Canadian Oncology Nursing Journal

Revue canadienne de soins infirmiers en oncologie

Volume 27, Issue 3 • Summer 2017
eISSN: 2368-8076

Canadian Association of Nurses in Oncology
Association canadienne des infirmières en oncologie

Systemic screening of distress: Portraits and cross-examination of the various stakeholders' perceptions, clinical perspectives, and research— Part I

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This article presents the findings of the first phase of a study with an exploratory sequential mixed research design (Creswell & Plano Clarke, 2007). It was made possible by financial support from the Canadian Association of Nurses in Oncology and the Fondation de l'hôpital Maisonneuve-Rosemont, a fund administered by the hospital's Centre d'excellence en soins infirmiers.

INTRODUCTION

Anyone who knows someone with cancer quickly realizes just how much this disease forces patients and caregivers to adapt throughout the care and treatment trajectory (Bultz & Carlson, 2006; Fitch, Howell, McLeod, & Green, 2012). The literature shows that 35–45% of people with cancer experience some degree of psychological distress (Carlson, Angen, Cullum, Goodey, Koopmans, Lamont, et al., 2004; Mitchell, Hussain, Grainger, & Symonds, 2011; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). This varies according to type of cancer, time since diagnosis and stage of the illness (Vachon, 2006). Many other factors are also present. Age, social support, medical background, coping styles and other individual variables (Weisman, 1976; Folkman & Greer, 2000, as quoted in Fitch, Howell, McLeod,

& Green, 2012; NCCN, 2012) also all influence the level of distress. Moreover, it has been recognized that some populations, particularly women with breast cancer and patients who have received hematopoietic cell transplants, experience greater levels of distress.

This means that one out of every two patients is experiencing distress (N=51) at the initial hematopoietic cell transplant consultation (Trask, Paterson, Riba, Brines, Griffith, Parker, et al., 2002). Survivors are no exception. They also face sizeable challenges, as a study of late mortality in hematopoietic cell transplant survivors (N=1479) illustrated. Bathia and colleagues reported in this study that “long-term” transplant recipients (monitored for a median 9.5 years) have 14 times more health problems that keep them from holding a job, as compared to their same-age siblings. These challenges influence their quality of life and their functional well-being (Bathia et al., 2007). Moreover, the authors indicated that 22% of long-term survivors suffer psychological problems, including anxiety, depression, and somatization. Seven percent express suicidal ideation (Sun, Francisco, Baker, Weisdorf, Forman, & Bathia, 2011). A 2008 study indicated that 43% of long-term survivors feel psychological distress (Rusiewicz, DuHamel, Burkhalter, Ostroff, Winkel, Scigliano, et al., 2008).

Women with breast cancer are a particularly vulnerable group when it comes to psychological distress in the continuum of care (Groenvold, Petersen, Idler, Bjorner, Fayers, & Mouridsen, 2007; Grunfeld, Coyle, Whelan, Clinch, Reyno, Earle, et al., 2004). Studies show that around diagnosis, these women experience distress that requires special attention in 30–40% of cases (Compas & Luecken, 2002; Howard-Anderson, Ganz, Bower and Stanton, 2011). Moreover, a study quoted in Vachon (2006) and carried out with long-term breast cancer survivors indicated that 18% of participants meet the criteria for post-traumatic stress syndrome (PTSS) and more than half (58%) present two of the three groups of PTSS symptoms (Amir & Ramati, 2002, as quoted in Vachon, 2006). These data are major when we consider that women treated for breast cancer and men treated for prostate cancer make up the largest group of cancer survivors (Canadian Cancer Society, 2013).

According to this partial summary of an extensive scientific literature, psychological distress is a prevalent problem that has major consequences for hematological cancer patients

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DOI: 10.5737/23688076273224235

who receive transplants, as therapeutic modality, or for breast cancer patients. It justified the necessity to study the psychological distress experienced by the treatment clientele in our facility. Moreover, the many clinical observations that have been repeated over time and carried out by different members of our research team lead us to see anxiety as a prevalent symptom in these two distinct clienteles that, in turn, could partially explain the above-described psychological distress.

Various studies confirm the prevalence of anxiety in these populations, although the literature is more abundant for breast cancer patients than for transplant recipients. This can be explained by the fairly low incidence of hematological cancers, the low prescription rates of hematopoietic cell transplant as treatment options and the high mortality rate in this group (Niess & Duffy, 2004; Canadian Cancer Society 2013¹). However, few researchers in the nursing sciences have explored the factors contributing to the anxiety and distress these patients experience using a periodically applied and systematic screening tool. Yet, this kind of data is especially important for developing nursing practices and an adapted service offer. This justifies our interest in deepening the understanding of the distress experienced by these two populations. To do so, we will explore the different facets of anxiety, as well as other aspects of the screening process, particularly relational aspects, which will be addressed in a second article.

