

TITLE OF MANUSCRIPT

Development, implementation, and evaluation of an Advance Care Planning program for professionals in palliative care of people with intellectual disability

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Abstract

In this paper we describe how an advance care planning (ACP) program was developed, implemented, and evaluated. Our aim was to improve ACP in palliative care for people with intellectual disability (ID). The program was based on ten competencies needed for ACP and was developed in a co-design process with people with ID, relatives and professionals. The program was implemented in six ID care organizations in the Netherlands and consisted of an information pack, a training course, and an implementation interview about implementing ACP. Professionals indicated that their competencies had improved, particularly regarding communication and the application of ACP as a standard element in palliative care practice. This program therefore seems helpful in training ID care professionals in the competencies needed for ACP.

Key words: Advance Care Planning, Palliative Care, Intellectual Disability, End of Life

Introduction

According to the World Health Organization (WHO, 2019), palliative care is “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”. There has been an increase in awareness of end-of-life and palliative care issues in recent years for people with intellectual disability (ID) (AAIDD, 2012; Tuffrey-Wijne et al., 2016).

The WHO definition on palliative care was extended in the Dutch Palliative Care Quality Framework to refer to “patients and their families facing the problem associated with a life-threatening illness or *vulnerability*” (Boddaert, Douma, Dijxhoorn, & Bijkerk, 2017). This extension means the definition also applies well to palliative care for people with ID. Previous studies have shown that a higher percentage of people with ID are susceptible to life-threatening somatic conditions (such as serious respiratory or cardiovascular conditions) — often from a relatively young age — than of people without ID (Evenhuis, Schoufour, & Echteld, 2013). People with profound intellectual and multiple disabilities are particularly susceptible (O'leary, Cooper & Hughes-McCormack, 2018; van Schrojenstein Lantman-de Valk & Walsh, 2008). They need care from birth that is geared to the quality of life, comfort and pain relief — in other words, palliative care. At the same time, people with ID are living longer on average because of improvements in medicine and their deaths are now often preceded by a period of illness and increasing vulnerability (Friedman et al., 2012; Coppus, 2013; Heslop et al., 2014).

Good palliative care requires Advance Care Planning (ACP) (Chan, Ng, Chan, Wong & Chow, 2019). ACP lets people define objectives and preferences for future medical treatments and care, discuss these objectives and preferences with relatives and care professionals, document them and revise them if necessary (Rietjens et al., 2017). The patient's wishes and needs are given priority and are recorded in their care plan. The care plan can also include advance care directives, which are legal documents recording preferences for a surrogate decision-maker and regarding life-prolonging

procedures (Hemsley et al., 2019). However, ACP is about more than just using an Advance Care Directive. The primary focus in ACP is on the process of communication about future physical, psychological, social and spiritual care needs, which goes beyond the completion of advance directives.

ACP helps put the person with ID in control and improves the quality of the palliative care (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014; Chan & Pang, 2010; Hammes, Rooney, Gundrum, Hickman, & Hager, 2012). It also increases the likelihood that the person with ID will receive care commensurate with their wishes and expectations (Heslop et al., 2014; McKenzie, Mirfin-Veitch, Conder, & Brandford, 2017). Relatives can provide support for the person with ID and they play an important role in ACP conversations and decisions (Voss et al., 2019b; Wagemans et al., 2012). Because possible scenarios are considered at an early stage, there are fewer unforeseen situations, which has a positive effect on the quality of life of the person with ID (Detering, Hancock, Reade, & Silvester, 2010; Heslop et al., 2014).

For ACP to work, the person with ID's wishes and needs have to be identified at an early stage. However, professionals often find it difficult to recognize the needs of individuals with ID, especially the need for palliative care (Voss et al., 2017; Vrijmoeth, Barten, et al., 2016; Vrijmoeth, Christians, et al., 2016; Friedman et al., 2012). This is partly because people with limited cognitive and communicative capabilities have difficulty expressing their wishes and needs (Heslop et al., 2014; Stein, 2008; Tuffrey-Wijne, Bernal, & Hollins, 2010; Tuffrey-Wijne, Bernal, Hubert, Butler, & Hollins, 2010; Tuffrey-Wijne & McEnhill, 2008; Vrijmoeth, Christians, et al., 2016).

