Improvement of palliative care for people with intellectual disabilities: a multi-site evaluation

Anke J.E. de Veer, PhD[1], Hille Voss, PhD[1], Anneke L. Francke, PhD[1, 2, 3], Y. de Man, PhD[1]

[1] NIVEL, Netherlands Institute for Health Services Research, P.O. Box 1568, 3500 BN Utrecht, The Netherlands.

[2] Amsterdam UMC location Vrije Universiteit Amsterdam, APH Amsterdam Public Health research institute, Van der Boechorststraat 7, 1081 BT Amsterdam, The Netherlands.

[3] Expertise Centre Palliative Care Amsterdam UMC

Abstract

Background. To improve the quality of palliative care, six evidence-based tools were implemented in ten care services specialised in care for people with intellectual disabilities. Contextual differences were taken into account by using a participatory action research approach.

Method. The RE-AIM framework (Reach, Effectiveness, Adoption, Implementation and Maintenance) structured the evaluation. Data sources were online questionnaires completed by 299 professionals at baseline (response 45.2%) and 250 professionals after 2.5 years (35.1%), 11 semi-structured group interviews with 43 professionals, field notes and implementation plans.

Results. 767 professionals and 43 teams were reached. The effectiveness of the intervention was demonstrated in an improved knowledge of palliative care policy and increased competences among professionals. 79% of the professionals adopted tools in the toolbox. The participatory action research method was perceived as valuable in driving change.

Conclusions. Improving palliative care needs a context-specific, flexible approach, with involvement of all stakeholders.

Introduction

A growing number of people with intellectual disabilities experience age-related health problems, such as cardiovascular diseases, cancer and dementia, and need palliative care (Heslop & Glover 2015; Patja et al. 2000; Schoufour et al. 2014). Therefore care services specialised in care for people

with intellectual disabilities need to be prepared to provide palliative care. However, people with intellectual disabilities lack access to high-quality palliative care (Tuffrey-Wijne et al. 2016). Knowledge about the best strategies to improve palliative care practice in care services specialised in care for people with intellectual disabilities, hereafter care services, is scarce (Adam et al. 2020; Edwards et al. 2018).

The care services in this study are residential services exclusively designed for this population. In addition to the daily care staff mostly consisting of social workers, these services employ various disciplines, including nurses, physicians, physiotherapists, speech therapists, spiritual care providers, and psychologists. In improving the provision of palliative care, there are two main challenges. Firstly, there is a low prevalence of people in need of palliative care. Palliative care in these care settings differs from other care settings such as nursing homes and hospices, where the death rates and therefore numbers of people in need of palliative care are much higher (Todd et al. 2020; Voss et al. 2021a). Therefore, the development of palliative care policies is often not a management priority.

Secondly, professionals lack the necessary palliative care competencies. In the Netherlands, as well as in other countries, most professionals who support people with intellectual disabilities are social workers with a vocational or bachelor training in social work who generally have not received palliative care training as part of their initial education. Research has shown that these professionals often feel inadequately equipped to provide palliative care and talk about death and dying (Bekkema et al. 2014, 2015a; Dunkley & Sales 2014; Tuffrey-Wijne & Rose 2017; Wark et al. 2014; Wiese et al. 2015).

Over time, a large number of palliative care tools have become available to improve palliative care in various settings (Moore et al. 2020). While it is known that these tools can also be successfully implemented in care services specialised in care for people with intellectual disabilities (Voss et al. 2021ab), achieving long-lasting sustainable change remains challenging. A previous study assessing the sustainability of innovations in 63 healthcare organisations in the Netherlands found that 37% of the innovations were sustained (de Veer, et al. 2021). Organisations were more likely to achieve sustainment of change when there was alignment between the tool and the organisation's palliative care policy. Additionally, management involvement has been found to increase sustainment. These findings imply that improving palliative care in care services requires a context-sensitive approach. This is in accordance with implementation frameworks that promote starting with an analysis of possible factors that influence successful implementation and selecting implementation strategies based on this analysis (Bartholomew et al. 2011; Fleuren et al. 2014; Grol et al. 2005; Sommerbakk et al. 2016).

[Table 1]

Based on these findings, six evidence-based tools were offered as tools to improve palliative care, each addressing a perceived difficulty in palliative care provision (Bekkema et al. 2014, 2015ab, 2016; De Veer et al. 2017). The tools addressed difficulties that were often felt to exist in identifying symptoms and needs, cooperation, and the palliative care competencies of professionals (Voss et al. 2023). The tools made up a toolbox, that was introduced in ten Dutch care services and studied using participatory action research during a funded period of 2.5 years (from September 2020 to March 2023). Participatory action research is context-sensitive (ICPHR 2013). The participants (disability professionals, management and people with intellectual disabilities and their families) worked together closely, with one participatory action research group per care service. In co-creation, practical knowledge was generated which was grounded in the specific setting. The co-creation implied that tools were chosen and implemented in a way that best suited the specific context. A description of the intervention can be found in Appendix 1.

