


“I Want to Help Others Like Me”: A Pilot Qualitative Study on Patients’ Participation in a Screening for Distress Program

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Abstract

Screening for distress was implemented in our academic hospital with the engagement of patients as partners. Little is known about how they appreciate such participation. This pilot qualitative study aimed to explore their experience. Six participants completed a semi-structured interview, which was transcribed verbatim. Thematic analysis was performed on the transcripts. Four themes emerged: “opinions about their participation”, “working with others”, “role of patient partners”, and “barriers encountered”. Mean global satisfaction reported on a Likert scale reached 8.92 over 10. Our preliminary findings suggest that patients-as-partners appreciated their participation, and also identified barriers that should be explored in future quality improvement (QI) projects.

Keywords

cancer care, patient engagement, distress screening, quality improvement, mental health, patient experience

Introduction

Nearly 40% of patients living with cancer will experience significant distress during their illness journey (1, 2). To better identify and help these patients, screening for distress has been integrated more frequently into cancer care centers worldwide (3, 4). It has now become a clinical standard of practice (1, 5–8) and a cancer system performance indicator (9). However, implementing screening for distress represents an important challenge for cancer care centers (3). Successful implementation generally involves overcoming barriers and the use of efficient strategies (7, 8, 10–16).

Patient participation in healthcare organizations is now recognized as a standard of quality and safety in health policies and institutions (17–19). Involving patients has also become a priority in quality improvement (QI) in healthcare, including in mental health and cancer care (20–23). “Patients-as-partners” are generally defined as former patients that have experienced medical treatment and faced the impact of illness on their quality of life. These patients’ contributions help healthcare organizations to focus on patients’ real needs while ensuring that the patients themselves see the experience as positive (22, 24–26). Inspired by this partnership approach, our academic hospital center had patients participate in a QI project of implementing systematic screening for distress practice in outpatient settings (27). Patients-as-partners played one

or more roles in that program, such as participating in the creation of clinical tools, being a member of an interdisciplinary psychosocial team, or participating in training workshops on distress screening and management. This program was inspired by other centers’ experiences and was designed to reach standards of practice, optimize resource utilization, and better integrate psychosocial care in everyday care (1, 6, 28, 29). Complete information about this program and its key elements are described elsewhere (27). To facilitate its implementation, 2 oncology teams were initially targeted in our cancer care to first adopt this practice as a pilot project and then expand it to all teams.

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Table 1. Consolidated Criteria for Reporting Qualitative Research (COREQ) Criteria.

Domain 1: Research team and reflexivity	
<i>Personal characteristics</i>	
Interviewer/facilitator	Nurse in oncology
Credentials	MSc.
Occupation	Nurse
Gender	Female
Experience and training	Academic researcher and clinical nurse
<i>Relationship with participants</i>	
Relationship established	Did not know any participant before the study and was not a research member.
Participant knowledge of the interviewer	None of the patients-as-partners knew the interviewer prior to the interviews.
Interviewer characteristics	No characteristics were reported
Domain 2: Study design	
<i>Theoretical framework</i>	
Methodological orientation and theory	Qualitative design
<i>Participant selection</i>	
Sampling	Participants were selected by convenience sampling, mostly by their physician
Method of approach	By phone or email, by one of the researchers to explain the nature and the goals of the research project
Sample size	9 patients-as-partners
Nonparticipation	3 participants dropped out (unexpected health reasons, family obligations or agenda limitations) after the first or the second meeting
<i>Setting</i>	
Setting of data collection	Meeting room in a hospital
Presence of nonparticipants	No
Description of sample	See Methods
<i>Data collection</i>	
Interview guide	The questionnaire included open-ended questions (Table 2)
Repeat interviews	No
Audio/visual recording	Audio recording and verbatim translation
Field notes	Yes
Duration	The interviews lasted 45 min. The interviews were done within a month.
Data saturation	Research team members debriefed following each interview, after having read the transcripts and decided when data saturation occurred. Saturation was obtained after the sixth participant.
Transcripts returned	No
Domain 3: Analysis and findings	
<i>Data analysis</i>	
No. of data coders	1 data coder and 4 reviewers
Descriptions of the coding tree	Yes—4 themes and 9 sub-themes (see <i>Results</i>)
Derivation of themes	Data derived themes
Software	QDA Miner
Participant checking	No
<i>Reporting</i>	
Quotations presented	Yes
Data and findings consistent	Yes
Clarity of major themes	Yes—4 major themes are reported in this publication
Clarity of minor themes	Yes—9 sub-themes are reported in this publication

