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## **Cover Page Footnote**

The authors wish to acknowledge the work of Isabelle Lamontagne and Catherine Morin-Boulay in phase 1 of the study and wish to express their deepest gratitude to all the study participants who took the time to share their experience and opinions in order to help improve our services.

## Usefulness of a patient experience study to adjust psychosocial oncology and spiritual care services according to patients' needs

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### Abstract

Little is known about how cancer patients experience psychosocial and spiritual care services and about what services they feel should be offered in order to help them meet their actual needs. This study's main goal was to examine how cancer patients experienced the psychosocial oncology and spiritual care (POSC) services they received, in order to adjust the service offer according to their expressed needs and expectancies. A qualitative design approach was used. The study was conducted in two phases: (1) Collection of the patients' perspective and divulgence of the results to the clinical team and managers; and (2) assessment of the impact of the patient experience study results on the clinical team's services and managerial decisions. Suggestions for improvement were gathered mainly around the themes of service delivery and information about services. Contrary to what was expected, delays to access service responded to patients' needs and expectations. According to clinical managers, patients' perspectives on their services legitimized the maintenance of certain services, and were levers that helped make coherent and targeted changes. They felt the changes they made were patient-driven instead of being driven by staff's perception of patients' needs. The fact that results emerged from a fairly large and structured patient experience evaluation had an impact on the motivation of stakeholders to initiate changes. These results suggest that collecting patients' perspective will likely help clinicians and managers tailor service delivery to meet patients' needs and expectations and may contribute to set more informative standards regarding access to care delays.

### Keywords

Keywords. Cancer, oncology, psychosocial oncology, patient experience, spiritual care, needs, expectancies, service delivery, service offer

**Acknowledgements** The authors wish to acknowledge the work of Isabelle Lamontagne and Catherine Morin-Boulay in Phase 1 of the study and wish to express their deepest gratitude to all of the study participants who took the time to share their experience and opinions.

### Introduction

Cancer is a major disease affecting a significant proportion of the population.<sup>1</sup> In addition to many physical challenges, individuals with cancer face many emotional, social, professional, informational and spiritual challenges.<sup>2-4</sup> Given that cancer patients' concerns have been shown to be significantly associated with quality of life, assessment of patients' concerns should be multidimensional in nature, and care should be provided to help patients improve their quality of life.<sup>4,5</sup> Recognition of the many challenges and needs of patients with cancer has brought a shift from the traditional tumor-focused approach to an approach that considers all of the patient's life spheres. The shift from treating cancer in acute care to treating cancer as a chronic disease has also corresponded with

the more recent focus on quality of care.<sup>6</sup> However, little is known about how patients define quality of care and about what services they feel should be offered in order to help them meet their actual needs.

On the one hand, some studies show that many of these patients' needs go unmet<sup>7</sup>, especially regarding spiritual care needs<sup>8</sup> while on the other hand, some studies report that although patients might screen positive for distress, low rates of referral acceptance have been observed,<sup>9,10</sup> suggesting there may be discrepancies between how the care team perceives their patients' needs and the actual needs of patients. For example, in a study with breast cancer patients, those who refused psychosocial services typically reported that they did not feel the need for psychological help because they felt the stressors or physical distress were transient. Some patients also

spoke about their need to cope with these challenges on their own, or that they had extensive social support in place to help them face these challenges. On the other hand, women who accepted referral to psychological services often struggled to cope with several losses and long-term effects, had existential issues, or reported not having the social support they needed.

Psychosocial oncology is a recently developed multi-disciplinary field of practice. It covers the psychological, social and behavioral dimensions of cancer, including the diagnosis and management of psychological morbidity and distress across the cancer continuum, recognition of lifestyles and behaviors as potential contributors to cancer risks and prognosis, and the need to include close ones and carers in a comprehensive model of supportive care.<sup>11,12</sup> A report from the Institute of medicine (IOM) finds that psychosocial services can provide significant benefits in quality of life and success in coping with serious and life-threatening disease for patients and their families.<sup>4</sup> As patient care is shifting towards a more holistic approach, composition of care teams, delivery of care and service offer are also changing and it is now recognized that psychosocial services for cancer patients should be accessible and provided in a timely manner.<sup>7,13</sup> However, a better understanding of which services to offer, by whom and when, is warranted to optimize service delivery.

