



# BMJ Open Learning-by-doing: the importance of experiential knowledge sharing for meeting the information needs of people with colorectal cancer in Germany – a qualitative study

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## ABSTRACT

**Objective** The aim of this article is to understand how, when and why the topics of information and information needs arise when people diagnosed with colorectal cancer (CRC) narrate their illness experiences.

**Methods** Guided by principles of grounded theory, a qualitative interview study was conducted that collected a wide variety of illness experiences with CRC in Germany using maximum variation sampling. Sampling criteria included place of residence, age at interview, age at diagnosis, treatment, disease course and sociodemographic factors such as varying family backgrounds and professions.

**Setting and participants** Men and women diagnosed with CRC in different parts of Germany were sought via physicians, social workers and psychologists in hospital settings, organisations offering psychosocial support for patients with cancer, self-help groups, rehabilitation centres, newspapers and personal contacts. The interviewees in the final sample (n=41) had been diagnosed with CRC between 4 weeks and 36 years prior to the interview.

**Results** Three inter-related categories of information needs emerged from the analysis: the need for non-medical information for daily life; the challenge of integrating the bodily changes that accompany CRC in everyday life; and sources of non-medical information concerning handling daily life. Learning to live with the bodily changes of CRC in everyday life was described as a long process of learning-by-doing. While sources for medical information were clear, finding practical information was often a challenge. The best source of such information was often seen to be other people living with the disease, who shared their experiential knowledge, as well as stoma and nutritional therapists.

**Conclusion** Information needs are part of the process and struggle to normalise everyday life after a disruptive diagnosis and treatment. Providing access to practical knowledge and information from others with CRC experience may be an important resource for patient support.

## Strengths and limitations of this study

- An advisory board consisting of practitioners, self-help group members and individual patients with colorectal cancer (CRC) was involved in the sampling strategy and initial analysis.
- Maximum variation sampling considered variations in age, time since diagnosis, disease severity, familial/living situation and geographical regions in Germany, to ensure a wide range of experiences.
- Narrative interviewing techniques captured the everyday challenges and needs of people affected by CRC.
- The use of grounded theory principles allowed us to understand information needs in the context of individual illness experiences.
- The interviewees' assessments of their information needs could have been strongly affected by their current situation, as well as by the availability of information at the time of their diagnosis (which in our sample ranged from 4 weeks to 36 years prior to the interview).

## INTRODUCTION

Colorectal cancer (CRC) is the second most common cancer in Germany for men and women.<sup>1</sup> CRC is mostly treated through surgery (colectomy), often followed by chemotherapy or radiation therapy, depending on the tumour stage.<sup>2</sup> Due to advances in treatments and earlier diagnosis, survival rates are increasing.<sup>1</sup> In Germany, the age-standardised mortality rates have declined for both sexes over the last 10 years.<sup>3</sup> Data from 2015 to 2016 suggest that the relative 5-year survival rates for CRC are approximately 63% for women and 62% for men.<sup>4</sup> CRC is used as an umbrella term for a range of cancers, which may have quite different effects

and long-term consequences. For example, patients with rectal carcinoma often receive a permanent stoma (colostomy) if the sphincter muscle has to be removed. Patients with a colon or rectum carcinoma might receive a temporary stoma. If parts of the large intestine are removed, an ileostomy, which is attached directly to the small intestine, might be required. New challenges may arise if a stoma is reversed, as it can take some time for the bowel to work normally again.<sup>5</sup> Overall, studies investigating the effects of the disease on patients have mostly dealt with the physical changes, such as bowel function, nutrition and living with a stoma, and health-related quality of life.<sup>2 6–17</sup>

