Paediatric occupational therapy: Addressing parental stress with the sense of coherence

Rochelle Stokes, Liisa Holsti

Key words
Paediatric occupational therapy
Parents of disabled children
Stress
Theory

Abstract
Background. Families of children who have disabilities experience multiple stressors. “Sense of coherence” (SOC) reflects a person’s view of life and his or her capacity to respond to stressful situations. Purpose. The purposes of this paper are to (1) introduce the concept of SOC; (2) review the literature on the stresses experienced by parents of children with disabilities; and (3) discuss how SOC can be used to evaluate systematically and to address effectively parents’ resiliency against stressors.

Key Issues. The literature shows a strong correlation between parental stress, avoidant coping, depression, and low SOC. Preliminary evidence suggests that an early intervention program can help increase parents’ SOC. Implications. Occupational therapists can use the SOC as a framework from which to identify the strength of a parents’ SOC, and, when deemed to be low, help create a process for enhancing resilience.

Résumé

Numerous studies have shown that parents and caregivers of children with disabilities experience higher rates of stress (Baker, McIntyre, Blancher, Crnic, & Low, 2003; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hoare, Harris, Jackson, & Kerley, 1998; McAuley, McCurry, Knapp, Beeham, & Sleed, 2006; Montes & Halterman, 2007; Rimmerman & Stanger, 2001; Sanders & Morgan, 1997). Along with stress, parents of children with disabilities have also been shown to have higher rates of depression, health problems, and a lower quality of life (Eker & Tuzun, 2004; Veisson, 1999). This parental stress has a direct impact on a child’s physical and socio-emotional development (Calderon & Greenberg, 1993; Guralnick, 2000). Occupational therapists are involved regularly in the care of children who have disabilities and play a critical role in supporting their optimal development (Case-Smith & Cable, 1996; Mulligan, 2003). Often therapists rely on families to implement recommendations and to work towards developmental goals. To opti-
mize a child's developmental potential, it is critical for occupational therapists to address a child's developmental goals from a family-centered perspective; this philosophy can encompass understanding how to support parents through difficult times related to the implementation of early intervention services for their child.

In many paediatric settings, occupational therapists have an opportunity to build a rapport and a strong relationship with the family that can last many years. As a result, occupational therapists are in a unique position to help parents and caregivers facilitate change so that together they can continue to effectively support the child's optimal development. However, to do this successfully, occupational therapists need an appropriate theoretical framework from which to work. When generating hypotheses about the origins of problems, therapists may need to draw upon various types of theoretical approaches: theories pertaining to occupational performance and theories specifically about human beings. The latter category of theories is often borrowed from other disciplines (Fearing, Law, & Clark, 1997).

Aaron Antonovsky, an American-Israeli medical sociologist, created the concept of the "sense of coherence" (SOC) to indicate an individual's general orientation to life. SOC is an indicator of resilience and personal strength that represents one's capacity to respond to stressful life events (Antonovsky, 1993) and has been shown to be a predictor of good health and well-being (Johnson, 2004; Richardson & Ratner, 2005). People with a strong SOC regard their environment and the events in their everyday life as comprehensible, manageable, and meaningful. Although the SOC has been used in 33 languages and in 32 countries, in the occupational therapy community, this theory is relatively unknown.

In the last 10 years, only a few publications in occupational therapy research have examined the SOC concept and its relationship with occupation. This research highlights the relevance of the SOC to theories and concepts related to our profession. (Branholm, Fugl-Meyer, & Froldune, 1998; Falkdal, Edlund, & Dahlgren, 2006; Hakansson, Svartvik, Lidfeldt, & Nebrand, 2003; Lillejell & Jakobsen, 2007; Schult, Soderback, & Jacobs, 2000). To date, no research in occupational therapy has been conducted examining the relationships between the SOC, occupation, and parental stress in the paediatric setting.

