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In My Time of Dying: Ethical Considerations in End of Life Care for Individuals with a Substance Use Disorder

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Introduction

Palliative care (PC) has the ability to enhance quality of life for people who are diagnosed with a life-limiting, serious illness. However, there are populations whose experience of PC may not measure up to the standard of care that most palliative patients receive. Individuals with substance use disorders (SUD) often encounter barriers to optimal care. The World Health Organization (WHO) defines SUDs as "a group of conditions related to alcohol or other drug use," all of which include the use of psychotropic substances that may or may not have been prescribed clinically.[1] These include alcohol, opioids, cannabinoids, sedatives, hallucinogens, cocaine, and other stimulants such as tobacco. This paper will focus on more stigmatized SUDs related to alcohol, opioids, and illicit substances, as many PC programs do not have adequate knowledge on how to

care for these individuals and their unique concerns. This paper will examine common barriers to PC in the general population and discuss those exclusive to those with an SUD. Recommendations on improving access to PC for both populations are also discussed.

General Barriers to Palliative Care

According to the WHO, an estimated 40 million people worldwide need PC yearly. However, despite increasing options related to PC, gaps persist in the number of people eligible for it who are accessing it in the United States and globally. The focus of this paper will be issues pertinent to the United States. Palliative care is a specialized treatment approach for individuals of any age with a serious illness.[2] The goal of PC is to improve the quality of life of patients with potentially life-threatening illness and their families and/or caregivers. This is achieved

through the prevention and relief of suffering by means of early identification and treatment of pain and other problems physically, psychosocially, and spiritually related to their condition.[3] Hospice care is distinctly different, because it is PC that is exclusively for those with a prognosis of death within six months. However, while this distinction exists, its bearing upon the present topic is minimal. Thus, I will remain largely focused on PC throughout this essay.

Unfortunately, only about 14% of people who need PC receive it.[4] In the United States, it is estimated that about 6 million would benefit from PC services, yet less than 2 million access these services each year.[5] One of the primary reasons for this is the variability in access due to geographic and other setting-related characteristics. For instance, a 2019 study by the U.S. Center to Advance Palliative Care (CAPC) showed that 90% of hospitals with PC are located in urban areas, while only 17% of rural hospitals with 50 or more beds report having PC programs.[6] That means someone with a serious illness living

in an urban area has access to significantly more hospital PC programs than those living in regions that are largely rural.

Lack of understanding about PC also impacts its utilization. PC nurses perceive communication as the number one issue that needs improvement in end-of-life care. This includes dialogues between healthcare teams and providers, and providers, patients, and their families.[7] Healthcare providers often remark that they either "lack time" or are "reluctant" to have conversations about end-of-life care for various reasons.[8] Topics such as clarification of resuscitation wishes, potential treatment plans if the prognosis deteriorates, appointing a surrogate decision-maker, or clarifying goals at the end of life and after death are glossed over or avoided because physicians do not believe their patients are ready for such conversations, they do not want patients to give up hope, and/or they perceive such discussion as an indication of failure on the physician's part.[9]

There is also a lack of public awareness of what PC is and what services it provides. This particular barrier to access is wrought by fear surrounding conversations about the end of life as well as misinformation about what PC requires from the patient, including the notion that they must forgo all treatment.[10] In one study regarding end-of-life communication barriers, it was found that 58% of those interviewed did not want to engage in such conversations with their providers.[11] Other patient-related barriers include lack of awareness of hospice as an option, preference for more aggressive therapies, conflict between spiritual beliefs and the goals of PC, and an inherent mistrust of the medical system.[12] Many of these perceptions also stem from a lack of knowledge or poor observations regarding what palliative and hospice care are—for instance, that hospice care "bumps people off" or is a sign of "giving up." These individuals may also be unaware of the severity of their illness, which depends on how truthful the doctor and family have been about their prognosis. Patients and their families may also believe that acknowledging the severity of their illness may hasten the patient's death.[13]

Another barrier to PC access is a lack of adequate medical and nursing workforce with training and expertise in PC. Currently, the United States has 7,600 physicians who are board certified in PC.[14] Unfortunately, these numbers are dwindling. This means that many providers who are working with patients who have a serious illness and referring them to PC are not adequately trained to handle end-of-life care. This trend will continue as burnout among these specialized providers continues and the number of incoming physicians and PC specialists remains stagnant. Aside from the fact that the number of specialty physicians entering the field cannot meet current and burgeoning demands, limited funding also creates a barrier to adequate PC access. For graduate medical education, funding is provided through Medicare, which caps the number of slots in teaching hospitals each year at 80,000—a number that has not changed since 1997 despite changing demographics and the introduction of new specialties like PC.[15] There is also a reluctance from primary care physicians to engage with end-of-life curriculum beyond what is currently required because current curriculum already has a demanding training load and there is an expectation that PC specialists will fill in gaps.[16] The combination of lack of specialists, lack of knowledge of services by non-specialists and other healthcare workers (i.e., nurses), and a reluctance to refer to PC services only perpetuates the inequities present in access to and utilization of PC services.

