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|-------------------|---|
| Postprint Version | 1.0   |
| Journal website   | <a href="http://www.pec-journal.com/article/S0738-3991(14)00194-3/abstract">http://www.pec-journal.com/article/S0738-3991(14)00194-3/abstract</a> |
| Pubmed link       | <a href="http://www.ncbi.nlm.nih.gov/pubmed/24938912">http://www.ncbi.nlm.nih.gov/pubmed/24938912</a>   |
| DOI               | 10.1016/j.pec.2014.05.014   |

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## Decision making about medical interventions in the end-of-life care of people with intellectual disabilities: A national survey of the considerations and beliefs of GPs, ID physicians and care staff

NIENKE BEKKEMA<sup>A</sup>, ANKE J.E. DE VEER<sup>A</sup>, ANNEMIEKE M.A. WAGEMANS<sup>B</sup>, CEES M.P.M. HERTOIGH<sup>C,E</sup>, ANNEKE L. FRANCKE<sup>A,D,E</sup>

<sup>a</sup> NIVEL, Netherlands Institute of Health Services Research, Utrecht, The Netherlands

<sup>b</sup> Koraalgroep, Maasveld, Maastricht, The Netherlands

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

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

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

### HIGHLIGHTS

- Professionals believe that considerations about quality of life are most important.
- Quality of life and wellbeing are frequently taken into account in decisions about medical interventions.
- Seventy percent believe that people with ID should always be informed about interventions.
- Family's wishes are explicitly considered more often than the wishes of the person with ID.

### ABSTRACT

**Objective:** This paper explores the personal beliefs and specific considerations of professionals regarding decisions about potentially burdensome medical interventions in the end-of-life care for people with intellectual disabilities (ID).

**Methods:** A survey questionnaire covering decision making about potentially burdensome medical interventions was sent to nationally representative samples of 294 ID care staff-members, 273 ID physicians and 1000 GPs.

**Results:** Professionals predominantly believed that considerations about quality of life are most important. Quality of life and wellbeing were also frequently considered in both decisions to start/continue an intervention and decisions to forgo/withdraw an intervention. Seventy percent believed that people with ID should always be informed about interventions, and 61% would respect a refusal

by the person. The family's wishes were explicitly considered more often than the wishes of the person with ID.

**Conclusion:** Although respondents agree that the quality of life is highly important, the wishes of people with ID (especially of those with severe/profound ID) were often not considered in decisions about potentially burdensome medical interventions.

**Practice implications:** To enhance the active involvement of people with ID in decision making we recommend that professionals integrate collaborative principles in decision making and make use of pictorial and easy reading resources.

## 1. INTRODUCTION

End-of-life care is the total care that aims to maintain the best possible quality of life until death. According to the WHO [1], end-of-life care provides relief from pain and other distressing symptoms, and may start early in the course of a life-threatening illness. The focus on quality of life has consequences for choice of medical interventions [2], [3] and [4]. Medical interventions can improve wellbeing but may also be quite burdensome for somebody with a life-threatening illness. Decisions about whether to use or forgo medical interventions are therefore of paramount importance. These decisions may be especially difficult when it comes to people with intellectual disabilities (ID). This article presents a study of the beliefs and considerations that influence such decisions.

There are several reasons why decision making about medical interventions at the end of life can be more difficult in the case of people with ID. First, it may take more time before palliative care needs are recognised. A study in the UK showed that people with ID had more delays in the diagnosis and treatment of their final illness and received less opioid analgesia than a group without ID [5]. Second, many people with ID do not fully understand the reasons, impact and consequences of medical interventions. Communication about medical interventions and assessing their wishes and needs is often difficult [6], [7], [8] and [9]. Heslop et al. [5] found almost no documentation on what people with ID understood about their condition and medical interventions. Similarly, Wagemans et al. [10] found no evidence in medical files that people with ID were involved in end-of-life decision making. Not understanding their illness and intervention options can lead to considerable distress in people with ID [7]. Third, determining the wellbeing of people is an important element in end-of-life care. The identification and management of pain and other symptoms can be complicated in people with ID, as signals that express pain or distress are hard to recognise [11], [12] and [13]. Difficulties in determining wellbeing may lead professionals to rely on biased presumptions about a person's needs and values [14] and [15].

