

## Community-Based Palliative Care for Patients with Cerebral Palsy and Intellectual Developmental Disability: A Mixed-Methods Analysis of Current Practices

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### Abstract

*Individuals with Cerebral Palsy (CP) and/or Intellectual and Developmental Disabilities (IDD) face difficulties accessing equitable palliative care. This study uses a mixed methods approach to assess the knowledge and comfort of community-based healthcare workers in providing palliative care for this patient population. Quantitative data from 54 palliative care practitioners was obtained through an online survey and qualitative analysis was obtained through a subsequent semi-structured interview with a focus group of four providers. Findings suggest providers were most confident in managing physical symptoms (66.7% dyspnea, 68.6% pressure ulcers, 72.7% restlessness) and having goals of care discussions (89.5%), but least confident in managing emotional pain (41.1%), grief (28.6%), and prognostication (34.6%). Similar themes were identified in the focus group, with an emphasis on the importance of patient autonomy and communication, as well as the challenge of facing personal and systemic biases. Importantly, both the survey and focus group echoed the need for more training that specifically addresses the needs of this population. Results suggest that challenges and discomfort in providing palliative care to patients with CP and IDD continue to exist and further training that incorporates the meaningful perspectives of these patients is needed.*

## Introduction

With improvements in healthcare and social services over the past decade, patients with cerebral palsy (CP) and severe to profound intellectual developmental disability (IDD) are now more likely to face age-related illnesses than ever before. Conditions such as cancers, cardiovascular disease and respiratory disease are increasing in number among this population and pose important requirements in end-of-life care (Kirkendall et al., 2012; Ryan et al., 2011; Tuffrey-Wijne et al., 2007). A palliative approach to care, one that focuses on prioritizing patients' goals of care and quality of life, would be beneficial, however this has traditionally been implemented under the scope of pediatric care. There is currently limited knowledge on end-of-life care for adults with IDD (Sue & Mar, 2021; Sue et al., 2019). Additionally, there has been a three-fold increase of individuals with CP and IDD living in a community setting over the past 20 years, meaning there are more individuals requiring community-based care than ever before (Kirkendall et al., 2012). The context of palliative care for individuals with CP and IDD has changed substantially with advances in healthcare and changing demographic factors.

Patients with CP and severe to profound IDD face unique healthcare challenges, including palliative care. This patient population may experience complex symptomatology and unpredictable clinical trajectories that make management and prognostication difficult (Sue et al., 2019; Wark et al., 2017). Importantly, communication difficulties are prevalent among patients with CP and IDD and has been a commonly reported challenge among palliative care physicians (Adam et al., 2020; Shady et al., 2022; Sue & Mar, 2021). Symptoms of pain or emotional distress are often communicated nonverbally and as such, symptoms are often poorly recognized (Adam et al., 2020; Sue et al., 2019). Additionally, palliative care physicians do not consistently talk to this patient population about death and dying (Foo et al., 2021) and these patients are often excluded from discussions surrounding goals of care and advanced care planning (Sue et al., 2019; Voss et al., 2021). Studies have also shown that healthcare providers report low confidence in providing palliative care to this patient population due to a lack of knowledge, training, and experience (Adam et al., 2020; Sue & Mar, 2021). Overall, important gaps in knowledge and care exist surrounding end-of-life care for adults with CP and severe to profound IDD. There is a need to further elucidate what the baseline knowledge of palliative care providers is to better understand what areas need to be improved. The aim of this study is to assess the knowledge and comfort of healthcare providers in providing community-based palliative care for patients with CP and severe to profound IDD.

## Materials and Methods

### Study Design

This was a mixed-methods qualitative study, consisting of a 25-question online survey using a Likert-scale format, and a virtual focus group. Survey questions were developed based on a narrative literature review on the topic of community-based palliative care for patients with IDD. Survey questions were intended to address key points and challenges identified in previous literature. Focus group questions were developed using key points identified in the survey results.

