Implementation and sustainment of palliative care innovations within organizations for people with intellectual disabilities: A multi-method evaluation

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ABSTRACT

Background: Providing palliative care for people with intellectual disabilities (ID) is challenging and professionals caring for people with ID often received limited training in palliative care.

Objective: To gain insight into the implementation and sustainment of palliative care innovations, originally developed for the general palliative care population, in organizations for people with ID.

Methods: A multi-method evaluation was performed of nine implementation projects concerning three palliative care innovations. Methods included document analyses of project proposals and reports, group interviews with project managers and professionals, and a questionnaire completed by projects managers. Factors influencing implementation were categorized using the Consolidated Framework for Implementation Research.

Results: The three innovations were applicable in organizations for people with ID, although some adaptations had been made. Implementation activities were focussed on training, cooperation and dissemination of the innovation. Influencing factors were mostly related to the inner setting of the organization, including management support

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and available resources. Five of the nine project managers were not sure if the innovation was sustained properly within their organization.

Conclusions: Innovations originally developed for use in the general palliative care population can be successfully implemented in organizations for people with ID, although adaptation to the specific care setting might be necessary.

Introduction

The life expectancy of people with intellectual disabilities (ID) is increasing.[1-3] As a result, people with ID are increasingly experiencing life-threatening conditions that are particularly likely to affect older people, such as chronic cardiovascular diseases, chronic lung diseases, cancer and dementia.[3] The World Health Organization[4] defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".

According to the Dutch Palliative Care Quality Framework,[5] palliative care should be provided for "patients and their families facing the problems associated with a life-threatening illness or vulnerability". People with ID are vulnerable in many ways (both physically and psychosocially) and often have to deal with multiple and complex health problems throughout their lives. People with profound intellectual disabilities and multiple disabilities in particular are susceptible from a young age to life-threatening somatic conditions and therefore may require palliative care from birth on.[6]

Identifying palliative care needs and adequate provision of palliative care for people with ID can be challenging, because people with ID often experience difficulties in understanding their illness and are not always able to verbally communicate their feelings and symptoms to others.[7-9] This makes it hard for professionals to assess and discuss the wishes and needs of people with ID.[10]

Moreover, professionals caring for people with ID are often social workers, rather than nurses or physicians, who have no or limited training in palliative care.[11,12] In addition, training material and innovations on palliative care geared to professionals providing care for people with ID are scarce.[13-15]

A final challenge concerns the joint provision of palliative care by relatives and care staff. This can be challenging if perceptions of what ensures good end-of-life care differ between staff and relatives. However, if professionals and relatives agree about care goals and cooperate, this can greatly enhance the quality of care and joint interpretation of symptoms.[12]

Although there are specific challenges, many of the palliative care needs of people with ID are similar to those of the general population. Therefore, we expected that e possibly with some adaptations e palliative care innovations that were originally developed for use in the general population, might also be helpful for improvement of palliative care and pro-active communication about needs for future care (advance care planning) in people with ID.

In the Netherlands, a variety of palliative care innovations were implemented in the National Quality Improvement Programme for Palliative Care between 2012 and 2016.[16] Nine of the 76 implementation projects within the framework of this national programme were carried out in organizations providing residential care for people with ID.

In general, it is important for successful implementation of care innovations to consider the innovation's fit with the specific patient population and context.[17,18] In addition, successful implementation is influenced by factors described in the Consolidated Framework for Implementation Research (CFIR): the characteristics of the innovation, the outer setting, the inner setting, the individuals involved and the process of implementation.[19,20]

To our knowledge, no research has been done regarding factors influencing the implementation and sustainment of palliative care innovations in organizations providing care for people with ID. This paper aims to give insight into how palliative care innovations, originally developed for the general

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population of palliative care patients, can be implemented and sustained in care organizations for people with ID. The research questions are:

1. How were the palliative care innovations implemented in organizations providing care for people with ID, within the framework of the Dutch National Quality Improvement Programme for Palliative Care?

    a. What were the planned implementation activities and to what extent were these plans realized in the project period of one year?
    b. What adjustments to the innovations were needed to enhance implementation specifically in care organizations for people with ID?

2. What facilitators and barriers influenced implementation of the palliative care innovations in care organizations for people with ID?
3. To what extent were the innovations sustained within the organizations one to three years after the start of the implementation, and which factors played a role in the sustainment?

