Putting life on hold: A longitudinal phenomenological-hermeneutic study of living with [or close to someone with] an enterocutaneous fistula before and after reconstructive surgery

Karolina Härle RN, MSN, PhD Student1 | Sussanne Börjeson RN, PhD, Professor2 | Olof Hallböök MD, PhD, Professor1 | Pär Myrelid MD, PhD, Associate Professor1 | Ingela Thylèn RN, PhD, Associate Professor3

1Department of Surgery, and Department of Biomedical and Clinical Sciences, Linköping University, Linköping, Sweden
2Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden
3Department of Cardiology, and Department of Health, Medicine and Caring Sciences, Linköping University, Linköping, Sweden

Correspondence
Karolina Härle, Department of Surgery, University Hospital, SE-58185 Linköping, Sweden.
Email: karolina.harle@liu.se

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Abstract
Aims and Objectives: Illuminate meanings of living with [or close to someone with] an enterocutaneous fistula before and after reconstructive surgery.

Background: Enterocutaneous fistula is a serious condition affecting the well-being and social life of both patients and families, sometimes for several years.

Design: A longitudinal qualitative design.

Methods: Patients and families (n = 14) were followed with dyadic interviews at three occasions, conducted 2017–2020. The interviews were analysed with a phenomenological-hermeneutic approach. COREQ guidelines were followed.

Result: Living with an enterocutaneous fistula was explained as life being put on hold, while living in a bubble for an uncertain time. This bubble meant facing an unpredictable and restricted life where the dyads were forced to take control over the situation despite being vulnerable inside, striving to resume normality. The patients dealt with never-ending symptoms such as leakage from the fistula, pain and fatigue, while the family supported with practical matters and just being close. Dependency on intravenous fluids resulted in social isolation, which caused mood swings and depressiveness. In this situation, healthcare professionals often became a substitute for other interactions, but the lack of understanding about the dyads’ situation, affected their trust in the healthcare. Despite all, they still had belief in the future, the patients having higher expectations than the family.

Conclusions: Living with an enterocutaneous fistula meant a daily life struggling with many limitations. This implies that the transition was associated with difficulties and the dyads strived to accept their situation.

Relevance to Clinical Practice: The findings indicate that these patients must be cared for with a multidisciplinary approach. A person-centred health plan could impact on the dyads’ feeling of control and thereby making them less dependent on healthcare.
1 | INTRODUCTION

Living with an enterocutaneous fistula (ECF) is a rare but serious and complex condition (Quinn et al., 2017), which affects the individual's health, well-being and ability to take care of themselves (Harle et al., 2015). An ECF is an abnormal connection that develops between the gastrointestinal tract and the skin. Most ECFs occur as a complication of abdominal surgery but may also occur spontaneously due to an underlying condition, such as Crohn's disease or an abdominal injury or trauma (Quinn et al., 2017). The incidence of ECF is limited but depends on the underlying abdominal pathology. It has been estimated to vary between 1% and 2% after abdominal surgery (Hatchimonji et al., 2020), while the incidence is slightly higher in patients with Crohn's disease (Lightner et al., 2020). If there is a spontaneous closure of the fistula, this usually occurs within 2 months. If the fistula does not heal on its own, a surgical intervention is needed (Lloyd et al., 2006). It takes at least 6 months to prepare the patient for reconstructive surgery (Atema et al., 2016; Grainger et al., 2018; Lloyd et al., 2006). During this prehabilitation period, the patient's physical, nutritional and medical conditions need to be strengthened (Atema et al., 2016; Grainger et al., 2018; Slater, 2011). While waiting for surgery, it is highly advantageous if the patient can be cared for at home since waiting in hospital involves a poorer prognosis and a high risk of increased morbidity and mortality (Quinn et al., 2017). The patient's needs include wound care and nutritional and physical rehabilitation. The complex and specialised homecare—both before and after reconstructive surgery—requires careful planning (Slater, 2011). All this suggests that living with an ECF affects not only the individual but also the family (Harle et al., 2015) and requires a multidisciplinary team approach with long-term care (Grainger et al., 2018; Quinn et al., 2017).

2 | BACKGROUND

Living with an ECF involves limitations in daily life, including social isolation, being dependent on others and needing a supportive environment (Harle et al., 2015). The condition is associated with intestinal failure with high output and loss of intestinal contents (e.g. fluid, nutrients and electrolytes) from the fistula, requiring intravenous supplementation and parenteral nutrition (Atema et al., 2016). Those living with a fistula often experience feelings of depression, fear and anxiety (Hoeflok et al., 2015), as well as bodily concerns, loss of self-esteem and impaired health-related quality of life (HRQL) (Grainger et al., 2018; Harle et al., 2015; Visschers et al., 2008). This emotional and mental distress are usually related to pouching problems and leakage from the fistula which, together with a need for around-the-clock intravenous fluids and parenteral nutrition, restricts social and physical activities (Harle et al., 2015; Hoeflok et al., 2015). Many patients with ECF become dependent on high doses of analgesics, often morphine, leading to an already burdensome situation and also complicating postoperative pain control (Grainger et al., 2018). Despite this complex situation, longitudinal studies on the current subject are lacking. Visschers et al. (2008) asked 62 patients with an ECF who had undergone reconstructive surgery if they could retrospectively evaluate their health and score their health status before and during the presence of ECF. Significant differences between the periods were found. Subjective health after surgery was considered lower than before the fistula but had improved compared with the presence of ECF. Still, the patients rated their HRQL lower than their matched controls (Visschers et al., 2008). This confirms the need for qualitative studies describing in depth how patients with an ECF experience their illness trajectory before and after reconstructive surgery. Additionally, as the family plays an essential role in the individual's life, it important to gain deeper insights from family members' perspectives to support the dyads.
3 | THE STUDY

3.1 | Aim
To illuminate the meanings of living with [or close to someone with] an enterocutaneous fistula before and after reconstructive surgery.