THE HISTORY OF OUR ESTABLISHMENT'S SYSTEMATIC SCREENING FOR DISTRESS

In 2009, the Canadian Partnership Against Cancer (CPAC) and the Canadian Association of Psychosocial Oncology (CAPO) issued recommendations for assessing adult cancer patients' needs for psychosocial care. Screening for psychological distress is recommended for use as a first indicator—or alarm—that alerts caregivers of patients' needs for psychosocial care. Accreditation Canada considers emotional distress to be the sixth vital sign, after blood pressure, temperature, pulse, respiration and pain, and they incorporate it as a standard of care in their Qmentum program called Services de traitement du cancer et oncologie (Fitch, Howell, McLeod and Green, 2012; Programme Qmentum, 2010).

To better meet the psychosocial needs of people undergoing cancer treatment at Hôpital Maisonneuve-Rosemont (HMR), in January 2012, we implemented a tool to systematically screen for distress. During this period, the HMR's oncology clientele program targeted three pilot sites to implement the tool: the walk-in oncology clinic, the CRID breast cancer centre (Centre de référence pour investigation désigné) and the palliative care unit. The screening was extended to the hematological cancer unit in April 2013, and then to the allogeneic transplant unit and to the breast cancer radiation-oncology unit in September 2013. In July 2013, we reviewed the administration time the screening tool took at the oncology centre and the CRID. A version identical to the other sectors was implemented in palliative care in October 2013.

In summer 2012, a work group examined the results of the implementation of this tool on the above-mentioned units. At that time, preliminary data indicated that interactional and

contextual aspects were determining factors in clinical practice. Therefore, we sought not only to collect data from the implementation of this tool with these units' clienteles, but also to obtain information from nurses and patients about the relational and organizational issues influencing the implementation of systematic screening in oncology for patient distress.

METHODS

Design

An exploratory sequential mixed research design was developed and used to capture complex realities, such as nurse-patient interactions around topics that are potentially emotionally charged in a new and unpredictable context (Foss & Ellefsen, 2002).

Study Objectives

This study had five distinct goals. As mentioned above, this article will present the results of the study's first phase (the first objective). A second article will present the results of objectives 3 and 5. Note that objective 4 will be met by the last phase of the study, which will be carried out in 2017. The study objectives were set according to the populations under study. The first three were identical for the two cancer clienteles. The fourth objective specifically targets the hematological cancer and transplant population, while the fifth focusses on breast cancer patients.

Hematological and Breast Cancer Populations

Objectives:

1. To collect information on the psychological distress experienced by the targeted clientele at specific moments of the care trajectory (Phase 1);
2. To collect information on the process of implementing systemic screening for distress in the various sectors affected by the screening (Phases 1–3);
3. To better know nurses' perceptions of this systemic screening for distress in the context of hematological cancers, hematopoietic cell transplants and breast cancers (Phase 2).

The fourth objective was described as follows:

4. To better know patients' perspective on this systemic screening for distress in the context of hematological cancers and hematopoietic cell transplants (Phases 2 and 3).

The fifth objective was:

5. To better understand female breast cancer patients' perceptions of the screening for distress (Phase 2).

Although similar, these last two objectives are distinct in terms of the kind of data. We questioned transplant recipients using quantitative tools (questionnaires), but intend to use qualitative tools as well. These two methods for collecting information are complementary in that the questionnaires led to a better understanding of perceptions. An interview with

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1. Blood cancers (for all sites) are the fifth most frequent cancer. Although chances of survival have clearly improved over recent years, the five-year survival rate is 67% for lymphoma and 58% for leukemia, as compared to 88% for breast cancer.

open questions allows each participant to freely express his or her point of view. Moreover, the results of Phases 1 and 2 of our study encourage us to continue in this direction, as perceptions are central to these two articles.

Ethical considerations

This study obtained an ethical certificate in early 2013 from the learning establishment in which it was conducted. It should be mentioned that since systemic screening for distress is considered a standard oncological intervention, no consent other than verbal agreement from the clientele at the time of screening was required. However, written consent was obtained from participants for all other phases of the study.

DATA COLLECTION AND ANALYSIS

Description of the data collection tools for Phase 1

The tools described in the following paragraphs made it possible to reach the study's primary goal of gathering information on the psychological distress experienced by the targeted clientele at specific times in the care trajectory.

Distress Screening Tool (DST)

The distress screening tool (DST) chosen at HMR was the same instrument used by the Centre hospitalier universitaire de Québec (CHUQ). We obtained authorization to adapt and reproduce this tool, which meets the requirements laid out in the Pan Canadian Guideline: Assessment of Psychosocial Health Needs of the Adult Cancer Patient (Howell et al., 2009).

It is made up of three specific measurements. First, the distress thermometer (DT) measures an item (psychological distress) using an 11-point scale (0–10), allowing patients to indicate their average level of distress in the past week, including the day of the measurement.

The DT was validated in various studies with different groups of cancer patients, particularly on a bone marrow transplant unit (NCCN, 2012). A clinical threshold of five was chosen to lead to a more in-depth evaluation of patients' distress and, eventually, referrals for further professional help. This threshold was also chosen by CHUQ; it demonstrates the best balance between sensitivity and specificity, for referral to psychosocial workers (personal correspondence, De Serres, CHUQ).