Materials and methods

Design

A multi-method evaluationwas conducted, involving document analyses of the project proposals and final reports, qualitative group interviews and a structured questionnaire completed by project managers. These project managers worked for the participating organizations and coordinated the implementation projects in question. The various methods complemented each other to provide a more in-depth understanding of the implementation and sustainment process of palliative care innovations.[21-23]

Context

This evaluation study was a sub study within the broader evaluation of the National Quality Improvement Programme in the Netherlands.[16] During the programme period (2012e2016), health care organizations were invited to choose a specific innovation and to submit a project proposal to the Netherlands Organization for Health Research and Development. Nine project proposals of care organizations for people with ID were accepted and received a grant to implement the innovation. The formal project period lasted one year, all nine projects started between 2014 and 2016. The questionnairewas completed by project managers in 2018; this was three years (n ¼ 1), two years (n ¼ 2) or one year (n ¼ 6) after the end of the formal project period.

The participating organizations provided residential care for people with ID living in group homes in the community or in largerscale supported accommodation facilities. Professional staff working onsite in these accommodations were mostly educated as social workers or nurses. The palliative care innovations chosen in the projects concerned:

   - a tool ('Signal Box') to identify palliative care needs, or
   - the introduction of a specialist palliative care consultant, or
   - a communication intervention ('Dying Your Own Way') to support the communication between patients, their families and professionals about the patient's wishes and needs at the end of life.

The three above-mentioned care innovations were implemented in respectively three, four and two implementation projects in organizations for people with ID. For more details about the palliative care innovations, see Table 1.

[Tabel 1]

Data collection and analyses

Multiple sources of data were used to answer the research questions (see Table 2):

(a) Document analysis of project proposals and final reports on the implementation projects written by the project manager was conducted. A structured extraction form developed by the authors of this study was used to extract relevant data from the documents, with topics concerning general characteristics of the organization, implementation activities and influencing factors.. The project proposals described the aim of the project and planned implementation activities. The final reports described to what extend the aim had been achieved and the implementation activities were realized, and which facilitators and barriers played a role.

(b) Qualitative group interviews (n ¼ 9) with the project managers and other professionals involved in the innovation, such as nurses, social workers, palliative care specialists and managers, were conducted for each project separately one year after the start of that specific project. A topic list was used to guide the interviews, concerning questions about whether the innovation was implemented as planned, what the facilitators and barriers were for the implementation, which implementation activities were carried out and whether the project managers and other stakeholders felt implementation had been successful and effective. The group interviews took around 1 h, were audio-recorded and transcribed verbatim. The group interviews were analysed qualitatively with the aid of the software package MAXQDA, using the principles of thematic analysis.[24] In a first step, the three authors (AF, AdV, and HV) read all documents to become familiar with the data. Then, in a second step, the interview transcripts were inductively coded by two authors independently (AF and HV or AdV and HV). Subsequently, these codes were grouped and categorized with the aid of the five main constructs of the CFIR19: characteristics of the innovation (the core components and adaptable elements, structures and systems related to the innovation), the outer setting (the context outside the organization), the inner setting (the context within the organization), the characteristics of the individuals who implemented the innovation, and the implementation process. The codes were linked directly to the content of the interview fragments. In the third step of our thematic analysis, the codes and their assignment to the constructs of the CFIR were discussed by all authors in order to reach consensus. After that, the main themes related to the codes were reviewed and compared, taking account of the coded material in the interview transcripts and comparing transcripts. In step five, the names and specifics of each theme were further refined and defined in a discussion with all the authors. In the last step, the themes, content and associated quotations were reported in this paper.

(c) Questionnaire completed by project managers (n ¼ 9) in 2018, one to three years after the implementation project. Seven project managers completed the questionnaire online, while the two other project managers preferred to complete the questionnaire in a telephone interview. The first part of the questionnaire included closed-ended questions about the sustainment of the innovation: "Is the innovation still being applied?" ("yes", "partly", "no"), and "Is the innovation well implemented and sustained?" ("yes", "I'mnot sure, but I do think so", "I'mnot sure, but I don't think so", "no"). Project managers also indicated if they thought the innovation currently had added value for patients, family or professionals ("yes", "no"). At the end of the questionnaire, two open-ended questions were included about the barriers and facilitators for sustaining the innovation. The answers were coded according to the codes developed from the group interviews. The information from the questionnaire was analysed descriptively using STATA version 15.

[Tabel 2]

Results

Implementation process of palliative care innovations

Planned and realized implementation activities

The first research question concerned planned and realized implementation activities and the adjustments made to the innovation. The planned and realized implementation activities consisted of training for professionals, cooperation with other organizations and other implementation activities, mainly focussing on dissemination of the innovation (see Table 3).

All nine projects planned and realized training as part of the implementation process. The number of professionals who received training varied between the implementation projects, depending in part on the kind of innovation. In the projects implementing the Signal Box, between 17 and 49 professionals attended workshops and a train-the-trainer course; in the projects implementing the Dying Your Own Way communication intervention ten professionals were trained; and in the projects introducing a specialist palliative care consultant, between two and six professionals completed nine training days to become a palliative care consultant.