3.2 | Design
A longitudinal qualitative design with a phenomenological-hermeneutic approach (Lindseth & Norberg, 2004) was applied. The method was first presented in 2004 and the theory behind the method was further elaborated in 2021 (Lindseth & Norberg, 2022). Patients and family members were followed over time with in-depth dyadic interviews (Morgan et al., 2013). This manuscript has been prepared in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ – Appendix S1) guidelines (Tong et al., 2007).

3.3 | Study participants
The patients were consecutively included between April 2017 and December 2018 when they were referred to, or hospitalised at, a tertiary referral centre in Sweden. The researchers had access to the study population by the physician in charge who informed the researchers when a patient with an ECF was admitted to the surgical ward. The criteria for inclusion were patients with an ECF, older than 18 years of age and able to communicate in Swedish. All patients during the inclusion period fulfilled the inclusion criteria (n = 9) and were invited to participate by the first author. They were given oral and written information about the study and were given 1 week to consider participation, whereof one declined. The patients who accepted participation were in turn asked to appoint a family member. No family member declined. One interview served as a pilot interview, and seven dyads (patient and family member pairs) were ultimately included. The participants were referred from different parts of Sweden. None of them came from the tertiary referral centre’s primary catchment area. The first author was not involved in the study participants’ care. The participants’ characteristics are described in Table 1.

3.4 | Data collection
Data were collected between April 2017 and January 2020 through in-depth dyadic interviews performed by the first author on three occasions: 1–12 weeks before surgery, 7–15 weeks after surgery and 13–16 months after reconstructive surgery. The time and place for the interviews were arranged according to the participant’s wishes. Sixteen of the 21 interviews took place in the participants’ homes and five in a secluded location at the hospital. An open interview guide was used on all three interview occasions. To ensure the credibility of the interview guide, a pilot interview was performed with one patient and one family member, who were interviewed separately in the first and second interviews but together as a dyad in the third interview, resulting in two new questions regarding healthcare experiences and thoughts about the future. The pilot interviews were not included in the present study. The following introductory questions were used: ‘Can you tell me about your experiences of living with [or close to someone with] an ECF?’ (first interview), ‘Can you tell me about your experiences now you [or a close family member] have recently undergone reconstructive surgery?’ (second interview) and ‘Can you tell me about your experiences now at least one year has passed since reconstructive surgery?’ (third interview). To encourage narration, and to clarify and enhance understanding, probing questions were used during the interview, such as ‘Can you tell me more about that?’ or ‘How did you feel about that?’ Before the second and third interviews, the first author listened to the previous interviews to follow-up on what had been said before.

### TABLE 1 Dyad characteristics

<table>
<thead>
<tr>
<th>Dyad</th>
<th>Patient’s age(^a) and gender</th>
<th>Family member’s age(^a) and gender</th>
<th>Relationship</th>
<th>Time(^b) with an ECF</th>
<th>Dependent on fluids/PN</th>
<th>Before</th>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>35 M</td>
<td>75 F</td>
<td>Mother</td>
<td>50</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>75 M</td>
<td>50 F</td>
<td>Daughter</td>
<td>15</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>75 M</td>
<td>65 F</td>
<td>Wife</td>
<td>25</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>30 M</td>
<td>55 F</td>
<td>Mother</td>
<td>10</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>70 F</td>
<td>70 M</td>
<td>Partner</td>
<td>15</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>80 M</td>
<td>80 F</td>
<td>Wife</td>
<td>20</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>50 F</td>
<td>55 M</td>
<td>Husband</td>
<td>25</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: F, Female; M, Male; PN, Parenteral nutrition.
\(^a\) Rounded to the nearest five interval.
\(^b\) Months living with an ECF at inclusion (i.e. first interview).
for example: ‘During the last interview, you described your concern. How does it feel now?’ To benefit from interviewing dyads, follow-up questions such as ‘How do you feel when your relative says this?’ was asked. At the end of the interviews, the dyads were asked if they had anything else to share about their experiences. Notes were taken during the interviews to ease probing questions. These notes were not used in the analysis. The interviews were tape-recorded and transcribed verbatim. The average interview lengths were 49 (44–61) minutes for the first interview, 41 (34–48) minutes for the second interview and 42 (29–62) minutes for the third interview.

3.5 | Ethics considerations

The principles of the Declaration of Helsinki (2013) were followed. The participants were informed that participation was voluntary, and that they could withdraw their participation at any time without giving a reason. All material was treated confidentially. The dyads were given the opportunity to ask questions after the interviews. All participants were given a telephone number for the research team. Ethics approval was obtained from the Regional Ethical Review Board (ref. 2017/121–31).

