The challenge of caring together
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General discussion
The aim of this thesis was to explore end-of-life care for people with ID from the perspectives of people with ID, relatives and professionals. In this final chapter, first the principal findings in Chapters 2 to 7 are presented. This is followed by reflections on these results, methodological considerations and discussion of the implications for practice, policy and research.

**Findings about care approaches, needs and wishes**

Two qualitative studies were conducted to explore shifts in care approaches and attitudes among professionals and relatives, the important dimensions of the caring relationship at the end of life from the perspectives of people with ID, and how the autonomy of people with ID is respected at the end of life.

**Towards wellbeing and comfort care by being there for the person**

In qualitative interviews with relatives and care staff, we found that at the end of life of a person with ID, the care approach shifted from a focus on activation and social participation towards a focus on wellbeing and comfort, taking over tasks and symptom relief (Ch. 2). In doing this, relatives and care staff increasingly had to let go of their usual care strategy and adapt to what was still possible.

Within end-of-life care, being there and making more time available to be close to the ill person were regarded as important by both care staff and relatives, as well as by people with ID themselves. Care staff and relatives regarded being there as an important value underlying the shift towards comfort care and taking over tasks. In group interviews, people with mild ID also highlighted being there as one of the most important dimensions of caring relationships at the end of life (Ch. 3). In the view of people with ID, an ill person needs dedicated people who are there for him/her at the end of life, to provide adequate practical, emotional, social and spiritual support. This highlighted the opinion of people with ID that being there should cover all aspects of end-of-life care.

People with ID also emphasized the importance of creating positive, active experiences while being there for the ill person; e.g. going on day trips or a longer holiday, ‘living life to the full’ and fulfilling last wishes. So although activating the person becomes less important, opportunities to undertake positive and active experiences in the remaining life of an ill person with ID should still be created.
‘Reading’ needs and jointly interpreting signals

Another shift in the care approach of relatives and professionals concerned a stronger reliance on the joint interpretation of signals expressing distress, as verbal communication with the person with ID was often hampered (Ch. 2). Physicians who were interviewed about cases of people with ID receiving end-of-life care indicated that they relied heavily on information from people closely involved with the person, mostly relatives and care staff. Finding a common language to talk about signals could be a hurdle.

Reading needs was particularly demanding for relatives of people with severe/profound ID: the dependency of these persons became magnified, leading to another shift in their care approach. Properly interpreting symptoms could be further hampered by a lack of knowledge among ID care staff, e.g. about basic end-of-life care and the use of instruments to measure pain or other symptoms (Chs. 4 and 7).

‘Attentiveness’ was regarded as important for reading needs by both professionals and relatives and by people with ID. Attentiveness to the signals of distress and pain, preferably by people who are closely involved, was recognized as a value underlying the shift towards stronger reliance on joint interpretations (Ch. 2). People with mild ID also recognized that a person who cannot talk needs familiar people who can closely observe his/her behaviour and facial expressions (Ch. 3).

The involvement of care staff and relatives

When the death of a person becomes imminent, the interweaving of emotional and professional involvement increasingly becomes a struggle for ID care staff, leading to another shift in their care approach (Ch. 2). Care staff have often built strong long-term caring relationships with their clients, and struggle to achieve a balance between warm care and professional distance. Being able to reflect on their own emotions, capabilities and caring relationships was an important value underlying this shift.

The growing awareness that the person with ID actually has two ‘families’ - relatives and the care staff - constituted the last shift made in end-of-life care (Ch. 2). The proximity of these two ‘families’, who know the person best and wish to offer him/her warm and loving care, could be very valuable. Yet if perceptions of what constitutes good care differ between care staff and relatives and communication fails, the good intentions to provide joint care can turn into a burden and source of distress for the dying person. The lack of end-of-life care...
expertise may put ID care staff on a same level in terms of knowledge as relatives (Chs. 2 and 7). Yet some relatives expected care staff’s expertise to be on a higher level, which could put extra pressure on the relatives’ cooperation with care staff (Ch. 2).

Respecting autonomy and wishes

The qualitative studies also highlighted the importance of respecting the autonomy of people with ID at the end of life, as well as the challenges that are inherent to such a difficult task. According to people with mild ID, properly handling a person’s wishes is a central element of caring relationships at the end of life (Ch. 3). This handling of wishes concerned care wishes and wishes for a final pleasant event as well as wishes regarding the funeral. ‘Handling wishes’ referred not only to ascertaining wishes but also to recording and - especially - honouring them.

Yet, dealing with wishes and respecting autonomy does not always happen as a matter of course, as indicated by both people with ID and the people caring for them. Some people with ID were sceptical about the honouring of wishes or talked intensely about their fear that their end-of-life care wishes would not be honoured. This seemed influenced by their prior life experiences (Ch. 3). In addition, relatives and professionals encountered numerous challenges in respecting the autonomy of a person with ID, such as eliciting current and hidden last wishes, dealing with conflicting wishes, ascertaining information needs and communicating about illness and death (Ch. 4). Many relatives and professionals struggled for example to find a balance between protecting the person with ID and giving them more information.

Trust, caring relationships were found to be crucial for acknowledging and respecting the wishes of a person with ID. Autonomy could best be seen as a product of joint work that imposes high demands on relational qualities, such as attention to information needs, connecting with the person and giving them the space to show their wishes and preferences (Chs. 3 and 4).

Findings about decision making

Place of care: familiarity of the environment and end-of-life care expertise

A quantitative survey study was conducted to investigate the considerations and beliefs of care staff, ID physicians and GPs when confronted with difficult end-of-life decisions. Receiving end-of-life care in the person with ID’s own home environment, and the 24/7 availability of end-of-life care were important considerations in
decisions about the place of end-of-life care (Ch. 5). Almost all professionals were in favour of keeping the person at home, which may also relate to the strong bonds between care staff and their clients (Ch. 2). Indeed, most of the clients described in the case section of the survey were able to stay in their own home environment, which is a larger number than in the general population. The main considerations to keep the person at home were the familiarity of the environment and the end-of-life care expertise of the team. Insufficient expertise and a lack of adequate equipment were main considerations to transfer a person to a different setting.