The objective of this study was to gain insight into the added value of the toolbox and the participatory action research approach in promoting sustainable high-quality palliative care. This knowledge can be used to establish a best-practice method for delivering sustainable palliative care for people with intellectual disabilities. The evaluation was structured according to the RE-AIM framework's Reach, Effectiveness, Adoption, Implementation and Maintenance dimensions (Glasgow et al. 2019; Holtrop et al. 2021).

The specific research questions addressed in this study were:
1. To what extent were professionals, people with intellectual disabilities and their families reached during the intervention period?
2. What was the effectiveness of the intervention with respect to (i) care services' palliative care policy, (ii) the professionals' palliative care competencies, and (iii) the quality of palliative care for people with intellectual disabilities?
3. How did professionals assess the adoption, implementation and maintenance of the tools and what factors hindered and facilitated this?

Methods

Setting
Ten residential care services throughout the Netherlands took part in the project on a voluntary basis. The care services varied in size, and provided support to approximately 450 to a maximum of 6,000 (median 1,375) people with mild-to-severe or profound ID. In addition to the daily care staff, the services employ various supporting disciplines, including nurses, physicians, physiotherapists, speech therapists, spiritual care providers, and psychologists. Each care service received separate funding based on an approved project proposal.

Study design and data collection
The evaluation used a mixed-methods design. The data sources that were used were:
(a) A questionnaire administered via email to professionals at the beginning (pre-test) and end (post-test) of the implementation period. The questionnaire items were based on a previously validated questionnaire on experiences with palliative care (Joren et al. 2021). The questionnaires were completed fully by 299 professionals at baseline (response 45.2%) and 250 professionals at the end of the intervention period (response 35.1%).
(b) Group interviews conducted at the end of the intervention period (YDM, ADV), using a topic list. The interviews focused on the adoption, implementation and sustainment processes, influencing factors, and value of the intervention. Eleven group interviews were conducted, one for each care service, except for one service where two interviews were conducted. A total of 43 persons participated in the interviews, consisting of 13 nurses, 13 policy staff (project managers), 9 team coordinators, 4 spiritual carers, 3 social workers and 1 physician. They were all members of the participatory action research groups carrying out the project in the individual care services.
(c) Field notes. Researchers systematically collected data throughout the intervention period, for example plans, self-assessment reports, and notes by the researchers (HV, ADV) based on observations, site visits, telephone calls and national meetings.

Ethics approval and consent to participate
The study protocol was approved by the Medical Research Ethics Committee in Utrecht (METC Utrecht, reference number WAG/mb/20/020943). The study was conducted according to the principles of the General Data Protection Regulation. Informed consent was provided by all professionals involved who filled in the digital questionnaire and were interviewed. Anonymity of the

respondents was strictly safeguarded in the analyses, reporting and storage of the data. Access to the data was limited to two researchers (ADV and YDM).

Descriptions of concepts, operationalisation and analyses

Reach (research question 1 is operationalised as the number of professionals reported by the care service as being reached, the number of teams involved and the characteristics of the people whom they cared for (source: field notes), and the involvement of people with intellectual disabilities and family members (sources: field notes and interviews).

Effectiveness (research question 2) is operationalised as the perceived impact of the implementation of the tools on (i) palliative care policies in the care service, (ii) the palliative care competencies of professionals, and (iii) the quality of palliative care. The questions asked and answer options are discussed in the Results section. Differences between pre-test and post-test answers were tested using linear regression analyses. Weights were applied to account for differences in the number of completed questionnaires across each care service. By assigning weights, we give equal significance to the responses from each care service. The quantitative data obtained from the questionnaires were analysed using STATA 16.0. Statistical significance was determined using a p-value of ≤ .05.

Adoption (research question 3) is described as the willingness of professionals to use the tools. It is measured by two questions in the post-test questionnaire.

Implementation (research question 3) is described as the involvement of representatives in the participatory action research group and the tools implemented by them. These data were derived from interviews and field notes.

Maintenance (research question 3) refers to the expectation that the tools would become integrated into the daily practices. It is measured by one question in the post-test questionnaire (see Results section).

Factors influencing adoption, implementation and maintenance (research question 3) were derived from the verbally transcribed interviews using MAXQDA 2022 by two researchers (ADV, YDM). Reflexive, inductive thematic analysis was performed, following the steps outlined by Braun and Clark (2006). In the first step, both researchers independently familiarised themselves with the data by reading two transcripts and identifying relevant fragments. They selected fragments, and raw codes were deliberated upon and discussed to determine whether they corresponded to one of the five RE-AIM dimensions. In the next step, one researcher (ADV) coded four additional transcripts based on the initial raw data codes and introduced additional codes when necessary. The set of initial codes was reviewed, discussed, and modified if needed. The researchers then openly searched and discussed themes related to factors that influence adoption, implementation and maintenance. To further structure the code tree of influencing factors, the researchers utilised the domains of the Consolidated Framework for Implementation Research (CFIR) (Damschroder et al. 2022). CFIR distinguishes five main domains: the innovation, the outer setting, the inner setting, the individuals and the implementation process. The innovation refers to the tools being implemented. The outer setting covers the context within which a care service operates. The inner setting covers elements within the care service. The individuals are the people involved in the implementation process. And the implementation process itself refers to the activities aimed at making sure the tools are used.

