

Understanding the complexities of shared decision-making in cancer: a qualitative study of the perspectives of patients undergoing colorectal surgery

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This work was presented as an oral presentation at the Canadian Surgery Forum in September 2015.

Accepted for publication
Feb. 1, 2016

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DOI: 10.1503/cjs.013415

Background: Decisions leading up to surgery are fraught with uncertainty owing to trade-offs between treatment effectiveness and quality of life. Past studies on shared decision-making (SDM) have focused on the physician–patient encounter, with little emphasis on familial and cultural factors. The literature is scarce in surgical oncology, with few studies using qualitative interviews. Our objective was to explore the complexities of SDM within the setting of colorectal cancer (CRC) surgery.

Methods: An interdisciplinary team developed a semistructured questionnaire. Telephone interviews were conducted with CRC patients in the practice of 1 surgical oncologist. Data saturation was achieved and a descriptive thematic analysis was performed.

Results: We interviewed 20 patients before achieving data saturation. Three major themes emerged. First, family was considered as a crucial adjunct to the patient–provider dyad. Second, patients identified several facilitators to SDM, including a robust social support system and a competent surgical team. Although language was a perceived barrier, there was no difference in level of involvement in care between patients who spoke English fluently and those who did not. Finally, patients perceived a lack of choice and control in decision-making, thus challenging the very notion of SDM.

Conclusion: Surgeons must learn to appreciate the role of family as a vital addition to the patient–provider dyad. Family engagement is crucial for CRC patients, particularly those undergoing surgical resection of late-stage disease. Surgeons must be aware of the uniqueness of decision-making in this context to empower patients and families.

Contexte : Le choix de subir une chirurgie est toujours source d'incertitude en raison du fragile équilibre entre l'efficacité du traitement et la qualité de vie. Les études antérieures sur la prise de décision partagée se sont concentrées sur la relation médecin–patient; on a accordé peu d'importance aux facteurs familiaux et culturels qui entrent en jeu. En outre, la documentation scientifique ne foisonne pas d'études sur l'oncologie chirurgicale, et seules quelques données ont été recueillies au moyen d'entrevues qualitatives. Notre but était d'examiner les difficultés de la prise de décision partagée dans le contexte d'une chirurgie pour un cancer colorectal.

Méthodes : Une équipe interdisciplinaire a conçu un questionnaire semi-structuré au moyen duquel nous avons interviewé par téléphone des patients atteints d'un cancer colorectal et suivis par le même chirurgien oncologue. Nous avons atteint le seuil de saturation des données, puis réalisé une analyse thématique descriptive.

Résultats : Pour atteindre la saturation, nous avons interrogé 20 patients. Trois thèmes principaux sont ressortis. D'abord, la famille était considérée comme un précieux ajout au tandem patient–médecin. Ensuite, les patients ont énuméré quelques éléments qui facilitent la prise de décision partagée, notamment la présence d'un bon réseau de soutien social et d'une équipe de professionnels compétente. À noter : même si la langue était perçue comme un obstacle, nous n'avons observé aucune différence entre les patients qui maîtrisent bien l'anglais et les autres en ce qui concerne l'engagement. Enfin, les patients ne sentaient pas que leur opinion comptait pour beaucoup dans la prise de décision, ce qui remet en question la notion même de prise de décision partagée.

Conclusion : Les chirurgiens doivent voir la famille comme un acteur de soutien essentiel au tandem patient–médecin. La participation de la famille est cruciale pour les patients atteints d'un cancer colorectal, surtout pour ceux qui subissent une résection chirurgicale à un stade avancé de la maladie. Les chirurgiens ne doivent pas oublier que chaque cas est unique, afin d'autonomiser les patients et leur famille.

The decision to undergo surgery is arguably the most difficult task a patient may have to undertake. Treatment decision-making is particularly challenging for patients with colon cancer owing to the presence of substantial trade-offs between therapeutic effectiveness and post-treatment quality of life¹ in addition to the inherent risks associated with complex surgical procedures.

