

## Challenges in distress screening implementation

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### ABSTRACT

Patients diagnosed with cancer suffer from psychosocial distress that can lead to negative health outcomes and worse quality of life. With the historical developments in regards to recognition of psychosocial distress, some institutions adopt the distress management guidelines and screen cancer patients at periodic times across the trajectory of care; however, the adoption of these guidelines into everyday clinical practice has been slow, posing a serious problem for the health of cancer patients. The status of distress management has developed slowly from the recognition of existential plight in late 1970s to guidelines recommended by the National Comprehensive Cancer Network, the Institute of Medicine, the American College of Surgeons (ACoS) Commission on Cancer (CoC), the American Society of Clinical Oncology (ASCO), the Alliance for Quality Psychosocial Cancer Care and by agencies in other countries in the late 1990s. All have been working on the same issue: how should distress screening be disseminated as a routine practice in cancer care? It is a challenge for policy makers to establish evidence-based policy while also mandating institutions to adopt guidelines to implement psychosocial distress screening as a patient-centered standard. This paper identifies the advancement of psychosocial distress screening in cancer care through clinical practice guidelines and health policy and outlines the need for the expeditious adoption and implementation of distress screening in cancer care throughout the world.

**KEYWORDS:** psychosocial, distress, screening, development, adoption, guideline, policy, cancer, patient-centered care

### INTRODUCTION

Patients with cancer may suffer from psychosocial distress during the course of their disease. In a study of 4496 cancer patients, the overall prevalence of distress was 35.1% [1] and a recent review showed that the prevalence of all types of mood disorders in patients with various types of cancer was 38.2% [2]. In newly diagnosed patients and those experiencing a recurrence, estimates of significant distress range up to 40% [3]. Unfortunately, routine psychosocial screening of patients is not the norm [4]. Without routine screening, cancer care clinicians are not likely to identify distressed patients. Based on the evidence supporting distress screening, the Institute of Medicine has called for routine distress screening in cancer care, and leading professional organizations, such as the American Society of Clinical Oncology, the American Psychosocial Oncology Society, the Association of Oncology Social Work, and the Oncology Nursing Society, have endorsed routine distress screening. The American College of Surgeons Commission on Cancer has mandated distress screening in cancer care as an accreditation standard [5]. Despite this understanding of the need for distress screening in cancer care, implementation of distress management is slow [6]. This paper outlines the long journey from clinical practice guidelines to mandated policy and highlights the importance of accelerating adoption and implementation of routine distress screening in cancer care.

#### 1. Definition of distress

The National Comprehensive Cancer Network (NCCN) defines distress as “an emotionally

unpleasant psychological (cognitive, behavioral, emotional), social, and/or spiritual experience that might interfere with a patient's ability to effectively cope with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis" [7]. The NCCN Distress Management Clinical Practice Guidelines recommend that all patients should be screened with the Distress Thermometer (DT), a numerical analog scale ranging from 0 (no distress) to 10 (extreme distress) accompanied by a problem list [8]. The problem list asks patients about sources of distress: practical, family, emotional, and physical problems and spiritual or religious concerns [9].

## **2. The historical development of distress screening**

### **Existential plight**

In 1976, Weisman and Worden identified existential plight as an emotional condition that begins at the time of a definitive diagnosis and continues for two or three months, or approximately 100 days, into the illness. The initial assessments of existential plight involved semi-structured interviews and psychosocial testing, using a Minnesota Multiphasic Personality Inventory (MMPI) and a Thematic Apperception Test (TAT) and rating scales. The results showed that early recognition of vulnerability, through understanding the importance of existential plight, might point to psychosocial interventions that improve patients' quality of life [10]. In other studies, Worden and Weisman went on to find that more than two-thirds of patients newly diagnosed with cancer who were at risk for cancer-related distress accepted screening [11]. A few years later, they reported patients at high risk for distress who were screened and offered psychological intervention showed a significant decrease in distress and a significant increase in problem solving [12].

### **The development of distress screening scales**

In 1976, McCorkle and Young developed the Symptom Distress Scale (SDS), the first scale to measure physical and emotional symptom distress with patients with cancer. The thirteen-item scale

was designed as a self-administered, self-report, liker-type scale that ranges from 1 to 5. Total symptom distress can be obtained as the unweighted sum of the 13 items with scores ranging from 13 to 65. Higher scores indicate higher degrees of symptom distress [13]. McCorkle and others have used the SDS as an outcome measure to evaluate the effectiveness of an advanced practice nursing intervention in adults with multiple types of solid cancers. In 1996, a new visual analog scale rating emotional distress, "the Distress Thermometer," was created. It asked patients to indicate their level of distress on a scale of 0 to 10 [8]. In 2005, the Distress Thermometer established 4 as the cut-off score yielding optimal sensitivity and specificity [14]. In 2013, the NCCN Distress Management guideline recommended the Distress Thermometer should be accompanied by a problem-list [8].

