

ORIGINAL RESEARCH

Learning from the collective story: Information needs of people with colorectal cancer

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Abstract

Background: Our inter-professional research team believes that providing useful, relevant, and timely information for people diagnosed with cancer is a key component of ethical and quality care. This paper fills a gap in the literature on the information needs of people affected by colorectal cancer by presenting the voices of people affected.

Methodology and methods: Finding no comprehensive research that fully identifies the information needs of people with colorectal cancer from their perspective, we designed a research project using the methodology narrative. Using three sources of data – stories found in the literature analysed using the method scoping review, researcher experience, and first hand accounts – we present a narrative of the *what*, *when*, and *how* of information needs of people with colorectal cancer.

Findings: This re-storying can be represented by four very broad themes: i) finding my way in the moment(s), ii) understanding treatment, iii) ways to live, and iv) post treatment information needs. It also considers how people want/need information at various points along the care trajectory.

Summary: This narrative begins and ends with the assertion that every person is unique and, to follow the principles of patient-centred care, healthcare providers must determine how each person's information needs can best be met, thereby improving people's experience not only of receiving care, but of living with cancer.

Key words

Colorectal cancer, Information needs, Supportive care, Narrative

1 Introduction

Many healthcare professionals working in cancer care strive not only to provide excellent medical care, but also to improve the experience of people receiving care. Known to benefit people's experience is the provision of appropriate and timely information, which requires an understanding of those information needs^[1]. Our inter-professional research team, consisting of healthcare providers in the disciplines of nursing, pharmacy, dietetics, social work, library science, and radiation therapy as well as academic health researchers, has focused our energies on understanding the information needs of people diagnosed with colorectal cancer. In our previous research, including a detailed scoping review, we discovered that literature discussing the information needs of people affected by colorectal cancer rarely did so from the perspective of

these people. This paper reports on our unique study using the methodology of narrative that serves to fill this gap in the literature. It presents a re-storying of people's voices found in three sources of data: i) literature, ii) feedback from people affected by colorectal cancer and clinicians who work with them, and iii) researchers' experience.

The structure of the paper is as follows. We present the methods we used to collect our three sources of data. We describe the methodology of narrative that pulls together the perspective of people with colorectal cancer from these data. Included in this section is an outline of the methods of our scoping review that provided the literature. An analysis of this collective material produced what we are calling a narrative of the information needs of people diagnosed with colorectal cancer. Our goal is to better understand people's information needs and generate a narrative to inform the practice of healthcare providers in a position to meet those needs, thereby improving people's experience not only of receiving care, but of living with cancer.

2 Research methodology and methods

This project of presenting a narrative follows up on our previous scoping study^[2, 3] to answer the question: What are the information needs of people with colorectal cancers? During that study, our analysis prompted us to do a follow-up search of that literature looking specifically for the voices of people with colorectal cancer to better answer our research question. Of the original 239 articles collected in our scoping study, only 64 met this next level of inclusion criteria. We analysed this literature as one of our data sources using the method outlined by Popay *et al.*^[4]. It is our methodological triangulation of three data sources and their analysis, however, that produces a reliable narrative presented in this paper. Methodological triangulation, according to Maggs-Rapport^[5, p219], "may be the key to telling a credible story whilst at the same time convincing the audience that data collection and analysis are carried out in a thorough and unprejudiced manner". We believe this study has enabled us to move closer to better understanding the information needed and/or wanted by people with colorectal cancer as we consider optimal approaches to providing better informational support as part of quality care.

2.1 Narrative

We borrowed methodological features of narrative inquiry, which has a long standing history in education scholarship but has increasingly been taken up in other disciplines such as psychology, sociology, theology, critical theory, and anthropology. Narrative inquiry does not remove the voice of the researcher as it focuses on the voice of participants. Rather, as researchers, we engaged in a process called connected knowing^[6], in which the knower is personally attached to the known. Researchers insert themselves into the other's story as a way of coming to know this story and giving voice to the other^[7]. Narrative inquiry is a collaboration between the participants (we consider people we met in person and those whose voices appeared in the literature as participants) and the researcher, whose stories are given authority.

Early theorizing of narratives attend not so much to the narrative itself but to the knowledge it generated about the substance 'behind' it^[8]. However, Somers^[9, p606], argues that through narrative, we also "come to know, understand, and makes sense of the social world." Cancer care is dominated by a medical model yet we know that people's experience is largely lived outside the medical sphere in the social world. According to Hyden^[8], "patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice." Narrative can capture central features of people's illness experiences, social contexts, and daily life.

Our study did not rely solely on personal encounters with participants. Within narrative inquiry, there is an acknowledgment that data may come from different sources^[7]. We began by analysing the literature. While this process produced a synthesis of the narratives therein, these narratives were unidimensional. The experiences of our research team introduced another dimension; each of us has heard many people with cancer tell their story. Missing still, however, were the actual voices of the authors of those stories. It was during a day-long consultation workshop with people that we gained an understanding of the richness of their experience. In other words, people at this workshop breathed life into the stories found in the literature and relayed by research team members. Hence, we have three sources of stories of people with

colorectal cancer: the literature, participants at the workshop, and experiences and recollections of the clinicians and researchers on our research team. Thus, rather than drawing a comparison between these data, the narrative we present here is a re-storying of collective experience.

2.2 Literature search

This paper originated with our analysis of the literature collected in an earlier scoping review ^[2]. For that review, we searched Ovid MEDLINE, Pubmed, Embase, CINAHL, PsycINFO, Cochrane and Google Scholar. In addition, we looked for clinical trials, practice guidelines, meeting abstracts and dissertations and searched other sources of “grey” literature. We conducted a hand-search of key journals and scanned the reference lists from relevant articles to identify other papers that may not have been found in the initial search. We also searched the Social Science Citation Index for articles that may have cited some of the key articles we retrieved.

Our original search was broad in order to be as comprehensive as possible. We used search terms such as: patient education, patient information, patient satisfaction, patient preference, patient participation, patient perception, consumer health information, consumer satisfaction, information seeking, access to information, communication, attitude to health, awareness, decision making, self-care, uncertainty, nutritional support, social support, self-help groups, counselling, patient discharge, after care, and continuity of patient care. We also included terms such as physician-patient relations, attitude of health personnel, nurse’s role, pharmacists, nutritionists, caregivers, spouses, family, and friends in order to capture articles about the information provided by health professionals or needed by the families and caregivers of patients. In addition, we included terms that captured the sources of information patients might use, such as information services, information dissemination, information centres, pamphlets, handouts, audiovisual aids, teaching materials, internet, hotlines, and computer-assisted instruction. The original search was limited to articles published in English between January 1994 and April 2010. For this project, we updated the search to include literature published from May 2010 to September 2011.

2.3 Inclusion/exclusion criteria

Included in our scoping review were studies that mentioned in any way the information needs of people who have or have had a diagnosis of colorectal cancer, their families and caregivers, or the information sources used by them. Studies about screening and prevention were excluded. Studies about genetics were excluded, unless they were about the information needed by or provided to people who have/had colorectal cancer. We also excluded studies that included other types of cancer in addition to colorectal cancer but did not discuss the needs of colorectal cancer patients separately from the other cancer patients. Studies about risk, mortality, epidemiology, drugs, cancer incidence, nutritional status, diet therapies, wait times, colitis, Irritable Bowel Syndrome, Crohn’s Disease, Familial Adenomatous Polyposis, diverticulitis, inflammatory bowel, or the information or educational needs of health professionals were also not included. Descriptions of treatments, book reviews, policy analyses, case histories, and test validations were excluded. Implementing these inclusion/exclusion criteria produced 239 articles in our original search and 57 additional articles in our updated search. For this project we applied a second level of inclusion/exclusion criteria and included only studies in which patients had been consulted for their views. From our original scoping review, 64 articles met these criteria, and 28 additional articles from our updated search were included ^[11-102].

