



Liver cirrhosis turns life into an unpredictable roller-coaster: A qualitative interview study

Short Running title

Liver cirrhosis turns life unpredictable

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Contribution of paper

All authors designed the study together. The corresponding author conducted all interviews. The first and last author did the initial inductive data analysis. The final data analysis was discussed and consented to by all authors. The first and last author developed a first draft of the article. All authors then contributed to the manuscript, and finalised it together. All authors have read and approved the final manuscript.

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ABSTRACT

Aim: To explore how persons living with liver cirrhosis experience day-to-day life.

Background: Liver cirrhosis is the sixth most common cause of death among adults in Western countries. Persons with advanced liver cirrhosis report poor quality of life, in comparison with other chronic diseases. However, knowledge regarding day-to-day life during earlier stages of the disease is lacking. In other chronic diseases, the suffering process is well explored, while in liver cirrhosis suffering is insufficiently investigated.

Design: An exploratory study, with a qualitative inductive interview approach.

Methods: A purposive maximum variation sample of 20 informants with liver cirrhosis aged 25-71, from two gastroenterology outpatient clinics in mid-Sweden, were interviewed from September 2016 to October 2017. Interview data were analysed inductively with qualitative content analysis. Reporting followed the COREQ guidelines.

Results: The experiences of day-to-day life living with liver cirrhosis comprised four sub-themes. Living with liver cirrhosis implied *varying levels of deterioration*, the most apparent being exhaustion or tiredness. The informants had to find ways of *adapting to a new life situation*. The insecurity of future health evoked existential reflections such as *feeling emotionally and existentially distressed*. Shame and guilt were reasons for *feeling stigmatised*. These sub-themes emerged into one overarching theme of meaning: *life turns into an unpredictable roller-coaster*. This is based on experiences of liver cirrhosis as an unpredictable disease with fluctuating symptoms, worries and disease progression.

Conclusion: Living with cirrhosis implies an unpredictable condition with a progressive, stigmatising disease. The fluctuating symptoms and deep concerns about future life pose an increased personal suffering.

Relevance to clinical practice: Within healthcare, knowledge of the person's experience is vital to enable and fulfil the person's healthcare needs. Clinical registered nurses need a person-centred approach to strengthen their patients to cope with their new life situation.

KEYWORDS

Chronic illness, Experiences, Interview, Liver cirrhosis, Nursing, Patients, Qualitative research, Suffering, Patient-centred care

What does this study contribute to the wider global community?

- Globally the population living with liver cirrhosis is growing. This is mainly due to an increased prevalence of obesity.
- Almost all informants experienced extreme tiredness, threats to their future health and reduced social life. The tiredness could be periodic, constant or occur unexpectedly, which influenced both day-to-day and social life.
- The variation regarding whether the interviewed persons noticed the disease at all, or felt that it permeated everything in their day-to-day life, highlights the need of a

person-centred approach. To achieve person-centred care, registered nurses specialised in hepatology have a significant role in the healthcare team.

1. BACKGROUND

This paper focus on day-to-day life experiences of persons living with liver cirrhosis. Liver cirrhosis is a chronic disease affecting persons' health related quality of life (Younossi et al., 2001) globally. The central parts of nursing care, to relieve the multidimensional aspects of suffering, are well explored following other chronic diseases (Hueso Montoro et al., 2012). According to Flagg (2015), the concept of person-centred care involves an alliance between the patient and healthcare provider in collaboration towards shared understanding and goalsetting. Awareness of the person's experiences of living with the disease is vital to optimize a holistic person-centred care (Fridlund, 2014). However, knowledge of how person-centred care shall be performed in liver cirrhosis is largely unknown (Saberifiroozi, 2017). Morse's theory of suffering (Morse, 2003) will be used to interpret and understand the results of experiences regarding liver cirrhosis.

Liver cirrhosis is the sixth most common cause of death among adults in developed countries (Lim & Kim, 2008), resulting in 170,000 deaths per year in Europe (Blachier, Leleu, Peck-Radosavljevic, Valla, & Roudot-Thoraval, 2013), and is the final stage of longstanding chronic liver disease of different aetiology (Nusrat, Khan, Fazili, & Madhoun, 2014). The mean age at diagnosis is 60 years, and about two-thirds are men (Nilsson, Anderson, Sargenti, & al., 2016). The disease is characterised by a numerous symptoms, for example fluid retention (ascites), various degree of confusion due to hepatic encephalopathy, acute gastrointestinal bleeding from varices, or bacterial infections (Nusrat et al., 2014). At the time of diagnosis, almost 50% of patients present one or more symptoms (Nilsson et al., 2016). When liver disease advances to liver cirrhosis, the person's health-related quality of life successively decreases (Younossi et al., 2001). Unless a curative liver transplant is possible, the symptom management is palliative (Langberg, Kapo, & Taddei, 2018).

