

Towards inclusive palliative care: participatory development of best practice recommendations for people with intellectual disabilities in Eastern Switzerland

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Received: 16 June 2026 / Accepted: 8 October 2026

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Abstract

Background People with intellectual disabilities face significant inequalities in accessing palliative and end-of-life care. Despite growing care needs driven by increased life expectancy and a higher prevalence of chronic and life-limiting conditions, this population remains systematically underserved. In Switzerland, no cross-institutional framework tailored to this group exists. This study aimed to co-develop best practice recommendations for palliative and end-of-life care for people with intellectual disabilities in Eastern Switzerland.

Methods The project was guided by the Joanna Briggs Institute (JBI) Model of Evidence-Based Healthcare, supported by an advisory board, and informed by a narrative literature review. Quantitative data were collected via a questionnaire across residential care facilities for people with intellectual disabilities in Eastern Switzerland. Qualitative data were gathered through interviews and workshops with people with intellectual disabilities, interviews with family caregivers, and focus groups with professionals. Data were analysed descriptively and using the Framework Method; mixed methods integration followed a convergent design, using joint display tables. Recommendations were piloted in one residential care facility using the JBI Getting Research into Practice tool.

Results Based on integrated findings and advisory board input, 21 best practice recommendations were developed across four domains. In education, recommendations address palliative and end-of-life care integration into undergraduate curricula, continuing education for professionals, leaders, and family caregivers, access to needs-assessment tools and evidence-based resources, and inclusive learning formats for people with intellectual disabilities. In communication, recommendations focus on fostering staff preparedness, enabling open conversations about death and dying, and systematic documentation of end-of-life wishes. In collaboration, recommendations call for knowledge of regional palliative care networks, clear referral pathways, documented interprofessional exchange formats, and active involvement of family caregivers and legal representatives. In the system domain, recommendations address network integration, designated palliative care leads, institutional palliative care culture, and policy recognition.

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Conclusions The 21 best practice recommendations, grounded in evidence and co-developed with people with intellectual disabilities, family caregivers, and professionals, provide a practical framework for improving palliative and end-of-life care. Future research should prioritise examining how such recommendations can be effectively implemented across diverse care settings, while retaining the participatory approach that proved central to this project.

Keywords Palliative care · End of life care · Intellectual disability · Developmental disability · Practice development · Interprofessional collaboration

Abbreviations

EAPC European Association for Palliative Care

JBI Joanna Briggs Institute

Background

People with intellectual disabilities represent approximately 1% of the global population, with prevalence estimates ranging between 1% and 3% across studies and definitions [1]. According to Schalock et al. [2], intellectual disability is characterised by significant limitations both in intellectual functioning and in adaptive behaviour, originating before the age of 18. With advances in social and medical care, life expectancy in this population has increased substantially over recent decades, and the number of people with intellectual disabilities aged over 60 years is expected to rise significantly in the coming years [3, 4]. Alongside this demographic trend comes a rising prevalence of chronic, age-related, and life-limiting conditions, and consequently a growing need for palliative and end-of-life care [5, 6]. However, this need is not confined to older age: people with severe or multiple disabilities frequently encounter complex health challenges from early childhood onwards, meaning that palliative and end-of-life care needs may arise at any point across the lifespan [3, 7].

Despite this reality, people with intellectual disabilities continue to face significant and well-documented inequalities in accessing appropriate palliative and end-of-life care. Their conditions are often diagnosed at a late stage, and they are less likely to be referred to specialist palliative care services or to have their end-of-life wishes documented and respected [5, 7].

These inequalities reflect challenges that extend across the entire care continuum: professionals in general and specialist palliative care settings frequently lack the knowledge and experience needed to support people with intellectual disabilities effectively, while social care staff, conversely, often lack the competencies required to manage complex palliative and end-of-life care situations, such as symptom management or recognising signs of the dying phase [5, 6, 8].

Professionals working in residential care facilities for people with intellectual disabilities are in a particularly important role in palliative and end-of-life care. A nationwide study estimates that approximately 20,000 adults live with intellectual disabilities in Switzerland, a substantial proportion of whom reside in residential care facilities. By the age of 40, approximately 75% do so, and many express a preference to remain there until death [9]. Analyses of resident data from residential care facilities across Switzerland also indicate a marked increase in the percentage of people aged 55 and older with intellectual and/or physical or psychological disabilities in long-term care [10–12]. Given these trends, residential care facilities constitute the primary focus of palliative and end-of-life care for this population. The close relationships that characterise residential care can be a source of continuity and trust for dying residents, but can equally expose staff to a profound emotional burden [13].

Addressing the challenges in palliative and end-of-life care provision for this population requires not only individual training and support, but systemic, evidence-informed interprofessional approaches across institutions [5, 6, 9]. Developing contextually relevant and implementable practice recommendations in turn calls for the

integration of multiple forms of evidence alongside the meaningful involvement of those most affected by the issues under investigation [14, 15].

In Switzerland, despite explicit acknowledgement of the specific palliative and end-of-life care needs of people with intellectual disabilities in national policy documents [16, 17], no cross-institutional framework tailored to this population has been developed and systematic evidence on palliative and end-of-life care practices remains lacking.

This paper reports on a project conducted in Eastern Switzerland, the primary aim of which was to co-develop best practice recommendations for palliative and end-of-life care for people with intellectual disabilities. To support this aim, the study first assessed the current state of care and subsequently identified needs, barriers, and facilitators from the perspectives of people with intellectual disabilities, family caregivers, and professionals. The resulting recommendations were subsequently piloted in one residential care facility.

Throughout this paper, we refer to both palliative care and end-of-life care, as palliative care is often mistakenly equated with end-of-life care, even by healthcare professionals [18]. We understand end-of-life care as part of palliative care, commonly referring to the last months of life or less [19].