Concerns related to cost and insurance coverage of palliative and hospice care by healthcare consumers, their families, and even providers also create barriers to these services. Many families simply do not understand what is covered by their insurance companies with regards to PC and hospice. A study by the National Hospice Foundation showed that 90% of Americans do not realize that hospice care is fully covered through Medicare.[17] In fact, Medicare, Medicaid, and most private health insurers provide a full array of PC services for patients who are hospitalized or in hospice care and their families.

Barriers to Palliative Care for Individuals with Substance Use Disorder

Although individuals living with an SUD share many of the same barriers as the general population with regard to accessing PC, they also have unique obstacles to navigate. The actual number of individuals in palliative or hospice care with an SUD is not entirely known, although some studies suggest that the numbers probably mimic that of the overall population. The 2018 National Survey on Drug Use and Health estimated that 19.7 million (6.0%) Americans aged 12 years or older had an SUD. Other studies estimate that up to 25% of palliative and hospice care patients present to treatment with an active SUD or in recovery from one.[18]

Consider that the U.S. population of persons 65 and over is rising exponentially. According to the Global Burden of Disease Study, mental health and SUD conditions account for 7.4% of the global disease burden worldwide, and this percentage is expected to increase. Neuropsychiatric disorders (including SUDs) are also expected to comprise 5 of the top 10 causes of disability worldwide. The Census Bureau estimates that by 2050 the U.S. population of persons 65 and older will increase to 70 million.[19] Despite research that suggests that drug use diminishes as individuals age, the Baby Boomer generation continues to show a higher rate of drug abuse and misuse than previous generations, although Generation X (1963–1982) and Millennials (1983–2002) show significantly higher rates of alcohol, marijuana and opioid use, misuse, and abuse in comparison.[20] The potential for opioid abuse related to pain management has also increased with the introduction of highly addictive drugs such as Oxycontin and increasing costs associated with its production and distribution. With 94% of palliative and hospice care patients entering care at 65 or older, a consideration about the impact of SUDs, cognitive function, and risks at the end-of-life is necessary if optimal care is to be provided.[21]

The impact of an influx of older adults with comorbidities on a PC model that is already ill-equipped to handle palliative patients with an SUD should not be understated. While empirical research on geriatric PC is scarce, there is evidence that the type of care older adults are receiving is already severely lacking compared to their younger counterparts. This means that the unique, unknown, or misunderstood needs of older adults with SUDs often go unchecked or are misdiagnosed.[22] Inconsistent screening protocols might cause providers to overlook the symptoms of SUDs or attribute them to the diseases or comorbidities associated with their PC enrollment. Not only can unconscious

or conscious stigma and/or bias related to SUDs impede the healthcare experience for this population, but the additional burden of ageism can also further inhibit seeking and obtaining care and have a negative impact on patient outcomes. Ageism is defined by the WHO as stereotypes, prejudices, and discriminatory actions that are conceived, felt, and acted upon on as a result of as person's age.[23] These can be experienced at the intrapersonal, interpersonal, and institutional/systematic levels—for instance, thinking that older people are difficult to deal with, are frail and helpless, or ignoring older people's needs in favor of those of younger patients.

Perhaps the biggest barrier facing individuals with an SUD is the stigma associated with these disorders. In fact, there exists such a gap between the number of individuals with SUDs and those who receive any form of treatment for them in any setting that the National Institute on Drug Abuse identified understanding and decreasing the stigma of SUDs as a major priority moving forward.[24] Stigmas set an individual or group apart from "normal" society, thus inviting stereotyping, prejudice, and negative actions towards those who possess what sociologist Erving Goffman called the "mark of disgrace."[25] Substance use disorders are more highly stigmatized than any other health condition; therefore, individuals living with them experience negative reactions at a higher rate.[26] These individuals are more often perceived as dangerous or unpredictable, unable to make autonomous decisions about treatment or finances, or blameworthy or responsible for their SUD, non-compliance to treatment, and/or moral failures.[27] This perception not only comes from the public, it persists in the medical field. It manifests in the form of lower-quality care and hesitance or resistance to administering certain types of treatment. It can affect the individual with an SUD in the form of self-stigma; that is, awareness of public attitudes, beliefs, and behaviors towards someone with their illness can affect mental and physical health.[28] This can lead to lower self-esteem, decreased self-efficacy, and feelings of uselessness. Structural stigma also occurs in the form of lower levels of funding for treatment, limited access to treatment modalities, and other institutional policies that enhance stigma and further marginalize those with an SUD.[29]

