Development and implementation of a comprehensive psychosocial screening program in a Brazilian cancer center

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Abstract
Objective International guidelines recommend routine screening for distress as part of care practices. Accordingly, a Brazilian cancer center developed and implemented a distress screening program (DS) in 2007, which was enhanced in 2009 through the inclusion of a psychosocial care meeting group (DS + PCM) regarding patients’ psychosocial needs. The current paper will provide an overview of the development and pilot implementation of this program and initial analyses to assess patient outcomes and report initial results to extend international research on this key aspect of cancer care.

Method Patients were assessed for distress, anxiety and depression, and in the DS + PCM phase for quality of life at the first day of chemotherapy infusion, at midpoint, and at treatment end. We compared data from program phases (DS vs DS + PCM), with a sequential cohort design and mixed effects modeling.

Results Clinical and demographic characteristics were similar between groups. Patients receiving DS + PCM showed significantly lower distress and depression/anxiety upon chemotherapy initiation (Ps < .001). While both groups reported significantly lowered distress and total depression/anxiety scores across time (Ps < .003), patients receiving DS + PCM maintained the lowest distress and total anxiety/depression at all assessments. Patients from DS + PCM group also reported improvements in quality of life over time.

Conclusions The current study provides preliminary evidence that a multidisciplinary structured screening program utilizing validated measures and team meetings is associated with reduced impairment in patients’ psychological well being. This program provided more opportunities for collaboration among providers with increased multidisciplinary meetings, enabled patients to more easily report problems, and ensured rapid access to relevant resources.

KEYWORDS
distress, cancer, guidelines, oncology, psychosocial care

1 INTRODUCTION

Approximately, 35% of cancer patients will experience significant distress during the disease continuum.1 National agencies, researchers, and clinicians alike have thus proposed that distress be assessed as part of routine cancer care,2–7 and that supportive care services be available to patients and survivors in a comprehensive and culturally sensitive manner.7,8 Further, distress has been proposed as the sixth vital sign and greater efforts have been encouraged in recognizing the psychosocial aspects of the cancer experience.6,9,10

The guidelines proposed by the National Comprehensive Cancer Network (NCCN) and the Institute of Medicine identify 4 process components constituting best practices—screening, assessment, treatment, and follow-up. The guidelines explain that providers should be engaged in each phase of these processes.7,11 Follow-up and communication with the members of the oncology treatment team is also an
important component in the overall management of patient distress.\(^{12}\)

In practice, several institutions have implemented distress screening procedures based on these process components.\(^{8,12}\) Researchers have also endorsed the benefits of these continuum-of-care standards.\(^{13-16}\)

In Brazil, however, no specific guidelines for distress management in cancer care have previously been formulated, and supportive care has been described by independent clinical effort. Thus, quality and adherence to international recommendations vary. Similar to efforts elsewhere, a lack of formal partnerships between health care teams and institutions, limited knowledge and recognition of the importance of psychosocial care among professionals and patients, and a paucity of resources dedicated to supportive care practice and research have hampered the development and implementation of psychosocial care guidelines.\(^{17}\) In addition, health care in Brazil remains somewhat a paternalistic approach, showing a tendency of patients to prefer that the physician make health care decisions for them, in a more passive decision-making approach.\(^{18}\)

In 2007, in recognition of the need to provide comprehensive, formalized, and evidence-based psychosocial cancer care, a distress screening program (DS) was developed and implemented in a cancer center in Brazil. The current paper describes this developmental process, pilot implementation, and initial program results in order to extend research on this key aspect of cancer care. We use mixed-effects modeling to learn whether different phases of the implementation of this program resulted in significant outcome differences across sequential patient cohorts (hypothesizing that implementation of a DS would improve patient outcomes). In addition, we provide an overview of the potential challenges associated with implementing guidelines in non-English speaking cultural settings outside the United States and United Kingdom, where the original guidelines were developed.