The World Health Organization (1995) defines health as a condition of complete physical, mental and social well-being, not just absence of disease. A physiological health dysfunction defines a disease, while being hindered from achieving vital goals due to physical or psychological dysfunction defines illness (Nordenfelt, 2006). In chronic diseases, other than liver cirrhosis, progressive physical and social losses have negative impact on the dignity of the affected person (van Gennip, Pasma, Oosterveld-Vlug, Willems, & Onwuteaka-Philipsen, 2015). Also, illness representation, namely the person's beliefs and expectations of the illness (Pai, Li, Tsai, & Pai, 2019), energy loss and/or a chronic tiredness, often referred

to as fatigue, affect the patient's psychological well-being (Zwarts, Bleijenberg, & van Engelen, 2008). The perspectives of disease and illness may have synergistic effects on each other (DeJean, Giacomini, Vanstone, & Brundisini, 2013; Nordenfelt, 2006). Conversely, experience of illness does not necessarily correspond to the grade of physiological disease (Wikman, Marklund, & Alexanderson, 2005). Inasmuch, in presence of a disease a person experience a synergistic combination of physical and psychological illness, sometimes difficult to distinguish.

Disease in this study relates to the physical liver damage, while illness is used in terms of person's experiences of the disease. Reaction to a disease or illness depends on an individual's internal sense of coherence, involving three components: comprehensibility, manageability and meaningfulness (Antonovsky, 1987). A person with high level of coherence often finds life manageable and meaningful, whereas one with low sense of coherence often feels unfortunate, is more passive and has a sense that existence is incomprehensible (Antonovsky, 1987). An increased understanding and coherence to one's illness is commonly followed by decreased depression or anxiety (Pai et al., 2019). One's social context influences the use of healthcare, and adaptation to self-management or lifestyle changes (Cockerham, Hamby, & Oates, 2017). To successfully transform lives into a new normality and "positive living" despite a chronic disease, people first have to develop qualifications of acceptance, coping, self-management, integration and adjustment (Ambrosio et al., 2015). If a person is unsuccessful, the process may end with negotiation or partial control of the new situation. The transformation may be interrupted by deteriorating health (Ambrosio et al., 2015). In a meta-analysis, Montoro et al. (2012) concluded that fear was a core feeling of suffering that is also shared with relatives. The concept of suffering thus seems to be central and a frequently discussed topic within nursing and contemporary healthcare literature (Milton, 2013).

1.1 Theoretical framework

According to nursing research, suffering has developed from something that should be discouraged, to being regarded as part of life, and even something that can bring meaning to life (Travelbee, 1997). Suffering is a broader concept than illness, which involves both physical, psychological and spiritual aspects of one's life together with others. According to Janice Morse (2003), a chronic disease is likely to transfer a person into suffering. She further argues that the person may "turn off" and hold back feelings, making suffering invisible to

others. “Turning off” delineates a survival strategy, when suffering feels insufferable, and one lacks capacity to approach suffering. Morse explains this phase as *enduring*. Since the restrained feelings must be expressed, the individual can *escape from enduring* during short episodes, for example, by expressing anger over minor matters. Thereafter, a *transition* occurs by entering the next phase of *emotionally released suffering*. In this phase, the person expresses feelings through e.g. moaning, sobbing, crying or constantly weeping. The person can also *escape from suffering*, for example, through sleeping, drinking or overeating, in trying to remove him or herself from the situation. Escape from suffering provides a temporary relief, since suffering consumes considerable energy. It is possible to move back and forth between these phases. Morse argues that in this way a person gradually moves from suffering towards acceptance and *self-reformulation* (Morse, 2003). Self-reformulation can be seen as an end-product of suffering, which teaches the person new perspectives on life, and makes them wiser (Mayan, Morse, & Eldershaw, 2006). Morse’s theory of suffering will be used to discuss the findings of the present study.

Liver cirrhosis is medically complex (Nusrat et al., 2014). Compared to healthy persons, liver cirrhosis is associated with poor health related quality of life, equivalent to other chronic diseases (Younossi et al., 2001). Fatigue (Kim, Oh, Lee, Kim, & Han, 2006a), psychological distress (Kim, Oh, & Lee, 2006b) and abdominal symptoms (Kalaitzakis, Josefsson, & Bjornsson, 2008) are most frequently reported. Symptoms due to liver disease increase when the disease progresses (Nusrat et al., 2014). Persons with liver cirrhosis generally have low knowledge about the disease (Volk, Fisher, & Fontana, 2013), which increases illness and preventable hospital admissions (Volk, Tocco, Bazick, Rakoski, & Lok, 2012). To perform nursing care for patients with liver cirrhosis, in order to reduce suffering (Milton, 2013; Orem, 1980) and to achieve patient-centred care, registered nurses need increased understanding of how the population experiences the illness (Fridlund, 2014). The experiences of living with liver cirrhosis have mainly been studied in advanced disease (Abdi, Daryani, Khorvash, & Yousefi, 2015; Fagerstrom & Hollman Frisman, 2017). Day-to-day experiences of living with this disease from time of diagnosis to advanced disease are thus lacking. This study aims to explore how persons living with liver cirrhosis experience day-to-day life.

