Undertaking responsibility and a new role as a relative: a qualitative focus group interview study

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Title: Undertaking responsibility and a new role as a relative: a qualitative focus group interview study

Running title: Being relatives and adapting to a changed role within the family

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Keywords: Oesophageal Cancer, Family, Experiences, Surgery, Qualitative Research, Decision-Making

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We would like to thank relatives who participated in the study. We would also like to thank the quality coordinator who assisted as co-moderator during interviews contributing to the success of the focus group interviews.

Conflict of Interest
None to declare

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Abstract

Title: Undertaking responsibility and a new role as a relative: a qualitative focus group interview study

Background: Being a relative of a patient with oesophageal cancer can evoke strong emotions and uncertainty about the future. As a consequence of the treatment course for oesophageal cancer and an increase in outpatient treatment, relatives are becoming increasingly responsible for patients’ physical and emotional care. There is a lack of research exploring relatives’ experiences with illness, treatment, and decision-making.

Aims and objectives: To explore relatives’ experiences with illness, treatment of the patient, and decision-making in the context of oesophageal cancer.

Design: A qualitative explorative design was chosen.

Methods: We conducted two focus group interviews with 11 relatives. The analysis was based on Ricoeur’s theory of interpretation.

Results: Throughout illness and treatment, relatives faced the fear of loss, leading to distress and anxiety. Relatives were simultaneously taking responsibility and asserting a new role during treatment as they regarded treatment as a joint affair. Regarding decision-making, relatives positioned themselves on the sidelines, awaiting the authority of the patients and health care professionals to give them space for participation.

Conclusion: Relatives of patients with esophageal cancer undergoing treatment are suppressing their anxiety and doubt about the future. As they are undertaking responsibility during treatment, they are claiming control in new areas, which leads to changing roles within the family. However, they do not feel empowered in decision-making because they recognize patients’ decision-making authority. This study highlights the complexity of balancing patients’ authority with acknowledgment of relatives’ role as active collaborators.

Keywords
Oesophageal Cancer, Family, Experiences, Surgery, Qualitative Research, Decision-Making

Introduction
Living with cancer means the whole family is affected and facing fear and anxiety, derived from the uncertainty of the cancer prognosis (1). However, the health care system often neglects the roles and needs of relatives (2-4). Approximately 400,000 patients per year worldwide receive a diagnosis of oesophageal cancer or cancer in the oesophageal junction (EC), making it the eighth most common cancer (5). Out of the total number of patients with EC worldwide, the five-year survival rate is 15-34% (6, 7), leading to concerns about the future for patients and relatives (4, 8). The treatment course in Denmark and most other countries include surgery in combination with chemoradiation or chemotherapy, with a duration of 6-9 months (7, 9). As a consequence of the treatment course and an increase in outpatient treatment, relatives are becoming increasingly responsible for patients’ physical and emotional care (10, 11).

**Background**

Relatives of patients experience cancer as a death threat for the patient, bringing up strong emotions and a loss of certainty about the future (12-14). Moreover, relatives often adopt the position of buffers, feeling responsible for protecting the patient from distress, and sometimes withholding information (14). Relatives feel obliged to be strong for the surrounding family, adding to their feelings of isolation at a time when they are suffering from distress (14, 15).

Treatment for EC is strenuous, causing patients and relatives to struggle with side effects and the effects of the treatment, and eating after surgery is a particular challenge (12, 16, 17). As a consequence of the patient’s decreased physical capability during and after treatment for EC, cancer becomes an intrusion into the family’s everyday life and routines (1, 13). Symptoms arising as results of surgical treatment include an early sense of satiety, bloating, nausea, diarrhea, and reflux, affecting patients’ quality of life on a physical, social and emotional level (18, 19). Relatives can feel a loss of togetherness and social isolation caused by patients’ eating difficulties, making eating an event full of distress and anxiety, not a unified family ritual (1, 13, 14).

