

TITLE: Shared decision-making with people with intellectual disabilities in the last phase of life: a scoping review
AUTHORS: A.Noorlandt, M.Echteld, I.Tuffrey-Wijne, D.Festen, C.Vrijmoeth, A.van der Heiden, I.Korfage
ACCEPTED FOR PUBLICATION in *Journal of Intellectual Disability Research* on 18 August 2020

This is the peer reviewed version of the following article: Noorlandt, H. W., Echteld, M. A., Tuffrey-Wijne, I., Festen, D. A. M., Vrijmoeth, C., van der Heide, A., and Korfage, I. J. (2020) Shared decision-making with people with intellectual disabilities in the last phase of life: A scoping review. *Journal of Intellectual Disability Research*, 64: 881– 894, which has been published in final form at <https://doi.org/10.1111/jir.12774>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.

Title: Shared decision-making with people with intellectual disabilities in the last phase of life: a scoping review.

Running head: Shared decision-making with people with ID.

Background: Shared decision-making (SDM) is the process in which healthcare professionals and patients jointly discuss and decide which care and treatment policy is to be followed. The importance of SDM is increasingly being recognised across health settings, including palliative care. Little is known about SDM with people with intellectual disabilities (ID) in the last phase of life. This review aimed to explore to which extent and in which way people with ID in the last phase of life are involved in decision-making about their care and treatment.

Method: In this scoping review, we systematically searched in the Embase, Medline and PsycINFO databases for empirical studies on decision-making with people with ID in the last phase of life.

Results: Of a total of 281 identified titles and abstracts, ten studies fulfilled the inclusion criteria. All focused on medical end-of-life decisions, such as foregoing life-sustaining treatment, do-not-attempt-resuscitation orders or palliative sedation. All studies emphasise the relevance of involving people with ID themselves, or at least their relatives, in making decisions at the end of life. Still, only two papers described processes of decision-making in which persons with ID actively participated. Furthermore, in only one paper best practices and guidelines for decision-making in palliative care for people with ID were defined.

Conclusion: Although the importance of involving people with ID in the decision-making process is emphasised, best practices or guidelines about what this should look like are lacking. We recommend developing aids that specifically support SDM with people with ID in the last phase of life.

Keywords: shared decision-making, intellectual disabilities, palliative phase, end-of-life, decision-making, scoping review.

Introduction

In palliative care, the emphasis on shared decision-making (SDM), i.e. decision-making by health care professionals and patients (Charles et al., 1997) is growing. Palliative care is *“an approach that improves quality of life of people with life limiting conditions due to illness and frailty and their families”* (WHO). Timely recognition of the palliative phase is key to allow discussion of preferences and to apply these in provided care (Vrijmoeth et al., 2016b, Vrijmoeth et al., 2016a). A structured approach may provide support in these SDM processes.

The concept of SDM first appeared in literature in 1997 (Charles et al., 1997). Through SDM patients can be included in decision-making when multiple treatment options coexist (Stiggelbout et al., 2015). Ideally, healthcare professionals clearly explain relevant care or treatment options and support patients in weighing their preferences and values in the context of these options before a treatment decision is made (Stiggelbout et al., 2012). A systematic review showed that patients who participated in SDM tended to report positive outcomes, such as a higher degree of patient satisfaction and less decisional conflict (Shay and Lafata, 2015). SDM is often mentioned in the context of medical treatment, but is also applicable in non-medical care and support, such as adjusting daytime activities and hobbies (Stiggelbout et al., 2015). So far, SDM models have not specifically described their use by people with intellectual disabilities (Elwyn et al., 2012, Charles et al., 1999, Towle and Godolphin, 1999, Makoul and Clayman, 2006).

The relevance of involvement of people with intellectual disabilities (ID) in SDM might be obvious. However, in practice assessing preferences and values of people with ID can be hindered by their ID or co-morbid conditions. Involvement of close proxies may be required. Other barriers for SDM include negative attitudes and lack of knowledge and skills in health care professionals (Stiggelbout et al., 2015). In addition, it can be difficult for people with ID to weigh the different options and to oversee their consequences in the longer term. People with ID may not always comprehend the information about and implications of their illness, which limits their decision-making capacity (Tuffrey-Wijne, 2013, Szmukler, 2019).

