

Accessing Information in Order to Manage The Strain of a New Demanding Role—A Qualitative Study of the Next of Kin of Patients after Colorectal Cancer Surgery

Abstract

Objectives: The aim of this study was to explore next of kin's experiences of information and their information needs after the patient's discharge for colorectal cancer surgery.

Methods: Sixteen next of kin were interviewed twice during the first seven weeks after the patient's discharge from hospital. The interviews were analysed through qualitative content analysis.

Results: The participants in this study needed to access information so as to manage the strain of a new and demanding role as next of kin to a person with colorectal cancer. That role consisted of different parts: managing their own feelings and anxiety, sharing and participating in the patient's life and supporting the patient and the rest of the family practically and emotionally. The waiting times increased the experience of uncertainty and made the adaptation to the role more difficult. The participants needed to receive their own information and support in order to be able to handle and balance the situation. They needed to share different parts of the patient's cancer trajectory with them and have access to the same information.

Conclusions: The next of kin needed to be included more actively in the patient's cancer trajectory in order to manage the strain of being a support during the initial period at home. Participation in the information and the patient's discharge planning are crucial in order to help patients regain control after colorectal cancer surgery.

Keywords: Colorectal neoplasms; Surgery; Relatives; Information; Discharge; Qualitative research

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Introduction

Being the next of kin to a patient returning home after colorectal cancer surgery is a challenging situation, trying to face one's own fear and anxiety while supporting the patient both emotionally and practically to the best of one's ability [1-2]. The next of kin often provide the main support when patients reach home and they are mostly alone in that function [3-4]. They perceive themselves as being ill-prepared for what to expect when the patient returns home from hospital and express a need for more planning and information before discharge [5]. The

unsatisfying situation for the next of kin of patients with colorectal cancer (CRC) emphasizes the need for more and deeper knowledge in order to acknowledge their situation and information needs.

A shorter length of stay in hospital has become more common and this has implications for both the patient's and the family's ability to assimilate information and to prepare for discharge [6-7]. The shorter stay in hospital also means that patients return home earlier in the process of recovery and more symptoms and needs can be expected. Patients who live alone are known

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to have a significantly longer stay in hospital [8] which gives an indication of the demand on next of kin to handle advanced care and support during the initial period at home.

Patients' information needs are known to differ during the cancer trajectory and the discharge from hospital to home is a critical transition where the need for information is increased [9-10]. The ways in which the next of kin and their specific needs of information relate to the patient's trajectory is rarely described or defined; for example, if they have their own trajectory or in what ways they participate in the patient's trajectory. The experience of the next of kin of patients with CRC of being marginalized and unrecognized by the healthcare professionals is an indication that they feel left out of the patients' trajectory [11]. This has implications for how the next of kin perceive their participation in the patients' care and their own role as care givers, and it affects their own health. In a study with 130 next of kin caring for patients with different cancers (including CRC), as many as 66% showed signs of depression [3]. This vulnerable situation for the next of kin of patients with CRC enhances the need to study the importance of information in facilitating their situation the first seven weeks after discharge.

Aim

The aim of this study was to explore next of kin's experiences of information and their information needs after the patient's discharge for colorectal cancer surgery.

Method

Design

The interviews with next of kin were performed twice during the first seven weeks at home after the patients' discharge following colorectal cancer surgery. The study was designed to comprise both the initial period at home and the period after the postoperative visit, when the results from the tissue samples and further treatment had been discussed with the patient. The focus of the interviews was on how the next of kin experienced the information and on what their own information needs were, i.e., what they would have needed before the patient's discharge from hospital. At the time of the second interview some patients had already been informed about chemo-therapy and a few had received their first treatment.

Participants

Next of kin to patients who had had surgery for colorectal cancer without receiving a stoma at three hospitals in southern Sweden were evaluated for inclusion. They were included if they lived together with the patient, and if both parties consented to the interviews [12]. Patients received written information about the study in the hospital, which they handed over to their next of kin. Written informed consent was signed.

