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# Research in Developmental Disabilities



## Health related quality of life in parents of six to eight year old children with Down syndrome



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### ARTICLE INFO

#### Article history:

Received 13 May 2013

Received in revised form 4 September 2013

Accepted 4 September 2013

Available online 28 September 2013

#### Keywords:

Down syndrome

Parents

Health related quality of life

Predictors

Cross-sectional study

Social support

Leisure

### ABSTRACT

Raising a child with Down syndrome (DS) has been found to be associated with lowered health related quality of life (HRQoL) in the domains cognitive functioning, social functioning, daily activities and vitality. We aimed to explore which socio-demographics, child functioning and psychosocial variables were related to these HRQoL domains in parents of children with DS. Parents of 98 children with DS completed the TNO-AZL adult quality of life questionnaire (TAAQOL) and a questionnaire assessing socio-demographic, child functioning and psychosocial predictors. Using multiple linear regression analyses for each category of predictors, we selected relevant predictors for the final models. The final multiple linear regression models revealed that cognitive functioning was best predicted by the sleep of the child ( $\beta = .29, p < .01$ ) and by the parent having given up a hobby ( $\beta = -.29, p < .01$ ), social functioning by the quality of the partner relation ( $\beta = .34, p < .001$ ), daily activities by the parent having to care for an ill friend or family member ( $\beta = -.31, p < .01$ ), and vitality by the parent having enough personal time ( $\beta = .32, p < .01$ ). Overall, psychosocial variables rather than socio-demographics or child functioning showed most consistent and powerful relations to the HRQoL domains of cognitive functioning, social functioning, daily activities and vitality. These psychosocial variables mainly related to social support and time pressure. Systematic screening of parents to detect problems timely, and interventions targeting the supportive network and the demands in time are recommended.

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## 1. Introduction

Down syndrome (DS) is characterized by developmental disability and is associated with various health problems such as congenital heart disease, hearing loss and endocrine disorders (Roizen & Patterson, 2003). The estimated birth prevalence of Down syndrome in the Netherlands is 14–16 per 10,000 live births, resulting in an annual estimated 275–322 live births of children with DS (De Graaf et al., 2011; Weijerman et al., 2008). The moment that parents are first informed about the condition of their child is an emotional and stressful event (Hedov, Wikblad, & Annerén, 2002). Aside from the initial emotional impact, children with DS also have an influence on family life, since they need extra care throughout their life, which is most often provided by parents (Crowe & Florez, 2006). It is therefore not surprising that raising a child with DS has been found to be associated with higher levels of parental stress and reduced well-being in parents (Dabrowska & Pisula,

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2010; Hedov, Annerén, & Wikblad, 2002; Sloper, Knussen, Turner, & Cunningham, 1991). Yet, some authors suggest that the impact of raising a child with DS is relatively mild compared to raising children with other disabilities (Dumas, Wolf, Fisman, & Culligan, 1991; Hodapp, Ly, Fidler, & Ricci, 2001). In addition, it is important to note that families of children with DS also report positive perceptions of the impact of raising a child with DS (Hastings & Taunt, 2002; Skotko, Levine, & Goldstein, 2011).

Several studies identified factors that were associated with higher levels of stress and reduced well-being in parents of children with DS. These include socio-demographic factors like lower socio-economic status, a higher number of children and (higher or lower) age of the child with DS (Dabrowska & Pisula, 2010; Fidler, Hodapp, & Dykens, 2000; Hodapp, Ricci, Ly, & Fidler, 2003; Sloper et al., 1991). Also, child functioning variables such as behavioral problems, communicative impairment, health problems and diminished self-sufficiency of the child were found to be of negative influence (Abbeduto et al., 2004; Bourke et al., 2008; Hodapp et al., 2003; Sloper et al., 1991). Finally, psychosocial factors such as maladaptive coping styles of parents, less dispositional optimism, lower quality of the (marital) relationship, and a lack of social support were associated with negative consequences (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Sloper et al., 1991; van der Veek, Kraaij, & Garnefski, 2009a).