Given the lack of literature on SOC in paediatric occupational therapy, the purpose of this paper is threefold: (1) to introduce the concept of the sense of coherence in the context of parental stress, (2) to review the literature on the stresses experienced by parents of children with disabilities, and (3) to discuss how SOC can be used to systematically evaluate and effectively address parents' resiliency when faced with stressors. The implications for the use of this theory will be discussed in the context of paediatric occupational therapy.

**Sense of Coherence**

In the 1970s, researchers began to be interested in the factors that promoted health. This paradigm shift was in opposition to the pathogenic model, which asks the question "Why do people get sick?" Instead, Antonovsky asked the question "Why do people stay healthy?" (Antonovsky, 1979). He saw people on a health–disease continuum with an individual's movement along this continuum related to how he or she deals with the stressors encountered in everyday life. If a person can appropriately manage the tensions surrounding a life stressor, then the outcome of the stressor may be neutral or positive, moving the individual towards the healthy end of the continuum. Alternatively, if tensions surrounding the stressors are poorly managed then a person may move towards the disease end of the continuum.

Antonovsky focused his research on studying general resistance resources (GRR) and their relationships to the health–disease continuum. An analysis of the relationships shows that only SOC correlated highly with overall health status and also appeared to be the intervening variable between the other resources and health (See Figure 1).

The three intertwined components of the SOC required for successful coping are (1) comprehensibility (the cognitive component): a person's ability to make sense of what is happening; (2) manageability (the behavioural component): the enhanced confidence that the resources available are adequate; and (3) meaningfulness (the motivational component): increased motivation to engage in the challenges faced. Over time, experiences that facilitate the development of these three components foster a strong SOC, and the stronger one's SOC, the more ability one has to employ cognitive, affective, and instrumental strategies that lead to coping and well-being (Antonovsky, 1987). Derived from the concept of SOC, the sense of coherence scale (SOC-29, SOC-13) is comprised of three subscales: meaningfulness, comprehensibility, and manageability. It has been found to be a reliable, valid, and cross-culturally applicable instrument that is able to measure how people manage stressful situations and stay well (Eriksson & Lindstrom, 2006).

The uniqueness of the SOC concept is that it is not a specific coping style but rather the ability to be flexible in selecting coping behaviours that are judged to be appropriate. If one has a strong SOC, then one has the motivational and cognitive bases for transforming one's potential resources into actuality, thereby promoting health (Antonovsky & Sourani, 1988).

**Parental Stress**

The birth of a child with a disability has a significant impact on a family with ensuing demands on the parents to advocate for their child, to manage medications and nutrition, and to manage repeated and multiple appointments with professionals. These families must also cope with various uncertainties about their children's medical conditions and their futures. Anthony et al. (2005) defined parenting stress as the difficulty emerging from the demands of being a parent, which affects behaviour, well-being, and the child's adjustment. This stress can be expressed in different ways, including social isolation, emotional depression, and relationship conflict (Keller & Honig, 2004; Margalit, Leyser, Ankonina, & Avraham, 1991). All families and parents experience stress, whether they have a child with a disability or not. However, recent literature describes differences in the stress that is experienced by parents who have a child with a
Sloper and Turner (1992) highlight the first category of stressors, the difficulties families have in seeking medical information. In a sample of 107 families of young children with severe disabilities, despite their being in touch with numerous professionals and services, many of the families described their needs as being “unmet.” The greatest areas of unmet needs were related to provision of information; 59% of families felt like they lacked information about services and 43% felt that they lacked information about their children’s conditions. Furthermore, families’ unmet needs were associated with high levels of family strain. Hawley, Ward, Magnay, and Long (2003) confirmed the association between parental stress and unmet information needs. Their study assessed parental stress of 97 parents following paediatric traumatic brain injury. Regardless of injury severity, one-third of families claimed no information was given to them at the hospital following the injury; 70% of families felt that their information needs were unmet. While the unmet information needs of parents were not directly correlated with parental stress, it was found that, overall, parents of children who suffered a traumatic brain injury experienced significantly greater stress than parents of control children.