The study addressed the following research questions:

1. What is the current state of palliative and end-of-life care for people with intellectual disabilities in Eastern Switzerland?
2. What needs, barriers, and facilitators do people with intellectual disabilities, family caregivers, and professionals identify in relation to this care?
3. What best practice recommendations can be derived from these findings?

Methods

This project was guided by the JBI Model of Evidence-Based Healthcare, which integrates evidence generation, synthesis, transfer, and implementation [20, 21]. We applied the JBI Evidence Implementation Framework to structure the project phases, combining primary evidence generation and evidence synthesis with participatory recommendation development. The project integrated research evidence with perspectives of people with intellectual disabilities, family members, and professionals to develop best practice recommendations [20, 21]. We followed the Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) to guide the reporting [22]. As the guideline is designed to accommodate a broad range of approaches to healthcare improvement and explicitly acknowledges that not all items may be relevant or applicable to every manuscript, items that were not applicable or only partially applicable - given the nature of this project - were documented and justified.

Phase 1: identify practice area/problem with stakeholders

To establish a network that would support the project and extend beyond its duration, we undertook an initial stakeholder engagement process. We conducted exploratory interviews with three nursing professionals specialised in palliative care in Eastern Switzerland (hospice, home-based palliative care, hospital palliative care unit) and one social care professional working in a residential care facility for individuals with intellectual disabilities. Through extensive stakeholder mapping, we identified key organisations and individuals involved in the provision of palliative and end-of-life care for people with intellectual disabilities in Eastern Switzerland.

Phase 2: engage change agents

Engaging people with intellectual disabilities, family caregivers, and professionals as active partners instead of positioning them as passive subjects of research is understood to enhance the relevance, acceptability, and

implementation potential of the resulting practice recommendations [23–25]. After identifying key stakeholders in Phase 1, we established an advisory board, comprising of a person with an intellectual disability, a family caregiver, a specialist palliative care nurse, a palliative care physician, a registered nurse, a social educator, a disability services expert and a spiritual care provider. The advisory board contributed to the interpretation of findings and the development of practice recommendations through four workshops, one for each domain. The person with an intellectual disability participated as a representative of a broader participatory group of five people with intellectual disabilities, convened by drawing on an existing participatory research group that had previously collaborated in an earlier project [26]. Given the complexity of developing recommendations across all four domains, this participatory group focused its active involvement specifically on the domain of communication and the corresponding recommendations, including the development of appropriate tools to facilitate conversations about the end of life.

Phase 3: assessment of the context and the readiness for change

We collected quantitative and qualitative data using a convergent mixed methods design [27] to assess the current state of palliative and end-of-life care for people with intellectual disabilities and to identify needs, barriers, and facilitators.

Quantitative data were collected using a self-developed questionnaire. All residential care facilities for people with intellectual disabilities in Eastern Switzerland ($N=48$) were invited to participate. We created two versions of the questionnaire: one for the leaders of the residential care facilities, which included overarching questions on organisational aspects (e.g., skill-grade mix, staff turnover, availability of a formal palliative care framework), and one for the care staff working directly with people with intellectual disabilities in their groups. The questionnaire for the care staff included the Group Home Culture Scale (GHCS), which has been used in previous projects to assess the culture of palliative and end-of-life care in residential facilities for people with intellectual disabilities [28, 29]. Moreover, the staff questionnaire also included variables related to the implementation of palliative and end-of-life care practices and sociodemographic characteristics. The quantitative component included 29 residential care facilities. Within these facilities, 86 care teams participated in the survey. Across these teams, a total of 454 professionals completed the questionnaire.

Quantitative data were analysed descriptively using IBM SPSS Statistics version 28 (IBM Corp., Armonk, NY, USA). Data from leaders of residential care facilities were analysed at the institutional level ($N=29$), while staff data were aggregated to the team level by computing mean scores across team members prior to analysis ($N=86$ teams). This procedure is consistent with the conceptual basis of the GHCS, which was developed to measure shared staff perceptions of organisational culture at the group home level [28]. Categorical variables were analysed using absolute and relative frequencies; for metric data, descriptive statistics such as the mean, median, and standard deviation were calculated.

Qualitative data were collected through semi-structured interviews with six people with intellectual disabilities (two women, four men) and four workshops (two LEGO® Serious Play® workshops, two Playmobil® workshops) with eight people with intellectual disabilities (four women, four men). Visual, creative and playful methodologies have been recommended to enhance communication and support meaning-making with people with intellectual disabilities, especially for end-of-life topics [30, 31]. We selected LEGO® Serious Play® and Playmobil® as tangible tools that do not exclusively rely on verbal articulation and can support people with intellectual disabilities in expressing thoughts and feelings that might be difficult to express verbally only [32]. This approach is well suited to the heterogeneous communication profiles of people with intellectual disabilities [33]. Reference persons within the residential care facilities selected suitable participants with intellectual disabilities for the interviews and workshops (age 18 years or older, at least partial ability to communicate verbally). Interviews and workshops with people with intellectual disabilities addressed their experiences of witnessing family members or co-residents in palliative and end-of-life care situations, as well as their own thoughts, feelings, and wishes regarding the end of life, their knowledge of end-of-life topics, and their support needs. Interviews and workshops

with people with intellectual disabilities were conducted in the presence of social or health care professionals of the corresponding residential care facility, and institutional contact persons were identified in advance to provide follow-up support should participants experience distress or emotional concerns arising from their participation.

