The Oxford Textbook of Palliative Social Work

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SECOND EDITION

Terry Altilio, Shirley Otis-Green,
and John G. Cagle

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We dedicate this book to palliative and hospice social workers—both the seasoned practitioners with their wealth of experience and wisdom as well as the fledgling learners, who are poised to enter our field. Your hard work, challenging questions, and commitment inspire and sustain us. You continue to build and shape our specialty by learning, questioning, practicing, teaching, researching, advocating, and leading—to ultimately serve our patients, families, profession, and communities with ever expanding competence and compassion.

To those whose voices are reflected in these pages . . .
Voices— past & present
calm & cacophonous
compassionate & caring
courageous & confrontive
halting & hesitant
heard & unheard
joyful & jubilant
mellow & meek
pleading & piercing
raging & raucous
soft & sorrowful
tender & tremulous
May this work hone our listening and bring excellence to our response.

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Forewords

Susan Blacker

The publication of the Second Edition of this important social work textbook provides the opportunity for us to collectively reflect and honor social work leadership in palliative care—past, present, and future. Two decades have passed since a formalized vision for the full potential of social work as a core profession within palliative care began to take shape.[1] This vision, of course, had roots in the experience and wisdom of social workers practicing in specialties such as cancer care, hospice, and HIV/AIDS programs. It was recognized that to evolve as a distinct specialty within the profession, as was occurring in medicine and nursing, palliative care needed to become a focus within social work. Training programs were needed, based on competencies and standards of practice, and those social workers already working in palliative care and hospice needed support, further education, and research to affirm their practice and to demonstrate their full potential and impact.

Palliative care as we know it today was still emerging in the early 2000s, when the opportunity for social workers to be part of a national leadership dialogue and change movement focused on improving care of the dying came about through important initiatives—including the Social Work Leadership Development Award program (Project on Death in America/Open Society Institute).[1, 2] This particular program, under the direction of Grace Christ, DSW, provided financial support to further the innovative ideas of 42 social workers in five cohorts selected for their potential to make a significant impact on care for those with serious illness within their organization's scope and sphere of influence. It provided a unique opportunity for social work experts to become visible and accessible leaders in both profession-specific and interdisciplinary arenas.[1]

These projects focused on practice, education, and research and were varied and successful, but what was even more transformative was what happened when these social workers came together and imagined more possibilities. The creation of a social work agenda in end-of-life and palliative care was identified as an essential and strategic next step to propel the profession within this field forward. This resulted in the convening of two international Social Work in Palliative Care Leadership Summits, which occurred in 2002 and 2005. These strategic meetings brought together social work clinicians, educators, researchers, and leaders of organizations with an interest in or focus on social work and/or palliative care and challenged them to define a pathway to advance the profession in this expanding field of practice.[3] Participants came from the United States, Canada, United Kingdom, and Singapore. The overarching aims were to continue momentum within the profession to make end-of-life and palliative care an important strategic area of focus; further develop a network of organizations and leaders; create a mechanism for collaborative efforts; further the profession's evolution in the areas of policy/advocacy, practice, research, and education; and identify key strategies, initiatives, and action plans to achieve these goals.[3]

Looking back, we can see that these efforts were foundational for the profession and identified the need for so much that we can point to today that did not exist only two decades ago:

- The National Association of Social Workers (NASW) Standards for Palliative and End-of-Life Care
- Masters-level courses and post graduate certificate programs in palliative care offered at multiple schools of social work and post-master's fellowship programs for advanced training
- *The Journal of Social Work in Palliative and End-of-Care*
- The Social Work Hospice and Palliative Network (SWHPN)
- An exam-based Advanced Palliative Hospice Social Worker Certification (APHSW-C)
- The First Edition of this very textbook.

Social work and palliative care leaders around the globe have looked to, and built on, these efforts—creating other important change initiatives. The Social Work Competencies on Palliative Education (SCOPE)[4] in Canada (Canadian Hospice Palliative Care Association) is one example, and the European Association of Palliative Care's Social Worker Task Force and its competencies project are yet others.[5]

Today, social workers are working in positions within palliative care programs that simply did not exist 20 years ago. They are providing mentorship for an ever-increasing number of new social workers who are interested in end-of-life care, taking on project and program leadership roles, presenting and writing about their ideas and experiences, and generating new knowledge through research. Yet, despite the tremendous growth of social work in palliative care, in many ways the aims of the leadership summits continue to be just as relevant for our profession today. We will come to fully understand the toll of a global pandemic and how it has illuminated in new ways the essential need for palliative care expertise and capacity within the healthcare system. With the palliative approach becoming even more integral to serious illness care, we can further define the areas of practice, education, and research that we are so well equipped to lead. And it is imperative to redouble our commitment and efforts to ensuring equity for all with respect to access to high-quality care at the end of life.

The history of social work in palliative care is—in and of itself—a remarkable story of how social workers can use their skills of influencing, negotiating, collaborating, and consensus building to define and advance a common goal. The leaders who championed the development of a clear vision and roadmap for the advancement of social work in palliative care knew what was possible. The editors and authors of this book have importantly documented what the profession has since become. And its readers will bring this ever-expanding and deepening knowledge base to the care of patients and families of the future.

Together—with shared purpose and values—we can continue to face the challenges and embrace the opportunities for social work in palliative care through the next two decades.

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Betty R. Ferrell

I concluded my foreword for the First Edition of this book in describing the *Oxford Textbook of Palliative Social Work* as defining the field and that in doing so "there is no turning back." Fortunately, the leaders in palliative social work have not turned back; they have continued to be strong voices of advocacy for patients and families facing serious illness. The first edition of a textbook is sometimes a bold leap into the unknown. It is an important leap defining the presence of an undeniable force and in so defining, the field is changed, the splash becomes a presence and a voice that can't be silenced. A second edition is a different endeavor. It is the invitation to dive deeper. It is an opportunity to consider the ripples from the first edition but now to dive deeper, challenge the field, honor the advances in the field but do what social workers do best—ask the difficult, deeper questions.

Our field of palliative care is quite young in many respects, a few decades that are attempting to disrupt centuries of healthcare that have denied most of the precepts we hold to be true about quality care for patients, families, and communities. Patient autonomy, informed choices, patient values, social justice in healthcare, psychosocial and spiritual support—these are still fragile concepts in a reductionist paradigm of care focused on the disease, not the person living with the disease. Yet the field we share as an interdisciplinary endeavor is rapidly advancing and enormous changes in palliative care have occurred in the short span of years since the First Edition of this Text was written. Political and social events have created doubt about our true intent to honor all people and to strive for equal access to care. The poorest and most vulnerable? They have become poorer and more vulnerable just in the time since the First Edition was written—and more voiceless in a system dominated by forces that do not reflect the essential domains of the social work profession.

This Second Edition was published in close proximity to the initiation of specialist-based credential of Palliative Social Work—a defining moment for the field. This Text defines that specialty field and is its foundation. This Second Edition takes seriously the challenge of developing evidenced-based practice; this is not a meaningless academic pursuit but rather a commitment to advocate for care that honors the people we serve through scientific care and measurable outcomes. That is the essence of defining any profession—a group of people who are committed to the needs of society. No one takes that challenge more seriously than social workers.

In recent years, in my own work as a nurse in palliative care, I often cite definitions of the term “palliative care” in my lectures, papers, and other work. I cite the National Consensus Project definition, the World Health Organization definition, and the developing evidence base for our field which is helping us to refine those definitions. But I then generally conclude that my favorite definition of all is this: Palliative care is the kind of care we would want if we, or someone we love, is facing serious illness.

I can tell you with all certainty that the palliative care I want for myself and those I love includes a social worker. I am incredibly grateful to the authors and editors of this Text which give me confidence that I will receive that care.

Kathleen M. Foley

The chapter titles in this new expansive edition tell the story well. Together, they provide both extraordinary evidence and true validity to the expansive leadership role of social work in every aspect of palliative care. Since the First Edition, groundbreaking research and policy reform have ended the debate about the scientific underpinnings of palliative care and its contribution to improved patient and caregiver outcomes. Multiple studies in both resource-rich and resource-limited countries demonstrate that palliative care improves the quality of life for patients and their families. When used concurrently with new technologies, such as innovative chemotherapy in cancer patients or cardiac assist devices in patients with cardiac disease, studies show that palliative care improves quality of life, mood, and symptom control and facilitates patient and family decision-making.

The World Health Organization in 2016 led with policy reform passing its timely resolution calling on countries to integrate palliative care into national healthcare systems.[1] In 2018, the Lancet Commission report on *Alleviating the Access Abyss in Palliative Care and Pain Relief—An Imperative of Universal Health Coverage*[2] furthered support for this integration by demonstrating practical methods for countries to use to assess “serious health related suffering” as an indicator of the need for palliative care, thus launching a major effort to help country policymakers assess and budget for palliative care services. A new, expanded, consensus-based definition of palliative care has emerged defining palliative care as “the active holistic care of individuals across all ages with serious health related suffering due to severe illness and especially of those near the end of life.”[3] (p.754) As well in 2018, Pope Francis led a Vatican-based initiative called Pal-Life[4] encouraging all countries to expand palliative care programs and, in 2020, the World Health Organization again reiterated the essential role for palliative care in public health during the COVID-19 pandemic.

This new edition highlights these transformative events in clinical science and policy. Yet only a few countries include palliative care in their universal health coverage programs. Adequately and appropriately calculating the costs of palliative care by government healthcare economists has thwarted its full incorporation into national health plans. Lack of comprehensive data on the costing of social work services has added to the difficulties of developing costing models that can be readily adapted at a country level to ensure full access to social work expertise.

This Text stands as the authoritative source for the clinical imperative of full social work integration and gives witness to the critical role of social work expertise in the care of patients and families. Social workers are essential members of the team as evidenced by the professional contributions described in this Text. The future for financial reimbursement to sustain the expansion of this essential expertise seems optimistic, given the degree of professionalism and high-quality standards currently supported by social work leaders in palliative care.

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George Handzo

I am honored to write in support of this wonderful volume and the wonderful professionals who have contributed to it. I am fortunate to have been trained my whole career to believe that those we serve are best cared for if social workers and chaplains are a close team representing the psychosocial-spiritual component of care. In my first year of seminary, by chance, my "field placement" was at a group social work agency where I learned to run groups for children and adolescents. Thus, I learned about social work practice before I learned how to do ministry. In over 20 years as the chaplain for pediatrics at Memorial Sloan-Kettering Cancer Center, I would not have imagined working with a patient and family without coordinating with one of the pediatric social workers. We brought distinct skill sets and scopes of practice, but they were complementary—and I was always convinced that we added more value working together than we did working separately.

It was only well into my career that I realized that the systems we work in all too often set chaplaincy and social work against one another, competing for the scarce resources often allocated to psychosocial-spiritual care. In these systems, we have sometimes lost sight of the reality that the best chance of increasing those resources and improving care is to work together, coordinate our care, and advocate together for the high standards of care we all believe in. While every palliative care model and guideline emphasizes the need for both a social worker and a chaplain on the team, it is still too often true that one or both are absent. So there is much work to do.

I trust that this volume will be a major resource to bolster the case for palliative social work and educate both social workers and members of other disciplines on the important contributions social workers make and how they get it done. In solidifying and supporting best practice in social work, it will raise the bar for all of us. My gratitude to the editors and to all who have made contributions to this volume. People will receive better care because of this work.

Matthew J. Loscalzo

It is not possible to talk about this Second Edition of the *Oxford Textbook of Palliative Social Work* without rooting its parallel story with the COVID-19 pandemic and the glaring inequities that have been exposed. From its inception as a profession, social work has had a particular commitment to caring for populations who have been treated inequitably, especially the poor. This does not mean that physicians, nurses, psychologists, chaplains, and others are not also responsible for promoting equity and fairness. They are. But there is an inescapable, special, and specific ethical charge to social workers to be advocates and unrelenting compassionate warriors for social justice. There is no space in this struggle for social workers who are not well versed in the true meaning of the biopsychosocial-spiritual model! Thankfully, this Second Edition could not be written at a better time.

It is the foundation of social work to be the connectors of the biopsychosocial-spiritual model of care, as we are the *connective tissue of the healthcare system*. Our credibility and most meaningful contributions result from this multidimensional perspective in synergy with evidence and strengths-based interventions that create the potential for generalized growth in one's personal and social life. It is essential that we understand our lives as they are, without delusions: inevitable periods of suffering, too-limited time with those we hold most precious, and pervasive social inequality and unfairness to be confronted. All create opportunities for personal accountability to make things better and for courageous and relentless resistance to what has become the existing "comfort with corruption." Our acts of applied compassionate expertise and aspirations to attain personal meaning are highlighted in the words, wonderings, and wisdom of the authors in this Text.

Levels of wellness and health are inextricably linked to social equity. The pandemic of 2019–2021 lifted the veil on multiple pernicious and long-standing institutionalized inequities across social strata. In many ways, the present crisis hearkens back to the pandemics of the 14th century and in 1918, where there were also unconscionable wealth and resource imbalances reinforced by impermeable social structures. Across these pandemics, the stories are the same as today: Poverty drives the degree of vulnerability and suffering, while racism and political opinions (masquerading as religious moralism), reinforces the dehumanization and demonization of the most vulnerable populations.

