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Engaging patients as partners in cancer care: An innovative strategy to implement screening for distress?

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ABSTRACT

Patient distress is frequently missed in everyday cancer care, yet can be associated with decreased quality of life and satisfaction with care, as well as increased risk for comorbidity and morbidity. Considered as an aspect of a patient-centred approach, screening for distress is now an international standard of practice and constitutes an accreditation criterion for cancer centers in the USA and Canada. Inspired by existing health partnership models, the Centre Hospitalier de l'Université de Montréal's (CHUM) Integrative Cancer Care Center recruited patients to act as partners during the creation and implementation of its screening for distress program. Patient partner roles in the program included becoming a member of a specialized psychosocial oncology team, contributing to a healthcare professional training program and helping to select tools to detect distress. This paper describes why and how the CHUM cancer care centre developed an innovative screening for distress program, using a patient partnership approach, to better meet the needs of patients with cancer.

Key words: patient partnership, distress screening, cancer care, oncology, mental health, patient navigator

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INTRODUCTION

Recent studies estimate that almost 40% of patients with cancer will experience significant distress during their illness (Carlson et al., 2004; Howell et al., 2015; Zabora et al., 2001). Distress is often called the “sixth vital sign” that needs to be monitored systematically by oncology professionals, but is frequently under-recognized in everyday practice among patients with cancer (Bultz & Carlson, 2006). Persistent distress has been associated with several negative outcomes, including decreased quality of life, dissatisfaction with care, high cost of care, and increase risk of morbidity (Rivest et al., 2017).

Individuals with cancer will often fail to express their emotional experience to their oncologist, either because they feel embarrassed, fear being stigmatized, or do not know that distress can be addressed by their oncology team (Fitch & McAndrew, 2011). Despite their emotional distress, they will also often decline help offered (Clover et al., 2015). Studies report clinician's accuracy in detecting patients' distress without systematic screening is between 10% and 28% (Werner et al., 2012) and many report having received little training in identifying and managing psychosocial issues. Through the incorporation of systematic screening for distress in routine cancer care, patients can have the opportunity to communicate their concerns to their healthcare providers who can then more effectively address significant distress, and facilitate access to personalized mental health services based on the type and severity of distress reported. This patient-centred approach helps inform cancer care professionals about each person's specific needs and well-being, and can guide their clinical decision-making (Expérience globale du cancer, 2012).

There have been significant changes in screening for distress approaches around the world over the last few years. This best practice has been recently integrated more frequently into U.S. comprehensive cancer care centres, than it used to be (Donovan et al., 2019; Riba et al., 2019). In Canada, it has not only become a clinical standard of practice (Group, 2009; Howell et al., 2015; Rivest et al., 2017), but also an accreditation criterion (Qmentum, 2016) and an important cancer system performance indicator (Canadian Partnership Against Cancer, 2018). This paper describes why and how the Centre Hospitalier de l'Université de Montréal Cancer Care Centre (CICC) innovated during its distress screening program implementation by using a patient-partnership approach to facilitate overcoming some barriers and ultimately better meet the needs of patients with cancer.

CHALLENGING BARRIERS TO ROUTINE SCREENING IN CANADA

Despite strong recommendations for systematic screening for distress, many administrative, ethical, cultural, and political barriers to program implementation in cancer care centres have been documented (Fitch & McAndrew, 2011; Howell et al., 2013; Pirl et al., 2014; Zebrack et al., 2015; Ehlers et al., 2019; Donovan et al., 2019). In Canada, screening for distress is practised more frequently than in the past, although not everywhere or among all patients (Canadian Partnership Against Cancer, 2018). This was also the case of the CICC where this practice has been implemented progressively over the past years.

Although healthcare professionals may consider distress assessment as an essential aspect of their work (Zebrack et al., 2015), studies report resistance by frontline clinicians to systematically using distress screening tools for many reasons, such as a general skepticism regarding the value of systematic distress screening, or a lack of training and support (Mitchell, 2013; Rivest et al., 2017; Donovan et al., 2019). Among cancer healthcare providers, oncology nurses are recognized as key actors in the adoption of distress screening practices, as they often have close relationships with patients and their loved ones during the care trajectory (Howell et al., 2013; Expérience globale du cancer, 2012; Rivest et al., 2017). While some professionals justify their resistance to distress screening by claiming there is a lack of resources to adequately respond to it when detected, others believe that screening for distress in practice is unlikely to occur without a continuous evaluation process (Carlson et al., 2013; Coyne et al., 2013).