In spite of limited or absent decision-making capacity, people's preferences have to be taken into account. Article 12 recognises the right of people with ID to (United Nations, 13 december 2006) be recognised by law as a person equal to others (United Nations, 13 december 2006). People with ID have the right to be supported in making choices even if they cannot make such decisions by themselves (Szmukler, 2019). See Box 1 for an example.

Knowledge about how to engage people with ID in decision-making in the last phase of life is limited and research is still scarce. This review aimed to explore in which way people with ID in the last phase of life are involved in decision-making about their care and treatment.

Methods

Design

Given the exploratory nature of this study we opted for a scoping review. This is defined as: *"a form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence and gaps in research related to a defined area or field by systematically searching, selecting and synthesizing existing knowledge"* (Colquhoun et al., 2014). We followed the PRISMA Scoping Review Guidelines (Tricco et al., 2018). (See appendix 1). In collaboration with a biomedical information specialist, we systematically searched the electronic databases Embase, Medline and PsycINFO in October the 2018 and updated the search in September 2019. We used relevant search terms and synonyms related to intellectual disability, shared decision-making and palliative care (See appendix 2 for the EMBASE search protocol).

We used the following inclusion criteria: 1. study with or about people with ID in the last phase of life; 2. occurrence of elements of decision-making in practice in experimental or observational studies; 3. peer-reviewed journal; 4. written in English. We applied no limits on date of publication. We excluded editorials, letters and conference reports; and checked systematic reviews and meta-analyses for useful references.

Procedure

Two researchers (HN and IK) independently screened titles and abstracts. Disagreements about study inclusion were resolved by discussion by HN, IK and ME. They developed, reviewed and approved a data extraction form containing title, country, study aim, study design, described decisions and involvement

of people with ID in the process of decision-making. HN and ME pilot tested this form by independently extracting data from one study and comparing their results. Changes to the data extraction form were not required. Using this form, HN and ME independently extracted data from the remaining studies.

Aiming at high inter-rater agreement, HN, IK and ME discussed the results to identify elements of decision-making and possible differences in the interpretation of these elements. To evaluate, structure and describe processes of decision-making as identified in this review, we looked for a suitable SDM framework. We opted for the SDM model of Van de Pol (van de Pol et al., 2016) since it is aimed at frail patients with multimorbidity, in the context of a continuous SDM process and takes into account the involvement of relatives. Van de Pol's model distinguishes six steps, see Box 3. In brief, these steps are 1.Preparation (history; problem analysis); 2.Goal talk (identify discussion partner; identify patient values and goals of care); 3.Choice talk (summarise and offer choice; patient formulates treatment aims); 4. Option talk (personalised treatment aims are discussed); 5. Decision talk (focus on preferences, connect to the patients values, goals of care and treatment aims, decide); 6. Evaluation (evaluate the SDM process; prepare a treatment plan).

Results

We found 281 articles. After the selection process, as shown in Figure 1, 10 studies were included for data extraction.

Study characteristics

Of the ten included studies, eight were conducted in the Netherlands, one in Australia, and one in the United States. Six studies were (semi structured) interview studies (Zaal-Schuller et al., 2016, Zaal-Schuller et al., 2018, Bekkema et al., 2015, Wagemans et al., 2013a, Wagemans et al., 2013b, Van Thiel et al., 1997), two included multiple case studies (Tuffrey-Wijne et al., 2018, Watson et al., 2017), one was a single case study (Lohiya et al., 2003) and in one study medical files were examined (Wagemans et al., 2010). All studies had an observational design.

