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General introduction
Joe, a man aged 40 with a severe intellectual disability (ID), suffered from incurable lung cancer. He lived in a small-scale residential home on the premises of an ID care provider. Joe’s situation worsened and communicating with him became an even greater challenge. Joe’s sister: “I really wanted to talk to him at the same level for just one day – so that he could tell me what he wanted and how he felt”. The question was raised where Joe would stay. Joe’s social worker was emotional about this: “Clients often move to a more specialized care setting, but the wish of the whole team was: Joe should stay here. We wanted to do it ourselves [...] We all loved Joe. He was more than just a client to us”. Although Joe’s sister was happy that Joe could stay with his familiar care staff, she struggled to cooperate with the staff and was critical about their experience of end-of-life care: “I think they lack a lot of experience, which they cannot be blamed for, as they don’t often have one of their clients dying. You really miss that experience though, as relatives”.

Joe’s case highlights how challenging end-of-life care for people with ID can be. Communicating with Joe, discovering what his needs and wishes are, the team’s expertise and cooperation between his sister and care staff - none of these things are self-evident. These challenges, amongst other topics, will be addressed in this thesis in an attempt to explore further the nature of end-of-life care for people with ID. This introduction first considers the characteristics of people with ID, their care and the way they age. Then, key literature on the challenges in end-of-life care for people with ID is presented as well as the role of relational aspects within this care. At the end of the chapter, the aim and structure of the thesis are set out.

**Characteristics of people with intellectual disabilities**

Individuals with ID are characterized by significant limitations, from before the age of 18, in both intellectual functioning and adaptive behaviour (Schalock et al. 2010). Usually, an IQ below or around 70 indicates a limitation in intellectual functioning (AAIDD 2015a). There are no exact numbers of the prevalence of ID in the Netherlands, but recent estimates suggest there are approximately 142,000 people with an ID with an IQ < 70, of whom 74,000 people with an IQ between 70 and 50 and 68,000 people with an IQ below 50 (Woittiez et al. 2014). Traditionally, the level of intellectual functioning is classified as follows: mild IQ (IQ 50/55-70), moderate ID (IQ 35/40-50/55), severe ID (IQ 20/25-35/40) and profound ID (IQ below 20/25) (Buntinx et al. 2014).
Care for people with intellectual disabilities

In 2013, 163,615 people in the Netherlands had an indication for care based on their intellectual disability (monitor langdurige zorg 2015). In the Netherlands, the care for people with ID is often provided by ‘ID care services’. These are usually services that primarily provide care for people with ID, or a service offering combined care for people with intellectual and/or other disabilities, such as sensory and physical disabilities (Kwartel 2013). In 2013, 72,200 people with ID lived in accommodation provided by an ID care service (VGN 2015).

Since the de-institutionalization of the care for people with ID in the 1970s, more people with ID live within the community, in group homes or ordinary homes. As in other Western countries, the trend towards integration in society and community-based care is strong in the Netherlands (United Nations 2006; WHO 2011). Yet European countries do differ in their policies related to the process of de-institutionalization. In countries such as Sweden and Norway, large residential institutions no longer exist and the process of de-institutionalization in the UK is well advanced too (Beadle-Brown et al. 2007; Mansell & Beadle-Brown 2010). In the Netherlands and countries such as Belgium, Germany, Spain and Greece, de-institutionalization is progressing, but residential settings still exist (Beadle-Brown et al. 2007; Mansell et al. 2007). Although exact numbers are lacking, this may mean that relatively more people with ID live within institutional or semi-institutional settings in the Netherlands compared to other countries such as the UK.

In the Netherlands, care staff for people with ID have varying backgrounds, but the large majority are social workers (in Dutch: agogisch begeleiders), followed by nurses and care and nursing assistants (VGN 2015). As reflected in data for 2004 and 2014, the proportion of nurses working in the care for people with disabilities in the Netherlands is decreasing, while the proportion of social workers is increasing (van der Windt & Bloemendaal 2015; van der Windt & Talma 2005). Internationally, the background, training and qualifications of care staff in ID care are not well defined. An expert consultation among several European countries suggests that ID care staff in Europe differ in their qualifications, and encompass e.g. staff with limited educational qualifications, social workers and nurses specialized in ID (Bekkema et al. 2015). Reports from the UK suggest that many UK care staff members who support people with ID on a day-to-day basis have no formal qualifications (Mansell 2006).