In the past and at present, across the globe, corrupt "*strong men*," posing as leaders, have been able to effectively use the *old reliable* levers of separation, isolation, and decimation. But this is a dangerously incomplete story. There are always opportunities for the bold. Following both the 14th century and 1918 pandemics, there were major changes set in place in the social structures that directly led to greater social mobility overall. In the United States, an already powerful women's movement for the right to vote gained even greater momentum and ultimately achieved victory in 1920; this was no accident. Clearly, there remains much to be done to seriously address the need for voting rights equality and to reverse the inequities that continue to speak loudly to a profession committed to social justice, and there is a unique opportunity to do so.

Yet the point is that social disruption is always an opportunity for change—*Never wait for the cement to dry*!

Building on the successful First Edition of the *Oxford Textbook of Palliative Social Work*, the Second Edition is more diverse in almost every respect. This enhancement has paid off in the breadth, depth, and usefulness of the rich content. Although the textbook still covers the essentials of what matters most to patients and their families in palliative care, this edition also, quite wisely, goes to the foundational elements of collaboration with other healthcare professionals and leadership, and addresses the importance of creating and maintaining mentally healthy social work teams. The contributing authors are national and international pioneers in palliative care. These are leaders who support and enrich the foundation of the specialty, working day after day to model exemplary social work and palliative care practice while others find their voice in academic, institutional, and policy leadership. Ultimately, the *Oxford Textbook of Palliative Social Work* clearly illustrates the role of social work as the "connective tissue" across the health and illness spectrum. This bottom-up and top-down strategic approach captures the true richness of the contributions to biopsychosocial-spiritual care in a manner that is applied, practical, and at its best—strengths-based. This blend of what exists, and even more, what is possible, builds on the past, while reimagining leadership roles for social justice and the celebration of unleashed human potential.

Diane E. Meier

The central thesis of palliative care is that human suffering is important and worthy of attention inside healthcare systems. Not only does the field call attention to the reality of suffering in its many forms but also to the growing evidence that standardized approaches to assessment, treatment, and follow-up can significantly reduce suffering and return the person to a life that they consider to be worth living. Therapeutic nihilism—often expressed with the phrase "there's nothing more that we can do"—is no longer acceptable. There is always the possibility of addressing and reducing suffering through expert care, attention, and focus on what is most important to the patient, their families of origin, and choice. Because suffering may manifest in physical symptoms like pain or difficulty breathing; or in emotional distress like anxiety and depression; or in existential-spiritual torment like a sense of meaninglessness and loss of identity and purpose; or in overwhelming strains on families and care partners—palliative care must be delivered by an interprofessional team representing the range of disciplines trained to identify and intervene in this broad spectrum of human experience. As articulated in the guidelines of all four editions of the National Consensus Project for Quality Palliative Care, specialty-level palliative care must include professionals from social work, chaplaincy, nursing, and medicine in order to reliably help patients and their families.

Roughly 80% of disease and its consequences have been traced to what are often referred to as the social determinants of health—things like having a living wage, safe housing and neighborhoods, protection from the stresses of violence, poverty, and despair, access to nourishing food and transportation, and being part of a network of supportive family and community. Only 20% of disease and suffering has its root specifically in de novo medical illnesses such as genetic disorders or childhood cancers. If ours were a logical system, most people working and most of the money in healthcare would be under control of social workers, followed by nurses and chaplains, with doctors reserved for those times when surgery or medical therapies would make a difference. Much of the over $3.6 trillion spent annually in the United States on medical care would instead be allocated to building safe and healthy neighborhoods, providing a guaranteed income, and ensuring equitable access to quality education. But we do not work in a logical system. We work in a medical industrial complex, spending far more than any other country and achieving some of the worst health outcomes among other developed nations.

- The United States spends more on healthcare as a share of the economy—nearly twice as much as the average Organization on Economic Cooperation and Development (OECD) country—yet has the lowest life expectancy and highest suicide rates among the 11 nations.
- The United States has the highest chronic disease burden and an obesity rate that is two times higher than the OECD average, both due to consequences of poverty.
- Compared to peer nations, the United States has among the highest number of hospitalizations from preventable causes and the highest rate of avoidable deaths.

Palliative care is a grassroots response to the illogical society and healthcare system in which we find ourselves. People in our field name and shine a light on the patient and family suffering that we see in our society and our healthcare systems—the rapid spread and success of palliative care in recent years suggests that others can see it, too, and want to respond to the human suffering all around them. I think about palliative care as a Trojan Horse—bringing into the house of medicine a revolutionary approach to care—learning about the person in front of us; understanding what is important to them and what they need to get there; and working with them to achieve those goals. Our field offers a reminder to medicine of the need to return to its "true north"— with a focus on providing personalized, contextualized care from a whole person perspective. And as healthcare moves from the hospital into the community, our palliative social work colleagues' commitment to social justice becomes ever more critical.

Palliative social workers are essential in furthering this healthcare transformation—whether providing evidence-informed interventions, modeling nuanced communication, advocating for policies that address the social determinants of health, engaging in innovative research, or seeking resources as often what patients need most is food, housing, money, transportation, and human care and support.

> *"Not everything that is faced can be changed, but nothing can be changed until it is faced."*
>
> James Baldwin

We have to see and name what is wrong in order to change it. Social workers live in reality and help the rest of us to do so, too. This textbook shines a light on how social workers see and engage with reality alongside our patients and their families. It is a great place to get a handle on the ways in which our health system and society fails the people it is meant to serve—and how social workers never look away.

Russell K. Portenoy

The Second Edition of the *Oxford Textbook of Palliative Social Work* is a milestone in the decades-long evolution of palliative care as an interprofessional model of healthcare for populations with serious chronic illness. It is an essential resource for those trained in social work who seek a deeper understanding of palliative care to inform work in the hospital, nursing home, or community, and for those social work professionals who choose to acquire specialist competencies in this discipline. It is also a record of the progress realized by this young discipline and a testament to the creativity and clinical acumen that has brought this progress to the profession of social work.

The focus of this consequential volume is social work, but its organizing framework derives from a clinical imperative that has driven acceptance of palliative care in many professions. The *Oxford Textbook of Palliative Social Work* promotes a vision of professional caregiving that needs constant renewal and emphasis, and it has been characterized as patient-centered, whole-person, humanistic, and family-focused—caregiving that is specifically intended to mitigate the suffering and burdens of illness experienced by seriously ill patients and their families, particularly in the context of advanced illness and imminent dying. This vision acknowledges the complexity of human suffering, the manifold sources of distress reported by patients and their families, and the importance of individual variation in the response to an illness and its consequences.

Social work is particularly attuned to this complexity. Its core practices begin with the premise that variation in the experience of illness extends well beyond medical realities to reflect a continually shifting array of interactions between the individual's psychology, culture, faith, and other factors, family dynamics, and social determinants of health. The *Oxford Textbook of Palliative Social Work* is a strong introduction to many of these issues, all in the context of serious chronic illness.

Although intended for social workers, the *Oxford Textbook of Palliative Social Work* also describes the contours of the discipline in broadly applicable terms. In this sense, it joins other tomes intended for physicians, nurses, or others in providing an interprofessional foundation for palliative care. It furthers an international effort to build consensus about the definition and nature of the discipline. Consensus-building of this type is essential if the principles and precepts of palliative care are to be translated into the best practices and professional competencies that can improve outcomes for the very ill and their families.

Although the consensus-building role played by this volume and other major texts is implicit, it is extremely important and worthy of some historical context. The term "palliative care" dates to the mid-1970s, when Dr. Balfour Mount applied the term to a new clinical service at Montreal's Royal Victoria Hospital. This service, which grew to include inpatient consultations, an inpatient unit, and a home care program, was created to provide comprehensive medical, nursing, psychosocial and spiritual care for cancer patients with advanced illness. "Palliative care" was derived from the Latin word meaning "to cover or cloak" and was used to avoid negative connotations related to an older term, “hospice,” which was commonly viewed as place that provides end-of-life care.

Although “hospice,” from the Latin word meaning host and guest, has for centuries been applied to home-like units that care for the dying, the modern use of the term dates only to the mid-1960s, when Dame Cicely Saunders established London’s St. Christopher’s Hospice as a treatment setting for those with advanced cancer and short life expectancies. This model of hospice provided comprehensive care to the patient and family to improve the quality of life at the end of life, and in so doing, increase the likelihood of a comfortable and dignified dying, with suffering minimized for the patient and family.

Beginning in the 1970s, pioneering clinicians in many countries recognized the challenges faced by patients and families living with advanced illness, the limitations of conventional healthcare systems in ameliorating suffering at the end of life, and the importance of a whole-person approach to the care of the chronically ill. These clinicians took note of the models developed by Saunders, Mount, and others, and they designed and implemented numerous programs that mirrored their operational components. The design of these programs was determined by local resources and needs; some were described as palliative care and some as hospice, and there was no set of distinguishing services connected to each of these labels.

This formative period was ripe for confusion about the definition and nature of the comprehensive care model developing to address suffering in the context of serious chronic illness. This confusion increased several decades later when the oncology community adopted the term “supportive care” to describe another, similar care model, which pursued the same objectives as palliative care and hospice, but also focused on problems related to antineoplastic therapy and sometimes survivorship. Other programmatic labels and terms appeared around the same time—“palliative medicine” and “psycho-oncology,” for example—and potentially added to confusion about the core elements of a growing clinical discipline.

Remarkably, a 2013 systematic review of the peer-reviewed literature from 1948 to 2011 identified 24 published definitions for palliative care, 17 definitions for hospice, and 13 definitions for supportive care.[1] A qualitative review of the English and German literature found 37 English and 26 German definitions for palliative care or palliative medicine[2] and another systematic review of the English literature found 17 definitions of supportive care.[3] Even as recognition of hospice and palliative care in many types of service delivery systems effloresced, and its powerful messages about the value of holistic healthcare took root, there was poor agreement about the definition and core principles, and the ability to develop best practices and standards aligned with these principles was hampered.

Fortunately, this problem was recognized, and efforts were joined to establish international consensus about the definition and core principles that are the foundation of clinical programs. Progress has been made and major textbooks devoted to the field, including this one, have assisted in the development of common understandings.

In 1990, a working group of the World Health Organization (WHO) posited that “palliative care is the active total care of patients whose disease is not responsive to curative treatment.”[4(pp.11–12)] This definition noted that palliative care “regards dying as a normal process . . . [and] neither hastens nor postpones death” and stated that “aspects of palliative care are also applicable earlier in the course of illness.” It averred that palliative care “requires a team approach, which recognizes that all healthcare workers have roles to play.”

This early statement of key principles has been very influential but did not by itself redress the nomenclatural inconsistencies and diverse interpretations being applied during the creation of clinical programs. It could not inform the development of professional competencies or establish practice standards for palliative care.

A working group of the European Association for Palliative Care (EAPC) subsequently proposed additional defining elements for palliative care.[5,6] This work supported the WHO definition—noting that palliative care “affirms life and regards dying as a normal process . . . neither hastens nor postpones death and sets out to preserve the best possible quality of life until death”[4]—and adds that palliative care “is interdisciplinary in its approach[,] encompasses the patient, the family and the community in its scope, [and provides] for the needs of the patient wherever he or she is cared for. ”

The EAPC undertook a formal consensus-building approach to further refine the core principles, norms and standards for palliative care.[7] The group of European experts who contributed concluded that respect for patient autonomy and support for patient dignity are core values, and that a multiprofessional and interdisciplinary approach to the management of complex needs is required to support the array of services necessary to improve quality of life in the context of serious illness.

Although the challenge of end-of-life care was emphasized in the consensus-building process undertaken by the EAPC, neither the specific diagnoses that would qualify a patient for palliative care nor the centrality of end-of-life care to the clinical discipline yielded broad agreement. Subsequently, however, a consensus has emerged that palliative care is appropriate for any population with any type of chronic disease that is not curable and may foreshorten life—variably described "life-limiting," "life-threatening," or "progressive and incurable." Short prognosis may increase the need for interventions that reflect the objectives of palliative care, but imminent dying does not describe a qualifying condition. Instead, a palliative care approach is appropriate from the time of diagnosis, and for this reason, most interventions that promote palliative care objectives are delivered by primary clinicians during the routine management of chronic illness.

A more recent initiative by the International Association of Hospice and Palliative Care (IAHPC) endorses the key elements of prior work and expands on several of them.[8] This work was the culmination of a consensus process that first engaged a multidisciplinary group of 38 individuals in 22 countries, and then surveyed more than 400 IAHPC members working in 88 countries. The definition states that palliative care is the "active holistic care of individuals across all ages with SHS [serious health-related suffering] . . . and especially of those near the end of life." The central aim is to improve the quality of life of patients, their families and their caregivers through prevention and management of physical, psychosocial, and spiritual concerns. It states that palliative care is needed throughout the course of an illness, in conjunction with disease-modifying therapy, and it highlights the importance of communication, goal-setting, and respect for the culture and values of the patient and family. Importantly, it explicitly states that palliative care is provided routinely by professionals with "basic palliative care training" and that patients or families with complex needs may benefit from access to specialists working in multi professional teams.