Sixteen next of kin were interviewed twice during the first seven weeks after the patient's discharge from hospital. Ten of the next of kin were women and the age varied between 18 and 83 (median 67). They co-habited with a spouse or partner except

for one next of kin who lived with a parent. Their occupations covered both white-collar and blue-collar work.

At the time of the second interview one patient had unexpectedly received information that the diagnosis was a benign tumour and the inclusion criteria was no longer fulfilled, thus the second interview of that next of kin was excluded from the analysis.

Interview

The interviews were performed individually in the person's home and on two occasions: 1-2 weeks after discharge and a second time, 5-7 weeks after discharge. The interviews were performed twice in order to increase the variation in the material and to cover both the initial period at home and the time after the prognostic information at the post-discharge visit one month after discharge. The median number of days between discharge and the first interview was 9 days, and between the post-discharge visit and the second interview 21 days.

The same person (ML) performed all the interviews and made an assessment of the content of the interviews and estimated that the last interviews did not add new information to motivate further inclusion of participants. The thirty-one semi-structured interviews were transcribed verbatim and resulted in 311 pages of text altogether, varying between 4.5-21.5 pages per interview (A4 format, single-spaced).

The questions were similar at both interviews and started with a question like: Can you tell me about the information you received at the time of discharge and what information you consider to be important now? An interview guide was used and embraced the following areas: Experiences related to receiving information at the time of discharge; the kind of information needed by next of kin in order to handle the situation; which information was the most important, and how the next of kin wished to receive the information.

Analysis

Qualitative content analysis was used to analyse the transcribed text from the interviews. Content analysis comprises different applications for interpreting data. In this study a conventional approach is used including both manifest and latent analysis [13]. The conventional approach is used when the study is designed to describe a phenomenon about which existing literature is limited. The advantage is the gaining of direct information from study participants without applying preconceived categories or theories. Content analysis can also be divided into manifest and latent analysis, where manifest refers to those elements that are physically present in the text while the latent content is extended to an interpretive reading of the symbolism underlying the data [14].

All text from the first interviews was read as a whole several times (ML and EA). Meaning units related to the aim of the study were identified in the text and labelled with codes by the first author. The whole interviews and the codes were discussed by the three analysers (ML, EA and RK) at several meetings and lead to seven areas with different content. These areas turned into seven subcategories which then became three main categories. Then the text from the second interviews was read and analysed

in the same way. The categories and all subcategories from the first interviews were confirmed, but the content and meaning became richer and deeper. The subcategory concerning treatment with chemo-therapy was initially rather tentative but became more obvious and comprehensive after analysing the second interviews. In the last step, all four authors reflected upon the findings and came to an agreement on one overall theme, and on categories and subcategories. The computer programme NVIVO10 was used to sort the meaning units into subcategories [15].

Ethical considerations

Every precaution was taken to protect the privacy of the participants and the confidentiality of their personal information and to minimize the impact of the study on their physical, mental and social integrity [16]. If the interview situation highlighted any need for further emotional support, contact with a counsellor was offered. One participant chose to meet a counsellor several times. The participants could also relinquish the study at any time. This project was evaluated in a regional ethics review board (Reg. no. 558/2006).

Results

The overall theme of Accessing information in order to manage the strain of a new demanding role revealed how the next of kin needed information in order to manage the new and demanding role of supporting the patient at home (**Table 1**). The information they received was often experienced as being unplanned and random and did not prepare them for the first weeks at home after the patient's discharge from hospital. They did not receive the information they needed in order to increase their own wellbeing or to manage the responsibility of supporting the patient and the family. This made them reflect upon what kind of information they really needed, when they needed it and how their situation could be improved.

The role of the next of kin changed from being a visitor during hospitalization to functioning as the main support after discharge from hospital. At home they supported the patient and the rest of the family practically and emotionally, but did so while struggling with their own feelings of fear and anxiety.

Participating in the patient's life

Being part of the patient's cancer trajectory was important for the next of kin and when they felt excluded by the patient or by healthcare professionals it became harder to provide the necessary support. Three subcategories concerning the importance of information for participation emerged from the interviews:

Receiving information, a necessity for participation; Becoming familiar with the disease and its trajectory, and Becoming familiar with further treatment.

