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## Perspectives of people with mild intellectual disabilities on care relationships at the end of life: A group interview study

NIENKE BEKKEMA<sup>1</sup>, ANKE JE DE VEER<sup>1</sup>, CEES MPM HERTOGH<sup>2,3</sup>, ANNEKE L FRANCKE<sup>1,3,4</sup>

<sup>1</sup>Netherlands Institute of Health Services Research (NIVEL), Utrecht, The Netherlands

<sup>2</sup>Department of General Practice and Elderly Care Medicine, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

<sup>3</sup>Expertise Center for Palliative Care, VU University Medical Center, Amsterdam, The Netherlands

<sup>4</sup>Department of Public and Occupational Health, EMGO Institute for Health and Care Research, VU University Medical Center, Amsterdam, The Netherlands

### ABSTRACT

**Background:** Care relationships are crucial in tailoring the end-of-life care of a person with intellectual disabilities (ID) to their needs. Yet, almost all studies on end-of-life care for people with ID have been conducted among caregivers. The views of people with ID about care relationships at the end of life have not been a specific focus of research.

**Aim:** To explore relevant dimensions of the care relationships in end-of-life care from the perspectives of people with mild ID in the Netherlands.

**Design:** Group interviews were conducted using nominal group technique. Interviews were inductively analysed by two researchers.

**Setting/participants:** Seven groups participated (33 people). Inclusion criteria were as follows: having mild ID, being able to decide about participation and give informed consent, and not receiving end-of-life care. All groups were interviewed twice.

**Results:** Two dimensions of care relationships were found: (1) 'Ascertain, record and honour wishes' of the ill person. Adequately dealing with care wishes, 'last wishes' and funeral wishes was of central importance: 'it's about their life'. We found an emphasis on control that seemed to reflect the participants' experience that respecting autonomy does not always happen. (2) 'Being there': Ill people need people who are there for him or her, practically, as well as emotionally, socially and spiritually. Participants placed specific emphasis on providing positive experiences.

Conclusion: The views of people with mild ID highlight the high demands which end-of-life care imposes on relational qualities of caregivers. This study shows the added value and potential of involving people with ID in studies on end-of-life care.

### **What is already known about the topic?**

- Care relationships are crucial in tailoring the end-of-life care of people with intellectual disabilities (ID) to their needs.
- Almost all studies on end-of-life care for people with ID have been conducted among care professionals or relatives.
- The views of people with ID themselves about care relationships at the end of life have not been explored.

### **What this paper adds?**

- According to people with mild ID, ascertaining, recording and honouring wishes are central dimensions of care relationships at the end of life.
- The prior experiences of people with mild ID highlight the fact that respecting their autonomy does not happen as a matter of course.
- Terminally ill people with ID need other people to be there, in a practical, emotional, social and spiritual sense.
- Creating opportunities and positive experiences in end-of-life care is important for people with mild ID.

### **Implications for practice, theory or policy**

- End-of-life care places high demands on the relational qualities of caregivers, such as being able to ascertain the ill person's wishes, console them and empathise with them.
- People with mild ID are able to discuss ideas about end-of-life care and should be involved more systematically in research and practice development.

## **INTRODUCTION**

Individuals with ID are characterised by significant limitations, from before the age of 18 years, in both intellectual functioning and adaptive behaviour.<sup>1</sup> Many people with ID rely on others for care and support. People with ID form a diverse and special group of care recipients in end-of-life care, for example, because of their limited level of understanding and the challenges of communicating with them.<sup>2-4</sup> End-of-life care for people with ID needs improvement as palliative care needs are often not recognised until late,<sup>5</sup> cooperation between palliative care services and ID care services is often suboptimal and many care professionals in ID care lack expertise in end-of-life care.<sup>6-12</sup> Moreover, people with ID are not always involved in communication about their illness and decision making.<sup>3,10,13-16</sup> This poses the risk that end-of-life care is not adequately adapted to their needs.

