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Addressing existential suffering

Physicians can feel better equipped to deal with a dying patient's emotional experience by considering some relevant contributions of existential philosophers and being aware of possible interventions, including manualized therapies.

ABSTRACT: Existential distress is often present in terminal illness and may be associated with syndromes such as depression, anxiety, and desire for hastened death. Physicians with expertise in managing physical pain may feel unequipped to address social, psychological, and spiritual aspects of pain. Through a brief exploration of the foundations of existentialism and existential psychotherapy, this article aims to demystify existentialism and provide practical tips for addressing existential suffering, even in parents and children with terminal illness. Formalized interventions that assist patients with existential issues are recommended. Physicians are encouraged to get support in exploring domains that they may feel are outside their scope of practice, such as spirituality, and encouraged to adjust boundaries in the doctor-patient relationship in palliative care settings. With the aid of a physician who addresses existential suffering, it is possible for patients to transition from feeling hopeless to feeling more alive than ever.

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"It feels as though I'm traveling further and further into a cave that's getting darker and narrower, and there's no way to go back."

Patients with terminal illness express existential suffering and spiritual distress in a number of different ways. Hearing a patient say the words above, a physician may feel paralyzed or poorly equipped to respond. What can you really say when a patient has a progressive terminal illness? There is no denying the illness, and no denying the patient's experience of it. However, the feelings of dread, powerlessness, and loss of control that a physician may experience on hearing these words can be used to help the patient. Experiencing these emotions shows our capacity to understand or perceive some of what our suffering patients are feeling. Though initially difficult for us to experience, these feelings can become a guide to what a patient needs help with.

Foundations of existentialism and existential psychotherapy

Existentialism is something we have usually heard of, but few of us know much about. And lots of us feel intimidated by the term because we do not really understand what it means. It sounds like something we might have studied at university if we had not been so busy taking all the medical school prerequisites. Fortunately, a physician does not need to be a philosophy major to understand the core concepts of existentialism and use that understanding in the care of patients.

Clearly, talking to patients about death is key to helping them cope with anxiety about it. By taking something as nebulous as death and discussing it in more concrete terms in regular conversation, we can make death less frightening and unpredictable for our patients. And in that same spirit, by considering some relevant contributions from a few existential philosophers and thinkers, we can feel better equipped to do this.

Kierkegaard

Søren Kierkegaard is widely regarded as the father of existential philoso-

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phy.[1] His work often focused on personal choice and commitment, and how everyone lives as a "single individual."[2] Kierkegaard also explored the emotions of people making significant life decisions, and certainly there can be often a number of these to make at the end of life in a modern medical system.

Martin Heidegger extended Kierkegaard's idea of living as a single individual to dying as a single individual, proposing that death is an entirely personal experience that must be taken on alone.[3] Patients do sometimes experience a new and distressing sense of aloneness at the end of life, knowing that nobody is going to share this specific experience with them. The feeling of being the only one who can make choices about how to live out final days can be overwhelming.

While some at the end of life take great comfort from their faith, others may find their unfortunate circumstance cause them to question it. Kierkegaard theorized that there is no faith without uncertainty or doubt.[4] He described how faith is not required to believe in something tangible like a chair, but is necessary to believe in something for which there is little or no evidence. In other words, faith is required when there is significant uncertainty or doubt, and without uncertainty or doubt there may be little role for faith. The concept of a "leap of faith" originates in Kierkegaard's writings, although he does not use this exact phrase. One can suggest to a patient that fear centred on uncertainty surrounding death is common and that the doubt they are feeling may actually be an opportunity to strengthen their faith rather than to abandon it. While not directly related to Kierkegaard's ideas, another potentially comforting aspect of uncertainty is that it means you have wiggle room or flexibility and that nothing is set in stone.

Nietzsche

Friedrich Nietzsche is intimately associated with the concept of nihilism, which in turn is related to existential nihilism—the idea that life has no meaning or purpose. Patients at the end of life may experience a kind of existential nihilism and say that their existence has been meaningless or that there is no longer any point in being alive. Nietzsche argued that our primary driving force is not meaning or happiness, but rather the "will to power" or pursuit of high achievement and reaching the best possible position in life.[5] If this is our primary driving force, it is understandable that patients who have had great success in their careers or other pursuits may feel there is no longer any purpose to their existence once they are seriously ill.

