Exploring self-management in patients with liver cirrhosis and the role of eHealth and wearable technologies

A mixed method study

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A. (Amber) Westendorp

Under supervision of prof.dr.ir. R.M. (Ruud) Verdaasdonk, dr. S.M. (Stéphanie) van den Berg, dr. M.M.J. (Maureen) Guichelaar (MST) & dr. W.J. (Willem) van den Brink (TNO)

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Abstract

Background: Liver cirrhosis is a progressive disease that leads to liver dysfunction and serious complications, with decompensated cirrhosis posing significant risks to health. Self-management, including lifestyle changes, is essential for improving patient outcomes. However, challenges such as limited disease knowledge and psychological barriers hinder effective management. Emerging eHealth technologies and wearables offer potential solutions by enabling continuous monitoring and personalized support. Despite their promise, research on their impact for liver cirrhosis patients is limited. This study explores how eHealth and wearables can enhance self-management and examines the attitudes of patients and healthcare professionals toward their use.

Methodology: This research employed an observational design with a mixed-methods approach. The qualitative component involved semi-structured interviews with six patients and six healthcare professionals. Participants were recruited via specialists and nurse practitioners during outpatient visits and provided informed consent. The interviews explored attitudes toward self-management, eHealth, and wearables, using validated tools such as the Self-Management Screening Instrument (SeMas). The results of the interviews informed the development of a survey, administered through the Dutch Liver Patient Association (NLV), targeting patients with self-reported liver diseases. Survey data included demographics, disease-specific factors, quality of life (measured using the SF-12), and self-management levels (measured using the PAM-13). Statistical analyses, including descriptive statistics and Independent Samples t-tests, were conducted using SPSS to explore differences across subgroups.

Results: The study involved 188 participants, of whom 80 (43%) were diagnosed with liver cirrhosis. Among the liver cirrhosis group, 57 (71%) had compensated cirrhosis, and 23 (29%) had decompensated cirrhosis. The results revealed that while patients with liver cirrhosis recognize the importance of self-management, they face significant challenges, including low health literacy, financial barriers, and difficulty in maintaining lifestyle changes. The majority of patients expressed a desire for greater control over their health and showed a strong interest in eHealth and wearable technologies to support self-management. However, the adoption of these tools remains limited, with cost and lack of awareness being primary barriers. Healthcare professionals viewed eHealth and wearables as valuable tools for enhancing patient autonomy but emphasized the need for education and tailored support to avoid data overload and promote effective use. The analysis revealed that self-management and attitudes towards eHealth and wearables were shaped by factors such as disease severity, gender, and education, highlighting the need for tailored interventions.

Conclusion: Improving self-management in patients with liver cirrhosis requires a comprehensive approach that enhances education, addresses challenges such as low health literacy and difficulty maintaining healthy lifestyles, and provides structured support. Patients expressed a strong need for more information and better access to resources and guidance. EHealth and wearables hold significant potential to improve self-management among liver cirrhosis patients by offering real-time feedback, motivation, and structured support. While patients are generally willing to adopt these tools, barriers such as cost, privacy concerns, and usability must be addressed. Healthcare professionals highlight the importance of integrating these technologies into care plans with proper guidance to maximize their benefits. Future research should focus on developing personalized interventions, addressing barriers to adoption, and evaluating the long-term impact of these technologies on health outcomes and patient empowerment.

Contents

1. Introduction

Liver cirrhosis is a chronic condition caused by inflammation and fibrosis of the liver, leading to the replacement of normal liver architecture by fibrosing noduli. This slow process disrupts blood flow and hepatocellular function, progressing from an asymptomatic phase (compensated cirrhosis) to a symptomatic phase (decompensated cirrhosis). Decompensated cirrhosis is characterized by complications such as ascites, variceal bleeding, hepatic encephalopathy and non-obstructive jaundice [1,2,3]. Only one-third of individuals with cirrhosis are aware of their condition and it is a significant contributor to global morbidity and mortality, accounting for 2.4% of total deaths in 2019. The Global Burden of Disease (GBD) Study estimates 112 million cases of compensated cirrhosis and 10.6 million cases of decompensated cirrhosis (in 2017) worldwide. Most common causes include hepatitis B and C, alcohol-associated liver disease and metabolic dysfunction-associated steatotic liver disease (MASLD), previously known as NAFLD [4]. MASLD, characterized by ≥5% hepatic fat accumulation in non-alcoholic individuals, is linked to obesity, dyslipidemia and type 2 diabetes. MASLD is the leading cause of chronic liver disease, with an incidence of 20 per 10,000 person-years and significantly impacts mortality, survival and quality of life while also affecting extra-hepatic organs and pathways [5,6,7].

Self-management, including lifestyle changes, is the primary recommendation for patients with MASLD. Determining and enhancing the self-management of patients with chronic liver diseases is essential, enabling healthcare professionals to provide personalized interventions that improve health outcomes [8]. Self-management is defined as the care individuals take to maintain their health and wellbeing, which includes leading a healthy lifestyle, addressing social, emotional, and psychological needs, managing long-term conditions and preventing further illness or accidents [13]. For liver cirrhosis, self-management involves gaining knowledge about the disease, addressing symptoms, adhering to prescribed regimens, attending routine follow-ups and communicating with healthcare professionals. Improving self-management in liver cirrhosis patients requires increasing their knowledge about the disease and its management, as inadequate knowledge is linked to more complications [9].

EHealth, characterized as health services and information delivered or collected through the Internet and related technologies, represents a promising tool for improving self-management [11]. Despite its growing application in healthcare, there is limited research on the impact of eHealth and wearables on self-management for patients with liver cirrhosis.

This study broadly aims to explore the potential for improving self-management in patients with liver cirrhosis and to understand the attitudes of these patients and healthcare professionals towards eHealth and wearables.

2. Theoretical framework

2.1 Self-management in chronic liver disease

Unlike most chronic diseases, liver cirrhosis develops after a long asymptomatic period of fibrosis progression, with the condition becoming more severe. This makes it difficult to monitor and manage on a day-to-day basis [10]. Changing lifestyle behaviour is not easy, the majority of patients have not yet reached their goal, difficulties are related to sustainability of compliance, social support or time and place constraints [11]. The literature on lifestyle modification in patients with MASLD is limited by strong heterogeneity, both in the population studied and in the lifestyle intervention itself. As a result, the optimal lifestyle modification for patients with MASLD remains unknown. With the prevalence of MASLD expected to increase to over 20% by 2030, there is a clear unmet need to determine the most effective lifestyle modification to reduce the large global public health burden of this common disease [12].

In order to improve quality of care and quality of life, and to contain healthcare costs, there is a strong emphasis in current guidelines and standards of care on improving self-management in people with chronic conditions [13]. Self-management is the ability of individuals to manage their symptoms, treatment, physical and psychological effects and lifestyle changes. Self-management plays an important role in improving the condition of many chronic diseases. Self-management allows patients to control or reduce the impact of the disease on their physical health status by better coping with psychological problems and adapting their daily health-related behaviours. Self-efficacy, defined as one's belief in one's ability to perform behaviours to achieve a specific goal, is an essential component of self-management in chronic disease. It helps to facilitate self-management and determine its sustainability when patients face barriers caused by their condition. In addition, it can lead to beneficial changes in health behaviour through goal setting and self-monitoring [11].

The results of a cross-sectional study showed several significant factors related to the level of self-management in patients with liver cirrhosis. Patients' psychological status, disease severity and self-efficacy were predictors of self-management behaviours. To facilitate self-management, it is therefore important to reduce depression and increase self-efficacy. In addition, knowledge about self-management needs to be increased and patients need help to cope with the stress associated with their illness [9]. Given the importance of these factors, assessing disease knowledge and self-management in patients with liver cirrhosis is crucial. However, there’s a notable gap in the literature regarding validated instruments specifically designed to evaluate self-management in this patient population. To address this, several instruments have been explored that could potentially aid in assessing the level of self-management.

One such instrument is the Patient Activation Measure (PAM), which was developed to better assess patients' individual self-management skills [15]. The instrument has been adapted into a shorter version with 13 items, whereas the original instrument had 22 items. Scores on the PAM classify people into one of four progressively higher activation levels. Tailored care according to a patient's activation level leads to improved scores on clinical indicators, better medication adherence, and a reduction in hospitalizations and emergency department visits. Increases in patient activation are followed by improvements in self-management behaviour.

Another instrument is The Health Education Impact Questionnaire (heiQ), a self-report questionnaire that assesses eight independent key self-management skills in patients with chronic conditions [16]. The tool was originally developed to determine the benefits of health education programs for a wide range of patient groups and specifically aimed to provide useful information for health professionals, researchers and policy makers.

Although the two instruments mentioned above are current generic self-management measures, no generic instrument was available to identify factors that could hinder successful self-management. To fill this gap, the self-management screening questionnaire (SeMaS), was developed [13]. The SeMaS is a 27-item questionnaire that is generally applicable to patients with chronic diseases. It assesses multiple dimensions relevant to self-management, including disease burden, locus of control, self-efficacy, social support, coping style, anxiety, depression and skills. The screening with SeMaS results in three categories per aspect, which are, capable of (more) self-management, capable of self-management with minor barriers, and major barrier(s) for (more) self-management.

Table 1 shows the characteristics and applications of the existing self-management instruments that are mentioned above; the Patients Activation Measure (PAM), the Health Education Impact Questionnaire (heiQ) and the Self-Management Screening questionnaire (SeMaS).

Instrument	Items	Aim	Focus
PAM	13 (short version)	Measure self-management skills	Four activation levels
heiQ	40	Originally developed to determine benefits of health education programs	Eight independent key self-management skills
SeMaS	27	Identify factors that could hinder self-management. Assesses multiple dimensions.	Disease burden, locus of control, self-efficacy, social support, coping style, anxiety, depressions and skills

Table 1: Self-management instruments

2.2 eHealth and wearables

This research aims to explore the attitudes of both patients and healthcare professionals towards eHealth and wearables, and how these technologies could potentially enhance self-management for patients with liver cirrhosis and MASLD. Therefore, it's essential to examine current gaps in the literature regarding the use of eHealth in managing chronic liver conditions.

Mobile technology, through wearable devices and smartphone applications, facilitates the continuous collection of data related to the user. This expanding field has emerged as a result of two components: wearable technology and smartphone-based applications [17]. As an innovative health care delivery method, eHealth is being adopted to address the growing demand for long-term care. Positive effects of eHealth services on patients' health outcomes are indicated by meta-analyses, providing encouraging evidence that eHealth is a beneficial approach to facilitate the modification of unhealthy behaviours in patients with MASLD [11].

Wearable technology represents a mobile device which collects and analyzes real time data relating to the consumer. The potential of mobile technology to monitor at-risk patients and prevent hospital readmissions is particularly relevant for patients with liver cirrhosis. Currently, the readmission rate for patients with cirrhosis is approximately 50%, indicating that existing monitoring strategies in outpatient settings are insufficient. Readmissions are often caused by medication non-adherence, lack of close follow-up or infections. One potential application of mobile and wearable technology could be for example monitoring heartrate, temperature and blood pressure to discover infections. By monitoring the weight, blood pressure and abdominal distension you could possibly detect ascites [17].

There's a gap in the literature regarding mobile technology-based structured lifestyle interventions in patients with MASLD, including those with compensated liver cirrhosis. To address this, a study tested a 6-month mobile technology-based structured lifestyle intervention in these patients. Prior research has shown that mobile technology devices can enhance the acceptability and perceived value of such interventions by providing real-time feedback. In this study, the majority of participants (64%) reported that daily step counting motivated them, and 69% of participants maintained or increased their step count. After 6 months, improvements were observed in metabolic, liver-related and physical function outcomes, including lipid panels (HDL, LDL, TG) and HgA1c. Participants also showed improvement in the 6-minute walk test (6MWT) [18]. In addition, another study showed that using a mobile app during lifestyle coaching can improve self-management. The mobile app provides personalized information, advice and interactions to facilitate self-management behaviours in patients with MASLD. Increased levels of self-management facilitate healthy behaviours for weight loss and reduction of liver fat [19].

Engagement with the digital program is an important aspect of the effectiveness of the digital intervention. Maintaining engagement and interest is key to achieving clinical improvements. Engagement with the digital program can be influenced by several elements: recruitment methods, participant characteristics, app design and level of support. The level of support, particularly coaching, is essential to enhance engagement and increase accountability and motivation [20].

2.3 Research questions

Despite the increasing recognition of the importance of self-management in improving outcomes for liver cirrhosis patients, significant gaps remain in existing literature. Current research has not sufficiently addressed the levels of self-management among these patients or the specific barriers they face in adopting effective self-management behaviours. Furthermore, while eHealth and wearables have shown promising results in other chronic conditions, their application and acceptance among liver cirrhosis patients remain underexplored. This study aims to address these gaps formulating the following main research questions and their corresponding sub-questions:

Main research question 1: "How can the current levels of self-management be improved in patients with liver cirrhosis?”

Sub questions:

1.1 What are the current levels of self-management among patients with liver cirrhosis?
1.2 How do healthcare professionals perceive self-management and how can they support patients in improving it?
1.3 What barriers and facilitators to self-management are reported by patients with liver cirrhosis?
1.4 Are patients willing to take an active role in increasing self-management?
1.5 What information do patients receive about their condition and is it perceived as sufficient?
1.6 How do factors such as disease severity (compensated vs. decompensated), gender and education influence self-management and information needs?

Main research question 2: “What are the attitudes of patients with liver cirrhosis towards eHealth and wearables?”

Sub questions:

2.1 What is the current usage of eHealth and wearables among patients with liver cirrhosis?
2.2 What are healthcare professionals’ perspective on the use of eHealth and wearables in managing liver cirrhosis?
2.3 How willing are patients with liver cirrhosis to adopt eHealth and wearables?
2.4 What benefits and limitations of eHealth and wearables are perceived by patients with liver cirrhosis?
2.5 How can eHealth contribute to increasing self-management in patients with liver cirrhosis?
2.6 How do factors such as disease severity (compensated vs. decompensated), gender, education and age influence the use of eHealth and wearables?

3. Methodology

3.1 Research design

The research used an observational design and a mixed methods approach, combining qualitative and quantitative research. The qualitative part consists of semi-structured interviews with both patients and healthcare professionals. The responses from the interviews were used as input for the quantitative research, which was a survey. Data was collected between April and November 2024.

3.2 Case selection

The research is approved by the ethical board of both Medisch Spectrum Twente (MST) and University of Twente (UT). These two committees serve distinct functions. The Medical Ethics Review Board of MST is the one authorized to grant approval for research involving patients, as it assesses compliance with the Dutch Medical Research Involving Human Subjects Act (WMO). This research is considered as non-WMO applicable. Ethical approval was obtained on the 4th of April 2024 from the Ethics Committee of UT and on the 1st of May 2024 from MST. Inclusion and exclusion criteria were formulated for the interviews and survey, see table below.

	Inclusion criteria	Exclusion criteria
Semi-structured interviews	Patients with liver cirrhosis without signs of overt hepatic encephalitis or active alcohol usage. Healthcare professionals who are involved in the care of liver cirrhosis patients, including nurses, specialists and nurse practitioners.	Overt hepatic encephalitis Active alcohol usage Healthcare professionals who aren't involved in the care of liver cirrhosis patients.
Survey	Patients with a (self-reported) liver disease and who are able to complete an online questionnaire. Participants must be 18 years or older.	Patients without (self-reported) liver disease and under the age of 18 years. Patients who aren't able to complete an online questionnaire.

Table 2: Inclusion and exclusion criteria

Patients who participated in the semi-structured interviews were recruited by their nurse practitioner or specialist during their outpatient visit. They received a patient information form (Appendix A) to inform them about the research and the data management plan and after a few days recruited participants received a phone call if they wanted to participate in the research. Healthcare professionals were also recruited by the specialist, received a PIF and received an e-mail if they wanted to participate. Informed consent was obtained by the researcher before the interview took place. Eventually, six patients and six healthcare professionals were interviewed. The interviews lasted a maximum of 30 minutes to minimize the burden on patients and healthcare professionals.

Participants for the survey were recruited through the Dutch Liver Patient Association (NLV), based on convenience sampling. Recruitment was carried out in two ways: first, by promoting the research during a presentation at an NLV patients conference, followed by distributing flyers afterwards; second, through an information letter about the study published on the NLV platform. The information letter contained a link that directed participants to a questionnaire created with Qualtrics. The first page of the questionnaire consisted of a general explanation of the research, while the second page explained participants' rights and provided information about the anonymity of the participants. Active informed consent had to be given in order to proceed to the questions (Appendix D).

3.3 Data collection

Data was collected from April to November 2024. As mentioned above, data was collected using a mixed-methods approach, collecting both qualitative and quantitative data. The data was collected in Dutch.

3.3.1 Semi-structured interviews

First, semi-structured interviews were conducted with patients and healthcare professionals. During the interviews, patients were asked about their knowledge and attitudes towards eHealth and the willingness to use wearables for their health. Healthcare professionals were asked about the same topics, but in a different way. Self-management interview questions were developed using the Self-Management Screening Instrument (SeMas). A questionnaire developed in Germany for surgical patients was used as a tool to formulate questions about eHealth [21]. Both these instruments were used as a tool, the final interview questions were formed after multiple meetings with the research team. Once the questions were developed, they were incorporated into an interview script (Appendix B, C). The script describes in detail how many questions are asked, in what order, how much time is available per topic, and so on. During the interviews, the script was used to ensure that the interviews ran as smoothly as possible. The script also provided a consistent definition of self-management and eHealth/wearables, all participants received the same explanation.

3.3.2 Survey

The survey was constructed using a combination of validated instruments and insights derived from interviews with patients and healthcare professionals. Questions and answers from the interviews were used as a basis for designing part of the questions and the response options in the survey. Key themes, insights and gaps identified during the interviews, such as barriers and facilitators to eHealth/wearables use, meaningful aspects in life and variations in self-management practices, were translated into specific survey questions and response options. The survey collected data on participants' demographics, disease-related factors, and quality of life (QOL). It included variables such as age, gender, disease stage, and other relevant characteristics. Additionally, the survey gathered information on the level of self-management in liver cirrhosis patients, as well as their knowledge of and attitudes towards eHealth and wearables.

Demographics

Demographic information was gathered from the participants. Gender and education were collected through multiple-choice questions, while age was asked in years. Education was categorized using the following answer options: **1)** no formal education **2)** primary education **3)** pre-vocational education (VMBO), lower secondary education (HAVO/VWO), MBO level 1 **4)** upper secondary education (HAVO/VWO), vocational education (MBO levels 2-4) **5)** higher professional or university bachelor's degree **6)** higher professional or university master's degree. These answer options were eventually grouped into three main education levels: primary, secondary and tertiary education.

Primary education	1) no formal education 2) primary education
Secondary education	3) pre-vocational education, lower secondary education 4) upper secondary education, vocational education
Tertiary education	5) higher professional or university bachelor's degree 6) higher professional or university master's degree

Employment status was divided into two main categories, employed and unemployed, with further subcategories detailing work activities and reasons for unemployment. To calculate someone's body mass index (BMI), participants provided their weight and height.

BMI was calculated using the formula: weight/ (height x height). BMI categories were defined as follows: below 18.5 indicates underweight, 18.5–24.9 indicates normal weight, 25.0–29.9 indicates overweight and 30.0 and above indicates obese.

Disease-related factors

Participants were asked whether they had ever been diagnosed with liver cirrhosis. The current stage of their liver cirrhosis was assessed by having participants self-classify their condition into one of the three stages, which categorized the cirrhosis as either compensated or decompensated.

