ORIGINAL ARTICLE



Lessons learned about virtual cancer care and distress screening in the time of COVID-19

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Abstract

Purpose Cancer-related biopsychosocial distress is highly prevalent across the cancer care continuum. The implementation of screening patients for biopsychosocial distress has become a standard of practice in cancer care. With the presence of COVID-19, clinical care has shifted from in-person care to virtual care in many instances. One of the realities of COVID-19 is the significant decrease in screening patients for biopsychosocial symptom burden.

Methods Given that screening for distress has become an accreditation standard in many cancer programs, in the province of Alberta, Canada, all patients are screened for distress with every visit to the cancer centre. Given the presence of COVID-19, much of cancer care has shifted to being delivered virtually (through mediums such as Zoom). In this paper, we present pre- and post-COVID data on the frequency of distress screening and its impact on patient care.

Results A review of pre- and post-COVID-19 screening for distress questionnaires revealed that patients who received virtual care were less satisfied in the areas of emotional support and received less resources and referrals to supportive care. **Conclusion** The rapid integration of virtual care without the inclusion of a standardized distress screening tool was akin to a natural experiment, as two groups (virtual and in-person clinic patients) received different levels of care and interventions. Without the inclusion of distress screening, the clinical conversation around symptoms is less likely to occur and results in fewer referrals to best practices in supportive care services. Lessons learned about virtual cancer care without distress screening in the time of COVID-19 demonstrates significantly fewer patients being screened for distress and subsequently has resulted in less supportive care referrals. Going forward, we must find ways to ensure that virtual cancer care continues to support distress screening and best patient-centric care.

Keyword Patient-reported outcomes; Distress screening; Psychosocial oncology; COVID-19

Background

In the care of cancer patients, psychosocial oncology has been incorporated as a standard in most cancer care organizations. No longer can we think only about cure;

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importantly, cancer care must also strive to support cancer patients through diagnosis, treatment, palliation and living with cancer and its side effects and symptoms. Along with the growth and development of psychosocial oncology and supportive care programs, biopsychosocial screening for distress has become globally endorsed as a standard of practice in most cancer care programs.

With the onset of COVID-19, cancer care, including psychosocial and supportive care delivery, has shifted from inperson to virtual care. In this paper, we will examine how screening for biopsychosocial distress has been impacted by the shift to virtual care [1, 2].

Biopsychosocial screening for distress (sixth vital sign) was first proposed in 2005 [3] and has been widely endorsed globally as a standard of quality cancer care [4]. The importance of distress screening is now widely seen as an accreditation standard in many countries, societies and cancer care



organizations [5]. Research has demonstrated that distress screening alone is not an intervention but rather a prompt for patients to respond to key concerns raised on a standardized questionnaire and requires the healthcare team to acknowledge and address these symptoms and concerns in the clinical encounter with the patient.

A standardized multifactorial screening for distress tool can specify key physical and psychosocial concerns and, if followed-up by the clinical team, can serve to facilitate a discussion between patient and care provider. These patient-centric conversations between patients and their care team allow for shared decision-making regarding which strategies may be best suited to manage/mitigate the patient's symptoms and/or concerns [6]. The use of a standardized questionnaire adds specificity to the most distressing concerns and can replace the broad salutation of "how are you doing" leading to a much more meaningful conversation, assessment and treatment plan.

In Canada, and specifically in the province of Alberta, every cancer patient is provided the opportunity to complete a screening for distress questionnaire, now called the Putting Patients First (PPF) form. Cancer Care Alberta (CCA) has a standard operating procedure that outlines the expectation for routine and repeated distress screening for all ambulatory cancer patients at key times across their care trajectory, including at first consult, once per treatment cycle and at follow-up appointments [7]. This information collected from patients on the PPF is referred to as patient-reported outcomes (PROs).

In Alberta, the decision to integrate distress screening and PROs as part of routine clinical care was based on an accreditation standard for ambulatory cancer agencies in Canada [8]. The PPF includes two measures, the revised Edmonton Symptom Assessment System (ESASr) [9, 10] and the Canadian Problem Checklist (CPC) [11], selected in alignment with the national reporting criteria established by the Canadian Partnership Against Cancer (CPAC) [12].

Province-wide implementation for all cancer patients started in 2012 with the PPF being used at all 17 ambulatory cancer facilities within Alberta [13]. Implementation strategies included workflows and targeted practice change support to ensure that each PPF questionnaire was administered and reviewed within the clinical encounter and that a shared decision-making process was enacted with the patient to identify the most meaningful clinical response to the patient's priority concerns [11, 14].

