



Special Article

Psychological Aspects of Care in Cancer Patients in the Last Weeks/Days of Life

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Palliative care is comprised of an interdisciplinary team (IDT) approach with members from different disciplines who collaboratively work together to reduce multidimensional components of pain and suffering and improve quality of life for patients coping with a terminal illness. Psychosocial team members are integral to the palliative care IDT and provide expertise in assessment and empirically validated interventions to address psychological distress. The following paper will provide a review of different facets of psychological distress experienced by advanced cancer patients such as psychological disorders, existential distress, spiritual distress, caregiver distress, parental distress, and grief. Finally, an overview of commonly used screening and assessment tools as well as psychological interventions relevant for the palliative care population is presented.

Key words Palliative care, Palliative supportive care, Psychosocial care, Psychosocial oncology, End of life, End of life care, Psychological distress, Emotional distress

Introduction

End of life for advanced cancer patients has been associated with suffering and significant symptom burden that has facilitated the development of palliative care specialty services. Per the National Comprehensive Cancer Network (NCCN) Guidelines, palliative care is an interdisciplinary comprehensive approach to symptom management, which includes the physical, psychological, social, and spiritual care of patients and their families in an effort to maximize quality of life [1]. Quality of life is comprised by physical, psychological, existential and spiritual components [2]. One reason palliative care is so effective in addressing multidimensional aspects of suffering and pain is largely due to the collaboration of members of the interdisciplinary team (IDT) which is a core component of palliative care [3]. Palliative care IDT approach has been associated with positive outcomes including improved symptom control, less inpatient admission days, and lower overall hospital costs for advanced cancer patients [4,5]. In addition, IDTs have been associated with increased chance of patients receiving care congruent with patient and family values and death occurring in preferred setting [5].

A recent systemic review of palliative care interventions revealed the most provided service is first symptom management (88%), followed closely by psychological support/counseling (81%) and then disease education (75%) [6]. The field of palliative care has made significant contributions to address suffering at end of life for advanced cancer patients,

particularly in regard to addressing psychological distress in the past three decades. Psychological services that can significantly contribute to the IDT model include knowledge in psychological assessment; evidenced-based psychological treatments for individuals, families and groups; education; research; and consultation, supervision and staff support [7,8]. The following article will provide an overview of psychological issues and contributions in palliative care for advanced cancer patients.

Facets of Psychological Distress and Prevalence

Psychological distress, which can include emotional, existential, spiritual, and social components, has been associated with greater physical symptom severity, suffering, and mortality [9,10] with research indicating that psychological and adjustment issues contribute 64% of variance in predicting suffering levels [10]. Psychosocial symptoms have also been reported to worsen closer to death [11]. However, another study found that proximity to death was not associated with higher rates of depressive and anxiety disorders but increased existential distress, physical symptom burden and increased wish to die [12]. One study that compared different samples reported that 59.3% palliative care patients endorsed psychological distress compared to only 24.5% cancer outpatients and 16.5% general community [13]. Please see Fig. 1 for types of psychological distress that will be dis-

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Psychological Disorders

Differences in operational definition of distress, measurement methods and methodological issues contribute to varied prevalence rates of distress in cancer and palliative care samples [14-16]. In a large sample of 9,000 cancer patients, distress prevalence was 35.1% with highest rate being 43.4% for lung cancer patients to 29.6% for gynecological cancers [17]. In a large epidemiological study of cancer patients that measured mental disorders with a 4-week prevalence by a standardized clinical interview, 31.8% of cancer patients were found to meet criteria with the most prevalent being anxiety disorders (11.5%) followed closely by adjustment disorders (11%) [18]. Similarly, a meta-analysis of studies that conducted comprehensive structured clinical interviews of cancer patients found a combined prevalence across all samples of 32% meeting criteria for a mental health condition [19].

Although some studies have reported increased distress closer to death [11,12], rates for mood disorders were slightly lower in a meta-analysis of palliative care studies which found rates of 24.6% for combined minor and major depression, 15.4% for adjustment disorders, and 9.8% for anxiety disorders. In this meta-analysis, there were no significant differences between palliative care and non-palliative care settings, noting some combination of mood disorders to occur in 30%-40% of patients [20]. Another study sample of 1,940 palliative care patients found 73.1% to meet criteria for adjustment disorders, 4.7% depressive disorder, and 4.4% anxiety disorder [21]. Finally, an Australian study that surveyed 1,880 palliative care patients reported 66% endorsed depressed feelings, 20% reported severe patient anxiety and 45% severe family anxiety [22].