Additionally, participants were asked about their underlying liver disease and whether they had any comorbidities, referring to other physical or mental health conditions. Participants were also asked about their adherence to the Dutch Guidelines for Healthy Physical Activity (NNGB), as well as their drinking habits and dietary choices. This information helped assess their lifestyle in relation to their liver disease.

Quality of Life (QoL)

Quality of life was assessed using the Short Form Health Survey 12 (SF-12). The SF-12 measures perceived health or health-related quality of life. The SF-12 is a shortened version of the SF-36. The SF-12 consists of twelve items divided into eight subcategories: general health, physical functioning, physical role, emotional role, bodily pain, vitality and social functioning. To gain deeper insights into mental health and vitality, the more detailed SF-36 was used for these dimensions. Responses were given on 3 to 6-point Likert scales, and scoring followed the SF-12 and SF-36 manual [27].

Self-management and eHealth

Before exploring participants' views on self-management and eHealth/wearables, a clear definition of these concepts was provided to ensure a shared understanding. Questions on eHealth and patient's attitude towards eHealth were formed by analyzing the responses on the questions from the interviews. The questions incorporated into the questionnaire assess different eHealth devices and the use of these devices among liver cirrhosis patients. Next to this, patients are asked about their willingness to use these devices and if they foresee any contributions and/or limitations considering the devices.

The PAM-13 and responses from the interviews were used to develop the self-management questions for the survey and to gain insight into the level of self-management in liver cirrhosis patients. The PAM-13, Patient Activation Measure, measures a person's level of activation. Participants are classified into one of four progressively higher activation levels associated with specific self-care and other health-related behaviours. A higher score on the PAM is positively associated with various health-related behaviours, especially self-management [22].

To analyze the questions regarding self-management and eHealth, it's important to understand from whom patients received information about their disease and what kind of information. Therefore, the questionnaire includes three questions related to information provision. These questions also provide insight into patients' level of satisfaction with the information they were given.

3.4 Data analysis

3.4.1 Semi-structured interviews

Interviews with patients and healthcare professionals were recorded and then transcribed using Amberscript. Once transcribed, the most relevant responses for addressing the research questions were systematically coded using ATLAS.TI 24. The coding process was conducted in three phases. During the initial phase, open coding was used. Segments of text were marked, and codes were assigned representing different themes, concepts or ideas.

This coding frame was partly informed by the interview questions, as the questions for patients and healthcare professionals were already pre-labeled in the interview script.

However, the focus remained on addressing the research questions while still allowing for inductive coding, meaning that new themes emerged naturally from the data. After open coding, axial coding was used. Related codes were grouped into overarching codes. In the final phase, a list of codes with corresponding passages was produced. The list with the different codes were translated into key themes. These key themes with different phrases were used to address the research questions. Furthermore, the results from the interviews were used to develop questions and response options for the survey. A flowchart illustrating the key themes and their associated codes is presented below.

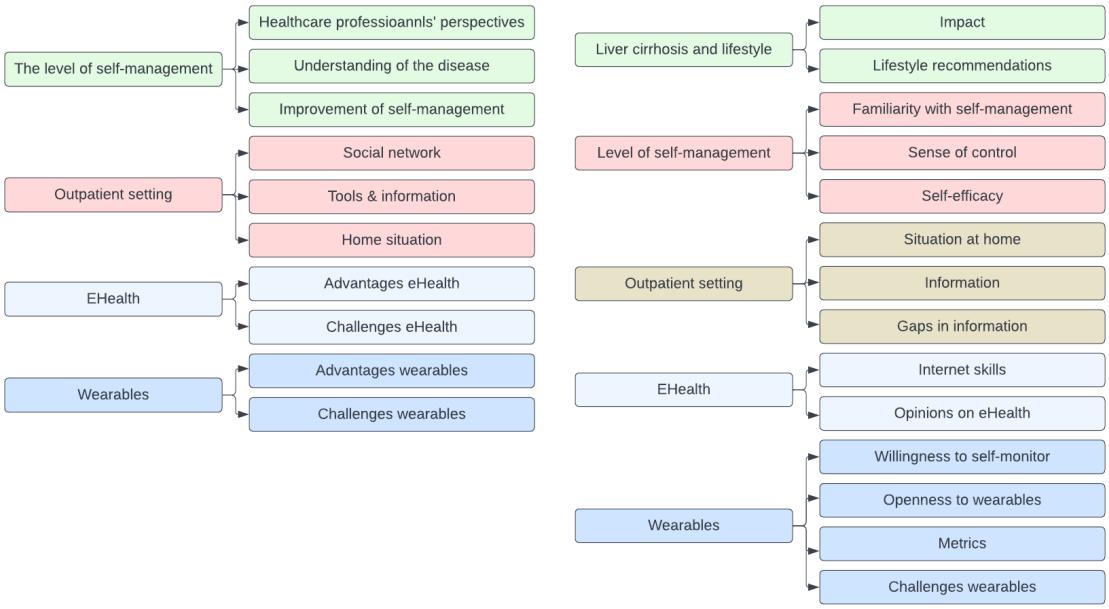

Figure 1: Key themes & codes, professionals (left) and patients (right)

3.4.2 Survey

To analyze the data from the survey, several statistical tests were performed. The data collected from Qualtrics.com was imported into SPSS version 29.0.2.0 for Windows (SPSS Inc.) to conduct all the statistical analyses.

To assess the participants' quality of life (QOL), descriptive statistics were used to analyze the domain scores and overall score, which are presented as means and ± standard deviations. The same method was applied to analyze the PAM-13 scores. To examine the attitudes towards eHealth and wearables, as well as the participants' information needs, descriptive statistics were used for the various variables.

To address sub questions 1.6 and 2.6, which examine group differences based on status of liver cirrhosis (compensated/decompensated), gender and education level, an Independent Samples t-test was conducted for all tables where it was applicable. A p-value of less than 0.01 was considered statistically significant for all tests.

4. Results interviews

A total of 12 interviews were conducted, six with healthcare professionals and six with liver cirrhosis patients. All interviews took place individually at Medisch Spectrum Twente. The healthcare professionals represented various roles, including one specialist, one doctor not in specialist training, two residents, one nurse practitioner and one physician assistant. The interviews questioned differed between the healthcare professionals and patients, so the results are presented separately. This separation allows for a more nuanced interpretation, as the two groups bring distinct perspectives to the research topics. While patients provide insights into their experiences, challenges and needs, healthcare professionals offer a broader, systematic view and professional expertise.

4.1 Interviews with healthcare professionals

From the interviews with the healthcare professionals, 11 codes were identified to various quotations, covering four key themes: self-management, outpatient setting, eHealth and wearables. A total of 115 quotations were analyzed, the following key themes summarize the most important perspectives of the healthcare professionals.

4.1.1 The level of self-management

This theme includes four codes related to the level of self-management in patients with liver cirrhosis, with 24 quotations falling under the perspective of healthcare professionals.

Healthcare professionals' perspectives

Most professionals agreed that liver cirrhosis patients generally have low levels of self-management. Contributing factors include: understanding of the disease, the disease's etiology, the patient's overall attitude, socioeconomic status (SES) and stress management.

The most frequently mentioned factor was the understanding of the disease. Healthcare professionals noted that patients with lower levels of understanding of the disease, especially those with language barriers or lower SES, face greater challenges in managing their condition.

Despite low levels of self-management in most patients, some professionals were optimistic about a small group of motivated patients who actively work to improve their self-management.

Understanding of the disease

A key code, with 12 quotations, emphasized that many patients, especially those with lower intelligence, SES or language barriers, struggle to understand their disease. This lack of understanding hinders the ability to manage the disease, such as adhering to weight management or lifestyle changes. Healthcare professionals emphasized the importance of educating patients repeatedly about their condition and consequences of their choices, such as alcohol consumption. were categorised under understanding of the disease.

Improvement of self-management

A total of 17 quotations fell under this code, which combined two separate codes: **chances** and **success factors**. Healthcare professionals noted that stress management, offering perspective (e.g., explaining the importance of disease management, elaboration on the future ahead) and involving a multidisciplinary care team could improve self-management. Where stress management is an important success factor in self-management. Motivation and therefore self-management also increased in patients after liver transplantation, because these patients are aware of the importance to change their behaviour for themselves and their recovery.

The level of self-management	
Codes	*Quotations*
Healthcare professionals' perspectives	"For the average patient I see during their first clinic visit, I believe the level is low." "The causes of liver cirrhosis vary and liver cirrhosis is found across all social and educational levels. This diversity also influences how patients manage their condition and respond to self-management instructions or lifestyle recommendations. Factors like low health literacy or denial can further impact their adherence."
Understanding of the disease	"Understanding, disease awareness, living conditions." "Some people simply don't know what to look out for or understand their bodies well. Helping them gain insight into their condition can make them recognize issues earlier."
Improvement of self-management	"Stress management plays a key role. People who stay calm can think through problems and find solutions, while those under high stress often feel overwhelmed and unable to act. Keeping stress low helps patients think clearly and make informed decisions." "I'm optimistic about patients' potential, as many become diligent in tracking their health, like blood pressure and diet, after a liver transplant."

4.1.2 Outpatient setting

The second theme focuses on the outpatient setting, containing three codes: social network, tools & information and home situation.

Social network

Involving the patient's social network is crucial for effective care. However, many patients attend appointments alone and some lack a support network altogether. In these cases, professionals must engage other care providers, such as GPs or home care services, to ensure proper support for their patients. This code contains eight quotations.

Tools & information

Professionals highlighted the importance of tools and information in patients care in nine quotations. Nurse practitioners, in particular, were seen as key to helping patients understand their disease and necessary lifestyle changes. The use of websites, pamphlets and other materials was also emphasized as essential for patient education.

Home situation

Healthcare professionals acknowledged in four quotations that a patient's home situation, such as financial constraints, can affect their ability to manage their disease. For example, patients who face financial difficulties may prioritize essential expenses over purchasing items, such as wearables, that could support more effective disease management.

Outpatient setting	
Codes	*Quotations*
Social network	"In some way, you try to involve the person in their environment to provide support. Otherwise, you may need to consider options like home care." "Feeling supported helps create mental space for self-management."
Tools & information	"The main resource we use is the nurse practitioner, as they have more time to discuss lifestyle, diet and other topics." "Internet, pictures, the physical aspect – I also have a nice sketchbook where I can draw from."
Home situation	"It's important to consider the patient's home situation, including their financial circumstances."

4.1.3 eHealth

The third theme addresses the potential role of eHealth in patient care, which is divided into advantages and challenges.

Advantages eHealth

11 quotations were categorized under this code. Professionals agreed that eHealth could offer patients a greater sense of control over their disease, which in turn could enhance self-management. Some professionals also noted that eHealth and wearables could increase motivation and disease understanding, particularly in more technologically proficient patients. For patients it's important to know which factors to improve, like weight, diet, exercise, etcetera. Monitoring those patients closely during the use of eHealth and wearables at home, can help evaluate if the patients are improving specific factors.

All professional have a positive opinion regarding the implementation of eHealth, now or in future. This is due to the fact that there's a high prevalence of liver diseases and the prevalence is even getting bigger in the future. All professionals do agree that there's a need for change to manage the care for the liver cirrhosis patients. The healthcare professionals think that eHealth can contribute to the self-management of their patients because it can increase self-control, motivation, understanding of the disease.

Challenges eHealth

Despite its advantages, professionals highlighted, through 13 quotations, several challenges to the implementation of eHealth. These include ensuring that the technology is not too complex or overwhelming for patients, avoiding over-reliance on digital tools and making sure patients understand the purpose of eHealth interventions. Additionally, there is concern that eHealth could lead to information overload, with patients fixating on medical data that may be difficult to interpret. Autonomy must be created, but dependence on the healthcare professionals to explain terms must be avoided. When eHealth is implemented, support must be created in both patients and healthcare professionals. To create support, people need to be informed about eHealth and the contribution of eHealth to them.

eHealth	
Codes	*Quotations*
Advantages	"I think by using eHealth, you can help people feel more in control of managing their own illness, which increases their sense of responsibility. It also gives more insight into where you can assist and what they can manage on their own." "I'm positive about it. While there's some uncertainty about how it should be implemented, technology is increasingly entering healthcare. Whether we like it or not, we'll have to deal with it, especially to manage the growing number of patients. It would be great for both healthcare professionals and patients."
Challenges	"A clear explanation of why something is being implemented and what it brings to both the patient and the healthcare providers." "I think it's important to keep things clear and manageable, focusing on a few key items. Patients shouldn't get overwhelmed by data they can't interpret, as this creates unnecessary dependence on us. The goals is to foster autonomy while also allowing us to monitor things earlier, without making them overly reliant."

4.1.4 Wearables

The final theme focuses on wearables, examining both their advantages and challenges. Only additional advantages and challenges are presented, because some overlap with those of eHealth.

Advantages wearables

Healthcare professionals agreed that wearables could offer continuous feedback, which might increase patients' awareness of their disease and improve self-management. Wearables could also help patients feel more connected to their healthcare professionals, which may increase their sense of accountability. Additionally, wearables allow healthcare professionals to monitor patients remotely, potentially preventing complications.

Challenges wearables

Concerns were raised about patients becoming overly focused on wearables and their medical data. Professionals also emphasized the importance of gradual implementation and ongoing support. Managing the resources (time, personnel and money) required for wearables is also a key consideration in the implementation process.

Wearables	
Codes	*Quotations*
Advantages	"It provides continuous feedback about their own lives, making them more aware of their illness, its effects on their body and how they feel. This helps them take specific actions based on real-time feedback." "It's great to track such things closely, allowing for better monitoring of patients than we currently can." "If you can catch someone earlier and start treatment, it might prevent worse outcomes, like longer hospital stays."
Challenges	"People shouldn't become obsessive about using them." "Setting things up properly from the start and stepping back is much better than fixing issues later when problems arise." "I think everyone is very active and enthusiastic at first, but the challenge is to keep it up and make it a lasting habit."

4.2 Interviews with patients

Six patients with liver cirrhosis were interviewed to gain insights into their experiences and perspectives. The analysis identified 14 codes, which were grouped into five key themes: liver cirrhosis and lifestyle, self-management, outpatient setting, eHealth and wearables. A total of 143 quotations were categorized under these themes, which are summarized below.

4.2.1 Liver cirrhosis and lifestyle

The first theme is called liver cirrhosis and lifestyle, which is divided into two codes: impact and lifestyle recommendations.

Impact

This code contains 14 quotations. Patients describe liver cirrhosis as a condition that significantly affects their daily lives. Symptoms like fatigue are particularly challenging, forcing patients to frequently rest after short activities. Patients reported social isolation and job loss as a result from the emerging fatigue.

In more severe cases, complications like hepatic encephalopathy led to hospitalization and significant cognitive and motor issues, requiring patients to relearn basic functions such as speaking, walking and writing. The symptoms and dealing with them was described as distressing and life-altering. The impact of liver cirrhosis and its complications leaves patients feeling frustrated by their inability to keep up with others or maintain normal levels of activity.

Lifestyle recommendations

11 quotations fit under this code. Patients recognized the importance of an active lifestyle and balanced diet but found these adjustments challenging. Social situations involving alcohol posed additional difficulties. While lifestyle changes were seen as crucial, patients emphasized the need for structured support to maintain discipline.

Liver cirrhosis and lifestyle	
Codes	*Quotations*
Impact	"If I do something, I can manage for about an hour, but then I'm exhausted and need to lie down or sit quietly."

	"It mainly affects me socially and professionally. I lost my job after being sick too long, ended up disable to work."
Lifestyle recommendations	"Step one is turning it into action, I did it (movement) through a structured program. However, once that fades, I lack the self-discipline. It's not yet part of my lifestyle, not in my system."

4.2.2 Level of self-management

This theme comprises three codes: familiarity with self-management, sense of control and self-efficacy.

Familiarity with self-management

Seven quotations reflect patient's understanding of self-management. Most were familiar with the concept, defining it as taking responsibility for their health by monitoring and making necessary adjustments. Patients emphasized the importance of their own involvement in treatment, viewing it as a partnership with healthcare professionals.

Self-management practices identified included monitoring health, maintaining a healthy diet, staying physically active and engaging with treatment plans. Patients highlighted the importance of their active participation in making lifestyle adjustments effective in daily life.

Sense of control

This code includes five quotations. Patients were asked if they believed they had control over their health. While some felt they did not have complete control, they recognized significant influence through self-management. They emphasized the importance of staying motivated and alert, noting that tools like eHealth and wearables could provide helpful reminders and support between appointments.

Patients reflected on past behaviours, such as alcohol consumption and being overweight, acknowledging their contributions to their condition. While they recognized the limits of control, they believed lifestyle changes and the use of health-monitoring tools could positively influence their health.

Self-efficacy

Nine quotations describe patients' confidence in their ability to implement health changes. Confidence levels varied, with some patients feeling capable but acknowledging challenges like maintaining consistent exercise routines.

One patient recovering from surgery noted their confidence was still developing as they worked to regain trust in their body. Others highlighted the importance of support from healthcare professionals in building their self-efficacy. Overall, patients identified recognizing the need for change as an important first step but found it difficult to translate awareness into consistent actions.

Level of self-management	
Codes	*Quotations*
Familiarity with self-management	"Self-management involves monitoring your health, eating healthy, exercising and paying attention to your body's signals, then taking timely action." "You receive guidelines and need to evaluate how to follow them, such as with a diet. You assess if adjustments are needed, discuss this with your healthcare provider, and align with them. If you don't contribute, the provider can't do much with the short contact."
Sense of control	"I do have a large part of it in my hands, not everything of course. You can get things you have no control over. But I do think I have some control over it."
Self-efficacy	"I do have trust, but sometimes it fades. There are times when I don't feel like it and think, *"I know I should, but I wish I didn't have to."* But it is what it is, so I must take care of it."

	"I've had a tumour removed, it's a matter of time to regain control and trust in my body."

4.2.3 Outpatient setting

This theme includes three codes: situation at home, information and ***gaps*** in information.

Situation at home

13 quotations address the role of support in self-management. Social support varied widely, with some patients relying on family and friends, while others preferred to manage their condition independently.

A supportive network was seen as valuable for promoting positive behaviours like physical activity and self-management. However, some patients chose to hide their condition in professional settings, limiting potential support.

Information

19 quotations reveal patients' approaches to seeking health information. Most relied on trusted sources like the "Maag Darm Lever Stichting" or "Gezondheidsplein", as well as brochures.

One patient reflects on reading articles that were motivating and reassuring about their condition. The patient gathered information from various platforms, including scientific literature, podcasts and educational videos from medical centers. The patient emphasizes the importance of using reliable medical websites and being critical of online resources, seeking information that enhances the understanding and empowers to ask relevant questions to their professional.

Patients expressed the importance of reliable and accessible information to enhance their understanding and engage meaningfully with healthcare professionals.

Gaps in information

Seven quotations highlight gaps in the availability and clarity of information, particularly regarding dietary and medication guidelines for patients with both diabetes and liver cirrhosis. Patients emphasized the need for comprehensive, multidisciplinary advice addressing various health factors such as hormonal changes and heart conditions.