The use of stigma-reduction methods for healthcare professionals and paraprofessionals can aid in the reduction of stigma towards individuals with SUDs. Such methods include educational interventions where participants learn about the SUD, stigma, and their effects on health; skill-building activities that allow providers to acquire skills to work with stigmatized populations; hands-on learning wherein participants actively assist in interventions with stigmatized populations; group contact that also involves working alongside persons with lived experience; and structural changes that involve policy changes at the institutional level, providing clinical materials or facility restructuring.[30]

Ongoing prejudice and discrimination towards those with an SUD can create a barrier to PC treatment—particularly those with an opioid use disorder (OUD), considering pain management is a key component of PC.[31] A 2016 study of physicians in various fields showed high levels of desire for social distance from people with an OUD: many were unwilling to have a person with prescription OUD marry into the family (79%) or to work closely with the respondent on the job (77%). More than half (66%) viewed people with a prescription OUD as more dangerous than the general population.[32] Palliative care providers remain hesitant to provide care to a chronically ill person with any history of an OUD for a variety of reasons. One recurring theme is, as one PC nurse put it: "We are not trained in addictive medicine."[33] Others fall back on misconceptions and misrepresentations of OUDs fueled by structural and public stigma: "This is not a comfortable situation for a clinician to be in, where now I have to be a cop."[34] This quote also alludes to another concern within the medical community: the possible legal ramifications of exceeding prescribing limits or the repercussions associated with unintentional consequences such as an overdose. These, in and of themselves, attach stigma related to the prescriber's intentions and actions.[35]

Ongoing stigma towards individuals with past or current histories of OUD in these instances only serve as yet another barrier towards PC. For instance, individuals who have a debilitating or terminal illness may qualify for PC at some point over the course of their illness. During this time, they may also require pain management. Chronic pain management for those with an SUD is already of concern, especially considering it is known that individuals with active or history of substance abuse are known to be at high risk for undertreatment for pain.[36] So while diversion or misuse of pain medications in palliative or hospice care may be related to OUD, other factors such as those related to maladaptive coping (chemical coping) or uncontrolled pain may also be a cause. Those with an active SUD are also at a disadvantage in places that cannot or will not accommodate current/ongoing drug or alcohol use. This may put an additional burden on their health if they are denied PC or are forced into withdrawal.[37] The question becomes whether it is more important to address the SUD or relieve the patient's suffering from their life-limiting illness and highlights ethical dilemmas created by a desire to control the SUD and balance symptoms of their illness.

Denying equal access to PC on the basis of a stigmatized condition challenges the bioethical principles of justice, beneficence, and nonmaleficence. In bioethics, justice refers to the idea that everyone should have equal access to healthcare. The principle of beneficence requires providers to provide the most beneficial care, while nonmaleficence asks them to "do no harm."[38] Denial of care on the basis of status as an active substance user calls all of these principles into question and may be considered unethical. It could also be argued that requiring PC candidates to be non-users challenges the principle of respect for autonomy, which acknowledges that autonomous individuals are free to make their own decisions so long as they are cognitively capable and it is an informed, voluntary decision. Contingencies such as non-usage may be considered coercive and impact the patient's decision. Lack of understanding of these issues can compromise palliative or hospice care for an individual with an SUD who is often under more scrutiny than other "normal" patients. Currently there is a paucity of studies regarding hospice and PC medicine providers' competence to diagnose SUDs, but one study did

show that less than half (48%) had a working knowledge of addiction, and a majority (60%) had four hours or less training on opioid misuse.[39]

Acknowledging that there are gaps both in the administration of PC to individuals with SUDs and the amount of empirical research being done to analyze and address such gaps is vital to the process of improving and enhancing PC for this population. It is promising that there is growing academic interest in this issue, as the paucity of literature is in and of itself an ethical concern. No universal solution currently exists. However, there are strategies that may be useful in alleviating inequities that still exist in PC models. Although systematic research of PC for individuals with an SUD is scarce, what we can draw from what little research we do have on this population, as well as documented experiences of addicted and non-addicted individuals in PC, may be useful in the generation of recommendations for improving and enhancing current models of PC to include the needs of those living—and dying—with an SUD.

