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Case Report

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Expression of existential suffering in two patients with advanced cancer in an acute palliative care unit

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Abstract

Background. Recognizing and managing existential suffering remains challenging. We present two cases demonstrating how existential suffering manifests in patients and how to manage it to alleviate suffering.

Case description. Case 1: A 69-year-old man with renal cell carcinoma receiving end-of-life care expressed fear of lying down "as he may not wake up." He also expressed concerns of not being a good Christian. Supportive psychotherapy and chaplain support were provided, with anxiolytic medications as needed. He was able to express his fear of dying and concern about his family, and Edmonton Symptom Assessment System scores improved. He died peacefully with family at bedside. Case 2: A 71-year-old woman presented with follicular lymphoma and colonic obstruction requiring nasogastric drain of fecaloid matter. Initially, she felt that focusing on comfort rather than cure symbolized giving up but eventually felt at peace. Physical symptoms were well-controlled but emotionally she became more distressed, repeatedly asking angrily, "Why is it taking so long to die?." She was supported by her family through Bible readings and prayers, but she was distressed about being a burden to them. An interdisciplinary approach involving expressive supportive counseling, spiritual care, and integrative medicine resulted in limited distress relief. Owing to increasing agitation, the patient and family agreed to titrate chlorpromazine to sedation. Her family was appreciative that she was restful until her death.

Conclusion. Existential suffering manifests through multiple domains in each patient. A combination of pharmacologic and non-pharmacologic techniques may be needed to relieve end-of-life suffering.

Introduction

Existential suffering can often manifest itself in patients with advanced illnesses (Lichtenthal et al., 2009; Steinhauser et al., 2017). Recognizing existential suffering as distinct from other similarly presenting conditions, such as depression, can be challenging in the clinical setting due to multiple definitions in the literature and the absence of a specific category in Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (Yalom, 1980; Boston et al., 2011). The authors state that there can be a duality of definitions because existential suffering is related to spiritual suffering (Boston et al., 2011). Despite this challenge, four domains have been defined through which existential suffering can be expressed: mortality, freedom, meaninglessness, and isolation (Strang et al., 2004; Grech and Marks, 2017a). Mortality is defined as one's awareness of death and a wish to continue to live; freedom is the reality that choices in life have consequences and encompasses unresolved conflicts with one's self or others; meaninglessness is difficulty finding the meaning of life when faced with the inevitability of death; and isolation is defined as the feeling of isolation from a larger community (Grech and Marks, 2017a).

The assessment of existential distress can be challenging due to the various ways it can be expressed (Boston et al., 2011). Incorporating clinical instruments, such as the Edmonton Symptom Assessment System–Financial Distress and Spiritual Pain (ESAS-FS), may provide clues to the presence of existential distress (Bruera et al., 1991; Delgado-Guay et al., 2016). The management of existential distress includes a variety of psychotherapeutic modalities including meaning-centered psychotherapy, dignity therapy, and supportive-expressive group therapy (Frankl, 1952; Breitbart et al., 2004; Grech and Marks, 2017b). By promoting open-ended discussions and exploring meaning, the goal of the therapies is to restore patients' ability to maintain awareness and appreciate their value and purpose (Breitbart et al., 2004).

Herein, we review the course of events that occurred in the hospitalization of two patients in an acute palliative care unit (APCU) in a comprehensive cancer center. We aim to explore

how the overarching theme of existential suffering manifested itself through the aforementioned domains, and the modalities employed to manage the symptoms of each patient.

Case descriptions

Case 1

A male in his 60s with an advanced solid tumor metastatic to the lungs that progressed despite multiple lines of cancer treatment presented to the emergency room due to shortness of breath. The patient had frequent hospitalizations for dyspnea and weakness due to progressive illness and recurrent malignant pleural effusions. The patient and his primary oncologist had decided that he would pursue only comfort measures for his treatment after admission, and he was transferred to the APCU for symptom management. His dyspnea, delirium, pneumonia, sodium, and renal function levels improved upon transfer to the APCU.

Despite the improvements in the patient's physical condition, the APCU interdisciplinary team had a difficult time communicating with him because his interaction with the team was characterized by one-word responses and lack of eye contact. Additionally, the patient refused to lie in bed and instead, spent days and nights in his recliner. The patient's work-up did not demonstrate organic brain disease, including metastatic disease to the brain, and the psychosocial team's evaluation of the patient determined that he did not have any underlying comorbid psychiatric illness. Despite his lack of engagement with the team, continuous supportive psychotherapy and spiritual care were provided. Through counseling, the patient eventually expressed significant fear of death and the dying process, including anxiety about what would happen to him during the dying process and after death. He described his fear of being in pain and feeling breathless, as well as a "dark ring" closing around him, reflecting his history of claustrophobia. He worried that if he went to sleep, he would not wake up again, which explained the reason why he did not want to lie in the bed to sleep in the APCU. Additionally, he was disturbed by his worsening generalized weakness and progressive inability to move his legs (his wife had become paraplegic prior to her own death).