2. METHODS

2.1 Design

The study has an exploratory design, with a qualitative interview inductive approach. Semi-structured interviews were performed and analysed with qualitative content analysis according to Krippendorff (2018) and Graneheim and Lundman (2004; 2017).

2.2 Settings and participants

Inclusion criteria were: (I) diagnosis of liver cirrhosis, confirmed by laboratory results, ultrasound or computer tomography, set at minimum 6 months prior to the interview, (II) age between 18 to 80, and (III) fluency in Swedish. Exclusion criteria were: (I) advanced comorbidity such as chronic obstructive lung disease, chronic heart failure, current malignant disease, psychosis, and (II) persistent symptomatic hepatic encephalopathy grade 2 to 4 ("Hepatic encephalopathy in chronic liver disease: 2014 practice guideline by the European Association for the Study of the Liver and the American Association for the Study of Liver Diseases," 2014).

To ensure a variation of experiences among the informants, they were recruited at two gastroenterology outpatient clinics: One university hospital and one rural hospital in mid Sweden. After review of medical records, a maximum variation sampling technique was used, involving purposive selection of informants (Polit & Beck, 2012). Variation was sought based on gender, age, disease aetiology and severity, time since diagnosis, vocation etcetera (Table 1). Information letters were sent from August 2016 to May 2017. Within two weeks, each informant was called and invited to participate in the study. Based on those who accepted participation, the next five informants were strategically chosen. Twenty out of forty-seven respondents accepted participation (Table 1). All authors were involved in the recruitment process, but the corresponding author collected all interview data. Child Pugh score (Durand & Valla, 2008) was used as a demographic measure of liver disease severity. A majority of the informants had mild to moderate liver cirrhosis, Child Pugh A, at the time of the interview. Seven informants with Child Pugh A had previously experienced at least one episode of a more advanced disease, Child Pugh B or C. The psychometric hepatic encephalopathy score (Weissenborn, Ennen, Schomerus, Norbert, & Hartmut, 2001) was used to detect asymptomatic or mild hepatic encephalopathy at the time of each interview. One informant with symptomatic hepatic encephalopathy during periods had mild hepatic encephalopathy at the time of the interview.

2.3 Data collection

All 20 semi-structured interviews were conducted face-to-face by the corresponding author who had no previous care-provider relationship with the informants. The interview guide was tested in one pilot interview. To increase depth of the informants' narratives, two additional probing questions were added to the interview-guide. The pilot interview was not included in the study. The following 20 interviews were conducted from September 2016 to October 2017 in a quiet room at the hospital. The interview-guide included five open questions: "Please tell how it is for you to live with liver cirrhosis?", "How did you first notice the liver cirrhosis?", "Tell me about days when you feel good", "Tell me about days when you feel worse", and "What would you need to make your everyday life easier?" To gain a deeper understanding, each question was followed by more specific and probing questions, such as: "Tell me more", "How does that affect your day-to-day life?", "What are the differences in your life today compared to the life you lived before you were diagnosed with liver cirrhosis?" or "How do you manage that?" The interviews were audio recorded and transcribed verbatim. Interviews ranged from 24 to 108 minutes (mean 65), comprising a total of 22 interview hours. Demographic data were collected after each interview.

2.4 Data analysis

Inductive qualitative content analysis was performed in a systematic process (Graneheim & Lundman, 2004; Graneheim et al., 2017; Krippendorff, 2018). First, an overview of the whole content of the transcriptions was grasped by repeatedly reading through the text (Graneheim & Lundman, 2004; Krippendorff, 2018). *Meaning units* answering the study purpose were then chosen, condensed (Graneheim & Lundman, 2004) and named with a *code* (Graneheim & Lundman, 2004; Krippendorff, 2018), closely reflecting the text content. The codes were sorted into exhaustive and mutually exclusive *categories* (Graneheim & Lundman, 2004; Krippendorff, 2018). To explain 'what is going on', eleven categories were abstracted into four *sub-themes* (Graneheim & Lundman, 2004). Finally, one *theme of meaning* (Graneheim et al., 2017; Krippendorff, 2018) emerged enlightening 'the meaning of the informants' stories' regarding living with liver cirrhosis. NVivo software [NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018] was used for initial sorting of data. Thereafter, an alteration in-between software and manual analysis was performed to facilitate the process and give an overview of the data. Two of the five authors had no previous knowledge on liver cirrhosis, which contributed to minimising preconceptions in the analysis. Interviews and analysis were performed in Swedish. Verbatim quotations were translated into English by a professional interpreter.

2.5 Ethical considerations

The Regional Ethical Board in Uppsala, Sweden approved the study in 2016. The informants provided signed informed consent after receiving written and oral information about the study. To ensure transparency, the reporting followed the Consolidated criteria for Reporting Qualitative Research guidelines (Supplementary File 1) (Tong, Sainsbury, & Craig, 2007).