Recommendations for General Palliative Care Improvement

A 2020 review of challenges present in the provision of PC for cancer patients noted that there were several policy and/or payment-level challenges to implementing and maintaining adequate PC, including lack of funding, lack of a comprehensive national PC plan, a fragmented or weak healthcare system, and lack of government support.[40] On a global scale, the WHO identifies lack of integration of PC into national health policies and systems as a barrier to it.[41] As for the United States, the National Academy of Medicine (NAM) recommends financial and policy reform by public and private insurance and healthcare delivery programs for patients with serious illnesses or in need of end-of-life care. They note that any financial incentives that currently exist are written into Medicare and Medicaid reimbursement guidelines, often resulting in fragmented care and an increased risk of unnecessary services that would itself constitute Medicare fraud and/or abuse.[42]

Issues such as these at the policy and payment levels of care can be addressed by designing and implementing a national PC policy. This can be achieved through the involvement of stakeholders, budget support, and negotiating for secure government or health insurance funding provisions. Enhancing and increasing research about PC were also identified as essential policy facilitators that help in identifying the needs of and gaps present in the delivery of PC. In 2014, the World Health Assembly approved its first global resolution on PC, calling upon the WHO and its Member States to improve access to PC as a core component of health systems.[43] In an attempt to address gaps that persist in access and utilization of palliative services globally, they emphasized the need for national-level changes that include: health system policies that integrate PC services into national healthcare systems; policies that strengthen and expand human resources, including training of existing health professionals and inclusion of palliative curricula into training programs for new health care professionals; educating volunteers and the public; and policies that ensure the availability of "essential medicines" for managing symptoms, particularly opioid analgesics.[44]

Recommendations from U.S. stakeholders such as the NAM, CAPC, and the National Palliative Care Research Center are like those of the WHO. These organizations emphasize the need for policies that enhance clinician skills, workforce development, increased public awareness (especially at the state level), payment reform, enhanced quality and standards for PC services, and promotion of PC research.[45] Since the recognition of PC as a distinct medical subspecialty in 2008, organizations such as the CAPC and National Palliative Care Research Center have offered guidance at the state and national level to address these concerns. Some states have passed laws that require continuing education in PC and closely related topics such as pain management and safe opioid prescribing. Private health plans now recognize and require clinician training in basic palliative components. In the United States, there is now board certification in PC for physicians and PC certification for nurses as well.[46] Changes in payment systems are also progressing. Medicare allows specific payment for advance care planning and complex chronic care management. Several private insurance companies are also changing the way they address payment for PC at hospital and non-hospital levels. To address the issue of quality of PC, the United States' National Quality Forum established the Geriatrics and Palliative Care Standing Committee to more rigorously review and enhance quality measures for older adults receiving PC services. Research focused on PC has also received more attention and funding in recent years.[47]

What some of these global- and national-level reports sometimes fail to consider or adequately address are the barriers to PC that exist within organizations, such as limited physical infrastructure and geographical considerations that could hinder access.[48] These could be addressed within policies created at the state, national, and global level—specifically those related to funding, training, and workforce. While gaps in these areas persist, progress in recent years is encouraging. A micro-level analysis of the barriers to PC shows that individual- and social-level barriers largely focus on knowledge, attitudes, beliefs, skills, and the culture of families, healthcare practitioners, and the public. Barriers could be addressed by providing continuous education for providers as well as adequate education to patients, families, and the public regarding PC services. Person-centered PC that includes cultural aspects of care and values patients' personal preferences and beliefs is another step towards enhancing access to and provision of these services.

Recommendations for Palliative Care Improvements for Individuals with Substance Use Disorders

As stigma continues to hinder efforts to provide equitable care for individuals with SUDs in general aspects of healthcare, let alone for specialty services such as PC, the consensus among providers and consumers of such services is that there is a lack of education both on PC and SUDs. One way to address this is to provide healthcare providers with foundational understandings of stigma and how it manifests in healthcare. The use of a theoretical framework such as the Health Stigma and Discrimination Framework would be beneficial in this regard, as it updates previous frameworks that tend to focus on one condition in isolation or generally only mental health conditions.[49] The Health Stigma and Discrimination Framework follows the process of stigmatization across the socio-ecological spectrum of health, which varies according to economic context. It also makes an important distinction from other

frameworks in that it does not distinguish the "stigmatized" from the "stigmatizer," thus eliminating the chance of developing an "us" versus "them" mentality that is inherent in the stigmatization process. This framework could not only be used in clinical training but also as a guide for intervention development, measurement, research, and policy.