### **National Comprehensive Cancer Network**

In 1997, the NCCN's multidisciplinary panel developed the first set of standards and clinical practice guidelines for psychosocial care in cancer [15]. By 2003, the NCCN Distress Management guidelines required that all patients should be screened for distress during the initial visit, at appropriate intervals, and as clinically indicated, especially with changes in disease status such as remission and recurrence [16]. In 2007, the NCCN made a case for designating distress as the sixth vital sign after pulse, respiration, blood pressure, temperature, and pain, to ensure that distress management, like pain management, would become a routine part of cancer care [17]. In 2013, the NCCN developed consensus-based identification and treatment of psychosocial distress in patients with cancer. The purpose of this standard is to help oncology teams identify patients who require referral to psychosocial resources. It also gives oncology teams guidance on interventions for patients with mild distress to ensure that all patients with distress are recognized and treated [18].

### **Institute of Medicine**

The 1997 Institute of Medicine (IOM) report, *Approaching Death: Improving Care at the End of Life*, provided the guiding principles on how approaching death is an integral and important part of health care and how the failures to use knowledge to prevent and relieve distress should be

viewed as clinical and ethical failures [19]. In the 2001 report, *Improving Palliative Care for Cancer*, clinical practice guidelines and standards for the management of distress were suggested, saying that practices must incorporate the psychological, social, existential, spiritual, and religious issues faced by patients [20]. In 2004, the report titled *Meeting Psychosocial Needs of Women with Breast Cancer*, addressed oncologists and other medical professionals responsible for the care of women with breast cancer, advocating the need to incorporate planning for psychosocial management as an integral part of treatment [21]. The 2008 report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, placed an emphasis on providing appropriate psychosocial health services [22]. The 2013 report, *Delivering High-Quality Cancer Care*, stated that meeting psychosocial health needs in end-of-life care is especially important and that care plans should address a patient's psychosocial health needs [23].

#### **The Alliance for Quality Psychosocial Cancer Care**

In 2008, the Cancer Support Community and the American Psychosocial Oncology Society joined forces to bring together key professional and advocacy stakeholders to form the Alliance for Quality Psychosocial Cancer Care. One of the purposes of the Alliance is to advocate policies to ensure that all patients are screened and have access to quality psychosocial care. The alliance also submitted a letter to the IOM National Cancer Policy Forum, urging the inclusion of policies that implement the recommendations of the *Cancer Care for the Whole Patient* report in the IOM's future work and in policy proposals [24].

#### **The International Psychosocial Oncology Society (IPOS)**

Following the World Congress in June, 2010, IPOS proposed a new international standard, supporting the integration of psychosocial care in routine cancer care by establishing it as the 6<sup>th</sup> Vital Sign, after temperature, blood pressure, pulse, respiration and pain [25].

#### **Other countries**

Other countries have begun to make advancements in psychosocial distress care as well. In 1999 the

Canadian Association of Psychosocial Oncology (CAPO) published *National Standards for Psychosocial Oncology*, the first document of its kind worldwide, which focused on the structure of programs, professional issues, patient/family services, research, evaluation, and professional development [26]. In 2006, the CAPO Board of Directors revised the standards of psychosocial care to include assessment, evidence based intervention, and access to psychosocial care [26]. In the same year, Canada developed a set of standards for quality care, establishing psychosocial distress as an integral part of routine care. It was deemed the Sixth Vital Sign [27]. In 2010, a Pan-Canadian Practice Guideline addressed emotional distress, anxiety, depression, appropriate screening and/or assessment, and management of depression and/or anxiety in adults with cancer [28].

In Australia, the National Breast Cancer Centre and National Cancer Control Initiative collaborated to develop clinical practice guidelines to incorporate screening into routine clinical care of adult patients with cancer [29].

The United Kingdom's National Institute for Clinical Excellence (NICE) produced guidelines on psychosocial aspects of cancer requiring a four-level model of professional psychological assessment and intervention to be implemented in each Cancer Network [30]. The Council of the European Union cancer screening standard recommended using evidence-based strategies to achieve management of patients' quality of life and provision of psychosocial care services [31]. In 2011, the IPOS required ensuring psychosocial care services be consistent with clinical practice guidelines as part of routine care [25].

### **3. Distress screening as a mandated policy**

In addition to evidence-based clinical practice guidelines, stricter policies have been designed by some professional organizations to address psychosocial needs associated with cancer. These policies involve routine screening for emotional distress in patients as a part of quality cancer care [32].

#### **The American College of Surgeons Commission on Cancer (COC)**

In 2011, the COC approved new standards to promote patient-centered care, which included psychosocial

distress screening [5]. The COC Psychosocial Distress Screening Standard requires that a cancer center's cancer committee develop and implement on-site psychosocial distress screening and referral for the provision of psychosocial care. The process requirements encompass six components, including timing, method, tools, assessment, referral and documentation [5]. In 2015, the COC will require cancer centers to implement screening programs for psychosocial distress as a criterion for accreditation [33].