3.6 | Data analysis

To interpret and analyse the interview text, a phenomenological-hermeneutic approach was applied (Lindseth & Norberg, 2004). This method is derived by Ricoeur’s work on hermeneutical interpretation (Ricoeur, 1992) and Husserl’s work on phenomenology (Husserl & Moran, 2001) and further developed by Lindseth and Norberg (2004, 2022). The text interpretations consisted of dialectical movements between understanding the whole text and explaining parts of it. The interpretation and analysis process involved three phases: naive reading, structural analysis and comprehensive interpretation.

3.6.1 | Naive reading

The first reading aimed to provide an initial understanding and an idea of what the narratives were about. The text was read several times to grasp its meaning as a whole. A naive understanding of what it means to live with [or close to someone with] an ECF (hereinafter shortened to ‘what it means to live with’) was formulated by the first author and later validated in the structural analysis.

3.6.2 | Structural analysis

A thematic analysis was performed with a focus on illuminating the meaning of living with an ECF before and after reconstructive surgery. The text, with one dyadic narrative at a time (i.e. consisting of all three interviews for each dyad), was divided into meaning units. The meaning units were then condensed and merged into preliminary subthemes, based on their similarities and differences. Some preliminary subthemes overlapped and after further condensation, three themes and seven subthemes were generated by the researchers through the process of analysis. Disagreements were discussed until consensus was reached (Lindseth & Norberg, 2004). An example of the analysis process is presented in Table 2. In the findings section, the quotations are referred to as P (patient), F (family member) or D (dyads), combined with the interview number (1–7) and interview occasion (1–3) in brackets, for example (P6;1).

3.6.3 | Comprehensive understanding

This step includes the critical, in-depth interpretation that reflected the researcher’s preunderstanding of the phenomenon, the naive reading and the findings from the structural analysis. The naive reading, themes and subthemes were reflected upon in relation to the aim of the study. This understanding, together with existing knowledge from the literature, revealed a deeper meaning of the text (Lindseth & Norberg, 2004).

3.7 | Rigour

In phenomenological-hermeneutics, the investigated preunderstanding is fundamental (Lindseth & Norberg, 2004). The first author has experience of caring for patients with an ECF. Since interviews with more than one person at the same time can encourage deeper narratives (Morgan et al., 2013) and stimulate ideas that might not have been recognised or remembered, dyadic interviews were chosen. In-depth interviews were chosen since they can encourage participants to describe the lived experience (Lindseth & Norberg, 2004). In the naive understanding, the first author tried to address the pre-understanding by refraining from judgements and conclusions as lived experiences were narrated. This was done by trying to keep an open mind and ‘allowing the text to speak’, which was facilitated by the author’s critical attitude to data. Lincoln and Guba’s (1985) framework of trustworthiness in qualitative research was used. To ensure the credibility of the study, the analysis followed the method step by step and the first, second and fifth authors conducted the structural analysis separately and together (Lincoln & Guba, 1985). The second and fifth authors’ pre-understanding was derived from a methodological and clinical nursing perspective, based on their experiences as seniorresearchers and nurses in acute and oncology care settings. During the structural analysis, the authors tried to view the text as objectively as possible to validate or invalidate the naive understanding. In the comprehensive understanding, the authors interpreted the text as a whole based on their pre-understanding, using critical reflection.
to become aware of aspects of their pre-understanding (Lindseth & Norberg, 2004). Describing the analysis process (where every step towards conclusion can be followed) and using quotations representing all participants strengthened the dependability of the study. Transferability was established with a thorough description of the data collection and the analysis procedure. Confirmability was strengthened by comparing the findings with previous studies and having the findings reviewed by all co-authors (Lincoln & Guba, 1985).

### 4 | FINDINGS

#### 4.1 | Naive understanding

Living with an ECF meant living a restrictive everyday life throughout the illness trajectory, involving practical, social and emotional challenges related to the ECF. For the patient, it involved pain, odour and fluid leaking from the ECF, as well as wound dressing problems. For the family member, it meant being a constant informal carer. Together, it involved isolation and psychological distress for both the patient and the family member. Living with an ECF also meant feeling dependent on healthcare professionals. Although the dyads experienced daily struggles, they also had faith in the future and looked forward to resuming their daily activities from before the ECF. One year after reconstructive surgery, some dyads had begun to approach their former life, while others were still dependent on intravenous fluids and parenteral nutrition even if the fistula was healed.

#### 4.2 | Structural analysis

Living with an ECF before and after surgery was explained in one overarching theme: Life on hold—living in a bubble for an uncertain length of time. The themes (subthemes) are intertwined, constituting
a complex whole of the ECF trajectory and consist of: (1) facing an unpredictable and restricted life (Dealing with never-ending symptoms, being stricken by psychological distress and feeling a need for a supportive environment), (2) feeling forced to take control despite being vulnerable inside (being dependent on others and having a lack of trust) and (3) striving to resume normality (having faith in the future and re-evaluating one's own expectations continuously) – see Figure 1.