3. FINDINGS

The data analysis of how the 20 interviewed persons living with liver cirrhosis experience day-to-day life resulted in fifty-one codes sorted into eleven categories (Table 2). Through abstraction, four sub-themes: ‘Varying levels of deterioration’, ‘adapting to a new life situation’, ‘feeling emotionally and existentially distressed’ and ‘feeling stigmatised’ were identified. A theme of meaning reflecting the underlying message of the sub-themes was identified and titled ‘life turns into an unpredictable roller-coaster’ (Table 2). The findings will be further described below under sub-theme and theme of meaning headings, with categories written in italics.

3.1 Varying levels of deterioration

The informants described a multifaceted illness experience as the liver cirrhosis changed *from unnoticeable to noticeable disease* with numerous noticeable signs. In addition, the disease progression fluctuated, from slow progression to rapid fluctuation on a day-to-day basis, and even from one moment to another. Some informants experienced no actual physical limitations due to the disease. They expressed a difficulty in understanding the seriousness of the disease and lived their lives unhindered, neglecting the disease severity:

Since I don't feel bad. Then, you don't think it's serious either ... I live normally.

(Informant 20)

One third of the informants had recovered after periods of acute symptoms and illness. They expressed a sense of physical healing, getting stronger and gaining weight. During asymptomatic periods, they felt appreciation, and were aware that illness feelings might become intensified.

Many informants described changed bodily appearance and/or discomfort, such as rapid weight loss, tumescent body due to fluid retention, yellow skin colour, skin “spiders”, contusions, extreme tiredness, gastrointestinal symptoms, muscle weakness or pain. Most of

the informants described extreme tiredness to a various degree. Some felt physical exhaustion they had never experienced earlier in life. The exhaustion could be present in periods, part of the day or constantly, and affected their ability to concentrate as well as their social life. The manifestation of the disease varied *from gradual to quick progression* and deterioration could be with day-to-day or even hourly variations:

It is very different day-to-day ... how much do I cope ... sometimes ... I don't go outdoors ... It can be different in the morning and afternoon ... you are very perky in the morning ... you have thought damn now I will ... go and visit the grandchildren ... but then when it is noon when the bus is going to go, then I feel in my legs; no, it is not possible, I should probably go to bed and rest. (Informant 6)

I ... felt, boom, boom, my pulse ... I was so breathless from just going up a flight of stairs ... I couldn't figure out what it was ... then, I had a haemoglobin test ... it was at 34 ... then the blood had slowly leaked ... I had become used to it ... I never fainted ... I was so tired. (Informant 7)

Such acute episodes led to reflection and awareness of the serious health state. Some described moments of well-being to be rare and their lives as a struggle to survive.

3.2 Adapting to a new life situation

The new life situation with liver cirrhosis, resulted in an interest to *optimise health based on requirements and ability*. The majority had to make priorities due to lack of energy, and others performed self-care to relieve symptoms. Half of the informants were advised by the physician to make lifestyle changes, for example, stop drinking alcohol, reduce salt intake, drink less fluids and be more physically active. These requirements were sometimes recognised as a sacrifice that made life dull. Informants treated with diuretics or laxatives reported that they often had to stay close to toilets, usually at home, compelling them to choose between social activities or adhering to prescribed medication:

I have no problem eating that medicine, but ... I have to plan ... I have to go to the toilet quite often ... then I never get outside ... because I have to have access to the toilet all the time ... I have diarrhoea. So ... I will certainly start to take that when things have gone a little too far. (Informant 18)

Three out of nine informants who held an employment could not work at all. Those who worked experienced sensitivity for stress, leading to increased need for peace, quietness and rest during the workday. Some informants had to compensate for sleep by taking sick leave to recover. One informant expressed adaption in sexuality due to impotence and instead expressed love through endearment and affection. The illness prompted the informants to learn more about the disease, for example recognising acute symptoms and possible ways to optimise health. They searched the information on websites, or from healthcare professionals. The information was sometimes found to be inexplicit and difficult to understand by the informants.

A few informants reported having to *become dependent on relatives*, for example, partners and children, regarding practical issues or to feel safe. Relatives were perceived as being their ‘safety lines’ in acute situations. When relatives reacted on, for example, early symptoms of confusion, informants felt more secure. Relatives could also facilitate day-to-day life by helping out with practical matters, e.g. medicine intake, shopping, cooking or cleaning. Those informants who were still working reported that colleagues had supported them in performing tasks, when needed:

I have a work buddy ... she notices immediately and then she takes on a greater responsibility ... then, I get to take it a little easier. (Informant 2)

3.3 Feeling emotionally and existentially distressed

A majority of informants experienced that liver cirrhosis made them uncertain and to *worry about the future*. Some were concerned whether their goals and dreams in life would be fulfilled. They were also concerned about the unpredictable state of their liver, the potential risk of cancer and whether they would get a liver transplantation, or not.

