

ORIGINAL ARTICLE

Being an informal caregiver for a relative with liver cirrhosis and overt hepatic encephalopathy: a phenomenological study

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Aims and objectives. To explore the experiences of being an informal caregiver for a relative with liver cirrhosis and overt hepatic encephalopathy.

Background. Overt hepatic encephalopathy is a common complication in patients with liver cirrhosis. It is associated with decreased quality of life for patients, and presents a major burden for caregivers. The involvement of informal caregivers in medical care is recommended, but it has not been clearly described. An understanding of the experience of caregivers is needed to improve the support provided to them by healthcare professionals.

Design. A qualitative, interpretative, phenomenological approach was used.

Methods. Twelve informal caregivers participated in qualitative interviews. The analysis followed the six steps of the interpretative phenomenological approach.

Results. Caregivers' experiences were described using five themes: (1) feeling overwhelmed by their loved one having unexplainable symptoms and behaviours; (2) learning that this and previous experiences were complications of liver disease; (3) becoming aware of the symptoms of hepatic encephalopathy; (4) having feelings of being tied down and (5) experiencing and overcoming obstacles in working with healthcare professionals.

Conclusions. This study provides insight into caregivers' experiences and the consequences for their lives. The first occurrence of symptoms was a shock, but receiving the diagnosis was seen as an important step in understanding and learning. Caregivers provide daily assessments of their relatives' conditions, and they feel responsible for medication management. Over time, the caregivers impressively showed how they were able to incorporate their personal experiences into caregiving and to accept more accountability in managing the disease.

Relevance to clinical practice. Nurses should acknowledge caregivers as experts in caring for their loved ones. Nurses can assist caregivers in managing an episode

What does this paper contribute to the wider global community?

- Overt hepatic encephalopathy is an incomprehensible and frightening event for informal caregivers, and having it diagnosed offers them understanding and relief.
- Caregivers accept responsibility for patients' daily care, especially in monitoring symptoms.
- The caregivers' experiences with relatives who have had episodes of overt hepatic encephalopathy were part of their learning processes to understand and develop expertise in managing this specific complication of liver disease.

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of hepatic encephalopathy and can provide individualised interventions to ease the future burden.

Key words: chronic illness, hepatic encephalopathy, informal caregiver, lived experiences, liver cirrhosis, nursing

Accepted for publication: 28 February 2016

Introduction

Thirty to forty percent of patients with liver cirrhosis will experience at least one episode of overt hepatic encephalopathy (OHE), a severe clinical manifestation of hepatic encephalopathy (HE). HE is a brain dysfunction caused by liver insufficiency and/or portosystemic shunt (American Association for the Study of Liver Diseases (AASLD) & European Association for the Study of the Liver (EASL) 2014, p. 643). It is characterised by a broad range of neurological symptoms and behavioural abnormalities, often described and graded using the West Haven Criteria (WHC) (Table 1) (Wakim-Fleming 2011, AASLD & EASL 2014). Serious symptoms of OHE (WHC grades 2–4), such as dyspraxia, inappropriate behaviour, confusion or coma, often lead to hospitalisation (Volk *et al.* 2012).

Because patients often suffer from fatigue, forgetfulness and confusion, their partners or family members frequently provide care for their loved ones. Without having a professional background, they assume the role of so-called informal caregivers (American Liver Foundation 2013). To adopt this role successfully, informal caregivers require knowledge and training, especially concerning adherence to medication regimens and recognition of the early signs of OHE (Bajaj 2010, Neff 2010, Volk *et al.* 2010, Bajaj *et al.* 2011a, Rakoski *et al.* 2012, AASLD & EASL 2014).