4.3 | Life on hold—living in a bubble for an uncertain length of time

Life on hold—living in a bubble for an uncertain length of time—meant that life was put on pause without knowing for how long. The dyads had been in this bubble for several years while normal life continued outside. Before reconstructive surgery, they expected that life would return to normal more quickly and it was a disappointment when it did not. Shortly after surgery, only a few of the dyads' lives had gradually return to normal. One year later, some of the patients still had symptoms related to the fistula or the underlying disease, meaning that their lives were still on pause. Some of the patients were still dependent on intravenous fluids and homecare. Even though the fistula was healed, there were significant limitations in daily life. Figure 2 illustrates the number of meaning units mirroring the trajectory in each theme/subtheme and the distribution of lived experiences between patient and family member.

4.4 | Facing an unpredictable and restricted life

4.4.1 | Dealing with never-ending symptoms

The dyads were confronted with several symptoms restricting their daily lives, and it was sometimes difficult to see an end to the misery. One main problem for the patients before reconstructive surgery was leakage from the ECF due to high fistula output and dressing problems. However, many different symptoms combined caused suffering.

P:... I think many people don't understand what... that there's a lot of suffering involved with having this. That there's a lot surrounding it, it's not just having it leaking, it affects your whole life, and for family too. It's not just that it leaks all the time – it affects everything, everything in your life. You cannot have a social life, you cannot do what you want, you cannot even go out shopping, even if you do dare to occasionally, you can bet it'll start leaking.

(P5;1)

The leakage made everyday life unpredictable. The restrictions and fear made the patients unwilling to leave home and being dependent on intravenous fluids made it impossible in practice. The patients had been hospitalised for a long time, often even months before the onset of the ECF. The prolonged prehabilitation period, the reconstructive surgery phase, and in some cases, prolonged rehabilitation due to
post-surgery complications also contributed to loneliness for the family members. Even though the family members were not ill, some of the daily restrictions were the same as for the patients.

F: Yes, it gets a bit isolated, it does. P: Yes, I sometimes think you have been more isolated than me, because I have contact with many others, and I email many people, and talk on the phone and so on. I think you have often been more isolated than me. F: Yes, but I go out with the dog in any case. P: Yes, you do meet some people. F: No, I do always meet people when I’m out walking and so on.

(DS;1)

Having difficulties leaving home meant losing many of their social relationships, and they became socially isolated. Loss of friends and social interactions was something that most of the dyads still experienced more than 1 year after the surgery. It was not easy to return to previous social relationships when friends distanced themselves. This meant that the dyads lived in isolation close to each other and a few other family members or friends, even when the fistula was healed.

F: Yes, it’s not bloody great. P: No. F: So you could say that this has actually meant for us that we do not like to go to restaurants or go and sit in the cinema or anything like that. Because the idea that you cannot avoid it [referring to leakage] coming, if it happens in the cinema, oh, like, what the hell do you do then. P: Yes. F: Or in restaurants, places where there are lots of people. P: Yes, but at least you know where the toilets are in town.

(D7;3)

All patients had fatigue and reduced energy after the reconstructive surgery, and several of them had new symptoms such as high ostomy output, diarrhoea or new fistulas. Physical restrictions such as reduced muscle mass and strength caused frustration. As a family member, it was hard to stand by and be unable to alleviate the negative impact the ECF had on their life.

F: But obviously it’s very hard to follow the disease and only, only be able to watch and not be able to do anything. We’ve wished about a million times that they could just take this disease away, but of course it does not work like that. You just have to be there and try to do as much as you can, to support and help. I think we have actually wholeheartedly devoted ourselves to that, yes, or for this half a year in any case.

(F4;2)

4.4.2 Being stricken by psychological distress

Many years of struggling with an ECF affect both the patients and the family members negatively. For the patients, the psychological distress before surgery meant a lot of fear: fear of leaks, fear of surgery and fear of not getting rid of the fistula. The patients never felt secure, and the social isolation combined with a loss of friends caused depressiveness. A lot of negative thoughts about life were aroused and they wondered whether life was worth living.

P: To put it very briefly, you spend 24 hours a day with the possibility that the fistula can leak, that something’s happening. I never feel secure, so if you go off on a visit, you are on tenterhooks: ‘I just
hope nothing happens now... That's putting it very briefly, and it means that you... are affected mentally. I'm not the same person that I was two years ago... At least, I myself do not think I'm... I wasn't particularly cheerful back then, but I'm even less so now and it's very much... now this fear... but if you are at home, it's OK.

(P3;1)

For the family members, the psychological distress meant being continuously anxious for the patient, which had a negative impact on daily life.

F: You had to be on your guard and ensure that nothing happened [referring to the son], day and night. Sometimes I did not dare go to bed, sometimes I sat on the sofa and slept to keep a check on the situation.

(F1;1)

It was a painful situation, and the family members often felt helpless and frustrated. Always being there for the patient while also taking care of themselves was tiring and mentally demanding. For some, this distress was still noticeable one year after reconstructive surgery.

F: I always tend to say that it's been, it's so horrible, and that's because it's really, really, really hard to, just being able to watch and being able to help as well as I can, of course. But he is a fighter unlike any other. But of course, it wears the parents down, too. That, I mean that all the time thinking, 'I wonder how it is, and will we go then, and does he want us to come or does he want to go on his own. Because it's sometimes like that, too, which is completely understandable. We cannot sit with him around the clock. But we have been there and when we have needed to.

