

**Review Article**

# Barriers to Palliative Care Access in Patients With Intellectual Disability: A Scoping Review

Josselyn Velepucha-Iniguez, MD, Patricia Bonilla Sierra, MD, and Eduardo Bruera, MD

Department of Health Sciences (J.V.I., P.B.S.), Universidad Técnica Particular de Loja (UTPL), Loja, Ecuador; Department of Palliative, Rehabilitation and Integrative Medicine (E.B.), The University of Texas MD Anderson Cancer Center, Houston, TX, United States

**Abstract**

There is limited knowledge about inequalities regarding palliative care access among patients with intellectual disability. The present scoping review aimed to identify the existing barriers that limit access to palliative care (PC) in patients with intellectual disability. **Methods:** We conducted a literature review on publications since 2014 from three databases (MEDLINE, Biomed Central, and Elsevier Scopus), along with hand searches in scientific journals. The review included peer-reviewed studies written in English and Spanish language with quantitative and qualitative study designs. The participants were patients with intellectual disability and health professionals who had worked with them or had experience in palliative care. **Results:** 22 studies met the selection criteria. The barriers identified were under referral to palliative care, reduced access, communication, and limited knowledge and experience by health professionals. **Conclusion:** Patients with intellectual disability do not get referred to PC frequently. Health professionals and caregivers do not recognize when it is necessary to make a referral, and they need to improve their communication abilities. Also, health care workers need more training in PC, pain management, anticipation of death, and use of opioids. More research and education on the palliative care needs and care for patients with intellectual disabilities is needed. *J Pain Symptom Manage* 2022;000:e1–e10. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

**Key Words**

Intellectual disability, palliative care, palliative care access, scoping review

**Key Message**

There is a wide lack of knowledge of palliative care and intellectual disability among healthcare professionals and caregivers. Referrals to palliative care are small and there are limited clinical guidelines and tools that can be used in this population. Healthcare workers have limited training in palliative care and they need to develop communication skills for patients with intellectual disability.

**Introduction**

Worldwide the life expectancy has improved in the general population including those with intellectual disability.<sup>1</sup> These patients develop the same chronic diseases associated with age as the general population, who can benefit from palliative care (PC).<sup>1,2</sup>

According to the IAHP (International Association of Hospice and Palliative care) definition, PC includes prevention, early identification, evaluation, and management of physical, psychological, and spiritual symptoms and social necessities. It aims to improve quality of life of patients, families, and caregivers. It may positively influence the course of illness and are applicable throughout all health care levels.<sup>2</sup>

However, people with Intellectual disability lack equitable access to quality health care.<sup>3</sup> This issue is important as PC is established as a human right,<sup>4</sup> and research indicates that early access to PC enhances quality of life of the patients and their families.<sup>5</sup> As a result, people with intellectual disability deserve holistic and quality PC with good control of physical symptoms as well as psychosocial and spiritual support and

Address correspondence to: Josselyn Velepucha-Iniguez, MD, Department of Health Sciences, Universidad Técnica Particular de Loja (UTPL), Loja 110107, Ecuador. E-mail: [jcvelepucha@utpl.edu.ec](mailto:jcvelepucha@utpl.edu.ec)

Accepted for publication: 11 August 2022.

excellent communication regarding goals of care and end of life planning.

The main aim of this scoping review was to identify possible barriers to PC delivery to patients with Intellectual disabilities.

## Methods

A scoping review related to PC in patients with intellectual disabilities was conducted. The purpose of this review was to provide a narrative synthesis about barriers that patients with intellectual disabilities face when they require palliative care. The items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) were checked, to ensure that all items were accomplished.<sup>6,7</sup> MEDLINE, Scopus, and Biomed Central were searched to identify published, peer-reviewed studies. To develop a search process, the research question was established using the PICO strategy (population, intervention, comparison, and outcome) as shown in [Table 1](#). Based on this strategy, the search objectives were established, and the MESH (Medical Subject Heading) terms were obtained. The MESH terms used were: “Intellectual Disability”, “Palliative care”, and “Palliative Medicine”. In order to acquire studies in the Spanish language, the following keywords were used: “Discapacidad Intelectual” and “Cuidados Paliativos.” Boolean operators were used (“AND”, “OR”) to optimize the research. Finally, the search strategy was given including a manual search of journals related to intellectual disability, such as the *Journal of Applied Research in Intellectual Disabilities*, *British Journal of Learning Disabilities*, *Research in Developmental Disabilities*, *Journal of Intellectual & Developmental Disability*, *Palliative Medicine*, and *International Journal of Environmental Research & Public Health*. The most recent search was done in May 2020 and a total of 22 studies were reviewed and analyzed in this research.

Eligibility criteria included peer-reviewed studies published between the period of 2014 to 2020, in order to get the most recent data. Studies with participants with intellectual disabilities or caregivers and health-care workers related to patients with intellectual disabilities were included. Studies published in English or Spanish, with quantitative and/or qualitative study

designs, also retrospective and/or prospective study designs. Finally, the results of the studies included described barriers to access to palliative care.

