

Older patients' experiences with a clinical pathway for colorectal cancer: a qualitative study

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Title

Older patients' experiences with a clinical pathway for colorectal cancer: a qualitative study

Background

A way to deal with the complex management and interdisciplinary care of cancer is to develop clinical pathways (CPs). CPs are not specifically designed for older cancer patients with their own specific problems. Knowledge of their experiences can contribute to optimise CPs for older patients.

Aim and Research Question

Aim: To provide insight into how older CRC patients with colorectal cancer (CRC) experience a clinical pathway (CP). This evaluation can be used to adapt, if necessary, CPs to their specific wishes to improve quality of care and patient satisfaction.

Research question: How do older CRC patients experience a CP?

Method

A qualitative research study was performed in two general Dutch hospitals. One-time semi-structured interviews were conducted with twelve patients. Data were analysed using the Qualitative Analysis Guide of Leuven.

Results

Six themes emerged as important in older patients' experiences of a CP. Four themes (time, coordination and case management, communication and information) referred directly to components of a CP. Two others themes (relationship patient-professional and privacy) go beyond the CP. Procedural experiences could be distinguished from relational. Generally patients were satisfied about all themes. Negative experiences worked through in almost all other experiences.

Conclusions

Information, communication and relationship patient-professional are critical themes and appear to determine the degree of satisfaction. Relationship patient-professional is not a component of a CP but it is an experience that contributes with the other two themes to the experienced satisfaction.

Recommendations

Further studies are required to investigate experiences of younger patients and other cancer CPs. By developing a CP for older patients attention must be paid to relationship patient-professional and privacy beyond the components of a CP.

Keywords

Clinical pathway · colorectal cancer · elderly · experiences

Dutch Summary / Nederlandse samenvatting

Titel

Ervaringen van oudere patiënten met een klinisch zorgpad voor dikke darmkanker: een kwalitatieve studie

Inleiding

Klinisch zorgpaden kunnen dienen om de complexe multidisciplinaire oncologische zorg te organiseren. Zorgpaden zijn niet specifiek ontworpen voor oudere oncologische patiënten met hun specifieke problemen. Kennis over hun ervaringen kan bijdragen aan het optimaliseren van zorgpaden voor oudere patiënten.

Doel en onderzoeksvraag

Doel: Verkrijgen van inzicht in ervaringen van oudere patiënten met dikke darmkanker met een klinisch zorgpad. Deze ervaringen kunnen gebruikt worden om, indien noodzakelijk, zorgpaden aan te passen aan hun specifieke wensen ter verhoging van kwaliteit van zorg en patiënttevredenheid.

Onderzoeksvraag: Hoe ervaren oudere patiënten met dikke darmkanker een klinisch zorgpad?

Methode

Algemeen kwalitatief onderzoek met een-op-een semigestructureerde interviews met twaalf patiënten in twee algemene Nederlandse ziekenhuizen. Data zijn geanalyseerd middels de Qualitative Analysis Guide of Leuven.

Resultaten

Zes thema's waren belangrijk in de ervaringen van oudere patiënten met een klinisch zorgpad. Vier thema's (tijd, coördinatie en casemanagement, communicatie en informatie) verwezen rechtstreeks na componenten van een klinisch zorgpad. Twee andere thema's (relatie patiënt-professional en privacy) gaan verder dan deze componenten. Procedurele ervaringen konden worden onderscheiden van relationele. Over het algemeen waren patiënten tevreden over alle thema's. Negatieve ervaringen werkten door in bijna alle andere ervaringen.

Conclusie

Informatie, communicatie en relatie patiënt-professional zijn cruciale thema's en lijken de mate van tevredenheid te bepalen. Patiënt-professional relatie is geen component van een

zorgpad maar is een ervaring die met de andere twee thema's bijdraagt aan de ervaren tevredenheid.

Aanbevelingen

Verdere studies zijn nodig om de ervaringen van jongere patiënten en met andere oncologische zorgpaden te onderzoeken. Bij het ontwikkelen moet er voor oudere patiënten, naast de componenten van een klinisch zorgpad, aandacht zijn voor de relatie patiënt-professional en privacy.