Although palliative care continues to be poorly understood by the lay public, this consensus-building has led to a gradually improving understanding on the part of healthcare professionals. Palliative care is now widely viewed as a model of care, with key definitional elements, core principles, and a clinically essential framework of best practices, norms, standards, quality metrics, and professional competencies. Diverse types of healthcare delivery systems and many types of healthcare professionals provide interventions that address the objectives of palliative care. Although there is wide variation in practice, and ongoing concerns about the ability of systems and caregivers to meet the ever-expanding needs of chronically ill populations, particularly in resource-poor environments, a growing understanding of the model of care is a necessary step in the global effort to improve access to palliative care. Work that continues in many countries, exemplified by the *National Consensus Project Practice Guidelines for Quality Palliative Care* ((4th edition)) in the United States,[9] may continue to reduce variation in palliative care delivery systems, driving innovation, supporting codification of professional competencies, and improving the likelihood of positive outcomes as palliative care is integrated throughout healthcare systems.

The *Oxford Textbook of Palliative Social Work* makes a major contribution to this remarkable evolution of a discipline in healthcare. It is a timely record of the advances that have been made in the profession of social work, a roadmap to encourage best clinical practices, and a sign of continuing progress in the ability of social work professionals to provide competent palliative care to growing populations with serious illness.

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Preface

> Be a voice not an echo.
>
> — *Albert Einstein*

The Second Edition of the *Oxford Textbook of Palliative Social Work* has been a true *labor* of love. This edition was conceived to help coalesce and honor the growing body of knowledge available to enhance the practice and advocacy efforts of palliative social workers. Our intention is that this repository of clinical wisdom and empirical guidance will improve the care, interventions, and support that we provide to the patients and families whom we serve. Our desire to advance the field and inspire excellence is tempered by a recognition that, as a profession and as human beings, we continue to evolve and learn. To this end we readily admit that, despite containing over 100 chapters, the content herein is only part of a larger and ongoing conversation about who we are as palliative social work professionals and individuals.

The launching of the Second Edition of the Oxford Text began in July 2019—a time that seems so far removed from the tumultuous world that evolved. As we joined authors from around the world, the global COVID-19 pandemic and tragic public killings of Black people demanded that we look at ourselves, others, and the institutions that we support, and that support us. We were, and continue to be, challenged to stay committed and true to our professional values—without becoming jaded, compromised, or complicit—in this venerable mission of building and providing exceptional palliative and hospice services for all.

COVID-19 brought us all closer to the world of patients and families and the uncertainty and threat that are often unwelcomed companions of serious illness. This uncertainty and threat, for some, was compounded by the reality that their identities, how they looked, or the language they spoke may impact the care they could receive from systems that have been less than trustworthy. The life-threatening reality of COVID-19 demanded that many communities had to interact with the very systems that have delegitimized their illness experience, exploited, neglected, and underserved them. Ethical decision-making went on public display with open conversations about which populations deserved access to limited resources. The choice to wear a mask was politicized and infused with controversy not only about the nature of the "truth" of the pandemic but also about the values we hold dear—individual freedom weighed against responsibility to our fellow companions on this planet. Individual autonomy was at odds with serving the greater social good. We have been witnessing and living *relational ethics*—listening to varied views of what guides our relationships and responsibilities to each other.

The definition of "essential workers" provided another lens to view the impact of inequities that put some at greater risk of illness and death than others. Conversations about racism, entrenched white privilege, how Black Lives Matter, social justice, systemic, and structural inequities joined conversations about our intersectional identities and collective priorities. As this Text evolved, so too did conversations, dialogues, and disagreements about how best to describe the unique identities of persons who make up the mosaic of our world. These "essential" conversations began months ago as we were asked to consider whether including a chapter specifically focused on the care of the LGBTQ community contributed to further "othering." Through many communications and exchanges we have explored this and other topics of similar sensitivity. We were very clear about capitalizing "B" when referring to Black individuals, but struggled with when, where, and whether to capitalize the "w" when referring to White persons or when mentioning white supremacy.

We pondered questions with authors during the meticulous process of editing this Text. What is the attributed meaning of using first names of patients no matter their respective identities and roles? We wondered how culture and geographic variables influence those clinical decisions. And we made choices amidst a complex and rapidly changing landscape of language—choices you will encounter as you move through this Text, which invite your attention and thoughtfulness—decisions with which you may or may not agree.

The ubiquitous presence of technology demanded our participation in a most intimate and inhumane act as we watched cell phone footage of the second-by-second account of George Floyd's life being publicly and brutally taken from him. We have witnessed the ripping away of children from their families at our borders, inviting us to reflect on the histories shared across many communities—children sold during slavery, Indigenous children sent away, families exterminated through genocide. As a profession and a specialty that honors each unique life, we served those impacted by COVID-19 and watched as the number of deaths rose to over 4.5 million worldwide. We worked and adapted to meet the soaring needs of patients, families, and colleagues as we experienced a sociopolitical system seemingly unable to move beyond historic silos, politics, and obstructionism. We learned to value, perhaps as never before, the people who drive our buses, stock our shelves, deliver our food, and clean our health spaces. And we came in close touch with the structures that perpetuate the health and living conditions that inform the imbalance and simple unfairness of how the inequitable impacts of social determinants of health translate to the *millions* who have lost jobs, homes, and too often, their lives.

Amid all of this, our authors adapted their work worlds, their family lives, and sequestered precious time to write chapters enriched by their lived experiences, knowledge, practice wisdom, and the concurrent sociopolitical contexts—assaults on truth and values we have for so long held close. We have all been asked to look at what it means to be a profession with a social justice mandate; a profession which uses language and silence as foundational tools in its work. And some continue to question whether we, as social workers, have muted our singular and collective voices rather than naming and confronting the many oppressive and traumatizing forces that contribute to human suffering, which we are called to assuage and palliate.

It is in this context that the authors and editors have written and rewritten. We are confident that the chorus of diverse and competing voices has made this a better book—demanding that we hold ourselves accountable as a clear and emanating voice, rather than as an "echo" in palliative and hospice care. Authors have raised questions that were not explored in the inaugural Text when our identities and position within this specialty were still closely linked to the authority of our nurse and physician colleagues. Over the past decade social work practice has continued to integrate scientific data, not using such data to essentialize the individuals we meet, but rather as one aspect of the richness of this work that evolves from the blend of knowledge and narratives—the unique stories patients and families bring.

This Second Edition looks at the language surrounding palliative care and hospice and the values which frame this work, inviting a consciousness of its marriage to Western values. The primacy of "education and information," "self-determination," "individual autonomy"—ideas that frame palliative care dialogue do not always cohere with spiritual beliefs, cultural values, and the varied "ways of knowing" central to mastery for many. Authors have broadened the concept and process of advance care planning to recognize the place of relational autonomy affirming the essential importance of relationship and conversation—which for many families will never make its way to a signed legal document. This Second Edition broadens the concept of caregiver to invite the choice to use "care partner" as more reflective of many relationships and of the clinical goal of supporting independence and agency as the balance in relationships may or may not be impacted by the illness itself.

Authors have contributed chapters on many discreet interventions, linking available data to narratives, to inform our work, whether practice, policy, education, or research. Such chapters encourage practitioners to move beyond describing their profound and rich work as simply "provided support" as they communicate within teams and in clinical documentation. Our practice is intentional, deliberate, evidence informed—and most of all—person centered.

Palliative social work is an extraordinary, exciting, demanding, and humbling field. We bear witness to the impermanence and richness of life's journey, the incredible toll of illness, resilience, tenacity, and the intimacy of human connection. While we practice as individuals, our work is interprofessional, interdependent, interconnected, and interwoven. This profession requires a curious mind and impassioned spirit. It summons our sense of compassion, quiet patience, respectful humility, a sustained commitment to discovery, and working at the top of our professional credentials. This Text weaves together the foundations of social work practice and its world view. It is intended to capture the breadth and depth of the specialty, not as the consummate body of our professional knowledge, but rather as a reflection of how far we have come as a field *and* as a fervent call to action to address the many inequities that have existed for far too long.

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SECTION I

Converging Contexts of Care

"It is so important to advocate for things that may not always seem possible. Getting to work with patients/families at the end of their life is the ultimate honor."

~Lauren G. Markham, MSW, LCSW, APHSW-C

"In this work, one witnesses both depths of human suffering and heights of human transcendence that can inspire both awe and fear. At those times, I have found that surrendering my need to be ' an expert' and instead, allow myself to simply be a ' human' is the wisest action."

~Kerry Irish, LCSW, OSW-C, FAOSW

"Never underestimate the power of deep presence, generous listening and compassionate curiosity."

~Lori Eckel, LCSW, APHSW-C

"I don't seek out the storms, but I'm always learning to let them teach me, and to serve as a hearthstone for purposeful engagement of this great work. Always learning. Always curious. Always in awe of the privilege we share in holding grace and space for the benefit of others."

~Cryss BlackWolf, MSW, LSWAIC

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Centering the Lens of Social Justice

Eucharia Borden, Meagan Lyon Leimena, and Bridget Sumser

> Justice is what love looks like in public.[1]
>
> **—Cornel West**

Palliative care is rooted in the conceptualization and application of whole-person care. Since its inception, palliative care has gathered the voices of many to best understand the dynamic experience of people living with serious illness and facing the end of life. Interprofessional collaboration in direct clinical care, program development, education, policy, and research is essential to this mission and inherently creates high-quality care while informing healthcare at large.

The field of social work is rooted in a commitment to social justice emanating from an analysis of how power, privilege, and oppression impact everyone. "Full and equal participation of all groups in a society that is mutually shaped to meet their needs, social justice includes a vision of society in which the distribution of resources is equitable" and all members of a space, community, or institution, or society are "physically and psychologically safe and secure."[2(p.21)] All dimensions of social work practice aim to understand and fundamentally address the inherent inequality of our social systems with a critical analysis that considers the micro through the macro. Equality and equity are key concepts to distinguish. Equality is seeking to achieve an outcome such as fairness by giving everyone the same access or allotment. Equity, in pursuit of the same goal, seeks to achieve this by giving access or allotment based on need and circumstances. This is important for social workers to metabolize as it demands an appreciation of being where an individual is, with a keen understanding of the multifactorial influences acted upon them. Thus, the traditional model of biopsychosocial-spiritual care requires a critical understanding of social and political structures that create explicit experiences of power and oppression. This practice spans micro, mezzo, and macro realities, and it is personal, in that it is dynamic and relational between social workers and those who they work with and serve. Macro realities specifically include an active recognition of the ways social workers participate in and perpetuate our social and political systems. Additionally, awareness of the micro brings attention to the macro—the practice of palliative care varies regionally across the globe, depending on the political and economic realities, and cultural agreements.

This chapter will explore theoretical frameworks to both complicate and clarify lived experience of patients, families, and self through systems of power as well as tools for reflection to catalyze self-awareness. The intent is to understand the impact of the pervasive sociopolitical systems of oppression, namely imperialism, patriarchy, and white supremacy. Legal scholar Frances Lee Ansley's distinction of white supremacy is instructive to guide conceptualizing this oft used term:

> By "white supremacy" I do not mean to allude only to the self-conscious racism of white supremacist hate groups. I refer instead to a political, economic and cultural system in which whites overwhelmingly

> control power and material resources, conscious and unconscious ideas of white superiority and entitlement are widespread, and relations of white dominance and non-white subordination are daily reenacted across a broad array of institutions and social settings.[3] (p.1024)

To further contextualize this term for the purposes of this chapter, white supremacy is being used here to illustrate the deeper genesis and driving motivations of other related concepts like white privilege and institutional racism. Grounding this in palliative care practice, to examine and challenge white supremacy, would be to hold the experiences of marginalized peoples, including Black, Indigenous, and People of Color, within the healthcare system. How do the underlying values of Western medicine, such as autonomy, relate to the lived experience of our patients? To be curious about this experience requires a critical awareness and critique that understands autonomy as a Eurocentric value system that does not apply to all people. It includes attention to the values and frameworks centered in our language, both medically and culturally, that often prize personal responsibility, autonomy, productivity, and outcomes. Additionally, not utilizing interpreters appropriately (asking family members to act as translator) does not center the psycho emotional needs of patients and families; rather, it prioritizes or accommodates a system that is not built to easily support people who primarily speak languages other than English.

This is a lifelong praxis—the weaving together of theory and practice to create action that is self-aware.[4] Humility, curiosity, and flexibility are foundational capacities strengthened over time, promoting our ability to see new aspects of what may seem to be a familiar landscape. At some point, this becomes the way you see the world. This awareness and critique, matched with personal action and coalition building, make social change possible. For the authors, this starts with a clear declaration that this chapter has been written across race—Black and White voices working together to speak to a common vision amid the most outwardly racially charged time in decades. To not name this explicitly would be to participate in the system that expects academic work to be disconnected from the personal, therefore potentially perpetuating assumptions as to whose voices are centered and dominant in the literature.

Academic texts often aim to write theory that is timeless. It is impossible to explore theories seeking to challenge and deconstruct systems of power and oppression without grounding examples in present-day realities. As this chapter is being written in 2020–2021, it explores the theories of the ecological systems model, intersectionality, and anti-racism, as well as the impacts of the COVID-19 pandemic, and the many public murders of Black people in the United States by police. At any time in history, these theories, and the lens they co-create, can be applied to individual and collective experience. We write about them today, with a deep hope that at some point in the future, they will feel historic and will have become the fuel for profound societal transformation.

