Systematic screening of distress: Portraits and cross-examination of the various stakeholders’ perceptions, clinical perspectives, and research—Part 2

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INTRODUCTION

In our study’s first phase, which dealt with the screening of distress in breast or hematological cancer patients and was the topic of Part 1 of this article (Tremblay et al., 2017), we painted a portrait of the distress of these two groups of participants. We highlighted that although nearly 34% (33.9%) of our sample (N=532 participants) reached a clinical score of 5 or more on the Distress Thermometer (DT), only a low percentage (22.7%) wished to receive help with problems expressed in the screening process. This somewhat low percentage dropped further at Time 2 (14.7%). This DT score justified a more targeted assessment of the distress. This was also the case for the following results: slightly over 1 in 4 patients (26.6%) displayed an Edmonton Symptom Assessment System (ESAS) score superior or equal to 5 for anxiety at Time 1, and 18.4% did at Time 2. For depression, 9.4% of patients scored higher or equal to 5 at Time 1, and 9.5% did at Time 2. These situations should prompt further exploration, generally by a psycho-oncologist.

It was also noted that study participants were more likely to accept referrals when offered during discussion of patients’ Distress Screening Tool (DST) results (40% of cases at Time 1 and 33% at Time 2). This is clearly significant for clinical nursing practice, as other moments in the care trajectory (such as the treatment period and admission to the transplant unit) are also more favourable to acceptance of the help offered.

Another significant finding: At Time 2, the proportion of patients with a score greater than or equal to 5 on the DT dropped to 28.1%. However, this reduction occurred whether or not the referral had been accepted or refused, except in the case of social issues where levels of distress were significantly lowered when the patient accepted. These results may indicate both the cancer clientele’s capacity for resiliency and the benefits of support and education, mainly by nurses, that go greatly undocumented (De Marinis, et al., 2010; Tremblay et al., 2017).

The various phenomena described in Phase 1 of this study justify our interest in better understanding the various relational issues behind these results, particularly patients’ and nurses’ perceptions of systematic screening for distress, to explore its content and its points of convergence and divergence. The rest of this article will therefore present the findings of Phase 2 of this study regarding these perceptions.

METHODS

Design

As described in Part 1, 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. This article will present the results of Objectives 3 and 5, and part of 4. 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 focuses 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 systematic screening for distress in the various sectors affected by the screening (Phases 1–3);
3. To better know nurses’ perceptions of this systematic 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 systematic 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).

Ethical considerations
We reiterate the ethical considerations mentioned in Part 1 of this article. This study obtained an ethical certificate in early 2013 from the learning establishment in which it was conducted. It should be mentioned that since systematic 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
The instruments used in this phase of the study—a questionnaire of nurses’ perceptions (QNP) and a questionnaire of patients’ perceptions (QPP)—were developed from study findings (Asselin, 2012; Blais, 2012) on systematic screening for distress presented in November 2012 to the CHU de Québec during an Oncology Scientific Day. Moreover, two English-language questionnaires developed by Alberta Health Services (AHS, 2012, A and B) were used to gather both the patients’ perceptions of the quality of care and nurses’ perspectives on the screening for distress instrument, as part of the IPODE Project for the implementation of screening for distress.1 These questionnaires were also improved upon following the findings of a focus group of nurses in the implementation process of screening for distress in our healthcare centre. The AHS’s tool was translated into French and adapted with permission.

The QPP is a mixed questionnaire (both quantitative and qualitative) of 15 questions with sub-questions. It addresses various aspects connected to screening for distress, particularly the ease of completing the DST, the utility of the DST, if the screening process is emotionally troubling, the help requested and the help received.

The QNP has 15 questions with sub-questions. It is also a mixed questionnaire. It addresses the meaning and importance nurses ascribe to the screening. It also measures nurses’ perception of the importance patients ascribe to this screening, and nurses’ comfort with various aspects of their screening practice.