Next, all transcripts were coded, and themes were named and described. Finally, the researchers reviewed the codes, themes and interpretations from their analysis; they found a high level of consensus.

Results

[Table 2]

Reach

During the implementation period, 43 teams were reached (2 to 8 per care service, median of 4). By the end of the intervention period 767 disability professionals were reached in the ten care services (42 to 153 per care service, median of 59). These professionals provided care to individuals with mild to severe or profound intellectual disabilities residing in community-based group homes and/or residential settings. Additionally, seven of the service teams provided care to individuals with other or additional disabilities, including sensory disabilities, physical disabilities, acquired brain injury, chronic and progressive diseases, psychiatric disabilities and autism spectrum disorders. Table 2 shows that the majority of professionals who completed the questionnaires were social workers (74% at baseline and 67% at the end) or nurses (10% at baseline and 10% at the end).

In seven care services, family members were reached, either through newsletters or through an organised meeting. Three care services extended these methods to include people with intellectual disabilities themselves.

[Table 3]

Effectiveness

The results show that over three-quarters of the professionals thought that all three goals had been achieved (table 3). When comparing pre-test and post-test data, this is confirmed for the organisational policy and experienced competencies. However, there was no statistically significant improvement in the quality of palliative care as measured by the questionnaires.

[Table 4]

[Table 5]

Adoption

Over three quarters of the professionals who filled in the questionnaire adopted the toolbox. They perceived the tools as useful and potentially beneficial in enhancing palliative care (Table 4). Although the remaining professionals were less convinced, they still had a positive impression of the tools.

Table 5 shows that factors influencing adoption were identified across all CFIR domains. The interviews confirmed that the practicality and user-friendliness of the tools in the toolbox facilitated adoption. According to the interviewees, the extra subsidy options enabled care services to apply for subsidy for the implementation activities, and the public attention given to palliative care increased awareness among professionals and family. Due to the COVID-19 pandemic, which demanded significant time and energy from professionals, most care services had a delayed start. Other barriers to adoption were related to the inner setting and individual daily care staff. Motivation among daily care staff was sometimes hindered by a lack of people in need of palliative care, and the fact that other projects demanded their attention. In addition, daily care staff's mindset often focused on encouraging development and participation, self-employed staff lacked the motivation to invest in improvement projects, and a fear of talking about death and dying among daily care staff hindered adoption as well.

Promoting adoption of the tools was easier when the care service had a general policy that individuals could reside in the facility until their death and should receive good palliative care

emerged as an important factor promoting adoption of the tools. Additionally, adoption was facilitated if teams had previously encountered deaths and had had motivators eager to improve palliative care.

The interviewees indicated several activities that promoted adoption. The initial assessment of current palliative care practices motivated professionals and management to carry out the implementation activities. Activities to encourage daily care staff participation included establishing personal contacts, early daily care staff involvement in choosing the tools, and responding to their concerns and fears.

Implementation

Implementation started with the formation of participatory action research groups, consisting of disability professionals and managers (Table 4). However, the involvement of people with intellectual disabilities and family members in the participatory action research groups was generally limited. Seven care services chose two tools, while three services opted for three tools. All six tools were chosen by at least two care services, with the most commonly chosen tools being the roadmap for identifying and analysing palliative care needs and the specialist palliative care consultant (Table 4).

Factors related to implementation of better care were observed across all CFIR domains (Table 5). The tools in the toolbox were generally regarded as easily adaptable to local contexts and needs. During implementation, influencing factors primarily concerned the role of participating individuals and the design of the implementation process. According to the interviewees, various individuals played a role in facilitating the implementation, including managers, committed initiators, enthusiastic and proactive daily care staff striving to improve palliative care, and policy staff assisting with practical matters. The involvement of family and people with intellectual disabilities was also perceived as facilitating the utilisation of the new tools, and the presence of role models showing colleagues how to provide palliative care was beneficial.

The participatory action research method was highly valued for supporting the implementation of new care practices. Its stepwise approach, involving cycles of planning, doing, checking and acting, offered flexibility and adaptability to the specific context. Planning, based on a stakeholder analysis, and monitoring were necessary to structure the process and keep activities going. It was seen as advisable to start small, with only a few similar teams who can learn from one another. Early on in the implementation process, daily care staff received training in palliative care. This was preferably done in small groups that provided a safe space for discussing fears and answering questions. Sharing information with other professionals in the care service, as well as with management and family, increased the visibility of the tools and stimulated involvement in intervention activities.

The original aim was to compose participatory action research groups of representatives of important stakeholders such as management, disability professionals, people with intellectual disabilities and family. It was found to be difficult to involve people with intellectual disabilities and their families. This was resolved by the formation of a core group and a broader group that could be involved on an ad hoc basis.

