

Do-Not-Attempt-Resuscitation orders for people with intellectual disabilities: dilemmas and uncertainties for ID physicians and trainees. The importance of the deliberation process

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Abstract

Background Not much is known about Do-Not-Attempt-Resuscitation (DNAR) decision-making for people with intellectual disabilities (IDs). The aim of this study was to clarify the problems and pitfalls of non-emergency DNAR decision-making for people with IDs, from the perspective of ID physicians.

Methods This qualitative study was based on semi-structured individual interviews, focus group interviews and an expert meeting, all recorded digitally and transcribed verbatim. Forty ID physicians and trainees were interviewed about problems, pitfalls and dilemmas of DNAR decision-making for people with IDs in the

Netherlands. Data were analysed using Grounded Theory procedures.

Results The core category identified was 'Patient-related considerations when issuing DNAR orders'. Within this category, medical considerations were the main contributory factor for the ID physicians. Evaluation of quality of life was left to the relatives and was sometimes a cause of conflicts between physicians and relatives. The category of 'The decision-maker role' was as important as that of 'The decision procedure in an organisational context'. The procedure of issuing a non-emergency DNAR order and the embedding of this procedure in the health care organisation were important for the ID physicians.

Conclusion The theory we developed clarifies that DNAR decision-making for people with IDs is complex and causes uncertainties. This theory offers a sound basis for training courses for physicians to deal with uncertainties regarding DNAR decision-making,

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as well as a method for advance care planning. Health care organisations are strongly advised to implement a procedure regarding DNAR decision-making.

Keywords advance care planning, decisions, Do-Not-Attempt-Resuscitation, end of life, ethics, intellectual disability, palliative care

Introduction

DNAR means Do-Not-Attempt-Resuscitation, and this paper discusses pre-emptively issued DNAR orders. These are legal orders issued in advance which tell a medical team not to perform cardio-pulmonary resuscitation on a patient. ID physicians (physicians whose caseload consists exclusively of people with IDs) do not find DNAR orders an easy matter. Many aspects in the process of DNAR decision-making are unclear, causing feelings of uncertainty among ID physicians. Although a DNAR order does not affect other medical treatments, such orders are often part of a broader range of end-of-life decisions and fit into the concept of advance care planning (Kingsbury 2009). End-of-life decisions are defined as those decisions at the end of life which *may* shorten life, but are *not aimed* at shortening a patient's life, and need to be discussed with all stakeholders including the patient, next-of-kin and the attending physician. End-of-life decisions including DNAR are relevant to significant numbers of people with IDs (Wagemans *et al.* 2010) as well as to the general Dutch population (playing a role in 58% of all deaths in 2010) (Onwuteaka-Philipsen *et al.* 2012). Advance care planning is the process whereby patients, in consultation with professionals and often supported by their relatives, discuss and lay down their preferences for future health care and prepare for future treatment decisions. Advance care planning appears to improve end-of-life care and patient and family satisfaction (Detering *et al.*, 2010).

In everyday life, resuscitation attempts are unsuccessful in 70–98% of cases and effects after successful intervention are not clear (Lippert *et al.* 2012). Despite the fact that the chance of survival features prominently in discussions, DNAR decisions are made on the basis of problems at a given moment, rather than on the basis of expected survival (de Vos *et al.* 1998). When the burden of resuscitation is not in

balance with the benefits for a patient, resuscitation is called futile and is not in any patient's best interests. The concept of futility, however, is not very helpful in decision-making as it is very subjective, and it is difficult to establish whether resuscitation is futile or not (Stewart 2012). In most European countries, the current professional opinion is that physicians cannot be forced to provide any treatment, including cardiopulmonary resuscitation, that they believe will not be successful or where the risks are likely to outweigh the benefits. Physicians do not need the patient's or the family's consent in decisions about futile care, although they should as a general rule discuss it with the patient, or with the family of a patient who lacks the capacity to make their own decisions (Dyer 2012). Because the chances of survival are unclear, physicians can hardly be certain about a DNAR decision and decisions cannot be made without consulting the patient or their relatives (de Vos 2001).