The total number of participants across all studies was 317, ranging from 1 to 89 per study and included parents, physicians and people with ID. All studies involved interviews with and examination of the role of target groups. Five studies focused on health care professionals and relatives of people with an ID (Watson et al., 2017, Wagemans et al., 2010, Bekkema et al., 2015, Zaal-Schuller et al., 2016, Zaal-Schuller et al., 2018), four on health care professionals (Van Thiel et al., 1997, Wagemans et al., 2013a,

Tuffrey-Wijne et al., 2018, Lohiya et al., 2003) and one on relatives of people with an ID (Wagemans et al., 2013b). Eight studies were published within the last 10 years; the other two were from 2003 and 1997.

All studies focused on end-of-life decision-making, e.g. deciding about life-prolonging treatments. All studies focused on adults with ID; four studies also focused on children with ID (Wagemans et al., 2013b, Bekkema et al., 2015, Zaal-Schuller et al., 2016, Zaal-Schuller et al., 2018); six studies included people with various levels of ID (Wagemans et al., 2010, Wagemans et al., 2013b, Wagemans et al., 2013a, Bekkema et al., 2015, Watson et al., 2017, Van Thiel et al., 1997), two studies focused on people with profound ID (Zaal-Schuller et al., 2016, Zaal-Schuller et al., 2018), one involved people with mild ID (Tuffrey-Wijne et al., 2018) and one people with moderate ID (Lohiya et al., 2003).

In four studies people with ID received residential care (Wagemans et al., 2010, Wagemans et al., 2013a, Van Thiel et al., 1997, Lohiya et al., 2003), in four studies they received residential and community based care (Wagemans et al., 2013b, Bekkema et al., 2015, Tuffrey-Wijne et al., 2018, Watson et al., 2017), and for two studies this was not specified (Zaal-Schuller et al., 2018, Zaal-Schuller et al., 2016), see Table 1 for an overview.

1. Preparation: history and problem analysis

Life history of the person with ID

Five articles included a description of how the life history of the person with ID was taken into account in the decision-making process (Wagemans et al., 2013b, Zaal-Schuller et al., 2016, Watson et al., 2017, Bekkema et al., 2015, Van Thiel et al., 1997). In two studies, life stories helped to provide information about people's preferences considering health and treatment (Wagemans et al., 2013b, Watson et al., 2017). In one study the views of parents and physicians on the quality of life of people with ID were reported to differ (Zaal-Schuller et al., 2018).

Problem analysis

In one study the experiences of 17 parents of children with profound multiple and intellectual disabilities (PMID) during end-of-life-decision-making were reported (Zaal-Schuller et al., 2016). These parents reported they had to explain to physicians how their child was feeling and, for example, when their child was in pain (Zaal-Schuller et al., 2016). Parents mentioned to prefer starting the end-of-life

decision-making process with a physician who already had a relationship with their child and therefore could better analyse their child's problems. They believed that a physician who is aware of the history of their child can provide better treatment than a physician without that awareness (Zaal-Schuller et al., 2016).

2. Goal talk: identify discussion partner and identify patient values and goals of care

All articles emphasised that the extent to which people with ID may be partners in the decision-making process is dependent upon their capacity to make difficult choices. In her description of the participation of people with ID in decision-making processes about euthanasia and assisted suicide requests, Tuffrey-Wijne noted two aspects that are difficult for people with ID: appreciating the significance of the information, and weighing of treatment options and their consequences (Tuffrey-Wijne et al., 2018). In eight identified studies, people with ID did not participate in the decision-making process. In one study a case is described in which care professionals thought it was better to tell a woman with ID she had reached the last phase of life, whereas her family did not want to inform her, to protect her from distress (Wagemans et al., 2010).

Two studies described the involvement of people with ID in the decision-making process. In the described euthanasia and suicide requests study from Tuffrey-Wijne et al, each case report included the statement "the physician had sufficiently informed the patient about his/her situation and his/her prospects" (Tuffrey-Wijne et al., 2018). The authors noted that there is no information about how the people with ID were helped to understand this information (Tuffrey-Wijne et al., 2018). In another study it was stated that two people with ID were involved in the decision-making process, but it was not specified how (Van Thiel et al., 1997). In five studies it was not clear how the signals, values and goals of care of people with ID were weighted in the decision-making process (Van Thiel et al., 1997, Wagemans et al., 2013b, Wagemans et al., 2013a, Tuffrey-Wijne et al., 2018, Lohiya et al., 2003).