Receiving information, a necessity for participation

Being the next of kin of a patient meant being involved and outside at the same time. The degree to which they could

actually participate depended, to some extent, on the healthcare professionals' ability to invite the next of kin to do so, and on their own willingness to be included in the patient's cancer trajectory. However, the patient appeared to be the one who primarily controlled the extent to which the next of kin could be involved. In most cases the degree of involvement was not discussed explicitly, but was rather dependent on family roles they had had before the cancer diagnosis.

He receives the information, but he needs to handle things in his own way, that's just the way it is, and it's a tumour and, well that's nothing to be down about, and that's his way of handling it, but it isn't mine (1F).

Some patients wanted their next of kin to share all aspects of the disease, the care and the information, while others kept most of the information to themselves. When the next of kin did not feel included their role became more passive and they left more to the patient to manage on his/her own. When the patient withheld information it could be seen as being considerate, even if the next of kin often wanted to be involved and to know more. The relationship with the patient clearly affected both the need for information and participation. Some next of kin left the decisions to the patient and accepted being left out and at home during discharge from the hospital and during visits to the doctor. However, at the time of the second interview some had reconsidered this and then clearly stated that they intended to accompany the patient from now on; for instance when meeting the oncologist and discussing chemo-therapy.

The information for the next of kin was rather fragmented. It was quite common to describe the participation in different information meetings as being unplanned and random, they were sometimes unaware of the meeting taking place or what would be discussed. Some managed to participate in the discharge conversation together with the patient seeing this as an important opportunity in which to participate and prepare for the return home. Others shared a rapid, unprepared conversation late in the afternoon together with the patient and this was an unsatisfying experience. It was quite common to receive a phone call from the patient that they were on their way home and that the discharge information had already been given.

Most of the participants preferred verbal information and emphasized the importance of having a separate room and

Table 1 Interpretation of next of kins' experiences.

Theme: Accessing information in order to manage the strain of a new demanding role	
Categories	Subcategories
Participating in the patient's life	Receiving information, a necessity for participation Becoming familiar with the disease and its trajectory Becoming familiar with further treatment
Being a support	Making daily life work at home Supporting the patient and the family
Being in a condition of waiting	Being hampered by waiting times Feeling anxiety and uncertainty while waiting for information

enough time to ask questions. They generally wanted to receive the information together with the patient; it felt safer to share this experience and they could help each other remember. It was important to feel respected and included in the meeting and when they were left out or ignored it was a very negative experience. They noticed carefully how they and the patient were treated during the information and wanted the meeting to be like a mutual relationship with the healthcare professionals.

When it's a person who tells you truthfully, and tells you everything, and you're allowed to ask; they take their time....verbally, you're always there, they show you more respect sort of, because you think, you feel more, it's like they're saying that it's us they care for, that's how it felt (2F).

In addition to verbal information they wanted the general information to be in writing and include pictures of the large intestines and a glossary where difficult terms and concepts were explained. The importance of having someone to contact at the hospital was emphasized and when this was used by the patients the next of kin saw it as supportive.

Some of the next of kin were very active in searching for additional information in brochures and on the internet. The search for information was used to handle the anxiety they felt and sometimes it made the situation more tolerable but the reverse was also seen when, for example, reading about the prognosis increased fear and distress. More women than men searched actively for information and some of them wanted to have conversations with the healthcare professionals on their own. Some women knew their partner did not ask so many questions or thought that they did not ask the right ones. It was more common among men to let the female patient receive most of the information on their own and then let them forward what was regarded as important. It could even be seen as distrust to search for additional information beyond what the partner had already shared with them. The previously set roles in the families were described as being part of this approach.

Reflecting upon the right to know, and being invited by the healthcare professionals to ask questions, was clearly articulated, and the participants expressed a need for straight and honest information. They spent a considerable amount of time pondering over what kind of information they had received and felt frustrated and angry when the information was presented negatively or when they suspected that it was hidden from them or the patient.

Are you really telling the truth, so it's not just that you're trying to be nice, just so that the patient doesn't break down or get really worked up or so, I know that's the kind of thoughts I had (3F).