**Use of medical interventions: quality of life and wellbeing**

Quality of life was the consideration most frequently mentioned in decisions about potentially burdensome medical interventions, such as chemotherapy, life-prolonging surgery, pain medication by infusion pump or further diagnostic investigations (Ch. 6). In addition, the client’s wellbeing was frequently considered in both decisions to start or continue an intervention and decisions to forgo or withdraw an intervention. Most decisions concerned the rejection or withdrawal of the intervention.

**Involving the person with ID in decisions**

The beliefs of professionals regarding the wishes of the person with ID differed between decisions about the place of care and decisions about the use of medical interventions. Professionals predominantly believed that the wishes of the person should always be leading when deciding upon the place of end-of-life care (Ch. 5). Yet only a minority of professionals believed that the wishes of the person with ID should always be leading in decisions about medical interventions (Ch. 6). It may be that professionals believe that people with ID are less able to decide about complex medical matters than about more practical matters.

In both type of decisions, explicit involvement of the person’s wishes was low in practice and relatives’ wishes were more likely to be explicitly considered. Only a small minority of professionals explicitly mentioned that the wishes of the clients were taken into account in practice (Chs. 5 and 6). In particular the wishes of people with severe/profound ID were often not explicitly taken into account. Involving people with ID in decisions and respecting their wishes seemed not to happen as a matter of course, which is in line with the findings of Chapter 3 and Chapter 4.
Findings about the training needs, expertise and resources of ID care staff

Expertise is needed to ensure good end-of-life care for clients with ID. A quantitative survey was conducted to evaluate the quality of end-of-life care as perceived by social workers and nurses working in ID care services, their training experiences and training needs, and consultation options regarding end-of-life care.

Although ID care staff positively evaluated the quality of end-of-life care provided by their team or within their department, only 15% felt adequately trained to provide good end-of-life care (Ch. 7). Care staff wished for additional training, particularly in supporting clients in dealing with the impending death and the farewell process. Expertise is important to provide end-of-life care in the home environment, as we found that lack of expertise was the foremost argument for transferring a client to another care setting (Ch. 5).

Although palliative care consultations teams are available for consultation all over the Netherlands for all healthcare professionals, half of the respondents were unaware of the availability of these services. As expected, nurses were more involved in end-of-life care, had received more training in end-of-life care and had fewer training needs than social workers. This is in line with the finding in Chapter 4 that social workers struggled to respond adequately to a client’s needs because of a lack of nursing skills and basic end-of-life care knowledge.
Reflections on the quality of end-of-life care

The value of familiar people being there

It is generally known that people with ID are a vulnerable ageing group because of their poor health status (e.g. Tuffrey-Wijne et al. 2007a; Hermans & Evenhuis 2014; Mccarron et al. 2013). This thesis indicates that at the end of life of people with ID, their dependency and vulnerability seems even more pronounced, for instance because of the complexity of assessing their needs. Being close to familiar caregivers and being in a familiar surrounding may be particularly important for this vulnerable group. The findings of this thesis highlight that it is vital for people with ID to be surrounded by familiar care staff and relatives, who know how to ‘read’ their needs and identify signals such as distress and pain. Relatives and care staff ‘who are there’ and take time to acknowledge and address these needs can therefore be a big strength in enhancing the quality of life, as indicated by both people with ID and relatives and professionals in our studies. The power of ‘being there’ has also been acknowledged by Todd (2013), who found that ID care staff experienced a client’s death as a ‘good death’ when they were able to ‘be there’ for the person with ID in the different phases of end-of-life care.

‘Being there’ and providing good end-of-life care impose high demands on the relational qualities of professionals and relatives, as also highlighted by this thesis. Qualities that were found to be important included the ability to uncover wishes, listen carefully, empathize and closely observe the behaviour of the person with ID. These qualities fit with the core values of ‘good care’ in care ethics, such as attentiveness to recognize the need for care (e.g. Leget 2007; Tronto 1993). Leget for example emphasized the value of ‘inner space’: an attitude of listening attentively to dying patients with an open heart and mind in order to unravel their real needs and questions (Leget 2007). The relational qualities also align with the vision that care is reciprocal (Hertogh 2009; Hertogh 2010) and the awareness that care should be provided in such a careful way that the person receiving the care is able to be responsive to this care (Hertogh 2009). Recognizing care needs and responses to care in ill people with ID can be quite complex. The proximity of ID care staff who are experienced in communicating with people with ID, and who have often built a long-term relationship with a person with ID, can therefore provide people with ID with a sense of security that may be particularly important for them.
Responsibility and expertise in providing good end-of-life care

Caring also implies taking responsibility for providing this care, another core value of ‘good care’. The care staff who participated in our studies predominantly felt strongly about their wish to remain the primary caregiver until the end. This strong willingness to provide end-of-life care has also been found in other studies among ID care staff (Wiese et al. 2012; McCarron et al. 2010). This indicates that ID care staff do wish to take on the responsibility for providing end-of-life care.

Yet, in line with care ethics, competence is a key core value of end-of-life care in addition to responsibility. Tronto (1993), a care ethicist, reasons for instance that although there may be an intention to provide good care, care needs cannot be met if there is a shortage of knowledge or skills. And it is precisely this competence that seems to be a weakness within ID care services: only 15% of the care staff respondents in our study felt adequately trained to provide good end-of-life care. This lack of expertise has also been found in several other studies of end-of-life care for people with ID (e.g. Ng & Li 2003; Ryan et al. 2010; Botsford 2004, Wiese et al. 2012, McCarron et al. 2010). We found that in particular the use of instruments to measure pain or other symptoms was barely covered in the vocational training of care staff. This is alarming since pain and symptom relief is a very important part of end-of-life care (WHO 2015), and the identification and management of pain and other symptoms can be particularly hard in the case of people with ID, especially at the end of their life (e.g. Ryan et al. 2010).