So far, most studies addressing medical interventions in the end-of-life care of people with ID have either been case descriptions [14] and [15] or have focused specifically on decisions with a possible life-shortening effect [16] and [17]. Yet many medical intervention may be potentially burdensome for people with ID who need end-of-life care due to their limited level of understanding and communication difficulties. As far as we know, these decisions have not been explored. Neither do we know

whether decisions to start an intervention are based on different considerations than decisions to forgo an intervention. To enhance well-considered decision making, we need insight into the beliefs and actual considerations of professionals in such situations. The research questions are:

1. What considerations do the professionals concerned take into account in actual decision making about the use of potentially burdensome medical interventions? Are decisions to start or continue a medical intervention based on different considerations than decisions to withdraw or forgo a medical intervention?
2. What beliefs do professionals have with regard to the use of potentially burdensome medical interventions in the end-of-life care for people with ID? Do care staff, ID physicians and GPs differ in these beliefs?

## **2. METHODS**

### **2.1. Research subjects**

A pre-structured questionnaire was sent to three groups of professionals:

1. Care staff employed by care services for people with ID, recruited from an existing national research panel of care professionals in the Netherlands [18] and [19]. This research panel consists of a national sample of registered nurses, certified nursing assistants and social workers who are prepared to fill in questionnaires on current topics in health care. All panel members who worked in ID care services (a total of 294 people) were sent a questionnaire.
2. ID physicians, who had received three-year specialist education in the care for people with ID and who are generally employed by an ID care service. All members of the Dutch professional association of ID physicians (a total of 273) were sent a questionnaire.
3. General practitioners. In the Netherlands, people with ID receive medical care from either an ID physician or a GP, with GPs commonly caring for people with mild ID living in the community. GPs were recruited by sending a questionnaire to a nationally representative sample of 1000 GPs, drawn from the national registration of about 9000 GPs in the Netherlands [20].

### **2.2. Survey questionnaire**

The questionnaire focused on (1) the respondents' background characteristics, (2) the case-related considerations that played a role in decisions about transitions in the place of care and medical interventions and (3) personal beliefs about transitions in the place of care and potentially burdensome medical interventions, such as chemotherapy, life-prolonging surgery, radiotherapy, tube feeding, pain medication by infusion pump, further diagnostic investigations or punctures that may in some sense be burdensome for the person with ID. This paper focuses on decisions regarding medical interventions.

The questionnaire items relevant for this paper were based on a scan of the relevant literature (e.g. about decisions regarding chemotherapy, tube feeding and further diagnostic investigation in the end-of-life care for people with ID [7], [10] and [14]), on the results of two group interviews with professionals and family members, and on two group interviews with people with mild and moderate ID.

[TABLE 1]

1. Questions were included on the respondent's background and work-related characteristics.
2. The considerations used in decisions on medical interventions were explored by open questions about the last person with ID for whom the respondent provided end-of-life care. Respondents were asked if a potentially burdensome medical intervention was considered (using response categories, see Table 1) and whether it was decided to start/continue or forgo/withdraw this intervention. If more than one intervention was considered, the respondent chose one intervention to answer the questions about. Respondents were asked what considerations in the case of that specific person led to the decision to start/continue or forgo/withdraw the intervention (open text field).
3. Personal beliefs about the use of potentially burdensome medical interventions were measured by eleven statements that incorporated different considerations about the use of medical interventions in end-of-life care (the response categories were 'strongly agree', 'agree', 'neutral', 'disagree' and 'strongly disagree').

For GPs, the questions on end-of-life care formed part of a broader questionnaire on their experiences with patients with ID. GPs usually have only a few patients with intellectual disabilities in their practice [21] and will therefore have little or no experience with end-of-life care for people with ID. Therefore, GPs were not asked the specific questions about their last patient with ID who needed end-of-life care. The questionnaire was tested for comprehensibility and completeness among six ID physicians and six ID care staff members.

### 2.3. Analysis

To answer *research question 1*, all considerations that were mentioned by the respondents in the open text field were coded using a code system partly based on the preliminary scan of relevant literature and group interviews (see questionnaire section) and extended with new codes that emerged from the data. Two authors (NB and AdV) coded the answers (Cohen's Kappa for inter-rater reliability: 0.93). Fisher's exact tests were used to explore differences in considerations between decisions to start/continue a medical intervention and decisions to forgo/withdraw a medical intervention. The cases reported were checked for possible double counting: all cases included are unique cases.

