Social Sciences Innovations and Change Reviews

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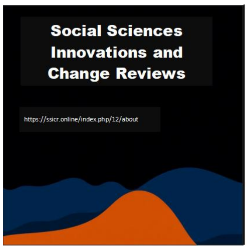

Role of Social Workers in Palliative and End-of-Life Care

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1. Abstract

The role of social workers in palliative and end-of-life care is crucial in addressing the multifaceted needs of patients and their families during challenging times. This research explores the various responsibilities social workers undertake, including emotional support, advocacy, and facilitation of communication between healthcare teams and families. Social workers are instrumental in assessing the psychosocial needs of patients, providing counseling, and connecting families with community resources to alleviate stress and enhance quality of life. By employing a holistic approach, they help navigate the complexities of healthcare systems, ensuring that patients' wishes and values are respected. The study also highlights the importance of interdisciplinary collaboration, where social workers work alongside medical professionals to provide comprehensive care that addresses both physical and emotional needs. Furthermore, this research underscores the necessity of training and support for social workers to effectively manage the challenges associated with end-of-life care. Ultimately, the findings aim to reinforce the integral role of social workers in promoting dignity, comfort, and support during the final stages of life.

Keywords: Social workers, palliative care, end-of-life, emotional support, interdisciplinary collaboration, advocacy, psychosocial needs, community resources.

1. Introduction to Palliative and End-of-Life Care

Available in the developed world for patients receiving care for serious, life-threatening illnesses, palliative and end-of-life care offers essential comfort and social support to patients. Its goal is to maintain or enhance that patient's quality of life while seriously ill and support the family. Yet, to appreciate the roles that social workers play in such care, we must begin by trying to get an idea of how such care is offered. (Goldberg & Warburton, 2022)

Palliative care is delivered according to a holistic, rather than a disease-specific approach. This type of care is designed to meet a person's physical, psychological, social, and spiritual needs, as well as the needs of the patient's family. Palliative care is not limited to the dying stages; rather, it can be initiated at the time of diagnosis of a life-limiting illness and continued through death and into the bereavement experience of the person's loved ones.

Palliative care can be offered in a variety of settings, including general hospitals, inpatient hospice or palliative care units, residential hospices, supportive care centers, intensive care units, community settings, outpatient specially tailored care, home care tailored to the terminally ill, and recovery of the dying patients. In contrast to this type of care, which is designed to help people feel better and remain comfortable in their position of care, curative care is designed to cure the illness. Palliative care is a complement to curative treatment, not a replacement. The goal of palliative care is to prevent and alleviate suffering and support the best possible quality of life for patients and their families, regardless of the stage of the disease. Palliative care focuses on preventing, identifying, and treating symptoms in the early stages of the disease.

Palliative care is a valuable complement to the curative care of advanced chronic conditions, given the care that palliative care emphasizes in serious, life-threatening, and debilitating diseases, even if the curative approach develops alongside the degree. It is not dependent on the treatment that the acute services receive concurrently. Care can be provided in centers with specialist expertise or as part of a geriatric assessment; however, the principles of care are relevant to the range of care providers and regardless of setting. This module does not address non-specialist training. Palliative care provision is an appropriate topic for further development of the Specialist Care Services for Death and Dying and Advanced Medical Care. Concern is further provided in additional reading, with specialist cancer and palliative care topics, two levels of specialist topics, and additional topics such as pediatrics, social care, community and daycare services, and support workers.

2. The Importance of Social Workers in Palliative Care

One of the hallmarks of effective and state-of-the-art palliative care is comprehensive, interdisciplinary care that responds to the unique needs of each patient and family. Although the bulk of palliative and hospice care is provided by nurses and other health care professionals, social workers play a critical role in providing direct patient and family supportive care interventions while also facilitating communication among team members. As experts in assessment and the provision of psychoeducation and individualized care planning, social workers have expertise in social and psychological adaptation to serious illness. (Hadley & McGrath, 2022)

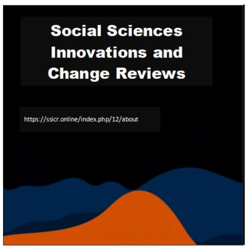
Skillful, compassionate social work interventions can provide the emotional, psychological, spiritual, physical, and relational support that patients and their families need when they confront serious illness. Social workers are trained to provide comprehensive and biopsychosocial assessments that guide care planning, reflecting patient and family-centered goals of care – essential principles in the provision of quality palliative care. Those assessments guide the care plan, including the delivery of consistent, evidence-based interventions that can address what patients and families are most worried about and prioritize their needs.

