Symptoms and distress among patients with colorectal cancer: - the next of kin experiences

Ekholm K¹, Grönberg C¹, Börjeson S², Berterö C².

¹Department of Oncology, Linköping University Hospital, SE-581 85 Linköping, Sweden
²Department of Medical and Health Sciences, Division of Nursing Science, Faculty of Health Sciences, Linköping University, SE-581 85 Linköping, Sweden

Corresponding Author;

Carina Berterö, RNT, BSc, MScN, PhD, Professor
Department of Medical and Health Sciences
Division of Nursing Science
Faculty of Health Sciences
SE-581 85 Linköping
SWEDEN
Tel +46 10 1037768
Fax +46 13 123285
e-mail: carina.bertero@liu.se
Abstract

**Purpose.** To identify symptoms/distress among patients with colorectal cancer, from the viewpoint of the next of kin, before and after chemotherapy, and to establish whether there are any barriers to reporting these.

**Methods.** Individual face-to-face interviews with fourteen next of kin were conducted. Qualitative content analysis was used to analyze the transcripts.

**Results.** Three areas were identified: symptoms presented, influences on life for the next of kin, and barriers to reporting symptoms/distress. Nine symptoms were raised as most common by the next of kin. All next of kin talked to a large extent about how the patient’s disease and treatment affected them. It affected them psychologically, they had to revaluate their life, and it influenced their social life. Almost all next of kin denied that they experienced any barriers to reporting symptoms/distress though they mentioned the lack of proper communication and lack of time.

**Conclusions.** Although it was not the main purpose of the study, the next of kin raised concerns about the patient’s disease and treatment and how it influenced their life. They mentioned barriers to reporting symptoms, but not to a large extent. The symptoms reported before and during chemotherapy were similar to those found in other studies.

**Keywords:** Colorectal cancer, next of kin, influences on life, symptoms, barriers, qualitative content analysis
Introduction
Cancer affects the whole family, not only the patient. People living close to patients with cancer report having psychological disorders in the same way as the patients do (1, 2, 3). The next of kin is seen by the patient as the person closest to him/her; a family member or a friend. Living with a person with cancer means a changed life situation for the next of kin and leads to changed routines and roles in the family (1, 3, 4, 5). Sometimes patients change due to their disease, which can lead to conflicts. It can be hard to accept that the patient is tired and does not have the same strength. The next of kin has to deal with their own new role in the relationship (5). Next of kin experience that it is important that life continues as normally as possible, and describe friends and other people around them as important to maintaining normality (3, 4, 5). It has been described that the next of kin and the patient revaluate their life together and prioritize things in life differently to before the diagnosis (4, 5).

In this study, the focus is on colorectal cancer (CRC), the third most common type of cancer in the world (6, 7). CRC is more common in industrial countries such as the USA, Europe, Australia and New Zealand (8). More than 70% of the patients with CRC are over 65 years old (6, 9). Early stage CRC does not often present symptoms or gives non-specific symptoms such as changed bowel habits and abdominal discomfort. Specific symptoms for CRC appear later during the disease and can include, for example, changed toilet routines, abdominal pain, nausea, vomiting and bleeding when visiting the toilet (6).

The primary treatment for CRC is surgery. Adjuvant chemotherapy for CRC in stages II and III is given in the form of FU/LV in different combinations with additional chemotherapy (oxaliplatin, irinotecan and capecitabine) and/or target agents (cetuximab, panitumumab and bevacizumab). Patients in stage IV disease with hepatic or pulmonary metastases are recommended to undergo surgery of the metastases if they are expected to be completely removed, and chemotherapy before and/or after (7, 10, 11). Side effects of chemotherapy vary depending on the agents used: myelosuppression, nausea, diarrhoea, neurotoxicity and hand-foot syndrome have been reported (12, 13). The worst and most distressing side effect of chemotherapy for patients with CRC is fatigue (13, 14, 15).

For patients with CRC, both the disease and the treatment cause troublesome symptoms and side effects (16). To the best of our knowledge there are no studies that, from the next of kin’s point of view, focus on the patient’s symptoms and side effects of chemotherapy. In addition, no studies have been found whose focus is on possible barriers to reporting symptoms. The aim of this study was, from the next of kin’s point of view, to identify symptoms/distress before and after chemotherapy, and establish whether there were any barriers to reporting these.

