

RESEARCH ARTICLE

A qualitative study of self-management experiences in people with non-alcoholic fatty liver disease

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Abstract**Aim:** The aim of the study was to explore the experiences of self-management in patients with non-alcoholic fatty liver disease (NAFLD).**Design:** The study employed an exploratory descriptive qualitative study using focus group interviews.**Methods:** Twelve participants with NAFLD were recruited from a university hospital in South Korea. The date of data collection was from November–December 2018, and the data were analysed using Braun and Clarke's thematic analysis.**Results:** Three themes and seven subthemes were identified. The themes were (1) facing unexpected obstacles, (2) finding my own path and (3) unmet support needs from healthcare providers. Subthemes included (1) ambiguity in changing lifestyle, (2) confusion caused by inconsistent information overload, (3) not knowing much about the liver nor NAFLD, (4) putting small plans into action every day, (5) getting help from family and friends as care partners, (6) needs for tailored medical help and (7) needs for caring and attentive attitudes.**KEYWORDS**

non-alcoholic fatty liver disease, qualitative research, self-management

1 | INTRODUCTION

Non-alcoholic fatty liver disease (NAFLD), which is characterized by excessive fat accumulation in the liver in people without excessive alcohol use, affects approximately one fourth of the global and South Korean populations (Araujo et al., 2018; Bellentani, 2017; Kwak & Kim, 2018). Once NAFLD has progressed, it is irreversible and can lead to liver fibrosis, cirrhosis or hepatocellular carcinoma (European Association for the Study of the Liver, 2016). The progression of NAFLD not only imposes a clinical burden on patients but also affects their survival rate and quality of life (Perumpail et al., 2017; Younossi & Henry, 2015). A recent study reported NAFLD-related cirrhosis and hepatocellular carcinoma as the second leading cause of liver transplantation in the United States (Bellentani, 2017).

Further, studies have demonstrated that people with NAFLD have a higher mortality rate than the general population (Bellentani, 2017; European Association for the Study of the Liver, 2016).

Unlike alcoholic fatty liver disease, for which the main risk factor is excessive alcohol consumption, risk factors for NAFLD include obesity, dyslipidaemia and type 2 diabetes. However, in the absence of a pharmacological therapy, NAFLD treatment is focused on metabolic profile improvement (Araujo et al., 2018; Bellentani, 2017). Clinical guidelines for managing NAFLD emphasize lifestyle modification, which includes a low-calorie diet; lower intake of refined carbohydrates, fat and sugar; and increased physical activity (European Association for the Study of the Liver, 2016; Katsagoni et al., 2017). This suggests that patients with NAFLD require lifetime disease monitoring and management.

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2 | BACKGROUND

Self-management is the ability to engage in health-promoting behaviours and deal with one's own health problems (Lorig & Holman, 2003; Schulman-Green et al., 2012). It improves not only disease-related physiological outcomes but also other health-related outcomes, such as anxiety, depression and quality of life (Lin et al., 2017). Moreover, it may prevent hospital admissions and emergency department visits (Wang et al., 2017), which could reduce excessive medical costs.

However, it is challenging for people with long-term diseases to change and maintain health behaviours. Thus, the role of healthcare providers (HCPs) is crucial in this regard. HCPs provide patients with basic health information and instructions on management of the disease, help them overcome difficulties in disease management and encourage them to continuously sustain health behaviours (Westland et al., 2018). To do so, HCPs need to understand how people are managing their disease, solving problems and making relevant decisions in everyday life (Shirazian et al., 2016). Although self-management and lifestyle modification is the first-line therapy for NAFLD, studies have not focused much on the experiences of self-management in this population. An exploration of self-management experiences in people with NAFLD would yield valuable insights, facilitating the provision of better support from HCPs.

The purpose of this study was to explore self-management experiences in people with NAFLD, with emphasis on issues about self-management. The research question was, "How do people with NAFLD manage their disease in everyday life?"