In addition, all nine projects planned activities aimed at cooperation with other organizations, such as other care organizations for people with ID or organizations within a palliative care network. In most projects, cooperation was successfully realized. However, two organizations (implementation projects 2 and 3) that planned to work together did not succeed in doing so. In implementation project 6, contact was made with a hospital, but this had not yet resulted in actual cooperation.

All projects also planned for and realized other implementation activities, in full or in part. These activities mainly focussed on dissemination of the innovation within their organization by making use of internal communication networks and social media, distributing flyers, and organizing meetings to inform professionals or other stakeholders about the innovation. Other implementation activities concerned embedding the innovation within existing workflows or systems, appointing opinion leaders who were responsible for the use of the innovation, and reflecting on or evaluating the use of the innovation.

Adjustments to the innovation

In five of the nine implementation projects, there were plans to further develop the innovation to align it with the specific needs of people with ID. However, according to the final reports, only two implementation projects managed to do so in practice, see also Table 3. In implementation project 2, in which the Signal Box was implemented, an instrument for recognizing palliative care needs specifically in people with ID (PALLI[25,26]) was incorporated in the training for professionals. In implementation project 8 regarding the Dying Your Own Way communication intervention, short movies about palliative care specifically for people with ID were developed and used as a visual tool in training.

Facilitators and barriers for implementation

The second research question focussed on facilitators and barriers for implementation. Various influencing factors for implementation were identified, see Table 4. In the text, the influencing factors are marked in italics and further explained.

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Influencing factors: characteristics of the innovation

Five characteristics of the innovation influence the implementation process: the applicability of the innovation, the quality of the materials and training, the fit of the innovation with the Influencing factors: characteristics of the innovations Five characteristics of the innovation influence the implementation process: the applicability of the innovation, the quality of the materials and training, the fit of the innovation with the patient group, the complexity, and the costs of the innovation. The applicability, which is regarded as the degree to which the innovation has been found useable and valuable in practice, was considered to be high in all implementation projects. As an example, a participant talking about the Signal Box said that the instrument could be widely used within the organization and was found to be valuable in practice by different professionals:

There's an awful lot of enthusiasm, in particular about the practical applicability of the Signal Box. There's not really anyoned at least from the feedback we've had d who has said they can't do anything with this or that it isn't remotely appropriate. The daily care professionals themselves, the supervisors, also find it really easy to use d of course it is very concrete. You just ask questions and you're able to give an answer. But we also see that the group around themdthe doctors and behavioural specialistsdalso find it very valuable. (Source: interview, implementation project 3, Signal Box).

Secondly, the high quality of the materials and training facilitated implementation. For example, project managers and professionals perceived the design, content and presentation of the materials in the Signal Box to be of high quality. The communication intervention Dying Your Own Way was found to be of high quality because of its constructive content with an obvious start and end.

Nevertheless, barriers regarding the characteristics of the innovation were also mentioned. Regarding Dying Your Own Way, the focus on 'Dying' was mentioned as a factor obstructing implementation. Talking with people with ID and/or their relatives about ways of dealing with dying was perceived as too challenging and raw for some professionals, who rather preferred to talk about styles in how to live their remaining life. As one participant said:

That's why I do wonder sometimes whether it might help if you didn't call it 'dying' but 'styles of living' instead. Don't see it as palliative care but see it as … Because that's very challenging for supervisors. Whereas I knowfor sure that they could use it, shall we say. And that's difficult with the Dying Your Own Way method. To say, 'Right, we're going to spend a morning talking about styles of dying'. (Source: interview, implementation project 8, Dying Your Own Way).

A third influencing factor concerned the fit with the specific patient group. The lack of fit was experienced as a barrier because the innovations and corresponding training were not specifically developed for professionals caring for people with ID. Concerning the palliative care consultant training, some of the professionals involved said that the training focused too much on the medical dimension of palliative care. They missed information about how to deal with psychosocial and spiritual needs, and about their changing roles and responsibilities when providing palliative care for people with ID. Regarding the Signal Box, participants said that they missed specific information in the instrument about relevant symptoms for people with ID in the palliative phase such as epilepsy and auto-mutilation.

The complexity of the innovation was a fourth influencing factor for implementation. Professionals said they found it complex to determine when the innovation could be used, for example when the palliative care specialist can be consulted or at what moment in the illness trajectory or life course of an individual the Signal Box can be helpful, which was considered as a barrier for implementation. Also, the professionals who completed the training to become a palliative care consultant said it was challenging because they had little time available for their work as a consultant in addition to their regular work tasks. Furthermore, the Dying Your Own Way innovation was perceived as intensive due to the frequent meetings and workshops included in the training programme.

