

## **End-of-life decision making for people with intellectual disabilities from the perspective of nurses**

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**Background:** Little is known about the involvement of nurses in the process of making end-of-life decisions for people with intellectual disabilities (IDs). The aim of this study was to clarify this process from the perspective of nurses.

**Method:** This qualitative study involved nine semi-structured interviews with nurses working in chronic care, conducted after the deaths of patients with IDs in the Netherlands. The interviews were transcribed verbatim and analysed using Grounded Theory procedures.

**Results:** The core characteristic of the position of the nurses and of the way they supported the patient was “Being at the centre of communication”. Related categories of topics emerging from the interviews were “Having a complete picture of the patient”, “Balancing involvement and distance”, “Confidence in one’s own opinion” and “Knowledge about one’s own responsibility”, all of which were focused on the patient. This focus on the patient with IDs might explain why the nurses could make valuable contributions to such an important subject as end-of-life decisions. People with IDs themselves were not involved in the decisions. The nurses were not always aware who was ultimately responsible for the end-of-life decisions.

**Conclusion:** Nurses are in a unique position to support the process of end-of-life decision making. It is important to use their knowledge and give them a more prominent position in this decision-making process. It should be clear to all involved who is ultimately responsible for making the end-of-life decisions.

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## Introduction

People with intellectual disabilities (IDs) nowadays live longer than was previously expected (Patja, Molsa, & Iivanainen, 2001), and death, dying and palliative care are as important to them as to the general population. Access to palliative and hospice care is not always easy for the general population, but people with IDs meet more problems when they need end-of-life care (Friedman, Helm, & Woodman, 2012). Collaboration between palliative care services and ID services is hampered because those working in palliative care lack the skills for caring for people with IDs (Bailey, 2014). Conversely nurses working in ID services report that they lack sufficient training for palliative care (Bekkema, de Veer, Hertogh & Francke, 2014). End-of-life care for people with IDs is a part of general health care, but also has special features (Friedman, 2010). Communication is the most striking characteristic, including on the one hand the communication with people with IDs themselves and on the other hand the communication within their network of relatives and professionals. Communicating with people with IDs in a palliative care setting is not always easy as people with IDs may misunderstand verbal information. Communicating bad news should be a process, not a single event and professionals need an active attitude to assess complaints and symptoms (Tuffrey-Wijne, 2013; Tuffrey-Wijne, Bernal, Hubert, Butler, & Hollins, 2010; Tuffrey-Wijne & McEnhill, 2008).

Normally, patients should play a key role in any decision-making process that affects their lives, but people with IDs are sometimes unable to do so. Assessment of someone's capacity to decide is a part of the decision-making process and is often not straightforward. England and Wales have a model where medical decisions for those who lack the necessary mental capacity are based on an assessment of "best interest", rather than on substituted decision making; it offers the explicit opportunity to take into account a broad range of views (Department for Constitutional Affairs, 2007; Joyce, 2010). In the Netherlands, it is the responsibility of the relevant health care professionals to assess this capacity where health care decisions are concerned (WGBO, 1994) and to consult with the patient's representative, as stipulated in the Contract of Medical Treatment Act (Welie, Dute, Nys, & van Wijmen, 2005). The patient's representative has the role of substitute decision maker. Nurses, such as trained ID nurses, have no formal part in the decision process, even though they have often cared for the patients for a very long time. Ultimately the ID physician (physician for people with IDs) has the medical responsibility for end-of-life decisions and end-of-life care. Ideally, the relatives, the nurses and the physician will work together in the daily end-of-life care for people with IDs, listen to each other and try to come to a sensible policy for the palliative care trajectory.

Such a palliative care trajectory often involves having to make end-of-life decisions, i.e. those decisions which can lead to or hasten death, whether intentionally or not. They include withdrawing or not starting medical treatment, pain relief treatment with possible life-shortening side-effects, and ending a patient's life with or without his or her request. These kinds of decisions are extremely important in the lives of most people, and are known to play a substantial part in the process of dying in half of the deaths in Western countries (van der Heide et al., 2003).

