End-of-Life Decision Making and Care

ISSUE STATEMENT

Social workers incorporate a life-cycle approach to policy and practice, meaning that they attend to opportunities, tasks, and challenges that may arise in various stages of life, from birth and early childhood through to adolescence, adulthood, and older adults. Although some people associate end-of-life (EOL) decision making and care with older adults, EOL concerns may arise at various life stages. Social workers believe that social policies and laws should be supportive of individuals and families as they experience a range of physical, psychological, social, spiritual, cultural, financial, and legal concerns during the final months, weeks, and days of their lives. Social workers understand that death, dying, and bereavement involve psychological and social processes, rather than just medical processes and decision making (Taels et al., 2021). Social workers are attentive to the significant economic and health disparities that exist across various racial and ethnic groups. When considering issues related to EOL care and decision making, the National Association of Social Workers' (NASW, 2021) *Code of Ethics* reminds social workers to address disparities, advance social justice, respect the dignity and worth of all people, and use cultural humility to attend to cultural and socioeconomic differences. Social workers understand the importance of working collaboratively with individuals, families, other professionals, and policy makers for the benefit of their clients, communities, and society as a whole. This policy statement strives to inform social work advocacy regarding EOL concerns building on the ethical principles of autonomy, beneficence, nonmaleficence, justice, access, and integrity (Beauchamp & Childress, 2022).

For some individuals and families, discussing EOL decision making and care can be challenging. Some people have limited understanding about their EOL options. Others may have limited resources, making it difficult to obtain the care they desire or facilitate the options they desire. Some people (including social workers) may be uncomfortable discussing these EOL concerns due to spiritual-religious beliefs or cultural taboos around discussing death or EOL decision making and care. Although many EOL care decisions are not controversial, others may give rise to conflict between family members, social workers, other professionals, politicians, and the public at large. Thus, it is important to engage in discussions regarding EOL concerns with empathic understanding, respect for diverse values and beliefs, genuineness, and compassion.

Key Concepts

To engage in meaningful discussions, policy development, and advocacy regarding EOL decision making and care, it is important to understand key concepts related to these concerns. The following definitions offer guidance on how these terms are being used in this document.

EOL Care: support during the final days, weeks, or months of someone's life, including personal care from family, friends, informal support systems, social workers, physicians, nurses, and other practitioners. EOL care assists with various physical, psychological, social, and spiritual needs.

Palliative care: EOL care focusing on improving quality of life, including comfort and management of pain and stress related to any illnesses or medical conditions that the individual is experiencing.

Hospice care: care focusing on quality of life during the last few months of a person's life (as defined by healthcare insurance laws; e.g., six months). Whereas palliative care can be combined with curative care (treatments aimed at curing a disease or condition), hospice care is only provided after a decision has been made not to pursue curative care for the terminal illness.

Curative care: healthcare treatments or interventions designed to cure a condition or disease, rather than to alleviate pain or suffering or to extend life.

Long-term care: provision of medical care and/or personal services for a person who needs assistance with tasks of daily living due to a chronic disease, disability, or condition.

Medical aid/assistance in dying (MAID): medical assistance that individuals may receive regarding the timing and manner of their death.

Surrogate decision makers or proxies: people assigned to make decisions on behalf of another person under particular circumstances. When an individual has mental capacity, that person may assign proxies using advance directives or other legal documents. If an individual does not have legal capacity to make decisions, state laws prescribe who may make decisions on their behalf (e.g., spouse, next-of-kin). Depending on the state, courts may appoint a guardian or conservator.

Ethical principles: broad guidelines for moral behavior, including autonomy, beneficence, nonmaleficence, justice, social justice, respect for the dignity and worth of all people, and access to service (Beauchamp & Childress, 2022; NASW, 2021).