2 | METHODS

2.1 | Setting

*Centro de Câncer de Brasília* (CETTRO) is a private multidisciplinary cancer center, located in Brazil's Federal District, which has been in operation since 1995 and expanded in 2002 to become a day clinic. An average of 15 new patients per month start chemotherapy at this center. As a private center, the majority of patients have health insurance and usually come from high socioeconomic backgrounds and with high literacy levels. CETTRO is a private institution, in which patients pay for all services. However, there is no additional fee for the DS. The institution agreed that this program would be the Psycho-Oncology Service's routine, considering the importance of including all of the patients in the DS. The Psycho-Oncology Service seeks to provide all patients with appropriate supportive care resources across their disease continuum.

The DS was developed from existing international guidelines,\(^{2-5}\) and adapted to the context and culture of the institution and the country. We reviewed distress screening guidelines published by major agencies over the past decade and delineated general characteristics and recommendations which would be feasible to implement. Consideration was given to implementation issues, screening intervals, suitability of measures, options for intervening with distressed patients, and goals for referral and follow-up.

In a prior study, the distress thermometer (DT) was translated and validated as a clinical screening tool and established a baseline for distress levels among patients at this cancer center.\(^{19}\) Most patients (62.5%) reported clinically significant distress at some point during their treatment.\(^{20,21}\) All studies were approved by the ethics committee of the Health Sciences Faculty at Brasília University; a license agreement was obtained for use of the instruments described below.

2.2 | Participant groups

2.2.1 | First phase: distress screening (DS) program group

For phase I (2007-2009), patients were screened on the first day of chemotherapy and completed 2 follow-ups at approximately the midpoint and end of treatment. At initial screening, a 10-minute semistructured interview was conducted during the chemotherapy infusion procedure. Patients subsequently completed a 20-minute assessment packet at initial screening and completed the same packet at both follow-up time points (also during chemotherapy infusion). The screening packet included measures of distress (DT), anxiety and depression (Hospital Anxiety and Depression Scale [HADS]). Demographic and clinical information were already collected, per routine care, and available via medical chart. Patients' feedback regarding the screening procedure was uniformly positive, with many noting it as an important opportunity to raise concerns and receive validation of their cancer experience. In this phase I there is no feedback with the health team. Patients with moderate to severe distress were referred to the mental health services (psychologist or psychiatrist).

2.2.2 | Second phase: distress screening program plus psychosocial care meeting group (DS+PCM)

Initial feedback on the DS was received. As documentation of distress in the patient's health record was felt to be insufficient, physicians wished to add routine interdisciplinary meetings to discuss patients' psychosocial needs.\(^{21}\) Thus, for phase II (2009-2014), this meeting, occurring in addition to the DS assessment, was implemented every 2 months to discuss each patient undergoing treatment (data obtained on the first day of chemotherapy and on the follow-ups), with the same screening measures and schedule as described above. A health-related quality of life (HR-QoL) measure was also recommended and added: the Functional Assessment of Chronic Illness Therapy-General (FACT-G). It is important to note that for both phases only new patients starting a new medical treatment regimen (first line of treatment) were included and that the screening routine was maintained at phase II—first day of chemotherapy and 2 follow-ups at midpoint and end of treatment. The first interdisciplinary meeting for each patient occurred prior to the initiation of treatment. For these new patients we also include a prior appointment with the health team (before the chemotherapy infusion) to address concerns related to the treatment (eg, doubts and fears related to side effects, exams, and appointment).

For this meeting a summary of all screening results was prepared. A psychologist leads the psychosocial care meeting (PCM) presenting each patient's results to the physician and nurse responsible for the
case. Patients did not participate. Based on the distress screening results, patients were categorized as high or low risk and the following treatment algorithms used: (1) for those judged to possess moderate to severe distress (DT ≥ 4), the reasons were clarified and an appropriate treatment or referral to specialized care (psychologist, psychiatrist, physiotherapist, nurse, or own oncologist) implemented; (2) for those judged to possess no, or mild, distress (DT ≤ 3), educational material, emotional support, and referrals were offered and routine care provided. At the midpoint and conclusion of chemotherapy treatment, screening results were once again presented at the PCM and psychosocial treatment decisions reassessed based on the algorithm noted above; patients were reclassified according to the treatment algorithm at the follow-up time points. These follow-up discussions focused on patients’ adjustment to treatment, whether any psychosocial concerns, potential symptoms, or side effects important to consider in ensuring comprehensive care had arisen. All pertinent details of these discussions and referrals made were documented in patients’ health records.