The second category of stressors suggested by Guralnick (2000) has suggested one way of thinking about the potential stressors that confront families of children with developmental disabilities. Here stressors can be classified into four categories, those related to (1) the difficulties families have in seeking medical information, (2) the interpersonal and family distress experienced upon receiving a diagnosis, (3) the stress placed on family resources, and (4) threats placed upon the ability to confidently parent. These four categories of stressors influence a child’s development adversely and can affect family interaction patterns in three ways: (1) the quality of parent-child interactions, (2) the child’s experiences that occur within the larger physical and social environment that his or her parents organize, and (3) the health and safety that the family provides (Guralnick). Stressors affect a child’s development when they perturb one or more of the three patterns of family interaction. When parents have difficulties coping adequately and adapting to stress, there can be significant implications not only for their quality of life, but also for the development and well-being of their child.

Evidence on parental stresses associated with having a child with disabilities supports Guralnick’s (2000) categories.

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(2000) is that of the interpersonal and family distress experienced upon receiving a diagnosis. Lawson (2004) conducted a qualitative study that examined parents caring for their children with disabilities and their experiences of the disclosure of their children's impairments. For the parents in this study, the experience was negative and they felt that the services were not meeting their needs. A study by Quine and Rutter (1994) also investigated parent satisfaction with medical communication at the time of diagnosis of a child's severe disability. Of the 160 parents involved in this study, 58% stated they were dissatisfied with the communication. While interpersonal and family distress can be experienced at the time of initial diagnosis, it can also have serious implications beyond this period. A study by Rone-Adams, Stern, and Walker (2004) examined the relationship between caregiver stress and parent participation in physical home therapy programs for their child with a disability. While this study was aimed at addressing parental involvement in their child's therapy, the researchers found that there was a statistically significant relationship between interpersonal and family problems, parental stress, and parental involvement in therapy programs. The results from this research demonstrated that a caregivers' level of participation can be predicted by the levels of stress that they are experiencing. This study is critical as previous literature has shown that increased parental involvement improves a child's outcomes (Kendall, Sloper, Lewin, & Parson, 2003; Law & King, 1993; Piggot, Paterson, & Hocking, 2002).

The third category of stressors is that of the stress placed on family resources. Warfield (2005) tested family resources, parenting challenges, work rewards, and work demands as predictors of parenting stress among parents of five-year-old children with disabilities. Warfield showed that the number of children in a family significantly correlated with less income and showed a trend toward greater difficulty finding childcare. As a result, greater demands are placed on parents with fewer resources, which leads to greater parental stress. Finally, addressing the fourth category of parental stressors, that of the threats placed upon the ability to parent confidently, is a study by Hassall, Rose, and McDonald (2005). Researchers investigated the relationship between parental cognitions (parenting self-esteem and parental locus of control), child characteristics, family support, and parenting stress. They found a strong inverse relationship between the Parenting Stress Index and the Parenting Sense of Competence Scale. Parenting stress in mothers of children with disabilities was associated with their locus of parenting control and their sense of satisfaction with parenting.

The Sense of Coherence and Parental Stress

Antonovsky believed SOC reflects a person's view of life and capacity to respond to stressful situations. SOC is a personal way of thinking, being, and acting with an inner trust, which leads people to identify, benefit, use, and re-use the resources at their disposal (Lindstrom & Eriksson, 2005). While the literature suggests that parents with children who have disabilities experience significant stress, we know this is not the case for all parents who have children with disabilities. Recent literature is highlighting the positive impacts that children with disabilities have on their families (Bayat, 2007; Blancher & Baker, 2007; Hastings & Taunt, 2002). The following example illustrates how SOC may facilitate parental adjustment to having a child with a disability. A mother has been recently informed that her daughter has a severe disability. If this mother has a high SOC, she would believe that she has the capacity to deal with this new situation. She would view her situation as a challenge but, then with time, select an appropriate coping strategy that works for her. This mother would feel confident in her abilities to access the resources available to her. Her strong SOC would help her move towards the health end of the health-disease continuum and experience less overall stress. Alternatively, if this mother has a low SOC and has received the diagnosis that her daughter has a severe disability, she may feel overwhelmed and select an avoidant coping mechanism. This will make it harder for her to mobilize the resources needed to help her and her child during this difficult time.