Outpatient setting	
Codes	*Quotations*
Situation at home	"I don't ask for help from everyone, and I don't tell people about my illness, for example, at work. So if you don't share it, you can't expect help. But my family is supportive, although some people don't take it into account."
Information	"At first, I didn't look for information, but I got curious and started searching. I'm very mindful of the sources, though." "Definitely the *"Maag Darm Lever Stichting"* and also "*Gezondheidsplein"* and similar sites."
Gaps in information	"Sometimes the guidelines for diabetes differ from those for liver cirrhosis, so they don't always align. It can be confusing when it comes to advice on what you should or shouldn't do. I would find clearer guidance helpful."

4.2.4. eHealth

The fourth theme eHealth comprises two codes: internet skills and opinions on eHealth.

Internet skills

Six quotations reflect varying levels of internet proficiency. While some patients were adept at using digital tools, others expressed limited familiarity, relying on basic applications like WhatsApp.

Opinions on eHealth

Nine quotations describe patients' views on eHealth. While some patients were unaware of digital health tools, others valued their potential to improve self-management. Patients emphasized the need for functionality and expressed concerns about incomplete medical records in patient dossiers. They desired comprehensive access to their health data to enhance understanding and engagement.

eHealth	
Codes	*Quotations*
Internet skills	"I think I'm a standard internet user. I have a question in mind, and I use the internet to find answers."
Opinions on eHealth	"It would be great to have everything in my patient file, but I can look up some things online. The issue is that not everything is included, which I find incomplete and uncomfortable."

4.2.5 Wearables

Eventually, the last theme consists of four codes: willingness to self-monitor, openness to wearables, metrics and challenges with wearables.

Willingness to self-monitor

This code holds 13 quotations which describe the willingness of patients to self-monitor. Most patients expressed a willingness to use technology, such as smartwatches or apps, to track health metrics like steps, blood pressure and vital signs. However, they emphasized the importance of balance, stressing that self-monitoring should not lead to stress or over-reliance on devices.

One patient noted that constant alerts from devices, such as those for atrial fibrillation, could create unnecessary stress and preferred relying on personal feelings of health rather than being overwhelmed by notifications.

Another patient raised concerns about becoming overly fixated on health metrics, potentially causing anxiety. Patients highlighted the need for a support system, such as healthcare professionals, who could assist in interpreting data and provide guidance when needed.

Overall, self-monitoring was seen as beneficial in moderation, with an emphasis on education to ensure effective use of these technologies.

Openness to wearables

15 quotations describe patients' openness to use wearables. With the exception of one patient who was generally unwilling to engage with technology, the majority of participants were open to using wearables for self-monitoring of their liver cirrhosis. This patient expressed interest in wearables only if future evidence demonstrated clear benefits for managing the condition.

The remaining patients were curious about wearables and expressed a willingness to explore their use, provided the devices were practical, functional and did not cause unnecessary stress.

There was a clear desire for simplicity and ease of use, ensuring that the technology could fit seamlessly into their lives without becoming burdensome.

Metrics

Patients were interested in tracking a range of health metrics, including: step count, weight, fluid balance, blood pressure, sleep quality, blood sugar levels and general liver function.

The potential of wearables to provide real-time feedback on these metrics was seen as valuable, particularly for gaining deeper insights into their health status and managing their condition more effectively.

Challenges wearables

This code contains ten quotations where patients address their concerns towards wearables and the challenges that may occur.

Several challenges and concerns about wearables were mentioned by patients, including:

- **Overwhelm from monitoring**: Some patients worried that an over-focus on health metrics could lead to anxiety and detract from enjoying life.
- **Inconvenience**: Forgetting to charge the device or dealing with periods where it wasn't worn at all was cited as a practical issue.
- **Discomfort**: Constant notifications, especially when the patient had already completed a task (like physical activity) without the device tracking it, led to frustration.
- **Adjustments and misuse**: One patient shared their experience of manipulating the device's settings to avoid constant reminders, suggesting that wearables may not always align well with individual preferences or lifestyle.
- **Social interaction**: A patient noted the potential social awkwardness when wearables' notifications distracted from conversations.
- **Scepticism toward healthcare providers**: Some patients voiced concerns that healthcare professionals might not fully embrace wearable technology or provide adequate support, potentially limiting the effectiveness of wearables in patient care.

Wearables	
Codes	*Quotations*
Willingness to self-monitor	"I just try not to get anxious about it. I think it should be more of an alert function." "To some extent, I monitor my health, but I focus on how I feel overall." "Weighing yourself is simple self-help, like checking for fluid retention, but you shouldn't do it 10 times a day. If tool can help measure, monitor and adjust positively, why wouldn't I use them?"
Openness to wearables	"I think I'll enjoy it and make use of it. I'm not the type to panic, for example, if my saturation is low. It's about keeping it enjoyable." "I'd try it if it's useful for me or beneficial for research."
Metrics	"I think blood pressure monitoring could be useful, though I'm not sure. I do like tracking steps and heart rate, and sometimes sleep as well. I should explore more because I think there's a lot more I could do than I can think of right now."
Challenges wearables	"I set up my watch with my correct age, weight and height to track my movement, but the reminders became annoying. I reset it to a fictional profile with no health issues, set a goal of walking 1 KM a day and stopped getting reminders. Having to constantly recharge it didn't work for me because I forgot." "If I have an old-fashioned doctor who thinks they're the expert in the white coat and doesn't value eHealth or wearables, then it won't work."

5. Results survey

The survey was developed using a combination of validated instruments and insights derived from the interviews, which highlighted specific areas to focus on. The interview results provided valuable information on aspects such as the use of eHealth and wearables, participants' preferences regarding these technologies and the perceived benefits and drawbacks. Based on these insights, the survey included targeted questions about the advantages and disadvantages of eHealth/wearables, as well as preferences for using specific types of tools. Further insights from the interviews emphasized the importance of autonomy in self-management, prompting the inclusion of questions regarding participants' desire for control over their health and treatment. Moreover, the interviews helped identify factors that contribute to self-management, such as social support, knowledge and motivation, which were integrated into the survey questions.

The survey was organized into multiple sections, each targeting a specific domain: **1)** demographic characteristics **2)** quality of life **3)** eHealth and wearables (questions formed by interviews) **4)** self-management (questions formed by interviews **5)** PAM-13 **6)** informational needs. For a detailed overview of the survey questions, see Appendix D.

A total of 306 participants started the questionnaire and 188 finished it. Therefore, the 118 participants who did not finish were excluded from the research. The remaining sample consisted of 188 participants. Finally, after completing the questionnaire, participants were given the opportunity to enter their email address if they wished to receive the study results. 151 participants provided their email address. The questionnaire took about 30-45 minutes to complete.

5.1 Demographic characteristics

A total of 188 patients were included in the study, of whom 80 (43%) were diagnosed with liver cirrhosis. Among the liver cirrhosis group, 57 (71%) had compensated cirrhosis, and 23 (29%) had decompensated cirrhosis. Figure 2 presents the descriptive statistics of the demographic characteristics of the participants.

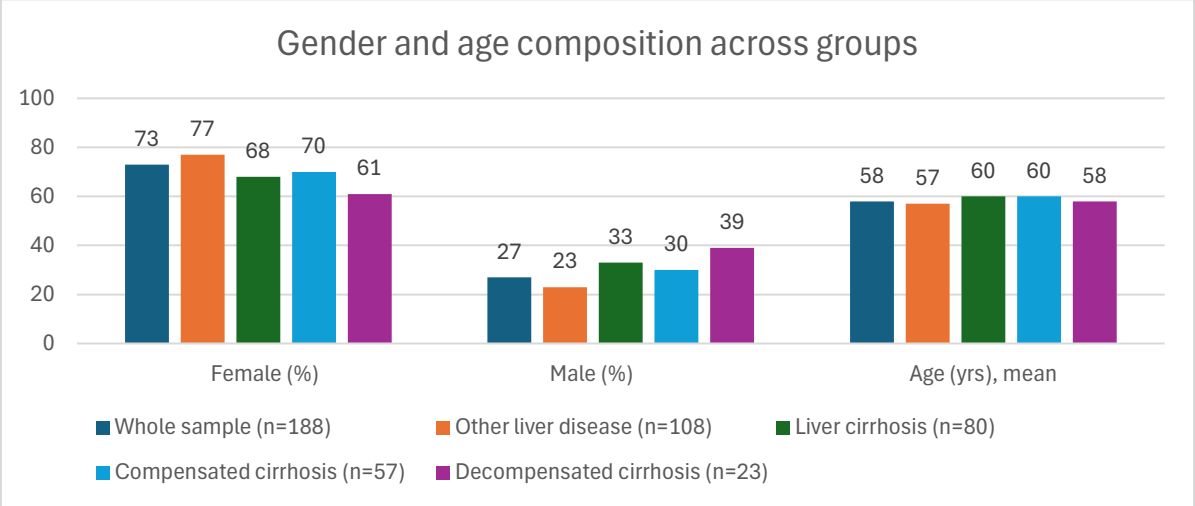

Figure 2: Age and gender across groups

Figure 3 shows educational attainment of the participants. In this case, primary education refers to no formal education or primary school education. Secondary education includes lower and upper secondary education, such as pre-vocational education, general secondary education and pre-university education, as well as vocational education (MBO levels 1-4).

Tertiary education refers to higher professional education or university-level education, including bachelor's and master's degrees. For those with compensated cirrhosis, the proportion of tertiary education was 46%, while it was slightly higher (65%) in the decompensated group, which looks similar to the control group (other liver disease).

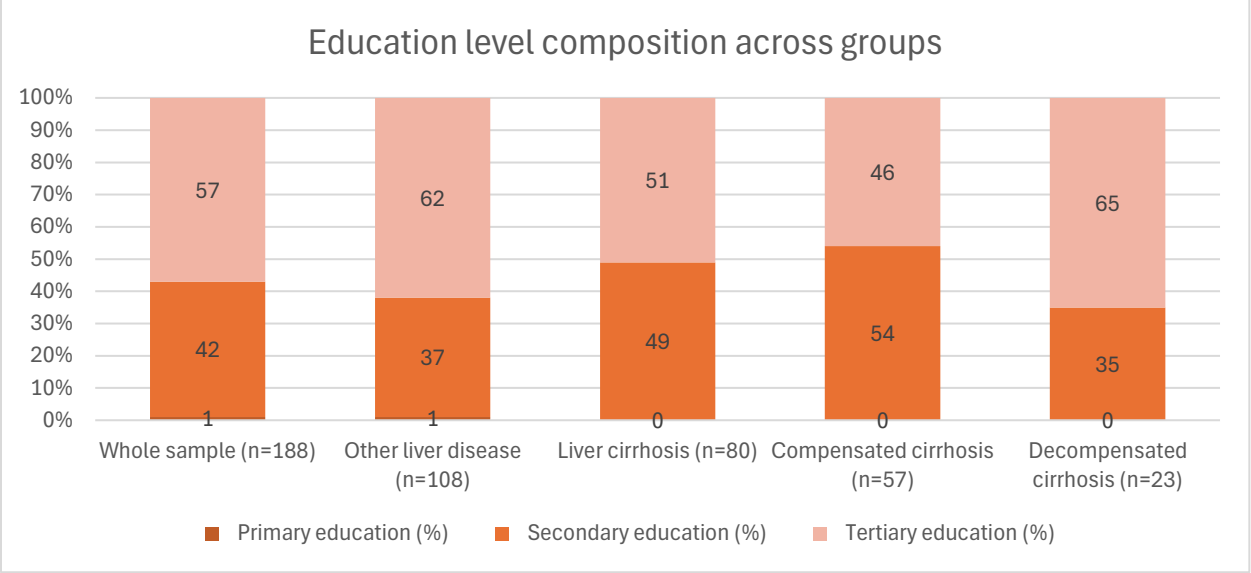

Figure 3: Educational attainment

Employment rates were comparable across groups, but participants with decompensated cirrhosis had a higher proportion of unemployment due to disability (50%) compared to the compensated cirrhosis group (37%) and the control group (33%).

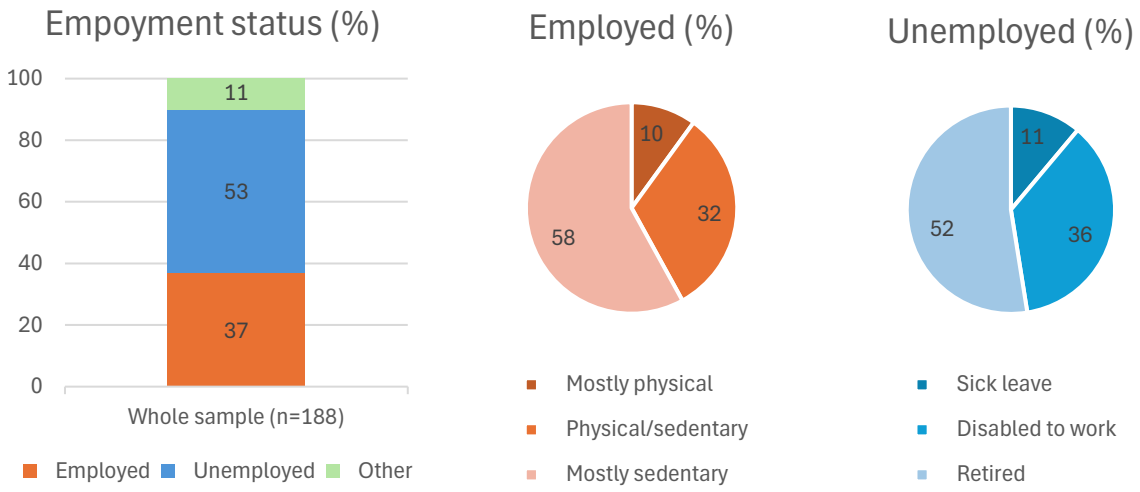

Figure 4: Employment status (whole sample)

5.2 Medical and lifestyle characteristics

Figure 5 summarizes the distribution of liver diseases across groups. The largest proportion, 46%, reported auto-immune hepatitis as their liver disease, followed by 33% with PBC or PSC. These proportions were similar across subgroups, except for the decompensated cirrhosis group, where 39% had auto-immune hepatitis and 26% had PBC or PSC. Viral hepatitis, storage diseases and MASLD were rare, occurring in 0-9% across groups.

The median time since diagnosis of any liver disease was 12 years, while for liver cirrhosis, it was 9 years. Time since diagnosis of liver disease was slightly longer in the compensated group (median of 17 years) compared to the decompensated group (median of 11 years).

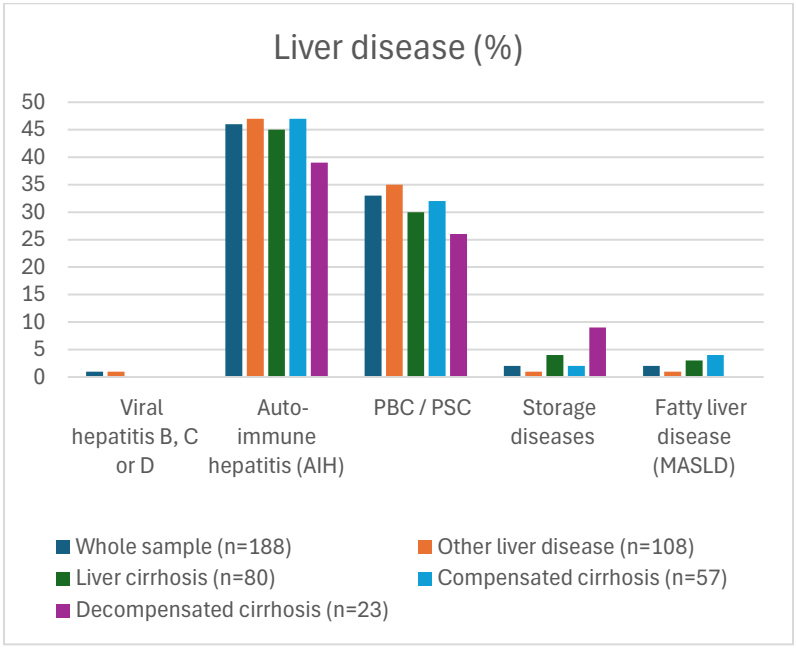

Figure 5: Liver disease by groups

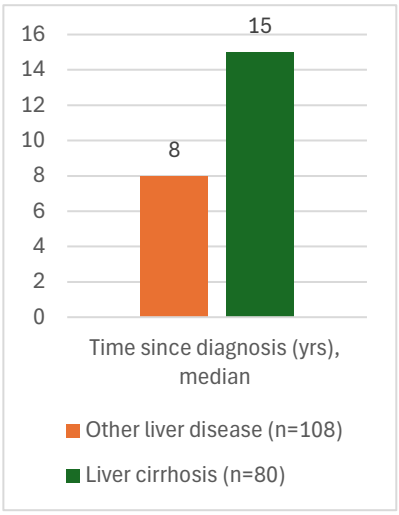

Figure 6: time since diagnosis

Current or past comorbidities were common in the study population, which are presented in figure 7. A significant difference was found in the number of malignancies/cancer cases, with participants with liver cirrhosis reporting a higher number of malignancies/cancer cases.

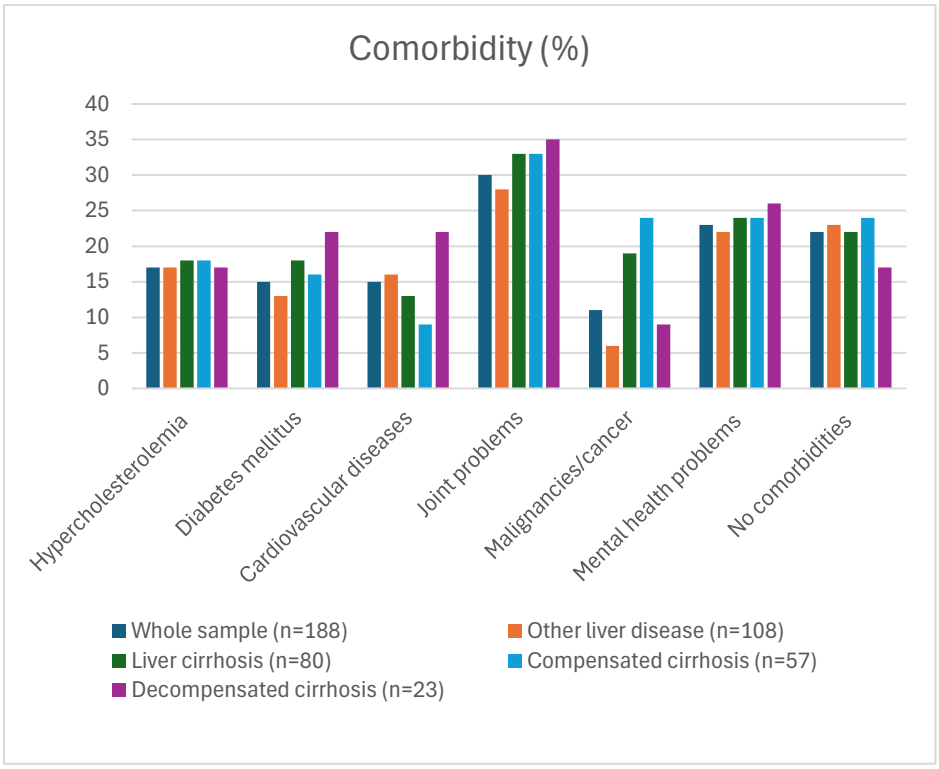

Figure 7: Comorbidity by groups

The mean BMI was consistent across groups, averaging 26 kg/m^2 (SD = 5) for the total sample. Regarding physical activity, 42% met the Dutch guidelines for exercise, defined as being moderately active for at least 150 minutes per week, while 63% indicated performing strength-building exercised at least twice a week. These proportions were slightly lower in the cirrhosis group, with 35% meeting the moderate-intensity norm in both the compensated and decompensated group.

