

A challenging journey: The experience of elderly patients and their close family members after major emergency abdominal surgery

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Rationale: Knowledge of how elderly patients undergoing major emergency abdominal surgery and their close family members experience the course of illness is limited. Little is known about how such surgery and hospitalisation affect elderly patients' daily life after discharge. It is well known that such patients have an increased risk of mortality and that their physical functional level often decreases during hospitalisation, which can make them dependent on family or homecare services. Critical illness and caregiving for a close relative can be a stressful experience for families, which are at risk of developing stress-related symptoms.

Aim: To explore how elderly patients and their families experience the course of illness during hospitalisation and the first month at home after discharge.

Method: A phenomenological study was conducted to gain in-depth descriptions through 15 family interviews

with 15 patients who had undergone major emergency abdominal surgery and 20 of their close adult family members. Data were analysed using a phenomenological approach inspired by Giorgi.

Findings: The essence of the phenomenon is captured in three themes: (1) Being emotionally overwhelmed, (2) Wanting to be cared for and (3) Finding a way back to life.

Conclusion: Patients and their close family members experienced the course of illness as a challenging journey where they longed for life to become as it was before illness. They experienced illness as a sudden life-threatening incidence. In this situation, it was crucial to be met with empathy from healthcare professionals. The patients' experience of fatigue and powerlessness remained intense one month after discharge and affected their and their close family members' lives.

Keywords: major emergency abdominal surgery, elderly patients, families, lived experiences, phenomenology, joint interviews, dyadic interviews.

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Introduction

Major emergency abdominal surgery (MEAS) is associated with a high incidence of complications (1) and

increased mortality in general and in the elderly population in particular, where complication rates exceed 30% and one-year mortality rates reach 25% (2–4). Elderly people, defined as people at 65 years or older (5), frequently experience severe complications or high mortality due to age, co-morbidity, polypharmacy and pathological response to surgery (3, 6, 7). Their physical functional level deteriorates during hospitalisation, increasing the risk of postsurgery dependency on homecare service and family (8, 9). Overall, patients

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undergoing MEAS are therefore at increased risk of readmission, social isolation and mortality after discharge (8). How these patients experience the course of illness is largely unknown. A study has found that patients recovering from colorectal cancer surgery felt physically powerlessness up to six months after discharge and limited in their ability to pursue social activities and perform activities of daily living (10). Other studies report that critically ill patients suffer from mental, cognitive and physical impairment after discharge, which may cause a decreased quality of life (11–13).

Critical illness and hospitalisation of a close relative are also a serious family stressor, and families may be overwhelmed by worries and fear that the patient may not survive (14–16). Serious illness has an impact on both patients and their close family members, and often close family members care for the patients after discharge (17–19). This may be satisfying and may improve the relationship with the patient (20); however, it often increases demands on family members, causing them to become both emotionally challenged and physically exhausted (20–22). Studies have found that family caregivers to elderly hospitalised patients and to patients recovering from critical illness are at increased risk of depression and impaired health-related quality of life (15–17). However, the caregiving burden should be seen in the light of closeness of family relationships, level of patient dependency, number of caregiver obligations and caregiver preparedness (23, 24). No studies have investigated how close family members experience caring for an elderly patient after MEAS.

Interviewing families may illuminate family members' experiences related to illness (25, 26). Family interviewing, a method not often used in current literature, implies a shift in focus from an individualised patient-centred focus to a focus on family members as well, taking specific considerations into account (19, 26).

Previous studies investigating elderly patients undergoing MEAS have focused mainly on the physical consequences of surgery (3, 4, 27). The present study focuses on the entire bio-psycho-social spectrum of MEAS by investigating how patients and their close family members experience the course of illness during hospitalisation and in the first month at home after discharge.

Method

A qualitative phenomenological study was conducted. Patients and their close family members' lived experiences were investigated in family interviews focusing on their various perspectives in a shared family context. Reflections may benefit from the dialogue in the family interviews and create clear and rich data (28, 29).

Participants

We recruited a consecutive sample of 15 patients having undergone MEAS and 20 of their close adult family members who participated in 15 family interviews from November 2017 until April 2018. Patients and their family members were recruited before discharge at three nonintensive care wards at the Gastro Unit at a large university hospital in Denmark. The family interviews took place in the patient's home approximately one month after discharge, which was the estimated time at which patients and family members were expected to have become used to the patient being back home and at which the impact of going through severe illness would show in daily life. Family was defined, according to Shajani and Snell, as 'Families are who they say they are' (30). In the present study, the patients decided who they considered family, and it was emphasised that family did not necessarily have to be near or first-order relatives; they could also be a close friend or a neighbour (30). In practice, the patients all considered spouses, siblings or adult children to be their closest family members. Inclusion criteria for patients were age 70 years or older, speaking Danish, or speaking another Scandinavian language, mentally alert and with no severe hearing disabilities. One to three family members participated in each interview, illustrated in Table 1.