Trefwoorden

Dikke darmkanker · ervaringen · klinisch zorgpad · ouderen

Introduction

Cancer is associated with ageing. As the population is ageing, the incidence of cancer is expected to rise in Western countries.¹ Colorectal cancer (CRC) is the third most common cancer worldwide and is strongly related to age with a sharp increase from 50 years and the highest rates about 85+.^{2,3}

The management of care of cancer patients is complex because cancer has a very significant impact on physical, emotional and social well-being.⁴ In addition, cancer patients often receive multiple treatments. Medical, nursing and other professionals are involved, both in hospital and community settings over prolonged periods of time.¹ Therefore, effective coordination of care is required to ensure all patients receive timely and appropriate health care. This will optimize patients' experience of care and outcomes, and maximize health service efficiency.¹ A way to deal with this complex and interdisciplinary care is to develop a clinical pathway (CP).⁵ A CP can be defined as "a method for the patient-care management of a well-defined group of patients during a well-defined period of time".⁶ It explicitly states the goals and key elements of care based on Evidence Based Medicine guidelines, best practice and patient expectations by facilitating communication, coordinating roles and sequencing of activities of the multidisciplinary care team, patients and their relatives.⁶ The aim of a CP is to improve quality of care and efficiency of resource usage, reduce risks and increase patient satisfaction.⁶

As in most western countries, Dutch healthcare professionals in hospitals create clinical pathways (CPs) from diagnostics till follow-up to provide optimal care for a homogenous group of cancer patients.⁷ CPs are developed by multidisciplinary teams, composed of all types of physicians, nurses, social workers and administrators who manage the disease processes and are responsible for patient care.⁵ Patients are not involved in this development. CPs are often not specifically designed for older cancer patients whose care is more complex than for younger patients. Main problems of older cancer patients are co-morbidity, poly-pharmacy, high prevalence of affective disorders, inadequate social support, functional, cognitive and sensory impairments, malnutrition and limited recall of information. These specific problems need comprehensive physical and psychosocial support, by different professionals.⁵

Two studies evaluated the effectiveness of CPs for CRC, developed for the surgical part in older patients.^{8,9} In one study, patient satisfaction was examined. Patients were overall satisfied with health care, information received before admission and length of hospital stay.

Implementation of a CP did not improve effectiveness.⁸ In the other study, the introduction of a CP improved quality of care and patient outcomes but patient satisfaction is unknown.⁹ These studies do not provide insight into the experiences of older patients with a CP from diagnostics to follow-up.

It remains therefore unclear if CPs for CRC, and the cure and care services provided from diagnostics to follow-up, relate to the specific problems of older patients and their associated wishes.

Problem statement, Aim and Research Question

Problem statement

CPs are not specifically designed for older cancer patients whose care is more complex. The problems of older patients require comprehensive physical and psychosocial support by different professionals. It is unknown if CPs address the specific problems and associated wishes of older CRC patients. Therefore, there is a need for studies to capture and describe the experience of older patients.

Aim

The aim of this study is to provide insight into how older CRC patients experience a CP. The evaluation of older patients can be used to adapt, if necessary, oncology CPs to the specific wishes of older patients to improve quality of care and patient satisfaction.

Research Question

How do older CRC patients experience a CP?

Method

Design and sample

An explorative qualitative research approach using semi-structured interviews was performed to explore older CRC patients' experiences of CPs and to understand the meaning patients bring to them.¹⁰⁻¹²

The population consisted of older patients who were treated for colorectal cancer and received care according to a CP which included a number of phases: referral for possible malignancy, diagnostics, treatment, follow-up and palliative care, if necessary.

The sample involved older patients treated with chemotherapy for CRC after surgery in two general Dutch hospitals. A standard numerical criterion is not available to refer to the older population, but the United Nations agreed cutoff is 60+ years¹³ which is used in this study. Conform Dutch cancer treatment guidelines, two groups can be distinguished based on age.¹⁴ These groups followed different tracks in the pathway. One group between 60 to 69 years old received a combination of intravenous and oral chemotherapy (capecitabine and oxaliplatin (CapOx)). The other group from 70 years or older only received oral chemotherapy (capecitabine) after surgery. The first group received chemotherapy at an outpatient clinic; the second group took chemotherapy at home. A purposive sample was obtained based on age, type of pathway and treatment phase.¹⁵ Given the aim of the study to capture experiences of a relatively homogeneous patient group, twelve interviews should be sufficient for the generation of meaningful themes and its interpretation.¹⁶

Participants

Patients were recruited from oncology departments of the two hospitals. Both use a similar CP to treat and provide care for patients with colorectal cancer. The inclusion criteria were: patients 60+ years, treated for CRC with first line adjuvant or palliative chemotherapy after surgery, having at least two cycles of chemotherapy, and able to speak and read Dutch. A total of eighteen patients met the inclusion criteria. Six patients chose not to participate, mainly due to limited physical condition. The remaining twelve patients were included, eight male and four female. Eight participants from one hospital and four from the other. Ten patients received chemotherapy after surgery, two patients were still not eligible for surgery (Table 1).