Receiving information about how to deal with the long-term effects of CRC is essential for patients to regain control over their lives following treatment.<sup>6 18–21</sup> Their information needs have been found to be particularly high immediately after and in the first weeks following discharge from hospital.<sup>18 19 22 23</sup> Lashbrook *et al*<sup>24</sup> analysed coping strategies among patients with CRC, breast and prostate cancer and found that patients with CRC explicitly highlighted seeking information in the survivorship phase to handle self-management and the return to social activities. The authors speculated that this might be due to the particular physical changes caused by CRC, especially following a colostomy, which requires more self-management than other cancer types.<sup>24</sup> Other findings suggest that information about the long-term management of CRC in particular seems to be lacking<sup>13 22 25</sup>; this includes information regarding problems with handling changes in bowel movements,<sup>2 26</sup> diet and nutrition and stoma care.<sup>13</sup> In the USA, it has been reported that information and support needs are not being met by healthcare providers because of decreasing contact in the follow-up phase.<sup>27 28</sup> In other studies, CRC survivors emphasised receiving ‘conflicting or confusing information’ regarding how to manage the disease in everyday life,<sup>23 26</sup> or they had doubts about the quality of the information received.<sup>26</sup> While it is recognised that information is crucially important for patients with CRC, and a wealth of information is now available, information needs nevertheless persist.<sup>29</sup> In general, treatment, rehabilitation, coping and interpersonal/social issues seem to present the most important information needs.<sup>30</sup>

Ormandy<sup>31</sup> contend that the term ‘information needs’ in health research and policy is often used but seldom defined. Such an intuitive understanding, they argue, risks being driven by a medical and research perspective regarding what patients ought to know, and not by what patients themselves think they need or want to know. Based on concepts derived from information sciences, Ormandy define information needs as the ‘recognition that your knowledge is inadequate to satisfy a goal that you have, within the context/situation that you find yourself at a specific point in the time’.<sup>31</sup> Such a definition considers not only the

content of the information need, but also why information is needed. As information needs are closely related to an envisioned aim or goal, the required information should be specific, so that the intended aim can be reached. The authors broadly conceptualise the context and situation in which information needs arise as being dependent on: the individual’s personal traits; psychological dimensions of the individual such as coping, stress and self-efficacy; the individual’s social position and illness/disease trajectory; the particular healthcare situation in which the need arises; as well as the time and timing of the need. Context is thus understood to include the individual and their environment,<sup>31</sup> and the authors thereby acknowledge the multilayered dimensions that influence information needs if defined from the individual patient’s perspective, rather than from a professional perspective.

Health information provides more than mere information; it helps patients manage emotions, such as the fear of cancer, to improve their health-related quality of life, and may help individuals feel reassured about their chosen treatment avenue.<sup>32–35</sup> Health information, information needs and coping with cancer may be entangled in multiple ways. The aim of this article is to understand how, when and why information and information needs arise for men and women diagnosed with CRC, through an analysis of their narratives of their illness experiences. In particular, we analysed the types of information that interviewees talked about, and the challenges they faced in receiving the needed information.

## METHODS

Guided by a research approach that is inspired by the principles of grounded theory such as simultaneous data collection and analysis, memo writing, analytic coding and category development,<sup>36–38</sup> a qualitative interview study was conducted to capture people’s experiences with CRC. The authors SA and GL-H collected in-person interviews between 2012 and 2015 throughout Germany. The narrative, guided interviews allowed interviewees to elaborate on their experiences with CRC. Both interviewers were women. The interviewers and involved researchers all have long-term experience in qualitative research. The interviews captured a wide range of illness experiences, which helped to develop a CRC module for the website [www.krankheitserfahrungen.de](http://www.krankheitserfahrungen.de),<sup>39</sup> which is part of the international research network Database of Individual Patient Experiences (DIPEX).

Interviewees included in the analysis presented here gave informed consent for the use of their interviews for research.

## Study sample

We used maximum variation sampling—with regards to place of residence, age at interview, age at diagnosis,

time since diagnosis, treatment, course of disease and sociodemographic factors (such as family background and profession)—to gather our study sample.<sup>40</sup> Interviewees were found through various avenues, including physicians, social workers and psychologists in hospital settings, organisations that offer psychosocial support to patients with cancer, self-help groups, rehabilitation centres, newspapers and personal contacts. After the first 10 interviews had been analysed, SA organised a meeting with the advisory board—which consisted of practitioners, self-help group members and individual patients with CRC—to discuss the initial findings, in order to establish the remaining sampling strategy to ensure that all important aspects of the experience of CRC were captured. Sampling continued until interview partners provided no additional information regarding CRC experiences.