## **Setting and Data Collection**

The survey was distributed by email to physicians in Canada who were part of the College of Family Physicians of Canada Palliative Care (CFPC) Member Interest Group and/or the CFPC IDD Member Interest Group. Recipients were also asked to share the survey with allied health professionals who were involved in the provision palliative care for this patient population. The survey was composed of 25 questions on various aspects of palliative care for individuals with CP and IDD, including healthcare provider confidence and perceived gaps. (Appendix 1). This was a convenience sample intended to obtain a reasonable cross-section of primary care practitioners throughout Canada. Survey data was collected between April 26, 2021, and April 16, 2022. Sixty-four responses were recorded.

The focus group occurred via Zoom on June 22nd, 2022. Participants were recruited via email addresses provided by survey respondents that had indicated an interest in participating in a focus group. The group was composed of three palliative care physicians and one spiritual health practitioner, all of whom had a special interest in the care of individuals with IDD. The focus group was conducted by 3 researchers (A.D.; M.W.; I.L.). This took on a semi-structured format; questions were open-ended and guided by the results of the online survey.

## **Ethics Approval**

Ethics approval was obtained from the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

## **Data Analysis**

Survey results were analyzed using the platform through which the survey was distributed, Qualtrics. Survey results were expressed as a percentage of participants who selected each response on the Likert-scale.

The focus group transcript first underwent independent narrative review by three researchers (A.D.; M.W.; I.S.). A consensus regarding common themes was reached without any disagreements to resolve. Informed by the overarching themes identified in the narrative review, manual codes were created by A.D. in NVivo 12 to perform a thematic analysis. The same three researchers then coded the transcript and identified the exemplar quotes. Individual coded transcripts were compared. The average percentage of transcript coverage between reviewers was used as the final result for each theme. The other four researchers were in agreement with the thematic analysis coding and findings.