Becoming familiar with the disease and its trajectory

Getting access to information about the disease and its trajectory was necessary in order to be able to participate in the patient's life. The information that was considered the most important was about the cancer; if it was malignant and if it could spread further in the body and where metastases were most likely to emerge.

What you really want to know is whether it'll spread, nothing else

really....now they've cut away so much, so maybe there's nothing left, that's how you want to look at it (4M).

Information on the position of the tumour, how long it had been there for and how fast it was growing was of interest. What was done during surgery and how much of the intestine that had been removed was other desirable information. It took time to process the patient's cancer diagnosis, and there was uncertainty about where in the cancer trajectory the patients actually were at the moment; they wanted to know when this hardship would finally be over. Many thoughts returned again and again; if the cancer had spread, where it could recur and what the presence of cancer cells in the lymph nodes really meant. Questions about death and prognoses were not answered by the healthcare professionals and some inconsistency could be discerned in regard to this kind of information. Some expressed a wish to know if the patient was cured or not, while others conveyed conflicting desires between wanting to know and not being able to handle severe information.

Becoming familiar with further treatment

At the time of the first interview the interest for further treatment and the follow-up were somewhat present but the interest clearly increased in the second part of the interviews. At the post-discharge visit at the surgical department the results of the analysis of the tissue sample were discussed. Being the next of kin of a patient with cancer in the lymph nodes and in need of chemotherapy was quite different from receiving information about a better prognosis. It was an additional crisis to overcome and it came only shortly after receiving the cancer diagnosis; new worries and a new need for information appeared again. The hope of soon being able to regain a normal family life were dashed to the ground and the future became a lot harder to plan for and predict.

The need for chemo-therapy felt confusing and like a contradiction for some participants since they had heard that the surgery went well and all the cancer had been removed. The information about preventive treatment then came as a surprise and increased the feeling of insecurity. On the other hand, when no cancer in the lymph nodes was seen, the need for further information obviously decreased and only a few questions on follow-up and the future were in focus.

The word chemo-therapy was negatively charged and worries about the patient's body and what side effects that might occur were very common. A few patients had already started their treatment and when serious side effects were seen it created fear in the next of kin and made it hard for them to stand by and watch. Some even feared that the patient might not survive the treatment.

I thought he looked so wretched, I thought how he was going to have treatment for a period of six months and that this was just the beginning, how's this going to end... it's like what you've heard before, like you feel bad, and then I thought, if it's that bad he could actually die... (3F).

Practical information on how long the treatment would last, why they were treated two days after each other and how the dosage for chemo-therapy was calculated was interesting information to receive. Information about further treatment with chemo-

therapy also led to questions about prognosis and to what extent the chemo-therapy would improve that.

Being a support

The cancer and the following treatment changed the roles in the family and became a strain on the relationships. The next of kin clearly needed to be better prepared before discharge since the new role involved new responsibilities, both emotional, social and practical. The category, *Being a support*, comprises two subcategories: *Making daily life work at home* and *Supporting the patient and the family*.

Making daily life work at home

The next of kin received, or took on, the responsibility of making everyday life work at home after the patient's discharge from hospital. During these first days it became clear to them what the new role implied and they were not prepared for it. The necessity of being actively involved in the information and discharge process became evident and they requested information on: diet advice, activity and training, wound care and what normal bowel function after surgery is like.

What I would've wanted was that I would've been more prepared for what I got home, that it could be like this... what he should and shouldn't do, I mean the first few days when he was at home, when he comes home, I would've liked to know, food, how much he should move around, of course you can't say exactly, but more or less, what's best for him to drink, well basically drink, food and exercise, what to think about, I would've wanted that (1F).

The healthcare professionals' lack of knowledge about patients' home situations and the need for next of kin to be prepared for this new responsibility were some of the recurring reflections. Having an older partner to care for while being sick and frail oneself was an additional hardship, and a need for practical help during this first period at home appeared, such as for cleaning and washing clothes.