Methods
Setting and sample
A qualitative research design was chosen in order to understand how symptoms/distress among patients with CRC are experienced by the next of kin and if they describe barriers to reporting these symptoms/distress (17). Individual face-to-face interviews were conducted. The study was a part of a larger study carried out at two hospitals in southern Sweden. The participants were next of kin to CRC patients. The inclusion criteria for the study were (a) being older than 18 years of age, (b) being identified as a next of kin by a patient receiving FOLFOX, Xeloda or XELOX chemotherapy for CRC, and (c) being willing to share experiences with us. Purposive sampling was used in order to recruit the most informative participants (17). Patients were identified by the responsible physician together with the process leader of the study. Every fourth next of kin to the patients involved in the study was asked to participate, and the inclusion continued for one year. At the time of data collection all patients had received a similar volume intensity of chemotherapy; for patients who were treated with a 2-week treatment course with
XELOX or Xeloda the interviews with next of kin were conducted after the second chemotherapy session, and for patients who received treatment with the FOLFOX, 2-day treatment, the interviews were after the third chemotherapy session. The study was approved by the regional Ethical Review Board in Linköping, and the next of kin and the patient gave their written consent before entering the study.

Data Collection
Data were collected using qualitative interviews. The interviews were conducted at a place chosen by the next of kin, some in their home, and some at a consultation room at the hospital. An interview guide was used consisting of two domains. Every interview started with an open question in which the next of kin were asked to describe the patient’s disease and symptoms and mention if there were any barriers to reporting symptoms. The interview continued with further questions to make things clearer (18). Two interviewers carried out all interviews. Each interview took about 60 minutes, was audio-taped, and then transcribed verbatim. Fourteen next of kin were interviewed. The participants were wives (8), husbands (5) and one son, aged between 25-70 years.

Data analysis
Qualitative content analysis was used to analyze the transcripts (17, 19). This was a continuous process of carefully and thoroughly reading and re-reading the transcripts, being vigilant for variations in data and searching for patterns. After attentive reading and due to the research question, three areas emerged. For the first area, directed content analysis was used. Segments of text were sorted according to symptoms, which became the categories. For the other two areas, conventional content analysis with interpretation was used. The analysis started with coding, in which patterns and segments of text that captured key concepts were identified. One interview after another and one area at a time were analyzed this way. The coding were made by the two first authors independently and then further analysis and discussions ensued until agreement was reached. The codes were sorted into categories based on their content and meaning. The name of the categories were developed from interpretation of the data. In order to increase the trustworthiness of the findings the analysis was subjected to peer debriefing and was continuously scrutinized by two additional researchers who gave their viewpoint, and discussions were held during the process (19).

Results
The analysis identified three areas: symptoms presented, influences on life for the next of kin, and barriers to reporting symptoms/distress.

Symptoms presented
Nine symptoms were mentioned by the next of kin as being the most common among patients with CRC before and after chemotherapy. These symptoms were clearly expressed and described, and were as follows;

Fatigue
Fatigue was frequently mentioned both before (9/14) and after chemotherapy (11/14). The patients were more tired than usual. They could not manage doing things they used to and sometimes had a hard time getting up from bed. After chemotherapy almost all were or looked tired. Fatigue was described as not having the power to do things in the same way as before. Some said that the grade of the patient’s fatigue was prominent; from hardly being able to go to the toilet some days, to falling asleep while watching TV. This tiredness seemed to influence the patient’s ability to concentrate and affected their mood.

Intestinal disorders
This was the most common symptom before chemotherapy (11/14). Symptoms reported were stomach pain, stomach spasms, a swollen feeling in the stomach, constipation problems and blood in the faeces, which the patient thought was due to haemorrhoids. During chemotherapy, intestinal disorders were still a problem for some (6/14), constipation and diarrhoea were the most common symptoms mentioned even though problems with sudden stabbing pains in the stomach and swelling of the stomach could appear.

**Nausea**
Half of the next of kin (7/14) reported that the patients had problems with nausea after chemotherapy, only one reported this before chemotherapy. The nausea varied from being mild to severe with vomiting, and increased with every treatment. Some (5/14) reported that the patient had problems with taste changes after chemotherapy. The food did not taste like it used to and it changed from one day to another.

**Uneasiness**
Before starting chemotherapy some (5/14) mentioned that the patient was changed somehow. After surgery the patients were more labile and sensitive to touch. During chemotherapy many (9/14) thought the patient had some sort of psychological effect. They described patients as being nervous, worried, irritated, crying more easily, being depressed, having a hard time relaxing and talking with close relatives, having a fluctuating temper, and not being themselves. The anxiety interrupted the patients sleep, especially before going to the hospital for a new cycle of chemotherapy.

**Hand-foot-syndrome**
Pricking sensations in hands and feet that came almost directly after chemotherapy were frequently reported (8/14). The patients had problems holding cold things in their hands and had to wear gloves when fetching things from the refrigerator. A general sensitivity to cold things was mentioned, as well as dry and fissured hands.