1. EDOPI-IPODE. An online educational screening for distress program that was designed to train staff (namely, nurses). Global Cancer Experience, (2012) CPAC. Screening for Distress, the 6th Vital Sign: A Guide to Implementing Best Practices in Person-Centred Care. www.cancerview.ca

Parametrical tests were performed when the sample size so allowed. The qualitative analysis was carried out according to a simple categorization by the two main researchers (NT and OR), independently at first. They let the themes emerge from several readings of the handwritten answers. A first categorization was made for each question. The researchers then distilled the themes and compared the categories obtained. For each question, nearly perfect consensus was reached upon first comparison, and discussion led to consensus for the remaining categories.

RESULTS
Sample characteristics
Patient participants
Our convenience sample was made up of 122 cancer patients, 80 of whom had breast cancer and 42 hematological cancer. Recruitment took place throughout 2014. To be eligible for the study, participants had to have completed the DST process at least once. Those who had not were excluded from the study. This questionnaire did not collect sociodemographic data. However, the same groups of participants were solicited for the study’s second phase as for its first, when age and diagnosis were obtained. It is, therefore, reasonable to think that this information can be transposed to Phase 2.

Nurse participants
Our convenience sample consisted of 45 nurses, a majority of whom (64.4%) work with hematological cancer patients. A smaller proportion worked mainly with breast cancer patients (1.3%) and 20% with patients with various cancers in chemotherapy or radiotherapy. This distribution of nurse participants reflects the distribution in our establishment’s oncology department. More of these nurses work with a hematological cancer clientele given they are affiliated with a hospital unit that covers three work shifts, as compared to nurses working in walk-in oncology clinics with patients who have all types of cancer or to nurses working just with breast cancer patients.

Patient perceptions of the questionnaire
Presentation
Of the 122 participating patients, a vast majority (97.5%) was presented with the screening instruments (three breast cancer patients reported that they had not seen the tool).

Ease of completion
The majority of study participants (77%) found the screening tool “easy” to use. Some participants (17.2%) found the instrument “somewhat easy” to complete, or “difficult” (3.3%). Information was missing for three people. Although more hematological cancer patients (7.5%) than breast cancer patients (1.3%) found the tool difficult to use, this difference is not significant.

Purpose
Two main themes emerged from participants’ answers to the question “In your opinion, what is this questionnaire used for?” (An H preceding the participant number indicates a hematological cancer patient, while an S is used for participants with breast cancer.)
The first theme grouped patients verbatim on evaluation or screening for distress, stress, anxiety, needs or fears. The following illustrates this theme:

S39: It is used to screen for psychological distress stemming from the experience of breast cancer (in my case).

The second theme grouped patients verbatim on help. Participants answered that the DST is intended to help them or professionals. The instrument is perceived as being used to see if patients need help or to identify necessary actions to help them or redirect them to appropriate resources. Two verbatims illustrate this theme:

S2: To measure the degree and type of help patients need.

H14: To validate my fears and measure my level of anxiety so as to orient me toward necessary resources, if needed.

Perceived utility and explanations

To the question “Did you find it useful to complete the screening for distress questionnaire?” a vast majority of participants (81.1%) answered yes. Four people checked both yes and no. After reading their comments when asked to specify the reasons for this double choice, we considered them a yes. Figure 1 presents the answers to this question.

The major theme that emerged from our analysis of the reasons behind an affirmative answer was the introspective character of the screening tool. To our knowledge, no study has yet shed light on this element. According to our participants, completing the tool was an opportunity to take stock of their emotions or experiences, as the following verbatims illustrate:

S2: “I was feeling strong. When I read through the questions though, I felt weaker than I thought. That surprised me.”

S69: “Yes. This was the moment when I realized just how much anger I was feeling about this diagnosis. I felt deep-seated injustice.”

S76: “It allowed me to clarify my stress and see what my needs were.”

Participants also perceived the tool to be useful because it was a form of sharing or communication around their experience and emotions.

S38: “Yes, I was able to express some anxiety that, although minimal, I hadn’t shared with my family. It was a relief.”

The instrument also reassured patients on what can be done or what help was available, if desired.

S18: Yes, because after being told you have cancer, you feel overwhelmed. It was good to know that you can get help…”

Moreover, 15 participants justified their “no” by the absence of distress or feeling the need for help, as shown by these verbatims:

H5: “I said ‘no’ because I already knew what to expect of the hospitalization so I didn’t experience any distress during my stay there.”