Additionally, four semi-structured interviews were held with family caregivers (two parents, two brothers), and two focus groups were conducted with ten professionals involved in the provision and coordination of palliative and end-of-life care for people with intellectual disabilities. These interviews and focus groups explored concrete case examples of palliative and end-of-life care, including key moments, (unmet) needs, available forms of support, and key persons involved, as well as participants' wishes for future palliative and end-of-life care provision for people with intellectual disabilities. Family caregivers and professionals were recruited through convenience sampling via advisory board members, who served as facilitators by drawing on their professional and personal networks. Inclusion criteria for family caregivers and professionals were age 18 years or older and sufficient spoken German.

Qualitative data analysis was based on the Framework Method [34, 35] using the software MAXQDA 24. This method is well suited to applied health services research and allows for systematic analysis using summaries and notes. Two authors (D.B. and G.M.) independently documented each interview using summary protocols, interview notes and verbatim transcriptions of particularly illustrative quotations, which were subsequently consolidated to form the basis for further analysis. Full verbatim transcription was not undertaken, as the primary aim was to inform the development of practice recommendations within an applied health services research context [34]. Analysis then followed the five steps of the Framework Method [35]: familiarisation with the data, identifying a thematic framework, indexing, charting, and mapping and interpretation.

Two Authors (D.B. and G.M.) independently familiarised themselves with the consolidated data. Data were then analysed using a deductive-inductive approach. Predefined thematic categories based on the model by Adam et al. [5] were applied deductively during the development of the thematic framework and indexing stages. These included education (e.g., staff knowledge, training, and experience in palliative and end-of-life care), communication (e.g., staff skills in assessing and addressing the needs of people with communication difficulties), collaboration (e.g., partnership working between intellectual disability and specialist palliative care services), and system-level factors (e.g., staffing levels, funding, and organisational/management support). During charting, D.B. and G.M. organised the data into a thematic matrix in MAXQDA 24 and inductively developed subcategories within these categories to reflect participants' perspectives and emerging themes. Both authors then jointly conducted mapping and interpretation to identify patterns and derive findings across cases.

The thematic matrix subsequently served as the basis for joint display Table [36], in which quantitative findings were integrated alongside qualitative themes to facilitate mixed methods interpretation [see Additional file 1].

Phase 4: review practice against evidence-based criteria

The joint display tables integrating quantitative and qualitative findings served as the basis for regular meetings within the research team and with the advisory board to jointly review and interpret the results from the data analysis. Based on this collaborative process, practice recommendations were developed. The involvement of stakeholders in the interpretation of findings and development of recommendations is recognised as an important strategy to enhance the relevance and applicability of health and social care innovations [14, 15, 24].

The practice recommendations were further informed by a non-published narrative review of relevant national and international literature on palliative and end-of-life care for people with intellectual disabilities, conducted by the authors following the guidance of Ferrari [37]. Literature was identified through searches of PubMed (MEDLINE) and CINAHL, supplemented by hand-searching of reference lists of relevant articles. No formal quality appraisal was conducted, as the purpose of this review was to provide contextual evidence to inform recommendation development rather than to synthesise evidence on a specific clinical question.

Phase 5: implement change to practice

In this phase, we initiated the implementation of the recommendations in a residential care facility for people with intellectual disabilities through four structured workshops. We used the JBI Getting Research into Practice (GRiP) tool to address barriers and implementation strategies [20, 21].

Phases 6 and 7, which involve re-assessment and sustainability planning, were beyond the scope of this project.

Results

Based on the integrated findings of the quantitative and qualitative data collection, the narrative review and in collaboration with the advisory board, we developed 21 best practice recommendations across four domains: education, communication, collaboration, and system. The recommendations are presented in Table 1.

The following sections present the findings according to the four domains education, communication, collaboration, and system. Within each domain, qualitative and quantitative findings are synthesised and linked to the corresponding best practice recommendations. The narrative review of relevant national and international literature informed the development of the recommendations alongside the primary evidence generated in this project; the literature sources drawn upon are indicated in Table 1. Detailed qualitative and quantitative results are presented in the additional files [see Additional files 1 and 2].

Education

Residential care facilities showed a mixed picture regarding education and competence in palliative and end-of-life care. Quantitatively, perceived competence in supporting physical, emotional, and spiritual wellbeing at the end of life was generally high across care teams (GHCS Subscale 3: $M=4.21$, $SD=0.33$). However, only 34.5% of all participating residential care facilities offered training programmes on palliative care and only 13.8% offered this on a regular basis. Although 62.1% of facilities employed at least one professional with palliative care training, two thirds of care teams were unaware of whether trained colleagues existed within their own institution. Access to educational programmes on death, dying, and bereavement for residents themselves was reported by only 14.0% of teams.

Moreover, palliative and end-of-life care is largely absent from undergraduate curricula in social care professions, while care for people with intellectual disabilities is not systematically included in nursing education, indicating a critical gap that needs to be addressed (Recommendation 1). This educational deficit was said to contribute to social care professionals' unfamiliarity with symptom assessment and management, on the one hand, and health care professionals' unfamiliarity with caring for people with intellectual disabilities, on the other hand, which were identified as potential sources of stress on both sides.

