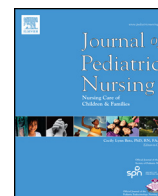




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Hope in Parents of Very-Low Birth Weight Infants and its Association with Parenting Stress and Quality of Life

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ABSTRACT

Purpose: Being a parent of a very-low-birth-weight (VLBW) infant can be stressful. We aimed to describe parental hope 42 months after the birth of a VLBW infant and determine whether there is an association between hope and parenting stress with quality of life (QoL), respectively.

Design and Methods: Fifty-nine parents of VLBW infants completed questionnaires about hope, parenting stress and QoL. Pearson correlation coefficients (r) and linear regression models were used to examine the relationship between the selected variables. To compare groups, t -test was used and Cohen's d for effect size was calculated. **Results:** Parents of VLBW infants were more hopeful than the general population ($p < 0.001$). Parenting stress and hope were both independently associated with QoL ($p < 0.001$). The subgroup of parents of infants with birth weight < 1000 g had less hope ($p = 0.041$) and higher parenting stress ($p = 0.041$) than parents of infants with birth weight 1000–1500 g.

Conclusions: Hope and parenting stress were both independent determinants of QoL. Parents of the presumably sickest infants had less hope and higher parenting stress than parents of VLBW infants with a birth weight over 1000 g. Hope should be further explored as a coping mechanism in parents of VLBW infants.

Practice Implications: The clinical implications of the strong association between hope, parenting stress and QoL remain to be determined, but reducing stress and strengthening hope seem to be important. This should be taken into account both at hospital discharge and at follow-up, especially for lower-birth-weight infants.

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Introduction

Being the parent of a sick and very-low-birth-weight (VLBW), (i.e. with a birth weight < 1500 g), infant can be stressful (Carson, Redshaw, Gray, & Quigley, 2015; Howe, Sheu, Wang, & Hsu, 2014; Misund, Braten, Nerdrum, Pripp, & Diseth, 2016; Shaw et al., 2006; Singer et al., 1999). A prolonged stay in the neonatal intensive care unit (NICU), as well as challenges in the period immediately after discharge from hospital and during the child's early years, may add to the stress related to being a parent and affect parents' quality of life (QoL) negatively (Schappin, Wijnroks, Venema, & Jongmans, 2013).

Stress in parents may have consequences for their children's emotional and behavioral development (Hoffenkamp et al., 2015; Huhtala et al., 2011). Huhtala et al. (2012) demonstrated a positive association

between parental well-being and the later behavioral problems and cognitive development of VLBW infants at 3 years of age. Because VLBW infants already have an increased risk of impaired development (Moster, Lie, & Markestad, 2008), negative influences that could further impair development, such as parental stress should be minimized. Knowledge about how to help parents of VLBW reduces their stress is thus expected to be of benefit to their children.

Hope has been shown to modify the stress experienced by caregivers of adult patients (Rustoen, Cooper, & Miaskowski, 2010), but the significance of hope in caregivers of VLBW infants has not been described. Hope can be defined as a multidimensional dynamic life force that is characterized by a confident yet uncertain expectation of which is realistically possible and personally significant (Dufault & Martocchio, 1985). As hope is future oriented, and the future is particularly uncertain for these parents, hope can be assumed to be of significance for them.

Hope has been reported to have an impact on psychological adjustment in parents (Folkman, 2010). A process of appraisal precedes

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evaluation of stressful situations. Hope might be helpful in various stages of this appraisal process (Folkman, 2010), and may therefore be protective against the negative impacts of stress. Further, a strong association between parental hope and family functioning has been demonstrated (Kashdan et al., 2002).

The stress experienced by individuals affects QoL negatively (Ames, Jones, Howe, & Brantley, 2001). QoL is defined by subjective experiences, states and perceptions, which are affected by subjective functioning and personal expectations (Wilson & Cleary, 1995). There is little research about the QoL of parents of VLBW infants (Doering, Moser, & Dracup, 2000; Nordheim, Rustoen, Iversen, & Nakstad, 2016; Wolke, Baumann, Busch, & Bartmann, 2017). A study of the parents of children with autism showed that accepting responsibility for their own situation was the only coping strategy that improved the QoL of stressed parents (Dardas & Ahmad, 2015). The authors speculated that this coping strategy gave the parents a greater sense of control. Hope might work through the same mechanisms to help parents cope better with stress and thus improve their QoL.

The aims of the present study were to examine hope in parents of VLBW-infants at their chronological age of 42 months, and to assess the relationship between hope, parenting stress and QoL. Infants with a birth weight < 1000 g are at particularly high risk of developing complications due to their prematurity. We therefore wanted to examine whether a birth weight < 1000 g additionally affects hope, parenting stress and QoL. We hypothesized that high levels of hope can neutralize some of the negative effects of parenting stress on QoL.

