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Existential suffering as an indication for palliative sedation: Identifying and addressing challenges

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Guest Editorial

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The revised 2023 framework on palliative sedation from the European Association for Palliative Care (EAPC) observes "a shift towards a broader recognition of refractory existential suffering as a possible indication for palliative sedation" (Surges et al. 2023). Yet several recent systematic reviews identify unresolved questions about how existential suffering is defined, assessed, and treated in palliative care (Boston et al. 2011; Ciancio et al. 2020; Rodrigues et al. 2018). A lack of clarity and consensus on these questions is likely a barrier to the optimal care of patients with existential suffering at the end of life, as well as a source of misunderstanding and controversy with respect to the use of palliative sedation to treat refractory existential suffering (Boston et al. 2011; Ciancio et al. 2020; Kirk and Mahon 2010; Quill et al. 2009; Rattner 2022).

In a systematic review, Boston et al. (2011) identified 56 unique definitions of existential suffering. As such, it is not surprising that organizational guidelines define existential suffering in broad terms. The EAPC defines existential suffering as "feelings of hopelessness, helplessness, fear of death, disappointment, loss of self-worth, remorse, loss of meaning and purpose in life, disruption of personal identity, or loss of dignity" (Ciancio et al. 2020; Surges et al. 2023). Similarly, the National Hospice and Palliative Care Organization (NHPCO) defines existential suffering as that "arising from a sense of meaninglessness, hopelessness, fear, and regret in patients who knowingly approach the end of life" (Kirk and Mahon 2010).

Furthermore, some authors differentiate between existential suffering and existential distress. Schuman-Olivier et al. suggest that existential distress is a subtype of existential suffering that occurs in the terminally ill or dying (Schuman-Olivier et al. 2008; Surges et al. 2023). By contrast, 1 systematic review cites multiple studies that describe suffering as an "all-encompassing, enduring, and intense experience," distinct from distress as a "transient or fleeting experience" (Rattner 2022). This article preferentially utilizes the term existential suffering as a broad term that does not imply proximity to death.

Apart from the challenge of defining existential suffering, many authors have raised concerns about the inherent subjectivity and ambiguity in the evaluation of existential suffering (Boston et al. 2011; Ciancio et al. 2020; Rattner 2022; Rodrigues et al. 2018). Patients may face various barriers in expressing their suffering, including the difficulty of finding adequate words, further complicated by time-limited clinical encounters (Best et al. 2015; Boston et al. 2011). For some patients, it may be challenging to distinguish between physical suffering and categories of "non-physical" suffering such as existential, spiritual, psychological, emotional, and social (Boston et al. 2011; Ciancio et al. 2020; Rattner 2022). Two systematic reviews identify the use of multidisciplinary teams – such as those with psychological, spiritual, and biomedical expertise – as potentially helpful in assessing existential suffering (Boston et al. 2011; Ciancio et al. 2020).

Yet another issue is to determine what "refractoriness" means in relation to the use of palliative sedation to treat refractory existential suffering. The EAPC acknowledges that establishing the refractoriness of existential suffering is challenging because "the severity of the distress may be very dynamic and idiosyncratic, and psychological adaptation and coping may occur" (Surges et al. 2023). By contrast, the NHPCO considers it a still-unresolved question as to whether palliative sedation should be used to treat existential suffering, and calls for more research to explore alternative interventions (Kirk and Mahon 2010). One systematic review observes the lack of a clear theoretical framework for treating existential suffering apart from psychiatric and psychoanalytic approaches (Boston et al. 2011).

In response to these ongoing challenges, we propose the following as priority areas for research and clinical practice: (1) development and validation of instruments to guide clinicians' assessments of existential suffering; (2) study of the potential overlap and interplay between existential suffering, other nonphysical forms of suffering, and physical symptoms; and (3) development and evaluation of alternatives to palliative sedation to treat existential suffering.

Development and validation of instruments

The quest for a scale to measure existential suffering is hampered by the absence of any agreed upon definition. Nonetheless, several instruments have been developed that seem to capture aspects of what the literature typically describes under the label, "existential suffering" (Best et al. 2015; Boston et al. 2011). One of the best-known instruments to identify some aspects of existential suffering in patients with advanced illness is the Demoralization Scale (DS) (Kissane et al. 2004). Kissane et al. developed this 24-item scale to recognize patients who are demoralized but not clinically depressed. The DS identifies several domains of existential suffering, including disheartenment, loss of meaning and purpose, dysphoria, helplessness, and sense of failure. It has been externally validated in its original version as well as several shortened forms (Belvederi Murri et al. 2020; Bobevski et al. 2022; Robinson et al. 2016).

However, apart from identifying patients who experience aspects of existential suffering, the DS and its variants are not designed to prompt specific clinical interventions or referrals. Additionally, these instruments do not evaluate forms of nonphysical suffering – such as spiritual and social suffering – that may closely relate to existential suffering and even fit within some definitions of the term.

