

# Chapter 2

## Providing Psychosocial Distress Screening, Coping Resources, and Self-care to Newly Diagnosed Cancer Survivors in a Canadian Small Town Setting

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### Introduction and Background

Over 12 million new cases of cancer are diagnosed worldwide every year. This number is projected to increase to about 19 million by 2024 and double by 2050. As a result of improved treatments and knowledge there are now over 28 million survivors living with a personal history of cancer. While most survivors adjust well over the long term, others do not and few receive comprehensive care that meets their needs. In many ways, the race to find more effective bio-medical treatments appears to have outpaced the search for ways to aid patients' psychosocial well-being.

Psycho-oncology is the specialty that studies the psychological, social, and spiritual factors that affect the quality of life of cancer patients and their loved ones. Psycho-oncology contributes to the multidisciplinary approach to cancer through its role in clinical care, education, and research. Because of the formation of psycho-oncology as a discipline, guidelines and standards for psychosocial care have been developed and endorsed by several national and international scientific societies.

Cancer rehabilitation and survivorship care focus on rebuilding the lives of those with cancer and maximizing functioning and quality of life. Many care plans begin as treatment ends to prepare patients for their return to a new normal phase of life. These plans are meant to empower and inform both the survivor and the health-care team. There are fewer care plans for newly diagnosed patients, although research has shown that early intervention for distress can enhance compliance and efficacy of treatment, reduce side effects, and improve quality of life and satisfaction. As the

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Institutes of Medicine (IOM, US) stated, “some elements of care simply make sense to improve patients’ experience of living with cancer” (Vos et al. 2015).

Thus, the statement, “no health without mental health” has become the basis of standards and clinical guidelines for cancer care in many countries around the world including Canada. According to the National Cancer Institute’s *Dictionary of Cancer Terms* (2012), the concept of cancer survivorship encompasses:

The physical, psychosocial, and economic issues of cancer exist from diagnosis until the end of life. These issues focus on the health and life of a person with cancer beyond the diagnosis and treatment phases [and] include issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Over the last 25 years, many studies in psychosocial oncology have found that 30–40 % of cancer patients have difficulty in adapting, and have emotional disorders, such as depression, anxiety, irritable mood, and feelings of demoralization (Meyer and Mark 1995). Clinically significant distress is linked to reduction in well-being, quality of life, poor adherence to treatment, and a longer time to recover. Caregivers are also not immune to such distress, which is linked to their own psychosocial morbidity (Sundar et al. 2013).

Prevention of distress is a proactive position that provides patients with coping skills and resource tools, thus making them able to successfully handle their cancer journey. Patients, survivors, caregivers, and health-care personnel in Canada have long been advocating for a total care person-centered cancer system—one that intentionally focuses on what is of importance to the patient and attends to the range of his or her needs (not just the tumor). They require quality care that is comprehensive, coordinated, and continuous. They want future patients to have a better experience during the cancer journey than the current system provides. In such an improved scenario, the inter-professional team works in partnership with the cancer patient and his or her family to ensure that care is responsive, person-centered, and tailored to their specific needs. In recent years, three significant events have occurred in Canada to spearhead the move to person-centered oncology care: First, The Cancer Control Strategy for Canada has mandated that all patients be screened for distress starting at diagnosis, using standardized recommended measures, and referring those with distress to community or hospital resources. A recent set of guidelines for screening and assessment and care of psychosocial distress in Canada has advocated specific actions for all adult cancer patients. Second, providing psychosocial care to cancer patients is now an accreditation standard with the Canadian Hospital Accreditation Board for Regional Cancer Centers. Third, distress is now considered to be the sixth vital sign in caring for hospitalized and community-based patients, (following the five vital signs of temperature, pulse, respirations, blood pressure, and level of pain (Bultz and Johansen 2011).