Although it may be a manifestation of depression or some other modifiable condition, existential nihilism is a concept that great minds have either supported or struggled with, and one that is not easy to dismiss out of hand. However, there are certainly alternate views that may facilitate a patient's leap of faith to a more comfortable opinion.

Sartre

Jean-Paul Sartre argued that "existence precedes essence"[6] and that it is not until we have engaged with life and done things that we can look back and see our "essence" reflected in what we have done. At the end of life, patients may feel they are returning to mere existence. Sartre even suggested that death results in us existing only to the outside world, leaving evidence of a uniquely individual experience of existence that is no longer present. The thought of retreating from essence to existence only to others could certainly be a frightening one. In contrast, Sartre also wrote about needing to experience "death consciousness"[7] in order to discover what is really important in life, and patients sometimes describe this as a kind of "silver lining" to being terminally ill. Unfortunately, this can also be experienced as a terrible realization that much of life was not spent on what the patient now views as most important.

Frankl

Viktor Frankl was an Austrian psychiatrist who spent 3 years in Nazi concentration camps. In contrast to Nietzsche's "will to power," Frankl maintained that "will to meaning" is the primary driving force of human behavior. His experiences in the concentration camps are described in his book *Man's Search for Meaning,*[8] which confirms his belief that meaning can be found in any situation, even in great suffering. He theorized that finding meaning in difficult situations gives us the will to continue living through the worst of circumstances. Frankl's ideas are now being applied in modern evidence-based psychiatric interventions for patients with advanced cancer as meaning-centred psychotherapy.[9,10]

Yalom

Irvin Yalom has written extensively on existential psychotherapy,[11] where psychiatric symptoms or inner conflicts are viewed as the result of difficulties in facing what he describes as the four "givens" of human existence: mortality, meaninglessness, isolation, and freedom. Existential psychotherapy focuses on identifying which of these existential givens patients are struggling with and helping them to respond in positive ways. Certainly, acute appreciation of one's mortality, disconnection from meaning, feelings of isolation, and uncomfortable freedom in making difficult choices can all play a significant role in existential suffering at the end of life.

What is existential suffering?

If you are still not sure how to define existential suffering, you are not alone. In a review of existential suffering in the palliative care setting, Boston and colleagues[12] reviewed 64 papers and found 56 different definitions. Themes common to the descriptions of existential suffering included lack of meaning or purpose, loss of connectedness to others, thoughts about the dying process, struggles around the state of being, difficulty in finding a sense of self, loss of hope, loss of autonomy, and loss of temporality.

Cicely Saunders introduced the concept of total pain, which encompasses physical, social, psychological, and spiritual suffering.[13] Spiritual factors (e.g., belief in life after death), psychological factors (e.g., sense of self), and social factors (e.g., connectedness to others) can easily be seen in the descriptions of existential issues listed above, so perhaps existential suffering is best thought of as distress within these three spheres of total pain. However, it is important to note that the divisions between these different sources of pain are artificial as all three spheres are connected. For instance, we have all had the experience of physical pain being exacerbated by emotional context (e.g., hitting your head on something in the middle of a frustrating day). It is also wrong to imagine we can treat any of these spheres in isolation. Opiate medications for physical suffering, for example, have significant psychological effects. An important corollary to this is that addressing social, psychological, and spiritual pain is likely to affect a patient's experience of physical pain as well.

What is the physician's role in the face of spiritual distress?

Looking at social, psychological, and spiritual suffering, spiritual distress is likely to be viewed as the most remote from a physician's core training. Many equate spirituality with religion and, understandably, physicians are reluctant to discuss religions they may know little about. Physicians are about half as likely as patients to hold a particular spiritual belief.[14] Even if a physician follows a religion, he or she might be concerned about being intrusive,[15] and some guidelines for communicating with patients about spiritual issues caution against discussing your own religious beliefs, stating they are generally not relevant.[16] However, it is possible to bring wisdom from the world's major religions into therapeutic discussions about illness and death without intrusively promoting a particular faith. It is always helpful to know what a patient's spiritual beliefs are, and questions based on the FICA spiritual history tool[17,18] can help you do this (see the **Table**).

