

Aging Meaningfully: The Ethics of Existential Suffering for Older Adults in Healthcare

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Résumé de l'article

La souffrance existentielle (SE) peut être particulièrement répandue chez les personnes âgées et compte tenu du vieillissement croissant de la population canadienne, la prise en compte de la SE dans les soins aux personnes âgées sera une préoccupation urgente dans les années à venir. La SE est un effet secondaire du vieillissement qui implique la perte de sens, d'identité personnelle, d'autonomie et d'espoir. Cet article se concentre sur l'une des causes de la SE chez les personnes âgées, à savoir la perte de sens (PS). Le sens devient de plus en plus nécessaire au bien-être à un stade avancé de la vie, en raison des effets positifs qu'il confère à l'humeur, à la santé et à la longévité. Je soutiens que lorsque la PS survient dans un contexte de soins de santé, les prestataires de soins de santé (PSS) ont le devoir 1) de comprendre la SE et la PS et 2) de répondre aux adultes plus âgés qui ont de la SE en raison de la PS. Les PSS peuvent ne pas être en mesure de soulager la SE ou la PS, mais ils sont obligés de faire une tentative raisonnable. Pour justifier cela, je m'appuie sur trois valeurs fondamentales des soins de santé : la *confiance*, la *compassion* et la *bienfaisance*. En réfléchissant à chacune de ces valeurs, il devient évident que la SE et la PS méritent l'attention des PSS. En plus de cet argument, je reconnais que la SE ne se limite pas à la vieillesse et qu'il n'incombe pas uniquement aux PSS de s'en préoccuper. Des facteurs sociaux plus larges et des initiatives de santé publique peuvent aider les personnes à tous les stades de la vie à préserver le sens. En sensibilisant les PSS à la SE dû à la PS, cet article fournit également une liste non exhaustive de trois psychothérapies qui méritent d'être explorées ou mises en oeuvre pour les patients souffrant de SE dû à la PS, à savoir : La psychothérapie en soins palliatifs, la psychothérapie de groupe centrée sur le sens et la thérapie de la dignité.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

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Gabrielle Tsai^a

Résumé

La souffrance existentielle (SE) peut être particulièrement répandue chez les personnes âgées et compte tenu du vieillissement croissant de la population canadienne, la prise en compte de la SE dans les soins aux personnes âgées sera une préoccupation urgente dans les années à venir. La SE est un effet secondaire du vieillissement qui implique la perte de sens, d'identité personnelle, d'autonomie et d'espoir. Cet article se concentre sur l'une des causes de la SE chez les personnes âgées, à savoir la perte de sens (PS). Le sens devient de plus en plus nécessaire au bien-être à un stade avancé de la vie, en raison des effets positifs qu'il confère à l'humeur, à la santé et à la longévité. Je soutiens que lorsque la PS survient dans un contexte de soins de santé, les prestataires de soins de santé (PSS) ont le devoir 1) de comprendre la SE et la PS et 2) de répondre aux adultes plus âgés qui ont de la SE en raison de la PS. Les PSS peuvent ne pas être en mesure de soulager la SE ou la PS, mais ils sont obligés de faire une tentative raisonnable. Pour justifier cela, je m'appuie sur trois valeurs fondamentales des soins de santé : la *confiance*, la *compassion* et la *bienfaisance*. En réfléchissant à chacune de ces valeurs, il devient évident que la SE et la PS méritent l'attention des PSS. En plus de cet argument, je reconnais que la SE ne se limite pas à la vieillesse et qu'il n'incombe pas uniquement aux PSS de s'en préoccuper. Des facteurs sociaux plus larges et des initiatives de santé publique peuvent aider les personnes à tous les stades de la vie à préserver le sens. En sensibilisant les PSS à la SE dû à la PS, cet article fournit également une liste non exhaustive de trois psychothérapies qui méritent d'être explorées ou mises en œuvre pour les patients souffrant de SE dû à la PS, à savoir : La psychothérapie en soins palliatifs, la psychothérapie de groupe centrée sur le sens et la thérapie de la dignité.

Mots-clés

souffrance existentielle, personnes âgées, perte de sens, démoralisation, soins palliatifs, thérapie de la dignité, éthique clinique

Abstract

Existential suffering (ES) can be particularly prevalent among older adults, and with Canada's growing aging population, addressing ES in senior care will be a pressing concern in coming years. ES is a side effect of aging that involves losing meaning, self-identity, autonomy, and hope. This paper focuses on one cause of ES among older adults, namely, the loss of meaning (LoM). Meaning becomes increasingly necessary for well-being at later stages in life, due to the positive effects it confers on mood, health, and longevity. I argue that when ES arises in healthcare settings, healthcare providers (HCPs) have a duty to 1) understand ES and LoM and 2) respond to older adults who experience ES because of LoM. HCPs may not be able to alleviate ES or LoM, but they are obliged to make a reasonable attempt. To justify this, I draw upon three fundamental values in healthcare: *trust*, *compassion*, and *beneficence*. By reflecting on each of these values, it becomes clear that ES and LoM deserve attention from HCPs. In addition to making this argument, I recognize that ES is not only limited to old age nor solely incumbent on HCPs to address. Broader social factors and public health initiatives can help people at all life stages to preserve meaning. In raising awareness in HCPs about ES due to LoM, this paper also provides a non-exhaustive list of three psychotherapies that deserve exploration and/or implementation for patients suffering from ES due to LoM, namely: Palliative Care Psychotherapy, Meaning-Centred Group Psychotherapy, and Dignity Therapy.

Keywords

existential suffering, older adults, loss of meaning, demoralization, palliative care, dignity therapy, clinical ethics

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INTRODUCTION

Canada's growing aging population will require more attention and investment in senior care. By 2030, nearly one-quarter of the Canadian population will be older adults (1). Many older adults suffer compounded losses as part of the aging process, such as losing their physical abilities, cognitive function, independence, and the presence of their loved ones. They may also experience negative stigma and stereotypes associated with aging, especially when aging is viewed as a disease as opposed to a natural process of life (2). Those who live with these multi-dimensional losses may experience a pressing side effect, namely, existential suffering (ES). ES is an embodied negative experience that involves losing meaning, self-identity, autonomy, and hope. In this paper, I focus on one cause of ES, the loss of meaning (LoM).