When patients arrive at a crossroads of medical or surgical options, most wish to participate alongside their clinicians in making decisions.² In fact, various studies have investigated the shared decision-making (SDM) process between the physician and patient across different clinical settings.^{3–10} For instance, Bélanger and colleagues¹¹ elucidated the concept in palliative care using narrative synthesis, exploring patient preferences for SDM, the level of patient participation in decision-making and the barriers and facilitators to SDM. In the field of cancer care specifically, the evidence suggests that critically ill patients generally prefer to be involved in decision-making with the health care team and that providing information about care options and maintaining realistic expectations may increase patient engagement.^{2–10}

While the literature on SDM focuses on the patient's direct encounter with the physician and health care team, there is little to no emphasis on the interplay between familial and cultural influences and decision-making within a model of patient-centred care. Research on this topic is especially scarce in the field of surgical oncology, with a lack of studies using qualitative interviews to explore these issues from the patient's perspective. Therefore, the objective of this study was to examine the complexities of the longitudinal and interactive process of SDM among patients, their families and the health care team in colorectal cancer (CRC) surgery.

METHODS

Participants

Adult patients (≥ 18 yr) who underwent surgical resection for suspected or pathologically confirmed CRC and who were in early postoperative follow-up (< 3 mo) in the Gastrointestinal Oncology Clinic at Princess Margaret Cancer Centre or Toronto Western Hospital (part of the University Health Network in Toronto, Ont.) were eligible to participate. The University Health Network is a multi-institution tertiary academic centre located in a large urban city, serving a culturally diverse and complex patient population.

We used convenience sampling, a form of nonprobability sampling, to identify patients for prospective recruitment from a single surgeon's (F.A.Q.) clinical practice.¹² All patients approached to take part in the study were fully aware of their diagnosis and were considered physically and psychologically able to cope with the interview process. We obtained informed consent from all patients before their participation in the study. The protocol was

approved by the University Health Network Research Ethics Board before study initiation.

Data collection

An interdisciplinary team consisting of a psychiatrist, surgical oncologist and nurse navigator developed a semi-structured interview guide that addressed 3 broad areas: history of illness, participation in treatment decisions and demographic characteristics. The interview guide, consisting of both open-ended questions and question probes used to facilitate the discussion, allowed flexibility to elicit individual views and descriptions of experiences.

All interviews were conducted by telephone. Patients were first asked to briefly recount their health care experiences since receiving the diagnosis of CRC. This provided an overview of preoperative and postoperative care, including therapies received, and enabled subsequent in-depth exploration of participation in treatment decision-making. Several open-ended questions were used to ascertain perceptions of choice, preferences for participation in decision-making, and factors that helped or hindered decision-making, including the following:

- "Can you tell me about your decision-making process leading up to surgery?"
- "Can you tell me about the information that was given to you during the decision-making process?"
- "Can you identify any factors that played a role (good or bad) in this decision-making process?"

These questions were followed by a series of probing questions used when necessary to stimulate deeper thinking about the issues. Demographic data were also collected from patients, and specific tumour staging information and surgical procedure type were obtained from electronic patient records.

Data analysis

Interviews were audio-recorded and transcribed verbatim by an independent transcriptionist. All identifying information was removed from transcripts before analysis to maintain anonymity. Transcripts were hand-coded following each interview to allow iterative data collection and analysis, whereby new and emerging concepts could be further explored in subsequent interviews. Descriptive coding was used to identify distinct concepts, which were later grouped into categories. The research team met consistently to discuss emerging ideas and categories. Upon achieving data saturation (the point at which no new information that was relevant to the research question emerged), these categories were further analyzed and refined to identify overarching themes in the attitudes, perceptions and experiences of patients.^{13–15} Sociodemographic and clinical data were summarized using descriptive statistics.

RESULTS

Sociodemographic characteristics

The patient sample ($n = 20$) included 11 men (55%) and 9 women (45%; Table 1). Eleven patients were 70 years of age or older. The mean age of the sample was 71.5 (range 42–88) years. Eleven patients had colon cancer and 9 patients had rectal cancer, with all stages of disease represented from carcinoma in situ (stage 0) to stage IV cancer. Almost half of the patient cohort received neoadjuvant chemotherapy/radiotherapy in addition to surgery. Fifty percent of patients reported English as their primary language. Patients came from a variety of backgrounds, including Canadian, European, Southeast Asian and Latin American descent. Patient education ranged from none to a graduate or postgraduate degree, with 55% completing up to elementary or high school. The vast majority of patients were either retired or currently unemployed, which may be a reflection of the age distribution, as most patients were older than retirement age (≥ 65 yr).

