까지의 기간 이내에 연구에 참여하시게 됩니다. 다음에 해당되시면 참여하실 수 있습니다.

- 구체적인 선정 기준은 다음과 같습니다.
  (1) 간경변증 진단받고 6 개월 이상 경과된 자
  (2) 의식상태가 명료하고 의사소통이 가능한 20세 이상의 성인환자
  (3) 언어적 의사소통이 가능하고 연구의 목적을 이해할 수 있는 자로 연구참여에 동의한 자
- 제외 기준은 다음과 같습니다.
  (1) 치매 및 간성혼수로 인해 인지 기능의 장애가 있는 자
  (2) 간암이 동반되거나 다른 진행성 암이 진단되어 치료 중인 자

3. 연구 방법

귀하가 본 연구에 참여하기로 결정하셨다면, 하단의 대상자 동의서 양식에 서명하시면 됩니다. 서명 전 연구에 관하여 궁금한 사항이 있다면 연구자에게 질문하여 주십시오. 동의서에 서명하신 이후에, 간경변증 자가관리를 하면서 경험한 내용들에 대해서 귀하는 주 보호자와 함께 심층면담에 참여하게 됩니다. 심층면담은 병원 내 상담실과 같이 독립적이고 조용한 장소에서 약 30-60 분 정도 진행될 것이며, 정보의 정확성과 완전성을 위해 면담 내용을 귀하의 동의 하에 녹음할 예정입니다. 수집된 자료(녹취록)은 실명 대신 기호를 부여하여 익명성을 유지할 것입니다.

4. 연구에 참여하여 기대할 수 있는 이익

귀하가 본 연구에 참여하는데 있어서 직접적인 이득은 없습니다. 그러나 귀하가 면담을 통해 나눠주신 내용은 이 연구가 자가관리 도구를 개발하는데 반영됨으로써 향후 간경변증 환자의 자가관리 향상을 위한 기초자료로 활용될 수 있다는 점에서 중요한 학문적 의의가 있습니다.

Appendix 10. Informed consent form of main survey for scale evaluation (continued)

5. 연구에 참여 하여 예상되는 위험 및 불편

본 연구는 침습적 성격이 아니며 최소한의 위험수준에 해당되나, 심층면담 과정에서 힘들거나 피로하다고 느끼면 연구자에게 이야기해 주십시오. 연구자는 면담을 중지하고 귀하께서 충분한 휴식시간을 가질 수 있도록 하겠습니다.

6. 연구 참여에 따른 보상

귀하가 본 연구에 참여하시는 것에 대한 감사의 표시로 면담 완료 후 소정의 답례품(2만원 상당의 답례품)을 드립니다. 1회 면담 후 자료분석 과정에서 면담 내용의 확인 및 추가 질문이 필요한 경우 전화상으로 추가 면담을 진행 할 수 있습니다. 추가 면담 시간은 약 5-10분 정도로 예상되며, 추가 면담에 대한 별도 답례품은 없습니다.

7. 정보 수집 및 제공

본 동의서에 서명함으로써 귀하는 연구진이 귀하의 개인(민감)정보를 수집하고 사용하는데 동의하게 되며, 연구에서 수집된 자료는 본 연구 목적으로만 사용할 예정이며 제3자에게 제공하지 않을 것입니다.

(1) 개인정보의 수집·이용 목적: 본 연구를 위해서만 수집되며 연구가 종료되면 3년간 보관하고 이후 파기될 것입니다.

(2) 수집하려는 개인(민감)정보의 항목: 성별, 출생년도, 결혼 상태, 최종 학력, 현재 직업 유무, 인지하는 주관적 건강상태, 복용 약물과 의무기록을 통해 기저질환, 이환기간을 확인합니다.

(3) 개인정보의 보유 및 이용 기간: 귀하의 개인(민감)정보를 보유 및 이용하는 기간은 본 연구 관련 자료인 녹음 파일, 필사자료 및 증례기록지와 함께 대학에 소속된 연구자의 연구실에 잠금 장치가 있는 캐비닛과 타인의 접근이 어려운 컴퓨터에 3년간 보관할 예정입니다.