Guralnick's (2000) categorization system for parental stressors, while not specific to SOC, can be used to demonstrate how each component of a parent's SOC can be challenged: (1) comprehensibility (cognitive/knowledge component); (2) manageability (the feeling that the resources are there to meet the demands posed by the stressor); and (3) meaningfulness (the belief that demands are challenges worthy of investment and commitment). For example, (1) sorting through and obtaining information is one of the primary areas of stress that families experience. This point demonstrates how the feeling of comprehensibility is deemed essential by families but is often under threat. (2) The interpersonal and family distress that families experience, as well as the financial burden and time constraints, affects a family's emotional, social, and financial resources, which has an impact on a parent's sense of manageability. (3) The threats to a parents' sense that they can parent confidently and effectively, while also obtaining enjoyment from this role, demonstrates the SOC component of meaningfulness.

Articles by Margalit et al. (1991; Margalit, Raviv, & Ankonia, 1992) helped to lay the groundwork for research on SOC and parents of children with disabilities. Both studies found that parents of children who have disabilities reported a lower SOC, an increased use of avoidant behaviours, and viewed their family climate as less supportive. A more recent study by Olsson and Hwang (2002) aimed to test whether the concept of SOC could facilitate an understanding of individual differences in psychological adaptation in parents of a child with an intellectual disability (ID), and why these parents generally experienced higher levels of stress. Results of the study demonstrated that mothers of children who have autism had lower SOC levels than mothers of children with an ID, who in turn had lower SOC levels than the control mothers. The researchers attribute the differences between SOC scores for parents of children who have autism and those parents who have children with an ID to the severe behaviour disturbances and decreased social responsiveness often observed in children diagnosed with autism. Previous research has linked high stress with severe behaviours; this association, along with personal life restrictions, may be attributing to the low SOC scores found in these parents (Olsson & Hwang).
In 2006, Oelofsen and Richardson extended the research and examined SOC in parents of children with developmental disabilities (DD) along with measures of parental health and parenting stress. They found that mothers and fathers of children with a DD reported high levels of parenting stress, with 84% of mothers and 67% of fathers’ scores falling in the clinical range on the Parenting Stress Index (PSI); parents of children with DD had significantly weaker SOC scores than parents of children without DD. This study did not measure parents’ SOC levels before the birth of their children with disabilities; therefore, it is possible that some of these families had lower SOC scores to begin with. Oelofsen and Richardson suggest that while this may be the case, an alternative explanation for the findings is that the lower SOC levels among parents with DD could be an indication that life-changing events could weaken individuals’ SOC levels without a return to previously strong SOC levels. Further research is needed to test this hypothesis.

The research to date pertaining to SOC in relation to parents’ of children with disabilities has been primarily descriptive and exploratory, but it suggests that a strong correlation exists between parental stress, avoidant coping, depression, and a low SOC (King et al., 2006; Margalit et al., 1991; Margalit et al., 1992; Oelofsen & Richardson, 2006; Olsson & Hwang, 2002). While this research has been foundational in understanding the importance of the theory of salutogenesis and how it relates to parents of children with disabilities, very little research has explored whether it is possible to have parents who have SOC levels that improve despite experiencing life altering events or whether parents’ SOC levels can be changed with an intervention.

A study by Margalit and Kleitman (2006) is the only study to date that has involved the use of an intervention. In a group of 70 mothers with children aged 2 to 39 months diagnosed as at-risk children with developmental delay received a one-year early intervention program. The intervention included weekly sessions with speech therapy, occupational therapy, and aquatic therapy. During these weekly sessions, therapists worked with the children and instructed mothers on how to continue the directed activities at home. This program placed emphasis on mothers’ peer support and on facilitation of the parent-child transactions in terms of reciprocity and affective warmth.

