

Palliative care for patients with communication and cognitive difficulties

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Abstract

Objective To help increase the confidence of both caregivers and clinicians in providing palliative care to adults with intellectual and developmental disabilities (IDD) using an easy-to-follow framework to improve and overcome barriers to effective palliative care in this population.

Quality of evidence A literature review was conducted to explore recent best evidence to address these palliative care needs and to allow for a focused opportunity to consider the details of implementing clinical practice guidelines in the palliative care context. Evidence ranges from level I to level III.

Main message Pain and psychological and emotional distress are important issues for individuals with IDD, as they can be difficult to assess and measure, and often present atypically, especially in those with limited communication skills. Further, little is known about end-of-life needs in the adult population with IDD, especially for those living in community residences. The conducted literature review of patient, caregiver, and clinician experiences exposed considerable barriers, including incorrect assumptions about patients' capacity to understand and discomfort of both caregivers and clinicians with open communication. This has resulted in exclusion of adults with IDD from their own care, which has proven harmful. Maximizing time in familiar surroundings and establishing trust and continuity are crucial. Sometimes trial and error with empiric use of comfort medications is necessary, but this can be mitigated with careful examination of distress patterns and judicious use of diagnostic testing. It is always best to integrate the palliative approach into the existing pattern of care.

Conclusion The validated tools and recommendations provided will assist with communication, symptom interpretation, treatment decisions, advanced care planning, addressing grief, and important considerations in end-of-life care.

Soins palliatifs aux patients ayant des difficultés cognitives et de communication

Résumé

Objectif Contribuer à rendre les aidants et les cliniciens plus confiants lorsqu'ils prodiguent des soins palliatifs aux adultes ayant des déficiences intellectuelles et développementales (DID), au moyen d'un cadre conceptuel facile à suivre pour atténuer et surmonter les obstacles à des soins palliatifs efficaces dans cette population.

Sources de l'information Une recherche documentaire a été effectuée pour explorer les données factuelles les meilleures et les plus récentes afin de répondre à ces besoins en matière de soins palliatifs, et pour permettre une réflexion ciblée sur les éléments détaillés de la mise en œuvre d'un guide de pratique clinique dans le contexte des soins palliatifs. Les données probantes sont de niveaux I à III.

Editor's key points

- ▶ The experiences of caregivers, clinicians, and patients reveal many barriers to optimal palliative care provision for adults with intellectual and developmental disabilities, including exclusion from involvement in their own care, which can lead to unclear goals of care and a less patient-centred approach.
- ▶ Current literature provides best-evidence approaches for overcoming barriers in communication, symptom interpretation, treatment decisions, advanced care planning, grief, and important considerations at the end of life.
- ▶ Following a framework such as the authors present here will improve palliative care for adults with intellectual and developmental disabilities, while increasing the confidence of clinicians and caregivers.

Points de repère du rédacteur

- ▶ Les expériences des aidants, des cliniciens et des patients révèlent de nombreux obstacles à la prestation de soins palliatifs optimaux à des adultes ayant des déficiences intellectuelles et développementales, notamment l'exclusion de la participation à leurs propres soins, ce qui peut entraîner une imprécision dans les objectifs thérapeutiques et une approche moins centrée sur le patient.
- ▶ Les ouvrages scientifiques actuels proposent des approches fondées sur les meilleures données factuelles pour surmonter les obstacles à la communication, interpréter les symptômes, prendre les décisions thérapeutiques, procéder à la planification préalable des soins, et pour faire face à la tristesse et à d'autres importantes considérations en fin de vie.
- ▶ L'adoption d'un cadre conceptuel comme celui présenté ici par les auteurs améliorera les soins palliatifs aux adultes ayant des déficiences intellectuelles et développementales, tout en renforçant la confiance des cliniciens et des aidants.