(F4;3)

Most patients had decreased anxiety levels shortly after surgery, but they still experienced fatigue and mood swings.

P: I'm not so depressed that I need help or anything like that, but I do not recognise myself, I usually have so much energy.

(P5;2)

One year after surgery, some patients still experienced psychological distress.

P: The hill gets steeper all the time, but it is what it is and you have to try to take it as it comes. But as I said, you get depressed sometimes and you do not know what the hell you'll do.

(P6;3)

4.4.3 | Feeling a need for a supportive environment

The dyads needed a supportive surrounding environment to manage life with an ECF. Otherwise, there was a risk that they would feel forgotten and abandoned. Having someone who cares could be crucial to reduce depressive symptoms. Support was important within the dyads, but also from extended family and friends. The family member's support was a lifeline for the patients, and without it would have been harder to cope with the situation.

P: But he [referring to the husband] notices things, like when I do not feel well. Even if I do not say anything, he says: 'Now we'll go and rest, because I can see you don't feel well,' he says. He's very observant.

(P5;1)

In the absence of social interactions with family and friends, healthcare professionals often became a substitute for the dyad's normal social relationships.

P: I do not have so many friends left because they, they do not know, I do not know whether they do not dare to come or what it actually is, but it's gotten a bit lonely, so I have more, the staff, they are my best friends. It's them who make you keep on going, it's better being in the hospital.

(P4;1)

The support from healthcare was essential and was an opportunity to continue to fight and look ahead. Homecare was positive for most dyads and provided a sense of security. They felt part of a context and not just one in a crowd of patients. The patients wanted to be seen as a person behind the disease, not just as a disease. The healthcare professionals' competence made the dyads' daily lives easier and increased independence. A good dressing plan from an ostomy therapist or a backpack to carry intravenous fluids made the dyads freer and reduced their social isolation. Even before surgery, the dyads had needed support from healthcare for a long time. After surgery, their needs varied but all dyads still needed some form of medical support, such as administration of fluids or nutritional advice. There was a feeling of insecurity when the care was discontinued after a long period of illness, during which time there was a fear of setbacks. This meant that a few of the dyads experienced emptiness when they no longer needed in-patient care or homecare and had to adjust to the new situation.

F: And then there's something that you might not always think about, but there's been a big change from having had so many visits a day from various healthcare workers to nothing. It's been noticeable.

P: That's possible. F: Yes, you still miss it somehow, yes. P: Yes, it's clear that... F: Not being sick, no, but just people coming.

(D2;3)
4.5 Feeling forced to take control despite being vulnerable inside

4.5.1 Being dependent on others

The patients were dependent on both the family member and healthcare professionals. The family members played an important role helping with practical matters, medical treatment, taking care of the household and just being close. Bringing appliances, nutritional drinks, fluids and medicines home from the pharmacy was often the family member’s responsibility. The dyads struggled to be independent, and one way to take control was that the family members became a carer to make sure practical matters worked out well.

F: Yes, well, I, it’s certainly been, how can I put it, very hard of course. I do not know, I’ve only done what I could, to help with my hands and yes, I do not know. Helped him with dressings and so on. Otherwise, it’s yes, it’s been, it’s OK, it’s such a shame for him so we do not know where to go sometimes, but I have not gone anywhere, no, I’ve stayed. What can I say? I’ve just been there.

(F4:1)

The need for help with changing dressings and administering fluids made the dyads vulnerable and dependent on homecare every day.

P: The leakage is not nice, either, when it happens. If I cannot fix it myself, which I could not to begin with, because then I was terrified about this, instead we had to call homecare and all the hassle that involves.

(P6:1)

Even after reconstructive surgery, some patients remained dependent on homecare. There were different nurses working in the healthcare district, and the dyads were forced to accept unknown people coming daily in this vulnerable situation. They looked forward to being independent after reconstructive surgery. One way for the dyads to become independent was when they could practise selfcare or were involved in the care planning.

P: We set the drip in the morning now. We did it in the evening before, and the whole evening was taken up then. We did not really know when they [referring to homecare] come, and so on. Now we take it in the morning, and I manage to go out for a stroll before it’s set up.

(P6:2)

Being dependent on homecare also meant that the home felt like a healthcare facility. The home needed to be adapted based on homecare requirements, for example with hospital beds, meaning that some dyads needed to have separate bedrooms. This had a negative effect on their relationship. The dyads also needed to store large amounts of fluids and dressing materials, which increased the feeling that it was no longer a home. These changes were more difficult for the family members to accept than the patients.

F: Yes, I’ve thought purely in general terms that this is, like, not a home anymore, because I’ve never known who has opened the door [referring to homecare]. We cannot lock the door, as they do not have a key.

(F6:1)

Extensive medical care needs meant that some patients had to be cared for at nursing homes at times. This was a negative experience, as they generally preferred being cared for at home. Although the dependency on healthcare was negative, they were grateful that homecare was available.