The results of this study suggest that mothers’ stress at the beginning of the intervention was significantly predicted by their SOC scores (higher SOC predicted lower levels of stress). Initial experiences of stress at the beginning of the intervention, family cohesion, and maternal satisfaction derived from the intervention all predicted stress levels at the end of the intervention. Mothers who perceived the intervention as helpful and beneficial experienced decreased levels of stress. A resilient group of mothers was identified who began the intervention with lower SOC scores than the non-resilient group of mothers. At the end of the intervention, the resilient group was identified with higher SOC levels and reported lower levels of stress. The comparison group ended the intervention with lower SOC levels and higher levels of stress (Margalit & Kleitman, 2006).

Although this study has a number of weaknesses, such as intervention bias, it does provide occupational therapists with preliminary evidence that supports the use of an intervention to help increase parent’s SOC levels. This study found that mothers who perceived the intervention as helpful, providing clear guidance for their concerns and enabling them to contribute effectively to their child’s development, experienced less stress because they regarded their situation as being manageable (Margalit & Kleitman, 2006). This research supports the importance of an occupational therapist doing an assessment of a parent’s SOC level so the therapist understands to what extent the parent believes that interventions by the occupational therapist can promote change. Current research is demonstrating the significance of parental empowerment, in addition to direct therapeutic contact with children, in order to support a child’s development (Melnyk et al., 2004). A combination of occupational therapy interventions that address both of these areas is where the profession has a role.

**Implications for the Pediatric Occupational Therapist**

While studies have shown that parenting a child with a disability can create greater stress levels and depression in parents, we know that this is not the case for all parents of children with disabilities. Having a child with a disability increases the probability of stress in parents but does not assist in predicting how an individual parent will be affected (Olsson & Hwang, 2002). Antonovsky (1987) argued that a person’s view of her/himself and the world is critical in understanding the consequences of a life stressor. A parent who has a child with a disability but who also has a strong SOC may be more likely to adapt to the stressors she or he encounter and perceive the situation as a challenge, while parents who have a low SOC may perceive their circumstance as a threat and have difficulties selecting the appropriate coping mechanisms to deal with the situation. A parent who receives the diagnosis that the child has a disability could view this news as an “acute stressor,” but if this acute stressor alters a person’s life, it can turn into a “chronic stressor.” Antonovsky (1993) found that chronic stressors can lower one’s SOC level over time. Therefore, one can view SOC as a flexible means of adapting to a stressful event (process), but, if the event is chronic, the SOC can be changed by the stressful event (outcome). Occupational therapists who are interested in facilitating the development of a child with a disability and in supporting parents doing the same could look at addressing a parent’s SOC from a “process and outcome” framework. For new parents who have a child with a disability, occupational therapists can use the Sense of Coherence Scale (SOCS) to determine the parents’ SOC levels and, therefore, their potential to cope effectively with their new situation. Therapists can develop interventions to help decrease the risk that the parents’ life situation will turn into a chronic stressor. For parents who are already dealing with chronic stressors, therapists can use interventions to help raise parents’ SOC levels so that they can overcome their stressors independently.

Currently, research is very limited on whether the use of an intervention in a pediatric setting can alter a parent’s SOC. However, until further research is conducted, occupational therapists can consider using the SOC as a framework within
their pediatric occupational therapy settings. Each component of the SOC (comprehensibility, meaningfulness, and manageability) can be explored in order to create interventions or can be used in conjunction with pre-existing interventions.

Therapists can address “comprehensibility” by fulfilling a parent’s information needs; helping them to understand their child’s disability and the services and professionals available. Therapists can help direct families to resources in the community and within their professional setting or put them in touch with other professionals, such as social workers or counselors. Therapists may need to spend more time with families, discussing how their child’s disability is affecting the child’s activities of daily living and look at other avenues (e.g., teaching videos, diagrams, Web sites) to help them understand what is taking place in the present and what to expect in future.