## Study Selection

One author J.V-I searched in the electronic databases and obtained 835 articles, subsequently, excluded articles published before January 2014, leaving a total of 555 studies. Through the hand search in scientific journals obtained 9 additional studies, leaving a total of 564 studies. Then, the author screened and analyzed the titles and abstracts of the articles, looking for studies that have relevance with PC in patients with Intellectual disability, and through this, discarded 484 articles. Full text of 80 articles were reviewed, and studies that met the inclusion criteria and that answered the research question were included. Finally, 22 studies were selected as shown in [Fig. 1](#). The final search strategy for MEDLINE can be found on [Appendix 1](#). This review did not have a registered protocol. The authors P.B and J.V-I reviewed the selected literature and only articles in peer-reviewed journals that met the selection criteria and that answered the research question were included in order to obtain quality studies. The studies methods and results were evaluated through a critical reading to make sure they were reliable and relevant.

## Charting the Data

Information about each study were collected from the original publications by the first author in [Table 2](#), including author, year, study design, participants, source of data collection and main findings. Then a second author P.B reviewed the information.

## Data Synthesis

The first author conducted a content review of the selected studies, looking for recurring themes and findings, then organized under a list of thematic headings and with the second author P.B reviewed and agreed on the main topics.

## Results

A total of 22 studies were analyzed, the majority were from developed countries (Netherlands, United States, England, other countries). The study methods were quantitative (12 studies), qualitative (8 studies), and mixed studies (2 study). The study designs were descriptive, cohort studies, and correlational studies. A total of 26 982 participants were included from the different studies. Most participants were patients with intellectual disability (n: 24,700). Other participants were professional caregivers, team leaders of institutions that care for patients with intellectual disability, physicians, intellectual disability specialists, oncologists,

Table 1  
PICO Strategy.

	P (Population)	Patients With Intellectual Disability
PICO Strategy	I (Intervention)	Access to PC
	C (Comparison)	Does not apply to this study
	O (Outcome)	Barriers to access PC

PC, palliative care.