Social care professionals consistently described palliative and end-of-life care as “a process of learning by doing (Focus group 1)”, with each situation adding incrementally to their experience rather than drawing on a shared, institutionally embedded knowledge base. A recurring theme across family caregivers and professionals was uncertainty about prognosis, how to recognise deterioration, and how to act in complex end-of-life situations. Misconceptions were widespread: some family caregivers assumed dying residents were suffering from starvation due to reduced food intake, while professionals described assumptions equating the use of morphine with euthanasia. Residents sometimes held concrete but fear-laden ideas about death: “Suffering. Everyone who dies, suffers. (Person with intellectual disability 5)”. The need for inclusive training programmes targeting all stakeholders, including people with intellectual disabilities, for instance through peer-based approaches, was highlighted (Recommendation 2, Recommendation 3). Another finding was that existing knowledge was frequently tied to specific individuals rather than embedded in institutional structures, and that this knowledge was lost when trained staff discontinued their employment. The importance of regular in-house training was therefore

Table 1 Best practice recommendations for palliative and end-of-life care for people with intellectual disabilities

Domain	No.	Best Practice Recommendation	Source of evidence
EDUCATION	1	Both palliative and end-of-life care and the care of people with intellectual disabilities are systematically integrated into undergraduate curricula in nursing, social work, and social pedagogy.	P, AB [5, 6]
	2	People with intellectual disabilities have access to appropriate, inclusive formats (including peer-led programmes) through which they can engage with topics related to palliative and end-of-life care.	AB, Q [5, 6, 38, 39]
	3	Professionals and family caregivers involved in palliative and end-of-life care for people with intellectual disabilities have access to continuing education in palliative care.	F, P, AB, Q [6, 13, 38, 40, 41]
	4	Professionals in residential care facilities are familiar with appropriate tools to assess the palliative and end-of-life care needs of people with intellectual disabilities, as well as those of their family caregivers.	F, P, AB [5, 6, 38, 42, 43]
	5	Evidence-based resources on palliative and end-of-life care for people with intellectual disabilities are readily accessible to both professionals and family caregivers.	F, P, AB [38, 40, 44]
	6	Leaders of residential care facilities for people with intellectual disabilities participate in education and training in palliative and end-of-life care.	AB [5, 40, 45]
COMMUNICATION	7	Residential care facilities create structured opportunities for staff to reflect on their personal attitudes, thoughts, and emotions related to illness, dying, death, and bereavement.	AB, Q [13, 46–48]
	8	Residential care facilities establish conditions that enable and support open conversations with residents and family caregivers about illness, dying, death, and bereavement.	PID, F, P, AB, Q [5, 6, 30, 38, 47, 49–51]
	9	Within the interdisciplinary care team, clear responsibility is assigned for ensuring that the expressed or presumed end-of-life wishes of people with intellectual disabilities are systematically elicited and documented.	F, P, AB [38, 50, 52]
	10	Interdisciplinary care teams identify key transition points at which the expressed or presumed end-of-life wishes of people with intellectual disabilities are routinely assessed.	F, AB [52, 53]
	11	Accessible and appropriate tools are provided to support people with intellectual disabilities, their family caregivers, and professionals in eliciting and documenting end-of-life wishes.	PID, AB, Q [5, 6, 25, 31, 38, 43, 50, 54, 55]
COLLABORATION	12	Family caregivers and legal representatives are actively involved in palliative and end-of-life care and receive comprehensive information about it.	PID, F, P, AB [5, 6, 38, 41, 56]
	13	Professionals and family caregivers are familiar with the roles and services of key stakeholders within regional palliative care networks.	F, P, Q, AB [5, 6, 44]
	14	Clear and consistent internal procedures are established within residential care facilities for engaging relevant palliative care contacts, both within and outside the institution.	AB [5, 6, 38, 40, 45]
	15	Structured interprofessional exchange formats (e.g. multidisciplinary case conferences, round-table discussions, and ethics consultations) are routinely used in the delivery of palliative and end-of-life care for people with intellectual disabilities.	F, P, AB, Q [5, 40, 57]
	16	Outcomes and agreed interventions arising from interprofessional palliative care coordination are documented and made accessible to all relevant parties.	AB [5, 53, 57]
SYSTEM	17	Leaders and staff of residential care facilities for people with intellectual disabilities aspire to a palliative care culture that takes into account the holistic support needs of people with intellectual disabilities, family caregivers, and professionals.	PID, F, P, AB [5, 6, 13, 38, 44]
	18	In every residential care facility for people with intellectual disabilities, palliative care leads are designated.	AB [40, 44]
	19	Palliative care leads in residential care facilities form a regional committee that promotes the cross-institutional exchange of knowledge in caring for people with intellectual disabilities at the end of life.	AB [38, 40, 44]
	20	Residential care facilities for people with intellectual disabilities are perceived as an active part of the Eastern Switzerland palliative care landscape.	P, AB, Q [5, 40, 44, 45]
	21	People with intellectual disabilities are explicitly recognised and addressed in cantonal (sub-national) and national palliative care strategies and policy frameworks.	AB [5, 6, 9, 17]

Recommendations were developed through a participatory process integrating generated and synthesised evidence with perspectives of people with intellectual disabilities (PID), family caregivers (F), health and social care professionals (P), and the advisory board of the project (AB), as well as quantitative data from the participating residential care facilities (Q)

emphasised. This training should include building familiarity with appropriate tools to assess the palliative and end-of-life care needs of people with intellectual disabilities and their family caregivers (Recommendation 4). Continuing training and standardised procedures were seen as a means of anchoring knowledge at the institutional level, independent of individual staff members. Institutional anchoring was also understood to include ensuring that knowledge resources always remain readily accessible to both professionals and family caregivers (Recommendation 5).

Leadership involvement was further considered critical for anchoring palliative and end-of-life care knowledge within institutions: participants noted that leadership staff were largely absent from palliative and end-of-life care education programmes, suggesting limited palliative and end-of-life care knowledge among those in management positions. Leaders may fail to recognise palliative and end-of-life care needs of their residents as they are often removed from day-to-day practice. It was therefore considered essential to actively involve institutional leaders in relevant education programmes so that palliative and end-of-life care are recognised as an organisational priority (Recommendation 6).

Communication

The findings consistently highlighted that communication about death, dying, and end-of-life wishes is both central to good palliative and end-of-life care and insufficiently supported in current practice. The involvement of people with intellectual disabilities in decision-making was rated positively overall (GHCS Subscale 2: $M=4.00$, $SD=0.35$). 69.8% of care teams reported documenting residents' end-of-life wishes and 72.1% of care teams reported documenting residents' personal experiences related to dying and grief. However, around one quarter of teams remained unaware of whether residents' end-of-life wishes were documented, and around a third of teams were unaware of whether advance care planning had been used.