Uncertainty among professionals about various aspects also serves as a barrier to ACP. It is not always clear who is responsible for taking the initiative for ACP as several different professionals may be involved in the care delivery, for example physicians, nursing staff, caregivers, social workers and behavioural experts (Voss et al., 2017). Furthermore, not all professionals know when to start ACP. What the medical condition means for an individual's future may also be unclear. Moreover, some professionals believe that ACP causes stress and anxiety among people with ID and/or their

relatives (Tilburgs et al., 2018; Voss et al., 2019a). They may feel uncomfortable with the emotions that ACP conversations can evoke and some professionals lack the communication skills to discuss emotionally charged subjects (Tuffrey-Wijne, Bernal, & Hollins, 2010; Winzelberg, Hanson, & Tulsky, 2005) and feel insufficiently equipped to provide good palliative care (Bekkema, de Veer, Albers, et al., 2014; Dunkley & Sales, 2014; Wiese, Stancliffe, Balandin, Howarth, & Dew, 2012).

As far as is known, no ACP program had been developed yet for professionals caring for people with ID. It is important to have a program geared to this specific group as people with ID and their relatives vary considerably in how they want (and are able) to consider the future (Heller & Caldwell, 2006; Wagemans et al., 2013). It is particularly difficult to determine what constitutes good quality of life for people with ID who have difficulty expressing themselves verbally (Wagemans et al., 2012). Consequently, care professionals need to use a sensitive, tailored approach in ACP for people with ID.

In the Netherlands, medical care is usually provided by general practitioners (GP) or specialized ID physicians. Specialized physicians who work with people with ID have three years of specialist training in the care for people with ID and are generally employed by an ID care service. Dutch GPs mainly care for people with mild ID living in the community, while specialized ID physicians largely care for people with moderate or severe ID, often in residential care. ID care staff in residential settings have varying backgrounds, but most are social workers or nursing staff (registered nurses or certified nursing assistants). The physician conducts the ACP conversations about the policy for medical care. However, social workers and nursing staff involved in the daily care of the person with ID also have an important role as they often conduct ACP conversations concerning the wishes and needs for future care.

Aim

The aim of this article is to provide information about the development, implementation and

evaluation of an ACP program, defined as an intervention program aimed at improving ACP for palliative care among people with ID.

We answer the following research questions:

1. How did the development process inform the ACP program content?
2. What were the perceived effects of the ACP program on professional knowledge, skills, and application of ACP competencies?

Method

Participants

People with ID, relatives, and professionals who participated in the development, implementation and/or evaluation of the ACP program, were recruited from six care organizations in the Netherlands, supporting people with mild to severe ID living in group homes with 24-hour care or in residential settings. Physicians who were employed at the ID care organizations functioned as recruiters in our study. Relatives and professionals involved in the development of the ACP program received a letter from the relevant ID care organization informing them about the aim and content of the project and asking them to sign an informed consent form if they agreed to participate in the file analyses and interviews ($n=63$), in-depth interviews ($n=15$) or co-design sessions ($n=12$). Other than being close to a person with ID in the palliative phase or to an individual with ID who had recently died after a period of illness, there were no inclusion criteria.

People with ID involved in the development of the ACP program were informed by their care staff about the project, and could then verbally provide informed consent if they wished to participate in the in-depth interviews ($n=5$) or co-design sessions ($n=3$). The inclusion criteria were: (a) having an understanding of the concept of death and dying; (b) having previous experience with being seriously ill and/or being hospitalized themselves; and (c) being at least 18 years old. We asked care staff to assess these criteria in their clients with ID. Because of ethical reasons, people with ID

who had a life-limiting illness or received palliative care themselves were excluded from participation.

A diverse group of 58 professionals who work in ID care took part in the ACP program, with between 7 and 13 from each care organization. Each organization was free to select and invite professionals for whom they felt it was relevant to participate. To evaluate the program, 53 of the 58 participants were sent a digital questionnaire (no e-mail address was available for five participants). The participants who evaluated the program (79%) consisted of physicians (n=19), social workers (n=8), nurses (n=6), and other professionals (n=9).

Procedure

The development, implementation, and evaluation of the ACP program consisted of five successive phases (Table 1). In *Phase 1* of the development process, the project group (the co-authors of this article) studied three sources (see also Table 1). The first was a systematic international review of what is known about ACP in the palliative phase for people with ID (Voss et al., 2017). Secondly, the project group used the results of patient file analyses and structured interviews with the associated relatives and professionals (Voss et al., 2019a). Thirdly, results from in-depth interviews with people with moderate ID, relatives and professionals (Voss et al., 2019b) were used as the basis for choices about what the ACP program should cover.