Rates of depression in advance disease patients range from 23% to 58% with it being more prevalent in later stages of cancer [23]. Depression severity was significantly associated with increased physical symptoms, symptom distress and symptom severity independent of cancer type, functional status, chemotherapy status and survival time [24]. Meta-analysis review reported depression associated with increased mortality in cancer patients [25].

Existential Distress

In addition to psychological disorders, cancer patients and caregivers facing end of life are also at risk of experiencing existential distress. One significant challenge regarding existential distress is that various definitions and terminol-

ogy have been used interchangeably in the palliative care literature [26]. Broadly defined, existential distress refers to suffering due to issues related to 'identity, personal integrity, or an unfulfilled past, as well as issues related to future concerns such as meaningless, hopelessness, death, futility, and religious worries' [27]. Four major domains have been identified to categorize clinical presentations of existential distress [28]. First, is freedom which is the idea that all humans have choice and one may experience distress if he/she regrets past decisions or has unresolved conflict or guilt. Second, is meaning which may cause distress if one is questioning, searching or has experienced loss of meaning or purpose of self and/or life. Third, is isolation which refers to feeling disconnected, abandoned or separated from larger community. Fourth and final is death or mortality which includes anxiety and fear of dying, the afterlife and separation from loved ones [28].

Lacking a definitive definition for existential distress, there have been various constructs to operationally define existential distress including death anxiety, hopelessness, and desire of hastened death [29]. One such form of existential distress that has been gaining momentum in the palliative care literature is the concept of demoralization. Demoralization has been demonstrated in terminal patients and described as a spectrum beginning with disheartenment or mild loss of confidence, which can then lead to despondency, then despair and then full-blown demoralization syndrome [30]. Demoralization is characterized by diminished morale when one's principals, values or standards are threatened and has been observed in health care workers when facing significant stress that cannot easily be addressed [31,32]. Kissane et al. [33] identified five factors of demoralization, which include loss of meaning, dysphoria, disheartenment, helplessness, and a sense of failure. A prevalence range of 13%-23.1% of demoralization in advanced cancer patients has been found in the literature [34,35].

Demoralization has been distinguished from depression and defined as is a sense of hopelessness and helplessness when purpose and meaning are lost [35]. Although depression and demoralization are correlated, demoralization is not accompanied by anhedonia, a hallmark symptom of major depression and studies have found patients who endorse demoralization but not meet criteria for depression [36,37].

Spiritual Distress

The European Association for Palliative Care (EAPC) defines spirituality as 'the dynamic dimension of human life that relates to the way person (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self,

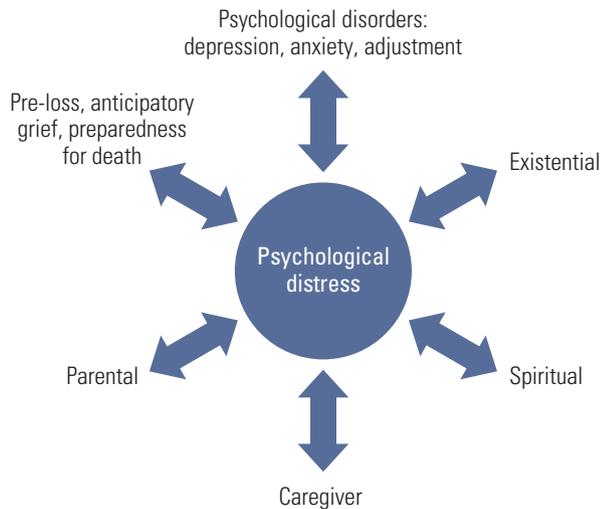


Fig. 1. Facets of psychological distress.

to others, to nature, to the significant and/or sacred' [38]. As an example, spiritual wellbeing may be accomplished by one's belief in a benevolent and kind world thus encouraging the practice of kindness towards others which provides purpose and meaning in life for this individual. Not having opportunities to engage in charitable or volunteer activities due to a serious illness may cause spiritual distress in the sense of loss of connection to others as well as loss of meaning and purpose due to lack of opportunities to practice kindness.

