End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives

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Abstract

Background: Not much is known about the process of end-of-life decision-making for people with intellectual disabilities.

Aim: To clarify the process of end-of-life decision-making for people with intellectual disabilities from the perspective of patient representatives.

Design: A qualitative study based on semi-structured interviews, recorded digitally and transcribed verbatim. Data were analysed using Grounded Theory procedures.

Participants: We interviewed 16 patient representatives after the deaths of 10 people with intellectual disabilities in the Netherlands.

Results: The core category ‘Deciding for someone else’ describes the context in which patient representatives took end-of-life decisions. The patient representatives felt highly responsible for the outcomes. They had not involved the patients in the end-of-life decision-making process, nor any professionals other than the doctor. The categories of ‘Motives’ and ‘Support’ were connected to the core category of ‘Deciding for someone else’. ‘Motives’ refers to the patient representatives’ ideas about quality of life, prevention from suffering, patients who cannot understand the burden of interventions and emotional reasons reported by patient representatives. ‘Support’ refers to the support that patient representatives wanted the doctors to give to them in the decision-making process.

Conclusions: From the perspective of the patient representatives, the process of end-of-life decision-making can be improved by ensuring clear roles and an explicit description of the tasks and responsibilities of all participants. Regular discussion between everyone involved including people with intellectual disabilities themselves can improve knowledge about each other’s motives for end-of-decisions and can clarify expectations towards each other.

Keywords

Palliative care, intellectual disability, end-of-life decisions, ethics, shared decision-making, patient representatives, quality of life

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Introduction

End-of-life decisions are extremely important in the lives of most people and are a major aspect of the process of dying in half of the deaths in the Western countries, in the general population as well as for people with intellectual disabilities (IDs). An ID is characterised by significant limitations both in intellectual functioning and in adaptive behaviour, originating before the age of 18 years. Legal frameworks vary from the best interest model (England and France) to the representational or substituted judgement model (the Netherlands, Germany, Belgium and USA). Although the legal circumstances are clear, there are significant cultural differences between countries. In the Dutch system, the doctor needs consent from the patient or the representative (often close relatives like parents, adult children or adult siblings). The representative has to act as a good and careful representative, but cannot refuse a necessary treatment nor enforce tests or treatment. Other health-care professionals like nurses or social workers have no legal role in end-of-life decisions. Health professionals for people with IDs tend to allocate an important role to the patient representatives, who are obliged to involve the patient and consider carefully his quality of life. Ultimately, it is the ID physician (physician for people with IDs) who has the medical responsibility for end-of-life decisions in the Dutch system.

Despite this responsibility, the doctor, the patient with IDs and the patient representative have to prepare end-of-life decisions together, to share decision-making and to make treatment decisions. Insights into the process of shared decision-making are growing, and the importance of clinician–patient relationships with regard to supporting patient autonomy and hence shared decision-making has become more fully recognised. The participation of patient representatives makes the treatment decisions even more complex.

The role and influence of patient representatives in the process of making end-of-life decisions for people with IDs have not been clearly described. Who feels responsible, who takes responsibility, and do representative, patient and doctor share the decision? Does quality of life play an important role? What are important considerations in the decision-making process? What makes the process a good process? The aim of the present study was to clarify the process of end-of-life decision-making for people with IDs as seen through the eyes of the patient representatives.

Methods

Setting and sample

In the Netherlands, people with IDs live at home with their family, in small living facilities or on a larger campus, and are under the care of family physicians or ID physicians (physicians exclusively caring for people with IDs). The ID physicians working in different residential settings for people with IDs were asked to select any of their patients who had died in the past year (excluding sudden deaths). The patient representatives in this study were contacted by phone by the ID physicians who had cared for the patients towards the end of their lives. None of the representatives refused to participate.

Representatives were invited for a 1-h interview about the process of end-of-life decisions, to be held at a place of their own choice. Subsequently, the representative, the ID physician and the most closely involved professional care provider were interviewed separately by the first author. The involvement of a representative was an inclusion criterion, as we were interested specifically in their contribution. Written informed consent was obtained before the interviews were conducted.

Of the first eight deceased patients who were included, two had a profound ID, four had a severe and one a moderate ID (ID range = 0–70 IQ points, profound, severe, moderate and mild). To include more patients with mild IDs, we approached more ID physicians. This resulted in two additional cases of patients with mild IDs (Table 1).