Therapists can help parents see the importance of having hope and encourage them to see the possibilities that lie ahead, thus creating a sense of “meaningfulness.” This support may involve putting families in touch with other parents in similar situations who have been found to be “resilient.” These parents can act as mentors, offering support and guidance. Therapists can also help enhance a parent’s sense of meaningfulness by encouraging them to pursue their own personal interests and goals. The belief that life makes sense emotionally is very connected to meaningfulness and will help parents feel that the demands they will encounter are worthy of their energy (Olsson & Hwang, 2002). Indeed, a qualitative study by King et al. (2006) found that parents come to gain a sense control over their situation and a sense of meaning in life by thinking differently about their child, their parenting role, and the role of the family. Therapists can help facilitate a sense of meaningfulness by validating parents’ feelings of lacking control and possible disappointment and help them to see their children’s positive contributions (King et al.).

The final component of SOC, manageability, addresses the ability to use coping strategies flexibly. Paediatric intervention settings can provide parenting stress programs that teach parents problem-solving skills and time management as well as assertiveness and relaxation skills (Oelofsen & Richardson, 2006). In a multidisciplinary setting, programs could be created to address specific cognitive strategies that parents can use to help them cope with stressful or difficult situations. Parents may also benefit from specific strategies on dealing with difficult behaviours that may manifest while working on developmental skills, such as toilet training or feeding.

Antonovsky (1979) believed that the development of one’s SOC was also based upon the extent to which one’s life experiences were characterized by consistency and participation in shaping outcomes. Occupational therapists already use the process of enablement to encourage clients to participate in shaping their own lives (Canadian Association of Occupational Therapists, 2002). This process of enablement can be used with parents within a family-centered approach. Further emphasis can be placed on encouraging parents to participate in decision making and to act as collaborators throughout the intervention or rehabilitation process if their SOC is identified as being low. This process will help to facilitate a parent’s sense of meaningfulness from their experience. The SOC concept highlights how each family and each parent in the family whom a therapist encounters is unique, as each parent holds a different worldview, therefore, coping and adapting differently to their child’s disability. The SOC concept encourages paediatric occupational therapists to strive towards empowering parents so that they have the tools to help advance their child’s development.

Conclusion

When an occupational therapist works with a child with a disability, a partnership is formed with that child and his or her family. This partnership may last the length of a two-day assessment or over years in an early intervention setting. Occupational therapists are often keenly aware of the burdens and stressors that families face. The SOC is a framework that paediatric occupational therapists can use to identify the strength of a parent’s SOC and, when deemed to be low, help create a process for enhancing resilience. Research has demonstrated that there is a relationship between parental stress and a low SOC. Although all parents may face stress initially when their child is born, those parents with a high SOC over time are able to see their situation as challenging and manageable, versus parents with a low SOC, who may have difficulties selecting a coping mechanism to help them manage the stressors they encounter.

While the research examining the use of therapeutic interventions in paediatric settings to alter a parent’s SOC is scarce, there is emerging literature that suggests therapists can have an impact on parents’ SOC and, in turn, on the stresses that they are experiencing. Using the SOC Scale (SOC-29, SOC-13) can be a starting point for helping occupational therapists identify how they may focus their interventions and recommendations or for determining whether they may need to refer parents on to more services. Pediatric occupational therapists structure their practice around promoting the development of children. By helping families to raise or maintain a high SOC, therapists are also working to help parents feel confident in their abilities as parents and, therefore, to experience less stress. Parents may then feel better equipped to work with therapists on their child’s developmental goals.

Key Messages

- SOC provides a framework for occupational therapists describing how a person’s view of her- or himself and the world is critical in understanding how they may adapt to a life stressor.
- Research has demonstrated that there is a relationship between parental stress and a low SOC.
- Addressing the three components of SOC (comprehensibility, manageability, and meaningfulness) in occupational therapy intervention can facilitate parent SOC, better enabling parents of children with disabilities to manage stress.
Acknowledgements

The authors would like to express their gratitude to Dr. Lyn Jongbloed for reviewing an earlier draft of this paper.

References


