Summary
Providing good care for people with an intellectual disability (ID) at the end of life does not happen as a matter of course, for example because the intellectual disability makes it difficult for people to clearly express their wishes and care needs. Various people are involved in providing this care and they all have their own outlook on it. The aim of this doctoral research is to obtain a better picture of end-of-life care for people with ID, from the viewpoints not only of people with ID but also of relatives, care staff and physicians.

Introduction

Chapter 1 introduces the theme of the research. Intellectual disabilities are characterized by significant limitations in both intellectual functioning and adaptive behaviour that have arisen before the age of eighteen. People receive care and support above all from ID care services, mostly from care staff trained in social work, as well as nurses and nursing assistants. Medical care is generally provided by GPs and physicians specializing in the intellectually disabled (ID physicians). People with ID who are ageing are a vulnerable group: they often suffer from chronic diseases and multi-morbidity is more common than in the general population. Because the population group with intellectual disabilities is ageing and they often suffer from chronic, progressive diseases over lengthier timeframes, increasing numbers of people with ID are receiving end-of-life care.

Care at the end of life, also known as palliative care, is care that focuses on the quality of life for people with an incurable and ultimately fatal condition. It is known that care at the end of life for people with ID can be a challenge, for example because people with ID often have difficulty getting their wishes and needs across. The net result of this can be that they are not involved in the decisions about the final stage of life. In addition, there is a lack of knowledge among care staff in the ID care sector about somatic conditions and end-of-life care; that a client is suffering from an incurable condition is often only diagnosed at a relatively late stage. Often there is also relatively little cooperation between professionals in the ID care sector and professionals with specific expertise in end-of-life care.

The involvement of many different people means that attention needs to be paid to the relational aspects of this care. The challenges and bottlenecks mentioned earlier can also result in ethical questions coming to the fore, such as what is actually good care for someone with an intellectual disability at the end of their life, and who can
best take the decisions about such care. Care ethics, which is based on a view of human relationships and assumes the fundamental vulnerability and dependence of people, can help think through these ethical questions and relational aspects. Key ethical values such as attentiveness, responsibility and competence can help interpret research findings.

**Part 1: Care, needs and wishes of people with ID at the end of life**

**Chapter 2** presents the results of a retrospective case study. Forty-five interviews with relatives and professionals in twelve cases of people with ID who had recently died provided the basis for the analysis. This chapter shows five important shifts at the end of life for people with ID:

1. Care staff and relatives develop a new care strategy focused on offering comfort, tackling the symptoms and taking over tasks from the ill person. Many care staff members and relatives struggle to let go of the care strategy that they were used to, which was one of encouraging participation and independence.

2. In the final phase of life, finding a balance between keeping a professional distance and providing warm and tender care increasingly becomes a struggle for care staff (who are often closely involved emotionally).

3. Mutual cooperation among professionals, and between professionals on the one hand and relatives on the other, becomes increasingly important for recognizing and interpreting signs of pain or other symptoms.

4. Relatives experience more responsibility for taking medical decisions, which is related to the ill person’s increasing degree of dependence.

5. Awareness grows at the end of life that the ill person often has two ‘families’ who are looking after them: their biological family and the care staff.

Within these shifts, six values in the way relatives and care staff act appear to be important: ‘being there’ for the ill person, being responsive to their needs, being attentive to personal wishes and needs, reflecting on their own emotions and care relationships, being responsible for taking joint decisions in the interests of the ill person, and being open for cooperation, and sharing the care with others.

**Chapter 3** presents the results of qualitative group interviews held with people with mild ID. These were aimed at studying what people with ID themselves find
important within the care relationships for end-of-life care. Seven groups of people with mild ID (33 people in total) who were not receiving end-of-life care and were not incurably ill participated twice each in group interviews that were based on a nominal group technique adapted for the target group and the objectives of this study.