A little scary that you can't see any signs ... but a lot of things might just happen in the body and you don't know about it. (Informant 9)

Some expressed inability to plan activities, and worried that the next day might be worse than they expected. Beyond the future physical concerns, some informants in working age were also worried about their future economic situation. Others described the *loss of social relations* when activities declined due to exhaustion. They had to prioritise between work, family or leisure when they felt unable to do anything but rest. The informants felt that others

failed to understand the tiredness and inability they had to manage activities like others, which made some informants sad:

[It is] *Hard for others to understand that I am tired and that I don't have any energy to do things; I think that is difficult ... with friends and so on, that you are boring.*

(Informant 9)

Three of the informants had been recommended to abstain from having biological children or had been denied to adopt children due to the liver disease. For those, childlessness meant feelings of grief. Others explained the disease as an obstacle to find a partner.

Half of the informants reported to *find it difficult to talk about the disease* and kept their anxieties and feelings to themselves in order to spare close relatives from worry. Since the liver disease was invisible to others, informants sometimes felt misunderstood. They tried not to complain or look fragile in public. To tell the truth about the seriousness of the disease was particularly difficult for informants with alcoholic disease.

A majority of informants could *feel apathetic and depressed* due to their liver disease. For some this was sporadic, while others were constantly in a low mood. Social activities could sometimes relieve this feeling. In periods of tiredness, exhaustion, or low mood, informants described themselves as apathetic and inactive. Not being able to perform ordinary activities caused frustration and unhappiness:

Many [persons]... I spend time with ... have the pleasure of doing things and that's where I find myself losing ... I feel that I want to be able to do more, I want to be happier ... the tiredness that I feel ... the little extra does not exist. (Informant 4)

Thoughts about the future and realising that the disease could lead to early death presented a difficult process to *relate to a potentially fatal disease*. Some experienced that awareness and grief about the seriousness of the disease came gradually when the disease progressed:

I don't know how to ... get it out, it took ... many years before I could cry over things, I have ... never cried before, but now I cry about everything. (Informant 2)

The informants reported different strategies for coping with concerns about their health status. A majority focused on positive aspects of life, hoping for the next day to be better.

Half of them felt a need to discuss their life situation with someone they trusted, for example, family, friends or colleagues. These relations were described as a psychological support and

‘lifeline’, particularly for some with alcohol abuse to stay sober. Informants that were severely ill were tempted sometimes to resign, and ‘live life’ as they wished until the end of life. Others expressed hope for improved health or a liver transplantation.

3.4 Feeling stigmatised

A majority of the informants had experienced emotions of shame and/or guilt. Shame was expressed in relation to other persons, while guilt could be directed towards both oneself and others. The liver cirrhosis caused them to *feel ashamed*, mainly due to a prejudice in the general community that cirrhosis is synonymous with alcohol abuse, hence a self-inflicted disease. Some informants depicted themselves as “labelled” by the disease. Therefore, the informants used the phrase *liver disease*, rather than cirrhosis, to circumvent questions or being condemned:

I understand people who think if you say I have cirrhosis, then alcoholic ... now I don't say anymore that I have cirrhosis, but I have liver disease; it sounds a bit easier.
(Informant 11)

A few informants ransacked themselves, looking for reasons why they got the disease. They felt like “a complainant”, causing colleagues extra workload, contributing to *feel guilt* towards oneself and/or relatives:

Then came the qualms of conscience, with work and work buddies ... but good God, you're not that bad, you can work ... because you want to. (Informant 4)

Previous or present alcohol intake, broken relations, being a burden to society because of, for example, increased healthcare costs and sick leave periods contributed to feelings of guilt. To cause ones family worry and suffering, for example during acute disease deteriorations with gastrointestinal bleeding and confusion, was another reason for experiencing guilt. Some also expressed fear of transmitting the liver disease to their children, which had made someone avoid getting biological children.

3.5 Life turns into an unpredictable roller-coaster

One metaphorical picture emerged from data as a theme of meaning. Living with liver cirrhosis was interpreted to be, like riding a roller-coaster – the ride symbolising varying course of the disease as a smooth sloping journey, suddenly interrupted by sharp loops or into constant small bumps or turns of variable sizes and direction. To adapt to the new life

situation, informants felt they had to perform self-care or to change their previous lifestyle. To manage new demands was experienced as burdensome, literally viewed as the roller-coaster's gravity. The feelings of hope reduced gravity. To "hold on to the roller-coaster", informants made efforts to understand the disease and performed self-care on their own or with support from relatives. Furthermore, the unpredictable roller coaster is a symbol for the insecurity of the sudden changes of direction – to the left, to the right, up, down – causing emotional and existential distress. Informants' worry, feelings of stigmatisation and loss of social context were imagined as a halting and shaky roller-coaster ride, in which passengers got motion sickness, nauseous and dizzy.