Although the care staff in our studies were often willing to provide end-of-life care, some were also insecure or felt incompetent, in particular if they had never provided end-of-life care before. Possible reasons for a lack of expertise are a general deficiency in the body of knowledge with regard to end-of-life care for people with ID (e.g. symptom and pain management and communication), and a shortage of end-of-life care training for ID care staff. If care staff do not have the expertise to recognize end-of-life care needs, they may have trouble identifying when care is required. A lack of knowledge and skills among ID care staff may therefore lead to poor end-of-life care, e.g. because they miss signs of pain, are not able to recognize or correctly treat particular symptoms such as pain, anxiety or swallowing disorders, or do not know how to comfort the client. A telling point is our finding that a lack of expertise was the most frequently cited consideration in decisions to transfer the person with ID to another care setting.
Opportunities for providing good quality end-of-life care within ID care services

Although this thesis highlights the aspiration among ID care staff to take on end-of-life care for their clients, additional relevant training is essential for ensuring good end-of-life care for people with ID. Additional training should take into account the holistic nature of end-of-life care, as people with ID have physical, emotional, social and spiritual needs that are similar to those of the rest of the population (Tuffrey-Wijne & McLaughlin 2015). As ID care staff teams are often multidisciplinary, composed of nurses as well as social workers, a well-trained care staff team could potentially allow for a good ‘skills mix’ within the team.

Moreover, intensified partnerships between ID care services and specialist end-of-life care services could also considerably improve the quality of end-of-life care within ID care services. End-of-life care is still a rather infrequent type of care in ID care services, and ensuring that all ID care staff have sufficient knowledge to address the full scope of possible end-of-life care needs would be impossible, and indeed not desirable. That is where the input of end-of-life care specialists may make a big difference. As ID care staff are experienced in supporting people with ID and identifying their particular needs, and end-of-life care specialists can bring in specialized end-of-life care skills, collaboration between these services is key to the successful provision of end-of-life care for people with ID (EAPC European white paper on end-of-life care for people with ID; Tuffrey-Wijne & McLaughlin 2015). But although cooperating with specialized end-of-life care services and drawing on their expertise may help to significantly improve the quality of end-of-life care for people with ID, our study shows that many ID care staff members are still unaware of these external facilities. So in order to improve the access of people with ID to these services, more information should be provided about the option of partnerships between ID care services and specialist end-of-life care services.

Reflections on the wishes of people with ID

Being able to die according to your own preferences is generally found to be an important value in end-of-life care (Patrick et al. 2003). Also, the ‘Caring at the End of Life Position Statement’ by the American Association on Intellectual and Developmental Disabilities sees honouring wishes and autonomy as an important principle (AAIDD 2015). Yet, although the significance of these principles is undisputed, they do not tell us how they relate to the complexity of the daily care for people with ID who have an incurable illness.
“You should listen to her wishes. Meet her wishes. It is about her. What she wants. And how she wants it. That’s the last thing you can do for her”

This quote by Marcel (mild ID) reflects the finding of this thesis that people with ID, in line with the general principles, indeed believe that honouring the wishes of the incurably ill person is central to good end-of-life care. Professionals and relatives also predominantly believe that the person’s wishes are important and that the person should be involved. Yet it is not simple, as shown by the complexity of involving people with ID in decisions and by the apparent lack of trust in the ability of the person to become involved.

The complexity of involving people with ID in decisions

This thesis highlights the fact that professionals hold varying beliefs regarding people with ID’s involvement in decisions. For instance, professionals predominantly believed that the wishes of the person are leading in decisions about the place of end-of-life care, but not in decisions about medical interventions. Moreover, although being informed about the diagnosis and treatment options is the basis for informed decision making, less than 70% of professionals believed that people with ID should always be informed about medical intervention options. What may play a role is that professionals wish to protect people with ID from complex medical information that they presumably cannot fully understand, or that they prefer to inform a relative or other representative.

This thesis also showed that the explicit consideration of people with ID’s wishes in practice was rare, in particular of the wishes of people with severe/profound ID. The wishes of relatives were more likely to be explicitly considered than the wishes of the person with ID. This is in line with other studies on end-of-life care for people with ID, which showed that people with ID are not always involved in communication and decisions (Tuffrey-Wijne et al. 2009; Tuffrey-Wijne et al. 2010; Wagemans et al. 2010; Wagemans et al. 2013). Although our research did not provide insight into the person’s decision-making capacity, it may be that the people with ID in our decision-making studies were believed to be incapable of making decisions, and that therefore their wishes were not prioritized. However, the incapacity to decide should not be assumed beforehand, as also stated by the European White Paper on end-of-life care for people with ID: people with ID should be assumed to have the capacity to make decisions concerning their care and treatment, unless this is demonstrated not to be the case (EAPC: Tuffrey-Wijne & McLaughlin 2015). Moreover, even when a person is incapable of making decisions,
that does not absolve professionals and relatives from the responsibility to try to uncover his/her wishes and take these into account.

Trust in the person’s ability to be involved
Our findings on respecting wishes and autonomy suggest that trust in the person’s ability to be involved in end-of-life care seems to be a central issue. Many professionals and relatives in our studies found it hard to talk about illness and death to people with ID (for example, Cassandra’s caregivers in Chapter 4). They often oscillated between providing information and protecting the person from information, as they felt that information might harm them. These professionals and relatives may lack trust in the person’s ability to be involved, or they may lack trust in their own ability to involve the person with ID. This lack of trust was also visible among the people with mild ID who were interviewed, as some of them were quite sceptical and displayed distrust when talking about the honouring of their own wishes. This distrust might be a reflection of the daily life experiences of people with ID within an ID care setting, as this can to some extent be characterized by supervision and a lack of freedom of choice.