To answer *research question 2*, the percentages selecting 'agree'/'strongly agree', means and standard deviations (SD) were calculated to measure the beliefs of professionals. ANCOVAs were performed to explore differences in beliefs between groups of professionals. The ANCOVAs included an adjustment for the possible influence of experience (yes/no) in end-of-life care and for the interaction between experience in end-of-life care and professional background. All analyses were performed using Stata 12.1.

### 2.4. Ethical considerations

The protocol for conducting the preliminary group interviews with people with ID (used to compose the questionnaire) was approved by the Medical Ethical Committee of the VU University Medical Center. The preliminary group interviews with professionals and family members and the protocol for the questionnaire study and did not involve imposing interventions or actions, and in such cases no approval by an ethics committee is required in the Netherlands (according to the Medical Research Involving Human Subjects Act, see <http://ccmo-online.nl>). All respondents received a letter informing them of the aim of the study. Study participation was voluntary. The responses were anonymous and non-traceable to individuals.

### **3. RESULTS**

#### **3.1. Background of the respondents**

The overall response rate was 46% with 718 questionnaires being completed. The response rate among care staff was 67% ( $n = 196$ ), among ID physicians 53% ( $n = 145$ ) and among GPs 38% ( $n = 377$ ). The group of care staff ( $n = 196$ ) was comprised of 85 registered nurses, 8 certified nursing assistants and 103 social workers. All responding GPs (377) had patients with ID in their practice and 107 (28% of the 377 GPs) filled in the questions on end-of-life care. The responding ID physicians had on average less work experience as a professional (12.8 years) than care staff (20.3 years) and GPs (18.5 years). ID physicians had more experience of providing end-of-life care for people with ID (94%) than care staff (63%). Of the 377 GPs with patients with ID in their practice, 24% had experience with end-of-life care for this patient group.

#### **3.2. Background medical interventions**

A total of 248 care staff and ID physicians completed the questions about the last person with ID for whom they provided end-of-life care. A potentially burdensome medical intervention was considered in 145 of the 248 cases described (58%). Of these 145 persons, 85% died less than two years ago, 52% had mild/moderate ID and 48% severe/profound ID, and 37% died of cancer, 17% of an overall decline due to old age, 14% of dementia, 6% of heart failure, 5% of stroke, 2% of asthma/COPD and 19% of another/unknown disease.

Table 1 shows that decisions to start or continue an intervention often concerned pain medication by infusion pump or tube feeding. Decisions to forgo or withdraw an intervention often concerned further diagnostic investigations, tube feeding or pain medication by infusion pump.

#### **3.3. Considerations in decisions about the use of potentially burdensome medical interventions**

Considerations that were taken into account in decisions about the use of potentially burdensome medical interventions care were described for a total of 140 people. Table 2 shows that three types of considerations were taken into account in at least 20% of the decisions to start or continue an intervention: considerations regarding the quality of life and wellbeing (52.5%), the wishes/preferences of family members (23.0%) and the wishes/preferences of the person with ID (21.3%). Five types of considerations were taken into account in at least 20% of the decisions to forgo or



withdraw an intervention: considerations regarding the futility of the intervention (38%), the quality of life and wellbeing (36.7%), the direct physical strain of the intervention on the person (27.9%), the wishes/preferences of family members (27.8%) and the direct emotional strain of the intervention on the person (25.3%). The wishes/preferences of people with mild/moderate ID were taken into account more often (27.8%) than the wishes/preferences of people with severe/profound ID (2.9%).

**[TABLE 2]**

Prolonging the life of the person with ID and curative goals were taken into account more often in decisions to start or continue the intervention than in decisions to forgo or withdraw the intervention. The futility of the intervention, the direct physical strain of the intervention and the availability of an alternative intervention were taken into account more often in decisions to forgo or withdraw the intervention than in decisions to start or continue the intervention.