Procedure

Oncologists, nurse practitioners and oncology nurses of the outpatient clinic of both hospitals were informed by the researcher (EFWK) about the study and the procedure to inform patients. Patients were recruited between February and mid-April 2014. All patients who met the inclusion criteria were asked to participate in the study via a letter of invitation with information about the study from the oncologist, nurse practitioner or oncology nurse. A couple of days later, the researcher phoned the patient to give additional information and discuss participation in the study. Prior to the interview, written informed consent was obtained. Seven interviews were performed at patient's home and five in a private area in the hospital at the request of the patients. In five cases a partner was present during the interview. Prior to the interview, partners were requested to only complement important experiences.

The study was conducted according to the principles of the Declaration of Helsinki and in accordance with the Medical Research Involving Human Subjects Act (WMO).^{17,18} Ethical approval was provided by a national medical ethical committee and by the local science committees of the participating hospitals. All interviewed patients were assured that participation was voluntary and that all data would be treated confidentially.

Data collection

Semi-structured interviews were performed to assess patient's experiences.¹⁵ Interviews lasted one hour per patient and were carried out by the researcher and audio taped. The research question was presented into topics, based on the definition of a pathway, components for effective cancer care coordination and practical professional experience of the researcher.^{1,6} The interview guide is shown in table 2. The first question, regarding their well-being at that moment, was intended to socially connect. Data about disease and treatment were collected from patient's nurse and demographic data from patients themselves. The outcomes of the study are based on the topics and other topics that matter in the experiences of patients.

Data analysis

Interviews were transcribed verbatim. Data were analysed using the two parts of the Qualitative Analysis Guide of Leuven (QUAGOL) which is developed and therefore used to capture the rich insights of qualitative interview data.¹⁹ In the first part, the essence of the patient's story was articulated in answer to the research question. Raw data were

transformed into manageable concepts. In the second part, the list of concepts was drawn up in the qualitative software program QRS NVivo10.²⁰ Each significant fragment of the interviews was linked to one of the concepts of the list, allowing a systematic analysis of the concepts based on empirical data. This part ends with a description of the results.¹⁹ Data analysis alternated with data collection. During this iterative process, the analysis of the interviews was discussed in the research team to identify concepts and theoretical issues.¹⁵ The data was analysed by constant comparison. After analyzing the first three interviews, new codes were formulated and tested in the next interviews.¹⁰

The research team consisted of four members with a mixture of expertise in the field of oncology and qualitative research. Peer debriefing, investigator triangulation, audit trail and reflecting by the researcher on her own perceptions and observation were used to optimize the methodological quality of the study.¹⁵ The researcher is working in one of the hospitals. She was indirectly involved in the development of the CP for CRC in this hospital. She did not participate in patient care.

Theoretical saturation was reached. After ten interviews, no new themes could be identified which were important for the study¹⁵, confirmed by the last two interviews.

Results

Six themes emerged through data analysis, which illustrate how older CRC patients experienced a CP. Four themes (time, coordination and case management, communication, and information) paralleled the topics of the interview guide that referred directly to the essential components of a CP. Two additional themes (relationship patient-professional and privacy) emerged from the data. Each theme is presented in the results with its subthemes. The descriptions are illustrated with quotations which are marked with the participant's number. See table 3.

Two patients mentioned a negative experience, namely receiving an erroneous diagnosis and an annoying diagnostics process. This affected almost all their other experiences. For these two patients, the themes related to procedural experiences could be distinguished from relational experiences. Some themes were interrelated, other self-contained. See figure 1. The experiences of the other ten patients were predominantly positive with a distinguishable division of procedural and relational themes.

No differences were found between patients from the two hospitals, gender, age groups or adjuvant or palliative treatment.

Time

Time was mentioned in all interviews and had a variety of meanings for patients. The duration of diagnostics and treatment were distinguished from the time reserved by the various professionals, and from the remaining time to live.

Time of diagnostic and treatment

Waiting time of the first visit to a physician until the colonoscopy was short in most cases, some days or weeks. One patient felt that two months were very long. There was no indication to do the colonoscopy earlier. The fact that all patients received the preliminary results immediately after the colonoscopy and that the diagnostic process was started, was a positive experience for all. Examinations followed quickly after each other and treatment was started soon thereafter. For one patient, the process seemed to stagnate, but this was anticipated by the case manager.