It is important to distinguish between spirituality and religiosity. While spirituality refers to meaning and purpose in life, religiosity refers to set of beliefs about the transcendent or higher power shared by a community and organized behaviors, writing and practices that can serve as a pathway to experience and practice spirituality [39,40]. For example, spirituality may refer to identifying and practicing personal experiences to foster inner peace and meaning such as connecting with nature while an example of religiosity might be attending a church service to participate in worship and prayers with others who believe in the same higher being. Interestingly although spirituality has been correlated with less psychological distress, the same has not been found for religiosity [41,42].

Spiritual distress, endorsed by approximately 25% of cancer patients [43] is another aspect of distress that warrants proper identification and attention by palliative care providers, especially psychologists who should include in psychological assessment patient's spiritual needs to help understand patient's values, belief system, spiritual history, distress and needs [44]. Understanding of one's spirituality may provide insight into a patient's worldview and coping

preferences, which could direct psychotherapy and interventions including collaboration with spiritual care professionals to meet patient's spiritual needs.

Spirituality in the palliative context is integral for how some patients interpret and cope with their illness especially at end of life and influences medical decision-making at end of life [45]. Spiritual wellbeing and meaning in life served as protective factors from psychological distress at end of life and positively associated with quality of life [2,40]. Spiritual wellbeing has been negatively correlated with psychological distress including anxiety and depression, hopelessness, wish for hastened death and suicidal ideation [41,42,46]. While medical teams providing spiritual support is controversial, a study demonstrated spiritual support from medical team providers including chaplain visits were correlated with higher quality of life at death [39]. Additionally, results from the same study, patients whose spiritual needs were supported were more likely to receive hospice and less likely to choose aggressive treatment.

Caregiver Distress

In addition to relieving the suffering of patients, palliative care utilizes a holistic family centered approach to provide psychosocial support for family members, especially caregivers, who also experience significant symptoms and distress due to the burden of caregiving for loved one particularly at the end stage of life. A meta-analytic study showed a positive correlation between cancer patient and caregiver distress [47]. A recent study found 96% family caregivers of advanced cancer patients endorsed clinically significant distress including 43% moderate to severe anxiety and 41% depression [48]. A similar study but of caregivers of terminal patients admitted in a palliative care unit reported 77% endorsed probably significant distress with 76.1% endorsing anxiety and 77.4% depression [49]. This finding leads support to the needs and challenges experienced by caregivers increase over time and approaching death and at times, may be greater than those of the terminally sick patient [50,51].

Parental Distress

One area that palliative care psychosocial providers have recently invested in addressing is for advanced cancer patients who have young children. Parental status for cancer patients has been associated with higher rates of anxiety, depression and decreased quality of life, particularly at end of life [52-54]. Parenting concerns in patients with metastatic cancer was the primary predictor of anxiety and depression

[55]. Several studies have shown that parents are distressed about impact of their cancer and death on their young families, inability to parent while undergoing treatment and due to physical limitations and feel inadequate in communicating their diagnosis and prognosis to their children [55-60]. Advanced cancer patients who are parents of young children are more likely to prefer aggressive treatment over palliative care and less likely to initiate advanced care planning [61,62].

Pre-loss, Anticipatory Grief and Preparedness for Death

Prior to the actual death event, patients and caregivers experience multiple losses and grief starting with a cancer diagnosis including but not limited to loss of physical abilities, independence, job/career, financial savings/stability, relationships, future goals/dreams and so much more. Multiple compounded losses and grief during the cancer trajectory puts both patient and caregiver at risk for psychological distress [63,64]. Once patient transitions to end of life care and impending death has been forewarned, patients and caregivers may experience pre-loss grief, which has been operationalized in the literature as anticipatory grief and is also referred to as preparedness for death [65]. Anticipatory grief refers to grief experienced prior to the death. Severe pre-loss grief is associated with depressive symptoms, high caregiver burden, low preparedness for death, and low level of communication about dying [66]. High pre-loss grief and low preparedness for death is associated with poor bereavement outcomes including poor post loss adjustment and complicated bereavement [66,67]. Being unprepared for death is associated with greater depression, anxiety and complicated grief and sense of preparedness associated with 2.4 times less likely to have complicated grief [68].

