

From patient-reported outcomes (PROs) to family-reported outcomes (FROs): Acceptability and perceived usefulness of routine screening in cancer care

Original Article

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Abstract

Objectives. To explore the acceptability of screening for family-reported outcomes (FROs) among cancer caregivers (unpaid family members or friends who provide support to patients with cancer) and identify from their perspective the key components of a FRO screening program.

Methods. Using a qualitative descriptive design, semi-structured interviews were undertaken with 23 adult caregivers of people with cancer between 2020 and 2021. Interview questions focused on acceptability of FRO screening, types of FROs, timing/frequency of screening, preferred resources following screening, and communication of FROs to patients and clinicians. Participants were recruited in Canada. Interviews were audio-recorded, transcribed verbatim, and analyzed using thematic analysis and constant comparison.

Results. Almost all caregivers welcomed FRO screening in usual care and viewed it as an avenue toward obtaining more resources. Other potential benefits of FRO screening included increased self-reflection and role acknowledgment. Caregivers prioritized screening for emotional symptoms, and most preferred that the results be shared with the patient's treating team rather than their primary care provider. Caregivers did not want results to be shared with patients, instead favoring learning how best to discuss results with patients. Many spoke of a "one stop shop" containing all relevant information on caring for the patient (first) and for themselves (second). Opinions regarding timing and frequency of FRO screening differed. Periodic administration of FRO measures, with each one not exceeding 20 minutes, was deemed appropriate.

Significance of results. This study extends the concept of patient-reported outcome measures to caregivers, and findings can be used to guide the development of FRO screening programs.

Introduction

High-quality cancer care in Canada relies on caregivers (Lambert et al. 2016). A caregiver is defined as an unpaid person most involved in providing physical, instrumental, and/or emotional support to patients (Soothill et al. 2001). With the shift toward community-based cancer care (Institute of Medicine (IOM) 2008), caregivers play a vital role supporting and improving the health of patients with cancer (Northouse and McCorkle 2010; Sinha 2013). Their key roles include monitoring treatment side effects, assisting with activities of daily living (ADLs), coordinating care, administering medication, liaising with the medical team, advocating for patients, and providing emotional support (Lambert et al. 2016). Despite this, the work of caregivers is frequently unacknowledged and undervalued. In undertaking this work, caregivers often receive minimal formal support, resulting in poor caregiver or family-reported outcomes (FROs) such as high anxiety and low quality of life (QOL) (Girgis and Lambert 2009; Hagedoorn et al. 2008; Kim and Schulz 2008; Lambert et al. 2014, 2013a, 2012a). Such impact has been shown to limit caregivers' ability to fulfil their roles (Lambert et al. 2013b) and to predict patients' institutionalization (Cepoiu-Martin et al. 2016).

Cancer care has a long history of screening for patient-reported outcomes (PROs). The systematic screening of PROs in usual care has been shown to improve patient satisfaction, patient-centered communication, clinician recognition of symptoms, and workflow efficiency as well as decrease symptom severity and utilization of health-care services and increase

patient QOL and survival (Basch et al. 2016; Di Maio et al. 2022; Graupner et al. 2021; Howell et al. 2015; Kotronoulas et al. 2018; van Egdom et al. 2019). Despite an increased focus on family-centered care, there has been less attention given to FRO screening in usual cancer care (Aubin et al. 2021).

FROs are defined as the consequences of caregivers' roles and responsibilities on all spheres of their life and health, such as their QOL or level of distress, as reported by caregivers. The term "caregiver-reported outcomes or CROs" is purposefully not used, to disambiguate from "clinician-reported outcomes." A Delphi study of priorities for caregiver research found that screening to identify caregivers at greatest risk of burden was a priority across all 4 stakeholder groups who participated (caregivers, clinicians, managers, and researchers) (Lambert et al. 2019). Several FRO screening programs have recently been proposed (Aubin et al. 2021; Hawkes et al. 2010; Howard et al. 2022), often relying on similar measures, processes, and approaches as those used for PRO screening programs, with mixed results in terms of acceptability and efficacy. Few studies have examined how key processes involved in implementing PROs in cancer care need to be adapted to the particular context of FROs (Howard et al. 2022). The objectives of this study were to explore from caregivers' perspectives: (a) the acceptability of screening for FROs; (b) key components of an FRO screening program; and (c) the types of support needed to manage FROs. This study was part of a larger program of research focused on the electronic implementation of PROs and FROs in cancer care in Quebec, Canada (e-IMPAQc.com) (Lambert 2022b).

Methods

Design

This was a qualitative descriptive study (Magilvy and Thomas 2009; Sandelowski 2000) conducted from 2020 to 2021 (amidst initial COVID-19 waves). Ethics approval was obtained. The consolidated criteria for reporting qualitative research (COREQ) guided reporting (Tong et al. 2007).

Sample

A convenience sample of 23 caregivers was recruited (see Figure 1). Caregivers were family members, partners, or friends providing unpaid support to someone with cancer for at least 3 months. Other inclusion criteria were being 18 years and over and speaking either English or French. Inclusion was not based on the type of treatments or cancer diagnosis. Ineligible caregivers included those who could not complete the consent process due to language barriers or cognitive issues. Eligibility was determined based on caregivers' self-report during a screening recruitment interview with a research assistant (RA).