Between November 2008 and June 2010, 10 cases were included, and semi-structured interviews were held by the first author (an experienced female ID physician who worked at a residential setting not included in this study). This article reports the views of the patient representatives about end-of-life decisions for people with IDs.

Ethical approval

The Ethics Committee of University Hospital Maastricht and Maastricht University approved the study.

Data collection and analysis

Data collection

An interview guide was developed, as no existing questionnaire was available. The interview guide was based on concepts found in the literature, discussions with the project members and a pilot interview, and was reviewed by experts (a professor of health law, a professor of ethics of health care and a senior researcher in palliative care). This resulted in four topics about the respondents and their roles, the considerations that were used, the concept of quality of life and the decision-making process (for details see Appendix 1). Topics and probing questions were piloted in two interviews with patient representatives, who were not included in the final sample.

Interviews were conducted at home, in some cases with more family members present. The interviewees knew that the interviewer was an ID physician. Field notes were made to record impressions of the interviewees and their environment, for example, the prominent
place of a photograph of the deceased. In these field notes, certain important statements, often made after the recorder had been stopped, were noted with consent of the interviewees. All interviews were recorded on a digital voice recorder and typed out verbatim.

Analysis

The interviews were analysed following the procedures of Grounded Theory, a qualitative research method. This method is used to develop a theory about a phenomenon, featured by a constant comparative method with open, axial, and selective coding phases. The first six interviews were open-coded, which yielded a list of key words and associated concepts. After six interviews, data saturation in the open coding phase was reached. On the basis of the axial coding phase (seventh to tenth interviews), we defined a core category, after which the other major categories were linked to this category. The NVivo computer program was used to store and organise the data.

All interviews were coded by the first author and analysed by one of the other members of the project group (researcher triangulation) or a doctor interested in end-of-life decisions (peer debriefing). The codes were discussed, and if necessary rearranged and refined and new concepts were added on the basis of these discussions. Data from interviews with doctors and caregivers were used to refine the analysis of the data of patient representatives (data triangulation).

Results

The 10 interviews with patient representatives ultimately yielded three categories, each of which is discussed in the following. The core category was that of ‘Deciding for someone else’, which identifies the context in which patient representatives make end-of-life decisions. The categories of ‘Motives’ and ‘Support’ were connected to ‘Deciding for someone else’. ‘Motives’ refers to prevention from suffering, patients who cannot understand the burden of interventions, emotional reasons and ideas about quality of life. ‘Support’ refers to the support which doctors are supposed to give to patient representatives in the decision-making process.

Deciding for someone else

Deciding for someone else involves at least two participants, the person who decides and the person for whom a decision is made. The person who felt responsible for deciding was mostly a family member who was the legal patient representative (Table 1).

Most patient representatives had known their loved ones for a lifetime and based their decisions on an intimate knowledge of the patient. A suitable decision did justice to their loved one, fitted in with their life story and did not harm them. The patient representatives had to decide between various options, such as forgoing treatment (e.g. antibiotics or chemotherapy) or continuing certain treatments (e.g. gastric tube and hospital admission), and felt highly responsible for the outcomes. The discussions frequently involved do-not-attempt-resuscitation (DNAR) decisions. As the patient representatives wanted to avoid any suffering for their loved ones, they tended to decide to withhold or withdraw tests or treatment, especially if they felt these might be futile:

(Respondent 6) Sister: but I was like: if she has to go through all that too, with this minimum of life she has left. And then all this pain on top of that. I felt, well, ... that wouldn’t do. So we

Table 1. Study population (patients and representatives).