Nurses' contributions to end-of-life care for people with IDs are usually important and intensive (de Veer, Francke, Speet, & Poortvliet, 2004; Todd, 2013; Wiese, Stancliffe, Balandin, Howarth, & Dew, 2012). They have often been involved in the lives of these people for many years, caring for them on a daily basis. In these

years they have learnt a great deal about their needs and preferences and often know them more intimately than some (often distant) relatives. As a consequence, they would seem to be well equipped to support the people with IDs, as well as the doctors and relatives, when end-of-life decisions are required. This position may be unique compared to that of nurses in hospitals and nursing homes, who care for patients over a shorter period. The balance between involvement and emotional distance can be difficult for nurses in ID care.

A study among Irish paid carers for people with IDs found that they thought end-of-life care was an important part of their work, and they sometimes experienced being pushed aside by relatives who re-establish contact at the end of life and make decisions for their loved ones without listening to staff (Ryan, 2011). Although staff found making decisions about end-of-life care issues difficult and stressful, they also felt that they had in-depth knowledge of the people with IDs and as a consequence could contribute to the process. A study among nurses involved in palliative care found that nurses working in psychiatric care had a greater desire to be involved in end-of-life decisions than those working in other health care sectors (de Veer, Francke, & Poortvliet, 2008).

Nurses at an intensive care unit in England saw their role in end-of-life decision making as supporting the family, being an advocate for the patient and helping the medical staff to establish the right moment to withdraw treatment (McMillen, 2008). In another study, nursing roles were described as presenting the “big picture” of the patient’s deterioration and acting as the nodal point for exchange of information (Liaschenko, O’Conner-Von, & Peden-McAlpine, 2009). Not being involved in end-of-life decisions can cause feelings of anger, frustration and powerlessness among nurses (Yang & McIlfatrick, 2001). Belgian nurses felt that they could make important contributions to end-of-life decisions (Inghelbrecht, Bilsen, Mortier, & Deliens, 2009). In geriatric care, the opinions of nurses turned out to be important, as nurses were consulted about Do Not Attempt Resuscitation (DNAR) orders in up to 72% of cases (De Gendt et al., 2007). Finnish nurses also offered their opinion on the appropriateness of a DNAR order for a particular patient (Hilden, Louhiala, Honkasalo, & Palo, 2004).

In a systematic review of the literature about end-of-life decision making in acute care, three nursing roles emerged, the first being that of information broker, the second that of supporter and the third that of advocacy (for patients and relatives) (Adams, Bailey, Anderson, & Docherty, 2011).

Although it may be clear from these examples that nurses play an important role in end-of-life care for people with IDs and want to be involved in end-of-life decisions, many aspects of the role and influence of nurses in the process of making end-of-life decisions for people with IDs have not been studied before. Who feels responsible, who takes responsibility, and do the patient’s representative, the patient and the doctor share the decision? This study set out to explore these themes as seen through the eyes of the nurses. The results of the studies about the contributions to end-of-life decision making by doctors and representatives have been published separately (Wagemans et al., 2013a; Wagemans et al., 2013b).

## **Methods**

### ***Setting and sample***

In the Netherlands, people with IDs may live at home with their family, or may live in small residential facilities or on larger campuses. At home they receive medical care from family physicians (general practitioners), in residential care from ID physicians (physicians whose caseload consists exclusively of people with IDs).

The present study was part of a research project about end-of-life decisions, in which a group of 12 ID physicians were invited to participate. Their patients with IDs were living in small residential facilities in the community or on a larger campus. The ID physicians were part of a group that met for peer review six times a year and had known each other for a long time, in most cases more than ten years. The first author (AW) had been part of this group from the start.

In 2008 AW asked the peer review group to select any of their patients who met the following inclusion criteria: (a) died in the past year (excluding sudden deaths); (b) after a process of end-of-life decisions; and (c) involving relatives who agreed to participate in the study. The ID physicians contacted the relatives and the most significant nurses and asked if they would agree to a face-to-face interview. Since the deceased patients had lived in institutional settings (on a larger campus or in small residential facilities), the nurses involved were familiar with chronic ID care.

The research project consisted of three interview studies: interviews with the relatives, the doctors and the nurses. This paper concerns the interview study with nurses and one was male.

All but one (a social worker) of the ten nurses were ID nurses. Such nurses have completed a three-year vocational training course in ID care, including health care. They had an average total work experience of more than ten years in chronic care, and their age ranged between 35 and 50 years.