Another approach to mitigating stigma in the treatment of individuals with SUDs is the use of "dignity-enhancing care." Initially developed by Chris Gastmans for nursing practice, dignity-enhancing care privileges dignity while providing care.[50] Respect for dignity has come to mean different things depending on the interpretation of what "dignity" means. Whether one believes it is dependent on merely being human, or that dignity is bestowed upon all from God, dignity-enhancing care speaks to the assertion that respect for dignity is an ethical imperative—regardless of an individual's status.[51] Individuals with SUDs are often not treated with dignity because of their health condition. Dignity-enhancing care uses lived experience as a starting point to address this. It employs interpretative dialogue as a normative standard to access the other's lived experience. Respecting a person's dignity requires understanding the person holistically; this is achieved through effective, meaningful communication. The aim of the communication is to understand the patient as a person and then, after multiple dialogues between the patient and provider team, to design the care plan.[52] The purpose of this approach is to heal, not simply to fix the wound. This is particularly important in palliative patients, who are striving to find ways to improve their quality of life while living and dying with serious illnesses.[53] This is evident in the increased push for "death with dignity" laws that have passed in recent decades.[54]

Provider education should also include a component that focuses on SUDs, as they are not isolated to any aspect of healthcare. As reports have shown, interest in and need for PC training for medical students and nurses is on the rise. Despite this, there is a distinct lack of experience in PC staff with individuals with an SUD. These individuals interact with the healthcare system for similar reasons as the general public, so it is vital that healthcare professionals have a basic understanding of the pathology of SUDs and their effect on all aspects of health. Education of this type complements and supports any education of stigma and stigmatizing health conditions.[55]

Public education on SUDs has changed dramatically over the course of the first part of the twenty-first century. In a sharp contrast to the punitive nature with which drug use and misuse was handled in the twentieth century, the U.S. federal government has gradually shifted its drug control approach to a policy focused on prevention, treatment, and rehabilitation. In 2018, the U.S. Surgeon General released "Facing Addiction in America: The Surgeon General's Spotlight on Opioids," which calls for a change in the way society addresses SUDs.[56] It emphasizes the importance of focusing on prevention and treatment and considering the biological, psychological, and social factors that influence SUDs. This change in focus can facilitate more cogent understandings about SUDs and influence the way in which people who have SUD engage with the healthcare system. However, media continue to control certain narratives about the opioid epidemic that perpetuate negative stereotypes about substance use/misuse in general.[57] Creation of public health educational campaigns such as "Stop the Stigma" serve to inform the public about the realities of SUDs and may also help mitigate personal-level stigmas that often prevent people from seeking help for their SUD. On the same level, public health campaigns for PC like the Public Health Strategy developed by the WHO can also promote awareness and education surrounding PC services.[58] The hope is to make PC and discussions about end-of-life services more common and easier to access.[59]

Provision of PC services must also adapt to provide equitable care for individuals with SUDs. This will require organizational changes, as policies and procedures for caring for this population within the purview of PC are underdeveloped or nonexistent. These may include changing the way(s) in which PC patients are screened for drug use/misuse; developing/expanding interdisciplinary relations with departments such as addiction therapy to provide additional, disease-specific supports; incorporating evidence-based treatments such as medication-assisted treatment and/or harm reduction methods into PC; and collaborating with researchers to develop/improve protocols for individuals with SUDs within the health system being served.