Supporting the patient and the family

Engaging in the role of being the coordinator and the facilitator of support for the patient and the rest of the family seemed to come without discussion and the role was implied more than explicit. It turned out to be a demanding role, but also made the next of kin feel important and needed in that function. When reflecting upon the family situation during the first weeks after discharge their situation was described as complex and consuming and it was clear that their own needs as next of kin were put aside during this period. The patient, children, relatives and friends all needed emotional support from the next of kin to manage the consequences of the cancer. Having access to information about the disease and the treatment was a prerequisite for them in order to constitute a support. Being both a next of kin and a parent to children living at home created many thoughts and additional worries. They wondered over what information and support the children needed, and wanted to receive advice on how to help them in the best possible way. Some days the patient required all their time and attention and they felt that the children's needs were put aside.

It was important to have a close relationship with the patient

and to be able to share and discuss not only practical matters but information about the future as well. The closeness to the patient was also related to how much support the next of kin gave. The effect of cancer on the family could imply both irritation and friction as an additional burden. However, it could also bring about a feeling of how important the relationship was to them and that this hardship made it even stronger.

We're in this together, we've managed really well, he's the one who's been operated on but there has to be two of you to manage anything (5F).

Some of the next of kin had been sick for years and the patient had supported them previously. Now, when the patient had cancer, the roles in the family changed and the next of kin needed to turn from being the sick and receiving part to being the one providing support. This increased the burden and made the adaptation to the situation even harder to manage.

The surgery had an impact on the families' social life but the chemo-therapy even more so, since some of the side effects seriously affected the patient's ability to manage activities away from home. Not being able to meet friends and do different recreational activities led to frustration and a feeling of social isolation for the next of kin as well.

We can't isolate ourselves, I mean we have to see other people, or especially X who's alone here, he has to see people, I mean I don't have the same need but he really has to get out and think about other things, and we have to do something (3F).

Being in the condition of waiting

Waiting for information made an already painful situation worse and life halted during such times while anxiety increased. Lacking information about the reason for the long waiting time and what exactly they were waiting for, made it even harder to endure. *Being hampered by waiting times* and *Feeling anxiety and uncertainty while waiting for information* were the subcategories comprising two perspectives on waiting.

Being hampered by waiting times

The waiting for new information or for treatments to start was experienced as being too long. Both the length of the period and the importance of the expected information contributed to the anguish during this time. Life could not start fully again until the information had been received. The next of kin experienced many different waiting times even during this short time of the patient's cancer trajectory; waiting for a set time for discharge, waiting for answers from the x-ray examinations and from the analysis of the tissue sample, or receiving a time for a visit at the surgical or oncological clinic.

That it took such a long time, I think was the pits, having to go for 14 days over Christmas, waiting to talk to the doctor who would be ruling our lives for the next six months, I think that was really outrageous (6F).

Social life was affected by the waiting times. When it took days or weeks to receive information about the time for the postoperative visit or when to start the chemo-therapy, it became hard to plan different activities with friends and to realize travel plans. Many

participants felt that they should have been given a call with an explanation if the waiting period was prolonged unexpectedly.

It's one thing if they say that we'll let you know within 2-4 weeks and then they phone and say, sorry, we can't say yet because... then we know that, but when you don't hear anything, have they forgotten about us or what (7M).

Feeling anxiety and uncertainty while waiting for information

Waiting for different kinds of information was experienced as a severe suffering. Having to wait for answers caused anxiety and uncertainty, every day of waiting turned into painful expectation.

It's taken too long, the patient and also their relatives get nervous from all this waiting, just wait, every day was suffering... (8M).

The waiting was hard to endure, both in a shorter and a longer perspective

The shorter perspective concerned information about the current situation with doctor's visits and when treatments would start, while the longer perspective concerned the future that they might have to spend without their partner or parent. In this stressful situation some of them started to worry for their own health and experienced symptoms like sleeping problems or a lack of appetite. When, on the other hand, the information was directed to meet the needs of the whole family it provided a well needed pause and some rest for the next of kin.

I mean we did feel, like really safe in some way when we left, because I thought, he was really fantastic, he had such a comforting effect on both of us...I felt calmer by being allowed to be there (3F).