Early and honest communication about end-of-life topics was consistently described as important, not least because people with intellectual disabilities living in residential care facilities are constantly confronted with death and loss in their daily lives. Co-residents asked to visit the dying person's room, spoke about the impending death among themselves, and often possessed a keen sensitivity to subtle changes in the person who was dying. Yet their communication needs were not always adequately met. Professionals described feeling overwhelmed by co-residents' reactions to another resident's death, which sometimes led them to respond protectively rather than addressing co-residents' need to talk about it. One professional described how, during the dying process, co-residents had been actively included, but once the death had occurred, openness abruptly ended. A 'bubble around death' was created, to which co-residents were given no access: "All of a sudden the door was closed. All of a sudden the bed was empty." (Focus group 2).

Some interview participants with intellectual disabilities had already engaged in advance care planning with clear, documented wishes. Others preferred not to engage with end-of-life topics at all. Nevertheless, their accounts illustrated the emotional depth and complexity with which they engaged with death and dying. Some had traumatic bereavement experiences without ever having been given the opportunity to talk about them. A family caregiver recounted: "My sister was never really told that her father had died. Her mother always avoided the topic, only saying that the father wasn't there anymore. And I don't think my sister was ever able to grieve for her father, because she didn't know what was going on. 'Where's Daddy?', she kept asking." (Family caregiver 4) Existential fears about what follows death were expressed, alongside the recognition that talking about death can help alleviate fear, even if it does not eliminate it entirely. A person with intellectual disability described his existential fears as follows: "You don't know what you'll see afterwards. Let's say there's an eternal death. You can't really imagine that. Where you're completely destroyed and there is nothing left. That's not a nice feeling, being wiped out." (Person with intellectual disability 3).

Moreover, it was emphasised that people with intellectual disabilities often choose the person they trust for conversations about end-of-life topics, meaning all staff may be confronted with these topics regardless of their role and that these conversations can arise unexpectedly during everyday activities. It was consistently highlighted

that inner preparedness, meaning the ability to engage with one's own attitudes, thoughts, and emotions around illness, dying, and death, is a prerequisite for sensitive and appropriate communication with people with intellectual disabilities. Actively fostering this inner preparedness through structured institutional opportunities was mentioned as essential to promote conversations about end-of-life topics (Recommendation 7).

A particular challenge concerned communication with people with intellectual disabilities themselves about illness, dying, and death. Both family caregivers and professionals sometimes cited cognitive and communicative limitations as a reason for not engaging residents in end-of-life conversations. Unfamiliarity with individual non-verbal communication patterns was identified as a barrier, particularly for professionals outside the residential care facilities. One family caregiver explained how she tried to communicate non-verbally with her daughter about her impending death: "When she was doing so poorly, I also tried to explain it to her. But then I just said, 'You'll be able to go to Grandpa soon, or to M., who passed away in the residential group.' And sometimes she would gesture like this (pointing upwards). I think she did understand some of what was happening." (Family caregiver 1) Picture-based and narrative resources were highlighted as particularly well-suited to opening conversations about dying, death, and bereavement with people with intellectual disabilities. Where verbal communication is limited or absent, it was emphasised that all team members should be encouraged to contribute their observations to "uphold the voice of the resident" (Advisory board). Taken together, these findings reinforce the importance of institutional conditions that enable open conversations about illness, dying, death, and bereavement, adapted to individual communication needs and abilities, and inclusive of family caregivers and the entire residential community (Recommendation 8).

Within residential care facilities, advance care planning was described as heavily dependent on individual initiative of care staff and rarely embedded in routine practice. Family caregivers reported the burden of decision-making, particularly in the absence of prior conversations, and valued clear and timely communication from professionals. One family caregiver reflected on the value of early preparation: "We had already talked about it before the acute situation arose. I've told other parents: do it. Because then you talk about it, and you know the other person thinks the same way. (Family caregiver 3)". These findings informed recommendations for the systematic identification and documentation of end-of-life wishes, with clear responsibility assigned within the interdisciplinary team (Recommendation 9), for the identification of key transition points at which wishes are routinely reassessed (Recommendation 10), and for the provision of accessible and appropriate tools for all parties involved in end-of-life care planning (Recommendation 11).

Collaboration

The findings revealed considerable variability in the extent to which residential care facilities were integrated in broader palliative care networks. While nearly half of all care teams reported having experienced a death of a resident within their care group, only 17.4% had previously collaborated with a mobile specialist palliative care service. 41.9% were unaware of whether opportunities to collaborate with specialist palliative care services existed at all.

A further aspect of collaboration concerned family caregivers and legal representatives. Ensuring that family caregivers were not left alone during palliative and end-of-life situations was considered essential across all participant groups. Close consultation between legal representatives and family members was valued. A family caregiver also described how close collaboration with hospice staff fostered mutual trust: "We noticed that we were simply working together in preparing for the end. They knew what we needed to pay attention to. (...) The nursing staff said: 'What should we dress her in afterwards? Have you already thought about what she should wear?' That was tough in the moment (...). But afterwards I was so glad I didn't have to think about that. We could just take the outfit I was used to seeing her in." (Family caregiver 1) However, family members were not always available or emotionally able to fulfil this role, and legal representatives sometimes felt overwhelmed by the emotional burden and withdrew from end-of-life decisions: "Normally it would have been his job to organise things like the hospital bed, but I appreciated that he asked whether we wanted to take it on, because we were

closer to D.” (Family caregiver 4). In some cases, residents had no family members involved at all, making the roles of the residential care facility staff and legal representatives all the more important. Sensitive and respectful collaboration with family caregivers and legal representatives, including their active involvement in end-of-life care planning and comprehensive information about palliative and end-of-life care, was therefore identified as a central recommendation (Recommendation 12).