Design and methods

The parent cohort

Mothers and fathers ($n = 59$) of infants with a birth weight < 1500 g born May 2010–April 2011 in three university hospitals in the area of the Norwegian capital of Oslo were included. The parents were recruited from a follow-up study of parents of infants participating in a randomized controlled trial (RCT) of enhanced nutrition ($n = 31$) and from parents whose infants never participated in a RCT but were born in one of the three study hospitals 1–6 months before or after the recruitment period for the RCT ($n = 31$) (Nordheim et al., 2016). The parents in the follow-up study were assessed twice, first during their stay with their infant in the NICU ($n = 62$) and then as the infants reached a chronological age of 42 months ($n = 59$). As both an index for parenting stress and a measurement for hope (see data collection section) were included at 42 months, we chose this time point for the present study.

Norwegian national guidelines define infants with a birth weight < 1000 g as at particularly high risk of developmental complications (The Norwegian Directorate of Health, 2007), and maternal distress has been found to be associated with the degree of prematurity (Singer et al., 1999). Therefore, we analyzed the difference between parents of infants with a birth weight < 1000 g ($n = 21$) with those with infants with birth weight 1000–1500 g ($n = 38$).

Ethics

The study was approved by the South Eastern Regional Committee for Medical and Health Research Ethics and by the local privacy legislation authority at Akershus and Oslo University hospitals.

Data collection

Standardized questionnaires also used in another study (Nordheim et al., 2016) were sent to the parents of VLBW infants by mail after they had given their written consent to participate. Information about their sex, age, marital status and the number of their other children was collected from the questionnaires (Table 1).

Table 1
Demographic and clinical characteristics of the parents ($n = 59$).

	N	(%)
Sex, men	28	(47.5)
Have additional children	29	(43.8)
Lives with the child's parent	56	(94.9)
	Median	(Range)
Number of children	1	(1–4)
Parent age (years)	35.5	(25–50)
GA of infant (weeks)	28.9	(24–36)
Birth weight of infant (g)	1149	(571–1493)

Abbreviations: GA: Gestational Age.

The Herth Hope Index (HHI) (Herth, 1992) was used to measure hope. The HHI is based on the definition of hope by Dufault and Martocchio (1985) and is composed of 12 items related to cognitive and affective factors and interconnectedness between the self and others. The score for each item ranges from 1 (strongly disagree) to 4 (strongly agree) (Herth, 1992). Both scores on single items (from 1 to 4) as well as a total score (from 12 to 48) are available. Higher scores indicate higher levels of hope. The HHI has shown satisfactory validity and reliability in different Norwegian samples (Rustoen et al., 2003; Schjolberg, Dodd, Henriksen, & Rustoen, 2011), in caregivers of patients with cancer (Lohne, Miaskowski, & Rustoen, 2012) and in the general population (Rustoen et al., 2003).

The Parenting Stress Index (PSI) (Abidin, 1995) was selected in the present study as it measures stress in parents and also captures the parent's perception of the child. PSI consists of two main domains—the Child Domain and the Parent Domain. The Child Domain measures stress related to how the parents perceive their child on six subscales—adaptability, acceptability, demandingness, mood, distractibility/hyperactivity and reinforces parent. The Parent Domain measures stress related to parental functioning on seven subscales—depression, attachment, restriction of role, sense of competence, social interaction, relationship with spouse and parental health. The sum of the two domains gives the PSI Total Stress score. In addition, a Life Stress score measures the impact of life events and circumstances causing stress in the preceding 12 months. The PSI is standardized for parents of children 1 month to 12 years of age and comprises 101 statements scored on a five-point scale (1–5). Higher scores indicate more stress. The PSI has been tested in Norwegian samples (Kaarens, Ronning, Ulvund, & Dahl, 2006), and data from the general population and from parents of different patient populations are available (Abidin, 1995).

The Quality of Life Scale-Norwegian version (QoLS-N) was selected in the present study as it has been widely used in the Norwegian general population (Burckhardt & Anderson, 2003; Diseth, Tangeraas, Reinfjell, & Bjerre, 2011; Wahl, Burckhardt, Wiklund, & Hanestad, 1998). QoLS-N is composed of 16 items by which the respondents rate their satisfaction with various aspects of life. Higher scores on a seven-point scale (1–7) indicate a better QoL. The scale has been reported to have solid psychometric properties (Burckhardt & Anderson, 2003). Its validity and reliability have been well established, and data from the Norwegian general population are available (Wahl, Rustoen, Hanestad, Lerdal, & Moum, 2004).

Statistical analysis

Mean and standard deviation (SD) (for normally distributed data) or median and range (for skewed data) for the different indexes and items were calculated. We assessed the normality of the data by visual inspection of the Q-Q plots. Missing responses were handled according to the recommendations of the authors of the individual questionnaires. Therefore, indexes with less than the recommended number (e.g. 80%) of completed items were excluded to ensure validity.

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