Data collection

We used a semi-structured interview guide developed based on current literature. The guide was used as inspiration during the interviews with the interviewer remaining open to any descriptions of the phenomena. Family interviews differ from individual interviews or focus group interviews by virtue of the interviewees' pre-existing relationships and shared experiences (26, 29). The interviewee shared their experiences and listened to each others' narratives. They encouraged each other to express their perspectives by confirming, complementing or contradicting each other (31), which stimulated reflections within the family (28, 29). The approach contributed to a variety of data nuances and details, and thereby a more in-depth understanding of the phenomenon (25, 26, 29). The family interviews began by approaching the patient and his or her family member(s) in a dyadic interview (two participants) or joint interview (three or more participants) (29, 31) by telling them that both individual and shared experiences were typically present in families and that they were all of interest to the study (32). Open questions were asked to stimulate reflection (30). Thus, the interviewees were all invited to elaborate on questions. We used wordings such as 'Could you please describe how you experience the course of

Table 1 Characteristics of participants, *n* = 35.

Patient ID	Gender	Age	Ostomy Yes/no	Retired from work yes/no	Civil status	Close family members participating in family interviews	Work/retired/other
1	Female	75	No	Yes	Living alone	Son + daughter in law	Work + work
2	Male	76	Yes	Yes	Living alone	Daughter	Work
3	Female	73	Yes	Yes	Living alone	Daughter	Work
4	Male	79	Yes	Yes	Living with a spouse	Spouse	Retired
5	Female	73	Yes	Yes	Living alone	Grandson (adult)	Other
6	Male	73	Yes	Yes	Living with a spouse	Spouse	Retired
7	Female	74	Yes	Yes	Living alone	Daughter in law, niece + husband of niece	Work + work + work
8	Male	70	No	Yes	Living with the brother	Brother	Retired
9	Female	89	No	Yes	Living alone	Daughter	Work
10	Female	86	No	Yes	Living alone	Daughter	Work
11	Female	80	No	Yes	Living alone	Daughter	Work
12	Male	90	Yes	Yes	Living alone	Daughter + son	Work – work
13	Female	74	No	Yes	Living with a spouse	Spouse	Retired
14	Female	75	Yes	Yes	Living alone	Son + daughter in law	Work + work
15	Male	77	No	Yes	Living alone	Son	Work

illness and its impact on your daily life until now?', 'Which feelings did you experience during illness, and how did this affect you as a family?' Additional questions such as 'Could you tell me more about...?' 'Can you explain in more detail...?' were used to obtain more depth and detail (33). All interviews were digitally recorded and transcribed verbatim; the interviews lasted 22–73 minutes (mean 49 minutes). Data saturation was reached when no new topics emerged (33).

Ethical consideration

All patients and their close family members were invited to participate in the study by the researcher during the hospital stay. They received oral and written information, and they were informed that some participants may become emotionally affected and that they should only share the thoughts and emotions that they felt comfortable sharing (26). Patients, then, signed a written consent form, agreeing to be contacted by the researcher by phone within two weeks after discharge. This gave them time to decide whether they wanted to participate in family interviews one month after discharge. The patients and their close family members then signed a final written consent form just before the interview took place in the patient's home. It was emphasised that participation was voluntary and could be discontinued at any time. The participants were guaranteed confidentially according to the Helsinki declaration (34). Data were stored in a logged-in file drive. Approval was obtained from the Danish Data Protection Agency (ID no.: AHH-2017-067; i-suite no. 05790). The Danish ethical committee assessed that no approval was required, according to the Danish law, since there was no biomedical intervention in the study (ID no.: 17007271).

Data analysis

Husserl's descriptive phenomenology was the philosophical foundation and epistemological stance for the present study (35). A main component in the phenomenological methodology is phenomenological reduction. This implies bracketing from our preunderstanding, which allows us to be aware of the phenomenon as it appears (36, 37). Conducting the interviews, the first author sought to bracket her own prior understanding and preconceptions (37). To become conscious of her preconceptions (38), the first author was interviewed by an experienced researcher prior to the family interviews. Thereby, the first author realised that she had not fully adapted a system-theoretical approach, which made her focus more on the patients and less on their families. Being conscious of this made it possible for her to stay curious and open to the phenomenon investigated (38). A phenomenological method inspired by Giorgi was employed to analyse the data (37). This method represents a way for approaching phenomenology as a scientific method that is suitable for obtaining in-depth reflections (37). Giorgi's four-step method was used to systematically organise data into themes capturing the essence of the phenomenon (38). The first step was to read the text several times to get a sense of the whole, adopting a phenomenologically reductionist stance to obtain insight into the participants' lifeworld. The second step consisted in determining meaning units, being sensitive to the psychological shifts in meaning, but without resorting to use of pre-established or prejudged criteria (37). This was done by marking shifts in the text every time the psychological meaning changed. The third step was to transform participants' natural expressions of attitude into