Complexities of shared decision-making

We identified 3 major themes or factors that appeared to shape decision-making in this context: the role of family and social support, facilitators and barriers to patient confidence and informed decision-making, and perceived lack of control and choice.

The role of family and social support

Family is a crucial adjunct to the physician–patient interaction. Specifically, family members may assume 1 (or more) of 3 roles in SDM. First, a patient's family may offer opinions and ideas toward treatment or collaborate with patients when making decisions about their care, and therefore ultimately influence decisions. This can also impact motivation toward treatment. Patients 5 and 7, respectively, stated,

It was my decision and my family's decision. When we knew that I had cancer, we immediately followed this up. We discussed all the options together and I considered what my

Table 1. Demographic and clinical characteristics of the patient cohort

Characteristic	No. (%) of patients	Characteristic	No. (%) of patients
Sex		Education	
Male	11 (55)	None	1 (5)
Female	9 (45)	Elementary	5 (25)
Age, yr		High school	6 (30)
< 50	1 (5)	College	2 (10)
50–59	1 (5)	Undergraduate*	3 (15)
60–69	7 (35)	Graduate or postgraduate	3 (15)
≥ 70	11 (55)	Employment status	
Primary language		Unemployed/retired	18 (90)
English	10 (50)	Employed	2 (10)
Portuguese	5 (25)	Tumour site	
Arabic	1 (5)	Colon	11 (55)
Filipino	1 (5)	Rectum	9 (45)
Polish	1 (5)	Cancer stage	
Russian	1 (5)	0 (carcinoma in situ)	1 (5)
Spanish	1 (5)	I	4 (20)
Race		II	4 (20)
Portuguese European	5 (25)	III	6 (30)
Italian European	3 (15)	IV	5 (25)
African	2 (10)	Surgical procedure	
British	1 (5)	Lower anterior resection	10 (50)
White Canadian	1 (5)	Hemicolectomy	5 (25)
Jewish Canadian	1 (5)	Abdominoperineal resection	2 (10)
Ecuadorian	1 (5)	Subtotal colectomy	2 (10)
Filipino	1 (5)	Total colectomy	1 (5)
Israeli Muslim	1 (5)	Neoadjuvant therapy	9 (45)
Latin American	1 (5)		
Polish European	1 (5)		
Russian European	1 (5)		
Spanish European	1 (5)		

*One participant completed only the first year of university.

children were telling me. Sometimes they knew more about the benefits of surgery or chemotherapy than I did.

It's my kids, my kids they want me to live and so does my wife. My kids say 'Daddy, we don't want you to die.' And this played a big role in my decision-making process.

Second, family members can function as interpreters for patients whose primary language is not English, obviating the need for third-party translators. This may result in greater patient honesty, trust and comfort, and thus serve to support patient decision-making. One patient's son said,

There is a language barrier so at all times, it would be either myself or my sister with him while he's speaking with the physician or any health care team member, and as such, we would do our best to give him all of the relevant information that they shared with us. He would often take the initiative to make decisions on his own.

Finally, family and friends are a source of practical, emotional and psychological support for patients. Patients 19 and 16, respectively, stated,

Even my daughter-in-law comes, she drives me down to clinic, my son too, and oftentimes my daughter. As a family, we are together.

I have a lot of friends in and around the community. And they're very supportive, always there to give encouraging words of support.

Furthermore, having a robust social support network reduces the burden of decision-making, eases uncertainty and improves patient experience. Patients 8 and 13, respectively, stated,

I think the whole thing was not knowing what the outcome was going to be, whether I was going to be okay after having the surgery. But I had excellent support from my husband and my family so that helped mitigate some of the anxiety.

My family and friends are my go-to source for emotional and psychological comfort. I can't imagine how I'd deal with a diagnosis like stage III colon cancer without their everlasting support. They keep me sane and most importantly, they make me happy, even when everything else is not going my way.