Caring and trusting relationships contribute to a better quality of life for patients in need of end-of-life care.<sup>17</sup> As many people with ID become even more dependent on others due to the combination of existing cognitive impairments and physical impairments resulting from a life-limiting illness, good caring relationships are of paramount importance for terminally ill people with ID. Several studies among care

professionals and relatives have shown the importance of relational aspects in end-of-life care for people with ID, such as being responsive to the person's needs, having a trusting relationship and giving them space to show their wishes and preferences.<sup>2,18-21</sup>

Almost all scientific studies on end-of-life care for people with ID have been conducted among care professionals or relatives.<sup>2,8,9,11,14,20</sup> Studies exploring the views of people with ID about end-of-life care are rare. Among the few exceptions is the work of Tuffrey-Wijne, who used an observational approach to study the experiences and needs of people with ID who had cancer. She found, for example, a lack of power to make decisions among people with ID and a lack of adequate information about their illness.<sup>3,10,22</sup> Tuffrey-Wijne et al.<sup>23</sup> also tested and adapted the nominal group technique, where a single question is used to generate, record, discuss and rank ideas, to elicit the views of people with ID on the provision of end-of-life care. Another relevant study was performed by McLaughlin et al.,<sup>24</sup> who held focus group interviews with people with ID about end-of-life care with the aim of using the findings to improve education for professionals. These studies demonstrate that people with ID are indeed capable of participating in studies on end-of-life care. But although their findings did include some relational elements, such as 'having family and friends around', they did not focus specifically on care relationships in end-of-life care.

It is evident that end-of-life care should be tailored to the person with ID's needs, and that care relationships are crucial in achieving this goal. So far, it is not known which dimensions of the care relationship people with ID themselves find important for good end-of-life care. People with ID may have different perspectives to care professionals and relatives, or place different emphases, on how people should take care of the incurably ill. Hence, the aim of this study is to explore the relevant dimensions of the care relationship in end-of-life care from the perspectives of people with mild ID.

## **METHODS**

### **Design**

Seven groups of people with mild ID were interviewed twice each, using qualitative group interviews. An adapted nominal group technique was used to structure the discussion. For this purpose, we further adapted the technique as used by Tuffrey-Wijne et al.<sup>23</sup> to suit our specific goal and piloted it successfully.<sup>15,16</sup>

### **Participants**

This study was conducted in the Netherlands in 2013–2014. A total of 33 people participated. Inclusion criteria were having a mild ID, being able to decide about participation and give informed consent, and not receiving end-of-life care. Although the inclusion criterion about not receiving end-of-life care was mentioned in the information letter for care professionals, it became clear during an interview that one participant had recently been diagnosed with incurable cancer. At his own request, he continued to join the discussions, which he enjoyed. Careful precautions were taken to ensure that the discussions were not stressful for him or the other participants. Six groups were recruited through six ID care services, and one group was recruited through a theatre company. To provide a safe environment, group sizes were kept small and interviews were held at a familiar location. All participants within a group

knew one other. One group consisted of actors in a theatre company, three groups of members of the local client council and three groups of co-residents. All participants received support from an ID care service. Most participants had (voluntary) work and/or hobbies (Table 1).

**[TABLE 1.]**

Ages ranged from 21 to 84 years; the mean age was 58 years and 76% of the participants were over 50. A total of 61% were men.

**Data collection**

The number of groups was not predetermined. In accordance with qualitative principles, data collection and analysis were conducted in a cyclical process. Data saturation – the point at which researchers did not observe any new information or themes – was attained after seven groups had been interviewed. In total, 14 group interviews of approximately 1 hour took place. N.B. facilitated 12 interview discussions and N.B. and A.d.V. jointly facilitated two interviews. Field notes were written after each interview. A familiar care professional was present during all interviews to help create a safe environment. We applied nominal group technique as follows:

During the first interview, a short picture story was told about a woman with ID who heard from her doctor that she was incurably ill. Participants were asked the following question: *what can people do to take good care of her?* The interviewer explained that all sorts of ideas were welcome and equally important. Participants were first asked to think for themselves and were then invited to share their thoughts. Ideas were discussed in the group and the interviewer encouraged the participants to come up with more ideas. All ideas were written down. Once no more new ideas emerged, the ideas were summarised. Sometimes one or two new ideas were added. Finally, the first interview was evaluated and brought to a close.