Second, the distress thermometer comes with a problem list for patients (PLP). Users check the problems they are experiencing from the list. These difficulties are grouped into six categories. These problem categories are used in providing support care to cancer patients. This framework is a reference for the process of implementing a distress screening tool (Fitch, 2008). In this list, psychological elements are grouped with emotional elements. This list is proposed in the Guide to Implementing Screening for Distress: The 6th Vital Sign (CPAC, 2009). We added the item "protective isolation" to the social and family section of this list, since no item covered this aspect that is quite specific to hematopoietic cell transplant recipients (i.e., prolonged neutropenic isolation).

Finally, the *Edmonton* Symptom Assessment System (ESAS) helps patients note, on a visually analog scale of 0–10 the intensity of 10 symptoms (with one optional symptom) over the past

24 hours. The ESAS is a reliable psychometrics tool and has been validated on various populations, including advanced-stage cancer patients and patients in their first steps of treatment (CPAC, 2009).

We also chose a clinical threshold of five for anxiety and depression. This is because it would appear that five is the limit at which psycho-oncological assessment must be carried out. Again, this is also the threshold used by CHUQ. However, the clinical judgement in any given situation can diverge from pre-determined recommendations. For example, anxiety reported by the DST can be excessively high before a medical appointment. In such a case, referral could be put off until the patient's anxiety is re-evaluated post-appointment. Referral is always at the consulting professional's discretion. And, moreover, as we will see, certain results demonstrate this clinical reality.

Moreover, the screening tool used allows the patient to indicate his or her desire to receive or not to receive help for the identified problems. The professional then reviews the completed questionnaire's answers with the person and, according to the results, provided individualized intervention to foster the relief of symptoms or distress.

A follow-up form for the screening tool allowed nurses and any other professional conducting the screening or follow-up to make note of the interventions suggested to patients after the results. On this form, some medical information (e.g. diagnosis and stage of cancer) is required as is the patients' position in the trajectory. A fourth tool, the *Trajectoire globale de réponse à la détresse* (response trajectory to psychological distress) guides referral to various professionals offering psychosocial support in the program (see Figure 1).

Time measurement of the distress

Time 1. For breast cancer patients, Time 1 was their third medical appointment, during which the treatment plan is generally decided upon. For most hematological cancer patients, Time 1 was the patient's admission to the care unit or, more infrequently, at Day 1 of the second cycle of chemotherapy.

Time 2. For women with breast cancer, Time 2 was the Day 1 of the second cycle of chemotherapy, the third week of radiation therapy, or the pre-surgical information session. For hematological cancer patients, Time 2 was the patient's hospital discharge or, less frequently, re-admission if the form was not completed at discharge.

Times 3 and 4. A DST used as part of medical follow-up to transplants, during treatment for the two targeted populations, or during the palliative-care phase.

Let us specify here that all statistical analysis was carried out with SPSS software.

RESULTS

Sample characteristics

Between August 1, 2013, and August 31, 2014, 582 Distress Screening Tool (DST) questionnaires were distributed at Time 1 (T1). Of these 582 questionnaires, 50 patients (or 8.6%) did not wish to answer. At Time 2 (T2), we obtained 151 completed DST of the 532 DSTs. This low response rate can be

explained by the difficulty to systematize the distress screening process at times other than T1. Of the 151 respondents at T2, 52 were men (34%) and 99 were women (66%).

We excluded Times 3 and 4 from all analyses due to the low number of completed questionnaires (42 and 10, respectively). The portrait of distress drawn in this article is, therefore, based primarily on the T1 results of 532 completed tools. The variation of distress, the thresholds, and the response to needs over time were based on the 151 DST completed at T2.

Moreover, 505 follow-up forms to the DST were completed by nurses out of 532 (228 for participants with hematological cancers and 277 for those with breast cancer). The amount of valid data is specified each time.

Table 1 presents study participants, according to the type of cancer of the respondents and non-respondents.

We collected the reasons given for refusal to participate; certain patients did not wish to give a reason. For T1, 24 of the 50 patients who refused to participate in the study justified their refusal. Among them, 18 women with breast cancer answered that they did not feel the need to take part. Other reasons provided were, in ascending order, incapacity (N=3), lack of understanding of French (N=2) and not wanting to talk about emotions (N=1). The statistical analyses (chi-square and t-test) showed no distinction between non-participants and participants in terms of age, gender, or diagnosis.

The average age of all participants was 58 years at T1, with a minimum of 18 years and a maximum of 95 years. The standard deviation was 14 years. The average age of participants at T2 was 54 years, with a minimum of 22 years and a maximum of 85 years. The standard deviation was 13.5 years. Patients with breast cancer were significantly older than patients with hematological cancers at T1. The average age for breast cancer patients was 62 years (SD 12.3), or 10 years older than hematological cancer patients, the average age of whom was 52 years (SD 13.7). T-test results indicated that this difference was significant at T1 ($t=-8.8$; $p=0.000$) and at T2 ($t=-4.4$; $p=0.000$).

Figure 1 shows the different diagnoses for patients with hematological cancers. This data was available for 228 participants. Leukemia was the most prevalent diagnosis at 39%, followed by non-Hodgkin's lymphomas at 27%.

