



Navigating End-of-Life Needs for a Person With Intellectual Disabilities and Their Caregivers

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People with intellectual disabilities (IDs) are living longer, with many experiencing significant barriers to accessing palliative care and hospice services. Families, caregivers, and direct support professionals comprise essential portions of the community of support often surrounding a person with IDs. For a variety of reasons, including clinician bias and communication difficulties, many people with IDs are excluded from critical conversations regarding their health and life. This article uses a blended case study to explore the complexities and unique considerations in ensuring ethical and practical end-of-life care for people with IDs. Decision-making must center on the person with ID and include them in ways they can understand, thus facilitating their right to autonomy. A collaborative approach to care with shared expertise between caregivers and hospice and palliative care services is key to providing effective, patient-centered care at the end of life. There are tremendous areas of opportunity to improve end-of-life care for this population by partnering with people with IDs, their families, and caregivers.

disability is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior.³ Intellectual functioning refers to general mental capacity, such as learning, reasoning, and problem-solving, whereas adaptive behavior is the collection of conceptual, social, and practice skills that are learned and performed by people in their everyday lives.³

The 21st century marks the first time in history that there will be millions of people with ID living as older adults.⁴ Despite advances in longevity, people with ID continue to experience health care disparities.² There is increasing evidence that having an ID is a risk factor for mortality in multiple illnesses.⁵⁻⁸ Although adults with ID deserve equal access to high-quality hospice and palliative care (HAPC) as those without ID, palliative care services are underused by adults with ID,^{9,10} and there are considerable barriers to overcome.^{11,12} Exploring end-of-life (EOL) care for adults with ID is still relatively new, and further work is needed to determine how to best support community agencies and their staff by removing some of the barriers to providing EOL care.² Following a blended case study highlighting several ethical and practical challenges that may arise when caring for adults with ID at the end of life is a discussion of caregiver considerations, ethical dilemmas, and nursing implications.

KEY WORDS

autonomy, caregiver, direct support professional, ethics, hospice, intellectual disabilities, palliative care

It is estimated that 1% to 3% of the global population—as many as 200 million people—has an intellectual disability (ID).¹ Over the last 2 decades, life expectancy for adults with IDs has increased, and many in Western nations are living long enough to acquire the same chronic and life-limiting illnesses as the general population.² Intellectual

CASE STUDY

Jimmy is a 78-year-old man with severe ID and with sepsis due to aspiration pneumonia who is admitted to the hospital. During the hospitalization, he was diagnosed with widely metastatic cancer most likely of pancreatic origin. He was initially brought to the hospital by emergency medical services after his primary direct support professional (DSP) noted a fever of 103°F and “difficulty catching his breath.” Jimmy is a resident of a small residential group home with 2 other individuals with ID and their DSP caregivers. Jimmy has lived in his home for over 10 years. Jimmy enjoys spending time with his family, primarily his sister Clara and niece Jackie, who live in another state; listening and dancing to music, especially Elvis Presley; feeding his fish; and eating ice cream. Jimmy’s primary community nurse, Jill, and DSP, Imani, are very involved and often present at the bedside as he is admitted to the hospital for

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further workup and management. In general, the hospital nurses report finding their presence helpful, as they can provide much of Jimmy's medical and social history, but at times there is conflict reported between the community and hospital staff because of role confusion.

Jimmy's prognosis is estimated to be poor. He responds well to antibiotics for sepsis, but he is considered a poor candidate for cancer-directed therapies because of his performance status (Eastern Cooperative Oncology Group 3 at baseline mainly due to physical disability). Hospice is recommended by the oncologist to the medical team. Initially, the nursing staff and medical staff at the hospital are unsure of who makes Jimmy's medical decisions. In his electronic medical record, the name and contact numbers of his sister, primary DSP, and community caseworker are provided; thus, all parties are engaged by the medical team. Jimmy's DSPs and community caseworker report uncertainty about providing EOL care in the home as discussions begin. Hospital nursing expresses concern that hospice is being recommended because of Jimmy's ID. The palliative care team is consulted to assist with complex medical decision-making around goals of care.

CAREGIVER CONSIDERATIONS FOR PEOPLE WITH ID

The research- and consensus-based definition of palliative care includes the goal to “improve the quality of a life for patients, their families, and their caregivers.”¹³ It is essential to the practical and ethically appropriate care of people with an ID that health care clinicians value and support the roles of all the caregivers, paid and unpaid, involved in the care of persons with ID.¹⁴ Serious and terminal illness for a person with ID has a ripple effect on an entire community of support surrounding the individual. This can often include family, friends, partners, DSPs, primary medical and clinical staff, and others.

