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Introduction

Improvements in treatment and health technologies have led to a substantial rise in life expectancy in children and adolescents with chronic illness. It is now estimated that up to 90 % of children with chronic illness will survive into adulthood (Pai & Schwartz, 2011). While these improvements are welcome, they bring with them new challenges for hospital services. Not least is the need for new ways of working with patients, in order to take into account the unique developmental and psychosocial needs of adolescents and young adults with chronic conditions (Sawyer, Drew, Yeo, & Britto, 2007).

Traditional care has been based on identification of health deficits and providing interventions to alleviate or resolve those deficits (Rotegard, Moore, Fagermoen, & Ruland, 2010). While such an approach to care remains legitimate it is insufficient in addressing health needs (Burns, 2009).

Successful coping with chronic illness requires the adolescents to take control of their own care and management. Developmentally adolescence is itself a challenging time as the young person moves from childhood to adulthood. This life stage transition has its own stresses which can be exacerbated by the accompanying stresses associated with their condition.

A crucial period for the adolescents is when they move from pediatric care to adult services. Successful transition is essential for the maintenance of health. It has been well-established that adolescents are at greater risk of non-adherence than children and adults. The consequences of a failure to successfully transition can be seen in transplant services: Up to a third of adolescents transitioning from pediatric to adult services have experienced rejection within 3 years (Beard, 2013).

There is a paradox to non-adherence in adolescents: Whereas it is medically dangerous and therefore needs to be prevented or corrected, non-adherence to a certain extent makes sense psychologically, as adolescents try to develop a sense of self that is separated from their parents and that is not dominated by illness. Thus, the experience of non-adherence, although particularly risky for certain groups of young patients, may from the psychological point of view be seen as a step in the process of internalizing motivation to self-care. When faced with the occurrence of non-adherence behaviors in their patients, practitioners need to carefully and respectfully investigate what it means for a particular patient to be non-adherent, as this apparently destroying behavior may in fact reveal attempts to construct one's self psychosocially and developmentally (Wolff, Strecker, Vester, Latta, & Ehrich, 1998). The need to establish a continuous and valuable sense of self is probably the most important developmental challenge met by adolescents (Luyckx, Goossens, & Soenens, 2006).

Adolescents with a chronic condition have to cope with an extra challenge: The psychological challenge of

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integrating one's identity as an ill person with other dimensions of one's identity, in order to experience life and illness as challenges worth living. Indeed, risks may arise and translate into self-management difficulties when an adolescent's identity as an ill person is overshadowing other identities (Tilden, Charman, Sharples, & Fosbury, 2005).

Illness centrality refers to the extent to which the illness experience plays a central or peripheral role in an individual's self-definition (Helgeson & Novak, 2007). There is some evidence that illness centrality is detrimental to well-being (Helgeson & Novak, 2007; Park, Bharadwaj, & Blank, 2011), psychosocial adjustment to illness (Morea, Friend, & Bennett, 2008), and the development of self-care abilities (Adams, Pill, & Jones, 1997; Helgeson & Novak, 2007; Tilden et al., 2005). The successful integration of various identities into a consistent sense of self should therefore be acknowledged as an important developmental task which healthcare providers should support in adolescent patients.

In order to do so, healthcare practitioners need to truly embrace the health promotion orientation. This means that healthcare providers, as Antonovsky puts it, need to "focus on salutary rather than risk factors, and always see the entire person (or collective) rather than the disease (or disease rate)" (Antonovsky, 1996). In other words, healthcare providers should acknowledge and support their young patients' self-care needs in the three dimensions that were identified by Kickbusch (1989) as defining self-care in the broader perspective of health promotion (as opposed to narrow disease management and prevention): psychosocial life, general health, and responses to illness demands (Kickbusch, 1989). Whereas self-management usually refers to developing autonomy in managing one's condition and treatment in everyday life, self-care is a broader concept, which encompasses not only autonomous management of medical and treatment-related tasks, but also the capacity to attend to one's broader psychosocial needs (Pelicand, Fournier, Le Rhun, & Aujoulat, 2015). In other words, practitioners need to help people "take greater control of the non-medical determinants of their own health" (Herbert, Visser, & Green, 1995). This is precisely the aim of clinical health promotion (Herbert et al., 1995). However, the results of a recent literature review in the field of pediatric diabetes show that most studies on self-care fail to address the psychosocial dimension of it (Pelicand et al., 2015). Parents should be encouraged to make consistent demands and provide consistent support not only with medical aspects, but also with regard to psychosocial issues (including relations with peers) that matter to their adolescent children.