phenomenological expressions (37). This was done by investigating every meaning unit and transforming the meaning into more suitable psychological descriptions of the experiences. In the fourth step, the psychological descriptions were interpreted and transformed into statements regarding the interviewees' experiences with the course of illness and its impact on everyday life. Furthermore, the statements were condensed into three themes representing the essence of the phenomenon (10, 38, 39). The themes embraced the experiences of patients and their family members. The analysis utilised the interaction within the families where sharing and comparing perspectives contributed to obtain rich data (29). However, the analysis focused on the perspectives in a family context and less on the interaction between the family members (28, 31, 40). Investigator triangulation was performed several times during the process of analysing the data to enhance the credibility and trustworthiness of the interpretation (41). An example of the first four steps in the analysis is visualised in Table 2.

Findings

Patients and their close family members described the course of illness as a challenging journey where they long for life to become as it was before illness struck. The journey is illustrated in three themes: (1) Being emotionally overwhelmed, (2) Wanting to be cared for and (3) Finding a way back to life, which represents the essence of the phenomenon.

Being emotionally overwhelmed

Experiencing critical emergency illness was a tremendous shock to patients and their close family members. Emotional turbulence characterised a situation where they felt overwhelmed by emotions like anxiety, uncertainty and chaos. Before admission, most patients had gone through hours of severe abdominal pain and vomiting that seemed unendurable. Loss of control over bodily responses, feelings of helplessness and difficulties seeing when their fragile condition would come to an end made some of the patients wish for an ultimate release from their sufferings.

...if they would just let me close my eyes. I didn't want to live anymore (Interview-11, patient)

Family members tried to navigate a situation they described as chaotic, not knowing whether the patient would survive.

...my day was completely chaotic. I couldn't get in contact with anybody to hear if the surgery had gone well. (...) finally, I went there... (Interview-11, daughter)

The patient's limited ability to communicate while in a severely weakened condition caused questions about cardiopulmonary resuscitation to become a family decision, which increased family members' feeling of shock.

Several patients felt emotionally out of balance during hospitalisation and had difficulties collecting their

Table 2 Example of step 1-4 inspired by the phenomenological approach by Giorgi (2009).

Step 1 Raw data	Step 2 Determinate meaning units	Step 3 Transformed meaning units	Step 4 Statements regarding the phenomena
Patient: Well...my legs are powerless... Son: Yes, before you could walk up and down the stairs yourself. He can't do that now...at least not without help. Patient: No I need help to walk up the stair. But to walk down, I hold on to the banister because one time I almost tripped when I walked down. But to walk up the stairs...I have to forget about that. I am sick of being stuck in my apartment on the second floor - walking from the bedroom to the kitchen. That's how my days go by. I'm sick of it...really. But I can't do anything else.	Patient: Well...my legs are powerless...// Son: Yes, before you could walk up and down the stairs yourself. He can't do that now...at least not without help.// Patient: No I need help to walk up the stair. But to walk down, I hold on to the banister because one time I almost tripped when I walked down. But to walk up the stairs...I have to forget about that.// I am sick of being stuck in my apartment on the second floor - walking from the bedroom to the kitchen. That's how my days go by. I'm sick of it...really. But I can't do anything else.//	The patient experiences a loss of strength in his legs. The son explains that his father can't walk up and down the stairs by himself. The patient experienced how he almost tripped when he tried to walk down the stairs by himself. The patient describes how not being able to leave his apartment makes him feel stuck and he is sick of it.	Loss of strength in the legs. The parent has become dependent on others. Not being able to leave home. Not being able to leave home. Essence of the phenomena: Finding a way back to life

thoughts, but at the same time, they had no clear memory of what had happened. The family members, especially the adult children, were shocked to see their close relative being seriously ill and helpless. Likewise, the patients were uncomfortable letting their families witness them being ill and helpless. Nevertheless, they were thankful that their family visited them often; it made them feel cared for and less alone.

Wanting to be cared for

The unexpected and overwhelming situation evoked a request to being cared for in both patients and family members. During hospitalisation, they experienced both positive and negative episodes with healthcare professionals. These episodes left a deep, lasting impression. Patients and family members emphasised that, along with being well informed, it was important to be met with kindness and to feel welcome. They all described episodes with healthcare professionals being friendly and helpful, which made them feel safe. They also found healthcare professionals to be busy and overloaded with work, and appreciated whenever nurses or physicians took time to provide information.

...he (the surgeon) was incredible telling us what had happened and what was going to happen, and what were the risks. Then we had a qualified basis to help us make decisions. (...) We were really happy about that. We were fully informed. (Interview-10, daughter)

Any healthcare professional initiatives indicating that they saw the person behind the patient or paid attention to the family members' needs were treasured by patients and their families. It could be small gestures such as a smile, saying a friendly hello, holding a hand, being humorous, or showing interest in the patient or a family member as persons.