A substantial number of peer-reviewed meta analytic research studies have tested various psychosocial educational interventions delivered by professionals or volunteers, and concluded that patients benefited from positive outcomes. Research has shown that early intervention for distress enhances compliance and efficacy of treatment, reduces side effects, and improves quality of life and satisfaction. A systematic review involving breast cancer patients found that positive coping

strategies and a confident self-appraisal of the threat of the disease were among the most frequently reported factors linked to post-traumatic growth (Andersen et al. 2008). In another study, coping well during treatment and feeling a sense of personal control were found to mediate the relationship between physical symptoms and depression when treatment is over (Jacobsen 2009). Patients receiving radiotherapy who had a sense of self-efficacy before treatment had less symptom severity and anxiety post-treatment (Jacobsen et al. 2011). Lowering stress mediated the relationship between stress management skills and both physical functioning and emotional well-being for advanced prostate cancer survivors (Giesler et al. 2005).

Fostering patients' self-management has frequently been an area of relative weakness (Coleman and Newton 2005; Fitch 2009; Whitney et al. 2015). Most cancer patients are not currently adopting healthy behaviors, such as exercise and good nutrition, a fact which ultimately results in greater disease risks and health-care costs (Grant et al. 2012). Self-care strategies are not only useful in the transition to post-treatment care, but they are also useful in the diagnostic and early treatment phase to manage the ongoing effects of treatment. Active patient engagement plans empower and help return a sense of personal control, as their role in recovery becomes evident. Such plans are considered components of person-centered care where the needs of each individual are taken into account (Stanton 2012).

Many programs continue to rely on a group counseling model with supplemental written or internet-based information (Spiegel et al. 2007). We know that patients' preferences for the type of support they receive is the strongest predictor of a program's success (Whitney et al. 2015). Several models have been proposed to meet the needs of cancer patients; however the shared-care approach has generally been accepted as the optimal way to meet those needs (Carlson et al. 2004). An essential component of any model is to share relevant patient information among the various health-care professionals involved in a timely manner.

In spite of the enormous work carried out by the founders of psych-oncology, such as Dr. Jimmie Holland, many hospitals and clinics still struggle to find the best way to implement current recommendations. There has been an increase in person-centered care, but screening and intervening are costly in both time and money. One step that has been somewhat neglected involves the development of an action-oriented self-care patient and family introduction to screening with appropriate follow-up steps. While most cancer centers recognize the value of having a program for newly diagnosed patients, they also want to design their own programs to fit with their beliefs and resources. Busy oncology centers, even in Canada, find it difficult to achieve a true "buy-in" to the importance of psychosocial care. We were interested in developing a simple platform that could be easily adopted and modified by individual centers into their own personalized programs. Pre-empting problems that may arise is a form of prerehabilitation that has been advocated (Silver and Baima 2013). We have noted that survivorship care plans can increase patients' feelings of confidence, satisfaction, and well-being; could a plan based on engaging patients in self-care strategies presented at the start of treatment be feasible and produce positive results? (Lauver et al. 2007; Silver and Baima 2013).

This chapter presents a pilot program to address current issues of time, personnel, process, content, and outcomes related to the delivery of psychosocial care to newly diagnosed middle aged or older adults living in a primarily rural setting in Ontario, Canada. This project was not a research study but the pilot implementation of a simple screening and patient education plan. Our goal was to develop a brief, one-time session working with individual patients and a significant family member using self-care strategies that would lower their levels of distress. The program was designed to screen newly diagnosed patients for distress, educate them on how to monitor themselves for distress, and seek out appropriate resources. To further empower patients and their families, we presented a brief introduction to basic coping strategies (Edgar 2010).