2.4 Literature data collection and extraction

We were very intentional in our reading of the literature with a sole interest to “hear” the voices of people who have/had a diagnosis of colorectal cancer. Each article was read with a focus on what people had to say about information needs. Are there lessons to be learned or a context in which we can understand the *what*, *when*, and *how* about providing information? Data collected included: *Background Information* (citation, study design, characteristics of population, aim/goal of paper, disciplinary perspectives and expertise of the researchers); *Findings* (what types of information people say they need/want, timing of receiving information as indicated by people, format and source of information); and *Additional information*

(anything noteworthy about the paper that was relevant to our study but that was not captured in the previous sections). We grouped and clustered similar concepts and performed a thematic analysis of the data.

2.5 Consultation

Given our primary interest was the voice of people diagnosed with colorectal cancer, it was imperative that we seek the input of people to solicit their feedback, which became another source of data. We accomplished this task at a day-long workshop to which we invited people affected by colorectal cancer and clinicians who worked with them from around our western Canadian province. We invited colleagues from other cancer treatment centres in our province to participate and to suggest patients who might be interested in participating. Their participation was dependent on their availability and, for those out of town, ability to travel. Of those we invited, fifty-three people participated in the workshop: 16 with a history of colorectal cancer with ages from mid 20s to mid 70s, six family members, 21 clinicians, and 10 members of the research team. Discussions, first in pairs followed by small groups, were framed by questions we posed to elicit experiences of receiving information. The groups then presented important points of their dialogues to the larger group, which in turn discussed key points and agreed upon a set of recommendations about how we might better meet the needs of people with colorectal cancer. We often heard sentiments such as: “if I had known then what I know now.” We wanted to capture what they *know now* and share it with people earlier in their cancer care experience.

2.6 Experience of research team members

The many experiences our research team members brought to our discussions were the final source of data collected throughout the data collection and analysis processes. These stories, from clinical or previous research experience, remain the impetus for this research focus.

2.7 Data analysis

An initial analysis of the literature produced some suggested themes that the team agreed both reflected their sense of the literature and could be presented to participants at the workshop. Group discussions at the workshop were recorded and analysed to determine if the themes found in the literature adequately reflected messages in the discussions. We added to our description of the themes and created new themes as necessary based on analysis of these discussions. We went back to the literature and conducted a more thorough analysis using the revised and agreed upon themes. Researcher experience and reflections on patients’ stories were also analysed using these themes. As a result, our analysis was an iterative process and the re-storying is told from the collective stories found in all three data sources.

3 Findings and discussion: Exploring relationships in the stories

3.1 Setting the context of analysis

“ ‘Oh yes, I always like to know everything, good or bad, whatever and then I can make an informed decision.’ ”^[30, p679]

“ ‘They were trying to give me information....I said, just do it, you know, before I change my mind....you can tell me all about it after.... I was too bloody frightened, I didn’t want to know.’ ”^[92, p33]

Our analysis is not meant to draw comparisons between the data sources but to illustrate a collective story. Presentation of our analysis needs to be prefaced by our assertion that people with colorectal cancer are not a homogeneous group, as the preceding quotes indicate. There is no one unitary or universal person with this diagnosis; not everyone shares the same point of view. There is no one story. Rather,

(S)ituational factors play a decisive role in the construction of narratives and ... we continually produce new narratives in new contexts. Thus, it seems all the more evident that it is not a question of the narrative, but rather of different possible narratives which are determined by situational factors, particularly by the interaction between narrator and listener ^[8, p52].

This heterogeneity poses a challenge. However, when “patient-centred care” appears as a principle of care, as is stated by many within the centre in which our research team is located, it behooves us to strategise how to meet the needs of individuals and not assume that one size fits all. As was revealed in our analysis, many people desire to have information tailored to their unique situation. “We want tailored information versus standardised information; we wanted to be treated as unique.” (workshop) Furthermore, inherent in narrative inquiry is interpretation ^[7]. Our goal is not to make generalisable statements but to become cognisant of the various narratives of which those interested in attending to the information needs of people with colorectal cancer need to be aware. Thus, we hope readers will not assume generalisability or homogeneity in the following analysis. Referencing the literature is straightforward and we do that below. However, referencing people’s voiced experience and stories is more challenging; it is implied throughout our analysis as presented below, even if not explicitly referenced. Because the workshop component of this project came under quality assurance at our organization, we were exempt from requiring ethics approval. Thus, the quotes noted to be from the workshop included in this paper are not attributed to any one person.

Our interest was in the *what*, *when*, and *how* of information needs of people with colorectal cancer *from their perspective*. These elements are not linear; but intersect at various points. While on paper, we may present each in isolation, in practice, we must be aware of the multidimensional and complex nature of serving the information needs of people with cancer. Asking people new to a situation as complex and, arguably, as scary as a cancer diagnosis what they need to know is tricky. “You don’t know what you don’t know until you know it.” (workshop) Assuming people with a cancer diagnosis will know what information to ask for seems unreasonable; how can they know now what they will need to know tomorrow? They rarely know what is going to happen, how they will feel, what to expect, and, therefore, what to ask: such is a common experience of people affected by cancer.

3.2 The what

The story of people with colorectal cancer as it relates to what information they need and/or want can be represented by four very broad themes that emerge: i) finding my way in the moment(s), ii) understanding treatment, iii) ways to live, and iv) post treatment.

3.2.1 Finding my way in the moment(s)

I knew at that state that I would need information. Immediately practical things you think about like, ‘will we be able to go on the holiday we’ve booked’, um, to ‘how much work time will I need off work’. Health questions like, (the) first thing I wanted to know, really, about cancer, ‘what’s the prognosis?’ Well you really want to know ‘am I going to die’ ^[93, p44].

Receiving a diagnosis of cancer launches people into a whole new world. People undertaking the work of negotiating their new reality and the system at every step of the way state there is a plethora of information they need to know and understand in order to make decisions and manage their life. It includes information that is both general and specific about cancer such as: the disease process and the nature of their illness ^[32, 47]; the meaning of test results ^[80]; what to expect in terms of treatment as they contemplate future decisions including risks and benefits; possible/expected outcomes ^[31, 32, 42, 47, 67, 68, 72, 75, 82]; complications and recovery times ^[67]; adjusting to caring for a stoma ^[31, 74, 78, 80] alternative treatments ^[75, 82]; survival rates ^[32, 36], and options regarding timing of decision making ^[42]. The information needed at any one moment is often linked to the decisions people need to make in the next moment.

No matter where they are on their cancer care trajectory, people value having information on whom to contact^[21, 25, 68, 77] when arranging tests, supports, and other requirements^[33]; where to find help^[25, 68]; or, if necessary, an advocate. People spoke passionately about wishing they had someone they could contact outside of scheduled appointments, pointing to a gap in much of cancer care. Information about key contacts is needed throughout people's experience.

3.2.2 Understanding treatment

The majority of people with colorectal cancer have some kind of treatment: surgery, chemotherapy, and/or radiation as well as medication to deal with (side) effects. We problematise the notion of "side effects," proposing that they are effects that have significant impact, more than is insinuated when referred to as "side" effects. For assistance in making decisions about treatment, many want information about options^[12, 68, 81, 82] and what is involved in each treatment including how it works (for example, will it lead to a cure? stop the spread of disease?) and how it relates to their diagnosis^[12, 17, 19, 20, 24-27, 33, 44, 50, 54, 60, 64, 65, 67, 72, 74, 82]. Many also want to understand potential side effects of treatment to help them prepare^[19, 24, 26, 33, 38, 43, 44, 48, 50, 54, 60, 67, 68, 74, 77, 85], risks involved, for example impotence^[74, 83], and alternatives they might consider^[26, 42, 60]. People are rarely passive recipients of treatment; many want to learn about recent news on cancer research and treatments as well as clinical trials^[26, 81]. Getting treatment is such a significant part of having cancer and people are pretty clear they need relevant information as they make decisions, organise their lives around treatments, and manage effects.