Seven studies, stated the importance of including the people who care for and about a person with ID in the decision-making process (Watson et al., 2017, Bekkema et al., 2015, Wagemans et al., 2013a, Wagemans et al., 2013b, Tuffrey-Wijne et al., 2018, Van Thiel et al., 1997, Zaal-Schuller et al., 2018). Judicial regulations around decision-making for people with ID who lack capacity vary. In the Netherlands (where most studies were based), parents or other legal representatives have to make decisions for persons with ID who lack decision-making capacity, although a physician remains

ultimately responsible for the medical care as provided (Zaal-Schuller et al., 2016, Wagemans et al., 2010, Wagemans et al., 2013a, Wagemans et al., 2013b, Van Thiel et al., 1997, Lohiya et al., 2003, Zaal-Schuller et al., 2018). Watson et al stated that to properly represent the interests of a person with severe to profound ID an emotionally involved support network is needed (Watson et al., 2017). They developed a continuum of so-called relational closeness tools which can be used to find out who is close to a person with severe or profound ID (Watson et al., 2017). To support such networks they developed a supported decision-making framework (Watson et al., 2017). They characterise supported decision-making *“as a process of enhancing the decision-making capability of people with severe or profound intellectual disability through collaborative support from a group of people in the relevant person’s life who know them. An important component of this approach is the use of a circle of support, a group of key members of the concerned person’s life who have a good understanding (or are committed to developing one) of the person’s life history, personal characteristics and their preferences”* (Watson, 2016).

3. Choice talk: summarise, offer choice and patient formulates treatment aims

In two studies, people with ID were informed about their situation and their prospects (Tuffrey-Wijne et al., 2018, Van Thiel et al., 1997). In one study this was done by “sufficiently informing her at her own level” (Tuffrey-Wijne et al., 2018). In another study this process remained unclear (Van Thiel et al., 1997). In the eight other studies patient representatives and physicians formulated treatment aims without direct involvement of people with ID (Wagemans et al., 2010, Wagemans et al., 2013b, Wagemans et al., 2013a, Bekkema et al., 2015, Zaal-Schuller et al., 2018, Zaal-Schuller et al., 2016, Lohiya et al., 2003, Watson et al., 2017).

Watson et al. (2017) described how available treatment options for a person with a profound disability were explored by a group of people who knew him very well (Watson et al., 2017). Zaal-Schuller et al. (2016) described how 17 parents anticipated the recurrence of serious illness of their children. “Almost half of them” believed that it would have been easier to discuss end-of-life decisions with the physicians earlier, when their child was still in a stable condition (Zaal-Schuller et al., 2016).

According to one study, parents and physicians agreed about three elements being key to quality of life of children with profound intellectual and multiple disabilities: 1.the ability to enjoy themselves, 2.the absence of physical problems and 3.comfort (Zaal-Schuller et al., 2018). Some parents thought that not

all important aspects of quality of life had been fully explored in discussions with care professionals. Physicians, on the other hand, reported they already knew parents' views on quality of life and were therefore not discussing it (Zaal-Schuller et al., 2018). Another study described how instead of parents, an ethics committee participated in choice talk (Lohiya et al., 2003).

4. Option talk: personalised treatment aims are discussed

According to one study physicians and parents agreed that disagreements between physicians and parents could ultimately improve the end-of-life-decision-making process, because these enabled the exploration of alternative treatments (Zaal-Schuller et al., 2016). Another study, based on 9 interviews with ID physicians, stated that wishes of relatives weighed heavily when discussing treatment options (Wagemans et al., 2013a). In eight out of nine cases presented by Wagemans et al. (2013a), physicians followed the relatives' wishes about treatment choice. Parents and physicians indicated that if an invasive treatment was not expected to lead to a significant improvement of the child's quality of life, they would rather withdraw or withhold that treatment (Zaal-Schuller et al., 2018, Wagemans et al., 2013b)

Lohiya et al (2003) reported how difficult it is when people with ID have never been able to express their values or preferences (Lohiya et al., 2003). Watson et al. (2017) explained, that, in terms of roles, people with ID express their preferences (for example by behaviour, eye movement, vocalisation, self-harm or facial expression), whereas the professionals or relatives need to respond to these preferences by interpreting and acknowledging them.