People with mild ID find two elements important within the care relationships at the end of life: dealing with the ill person’s wishes, and ‘being there’. Dealing with people’s wishes covers not only finding out and recording what they want (such as wishes about the care, final wishes for things that the ill person would still like to do, and what they want for the funeral) but also respecting those wishes. People with ID are sometimes afraid that their wishes will not be respected, something that seems to be based on their previous experiences in the care sector. ‘Being there’ is about offering practical support (for example with getting dressed, eating and drinking, as well as getting medical help from a physician), as well as emotional support (comfort, empathy, listening), social support (such as offering distractions) and spiritual support (such as talking about the impending death, their beliefs, or life). People with mild ID believe it is important to be able to have positive experiences and live comfortably to the very end.

The modified nominal group technique seems suitable for finding out what ideas people with ID have about end-of-life care. It is important here to give the participants a thorough explanation of the purpose of the study, to make sure that a trusted person is present during interviews, to use (supporting) image material and to hold two successive meetings so that the sessions do not last too long and the participants have time to prepare themselves for the second meeting. It is also important to make sure there is support outside the sessions, should any of the participants feel a need for it.

Chapter 4 is also based on the retrospective case study, describing how care staff and relatives actually respect the autonomy in the care at the end of life. Respecting the autonomy of people with ID comes to the fore in particular during transitions, for instance when helping the ill person understand new information about their condition, finding out about any changes to the needs and wishes, and in important decisions. Professionals and relatives however often find it difficult to work out just how much information the ill person wants about the disease, particularly in people with severe ID. Care staff and relatives often do not really know how they should communicate about severe illness and death, and social workers in particular do not
know enough about care at the end of life. Finding out what people want is complex, particularly because wishes can change at the end of life and because the wishes of people with severe ID are often ‘hidden’. In addition, the wishes of the person who is ill can sometimes conflict with the wishes of others. On top of that, the increasing dependency of the ill person is difficult, in particular for the relatives of people with severe ID, especially when they have to take important decisions.

A variety of skills of the care staff and relatives turn out to be important for respecting autonomy: paying attention to the ill person’s need for information, connecting, recognizing care needs, creating scope for the wishes and preferences to be expressed, and being able to discuss dilemmas.

Respecting the autonomy of people with ID at the end of their lives is, in terms of care ethics, a ‘relational construct’ that can be achieved together with the ill person.

Part 2: Decision making at the end of life of people with ID

Chapters 5 and 6 are about a survey in the form of a questionnaire for care staff about decisions involving the place of care and potentially burdensome medical interventions, such as further diagnostic investigations, chemotherapy, an operation to extend the lifespan or pain control using an infusion pump. The questionnaire was sent to 294 ID care staff (67% response), 273 ID physicians (53% response) and 1000 GPs (38% response).

The professionals surveyed believe that everything possible should be done to ensure that the client can remain in their own home until the very end (Chapter 5). They also believe it is important that 24-hour care should be available. When deciding not to move the client, the familiarity with their own residential environment is an important consideration, as is the expertise of the team in providing care at the end of life. Considerations in favour of moving a client are largely related to the lack of expertise in their own team and the client’s home not being suitably laid out. Although many professionals believe that the client’s wishes about where they want to live should always be paramount, the client’s wishes were not often listed as one of the considerations. This discrepancy suggests that more attention should be paid to involving people with ID in such decisions.

Furthermore, professionals listed the quality of life and the wellbeing of the ill person the most often as considerations in decisions about whether or not to start or continue a potentially burdensome medical intervention (Chapter 6).
Professionals have a range of opinions about whether people with ID should or should not always be informed about a medical intervention. Opinions also differ as to whether a person’s rejection of a medical intervention should always be respected. The wishes of relatives are explicitly listed more often as a consideration than the wishes of the ill person themselves. The best way to involve people with ID in medical decision-making needs further investigation.

Part 3: Expertise and training needs of ID care staff

Chapter 7 presents the results of a survey study among care staff in the ID care sector. It examines what care staff think of the quality of end-of-life care within their team or department, what training they have had about care at the end of life, and what additional training they would like to have for it. The questionnaire was sent to 181 care staff members (72% response).