Finally, a feature of cancer that is infrequently discussed: finances. Being sick can be expensive if people need to take time off work and/or pay for medications. "People are unaware of how much of a financial strain it can be; we need to be told about the costs." (workshop)

3.2.3 Ways to live

While receiving a diagnosis of cancer interrupts the normalcy of life, people look for ways to adjust to this interruption. Valued, although often contradictory, is information on diet and nutrition both during treatment and in recovery^[11, 12, 22, 23, 26, 29, 38, 40, 43, 66, 68, 77, 81, 92]. To manage much of life's dailiness, people want information on how to resume exercise and activity^[40, 43, 44, 87, 89], ways to relax^[67], work/employment/financial issues^[12, 17, 24, 33, 40, 43, 93], as well as issues relating to sexuality and intimate relationships^[12, 34, 43, 46, 78], on-going psychosocial and emotional issues^[12, 26, 33, 43, 60, 67, 68], changes in family relationships^[12, 24, 43] and bowel function including bloating, diarrhea, wind/gas, difficulty emptying bowels, and stoma care and supplies^[44, 66, 67, 78].

Many people seek information that implicitly speaks to their sense of self, identity, and spirituality. Such information will help them manage fears such as cancer spreading^[95, 96], not being able to do the things they used to do, ongoing fatigue^[68, 95, 96], reduced sexual function^[15, 16], and pain^[11, 29]. People want to understand how realistic their fears are and how worried they should be. Even when treatment has been deemed by clinicians as successful, these fears often continue. People told us that it is the daily features of life that are so often complicated by cancer and treatment and they crave information on how to manage and carry on.

3.2.4 Post-treatment

"We felt like our lifeline was disconnected." (workshop) The end of treatment often signals the end of a regular connection with the cancer centre and by default, support. This transition to a "new normal" is challenging and fraught with anxiety. People tell us they *wish they had known* information that would have helped them cope during this time. Some of this information is specific to particular treatments^[21, 27, 70, 86, 87]. "Nobody told me that I was going to put on weight, or have bowel irregularities. I also did not know that I had to learn about foods I could and could not eat. I had to educate myself. My [PCP] was not very helpful about informing me about what is normal."^[17, p103] Many often want to know what long term physical, psychosocial, and social effects^[17, 21, 24, 27, 42, 68, 80, 86, 87] or changes in sexuality^[76], or other bodily (particularly bowel and stoma) functions^[29, 40, 67, 74, 78, 80] to expect after treatment. Along with an interest in normal physiological and psychological changes^[63, 102], people often want realistic information on recovery^[29, 40, 74, 76, 77], and on recognising symptoms of recurrence^[17, 31, 43, 68, 71]. Information on approaches to lifestyle issues after treatment such as

diet^[17, 62, 72, 77, 80], exercise^[89], and returning to work and other activities^[17, 24, 27, 87] are often missed when treatment is the focus. And finally, many people want a summary of tests and treatment received^[17], information on follow-up^[24] and support services, contact people for future concerns, and details about monitoring^[17, 42, 43, 51]. The research on post-treatment (often called survivorship) has resulted in the distribution of care plans in many jurisdictions that, when detailed enough, will provide some of this needed information. The UK is taking this concept further by creating care plans near the beginning of treatment and updating throughout^[103]. “You need to have these things written down for you. When you attend your appointments, you are in a kind of state of shock and you do not remember what has been told to you. ...it would have been very useful to have received this document.”^[17, p102]

3.3 The when

Attending to the information needs of people with colorectal cancer is complex; it is not a linear process. There are many points along the trajectory of people’s cancer experience during which people (may) want/need information: diagnosis, before surgery, leaving hospital post surgery, various periods post surgery, deciding on treatment, before treatment, during treatment, end of treatment, and post-treatment. In keeping with our earlier argument that there is not one universal person with colorectal cancer, we propose that not everyone will experience each of these points, want/need the same information, or want/need it at the same time. The people with whom we consulted were adamant about this issue. The point of diagnosis is a good example of a time when people’s needs/wants vary considerably. Some people want as much detailed information as possible about everything that may be relevant to them. Others are overwhelmed and need to absorb the diagnosis before learning more^[102]. The challenge for healthcare (thus information) providers is to learn how to recognise in each person what is most appropriate – and when.

At the time people receive a diagnosis, many want to know their chances of survival^[17, 36] and/or details of their diagnosis in writing so they can refer back to it^[17]. As they need to make treatment decisions, people want information about their options, including alternative treatments^[75]. This is a time when people have many questions about the decisions facing them^[24]. Regardless of the treatment, they want to know what to expect, potential effects, and how to prepare^[77]. This desire, however, is not universal. “Some described how the shock at being diagnosed with cancer prevented them from asking questions. For example, one patient commented: P- ‘I felt like my mind became blocked. I couldn’t have asked questions, lots of things I would have liked to have asked, later on, but at the spur of the moment, I couldn’t think of anything.’”^[92, p30]

If having surgery, most people want to know what will be done during surgery and what they can expect afterwards^[27] – particularly the likelihood of an ostomy – and the effects of surgery and/or other treatment on aspects of life such as sex^[27, 31, 34, 44, 46, 54, 66, 67, 75, 76, 78, 84]. Many want this information before surgery – and maybe again after surgery^[23, 80]. Discovering that their ability to be sexually intimate was impaired after surgery came as an unwelcomed shock to many. Clinicians need sensitive approaches to determine how much information people want. According to Thurston^[92, p32], “Some stated that they were keen to be given as much information as possible, feeling that this made the process of treatment easier for them. In contrast, other respondents described fear as preventing them from seeking explanations, in particular demonstrating reluctance to listen.”

An argument is made by many, particularly workshop participants, that immediately after surgery, when people are feeling the effects of the anaesthetic, is not a good time to tell them anything^[66, 100]. “(W)hen the doctors came, they did talk over you. And of course, you’re not feeling well, you’re not in a position to ask ‘what exactly is going on?’”^[100, p317]

The need for information is not over when treatment is complete. People articulate feeling lost as they discontinue treatment^[104] and lose ready access to care providers of whom they can ask questions. They often feel unprepared to handle the issues facing them, including unexpected experiences that include physiological, psychological, and social changes^[29, 40, 63, 68, 80, 102]. Receiving this information before treatment ends offers a sense of security: people know what they might expect and options on how to manage. High on the list of issues is bowel function and adjusting to bowel

changes^[29, 40, 63, 66, 102], diet, nutrition^[38, 72, 77, 80, 92], stoma care^[21, 24, 67, 74, 78, 80], and sexuality^[76, 78]. The fear of recurrence is one many people with cancer carry for a long time; information on recognising signs of recurrence^[29, 31, 40, 63, 68, 71, 102] is linked to information on recovery^[74, 76, 77] and can put people at ease. Feelings of being cast adrift^[104] may be alleviated by knowing there are planned follow-up tests and appointments with healthcare providers as well as a contact number^[41, 51, 53].

3.4 The how

To reiterate, the *what*, *when*, and *how* of providing information cannot be considered in isolation from one other. This argument is most evident when looking at *how* information is best given to people; the *how* is pivotal in that it feeds into the *what* and the *when* and, perhaps most importantly, is often overlooked. As with the other two spheres we have addressed, there is no one way to look at *how*.