The "stage of cancer" was available for 489 participants (this element was entered on the screening tool follow-up form). Nurses indicated "not applicable" 47% of the time (which can be explained by the hematological cancer sample, for whom "stage

of cancer" is inapplicable). If this choice is excluded, 62% of the breast cancer sample was at a locoregional stage and 18% at a local stage, while another 18% was at a metastatic stage.

The distress thermometer score

The average level of distress at T1 was 3.2; with a minimum of 0, a maximum of 10 and a standard deviation of 2.73. At T2, the average level of distress was 2.84 (SD=2.7). On average, the women's level of psychological distress was 3.3 (SD=2.8), or 0.4 point higher than the average level of men's distress. The self-reported score fell at 2.9 (SD=2.4). T-test results indicate that this difference is significant to the threshold of 1%: $t=-1.8$; $p=0.067$.

On average, the level of distress of breast cancer patients is 3.3 (SD=2.8), or 0.1 point higher than the average level of distress of hematological cancer patients, but this difference is not significant ($t=-0.614$; $p=.539$).

We should note that the average of hematological cancer patients dropped to 2.6 at T2 (a reduction of 0.6). That of breast cancer patients also dropped, but more slightly: the average at T2 fell at 3.1 (a reduction of 0.2). This difference was not significant at T2 ($t=-0.962$; $p=.338$).

Figure 1: Diagnoses of hematological cancers

Table 1: Participants						
	T1			Total T1	Total T1	Total T2
	Incomplete	Men	Women	Valid	Distributed	Valid
Cancer						
Hematological	14	151	92	243	257	83
Breast	36		289	289	325	68
Total	50			532	582	

The following tables show the thermometer score according to gender and type of cancer at T1.

Table 2a and 2b: Thermometer scores at T1, according to gender and type of cancer			
Gender	N	Average	Standard deviation
Men	136	2.9	2.4
Women	374	3.3	2.8
Total	510	3.2	2.7

Cancer	N	Average	Standard deviation
Hemato	225	3.2	2.5
Breast	285	3.3	2.8
Total	510	3.2	2.7

Clinical threshold at the DT

In all, nearly 34% (33.9%) of patients had a score above or equal to five on the distress thermometer. There was no significant difference according to gender or type of cancer. At T2, the proportion of patients with a score above or equal to five dropped to 28.1%. However, we see a difference by gender at T2. Thirty-three percent of women reached the clinical score, as opposed to 17.8% of men ($\chi^2=3.4$; $p=.06$).

Clinical threshold for anxiety and depression

A little over one in four patients (26.6%) presented a score above or equal to five at T1. Anxiety is greater in female than in male participants. Thus, at T1, 30.3% of women reached the clinical score for anxiety ($\chi^2=9.2$; $p=.002$) while 17.3% of men attained this level. These proportions dropped at T2, but the difference between men and women remained significant: 9.8% of men vs. 22.9% of women ($p=.05$).

Significant differences also appeared at T1 and T2, according to type of cancer. At T1: nearly 1 in 5 hematological cancer patients (19.8%) reached the clinical threshold, while a third (32.4%) of breast cancer patients did ($\chi^2=10.9$; $p=.001$). At T2, this difference persisted: 13.4% of hematology patients had a score of five or above vs. 24.6% of breast cancer patients ($\chi^2=3.03$; $p=.08$).

For depression, we see that only 9.4% of patients had a score above or equal to five at T1. At T2, the proportion of patients with a score above or equal to five remained stable at 9.5% of patients. However, a significant difference can be seen by gender at T1: 5.4% of men, as opposed to 11% of women, reached the clinical score for depression at T1 ($\chi^2=3.8$; $p=.05$). Although proportions remained identical at T2 (5.8% of men vs. 11.5% of women), this difference is no longer significant. Moreover, 7.2% of hematological cancer patients had a score of five or more, while 11.4% of breast cancer patients reached this threshold. The same proportions were observed for T2. For depression, no difference according to type of cancer is significant at T1 or T2.

Evolution of clinical scores across time

DT

The following findings stem from repeated measurement ANOVAs and led us to identify a significant drop in the thermometer score between T1 and T2 for the entire sample [$F(1; 1)=3.62$; $p=.06$].

However, the findings did not show a significant effect of the interaction time*type of cancer [$F(1; 1)=0.07$; $p=.787$]. Thus, when the evolution according to type of cancer is examined, a significant drop in the thermometer score between T1 and T2 can be observed, regardless of type of cancer. The effect of help on the thermometer score of the two groups of patients (those who accept help versus those who do not accept help) were compared across time. The variable of interest is the thermometer score. The findings do not show significant effects of help lowering the thermometer score ($F=1.05$; $p=.3$). However, they show that the two groups have lower scores at T2 than at T1 ($F=4.3$; $p=.04$). The average level of distress lowers significantly between T1 and T2, whether or not patients accept help.

Clinical scores for anxiety and depression

A reduction over time in the number of patients with clinical scores for anxiety could be seen. Analysis showed that this difference in proportion was significant for women between T1 and T2 ($\chi^2=19.20$; $p=0.000$). As a result, for example, fewer women reached the clinical score for anxiety at T2 ($N=20$) than at T1 ($N=27$). However, the results of the repeated measure ANOVAs showed that the average score for anxiety dropped over time, just as much for patients who accepted help as for those who refused it, at a threshold of 1% ($F=2.9$; $p=.09$).