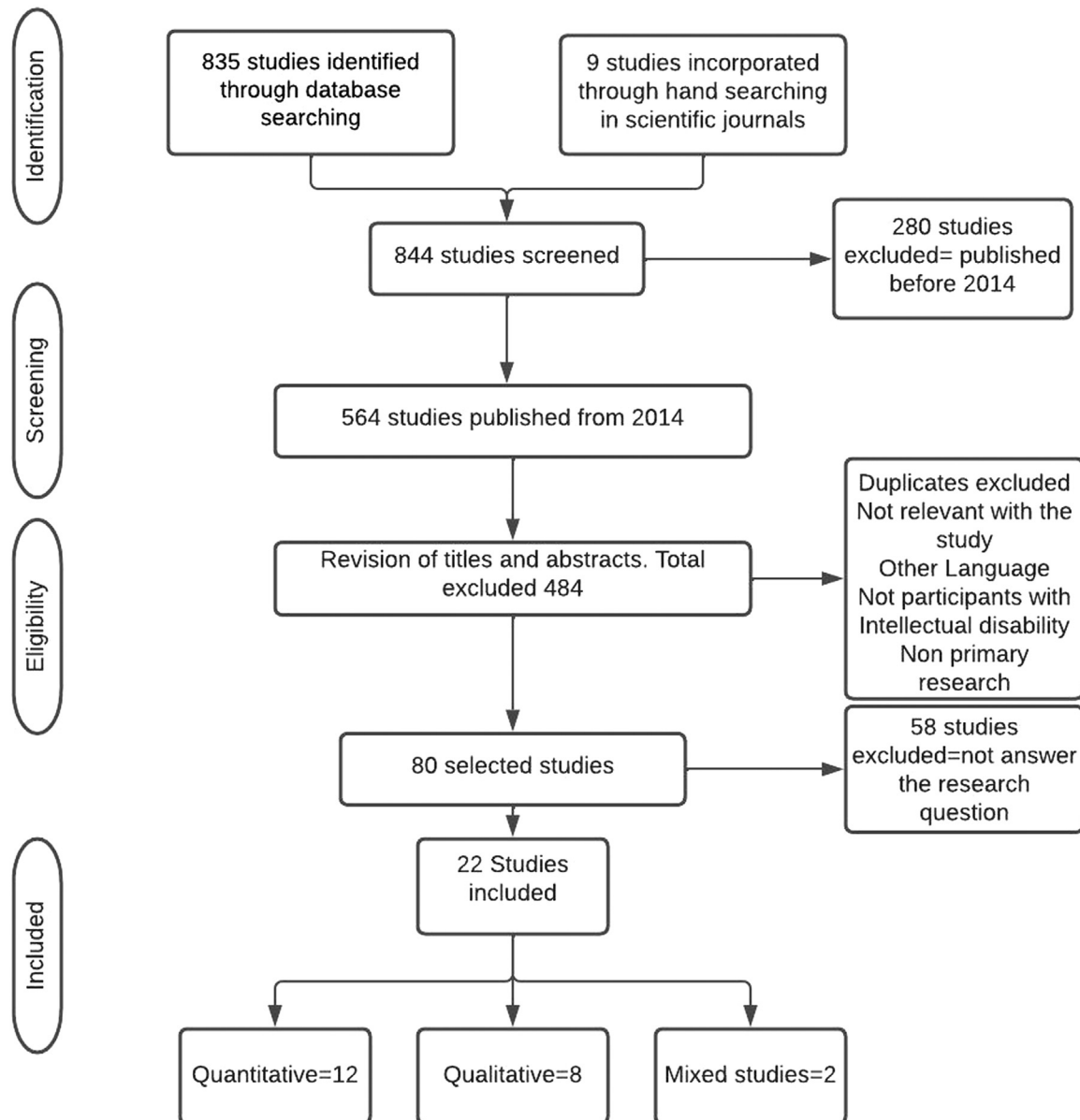


Fig. 1. Flow diagram of studies extraction.

anesthesiologists, family medicine, oncological surgery, internal medicine, onco- hematological pediatrics, intensive care, nurses, psychologists, nursing assistants, social workers, and medical assistants.

Five barriers to palliative care access for patients with intellectual disability were found:

1. Difficult health care access
2. Under referral to PC
3. Communication
4. Lack of clinical practice guidelines and diagnostic tools
5. Limited experience and preparation of the healthcare providers.

#### *Difficult Health Care Access*

Six studies concluded that one of the major barriers that patients with intellectual disability must face is the difficulty accessing health services when required.<sup>8-13</sup> They described that in rural areas this problem is exacerbated, due to the lack of local establishments, however, urban groups expressed difficulty in obtaining a medical appointment from specialists.<sup>8</sup> Not only patients reported this problem, but also health professionals who work with them since a study found that 50% of professionals were unable to consult an expert outside the organization in which they work.<sup>9</sup> Likewise, they faced complications when obtaining a medical

Table 2  
Data Extracted From Included Studies.

Study	Study Design	Population Study	Data Collection	Main Findings
Bekkema, Veer, et al., 2014	Quantitative	N = 181 Nurses = 87 Nursing assistants = 6 Social workers = 36	Survey	Training and educational needs of the healthcare workers about Intellectual disability. Expert consultation opportunities outside the organization where the participants work.
Lindley et al., 2017	Quantitative Retrospective	N = 1012 Patients with intellectual disability: 173 P: 839 Children from 0 to 20 yrs old	Statistical analysis	Children with intellectual disability were enrolled in hospice less than the control group. 10% of children with intellectual disability was enrolled in hospice, and the average length of stay was 1 day.
Mastebroek et al., 2016	Qualitative	N = 21 mild and moderate intellectual disability.	Interviews	Barriers to communication about the health status to patients with Intellectual disability in the practice of general medicine.
Navas et al., 2019	Qualitative	N = 216 Coordinators = 65 Psychologists = 63 Nurses = 47 Social workers = 24 Physicians = 22	Survey	Feedback about deficiencies in the health system that prevent access to healthcare to patients with intellectual disability.
Newton & Sebbens, 2020	Mixed methods	N = 64 Medical assistant = 37 Nurses = 25 Physicians = 2	Survey	How the education of medical professionals about PC had impact in PC referrals. Reasons for late referral or not refer at all.
Ollalla Gallo, 2016	Qualitative	N = 20 Physicians = 9 Nurses = 6 Psychologists = 2 Nursing assistants = 2 Social workers = 1	Interviews	Level of knowledge about intellectual disability and experience about detection of symptoms and psychological, spiritual, and social needs of patients with intellectual disability among healthcare workers.
Sampson et al., 2015	Quantitative	13 countries from the European Pain and Impaired Cognition network	Analysis of clinical practice guidelines	From 11 guidelines reviewed, only 4 recommended specific tools to evaluate pain management for patients with cognitive disabilities (Italy, the Netherlands, Spain, and the United Kingdom).
Segerlantz et al., 2020	Quantitative, retrospective	Patients with intellectual disability = 15,319 General population = 72,511	Statistical analysis	The utilization of end-of-life care in the last year of life in cancer patients with intellectual disability is less than patients without intellectual disability. PC was use in 16 patients with intellectual disability for 24 occasions, compared with 132 patients without intellectual disability who used in 132 occasions.
Tuffrey-Wijne & Rose, 2017	Qualitative	N = 20 Professional caregivers = 13 Managers = 7	Interviews	Participants expressed lack of preparation and fear when giving bad news to a patient with death prognosis
Vrijmoeth et al., 2016	Quantitative	Physicians = 169 Patients with intellectual disability = 97	Survey	Less than half of the participants had never provided PC to a patient with an intellectual disability. There is a difficulty in the diagnosis of a death prognosis, 22,6% made the diagnosis in the last week of the life of these patients, and 42% in the last month. Physicians do not discuss the possibility of PC, 30,4% discussed it in the last week of the life of the patient, and 35.9% discussed it in the last month of life. None of them talked about it in the last three months.