Each person has a preferred way of learning information: a one-size-fits-all approach does not work. This overarching message of having information personalised so the content and method of delivery are appropriate to each person's unique situation^[34, 46] was loud and clear from the people we consulted and is concomitant with person-centred care. People appreciate clinicians skilled in recognising how much information to provide each person and in what way. Vision and hearing challenges need to be considered. Cultural sensitivity is also an important consideration when providing information. Similarly, people usually want information continuously over time, not just once^[19, 51, 92, 102]. "Reiterate information more than once. We need continuous learning." (workshop) Tools such as care plans inform people what the steps may be along the way: "I wanted to know the next step at the beginning of the journey, to know how long I should expect to wait. Care plans give the patient and family a little of the control." (workshop)

People have varying views on how information could be given. Overwhelmingly, they want a personal face-to-face encounter with someone they can understand^[19, 20, 27, 66, 97, 98] and trust^[11, 29, 41, 51-53, 66, 71, 75, 77, 80, 82, 84, 97, 98, 102]. Telephone encounters can also be a way to connect, particularly for follow-up information^[22, 43]. Increasingly, email is a way to seek and receive information, particularly when clinicians are difficult to reach on the phone or see in person. Healthcare professionals (nurses, oncologists, family physicians, dietician and to a lesser extent physical therapists and complementary and alternative medicine practitioners) were often the primary source of information^[66, 67, 70, 88]. Many view their cancer specialist as their main source of information and see family physicians as a support to fill in the gap of questions not answered by the oncology team^[80]. On the other hand, nurses are experienced as important sources of information^[27, 35, 44, 62, 70, 91] and able to make sense of what physicians had said^[19]. Many people valued opportunities with nurses such as during "chemo teach" (patient education sessions) to receive information.

My interaction with all the doctors has been positive, but additional training in supplying information to patients is needed. Some terms are on a high level, and because this is a change in a person's life, an explanation about what has happened, how it has happened and what will happen must be made in common terms. Also, once a form of treatment is recommended, details of what happens to the body, side effects and physical and mental changes should be explained. Of course, patient involvement in reading and talking to other patients and doctors is important, but most of this information should be provided by the doctors^[55, p11].

A recurring theme was the desire to have clinicians communicate with each other about their respective plans and provide consistent information^[11, 29, 51-53, 66, 97, 102] and to feel their care was coordinated^[12, 13, 33, 43, 67, 68]. Similarly, and as noted above, many people would like to (and infrequently have) contact someone of whom they can ask questions both during and following treatment^[21, 25, 43, 68, 72, 77]. While clinicians are the preferred people to provide information, peers (others who have a similar diagnosis)^[11, 40, 48, 54, 66, 94, 98, 99, 102] also may be useful sources of information. People are often reassured by someone who has "been there." Some – but not all – find "survivor" stories helpful^[59]; but some stories may be "scary". Others really only trust information that came from a healthcare provider; talking to peers in chat rooms on line was seen as potentially problematic. Librarians, navigators, and lifestyle counsellors can provide emotional and/or practical support^[33, 102] as can community organisations such as cancer societies^[97].

Many people expressed a desire to have more time with their physicians so they can ask questions^[48] and understand their rationale for treatment recommendations^[82]. There were many suggestions to clinicians for approaches to communicating information: unhurried – take time^[59]; be clear, straight forward, understandable, direct, realistic, informative, honest, attentive, thorough, give the facts^[27, 43, 53, 59, 97] with empathy, and do not use euphemisms^[100]. People typically do not want to be talked down to, have knowledge “dumbed down” (workshop), feel patronised, or be talked over as if they are not there^[100].

I felt my physicians showed great customer service and bedside manners. They took their time and explained to me what was going on, and they drew diagrams to further assist me in understanding. They also provided me with names of survivors to contact for encouragement and a list of books to read. By touching my shoulder and legs when I laid in bed, they helped me to relate to them as human and not larger than life^[55, p11].

According to McCahill^[59], how a healthcare provider describes someone’s situation and choices for treatment will influence their experience of treatment. The surroundings play an important role: a relaxed friendly atmosphere encourages people to ask questions or discuss issues^[51]. Many state the importance of having a friend or family member at meetings^[97, 100] to take notes and help remember all the information that is provided or record meetings with clinicians; “you need two sets of ears.” (workshop) Additionally, people acknowledge their family is going through this with them and need information as well for themselves. “Their role is not as clearly defined as the patients’.” (workshop)

Beyond receiving information through personal encounters, people appreciate that written information such as booklets and pamphlets^[17, 19-22, 26, 27, 29, 30, 42, 44, 51, 52, 66, 86, 97] help to trigger information given verbally and allow the opportunity to go over the information and make decisions. “Chemotherapy did make me really tired and less productive at work, particularly after the first few sessions. The leaflet helped me realise this was normal.”^[14, p6] This information, too, needs to be accessible, easily understood, comprehensive, and clearly structured^[21, 32, 53, 86]. Some people see the value in diagrams in written materials^[21, 59] to understand anatomy. Similarly, videos are seen as useful as long as they are realistic.

‘Don’t pay attention to other people or even ... well, in my case the Internet was kind of, I don’t know if you can call it false information, but it certainly didn’t help my husband.’ [...] ‘Well, you know the things that could have gone wrong during the surgery, which, you know, I didn’t go into it with my eyes closed. I researched everything on the Internet to find out how often ... I went through WebMD for a lot of it and just read what the risks of surgeries would be.’^[59, p71]

Searching the Internet is on the increase^[48, 59, 66, 81, 97], with many people accessing it for information to assist them in making decisions^[30, 52]. But as the quote suggests, information found there is not consistently useful. Because not everything on the Internet is trustworthy, complete, or relevant, some express caution^[59, 94]. People want to know about reliable sites. Furthermore, because the Internet is not used by everyone^[81], clinicians cannot assume people will have access to it.

In any form of information communication, the use of statistics in both written and verbal formats is up for debate: some want to hear them while others do not.

4 Summary

We have endeavoured to present a collective story about the information needs of people with colorectal cancer by drawing on data from several sources. It is clear that the possible narratives of people with colorectal cancer are many. By highlighting that there is no one way to think about providing information, we have presented a challenge to clinicians. We aspire to an inclusive concept of care that is more than attending solely to people’s medical needs. Just as each person’s treatment is unique to their situation, so, too, are their needs for information.

According to Worster and Holmes,

It cannot be assumed that individuals understand what they are told; communication does not always equate with understanding. Though appropriate information helps patients to make informed decisions about their care and enhances coping and psychological health [...] the literature suggests that patients with cancer often receive insufficient information [...]. This raises questions as to whether they are not given the information they need or whether they fail to understand what they are told. This is a subject for future research ^[100, p320].

This paper begins to address Worster and Holmes' concerns. We contend, however, that their first statement warrants problematising. "It cannot be assumed that individuals understand what they are told" is too simplistic. Our research reveals that what, when, and how people are given information will contribute to their understanding. Threads common to all three are the notion of heterogeneity, the inappropriateness of generalisability, and the idea that one size does not fit all.

The story about the *what*, the areas about which people want information, appears in four general themes: finding my way in the moment(s), understanding treatment, ways to live, and post-treatment. Throughout the care trajectory, people will go through countless experiences, each different from the previous. They need information that will help them deal with each of these moments and the decisions they must make along the way. Decisions about treatment require information about the nature of treatment, (side) effects, and how to organise their lives around treatment. Daily life continues and people want information to assist their adjustment to life while dealing with cancer – and after treatment. Information is needed across the continuum of care, not just at one point of time: the *when*. The experience of cancer is not linear and neither can the sharing of information be. Each person will want information at a time that works for them and people hope their health care providers are skilled enough to make this assessment and not make assumptions. The *how*, again, cannot be the same for everyone. Health care providers, the most trusted source of information, need to be clear, understandable, unhurried, and consider myriad issues: language, culture, hearing ability, and other health and family issues. People want to know their care is well coordinated, that their health care providers know what one another is doing and planning. Other sources of information such as the Internet and written sources are also useful ways to communicate.