Previous studies provide valuable knowledge about relatives’ experiences of living with patients with EC (1, 13), and their subsequent role in rehabilitation and caregiving (12, 20). However, studies investigating relatives’ experiences in the context of EC are few. Several studies address the fact that patients with cancer seek information and guidance, enabling them to make the necessary decisions (21-23). However, relatives’ needs and roles in decision-making are not described. How patients’ EC influences relatives’ lives, and the ways they participate in decisions during treatment are essential, as they all feel fear, anxiety, and uncertainty about the treatment and prognosis of cancer. The concept of shared decision-making (SDM) is discussed internationally in health care (24-26).
SDM, it is up to patients and health professionals to decide whether relatives are invited to participate and be active in decisions. However, relatives’ experiences with the EC treatment course and their participation in decisions have not yet been investigated. Therefore, this study aimed to explore relatives’ experiences with illness, treatment of the patient, and decision making in the context of EC.

**Methods**

**Design**

An explorative study with focus group interviews was conducted, which provided opportunities for relatives to narrate their experiences and understandings collectively (27). We based the analysis and interpretation on Paul Ricoeur’s theory of narrative and interpretation (28, 29) and chose to use photographs as further interpretations of previous participant observations and interviews, presented elsewhere (4). Ricoeur combines phenomenology with a critical hermeneutic philosophy, making it possible to create new understanding from the text through critical interpretation (28).

**Setting and participants**

The study was conducted in Denmark. Here, treatment for EC is highly specialized, and curative treatment typically consists of neoadjuvant chemotherapy, surgery, and after a recovery period, adjuvant chemotherapy, leading to a treatment duration of 6-9 months (7). A total of 19 relatives were recruited by the first author and individually interviewed before the start of the patient’s treatment. These results are reported elsewhere (4). Out of these 19 relatives, cancer in four patients was assessed as advanced. These patients started palliative oncological treatment, and their relatives discontinued the study. One relative was physically unable to travel for an interview, and another three relatives were not able to participate on the given dates. The remaining 11 relatives participated in a focus group interview, after the completion of the patient’s treatment.

Relatives were chosen from within the family and invited to participate at the patients’ first consultation regarding the treatment plan. Inclusion criteria were the following: close relatives of patients undergoing surgery and perioperative oncological treatment with biopsy-confirmed EC (adenocarcinomas), and Danish speaking over 18 years. The characteristics of relatives appear in Table 1.

**Insert Table 1 about here**

**Ethics**
The study was conducted in accordance with the Declaration of Helsinki (30) and approved by the Danish Data Protection Agency (ID. No. 16/155593). In accordance with Danish legislation, regional health research ethics committees were informed and ruled that the study required no ethical approval. Relatives and patients received oral and written information about the study and gave signed informed written consent. Respect and consideration for relatives’ well-being and integrity were our highest priorities during the focus group interviews. Before the start of the interview, oral information was repeated, and relatives were informed about confidentiality and anonymity in the presentation of the data. Recordings and transcriptions were processed and stored confidentially. Because we refer to a small population in a specific geographical region, we obscured all personal characteristics in this article to ensure relatives’ anonymity as recommended by Morse and Coulehan (31).

Data collection
Two focus group interviews, with five and six participants, respectively, were conducted at the hospital in March and August 2018. Interviews lasted 86 and 92 minutes and focused on three main themes: a) relatives’ experiences with the EC illness- and treatment course, b) relatives’ experiences with their role and their need for involvement, and c) relatives’ experiences with decision-making. Photo interviewing was used as a frame in the focus groups (32). A photo can often narrate and explain, rather than give a direct answer, and this approach can also ensure that data are collected inductively (32). Photos served as an icebreaker and facilitated a nuanced and free conversation. Interviews were audio-recorded and transcribed to text (in native language). The first author supplied photos with consent from the producers depicting different situations, feelings, and issues. At the beginning of the interview, participants were introduced to the focus group and told to collect six photos among 19 displayed photos. The photos should identify essential perspectives and experiences in connection with illness, treatment, and decision-making. Relatives were asked to narrate their experiences through their collections of photos.

The first author (MKL) conducted focus groups interview together with a co-moderator. MKL’s role as moderator was to present topics for discussion and to facilitate discussion between relatives. The quality manager in the Department of Surgery participated as a co-moderator and made observations of non-verbal communication, group interaction, supplementing with elaborating questions at the end of the interview (27, 33).

