

## Guest Editorial

\*Patient-partner as well.

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# Screening for distress in cancer care: How to overcome barriers after unsuccessful implementation?

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**Introduction**

Coping with cancer and its treatment exposes patients to unmet needs and a significant risk of experiencing distress during their illness trajectory (Howell et al., 2015; Canadian Partnership Against Cancer and Partenariat Canadien Contre le Cancer, 2018). About 40% of cancer patients will display distress at any phase of treatment (Donovan et al., 2020). When indicated, systematic screening for distress in cancer patients can help identify unmet needs, improve their quality of life, decrease healthcare costs, and facilitate access to psychosocial and mental healthcare resources (Mitchell, 2013; Pirl et al., 2014; Howell et al., 2015). Screening for distress is worldwide recommended and often required for accreditation (Ng et al., 2021). For over a decade, international guidelines have recommended the implementation of screening for distress programs in cancer patients. Programs have been implemented with high success rates in many countries. Knies and colleagues published in 2018 the results of a study regarding the impact of a training program for implementing screening for distress. Interestingly, 95% of the implementation goals were successfully completed by cancer centers that have adhered to the training programs, after just 2 years of participation (Knies et al., 2019). To guide institutions in choosing effective models and locally contextualize principles, some experts recommended in fact further studies that evaluate minimum components (McCarter et al., 2020).

The COVID-19 pandemic has led to important reorganizations in healthcare systems resources. Recent data have shown that the prevalence of distress for cancer patients whose treatments have been delayed is higher than expected (Forner et al., 2021) and that telemedicine has also been rapidly adopted (Rivest et al., 2021). However, the pandemic has limited screening for distress practice and consequently has adversely affected access to supportive and psychosocial oncology services (Bultz and Watson, 2021). This now might be an opportunity for cancer centers that have not yet implemented screening for distress programs to begin to do so, and to revise it for those who successfully adopted it. The objective of this paper is to highlight the various challenges and barriers in implementing screening for distress among oncology centers and to raise questions whether existing data is sufficient to guide institutions to overcome them.

**Is screening for distress still relevant?**

Implementation of screening for distress can be challenging and may be unsuccessful. Indeed, several problems may be encountered by the oncology management team that sets up the program (Donovan et al., 2020). Although screening for distress is recognized as a standard of care (Bultz et al., 2021), experts have recently argued that the implementation of distress screening should be improved (Dekker et al., 2020). But how to do so remains an unanswered question. Sustainability of the distress screening practice is also a long-term challenge yet is critically important. Initial screening efforts from professionals might be impeded after some time if no clear benefits for patients are observed. In fact, a recent study revealed that sustainability might potentially be enhanced by formally integrating distress screening with existing practices and ensuring the engagement of all stakeholders (Groff et al., 2018).

Screening for distress implementation remains very relevant as these programs have been shown to significantly improve the general outcomes for cancer patients and healthcare systems (Bultz et al., 2021). Being attentive to our patients' emotional distress in cancer care and offering psychosocial care when needed has been beneficial for patients and their loved ones, as well as for the health care systems (Faller et al., 2013; Ng et al., 2021). Although psychosocial interventions are effective, a significant proportion of distressed cancer patients do not receive these interventions, because they do not have access to it or because they decline assistance.

Screening for distress has been associated with better quality of life, lower direct and indirect costs of care, less morbidity, better satisfaction with received care, and both improved symptom management and adherence to treatment (Diplock *et al.*, 2019). Not addressing cancer patients with persistent distress can constitute a risk for them, as well as to their loved ones. It can also significantly alter their quality of life. Such programs are not only an effective way to better identify those patients with significant distress during their cancer trajectory, but they can also help patients access adequate comprehensive care and also facilitate patient engagement and active participation in their cancer journey (Bultz *et al.*, 2021). Such programs can calibrate access to psychosocial care depending on the severity and type of distress (Howell *et al.*, 2015).