As one nurse left her job, nine interviews were held between November 2008 and June 2010. This paper reports the viewpoints of the nurses on 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***

Since no questionnaire on the end-of-life decisions preceding the deaths of people with IDs was available, we developed an interview guide, based on concepts found in the literature, discussions with the project members and a pilot interview with an ID physician. The guide was reviewed by experts (a professor of health law, a professor of ethics of health care and a senior researcher in palliative care). The guide was piloted in two interviews, which were not used for the final sample, and encompassed four topics and probing questions about the participants and their roles, the considerations they had used, the concept of quality of life and the decision-making process (for details see Appendix 1).

All interviews were recorded on a digital voice recorder and transcribed verbatim. The names and other personal details of the participants were removed and replaced by a code. After each interview, field notes were made to record impressions of the interviewees and their environment and to record certain important statements,

often made after the taped conversation had ended. The interview guide was adapted to reflect emerging themes, following Grounded Theory principles.

### *Analysis*

The interviews were analysed following the procedures of Grounded Theory, a qualitative research method used to develop an inductively derived theory about a phenomenon (Corbin & Strauss, 2008). The Grounded Theory approach uses a constant comparative method in the analysis process, with open, axial and selective coding. Open coding is a process of exploring the text and selecting words and concepts which are connected with the questions and themes of the study (Corbin & Strauss, 2008). The first five interviews were open-coded, and yielded a list of key words and associated concepts. These words and associated concepts were grouped into a structure. After five interviews, data saturation was reached in the open coding phase.

The sixth to ninth interviews were axially coded, which means that the concept structure was broadened and concepts were defined in more detail. Selective coding was done by rereading all nine interviews with the aim of identifying the core category, after which the other major categories were linked to this core category. Triangulation of data (using other sources to broaden the view and to prevent a restrictive perspective) was achieved by interviewing different sets of stakeholders (physicians, relatives and nurses) in different parts of the research project (Wagemans et al., 2013a; Wagemans et al., 2013b). The Nvivo computer program was used to store and organise the data (Bazeley, 2007).

All interviews were analysed by the first author. In addition, each interview was also analysed by one of the other members of the project team or a physician interested in end-of-life decisions (investigator triangulation). The first author wrote overall instructions for open, axial and selective coding for the researchers involved in the analysis process. Peer debriefing was used in all phases of the analysis to prevent the first author being “blinkered” (i.e. the risk that the first author would be trapped in a narrow mode of thinking and would lose creativity and openness). Discrepancies of coding were discussed to support the identification of concepts and relationships between concepts. During the entire process of data collection and data analysis, a log file was used to record thoughts about additional research questions, about concepts and their relationships, and to identify the core category.

## **Results**

The nine interviews with nurses ultimately yielded five categories of topics, each of which is discussed below. The core category we identified was “Being at the centre of communication”, which describes the most significant contribution of nurses to the process of end-of-life decisions. This core category was supported by “Having a complete picture of a patient”, “Balancing involvement and distance”, “Confidence in one’s own opinion” and “Knowledge about one’s own responsibility”.

### **Being at the centre of communication**

The nurses felt that they were at the centre of communication around the patient at the end of life. They cared for the patient, saw and interpreted complaints and symptoms, and subsequently informed the doctor and the relatives. The people with IDs had lived

their lives in the same care settings as that in which they died. Staff were familiar with chronic care and saw end-of-life care as an important and natural part of their job. Only one of the deceased died in a hospital, the others died in their familiar care settings.

The nurses seemed to be used to their position in end-of-life decision making and were particularly involved in end-of-life care (see table 1 nurse [N]1 for supporting quotations). End-of-life care was a matter of course for nurses and they supposed that end-of-life decisions were up to the relatives. They gave the relatives enough space to make the end-of-life decisions and in the meantime used their position and knowledge to influence both the doctor and the relatives (see Table 1, N 3a and N5).

Nurses and relatives could have different views on the patient's condition and health decline, with nurses talking about palliative care whereas the relatives were not yet ready for that. These conflicting views were caused by differences with regard to intimate knowledge about the patient, and could bring about tensions in the relationship between nurses and relatives (see Table 1, N 8). Evidently, the views of the nurses did not always coincide with those of the relatives. In some cases relatives took the lead in the end-of-life trajectory, while in other cases they gave in to the nurses, as they felt that the nurses had made important contributions to the lives of their loved ones. The relatives were often more protective than the nurses and insisted on not breaking the bad news to their loved ones. As staff cared for them every day, however, they found it difficult not to be honest.