For the clinical score for depression, the chi-square test results showed a significant difference of proportion between T1 and T2. Fewer patients with a clinical score of depression were observed at T2 than at T1, in both men ($\chi^2=4.117$; $p=.042$) and women ($\chi^2=23.602$; $p=0.000$) and across types of cancer. However, the results of the repeated measure ANOVAs show that the average scores for depression do not evolve over time ($F=0.2$; $p=.6$). The intensity of the score for depression was thus observed to be stable, whether or not patients accepted help.

Problems over the last week

Patients spoke of the problems they encountered in their experience. They were presented with a list of 26 problems/concerns grouped into six categories (practical, social, emotional, spiritual, informational, and physical problems). On average at T1, patients declared 4.9 problems ($SD=4$) and 3.7 problems at T2 ($SD=3.2$). The graph below shows the percentage of patients who checked the various problems from the list.

The percentages of problems in the emotional problems category were the highest. Only a quarter of patients (25.4%) experienced no problem in this category while more than three quarters (77.8%) checked none of the problems in the spiritual category. Table 3 shows the number of items checked by category of problems.

The following graphs show the various results for each category of problem at T1 and T2 for all of the sample.

Graph 1: Number of problems at T1 and T2

Table 3: Number of items selected by problem categories at T1

Problem categories	Total number of items	Number of items per category of problems (%)							
		0 item	1 item	2 items	3 items	4 items	5 items	6 items	7 items
Practical prob.	4	64.2	24.1	9.8	1.1	0.8			
Social prob.	4	48.6	32.4	14.7	3.6	0.8			
Emotional prob.	7	25.4	29	19.4	14.1	6.6	3.4	0.8	1.3
Spiritual prob.	3	77.8	18.1	3	1.1				
Informational prob.	4	57	23.4	11.3	4.2	4.2			
Physical prob.	4	35.7	33.5	21.6	7	2.3			

Graph 2: Practical problems experienced

Graph 3: Social problems experienced

Graph 4: Emotional problems experienced

Graph 6: Informational problems experienced

Graph 5: Spiritual problems experienced

Graph 7: Physical problems experienced

Graph 8: Average scores for various symptoms at T1 and T2

Summary of the problems experienced

In decreasing order, the most frequently experienced problems were: fear (50%), sleep (42%), family (35%), understanding the illness and treatment (31%), coping with the illness (31%), and sadness (31%). Emotional problems seem to be one of cancer patients' main concerns. Spiritual problems are listed by few patients.

Men and women differ in the problems they experienced. When chi-square tests turned up significant differences, women claimed to experience more problems. At T1, there were 15 significant differences according to gender (out of 26 variables). Of these 15 significant differences, women were more frequent than men to have declared experiencing a problem for 11 variables. Thus, women reported more frequently than men

experiencing fear (53% of women vs. 44% of men; $\chi^2=3.2$; $p=.07$), feeling sadness (34% of women vs. 24% of men; $\chi^2=4.3$; $p=.037$), changing appearance (14% of women vs. 6% of men; $\chi^2=5.78$; $p=.016$), a loss of interest in usual activities (15% of women vs. 9% of men; $\chi^2=3.49$; $p=.062$), coping with the illness (34% of women vs. 22% of men; $\chi^2=6.74$; $p=.009$), questioning their relationship with God (5% of women vs. 0% of men; $\chi^2=2.72$; $p=.09$), being worried about understanding the treatment and illness (34% of women vs. 22.5% of men; $\chi^2=7.1$; $p=.08$), making decisions (17% of women vs. 9% of men; $\chi^2=2.9$; $p=.08$), accessing resources (18% of women vs. 9% of men; $\chi^2=5.6$; $p=.02$), experiencing memory issues (32% of women vs. 20% of men; $\chi^2=6.8$; $p=.009$), and sleep problems (47% of women vs. 36% of men; $\chi^2=9.1$; $p=.01$).

Moreover, men and women did not face the same problems. Men were more affected by problems related to sexuality (11.9% of men vs. 6% of women; $\chi^2=4.21$; $p=.04$), neutropenic isolation (12.6% vs. 6%; $\chi^2=5.79$; $p=.02$), work (16.6% vs. 10%; $\chi^2=3.74$; $p=.05$) and finances (20.5% vs. 14%; $\chi^2=3.01$; $p=.08$). Women more frequently reported emotional problems and information-related problems.