### *Intervention*

We based the program on the constructs of coping appraisal and efficacy. When confronted by a diagnosis of cancer, people typically engage in the cognitive process of appraising the nature of the stressor (e.g., threat, actual harm, or loss) and whether they have the means to cope with it. Coping appraisal of one's cancer has been related to anxiety and adjustment in that the higher the perceived threat, the lower the level of well-being and the greater the level of distress (Lazarus and Folkman 1984). Coping efficacy is a form of self-efficacy that refers to people's beliefs about their ability to negotiate particular stressors or obstacles. These beliefs are assumed to affect how people perceive and react to adverse life events and conditions. Favorable perceptions of coping efficacy are likely to help people organize and deploy the coping methods at their disposal, draw effectively on environmental supports, and persist at problem solving when faced with difficult conditions. In the domain of cancer survivorship, coping efficacy includes beliefs about one's ability to deal with myriad challenges posed by the cancer experience, such as coping with treatment-related side effects, seeking and understanding medical information, and obtaining support to manage treatment and recovery. Although the literature on cancer-specific coping efficacy is somewhat limited at this point, available data suggest that stronger efficacy is related to positive outcomes such as higher quality of life (QOL) and fewer negative emotions (Lauver et al. 2007; Silver and Baima 2013).

The session was introduced to staff and patients as a step in the development of total patient care with the emphasis on meeting the psychosocial and educational needs of the person with cancer and his or her family. At the start of the session, for evaluative purposes, the following screening and assessment tools were administered as paper and pencil forms:

1. *The Edmonton Symptom Assessment Scale (ESAS)* (Bruera et al. 1991).  
ESAS assesses nine symptoms that are common to most cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and

shortness of breath. The severity of each symptom on a rating scale of 0–10 is measured by the patient at the time of the assessment. It is the patient’s perception of the severity of the symptom that matters.

2. *The Canadian Problem checklist (3).*

This is a short list of problems in six domains; practical, emotional, physical, spiritual, social, and informational. These items have been reported in peer-reviewed literature to be correlates of distress.

3. *The Distress Thermometer*

On a scale of 1–10 where 0 means no distress at all and 10 refers to the worst distress possible, patients recorded where they stood at a designated time period such as the present moment or day (Bultz and Johansen 2011). Box 1 illustrates the Distress Thermometer.

### **Box 1: The Distress Thermometer**

Learning to measure and manage your stress can make a difference in your life. In fact, in health care today distress (or stress) is now known as the sixth vital sign (after temperature, pulse, respirations, blood pressure, and pain). The best way to keep your distress in check and to know that you are still in control of your life is to cope well.

*The Distress Thermometer* is a simple tool that lets you measure your distress, take charge of it, and helps identify what is causing it. Continue to measure your distress, and follow the recommendations for your score.

#### **How to use the Distress Thermometer**

Circle the number that best describes the distress you have felt in the past week. Next, check the boxes on the Canadian Problem List that apply to you to identify what has been contributing to your distress. Find resources as needed to help deal with your concerns.

We followed the recommendations provided by the Pan Canadian Practice Guidelines developed by expert panelists and a critical literature review carried out by members of the Canadian Partnership against Cancer, and the Canadian Association of Psychosocial Oncology (CAPO) for screening, assessment, and appropriate referral to community or hospital resources. The distress algorithms were guidelines to appropriate referrals according to the patient’s level of distress. The facilitators for this pilot program were the author and an experienced social worker/family counselor. We met individually with patients and a family member of their choice within 6 weeks of their first appointment with the oncology team. Each session lasted an average of 45 min. The format for the session has been operationalized and standardized for teaching and implementation, primarily through close adherence to the content and order of the booklet.

The facilitators began by stressing the values of learning to cope well, regaining a sense of personal control, and keeping track of distress levels that could interfere with good health and well-being. We provided a booklet on coping, developed initially by the West London Cancer Network, UK, and adapted and renamed, *Cancer Coping Resource Program, Coping with distress: Making a difference*. The contents included the distress thermometer with instructions, the Canadian Problem list, resources specific to individual needs, and several coping strategies. The booklet was divided into two sections, one which provided specific support services, resources, and useful contacts in the local area, and other explained the importance of screening for distress and ways of preventing its severity through active participation in one's health care and learning coping strategies that took advantage of each patient's individual strengths (Miaskowski 2004). Boxes 2 and 3 provide further excerpts from the booklet.