(Continued)

Table 2  
Continued

Study	Study Design	Population Study	Data Collection	Main Findings
Vrijmoeth et al., 2016	Qualitative	Physicians = 10	Interviews	How the need for palliative care is recognized in people with intellectual disability.
Wark et al., 2017	Qualitative	N = 35 Urban residents = 13 Rural residents = 22	Interviews	Barriers to access end-of-life care in patients with Intellectual disabilities in rural and urban locations.
Todd et al., 2020	Quantitative, retrospective	Deceased intellectual disability patients = 146 Health care workers = 38	Survey	Level of recognition of a death prognosis and use of PC in patients with intellectual disability
Tuffrey–Wijne et al., 2020	Quantitative	Patients with intellectual disability = 152 Health care workers = 690	Survey	Level of communication skills of staff who work with patients with intellectual disability. Level of information about the diagnosis and prognosis provided to patients with Intellectual disability.
Gray & Kim, 2020	Quantitative	Professional caregivers = 149	Survey	Training needs of professional caregivers about PC and main topics caregivers prefer to be trained on.
Hussain et al., 2019	Mixed methods	N = 420 Physicians = 43 Professional caregivers = 39 Caregivers = 31 Team leaders = 83	Survey	Level of knowledge about PC of the staff that supports older adults with Intellectual disability. Main topics they need training
Kim & Gray, 2018	Qualitative	Professional caregivers = 54	Interviews	Challenges caregivers faced. Difficulty in communication, anticipating a death prognosis, and lack of training in general topics about intellectual disability, PC and communication.
Hunt et al., 2019	Quantitative	N = 36 Patients with intellectual disability = 158	Survey	Lack of utilization of end-of-life care, only 18% received attention from a PC specialist, and 78.2% didn't know their death prognosis.
Sandberg et al., 2016	Quantitative, retrospective	Patients with intellectual disability = 7936 General population = 7936	Statistical analysis	Use of health services in elderly patients with Intellectual disability compared to the general population in the period 2002 to 2012.
Smith et al., 2020	Quantitative	Patients with intellectual disability = 553	Survey	Communication skills related with the level of Intellectual disability.
Bekkema, et al., 2014	Quantitative	Health care workers = 248	Survey	When making medical decisions half of the health care workers believed that patient's autonomy were important and more than half of participants believed that they should not consider their opinion when it differs from their own opinion. When the patient cannot decide for himself 40% of health care workers believed that the opinion of the physician was the only important.
Dávalos-Batallas et al., 2020	Qualitative	N = 28 Oncologists = 10 Anesthesiologists = 5 Intensive care = 1 Internal medicine doctors = 1 Physician = 1 Surgeon oncologist = 1 Pediatric onco-hematologist = 1	Interviews	Physicians did not recognize the need of PC. On the medical curricula there is not PC and there is a wide unknowledge about this specialty.

appointment, and there was no communication or coordination between the health professionals who attended them, which made it harder to treat them holistically.<sup>12</sup>

Compared to the general population, older patients with intellectual disability had less access to health services,<sup>13</sup> and even less in the last year of his life, in the PC service.<sup>10</sup> This barrier was not limited to older patients, pediatric patients had to face the same difficulty in accessing PC and hospice care.<sup>11</sup>

#### *Under Referral to PC*

Only 18% of patients with intellectual disability received PC at the end of their life in the United Kingdom.<sup>3</sup> On the other hand, in the United States, half of the health professionals who worked with pediatric patients with Intellectual disability did not refer any patient to PC for various reasons: “The family doctor refused to make the referral,” “the parents asked not to be referred,” “the doctor did not know who qualified to be referred,” “the doctor did not know how to make the referral”. Nevertheless, after training and informing the participants an increase in referrals and comfort level was detected.<sup>14</sup> In contrast, half of the health professionals do not take into account the autonomy of patients with intellectual disability in terms of medical decisions at the end of life and if they are not capable of making decisions for themselves, half believed that family members must decide for the patient, and 38% believed that the doctor’s decision was the final one.<sup>9</sup>