## **Results**

### **Survey Results**

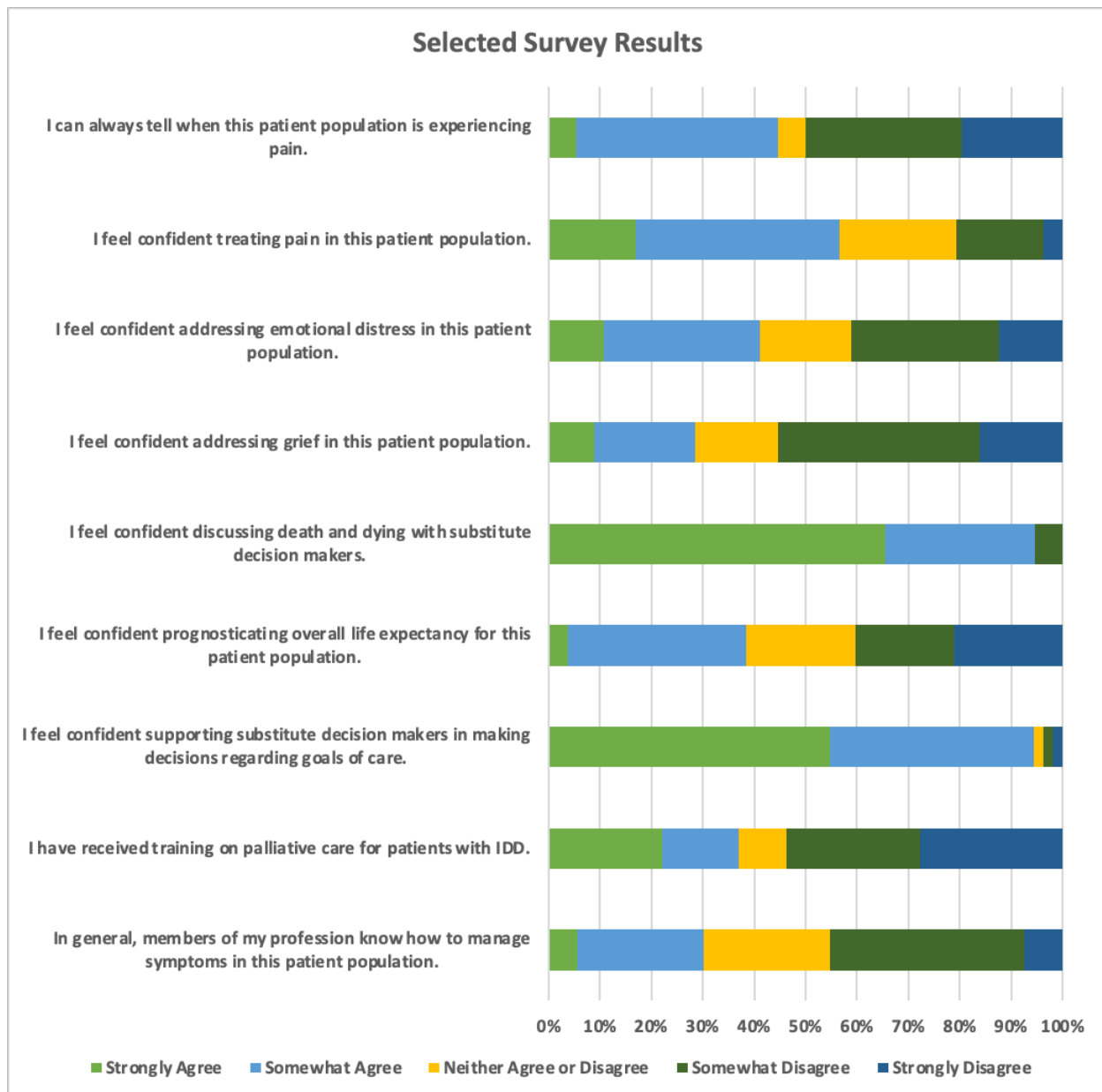
Sixty-four health care practitioners participated in the survey. Participation was recorded as consenting to participate and completing a minimum of 1 additional question from the survey.

The study completion rate was 84.6% (54/64). Demographic data for all participants is displayed in Table 1. Selected survey results are displayed in Figure 1.

**Table 1**

*Demographic Data of Survey Respondents*

Characteristic	Number of respondents (N=64, %)
Profession	Physician – 36 (56.3%)
	Nurse – 9 (14.1%)
	Social Worker – 3 (4.7%)
	Nurse Practitioner – 2 (3.1%)
	Physiotherapist – 3 (4.7%)
	Other – 11 (17.2%)
	No answer/ Prefer not to answer – 0 (0%)
Age (Mean [SD])	48.4 [12.4]
Gender	Female – 41 (64.1%)
	Male – 21 (32.8%)
	Non-binary – 1 (1.6%)
	No answer/ Prefer not to answer – 1 (1.6%)
Approximate number of community-based patients with CP and/or IDD treated with palliative care needs?	0 – 8 (12.5%)
	1-9 – 24 (37.5%)
	10-19 – 12 (18.8%)
	20-49 – 7 (10.9%)
	50-99 – 3 (4.7%)
	≥100 – 7 (10.9%)
	No answer/ Prefer not to answer – 3 (4.7%)

**Figure 1***Selected Survey Results*

Note: All questions were prefaced with “The following statements apply to patients with cerebral palsy and severe to profound intellectual and developmental disabilities with palliative care needs. Please rate your agreement with each statement.”

### ***Confidence in identifying and treating physical symptoms***

Respondents were somewhat confident in their abilities to identify and treat physical symptoms of disease in patients with CP and/or IDD. Nearly half (44.6%) of respondents somewhat or strongly agreed to being able to always identify pain in this population, and 56.6% somewhat or strongly agreed to feeling confident treating pain in this population. Participants reported the

most confidence treating physical symptoms including dyspnea (66.7%), pressure ulcers and restlessness (68.6%) and agitation (72.7%).

