

Patients' experiences with continuity of cancer care in Canada

Results from the CanIMPACT study

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Abstract

Objective To explore patient perspectives on and experiences with the coordination and continuity of cancer care.

Design Qualitative study using semistructured telephone interviews.

Setting Canada.

Participants Thirty-eight breast and colorectal cancer survivors 1 to 4 years after diagnosis.

Methods Using a constructivist grounded theory approach, semistructured telephone interviews were conducted with the participants. The interviews were digitally recorded, transcribed verbatim, and proofread. Transcripts were reviewed to create a focused coding scheme that was used to develop categories for participants' experiences.

EDITOR'S KEY POINTS

- The goal of this study was to explore how patients experience continuity of cancer care. However, continuity of care is not a concept easily recognized by patients. Patients perceived the cancer care continuum (diagnosis, treatment, and survivorship) and continuity of care as cancer care in general, and their cancer care experience was typically framed by their relationships with their health care providers (HCPs).
- Based on patients' experiences, the core components of providing good continuity and well coordinated care include good communication, positive relationships with HCPs, timely information sharing, and access to care.
- Communication processes in cancer care are directly related to how patients experience continuity of care. Patients identified good communication as a core component of feeling that they were connected to their HCPs and that their overall cancer care was well coordinated. Effective communication was the foundation of a positive experience with cancer care, and poor communication often led to a negative experience with cancer care.

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Main findings Although this study focused on the continuity of cancer care, patients described their experiences with cancer care in general, concentrating predominantly on their relationships with individual health care providers (HCPs). Based on patients' experiences, several themes were identified as the core components of providing good continuity and well coordinated care. The most important overarching theme was communication, which overlapped with 4 other themes: patient-HCP relationships, the role of HCPs, lack of access to care, and timely and tailored information.

Conclusion Patients believed that good communication between HCPs and patients was key to improving the overall continuity of cancer care. Continuity of care is an important theoretical concept in cancer care, but it is not easily recognized by patients. They perceive the cancer care continuum and continuity of care as cancer care in general, which is typically framed by the individual relationships with their HCPs. Future research and interventions need to focus on finding and testing ways to improve communication to enhance continuity of cancer care.

Ce que les patients pensent de la continuité de soins pour leur cancer

Résultats de l'étude CanIMPACT

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Résumé

Objectif Vérifier ce que les patients pensent de la coordination et de la continuité des soins de leur cancer et l'expérience qu'ils en ont.

Type d'étude Étude qualitative au moyen d'entrevues téléphoniques semi-structurées.

Contexte Le Canada.

Participants Un total de 38 survivants du cancer du sein ou du cancer colorectal, entre 1 et 4 ans après le diagnostic.

Méthodes Au moyen d'une méthode de théorisation ancrée constructiviste, des entrevues téléphoniques semi-structurées ont été effectuées avec les participants. Ces entrevues ont été enregistrées sur support numérique, transcrites mot à mot et corrigées. Les transcrits ont été révisés afin de créer un mode de codage plus précis, lequel a servi à développer des catégories permettant de classer les opinions des participants.

Principales observations Même si l'étude portait principalement sur la continuité des soins du cancer, les patients décrivaient leur expérience des soins du cancer en général, en insistant sur leur relation avec certains de leurs soignants. À partir des expériences des patients, on a pu identifier plusieurs thèmes comme étant les éléments principaux qui assurent des soins continus et bien coordonnés. Celui qui était assurément le plus important était la communication, laquelle était en rapport avec 4 autres thèmes: la relation patient-soignant, le rôle des soignants, un manque d'accès aux soins et une information adaptée partagée en temps opportun.

Conclusion Les patients estimaient qu'une bonne communication entre patients et soignants est la clé qui permet d'améliorer la continuité des soins du cancer. La continuité des soins des cancéreux est un important concept théorique qui n'est pas toujours bien compris par les patients. Ils perçoivent le continuum des soins du cancer et la continuité des soins comme étant les soins du cancer en général, qui dépendent généralement de leur relation avec leurs soignants. Les études et les interventions futures devront s'efforcer surtout de trouver et de tester des façons d'améliorer la communication afin de favoriser une bonne continuité des soins.