All of these findings provide valuable insight into the issues parents face. Yet, the outcome-measures stress and well-being cannot depict the wide spectrum of possible affected and unaffected domains of life. For a more extensive evaluation of parental functioning, health related quality of life (HRQoL) is a useful concept. HRQoL is a widely adopted multidimensional concept that emerged during the 1980s, and comprises a range of possible domains, including physical, emotional and intellectual functioning, the ability to participate in valued activities within the family, in the workspace and in community, and the resulting sense of well-being and comfort (Naughton & Shumaker, 2003; Patrick & Erickson, 1988). Although HRQoL is frequently used to evaluate the functioning of parents with children with various disorders, few reports on the HRQoL of parents of children with DS are available. The HRQoL of parents of children with chronic conditions, both with or without developmental disabilities, has been found to be lower compared to parents of children without chronic conditions, with different disorders being associated with varying profiles of HRQoL in parents (Davis & Gavidia-Payne, 2009; Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag, & Grootenhuys, 2008; Hatzmann, Valstar, et al., 2009; Khanna et al., 2011; Lin et al., 2009). Concerning HRQoL in parents of children with DS, a Swedish study showed that mothers of children with DS reported poorer vitality than their spouses, and poorer vitality and mental health than mothers in the control group (Hedov, Annerén, & Wikblad, 2000). In two small, exploratory studies, Brazilian parents of children with DS scored lower in the psychological and environmental domain of the WHOQOL-BREF questionnaire, the latter domain encompassing financial means, housing and opportunities for recreation (Buzatto & Beresin, 2008; Murphy, Herrman, Hawthorne, Pinzone, & Evert, 2000; Oliveira & Limongi, 2011). The Dutch Care-project, of which we employed the database for our current study, revealed that parents of children with DS scored lower in the domains cognitive and social functioning, daily activities and vitality than parents of children without a chronic condition (Hatzmann et al., 2008). In summary, all these HRQoL-studies showed that parents of children with DS tend to experience lowered HRQoL regarding vitality, leisure (social functioning, daily activities, and recreation), and mental- or psychological health. However, none of the above-mentioned studies analyzed predictors of parental HRQoL thoroughly.

Predictors of HRQoL have been studied in the broader group of parents of children with developmental disabilities, which also comprises children with DS. Factors that were found to be associated with lower HRQoL show considerable overlap with those related to parental stress and well-being in parents of children with DS. These factors concern mainly child functioning and psychosocial variables. A lower household income, higher levels of functional impairment and behavioral problems of the child, higher experienced burden, less social support, maladaptive coping style of parents, less participation in health promoting activities, and poorer professional support were all related to lower HRQoL outcomes (Bourke-Taylor, Pallant, Law, & Howie, 2012; Browne & Bramston, 1998; Davis & Gavidia-Payne, 2009; Khanna et al., 2011; Lin et al., 2009).

For the current study, aimed at tracing factors that are associated with HRQoL in parents of children with DS, we analyzed the data from the Care-project, described in Hatzmann et al. (2008). As a conceptual framework for variables that could be related to HRQoL of parents of children with DS, we used the model of Hatzmann, Maurice-Stam, Heymans, and Grootenhuys (2009). In their model, variables were clustered as 'socio-demographics', 'disease related variables', and a range of psychosocial mediating variables (e.g. leisure time and emotional support). Since our sample size was more limited, we could not analyze mediation. We therefore employed these as direct predictors of HRQoL instead of analyzing mediation, and renamed those variables 'psychosocial variables'. Finally, 'disease related variables' were renamed into 'child functioning' because this covers the meaning of the concerning variables in our sample. This resulted in a model comprising three clusters of variables that were hypothesized to be directly related to HRQoL: 'socio-demographic variables', 'child functioning' and 'psychosocial variables'. The objective of our study was to determine whether socio-demographics, child functioning and psychosocial variables were related to cognitive functioning, social functioning, daily activities and vitality, the HRQoL-domains in which parents of children with DS scored lower than parents of children without a chronic condition.

## 2. Materials and methods

### 2.1. Participants

The data regarding HRQoL of parents of children with DS were gathered within the scope of the Care-project: a large, cross-sectional study on the consequences for parents of caring for chronically ill children, including parents of 100 children

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