Our grandson had made a drawing, and a nurse hangs it on the wall so that you could see it. I like when they take care of the patient in another way than just saying, "Now I will take a blood sample" (Interview-6, wife)

Yes, I agree... it matters, especially when you are hospitalized for a long period (Interview-6, patient)

However, more than half of the patients and their close family members described an attitude in some of the healthcare professionals that they perceived as unfriendly, and they did not feel sufficiently informed, which made them feel uncertain and worried. The worries increased when they felt that they had to seek information themselves without knowing how. A patient explained that she felt unable to ask the right questions.

Moreover, several family members experienced being confused and forgetting asking questions or did not know what to ask. Lack of information and shifting staff made them feel that the time of hospitalisation was a turbulent period. The experience of different physicians reading the patient's medical file time and time again gave an impression of discontinuity. Patients wondered why nurses being responsible for them one day would suddenly be responsible for other patients the next day, and the patients felt annoyed telling the same story repeatedly.

Some patients experienced unpleasant episodes where they felt ignored by the nurses or treated in unkind ways. Such experiences made one of the patients feel humiliated, and the feeling of humiliation stuck in her consciousness even a month after discharge.

Well...I can still wake up at night thinking about the hospital stay. It was awful because sometimes I felt humiliated. I have never felt that way before. It's really not a nice feeling. (Interview-3, patient)

Also, family members experienced episodes where they felt overlooked and ignored, with healthcare professionals' attitude indicating that they were busy and not to be disturbed. This caused family members to hold back questions. An unwelcoming attitude made family members uncertain and worried, causing them to feel a need to spend more time at the hospital, feeling responsible for caring for the patient.

Several times, when I visited my mother, she was thirsty but had no water...nothing! (...) Then I went there three times a day (Interview-3, daughter)

The patients' need to feel cared for continued after discharge. Patients living with a spouse generally felt comfortable going home because they had someone who cared for them and managed practical daily tasks if needed. Some who lived alone worried being alone because their physical performance had decreased, and they were unsure whether they could manage everyday tasks on their own. Neither patients nor families felt involved in the discharge process or they felt that they had no influence on the discharge date. This decision was taken suddenly by the healthcare professionals, and it came on one or two days' notice. The short notice was a challenge for the patients living alone and for their adult children, especially when coordination between hospital and homecare services failed. Some of the adult children felt left alone with the responsibility to coordinate the homecare services.

I talked to a nurse at the hospital and she said that you might be discharged on Friday. They would let me know, but they didn't. (...) They said that there would be a care worker taking care of you when

you came home, but no one came. And you were confused and not feeling well. (...) Frankly, it made me really scared. (Interview-9, daughter)

Finding a way back to life

Being discharged from hospital was a milestone for patients and their families. They all longed to return to life as it was before illness struck. However, this was challenging because physical powerlessness and especially loss of strength in the legs affected patients' ability to do what they did before falling ill. The situation made close family members help perform tasks like shopping for groceries, cooking dinner, washing clothes, and communicating with the homecare services, especially in the first weeks after discharge. For some family members, this became a natural part of their daily life, and they were able to balance their time and energy. For most of the adult children, it tipped the work-life balance, and they tried to manage by spending less time with their own families and skipped some daily activities.

I don't want to blame anyone, but my life has been on stand-by. I haven't been to the dentist, haven't collected my glasses and so on. I have been working, and then visiting my mother...that's all...because I haven't had time for anything else (start crying). (Interview-11, daughter)

The patients and their families' social life was also affected by patients' severe fatigue and loss of muscle strength. Overwhelming fatigue caused some patients to withdraw from attending social activities or to attend without being present.

I feel so tired, really tired. We went to a birthday party yesterday and suddenly I fell asleep on the couch... what can I do... (Interview-6, patient)

A spouse expressed frustration and bitterness because her husband did not have the energy to participate in social life like before falling ill; it made her feel lonely. Other spouses did not express frustrations of the situation, but either attended social activities themselves or stayed home. Both patients and their families found the recovery process to be slow. A patient described the process as an unequal struggle where a huge effort to do exercise resulted only in slow progress. Several patients participated in an exercise programme in their municipality. Some of them exercised by themselves at home but found it hard to keep up the motivation.

For two of the patients, the loss of muscle strength had severe consequences; they were no longer able to leave their homes by themselves because they could not walk the stairs. Not being able to go outside had a significant adverse effect on their lives and emotional well-being.

I'm sick of being stuck in my apartment on the second floor – walking from the bedroom to the kitchen. That's how my days go by. I'm sick of it...really. But I can't do anything else. (Interview-15, patient)

To share worries and frustrations was significant to patients and family members but was handled in different ways. The very thought of being a burden caused some of them to keep their worries to themselves. Spouses typically shared their thoughts, while patients living alone either spoke with their daughter or son or kept their worries to themselves because they did not want to burden their adult children or friends. The adult children typically shared worries with their siblings, spouses, friends or colleagues, which eased their frustration and stress.