According to the interviewees, networking with other care services specialised in care for people with intellectual disabilities a positive impact on the implementation process, enabling the exchange of ideas and sharing of successes and failures. The implementation was felt to have been hampered by the high rate of COVID-19 infections among people with intellectual disabilities and daily care staff, as well as restrictions such as social distancing.

Maintenance

Disability professionals were less sure about maintenance, with 52% being not fully sure and 38% being convinced that the tools were well implemented and sustained (Table 4). Ten per cent of the professionals reported a lack of proper implementation and sustainment.

The interviewees reported that the high turnover of staff and the high workload jeopardised continuity (Table 5). Reasons for optimism were changes in the inner setting such as the presence of a palliative care expert team committed to improving palliative care, the inclusion of palliative care in the organisational policy, a communication infrastructure to keep in touch and inform each other, and an electronic information system that provided access to palliative care policies, tools, guidelines and experts within the care service.

Furthermore, optimism regarding maintenance was boosted by individuals, for example through managers' recognition of the importance of palliative care, the presence of motivators, and daily care staff's motivation to further improve palliative care. After the formal implementation period ended, new plans and activities were already being initiated. The available opportunity to apply for a new grant was experienced as facilitating the maintenance and further improvement of palliative care.

Discussion

This study aimed to gain insight into the added value of the toolbox in promoting sustainable high-quality palliative care, and the participatory action research approach in promoting sustainable high-quality palliative care. The research questions were structured by the dimensions of the RE-AIM framework. The intervention mainly reached daily care staff, which is also the largest group in care services for people with ID. People with intellectual disabilities and their families were reached less often. Effectiveness was demonstrated in professionals' better knowledge about palliative care policies and perceived palliative care competencies, but no statistically significant improvement was observed in the perceived overall quality of palliative care. Adoption was generally achieved because disability professionals were positive about the usefulness of the toolbox. Implementation of the tools was accomplished. All care services implemented two or three tools. Regarding maintenance, while 90% expected that the tools would be implemented properly and sustained, only 38% expressed complete confidence in the maintenance of the implemented changes.

Various facilitators and barriers were identified. The tools were generally valued as easy to use, and the possibility to adapt tools to fit the local context facilitated adoption and implementation. The level of adoption was generally affected by factors within the inner setting and characteristics of the individuals involved. Barriers were overcome by assessing current palliative care practices and revealing problem areas together with daily care staff. Implementation was mainly influenced by characteristics of individuals and the implementation process. The participatory action research method proved valuable in driving change, with its flexibility and possibilities of piloting being highly valued. Finally, maintenance was expected because of changes in the inner setting or infrastructure of the care service, as well as the ongoing commitment of individuals to improve palliative care. However, maintenance was threatened in particular by high staff turnover and a heavy workload.

The toolbox was perceived as a valuable aid for improving palliative care, since the tools were easy to adapt and use in practice. The tools address different possible gaps in palliative care provision: identification and analysing symptoms, including timely identification of the palliative phase, the coordination and continuity of care, communication, shared decision-making, basic knowledge about palliative care, and needs assessment in people with intellectual disabilities. The ten care are services chose different combinations of tools to implement, as detailed in Table 4. For instance, one care service opted for a specialist palliative care consultant along with the roadmap for identifying and analysing palliative care needs, while another chose the shared decision-making tool and the book 'Caring until the last day'. Even within a single care service, participating teams exhibited a preference for different tools. This illustrates the necessity of a context-specific approach to improving palliative care. The participatory action research method was perceived as a valuable approach to implementing tools, in particular because of the assessment of prevailing palliative care policies and the wishes of professionals at the start, the involvement of a diverse group of stakeholders in the action research group, particularly daily care staff, and the flexibility in adapting

implementation plans. As mentioned in the introduction, such a context-sensitive approach aligns with previous implementation research results.

Although the request by the funding organisation (ZonMw) was made beforehand to involve people with intellectual disabilities and their families in the participatory action research groups, intensive involvement of people with intellectual disabilities and their families was not achieved. People with intellectual disabilities and their families were also not always informed about the intervention. This hesitance to involve them may be attributed to professionals' reluctance to discuss topics related to death and dying, a finding consistent with previous studies (e.g. Adam et al. 2020; Bekkema et al. 2014; Foo et al. 2021; Noorlandt et al. 2020; Voss et al. 2021b). However, those care services that did involve them were enthusiastic about the response, as it often sparked meaningful conversations. Therefore, while direct participation in the participatory action research group may not always be feasible, it is strongly recommended to find alternative ways to involve people with intellectual disabilities and their families.

The intervention resulted in a better knowledge among professionals of palliative care policy in the care service and increased perceived palliative care competencies. However, these effects did not translate into a statistically significant improvement in the perceived quality of palliative care. Full implementation remains a work in progress and ongoing activities are needed to ensure the delivery of high-quality palliative care. In addition, the intervention was carried out during the COVID-19 pandemic and a time of major labour market shortages, which placed a heavy burden on everyone in care services. An explicit palliative care policy and competent professionals are crucial for delivering high-quality care, and these aspects had improved by the end of the intervention period. Moreover, the general expectation was that activities to improve palliative care would continue, providing hope for sustained improvements in the quality of care in the long term.