POINTS DE REPÈRE DU RÉDACTEUR

- Cette étude avait pour but de vérifier l'opinion des patients sur la continuité de soins pour leur cancer. Précisons toutefois que le concept de continuité des soins n'est pas toujours bien compris par les patients. Ils voient le continuum des soins du cancer (diagnostic, traitement, survie) et la continuité des soins comme les soins pour le cancer en général, et l'opinion qu'ils en ont dépend habituellement de leur relation avec les soignants.
- D'après l'expérience qu'en ont les patients, les principaux facteurs qui assurent une continuité et une coordination adéquates des soins sont une bonne communication, une bonne relation avec les soignants, un partage de l'information en temps opportun et un bon accès aux soins
- Les processus de communication sont directement liés à la façon dont les patients expérimentent la continuité des soins.. Pour eux, une bonne communication est un élément primordial qui leur permet de sentir qu'ils ont une relation adéquate avec leurs soignants et que les soins de leur cancer sont bien coordonnés. Une communication efficace était donc à la base d'une expérience positive des soins du cancer, tandis qu'une mauvaise communication entraînait souvent une expérience négative de ces soins.

Cet article a fait l'objet d'une révision par des pairs.
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Cancer care is often fragmented, as patients frequently transition between different health care providers (HCPs) in multiple settings and sometimes across several geographic areas. Over the years research has been undertaken to understand the relationship between cancer patients and their HCPs; however, this is an evolving relationship that changes with the advancement of cancer treatments.¹⁻⁴ A key component of this relationship is the provision of well coordinated and efficient care.^{5,6} Thus, the continuity of cancer care has become a crucial issue along the entire cancer care continuum.⁷⁻⁹ The College of Family Physicians of Canada has identified continuity of patient care as 1 of the 3 core components of their education curriculum.¹⁰

Continuity of care is defined as the extent to which the care experienced by a patient is coherent, connected, and situated within his or her unique needs and personal circumstances.¹¹ Although the terms *coordination of health care* and *continuity of care* are often used interchangeably, *coordination of health care* focuses on how services are delivered, whereas *continuity of care* describes how an individual experiences the integration of services.¹¹⁻¹⁴ Although the parameters of continuity of care might differ across health disciplines, 3 core domains of continuity have been identified: relational, informational, and management continuity.^{11,15} The last 2 types are system focused, while relational continuity focuses on the patient-provider relationship. As cancer patients work with different HCPs in a multitude of settings over time, it is important to foster relationships between patients and HCPs (relational continuity), enhance the exchange of information among HCPs (informational continuity), and increase the level of collaboration to organize patient care to ensure that it is coherent and connected (management continuity). Freeman and Shepperd point out that continuity of care is typically framed within the context of the process of care, which is usually defined by clinicians and researchers; however, they note that further research is needed to explore what continuity of care means to patients.¹⁶

This study is nested within a larger mixed-methods program of research from the CanIMPACT [Canadian Team to Improve Community-Based Cancer Care along the Continuum] study. This larger study is focused on improving the coordination and continuity of care, particularly between family physicians and cancer specialists, for breast and colorectal cancer patients. The specific goal of this qualitative study was to explore patients' perspectives on and experiences with continuity of cancer care in Canada.