Discussion

Patients and their close family members found themselves emotionally overwhelmed when illness struck. Facing a life-threatening situation, they were torn out of their everyday life. Previous studies report that emergency surgery is challenging for patients because they are acutely unwell, in severe pain and deeply distressed (42, 43). Our findings are similar to those reported in studies investigating critically ill patients, where patients experience shock and anxiety, and are dithering between inner strength and thoughts of giving up life (44). Likewise, families feel helpless and shocked, and found it difficult to manage their emotions (16). In our study, close family members were a crucial support to the patients, and they spend many hours at the hospital. After discharge, they continued providing support by helping with various tasks. This could indicate that patients and families endured the illness as a family experience. From a sociological perspective, families interact as social units and they often commit to a responsibility for maintaining health and quality of life within its members (45). The sense of being a family may even strengthen when a close relative is hospitalised with critical illness, and it is that sense of being a unit that gives them the ability to endure the emotional turbulence accompanying life-threatening illness (16, 19).

In this challenging situation, patients and their close family members experienced a need to feel cared for by healthcare professionals. The meeting with healthcare professionals caused strong feelings spanning from gratitude and appreciation to anger, bitterness and distress, and it occupied both patients and family members' minds even after discharge. The importance of humanised care has been emphasised by patients and family members, especially in relation to situations with critical illness and hereby high dependence of the staff (16, 46). To be seen

and heard as a person is crucial to the feeling of well-being, and negative interactions can have long-term consequences, eroding confidence in healthcare professionals (43). In our study, some patients and family members described how they were met with a kind attitude from healthcare professionals. However, several interviewees felt overlooked and ignored, as well as uninformed. Numerous studies report similar findings where patients and families experienced lack of information, respect and empathy during hospitalisation, which made them feel vulnerable and emotionally distressed (43, 47, 48). Being admitted to a caring ward and feeling well informed have been found to lead to higher patient satisfaction and even improved survival (42, 49). One way of supporting patients and families during hospitalisation and after discharge may be to apply the therapeutic family conversation model, which aims at supporting the well-being and resilience of patients and their families (30, 50). However, the model requires education of nurses so that they can acquire necessary skills to facilitate families in finding solutions to alleviate emotional and physical suffering (30).

Finding a way back to life endeavouring to return to daily life as it was before illness is a challenging journey. In our study, fatigue, powerlessness and loss of muscle strength in the legs were the most prominent symptoms among discharged patients. The physical symptoms limited the patients' ability to manage everyday tasks and attend social activities. This affected emotional well-being for some; impatience and frustration accumulated; and the recovery process seemed like an unequal struggle. Likewise, studies investigating patients recovering from colorectal cancer surgery (10, 51) and patients recovering after critical illness (13, 44) to refer to normal life as it was before illness; however, the postoperative recovery process was slow and not comparable to life before surgery (10, 51). For critically ill patients, full recovery was not always achievable due to cognitive or physical impairment, which was hard to accept (13, 44).

In our study, we found that close family members were affected by the situation in different ways. For spouses, it felt natural to stand by their loved ones and provide support during illness. The situation caused only small changes in the way they shared everyday tasks; a change they considered as temporary. Nevertheless, their social life was affected, and spouses often renounced from social activities and instead stayed home. The renouncement of leaving the patient alone may reflect a feeling of personal responsibility to care for the patient after discharge, and, in some cases, to detect changes that might require medical attention (17). In our study, the spouses expressed relief having the patient back home. The awareness of growing older together and considering illness a temporary situation may have caused them to find the situation easier to cope with. However, most of the patients in our study lived alone and the effect on

the lives of adult children who cared for a parent living alone was more extensive and tipped the work-life balance for some. Born-van Zanten describes how families often assist the patient with routine housework after discharge and that family members' feeling of responsibility for the patient may lead to stress or depression, which affects their own lives (22). Family care can be seen as a valuable but also hidden aspect of care, a care that effectively caters for the well-being of the care receiver, but also an underestimated resource in caring for elderly people (20). Reasons for engaging in caregiving for a family member are often referred to as a natural duty or a meaningful choice (20). Other motivating factors include perceived gaps in the professional healthcare system, love for the family member, a feeling of making a difference and the opportunity to provide personalised care (20, 52). Whether the close family members in our study supported a spouse or a parent out of feelings of obligation or as a voluntary choice is not evident.

Methodological considerations

In-depth interviews are one of the best methods for gaining insight into patients and their close family members' lived experiences (37). We achieved an exhaustive understanding of the essence of this phenomenon. However, a combination of in-depth interviews and observations may have strengthened the credibility of our study (53).