### Data collection

The structured interviews all began with the same open-ended question, with the aim of starting a narration: ‘Maybe you can start by talking about how your life was when you first became aware of the signs of CRC and how it went from there. Take your time and talk about how one thing led to another’. After this initial narrative sequence, follow-up questions were asked to ensure that all relevant aspects were captured. The interview guideline for the follow-up questions was developed based on a literature review and the covered topics, such as time of diagnosis, treatment, receiving information, information needs before and after treatment, information seeking, influence of the stoma (if applicable), experiences of consultations, experiences with healthcare institutions, decision-making processes, living with cancer and experiences with self-help groups (see online supplemental file). SA and GL-H conducted the interviews in a location of the interviewees’ choice, mostly in their homes. SA sent transcripts to the interviewees for approval. Interviewers wrote an interview protocol<sup>41</sup> after each interview to record in a standardised manner the setting of the interview, including the place of the interview and the emotional atmosphere, and the interviewer’s first impressions regarding the interviewee’s illness experiences.

### Data analysis

Interviews were transcribed verbatim. Interview data, coding and memos were managed using MAXQDA. We first identified all relevant text passages in the interview transcripts through a lexical search of the word ‘information’ in MAXQDA. In addition, MK read all of the interviews to ensure that text passages that talked about information, but did not use the term, were also included in the analysis. Passages not captured by the lexical search were usually characterised by a substitution of the word information for other terms like ‘thing’.

Our analysis strategy used aspects of grounded theory, particularly in terms of line-by-line coding, the writing of memos, and synthesising the codes into conceptual categories in order to analyse all identified text passages per interview.<sup>38</sup> To develop the initial codes and memos, we began by posing the following questions to the identified text passages: What is being talked about? And what type of situation is this? This analysis was conducted primarily by MK in collaboration with CH. After each interview, MK wrote a condensed memo, sorting the codes in relation to one another. In order to develop theoretical ideas regarding the topic of information across all interviews, these condensed memos were compared constantly with the findings of the next analysed interview. Throughout this process, all thoughts and ideas that arose from the coding process and the detailed reading of the complete interview transcripts were documented in memos and discussed with CH. Several memos were established for each interview transcript and for each code throughout the analytical process.

Based on this analysis, MK summarised the findings regarding the occurrence of the topic of information in the interviews: what was discussed, when, how and why? With each interview analysis, MK expanded the findings, integrating new aspects into her initial ideas and preliminary categories and noting similarities and differences. MK and CH held regular data meetings to check the appropriateness of the analysis and the findings. After coding of the first 15 interviews was completed, the inter-related categories were established and remained stable throughout the analysis of the remaining 24 interviews.

To cross-check the findings, particularly to investigate different aspects of context that may influence discussions about information, MK conducted additional comparative analyses between those with and those without a stoma, regarding stoma type, years since diagnosis (less than 5 years, 5–10 years and more than 10 years prior to interview), and whether treatment was received in a certified CRC centre. In addition, MK participated in a monthly meeting with a qualitative research group at the Institute of Public Health – Charité-Universitätsmedizin, where she regularly discussed her analysis steps, memos, categories and findings, to ensure the grounding of the results in the data.

### Patient and public involvement

This interview study involved an advisory board throughout the data collection process. This board consisted of practitioners such as medical doctors, social workers and psycho-oncologists, as well as representatives from self-help groups and individual patients with CRC. The advisory board was involved in the design of the sampling strategy and in the identification of appropriate interviewees. The board members were also presented with the initial findings.

**Table 1** Interviewee characteristics (n=41)

Gender	
Women	21
Men	20
Age at diagnosis: range (years)	25–78
Age category (years)	
20–39	2
40–49	5
50–59	9
60–65	9
>65	16
Years since diagnosis: range	
<5 years	20
5–10 years	12
>10 years	9
Active in self-help group/activities	
Yes	23
No	17
Working status at diagnosis	
Working	12
Retired	29
Recurrence/metastasis	17
Type of treatment(s) received	
Surgery	40
Chemotherapy	29
Radiation	19
No treatment (yet)	1
Stoma	
Ileostomy	13
Colostomy	11
Stoma reversal	7*

\*Of the 24 interviewees who had a stoma.