In 2015, with the PPF being used in routine practice provincially, work began to capture patient responses to the screening questions digitally within CCA's provincial electronic medical record (EMR), as clinicians identified several shortfalls to the paper based screening process: (1) its inability to draw attention to worsening symptoms or clusters of symptoms that amplify symptom burden [15] and (2)

duplication of work in clinical documentation. As a result, a hybrid approach was designed to transfer distress screening data into the EMR, where the patient would complete a paper PPF in the waiting room, and after clinical review, a clinician would enter the PRO data along with their clinical intervention notes into the EMR. This allowed for streamlined documentation and access to digital PRO data. Once the data entry was integrated into practice, four different PRO dashboards were developed to aid in clinical care and program planning and reported PRO data at the individual (micro), clinic or institution (meso) and the provincial program (macro) levels [16]. Importantly, CCA is now able to categorize and account for overall PPF distress screening completion rates along with overall patient symptom burden and referrals for any given patient or population.

Patient-reported outcome data: pre and during COVID-19

Prior to the onset of the COVID-19 pandemic in Alberta, Canada (March 2020), over 53,000 unique cancer patients had completed at least one PPF, with over 227,000 screens entered into the EMR. On March 11, 2020, the World Health Organization declared COVID-19 a global pandemic and called for countries to take a whole-of-government, wholeof-society approach, built around a comprehensive strategy to prevent infections, save lives and minimize impact [17]. By March 15, 2020, there were numerous in-person clinic closures and cancellations of medical procedures across the province of Alberta. Alberta Health Services (AHS) facilities were allowed to remain open, but CCA immediately went into emergency contingency planning so that, wherever appropriate, cancer patients could receive their care virtually instead of in-person at the province's tertiary and community cancer centres.

Prior to the COVID-19 pandemic declaration, almost all ambulatory cancer care appointments took place in-person, and the province's cancer patient distress screening completion rate was sitting at about 75%. Following COVID-19 being declared a pandemic, where possible, outpatient appointments were conducted virtually. On average since the pandemic started, over 79,861 (36%) outpatient appointments in CCA have occurred virtually (Fig. 1), with 98% of virtual appointments occurring via telephone due to limitations of our existing electronic platforms. Further, the clinical process during most virtual visits is different from the approach for in-person visits, as the oncologist/nurse practitioner often conducts the virtual visit independent of the interdisciplinary clinical team who otherwise would have been involved in the clinical care. As distress screening is an organizational requirement, a workflow was proposed in order to gather PRO data from patients via telephone assessments prior to each virtual visit but was deemed too



labour-intensive at most clinical sites. This has resulted in an imbalance in PPF completion rates with in-person completion rates remaining around 70%, but virtual visit PPF completion rates falling to 15% as the historical workflow depended on in-person completion in the waiting room (see Figs. 1 and 2).

Method

In an effort to quickly understand the impact of declining PPF completion rates in virtual visits, administrative data for all of CCA was reviewed for the first 3 months of the

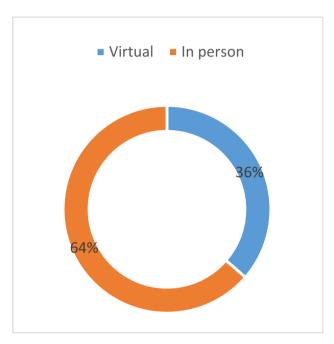


Fig. 1 Ambulatory Oncology Clinic Visits April 1, 2020 – Jan 1, 2021. A total of 79,861 virtual and 139,730 in-person visits were conducted

Fig. 2 PPF completion (virtual visits versus in-person visits) from April 1, 2020 to January 1, 2021. *Visit numbers differ from previous graph as this graph only represents visits where a PPF was expected to have been completed as per established workflow

pandemic (April to June 2020), revealing a marked difference (ratio of 5 to 1) in the supportive care referral rates between patients seen in-person and those seen virtually (Figs. 3 and 4).

Based on these early numbers and concern regarding the drop in both PPF completion rates and supportive care referrals, CCA embarked on a robust patient experience evaluation, surveying over 400 patients to assess their experience with receiving virtual care.

Results

This evaluation revealed that patients who received virtual care were less satisfied in the areas of emotional support, receiving resources and referrals and the involvement of family and friends in their care [18], showing a strong consistency between the administrative and patient experience data sets. The rapid integration of virtual care, often delivered by a single clinician, without the aid of a standardized distress screening tool was akin to a natural experiment, as two groups of patients received different interventions concurrently.

