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End-of-life decision-making for children with severe developmental disabilities: The parental perspective



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ABSTRACT

Background and aims: The objectives of this integrative review were to understand how parents of children with severe developmental disorders experience their involvement in end-of-life decision-making, how they prefer to be involved and what factors influence their decisions.

Methods and procedures: We searched MEDLINE, EMBASE, CINAHL and PsycINFO. The search was limited to articles in English or Dutch published between January 2004 and August 2014. We included qualitative and quantitative original studies that directly investigated the experiences of parents of children aged 0–18 years with severe developmental disorders for whom an end-of-life decision had been considered or made.

Outcomes and results: We identified nine studies that met all inclusion criteria. Reportedly, parental involvement in end-of-life decision-making varied widely, ranging from having no involvement to being the sole decision-maker. Most parents preferred to actively share in the decision-making process regardless of their child's specific diagnosis or comorbidity. The main factors that influenced parents in their decision-making were: their strong urge to advocate for their child's best interests and to make the best (possible) decision. In addition, parents felt influenced by their child's visible suffering, remaining quality of life and the will they perceived in their child to survive.

Conclusions and implications: Most parents of children with severe developmental disorders wish to actively share in the end-of-life decision-making process. An important emerging factor in this process is the parents' feeling that they have to stand up for their child's interests in conversations with the medical team.

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What this paper adds?

This is the first integrative review that describes the experiences of parents of children with severe developmental disabilities regarding end-of-life decision-making for their child. The objective was to understand how parents experience their involvement in end-of-life decision-making, how they prefer to be involved and what factors influence their decisions. Nine eligible studies were selected after an electronic database search. The main outcome was that the degree of parental involvement within and across these studies varied widely. This degree ranged from parents having no involvement at all to parents being the sole decision-maker. Parents also differed considerably in their personal preferences of how they wished to be involved in the decision making process for their child.

Parents indicated that they felt guided by two main factors: their desire to do what they considered to be the best for their child and their perception of their child's quality of life. Some parents added that it seemed as if physicians regarded the life of their child as less valuable than the life of a normally developing child. This last factor often made parents feel that they had to advocate for their child's interests.

1. Introduction

Medical End-of-Life decisions (EoLDs) can lead to or hasten death, intentionally or not. These decisions include withholding or withdrawing life-prolonging treatment (such as mechanical ventilation, tube feeding, or dialysis) and alleviating pain or other symptoms with drugs that may have a life-shortening effect. Administering, prescribing or supplying drugs to end a patient's life at the patient's explicit request also falls within the scope of EoLDs (van der Heide et al., 2003). In the Netherlands – similar to other countries – this is prohibited in neonates, infants, children and people with intellectual disabilities who are mentally incompetent to make an explicit request (*Termination of Life on Request and Assisted Suicide Act, 2002*). Yet, a legal provision exists which allows physicians under strict conditions to deliberately end the life of a newborn who experiences severe suffering without any prospect for improvement. These conditions are described in the Groningen protocol (Verhagen & Sauer, 2005; Willems, Verhagen, van Wijlick, & C, 2014).

Sixty-eight percent of all deaths of Dutch children between 0 and 1 year of age are preceded by an EoLD. In children between 1 and 16 years of age, 36% of all deaths are preceded by an EoLD (Vrakking et al., 2005, 2007). In children with severe developmental disabilities (SDDs) this percentage is still unknown. SDDs are defined as severe chronic disabilities that can be cognitive, physical or both. They are characterized by a delay in development, based on the expected stage of development at a certain age. The disabilities appear before the age of 22 and are likely to be lifelong (Schalock et al., 2010). Two studies investigated the prevalence of EoLDs among deceased intellectually disabled adults who lived in care-providing agencies in the Netherlands (van Thiel, van Delden, de Haan, & Huibers, 1997; Wagemans, van Schrojenstein Lantman-de-Valk, Tuffrey-Wijne, Widdershoven, & Curfs, 2010). While the first study showed that 44% of all reported deaths were preceded by an EoLD (van Thiel et al., 1997), the second study reported this percentage to be 57% (Wagemans et al., 2010). This implies an increase of 13% over a period of 15 years. A study by van der Heide et al investigated end-of-life decision-making (EoLDM) in the general Dutch population and concluded that 44% of all deaths were preceded by an EoLD (van der Heide et al., 2003).

Children with a SDD have a greater chance to suffer from complex medical problems (Chaney & Eyman, 2000; Oeseburg, Dijkstra, Groothoff, Reijneveld, & Jansen, 2011; van Schrojenstein Lantman-de Valk et al., 1997) and generally have a shorter life expectancy (Bittles et al., 2002; Strauss, Shavelle, & Anderson, 1998). Hence, parents of children with SDDs will be confronted with medical decisions more often than other parents.

A challenging question in medical decision-making, and especially in EoLDM, is in what way and to what extent parents should be involved. Different degrees of involvement are possible: parents may be the sole decision-makers and bear the final responsibility; they may participate in the decision-making process and share in the final responsibility; they may have considerable input while the doctor makes the final decision; or they may have no involvement at all (Gillam & Sullivan, 2011). In the United States and Canada, parents are expected to be the primary decision-makers for their children in EoLDM, based on prevailing moral and legal traditions (Choong et al., 2010; Eden & Callister, 2010). By contrast, in European, Middle Eastern and South American countries, the medical and public opinion dictates that parents lack sufficient medical knowledge to make these decisions and, even more importantly, should be protected from the burden of this responsibility

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