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LITERATURE REVIEW

“Is gestational age a factor in determining the health-related quality of life of children and young people born preterm?” A critical review of the literature

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Available online 16 December 2009

KEYWORDS

Premature;
Quality of life (QoL);
Health-related quality
of life (HRQoL);
Literature review;
Outcomes

Abstract This review offers an in-depth critical exploration of 5 studies investigating the relationship between prematurity and health-related quality of life (HRQoL) in preschool children, adolescents and young adults. Innovations in neonatology have meant that children born preterm have a better chance of surviving than in previous decades, but less is known about the influence of prematurity on the subsequent HRQoL of survivors.

In the papers reviewed, gestational age is negatively associated with cognitive and physical functioning, but the relationship between gestational age and HRQoL differs between groups. The review concludes that whilst these studies make a valuable contribution to understanding the HRQoL of children who were born preterm, standardisation between approaches would enable improved comparison between cohorts. Further research is needed to set the standards against which the HRQoL of children can be measured and conceptualised, and to take into account the wider concept of quality of life (QoL).

Introduction

Innovations in medical science have meant that children born preterm³ have a better chance of surviving than in previous decades (Wood et al., 2000). More are surviving at the lower limits of

³ Gestational age of <37 weeks (Forfar et al., 1973).

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viability, and for longer (El-Metwally et al., 2000; Levene, 2004). Although most preterm babies survive without significant problems, around half of those born extremely prematurely⁴ have a disability that is likely to affect their daily life (Johnson et al., 2009). In particular, prematurity is associated with neurological and developmental delay (Vohr et al., 2000), behavioural problems (Bhutta et al., 2002; Gardner et al., 2004), cognitive impairment (Wood et al., 2003), learning disability (Saigal et al., 1991), asthma, cerebral palsy and visual disability (Hack et al., 2005).

Morbidity resulting from prematurity often continues throughout childhood and into adulthood, and an increase in survival rates has meant that the absolute number of premature babies surviving with chronic morbidity or disability is growing (Lorenz et al., 1998). There is therefore an ongoing need to assess the long-term health outcomes of preterm populations, especially in terms of the impact that morbidity or disability may be having on their experience of life. Because the risk of adverse outcomes increases as gestational age decreases (Costeloe et al., 2000; Doyle, 2001), there is also a need to consider these outcomes in relation to the point at which invasive or aggressive medical treatment of children born at the gestational limits of viability should be sustained or withheld (Miller, 2007; Levene, 2004). As such, the importance of understanding the relationship between gestational age and long-term outcomes is vital.

Research into the long-term outcomes of children born preterm has generally focused on understanding their health in relation to functional ability and the presence or absence of physical sequelae (Donohue, 2002; Eiser and Morse, 2001). However, contemporary concepts of health have evolved to include mental and social well-being and not merely the absence of disease or infirmity (WHO, 1948). Measuring the impact of prematurity using a disease-specific approach has therefore been criticized for being too narrow a yardstick to reflect a holistic concept of health (Gray et al., 2007; Saigal et al., 2006; Theunissen et al., 2001), and interest has turned towards assessing outcomes according to the concept of quality of life (QoL). The WHO (1997) describes QoL as “a broad-ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (p. 2). Measuring

long-term outcomes according to the concept of QoL may therefore provide a wider perspective on a person’s experience of life after preterm birth.

So far, investigation into the long-term outcomes of children and young people born preterm has generally focused on assessment of health-related quality of life (HRQoL), a sub-area of QoL designed to measure “the impact of health conditions on the person’s total well-being, including his or her psychological, social, and physical health status” (Saigal et al., 2006, p. 1141). Research into HRQoL applies a quantitative approach, using multidimensional scales to measure several aspects of health simultaneously (Eiser and Morse, 2001). For example, subjects may be asked to respond to questions about their physical and psychological health using a series of pre-set statements, viewpoints or descriptions. Questions and answers are formatted in such a way as to generate data suitable for statistical analysis (Likert, 1932; Ware and Sherbourne, 1992; Landgraf et al., 1998; Furlong et al., 2001).

HRQoL measures often include an element of self-report, with the aim of gaining individual subjective perspectives on various aspects of health, by allowing subjects to convey their feelings or attitudes towards health states (Verrips et al., 1997; Fekkes et al., 2000), or to ‘gamble’ existing health states against hypothetically preferable ones (Saigal et al., 2006). For young or cognitively impaired subjects, proxy respondents are often used, with parents or caregivers answering on behalf of the child.

Most existing research into the HRQoL of children or young people born preterm suggests that while gestational age is linked to physical and cognitive impairment, survivors do not always perceive impairment as impacting negatively on their HRQoL. A literature review by Donohue (2002) concluded that although children born preterm reported poorer overall health than their term-born peers, self-reported QoL and HRQoL was similar between groups. More recently, (Zwicker and Richardson Harris, 2008), conducted a systematic review of studies published between 1994 and 2005 reporting on the HRQoL of populations born preterm from infancy to adulthood, and synthesized the results to extrapolate and describe the key findings. It found that parents or caregivers of preschool-aged children often gave their preterm children lower HRQoL scores than their term-born peers, but that when adolescents and young adults self-reported, their HRQoL was not significantly different between groups (Zwicker and Richardson Harris, 2008).

⁴ <25 weeks (Johnson et al., 2009).

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