**3.4. Beliefs about the use of potentially burdensome medical interventions**

Table 3 shows that almost all professionals (92.6%) believe that considerations regarding the quality of life are the most important considerations in decisions about potentially burdensome medical interventions. Most professionals (72%) believe that the client's possible unease outweighs prolongation of life. The client not being able to cooperate with a medical intervention is generally not perceived as a reason to forgo the intervention. A majority (69.5%) believe that people with ID should always be informed about intervention options, even when the possibility of communication is limited. Less than half of the professionals (43.6%) believe that the wishes of the person with ID should be leading, yet rather more professionals (56.5%) believe that these wishes should prevail when they are not in line with the opinion of professionals. A slight majority (60.8%) believe that a refusal of the intervention should be respected, yet a similar proportion (60.1%) believe that if a person with ID refuses an intervention, their decision-making capacity should be tested. If a person with ID is unable to decide for themselves about a medical intervention, more professionals believe that the opinion of relatives is decisive (52.1%) than believe the opinion of the physician should prevail (39.8%). ID physicians are the only professional group giving more weight to the opinion of the physician than of the relatives.

**[TABLE 3]**

There are differences, albeit small, in beliefs between the three groups of professionals: care staff are most likely to believe that the wishes of the person with ID should be leading and they are also more likely to follow the opinion of relatives rather than the opinion of the physician. ID physicians are most likely to believe that the quality of life is the most important consideration in decisions, are most likely to believe that if a person with ID refuses an intervention their decision-making capacity should be tested, and are less inclined to always inform the person with ID about intervention options. GPs are most likely to believe that hospital admission

should be avoided and that an intervention should be avoided if it is not possible for the client to cooperate properly.

#### **4. DISCUSSION AND CONCLUSION**

##### **4.1. Discussion**

This study explored actual considerations and personal beliefs of professionals regarding decisions about potentially burdensome medical interventions in the end-of-life care for people with ID.

Regarding actual considerations, the study shows that decisions about potentially burdensome medical interventions are often made in the end-of-life care of people with ID. Most of the decisions described in our study resulted in the rejection or withdrawal of a potentially burdensome medical intervention, mainly based on considerations regarding the futility of the intervention and the quality of life and wellbeing of the person. Considerations about the quality of life and wellbeing were the commonest considerations in decisions to start or continue an intervention. Generally, an important aspect of quality of life in end-of-life care is pain relief [1]. Decisions about pain medication by infusion pump were the decisions most frequently mentioned in this study. The majority of these decisions resulted in the start or continuation of the infusion pump, which indicates that in these cases the relief of pain outweighed the possible distress that the infusion pump might cause the person. As other studies have indicated, decision making about pain interventions should always be preceded by careful identification of pain, as assessing pain in people with ID can be very complicated [5], [11], [12] and [23].

Regarding personal beliefs, almost all professionals, and ID physicians in particular, found the quality of life of the person with ID the most important consideration. This finding is in line with studies within the general population on decision making about medical interventions at the end of life [2], [3] and [22]. Yet what wellbeing actually means can best be determined by the people with ID themselves. Many people with ID will need the help of relatives and professionals to clarify their values and wishes, for example by eliciting the life story of the person with ID as a means of clarifying their values and preferences, preferably before the onset of the illness [14].

##### **4.1.1. Right to know**

Although most respondents (69.5%) agreed with the statement that people with ID should always be informed about intervention options, a minority (30.5%) had another opinion. The 69.5% that agreed with this statement may be seen as a low percentage given the patient's legal right to be informed about medical interventions. Several explanations may account for this finding: professionals may want to protect people with ID from complex information they presumably cannot (fully) understand. This may reflect moral challenges in truth-telling, which have e.g. also been found in advanced dementia care [24]. Moreover, informing people with ID about medical interventions can be hampered by communication barriers [6], [7], [8] and [9]. It may also be that professionals prefer to inform a family member or other representative. Yet even people who lack decision-making capacity have a right to be informed. The decision not to inform the person with ID should therefore not be based on fear or prejudgments.

#### **4.1.2. Wishes of the person with ID**

Only 43.6% of the professionals believe that the wishes of the person with ID should always be leading in decisions about medical interventions, whereas we described in another paper that 72% believe that this wish is leading in decisions about the *place* of end-of-life care [25]. Probably, professionals believe that people with ID are less able to decide about complex medical matters than about more practical matters such as where they want to spend the end of their life. The wishes of people with severe/profound ID in particular were rarely taken into account (2.9%).

Care staff appear to be more in favour than physicians of giving the clients' wishes priority in decisions about medical interventions. This finding is in line with the findings presented in the paper about decisions regarding the place of end-of-life care [24], indicating that care staff find it important to encourage self-reliance in clients.