At T1, 10 significant differences can be observed according to type of cancer. Of these 10 differences, 4 specifically affected hematological cancer patients: sexuality (11.5% vs. 5% of breast cancer patients; $\chi^2=7.19$; $p=.007$); protective isolation (13.2% vs. 3%; $\chi^2=15.6$; $p=0.000$); finances (21.0% vs. 12%; $\chi^2=7.7$; $p=.005$), and; feeling like a burden to others (20.2% vs. 13%; $\chi^2=5.36$; $p=.02$). These are almost the same differences observed according to gender. Inversely, breast cancer patients are more numerous than hematological cancer patients to experience fear (54% breast cancer vs. 45% hematological cancers; $\chi^2=3.98$; $p=.05$), loss of interest in usual activities (17% vs. 9%; $\chi^2=5.5$; $p=.019$), worry about understanding treatment and the illness (34% vs. 27%; $\chi^2=3.1$; $p=.08$), difficulty making decisions (17% vs. 12%; $\chi^2=2.9$; $p=.08$), worry about resources (19% vs. 12%; $\chi^2=6.5$; $p=.01$), and sleep problems (47% vs. 36%; $\chi^2=7.1$; $p=.03$).

Less significant difference was observed at T2 than at T1. Nonetheless, it would seem that emotional issues persisted in time since at T2, six differences can be observed according to gender.

Symptoms experiences

At T1, like at T2, the median number of symptoms fell at five. The modal value at T1 was six symptoms, with a percentage of 15.6%. At T2, there were two modes: four and five symptoms, with a percentage of 17.2% for these two values. Men and women presented a similar number of symptoms, with an average of 2.4 symptoms per patient. At T1 and T2, there was no significant difference between genders ($\chi^2=14.3$; $p=.11$) or types of cancer ($\chi^2=9.8$; $p=.37$).

Graph 8 shows the average scores for the various symptoms at T1 and T2.

The three symptoms for which the intensity was the highest at T1 were: fatigue (average of 3.46), well-being (average of 3.16), and anxiety (average of 2.81). Fatigue and well-being were almost always present at T2 (average of 3.26 and 3.03

respectively), while appetite scored third (average of 2.67). A relative stability in the intensity of symptoms could be observed between T1 and T2, with the least and most prominent symptoms being the same at T1 and T2. A reduction in intensity could also be observed for almost all symptoms, except depression, sleepiness, and appetite.

Explanations for the variation

Gender and type of cancer were closely tied in this study. We used multiple linear regressions to determine if the differences observed could be attributed just to gender, just to the type of cancer or to both. It is interesting to note that the independent variables (gender and type of cancer) did not all have a significant effect. Our results show that only the variable of gender had a significant impact ($B=0.7$; $p=.05$) on the thermometer score, while type of cancer had no significant effects ($B=-0.2$; $p=.39$). In regards to symptoms, our results show that type of cancer had a significant effect on appetite ($B=-0.64$; $p=.059$) and pain ($B=-0.57$; $p=.059$). Hematological cancer patients had higher scores for these two variables. However, there was no effect of gender.

Gender had a significant effect on fatigue ($B=0.67$; $p=.06$), depression ($B=0.39$; $p=.03$), and anxiety ($B=0.64$; $p=.01$). Being female was associated with an increase in the intensity of symptoms for these variables. There was no significant effect of the type of cancer on these variables.

It was rare that the two variables played a simultaneous role, except for nausea, where gender ($B=0.53$; $p=.04$) and type of cancer ($B=-0.47$; $p=.04$) had an effect. Since these two factors are cumulative, it was women with hematological cancers who were the hardest hit.

Type of cancer or gender had a significant effect on the variables of interest, but rarely on both at the same time. When gender had a significant effect, it was to women's disadvantage, since they scored higher than men. When it was type of cancer that had a significant effect, hematological cancer patients had higher scores, regardless of gender.

Let us now examine the effects of the number of symptoms and problems on the thermometer score. The value of non-standardized coefficients indicated just how the thermometer score varied according to the independent variable. We saw that for each additional problem reported by the patient, his or her thermometer score increased by 0.28 at T1, and by 0.46 at T2. Therefore, a patient who reported 10 problems at T1 had a score 2.8 points higher than a patient who reported no problems (4.6 points more at T2). We also observed in light of the results of these analyses that many problems had more effect at T2 than at T1. For the two times of measurement, the effect of the number of problems was stronger than the effect of the number of symptoms.

Help desired

When asked "Would you like to receive help for one of the problems listed above?"

- 22.7% wished to receive help at T1
- 14.7% wished to receive help at T2

No significant difference was noticed between genders or types of cancer at either T1 or T2.

Referrals offered and accepted

At T1, the referrals most frequently offered to patients were, in descending order: oncology psychologist (26.4%), social worker (4.1%), and clinical counsellor in nursing care (3.5%). Inversely, the referrals least given to patients were: physiotherapist (0.2%), pharmacist (0.2%), another establishment (0.2%), and nurse (1.1%).

In a majority of cases, only one referral was offered (88%). Women were more numerous than men to be referred to an oncology psychologist (27.4% vs. 23.6%) and a social worker (5.1% vs. 1.6%). Inversely, men were more frequently referred to a doctor (4.7% vs. 1.5%) or a nutritionist (5.5% vs. 1.8%).

Similarly, breast cancer patients were much more numerous than hematological cancer patients to be sent to an oncology psychologist (29.2% vs. 22.8%) or a social worker (5.9% vs. 1.9%). Inversely, hematological cancer patients tended to be referred to doctors (2.9% vs. 2%) or nutritionists (5.3% vs. 0.8%).