Wanting to receive information about the prospects for the future was in contrast to needing to know the worst. Thoughts about how the future would turn out and being deprived of the person one was closest to, were mixed with thoughts on practical concerns for the family's economy in times to come. Sharing the darkest thoughts with someone was seen as important, but few of the participants had this kind of discussion with the patient. When they felt that the patient tried to shield them from severe information or did not share their concerns with them it had the opposite effect and instead increased their anxiety.

He doesn't tell us anything, so he thinks that like that he's protecting me, but it's the opposite, then I go and imagine all sorts of things, it's like that..., that I think it's like this or that, or worse, it's natural...well, it's the disease of course, that he hasn't told us everything, and what the doctors have said and so on, then you go and, try and ask him, but he doesn't answer (9F).

The situation was similar in relation to healthcare professionals; when they avoided serious questions it exacerbated the worries even more.

Discussion

The participants in this study needed to access more information in order to manage the strains of the demanding new role as next of kin of a person with colorectal cancer. That role consisted of different parts: managing their own feelings and anxiety, sharing

and participating in the patient's life and supporting the patient and the rest of the family practically and emotionally. The waiting times increased the experience of uncertainty and made the adaptation to the role more difficult. The participants needed to receive their own information and support in order to be able to handle and balance the situation. They needed to share different parts of the patient's cancer trajectory with them and have access to the same information.

The variation in civil status among next of kin was slight, all participants but one were spouses. However, the distribution in age varied more and some of the younger participants had children living at home and it increased the variation in the material.

Some of the interviews were quite short, but in general the texts showed that the participants elaborated on the questions and included many examples and short stories on how they perceived the role of being the next of kin of a patient with cancer and the information needed to manage that role. They had a strong desire to talk about that strain and how they had adapted to it. The information needs of our participants are confirmed by another study where the main focus was on how next of kin view patients' symptoms during chemo-therapy for CRC [17]. The next of kin showed a great need for talking about their own experiences and revealed several areas of unsatisfied needs.

In the design of this study a second interview was chosen in order to cover a specific period of the patients' cancer trajectory. Another advantage of repeating interviews can be to increase the depth of the interviews [18-20]. The findings showed that the participants had used the time between the two interviews to reflect more and deeper upon the information and what it meant to them as next of kin. A few even changed their approach from letting the patient take care of all the doctor's visits by themselves to clearly stating that they would accompany them from then on. It seems reasonable to believe that the second interview resulted in not only more information but also in a greater depth and richness of the data.

There was about one month between the interviews. This could be considered as a short part of the cancer trajectory but it did include the first critical days at home and the time just after the patient's post-discharge visit. These two occasions were not compared but some variation could, nonetheless, be detected. The interest for information concerning chemo-therapy increased at the time of the second interview. The same was seen regarding how they described their own role as next of kin, they could use more of an outside perspective when reflecting during the last interview.

All authors had some experience from different kinds of surgical cancer care. Great care was taken to increase the credibility and objectivity of the study and to let the results emanate from the participants' data and not from the authors' pre-understanding [21]. All results were discussed many times and from different angles in order to reduce the risk of a biased influence. To increase the quality of the analysis, all four authors read some of the interviews and two of them read all of the interviews several times.

The next of kin in our study needed more information than they had access to, while a few were satisfied with the overall information and care. Lacking information made participation in the patient's cancer trajectory hard to achieve and without participation they could not fulfil their role as support in a satisfying way. The next of kin clearly needed to be better prepared before the patient's discharge in order to manage their new role and the adherent responsibilities. When the information had been satisfactory at times it usually involved a personal meeting with a healthcare professional where the next of kin felt recognized and included in the patient's life.

The importance of information for next of kin has been known for quite some time but still constitutes a recurring and unsatisfied need and receiving information is valued even higher than emotional support [5,22]. The information needs and the motivation to seek information are multifaceted and influenced by many factors. Some personal factors are more fixed like age and gender, while others relate to individual experiences like knowing someone with cancer previously [23]. The importance of information, that it is applicable, easy to access and that it can be used to change and improve the situation are factors that will affect the perception of information needs and the level of activity in information seeking. The information needs also vary according to particular stressors that change during different phases in the cancer trajectory [24]. The variation of these factors can explain why the healthcare professionals managed to satisfy the information needs among a few participants, while most of them expressed a decided need for receiving more.