### **Box 2: Booklet Introduction**

Having cancer is like taking a car trip over a hazardous road with oil spills, accidents, bumps, and very hot weather. How do you prepare for such a journey? You set some goals at the start. You intend to keep a helpful, hopeful, and realistic attitude whether your journey goes smoothly or not. You expect to have a good trip while being ready for any setbacks. For example, you anticipate comfort and safety with air conditioning, seatbelts, and air bags, and you also prepare for troubles by bringing extra oil, water, and spare tires with you.

Your goal for your cancer journey is to travel your route with a sense of personal control, having a healthy body and following your treatment plan. Coping well with whatever happens means you will experience a more successful journey.

Here are three “doable” objectives for us to work on today so that you can continue with them at home:

1. Become an active participant in your own care and life.
2. Realize that you can handle whatever comes your way because you have both inner strength and available resources.
3. Measure your distress level and keep it low through good coping.

When you are on your journey and when you look back on it, you want to be able to say that you handled it well. We do not have control over what happens to us, but we have total control over how we cope with it, and that makes all the difference.

### **What is good coping?**

It is a active problem solving that is optimistic, flexible, realistic, and practical, and lifts you beyond distress and despair. It is having a plan to look after yourself to achieve a calm sense of personal control. Coping well is linked to a better cancer journey.

A goal needs a plan or else it is merely a wish, so here is a simple, workable plan to achieve good coping and lower distress.

- Complete the distress thermometer and the problem list on the following pages.
- Practice some good ways of coping.
- Find and use resources that are helpful and meet your needs.

### **Box 3: Excerpt from booklet on tools for coping**

#### **Some Good Coping Tools**

**Exercise** of some kind 5 days out of 7, and keeping active in general are more than suggestions, they are essential to your well-being. Even small amounts of exercise a few minutes at a time are better than nothing, so feel good about starting small. Getting in better physical shape is a goal for you. What are your plans for doing it?

**Remember how you successfully coped** with stressful times in the past. Think about some of the things you are doing now to help you cope, for example; talking to close friends and family, going out, exercising, listening to music, and keeping a hopeful frame of mind. Identifying your strengths, and patting yourself on the back for them, can help you understand and be grateful for them.

List some of your strengths that have helped you cope well throughout your life:

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#### **Learn to deal with a changed health-care system**

The biggest change in today's health-care system is a shift from the patient being passive to being an active member of the team. You are the expert on your own body and yourself. Take ownership for making your body as healthy as possible—through eating well, having a good balance between exercise, rest and sleep, and coping with stress. Exercise is especially effective at reducing pain, fatigue, and improving mood and sleep.

You are the center of your health-care team. It is up to you to express yourself, say what is important to you and ask questions. Be as much a part of decision-making about your care as you want. When patients participate in their fight for recovery they move from feeling helpless to feeling in control.

Before your doctor's appointment, write down any concerns and questions so you do not forget to ask them, and ask for simple explanations to make sure you understand. Take someone with you to be another pair of ears and eyes. Having a friend or relative support you is important to your well-being. Medical care today is complicated and needs lots of coordination among many people who are doing the best they can. No news or information about your care may mean that somehow something has been forgotten or slipped through the cracks. If in doubt, ask!

*Other tools included in the booklet*

**Learn how your thoughts affect your feelings.**

**Deep breathing**

**Mindful meditation**

In summary, you now can measure your level of stress and have six proven coping tools to practice. We know these will make your cancer journey easier and healthier. You will have done your best, and will feel that sense of personal control.