Foundational Theories and Concepts

Praxis is an iterative process by which a theory is enacted, embodied, or realized and further revised. It is a process of integration that relies on self-awareness and practice over time. It evolves as we grow and learn, make mistakes, reflect, and try again. It goes beyond the application of a theory or knowledge base, beyond directions of what to do or not do. Praxis creates a space of listening and reflecting; it is relational and lived.[5]

This chapter explores the theories of ecological systems theory, intersectionality, and anti-racism to set a backdrop for the text at large while suggesting the possibility that palliative social work is always a social justice practice. These theories are lenses to locate yourself and examine the ways your location informs your work—how your unique and overlapping identities impact how you approach your work, your responsibilities, and your rights. These theories presume everything making you who you are, including family of origin, religion, your relationships to dominant social and cultural forces, to name a few, also shape you as a social worker who is working in our complex social and medical systems of care. While these ideas may not be explicitly cited in every chapter in the book, they are an invitation to enhance critical thinking regardless of topic. May they accompany your reading and reflection, informing your capacity and confidence to catalyze social change, centering the experiences of those historically marginalized.

Ecological Systems Theory

Urie Bronfenbrenner originally developed the ecological systems theory to explain child development, but it has since been extrapolated to other populations and settings. This is an approach commonly used in social work training and education, familiar to many as a means of conceptualizing the influences on an individual. Using a division of interpersonal and social distinctions, the theory offers an explanation for the various spheres individuals inhabit and the ways their systems overlap to shape human development, relationships, and experiences.[7] Briefly, the microsystem (micro) refers to the smallest unit within which an individual orbits, including their most intimate spaces and relationships of home, family, and friends. The mezzosystem (mezzo) refers to a larger system within which an individual interacts—the aspects of the community where working, learning, travel, and transactions occur. The macrosystem (macro) refers to the largest social spheres of impact—political, social, and cultural systems and influences. Macro-level forces are both seen and unseen, affecting our political climate and shaping laws, customs, and institutions. These spheres overlap and interact to shape us all.

This theory is often invoked for social workers to access greater understanding of the patient-family context and to address the social determinants of health. For palliative social workers, it is essential to consider these spheres of influence when thinking about illness, healthcare access and use, advance care planning, and bereavement. The home where a patient lives, from its structure and access to caregivers, can shape their health, experience of illness, and treatments. The landscape of neighborhoods and communities, including the presence of environmental toxins, can create and ripen opportunities for certain diseases. They can also influence the trajectory of an illness, from the proximity and quality of pharmacies, transportation, and healthcare facilities to the availability of healthcare providers who share culture and language.[8–10] And in the United States, few, if any, illnesses or end-of-life experiences exist outside of the systems of healthcare financing, including insurance coverage and individual financial responsibilities for care and caregiving. Using the lens of these systems is instructive for social workers to maintain a multidimensional view of a patient as a person living in a complex world, shaped by dynamic forces. These forces can intermingle as well. A religious tradition might strongly influence a patient's treatment decisions, advance care planning, caregiving preferences, end-of-life wishes, and the bereavement of family and friends.[11,12]

Importantly, this theory can also be used for self-examination and self-reflection. With the intention of understanding influences and opportunities for intervention, perhaps the theory can best be harnessed as a way to begin a critical inward evaluation of ourselves, to locate what shapes and animates us, both personally and professionally. Engaging with families who have sick infants or children receiving palliative care services might feel especially tender for social workers who have lost a child due to illness, accident, or a pregnancy loss, or for families at similar stages of life. Working with patients who have radically different lives, politically, socially, and interpersonally, might stretch a social worker to expand or reimagine their frameworks about clinical practice, family, work, or civic participation.

This self-evaluation can include our most intimate spaces of upbringing and family and move outward, to team, communities, and the larger societies in which we traffic to know what we bring to the profession and practice of social work. For example, consider the mighty forces of families of origin and creation, systems of education, including social work curricula, and relationships of power and privilege one social worker brings to their practice. In palliative care, where we are repeatedly given the opportunity to examine the preferences and priorities of patients, we have the same opportunity to examine what we bring to our work.

To personalize, we bring the micro environments of our families, including birth order and roles within family structures. Perhaps this influences how we manage conflict or power struggles, the roles we fulfill on teams, or the situations we embrace or avoid in our practice. For example, if forming alliances has been a historically protective and useful practice for someone as they negotiate relationships, this might be enacted in professional teams as a means to manage group dynamics. If someone primarily values a Western model of medicine over more holistic approaches to care, they might undervalue the role or utility of alternative and complementary therapies—consciously or unconsciously. Further, the language we choose, the cultural mores we embrace or delegitimize, and the power structures we identify with all influence our work. In social work education, training and practice, the ongoing exercise of examining countertransference is an established pathway for this examination. For many, this practice may have historically excluded rigorous and honest assessment of one's location to power, privilege, and oppression. A place to begin is to acknowledge and be open to interrogating these influences—and then deepen with iterative examination and action.

Palliative care itself is an invitation for analysis of these spheres of influence applied not only to those we care for but to the larger systems driving healthcare access and quality, as well as our responsibilities within them. The idea of parallel process might be useful in conceptualizing for oneself, as we can appreciate the incredible value in understanding the myriad influences guiding a person facing a life-threatening illness, the many ways the care we provide is equally shaped by the influences of our families, communities, and relationships to power and oppression.

Intersectionality

> I am suggesting that Black women can experience discrimination in ways that are both similar to and different from those experienced by white women and Black men.[13(p.149)]
>
> —*Kimberlé Crenshaw*

The theory of intersectionality, developed by Kimberlé Crenshaw, a leading scholar of critical race theory, was born out of the Black feminist movement.[13] Intersectionality identifies the interconnected nature of social categorizations (including but not limited to race, class, and gender) creating overlapping systems of discrimination or oppression.[14] The theory of intersectionality was a direct response to the ways in which white feminism did not account for the experience of Black women, as being Black and a woman compounds the individual experiences of racial and gender-based oppression to create a third intersected space.

Importantly, intersectionality can be used to better understand experiences of power and oppression, and the ways one person can experience both. For those who fall dominantly on the side of the privileged, the concept of intersectionality invites a space of reflection as to how best to use that privilege in service of justice and equity, while recognizing the symbolic relevance of our social identities. For example, when walking into the room of a patient, who do they see? How does who they see relate to who they are? Research shows that patients across racial backgrounds prefer "like" providers.[15] Paying attention to racial alignment or difference within the existing power dynamic of the clinician–patient relationship may provide insight in the process of rapport building. Without being prescriptive, is it possible to be curious about the interpersonal, relational experience and meaning of intersectional identities. A beginning: as social workers, we have a historical understanding that some may have a negative response to the notion of a "social worker." When meeting a patient, if you notice a certain recoil when you introduce yourself as a social worker, can you be curious about where that comes from? How would you explore their reaction? Surfacing past experiences of patients and families promotes an opportunity for rapport and trust building. These experiences may directly relate to parts of our identities. How do we respond? How do we show up fully to what is happening relationally across identities? How do we address the desire to be cared for by someone with a similar lived experience if this is not possible? By asking these questions, we can find our ways into authentic and explicit engagement with the power dynamics that present themselves in myriad ways between any two (or more) people. This is a practice toward the full "use of self" and requires self-inquiry into what our identities may represent to others.

Positionality is the social and political context that creates your identity in terms of race, class, gender, sexuality, and ability status. Positionality also describes how your identity influences, and potentially biases, your understanding of and outlook on the world.[16] Understanding our positionality helps us move away from a concept of social justice that focuses on service to marginalized communities without consideration of our own role within systems of power. This service to others without critical reflection bypasses the intrapersonal work of understanding how we have each been socialized by systems of power and oppression, and therefore, how we may unintentionally perpetuate the same systems most of us would say we work against. For example, when White people identify as "not racist," it can be hard to understand, reflect on, or take responsibility for the unconscious microaggressions that are common in healthcare settings.

Intersectionality is constructed of many facets of identity, including race, gender, ethnicity, class, physical abilities/qualities, and sexual orientation, as well as language, nationality, profession, education, creed, political ideology, marital status, military experience, parental status, regional location, and so on. Everyone experiences oppression differently based on their social identities (positionality). The anti-racist scholar Peggy McIntosh defines privilege as "an invisible package of unearned assets that [one] can count on cashing in each day, but about which [one is] 'meant' to remain oblivious."[17 (p.1)] Being in a place of privilege refers to the social identities that benefit from oppression by belonging to a dominant group. Intersectionality highlights the ways we can be simultaneously privileged and marginalized.

Becoming able to identify the culture created by the values and beliefs of the dominant groups enhances our ability to engage and challenge assumptions that work to silence and marginalize in service of maintaining the status quo. That happens interpersonally (micro) through the systemic (macro). By locating ourselves within the systems of power and oppression, dominant and marginalized communities, we begin to lay the groundwork of understanding that can fuel the work of addressing social injustice over time. As social workers, it is easy to identify as a helper, as someone who reaches out in service, a broker and gatekeeper of support and resources. That mentality could lend itself to think social justice practice is about others. If we think the work of social justice is outside of us, it is something that can be paused. For example, while patriarchy positions power with cisgender men, it simultaneously dehumanizes men, asserting that masculinity is unaffected, independent, and untouchable. This creates a culture that stifles emotional and creative expression in men, potentially limiting the potential to experience and make contact with their entire personhood. As such, as a man, to challenge patriarchy serves to promote a world that is equitable and safe for women as well as a world that supports men to express their whole selves. Our liberation—our freedom—is interconnected; the systems that oppress some limit the humanity of all. To understand that, we must seek to better understand ourselves.

> . . . If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.[18]
>
> —*Lila Watson*

Anti-racism

> The opposite of racist isn't "not racist." It is "anti-racist."
>
> —*Ibram X. Kendi*[19]

Race is a socially constructed concept that categorizes and characterizes seemingly distinct populations in order to give or deny benefits and privileges. Race was created largely for the purposes of subjugation for the purposes of exploitation—to make "other" and less human. This enabled a defense of African slavery. Early American concepts of race were utilized to justify the system of capitalism, which was dependent on forced labor and enslavement of African people. Alongside the conceptual development of race was also White and slave—words and concepts that have evolved over time. Racial hierarchy affects every part of life in the United States. Racist policies are rooted in the formation and foundation of this country. To be anti-racist is to fight racism. Anti-racist practice asks that every thought, idea, and action be considered racist or not racist. This binary approach moves away from blanketing individual people as racist (which is often immobilizing), to empower constant reflection and action to create social change. It is not about who you are, but rather, what you do. Anti-racism sees the roots of problems in power and policies rather than individual behavior or groups of people.

Anti-racism requires a thorough understanding of history to grasp how local, state, and federal policies have positioned communities of color to create the current crisis. It also requires an individual understanding of one's own position in a racist society. This awareness informs action at all levels, interpersonally to systemic. Let's explore what such inquiry could look like: Are communities of color cohorted in specific neighborhoods in your local region? How did that happen? Does that create a disparate experience from neighborhoods predominantly occupied by White people? How do you participate in this?

Integrating anti-racism into palliative care practice is multilayered, with different opportunities dependent on one's position and focus of work. It is interesting to interrogate the assumptions of palliative care against a lens of anti-racism. What does the field's commitment to autonomy represent to cultures that do not adhere to the western European and American notions of individualism? When we work consciously to identify values and beliefs to assist in care planning or medical decision-making and invite them to project into the future, are we unconsciously and concurrently asking people to cooperate with a worldview that does not align with their own, perhaps inadvertently overlooking their unique perspectives, history, and lived experience?

Let's consider a patient example regarding decision-making. A multigenerational Black Baptist family has shared repeatedly they cope "one day at a time." Ms. Walker is 98 years old and the matriarch of the family. She is in the intensive care unit, supported by a ventilator and 24-hour dialysis due to advanced heart disease. The healthcare team has taken to calling her Selma as that is how she is known to the wide group of family and church members who visit. The healthcare team is feeling anxious about "prolonging her dying" and would like to have a family meeting to outline what the coming days to weeks may hold and to discuss what Selma "would want." Her family, represented primarily by her oldest granddaughter, has shared they are clear she would want all interventions, as breath is life, and her life in all forms, is a great gift to family; she embodies the family history, the stories and narrative across generations. The team pushes on with a family meeting. Ninety minutes spent reviewing her care and posing potential paths forward and the outcome is the same. The family is clear and requests any interventions that might extend her survival. The team is distressed and talks among themselves about Selma's "suffering." They try to make peace by assuming that Selma's family is pursuing all interventions possible because "they probably don't trust the healthcare system and need to have control."

This is not an uncommon story. If we interrogate this narrative with an anti-racist lens, there are multiple points for action. First, we see the collision of accepted values and beliefs of medical professionals (to not extend dying) with that of a family (to value ongoing life and all that Selma represents by any means possible). By insisting on a family meeting when family has made their preferences clear and have reflected on Selma's wishes, the system is potentially working to break down their position, to convince or coerce them to do something to soothe the angst of providers—an angst informed by institutional pressures such as length of stay and allocation of resources. By asking what Selma would want, there is an assumption that the coherent and consistent guidance of the family has not represented her personhood. This action delegitimizes their role and words, privileging a decision-making style that promotes individualism while assuming Selma's choice would be different than what her family can represent. The comments made after, while an attempt on behalf of providers to make sense of an outcome they cannot control and creates distress, lose sight of the individual and rely on an assumption related to the Black experience of the healthcare system. Anti-racist social work practice would interrupt at every one of these intersections and bring the conversation back to Selma's family structure, their perception of suffering, assisting the team in identifying the values and biases they are projecting onto Selma and her family—to not allow bias and stereotypes to pass unchecked. This would be an opportunity to identify the structural influences driven by finance and regulation, often the ghosts in the room that pass through clinicians to pressure patients and families. Allowing these moments to pass without comment, inquiry and challenge abandon patients and families as well as our palliative care colleagues who aspire to be the best that they can be.