(4) 귀하는 위 개인(민감)정보 수집 및 이용, 제공에 대한 수락 여부를 자유롭게 결정할 수 있습니다. 귀하가 개인(민감)정보 수집 및 이용, 제공에 수락하지 않는 경우에도 귀하에 대한 진료와 처방에 어떠한 불이익도 발생하지 않습니다.

8. 개인정보 및 기록에 대한 비밀보장

귀하의 자료는 개인정보보호법에 따라 적절히 관리됩니다. 관련 정보는 잠금 장치가 있는 연구실 캐비닛 및 연구자 외 접근이 어려운 컴퓨터에 보관되고, 관련 연구진들만이 접근 가능합니다. 모니터 요원, 점검 요원, 연구심의위원회는 관련 규정이 정하는 범위 안에서 본 연구의 실시 절차와 자료의 신뢰성을

Appendix 10. Informed consent form of main survey for scale evaluation (continued)

검증하기 위해 연구 결과를 직접 열람할 수 있습니다. 귀하가 본 동의서에 서명하는 것은, 이러한 사항에 대하여 사전에 알고 있었으며 이를 허용한다는 의사로 간주될 것입니다. 연구 종료 후 연구관련 자료는 3 년간 보관되며 이후 전사본은 분쇄될 것입니다.

9. 참여/철회의 자발성

귀하의 연구참여는 자발적이며 언제든지 연구 참여 철회할 수 있습니다. 이 경우 연구와 관련하여 추가적인 정보를 수집하지 않을 것이며 이전까지 수집된 정보를 폐기할 것입니다. 귀하가 본 연구에 참여하지 않아도 귀하께는 어떠한 불이익도 없습니다.

10. 연락처

이 연구에 관하여 궁금한 점이 있거나 연구와 관련이 있는 상해가 발생한 경우에는 아래의 연구자에게 연락하여 주십시오.

연구 책임자 : 장연수 (연세대학교 간호대학 교수)

연구자 주소 : 03722 서울특별시 서대문구 연세로 50-1

연락처: 연구담당자 권오영 ☎ 02-2228-3368/010-3396-5020, E-mail: nursing502@naver.com

대상자로서 귀하의 권리에 대하여 질문이 있는 경우에는 연구자에게 말씀하시거나 다음의 번호로 문의하실 수 있습니다.

세브란스병원 연구심의위원회 02-2228-0430~0434

세브란스병원 임상연구보호센터 02-2228-0450~0454

Appendix 10. Informed consent form of main survey for scale evaluation (continued)

대 상 자 동 의 서 (환자용)

연구제목 : **간경변증 환자의 자가관리 측정도구 개발**

※ 아래 항목을 읽고 동의한다면, 좌측 상자 기호에 V 표시해 주시기 바랍니다.

- □ 본인은 이 설명문을 읽었으며, 본 연구의 목적, 방법, 기대효과, 가능한 위험성, 건강 정보 관리 등에 대한 충분한 설명을 듣고 이해하였습니다.
- □ 이 연구목적으로 개인(민감)정보 수집·이용·제공 등에 관한 설명을 이해하였습니다.
- □ 모든 궁금한 사항에 대해 질문하였고, 충분한 답변을 들었습니다.
- □ 이 연구에 동의한 경우라도 언제든지 철회할 수 있고, 철회 이후 어떠한 불이익도 발생하지 않을 것임을 확인하였습니다.
- □ 본인은 설명문 및 작성된 동의서 사본 1 부를 받게 될 것입니다.
- □ 충분한 시간을 갖고 생각한 결과, 본인은 이 연구에 참여하기를 자유로운 의사에 따라 동의합니다.