Message principal La douleur, de même que la détresse psychologique et émotionnelle sont des problèmes importants pour les personnes ayant des DID, parce qu'elles sont difficiles à évaluer et à mesurer, et qu'elles se présentent souvent de manière atypique, surtout chez les personnes qui ont de la difficulté à communiquer. De plus, les connaissances sont limitées à propos des besoins en fin de vie chez la population adulte ayant des DID, en particulier chez les personnes vivant dans une résidence communautaire. La révision effectuée par les auteurs des ouvrages sur les expériences des patients, des aidants et des cliniciens a fait ressortir des obstacles considérables, y compris des présomptions erronées de la capacité des patients de comprendre, et le malaise ressenti par les aidants et les cliniciens à communiquer ouvertement. Par conséquent, des adultes ayant des DID ont été exclus de leurs propres soins et ont, de ce fait, subi des préjudices. Il est essentiel de maximiser le temps passé avec eux dans un milieu familial, et d'établir la confiance et une continuité des soins. Il est parfois nécessaire d'utiliser empiriquement et par tâtonnement des médicaments pour les soulager, mais il est possible de l'éviter en examinant attentivement les signes de détresse et en utilisant judicieusement les tests diagnostiques. Il vaut toujours mieux intégrer l'approche palliative dans le modèle de soins existant.

Conclusion Les outils validés et les recommandations présentés aideront à mieux communiquer, à interpréter les symptômes, à prendre les décisions thérapeutiques, à procéder à la planification préalable des soins, et à faire face à la tristesse et à d'autres importantes considérations dans les soins en fin de vie.

Intellectual and developmental disabilities (IDD) are defined as physical or mental impairment occurring before age 18.¹ In the past decades, improvements in health and social care have led to prolonged life expectancy in this population; hence, they are increasingly developing conditions that have higher incidence with age, such as cancer.^{2,3} Owing to deinstitutionalization movements, they are also living in the community more frequently, with a 3-fold increase in the past 20 years.²

The "Consensus guidelines for primary health care of adults with developmental disabilities" were originally developed via a consensus colloquium in 2006 involving knowledgeable and experienced clinicians and researchers in IDD from across Canada and abroad.⁴ Versions updated via similar colloquia have since been published.^{5,6} In the 2018 Canadian consensus guidelines on the primary care of adults with IDD, pain and psychological and emotional distress are addressed.⁶ These are important issues for individuals with IDD, as they can be difficult to assess and measure, and often present atypically, especially in those with limited communication skills. The only indicators of pain and psychological and emotional distress might be nonspecific changes in

vital signs and changes in usual behaviour. The guidelines recommend screening by soliciting caregiver input and using assessment tools adapted for adults with IDD. Possible causes of pain and psychological and emotional distress should be approached systematically in a patient-centred, biopsychosocial-spiritual manner. Such an approach should also be used to develop a diagnostic formulation to guide intervention decisions.

Quality of evidence

A search was performed using PubMed, MEDLINE, EMBASE, Cochrane, CINAHL, Web of Science, Scopus, and Google Scholar using variants of the terms *palliative*, *end-of-life*, *developmental disabilities*, *intellectual disabilities*, and *learning disabilities*. This literature review of patient, caregiver, and clinician experiences providing palliative care to individuals with IDD allows for a focused opportunity to consider the details of implementing the 2018 guidelines while addressing specific palliative care needs. Evidence ranges from level I to level III. Currently, little is known about end-of-life needs in the adult IDD population, especially for those living in community residences. In the general population, the end-of-life period is one that is relatively predictable despite diverse issues, allowing for effective anticipation of end-of-life care needs and their management. This article outlines some of the necessary steps in a framework for overcoming barriers to optimal palliative care for people with IDD, in order to improve on both equitable and high-quality palliative and end-of-life care.

Main message

Experiences of caregivers, health care providers, and patients

Caregiver experiences: Barriers to palliative and end-of-life care can occur from caregivers' lack of understanding or knowledge regarding a patient's focus of care in advanced life-limiting illness. For example, community residence staff might be unwilling to recognize a resident's illness² or not want to speak to the resident about the seriousness of the condition.³ This can lead to misplaced strategies by the caregivers (that can include responding to cues by changing the subject or attempting to reassure without addressing the issue), to fear of causing harm by engaging in such conversations, or to concerns of frightening the patient or provoking an uncontrollable emotional response.³

Caregivers have voiced that they feel ill-equipped for open communication regarding dying and death with this population³ and, instead, tend to withhold potentially upsetting information (**Box 1**).^{7,8} The more complex patients' needs are, the more deliberately they are excluded from involvement in the dying process.⁹ Thus, people with IDD might interpret illness and treatments as punishment for wrongdoing and might not understand why their families or caregivers are sad.¹⁰