A study by Tuffrey-Wijne et al. (2010) highlighted that when people with ID are not involved (or not enough) in communication or decisions related to their end-of-life care, they can feel distressed because they do not understand what is happening, and this lack of understanding affects their ability to make decisions. Although not involving someone may be motivated by a desire to protect them and by caring intentions, protecting, according to Tronto, does not take the needs of that person as a starting point for what must be done (Tronto 1993, p. 105). A risk is that by protecting the person with ID, their real end-of-life care needs and wishes are lost sight of. Hence, it is highly important to find the trust in the person’s ability to be involved, at a level that suits their capabilities.

Respecting autonomy as a relational concept
Respecting the autonomy of people with ID at the end of their lives is best seen as a relational concept, as is shown by this thesis. When talking about respecting the autonomy of people with ID, their dependency always comes to the fore. People with ID, like other people with decision-making disabilities, are vulnerable and dependent on others to maximize their participation in decisions (Peisah et al. 2013). A relational concept of autonomy gives more space to this dependence of people. It fits with care ethics, which regards dependency as essential to human
relationships (Agich 2003; Tronto 1993; Verkerk 1999 & 2001) and in which asymmetrical relationships are seen to be as morally relevant as symmetrical relationships (Kittay 2011). Our findings suggest that respecting autonomy can be attained by relatives and professionals adopting an open, active and reflective attitude. In doing this, much can be learned from existing models, such as supported decision making for involving people with cognitive disabilities, and for breaking bad news to people with ID (Peisah et al. 2013; Tuffrey-Wijne 2012). When there is a basic trust that the person can be involved in his or her own way, and when relatives and professionals proactively seek means to achieve this, by e.g. assessing the capabilities of the person with ID, simplifying the information and maximizing their ability to understand, the person with ID’s wishes may actually take centre stage in their end-of-life care.

Reflections about relationships based end-of-life care for people with ID

The nature of end-of-life care for people with ID and the involvement of many different people call for good cooperation and good caring relationships. The results of this thesis confirm for example that symptom relief and uncovering the needs of a person with ID become a real team effort at the end of life: relatives, care staff and physicians have to cooperate to find a common language to talk about what they see. The European White Paper highlights the fact that collaboration between those who know the person well and those who are experts in symptom management is crucial to ensure adequate symptom management for people with ID (EAPC: Tuffrey-Wijne & McLaughlin 2015). Yet, this thesis also demonstrates that cooperation and safeguarding a professional caring relationship is not always easy.

About feeling one family and the ownership of the person

Experiences of relatives regarding the cooperation with care staff varied. On the one hand, co-caring was experienced as special, powerful and constructive by relatives, and as a support for the whole family. In some cases it even felt as if care staff and relatives were acting as one family in the support for the ill person with ID. Yet, in other cases communication failed and co-caring became stressful for relatives. Some relatives experienced the end of life as something intimate that should only be shared with relatives. They experienced the input of care staff as an infringement of their privacy or rights as a representative. Others had mixed feelings regarding the quality of care in the ID organization, or the level of end-of-life care expertise among
care staff. Other care settings such as nursing homes and care homes also encounter challenges in shared end-of-life care by relatives and professionals (e.g. Livingston et al. 2012; Thompson et al. 2012; Gjerberg et al. 2011). Yet what is different here is that relationships between relatives and ID care service staff often go back decades. The fact that both the family and the care staff at the ID care service are often deeply emotionally involved over a long period of time is probably unique to ID care. Therefore, old feelings may surface again and may lead to conflicts about the ‘ownership’ of the person with ID.

**About being overwhelmed, friendship, reflection and caring for carers**

Providing end-of-life care can be quite overwhelming for care staff members, as this thesis highlights. Strong emotional, long-term bonds between care staff and clients make ID care unique across the healthcare sector. These bonds also appear in e.g. attachment studies and social network studies, which demonstrate the significant role that care staff often fulfil in the lives of people with ID (de Schipper et al. 2005; van Asselt-Goverts et al. 2013). In our studies, some care staff members even described their relationship with their client in terms of ‘a special bond’, ‘love’ or ‘friendship’. In contrast to nursing home staff, for example, ID care staff had often cared for their client in the active stages of his/her life. We found that it could be particularly hard for ID care staff to let go of a person they previously helped to fully participate in life.

Precisely because of these friendship bonds between care staff and clients, reflection on this caring relationship becomes tremendously important for ID care staff who provide end-of-life care. The value of reflection has become visible in earlier writings. For instance, Nouwen (1997) describes the importance of presence, trust and time for building a friendship in caring for a person with severe/profound ID, and sees reflecting on this caring relationship as an inner process that could ensure good care. Tronto reasons that one needs to be able to postpone one’s own concerns in order to be attentive to others: it is a great moral task to “stand back from the ongoing processes of care and ask: what is going on here?” This requires e.g. honesty and a continuous evaluation of the care provided (Tronto, 1993 p. 141).

Yet are ID care staff able to reflect on their caring relationships? This thesis suggests that in order to deal with their emotions, ID care staff need to reflect on their caring relationship with their client, their relationship with relatives, their own emotions and thoughts on end-of-life care and the possible intertwining of the interests of the client and their own interests. This is a lot to ask from care staff, who
are often not highly educated and for whom end-of-life care is not regular care. This is why the support and ‘care for carers’ (care staff) is so essential. Caring for your own needs is important in order to be alert to the needs of others. The necessity of care for carers has also been stressed in studies within other settings, such as dementia care. In dementia care, carers e.g. encounter moral challenges around truth-telling (Hertogh et al. 2004). Furthermore, providing person-centred care on a daily basis is found to be highly demanding for dementia carers, as this asks for a continuous deep involvement and confronts them with the loss of a common shared world of meaning (Hertogh 2004; Hertogh & The 2008). In demanding care situations, such as dementia care and end-of-life care for people with ID, care for carers is indispensable. Yet we hardly encountered any formal implementation of care for carers in our studies, which may mean that this is lacking. Other papers have also seen a gap in care for ID carers and noted that ID care staff may (unjustly) not be seen as ‘mourners’ (Tuffrey-Wijne & McLaughlin 2015). Care for carers should therefore receive more attention, as it may vastly improve the confidence and qualities of ID care staff in providing end-of-life care.