Although legislation differs among countries, legislation in most European countries implies that physicians are ultimately responsible for the end-of-life decisions (Welie *et al.* 2005, Joyce 2010). The European Resuscitation Council Guidelines states that it should be clear to relatives that the ultimate DNAR decision is made by a doctor and that the relatives do not need to carry the burden of such a decision (Lippert *et al.* 2012). The position of Dutch physicians is described in the Contract of Medical Treatment Act (WGBO) (WGBO 1994). This act states that Dutch physicians need the consent of relatives for health decisions regarding people who lack the capacity to decide for themselves (children as well as adults), but physicians are ultimately responsible for the decision-making and may bypass the relatives. Dutch physicians interpret the act in different ways. Some inform relatives and ask for permission, others only inform them or, at the other extreme, give them the decisive voice (de Vos *et al.* 2011), depending on the nature of the decision. There is not always a dialogue between physicians and relatives about decisions for incompetent patients, and relatives have been bypassed by physicians in 5–37% of DNAR orders (van Delden *et al.* 2006).

People with IDs cannot always take their own decisions about the end of life, and relatives perceive an increasing sense of responsibility to support them in decision-making or to make decisions on their behalf (Bekkema *et al.* 2015). Questions emerge about

treatment decisions for those people with IDs who depend on others for daily care and who are affected by multiple conditions like epilepsy, osteoporosis and dysphagia. However, a recent study in six acute NHS service trusts in England questioned the arguments on which DNAR decisions for people with IDs were based, as these decisions seemed to be based on inappropriate assumptions about quality of life (Tuffrey-Wijne *et al.* 2014).

In the Netherlands, health care organisations for people with IDs need clarity about DNAR decision-making in terms of written orders and legal forms (Van Dartel 2006), and the paid care staff has to know what to do in emergency situations if they encounter someone who may need to be resuscitated.

This study set out to clarify non-emergency DNAR decision-making for people with IDs from the point of view of ID physicians and trainees in the Netherlands. As these physicians are experienced regarding medical care for people with IDs, this study focused on their views. What are the considerations for making a DNAR decision? Is quality of life a consideration and for whom? Who is involved, in what way? What are the problems, pitfalls and dilemmas for the physicians?

Methods

Setting and sample

Participants were recruited through a request at the annual meeting of the NVAVG (Dutch Association for ID Physicians) followed by an email. The ID physicians and trainees were invited either for a semi-structured individual interview (I) or for a focus group (FG) interview on the problems with DNAR decisions for people with IDs. Seventeen ID physicians responded. Because trainee ID physicians were poorly represented, another focus group was recruited from the Dutch vocational training programme for ID physicians. To fit in with the schedules at the university, three trainee ID physician groups were formed. First, individual interviews were held to explore ideas, followed by focus groups to generate in-depth discussion, and at the end of the data-gathering process, an expert meeting (EM) was held to test the outcomes. Those attending the expert meeting were experienced regarding the subjects of ID, decision-making and end-of-life decisions, and

included relatives, a professor of ID, a professor of neonatology and decision-making, a professor of ethics and ID, together with several ID physicians with a specific background (engaged in vocational training, an ethics advisory body and members of the board of the professional organisation of ID physicians). A total of 40 ID physicians and trainees and 12 other experts took part in the study (for a breakdown, see Table 1).

Data collection

An interview guide was developed, based on concepts found in the literature, discussions with the project members and a pilot interview (Lindlof and Taylor 2002). The guide was reviewed by researchers familiar with end-of-life decision-making (a professor of health law, a professor of ethics of health care and a senior researcher of palliative care). This resulted in four topics, namely the considerations used, the decision-making process, the participants and their roles, and the pitfalls (for details see Appendix 1). The topic list was tested in two individual interviews with a senior ID physician and a trainee physician, who were not included in the final sample. The same topic list was used in both the semi-structured individual interviews and the focus group interviews (Kitzinger 1995). All interviews were conducted in the work settings or at the university between December 2009 and June 2012.