#### **4.1.3. Role of the family**

The family's wishes were explicitly considered more often (25.7%) than the wishes of the person with ID (15.7%) and professionals' wishes (12.1%) when making decisions about potentially burdensome interventions. Moreover, professionals, especially care staff, frequently believe that if people are unable to decide for themselves, the opinion of relatives should be decisive rather than the opinion of the physician. Wagemans et al. [16] also found that substantial weight is given to the opinions of the relatives of people with ID in the case of end-of-life decisions.

According to the Dutch Medical Treatment Contract Acts (WGBO), a patient should give informed consent to a proposed medical intervention. If a person lacks decision-making capacity, a representative (usually a relative) can give consent to the medical intervention. Making medical decisions in end-of-life care is the joint responsibility of all involved, with physicians having ultimate formal responsibility. It is noteworthy that only 60.8% would respect a refusal by a person with ID of a potentially burdensome intervention, and that 60.1% believe decision-making capacity should be tested after a refusal. This indicates that refusals are complicated and raise questions about decision-making capacity.

#### **4.1.4. Strengths and weaknesses**

A strength of this study is that we studied both actual considerations and personal beliefs, which gave a more profound insight into decisions on medical interventions in the end-of-life care of people with ID. Another strength is that we were able to incorporate the perspectives of three different groups of professionals who work with people with ID: care staff, ID physicians and GPs.

A limitation is that we framed the respondents' choice of medical interventions by giving them a set list to choose from, which may have influenced the respondents' choices. A second limitation is the possible recall bias regarding the last client with ID for whom the respondent provided end-of-life care: professionals may be more likely to recall clients who made a great impact on them. A third limitation is that we do not know what the personal input and role of the respondent was in the decision-making process. Different professionals may have other ideas about which considerations are relevant or decisive in decisions about medical interventions. Moreover, the actual considerations of GPs, as well as the perspectives of people



with ID and their relatives were not included in this study. More in-depth qualitative research on the course of decision-making processes is necessary, including different perspectives and responsibilities.

#### **4.2. Conclusion**

Quality of life and wellbeing were frequently considered in both decisions to start or continue an intervention and decisions to forgo or withdraw an intervention.

Although respondents agree that quality of life is highly important, the results give a diffuse picture of decision making about medical interventions in the end-of-life care for people with ID. Professionals hold varying beliefs on whether people with ID should always be informed about medical interventions and whether a refusal by the person with ID should be respected. Moreover, the wishes of people with ID (especially of those with severe/profound ID) were often not considered in decisions about potentially burdensome medical interventions.

#### **4.3. Practice implications**

The results of this study raise questions about how to actively involve people with ID in decision making and how to acknowledge their wishes: e.g. should all people with ID always be informed, how should refusals be tackled, whose opinion should prevail when decision-making capacity is lacking and how to make shared decisions with people with ID, including those with severe/profound ID? This highlights another question, namely whether standard informed-consent procedures can adequately incorporate the preferences of people with ID. These procedures assume a liberal notion of patient autonomy where people should be able to decide without interference from others. Yet, many people with ID will have difficulties expressing themselves and need the help of others to decide about medical interventions [6], [7] and [26]. A relational notion of patient autonomy where people reach autonomy with the assistance of others may therefore be more appropriate [6], [27], [28] and [29]. To improve the active involvement of all people with ID in decisions, resources such as pictorial guides and easy read books or websites could be used to assist in this process (for resources also see <http://www.pcpld.org>; the Palliative Care for People with Learning Disabilities Network). Moreover, professionals can learn from existing models such as (1) the 'ASK ME' collaborative model of supported decision making for involving people with cognitive disabilities; which includes steps such as assessing the person's strengths and deficits, simplifying the task, understanding their values and maximising their ability to understand [30]. and (2) the model of Tuffrey–Wijne about for breaking bad news to people with ID in which small pieces of information about e.g. the intervention are added one by one to the current knowledge of the person [26].

#### **ACKNOWLEDGMENT**

The study was funded by ZonMw, the Netherlands Organization for Health Research and Development.