Concerning alcohol consumption, alcohol use was reported by 19% of the total sample, consumption was the same across subgroups, among participants with decompensated cirrhosis, alcohol consumption was lower, at 13%. Adherence to dietary recommendations was reported by 26% of the total sample, among participants with decompensated cirrhosis, 17% followed dietary recommendations.

5.3 The quality of life of liver patients

The SF-12 instrument has a normative overall score of 50, with a standard deviation of 10. Scores range from a minimum of 0 to a maximum of 100. A score below 50 indicates impairment in a specific domain. In the total sample, scores were above the normative value of 50 for all domains except for Vitality, General Health and Role Physical. Overall QOL scores were similar across groups, varying from 55 to 57. No significant differences were found in the overall quality of life or in any of the subdomains when comparing the different groups.

Table 3: General descriptive of aspects of QOL (n = 188)

			Liver cirrhosis		
QOL aspect	Total sample	Other liver disease (n=108)	Liver cirrhosis (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)
	M (SD)	*M (SD)*	*M (SD)*	*M (SD)*	*M (SD)*
Bodily pain (SF-12)	74 (26)	75 (26)	73 (27)	76 (23)	65 (34)
Role Emotional (SF-12)	70 (40)	70 (41)	71 (38)	74 (37)	65 (41)
Physical functioning (SF-12)	68 (30)	70 (29)	66 (31)	66 (31)	65 (33)
Mental Health (SF-36)	67 (18)	68 (17)	66 (18)	65 (17)	67 (21)
Social functioning (SF-12)	55 (29)	56 (30)	54 (28)	51 (28)	61 (27)
Vitality (SF-36)	42 (24)	42 (24)	41 (25)	41 (23)	41 (29)
General Health (SF-36)	39 (19)	39 (19)	38 (19)	38 (19)	40 (20)
Role Physical (SF-12)	35 (45)	37 (46)	31 (45)	28 (44)	39 (45)
Overall QOL	56 (21)	57 (22)	55 (21)	55 (19)	56 (25)

5.4 Self-management and self-monitoring

The Patient Activation Measure (PAM-13) was utilized to evaluate the level of patient activation within the sample. Higher PAM scores indicate greater levels of patient activation. Participants are categorized into one of four progressively higher activation levels, which are linked to specific self-care and other health-related behaviours. Levels 1 and 2 represent lower patient activation, while levels 3 and 4 reflect higher activation. The cut-off scores for each level are as follows: Level 1 (≤ 47), Level 2 (47.1 – 55.1), Level 3 (55.2 – 67) and Level 4 (≥ 67.1). Table 4 displays the number of participants in each PAM level for the different subgroups: liver cirrhosis status, gender and education.

Table 4: Patients in level 1-4 by liver cirrhosis status, gender and education level (n = 188) n (%)

		Liver cirrhosis				Gender		Education	
	Whole sample (n=188)	No (n=108)	Yes (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)	Female (n=137)	Male (n=51)	Primary/Secondary (n=75)	Tertiary (n=106)
Level 1	8 (4)	7 (7)	1 (1)	1 (2)	0 (0)	7 (5)	1 (2)	5 (7)	3 (3)
Level 2	15 (8)	5 (5)	10 (13)	7 (12)	3 (13)	13 (10)	2 (4)	7 (10)	7 (7)
Level 3	69 (37)	40 (37)	29 (36)	19 (33)	10 (44)	56 (41)	13 (26)	30 (41)	37 (35)
Level 4	96 (51)	56 (52)	40 (50)	30 (53)	10 (44)	61 (45)**	35 (69)**	32 (43)	59 (56)

** p<0.01 difference tested with an independent samples t-test

Table 5 shows that the PAM scores for the entire sample exceeds the cut-off score of 67.1, placing the sample in Level 4. Similarly, the subgroups analyses by gender, education and liver status also fall within Level 4. This indicates a high level of patient activation across the overall sample and all subgroups. The analysis revealed a significant difference in PAM scores between females and males, with males more likely to have a higher score. However, no significant differences were found for liver cirrhosis status or education.

Table 5: PAM score by liver cirrhosis status, gender and education level (n = 188)

		Liver cirrhosis				Gender		Education	
	Whole sample (n=188)	No (n=108)	Yes (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)	Female (n=137)	Male (n=51)	Primary/Secondary (n=75)	Tertiary (n=106)
PAM score	68.99 (13.78)	69.23 (14.14)	68.67 (13.37)	68.71 (13.15)	68.56 (14.19)	67.16 (13.85)**	73.93 (12.43)**	67.20 (15.92)	70.10 (12.34)

** p<0.01 difference tested with an independent samples t-test

Table 6 summarizes the responses of participants on various aspects of disease control and self-management, as well as their willingness to adopt eHealth solutions. The mean scores for these responses can range from 0 to 10, with higher scores indicating greater perceived control or a higher willingness to engage in specific activities.

A comparison of scores, by utilizing a t-test, revealed a statistically significant difference between participants with and without liver cirrhosis for receiving help from others.

This showed that participants with liver cirrhosis were significantly more likely to receive help from others compared to those without liver cirrhosis.

The overall results suggest a high level of patient activation and a strong willingness to adopt modern tools for disease management, particularly self-measurements and wearables. However, relatively lower scores for receiving help from others point to an opportunity to develop additional support systems to improve self-management outcomes.

Table 6: Questions about control, self-measurements, wearables and eHealth by liver cirrhosis status (n = 188)

Questions	Whole sample (n=188) *M (SD)*	Other liver disease (n=108)	Liver cirrhosis (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)
Like to have control over disease	7.90 (1.86)	8.00 (1.89)	7.78 (1.88)	7.93 (1.96)	7.39 (1.64)
Currently control over disease	6.58 (2.11)	6.55 (2.18)	6.63 (2.03)	6.47 (2.05)	7.00 (1.98)
Willing to perform self-measurements at home	8.67 (1.78)	8.76 (1.83)	8.55 (1.71)	8.58 (1.70)	8.48 (1.76)
Willing to use wearables to monitor liver disease	6.98 (2.95)	7.06 (2.93)	6.88 (3.00)	6.68 (3.12)	7.35 (2.67)
Could eHealth enhance self-management	6.83 (2.47)	6.82 (2.55)	6.84 (2.37)	6.65 (2.48)	7.30 (2.10)
Receiving help from others	4.88 (2.96)	4.40 (3.06)**	5.53 (2.70)**	5.11 (2.70)	6.57 (2.45)

1 Scores are on a scale of 0-10, a higher score indicates more control/willingness

** p<0.01 difference tested with an independent samples t-test

Table 7 summarizes the results of questions related to disease control and self-management across subdomains gender and education level. Participants with tertiary education showed a stronger desire for more control (8.29) compared to those with primary or secondary education (7.41).

Table 7: Questions about control, self-measurements, wearables and eHealth by gender and education level (n = 188)

Questions	Female (n=137)	Male (n=51)	Primary/secondary education (n=75)	Tertiary education (n=106)
Like to have control over disease	8.02 (1.84)	7.59 (1.98)	7.41 (2.17)***	8.29 (1.46)***
Currently control over disease	6.43 (2.19)	6.98 (1.86)	6.35 (2.26)	6.75 (1.98)
Willing to perform self-measurements at home	8.68 (1.82)	8.56 (1.68)	8.36 (1.78)	8.93 (1.57)
Willing to use wearables to monitor liver disease	7.20 (2.90)	6.39 (3.03)	6.89 (2.62)	7.10 (3.11)
Could eHealth enhance self-management	6.96 (2.34)	6.47 (2.78)	6.96 (2.33)	6.78 (2.46)
Receiving help from others	4.81 (2.89)	5.06 (3.15)	4.83 (3.06)	4.83 (2.88)

1 Scores are on a scale of 0-10, a higher score indicates more control/willingness

** p<0.01 difference tested with an independent samples t-test

*** p<0.001 difference tested with an independent samples t-test

5.5 Wearable usage

Figure 8 summarizes the participants' current use of wearables. The most commonly used devices for health monitoring were smartphones and smartwatches, with nearly all participants using these devices on a daily basis. Participants without liver cirrhosis (33%) were significantly more likely to use smartwatches compared to those with liver cirrhosis (18%).

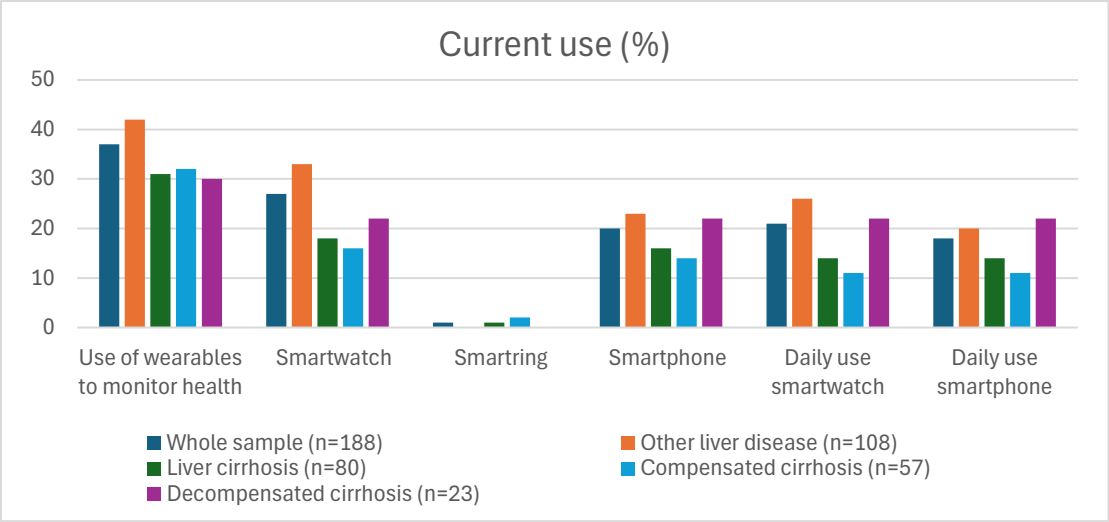

Figure 8: Current use wearables

Regarding willingness to use wearables, 75% of the participants expressed interest in using a smartwatch for health monitoring. This was slightly lower in the compensated cirrhosis group (70%) and higher in the decompensated cirrhosis group (83%).

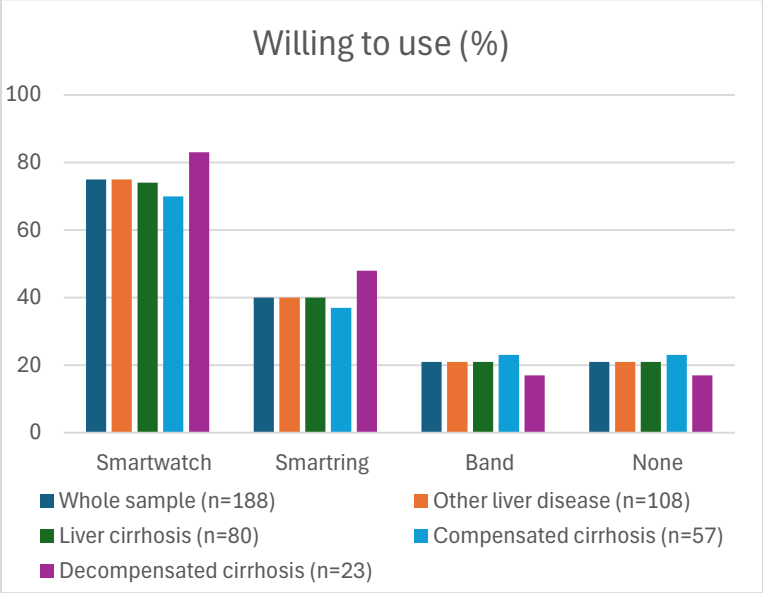

Figure 9: Willing to use wearables

The primary challenges (figure 10) identified for using wearables were cost (38%), with participants in the decompensated cirrhosis group reporting a slightly higher concern (48%). Other concern included the feeling of being overwhelmed by medical data (30%). However, 28% of participants indicated that they did not anticipate any challenges.

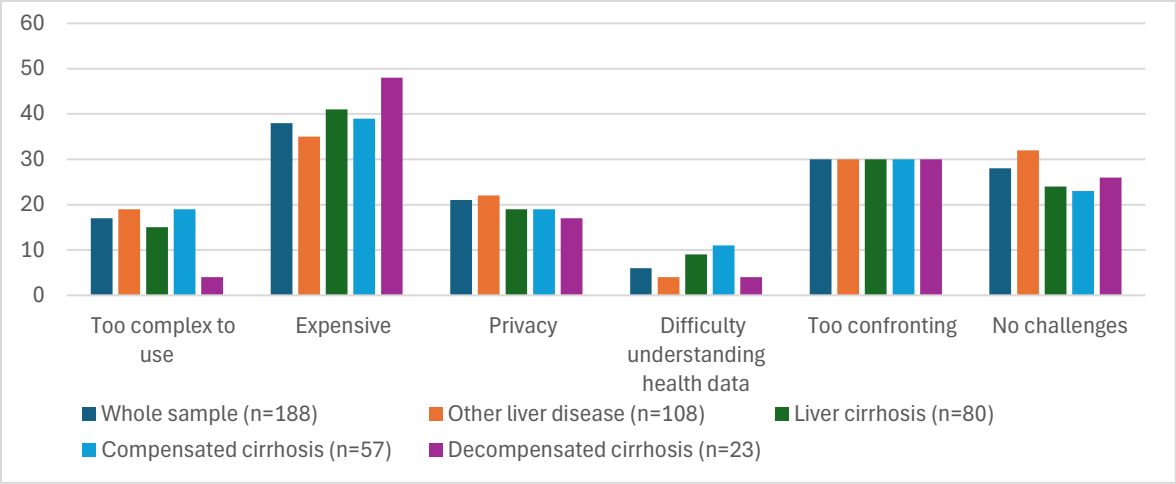

Figure 10: Challenges/barriers wearables (%)

The most frequently cited advantage of using wearables was the ability to gain more insight into medical data, with 75% of the participants highlighting this. Only 14% believed there were no advantages to using wearables. Participants without liver cirrhosis were significantly more likely to expect quicker access to health data compared to those with liver cirrhosis.

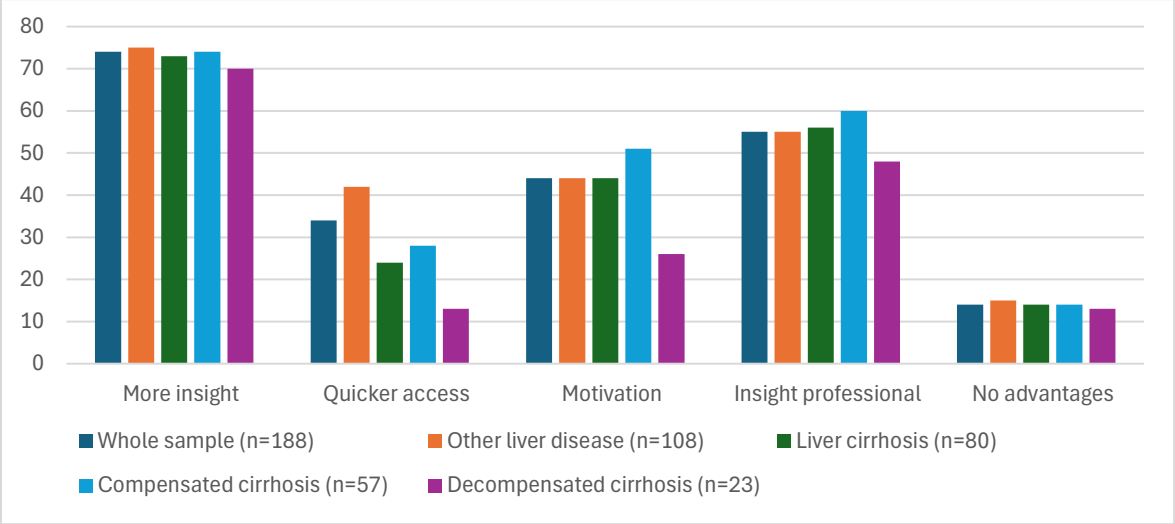

Figure 11: Advantages wearables (%)

Participants indicated a desire for insight into multiple health measurements, including sleep patterns, heart rate and oxygen saturation. Additionally, some participants suggested other areas of interest, such as diet, liver condition and blood sugar levels. Furthermore, 77% of participants expressed a preference for sharing their medical data with professionals, while 21% wanted to keep this information private. These trends were consistent across the subgroups.

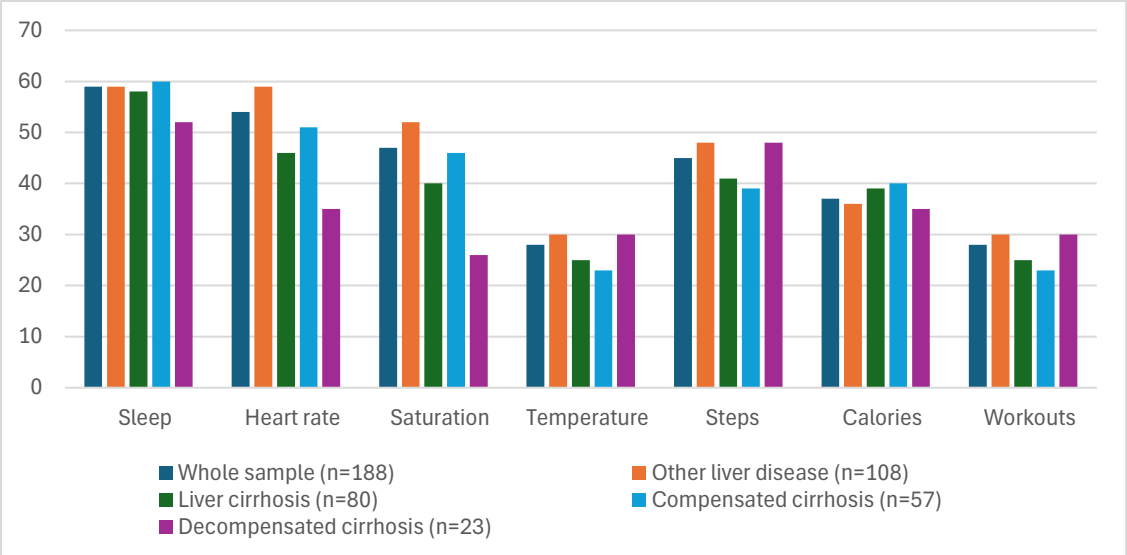

Figure 12: Measurements wanted (%)

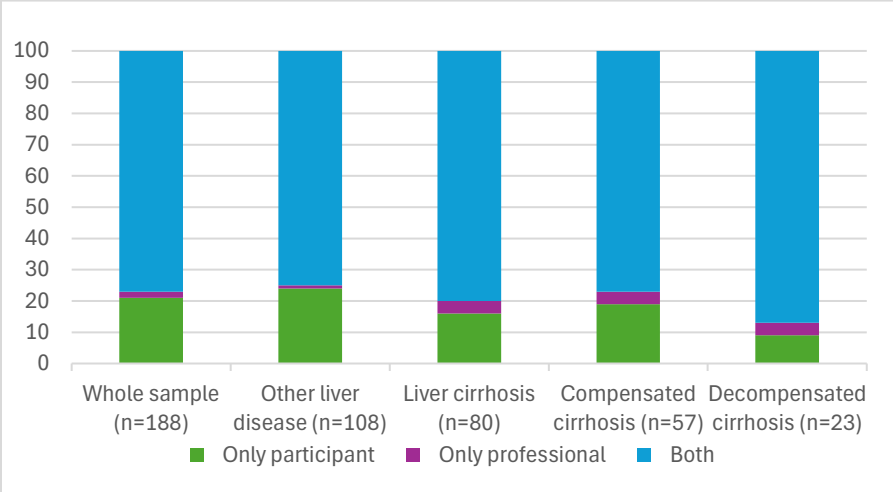

Figure 13: Permission to check data (%)

Wearable usage was also analyzed by gender and education, figure 14 summarizes the significant differences between these subgroups. Females were more willing to use a smart ring for health monitoring compared to males, and participants with tertiary education showed greater willingness to adopt a smart ring than those with primary/secondary education. Regarding barriers, females were more likely to cite privacy concerns. Additionally, participants with tertiary education were more likely to indicate a preference for sharing their medical data exclusively with themselves, compared to those with primary/secondary education.