Time of professionals

Several patients mentioned time and attention taken by the professionals. Although patients knew that the available time of the physicians was limited, there was sufficient time to discuss topics that required attention. Apart from the limited time of physicians, there was sufficient time available with nurse practitioners and oncology nurses. The physician informed about the results and explained the treatment plan. Nurse practitioners and oncology nurses added relevant information and took time to ask about the patient's well-being.

Perception of patient

For one patient, time was especially linked to life perspective. His diagnosis was adjusted after it turned out that the cancer had spread and that curative treatment was still an option but with some uncertainty.

Coordination and case management

For patients, coordination of examinations and treatments and persons responsible for them were related. Experiences regarding making appointments and keeping them, accessibility professionals, and transfer of care were mentioned.

Making appointments and keeping them

In one hospital, the coordination and making appointments was handled by the case managers (nurse practitioners or oncology nurses) for the entire CP. In the other hospital, the diagnostics and surgical treatment is done by the nurse practitioner, but the treatment with chemotherapy is done by the oncology nurse. For most patients, it was evident who was responsible for coordination and in both hospitals patients were satisfied with it. The experiences with making and keeping appointments by outpatient assistants and physicians were mentioned by some patients. Their experiences were different. Appointments were usually neatly arranged and executed. However, one patient had to request for the appointments several times. This gave him the impression that something went wrong. This patient found that a person responsible for the coordination of the whole pathway, was missing.

Accessibility professionals

Most patients found that they could call the hospital in case of questions and that they received satisfactory answers. They mainly contacted the nursing professionals. At one occasion the phone was not answered although the correct number had been called. This patient mentioned this point a number of times, and it was important to him. He could imagine that this would be similar for other patients.

Transfer of care

The experiences with regard to the transfer of treatment and care between different physicians and nurses involved were different. Most patients experienced that everyone was aware of their medical history. For others it was the opposite situation, but they found it a positive experience. Telling their history and complaints again, after which every professional added a different emphasis, contributed to a better understanding and dealing with the subject. One patient was surprised that the transfer from one physician to another was done in written form only. Had it been done verbally, the incorrect diagnosis would possibly have been identified earlier, he said.

Communication

The importance of communication was mentioned by many patients. Mostly in general terms, if the communication was positive. Patients experienced that they could communicate with physicians and nurses as equals. In situations where some patients had a negative experience with communication, this was often related to providing incorrect information: by

physicians with contradicting statements regarding examinations to be done, or about giving a wrong diagnosis.

Information

All patients mentioned their experiences regarding the oral and written information they received. Patients found that they received the right information at the right time. This was a positive experience. Written information on examinations, treatment and side effects were an addition to oral information, regardless of the professional from which it was obtained. The provision of information paralleled the stages of the CP. At the same time, there was room to deviate from the protocol to meet the wishes of the patient. The erroneous information about the incorrect diagnosis was found most crucial by one patient; the other experiences were subordinate for him.

Relationship patient-professional

All patients reported relational aspects with physicians, nurse practitioners and oncology nurses. The relationship with these professionals was perceived as open, honest and fair by most patients. The patients felt at ease, could ask anything and were reassured. A damaged relationship was determined by faulty communication and information. Aspects of relationship were trust and honesty, room for uniqueness of patients and personal input.

Trust and honesty

For half of the patients, the way care was experienced in general was determined by trust in the professionals by openness and honesty, and because of the information that was provided. One patient remarked that trust was partly determined by the open mindset about treatment elsewhere if it would no longer be possible in this hospital. The cause for lack of trust was articulated clearly by the two patients with the negative experiences. These patients appreciated the fact that the errors were admitted honestly. The relationship with the relevant physicians remained damaged but the trust in the treatment process continued or returned because of the honesty.

Uniqueness of patient

Two patients explicitly mentioned that the care was tailored to their situation. Once by a physician who became a patient himself, and once by a simple man of few words. Another

patient referred to the uniqueness of each individual. A place for this should remain in a CP, regardless of procedures and protocols.

Personal input

Room for initiative and making decisions regarding treatment was experienced by all patients. At the same time, there was no doubt about treatment advice given by the multidisciplinary team.

Privacy

Some patients underlined the importance of privacy during hospitalization in a single room. Due to physical symptoms and side effects, but also to promote the recovery. Privacy during application of chemotherapy, to a patient with a public position, so as not to be recognized by everyone.