Discussion

The data shared here points to several key learnings. (1) Using a standardized approach for symptom and distress screening in a virtual visit is just as important, if not more important as it is in an in-person encounter, as clinicians have even fewer non-verbal queues available to them in a virtual encounter [19]. They cannot see the distress the patient may be experiencing due to unmanaged or escalating symptoms, such as a change in gait, a look of fear, anxiety or depression. (2) Without the inclusion of this patient-reported symptom/distress assessment, the clinical conversation is less likely to result in a referral to a supportive care service [20]. (3) An interdisciplinary approach

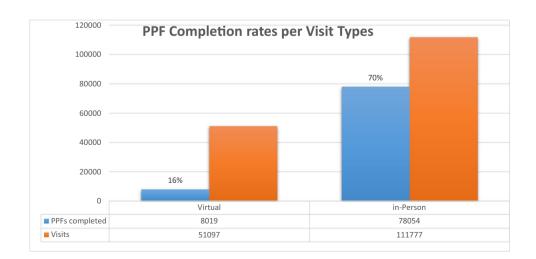




Fig. 3 Referral volumes by department April to June 2020 (depending on if in-person clinical appointment versus a virtual clinical appointment)

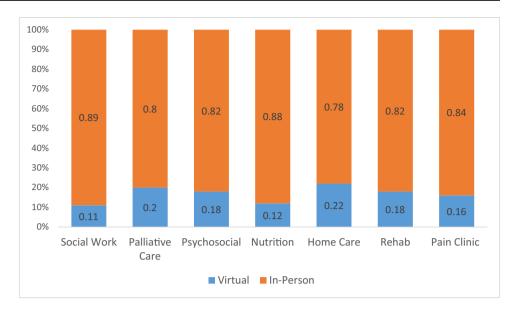
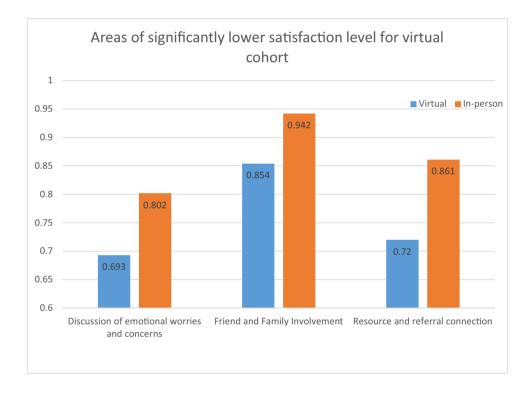


Fig. 4 Areas of significantly lower patient satisfaction when care was received in a virtual visit



to care may in fact increase the likelihood that a patient may receive supportive care referral [21]. In CCA, registered nurses are the professional group that is primarily responsible for the initial review of the PPF. They use it as a communication tool to initiate a dialogue with the patient about their symptoms and concerns and to identify potential symptom management and supportive care actions. If the actions required are outside of the registered nurses' scope of practice, they then engage with the most appropriate provider on the team who can manage the issue. For example, a referral to the complex pain clinic would be completed by the physician/nurse practitioner. (4) A digital

workflow for collection of the PPF/distress screening tool is required, as collecting this information over the phone is still too labour-intensive in most situations [22].

Conclusion

Since screening for distress (sixth vital sign) has become an accreditation standard, the integration of routinely collecting distress screening, associated with clinical review, has increasingly become a clinical standard in cancer care programs in



Canada. In our provincial cancer program, despite significant progress with the provincial PRO initiative and integrating the PPF into routine workflows, COVID-19 and the move to providing much of cancer care virtually have led to significantly fewer patients being screened for distress, which has resulted in less supportive care referrals. The argument can be made that these referrals are now more important than ever before as the COVID-19 pandemic has negatively impacted the emotional well-being of entire populations, let alone cancer patients [23]. It is clear that COVID-19 has provided an important teachable moment. In this natural experiment, we witnessed the negative impact of removing a standardized process to identify, assess and manage distress from ambulatory oncology clinic workflows, which has emphasized the essential link between distress screening and the connection to supportive care referrals. As Churchill said, "Never let a good crisis go to waste". We must now find ways to ensure that virtual cancer care continues to support the best patientcentric care. Digital strategies that allow patients to complete their distress screening from home are also now required. We can no longer rely on in-person workflows. All patients must be screened for distress, and clinical conversations around symptom and distress management must continue to occur regardless of whether it is in-person or virtually. The urgency is the opportunity!

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