대상자 성명		서명		서명날짜	

설명한 연구자의 성명		서명		서명날짜	

Appendix 11. Survey questionnaire

□ 다음은 귀하께서 간경변증을 스스로 관리하는 정도를 알아보기 위한 질문입니다. 각 문항을 읽고 해당하는 곳에 V 표 해주십시오.

문 항	전혀 그렇지 않다	그렇지 않다	보통이다	그렇다	항상 그렇다
1. 나는 식사를 규칙적으로 한다.	①	②	③	④	⑤
2. 나는 날 것이나 오염된 음식을 피하고 익힌 음식을 먹는다.	①	②	③	④	⑤
3. 나는 매 끼니마다 고기, 생선, 두부, 계란, 해산물 등의 음식을 탁구공(8g정도) 2-3개 정도의 크기로 섭취한다.	①	②	③	④	⑤
4. 나는 매 끼니 충분한 양의 식사를 하고 있다.	①	②	③	④	⑤
5. 공복이 길면 근육량이 감소될 수 있으므로 나는 3-4시간 간격으로 소량의 음식을 자주 섭취한다.	①	②	③	④	⑤
6. 나는 배변을 원활하게 하기 위해 채소나 과일 등 섬유질이 있는 음식을 섭취한다.	①	②	③	④	⑤
7. 나는 과식을 하지 않는다.	①	②	③	④	⑤
8. 나는 음식을 섭취할 때 그것이 간경변증에 영향을 주는지 알아본 후 섭취한다.	①	②	③	④	⑤
9. 나는 피로가 느껴지면 충분히 쉰다.	①	②	③	④	⑤
10. 나는 매일 충분히 잔다.	①	②	③	④	⑤
11. 나는 술을 마시지 않는다.	①	②	③	④	⑤
12. 나는 규칙적으로 운동을 한다.	①	②	③	④	⑤
13. 나는 스트레스나 불편한 감정이 생겼을 때, 그것을 해결하고자 한다.	①	②	③	④	⑤
14. 나는 간경변증 관리를 위해 정해진 날짜를 지켜 정기적으로 병원 진료를 받는다.	①	②	③	④	⑤
15. 나는 간경변증 관리를 위해 처방에 따라 정기적으로 검사를 받는다.	①	②	③	④	⑤
16. 나는 처방 받은 약물을 투여 목적과 용량에 맞게 복용한다.	①	②	③	④	⑤
17. 나는 처방 받지 않은 약물의 복용에 대해 의료진과 상의한다.	①	②	③	④	⑤
18. 나는 의사가 허용한 영양제만 복용한다.	①	②	③	④	⑤
19. 나는 간경변증과 관련된 신체적 변화가 생겼을 때, 병원 진료를 받는다.	①	②	③	④	⑤
20. 나는 복수나 부종의 발생을 모니터링하기 위해 규칙적으로 체중(혹은 복부둘레)을 측정한다.	①	②	③	④	⑤

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Appendix 11. Survey questionnaire (continued)

22. 나는 잇몸 출혈을 예방하기 위해 부드러운 칫솔모를 사용한다.	①	②	③	④	⑤
23. 나는 건조하거나 가려운 피부관리를 위해 옷을 헐렁하게 입거나 처방된 로션을 바른다.	①	②	③	④	⑤
24. 나는 배변 시 혈변(붉은색 혹은 검은색)이 있는지를 확인한다.	①	②	③	④	⑤
25. 나는 복수가 차면 물 섭취량을 줄인다.	①	②	③	④	⑤
26. 나는 간경변증을 대부분 혼자 관리한다.	①	②	③	④	⑤
'가족'은 혈연 혹은 돌봄을 제공해주는 사람입니다. 26번에서 '④그렇다' 혹은 '⑤매우 그렇다'고 대답한 경우에도, 최소한의 도움을 주는 사람을 떠올리며 27-33번 문항에 답해주세요.					
27. 나의 가족은 간경변증과 관련된 일상생활 관리에 도움을 준다.	①	②	③	④	⑤
28. 나의 가족은 예정된 시간에 간경변증 진료와 치료를 받을 수 있도록 도움을 준다.	①	②	③	④	⑤
29. 나의 가족은 처방된 약물이나 허용된 건강 보조제를 안전하게 복용할 수 있도록 도움을 준다.	①	②	③	④	⑤
30. 나의 가족은 간경변증과 관련된 식이 관리에 도움을 준다.	①	②	③	④	⑤
31. 나의 가족은 간경변증과 관련하여 나의 의식 상태를 인지할 수 있다.	①	②	③	④	⑤
32. 나의 가족은 간경변증 관리에 대한 정보가 있으면 나에게 알려준다.	①	②	③	④	⑤
33. 나는 나의 가족을 통해 정서적으로 지지를 받는다.	①	②	③	④	⑤

