Gastroesophageal reflux disease (GERD) is the most common pathology related to paraesophageal hernia (Maret-Ouda, Markar, & Lagergren, 2020). Most individuals can be treated effectively with proton pump inhibitors. Only a minority require surgical treatment, despite the fact that GERD is the major indication for paraesophageal hernia surgery worldwide. Large paraesophageal hernias (LPEHs) present differently and predominantly occur in the aging population. LPEH can present acutely with gastric volvulus, ischemia, perforation, and gangrene but may also lead to chronic low-grade symptoms (Casteleijn, Ponten, Van de Poll, Nienhuijs, & Smulders, 2017).

**Background**

Surgery is the only available treatment of these LPEHs. Some authors recommend early repair of an intrathoracic stomach to avoid the risks associated with gastric volvulus, ischemia, perforation, and hemorrhage. The symptom burden and effect on general health motivate treatment in these individuals.
improved perioperative mortality and reduced morbidity associated with elective laparoscopic hernia repair (ELHR) of LPEH have stimulated the ongoing debate regarding the appropriate time for repair and the safety of watchful waiting (WW); that is, surgical treatment only when complications appear (Jassim et al., 2014; Sorial et al., 2020).

Proponents of WW cite evidence that the historical risks, including high mortality and morbidity associated with gastric volvulus and strangulation, are overestimated (Siegal, Dolan, & Hunter, 2017; Stylopoulos, Gazelle, & Rattner, 2002). Furthermore, emergency surgery due to volvulus, incarceration, gangrene, or bleeding is a rare event and the emergency can be handled by endoscopic measures (Bhayani et al., 2013). Data have demonstrated that where ELHR is routinely recommended, it is beneficial in fewer than one out of five LPEH patients compared with WW. Even if emergency surgery is required, the burden and risk of such a procedure are not as severe as was considered in the past (Sorial et al., 2020). Prediction scores have been proposed for evaluating individuals who may benefit from surgery, but these scores predominantly focus on risks rather than symptom burden and the possibilities to relieve it (Ballian et al., 2013).

In the literature, the chronic symptoms caused by LPEH are only occasionally considered an indication for EHLR and frequently described as low-grade symptoms, although robust evidence for grading the symptom burden in these individuals is rare. Several reports present evidence of symptom reduction and good quality of life after ELHR but do not include baseline data (Castelijns, Ponten, Vd Poll, Bouvy, & Smulders, 2018). Such data are mostly based on quality-of-life questionnaires. The paucity of data pertaining to symptom burden and effect on general health in individuals with hiatal hernia makes the decision difficult as to whether to operate or not.

During the planning of a prospective cohort study on patients scheduled for EHLR in our center, we realized that the descriptions of mechanical symptoms in the electronic health records of patients were simplified, laconic, and inaccessible for grading and systematization. We also became aware that our understanding of health in individuals with LEPH and their symptoms was insufficient. In the present study, the concept of health is considered an integral part of life, meaning that health is compatible with bearable suffering. Health is a complete experience that is more than the absence of illness and if we view health as a wholeness, any kind of suffering implies that this wholeness has been disrupted (Eriksson, 2006). The aim of this study was to explore how individuals suffering from Grade II–IV hiatal hernia describe their symptoms and health, as well as how the disease affects their life.

Methods

Participants

All patients planning to undergo ELHR for LPEH between July 2017 and September 2021 in Skaraborg Hospital, Sweden, were invited to participate in the study. Inclusion criteria were ability to understand and speak Swedish and the presence of a Grade II–IV primary hiatal hernia verified by means of a thoracoabdominal computed tomographic (CT) scan. The total number of patients scheduled for the procedure was 27. Two patients were not invited to participate due to a misunderstanding within the research group. One patient was not included because of inability to understand Swedish, whereas another was excluded as she/he had a previous operation for LPEH. A fifth patient was excluded after the interview because the type of hiatal hernia was not verified and there had been an operation because of severe GERD and esophagitis.

Twenty-two patients were included in the final analysis, and their characteristics are presented in Table 1. None of the patients smoked at the time of the study, but the majority had a history of smoking. Obesity was present in eight patients, and the body mass index (BMI) range was 22.6–32.9. The consumption of proton pump inhibitors was low. ATC class A02BC01, A02BC02, A02BC03, and A02BC05 medication was present in 19 of the 22 patients, and the highest daily dose was 40 mg of esomeprazole.

Data Collection Process

The interviewer phoned the patients 1–2 weeks before admission and described the study, including information about the aim and that participation was voluntary. Thereafter, a secretary at the ward distributed an information letter together with an informed consent form to the potential participants. The interviewer phoned each patient again after 3–4 days to ascertain whether she/he agreed to participate in the study.