Patients accepted these referrals in 40% of cases at T1, and 33% of cases at T2. No significant difference was observed according to gender at T1; men and women both accepted referrals in similar proportions. However, it was observed that women accepted help more frequently than men at T2. Forty-two percent of women accepted help at this time while only 16% of men did so ($\chi^2=6.45$; $p=.01$). In regards to type of cancer, there was no significant difference at T1. The difference was, however, significant at T2: 23% of hematological cancer patients accepted the referral while 50% of breast cancer patients did so ($\chi^2=7.03$; $p=.08$).

Patients were more likely to accept referral for help at specific times in the care trajectory. Hemato-oncological patients accepted help more frequently during treatment, showing a rate of 62.5% acceptance ($\chi^2=4.8$; $p=.02$). Hemato-oncological patients also accepted more help at the time of admission to the unit, with 45% acceptance. Inversely, help was more frequently refused by patients during consultations or at the start of hemato-oncological treatment (81% refusal; $\chi^2=4.1$; $p=.042$) or at the end of hemato-oncological treatment (85.7% refusal; $\chi^2=3.5$; $p=.06$).

Limitations in the study's first phase

Despite efforts to monitor the implementation of the DST with the various teams involved (e.g. clinical and scientific committees, focus groups, training teams, discussion groups) and consequently to collect data, some information was missing from this screening tool monitoring process. In hindsight, we realize that this tool was maladapted to a clientele being treated for hematological cancers. As a result, we have chosen not to present certain findings based on this tool. Our results are nonetheless quite solid in terms of the portraits they draw of the psychological distress shown by our study's target clientele at two times of measurement in the care trajectory. We are of the opinion that our findings can be generalized, even though some resources-related aspects would be undoubtedly different.

DISCUSSION

Our study confirms certain findings of past studies, particularly in regard to the prevalence of psychological distress. Nearly 34% of our sample experienced the clinical threshold of distress at T1, a finding that is similar to the results presented in the introduction. Over a quarter of patients (26.6%) reached the clinical threshold for anxiety and about 9.4% reached the clinical threshold for depression (let us remember that these thresholds require psycho-oncological assessment). The prevalence of anxiety reported in our study is higher than that described by Mitchell and colleagues (2013) in a wide-reaching meta-study that compared cancer survivors and people in good health. Sixteen studies assessed depression and 10 examined anxiety. The prevalence of anxiety was nearly 18% (17.9%) in cancer survivors ($N=48,964$), as compared to 13.9% of the non-cancer population ($N=226,467$). The rate of depression was 11.6% ($N=51,381$) in cancer survivors and 10.2% in the control group ($N=217,630$). This large-scale study examined people who had been diagnosed with cancer at least two years prior, while our study's sample was made up of a majority of women who had been very recently diagnosed with breast cancer (fewer than three weeks) and a certain number of patients with hematological cancers had also just been diagnosed (although the true number is not known). This could, in part, explain the difference observed in regard to anxiety. It is known that high levels of anxiety are common in people who have just been diagnosed and that these levels are reduced as patients adjust to their new reality (Hammeleft, 2015).

Another study by Mitchell, conducted in 2007, compared the efficacy of summary screening tools, such as the distress thermometer, with that of a standardized scale, such as the Hospital Anxiety and Depression Scale (HADS), the Beck Depression Inventory (BDI) and clinical interviews. Mitchell indicated that short screening tools, such as those used in our study, are more effective in detecting the presence or absence of symptoms than clinically significant problems (Mitchell, 2007). Therefore, according to Mitchell (2007), 11 out of 20 patients who reach thresholds for anxiety are clinically anxious, but the remaining 7 patients who reach this threshold are clinically depressed. However, in every 20 patients who test negative, one case of depression and four cases of anxiety were missed. For psychological distress, the thermometer generates nine false-positives and four false-negatives. As Mitchell emphasizes, the thermometers' cut-off thresholds can, of course, be modified, but increased sensitivity would increase its loss in specificity, and vice versa. Moreover, as Coyne points out (2013), although summary screening tools were validated, these tools' cut-off thresholds were not. This is why screening for distress, like all screening tests, is the beginning or pursuit of a discussion and assessment, and not an answer in and of itself.

Many questions arose from our findings. For example, does screening for distress improve cancer patients' outcome? This is, in fact, a two-folded question, the first part of which is: Are the interventions themselves effective in reducing psychological distress? And the second is: Does the screening improve the care results? There is currently very little literature showing the efficacy of psychosocial and psychopharmacological

interventions in reducing distress (Coyne, 2013). A second question remains unanswered, as Faller, Schuler, Richard, Heckl, Weis, and Kuffner (2013) and Salmon, Clark, McGrath and Fisher (2014) also assert.

On the one hand, our study shows distress levels in our sample dropped over time. However, since this came whether or not patients accepted help, our result confirms other studies' findings (Henselmans, Helgeson, Seltman, de Vries, Sanderman, & Ranchor, 2010; Lam, Bonnano, Mancini, et al., 2010 as quoted in Coyne, 2013) that psychological distress can be of limited length and resolved without specialized services. In light of these results and our clinical experience, we are inclined to believe that cancer patients have many inner and familial resources to draw on and that help them coping and ensure their resiliency over time. These can be strengthened and honoured. We will address this aspect in a second article.