This is not easy work to do. It requires thorough investigation of the values and beliefs that run deep through healthcare representing the cultures that hold power explicitly related to race—whiteness and therefore white supremacy. At times, that could mean breaking away from the safety and comfort that exists on teams because of the ways we are united in ideology that is often assumed and sustained through group think. However, interruption at this level is the work of everyday social work practice and can have a deep and meaningful impact on clinical care, institutions, colleagues, and ultimately, policy. By inviting the depth of discovery that evolves when we move beyond assumption and our bias, the outcomes that were once disappointing can be celebrated as they reflect our best efforts to live the values palliative care and social work ascribe.

More Questions Than Answers

To harness the aforementioned frameworks toward social change and justice, we are left with more questions than answers. While there are obvious applications to clinical practice, education, and research, sustainable change and influence in external spaces requires ongoing self-reflection. Table 1.1 explores potential questions, based on the aforementioned frameworks, to guide inquiry in service of action and honing our ability to understand and appreciate different perspectives. We have chosen examples from clinical practices, not because the actions taken were right, but to offer examples for contemplation and discussion.

Caring for an Interconnected World

We are inherently interconnected and interrelated. From the way we live and work to how we become sick and seek care, we are connected. A public health perspective, for example, demands we think collectively and consider complexities, resiliencies, and vulnerabilities of a group instead of a purely individual perspective, and this shapes decisions about resources—financial, material, and human.[20] Social workers, in training and practice, strive to embrace a systems perspective recognizing the contextualized interconnectedness of individuals and their environments. Further, thinking collectively, we are accountable for equity and justice in greater measure than thinking as individuals.

Privilege and oppression are inextricably linked and socially embedded. Social workers are largely familiar with the person-in-environment approach to contextualizing an individual within their larger environments.[21] Similarly, we as individuals act upon and influence our systems, from our professional clinical interactions to our political engagement and everything in between, in our communities, neighborhoods, and organizations. Our systems, including public health and healthcare, reflect our interdependence. Overarching cultural mores, largely tied to the United States' white, imperialist, and capitalist history, espouse a myth of rugged and exceptional individualism. But we know our safety, health, and well-being are and have always been strongly tied to the actions and decisions of others. Our implicit and explicit biases shape our actions within these micro and macro systems.

We are a collective organism, dynamically influencing each other. At some times more than others. This is shown in harsh relief when families of patients can afford to privately

Table 1.1 Questions to Guide Inquiry and Action

Framework	Questions	
Ecological theory	What is my relationship to autonomy—individual and relational? How do I understand my own overlapping systems? How can I act to influence micro, mezzo, and macro systems?	A 79-year-old Latina patient routinely defers to her daughter and grandson to make decisions about her future care at home in the community and advance care planning. The (treatment) team members want to talk to the patient alone about a skilled nursing facility, with the goal of discerning her "personal preferences." A young, White, cisgender, female social worker on the team reflects the patient's consistently expressed preference for family decision-making and suggests they honor the larger systems in place that support and sustain her in her home and community. How can we advocate on her behalf to support the values she has consistently espoused? How can we identify the values and intentions informing the team's agenda?
Intersectionality	What are my own overlapping identities (race, ethnicity, religion, gender, age, etc.)? How does identity shape experiences with power, privilege, or oppression?	Following a patient's appointment, a White, male physician discusses his astonishment after learning that his retired, 85-year-old Black female patient was "a brilliant physician." A Black, cisgender, female social worker challenges the physician's statement and reaction, pointing out that the patient's characteristics aren't mutually exclusive; stereotypes about patients contribute to ongoing disparities in care.
Anti-racism	Do I understand the history of racist policy in the United States? How do I proliferate racist ideas? Do I speak up and challenge racist statements?	In rounds, a White physician suggests that a Black patient is choosing not to change her code status because "she most likely does not trust the medical system." A White, cisgender queer female social worker reframes to highlight individuality versus generalizations, stating, "It is important to remember the history of medical abuse of marginalized populations while explicitly assessing her choice individually instead of making assumptions about factors contributing to her decision."

pay for a professional caregiver, at a rate below a livable wage, and this caregiver must in turn make decisions about their own family and caregiving options within these financial and practical confines. If, for example, a home health aide is unable to afford safe and reliable child care for their young children, while caring for someone else's parent as their employment, then their collective circumstances are bound together. The privilege of one family depends on the oppression of another. Palliative care is one lens and opportunity through which to view our interconnectedness and to work toward its fullest and best expression. This lens focuses an active and ongoing attention to alignment with oppressive systems and prescribed ways of thinking. While supporting someone at the end of life, if a social worker defines quality of life as the ability to be productive, communicate overtly, and engage with others, then this can stand in direct contradiction to a patient and family who consider the length of life and shared presence as priorities for making healthcare decisions. Social workers can lead in the careful examination of why productivity and external engagement are their metrics of quality of life, and how each has absorbed values, perhaps unconsciously, from the systems and specialties in which they work.

When clinicians can truly center work on the individual, taking the time and energy to co-create a plan of care that is meaningful, then we all stand to gain. Personally and professionally, these clinical relationships and moments can be fulfilling and enriching, both humbling and teaching us. And being a witness to a patient and family experiencing illness, death, grief, and bereavement with authenticity and self-defined dignity might also inspire awe and reflection. Part of the beauty of this work, is how its meaning can be uniquely and personally constructed in our practice.

In healthcare generally, and palliative care specifically, our teams are another example of this expression. An expansive view of the team includes all members of a healthcare facility working in concert to care for a patient and their family. This can include social workers, physical and respiratory therapists, nurses, doctors, patient care technicians, custodians, nutritionists, chaplains, and food service workers, to name a few. If we take a similarly broad view of providing care, then we can invite and appreciate everyone who contributes to care in these settings. Take for example, the seriously ill patient lying in a hospital bed. The medical care they receive from doctors, nurses, and therapists is of clear and irreplaceable value. The same is true for the interventions, integration, and coordination delivered by social workers. And so is the care, service, and consideration of the custodial and nutrition staff, as well as the other agents of the larger hospital system working together to support healing and care. The sheets laundered and changed on the bed where this patient lies are also important and meaningful, though this work is not always recognized explicitly and may be valued differently. Still necessary, and yet ordered or ranked differently, are the individuals who deliver these services. Perhaps reimagining these units as more of a whole, interconnected care system working in concert to promote the sort of high-quality care spoken and written about might elevate us all while simultaneously deconstructing hierarchies. (For additional information, see Chapter 10, “Walking across to Collaboration.”)

The adverse impact of COVID-19 in communities of color, combined with protests in response to police brutality within Black and African American communities (e.g., the 2020 public murder of George Floyd), highlights the imbalances of power, oppression, and privilege. These superimposed constructs led to a national conversation about what is considered essential for Black people to truly live without discrimination and fear. Social injustices have been called out as the world begins to activate the strength of what connects us, such as the desires to be heard, feel safe, be treated equally under the law, and to have life, as well as quality of life. But who defines *quality*? Who gets invited into those conversations? Are the voices of patients and their family caregivers valued and included, or are the voices of palliative care professionals and the cultures of institutions and policy the loudest? When we encounter patient or family systems in target groups for oppression, it is our responsibility to value their dignity and worth as stated in our ethical principles not as an expert but as a partner in shared discovery.[22] Cultural humility, a term coined by Melanie Tervalon and Jan Murray-Garcia in 1998, is a process where one “relinquishes the role of expert to the patient, becoming the student of the patient with a conviction and explicit expression of the patient’s potential to be a capable and full partner in the therapeutic alliance.”[23(p.121)] In subsequent chapters, the three dimensions of cultural humility will be explored more fully: lifelong learning and critical self-reflection; recognizing and challenging power imbalances; and institutional accountability.

Another critical component to examine as you read the chapters that follow are the ways in which we care for one another. At the beginning of the COVID-19 pandemic, the word *essential* became the focus of many articles, news reports, and commercials. Perhaps not used on a daily basis, it is a common term that is widely understood. Essential is defined as something that is of the utmost importance, indispensable or necessary. Items, goods, characteristics, and even people can be described as essential.

Initially, the United States was focused on medical providers and other front-line workers, who were treating or caring for gravely ill patients across the nation. Subsequently, there was a shift to include a focus on essential services, including recommendations for the types of businesses and services that should remain open and available. There was also a focus on products or goods considered essential for sheltering in place for an extended period of time. But, as the virus spread and the number of active cases began to rise, along with the death count, we began to hear about essential measures that were required to slow the spread, and discussions about essential workers broadened. Suddenly, professional groups such as custodial workers, mass transit drivers, grocery store employees, and teachers became the center of our conversations about who were essential to help us care for our sickest patients or teach our children. It became clear that risks taken by *essential* workers were not the same; some essential workers took greater risks as they brought food, transported people, or stocked shelves.

Initially, the world felt like a nation without borders, as though we were on the same team, each doing our part to unite against a silent viral killer that also had no borders. We were asked to find new ways to connect with and support each other from a distance; however, if human beings are inherently social, then what did it mean to maintain distance at a time when we needed each other the most?

Ultimately, more questions than answers began to emerge. How do we care for one another? It’s a simple question with many possible responses; some of which are drastically different pre-pandemic versus post-pandemic. While there was exponential growth in the area of virtual connectivity, there was also exposure to the digital divide. As we focused on offering assistance to those in need (i.e., older adults or those living with disabilities), we were faced with the growing needs, such as access to food, of the millions who became unemployed with each passing week. While some of us were facing the daily challenges of working from home, others were struggling to keep their homes, while many could not stay at home or lived in circumstances that put them at risk. Most disturbingly, as some were figuring out how to live in this “new normal,” inequalities were exposed in ways that could not be ignored. As social workers, it is imperative to use our voices and activate our own collective ability to confront the systems that reinforce ongoing healthcare disparities, racism, and discrimination.

A Call to Action

There is a global call to action to address racial inequity and injustice. The disparities true in our healthcare system at large are blatant as we understand it is Black and Brown communities that disproportionately experience serious illness and death from the coronavirus, already laboring under a burden of disproportionate morbidity and mortality compared to White peers in the United States.[24]

The field of social work can rise to this occasion—social justice is stitched into the very fabric of our profession. Consciousness begins with self-reflection, acknowledgment of our own intersectional identities and privileges, and flows to awareness of oppressive structures.

The work starts by looking inside, by locating ourselves within the systems, in service to the liberation of all. It does end not there. This awareness informs actions to interrupt and build better. Listening to and amplifying marginalized voices silenced within our communities are important steps in addressing injustice. For those learning and teaching in educational settings, including schools of social work, speaking up and speaking out where the structures of white supremacy remain, is both an opportunity and an obligation. This might look like representative faculty and teaching staff and rigorous review of curricula and texts for diverse perspectives, valuing lived experience as well as academic data and traditions. This reflection would include an honest assessment of the role social work has played in the oppression of Black and Brown communities, shining a light on the past to inform the education going forward.

This work is about reconsidering and challenging the status quo in health systems and in the intimate spaces of our palliative practice[25]. It invites voices to articulate that the accommodations that have been made to quality and access are not acceptable. The late Dr. Fitzhugh Mullan, a physician and health policy expert, shared over a decade ago his repugnance with the concept and acceptance of the "healthcare safety net."[26]

> It seemed to me an insult to the dignity of patients that they would get no more than uncertain, makeshift, last-resort medicine. Worse, the term, trotted out antiseptically in policy circles, seemed a capitulation to doing anything better for the medically disenfranchised and a happy codification of the idea that haphazard, second-class care was part of the American way of life.[26] (p.1186)

Here Mullan is naming the fundamental injustices of having different systems of care—one for the medically disenfranchised who bear the brunt of social oppression and discrimination and another for those who can afford, and *are* afforded, higher quality, more reliable care. He is rejecting the notion that beyond the existence of these different systems of care, many have acquiesced to and accepted that these systems are an end in themselves, abandoning the hope of building systems and environments from which people no longer need to be "saved."

Social workers working in healthcare can ask themselves how they are aligned with and perpetuating unequal systems of care. What has been deemed acceptable that needs reconsideration? Palliative and hospice clinicians as they consider Selma and her family and the disparities identified with this text—might join to discover avenues, as clinicians, teams, institutions and organizations for mitigating disparity and its corrosive impacts. It is not enough to work as an individual invested in high quality, whole person care without attunement to the larger social and political contexts of that care. For social workers, adopting an actively anti-racist practice, one guided by historical and current consciousness, that espouses justice, dignity, and equity evolves from the fabric of our profession and from the belief that colleagues across disciplines aspire to the same intention.

Resources/Additional Reading

The following list provides resources across modalities to support ongoing learning and reflection.