Facilitators and barriers to decision-making

Facilitators and barriers in the decision-making process affect patient confidence in their care and ability to make informed decisions. For instance, patient perception of quality and staff characteristics can strengthen trust. Patients 2 and 3, respectively, stated,

I'm so lucky because I have very good doctors. I am glad I went to the right hospital and received treatment from an excellent team of surgeons and nurses. They treated me, they made sure I lived as long as possible.

I know I am going for a big surgery and I only believe in you. I believe in your books, I believe in your education, and I believe that you are a good doctor. I don't believe in anything else.

Moreover, patients rely on the information they receive from providers in order to make decisions. Patients 7 and 14, respectively, stated,

We definitely trusted the information. We relied on the doctors and the staff. Our surgeon was very reassuring. He said that he would have treated his dad in the same way, you know? And the fact he was confident in his approach, it made us feel very comfortable and safe.

I felt very secure, in his explanation of what he was going to do. I was very confident in him, as it seemed like he had a good handle on what I was going through. He's a fabulous doctor, I can tell you that!

Additionally, personal beliefs and convictions can help patients cope through the decision-making process. Patients 20 and 1, respectively, stated,

I rely on the specialist. I have faith and they are the experts so I put myself in their hands. And the hands of God of course."

I know it's a little hard for me, but what can I do? I try to survive. I don't want to die yet. I don't want to give up, I want to go all the way. I hope I can stay in this world a little bit more.

However, language is a potential barrier to the SDM process. Patient 11's family and Patient 8, respectively, stated,

Certainly the language barrier is there. Another barrier I would identify is the lack of educational resources on his particular type of cancer that he can read and understand, like in his language.

Although we were happy with the care we received, it made it tough at times to really understand what my options were. I can manage with English, but getting information in Spanish definitely would have made a big difference in the decision-making process.

Lack of choice and control in decision-making

Many patients feel a limited sense of control over decisions and that there are limited alternatives for treatment. This

is particularly true if patients are admitted to hospital on an emergency basis. Patients 18, 16 and 7, respectively, stated,

It was done so quickly I did not really have a chance to make any decisions. I just did exactly what they told me to do.

On Tuesday I got a phone call and on Thursday I was on the operating table. There weren't any real decisions to make. It was made for me.

I do whatever they tell me to do. It's not like I was given much of a choice or menu of options anyways!

Furthermore, the life-threatening nature of the initial cancer diagnosis leads patients to believe that surgical intervention is inevitable and that there are few, if any, decisions to be made. This perception of lack of choice and control in decision-making is held by patients across all cancer stages. Patient 9 stated,

(...) he told me the most is 3 months if you don't get the surgery. In my mind, this meant that I really didn't have much of a choice. I had to get this thing out of me, otherwise, it will take my life.

In fact, many patients in our study were given limited options. They were told or advised what treatment course would be taken (and patients generally accepted this).

Influence of sociodemographic and cultural factors

It is important to recognize that all 3 themes transcended differences in sociodemographic variables, such as age, language, race and education. Patient 3 stated,

Finding support in your family and friends is a lot more important than cultural background I think. Background, we are all the same. Whether we are born in a different country, raised to a different value, but if you have these values I think you go through life a little easier.

While several patients identified language as a potential barrier to the SDM process, their level of involvement in

decision-making, as measured using a 10-point Likert scale, did not differ from that among patients who spoke English as a primary language (Table 2). The number of family members present in clinic was also similar between the groups. When patients were stratified based on race, there was no difference in level of involvement in care or familial support.

DISCUSSION

Using a qualitative research design, we studied the complexities of SDM for patients undergoing a major operation for CRC. Three major themes were identified that represent factors shaping decision-making in this setting: 1) family plays a central role in supporting patients, and social support reduces patient burden; 2) patient confidence in care and the decision-making process is influenced by facilitators and barriers, such as provider communication and information; and 3) patients experience and accept a lack of control and limited choice in treatment decisions. These findings persisted across race and disease stage, which suggests that cultural influences may be less important in patient decision-making than family engagement and social network. More importantly, this calls into question the very notion of SDM in colorectal surgical oncology.