EOL Care: Choices and Decision Making

EOL Choices

When choices are made about EOL care to include the continuation of aggressive curative treatment, such choices should be supported. However, the decisions must be informed. Informed choices arise from EOL conversations, which can be difficult. One of the reasons for this is the persistent problem of access to healthcare in the United States (Kaiser Family Foundation, 2022). Due to economic disparities and lack of access to healthcare services, many people are not concerned with the right to voluntarily forgo curative healthcare, but worry instead about getting enough curative care. Another reason is many people in the United States are distrustful of the medical establishment. In part, this is due to historical events like broad support for eugenics in the 1920s (Stern, 2020), the long-running Tuskegee Syphilis Study (Stein, 2017), and the contraceptive trials in Puerto Rico of the 1950s (American Experience, n.d.). A third reason EOL care conversations may be difficult stems, at least in part, from the first two. For some, it is the belief that EOL care is not care at all, but instead a cost containment measure borne by those less valued by the healthcare system, including people of color, people living with disabilities, and people with limited financial resources. With these concerns in mind, it is of paramount importance that the effort to enhance access to quality EOL care is not an isolated undertaking, but is instead part of the important effort to ensure that all people in the United States, from birth until death, have equal access to the continuum of quality health care.

EOL care frequently happens as part of an extended period of long-term care. Medicare does not pay for long-term care (Medicare.gov, n.d.). This means that families, and particularly women, often bear the emotional and financial burden of providing this care (Family Caregiver Alliance, 2015). Most hospice care is paid for by Medicare, but other insurance, including Medicaid and private healthcare insurance, may also pay for hospice care (National Hospice and Palliative Care Organization [NHPCO], n.d.). Pursuant to Medicare regulations, all hospice patients have a right to receive effective pain management and symptom control for conditions related to terminal illness, and to be involved in the development of their plan of care (42 C.F.R. § 418.52[b]).

Ninety-eight percent of Medicare-covered hospice care is delivered at the routine home care level of care (MedPAC, 2020). Most hospice care is received in the patient's home

(MedPAC, 2020). This means that the hospice team, which might include nurses, social workers, aides, physical therapists, and chaplains, will visit the home intermittently. There is evidence that some hospice programs do not provide sufficient support to families. For instance, in 2013, nearly 5 percent of Medicare-certified hospices did not provide any skilled visits in the last two days of life to more than 50 percent of their patients (Federal Register, 2015).

An alternative to receiving hospice care in the home is receiving care in a skilled nursing facility (MedPAC, 2020). Notably, in 2018, 42.7 percent of hospice care was delivered to patients living in nursing facilities (NHPCO, 2020). This is, however, only possible if the facility and the hospice provider have a written contract regarding the provision of professional management and room and board (Centers for Medicare & Medicaid Services, 2020). When a Medicare beneficiary receives hospice care at the routine home care level of care while staying in a nursing facility, Medicare will not pay the cost of the room and board, which can be very expensive (Levine & Esposito, 2021).

EOL Decision Making

EOL choices inform decision making, which influences the outcomes and action associated with whether to withhold or withdraw potentially life-prolonging treatment (Akdeniz et al., 2021). The overarching goal of EOL decision making is to prevent or relieve suffering, using person-centered approaches that respect the dignity and self-worth of diverse patient populations, with particular attention to avoiding dominant frameworks that contribute to healthcare inequities (Jones et al., 2022).

It has been recommended that such preferences for and against treatment or interventions be discussed in advance of a medical crisis and/or serious illness (Bullock-Johnson & Bullock, 2022). In the absence of individual competence or capacity to make decisions for oneself, substituted judgment may be necessary. Ethicists have argued that decisions should be based on substituted judgment when possible (American Medical Association [AMA], 2016). Social workers should understand how a person's racial/ethnic and cultural background informs their EOL care decisions. Cultural competency has been widely accepted in social work as a standard that decreases disparities in quality of services delivered to historically marginalized racial and ethnic groups (NASW, 2021).

Different cultural and ethnic groups may have various expectations about goals of care and the type of care they wish to receive. Goal-concordant EOL care takes into consideration personal and family traditions surrounding the death, dying and EOL decision (AMA, 2016). Moreover, a person's historical experiences with the healthcare systems may influence how they prefer to achieve comfort care and pain management, who and how many members of their social support network they wish to be present at the time of death, who may serve as the surrogate decision maker, and where the individual prefers to die.

