



## Routine symptom screening and supportive care needs

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Routine application of patient-reported outcomes (PROs) has been shown to improve care needs through early identification and monitoring of symptoms, to improve quality of life by facilitating communication between patients and health care providers [1, 2], to reduce emergency and unscheduled hospital admissions [1], and to prolong survival [3, 4].

The Edmonton Symptom Assessment System (ESAS) is a PRO measure (PROM) for common symptom screening and monitoring in routine clinical practice and research. By virtue of its validity, simplicity, brevity, and ease of use, the ESAS has been widely translated and applied in diverse settings, including palliative care, supportive care, cancer, nephrology, and hospital and ambulatory care [5]. Since its inception, the ESAS has been revised and validated in various PROMs, such as the ESAS-r, the ESAS-r+, and the most recently developed ESAS for Ambulatory Cancer settings (ESAS-r Cancer) [6]. This revised ESAS-r Cancer is of timely interest. Indeed, the addition of six symptoms/physical problems (diarrhea, constipation, numbness or tingling, problems with sleeping, thinking, and mobility) commonly affecting cancer patients enhances the usefulness of this assessment tool for routine screening of self-reported physical symptoms and anxiety and depression in daily clinical practice.

Most, though unfortunately not all, patients receiving treatment in cancer, supportive care, and palliative care are assessed via self-reported questionnaires specifically designed to evaluate physical symptoms. The same questionnaires are often used in research. In both clinical practice and research, however, patients are reluctant to routinely fill in self-reported questionnaires. In Watson et al.'s study [6], for example, 71% of the patients did not complete and return the three questionnaires they were sent.

In our clinical practice, we have observed that during their first visits, patients respond to self-reported questionnaires willingly and with due care. A possible explanation for slackening motivation to respond is that regular assessment may engender disinterest in answering the same repeated questions about physical symptoms, particularly after symptoms have begun to improve acceptably and stabilize.

Furthermore, we can hypothesize that when symptoms and physical problems become acceptable, other problems emerge. Patients start to cope with their real needs and sources of worry, which they are often hesitant to discuss with their health care providers because not everyone and not all providers want to be involved in non-medical concerns. Studies into the implications of these points are missing.

Previous studies have shown that, whichever the disease stage, the needs underlying distress may be spiritual [7, 8], social [9–12], or financial [13–15], a lack of meaning or hope in life, feeling like a burden, and conflicts within the family [7, 8]. We cannot know the extent and the ways in which such suffering can interfere with a patient's well-being, sleep, and appetite or lead to fatigue, anxiety, and depression unless we conduct a comprehensive assessment of PROs that address a patient's most basic needs. When we see that physical symptoms do not improve or worsen, despite increased drug dosage or combination with other drugs, we should investigate further whether the suffering is physical and/or the patient feels misunderstood somehow.

A recent systematic review and expert report noted that spirituality is important for most patients with a serious illness, spiritual needs are common, and spiritual care is keenly desired by these patients. Also, spirituality can influence medical decision-making. The provision of spiritual care was found to be associated with better end-of-life outcomes, while unaddressed spiritual needs were associated with poorer patient quality of life. Despite this evidence, the spiritual needs of patients with serious illness often go unmet [7].

Tracy Balboni and Christina Puchalsky, two researchers in spiritual care [7, 8], have strongly suggested that front-line

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physicians and nurses should assess spiritual needs by plainly asking patients, for example, “Are you in peace?, Do you have spiritual pain?, Do you need spiritual help?, Do you have or would you like to have someone you can talk to about spiritual or faith matters?” They underlined the importance of eliciting patient needs in order to adequately address supportive care needs.

We realize that while assessment on a numerical scale from 0 to 10 or a verbal scale may not be the ideal tool, it can determine whether a concern or an unmet need is present or not and if present, how serious it is.

This also holds for the assessment of anxiety and depression, which is evaluated first on a scale from 0 to 10; when the score is > 3 out of 10, it is useful to study the symptoms closer with a specific questionnaire such as the Hospital Anxiety Depression Score (HADS) [9].