2.3 Outcome measures

For phases I and II data on demographic variables, including patients’ age, gender, marital status, education, cancer diagnosis, and disease stage, were collected from patient records. Additional interviews and assessments are described below:

Semistructured interview: A psychologist collected a brief psychosocial history, patient’s comprehension of their diagnosis/treatment, and information on potential risk factors (eg, personal or family history of psychiatric disorder, comprehension difficulties related to diagnosis/treatment, family history conflicts or difficult events, and inadequate social support) for psychosocial complications.

Distress thermometer: A self-report Brazilian Portuguese version of the NCCN Distress Guidelines was used. First, patients were asked to rate their distress level during the previous week on an 11-point visual analogue scale—ranging from 0 (no distress) to 10 (extreme distress). Second, patients were asked to endorse problems that they have experienced in the same period across 35 problems, grouped into practical, family, emotional, spiritual, and physical problems. The cutoff score of 4 was used to indicate clinically significant distress, as determined by the developers and an extensive literature review. This cutoff was also suggested by the validation study of the Portuguese version of the DT. In this previous study, the receiver operating characteristic (ROC) curve analyses indicated a cutoff score of 4 yielded an area under the ROC curve of 0.82 with a sensitivity of 0.82 and specificity of 0.98. Hospital Anxiety and Depression Scale: A Brazilian Portuguese version of the HADS was used. This is a 14-item, self-report questionnaire in which patients rated how they felt during the previous week on a 4-point Likert scale. The questionnaire is composed of depression and anxiety subscales (7 items for each). The total score ranges from 0 to 42 for all 14 items, and each subscale is scored from 0 to 21. Subscale scores of 9-21 indicate greater depression and 8-21 greater anxiety on respective subscales.

The Brazilian Portuguese version of the Functional Assessment of Chronic Illness Therapy-General (FACT-G) was the only instrument used just in phase II. The FACT-G is composed of 27 items that evaluate quality of life on 4 domains of “well being” (physical, social/family, emotional, and functional) on a 4-point Likert scale. The total FACT-G score is the sum of the scores for the 4 subscales. Scores range from 0 to 28 for the physical, social/family, and functional subscales, 0-24 for the emotional subscale, and 0-108 for the total score.

2.4 Analytic strategy

Mixed-effects modeling compared data from patients who met inclusion criteria described below (n = 548) based on whether they received DS in phase I, or DS + PCM in phase II. Analyses tested group differences at the initial screening, and differential change across the follow-up time points for each outcome. Both fixed (group average effects) and random effects (within-individual variability) were estimated. Fixed effects for group, time, and the group × time interaction were included in all models. In addition, sociodemographic covariates (ie, age and gender) were entered and retained in final models as appropriate. All main effects and 2-way interactions with time were entered into the model. A backward elimination process was employed in which terms (P > .05) were eliminated from each model until a final solution was reached. All statistical tests were 2-sided. The Statistical Package for the Social Sciences: release 22.0 was used.

3 RESULTS

3.1 Sample

A total of 642 patients participated in the study, including 200 from phase I (DS) and 442 from phase II (DS + PCM). Of the total sample, 94 (14.6%) were excluded in subsequent analyses because of missing data at follow-ups, leaving 548 patients—154 at phase I and 394 at phase II. Primary reasons for missing data included death (76.4%), switching to different hospitals for treatment (11.8%), incompleteness of recommended treatment regimen (6.5%), or moving away to different region (5.4%). All patients approached consented to participate in this study.

Clinical and demographic characteristics of the 2 groups were similar, with the majority of the overall sample being female (67.4%), married (61.2%), college educated (60.5%), and with a mean age of 55.4 years. Most frequent cancer diagnoses were breast (26.5%), gastrointestinal (24%), and hematological (22.6%), with 66.1% diagnosed at an advanced disease stage. The only significant statistical differences found between samples were associated with disease diagnosis, with gastrointestinal cancer more prevalent in the DS group (P = .03; Table 1).