H30: “I wasn’t distressed.”

S23: “Since I didn’t feel anxious or any other symptom, it wasn’t useful. Except, perhaps, to realize that I was handling the situation pretty well.”

S67: “I didn’t really need help.”

However, among the “no” answers, one female participant reported that she had not received follow-up and another said that nothing had been done with her answers.

Emotional discomfort at completing the instrument and the reasons given

Again, a vast majority of patients—89.3%, or 109 patients—declared that they had not found the screening for distress questionnaire to be troubling or inconvenient. Inversely, 9% of patients (11 patients) found the questionnaire to cause emotional discomfort. Two patients did not answer this question. Note that among the 11 people who answered “yes,” five explained that it was because completing the questionnaire stirred emotions or caused awareness of their true feelings:

H3: “It stirs emotions. It was a necessary evil.”

S69: “Even if it’s useful, it was troubling at the time because it forced me to ask myself what I was experiencing. Honestly, I think that I was still refusing to admit that I had been diagnosed with breast cancer.”

S70: “It’s when I realized that the experience of having breast cancer could affect me and my loved ones so much.”

Figure 1: Usefulness of the screening questionnaire

Figure 2: Discussion with a professional after completing the instrument
Help and services offered

More than 40% (40.2%) answered no to the question “After having completed the screening for distress questionnaire, did a professional discuss your answers with you?” Figure 2 illustrates these answers by type of cancer.

To the question “Were you offered the help you needed to meet the needs and concerns you expressed?” 71.4% of breast cancer patients and 66.7% of hematological cancer patients answered affirmatively. Therefore, 28.4% of breast cancer patients and 33.3% of hematological cancer patients were not offered the help they needed. Again, a majority of the negative answers can be explained by these patients not expressing their need for help, as the two following verbatims illustrate:

H2: “No, I always said I didn’t need any specific help.”
S2: “If I needed help, I would have called her for sure.”

However, other people did not receive a desired response to their needs:
S9: “No one followed up with me about this. My family is supporting me, and that’s already a lot.”
S75: “I was referred to a psychologist, but my need was more for support from medical staff (nurse and doctor).”

To the question “Did you accept this help?,” 62.3% of breast cancer patients said they accepted, while 60.9% of hematological cancer patients accepted and 36.7% refused. See Figure 3.

Here is a glimpse of the participants’ specifications:
S33: “No. But I don’t really need any, for right now at least. I’ll give my turn to people who are in worse shape.”
S67: “No. I was feeling strong enough and my family is here to help me through this trial.”
S12: “Yes, I think the medical staff should be encouraged to offer help so it would become a habit and a reflex.”
S69: “Yes, the first time I refused, but when I learned that I also had to have chemo, my nurse navigator suggested again that I meet with a psychologist. I accepted.”

Services received and delays

Of the 47 patients who accepted the help, 34 received a service while 13 did not receive the offered service (27.7%). Figure 4 shows the delays before receiving the service. More than 60% of participants received the service within a few days, and 35.3% received it the same or the next day.

Overall satisfaction (Table 1)

Only 1.6% and 3.3% of patients (N=6) declared being “dissatisfied” or “somewhat satisfied,” respectively, by the identification of their distress and the help offered to them. Conversely, a great majority of patients claimed to be satisfied (38.5%) or very satisfied (36.1%). This proportion increased considerably if those who nuanced their choice of answer are excluded. We should note here that 20.5% of patients did not answer this question. See Figure 5 for the overall level of satisfaction, which for the two groups of patients is different at a threshold of 1% (khi²=7.236; p=0.065).

| Frequency | Percentage | Valid percentage | Cumulative percentage |
|-----------|------------|------------------|-----------------------|
| Valid     |            |                  |                       |
| Not at all satisfied | 2 | 1.6 | 2.1 | 2.1 |
| Somewhat satisfied | 4 | 3.3 | 4.1 | 6.2 |
| Satisfied | 47 | 38.5 | 48.5 | 54.6 |
| Very satisfied | 44 | 36.1 | 45.4 | 100.0 |
| Total     | 97 | 79.8 | 100.0 |
| Missing   | 25 | 20.5 |           |
| Total     | 122 | 100.0 |

Figure 3: Suggested help perceived as adequate in response to the expressed needs

Figure 4: Delays in receiving the service

Figure 5: Overall satisfaction, according to type of cancer
Edmonton Symptom Assessment System (ESAS)

Nearly three quarters of patients (71.35%) entirely agreed with the statement “The ESAS is important because it allowed my healthcare team to know my symptoms and their severity.” Nonetheless, more than 1 in 10 patients (13.1%) only somewhat agreed with this statement. Table 2 shows the distribution of participant answers.