As regards medical care, people with ID in the Netherlands are usually cared for by general practitioners (GPs) or ID physicians. Dutch ID physicians have received
People with intellectual disabilities: a vulnerable ageing group
Health care has improved to such an extent that people with intellectual disabilities are also living longer than in previous decades (Coppus 2013). Yet adults with ID often age while suffering from various life-limiting chronic illnesses, such as progressive cancer, chronic cardiovascular diseases, chronic lung diseases and dementia (Janicki et al. 1999; Tuffrey-Wijne et al. 2007). A Dutch study among 1050 people with ID aged 50 and older showed that their frailty is comparable to the frailty of people aged 75 and older in the general population (Evenhuis 2014). Also, the prevalence of multimorbidity is high: 79.8% of the people with ID aged over 50 in the study suffered from two or more chronic conditions (Hermans et al. 2014). An Irish study on multimorbidity showed similar results and even showed that multimorbidity was high (63%) in a younger age group of people with ID (40-49 years) (Mccarron et al. 2013). Appropriate identification and management of increasing comorbid conditions is further complicated by the variety of syndrome-related ageing issues (Perkins & Moran 2012). Their poor health status in combination with their intellectual disabilities makes people with ID a vulnerable ageing group.

End-of life care for people with intellectual disabilities
As people with ID live longer and age with chronic illnesses, they suffer longer from conditions that eventually lead to their death. As a result, more people with ID are in need of end-of-life care for a longer period.

There are several definitions of end-of-life care. In this study, end-of life care is defined as the care aimed at the quality of life of a person with a life-threatening illness that is expected to result in the person’s death. The quality of life is enhanced by relieving pain and other distressing symptoms, incorporating the holistic needs of people as reflected in physical, psychological and spiritual support. End-of-life care parallels ‘palliative care’. Palliative care is defined as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early
identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2015). Palliative care may start early in the trajectory of a life-threatening illness, and curative and life-prolonging interventions may initially co-occur with palliative care (Lynn & Adamson 2003). 1

End-of-life care for people with intellectual disabilities may be particularly difficult because of the combination of complex medical problems, behavioural problems (in some cases) and limitations to verbal communication. Research literature indicates challenges in several areas:

- **The challenge of communication with people with ID.** Communicating with people with ID about their illness and their wishes and needs is found to be challenging (Tuffrey-Wijne et al. 2007). E.g. adequately assessing symptoms in people with severe/profound ID and severe communication problems is found to be very difficult (Tuffrey-Wijne et al. 2007). Moreover, for staff in palliative care services, communicating with people with ID can generally be difficult as these professionals are not trained in this or used to doing it (Stein 2008; Tuffrey-Wijne et al. 2008). Barriers to communication can hamper a good provision of end-of-life care (Tuffrey-Wijne et al. 2009 and 2010).

- **Lack of involvement of people with ID.** Studies suggest that people with ID are not always adequately involved in communication about their illness and in decisions about end-of-life care (Tuffrey-Wijne et al. 2009 and 2010; Wagemans et al. 2010 and 2013). E.g. Tuffrey-Wijne found that although most participants with ID were told they were ill, many were not helped to understand what this meant. Furthermore, in a retrospective study of medical files, Wagemans et al. (2010) found no evidence in the files that people with ID were involved in end-of-life decision making. The studies highlight how complex it is to involve people with ID who are near the end of their life in communication and decisions.