Other instruments assess for suffering or distress more broadly. The distress thermometer is a visual analog scale that allows patients to rate their emotional distress (Graham-Wisener et al. 2021; Ma et al. 2014; Roth et al. 1998). A variety of suffering scales – including the suffering pictogram (Beng et al. 2017), State Of Suffering-Five (SOS-V) (Ruijs et al. 2009), suffering assessment questionnaire (Encarnação et al. 2018), and suffering assessment tool (Baines and Norlander 2000) – capture aspects of existential suffering, yet often as part of a larger assessment of symptom burden and without emphasis on forms of nonphysical suffering. The same is true of the Memorial Symptom Assessment Scale (Portenoy et al. 1994) and the Edmonton Symptom Assessment System (Hui and Bruera 2017).

Ideally, instruments to guide clinicians' assessments of existential suffering would consider various forms of nonphysical suffering, including existential, spiritual, psychological, emotional, and social. They would also ask about patients' coping mechanisms, sources of support, and experiences with previous therapeutic interventions as an important foundation for ongoing clinical evaluation and care (Bovero et al. 2018; Xiao et al. 2021).

Study of the relationship between existential and other forms of suffering

Further complicating matters, physical and existential suffering are often knitted together tightly in patients' experiences. Cicely Saunders's concept of "total pain" emphasized the fundamental relationship between physical symptoms and forms of nonphysical suffering, which she designated as "mental distress and social or spiritual problems" (Saunders 2001). The NHPCO similarly employs a broad conception of suffering, which "can be the result of injuries to many aspects of the self, including … the physical, psychosocial, spiritual, temporal, and existential realms" (Kirk and Mahon 2010).

In addition, the 2023 EAPC framework recognizes that existential suffering includes a number of distinguishable nonphysical components (Surges et al. 2023). The framework therefore recommends that existential suffering should only be deemed refractory "following comprehensive assessment by experts in palliative care, considering the psychological, social and spiritual components of suffering" (Surges et al. 2023). In other words, assessments of existential suffering should not simply be confined to a narrow construct or definition but shloud broadly examine various and potentially related forms of nonphysical suffering.

One systematic review points out that existential suffering is sometimes understood in the literature to include spiritual, psychological, and social issues – although the literature shows no consistent pattern (Boston et al. 2011). Another systematic review contrasts Saunders's and Cassell's view of "suffering" as integrated and multidimensional with the tendency across multiple studies "that researchers, patients and clinicians distinguish physical from nonphysical aspects of suffering" (Rattner 2022).

Considering this heterogeneous literature, it is imperative for future studies to explore and characterize the potential overlap and interplay among the various nonphysical forms of suffering, as well as the relationship between physical and nonphysical suffering. Otherwise, the conditions for designating a patient's existential suffering as "refractory" will remain ill-defined and controverted.

Alternatives to palliative sedation for existential suffering

It is often recommended that palliative sedation only be undertaken as a last-resort option, but few studies have explored potential alternatives to palliative sedation. The strongest evidence for treating patients with existential suffering at the end of life comprises various forms of psychotherapy (Bauereiß et al. 2018; LeMay and Wilson 2008; Vehling and Kissane 2018). Several of these approaches have demonstrated effectiveness in randomized controlled trials, including meaning-centered group psychotherapy (Breitbart et al. 2015) and individual meaning-centered psychotherapy (Breitbart et al. 2018), which improved spiritual well-being and quality of life and reduced desire for hastened death; dignity therapy, which improved quality of life and sense of dignity (Chochinov et al. 2011); and Managing Cancer and Living Meaningfully (CALM), which alleviated depressive symptoms and improved end-of-life preparation (Rodin et al. 2018). Additional randomized controlled trials are currently underway, including a study involving Meaning and Purpose therapy (Kissane et al. 2019).

More broadly, the effects of spiritual, psychosocial, and mind–body interventions for patients with life-limiting illness have been the subject of systematic reviews and meta-analyses (Hall et al. 2018; McLouth et al. 2021; Oh and Kim 2014; Park et al. 2019; Xing et al. 2018). Overall, these analyses are limited by the heterogeneity of the literature reviewed – for instance, 2 meta-analyses of spiritual interventions for patients with cancer combined psychotherapy interventions with nursing- and oncologist-driven spiritual interventions in their statistical analyses (Oh and Kim 2014; Xing et al. 2018). Future research is needed to explore the potential effectiveness of interventions other than forms of psychotherapy, including meditation and relaxation techniques (Hall et al. 2018).

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Regarding pharmacologic treatments, there is a growing interest in the potential benefit of ketamine and other psychedelics for the treatment of existential suffering (Decazes et al. 2023; Niles et al. 2021; Schimmers et al. 2022). However, a stronger evidence base involving larger, high-quality studies is still needed before these approaches can be recommended for clinical use (Niles et al. 2021; Schimmers et al. 2022).

As the evidence grows for alternatives to palliative sedation for patients with existential suffering, a clear framework is needed to guide clinicians as they consider treatment options for their patients (Boston et al. 2011). Greater development and availability of methods to relieve existential suffering in a timely and safe manner may reduce the number of cases in which existential suffering is considered "refractory" (Surges et al. 2023).

Conclusion

Improving the care of patients with existential suffering in palliative care requires better instruments to evaluate existential and other nonphysical forms of suffering, a greater understanding of the potential overlap among various forms of suffering, and the continued development of alternatives to palliative sedation. Greater clarity and capability regarding approaches to existential suffering may change the conversation about whether and when palliative sedation is indicated for these patients.

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