**Reflection on the challenge of caring together: fostering three caring relationships**

End-of-life care for people with ID is a challenge of caring together. Although care for people with ID inevitably builds on relationships, this thesis highlights the fact that the value of good caring relationships seems amplified at the end of life. In encouraging caring together in end-of-life care for people with ID, three caring relationships need to be fostered: the relationship with the person with ID, relationships among professionals and the relationship between relatives and professionals.

In the first place, caring together means involving the person with ID. Building a form of end-of-life care that meets the wishes and preferences of the person with ID means regarding autonomy as a product of joint work, and regarding end-of-life care as shared care. There needs to be trust that the person can be involved in his or her own way and means to achieve this need to be sought proactively, e.g. by focusing on and assessing their capabilities, simplifying the information and maximizing their ability to understand.

Second, caring together also means sharing the care among professionals. ID care staff, physicians and other professionals need to share their expertise and knowledge about the person with each other, as well as with professionals outside...
ID care. This implies training ID care staff in end-of-life care topics so that they are more able to provide this care and feel more confident in doing so. It also implies cooperation with services outside ID care, such as specialized end-of-life care services, which may increase the access of people with ID to generic end-of-life care services. It also means providing good ‘care for carers’; adequate support for those care staff members who are confronted with the care and loss of their incurably ill client.

Third, relatives and professionals need to join forces to provide care together. If relatives and professionals are able to come together and communicate openly about their views on good end-of-life care, co-caring by both relatives and professionals can lead to warm, loving care in the proximity of the very people who are most important to the person with ID.

**General methodological considerations**

This thesis built upon four studies that explored the perspectives of the main stakeholders in end-of-life care: people with ID themselves, relatives and professionals. The thesis combined the insights of the four studies and presented an overall reflection on end-of-life care for people with ID. It has added value to existent studies, which often paid attention exclusively to the staff's perspective. Another advantage was that the four studies were performed in consecutive order. As researchers learn along the way, this enabled us to integrate the insights and lessons from one study and incorporate them into the next study.

The combination of quantitative and qualitative designs is also a strength. By performing mixed-methods research, we were able to gain insights into the perspectives of representative groups of professionals, as well as in-depth insights into the experiences and stories of professionals, relatives and people with ID.

Another strength is that the studies were performed in close cooperation with experts directly involved in ID care. The studies delivered many practical insights, which were validated and refined in consultation with experts in the field. The close cooperation with practitioners also enabled us to develop practical guides and tools.

However, the explorative character of the qualitative studies in particular means that caution should be exercised in generalizing the results, as ID care is a hugely diverse care setting, both with regard to the people with ID themselves and with regard to their caring contexts.
Methodological considerations per study

Retrospective multiple-case study
Chapter 2 and Chapter 4 were based on a retrospective multiple-case study. The cases of recently deceased people with ID were reconstructed by interviewing 47 relatives and professionals who were closest to the person in question at the end of their life. From this multiperspective focus, we were able to reconstruct the stories of 12 deceased people with ID, incorporating the viewpoints of all the people who were most closely involved. This helped avoid giving too much emphasis to one viewpoint, for instance the viewpoint of the professional.

In the multiple-case study we therefore explored 12 cases. Several measures were taken to enhance the scientific rigour of the research:

1) Participants were selected purposively in order to obtain a relatively diverse sample of client cases with regard to age, living situation (own apartment, group home or residential home), place of death (own home, parents’ home, intensive care facility of an ID care service, hospital or hospice), kind of disease and severity of ID (mild, moderate or severe/profound ID). In this way, client cases in a variety of situations could be studied.

2) The principle of data saturation was used: we reached data saturation after studying 12 cases, meaning that we did not identify any new relevant information or themes in the last interviews. Data collection and analysis alternated in a cyclical process in accordance with key principles of qualitative research (Green & Thorogood 2004), until we attained this data saturation point (Ando et al. 2014).

3) To ensure reliability and to enrich the data analyses, all interviews were analysed by the principle researcher and at least one co-researcher. The different analyses were then discussed.

4) To validate and enrich the analyses, we discussed the findings in two focus groups with ID caregivers, trainers and policy experts.

However, a limitation is that we studied the client cases retrospectively, so the experiences of the interviewees may have been subject to a recall bias. A second limitation and consequence of this retrospective design is that the experiences of the people with ID themselves could not be studied.
**Group interview study among people with mild ID**

Chapter 3 was based on a group interview study with people with mild ID, using the nominal group technique to structure the discussion. This technique was specifically adapted for people with ID by Tuffrey-Wijne *et al.* (2007b). These group interviews have added value since studies exploring the views of people with ID about end-of-life care are very rare. The nominal group technique adapted for this specific target group appeared to be very useful in eliciting the perspectives of people with mild ID. A clear explanation of the aim of the group interviews, the presence of familiar care professionals, the use of a pictorial story, holding two separate group interview meetings and the structured process of validation and ranking all seemed to contribute to its success. In this study we held interviews with seven groups and a total of 33 people with mild ID who were not receiving end-of-life care. We sought to enhance the scientific rigour and richness of the analyses through:

1. Purposive sampling of clients from diverse groups (members of the local client council, residents from ID care services and members of a theatre group for people with ID);
2. Using the principles of data saturation and the cyclic process of data collection and analysis;
3. Independent analyses and subsequent discussions in pairs consisting of the principle researcher and one of the co-researchers.

The decision to only include people with ID who were not at the end of life themselves was carefully made after considering our responsibility in safeguarding the emotional security of client participants. Yet the views of our respondents may differ from clients who are actually receiving end-of-life care. Another limitation is that we only included people with mild ID, so the views of people with moderate and severe/profound ID remain unknown.