Recruitment

Participants were recruited (a) with the help of clinicians at 1 cancer center; (b) from the team's 2 previous studies; (c) via social media, including Facebook and the study's website (e-impacq.com); and (d) through community organizations. Caregivers recruited through clinicians gave permission for their name and phone number to be forwarded to the RA who then followed up with study information. Patients or caregivers who participated in other studies and had consented to receive information about future studies were phoned or e-mailed a study invitation. Those recruited via social media or community organizations completed an online form indicating their contact information for follow-up by the team. The RAs assessed the eligibility of all caregivers and provided detailed study information. Eligible caregivers were then sent the consent form by mail or e-mail for their review. The RAs communicated with the caregiver to respond to any questions about the consent form and to schedule the interview. Consent forms were signed prior to the interview. Participants did not know the interviewer prior to the study.

Data collection

Caregivers were invited to 1 interview, which lasted between 30 and 110 minutes and was conducted in either English or French by 1 of

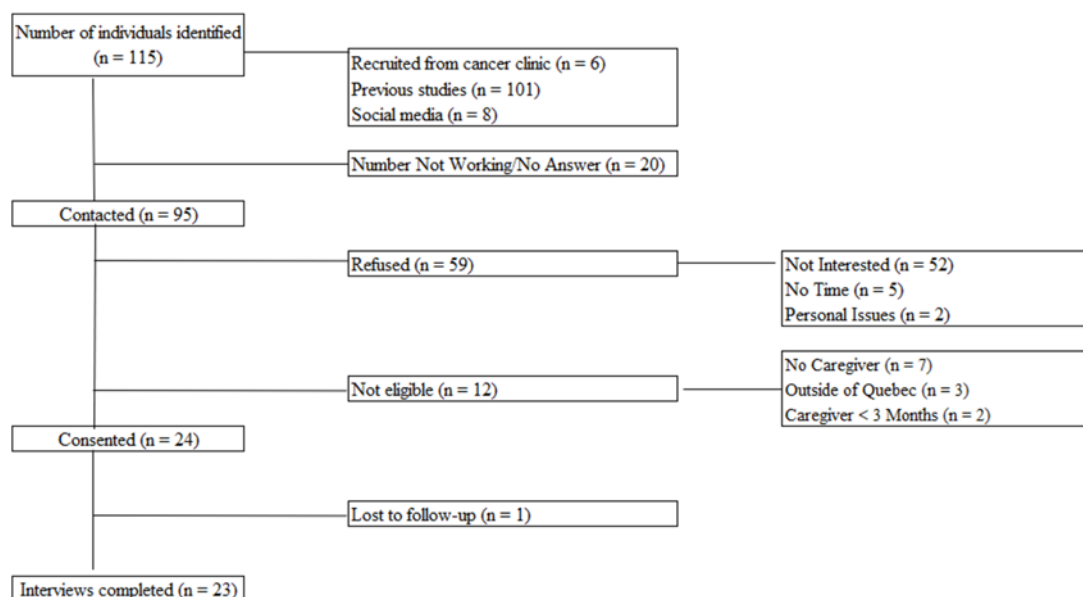


Figure 1. Recruitment flowchart.

the 2 bilingual female RAs (including MM). Interviews were held over the telephone or using Microsoft Teams, based on participants' preferences. All interviews were audio recorded, and interviews held over Teams were also video-recorded. Interviewers began with a description of PROs and how their use might carry over to FROs. The interview guide was used with flexibility to explore (a) appropriateness of screening for FROs; (b) types of FROs that should be screened; (c) types of support needed in managing challenges of caregiving; and (d) sharing of FRO results.

Data analysis

All audio-recordings were transcribed verbatim in the original language in which they were conducted, and transcripts were de-identified. The descriptive data analysis was completed in English, using thematic analysis (Braun and Clarke 2006), based on a constant comparison method (Leech and Onwuegbuzie 2007, 2008) using NVivo 12 (QSR International 2018). Two experienced bilingual RAs (including KL, different than those who conducted the interviews) completed the coding. The RAs established a preliminary codebook independently after reading the first 3 transcripts. They then met regularly to discuss the codes and resolve discrepancies. Subsequently, they continued coding the same transcripts independently, meeting to resolve discrepancies, until consistency in coding was attained, which was after coding 5 additional transcripts. Then, only 1 RA (KL) completed the analysis, revising the codebook as needed and discussing coding at regular team meetings. Data were coded inductively, with similar codes grouped into categories, which subsequently formed themes. Excerpts in French were translated into English.

Sample size

Recruitment continued until data saturation was reached, estimated to have occurred at the 15th interview. Interviewing continued with caregivers with different demographic characteristics to ensure no new themes were identified.

Results

Almost half of caregivers were between 50 and 59 years old. An almost equal proportion of females and males participated. Most caregivers were the spouse or partner of the person for whom they provided care. Table 1 further details caregivers' sociodemographic characteristics.