<table>
<thead>
<tr>
<th>Case number</th>
<th>Age (years)</th>
<th>Level of intellectual disability</th>
<th>Medical problems/cause of dying</th>
<th>Family member/legal representative</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>78</td>
<td>Mild</td>
<td>Physical and mental deterioration due to multiple strokes</td>
<td>Brother; his spouse and a sister</td>
</tr>
<tr>
<td>2</td>
<td>40</td>
<td>Mild</td>
<td>Cancer</td>
<td>Two volunteers: legal representatives</td>
</tr>
<tr>
<td>3</td>
<td>50</td>
<td>Severe</td>
<td>Parkinson’s disease</td>
<td>Sister</td>
</tr>
<tr>
<td>4</td>
<td>43</td>
<td>Profound</td>
<td>Feeding problems and bowel obstruction</td>
<td>Mother and father</td>
</tr>
<tr>
<td>5</td>
<td>57</td>
<td>Severe</td>
<td>Down’s syndrome and dementia</td>
<td>Sister</td>
</tr>
<tr>
<td>6</td>
<td>51</td>
<td>Severe</td>
<td>Feeding problems, general decline and sudden death</td>
<td>Mother and sister</td>
</tr>
<tr>
<td>7</td>
<td>66</td>
<td>Profound</td>
<td>Neurological decline and serious hypothermia</td>
<td>Sister</td>
</tr>
<tr>
<td>8</td>
<td>47</td>
<td>Moderate</td>
<td>Cancer</td>
<td>Two sisters</td>
</tr>
<tr>
<td>9</td>
<td>73</td>
<td>Mild</td>
<td>chronic obstructive pulmonary disease (COPD)</td>
<td>Brother</td>
</tr>
<tr>
<td>10</td>
<td>68</td>
<td>Mild</td>
<td>Cancer</td>
<td>Nephew</td>
</tr>
</tbody>
</table>
were like: let’s just let her life go the way it’s going now, without interventions.

Deciding to start tube feeding was very difficult for one sister because she knew eating was one of the few small pleasures for her brother:

(R3) But that was the hardest part, I thought, I found that very hard indeed: *name of patient* was someone who was profoundly disabled, to put it in everyday terms. So he had few hobbies, in fact none. And eating was one of the things he really loved ... And well, this eating was now being taken away from him [by the introduction of a gastric tube]. That’s what it came down to. And that was really tough for me.

The patient representatives were not sure about the boundaries and limitations of deciding for someone else, not sure about the relevant legislation, but felt morally responsible for the decisions, just as the doctors were legally responsible. As one patient representative said,

(R7) My brother and sister felt that I was the one taking the decision, and they wondered whether I had the right to do that. I then said, well, the doctor is supporting me. The doctor left the decision to me. It would have been easier for me if things had been clearer. The doctor might have been clearer ... I was never told that it’s the doctor who is actually responsible.

According to the patient representatives, even patients with moderate or mild disabilities were unable to make choices, such as whether or not to start chemotherapy or be admitted to a hospital for aggravating treatments. As a brother said,

(R9) Yes, you’re right, [my sister’s] is a doubtful case. She knows very well what dying means, what being ill means. But if she’s really ill, the capacity for rational thinking in her situation becomes very difficult ... She would probably have said no, no pain. As she hated pain ... She would probably have said well, if I’m going to heaven anyway, then let it be like this, that sort of thing.

A couple (where the woman was the representative) said,

(R2) M(an): That ... was really impossible. But he was good at certain things, like telling the time and that sort of thing. W(oman): Computers, technology. I(nterviewer): But you never discussed with him whether he wanted to be resuscitated?

W: No.
M: No.
W: Death was a topic we never raised with A. We talked about it indirectly, when others ... But not with A himself. M: I think ... you couldn’t discuss that with him, resuscitation.

W: He would totally panic. He couldn’t deal with that.
M: No, but then he couldn’t really understand what it was.

Apart from the doctors, no other professional care providers, such as nurses, social workers or priests, played a role in the decision-making process, although patient representatives appreciated their help and involvement in the end-of-life care:

(R2) I: Well, have you had any support apart from ... I gather that one of the doctors at the institute and the doctor at the hospital gave you support, and also supported you in taking decisions. Is that right?
W: Yes.
M: Yes.
I: Did the nurses have a part to play in that?
M: No. Not really.

**Motives**

The main consideration in the decision-making process was ‘we couldn’t go on like that’, based on ideas about quality of life and weighed against the decline in the life of the loved ones. The quality of life was often described as very basic, enjoying food, holding someone’s hand, sunshine, playing on a trampoline, foot massage, or drinking *advocaat* liqueur. At the time of decision-making, patient representatives felt that the quality of life was only just acceptable and should not be reduced any further. The following quote is from a representative of a man with mild IDs and severe physical impairments who had bladder cancer:

(R2) So we knew what operation A would have to undergo, and we gave permission for it. And we had also agreed with the urologist, and had it entered into the file, that if anything should go wrong during the operation, the surgeon would make the decision in such a way that A would not come out of surgery even more impaired, even less than what he has and can do now. We didn’t want that to happen to him.