Phase 2 of the development process consisted of co-design sessions with people with ID, relatives and professionals. The aim of the sessions was to develop a program that both fits the needs of people with ID and their relatives, and fits with what professionals require and are able to do. We followed the principles of Experience-Based Co-Design (EBCD) (Bate & Robert, 2006; Robert et al., 2015). In EBCD, various groups of stakeholders collaborate closely for a relatively long period in developing an intervention. The participants' experiences and the discussion of these experiences constitute important input for the intervention. In this instance, the stakeholders were people with ID, relatives and care professionals.

Two co-design teams were formed. The first team consisted of two relatives of people with ID, two physicians, seven social workers and a pastoral worker from an organization that provides support and care for people with ID. This team met four times, with each session lasting 1.5 hours. The sessions with relatives and professionals were led by two project group members (AW and AV). The first co-design session focussed on the importance of ACP, what the right moment to discuss ACP is, who should take the initiative for ACP, and how the person with ID should be involved. In the second session, participants discussed the content of the ACP program. They also came up with the content of and approach for a conversation about ACP. In the third session, the broad outline of an ACP conversation as formulated in session two was further refined in the form of guidelines for such a conversation. Prior to the session, each participant had noted down the desired elements for such ACP conversation guidelines. They also discussed and gave feedback on an information folder about ACP for relatives. The guidelines for an ACP conversation were finalized in the fourth and last session. Participants also reflected on the topics that had arisen during the four sessions and used this to produce a summary of the components that the ACP program should contain.

The second co-design team consisted of three people with moderate ID from one ID care organization. This co-design team met three times. The aim of the sessions with this team was to highlight the views of people with ID on their future care and on talking about this so that their wishes could be taken into account in the ACP program. In the co-design sessions with people with ID, a fictional person (Anne) was introduced who was seriously ill. Illustrations forming a narrative were used. The participants with ID could use them to create their own story. Previous studies had shown this to be an approach that works well in allowing people with ID to talk about illness and death (Bekkema, de Veer, Hertogh, & Francke, 2016; Tuffrey-Wijne, 2013). In the first session, the participants discussed what they would find important if they were ill, what kind of assistance they would want and who they would want to deliver that assistance. In the second session, the participants discussed what people with ID need when they are ill and who they would want and be

able to discuss this with. The third session covered decisions about treatment. Some examples were given, such as whether or not to resuscitate someone or send them to the hospital.

In *Phase 3* of the development process, two project team members (AW and AC) worked with two external educational experts (specialized in communication training for medical professionals) to develop the training course within the ACP program, building on phases 1 and 2. The project team members and educational specialists met six times to discuss and design the training course.

In *Phase 4* of the project, the ACP program was implemented in six ID care organizations in the Netherlands. All these organizations had also been involved in the earlier project phases. The ACP program consisted of three elements: an information pack, two training sessions, and an implementation interview. The information pack included an article in Dutch about ACP (Hertogh, 2017) and various links to research publications about decision-making in palliative care for people with ID (Bekkema, de Veer, Wagemans, Hertogh, & Francke, 2014, 2015; Bekkema, Tuffrey-Wijne, et al., 2015) and to the Dutch Palliative Care Quality Framework (Boddaert et al., 2017), which describes what is important for high-quality palliative care. The information pack also contained practical tools: guidelines for ACP conversations, a palliative care checklist and a method for discussing the wishes of people with ID (Bekkema, de Veer & Francke, 2015).

The two training sessions formed the central component in the ACP program. Each session lasted two hours, with four weeks between the first and second session. The training was given by two ID physicians (project group members AV and AW) who have extensive experience of ACP among people with ID. The training sessions were held in the participants' own organization and were aimed at professionals with a range of backgrounds and tasks in the delivery of palliative care within a given organization. The idea behind this was to encourage closer cooperation between the different professionals within the organization. The training course also covered awareness of the different ways in which people deal with dying and what that means for communication, how to deal with ethical dilemmas and how to conduct discussions of wishes and needs. There was room for

participants to air their own dilemmas and discuss cases. The participants were given homework assignments for the period between the two sessions.