Some strategies or facilitators have been recommended to institutions for successful implementation. Among others, these could include educating professionals about existing guidelines, making them more aware of their role and responsibilities regarding screening and psychosocial referral, obtaining institutional support, creating an interdisciplinary psychosocial committee or using electronic health records (Howell et al., 2012; McCarter et al., 2018; Ercolano et al., 2018; Ehlers et al., 2019). Overcoming these barriers remains a real challenge in clinical practice in Canada, especially in high volumetric centres where screening might be perceived as a burden or where the time to do it appears too great to clinicians (Donovan et al., 2019). Any additional innovation likely to facilitate professionals' acceptance of this recommended practice or even improve the process of implementation is still of interest.

PATIENT-PARTNERSHIP APPROACH AS A FACILITATOR?

In recent years, healthcare has experienced a significant paradigm change from paternalist strategies to patient-centred approaches (Karazivan et al., 2015). Some experts have mitigated in favour of another change in perspective, promoting partnerships between patients and their healthcare team to include patients in conversations about their needs and decision-making (Karazivan et al., 2015; Pomey et al., 2015). Patients' contributions to healthcare organizations have been

experienced positively by patients themselves and included participation in quality improvement projects (Bombard et al., 2019). The "Patients as Partners" concept, which recognizes the patient's experiential knowledge, has inspired initiatives that engage patients in healthcare organizational decisions, including in mental health and cancer care (Flora et al., 2015; Ewalds Mulliez et al., 2018; Clavel et al., 2019).

Patients are now considered to be a critical source of information about the quality of cancer care and important contributors to optimal psychosocial care (Bernardo et al., 2019). Recent cancer care research has focused on efficiency and cost-effectiveness of patient navigation interventions, which involves including patients with cancer as part of healthcare teams (Canadian Partnership Against Cancer, 2018). Including patients as key actors when setting up a new practice in cancer care might then strategically help to make certain the focus is on real patients' needs rather than what medical professionals think the patient needs.

Patient-specific factors reported as barriers in distress detection include lack of knowledge regarding distress and embarrassment or shyness about revealing symptoms of distress. Healthcare providers, on the other hand, report difficulties identifying those patients in need of distress screening, and lack of clear guidelines on how to explore distress and how to provide help to patients reporting distress. Since a *patient as partner* is a former patient who has experienced cancer treatment and faced the impact of that disease and treatments on life and quality of life, they could assist healthcare providers and leaders to ensure that the services offered are in alignment with their real personal experiences of the cancer journey.

Based on the partnership approach described above, the CICC estimated that *patients as partners* would probably be key actors in overcoming barriers to screening for distress. Being engaged in the implementation process, they would potentially promote the importance of recognizing distress during the cancer journey, make the program more focused on real patients' needs and preferences, and facilitate healthcare providers' acceptance regarding distress screening implementation. In that perspective, we thought the *patients as partners* would act as a facilitator for successful implementation.

PATIENT'S ENGAGEMENT TO FACILITATE SCREENING FOR DISTRESS IN MONTREAL

The Centre Hospitalier de l'Université de Montréal (CHUM) includes an Integrated Cancer Care Center (CICC), among the largest cancer care centres in Canada, which offers supra-regional services for the treatment of complex cancer cases. Its specialists and healthcare professionals provide cancer care based on best practices recommendations and are also involved in clinical, basic and evaluative research. Inspired by the mental health and oncology partnership initiatives reported above, the CHUM recruited former patients, mainly with the help of physicians and nurses, by asking them to contribute directly to the creation, implementation and continuous improvement process of a Distress Screening Program.

The *patients as partners* were invited to play different roles and be involved in many facets of the program including:

- Ensuring that all emotional needs were taken into account in distress management
- Providing insider's perspective on the distress experience throughout the care trajectory
- Suggesting solutions for screening challenges to overcome barriers
- Participating in continuous improvement processes
- Helping to select clinical distress screening tools that would be user-friendly, simple, relevant and focused on currently unmet needs
- Contributing to the development of the communication plan, including the creation of promotional tools for patients and their loved ones
- Participating in the planning and the delivery of the training program to enhance knowledge and quality of action in psychosocial oncology care
- Promoting the program to leaders and decision-makers to highlight the patient's opinions about the relevance of the distress screening program.