MAID

Practitioners working with patients who qualify for hospice services seek to assess and provide options for relief of symptoms such as physical pain, emotional pain, and spiritual distress. Some states have further sought to expand patient's rights to exert control over their dying process by enacting legal avenues for a medically supported hastening of death. The identification and discussion of these laws varies within the literature and legal statutes including "right to die" laws, physician aid in dying, death with dignity, and the term used in this document, MAID.

Legal Framework

Legislation in support of MAID options often stresses compassionate care and comfort through the EOL and for patients to have the opportunity to exert control over their own dying process. As of 2022, various forms of legislative statutes have legalized MAID.

Social work and other healthcare practitioners should note that federal policies do not currently permit federally backed healthcare program funding to be used in whole or in part to cover MAID prescriptions or services provided to facilitate hastening the death of terminally ill patients (Restriction on use of Federal Funds Under Health Care Programs, 2011).

Addressing Bioethical Concerns

Some healthcare practitioners, including social workers, may be ethically opposed to supporting MAID, citing issues of protecting life or the bioethical principle of nonmaleficence, an obligation to not cause harm (Dugdale et al., 2019; Schroepfer et al., 2022). Hospice and palliative care organizations may also voice objections to MAID practices specifically pertaining to the concept of hastening death (NHPCO, 2021). Hospice and specialist palliative care practitioners have battled long-standing public misconceptions and misinformation against the idea that their services exist to hasten death (Flieger et al., 2020; Shalev et al., 2018), and stress that their interventions are intended to assist patients in seeking comfort over their symptoms throughout the natural biological decline at EOL, which neither hasten nor postpone dying. MAID practices, however, may represent the antithesis of this messaging.

Some advocacy groups speaking on behalf of the disability community have voiced concern that MAID represents a danger in devaluing people’s lives based on abilities, noting observed early patterns of patients who pursued MAID for reasons equated to loss of dignity and control over bodily functions rather than to seek relief from pain (Hofman, 2018). As such, some in the disability community distrust medical providers’ ability to value the life of individuals with disabilities (Disability Rights Amici, 2016).

Further systemic discrimination based on racial or ethnic group identity, country of origin, gender identity and expression, sexual orientation, or any other characteristics historically linked to healthcare bias or exclusion may disproportionately impact access to information, limit access to options, and belie trust in the delivery of care (Bazargan et al., 2021). Individuals with physical limitations or disabilities may be unable to choose MAID options due to lack of physical ability to self-administer life-ending medication, which thus far in the United States is a requirement of the service (Shavelson et al., 2022). Those who are under resourced or of lower socioeconomic status may similarly lack access to MAID due to the added expense of costly medications which must be paid out-of-pocket as they are not covered by federal or private insurance (Buchbinder, 2018). Until such issues are addressed, and barriers alleviated, MAID may be an option primarily limited for use by those with both financial and social privileges. There is a need for additional research exploring demographics of participants and outcomes in states where MAID is a legally sanctioned option to address these and other social justice and equity concerns (Buchbinder, 2018; Kozlov et al., 2022).

Notwithstanding these concerns, social workers are ethically obligated to support clients' rights to self-determination (NASW, 2021, standard 1.02), which includes promoting autonomy over the dying process within the legal boundaries as dictated in each state. Further, the beneficence principle adds credence to the MAID stance for those who view MAID as providing an act of mercy and kindness for patients who wish to exert more control over their death.

POLICY STATEMENT

NASW promotes respect for dignity, quality of life, and self-determination, as defined by each person approaching the EOL. Accordingly, NASW supports legislation, policies, practices, programs, regulations, and research that promote the following principles and goals related to clients’ EOL care, decision making, and MAID.