3.2 Outcome data

3.2.1 Psychological distress

Mixed-effects modeling showed that patients receiving DS + PCM reported significantly lower distress (DT) and total depression/anxiety (HADS) upon chemotherapy initiation relative to patients receiving DS (Ps < .001). We attribute these significant baseline group differences to the improvements in multidisciplinary collaboration, attention to distress screening, and care made across time—based on what was
learned from the DS group and prior to caring for the DS + PCM group. While both groups reported significantly lowered distress and total depression/anxiety scores across time (Ps < .003), patients receiving DS + PCM maintained the lowest distress and total depression/anxiety at all assessments (Table 2).

The prevalence of moderate to severe distress (DT) in the DS group was: T1 = 67%, T2 = 30.8%, and T3 = 16.2%. As above, the incidence of patients with moderate to severe distress was lower in the DS + PCM group: T1 = 40.3%, T2 = 14.4%, and T3 = 5.6%. We also observed changes over time in the frequency of problems reported on the problem list. Emotional and physical problems were the main problem areas reported (Table 3). The prevalence of emotional problems reported by the DS and DS + PCM groups across treatment were T1 = 95% and 85.1%; T2 = 76.9% and 62.4%; T3 = 79.2% and 44.4%, respectively; and for physical problems: T1 = 97% and 92.3%; T2 = 94.1% and 94.6%; T3 = 90.9% and 89.6%, respectively.

### 3.2.2 | Health-related quality of life

As we only had HR-QoL data from phase II, the comparative mixed-effects modeling analysis was not possible. However, in contrasting these data with the normative data of the general US adult population, we observed that our patients reported an average HR-QoL score the 50th percentile of the US norm at T1 (mean [M] = 86.2; standard deviation [SD] = 13.8) that improved by T2

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Equivalence of groups at baseline screening on sociodemographic, disease/prognostic, and psychosocial variables</th>
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</thead>
<tbody>
<tr>
<td>Variable</td>
<td>DS (n = 200) Mean (SD)/%</td>
</tr>
<tr>
<td>Sociodemographic</td>
<td></td>
</tr>
<tr>
<td>Age, y</td>
<td>55.45 (15.68)</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>63.0%</td>
</tr>
<tr>
<td>Education (at least college degree)</td>
<td>56.0%</td>
</tr>
<tr>
<td>Marital status (married)</td>
<td>62.0%</td>
</tr>
<tr>
<td>Type of cancer/disease stage</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>22.5%</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>29.5%</td>
</tr>
<tr>
<td>Hematologic</td>
<td>23.0%</td>
</tr>
<tr>
<td>Gynecological</td>
<td>9.5%</td>
</tr>
<tr>
<td>Lung</td>
<td>5.5%</td>
</tr>
<tr>
<td>Genitourinary</td>
<td>4.5%</td>
</tr>
<tr>
<td>Others</td>
<td>5.5%</td>
</tr>
<tr>
<td>I-II</td>
<td>26.0%</td>
</tr>
<tr>
<td>III-IV</td>
<td>63.5%</td>
</tr>
<tr>
<td>Unknown</td>
<td>10.5%</td>
</tr>
<tr>
<td>Measures</td>
<td>Possible range</td>
</tr>
<tr>
<td>Distress (DT)</td>
<td>0-10: 5.2 (2.6)</td>
</tr>
<tr>
<td>HADS—anxiety</td>
<td>0-21: 10.1 (5.1)</td>
</tr>
<tr>
<td>HADS—depression</td>
<td>0-21: 7.9 (4.9)</td>
</tr>
<tr>
<td>FACT-G</td>
<td>-</td>
</tr>
<tr>
<td>Physical well being</td>
<td>-</td>
</tr>
<tr>
<td>Social/Family well being</td>
<td>-</td>
</tr>
<tr>
<td>Emotional well being</td>
<td>-</td>
</tr>
<tr>
<td>Functional well being</td>
<td>-</td>
</tr>
</tbody>
</table>

DS, distress screening program; FACT-G, Functional Assessment of Chronic Illness Therapy-General; HADS, Hospital Anxiety and Depression Scale; PCM, psychosocial care meeting; SD, standard deviation.