A lower proportion of patients (57.4%) agreed with the statement “My healthcare team took my ESAS score into consideration when determining my treatment plan.” Nearly 14% (13.9%) of the sample did not answer this question. The same proportion did not have an opinion on the subject.

Figure 6 displays, according to type of cancer, the percentage of agreement with the statement “My pain and symptoms are reduced to a comfortable level.” Note that 23% of the sample answered “always” and nearly 42% (41.8%) reported “most of the time.”

Nurses’ perceptions of screening for distress

Meaning

Two broad thematic categories emerged from answers to the question “What does screening for distress mean to you as a nurse?” The first category encompasses various verbs used to describe the identification, evaluation, screening, and tracking of clients’ problems, emotions, and concerns throughout the care trajectory that fit into a more global experience.

The second category encompasses the various verbs used to indicate the end goal of the process: help, support, and redirect to resources. Figure 7 refers to the theoretical model emerging from the meaning nurses ascribe to screening for distress, as developed by the researchers from the nurses’ themes.

Table 2: The ESAS is important because it allows my healthcare team to know my symptoms and their severity

|                  | Frequency | Percentage | Valid percentage | Cumulative percentage |
|------------------|-----------|------------|------------------|-----------------------|
| Valid            |           |            |                  |                       |
| Completely disagree | 1         | 0.8        | 0.9              | 0.9                   |
| Somewhat disagree | 3         | 2.5        | 2.6              | 3.4                   |
| Somewhat agree   | 16        | 13.1       | 13.8             | 17.2                  |
| Completely agree | 87        | 71.3       | 75               | 92.2                  |
| No opinion       | 9         | 7.4        | 7.8              | 100.0                 |
| Total            | 116       | 95.1       | 100.0            |                       |
| Missing          | 6         | 4.9        |                  |                       |
| Total            | 122       | 100.0      |                  |                       |

Importance

The majority of nurses answered “important” to the question “Just how important do you think it is to systematically screen for patients’ distress?” Indeed, 60% of nurses considered that it is important to systematically screen for patient distress, while 33.3% of nurses felt it is “crucial” and 6.7% considered it “somewhat important.” It is interesting to note that no nurse reported systematic screening to be “not at all important” or “not very important.”

Perception of patients’ perceptions

According to our nurses, patients do not perceive the same importance of systematic screening for distress as they do (22.7% of nurses). Only 11.1% of nurses considered patients perceive screening for distress with the same importance. A great proportion of nurses (64.4%) answered “other” to this question. And the qualitative analysis of these “other” showed that almost all wrote, “It depends. For some yes, for others no.” Based on participant comments, it can be deduced that nurses’ perceptions of patients stem from many factors that arise in interactions or from the context, including the time of screening, the patient’s attention and speed responding, the nurse’s perception of the patient’s interest, whether the patient feels the need for help, or refuses or accepts the referrals. Their diverse screening experiences influence these perceptions.

18: “I think this depends on how the DST is explained and presented to the patient, as well as to the patient’s state of health at arrival.”

Figure 6: My pain and symptoms were reduced to a comfortable level

Figure 7: Meaning nurses ascribe to screening
I15: “It varies greatly from one patient to another. Some find
the DST important, while others seem annoyed when we
present it to them.”

I26: “Maybe yes for some (those who accept help more eas-
ily), but for others it’s just more paperwork to fill out at a
time when they already have a lot of things to manage or are
already struggling to understand what’s going on.”

I29: “It depends on the patients. I think that even if we tell
them to be sincere and that it’s for them that they’re filling
out the DST, some will still just get rid of it or are too proud
to ask for help. But this is far from the majority.”