Recorded, semistructured interviews were conducted at the hospital in connection with the preoperative admission appointment 1–2 days before surgery. An interview guide was developed according to Brinkman and Kvale (2015) to ensure that the content of the interview corresponded with the aim. The interview included the following questions: “How do you experience your health now before the operation? What are your expectations for the upcoming operation? Do you have any other concerns?” Depending on the informants’ answers, relevant follow-up questions were posed. The interview ended with the following question: “Is there anything else you would like to tell
Being caught in a Vicious Circle

Data Analysis

The interviews were analyzed by latent qualitative content analysis. This type of analysis is characterized by going beyond the actual words in the text and being open to the underlying depth and meaning conveyed by the participants’ statements (Lindgren, Lundman, & Granheim, 2020). The text was first read and reread to gain an overall impression, after which it was divided into meaning units in line with the aim of the study. Each meaning unit was labeled with a code, and a search was made for patterns in these codes. Codes that expressed related meanings were compared and grouped into preliminary themes based on similarities and differences. Those with similar content were thereafter sorted into subthemes. The underlying meaning of the findings resulted in an overarching main theme encompassing the latent message uniting all six subthemes (Lindgren et al., 2020) (Table 2). The analysis was performed by means of reflective discussions between three of the authors (B.W., S.L., and P.A.L).

The researcher’s interaction is described in terms of reflexivity and relationality (Hall & Callery, 2001). Improving rigor around these issues also includes the idea that the researcher identifies and reflects on the preconceptions she/he brings to the study. However, as long as the researcher acknowledges her/his preunderstanding, bias is minimized (Malterud, 2001).

The interviewers’ (J.S., H.S., and E.L.) preunderstanding consisted of caring for patients suffering from LPEH both before and after surgery. The coauthors’ (J.S. and P.A.L.) preconceptions were due to many years of working as surgeons. The coauthors’ (B.W. and S.L.,) preunderstanding comprises a caring science perspective encompassing knowledge, experience, as well as a sense of duty and commitment accumulated over many years of anesthesia care for such patients.

Ethical Considerations

The individuals who decided to participate in the study were informed of their right to end their participation at any time, were guaranteed that this would not affect their treatment and care in any way, study records would be kept confidentially, and their contributions would be unidentifiable in the final report. The study was approved by the Central Ethical Review Board in Stockholm (No. Ö 17-2017).

Results

The results consist of one main theme “Being caught in a vicious circle.” Central to the informants’ descriptions is their commitment to strategies for managing the

TABLE 2. Example of the Analysis Process in Accordance With Lindgren et al. (2020)

<table>
<thead>
<tr>
<th>Meaning Units</th>
<th>Condensed Meaning Units</th>
<th>Code</th>
<th>Subtheme</th>
<th>Main Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“If I eat just a tiny bit too much, gastric juice comes up, pieces of food ... it takes two hours to go away, then my stomach is no longer so full.” (6)</td>
<td>Can’t stop food coming up.</td>
<td>Can’t control my body.</td>
<td>The symptoms have seized control over my health.</td>
<td>Being caught in a vicious circle.</td>
</tr>
</tbody>
</table>
ever-present and unpredictable symptoms that have seized control over their health. This trapped them in a hopeless and isolated existence with a great deal of mental and physical suffering; that is, a vicious circle from which they were unable to escape. Even though their health could be experienced as the worst imaginable, there were still moments of hope. The emerging subthemes were as follows: “Distressing and uncertain times,” “The symptoms have seized control over my health,” “Loss of energy and strength,” “Strategies for managing daily life,” “Loss of a social life,” and “Moments of hope despite failing health” (Figure 1).

**Distressing and Uncertain Times**

The initial severe symptoms of the hiatal hernia appeared on and off, and gave rise to worry and distressing thoughts. “Something alien and frightening was happening to and going on in my body—what is wrong with me?” There were many acute hospital visits due to the difficulty of establishing a diagnosis. The informants went through a difficult and uncertain time until they received a diagnosis of what was causing their health problems.

There have been so many weird symptoms. Didn’t make any connections at all to my stomach. Visited a doctor in a completely different context. Crickey, they started acting very quickly, they believed I had had a heart attack. (6)

Despite the uncertainty and an increasingly difficult situation, some individuals stopped seeking medical care. The lack of energy and sense of hopelessness were overpowering.

I have made two acute visits. How do I know that it’s not my heart that is acting up? But it hasn’t been. Apart from that, I haven’t sought healthcare very often. Should have gone more times but haven’t had the energy. But at that

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**Figure 1.** The vicious circle, schematic presentation of the theme and subthemes presented in the study.
very moment I don’t give a damn, I might die. It’s been sooo hard. (20)

The Symptoms Have Seized Control Over My Health
Many informants reported being unable to control the symptoms caused by the disease. Vomiting, pain, cramps, and coughing could occur at any time in any place, crippling their life. This meant that their life was ruled by symptoms and suffering they were unable to escape from.