As healthcare aims to promote health and alleviate suffering, it is imperative that healthcare providers (HCPs), especially interprofessional teams, assist patients to regain meaning. The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (3). Since mental well-being is a critical factor for overall well-being, ES is addressed here as a health concern that can lead to mental illnesses and demotivate patients from trying to maintain or improve their health. To address ES for older people, it is necessary to conduct

a deep investigation of the various components that may contribute to ES. More specifically, my focuses will be on cases where one factor, the LoM, may negatively affect psychological well-being or exacerbate pre-existing illnesses.

As a disclaimer, it is crucial to note that LoM is not always a medical matter, nor is it only experienced by older adults. So I am not suggesting that older adults must connect with HCPs whenever they have existential questions related to LoM. And some older adults do not experience ES at all. Further, ES and LoM are not limited to old age: it is present at every age and may occur due to disability in children caused by birth defects; in teenagers experiencing addiction, bullying, and failures; and in adults living through illness, unemployment, and divorce.

Even though individuals at any stage in life may experience existential suffering, I will focus on the older population since they are more vulnerable to harm associated with experiencing ES and LoM. I recognize the risk of focusing on ES in older adults in healthcare, as it can lead to ageist biases that only older adults have a lower sense of meaning and medicalize the problems they face when LoM and ES are not exclusively medical issues. Nevertheless, older adults are a marginalized population that could receive decreased quality of care; for instance, some treatment options are seen as futile for older adults, but they have been shown to be effective in terms of improved health and cost-benefit (4). Suicide is a heightened risk for older adults with ES, and older adults have the highest rates of death by suicide in most regions of the world (5). This is likely because some of the common drivers of suicide – chronic illness, functional disability, and social isolation – become more acute towards the end of life (6). So, considering that suicide prevention is a global health priority, we should look at equitable ways to help older adults. This paper assumes that helping older adults maintain a sense of meaning will reduce suicide ideation and collateral threats to well-being when they struggle to see the point in living. But overall, HCPs should aim to provide equitable care for people of all ages who experience LoM and ES.

I also resist the claim that HCPs are the only ones responsible for addressing ES. Since healthcare is now mostly socialized and industrialized, managed by governments and insurance companies, these stakeholders of healthcare also share the responsibility to prevent and ameliorate ES. Healthcare resources and patient interaction time are often limited, so family and community-based programs may better identify and address ES. However, I do think that if LoM can exacerbate pre-existing illnesses for certain older adults, and if these older adults seek support from a trusted HCP, then there is a responsibility to respond in a manner that is informed and appropriate. All members of the interprofessional team (e.g., social workers, occupational therapists) share this duty and may have far more to offer for ES than physicians (in specialties that do not offer direct mental health care). Other healthcare professionals may have longer and more direct interactions with patients and have better strategies to increase patient well-being and sense of meaning. For instance, social work “engages people and communities to address life challenges and traumatic events, to create change, and to build resiliency” (7). Occupational therapy aims to “enable people to participate in the activities of everyday life” (8). Like physicians and nurses, these professionals all hold similar ethical values of trust, compassion, and beneficence toward their patients, so they are equally responsible for helping people with LoM (7-10).

To demonstrate that HCPs share responsibility for understanding and appropriately caring for older adults with LoM, the first section of this paper introduces the concept of meaning – what it is, why it is important, and how the search for it can be adaptive. Then, to justify the duty of HCPs to respond to patients who experience ES, the second section draws upon three widely-held values in healthcare – trust, compassion, and beneficence. Finally, the third section presents evidence-based interventions that HCPs can use to help patients regain meaning or make proper referrals.

MEANING IN LIFE

If HCPs have a professional duty to support older adult patients who experience LoM, it is essential as a first step to clarify what we mean by meaning in life. According to existential/positive psychology experts Frank Martela and Michael F. Steger (11), meaning comes from having a sense of purpose, coherence, and significance in one's life. It helps to direct and motivate us towards valued life goals; understand our lives in the context of past, present, and future; and help us feel as though our existence matters in the larger world. Thinking about meaning in life also encourages individuals to search for meaning beyond themselves by contemplating questions such as: What can I contribute to the world? Why does my existence matter? Ultimately, exploring and finding meaning in one's life is an unavoidable, essential, and ongoing process that we all pursue to achieve well-being and live a fulfilled life (11).

Modern psychology provides empirical evidence that having meaning benefits well-being. Although the content of meaning varies for each person at different stages in life, there are common themes that relate to many people, such as their roles, occupation, family, contribution to the community, creativity, or appreciation of beauty (12). Amongst these common themes, positive relationships with others offer the most consistent and compelling sources of meaning, especially love between family members, romantic partners, and friends (13). Religion and spirituality (e.g., love for God, belief in something beyond ourselves) are also positively linked to physical and psychological health via multidimensional influences, one of which is a meaning system that shapes how individuals interpret, evaluate, and respond to various experiences and encounters (14). People who have meaning in life are happier, have higher life satisfaction, are more engaged in their work, have a better immune system and buffer against stress, and live longer in general (15). Although the search for meaning occurs at all life stages, it is more associated with decreased life satisfaction, increased negative emotions, and increased risk of depression during later life stages (16). Therefore, older adults need more care and support when searching for meaning.

To ensure that HCPs know how to identify and respond to ES, it is necessary to gain a nuanced understanding of how it is experienced. One way of doing this is learning from the anecdotes of older adults who have experienced ES from LoM, as exemplified in the two cases below (2).

Case 1: LoM from physical impairments and loss of self-identity

After retirement Babette (87) painted a lot. Her living room is fully decorated with all kinds of colorful paintings. All made by herself. Painting was the way for her to express herself. But when we talk about it, she sadly says: 'I can't see it anymore, I just see black.' In recent years, she's had many injections in her eyes, but it's not helping. 'Cataract has won. My world has no color anymore. I had to give up a lot: my car, later on my 45-kilometer car, my bicycle. You lose all your freedom. I can no longer help anyone, no longer write, no longer paint. At best, I can just chatter on the phone. So much is falling away...' She experiences the losses she has to bear as an assault on her identity, saying: 'Actually, I am no longer human.'