Policies Related to EOL Care and Decision Making

With regard to EOL care, NASW supports policies that promote the following:

- open communication with clients, family members, and other support systems about the full range of options for EOL care, the potential benefits and risks associated with each option, and the types of care offered by social workers, physicians, nurses, and other health or mental health providers
- equitable access to affordable, comprehensive, person- and family-centered services, including general healthcare services, long-term care, palliative care, and hospice care, to maximize physical, psychological, social, and spiritual quality of life
- sustainable public and private reimbursement for advance care planning and hospice and palliative care, including, but not limited to, the Medicare hospice benefit, services available to Medicaid beneficiaries, and federal and state health insurance marketplace (exchange) plans
- preservation of economic support programs and expansion of residential care and home- and community-based services, including support for family caregivers, to enable people to live and die in their setting of choice
- insurance coverage for payment of room and board for those receiving home care level of hospice care in an institutional setting, to include skilled nursing facilities, nursing facilities, and hospice facilities
- continuity of care across service settings, with particular attention to interprofessional collaboration and client transitions between healthcare practitioners and settings
- prevention of client abandonment during transitions of care and in situations in which

healthcare practitioners' values conflict with clients' choices

- protection of people in vulnerable situations from neglect, coercion, discrimination, or abuse, including people who may be vulnerable due to disabilities, lack of resources, or experiences of racism, sexism, homophobia, transphobia, or other forms of discrimination and oppression
- sufficient regulatory oversight of EOL care to ensure appropriate levels of caregiver support and to ensure that people receiving EOL care receive effective pain management and symptom control and are given the opportunity to be involved in the development of their plan of care.

Policies Related to EOL Decision Making

With regard to EOL decision making, social workers support the following:

- engagement in a process of advance care planning—including, but not limited to, completion of advance directives—with respect for each person's decision-making capacity, values, and choices
- advance directives, with consideration of each individual's values and unique medical and social context
- the role and responsibilities of healthcare agents and surrogate decision makers
- protections for people in vulnerable situations, including people with disabilities, to guard against exploitation, abuse, or coercion in EOL decision making and care.

Policies Related to MAID

The NASW (2021) *Code of Ethics* provides a number of ethical principles and standards that relate to MAID: (a) Social workers should respect the right of clients to self-determination (standard 1.02) and informed consent (standard 1.03), including the right to access MAID or other EOL care. (b) Social workers should not impose their values or beliefs on clients (standard 1.06). (c) Social workers should ensure clients have access to needed services (Principles section). (d) Any social worker or who may be ethically or morally opposed to participating in the care of a patient who has chosen MAID or voluntarily stopping eating and drinking should be supported in transferring care responsibilities to another practitioner (standard 1.16[a]).

Given these ethical principles and standards, NASW supports policies that promote:

- a person-centered, interprofessional approach in which social workers and other helping professionals work collaboratively with clients and family members, with a focus on the wishes and best interests of clients
- in states with legislation that allows MAID, the laws should: (a) ensure that all people considering MAID have access to the full range of EOL care options; (b) provide clear criteria to determine whether the individual considering MAID is providing free, informed consent and is not being subjected to coercion; and (c) permit people to rescind their decision to pursue MAID at any time
- federal and state laws that authorize services and allow for coverage for medications and services for MAID, including insurance payment
- at the state and federal level, allow for MAID by (a) providing a legal framework to allow individuals to access MAID; (b) providing safeguards to ensure that MAID is provided only when an individual provides fully informed and voluntary consent; and (c) respect the values, beliefs, and morals of all individuals with regard to EOL decision making, including choices regarding curative care, palliative care, and MAID.

Policies Related to Education, Training, and Support

NASW supports policies related to education, training, and support, including the following:

- expansion of educational opportunities and training for all health and social welfare professionals that address EOL decision making and care, including issues related to clinical practice, cultural humility, managing ethical issues, organizational development, and community empowerment
- access to professional development opportunities (including mentoring, supervision, consultation, continuing education, workforce development, credentialing, competence, and postgraduate training) specific to EOL decision making and care
- development of critical self-awareness of personal values and beliefs among social workers and other professionals regarding death and dying
- tools and training to facilitate culturally and linguistically appropriate care
- self-care for social workers and other professionals helping individuals, families, and communities with respect to EOL decision making, care, and MAID, including support for coping with professional grief reactions.

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