



## Considering quality of life in end-of-life decisions for severely disabled children

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### ABSTRACT

**Background:** End-of-life decisions (EoLDs) are very difficult to make. How parents and physicians incorporate quality of life (QoL) considerations into their end-of-life decision making (EoLDM) for children with profound intellectual and multiple disabilities (PIMD) remains unknown.

**Aims:** To determine which elements contribute to QoL according to parents and physicians, how QoL is incorporated into EoLDM and how parents and physicians discuss QoL considerations in the Netherlands.

**Methods:** Semi-structured interviews were conducted with the physicians and parents of 14 children with PIMD for whom an EoLD had been made within the past two years.

**Results:** Parents and physicians agreed on the main elements that contribute to QoL in children with PIMD. The way in which QoL was incorporated differed slightly for different types of decisions. Parents and physicians rarely discussed elements contributing to the child's QoL when making EoLDS.

**Conclusions:** and Implications Although QoL was highly important during EoLDM for children with PIMD, parents and physicians did not fully explore the elements that contribute to the child's QoL when they made EoLDs. We recommend the development of a communication tool that will help parents and physicians discuss elements that contribute to QoL and the consequences these elements have for upcoming decisions.

### What this paper adds

Through interviews of the parents and physicians of the same disabled child, we explored how both parties value and discuss elements that contribute to that child's QoL. Parents and physicians generally agree on the elements that contribute to QoL in children with PIMD. The three elements both parties mentioned most were as follows: 'the ability to enjoy', 'absence of physical problems', and 'comfort'. However, noticeable differences were also observed: parents considered 'basic awareness' and 'lack of awareness of impairments and limitations' as an important element of QoL, while physicians attached more value to '(perspectives

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on) cognitive development' and 'ability to have contact with others'. Although QoL was a very important guiding factor for parents and physicians during the EoLDM process, they did not fully and concretely explore the factors that affect QoL. This study provided a starting point for the development of a communication checklist that could be used to discuss important elements of QoL. This type of checklist might improve mutual understanding between parents and physicians, which in turn would help in reaching the best possible decision for each individual child.

## 1. Introduction

Children with complex chronic conditions are responsible for the greatest growth in children's use of hospital resources, especially in their last year of life (Ananth, Melvin, Feudtner, Wolfe, & Berry, 2015; Berry et al., 2011; vanRussell & Simon, 2014). Additionally, discussions regarding limiting or withdrawing life support most often occur in this patient group, (Keele et al., 2016; Michelson et al., 2013) which includes children with profound intellectual and multiple disabilities (PIMD). Children with PIMD have an IQ  $\leq$  25, sensory impairments and severe motor disabilities, manifesting in the inability to move independently (Nakken & Vlaskamp, 2007). These children generally suffer from complex life-limiting conditions, (Bittles et al., 2002; Chaney & Eyman, 2000; Katz, 2003; Oeseburg, Dijkstra, Groothoff, Reijneveld, & Jansen, 2011; van Schrojenstein Lantman-de Valk et al., 1997; Strauss, Shavelle, & Anderson, 1998) and insight into end-of-life decision making (EoLDM) for children with PIMD is thus highly relevant for clinical practice.

End-of-life decisions (EoLDs) include decisions to withhold or withdraw life-prolonging treatment (such as mechanical ventilation, tube feeding and dialysis) and decisions to alleviate pain or other symptoms by using drugs that may lead to or hasten death (Nakken et al., 2003). In the Netherlands, legislation around EoLDs for children is recorded in the Dutch Medical Treatment Act (WGBO) (Dutch Medical Treatment Act, 2006). In children who lack decision-making capacity, informed consent from their parents is needed before treatment can be started. However, if a parent refuses to allow treatment but there is no question that this treatment is obviously necessary, the physician is allowed to treat the child without parental consent. In cases in which treatment clearly will not be beneficial to the patient, physicians are not obligated to provide treatment, even when parents request it. In practice, parents are given ample opportunity to participate in the EoLDM process as recommended in national guidelines (Dutch Medical Treatment Act, 2006; NVK, 2013).

Parents and physicians may decide to withhold or withdraw life-prolonging treatment if they consider this treatment to be ineffective (i.e., it does not contribute to resolving the patient's medical problems), inappropriate (i.e., the burden greatly outweighs the benefits) and/or nonbeneficial (i.e., the treatment does not contribute to recovery to a minimum level of quality of life (QoL)) (Santonocito, Ristagno, Gullo, & Weil, 2013). Patients with PIMD lack decision-making capability, and parents and physicians must therefore make EoLDs on their behalf. Many studies have revealed that, in addition to the diagnosis and related prognosis (Meert, Thurston, & Sarnaik, 2000; Meyer, Burns, Griffith, & Truog, 2002; Michelson et al., 2009; Sharman, Meert, & Sarnaik, 2005), serious concerns regarding the child's QoL (Curley & Meyer, 2003; Meyer et al., 2002; Michelson et al., 2009; October, Fisher, Feudtner, & Hinds, 2014; Rapoport, Shaheed, Newman, Rugg, & Steele, 2013), including current and future pain and suffering (Meert et al., 2000; Sharman et al., 2005), are the main reasons parents and physicians consider EoLDs.

The consideration of QoL in EoLDM for children with PIMD raises important concerns. One concern is that some aspects of QoL, such as socio-emotional well-being and social inclusion, can only be assessed from the subjectively perceived experience of the individual through self-report. Children with PIMD are incapable of providing accurate self-reports. A recent systematic review by Townsend-White et al. concluded that no validated instrument exists that can be used to measure the QoL of individuals with PIMD (Townsend-White, Pham, & Vassos, 2012). Subjective, personal values remain important in the assessment of QoL in this patient group. The values that parents of children with PIMD attach to the various elements that contribute to QoL may differ from those of physicians. As previous studies indicate, physicians presume that disabilities adversely affect QoL more often than parents (Morrow, Hayen, Quine, Scheinberg, & Craig, 2012). Physicians also place a higher value on cognitive functioning and independent living than parents (Saigal et al., 1999; Janvier, Farlow, & Wilfond, 2012). These differences show that a value-neutral approach may not be achievable (Wilfond, 2014).

Most studies to date have examined how QoL considerations are accounted for in EoLDM for children admitted to Pediatric Intensive Care Units (PICUs) (Curley & Meyer, 2003; Meert et al., 2000; Meyer et al., 2002; Michelson et al., 2009; Sharman et al., 2005), and few have explicitly focused on children with PIMD. This study thus aims to address three questions: 1) What elements do parents and physicians consider important for QoL in children with PIMD; 2) How do parents and physicians incorporate QoL during EoLDM; and 3) How do they discuss QoL during EoLDM?

## 2. Methods

### 2.1. Study design

We conducted semi-structured interviews with parents and physicians of children with PIMD for whom an EoLD had been made in the last two years. We first interviewed the parents, who were invited to participate alone or together with their partner. At the end of the interview, the interviewer asked the parents for their consent to contact their child's physician for an interview. Physicians received information about the study via e-mail. Two weeks later, the interviewer contacted them by telephone to obtain consent. This time frame was chosen to give physicians sufficient time to consider their participation. During this phone call, any remaining concerns or questions the physicians had about the study were addressed. They were ensured absolute anonymity and were given the

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