### ***Confidence in identifying and treating emotional distress/grief***

Identifying and treating emotional grief and distress were the topics with which respondents were the least confident. Nearly half (44.6%) of participants somewhat or strongly disagreed to always knowing when patients with CP and/or IDD are in emotional distress, and 41.1% agreed they felt confident addressing emotional distress in this population. Regarding grief, most respondents (55.4%) somewhat or strongly disagreed to being able to identify when persons with CP and/or IDD are experiencing grief, only 28.6% indicated feeling confident treating grief.

### ***Goals of Care Discussions***

Respondents had the highest rates of confidence regarding goals of care discussions and supporting substitute decision makers for those with CP and/or IDD. Most respondents (89.5%) indicated they felt confident supporting substitute decision makers regarding goals of care. Confidence discussing death, end of life, and specific facets of goals of care (enteral feeding, quality of life, resuscitation) ranged from 80.0% to 94.5%. Respondents felt the most confident discussing death and dying with substitute decision makers and felt the least confident discussing this with the patient. Participants were uncomfortable prognosticating life expectancy for this population; only 34.6% somewhat agreed and 3.8% strongly agreed that they were confident doing so.

### ***Policy and Training***

Only 37% of participants indicated that they had received specific training in providing palliative care for persons with CP and/or IDD. When asked whether members of their profession knew how to manage symptoms in this population, only 24.5% somewhat agreed while 5.7% strongly agreed. When asked if their professional organization had guidelines for symptom management for persons with CP and/or IDD, 50% of respondents disagreed or strongly disagreed. Results were similar for those asked about guidelines in their workplace, with 30% of participants somewhat or strongly agreeing their workplace had guidelines for symptom management in this population.

### ***Focus Group Results***

During initial analysis 20 codes were identified and were grouped into the following themes: (1) Patient Autonomy, (2) Goals of Care Discussions, (3) Symptom Management, (4) Bias, (5) Communication, (6) Prognostication, and (7) Including Caregivers. Themes and subthemes, along with average transcript coverage, can be found in more detail in Figure 2.

**Figure 2***Focus Group Themes and Subthemes*

<b>Code (w/ subcodes):</b>	<b>Transcript Coverage:</b>
<b>Patient Autonomy</b> <ul style="list-style-type: none"> <li>· Values</li> <li>· Patient-first</li> <li>· Spiritual Care*</li> </ul>	20.17%
<b>Symptom Management</b> <ul style="list-style-type: none"> <li>· Symptom Identification*</li> <li>· Pain</li> <li>· Spasticity</li> <li>· Mental Health</li> </ul>	17.81%
<b>Communication</b> <ul style="list-style-type: none"> <li>· Discomfort</li> </ul>	10.06%
<b>Bias</b> <ul style="list-style-type: none"> <li>· Systemic Discrimination*</li> <li>· Assumptions</li> <li>· Discomfort</li> </ul>	9.72%
<b>Goals of Care Discussions</b> <ul style="list-style-type: none"> <li>· Spiritual Care</li> </ul>	8.15%
<b>Prognostication</b>	5.92%
<b>The Inclusion of Caregivers</b> <ul style="list-style-type: none"> <li>· Caregivers as experts</li> </ul>	5.36%

\*indicates the most commonly identified subtheme.

***Patient Autonomy***

The most identified theme from the focus group was the importance of patient autonomy for those with IDD and/or CP receiving palliative care. Healthcare practitioners noted patients were

seldom encouraged or given the opportunity to make their own healthcare decisions. Assumptions about patients' decision-making capacity were often made without investigating their comprehension of the risks and benefits of a specific decision, and it can lead to them being left out of their own care, as suggested by one participant's comments:

Just because someone doesn't have the capacity to answer one particular question about their health doesn't mean they don't have the capacity to answer another question. And I find that understanding the nuance of that is difficult for people who don't really have that experience, so often they just assume that the patient doesn't understand.