METHODS

We selected a qualitative constructivist grounded theory methodology for the data collection of this component of the study so as to be able to "give voice to the

participants."¹⁷ Constructivist grounded theory is rooted in grounded theory, but focuses on the subjective "inter-relationship between researchers and participant[s]."¹⁸ The construction of theory is an outcome of the interpretation of the stories the participants tell (in the interviews).¹⁸ Based on the constructivist grounded theory approach as characterized by Charmaz, we conducted semistructured telephone interviews with self-referred breast and colorectal cancer survivors from across Canada 1 to 4 years after diagnosis.^{17,19} Before participant recruitment and data collection, ethics approval was obtained from all relevant research ethics boards.* Patients were recruited using a theoretical sampling technique to ensure a diverse representation of patients based on age, breast or colorectal cancer, geographical region, and urban or rural residence.²⁰ Recruitment information was distributed via breast and colorectal cancer groups such as ostomy support organizations or support groups, electronic newsletters, online message boards, public forums, and social networking sites. Interested breast or colorectal cancer survivors contacted the research coordinator (J.E.) via e-mail, Facebook, Twitter, or a toll-free telephone number and were then screened for eligibility once they agreed to participate. Recruitment was terminated when saturation of themes occurred.¹⁹

Before the interviews, potential participants were sent a copy of the consent form and were invited to discuss any questions or concerns about the study. Procedures for oral consent were followed before the commencement of the interview.²¹ All interview questions were open ended. The interview began with a question asking patients to describe their cancer care experiences starting with the time leading up to the diagnosis through to where they were in their cancer journey at the time of the interview. Other questions focused on experiences with the coordination of care, the roles of the HCPs involved in their care, self-management, personalized medicine, and recommendations to improve cancer care. After the interview, sociodemographic information was collected to create a patient profile. Results related to the questions of personalized medicine have been reported elsewhere (O'Brien et al, unpublished data, 2016).

Interviews were conducted on the telephone and not in person owing to cost considerations, as participants were spread out all over the country. The interviews were digitally recorded, transcribed verbatim, and proofread. Three co-investigators (B.M., J.C.C., M.A.O.) and the research coordinator (J.E.) each read and discussed the same 3

*Ethics approval was obtained from the following research ethics boards: Horizon Health Network, University of Toronto, University of Manitoba, Newfoundland and Labrador Health Research Board, University Health Network (Toronto), University of Alberta, and the Centre hospitalier universitaire de Québec, Laval University.

transcripts to create the focused coding scheme during a 2-day face-to-face meeting. The purpose of the coding was to develop categories that “crystallize participants’ experience[s].”¹⁹ The research coordinator continued the coding and the refinement of the codes for the remainder of the transcripts; all 4 of the researchers were in regular e-mail contact during this coding process. All transcripts were coded line by line, using the constant comparison method and with the assistance of NVivo, version 10, qualitative data analysis software. In grounded theory studies, data collection and analysis occur simultaneously to allow the researchers to use the data as it is analyzed to guide the rest of the study.¹⁷ Patients received a study summary of findings at the completion of data analysis and were invited to review and comment as a form of member checking.^{17,22} The intent of this study was not to develop a new theoretical framework but to theorize about how patients experience the continuity of cancer care.

FINDINGS

Thirty-eight breast and colorectal cancer survivors participated in a telephone interview: 20 female breast cancer survivors; 10 female colorectal cancer survivors; 6 male colorectal cancer survivors; and 2 female cancer survivors diagnosed with both breast and colorectal cancer. Participant characteristics are presented in **Table 1**.

The goal of this qualitative study was to explore breast and colorectal cancer patients’ experiences with the

Table 1. Characteristics of patients (N = 38): Mean age at diagnosis was 57 (range 32–86).

CHARACTERISTICS	N (%)
Sex	
• Male	6 (16)
• Female	32 (84)
Type of cancer	
• Breast	20 (53)
• Colorectal	16 (42)
• Breast and colorectal	2 (5)
Location	
• Urban	27 (71)
• Rural (< 10 000 population)	11 (29)
Region*	
• Western Canada	16 (42)
• Central Canada	13 (34)
• Eastern Canada	9 (24)

*Western Canada includes British Columbia, Saskatchewan, Alberta, and Manitoba. Central Canada includes Ontario and Quebec. Eastern Canada includes New Brunswick, Prince Edward Island, Nova Scotia, and Newfoundland and Labrador.