- **Lack of expertise in end-of-life care.** To provide comprehensive, multidisciplinary end-of-life care to this challenging population, care staff and other professionals need various kinds of knowledge and skills. Yet studies suggest that care staff working with people with ID often lack expertise in

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1 In English, the term ‘end-of-life care’ is sometimes associated exclusively with terminal care (care in the final days or hours). We use ‘end-of-life care’ (and the Dutch equivalent ‘zorg aan het levens einde’) as a broader concept describing care that may start long before death (even months or years earlier). In this sense, end-of-life-care is a synonym for palliative care as defined by the WHO (www.WHO.int)
end-of-life care (Ng & Li 2003; Botsford 2004; Ryan et al. 2010; McCarron et al. 2010; Tuffrey-Wijne et al. 2007; Dunkley & Sales 2014). E.g. Ryan et al. (2010) found that Irish ID care staff often lacked confidence and training in end-of-life care. Likewise, a study in Australian ID community group homes revealed that less than one third of the professionals concerned received any training in end of-life care (Wiese et al. 2012). A review by Dunkley and Sales (2014) highlights that the training requirements of care staff need to be identified and that staff confidence needs attention.

- **Suboptimal cooperation between palliative care services and ID care services.**
  The literature suggests there is too little collaboration between ID care services and specialist palliative care services, such as hospices or palliative care units in hospitals or nursing homes (Dunkley & Sales 2014). Effective collaboration may be hampered by differences in care approaches between these services and by skill limitations (Friedman et al. 2012; McCarron et al. 2010; Ryan et al. 2010; Tuffrey-Wijne et al. 2008).

- **Late recognition of needs for end-of-life care.** The above may contribute to the fact that the end-of-life care needs of people with ID are often recognized only at a late stage, when death is very close (Heslop et al. 2013). This is alarming, as late recognition may lead to sub-optimal care and unrelieved suffering in the final stage of life.

The challenges in end-of-life care for people with ID pose the risk that end-of-life care is not being properly adapted to the needs of people with ID. End-of-life care for people with ID should therefore be further explored and improved by incorporating the perspectives of the most important stakeholders: people with ID, relatives and professionals (in particular care staff and physicians).

**Relational aspects and care ethics**

The abovementioned challenges reveal that various people are involved in end-of-life care for people with ID and that many of the challenges are relational issues at heart. Taking Joe’s case, cited at the start of the Introduction, as an example: uncovering the needs and wishes of Joe, who was severely disabled, inevitably required good relational skills. Honouring the wishes and autonomy of people with ID at the end of their lives is generally seen as an important principle (AAIDD 2015b). Yet uncovering the wishes of people like Joe may be complex and not self-evident. Besides, Joe’s relatives and care staff had to build a relationship in order to find ways to cooperate and provide proper end-of-life care for him. Hence, caring for
someone like Joe is not easy. It likely raises ethical issues, such as what is the best care for Joe and who should decide about this care.

In order to explore such ethical issues within the practice of end-of-life care for people with ID, care ethics may provide a useful approach. There are two relevant reasons why care ethics is well suited to a better interpretation and understanding of end-of-life care for people with ID and its relational aspects: 1) care ethics is based on a relational human-centred vision and thus aligns well with end-of-life care, focusing both on patients and their significant others (Leget 2013); 2) care ethics also aligns well with the care for people with ID, as care ethics is based on the fundamental vulnerability and dependence of people, and most people with ID have always been more or less dependent on others. At the end of life, when people with ID become increasingly frail, this dependency may be even more pronounced.

By homing in on the dependency of people and the importance of care relationships, care ethics may contribute to our understanding of the practice of end-of-life care for people with ID. Core elements of care ethics are for example: attentiveness to recognize the need for care, responsibility for taking on the care when the need for care is recognized, competence (the moral quality, knowledge and resources) to provide actual care, and the responsiveness of the care receiver to the care (Tronto 1993). Care ethics has become important in the thinking about people with ID (e.g. Verkerk & Maeckelberghe 2003; Kittay 2011). Care ethicist Kittay for example states “It is only with care, and care of the highest quality, that she can be included, loved, and allowed to live a joyful and dignified life”, when she writes about her own daughter with severe ID (Kittay 2011, p. 52).