A total of 20 patient interviews were completed, at which time data saturation was achieved. A recent experiment using 60 qualitative interviews found that saturation occurred within the first 12 interviews and that elements for meta-themes were present as early as the first 6 interviews.¹⁶ Therefore, we believe that our sample size was sufficient for thematic exploration of this topic.

The findings from our study add meaningful substance to the existing, yet very limited, body of literature on SDM among patients with CRC undergoing surgery. Previous studies have focused almost exclusively on the physician-patient interaction, with little, if any, emphasis on the impact of familial or cultural factors in the SDM process.^{1-11,17-28} Patients in our cohort valued family as a crucial adjunct to the health care team, recognizing 3 specific roles for family members (collaborators, interpreters and supporters) that enable and influence decision-making while reducing the burden on patients and enhancing their overall experience. Consequently, within a model of patient-centred care, the involvement of family in patient decision-making is an important consideration for surgeons and other health care providers involved in their cancer care. Moreover, family engagement appears to be important despite race, and level of involvement in decision-making is similar between patients who speak English as a primary language and those who do not (likely owing to the presence of family members in clinic who provided translation). Although family members may not have the same level of health

Table 2. Level of involvement in care and social support by primary language and race*

Characteristic	Factor; mean (median)	
	Level of involvement	No. of family members in clinic
English as primary language (n = 10)	9 (10)	2 (2)
English as secondary language (n = 10)	8 (10)	1.9 (2)
European (n = 11)	8.2 (10)	1.9 (2)
Non-European (n = 9)	8.9 (10)	2 (2)

*Rated on a 10-point Likert scale.

literacy as professional interpreters, they may be able to facilitate understanding by serving as a cultural advisor or advocate for the patient. While it is essential to make professional interpreters available, family involvement is often important to a patient's identity and can facilitate informed and autonomous decision-making.²⁹ Psychosocial oncology services should be used to augment emotional and psychological support, especially for patients who do not have a strong social support network.

Furthermore, favourable surgeon characteristics and adequate patient education can improve perception of quality and confidence in the care being delivered. Seriously ill patients tend to value a surgeon who is capable of balancing honesty and open communication with hope and empathy.³⁰ A confident and compassionate surgeon must also strive to educate patients about their disease, as patients who are psychologically prepared for surgery tend to have better surgical outcomes. Meeting the patient's need for information regarding the surgical experience can also alleviate certain fears and misunderstandings about care. Patients who are more knowledgeable about what to expect after surgery and who have an opportunity to express their goals and opinions often cope better in the postoperative period.³¹ A humanistic bedside manner, therefore, goes a long way in fostering a strong doctor-patient relationship, which ultimately empowers patients and their families to make informed treatment decisions with a high degree of satisfaction.

A limited sense of control over decisions and a perception of lack of choice were also pervasive in the patient interviews. A majority of patients expressed an increased sense of vulnerability. Patients, particularly those admitted to hospital on an emergency basis or with end-stage disease, felt helpless as they believed that progression of disease was out of their hands. Despite being informed about treatment alternatives, the life-threatening nature of CRC led patients to believe that surgical intervention was inevitable. In the future, informing patients about genetic predisposition and the role of lifestyle factors in cancer may reduce fatalistic attitudes and increase their sense of control over their diagnosis.

Although SDM among patients, families and health professionals is increasingly advocated as optimal, there is contradictory evidence as to what role patients with cancer prefer to play in the decision-making process. A previous study reported that patients with CRC wanted to be informed and involved in their care, but did not necessarily want to make any decisions.¹ Another small pilot study of patients with CRC found that more than two-thirds of participants preferred a passive decision-making role; however, 80% of patients in the study said that they had not been presented with any treatment alternatives.²⁶ We found similar results. Although patients in our study were educated about their diagnosis

and treatment options —surgery, radiation, chemotherapy, and watchful waiting — a majority were comfortable with deferring the final decision and treatment plan to the “expert” members of the health care team. Notably, surgery remains the primary curative treatment for CRC, and so it is understandable that many patients may believe it to be their only option.