It affects me in a really bad way. Like being stuck for two hours over a basin with my mouth open and I keep belching with food and froth coming into my mouth, and it’s unpleasant and tastes bad and you spit and spit and try to freshen up with water and such, but it’s so painful … I just moan and want time to pass so that I can go to bed. (6)

Several individuals felt they had lost their normal life, their freedom, and health.

Life feels very tough and diminished because I’m really, really tired all the time. I never know when the cramps will start, therefore I don’t enjoy eating and I don’t appreciate being invited for dinner. Being at work is also very difficult. I have been taken ill several times at work. Sometimes I’ve had to go home and sometimes I’ve tried to stay, but it hasn’t been possible. (20)

Loss of Energy and Strength
Over time, the disease depleted both the body and the soul of motivation, hope, and quality of life. The informants rated their health as the worst imaginable and beyond their control.

It’s like … the hopelessness and energy and everything … the quality of life … they just aren’t there. I’m so devoid of energy that I have sort of no motivation, unless somebody is whipping me … totally lacking health or … it’s completely worn down, it’s equally bad all the time, it’s like a vicious circle. (5)

Worrying about their stomach and its uncertain reactions completely drained them of energy and was constantly present.

As the stomach is not well, the whole body is unwell. I have also been very tired during this period and it may be that it’s partly in my head due to not knowing how things will turn out. It takes quite a lot of energy to focus on the stomach and think, I dare not eat so much now. (10)

Strategies for Managing Daily Life
As time went by, it became necessary to find strategies in order to master the disease and divert one’s thoughts. Strategies could include restricting oneself to a certain type of food, being dependent on having a toilet nearby, or being forced to return to bed several times during the day. Fasting throughout the working day was yet another necessary sacrifice to make one’s life manageable. However, despite this strategy being successful, life was still not experienced as dignified.

All the time when I’m working, I survive on water. I don’t eat dinner there because it gives me stomach pain and I start vomiting and that’s just not possible in the home care service. I try to be as empty as possible to be able to work. I eat when I get home. I don’t even feel like trying. There is nothing dignified about this life. (10)

There was the belief that it was possible to forget about the disease, at least for a while, by spending time with loved ones. Not being alone momentarily distracted them from thoughts about the disease.

I think that one can sort of push it aside [the disease/symptoms] when one is sitting down and talking with others or spending time with the grandchildren or whatever. One can forget for a while, then one doesn’t think of oneself in that way … but it’s when you come home to the loneliness. (2)

Loss of a Social Life
The unpredictability of the symptoms meant that the body could not be trusted. It was extremely embarrassing when the body revolted by making bodily sounds and evacuations. The informants preferred to stay at home and suffer by themselves rather than exposing themselves or their friends to discomfort. This led to isolation and lack of a social life.

I’ve been reluctant to [have dinner together with others] because if it sets in while you’re out somewhere—then you either have to just go home or, if it’s very serious, go in [to hospital]. Then that’s hanging over you all the time so it’s just as well to stay at home. And then it’s no fun for my friends either, I have to take a small portion and if I feel like having more, then I don’t dare to do so, because then I will throw everything up again and that’s not very nice. (2)

I can’t go to the cinema and I can’t book a holiday. Then I’ve been a member of the church sewing circle, but I haven’t been able to go to church either. I can only say “no,” I would rather not socialize with anybody. (5)

Moments of Hope Despite Failing Health
The informants longed for their former life and health, which they perceived had been lost. Nothing could be worse, and all their hope was pinned on the pending operation.

I hope to have a better life and be able to breathe, not having to vomit and having no pain … perhaps regain my rather active occupation. A life that is more fun, that’s what I hope for. A life that I feel is taken from me right now. (24)
I hope to be able to get help, have been thinking that I may have to live with this and then I know that at some time we need to talk to 12. (10)

**Discussion**

The 22 individuals in this study all stated that their experience of health is affected by severe symptoms, which make them feel unable to live a normal life. Even in cases where a measuring instrument is validated and reliable in a research context for a particular group, approximately 30% of data will remain concealed because of the risk of the subject being forced to choose a statement that does not fully correspond to her/his experiences (Bergh, Sjöström, Odén, & Steen, 2001). Furthermore, health and suffering are parts of human reality and take many different forms. For this reason, it is important not only to focus on the trustworthiness of a measuring instrument in a group of informants but also to allow the individual to describe what the illness means to her/him. This may provide an understanding of how they experience their situation. We have been unable to find any previous studies on individuals describing their suffering caused by LEPH in their own words. Therefore, without any preconceived hypotheses, semi-structured interviews along with latent content analysis were used.