In sustaining improvements, special attention should be paid to safeguarding the palliative care competencies of professionals. Our results indicate that training is most effective when using examples of deceased people known to participants or of actual people with intellectual disabilities who are currently in need of palliative care. This finding aligns with a Delphi study on educating incoming daily care staff because of their limited knowledge (Kersten et al. 2023). Daily care staff should be provided training in an accessible and inspiring way, encouraging knowledge and experience sharing, and the integration of knowledge into their daily work. The high turnover of professionals is a serious risk for the maintenance of the changes achieved. In our study, teams participated because they looked after groups of frail or older people. Despite this, only 60% of the participating disability professionals reported that they had provided palliative care during the preceding two years (i.e. the duration of the intervention period) (De Man et al. 2023). Training in applying tools is most effective when a team is already caring for one or more people in the final stage of life. Daily care staff could however be given basic knowledge about palliative care in an earlier phase, for example by using the tool 'Caring until the last day' in the toolbox. Basic knowledge is found to increase perceived efficacy (Kim et al. 2021) and therefore serves as a starting point for further on-the-job learning if someone needs palliative care, at which point more specific tools can be introduced.

Strengths and limitations

This study provides initial insights into the added value of a toolbox and strategies for improving palliative care practices in care services, taking the context into account. Because this multi-method and multi-source evaluation can be considered as ten different case studies, the results are rich. Another strength of this study is the integration of the concepts of the RE-AIM framework and CFIR. This combination facilitated the analysis of the data. Previous evaluation studies (King et al. 2020; Klop et al. 2022) have demonstrated the value of combining RE-AIM with a model with CFIR.

As said, one limitation is that we did not interview persons with intellectual disabilities or their families since they were not actively involved in the participatory action research groups. Another limitation is that participants may have given socially desirable answers. While this is compensated by using many different data sources, it is advisable to consider employing more direct measures to assess the experiences of individuals with ID regarding access, timing, and quality of palliative care.

Implications for practice

Our research shows four strategies that managers of care services can deploy to improve palliative care: (1) having a vision and policy that allows individuals to continue residing in their residential group until their death, (2) setting up a palliative care expert team to disseminate knowledge and provide support to care teams, (3) encouraging participation in regional networks of healthcare organisations providing palliative care to enable collaboration and knowledge sharing, and (4) enabling easy access to a variety of tools through an electronic documentation system and offering training possibilities for daily care staff.

A second recommendation for practice refers to the timing of palliative care training for daily care staff. Considering the relatively low number of individuals requiring palliative care, it seems inefficient to thoroughly train all daily care staff at all times. Instead, it is recommended to offer basic training to all daily care staff and extra training on the job when a person in their care requires palliative care. Multidisciplinary experiences can be shared during team meetings.

Finally, timely identification of palliative care needs remains a challenge, particularly when daily care staff have only had basic training. Timely identification is necessary to deliver appropriate palliative care, yet people with intellectual disabilities are found to be under-served (Segerlantz et al. 2020; Velepucha-Iniguez et al. 2022; Voss et al. 2021b; Vrijmoeth et al. 2016). The palliative care policy and the palliative care expert groups within care services should pay extra attention to tackling this problem by ensuring strategies for early identification and appropriate access to palliative care services.

Conclusion

The toolbox, with a variety of easily adaptable tools, has proven valuable in improving palliative care. Tools were chosen based on the individual care service's change needs. Improving palliative care in care services specialised in care for people with intellectual disabilities needs a context-specific and flexible approach, with the involvement of all stakeholders, including management. High staff turnover, heavy workloads and the low prevalence of people in need for palliative care make it harder to maintain the implemented changes. Strategies to enhance maintenance should focus on addressing these barriers, providing ongoing support and training to daily care staff, and fostering an organisational culture that prioritises palliative care.

Abbreviations
CFIR: Consolidated Framework for Implementation Research
RE-AIM: Reach, Effectiveness, Adoption, Implementation, Maintenance

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Tables and figures

Table 1   Possible difficulties in the provision of palliative care and the tool addressing each difficulty

Difficulties in	Tool
(1 identification and analysing symptoms, including timely identification of the palliative phase	Roadmap for identifying and analysing palliative care needs (Giesen et al. 2018)
(2) coordination and continuity of palliative care	Specialist palliative care consultant - the introduction of a professional with specific expertise in palliative care who can be consulted by other professionals for coaching, support and advice (HAN 2023)
(3) communication about death and dying	STEM or 'Dying your way' - a method and training programme to facilitate communication about dying and care preferences at the end of life (Jansen & Donders 2023)
(4) shared decision-making among professionals, person with ID, and family	Decision-making about medical interventions and the best place for palliative care - a stepwise method for making shared and carefully considered decisions (Bekkema et al. 2023a)
(5) basic knowledge about palliative care of daily care staff and other professionals	'Caring until the last day' - an easy-to-read book for professionals with an introduction to palliative care, relevant topics, suggestions and case descriptions (Bekkema et al. 2023b)
(6) assessing the needs of the person with ID	'What do I want? What if I don't get better…?' - a workbook for discussing and recording people's wishes (Bekkema et al. 2023c)