Individual interviews were held in order to generate a list of key concepts. These were further explored in focus group interviews, during which professionals could discuss the whys and wherefores of DNAR decisions with each other. The findings emerging from this were then presented to and discussed in the expert meeting. All individual interviews, focus group interviews and the general discussion from the expert meeting were recorded on a digital voice recorder and transcribed verbatim. The individual interviews were conducted by one of the authors, while the focus group interviews and the expert meeting had an independent moderator assisted by one or two of the authors.

Analysis

All interviews were analysed following the procedures of Grounded Theory, a qualitative research method (Corbin and Strauss 2008). This method is used to

Table 1 Numbers and backgrounds of participants in interviews, focus groups and the expert meeting. Focus of interviews, focus groups and expert meeting

	Four semi-structured interviews	Five focus groups	One expert meeting
ID physicians	3	16	8
Trainee ID physicians	1	12	
Others (4 relatives, 1 professor of ID, 1 professor of neonatology and decision-making, 1 professor of ethics and ID; 5 ID physicians with different backgrounds (engaged in vocational training, ethics advisory body, physicians' board)).			12
Focus	Exploring uncertainties	Discussing uncertainties	Testing outcomes

develop a theory about a social phenomenon, based on data from daily life (i.e. experiences), characterised by a constant comparative method with open, axial and selective coding phases. The qualitative analysis involves examining and interpreting the data to elicit meaning, gain understanding, and develop empirical knowledge (Corbin and Strauss 2008).

The four individual interviews were open-coded, yielding a list of key words and associated concepts. The analysis of the first focus group interview with experienced physicians ended in data saturation in the open coding phase. At this point, it became clear that behavioural disorders were sometimes a contributing factor for DNAR, so we decided to hold a second focus group session with experienced physicians to explore this aspect further and to ensure that all important considerations and problems were identified. Of the three focus group interviews with trainee ID physicians, only one was used for axial coding because no new information emerged.

The third focus group was used to continue axial coding, which was used to define a core category, and to explore the relationships between the core category and the other major categories. Selective coding took place by reading the transcripts of focus groups 4 and 5 and rereading all the focus group interviews. This confirmed the major categories selected in the axial coding phase and their relationships.

In May 2012, the results of the analyses were presented at an expert meeting with a broad range of Dutch ID physicians (members of the executive board of the NVAVG, continuous education group, ethical committee, vocational training programmes). The experts were asked if they recognised the findings and

whether any important themes had been omitted. The expert meeting was used to assess the categories developed and define them more precisely. No new categories emerged.

All interviews were analysed by the first author and one of the other members of the project group, or a doctor interested in end-of-life decisions (researcher triangulation). The codes were discussed by the two researchers involved in the analysis of a particular interview. If necessary, codes were rearranged and refined, and new concepts were added on the basis of these discussions. The NVivo computer programme was used to store and organise the data (Bazeley 2007).

Results

After analysis via open, axial and selective coding, we identified three categories on which we built a theory concerning the process of DNAR decision-making. The core category we identified was 'Patient-related considerations when issuing a DNAR order'. This category was linked to two other categories 'The decision maker role' and 'The decision procedure in an organisational context' (see Fig. 1). The views of (experienced) physicians and trainee physicians are presented together here, as the analysis showed that the trainees views and uncertainties did not differ from those of their experienced colleagues. The quotes below were retrieved from the focus groups (FG) with ID physicians (P) and trainees (T), interviews (I) and the expert meeting (EM).

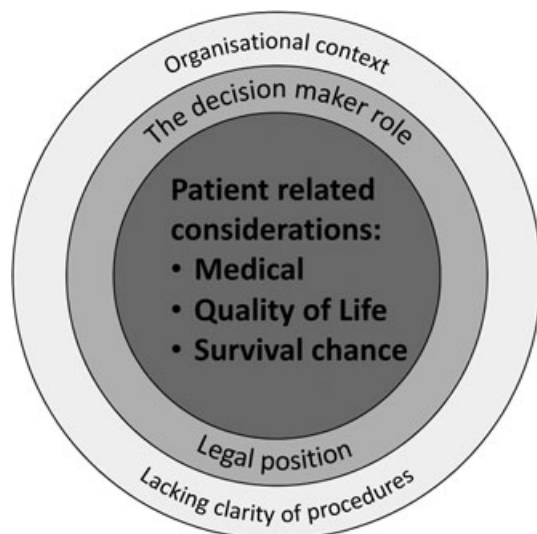


Figure 1 Results of the analysis.