3 | METHODS

3.1 | Design

This was an exploratory descriptive qualitative study using focus group interviews (FGIs). FGIs are conducted to gain insight into participants' experiences and perceptions about a topic (Nyumba et al., 2018). They allow people to express their thoughts more comfortably and freely, just as in real life (Tausch & Menold, 2016). Thus, they provide rich qualitative data that can widen our understanding of the topic from participants' freely shared experiences. The FGI methods were deemed appropriate for this study because patients

could have been reluctant to share their self-management experiences or unmet needs from HCPs in individual interviews with investigators, who are HCPs themselves. Study reporting was based on the COnsolidated criteria for REporting Qualitative research guidelines (Tong et al., 2007).

3.2 | Participants

Twelve people with NAFLD were recruited from the liver centre of a university hospital in Seoul, South Korea. The inclusion criteria were (1) above 19 years and (2) having been diagnosed with NAFLD for at least 6 months. We selected patients who had been diagnosed at least 6 months previously because it was believed that they would have a better understanding of self-management and could offer deeper insight into such experiences than newly diagnosed patients. The exclusion criteria were (1) hepatitis B or C virus carriers, (2) diagnosis of secondary NAFLD and (3) diagnosis of liver cirrhosis. This was because the standard treatment of liver virus, secondary NAFLD and liver cirrhosis differs from that of primary NAFLD.

Physicians reviewed the list of patients who were scheduled to visit the outpatient clinic and selected those who met the criteria. They then explained the purpose of the study to eligible patients; those who were interested met the research assistant in the next room, where they were provided with a detailed explanation about the study and the interview process. Only those who were willing to participate were provided with consent forms, and the research assistant arranged the interview schedule based on participants' preferences.

Forty-seven patients met the research assistant at the outpatient clinic, of whom 35 refused to participate for the following reasons: physical distance from the clinic ($N = 12$), busy schedule ($N = 9$), not feeling well ($N = 8$) and did not feel like it ($N = 6$).

3.3 | Data collection

Three FGIs were conducted from November–December 2018. The number of participants in each focus group ranged from two–six. The groups were assigned in a way that would ensure members' heterogeneity in terms of gender, age and time since diagnosis to facilitate the sharing of broad experiences and more

Question types	Sample question
Starting question	Could you introduce yourself?
Introductory question	How long have you been diagnosed with NAFLD?
Key questions	How do you manage your NAFLD? What were your experiences of self-management of NAFLD? How do you want your healthcare provider to help you?
Ending question	Is there anything you would like to talk more concerning managing NAFLD?

TABLE 1 Interview guide

Abbreviation: NAFLD, non-alcoholic fatty liver disease.

collective views (Nyumba et al., 2018). The investigators were two physicians (male), one nursing professor (female) with a PhD and a doctoral student (female) with an MSN degree, and the interviews were conducted by a nursing professor and a doctoral student. The investigators developed an interview guide with semi-structured questions based on Krueger and Casey's guide (2014) (Table 1). The interviews took place in a quiet and private conference room. The investigators greeted the participants upon their arrival, introduced themselves and reminded them about the study purpose, the FGI method and the role of the moderator. All participants agreed to have the interviews audio-recorded. Memos were taken to capture the context, situation and atmosphere during the interview, and thoughts that came to mind. Interviews were conducted until data saturation was reached, and no additional codes were identified. The duration of each interview was approximately 70 min, after which the investigator briefly summarized the results to the interviewees. One investigator transcribed the interview recording files. Credibility was ensured by using investigator triangulation in data collection and the analysis process, and by summarizing the discussion at the end of every interview. Additionally, we tried to achieve transferability by using a thick description of the findings.

3.4 | Data analysis

The data were analysed using thematic analysis, as outlined by Braun and Clarke (2006). Thematic analysis is the process of identifying and organizing meaningful themes in the data. Six phases guided the analysis process: (1) getting familiar with the data, (2) generating the initial codes, (3) searching for themes, (4) reviewing the themes, (5) defining and naming the themes and (6) producing the report. The investigators independently read the transcripts several times to get an overview of the content and understand its meaning. The first investigator coded the data by comparing the content of the interviews. Thereafter, the second investigator reviewed the codes. Subthemes were identified from categories with similar codes, which represented similar results, and the relationships among themes were considered. The investigators reviewed the codes in each theme to verify their relevance; repeated discussions were conducted until a consensus was reached. Subsequently, distinct theme names were finalized.