The third element of the ACP program, the implementation interview, took place one month to three months after the second training session in the organization in question. One of the trainers (AW) travelled to the organization for the implementation interview. The interviews were held with a number of core members from the group that had attended the training sessions, along with other stakeholders in the organization such as managers. The aim of the interviews was to discuss progress in implementing and continuing ACP within the organization. Other issues discussed in the interview were whether and how ACP was integrated in palliative care and whether further work was needed on improving the competencies for ACP.

In *Phase 5*, an evaluation was performed to determine whether the ACP program had led to an improvement in the competencies of the professionals who had taken part and in their use of ACP in their daily practice. To this end, the participants completed a digital questionnaire six months after the second training session.

Materials

Professionals who took part in the ACP program were sent a digital pre-structured questionnaire to evaluate the program. Participants were asked (1) how they felt about their command of the ACP competencies (rated on a 3-point Likert scale: ‘insufficient’, ‘sufficient’ or ‘good’), (2) if they felt their ACP competencies had improved after the ACP program (response options: ‘yes’ or ‘no’), and (3) if they felt they had become better at applying their ACP competencies in their work (response options: ‘yes’, ‘no’ or ‘don’t know’). A draft version of the questionnaire had previously been tested within the project group and on two social workers to check the comprehensibility and validity of the content. Differences between physicians and other professionals were tested for statistical significance using Fisher’s exact tests (in STATA, version 15). For the purpose of the analysis, the

responses to questions 1 and 3 were dichotomized by merging the responses ‘sufficient’ and ‘good’ (question 1) and ‘no’ and ‘don’t know’ (question 3).

Ethical Approvals

The research protocol was assessed and approved by the Medical Ethical Committee of Amsterdam University Medical Centre. Participation in the study was voluntary and all participants gave their informed consent. Research data were anonymized before analysis.

Results

Development of the ACP program

Based on the comprehensive study of the results from three sources (an international review, an analysis of patients’ medical files, and interviews in project phase 1), followed by discussions and reflections in the project group, the professional competencies (knowledge, attitudes and skills) that should be the focus of the ACP program were formulated. The co-design sessions (phase 2) with people with ID, relatives and professionals and consultations with educational experts (phase 3) were used to further develop the ACP program centred on these competencies. Table 2 provides a summary of the ten resulting competencies, the associated aspects and the specific sources showing the need for that competency. The form, content and competencies that each element of the ACP program covers is described in Table 3.

The sources show that it is important for professionals to recognize a need for palliative care in a person with ID (competency 1). They should also be aware that palliative care needs can change over time (competency 2). Not all professionals know what palliative care is and how to recognize this care need in people with ID. Professionals often do not act proactively or systematically in assessing changes in symptoms, problems and care needs. The various sources also suggest that professionals sometimes feel a reluctance to discuss the end of life and the care that will then be needed. Discussions about future care are often postponed until urgent problems arise or someone

becomes terminally ill. It is important for professionals to be prepared to talk about wishes, agreements and care needs (competency 3).

Professionals also appeared to keep few records on ACP decisions in medical files; if anything was documented at all, it was usually only medical end-of-life decisions, such as a non-resuscitation policy. Conversations about wishes and agreements about psychosocial or spiritual care were not documented. It therefore seemed necessary to include the reporting of needs and wishes concerning future care and decision-making (competency 4) in the ACP program.

Professionals said they did not always know who was responsible for ACP, what their own role or task was and whether or when they should initiate ACP. ACP should be applied as a process, in which it is important to know which tasks and responsibilities belong to whom (competency 5).

It also became apparent that people with ID often were not involved in ACP. Professionals found it difficult to involve people with ID. In the in-depth interviews, people with ID said they would like to talk with people they know well about their illness and future care, and they would like to receive personal attention and time when ill. In order to align the delivery of care with the needs and wishes of people with ID, they must be involved in important decisions, depending on their capabilities and needs (competency 6).

Another finding was that a range of different professionals are involved in ACP. ACP turns out to be teamwork in which it is important to maintain close contact with all the relevant individuals. If the interests of the person with ID are to be served, everyone should be heard. The interviewed professionals said that is why it is important for professionals to communicate openly with one another, relatives and the person with ID, and to take time to prepare for future scenarios (competency 7).

It transpired that ethical dilemmas often play a role in decisions on what constitutes good care and quality of life for people with ID; this was something that therefore required attention (competency 8). It also became apparent that panic situations can arise if there is no one with palliative care experience in a team. There is therefore a need to evaluate ACP processes and learn

from one another (competency 9).