[Tabel 3]

The last influencing factor regarding the characteristics of the innovation was costs. High costs, for example associated with training for professionals as part of the implementation, hindered further implementation because not all professionals within an organization could be included due to financial limitations. A project manager said:

We would like to continue [the innovation]. But the costs of hiring the trainer are so high. (Source: interview, implementation project 9, Dying Your Own Way).

Influencing factors: the outer setting

Regarding the outer setting, two influencing factors werementioned: cooperation with other organizations and the national policy and incentives. Cooperation with other organizations was mentioned in all projects as a facilitator for implementation. Project managers found it important to learn from other organizations, and to share their own knowledge and expertise. They cooperated with other care organizations for people with ID, but also with other organizations or care settings, such as hospitals and regional palliative care networks. One participant said that, because the importance of palliative care for people with ID was widely recognized, she found organizations to be very willing to cooperate and share information:

Once I got involved with this and started searching the Internet and phoning people and sending them e-mails, saying 'Hey, I'm working on this and I hear you're doing whatever' … I e-mailed Person M because she's got a palliative unit in her organization, of course. I found there was an incredible willingness to share information. I have yet to speak to an organization that says, 'Well, we've developed this manual but you can't have it'. It's often a question of: 'Here it is, see what you can get out of it'. Precisely because everyone recognizes the importance of setting that care up well.(Source: interview, implementation project 4, specialist palliative care consultant).

[Tabel 4]

The need for cooperation also arose because caring for incurably ill people in the final stage of life was not everyday practice in the organizations involved. The organizations had relatively fewdeaths among people with ID and the participants explained they had little experience in supporting people with ID at their end of life. In order to increase the use of the innovation and develop expertise, organizations found it helpful to be able to work together with other organizations for people with ID.

Other facilitating factors for the implementation that were mentioned concerned national policy and incentives. The implementation projects' organizers submitted an application to participate in the National Quality Improvement Programme for Palliative Care and, if accepted, were granted money to implement the innovation. One participant said that the participation in the National Programme and the associated obligations, for example writing a project proposal, helped in starting up the implementation and boosted implementation within the organization:

The National Quality Improvement Programme for Palliative Care gives a really good basis for initiating genuine change and improvement. It gives you not only a temporary financial boost, but also a real plan, not just some optional project proposal. (Source: interview, implementation project 6, specialist palliative care consultant).

Influencing factors: the inner setting

Most influencing factors mentioned by participants concerned the inner setting of the organization. First of all, according to the participants, the involvement of the board and management in the project was necessary to start and facilitate the implementation in the

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organization. Project managers mentioned that the board or management endorsed the importance of implementation, which was seen as a facilitating factor for implementation. Also the high priority given to palliative care within an organization, often due to a growing number of ageing or frail people with ID, was a facilitating factor for implementation. In some of the organizations, palliative care was explicitly mentioned in their vision and policy documents and implementation was therefore supported.

A third influencing factor regarding the inner setting which came up in most implementation projectswas the integration of the innovation in existing workflows or systems. Thiswas seen as another important facilitator. Integrating the innovation was done in several ways, for example by inserting the Signal Box instrument in the organization's reporting system, inviting the palliative care specialists to attend regular team meetings, or including Dying Your Own Way in existing training opportunities.

A fourth influencing factor was the degree to which the organization had self-directing teams rather than a hierarchical structure. This was mentioned as a barrier for implementation. If professionals in self-directing teams were not motivated or set other priorities, it was found to be difficult to stimulate the use of the innovation. One participant said that the absence of a clear leader who tells others what to do hindered implementation:

What we do see … Because we also switched to self-directing teams, we lost an entire stratum of team leaders. And then you do see that sometimes you simply, well, miss someone you can speak to in some cases. And sometimes that resolute person who says, 'Hey, this is what we agreed, so we should stick to that'. (Source: interview implementation project 6, specialist palliative care consultant).

A fifth influencing factor related to the organization was multidisciplinary collaboration. Participants explained that in palliative care for people with ID, different professionals were involved, such as daily caregivers, physicians, specialized physicians for people with ID, behavioural specialists and spiritual caregivers. Involvement of a multidisciplinary group of professionals, and good and frequent communication and collaboration between these professionals, boosted the use of the innovation and was considered as a facilitating factor for implementation.

Other influencing factors were organizational instability, for example because of personnel changes or reorganizations, and insufficient available resources such as time, money and materials. These factors were mentioned in all projects as barriers for implementation. Project managers explained that it was important to choose the right moment to start the implementation, a moment when there is sufficient time available.