<table>
<thead>
<tr>
<th>TABLE 2</th>
<th>Mixed-effects models comparing fixed effects group trajectories</th>
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</thead>
<tbody>
<tr>
<td>Outcome</td>
<td>Effects</td>
</tr>
<tr>
<td>DT</td>
<td>Group</td>
</tr>
<tr>
<td></td>
<td>Time</td>
</tr>
<tr>
<td></td>
<td>Quadratic term</td>
</tr>
<tr>
<td></td>
<td>Group × time</td>
</tr>
<tr>
<td></td>
<td>Group × quadratic</td>
</tr>
<tr>
<td>HADS</td>
<td>Group</td>
</tr>
<tr>
<td></td>
<td>Time</td>
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<td></td>
<td>Quadratic term</td>
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<td></td>
<td>Group × time</td>
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<td></td>
<td>Group × quadratic</td>
</tr>
</tbody>
</table>

DT, distress thermometer; HADS, Hospital Anxiety and Depression Scale.

*P < .05; **P < .01; ***P < .001.
TABLE 3  Percentages of the distress screening program (DS) and distress screening program plus psychosocial care meeting (DS + PCM) groups endorsing clinically significant distress on the Distress Thermometer (DT) or the presence of distress-related problems over the course of treatment

(M = 90.3; SD = 11.8) and T3 (M = 92.4; SD = 11.5), being at the 75th percentile of the US norm by T3.

4 | DISCUSSION

A new distress screening and referral routine was implemented institutionally in a Brazilian cancer center in line with international standards, providing preliminary evidence of the feasibility and positive effects of such efforts within a different cultural context. Findings from comparing phase I with phase II may suggest the additional benefit of the DS + PCM. We observed that it was possible to give a voice to the patients’ experience, improving the communication between patients/families and the health team, and encouraging the patient to become more active in his or her treatment, although this observation was not measured. Notably, our initial analyses highlighted the potential benefit of interdisciplinary meetings (PCM) in addition to screening,
with less impairment across outcomes for the DS + PCM group. We also made clinical observations that patients began to pay more attention to their physical symptoms, feelings, and thoughts, becoming more engaged in their own care across time. These procedures assured patients’ access to psychological assistance and also favored a greater integration of the psychosocial model in our patient care.

At the beginning of the treatment, we noted a high prevalence of moderate to severe distress, particularly during phase I. The prevalence of moderate to severe distress may, of course, relate to the impact of the diagnosis and the patients’ anticipation of chemotherapy treatment. It might also relate to cultural differences in adjustment to cancer that are present in Brazil. Finally, we note that many of the patients at CETTRO had been diagnosed with advanced disease, which may have increased the average level of distress in our patient sample. It is also worth mentioning that the DT is known to be more sensitive than specific.\textsuperscript{22} We do have the available resources in our setting and the PCM to help us to address or to establish a further assessment, and we feel that it is better to overestimate—rather than potentially underestimate—the number of patients with significant distress. However, this discrepancy may certainly be more unmanageable in many settings. We have thus opted to maintain the screening routine with the DT plus the HADS as well as to conduct further assessments to address specific domains, condition, or problems.\textsuperscript{26,29}

In general, the adaptation and implementation of the screening guidelines was achieved with minimal difficulty, served as a first step to destigmatize mental health issues and provided a basis for further intervention. The information available from international guidelines was sufficiently flexible for adaptation to our clinical setting using our available resources. The screening measures, with meaningful clinical cutoffs, helped guide discussions and garner acceptance of screening among multidisciplinary team members. The screening routine helped to identify areas for improvement in patient care, indicated that distress is prevalent among patients (particularly at the start of treatment), reinforced the importance of comprehensive cancer care and the need to translate some of the existing resources to Portuguese (eg, patient education materials), and provided standardized feedback for health professionals involved in this integrated treatment program. Further, the ability of this service to present distress screening data to validated and reliable measures enhanced interest in the Psycho-Oncology Service and provided data that health professionals could monitor among their patients. This study also highlighted the feasibility and benefits of embedding the psychologist in the team in a smaller cancer center, as a strategy to decrease or perhaps even prevent some psychosocial symptoms. Anecdotally, it was observed that professionals from a variety of care teams came to appreciate the importance and relevance of psycho-oncology and expressed an interest in how collaborative psychosocial care can make a valuable contribution to the patient experience.

