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Existential distress in cancer: Alleviating suffering from fundamental loss and change

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Illness can take life to the very edge of the abyss, where suffering and death threaten the beauty and worth of a person, where the myth of control is realized, where sadness and ambiguity replace creativity and love, where time is running out...here angst about existential issues challenges our humanity. As Tolstoy wrote, “At one moment a gleam of hope, the next a raging sea of despair, and always pain, always misery and pain, over and over again. All this lonely misery was terrible” (p.146, *The Death of Ivan Ilyich*). Tolstoy describes Ilyich as trapped by his progressive illness, struggling and writhing in a “black sack” from which there was no escape, aware that every moment, “he was drawing nearer and nearer to what terrified him” (p.159).

Although existential suffering in the context of life-threatening illness has long been called to attention ¹⁻³, only recently have researchers studied this phenomenon more rigorously. Common to this proliferating body of literature is the conceptualization of existential distress as a distinct, painful psychological state, that ⁴⁻⁹

- results from a stressor that challenges fundamental expectations about security, interrelatedness with others, justness, controllability, certainty and hope for a long and fruitful life;
- brings a flood of distressing emotions including fear, outrage and horror at the possibility of death; concern about autonomy, suffering, or being a burden to others; a sense of profound loneliness, pointlessness or hopelessness; grief, regret or embitterment about what has been missed in life; and shame if dignity is lost, doubt and disbelief prevail, or expectations about coping are not met;
- has been operationalized by the constructs of *fear of cancer recurrence*, *death anxiety*, *demoralization*, *dignity-related distress*, *hopelessness*, *spiritual distress*, and *the desire for hastened death*, which include the aforementioned facets in varying combination and emphasis;

- fluctuates and occurs on a continuum of severity, where severe and enduring levels are clinically significant and maladaptive in a noteworthy subgroup;
- may occur co-morbidly with other psychiatric disorders but also in their absence, when physical pain is well treated, social support is available, and the person has been perceived as robust; and finally
- has a significant impact on health care outcomes.

Two meta-analyses featured in this issue ^{10,11} illustrate the progress of the last decade. Yet there is much uncertainty about how to recognize and address existential distress in cancer care. Much remains to be learned about this crucial state of mind. This special issue brings together different lines of current research in the hope of deepening our understanding of this phenomenon. We begin by posing a set conceptual and practical questions, reviewing what is known, and identifying what needs to be addressed to move the field forward.

How does existential distress arise?

That distress and suffering, but also growth and mastery may arise from confrontation with existential threat is a long-standing idea. Long ago, Jaspers ¹² identified that a life-threatening disease created a *limit situation*. Although they are givens of our human nature, the finitude of life, any restriction to freedom, reduction of meaning, or isolation from others are thoroughly unwelcome yet inescapable eventualities. Cancer brings such losses through a shortened lifespan, prognostic uncertainty, altered relationships, and impaired physical functioning, autonomy and controllability ^{6,13,14}. When personal beliefs and goals are disrupted, individuals may renegotiate what is meaningful ¹⁵. Notwithstanding this, Salander highlights how illness interferes with the ability to continue a daily routine that provided security and sense of purpose, masking the limits of our human existence ¹⁶. The idea that attaching to normality

can be a source of adjustment fits well with Folkman's¹⁷ observation that "infusing ordinary events with meaning" helps ameliorate stress and uncertainty.

Fear of cancer recurrence has been one recent focus of inquiry¹⁸. A recent integrative model identified threat of loss and death, ongoing uncertainty and limited control, and ongoing reminders of cancer are relevant sources of anxiety for all patients with cancer¹⁹. Advanced cancer brings fear of the process of dying, its consequences for close others, regret about not having reached important goals and being a burden, well exemplified by studies using the Death and Dying Distress Scale (DADDS) and the Patient Dignity Inventory (PDI)^{20,21}. Similar fears underlie the fear of recurrence in cancer survivors. Death anxiety has many presentations and ways of being masked²². For death anxiety and fear of cancer recurrence alike, both very low levels (over-avoidance) and very high levels (over-rumination, excessive worry) have been found to be maladaptive²³. A better understanding of the dynamics of how individuals approach versus deflect from existential threat would be of value to psycho-oncology interventions²⁴. A renewed interest in cognitive-existential interventions for fear of cancer recurrence supports this direction^{18,25}.