Access to specialist palliative care professionals, including around-the-clock availability, was reported to increase confidence among care teams. Specialist palliative care services were described as reducing team pressure, particularly regarding medication management. All palliative and end-of-life care situations in residential care facilities were described as warranting early specialist palliative care involvement, given the limited decision-making capacity of many residents and the overall complexity of their palliative and end-of-life care needs. Early involvement of specialist palliative care services was considered to help prevent under-provision.

Moreover, networking with general practitioners, home care services, hospitals, and spiritual care providers was consistently described as essential to high-quality palliative and end-of-life care. Volunteer services provided significant relief, yet professionals noted they had often been unaware of such services previously. Going forward, they recognised them as a valuable resource for end-of-life accompaniment. Overall, collaboration with external providers was experienced as mutually enriching, offering opportunities to learn from one another across professional boundaries. Familiarity with the roles and services of key stakeholders within regional palliative care networks (Recommendation 13) and clear internal procedures for engaging palliative care services (Recommendation 14) were therefore identified as prerequisites for effective collaboration.

Within interprofessional collaboration, residential care facility staff frequently assumed an intermediary role, acting as translators and advocates for residents in interactions with family caregivers and health professionals, particularly general practitioners. However, residential care facility staff sometimes felt they lacked the professional standing to advocate effectively in medical contexts. In such situations, specialist palliative care services took on this role: “The mobile specialist palliative care team worked out the treatment plan together with the GP. That took some of the pressure off us always having to approach the GP, who would think, ‘now don’t make such a fuss.’ It’s different when I, as a ‘little social worker’, say, ‘I need a prescription for morphine because the resident is dying.’ When the mobile specialist palliative care team says it, it carries a completely different weight.” (Focus group 2) Beyond individual advocacy, structured formats such as round-table discussions and ethics consultations were identified as important, providing a neutral space for shared decision-making (Recommendation 15). It was further emphasised that decisions and agreed interventions arising from interprofessional coordination should be systematically documented and made accessible to all members of the care team (Recommendation 16): “The care team wanted us to establish a treatment plan for how to act in different situations. So, the care team, the home care service, and I sat down together with the GP. And the GP said: ‘The more thoroughly we document this, the better it is for the whole team. Then they’ll know exactly where they stand.’” (Family caregiver 4).

System

Overall, staff demonstrated broadly positive attitudes towards death and dying (GHCS Subscale 1: $M=3.99$, $SD=0.37$) and a strong sense that end-of-life care is an organisational responsibility (GHCS Subscale 4: $M=4.10$, $SD=0.43$). 62.1% of the participating residential care facilities reported having a formal palliative care framework in place. However, approximately one third of care teams in these facilities were unaware of its existence. 75.9% of all participating residential care facilities had experienced at least one death in the past three years, indicating that end-of-life care is a concrete and recurring reality in these settings. The vast majority of facilities (93.1%) reported that residents could generally remain in the residential care facility until death. However, 51.7% had transferred at least one resident to another institution at the end of life in the past three years. This pattern coincided with limited nursing capacity in residential care facilities, as reported in both the survey data and interviews. Indeed, nursing professionals accounted for only 7% of the total sum of employment percentages across all staff, compared to 50% for social care professionals.

Despite structural challenges, professionals demonstrated a strong sense of commitment to palliative and end-of-life care, sometimes at considerable personal cost. It was emphasised that palliative and end-of-life care within residential care facilities for people with intellectual disabilities cannot function without adequate staffing and meaningful appreciation of the extra effort made by the care staff, including financial recognition, involvement in leadership roles, and institutional support. Supportive institutional leadership that actively promotes a palliative care culture as a lived reality and openly addresses personal and institutional limits was experienced as helpful (Recommendation 17). Professionals reported that end-of-life situations took a considerable emotional toll on them: “People say we’re professional and trained, don’t they. But when you’ve been someone’s key contact person for years, it really gets to you. Regardless of how professional you are. The administrative side of things runs smoothly. The morphine, the pain medication, all of that. But it really affects you deeply.” (Focus group 1) The need for structured opportunities for reflective practice, as part of a palliative care culture, was consistently identified as essential but not systematically available. Furthermore, establishing opportunities for mourning and farewell for co-residents, family members, and professionals within the residential care facility was considered important across all participant groups.

The data also highlighted the need for designated palliative care leads within each residential care facility as a structural prerequisite for sustainable practice improvement (Recommendation 18). Beyond coordinating palliative care processes and quality assurance within their institution, these leads should actively empower colleagues and foster a palliative care culture in daily practice.

At a regional level, it was emphasised that a network of these palliative care leads would be more effective than isolated centres of excellence. Regular network meetings would enable shared learning and the exchange of experience (Recommendation 19). Existing exchange formats, however, have yet to reach frontline staff: “There are general exchange meetings between residential care facilities, but frontline staff never hear about them. Yet that’s exactly what they would need with regard to palliative care.” (Advisory board member) Palliative care leads should also participate in regional palliative care network meetings, ensuring that residential care facilities for people with intellectual disabilities are visible and recognised as part of the broader palliative care landscape (Recommendation 20).

At a broader structural level, a significant policy gap was identified: residential care facilities are increasingly confronted with end-of-life situations as their residents age, yet people with intellectual disabilities are not explicitly addressed in cantonal (sub-national) palliative care strategies. It was emphasised that political acknowledgement of this reality is needed, and that the inclusion of people with intellectual disabilities in both national and cantonal palliative care strategies is the minimum required to make this visible (Recommendation 21).

