

Sense of Coherence and Resolution with Diagnosis among Parents of Adolescents with Type 1 Diabetes



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Key words:

Diabetes; Parenting; Adolescents; Sense of coherence; Resolution with diagnosis **Introduction** The current study focuses on parents' sense of coherence and its association to their resolution of the child's disease.

Methods: We conducted a study of 122 mothers and fathers of adolescents who had been diagnosed with type 1 diabetes to assess their SOC and their reactions to their child's diagnosis.

Results: A significant difference was found in SOC between parents who have come to terms with their child's disease and parents who have not.

Conclusion: Findings may testify to the importance of parents' state of mind as a resource for reconstructing their caregiving system.

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THE DIAGNOSIS OF a chronic disease in a child necessitates reorganizing the everyday lives of the child and the family, including redistributing family roles, coping with functional and emotional overload, and enduring changes in the family's financial situation (Melamed, 2008). Most research on children with chronic diseases addresses, in depth, the implications of the disease for patients and their families, focusing on negative factors in the child's health and psychological adjustment. This research is anchored in the view that the lack of such negative factors in the individual necessarily indicates that he or she is in good health. In contrast, a positive approach advocates resources that help individuals achieve health and well-being despite illness and other stress factors (Seligman & Csikszentmihalyi, 2000), as well as the presence of positive factors such as satisfaction and self-appreciation that indicate health and well-being (Sagy & Dotan, 2001). Hence, research taking this approach focuses on factors that promote health and emotional well-being.

Antonovsky (1979) claimed that a high incidence of illness and stress in an individual's life forms the basis for assuming that the human system has a built-in disability, is subject to unavoidable entropic processes (an inevitable and steady deterioration of a system or society), and ends in death. Hence, the pathogenic approach according to which individuals belong to one of two polar categories – "ill" or "healthy" - does not properly describe human reality. Instead, the salutogenic approach situates individuals along a continuum with "ease" at one extreme and "dis-ease" at the other. This approach raises questions with respect to all individuals: To what extent are their lives dangerous? And how are they able to cope with these dangers? Furthermore, a focus on reducing risk factors is not sufficient, because although it may explain disease prevention, it fails to explain how individuals can progress toward health. Antonovsky (1979) coined the term sense of coherence (SOC) to refer to a resource that promotes individual health and that may contribute to health. A SOC involves 'a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (a) the

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stimuli from one's internal and external environments in the course of living are structured, predictable, and explicable; (b) the resources are available to one to meet the demands posed by these stimuli; and (c) these demands are challenges, worthy of investment and engagement' (Antonovsky, 1987, p. 19). Antonovsky (1998) claimed that individual, familial, social, and cultural factors; personality structure; early parent—child relationship; social support; and religious beliefs all shape an individual's subjective perception of the world, and that these perceptions are relatively stable over one's life span.

Research on parents' SOC and their own well-being showed that the SOC of parents of children with chronic diseases is a resource that enables them to view the disease as less threatening and to perceive their child as healthier, while encouraging them to cope better with their situation and sustain a higher quality of life (Hintermair, 2004; Olsson & Hwang, 2002; Svavarsdóttir & Rayens, 2003). The current study focuses on SOC in the context of the parental caregiving system, and it asks whether parents' SOC may be associated with better resolution of the adolescent child's disease.

Bowlby (1980, 1982), the founder of attachment theory, pointed to two complementary and distinct behavioral systems—the attachment system, or the motivational system of the infant to receive care, and the caregiving system, or the motivational system of the parent to give care and protection. Bowlby (1980, 1982) claimed that the behavioral system is governed by higher processes, namely representations—and, with regard to the caregiving behavioral system, "parenting representations." These are expected to include a representation of the child, of the self as a caregiver, of the parental goals, and of the ways to achieve them (Bretherton & Munholland, 1999). Representations regulate, interpret, and predict parent and child behaviors, thoughts, and feelings based on actual experiences in the caregiving context as well as on conscious and unconscious mechanisms (Bugental, 1992; Collins & Luebker, 1994; Grusec, Hastings, & Mammone, 1994; Solomon & George, 1996).

Parental resolution of the child's diagnosis of chronic disease is a specific and important aspect of parenting representation that may serve as a resource for the health and adjustment of the child. Pianta, Marvin, Britner, and Borowitz (1996) claimed that after a child has been diagnosed with an illness or a disability, the parental caregiving system is shaken by the "loss of the perfect child," which is tantamount to the "death" of the parents' existing beliefs, perceptions, emotions, and expectations with respect to their child. From this moment on, an adaptation process begins, at the end of which parents should become reconciled to and accept their child's disease. Parents who come to terms with their child's disease are likely to be left with a sense of trauma, but without the feelings of confusion and depression they experienced at the outset. This resolution helps parents to cope with the new reality and its concomitant difficulties and to generate a new balance between the child's needs and his or her capabilities.

Based on the Adult Attachment Interview (AAI; George, Kaplan, & Main, 1985), which examines resolution with respect to loss, Pianta and Marvin (1992b) developed the Reaction to Diagnosis Interview (RDI) to examine parental resolution of the diagnosis of a child's disease/disability. The authors described the attributes of "resolution" as recognizing changes since the diagnosis, carrying on with one's life, no longer actively searching for causes, viewing the child's capabilities properly and realistically, and expressing a balanced view of the negative and positive elements in caring for the child. In contrast, parents who lack resolution vary in their responses to diagnosis. Some have unrealistic perceptions of their child and his or her disease; others actively seek causes while remaining overcome by ongoing grief, pain, anger; some feel confused or disorganized; and others see themselves as the main victims of the diagnosis and feel helpless in the battle against their child's disease, or feel emotionally and cognitively cut off from the diagnosed situation. Although an earlier study found parental resolution to be unrelated to disease type or severity, to the time since diagnosis, or to the child's developmental age (Sheeran, Marvin, & Pianta, 1997), a recent study found unresolved reactions to occur significantly more often among parents of younger children and parents of children with more severe motor disabilities (Schuengel et al., 2009). The present study focuses on SOC and resolution with the diagnosis of type 1 diabetes.

Diabetes mellitus type 1 (also known as type 1 diabetes, IDDM, or juvenile diabetes) is one of the most common chronic diseases among children; 15,000 children are diagnosed each year in the United States (Juvenile Diabetes Research Foundation, 2013). The disease is caused by autoimmune destruction of insulin-producing beta cells of the pancreas, leading to deficient insulin production, which renders the body unable to control the amount of sugar in the blood. Total dependence on an outside source of insulin has short-term and long-term implications, including cardiovascular disease and problems with limbs, blindness, kidney failure, coma, and even death (Edgar & Skinner, 2003). The complex treatment and new lifetime regime affect the routines of child and parents alike, posing developmental as well as diabetic behavioral and emotional challenges to parents (Martz & Livneh, 2007). Hence, the child's diagnosis places parents at risk of emotional morbidity, characterized by depression, anxiety, and posttraumatic responses (Landolt, Vollrath, Laimbacher, Gnehm, & Sennhauser, 2005), and may lead them to view the caregiving as a burden (Anderson, 2011; Cunningham, Vesco, Dolan, & Hood, 2011). Successful coping with these challenges and a decline in stress symptoms have been found to appear as soon as during the first year, although this process has also been found to be affected by the progress of the disease (Hesketh, Wake, & Cameron, 2004).

The current study hypothesizes that parents who have a higher SOC are better able to view their child's disease as less threatening, to perceive their child more holistically, to recognize the change since the diagnosis, to view the child's capabilities properly and realistically, and to express a balanced view of

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