Three sub themes were identified under the topic of autonomy: (a) Patient-first, (b) Spiritual Care, and (c) Values. Focus group participants agreed that to have autonomy for these patients, their needs and opinions must be prioritized. Participants also expressed that asking about a patient's core values, especially at the end of life, is key to making healthcare decisions on their behalf should they lose capacity.

### ***Symptom Management***

Identifying and managing patient symptoms was broadly identified as a challenge in this population. Subthemes under this overarching theme included (a) symptom identification, as well as specific symptoms uniquely difficult to manage in this population: (b) spasticity, (c) pain, and (d) mental health symptoms. Participants shared that many providers lack experience identifying and interpreting symptoms in this population (particularly in non-verbal patients). Spasticity, according to one participant, was often a mechanism to communicate discomfort or pain.

Participants also identified pain as being challenging to identify and address. They noted some clinicians dismiss pain as "part of their disease", and many struggle as there is no objective measure of pain. For these reasons, physicians are often relying on caregivers to identify pain. Practitioners also noted depression and anxiety were difficult to diagnose and treat.

### ***Communication***

All participants expressed that communication with persons in these populations, though challenging, is vital to providing adequate palliative care. Many participants had developed strategies including simplifying language, scheduling extra time for the appointment, using visual representations to rate pain, and involving caregivers who can provide information on the patient's non-verbal communication styles. The sub-theme identified under communication was physician discomfort. All participants agreed that there is "No excuse not to communicate with people, regardless of their perceived and receptive communication and cognition."

### ***Bias***

Focus group participants stated that biases about and against this population were prevalent in healthcare both at the individual and systemic levels. The most commonly identified subtheme was systemic discrimination. As one participant stated:



Healthcare often wishes to apply generic values that typically represent the cultural powers in society... white, Christianity-based, upper middle-class values. And it's not reflective of many of our patients and the community and culture that they're housed in.

This reflects that the values in the healthcare system often do not consider those in marginalized groups, and as such, present systemic barriers in providing equal and adequate care for patients with IDD.

The second sub-theme identified was the assumptions made about persons with IDD and CP. Participants felt that healthcare practitioners treat those with IDD and CP at a lower quality than those without due to individual assumptions and biases:

Discrimination against people with cognitive impairment is certainly very real, that the lengths to which healthcare practitioners feel appropriate to go with someone with normal cognition is often different than someone with impaired cognition.

The final sub-theme identified under bias was discomfort. Focus group participants described past experiences wherein practitioners had relied on assumptions and pre-existing biases when lacking comfort treating these populations.

### ***Goals of Care Discussions***

The goals of care discussions were difficult to initiate for this population, but vital to adequate care, according to the participants. The subtheme of spiritual care was also identified as part of goals of care discussions.

### ***Prognostication***

All participants noted there was a lack of confidence and comfort in prognosticating life expectancy for those with IDD and CP. Participants stated that difficulty estimating life expectancy can result in rejected billings, poorer overall care, and difficulty making decisions about care discontinuation near the end of life.

### ***The inclusion of caregivers***

The final theme identified was the role of the caregiver as the expert when providing palliative care to this population. One participant stated:

In terms of caregivers, it's really important to get their perspective on what the patient looks like when they're well... even very minor, subtle changes in their expression and their behavior and even tone can indicate something like pain, right? But if it's your first time seeing the patient, you don't know what their baseline is like.

## Discussion

This study seems to be the first to specifically interrogate the experiences of palliative care providers working in the community setting with people with IDD. Previous research in the Canadian population has emphasized the importance of patient-centered care, a theme that was reiterated in the present study's focus group. A 2019 review of palliative care for patients with IDD came to the following conclusion:

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 (Sue et al., 2019).