The working relationship with the doctor was taken for granted (see Table 1, N 3b) but the relationship with relatives needed more care and took time and effort. The nurses tried to cooperate with relatives in an open relationship and intended to support them, and sometimes felt supported by relatives.

### **Having a complete picture of the patient**

Being at the centre of communication requires having a complete picture of the patient. The nurses tried to present a realistic overall picture of the patient's health situation to the relatives. In many cases, this was based on having known the patient for years, allowing the staff to detect their gradual deterioration.

It was this deterioration which caused them to contact relatives and doctors in order to get together for the purpose of end-of-life planning. In some cases, the nurses had known the patient for more than a decade and had clear ideas about the patient's needs and wishes, beyond the health situation, including quality of life (see Table 1, N 7). The nurses believed that they sometimes knew more about the health situation of the person they cared for than the relatives, as they saw the patient more often than the relatives and consequently could gauge the situation on a more solid daily basis (see Table 1, N 3).

The nurses felt that the patients themselves were not fully capable of making their own end-of-life decisions, like the decision to forgo treatment. Consequently, they felt obliged to stand up for their patients and give their own opinion. At this point, tensions, or even a sense of competition, could enter into the relationship with relatives, if they had different views on the patient's needs and wishes. For instance, two sisters of a patient with ID wanted and asked for palliative sedation for their

sister, who had cancer, while the nurses and the doctor thought this was not indicated at that moment. At an earlier stage, staff and relatives had different views on how to communicate with the patient, with different opinions on what the patient could understand and whether she could bear the knowledge that she was dying. The position of the nurses at the centre of communication made them feel obliged to stand by their patients (see Table 1,N 8). Being put on the side-line by relatives was not easy for the nurses, and made them feel frustrated about their own position.

### **Balancing involvement and distance**

Being at the centre of communication required involvement and sometimes distance. Involvement with the lives of the people with IDs for whom they cared was a matter of course for the nurses (see Table 1,N 7).

Nurses were aware of the fact that their patient was going to die and that they would miss this person as someone important to them. This sense of commitment made recognition of their work by the representatives important to them (see Table 1,N 5).

The combination of being involved with the life of a patient and not becoming emotional about it was difficult. Being involved was their personal contribution to good care, but the organisation they worked for would require them to keep professional distance (see Table 1,N 4). On the other hand, this involvement took no great efforts and reflected the pleasure staff took in their work. One of the patients was more open to contact and small talk at the end of her life and made clear how she enjoyed the company of staff (see Table 1, N 8). Staff wanted to follow their patients, to respond to what they wanted, to show their involvement and nearness.

(Table 1 about here)

### **Confidence in one's own opinion**

Nurses' confidence in their own opinion supported the position of being at the centre of the communication. The nurses developed a complete picture of a patient, and had clear ideas about what was important in their client's life, based on their daily care (see Table 1, N 5).

Nurses were confident regarding their knowledge about the client's wants and needs and even about what quality of life meant to him or her (see Table 1, N 9). End-of-life care was an important part of their work and a matter of course. As a result, the nurses had a strong opinion about what constituted good care at the end of life, including the nature of end-of-life decisions. They felt certain about their own role (see Table 1, N 7). Nurses asked themselves what the quality of life would be after resuscitation, and tried to focus on the patient's needs and wishes, and were inclined to let the patient go (see Table 1, N 1). Although nurses were confident in their own opinion on the quality of life of the patient, they knew their responsibility in end-of-life decision making.

### **Knowledge about one's own responsibility**

Nurses knew that they could not take, and did not need to take, responsibility for end-of-life decisions, and this position meant that they could freely discuss ideas about a patient's quality of life, knowing that they were not responsible for the decision. But

sometimes it was frustrating to them to experience that it was up to the relatives to make an important decision like deciding whether a hospice would be a better care setting. Although the nurses knew that they were not responsible, they felt an emotional urge to use their influence for the benefit of their patients (see Table 1, N 4).

Nurses had specific ideas about the needs and preferences of their patients, and tried to influence the end-of-life trajectory. They felt that it was the responsibility of the relatives to decide, not that of the physician (see Table 1, N 7).