Table 2   Reach: Types of disability professionals who filled in the questionnaire at the beginning (pre-test) and end (post-test) of the funded implementation period (multiple answers possible)

	Pre-test N=299 %	Post-test N=250 %
- daily care staff	73.9	66.8
- nurse	9.7	10.0
- palliative care consultant (nurse specialised in palliative care)	1.0	2.4
- team leader	6.7	7.6
- psychologist	4.0	7.6
- physician, general practitioner, medical specialist for people with intellectual disabilities	1.7	2.0
- spiritual caregiver	1.3	0.4
- Allied health professional (e.g. physiotherapist, speech therapist)	2.0	1.2

Table 3 Effectiveness: changes in the organisational policy, palliative care competencies and quality of palliative care (weighted %)

	Pre-test N=299 %	Post-test N=250 %	p
Policy of the care service			
- the palliative care policy in my care service has changed over the last two years (n=199)[1], % improved		83.4	
- presence of a protocol or guide for palliative care (n=192, 209)[2], % yes	80.0	94.9	<.0001
- presence of a team specialised in palliative care (n=191, 203)[2], % yes	71.1	86.3	<.0001
- presence of a palliative care consultant (n=148, 163)[2], % yes	72.4	86.1	.003
- possibility for training in palliative care (n=192, 215)[2], % yes	85.6	96.3	<.0001
Competencies in palliative care			
- my competencies in providing palliative care have changed over the last two years (n=227)[1], % improved		77.7	
- how competent are you in giving palliative care? (n=297, 247)=192, 209)			<.0001
- very	14.7	27.6	
- fairly	42.4	49.5	
- somewhat	34.9	22.6	
- not	8.1	0.4	
Quality of palliative care			
- the quality of palliative care in my care service has changed over the last two years (n=200)[1], % improved		79.3	
- what is your perception of the quality of palliative care?[3] (n=265, 235), % (very) good	55.1	60.8	.197

The number of respondents of varies due to missing values. Numbers are of respondents in pre-test, post-test surveys. 1 Answer options improved/remained the same/worsened 2 Answer options yes/no/don't know. 'Don't know' is classified as a missing value. 3 Answer options very good/good/sufficient/moderate/poor.

Table 4   Adoption, implementation and maintenance of the activities to improve palliative care

	%
Adoption[1]	
- Are you convinced that the project: "Toolbox: getting started with palliative care for people with an intellectual disability" can lead to better palliative care? (n=246), weighted	
- definitely yes	78.2
- I don't know for sure, but I think so	20.9
- I don't know for sure, but I don't think so	1.0
- no	0.0
- Do you expect the introduced tool or combination of tools to be useful for people requiring palliative care? (n=155)[2]	
- definitely yes	78.7
- I don't know for sure, but I think so	20.7
- I don't know for sure, but I don't think so	0.0
- no	0.7
Implementation	**no. of care services**
Representatives in action research groups (n=10 care services) [3]	
- disability professionals	10
- management or staff	10
- people with intellectual disabilities	4
- family	3
Tool (n = 10 care services) [4]	
- roadmap for identifying and analysing palliative care needs	7
- specialist palliative care consultant	5
- STEM or 'Dying your way'	3
- Decision-making about medical interventions and place of palliative care	2
- 'Caring until the last day'	3
- 'What do I want? What if I don't get better…?'	3
Maintenance[1]	
- Is the tool or combination of tools properly implemented and sustained? (n=155) [1]	
- definitely yes	38.1
- I don't know for sure, but I think so	51.6
- I don't know for sure, but I don't think so	7.7
- no	2.6

The number of respondents varies due to missing values.

[1] Source: post-test survey among disability professionals; [2] Question is only asked if the respondent knew which tools were implemented. Therefore the n is lower and percentages are unweighted; [3] Sources: field notes and interviews; [4] Source: field notes.

Table 5   Factors facilitating and hindering adoption, implementation and maintenance, structured by main CFIR domains