After 2–3 weeks, the second interview took place. In the meantime, the interviewer had ordered the ideas of the group and had made a card illustrating each idea. The number of ideas per group varied from 8 to 13. The goal of the second interview was threefold: to validate the results of the first interview, add any in-depth insights and rank the ideas. The ideas were presented and participants were asked whether they recognised the ideas. They were invited to add insights and further explain their ideas. Each participant then received a set of cards and was asked to divide the ideas into two piles, one for the ‘best’ ideas and one for other ideas – until four best ideas were left over. Some participants needed assistance in this selection process. Participants then voted using ballot boxes; the top best idea received four points, the next best idea three and so on. Votes were counted and the three ideas with the most points were announced to the group. Finally, the second interview was evaluated and brought to a close. Participants’ reactions to the interviews were very positive in all groups.

Aftercare was discussed with the care professional to ensure that support was available. Participants were told who they could turn to within the care service if they needed emotional support and were given the contact details of the researcher if they wished to talk to the researcher. All participants received a feedback report listing the ideas, the outcome of the voting and the interviewer’s contact details.

## Analysis

Interviews were audiotaped and transcribed verbatim. Data were analysed inductively, using thematic analysis.<sup>25</sup> Important elements of thematic analysis are familiarising with the data, generating initial codes, searching for themes, reviewing and defining themes and writing down the results. Thematic analysis was applied as follows: interviews were re-read and codes were ascribed to those text fragments potentially reflecting dimensions of care relationships. Descriptive codes were used directly based on interviewees' wordings (such as *ask what she wants to eat*), as well as interpretative codes (such as *providing consolation*). Interview fragments with the same codes were constantly compared. To ensure reliability, all interviews were coded independently by N.B. and by one of the co-authors. Correspondence between interpretations and the original interviews was continuously verified, and differences in analysis and interpretations were discussed. After coding all transcripts, potential themes were formulated. These themes were then reviewed in relation to the coded text fragments and transcripts. Finally, themes were refined and written down. MAXQDA 2011 was used to facilitate the analysis ([www.MAXQDA.com](http://www.MAXQDA.com)). The quantitative outcomes of the voting gave direction to the prioritising of ideas, but were not part of the qualitative analyses. The voting outcomes have also been used to compile a practical book about end-of-life care for people with ID.<sup>26</sup>

## Ethical consideration

The protocol and topic list for conducting the group interviews were approved by the Medical Ethical Committee of the VU University Medical Centre. Prior to the interviews, all participants received a pictorial information letter informing them of the aim and course of the study, as well as an accessible informed consent form. The information letter explained that study participation was voluntary. If needed, a care professional helped the participants with reading the information. The study goal and procedure were repeated orally before the start of the interview. All participants gave written informed consent. The transcripts of the interviews were made anonymous and non-traceable to individuals.

## RESULTS

Two main dimensions of care relationships in end-of-life care could be identified from the interviews with people with ID: *ascertaining, recording and honouring the wishes* of the ill person and *being there* to provide *practical*, as well as *emotional, social* and *spiritual* support (Figure 1). The dimensions are explained below, illustrated by participants' quotes (names used are not the participants' real names).

### [FIGURE 1.]

#### Ascertain, record and honour wishes

##### *Ascertaining wishes*

Participants indicated that ascertaining the incurably ill person's personal care wishes and preferences is very important. Care professionals and relatives should find out what the person's practical care wishes are, such as which food they like or if they would like television or music in their room. The same applies to wishes regarding place of care: either home or another setting, and the person's medical care preferences, for example, regarding pain medication or medical treatments. Knowing

these wishes helps ensure that the person feels as good as possible; as one respondent put it, 'it is about *their* life'. Talking to the person and asking what he or she wants was mentioned as a way of ascertaining their care wishes. Or, if he or she is unable to talk, having preferably familiar people closely observe their behaviour or facial expressions:

- *Paula*: 'They should ask: "Can I get you anything? What can I do for you? Can I do some grocery shopping for you? Do you want to go outside? In a wheelchair, or ...?"' (I6R1)
- *Bert*: (If the person is unable to talk): I think the people who know her, her family and friends, the ones who were always around her, looked after her and sympathised with her, they should be able to see from her behaviour what her wishes are. (I1R3)