**Quantitative survey study about decision making**

A total of 718 professionals took part in the survey study on decision making about the place of end-of-life care and the use of burdensome medical interventions (Chapters 5 and 6). An important strength is that we were able to recruit a nationwide sample of professionals by using one nationally representative sample of GPs (Van Hassel and Kenens 2013) and one nationally representative sample of nurses and social workers (Albers *et al.* 2014; De Veer *et al.* 2011), and one members’ list that covered almost all practicing Dutch ID physicians. We were therefore able to incorporate and compare the perspectives of three different
groups of professionals who work with people with ID. A limitation is the possible recall bias, as the considerations in decision making were explored by open questions about the last person with ID for whom the respondent provided end-of-life care. Hence, professionals may be more likely to recall clients who made a great impact on them. Another limitation is that we do not know what the personal input and role of the respondent was in the decision-making process. Different professionals may have different ideas about which considerations are relevant or decisive in decisions. Moreover, the actual considerations of GPs, as well as the perspectives of people with ID and their relatives, were not included in this study.

Quantitative survey study about expertise and training needs
Chapter 7 was based on a survey study about the quality of end-of-life care, past training, needs for training, and expert consultation opportunities among 130 nurses and social workers working in ID care services. An important strength of this survey study is the relatively high response rate (71.8%). However, a limitation is that most questions in the study were about perceptions, so we cannot be sure about the actual end-of-life care knowledge and skills of ID care staff.
Implications for practice and policy

End-of-life care for people with ID is about caring together, and in many ways a real team effort. This can be translated into the following recommendations for practice and policy.

1. Improve the involvement of people with ID in end-of-life care

This thesis underscores the complexity of involving people with ID in end-of-life care and the importance of proactively seeking ways to involve the person in end-of-life care on his/her own terms. As highlighted by this thesis, it is hard for many relatives and professionals to uncover and respect their wishes and involve the person with ID in decisions regarding the place of care or the use of medical interventions. In order to involve the person with ID and respect their autonomy, professionals and relatives should aim to adopt an open, active and reflective attitude.

Much can be learned from existing models that were developed in other studies. One example is the ‘ASK ME’ collaborative model of supported decision making for involving people with cognitive disabilities; which includes steps such as assessing the person’s strengths and deficits, simplifying the task, understanding their values and maximizing their ability to understand (Peisah et al., 2013). The model of Tuffrey-Wijne about breaking bad news to people with ID is also an important tool. Within this model, relatives or professionals break up information about e.g. a medical intervention into small pieces, and these pieces are added one by one to the current knowledge of the person (Tuffrey-Wijne 2012).

To further improve the active involvement of people with ID, resources such as pictorial guides and easy-read books or websites could be used to assist in this process. Resources can be found for example on www.pcpld.org: the Palliative Care for People with Learning Disabilities Network. In the Netherlands, several versions of ‘wish books’ exist. These are books for recording the wishes of the person with ID concerning the funeral service and the contact details of relatives and other closely involved people. A version of a wish book (in Dutch) is included in a ‘signpost’ with information on end-of-life care. A practical ‘working book’ for people with ID was developed on the basis of our group interview study (Chapter 3). This practical book can be used to assess and record the wishes of people with mild ID regarding their end-of-life care (Bekkema et al. 2015a).

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2. Increase the end-of-life care knowledge and skills of ID care staff

This thesis showed that ID care staff often lack knowledge and expertise regarding end-of-life care, which may lead to a) poor recognition of end-of-life care needs and b) poor treatment. Care staff should know how to appraise the end-of-life care needs of their clients, assess their own skills and assess who (within or outside their organization) is best able to provide this care. ID care services must therefore take adequate measures in order to equip care staff with the necessary expertise to be able to identify and sufficiently meet the end-of-life care needs of their clients. These needs are holistic, as confirmed by e.g. the people with mild ID in our study, so training should focus on symptom management as well as practical, emotional, social and spiritual support. Due attention should also be paid in training to ‘soft’ skills, as end-of-life care imposes high demands on the relationship qualities of caregivers - e.g. their ability to uncover wishes, listen carefully, empathize and closely observe the behaviour of the person with ID.

Training should focus particularly on the assessment of pain and other symptoms. People with ID, in particular those with severe/profound ID, have an increased risk of pain, related to problems with their physical health and general health (van der Putten & Vlaskamp 2011). This thesis underscores how challenging the identification of pain, anxiety and other signals of distress in people with ID is, and reveals that ID care staff receive almost no training in the use of assessment instruments. An awareness of the complexities of assessing pain and distress in people with ID is highly important, as also indicated by the White Paper on palliative care for people with ID: symptoms in people with ID may be masked, or expressed through behavioural changes (EAPC: Tuffrey-Wijne & McLaughlin 2015). Moreover, professionals should be conscious of the risk of ‘diagnostic overshadowing’: making diagnoses in which symptoms are incorrectly attributed to the intellectual disability instead of the disease. A systematic review of pain in people with ID shows that behavioural indicators of pain may include motor activity, facial activity, nonverbal vocal expression and socio-emotional indicators (De Knegt et al. 2013). Instruments have been developed to assess pain in people with communication difficulties and may contribute to a better management of pain and other symptoms (e.g. the DisDAT: Regnard et al. 2007; the Rotterdam Elderly Pain Observation Scale (REPOS): van Herk et al. 2009 and STOP-ID!, a self-reporting tool on pain in people with ID: De
General discussion

Knegt et al. (2015). Also, guidelines have been developed in the Netherlands to improve the identification of pain and physical problems in people with ID.2

Several other actions have been undertaken in the Netherlands to improve end-of-life care for people with ID:

- A number of ID care services have joined the national palliative care improvement programme of ZonMw (The Netherlands Organization for Health Research and Development), implementing end-of-life care interventions within their service. Examples of these interventions are ‘Signalling by carers’, a training course designed to improve the identification of changes in the condition, daily living activities or behaviour of clients receiving end-of-life care; ‘Stem-inspiration cycle’, a training course designed to make professionals and managers aware of their own values and norms when providing end-of-life care; and ‘End-of-life care consultants’, a programme for training nurses from ID care services in advising ID care teams about end-of-life care.