Case 2: LoM from loss of self-worth and productivity

Roelof (93) feels that there is very little [meaning left in life]: 'My life is just trivial. Worthless futility... Life itself is no longer attractive. Eh, it does not matter anymore. I keep on doing things, because, uh, I simply need something to do. Indeed, I have to try to fill the gap by being busy. Because I always have been busy. That's why I'm always looking for something. But I'd rather prefer doing nothing... Look, I can lie down in bed and stop eating and drinking. My discipline is big enough to do so, as far as I feel. But well, I have a partner, so I have to wait. And she has a totally different opinion. She simply doesn't want to die yet, although she's highly disabled... But for me, I'm totally done with it. Life has no value anymore. When I'm dead, everything will be 'cleaned up'.'

These anecdotes show how various compounding reasons can lead to LoM (e.g., physical impairments, lack of productivity, loss of self-identity, loss of self-worth) and how meaning is paramount for older adults to make sense of their life's value. It is important to note that if HCPs engage in a discussion with patients about ES, then their responsibility is not to inform patients where their meaning should come from. Rather, they should facilitate the process of finding meaning. Existential questions can only be answered when a person takes responsibility for discovering their purpose, as no one else can determine what is meaningful for another person (17).

It may be difficult for older adults to regain meaning since they have already experienced many irreversible losses. Suppose an individual derived meaning from working as a construction worker because they see it as a direct way of contributing to society and people's welfare. After retiring, they may experience LoM and suffer ES because they no longer have the physical strength or opportunity to continue pursuing construction work, which was their sole or main source of meaning. Thus, when older adults lose the ability to engage in things that are meaningful to them, they may question why they still matter in the world, particularly in cases when they are no longer 'productive' members of society and certain abilities cannot be regained. When this occurs (i.e. when an older adult experiences ES because of losing the ability to engage in activities that contribute to prior meaning), the focus should be not on how we can restore the losses, but rather on how we can help these people regain meaning and live meaningfully despite those losses.

To develop a deeper understanding of why meaning is integral to well-being and the potential adaptive benefits of ES, I will present some evidence from positive psychology and Victor Frankl's logotherapy to consolidate why it is imperative to help older adults regain meaning.

Positive Psychology

Positive psychology, as the scientific study of human flourishing, regards meaning as the underlying motivation for everything we do to live a happy and fulfilled human life (18). Studies reveal that a flourishing life entails actualizing our potential and maximizing the benefit of five essential factors: positive emotions, engagement, relationships, meaning, and accomplishments (19). Among these five factors, recent research suggests that *meaning* is the most important factor insofar as it underscores all of the other four factors that we attempt to maximize (20). Meaning helps us to persevere in our work, relationships, and goals especially when difficulties arise. Without seeing the meaning behind things that contribute to happiness – like friendships, positive experiences, and engaging work – it would be hard to do anything in life and to truly be happy. In short, meaning is inherent in all human endeavours that direct us toward well-being.

Although ES may seem as though it is an inherently and exclusively negative experience, ES *can* result in a positive outcome when channelled as an impetus to find meaning in life. This implies that if ES leads older adults to explore deeply and purposefully meaning in life, then they may be able to better cope with difficulties in life and even find peace in the face of death. As indicated by Wong (21), another well-cited existential positive psychologist, the quest to find meaning is a necessary and worthwhile process. Every cry for meaning is an attempt to make suffering more bearable and find a purpose for living, which may urge us to move forward in life despite obstacles and suffering that may arise. Ultimately, the search for meaning can have adaptive value because it helps enhance our resilience, personal growth, and flourishing (22).

Logotherapy

Similarly, it may be helpful for HCPs to understand the search for meaning as a natural human response to suffering. Logotherapy is a scientific school of psychotherapy that considers meaning as the ultimate end of human life and the reason humans can keep going even when experiencing tremendous suffering. In Frankl's book, *Man's Search for Meaning* (17), he describes his experience as a Holocaust survivor and how he and his comrades coped with tremendous physical and mental suffering during the war. Those who were the first to perish were the ones who lost meaning and gave up on life, while those who maintained or found meaning continued to survive. Frankl argues that the aim of human life is to find meaning and not necessarily happiness. Each individual needs to come to terms with their unique existence and why they should keep living, especially when suffering arises.

Frankl emphasizes that the freedom to choose how we react to suffering could be what makes life worth living (17). This freedom cannot be taken away from an individual no matter how much suffering is inflicted. In this sense, if older adults experience ES due to the aging process, HCPs involved in their care can help older adults realize this freedom by emphasizing that they are worth more than their suffering and that they have intrinsic worth beyond unavoidable losses. Rising above and beyond ES and seeing it as an opportunity to grow in resilience instead of dwelling in despair could help older adults live better lives. Not all older adults will be able to transcend their suffering, but if they try to do so, HCPs should be aware of its benefits and accompany them in this process.

Etiology of ES

Having gained a deeper understanding of meaning in life and its importance, it is useful to now explore a theory for how LoM leads to suffering. The search for meaning progresses in phases and does not lead to suffering directly. The etiology of suffering is a "multidimensional and dynamic experience of severe stress" stemming from perceived internal or external threats (stressors) to the integrity of self. These stressors could stem from three sources – *self*, *nature*, and *system*: 1) Self, through lifestyle, philosophical view, and expectations; 2) Nature, through diseases and accidental catastrophes; and 3) the System, through the intentional and unintentional harm we inflict on each other.

These stressors are mediated by emotions (distress) and motivate us to eliminate the source of stress by coping and adapting if, that is, we have sufficient psychosocial and personal resources. Insufficient resources can cause one to perceive the threat as unavoidable and ultimately succumb to hopelessness and exhaustion (suffering) (23). ES is associated with many clinical symptoms, such as reduced quality of life, increased anxiety and depression, suicide ideation, and desire for hastened death. Recognizing ES through the manifestation of these symptoms can help HCPs address them (24). With this progressive view of ES from LoM, healthcare providers then arguably have a duty to intervene as early as possible to help prevent LoM from becoming chronic ES.

When a patient is already suffering, it is critical to identify the stressors and associated emotions. How HCPs respond to older patients' suffering influences the extent of suffering experienced. In other words, if HCPs do not respond empathetically to patients with ES, that could exacerbate their suffering, which can derive from an interpretation of external events using our thoughts, beliefs, and judgements (25). As a result, older patients' reaction to distress and the degree of ES varies depending on their interpretation of pain, culture, and coping resources (26). Those who do not think HCPs will care or help alleviate ES can thus experience greater suffering (27). Cicely Saunders, the founder of the modern hospice movement and palliative care culture, formulated the concept of "total pain" as the sum of suffering experienced from an interaction between physical, psychosocial, social, and spiritual domains (28). HCPs should understand that ES can arise from losing meaning in different, distinct domains, and thus require HCPs' attention and understanding.