Appropriateness of FRO screening

All but 1 caregiver, who felt the focus should remain on the patient, supported the proposition of collecting FROs. For most, completing FRO measures was viewed, first and foremost, as a means of accessing information and resources needed to provide care to patients and, secondarily, for their own self-care. Caregivers explained that although questions pertaining to patients' conditions might get answered, the main gap in health services was guidance on how best to care of patients:

[...] At the medical level we were very well supported. But more at the level of the other components. The issue of food, for example. I have cancer, I'm undergoing chemotherapy, I feel nauseated, naturally I have trouble eating, I'm undergoing radiotherapy treatment, it burns, it hurts, what cream can I

Table 1. Sociodemographic characteristics of participating caregivers ($N = 23$)

Sociodemographic characteristics	N (%)
Age	
<40	3 (13.0)
40–49	2 (8.7)
50–59	10 (43.5)
60–69	5 (21.7)
≥ 70	2 (8.7)
Unknown	1 (4.4)
Sex	
Female	12 (52.2)
Male	11 (47.8)
Education	
High school	3 (13.0)
Post-secondary diploma	7 (30.4)
Undergraduate degree	7 (30.4)
Graduated degree	5 (21.7)
Unknown	1 (4.4)
Marital status	
Married	13 (56.5)
Separated	1 (4.4)
Single	4 (17.4)
Common law	2 (8.7)
Widowed	2 (8.7)
Unknown	1 (4.4)
Employment status	
Full time	11 (47.8)
Part time	6 (26.1)
Retired	1 (4.4)
Sick leave	4 (17.4)
Unknown	1 (4.4)
Relationship to patient	
Spousal relationship	15 (65.2)
Non-spousal relationship	5 (21.7)
Unknown	3 (13.0)
Patients' cancer type	
Breast	11 (47.8)
Thyroid	1 (4.4)
Lymphoma	2 (8.7)
Pancreatic	1 (4.4)
Brain	2 (8.7)
Colorectal	2 (8.7)
Multiple myeloma	1 (4.4)
Kidney	1 (4.4)
Lung	2 (8.7)

(Continued)

Table 1. (Continued.)

Sociodemographic characteristics	N (%)
Patients' stage of cancer at diagnosis	
Early stage	6 (26.1)
Advanced stage	8 (34.8)
Unknown	9 (39.1)
Patients' stage of treatment	
In treatment	2 (8.7)
Post-treatment	17 (73.9)
Deceased	2 (8.7)
Unknown	2 (8.7)
Patients' cancer treatment	
Surgery	9 (39.1)
Chemotherapy	15 (65.2)
Radiotherapy	7 (30.4)
Other	3 (13.0)
Unknown	1 (4.4)

use ... all these little things, I find that it was limited in terms of information. (female, 02010)

This lack of support resulted in caregivers not feeling they could address patients' symptoms, or that they used a trial-and-error approach in doing so. Not knowing how best to respond to patients' needs contributed to caregivers' increased distress and burden. Few caregivers asked questions during clinical appointments with patients: "If you do not ask the doctor, they will never volunteer the information" (female, 02016). But they acknowledged feeling that oncologists either did not have time to address their concerns or did not wish to respond to additional questions because their focus was on the patient's treatment.

Other perceived benefits of FRO screening included legitimizing the caregiver's role, feeling acknowledged, and decreasing isolation. One caregiver shared:

It would have been a nice acknowledgement and I bet for some people it could open floodgates of a lot of questions, the ability to share exactly what you're going through. (male, ID 02013)

These benefits were inextricably linked to caregivers currently feeling excluded from the patient's care: "[...] at the beginning, there is not much space for caregivers, really not. It's like we don't exist [...] the patient's doctor, he doesn't care about us" (female, 02018). This was exacerbated by the pandemic. Screening for FROs was seen as a much-needed change in cancer care to legitimize their role. The last reported benefit of screening for FROs was an opportunity for self-reflection, to pause and consider how they were feeling and how the patient's experience affected their health.

Types of FROs

Data analysis identified 5 categories of FROs, summarized in Table 2. FRO categories were not given the same importance.

Table 2. Type of FROs identified (N = 23)

Type of FROs	N (% ^a)
Emotional symptoms (mentioned by 21 participants)	
Anxiety	10 (43.5)
Mental fatigue	10 (43.5)
Stress	8 (34.8)
Isolation, feeling invisible	5 (21.7)
Helplessness	4 (17.4)
Depression	2 (8.7)
Feeling guilty to take time for self	2 (8.7)
Practical and social issues (mentioned by 19 participants)	
Managing housework	8 (34.8)
Practical information and knowledge	6 (26.1)
Transportation	4 (17.4)
Access to resources	3 (13.0)
Communicating with family and friends	2 (8.7)
Childcare	1 (4.4)
Adjustment to changes in relationship role	1 (4.4)
Cancer care (mentioned by 11 participants)	
Help patients with activities of daily living (e.g., shower)	7 (30.4)
Care coordination/communicating with health-care team	6 (26.1)
Medication management	4 (17.4)
Symptom management (e.g., side effects of radiotherapy)	2 (8.7)
Help deciphering medical information	1 (4.4)
Access to more resources	1 (4.4)
Physical symptoms (mentioned by 10 participants)	
Sleep problem	4 (17.4)
Physical fatigue	4 (17.4)
Lack of appetite	3 (13.0)
Shortness of breath	1 (4.4)
Financial stress (mentioned by 9 participants)	
Parking/transportation fees	5 (21.7)
Dealing with insurances companies/government benefits	4 (17.4)
Reduced salary	2 (8.7)

^aParticipants may have mentioned more than 1 symptom/challenge.

Emotional symptoms

Almost unanimously, caregivers prioritized screening for emotional symptoms.

It was very, very stressful, in terms of distress and depression. I was (sigh) almost clinically depressed for several months. I'm slowly coming out of it, but this is something that perhaps could have happened, if perhaps at the very beginning I'd ... well ... on the one hand it was perhaps inevitable that I'd go through a phase like this. (male, 02003)

In prioritizing patients' needs, about half of caregivers reported losing perspective of their own needs and feeling guilty for taking time for themselves: "when you are a caregiver, you forget about yourself [...] you feel guilty for taking care of yourself" (female, 02018).