Box 1. Feedback from clinicians and patients

Feedback from clinicians and patients with IDD reflects that communication is the most problematic barrier to end-of-life care:

- “Difficult to know if the patient did understand what we were telling him or the treatment we were giving. It therefore made it difficult to know if what his mother said were his wishes were truly his wishes, or maybe her wishes” (Clinician)⁷
- “They talked to me, but they were using language that I didn’t understand I didn’t have a clue what was going on, and I was very, very scared” (Patient with IDD)⁷
- “They didn’t want me to be worried. But if I’d known about it earlier, it wouldn’t have worried me at all” (Patient with mild IDD)⁸

IDD—intellectual and developmental disabilities.

Health care provider experiences: Good-quality end-of-life care also depends on the clinician’s ability to understand and communicate with the patient. Barriers to adequate care include clinicians not recognizing that their assessment of patients’ quality of life (QOL) is based on an incomplete clinical picture. The patient’s condition and function during, for example, a hospital admission provides limited insight into QOL and the family’s experience, as the bias is that the patient and caregivers are being seen at their worst.¹¹

Lack of adequate communication continues to hinder good end-of-life care and is most problematic with patients with severe or profound disabilities. Nevertheless, clinicians might be anxious or stressed in caring for patients with even “mild” disabilities.^{3,12} Clinicians have expressed uncertainty about what and how information is understood or processed and dealt with by both patients and their caregivers.³ They might incorrectly assume that a person with IDD is not capable of participating in care planning.^{2,12} Therefore, they are commonly overreliant on carers to meet communication needs, rather than engaging in any direct communication with the person with IDD.^{3,12}

Furthermore, other authors have shown that clinicians might use traditionally validated pain assessment tools inappropriately, treating all expressions of distress with analgesics, rather than trying to distinguish between physical pain and emotional distress.¹³ Alternatively, patients might receive less attention and management of symptoms such as pain, as found by authors of a UK study in which patients with IDD received less opioid analgesia compared with patients without IDD.¹⁴

Unfortunately, palliative care specialists generally have limited experience caring for people with IDD; meanwhile, those familiar with the needs of adults with IDD have limited knowledge about palliative care.^{15,16} Therefore, a more collaborative relationship between these groups is needed.¹⁵

Patient experiences: There is no evidence that people with IDD have less need for information about illness, dying, or death.^{3,17} There is evidence, however, that people with IDD are less likely to ask questions and initiate conversations.³

Patients with IDD might have difficulties with abstract concepts such as death, knowing death is imminent, understanding difficult concepts (treatments, importance of treatment, palliative care, informed consent), sharing feelings and talking about illness with others, and being treated differently because of their disability.^{9,17,18} However, people with mild IDD often indicate some awareness of their condition, either directly in conversation or indirectly by mood and behaviour changes.³ For people with severe or profound IDD, on the other hand, marked uncertainty exists as to whether they are aware of the development of life-limiting conditions such as cancer.³

Helpful practices including planning, symptom interpretation, treatment decisions, and communication

Advanced care planning: An early referral to palliative care allows for a longitudinal experience that over time can build trust and familiarity with staff, supports, and services.^{19,20} This is important in particular for patients with IDD and their caregivers, as lack of trust, continuity, and authentic relationships have been shown to negatively affect quality of care.²⁰ This also allows palliative health care professionals to take the time to gain knowledge of a patient’s lifestyle and usual behaviour.¹⁹ The goal is to integrate the palliative approach (symptom control, comfort, family support, discussions about goals of care, and advanced care planning) into the existing pattern of care.¹¹

Authors of a study of 850 residents at a developmental centre in the United States reported that only 2 had a completed advanced directive.²¹ Advanced care planning might include preferences about where to die; when to treat or withhold treatment; cultural, spiritual, or religious needs; and funeral planning.^{2,18,22} To help facilitate this, National Health Service in the United Kingdom has produced a template for an “end-of-life book” designed for the IDD population.^{23,24}