ETHICAL ANALYSIS

Current Issues in Addressing LoM

Although the focus of this paper is on the ethics of ES from LoM, I acknowledge that HCPs face practical barriers to helping patients due to difficulties in identifying ES, lack of training on how to address it, and time constraints (29). Many HCPs (even palliative care doctors) who work with older adults struggle to understand LoM and are untrained on how to intervene appropriately (30). Consequently, they may ignore ES out of fear of imposing their view of the meaning of life on patients or usurping authority if they offer insights into the potential meaning of their patient's suffering. As a result, some HCPs may want to keep a professional distance and argue that ES is not a medical matter but rather a personal or spiritual quest. However, unresolved existential questions could be debilitating and result in psychological distress that causes even more suffering than physical pain (30). Furthermore, older adults may perceive that some HCPs do not have time to hear about the psychological and social aspects of their lives and so may not consider sharing these aspects. So, to avoid harm from internalized ES, I suggest that HCPs should *elicit* information about possible ES by making observations and asking questions.

Another practical limitation is the lack of time and attention for HCPs to address ES when other patient demands are high. The onus to help patients with ES may be delegated to family members, something that may not always be a viable solution if the older patient does not have family members or if the family members refuse to be involved in their care. Many HCPs are unaware of evidence-based solutions to help patients overcome ES from LoM. So even though my focus here is on the ethical duty of HCPs to respond to ES and LoM, some evidence-based strategies can provide guidance and indirectly address some of these practical limitations.

Three fundamental values in healthcare are helpful for framing my argument – trust, compassion, and beneficence – and, as I will show, tie into older patients' needs when experiencing ES from LoM and why HCPs should intervene when patients request help and support in overcoming ES.

Trust

Trust is integral to the patient-HCP relationship and a fundamental aspect of healthcare. Trust refers to the patient's expectations that HCPs will do what is in the patient's best interest, with good will, and not exploit their inherent vulnerability (31). It is an unwritten agreement that results from a lack of choice or occurs in the context of asymmetrical relationships, such as the one between HCP and patients, and leads to reassurance and confidence between the two parties. HCPs and patients are working towards the same goal of promoting health and alleviating patient suffering. Trust therefore facilitates, catalyzes, and sustains this cooperation. Some related ethical virtues that enhance trust in HCPs include compassion, honesty, humility, integrity, and prudence (10). If older patients come to HCPs with ES concerns, they believe the HCP will respect their dignity, honour their choices, and not exploit them. Without trust, HCPs cannot provide high-quality, ethical care.

Trust is also needed to facilitate good relationships between older patients, their children, and their extended support network. Although happiness may not be, as Frankl suggests, the end goal, it is an important component of one's psychology. Positive psychology has consistently shown that people who have healthy, positive relationships are the happiest (32). Interestingly, many older adults value relationships with their children the most out of all other relationships, such as their friends, grandchildren, or even significant others (33). HCPs should thus be aware of these relationship dynamics and facilitate the involvement of the older patients' children, if desired by patients. Additional analysis shows that mattering to other people is significantly correlated to increased wellness, greater purpose in life, and reduced levels of depression in older adults (33). Therefore, HCPs should earn the trust of family members when they are involved in the older patient's search for meaning and work with them to create the best care possible.

Another aspect of trust is related to the duty to provide continual care to patients. When patients are experiencing ES, they trust that their care providers will not abandon them even if they are "incurable". Again, the goal of healthcare is to promote health and relieve suffering. So even though there are no further appropriate curative or disease-directed options, patients trust HCPs to still care for them. Similarly, trust is also needed for deep encounters to take place. Older adults' existential questions are primarily concerned with self-evaluation and regrets, with questions like: Has my life been worthwhile? What happens to me after I die? How can I find peace, comfort, and hope in the face of death (21)? A trusting relationship is, therefore, necessary to explore these deep questions as they require high levels of sensitivity, confidentiality, and a non-judgmental attitude.

Compassion

The second ethical commitment requiring HCPs to help older patients with ES is compassion. HCPs must recognize suffering and vulnerability, understand the unique circumstances of the patient, and work to alleviate the patient's suffering, and accompany the suffering and vulnerable patient (10). As mentioned before, ignoring, or having a negative response to suffering exacerbates patient suffering. HCPs do not need to "solve" their patients' suffering, but they do need to be present and acknowledge their both own struggles and those of their patients, and be willing to encounter pain and sadness by listening and connecting with their patient's stories (2).

Compassion means meeting the needs of patients to feel connected and understood. Some HCPs think that ES is something that should be immediately referred to spiritual care since it falls outside of their medical field of expertise. However, holistic care for patients extends beyond the biomedical. Qualitative studies have shown that the presence of others and connectedness are predominant needs of patients experiencing ES (30). Patients desire the presence of HCPs who are willing to sit down, listen, and talk with them (34). Moreover, patients approaching the end of life want staff members who are "daring to listen" and not "shutting off" difficult conversations (35). Even just the presence of another person carries significant meaning for patients suffering existentially.

Other than the older adult with ES, their family members or caregivers may also need support, as they may feel unable to share their own fears and thoughts when accompanying someone with ES (30). HCPs working with older adults are uniquely positioned to coordinate resources and make referrals for addressing ES in their patients since family members may be unaware of ways to help older adults regain meaning. In short, compassion is needed on the part of HCPs to empathize with what older adults are going through and provide the best support.

HCPs should show compassion towards patients because the search for meaning can be a difficult process – finding meaning in life can be hard to do, just from thinking about it. For most people, we need to actively search for meaning through activities such as meeting people, having new experiences, or reframing our approach to suffering (17). However, older adults who are unable to live a life they envision or do activities of their choosing may find it harder to regain meaning. HCPs should give patients freedom regarding how they search for meaning because each person ultimately has the responsibility to find their specific meaning, and which may shift over time in response to different internal and external factors. Sometimes ES may arise due to some unmet needs, such as not receiving proper care; so ES from LoM must not be misconceived as a mental disorder

or disease (17). Rather, existential distress is a natural response to losses in life and an indication of the need to redefine meaning.