The *CICC Screening for Distress Program* was inspired by other Canadian programs that have been successfully implemented and was designed to reach Canadian and International standards of psychosocial oncology practice, including patient-reported outcomes measurements, optimizing psychosocial resources utilization, and better integration of psychosocial services into everyday cancer care (Blais et al., 2014; Bultz, 2017; Howell et al., 2015; Pirl et al., 2014). A clinical nurse specialist (CNS) and a psychiatrist, both specialized in oncology, worked collaboratively and were responsible for the

program development. They were mandated to design, along with local administrative support, a screening for distress program and a plan for step-by-step implementation according to successful strategies tested in Quebec and in Canada (Blais et al., 2014; Howell et al., 2012; Howell et al., 2015). The program was first tested in a pilot project in 2017 with two cancer teams and since 2018 has progressed and extended to the whole cancer centre. The *Program* consisted of six key components (see Figure 1), which are described below:

Engaging patients as partners: Clinicians (i.e., oncology nurses, surgeons, psychiatrists) and the hospital's Patients Partnership Program identified and invited 10 patients who had been treated for cancer at the CICC in the past years to participate in the creation and implementation of the distress screening program. They were given the opportunity to become a member of the specialized psychosocial oncology team and a research project focused on patient-partner specific contributions. Of the 10 patients recruited, eight accepted; two were not able to participate for health reasons or agenda limitations. Before their involvement, all were trained by the Centre Hospitalier de l'Université de Montréal Health Promotion Department and met with the distress screening program coordinator to become more familiar with distress screening practice. At present, three patients remain involved in the program, and two new ones were recently recruited to fulfill the mandate. *Patients as partners* constituted a key factor for our project in the implementation process and became our preferred tool to convince even the most reluctant or resistant individual about that new practice. This component appeared to be a game-changer in overcoming some barriers of implementing the program.

Figure 1. The six components of the Distress Detection Program of the Integrated Oncology Center of the Centre Hospitalier de l'Université de Montréal

Specialized psychosocial oncology team (including patients): An interdisciplinary team of experts specialized in cancer care was formed. The members included an oncology nurse, two Clinical Nurse Specialists (CNS) in oncology and mental health, an oncologist, psychiatrists, a spiritual care worker, a social worker, a sex therapist, a psychologist, a community support centre representative, a mental health nurse, and *patients as partners*. The ratio of clinicians to patient partners on this specialized team is about two clinicians for one patient partner (2:1). We thought this would stimulate close interaction between clinicians and patients and allow for a greater diversity of experiences and points of view. It also promotes a climate that facilitates exchanges by giving a fairer representation to *patients as partners*. The team was co-led by a CNS and a psychiatrist. All members meet four times per year to continuously improve the program.

Clinical tools box for professionals: As recommended by the Quebec Minister of Health and Social Services, three screening tools were chosen for its program: the Distress Thermometer (Donovan et al., 2014), Canadian's Problem Checklist (Bultz et al., 2011), Edmonton Symptom Assessment System-revised (EESAS-r) version (including an item on sleep symptom) (Watanabe et al., 2012; Savard & Ivers, 2019). A referral tool was designed to help clinicians select appropriate psychosocial services based on psychosocial criteria. This tool facilitates the documentation of the rate and type of psychosocial oncology referrals and promotion of the specific contribution of psychosocial professionals to cancer care. To ensure the clinical management of distress aligns with our program and psychosocial standards, an algorithm called "Response to Distress Trajectory" was created to guide clinicians in responding to the identified distress. This algorithm is also meant to help with the interpretation of the results of the distress screening, setting thresholds for each screening tools (mild distress from 0 to 3; moderate distress from 4 to 6; and severe distress from 7 to 10 on the DT or ESAS-r item). It uses a stepped-care approach inspired by reports of successful implementation experiences (Blais et al., 2014) and Canadian psychosocial oncology good clinical practices (Howell et al., 2015), such as referring the patient to the Emergency Room when required, recommending psychological care if needed or preferred by the patient, or giving access to pharmacotherapy if indicated (i.e., for moderate-to-severe distress associated with anxiety, depression and insomnia symptoms).