coordination and continuity of cancer care. However, as the study progressed, it became clear that *coordination of care* and *continuity of care* were not easily defined or recognized by patients; these are constructs defined by clinicians and researchers. Most patients perceived the experiences with coordination of care and continuity of cancer care as cancer care in general, and described their continuity of care more as their individual relationships with the various HCPs and not how the transition and integration of care among various HCPs took place. Patients mostly focused on what happened with their cancer care at a personal level rather than at a system level. As the following breast cancer survivor described, even though she had good access to care and she perceived that the coordination of her care ran smoothly, she was still missing the link to bring all of these parts together on a personal level: “Accessing care was good. They were all wonderful and very supporting, and everything ran smoothly Um, but it was very distinct units that I was going to, and there really was no one, you know, one point of continuity.” (Female, Breast cancer, Interview 1)

She went on to suggest a solution to the missing connection: to have one contact person to act as a link between the patient and all of the HCPs involved.

My family doctor was being copied on things, but at this point I’m dealing with the specialists directly. And, and I’m moving from one unit to another To me it would’ve been so helpful to have like one contact person throughout the process that I could call with questions and help me understand what was going on, like a nurse coordinator. (Female, Breast cancer, Interview 1)

Although patients in our study talked more in general terms about their overall cancer care rather than specifically about the continuity of care, we have identified the following themes based on their experiences, which are the core components of providing good continuity and well coordinated care. The most important overarching theme was communication. Four other main themes were as follows: patient-HCP relationships, the role of HCPs, lack of access to care, and timely and tailored information. These 4 themes are also not mutually exclusive and often overlap, with communication being at the core of all of the themes described. Patients often shared both positive and negative experiences related to these themes. When the experience was seen as positive (eg, good patient-HCP communication), then patients were more likely to be satisfied with the cancer care in general.

Communication. Communication, good or bad, influenced all areas of care and the overall cancer care experience. Patients wanted HCPs who listened, explained, and were approachable and accessible. One patient

described his experiences with 2 different surgeons (one experience was negative and one was positive) and the difference good communication made to his cancer care experience. His first negative communication experience with a cancer specialist was described as follows:

The surgeon comes in and he tells me his name and then he starts telling me horror stories about what he's going to be doing to me ... and I said, "Do you know my name? Do you know who I am?" And he looked at my chart and said, "Oh, your name is [insert name]. I said, "Oh, did you know my name before you looked at the chart?" And he said, "Well, I know you have cancer." I said, "First of all, I am a person; I am not a person with a disease. I am a person who happens to have a disease right now." (Male, Colorectal cancer, Interview 20)

After transferring his care to a different hospital, the communication experience with a different surgeon changed his outlook on his cancer care for the better.

The surgeon comes over and introduces himself and he said, "Look [insert name], I'm going to tell you right now that chances are you have a malignant cancer. You will have thousands of questions to ask and I'm here to answer all of them." I knew at that point that I was in the best hands that I could possibly be in. (Male, Colorectal cancer, Interview 20)

Another communication issue that influenced patients' experiences was how poor information technology affected the ability of HCPs to have timely access to health records. Patients described frequent delays in the system related to incompatible or out-of-date electronic medical records, which added stress for the patients.

I had some severe complications during surgery; in fact, I almost died. Two weeks later I went to see my medical oncologist and he didn't know anything about this. When he went to look it up in the system, the reports hadn't even been scanned into the system yet. I mean, my medical oncologist not being able to access reports when I almost died 2 weeks ago, like that's a big deal. (Female, Breast cancer, Interview 1)

Patient-HCP relationships. Patients' relationships with their HCPs had a considerable influence on their overall cancer care experiences. This relationship was often determined by communication style (eg, friendliness), approachability, and availability of the HCP, as well as having feelings of trust toward the HCP. If patients trusted the HCP, they typically felt confident in that HCP's ability to provide high-quality care. However, if this trust was broken—for example, owing to a delayed diagnosis—then patients had difficulty regaining that trust or

respecting that HCP's professional ability. The importance of this relationship was most often discussed in relation to the family physician.