Data analysis and interpretation

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The software program NVivo Version 12 was used to structure data and facilitate further analysis (34). Data were analysed and interpreted based on Ricoeur’s theory of interpretation in three steps: a naïve reading, a structural analysis, and a critical interpretation (28, 29, 35).

In the naïve reading, interviews were read several times to acquire an overall understanding of the text. According to Ricoeur, this initial reading should be based on an open approach towards how the text moves and affects you, which leads to the first initial level of understanding (28, 36).

Following the naïve reading, the structural analysis was carried out, which can be seen as mediation between two stages of understanding, the naïve reading and the critical interpretation, and is an explanatory procedure (28). In the structural analysis, a further understanding of relatives’ experiences was reached by focusing on units of meaning across the data based on “what is said.” This refers to quotations that illuminate meanings and represent the data. Through further interpretation, units of significance were identified as descriptions of “what the text talks about.” The process of structuring units of meanings and significance and of extracting themes is dialectical. The analysis moves forward and backward from understanding to explanation, and then from explanation to comprehension. Ricoeur describes this as a process and a dynamic interpretative reading (28). Based on the units of significance, final themes were further interpreted. Finally, themes were discussed and interpreted with relevant research results and theory, which expanded the interpretation from an individual to a universal level. Table 2 provides examples of the structural analysis.

**Insert Table 2 about here**

**Researcher reflexivity and trustworthiness**

The first author conducted the focus group interviews together with a co-moderator. Both are experienced interviewers and experienced nurses within the surgical and oncological field. Throughout the interview and analysis, preconceptions were acknowledged and put into dialogue. According to Ricoeur, the fixed text (in this case, transcriptions of the interviews) creates a distance and takes a life on its own, providing a basis for interpreting the text (28, 35). The first author conducted the initial analysis, and the subsequent analysis was discussed and refined through continuous discussions and contributions by the co-authors. The trustworthiness of the study was strengthened by illustrating the relatives’ descriptions using direct quotations.

**Results**

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The naïve reading and structural analysis identified three themes: a) facing the fear of loss, b) undertaking responsibility and a new role as a relative and c) participation - a matter of watching from the sideline. The first theme, “facing the fear of loss,” reflects the relatives’ experiences with the illness and possibility of losing the loved one, and the second theme, “undertaking responsibility and a new role as a relative,” expresses relatives’ experiences throughout illness and treatment. The third theme, “participation – a matter of watching from the sideline,” reflects relatives’ needs and roles regarding participation in treatment decisions. Themes will be elaborated in the following.

**Facing the fear of loss**

Throughout illness and treatment, relatives lived with anxiety and fear of losing the patient. Being confronted with the EC diagnosis and the enduring treatment meant that life itself no longer could be taken for granted. Relatives expressed that they had concerns about the future and were more affected emotionally than the patient was:

> Well, my husband has been cool and collected. I think I was more affected. The worries were terrible. I went for walks for hours, sobbing uncontrollably, just to get it out of my system. I talked to the children and my husband about it, but my husband couldn’t understand my sorrow.

P2

Relatives were burdened by anxiety and uncertainty regarding the future and were often isolated with their anxiety, always in consideration for the patient. Interviews showed that EC illness gave rise to speculations about losing the patient and how they could manage without the patient if the worst happened:

> We talked about if we should stay on at the house or sell it. We had to discuss this without being too tearful. The possibility is there for one of us dying quickly. We know the likelihood of dying is there.

P4

Relatives were confronted not only with the mortality of the patient but also with their mortality. This caused reflections about economy and practical issues, such as whether the house was too large for the remaining person to manage. Confronting and talking about the worst-case scenario helped relatives deal with EC and treatment. Some relatives expressed their sorrow and possible loss of togetherness:
Well, I have thoughts about how long we can walk side by side. This has been on my mind. The hope gets better on the other side of treatment. It has been difficult. The thoughts are about what will happen. Can I keep him alive? It was so hard on me, especially when he was admitted again after surgery and discharge. P13

Relatives were always alert and trying to adjust when something unexpected happened. They suffered from distress, often isolated in their sorrow.