Readings

Crenshaw, Kimberle. (1991). *Mapping the margins: Intersectionality, identity politics and violence against women of color*.

DiAngelo, Robin. (2018). *White fragility: Why it's so hard for white people to talk about racism*.

hooks, bell. (1994). *Teaching to transgress*.

Lorde, Audre. (2018). *The master's tools will never dismantle the master's house*.

Lutz, Helma, Vivar, Herrera, Teresa, Maria, & Supik, Linda (Eds.). (2011). *Framing intersectionality: Debates on a multi-faceted concept in gender studies*.

Menakem, Resmaa. (2017). *My grandmother's hands: Racialized trauma and the pathway to mending our hearts and bodies*.

Moraga, Cherrie, & Anzaldua, Gloria. (Eds.). (1981). *This bridge called my back: Radical writings by women of colour*.

Saad, Layla. (2020). *Me and white supremacy*.

Podcasts

The 1619 Project:

An audio series on how slavery has transformed America, connecting past and present through the oldest form of storytelling.

Code Switch:

Direct and explicit conversations about race hosted by journalists of color. The show explores how race impacts every part of society—from politics and pop culture to history, sports and everything in between, making the link to how we are *all* part of the story.

Intersectionality Matters!:

A podcast hosted by Kimberlé Crenshaw, an American civil rights advocate and a leading scholar of critical race theory.

Training

Facing Race Annual Conference: A National Virtual Conference:

This conference is presented by Race Forward, a national nonprofit working to advance racial justice in our policies, institutions, and culture.

McSilver Institute: Identity, Bias, and Cultural Humility: Connecting to Ourselves and Others:

The McSilver Clinical Education and Innovation Department (CEID) focuses on a unique array of programs, trainings, and tools to support practitioners and organizations working within poverty-impacted communities.

Organizations

The People's Institute for Survival and Beyond (PISAB):

A national and international collective of anti-racist, multicultural community organizers and educators dedicated to building an effective movement for social transformation.

Showing Up for Racial Justice (SURJ):

A national network of groups and individuals working to undermine white supremacy and to work for racial justice. Through community organizing, mobilizing, and education, SURJ moves White people to act as part of a multi-racial majority for justice with passion and accountability.

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2 Health Equity in Palliative Care

Tessa Jones, Frances Nedjat-Haiem, and Karen Bullock

> Of all of the forms of inequality, injustice in health is the most shocking and inhumane.
>
> —*Dr. Martin Luther King, Jr.*

Key Concepts

- The determinants of health are the social, economic, political, and environmental forces that underlie health disparities.
- Health disparities are the unfair and avoidable health and healthcare differences experienced between groups.
- Health equity is the commitment to reducing and eliminating health disparities in health services and resources (i.e., social justice in health).

Introduction

There are significant and measurable differences in health and rates of mortality and morbidity, which exist between nations globally and within the populations of countries. These pervasive and largely avoidable health differences can be linked to the advantages and disadvantages that individuals face in economic, social, and political spheres throughout the life course.[1] The opportunity to achieve optimal health is not equal for all individuals. No matter where one lives in the world, the risk of illness and disease is far greater for those lower on the socioeconomic spectrum.[2] At the heart of social justice lies health equity, as any consideration of equity and justice inherently includes a discussion of illness and health.[3] The determinants of health, or the social, political, economic, and environmental forces that determine health, are estimated to account for 80%–90% of modifiable factors that influence an individual's health outcomes, while health and medical care account for only 10%–20% of the modifiable contributors.[2] The impact and influence of healthcare on the health of the population is undeniable but must be considered within the larger social, economic, political, and environmental contexts within which healthcare occurs.[4]

In the United States, Black, Indigenous, and other People of Color face disadvantages in their access to healthcare, the timeliness of care, and the quality of the care they receive.[5] The National Healthcare Disparities Report[6] confirmed racial inequity in access to preventive services, acute treatment, and chronic disease management, with White people having much greater satisfaction with their patient–provider engagement and health outcomes. By and large, in this health report, White patients received a better quality of care than Black Americans, Hispanic, American Indian, and Asian patients.

In healthcare for those living with serious illness, inequities continue to exist across care systems, specifically structures (affordability, organizational structure/setting, payment systems), processes (acceptability of care, communication and trust, cultural competency, care delivery), and patient outcomes (pain and symptom management, patient and caregiver satisfaction, quality of life). The pervasive lack of knowledge and awareness of the scope of such health inequities in the care for persons with serious illness creates, maintains, and perpetuates barriers to effective action toward more equitable care across groups.[7] The racial and ethnic populations that are underrepresented in palliative care are the same populations that experience structural barriers that limit healthcare access. In the United States, underrepresented racial and ethnic populations (e.g., African American and Hispanic groups) often lack the income to purchase care and may not receive healthcare as a benefit of employment.[8] Such gaps in access to healthcare prevent individuals from connecting with providers along an illness course. Those who do connect with providers may face additional health literacy barriers, as health information may be presented in a manner that overlooks important cultural, linguistic, or educational factors that can contribute to confusion or an incomplete understanding about the clinical milieu and treatment options. Such disconnects and lapses in communication can further disadvantage underrepresented populations when dealing with advanced and chronic illness.

Palliative social workers are concerned about the practice and application of social justice approaches in our efforts to achieve health equity.[9] As long as we see evidence that White patients are receiving better quality of care than Black, Hispanic, American Indian, and Asian American patients,[6] health equity in palliative care must be called into question. Palliative social workers are integral and important in identifying the challenges, success, and unrealized potential in culturally responsive care for persons living with serious illnesses. Furthermore, social justice action and advocacy for racially diverse patients and families are necessary steps in the right direction in addressing health disparities. Palliative social workers, equipped with an education in social justice best practices and clinical experience in palliative healthcare, are particularly well situated to provide evidence-based leadership in demonstrating and developing strategies to eradicate health disparities and promote health equity in palliative care.

Health Disparity, Health Equity, and Social Justice

Operative public policies require clear, contextually relevant definitions to support the development of strategies and goals for identifying modifiable conditions that render individuals socially and medically disadvantaged.[10] Yet the concept of health equity cannot adequately be addressed in the absence of a discussion about health disparity.[11]

The National Institutes of Health define health disparities as “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.”[12(para.4)] The former Surgeon General, David Satcher, operationalized health disparities as being inclusive of social determinants of health outcomes shaped by a set of sociopolitical forces that are avoidable and unfair.[10] Health disparities exist by education, race, ethnicity, sex, sexual orientation, and place of residence.[5,11,13] They are the avoidable and unfair differences in health, while health determinants are the fundamental contributors to these differences or inequities. Definitions are necessary to guide providers in ethical principles and human rights practices on which to build palliative care standards. Research has begun to address the social determinants of health that influence equity in clinical preventive services to reduce the gaps in health disparities.[14] The determinants of health capture the important social, political, environmental, and economic forces influencing people’s health around the world. These forces encapsulate the root causes of health inequities. They include but are not limited to health access, education, income distribution, racism, stigma, public policy, food security, and housing or living environment. Early onset of health access, continued healthy behaviors, and reduced environmental risk[15] can have lasting positive effects on length of life and health maintenance over one’s life course. Conversely, social and economic forces can negatively impact an individual’s access to preventative healthcare, risk of chronic illnesses, and life expectancy, and they can increase risk of exposure to environmental toxins, occupational hazards, or food insecurity.[15]

Health equity is social justice in health or the commitment to reducing and eliminating health disparities. Equity in palliative care has become an important priority across the United States.[16] However, disparities continue to exist in care structures, processes, and patient outcomes.[15] The World Health Organization has long committed to the grand challenge of eliminating health disparities worldwide.[11] Yet many racial and ethnic disparities abound, including inequitable access to unbiased, high-quality symptom management in the United States across all healthcare settings, including emergency rooms, inpatient services, outpatient clinics, and nursing homes.[6]

Social workers are uniquely trained and prepared to incorporate palliative practices that are social justice focused. As examples, social workers are poised to confront how disparities are connected to the following aspects of palliative care practice: (1) structure and processes to support and coordinate patient care; (2) physical aspects of care, including pain and symptom management and discharge planning; (3) psychological and social aspects of care to recognize needs and intervene to mitigate impact on health; (4) spiritual, religious, and cultural aspects that influence care and decision-making; and (5) any ethical or legal issues that might arise during illness and the last phase of life.[17] According to the National Association of Social Workers (NASW) Code of Ethics, social workers are expected to reduce social stigma and ensure a person's dignity and self-worth to reduce inequalities.[18] For example, as a fundamental moral imperative, social justice posits that all persons are entitled to have their basic human needs met, regardless of differences, such as economic status, class, gender, race, ethnicity, sexual orientation, citizenship, religion, age, disability, or health.[19] Palliative social workers' efforts at achieving equity must be evidence-informed with a social justice framework. Such a framework will acknowledge the complex problem as being linked to the lack of culturally sensitive standards in training programs and to the absence of accountability of interprofessional teams to incorporate knowledge and understand the magnitude of the global health inequities. This chapter presents working definitions of health equity, health disparities, and social justice; a theoretical framework in which to view the various types of influences on underrepresented populations receiving palliative care; a summary of evidence on the effects of some of these categories; and a research agenda for guiding efforts to improve knowledge upon which to build equity.

The Socio-Ecological Model

Essential in addressing health inequities in palliative care and developing social work led interventions that do just that is understanding how and where health inequities exist. The socio-ecological model is a theoretical framework that offers a lens through which we can consider how and where health inequities in palliative care operate. The socio-ecological framework helps to parcel out the many interacting layers of health determinants and disparities in palliative care. The framework can also help to uncover the pathways and mechanisms through which inequities develop and persist. Knowledge of such pathways and mechanisms can inform interventions that aim to reduce inequities in health and healthcare for the seriously ill.

Bronfenbrenner's socio-ecological model, first introduced as a model of human development, has been adapted and widely used in health research that looks at the various layers and systems that impact an individual's health.[16] Applied to the health of persons experiencing serious illness, this framework stresses that an understanding of an individual's clinical presentation requires an understanding of environmental, social, cultural, political, and historical contexts within which the individual and their illness reside.[16] When we consider palliative care through the lens of this framework, we approach an individual's disease or symptom presentation as the product of individual, environmental, social, organizational, political, and historical factors. In short, the model encourages us to assess the impacts of the determinants of health on the individual and family's experience of serious illness.

At the individual level of the model, we can consider factors such as health behaviors, patient education or knowledge, health literacy, personal characteristics, or genetic predisposition. Environmental, social, political, and historical factors may include the individual's geographic location; environmental exposures; social supports; health insurance coverage; structural inequities in health policies; and history of trauma, stigma, racism, marginalization, or lack of access to education; and healthcare history. For individuals and families living with serious illness, disparities exist and are reinforced in individual, environmental, social, political, and historical domains. Furthermore, these domains are highly interconnected with inequities at one level of the model having ripple effects throughout the entire web of the system. For example, health inequities that exist in policy have a direct impact on reimbursement incentives that contribute to inequities in healthcare organization structures and provider practices. Such inequities directly affect patient decision-making, treatment course, health behaviors, and patient health outcomes. In the United States, an individual from a low socioeconomic status is more likely to have no, or limited, health insurance coverage. Higher copays or other out-of-pocket healthcare costs disincentivize the individual from seeking out healthcare. Such additional expenses can also have the effect of increasing the individual's risk of unmanaged symptoms, engaging care late in the disease progression, and may lead to otherwise avoidable serious illness impacts.

The historical domain of the socio-ecological model reminds us that the individual, interpersonal, organizational, community, and policy domains are not stagnant or cross-sectional, but rather, change, evolve, and are affected by the passage of time. Health disparities and adversities accumulate over an individual's life course, and their effects are felt across generations. Research has shown that an individual's zip code or quality of neighborhood and school are more important in predicting health outcomes than the individual's genetic code.[21] The impacts of structural inequities can begin prebirth, starting with disparities experienced in maternal-child health, and extend and accumulate to the end of life. Experiences or exposures such as racism, historical trauma, adverse childhood events, trauma, implicit bias, and harmful environmental exposures all have significant and measurable impacts on the health and future health of the individual.[21] An understanding of how cumulative adversities impact health is particularly relevant when working with individuals and families living with serious illness, which is often a culmination of a lifetime of adverse health events compounded by these structural inequities and disadvantages.

At the core of historical discrimination are social determinants of health, including racism and poverty. Moreover, racism as a fundamental cause of racial and ethnic health disparities, particularly in the United States, warrants attention. Achieving health equity in palliative care requires knowledge, awareness, and cultural competency skills that are action oriented toward eliminating racism.