Patient-related considerations when issuing Do-Not-Attempt-Resuscitation orders

The most important considerations for physicians when issuing a DNAR order were longstanding chronic medical conditions like congenital physical defects and epilepsy. Considerations like diminished life expectancy, advanced age and severe decline in health status were often mentioned.

‘My experience especially with clients with profound and multiple intellectual disabilities is that you often start such a discussion when they’re poorly. It doesn’t mean they’re terminally ill, but it’s more that he has pneumonia or he’s ill, and the expectation is often that it will recur. Then it’s good to discuss this and see what’s to be done in this kind of situation. And that often includes whether to resuscitate or not, that’s part of it.’ (FG1,P)

Physicians saw it as their task to assess what constitutes a meaningful medical intervention.

‘In any case, we said that if she starts to experience real impairments, starts to lose functions, that’s when the DNAR policy will be effectuated. As it is, the relatives feel she has a comfortable life, so if anything were to happen, they’d prefer .. [resuscitation]. And as a doctor you then have to estimate whether that would constitute a meaningful medical intervention.’ (I1,T)

Although they were unsure about the evidence, the ID physicians estimated the chances of survival through resuscitation to be very low, in the general population as well as for people with multiple disabilities. The whole process of resuscitation and recovery was seen as very burdensome and not suitable for those people who could not go through the whole trajectory into Intensive Care and further treatments. In addition, they expected a diminished quality of life afterwards. As one ID physician said about a successful resuscitation: ‘The effect was that she ended up at a lower level. So you could ask yourself if it had had an effect. Well, it had an effect: she was still alive, but at a lower level.’ (FG2,T)

Profound or severe intellectual disability was considered to contribute to a DNAR decision, because of brain damage after resuscitation coming on top of existing brain problems. Physicians also felt that people with profound and severe IDs were more vulnerable and that quality of life was lower for them.

‘Of course he had a very low intellectual level, I’d say severely to profoundly disabled. So that means, and I discussed this with his parents of course, that the chances of successful resuscitation are naturally much lower.’ (FG2,P)

Quality of life was difficult for ID physicians to use as a reason for issuing DNAR orders, and ID physicians tended to leave the judgement to the relatives.

‘To what extent are they suffering? That’s often very difficult to say, especially if someone can’t communicate.’ (I1,T)

The quality of life of some relatives was reduced by the need to support the person with IDs.

‘However, I think there’s a sliding scale of quality of life of the clients, but also that of relatives, who may be so burdened by having a child with ID that they feel like, if something should happen and he should die of it...’ (FG2,P)

The physicians reported several important considerations being mentioned by the relatives, such as ‘he has had enough problems’ and ‘let my child die before I die’. According to the physicians, declining health status was an important reason for relatives to ask for DNAR. Sometimes, very severe behavioural disorders were a reason for parents to ask for a DNAR order.

'If the boy hadn't exhibited this highly problematic autistic behaviour, I probably wouldn't have agreed (to issue a DNAR order).' (FG2,P)

Physicians hesitated about behavioural disorders as an argument for DNAR, but some physicians could understand the parents' wish and would issue such an order.

'So, erm, anyway, on one occasion I did agree to it. Not so much based on, let's put it clearly, medical indication, but on a very different, well ... lack of prospects in this whole complex of behavioural problems. And well, the parents themselves also mentioned this to some extent. And that's always a dilemma I think. Anyway, in the end I, I also thought that was a We then decided together that this [i.e. not to resuscitate] might be a good option.' (FG2,P)

The decision maker role

The impact of the ideas and opinions of the relatives in the decision-making process was unclear. The physicians experienced tensions between the ideas of the relatives, their own professional arguments and the physician's position as decision maker. Could a relative decide whether or not a DNAR order would be issued, especially if no urgent medical reasons existed?