A final influencing factor concerning the inner setting was needs and characteristics of clients/relatives. Participants explained that for some people with ID and close family members, it was difficult or too challenging to talk about palliative care and death, because the need for palliative care was not always understood or accepted. This was mentioned as a barrier for the use of innovations, which focussed on pro-active communication about palliative care needs and discussing wishes around the end of life. However, participants also said that some relatives of people with ID did see the importance of talking about wishes and needs for future care, which boosted the use of the innovation:

I sat in on a meeting and relatives were there too. The care professionals had the attitude of 'Right, we'll tackle this topic'. So at some point they started talking about death, whereas the client wasn't anywhere near that stage. At first, it was a bit like, 'OK, what's happening now?' But there came a point where the relatives saw the benefit of reflecting on this already. Then they asked us about the wishes booklet: had we actually filled it in, well we really should do that. So they came up with it themselves and starting discussing things with us. (Source: interview, implementation project 7, specialist palliative care consultant).

Influencing factors: characteristics of professionals or teams

Three influencing factors were found regarding the characteristics of the professionals or teams. Motivation for participation among professionals and teams was an important facilitating factor for implementation. The project managers mentioned in the interviews that some of the teams involved had already seen palliative care as important before the implementation project, and therefore those professionals were interested in becoming involved and motivated to participate in the training and use the innovation. At the start of the project, the awareness of the importance of palliative care was less clear in other teams, which was seen as a barrier for implementation, for example because professionals held the opinion that the people they cared for did not (yet) require palliative care. One team leader said that, while they cared for ageing people with ID, investing time in palliative care was not seen as a priority:

Right, I can only speak formy own teambut it wasn't feasible for me to tackle it with the entire team in one go because it simply costs too much time. If we already need three half-days for training in it, let alone how you train a team that doesn't have much affinity with the subject … the target group isn't yet big enough, shall we say. Our group is getting older but not yet to the extent that you think, 'Well, we really need this'. (Source: interview, implementation project 1, Signal Box).

Moreover, professionals in care organizations for people with ID were not always experienced in palliative care, and therefore felt they lacked knowledge and skills regarding palliative care or felt unsure about using the innovation, which was another barrier for implementation. Participants explained that professionals found it difficult to discuss end-of-life issues, and they required experience to feel comfortable and secure.

Influencing factors: the implementation process

Five influencing factors were mentioned regarding the implementation process. First of all, planning and clarity of goals were often mentioned as facilitators. Project managers said that it was important to make a clear implementation plan before the start of the implementation, together with the professionals involved, which the management or board also approves and which clearly describes the aim and goal of implementation within the organization.

During the implementation process, another important facilitator was announcing and stimulating the use of the innovation. Various dissemination strategies and materials were used to promote the implementation, such as distributing flyers, organizing meetings, mentioning the innovation in newsletters and making use of social media. A project manager explained the importance of spreading information about the innovation:

I notice that it helps. Even a small piece of information on our webpage. Not everybody will read it, but at least the people who do are informed. The same text is spread in the newsletter or send to the medical consultation board. So we use existing channels to make people enthusiastic. (Source: interview, implementation project 1, Signal Box).

A third influencing factor was involving the right people in the implementation process. This was done in implementation projects in different ways. One project leader of an organization that implemented palliative care consultants said that professionals had to apply to be included in the training and they made use of strict selection criteria. In another implementation project concerning the Signal Box, the team manager decided which professionals they wanted to involve and how. Moreover, having an 'opinion leader' or professional who was responsible for implementation was a fourth influencing factor, seen as an important facilitating factor in boosting the use of the innovation. One participant even said that the success of the implementation depended on the opinion leader:

That has been a pitfall in the sense that, well, the whole process of implementing it in the home depends crucially on the opinion leader who is in charge of doing it.Well, some manage just fine and others find it more difficult. (Source: interview, implementation project 1, Signal Box).

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The last influencing factor related to the implementation process, reflecting on and evaluating the use of the innovation with the professionals involved, facilitated implementation. Participants found it helpful to know if and how professionals made use of the innovation in practice, in order to find out if changes were required to the implementation process.

Sustainment of innovations

The third research question focused on the sustainment of innovations within the organizations. According to the questionnaire completed by the project managers (n ¼ 9), all organizations were still using the innovation one to three years after the start of the implementation. Also, they all believed that the innovation currently had added value for the people with ID and their families, and professionals. According to the project managers, people with ID more often died in their preferred place of death, there was more attention for palliative care and advance care planning within the organization, professionals gained more knowledge on palliative care, communication improved, and there was more cooperation with other professionals and other organizations.

On the other hand, when the project managers were asked if they felt the innovation was well implemented and sustained within their organization, five of the nine were hesitant. One project manager responded "I'm not sure, but I don't think so", four project managers answered "I'm not sure, but I think so", and four project managers answered "Yes".