The researcher who performed the interviews was not an experienced interviewer, which may have been a study limitation. However, being aware of her preunderstanding made it possible for her to bracket any preconceptions and stay open to the phenomenon. Furthermore, not being employed as a nurse at the unit and hence not representing 'the system' was an advantage because this may have made patients and family members speak more freely about their experiences of the hospitalisation and the illness trajectory. This may increase the confirmability of the study (53).

A potential limitation is the risk that the interviewees give convenient rather than honest reflections out of consideration for the others (26, 54). Separate individual interviews with family members may have been another way to obtain data since such interviews allow family members to tell their narratives while still preserving confidentiality and without interference from the other interviewees (40). However, we aimed to capture the essence of the various perspectives where the participants describe and interpret their experiences within a shared family context (40). Furthermore, we argue that family interviewing may benefit from a synergistic effect and reveal essential phenomena that would not have been uncovered in individual interviews (25). It is possible that some of the family members moderated their answers and avoided talking about sensitive topics. Still,

generally, we found that they expressed their feelings openly, which showed in their expressions.

Patients and families provided no feedback on our findings, which may be criticised. However, the interviews were performed in a specific moment in a specific context, which makes verification of data questionable (33). Instead, investigator triangulation was performed several times in the process, which may strengthen the credibility and trustworthiness of our interpretation of the data (41).

Conclusion

All patients undergoing MEAS and their close family members experienced this as a challenging journey where they longed for life to become as it was before illness struck. However, the journey was not a straightforward process; instead, it was perceived as a struggle with challenges that had either to be overcome or integrated into life. The experience of the illness as a sudden life-threatening incidence caused patients and their close family members to be emotionally overwhelmed. In this critical situation, it was crucial to be met with kindness from healthcare professionals and to feel well informed. The meeting with the healthcare professionals left an impression that occupied their minds even one month after discharge. The physical side effects of surgery and hospitalisation were still intense one month after discharge and affected the patients' ability to handle daily tasks and attend social events. Close family members helped with various tasks; and for spouses, it felt natural to support their loved one during illness. However, most of the adult children who cared for a parent living alone felt that their life–work balance was challenged and this caused frustration.

References

- 1 Tahiri M, Sikder T, Maimon G, Teasdale D, Hamadani F, Sourial N, Feldman LS, Guralnick J, Fraser SA, Demyttenaere S, Bergman S. The impact of postoperative complications on the recovery of elderly surgical patients. *Surg Endosc* 2016; 30: 1762–70.
- 2 Cooper Z, Lilley EJ, Bollens-Lund E, Mitchell SL, Ritchie CS, Lipstiz SR et al High burden of palliative care needs of older adults during emergency major abdominal surgery. *J Am Geriatr Soc* 2018; 66: 2072–8.
- 3 Scott MJ, Baldini G, Fearon KC, Feldheiser A, Feldman LS, Gan TJ, Ljungqvist O, Lobo DN, Rockall TA, Schricker T, Carli F. Enhanced Recovery After Surgery (ERAS) for gastrointestinal surgery, part 1: pathophysiological considerations. *Acta Anaesthesiol Scand* 2015; 59: 1212–31.
- 4 Wolsted H, Moller AM, Tolstrup MB, Vester-Andersen M. A description of deaths following emergency abdominal surgery. *World J Surg* 2017; 41: 3105–10.
- 5 European Commission. The 2018 Ageing Report: Economic & Budgetary Projections for the 28 EU Member States (2016–2070) 2018 [Available from: https://ec.europa.eu/info/sites/info/files/economy-finance/ip079_en.pdf.
- 6 Ukkonen M, Kivivuori A, Rantanen T, Paajanen H. Emergency abdominal operations in the elderly: a multivariate regression analysis of 430 consecutive patients with acute abdomen. *World J Surg* 2015; 39: 2854–61.
- 7 Balentine CJ, Naik AD, Berger DH, Chen H, Anaya DA, Kennedy GD. Postacute care after major abdominal surgery in elderly patients: intersection of age, functional status, and postoperative complications. *JAMA Surg* 2016; 151: 759–66.
- 8 Jonsson LR, Ingelsrud LH, Tengberg LT, Bandholm T, Foss NB, Kristensen MT. Physical performance following acute high-risk abdominal surgery: a prospective cohort study. *Can J Surg* 2018; 61(1): 42–9.
- 9 Petrucci L, Monteleone S, Ricotti S, Giromini E, Gullace M, Ambrosini E,

The findings in this study provide valuable insight into patients and their close family members' experiences. Unquestionably, to be able to respond properly to patients and family members' needs, healthcare professionals must acquire in-depth knowledge of their lived experiences during the whole course of illness.

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Author contribution

JJP, AB and BØ contributed to study design. JJP and AB contributed to data collection, analysis and preparing of the manuscript. AB, BØ, ES and SJR contributed to critical revision of the manuscript. All authors read and approved the final manuscript.