Discussion

The findings of this study provide a nuanced picture of palliative and end-of-life care in residential care facilities for people with intellectual disabilities in Eastern Switzerland. Elements of good practice were evident, such as generally positive staff attitudes towards palliative and end-of-life care and efforts to enable residents to remain in their familiar environment until death. At the same time, important gaps emerged across the domains of education, communication, collaboration, and system. To address these gaps, the present study moves beyond problem description towards co-developed, actionable guidance grounded in primary evidence. A total of 21 best practice recommendations for palliative and end-of-life care for people with intellectual disabilities in Eastern Switzerland were developed.

Although general palliative and end-of-life care standards provide an essential foundation, their application to people with intellectual disabilities remains challenging. Differences in communication needs, cognitive impairment, and decision-making processes introduce complexities that are not always sufficiently addressed within generic frameworks [5]. The consensus norms for palliative care of people with intellectual disabilities, established by the European Association for Palliative Care (EAPC) through a Delphi process involving 80 experts

from 15 European countries, are therefore particularly important [38]. The recommendations developed in our study show substantial thematic convergence with the EAPC norms. Recommendations on education and training, communication and advance care planning, interprofessional collaboration, and the holistic support needs of all parties involved all find direct correspondence in the EAPC norms, as does the call for explicit policy recognition of this population. However, while the EAPC norms describe what good palliative care for this population should look like, they were explicitly framed as aspirational norms rather than implementable standards, with the authors acknowledging that application would vary substantially across European contexts. The authors identified the challenges of applying agreed-upon norms across different national and organisational contexts as a future research priority [38]. The present study directly contributes to this agenda by providing empirical evidence on the conditions under which these aspirational norms can be realised in practice, and by contextualising them at the professional, organisational, and policy levels [58, 59]:

At the professional level

The absence of a shared language and mutual familiarity between disability and palliative care services constitutes a structural barrier to the collaborative practices envisaged in several recommendations. Residential care staff frequently assumed an intermediary role in interactions with health professionals. While this role reflects staff commitment and their relational knowledge of residents, it also exposes a structural gap: social care professionals were expected to advocate in medical contexts for which they often felt insufficiently equipped. This challenge is closely linked to the absence of a shared language and common framework between discipline groups, which has been identified as a key barrier to effective collaboration in previous research [57]. The use of standardized, cross-professional assessment instruments is therefore recommended, as they facilitate interprofessional communication and support continuity and coordination of care across services [60]. Furthermore, building the necessary relationships and referral pathways requires dedicated time and cross-institutional investment that goes beyond individual goodwill. Previous research has pointed to the potential of interprofessional education in fostering cross-professional understanding and familiarity with different professional cultures, including through shared courses in pre-qualification training [61, 62].

A further dimension concerns the inner preparedness of professionals themselves. Our data showed that many social care professionals felt ill-equipped to engage with end-of-life topics, describing a sense of being overwhelmed when confronted with conversations about death and dying. This finding is consistent with broader evidence demonstrating that professionals' own unresolved attitudes towards death and dying constitute a significant barrier to effective end-of-life communication: Higher levels of death anxiety have been associated with avoidance of conversations about dying, reduced willingness to address advance care planning, and lower confidence in end-of-life care [63, 64]. Actively fostering inner preparedness through educational and institutional opportunities [46], rather than treating it as a private matter, is therefore not only an ethical imperative but also a prerequisite for professional resilience and care quality, and connects directly to the organisational conditions discussed below.

At the organisational level

The finding that palliative and end-of-life care knowledge within residential care facilities was often tied to specific individuals rather than embedded in institutional structures, and that end-of-life outcomes consequently depended on individual staff members' commitment rather than systematic procedures, aligns with international literature [5, 65]. Previous research has illustrated that the focus must shift to ensuring that good practice is sustained, replicated and embedded within organisational policies and cultures [45, 65, 66]. Establishing a palliative care culture is therefore a prerequisite for the successful and sustainable implementation of palliative and end-of-life care in daily practice [65, 67]. A qualitative study [68] on the experiences of nursing managers in implementing palliative care in long-term care facilities found that managers play a crucial role at every stage

of this process. In the early phases of implementation in particular, managers need to prioritise staff training and the resolution of internal organisational challenges. Consistent with this, an interview study in intellectual disability residential or supported living services found that in organisations where managers provided positive role modelling by openly engaging with death and dying, junior staff felt more comfortable addressing these topics themselves [46, 47].

Furthermore, our findings indicate that the absence of institutional leaders from palliative and end-of-life care education might impair their capacity to recognise residents' palliative care needs and to assess the training requirements of their staff. Without adequate palliative and end-of-life care knowledge and leadership competencies at the managerial level, the capacity to initiate, sustain, and evaluate practice improvements remains limited, as these competencies underpin organisational learning, change management, and quality improvement [68, 69].

At the policy level

Specific financing mechanisms within the Swiss healthcare system must be considered when interpreting our study findings. Cantons are primarily responsible for financing institutional housing for people with intellectual disabilities, and this funding also covers nursing-related services, at least in part [70, 71]. However, as residents' care needs grow, facilities report that the care provided is not adequately reflected in the needs-assessment systems used for funding, and they see a need for action regarding how nursing care is recorded and reimbursed [70]. One option is to acquire nursing-home status, that is, inclusion in the cantonal nursing-home list, which entitles a facility to provide nursing care at the expense of mandatory health insurance [72]. Once a facility has this status, its nursing care is reimbursed through fixed per-diem payments based on residents' assessed care levels [73]. However, because both inpatient and outpatient nursing tariffs are drawn from the same financing mechanism, the allocation of costs between inpatient and outpatient nursing care remains contested in practice, leaving institutions administratively and financially hesitant to involve outpatient nursing care services, such as nurse-led specialist palliative care services [74]. This specific gap has been partially addressed by a 2026 amendment to the Health Insurance Benefits Ordinance (KLV): from January 2027, nursing homes can claim additional reimbursement – separate from the standard per-diem rate – for up to ten hours of mobile specialist palliative care per resident within a four-month period [75]. This is an interim, albeit very limited, solution until uniform financing of nursing care takes effect in 2032, which will establish a single tariff structure for all nursing care regardless of setting [76].