5. Decision talk: focus on preferences, based on the patients' values, goals of care and treatment aims, decide

If people with ID were involved in decision-making processes, it was not clear how the physician helped them to understand their situation (Van Thiel et al., 1997, Tuffrey-Wijne et al., 2018). In two studies people with ID were not involved in the decision-making process because of their lack of decisional competence (Zaal-Schuller et al., 2018, Wagemans et al., 2013a).

In four studies, the difficulties patient representatives may experience when having to decide between various options, including feeling morally responsible for end-of-life decisions they have to make, were shown (Wagemans et al., 2013b, Wagemans et al., 2010, Wagemans et al., 2013a, Bekkema et al., 2015).

6. Evaluate: evaluate the SDM process and prepare a treatment plan

In one study, when asked about the provision of information, parents stated they felt a lack of information during the end-of-life decision-making process (Zaal-Schuller et al., 2016). When they were provided with information they felt they lacked the necessary medical background to put that information in the right context. However, parents felt the physician took them seriously as being experts about their children and allowed them to influence the decision-making process (Zaal-Schuller et al., 2016). Based on 16 interviews with patient representatives, Wagemans et al (2013b) indicated that patient representatives found support of a doctor very important in the decision-making process. According to Wagemans et al. physicians sought consensus with relatives and paid care staff. In this process, physicians often gave greater weight to a good relationship with relatives and paid care staff than to their own assessment of -the best interest of the person with ID (Wagemans et al., 2013a).

Discussion

This review is the first to provide an overview of how decision-making with people with intellectual disabilities (ID) in the last phase of life is practiced. The results show us that making decisions together with people with ID is not common practice. We found that people with ID participated in the decision-making process in only two out of ten studies (Van Thiel et al., 1997, Tuffrey-Wijne et al., 2018). Where people with ID participated it was largely unclear how this process was enabled and what kind of support, if any, was provided to the people with ID.

Most authors stated that relatives and care staff know persons with ID best (Watson et al., 2017, Bekkema et al., 2015, Wagemans et al., 2013a, Wagemans et al., 2013b, Tuffrey-Wijne et al., 2018, Van Thiel et al., 1997, Zaal-Schuller et al., 2018). They know how to communicate with the person with ID and how to interpret the signals they are giving (Bekkema et al., 2015, Watson et al., 2017). By using this information, it is possible to act on the preferences of people with ID, even if they themselves cannot articulate them clearly, and to make decisions that match their wishes and preferences (Watson et al., 2017). That is why good communication between relatives and professionals is important (Wagemans et al., 2013a, Zaal-Schuller et al., 2016, Bekkema et al., 2015, Watson et al., 2017). Using documentation such as videos and diaries can help to match decisions with the preferences of people with ID (Watson et al., 2017), even when they cannot participate actively in the decision-making process, or do not have sufficient decision-making capacity (Watson et al., 2017).

The existing literature offers few good examples of SDM models for people with ID. Based on Elwyn's SDM model (Elwyn et al., 2012), Van de Pol developed a model for SDM with frail older people. This takes into account co-morbid conditions and involvement of relatives and considers decision-making as a process rather than a one-off event. The model could provide a good basis for SDM for people with ID (van de Pol et al., 2016). Van de Pol's model does not pay attention to eliciting values that are important for the patient or how to address decision-making capacity.