On the other hand, we must also acknowledge that psychological distress may very well increase over time, since T2 corresponded for many of the patients in our sample with intense periods of treatment (women with breast cancer in radiation therapy or chemotherapy). Moreover, T2 was for others a time of rest (hematological cancer patients or transplant recipients) when treatment-induced side effects, or the fear of recurrence or progression were still felt. Fear is one of the elements most frequently associated with psychological distress (Herschback, Keller, Knight, et al. (2004) quoted in Suchocka-Capuono and Bungener, 2010). In addition, we do not know with any certainty what care was offered and received other than referrals. It is therefore possible that other interventions were useful to the patients in our sample. Moreover, we know that the follow-up to the distress screening tool was insufficiently completed in many cases, as nurses admitted at several times during implementation meetings. This observation should be considered all the more that nurses do not necessarily document all their psychosocial interventions or the advice they give for various symptoms. Our team of researchers have repeatedly observed this phenomenon, which makes analysis a risky undertaking, and encourage utmost prudence.

Our study drew up portraits of the distress of our two targeted populations. These portraits were similar in several ways but also displayed their own specificities and challenges. Exceptionally, they grouped a major proportion of men with hematological cancers. This allowed us to cast light on the effects of gender on psychological distress, as well as on several effects associated with type of cancer. Our results therefore indicated a possible influence of traditional "male" values on experiencing problems and asking for help. The men in our study showed lower levels of distress (on average, 0.4 points less than women, whose self-reported score was 3.3) despite facing much more uncertain prognoses than women with breast cancer. Moreover, at T1, 17.3% of men vs. 30.3% of women reached the clinical score for anxiety. These proportions were lower at T2, but the difference between men and women remained significant: 9.8% of men vs. 22.9% of women. Although at T1 men and women accepted similar levels of help, at T2, we saw that women accepted help

more frequently than men. Indeed, 42% of women accepted help vs. 16% of men. These results led us to believe that men and women are indeed influenced by and conform to stereotypes of femininity and masculinity. Many authors have pointed out that this social construction of masculinity influences health and illness, and how men express their feelings, minimize their worries about their health, and prefer to manage their problems themselves (Berger, 2011; Galdas, Cheater & Marshall, 2005; Schofield, Connell, Walker, Wood & Butland, 2000). According to Berger (2011), the value given to autonomy, self-esteem, and the "masculine ego" would explain in part why men rarely ask for help.

However, we must also nuance these results. On the one hand, as mentioned above, in our sample, more women than men were newly diagnosed. Should the effect of a recent diagnosis or other factors on the level of distress and acceptance of help be examined? On the other hand, it is also true that if men with hematological cancers (who are, on average, 10 years younger than women with breast cancer and in the labour market) had more problems related to work and finances and tended more to see themselves as a burden to others, they were also isolated for long periods. Sometimes, these men were immunosuppressed for several months or even years after the transplant and, as a result, were frequently incapable of returning to work. Therefore, our results may show the financial and social impact of certain cancer treatments at certain times of life, as much as they illustrate socio-culturally constructed realities.

According to Fitch et al., lessons learned from concerted efforts to meet cancer patients' psychosocial needs emphasize the importance of screening and early intervention for psychological distress by oncology nurses (Fitch et al., 2012). Real obstacles to the optimal use of the screening tool appeared throughout the study. This aspect will be addressed in the next article. Nonetheless, writings by Fulcher and Gosselin-Acomb (2007) discuss how nurses are concerned about their workload and lack of time, as well as about their skills at conducting distress screening (Arantzamendi & Kearney, 2004; Mitchell, Kaar, Coogan, & Herdman, 2008 quoted in Fillion, Cook, Blais, et al., 2011). Our study in the field helped us identify other obstacles. The lack of intimacy typical of open-plan treatment rooms, for example, is not conducive to emotional conversations between professionals and patients. Another aspect of screening for distress that should be considered is the discomfort certain professionals feel in questioning patients about touchy subjects. The more uncomfortable the subject, the more time it takes to talk about it. Yet, professionals tend to devote more time to comfortable subjects, which also take less time to accomplish (personal exchange with Deborah McLeod, 2012. Research Day for the Systemic Screening for Distress).

Recommendations and conclusion

In light of our observations in this study, we believe these clinical and research recommendations to be necessary:

- Reinforce nurses' training in conducting screening. Such training should include strengthening cancer patients' coping strategies through a true care partnership.

- Encourage and support nurses to better document their actions, particularly their psychoeducational or psychosocial support interventions. According to a study by De Marinis, Piredda, Chiara Pascarella, Vincenzi, Spiga, Tartaglino, Alvaro, and Matarase (2010), only 40% of nurses' actions are documented. Clinical educators and supervisors should accord real importance to this task.
- Pay more sustained attention to requests for referrals, particularly from men with cancer. It is necessary to develop methods for better presenting the reasons and usefulness of referrals, like better accompanying the patient in this process and following up on results.
- Offer an environment and conditions that are favourable to using the DST.

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