How Do Salutogenic Concepts Relate to the Needs of Adolescent Patients with Chronic Conditions?

The process of developing autonomy and responsibility for treatment and psychosocial life-related tasks needs to be supported in developmentally appropriate ways. This entails counseling parents about what is developmentally appropriate at different ages in terms of shared management of a pediatric condition (Bell et al., 2008; Kieckhefer & Trahms, 2000). A key factor involved in a successful transition process, is that of a good collaboration between the young patients, their parents, and the whole healthcare team in supporting the young patients' growing self-management capacity (Modi et al., 2012). As van Staa et al. put it, transition programs need to "focus on strengthening adolescents' independence without undermining parental involvement" (van Staa, Jedeloo, van Meeteren, & Latour, 2011).

The importance of family factors has been evidenced in a systematic literature review which examined the factors influencing the development of a strong sense of coherence in adolescents (Rivera, García-Moya, Moreno, & Ramos, 2013). Antonovsky's sense of coherence is a three-dimensional construct, that he operationalized with a 29-item scale (and a shorter 13-item scale) to measure a general life-orientation which encompasses a sense of comprehensiveness, manageability, and meaningfulness (Antonovsky, 1993). Scoring high on the sense of coherence has been repeatedly found to associate with better health outcomes (Eriksson & Lindstrom, 2005, 2006).

As they transition from parentally controlled care to self-managed care and from pediatric care to adult care, chronically ill adolescents are facing many challenges, one of them being to find their own ways of fitting their medication intake schedule into their daily life-schedules.

However, on their road to independence, adolescents and young adults with chronic conditions do not face only cognitive and behavioral challenges related to the understanding and management of their condition. They also face important psychological and spiritual challenges, one of them being to make sense of their own medical history, in order to develop a sense of meaning and purpose for their lives (Aujoulat et al., 2014). This three-faceted -cognitive, behavioral, and spiritual- challenge is well-captured in Antonovsky's aforementioned three-dimensional construct of the sense of coherence (Antonovsky, 1996; Antonovsky & Sagy, 1986).

What makes the sense of coherence unique among other health outcome measures, is that it combines the dimension

of meaningfulness to that of control, a psychological construct generally associated with successful processes of adaptation and coping (e.g., self-efficacy, healthlocus of control, etc.). Indeed, whereas great emphasis is usually put on the importance of cognitive and behavioral factors to better control one's condition, the dimension of meaningfulness is of utmost importance to those who experience chronic illness (Hydén, 1997; Mathieson & Stam, 1995; Toombs, 2013). People with chronic conditions often struggle with conflicting priorities of managing illness and containing symptoms while engaging in activities that are congruent with valued social roles and positive identities (Townsend, Wyke, & Hunt, 2006). Meaningfulness is a very important and yet too often neglected issue in prevalent theorizations of chronically people's empowerment processes (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008; Aujoulat, Young, & Salmon, 2012). Findings from a qualitative study with patients with advanced cancer support this hypothesis with some insight from in-depth interviews that meaning is an important part of an adaptive process towards developing a strong sense of coherence and a positive sense of self (Lethborg, Aranda, Bloch, & Kissane, 2006). Moreover, a recent study on emerging adults provides evidence of a relationship between meaning and psychosocial adaptation, with young people scoring high on the presence of meaning in their lives showing the most adaptive psychosocial functioning (Dezutter et al., 2014).

In light of the challenges faced by young people who grow into adulthood with a chronic condition, Antonovsky's sense of coherence construct potentially provides a general framework to set directions toward developing autonomy-supportive self-management interventions in health promotion-oriented healthcare settings. In other words, we hypothesize that patient education interventions need to focus on three types of objectives if they are to strengthen the capacity to self-care in adolescent patients: that of (1) developing sufficient and adequate information in general health and disease-related issues, (2) finding the necessary resources to successfully manage one's condition while pursuing one's own life goals, and (3) developing a valuable and continuous sense of self and purpose.