Furthermore, compassion helps HCPs and patients accept the limits of life and healthcare. There is a finiteness and finality as human beings and a mystery about life and death that is beyond what we know and can control (17). Likewise, aging is a natural phenomenon that exposes the limits of medical treatments. Suffering is a multi-dimensional and integrative experience. So, HCPs must treat suffering from a whole-person approach rather than just the narrow approach of physical, spiritual, or psychiatric symptoms. Suffering may be relieved by removing perceived threats to the person and restoring health when possible. When this is not possible, redefining threats and finding new meaning and hope may prove useful. Alternatively, a combination of both strategies may lead to better outcomes. Since suffering is a dynamic and subjective experience, frequent and tailored assessments of the patient's and family's needs and perceived threats are required. Caring for people suffering entails a great privilege and responsibility, and some patients may find meaning in life through the care they receive from HCPs (26).

Beneficence

Finally, beneficence is one of the fundamental commitments of the health professions to patient well-being and it thus requires HCPs to care for older patients with LoM (10). HCPs must always act to benefit the patient and promote their interests. They must also provide appropriate care and management across the care continuum, including until the end of their patients' lives. Ignoring ES can foster mistrust between patients, HCPs, and the medical system. Since most older adults are cared for by HCPs and eventually die in healthcare settings, HCPs must be aware and equipped on how to respond to ES (36).

What is good or beneficial for a patient is something that patients and HCPs must and can co-create. Each person has unique dimensions to be considered when they experience ES. Each patient must be treated as a unique person, taking into consideration the various dimensions of their personhood – their personality, character, past experiences, family ties, culture, relationships, values, and behaviours (37). Older adults should provide their own values and input to what can help them regain meaning, while HCPs try to integrate this with their professional expertise. A commitment to patient benefit ensures better health outcomes because patients who share the same goals as HCPs are more likely to want to get better, follow treatment plans, and change their lifestyles to improve their well-being.

Patient-centred care is also closely linked with beneficence in that it “fosters respectful, compassionate, culturally appropriate and competent care that is responsive to the needs, values, beliefs, and preferences of patients.” (38). HCPs have a duty to care for the whole person, not just an illness or disease symptoms. It is important to build comprehensive expertise in addressing ES because different patients have different needs. People who experience ES may not necessarily have depression, even though these are highly correlated (39). So while psychiatric care may help some patients, other individuals may want to pursue nonmedical treatments such as prayer. Still, some patients may find exploring ES intrusive or uncomfortable if seeking meaning in suffering adds unnecessary psychological suffering. Overall, HCPs should work closely with specialists in spiritual care and psychiatry to best meet their patient's needs.

EVIDENCE-BASED INTERVENTIONS

Having argued for the necessity for HCPs to respond to ES in older adults, the natural follow-on question is what HCPs should do in response. Below, I present some evidence-based psychotherapy interventions that may help address ES. The expectation is not for all HCPs to become experts in providing all possible therapeutic approaches to respond to ES; rather, they should have sufficient familiarity to either offer and/or refer patients to whatever approach may most likely benefit. Not all older adults suffering from ES will want to engage in these psychotherapies, but if they do, HCPs should have these options in mind and be ready to mobilize the necessary resources (e.g. referrals).

Palliative Care Psychotherapy

A psychotherapy framework with eight steps to help patients is frequently used in palliative care to assess and address ES (Appendix 1). This framework proceeds in steps to help HCPs connect with the patient, identify the underlying causes, create another narrative, help patients build resilience, and reshape the approach to suffering. Reframing is a critical step in learning to overcome ES. HCPs can help older patients to realize that meaning changes as they age and undergo losses. Throughout our life stages, we make sense of our lives and the world by continuous meaning reconstruction. When a life-threatening or life-altering diagnosis occurs, it forces the revision of one's life narrative. In these cases, patients themselves need to want to emerge from ES to search for meaning and overcome suffering. If they choose to do so, HCPs may play an important role in helping patients and their families find meaning and purpose (40). All HCPs should know about this and help patients navigate these questions or at least refer them to someone who can help.

Meaning-Centred Group Psychotherapy

Meaning-Centred Group Psychotherapy (MCGP) was developed to help patients with advanced cancer to enhance their sense of meaning (41). This therapeutic approach focuses on asking patients about what is most important in their lives – including their goals, roles, values, and pursuits – to help them maintain a coherent story of themselves, affirm existing sources of meaning, and/or reframe the value of their life. This therapy aims to “[create] goals that sustain purpose, value relationships, express gratitude, and focus on living until death intervenes” (12).

Research shows that explicitly discussing meaning helps patients overcome LoM. Ninety patients with advanced cancers were randomly assigned to an eight-week MCGP or general supportive group psychotherapy in which they used didactics, discussion, and experiential exercises that focused on the theme of meaning and terminal illness (41). Example discussion questions included “Reflect on your life and identify the most significant memories, relationships, traditions, etc., that have made the greatest impact on who you are today.” These patients also explored the attitudinal sources of meaning through experiential exercises using questions like: “What would you consider a good or meaningful death? How can you imagine being remembered by your loved ones?” After eight weeks, the MCGP had more significant increases in spiritual well-being and sense of meaning compared to the general supportive psychotherapy group. This study showed that explicitly talking about meaning in life and facing death was more effective than just having general psychological support, with the strongest treatment effects in feelings of meaning and peace (41).

Dignity Therapy

Another evidence-based strategy is Dignity Therapy (42,43), developed by Dr. Harvey Max Chochinov, a palliative care psychiatrist, to help patients maintain a sense of self as they approach their last days (44). There is increasing evidence that Dignity Therapy (DT) could also help older patients who are not in palliative care since ES is significantly correlated with measures of suffering, well-being, depression, anxiety, and rating and satisfaction with quality of life (45). Before developing this therapy, Chochinov and his colleagues conducted research that identified eight important factors that contributed to patients' sense of dignity and ways of conserving these factors (Appendix 2) (46). Based on these eight factors, they created a Patient Dignity Inventory (PDI) to obtain a snapshot of a patient's sense of dignity and meaning concerning how they are doing and how their care is proceeding (Appendix 3). It could be pertinent for HCPs to conduct a PDI because identifying sources of distress is critical to understanding ES and helping HCPs deliver quality care.