Ethical approval

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- Ferriero G, Dalla Toffola E. Disability after major abdominal surgery: determinants of recovery of walking ability in elderly patients. *Eur J Phys Rehabil Med* 2018; 54: 683–9.
- 10 Jakobsson J, Idvall E, Kumlien C. The lived experience of recovery during the first 6 months after colorectal cancer surgery. *J Clin Nurs* 2017; 26: 4498–505.
 - 11 Maley JH, Brewster I, Mayoral I, Siruckova R, Adams S, McGraw KA, Piech AA, Detsky M, Mikkelsen ME. Resilience in survivors of critical illness in the context of the survivors' experience and recovery. *Ann Am Thorac Soc* 2016; 13: 1351–60.
 - 12 Daniels LM, Johnson AB, Cornelius PJ, Bowron C, Lehnertz A, Moore M, Shen YC, Schulte PJ, Pendegraft RS, Hall KR, Bauer PR. Improving quality of life in patients at risk for post-intensive care syndrome. *Mayo Clin Proc Innov Qual Outcomes* 2018; 2: 359–69.
 - 13 Backman CG, Ahlberg M, Jones C, Frisman GH. Group meetings after critical illness-Giving and receiving strength. *Intens Crit Care Nurs* 2018; 46: 86–91.
 - 14 Nelms TP, Eggenberger SK. The essence of the family critical illness experience and nurse-family meetings. *J Fam Nurs* 2010; 16: 462–86.
 - 15 Chan EY, Lim ZX, Ding YY, Chan YH, Lim WS. Development of a brief caregiver-centric screening tool to identify risk of depression among caregivers of hospitalized older adults. *J Nutr Health Aging* 2019; 23: 578–85.
 - 16 Mendes AP. Impact of critical illness news on the family: hermeneutic phenomenological study. *Rev Bras Enferm* 2018; 71: 170–7.
 - 17 Choi J, Lingler JH, Donahoe MP, Happ MB, Hoffman LA, Tate JA. Home discharge following critical illness: A qualitative analysis of family caregiver experience. *Heart Lung* 2018; 47: 401–7.
 - 18 Benzein E, Olin C, Persson C. 'You put it all together' - families' evaluation of participating in Family Health Conversations. *Scand J Caring Sci* 2015; 29: 136–44.
 - 19 Eggenberger SK, Nelms TP. Being family: the family experience when an adult member is hospitalized with a critical illness. *J Clin Nurs* 2007; 16: 1618–28.
 - 20 Carlsen B, Lundberg K. 'If it weren't for me...': perspectives of family carers of older people receiving professional care. *Scand J Caring Sci* 2018; 32: 213–21.
 - 21 Stromberg A, Luttik ML. Burden of caring: risks and consequences imposed on caregivers of those living and dying with advanced heart failure. *Curr Opin Support Palliat Care* 2015; 9: 26–30.
 - 22 van den Born-van Zanten SA, Dongelmans DA, Dettling-Ihnenfeldt D, Vink R, van der Schaaf M. Caregiver strain and posttraumatic stress symptoms of informal caregivers of intensive care unit survivors. *Rehabil Psychol* 2016; 61: 173–8.
 - 23 Bahrami M, Etamadifar S, Shahriari M, Farsani AK. Caregiver burden among Iranian heart failure family caregivers: A descriptive, exploratory, qualitative study. *Iran J Nurs Midwifery Res* 2014; 19: 56–63.
 - 24 Helene V, Laura M, Caroline T, Bertrand G, Ariane B. Acute critically ill elderly patients: What about long term caregiver burden? *J Crit Care* 2019; 54: 180–4.
 - 25 Eggenberger SK, Nelms TP. Family interviews as a method for family research. *J Adv Nurs* 2007; 58: 282–92.
 - 26 Voltelen B, Konradsen H, Ostergaard B. Ethical considerations when conducting joint interviews with close relatives or family: an integrative review. *Scand J Caring Sci* 2017; 32: 515–526.
 - 27 McCutcheon T. The ileus and oddities after colorectal surgery. *Gastroenterology nursing : the official journal of the Society of. Gastroenterol Nurs Assoc* 2013; 36: 368–375. quiz 76–7.
 - 28 Bradbury-Jones C, Sambrook S, Irvine F. The phenomenological focus group: an oxymoron? *J Adv Nurs* 2009; 65: 663–71.
 - 29 Morgan DL, Ataie J, Carder P, Hoffman K. Introducing dyadic interviews as a method for collecting qualitative data. *Qual Health Res* 2013; 23: 1276–84.
 - 30 Shajani Z, Snell D. *Wright & Leahey's Nurses and families: A guide to family assessment and intervention*. 7th ed. 2019, F.A. Davis, Philadelphia, 380 s. p.
 - 31 Polak L, Green J. Using joint interviews to add analytic value. *Qual Health Res* 2016; 26: 1638–48.
 - 32 Fjose M, Eilertsen G, Kirkevold M, Grov EK. "Non-palliative care" - a qualitative study of older cancer patients' and their family members' experiences with the health care system. *BMC Health Serv Res* 2018; 18: 745.
 - 33 Kvale S, Brinkmann S. *Interviews: learning the craft of qualitative research interviewing*, 3rd edn. 2014, Sage Publications, Thousand Oaks, Calif, xviii, 405 sider p.
 - 34 Association WM. WMA Declaration of Helsinki – Ethical principles for medical research involving human subjects <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
 - 35 Berghofer P. Husserl's noetics – towards a phenomenological epistemology. *J Br Soc Phenomenol* 2019; 50: 120–38.
 - 36 Gallagher S, Zahavi D. Phenomenological method. *The phenomenological mind*, 2nd edn. 2012, Routledge, London New York. xiv. 271 s., illustreret p.
 - 37 Giorgi A. The Phenomenological Method. *The descriptive phenomenological method in psychology : a modified Husserlian approach*. 2009, Duquesne University Press, Pittsburgh, Pa, xiv 233 s. p.
 - 38 Giorgi A. Concerning the application of phenomenology to caring research. *Scand J Caring Sci* 2000; 14: 11–5.
 - 39 Sadala ML, Adorno Rde C. Phenomenology as a method to investigate the experience lived: a perspective from Husserl and Merleau Ponty's thought. *J Adv Nurs* 2002; 37: 282–93.
 - 40 Hochman Y, Segev E, Levinger M. Five phases of dyadic analysis: stretching the boundaries of understanding of family relationships. *Fam Proc* 2020; 59: 681–94.
 - 41 Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum* 2014; 41: 545–7.
 - 42 Jones CH, O'Neill S, McLean KA, Wigmore SJ, Harrison EM. Patient experience and overall satisfaction