Finally, it is important that professionals integrate ACP in day-to-day care. However, that is not yet standard practice. The lessons the professionals learn in the program need to become embedded in their daily practice (competency 10).

Evaluation of the ACP program

After the implementation, the ACP program was evaluated (phase 5). Most respondents (88%) said they had provided palliative care to one or more people with ID since the training course. When asked about the extent to which professionals now mastered the competencies required for ACP, most (>85%) replied that they mastered the competency in question sufficiently or good (see Table 4). Two competencies were estimated as less strong: paying attention to ethical dilemmas (competency 8; 21% felt they were insufficiently competent) and ability to reflect on ACP (competency 9; 19% felt they were insufficiently competent).

For all competencies, at least half of all participants (range 57–79%) felt their level of competence had improved thanks to the ACP program. At least 70% of the participants thought they were better able to talk about wishes, agreements and care needs (competency 3), applied ACP more often in the delivery of care (competency 5), paid more attention to dilemmas (competency 8), were better able to reflect on ACP (competency 9) and were better at communicating the importance of ACP (competency 10). The participants saw least improvement in the identification of symptoms, problems and care needs (competency 2), reporting in writing (competency 4) and collaboration with people with ID, relatives and the other professionals involved (competency 7). In general, an improvement in a competency also meant that the professionals felt they were using it more often and more effectively in their daily care of the people with ID.

Physicians saw less improvement in two competencies than non-physicians (social workers, nursing staff and other professionals). The physicians also saw less change in the application of the competencies in their daily care delivery than the non-physicians (see Table 4).

Discussion

This article described the development, implementation and evaluation of an ACP program in palliative care for people with ID. Results from various sources (an international review, an analysis of patients' medical files, and interviews) were used in the development of the ACP program; the project group drew on them to come up with ten important competencies that professionals should have for ACP with people with ID. These sources and other previous research (Vrijmoeth, Barten, et al., 2016; Wiese, Stancliffe, Dew, Balandin, & Howarth, 2014) showed that professionals have difficulty recognizing a need for palliative care, they feel they lack the necessary expertise to use ACP in the palliative phase for people with ID, and they find it difficult to talk about the end of life. The competencies addressed in the ACP program were geared to resolving these problems. Co-design sessions with people with ID, relatives and professionals and consultations with educational experts were used to develop an ACP program centred on the competencies. The program had three main elements: an information pack, two 2-hour training sessions, and an implementation interview.

This ACP program is unique. In our international review, we did not encounter a single comparable program in palliative care for people with ID (Voss et al., 2017). It is important to have a dedicated ACP program for professionals caring for people with ID, as assessing the wishes and needs of this group is often a challenge. People with ID often have complex, multimorbid and/or psychosocial care issues and limited communicative capacities, which makes it particularly difficult to determine what would constitute good care (Heslop et al., 2014; Stein, 2008; Tuffrey-Wijne, Bernal, & Hollins, 2010; Tuffrey-Wijne, Bernal, Hubert, et al., 2010; Tuffrey-Wijne & McEnhill, 2008; Vrijmoeth, Barten, et al., 2016).

Many professionals do not feel competent and confident enough to provide this group with palliative care (Bekkema, de Veer, Albers, et al., 2014; Dunkley & Sales, 2014; Wiese et al., 2012), which can make it difficult to discuss ACP. This ACP program is a response to the specific questions of professionals concerning communication with incurably ill people with ID and their relatives, and how best to assist them. Given that the content of the ACP program is based in part on our

international systematic review, the results of the current study are relevant not just for Dutch care professionals. The professional competencies, and the knowledge, attitudes and skills that were identified apply in a broader international context and could offer a way to improve ACP in palliative care for people with ID.

The in-depth interviews and co-design sessions with people with moderate ID show that they are willing to be involved in ACP, in a manner appropriate to their capacities and needs. Previous studies had already shown that people with mild ID want to be informed about their state of health, to be listened to and to be asked more about their care wishes (Bekkema et al., 2016; McKenzie et al., 2017; Tuffrey-Wijne, Bernal, Jones, Butler, & Hollins, 2006), and that now seems to apply to people with moderate ID as well.