Sometimes patients with EC fought singlehandedly with their fears:

My father-in-law ordered the coffin after he had the consultation about diagnosis and treatment. He isolated himself during the treatment. He had been preoccupied when we talked to him, not present at all. Now we have his presence again, and we can talk about ordinary things. We can believe we are on the other side..., P8

When patients withdraw from the family, relatives were precluded from sharing their fear leading to feelings of isolation and loneliness. This gave rise to a gap between patients and relatives, who could see how troubled the patient was. Consequently, relatives experienced a loss of togetherness, leading to an even more burdensome period.

The possibility of relatives and patients communicating about the worst-case scenario, about losing the patient, made providing mutual support for each other easier. Relatives acknowledged the necessity of considerations about possible death:

You have to discuss these things. What if treatment and recovery don’t go well? You have to talk within the family about the possibility of a poor outcome. What about the funeral? How would you like it to happen? I think it’s a good thing to have discussed, even if it isn’t pleasant. P2

Facing the uttermost fear helped relatives confront illness and loss of certainty about the future. At the same time, relatives and patients shared the burden of the pervasive awareness of the illness-and treatment course, and they could face the fear of a possible lethal outcome together.

Undertaking responsibility as a relative and adjusting to a new role

During the patients’ treatment with chemotherapy, relatives were preoccupied with time schedules for medication and treatment. They saw the treatment schedule as a joint event, supporting the patient to remember medication at the appointed hours. This, however, could be experienced as a strain on and disruption of everyday life:
The treatment was especially difficult during chemotherapy. He was not allowed to eat an hour before medication and an hour after. We knew it was vital for him to eat, so we looked at the clock all the time. It was like being slaves of the clock. It was awful. P2

Because of the treatment schedule, relatives experienced a restricted daily life, adjusting to new routines. Thus, cancer and treatment intruded upon daily lives and routines.

Relatives were on the sidelines, undertaking responsibility for treatment to a large degree, constantly vigilant about how treatment affected the patient. Especially the burdensome task of eating was perceived as a mutual struggle:

He cannot figure out about sizes and frequency of meals. He has many problems with pain in the stomach if he eats too much or the wrong things. We find it difficult to figure out what he can eat. P6

Troubles with eating became a joint concern, and relatives were deeply engaged with adjusting to new eating habits, undertaking a huge responsibility, and constantly alert to whether the patients lost or gained weight:

The food thing is omnipresent. We have been told that he is not allowed to have further weight loss. I am watching what he eats, constantly pushing him, giving him protein drinks or yoghurt, which he can’t stand. Then I bake protein bars, which he doesn’t want. It’s frustrating that he has lost so much weight. P15

The worry about patients’ weight was, largely, associated with patients’ progress and recovery, making meals into events burdened with anxiety and despair. If the patient was struggling, that could destroy hope for progress. Some relatives could not bear to see the patient’s struggle:

I had a hard time with the food and meals, sitting there, seeing he couldn’t get the food down in his throat. Often I had to eat in another room. I couldn’t stand looking at him battling with the food. I have been deeply emotionally affected by this. P13

Meals as joyful shared events turned into demanding affairs, escalating relatives’ feelings of anxiety and loneliness. Moreover, meals during the treatment course and recovery became stressful events.

Once relatives were engaged in helping and supporting the patient with EC, the former relationship between relatives and patients could change. The changed life situation caused relatives to reflect on the distribution of roles within the family:
My husband has always been in charge of the expenses; he really likes that. I used to be okay with him in charge. But after he got sick, I demanded that he introduced me to the financial part. It’s no use if I don’t know what to do. P15

Relatives claimed control in areas they usually did not handle. Claiming control seemed to be part of coping with a changed life situation. Knowing that they could manage areas such as expenses made them more at ease with the threat of cancer. Because they took this responsibility, to a great extent their role was often on the patient’s side during the treatment as an active collaborator trying to manage the side effects and complications. However, some relatives expressed that their positions as collaborators meant that they assumed command in the relationship, which they could find difficult:

Sometimes I felt like a mother talking to a child. “Remember to do this and that.” I have become the person who looks after him. In a way, I’ve become his relief organization, so his life can move on as smoothly as possible. P4

Relatives felt responsible and often assumed the authority in adjusting to treatment. This led to a changed balance within the family, and sometimes wives thought they took a motherly role towards their patient husband. Relatives experienced the shifts in authority and changed roles within the family as a natural development. However, they still struggled to adapt to changed everyday lives, and sometimes the change was associated with the loss of their precancer life.