Patients were not asked to give a history of their treatments or illness, but simply to recount their most pertinent issues using the ESAS and the problem list. The facilitators did not have access to patients' medical records, and the only information required was the name of their oncologist and the patients' birth date, for purposes of identification and transfer of summary information. Our intentions were to educate them about their role in managing their health and well-being and show them how to measure and handle their distress at home through the use of resources and coping strategies. In particular, the session emphasized the value of exercise, the need to regain a sense of personal control, be aware of one's own strengths, and take an active role in health care. Mindful meditation, deep breathing, and a schematic of how thoughts influence feelings were also presented.

A specific plan for future distress management was designed in collaboration with each patient. After the session was over, the facilitators completed a brief summary page on the patient's status, which was forwarded to the treating team. (Refer to Box 4).



**Box 4: Results from the Oncology Distress Management Program**

Name of Patient \_\_\_\_\_ Date \_\_\_\_\_

Total ESAS score \_\_\_\_\_

Pain \_\_\_\_\_ Tired \_\_\_\_\_ Nausea \_\_\_\_\_ Depression \_\_\_\_\_ Anxiety \_\_\_\_\_  
Drowsy \_\_\_\_\_ Appetite \_\_\_\_\_ Wellbeing \_\_\_\_\_ Dyspnea \_\_\_\_\_

Distress Thermometer Level \_\_\_\_\_

Canadian Problem List \_\_\_\_\_

- Practical
- Emotional
- Physical
- Spiritual
- Social
- Informational

Resources given \_\_\_\_\_

Comments \_\_\_\_\_

Two month follow up  
Date scheduled \_\_\_\_\_  
Outcome \_\_\_\_\_

CopeSmart Signature \_\_\_\_\_  
Oncology Clinic Review Signature \_\_\_\_\_

We telephoned patients up to 2 months later to reassess their distress level and provide resources as needed. Two university nursing students were hired to carry out the final evaluation by phone between 3 and 4 months, using Likert scales and open-ended questions.

## Results

There were 612 newly diagnosed patients seen at the oncology outpatient clinic during the 3 months we had set aside for the intervention; we received referrals for 105 patients and were able to interview 71. Only a small number, 7 of the 105 said they felt they were coping well and were not in need of a session on managing distress and learning about coping. At the final evaluation, the students were able to reach 60 patients.

Over two-thirds of the patients attended with a significant other who participated in the session by sharing both support and concerns related to family and disease issues. Seventy percent of the patients were female, and their ages ranged between 40 and 80, with an average age of 60. There was a variety of cancer types and stages.

### *Satisfaction and Distress Levels*

The average distress level at the start of the program was 4.2. Forty-nine percent of the patients scored 5 or higher on the distress scale at the start of the project. This figure is at the high end of other screening results across Canada where the reported scores for distress levels of 5 or more range from 18 to 38 % (Carlson et al. 2004). Eight patients or 12 % scored above 7 at the program's start. At the 3-month follow-up, distress scores were significantly lower. The average distress level had dropped to 2.6. Twenty percent scored between 5 and 7 but no one scored above 7. At the evaluation, we asked if they had measured their distress since their meeting. Measuring distress using the distress thermometer is a new concept that none of the patients had been introduced to before, yet 38 % said they had continued to measure their distress using the tool.

### *Canadian Problem List*

The number of concerns expressed ranged from 0 to 20, with a mean of 6.2. Physical problems were greater when the patient had started chemotherapy. Most patients were well prepared for chemotherapy by previously attending a class for all newly diagnosed patients that included chemo types, side effects, and delivery methods. The major physical symptoms were fatigue, pain, sleep, breathing, eating, tingling, and indigestion. The highest ranked concerns were emotional in nature: 63 % were worried, 57 % were anxious, and 53 % were afraid of the future (Refer to Table 1 for a complete list).