The CHU de Québec-Université Laval is an 1800-bed university teaching healthcare organization. It is comprised of five hospitals situated in the Quebec City region and is one of the largest university teaching healthcare centers in Canada. It delivers general, specialized and ultra-specialized care to close to two million people.

In 2005, a multidisciplinary team was brought together to offer psychosocial and spiritual care services to its oncology patients. This study's main goal was to examine how patients with cancer experienced the services they received from the psychosocial oncology and spiritual care (POSC) team, and the extent to which they felt their needs were met. Our goal was to better understand patients' experience and needs and to adjust the service offer according to their expressed needs and expectancies.

## Methods

The study was conducted in two independent phases: (1) collection of the patients' perspective and divulgation of the results to the clinical team and managers (Phase 1); and (2) assessment of the impact of the patient experience study results on both the

clinical team's service offer and on managerial decisions (Phase 2). The POSC team managers were solicited to participate in Phase 2 close to one year after results from the patient experience assessment (phase 1) were presented to their team and they invited all team members to participate in Phase 2. A qualitative approach was used to assess both phases, using individual interviews with patients in Phase 1 and focus groups in Phase 2.

### Phase 1- Assessment of patients' perspective and experience

#### *Participants and procedures*

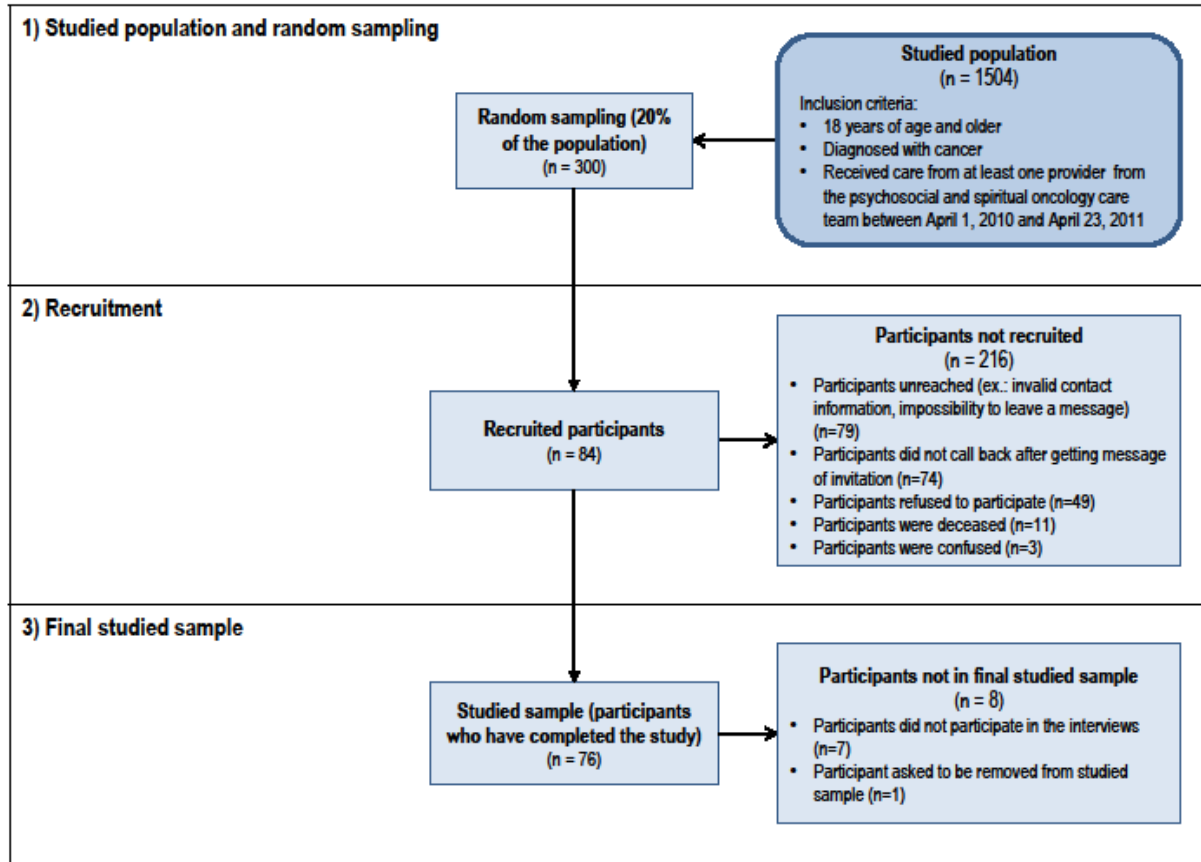
To identify potential participants, a representative sampling of the studied population was performed. This population was comprised of 1504 adults (18 years of age and older) diagnosed with cancer and who had received care from at least one POSC provider at the CHU de Québec-Université Laval (psychiatrist, general practitioner, psychologist, social worker, sex therapist, occupational therapist, clinical nurse specialist, and/or spiritual care counsellor) between April 1, 2010 and April 23, 2011. A total of 300 potential participants were identified through random sampling. A total of 76 patients (aged 26-83 years; 62% women) took part in this study. The majority was married or living with a partner (74%), 42% had a high school degree, 15% a college degree, and 38% had a university degree. See Figure 1 for the recruitment flow chart.