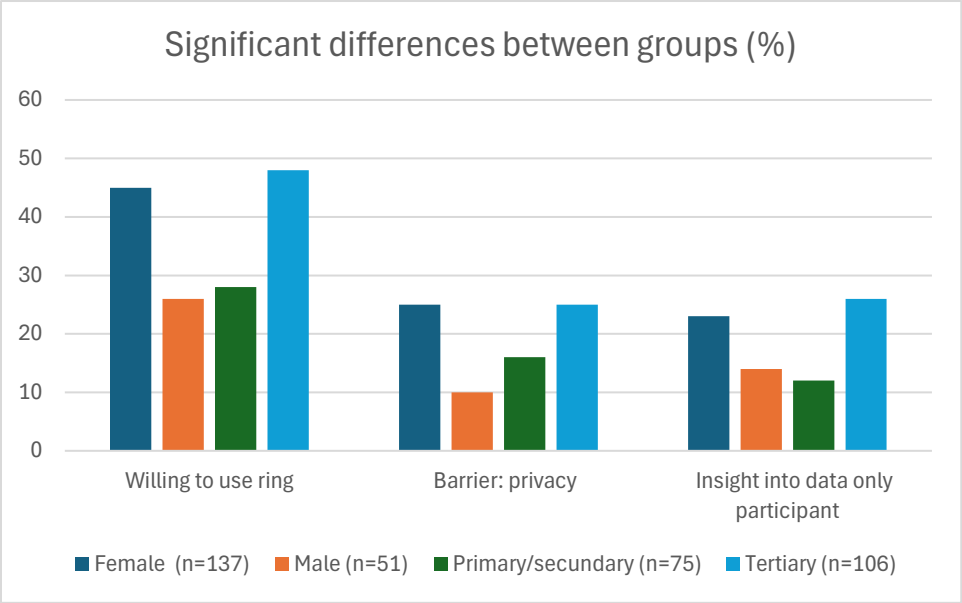

Figure 14: Differences wearable usage subgroups

5.6 The informational needs of liver patients

Table 8 provides an overview of the information participants reported receiving about their disease and their requests for additional information. Satisfaction with the amount of information received varied across topics. The majority (81%) indicated they received enough information about the nature of their disease, which was also the topic with the fewest requests for additional information.

For all topics, participants were more likely to report receiving "enough" information compared to "little" or "no" information. The mean scores for all topics exceeded 2.00, except for information on apps/websites, which also had the highest number of participants requesting additional information. Conversely, contact with fellow patients was the topic most frequently reported as receiving "no information", though fewer participants expressed a need for additional information on this topic.

Table 8: Information that was received by participants and the request for more information per topic (n = 188)

Information received about	No information (1) n (%)	Little information (2) n (%)	Enough information (3) n (%)	Mean (SD)	More information wanted n (%)
What is the liver disease	3 (1.6)	32 (17)	153 (81)	2.80 (.44)	78 (42)
Causes of the disease	31 (17)	63 (34)	94 (50)	2.34 (.75)	114 (61)
Consequences of	11 (6)	53 (28)	124 (66)	2.60 (.60)	114 (61)
Treatments	21 (11)	60 (32)	107 (57)	2.46 (.69)	119 (63)
Self-improvement	29 (15)	62 (33)	97 (52)	2.36 (.74)	116 (62)
Diet	44 (23)	69 (37)	75 (40)	2.16 (.78)	110 (59)
Exercise	57 (30)	62 (33)	69 (37)	2.06 (.82)	110 (59)
Contact with fellow patients	63 (34)	50 (27)	75 (40)	2.06 (.86)	83 (44)
Apps/websites	63 (34)	69 (37)	56 (30)	1.96 (.80)	118 (63)

Table 9 summarizes participants' information needs across different topics based on gender and education level. Significant differences were observed in several areas. Female participants were significantly more likely than males to request additional information on the consequences of the disease, diet, exercise, contact with fellow patients and apps/websites. No significant differences were observed in information needs based on education level.

Table 9: Information needs by gender and education (n = 188)

More information	Gender		Education	
	Female (n=137) n (%)	Male (n=51) n (%)	Primary/secondary (n=75) n (%)	Tertiary (n=106) n (%)
Which type of liver disease	64 (47)	14 (28)	35 (47)	41 (39)
Causes of the disease	88 (64)	26 (51)	49 (65)	61 (58)
Consequences of	91 (66)**	23 (45)**	45 (60)	65 (61)
Treatments	93 (68)	26 (51)	50 (67)	65 (61)
Self-improvement	90 (66)	26 (51)	50 (67)	63 (59)
Diet	90 (66)***	20 (39)***	49 (65)	58 (55)
Exercise	90 (66)***	20 (39)***	50 (67)	57 (54)
Contact fellow patients	70 (51)***	13 (26)***	37 (49)	44 (42)
Apps/websites	95 (69)**	23 (45)**	49 (65)	64 (60)

** p<0.01 difference tested with an independent samples t-test

*** p<0.001 difference tested with an independent samples t-test

Table 10 summarizes participants' information needs across various topics based on liver cirrhosis status. Participants with decompensated liver cirrhosis generally reported a lower desire for more information on several topics compared to participants with compensated liver cirrhosis. However, no significant differences were found between the two liver cirrhosis groups (compensated and decompensated) or between the no liver cirrhosis and liver cirrhosis groups.

Table 10: Information needs by liver cirrhosis status

			Liver cirrhosis	
More information	Other liver disease (n=108) n (%)	Liver cirrhosis (n=80) n (%)	Compensated liver cirrhosis (n=57) n (%)	Decompensated liver cirrhosis (n=23) n (%)
What is the liver disease	44 (41)	34 (43)	24 (42)	10 (44)
Causes of the disease	64 (59)	50 (63)	36 (63)	14 (61)
Consequences of	62 (57)	52 (65)	40 (70)	12 (52)
Treatments	65 (60)	54 (68)	42 (74)	12 (52)
Self-improvement	68 (63)	48 (60)	37 (65)	11 (48)
Diet	62 (57)	48 (60)	37 (65)	11 (48)
Exercise	61 (57)	49 (61)	35 (61)	14 (61)
Contact fellow patients	49 (45)	34 (43)	27 (47)	7 (30)
Apps/websites	67 (62)	51 (64)	39 (68)	12 (52)

6. Discussion

This study explored the perspectives of healthcare professionals and liver cirrhosis patients regarding self-management, the attitudes towards eHealth and wearables and the willingness to use these for monitoring their health or disease. Several significant findings emerged, shedding light on both the challenges and opportunities for enhancing self-management and use of eHealth/wearables in patients with liver cirrhosis. Below, findings are discussed in the context of the study's research questions.

6.1 How can the current levels of self-management be improved in patients with liver cirrhosis?

Improving self-management in patients with liver cirrhosis requires an approach that includes enhancing education, addressing several challenges such as low health literacy and difficulty maintaining healthy lifestyles and providing structured support. Patients need better access to resources and guidance. Additionally, eHealth tools and wearables could provide ongoing support, motivation and real-time feedback to help patients manage their health more effectively and improve self-management.

6.1.1 Current levels of self-management

Findings from the interviews revealed that while many patients were familiar with the concept of self-management and defined it as taking responsibility for their health, implementing consistent practices such as monitoring health, maintaining a balanced diet and staying physically active proved challenging.

Survey data reflected this, showing high patient activation (PAM-13 score of 68.7 indicating level 4), but low adherence to self-management behaviours such as exercise (35% meeting Dutch guidelines for physical activity) and dietary recommendations (26%). While patient report a moderate sense of control over their disease (6.63), they express a desire for greater control (7.78). This highlights that, despite motivation and awareness, effective self-management often requires additional factors such as consistent support and tailored interventions. Previous research confirms these findings, highlighting psychological status (especially anxiety and depressive symptoms), disease severity, and self-efficacy as significant predictors of self-management success [9].

6.1.2 Healthcare professionals' perspectives

Healthcare professionals noted that many liver cirrhosis patients struggled with self-management, often due to low health literacy, financial constraints, and stress. They emphasized that continuous education and feedback are critical, particularly for patients with lower health literacy or those from lower socioeconomic backgrounds. Stress management was also highlighted as a crucial factor in successful self-management. Professionals observed that patients who managed stress well were more engaged in self-care, suggesting that interventions should include mental health support.

Interestingly, there was a discrepancy between patient-reported self-management levels and healthcare professionals' perceptions. While the survey data suggested high activation levels, healthcare professionals viewed self-management as generally low. This contrast may be explained by the fact that patient activation, motivation and awareness, does not always translate into actual behaviour change. While patients may express confidence in their ability to manage their condition, external and internal barriers may prevent them from taking consistent action. This finding underscores the importance of not only educating patients but also addressing the barriers that hinder self-management.

6.1.3 Barriers and facilitators

Data from the interviews and survey identified key barriers and facilitators to self-management in liver cirrhosis patients. Patients valued structured support and collaboration with healthcare professionals, highlighting that self-management thrives on ongoing guidance rather than individual effort. Regular follow-ups, tailored coaching, and structured care could sustain patient engagement.

Access to educational tools emerged as a key facilitator, empowering patients to make informed health decisions. However, knowledge alone was insufficient, patients needed clear, actionable strategies and ongoing reinforcement to maintain healthy behaviours. Many acknowledged the role of lifestyle changes, such as reducing alcohol consumption, but lacked the necessary tools, motivation, or support to sustain these changes.

Persistent barriers included financial constraints, lack of information, and difficulty maintaining lifestyle changes. Financial issues limited access to healthy food, exercise, and digital health tools. Many educational resources were perceived as too complex or insufficiently tailored. Only 35% of liver cirrhosis patients met Dutch exercise guidelines, likely due to fatigue, physical limitations, or lack of tailored programs.

Social support was moderate, with cirrhosis patients scoring 5.53 compared to 4.40 in non-cirrhosis patients, indicating a risk of social isolation. Interviews confirmed that patients often relied on close family members, emphasizing the need to strengthen peer support networks both offline and digitally. Findings from a previous study also highlight the crucial role of social support in improving self-management behaviours [27].

Despite these challenges, patients were optimistic about eHealth's role in self-management, scoring 6.84. If usability, cost, and accessibility barriers are addressed, digital tools could provide motivation, real-time feedback, and structured support to help patients sustain healthy behaviours.

6.1.4 Willingness to actively improve self-management

Interviews highlighted patients' recognition of the need for change but noted challenges in translating this awareness into consistent actions. Some participants emphasized that tools like eHealth and wearables could provide the necessary motivation and support. The majority of patients expressed willingness to improve their self-management, with survey data showing high willingness in self-measurements at home and wearable use. However, interviews highlighted that many patients struggle to translate this willingness into consistent action without external reinforcement. This suggests that coaching and real-time feedback from digital tools may be essential for sustaining self-management behaviours over time.

6.1.5 Sufficiency of information

Patients generally felt like they received sufficient information about their disease (81%), but notable gaps remained in areas like causes of the disease, dietary recommendations and available digital tools. For example, dietary recommendations for liver cirrhosis can be complex due to comorbidities or medication interactions, requiring more tailored and practical guidance. Additionally, patients were generally unaware of specific apps, websites, or eHealth solutions that could assist in their self-management, indicating a need for more accessible and targeted resources. The need for more information directly impacts self-management, as patients who lack clear guidance may struggle to make informed decisions about their health. Without adequate knowledge, they may find it difficult to implement lifestyle changes, adhere to dietary restrictions, or utilize available digital tools effectively. Interestingly, patients showed little interest in peer support, preferring to seek help from personal contacts or healthcare professionals.

6.1.6 Factors of influence

Patients with compensated cirrhosis were more likely to be in PAM level 4 compared to those with decompensated cirrhosis, suggesting that self-management abilities decline as the disease progresses. Decompensated cirrhosis patients may face greater physical limitations that hinder their self-management efforts, leading to lower patient activation. Interestingly, patients with decompensated cirrhosis reported receiving more help from others than those with compensated cirrhosis, which was also reflected in the Quality of Life (QOL) assessment, where decompensated patients had a higher score in social functioning. This finding aligns with expectations, as patients with more advanced disease often rely more heavily on caregivers, family members, or healthcare professionals for support.

Men were notably more likely to be classified in PAM level 4 compared to women. Furthermore, men had significantly higher PAM scores (73.93) than women (67.16), highlighting the influence of gender on patient activation, with men demonstrating greater engagement in self-management. Previous studies have also shown that women tend to rate their health lower than men, suggesting that women may encounter distinct challenges when it comes to managing their health [26].

Patients with tertiary education had higher rates of activation, with more individuals in PAM level 4 compared to those with secondary education. This group also expressed a greater desire for control over their disease (8.29) than those with primary or secondary education (7.41). Higher education is often associated with better health literacy and improved self-management behaviours. However, it's important to note that other barriers may still hinder behaviour change, indicating that education alone is not a sufficient predictor of self-management success. Tailoring interventions to the specific needs of men and women, as well as considering varying education levels, could increase the effectiveness of self-management strategies.

Regarding information needs, patients with tertiary education and women generally desired more information, although the differences between these groups were less than 10%. Disease severity also played a role in information needs, with those having compensated cirrhosis seeking more information on certain topics compared to those with decompensated cirrhosis.

Higher education levels were more common in patients with decompensated cirrhosis (65%) compared to compensated cirrhosis (46%). However, despite the higher education, decompensated patients had a high unemployment rate due to disability (50%), suggesting that disease severity may reduce the advantages of education. Interestingly, patients with compensated cirrhosis had a longer median time since diagnosis (17 years) compared to those with decompensated cirrhosis (11 years), suggesting that factors other than disease duration, such as lifestyle or comorbidities, may drive cirrhosis progression.

While education and disease duration are relevant to self-management, the severity of the disease itself may be a more decisive factor in a patient's ability to manage their condition effectively. This indicates the importance of providing personalized care that accounts for both the physical and psychological challenges associated with different stages of liver cirrhosis.

6.2 What are the attitudes of patients with liver cirrhosis towards eHealth and wearables?

Patients generally show a positive attitude towards eHealth and wearables, with strong interest in using these technologies for self-monitoring and disease management. However, concerns about privacy, cost and data overload exist.

Despite these challenges, most patients are willing to adopt these tools, especially if they can help with managing their condition and improving self-management practices.

6.2.1 Current usage of eHealth and wearables

Interviews revealed that smartphone use was common, but wearable adoption was constrained by factors like cost and lack of awareness about available technology. Survey results indicated that wearable use for health monitoring is lower in patients with liver cirrhosis (31%) than those without cirrhosis (42%). There's a significant difference between these groups in the current use of a smartwatch, with patients with liver cirrhosis being less likely to use a smartwatch. However, willingness between these groups is the same.

These findings are in contrast to other studies where wearables were increasingly used for real-time health monitoring [23]. Given the potential benefits of wearables in tracking health measurements, higher adoption rates were expected. The gap between high smartphone use and low wearable adoption suggests that awareness and accessibility issues may be key barriers, rather than a direct rejection of wearable technology. Cost (41%) and lack of awareness were commonly cited as reasons for not using wearables, indicating that many patients may not fully understand the benefits of wearables or lack financial resources to purchase them. This suggests a need for affordable, disease-specific wearables with tailored guidance.

6.2.2 Perspectives of healthcare professionals

Healthcare professionals emphasized the potential of eHealth and wearables to enhance self-management through real-time data, motivation and disease understanding. However, they highlighted challenges such as complexity, the need for patient education and potential data overload. For instance, one professional stated:

"Patients shouldn't get overwhelmed by data they can't interpret, as this creates unnecessary dependence on us. The goals is to foster autonomy."

While healthcare professionals support eHealth and wearables solutions, their concern about dependence is notable. Wearables are often promoted as tools that empower patients, but professionals worry that excessive or poorly understood data might have the opposite effect. This highlights a potential gap between the intention of wearables and their real-world implementation, without proper guidance, wearables may create more stress rather than fostering patient autonomy.

6.2.3 Willingness to adopt eHealth and wearables

Interviews revealed that patients were generally open to incorporating eHealth and wearables into their daily routines, particularly if these tools could positively impact their disease management or enhance their self-management practices. Survey results further supported this finding, with strong willingness to engage in self-measurements at home (8.55) and to use wearables for disease monitoring (6.88). Notably, 74% of participants expressed a willingness to use a smartwatch for health monitoring.

While current usage rates are low, a majority of participants expressed willingness to integrate these technologies into their routine to monitor their health. This suggests that barriers are more practical rather than attitudinal. Patients may be open to digital health but hesitant due to financial concerns or skepticism about effectiveness.

6.2.4 Perceived benefits and limitations

Patients highlighted several benefits of eHealth and wearables, including improved insights into health metrics, reminders for self-management tasks, and enhanced communication with healthcare professionals. However, they also identified challenges, such as overreliance on technology, concerns about privacy, and discomfort caused by constant notifications. Survey results revealed that cost was the most common barrier (41%), while more insight into health data the most cited benefit (73%).

The strong interest in gaining more insight into health data contrasts with the lower actual usage of wearables (31%). This suggests that while patients value information, they may not yet see wearables as a necessary tool to obtain it, Barriers such as cost, usability, and lack of knowledge about benefits likely contribute to these lower usage rates. Additionally, patients with liver cirrhosis were significantly less likely to perceive quicker access to health data as a benefit, which might further explain the lower usage.

6.2.5 Contribution to self-management

Both patients and healthcare professionals recognized that eHealth and wearables could empower patients to take greater control over their health. Through real-time feedback and reminders, these technologies were seen as essential tools for maintaining lifestyle changes and preventing complications. However, both groups emphasized the importance of proper guidance and integration into care plans to maximize their effectiveness. Participants from the survey expressed that eHealth could enhance self-management (6.84), and they showed a high desire for more control over their disease (7.78).

6.2.6 Factors of influence

The study explored how disease severity, gender, and education influence the use of eHealth and wearables. Decompensated cirrhosis patients showed greater willingness to use wearables (83%) compared to compensated patients (70%). However, there was no difference in actual wearable use between these two groups. This lack of difference in health monitoring based on disease severity was unexpected, as one might assume that patients with more severe disease would be more motivated to track their health, but this was not reflected in usage patterns.

Patients with tertiary education were 11% more likely to use a smartwatch compared to those with secondary education. Education level may influence technology adoption, but privacy concerns were also highest among those with tertiary education, who were more likely to restrict access to their medical data. Privacy concerns were also significantly higher among women.

