



Distress and everyday problems in Dutch mothers and fathers of young adolescents with Down syndrome



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ABSTRACT

Background: To provide targeted support to parents of children with DS, knowledge of their distress and everyday problems is crucial. For this purpose, psychosocial screening instruments can be a valuable addition to routine clinical practice.

Aims: To determine differences on a psychosocial screener concerning distress and everyday problems in parents of young adolescents (YAs) with DS versus control parents and in mothers of YAs with DS versus fathers.

Methods and procedures: We compared outcomes of the Distress Thermometer for Parents in 76 mothers and 44 fathers of 11–13-year-olds with DS versus 64 mothers and 52 fathers of age-matched children without DS (comparing mothers and fathers separately). Additionally, we compared mothers and fathers within 34 parent couples of YAs with DS.

Outcomes and results: Clinical distress was not more frequent than in control parents. Mothers further did not report more everyday problems and only differed from their controls on one problem domain and some problem items. Fathers, however, reported more problems than their controls across most domains and wished to talk to a professional about their situation more frequently. Outcomes in mothers and fathers within parent couples did not differ significantly.

Conclusions and implications: This is one of few studies to report on the use of psychosocial screening instruments in parents of children with DS. Our results suggested that attention for fathers of YAs with DS is required. Psychosocial screening instruments that inquire about specific problems and the wish for referral can play an important role in achieving this.

What this paper adds

Although numerous studies have focused on parental distress, this paper is one of few to systematically assess everyday problems in parents of young adolescents with DS. Moreover, this paper incorporates the perspectives of both mothers and fathers. We used a psychosocial screening instrument that is frequently used in clinical practice: the Distress Thermometer for Parents. Neither mothers nor fathers of young adolescents with DS reported more clinical distress than control mothers and fathers. Furthermore, mothers only

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differed slightly from control mothers in the frequency of reported problems. Fathers, however, reported significantly more everyday problems than their controls across a wide range of domains and showed more interest in talking to a professional about their situation. These relatively unfavourable outcomes in fathers suggest that their needs should be attended to in the care for families of young adolescents with DS. The distress score alone did not reveal these needs, while the problem items did; this suggests that discussion of specific problems and the wish for referral is required in clinical practice to determine the need for assistance. Screening instruments such as the one used in this paper can facilitate a targeted discussion of these psychosocial issues.

1. Introduction

1.1. Background

Down syndrome (DS) is the most common genetic cause of intellectual disability (De Graaf et al., 2011). Besides intellectual disability, DS is accompanied by increased risks for health problems such as congenital heart disease, endocrine disorders, and leukaemia (Roizen & Patterson, 2003). Parents of children with DS have been generally found to show poorer outcomes than parents of children without developmental disabilities concerning stress, well-being, and quality of life (Dabrowska & Pisula, 2010; Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Hedov, Anneren, & Wikblad, 2002; Marchal, Maurice-Stam, Hatzmann, Van Trotsenburg, & Grootenhuis, 2013; Roach, Orsmond, & Barratt, 1999). Compared with parents of children with other conditions associated with intellectual disability, however, the negative consequences seem relatively modest (Esbensen & Seltzer, 2011). Also, many parents reported to experience personal growth thanks to raising a child with DS (King & Patterson, 2000; Skotko, Levine, & Goldstein, 2011). Furthermore, most families of children with DS appear to show essentially normal family functioning (Cunningham, 1996; Povee, Roberts, Bourke, & Leonard, 2012), while divorce rates may be even lower than in the general population (Cunningham, 1996; Urbano & Hodapp, 2007). So, raising a child with DS appears to be a challenge, but one that many parents experience as worthwhile and that most families can adapt to.

Successful adaptation to the challenges of raising a child with DS depends on the resources of the family and one of these resources is support from health care professionals (Davis & Gavidia-Payne, 2009). To provide targeted support, health care professionals should be aware of the type of practical and emotional problems that parents of children with DS are likely to encounter. For this purpose, studies of specific outcomes that relate to everyday life are needed, yet these studies are far less abundant than studies of parental perceptions and emotions (Hodapp, 2007). For example, we could only identify one study that systematically inquired specific everyday problems reported by parents of children with DS (Hedov et al., 2002). This study, alongside studies of health related quality of life, suggests that the specific problems that parents struggle with focus on worries about the future of their child, time demands, sleep, vitality, social support and mental health (Bourke et al., 2008; Hedov, Anneren, & Wikblad, 2000; Marchal et al., 2013). This type of studies is essential if we want to understand the extent of consequences that parents experience in daily life as well as their need for practical assistance.

These previous studies of parental everyday problems and health related quality of life are limited in that they all concerned parents of children at early school age, or parents of children with DS in wide age ranges. Yet, the experience of parents may change substantially with age of the child (Cuskelly, Hauser-Cram, & Van Riper, 2008); several studies suggest that parents experience an increased burden as the child grows older (Hauser-Cram et al., 2001; Hodapp, Ricci, Ly, & Fidler, 2003; Lanfranchi & Vianello, 2012). It is important, therefore, that studies of parental functioning take the age of the child into account, preferably employing a longitudinal design, or at least describing parental functioning within a limited age range of the children. Furthermore, in previous studies, mothers are overrepresented, even though the experiences of mothers and fathers raising a child with DS are not likely to be identical due to e.g. culturally defined expectations of family roles. Although recent studies found few differences between mothers and fathers of children with DS concerning, for instance, stress (Dabrowska & Pisula, 2010; Lanfranchi & Vianello, 2012), mothers and fathers do appear to differ in the type of stressors they experience. For mothers these concern fatigue, vitality, care responsibilities and social support, while fathers appear to experience more problems concerning attachment to their child, acceptability of their child to others, and financial consequences (Cuskelly et al., 2008; Hedov et al., 2000, 2002; Hodapp, 2007).

Beside knowledge of frequent problems at a group level, psychosocial screening or monitoring of individual families in clinical practice can ensure early detection and timely referral to targeted support (Kemper & Kelleher, 1996). Although psychosocial screening and monitoring have been successfully implemented in diverse medical settings (Haverman et al., 2014; Valderas et al., 2008), we could not identify reports of this in the care for families of children with DS. This is surprising given the potential psychosocial consequences of raising a child with DS. More knowledge about the outcomes of such screeners can provide practical and theoretical considerations for the use of such instruments in clinical practice.

In the current study we focused on parents of young adolescents (YAs) with DS and included the perspectives of both mothers and fathers. We used a psychosocial screening questionnaire concerning distress and everyday problems that is frequently applied in Dutch clinical practice. We aimed to determine whether clinical distress and everyday problems were more frequent in mothers and fathers of YAs (11–13 year olds) with DS than in control parents of age-matched children without chronic disorders. Mothers and fathers were analysed separately to account for possible gender differences. Furthermore, we aimed to determine whether clinical distress and everyday problems differed between mothers and fathers in parent couples of YAs with DS.

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