While some written information for patients and family members is available (American Liver Foundation 2013, European Liver Patients Association (ELPA) 2015), a recent qualitative study of patients with advanced liver disease and their informal caregivers revealed that caregivers felt uncertain (Kimbell *et al.* 2015). The uncertainty interfered with their management of their relative's illness and influenced their everyday lives, and they required more information and better education from professionals. One of the primary responsibilities of professional nurses (International Council of Nurses (ICN) 2014) is to provide education and support for patients and their families. Therefore, given that informal caregiving is an individual experience influenced by the severity of the illness and its trajectory (Grey

Table 1 WHC (West Haven Criteria), ISHEN (International Society for Hepatic Encephalopathy and Nitrogen Metabolism) and clinical descriptions, adapted from table 2 from the Clinical Practice Guidelines (AASLD & EASL 2014, p. 645)

| WHC | ISHEN | Description |
|------------|------------|---|
| Unimpaired | Unimpaired | No encephalopathy at all; no history of HE |
| Minimal | Covert | Psychometric or neuropsychological alterations on tests exploring psychomotor speed/executive functions or neurophysiological alterations without clinical evidence of mental changes |
| Grade 1 | Covert | Trivial lack of awareness Euphoria or anxiety Shortened attention span Impairment of addition or subtraction Altered sleep rhythm |
| Grade 2 | Overt | Lethargy or apathy Disorientation with time Obvious personality changes Inappropriate behaviour Dyspraxia Asterixis |
| Grade 3 | Overt | Somnolence to semistupor Nonresponsiveness to stimuli Confusion Gross disorientation Bizarre behaviour |
| Grade 4 | Overt | Coma |

et al. 2006, Adelman *et al.* 2014), nursing interventions targeting the severely ill hepatic patient and his or her family should also be based on the patients' and families' experiences and needs.

Background

Living with a chronic illness affects both patients and their families (Corbin & Strauss 1988, Kuyper & Wester 1998, Levine *et al.* 2010, Crespo *et al.* 2013). Family members

are often called on to be informal caregivers (Levine *et al.* 2010, Organisation for Economic Co-operation and Development (OECD) 2010). In addition to helping with activities of daily living, the informal caregiver often monitors and manages symptoms, administers medications, coordinates care and provides emotional support (Corbin & Strauss 1988, Kuyper & Wester 1998, Levine *et al.* 2010, Rakoski *et al.* 2012).

Informal caregiving is highly valuable and successful in preventing complications and hospital readmissions (Rakoski *et al.* 2012, Golics *et al.* 2013, Adelman *et al.* 2014, Jeffs *et al.* 2014). Unfortunately, informal caregivers often describe a lack of training and of acknowledgement from healthcare professionals (Hasselkus & Murray 2007, Given *et al.* 2008, Adelman *et al.* 2014).

Informal caregiving has both positive and negative impacts on caregivers. Positive attributes have been described in the development of closer family relationships or the receiving of acknowledgement and acceptance from relatives or healthcare professionals. In contrast, new life rhythms, role shifts, an exhausting workload, alterations in relationships and loss of freedom can be stressful and can lead to an increase in caregiver burden (Corbin & Strauss 1988, Kuyper & Wester 1998, Grey *et al.* 2006, Levine *et al.* 2010, Schulman-Green *et al.* 2012, Golics *et al.* 2013, Adelman *et al.* 2014, Årestedt *et al.* 2014).

Although most studies of liver cirrhosis and HE have focused primarily on diagnosis, treatment, prevention of symptoms or quality of life, three studies have investigated the caregiver burden for informal caregivers. They examined the awareness of HE (Montagnese *et al.* 2012), the financial and emotional burden of HE (Bajaj *et al.* 2011b) and the burden of and quality of life in advanced liver disease (Nguyen *et al.* 2015). These studies reported that caregiver burden increased after HE or when the neuropsychiatric status of the patient deteriorated, but knowledge of the disease also increased (Montagnese *et al.* 2012). These quantitative studies in caregivers provided important information about the associations of HE with burden and awareness, but they did not consider the broader perspective of how HE is perceived by caregivers, the meaning of this experience or the tasks that caregivers perform in caring for their loved ones.

With the assumption that informal caregivers are important to and involved in the care process, gaining a broader picture of how caregivers experience OHE and what their needs and challenges are will help nurses to improve their support for caregivers. The aim of this study was to explore the experiences of being an informal caregiver for a relative with liver cirrhosis who has had OHE.