4.5.2 Having a lack of trust

The dyads experienced a lack of knowledge among healthcare professionals, both at hospitals and with homecare. In some cases, healthcare professionals did not know about the disease or understand about life with an ECF, while the dyads had lived with illness for a long time and had good knowledge about their situation. Not feeling confident in the healthcare system disappointed them, which increased the feeling of vulnerability. There were often several healthcare professionals involved, but only a few that the dyads trusted.

P: To begin with, I did not think it mattered much. But when you have to tell the same story a thousand times, you get, you get a bit tired of it. And what I’ve found worst, before I started dealing with the opening and the drip and itself, I sometimes thought that they do not, I had to tell one of them: ‘Now you need to change your gloves, now you need to disinfect yourself, now you need to do this, and now you need to clean up’. Because I’m so careful myself.

(P5:1)

This lack of trust meant that some family members felt forced to take control of certain aspects of care and became the patient’s advocate in the interaction with healthcare.

F: This issue that you feel when you go to a doctor or someone in healthcare that they have read the patient’s notes, and that you do not need to sit with your ears pricked up and say ‘Wait, wait, where did you get that from?’, that you can relax and feel that now I know they are ready up and you can feel confident about that.

(F7:3)
Receiving continuous information and having regular contact with a healthcare professional reduced the feeling of vulnerability. The waiting time for reconstructive surgery was sometimes long and was like a vacuum where neither the referring hospital nor the reconstructive centre took responsibility for providing information about what to expect regarding fistula care, nutrition status and suitable times for reconstructive surgery. The handover between different healthcare institutions created anxiety and uncertainty and the lack of continuity was something that made them feel abandoned and vulnerable.

The dyads also experienced a lack of understanding from the healthcare professionals about their fatigue and the slow post-surgery recovery, which affected their trust in the healthcare. The healthcare professionals expected a faster return to a normal life and work than was actually possible:

**P:** She [referring to the doctor] does not understand that, that I'm so exhausted because it was the first thing she said: ‘Yes, but is it possible that...’ She was going to sign me off sick for one or two weeks, and then I was going to start working again... But I said, ‘It was really hard for me just to get here’.

**P7:2**

4.6 | Striving to resume normality

4.6.1 | Having faith in the future

Even though life with an ECF placed great limitations on daily life, the dyads believed in a better future where they could return to a more normal life. Having this belief was important to cope with the situation. Before surgery, they looked forward to getting rid of the leakage problems, dependence on fluids and homecare. They had faith that they would be able to return to a normal existence, resume normal social activities and where relevant start working again.

**P:** Now, like, a new period starts that you can look forward to and try to help the body as much as possible to get fit again and have a little energy. And by having energy, everything happens automatically then, you can do things. So, it's not, like, what the hell will we do today, and waiting for surgery, and that takes years. Now you have faith in the future, which can be good, really good. You feel, if everything goes well, you feel yourself getting stronger and stronger, and it's healing, and I can exercise and so on, so that's very pleasing.

**P6:1**

Hope for the future increased when the patients were referred to the reconstructive centre. Even if most of the patients still had symptoms shortly after surgery, the dyads had a lot of hope for the future and expectations of returning to a more normal life.

**F:** If I think back to the last time, you were here, for example, we both have a much more regular life now.

**P:** Everything is calmer since this bag [referring to fistula appliance] came away that could sometimes be a problem. Now I have this [stoma] and now there's no leakage so you can be more relaxed when you go out. Things can still happen, but it feels harmonious somehow if we go somewhere.

**D6:2**

For some of the dyads, the goal was not a full return to their previous lives, but they had faith that the symptoms would decrease so that physical and social activities could be resumed. Many of the social restrictions caused by the ECF were reduced shortly after reconstructive surgery and it felt good to have their former life back.

**P:** Now I have other social activities, it's more that I've started to go back to the usual so that I can, if I dare, I can visit others and they can visit me, and in a completely different way. And I have a lot of contact by phone, and so on. Of course, I could have also had that before, but it, it's been strange. I have not been like one of the gang. Now I'll be able to walk and paint, and I have not been able to go to the art association and meet friends there, and the research association. So now I'm getting my old life back.

**P5:2**

4.6.2 | Re-evaluating one's own expectations continuously

The dyads adapted well to the fact that the recovery was not as fast as they had hoped. Having had high expectations before surgery, like being able to travel or return to work quickly, the patients were now satisfied with small advances such as being able to walk short distances.

**F:** It wasn't like we had thought, because we'd imagined that yes, now he'll be healthy and have his operation, and now he'll start working and so on, and it wasn't like that at all, but I think it's working well so far.

**F4:2**

In several of the dyads, one of the two had higher goals and expectations than the other. When the dyads had not set common goals, the other's high expectations resulted in uncertainty and became an unnecessary stress. Often it was the patients who had higher
expectations while the family members were more sceptical. For the family members, it was a good thing that the patient was still alive, and they were not in such a hurry. Thus, the dyads had to struggle to share a view of the possibilities and limitations.

P: When I’ve been healthy, we have tried to go away for a few days before Midsummer and then the Midsummer holiday... so this year we'll go away.
F: Yes, we’ll see. Do not get too far ahead now, I've learnt that now, one day at a time. P: And I’m planning, like a steam engine, just 'We will, we will, we will.'
F: But then we hit a setback. P: Yes, yes. F: There have been so many. P: Yes, yes, but you learn from them. F: Yes, we have learnt so much that things might not be the way we thought.