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## TABLES

**Table 1. Potentially burdensome medical interventions that were considered (%).**

|  | <b>Decision:<br/>start/continue<br/>(%)</b> | <b>Decision:<br/>forgo/withdraw<br/>(%)</b> | <b>Total<br/>(%)</b> |
|--|---|---|----------------------|
| Pain medication by infusion pump   | 38.1  | 13.4  | 24.1                 |
| Tube feeding   | 15.9  | 22.0  | 19.3                 |
| Further diagnostic investigation<br>(e.g. origination carcinoma, heart<br>failure tests)               | 4.8   | 26.8  | 17.2                 |
| Other intervention (e.g. placing a<br>suprapubic catheter or stoma,<br>providing oxygen and dialysis). | 14.3  | 8.5   | 11.0                 |
| Chemotherapy   | 6.4   | 11.0  | 9.0                  |
| Life-prolonging surgery  | 4.8   | 7.3   | 6.2                  |
| Administering antibiotics  | 3.2   | 3.7   | 3.5                  |
| Pain medication (other than infusion<br>pump; e.g. by injection)                                       | 6.4   | 0.0   | 2.8                  |
| Radiotherapy   | 3.2   | 2.4   | 2.8                  |
| Unknown intervention   | 1.6   | 3.7   | 2.8                  |
| (Veni)Puncture   | 1.6   | 1.2   | 1.4                  |
| <b>Total</b>   | <b>100 (n = 63)</b>                         | <b>100 (n = 82)</b>                         | <b>100 (n = 145)</b> |

**Table 2. Considerations in decisions about potentially burdensome interventions (% of cases in which a consideration was taken into account).**

|  | <b>Total<br/>(n =<br/>140)<br/>(%)</b> | <b>Decision:<br/>start/continue (n<br/>= 61) (%)</b> | <b>Decision:<br/>forgo/withdraw (n<br/>= 79) (%)</b> |
|--|--|--|--|
| Quality of life and wellbeing (e.g. mobility, minimising suffering, no pain, tranquillity, comfort, dignity)                                     | 43.6                                   | <b>52.5</b>  | <b>36.7</b>  |
| Wishes/preferences of family members   | 25.7                                   | <b>23.0</b>  | <b>27.8</b>  |
| Medically meaningful intervention/medical futility**   | 22.9                                   | 3.3  | <b>38.0</b>  |
| Direct emotional strain of the intervention on the person (e.g. understanding of the intervention, fear/stress due to the intervention/hospital) | 19.3                                   | 11.5   | <b>25.3</b>  |
| Direct physical strain of the intervention on the person (e.g. weak health, fast decline in physical condition)**                                | 17.9                                   | 4.9  | <b>27.9</b>  |
| Wishes/preferences of person with ID   | 15.7                                   | <b>21.3</b>  | 11.4   |
| Wishes/preferences of professionals  | 12.1                                   | 14.8   | 10.1   |
| Availability of an alternative intervention (e.g. less invasive intervention such as oral pain relief instead of by infusion pump)*              | 4.3                                    | 0.0  | 7.6  |
| Prolonging the life of the person with ID*   | 3.6                                    | 8.2  | 0.0  |
| Curative goal*   | 3.6                                    | 8.2  | 0.0  |
| Possibility of the person with ID to cooperate with intervention (e.g. leave tube unattached, cooperate during diagnostic investigation)         | 3.6                                    | 0.0  | 6.3  |
| Age of the person with ID  | 2.9                                    | 1.6  | 3.8  |
| Diagnostic uncertainty   | 2.1                                    | 3.3  | 1.3  |
| Professionals involved not authorised to work with intervention (e.g. providing tube feeding)  | 1.4                                    | 0.0  | 2.5  |
| Costs of the intervention  | 0.7                                    | 0.0  | 1.3  |



Please note; in 10.7% of the cases other remarks were made that could not be clustered into a meaningful category. Numbers in bold refer to considerations mentioned in at least 20% of the decisions.

\* Fisher's exact test:  $p < 0.05$ .

\*\* Fisher's exact test:  $p < 0.01$ .