Sometimes the relative’s role was as a buffer:

I had a hard time during treatment. The treatment was so hard on him. Sometimes he couldn’t handle it and told me he didn’t care about life anymore. If he has pain, he doesn’t believe in the effect of treatment. I try to calm him down, and sometimes he calls me a stupid cow. Then, I try to talk with him to make him more at ease with the situation. P10

The position as buffer entailed the relative’s serving as a target for patients’ frustrations, trying to be supportive and optimistic. Relatives were constantly in a position of hiding their fears and anxiety, wanting to be strong and authoritative, always believing in treatment on the surface, and continuously suppressing their anxieties and doubts regarding the future.

**Participation - a matter of watching from the sidelines**
Relatives did not think they should be active in the hospital context, in consultations with health professionals and decision-making. Although relatives reflected on their lack of information, they took a passive position, not asking questions, awaiting the directives of health professionals. Some relatives expressed a lack of courage to pose questions:

We could have asked because we talked at home about how the anatomy would be after surgery. But it was very late that we got that information. Perhaps we lacked the courage to ask. P7

The lack of courage to ask questions could be attributable to a belief in the authority of health professionals as experts who knew best. It could also be attributable to relatives looking upon themselves as appendages to patients, not wanting to interfere with questions. In their opinion, consultations belonged to the patient:

He has the illness. He decides and has the authority. It’s his body under the influence of treatment. I try to be in the background during consultations. Towards the end of the consultation, I can pose questions. P4

Relatives positioned themselves on the sideline, subjected to the authority of both the healthcare professional and the patient. Therefore, they depended on patients and healthcare professionals to give them space and acknowledge their roles as relatives. Some relatives stated that they needed to call attention to themselves:

If you got up, then the health professionals would say hello. They didn’t invite you, nor were they dismissive of you. But if you are quiet and don’t follow the patient, then I don’t know if they know you are on the sideline. They don’t ask. P15

Relatives did not feel rejected, but they reflected on the missing invitation to be part of the treatment course and decision-making. One male relative reflected especially on his absent participation at discharge:

She came home on day nine after the operations. She was at home for two days. Then she was admitted to the hospital again with dehydration and diarrhea. No health professionals involved me in this decision. P12
If relatives were to participate, they needed to authorize themselves, making themselves visible and claiming their roles as relatives. In their experience, they often were invisible and not seen as an integrated part of the treatment course:

On rounds during admission for surgery, or during consultations in general, my husband could ask questions, but I didn’t have the space to ask questions, not unless my husband allowed it. Sometimes as a relative, you have questions yourself. It is my husband who is ill, but I can also have questions. At discharge, he was sent home with a message about meals. I think they could have involved me as his relative. P4

The missing empowerment by patients and health professionals caused relatives to have unanswered questions. On the one hand, they saw themselves as active participants in managing the effects of treatment. On the other hand, they had to fight for their participation. Relatives felt responsible, but they were not invited to participate in decisions with impacts on mutual everyday life. Therefore, they might feel isolated and in distress with no option but to follow the decisions made by patients and health professionals.

Discussion

This study revealed that relatives navigated between demands of the EC treatment course and fear of loss, leading to distress and feelings of isolation. Simultaneously, relatives tried their best to support patients, neglecting their own needs. The distribution of roles within the family could change, as relatives undertook responsibilities and claimed control in areas they were not used to handling. However, regarding decision-making, they were passive and watched from the sidelines. Patients and relatives are dependent on each other and are vulnerable in the context of EC, leading to consequences for the relationship. In the following, the relations between roles, gender, identity, relationships, and decision-making will be discussed from a care-ethical perspective.