#### *Data collection and analyses*

Individual semi-structured interviews were conducted between the months of May and July 2011. Aims were to document patients' experiences with the POSC team providers and their opinion and perspective on several aspects of the services. Interviews took place either on hospital site or via telephone when patients weren't able to attend on site. A staff member of the hospital's patient experience evaluation office, which is completely independent from the POSC team, conducted all interviews. Factual data on service delivery and time to access care was obtained through the Gulper hospital database to validate patient information.

An interview guide was used to collect patients' experiences, perspectives and opinions. Its framework was constructed to include all aspects of the patient trajectory across POSC services and main dimensions of patient experience<sup>14</sup>. Six main themes were included: distress screening, presentation of the services, referral to the POSC team and access to care, initial assessment, supportive interventions and treatments, and end of services. The interview guide content was validated by a subgroup of patients (n=3) to ensure important aspects were represented in the interview guide and to ensure theme questions were well

Figure 1. Recruitment flow chart



understood. Content was also validated with the POSC team to ensure that all important aspects and the team’s preoccupations were covered. All interviews were audio taped, transcribed verbatim, and data was analyzed using QDA Miner© software package.<sup>15</sup>

**Phase 2- Impact of patient experience study on clinical team and managerial decisions**

*Participants and procedures*

A focus group comprised of 17 members of the POSC team (psychiatrists, n=2; general practitioner, n=1; psychologist, n=1 and psychology trainee, n=1; social workers, n=4; sex therapist, n=1; occupational therapists, n=2; clinical nurse specialists, n=2; and spiritual care counselors, n=3) was conducted in May 2013, one year after the team had received the results from the patient experience study, to collect information on the impact that the patient experience study had on their service offer.

A semi-structured interview with the team’s medical and administrative co-managers was also conducted in

July 2013 to collect information on their perception of the impact the patient experience study on their team’s care delivery and on the usefulness of the study results for decision making regarding revision of their service offer.

Both the focus group and semi-structured interview discussions were audio taped, transcribed verbatim, and data was analyzed using QDA Miner© software package.<sup>15</sup>

**Results**

**Phase 1**

Suggestions for improvement made by participants were gathered mainly around the themes of *information about available services* and *“service delivery”*. In terms of information about the available services, the majority of participants (n=43; 57%) reported that they received only very succinct information about available POSC services, while 45% of participants (n=34) reported that they received no information about other POSC

available services except for the service they had received. Some participants specifically suggested that spiritual care services and some psychosocial services, such as sex therapy, should be readily accessible and publicized. Most participants reported not having received any written materials (e.g., flyer) or seen any advertisement of the services. According to several respondents, written information on these services should be systematically offered to patients since they do not necessarily know these services are available and, most importantly, may feel uncomfortable asking about them.

Regarding accessibility and service offer, participants (n=5, 7%) suggested that some of the psychosocial and spiritual care services should be made available for family members and close ones. The main justifications were that this practice might encourage implication of the spouse or partner in care processes, provide them with support and help alleviate their distress. Regarding the sex therapy service offer, of the 5 (7%) recruited patients that received these services, three found that the services did not quite respond to their needs, particularly in terms of the approach used and felt a more integrated approach within the different services would be more helpful.