## RESULTS

### Sample description

To present a broad range of experiences with CRC, SA and GL-H interviewed a total of 43 men and women. Of this total, 42 gave consent for the interview materials to be used for research. For the purpose of this study, we excluded one additional participant, because the interviewee had a genetic predisposition but not a cancer diagnosis at the time of interview. The presented analysis is thus based on 41 interviews (table 1).

### Discussing information

Despite the wide range in time since diagnosis, the results of the analyses in the subgroups were similar in terms of when, why and how the topic of information and information needs arose in their narratives. We therefore present the results jointly for all interviewees.

Interviewees distinguished between two different types of information, both in terms of what they needed and what types of information they received: medical information regarding the disease and its treatment; and information concerning handling the disease in everyday life. Interviewees were generally satisfied with the medical information they received over the course of the treatment phase, either verbally from physicians or in written form. They also regarded the sources of such medical information to be clear. However, information concerning the practical aspects of living with CRC was more difficult to find. Such practical information concerned how to handle the daily challenges of the disease, especially when experiencing bodily changes that influence day-to-day activities. Interviewees looked for ways to manage these changes in order to minimise their impact on their everyday lives. Learning how to live with these challenging bodily changes and to integrate them into their everyday activities was described as a long process of learning-by-doing, involving much trial and error, and for which there is no one-size-fits-all solution. Gathering relevant practical information is difficult, and sources other than medical organisations or physicians are required. Most interviewees sought out other patients with CRC, in person or online, as sources of such information.

In the following, we will describe the study findings in more detail with regard to how, when and why information needs arose in the context of patients' illness narratives, what types of information they looked for, and what was difficult to find. We present the findings according to three inter-related categories that emerged from the analysis: *the need for non-medical information for daily life*; *the challenge of integrating the bodily changes that accompany CRC in everyday life*; and *sources of non-medical information on how to handle daily life*. Relevant quotations are shown in table 2.

### The need for non-medical information for daily life

Information needs and a lack of information were rarely discussed in relation to the treatment phase. Interviewees generally had a positive feeling about the relationship with their physicians and mostly talked positively about the information they received from different physicians during consultations. Such information was often described as fulfilling their basic needs for medical knowledge concerning therapy and treatment. Information needs did arise, however, when patients started to return to their everyday lives. Interviewees were concerned about the influence of the disease on their daily life after their discharge from hospital. They described feeling unprepared once at home, without a clear picture of what to expect. They used words such as 'real', 'trustworthy' and 'lived' information to describe the type of information they were looking for and needed in order to handle life with CRC after hospital discharge.