Our findings show that relatives’ experiences with illness and treatments were based on varying needs and roles according to the demands of treatment and the relationships within the family. Relatives were deeply engaged, undertaking a collaborative role during treatment, always adaptive to requirements of treatment. Especially at mealtimes, they shared responsibilities perceiving meals as a we-thing, making some wives feel like they had taken on a motherly role. If we look upon this from a gender perspective, the female relatives respond to a care-ethical plea, which demands that they take care of the male patient. Therefore, the female relative recognizes and identifies the meal
as a caring activity. This is similar to Hopkinson’s (37) findings, revealing that relatives had a nurturing role, that could be seen as an extension of the usual role as a wife. Moreover, we found that relatives were struggling with their new roles and sometimes undertook a role as buffers that enabled them to hide their fears and vulnerabilities. McCorry (14) also revealed relatives as buffers, identifying relatives’ burden of responsibility for the patients’ recovery.

In this study, all relatives, except two, were women. This is in line with statistics, saying men ≥ 60 years are overrepresented among patients with EC, and the mean male: female ratio is 6:1 for patients with EC (7). How men and women perceive and understand illness and treatment can differ, and this knowledge is central to understanding illness and treatment responses (38). The female relative might accept responsibility for meals and medication as this calls for a caring plea and duty as a female relative. Furthermore, cancer is a relational illness (39) as patients and relatives are vulnerable and in a state of mutual dependency. In our study, the mutual dependency was displayed by relatives’ alertness at all times towards possible side effects to treatment and new habits at mealtimes, expressing their anxiety towards the illness. This is similar to other studies, showing that relatives express powerlessness towards illness, but is striving to regain control in cooperation with the patient (13, 39).

According to Ricoeur, narrative identity is configured and composed in a dialectical tension between the self and others. The tension is not outside, but inside the self, given that the self cannot be without others. Through identification with others, these others become parts of the composition of the self (40, 41). Moreover, according to Wenger et al., men’s health and illness behavior reflect varying alignments to masculine ideals such as strength, success, control, competitiveness, and self-reliance. In addition, it is said that men can be reluctant to engage with others about their distress, even with partners or spouses (42). Accordingly, the relationship between female relatives and male patients can be changed and challenged, and how male patients handle illness and treatment influence the familiar strategies and roles within families. Simultaneously, the relative has a relational connectedness with the patient and is part of how the patient incorporates EC into everyday life.

Regarding decision-making, relatives stated that they took a passive role in consultations and decisions. However, outside the consultations, they took on huge responsibilities and were active collaborators during treatment. Relatives, patients, and healthcare professionals recognized the patients’ authority to invite or neglect relatives, which is similar to other studies (1, 43, 44). Although relatives actively worked with the demands of treatment and provided emotional and
practical support, they acknowledged patients’ authority in decisions and did not think they should share these decisions. From a gender perspective, this could be explained as relatives’ acknowledgement and acceptance of the value for male patients of being in control of the treatment pathway.

Furthermore, relatives’ participation in decision-making depends on culture, the behavior of the healthcare professionals, permission given by the organization, roles within the family, and the age and health stage of relatives (43, 45). This study found that relatives acknowledged patient authority in decisions, whereas other studies identified relatives’ participation in decision making as enhancing patient involvement and autonomy in decisions (43, 45). Our study highlighted the complexity of balancing patient authority while acknowledging relatives’ roles as active collaborators during illness and treatment. Given the vital role of relatives’ in supporting patients with EC, it would be beneficial if health professionals welcome relatives’ attendance at consultations throughout the decision-making process. Seeing the family as a whole and as experts in their own lives and establishing a systematic approach to interaction with patients and relatives may require education in family theories. Family timeout in consultations is described as a way to engage relatives more actively in consultations (46). Health care professionals must consider and acknowledge relatives’ role in consultations and decision-making to make space for relatives and engage relatives more actively.