An et al. in this issue²⁶ show for the first time a close link between death anxiety as assessed by the DADDS and demoralization. The latter is characterized by feeling trapped and helpless, of having failed one's own or others' expectations, and that life is pointless looking forwards²⁷. A prospective analysis could extend An et al.'s²⁶ findings that the loss of morale may underlie death anxiety and show how both states develop over time.

Interested in why and how individuals experience different patterns of existential distress when confronted with cancer, Lo²⁸ applies Erikson's formulation of developmental conflicts. Existential themes are organized in layers that can be activated differentially by severe illness. Firstly, illness can interfere with individuals' intrapersonal "solutions" for specific developmental challenges – higher existential distress may result, for example, when

a person's sense of identity is closely linked to physical appearance and functioning (see Bickford et al.²⁹ for an illustration). Such struggle may become even more challenging in advanced disease, when a shortened life expectancy limits generativity and prompts life review. Masterson and colleagues³⁰ showed that 72% of patients with advanced cancer reported at least one aspect of unfinished business, with over half of these responses being related to family, relationships and realization of personally meaningful activities. Lo's²⁸ developmental perspective highlights how what is of meaning and value in life may be closely linked to the individual pattern of personal losses and changes.

Authors disagree about the relationship between existential and spiritual distress. Some understand spiritual distress as linked to a crisis in belief or loss of connection to a higher being³¹. Others do not see themselves as spiritual or religious, and prefer the concept of existential distress¹⁶. A practical approach could be to understand spiritual distress as one aspect of existential distress⁷.

Who is at risk for and what helps existential distress?

Regarding demographic and disease-related risk factors, a similar mixed pattern of findings has emerged for existential as for cancer-related distress in general. Women, those who are single, carry a higher symptom burden and receive less support report higher existential distress^{32,33}. Complex interactions of these factors may underlie the mixed findings across different cancer populations.

Looking deeper, we may ask "What is helpful about perceived positive social support in the context of uncertainty?" Soriano et al.³⁴ studied couples' responses to uncertainty, where the need for connectedness was high, yet not always sufficient to assuage existential treat. Health care providers were found to bolster support through person-centered care, instilling trust

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through shared decision-making, and thus lowering demoralization in patients with advanced cancer^{35, 36}.

Similarly, “what coping strategies ameliorate fear of recurrence?” Patients with a high intolerance of uncertainty and positive metacognitive beliefs about worry seem at a higher risk to engage in maladaptive behavioral processes such as avoidance, checking behaviors, and seeking constant reassurance from physicians³⁷. However, patients do not adopt the same coping responses, exemplified by Galica et al.³⁸ who found that the dimensions of the Fear of Cancer Recurrence Inventory (FCRI) did not load on a single second-order factor, indicating that the subscales, including coping strategies, should not be combined into a total fear of cancer recurrence score.

Taken together, we observe that the study of adjustment to existential challenge is in its relative infancy. Progress will likely occur with richer etiological models and application of sophisticated methods such as within-person analyses³⁴ that test hypotheses about individual adaptation mechanisms.

What is the threshold for clinically relevant existential distress?

There is no current consensus about the criteria that signify the clinical threshold at which existential distress ought to be deemed pathological. However, efforts to approach a definition are underway. A recent Delphi study suggested that fear of cancer recurrence be considered clinically problematic when (1) preoccupation with thoughts of recurrence or progression cause intense distress; (2) unhelpful coping strategies are adopted; (3) daily functioning is impaired; and (4) there is limited ability to plan for the future³⁹. Similarly, studies using interview criteria from the Diagnostic Criteria for Psychosomatic Research–Demoralization⁴⁰ report a very close association with scores on the Demoralization Scale. This is coherent with

demoralization being pathological when: (1) over a period of two or more weeks, (2) difficulty in coping with a stressor occurs, causing the person to feel trapped, helpless and unable to control or change the predicament; (3) a sense of failure results in meeting the expectations of self or others; and (4) a resultant sense of aloneness, hopelessness, or pointlessness develops due to lack of a worthwhile future. ⁴¹