Nurses who answered “no” to this question also referred to
their non-validated perceptions of patients.

I17: “No, I think they think it isn’t a big deal and things will
blow over.”

I12: “Somewhat. Some are annoyed at having to fill out
this document that maybe forces them to put words on their
problems. This is by self-pride or maybe because they aren’t
ready.”

Utility of the thermometer, the list of problems, and the ESAS
The majority of nurses (57.8%) felt the Distress
Thermometer and the accompanying list of problems was
“somewhat useful.” Some 28.9% found it to be “very useful”
and 13.3% found it to be “not at all useful.” In comparison,
many fewer patients found the ESAS “not at all useful” (2.2%).
A majority of nurses considered the ESAS to be “somewhat
useful” (53.3%) and many considered it to be “very useful”
(44.4%). Tables 3 and 4 present these results.

Positive and negative influences of the screening on nurses’
practice
Nurses were asked to identify from a list of statements
how the screening for distress positively or negatively influ-
enced their practice. The positive statements were that it:
made for a more specific evaluation; gave more contact with
people who need to manage symptoms; provided greater com-
prehension of what was going on with the person; made bet-
ter documentation possible; and other comments (if needed).
The list of negative statements included that it: takes time;
collects non-relevant data; is upsetting for the patient; makes
me uncomfortable as a clinician; and other comments (if
needed). The proportion of nurses who found that the DST
takes time was greater for those who work in walk-in oncology
clinics than for those who work with a hospitalized clientele.
Figures 8 and 9 show the items checked by the nurses and in
what proportion.

Table 3: Perception of the usefulness of the Distress
Thermometer and its list of problems

| Frequency | Percentage | Valid percentage | Cumulative percentage |
|-----------|------------|------------------|-----------------------|
| Valid     |            |                  |                       |
| Not at all useful | 6 | 13.3 | 13.3 | 13.3 |
| Somewhat useful | 26 | 57.8 | 57.8 | 71.1 |
| Very useful | 13 | 28.9 | 28.9 | 100.0 |
| Total     | 45         | 100.0            | 100.0                 |

Table 4: Perception of the usefulness of the ESAS

| Frequency | Percentage | Valid percentage | Cumulative percentage |
|-----------|------------|------------------|-----------------------|
| Valid     |            |                  |                       |
| Not at all useful | 1 | 2.2 | 2.2 | 2.2 |
| Somewhat useful | 24 | 53.3 | 53.3 | 55.6 |
| Very useful | 20 | 44.4 | 44.4 | 100.0 |
| Total     | 45         | 100.0            | 100.0                 |
Referrals offered
After the screening for distress, 86.7% of nurses suggested patients meet with a psychologist. This was the most frequently offered referral. Then, 71.1% of nurses suggested patients meet with a social worker. Less than half of the nurses offered a referral to a nutritionist (42.2%), a clinical advisor (33%), a doctor (26.7%), or a physical therapist (13%). Finally, nearly a third (31.1%) of nurses offered another referral, be it a spiritual advisor, psychiatrist, volunteer or community group.

Confidence in the stages of screening, the problem areas and the concerns
Nurses’ answers suggest that they feel more comfortable identifying and evaluating distress than responding to it and providing structured support. Therefore, they are more numerous to feel confident or very confident during the screening (81.1%) and evaluation (55.6%) than in responding to distress (46.7%) or providing structured support (36.4%). Some 13.6% report not feeling at all confident.

Interestingly, these results show that nurses feel “confident” or “very confident” in responding to informational (75.5%) and physical (84.5%) needs. Among these seven categories of needs, the results of the khi² tests show that the nurses’ confidence varies significantly according to their clientele for emotional needs (khi²=17.07; p=0.009) and psychosocial needs (khi²=15.82; p=0.045).

Moreover, nurses working with breast cancer patients seem to have more confidence responding to emotional needs: 33.3% of these nurses feel “very confident” in meeting patients’ emotional needs, versus 0% of nurses working with hematological cancer patients and 0% of nurses working with another clientele. This trend is the same for psychosocial needs. Indeed, 6.9% of nurses working with hematological cell transplant patients feel “not at all confident” and 0% feel “very confident.” They feel “somewhat confident” (20.7%) and “moderately confident” (37.9%). Barely 34% of them feel just “confident.”