#### *Communication*

Seven studies agreed that the difficulty of communication with patients with intellectual disability is the most frequent barrier.<sup>3,15–20</sup> Physicians have difficulty interpreting signs of the need for PC,<sup>20</sup> which increases according to their level of disability, being almost impossible to communicate with patients with severe intellectual disability.<sup>21</sup> Likewise, it was detected that the level of understanding of the situation they are going through was deficient. A considerable percentage did not understand their condition and prognosis at all. Most of the patients were not “aware” that they were going to die.<sup>1,15</sup> On the contrary, most patients with mild intellectual disability understood their situation, but, they expressed feeling that the doctors did not understand them, they felt nervous when talking with them due to how they communicated with technical words and long sentences, which resulted in problems understanding the diagnosis, the therapeutic plan and following the instructions and recommendations of the doctor.<sup>16</sup> It was not a problem limited to doctors, as caregivers had difficulty communicating with their patients when they had a prognosis of death. The caregivers limited themselves to supporting them in the process and did not focus on communication. The

reasons expressed were fear and little preparation about communicating bad news with these patients. They also indicated that patients have difficulty understanding their health status:<sup>17</sup>

One participant in a study undertaken in the United States reported: “You can’t sit them down and talk to them. It is hard. It is hard on us. We need a lot of information. How to deal with each individual that has a problem in coping with this.”<sup>19</sup>

In addition, the participants reported insufficient training in general topics and effective communications.<sup>18</sup> Another professional caregiver from the United States from the same study stated: “There’s a younger staff and the training is not sufficient. How to handle this situation because it’s a different approach.”<sup>18</sup>

#### *Lack of Clinical Practice Guidelines and Diagnostic Tools*

Around the world, there is a lack of research in the development of clinical practice guidelines on PC, specifically in patients with intellectual disability. There are diagnostic tools that can be used in the general population to detect the need for PC,<sup>19</sup> but there are no tools that can be applied to patients with intellectual disability, considering their specific needs and difficulties. There are no evaluation tools, therefore it was found that the detection of needs and physical symptoms, such as pain, is limited to the contributions of the caregiver and the family of the patients.<sup>22</sup> In a study carried out in the European Union, 14 of the most relevant clinical practice guidelines about PC from European Union countries were analyzed. Only 10 had clinical practice guidelines about pain management and only 4 of the 10 guidelines that met the requirements recommended the use of specific tools to detect symptoms such as pain for patients with cognitive disabilities (Italy, the Netherlands, Spain, and the United Kingdom).<sup>23</sup>

#### *Limited Experience and Preparation of the Healthcare Providers*

Among health professionals who work with patients with intellectual disability, there is poor training and preparation on PC. The studies found that physicians lacked the knowledge and skills to recognize the prognosis of death and when it was necessary to refer to PC. Only 22.6% were able to predict death in the last week of the life of the patients, negatively influencing timely referral to PC. Only 30% discussed the need to start PC in the last week of life, and 35.9% recommended it one month before the patient’s death.<sup>24</sup> The same occurred in health professionals from different areas, since less than half could anticipate the death of their patients before the last 3 months of life and more than half could not anticipate it at all.<sup>18,25</sup> The healthcare workers stated that they needed more training and



qualification in the care of specific physical, spiritual, social, and emotional needs in patients with intellectual disability. In addition, to require instruction on basic PC principles, pain management, planning, hospice care options in patients with Intellectual disability, communication of bad news to the family, and anticipation of death.<sup>26</sup>

Another study concluded that they required adequate preparation in generalities of aging, diseases associated with it, treatment, use of opioids, human rights and laws, symptoms, psychological, spiritual, and social needs. Additionally, they were unaware of the specific PC resources that can be used in patients with intellectual disability, such as protocols or access to opioids. Among the professionals who work daily with these patients, there was a lack of knowledge about the different levels of palliative care, when to make a referral and they do not know the basic concepts of PC.<sup>27</sup>

A Spanish participant in an interview stated: "There are people with intellectual disability who reach the end of life without a diagnosis of advanced or terminal illness. . . but they need PC. They have needs, perhaps more than others that do have a diagnosis."<sup>22</sup>

In Ecuador, there were no specific PC units or research related to the subject. Physicians stated that they were not trained to detect the need for PC, and still believed that it is only related to the specialty of oncology. In the undergraduate curriculum, PC is not included, and there was ignorance about this specialty.<sup>28</sup>

## Discussion

The studies analyzed indicate a number of barriers to PC access for patients with intellectual disability. One of the barriers reported consistently was difficulty in accessing PC services. This finding is likely related to the overall low access to PC services in low- and middle-income countries as shown in the ATLAS study of the Latin American Association of PC (ALCP).<sup>29</sup> This ATLAS shows that there is no PC service at the primary care level, which explains why access is more difficult in rural areas, where access to the second level of care services is almost impossible. On the other hand, there is a shortage of PC specialists to whom these patients could be referred,<sup>29</sup> which could explain why there are few and delayed PC referrals. A qualitative study identified lengthy waits in the emergency room and in medical offices, as a barrier to accessing health care, "some patients walked out of waiting rooms before they were seen by health providers". In the same way, caregivers and family members indicate that the visits were rushed, and some healthcare workers did not take the time to treat the patient in a holistic way. More research is needed to identify if this is a barrier to accessing palliative care.<sup>30</sup>