**Table 2** Discussing information needs: three inter-related categories and relevant quotations

Inter-related categories	Quotations
The need for non-medical information for daily life	<p><b>What information was talked about:</b></p> <p><i>And he [the doctor] explained everything very well. So he meticulously told me more than I wanted to know, yes – <b>but about what comes after, not really, he couldn't really.</b> That's why it's so annoying. Why can they not make a program out of it, offering people who are affected, if they want that? <b>So that I can talk to them, ask how they coped with the procedure and with the consequences.</b> (Male, 50–65 age range at time of interview)</i></p> <p><i>Physicians don't have that much time and talking to a doctor isn't the same as talking to someone else with CRC. This is much more emotional, or... not sure how to say this, but it is just much more trustworthy than the theoretical knowledge of a physician. (Male, 65–80 age range at time of interview)</i></p> <p><b>How information was sought:</b></p> <p><i>So I went to the bookstore and looked, or I watched when there was a program on TV, where I could read up or also on the internet, but it wasn't really that much. So I only had the books that my daughter gave me or that I bought myself. <b>And I also possessed one, two books that never interested me and I never read.</b> [...] What was not for me and that did not fit, I ignored. (Female, 50–65 age range at time of interview)</i></p> <p><i>Monday I was discharged, and Tuesday I took my computer and was searching for a group for my [stoma] bag, because I had questions, I needed help, I needed support. [...]. (Female, 35–50 age range at time of interview)</i></p>
The challenge of integrating the bodily changes that accompany CRC in everyday life	<p><i>And when it [the stoma] gets wet, then it gets tight. Then no gas can escape. The bag gets bigger. And pressure can build up in it. Then the whole thing is leaking at the pass ring. And then it starts again with the irritation of the skin. Ileostomy care is a craft, you have to learn it. <b>Learning-by-doing in this case.</b> (Male, 65–80 age range at time of interview)</i></p> <p><i>We stopped taking bus trips. We drive with our car, since you can go to a restroom at a gas station as needed. And there you can also change your clothes on the way, if something happens. Well, I'm fine with that. And I've learned to tighten my pelvic floor muscles through pelvic floor exercises, so that at least the bowel movements no longer constantly run away on their own. (Male, 65–80 age range at time of interview)</i></p>
Sources of non-medical information on how to handle daily life	<p><b>Stoma and nutritional therapists:</b></p> <p><i>This with the stoma nurse, with Nurse XG [name of the stoma nurse], [...] I really bought into her competence, she really knows her stuff. And I still have contact with her today, she still advises me. (Female, 50–65 age range at time of interview)</i></p> <p><i>And it's also quite common in hospitals today that there is always an extra nurse on the ward who is a trained stoma therapist, and who then shows you how the whole care goes and who explains everything. And fortunately for me that was also really great.[...] Because I could not imagine at first, or at the time in the hospital I still could not imagine what it would be like. (Male, 20–35 age range at time of interview)</i></p> <p><b>Others who have experienced CRC:</b></p> <p><i>And certain topics you can only discuss with other cancer patients. And I have to say that this gave me a lot and I still benefit a lot now here at home from my conversations with other patients. (Female, 50–65 age range at time of interview)</i></p> <p><i>That's easy – you just talk differently. Since the other person [fellow CRC patient] knows what I'm talking about when I say, "Oh, I have a skin irritation" or "What do you know, the plate is not holding". And you simply get tips or information. You just talk differently, and the other person knows what you are talking about. (Female, 35–50 age range at time of interview)</i></p> <p><i>And that, of course, you talk about things that you do not talk about with the non-patient. Especially about the stoma and bag and feelings in and around the belly – it's clear. And then she [fellow CRC patient] told me how it all is. How to attach a stoma [bag], how to clean it, what can happen and how to empty bags and – disasters, truly. (Male, 50–65 age range at time of interview)</i></p> <p><b>Self-help groups as an organised form of information for CRC patients</b></p> <p><i>Then at the hospital, someone visited me from the self-help group. That was a young woman, and then – I then specifically asked about restrictions and the like, and then she actually said: "Well, so with a colostomy everything is actually possible, if you want it". [...] So this visit gave me a lot back then [...], all my fears that I would have to continue my life completely, well, as a half-cripple, those fears actually went away [...]. (Male, 65–80 age range at time of interview)</i></p> <p><i>And at that time, this hospital pastor told me a sentence that today also explains why I'm so intensively involved in self-help. He told me that blind people cannot explain colours. (Female, 50–65 age range at time of interview)</i></p> <p><i>I've found that handling the bag, that's not the problem. People learn that. But most people fall into a deep hole. They believe that you can no longer go around normally. Can't do anything anymore. [...]. When I come and tell them [about myself], I come on my bike, they see that. (Male, 80+ age range at time of interview)</i></p> <p><i>Well, it's a pity [about the self-help group demographics], because I would've also liked to meet directly with people of my age who are affected. [...] Because our whole everyday life looks different [...]. (Male, 20–35 age range at time of interview)</i></p>

CRC, colorectal cancer.

Non-medical information included the influence of bodily changes on sports and leisure activities and on one's sex life, as well as dealing with partner reactions, controlling bowel movements with and without

a stoma, handling a stoma in general, and a leaking stoma. Such information covered practical issues like what types of clothes to wear with a stoma, nutritional information, and the influence of a stoma on one's

job situation or when travelling by public transport or long distances in general. While particular themes were linked to the age of the interviewee, the stage and type of the disease, and the treatment pursued, including stoma versus no stoma, all interviewees had concerns about returning to daily life and felt unprepared, though unsurprisingly interviewees with a stoma mentioned practical information needs more often than those without. This practical information was seldom part of what a physician told a patient, interviewees explained, because the influence and challenges of the disease are so unique and variable. Interviewees found little adequate information on such aspects, both in terms of what was given to them in writing or verbally during consultations. They explained that the provided information seemed inapplicable to their specific situation and that there is no one-size-fits-all solution to a problem when handling the disease in everyday life.