Conclusion

Ideally, it is the hope that the convergence of all these things will provide, at a minimum, adequate PC services throughout global healthcare systems. Global/national level policy changes, changes in organizational infrastructure, updated health provider curricula and training, and community/personal level interventions such as public health campaigns may all have a unique, positive effect on individuals with SUDs and people in general with regards to access to and experiences in PC. The desire for social justice in medicine in the form of equal access is not a concept that is relegated to principle-based ethical decision-making that is popular in Western bioethics; the desire to recognize, respect, and uphold the dignity afforded in all by God has become an edict in Judeo-Christian medicine.[60] Recognizing that every human has equal value in the eyes of God means that we recognize the dignity and vulnerability of others, regardless of where they are in their lives—from beginning to the end. In Pope John Paul II's encyclical letter *Evangelium vitae* he wrote:

The dignity of life is linked not only to its beginning, to the fact that it comes from God, but also to its final end, to its destiny of fellowship with God in knowledge of love of him.[61]

Understanding this, it is important for healthcare providers who are followers of Christ to advocate for patients who may benefit from PC—especially those who are particularly vulnerable to stigma and discrimination. In the meantime, it is essential that all stakeholders in palliative care focus on issues at every level of care to ensure equitability for everyone who would benefit from its services—including those with an SUD.

Notes

1. "Substance Use Disorders," in *Lexicon of Alcohol and Drug Terms* (Geneva: World Health Organization, 1994), 60, https://apps.who.int/iris/handle/10665/39461.

2. "Palliative Care: Key Facts," World Health Organization, August 5, 2020, https://www.who.int/news-room/fact-sheets/detail/palliative-care.

3. "Palliative Care: Key Facts."

4. "Palliative Care: Key Facts."

5. "Palliative Care Facts and Stats," Center to Advance Palliative Care, 2014, https://media.capc.org/filer_public/68/bc/68bc93c7-14ad-4741-9830-8691729618d0/capc_press-kit.pdf.

6. R. Sean Morrison et al., *America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals* (New York: Center to Advance Palliative Care and the National Palliative Care Research Center, 2019), 12, https://www.capc.org/shop/americas-care-of-serious-illness-a-state-by-state-report-card-on-access-to-palliative-care-in-our-nations-hospitals_7/.

7. Carmen W. H. Chan et al., "Nurses' Perceptions of and Barriers to the Optimal End-of-Life Care in Hospitals: A Cross-Sectional Study," *Journal of Clinical Nursing* 29, no. 7–8 (2019): 15, https://doi.org/10.1111/jocn.15160.

8. J. Randall. Curtis et al., "Why Don't Patients and Physicians Talk about End-of-Life Care? Barriers to Communication for Patients with Acquired Immunodeficiency Syndrome and Their Primary Care Clinicians," *Archives of Internal Medicine* 160, no. 11 (2000): 1690–96, https://doi.org/10.1001/archinte.160.11.1690.

9. Richard B. Balaban, "A Physician's Guide to Talking about End-of-Life Care," *Journal of General Internal Medicine* 15, no. 3 (2000): 195–200, https://doi.org/10.1046/j.1525-1497.2000.07228.x.

10. Curtis et al., "Why Don't Patients and Physicians Talk about End-of-Life Care?" 1691–92.

11. Curtis et al., "Why Don't Patients and Physicians Talk about End-of-Life Care?" 1691–92.

12. Ramona L. Rhodes et al., "Barriers to End-of-Life Care for African Americans from the Providers' Perspective: Opportunity for Intervention Development," *American Journal of Hospice & Palliative Medicine* 32, no. 2 (2015): 139–41, https://doi.org/10.1177%2F1049909113507127.

13. Rhodes et al., "Barriers to End-of-Life Care for African Americans from the Providers' Perspective," 141.

14. Morrison et al., *America's Care of Serious Illness*, 21.

15. Diane E. Meier, "Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care," *Milbank Quarterly* 89, no. 3 (2011): 353, https://doi.org/10.1111/j.1468-0009.2011.00632.x.

16. Pippa Hawley, "Barriers to Access to Palliative Care," *Palliative Care and Social Practice* 10 (2017): https://doi.org/10.1177/1178224216688887.

17. Albert J. Finestone and Gail Inderwies, "Death and Dying in the US: The Barriers to the Benefits of Palliative and Hospice Care," *Clinical Interventions in Aging* 3, no. 3(2008): 595–99, https://doi.org/10.2147/CIA.S2811.

18. Hunter Groninger and Michael Knapik, "Twelve-Step Programs and Spiritual Support at the End of Life," *American Journal of Hospice & Palliative Medicine* 36, no. 9 (2019): 807, https://doi.org/10.1177/1049909119832809.

19. Annie Fahy, "Invisible and Overlooked: Substance Use Disorders in Aging Adults," in *The Praeger Handbook of Mental Health and the Aging Community*, ed. Doreen Maller and Kathy Langsam (Santa Barbara, CA: Praeger/ABC-CLIO, 2018), 141–62.