Barriers for long-term sustainment mentioned by project managers were lack of involvement of the board and management and insufficient available resources (inner setting), and not having an 'opinion leader' or professional who is responsible for implementation (process). According to the project managers, everyone was still enthusiastic about the innovation after one to three years. Professionals were convinced of the innovation's applicability and its value in practice (innovation characteristics), which was an important facilitator for sustainment. Other facilitators for sustainment mentioned in the questionnaires were: cooperation with other organizations (outer setting), the priority given to palliative care within the organization (inner setting), and the professionals' motivation to use the innovation (characteristics of individuals or teams).

Discussion

This study described how palliative care innovations were implemented in organizations for people with ID. Training of professionals, cooperation with other organizations and dissemination of the innovation were important activities when implementing palliative care innovations. The innovations, originally developed for use in the general population of palliative care patients, were found to be applicable in care organizations for people with ID, although some adaptations had to be made. When making use of an existing innovation, it is important to consider how an innovation can be adapted to make it more suitable for a particular population or a better fit with the organization.[17,27] Two of the nine projects did indeed adapt the innovation, and in almost all projects there were plans for adaptations. The one-year implementation period might have been too short to adapt the innovation to fit the specific needs of people with ID, which requires expertise and practice.[28]

This paper also described facilitators and barriers for implementation. Categorized according to the Consolidated Framework for Implementation Research, most influencing factors concerned the inner setting of the organizations. As is the case in the implementation of palliative care innovations in other settings,[29,30] it was found to be important to have support from management, to have sufficient resources available and to integrate the innovation in existing workflows or systems. Moreover, the quality and applicability of the innovation and having an 'opinion leader' or professional who is responsible for implementation are important influencing factors.

Some influencing factors for implementation were related to the specific care setting of people with ID. The limited palliative care knowledge and skills of professionals working with people with ID,

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which has been highlighted in previous research,[9,11,28,31e33] was found to be a barrier for the use of the innovation. It is also known that professionals avoid the end of life as a topic and do not know how to talk about it. Therefore, it is very important to include training for professionals providing care for people with ID as part of the implementation of palliative care innovations. For example, professionals should be trained in how to inform people with ID about dying and death and in proactively discussing wishes and needs (advance care planning[34,35]). Moreover, cooperation with other organizations for people with ID was a facilitating factor for implementation and sustainment. Despite growing incidences of the life-threatening illnesses that affect older people, it is still the case that relatively few people in care organizations for people with ID need palliative care.[36] The European Association of Palliative Care White Paper about consensus norms for palliative care for people with ID also states that the on-going exchange of experiences and expertise and sharing best practices is necessary to ensure that people with ID have their palliative care needs met.[37]

Lastly, this paper focussed on the long-term sustainment of the palliative care innovations. After one to three years, the innovations were still used in all the ID organizations involved. Although project managers were convinced of the applicability of the innovation and its value for practice, five of the nine project managers were unsure whether the innovation was well implemented and sustained within their organization. Previous research also shows that effective implementation is challenging[38] and even when innovations are well designed, contextual factors may hinder implementation and sustainment of an innovation.[17,39] Barriers for long-term sustainment found in our study were lack of support from management, insufficient resources and the absence of an 'opinion leader'. It is recommended that organizations have resources available to sustain the future use of the innovation and appoint professionals for a long term who can lead the implementation and further use of the innovation.

Strengths and limitations

This study has a unique focus on implementing and sustaining palliative care innovations in care organizations for people with ID and offers important insights for practice. The inclusion of multiple care organizations, different palliative care innovations and multiple data sources (document analysis, interviews, and a questionnaire) leads to a comprehensive picture of influencing factors for implementation and sustainment and improves the generalizability of the results. Moreover, this study contributes to the implementation of innovations concerning timely identification of palliative care needs and pro-active communication about wishes for future care (advance care planning), which is important for high-quality palliative care. However, some limitations of this study should be noted.

One limitation concerns that the project reports were written by the project managers, and therefore these documents may represent a more positive image of implementation plans and achieved activities than was actually realized. In future research, additional observations on site during the formal project period could be conducted to gain more insight into the actual implementation process and its influencing factors. A second limitation concerns the fact that the questionnaire for project managerswas sent one to three years after the formal project period. This difference in timing of data collection may have caused variability in sustainment between projects. A final limitation is that it remains unknown how people with ID and their relatives experience the palliative care innovations and whether they think that the implementation of the innovation in question has improved palliative care.