Our study suggests that providers are only somewhat confident in the identification of most symptoms in this patient population. They particularly struggled to identify and manage emotional distress and grief. The importance of identifying grief in this patient group has been demonstrated by previous studies (Kirkendall et al., 2012; Stancliffe et al., 2016). Our participants indicated a need and desire for further training in palliative care for the IDD population, which, again, is substantiated by findings and recommendations from reviews on this topic (Sue et al., 2019).

The primary limitation of the survey was the use of a convenience sample. The physicians recruited for the focus group all had specific interest in the care of people with IDD, palliative care, or both, and thus they were likely already highly motivated to improve care for this patient population. Furthermore, due to convenience sampling, the geographic distribution of participants was unknown. Likert-scale questions did not allow for nuance in responses. Limitations of the focus group were the small sample size and selection bias.

Nonetheless, results from this survey and focus group provided insight into current practices and knowledge gaps in community-based palliative care for patients with IDD. The identification of such gaps in knowledge has potential utility in advancing practice guidelines and medical training.

## Conclusion

Survey results indicate many healthcare providers reported feeling a lack of confidence identifying and treating both physical and emotional pain symptoms for those with CP and IDD. Challenges to adequate palliative care for those with IDD and CP include symptom management, specifically symptom identification, communication, prognostication, and bias against this population. Of note, biases exist at both a systemic level, wherein discrimination towards individuals with IDD is prevalent among healthcare systems, but also at the level of individual healthcare providers themselves.

Focus group results echoed similar themes, with a strong emphasis on the importance of patient autonomy. There are various clinical tools such as *The Decision-Making Checklist* and *Communicating effectively with people with developmental disabilities*, both developed by the

Developmental Disabilities Primary Care Initiative at Surrey Place (Toronto, 2011), as well as national guidelines by The College of Family Physicians of Canada (Sullivan et al., 2018) that help providers in ensuring optimal decision-making for this patient population.

Some discomfort in providing these populations with quality palliative care may stem from a lack of training on the specific needs of persons with IDD and CP in this context. Training programs and practice guidelines should aim to include the perspectives of these populations to better address their needs. Although this study did not directly involve people with IDD, future research in this field should seek to include these valuable patient perspectives.

### **Key Messages from this Article**

**People with Disabilities:** You are deserving of equitable and inclusive palliative care that meets your goals and needs. You deserve to be prioritized in your own healthcare, including goals of care discussions, symptom management, and transparent communication.

**Professionals:** Palliative care providers for patients with IDD should aim to involve the patient in their own care, while implementing an unbiased and non-judgmental approach. Providers should seek to identify and counteract any personal biases or discomfort, as well as systemic biases, that may interfere with the quality of care.

**Policy makers:** Policies surrounding palliative care medicine should aim to increase the awareness and training of providers to the unique needs of patients with IDD. The inclusion of patients with IDD in policy-work is strongly encouraged in order to work towards more equitable changes.

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**Appendix****Appendix 1: Full Survey Responses**

Question:	Number (%) of respondents reporting "Strongly Agree"	Number (%) of respondents reporting "Somewhat Agree"	Number (%) of respondents reporting "Neither Agree Nor Disagree"	Number (%) of respondents reporting "Somewhat Disagree"	Number (%) of respondents reporting "Strongly Disagree"	Total Number of respondents for this question:
I can always tell when this patient population is experiencing pain.	3 (5.4%)	22 (39.2%)	3 (5.4%)	17 (30.3%)	11 (19.6%)	56
I feel confident treating pain in this patient population.	9 (17.0%)	21 (39.6%)	12 (22.6%)	9 (17.0%)	2 (3.8%)	53
I can always tell when this patient population is experiencing dyspnea.	5 (9.3%)	20 (37.0%)	8 (14.8%)	16 (29.6%)	5 (9.3%)	54
I feel confident treating dyspnea in this patient population.	12 (23.5%)	22 (43.1%)	3 (5.9%)	10 (19.6%)	4 (7.8%)	51
I feel confident treating spasticity and dystonia in this patient population.	8 (15.4%)	20 (38.5%)	9 (17.3%)	11 (21.1%)	4 (7.7%)	52
I feel confident treating pressure ulcers in this patient population.	14 (27.5%)	21 (41.2%)	7 (13.7%)	6 (11.8%)	3 (5.9%)	51
I feel confident treating restlessness and agitation in this patient population.	14 (25.5%)	26 (47.2%)	8 (14.5%)	6 (10.9%)	1 (1.8%)	55