After conducting a PDI, DT could be implemented should older patients wish for such support. This therapy invites patients to discuss issues that matter most or that they would most want to be remembered. Sessions are transcribed, edited, and returned with a final version that the patient can then bequeath to a friend or family member. In a study that evaluated the feasibility and impact of DT in patients approaching the end of life, almost all participants (91%) reported feeling satisfied with DT, 76% reported a heightened sense of dignity; 68% reported an increased sense of purpose; 67% reported a heightened sense of meaning; 47% reported an increased will to live; and 81% reported that it had been or would be of help to their family (47). Post-intervention measures of suffering showed significant improvement and reduced depressive symptoms. To sum up, Dignity Therapy may be the most well-supported and effective intervention for ES from LoM to date, making it useful for HCPs to know and make referrals for if their patients could benefit.

CONCLUSION

Older adults are more likely to experience ES due to LoM, at least in part because of the illnesses that they may endure as part of the aging process. In response to older adult patients who experience LoM, HCPs have an ethical obligation to acknowledge and make credible attempts to address EC and LoM. The values of healthcare entail trust, compassion, and beneficence, each of which justifies the responsibility for HCPs to understand and address LoM, even if they cannot successfully reduce its occurrence and severity. ES can have significantly negative effects on patients, and several interventions have been proposed as potentially effective means for addressing LoM. As part of their work, HCPs who learn to respond to patients' LoM and use these interventions where appropriate may be able to effectively reduce ES.

Besides the three evidence-based therapies, many community initiatives can also contribute to dignity-conserving perspectives and practices listed within Chochinov's Dignity Conserving Repertoire (Appendix 2). With increasing health care expenditure for the older adult population, Canada is strengthening support for preventative home and community-based care, so that long-term care homes can concentrate on older adults with the most serious needs (48). Improving the well-being of older adults and their caregivers could, in turn, enable older adults to uphold a positive sense of self, accept limitations, live in the moment, and maintain normalcy. Moreover, there are significant efforts to reinforce social connections and mitigate the negative effects of social isolation and loneliness in older adults. The Canadian government encourages citizens to share lessons learned or success stories through the media to promote best practices in caring for older adults in our communities (49). Sharing stories about aging well can help older adults maintain a sense of pride, hope, and legacy.

A concrete example of an innovative and effective community strategy for positive aging takes place at the Champion Intergenerational Enrichment and Education Center in Ohio, USA, where multiple generations come together to “build relationships, improve health and wellness, develop educational skills in children, and create a sense of purpose in the elderly” (50). These community-based initiatives could lead to greater engagement in a more natural and relaxed setting, require fewer resources than healthcare interventions, and prevent ES before it occurs or reduce its impact on an individual's health which would then require medical attention. Overall, healthcare professionals and the community should work together to respond to ES due to LoM in older adults.

Moving forward, we need a cultural and attitude change towards older adults and people of all ages who are suffering ES from LoM. Older adults are some of the most marginalized people in society because they seem to have no opportunities or future possibilities, but they have lived realities – potentialities actualized, meaning fulfilled, values realized – that can and should be acknowledge and valorized (17). It is important to know that meaning is critical at every stage of life and HCPs, families, and

society should share the responsibility for helping to prevent, manage, and diminish ES for people of all ages. Every person has intrinsic dignity and is worthy of support in this important regard. Healthcare does not have to find an answer to the meaning of life, but it should help people live meaningful lives.

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None to declare

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REFERENCES

1. Statistics Canada. [Population Projections for Canada \(2021 to 2068\), Provinces and Territories \(2021 to 2043\)](#). 22 Aug 2022.
2. van Wijngaarden E. [The darker side of ageing: towards an ethics of suffering that emphasises the primacy of witnessing](#). Journal of Population Ageing. 2021;14(3):323-42.
3. World Health Organization. [Constitution of the World Health Organization](#). 1946.
4. Scharf S, Flamer H, Christophidis N. [Age as a basis for healthcare rationing: Arguments against agism](#). Drugs & Aging. 1996;9(6):399-402.
5. World Health Organization. [Preventing suicide: a global imperative](#). Geneva: World Health Organization; 2014.
6. Richards N. [Old age rational suicide](#). Sociology Compass. 2017;11(3):e12456.
7. Canadian Association of Social Workers. [CASW Code of Ethics and Scope of Practice](#). 2020.
8. Canadian Association of Occupational Therapists. [CAOT Code of Ethics](#). 2018.
9. Canadian Nurses Association. [CNA Code of Ethics for Registered Nurses](#). 2017.
10. Canadian Medical Association. [CMA Code of Ethics and Professionalism](#). 2018.
11. Martela F, Steger MF. [The three meanings of meaning in life: Distinguishing coherence, purpose, and significance](#). The Journal of Positive Psychology. 2016;11(5):531-45.
12. Kissane DW. [The relief of existential suffering](#). Archives of Internal Medicine. 2012;172(19):1501-5.
13. O'Donnell MB, Bentele CN, Grossman HB, Le Y, Jang H, Steger MF. [You, me, and meaning: an integrative review of connections between relationships and meaning in life](#). Journal of Psychology in Africa. 2014;24(1):44-50.
14. Park CL. [Religiousness/spirituality and health: a meaning systems perspective](#). Journal of Behavioral Medicine. 2007;30(4):319-28.
15. Steger MF. Meaning in life. In: Lopez SJ, Snyder CR, editors. Oxford Handbook of Positive Psychology. Oxford: Oxford University Press; 2009. p. 679-87.
16. Steger MF, Oishi S, Kashdan TB. [Meaning in life across the life span: Levels and correlates of meaning in life from emerging adulthood to older adulthood](#). The Journal of Positive Psychology. 2009;4(1):43-52.
17. Frankl VE. Man's Search for Meaning. Boston: Beacon Press; (1946) 2006.
18. Ackerman CE. [What is the meaning of life according to positive psychology](#). Positive Psychology. 6 Feb 2018.
19. Seligman MEP. Flourish: A Visionary New Understanding of Happiness and Well-Being. New York: Free Press; 2011.