Screening and Assessment of Psychological Distress

Early psychological intervention, similar to the push for early palliative care, may prevent "normal" adjustment from progressing to diagnosable disorders. For this reason, several national mandates have called for routine psychological distress screening and the integration of psychosocial care for all cancer patients [1,69]. In terms of screening for distress symptoms, the Edmonton Symptom Assessment System (ESAS) is the most widely used in palliative care to screen for both physical, emotional and spiritual symptoms that has been validated and translated into over 20 languages [70]. Please refer to Table 1 for a list of commonly used screening

tools that include psychological distress symptoms in palliative care [70-81]. This list is not meant to be exhaustive of all screening instruments.

Although this article did not discuss delirium, prevalence estimates from 42%-58% of patients admitted on acute palliative care units indicate the necessity for proper screening and assessment so appropriate medical treatment can be administered [82]. Similarly, alcohol and substance use and disorder in cancer patients has been estimated from 2%-35% in one systematic review [83]. A study of young adult cancer patients with primarily hematological cancers reported prevalence rates of 80% alcohol, 15% tobacco, and 33% cannabis use in the past year [83]. Since both delirium and substance use and disorders impact psychological functioning, screening tools for both have been included in Table 1.

Once distress has been identified during the screening process, a comprehensive psychological assessment provided during initial clinical interview by a member of the psychosocial team member can be valuable in identifying appropriate empirically validated psychological interventions to tailor treatment to each individual patient and family. A clinical interview should include: current mood symptoms including severity, frequency and duration to identify if patient meets criteria for psychological disorder, psychiatric history, social and family history, current family/living situation including family dynamics and dysfunction, coping skills, sense of meaning, spirituality, current substance use and history, and also suicide risk assessment.

Clinical Interventions for Psychological Distress

Psychological treatments for general psychiatric population including empirically validated interventions such as supportive expressive therapy, cognitive behavioral therapy, acceptance and commitment therapy, and others have been utilized in the palliative care population to treat depression, anxiety symptoms and support coping [46,84-86]. In addition, several psychological interventions have been developed in past couple of decades to specifically address unique needs of palliative patients facing death. For example, Dignity Therapy was developed to address psychosocial and existential distress in terminally ill patients by facilitating discussion of patient's priorities and how they would prefer to be remembered [87,88]. Meaning-centered psychotherapy (MCP) is another intervention specifically created to address spiritual wellbeing and meaning for patients with advanced cancer in both an individual and group therapy formats [89,90]. MCP has also been adapted to utilize with caregivers as well as abbreviated to shorter number of sessions for

Table 1. Screening and assessment tools commonly used in palliative care settings

Name	Measures	Format	No. of items	Population
ESAS: Edmonton Symptom Assessment System [70]	Physical, psychological, spiritual and overall wellbeing symptoms	Self-report by patient, family or staff, 0-10 numeric rating 10 being worse	10	Palliative care patients, caregivers
MSAS: Memorial Symptom Assessment Scale [71]	Physical and psychological symptoms related to quality of life	Self-report, endorsed symptoms rated for severity, frequency and distress on 4 point categorical scale	32	Palliative care patients
CAMPAS-R: Cambridge Palliative Assessment Schedule [72]	Physical, carer anxiety, emotional symptoms	Self-report, endorsed symptoms indicated on line for severity and then for how much interference with normal activities or troublesome	20 with option to list other symptoms	Home palliative care patients
IPOS: Integrated Palliative Care Outcome Scale [73]	Physical, psychological, spiritual problems, communication needs including with family, practical support	Self-report by patient or proxy, 5 point Likert scale	20 patient version, 19 proxy version	Palliative patients
MDAS: Memorial Delirium Assessment Scale [74]	Severity of delirium symptoms	Clinician rated, 4 point scale	10 items	Cancer patients
CAGE-AID: Cutting down, Annoyance by criticism, Guilty feeling, and Eye-openers [75,76]	Screen for alcohol and drug use	Clinician interview yes/no responses	4 items	Adults
HADS: Hospital Anxiety and Depression Scale [77]	Depression and Anxiety	Self-report 5 point Likert scale	14 total, 7 items subscales for anxiety and depression	Medically ill adults
PHQ-9: Patient Health Questionnaire-9 [78,79]	Depression	Self-report 4 point Likert scale	9	Adults
C-SSRS: Columbia-Suicide Severity Rating Scale [80]	Suicide ideation and behavior	Interview or self-report, yes/no format	Depends on if items are endorsed	Adults
DS-II: Demoralization Scale-II [81]	Demoralization	Self-report rating from 0 never, 1 sometimes, 2 often	16	Palliative patients

practical and feasibility use with inpatient palliative care patients [91,92]. Please refer to Table 2 for a commonly utilized psychological interventions, which are not listed in any particular order nor an exhaustive list.