Methods

Design

This qualitative study used an interpretative phenomenological approach (IPA). This methodology is appropriate for describing and capturing individual human experiences and for exploring phenomena through the explanation and interpretation of caregivers' experiences (Smith *et al.* 2009, Creswell 2013). IPA allows researchers to explore the real-life worlds of ill people and their families (Spichiger & Prakke 2003).

Data collection

Participants were recruited from October 2013–February 2014 from an 850-bed tertiary hospital. The inclusion criteria for the study were as follows: (1) being an informal caregiver of a patient with liver cirrhosis; (2) having experienced at least one medically diagnosed episode of OHE, defined by WHC grades 2–4; (3) being 18 years old or older and (4) having the ability to communicate in German. The decision to include caregivers who had previously experienced OHE was made because the clinical presentation of the symptoms is clear, and the diagnosis is easier than in milder grades of HE. Physicians and nurses identified eligible informal caregivers and provided information about the study in the outpatient clinic and on the inpatient ward. If the caregivers were interested in participating in the study, their contact information was given to the first author (PKH). No patients or caregivers received direct clinical care from the researcher. After providing written informed consent, the caregivers were interviewed by the first author. The study protocol was approved by the regional ethics committee (EKSG 13/103/1B).

Twelve caregivers, eight women and four men (mean age 51.5), for 11 relatives with liver cirrhosis and OHE shared their experiences in qualitative interviews (two preferred to come together) (Table 2). Three relatives developed OHE during a hospitalisation and eight at home, seven of whom were subsequently hospitalised.

The first author conducted all the interviews at a place convenient to the caregiver, either at home or in the hospital. The open-ended interviews started with the following statement: 'Your loved one had a serious complication of liver disease that can be associated with behavioural problems and, in some cases, with loss of consciousness. Please tell me about your own experience in this situation.' This question aimed to stimulate free speaking and reflect-

Table 2 Participant demographics

| No. | Pseudonym | Caregiver | Relative with OHE | Years of illness | HE episodes Grade ≥ 2 |
|-----|-----------|---------------------------|-------------------|------------------|----------------------------|
| 01 | Emma | 28 years Sister-in-law | Female, 38 years | 10 | 20* |
| 02 | Felicia | 40 years Daughter | Female, 61 years | 35 | 1 |
| 03 | Gail | 66 years Wife | Male, 66 years | 7 | 1 |
| 04 | Hanna | 66 years Wife | Male, 69 years | 25 | 5 |
| 05 | Ian | 65 years Husband | Female, 66 years | 2 | 4 |
| 06 | Jackie | 44 years Partner | Male, 44 years | 6 | 1 |
| 07 | Kai | 59 years Brother | Male, 45 years | 22 | 2 |
| 08 | Lucy | 75 years Partner | Male, 64 years | 0.5 | 2 |
| 09 | Manfred | 61 years Husband | Female, 64 years | 2 | 4 |
| 10 | Nathan | 34 years Son | Female, 64 years | 2 | 2 |
| 11 | Olga | 27 years Daughter | Female, 52 years | 10 | 3 |
| 12 | Pam | 30 years Daughter | Male, 52 years | 5 | 2 |

*Patient with transjugular intrahepatic portosystemic shunt (TIPS).

ion. The researcher (PKH) encouraged the participants to elaborate about their thoughts, expectations and emotions during their experience with OHE (Smith *et al.* 2009).

At the end of the interviews, sociodemographic data were collected, including age, gender, nature of the relationship with the patient, time since the initial diagnosis of liver disease and experienced episodes of HE/OHE from the caregivers' perspective. The interviews lasted between 31–67 minutes (mean 45). All the interviews were audio-recorded and transcribed verbatim. Confidentiality was guaranteed because all personal identifiers were deleted, and the audio records were destroyed at the end of the study.

Data analysis

The analysis commenced following the third caregiver interview and was conducted simultaneously with the ongoing data collection. Preliminary insights were then incorporated into subsequent interviews. The analysis followed the six steps of IPA, as described by Smith *et al.* (2009): (1) read and reread every transcript to become familiar with the data; (2) explore the language and content, writing initial notes and codes; (3) bundle the initial codes so that themes emerge; (4) seek connections between themes; (5) move to

the next case, and (6) explore connections between cases and discuss the relationships between cases.