Other reasons identified are the misinformation of relatives and physicians about PC and when it is necessary to make a referral. Additionally, this situation is aggravated as it is harder to communicate with patients with intellectual disability. Patients with intellectual disability cannot fully express their ideas, manifest physical complaints, and psychological, spiritual, and social discomfort.<sup>21</sup> Health professionals also need to improve their communication skills, since, as indicated in a study, doctors speak with difficult words and complex sentences that prevent patients with mild intellectual disability from understanding the therapeutic plan and diagnosis.<sup>16</sup>

Assistive technology is a variety of devices or services that can help patients with disabilities maintain or improve their functioning and independence and promote their well-being, an example is a communication board, it can help the patient communicate by using symbols, letters, words, and phrases to create messages.<sup>31–33</sup> This tool may be helpful for communication with their healthcare providers if it was used for patients to indicate their symptoms and concerns. Unfortunately, patients with intellectual disability have limited access and the technology is underutilized and may be more difficult for patients with severe intellectual disability.<sup>34</sup> There are some barriers that limit access to assistive technology in patients with intellectual disability for example funding, lack of awareness and knowledge about this tool, negative beliefs, and lack of knowledge of caregivers.<sup>35</sup> In a study done in Europe directed to caregivers, in a survey they indicated that they mostly used assistive technology for communication and interaction, to relax or have fun, and to support participation in activities, but no for medical care, they also indicated a lack of knowledge and experience about assistive technology.<sup>34</sup>

In a large majority of studies, the lack of preparation and knowledge about Intellectual disability and PC is evidenced by healthcare workers, caregivers, and family members. The implementation of PC and intellectual disability is necessary for the undergraduate curriculum of health professionals who work with this population and in the same way in the postgraduate curriculum in medical specialties such as family medicine, internal medicine, oncology, pediatrics since they usually handle closely with these patients. In addition, it is necessary to educate the general population and the relatives about PC on when it is necessary to seek specialized care, and its benefits in the quality of life of patients. Likewise, better training is required for healthcare workers, both at the first level and in specialized care, on communication tools, detection of pain symptoms, and the need for PC. Therefore, it could be beneficial to establish clinical practice guidelines to help health professionals at the first level of care to detect the need for PC and provide with guidance on

how and when it is necessary to refer to the next level of care. It is also important to strengthen knowledge about the different levels of palliative care, management of physical and psychological symptoms, management of opioid medications, and communication tools. Further research is needed to identify potential barriers to palliative care access such as fear of taking away hope, or fear of abandonment by their clinician, that have been identifying by the general population.<sup>36</sup>

### *Strengths and Limitations*

This scoping review identified enough articles with participants with intellectual disability who required PC and health personnel who work with them. Consequently, it was possible to group the articles with similar results into sub-themes that encompass the barriers commonly found. Also, participants from different professions were included, who gave a global approach and distinct points of view on the needs of this population regarding PC. On the other hand, the language was a limitation, as we might have identified additional articles if we included languages beyond English and Spanish. And due to the methodology of the articles, there was some difficulty organizing the results, and this is the reason why a narrative methodology was chosen.

### *Conclusion*

Evidence from this scoping review suggests that patients with intellectual disability may have reduced access to PC than the general population. Access to healthcare and PC may not always be available to patients with intellectual disability, especially in rural areas due to lack of health centers. The number of patients who benefit from end-of-life care may be limited due to lack of referrals, difficulty in prognostication, and lack of communication especially, with patients with severe intellectual disability. Our review suggests that most patients may not understand their condition, prognosis, and therapeutic plan. Healthcare providers do not feel comfortable communicating a prognosis of death and manifest they need more training in palliative care and intellectual disability. This issue is aggravated by the lack of clinical practice guidelines for PC which should include tools that can be applied to patients with intellectual disability. This is one of the reasons why detection of physical symptoms and other needs are limited to the contribution of the caregiver. Further research could explore the effects of educating healthcare providers in palliative care, pain management, anticipation of death, referral to PC and use of opioids. Family members and caregivers should be educated in PC and intellectual disability. In this way, the number of referrals to PC from the first level of care would be increased. Therefore, it is essential to

carry out more research on the subject to make this public health problem visible, more education and training for health professionals, and the development of clinical practice guidelines that facilitate the preparation of these professionals, family caregivers, and patients with Intellectual disability.

### *Disclosures and Acknowledgments*

The authors declare no conflict of interest.

### *Authors' contributions*

J.V and P.B, conceptualized the review. JV devised the search strategies; JV conducted the study selection. J.V wrote the original draft preparation. PB y E.B reviewed and edited. All authors have read and approved the final manuscript.