Table 5 and Figure 10 display the results of the question “Just how confident do you feel responding to the needs patients express?”

Nurses’ screening experience
Sixty-two percent of nurse participants had conducted at least 10 screenings with their clientele. Two nurses had conducted over 100 screenings, while nine had done 20 or more. Among the others, there was a missing answer, and 15 nurses (33%) had conducted five screenings or fewer. About 5% had done between five and 10 screenings. Nurses were also asked to report how many of these experiences were difficult and how many were positive. For 57.8% of the sample, at least one experience was more difficult than others. Three nurses did not answer this question. Among those who had conducted many screenings, only one nurse had experienced several difficult screenings, about 25 out of more than 100. One nurse answered that both of her two screenings had been difficult.

14: “I don’t feel like I have the resources.”

For 44.4% of the nurses, there were more positive than negative experiences with the screening tool, while 13% reported having had as many positive and negative experiences. Two nurses did not answer. Two others could not answer. However, 15.6% of nurses had not had a positive experience.

Aspects of the screening that worked better or worse
Among the most frequently mentioned aspects that worked well were that the screening makes it possible to identify problems more quickly and at a good time, so as to offer appropriate services, and that it allows for a greater receptivity to patients’ needs, as well as better dialogue, evaluation, and follow-up. However, many nurses mentioned the lack of time for developing on the answers received, the lack of intimacy with the patient, and the moment chosen for the screening that was not favourable (for example, conducting the screening upon hospital admission, when trust with the patient had not yet been forged).
DISCUSSION

Although there was convergence between nurses’ and patients’ perceptions of the importance or utility of screening for distress, there is also divergence. The quasi-totality of nurses (93.3%) felt it is important and even crucial to conduct screening for distress. A majority of patients (81.1%) found it to be useful. However, the study showed that just over 1 in 10 nurses (11.1%) perceived the patient as ascribing the same importance as they to the screening. A majority of nurses (64.4%) answered “It depends.” And an analysis of nurses’ perceptions shows that various patient behaviours and their interpretations feed this perception. Therefore, patients refusing to complete the questionnaire, expediting its completion and letting time go by before completing it (when given at hospital admission) are perceived as signs that the screening is not important to patients.

We reported in Part 1 of this article that a vast majority of patients indicate that they do not want to be helped with problems or worries mentioned in the DST: 77.3% at Time 1 and 85.3% at Time 2. Let us remember that, for hematological patients, Time 1 corresponds with admission to the hospital unit and, in most cases, Time 2 to hospital leave. For women with breast cancer, Time 1 corresponds to a second and third meeting after the diagnosis and Time 2 was a day during the treatment period.

Moreover, many study participants refused the referrals offered. Among the 46% of the sample offered a referral at Time 1, it was accepted 40% of the time. Without counting that, a certain proportion of patients refused to complete the questionnaire because they did not feel the need (the main reason given for refusal to complete the tool in Phase 1). Our study also showed that the most frequently given reason by patients who receive the DST but feel it is not useful is not feeling the need for it.

It is difficult to determine what effect these perceptions have on nurses in the transfer and appropriation of this practice. Although some nurses shared what does not work so well (refusal, hesitation or resistance by some patients, particularly men, to talk about their psychological pain and the need for more resources to take action), much remains to be discovered. This definitely deserves to be explored further both in research and in clinical settings, and should be an opportunity to share experiences during staff training on screening for distress. Steele and Fitch (2008) mentioned that it can be difficult for professionals to recognize cancer patients’ autonomy and that these latter may decline the offered help, which can be non-desired. Some nurses also mentioned the absence of more positive screening experiences. To what should this be attributed? Inadequate preparation and training? Discomfort, embarrassment, limited beliefs about screening? Lack of cooperation? Again, there are more questions than answers. Some comments from nurse participants point to a need for training to develop greater support.

The utility of screening can also be called into doubt if the patient expresses not needing it. But what is this need exactly? Does the patient express having no need for help, no need to talk about it with us, or no distress at all? Many of the nurses’ verbatims mentioned that patients did not want to be helped, which does not mean that the nurse’s offer to talk or the help offered is not meaningful to them. This second phase of the study cast light on the introspective aspect of the screening that predominated in the themes on the instrument’s utility for the patient. This aspect deserves exploration in future research.