3.5 | Ethical considerations

This study was approved by the Institutional Board of Research of Severance Hospital, Seoul (No. 4-2018-0867). The researcher provided the participants with an explanation about the FGI method, process of data collection, expected benefits and possible harm. The participants were also informed about their right to withdraw from the study at any time. Their anonymity and confidentiality were ensured throughout the study.

TABLE 2 Participants' general characteristics

No.	Gender	Age (years)	Marital status	Length of diagnosis
1	Man	27	Not married	8 months
2	Man	51	Married	10 years
3	Man	40	Not married	6 years
4	Woman	69	Married	2 years
5	Woman	60	Not married	10 years
6	Woman	57	Married	>10 years
7	Woman	74	Married	3 years
8	Woman	33	Not married	3 years
9	Woman	66	Married	2 years
10	Man	70	Married	20 years
11	Man	62	Married	20 years
12	Woman	43	Married	10 years

4 | RESULTS

In this study, 60% of the participants were women, and the mean age was 53.8 ± 15.1 years (Table 2). Table 3 shows the themes and subthemes. Three themes and seven subthemes were identified from 127 codes. The major themes include: (1) facing obstacles, (2) finding my own path and (3) unmet support needs from HCPs.

4.1 | Facing unexpected obstacles

Although doctors had informed the participants about the importance of managing NAFLD, they did not receive personalized instructions from HCPs, especially about diet and exercise. Thus, they independently attempted to improve their lifestyles by taking food and dietary supplements, but the information from various sources was too overwhelming and inconsistent. From the accounts of most participants, it was evident that they did not know about the diseases and their conditions to improve their liver condition. This caused participants to experience confusion and frustration in the process of managing their NAFLD.

4.1.1 | Ambiguity in changing lifestyle

The participants thought that the HCP's instructions were too general and ambiguous. They did not know the criteria for and optimal extent of health-promoting behaviours, such as the degree to which to restrict their calorie and carbohydrate intake, and the amount of exercise and weight loss required. This provoked uncertainty in participants, especially those who had been relatively recently diagnosed.

All they (HCPs) say is 'lose weight' and 'exercise'. It's not like they say 'You have to jog for 45 minutes, at

TABLE 3 Themes and subthemes

Theme	Subtheme
Facing unexpected obstacles	1) Ambiguity in changing lifestyle 2) Confusion caused by inconsistent information overload 3) Not knowing much about the liver nor NAFLD
Finding my own path	1) Putting small plans into action every day 2) Getting help from family and friends as care partners
Unmet support needs from HCPs	1) Needs for tailored medical help 2) Needs for caring and attentive attitudes

Abbreviations: HCP, healthcare provider; NAFLD, non-alcoholic fatty liver disease.

least four times a week'. It is not specific. (...) 'Eat less carbohydrates', but I don't know how much 'less carbohydrates' is. Does that mean no carbohydrates at all? Or half the amount I eat during mealtime? It's very broad and obscure.

The doctor told me to exercise, but that was all. So, I just go to the gym five times a day and do aerobic exercise for one hour, but I am not sure if I am doing it right.

4.1.2 | Confusion caused by inconsistent information overload

As participants were faced with ambiguity about how to manage NAFLD, they independently tried to seek information about food or dietary supplements for a healthy liver from various sources, including TV programmes on health issues, newspaper articles, online consumer health information, websites, blogs and other people. The more they sought information, the more they were puzzled by the information overload and its inconsistencies.

You turn on the TV, and let's say five channels are broadcasting about managing NAFLD, saying eat this, eat that. What's funny is that each channel is recommending different food. How do I know which one to follow? Do I have to listen to all of them?

I took milk thistle every day because my daughter told me it was good for my liver, you know, from the internet. But then 'wolfberry' came up. Other friends say wolfberry is good for your liver too; I ordered and began taking wolfberry. What is next? There's too much information.

One blog says people with NAFLD should do aerobic, another blog says we should do resistance exercise, and the third blog says 'Do both exercises'. It's all different!