20. Peterson C, Park N. [Meaning and positive psychology](#). International Journal of Existential Psychology & Psychotherapy. 2014;5(1):1-8.
21. Wong PTP, Yu TTF. [Existential suffering in palliative care: an existential positive psychology perspective](#). Medicina. 2021;57(9):924.
22. Wong PTP. [Existential positive psychology and integrative meaning therapy](#). International Review of Psychiatry. 2020;32(7-8):565-78.
23. Henry B. [The ethics of suffering in the era of assisted dying](#). Annals of Palliative Medicine. 2017;6(2):173-7.
24. Bates AT. [Addressing existential suffering](#). BC Medical Journal. 2016;58(5):268-73.
25. Siler S, Borneman T, Ferrell B. [Pain and suffering](#). Seminars in Oncology Nursing. 2019;35(3):310-4.
26. Krikorian A, Limonero JT, Maté J. [Suffering and distress at the end-of-life: Suffering and distress at the end-of-life](#). Psycho-Oncology. 2012;21(8):799-808.
27. Gillear C. [Suffering: The darker side of ageing](#). Journal of Aging Studies. 2018;44:28-33.
28. Mehta A, Chan LS. [Understanding of the concept of "total pain": A prerequisite for pain control](#). Journal of Hospice & Palliative Nursing. 2008;10(1):26-32.
29. Amonoo HL, Harris JH, Murphy WS, Abrahm JL, Peteet JR. [The physician's role in responding to existential suffering: what does it mean to comfort always?](#) Journal of Palliative Care. 2020;35(1):8-12.
30. Boston P, Bruce A, Schreiber R. [Existential suffering in the palliative care setting: an integrated literature review](#). Journal of Pain and Symptom Management. 2011;41(3):604-18.
31. Sasiah S, Jaafar S, Yusof S, Ponnudurai G, Chung KPY, Amirthalingam SD. [A study of the nature and level of trust between patients and healthcare providers, its dimensions and determinants: a scoping review protocol](#). BMJ Open. 2020;10(1):e028061.
32. Diener E, Seligman MEP. [Very happy people](#). Psychological Science. 2002;13(1):81-4.
33. Dixon AL. [Mattering in the later years: older adults' experiences of mattering to others, purpose in life, depression, and wellness](#). Adultspan Journal. 2007;6(2):83-95.
34. Mako C, Galek K, Poppito SR. [Spiritual pain among patients with advanced cancer in palliative care](#). Journal of Palliative Medicine. 2006;9(5):1106-13.
35. Albinsson L, Strang P. [A palliative approach to existential issues and death in end-stage dementia care](#). Journal of Palliative Care. 2002;18(3):168-74.
36. Statistics Canada. [Deaths, By Place of Death \(Hospital or Non-hospital\)](#). Government of Canada. 27 Nov 2023.
37. Cassel EJ. [The nature of suffering and the goals of medicine](#). NEJM. 1982;306(11):639-45.
38. Centre for Addiction and Mental Health. [Patient- and Family-Centered Care](#).
39. Breitbart W, Rosenfeld B, Pessin H, et al. [Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer](#). JAMA. 2000;284(22):2907-11.
40. Romanoff BD, Thompson BE. [Meaning construction in palliative care: the use of narrative, ritual, and the expressive arts](#). American Journal of Hospice and Palliative Medicine. 2006;23(4):309-16.
41. Breitbart W, Rosenfeld B, Gibson C, et al. [Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial](#). Psycho-Oncology. 2010;19(1):21-8.
42. Chochinov HM, McClement SE, Hack TF, et al. [The Patient Dignity Inventory: applications in the oncology setting](#). Journal of Palliative Medicine. 2012;15(9):998-1005.
43. Jenewein J, Moergeli H, Meyer-Heim T, et al. [Feasibility, acceptability, and preliminary efficacy of dignity therapy in patients with early stage dementia and their family. A pilot randomized controlled trial](#). Frontiers in Psychiatry. 2021;12:795813.
44. Chochinov HM. Dignity Therapy: Final Words for Final Days. Oxford : Oxford University Press; 2012.
45. Chochinov HM, Hassard T, McClement S, et al. [The Patient Dignity Inventory: A novel way of measuring dignity-related distress in palliative care](#). Journal of Pain and Symptom Management. 2008;36(6):559-71.
46. Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. [Dignity in the terminally ill: A developing empirical model](#). Social Science & Medicine. 2002;54(3):433-43.
47. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. [Dignity Therapy: A novel psychotherapeutic intervention for patients near the end of life](#). Journal of Clinical Oncology. 2005;23(24):5520-5.
48. National Research Council Canada. [Challenge accepted: how to support older adults aging in place through a more sustainable long-term care model](#). Government of Canada. 1 Oct 2020.
49. Public Health Agency of Canada. [Age-Friendly Communities in Canada: Community Implementation Guide](#). 2012.
50. Ohio State University College of Social Work. [The Champion Intergenerational Center: A point of pride for the College of Social Work](#). Ohio State University. 11 Dec 2015.
51. Dignity in Care. [The Patient Dignity Inventory](#).