In terms of delays of access, according to the hospital database, delays for service delivery ranged from 2 days to 16 weeks after referral to the psychosocial oncology and spiritual care team. In 72% of the cases, initial assessment was conducted within a week after referral. The majority of the patients who commented on the delays of access (n=34/39) reported that they considered this delay reasonable (n=17) or fast (n=19). Some patients (n=2; 3%) mentioned that the delay was too short and they needed more time to “think things through”. On the other hand, other patients (n=4; 6%) reported that the delay was too long. Delays for these patients ranged between one and 16 weeks. The patient that had a 16-week delay had first asked that the appointment be delayed (Table 1).

Finally, some patients suggested that team members should touch base with patients who miss appointments and that this practice should be the same across all offered psychosocial and spiritual services. Some patients reported that although they knew they had full responsibility in attending their appointments, they felt that sometimes the illness course made it difficult to remember all the appointments or to reschedule a missed appointment, for example if they were too ill to attend on a day after chemotherapy.

## Phase 2

Managers and team members were surprised by the result showing that, in general, the delays of access

responded to patients’ needs and expectations. They were even more surprised by the observation that the delay was too short for some patients. These results were welcomed and contributed to alleviate the team’s preoccupations regarding waiting time. According to both stakeholder groups (clinical caregivers and managers), “*several patients’ comments remind us of how important our work is for the patient and their close ones, but also for us as professionals and individuals*”. Several team members reported that some of the patients’ comments served as reminders for “best practices”: “*Things that you forget to do, or with time seem less important, but apparently still are according to patients’ views*”. Managers and clinical professionals reported that they felt changes were patient-driven instead of being driven by staff’s perception of what patients need.

The clinical team also felt they had more directions regarding how to improve care. “*Instead of focussing on delays we can now focus on informing patients that the services exist*”. According to managers, five major targets were identified and the following changes were made:

- The team developed written information (flyers, poster signs) describing what services their team offered, including more explicit information on spiritual counselling, and publicized this information.
- The POSC managers presented Phase 1 results to support their request, presented to the hospital’s cancer care directors and to the regional spiritual counselling services’ directors, that spiritual counselling services be made available for all ambulatory patients, family members and close ones. According to the managers, the fact that patients themselves highlighted the need was a catalyst in getting the request endorsed. Consequently, a spiritual service offer to address this need was developed shortly after and is now available.
- The POSC team developed and implemented a group service for spouses, family members and close ones.
- Sex therapy services and the approach used were adjusted to better respond to patients’ and family members’ needs, which also meant offering sex therapy services in a more collaborative, coherent and integrated way across the POSC team.
- Before this patient experience study, the POSC team had adopted, in accordance to psychiatry’s accountability philosophy, a policy where patients were not contacted if appointments were missed. POSC team members identified and agreed upon the situations and circumstances in which it is relevant to contact a patient that has missed an appointment, for

**Table 1: Observed Delays Between Referral and Assessment**

<b>Observed delay</b>	<b>Number of patients</b>	<b>Percentage</b>
Less than 2 days	44	58 %
Between 2 and 6 days	9	12 %
Between a week and less than 2	7	9 %
Between 2 weeks and less than 3	3	4 %
Between 3 weeks and less than 4	4	5 %
Between 4 weeks and less than 5	4	5 %
Between 5 weeks and less than 6	-	-
Between 6 weeks and less than 7	1	1 %
About 16 weeks <sup>1</sup>	1	1 %
<i>Data not available</i>	3	4 %
<b>Total</b>	<b>76</b>	<b>100 %</b>

<sup>1</sup> The patient had initially requested that the assessment be delayed.

example in the cases where patients are identified as vulnerable. The POSC team wrote down a formal procedure in order to better harmonize their practice in cases of missed appointments across all team members.

According to clinical managers, patients' perspective on their service offer were levers that helped make coherent, targeted, changes based on a fairly large sample of patients' structured comments. "*Getting such a wealth of information legitimized the maintenance of certain services and increased the team's confidence to undertake some changes that they felt unsure about at the outset*". The fact that these points emerge from a fairly large and structured patient experience evaluation study has had an impact on the motivation of stakeholders to initiate changes to service offer and delivery of care.