### **The challenge of integrating bodily changes that accompany CRC in everyday life**

Handling the disease in daily life was often described as a process of learning-by-doing through trial and error. This was expressed both by interviewees who had had a stoma at some point in their disease trajectory and patients without a stoma, though the daily challenges described differed depending on whether the interviewees had had a colostomy, an ileostomy, a stoma with a chance of stoma reversal, or no stoma. Nutrition and handling the stoma were the most important themes.

Interviewees who had had a colostomy spoke of learning how to perform a colonic irrigation (inserting water into the colon through the stoma), as a way of controlling the timing of bowel movements. Interviewees contended, however, that achieving this level of control required years of experience in performing the colonic irrigation, as well as knowing what to eat. Similarly, handling stoma bags and finding suitable bags sometimes took several years. Interviewees without a stoma often talked about problems with incontinence or uncontrollable bowel movements. For them, it was important to understand how nutrition influenced their bowel movements and to find ways to live well with these bodily changes.

The two younger interviewees in our sample (less than 39 years at the time of interview) voiced particular information needs concerning work life, the influence of treatments on fertility, as well as questions related to their sex life.

Finally, the interviewees' non-medical information needs concerned overall coping strategies. For example, for some it was important to realise that a person could lead a 'normal' life and that the disease is not visible from the outside (even with a stoma). Some had known others with CRS and/or a stoma in the past associated with negative experiences including experiences such as a bad smell, blubbering sounds or constant travel to the loo.

To counter these former experiences and come to terms with their disease, they sought out information.

### **Sources of non-medical information on how to handle daily life**

The interviewees discussed information and information needs in connection to the process of adjusting to the new reality of their daily life after the diagnosis and treatment phases. The source of relevant information in this process was seen to be other people living with the disease, often described as 'role models', as well as stoma therapists and nutritionists.

#### **Stoma and nutritional therapists**

Stoma and nutritional therapists were considered the only medical personnel who were credible sources of information on daily life and coping, as they were familiar with the daily life problems faced by patients with CRC and could give valuable advice personalised to specific problems. Having a constant contact person in the form of a stoma therapist—prior to surgery, while in hospital, and later on at home again—from whom they received information on how to handle the stoma was highly valued by the interviewees.

#### **Others who have experienced CRC**

The fear of cancer recurrence and lasting effects was a common theme in the interviews. When facing these fears, the narratives of others with similar illness experiences gave interviewees a feeling of security and reassurance. Comparisons to other patients with CRC who served as role models or positive examples were made, and this motivated the interviewees to find ways to cope with the illness.

Many of the interviewees also looked to other patients with CRC to gather information on dealing with the everyday challenges of the disease. Some described feeling more empathy when talking to patients 'who have gone through it' already, and whom they described as being likeminded and on the same level, in comparison to talking to a physician. Looking to others with CRC was also done when interviewees sought information on how other people handle certain challenges, such as conducting a colonic irrigation at work, either to confirm or improve on their own approach; or they sought others to reassure themselves that a certain condition is a normal side-effect of CRC.

When searching for other patients with CRC, interviewees described looking for those who had experienced a positive disease trajectory and who had similar characteristics to themselves, for example same age, job or job position, disease trajectory, with or without a stoma, or similar long-term effects. In some cases, other patients with CRC were avoided, particularly after the treatment phase, because interviewees wanted to avoid talking about the disease. This was connected to a feeling of already having more than enough information, or because they felt too different from other patients with CRC.

### Self-help groups as an organised source of information

Some interviewees stressed the importance of receiving a visit from a member of ILCO, the main German self-help association for CRC, at their hospital bed, as this person could provide all the non-medical information they needed. Furthermore, seeing someone who also has CRC, who does not look sick but rather appears normal, was important for them to gain hope and motivation before starting their own treatment. Based on their own positive experiences with members of ILCO during their active treatment phase, some interviewees later became active themselves and led self-help groups or conducted hospital visits. They too stressed the difference between medical information and the practical information needed for handling the disease in daily life. For the two younger interviewees in our sample, self-help groups turned out to be less useful, as the themes discussed were not so relevant to them due to the age difference between them and the majority of the other members. They rather looked for others their age online.