4.1.3 | Not knowing much about the liver or NAFLD

The participants shared that they did not know much either about the functions of the liver or about the NAFLD. They could not determine what was important in NAFLD management in their everyday decision-making and did not know what to ask or refrain from asking their HCPs. Some participants got prescriptions at a local clinic for minor health problems; however, they did not tell the local clinic doctor or pharmacist that they had been diagnosed with NAFLD or ask about liver toxicity of the prescribed medications because they did not know that these details could be relevant to the management of their disease.

[After another participant mentioning the liver toxicity of Tylenol], I did not know it could be fatal! Nobody told me. A patient doesn't know medication can affect the liver. We don't have background knowledge. We don't even know what to ask them (HCPs)!

Last month, I told my doctor that I was managing NAFLD with a special recipe. He told me never to drink it because it is almost the same as eating potatoes every day. I was so shocked! I had been having it for years! I did not know that I should have asked him because it's... it's something healthy, you know? It's like there are so many things I don't know about the disease.

Once, because of rhinitis, I had medication prescribed at a small clinic. I had it for a couple of weeks, then at my follow-up visit, my doctor was surprised by the test results and asked me if I was taking any medication. I told him about rhinitis. Until then I hadn't known that I had to be careful about other medications.

4.2 | Finding my own path

Although participants encountered many difficulties in managing NAFLD at first, most of them found their own ways. Participants autonomously set and strictly followed their own rules concerning

dietary habits and exercise. Moreover, their family and friends played an essential roles in supporting their self-management in practical ways.

4.2.1 | Putting small plans into action every day

Some participants set their own goals and enforced small rules on themselves in managing NAFLD. The plans each participant had were quite specific, such as whenever going to the grocery store, no driving but walking, staying off salty seasoning or never missing routine check-ups of the liver every 6 months. These were the ways they coped with NAFLD in their everyday lives.

I try not to eat salty foods, like hot soup. Korean foods are all salty, right? We always eat kimchi, but kimchi is also salty. So, I eat white kimchi (kimchi without red pepper powder) only—the less salty one—or, you could take off the salty seasoning before you eat.

I work out in the gym for five hours a week. I set this rule for myself. If I don't go to the gym during weekdays, I work out on weekends and make it five hours a week in total.

I intentionally get off the bus one or two stops before my stop and I walk, or I walk one or two bus stop distances before taking the bus. If you check the pedometer on your cellphone, you get to walk a lot.

4.2.2 | Getting help from family and friends as care partners

Self-management was not maintained through the individual's efforts alone. As care partners, family members and friends not only facilitated in helping them manage NAFLD but also actively participated in patients' self-management practices. They motivated and encouraged the participants, and gave practical support including giving them health information or buying dietary supplements. However, some suggestions of health information from family members or close friends turned out to be unhelpful. When they recommended dietary supplements that are not medically proven, it could be detrimental to participants' liver condition.

My wife cares more about my disease (NAFLD) than I do. She always prepares a healthy meal—less carbohydrates, less salt—and reminds me about my follow-up visit schedule.

After 6 pm, my family never says things like, 'Mom, this is yum, try it', or 'Honey, try this bread'... They even try not to eat much after 6 pm because of me.

No cookies, no snacks. They know I should restrict carbohydrates and lose weight.

My friend suggested riding bicycles together for my liver. We live nearby, so after getting off work, we go to Han River Park. We get fresh air, chat, and ride bicycles when we go out to the park. This helped me lose a lot of weight.

One day, mom talked with the next-door neighbor, got the phone number of the seller of some dietary product, and made me take it for my liver. In the next clinic visit, my lab results showed a drastic increase, and the doctor found out that I had been taking a product which was not good for my liver.

My son-in-law bought me red ginseng extract, and... [Interrupted by another participant, "You should not eat it! It might be a burden to your liver!"] Really? I didn't know that... But my son-in-law bought it for me.

4.3 | Unmet support needs from HCPs

The participants shared that they could manage NAFLD better when they had more support from HCPs. High levels of unmet needs from their HCPs were identified, especially concerning their difficulties in managing NAFLD. They were concerned about not having received specific instructions or guidance. They wanted tailored medical help in managing their NAFLD, with an attentive and caring attitude from HCPs.