Although one could argue it is a religious leader's role, and not a physician's, to discuss spiritual or religious matters with a patient at the end of life, an equally strong argument could be made in support of a role for the physician by posing questions about training: What exactly is the training religious leaders receive to provide this kind of care? Is their training accredited in some way or based on evidence of effectiveness? Do religious leaders know more than palliative care specialists? These questions are posed here not to diminish the important role of religious leaders (some of whom do have specialized training in working with dying patients) in caring for patients at the end of life, but rather to suggest that physicians' knowledge and training should make them confident that they, too, have something to offer. In Boston and colleagues'[12] summary of how existential suffering is defined in the literature, many of the definitions focus on meaning and purpose, and these are concepts for which modern evidence-based medical interventions have been developed.[9,10]

Central to whatever role physicians play when helping patients deal with spiritual distress is the need for adequate support. Feelings such as sadness, isolation, inadequacy, or hopelessness can be experienced by physicians caring for seriously ill patients, and it is important for physicians to seek help for themselves. A concept discussed in psychotherapy supervision is parallel process, whereby issues that arise between a patient and a therapist are mirrored in the interactions of the therapist and the therapist's supervisor. This and other evidence shows that phy-

Table. Questions based on the FICA spiritual history tool to help physicians address issues of faith and belief with patients.

Faith and belief	"Do you consider yourself spiritual or religious?" "Do you have spiritual beliefs that help you cope with stress/difficult times?" "What gives your life meaning?"
Importance	"What importance does spirituality have in your life?" "How has your spirituality affected your experience of this illness?"
Community	"Are you part of a spiritual community?" "Does this community provide you with support?" "Can you reach out for help?"
Address in care	"How would you like me to address spiritual issues in your health care?"

sicians need connectedness and support to cope with their own existential distress.[19] In addition, providing the best possible care to dying patients generally involves recruiting assistance from others when that luxury is available. Just as with other kinds of clinical challenges, it is always a good idea to seek advice from peers who have likely had similar experiences. In larger centres, palliative medicine, psychiatry, social work, and spiritual care are all services to consider involving in a dying patient's care. In Canadian hospitals, most spiritual care providers are associated with the Canadian Association for Spiritual Care and are experts in supporting an individual patient's spiritual beliefs without promoting any of their own. Some hospitals also have a professional ethicist or ethics team to help with ethical dilemmas.

How can physicians address existential suffering?

As summarized by LeMay and Wilson,[20] existential suffering is associated with a number of clinical issues, including reduced quality of life, increased anxiety and depression, suicidal ideation, and desire for hastened death. Recognizing existential suffering can therefore alert us to the likely presence of symptoms we can address. Anxiety, depression, suicidal ideation, and desire for hastened death are addressed regularly by physicians (particularly psychiatrists) in other settings, and there is good evidence that our interventions work in the palliative care setting as well. For example, Holland and colleagues[21] showed that both fluoxetine and desipramine were effective in treating depression and improving quality of life in women with advanced cancer. Psychotherapeutic interventions such as cognitive-behavioral therapy (CBT), which is used routinely to treat depression and anxiety, can also be effective in treating terminally ill patients. For example, patients with serious illness sometimes describe a complete loss of identity, a problem that can be addressed using CBT to help patients identify this generalization or "all-or-nothing" thinking and aid them in recognizing core parts of themselves that remain unchanged. Depression and hopelessness have been found to be the strongest independent predictors of desire for hastened death in terminally ill patients[22] (stronger than poor physical function), and these are also both symptoms physicians can address.

As well as alerting us to the possible presence of clinical issues, existential suffering sometimes presents as another symptom. For example, if a patient with serious illness begins complaining of new-onset insomnia, a clarifying statement and question can elicit further information: "Sometimes people are afraid they're not going to wake up. Is that something you worry about?" Answers will often provide evidence of anxiety and existential suffering that require a broader approach and more than an order for zopiclone.