The analysis also showed that, for the most part, patients and nurses share the same comprehension of the goal of the tool (identifying concerns and problems that could interfere with well-being and that should prompt further emotional support and symptom management).

Clover, Mitchell, Britton, and Carter (2014) conducted a study to understand why patients in walk-in oncology clinics who reported emotional distress (4 and up on the DT) refused help. In their study, 71% of the sample (N=311) refused the help offered. Our study reported 77.3% of participants who did not want to receive help. However, this last number makes no distinction between those who reach the clinical score and those who do not. The reasons participants in the study by Clover et al. gave were that they prefer managing it alone (46%), they are already receiving help (24%), and their distress is not great enough (23%). These last two themes were also found in many of our study participants’ verbatims. Another recent study by Tuimman, Van Nuenen, Hagedoorn, and Hoekstra-Weebers (2015) presents similar results. In this study, 67% of patients did not wish to receive a referral and an additional 20% said “maybe” (N=1340). It was among single people that the wish to receive help was the highest. They were twice as likely to accept a referral as married patients. Johnson’s 2010 study, as cited in VanHoose et al. (2015) indicates, moreover, higher rates of distress among single women. Might we see in these findings the protective role for psychological health of the presence of a life partner? Partners are known to offer positive interactions, and emotional and social support that attenuates distress (Canadian Institute for Health Information, 2012). But who is supporting the family who is supporting the patient? The need to screen for distress in caregivers is increasingly felt, as screening becomes systematic with cancer patients (Direction générale de cancérologie, 2015).

Clover’s study also revealed that among those who feel their distress is insufficient to ask for help, 18% scored 8 or higher. Other studies should be conducted on this subject. The stigma associated with psychological help has been amply described, but its presence has a less negative influence with cancer (Clover et al., 2013, as quoted in Clover et al., 2014). Moreover, Salmon, Clark, McGrath, and Fisher (2015) warn that it can be harmful to patients to tell them they need help based on their answers. These authors also report study findings that indicate that, among those who experience emotional distress, less than half have sought or intend to seek help. And in another study quoted in Salmon et al. (Shimizu et al., 2010), less than a quarter accepted the referral to see a psycho-oncologist. In light of our and others’ findings, it would appear to us, as clinicians, that a referral should not be encouraged as the only possible response to a high score. Instead, this could be a poignant moment either to highlight a strength or to reflect on a
legitimate desire of the patient. As these authors mention, a positive screening should not be interpreted as an obligation or an expectation of patients to accept formal help. Analysis of their perceptions leads us to believe that for some people, screening does not have the same value. These avenues remain to be explored.

Our findings also shed light onto the fact that symptom management was very little addressed in our written comments from both patient and nurse participants. It should be noted that the majority of patients in Phase 2, like in Phase 1, was solicited at the beginning of their trajectory, or a moment when the symptom-related load is perhaps the least high (Baba, Fransson, and Lindh, 2007).

Scales such as ESAS were developed to facilitate clinical practice and measure care results (Baba, Fransson, & Lindh, 2007). A Swedish study reports, as we did, that caregiving staff considers the ESAS to be a good instrument to obtain information regarding patients’ symptoms, but that according to nurses, it is not useful during medical visits (Baba et al., 2007).

Our results show that when missing data are excluded, symptoms are either “always” (27.7%) or “most of the time” (50.5%) reduced to a comfortable level. Nonetheless, more than one in five patients is at best comfortable “often enough.” One person stated “never” and two “rarely.” Although the sample was small, can we do better or is discomfort inevitable? In implementing the DST in our establishment, we saw repeatedly that symptom management, particularly its evaluation and documentation, is not always optimal to ensure continuity of care. Although physical comfort has long received attention in oncology, there is still room for improvement in the area.