Screening for distress practice has been extensively studied for many years and continues to be implemented in cancer care. It is also the case for patients-as-partners' involvement has been progressively used in QI projects and decision making, both being standards of practice. However, to our knowledge, how patients-as-partners perceive their participation in a QI project on a screening for distress implementation has not been studied. The purpose of this pilot qualitative research was to explore patients-as-partners' experience in the screening for distress program development and implementation, to better

understand how they experience participating in psychosocial management, if they appreciate it and which challenges should be overcome to make their contribution feasible in academic hospital settings.

Methods

This qualitative pilot study took place from 2016 to 2018 at the Université de Montréal Hospital Center and has been approved by the local ethics board. The research team had

Table 2. Themes and Subthemes Obtained From Analysis.

Themes	Subthemes	Verbatims' examples
Opinions about the program	Making a positive contribution	"[We contributed] by suggesting how to say things, what words to use ... what words to avoid ... we knew we were helping to make a pamphlet that was going to be used (with) everyday people who [...] suffer from distress [...] We had to make it easy to understand ... without it being too simple. We had to make it suitable for almost everyone." (p2) "I felt I could ask any questions. I also felt like I was contributing to the group." (P4)
	Gratification and enjoyment	"I find it gratifying to be able to exchange viewpoints and to be able to tell the doctors: "You do a fantastic job but you should try putting yourself in the patient's shoes or try [asking] yourself ... what the patient is feeling." (p6) "It's a team effort and I think the pamphlet we made had some pretty interesting editorial content. I really enjoyed the experience." (p2) "[We] felt that [the patients who were being screened for distress] were full of compassion [when we met them in their clinic as patients-as-partners engaged in the project]. We felt [they] understood us. It was clear that we also understood them even though they had different experiences. So honestly, it was really nice because they were very selfless people. It was heartwarming." (p2)
Working with others	The work atmosphere	"The work was really done in harmony and ... in a consensual way too." (p2) "I found it interesting, it was at my own pace, there was no stress ... and everyone was nice. All our questions were answered quickly." (p5)
	Collaboration	"The patient partners got on really well with each other [...], it's been very enjoyable" (p6) "It was interesting to see that there was a kind of confidence. We felt we were really contributing and that the medical team wasn't rejecting our opinions and our proposals" (p2) "Collaboration was there, but it takes a while to set up. As I mentioned, it doesn't happen at the very first meeting. It happens over time, but time is short." (p3).
Role and motivation of patient partners	The perceived role of the patient-as-partner a distress screening program	"My role [during training] was simply to intervene if [I had] any experience with anything in the teaching presentations. If I could make links, or bridges if you like, between my experience and different themes like distress" (p2) "My role really was to help them, support them, with the distress questionnaire ... we chatted a lot. They talked a bit about their situation and whether they had any distress or not." (p5) "I think all committees should have patient partners. Their contribution is important [...] and when [...] a patient partner sees [another] patient partner, it's reassuring. You can see he's gone through the same things you've been through." (p3)
	Reasons for becoming a patient partner	"I think it's important to make a difference" (p3) "... I think a lot of people don't have a voice as such, so it's extremely important for other people to be their voice." (p4)
Barriers encountered	Time needed to participate in the programme	"We met three times and we still didn't come to a conclusion. Things take a long time!" (p3) "It's hard to find people who can make the investment to become a patient partner" (p3) "I would have liked to [participate in training] but unfortunately, because I work, it's a bit complicated for me [to be free on weekdays ...] It's a bit complicated." (p2)
	Difficulties integrating into the team	"Understanding the language of the health sector, like acronyms. [Doctors] talk to each other like that" (p4) "Granted, it's the medical world, but sometimes doctors don't speak to patient partners in an ideal way. They always use complicated words sometimes and can come across as a little too technical. I think they need to speak to [patient partners] in simpler terms" (p6)
	Lack of organization	"You want things to move forward and get organized, but in order for things to get organized, there needs to be more structure." (p3) "At the very beginning, you don't really know what you're doing." (p4)

4 members. It included a psychiatrist specialized in cancer care with a MA in medical education (J.R.; principal investigator), a nurse specialized in oncology with a MSc in nursing science (I.L.), researcher specialized in organizational ethics with PhD in management and a patient-as-partner as well (J.T.M.) and a researcher with a PhD in kinesiology (N.F.)