Watson and colleague's developed a supported decision-making framework for people with ID (Watson et al., 2017). This framework ensures that if people with ID are not able to participate in the decision-making process themselves, a key group around the person with ID participates on behalf of them, keeping the values and preferences of the person with ID in mind. Research into best practices with regard to SDM in the last phase of life shows some examples about other vulnerable populations. One study focused on people with dementia and their caregivers and the extent to which housing decisions matched with an interprofessional SDM approach (Garvelink et al., 2018). This study indicated that honesty, timely communication and advance care planning helped to better align decisions with preferences of patients. This research can potentially be used as a basis for the development of an aid to support SDM in people with ID in the last phase of life. The supported decision-making model of (Watson et al., 2017) could also be used as foundation to develop an SDM model for people with an ID. New research could focus on making this model suitable for people with ID with different levels of participation abilities. For future research, we would recommend that people with an ID are involved in the development and implementation of new approaches considering decision-making with people with an ID. The target group itself can provide valuable input about what does and does not work for them.

Implications for practice and research

Adequate SDM processes are underpinned by good relationships between physicians and relatives and care staff of people with ID (Wagemans et al., 2013a, Zaal-Schuller et al., 2016, Bekkema et al., 2015, Watson et al., 2017). Defining clear roles and responsibilities for everybody involved could improve the process of developing these relationships (Wagemans et al., 2013b). When parents and care staff build a strong relationship well before there is a crisis or a need for important end-of-life decisions they can better collaborate as a team when death is approaching (Bekkema et al., 2015). There is a need for cooperation in building up a shared understanding of the signals and needs of a person with ID. To make a good decision, professionals and relatives should be attentive to the expression and signals of need

and distress of the person with ID (Bekkema et al., 2015, Watson et al., 2017). Support may be even more necessary since people with ID may have limited experience in making important decisions that will affect their lives and may lack the necessary skills to make end-of-life decisions (Tuffrey-Wijne et al., 2018).

Strengths

This review sheds light on an important and timely concept. It also contributes to answering current questions around advance care planning and end-of-life-decision-making with people with ID (Wagemans and van Bokhoven, 2018, Voss et al., 2017, Wagemans and van Wijmen, 2014). We systematically searched the electronic databases in collaboration with a biomedical information specialist. Thereby two researchers (HN and IK) independently screened all abstracts for inclusion. Another strength is that we followed the PRISMA Scoping Review Guidelines (Tricco et al., 2018), which ensured complete and transparent reporting of our scoping review. The use of Van de Pol's shared decision-making model as a framework ensured that we used an inclusive conceptualisation of SDM.

Gaps and deficiencies

All studies were conducted in high-income countries, with a high proportion of Dutch studies (n=8). This limits the generalizability of the combined study results; due to differences in healthcare systems and cultures, it is unknown to what extent the results of this review can be generalised to other countries. The legislation around capacity and decision-making varies across countries. In addition, most people with ID received residential care, the number of participants was limited in most studies, and there was generally little variation in the level of ID.

Furthermore, the last phase of life was not clearly defined in the included studies and its interpretation may therefore differ per study. In addition, none of the studies found included a definition of SDM. These results are indicative of decision-making in the palliative care context being still in its infancy.

Conclusion

People with ID do not often actively participate in decision-making processes in their last phase of life, and their opinion about not being involved is unclear. Although it is emphasised in the literature that people with ID should be involved in decision-making in the last phase of life, a uniform best practice about what this should look like is lacking. Based on the results we recommend developing an aid that

specifically supports systematically taking preferences of people with ID in the last phase of life into account. As indicated in the literature, even if a person is not able to actually participate in the decision-making process, decisions can be aligned to the values and preferences of a person with ID (Watson et al., 2017). This can be achieved by involving the inner circle around the person with ID, and by looking at the life history and earlier medical experiences of the person with ID. To make good decisions, professionals and relatives should be attentive to the expression and signals of needs and distress a person with ID is giving. A good relationship between relatives and professionals is essential to ensure good end-of-life care in the best interest of the person with ID. Further research should be conducted to investigate what role people with ID see for themselves in SDM around end-of-life decision-making in the last phase of life.