Participants emphasised that the last phase in life should also bring some joy and peace. The person's 'last wishes' should therefore be ascertained, by, for example, talking about what *trips* they would still like to make or what unfulfilled *dreams* they have. The ill person may want to go on holiday to somewhere sunny, go on a boat trip or go back to a favourite holiday destination. Participants stressed that knowing last wishes is important as these would be the last nice things that a dying person could do; it may provide satisfaction and peace:

- *Mick*: There are 'wish' ambulances (ambulances that take incurably ill people on a trip under medical supervision). You can choose where you want to go. Going to the beach for example. Doing something you like. The last thing you can do, as it were. I really like that idea. (I2R1)
- *Isaac*: You want the person to stay cheerful [...] Maybe you can talk to her about her wishes. Maybe she wants to meet her favourite pop singer. [...]. I find these things very important. That she is not only sad, but also has some joy. (I7R4)

Furthermore, participants indicated that ascertaining the person's wishes about *the funeral* is important as well. Many participants had attended funerals and had already thought about their own wishes regarding the burial or cremation, funeral service and what should happen to their personal belongings. Some participants even advocated that a person should be able to choose his or her own moment of death. Yet, they were concerned at the same time that this was not a realistic option:

- *Marcel*: Nowadays they have donor cards, but you can't say: I had a good life, I can't get better and I don't want to live anymore. I think that's a pity. (I5R4)
- *Carol*: It is important that you tell others what you want, your last wishes. [...] That the funeral service is done by a vicar. And that the co-residents can say goodbye. You can say what kind of service you want. A cheerful one or a sad one. [...] what I would like is being carried away by a horse and carriage. [...] just like my Dad. [...] my personal belongings should go to charity, to homeless people. I want to decide about this myself. (I4R1)

### *Recording wishes*

The discussions about wishes also seemed to express a deep desire that the person with ID should be in control. Participants stressed that wishes should not only be ascertained but also be recorded. This applied to wishes regarding medical treatments and even more to funeral wishes. Early recording of wishes, 'on paper' or on the computer, was acknowledged as a way of ensuring that the wishes were known and honoured, including after death. Several participants had filled in a 'wish book', a book regularly used in Dutch ID care to write down someone's preferences for the funeral:

- *Leo*: (about having a wish book). Well, if people die, they have a wish: being buried or cremated. They can fill in a wish book. (I7R1)
- *Aron*: (about the person's wishes regarding medical treatment) It could be that you can't speak anymore at the end, but if you have it on paper, then your doctor would know and then they wouldn't make a wrong decision afterwards. (I5R3)

### *Honouring wishes*

Yet, ascertaining and recording wishes do not automatically mean that they are honoured, a point made vigorously by some participants. Some referred to times in their life when their wishes had not been honoured, or expressed a general distrust regarding the honouring of the wishes of people with ID:

- *Bert*: If you put your wishes on the computer, are you still in control? *Maria*: I put everything on paper: in the Catholic Church and then cremated. I wrote that down on the computer in the office. *Bert*: How are you so sure they will look there when you're dead? *Maria*: Because they will look in the computer. *Bert*: But you don't know that. You'll be dead. [...]. *Bert*: People don't want us to think for ourselves and make decisions. They want to arrange everything themselves, they think: we know best, and we will decide. [...] that's their attitude. [...]. *Maria*: Anne (the woman in the pictorial story) should know for herself what she wants. Not a care staff member. [...] We have a right to tell them our wishes and say yes or no. A care staff member shouldn't decide. If they tell me: you should be buried, I'll tell them: no, I don't want that. I want to be cremated. That is my choice. (I1R3 and I1R4)

According to the participants, the most important aspect of dealing with wishes in the care relationship was that people should make sure that the person with ID is in control, that their wishes take priority and are actually honoured:

- *Aron*: It is important to do what was agreed. Else the care staff will fill in things for her, and not stick to the agreements they made. [...] What the person wants is the most important thing. (Interviewer: so what the person wants should get priority?)
- *Aron*: If possible and after agreeing things. [...] if it isn't possible, they should say that honestly, and explain why it isn't possible. (I5R3)