Practical/social issues

Caregivers wanted to be asked about help needed for housework, accessing more information and resources, transportation (especially if the caregiver did not drive), and communicating information to family/friends. A few caregivers specified that practical concerns fluctuated based on the patient's state of health:

You have to do groceries and maybe your loved one's not feeling well, and so you don't want to leave your house; so just to go out to do chores is a challenge if nobody can stay with your loved one. (male, 02004)

Practical challenges were also exacerbated by a lack of preparedness and knowledge of how to take care of their loved one. Caregivers who did not get respite, those caring for young children, and those who could not accompany patients to treatments due to pandemic restrictions also reported high practical concerns. Conversely, these concerns were lower among caregivers who were retired or who did not co-habit with the patient.

Cancer care

Most often this included helping patients with ADLs, coordinating care with health-care providers and facilitating communication between the patient and providers, as well as managing medication and treatment side effects:

You are the one who provides continuity between the pharmacy, the doctor and sometimes I was even more aware of what medication he was taking than the doctors. It becomes so overwhelming. (female, 02018)

Physical symptoms

Most caregivers described significant fatigue primarily due to increased workload, lack of sleep, and not devoting sufficient time to their own diet and exercise. This was in stark contrast to some caregivers' desire to remain in good physical and mental health to maintain their role: "If the person is not in good health, it will be difficult to be a caregiver" (female, 02018).

However, many caregivers felt that their physical symptoms were a manifestation of their underlying emotional distress, which is why emotional FROs were prioritized:

The stress was really a mental stress, a mental fatigue. Physically, you don't feel tired. You don't feel like, "Oh, I don't want to get up today." You always think, "OK, what do I do? What do I say? Do I ask how she's doing? I think it's more of a mental stress, then it is a physical stress. (male, 02002)

Financial issues

Caregivers described the impact of parking and transportation fees, struggles with insurance companies, and reduced family incomes. The impacts were significant given the long-term and uncertain course of the illness, with some participants in financial debt.

Financially not everybody is able to cope with what's going to come because it's not short-term in some cases, it's long-term. (02004, male)

Support needed following FRO measures

Screening for FROs was deemed to be insufficient on its own by most caregivers. As 1 caregiver said, there should be "a living,

breathing person" (male, 02008) at the other end responding to results. Further, most caregivers spoke of needing a centralized resource for "cancer 101" (female, 02021) that is always available to which caregivers can refer as/when needed. Having such a "one stop shop" for evidence-based materials would palliate feeling overwhelmed by the amount of information available on the Internet and not always knowing how to decipher which sources were trustworthy. One caregiver said: "A centralized resource is by definition an excellent idea because we get lost in the details and you know that disaster scenarios run through our heads, and then we go to Google and it starts ... so there, it can get off to a bad start" (female, 02010). A few caregivers reported that having access to information and support following FRO screening would have the added benefit of making them feel less isolated: "To find resources, to find people with whom I can discuss the situation. Either a professional or a non-professional. You shouldn't feel alone in this" (female, 02023).

Key topics suggested by caregivers for this centralized resource included (in order of importance):

- Practical information about the role of caregivers**, what effective caregiving entails (how best to take care of patients), and what to expect.
- List of available resources** to help them respond to patients' needs. Of note, there was a preference for experiential information grounded in the reality of those who have lived through similar experiences. They wanted to hear what strategies had been used by others in similar situations and what worked for them.
- Tips on how to communicate with clinicians** in a way that would make them feel an integral part of the health-care team. Related to this were tips on how to deal with medical information overload (e.g., information processing aides, summary sheets).
- Tips on how to manage communication with patients and family/friends**, including how best to manage requests for information and offers of help. One participant used the analogy of a "bouncer" (female, 02010) to protect the patient. Caregivers also stated that while they needed help, they did not know what help to ask for from their social network. Caregivers also wanted to receive tips on constructively sharing their feelings with the patient.
- Self-care information** on how to manage their own symptoms and concerns (tailored to their FROs).

Logistical considerations in implementing FROs

Table 3 summarizes logistical considerations.

Timing

Most caregivers preferred a longer delay between the diagnosis and FRO screening, because they felt overwhelmed initially and they needed time to settle in their caregiving role. Fewer caregivers wanted to be screened as early as diagnosis or shortly after, emphasizing that the first screening was a means to obtaining early access to resources.

Most caregivers agreed that it would be appropriate to complete the FRO measures at the time of the patient's appointment. The very few caregivers who objected to this felt that they needed to focus on the patient (e.g., retain information shared by the physician) during appointments:

Table 3. Key logistical considerations

Key logistical consideration	Main finding
Timing	No consensus on when to start FRO measurement. Generally acceptable to complete these at the time of the patients' appointments
Frequency	Regularly, defined as daily to every 3 months
Length	15 and 30 minutes
Sharing results with patients	No
Sharing of results with oncology team and primary care physician	Oncology team preferred
Summary report	Quantitative and qualitative description
Follow-up care	Preferably a health-care professional in combination to an online resource

When the patient has an appointment we have time, because we are waiting so if it is done on a mobile application, we certainly have time to respond at that moment. That would be the best solution. (female, 02014)

Frequency

The majority of caregivers stressed that the screening needed to be done regularly, but what that meant specifically varied. Preferred frequency ranged from daily to every 3 months. About a third of caregivers thought it might depend on the severity of the patient's illness: "Every two weeks, but with an asterisk because it depends on who you're caring for and what level of disease is" (male, 02017). More importantly, about half of participants suggested that they needed to be able to determine the frequency based on their circumstances:

We could give recommendations, but the person has to choose, because there will be times when big changes will take place. There will be times when it will be very important to seek help. (male, 02003)

Length

The ideal length of time for completing the FRO measures was between 15 and 30 minutes. A few caregivers specified that this would vary depending on frequency, the relevance of the FRO measures, and on the time they had available to complete these:

One thing is to really adapt the questionnaire for caregivers, I understand that you start from the patient, but we experience truly different things [...] so it should be made more in line with the reality of the caregiver. (female, 02023)

Sharing results

Unanimously caregivers did not want to share FRO screening results with the patient so as not to burden them. Instead, they articulated a need for more information and support on how to share their feelings and experiences with patients.