On another note, we were surprised by the high percentage of cancer patients (40.2%) who reported the absence of discussion with a professional after having completed the tool. Although a different interpretation of the question could have occurred to explain this result (please see the Limitation section of this article), we must also admit that the desired discussion did not always occur. Yet, this feedback is undoubtedly the DST’s most crucial aspect, which is stressed in the training of screening professionals (Fillion et al., 2011). How can this be explained? Time (or lack of time) for the screening was mentioned spontaneously verbatim by more than four in 10 nurses (42.2%), and a great majority of them also identified the lack of time as an element with negative influence on using QNP. Nurses also named lack of time at all the stages of implementing the tool and all the stages of our study. This lack of time was also reported by different researchers (Absolom et al., 2011; Asselin, 2012; Arantzamendi & Kearney, 2004; Fillion et al., 2011; Mitchell, Kaar, Coggan, & Herdman, 2008). Screening occurs against a backdrop in which nurses are constantly rushed, which perhaps explains in part the findings. Patients also perceive a lack of time, which may lead some to choose to keep quiet, as certain clinical observations lead us to believe. Moreover, other studies also pointed to the ambiance in chemotherapy rooms—an environment that is not conducive to intimacy (Arantzamendi & Kearney, 2004)—and nurses are among the most sensitive professionals to this aspect (Absolom et al., 2011).

Our proposed theoretical model on the meaning nurses ascribe to screening tends to indicate that nurses are greatly in favour of screening for distress, but feel that it must fit into the realities of their practice that are conducive to this process. This proposal deserves to be included in clinical practice and training, and should be further developed by other studies.

Moreover, this theoretical proposal does not account for the introspective nature of the screening mentioned by patient participants. This bit of understanding deserves our full attention in clinical practice.

Our study also shows nurses have little confidence in responding to distress and providing patients with structured support, as these responses fall into the psychosocial and emotional areas in which nurses feel less confident. Moreover, a majority of referrals are to psycho-oncologists (86.7%). On this topic, Fillion et al. (2011) mentioned the success of implementing screening for distress as a key element in an effective training of healthcare workers.

Limitations in Phase 2

The greatest limitation in Phase 2 was the non-verification of the questionnaires before the study was launched. Although all members of the research team were familiar with the two questionnaires and gave their opinions on content and question phrasing, and although these two questionnaires were based on others used in other studies or surveys, certain methodological elements were not anticipated. For example, Question 6 of the QPP could be read as follows: “After having completed the screening for distress questionnaire, did a professional discuss your answers with you?” The choice of answer was yes or no, and no additional space was provided for specifications or comments. The surprisingly high proportion of negative answers (40%) leads us to believe that question was perhaps poorly interpreted. For example, were patients expecting to have a discussion with a professional other than the nurse, even if such a need was not articulated or identified after the screening?

Furthermore, Question 7 of the QPP asked patients if they had been offered the help they desired in response to the needs and concerns they expressed. However, if the patient did not feel she or he had received help, or had not expressed a specific concern, it was difficult to answer by yes or no. Luckily, as most respondents wrote in the margins and in the “Please specify” section, we were able to understand or interpret their perceptions of the situation.

The QNP also had a question that was subject to various interpretations. Question 11 asked nurses the number of times they had used the DST to conduct screening for distress. Some nurses answered in proportions (75%, 1/6 or ½), making their answers somewhat difficult to evaluate in terms of their user experience with the tool. We would have gained in validating our questionnaires beforehand. Since the number of nurses dedicated uniquely to breast cancer patients was very low (6), we had to be excessively cautious in comparing the various groups of nurses.
CONCLUSION

The results of our study’s Phases 1 and 2 confirmed and developed various aspects of screening for distress. Offering screening for distress not only allows us to offer a response, it also and especially allows us to adapt our offer. A recent study (VanHoose et al., 2015) shows that some problems lead more to distress. Financial issues, concerns, worries, anxiety and trouble sleeping are some of the problems that deserve more attention. Future studies might further explore offering more help in these situations. Our results will make it possible to pursue the implementation of screening in our establishment. We must also review our understanding of the tool’s end purpose with the two groups of participants. The introspective value of screening for the patient makes sense with their desire to turn to their personal resources, and professionals could further respect this. Conversely, the desire not to receive help deserves to be explored further, particularly with men. The interview-basedPhase 3 will focus on this theme in particular.

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