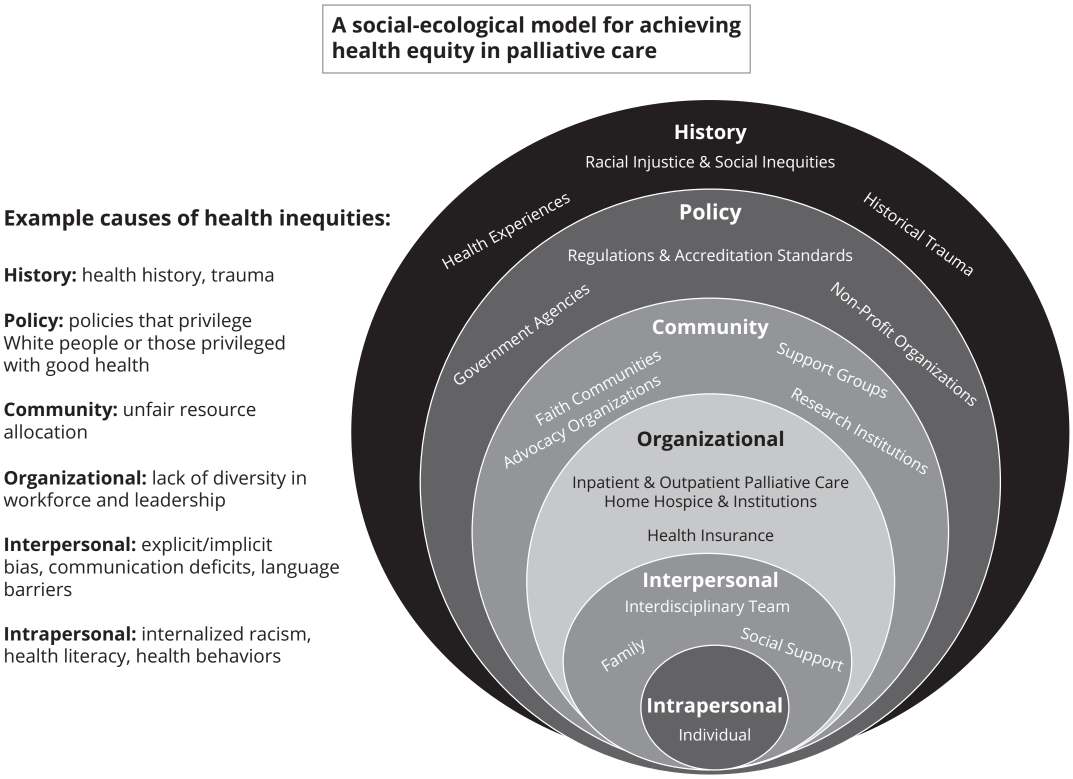
Racism is "a system (consisting of structures, policies, practices, and norms) that structures opportunity and assigns value based on phenotype, or the way people look."[22(p.9)] This system unfairly disadvantages some individuals and communities while unfairly advantaging others. The impacts of this system on health and serious illness are observable at all levels of the socio-ecological model. Racism influences the expectations individuals have about their own health, implicit and explicit bias in provider communication, unfair allocation of resources including those that are health and palliative care related, discriminatory workforce hiring and promotional practices, and policies that privilege White people. Racism influences all of the underlying forces that determine health, including political, economic, and social spheres. Given their social justice focus and ethical mandate, best practice in palliative social work engages specialized knowledge in systems interventions and expertise in clinical work with the seriously ill to support providers and organizations and take leadership positions in exposing and ending racism in palliative healthcare. All social workers, including those specializing in palliative care, must take leadership in adopting and promoting anti-racist practices.

Like racism and other forms of marginalization, living in persistent poverty or with low-income has significant impacts on health that accumulate over time. As the divide in income inequality continues to grow globally, so do the differences in life expectancies and differences in morbidity by income.[23] Economic inequality is a central issue in the United States, where the wealth gap between the richest and poorest Americans more than doubled between 1989 and 2016, ranking income inequality in America the highest of the G-7 global advanced economies.[24] Low-income Americans have dramatically higher rates of chronic and serious health conditions compared to their high-income counterparts.[23] In addition, low-income populations face more barriers in accessing healthcare for a myriad of reasons such as unfair resource distribution or health policies tied to income such as the employment-related insurance system in the United States.

The relationships between income, race, and health are significant. When applied to health equity, the web of the socioeconomic model reminds us of the complex intersectionality of health disparities. The overlapping factors, or intersection of disadvantages, converge to create increased vulnerability,[25] as low-income Black Americans have higher rates of mortality and morbidity than low-income White Americans.[23] These intersections have far-reaching and complex impacts on an individual's opportunity for optimal health. When individuals that have been disadvantaged by systems of oppression (e.g., socially and economically) face serious illness, they may also be at risk for experiencing healthcare inequities at the end of life. Specifically, individuals born outside of the United States who migrate to the United States in adulthood are at further risk for economic inequalities. Such economic disparities influence health-related quality of life through employment barriers, housing instability, food insecurities, and increased healthcare gaps.[26] Moreover, underserved populations in the United States can have financial burdens due to healthcare costs when managing illness and treatment because they lack employer-based health insurance. In addition to the issues they face as a result of their illness, they experience daily deficiencies in social, political, economic, environmental, and political spheres that have negative impacts on their health.[25]

In palliative care, we aim to eliminate disparities that exist because of the multifaceted social determinants of health. We can work to address inequities in care access, utilization, and quality. Using the socio-ecological model, we can consider possible interventions to reduce health inequities for persons with serious illness by considering how stakeholders at the various levels of the system can be targeted to improve health equity. Figure 2.1 is an adaptation of a model for achieving health equity presented by the National Academies of Medicine.[20] Our adaptation illustrates a socio-ecological model for achieving health equity in palliative care.[27] The model identifies key stakeholders at each level of the framework who can be engaged as agents of change for improving access to care and

Figure 2.1 Health equity in palliative care.



Example causes of health inequities:

History: health history, trauma

Policy: policies that privilege White people or those privileged with good health

Community: unfair resource allocation

Organizational: lack of diversity in workforce and leadership

Interpersonal: explicit/implicit bias, communication deficits, language barriers

Intrapersonal: internalized racism, health literacy, health behaviors

health equity in palliative care. A social work led intervention at the individual level may include patient engagement through a discussion of illness narrative, support in decision-making, and health or advance care planning education, while an intervention at the interpersonal level may take the form of provider training programs that educate providers on cultural humility and the impacts of explicit and implicit racial bias. As shown in Figure 2.1, an intervention at the organizational level aimed at improving health equity may engage healthcare institutions to tackle organizational level factors that reinforce inequities such as a lack of racial diversity in the workforce. An intervention at the community level may consist of community-led efforts to define the problem and mobilize assets such as faith groups or community leaders, in order to reach persons that have been historically marginalized and excluded from healthcare access. Finally, an intervention at the policy level that aims to improve health equity may include engagement with federal government agencies to advocate for policies that incentivize health equity.

COVID-19

The COVID-19 pandemic has unfortunately been a textbook example of how disparities, reinforced at all levels of the socio-ecological model, lead to inequities in healthcare and health outcomes for the seriously ill. Early data have indicated that across the United States, COVID-19 cases and deaths have disproportionately affected communities of color. For example, in Michigan, current data show that although the Black population makes up 14% of the total state population, they make up 33% of reported COVID-19 cases and 41% of reported deaths.[28] As we have discussed, the burden of illness is not distributed evenly across groups, and similarly, the associated burdens, risks of exposure, and risk of developing a serious illness as a result of COVID-19 have been unfairly distributed. The causes of these differences are multiple. Due to systemic racism, historically marginalized groups are more likely to have pre-existing health conditions and comorbidities and are therefore at greater risk of developing serious illness due to COVID-19.[29] In addition, the pandemic highlights existing inequities in healthcare access and resource allocation as low-resourced hospitals have fewer ventilators, less personal protective equipment (PPE), and lower testing availability. The overwhelming demands that COVID-19 has placed on healthcare systems around the globe have led existing systemic inequities to worsen. The healthcare, palliative care included, of diverse populations living with COVID-19 must be prioritized.[30]

There are also inequities in COVID-19 risk and exposure related to the workplace, for Black, Indigenous, and other Persons of Color who have been, historically, denied job opportunities, which have the associated freedom to work from home. People who have experienced historic discrimination and disallowed education and economic opportunities may be forced to commute and are more likely to be employed in public-facing occupations that pose challenges for social distancing and increase their risk for contracting the disease.[29] Inequities created by the lack of affordable housing, combined with structural and systemic means of marginalizing low-income individuals and families, may leave them with few options for avoiding cramped living environments or areas of high population density.

Furthermore, with the global economic forecast worse than that of the Great Depression, historically marginalized communities, in particular, are facing unemployment and worsening financial insecurities as a result of the pandemic.[31] This financial stress and poverty can be expected to have long-lasting impacts on the health of populations around the world for generations to come. Low-income groups who are experiencing financial hardships as a result of the pandemic must often navigate complex benefit systems that offer insufficient financial protection.[32] The extent of the impact of these inequities globally is yet to be seen and expected to be extreme, as the pandemic spreads to the most fragile economies and low resourced countries of the world.[32] (For additional information, see Chapter 26, "Palliative Care during the COVID-19 Pandemic.")

Evidence-Based Strategies to Reduce and Eliminate Health Inequities in Palliative Care

Despite advances in palliative care focused on symptom management and the reduction of suffering, there is a lack of information and evidence-based services specifically addressing racially and ethnically diverse populations, underserved, and marginalized communities. Noteworthy is the fact that political, socioeconomic, and environmental factors influence health disparities and negatively impact access to, utilization, and quality of palliative care services.[33] Moreover, it is recommended that further exploration of systemic racism and its impact on health inequities in palliative care be considered if we are to effectively reduce the gaps by facing socioeconomic limitations to quality care including those due to lack of health insurance, and cultural beliefs and values that impede healthcare use.[34] While the factors that influence health disparities in palliative care are well established, limited research focuses on systemic racism as a contributing source of health inequities and on evidence-based strategies that aim to improve health and equitable access to palliative care.

Social workers can provide evidence-informed leadership in demonstrating strategies to eradicate health disparities and promote health equity in palliative care by developing a palliative care workforce that is competent in providing cultural concordant care. While it is not feasible for palliative social workers to address all of the many determinants of health inequities, it is important for those in leadership roles to model behaviors and competencies, specifically aimed at addressing the pervasive inequities in palliative care. Advancing a social justice approach that is action oriented is recommended as best practice to improve access, utilization, and quality of palliative care services for all persons in need of serious illness care. Existing research has shown that interventions designed to eliminate inequities have small but meaningful impacts on hospice and palliative care access and quality for marginalized groups.[35] The socio-ecological model can be used as a guide to investigate how and where inequities in palliative care operate and identify interventions that invite social work leadership. At all levels of the socio-ecological model, patient/family, provider, community, organizational, and policy, social work can engage stakeholders and offer unique and highly valuable perspectives to the development of intervention research in health equity and palliative care.

Support in Decision-Making and Transitions

Social workers are educated and trained to assist patients and families with navigating complex healthcare services and supporting them through difficult decision-making processes. Across the continuum of care and disease trajectory, there may be changes in one's health that require a modification of treatment, new or discontinued interventions and plans, and revisiting goals and preferences for patients and family. For example, the choice to begin dialysis or choose a hospice plan reflects a transition to and from differing levels of care. Transitions such as these require emotional and structural support, so patients and families can process information and make informed decisions that respect their unique values and definition of quality of life until death. To provide this support, social workers must engage with patients to understand their unique illness narrative and build an appreciation of the way each patient makes cultural, economic, spiritual, and social meaning of their illness and its trajectory. In addition to the emotional and logistical support surrounding transitions of care, social workers are well situated to provide counseling interventions to mitigate the impact of serious illness on psychosocial health. There is evidence that counseling interventions designed for racially diverse groups living with serious illnesses may improve the congruence of end-of-life decisions between patients and designated surrogates.[35] Practice behaviors, such as incorporating cultural beliefs, sharing cultural norms, and validation for faith-based rituals, are a few specific approaches. It is essential to engage family. In addition to family, some patients may choose to involve a larger social and spiritual support network. Here there is an opportunity for shared and transparent conversations as providers work to assist in decision-making and remain neutral in their strategies to assist families.[9]

Patient Education

Research indicates that interventions focused on patient education for racial and ethnically diverse persons can influence patient receptivity to palliative and hospice care, desire for aggressive interventions near the end of life, and reduce decision-making conflicts.[35] Racially diverse groups have been shown to be less likely to complete advance directives or participate in advance care planning conversations.[33] Various issues contribute to these findings, such as lack of trust in healthcare systems, barriers to health literacy, and lack of knowledge about end-of-life decision-making,[36] in addition to cultural and spiritual values and beliefs which often impact patient preferences but may be culturally incongruent with Western-based medicine. Family-centered decision-making serves to guide the interventions of culturally competent clinicians who are able to pivot away from the standard focus on individual autonomy to comfort with relational autonomy. Relational autonomy values the social context of individuals and the "emotional and embodied aspects of decision-makers"[37(p.1)]—which are bound to influence patients' treatment choices and receptivity to end-of-life care.

Variations of family-centered decision-making among racial/ethnic populations indicate that decision-making cannot be understood without considering how one's family and community influences these decisions. Families who experience difficulty accessing healthcare and lack resources to manage health problems may also experience gaps in health literacy and have communication and decision-making preferences that require adaptation of culturally and spiritually respectful clinicians. Some consider prognostication assumptive as only a higher power knows the future. Some will not choose a surrogate decision maker because they expect their family and perhaps fictive kin to share decisions when they become necessary. Family context is essential to consider when we enter or initiate conversations about treatment and end-of-life decisions. For example, some families ask providers to protect their loved ones from hearing news of advancing illness or expected death, which happens more often when patients are older and non-English speaking.[38] Social workers trained in cultural competence and positioned from cultural humility are prepared to work with families to honor such cultural variance in preferences to ensure goal-concordant care and to mitigate the belief that only education is needed to help patients and families to ally with decisions or decision-making processes preferred by the healthcare system.