Generally, caregivers favored sharing results with a designated member of the oncology team (often a nurse or social worker) rather than their primary care physician. This was highlighted because, as 1 caregiver said: "I think it's important that the oncologist is aware of what's happening within the family dynamic, a person is more than just the result of blood tests" (male, 02008).

Fewer caregivers wanted to share results with their family physician. One caregiver explained: "the family doctor has neither the time nor the training, nor, in some cases, the interest" (male, 02003). Other reasons included: family physicians were not aware of the caregiver's burden, no access to primary care, and lack of trust in their family physician.

In essence, caregivers stressed that results should be sent to clinicians who were willing to receive them and who were equipped to ensure appropriate follow-up. Caregivers acknowledged that the clinicians' scope of practice would have to be extended:

The pivot nurse is the nurse of the patient, she is not the nurse of the caregiver [...] so her role would have to be expanded. (female, 02021)

FRO summary report

Most caregivers appreciated the opportunity to receive a summary of their FRO results to track their progress. They also suggested that the report needed to explain results and state how the results should be used. One participant explained "the score is not necessarily the way I prefer things to be communicated to me. I would prefer to be told 'according to your answers, we noted that, which could be ... we suggest this and that'" (female, 02022). A few caregivers were ambivalent about receiving the summary, arguing that a transient, small issue could get exaggerated and cause additional worry for them.

Discussion

The impacts of caregiving are well-documented; the focus is now on screening for these to ensure caregivers have access to the support needed (Lambert et al. 2016). This study explored acceptability of FRO screening from caregivers' perspectives and what they would want as part of an FRO screening program. Key findings include: (a) priority was given to screening for emotional FROs; (b) although common PRO measures are used with caregivers, they do not capture all FROs identified; (c) FRO screening is acceptable, but results need to be met with appropriate support; (d) caregivers focus on patients, highlighting the ongoing challenge of their engagement in interventions; (e) caregivers did not want their FROs to be shared with patients, but rather they wanted help communicating their concerns to patients; (f) caregivers preferred sharing their FROs with the oncology team rather than primary care physicians; and (g) there might be limited resources in cancer care for real-world implementation of FROs and innovative service delivery models might be required. Each finding is discussed in turn.

Five categories of FROs were identified; however, emotional FROs were prioritized. This finding corroborates the emotional toll that caregiving has on individuals, particularly when it comes to anxiety, mental fatigue, and stress (Lambert et al. 2016). A study by Howard et al. (2021) exploring the conceptualization of FROs similarly found that caregivers' emotions are a central FRO. Given some of the overlap between patients' and caregivers' needs (Lambert et al. 2012a), common PRO measures have been validated among caregivers, including the Distress Thermometer (DT) (Riba et al. 2019) and the Edmonton Symptom Assessment System (ESAS) (Aubin et al. 2021; Hawkes et al. 2010; Heckel et al. 2018; Rajeshwari et al. 2020; Watanabe et al. 2012; Wishart et al. 2021). When these measures are given to both patients and their caregivers (Hawkes et al. 2010; Rajeshwari et al. 2020), caregivers report more family and emotional concerns than patients.

Using the DT (Riba et al. 2019) and ESAS (Watanabe et al. 2012) can facilitate comparison of patients' and caregivers' results and potentially provide a starting point for developing FRO screening programs. These PRO measures are commonly implemented in cancer care, potentially facilitating an extension to caregivers. However, these measures do not fully capture some of the practical, social (e.g., managing housework, communicating with family and friends), and cancer care FROs identified by caregivers in the present study. Potentially, caregiver-specific measures such as the Supportive Care Needs Survey – partners and caregivers (Girgis et al. 2011) could be added to focus specifically on FROs.

The present study, and others (Aubin et al. 2021; Klagholz et al. 2018; Shaffer et al. 2019), found that screening for FROs was acceptable, but caregivers in our study emphasized that an extension of the FRO screening process is to match caregivers' concerns with appropriate health-care services. In Aubin et al.'s (2021) randomized controlled trial (RCT), 54 caregivers of patients with lung cancer were given the DT (Riba et al. 2019) and the ESAS (Watanabe et al. 2012) and 55 were part of the control group. An oncology nurse, hired for the study, followed up with caregivers and family physicians were made aware of the FRO results. Despite having a dedicated resource, the effects of the intervention were not significant. One explanation was that FRO screening took place every 2 months, and caregivers flagged that this did not correspond to key transition points for them, potentially underestimating caregivers' distress. Another reason was that the nurse was not accessed by caregivers as much as was anticipated, as caregivers tended to put aside their own issues to concentrate on the patient. Fewer than half of caregivers with distress seek help or accept referrals to services (Heckel et al. 2018; Wishart et al. 2021). Therefore, even if health-care resources are dedicated to FRO results, caregivers' engagement remains a concern. Wishart et al. (2021) found that only 18% of caregivers were adherent to their FRO measures, even if results then went to the oncology team. These findings, and those of the present study and of others (Aubin et al. 2021; Shaffer et al. 2019), emphasize a need to "market" the importance of FRO measures and how they can contribute to caregivers maintaining their role. None of the reviewed studies introduced FROs or had as part of their on-boarding an explanation of how completing these would ultimately improve patients' outcomes.