Strengths and limitations
Focus group interviews were part of a larger qualitative study (4, 8, 47), requiring that relatives and the first author MKL meet several times throughout treatment, building trust and confidence and leading to extensive narratives. According to Malterud, the researcher’s position and perspectives will always affect what the researcher is studying, which commits the researcher to establish meta positions and sharing preconceptions (48). Accordingly, MKL discussed the analysis with the cooperating co-authors.

By using photos, relatives had the opportunity to narrate rather than answer direct questions. Thus, the data were grounded in what the participant chose to share rather than being based on responses to predetermined questions (32). Photos and narratives enabled relatives to express their stories and the meanings of those stories, prompting detailed accounts and discussions.

The strength of focus group interviews was that participating relatives had something in common, making reflections and discussions possible. Planning and conducting focus groups is a challenge, as relatives have the inconvenience of meeting at a prearranged date, and three eligible relatives did not
participate. Individual in-depth interviews might give participants more space to talk about sensitive subjects, which they might not address in a social setting such as a focus group. However, relatives knew the moderator in advance, which helped to establish a trusting atmosphere during interviews.

The study’s trustworthiness was strengthened using direct quotations, illustrating relatives’ descriptions in the analysis. The process of analysis and interpretation was discussed with co-authors to identify patterns and diverse cases and to reflect on possible alternative interpretations. In addition, in the critical interpretation and discussion, the findings were discussed in relation to relevant theory and research, leading to movement from the individual level to a universal level.

The study was conducted in a public healthcare setting in Denmark, which might limit its transferability to other countries with different healthcare systems and different cultures. Participants were mostly female relatives giving voice to experiences of female relatives but with limitations in regards to the experiences of male relatives.

**Conclusion**

Relatives of patients with EC experience illness and treatment as a burdensome period filled with anxiety and distress. Relatives expressed feelings of isolation because they did not want to show their sorrow and anxiety to the patient. During treatment, relatives undertook responsibilities such as managing medication and adapting to new eating habits. Relatives’ responsibilities led to changing roles within the family, as they claimed control in new areas. Although relatives actively collaborated with the demands of treatment and provided emotional and practical support, they acknowledged patients’ authority in decisions and did not think they should share all decisions. From a gender perspective, this could be explained by relatives’ acknowledgement and acceptance of the male patients’ need to be in control of the treatment pathway.

A systematic approach is needed to establish an ongoing dialogue between patients, relatives, and health professionals. Health professionals must be flexible and open to the many ways relatives participate according to needs, age, and roles within the family. Acknowledging decision making as a dynamic process occurring before, between, and after consultations is vital.

**References**


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Table 1 Characteristics of relatives

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<thead>
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<td>Working</td>
<td>Wife, daughter-in-law</td>
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<table>
<thead>
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<th>Occupation</th>
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<td>Wife, brother-in-law, partner</td>
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**Table 2** Illustration of the systematic process in the structural analysis

<table>
<thead>
<tr>
<th>Units of meaning (what is said)</th>
<th>Units of significance (what the text speaks about)</th>
<th>Theme</th>
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<tbody>
<tr>
<td>How do we carry on to the other side of this illness? The illness is there for a long time. We don’t know when we will be affected by illness again. They took 42 lymph nodes at the operation. This is a lot, and even though the lymph nodes didn’t show anything, we don’t know if the illness will evolve. F2, P11</td>
<td>Living with uncertainty and fear of recurrence of the cancer</td>
<td>Facing the fear of loss</td>
</tr>
<tr>
<td>Because we don’t know if my husband is going to survive, I had to learn some stuff. He had to teach me, so that I could take care of these things, just in case… F1, P1</td>
<td>Accepting and taking responsibility in new areas as a consequence of EC.</td>
<td>Undertaking responsibility as a relative and adjusting to a new role</td>
</tr>
<tr>
<td>We have been to many consultations with health professional, always with a lot of information. My partner made it through treatment. I couldn’t make any difference, it was for them to decide. F2, P12</td>
<td>Being at consultations receiving lot information about treatment, accepting the health professionals’ expertise and decision authority.</td>
<td>Participation – a matter of watching from the sidelines</td>
</tr>
</tbody>
</table>