Although on the one hand nurses could influence relatives and the opinion of the doctor, they were also dependent on both. The end-of-life decisions included the DNAR decisions, which were considerably more important to the nurses than other end-of-life decisions, probably because they expected to be directly involved in situations in which resuscitation was needed. Their influence was so important that in one case the nurses convinced the relatives to reconsider and change the DNAR order (which is established in advance) (see Table 1, N 6). As nurses were sure about the limits of their own responsibility, they used this limited position for the benefits of their patients.

## **Discussion**

This study found that nurses in ID care felt that they were at the centre of communication, and were able to shape end-of-life care and influence end-of-life decisions. As they often had known and cared for the people with IDs for more than a decade, they had clear ideas about the patient's needs and preferences and showed confidence in their own opinion. Above all, they felt responsible for a well-managed end-of-life process. Tensions emerged when the views on quality of life differed between relatives and nurses.

From our study a picture emerged of a group of professionals who are involved in end-of-life care, are confident about their role in such care and are convinced of their knowledge about the lives, needs and preferences of the people they care for. In an informal way, they give direction to the end-of-life care, including end-of-life decisions, while knowing that they are not ultimately responsible for the decision. Many of them are convinced that it is relatives who are responsible (even though this is formally the responsibility of the physicians). In separate studies we found that the relatives also felt responsible for the end-of-life decisions and physicians indeed gave relatives the idea that they were in the position to decide (Wagemans et al., 2013b). In countries where health care is organised in a different way, nurses are less confident about their own capacity to support clients with IDs in end-of-life care (Tuffrey-Wijne et al., 2010; Wiese et al., 2012). A possible explanation could be that nurses in Dutch residential care are specially trained for ID care and sometimes have had supplementary training courses on end-of-life care.

The nurses in our study felt that the people with IDs they cared for were themselves unable to contribute to the end-of-life decisions, even though some of them had only mild IDs. As they know the persons with ID very well, their opinion seems important and should be taken seriously. Nevertheless it seems important to also involve the people with IDs themselves in end-of-life decisions (Tuffrey-Wijne, 2013; Tuffrey-Wijne & McEnhill, 2008). People with IDs are often shielded from confrontation with death and dying, next of kin and professionals want to protect them. Nurses need an open attitude to the involvement of people with IDs in the end-

of-life trajectory and should be trained in communication skills (Bekkema, de Veer, Hertogh, & Francke, 2014). Respecting autonomy is an important issue and should be more elaborated in the years to come. It implies a balance between protecting and giving information on the one hand and capacity to make decisions on the other hand. Advance care planning could help people with IDs in what they want regarding future care (Kingsbury, 2009). Moreover physicians and other health care workers need more education and skills specifically aimed on the care for the aging ID population including communication skills (Perkins & Moran, 2010). The nurses in our study had a clear overall picture of their patients and were often the ones to detect deterioration, which then led to discussions with relatives and physicians. The ID physicians also indicated deterioration as the reason to talk with relatives about end-of-life care (Wagemans et al., 2013a)

Studies in other health care settings have shown that important goals for nurses are those of supporting the relatives and helping the medical staff make decisions (Inghelbrecht et al., 2009; McMillen, 2008). In acute care, three nursing roles emerged, the first being that of information broker (informing physicians, informing family members and mediating), the second that of supporter (mainly for family members) and the third that of advocacy (speaking on behalf of patients and relatives) (Adams et al., 2011). Although expressed in other words, these roles are very similar to those described in the present study.

The nurses in our study did not always seem to know that it is the physicians and not the relatives who are ultimately responsible for end-of-life decisions. Nurses and physicians have different roles in end-of-life decisions: the physicians have to make the decisions, the nurses have to carry them out (Oberle & Hughes, 2001). As the nurses expected that they would be the ones who had to implement the decisions, they particularly regarded the DNAR decisions made in advance as important. The relatives of one patient in our study changed their preference for a DNAR order to one of resuscitation because the most closely involved nurse felt that she could not implement a DNAR decision.