The majority of care staff members are positive about the quality of the end-of-life care within their team or department. Nevertheless, 85% of them do not feel they are sufficiently well trained to provide good end-of-life care. Instruments for helping to measure pain, for instance, are rarely discussed in their training. Care staff would like additional training, particularly for assisting the client in dealing with the impending death and saying their farewells. In comparison with social workers, those with nursing backgrounds have had more training about care at the end of life and have less of a need for additional training. The questionnaire survey also shows that care staff are often not aware of the options for consultations about end-of-life care.

General discussion

Chapter 8, the general discussion, looks at the quality of care at the end of life. It points out how important it is that trusted people should be present for care at the end of life; people who know the ill person well and are well able to interpret their signals. ‘Being there’ requires good relationship skills that are related to a vision of care that is based on care ethics. The chapter also examines the fact that care staff are often strongly willing to take on the care at the end of life, as well as looking at the lack of knowledge and skills that they have in the palliative care domain. A lack of knowledge can for example result in signals pointing to pain or other symptoms.
not being (timely) recognized. The quality of care at the end of life can be improved inter alia through additional training for supervisors and better cooperation between ID care services and organizations that specialize in end-of-life care.

It is essential to find out the wishes of people with ID and increase their involvement in decisions about care at the end of life. Trust is a key factor in this: both confidence in the opportunities for the ill person to be involved and confidence in the skills of relatives and care staff for involving them. This trust is not always present, meaning that people with ID may feel they are not being understood and heard. This underlines the importance of a relational approach to respect autonomy.

Good cooperation is also essential for the recognition and alleviation of symptoms. The bonds between relatives and the ID case service – links that often go back years or even decades – make the care relationship between relatives and the care staff unique within the healthcare sector, as well as making it (potentially) very valuable for offering care jointly at the end of life. Nevertheless, the various challenges in the relationship between relatives and the care staff (such as conflicts about who decides or helps decide about what and the higher level of expectation that relatives have regarding the care staff members' knowledge) require greater openness in the communications and more support from the organization. This special bond that the care staff often have with their clients is discussed, along with what this means for end-of-life care. ‘Caring for carers’ is important, with plenty of scope for reflection among the care staff on their care relationships and their own emotions and values.

‘The challenge of caring together’ (the title of this thesis) is about the special attention that three care relationships require. Firstly, the relationship with the person with ID: involving the ill person in the end-of-life care and the decisions about it. Secondly, the relationships between professionals themselves, because good cooperation is extremely important in ensuring appropriate responses to symptoms (among other things). Thirdly, there is the relationship between professionals and relatives, because good relations between the parties involved are important for good care at the end of life.

Going on from what was described earlier, this concluding chapter contains practical recommendations for involving people with ID in their care and decisions about it, encouraging expertise and ‘care for carers’, cooperation between care staff in the ID care sector and professionals with specific expertise in end-of-life care, cooperation between relatives and professionals, and developing targeted policy for care at the end of life within the ID care sector.
This concluding chapter also looks at the methodological considerations. One limitation of this doctoral research is for instance that the opinions of ill people with ID who are already receiving end-of-life care were not studied. The viewpoints of co-residents of clients receiving end-of-life care were also not examined. However, the viewpoints of various other relevant parties were included: people with ID who are not yet ill, relatives of deceased people with ID, and various groups of professionals. This has made it possible to paint a rich and subtle picture of end-of-life care for people with ID.

Another strength is the combination of qualitative and quantitative methods, which allowed us both to obtain information from representative groups of professionals and to obtain insights into the personal stories of people with ID, their relatives and professionals.

A recommendation for further study is to obtain greater insights into (possible) limitations in the accessibility of care at the end of life for people with ID outside the ID care sector. Follow-up studies are also needed to obtain more insights into how to encourage good relationships between the ill person, relatives and care staff at the end of life. Research would also be desirable to obtain insights into the viewpoints of co-residents on end-of-life care. Other topics for follow-up research are caring for the relatives of people with ID, strategies for involving people with ID more in decisions about end-of-life care, and the possibilities for recognizing pain and other symptoms of people with severe ID at the end of life, as well as determining what their care wishes are.