'an excellent representative. But then she also wanted us to ... erm, although this person was in reasonable health ... to refrain from resuscitation. Though there was no medical reason.' (I1,T)

The ID physicians wanted to prevent conflicts with relatives, especially regarding quality of life, and left evaluating this quality to the relatives. An ID physician who wanted to make a DNAR decision said: 'If the parents might feel we have a very good rapport with our child. And we still see her smile, don't we? Someone with a very low intellectual level, and if I should then present them with a DNAR order, that would create a problem with the parents.' (FG1,P)

In this respect, however, the procedure was prone to conflicts, and physicians were unsure of their legal position. Some physicians asked the relatives to sign the DNAR order, to confirm that they had seen or approved it. Other physicians did not ask this, because they felt it was the doctor's professional decision and they did not want to burden the representative with this.

'Sometimes, at the start of the consultation, relatives say: now I'm the one who has to decide. So that's a reason for me to explain again ... that it's not their decision, but that we just want their opinion as one of the arguments to consider. And I've never heard about anyone finding it difficult to sign it. ... And personally, I also think well at least then it's clear that they were present at the consultation and ... okay, I think we're not officially obliged to.' (I3,P)

Specialists in hospitals were less strict about issuing a DNAR order, because they had other ideas about quality of life. As one ID physician expressed it:

'At the hospital they look downwards from the top of the scale, while we look upwards from the bottom end. What *can* they do? While they look at what someone *can't* do. So they start talking about non-resuscitation at a far earlier stage.' (FG2,P)

Relatives were important as partners in the DNAR process because they know the patient well. As one doctor said: 'Yes, he had this deformed thorax. Well, if that boy had very severe intellectual disabilities, and, and, erm ... well, what would be reasons for me not to do it? No, I think the view, the relatives' view would carry great weight.' (I3,P)

The physicians felt that the views of paid care staff were also important. People with IDs who lacked the capacity to make their own end-of-life decisions were not involved in the decision-making process.

The decision procedure in an organisational context

The DNAR orders were a part of a more comprehensive set of end-of-life decisions, even if the end of life was not necessarily imminent.

'It's usually not purely about resuscitating or not. It's always about a much wider set of decisions of various kinds, and resuscitation is only one area.' (FG1,P)

The physicians felt that it was not easy to find the right moment to discuss a DNAR order with relatives. At the same time, hospitals and paramedics in ambulances ask for clarity and want written instructions. Suitable occasions for talking about DNAR were reported to be the time when the person with IDs moves into a residential setting, or at a care plan meeting, or when a severe decline occurs in the client's health status. The physicians perceived an increasing tendency for relatives to ask for a DNAR

order earlier in the life of their loved ones, even though no life-threatening medical problems existed.

‘There are extreme cases where someone who's admitted here, that there's a written statement from a lawyer, sometimes even a notary public, with stamps and signatures of erm..., saying the client must not be resuscitated. So I then always explain that that has no legal validity...’ (I2,P)

The physicians thought it was important to start discussing DNAR in good time.

‘What I've noticed in recent years is that some families want to get these decisions on paper at an early stage. At a time when you think, well, this client is still in good health. But in many cases, something has happened in the family which meant that they had to make such a decision about their father, mother, grandfather or grandmother.’ (FG1)

Most physicians thought choking was an accident and should be treated as a non-natural death, implying that the person should be resuscitated even if a DNAR order had been issued. In some health care organisations, this was formally recorded in writing as an exception in the DNAR procedure.

‘Resuscitation is assumed to apply only in a situation of natural death. Anything beyond that, for instance someone threatening to die as a consequence of choking on something, you'll have to try your very best to revive them or keep them alive.’ (I1,T)

The status of the order was not clear, because while the attending physician might have issued an order in advance, at the moment when the order should be effectuated, bystanders might start resuscitation and another doctor in charge would make the ultimate decision to continue or terminate the resuscitation. The respondents therefore felt that the ultimate outcome of the DNAR procedure could be different from that planned in advance.