4.3.1 | Needs for tailored medical help

The participants were finding their own ways of managing their NAFLD, but at the same time, they were still unsure if they were managing their condition right. One participant said that he was only assuming that his self-management strategies are not bad because laboratory results and the liver fibrosis score were not getting worse. What participants wanted were specific and tailored guidance from their HCPs, and reliable health information.

They (HCPs) should tell patients things like, [pointing to one participant] 'Your condition right now is, I don't know, blah blah, so you should lose 5 kg', or [pointing to another participant] 'You are now 67 kg, and your state is blah blah, so you should lose 3 kg'.

What I really want from the hospital is a detailed menu, maybe even for a week; for today's breakfast, have this, for lunch, have that. It can be different

based on the patient's age, or health condition...or whatever, so something (menus or recipes) for me.

Doctors know their patients' health conditions best. I want them to tell me things like 'You are in your 60s and you have arthritis in your knees, so swimming is better than jogging'

4.3.2 | Needs for caring and attentive attitudes

The participants wanted their HCPs to display a caring attitude. They said that HCPs are only interested in test results, not them. They emphasize lifestyle modification but do not actually care much about how participants were managing the disease in their daily lives. Some participants even complained about not getting a sufficient explanation of their test results or their health condition and said that they were not much cared for by their HCPs.

We all visit the clinic once in six months. If the doctors or nurses would ask me specifically how I have been managing NAFLD every time I visit the clinic, I could tell them how I have been doing so far. Then I would be very motivated, but they don't ask me much.

They (HCPs) always tell me, 'You need to exercise, you need to do this and that', but they are not really interested in what I am doing to manage my liver condition.

I am the one who always asks the doctor about my condition. I ask, 'How are my test results?' and then the doctor says things like, 'A little better than the last test results', or 'similar to the last results'. I feel like they only focus on test results.

5 | DISCUSSION

To the best of our knowledge, this is the first study to explore self-management experiences in people with NAFLD. Based on the results about participants' experiences, there are three key points to discuss: (1) experiencing ambiguity about self-management, (2) having family members as care partners and (3) support needs from HCPs about tailored education and attentive attitudes.

Participants found their own ways of managing NAFLD in their daily lives, but this is not to say that they did not face obstacles. The difficulties arose mostly because they considered the self-management guidance provided by HCPs too generic and lacked knowledge about the disease. Previous studies with people with other long-term diseases have also reported ambiguity, confusion and frustration owing to a lack of specific guidance in managing the disease (Dwarswaard et al., 2016; Murphy et al., 2015). Also, given

their lack of medical knowledge, information overload might have aggravated patients' uncertainties.

Interestingly, for most of the participants, their family members acted as care partners. Care partners differ from caregivers in that patients are actively involved in the care dyad (Bennett et al., 2017). Cultural backgrounds may be closely related to this tendency of family and friends to be deeply concerned about and involved in a patient's health management. East Asian countries are characterized by family-centred cultures, in which the family plays a statistically significant role in a patient's self-management behaviour (Chen et al., 2016; Wah et al., 2019). Moreover, in South Korea and China, people traditionally view healthy food as medicine, which can boost one's health (Kyung Chung, 2015; Lee, 2014; Li-Geng et al., 2020). These cultural aspects result in family members or close friends trying to facilitate the patient's self-management, mostly by buying dietary supplements or healthy foods.

However, as they are not medical professionals, the information received from family members may not be evidence-based or medically proven, and dietary supplements could actually have serious hepatotoxic effects (Massart et al., 2017). These findings reveal that, particularly in family-oriented cultures, HCPs must seek to go beyond simply involving family members in patient self-management education. They should, instead, educate patients and family members about how inaccurate information could cause a patient's condition to deteriorate and the importance of consulting a doctor about any health information that is encountered.