Discussion

The experiences of older CRC patients with a CP can be subdivided into six themes: time, coordination and case management, communication, information, relationship patient-professional and privacy. Most patients are satisfied with respect to all themes. A very negative experience within one of the themes worked through in the other.

A case manager is essential for effective care coordination which includes three core elements: organization, information and relationship.¹ Many patients in this study experienced a good coordination of care by and a good relationship with the case manager. This corresponds to the study of Hendren et al. that described the valuable role of the case manager for cancer patients in troubleshooting and sifting the countless logistics of cancer care.²¹

A good patient-professional relationship and effective information exchange are critical dimensions of cancer care communication and they are interrelated.²² This is confirmed by patients in this study. Erroneous or contradictory information was reflected in the relationship and communication with physicians. In contrast, good communication improved the perceived quality of care as was noted by Kourkouta and Papathanasiou as well.²³ Effective patient-professional communication is essential for comprehensive cancer care.²⁴ Better oncology care means that the physician must provide more complex information to the

patient. But in less time, so write Baile and Aaron. This is a barrier to effective communication.²⁴ In this study, patients experienced time and attention at the physicians although their time was limited. After the visit to the physician, patients received further information from the case manager. Appropriate information given to cancer patients about their diagnosis and treatment improved satisfaction with care.²⁵ Patients in this study who received correct information were satisfied and those who received erroneous or contradictory information were not satisfied.

Soria-Aledo et al. evaluated satisfaction of older CRC patients about the surgical part of a CP. Patients were overall satisfied with health care, information received before admission and length of hospital stay.⁸ Generally in this study, CRC patients were satisfied about the surgical part of the CP but also about the diagnostics and treatment with chemotherapy. Patients emphasized different aspects when illustrating their satisfaction. An important aspect is to have trust in the professionals involved in the CP. Trust that is determined by openness, communication and information provided. Communication and information refer directly to the components of a CP. Trust and honesty in patient-professional relationship, emerged from the data.

In this study, some patients underlined the importance of privacy. A systematic review shows that the evidence of the effects of single rooms for patients is limited due to missing research.²⁶ Regarding satisfaction, patients in single rooms are more satisfied than patients in shared rooms.²⁶ Two other studies report the preference of older patients for shared rooms for different reasons.^{27,28} Further research is needed to explore the impact of single rooms on well-being and healing of patients.²⁶

Strengths and Limitations

There are few qualitative studies on older CRC patients' experiences of CPs. This study provides insight into the experiences of a CP of this group.

The researcher who conducted the interviews was an oncology nurse, which could have influenced the views presented by the patients. Knowing that the interviewer was a nurse, patients did not have to explain all medical particulars. This could be a strength but also a limitation, because the researcher may have interpreted the answers and did not ask for further clarification.

Patients came from two general Dutch hospitals who used similar CPs. Caution should be exercised when applying the findings to other settings with other CPs.

Conclusion

Older CRC patients' experiences with a CP are predominantly positive and determined by a combination of procedural and relational themes. A combination of information exchange, communication and relationship patient-professional are critical themes and appear to determine the degree of satisfaction for an important part. Relationship patient-professional is not a component of a CP but for older CRC patients it is an experience that contributes with the other two themes to the experienced satisfaction.

Recommendations

Further studies are required to investigate the experiences of younger patients and other cancer CPs. When they are all satisfied, it would mean that a CP for all adult cancer patients can be arranged in the same way.

When developing a CP, for older patients attention should be paid to the components of the definition of a CP but also to the two additional themes, namely relationship patient-professional and privacy.

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Tables

Table 1 **Characteristics of the Sample**

Patient No.	Age, y	Gender	Chemotherapy	Purpose	Number of chemotherapy	Surgery
1	66	Male	CapOx	Neo-adjuvant or palliative	3	Yes
2	64	Male	CapOx	Adjuvant	2	Yes
3	62	Male	CapOx	Palliative	4	Yes
4	74	Female	Capecitabine	Adjuvant	6	Yes
5	62	Male	CapOx	Adjuvant	8	Yes
6	79	Male	Capecitabine	Palliative	7	No
7	76	Female	Capecitabine	Adjuvant	7	Yes
8	81	Female	Capecitabine	Palliative	2	Yes
9	70	Male	Capecitabine	Palliative	2	No
10	75	Male	Capecitabine	Adjuvant	4	Yes
11	61	Female	CapOx	Adjuvant	2	Yes
12	75	Male	Capecitabine	Adjuvant	2	Yes

Table 2 **Interview guide**

Introduction
How are you doing?
What are your experiences?
Topics
Time
Coordination
Communication
Information
Case management
Conclusion
Based on your experiences, must something be changed in the clinical colorectal pathway for older patients?