20. Justin Christopher Yang, Andres Roman-Urrestarazu, and Carol Brayne, "Binge Alcohol and Substance Use Across Birth Cohorts and the Global Financial Crisis in the United States," *PLoS One*13, no. 6 (2018): e0199741, https://doi.org/10.1371/journal.pone.0199741.

21. Thomas L. Patterson and Dilip V. Jeste, "The Potential Impact of the Baby-Boom Generation on Substance Abuse among Elderly Persons," *Psychiatric Services* 50, no. 9 (1999): 1184–88, https://doi.org/10.1176/ps.50.9.1184.

22. Fahy, "Invisible and Overlooked," 147–51.

23. "Ageing: Ageism," World Health Organization, March 18, 2021, https://www.who.int/news-room/questions-and-answers/item/ageing-ageism.

24. Lawrence H. Yang et al., "Stigma and Substance Use Disorders: An International Phenomenon," *Current Opinion in Psychiatry* 30, no. 5 (2017): 378–88, https://doi.org/10.1097%2FYCO.0000000000000351.

25. Mike Fitzpatrick, "Stigma," *British Journal of General Practice* 58, no. 549 (2008): 294–95, https://doi.org/10.3399%2Fbjgp08X280092.

26. James D. Livingston et al., "The Effectiveness of Interventions for Reducing Stigma Related to Substance Use Disorders: A Systematic Review," *Addiction* 107, no. 1 (2011): 39–41, https://doi.org/10.1111%2Fj.1360-0443.2011.03601.x.

27. Yang et al., "Stigma and Substance Use Disorders," 378–88.

28. Magdalena Kulesza, Mary E. Larimer, and Deepa Rao, "Substance Use Related Stigma: What We Know and the Way Forward," *Journal of Addictive Behaviors, Therapy & Rehabilitation* 2, no. 2 (2013): 782, https://doi.org/10.4172%2F2324-9005.1000106.

29. Yngvild Olsen and Joshua M. Sharfstein, "Confronting the Stigma of Opioid Use Disorder—and Its Treatment," *JAMA* 311, no. 14 (2014): 1393–94, https://doi.org/10.1001/jama.2014.2147.

30. Laura Nyblade et al., "Stigma in Health Facilities: Why It Matters and How We Can Change It," *BMC Medicine* 17, no. 1 (2019): 25, https://doi.org/10.1186/s12916-019-1256-2.

31. David Hui, Joseph Arthur, and Eduardo Bruera, "Palliative Care for Patients with Opioid Misuse," *JAMA* 321, no. 5 (2019): 511, https://doi.org/10.1001/jama.2018.18640.

32. Alene Kennedy-Hendricks et al., "Primary Care Physicians' Perspectives on the Prescription Opioid Epidemic," *Drug and Alcohol Dependence* 165 (2016): 66–67, https://doi.org/10.1016/j.drugalcdep.2016.05.010.

33. Diane E. Meier and Larry Beresford, "Safely Managing Pain: People With Serious Illnesses—Palliative In Practice," Center to Advance Palliative Care, 2018, https://www.capc.org/blog/palliative-pulse-the-palliative-pulse-december-2018-balancing-pain-treatment-with-risks-of-comorbid-substance-use-disorder-for-patients-with-serious-illness/.

34. Meier and Beresford, "Safely Managing Pain."

35. Kelly K. Dineen and James M. DuBois, "Between a Rock and a Hard Place: Can Physicians Prescribe Opioids to Treat Pain Adequately While Avoiding Legal Sanction?" *American Journal of Law & Medicine* 42, no. 1 (2016): 21–28, https://doi.org/10.1177%2F0098858816644712.

36. Dineen and DuBois, "Between a Rock and a Hard Place," 5.

37. Marguerite Russo, "Comorbid Addiction at the End of Life: A Theoretical Approach," *Journal of Pain and Symptom Management* 43, no. 2 (2012): 469–70, https://doi.org/10.1016/j.jpainsymman.2011.12.260.

38. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics,* 7th ed. (Oxford: Oxford University Press, 2013).

39. Julie W. Childers and Robert M. Arnold, ""I Feel Uncomfortable 'Calling a Patient Out'": Educational Needs of Palliative Medicine Fellows in Managing Opioid Misuse," *Journal of Pain and Symptom Management* 43, no. 2 (2012): 254.

40. Hammoda Abu-Odah, Alex Molassiotis, and Justina Liu, "Challenges on the Provision of Palliative Care for Patients with Cancer in Low- and Middle-Income Countries," *BMC Palliative Care* 19 (2020): 55, https://doi.org/10.1186/s12904-020-00558-5.