## Discussion

These findings have yielded important information, both for clinicians and managers, on how patients perceived the POSC services they received. Overall, these results suggest that the patients' perspective and preferences is likely to help clinicians and managers tailor service delivery to meet patients' needs and expectations, and may contribute to set more informative standards regarding access to care delays in psychosocial oncology and spiritual care services. More specifically, collecting patients' perspectives and assessing their experience with the services have contributed to allay the team and managers' ongoing preoccupations about decreasing delays to access services.

Access to care is often a neuralgic aspect. This study has yielded an interesting finding regarding the need to

sometimes postpone service delivery to allow the patient some time to think things through and allow for some emotional processing to take place before they go on to receive POSC services. Rather than trying to make psychosocial oncology services accessible "right now" for every patient, clinicians should consider the patients' context and ask patients about their need and preference in terms of best time to receive the service. Thus, this research could be helpful in reflecting on possible benchmarks regarding acceptable delays of access for the delivery of psychosocial oncology services.

This study also showed how important it was for this team to receive feedback on their service delivery. It is noteworthy to mention that most of the changes, identified as improvement targets, were implemented in the year following presentation of Phase 1 results. While some comments were "reminders of best practices" for clinical staff, others required further reflection from the team.

The result regarding the need for more readily available information regarding sex therapy and even that this information be offered systematically is consistent with the findings by others that health care professionals are not adequately addressing the sexual information and support needs of people with cancer.<sup>16, 17</sup> For example, despite strong evidence that partners of men with prostate cancer experience difficulties associated with the impact of their illness, limited research has investigated the efficacy of psychosocial interventions for partners. However, these studies suggest that interventions which address both patient and partner's emotional distress, couple communication and sexual intimacy and aim at teaching new strategies and implement behavioral change show promising results in enhancing partner well-being.

### Takeaways: What to learn from this study about key features

#### About service offer...

- Settings which offer specialized psychosocial oncology and spiritual care should provide sufficient and readily available information about available services, including spiritual care and sex therapy, as many patients do not know the services are available and feel uncomfortable inquiring about them.
- Some of the psychosocial oncology and spiritual care services should be made available to family members and close ones as they represent privileged ways to provide support to partners and family members and engage them in their loved one's care.

#### From the clinicians' perspective...

- Feedback from their patients on the usefulness of their services and care was important for this interdisciplinary team in order to adjust service offer in accordance to their patient's needs and expectations but also to revive the meaning of their clinical work.
- For some clinicians, some of the patients' comments were best practices reminders.

#### From the managers' perspective...

- Patients' perspective on their service offer were levers that helped make coherent, targeted, changes based on a fairly large sample of patients' structured comments.
- Structured patient experience studies allow collecting key information about how service delivery is experienced by patients, and about how the services meet their needs, from their own perspective.
- The fact that results emerged from a fairly large and structured patient experience evaluation had an impact on the motivation of stakeholders to initiate changes.

Another theme that emerged from our study was that the spiritual care offer was not sufficiently publicized by the healthcare team. A recent review<sup>18</sup> shows that patients often experience multiple spiritual needs in the face of life-threatening illnesses and that spiritual care is an important component to the care of patients facing advanced illness. The review also suggests that patients largely desire medical caregivers to take an active role in providing spiritual care, but that this care component oftentimes remains insufficiently addressed by the medical system.

This study is not without its limitations. First, caution is warranted in interpreting these findings, as it is possible that an observation bias may have been present and contributed to explain some of the results. In our opinion, however, the fact that the POSC team managers initially proposed this patient experience assessment, and that Phase 2 was devised and proposed to the team a year after end of Phase 1 attenuates this bias. Furthermore, the team managers and clinicians were not aware that researchers would be following up. Second, generalizability of our observations is limited since this study was conducted in one geographical area. It can also be argued that the setting, i.e., a universal access healthcare system, may favor implementation of new services, and that patients may feel more inclined to use free access psychosocial services than in private healthcare systems. It would be interesting to replicate this study in other settings and in settings with other models of healthcare organization such as private/insurance based models.

Overall, these results suggest that collecting patients' experiences and perspectives with regards to the services they receive is useful to help clinicians and managers tailor service delivery to meet patients' needs, to identify quality improvement targets, and may contribute to set more informative standards regarding access to care delays in this specific field. Our results also lend weight to authors and cancer patients who have suggested that psychosocial oncology and spiritual care be fully recognized as a central part of cancer treatment and that these services be readily available.<sup>2,4,11,19</sup>

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