



Physicians' identification of the need for palliative care in people with intellectual disabilities



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ABSTRACT

Background: A growing number of people with intellectual disabilities (ID) is suffering from life-threatening chronic illnesses and is therefore in need for palliative care.

Aims: We aimed to explore how the need for palliative care is recognized in people with ID. **Methods and procedures:** We conducted a semi-structured interview study among 10 ID-physicians in the Netherlands.

Outcomes and results: Identification of people with ID in need for palliative care mostly results from a process in which multiple signals from different information sources converge and lead to a growing awareness. As a result, ID-physicians do not expect people to return to their prior level of health or functioning, but rather expect an irreversible decline leading to death. The presence, stage and prognosis of the disease, physician-patient interaction, and communication with proxies who provide contextual information are factors influencing the process.

Conclusions and implications: Distinctive for a population of people with ID are the frequent diagnostic uncertainty in people with ID, the patients' communicational abilities and the reliance of ID-physicians on close proxies. We argue for a proactive attitude of physicians regarding care and support of people with ID with palliative care needs.

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What this paper adds?

This paper provides insights in when and how the need for palliative care is recognized in people with ID. Furthermore, in our discussion we expand on differences in the identification process between the general population and a population of people with ID. Our results contain useful information for practice that may help to identify the need for palliative care in people with ID in a timely fashion. Early provision of palliative care in the disease trajectories facilitates healthcare professionals to achieve the highest quality of life and –dying for people with ID.

1. Introduction

In people with intellectual disabilities (ID), a trend of an increased life expectancy is seen (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Due to this increased life expectancy leading causes of death, such as cardiovascular diseases, respiratory diseases and cancer, resemble those of the general population (Heslop et al., 2014; Janicki, Dalton, Henderson, & Davidson, 1999). As a result, more people with ID experience a prolonged period of ill health and are therefore in need of palliative care, which is “a care approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO Definition of Palliative Care; World Health Organization, 2002).

Essential for adequate planning and early provision of palliative care is identifying those people who are in need of palliative care, because it enables healthcare professionals to anticipate their needs (Beernaert et al., 2015; Temel et al., 2010) and to communicate in an early stage about important end-of-life decisions (Bekkema, De Veer, Wagemans, Hertogh, & Francke, 2014; Wagemans, Van Schrojenstein Lantman-De Valk, Tuffrey-Wijne, Widdershoven, & Curfs, 2010). For example, medical decisions such as a Do Not Resuscitate (DNR) order, not referring to hospitals or to forego further treatments, are aspects that have to be discussed.

In general, there is a growing awareness of the importance of identifying the need for palliative care, but research on this topic is still scarce. A recent study found that the identification of the need for palliative care in a broader population of patients of Dutch General Practitioners (GPs) is a gradual process of multiple signals, such as diagnosis of a disease, increased care dependency, not recuperating, and social changes (Claessen, Francke, Engels, & Deliens, 2013). However, these results may not be generalizable to people with ID, because of the challenges healthcare professionals encounter when providing care for this population: for example, patient–professional communicational challenges, lack of medical knowledge among professional caregivers and delays in diagnosis, referral or treatment (Heslop et al., 2014; Bekkema, De Veer, Hertogh, & Francke, 2011; Tuffrey-Wijne & McEnhill, 2008).

Up to now, it seems that identifying people with ID who are in need of palliative care is not a common or conscious practice and, to the best of our knowledge, has not yet been addressed in scientific literature. Therefore, this interview-based study aimed to explore how physicians recognize the need for palliative care in people with ID. Insights in when and how the need for palliative care is recognized may provide useful information that helps in timely identification of people in need for palliative care.

2. Material and methods

This study builds upon an interpretative approach of qualitative research, more specifically that of the narrative tradition (Bal, 2009).

2.1. Participants and procedure

Between October and December 2013, we interviewed 10 ID-physicians about their experiences with identifying the need for palliative care in people with ID. The interviews are part of a larger study aimed at developing a tool that will help healthcare professionals to identify people with ID who are in need of palliative care. Since 2000, the medical specialism Intellectual Disability Medicine has been acknowledged in the Netherlands (www.nvavg.nl). Physicians who complete the three-year training are specialized in medical care for people with ID and are called ID-physicians. In the Netherlands, a General Practitioner (GP) or an ID-physician is the principal physician and responsible for the medical care for people with ID. For some people the GP is the principal physician and the ID-physician only provides care on GP's request or care for disability-related or syndrome-related problems (e.g., behavioural problems or epilepsy).

ID-physicians were purposively recruited out of 81 ID-physicians who, as part of the larger study, completed a retrospective survey about the care for their last patient with ID with a non-sudden death (Vrijmoeth et al., 2016). In the survey, 42 physicians gave permission to be approached for an interview. In order to include different perspectives and experiences the criteria for purposive sampling were physicians' work-experience, the underlying cause of death (cancer vs. non-cancer) and level of ID of the patient described in the retrospective survey. Based on earlier experiences with qualitative interview-based studies we approached a number of 10 ID-physicians; all of them agreed to participate. The final sample consisted of both ID-physicians and ID-physicians still in training.

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