In previous studies, our team found acceptability of self-directed interventions (booklets and web-based intervention) was high for caregivers (Lambert et al. 2020, 2022a). Providing caregivers with these low intensity interventions, following FRO screening, could increase their access to a (universal) minimal level of support. This suggestion is consistent with a previous study that found caregivers prefer to receive information from health-care professionals when their burden is high, but they prefer other information sources (e.g., internet) when burden is low (Longacre 2013). High-intensity support might then be offered within a stepped care approach (O'Donohue and Draper 2011), after caregivers have tried low-intensity interventions and only for those needing it. Stepped care might not only be more acceptable to caregivers but also conserves scarce clinical resources (O'Donohue and Draper 2011).

Unanimously caregivers preferred not to share their FRO results with patients. A result consistent with Howard et al.'s (2022) qualitative study, which found that reasons centered on the desire to protect patients from their struggles. However, Howard et al. (2022) also found that some caregivers saw that sharing FRO results was important for transparent communication with patients. Caregivers need to be able to decide whether FROs are

shared or not so as avoid compromising the manner in which patients and caregivers have decided to cope. Perhaps more importantly, caregivers identified the need for interventions that can help them improve their communication with patients. This corroborates findings from dyadic coping interventions (Lambert et al. 2022a, 2020) whereby caregivers often want to learn how to better respond to patients' emotions and in turn communicate their own feelings.

Caregivers in the present study expressed preference for sharing their FRO results with the patient's oncology team, as opposed to their family physician. One of the main reasons was uncertainty about family physicians' capacity and knowledge to address their needs, which echoes other studies (Aubin et al. 2021; Adams et al. 2012). Recognizing this, Mitchell et al. (2013) conducted an RCT of a family physician-based toolkit to facilitate caregiver support. The toolkit included a caregiver-reported needs checklist and a compendium of resources to respond to caregivers' needs. The intervention had mixed effects and seemed most efficacious among caregivers who were anxious or depressed at the outset of the study. Potentially, continuing to use this 2-prong approach – support health-care providers in responding to caregivers' needs along with the low-intensity interventions previously discussed might lead to even greater effects, without being overly costly.

Real-world implementation of PROs has been the focus of much research for over 2 decades, and despite this, implementation and spread remain limited (Basch et al. 2016; Di Maio et al. 2022; Graupner et al. 2021; Howell et al. 2015; Kotronoulas et al. 2018; van Egdom et al. 2019). Many cancer centers do not have dedicated resources for caregivers, posing a unique barrier to FROs implementation. Potentially, community-based models of care could address this gap in health services. For instance, Hawkes et al. (2010) explored the acceptability of using cancer telephone helplines to screen for PROs and FROs, based on who called. Among 114 caregivers, 90% scored ≥ 4 on the DT. This proportion might be higher than expected because this is among caregivers who reached out for help. Operators then triaged callers to follow-up care based on their DT levels. Operators did identify challenges in administering the DT (e.g., awkward to administer) and identified needs for training (Hughes et al. 2011). In another study (Heckel et al. 2018), helpline oncology nurses called caregivers recruited from cancer centers directly 3 times over a 4-month period. Needs identified by the DT were then addressed by the nurse who also facilitated navigation to other services. Caregivers' distress significantly decreased throughout the intervention.

Strengths of this study include recruiting caregivers across different age groups as well as an almost equal proportion of males and females. Interviews were conducted in either French or English, and both data collection and analysis were conducted by experienced RAs. A limitation is that we did not interview health-care professionals to obtain their perspective on FROs. Second, participants may have provided socially desirable answers, a common challenge in self-reports. Third, this study was conducted in the context of a publicly funded health-care system, limiting transferability to different health-care funding models.

In conclusion, despite increased focus on family-centered care, the implementation of FRO measures in cancer care remains scarce. This study provides foundational knowledge, from caregivers' perspective, on some of the key processes to consider in real-world implementation of FRO measures (e.g., type of FROs, response to these, sharing of results). Co-collecting PROs and

FROs would provide a holistic understanding of the dyads' challenges to further inform the service planning and delivery in a way that optimizes the health outcomes of both. Future studies would include piloting a FRO program that operationalizes caregivers' recommendations and explores clinicians' perspectives of FROs implementation.