References

- BEKKEMA, N., DE VEER, A. J., HERTOOGH, C. M. & FRANCKE, A. L. 2015. 'From activating towards caring': shifts in care approaches at the end of life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians. *BMC Palliat Care*, 14, 33.
- CHARLES, C., GAFNI, A. & WHELAN, T. 1997. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med*, 44, 681-92.
- CHARLES, C., GAFNI, A. & WHELAN, T. 1999. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*, 49, 651-61.
- COLQUHOUN, H. L., LEVAC, D., O'BRIEN, K. K., STRAUS, S., TRICCO, A. C., PERRIER, L., KASTNER, M. & MOHER, D. 2014. Scoping reviews: time for clarity in definition, methods, and reporting. *J Clin Epidemiol*, 67, 1291-4.
- ELWYN, G., FROSCHE, D., THOMSON, R., JOSEPH-WILLIAMS, N., LLOYD, A., KINNERSLEY, P., CORDING, E., TOMSON, D., DODD, C., ROLLNICK, S., EDWARDS, A. & BARRY, M. 2012. Shared decision making: a model for clinical practice. *J Gen Intern Med*, 27, 1361-7.
- GARVELINK, M. M., GROEN-VAN DE VEN, L., SMITS, C., FRANKEN, R., DASSEN-VERNOOIJ, M. & LEGARE, F. 2018. Shared Decision Making About Housing Transitions for Persons With Dementia: A Four-Case Care Network Perspective. *Gerontologist*.
- LOHIYA, G.-S., TAN-FIGUEROA, L. & CRINELLA, F. M. 2003. End-of-Life Care for a Man with Developmental Disabilities. *The Journal of the American Board of Family Practice*, 16, 58-62.
- MAKOUL, G. & CLAYMAN, M. L. 2006. An integrative model of shared decision making in medical encounters. *Patient Educ Couns*, 60, 301-12.
- SHAY, L. A. & LAFATA, J. E. 2015. Where Is the Evidence? A Systematic Review of Shared Decision Making and Patient Outcomes. *Medical Decision Making*, 35, 114-131.
- STIGGELBOUT, A. M., PIETERSE, A. H. & DE HAES, J. C. 2015. Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns*, 98, 1172-9.
- STIGGELBOUT, A. M., VAN DER WEIJDEN, T., DE WIT, M. P., FROSCHE, D., LEGARE, F., MONTORI, V. M., TREVENA, L. & ELWYN, G. 2012. Shared decision making: really putting patients at the centre of healthcare. *BMJ*, 344, e256.
- SZMUKLER, G. 2019. "Capacity", "best interests", "will and preferences" and the UN Convention on the Rights of Persons with Disabilities. *World Psychiatry*, 18, 34-41.

TITLE: Shared decision-making with people with intellectual disabilities in the last phase of life: a scoping review

AUTHORS: A.Noorlandt, M.Echteld, I.Tuffrey-Wijne, D.Festen, C.Vrijmoeth, A.van der Heiden, I.Korfage

ACCEPTED FOR PUBLICATION in *Journal of Intellectual Disability Research* on 18 August 2020