The ACP program was evaluated using a digital questionnaire that participants completed six months after the training ended. The response rate of 79% suggests that the questionnaire gives meaningful information about the results of the program (Archer, 2008). The training sessions focused mainly on communication and paying attention to ACP. The professionals felt their competencies had improved in those areas. After the ACP program, professionals saw most improvement in their communication with people with ID about their wishes, agreements and care needs, and in making sure that ACP is a standard element in the palliative care for people with ID.

A relatively high proportion of participants said they were competent in collaborating with the person with ID, relatives and other care professionals and in the early identification of symptoms, problems and care needs. These were competencies where improvement was seen least often after the ACP program; this could be because of the relatively high level of (perceived) competence at the outset. It is striking that previous research had shown that professionals often find it difficult to identify care needs (Vrijmoeth, Barten, et al., 2016; Wiese et al., 2014). One explanation for this discrepancy could be that precisely those professionals who were already skilled in identifying changes to care needs in people with ID, felt the need for training in how to deal with this and therefore opted to take part in the ACP program.

There was also relatively little improvement in the competency of reporting on wishes, agreements and care needs after following the program. Non-physicians, such as social workers and nursing staff, were more likely to see an improvement in the reporting competency than physicians. This could be because physicians are responsible for the medical policy and are already accustomed to reporting on this in the patient's file. Physicians conduct the conversations in which the medical policy and end-of-life decisions are discussed in contrast to social workers and nursing staff who may have informal conversations about future care needs. The policy is less clear on such conversations and when any decisions should be documented. We recommend that informal conversations *should* be documented if they cover wishes and needs for future care. At present, there is a great deal of variation between organizations in their electronic or paper reporting systems. Preferably, reporting systems would have a section (tab) on ACP as this would remind professionals of the need to document wishes, agreements and care needs (Hemsley et al., 2019).

Strengths and weaknesses

A strength of the ACP program is that it was developed in part through a co-design process with people with ID, relatives and professionals. The ACP program was implemented in six different ID care organizations. The evaluation suggests that the program boosts professionals' perceived competencies and promotes the use of ACP in practice.

One weakness is that no baseline measurement was carried out for the evaluation of the ACP program. It is therefore not known how the professionals assessed their competencies prior to the ACP program. The evaluation was also subjective as the participants assessed their own level of competence and may have given socially desirable answers. Consequently, while the evaluation provides indications, it does not yet give 'hard' evidence that this ACP program actually leads to ACP being used more often and more effectively in palliative care for people with ID.

Conclusions

As far as is known, the ACP program that was developed is the first ACP program for professionals delivering palliative care to people with ID. Ten competencies were identified as relevant for professionals based on a systematic review, examinations of patients' files and interviews. These professional competencies were incorporated in an ACP program developed in a co-design process with people with ID, relatives and professionals and in collaboration with educational experts. The program was successfully implemented in six ID care organizations.

Professional who took part in the ACP program experienced an improvement in the competencies that are required for using ACP in palliative care for people with ID, in particular in the competencies focusing on communication and using ACP as a standard element in palliative care. Reporting on wishes, agreements and care needs remains a point for concern, particularly among social workers and nursing staff. The differences between physicians and non-physicians regarding ACP competencies and improvements in those competencies might indicate a need to tailor aspects of the training sessions further to suit the different disciplines and roles of the participants. The program should be developed further and evaluated among people with ID and relatives to measure the effects in practice.

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Table 1. Phases in the development, implementation, and evaluation of the ACP program

DEVELOPMENT	
Phase 1:	Description of competencies that the ACP program should focus on based on the outcomes of: 1) a systematic international review of ACP for people with ID (Voss et al., 2018); 2) an analysis of the medical files of people with ID in the palliative phase (=15) and people with ID who had died less than six months previously (n=15). The analysis of the files was validated and refined using structured interviews with relatives (n=30) and professionals (n=33) involved in the care of the individuals in question (Voss et al., 2019a) 3) in-depth interviews with five people with moderate ID, seven relatives and eight professionals (Voss et al., 2019b).
Phase 2:	Development of a draft ACP program in co-design sessions with people with ID (n=3), relatives (n=2) and professionals (n=10).
Phase 3:	Development of the training course for the ACP program in consultation with two education experts.
IMPLEMENTATION	
Phase 4:	Implementation of the ACP program in six ID care organizations. The ACP program was aimed at care professionals, a total of 58 professionals took part in the program. The ACP program consisted of three elements: an information pack, two training sessions and an implementation interview.
EVALUATION	
Phase 5:	Participants were sent a digital pre-structured questionnaire to evaluate the ACP program. Participants were asked (1) how they felt about their command of the ACP competencies, (2) if they felt their ACP competencies had improved after the ACP program, and (3) if they felt they had become better at applying their ACP competencies in their work.