**Pain**
Pain before chemotherapy was mentioned by a few (4/14). The pain was felt in the back and over the kidneys. Pain on one side of the throat down to the shoulder was also mentioned. Only one patient had pain in the stomach after chemotherapy.

**Body changes**
Few next of kin mentioned that the patient lost some weight before (3/14) and after chemotherapy (2/14). Some noticed large loss of muscles and condition in the patient, darker and coarser hair, alopecia and spots on the face of the patient after being outdoors during chemotherapy.

**Mouth problems**
Problems with the mouth after chemotherapy were reported by few (4/14). Difficulties eating cold food and drink and an irritated feeling in the mucous membranes in the mouth were mentioned. These were worse three-four days after chemotherapy.

**Allergic reaction**
Few (2/14) said that the patients had fever and an allergic reaction, with nettle rash and a swollen face and tongue in connection with chemotherapy. Because of these problems, the patient had to end chemotherapy treatment. Allergic reactions many days after chemotherapy had been given were also reported.

**Influences on life for the next of kin**
Although the next of kin were asked about the patient’s symptoms/distress and if there were any barriers to reporting these, all the next of kin talked very much about how the patient’s disease and treatment had affected them. This area has five components.

**Psychological influence and burden**

Almost all the next of kin (13/14) were concerned about the patient. They said it was tough, they were worried and sad. They were concerned about whether the patient would survive. Even though they tried not to think about it all the time, suddenly the thoughts were there again. “You think about it all the time.../...it’s never gone from my thoughts” (Lkpg 28). There were feelings of fear; they were scared and thought that something bad would happen with the patient. They mentioned that patients could be reluctant to take their drugs, a situation described as more demanding for the next of kin than for the patient. A changed daily life with new routines and instructions concerning the treatment were reported. The next of kin had many speculations, feelings and thoughts about the patient’s disease. They felt frustrated when they could not get the chance to talk with the doctor alone.

**Re-evaluation of life and relationship**

Half of the next of kin (7/14) said the disease had changed their lives and that the situation caused insecurity. Their lives changed in that they got closer to the patient and they prioritized other things in life “it reminds you that you will not have each other forever.... and you take care of time in another way than before...” (Lkpg 10). They focused on living as good life as possible, and their families and relatives became more important. They seized their days differently, and did not take anything for granted. Some described their lives as circling around the treatment. Few (2/14) mentioned that their sexual life had altered; their sexual activity had stopped due to the absence of desire and there was no energy for sexual activities “I don’t know, but there is no desire” (Lkpg 13).

**Influence on social life**

Almost half of the next of kin (6/14) mentioned that the disease had influenced their social life. They felt a bit unsociable, not seeing friends as much as before because the patient felt tired. The next of kin described how they held themselves back in life. They described taking into account the chemotherapy treatment before planning a vacation; “We’ll have to take it between the treatments, if he copes with it” (Jkpg 22).

**Acceptance**

A few next of kin (4/14) talked about how they had resigned with the situation. They felt they did not have a choice and accepted that the patient sometimes had a varied temperament due to the disease and treatment, “You see, one tries to change it a bit to accept the situation” (Jkpg 19). Frustration over the situation changed into acceptance.

**Not prioritizing themselves**

The feeling of not being able to leave the house and go for a walk as they used to do was reported by some (4/14). They felt that they had to be home, checking on the patient. Changed sleeping routines were also mentioned.

**Barriers to reporting symptoms/distress**

Almost all next of kin denied that they had experienced barriers to reporting symptoms/distress. Despite this they mentioned lack of properly communication, situations when they felt the hospital staff did not have enough time, and troublesome tasks.
Lack of properly communication and individual information

Many (9/14) expressed lack of information, which made them feel unsure and frustrated. They described situations when they were uncertain how to act and when they were unsure whether the patient’s symptoms were caused by chemotherapy or not. They felt they did not have correct and concrete answers to all their questions, “I felt that I actually didn’t get any answer; they just said that one have to expect that one is feeling sick for a couple of days” (Jkpg 16). They were unsure whether the doctor or the nurse should answer their questions, and instead, they searched for information on the Internet. A feeling of being forgotten and not knowing where to phone for support were expressed. Due to these feelings, several expectations and self-made explanations for the patient’s symptoms appeared. Fatigue was explained as natural, caused by high age rather than caused by the disease or chemotherapy, and the side effects of chemotherapy were expected to be worse than they were “You had almost expected worse problems, you hear so much from others that they got sick and everything” (Lkpg 4).