This kind of care requires the expertise of social workers who view care provision and care planning through the relational lens of families, culture, spiritual beliefs, societal circumstances, and life experiences. They advocate to ensure that patients are heard and receive the care that reflects their humanity. Detection and attention to those needs rest heavily on social work expertise. Each and every one of these elements is fundamental to the provision of expert palliative care. Addressing social determinants of health also impacts health outcomes, including determining a hastened death or diminished quality of life. In recognition of the importance of the social determinants of health, social workers should have a significant role in addressing these concerns in palliative care practice. Social workers also facilitate communication between the patient and the care team, advocating for the patient and respecting his or her choices. Social workers work in concert with other team members to enhance team functioning. They contribute to each domain of palliative care, resulting in improved quality of life for the people and families for whom they care. Providing assessment and support for mental health needs as part of the overall care plan and focusing on mental health as integral to physical health are investment strategies.

2.1. Emotional and Psychological Support

One of the vital roles of social work in palliative care is to provide emotional and psychological support to patients and families facing life-limiting illness. Social workers are trained to assess and respond to the emotional and practical challenges that can accompany serious illness and to work with people to address fear and anxiety and help them come to an understanding of their likely prognosis. The aim of these interventions is to help individuals and families adjust to living with a life-limiting illness, rather than merely confronting them with their fear, thus facilitating recovery rather than wallowing in illness and grief. (Yarberry and Sims2022)

There is a growing body of literature to support the presence of social workers as counselors in inpatient units and in the community as a form of psychological pain relief. Communication with patients and families is essential. As practitioners of the therapeutic use of the self, individuals need to continually reflect on how they engage cure with care within themselves and others. The ability to be open and to hold reflective space facilitates mutual exploration and understanding and promotes healing. One technique widely used by allied health staff to help patients and families process their experiences, particularly when they lead to sadness and grief, is the family meeting. These meetings provide a forum where information about a person's condition and likely future can be gently disclosed and proper supports put in place. Social workers can also provide practical support to identify any extra needs that a bereaved family may have and link them to appropriate community services that are



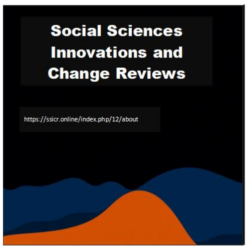
empathetic towards their experience. Given the role of mastery in combating adversity, building resilience through connecting to local supports is important. Strengths-based approaches are important to build a client's capacity and hope. Social workers can also support this process by helping those they work with to find renewed meaning in their lives following their crisis, not just focusing on the loss and sadness. Techniques used to help people achieve this, incorporating a strengths-based approach, include solution-focused and narrative therapies, family of origin, and genogram work. With regard to practice, an increased focus on emotional intelligence combined with clinical psychology therapeutic interventions has been adapted to be most beneficial when enhancing and facilitating emotional coping. Mindfulness can also form an integral part of intervention.

2.2. Assessment and Care Planning

This section will: • Outline the relevance of and the key domains in the work of social workers in palliative care and collaborative practice. • Provide some discussion.

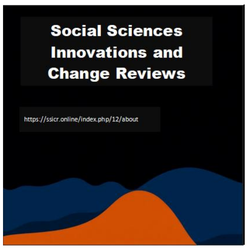
2.2. Assessment and Care Planning Social workers conduct assessments to gather comprehensive information about a patient's and family member's or carer's background and care needs; their wants, needs, and preferences; what is important to them; and their values. Assessments should be comprehensive, and if a social worker does not have information or experience with a problem, they should consult and/or collaborate with the interdisciplinary team. Care planning for patients should be done in collaboration with the patient and their family/carers and, in the context of the interdisciplinary team, based on the patient's goals, values, hopes, and needs. The resulting care plan should have a primary focus on what the team can do to support and assist the patient to live until they die ('living well'), with a subsection acknowledging any plans if they are to get better (recuperation) and a section considering potential end-of-life transition.