The computer software ATLAS.TI, version 7.0 (ATLAS.ti GmbH, Berlin, Germany) was used for data management. Descriptive statistics for sociodemographic data were performed using the Statistical Package for the Social Science (SPSS), version 21 (IBM Corp., Armonk, NY, USA). A peer group (SB, DS) and senior researchers (RM, DH) reviewed all the interviews for compliance with quality criteria, according to Yardley (2000) and Smith *et al.* (2009). The quality of the interviews was assessed regarding proper preparation of the researcher, the accuracy of the conversation and the transcription. The first author primarily performed the analysis, but for trustworthiness, two peers (SB, DS) and one senior researcher (RM) read and analysed several interviews independently. The codes were presented and discussed together.

Results

This study explored the experiences of twelve informal caregivers for their relatives with liver cirrhosis who have had OHE. Through the family members' descriptions, five different themes were identified: (1) feeling overwhelmed by their loved ones having unexplainable symptoms and beha-

viours; (2) learning that this and previous experiences were the complications of liver disease; (3) becoming aware of the symptoms of hepatic encephalopathy; (4) having feelings of being tied down and (5) experiencing and overcoming obstacles to working with healthcare professionals (HCPs). All the themes are highlighted with quotations from participants (pseudonyms, numbers and line numbers in the transcript).

Feeling overwhelmed by their loved ones having unexplainable symptoms and behaviours

A first event of OHE occurred totally unexpectedly for all the caregivers. Suddenly, the caregivers observed speech disturbances, compulsive behaviour and acute confusion. They described feeling anxious and helpless with the onset of these new, shocking and unexplainable symptoms. Because all the caregivers had had experiences with a relative with liver cirrhosis and other complications, OHE was seen as another severe blow in a difficult illness trajectory:

It's a shock. Well, first I thought, what's going on; this can't be true. [...] And then, somehow everything bubbled up, and then you start to cry [...] it just happens; it's just too much. We have already experienced so much with him. (Pam 12.56)

Many of the respondents felt concerned about their loved ones, who were described as partially or completely mentally absent. They felt as if their relatives' brains had only limited functions. They perceived it as 'a failure' (Jackie 06.055) or 'blackout' (Felicia 02.091), or they described observations as follows:

And then I woke up at night when she fell, and she was no longer responsive. It seemed as if the brain had been turned off. I called the ambulance. They came, and then it [brain] worked again. (Ian 05.163-167)

Professional help was sought immediately when the caregivers recognised that they did not know what to do because the symptoms were so severe, or their relatives had become aggressive. Often, they described it as a bad and helpless feeling:

I also get overwhelmed, and I don't really know what to do [...] she especially gets uncooperative. She won't do anything [...] she also gets very aggressive. (Olga 11.79-81)

Once the loved one was admitted to the hospital, the caregivers were impressed by the rapid effect of therapy. Symptoms seemed to disappear as quickly as they emerged. Caregivers observed their relatives returning to normal, as Jackie (06.039-047) described the day after admission:

'Then, he comes towards us as if nothing had happened. Now he is here again, I'd say, 95% like his old self'.

Learning that this and previous experiences were the complications of liver disease

As soon as the OHE experience was confirmed with a medical diagnosis, the caregivers understood that liver cirrhosis could have effects on cognitive function, behaviour and physical symptoms. Hanna (04.023) described it as follows: 'I didn't really realise that the liver goes into the brain like that'. All the caregivers described that this new information answered questions from previous experiences, in which suspicious signs had been observed in their relatives. Until the diagnosis of OHE was made, the caregivers sought their own explanations of the irritating symptoms. One caregiver described a recent situation at home:

And towards the evening I noticed, [...] that in his brain – I used to blame it on tiredness – [...] he was not able to absorb anything, or he just forgot. And the next day, he would wake up as if nothing had happened [...] he went to work. And in the evening, it just started again. (Jackie 06.023)

Other respondents experienced physical signs, such as tremors, and linked them with other well-known diseases: 'I thought he has Parkinson's disease because others from his family have it' (Hanna 04.67-71) or 'She is very tired; sometimes she sits at the table and falls asleep, but actually we are used to that with her, actually; it's also from the Methadone' (Olga 11.108).