‘In any case, the order always states that the doctor treating the client at that moment... that they can make their own decision. And though that doctor can fall back on the carefully considered DNAR order, they also have the authority to deviate from it.’ (I2,P)

The physicians reported that, on the one hand, DNAR is a medical end-of-life decision, but on the other hand, at the moment the decision should be put into effect, it is often the paid care staff who have to act immediately in an emergency situation.

‘Doctors may say it's a medical decision, but we're not present at the crucial moment and someone else has to make the decision.’ (EM,P)

The ID physicians felt that the most vulnerable part of the decision-making trajectory was the moment the decision should be effectuated.

Discussion

In this study, a theory was developed in which the process of deliberation with all important stakeholders (including people with IDs) about DNAR decisions is the core of the DNAR procedure.

The theory we developed is grounded in the three major categories, namely patient-related considerations, the decision maker role and the decision procedure in an organisational context.

First, with regard to patient-related considerations, the arguments most commonly used by physicians were the medical ones. Among the medical reasons involved in DNAR decision-making, aspects like futility of resuscitation and chances of success were difficult to interpret. The ID physicians in our study felt unsure about evaluating medical conditions against unknown and non-evidence-based chances of survival. This is in agreement with the fact that DNAR decisions are based on emerging problems and not on survival chances (de Vos *et al.* 1998). Physicians had their own ideas about quality of life, like the view that people with profound and severe IDs have a lower quality of life, but they were not sure whether they could express and use this in the decision-making process. ID physicians tended to leave the assessment of the quality of life to the relatives. The extent to which perceived quality of life influences the physician's decision has been an issue of concern in the UK, where cases have been highlighted of inappropriate DNAR orders for people with IDs (Meikle 2012, Tuffrey-Wijne *et al.* 2014). Insufficient quality of life for a client, as perceived by relatives whereas there are no severe medical problems, was the most dubious and problematic argument in the deliberation. There are no instruments to measure quality of life for those who cannot speak for themselves (Townsend-White *et al.* 2012). The concept of medical futility, which says that the burden of a treatment has to be in balance with the benefits for the patient, is not very helpful when weighing the burden of resuscitation against the

quality of life of people with IDs. Discussions about medical futility cannot be unilaterally settled by physicians but are part of the continual redefining of the boundaries of decision-making authority between physicians and patients (or next of kin). Disputes around medical futility cannot easily be solved, but are dynamic problems that should always be addressed in mutual discussions (Misak *et al.* 2014). People with IDs and their next of kin deserve an honest and open debate which is tailored to each individual and his or her circumstances. There is no 'objective' truth.

Second, regarding the decision maker role, ID physicians would prefer a clearer legal position vis-à-vis the relatives. In the Netherlands, this legal position is clearly defined in the Contract of Medical Treatment Act (WGBO) (WGBO 1994) as the role of the professional who is ultimately responsible for end-of-life decisions, but apparently the ID physicians did not have a clear idea of this. And if they had a clear idea of their role, they found it hard to negotiate and make a final decision. In the current legal situation, it might be important for physicians to accept the consequences of the role of decision maker and to make the decision, together with the patient (if he or she can) or relatives (if the patient is not able to do so) (Wagemans *et al.* 2013). Similar uncertainties about roles and legislation have also been reported as important issues in other countries (Boslet *et al.* 2016).

Third, procedural and organisational aspects like the status of a DNAR order, who signs the order and what is the right moment to discuss such an order remain to be resolved. A DNAR order is a pre-emptively issued order and such a decision is made in the tranquillity of advance care planning, but the moment when resuscitation has to be started is an emergency situation. The moment when bystanders (including paid care staff) have to decide whether to start resuscitation or not was regarded as the most vulnerable part of the decision-making trajectory, and the ultimate test for the procedure. As a consequence, health care organisations should take responsibility for the process of DNAR decision-making, and should train and implement the DNAR procedure. Is the order immediately available and clear to bystanders and paramedics? Currently, some hospitals are introducing red DNAR bracelets and studying the outcomes of their use (Beelen 2012). Bracelets might be a solution in hospitals, but are not

a solution for people outside a hospital, including people with IDs. Some health care organisations have indicated death by choking as an exception in their DNAR policy, because choking is seen as a non-natural death. However, it is becoming increasingly clear that choking is inextricably linked to dysphagia problems in many people with IDs, and is part of the specific epidemiology (Chadwick *et al.* 2002).