Notably, women and decompensated patients were more willing to use a smartwatch or smart ring (over 10%). Patients with tertiary education were particularly inclined to use a smart ring. The higher willingness among women to use a smartwatch or smart ring is particularly notable, as it suggests gender differences in health engagement and technology adoption. These groups may perceive more direct benefits from wearables, further indicating the need to tailor interventions based on gender and disease severity.

6.3 Existing literature

This study builds on prior research by confirming that self-management plays a crucial role in chronic disease care, particularly for conditions like liver cirrhosis. While previous studies have recognized the importance of self-management interventions in improving patients' knowledge and motivation [9], there was a gap in understanding the specific challenges faced by liver cirrhosis patients. Before this study, limited research had explored the direct application of eHealth and wearables in supporting self-management among this patient group.

Findings from this study extend current knowledge by identifying specific barriers, such as low digital literacy, financial constraints and concerns about data overload, which were previously underexplored. Additionally, while studies on other chronic diseases, such as COPD, have shown that digital health tools can support disease management by providing real-time monitoring, symptom tracking and feedback on health status [23], the applicability to liver cirrhosis patients remained uncertain. Similarly, research on chronic disease management for older adults has highlighted the promise of wearable patient monitoring systems in improving healthcare delivery. However, the successful implementation of these systems hinges on user acceptance. Raising awareness and ensuring the acceptance of both patients and clinicians are essential for the widespread adoption and effectiveness of these technologies [24,25].

6.4 Strengths and limitations

A key strength of this study is its mixed-methods design, which combines both qualitative and quantitative approaches to provide a comprehensive understanding of the perspectives of both patients and healthcare professionals. The survey had a larger sample size than initially planned, with 188 respondents, as it was open to all patients with liver disease. This broader inclusion allowed for valuable insights. However, one limitation is the relatively small sample of liver cirrhosis patients, which was smaller than originally intended.

Additionally, the study was conducted in the Netherlands, which may limit the generalizability of the findings to other regions or populations. The interview sample also had a gender imbalance, with only one female participant out of six, potentially limiting the diversity of perspectives captured. Furthermore, the analysis and coding of the interviews were conducted by a single reviewer, increasing the risk of subjectivity and personal bias, which could lead to selective interpretation of the data. The small interview sample size further restricts the ability to generalize findings, as the experiences of the participants may not fully represent the broader patient or healthcare professional population. Another limitation is that the interviews were conducted in Dutch, requiring translation of quotations into English. This process may have introduced variations in tone and expression. A secondary reviewer could have helped verify translations to minimize potential discrepancies.

The survey also had an imbalance in gender and disease severity, with a higher number of female participants and patients with compensated cirrhosis. Additionally, as the survey was distributed through a liver disease organization, it may have attracted more engaged and motivated patients, potentially affecting the representativeness of the sample. Patients willing to participate may have stronger self-management tendencies than the broader liver cirrhosis population, which could influence the study's findings.

6.5 Future research/recommendations

While this study has provided valuable insights into self-management and the role of eHealth and wearables in liver cirrhosis care, several areas warrant further exploration to enhance patient support and optimize digital health solutions. Future research should investigate how different subgroups of liver cirrhosis patients respond to and benefit from eHealth and wearable technology. Understanding whether disease severity influences the effectiveness of these tools is crucial for developing targeted and personalized interventions. Patients with decompensated cirrhosis, who often face greater physical and cognitive challenges, may require simplified or more supportive digital solutions to maximize usability and adherence.

A key area for future research is the sustainability of engagement with eHealth and wearables over time. While many patients initially express willingness to adopt these tools, little is known about long-term adherence.

Investigating factors that influence continued usage, such as the integration of coaching, personalized feedback, and motivational strategies, could help ensure these technologies contribute to lasting self-management improvements. Additionally, research should explore age-related barriers and facilitators in adopting eHealth solutions, as younger patients may be more comfortable with technology, whereas older patients might require more intuitive, user-friendly designs. Identifying these factors will help tailor interventions to diverse patient needs.

Given the role of social isolation as a barrier to self-management, future studies should explore how digital health solutions can facilitate peer or family support networks. Examining how eHealth platforms can foster stronger social engagement may be particularly beneficial for patients who experience stigma or have limited support from healthcare professionals or family members. Furthermore, integrating healthcare professionals into digital health strategies is essential. Research should assess the effectiveness of shared care models where clinicians can monitor patient data from wearables and provide timely interventions or guidance. Ensuring that eHealth and wearables complement clinical care rather than creating additional burdens on patients or providers will be crucial in maximizing their potential benefits.

Barriers such as cost, privacy concerns, and usability remain key challenges in eHealth adoption, requiring further investigation. Identifying strategies to reduce the financial burden of digital health solutions and making them more accessible to liver cirrhosis patients will be critical in increasing adoption rates. Privacy concerns, particularly among patients with higher education levels, should be addressed to foster trust and willingness to engage with these technologies. Additionally, ensuring that eHealth tools are easy to use and do not overwhelm patients with complex data is vital for their successful implementation.

Patients should be encouraged to actively engage with eHealth and wearable tools, as they have been shown to enhance self-management and disease control. These digital solutions can provide real-time feedback, motivation, and health monitoring to help patients make informed decisions. However, adequate support from healthcare professionals is necessary to help patients integrate these tools into their daily routines effectively. Education should focus on clarifying complex aspects of liver cirrhosis management, particularly regarding diet and physical activity, while also providing training on how to use digital health tools. Addressing concerns about privacy, usability, and data overload through clear communication and structured guidance will further improve adoption.

Healthcare professionals should take a more individualized approach to supporting liver cirrhosis patients, considering factors such as gender and educational background, which influence health behaviours and technology adoption. Tailoring interventions to men and women differently, and adjusting content based on education levels, will help ensure eHealth and wearable solutions are both accessible and effective. Additionally, clinicians should be trained to integrate digital health tools into their practice, utilizing real-time patient data to monitor progress, adjust treatment plans, and provide targeted guidance. Addressing concerns about data overload by ensuring that patients understand how to interpret health metrics is also essential in promoting confidence and reducing stress.

Building trust in digital health solutions requires transparency, particularly regarding privacy concerns. Healthcare professionals should provide clear information on how patient data will be used and protected, reinforcing confidence in these technologies. Ensuring that patients feel empowered rather than overwhelmed by digital health tools will be key to enhancing self-management and ultimately improving patient outcomes.

7. Conclusion

The findings of this study have important implications for both healthcare professionals and patients with liver cirrhosis. While patients exhibit awareness of the importance of self-management, translating this awareness into consistent behaviours remains challenging due to factors such as low health literacy, financial constraints, and psychological barriers like stress and anxiety. Additionally, patients expressed a strong need for more information and better access to resources and guidance. Healthcare professionals recognize these challenges and emphasize the need for continuous education, personalized interventions, and support systems to improve patient engagement in self-care. The interest in eHealth and wearables is evident among both groups, but the practical implementation presents challenges. For healthcare professionals, the integration of eHealth and wearables in clinical care offers an opportunity to enhance patient self-management, however, successful adoption depends on providing patients with adequate support, ensuring that these tools are accessible and easy to use. Patients, on the other hand, see potential benefits in gaining real-time insights into their health, but concerns about cost, privacy and usability must be addressed. Specifically, financial constraints may limit access to wearables, data security concerns may hinder trust and complexity fears may reduce engagement. Future research should explore strategies to make these technologies more inclusive and user friendly by reducing concerns and implement policy support. By addressing these challenges, eHealth and wearables could significantly improve the self-management of liver cirrhosis patients, ultimately leading to better health outcomes and quality of life.

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Appendix A. Patient Information Form (PIF)

Titel van het onderzoek
Zelfmanagement en eHealth in patiënten met levercirrose

Inleiding

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan een (medisch) wetenschappelijk onderzoek in Medisch Spectrum Twente, getiteld “Zelfmanagement en eHealth in patiënten met levercirrose”. U beslist zelf of u wilt meedoen. Voordat u de beslissing neemt, is het belangrijk om meer te weten over het onderzoek. Lees deze informatiebrief rustig door. Bespreek het met partner, vrienden of familie. Heeft u na het lezen van de informatie nog vragen? Dan kunt u terecht bij de onderzoeker, die onderaan deze brief vermeld is.

U bent gevraagd om deel te nemen aan dit onderzoek wat bestaat uit een interview vanwege uw chronische leverziekte (levercirrose) of omdat u betrokken bent als zorgprofessional.

1. Wat is het doel van het onderzoek?

Door middel van een kort interview hopen wij meer te weten te komen over zelfmanagement en eHealth in patiënten met chronische leverziekte. EHealth betekent elektronische gezondheidszorg; het gebruik van computers en internet in de medische wereld. Denk aan dingen zoals gebruikt van medische apps en smartphones. Over zelfmanagement stellen we enkele vragen om te begrijpen hoe patiënten met chronische leverziekte voor zichzelf zorgen en wat hij/zij wenst voor zichzelf en andere patiënten in de toekomst; hoe kunnen we zelfmanagement van patiënten met chronische leverziekte verbeteren?

2. Hoe wordt het onderzoek uitgevoerd?

Het onderzoek bestaat uit een gesprek van ongeveer 30 minuten met Amber Westendorp waarin zij u enkele vragen en standpunten zal voorleggen over zelfmanagement en eHealth. Zij verricht momenteel haar wetenschappelijke stage als onderdeel van haar opleiding aan de Universiteit Twente.

3. Wat wordt er van u verwacht?

Het interview vindt plaats aansluitend aan een polibezoek of onder werktijd, u hoeft dus niet op een ander moment naar het MST te komen. De gegevens worden anoniem behandeld.

4. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u meedoet aan het onderzoek. Deelname is vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft niets te tekenen. U hoeft ook niet te zeggen waarom u niet wilt meedoen. U krijgt gewoon de behandeling die u anders ook zou krijgen, hier verandert niks aan.
Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen. Ook tijdens het onderzoek. U hoeft geen reden te geven waarom u wilt stoppen.

5. Wat gebeurt er met uw gegevens?

Voor dit onderzoek worden geen persoonsgegevens gebruikt en bewaard. Het interview wordt geanonimiseerd, dit betekent dat de gegevens niet aan u gekoppeld kunnen worden.

Bewaartermijn gegevens

Uw gegevens moeten 15 jaar worden bewaard op de onderzoekslocatie (MST). Hierna worden de gegevens vernietigd.

Bewaring en gebruik van gegevens voor ander onderzoek

Uw gegevens kunnen na afloop van dit onderzoek ook nog van belang zijn voor ander wetenschappelijk onderzoek op het gebied van levercirrose. Daarvoor zullen uw gegevens 15 jaar worden bewaard. U kunt op het toestemmingsformulier aangeven of u hier wel of niet mee instemt. Indien u hier niet mee instemt, kunt u gewoon deelnemen aan het huidige onderzoek.

Intrekken toestemming

U kunt uw toestemming voor gebruik van uw persoonsgegevens altijd weer intrekken. Dit geldt voor dit onderzoek en ook voor het bewaren en het gebruik voor het toekomstige onderzoek. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Meer informatie over uw rechten bij verwerking van gegevens

Voor algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u de website van de Autoriteit Persoonsgegevens raadplegen.

Bij vragen over uw rechten kunt u contact opnemen met de verantwoordelijke voor de verwerking van uw persoonsgegevens. Voor dit onderzoek is dat: Amber Westendorp en Maureen Guichelaar.

Bij vragen of klachten over de verwerking van uw persoonsgegevens raden we u aan eerst contact op te nemen met de onderzoek locatie. U kunt ook contact opnemen met de Functionaris voor de Gegevensbescherming van de instelling [zie contactgegeven in bijlage A] of de Autoriteit Persoonsgegevens.

6. Zijn er extra kosten of krijgt u een vergoeding wanneer u besluit aan dit onderzoek mee te doen?

Er worden alleen de kosten voor de ziekenhuisbehandeling bij u of uw zorgverzekeraar in rekening gebracht indien u patiënt bent. U maakt geen extra kosten voor het onderzoek.

- Omdat u langer blijft na afloop van het polibezoek voor het interview krijgt u parkeervergoeding (uitrijkaart) voor de parkeergarage.

7. Door wie is dit onderzoek goedgekeurd?

De Raad van Bestuur van Medisch Spectrum Twente heeft goedkeuring gegeven om dit onderzoek uit te voeren.

8. Wilt u verder nog iets weten?

U heeft het recht om deelname te overwegen en vragen te stellen voordat u beslist om toestemming te verlenen voor deelname aan het onderzoek. Mocht u na het lezen van deze informatie nog vragen hebben over het onderzoek of overige vragen, aarzel dan niet om contact op te nemen met Maureen Guichelaar (MDL arts) via telefoonnummer XXX-XXXXXXX of Amber Westendorp (student Gezondheidswetenschappen) via telefoonnummer XXXXXXXXXX.

Indien u na zorgvuldige overweging besluit deel te nemen aan dit wetenschappelijk onderzoek, dan vragen we u om samen met de onderzoeker het toestemmingsformulier te ondertekenen en van een datum te voorzien.

Wij waarderen uw betrokkenheid en kijken uit naar uw mogelijke deelname aan het onderzoek.

Met vriendelijke groet,

Amber Westendorp, student Gezondheidswetenschappen en

Maureen Guichelaar, Maag-darm en lever (MDL)-arts

Bijlage

A: contactgegevens

B: Toestemmingsformulier

Bijlage A: contactgegevens voor Medisch Spectrum Twente

Onderzoeksteam:

Dr. M.M.J. Guichelaar, MDL-arts
Afdeling maag-darm- en leverziekten (MDL) van het MST
Telefoonnummer XXX XXX XX XX

Amber Westendorp , student Gezondheidswetenschappen
telefoonnummer XX-XXXXXXXX

Patiënten Service Centrum (voor afhandeling klachten)

U kunt op verschillende manieren een klacht indienen bij het Patiënten Service Centrum.

- Vul het online klachtenformulier in (te vinden op website MST).
- Bel met het Patiënten Service Centrum, telefoon (053) 4 87 20 45.
- Kom langs bij het Patiënten Service Centrum in de centrale hal, route C02.
- Stuur een brief aan MST, t.a.v. Patiënten Service Centrum, Postbus 50 000, 7500 KA te Enschede.

Meer informatie hierover vindt u op de website van MST.

Functionaris voor de Gegevensbescherming van het MST, via email: privacy@mst.nl
Tel. (053) 487 20 00

Voor meer informatie over uw rechten:
https://www.autoriteitpersoonsgegevens.nl/

Bijlage B: Toestemmingsformulier

Titel van het onderzoek
Zelfmanagement en eHealth in patiënten met levercirrose

Ik heb de informatiebrief voor deelname aan het onderzoek gelezen. Ik kon aanvullende vragen stellen. Mijn vragen zijn genoeg beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.

Ik weet dat meedoen helemaal vrijwillig is. Ik weet dat ik op ieder moment kan beslissen om toch niet mee te doen. Daarvoor hoef ik geen reden te geven.

Ik weet dat sommige mensen mijn gegevens kunnen zien. Die mensen staan vermeld in de informatiebrief.

Ik geef toestemming om mijn gegevens te gebruiken, voor de doelen die in de informatiebrief staan.

Ik geef toestemming om mijn onderzoeksgegevens 15 jaar na afloop van dit onderzoek te bewaren.

Ik geef wel/geen* toestemming om mijn gegevens 15 jaar na afloop van dit onderzoek te bewaren, zodat dit in de toekomst misschien gebruikt kan worden voor een nieuw onderzoek

Ik wil meedoen aan dit onderzoek.

Naam deelnemer:
Handtekening: Datum : __ / __ / __

Ik verklaar hierbij dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek. Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker (of diens vertegenwoordiger):
Handtekening: Datum: __ / __ / __

Aanvullende informatie is gegeven door (indien van toepassing):
Naam:
Functie:
Handtekening: Datum: __ / __ / __ ----------

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* Doorhalen wat niet van toepassing is.

Appendix B. Interview questions patients

Interview vragen patiënten – draaiboek 30 minuten

Volgende vragen zijn aan de hand van de dimensies van SeMas, betekent niet dat deze allemaal zo gesteld hoeven te worden. In de SeMas wordt een score gegeven van 1 tm 10, aan de hand daarvan scoort iemand laag, gemiddeld, hoog op gebied van zelf-management. Dit komt neer op drie "patiëntprofielen" 1. Klaar voor zelfmanagement, 2. Geschikt voor zelfmanagement, maar met aandachtspunten, 3. Momenteel niet geschikt voor zelfmanagement (informatie uit SeMas gehaald)

Introductie onderzoek & uitleg – 5 minuten

Definitie zelfmanagement: de zorg die mensen besteden aan hun eigen gezondheid en welzijn: het gaat om de dingen die ze doen

- om gezond te leven
- om aan hun sociale, emotionele en psychologische behoeften te voldoen
- om te zorgen voor hun langdurige aandoening
- om verdere ziekte of ongelukken te voorkomen

SeMas vragen – 10-15 minuten

1. **Last van ziekte:** wat voor invloed heeft uw levercirrose op uw dagelijks leven?
   Categorie: weinig last, gemiddelde last, veel last
   Hoe gaat u er mee om? Wat zou u graag verbeterd willen hebben, gezien uw ziekte?
2. **Bereidheid tot zelfzorg (zelf meten/wegen):** bent u bereid om zelf te meten hoe het met uw ziekte gaat?
   Categorie: niet bereid, enigszins bereid, bereid
   Vervolgvragen: Waarom wil u dit niet zelf meten? Wat zou u zelf willen doen, wat niet?
3. **Invloed op gezondheid**: Denkt u dat u zelf invloed heeft op uw gezondheid, heeft u dit zelf in de hand?
   Categorie: afhankelijk van anderen, enigszins invloed, geheel zelf in de hand
   Vervolgvragen: Wat is er volgens u nodig om meer invloed te krijgen op uw eigen gezondheid/ziekte? Hoeveel bent u in uw ziekte afhankelijk van de arts, verpleegkundige, etc.?
4. **Vertrouwen in eigen kunnen**: hoeveel vertrouwen heeft u in uw eigen kunnen om uw gezondheid te veranderen?
   Categorie: weinig, enig, veel
   Vervolgvragen: Wat heeft u nodig om vertrouwen te krijgen? Wat lukt wel, wat niet, waarom niet?
5. **Hulp van anderen:** in hoeverre krijgt u hulp van anderen bij het omgaan met uw ziekte? (sociale steun)
   Categorie: alles alleen, enige hulp, veel hulp
   Vervolgvragen: is er een bepaalde reden voor waarom u geen hulp ervaart vanuit anderen? Heeft u hier zelf invloed op?

Interviewvragen eHealth – 10 minuten

Definitie eHealth: EHealth betekent elektronische gezondheidszorg. Het draait allemaal om het gebruik van computers en internet in de medische wereld. Denk aan dingen zoals: online medische dossiers, video-afspraken, medische apps. (UITLEGGEN indien nodig)

Definitie wearables: elektronische apparaten, die op het lichaam gedragen kunnen worden. In deze context betreft het een wearable die continu gegevens meet, verzameld, verwerkt en teruggeeft. Dit gaat bijv. om de hoeveelheid lichaamsbeweging of de hartslag, etc.