Conclusions

This study shows that palliative care innovations originally successfully implemented in care organizations for people with ID. The three palliative care innovations were found to be applicable, although adaptation to the specific setting might be necessary. Training for professionals,

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collaboration with other organizations and dissemination activities are important elements when implementing palliative care innovations. Comparable to other healthcare settings, most factors influencing implementation concern the inner setting of the organization; they include having support from management and integrating the innovation in existing workflows. Organizations should have resources available to sustain the future use of the innovation and they should appoint 'opinion leaders' who are responsible for the implementation.

Funding

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Voss, H., Francke, A.L., Veer, A.J.E. de. Implementation and sustainment of palliative care innovations within organizations for people with intellectual disabilities: A multi-method evaluation. Disability and Health Journal: 2021, 14(2), 101049

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Tabels

Table 1   Description of the palliative care innovations.)

Palliative care innovation	Description
Signal Box	The Signal Box consists of an instruction and action plan, worksheets and information for care professionals about assessing palliative care needs and symptoms and about implementation of the tool. The aim of the Signal Box is to help the professional identify palliative care needs and articulate those needs, to strengthen cooperation with colleagues in this regard, to pro-actively communicate with others about palliative care needs and symptoms (advance care planning), and to meet the wishes and needs of the patients. Professionals learn how to use the Signal Box in workshops and a train-the-trainer course.
Specialist palliative care consultant	A specialist palliative care consultant spreads knowledge, methodologies and facilities related to palliative care within an organization. Professionals receive training to work as a specialist palliative care consultant within their organization. The training to become a specialist palliative care consultant consists of nine training days, with a total study time of 200 h. The training focusses on knowledge about palliative care, communication, palliative symptoms, coaching, spiritual care and ethical dilemmas.
Dying Your Own Way (in Dutch: 'STerven op je Eigen Manier' (STEM))	Dying Your Own Way is a communication intervention to accelerate expertise, to create awareness of the diversity of patients' wishes and needs at the end of life, and to improve professionals' ability to communicate pro-actively with patients and relatives about wishes and needs at the end of life. Dying Your Own Way involves information books and a card game for professionals, and a workbook for patients and relatives about wishes and needs related to the end of life. The innovation is supported by training meetings, workshops, and an e-learning course for professionals.

Table 2   Overview of information sources for each research question.

Research question	Information source
1. How were the palliative care innovations implemented in organizations providing care for people with ID, within the framework of the Dutch National Quality Improvement Programme for Palliative Care?	- implementation plans written by the project manager - final reports of the implementation projects written by the project manager - group interviews with project managers and other professionals
2. What facilitators and barriers influenced implementation of the palliative care innovations in care organizations for people with ID?	- final reports of the implementation projects written by the project manager - group interviews with project managers and other professionals
3. To what extent were the innovations sustained within the organizations one to three years after the start of the implementation, and which factors played a role in the sustainment?	- final reports of the implementation projects written by the project manager - group interviews with project managers and other professionals - online questionnaire completed by project managers

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Table 3   Overview of the implementation projects, setting, and planned and realized implementation activities.

Implementation projects		
Project number, innovation and setting	Planned implementation activities	Realized: yes, partly, no
1. Signal Box: a tool to identify palliative care needs *Implementation project in one location of an ID care organization which provides care for ageing people with ID*	*Training:* Provide training for 58 professionals with different backgrounds to work with the innovation. *Cooperation activities:* Results will be shared with various palliative care networks. *Other implementation activities:* - A protocol for using the innovation will be made. - The innovation will be part of regular team discussions.	*Partly:* 49 professionals were trained. *Yes* *Yes*
2. Signal Box: a tool to identify palliative care needs *Implementation project in a care organization providing residential care and support for people with ID*	*Training:* Offer training for 20 care staff who provide palliative care for people with ID throughout the organization. *Cooperation activities:* Working together with another ID care organization and the organization that developed the Signal Box. *Other implementation activities:* - An instrument to signal palliative care needs for people with ID will be added to the Signal Box. - A process evaluation will be conducted among participating professionals to check if changes are required.	*Partly:* 17 professionals were trained. *Partly:* Cooperation with another ID care organization was not realized. *Yes*
3. Signal Box: a tool to identify palliative care needs *Implementation project in three teams who provide care for ageing people with ID (aged ≥50) within an ID care organization*	*Training:* Plan to train 38 professionals to work with the innovation. *Cooperation activities:* Working together with another organization to develop an addition to the Signal Box focussing on palliative care needs of people with ID. *Other implementation activities:* - A kick-off meeting will be organized three months after the start of the project. - Knowledge about signalling palliative care needs will be spread throughout the organization.	*Yes* *No:* Cooperation with another ID care organization was not realized. *Yes*
4. Introduction of a specialist palliative care consultant *Implementation project in an organization providing care for people with ID, people with psychiatric disabilities and nursing-home residents*	*Training:* Three professionals working within the organization will be trained to become a palliative care consultant. *Cooperation activities:* Plan to work together with other organizations for people with ID. *Other implementation activities:* - A guide will be developed specifically for providing palliative care for people with ID. - Training will be developed for professionals and volunteers.	*Yes* *Yes* *Yes*
5. Introduction of a specialist palliative care consultant *Implementation project in two locations of an ID care organization providing residential care and support*	*Training:* Four professionals will be trained to become a palliative care consultant. *Cooperation activities:* Cooperation between different locations of the organization, with the palliative care network, and with external experts. *Other implementation activities:* - A kick-off meeting will be organized in both locations and an advisory committee will meet five times during the implementation project. - Palliative care consultants will be working throughout the organization.	*Partly:* One trained palliative care consultant resigned. *Yes* *Yes*
6. Introduction of a specialist palliative care consultant *Implementation project in three locations of an organization providing care for people with ID and people with psychiatric disabilities*	*Training:* Six nurses will be trained as palliative care consultants. *Cooperation activities:* - The organization will work together with a foundation for palliative care and the palliative care network. - Cooperation will be established between the organization and palliative care teams in hospitals in the north of the Netherlands. *Other implementation activities:* - Palliative care policies and instruments used within the organization will be further developed. - A guide will be developed specifically for providing palliative care for people with ID.	*Yes* *Partly:* - Cooperation with the palliative care foundation and the palliative network was realized. - Contact with a hospital was made, but there was no cooperation as yet. *Partly:* - Palliative care was embedded in the organizational policy; the 'Palliative care' handbook was updated. - The guide for providing palliative care for people with ID was not developed. *Yes*