Eighty-two percent of the patients said they were very satisfied and recommended that the program be continued, while 18 % said they were not sure. No one

**Table 1** Canadian problem list of concerns

	Ranking	Percent (%)
Worry	1	63
Nervousness	2	57
Fears	3	53
Fatigue	4	30
Sadness		
Pain	5	24
Sleep	6	23
Depression	7	22
Changes in appearance	8	19
Breathing	9	17
Eating	10	15
Understanding my illness		
Financial, insurance	11	14
Tingling		
Dealing with children, friends		
Intimacy	Each 12	10
Indigestion		
Knowing resources		
Dealing		

was dissatisfied with the program. Using multiple choice questions, we found that 77 % learned that coping and lowering distress were part of their care and 12 % said that they already knew that.

Only 8 % said that they did not receive useful information on handling their distress.

When we questioned them whether as a result of the session they now felt more able to cope and handle distress, only 4 % said they did not. Sixty-five percent answered yes very much and 31 % said somewhat. Most patients responded that they mostly or definitely felt a sense of control over the events in their lives, but we did not question them about this prior to the session. The booklet was found to be very useful by 65 % and somewhat by 18 %, while 17 % did not find it useful.

Thirty-six or over 50 % reported using one or more resources. About half of the resources used by the patients were ones they sought themselves, such as friends and family members. We asked three qualitative questions. One: what one thing from the meeting stood out; two, what kind of a role do you feel patients need to take in today's health-care system, and three, are there any comments you would like to add or any changes you would like to see made to the program. The qualitative questionnaire comments were positive. Comments such as the following were representative: *“greatly reduced my anxiety, enjoyed the meeting, knowing where to go for help, very helpful people to shoulder up with, answered all my questions, someone has time for me, gives you reassurance that you can do something yourself, helped by looking at my mindset, learning to be more*

*forthright.*” The major insight for patients that emerged from the comments was the importance of being active and asking questions. Comments stressed the importance of practicing to focus on the moment and not on the distress, learning to be calm and to take care of themselves. They were pleased with how the session went and appreciated the follow-up call because they had a sense of being listened to, of being heard. Two patients suggested that the timing of the program could be earlier after diagnosis, but others commented that they felt the timing to be about right. Patients were surprised that today’s health-care settings require more active participation than before, but they accepted this reality and seemed ready to take more control over their health care. For example, if test results were not forthcoming, they were prepared to call and inquire about them; if their oncologist’s explanations for treatments were hard to understand, then patients would request clarification.

## Discussion

It was remarkable that the mean distress level fell from 4.2 at the start of the program to 2.6 two months later. The number of patients with distress levels over 7 fell to zero from 12 %. Such improvements cannot be credited to the program alone but to a number of other contributing factors, such as patients starting chemotherapy, returning to a more familiar routine, a lessening of side effects, more time to adjust to the cancer experience, etc. Emotional problems were the most frequently cited although physical problems were also ranked as distressing to many. The nature of the problems presented by the patient and family member were highly related to current events within their social milieu, and it was the impact of having cancer on those events that concerned them. The significance of cancer within the family circle reminded us that the family is itself a unit of care with its own needs and boundaries.

We were impressed that 38 % continued to measure their distress and act on the findings, given that this was a new concept to them and that they were only introduced to it once.

We looked at time, personnel, process, content, and outcomes. The time required for the session was brief, an average of 45 min per patient plus an additional 10 min to complete a summary sheet for the oncology team. The personnel were the author and an experienced social worker. We envisage carrying out the same intervention using an operationalized format with carefully selected and trained volunteers who have themselves had a close experience with cancer. There is precedent for using volunteers in other settings for similar responsibilities (Eisner et al. 2009).

The process involved introducing the program early in the cancer trajectory before treatment started, as a part of standard care, focusing only on the patients’ needs, and engaging them in recognizing their own strengths and coping strategies (Coleman and Newton 2005; Schofield et al. 2006). The content relied on active patient involvement in learning how to measure and manage their own distress, and followed the guidelines presented in the booklet. Overall, the patient-reported

outcomes were highly positive. Patients were satisfied both with the program, and their subsequent ability to cope. The satisfaction felt by the patients reflects their desire to have their needs recognized. Patients felt more in control and realized their role as assertive and active members in their health care.