### *Appendix 1. Medline Search Strategy*

(palliative care[MeSH Terms]) AND (intellectual disability[MeSH Terms]),""palliative care""[MeSH Terms] AND ""intellectual disability""[MeSH Terms]", 112,23:43:47

(palliative care[MeSH Terms]) AND (intellectual disability[MeSH Terms]),from 2014 - 2022,("palliative care""[MeSH Terms] AND ""intellectual disability""[-MeSH Terms]) AND (2014:2022[pdat]),61,23:44:01

(palliative care[MeSH Terms]) AND (intellectual disability[MeSH Terms]),from 2014 - 2020,("palliative care""[MeSH Terms] AND ""intellectual disability""[-MeSH Terms]) AND (2014:2020[pdat]),51,23:44:13

((palliative care) OR (palliative medicine)) AND (intellectual disability),("palliative care""[MeSH Terms] OR ("palliative""[All Fields] AND ""care""[All Fields]) OR ""palliative care""[All Fields] OR ("palliative medicine""[MeSH Terms] OR ("palliative""[All Fields] AND ""medicine""[All Fields]) OR ""palliative medicine""[All Fields])) AND ("intellectual disability""[MeSH Terms] OR ("intellectual""[All Fields] AND ""disability""[All Fields]) OR ""intellectual disability""[All Fields]),219,23:45:05

((palliative care) OR (palliative medicine)) AND (intellectual disability),from 2014 - 2022,("palliative care""[MeSH Terms] OR ("palliative""[All Fields] AND ""care""[All Fields]) OR ""palliative care""[All Fields] OR ("palliative medicine""[MeSH Terms] OR ("palliative""[All Fields] AND ""medicine""[All Fields]) OR ""palliative medicine""[All Fields])) AND ("intellectual disability""[MeSH Terms] OR ("intellectual""[All Fields] AND ""disability""[All Fields]) OR ""intellectual disability""[All Fields])) AND (2014:2022[pdat]),146,23:45:26

((palliative care) OR (palliative medicine)) AND (intellectual disability),from 2014 - 2020,("palliative



care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields] OR ("palliative medicine"[MeSH Terms] OR ("palliative"[All Fields] AND "medicine"[All Fields]) OR "palliative medicine"[All Fields])) AND ("intellectual disability"[MeSH Terms] OR ("intellectual"[All Fields] AND "disability"[All Fields]) OR "intellectual disability"[All Fields])) AND (2014:2020[pdat])",128,23:45:32