## DISCUSSION AND CONCLUSION

### Discussion

The interviewees in our sample were generally satisfied with the amount and content of the medical and treatment-related information they had received, but they described a need for and a lack of information after the active treatment phase had been completed. This concurs with studies of other cancer types, which find that the period of transition after treatment is often a time of insecurity<sup>42–44</sup>: life is supposed to return to normal, yet normal life is different to what it had been before diagnosis. This ‘new normal’, as it has been described elsewhere, is characterised by the need to adjust to living with the bodily changes of the disease.<sup>44 45</sup> Among the interviewees in this study, unmet information needs arose when the acute phase was over and they wanted to return to a normal life, but they were facing significant and lasting effects on the body and its functioning as a result of CRC and its treatment. To reach this goal of normality, interviewees needed to learn how to effectively handle these effects; effects that also changed over time, and necessitated continual adjustment. This process is thus an ongoing one, a path of learning-by-doing characterised by trial and error.

The information that interviewees required in this process of returning to normal life covered aspects of handling the consequences of the disease and its treatment in everyday life; this mostly concerned nutritional changes, handling the stoma, bowel movements and sexual issues. In this stage, seeing others living with the disease and handling the bodily changes associated with CRC in everyday life, particularly problems with bowel movements and stoma use, helped to inform the strategies that the interviewees worked with to be able to go about their daily activities without being recognised as patients with CRC. The experiences of others gave the interviewees courage and motivation, helped them to cope with their new situation, and showed them that there

are other people affected by CRC who are getting on with their lives.

In a metaethnography on illness experiences with CRC, Hildebrandt *et al* describe the illness experiences as an iterative process of balancing, mastering and normalising. Throughout the illness trajectory, patients experience disruptions and challenges that they need to master, so that they can integrate the changes into their everyday lives.<sup>46</sup> Hildebrandt *et al* suggest that people diagnosed with CRC experience various transitions that require emotional, social and physical adaptations. In this process, they continually have to adapt to the new normal. We would suggest that it is this ongoing process of adapting to the new normal that is reflected in the information needs referred to by the interviewees in our sample. This was also mirrored in another survey study on CRC from the Netherlands, in which information needs were found to be highest after treatment, and concerned challenges such as future expectations, nutrition and physical activity.<sup>47</sup> Different from our study, however, den Bakker *et al* found the highest information needs of patients with CRC not only in the phase following treatment, but also in the adjuvant phase.<sup>48</sup>

The goal of normalising one’s life after a CRC diagnosis stood behind the information needs voiced in our study sample. Our study reveals how adjusting to the changes brought about by CRC and its treatment is an ongoing and very individual process of trial-and-error, meaning that there is no one-size-fits-all solution to information provision. For the interviewees learning to adapt to the new normal and how to deal with potentially challenging situations associated with bowel functions or a stoma, information was sought through the media and non-medical sources. In particular, interviewees sought out other people with CRC who had similar experiences with the disease, and who had succeeded in managing their everyday lives and activities to establish a new normal.<sup>49</sup> Fellow patients were not only a source of information, but their experiences also served as a coping strategy to help patients evaluate their own situation, in all phases of the disease trajectory. If talking to others with the disease and gathering information from them can be interpreted as a necessary part of the emotional management required for handling CRC and its potentially bleak outcomes,<sup>50</sup> then it is unsurprising that others with similar (perhaps negative) experiences were sometimes purposefully avoided and stories of hopeful outcomes we sought out.<sup>51</sup>