The participants had a high level of unmet needs about tailored self-management interventions. Tailored self-management intervention refers to the provision of detailed health information and guidance, such as the optimal frequency, intensity, and duration of exercise or the allowed carbohydrate intake. HCPs should thoroughly assess every dimension that could possibly have an impact on a patient's lifestyle or self-management behaviours: the intrapersonal, such as demographic and clinical characteristics, health literacy or educational level; interpersonal, including family dynamics and support systems; environmental, including physical surroundings, situations and cultural factors; and participants' preferences and needs. This is because a person's lifestyle is the result of the interaction between individual, familial, group, cultural and societal factors (Spacey, 2018). This aligns with the holistic approach in nursing, which views a person as a whole that interacts with the environment (McEvoy & Duffy, 2008). Individually tailored self-management education could reduce people's ambiguity about self-management, help set more specific and achievable goals and facilitate their implementation.

Another finding was the participants' need for HCPs to display caring attitudes. The important aspects of self-management in people with long-term diseases include control, empowerment and confidence (Hoffman, 2013). Displays of attentiveness and genuine interest from HCPs are known to be essential to supporting patients' self-management and empowering them (Salemonsens et al., 2020). Empowerment is a particularly statistically significant issue in the context of people with NAFLD for several reasons. Owing to the

lack of physical symptoms, people with NAFLD tend not to perceive the disease as very threatening or severe, and the perception of the illness influences management behaviour.

Moreover, the fact that pharmacological treatment for NAFLD has not yet been developed might lower participants' confidence in managing their disease. HCPs' being attentive involves not only monitoring liver function parameters but also closely assessing self-management behaviours with a validated tool during each follow-up visit and providing concrete feedback about health behaviours. This will serve to motivate patients to sustain advisable self-management behaviours in living with NAFLD, which will, in turn, increase their self-efficacy (Hoffman, 2013; Nicolai et al., 2018; Salemonsens et al., 2020). Thus, HCPs can enhance patients' implementation and maintenance of optimal health behaviours by closely assessing and providing feedback on self-management behaviours.

5.1 | Limitations

Despite the importance of the findings, this study has certain limitations, the first of which is the small sample size. Second, a pilot study for the interview guide and dissemination of the findings was not conducted owing to the timeline of the study. Third, the severity of NAFLD and the period after diagnosis were not considered. We suggest that future studies seek to explore self-management in people with NAFLD from different cultural contexts and settings and by accounting for disease severity, which may improve the transferability of the findings. A study exploring the difference in perceptions about NAFLD self-management between HCPs and patients should be conducted to understand the gap between the two stakeholders and develop tailored interventions for improving health outcomes in this population.

6 | CONCLUSION

This qualitative study unveiled the experiences of self-management in people with NAFLD. Although individual participants had their own strategies for self-management, they faced uncertainties because of the provision of overly general self-management education from HCPs and were puzzled by the vast amount of health information obtained from other sources, including the Internet, family or friends. Also, they desired their HCPs to display attentive attitudes and care about their self-management behaviours.

7 | RELEVANCE TO CLINICAL PRACTICE

This study informs HCPs about the self-management experiences and unmet needs of patients with NAFLD. The findings might provide meaningful insights into the optimal care of patients with NAFLD, and the pivotal role of HCPs in educating and guiding patients and

enhancing their self-management behaviours, particularly in family-centred cultures.

Lack of individualized guidance in lifestyle modification might provoke uncertainty and frustration in people with long-term diseases. HCPs should provide concrete and tailored self-management education considering the interpersonal, environmental and cultural factors that could affect self-management behaviours. This study could serve as the foundation of efforts to carefully design and implement tailored self-management intervention programmes for people with NAFLD or other long-term diseases. Also, it is important to involve statistically significant others in patient care, but HCPs need to guide them about the best ways to offer support, particularly in family-oriented cultures. This is because family members or close friends try to help patients in their own ways, but some efforts, including the provision of invalidated health information or dietary supplements, might not only prove unhelpful but may even cause harm. Therefore, HCPs' consideration of cultural background might be essential for providing safe and effective patient care. Moreover, HCPs need to display caring attitudes and build a therapeutic relationship with patients. Regular assessment and detailed feedback on health behaviours may be an overarching approach in helping foster lifelong health behaviours among patients with NAFLD.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest.

DATA AVAILABILITY STATEMENT

Author elects to not share data.

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