The position of the nurses in this trajectory is not one of formal responsibility, making them vulnerable in case of problems of communication. It might be better if the nurses had a clearer position in the trajectory of end-of-life decisions, as one of the major stakeholders, enabling them to provide their own input for the decisions. Dutch nurses are often in a unique position to contribute to end-of-life decisions for persons who are not fully capable of deciding for themselves, as they have known the patients and their relatives over a long period. In our study, nurses mostly felt supported by relatives, but in one case a conflict arose when relatives decided without consulting the staff and the ID physician. In an ideal world, relatives and nurses respect each other, knowing that both are needed and irreplaceable, but in practice there can be tension between these parties.

Our study provides a preliminary idea of the position of nurses in chronic care for people with IDs regarding the process of end-of-life decisions. The study was limited by the fact that we interviewed nurses in Dutch ID care, but not nurses in other settings. Nurses in hospitals care for their patients for much shorter periods, and do not know as much about the needs and preferences of their patients. In Dutch residential settings people with IDs have a relationship of many years with the nurses, while people with IDs living in community based settings only meet nurses when they are seriously ill. In addition, we only examined those processes of end-of-life decision making in which relatives were involved. Nurses will have a different, and probably stronger position in situations not involving relatives.

Data saturation was reached early in the analysis (and confirmed in later stages of the analysis). The interviewees appeared to share the same well-considered view on end-of-life care and apparently the same thorough approach.

Future studies should investigate the role and position of nurses in other settings. The contribution and involvement of nurses should be studied in those processes in which next-of-kin are absent. Likewise future studies should examine the contribution of people with IDs and make efforts to involve people with IDs in the study design.

In conclusion, we recommend an appropriate and clear position for nurses in the process of end-of-life decisions for people with IDs. A method should be developed in which all stakeholders are involved in a timely process of deliberating on what is needed to provide good care to patients with IDs (Wagemans et al., 2013a; Wagemans et al., 2013b). Advance care planning and shared decision making are part of this method, as are training courses on end-of-life discussions for professionals. Interventions to train and promote decision making skills for people with IDs themselves should be part of the method. Future studies should evaluate the effects of advance care planning on the quality of life for people with IDs. Guidelines should be based on the literature and supported by opinions of patients, relatives, nurses and physicians. The results of our study underline the importance of the position of the nurses in supporting patients and relatives when end-of-life decisions are at stake.

## **Appendix 1 about here**

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## **Appendix 1, 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 made the end-of-life-decisions, who influenced this process? Was the patient with IDs involved? What was the influence of the patient's capacity to decide, including the level of IDs? Did the nurses 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 their quality of life, and on what aspects of the life of their loved one was this based? Did the nurses take the quality of life into account?

*Arguments:* the arguments which led to an end-of-life decision. Did only medical arguments 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?

## Quotations from interviewed nurses illustrating categories of topics

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Table 1, quotations from interviewed nurses

<b>Categories</b>		
<b>Being at the centre of communication</b>	Nurse 1	Well, we usually sit around the table (in the patient's apartment): the doctor will be there, I will be there, the relatives are there. And the doctor explains the medical situation. And we usually, if the relatives want us to, add information from the nursing group: how do we perceive the patient through the day? Is she in pain for instance? What aspects of behaviour do we notice? Does she eat and drink well? You see, the doctor wouldn't know as much about that as we do. And so together we fill in ... you get the complete picture.
	Nurse 5	As staff we knew that her sister would miss her very much, as she was very closely involved with her. You hardly ever see that, that someone is so intensely involved with a relative with Down syndrome. ... And we very much respected her for it, being so intensely involved with her sister. And she respected us for doing our best to care for [name of patient] when she wasn't around.
	Nurse 3 (a)	That was a rather difficult discussion. Difficult for the family of course, to sort of get a clear idea, like "We [nurses] now regard [first name of patient] as being so ill that we want to offer palliative care." So purely offering the care she needs at this moment. And, well... yes, preparing for her death, really.
	Nurse 8	You're faced with this as a professional, and you want to be open and honest. I feel connected to you and I want to share with you. I want to help and support you. And then we're just sitting there pretending nothing's wrong. So that makes it difficult, as you want to be there for her on good as well as bad days. And there we were having to pretend the sun is shining and it's a beautiful day. And at the same time you saw A. deteriorate very, very fast. Really distressingly fast.
	Nurse 3 (b)	Well yes, we had a good working relationship with the doctor in this period, where we were able to say anything we wanted: what we thought, our feelings about it. And the doctor definitely listened to what we said. Yes, absolutely.