- *Marcel*: You should listen to her wishes. And 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. (I5R4)

## **Being there**

### *Being there in a practical sense*

Participants emphasised that when a person is incurably ill, (s)he needs care professionals or relatives to be there for practical help and doctors for medical help. This help is necessary as people may be very ill and unable to take care of themselves, for example, with regard to getting out of bed, washing, eating and drinking, and feeling comfortable. Participants also stressed the importance of continuous care and the availability of sufficient personnel. Regular physical presence is important, as well as 24/7 availability, for example, via an alarm system. Noteworthy, several participants had already contemplated whether they would be able to stay in their residence if they became ill. Some suggested that there would be insufficient staff where they lived:

- *Theo*: Somebody should be there. Someone who can help her. [...] I don't know if they have 24/7 care where she lives. That would be good. Good help. (I5R1)
- *Joe*: She should have an alarm bell. So she can call. And then they can come right away. (I6R2)

### *Being there in an emotional sense*

Participants associated 'being there' with emotional support as well. It meant not letting the person be alone and letting them know you are there to help them deal with their situation. Participants stressed that the person should be encouraged and consoled, for example, by saying comforting words, providing a listening ear and by empathising with their situation. This may help them calm down and not feel too sad. Familiar people who know and understand the person – in particular relatives and friends – were the best people to provide emotional support:

- *Aron*: You should visit, so she knows she isn't facing this alone. (I5R3)
- *Carol*: Say comforting words. That she doesn't need to be afraid. [...]. Tell her that it will be all right. That we are thinking about her. (I4R1)

### *Being there in a social sense*

Participants also strongly related 'being there' to social support. They described this in two different ways. The first way was instrumental: others should try to take the person's mind off his or her difficult situation so that (s)he is not always thinking about the disease, for example, by paying him or her a visit, reminiscing about shared memories, watching television, playing games together or getting some fresh air. The second way is related to fulfilling the person's last wishes. The person should be enabled to still experience fun and pleasure, for example, by accompanying the

person on a day out. Both approaches were directed at interacting with the person and helping him or her feel better and have more positive thoughts. Friends, co-residents and relatives were the best people to provide this social support:

- *Paula*: People should visit. The time will go quicker if someone is there, then you don't need to think about it. (I6R1)
- *Mick*: Take somebody outside if the weather is nice, and go for a walk. Try to make them think of other things, distract them. When my sister was ill, we took her on a trip in a wheelchair. On a boat with music. She really enjoyed that. That's something you could do for somebody, if it's still possible. (I2R1)

#### *Being there in a spiritual sense*

Participants also talked about the value of the support of spiritual caregivers, such as pastors, chaplains or general counsellors. Several participants said that spiritual caregivers are unable to cure you but they can provide spiritual guidance, bring peace and reduce fear. Some examples of how they could do this were looking back on your life, talking about fears, existential issues or religion and preparing the person for the terminal phase and imminent death:

- *Marcel*: You could talk to the pastor about how you want to be buried. [...] He could help you prepare for your death. Aron: And also bring up the nice things, the nice things that happened. (I5R4 and I5R3)
- *Bert*: If you're about to die, then it may help to hear about other people's experiences, or near-death-experiences of other people. [...]. Because many people are afraid. What will happen to you when you die [...]. If you talk about that, then you know that death is not something to be afraid of. That could be a personal victory. (I1R3)

#### **DISCUSSION**

In this study, seven groups of people with mild ID were interviewed twice. Two main dimensions of care relationships were found: (1) 'Ascertaining, recording and honouring wishes' and (2) 'Being there'. The first dimension is based on the view that adequately dealing with a person's wishes is of central importance in providing good end-of-life care: *it is about their life*. In caring for the person, their care wishes, last wishes and funeral wishes should not only be ascertained but also recorded and honoured. The second dimension is based on the participants' opinion that an ill person needs dedicated people who are there for him or her at the end of life. This support can be practical (providing practical and medical help), emotional (not letting the person feel alone and helping them deal with their situation), social (taking the person's mind off their situation and accompanying them in the fulfilment of their 'last wishes') and spiritual (providing spiritual guidance, bringing peace and reducing fear).