1. Hoe zijn uw vaardigheden met gebruik van internet (vraag uit SeMas)? Hoe zijn uw vaardigheden met smartphone? Apps? Wearables?
2. Na de diagnose van uw leverziekte: heeft u extra informatie opgezocht over uw ziekte en hoe dit te verbeteren?
    a. Zo ja: op welke manier? (internet, apps, brochures, familie, lotgenoten)
    b. Heeft dit bijgedragen aan hoe u naar de ziekte kijkt? Of hoe u met uw ziekte omgaat?
3. Wat mist u momenteel op gebied van eHealth?
    a. Evt opties: informatievoorziening, beter om gaan met ziekte, terugkoppeling over hoe het gaat, contact met specialist
4. Specifiek over wearables:
    a. Bent u bekend met het gebruik van draagbare apparaten?
    b. Zou u overwegen deze te gebruiken om uw gezondheid/ziekte te volgen? Waarom wel/niet?
    c. Welk type wearables zou u bereid zijn te gebruiken?

       Opties: polsband, smartwatch, medische patch, smartphone, smart ring, borst of buikband, anders
    d. Wat vindt u belangrijk dat een wearable meet?
    e. Waar zou u graag meer inzicht in willen krijgen?

Afsluiting – 5 minuten

Appendix C. Interview questions healthcare professionals

Interviewvragen voor zorgprofessionals omtrent zelfmanagement en eHealth – draaiboek 30 minuten

Introductie onderzoek & uitleg – 5 minuten

Definitie zelfmanagement: de zorg die mensen besteden aan hun eigen gezondheid en welzijn: het gaat om de dingen die ze doen

- om gezond te leven
- om aan hun sociale, emotionele en psychologische behoeften te voldoen
- om te zorgen voor hun langdurige aandoening
- om verdere ziekte of ongelukken te voorkomen

Vragen zelfmanagement – 10 minuten

1. **Niveau zelfmanagement:** hoe beoordeelt u het huidige niveau van zelfmanagement van uw patiënten met levercirrose?
   Categorie: geen sprake van zelfmanagement, weinig zelfmanagement, redelijk niveau, goed niveau
   Vervolgvraag: welke aspecten van zelfmanagement krijgen het meeste aandacht en welke hebben het meeste aandacht nodig? (zie definitie)
2. **Uitdagingen**: wat zijn volgens u de belangrijkste uitdagingen die patiënten met levercirrose kunnen tegenkomen bij het zelf managen van hun gezondheid?
   Vervolgvragen: hoe komt het denkt u dat juist dit de uitdagingen zijn voor deze patiëntengroep?
3. **Vertrouwen in eigen kunnen/zelfmanagement:** hoe informeert u patiënten over het belang van zelfmanagement bij levercirrose en hoe moedigt u hen aan om een actieve rol aan te nemen in de zorg voor hun aandoening? (en dus eigen kunnen bevorderen)
   Vervolgvragen: hoe zou u dit actiever kunnen doen/bevorderen? Waarom lukt dit nu nog niet? Wat heeft u hiervoor nodig?
4. **Hulpmiddelen/informatiebronnen**: welke hulpmiddelen of informatiebronnen vindt u van belang om patiënten te ondersteunen bij zelfmanagement?
   Vervolgvragen: wat is de reden dat u deze wel/niet gebruikt? Kent u hulpmiddelen of informatiebronnen waarvan u denkt dat deze eventueel als ondersteuning zouden kunnen dienen?
5. **Hulp van anderen:** in hoeverre en op welke manier betrekt u de omgeving van de patiënt bij het bevorderen van zelfmanagement?
   Categorie: De omgeving wordt er niet bij betrokken, weinig, redelijk, veel
   Vervolgvragen: Waarom niet, waarom wel? Hoe kunt u de patiënt motiveren dat hij/zij zijn/haar omgeving erbij gaat betrekken?

Vragen eHealth – 10 minuten

Definitie eHealth: EHealth betekent elektronische gezondheidszorg. Het draait allemaal om het gebruik van computers en internet in de medische wereld. Denk aan dingen zoals: online medische dossiers, video-afspraken, medische apps. (UITLEGGEN indien nodig)

Definitie wearables: elektronische apparaten, die op het lichaam gedragen kunnen worden. In deze context betreft het een wearable die continu gegevens meet, verzameld, verwerkt en deze teruggeeft. Dit gaat bijv. om de hoeveelheid lichaamsbeweging of de hartslag, etc.

1. Bent u bekend met eHealth en/of wearables en hoe denkt u dat eHealth kan bijdragen aan de zorg voor patiënten met levercirrose? (niet bekend = uitleggen)
   Bekend met eHealth → **Vervolgvragen**: Hoe bent u bekend geraakt met eHealth?
   Niet bekend → **Vervolgvragen**: Staat u ervoor open om meer te weten te komen over eHealth en hoe u dit kunt toepassen in de zorgverlening?
2. **Bekend**: Hoe is uw ervaring met het gebruik van eHealth en/of wearables in de zorg voor patiënten met levercirrose?
   Categorie: weinig, redelijk, veel
   Vervolgvragen: kunt u wat vertellen over de ervaring die u heeft met eHealth en/of wearables? Welke functie had eHealth en/of wearables in de zorgverlening voor uw patiënten?

   Niet bekend: Hoe komt het volgens u dat u nog geen ervaring heeft met eHealth of wearables?
   Vervolgvragen: Zou u nu u weet wat eHealth en/of wearables is, dit inzetten in de zorg voor patiënten met levercirrose? Waarom wel/niet?
3. Zijn er uitdagingen die u heeft ondervonden bij de implementatie van eHealth en/of wearables in de zorg voor patiënten met levercirrose, zo ja, hoe gaat u hiermee om?
   Vervolgvragen: waarom deze uitdagingen? Hoe komt dit? Hebben deze uitdagingen u tegengehouden om eHealth en/of wearables in te zetten in de zorgverlening?
4. Kunt u uitleggen welke rol eHealth, en in het specifiek wearables, volgens u kan spelen bij het ondersteunen van zelfmanagement bij patiënten met levercirrose?
   Categorie: bevorderende/belemmerende rol
   Vervolgvragen: waarom denkt u dit, kunt u dit uitgebreider uitleggen?
5. Wat zijn of kunnen volgens u de belangrijkste voor- en nadelen van het gebruik van eHealth/wearables bij patiënten met levercirrose?
   En waarom?
6. Welke vraag of vragen zou u willen stellen aan patiënten als het gaat om het gebruik van wearables voor zelf-management?

Afsluiting – 5 minuten

Appendix D. Survey questions

Vragenlijst zelfmanagement & eHealth bij chronische leverziekte

Beste belangstellende/deelnemer,

Hartelijk dank voor uw interesse in deze enquête! Hieronder vindt u meer informatie over het onderzoek.

Achtergrond leverziekten:
Een leveraandoening is een verzamelnaam voor allerlei ziekten van de lever. Enkele voorbeelden hiervan zijn: leververvetting (MASLD), levercirrose, levertumor en hepatitis. Er zijn verschillende oorzaken voor het ontstaan van leverziekten, zoals alcoholmisbruik maar ook virussen. Symptomen die kunnen voorkomen bij een leverziekte zijn onder andere zwellingen van de lever, geelzucht en vermoeidheid.

Achtergrond studie:
De enquête heeft als doel beter inzicht te krijgen in de aspecten waar patiënten met chronische leverziekten dagelijks tegenaan lopen. De enquête is onderdeel van een onderzoek dat wordt verricht in samenwerking met Medisch Spectrum Twente (MST), Universiteit Twente (UT) en Nederlandse organisatie voor toegepast-natuurwetenschappelijk onderzoek (TNO).

Uw bijdrage:
Uw deelname aan deze enquête en het invullen ervan stellen wij erg op prijs. De antwoorden op de vragenlijst worden anoniem verwerkt. Hoe meer mensen de vragenlijst invullen, des te beter de uitkomsten weergeven wat de ervaringen en behoeften van mensen met chronische leverziekten zijn. Het invullen van de vragenlijst duurt ongeveer 30-45 minuten.

Uitkomsten van de studie:
U kunt aan het eind van de vragenlijst aangeven dat u de uitkomst rechtstreeks per e-mail wilt ontvangen. Uw e-mailadres wordt in dat geval gescheiden van uw antwoorden bewaard. Dit betekent dat uw antwoorden volledig anoniem blijven.

Deelname aan deze enquête is geheel vrijwillig. Als u besluit mee te doen, kunt u op elk moment stoppen met de vragenlijst, zonder hiervoor een reden op te geven.

Het onderzoek wordt uitgevoerd door onderzoekers van het Medisch Spectrum Twente (dr. M.M.J. Guichelaar), TNO (dr. W.J. van den Brink) en de Universiteit Twente (prof. dr. ir. R.M. Verdaasdonk, dr. S.M. van den Berg en A. Westendorp).

Alle informatie die wij tijdens dit onderzoek verzamelen wordt gedurende 15 jaar beveiligd opgeslagen bij de Universiteit Twente. Alleen de betrokken onderzoekers hebben inzage in deze anonieme gegevens.
Mocht u vragen hebben over de vragenlijst of over juridische aspecten ten aanzien van het invullen van de vragenlijst, dan kunt u contact opnemen via: a.westendorp-1@student.utwente.nl.

Door hieronder 'ja, ik geef toestemming', aan te kruisen, geeft u te kennen:

- Dat u de informatie over dit onderzoek, de wijze van deelname, tijdsinvestering, gegevens en vertrouwelijkheid heeft gelezen en begrepen.
- Dat u per e-mail vragen heeft kunnen stellen over het onderzoek via het volgende e-mailadres: a.westendorp-1@student.utwente.nl
- Dat u toestemming geeft om uw anonieme antwoorden te gebruiken voor de doeleinden die op de informatiepagina beschreven staan.
- Dat u weet dat deelname vrijwillig is en u op elk moment uw deelname aan dit onderzoek terug kunt trekken, zonder opgave van reden.
- Dat u weet dat uw antwoorden en persoonlijke gegevens anoniem bewaard blijven.

○ Ja, ik geef toestemming

Hieronder volgen enkele algemene vragen over u en uw leverziekte. De vragenlijst is anoniem en de antwoorden zijn niet naar u te herleiden.

1. Wat is uw leeftijd?

_____

2. Wat is uw geslacht? (omcirkelen)
Man / Vrouw / Anders

3. Kunt u aangeven wat uw onderliggende leverziekte is?

O Chronische virale hepatitis B, C of D

O Vervetting van de lever (MASLD)

O Leverbeschadiging door alcoholgebruik

O Auto-immuun hepatitis (AIH)

O Galwegaandoening zoals Primaire Biliaire Cholangitis (PBC) of Primaire Scleroserende Cholangitis (PSC)

O Stapelingsziekte zoals Hemochromatose (ijzerstapelingsziekte), Alfa1-antitrypsine deficiëntie (A1AT) of de ziekte van Wilson (koperstapelingsziekte)

O Weet ik niet

O Anders, namelijk: _____

4. In welk jaar is de chronische leverziekte gediagnosticeerd?

_____

Levercirrose is verbindweefseling en verlittekening van de lever, ook wel leverfibrose of cirrose genoemd. Het ontstaat langzaam ten gevolge van een chronische leverontsteking. De chronische leverziekte kan verschillende oorzaken hebben, onder andere een vettige leverziekte (MASLD), ijzerstapeling (homochromatose), auto-immuunziekten en virussen.

5. Heeft u ooit de diagnose levercirrose te horen gekregen?

○ Ja

○ Nee (u kunt vraag 6 en 7 overslaan)

6. Kunt u aangeven in welk stadium van levercirrose u zich bevindt?

○ Stadium 1: gecompenseerde levercirrose, een beginnende cirrose die bij toeval wordt ontdekt. Er zijn geen klachten of verschijnselen.

○ Stadium 2: gecompenseerde levercirrose. Als er geen klachten zijn, maar eventueel wel slokdarmspataderen.

○ Stadium 3: gedecompenseerde levercirrose. Als er sprake is van (bloeding uit) slokdarmspataderen of het ontstaan van ascites (vochtophoping in de buik) en/of de aanwezigheid van hepatische encefalopathie.

7. Als u de diagnose levercirrose heeft gekregen, in welk jaar werd de diagnose gesteld?

_____

8. Heeft u naast uw leverziekte 1 of meerdere van de volgende aandoeningen, of wordt u behandeld voor 1 of meerdere van de volgende aandoeningen?

	Ja	Nee	In het verleden gehad, maar nu niet meer
… hoog cholesterol?	O	O	O
… hoge bloeddruk?	O	O	O
… diabetes (suikerziekte)?	O	O	O
… hart- en vaatziekten? (zoals hartritmestoornis, hartfalen, hartinfarct, herseninfarct, TIA etc.)	O	O	O
… problemen met gewrichten? (zoals artrose en reuma)	O	O	O
... kwaadaardigheden / kanker	O	O	O
... psychische / mentale problemen	O	O	O
... overig, namelijk: ……	O	O	O

9. Wat is uw lengte? (in cm)

_____

10. Wat is uw gewicht? (in kg)

_____

De volgende vragen gaan over uw kwaliteit van leven. Met deze vragen willen we nagaan hoe u zich de laatste tijd voelt, en hoe goed u in staat bent om uw gebruikelijke bezigheden uit te voeren.

11. Hoe zou u over het algemeen uw gezondheid noemen?

- ○ Uitstekend
- ○ Zeer goed
- ○ Goed
- ○ Matig
- ○ Slecht

12. Wordt u door uw gezondheid op dit moment beperkt bij deze bezigheden? Zo ja, in welke mate?

	Ja, ernstig beperkt	Ja, een beetje beperkt	Nee, helemaal niet beperkt
Matige inspanning, zoals het verplaatsten van een tafel, stofzuigen, zwemmen of fietsen	O	O	O
Een paar trappen oplopen	O	O	O

13. Heeft u in de afgelopen 4 weken een van de volgende problemen bij uw werk of andere dagelijkse bezigheden gehad, ten gevolge van uw lichamelijke gezondheid?

	Ja	Nee
U heeft minder bereikt dan u zou willen	O	O
U was beperkt in het soort werk of andere bezigheden	O	O

14. Heeft u in de afgelopen 4 weken een van de volgende problemen ondervonden bij uw werk of andere dagelijkse bezigheden ten gevolge van emotionele problemen (zoals depressieve of angstige gevoelens)?

	Ja	Nee
U heeft minder bereikt dan u zou willen	O	O
U deed uw werk of andere bezigheden niet zo zorgvuldig als gewoonlijk	O	O

15. In welke mate bent u de afgelopen 4 weken door pijn gehinderd in uw normale werk (zowel werk buitenshuis als huishoudelijk werk)?

- Helemaal niet
- Klein beetje
- Nogal
- Veel
- Heel erg veel

16. Hoe vaak gedurende de afgelopen 4 weken …

	Altijd	Meestal	Vaak	Soms	Zelden	Nooit
... voelde u zich levenslustig?	O	O	O	O	O	O
... was u erg zenuwachtig?	O	O	O	O	O	O
... zat u zo in de put dat niets u kon opvrolijken?	O	O	O	O	O	O
... voelde u zich rustig en tevreden?	O	O	O	O	O	O
... had u veel energie?	O	O	O	O	O	O
... voelde u zich somber en neerslachtig?	O	O	O	O	O	O
... voelde u zich uitgeput?	O	O	O	O	O	O
... was u een gelukkig mens?	O	O	O	O	O	O
... voelde u zich moe?	O	O	O	O	O	O

17. Hoe vaak hebben uw lichamelijke gezondheid of emotionele problemen u gedurende de afgelopen 4 weken gehinderd bij uw sociale activiteiten (zoals vrienden of familie bezoeken)?

- ○ Altijd
- ○ Meestal
- ○ Soms
- ○ Zelden
- ○ Nooit

Om na te gaan of eHealth/wearables kunnen worden ingezet om het zelfmanagement van patiënten met chronische leverziekten te bevorderen, vragen we u naar uw kennis en ervaring met eHealth/wearables en hoe u hier tegenaan kijkt.

Hierbij betekent **zelfmanagement** de zorg die mensen besteden aan hun eigen gezondheid en welzijn, het gaat om de dingen die ze doen om:

- Gezond te leven
- Aan hun sociale, emotionele en psychologische behoeften te voldoen
- Om te gaan met hun langdurige aandoening
- Verdere ziekte of ongelukken te voorkomen

EHealth betekent digitale gezondheidszorg, denk hierbij aan dingen zoals: online medische dossiers, video-afspraken, medische app.
Wearables zijn elektronische apparaten, die op het lichaam gedragen worden zoals een smartwatch, medische pleister of een smartphone. Een wearable meet, verzameld en verwerkt gezondheidsgegevens. Denk aan: beweging, hartslag, etc.

18. Maakt u gebruik van wearables voor het monitoren van uw gezondheid? (door middel van een smartphone, smartwatch, smartring, buik/rug band)

- ○ Ja
- ○ Nee (u kunt vraag 19 en 20 overslaan)

19. Welk type wearable gebruikt u? (U kunt meerdere antwoorden invullen)

- ○ Smartwatch
- ○ Smartring
- ○ Borst/buik/rug band
- ○ Smartphone
- ○ Anders, namelijk: _____

20. Hoe vaak maakt u gemiddeld gebruik van uw wearable(s)?

- ○ 1-2 keer per week
- ○ 3-4 keer per week
- ○ 5-6 keer per week
- ○ Dagelijks
- ○ Verschilt per wearable, namelijk: _____

21. In hoeverre bent u bereid om wearables te gebruiken om uw leverziekte te volgen? Omcirkel wat het beste bij u past, waarbij 0 = helemaal niet bereid, 10 = heel erg bereid

0	1	2	3	4	5	6	7	8	9	10

22. Welk type wearable zou u bereid zijn te gebruiken? (Er zijn meerdere antwoorden mogelijk)

- ○ Smartwatch (horloge voor meten van gezondheidsgegevens, bellen, muziek, etc.)
- ○ Smartring (ring waarmee je bijvoorbeeld bewegingen, hartslag en ademhaling kan meten)
- ○ Borst/buik/rug band (voor meten van fysieke activiteit, slaap)
- ○ Anders, namelijk: _____
- ○ Ik wil liever geen wearable gebruiken

23. Kunt u aangeven wat voor u (mogelijke) uitdagingen zijn in het gebruik van wearables? (Er zijn meerdere antwoorden mogelijk)

- ○ Te complex in gebruik
- ○ De aanschafkosten
- ○ Zorgen over privacy
- ○ Moeite met het begrijpen van de gezonsheidsgegevens
- ○ Te veel geconfronteerd worden met gezondheidsgegevens
- ○ Anders, namelijk: _____
- ○ Geen uitdagingen

24. Kunt u aangeven wat voor u (mogelijke) voordelen zijn in het gebruik van wearables? (Er zijn meerdere antwoorden mogelijk)

- ○ Meer inzicht in gezondheid en ziekte
- ○ Sneller toegang tot gezondheidsgegevens
- ○ Stimulatie voor gezond gedrag en nemen van medicatie
- ○ Beter inzicht in mijn ziekte voor de zorgprofessional
- ○ Anders, namelijk: _____
- ○ Ik verwacht geen voordelen

25. Wat zou u graag willen doen, maar wordt u momenteel te veel beperkt door klachten van uw leverziekte?

_____
_____
_____

26. Welk aspect van uw leven wordt het meest negatief beïnvloedt door de klachten van uw leverziekte?

_____
_____
_____

27. Wat wilt u voorkomen in de verdere ontwikkeling of complicaties van uw leverziekte?

_____
_____
_____

28. Welke factoren/klachten dragen volgens u bij aan de beperkingen, invloeden, en dingen die u wilt voorkomen die u heeft genoemd in de voorgaande vragen?