In most of the cases, there was time to think about future health-care decisions. Prevention from (further) suffering was an important motive in the decision-making process:

(R7) S(ister): Before May there were still periods when I thought she seemed content. You could tell that from the way she looked. She couldn’t say anything, but she’d be sucking things or playing with those towels. But after May she’d just be lying there and I couldn’t think of anything to make her happy. So I thought this will only get worse.

The patient representatives felt that their loved ones could not understand the burden of interventions, whether diagnostic or therapeutic. Two sisters expressed it this way:
Sister: The next time I went with her alone, yes. And then he [the gynaecologist] came back, the gynaecologist said that there were still opportunities for treatment. So I said, what would we be treating? Yes, but he still had some expectations. And when we saw how fast it went, we were, like, what would we be doing to her? How can we explain to her that she’ll have chemotherapy, that her hair will fall out.

Sister 2: We wanted to maintain that tiny bit of quality of life she still had as best we could.

Some motives were more emotional than others, as was illustrated by a mother who hesitated about surgery for a gastric stoma because she was not allowed to accompany her daughter:

I: I hear you were reluctant about this PEG tube, and also about further examinations. Can you explain why you were so reluctant about that? What was the reason for that?
Mother: Well, these things couldn’t be done here, or where I could accompany her. I would have to hand over my child, and I just knew she’d come out worse. (R6)

One representative said about a sister (a person who never spoke) that she would not have wanted to be resuscitated.

(R5) Yes/I thought it, ... it’s what [name of patient] would not have wanted, this resuscitation. It would then be OK for a while and then she’d have to go through it all again. I didn’t want that.

Support

The patient representatives appreciated the doctor’s support in the process of decision-making. The doctors should be closely involved in the process of decision-making, be empathic and give the patient representatives time to think and deliberate. Nevertheless, some representatives did not want the doctor to influence them in what they thought was important for their loved ones:

(R3) Sister: I got the feeling that she [the doctor] did have an opinion about it, but she never really expressed it. At least not as far as I can remember. And I actually liked that. As it would probably influence me. So she never said, like: ‘I’d do this or that’, or ‘Are you sure about that?’ She never said things like that.

Other patient representatives wanted the doctors to give personal advice:

(R5) Did the doctor support you?
Sister: Yes, she did, actually. If I proposed something, she might say that she [the doctor] might do the same, you know, about the decision I made. And I did feel that was ... since you have to make the decision all on your own ... My sister would say: ‘you should do what you think is best, you only want what’s best for her’. And if I discussed it with my sister, she might say: ‘Yes, that’s what I would do too’. But it’s good to hear that from a doctor. That she [the doctor] takes the same view.

The doctor should know the family and the different roles in the family, and positively value the role of the patient representatives:

(R3) Sister: I think she was very thoughtful in the way she dealt with the family. With the family’s wishes, but also with the family as a family. She knew exactly that someone was the mother or a brother, and she kept that very much in mind.

Some patient representatives had not visited their loved ones very often, which gave them a less prominent position in the decision-making process. As a brother said about his contribution to the process,

(R9) Brother: Well, I really have to say they did an excellent job.
I: And you feel you’ve been given the position that you were entitled to in this kind of process?
Sister: Yes, I think it would have been a bit arrogant of me to suddenly play the older brother who’s calling the shots.

Reassurance was an important part of the support:

(R5) Then I’d call one of them, and they’d immediately take it up. They’d immediately report it to doctor B. And she’d come round – well not immediately, that wouldn’t be possible of course – but she’d come round at least the next day. To see what the situation was like. If there was anything, doctor B would always phone me at home. I really appreciated that.

The support failed when there was a conflict of opinion between a doctor and a patient representative, as it emerged that the doctor was in the position to make the decision:

(R8) I: And how did you feel about that? What was your impression of the doctor at that moment?
Sister 1: Reluctant.
Sister 2: Distant.
I: And also, like, I’m the one to decide and this is how we’re going to do it.
Sister 1: I’ll do this, and I’m the one to decide. And he really made it very clear that there was this difference.

The patient representatives were not aware that it was possible to discuss decisions other than the DNAR with the doctor. This left them feeling unsupported:

(R6) I: ... we sometimes call that a minimal intervention policy. My question is whether you ever considered trying to come to an agreement with the doctor about that.
Sister: I think we said that but I wouldn’t know ... I think that if that’s the usual procedure I’d almost say that the signal should have come from the doctor or the nurse, ... Well ... now I’m hearing this, that you could write down more about that ... I wouldn’t have known about that myself.