References

- Adams E, Boulton M, Rose PW, *et al.* (2012) A qualitative study exploring the experience of the partners of cancer survivors and their views on the role of primary care. *Supportive Care in Cancer* **20**(11), 2785–2794. doi:10.1007/s00520-012-1400-4
- Aubin M, Vézina L, Verreault R, *et al.* (2021) A randomized clinical trial assessing a pragmatic intervention to improve supportive care for family caregivers of patients with lung cancer. *Palliative and Supportive Care* **19**(2), 146–153. doi:10.1017/S1478951520000711
- Basch E, Deal AM, Kris MG, *et al.* (2016) Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *Journal of Clinical Oncology Official Journal of the American Society of Clinical Oncology* **34**(6), 557–565. doi:10.1200/JCO.2015.63.0830
- Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* **3**, 77–101. doi:10.1191/1478088706qp063oa
- Cepoiu-Martin M, Tam-Tham H, Patten S, *et al.* (2016) Predictors of long-term care placement in persons with dementia: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry* **31**(11), 1151–1171. doi:10.1002/gps.4449
- Di Maio M, Basch E, Denis F, *et al.* (2022) The role of patient-reported outcome measures in the continuum of cancer clinical care: ESMO Clinical Practice Guideline. *Annals of Oncology* **33**(9), 878–892. doi:10.1016/j.annonc.2022.04.007
- Girgis A and Lambert S (2009) Caregivers of cancer survivors: The state of the field. *Cancer Forum* **33**(3), 167–171. doi:10.3316/informit.716556210043833
- Girgis A, Lambert SD and Lecathelinais C (2011) The Supportive Care Needs Survey for partners and caregivers of cancer survivors: Development and psychometric evaluation. *Psychooncology* **20**(4), 387–393. doi:10.1002/pon.1740
- Graupner C, Kimman ML, Mul S, *et al.* (2021) Patient outcomes, patient experiences and process indicators associated with the routine use of patient-reported outcome measures (PROMs) in cancer care: A systematic review. *Supportive Care in Cancer* **29**(2), 573–593. doi:10.1007/s00520-020-05695-4
- Hagedoorn M, Sanderman R, Bolks HN, *et al.* (2008) Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin* **134**(1), 1–30. doi:10.1037/0033-2909.134.1.1
- Hawkes AL, Hughes KL, Hutchison SD, *et al.* (2010) Feasibility of brief psychological distress screening by a community-based telephone helpline for cancer patients and carers. *BMC Cancer* **10**, 14. doi:10.1186/1471-2407-10-14
- Heckel L, Fennell KM, Orellana L, *et al.* (2018) A telephone outcall program to support caregivers of people diagnosed with cancer: Utility, changes in levels of distress, and unmet needs. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer* **26**(11), 3789–3799. doi:10.1007/s00520-018-4246-6
- Howard AF, Lynch K, Beck S, *et al.* (2021) At the heart of it all: Emotions of consequence for the conceptualization of caregiver-reported outcomes in the context of colorectal cancer. *Current Oncology (Toronto, Ont.)* **28**(5), 4184–4202. doi:10.3390/curroncol28050355
- Howard AF, Torrejón MJ, Lynch K, *et al.* (2022) To share or not to share: Communication of caregiver-reported outcomes when a patient has colorectal cancer. *Journal of Patient-reported Outcomes* **6**(1), 13. doi:10.1186/s41687-022-00418-1
- Howell D, Molloy S, Wilkinson K, *et al.* (2015) Patient-reported outcomes in routine cancer clinical practice: A scoping review of use, impact on health outcomes, and implementation factors. *Annals of Oncology* **26**(9), 1846–1858. doi:10.1093/annonc/mdv181
- Hughes KL, Sargeant H and Hawkes AL (2011) Acceptability of the Distress Thermometer and Problem List to community-based telephone cancer helpline operators, and to cancer patients and carers. *BMC Cancer* **11**, 46. doi:10.1186/1471-2407-11-46
- Institute of Medicine (IOM) (2008) *Retooling for an Aging America: Building the Health Care Workforce*. Washington (DC): National Academies Press (US).
- Kim Y and Schulz R (2008) Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health* **20**(5), 483–503. doi:10.1177/0898264308317533
- Klagholz SD, Ross A, Wehrle L, *et al.* (2018) Assessing the feasibility of an electronic patient-reported outcome (ePRO) collection system in caregivers of cancer patients. *Psychooncology* **27**(4), 1350–1352. doi:10.1002/pon.4658
- Kotronoulas G, Papadopoulou C, Simpson MF, *et al.* (2018) Using patient-reported outcome measures to deliver enhanced supportive care to people with lung cancer: Feasibility and acceptability of a nurse-led consultation model. *Supportive Care in Cancer* **26**(11), 3729–3737. doi:10.1007/s00520-018-4234-x
- Lambert SD, Duncan LR, Culos-Reed SN, *et al.* (2022a) Feasibility, acceptability, and clinical significance of a dyadic, web-based, psychosocial and physical activity self-management program (TEMPO) tailored to the needs of men with prostate cancer and their caregivers: A multi-center randomized pilot trial. *Current Oncology* **29**(2), 785–804. doi:10.3390/curroncol29020067
- Lambert SD, Duncan LR, Ellis J, *et al.* (2020) Acceptability and usefulness of a dyadic, tailored, web-based, psychosocial and physical activity self-management program (TEMPO): A qualitative study. *Journal of Clinical Medicine* **9**(10), 3284. doi:10.3390/jcm9103284
- Lambert SD, Faria R, Rosberger Z, *et al.* (2022b) L'utilisation des résultats de santé rapportés par les patients: Un atout dans le continuum de soins en oncologie. *Perspective Infirmière* **19**(3), 29–37.
- Lambert S, Girgis A, Descallar J, *et al.* (2014) Partners' and caregivers' psychological and physical adjustment to cancer within the first five years post survivor diagnosis (abstract). *Psychooncology* **23**(Suppl.3), 78.
- Lambert SD, Girgis A, Lecathelinais C, *et al.* (2013a) Walking a mile in their shoes: Anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Supportive Care in Cancer* **21**(1), 75–85. doi:10.1007/s00520-012-1495-7
- Lambert SD, Girgis A and Levesque J (2016) The impact of cancer and chronic conditions on caregivers and family members. In Koczwara B (ed), *Cancer and Chronic Conditions: Addressing the Problem of Multimorbidity in Cancer Patients and Survivors*. Singapore: Springer-Verlag London Ltd., 159–202. doi:10.1007/978-981-10-1844-2_6
- Lambert SD, Girgis A, Turner J, *et al.* (2013b) "You need something like this to give you guidelines on what to do": Patients' and partners' use and perceptions of a self-directed coping skills training resource. *Supportive Care in Cancer* **21**(12), 3451–3460. doi:10.1007/s00520-013-1914-4
- Lambert SD, Harrison JD, Smith E, *et al.* (2012a) The unmet needs of partners and caregivers of adults diagnosed with cancer: A systematic review. *BMJ Supportive & Palliative Care* **2**(3), 224–230. doi:10.1136/bmjspcare-2012-000226
- Lambert SD, Jones BL, Girgis A, *et al.* (2012b) Distressed partners and caregivers do not recover easily: Adjustment trajectories among partners and caregivers of cancer survivors. *Annals of Behavioral Medicine* **44**(2), 225–235. doi:10.1007/s12160-012-9385-2
- Lambert SD, Ould Brahim L, Morrison M, *et al.* (2019) Priorities for caregiver research in cancer care: An international Delphi survey of caregivers, clinicians, managers, and researchers. *Supportive Care in Cancer* **27**(3), 805–817. doi:10.1007/s00520-018-4314-y
- Leech NL and Onwuegbuzie AJ (2007) An array of qualitative data analysis tools: A call for qualitative data analysis triangulation. *School Psychology Quarterly* **22**, 557–584. doi:10.1037/1045-3830.22.4.557
- Leech NL and Onwuegbuzie AJ (2008) Qualitative data analysis: A compendium of techniques for school psychology research and beyond. *School Psychology Quarterly* **23**(4), 587–604. doi:10.1037/1045-3830.23.4.587