### Strength and limitations

Based on a sample of interviewees that spanned all age groups and geographical regions in Germany, we have shown the importance of understanding the information concerns of patients with CRC in individual context. However, our sampling strategy of maximum variation also meant that the range of time since diagnosis was very broad. Some of the information that some interviewees missed, especially regarding the everyday challenges of CRC—such as nutritional information and handling bowel movements or a stoma—may have been due to the time when they received their diagnosis and the organisation of healthcare delivery



at that time. Certification of specialised CRC centres in Germany began in 2006. Rehabilitation for CRC involves physiotherapy, patient education, relaxation training, functional training, psycho-oncological treatment, group sessions, nutrition counselling, occupational counselling, stoma care education and social services. Counselling by a stoma therapist and nutrition expert is mandatory.<sup>52</sup> Since CRC centres are more common in Germany today than 10–15 years ago, it may be that patients with CRC today will receive more information and thus have more knowledge on handling everyday challenges following discharge than their predecessors. At the same time, hospitals have had a social care unit that helped to organise rehabilitation and aftercare when necessary long before cancer centres were established. Rehabilitation, either immediately after treatment or later, is part of the social security system and lasts for around 3 weeks. Again the rehabilitation system in place has a long history in German healthcare delivery. Beyond the medical sphere, there is also ILCO, the national umbrella organisation for self-help groups for CRC across Germany, which was established in 1972. One of ILCO's key activities involves coordinating its members to make hospital visits to patients with CRC. In general, the German healthcare system is characterised by a well-established system of social and rehabilitation care, with statutory health insurance covering approximately 90% of all patients in Germany. This may well be a reason why narratives on information did not differ conceptually according to the time of diagnosis.

Similarly, all of the interviewees discussed facing the issue of how best to integrate the experienced bodily changes due to CRC into their everyday lives, as well as how to handle and manage the disease and its appearance in front of others. The information needs related to these common issues all refer to normalising life after the disease. They arise during a phase of transition, and contact with others with similar experiences may be an important source of coping strategies, as much as of practical information. The illness trajectories of patients with CRC in Germany have remained relatively stable over time, thus while it is true that changes in the medical and self-help infrastructure and information provision over the past decades has made it easier for patients with CRC to find the information they need, their information needs nevertheless remain crucial due to their individual nature. Using a research approach inspired by grounded theory to analyse the topic of information as it was discussed by interviewees enabled us to understand the importance of the specialised experiential knowledge of patients in managing the effects of CRC in everyday life. This may also help us to understand why some information needs are so difficult to address effectively.

To find interviewees for this study, we used the networks of many different medical and non-medical venues, including self-help groups. The very favourable attitude towards talking to others affected by CRC may partly be explained by this. Furthermore, while only a third of our interviewees were found through self-help groups, about half had experiences with such groups. This may nevertheless be seen as representative of the active engagement of self-help groups in Germany. Our strategy to find interviewees was

thorough; we aimed to gather a diverse sample, including those who were not seeking to share their experiences. The diversity of the sample helped us to understand the vulnerable phases in relation to (unmet) information needs that persist over time, and that are related to transition phases and living with the disease. The analysis method allowed us to understand information beyond medical aspects or the solely physical aspects of dealing with the disease, to capture the everyday challenges and needs of those affected by CRC.

## Conclusion

In this study, we found that people diagnosed with CRC discussed no unmet needs regarding medical information on the disease and its treatment. What they did require, however, and what was often seen as missing or harder to find, was practical information concerning living with the challenges of the disease. Using Ormandy's definition of information needs,<sup>31</sup> which emphasises what patients themselves think they need or want to know, we show that such needs arise for patients with CRC in the context of transitions; in particular, when patients are aiming to normalise their life again after a disruptive diagnosis and its long-term bodily consequences. Such practical information, which can only be acquired through lived experience, may be understood as experiential knowledge—which is supplementary to, and different from, medical knowledge—and this needs to be understood and valued in its own right.<sup>53</sup>

## Practical implications

Our study findings suggest the importance for patients with CRC of access to practical information from fellow (or former) patients. Thus far, most discussions about patient information provision have focused on the possible inclusion of stories or narratives that illustrate medical information. However, if we understand that patients' experiential knowledge may be important for other patients in terms of helping them to live with a chronic condition long term, then we have to think of ways to present such knowledge. This knowledge can be acquired through qualitative study designs, as Pols<sup>53</sup> suggests. The DIPEX international network may be a good venue for such information delivery, though more research is needed to find the most appropriate and efficient means of doing so.

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