41. "Palliative Care: Key Facts."

42. Elizabeth H. Dobbins, "Improving End-of-Life Care: Recommendations from the IOM," *The Nurse Practitioner* 41, no. 9 (2016): 26–34, https://doi.org/10.1097/01.NPR.0000490388.58851.e0.

43. José Miguel Carrasco et al., "Early Impact of the 2014 World Health Assembly Resolution on Palliative Care: A Qualitative Study Using Semistructured Interviews with Key Experts," *Journal of Palliative Medicine* 24, no. 1 (2021): 103–06. https://doi.org/10.1089/jpm.2019.0384.

44. "Palliative Care: Key Facts."

45. R. Sean Morrison et al., "America's Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation's Hospitals," *Journal of Palliative Medicine* 14, no. 10 (2019): 1094–96, https://doi.org/10.1089%2Fjpm.2011.9634.

46. Morrison et al., "America's Care of Serious Illness," 1094–95.

47. Morrison et al., "America's Care of Serious Illness," 1095–96.

48. Abu-Odah, Molassiotis, and Liu, "Challenges on the Provision of Palliative Care for Patients with Cancer in Low- and Middle-Income Countries," 55.

49. Gary Witham et al., "An Ethical Exploration of the Narratives Surrounding Substance Use and Pain Management at the End of Life: A Discussion Paper," *Nursing Ethics* 27, no. 5 (2020): 1344–54, https://doi.org/10.1177%2F0969733019871685.

50. Chris Gastmans, "Dignity-Enhancing Nursing Care: A Foundational Ethical Framework," *Nursing Ethics* 20, no. 2 (2013): 142–49, https://doi.org/10.1177/0969733012473772.

51. Susan Haack, "Christian Explorations in the Concept of Human Dignity," *Dignitas* 29, no. 3 (2012): 4–7, https://cbhd.org/content/christian-explorations-concept-human-dignity.

52. Gastmans, "Dignity-Enhancing Nursing Care," 142–49.

53. Adele Flaherty, Fahmida Hossain, and Alexa Vercelli, "Meeting at the Crossroads of Pain and Addiction: An Ethical Analysis of Pain Management with Palliative Care for Individuals with Substance Use Disorders," *Journal of Opioid Management* 17, no. 3 (2021): 207–14, https://doi.org/10.5055/jom.2021.0631.

54. Cicely Saunders, "The Evolution of Palliative Care," *Journal of the Royal Society of Medicine* 94, no. 9 (2001): 430–32, https://doi.org/10.1177/014107680109400904; Mara Buchbinder, "Access to Aid-in-Dying in the United States: Shifting the Debate from Rights to Justice," *American Journal of Public Health* 108, no. 6 (2018): 754–59, https://doi.org/10.2105/ajph.2018.304352.

55. Jeremy C. Kane et al., "A Scoping Review of Health-Related Stigma Outcomes for High-Burden Diseases in Low- and Middle-Income Countries," *BMC Medicine* 17, no. 1 (2019): 17, https://doi.org/10.1186/s12916-019-1250-8.

56. Sharon Reif et al., "The Washington State Hub and Spoke Model to Increase Access to Medication Treatment for Opioid Use Disorders," *Journal of Substance Abuse Treatment* 108 (2020): 33–39, https://doi.org/10.1016/j.jsat.2019.07.007.

57. Fiona Webster, Kathleen Rice, and Abhimanyu Sud, "A Critical Content Analysis of Media Reporting on Opioids: The Social Construction of an Epidemic," *Social Science & Medicine* 244 (2020): 112642, https://doi.org/10.1016/j.socscimed.2019.112642.

58. Conor Trindle, "Public Awareness Campaign to Push Benefits of Palliative Care Launched," Big News Network, September 15, 2020, https://www.bignewsnetwork.com/news/266401635/public-awareness-campaign-to-push-benefits-of-palliative-care-launched.

59. "Changing How We Think about Palliative Care," American Hospital Association, accessed March 23, 2021, https://www.aha.org/center/palliative-care.

60. Quentin I. T. Genuis, "Dignity Reevaluated: A Theological Examination of Human Dignity and the Role of the Church in Bioethics and End-of-Life Care," *The Linacre Quarterly* 83, no. 1 (2016): 6–14, https://doi.org/10.1179/2050854915y.0000000010.

61. Genuis, "Dignity Reevaluated," 11.