- Guidelines have been developed. They include a general guideline on end-of-life care for people with ID for professionals in this field3, covering e.g. diagnostics, treatment of symptoms, the farewell process and aftercare. Another guideline is about medical decisions at the end of life for physicians4, covering legal frameworks, ethical assumption, roles and responsibilities of stakeholders and including an aid for taking decisions at the end of life.

- Training has been developed, for example the blended learning education programme about end-of-life care for people with ID and a training course on palliative sedation for people with ID by the Netherlands Comprehensive Cancer Organization (www.iknl.nl), and training for end-of-life care volunteers in supporting people with ID (www.vptz.nl).

- Practical tools have been developed, such as: a ‘signpost’, to provide guidance in the care for people with ID5, covering e.g. communication issues, ethical questions and the coordination of care. Two practical tools for professionals have been developed on the basis of the studies underlying this thesis: ‘Caring until the last day’ (Bekkema et al. 2011), covering stories and

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3 http://www.pallaline.nl/verstandelijke-beperking (in Dutch)
5 http://www.kennispleingehandicaptensector.nl/kennispleindoc/showcases/WEGWIJZERpz-vg.pdf (in Dutch)
advice about end-of-life care for ID professionals, and ‘Decision-making about end-of-life care for people with ID’ (Bekkema et al. 2013a-c; Bekkema et al. 2015b), practical tools on how to make decisions about the best place for end-of-life care and the use of medical interventions in end-of-life care for people with ID.

Internationally, some end-of-life care training interventions for ID care staff have been developed (e.g. Reynolds et al. 2008; Reddall 2010; Hahn & Cadogan 2011; McLaughlin et al. 2012). Hahn and Cadogan (2011) for example developed, implemented and evaluated a palliative care curriculum and educational programme for ID care staff that covers e.g. general end-of-life care principles, values and choices, case-based scenarios, the spiritual and cultural context, the assessment of pain, and distress and symptom management. Reddall (2010) developed a palliative care resource for professional carers of people with learning disabilities, covering e.g. hospice care, cancer and symptom management. Other resources can be found at www.pcpld.org; the Palliative Care for People with Learning Disabilities Network.

3. Cooperate with end-of-life care experts outside ID care

Cooperating and sharing expertise with specialized end-of-life care services is vital for improving the quality of end-of-life care for people with ID. End-of-life care is still a rather infrequent type of care in ID care services and it is not possible for ID care staff teams to have all the necessary expertise to meet all end-of-life care needs. ID care staff should, however, know the boundaries of their own end-of-life care expertise and know when the input of other experts is necessary. Experts in end-of-life care can e.g. bring in specialized knowledge on the management of pain and medication, and expertise in advanced nursing treatments. ID care services as well as specialist end-of-life care services should invest in intensified partnerships and make ID care staff aware of the availability of consultation facilities.

Several developments are directed towards better cooperation within end-of-life care:

• In the Netherlands, ID care services can join the ‘palliative care networks’, a collaboration between healthcare providers in a particular region (www.netwerkpalliatievezorg.nl). These networks aim to optimize the organization of the end-of-life care for people in the region in question.

• A new development in the Netherlands is the creation of seven palliative care consortia to optimize end-of-life care throughout the Netherlands. Consortia are partnerships between expert centres, palliative care networks and the
Netherlands Comprehensive Cancer Organisation. End-of-life care for people with ID may also benefit from these new networks.

- Services may learn from best practices models that can promote partnerships between ID care and specialist end-of-life care services, e.g. from the partnership framework developed by McLaughlin et al. (2014).

4. Provide care for carers

If ID services wish to invest in the quality of end-of-life care, they should make care for carers a priority. The emotional struggles of ID care staff who provide end-of-life care seem to reveal an inner conflict, which is currently given insufficient consideration as we hardly encountered any formal implementation of care for carers in our studies. Sufficient emotional support should be given to ID care staff who provide end-of-life care, with due attention to intrapersonal and interpersonal reflection. Care for carers could for example cover sufficient information for care staff concerning the illness and prognosis of the illness, information on the organization’s policy and procedures regarding end-of-life care, emotional support from colleagues and supervisors, and the intrapersonal search for the meaning of suffering, death and end-of-life care.

Some general guidelines (in Dutch) on end-of-life care (about care in the last days of life and palliative sedation) pay attention to care for carers 6.

Moreover, Buijssen et al. compiled a book on care for carers (Buijssen et al. 2003). This book features stories by carers about providing end-of-life care and provides insights into how a ‘care for carers’ programme might be set up.

5. Foster close cooperation between professionals and relatives

Good cooperation between care staff and relatives can improve the quality of end-of-life care. This thesis shows that a successful co-caring relationship between relatives and care staff is powerful and a big strength in providing good end-of-life care for people with ID. Yet, in some cases, communication and cooperation fails, e.g. due to the inexperience of care staff, different perceptions on what good end-of-life care entails or friction based on earlier disputes. It is therefore recommended that care staff, as well as ID care services, continuously invest in strong, good co-

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6 www.oncoline.nl/richtlijn/item/pagina.php?id=32589&richtlijn_id=770
caring relationships with relatives, preferably at a much earlier (and therefore less emotional) stage in the lives of people with ID.

6. Better prepared ID care services: set up an end-of-life care policy
As more and more people with ID will need end-of-life care in the future, ID care services should be better prepared and should set up an end-of-life care policy within their organization. In line with the findings of this study, ID care services should acknowledge the following aspects in developing this policy:

- ID care services should recognize that end-of-life care is an indispensable part of the ID care provision within the organization. This thesis shows that end-of-life care is not a core activity within ID care. Hence, only when managers make end-of-life care a priority and take responsibility for providing this care will it be possible to achieve an improvement in the quality of end-of-life care. If the value of end-of-life care is openly advocated within an ID care service, end-of-life care policies can be co-created that inspire employees to take their care to the next level.