4. DISCUSSION

4.1 Discussion of findings

Four study sub-themes emerged as an answer to the aim of exploring how persons with liver cirrhosis experience their day-to-day life. These were: Varying levels of deterioration, adapting to a new life situation, feeling emotionally and existentially distressed, and feeling stigmatised. The most striking finding was, however, the appearance of a theme of meaning, 'life turns into an unpredictable roller-coaster', implying that living with liver cirrhosis is unpredictable. The narrow passage from feeling well to severely ill vary both between different persons and individually on a day-to-day basis. Even when the informants strived to optimise their health to be able to socialise, unpreventable things happened forcing them to cancel their plans. While they could never predict their energy level, they expressed a constant concern about their future health. The theme of meaning, 'life turns into an unpredictable roller-coaster' implies unexpected obstacles happening with fluctuating frequency. This notion has also been reported in previous studies, describing decompensated liver cirrhosis as 'being vulnerable' (Fagerstrom & Hollman Frisman, 2017) or 'confronting tension by internal stress or fear' (Abdi et al., 2015). The findings in the present study add more knowledge about the fluctuations in a person's energy level and concerns about their future, something that several informants felt already during their compensated disease.

The overwhelming tiredness, sudden urge to rest, and difficulties concentrating are consistent with fatigue felt with other chronic diseases (Zwarts et al., 2008). The impact of fatigue on day-to-day life forces informants to de-prioritise important activities in life, making them frustrated and unhappy. Previously, fatigue has been reported as a frequent and distressing symptom following liver cirrhosis (Kim et al., 2006a) that mainly affected physical activities (Wu, Wu, Lien, Chen, & Tsai, 2012). The findings in the present study adds new knowledge

how social life is influenced by fatigue. In addition, fatigue caused psychological distress and impaired the informants' ability to work. The fact that fatigue is experienced as being a greater problem than the disease itself is consistent with other chronic diseases (Franssen, Bultmann, Kant, & van Amelsvoort, 2003; Zwarts et al., 2008).

Although the informants did not express or phrased their experiences explicit as suffering, we think that our findings can be applied to consisting theories of suffering (Mayan et al., 2006; Morse, 2003). In conformity with Morse (2003) all of the informants in our study experienced suffering at various stages. According to Morse's theory, the informants adapt enduring strategies to cope with their suffering, e.g. by trying to think positive in spite of being aware of the shortened lifespan imposed by the disease. Other types of behaviour that enable the informants to function from day-to-day were being in a peaceful environment or being left alone or making compromises. Some informants expressed how they switched from the enduring to suffering phase and vice versa, allowing themselves to escape from enduring by letting out their feelings. Another example of the movement in-between enduring and emotional suffering was when informants described how they overcame the exhaustion and carried on with the activities anyway by enduring. While they did not want to show others they were sad or fragile, they chose to endure in public but suffered in private. Some chose one specific person they could entrust to sharing their true feelings with. The emotionally released suffering was exemplified with temporary intense emotions when they cried or screamed in solitude. For some, the emotional suffering phase was manifest and a constant state of low mood and lost joy and lack of energy. Some informants started to reflect on whether they had accepted the disease or not when they realised the seriousness of their disease. Only a few informants expressed hope; these feelings were mostly connected with possibility of liver transplant. Self-reformulation is viewed as the end stage of suffering, in which a person has learned new perspectives of life (Mayan et al., 2006). Remarkably, only one informant expressed signs of self-reformulation in our study. Further, in contrast to Cheng et.al. (2019) that most patients with multiple chronic conditions express acceptance and positive reframing, acceptance was a rare experience among our informants. Consistent with Morse's theory of suffering, informants in this study had reached different stages in the suffering process (Morse, 2003). However, it is not possible to draw any firm conclusions regarding self-reformulation in the present study due to the limited number of informants bringing up self-reformulation aspects. Since these persons displayed being fully occupied with handling and adjusting to their daily condition, perhaps they had not reached this state.

Nevertheless, it cannot be excluded that they might reach self-reformulation later. Also, the poor prognosis, with limited hope of cure other than a liver transplantation, may affect self-reformulation. This is in line with Ambrosio et al. (2015), suggesting that one obstacle to attain a new normality and a positive life despite the disease is, the occurrence of unexpected disease events in chronic illnesses. We believe that the results in the present study confirm Morse's theory and the described stages of suffering (Mayan et al., 2006; Morse, 2003) for healthcare professions to understand the expressions of suffering living with liver cirrhosis.