APPENDIX 1

Table 1. Framework for Helping Patients with Existential Suffering

Step 1	Connect with the patient as a human being	Given that existential suffering can overwhelm and threaten one's identity and human connections, helping patients feel that a clinician empathizes and will follow through may be powerfully reassuring that they are not alone in the world or abandoned. ^{10,11} Validating patients' responses to their situation and normalizing their distress can decrease their sense of isolation.
Step 2	Determine whether there is underlying psychiatric illness or physical symptoms which can be addressed	An undiagnosed underlying psychiatric diagnoses (delirium, depression, or anxiety) may be amenable to medication. Physical pain can also be a trigger for existential pain. Improvement in patient quality of life, in one study, produced improvement in existential well-being. ¹²
Step 3	Take a narrative history to enhance perspective	Clinicians act as witnesses and create a shared reality with a narrative history (ie, listening to the story of the patient's illness in relation to his life trajectory). ¹³ Patients also gain perspective on their current situation as clinicians give their story coherence and help them understand the significance of their stressors. ¹⁴ Additionally, patients are reminded of their identity as competent people who have overcome previous adversity. ¹⁴
Step 4	Analyze with patients why the stressors are so threatening; reveal what the patients' suffering means to them	Helping patients express their emotions can help clarify what about their situation is confusing or frightening. Do the circumstances challenge their self-worth? Do they feel afraid, betrayed, ill-fated, or trapped? Is their world view changing such that they feel they are being punished and if so why? Perhaps the stressors have upended their views on how the universe operated—for example, "If I'm a good person, nothing bad will happen to me."
Step 5	Query distorted, emotionally driven and disabling perceptions	A sense of helplessness is common in existential suffering as the patient grapples with the limitations of his or her own agency. Although in medical illness a patient is realistically often not in control of their treatment or bodily symptoms, what can be addressed are distorted perceptions, such as "nothing can change," and the belief that their choices and actions make no meaningful differences. The technique of disputation, central to cognitive behavior therapy ¹⁰ (eg, how the patient came to such a belief, and how well it fits the current facts), is useful for addressing irrational beliefs.
Step 6	Help the patient actively enlist sources of resilience to reshape the approach to suffering	Enlisting strengths and techniques patients have drawn upon to deal with existential assaults in their past maybe helpful. These may include problem solving abilities, emotional regulation techniques, drawing on a core identity, and relational coping by mobilizing social networks. ¹⁵ What strengths are a source of pride, and how might these help them face their current stressors with courage? What gives them meaning in life and hope? If patients have a religious or spiritual tradition, what does it offer? If they are a Christian, what does it mean to them that Jesus suffered, and called on his followers to "pick up their cross"? If they believe suffering should be somehow redemptive, or could be character building, in what way? If Muslim, do they believe their suffering is a task given them by Allah, and challenges them to respond in some way? If Buddhist, how do they understand the renunciation of desire? If they have valued being true to themselves, can they articulate their core values?
Step 7	Decide on a course of action moving forward once the sufferer is no longer acutely demoralized	For patients immobilized by existential suffering, formulating a course of action enables them to regain a sense of being an active agent. Patients need to be asked to consider their core values, prior experiences, and the emotional context which may be influencing their judgment. What are their priorities, and how do they want to redirect their efforts, given any new limitations? What is most important for them to preserve—perhaps a key relationship, a role, a valued ideal, or an aspect of their identity?
Step 8	Help patients live in accordance with their core values	Activities which reinforce a sense of community, transcendence, and meaning can help patients move from a posture of retreating from existential suffering to a posture of resilience. Such activities are found in Table 2.

Source (29)

APPENDIX 2

Table 2. Dignity Conserving Repertoire

Dignity Conserving Perspectives			
Factor	Definition	Dignity-Related Questions	Therapeutic Interventions
Continuity of self	Essence of who one is remains intact, in spite of advancing illness	"Are there things about you that this disease does not affect?"	• Acknowledge and take interest in those aspects of the patient's life that s/he most values • See the patients as worthy of honour, respect, and esteem
Role preservation	Ability of patients to function or remain invested in their usual roles, as a way of maintaining congruence with prior view of themselves	"What things did you do before you were sick that were most important to you?"	
Maintenance of pride	Ability to maintain a positive sense of self-regard or self-respect	"What about yourself or your life are you most proud of?"	
Hopefulness	Seeing life as enduring, or as having sustained meaning or purpose	"What is still possible?"	• Encourage and enable the patients to participate in meaningful or purposeful activities
Autonomy/control	Ability to maintain a sense of control over one's life circumstances	"How in control do you feel?"	• Involve patients in treatment and care decisions
Generativity/legacy	Solace or comfort of knowing that something of one's life with transcend death	"How do you want to be remembered?"	• Life project (e.g., making audio/video tapes, writing letters, journaling)
Acceptance	Ability to accommodate to changing life circumstances	"How at peace are you with what is happening to you?"	• Support the patient in his or her outlook • Encourage doing things that enhance his or her sense of well-being (e.g., meditation, light exercise, listening to music, prayer)
Resilience/fighting spirit	Mental determination exercised to overcome illness or optimize quality of life	"What part of you is strongest right now?"	
Dignity Conserving Practices			
Living in the moment	Focus on immediate issues in the service of not worrying about the future	"Are there things that take your mind away from illness and offer you comfort?"	• Allow the patients to participate in normal routines or take comfort in momentary distractions (e.g., daily outings, light exercise, listening to music)
Maintaining normalcy	Carry on usual routines and schedules despite changing health circumstances	"Are there things you still enjoy doing on a regular basis?"	
Finding spiritual comfort	Dignity-sustaining effect of turning toward or finding comfort within one's religious or spiritual beliefs	"Is there a religious or spiritual community that you are, or would like to be, connected with?"	• Make referrals to chaplain or spiritual leader • Enable the patients to participate in particular spiritual and/or culturally based practices

Sources: (44,46)

APPENDIX 3

Figure 1. Patient Dignity Inventory



Dignity IN CARE

The Patient Dignity Inventory (PDI)

For each item, please indicate how much of a problem or concern these have been for you within the last few days.

1 = NOT A PROBLEM	3 = A PROBLEM	5 = AN OVERWHELMING PROBLEM
2 = A SLIGHT PROBLEM	4 = A MAJOR PROBLEM	

1 Not being able to carry out tasks associated with daily living (e.g., washing myself, getting dressed) 2 Not being able to attend to my bodily functions independently (e.g., needing assistance with toileting-related activities) 3 Experiencing physically distressing symptoms (e.g., pain, shortness of breath, nausea) 4 Feeling that how I look to others has changed significantly 5 Feeling depressed 6 Feeling anxious 7 Feeling uncertain about illness and treatment 8 Worrying about my future 9 Not being able to think clearly 10 Not being able to continue with my usual routines 11 Feeling like I am no longer who I was 12 Not feeling worthwhile or valued 13 Not being able to carry out important roles (e.g., spouse, parent)	14 Feeling that life no longer has meaning or purpose 15 Feeling that I am not making a meaningful and/or lasting contribution in my life 16 Feeling that I have “unfinished business” (e.g., things that I have yet to say or do, or that feel incomplete) 17 Concern that my spiritual life is not meaningful 18 Feeling that I am a burden to others 19 Feeling that I don’t have control over my life 20 Feeling that my illness and care needs have reduced my privacy 21 Not feeling supported by my community of friends and family 22 Not feeling supported by my health care providers 23 Feeling like I am no longer able to mentally “fight” the challenges of my illness 24 Not being able to accept the way things are 25 Not being treated with respect or understanding by others
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Source (51)