Symptom interpretation: Accurate symptom interpretation in a nonverbal patient is dependent on the development of a meaningful relationship with the individual.² Many patients with IDD lack a communication repertoire to articulate distress in recognizable or socially acceptable ways.²⁵ For those caring for patients with IDD with whom they did not have previous relationships, interpreting changes in mood and behaviour or refusal to cooperate as symptoms of disability can lead to misdiagnosis or undertreated pain and anxiety.² Therefore, symptom assessment needs to be individualized based on the experience of the patient’s closest caregivers.¹⁰ Three main indicators of pain among people with cognitive impairments include increased

aggression, restlessness, and changes in speech (eg, whining, moaning, groaning).⁹ However, other indicators of distress can include active withdrawal from usual activities, not cooperating, and changes in body language.⁹ Likewise, symptoms might manifest as irritability, hyperactivity, inactivity, self-injurious behaviour, loss of appetite, and sleep problems.¹³

Versatile assessment tools can help for interpretation of symptoms. The Disability Distress Assessment Tool was developed to help clinicians and caregivers identify, communicate about, and document an individual's signs of distress and contentment.^{10,26} The Abbey scale is another simple tool for those who cannot communicate well verbally and it measures nonverbal expressions. This quick-and-easy numerical tool grades scores and converts them into levels of pain for a baseline or continuous measure.⁹ Other similar tools include the Planning Ahead to Manage Pain and Distress Confidently checklist⁹ and the Non-Communicating Adult Pain Checklist.²⁷ Unfortunately, trial and error or empiric use of comfort medications based on the most likely cause are often necessary.¹⁰ Careful examination of distress patterns, thorough physical examination, and judicious use of diagnostic testing can help mitigate this issue.¹⁰

Treatment decisions: Lives of great joy and happiness can be lived without capacity for complex thinking.¹¹ An unreflective overemphasis on the role of cognitive limitation in QOL can lead to strongly negative consequences, such as limiting the spectrum of care options.¹¹ Similarly, practitioners engaging in conversations about palliative and end-of-life care needs should avoid words such as *futile* or language that seems to undervalue a patient's life.²⁸ Such language might remind caregivers of previous incorrect predictions such as, "Your baby will never live to be an adult" or "Your child will never have a meaningful life."²⁸

As with the general population, risks and burdens of treatment need to be discussed.²⁸ Questions need to be asked about whether patients can comply with therapy, if sedation or restraints will be required, and whether treatments will result in undue pain, suffering, or fear.²⁸ For some, even a transfer to a medical facility could itself be very stressful because of the importance of routine and familiar environments.² Most important, there should be a positive effect on QOL after treatment for it to be considered.^{16,28}

Further, end-of-life situations can be difficult to predict.²⁹ Epidemiologically, it can be difficult to identify outcome indices and valid comparison groups.¹¹ Patients with IDD often have tortuous clinical trajectories, with many unexpected reversals and idiosyncratic responses to treatment.^{11,16,29} Patients might have had previous experiences when they were not expected to recover, but survived nonetheless.¹¹ Even a single resurrection-like experience can cause substitute decision makers to be reluctant to limit future interventions.¹¹

Despite challenging prognostication causing clinicians to be reluctant to hazard short-term prognoses, clinicians need to overcome their own sense of discomfort with being wrong about dire outcomes and be able to counter parents' unrealistic expectations for the endless restorative prowess of medical care.¹¹ Regardless, decisions about whether to use or forgo medical interventions can expectedly be difficult.¹⁶

Should noncurative treatment be chosen, the most important factors identified by patients with IDD for their end-of-life care were the wish to be involved in their own care, the importance of having friends and family around, the need to remain occupied, and the need to be physically comfortable.^{19,22,30} Strategies can include working closely with caregivers to maximize time in familiar surroundings and with familiar people and objects, identifying routines and activities the patient enjoys, and searching for opportunities to offer emotional reassurance.^{2,10}

Communication: Helpful communication strategies can be used to break the communication barrier. Instead of verbal communication, visual tools can be used to relay information from both sides, such as using a body map or pictures to indicate pain¹³ or using communication aides to help patients express themselves. Examples of such tools include the Books Beyond Words series, which includes 26 picture books designed to help adults with IDD understand and talk about difficult issues, including cancer and death,⁷ and *Getting on with Cancer*, a pictorial book designed to provide information about cancer for people with IDD.^{8,31} Authors of one study demonstrated that participants reading books with a supporter soon interspersed the story in the book with personal experiences.⁸ Another strategy can be to show an image of someone in a similar situation and ask what the fictional person might need or want.³⁰ Authors of a study of patients with mild to moderate IDD suggest many will base answers on personal experiences.³⁰