I can always tell when this patient population is experiencing emotional distress.	4 (7.1%)	21 (37.5%)	6 (10.7%)	17 (30.4%)	8 (14.3%)	56
I feel confident addressing emotional distress in this patient population.	6 (10.7%)	17 (30.4%)	10 (17.9%)	16 (28.5%)	7 (12.5%)	56
I can always tell when this patient population is experiencing grief.	3 (5.4%)	12 (21.4%)	8 (14.2%)	21 (37.5%)	12 (16.1%)	56
I feel confident addressing grief in this patient population.	5 (8.9%)	11 (19.6%)	9 (16.1%)	22 (39.3%)	9 (16.1%)	56
I feel confident supporting loved ones and caregivers as a patient approaches end of life.	34 (59.6%)	17 (29.8%)	3 (5.3%)	3 (5.3%)	0 (0%)	57
I feel confident having conversations around balancing quality of life and longevity with this patient population and their substitute decision makers.	28 (50.9%)	21 (38.2%)	4 (7.3%)	2 (3.6%)	0 (0%)	55
I feel confident discussing death and dying with substitute decision makers.	36 (65.4%)	16 (29.1%)	0 (0%)	3 (5.5%)	0 (0%)	55

I feel confident discussing death and dying with this patient population.	20 (36.4%)	22 (40.0%)	8 (14.5%)	2 (3.6%)	3 (5.5%)	55
I feel confident prognosticating overall life expectancy for this patient population.	2 (3.8%)	18 (34.6%)	11 (21.2%)	10 (19.2%)	11 (21.2%)	52
I feel confident supporting substitute decision makers in making decisions regarding goals of care.	29 (54.7%)	21 (39.6%)	1 (1.9%)	1 (1.9%)	1 (1.9%)	53
I feel confident in goals of care discussions specifically involving enteral feeding for this patient population.	25 (48.1%)	15 (28.8%)	4 (8.0%)	5 (9.6%)	3 (5.8%)	52
I feel confident in goals of care discussions specifically involving artificial hydration for this patient population.	24 (47.1%)	18 (35.3%)	4 (7.8%)	2 (3.9%)	3 (5.9%)	51
I feel confident in goals of care discussions specifically involving ventilation, resuscitation, and other critical care decisions for this patient population.	21 (41.1%)	22 (43.1%)	2 (3.9%)	4 (7.8%)	2 (3.9%)	51



I feel confident involving an ethicist in difficult decisions for this patient population.	30 (56.6%)	11 (20.8%)	10 (18.9%)	2 (3.8%)	0 (0%)	53
I have received training on palliative care for patients with IDD.	12 (22.2%)	8 (14.8%)	5 (9.3%)	14 (25.9%)	15 (27.8%)	54
In general, members of my profession know how to manage symptoms in this patient population.	3 (5.7%)	13 (24.5%)	13 (24.5%)	20 (37.7%)	4 (7.5%)	53
My professional organisation has guidelines for symptom management in this patient population.	1 (2.0%)	9 (18.0%)	15 (30.0%)	15 (30.0%)	10 (20.0%)	50
My workplace has guidelines for symptom management for this patient population.	3 (6.0%)	12 (24.0%)	6 (12.0%)	13 (26.0%)	16 (32.0%)	50

Note: All questions were prefaced with “*The following statements apply to patients with cerebral palsy and severe to profound intellectual and developmental disabilities with palliative care needs. Please rate your agreement with each statement.*”