- Longacre M** (2013) Cancer caregivers information needs and resource preferences. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education* **28**, 297–305. doi:10.1007/s13187-013-0472-2
- Magilvy JK and Thomas E** (2009) A first qualitative project: Qualitative descriptive design for novice researchers. *Journal for Specialists in Pediatric Nursing: JSPN* **14**(4), 298–300. doi:10.1111/j.1744-6155.2009.00212.x
- Mitchell GK, Girgis A, Jiwa M, et al.** (2013) Providing general practice needs-based care for carers of people with advanced cancer: A randomised controlled trial. *British Journal of General Practice* **63**(615), e683–690. doi:10.3399/bjgp13X673694
- Northouse LL and McCorkle R** (2010) Spouse caregivers of cancer patients. In Holland JC, Breitbart WS, Jacobsen PB, Lederberg MS, Loscalzo MJ and McCorkle R (eds), *Psychooncology*. New York: Oxford University Press, 516–521.
- O'Donohue WT and Draper C** (2011) *Stepped Care and e-Health: Practical Applications to Behavioral Disorders*. New York: Springer.
- QSR International** (2018) NVivo 12.
- Rajeshwari A, Revathi R, Prasad N, et al.** (2020) Assessment of distress among patients and primary caregivers: Findings from a chemotherapy outpatient unit. *Indian Journal of Palliative Care* **26**(1), 42–46. doi:10.4103/ijpc_163_19
- Riba MB, Donovan KA, Andersen B, et al.** (2019) Distress management, version 3.2019, NCCN clinical practice guidelines in oncology. *Journal of the National Comprehensive Cancer Network: JNCCN* **17**(10), 1229–1249. doi:10.6004/jnccn.2019.0048
- Sandelowski M** (2000) Whatever happened to qualitative description? *Research in Nursing & Health* **23**(4), 334–340. doi:10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g
- Shaffer KM, Benvenuto S, Zaleta AK, et al.** (2019) Feasibility and acceptability of distress screening for family caregivers at a cancer surgery center. *Oncology Nursing Forum* **46**(2), 159–169. doi:10.1188/19.Onf.159-169
- Sinha M** (2013) Spotlight on Canadians: Results from the General Social Survey. Portrait of caregivers. In: **Canada MoIS** (ed).
- Soothill K, Morris S, Harman J, et al.** (2001) What are the psychosocial needs of cancer patients and their main carers?. *Health and Social Care in the Community* **9**(6), 464–475. doi:10.1046/j.0966-0410.2001.00326.x
- Tong A, Sainsbury P and Craig J** (2007) Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* **19**(6), 349–357. doi:10.1093/intqhc/mzm042
- van Egdom LS, Oemrawsingh A, Verweij LM, et al.** (2019) Implementing patient-reported outcome measures in clinical breast cancer care: A systematic review. *Value in Health* **22**(10), 1197–1226. doi:10.1016/j.jval.2019.04.1927
- Watanabe SM, Nekolaichuk CL and Beaumont C** (2012) The Edmonton Symptom Assessment System, a proposed tool for distress screening in cancer patients: Development and refinement. *Psychooncology* **21**(9), 977–985. doi:10.1002/pon.1996
- Wishart LR, Brown B, Nund RL, et al.** (2021) A prospective study monitoring carer distress during (chemo)radiotherapy for head and neck cancer via an electronic platform. *Journal of Medical Radiation Sciences* **68**(2), 139–148. doi:10.1002/jmrs.448