As healthcare providers, we play a role in ensuring people's information needs are met as well as possible; we must consider how to deliver information differently according to the unique requirements of each patient. This research points to specific issues about which people want to know. More importantly, it reminds us that each person is unique. Given the importance of information to the provision of care and to people's experience with cancer, we are compelled to determine the best way to provide information as part of ethical practice to improve people's experience of cancer care.

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References

- [1] Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counseling*. 2005; 57(3): 250-261. PMID:15893206 <http://dx.doi.org/10.1016/j.pec.2004.06.006>

- [2] Van Mossel C, Leitz L, Scott S, Daudt H, Dennis D, Watson H, Alford M, Mitchell A, Payeur N, Crosby C, Levy-Milne R, Purkis ME. Information needs across the colorectal cancer care continuum: scoping the literature. *European Journal of Cancer Care*. 2012; 21(3):296-320. PMID:22416737 <http://dx.doi.org/10.1111/j.1365-2354.2012.01340.x>
- [3] Daudt H, van Mossel C, Scott S. Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology*. 2013; 13:48-56. PMID:23522333 <http://dx.doi.org/10.1186/1471-2288-13-48>
- [4] Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, et al. Guidance on the conduct of narrative synthesis in systematic reviews: a product from the ESRC methods programme. Unpublished report. University of Lancaster, UK. Version 2006; 1.
- [5] Maggs-Rapport F. Combining methodological approaches in research: ethnography and interpretive phenomenology. *Journal of Advanced Nursing*. 2000; 31(1): 219-225. PMID:10632812 <http://dx.doi.org/10.1046/j.1365-2648.2000.01243.x>
- [6] Elbow P. *Embracing Contraries: Explorations in Teaching and Learning*. Oxford: Oxford University Press; 1986.
- [7] Connelly FM, Clandinin DJ. Stories of experience and narrative inquiry. *Educational researcher*. 1990; 19(5): 2-14. <http://dx.doi.org/10.3102/0013189X019005002>
- [8] Hyden L. Illness and narrative *Sociology of Health & Illness*. 1997; 19(1): 48-69.
- [9] Somers MR. The narrative constitution of identity: a relational and network approach. *Theory and Society*. 1994; 23: 605-649. <http://dx.doi.org/10.1007/BF00992905>
- [10] Sinfield P, Baker R, Camosso - Stefinovic J, Colman AM, Tarrant C, Mellon JK, et al. Men's and carers' experiences of care for prostate cancer: a narrative literature review. *Health Expectations*. 2009; 12(3): 301-312. PMID:19754693 <http://dx.doi.org/10.1111/j.1369-7625.2009.00546.x>
- [11] Anderson AS, Caswell S, Wells M, Steele RJ, Macaskill S. "It makes you feel so full of life" LiveWell, a feasibility study of a personalised lifestyle programme for colorectal cancer survivors. *Supportive Care in Cancer*. 2010; 18(4): 409-415. PMID:19554354 <http://dx.doi.org/10.1007/s00520-009-0677-4>
- [12] Ayanian JZ, Zaslavsky AM, Guadagnoli E, Fuchs CS, Yost KJ, Creech CM, et al. Patients' perceptions of quality of care for colorectal cancer by race, ethnicity, and language. *Journal of Clinical Oncology*. 2005; 23(27): 6576-6586. PMID:16116149 <http://dx.doi.org/10.1200/JCO.2005.06.102>
- [13] Bain NS, Campbell NC, Ritchie LD, Cassidy J. Striking the right balance in colorectal cancer care--a qualitative study of rural and urban patients. *Family Practice*. 2002; 19(4): 369-374. PMID:12110557 <http://dx.doi.org/10.1093/fampra/19.4.369>
- [14] Bains M, Munir F, Yarker J, Steward W, Thomas A. Return-to-work guidance and support for colorectal cancer patients: a feasibility study. *Cancer Nursing*. 2011; 34(6): E1-12. PMID:21372705 <http://dx.doi.org/10.1097/NCC.0b013e31820a4c68>
- [15] Ball M, Nelson C, Jandorf L, Temple L, Carter J, Starr T, et al. Perspectives on women's experience with sexual dysfunction post rectal cancer treatment: a qualitative study. *Journal of Sexual Medicine*. 2011; 8: 45.
- [16] Ball M, Nelson C, Mulhall J, Shuk E, Temple L, Jandorf L, et al. Perspectives on men's experience with sexual dysfunction post rectal cancer treatment: a qualitative study. *Journal of Sexual Medicine*. 2011; 8: 39.
- [17] Baravelli C, Krishnasamy M, Pezaro C, Schofield P, Lotfi-Jam K, Rogers M, et al. The views of bowel cancer survivors and health care professionals regarding survivorship care plans and post treatment follow up. *Journal of Cancer Survivorship*. 2009; 3(2): 99-108. PMID:19415504 <http://dx.doi.org/10.1007/s11764-009-0086-1>
- [18] Beaver K, Booth K. Information needs and decision-making preferences: comparing findings for gynaecological, breast and colorectal cancer. *European Journal of Oncology Nursing*. 2007; 11(5): 409-416. PMID:17604693 <http://dx.doi.org/10.1016/j.ejon.2007.04.004>
- [19] Beaver K, Campbell M, Craven O, Jones D, Luker KA, Susnerwala SS. Colorectal cancer patients' attitudes towards involvement in decision making. *Health Expect*. 2009 Mar; 12(1): 27-37. PMID:19250150 <http://dx.doi.org/10.1111/j.1369-7625.2008.00515.x>
- [20] Beaver K, Jones D, Susnerwala S, Craven O, Tomlinson M, Witham G, et al. Exploring the decision-making preferences of people with colorectal cancer. *Health Expectations*. 2005; 8(2): 103-113. PMID:15860051 <http://dx.doi.org/10.1111/j.1369-7625.2005.00320.x>
- [21] Beaver K, Latif S, Williamson S, Procter D, Sheridan J, Heath J, et al. An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *Journal of Clinical Nursing*. 2010; 19(23-24): 3291-3300. PMID:20964750 <http://dx.doi.org/10.1111/j.1365-2702.2010.03407.x>
- [22] Beaver K, Wilson C, Procter D, Sheridan J, Towers G, Heath J, et al. Colorectal cancer follow-up: patient satisfaction and amenability to telephone after care. *European Journal of Oncology Nursing*. 2011; 15(1): 23-30. PMID:20584628 <http://dx.doi.org/10.1016/j.ejon.2010.05.006>
- [23] Beech N, Arber A, Faithfull S. Restoring a sense of wellness following colorectal cancer: a grounded theory. *Journal of Advanced Nursing*. 2012; 68(5): 1134-44. PMID:21895739 <http://dx.doi.org/10.1111/j.1365-2648.2011.05820.x>