#### **American Society of Clinical Oncology (ASCO)**

In 2014, ASCO adapted a policy from the Pan-Canadian Guideline on Screening, Assessment and Care of Psychosocial Distress, which declared that all patients with cancer should be evaluated for symptoms of depression and anxiety at periodic times across the trajectory of care. The guideline, and the adapted policy, recommend that health care practitioners should first identify the available resources for treatment in their institution before implementing the guideline [28, 34].

The American Psychosocial Oncology Society (APOS), the Association of Oncology Social Work (AOSW), and the Oncology Nursing Society (ONS) all recommended the implementation of distress screening guidelines. They represent over 36,000 health care professionals who provide psychosocial care to patients with cancer in the United States. The joint task force specifically developed consensus-based recommendations regarding the ACoS standard [35].

#### **4. The gap between guidelines and health policies**

A clinical practice guideline uses the latest evidence and expert consensus to guide clinicians regarding best practices. It is a source of high quality information not only for clinicians but also for policy makers and for patients [36]. A health policy, on the other hand, encompasses the “decisions, plans, and actions that are undertaken to achieve specific health care goals within a society” [37]. According to the World Health Organization, an explicit health policy defines a vision for the future, outlines priorities and the expected roles of different groups, and builds consensus and informs people [37]. A guideline is meant to be a map that provides evidence-based information in order to

advise practitioners and patients and families in matters of clinical care, while a policy is a standard created out of those guidelines that forces practitioners to abide by its edict. Although clinical practice guidelines regarding psychosocial distress screening in cancer care have been developed worldwide, too few health policies that offer explicit and enforceable methods of rapid implementation have come from these guidelines. Organizations across a number of different countries propose guidelines for this essential care that, for the most part, do not elevate much beyond suggestion. As a result they have all too often been easily ignored.

Further, the progress in implementation of NCCN guidelines has been modest at best. A survey between 2005 and 2012 found only a 7% increase in NCCN member institutions conducting routine screening. The number of institutions screening all outpatients routinely increased by 10% in 2012, but that still only represented 35% of all NCCN member institutions [38].

Recognition of psychosocial distress as part of the cancer journey is one of the most significant developments in cancer care in modern history [39]. The growing number of clinical practice guidelines that address psychosocial care reflects a burgeoning awareness of the value of evaluating and managing the psychosocial impact of cancer as part of routine clinical practice [40]. However, guidelines and recommendations can only affect the solution so much when little is done to implement them. More uniformed and enforced mandates are required in this country and around the world to truly move forward and adequately address the psychosocial needs of the millions of patients suffering from cancer.

In addition, funding for psychosocial services remains limited and office practices often cannot generate the funds to support psychosocial care without grants or philanthropy. In a resource-rich country like the United States this is simply unacceptable [17]. As the Chief Medical Officer to the American Cancer Society, Otis Brawley, puts it [41]: “Politicians almost always support basic research, but rarely support studies on the effectiveness of treatment”. He is broadly right; in the European Union and the USA, less than 10% of cancer research spending was on outcomes research in 2002-03 [42]. That figure is similar to what a recent study

on outcomes research in the United Kingdom suggests as well [43].

Overall this is an approach that needs to change. Adoption and implementation of strict and enforceable policies founded on evidence-based clinical practice guidelines is coming at a rate too slow and uneven to bring real change. A way forward is to have policies that accelerate adoption and implementation of routine distress screening in cancer care. Policy of swift compliance with these guidelines as part of the accreditation process should provide strong motivation for institutions to implement standards for distress screening and care of distressed patients, advancing cancer care far beyond past limitations.

## SUMMARY

Ever since Worden and Weisman's identification of existential plight in cancer in 1976, the prevalence of psychosocial distress in cancer patients has been an issue given much consideration to by those in the cancer care community. In the nearly 40 years since Worden and Weisman's breakthrough, organizations across the globe have developed guidelines aimed at addressing the needs of distressed patients with cancer. In the United States, from the development of the Symptom Distress Scale by McCorkle and Young in 1976, to the initial standards and guidelines of psychosocial care set forth by the NCCN and IOM in 1997, as well as other guidelines outlined by the Alliance for Quality Psychosocial Cancer Care in 2008, cancer care professionals have worked diligently to establish a standard of care sufficient with the needs of distressed patients with cancer. In countries across the world as well, such as Canada, the United Kingdom, and Australia, standards and guidelines have been developed to address patient needs. And yet, the development and implementation of these suggestions, recommendations, and guidelines have been too slow to adequately respond to the growing need for psychosocial care in cancer patients around the world. It took until 2011, 35 years after Worden and Weisman's development, for the COC to approve standards that included psychosocial distress screening as part of its standards. It wasn't until 2014 that ASCO developed a policy of its own. It won't be until 2015 that distress screening will be mandated

as part of the COC's institution accreditation process. In order to satisfactorily address the needs of distressed patients suffering from cancer, policies focusing on implementation of care must be mandated swiftly and efficiently across the globe over the next few years. Nearly 40 years in between recognition of the issue and the implementation of a solution is too long for patients with cancer to have to wait to get sufficient care for their mental distress. It's time to speed up the process and finally give these patients the care they need.

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## CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest associated with this work.

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