□ 다음은 귀하께서 다음과 같은 일을 얼마나 잘 할 수 있는지 <u>자신감 정도</u>를 알아보기 위한 질문입니다. 각 문항을 읽고 <u>해당하는 숫자</u>를 선택해 주십시오.

문 항	전혀 할 수 없다 ◀ ——— ▶ 매우 잘 할 수 있다
1. 근육강화나 유연성을 위한 가벼운 운동을 일주일에 3-4 회 정도 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
2. 걷기운동, 수영 혹은 자전거 타기 등과 같은 유산소 운동을 일주일에 3-4 회 정도 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
3. 증상 악화 없이 운동을 계속 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
4. 주변에서 제공되는 질병 관련 정보를 쉽게 찾을 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
5. 필요한 것(음식구입, 밥하기 혹은 자동차 이용 등)을 도와줄 수 있는 친구나 가족을 쉽게 찾을 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

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Appendix 11. Survey questionnaire (continued)

문 항	전혀 할 수 없다 ◀ ——— ▶ 매우 잘 할 수 있다
6. 정서적으로 나를 도와줄 수 있는 (말 들어주기, 고민 상담 등) 친구나 가족을 쉽게 찾을 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
7. 친구나 가족 외에 필요하다면 나의 정서적인 문제를 도와줄 수 있는 다른 사람을 찾을 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
8. 친구나 가족 외에 필요하다면 집안일(청소, 밥하기, 목욕하기, 마당 쓸기 등)을 도와줄 수 있는 다른 사람을 찾을 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
9. 질병과 관련되어 걱정되는 것을 의사에게 물어볼 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
10. 질병과 관련된 개인적인 문제를 공개적으로 의사와 상의할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
11. 의사와 의견이 다를 때 이에 대해 얘기하고 논의할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
12. 나는 질병을 여러 가지 방법으로 계속 관리할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
13. 질병과 관련된 증상이 변하는 것을 보고 언제 병원에 가야 하는지 판단할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
14. 내가 가진 만성 질환을 여러 가지 방법으로 관리하여 병원방문 횟수를 줄일 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
15. 일상생활을 방해하지 않도록 만성질환으로 인한 정신적 어려움을 감소할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
16. 질병이 일상생활에 영향을 주지 않도록 병원에서 처방한 약을 복용하는 것 이외에 다른 관리방법을 사용할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
17. 건강에 문제가 있어도 집안정리나 마당청소와 같은 집안일을 다 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
18. 건강에 문제가 있어도 나에게 주어진 일을 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
19. 건강에 문제가 있어도 생필품 구입과 같은 해야만 하는 일을 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
20. 건강에 문제가 있어도 나의 취미활동이나 여가 활동을 계속 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

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Appendix 11. Survey questionnaire (continued)