- TOWLE, A. & GODOLPHIN, W. 1999. Framework for teaching and learning informed shared decision making. *Bmj*, 319, 766-71.
- TRICCO, A. C., LILLIE, E., ZARIN, W. & ET AL. 2018. Prisma extension for scoping reviews (prisma-scr): Checklist and explanation. *Annals of Internal Medicine*, 169, 467-473.
- TUFFREY-WIJNE, I. 2013. A new model for breaking bad news to people with intellectual disabilities. *Palliat Med*, 27, 5-12.
- TUFFREY-WIJNE, I., CURFS, L., FINLAY, I. & HOLLINS, S. 2018. Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012-2016). *BMC Med Ethics*, 19, 17.
- UNITED NATIONS. 13 december 2006. *Convention on the Rights of Persons with Disabilities*. UN. [Online]. Available: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> [Accessed 14-09-2018].
- VAN DE POL, M. H., FLUIT, C. R., LAGRO, J., SLAATS, Y. H., OLDE RIKKERT, M. G. & LAGRO-JANSSEN, A. L. 2016. Expert and patient consensus on a dynamic model for shared decision-making in frail older patients. *Patient Educ Couns*, 99, 1069-77.
- VAN THIEL, G. J. M. W., VAN DELDEN, J. J. M., DE HAAN, K. & HUIBERS, A. K. 1997. Retrospective study of doctors' 'end of life decisions' in caring for mentally handicapped people in institutions in the Netherlands. *BR MED J*, 315, 88-91.
- VOSS, H., VOGEL, A., WAGEMANS, A. M. A., FRANCKE, A. L., METSEMAKERS, J. F. M., COURTENS, A. M. & DE VEER, A. J. E. 2017. Advance Care Planning in Palliative Care for People With Intellectual Disabilities: A Systematic Review. *J Pain Symptom Manage*, 54, 938-960 e1.
- VRIJMOETH, C., CHRISTIANS, M. G., FESTEN, D. A., GROOT, M., VAN DER HEIDE, A., VAN DER RIJT, C. C., TONINO, M. & ECHELD, M. A. 2016a. Physician-Reported Symptoms and Interventions in People with Intellectual Disabilities Approaching End of Life. *J Palliat Med*, 19, 1142-1147.
- VRIJMOETH, C., CHRISTIANS, M. G. M., FESTEN, D. A. M., GROOT, M., TONINO, M. & ECHELD, M. A. 2016b. Physicians' recognition of death in the foreseeable future in patients with intellectual disabilities. *Journal of Intellectual Disability Research*, 60, 207-217.
- WAGEMANS, A., VAN SCHROJENSTEIN LANTMAN-DE-VALK, H., TUFFREY-WIJNE, I., WIDDERSHOVEN, G. & CURFS, L. 2010. End-of-life decisions: an important theme in the care for people with intellectual disabilities. *J Intellect Disabil Res*, 54, 516-24.
- WAGEMANS, A., VAN SCHROJENSTEIN LANTMAN-DE VALK, H., PROOT, I., METSEMAKERS, J., TUFFREY-WIJNE, I. & CURFS, L. 2013a. The factors affecting end-of-life decision-making by physicians of patients with intellectual disabilities in the Netherlands: a qualitative study. *J Intellect Disabil Res*, 57, 380-9.
- WAGEMANS, A. A. & VAN BOKHOVEN, M. A. 2018. [Timely consideration of future care; advance care planning for people with intellectual disabilities]. *Ned Tijdschr Geneesk*, 162.
- WAGEMANS, A. M., VAN SCHROJENSTEIN LANTMAN-DE VALK, H. M., PROOT, I. M., METSEMAKERS, J., TUFFREY-WIJNE, I. & CURFS, L. M. 2013b. End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliat Med*, 27, 765-71.
- WAGEMANS, A. M. & VAN WIJMEN, F. C. 2014. [Advance care planning for people with intellectual disability]. *Ned Tijdschr Geneesk*, 158, A8433.
- WATSON, J. 2016. Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability. *Laws*, 5, 6.
- WATSON, J., WILSON, E. & HAGLIASSIS, N. 2017. Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *J Appl Res Intellect Disabil*, 30, 1022-1034.

TITLE: Shared decision-making with people with intellectual disabilities in the last phase of life: a scoping review
AUTHORS: A.Noorlandt, M.Echteld, I.Tuffrey-Wijne, D.Festen, C.Vrijmoeth, A.van der Heiden, I.Korfage
ACCEPTED FOR PUBLICATION in *Journal of Intellectual Disability Research* on 18 August 2020

WHO. *Definition of palliative care* [Online]. Available:

<https://www.who.int/cancer/palliative/definition/en/> [Accessed].

ZAAL-SCHULLER, I. H., WILLEMS, D. L., EWALS, F., VAN GOUDOEVEER, J. B. & DE VOS, M. A. 2016. How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities. *Res Dev Disabil*, 59, 283-293.

ZAAL-SCHULLER, I. H., WILLEMS, D. L., EWALS, F., VAN GOUDOEVEER, J. B. & DE VOS, M. A. 2018. Considering quality of life in end-of-life decisions for severely disabled children. *Res Dev Disabil*, 73, 67-75.