The Role of the DSP for People With ID

Although some individuals with ID reside independently or with family, many live in community-based residential programs (ie, group homes or supervised housing).¹⁵ In addition, for some people with ID who live independently or with family, transitions to community-based residential programs are common as individuals with ID age and their caregivers age, become ill, or die.¹⁶ Direct support professionals are a distinct workforce and an integral part of life in the community for people with ID.¹⁷ They are client-centered and held to a nationally validated Code of Ethics¹⁸ and role-related core competencies.¹⁹ There is inconsistency in training and integration of these competencies and recognition of the need for a more robust workforce with better wages, improved staff development, and decreased turnover.²⁰

The Challenges Associated With Conflicting Values and Care Priorities

Family members and HAPC clinicians may also lack an understanding of the role and importance of DSPs in the lives of individuals with ID. This can contribute to conflicts in care provision for the individual with ID. It is common for DSPs to have longitudinal relationships with the person with ID.^{21,22} Despite long relationships, meaningful connections, and unique insight into the individual, these caregivers can feel left out of decision-making, particularly at end of life. Ryan and colleagues²¹ found that DSPs experience challenging and stressful situations with families making EOL decisions with which they are they uncomfortable, and they do not feel prepared to properly advocate for the individuals with ID in their care when this occurs. Furthermore, despite the long-term caregiving relationship with individuals with ID, DSPs have reported being excluded from the EOL process²² and feeling unsupported in dealing with their grief because of a lack of recognition of the relationship.²³

Valuing the Role of the DSP in the Lives of People With ID

Clarification of roles in providing palliative and EOL care for people with ID is essential to coordinate effective comfort therapies. Nurses can have unclear expectations and understanding of DSPs for people with ID.²⁴ Conflict may arise when expectations are unmet or unexpectedly exceeded. For example, when a nurse expects a DSP to provide personal or specialized care and the DSP expects the nurse to complete it, disagreement may ensue. In fact, many DSPs do not have training or experience with providing personal care, as they are expected to help people with ID to learn how to do things for themselves.¹⁹ Conversely, divergence may occur when a DSP takes an advocacy role for the person with ID, and the nurse prioritizes a different care need. Advocacy is central to the DSP role, underscored by its inclusion as a core competency¹⁹ of the role and a key tenet in their Code of Ethics.¹⁸ Nurses and DSPs should prioritize aligning to understand each other's roles and responsibilities in order to provide optimal care for people with ID.

Unfortunately, multiple barriers exist to providing palliative care in ID community-based residential programs.²⁵ Direct support professionals report varying knowledge and experiences related to death and dying,^{21,26} a lack of experience or training in the provision of EOL care,²⁷ and feel ill-equipped to support individuals with ID with the aspects of EOL.^{9,21,28-30} Similarly, knowledge gaps exist for HAPC clinicians caring for individuals with ID related to communication, decision-making, and complex ID-related medical conditions.^{12,31} A lack of formal protocols, policies, and guidelines regarding EOL care for people with ID contributes to the gaps in knowledge and care for DSPs and HAPC clinicians.²⁵



ETHICAL DILEMMAS

Autonomy

Autonomy is understood as a person's intrinsic and unconditional worth and prioritizes retention of self-determination.³² Hospice and palliative care clinicians have an intimate understanding of the value of autonomy at all stages of serious illness, particularly at EOL. Individuals with ID are often excluded from participation in EOL decisions largely due to difficulties in communication and assumptions that they are not capable of understanding the meaning of death and thus do not have feelings about or reactions to their medical situation.^{33,34} In addition, health care providers have previously indicated, from their perspective, that people with ID are excluded from EOL decision-making because of issues with communication and cognition.³⁴ It is essential that nurses and caregivers engage people with ID in decision-making in ways the individual can understand to promote autonomy.³⁵

Multiple barriers exist for people with ID in having their needs and values understood, including communication difficulties.²⁵ Families and DSPs are often essential to the process of understanding the person with ID. Decision-making is most often successful and ethically grounded when centered on the individual with ID. It is imperative that nurses recognize that the presence of disability, including ID, does not automatically equate to incapacity or lack of ability to participate in decision-making, including at end of life.¹⁴ For people with ID, there is a complex balance of respecting autonomy and protecting those deemed incapacitated and with cognitive impairments. Nurses are responsible for following laws protecting the individual with ID, particularly those associated with decision-making, while also respecting the ethical principle of autonomy. Nurses must develop an understanding of the legal concepts as they apply to this population including informed consent, competency, capacity, guardianship, and guardianship alternatives.¹⁴

In addition to traditional practices of surrogate or substituted decision-making, where another person assumes responsibility on behalf of an individual, some people with ID can be assisted through a process known as supported decision-making (SDM).³⁶ In cases of SDM, the person with ID retains decision-making capabilities, with the support from another person (or persons) who explains issues to the individual and, in some cases, interprets their words or behaviors to determine values and preferences. Supported decision-making occurs in various ways, and proponents of this process identify it as preferable to guardianship, citing that it empowers people with ID and supports their dignity and autonomy in decision-making. Critics of this process identify persistent barriers that limit efficacy and consistency including inconsistent capacity assessments.³⁷ Ultimately, more research is needed to determine if the

goals of SDM are achieved within current structures.³⁶ Regardless of shared or surrogate decision-making processes, nurses have the responsibility to advocate for the inclusion of individual decision-making whenever appropriate in whatever way possible to the extent of their abilities.