Finally, the exclusion of people with intellectual disabilities from palliative care policy frameworks reflects a broader pattern of health inequity. As Gréaux et al. [77] demonstrated in a global scoping review on persons with disabilities more broadly, adverse health outcomes in this population are largely shaped by structural and systemic inequities rather than by the underlying condition itself, including the absence of targeted healthcare and government policies and frameworks for this group. The United Nations Convention on the Rights of Persons with Disabilities [78, 79], ratified by Switzerland in 2014, further obliges States Parties to recognise the right of persons with disabilities to the highest attainable standard of health without discrimination and to take all appropriate measures to ensure their access to health services, as well as to take their rights into account in all policies and programmes. These obligations cannot be fully met when this population is not consistently visible across national and cantonal palliative care strategies. Without explicit policy acknowledgement, the recommendations risk remaining the concern of committed individuals rather than becoming a systemic standard of care [5, 38].

Strengths and limitations

This project was guided by the JBI Model of Evidence-Based Healthcare, operationalised through the JBI Evidence Implementation Framework [20, 21], which provided a structured approach to translating evidence into practice recommendations through iterative stakeholder engagement. The integration of quantitative and qualitative data from multiple participant groups enabled a comprehensive and multi-perspectival assessment of the

current state of palliative and end-of-life care. The joint display approach [36] facilitated systematic mixed methods interpretation, allowing quantitative patterns to be contextualised through qualitative accounts and vice versa.

Critically, this project extended beyond the perspectives of professionals and family caregivers to include the voices of people with intellectual disabilities themselves - a group that remains systematically underrepresented in palliative care research. Moreover, the advisory board played a central role throughout the project in validating and interpreting findings and in identifying practical gaps that the research data alone could not capture. This participatory approach is consistent with growing evidence that co-production enhances the relevance and applicability of health and social care innovations [14, 15, 23, 24].

Several limitations should be acknowledged. The qualitative data collection did not include full verbatim transcription. Instead, summary protocols and selectively transcribed quotations were used. While this approach is well-suited to applied health services research [34, 35], it may limit the depth of interpretive analysis. Furthermore, the study was conducted in a single region of Switzerland, which constrains the generalisability of the findings. Transferability to other regions in Switzerland may be reasonably assumed given similarities in organisational structures and health and social care systems. However, cultural differences in the French- and Italian-speaking parts of Switzerland cannot be excluded and warrant further investigation.

Furthermore, the perspectives of people with intellectual disabilities living at home and receiving community-based support remain insufficiently represented in our study. Finally, the study exclusively included adults with intellectual disabilities.

Conclusions

This project demonstrates that palliative and end-of-life care for people with intellectual disabilities in Eastern Switzerland is characterised by significant gaps that are broadly consistent with findings from comparable international research, underscoring that the challenges identified reflect structural and cultural barriers requiring sustained, system-level responses.

The 21 best practice recommendations developed through this project provide a practically grounded, context-sensitive framework for improving palliative and end-of-life care for this population. Their development through integrating quantitative and qualitative evidence with the perspectives of professionals, family caregivers, and people with intellectual disabilities themselves, strengthens their relevance and applicability across different care settings. Importantly, the participatory approach also facilitated extensive networking across disciplines and organisations, bringing together stakeholders who had not previously collaborated in this field. This cross-sectoral connectivity should be considered in future projects as a prerequisite for the sustainable improvement of palliative and end-of-life care for this population.

Future research should prioritise the implementation of recommendations such as those developed in this project, examining how they can be effectively translated into practice across diverse care settings. Crucially, such efforts should retain the participatory approach that proved central to this project, ensuring that the perspectives of professionals, family caregivers, and people with intellectual disabilities continue to inform the ongoing development and refinement of palliative and end-of-life care practice.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1186/s12904-026-02376-7>.

Acknowledgements A special ‘thank you’ goes to all interview participants who shared their intimate experiences and feelings. We would also like to express our sincere gratitude to the many professionals from different disciplines who contacted us during the course of the project, offered their collaboration, and provided valuable feedback on the recommendations developed.

Authors’ contributions D.B., A.K., S.F.S. and C.W. were major contributors in the conception of the study and in acquisition. D.B. and A.K. were involved in data collection, in data analysis and in writing the manuscript. G.M. was involved in

data collection and analysis. S.O. was involved in the data analysis. D.B., A.K., S.F.S., A.G., A.Hin., A.Hir., E.S., J.A., S.S. and U.L.-R. contributed to the development of the practice recommendations. M.M. and E.B. were involved in writing the manuscript. All authors read and approved the final manuscript.

Funding We received financial support from the Ebnet Foundation.

Data availability The datasets generated and/or analysed during the current study are not publicly available due to confidentiality reasons, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate The Cantonal Ethics Committee of Eastern Switzerland clarified that the research project did not fall within the scope of the human research act (BASEC 2024–00616). For the qualitative interviews, written informed consent was obtained from all participants prior to participation. For participants with intellectual disabilities, the consent process was supported by a familiar support person from their residential care facility to facilitate understanding. We treated the collected data confidentially and ensured anonymity, data protection, and the right to privacy. The study adhered to the principles of the Declaration of Helsinki.

Consent for publication Not applicable.

Competing interests The authors declare no competing interests.

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