Comments made after the interview had ended

After the recording had been stopped and the session ended with a brief review of what had been said in the interview, one patient representative started to cry when she understood that the doctor had been responsible for the end-of-life decisions. Deciding for her sister had been a burden to her, notwithstanding the fact that she was convinced that the decisions had been correct. Another respondent said afterwards that she would have preferred to talk about more than a DNAR agreement and regretted the fact that nobody had informed her about the end-of-life issues that she could have discussed with the doctor. She felt it was important to discuss non-treatment decisions and pain relief, and to draw up written advanced directives in order to ensure implementation in the future.

Discussion

The patient representatives in this study felt highly responsible for the end-of-life decisions and were passionately involved in the process because they were not able to consult with the patient. Patient representatives had ideas about quality of life, prevention from suffering, and patients who cannot understand the burden of interventions. They sometimes had emotional reasons for their decision. They wanted the doctor to support them in the decision-making process.

The results of the present study are limited by the fact that it only included those deceased patients whom the patient representatives had known intimately throughout their lives. The study followed a qualitative design and explored the end-of-life decision process around 10 patients in detail. Member checks have not been conducted because we felt a second exposure would be burdensome for the participants who often expressed strong emotions during the interviews. Nonetheless, the study has offered important insights into issues that are relevant to patient representatives in making decisions for their loved ones.

The burden of responsibility when making decisions for their loved ones was heavy for the patient representatives, who were unaware that doctors are ultimately responsible for end-of-life decisions after careful consideration with patient representatives. In a systematic review on the effect on patient representatives of making treatment decisions for others (elderly and intensive care unit (ICU) patients), negative emotional burden was reported.14 In Norwegian nursing homes, the position of representatives regarding to end-of-life decisions was unclear and complex.15 The process of decision-making for incapacitated adults with IDs has not been studied.

The patient representatives in our study doubted very much whether their loved ones had the competence to decide about their own health, which implies the capacity to judge health-related interests and to make a suitable decision.16,17 The American Association on Intellectual and Developmental Disabilities states that careful observation and interaction over time will clarify what a person with IDs considers important. Although our data did not include life story work, its use would seem to be a tool that could be used in future. Life stories can help those patients who lack capacity to provide information about their own beliefs in health and treatment.18,19 Strategies for assisted and shared decision-making, life planning, and more careful communication could improve decision-making.20–22

Decline and deterioration of health and well-being were an important consideration for the patient representatives to make an end-of-life decision for their loved ones. The concept of quality of life is not only related to the life story of the person who is represented, but also to the life story of a family – family being one of the domains of quality of life.23

The doctor’s support was important for the representative, and this outcome corresponds with the ideas currently being developed in the world of informed shared decision-making, about the importance of relationships between clinicians and patients.11,24 Professional views and advice were helpful for patient representatives in end-of-life decisions for people with dementia.25 Competent patients and families wanted relationships with healthcare providers that affirm a more encompassing view on death and dying.26 The influence of relationships and the strategies for shared decision-making have not been studied for people with IDs.

From the perspective of the patient representatives, the process of end-of-life decisions could be improved by defining clear roles and responsibilities of all participants involved. If possible, people with IDs themselves should be involved in the decision-making process. Knowledge of their needs and preferences, quality of life and life stories could improve the decisions. Regular discussion between everyone involved will improve the understanding of each other’s role in the process. Further research is needed to study the process of decision-making for people with IDs.

An important goal could be to develop and implement effective written information and decision aids for patient representatives and people with IDs.

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Appendix I

List of interview topics about end-of-life decisions for people with intellectual disabilities

Roles – the roles of the different participants in the decision-making process. Who did take the end-of-life-decisions, who influenced this process? Was the person with intellectual disabilities involved? What was the link with the patient’s capacity to decide, including their level of intellectual disability? Did a professional care provider play a part in this process?

Quality of life – the quality of a patient’s life and its influence on the decision-making process. Did the patient’s representative have a clear idea about the quality of life of their loved one, and on what aspects of their life was this based? Did the patient representative take the quality of life into account?

Considerations – the considerations that led to an end-of-life decision. Did only medical considerations play a role, or were the patient’s verbal or non-verbal expressions taken into account? Was there an immediate reason to make the end-of-life decision?

Process – which aspects made this process good or bad in the eyes of the different participants?