Participants were eligible if they were at least 18 years of age, had been treated in our hospital for cancer and spoke French fluently. They were selected by convenience sampling, mostly by their treating physician or directly by the Health Promotion Department. Our hospital currently has about 120 patients-as-partners engaged in various programs, including 12 patients specifically involved in cancer care. At the time of the study in 2016 to 2018, engaging patients-as-partners in cancer care was a relatively new practice. All received a 7 h training by the Health Promotion Department to be considered a patient-as-partner. Their training focused on different topics such as the partnership model, role and responsibilities, active listening, etc. Participants of this study also received an additional 2 h of training to become more familiar with distress symptoms, screening, and management in cancer care. They were then formally contacted by phone or email, by one of the researchers to explain the nature and the goals of the research project. The main researcher was available to participants for questions.

The role of the patient-as-partner included participation in 4 areas: ie, being a member of the specialized team in psychosocial oncology, setting up the workshops/training program about distress screening and management, helping and accompanying patients during their distress screening, and acting as a consultant in the development of clinical distress screening tools (27). The workshop/training program was intended for medical professionals in cancer care and included 17 classes/courses/educational capsules about best practices on distress screening and management. Classes/courses were organized around sensibilization to distress, empowerment, and included formal presentations, as well as practical workshops with clinical vignettes to practice distress screening and management. Patients-as-partners' implication included testimony and sensibilization to the necessity of distress screening. With other professionals, patients-as-partners participated in the creation and continual improvement of the program through activities of the specialized psychosocial oncology team. This team included a psychologist, a spiritual care professional, nurses, a sexual therapist, psychiatrists, and social workers. During some outpatient clinics, where patients had been identified for distress screening, patients-as-partners have also offered support to patients in using and understanding the screening tool. Others were involved in a committee mandated to design and adapt clinical tools to facilitate and implement screening. Participants could choose to partake in one or more areas of the program and were asked at the end of the project to participate in an interview to share their experiences.

Participants took part in a 1-hour individual semi-structured interview conducted face-to-face at the hospital and audio-recorded. Interviews were all conducted in French with verbatim transcription. The questionnaire was elaborated by the team researchers to explore with open-ended questions their experience and was based on relevant literature (see Supplementary material), since no tools have yet been validated to measure patients' perception of their role (17). All researchers read the transcripts, participated in the coding, and did data analysis. Guidelines from the Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed to ensure research quality (see Table 1 for details). Research results were presented to participants in a group session.

Results

Of the 9 patients-as-partners contacted by the research team, all of them initially accepted to participate in the study. Three dropped out for unexpected health reasons, family obligations, or time constraints, after the first or the second meeting. The remaining participants were 4 women and 2 men, with an average age of 55 ± 16.2 years. All were former cancer patients who became patients-as-partners trained and involved in different programs or projects in our hospital, for an average of 16 months (min 1 month, max 68 months), which included the training period (see Supplementary material for more sociodemographic details). In terms of quantitative results, participants were asked to rate their satisfaction with their role in the QI pilot project on a Likert Scale (0 = least satisfaction; 10 = most satisfaction). Mean global satisfaction was 8.92 (min 8, max 10).

Themes obtained from qualitative data analysis revealed that patients-partners had different experiences during their participation in the program. See Table 2. Upon analysis of the data, the first main theme obtained was the “**opinions about the program**”. It was observed that many patients in fact reported their overall experience as “positive”. They were able to describe their role in the screening for distress program implementation and defined their contribution as beneficial and satisfactory despite all the challenges. Most had many roles in the project, some just one. Being involved in the psychosocial oncology team was reported as gratifying as their role was to make sure the patients' needs were better taken into consideration. Those who participated in the training program estimated their experience was positive and felt the professionals were authentically interested in the patients' perspective.

The second main theme was “**working with others**”. Most participants described the work atmosphere as positive, with medical professionals showing concern for patient-as-partners' opinions and views. Participants did not feel pressured for productivity from the medical team members. Good communication between the patients-partners and health care professionals was reported by most participants.

Participants felt the medical team had confidence in them and they felt respected in their role. Collaboration grew over time and was overall a satisfying experience.