**Table 3. Beliefs about the use of potentially burdensome medical interventions in the end-of-life care for people with ID.**

|   | % agree or strongly agree<br>Total (n = 434) | M (SD)<br>Total*<br>(n = 434) | M<br>Care<br>staff (n = 187) | M<br>ID<br>physicians<br>(n = 140) | M<br>GPs<br>(n = 107) |
|---|--|-------------------------------|------------------------------|------------------------------------|-----------------------|
| <b>Quality of life</b>  |  |                               |                              |                                    |                       |
| The client's quality of life is the most important consideration in deciding on a medical intervention. <sup>a</sup>                    | 92.6   | 4.28<br>(0.70)                | 4.14                         | 4.47                               | 4.25                  |
| <b>Emotional strain on the person with ID</b>   |  |                               |                              |                                    |                       |
| The potential unease the client may feel because of an intervention outweighs the potential prolongation of life.                       | 72.0   | 3.83<br>(0.86)                | 3.94                         | 3.77                               | 3.73                  |
| If a client has to be admitted to hospital for a medical intervention, you should be wary about using that intervention. <sup>b</sup>   | 44.4   | 3.23<br>(0.91)                | 3.13                         | 3.18                               | 3.46                  |
| <b>Cooperation of the person with ID</b>  |  |                               |                              |                                    |                       |
| If a client is unable to cooperate properly with the medical intervention, it is better not to start on that intervention. <sup>c</sup> | 33.1   | 3.06<br>(0.81)                | 2.96                         | 3.01                               | 3.31                  |
| <b>Wishes/preferences of the person with ID</b>   |  |                               |                              |                                    |                       |
| Clients should always be informed about options for intervention, even if the possibilities for communication are limited. <sup>d</sup> | 69.5   | 3.71<br>(0.85)                | 3.75                         | 3.54                               | 3.89                  |
| The client's wishes about whether to use the medical intervention are always leading. <sup>e</sup>                                      | 43.6   | 3.28<br>(0.87)                | 3.49                         | 3.15                               | 3.09                  |
| If a client does not want an intervention, this wish must be  | 60.8   | 3.61<br>(0.75)                | 3.73                         | 3.51                               | 3.53                  |

|   | % agree or strongly agree<br>Total (n = 434) | M (SD)<br>Total*<br>(n = 434) | M<br>Care staff (n = 187) | M<br>ID physicians (n = 140) | M<br>GPs (n = 107) |
|---|--|-------------------------------|---------------------------|------------------------------|--------------------|
| respected. <sup>f</sup>   |  |                               |                           |                              |                    |
| If a client's wishes are not in line with the opinion of the caregivers, the client's wishes prevail. <sup>g</sup>  | 56.5   | 3.58<br>(0.75)                | 3.76                      | 3.50                         | 3.36               |
| <b>Decision-making capacity of the person with ID</b>   |  |                               |                           |                              |                    |
| If a client refuses an intervention, their decision-making capacity in this matter should always be investigated. <sup>h</sup>                                    | 60.1   | 3.54<br>(0.88)                | 3.31                      | 3.91                         | 3.43               |
| If a client is unable to decide for themselves, the family's opinion about whether to use the medical intervention should be the deciding factor. <sup>i</sup>    | 52.1   | 3.43<br>(0.78)                | 3.65                      | 3.15                         | 3.39               |
| If a client is unable to decide for themselves, the physician's opinion about whether to use the medical intervention should be the deciding factor. <sup>j</sup> | 39.8   | 3.23<br>(0.77)                | 3.04                      | 3.43                         | 3.28               |

\* Range = 1–5, 1 = strongly disagree to 5 = strongly agree.

*p* values (*p* < 0.05) reported of post hoc Bonferroni test, after ANCOVA:

<sup>a</sup> Care staff versus ID physician: *p* = 0.000, ID physician versus GPs: *p* = 0.042.

<sup>b</sup> Care staff versus GPs: *p* = 0.009, ID physician versus GPs: *p* = 0.048.

<sup>c</sup> Care staff versus GPs: *p* = 0.001, ID physician versus GPs: *p* = 0.013.

<sup>d</sup> ID physician versus GPs: *p* = 0.004.

<sup>e</sup> Care staff versus ID physician: *p* = 0.002, care staff versus GPs: *p* = 0.001.

<sup>f</sup> Care staff versus ID physician: *p* = 0.031.

<sup>g</sup> Care staff versus ID physician: *p* = 0.005, care staff versus GPs: *p* < 0.001.

<sup>h</sup> Care staff versus ID physician: *p* < 0.001, ID physician versus GPs: *p* < 0.001.

<sup>i</sup> Care staff versus ID physician: *p* < 0.001.

<sup>j</sup> Care staff versus ID physician: *p* < 0.001, care staff versus GPs: *p* = 0.034.