Beneficence

The principle of beneficence is interpreted as the altruistic duty to promote good.³² For practitioners caring for people with ID, the beneficial actions of their health care providers may be clouded by unconscious bias and a lingering history of discrimination. The reasons for health care disparities in this vulnerable population are many. The contributions of bias from health care providers to this cycle must be acknowledged to be ended. In a recent national survey of physicians, 82.4% reported that people with ID were viewed as having a worse quality of life due to the presence of a disability.³⁸ Similarly, nurses in international studies expressed negative views toward the quality of life of people with ID compared with those without ID.^{39,40} These negative views have the potential to influence clinical judgment. For beneficence to be maintained, biases must be in check, and clinical recommendations for EOL care should not be based on the presence of disability, but rather the severity of diagnoses.

People with ID are at high risk of being subject to paternalism.⁴¹ Although nurses act ethically when beneficent, this can conflict with autonomy and progress to benevolent paternalism. What a clinician may view as best for the patient may not align with the individual's goals and preferences for his/her care. This contributes to incongruity and erodes the trusting relationships many nurses and health care professionals value with patients and families. The incongruity of beneficence and autonomy is a scenario commonly encountered by HAPC teams. Most often consults will be placed after the misalignment occurs. For beneficence to align with autonomy, clinicians must support patients by identifying common ground.³² Clinicians must not allow the presence of disability to inform their perception of quality of life and instead engage the individual and their caregivers in defining it for themselves.

NURSING IMPLICATIONS

Inherent within the core principles of HAPC is treating the patient and family as the unit of care. Improving the quality of HAPC provided for individuals with ID includes improving relationships with and support for DSPs. Previously identified educational and support needs of DSPs include pain and symptom assessment and management, anticipatory guidance of trajectory at EOL, and bereavement support.²⁷ The nurse should explore and support the evolution of mutually beneficial relationships. Direct support professionals benefit significantly from HAPC clinicians' expertise



in symptom management and other aspects of EOL care. Hospice and palliative care professionals can equally benefit from partnering with these communities of care to better meet the unique needs of individuals with ID.⁴²

Unique to caregiving, nurses understand the intersection of professionalism and meaningful connection. Direct support professionals can maintain professional boundaries while developing deep and meaningful emotional attachments to the person with ID, which many nursing professionals can appreciate. Given the nature of the often long and extensive relationships people with ID have with their caregivers and DSPs, these professionals may also benefit from bereavement support in coping with death and professional grief²⁷ and should be engaged for after-death services.

CASE CONCLUSION

As Jimmy's parents predeceased him, Clara is determined to be his legal surrogate decision-maker. His condition is considered terminal not because of his ID, and discussions about hospice take place. The HAPC team guides the family, DSPs, and community caseworker to include Jimmy in decision-making as much as possible. Jimmy understands death, as his parents have died. His DSPs and sister explain to the health care team that he does not have a strong concept of time and often interprets it very literally. Therefore, discussing his prognosis in terms of "weeks" could increase distress. It is decided to discuss his prognosis around special dates and holidays. Jimmy is supported in making his goals and preferences known with his sister and primary DSP present. It is explained that he has cancer and will die of it. He tells the health care team that it is most important to be home and spend time with his friends and favorite fish. Jimmy's sister wants to support her brother's wishes and desires for him to return home. The process of hospice and support provided is discussed in detail with his DSPs and family. His DSPs express increased comfort in taking care of him at home with this support in place to help guide them. Jimmy is discharged to his group home later the following day with hospice support and died peacefully within 3 weeks surrounded by family, friends, and his favorite fish. Bereavement support is provided to Jimmy's family, friends, and DSPs.

CONCLUSION

A collaborative approach to care between ID services, HAPC services, and all caregivers is key to providing effective, patient-centered care at the end of life.^{42,43} A multidisciplinary approach allowing shared expertise between and among team members is essential to effective collaboration.³⁰ In addition, the team must act in collaboration with the individual with ID and involve them in the decision-making as much as possible, thus facilitating their right to autonomy.²⁵

There is a tremendous area of opportunity to improve HAPC by partnering with people with ID, their families, and paid caregivers.

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