Just like physical symptoms, anxiety and depression, first-level screening of other concerns can be conducted by an oncologist, physician or nurse on the palliative care team or a general practitioner, whereas in-depth spiritual assessment can be done by a chaplain, pastoral counsellor, spiritual director, religious leader or other health care provider on the care team who has received appropriate training or by a social worker to help patients in dealing with social and financial problems. The patient is taken on by a team with diverse competences but united in seeking a common goal: a holistic approach to suffering. This is especially important in clinical practice in which screening can be used to disclose financial needs [10, 11], loneliness, and social problems [12].

In 2012, the ESAS was revised with the addition of two questions about spiritual pain and financial distress. This version was called ESAS-SF but was never validated. For their retrospective study of 292 encounters of advance-stage cancer patients, Delgado-Guay et al. [13] applied the ESAS-SF and found a correlation between spiritual pain and physical and psychological distress in over 40% of patients. In a later study investigating meaning in life as an indicator of resilience. Gravier et al. [14] reported that meaning in life correlated with spiritual pain, depression, and financial distress.

In 2022, ESAS-Total Care (ESAS-TC) was developed and validated in patients undergoing cancer treatment and in those with terminal cancer [15, 16]. The tool does provide for asking three basic questions: worries due to financial problems associated with illness, spiritual pain, and social isolation. In this way, a consultation can begin by addressing not only physical needs but also those underlying other needs. Patients can express themselves and we clinicians can better interpret the physical symptoms that patients experience.

Thus, a world opens where we can discover relationships between symptoms, problems, and unmet needs in cancer

patients. We can discover whether patients are able to purchase the drugs we prescribe. In our study, we found that a part of the patient’s stress was explained uniquely by financial, spiritual, and social suffering [15]. Furthermore, our findings showed that the new items assess different specific features that can be distinguished from the physical and psychological symptoms assessed with the original ESAS scale. Our results also provide evidence for the criterion validity of the scales, demonstrating the ability of symptoms to predict perceived stress. This observation is shared by previous studies that found that spiritual pain (7), financial toxicity [17], and loneliness [18] are all related to a patient’s physical and psychological distress.

In their recently published prospective, longitudinal cohort study, Yanez et al. [17] analyzed data from 2305 participants in the Northwestern University Improving the Management of Symptoms during and following Cancer Treatment trial. Outcomes at baseline and at 3, 6, 9, and 12 months postbaseline included depressive symptoms, anxiety, and financial hardship (FH). Financial hardship emerged as a prominent issue, with nearly half of participants experiencing some level of difficulty, depressive symptoms, and anxiety related to FH. The authors noted that “These findings underscore the need for a comprehensive approach in cancer care that concurrently addresses anxiety, depressive symptoms, and FH, recognizing their interconnected impact.”

Not to be underestimated are social isolation and loneliness [18]. Survival is known to be shorter in socially isolated cancer patients. Strengthening social support may help to improve treatment outcomes and well-being and to prolong survival [19]. Among the many different factors that besides loneliness influence survival are financial distress and spiritual suffering [20]. Assessment should go beyond physical and psychological symptoms to include other aspects of life that make up well-being and suffering. Comprehensive assessment of spiritual suffering, social isolation, and financial worries should be integrated in clinical practice for screening to adequately address supportive care needs. This type of evaluation may move clinical and research toward personalized total cancer care. Unlocking patients’ spiritual insights is just one of the myriad ways to identify and address patient needs in comprehensive holistic care. However, we are just at the beginning, and it is necessary to understand the compliance and acceptance of patients towards PROMS that evaluate their needs in a comprehensive way.

Moreover, we certainly cannot solve every patient’s need. However, bringing out a problem with a simple question could, within a team effort with social workers, chaplains, and volunteers, also lead to an alleviation of the patient’s suffering. Does this require more work? Of course, yes, but we are working for the patient’s quality of life.

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**Data availability** No datasets were generated or analysed during the current study.

## Declarations

**Competing interests** The authors declare no competing interests.

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