Assisting with patient loss of identity

Loss of identity or a defining role in life is a common part of existential suffering. Assisting patients to see that many things (possibly core values, relationships, interests, skills) have not been changed by their diagnosis can be very therapeutic. For example, a father who feels he is no longer fulfilling his role as a parent because his illness prevents him from playing catch with his son can benefit from being educated about how he is fulfilling another role: modeling for his son how to get through an extremely difficult experience. By demonstrating how to maintain relationships and recruit support, a parent provides an invaluable lesson for a child. Some parents also like to create legacy projects for their children, such as writing cards for each birthday up to a particular age. Older parents are often concerned about burdening adult children with having to care for them. They are used to giving rather than receiving care and the role reversal can be quite upsetting. In these cases an older parent can benefit from knowing that allowing adult children to pay back just a small

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fraction of the care they have received over many years helps them with their own feelings and ability to cope. There are clearly exceptions, but in general parents tend to speak highly of their children and enjoy telling clinicians about their children's positive attributes. "Where did they get that from?" is a simple, yet often very effective question for helping parents reflect on positive things they have passed on to their kids.

Children with terminal illness are another unique population. Adults' praise of children frequently involves telling them about what they are capable of achieving. Children may lose their sense of self-worth if they know there is nothing they can become as an adult.[23] How to best address existential concerns in children depends strongly on developmental stages.[24]

Supporting family members

Family members experience distress and require support as well. We all internalize aspects of our parents, and when a parent is dying both young and adult children may feel a core part of themselves or their life is dying. Related to children feeling that their purpose or worth is in "becoming" something to please encouraging adults, children may feel a loss of identity or purpose with a parent's death. Similarly, family members often grieve not only the loss of their loved one, but also the loss of their caregiving role, especially if the person has been ill for a long time. Educating family members about how common these feelings are and letting them know that these feelings will generally become less painful over time can reduce distress. In expressing condolences to family members, we commonly say something like "I'm sorry for your loss" or "This must be very difficult" to convey empathy. Following up such statements by asking "Who's supporting you right now?" communicates a greater impression that you care about how they are going to cope with their grief.

Adjusting boundaries

Holding a patient's hand for any length of time would be a boundary violation in many medical settings, particularly for psychiatrists who tend to avoid touching patients at all. Yet given that loss of connectedness to others is such a common theme in definitions of existential suffering, few things are more therapeutic than holding the hand of a dying patient who is otherwise alone. Similarly, placing a gentle hand on a patient's shoulder as you arrive or as you leave the bedside can communicate a connectedness or caring that might be difficult to convey appropriately in words. Best practice is always to observe appropriate boundaries in the doctor-patient relationship, but there is good reason to shift these boundaries in some palliative care settings.

Using formalized interventions

Formalized interventions include meaning-centred psychotherapy, an intervention developed at Memorial Sloan Kettering Cancer Center and aimed at helping patients with advanced cancer reconnect with experiential, creative, attitudinal, and historical sources of meaning;[9,10] Dignity therapy, created by Harvey Chochinov and colleagues in Winnipeg;[25] and Managing Cancer and Living Meaningfully (CALM) psychotherapy, developed by Gary Rodin and colleagues in Toronto.[26,27] LeMay and Wilson present a review of other manualized therapies for existential distress.[20]

Helping patients find a silver lining

Many dying patients see their newfound realization about being alive and knowing how they want to spend their time as a silver lining to a diagnosis of terminal illness. Unfortunately, this is sometimes paired with guilt or remorse related to a sense of not having spent their time well up to that point. Some patients may also feel there is now no opportunity for anything other than dying because of the large amount of time they "wasted." Helping patients with existential suffering realize they are still alive is often key. Some argue that hope is an act rather than a feeling. Children generally have a remarkable way of achieving hopefulness on their own. Youth in hospice generally have the same desires and interests as other young people, such as wanting to make friends and being interested in sex.[28]

As children, we develop an understanding of death-related concepts, including universality (all living things die), irreversibility (once dead, dead forever), nonfunctionality (all functions of the body stop), and causality (what causes death). Perhaps a new application of these concepts to the patient's own situation is what can lead to a sense of opportunity—that silver lining—rather than existential suffering. Patients with terminal illness know they are not a unique exception to universality, and they often know what is going to kill them (a personalized causality). They are also likely experiencing irreversible physical deterioration (nonfunctionality). They have fallen into the same cave as everyone else, it is getting darker and narrower as time goes by, and they even know what unfortunate companion is pushing them along. Hopefully, they can also realize they are still free to explore some of the cave's more beautiful features, to draw or write on the walls, to show courage in exploring some of the uncharted alcoves, and

to map out some of the more treacherous terrain for others who will follow.

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Competing interests

None declared.

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