- [24] Bell K, Lee J, Foran S, Kwong S, Christopherson J. Is there an "ideal cancer" support group?: key findings from a qualitative study of three groups. *Journal of Psychosocial Oncology*. 2010; 28(4): 432-449. PMID:20623417
<http://dx.doi.org/10.1080/07347332.2010.488140>
- [25] Blazeby JM, Soulsby M, Winstone K, King PM, Bulley S, Kennedy RH. A qualitative evaluation of patients' experiences of an enhanced recovery programme for colorectal cancer. *Colorectal Disease*. 2010; 12(10): e236-e242. PMID:19888959
<http://dx.doi.org/10.1111/j.1463-1318.2009.02104.x>
- [26] Boudioni M, McPherson K, Moynihan C, Melia J, Boulton M, Leydon G, et al. Do men with prostate or colorectal cancer seek different information and support from women with cancer? *British Journal of Cancer*. 2001; 85(5): 641-648. PMID:11531244
<http://dx.doi.org/10.1054/bjoc.2001.1945>
- [27] Broughton M, Bailey J, Linney J. How can experiences of patients and carers influence the clinical care of large bowel cancer? *European Journal of Cancer Care (England)*. 2004; 13(4): 318-327. PMID:15305899
<http://dx.doi.org/10.1111/j.1365-2354.2004.00477.x>
- [28] Broughton M, Doulton G, Topham C, Marks C. Informal out-patient discussions with patients following surgery for large bowel cancer: are they beneficial? *European Journal of Cancer Care (England)*. 1995; 4(2): 57-62.
<http://dx.doi.org/10.1111/j.1365-2354.1995.tb00057.x>
- [29] Busby K, Enston A. An audit of information for patients with colorectal cancer. *Colorectal Disease*. 2003; 5(1): 109.
- [30] Butow PN, Solomon M, Young JM, Whelan T, Salkeld G, Wilson K, et al. Consumer impact of an interactive decision aid for rectal cancer patients offered adjuvant therapy. *Colorectal Disease*. 2006; 8(8): 676-682. PMID:16970578
<http://dx.doi.org/10.1111/j.1463-1318.2006.00975.x>
- [31] Carlsson E, Berndtsson I, Hallen AM, Lindholm E, Persson E. Concerns and quality of life before surgery and during the recovery period in patients with rectal cancer and an ostomy. *Journal of Wound, Ostomy, & Continence Nursing*. 2010; 37(6): 654-661. PMID:21052026
<http://dx.doi.org/10.1097/WON.0b013e3181f90f0c>
- [32] Carney L, Jones L, Braddon F, Pullyblank AM, Dixon AR. A colorectal cancer patient focus group develops an information package. *Annals of the Royal College of Surgeons of England*. 2006; 88(5): 447-449. Mid:17002845
<http://dx.doi.org/10.1308/003588406X114686>
- [33] Carroll JK, Humiston SG, Meldrum SC, Salamone CM, Jean-Pierre P, Epstein RM, et al. Patients' experiences with navigation for cancer care. *Patient Education & Counseling*. 2010; 80(2): 241-247. PMID:20006459
<http://dx.doi.org/10.1016/j.pec.2009.10.024>
- [34] Da Silva GM, Hull T, Roberts PL, Ruiz DE, Wexner SD, Weiss EG, et al. The effect of colorectal surgery in female sexual function, body image, self-esteem and general health: a prospective study. *Annals of Surgery*. 2008; 248(2):266-272. PMID:18650637
<http://dx.doi.org/10.1097/SLA.0b013e3181820cf4>
- [35] Egglestone CL, Katory M. Evaluation of a nurse led follow up clinic for colorectal cancer: The patient perspective. *Colorectal Disease*. 2010; 12: 14.
- [36] Elkin EB, Kim SH, Casper ES, Kissane DW, Schrag D. Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions. *Journal of Clinical Oncology* 2007; 25(33): 5275-5280. PMID:18024875
<http://dx.doi.org/10.1200/JCO.2007.11.1922>
- [37] Galloway SC, Graydon JE. Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nursing*. 1996; 19(2): 112. <http://dx.doi.org/10.1097/00002820-199604000-00005>
- [38] Harrison JD, Young JM, Auld S, Masya L, Solomon MJ, Butow PN. Quantifying post - discharge unmet supportive care needs of people with colorectal cancer: a clinical audit. *Colorectal Disease*. 2011; 13(12): 1400-1406. PMID:20977588
<http://dx.doi.org/10.1111/j.1463-1318.2010.02478.x>
- [39] Heras P, Kritikos K, Karagiannis S, Serenes P, Argyriou A, Kritikos N. Needs and psychological distress in oncological inpatients with colorectal cancer. *Journal of Clinical Oncology (Meeting Abstracts)*. 2004; 22(14 suppl): 8181.
- [40] Ieropoli SC, White VM, Jefford M, Akkerman D. What models of peer support do people with colorectal cancer prefer? *European Journal of Cancer Care*. 2011; 20(4): 455-465. PMID:20738390
<http://dx.doi.org/10.1111/j.1365-2354.2010.01218.x>
- [41] Jackson J, Van Arman L, Rolnick C. PS2-19: Provider and survivor perspectives on components, timing and source of a colorectal-specific cancer survivor care plan. *Clinical Medicine & Research*. 2011; 9(3-4): 2. PMID:PMC3251433
<http://dx.doi.org/10.3121/cm.2011.1020.ps2-19>
- [42] Jefford M, Gibbs A, Reading D. Development and evaluation of an information booklet/decision-making guide for patients with colorectal cancer considering therapy in addition to surgery. *European Journal of Cancer Care (England)*. 2005; 14(1):16-27. PMID:15698383
<http://dx.doi.org/10.1111/j.1365-2354.2005.00504.x>
- [43] Jefford M, Lotfi-Jam K, Baravelli C, Grogan S, Rogers M, Krishnasamy M, et al. Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. *Cancer Nursing*. 2011; 34(3): E1-10. PMID:21045754
<http://dx.doi.org/10.1097/NCC.0b013e3181f22f02>