As long as caregivers had the feeling that they could manage their relatives on their own, they stayed home and endured the situation. If symptoms occurred in shorter intervals, or the status was constantly changing, the caregivers were increasingly alert. They wondered what was happening. After the diagnosis of OHE, they were able to make sense of previous experiences:

I missed the process of such a thing. [...] the mental cloudiness [...] I didn't know it was possible that it affects the brain in that way, that his ability to think would be so limited [...] I thought he was lazy or drunk. If I had known, I would have pointed it out earlier. (Kai 07.592-633)

Becoming aware of the symptoms of hepatic encephalopathy

A diagnosis of OHE was not only important to facilitating the caregiver's understanding of the illness trajectory but also to the caregiver being aware of the symptoms and act-

ing accordingly, thus enhancing specific skill development for future recurrences. Caregivers attempted to integrate the experiences into their daily lives with their loved ones.

Many respondents spoke about the episode of OHE as a starting point in becoming more aware of symptoms:

At first, it [the diagnosis of OHE] was a shock. However, it also helps [...] to maybe observe the disease course more carefully, to maybe respond faster if something happens again. [...] but I'd say, just to be sensitised, it was maybe good. (Jackie 06.203)

Subsequently, the caregivers became more adept in managing the disease. They described two tasks: repeated assessments; and acting in good conscience, rather than based on guessing, as Hanna described (04.047-087): 'I didn't know, so I just did'. They acted in good conscience when they used all their previous experiences to help them in decision-making and did their best.

The frequent assessments and testing for signs of OHE became key tasks and focuses for caregivers. They developed a 'sixth sense' for subtle changes, such as detecting small deviations in the relative's appearance or behaviour. Minor changes were perceived as warnings and alerts. For example, Ian (05.259) observed that, when his wife began laughing about nothing, the symptom indicated to him that 'the first stage of the next OHE is starting'. He was not alone in classifying his observations using a severity scale. Many spoke of phases, stages or percentages. Prior to OHE being diagnosed, they had not been aware of warning symptoms. Now, they felt confident that they could assess the situation earlier, even better than their relatives themselves:

I just notice it. I think someone who doesn't know her would say nothing is wrong. And I do see it, because the face muscles are slightly different. I feel like she looks more tired [...]. And then this undertone, just a sound, there is something wrong, and then I just think: now you have to pay attention! (Emma 01.049)

In addition to observing, some caregivers went a step further and systematically tested their loved ones. In this manner, the caregivers creatively developed their own strategies. Many described testing relatives' skills regarding technical devices to identify changes signifying possible OHE. Others allowed relatives to solve crossword puzzles, or they asked simple questions for validation when they became suspicious of a recurrence. However, not all of them tested their loved ones quite so overtly. Some felt guilty and maintained more secretive control, as with Hanna (04.147): 'Well, I almost feel it's like with a little child. And you wouldn't want that, to have such control'.

Caregivers accepted accountability for managing the disease, including different tasks. Detoxification was one of

the most important tasks for the caregivers. Some paid attention to the ways in which laxatives were taken, whereas others were able to rely completely on their relatives. Only a few consistently administered the laxatives as prescribed, and many were able to handle the developing OHE situation more flexibly. Some installed their own recording systems, such as tallies on the toilet. The prescribed target for bowel frequency was interpreted individually, usually the equivalent of once per day. Changing the diet was also an important task in detoxification. Some identified certain foods as being high in ammonia. The caregivers attempted to influence the course of OHE by avoiding these foods. Many found that a healthy diet, exercise and sufficient hydration were the most important preventive interventions.