My family doctor, I still have him as the family doctor because it's so difficult getting a doctor in this town ... I still have him and use him because I need him but I don't have a whole lot of respect for him anymore and that's only because I had such a hard time with my diagnosis, you know, getting things going for me, getting to the bottom of my illness. (Female, Colorectal cancer, Interview 33)

Role of HCPs. Uncertainty about HCPs' roles was described as a challenge by some patients. Many were uncertain of who was in charge of their care or who they should contact with cancer-related questions, particularly as they transitioned from acute care to the survivorship phase. In some cases, the patients were expected to be the managers of their care whether they wanted to be or not. This expectation was perceived as stressful by many patients.

I asked my oncologist the first time I met him. I said, "I feel like there are so many parts and people and, you know." I said, Who is the project manager? And he said, "You are." And I was like, what?! That sucks, I'm the sick person! (Female, Breast cancer, Interview 10)

On the flip side, patients who had positive cancer care experiences and seemingly good continuity of care between the various HCPs often attributed it to having one main contact person for all cancer-related questions. This contact person was often either a patient navigator, a nurse in the cancer clinic, or the patient's family physician.

Access to care. Another theme that was frequently discussed by the patients was access (or lack thereof) to care, specifically the difficulties getting appointments with their family physicians, if they had one, and difficulties finding a family physician if they did not have one. As one patient from a rural area explained: "I should change doctors but I'm in a small area and there's not a lot of doctors so I had to stay with my family physician I never saw her [family physician] again [after diagnosis] I could never get an appointment." (Female, Breast cancer, Interview 34)

Patients who had positive experiences accessing care often attributed them to the comprehensive cancer care program or clinic they attended. Many patients described these programs or clinics as a "1-stop shopping" care destination with access to a variety of HCPs in one place and fully coordinated care.

It's a comprehensive breast cancer program It includes physiotherapy, an occupational health nurse, an oncology nurse comes in to do a talk about different types of chemo drugs ... a dietitian You would go once a week and they would have all these different topics that they would go through I thought that was really well done. (Female, Breast cancer, Interview 5)

Timely and tailored information. Patients also discussed the importance of access to information about their disease and survivorship issues, specifically the timing of information sharing. Some described feeling overwhelmed at the time of their diagnosis when most of the information was given. Patients described how hard it was to process any additional information that was given beyond initial diagnosis and they thought that they retained little information. Patients recommended that the information offered to the patient be specific to his or her needs at that particular time, that the information be available in a variety of formats (eg, website recommendations, pamphlets) based on patient preference, and that consultations occur at a time suitable for the patient.

I wish they would have said to me, you know, "We have some information available. What do you think you would like to hear about now?" Because I didn't really want to hear about postmastectomy bras and whatnot at that time [when receiving the diagnosis]. I wasn't ready for that. (Female, Breast cancer, Interview 38)

Many patients also expressed a great need for more support and information from family physicians regarding cancer survivorship issues (eg, side effects of hormone therapies) and psychosocial concerns after cancer care has been completed. Patients believed that family physicians could benefit from more education in this area.

I had a lot of mental health issues when I was discharged and I got sent off to go live my life like everything is normal now You need psychosocial supports at that point as well [survivorship]. And you know, family physicians are just too busy to help you with that sort of psychosocial aspect. (Female, Colorectal cancer, Interview 36)

DISCUSSION

The results of our study highlight the importance of good communication, positive relationships with HCPs, the timing of information sharing with patients, and enhancing patient access to care to help improve continuity of cancer care and the overall care experience for patients. Continuity of care is an important aspect in all health care delivery; however, it is not an easy concept to define or

measure.^{7,11} Our findings are congruent with the 3 core domains of continuity (relational, informational, and management) identified in the literature,^{9,11,15} emphasizing the particular importance of relational continuity (communication and relationships between patients and HCPs) from the patients' perspective. Good communication is the cornerstone of high-quality cancer care, whereas poor communication can colour the entire cancer care experience as unsatisfactory and inadequate. Patients want to be treated with respect, kept informed, and encouraged to become active participants in their care decisions.