Adoption	Facilitators	Barriers
1. Innovation characteristics	Offering practical and easy-to-use tools and a clear implementation plan ensures that daily care staff and management believe that the activities are feasible.	
2. Outer setting	The available funding facilitates the uptake of activities within the care service to improve palliative care. Public attention being paid to palliative care has made people more aware of the importance of good palliative care and has made them more open to the project.	Due to the COVID-19 pandemic, team leaders were hard to reach and not willing to participate in the project. Care for the people took priority. Some daily care staff were less motivated to adopt a chosen tool because daily care staff from another care service had stated the tool was not usable.
3. Inner setting	The project goals and/or activities are in line with the policy goals of the care service or existing activities in the care service. Teams that have experienced the death of persons in their care or had persons requiring palliative care are more open to participating in the project. The COVID-19 pandemic increased the perceived need to adopt the project.	Teams that have not cared for dying persons do not feel the need to participate in the project. Teams that are already participating in other projects have little time and motivation for another new project.
4. Characteristics of individuals	Professionals who are committed and enthusiastic about the project and have a certain role and who motivate others and proactively initiate activities.	The mindset of social workers is focused on social care, stimulating development and participation, while somatic care and decline receive less attention. This picture is also sketched in recruitment campaigns for new daily care staff. The mindset of self-employed daily care staff. Due to the staff shortages, the care services also use many self-employed people and they are mainly focused on day-to-day operations and are not very motivated to commit themselves to additional activities. Fear of death and dying keep people away from the theme and therefore they cannot embrace the project.
5. Process	Assessing current palliative care practices and collecting priorities and preferences reveals areas for improvement, which in turn motivates people to participate in the project. Encouraging daily care staff participation through personal contacts makes daily care staff more enthusiastic about the project. Early collaboration with daily care staff and shaping the project together motivates them to participate. Discussing fears of death and dying removes barriers to embracing the project and opens the way to adoption.	The late involvement of daily care staff in the project leads to resistance in the team and unwillingness to adopt tools.
Implementation	Facilitators	Barriers
1. Innovation characteristics	Adaptability of tools. Tools in the toolbox can be modified, tailored, or refined to fit the local context or needs.	Implementation is hampered if the selected tool is too difficult to apply immediately, for example due to the lack of an implementation guide or the use of difficult (medical) terms.

Table 5 Continued

		Sometimes the costs of the innovation were not affordable for the care service.
2. Outer setting	Networking with other organisations leads to the exchange of knowledge and experiences, which supports the implementation process. Networking was sometimes organised by regional palliative care networks and was also possible between the ten care services that participated in the overall project.	The many COVID-19 infections among people with intellectual disabilities and daily care staff and restrictions such as social distancing made implementing more difficult.
3. Inner setting	Familiarity with other professionals through pre-existing regular meetings or professional relationships facilitates implementation. Shared vision that participation in the project entails certain obligations to participate in trainings and activities. This vision is propagated if the team leader also participates in training and activities. Time is made available to participate in the project and implement the tools.	Staff shortages and turnover lead to instable teams, which hinders implementation. Mission alignment: If it is unclear whether people can live in the care service until their death and an organisational standpoint on this is lacking, it is difficult to implement and deliver palliative care.
4. Characteristics of individuals	If management (such as executive leaders and directors) have confidence in the members of the participatory action research group and support the project objectives, they are more willing to facilitate activities. Having policy staff who assist or support implementation (facilitators). Having people who are committed and enthusiastic about the project and who motivate and proactively initiate activities. Daily care staff see the project as addressing a need for better support. Involvement of people with intellectual disabilities and their families by asking them which tools they prefer. By means of behaviour modelling, daily care staff can learn new behaviours by observing a colleague exhibiting these behaviours, such as starting a conversation about dying or observing symptoms (e.g. pain, dyspnea, anxiety).	Appropriate use of new tools is hindered because daily care staff are trained to focus on development and participation and have limited skills in recognising, discussing and providing palliative care. Implementation is hampered if daily care staff do not feel the need to improve palliative care. Lack of policy staff who assist or support implementation (facilitators).
5. Process	The members of the participatory action research group are diverse, with a range of competencies and roles. Cycles of planning, doing, checking and acting (PCDA) make the implementation process flexible and adaptable to the context. It is easier to start with small pilots and to expand activities to include other teams or add extra activities after pilots are successful. When going through the PDCA cycles, it is important to keep the focus on the pre-defined end goal. The flexible set-up must be accompanied by tight planning and monitoring of activities to ensure the continuity of the cycles.	A broad composition of the participatory action research group with members who are on an equal footing is difficult to achieve. It proved difficult to involve family and people with intellectual disabilities, and sometimes also daily care staff, in the participatory action research group. Instead, the project groups involved them on an ad hoc basis. Pilot testing is more difficult when teams are very different to one another because they may require different implementation approaches. For example, a team in a large residential area compared with a team in a community, or