The interesting overlaps between these definitions suggest that their conceptual integration could be worthwhile. One idea that would resonate well with its stressor-bound nature is to think of clinically elevated existential distress as an adjustment disorder, although criteria for the latter diagnosis have been vague and based on the clinician's judgement. The difficulty to cope, perceived incompetence to plan for the future, and impaired function with significant distress are common attributes that align with current specifications of adjustment disorder in DSM and ICD. This perspective would not understand existential distress-adjustment disorder as a "subthreshold problem" (hierarchically only diagnosed when criteria for depressive or anxiety disorders are not fully met), but a distinct entity that can be related to intense suffering. It is also coherent with the findings of Bobevski et al. ⁴², indicating a distinct and significant subgroup (13%) with moderate demoralization, significant functional impairment and increased risk for suicidal ideation. Two dominant symptom clusters of adjustment difficulty could exist: a) worried preoccupation with what could happen in an excessive attempt to control, and b) the disheartened despair about what cannot happen.

How frequent is existential distress in patients with cancer?

In the absence of consensus-based assessment standards, only preliminary data are available. Nanni and colleagues ⁴⁰ have found a frequency of 25% using the DCPR interview for demoralization, similar to one systematic review ⁴³, whereas others have found a lower

prevalence of clinically significant demoralization in the 13-18% range³³. Fear of recurrence is also high: a systematic review reported a prevalence of 49% using various criteria and instruments³². Using the brief 6-item Cancer Worry Scale, Custers et al.⁴⁴ found that half suffered from this distress, while using the Patient Dignity Inventory, Bovero et al.⁴⁵ reported one fifth distressed.

The co-morbidity of existential distress with anxiety and depression?

The clinical utility of the concept of existential distress is its differentiation from other forms of distress, although some co-morbidity with other psychiatric disorders is inevitable.

Existential distress has been distinguished from depression because a lack of pleasure and lowered mood need not be present, and from anxiety disorders because the explicit focus is on a life-threatening disease^{49,50}. Empirically, high levels of fear of recurrence were present in 13% of patients in the absence of an anxiety disorder⁵¹, and high levels of demoralization in 14% in the absence of anxiety or mood disorders⁵². Also, symptom classification studies point towards a differentiation of anhedonia and demoralization⁵³. Applying latent class differentiation, Bobevski et al.⁴² found that demoralization was present in two groups, where one had severe symptoms of anxiety and depression with high levels of demoralization (10%) and the second was characterized by moderate demoralization and low anxiety and depression (13%). These results are coherent with the idea that demoralization can occur independently, but also as a result of high levels of depression and anxiety. Self-report measures of existential distress have all demonstrated moderate to high correlations with those of depression and anxiety, typically ranging from 0.33 to 0.72⁵², comparable to the size of correlations between self-reported anxiety and depression.

The observation that many essential characteristics of existential distress are not adequately covered by current psychiatric nosology is supported by the significant subgroups of patients with moderate to high existential distress but no mental disorder. We are not pathologizing normal human experience, as some existential distress is surely part of our humanity, but rather searching for diagnostic categories that help to recognize severe and maladaptive existential states, thus empowering these patients to receive appropriate treatments.

Unrecognized existential distress mars health care outcomes

One important rationale behind the study of existential distress is that its management can reduce the risk for suicidal ideation, mental disorders, nonadherence to treatment, and low quality of death and dying. Fear of cancer recurrence has been related to lower quality of life, reduced functioning and problematic health behaviors³² and demoralization showed an independent impact on suicidal ideation beyond mood and anxiety disorders⁵².

When studying the relationship between existential distress and health outcomes, especially quality of life, researchers need to be aware of a potential item overlap between instruments. To the extent that existential distress measures include items that refer to well-being or its lack, it will not be surprising that they correlate closely with quality of life¹⁶. While some overlap with outcome measures may be unavoidable, studies should use existential distress measures based on a clear theoretical framework. The aim is to test prospectively their potential unique predictive impact on health care-relevant outcomes, while controlling for established factors such as anxiety, depression, and physical symptom burden.