Interventions that target patient and clinician education are one path to addressing disparities in palliative care access and acceptability. Social workers who build trust with patients and families, provide clear information about commitment to equitable and expert care, explore narrative and community connections while listening and supporting their decision-making style, and understand unique family structures. Palliative care patient education can focus on resources for care, expertise in managing symptoms, care and treatments that will be provided while assessing receptivity to information about end-of-life issues, advance care planning, or advance directives.

It is important to note that culture, spirituality, and religious values and beliefs influence participation in decision-making that aims to direct future events; therefore, providers must assess preferences to individualize these interventions the format of which might be in-person education or through audio or visual materials.[35] Social workers are well suited to design and implement patient education interventions that connect and reach the communities they are intended for (e.g., at church, food banks, or local news sources). Along with providing patient education that is in the patient's first language, culturally sensitive, and appropriate for the patient's level of health literacy, social workers can be instrumental in clarifying patient's goals of care and streamlining communication between patient, family, and providers. Historically, marginalized populations may have less experience navigating healthcare systems due to restricted access and limited comfort in the language used to describe symptoms and health behaviors, making it challenging to communicate effectively about serious illness, disease-related health needs, and care preferences.[9] In addition, medical systems and health communications are infused with an expectation that patients and families work and communicate through numbers when narrative is often the bridge to their understanding and collaboration. Building trust, continuity of relationship, and adapting patient education may offer additional support to underserved groups who may experience multiple medical transitions and repeat hospitalizations. Trust, continuity, and cultural adaptation of materials used to inform diverse patients may serve to mitigate confusion and ease the path to available services to enhance living with illness and coming to the end of life.

Provider Education, Interprofessional Collaboration, and Communication

At the interpersonal level, social workers in palliative care can address health inequities through provider education and improvements in interprofessional collaboration. Research shows that racial and ethnically diverse populations have lower satisfaction with provider communication in palliative care.[39] Furthermore, differences in communication have been linked to disparities in quality of care.[40] These differences include inadequate or absent communication that can lead to inaccurate or nonexistent documentation of treatment preferences, creating inconsistencies between patient preferences and the treatments received.[39] Conversations with providers influence patient and family decision-making and ultimately impact palliative care utilization and access. It has been found that in the inpatient setting, provider culture, religion, and ethnicity play an important role in providers' decisions to discuss palliative care and participate in decision-making with patients.[41] This can happen when providers have limited knowledge about palliative care and a lack of familiarity with the diverse culture of the patient population.

Interventions that aim to reduce and eliminate inequities and deficiencies in provider–patient communication target the existing disparities in palliative care access, utilization, quality, or patient outcomes. Although efforts have been made to increase provider knowledge in caring for diverse populations near the end of life and mitigating the impacts of implicit and explicit bias,[42] there has been limited evidence supporting their effectiveness in improving patient outcomes.[43] Research in the United States, however, demonstrates that healthcare providers across disciplines have implicit biases against diverse racial groups.[43] More research is needed to understand the impact of provider implicit bias on patient outcomes and develop effective interventions to minimize the effects of bias and associated disparities. Social workers are equipped to take leadership roles in this research by infusing a social justice framework, which carefully considers the role of power and oppression in palliative care relationships and is essential for one to understand how inequities are created in patient–provider engagement, or the lack thereof.

Clarifying how and why populations that have been historically disadvantaged feel dissatisfied with provider communication can be effective in developing culturally relevant interventions that address practice shortcomings and support diverse patients' needs. Moreover, social workers can help to address health inequities on the interprofessional and institutional levels.

In many settings, palliative care providers work together on teams (e.g., physician, nurse, social worker, and chaplain) to address the patient's and family's psychosocial distress; to relieve their physical, spiritual, and emotional pain and suffering; and to assist with decision-making along the continuum of illness. The organizational characteristics of team co-management, also called "interprofessional team collaboration," involve formal and informal rules to guide their work, which suggest best practices for end-of-life care.[44] Addressing patients' and families' palliative care priorities includes social workers vital to teamwork and patient care involvement.[45] Conflicts and ethical dilemmas can ensue, and gaps in services can increase, especially when teams do not function well and experience poor communication. Social workers are also instrumental in addressing psychosocial issues, including conflict and frustrations that can arise from barriers or gaps in services that impact team collaboration, outcomes, and patient care. Addressing disparities while managing patients' and families' medical care needs can be influenced by turf issues and the hierarchy between medical and nonmedical providers, which may create power differentials, especially when roles and responsibilities are blurred or unclear. Such dilemmas within interdisciplinary teams may arise when patient care is seen primarily from a medical lens or solely from a psychosocial spiritual lens. Creating opportunities to move beyond silos and power differentials to assist each other in considering the varied views and frameworks from which we practice can build consensus on how to proceed with care. (For additional information see Chapter 9, "A Commitment to Collaborate: Challenges and Opportunities.")

Because palliative care, as a discipline, emerged in the absence of a racial and ethnic lens through which to consider inequities and barriers to diversity and inclusion, it behooves social workers to advance the social justice imperative of advocating for change, so that individuals and groups that have been historically marginalized can receive equitable care. The focus on health equity and disparities, which is especially important in palliative care, aligns with the social workers' commitment to dignity and self-worth of all persons. Social workers are uniquely trained to apply a problem-solving practice approach that relies on skills and awareness to identify and address inconsistencies between intent and impact in working with diverse populations.[10] When social workers address these issues, conflict can ensue as can profound and meaningful exchanges between colleagues. When these shared professional perspectives are appropriately and thoroughly explored in team meetings or case reviews, such discourse may lead to greater awareness and knowledge that has the potential to increase cultural competence.[10]

Provider Education: Standards for Palliative Care Practice

The National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care indicate that best practices ideally include all people with serious illness in all settings, across all types of diagnoses, prognoses, and ages—and that palliative care is the responsibility of all clinicians and disciplines.[46] This mandate leads to an emphasis on primary palliative care, which brings the work of palliative care inequities to the doorstep of our health social work colleagues. Domain 6 of the NCP guidelines, Cultural Aspects of Care,[47] suggests that all team members be involved in maximizing cultural sensitivity to patient care and reducing disparities in care. Operational implications for this practice include conducting a cultural assessment that aims to maximize palliative care service delivery for individuals and families who have been historically excluded from healthcare systems, based on structural racism. Palliative care practice must include an assessment of all policies and practices that influence such disparities. Domain 8, Ethical and Legal Aspects of Care, suggests that all interprofessional team members understand social justice principles that negatively impact populations that are at risk for inequitable healthcare access and to address such barriers accordingly. For example, social workers assist patients, families, and other team members to consider how resources are allocated to improve care for all seriously ill individuals, especially when they experience healthcare disparities. In the aim of eliminating disparities in care, social workers can support interdisciplinary team members in patient or provider communication to encourage dialogue about resource allocation to reduce disparities among historically marginalized populations that were denied equal access to healthcare systems in the United States.[45]

Workforce Diversity, Translation Services, Referral Patterns, and Community Outreach

At the organizational level, social workers can address health inequities by looking closely at organizational structures and processes that perpetuate health inequities. Barriers at the organizational level include lack of diverse representation in the workforce, lack of timely and high-quality translation services, disparities in palliative care referral patterns, and a need for community outreach and partnerships to engage underserved communities.[33] Lack of diverse racial representation in hospice and palliative care staff may reinforce a barrier to utilization and access to palliative care services. Although the exact racial representation of the palliative and hospice workforce is unknown, overall in healthcare, disparities in the distribution of race/ethnicity in the workforce are well documented.[48] Furthermore, it has been found that concordance in the demographics of providers and the community improves access to care for underserved populations.[48] Social workers, especially those in leadership positions, can advocate for increased diversity in staffing on palliative care teams and educate healthcare leadership as to why this is important.

The availability of quality interpretation services is crucial in providing equitable palliative care. Language barriers have been identified by research as a significant obstacle to healthcare quality and access and are associated with higher rates of hospitalizations, inadequate or inappropriate medical-testing (e.g., diagnostics), and lower patient satisfaction.[49] In palliative care, the lack of trained interpreters utilized or available for patients with limited English proficiency is associated with worse quality end-of-life care and goals of care discussions.[50] To promote health equity, social workers can advocate that organizations prioritize the availability of necessary and consistent interpretation services and ensure that palliative care teams and primary clinicians make routine use of the available services.

Despite the clear demonstration that the burden of serious illness and associated symptoms is unevenly distributed across groups, research has shown that palliative care is underutilized by racial and ethnically diverse individuals and communities that could benefit from palliative care services. An element of this disparity in utilization and access is associated with palliative care referral patterns, that is, who receives a palliative care referral from non–palliative care providers.[41,51] Along with provider education, this issue must be addressed on the organization level, where health systems and processes ensure accountability and influence equitable referral practices. Social workers can take leadership by creating processes for team reflection about how to understand and influence this outcome in unique practice settings. They can also help to identify patients in need of palliative care services, developing guidelines for providers to follow to ensure equitable practices, and advocating that clinicians follow equitable palliative care referral practices.

Finally, at the organizational level, a barrier to palliative care utilization and access is the disconnection between healthcare organizations and historically marginalized communities. Interventions of community engagement are known to influence health service utilization.[35] Such interventions include the utilization of community health workers or patient navigators, telehealth, community forums, or engagement with community assets such as faith communities. Social workers can assume a leadership role in initiatives that aim to bridge the gaps between organizations, palliative care providers, and the community.

At the policy level, incentivized healthcare institutions become motivated to provide more equitable care for the seriously ill. Financial incentives can be directed toward expanding palliative care services, engagement with community-based stakeholders to improve care accessibility, and following guidelines developed to ensure equitable healthcare practices.[41,51] In addition, as the number of aging adults in the community continues to rise, policies must be created that support the needs of older adults living with serious illness in communities that have been historically denied access to healthcare, including access to quality home healthcare, primary care, and policies that improve transitions of care.

Conclusion: Practice Implications and Next Steps

A commitment to health equity in palliative care includes social work leadership in examining the determinants of health, the quality of palliative care services, and the complex relationships between patients and families experiencing serious illness. An understanding of these areas can be used to develop evidence-informed strategies designed to eliminate disparities in palliative care quality and patient outcomes.

Social work leadership is essential in research, in the defining and understanding of disparities in order to develop and test interventions, in clinical practice where social workers model the implementation of interventions, and in health administrative roles where advocacy focuses on change at the organizational and policy level. Certainly, the development and testing of interventions will be essential in eliminating disparities in palliative care as practicing clinicians continue to advocate and maximize the responsiveness of the systems in which they work. Research must first, however, prioritize detecting disparities in care access and quality, and then build an understanding of the underlying determinants and modifiable factors that lead to disparities in palliative care.[33]

Social work offers a unique and crucial perspective when building an understanding and examining the fabric of these disparities. Social workers can lead in community engagement to better understand the components of care that are most important to racial and ethnically diverse populations, while identifying attitudes and beliefs that may impact disparities. This could take the form of community-based participatory research, designing and implementing recruitment strategies for underrepresented groups, or developing and validating measurement tools.[52] Interventions can then be built on the evidence that this research provides. Examples of possible social work–led research and interventions include patient advocacy and education for diverse groups, overseeing access to timely and high-quality language assistance for those with limited English proficiency, improvements in patient–provider communication, and palliative care provider education.

There are countless social, economic, and political forces that determine the health of people around the world, including health access, education, income distribution, food security, and housing. The inequities that exist in these areas lead to unfair—and avoidable—health disparities, including preventable differences in how people experience serious illness, chronic disease, death, and whether they can access palliative care. Health equity is a commitment to reducing and eliminating avoidable differences in health. Any consideration of social justice and equity inescapably includes a discussion of health, as the burden of illness is not distributed evenly across groups. Social work is a profession uniquely rooted in a commitment to social justice, and as such, palliative social workers must commit to health equity in palliative care.

Learning Exercises

1. Write a personal reflection about the healthcare inequities that you have observed or experienced. What are some words you wish you had spoken or steps that you took, or wish you had taken, to acknowledge, prevent, or eliminate such disparities in healthcare?
2. Thinking about your place of employment or a palliative care setting that you are familiar with, what are some factors that facilitate or prevent health disparities at the interpersonal, organizational, community, and policy levels? What changes would you recommend for improving equitable access to care in this setting?

Resources/Additional Reading

CAPC—Health Equity:
The Center to Advance Palliative Care blog on the topic of health equity in palliative care, offering description of disparities in care access and quality and possible solutions.

Duke REACH Equity:
The Duke Center for REsearch to AdvanCe Healthcare Equity addresses racial and ethnic disparities in health by developing and testing interventions to improve the quality of patient-centered care in the clinical encounter.

National Academies of Science, Engineering and Medicine:
Provides independent, objective advice to inform policy with evidence, spark progress and innovation, and confront challenging issues for the benefit of society.

Social Work Hospice and Palliative Care Network (SWHPN):
A national network of social work professionals dedicated to providing the latest information, professional resources, policy updates, and new and emerging education and research best practices in palliative and hospice care.

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