_____
_____
_____

29. Gegeven uw vorige antwoord, wat vindt u belangrijk dat een wearable meet? Waar zou u graag meer inzicht in willen krijgen? (omcirkelen, meerdere antwoorden mogelijk)

Slaap / Hartslag / De hoeveelheid zuurstof in het bloed / Temperatuur / Stappen / Calorieverbranding / Workouts

○ Anders, namelijk: _____

30. Wie mag er inzage hebben in de gezondheidsgegevens die de wearable meet?

○ Alleen ikzelf

○ Alleen mijn zorgverleners

○ Zowel ikzelf als mijn zorgverleners

De volgende vragen gaan over zelfmetingen en regie voeren.
Bij de volgende vragen kunt u steeds antwoorden op een schaal van 0 tot 10, waarbij 0 = helemaal niet en 10 = heel veel. Geef alstublieft bij elke vraag het getal aan dat uw mening het beste weergeeft door het getal te omcirkelen. Daarna volgen drie open vragen.

31. In hoeverre zou u graag regie willen hebben over uw leverziekte en de behandeling hiervan?

0	1	2	3	4	5	6	7	8	9	10

32. In hoeverre heeft u momenteel regie over uw leverziekte en de behandeling hiervan?

0	1	2	3	4	5	6	7	8	9	10

33. In hoeverre bent u bereid om zelfmetingen thuis te doen? (bloeddruk meten, wegen, etc.)

0	1	2	3	4	5	6	7	8	9	10

34. In hoeverre denkt u dat de inzet van eHealth (app, smartwatch, smartphone, online dossier) uw zelfmanagement kan bevorderen?

0	1	2	3	4	5	6	7	8	9	10

35. In hoeverre krijgt u hulp van anderen bij het omgaan met klachten van uw leverziekte?

0	1	2	3	4	5	6	7	8	9	10

36. Wat zou u willen doen om uw gezondheid te bevorderen?

_____
_____
_____

37. Wat draagt voor u positief bij aan zelfmanagement van uw gezondheid?

_____
_____
_____

38. Wat belemmert u bij uw zelfmanagement van uw gezondheid?

_____
_____
_____

De volgende uitspraken en uw antwoord daarop geven een idee over (mogelijkheden) van zelfmanagement in invloed op uw eigen gezondheid. Hierbij betekent zelfmanagement de zorg die mensen besteden aan hun eigen gezondheid en welzijn.
Geef alstublieft voor elke uitspraak aan in hoeverre u het er mee eens of oneens bent door het vakje te omcirkelen.

39. Uiteindelijk ben ik zelf verantwoordelijk voor mijn gezondheid.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

40. Een actieve rol op me nemen in de zorg voor mijn gezondheid, heeft de meeste invloed op mijn gezondheid.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

41. Ik heb er vertrouwen in dat ik kan bijdragen aan het voorkomen of verminderen van problemen met mijn gezondheid.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

42. Ik weet wat elk van mijn voorgeschreven medicijnen doet.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

43. Ik heb er vertrouwen in dat ik kan beoordelen of ik naar de dokter moet gaan of dat ik een gezondheidsprobleem zelf kan aanpakken.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

44. Ik heb er vertrouwen in dat ik een dokter mijn zorgen durf te vertellen, zelfs als hij of zij daar niet naar vraagt.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

45. Ik heb er vertrouwen in dat het mij lukt om medische behandelingen die ik thuis moet doen uit te voeren.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

46. Ik begrijp mijn gezondheidsproblemen en wat de oorzaken ervan zijn.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

47. Ik weet welke behandelingen er zijn voor mijn gezondheidsproblemen.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

48. Ik heb veranderingen in mijn leefstijl (zoals gezond eten of bewegen) kunnen volhouden.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

49. Ik weet hoe ik gezondheidsproblemen kan voorkomen.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

50. Ik heb er vertrouwen in dat ik zelf oplossingen kan bedenken voor nieuwe problemen met mijn gezondheid.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

51. Ik heb er vertrouwen in dat ik veranderingen in mijn leefstijl (zoals gezond eten en bewegen) kan volhouden, zelfs in tijden van stress.

Helemaal niet mee eens	Niet mee eens	Mee eens	Helemaal mee eens	Niet van toepassing

Onderstaande vragen hebben betrekking op de informatie die u heeft gekregen van uw zorgverlener(s) en uw behoefte aan informatie.

52. Van wie heeft u informatie ontvangen over uw leverziekte?

	Ja	Nee
Van de huisarts	O	O
Van de maag-darm-lever arts	O	O
Van de diëtiste	O	O
Van de fysiotherapeut	O	O
Van de verpleegkundig specialist	O	O
Anders, namelijk:	O	O

53. Hoeveel informatie heeft u gekregen over ...

	Geen informatie	Weinig informatie	Voldoende informatie
... wat uw leverziekte is?	O	O	O
… wat de oorzaken van uw leverziekte zijn?	O	O	O
… wat de gevolgen kunnen zijn op lange termijn?	O	O	O
... mogelijke behandelingen voor deze gevolgen?	O	O	O
… wat ik zelf kan doen om zo lang mogelijk gezond te blijven?	O	O	O
... hoe ik mijn voedingspatroon kan verbeteren?	O	O	O
... hoe ik mijn beweegpatroon kan verbeteren?	O	O	O
… hoe ik in contact kan komen met lotgenoten?	O	O	O
... welke apps/websites er zijn met goede informatie over uw leverziekte?	O	O	O

54. Had u graag meer informatie willen hebben over ...

	Ja	Nee
... wat uw leverziekte is?	O	O
... wat de oorzaken van uw leverziekte zijn?	O	O
... wat de gevolgen kunnen zijn op lange termijn?	O	O
... mogelijke behandelingen voor deze gevolgen?	O	O
... wat ik zelf kan doen om zo lang mogelijk gezond te blijven?	O	O
... hoe ik mijn voedingspatroon kan verbeteren?	O	O
... hoe ik mijn beweegpatroon kan verbeteren?	O	O
... hoe ik in contact kan komen met lotgenoten?	O	O
... welke apps/websites er zijn met goede informatie over uw leverziekte?	O	O

Hieronder volgen een aantal laatste algemene vragen over u en uw dagelijks leven. Deze vragen zijn bedoeld om een nog beter beeld te krijgen van de deelnemers aan deze enquête.

55. Hoeveel minuten per week beweegt u (ten minste) matig intensief?
"Bij matig intensief bewegen gaan je hartslag en ademhaling omhoog. De inspanning kost moeite maar je kunt er nog wel bij praten. Bijvoorbeeld fietsen, wandelen of tuinieren."

O Ik beweeg zelden of nooit matig intensief

O Minder dan 60 minuten per week

O 60 tot 120 minuten per week

O 120 tot 150 minuten per week

O 150 minuten per week of meer

O 150 minuten per week en daarbij zelfs intensieve inspanning (zoals tennis, hardlopen of wielrennen).

56. Hoe vaak per week doet u spier- en botversterkende oefeningen?
"Activiteiten bestaande uit krachttraining en activiteiten waarbij het lichaam met het eigen gewicht wordt belast, zoals springen, gewichtheffen, traplopen, wandelen, hardlopen en dansen."

O Zelden of nooit

O Ongeveer 1x per week

O Ongeveer 2x per week

O Ongeveer 3x per week

O 4x per week of vaker

57. Volgt u een dieet?

O Ja, namelijk: _____

O Nee

58. Drinkt u wel eens alcohol?

O Ja

O Nee (u kunt vraag 35 overslaan)

59. Hoe vaak drinkt u alcohol?

O Dagelijks

O Vaker dan 1 keer per week

O 1 keer per week

O Ongeveer 1 tot 3 keer per maand

O Minder dan 1 keer per maand

60. Wat doet u op dit moment zelf nog meer om uw gezondheid te bevorderen?

_____
_____
_____

61. Hoe ziet uw daginvulling eruit?

O Ik studeer

O Ik werk ... uur per week _____

O Ik ben werkloos/werkzoekend

O Ik zit in de ziektewet

O Ik ben (gedeeltelijk) afgekeurd

O Ik ben met pensioen

O Overig, namelijk: _____

62. Als u werkt hoe ziet uw werkactiviteit eruit?

○ Voornamelijk fysieke activiteit

○ Voornamelijk zittend

○ Een mix van beiden

63. Tot slot: wat is uw hoogst afgeronde schoolopleiding?

- ○ Geen opleiding
- ○ Basisonderwijs
- ○ Vmbo, havo-, vwo-onderbouw, mbo 1
- ○ Havo, vwo, mbo 2-4
- ○ Hbo-, universiteit-bachelor
- ○ Hbo-, universiteit-master
- ○ Anders, namelijk: _____

Dit is het einde van de vragenlijst. Hartelijk dank voor uw deelname!
Benieuwd naar de uitkomsten van dit onderzoek? Indien u de uitkomsten per e-mail wilt ontvangen, dan kunt u hieronder uw e-mailadres invullen. Uw e-mailadres wordt gescheiden van uw antwoorden bewaard en niet voor andere doeleinden gebruikt.

✂ ----------

Ik wens de uitkomsten van dit onderzoek per e-mail te ontvangen.

- ○ Ja, mijn e-mailadres is: _____
- ○ Nee

Appendix E. Tables results

Table 11: Demographic characterisitics (n = 188)

			Liver cirrhosis		
	Whole sample (n=188) *n (%)*	Other liver disease (n=108)	Liver cirrhosis (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)
Gender					
Female	137 (73)	83 (77)	54 (68)	40 (70)	14 (61)
Male	51 (27)	25 (23)	26 (33)	17 (30)	9 (39)
Age (yrs), M ± SD	58 ± 12	57 ± 13	60 ± 11	60 ± 11	58 ± 11
Highest education					
Primary	1 (1)	1 (1)	0 (0)	0 (0)	0 (0)
Secondary	79 (42)	40 (37)	39 (49)	31 (54)	8 (35)
Tertiary	108 (57)	67 (62)	41 (51)	26 (46)	15 (65)
Employment status					
Employed	69 (37)	39 (36)	30 (38)	21 (37)	9 (39)
Mostly physical	7 (10)	3 (8)	4 (13)	3 (14)	1 (11)
Physical/sedentary	22 (32)	13 (33)	9 (30)	6 (29)	3 (33)
Mostly sedentary	40 (58)	23 (59)	17 (57)	12 (57)	5 (56)
Unemployed	99 (53)	58 (54)	42 (53)	30 (53)	12 (52)
Sick leave	11 (11)	6 (10)	5 (12)	4 (13)	1 (8)
Disabled to work	36 (36)	19 (33)	17 (40)	11 (37)	6 (50)
Retired	51 (52)	32 (55)	19 (45)	14 (47)	5 (42)
Other[2]	20 (11)	11 (10)	8 (10)	6 (11)	2 (9)

Table 12: (Self)reported medical and lifestyle characteristics of the participants (n = 188)

			Liver cirrhosis		
	Whole sample (n=188) *n (%)*	Other liver disease (n=108)	Liver cirrhosis (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)
Liver disease					
Viral hepatitis B, C or D	1 (0.5)	1 (1)	0 (0)	0 (0)	0 (0)
Auto-immune hepatitis (AIH)	87 (46)	51 (47)	36 (45)	27 (47)	9 (39)
PBC / PSC	62 (33)	38 (35)	24 (30)	18 (32)	6 (26)
Storage diseases	4 (2)	1 (1)	3 (4)	1 (2)	2 (9)
Fatty liver disease (MASLD)	3 (2)	1 (1)	2 (3)	2 (4)	0 (0)
Other[3]	31 (17)	16 (15)	15 (19)	9 (16)	6 (26)
Time since diagnosis (yrs), median (IQR)	12 (17)	8 (14)	15 (21)	17 (22)	11 (20)
Time since diagnosis liver cirrhosis (yrs), median (IQR)	9 (15)		9 (15)	8 (19)	9 (11)
Comorbidity [a]					
Hypercholesterolemia	32 (17)	18 (17)	14 (18)	10 (18)	4 (17)
Diabetes mellitus	28 (15)	14 (13)	14 (18)	9 (16)	5 (22)
Cardiovascular diseases	27 (15)	17 (16)	10 (13)	5 (9)	5 (22)
Joint problems	56 (30)	30 (28)	26 (33)	18 (33)	8 (35)
Malignancies/cancer	21 (11)	6 (6)**	15 (19)**	13 (24)	2 (9)
Mental health problems	43 (23)	24 (22)	19 (24)	13 (24)	6 (26)
Other[4]	67 (36)	47 (46)	22 (32)	16 (32)	6 (26)
No comorbidities	41 (22)	24 (23)	17 (22)	13 (24)	4 (17)

BMI (kg/m2), mean ± SD	26 ± 5	26 ± 4	27 ± 5	27 ± 5	26 ± 4
Sufficient NNGB					
Moderate intensity	78 (42)	50 (46)	28 (35)	20 (35)	8 (35)
Muscle-strengthening	119 (63)	68 (63)	51 (64)	37 (65)	14 (61)
Alcohol	36 (19)	22 (20)	14 (18)	11 (19)	3 (13)
Daily	1 (3)	1 (5)	0 (0)	0 (0)	0 (0)
> 1 / week	5 (14)	3 (14)	2 (14)	2 (18)	0 (0)
Once a week	11 (31)	7 (32)	4 (29)	4 (36)	0 (0)
1-3 / month	8 (22)	3 (14)	5 (36)	3 (27)	2 (67)
< 1 / month	11 (31)	8 (36)	3 (21)	2 (18)	1 (33)
Adherence to diet	49 (26)	28 (26)	21 (26)	17 (30)	4 (17)

Table 13: Wearable usage (n = 188)

				Liver cirrhois	
	Whole sample *n (%)*	Other liver disease (n=108)	Liver cirrhosis (n=80)	Compensated cirrhosis (n=57)	Decompensated cirrhosis (n=23)
Wearables to monitor health	70 (37)	45 (42)	25 (31)	18 (32)	7 (30)
Wearables current use					
Smartwatch	50 (27)	36 (33)**	14 (18)**	9 (16)	5 (22)
Smartring	1 (0.5)	0 (0)	1 (1)	1 (2)	0 (0)
Smartphone	38 (20)	25 (23)	13 (16)	8 (14)	5 (22)
Band	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Other[5]	7 (4)	3 (3)	4 (5)	3 (5)	1 (4)
Daily use (current use)					
Smartwatch	39 (21)	28 (26)	11 (14)	6 (11)	5 (22)
Smartphone	33 (18)	22 (20)	11 (14)	6 (11)	5 (22)
Willing to use					
Smartwatch	140 (75)	81 (75)	59 (74)	40 (70)	19 (83)
Smartring	75 (40)	43 (40)	32 (40)	21 (37)	11 (48)
Band	40 (21)	23 (21)	17 (21)	13 (23)	4 (17)
None	40 (21)	23 (21)	17 (21)	13 (23)	4 (17)
Barriers					
Too complex to use	32 (17)	20 (19)	12 (15)	11 (19)	1 (4)
Expensive	71 (38)	38 (35)	33 (41)	22 (39)	11 (48)
Privacy	39 (21)	24 (22)	15 (19)	11 (19)	4 (17)
Difficulty understanding health data	11 (6)	4 (4)	7 (9)	6 (11)	1 (4)
Too confronting	56 (30)	32 (30)	24 (30)	17 (30)	7 (30)
No challenges	53 (28)	34 (32)	19 (24)	13 (23)	6 (26)
Advantages					
More insight	139 (74)	81 (75)	58 (73)	42 (74)	16 (70)
Quicker access	64 (34)	45 (42)**	19 (24)**	16 (28)	3 (13)
Motivation	83 (44)	48 (44)	35 (44)	29 (51)	6 (26)
Insight professional	104 (55)	59 (55)	45 (56)	34 (60)	11 (48)
No advantages	27 (14)	16 (15)	11 (14)	8 (14)	3 (13)
Measurements					
Sleep	110 (59)	64 (59)	46 (58)	34 (60)	12 (52)
Heart rate	101 (54)	64 (59)	37 (46)	29 (51)	8 (35)
Saturation	88 (47)	56 (52)	32 (40)	26 (46)	6 (26)
Temperature	52 (28)	32 (30)	20 (25)	13 (23)	7 (30)
Steps	85 (45)	52 (48)	33 (41)	22 (39)	11 (48)
Calories	70 (37)	39 (36)	31 (39)	23 (40)	8 (35)
Workouts	52 (28)	32 (30)	20 (25)	13 (23)	7 (30)

Insight					
Only participant	39 (21)	26 (24)	13 (16)	11 (19)	2 (9)
Only professional	4 (2)	1 (1)	3 (4)	2 (4)	1 (4)
Both	145 (77)	81 (75)	64 (80)	44 (77)	20 (87)

Table 14: Wearable usage by gender and education level (n = 188)

	Female (n=137)	Male (n=51)	Primary/secondary (n=75)	Tertiary (n=106)
Wearables to monitor health	53 (39)	17 (33)	24 (32)	41 (39)
Wearables current use				
Smartwatch	38 (28)	12 (24)	14 (19)	32 (30)
Smartring	1 (0.7)	0 (0)	0 (0)	1 (0.9)
Smartphone	28 (20)	10 (20)	15 (20)	22 (21)
Band	0 (0)	0 (0)	0 (0)	0 (0)
Other[5]	6 (4)	1 (2)	2 (3)	3 (3)
Daily use (current use)				
Smartwatch	29 (21)	10 (20)	13 (18)	23 (22)
Smartphone	24 (18)	9 (18)	13 (18)	19 (18)
Willing to use				
Smartwatch	105 (77)	35 (69)	57 (77)	78 (74)
Smartring	62 (45)**	13 (26)**	21 (28)**	51 (48)**
Band	30 (22)	10 (20)	16 (22)	22 (21)
None	25 (18)	15 (29)	16 (22)	21 (20)
Barriers				
Too complex to use	22 (16)	10 (20)	15 (20)	13 (12)
Expensive	54 (39)	17 (33)	31 (42)	35 (33)
Privacy	34 (25)**	5 (10)**	12 (16)	26 (25)
Difficulty understanding health data	9 (7)	2 (4)	7 (10)	2 (2)
Too confronting	42 (31)	14 (28)	25 (34)	29 (27)
No challenges	38 (28)	15 (29)	18 (24)	33 (31)
Advantages				
More insight	105 (77)	34 (67)	54 (73)	80 (76)
Quicker access	47 (34)	17 (33)	25 (34)	37 (35)
Motivation	64 (47)	19 (37)	34 (46)	45 (43)
Insight professional	77 (56)	27 (53)	42 (57)	56 (53)
No advantages	19 (14)	8 (16)	10 (14)	15 (14)
Measurements				
Sleep	85 (62)	25 (49)	48 (65)	58 (55)
Heart rate	78 (57)	23 (45)	40 (54)	57 (54)
Saturation	69 (50)	19 (37)	35 (47)	52 (49)
Temperature	37 (27)	15 (29)	19 (26)	31 (29)
Steps	68 (50)	17 (33)	34 (46)	47 (44)
Calories	52 (38)	18 (35)	29 (39)	39 (37)
Workouts	40 (29)	12 (24)	21 (28)	29 (27)
Insight				
Only participant	32 (23)	7 (14)	9 (12)**	28 (26)**
Only professional	2 (2)	2 (4)	3 (4)	0 (0)
Both	103 (75)	42 (82)	62 (84)	78 (74)