## **Recommendations**

We recommend that a form of distress measurement be included in routine screening due to the relatively high levels of distress found at the start of the program. There is strong evidence that communication affects cancer patient outcomes, particularly satisfaction, psychological morbidity, and quality of life. Cancer patients rated good communication as a critical aspect of their medical care (Hack et al. 2005; Sharpley and Christie 2007). Perhaps one of the strengths of this project is the active listening by the facilitators. Facilitators did not have access to patients' charts so the patient was the only source of information. Since patients not only provided the facilitator with their most pertinent problems but worked out solutions together, the give and take of active listening took on a high level of importance. It is essential that such programs be sustainable, and able to be delivered by others than the front line oncology staff in busy, tertiary care settings. Community partnerships and resources, including volunteers, may be a realistic means to facilitate the implementation of such a program in the era of financial short falls.

## ***Implementation and Organizational Issues***

We received only 105 referrals out of a population of 630. Generally, it was the oncology nurses who decided who to refer. Most nurses explained to the patients and their families that the program was optional, thus making it easy for the patient to decline. When the oncologist recommended the program, patients willingly agreed.

There are volumes of literature that speak to the difficulty of implementing new programs into established cultures (Francke et al. 2008; Tuinman et al. 2008). How did we do with four essential requirements for successful implementation of the project? These requirements include consulting the organizational heads and front line staff, having organizational support, using a variety of strategies to ensure success, and continuous quality improvements. The chief oncologist and oncology project manager were strong advocates of the project and its potential. We did offer multifaceted targets of interventions including staff training, working with opinion leaders, policy development, audits, and ongoing feedback. We believe that our contact with the front line staff was not sufficient.

We concur with the literature that finds that programs that routinely screen and treat patients for distress are feasible, with some caveats. The introduction of the program to the front line staff is especially important in every aspect; how, when, where, how long, why, and how often (Loscalzo et al. 2011; Sollner et al. 2001). Staff were naturally reticent to fully integrate outsiders into the clinic, and in retrospect, we needed to have allocated much more time and many more resources to the introduction to the program (Andersen and Dorfman 2015). The facilitators were outsiders to the oncology clinic, and therefore were not part of the local culture. Many staff expressed the need to have resources in place that are quickly and easily accessed, and that are linked to the oncology center. This concern is reminiscent of the introduction of the pain ladder many years ago where staff were reluctant to use it, fearing they did not have the necessary resources to manage the patient's pain if it were measured.

We measured outcomes using the distress thermometer and open-ended questions, but comparisons across settings are frequently lacking. There are also many different outcomes that can be measured; we focused on patient satisfaction and levels of distress. Other outcomes of importance are the costs of running programs, the number of referrals made, long-term follow-ups, and other patient-reported outcomes. The outcomes themselves need to be assessed for their attention to quality and quantity. One general outcome that seems to be consistent among findings is that a screening process can improve communication between patients and their physicians (Fitzpatrick and Remmer 2011).

## Conclusions

A brief one-session intervention cannot address all the medical, individual, socio-cultural, and developmental aspects and outcomes, but it can make it easier for clinic staff to pick up on these issues and further explore them. We were pleased by the patients' responses and encouraged by their ability to learn new behaviors. With today's focus on using technology wherever possible to drive screening efforts, let us not forget that active listening to the patient's agenda, using their strengths, and helping them be active participants in their health care remain essential (Hack et al. 2005). We hope that this simple program can inspire other centers to build on it, replicate it, and assess it. Our future goal is to evaluate how well carefully selected and trained volunteers can function, using the same booklet, and following a similar protocol. Such a step is considered radical by some, yet we believe it holds the potential to expand these services to more and more patients. The volunteers would be included as members of the clinic or team, even with their limited role. A professional member of the oncology team could act as coordinator, mentor, and supervisor. These are plans for the future, and others will continue to find ways to create better person-centered care in oncology for all.

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