How do we ameliorate existential distress?

Interventions to relieve existential pain have received much less attention than those for anxiety and depression. The two meta-analyses featured in this issue reflect substantial progress since the review by LeMay & Wilson in 2008⁹. Bauereiß et al.¹⁰ have identified 30 RCTs testing existential therapies in predominantly advanced cancer patients, including trials of Supportive-Expressive Group Therapy, Cognitive-Existential Group Therapy, Dignity Therapy, Meaning-Centered Psychotherapy, Managing Cancer and Living Meaningfully (CALM) Therapy, and the Life Review, Narrative, Hope and Meaning-Making Intervention. While significant small to moderate pooled effects on post-treatment quality of life and existential well-being have emerged for existential therapies over control conditions, effects on anxiety and depression were significant only after exclusion of four studies with baseline group differences suggesting randomization difficulties. Two recent large trials with significant small effects on depression^{54,55} were published after this analysis. All told, clear benefits arise from existentially-oriented psychotherapy.

Looking specifically at fear of cancer recurrence, Hall et al.¹¹ identified 19 studies of the efficacy of cognitive-behavioral, relaxation, mindfulness and mixed mind-body interventions. They found small to medium effects compared to control conditions that were not moderated by type of treatment. Esplen et al.⁵⁹ tested the efficacy of Supportive-Expressive Group Therapy (SEGT) for women with hereditary breast cancer, where fear of the future development if cancer is targeted. While most interventions included 6 or more sessions, Davidson et al.⁵⁶ proposed that a single session which was CBT- and telephone-based in approach could help to alleviate fear of cancer recurrence. Future work may build on what has been learned from earlier cognitive-existential approaches²⁵ and integrate CBT-skills with death anxiety interventions⁵⁷. The techniques used in effective interventions for existential concerns are heterogeneous: shared identification of meaningful activity and priorities, review of strengths, accomplishments, the life story including missed opportunities

or regrets, crafting a legacy document, open exploration of losses and death-related fears, support for uncertainty, and mentalizing death to understand and achieve a sense of mastery over what the future might hold. More study of the process of therapy and what induces change is needed.

The rareness of suicide has led to few prevention studies, yet the international take-up of medically assisted dying creates an opportunity to see if psychotherapeutic interventions can prevent the premature ending of life based on fear of the future and demoralization. Banyasz et al.⁵⁸ suggest that an existential perspective can substantially improve understanding and relieve suicidal ideation. And of course, attention to caregivers and their needs offer relief for dying patients and should always be part of existentially-oriented work⁶⁰.

Suggestions for future research

The contributions featured in this special issue reflect the current state of the art with its emerging maturity, while opening up many questions at the same time. Much more integration is needed in these studies. We believe that the link between existential stressors, adjustment processes and existential distress patterns needs further inquiry.

Clearly, a threshold for what characterizes clinically relevant existential distress needs to be established. The high correlation between existential distress constructs suggests that greater consensus is possible about diagnostic categories, which would, in turn, lead to better recognition and treatment. Such studies should be longitudinal and include diverse populations of cancer patients to enable more generalizable conclusions about the relevance of existential distress.

There are topics that have received less attention in this special issue. Although relational aspects were relevant to some studies, existential loneliness, which can result from cancer's challenges to intimacy was not studied in detail. Related experiences of not feeling connected, that no one can help, or that important things have been left unsaid are featured in several existential distress measures, but more specific data on these aspects are lacking. Furthermore, only two studies incorporated the caregiver perspective. Caregivers may experience their own existential challenges as they observe the suffering and anticipate the loss of their loved one⁶¹. Little is known about the occurrence and relevance of existential distress in caregivers of cancer patients. Moreover, cultural differences in the expression of existential needs are not well understood. Although existential concerns are universal, culture and health care systems can influence different expressions.

Conversations about existential questions can be challenging. They may activate a clinician's own death anxiety or identification with a patient's loss of morale. Yet perhaps the lack of knowledge about the nature of existential distress and how it can be managed are the most relevant barriers to any clinician's sense of self-efficacy in dealing with existential themes. We hope that this special issue may inspire progress in this promising area of inquiry to improve cancer care.

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