Promotional and educational tools for patients and significant others: Studies report that up to 70% of patients decline help after distress detection and would prefer to use self-help (Clover et al., 2015). In order to provide information about distress and available resources, we developed a self-help patient guide called, "To Better Face Cancer." Other promotional and educational tools were developed for patients and their loved ones including:

- a webpage on the CICC website;
- a flyer to promote the program's website page and remind patients that help is accessible;
- a leaflet inspired from the Canadian Partnership Against Cancer (CPAC) documents to explain to patients the usefulness of completing a distress questionnaire;
- videos on different topics related to distress screening and management in cancer care (soon to be available on the website)

- an advertisement reminding individuals that the distress screening program is shown on the television screens in the CICC waiting rooms; and
- posters on the walls of oncology clinics stating that, "You don't have to be alone in facing cancer" (meant to remind patients about the distress screening program and the fact that help is accessible if needed).

All of these tools invite patients to ask for help from their caregivers and were created by the psychosocial oncology team with the help of the public relations hospital team.

Screening Program Performance and other psychosocial measures. We selected indicators to identify patients' needs, specify vulnerable populations, and measure resource utilization in accordance with the CPAC recommendations (Clover et al., 2015; Howell et al., 2015). Performance is measured by tracking the number of screening tools given to patients, as well as the number of referrals made to the Specialized Psychosocial Oncology Team. We hope to measure distress at regular times during the oncology care trajectory and observe the effect of the services received on patients' distress. Finally, patients' satisfaction with the program could also be measured.

Training program on psychosocial issues in cancer care and other topics related to distress management. Training programs have been considered to be a key component in the acceptance of distress screening programs (Blais et al., 2014). Coordinated by a CNS, our yearlong training program on distress screening and psychosocial issues in cancer care is offered to new professionals (such as oncology nurses) or other CICC professionals who want to be updated or refreshed on these topics. Based on a successful experience in Quebec City (Blais et al., 2014), it is a three-step program starting with a one-hour sensitization class that provides an overview of new screening practices and the program. The second part is a six-hour advanced course designed for oncology nurses on distress screening and management. The third part includes monthly interdisciplinary one-hour workshops that focus on 12 different topics such as management of fatigue, anxiety, depression, insomnia, suicidality, aggressive behaviour, transition to palliative care, and cancer-related sexual health concerns. Before each workshop, participants have access to an e-learning training module to learn some clinical pearls on the topic. When they attend the workshop, they can practise decision-making about distress management with clinical cases and discuss with a *patient as partner* about his/her experience during cancer journey. Following each workshop, participants are given an evaluation to gauge the workshop utility and success. These evaluations showed high satisfaction among participants, especially with regards to the *patient as partner* participation. This training program has been well received and popular among cancer care professionals. Qualitative responses on the post-workshop evaluation form are currently under analysis for future publication.

FUTURE DEVELOPMENTS

The *CICC Screening for Distress Program* is now entering an improvement phase, after the initial evaluation of the pilot phase with more than 54 patients screened and no overall

increased referral rate. Future developments include use of an internet-based platform to enhance efficiency, avoid the time-consuming aspect of distress detection, and facilitate continuous program performance analysis. We also hope to be able to share other patient-reported outcomes measures.

Some cancer care teams in the Quebec province were inspired by the program content, especially regarding the three-stepped and interdisciplinary training program, the response trajectory, and the involvement of patients-as-partners during implementation and have utilized them in their own implementations. A recent research project at our centre studied the feasibility and benefits of engaging *patients as partners* in the process of the creation and implementation of a distress screening program, from the perspective of the patients themselves and the team members. Patients involved as partners have spontaneously reported personal benefits to their participation, but the research results are currently being formally analyzed. Whether engaging *patients as partners* really made the program implementation a success will need further research.

CONCLUSION

This paper describes why and how the CHUM cancer care centre developed an innovative screening for distress program, using a patient partnership approach, to better meet the needs

of patients with cancer. Having *patients as partners* on the specialized psychosocial oncology team was, in our experience, an important component in the implementation of the CICC's Distress Screening Program. They were also key actors in the change process by reminding the healthcare providers of the importance of such practice. Future research should explore the *patients as partners* specific role in analyzing screening results and responding to barriers. Systematic distress screening is a recognized standard of quality that must be implemented in routine cancer care. Involving *patients as partners* in that quality improvement process might potentially help to overcome barriers and accelerate the change of culture.

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