문 항	전혀 할 수 없다 ◀ ——— ▶ 매우 잘 할 수 있다
21. 건강에 문제가 있어도 친구나 가족과 함께 해보고 싶은 일을 계속 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
22. 나의 신체적 불편감이나 통증을 감소시킬 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
23. 질환으로 인한 피로감이 내가 해보고 싶은 일을 방해하지 않도록 조절할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
24. 질환으로 인한 신체적 불편감이나 통증이 내가 해보고 싶은 일을 방해하지 않도록 조절할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
25. 내가 하고 싶은 일을 방해하는 다른 증상이나 신체적 문제를 조절할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
26. 나는 내가 하고 싶은 일을 방해하지 않도록 어떤 증상이나 신체적 문제를 해결할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
27. 내 힘으로 할 수 있는 것이 하나도 없다고 생각이 들어도 주눅들지 않을 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
28. 슬럼프에 빠지거나 슬픈 생각으로부터 벗어날 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
29. 외롭다는 감정으로부터 벗어날 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
30. 외롭다고 느낄 때 내 기분을 풀어주기 위해 무엇인가를 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
31. 주눅이 들 때 내 기분을 풀어주기 위해 무엇인가를 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩
32. 슬픈 생각이 들거나 슬럼프에 빠졌을 때 내 기분을 풀어주기 위해 무엇인가를 할 수 있다.	① ② ③ ④ ⑤ ⑥ ⑦ ⑧ ⑨ ⑩

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Appendix 12. The Korean version of final self-management scale for patients with liver cirrhosis (21 items)

요인 (문항수)	문 항	전혀 그렇지 않다 ←				→ 항상 그렇다
증상관리 (6)	1. 나는 복수나 부종의 발생을 모니터링 하기 위해 규칙적으로 체중(혹은 복부둘레)을 측정한다.	1	2	3	4	5
	2. 나는 복수가 차면 염분을 제한하여 섭취하고자 한다.	1	2	3	4	5
	3. 나는 잇몸출혈을 예방하기 위해 부드러운 칫솔모를 사용한다.	1	2	3	4	5
	4. 나는 건조하거나 가려운 피부관리를 위해 옷을 헐렁하게 입거나 처방된 로션을 바른다.	1	2	3	4	5
	5. 나는 배변 시 혈변(붉은색 혹은 검은색)이 있는지를 확인한다.	1	2	3	4	5
	6. 나는 복수가 차면 물 섭취량을 줄인다.	1	2	3	4	5
간경변증 특이적 생활습관 관리 (5)	7. 나는 날 것이나 오염된 음식을 피하고 익힌 음식을 먹는다.	1	2	3	4	5
	8. 나는 3-4시간 간격으로 소량의 음식을 자주 섭취한다.	1	2	3	4	5
	9. 나는 배변을 원활하게 하기 위해 채소나 과일 등 섬유질이 있는 음식을 섭취한다.	1	2	3	4	5
	10. 나는 피로가 느껴지면 충분히 쉰다.	1	2	3	4	5
	11. 나는 술을 마시지 않는다.	1	2	3	4	5
일반적 생활습관 관리 (4)	12. 나는 식사를 규칙적으로 한다.	1	2	3	4	5
	13. 나는 매 끼니마다 고기, 생선, 두부, 계란, 해산물 등의 음식을 탁구공(8g정도) 2-3개 정도의 크기로 섭취한다.	1	2	3	4	5
	14. 나는 매일 충분히 잔다.	1	2	3	4	5
	15. 나는 규칙적으로 운동을 한다.	1	2	3	4	5
의학적 치료이행 (3)	16. 나는 간경변증 관리를 위해 정해진 날짜를 지켜 정기적으로 병원 진료를 받는다.	1	2	3	4	5
	17. 나는 처방 받은 약물을 투여 목적과 용량에 맞게 복용한다.	1	2	3	4	5
	18. 나는 간경변증과 관련된 신체적 변화가 생겼을 때, 병원 진료를 받는다.	1	2	3	4	5
가족지지 (3)	19. 나의 가족은 간경변증과 관련된 일상생활 관리에 도움을 준다.	1	2	3	4	5
	20. 나의 가족은 간경변증과 관련하여 나의 의식 상태를 인지할 수 있다.	1	2	3	4	5
	21. 나는 나의 가족을 통해 정서적으로 지지를 받는다.	1	2	3	4	5