- ID care services should endorse the vision that end-of-life care is about caring together. In line with the abovementioned recommendations an end-of-life care policy should at least cover ways to involve the person with ID, roles and skills of the different professions within the service, ways to increase the expertise of care staff, cooperation with specialized end-of-life care services, co-caring with relatives and care-for carers.

- Finally, ID care services should make it easier for relatives and care staff to actually be there for the person. End-of-life care ultimately comes down to satisfactorily meeting the end-of-life care needs of the person with ID. Assessing if the right needs are being met is complex in people with ID, as this thesis stresses. Hence, services should prioritize and facilitate having care staff and relatives actually be there for the person with ID, so they can closely observe their needs and find out if their care has been effective.

Implications for further research

As end-of-life care for people with ID is a 'young' research topic, many topics deserve further exploration. The following recommendations are made for future research.
1. Explore barriers in equal access to end-of-life care provided by general care providers

People with ID have the right to enjoy the highest attainable standard of health, and the right to use the same community services and facilities as are available for the general population (UN 2006). People with ID therefore have the right to equal access to end-of-life care provided by general care providers outside ID care, such as hospice care and home care teams. It is as yet unknown how accessible end-of-life care by general care providers is for people with ID in the Netherlands, and what experience these providers have in caring for people with ID. International studies do indicate that people with ID are underrepresented in end-of-life care by general care providers (Tuffrey-Wijne & McLaughlin 2015; Heslop et al. 2013). Future studies should therefore provide insight into the accessibility of end-of-life care by general care providers for people with ID, and into ways in which these providers can deliver proper care for this special group. Moreover, studies should explore how ID care providers and general care providers can cooperate sufficiently to improve the quality of end-of-life care for people with ID, irrespective of the setting in which the person resides.

2. Explore the strengths and challenges of the triadic relationship between the client, relatives and care staff

Although the value of relationship-based care is well documented in ID care, the strengths and challenges of the triadic client-relatives-care staff relationship, in particular in times when emotions run high, needs further exploration. This thesis indicates how complex and sometimes family-like care relationships between relatives and care staff can be, and how these relationships may positively or negatively influence the quality of end-of-life care. Further investigations are therefore recommended into the underlying values of people with ID, relatives and care staff regarding end-of-life care. A useful method might be to offer participants of all groups the same vignettes representing a hypothetical end-of-life care situation or dilemma, and subsequently ask them questions about their perspectives and values. Vignettes have been used previously in research on sensitive subjects, e.g. on violence amongst children (Barter & Renold 2000).
3. Study support and aftercare for relatives of people with ID

Care for relatives is a relevant part of end-of-life care (WHO 2015, Tuffrey-Wijne & McLauglin 2015). From our qualitative multiple-case study we know for example that the family can feel overwhelmed when confronted with decisions at the end of life. They often feel that the person’s dependency is magnified, which makes them feel highly responsible in their role of ‘proxy’. We also found that it could be challenging for relatives to cooperate and co-care with care staff. Moreover, having a relative with ID can generally have a great impact on your family life (Tuffrey-Wijne & McLauglin 2015). Yet, professional support and aftercare for relatives of clients with ID was not the focus of our study, nor has it been of other studies of end-of-life care for people with ID. Further research could therefore provide insight into 1) relatives’ own support needs, and 2) how proper support and aftercare for relatives could be developed and implemented within end-of-life care for people with ID.

4. Incorporate the perspectives of co-residents in end-of-life care research

If people with ID live in a group home or residential setting, they have relationships with co-residents with ID. When someone in the group becomes incurably ill, co-residents have to deal with this, which may not be easy. Co-residents have their own feelings of loss and grief, which has been the subject of research by Todd (2010) and Read & Elliott (2007). Co-residents may in some cases also fulfil a valuable supportive role in end-of-life care. According to the people with ID who we interviewed, co-residents could play an important role in e.g. providing psychosocial support for the ill person. Yet, although co-residents might have a close relationship with the ill person, our studies have not incorporated their views. It is therefore recommended that future studies focus on the perspectives of these important stakeholders and study what they feel is important in end-of-life care and how they could be involved.

5. Develop models on how to involve people with ID in decision making

The wishes of people with ID are often not explicitly taken into account in decisions about the place of care and the use of burdensome medical interventions. Many issues concerning decision making arise from our studies, such as the following. Can standard informed-consent procedures adequately incorporate the preferences of people with ID? What factors influence decision making in end-of-life care for people with ID? How can the interests of the person with ID be distinguished from the interests of relatives and care staff when they are so deeply involved? Are
existing models for decision making, such as *shared decision making* (Bélanger *et al.* 2011) and *supported decision making for involving people with cognitive disabilities* (Peisah *et al.* 2013), suitable for (all) people with ID? Future studies should further investigate how people with ID could be involved in decision making in end-of-life care, including the exploration of which types of decision making models and frameworks are appropriate given the diversity of people with ID.

6. **Continue research on identifying and interpreting pain and other symptoms in people with ID**

Managing pain and other physical, psychosocial and spiritual problems and symptoms is of central importance in end-of-life care (WHO 2015). Pain can have a severe impact on the wellbeing and quality of life of people with ID (Walsh *et al.* 2011). Important research is being done (e.g. De Knegt *et al.* 2013 & 2015, van der Putten & Vlaskamp 2011). As highlighted by this thesis and many other studies, identifying and interpreting symptoms in people with ID is often difficult. It is therefore of vital importance that research is continued to better identify, interpret and relieve symptoms.

7. **Conduct more research on how to uncover the wishes and needs of people with severe/profound ID**

The complexity of uncovering the wishes and needs of people with ID in end-of-life care was a recurring finding in our studies, in particular regarding the care wishes of people with severe/profound ID. It appears to be hard to find out what they value in good end-of-life care, for example what makes them comfortable, what could help make them feel better, whether they are in pain or distress, and how they feel about transfers and the use of medical interventions. Hence, there is a need for insights into how wishes and needs could be uncovered. Future research could focus for example on the development of instruments or communication strategies to identify the wishes of people with severe/profound ID as well as their responses to end-of-life care.
References