Lack of time

Few (4/14) said that they did not raise all their concerns with the nurse or the doctor because they thought the hospital staff had so much to do. Chemotherapy treatment was experienced as an assembly line; “but these kinds of questions maybe need a longer answer...and the question is if she has enough time when there are so many patients to treat” (Lkpg 7). The feeling of being a troublemaker and wasting the hospital staff’s time was expressed, and so only the most important questions were asked.

Troublesome tasks

Things that were hard to talk about were mentioned by a few of the next of kin (4/14). One thing they brought up was that the patient was afraid of going to the hospital, “He is very afraid or..., has been previously anyhow, before every visit to the hospital” (Jkpg 10). Reduced sexual desire, loss of sexual activity and psychological changes were also mentioned as hard to talk about.

Discussion

The aim of this study was to identify symptoms/distress, among patients with CRC, before and after chemotherapy, from the next of kin’s point of view, and to establish whether there were any barriers to reporting these. However, our main finding was that the patients’ disease influenced the next of kin to a great extent.

We found fatigue, nausea, intestinal disorders and hand-foot syndrome as the most common symptoms reported. This is confirmed by other studies (11, 12, 13, 14, 15, 20, 21). However, we found that nausea worsened with every treatment, whereas other studies, in contradiction, have found that nausea decreases after every treatment (14, 15). The next of kin mentioned that the patients were psychologically changed. This confirms previous findings showing that patients may experience fear, be depressed, suffer from anxiety and change in their normal roles (21, 22).

Next of kin frequently reported that the patient’s disease and treatment affected them in many ways. Almost all expressed this as a psychological burden; they mentioned a changed daily life, new routines and changed roles. Similar results are found in other studies (4, 5, 23). They described a constant anxiety about the patient, and studies have shown that the next of kin report more emotional distress than the patients do (24). Also, health care use by next of kin to patients with CRC increases as well as diagnoses of psychiatric problems (25), and in general they have an increase in sick leave (3). This psychological burden makes next of kin more vulnerable and actually sick. In our study, the next of kin said that their attitude towards life had changed and they felt closer to their sick partner. They did not take the patient for granted, and their families and close friends had become more important. At the same time, we found that they felt unsociable. Other studies show that the disease changes their way of looking at life, and they
reevaluate what is important (1, 4). A feeling of isolation is described in another study (4). Some resigned with the situation. This is difficult for the next of kin who are supposed to be the healthy and strong ones. Studies show that next of kin keep their feelings and anxiety to themselves; they do not want to worry the patient (4, 5). This means that the next of kin do not make taking care of themselves a priority and thus are likely to get sick. It is of the highest importance that next of kin receive support in this demanding situation.

Next of kin denied that they experience any barriers to reporting symptoms, but our analyses showed situations where they said that they did not know what to report and/or did not report everything to the nursing staff. Lack of properly communication and individual information were mentioned. Next of kin are not satisfied with information given, and it is a difference in the information wanted by the patient and by the next of kin (23). The patient and the next of kin do not necessarily need the same questions to be answered (26). Information on non-medical topics such as the impact of cancer on relationships is more likely to be lacking than medically-oriented information (27). In our study, the next of kin said that they chose to report only a few selected symptoms that they thought were the most important. Somehow they got the feeling that the hospital staff were short of time, and therefore some questions were not asked.

We chose to analyze our transcripts with direct and conventional content analysis (19). When direct content analysis is used there is a risk that the researcher will find evidence that supports the theory, which can blind the researcher. We tried to avoid that by analyzing the transcripts first on our own (KE, CG) and then together. With conventional analysis there is a challenge to develop a complete understanding of the context and to find the key categories. By reading the transcripts many times, performing the analyses one by one, and then coming to consensus through discussion we have minimized this. Two additional researchers reviewed the analyses to increase the trustworthiness.

The next of kin are important for the patient (4), and a cancer diagnosis influences the whole family (24). It is therefore of the highest priority for healthcare providers to pay attention to the next of kin, giving them opportunities to talk in private about their feelings and thoughts concerning the disease and treatment. We need to improve and individualize the information we provide to the next of kin. In order to achieve this, a care navigator following the patient and the next of kin through the cancer trajectory would be a good support. Further research is necessary in order to investigate the needs of the next of kin.

Conclusions
In this study, the next of kin were asked to identify symptoms/distress among patients with CRC receiving chemotherapy, and barriers to reporting these, but mostly they discussed how the patient’s disease and treatment had psychologically affected them. It was a psychological burden that influenced their life in many ways. The symptoms reported agree on the whole with other studies made. The next of kin mentioned barriers to reporting symptoms, but not to a large extent.

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Conflict of interest

There is no financial relationship to FORSS who supported us with funding. As authors do we have full control of all primary data and agree the journal to review this data if requested.

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