<b>Complete picture of a patient</b>	Nurse 7	She'd been deteriorating for a number of years. So yes, you get to a stage where, well, if you, err, I wouldn't say measure the quality of life, but when you see that her quality of life is much lower than it used to be. ... Then yes I think it's our duty to do something about it. As they can't do anything themselves.
	Nurse 3	Well, yes, you could put it like that. But of course it's a matter of providing information. The relatives would come and visit for an afternoon once every so many weeks. And then they see [name of patient] at that particular moment, and they develop their own idea of the situation. The nursing staff see [name of patient] every day. And the doctor, especially when they're ill, also sees them every week, or even several times a week. And then it's easier to realistically evaluate their situation than as a relative who only comes round every few weeks.
	Nurse 8	But on the other hand we figured well if these sisters insist on this decision, they will go through with it, and then that's the decision that will be made. Then we'll have to be prepared to accept it. And that meant, that's a sort of acceptance. A sort of feeling that this is the decision made by these two sisters. And that means that as an organisation, you're more or less ignored.
<b>Balancing involvement and distance</b>	Nurse 7	Well yes, it won't be very long before this person is no longer there. And what does that mean to me, as someone who basically cares for them 24 hours a day? Well, I do notice that it causes certain feelings to emerge among the staff. You notice that when you talk about it with colleagues.
	Nurse 5	Well, I mean, it's kind of a thank-you, to say that they appreciated that [first name of patient A] has been well cared for here. And sometimes you need that, that people express that.
	Nurse 4	And that's why you feel heavily involved with these people. ... And this involvement, you sometimes get reproached for that; that you're too much involved, or too closely tied to them. Because you're supposed to adopt a so-called professional attitude, but if I have to adopt an attitude of remaining at a distance, then I can't do my job.
	Nurse 8	In a way that was like a whole new world opening up, to get closer to her. You'd even get staff coming in during their time off, just when they happened to be in the neighborhood, come cycling round to, err, just pop in and say hello to her.
<b>Confidence in one's own opinion</b>	Nurse 5	When you sat down with her, she'd clasp ... she was deaf and blind, but she'd smell that someone was sitting beside her. And then she'd hug you very tightly. ... In fact she enjoyed everything. You could tickle her and she'd laugh. Such a lot of things she enjoyed so much.

	Nurse 9	My impression was always that she actually really enjoyed life, but was also very much bothered by her disabilities , both physically and mentally. She had a good quality of life until the very end. Yes, I think I can really say that.
	Nurse 7	Well, yes, you do have a kind of controlling role there. ... You just discuss it with the doctor at that stage. And you gradually come to a conclusion, which the doctor thinks is justified and that we as nurses can agree with. And on the basis of that you discuss it with the relatives.
	Nurse 1	In view of her age, in view of the deterioration, you might say. It's mostly the deterioration. What good would it do her? If we were to resuscitate, sort of, compared to her current state. What would be the best for her? If she does pull through, and she comes out even worse off: what would that add to her life, I mean. That was a very important aspect. Sort of: we can offer her pain relief, and make things as comfortable as possible for her. Or we can resuscitate, and she might be able to do even less, come out even worse. In view of her current health status, and her age.
<b>Knowledge about one's own responsibility</b>	Nurse 4	And that's different from a home for the elderly, where there are also people dying every day. As it's really essential that these people can't do anything for themselves. You are their senses, their eyes, you're everything for them. One moment of inattention can have disastrous consequences.
	Nurse 7	As nurses, we don't have the authority to decide. We can make suggestions for what we ... would wish to be done for this person. But in the end it's always the relatives or a legal representative who decides. But you do discuss it with them on a regular basis. And in that respect it's very important that the doctors and the nursing staff are in agreement, as I think it would be very frustrating for the nursing staff if a policy is adopted that not all of the staff can agree with. Since we're the ones who have to carry it out.
	Nurse 6	I clearly indicated this to them. I said: "Well, I have serious doubts about this [the DNAR order]." And the relatives understood that: "Yes, we can imagine." But you also have to think of the relatives. What are you doing when you do resuscitate? You might actually make things worse. That's why it's such a difficult choice. What decision are you going to make?