Most patients in our study never really discussed continuity of care as it is understood by clinicians and researchers. Rather, through describing their cancer care continuum, they expressed their experiences of continuity. *Continuity of care* is defined in the literature as coherent and connected cancer care that takes patients' unique needs into consideration.^{13,14} However, it appears that the patients perceive their cancer care more in terms of the one-on-one interactions and care provided by HCPs (relational continuity of care) at any given time rather than a set of "behind the scenes" actions that take place to coordinate the care. As Haggerty and colleagues explained, coordination of care often refers to the collaboration among clinicians of which patients might not always be aware.⁹ Collaboration among HCPs has been identified as one of the key components of good continuity of care; however, these collaborations might not always be visible to patients and many are not aware of what happens behind the scenes.⁹

The importance of communication and relational continuity in cancer care is not a new finding. Studies have shown over the past 30 years that good communication and relationships with HCPs are priorities for improving care continuity and quality as well as being key elements for improving patient satisfaction.^{5,6,9,14,16,23-26} The US National Cancer Institute identified communication as an important issue and described 6 key functions of effective communication processes in cancer care: fostering clinician-patient relationships, exchanging information, responding to patients' emotions, managing uncertainty, making decisions, and enabling patient self-management.²⁶ Based on our findings, these core functions of communication processes in cancer care are directly related to how patients experience continuity of care. We theorize that although patients might not always identify specific elements of continuity of care, they do identify communication as a core component of feeling that they are connected to their HCPs and that their overall cancer care is well coordinated.

If effective communication is the cornerstone of good clinical practice and continuity in cancer care, why do patients still report experiencing ineffective and inadequate communication in many cases? It likely speaks to the complexity of effective communication, but further we

speculate that there are a number of other reasons as well. It could be that patients have unrealistically high expectations for the relationships with their HCPs, or perhaps that not enough emphasis has been given to communication-skills training in medical education programs. Many issues described in our study are experienced by patients during survivorship care. Growing numbers of patients are reaching that phase owing to an increase in cancer survival in general. As cancer care becomes more multifaceted and more HCPs (including family physicians) become involved in the care of individual patients, the complexity of communication needs and resources to fully address patient needs also increases. As the health care system shifts its priorities to provide more patient-centred care, finding ways to address these communication gaps and ways of fostering better patient-HCP relationships must become more of a priority to improve the overall continuity of care. Hence, we propose that future research and interventions need to focus on finding and testing ways to improve communication to enhance continuity of cancer care.

Limitations

Our study results are based on interviews with breast and colorectal cancer survivors and therefore might not reflect the experiences of individuals diagnosed with other cancers. As is most common in studies, our sample is based on a self-selected sample of patients; we acknowledge those who have experienced challenges with their cancer care might have been more inclined to participate. Also, as with most studies, more women than men participated, perhaps creating a sex bias.

Conclusion

Continuity of care is an important theoretical concept in cancer care but it is not easily recognized by patients. They perceive their cancer care continuum (diagnosis, treatment, and survivorship) and continuity of care as cancer care in general, which is typically framed by the individual relationships with the care providers. Good cancer care is built on the foundation of effective communication, and poor communication often leads to negative experiences regarding cancer care. This issue has been identified for some time but it is still prevalent in the current cancer care system. 

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Contributors

Ms Easley collected and analyzed the qualitative data and wrote the first draft of this manuscript. **Dr Miedema** was the lead of the qualitative group and supervised the data collection and analysis, assisted with the data analysis framework, and contributed to the writing and editing of the manuscript. **Drs Carroll and O'Brien** assisted with the development of the data analysis framework and contributed to the writing and editing of the manuscript. **Dr Manca** was also a member of the qualitative group and assisted with the editing of the manuscript. **Dr Grunfeld** is the principal investigator for the CanIMPACT team and contributed to the overall study design, managed team members, and contributed to the editing of the manuscript.

Competing interests

None declared

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