Table 2. Ten competencies and sources addressed by the ACP program

Competency	Knowledge (K), Attitude (A), Skill (S)	Source
1. Timely identification of the palliative phase	<ul style="list-style-type: none"> - Knows about palliative care (K) - Knows how to recognize the palliative phase (K) - Regularly assesses care needs (S) - Can recognize that someone with ID is in the palliative phase (S) 	B
2. Spotting changes in symptoms, problems and care needs in the palliative phase at an early stage	<ul style="list-style-type: none"> - Knows about care needs and how they change in the palliative phase in people with ID (K) - Knows about tools for identifying symptoms, problems and care needs (K) - Recognizes when there is a reason to assess or reassess this (K) - Knows what follow-up steps should be taken in the event of a change in symptoms, problems or care needs (K) - Can assess symptoms, problems and care needs (S) - Makes changes to the care in the event of a change in symptoms, problems or care needs (S) 	B
3. Communicating about wishes, agreements and care needs	<ul style="list-style-type: none"> - Knows that different people have different ways of communicating (K) - Is familiar with important communication techniques for ACP (K) - Can adjust own communication to allow for this (K) - Finds it normal to discuss future care (A) - Takes the initiative for ACP conversations in a timely manner with the people involved (S) - Regularly holds conversations about wishes, agreements and care needs, and any changes in these (S) - Applies conversational skills correctly; allows room for emotions (S) 	A, B, C
4. Reporting on wishes, agreements and care needs	<ul style="list-style-type: none"> - Knows how, where and what to report regarding ACP (K) - Finds it important to report on ACP (A) - Reports on wishes, agreements and care needs in the patient's (medical) file (S) 	B
5. Integrating ACP as a process in palliative care	<ul style="list-style-type: none"> - Knows the purpose and importance of ACP (K) - Knows how ACP should be deployed in the palliative phase (K) - Knows what tasks and responsibilities he/she has (K) - Finds ACP important in palliative care (A) - Applies ACP in palliative care as a process (S) - Takes the appropriate responsibility for his/her role in ACP (S) 	A, C
6. Taking the wishes of the person with ID into account	<ul style="list-style-type: none"> - Knows how to involve people with ID in ACP (K) - Is aware of the person with ID's wishes (K) - Gives priority to the interests of the person with ID (A) - Consults with the people involved about whether/how to involve the person with ID in ACP (S) - Acts in accordance with the wishes of the person with ID (S) 	A, B, C
7. Collaborating with the person with ID, relatives and other care professionals	<ul style="list-style-type: none"> - Knows who is involved with the person with ID (K) - Knows who he/she can go to for help or expertise (K) - Is in contact with the people involved and liaises with them (S) - Listens to and respects others (S) - Ensures or maintains a good relationship with the people involved (S) - Calls on the expertise of others where necessary (S) 	B, C
8. Paying attention to ethical dilemmas in ACP for people with ID	<ul style="list-style-type: none"> - Knows what dilemmas play a role in the target group of people with ID (K) - Knows the legal rules (K) - Knows who can be approached for assistance if necessary (K) - Creates an open, calm, respectful environment in which any dilemmas can be discussed (S) - Places himself/herself in another's position (S) - Explains the situation clearly (S) 	B, C

9. Fostering expertise in ACP within palliative care	<ul style="list-style-type: none"> - Knows what he/she finds difficult about palliative care and about discussing it (K) - Knows where there are points for improvement in himself/herself and in the team (K) - Is keen to learn from others (A) - Evaluates own capabilities, collaboration and how ACP process went (S) - Adapts or improves own actions based on new knowledge or learning points (S) 	C
10. Continuing ACP as a component of palliative care	<ul style="list-style-type: none"> - Communicates the importance of ACP to others involved in the care delivery (S) - Adopts and promotes a structured approach to ACP (S) - Brings in expertise, room and opportunity for training (S) 	A

A = systematic review (Voss et al., 2017), B= analysis of patient's files and interviews (Voss et al., submitted a), C= in-depth interviews (Voss et al., submitted b)

K = knowledge, A = attitudes, S = skills

Table 3. The form and content of the ACP program and the competencies that were covered