Analysis led to the third theme, which was “**role and motivation of patient-as-partners**”. The roles of patient-as-partners were perceived differently depending on the nature of their involvement in the QI project. In fact, some only participated in the psychosocial team and others only accompanied patients during their screening in outpatient settings. Most participants stated that their motivation to participate in such a project was to make things progress and to let their voices be heard. They also mentioned they accepted to participate to that QI project for different reasons, including a need for human contact that they wish they had had with other patients who had gone through the same experience. Most of the patients who participated had little experience as patients-as-partners before their participation in the project.

Finally, the fourth main theme obtained was “**barriers encountered**”. Few challenges to patients-as-partners’ participation was in fact identified. Some were related to the healthcare system, others to the psychosocial team members themselves. Participants reported that they were not enough occasions for the patients-as-partners and the medical staff to build team cohesion and trust, to exchange ideas together and develop a harmonized vision of distress management. Patients-as-partners involved in the training program wished they had a more active role in the workshops and suggested that 1 patient-as-partner should always be present at each workshop session. Some estimated that additional time should be allowed to the patients-as-partners’ narrative about her/his past experience of distress in the training program, as this element has been a key factor and especially appreciated by healthcare professionals. Patients-as-partners also reported medical professionals who worked with them did not adapt enough their medical jargon or technical terms. Those who helped patients to complete the screening for distress questionnaire felt they really had the opportunity of helping others, although they felt the integration of their role in outpatient settings was not structured enough.

Discussion

To our knowledge, this was the first study to qualitatively explore patients-as-partner’s experience in a screening for distress program in cancer care. Overall, participants reported positive benefits to their participation. They underlined the importance of good management to encourage their involvement and mentioned that they had the feeling of helping people suffering from cancer. This is consistent with previous data that revealed that most experiences reported by patients involved in health care projects were positive (26). Previous studies have reported positive outcomes such as increased self-esteem, feeling empowered, or independent (26). Our results showed that patients-as-partners might be motivated

by a will to improve things meaningfully and ultimately improve care for patients with similar illness trajectories.

The second significant finding was barriers to patient participation. For instance, patients-as-partners felt the medical jargon and administrative complexities (eg, steps to be taken in the institution before launching a program in clinic settings, or what healthcare professionals to include in the implementation process) were difficult to understand. Although the body of research on peer support and patient navigation exists in cancer care (25), little data has explored some barriers of patients’ involvement in QI project (22) or ethical issues regarding their participation (30), even less in psychosocial oncology care. Our results present a new perspective on some barriers perceived by the patients-as-partners when involved in this QI project in psychosocial oncology care.

This pilot study has some limitations. First, our study has a very small number of subjects. Secondly, since the study took place within only 1 academic tertiary center, the generalization of the data is limited and might not reflect the experiences of all cancer patients or care teams. Finally, the qualitative design by itself, because of its inductive nature, allows us to make some hypotheses about the patient-as-partners’ experience that would need to be verified in a deductive design. We also focused exclusively on the perspective of the patient-as-partner for this pilot study. We did not include the health professionals’ point of view, nor patients’ that were screened for distress and helped by patient-as-partner. Future studies on patient engagement in such psychosocial oncology programs could also explore the experience of patients screened for distress, as well as healthcare professionals.

Conclusion

Cancer care centers are emotionally charged clinical environments where patients might present with high level of distress that needs to be identified promptly and well managed. The findings of our pilot qualitative study revealed that patient-as-partners described their experience in this QI project as mostly positive. Results also shed light on potential barriers to patients’ involvement in QI of psychosocial cancer care, which could be addressed in future research studies. Investigating the collaboration experience between patients-as-partners, screened patients and healthcare professionals could also add an interesting potential perspective. Based on our pilot study, active participation of former patients in such psychosocial oncology QI projects appears feasible. These results could contribute to better prepare hospitals and medical professionals for patients-as-partner recruitment and retention by making them aware of barriers to their integration. Ultimately, their involvement could be seen as a facilitator to ensure better distress screening and management in cancer care.

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Ethical Approval

This study (16.197) was approved by the Centre Hospitalier de l'Université de Montréal Research Ethics Board.

Declaration of Conflicting Interests

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Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Centre Hospitalier de l'Université de Montréal Research Ethics Board.

Statement of Informed Consent

Verbal informed consent was obtained from the patient(s) for their anonymized information to be published in this article.

ORCID Author Statement


JR: conceptualization/formal analysis/writing/review and editing, VDJ: methodology/writing/review and editing, JTM: review and editing, NF: conceptualization/review and editing. DC: review.

Supplemental Material

Supplemental material for this article is available online.

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