(D7:2)

Even if the dyads’ expectations for the future were not completely fulfilled due to the outcome of the reconstructive surgery, they were forced to accept their future life including limitations. Re-evaluating one’s own expectations continuously and setting smaller goals was one way for the dyads to improve daily life and make it easier to motivate themselves.

P: But I mean, like I said last time, this restart, I thought this would pass, that I can start to be properly active again. And we thought we would be able to get away to the warm weather and all that. We've had to skip that. But now you have to change your goals here, it would be bloody nice to do away with this bed, sort things out down here and that I could stay up there [referring to the bedroom]. You have to, like, lower the level.

(P6:3)

5 | COMPREHENSIVE INTERPRETATION AND REFLECTIONS

Living with an ECF before and after reconstructive surgery meant dealing with never-ending symptoms and being stricken by psychological distress throughout the whole illness trajectory—life was put on hold and was described as living in a bubble for an uncertain length of time. Being dependent on others and dealing with a lack of trust in the healthcare forced the dyads to try to take control despite being vulnerable inside. A supportive environment, having faith in the future and continuously re-evaluating one’s own expectations implies that the dyads used different strategies to make life easier.

The concept of transition, ending with final acceptance, could be used to interpret the findings as a whole (Meleis, 2010). The dyads’ transitions in the present study started with a life without the fistula, followed by a life with an ECF, and ended with a life after reconstructive surgery. However, many patients did not resume their previous lives, and still needed complex care and experienced symptoms that restricted daily life even 1 year after reconstructive surgery. This implies that the transition was associated with difficulties and the dyads strived to accept their new life situations. Our findings are consistent with a previous study (Carlsson & Persson, 2015) which describes life with intestinal failure caused by Crohn's disease as a transitional process where the individual lives with the unexpected of not knowing from day to day how they will feel or what they will be able to do. According to Meleis's (2010) theory of transition, the process involves both the person and the environment, and different factors affect the individual response to a transition. The meaning of transitions, cultural beliefs and attitudes, socioeconomic status, preparation and knowledge affects the response patterns to the transition (Meleis, 2010). For the dyads in the present study, it was difficult to find meaning in why they had an ECF, a condition that no one was prepared for. As this is an uncommon condition, it was difficult to find information and the little information they received was often unclear as healthcare professionals also lacked knowledge. In the treatment process, patient-centred communication is essential for patient recovery and is fundamental to ensure optimal health outcomes. Effective communication between nurses, patients and family members has previously been shown to reduce uncertainty, increase social support and feelings of safety as well as patient satisfaction in care (Kwame & Petrucka, 2021).

Problems regarding leakages from the ECF, dressings and dependence on fluids and total parenteral nutrition made life unpredictable and restricted, which led to social isolation. Social isolation is a well-documented problem that affects physical health negatively and is associated with physical inactivity and poor sleep. Furthermore, it may also lead to depression, anxiety and an increased risk of premature death (Holt-Lunstad et al., 2015). The dyads in our study had not chosen their social isolation themselves. Several of the dyads showed symptoms of depression and anxiety, and some had even wondered if life was worth living. Being stricken by psychological distress may have several explanations, but it can certainly be exacerbated by social isolation and loneliness (Mikocka-Walus et al., 2021) and aggravate the transition to a life after reconstructive surgery. A loss of social interactions was something that most dyads still experienced more than 1 year after the reconstructive surgery, but those who had returned to a more normal life described less psychological distress and had accepted the situation. Mediating factors like having a supportive environment also affected the transition in a positive way. In the literature, social support has been found to have a stress-buffering effect, and social ties affect physical and psychological well-being (Cohen & Wills, 1985). The bodily and emotional benefits of social relationships are multifaceted. The patients in our study needed extensive support from family members and healthcare professionals. Even after reconstructive surgery, the dyads had a great need for support. Without a supportive environment, it would have been harder to cope with the transition. Social support can come from significant others, but also from a wider group of people (Thoits, 2011), as confirmed by our study. Our patients described support from their
close family members but also from the healthcare professionals. This is supported by findings from a study on patients with short bowel syndrome, emphasising the need for support from both family and healthcare professionals (Carlsson et al., 2001). Moreover, despite the association between physical and psychological well-being among informal caregivers being well established (Berglund et al., 2015), psychological and practical support from professionals to family members was lacking in the present study, although this was something the dyads expressed a need for. Adaptability has been found to be the most powerful predictor of carer depression when family supporting self-management in chronic patients. Families may need support to adapt to the challenges they face over time and nurses working in both hospital and community settings can play an important role in assessing how families are adapting to living with chronic illness and to explore strategies to cope with the situation (Whitehead et al., 2018).