Additional strategies might include allotting extra time for establishing the best way to communicate, rephrasing questions and explanations as needed, ensuring as much understanding as possible, and building on the therapeutic relationship by gaining trust.⁷ Avoid rushing on with questions if the patient does not immediately respond, as it might take longer for someone with IDD to think, process, and formulate responses.⁷ Because abstract thinking can be more difficult, explanations of what is happening might have to be based on the here and now.³² Even a concept like time or duration might need to be rephrased using index events (eg, "Did you have the pain at Christmas?" rather than "How long have you had pain?").⁷ Simple, non-euphemistic language introducing one concept at a time using short sentences is preferred.⁷ Be cautious when offering choices in a question, as some patients might simply repeat the final option offered. Re-asking by switching the words around can help mitigate this.⁷

When asked, many people with IDD relay that they want to be told truthfully and straightforwardly about what is going on.⁷ However, as in the general population, some prefer not to be told painful truths. Professionals still need to find out what the person wants to know.⁷ Whether the person has capacity to understand such information should be carefully thought through, but assumptions should not be made.⁸ Different people could have quite different opinions on the level of insight.³ When caregivers feel it is better to protect the person with IDD from bad news or discussions around death and dying, the person's right to information and involvement needs to be considered.^{8,18} Sensitivity is required to enable everyone involved to discuss the issue.⁸

When breaking bad news to people with IDD, a proposed model (the ARCH model for breaking bad news) suggests an ongoing process of disclosure to help build understanding over time, with the involvement of family carers (**Box 2**).^{17,19,33}

Grief: Like the general population, people with IDD can also experience grief. People who do not verbally communicate are at risk of having their expressions of grief overlooked.² For those who are nonverbal, grief will require some active form of creative expression such as painting, dance, or creating a photo album, in place of written or oral expressions of loss.² More opportunities for end-of-life learning and understanding might need to be provided to reduce distress and psychological morbidity, including complicated grief.¹⁸

Box 2. The ARCH model for breaking bad news

The following model can be helpful for communicating bad news to patients with IDD:

- **Ask:** Keep questions straightforward. Find out what is already known and what the patient wants to know
- **Repeat and clarify:** Be prepared to go over information repeatedly, in different ways (using books, photos, etc). Simplify if necessary
- **Check the level of understanding:** Explore how much the patient knows and what it means to him or her. Go back to previous stages as needed
- **Help the person express feelings:** Encourage expression of feelings, listen carefully, and give support. Help describe feelings and explore what the patient feels he or she might need next, future support options and choices, and letting other people know, if necessary

IDD—intellectual and developmental disabilities.
Data from Read and Morris.³³

Conclusion

Adults with IDD are no less deserving of high-quality palliative care than the general population is. However, a literature review³⁴ of patient, caregiver, and clinician experiences has exposed considerable barriers, some of which are easier to overcome than others. Owing to assumptions

about patients' capacity to understand, and the discomfort of both caregivers and clinicians with open communication about difficult topics, adults with IDD have often been excluded from discussions about their own care and the grieving process. This is ultimately harmful. Instead, we suggest including adults with IDD in all aspects of their care, assisted by validated tools and recommendations regarding communication, treatment decisions, advanced care planning, and anticipating, interpreting, and managing pain and other symptoms. Time needs to be taken to establish trust and continuity, and to maximize time in familiar surroundings. Sometimes trial and error with empiric use of comfort medications is necessary, but this can be mitigated with careful examination of distress patterns and judicious use of diagnostic testing. Further, it is always best to integrate the palliative approach into the existing pattern of care. The aim of this review is to improve palliative care for adults with IDD by increasing the confidence of both caregivers and clinicians using an easy-to-follow framework. As palliative care for adults with IDD increasingly becomes recognized as a crucially important topic, future research will benefit from collaboration between palliative care specialists and those with expertise caring for people with IDD.

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Contributors

All authors contributed to the literature review and interpretation and to preparing the manuscript for submission.

Competing interests

None declared

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