Table 3 Themes, subthemes and illustrative quotes

Themes	Subthemes	Illustrative quotes
Time	Time of diagnostic and treatment	<p>I have to say that I actually lay on the surgery table before I was even starting to get used to the diagnosis. Looking backwards, I think it's good that all happened quickly. I think that most patients would find it much more difficult to wait for weeks till something is happening. (3)¹</p> <p>The surgery would be in a couple of week, but then the nurse practitioner (<i>the case manager, EFWK</i>) said "I think that's too long." So I was called by the planning: next week Wednesday is the surgery. We thought: it will then still take a couple of weeks, but it turned out that the nurse already initiated everything. (5)</p>
	Time of professionals	<p>Look, clinicians give the diagnosis, whereas the nurse practitioner takes time to explain everything. Then a clinician doesn't need to do so, and can work with the next patient. I liked the way it is. (9)</p> <p>The nurses at the day unit are very open, you can ask them everything. They also tell you some things by themselves. They take, I noticed, time for that. Before you start with the infusion, they really take time for you to talk with you. (1)</p>
	Perception of patient	<p>When I talk about the perspective (<i>of time, EFWK</i>), that really turned upside down. First you have it, and then you don't have it. Then there is a period of uncertainty. On one hand you prefer this uncertainty, on the other hand you are afraid that it will be the wrong certainty. (1)</p>

Continued

¹ (..) is patient number; see table 1

Table 3

(Continued)

Themes	Subthemes	Illustrative quotes
Coordination and case management	Making appointments and keeping them	<p>The case manager came right there (<i>after the results of the colonoscopy, EFWK</i>). Ten minutes later. Perfect. And good. Good contact. (5)²</p> <p>But rather than the one that must keep the whole overview, that miss we all. (1)</p> <p>At that moment I started to feel things that were not good. Because no appointment for the biopsy was made. I had to call back for that instead of booking it immediately. When I called back, I still did not get a response. (1)</p> <p>Then I was told by: Tuesday, then the oncologist will contact you. But nothing happened Tuesday. And then I called myself and did not get her. And the next day, she called me. (1)</p>
	Accessibility professionals	<p>Although the oncological surgeon also had said: "If you want to talk, you can always call me." But I did not need it because the nurses were just clear enough. (2)</p> <p>I thought that was really sloppy. (<i>Telephone was not answered, EFWK</i>.) That should have been switched back to the central services. (3)</p>
	Transfer of care	<p>I think repeating complaints or so may also be important to give things a certain place. That if you can tell it more frequently, that you can handle it better it at some point. (3)</p>
Communication		<p>I must say, the communication so far goes well. (3)</p> <p>Then she says (<i>at completing of the evaluation form, EFWK</i>): "And the doctor?" I say: "Well, they don't have any communication." One doctor says: "You get a colonoscopy" and the other says: "You have to go home on Friday."(4)</p>

Continued

² (..) is patient number; see table 1.

Table 3

(Continued)

Themes	Subthemes	Illustrative quotes
Information		<p>But also that it's just clearly explained. Allso not that difficult words and all. (8)³</p> <p>And therefore also that conversation with the oncology nurse. Normally much later. But she (spouse, EFWK) wanted it right away. I'll know what's going to happen. And then, well, fine, if you want, we'll do that. Ready. Because then we have it all. We have the information at home and if we want to read, we can read. And want to set aside, we set it aside. (2)</p> <p>Yes, I'm just ordinary in the early stages not properly informed. And that I do not understand so well. Because the impression was that they were very open. (1)</p>
Relationship patient-professional	Confidence and honesty	I trust that doctor. I trust the honesty of that doctor. (6)
	Uniqueness of patient	You can beautifully record everything in protocols and procedures. But people remain different. One person has different needs than another. And that will always remain a matter of intuition, I think, for the people in the hospital. (1)
	Own input	<p>Yes, I could choose. If I had said: "I don't want that", then that would have been good as well. However, she did recommend it. (8)</p> <p>Then, this is the route. You have discussed that in the team. If you advise me that, I'm not going to say: "No, I won't do it." (5)</p>
Privacy		Because I'm sure that the recovery would have been faster if you, if you had been located separately immediately after the second operation, that that had gone better (spouse). (2)

³ (..) is patient number; see table 1