Table 3 (continued)

Implementation projects		
Project number, innovation and setting	Planned implementation activities	Realized: yes, partly, no
7. Introduction of a specialist palliative care consultant *Implementation project in one location of an ID care organization providing residential care and support*	*Training:* Two nurses will be trained as palliative care consultants. *Cooperation activities:* The organization will work together with palliative care networks. *Other implementation activities:* - Materials will be developed to introduce the palliative care consultants. - Training will be aligned with palliative care needs of people with ID in cooperation with other organizations.	 *Yes* *Partly:* - The palliative care consultants introduced themselves to the organization and made flyers. - Alignment of the training with palliative care needs of people with ID had not yet been realized.
8. Dying Your Own Way (in Dutch: STEM): a communication intervention *Implementation project in three locations of a care organization providing residential care and support for people with ID, people with non-congenital brain injury, people with physical disabilities and people with psychiatric disabilities*	Training: Ten professionals will be trained to work with the innovation. Cooperation activities: - The organization will work together with a palliative care network in the region and with the organization that developed the innovation. Other implementation activities: - The material will be modified to align it with the target group of people with ID. - A kick-off meeting, feedback and multidisciplinary meetings and an evaluation meeting with trained professionals will be organized.	Yes Yes Yes
9. Dying Your Own Way (in Dutch: STEM): a communication intervention *Implementation project in three teams within an ID care organization: a team of professionals who work with children with ID, a team of professionals who work with adults with ID, and a team of professionals who work with ageing people with ID*	*Training:* Three teams of professionals will be trained. *Cooperation activities:* - Cooperation will be established with other ID care organizations that implemented Dying Your Own Way. - Knowledge and experience of the implementation project will be shared with a foundation for palliative care and other relevant organizations. *Other implementation activities:* - A kick-off meeting, multidisciplinary meetings, and a final meeting will be organized. - Two opinion leaders will be appointed in each team. - Where necessary, the innovation materials will be adapted for people with ID.	*Partly:* Ten professionals participated in the training. Yes *Partly:* - Three meetings were organized: a kick-off meeting, an intermediate meeting, and a final meeting. - Opinion leaders were appointed. - The innovation materials were not adapted for people with ID.

Table 4 Overview of factors influencing implementation within the Consolidated Framework for Implementation Research constructs.

Characteristics of the intervention	Outer setting	Inner setting	Characteristics of professionals or teams	Process of implementation
-Applicability - Quality of materials and training - Fit with the target group - Complexity - Costs	- Cooperation with other organizations - National policy and incentives	- Involvement of board and management - Priority given to palliative care within organization - Integration of innovation in existing workflows or systems - Self-directing versus a hierarchical structure - Multidisciplinary collaboration - Organizational instability - Available resources - Needs and characteristics of clients/relatives	- Motivation for participation - Awareness of importance of palliative care - Knowledge and skills	- Planning and clarity of goals - Announcing and stimulating use of innovation - Involving the right people - Having an 'opinion leader' or professional who is responsible for implementation - Reflecting on and evaluating the use of the innovation