Social workers should strive to ensure that care planning is balanced and based on a knowledge of human behavior and experience. Specific areas of practice for social work intervention in care planning include strength-based approaches, commitment to understanding the patient's behavior in the context of their understanding, close collaboration with the care coordinator and the interdisciplinary team, explorations of



the historical and current background experiences of the patient and how it may impact a proposed or planned care, close consideration of family or natural support systems, discussion and exploration of the patient's ideas about their illness and care, exploration of the patient's ideas about their future, especially their desired future (including assessing hope and hopelessness), consideration of altering approaches due to the whole person's reactions (physical, psychological, spiritual, intellectual, emotional, social) to care and other situational pressures, consideration of the patients' needs and wishes (that are not usually acknowledged or catered for in care plans that routinely only use clinical/medical history in care planning) and working through with the person and the team to ensure a plan aligns. Effective care planning also:

- Enhances the satisfaction of people with care, as they feel cared for rather than just receiving care, and can show improvement in quality of life and comfort levels at the end of life.
- Enables social service-funded palliative care services to support patients and their families to live until they die, rather than premature institutional admissions with an increasing acuity of care. Social workers advocate for consistency across the health and community care continuum and support patients to access services and supports that will assist them in achieving their objectives.
- Ensures ongoing work with people and their families to enable them to live as well as possible until they die.
- Quality safety and risk assessments.
- Assessment of symptom management and emotional support requirements.
- Review of advanced care planning documents, ensuring any changes in the person's condition are duly noted and actioned.
- Referral, linkage, and advocacy support with other services, including those beyond the direct health and social service sector, such as legal aid, financial advice, and material aid.
- Family meetings or case reviews to discuss care concerns or future planning.
- Developing individual case plans.
- Named advice and backup to health professionals.



3. Collaboration and Interdisciplinary Teamwork

The role of social work as part of a palliative care team is relatively new. It is only in the last twenty-five years that social workers have worked alongside doctors and nurses providing care for people with terminal or life-threatening illnesses. Effective palliative and end-of-life care requires collaboration among health care professionals. Doctors, nurses, social workers, chaplains, and other professionals work together as part of an interdisciplinary team. Interdisciplinary teamwork is exceptionally important when caring for people who are very sick. The patient and family have many practical and emotional needs. Comprehensive medical, nursing, and psychosocial care is essential. (Mishna et al., 2022)

All team members work together to assess a patient's physical condition as well as his or her emotional, practical, spiritual, and social needs. They pool their assessment findings. Together they identify treatment goals and plan coordinated interventions. Physicians usually assume primary responsibility for medical care. They make sure that the patient's primary diagnosis is correct and that any potentially manageable conditions that the patient has are being treated appropriately. Nurses usually provide continuous assessment of the patient's symptoms. They also provide the bulk of daily personal care. Chaplains help to assess and address a patient's spiritual needs. They help draw attention to the spiritual and ethically ambiguous issues that often arise in life-threatening illnesses. Social workers are a vital part of the team.

They intervene in areas of patient care that reflect their training in managing psychosocial issues. Nurses and physicians do acknowledge and appreciate the unique and important perspectives that chaplains and social workers bring to the team. In turn, I think that the decision-making abilities of the team and our patients probably benefit from our participation. Collaboration, however, does not always come easily. The professions have different perspectives. Moreover, the act of collaborating on care can be hard when it involves communicating about things of which one is not proud or about which communication is hard or requires diplomacy.