Table 5 Continued

		teams with people with intellectual disabilities with very different characteristics. A PDCA cycle is not completed due to insufficient checking.
	Training in small groups. By involving a small number of daily care staff at the beginning, daily care staff become more involved in the lessons and feel safer, resulting in more depth. Encourage daily care staff's participation by providing basic information about palliative care and practising with cases they know. Continuously informing stakeholders (daily care staff, other professionals, management, family) increases the visibility of the project and stimulates involvement in project activities.	
Maintenance	**Facilitators**	**Barriers**
1. Innovation characteristics		
2. Outer setting	Networking with organisations stimulates information exchange and facilitates maintenance of the tools. New funding possibilities facilitate the maintenance of activities within the care service to improve palliative care.	
3. Inner setting	There is a dedicated and enthusiastic team of people in the care service with palliative care expertise who are committed to improving palliative care and willing to monitor palliative care and initiate new activities. An electronic documentation system, with information about palliative care experts who can be consulted, palliative care policy, tools and guidelines, that makes information in the care service easily accessible to professionals. Palliative care and the possibility for someone to live in the care service until the end of life are part of the care service's vision, policy and plans. A communication infrastructure has been set up for staff to keep in touch with one another and inform each other.	If there is no structural place in the electronic patient records for the recording of serious illness, it is not self-evident that attention will be paid to how a person with intellectual disabilities copes with illness and loss. Palliative care competencies are lost due to the departure of trained personnel, which makes it difficult to maintain good palliative care. Other duties and responsibilities distract daily care staff from keeping the focus on palliative care.
4. Characteristics of individuals	The continuity of activities is facilitated if key decision-makers (such as a director) recognise the importance of a good palliative care policy and good palliative care. Designated people who are committed to palliative care and who are willing to continue the activities aimed at providing palliative care. Sometimes this may be one of the daily care staff, sometimes a palliative care consultant (usually not a team member but a member of the nursing staff), sometimes both. Daily care staff are motivated to further improve palliative care.	
5. Process	There are plans for new activities after the end of the formal implementation period.	

Appendices

Appendix 1   *The intervention: aims, tools and participatory action research method*

The aims of the intervention was to improve palliative care, specifically: (1) To embed palliative care better in organisational policy; (2) To increase the competencies of professionals in palliative care; (3) To improve the quality of care for people with ID who stay in ID care services.
Toolbox The toolbox contained six evidence-based tools (Bekkema et al. 2014, 2015ab, 2016; De Veer et al., 2017): (1) Roadmap for identifying and analysing palliative care needs (Giesen et al., 2018); (2) Specialist palliative care consultant - the introduction of a professional with specific expertise in palliative care who can be consulted by other professionals for coaching, support and advice (HAN, 2023); (3) STEM or 'Dying your way' - a method and training programme to facilitate communication about dying and care preferences at the end of life (Jansen & Donders, 2023); (4) Decision-making about medical interventions and the best place for palliative care - a stepwise method for making shared and considered decisions (Bekkema et al., 2023a); (5) 'Caring until the last day' - an easy-to-read book for professionals with an introduction to palliative care, relevant topics, suggestions and case descriptions (Bekkema et al., 2023b); (6) 'What do I want? What if I don't get better…?' - a workbook for discussing and recording people's wishes (Bekkema et al., 2023c).
Principles of participatory action research (based on ICPHR, 2013) Participatory action research is locally situated in the reality of daily life and work. Various services and teams within an ID care service may undergo different processes. Participation is the defining principle throughout the process, and all whose life or work is affected by palliative care should be involved. All participants have control over the research process, and there is no principal investigator. Participants are equal to each other and empower one another to contribute to the process. The process follows a spiral pattern in which participants plan, do, check, act (PDCA) in repeating cycles.
Duration of the intervention period ID care services started the participatory action research in September 2020. The intervention lasted 30 months. The evaluation study took place from June 2020 to June 2023.
General elements of the participatory action research method The participatory action research method encompassed eight general elements: (1) Professionals of at least two groups per ID care service participated in the project. (2) Participatory action research group: Each ID care service formed a group consisting of professionals involved in palliative care, management, people with ID and their families. (3) Baseline assessment (pre-test): Each ID care service started with an assessment of how palliative care was organised and perceived by professionals within the teams. This assessment involved a self-evaluation tool to gain insights into the organisational palliative care policy (Jansen et al., 2018) and an online survey among professionals to assess the perceived palliative care policy, competencies and quality. The self-evaluation tool consisted of a medical file review and questions about nine core elements of palliative care, of which a standard had been previously formulated and approved in the Quality Framework for Palliative Care in the Netherlands (Boddaert et al., 2017) (4) Pre-implementation planning: Based on the results of the baseline assessment (element 3), each ID care service set goals, chose at least two tools from the toolbox, and identified and involved stakeholders. ID care services were asked to identify factors that facilitate or hinder implementation and incorporate them into an implementation plan. (5) Implementation and sustainability: Each ID care service implemented the selected tools using the PDCA (Plan-Do-Check-Act) cycle. Step by step, goals were addressed, while making changes if necessary. This repeating cycle produced a spiral pattern of continuous quality improvement. (6) Participation in a regional palliative care network, i.e. a formal partnership of organisations (e.g. nursing homes, hospitals, hospices, community care and psychiatry) involved in palliative care in a specific region: ID care services were encouraged to join a partnership. Participation is considered fruitful since organisations can learn from and consult each other. (7) Exchange of information, ideas and experiences: The ten ID care services participated in six national meetings, facilitating the exchange of information and the sharing of ideas and experiences. A website was also available for participants to access information, find contact details and engage in discussions.
(8) Endline assessment (post-test): At the end of the funded implementation period, the baseline measurements were repeated to evaluate the changes that occurred.