#### **Comparison with other studies**

'It is about what she wants and how she wants it': this statement reflects people with ID's desire that properly handling their wishes should be at the heart of caring relationships at the end of life. This is in line with the Caring at the End of Life

position statement by the American Association on Intellectual and Developmental Disabilities ([aidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life](http://aidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life)), which sees honouring wishes and autonomy as an important principle.

Autonomy is also a major principle in end-of-life care within the general population.<sup>27,28</sup> Yet what seems different here is the emphasis on control, which seems influenced by the prior experiences of the participants with ID. This was reflected in the fervent way in which participants discussed honouring wishes, their emphasis on advance directives, and in the distrust, scepticism and fear of some regarding whether their wishes would be honoured. Thus, respecting autonomy of people with ID does not seem to happen as a matter of course. This shows how crucial trusting caring relationships *throughout* life are for acknowledging and respecting the wishes of someone with ID, including at the end of life. This supports the view that autonomy is best seen as a relational concept<sup>2,29</sup> and that adequately dealing with people with ID's wishes requires continuous attention.

Being there, the other important dimension, was also felt to be important by caregivers of people with ID.<sup>19,21</sup> By referring to practical support as well as emotional, social and spiritual support, people with ID showed that they believe that dying people with ID should be treated as whole persons. This is in line with international definitions of end-of-life care and palliative care.<sup>30</sup> Noteworthy was the strong emphasis participants placed on being able to 'live life'. All people should have their mind taken off their situation, have positive experiences and be enabled to fulfil their last wishes. This focus on 'life' – which is occasionally highlighted in studies among the general population<sup>31</sup> – was not found so clearly in research among care professionals and relatives. Hence, this calls for more awareness of the need to create opportunities and positive experiences in end-of-life care for people with ID.

### **Strengths and weaknesses**

To our knowledge, this is the first study exploring the views of people with ID on care relationships in end-of-life care. The relevant dimensions add new insights to the few other studies in this area, for example, on cancer experiences of people with ID.<sup>3,10,22</sup> Their specific emphases, for example, the stress they put on honouring wishes and their fear that this might not happen, and their focus on positive experiences, demonstrate the added value of interviewing people with ID themselves, in addition to studies among caregivers and the general population.

The nominal group technique gave the discussion direction and structured the second meeting where ideas were further explored and validated. A clear explanation of the study, the presence of familiar care professionals, the use of a pictorial story and holding two separate meetings also seemed to contribute to its success.

A limitation of this study is that all except one participant were not receiving end-of-life care. As such, their views may differ from people who are receiving end-of-life care. Another limitation is that we only included people with a mild ID. Further research is needed to determine whether the nominal group technique – with some modifications – could be used for people with moderate ID. Including the perspectives of people with severe ID is complicated, yet of vital importance. Other methods, such as participant observations, may help to capture their views.<sup>3,10</sup>

## CONCLUSION AND IMPLICATIONS

The aim of the study was to explore the relevant dimensions of the care relationship in end-of-life care from the perspectives of people with ID. The two main dimensions found were dealing with wishes and being there. These dimensions and specifically the fear of people with ID that their wishes will not be respected show that end-of-life care imposes high demands on the relational qualities of caregivers, for example, their ability to uncover wishes, listen carefully, empathise and closely observe the behaviour of the person with ID. The results confirm the need for continuous knowledge acquisition and expertise building in this area, and for a better awareness of the good practices that have already been developed.<sup>32,33</sup> This study also shows the possibility and added value of involving people with ID in studies of end-of-life care. This highlights the potential for a more systematic involvement of people with ID in research and practice development, even when difficult topics are involved.

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## TABLES AND FIGURES

**Table 1.** Participants' background details.

	No. of participants	Age (years), range	Male	Female
Group 1	5	29–71	4	1
Group 2	7	62–82	3	4
Group 3	4	45–73	4	–
Group 4	3	54–68	3	–
Group 5	5	31–84	1	4
Group 6	4	39–65	3	1
Group 7	5	21–63	2	3
Total	33	Mean age: 58	20	13

**Figure 1.** Main dimensions of care relationships in end-of-life care.