This preference for passive decision-making has also been observed in patients with different cancers. A UK study of 150 women with newly diagnosed breast cancer reported that 52% relied on doctors to make decisions about their care, preferring instead to be involved passively in decision-making.²⁷ Similarly, a study involving 57 Canadian men with prostate cancer found that 58% favoured the same.²⁸ Patient acceptance of passive decision-making in cancer care might be reflective of their limited medical knowledge and general trust in medical expertise.^{27,28} This exemplifies the concept of “entrustment” described by McKneally and colleagues,³² who interviewed patients after major surgery. The patients they interviewed rejected the concept of weighing risks and benefits and other processes aimed to maximize their autonomy. They were also resigned to the risks of treatment and accepted the expert recommendation to consent to surgery. In essence, the patients in the study universally trusted “the competence and willingness of their surgeons to make good treatment decisions on their behalf.”^{32,33} Surgeons and other health care providers must strive toward cultivating a sense of trust and open communication with their patients in order to foster trust and further enrich the doctor-patient relationship.

There is a tremendous focus on cancer in the media and a relentless effort to fight advanced stages of the disease, which ultimately shapes public opinion and in turn patient motivation toward treatment in clinical practice. Patients are often willing to undergo aggressive treatments with small benefits in spite of major toxicity and treatment-related morbidity.³⁴ Surgeon bias toward surgery may also contribute to patient interest in surgery. However, in an era of conscious health spending, increased awareness of treatment options and the evidence surrounding each is important to improve public understanding of disease course. Furthermore, critical discussions among patients, families and providers about available treatment options are needed to prevent unnecessary intervention, as there is growing evidence that surgery may not add benefit in patients with some advanced cancers; for example, surgical resection of metastatic CRC in a patient with minimal symptoms attributable to the primary tumour often does not improve outcome and may delay systemic therapy.³⁵ Thus, there may also be a role for surgical oncologists in initiating early conversations about palliative care with patients and their families in select cases; SDM can serve as a platform to promote these discussions in the clinical setting.

Limitations

The results of our study are subject to several limitations. The findings represent the views of patients under the care of a single surgical oncologist. The use of convenience sampling, resulting in a cohort with 90% of patients older than 65 years, may also limit the generalizability of our results. Future studies should aim to recruit a diverse cross-section of patients undergoing CRC surgery with unique treatment experiences to further explore the themes presented in this study. Moreover, we focused on the disease-directed treatment decision-making process from the patient's perspective. Additional research that examines surgeon and other health care provider perspectives as well as other aspects of care would provide a more comprehensive picture of SDM in this context. For instance, it would be beneficial to explore the perspectives of patients who declined surgery and the decision-making process that results in a nonsurgical approach to CRC. Finally, although patients were in the early postoperative phase (within 3 mo of surgery) during interviews, some of our results may be limited by recall bias. In retrospect, postoperative patients may see their choice to undergo surgery as inevitable, thereby conveying a relative lack of choice or control in the decision-making process. This underscores the importance of future prospective studies to further elucidate the intricacies of SDM among patients with CRC.

Nonetheless, this study expands our understanding of the current milieu of SDM in CRC surgery. Surgeons and other health care providers must learn to appreciate the role of family as a vital addition to the patient-provider dyad and that familial influences are integral to SDM, patient satisfaction and empowerment. Physicians must also remain sensitive to each patient's unique preferences, as the term "decision-making" can be a potential misnomer, particularly for patients undergoing surgical resection of late-stage disease.

CONCLUSION

Sociodemographic factors, including age, culture and education, may be less important than family engagement and social support for patients who require surgical treatment for CRC. Health care providers must be aware of the uniqueness of decision-making in this context in order to empower patients and their families. Institutional measures must be undertaken to enhance patient education about SDM. Instructive resources, including information packages and brochures in a patient's primary language, can help patients and their families make informed and meaningful treatment decisions.

Acknowledgments: The authors are grateful for the support of those who assisted with study design.

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Competing interests: None declared.

Contributors: All authors designed the study. D. Hirpara acquired and analyzed the data, which M. Cleghorn and F. Quereshy also analyzed. D. Hirpara and M. Cleghorn wrote the article, which all authors reviewed and approved for publication.

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