Chances of survival, appraisal of resuscitation (balance between quality of life and appropriateness of intervention) and patient preferences are the three concepts in decision-making in hospitals (de Vos 2001). These three concepts relate to the categories of 'Patient-related considerations when issuing DNAR orders' and 'The decision maker role' of the theory developed in our study, which encompasses medical considerations (chances of survival), quality of life and futility (appraisal of resuscitation) and patient preferences as understood by relatives and paid care staff. Although the way these concepts are phrased differs between hospitals and ID care, the content of the concepts is similar and therefore important for the theory developed in our study on DNAR decision-making. A recently published comprehensive report about DNAR procedures and decision-making in NHS practice in the United Kingdom (Perkins *et al.* 2016) concluded that DNAR decisions should be seen as part of a broader framework of overall care and treatment. This conclusion is broadly supported by clinicians and other stakeholders. The authors recommended that professionals should be trained in the uncertainties of decision-making and should have sufficient time to engage in discussions and come to a decision.

This is in accordance with the theory that we developed, which shows that physicians feel unsure about DNAR decisions for people with IDs and that they have important reasons to be unsure. Because there are so few certainties, it is very important to carefully consider the decisions and discuss doubts and arguments together with people with IDs, their next of kin and other relevant persons involved. The process examining the pros and cons, discussing the insights obtained and coming to a decision takes time and requires respect for each position. Physicians should accept their role and shoulder the responsibility in the decision-making process. They should be systematically trained in decision-making skills in situations of uncertainty instead of suggesting

certainties. Advance care planning and clear organisational procedures could support this process. In sum, the process of deliberation with relevant participants is of the utmost importance and needs a prominent place in a DNAR procedure.

Strengths and limitations

In this study we interviewed ID physicians and not other medical specialists or general practitioners. Furthermore, only physicians interested in the subject participated in the interviews, the focus group interviews and the expert meeting. People with IDs and paid care staff were not involved in this study, and only a few relatives took part in the expert meeting. However, because it is the ID physicians and trainees who are used to caring for those people with IDs who have major health problems, this study has provided important insights into DNAR decision-making with regard to people with IDs.

The study was limited to the Netherlands and the way health care for people with IDs is organised in the Netherlands. Although other countries do not have specially trained ID physicians and therefore other physicians are engaged in the care for people with IDs, we feel that the results of our current study among physicians with more than average experience in health care for people with IDs are also valuable in an international perspective.

Conclusion

We developed a theory which showed that for various reasons, physicians feel unsure about DNAR decisions for people with IDs. Important uncertainties concern patient-related considerations (including quality of life), the position of the physician with regard to the relatives and uncertainties about policies in the relevant organisations. Physicians should be systematically trained in decision-making skills in situations of uncertainty and accept their role and responsibility in the decision-making process. Physicians should express these uncertainties and, within their professional organisation, develop a method of advance care planning that offers room to discuss the need for issuing DNARs. The procedures within an organisation should be the subject of further research in which they are described, implemented and evaluated. Results of such studies may further

support physicians in giving proper attention to the difficult health decisions to be made, which is of the utmost importance for people with IDs and their next-of-kin.

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Appendix I: List of interview topics about DNAR decisions for people with intellectual disabilities

Considerations

The considerations which lead to a DNAR decision. Do only medical considerations play a role, or are there other considerations, like quality of life? What was the immediate argument to make the DNAR decision?

Process

What aspects make this a good or a bad process?

Participants

Who makes the DNAR decision, who influences this process? Is the person with intellectual disabilities involved? Does paid care staff play a part in this process?

Pitfalls

What are the pitfalls, problems and dilemmas for the physician who has to make a DNAR decision?

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