KOREAN ABSTRACT

간경변증 환자의 자가관리 측정도구 개발

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간경변증은 대표적인 만성 간질환의 하나로 치명적인 합병증을 가진 질환으로 알려져 있다. 간질환의 원인을 치료하는 약물들의 개발로 인해 간경변증의 사망률이 줄어들고 있지만, 그 발생율은 여전히 증가하고 있다. 뿐만 아니라, 간경변증은 대상성 상태에서 비대상성 상태로 악화되면 간경변증으로 인한 심각한 합병증이 발생하여 환자의 예후와 생명에 위협을 초래한다. 환자의 적극적 참여로서의 자가관리는 간경변증 환자가 자신의 삶과, 건강, 그리고 안녕을 유지하고 개선하는데 중요하다. 그런데, 기존에 이러한 자가관리를 측정하는 도구들이 부족하여 본 연구는 간경변증 환자들이 일상생활에서 자신의 질환을 잘 관리할 수 있는 방안을 마련하기 위해 먼저 이들의 자가관리의 수준을 측정하기 위한 자가관리 측정도구를 개발하고 그 타당성을 평가하고자 하였다.

본 연구는 방법론적 연구로서 DeVellis가 제시한 도구개발과정을 기반으로 하여 서울에 있는 세브란스병원의 간경변증 환자를 대상으로 하여 도구개발과 평가의 2단계로 분류되는 총 8개의 과정으로 진행되었다. 도구개발 단계에서는 선행문헌 고찰과 간경변증 환자 10명을 대상으로 한 심층면담을 통해 초기 문항을 개발하였다. 이 문

항들은 2022년 6월에서 7월 기간 동안 세브란스병원의 전문가 10명에게 내용타당도 평가를 받고 간경변증 환자 20명을 대상으로 한 사전조사의 결과를 바탕으로 수정, 보완되어 33문항의 초기 자가관리 도구로 개발되었다. 도구평가 단계에서는 개발된 도구의 구성타당도 평가를 위해 간경변증 환자 169명을 대상으로 탐색적 요인분석을 실시하여 최종 도구의 요인과 문항을 구성하였고, 그 결과를 바탕으로 126명 간경변증 환자의 자료로 확인적 요인분석을 하여 도구의 모델 적합도를 확인하였다. 타당도가 평가된 도구는 Cronbach's α 계수와 만성질환 자기효능감 도구와의 동시타당도 평가를 통해 신뢰도를 검정하였다.

초기 자가관리 도구의 33문항은 문항분석 과정을 통하여 25문항이 선택되었다. 이 문항들은 탐색적 요인분석을 통해 5개 요인 21문항으로 추출되었으며 61.1%의 설명력을 나타내었다. 5개 요인은 증상관리 6문항, 간경변증 특이적 생활습관 관리 5문항, 일반적 생활습관 관리 4문항, 의학적 치료이행 3문항, 가족지지 3문항이었다. 확인적 요인분석 결과, 5개 요인으로 구성된 모델의 지표값 RMSEA는 0.059, SRMR은 0.070이었고, 각 요인 간의 상관관계 계수는 0.33-0.58의 범위로 나타났다. 동시타당도는 상관계수 0.47($p<.01$)이었으며, 도구의 전체 신뢰도 Cronbach's α는 0.90이었다.

간경변증 환자의 자가관리 도구는 5개 요인 21개 문항으로 최종 개발되었으며 5점 리커트 척도로 평가한다. 본 연구에서 개발된 자가관리 도구는 연구의 결과를 통해 그 타당도와 신뢰도가 확인되었다. 따라서, 개발된 간경변증 자가관리 도구는 간경변증 환자의 자가관리 수준을 규명하고 이들의 자가관리 행위를 향상시킬 수 있는 중재전략을 개발함에 있어 활용될 수 있을 것이다.

핵심되는 말: 간경변증, 자가관리, 도구개발, 내용타당도, 구성타당도, 탐색적 요인분석, 확인적 요인분석