The caregivers learned from their previous experiences to link certain symptoms to a possible start of the next OHE episode, and they responded promptly and immediately sought professional help:

However, when she vomits, [...] we have the feeling, now it [OHE] is coming back. We actually wait for it to come. However, we are always with her, close to each other. (Manfred 09.859-871)

Some caregivers first attempted to perform the tasks on their own, for example, ensuring that their relatives had sufficient rest and sleep because they were convinced that it could lead to an improvement. Many used techniques that they had observed in hospitals, such as omitting diuretics for a few days or temporarily increasing the doses of laxatives.

Having feelings of being tied down

The consequences of the disease, including the regular status assessments and tasks, often resulted in a feeling of being tied down. Two aspects of these feelings were described: one in the context of the caregivers and the second in the context of their relatives.

The first aspect of being tied down resulted when the caregivers increasingly accepted responsibility for their loved ones and their daily lives. They assumed the technical, financial or coordinative tasks. Caregivers realised that complex household work was difficult for their relatives; however, they still tried to involve them in everyday life. Tasks were often shared, especially well-known and simple work that was considered suitable, such as carrying out the trash or feeding the animals. They attempted to reorganise the more complex tasks, either by working together or by purposely slowing the pace. Jackie (06.087) described it as

follows: 'I try giving the beat'. Caregivers responded with patience and understanding, as Ian (05.055) described: 'She does everything much slower, and that can get annoying, but it is okay'. This change resulted, however, in a major increase in the caregiver's workload.

The second aspect of being tied down is from the need for repeated assessments for the symptoms of OHE. Whenever possible, the caregivers attempted to be with their loved ones at all times; they took their relatives with them and conducted their daily activities together. Caregivers not living in the same household intensified the amount of care given. Several times per day they called on the telephone or went over to the relative's home. They were afraid of the consequences or feared they would be scolded, so many pressured themselves not to miss any changes. They wanted to be able to react to changes as early and accurately as possible, and they feared that their loved ones might get into dangerous situations:

It is more like fear that he would hurt himself. We can't leave him alone anymore, because we live on the third floor. We wouldn't want him to suddenly have the idea to climb on the balcony or hurt himself. (Pam 12.132-136)

Most caregivers described 'feelings of being tied down' with great implicitness. They considered caring for their loved ones as normal. Nonetheless, they felt less independent, lacking means to retreat. Sometimes, relatives who were more demanding reinforced this feeling: 'He can't be alone anymore. He constantly comes to me. It is hard for me because it didn't used to be like that' (Hanna 04.299-311).

Experiencing and overcoming obstacles in working with healthcare professionals

Working with the HCPs was presented and discussed in different fashions. All the caregivers described obstacles to diagnosis and communication, most often in a first or emergency contact. In time, problems could be overcome due to the caregivers' having further experience with OHE.

As soon as the first suspicious signs occurred, many caregivers sent their relatives directly to a general practitioner (GP). However, they often found that even the GPs had difficulty detecting changes and symptoms and interpreting them as the consequences of liver disease. The caregivers felt that this lack of detection often resulted in delayed diagnosis. Not having a plausible explanation or concrete support caused much suffering, and they felt forced to 'simply endure'. For some respondents, the lack of detection was incomprehensible because they had repeatedly sent

their patients to doctors. Kai (07.144) wondered, 'who should have noticed; who should have intervened earlier?'

Others showed understanding for the GP. They were convinced that their own capabilities were due to their (sometimes multiple) experiences in recognising OHE. They had learned, from their everyday life situations, how to respond to the slightest changes, and they rated this experience as an advantage, compared to the GP:

He went to his family doctor, who said: Medically, I don't see anything alarming, not in the blood and not on the ultrasound. He could not assess the other aspects because he did not experience him over the whole day. (Jackie 06.023)

Caregivers often experienced difficulties communicating with HCPs. One reason was the problem of accurately describing their observations. Another reason was stigmatisation, particularly among the caregivers of relatives with addictions. They often sought emergency medical attention only after they had excluded other causes, including drug use. If HCPs retested their loved ones for substance intake, it upset the caregivers and caused them to be even more protective of their relatives:

The emergency physician thought that she should just sleep it off, and it would be ok afterwards. I thought to myself - that was not right. I have noticed that often my mother is labelled because she takes methadone and is an alcoholic. (Olga 10.055-060)

Caregivers with extensive experience with the healthcare system attempted to influence communication with HCPs positively by dressing nicer, as well as in the manner in which they spoke about the disease and its known complications, using medical terms. Later, caregivers preferred to bring their relatives to HCPs that they knew and where they had had good experiences. Many rated the contacts with the hepatologists as important, and they felt it was easier to be understood. However, in emergency situations, there were only two caregivers who had sought direct contact with hepatologists, whereas all the others went to a GP or emergency room. If their loved one was hospitalised, the caregivers felt relieved, as Ian (05.319) explained: 'I can leave her and be calm'.

Discussion

These findings from exploring the experiences of caregivers illustrated how deeply affected and involved informal caregivers are. The first episode of OHE was a shocking experience. Receiving the diagnosis was seen as an important step in giving a name to the situation, as well as learning and further developing skills in managing this complication.

Changes in relationships and difficulties in working with HCPs were common. In the third and fifth theme, the caregivers impressively described how they were able to incorporate their personal experiences into their daily lives and to accept greater accountability in managing their loved ones' diseases.

Experience is seen as an important and crucial step in adapting the management of a chronic illness (Grey *et al.* 2006). This study provided insight into the learning processes: a direct and repeated experience with the patient led to improvement in knowledge. Because OHE is a very demanding situation, all the caregivers had the reaction of needing to experience OHE to adapt their relatives' monitoring and observation strategies. The events of OHE led to a new perception of the relatives' situations, and past experiences made immediate sense in light of the actual event, changing how the past was interpreted and the expected trajectory of the illness for the future (Merleau-Ponty 2012). The study by Montagnese *et al.* (2012) described a similar finding. Informal caregivers learned from an HE experience and seemed to be better informed after an event.

Overall, the occurrence of OHE severely affected the lives of the caregivers, as described in the practice guidelines (AASLD & EASL 2014). Being confronted with a family member whose behaviour suddenly changed and who was reluctant to be helped caused the caregivers to experience strong, overwhelming emotions and fear. Examined in the context of chronic illness, the onset of new and deteriorating symptoms influences an illness trajectory as an acute phase or crisis (Corbin & Strauss 1988, Schulman-Green *et al.* 2012). New symptoms are known as risk factors for self-management and family management, and they often require changes in interventions, active external support and the adaption of coping strategies (Grey *et al.* 2006, Given *et al.* 2008). The caregivers in this study accurately described this situation. It also seemed that OHE was perceived as one additional and severe complication in an already demanding situation of living with a close relative with liver cirrhosis. They experienced liver cirrhosis as a chronic condition with all of its challenges, such as managing with symptoms, disability and emotional distress (Wagner *et al.* 2001, Holman & Lorig 2004).

Giving OHE a name seemed to be a key point in coping with the illness trajectory. Prior to knowing the diagnosis, the caregivers were often irritated about the fluctuating symptoms or behavioural changes, but none of them had linked these symptoms to liver disease. Hasselkus and Murray (2007) described caregivers initially interpreting cognitive symptoms as age related, as long as daily life was not severely affected. Similarly, the caregivers in this study

endured the situation and sought their own explanations. They remained at home until they could not manage the situation by themselves. A resulting hospitalisation provided the caregivers with feelings of relief, albeit temporary. Once the diagnosis of OHE had been made, the caregivers recognised that they were in a situation with new challenges, and they experienced increasing uncertainty about the future. Årestedt *et al.* (2014) described how caregivers coped with the impact of chronic illness by learning to manage in changing situations.