In addition, to psychological interventions, psychosocial providers often are skilled in facilitating and encouraging communication and often have the benefit of having established trusting therapeutic relationships with patients and family members which can be advantageous in facilitating

family goals of care meetings. Goals of care family meetings or end of life discussions are not unique to palliative care; however, palliative care providers are uniquely equipped and trained to facilitate these discussions that can highly affect the course of a patient's medical care. Study by Wright et al. [93] reported end of life discussions was associated with lower rates of ventilation, resuscitation, intensive care unit admissions and earlier enrollment in hospice services. Contrary to initial hypothesis, end of life discussions was not

Table 2. Commonly used psychological interventions in palliative care

Intervention	Purpose	Format	Intervention efficacy studies
Supportive expressive therapy [94]	Supportive techniques to create a safe, trusting and comfortable environment to form therapeutic alliance and expressive techniques to encourage discussion of personal experiences and emotions to support processing and interpretation of problem	Therapeutic technique used in individual or group therapy format that originated from psychoanalytic/psychodynamic framework	Significant decline in total mood disturbance and traumatic stress symptoms in metastatic breast cancer patients [95] Improve quality of life and psychosocial status in breast cancer patients [96] Anxiety, depression, anger decreased and coping improved in male gastrointestinal cancer patients [97]
Cognitive behavioral therapy [98]	Treatment for problematic symptoms by changing thought patterns, behaviors and emotions which are interrelated	Typically individual sessions ranging from 5-20 sessions	Improvement in functional and symptoms scales [99]
Acceptance and commitment therapy [100]	To reduce avoidance and enable acceptance of both positive and negative components of experience by developing psychological flexibility	Individual or group sessions ranging from 8-16 sessions	Reduced depressive symptoms, psychological distress, improvements in anxiety, characteristics and health-related quality of life [101]
Dignity therapy [87,88]	Psychosocial and existential distress in terminal patients	2 Sessions: first eliciting patient's life history and hopes for their loved ones and second session patient presented with narrative of first session and asked to edit or add content	Initial feasibility study found significantly less suffering and depression post-treatment but randomized, controlled trial demonstrated no significant difference between groups [88]
CALM: managing cancer and living meaningfully [102,103]	Focus on 4 domains: 1. Symptom management and communication with health care providers 2. Changes in self and relations with close others 3. Spiritual wellbeing and sense of meaning 4. Advance care planning	3-6 sessions over 3-month period	Efficacy studies had significant attrition but reported significant fewer symptoms of depression and death anxiety and significantly improved overall quality of life [103]
MCP: Meaning-Centered Psychotherapy [89-92]	Targets spiritual wellbeing and sense of meaning in advanced cancer patients	Structured manualized for either individual intervention (7 weeks/sessions) or group therapy (8 weeks/session) for advanced cancer patients and caregivers; Abbreviated 3 session format for palliative care setting	At post-treatment, improved spiritual wellbeing, quality of life, symptom burden, and symptom related distress but no significant difference between groups at 2-month follow-up [89]

associated with higher rates of depression or worry. This study also reported aggressive medical care was correlated with worse patient quality of life and higher rate of major depression for bereaved caregivers.

Conclusion

A hallmark of palliative care is using an IDT approach to address the multifaceted aspect of suffering and improve quality of life for advanced cancer patients at end of life. Psychological care providers are a crucial component of the

IDT and contributes expertise in assessment and treatment of psychological distress, which includes mental health disorders such as adjustment, depression, and anxiety as well as demoralization, existential, spiritual, family and social distress. Psychological care providers also attend to caregiver distress, family dysfunction, and unique needs of cancer patients with young children that could exacerbate distress during the dying process. Palliative care providers continue to face challenges of lack of resources that prevent the full benefits of an IDT approach to address pain and suffering. Future research should focus on continued development of empirically validated psychosocial interventions for palliative care patients at end of life. Other psychosocial issues such as body image, intimacy and sexuality, and financial

distress should be further explored in the palliative care population to continue to support overall quality of life.

Author Contributions

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Conflicts of Interest

Conflict of interest relevant to this article was not reported.

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