Program element	Content	Competency*
Information pack	Scientific literature about ACP, tools for identifying the palliative phase, guidelines for discussing ACP and a list of links to guides and tools	1,2,3,4,5,6,7,8
Training session 1	<p>Participants learn that people have different ways of communicating; this helps them apply conversational skills appropriately.</p> <p>Participants learn to listen to others and respect them.</p> <p>Each participant evaluates their own capacities in the ACP process by hearing from someone else what they found good about a conversation; they can then adjust their own behaviour accordingly if necessary.</p>	3,7,9
	<p>Case study 1, motives:</p> <p>Paying attention to ethical dilemmas in ACP for people with ID. This case study is an exercise in experiencing how difficult it is to have to take decisions for someone else.</p>	8
	<p>Case study 1, conversation practice:</p> <p>Participants learn conversational skills and adjust their own communication accordingly. In this case study, participants practice cooperating with the person with ID, relatives and other professionals. As ACP is teamwork, it is crucial that everyone has a say, including the person with ID (if possible).</p> <p>The participants gain an understanding of the different interests and learn that the interests of the person with ID must be given priority.</p>	3, 6, 7
	<p>Reflection report as homework</p> <p>This report can deal with:</p> <ul style="list-style-type: none"> - a conversation held by the participant about ACP or one aspect of ACP; - a case in which ACP was important. <p>Depending on the topic, the participants learn to reflect on the different competencies that are required for ACP. They become aware of the competencies that they have and those they still need to acquire.</p>	1,2,3,5,6,7,8,9
Training session 2	<p>Discussion of reflection reports:</p> <p>The participants experience recognition and acknowledgement from the other participants. They reflect on their own actions and receive feedback from the other participants.</p>	9
	<p>Theory:</p> <p>How to compile files, tools, the importance of the person with ID and their involvement, conversation topics, collaboration, ethics and legislation.</p>	1,2,3,4,6,7,8
	<p>Conversation practice 1:</p> <p>Talking about wishes, agreements and care needs. Participants practice applying the key conversational skills for ACP in the correct manner. Given the capabilities of the person with ID in this case, the relatives represent the interests of the person with ID. They experience ethical dilemmas in taking decisions. In this case study, they work with the social workers and the physician to come up with a shared ACP goal. They listen to one another and respect one another's opinions and views.</p>	3,6,7,8
	<p>Conversation practice 2:</p> <p>Talking about wishes, agreements and care needs, in which the interests of the person with ID take priority. In this case</p>	3,6,7,8

	study, participants work with all the parties involved, with due regard for the ethical dilemmas.	
Implementation interview	Integration of ACP in palliative care and enhancing expertise	5, 9, 10

* See Table 2 for the competency associated with a given number

Table 4. Ratings of perceived effects of the ACP program on competencies for palliative care

Competencies	Professionals (n=42) who felt their command of this competency was sufficient or good	Professionals who felt their command of this competency had improved as a result of the ACP program		Professionals who said they were better able to apply this competency in daily practice after following the ACP program	
		Physicians (n=19)	Non- physicians (n=23)	Physicians (n=19)	Non- physicians (n=23)
1. Timely identification of the palliative phase	93%	47%	74%	53%	70%
2. Spotting changes in symptoms, problems and care needs in the palliative phase at an early stage	98%	26%*	83%*	37%*	83%*
3. Communicating about wishes, agreements and care needs	93%	74%	83%	58%	83%
4. Reporting on wishes, agreements and care needs	88%	37%*	74%*	26%*	74%*
5. Ensuring that ACP is part of the palliative care for the person with ID [#]	88%	74%	74%	74%	83%
6. Taking the wishes of the person with ID into account	93%	58%	70%	53%	78%
7. Collaborating with the person with ID, relatives and other care professionals	95%	47%	65%	53%	74%
8. Paying attention to ethical dilemmas in ACP for people with ID	79%	63%	78%	42%*	87%*
9. Reflecting on the use of ACP in palliative care and considering what went well and what could be improved [#]	81%	58%	87%	42%*	74%*
10. Communicating the importance of ACP in your team or organization [#]	86%	58%	87%	58%	70%

Significant difference between physicians (n=19) and non-physicians (n=23), Fisher's exact test, *p<0.05.

[#]The wording for this competency differs from that of the competency as formulated in the ACP program (see Table 2).