- [44] Jonsson CA, Stenberg A, Frisman GH. The lived experience of the early postoperative period after colorectal cancer surgery. *European Journal of Cancer Care*. 2011; 20(2): 248-256. PMID:20345455 <http://dx.doi.org/10.1111/j.1365-2354.2009.01168.x>
- [45] Jorgensen ML, Young JM, Harrison JD, Solomon MJ. Unmet supportive care needs in colorectal cancer: differences by age. *Supportive Care in Cancer*. 2012; 20(6): 1275-1281. PMID:21691847 <http://dx.doi.org/10.1007/s00520-011-1214-9>
- [46] Karagiannis S, Heras P, Hatzopoulos A, Georgopoulou A, Kritikos K. Colorectal cancer patients' informational needs about sexuality related issues. *Journal of Clinical Oncology*. 2006; 24(18S).
- [47] Kerr J, Engel J, Schlesinger-Raab A, Sauer H, Holzel D. Doctor-patient communication: results of a four-year prospective study in rectal cancer patients. *Diseases of the Colon and Rectum*. 2003; 46(8): 1038-1046. PMID:12907897 <http://dx.doi.org/10.1007/s10350-004-7278-6>
- [48] Kidd L, Kearney N, O'Carroll R, Hubbard G. Experiences of self-care in patients with colorectal cancer: a longitudinal study. *Journal of Advanced Nursing*. 2008; 64(5): 469-477. PMID:18764852 <http://dx.doi.org/10.1111/j.1365-2648.2008.04796.x>
- [49] Kinney AY, Choi YA, DeVellis B, Millikan R, Kobetz E, Sandler RS. Attitudes toward genetic testing in patients with colorectal cancer. *Cancer Practice*. 2000; 8(4): 178-186. PMID:11898257 <http://dx.doi.org/10.1046/j.1523-5394.2000.84008.x>
- [50] Klemm P, Reppert K, Visich L. A nontraditional cancer support group: the internet. *Computers in Nursing*. 1998; 16(1): 31-36. PMID:9454992
- [51] Knowles G, Tierney A, Jodrell D, Cull A. The perceived information needs of patients receiving adjuvant chemotherapy for surgically resected colorectal cancer. *European Journal of Oncology Nursing*. 1999; 3(4): 208-220. [http://dx.doi.org/10.1016/S1462-3889\(99\)81332-5](http://dx.doi.org/10.1016/S1462-3889(99)81332-5)
- [52] Leigh NB, Shepherd HL, Butow PN, Clarke SJ, McJannett M, Beale PJ, et al. Supporting treatment decision making in advanced cancer: a randomized trial of a decision aid for patients with advanced colorectal cancer considering chemotherapy. *Journal of Clinical Oncology*. 2011; 29(15): 2077-2084. PMID:21483008 <http://dx.doi.org/10.1200/JCO.2010.32.0754>
- [53] Lithner M, Johansson J, Andersson E, Jakobsson U, Palmquist I, Klefsgard R. Perceived information after surgery for colorectal cancer: an explorative study. *Colorectal Disease*. 2012; 14(11): 1340-1350. PMID:22329948 <http://dx.doi.org/10.1111/j.1463-1318.2012.02982.x>
- [54] Little M, Jordens CF, Paul K, Montgomery K, Philipson B. Liminality: a major category of the experience of cancer illness. *Social Science & Medicine*. 1998; 47(10): 1485-1494. [http://dx.doi.org/10.1016/S0277-9536\(98\)00248-2](http://dx.doi.org/10.1016/S0277-9536(98)00248-2)
- [55] Love N, editor. *Patient Perspectives on Colorectal Cancer: Findings from a Comprehensive Survey of 150 Patients with Colorectal Cancer*. *Colorectal Cancer Update*, 2006.
- [56] MacLeod A, Branch A, Cassidy J, McDonald A, Mohammed N, MacDonald L. A nurse-/pharmacy-led capecitabine clinic for colorectal cancer: results of a prospective audit and retrospective survey of patient experiences. *European Journal of Oncology Nursing*. 2007; 11(3): 247-254. PMID:17188937 <http://dx.doi.org/10.1016/j.ejon.2006.10.001>
- [57] Manne SL, Meropol NJ, Weinberg DS, Vig H, Ali-Khan Catts Z, Manning C, et al. Facilitating informed decisions regarding microsatellite instability testing among high-risk individuals diagnosed with colorectal cancer. *Journal of Clinical Oncology*. 2010; 28(8): 1366. PMID:20142594 <http://dx.doi.org/10.1200/JCO.2009.25.0399>
- [58] Mathiesen TP, Willaing I, Freil M, Jorgensen T, Andreassen AH, Ladelund S, et al. How do patients with colorectal cancer perceive treatment and care compared with the treating health care professionals? *Medical Care*. 2007; 45(5): 394-400. PMID:17446825 <http://dx.doi.org/10.1097/01.mlr.0000254570.72414.be>
- [59] McCahill LE, Hamel-Bissell BP. The patient lived experience for surgical treatment of colorectal liver metastases: a phenomenological study. *Palliative & Supportive Care*. 2009; 7(1): 65-73. PMID:19619376 <http://dx.doi.org/10.1017/S1478951509000091>
- [60] McCaughan E, Parahoo K, Prue G. Comparing cancer experiences among people with colorectal cancer: a qualitative study. *Journal of Advanced Nursing*. 2011; 67(12): 2686-2695. PMID:21806670 <http://dx.doi.org/10.1111/j.1365-2648.2011.05772.x>
- [61] McGorm K, Rieger N. Complementary and alternative therapies used by patients who have colorectal cancer. *Australian Journal of Cancer Nursing*. 2004; 5(1): 25-28.
- [62] McMullen CK, Hornbrook MC, Grant M, Baldwin CM, Wendel CS, Mohler MJ, et al. The greatest challenges reported by long-term colorectal cancer survivors with stomas. *Journal of Supportive Oncology*. 2008; 6(4): 175-182. PMID:18491686
- [63] Mitchell PL, White CA, Austin Bowel Cancer C. Austin Bowel Cancer Consortium: changing culture in bowel cancer care. *Medical Journal of Australia*. 2004; 180(10 Suppl): S79-82. PMID:15139842
- [64] Molloy D, Smith LN, Aitchison T. Cytotoxic chemotherapy for incurable colorectal cancer: living with a PICC-line. *Journal of Clinical Nursing*. 2008; 17(18): 2398-2407. PMID:18705719 <http://dx.doi.org/10.1111/j.1365-2702.2008.02359.x>
- [65] Nagler RH, Gray SW, Romantan A, Kelly BJ, DeMichele A, Armstrong K, et al. Differences in information seeking among breast, prostate, and colorectal cancer patients: results from a population-based survey. *Patient Education & Counseling*. 2010; 81(Suppl): S54-62. PMID:20934297 <http://dx.doi.org/10.1016/j.pec.2010.09.010>

- [66] Nikolettis S, Young J, Levitt M, King M, Chidlow C, Hollingsworth S. Bowel problems, self-care practices, and information needs of colorectal cancer survivors at 6 to 24 months after sphincter-saving surgery. *Cancer Nursing*. 2008; 31(5): 389-398. PMID:18772664 <http://dx.doi.org/10.1097/01.NCC.0000305759.04357.1b>
- [67] Northouse LL, Schafer JA, Tipton J, Metivier L. The concerns of patients and spouses after the diagnosis of colon cancer: a qualitative analysis. *Journal of Wound Ostomy & Continence Nursing*. 1999; 26(1): 8-17. PMID:10036419
- [68] O'Connor G, Coates V, O'Neill S. Exploring the information needs of patients with cancer of the rectum. *European Journal of Oncology Nursing*. 2010; 14: 271-277. PMID:20236861 <http://dx.doi.org/10.1016/j.ejon.2010.01.024>
- [69] Ohlsson-Nevo E, Andershed B, Nilsson U, Anderzen-Carlsson A. Life is back to normal and yet not - partners' and patient's experiences of life of the first year after colorectal cancer surgery. *Journal of Clinical Nursing*. 2012; 21(3-4): 555-563. PMID:21883573 <http://dx.doi.org/10.1111/j.1365-2702.2011.03830.x>
- [70] Pan LH, Tsai YF, Chen ML, Tang R, Chang CJ. Symptom distress and self-care strategies of colorectal cancer patients with diarrhea up to 3 months after surgery. *Cancer Nursing*. 2011; 34(1): E1-9. PMID:20697270 <http://dx.doi.org/10.1097/NCC.0b013e3181e3ca21>
- [71] Papagrigroriadis S, Heyman B. Patients' views on follow up of colorectal cancer: implications for risk communication and decision making. *Postgraduate Medical Journal*. 2003; 79(933): 403. <http://dx.doi.org/10.1136/pmj.79.933.403>
- [72] Persson E, Gustavsson B, Hellstrom AL, Lappas G, Hulthen L. Ostomy patients' perceptions of quality of care. *Journal of Advanced Nursing*. 2005; 49(1): 51-58. PMID:15610381 <http://dx.doi.org/10.1111/j.1365-2648.2004.03263.x>
- [73] Porteous M, Dunckley M, Appleton S, Catt S, Dunlop M, Campbell H, et al. Is it acceptable to approach colorectal cancer patients at diagnosis to discuss genetic testing?: a pilot study. *British Journal of Cancer*. 2003; 89(8): 1400-1402. PMID:14562005 <http://dx.doi.org/10.1038/sj.bjc.6601332>
- [74] Pringle W, Swan E. Continuing care after discharge from hospital for stoma patients. *British Journal of Nursing*. 2001; 10(19): 1275-1288. PMID:11832841
- [75] Ramfelt E, Lutzen K. Patients with cancer: their approaches to participation in treatment plan decisions. *Nursing Ethics*. 2005; 12(2): 143-155. <http://dx.doi.org/10.1191/0969733005ne771oa>
- [76] Ramirez M, McMullen C, Grant M, Altschuler A, Hornbrook MC, Krouse RS. Figuring out sex in a reconfigured body: experiences of female colorectal cancer survivors with ostomies. *Women & Health*. 2009; 49(8): 608-624. PMID:20183104 <http://dx.doi.org/10.1080/03630240903496093>
- [77] Rozmovits L, Rose P, Ziebland S. In the absence of evidence, who chooses?: a qualitative study of patients' needs after treatment for colorectal cancer. *Journal of Health Services Research & Policy*. 2004; 9(3): 159-164. PMID:15272974 <http://dx.doi.org/10.1258/1355819041403231>
- [78] Rozmovits L, Ziebland S. Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qualitative Health Research*. 2004; 14(2): 187-203. PMID:14768457 <http://dx.doi.org/10.1177/1049732303260874>
- [79] Rubin DT, Gandhi RK, Hetzel JT, Kinnear SH, Aronsohn A, Wood G, et al. Do colorectal cancer patients understand that their family is at risk? *Digestive Diseases & Sciences*. 2009; 54(11): 2473-2483. PMID:19731030 <http://dx.doi.org/10.1007/s10620-009-0940-z>
- [80] Sahay TB, Gray RE, Fitch M. A qualitative study of patient perspectives on colorectal cancer. *Cancer Practice*. 2000; 8(1): 38-44. PMID:10732538 <http://dx.doi.org/10.1046/j.1523-5394.2000.81012.x>
- [81] Sajid MS, Shakir AJ, Baig MK. Information on the Internet about colorectal cancer: patient attitude and potential toward Web browsing: a prospective observational study. *Canadian Journal of Surgery*. 2011; 54(5): 339-343. PMID:21933528 <http://dx.doi.org/10.1503/cjs.011910>
- [82] Salkeld G, Solomon M, Short L, Butow PN. A matter of trust -- patient's views on decision-making in colorectal cancer. *Health Expectations*. 2004; 7(2): 104-114. PMID:15117385 <http://dx.doi.org/10.1111/j.1369-7625.2004.00257.x>
- [83] Salz T, Brewer NT, Sandler RS, Weiner BJ, Martin CF, Weinberger M. Association of health beliefs and colonoscopy use among survivors of colorectal cancer. *Journal of Cancer Survivorship*. 2009; 3(4): 193-201. PMID:19760152 <http://dx.doi.org/10.1007/s11764-009-0095-0>
- [84] Sanders T, Skevington S. Do bowel cancer patients participate in treatment decision-making?: findings from a qualitative study. *European Journal of Cancer Care*. 2003; 12(2): 166-175. <http://dx.doi.org/10.1046/j.1365-2354.2003.00370.x>
- [85] Sanoff HK, Goldberg RM, Pignone MP. Assessing the quality of initial consultations regarding adjuvant colon cancer therapy. *Clinical Colorectal Cancer*. 2010; 9(2): 113-118. PMID:20378506 <http://dx.doi.org/10.3816/CCC.2010.n.016>
- [86] Sawyer J, Wright FC, Moura SL, Maier BA, Fitch MI. Introducing a patient-focused care map in colorectal surgery: a pilot qualitative study of patients' and surgical oncology nurses' experiences. *Canadian Oncology Nursing Journal*. 2008; 18(1): 25-33. PMID:18512566 <http://dx.doi.org/10.5737/1181912x1812528>