The informants in this study expressed an awareness of their health status and how anxiety and depression had synergistic effects. Moreover, lack of social activities and reluctance to share emotions with relatives led to unhappiness or feelings of being a boring person. The synergistic effects of an illness and psychological health has previously been described by DeJean et al. (2013). Despite varying disease severity among our informants, all but one expressed anxiety or depression. The prominent experience of anxiety and depression already in early stages of liver cirrhosis contradicts the results of Kim et al. (2006b), describing an association between anxiety and depression with disease severity. Hence, one need to pay attention to those feelings and offer support already in early stages of the disease. In chronic kidney disease, a person-centred healthcare intervention improved psychological health by providing the patients with tools to manage stress (Havas, Douglas, & Bonner, 2017). In the present study it was obvious that living with liver cirrhosis implies an unpredictable life that rapidly changes from day to day, as like "riding a roller-coaster". These findings suggests that a person-centred care as described by Flagg (2015) is particularly important in liver cirrhosis.

Noteworthy, many of the informants expressed shame, despite non-lifestyle-related liver disease aetiology, for example, alcohol abuse. One example of this is how the disease is designated in conversations with others, for example, informants avoid calling the disease "liver cirrhosis" or feel they need to explain there are other causes to liver disease than alcohol abuse. The finding that informants experienced the disease as shameful when caused by alcohol abuse has been reported previously in studies regarding liver cirrhosis (Fagerstrom & Hollman Frisman, 2017). Feeling ashamed made persons more reluctant to seek social support since they were afraid of being misunderstood or judged. The informants' experiences of stigmatisation are consistent with previously studied cohorts in liver cirrhosis (Baker & McWilliam, 2003; Vaughn-Sandler, Sherman, Aronsohn, & Volk, 2014). Hence, it is of great importance within healthcare to identify persons that are stigmatised since they are less likely to seek support.

The informants expressed varied levels of motivation to perform self-care. Some actively searched for knowledge on how to perform self-care already in the asymptomatic phase. However, the informants found that information about liver cirrhosis was difficult to understand. If this was due to lack of adapted information from healthcare professionals, lack of comprehensible literature, or limited health literacy was not evaluated in this study. The importance of individualised information and collaboration in-between patients and healthcare professions to gain knowledge and involve patients, has been emphasised by Ibrahim, Sandström, Björnsson, Lindhoff Larsson and Drott (2019). Being responsive and adaptive to information, based on the patient's ability to understand, is also suitable in a person-centred approach (Flagg, 2015). Severely ill informants were motivated, but not always able to perform self-care themselves. Others expressed a will to carry on, living their life as if the disease did not exist. Knowledge about the disease and self-management are essential during progression of liver cirrhosis to reduce symptoms (Nusrat et al., 2014; Volk et al., 2013) and to avoid hospital re-admissions (Volk et al., 2012). In the present study, informants searched knowledge for self-care already in mild liver cirrhosis. Contrary to our results, Paterson et al. (1999) argues that motivation for self-care in diabetes increases with the disease stages. A possible explanation for this discrepancy may depend on differences in the informants' sense of coherence (Antonovsky, 1987) or internal or external social determinants (Cockerham et al., 2017) affecting self-management. Also, according to Ambrosio (2015), realising self-management is preceded by acceptance and coping. The natural variety in motivation for self-management (Miller & Rollnick, 2013) following an illness may motivate person-centred strategies to increase knowledge and coherence to decrease the psychological impact (Pai et al., 2019).

Many informants expressed having lack of knowledge about liver cirrhosis. Simultaneously, they showed interest in learning more about the disease. This is in line with the results of Abdi et al. (2015), who found that a person needs personalised information to raise an awareness to learn more and reduce stress. Previous educational interventions within healthcare have improved the knowledge of patients with liver cirrhosis (Volk et al., 2013) and may thus contribute to better outcomes.

4.2 Strengths and limitations

Qualitative content analysis conducted with both descriptive and interpretive analysis strengthens close descriptions of informants' narratives as well as interpretations of lived

experiences (Graneheim et al., 2017; Krippendorff, 2018). Despite that liver cirrhosis is more common in men, the study sample was equally gender distributed, which might be seen as a limitation. However, we argue it is important to an equally extent describe women experiences in the stigmatised disease liver cirrhosis. Also, the use of maximum variation sampling in combination with interviews, based on open-ended questions, facilitated to catch a wide range of experiences into data, to answer the study aim. These data collection strategies further strengthen the study's credibility (Graneheim et al., 2017; Graneheim & Lundman, 2004; Polit & Beck, 2012). To enable transferability of the findings, the descriptions of informants' demographics may help readers to apply the findings into other contexts. To avoid risk of pre-understanding influence on data, the interviewer ensured absence of previous healthcare relation with the informants. The research team was multidisciplinary including physicians and registered nurses, with expertise in both quantitative and qualitative methods, but not all with clinical background in hepatothology. This allowed for emic and etic viewpoints, which strengthens the study's confirmability. Throughout the analysis process, the authors had close collaboration within the research team, and discussed the study in several research seminars, which strengthens the dependability criterion (Graneheim et al., 2017; Graneheim & Lundman, 2004; Polit & Beck, 2012). The coding tree (Table 2) and informant quotations in the findings section further strengthens credibility and authenticity. The software NVivo enabled a continuous movement between coding and text by the researchers, during the analysis and reporting phases. Several informants expressed that they had never shared their experiences with another person before. To protect the informants' vulnerability, the interviewer strived for an empathetic and supportive approach as well as congruence to ethical guidelines (Kvale & Brinkmann, 2018). A few informants expressed exhaustion during the interview. After being served a snack, the interview continued without requests by the informant to discontinue the interview. In qualitative content analysis, there is risk of incongruence in level of abstraction or too roughly fractioned meaning units losing its context. However, the method allows a clear structure of the data analysis and the authors paid special attention to the context of the meaning units during condensation and abstraction process, to avoid this limitation.