- after emergency abdominal surgery. *BMC Surg* 2017; 17: 76.
- 43 Jangland E, Kitson A, Muntlin AA. Patients with acute abdominal pain describe their experiences of fundamental care across the acute care episode: a multi-stage qualitative case study. *J Adv Nurs* 2016; 72: 791–801.
 - 44 Alexandersen I, Stjern B, Eide R, Haugdahl HS, Engan Paulsby T, Borgen Lund S et al "Never in my mind to give up!" A qualitative study of long-term intensive care patients' inner strength and willpower-Promoting and challenging aspects. *J Clin Nurs* 2019; 28: 3991–4003.
 - 45 Ortiz YMBS-VM, Expósito M. Importance and recognition of the family in health care: a reflection for nursing. *Nurs Care Open Access J* 2017; 3: 307–309.
 - 46 Corner EJ, Murray EJ, Brett SJ. Qualitative, grounded theory exploration of patients' experience of early mobilisation, rehabilitation and recovery after critical illness. *BMJ Open* 2019; 9: e026348.
 - 47 Hvalvik S, Reiersen IA. Striving to maintain a dignified life for the patient in transition: next of kin's experiences during the transition process of an older person in transition from hospital to home. *Int J Qual Stud Health Well Being* 2015; 10: 26554.
 - 48 Netsey-Afedo MML, Ammentorp J, Osther PJS, Birkelund R. No time for reflection: Patient experiences with treatment-related decision-making in advanced prostate cancer. *Scand J Caring Sci* 2019. <https://doi.org/10.1111/scs.12794>
 - 49 Gupta D, Lis CG, Rodeghier M. Can patient experience with service quality predict survival in colorectal cancer? *J Healthc Qual* 2013; 35: 37–43.
 - 50 Petursdottir AB, Svavarsdottir EK. The effectiveness of a strengths-oriented therapeutic conversation intervention on perceived support, well-being and burden among family caregivers in palliative home-care. *J Adv Nurs* 2019; 75: 3018–3031.
 - 51 van Heinsbergen M, den Haan N, Maaskant-Braat AJ, Melenhorst J, Belgers EH, Leijtens JW, Bloemen JG, Rutten HJ, Bouvy ND, Janssen-Heijnen ML, Konsten JL. Functional bowel complaints and quality of life after surgery for colon cancer: prevalence and predictive factors. *Colorectal Dis* 2020; 22: 136–145.
 - 52 Glendinning C, Mitchell W, Brooks J. Ambiguity in practice? Carers' roles in personalised social care in England. *Health Soc Care Commun* 2015; 23: 23–32.
 - 53 Tobin GA, Begley CM. Methodological rigour within a qualitative framework. *J Adv Nurs* 2004; 48: 388–96.
 - 54 Norlyk A, Haahr A, Hall E. Interviewing with or without the partner present?—an underexposed dilemma between ethics and methodology in nursing research. *J Adv Nurs* 2016; 72: 936–45.