In order to provide patient-centred communication to patients, the next of kin need to be involved in all information from the very start of the cancer trajectory and continually during every phase [25]. Healthcare professionals need to identify the current phase for the patient as well as the individual information needs of the next of kin in order to facilitate their participation in the patient's cancer trajectory. To invite the next of kin to all meetings with the patient and include them in letters to the patient would emphasize their presence as an indispensable part of the patient care.

However, the inclusion of the next of kin in the patient's care presumes a family with rather healthy relationships. The degree of satisfaction with the relationships in the family is known to be a strong predictor of how the next of kin are capable of handling the role of being the person who is closest to a patient with CRC [26]. The same is seen among the patients. When their next of kin experience problems in their role, it makes it more difficult for them to adjust to the role of being a patient. One crucial factor is the communication between the next of kin and the patient, where better communication means less distress and better role adjustments for both parts [27]. Interventions aimed to improve the information and the care for both the family and the patient would therefore include one part that focuses on facilitating their mutual communication during the cancer trajectory.

Waiting for information increased anxiety and it was made worse when feeling left out of the patient's cancer trajectory. The next of kin described that the waiting was one of the hardest things to endure during this phase of the cancer trajectory. Life was put on hold and all other plans had to be put aside so that they would not

collide with important appointments. They also described it as difficult to balance the dominance of the cancer disease on family life, as well as to socialize with friends and realize travel plans. The waiting times increased the next of kin's feelings of anxiety and uncertainty, and when they saw how the patient suffered from waiting this added to their own hardship. Waiting times are identified as distressing for patients and families with other types of cancer as well. One study showed that 27% of patients with lung cancer experienced the waiting times as a problem and mostly connected it to deficient communication [28]. Another study highlighted the negative experience of waiting times during the first year after receiving a diagnosis of lung cancer; the worst waiting was the one without preparation and information [29]. These findings emphasize the importance of involving patients and relatives in the information process and of clarifying every step in the cancer trajectory and the reasons for the different waiting times.

The next of kin assume a responsibility for being the main support for the patient after they come home after surgery without really questioning it. When reflecting during the interviews they somehow understood the extent and strain of it. It is not clear how much of this responsibility that is placed upon them by the health care or how much of it that constitutes expectations from a close family member as part of the relationship. The next of kin's involvements in the patient's cancer trajectory are known to vary during different transitions [24,30]. Two transitions can be identified during the time of data collection for this study; one from active cancer treatment with surgery to the start of a rehabilitation phase. For one group the rehabilitation turned into an additional treatment that enhanced the seriousness of the cancer disease even more and became a second transition. However, patients with better prognoses are known to have ongoing health problems many years after the cancer surgery and therefore continue, to some extent, to be in need of support from next of kin [31].

When finding themselves in the start of the patient's cancer trajectory the next of kin could use more help from the healthcare professionals in order to define and handle the strain of their role. The importance for patients to receive continuous support from a specialist nurse in surgical and oncological care are well known, but were not implemented in these hospitals at the time of the interviews [32]. To include next of kin in patient-centred care could benefit them in regard to access to a specialist nurse. Even though research in this area is sparser it suggests that a specialist nurse can fill an important role both with regards to support and also as a source of information for the next of kin [33,34]. Another way of enhancing participation and access to information is to invite the next of kin together with patients to educational programmes [11]. However, all interventions to improve access to information along the cancer trajectory for both next of kin and patients will have the best impact if it is part of a comprehensive national care programme comprising both the care in hospital and the outpatient care.

In conclusion, the results in our study clearly emphasize the next of kin's needs of being more actively included in the patients' cancer trajectory in order to manage their new role of being a

support during the initial period at home. Participation in the information and the patient's discharge planning are crucial in order to help patients regain control after colorectal cancer surgery.

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