## References

- Hunt K, Bernal J, Worth R, et al. End-of-life care in intellectual disability : a retrospective cross-sectional study. 2019;1–9.
- IAHPC. Palliative care definition [Internet]. International Association for Hospice & Palliative care; 2019. Available at: <https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/>. Accessed June 6, 2022.
- Williamson HJ, Contreras GM, Rodriguez ES, Smith JM, Perkins EA. Health care access for adults with intellectual and developmental disabilities: a scoping review. *OTJR* 2017;37:227–236.
- Brennan F. Palliative care as an International Human Right. *J Pain Symptom Manage* 2007;33:494–499.
- Hui D, Bruera E. Integrating palliative care into the trajectory of cancer care. *Nature reviews clinical oncology*, 13. Nature Publishing Group; 2016. p. 159–171.
- Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. *Ann Intern Med* 2018;169:467–473.
- PRISMA. Preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews (PRISMA-ScR) checklist. p. 2–9. Available at: <http://www.prisma-statement.org/Extensions/ScopingReviews>. Accessed May 8, 2022.
- Wark S, Hussain R, Müller A, Ryan P, Parmenter T. Challenges in providing end-of-life care for people with intellectual disability: Health services access. *J Appl Res Intellect Disabil* 2017;30:1151–1159.
- Bekkema N, de Veer AJE, Wagemans AMA, Hertogh CPM, Francke AL. Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: A national survey of the considerations and beliefs of GPs, ID physicians and care staff. *Patient Educ Counsel [Internet]* 2014;96:204–209. <https://doi.org/10.1016/j.pec.2014.05.014>.
- Sandberg M, Ahlström G, Axmon A, Kristensson J. Somatic healthcare utilisation patterns among older people with intellectual disability : an 11-year register study. *BMC Health Serv Res [Internet]* 2016. <https://doi.org/10.1186/s12913-016-1880-x>.
- Lindley LC, Colman MB, Meadows Jr JT. Children with intellectual disability and hospice utilization. *Hosp Palliat Nurs Assoc* 2017;19.
- Navas P, Llorente S, García L, Tassé MJ, Haverkamp SM. Improving healthcare access for older adults with intellectual disability: what are the needs? *J Appl Res Intellect Disabil* 2019;32:1453–1464.
- Segerlantz M, Axmon A, Ahlström G. End-of-life care among older cancer patients with intellectual disability in comparison with the general population : a national register study. *J Intellect Disabil Res* 2020;747767:1–14.
- Newton K, Sebbens D. The impact of provider education on pediatric palliative care referral. *J Pediatr Health Care [Internet]* 2020;34:99–108. <https://doi.org/10.1016/j.pedhc.2019.07.007>.
- Tuffrey-Wijne I, Finlayson J, Bernal J, Taggart L, Lam CKK, Todd S. Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A UK-wide survey of intellectual disability support staff. *J Appl Res Intellect Disabil* 2020;23:1–12.
- Mastebroek M, Naaldenberg J, Den FA van, Mareeuw D, Lagro-janssen ALM, Valk HMJ/VSL de. Experiences of patients with intellectual disabilities and carers in GP health information exchanges : a qualitative study. *Family Pract* 2016;33:543–550.
- Tuffrey-Wijne I, Rose T. Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services : An interview study. *J Intellect Disabil Res* 2017;61:1–10.
- Kim J, Gray JA. Palliative care experiences and needs of direct care workers. *J Palliat Med* 2018;21:1094–1099.
- Gómez-Batiste X, Martínez-Muñoz M, Blay C, et al. Utility of the NECPAL CCOMS-ICO© tool and the Surprise Question as screening tools for early palliative care and to predict mortality in patients with advanced chronic conditions: a cohort study. *Palliat Med* 2017;31:754–763.
- Vrijmoeth C, Barten P, Assendelft WJJ, et al. Physicians' identification of the need for palliative care in people with intellectual disabilities. *Res Dev Disabil [Internet]* 2016;59:55–64. <https://doi.org/10.1016/j.ridd.2016.07.008>.
- Smith M, Manduchi B, Burke É, Carroll R, McCallion P, McCarron M. Communication difficulties in adults with Intellectual Disability: results from a national cross-sectional study. *Res Dev Disabil [Internet]* 2020;97:103557. <https://doi.org/10.1016/j.ridd.2019.103557>.
- Ollalla Gallo M. Cuidados paliativos en personas con discapacidad intelectual : estudio cualitativo desde la perspectiva de los profesionales del ámbito sociosanitario. *Medicina Paliativa [Internet]* 2016;207:9. <https://doi.org/10.1016/j.med-ipa.2016.02.008>.
- Sampson EL, van der Steen JT, Pautex S, et al. European palliative care guidelines: How well do they meet the needs of people with impaired cognition? *BMJ Support Palliat Care* 2015;5:301–305.
- Vrijmoeth C, Christians MGM, Festen DAM, Groot M, Tonino M, Echteeld MA. Physicians' recognition of death in the foreseeable future in patients with intellectual disabilities. *J Intellect Disabil Res* 2016;60:207–217.
- Todd S, Bernal J, Shearn J, et al. Last months of life of people with intellectual disabilities: A UK population-based study of death and dying in intellectual disability community services. *J Appl Res Intellect Disabil* 2020;33:1245–1258.
- Gray JA, Kim J. Palliative care needs of direct care workers caring for people with intellectual and developmental disabilities. *Br J Learn Disabil* 2020;48:69–77.
- Hussain R, Janicki MP, Knox M, Wark S, Parmenter T. Perspectives about support challenges facing health workers assisting older adults with and without intellectual disability

- in rural versus urban settings in Australia. *J Intellect Dev Disabil* 2019;44:174–183.
28. Dávalos-Batallas V, Mahtani-Chugani V, López-Núñez C, et al. Knowledge, attitudes and expectations of physicians with respect to palliative care in Ecuador: a qualitative study. *Int J Environ Res Pub Health* 2020;17:1–14.
29. Pastrana T, de Lima L, Pons JJ, Centeno C. Atlas de Cuidados Paliativos en Latinoamérica- Edición Cartográfica 2013 [Internet]. Asociación Latinoamericana de Cuidados Paliativos; 2013. p. 1–72. Available at: [www.cuidadospaliativos.org](http://www.cuidadospaliativos.org). Accessed March 8, 2022.
30. Ward RL, Nichols AD, Freedman RI. Uncovering health care inequalities among adults with intellectual and developmental disabilities. *Health Soc Work* 2010;35:280–290.
31. University of Washington. What is assistive technology? [Internet]. Access computing; 2022. [cited 2022 Jul 5]. Available from: <https://www.washington.edu/accesscomputing/what-assistive-technology>.
32. Boot FH, Dinsmore J, Khasnabis C, MacLachlan M. Intellectual disability and assistive technology: opening the GATE Wider. *Front Public Health* 2017;5:10. <https://doi.org/10.3389/fpubh.2017.00010>.
33. USAAC. AAC Devices [Internet]. USSAAC; 2021. Available from: <https://ussaac.org/aac-info/aac-devices/>. Accessed July 5, 2022.
34. Nijs S, Maes B. Assistive technology for persons with profound intellectual disability: a European survey on attitudes and beliefs. *Disabil Rehabil* 2021;16:497–504.
35. Boot FH, Owuor J, Dinsmore J, MacLachlan M. Access to assistive technology for people with intellectual disabilities: a systematic review to identify barriers and facilitators. *J Intellect Disabil Res* 2018;62:900–921.
36. Mounsey L, Ferres M, Eastman P. Palliative care for the patient without cancer. *Australian J General Pract* 2018;47:765–769.