### Barriers: What makes implementation difficult?

Implementing screening for distress stimulates a change in practice, which generally involves facing challenges and using efficient strategies to overcome them (Ercolano *et al.*, 2018). Over the years, experts, researchers, and patients have identified barriers at multiple levels, which may be from institutions, clinicians, and even patients themselves. Knies and colleagues reported that the most common institutional barriers to screening included: lack of staff, competing demands, and staff turnover (Knies *et al.*, 2019). Institutions may underestimate the support and time necessary to plan such change, especially for high-capacity cancer centers where change might take some time and relies on an integrated team effort. In fact, even small pockets of resistance within front-line clinicians can prevent successful systematic implementation. Also, perceived burden has been considered to be a significant barrier for clinicians. Oncology staff have reported in the past feeling overloaded with their routine tasks and perceive this change in practice as an additional burden. Lack of training and support on psychosocial issues, the fear of inadequate response to patients' distress, as well as the failure to offer appropriate resources and help, have been documented in healthcare professionals (Mitchell, 2013; Ercolano *et al.*, 2018; Knies *et al.*, 2019; Arnold *et al.*, 2021). Even when distress screening becomes part of routine cancer care, some barriers persist and need to be addressed on a long-term basis in order to monitor compliance (Pereira *et al.*, 2016).

From the point of view of patients, some might be hesitant or non-adherent with the demands of screening with multiple questionnaires. They might also be embarrassed to reveal their distress as they might think that the health system will not easily offer mental health services to address their distress. Notably, in a recent Canadian study conducted among head and neck cancer patients, usually known for high levels of distress, only 50% who screened positive for distress accepted psychosocial oncology referral (Cohen *et al.*, 2018).

### Facilitators: What is next after unsuccessful implementation?

Implementation success depends upon many variables, such as accuracy of the screening method, acceptability of the practice, and high-quality follow-up care offered after screening. Adherence to the training program seems to be one of the most potent facilitators, while at the institutional level facilitators are "buy-in," "institutional support," and "recognition of participants' expertise" (Knies *et al.*, 2019). In Canada, lessons learned from recent successful implementations revealed that key components

are essential for success, including an effective change management strategy, leadership, integration, customization, project management, and program evaluation (Fitch *et al.*, 2018). Jacobsen and Norton have also reported that indicator measurement and analysis of progression during the implementation process are necessary (Jacobsen and Norton, 2019).

Implementation of interdisciplinary collaboration with clinicians specialized in distress detection is an important supporting factor (Ehlers *et al.*, 2019). Studies have also reported that the introduction of electronic data collection appears to be a game changer in screening for distress adherence since it is less time-consuming for patients and healthcare practitioners (Ehlers *et al.*, 2019). Clinicians' adherence to new time-saving technology is, on the other hand, not guaranteed, since adaptation to changing practice takes time and can require significant institutional technology resources, both factors under study (Butow *et al.*, 2018). eHealth system-based screening has some limitations and is still being studied (Girgis *et al.*, 2018). There is still a significant proportion of patients who are not familiar with computers and/or lack internet access (Mattsson *et al.*, 2019). Other patients may fear confidentiality breaches. The participation of patients as partners has also been considered another potential innovative strategy (Rivest *et al.*, 2020). Telephone-based screening seems to be a good option for distress screening (Taylor *et al.*, 2020), as multiple and long online questionnaires might discourage patients using them or have limited value with patients who have limited literacy, cognitive limitations, or impaired vision.

Even with the best intentions and use of optimal implementation strategies, distress screening programs sometimes fail or remain only partially used in a cancer care settings. Some researchers have recently become interested in studying how to overcome those barriers (Fradgley *et al.*, 2020). What conclusion might an institution come to when implementation is unsuccessful? Although local contexts vary, motivating healthcare professionals and other stakeholders for a second try might seem to be the best solution, even if it often appears unachievable. On the other hand, avoiding continuous quality improvement does not appear an ethically acceptable position. Patients with cancer also deserve adequate mental health care that meets the highest standards of care. Despite the growing data on effective strategies and implantation facilitators, there remains little data on what are the key measures essential for the implementation strategy and what are the best predictors of program implementation success (McCarter *et al.*, 2018, 2020). All these questions remain unanswered and should warrant more research.

### Conclusion

Although barriers and strategies to facilitate successful implementation of screening for distress in cancer care have been described previously, further research is needed to guide institutions, stakeholders, and clinicians regarding how to overcome barriers which they may encounter in their cancer center and which strategies to use to avoid an unsuccessful implementation process. Such data appear essential for centers that still do not or only partially offer screening for distress. The status quo does not seem to be an option that would be beneficial for patients. It remains an ethical responsibility to continuously offer updated and best practices to cancer patients.

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