Although the patient had strong family support, he was concerned that his adult children were not close as a family. Spiritually, he identified himself as a Christian but felt that he was not a "good" Christian because he was not attending church regularly. Although his minister tried to help, he expressed that it was "between him and God" and that he hoped that "the Lord would forgive him of his sins."

Unfortunately, his respiratory status declined and he died four weeks after his admission to the APCU. His family expressed gratitude that he appeared comfortable and peaceful at his death.

Case 2

A female in her 70s with a recurrent hematologic malignancy presented to the hospital for fatigue and renal failure. Her hospitalization was complicated by the following: large bowel obstruction, hydronephrosis requiring ureteral stent placement, acute gastrointestinal bleeding, and chronic electrolyte abnormalities. After discussion with the medical teams, the patient and family decided to focus on comfort care without any additional aggressive interventions. Initially, she felt that focusing on comfort rather than a cure symbolized giving up, but eventually she felt at peace with their decision. She was transferred to the APCU for symptom control and end-of-life care one month after hospital admission.

During the patient's stay in the APCU, her physical symptoms were controlled through opioid adjustments for pain control and placement of a nasogastric tube to relieve her nausea. However, she appeared to have increasing emotional and spiritual distress even with constant support from her family, friends, and church community. She did not have any metastatic disease to the brain, nor did she have any comorbid psychiatric conditions as confirmed by the psychosocial team.

The patient became increasingly frustrated and repeatedly expressed angrily, "Why is it taking so long to die?" and "Why am I still here? I'm ready to die." She reiterated her faith in God and would tearfully state that she was ready for God to take her. Being connected to multiple tubes and lines and not being able to get out of bed or her room was another source of distress.

An interdisciplinary approach involving expressive supportive counseling, spiritual care, and integrative medicine resulted in limited distress relief. The integrative medicine team provided interventions for muscle tension pain, shortness of breath, and anxiety. Due to increasing uncontrolled anxiety and episodes of panic attack combined with existential suffering, the patient and family agreed to titrate chlorpromazine to provide sedation in an attempt to control severe restlessness. A sedation respite was conducted two days later, but the patient remained angry about her continued existence. Medication was adjusted to provide comfort thereafter. Her family expressed gratitude that she was restful until her death two weeks after transfer to the APCU.

Discussion

These two cases illustrate the continuum that existential suffering can encompass and the various management techniques that can be used to aid in its relief. Both patients also benefitted from receiving care in an APCU that utilized focused symptom management and psychosocial interventions via an interdisciplinary team approach. APCUs have been shown to help patients who have a high symptom burden, including physical and psychosocial distress, and to help facilitate the discharge of these patients back to the community (Rigby et al., 2008; Shin et al., 2014).

In the case of our first patient, the existential domains of mortality and isolation were present. The domain of mortality was manifested in frequent questions and anxiety regarding pain and suffering that would occur in the dying process and refusal to lie down, as he feared passing in his sleep (Yalom, 1980). In respect to the domain of isolation, the patient had difficulty expressing his concerns about his death and the well-being of his family out of concern for his perceived lack of unity among his children after his death. Our measure of improvement in this patient was that he was able to open up about his thoughts and feelings regarding the suffering that he was experiencing.

Our second patient was ready for death to occur and became very distressed when this process was not happening as quickly as she wished. Her experience can be categorized into the domain of meaninglessness. She had lost her identity and role in her family as the primary caregiver. The titration of sedating medication was agreed upon to reduce patient and family distress only after all other measures failed.

The identification and quantification of the severity of existential distress offer unique challenges to the care team (Kelly et al., 2006). Screening for spiritual/existential distress, identifying

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spiritual needs, and facilitating appropriate spiritual care throughout the continuum of care is fundamental in our daily care for patients living with advanced illnesses, as spiritual pain might increase the expression of physical and psychosocial symptoms (Delgado-Guay et al., 2016). The interdisciplinary palliative care model of spiritual care encourages us to integrate the spiritual domain in the overall screening and history-taking process, as well as to conduct a full spiritual assessment by a professional chaplain as needed (Puchalski et al., 2014; Ferrell et al., 2018). There is a high prevalence of spiritual needs and concerns among patients facing life-threatening diseases along with their caregivers, particularly among ethnic minorities, and even among patients who do not consider themselves religious or spiritual (Alcorn et al., 2010; Delgado-Guay et al., 2011; Delgado-Guay, 2014).

Conclusion

Existential suffering may occur more often than is normally recognized. Current literature reports the use of psychotherapeutic techniques and spiritual care to help manage the patient's suffering, followed by pharmacologic management if refractory (Morita, 2004; Kissane, 2012; Vehling and Kissane, 2018). Further research is needed to understand, recognize, and treat existential suffering and distress in patients who are terminally ill.

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