- [87] Simpson MF, Whyte F. Patients' experiences of completing treatment for colorectal cancer in a Scottish District General Hospital. *European Journal of Cancer Care (England)*. 2006; 15(2): 172-182. PMID:16643265
<http://dx.doi.org/10.1111/j.1365-2354.2005.00634.x>
- [88] Smith-McLallen A, Fishbein M, Hornik RC. Psychosocial determinants of cancer-related information seeking among cancer patients. *Journal of Health Communication*. 2011; 16(2): 212-225. PMID:21207310
<http://dx.doi.org/10.1080/10810730.2010.522227>
- [89] Spence RR, Heesch KC, Brown WJ. Colorectal cancer survivors' exercise experiences and preferences: qualitative findings from an exercise rehabilitation programme immediately after chemotherapy. *European Journal of Cancer Care*. 2011; 20(2): 257-266. PMID:20649808
<http://dx.doi.org/10.1111/j.1365-2354.2010.01214.x>
- [90] Sun V, Borneman T, Koczywas M, Cristea M, Piper BF, Uman G, et al. Quality of life and barriers to symptom management in colon cancer. *European Journal of Oncology Nursing*. 2012; 16(3): 276-280. PMID:21783415
<http://dx.doi.org/10.1016/j.ejon.2011.06.011>
- [91] Taylor C, Richardson A, Cowley S. Surviving cancer treatment: an investigation of the experience of fear about, and monitoring for, recurrence in patients following treatment for colorectal cancer. *European Journal of Oncology Nursing*. 2011; 15(3): 243-249. PMID:21530395
<http://dx.doi.org/10.1016/j.ejon.2011.03.010>
- [92] Thurston M, Perry C, Kirby K. Exploring Colorectal Cancer Patients' Perceptions of the Quality of their Care: A Qualitative Study in Malton. Chester: University College Chester, UK, Centre for Public Health Research, 2003.
- [93] van der Molen B. Relating information-needs to the cancer experience. 1. Jenny's story: a cancer narrative. *European Journal of Cancer Care (England)*. 2000; 9(1): 41-47. <http://dx.doi.org/10.1046/j.1365-2354.2000.00191.x>
- [94] Walsh MC, Trentham-Dietz A, Schroepfer TA, Reding DJ, Campbell B, Foote ML, et al. Cancer information sources used by patients to inform and influence treatment decisions. *Journal of Health Communication*. 2010; 15(4): 445-463. PMID:20574881
<http://dx.doi.org/10.1080/10810731003753109>
- [95] White K, D'Abrew N, Katris P, O'Connor M, Emery L. Mapping the psychosocial and practical support needs of cancer patients in Western Australia. *European Journal of Cancer Care*. 2012; 21(1): 107-116. PMID:21838725
<http://dx.doi.org/10.1111/j.1365-2354.2011.01270.x>
- [96] White VM, Macvean ML, Grogan S, D'Este C, Akkerman D, Ieropoli S, et al. Can a tailored telephone intervention delivered by volunteers reduce the supportive care needs, anxiety and depression of people with colorectal cancer?: a randomised controlled trial. *Psycho - Oncology*. 2012; 21(10): 1053-1062. PMID:21769989
<http://dx.doi.org/10.1002/pon.2019>
- [97] M. D. Will. Self-talk: inner work of living with colorectal cancer. [n.p.]: University of Alberta, 2002.
- [98] Wilson S. Patients and relatives tell us what they need to know through their narratives: an exploratory qualitative study. *British Journal of Healthcare Computing & Information Management*. 2005; 22(4): 21-22.
- [99] Wilson TR, Birks YF, Alexander DJ. A qualitative study of patient perspectives of health-related quality of life in colorectal cancer: comparison with disease-specific evaluation tools. *Colorectal Disease*. 2010; 12(8): 762-769. PMID:19341398
<http://dx.doi.org/10.1111/j.1463-1318.2009.01857.x>
- [100] Worster B, Holmes S. A phenomenological study of the postoperative experiences of patients undergoing surgery for colorectal cancer. *European Journal of Oncology Nursing*. 2009; 13(5): 315-322. PMID:19482512
<http://dx.doi.org/10.1016/j.ejon.2009.04.008>
- [101] Worster B, Holmes S. The preoperative experience of patients undergoing surgery for colorectal cancer: a phenomenological study. *European Journal of Oncology Nursing*. 2008; 12(5): 418-424. PMID:18842456
<http://dx.doi.org/10.1016/j.ejon.2008.05.007>
- [102] Wright FC, Crooks D, Fitch M, Hollenberg E, Maier BA, Last LD, et al. Qualitative assessment of patient experiences related to extended pelvic resection for rectal cancer. *Journal of Surgical Oncology*. 2006; 93(2): 92-99. PMID:16425312
<http://dx.doi.org/10.1002/jso.20382>
- [103] National Cancer Survivorship Initiative. 2013; Available from: <http://www.ncsi.org.uk/>. Accessed February 20, 2013.
- [104] Purkis ME, van Mossel C. Cancer as a contested illness: seeking help amidst treatment. In: Moss P, Teghtsoonian KA, editors. *Contesting Illness: Processes and Practices*. Toronto: University of Toronto Press; 2008.