Nevertheless, certain adjustments were necessary to translate and implement these international guidelines to our clinical and cultural setting. For example, we observed that linking assessment to the treatment phase became a screening routine that was most viable and logical for the health team, ensuring follow-up and integration as part of routine care. Further, the multidomain screen helped to check the efficacy of measures and to give us more information about our patients’ experience. Finally, despite cultural difference, the term distress was well accepted by patients and team members. It is important to note that in the first year (2007) of this program, we conducted a qualitative study (n = 100) that included a structured interview, analysis using ALCESTE (Analyse Lexicale par Contexte d’un Ensemble de Segments de Texte), and content analysis based on Bardin.\textsuperscript{29–31} We examined whether alternative terms for “distress” (eg, “stress”) would be more acceptable to patients in this cultural context.\textsuperscript{29} As a result of these analyses, it was observed that distress was perceived as a synonym of irritation, anxiety, impatience, worry, nervousness, and nuisance; many patients described their experience as distress, and not as stress.\textsuperscript{29} In view of these results, we observed that stigma still remained and that patients preferred to use the term distress, even though it was necessary to explain the meaning of this term to some patients using the NCCN definition.\textsuperscript{2,29}

The implementation of this program was conducted gradually, with ongoing discussion with relevant clinical team members. These discussions provided the opportunity to develop strategies to enhance psychosocial care from the beginning and throughout treatment. This included the development of educational materials for specific chemotherapy regimens (information about common side effects and reasons to call the doctor) and the coordination of appointments with nurses to explain and clarify any questions regarding treatment schedule, exams, and procedures.

Importantly, the program also promoted greater communication and integration of care goals between the psychology supportive care service and the physician service. It allowed the health team as a whole to develop a greater understanding and appreciation of the psychosocial issues facing their patients, offered insight into the patients’ perspective of dealing with cancer and treatment, and provided them with practical, evidence-based recommendations that could be incorporated into their routine clinical care of cancer patients. It is interesting to observe how the DS customized the treatment, focusing on specific patient needs. Finally, the routine screening implemented enabled patients and providers to more easily recognize and report emergence of problems and ensure rapid access to relevant resources. In response to the work completed in 2011, the DS program was recognized as an important component of our quality practice-accreditation program. The next phase of development will be to expand our screening program to include patients undergoing other treatments (surgery and oral chemotherapy) and to cancer survivors.

Regarding limitations, we acknowledge that the phase-based nature of program implementation may limit the analytical conclusions that can be drawn; however, the flexibility and responsiveness of the program were critical in limiting initial barriers and resistance from health care providers. The iterative implementation of the program, guided by feedback from patients and providers, also enhanced team members’ interest and investment in the program’s goals. Other limitations should be noted including the limits inherent to self-report data, no control group for comparisons, and little control over confounding variables. Finally, some of our clinical observations (eg, patients drawn by patients) were not measured and reported here as observations only. Future studies should examine patients’ perceptions about the program implementation. Moreover, we note that it may be difficult to implement a DS in a similar manner within a larger cancer center,
or across an entire nation. The use of technology will undoubtedly be vital to these endeavors.

In summary, the present study reports the successful development and implementation of a psychosocial screening program in Brazil, showing the viability of incorporating international guidelines in different cultural contents. Initial findings suggest that routine screening and team meetings were associated with improvements in multiple psychosocial domains for patients and thus extended our clinics commitment to comprehensive psychosocial cancer care. Further research, including the implementation of this program in different institutions in Brazil and other South American countries, is required.

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