5. CONCLUSIONS

Exploring how persons living with liver cirrhosis experience day-to-day life, led to four sub-themes of: Varying levels of deterioration, adapting to a new life situation, feeling

emotionally and existentially distressed, and feeling stigmatised. Further, a theme of meaning, mirroring the underlying message of the sub-themes was identified and titled 'life turns into an unpredictable roller-coaster'.

The theme of meaning explains life with liver cirrhosis as a gradually increasing unpredictable condition. The suffering process starts early and gradually increase to daily suffering. Even if informants strive to find new balance in their lives, the final stage of suffering, self-reformulation, was difficult to detect in this study.

6. RELEVANCE TO CLINICAL PRACTICE

To optimise daily life for patients, registered nurses and other healthcare professions need to place special attention on understanding the unpredictable day-to-day life patients with liver cirrhosis may experience. Registered nurses should also be aware of the variations in knowledge, self-management abilities and motivation among the patients. This highlights a need for personalised strategies for patients with liver cirrhosis, to relieve the suffering and enabling them to carry on their lives despite the illness. We believe that increased involvement of registered nurses in this process is beneficial.

When implementing the results of this study into healthcare, registered nurses are encouraged to actively explore the individual's suffering process associated with liver cirrhosis. Only when the unique situation of each person is understood, patient-centred approach may commence (Fridlund, 2014) in order to retain personal dignity by taking advantage of functionality (Hjorth et al., 2018; Orem, 1980). Also, registered nurses may offer support to relieve stigmatisation and psychological impact to achieve positive living despite a fatal disease (Hjorth et al., 2018). For example, to facilitate encounters with patients, Orem's self-care deficit nursing theory (Orem, 1980) and motivational interviewing techniques (Miller & Rollnick, 2013) may be valuable in nurse-led clinics in liver cirrhosis. The informants' descriptions of rapid health changes in addition to frequent hospital re-admissions reported by Volk et al. (2012) motivate increased registered nurse involvement in outpatient healthcare.

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Table 1. Demographics of informants

Characteristics	Classification	N
Gender	Men	10
	Women	10
Age	18-39	2
	40-64	11
	65-79	7
Ethnicity	Swedish	18
	European	0
	Outside of Europe	2
Marital status	Single	4
	Cohabiting	16
Level of education	None	1
	Elementary school	3
	Upper secondary school	10
	University	6
Employment	Student/working	7
	Sick leave	3
	Retired	5
	Disability pension	3
	Other	2
Child Pugh score †	A	13
	B	4
	C	3
Aetiology of liver cirrhosis	Alcohol	4
	Hepatitis B/C	2
	Primary Biliary Cholangitis	1
	Primary Sclerosing Cholangitis	4
	Autoimmune hepatitis	2
	Non-alcoholic steatohepatitis	5
	Cryptogenic	1
	Overlap Autoimmune hepatitis/ primary biliary cholangitis	1
	Time since liver cirrhosis diagnosis	6-11 months
1-2 years		2
3-4 years		7
5-10 years		6
>10 years		2
Hepatic encephalopathy ‡	None	12
	Asymptomatic or mild	8

† Algorithm based on albumin, bilirubin, INR, presence of ascites and hepatic encephalopathy. Median two-year survival rate Child Pugh A: 85% B: 60% and C: 35% (Durand & Valla, 2008)

‡ Detected with Psychometric hepatic encephalopathy score, score <-4 was cut off for asymptomatic or mild hepatic encephalopathy (Weissenborn et al., 2001). Symptomatic hepatic encephalopathy was assessed according to the West Haven criteria ("Hepatic encephalopathy in chronic liver disease: 2014 practice guideline by the European Association for the Study of the Liver and the American Association for the Study of Liver Diseases," 2014)

Table 2: Categories and themes regarding informants' experiences of living with liver cirrhosis

Categories	Sub-themes	Theme of meaning
From unnoticeable to noticeable disease	Varying levels of deterioration	Life turns into an unpredictable roller-coaster
From gradual to quick progression		
Optimise health based on requirements and ability	Adapting to a new life situation	
Become dependent on relatives		
Worry about the future	Feeling emotionally and existentially distressed	
Loss of social relations		
Find it difficult to talk about the disease		
Feel apathetic and depressed		
Relate to a potentially fatal disease	Feeling stigmatised	
Feel ashamed		
Feel guilt		