The number of participants can be regarded as adequate, as they provided a sufficient amount of rich data. During the process, the authors (B.W., S.L., and P.A.L.) ensured that the analysis corresponded to the aim and that all data were analyzed both separately by each author and thereafter together. The authors' different experiences made it possible to challenge each other's preunderstanding and to return continuously to the data for confirmation of interpretations, as well as reflection on methodological procedures. According to Graneheim, Lindgren, and Lundman (2017), this can be considered a strength in terms of ensuring confirmability. Despite creative and reflective discussions between the authors throughout the analysis process, some content in the subthemes may appear to be overlapping. However, human experiences are often intertwined and therefore it is not always possible to achieve mutually exclusive themes (Lindgren et al., 2020).

For individuals suffering from LPEH Grade II–IV, life is an overall experience of an inescapable situation, in this study described metaphorically as “Being caught in a vicious circle.” This theme highlights the informants limitations and powerlessness, as well as the suffering they are forced to endure. This is in line with Eriksson (2006), who claims that at some point in time, every person is confronted with unendurable suffering that feels like an inescapable situation.

The participants described a distressing and uncertain time when they urgently sought help from healthcare professionals on several occasions without obtaining a definite diagnosis. Continued uncertainty, fear, insecurity, and severe symptoms dominated their health. Dodd et al. (2001) argue that symptom experiences include an individual's perception of a symptom, evaluation of its meaning, and her/his response to it. This refers to whether an individual notices a change in the way she/he usually feels or behaves. People evaluate symptoms by making judgments about the severity, cause, treatability, and effects on their lives. It is vital for professionals to be vigilant in acknowledging that symptoms are more than separate physiological or psychological states (Dodd et al., 2001). Kirmayer, Groeleu, Looper, and Dao (2004) highlight the term “medically unexplained symptoms” as a social and clinical predicament rather than a specific disorder, arguing that it is not a replacement for the concept of a somatoform disorder but a way of drawing attention to a situation in which the meaning of distress is contested. The informants in our study described this as severe suffering, which gave rise to hopelessness and resignation.

In line with a recently published study exploring experiences in individuals with laryngotracheal stenosis, our results demonstrate that the participants fear of vomiting, coughing, regurgitations, and cramps was overwhelming and forced them to refrain from having a meal together with friends (Clunie et al., 2022). Attempting to have a meal in a restaurant on rare occasion frequently resulted in humiliating consequences such as spending several hours in a public lavatory. It is well known that a feeling of being unable to eat “properly” may result in shame and guilt (Carlsson, Ehrenberg, & Ehnfors, 2004; Elsner, 2002; Jacobsson, Axelson, Österling, & Norberg, 2000; Medin, Larson, von Arbin, Wredling, & Tham, 2010). Under such circumstances, it is understandable that meals often became a must to survive or an ordeal that had to be endured, which not only reduced the joy of eating but also resulted in social withdrawal. Thus, to use some of sociologist Erving Goffman’s (1990) metaphors for interactions and social life, the person was forced to eat “offstage” to avoid stares from the audience. As health is linked to meals, as well as commensality which provides a sense of social affinity and well-being, we argue that the participants in our study failed to achieve health while their LPEH-related symptoms remained (Nyberg et al., 2018).

Our findings also highlight tensions between deprived dignity and a meaningful social context including strategies for managing daily life to avoid the risk of shame. Despite meticulous planning, the
individuals were unable to trust their body, causing them to lose their motivation and energy to organize activities outside the home. They described their health as the worst possible and felt deprived of the opportunity to live their lives as they wished. Thus, the social meaning in life and human dignity that are vital for the experience of health were overshadowed by the suffering that Eriksson (2006) termed “relation-less;” that is, a suffering the person carries within and which has been caused by a feeling of insufficiency and ability to live the life he or she would wish to live.

The participants in our study longed for their former life and health and expressed hope despite suffering, described by means of the subtheme “Moments of hope despite failing health.” This is in line with a metasynthesis demonstrating that, by its very nature, hope points to the future and is a sense of the possible even in the midst of great suffering (Lohne, 2022). A gleam of hope enters the vicious circle.

**Conclusion**

Individuals living with LPEH suffer significantly from their symptoms, which affects their daily life and impacts their health. Trapped in an isolated and hopelessness, the participants experienced immense mental and physical suffering, the underlying meaning of the metaphor “Being caught in a vicious circle” from which escape seemed impossible. Nothing could be worse. However, despite the severity of their health issues, there were occasional glimpses of hope due to the upcoming operation. Although volvulus and incarceration are rare occurrences, the burden of symptoms and their impact on general health make surgical intervention a necessary consideration for these individuals.

Finally, it is important not only to have knowledge of symptom diagnosis and treatment methods but to support this patient group through meaningful dialogue about their current life circumstances, potential setbacks they may face, and the situations they need to handle to begin the exit from the vicious circle. Follow-up studies using the presented methodology should be conducted after surgery and are now being applied by our study group.

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