All the caregivers considered the close monitoring and evaluation, especially of cognitive symptoms, to be their main tasks in daily life. Given *et al.* (2008) found that caregivers adopted complex tasks, such as administering medications or supervising patients. In our study, the caregivers were able to observe subtle changes in language, expressions or behaviour. They believed they could positively influence the trajectory by having learned from their previous experiences; they knew the individual symptoms and rated them in terms of severity. The goal was to avoid recurrence of OHE by recognising early changes. As recommended by Cordoba *et al.* (2014) and Leise *et al.* (2014), all the caregivers knew that laxatives and antibiotics are important treatments, but they also had their own interventions, such as diet and exercise. They spoke of 'acting in good conscience' because some respondents did not feel that they were well informed about treatment or the disease trajectory, but they acted as well as they could, as previously described (Given *et al.* 2008). In addition, although many caregivers considered symptoms such as vomiting or the side effects of diuretics to be triggers for HE, they did not know most of the risk factors (Bajaj *et al.* 2011a, Volk *et al.* 2012, Leise *et al.* 2014). It might be that caregivers are well instructed about the use and effects of lactulose, but information about precipitating factors for OHE and the diversity of symptoms is missing.

Previous studies have shown that the caregivers' perceived burden increases after experiencing OHE (Bajaj *et al.* 2011b, Montagnese *et al.* 2012, Nguyen *et al.* 2015).

Consequences for the caregivers' personal lives included accepting more responsibility for housework and adapting their daily lives, and they described alterations in their relationships, similar to caregivers of other patients with chronic diseases (Corbin & Strauss 1988, Kuyper & Wester 1998, Grey *et al.* 2006, Levine *et al.* 2010, Schulman-Green *et al.* 2012, Golics *et al.* 2013, Årestedt *et al.* 2014). The caregivers in this study felt tied down due to the impression that they were not able to leave their relatives alone or the need for frequent assessments of them. Interestingly, they did not speak of their responsibilities as nega-

tive, perhaps because the symptoms were fluctuating rather than constant. Caregivers could talk about good times between episodes, when they found some relief from the stresses. Overall, they appeared rather humble and seemed not to be aware of the importance of the work they did. Furthermore, caregivers' confidence in having more accountability in managing HE also influenced their interactions with HCPs. Caregivers felt that they had the skills to recognise HE/OHE, and they wanted to be recognised as experts in their loved ones' diseases, as also described by Bianchi *et al.* (2012).

The study findings should be interpreted with some caution because of limitations in recruitment, data collection and data analysis, including the following: (1) many potential participants were excluded because of language problems; (2) only one interview was conducted per participant and (3) the results were not shared directly with the participants. Despite these limitations, the findings were reviewed and discussed with healthcare professionals and researchers, and they seemed to be comprehensive with the clinical expertise. Therefore, the findings might be transferrable to other informal caregivers.

Conclusion

Exploring informal caregivers' experiences of OHE provided rich insight into the impact of OHE on informal caregivers, including their learning experiences, their development and adaption of specific skills and tasks within the illness trajectory and the consequences for their lives.

The first episode was a shock, but receiving the diagnosis was seen as an important step in understanding and learning. Caregivers provided daily assessments of the patients' conditions and felt responsible for medication management. Changes in relationships and difficulties in working with

HCPs were common. Over time, the caregivers impressively showed how they were able to incorporate their personal experiences into their daily lives and to accept greater accountability for managing their loved ones' diseases.

Future research should focus on the development of nursing interventions to decrease caregiver burden by providing support based on their specific needs.

Relevance to clinical practice

The findings of this study confirmed that the caregivers of patients with liver cirrhosis and OHE play vital roles. They supported the suggestions of the existing literature to integrate informal caregivers proactively into care planning and delivery and to provide ideas to develop improved care strategies. First, not only nurses but all healthcare professionals should encourage and acknowledge informal caregivers as important partners and experts in assessing and managing the patient's situation. Second, reprocessing an episode of OHE can prevent the placing of an additional burden on caregivers. Nurses can support caregivers by offering them an opportunity to discuss their experiences. Third, individualised education can be provided to inform caregivers about the learning process and to support them during their individual experiences of OHE.

Acknowledgements

No financial support.

Contributions

Study design: PKH, RMI, DHS; Data collection and data analysis: PKH, SB, RMI, DS, DHS; Manuscript preparation: PKH, SB, RMI, DS, DHS.

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