4. Ethical and Cultural Considerations in End-of-Life Care

Ethical and Cultural Considerations in Palliative and End-of-Life Care End-of-life care should be responsive to patient values, beliefs, and preferences while being consistent with the patient's expressed care and treatment choices. Healthcare providers have broad discretion to decide such items as therapy, treatment, and day-to-day care that are most consistently in accordance with current professional standards. Legally and ethically, they are bound to respect a patient's values, beliefs, and preferences when individualizing care or when their decisions affect broader health services or policy issues. Resolving ethical issues often necessitates balancing several principles. This is where social workers can make particular contributions. Ethical evaluation, case exploration, and policy development are paramount in situations of ethical conflict. Given an extensive knowledge of patients' personal and cultural contexts, the social worker's communication skills, values, and knowledge of agency guidelines contribute to resolving ethical dilemmas. (Pink et al., 2022)

The recent emphasis on cultural competence in the healthcare field is intrinsically tied to this ethical consideration because culture is a primary source of values and life patterns and thus underlies patient preferences and decision-making. However, there is a lack of specific empirical data documenting variations among cultures and subcultures in end-of-life practices. Most studies to date indicate that the impact of culture in end-of-life situations is more complex and involves a quite general range of sociocultural factors across all societies, including other demographic and disease course-related variables. The emphasis on social support and the family as key to end-of-life care is common.

Cultural issues extend to the area of access to care and the inequities in such care for poor people, the elderly, and minorities. Marginalized groups tend to experience relatively less access to hospice care, home care, hospital services, and cancer control programs, and they disproportionately use hospital emergency rooms, which may delay the receipt of care consistent with their long-term care preferences. Two decisions underpin ethical end-of-life care concerning advance care planning: 1) the patient’s right to refuse care, even if refusal of life-sustaining treatment leads to death; and 2) eligibility for surrogate decision-making when the patient is unable to decide. Summary • Patients approach and perceive end of life differently. • The ethical principle of respect for patients’ values, beliefs, and preferences is of prime importance. • Ethical handling of a case may necessitate balancing multiple ethical principles. • Culture profoundly influences patients' views about desirable treatment outcomes. • Ethnicity also influences preferences for care in control over decisions, comfort with provider sympathy, and appreciation for religious coping. • Access and equity issues are more pronounced in some cultural groups; disparities in hospice use have been well documented.

5. Challenges and Future Directions in Social Work Practice

Several challenges must be considered as the role of social workers in palliative and end-of-life care gains increased recognition. Social workers can often carry high caseloads and be met with challenging family dynamics while caring for individuals with terminal illness. The emotional burden of caseloads and difficulty navigating workplace stressors can lead to burnout, compassion fatigue, and high rates of staff turnover. If social workers are to feel supported in these settings, they must be provided with adequate and comprehensive support services.

Further, minimal healthcare policy addresses palliative care in the United States, and nothing mandates coverage for any of the services offered by specialty palliative care programs, which can prove difficult for the hospital systems or specialty programs in non-profit or free-standing centers. Both specialty programs and social workers need to be funded appropriately in order for quality care to be provided across the field. (King et al.2022)

Looking ahead, the social work role will continue to be multifaceted. With the current workforce’s limited palliative care-related social work practice experience, social workers are encouraged to engage in regular professional development activities through training, connections with geriatric and palliative care professional groups and associations, grand rounds, and coursework around the topic of chronic illness and aging. Continuous feelings of professional novelty encourage social workers to continue expanding their knowledge and scope of practice, and tools to better advocate for themselves in multidisciplinary settings will contribute to overall satisfaction, although there is limited research to support the potential overall professional improvement through continuing education around palliative care for existing practitioners.

As further research in the area continues to grow and advance, more evidence-based best practices are established, social workers will be able to adapt evidence-based interventions to enhance care delivery and expand their role within palliative care models. Additionally, social workers should continue to seek collaborations with integrative medicine specialists, health policy advocacy groups, and biomedical research to sit at the forefront of the field. At the same time, models and electronic health records will likely permeate genetic and gerontology practice alike, improving accuracy and efficiency. This will extend into interactive computer programs and other formats to help social workers implement experiential best practices research in a cost-effective manner. (Dominelli, 2022)

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