**Aim and structure of this thesis**

End-of-life care for people with ID is a relatively young research topic (Todd 2003; Todd et al. 2013). Only in recent years has the volume of research and the scientific body of knowledge slowly started to increase. The general aim of this thesis is to further explore end-of-life care for people with ID from the perspectives of people with ID, relatives, care staff and physicians. This thesis aims to gain a better understanding in three areas: 1) the care, needs and wishes of people with ID at the end of life; 2) decision making at the end of life of people with ID; and 3) the end-of-life care expertise and training needs of ID care staff. Six research questions were formulated, and several different research methods were used to address these questions. This thesis is set up as follows:
Part 1: Care, needs and wishes of people with ID at the end of life

Part 1 concentrates on the care, needs and wishes of people with ID at the end of life. It describes whether and how relatives, care staff and physicians change their care approach and attitudes when the death of a person with ID is imminent, as end-of-life care may not be naturally embedded in ID care services. It also deals with the dimensions of the care relationship that people with ID themselves find important for good end-of-life care, as people with ID may have different views on care than care staff, physicians and relatives. Finally, it studies how relatives, care staff and physicians shape respect for autonomy in the end-of-life care for people with ID. The following main research questions will be addressed in Chapters 2 to 4:

- Chapter 2. Do relatives, care staff and physicians perceive a shift in their care approach and attitudes when the death of a person with ID is imminent? And if so, what shifts in care approaches and attitudes do they perceive? And what values underlie these shifts?
- Chapter 3. Which dimensions of the care relationship in end-of-life care are perceived as relevant from the perspective of people with ID?
- Chapter 4. How do relatives, care staff and physicians shape respect for autonomy in the end-of-life care for people with ID?

Two qualitative studies were conducted to answer these research questions. The first study (Chapters 2 and 4) consisted of a retrospective multiple-case study design, interviewing those relatives, care staff members and physicians involved in the care for a person with ID at the end of life.

The second qualitative study (Chapter 3) consisted of group interviews with participants with ID, using the nominal group technique to guide the discussion.

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

Part 2 addresses decision making in end-of-life care for people with ID. Two types of decisions that often have to be made and may lead to dilemmas are decisions regarding the place of end-of-life care and the use of medical interventions. Is it better to move a person with ID to a place offering more specialized care, but which is not familiar to the person? And should one start a medical intervention that is potentially burdensome for a person due to their limited level of understanding and communication difficulties? To enhance well-considered decision making, we need insight into the beliefs and actual considerations of care staff and physicians in making such decisions. The following research questions will be addressed in
Chapters 5 and 6, based on a quantitative survey study among ID care staff, ID physicians and general practitioners:

- Chapter 5: What considerations and beliefs do care staff and physicians have concerning decisions on the place of end-of-life care for people with ID?
- Chapter 6: What considerations and beliefs do care staff and physicians have concerning decisions about the use of potentially burdensome medical interventions in the end-of-life care for people with ID?

Part 3: Expertise and training needs of ID care staff

Part 3 focuses on the expertise and training needs of care staff working in ID care services in the Netherlands. Although growing attention has been paid in the Netherlands to the quality of end-of-life care in ID care services, earlier studies suggest that ID care staff may have insufficient expertise in end-of-life care (Bekkema et al. 2011). In order to further promote good care for incurably ill people with ID, more insight is needed into vocational training in end-of-life care, the training needs and the consultation options of ID care staff (nurses as well as social workers). The following research question will be addressed in Chapter 7, based on a quantitative survey study among care staff:

- Chapter 7: What views and needs do care staff in ID care services have with regard to their expertise and training in end-of-life care?

Finally, Chapter 8 concerns the general discussion, in which reflections are made concerning the main findings, methodological considerations are discussed, and the implications for practice, policy and research are examined.
References


Leget C. (2013) *Zorg om betekenis Over de relatie tussen zorgethiek en spirituele zorg, in het bijzonder in de palliatieve zorg*. (Care about meaning. About the relationship between care ethics and spiritual care, in particular palliative care). Oratie (Oration); Humanistics University Press.