Other factors affecting the transition were dependency on others and a lack of trust in healthcare. This forced the dyads to take control of the situation, despite being vulnerable inside. Perceived control is about the individual’s belief in his or her own ability to exert influence over internal states and behaviours, as well as one’s external environment (Pagnini, 2016). For the family members in the present study, taking control could involve assuming the role as an informal caregiver and having good insight into all aspects of care over a long period of time. This was also found by Carlsson and Persson (2015), where two of the most important strategies for coping with intestinal failure were having control and not being controlled by the disease. The same study also showed that the patients experienced a lack of respect, a lack of competence and a lack of understanding from healthcare professionals, which was also confirmed by our study. Another study by Fortune et al. (2005) on intestinal failure and home parenteral nutrition showed that control over their condition and the treatment making sense to the patient reduced the level of emotional distress. All patients in our study had experienced long hospitalizations and they had all been in need of homecare nursing, which lead to dependency on others. In a qualitative study of patients receiving homecare in Sweden (Holmberg et al., 2012), the patients reported experiences of threats to their dignity, integrity and autonomy, as well as to their trust in nursing care. The patients had to deal with this ambiguity of accepting care, while simultaneously maintaining independence and privacy. These findings are in consonance with the present study.

In the present study, striving to resume normality represented final acceptance of the transition. Having faith in the future and re-evaluating one’s own expectations were expressed throughout the illness trajectory but were most prominent 1 year after the reconstructive surgery. This finding can be understood by Roy’s adaption model (Roy et al., 2009). Even if the fistula was healed, life did not return to what it was before, and the dyads had to adapt to the new conditions. Humans are affected by various stimuli, which for the dyads in the present study could be fear of leakage, pain, anxiety and fatigue. How a person copes with a situation affects their behaviour (Roy et al., 2009). The patients in the present study needed intravenous fluids and nutrition, and even if these were vital needs, it was hard to adapt to the new situation since it contributed to social isolation. It was also hard to adapt to the fear of leaks and fatigue.

Roy et al. (2009) describe how those who have adapted well have a clear picture of their identity and perceive themselves as significant. The dyads in the present study had such a restricted life that they felt helpless. They described how many friends distanced themselves, which was difficult to adapt to. For some, healthcare professionals were their only social contact during the illness. Humans have a basic need for close and caring relationships with other people, and to experience security in these relationships. Dysfunctional relationships can instead create hostility and emotional discomfort (Roy et al., 2009). This was what some of the dyads described about the adaptation to homecare and the lack of trust in healthcare professionals. Even if the dyads did not accept the situation, they hoped for a better future and by setting reasonable new goals they also found acceptance in the present and continued to fight for life.

5.1 | Limitations

This study illuminates patients’ and family members’ perspectives from a trajectory perspective of living with an ECF, which has not been described before. This perspective can give an understanding of how an ECF affects patients and family members in different phases of the trajectory. We aimed to explore the diversity of the individual’s experiences, which was done by including both men and women, ranging widely in age. Purposive selection would be preferable but was not possible for this rare disease. Instead, the participants were included consecutively. One strength was that the participants were from different locations in Sweden and had different access to healthcare for geographical reasons. Another strength was that the dyads helped each other deepen their stories, but there is a risk that interpersonal relationships influenced what each person felt comfortable sharing. Another potential limitation was that the dyads felt pressure to position themselves in a certain way, for example as coping well, which may have influenced the data. The findings may not be transferred and applicable to all patients and family members with ECFs, since the descriptions could differ depending on the time of the interview and on social and cultural factors. On the contrary, the findings may be transferred to other patients living with ECFs, since the study included differences in gender, age and other demographic variables. Finally, after having interviewed seven couples there was a saturation of information from the dyads and new experiences did not arise.

6 | Conclusion

Living with an enterocutaneous fistula affect the life of the patient and the family in various ways, and they are facing an unpredictable and restricted life for an uncertain period of time. The patients are struggling with various restrictive symptoms like pain and fatigue, as
well as psychological distress. The necessity of intravenous fluids, parenteral nutrition and help with dressing and leakage problems of the fistula make the patient and their close family members dependent on others and socially isolated. In this situation, they are feeling forced to take control of the situation, despite being vulnerable inside. Even though the transition is associated with difficulties, the dyads believe in a better future and strives to resume normality.

7 | RELEVANCE TO CLINICAL PRACTICE

Enterocutaneous fistula is a complex condition with several problems for patients and their families. A care plan based on the patient’s and the family member’s stories and a documented dressing plan based on the patient’s experience of appliances, together with knowledge from a stoma therapist, could be successful and reduce leaks. This may lead to less socially isolated dependent dyads, enabling them to be more physically active. Patients should be cared for with the right competence at all levels, and multidisciplinary teamwork is necessary. Careful planning is required at the time of discharge from hospital, and a person-centred approach can make this more efficient. If patients are viewed as individuals who are competent to be involved in the planning of their own care, person-centred care may improve the discharge process. Promoting self-care can lead to more independence from healthcare professionals. Where possible, homecare should be based on the patient’s daily routines and not only what suits the homecare system. Because of their complex condition, these patients should have their own contact nurse. Otherwise, a lack of continuous follow-up or inadequate communication between inpatient and outpatient care providers may aggravate the patient’s process of transitioning to everyday life. The dyads felt a lack of professional psychological support, so everyone suffering due to ECF should be offered professional psychological support.

AUTHOR CONTRIBUTIONS
KH, SB, OH, PM and IT designed the study and prepared the manuscript. KH collected data. KH, SB and IT analysed the data.

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CONFLICT OF INTEREST
The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

REFERENCES


SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.