On the other hand, the sense of coherence construct may be seen also as a valuable patient outcome, to assess the impact of patient education interventions. As the sense of coherence questionnaire is generic and has been translated and validated in many languages, it is potentially a valuable instrument to enable comparisons across different countries with different healthcare systems. In the following paragraphs, based on the findings of a scoping literature search, we will look at how the sense of coherence has been used in research on adolescents with chronic conditions. More specifically, we will look at how the sense of coherence may be associated with important

medical as well as psychosocial outcomes that are relevant to adolescent health and development: (1) adherence and self-care; (2) general health behaviors; (3) perceived health, quality of life and general well-being; and (4) a sense of self and identity.

Sense of Coherence in Relation to Adherence and Self-Care

We hypothesized that a strong sense of coherence in young people with chronic conditions would be an indicator of successful self-management work, and searched the literature for evidence of a relation between scoring high on sense of coherence and developing specific self-care abilities, including motivation to self-care and treatment adherence.

However, studies looking at the impact of the sense of coherence on adherence or self-care in chronically ill pediatric patients are scarce. In a study involving 123 adolescents with cystic fibrosis, scoring higher on the sense of coherence was significantly associated with self-care agency (Baker & Denyes, 2008). With reference to Orem's theory of self-care (Orem, 1985), the authors defined self-care agency as encompassing health knowledge, decision-making capacity, valuing of and attention to health, as well as having enough energy to care for oneself (Baker & Denyes, 2008).

Our search for other studies regarding possible associations between sense of coherence and adherence or self-care yielded mixed results. Moreover, although some of them may have included late adolescents or young adults, none of the identified studies was specifically carried out in pediatric settings. We believe however that the following results are worth reporting, so as to further confirm the relevance of our hypothesis that it is worth investigating the sense of coherence in relation with self-management issues in adolescent patients.

Although some of the studies carried out with adult patients did not confirm the hypothesis that sense of coherence is related to higher adherence rates or self-management issues (Corless et al., 2006; Kamwendo, Hansson, & Hjerpe, 1998), a significant relationship between the sense of coherence and adherence was evidenced in the field of HIV, where less adherent patients were found to score lower on the sense of coherence (Cederfjall, Langius-Eklöf, Lidman, & Wredling, 2002). Conversely, a significant relationship between good adherence and higher scores of sense of coherence was found in relation to hypertension (Nabi et al., 2008), as well as type 1 and type 2 diabetes (Cohen & Kanter, 2004). Moreover, the sense of coherence was found to impact positively one's motivation to self-care, in patients with HIV (Sodergard, Halvarsson, Lindback, et al., 2006; Sodergard, Halvarsson, Tully, et al., 2006), patients

with tuberculosis (Corless et al., 2006), and patients needing to attend a cardiac rehabilitation program after infarct (Breuer & Etienne, 2001).

Sense of Coherence in Relation to General Health Behaviors

Self-management of a chronic condition entails not only monitoring symptoms, attending to health visits and taking medications as prescribed. Chronically ill adolescents also need to develop a positive attitude toward their health in general, and avoid risky health behaviors, as these, precisely because of their chronic condition, might deteriorate their health even more than that of their healthy peers with similar behaviors (Sawyer, Drew, & Duncan, 2007; Sawyer, Drew, Yeo, et al., 2007). As part of a general self-care issue, we therefore searched the literature for some evidence of how the sense of coherence relates to general health behaviors in adolescents with or without chronic conditions. We hypothesized that the sense of coherence would have a protective effect for general health behaviors.

Indeed, a prospective cohort follow-up study in Finland evidenced that a strong sense of coherence in 15-year-old adolescents was significantly associated with better social competence and less drinking and smoking (Mattila et al., 2011). However, no such evidence emerged from another Finnish study, conducted in a sample of young students followed up for 3 years (Kuuppelomäki & Utriainen, 2003). The association between the sense of coherence and two major risk behaviors—drinking and smoking—that represent a very high burden in terms of incidence and prevalence of non-communicable diseases worldwide, is therefore inconsistent and needs further investigation.

We further looked at associations between the sense of coherence and physical activity, which is an important protective factor for people's health. Positive and reciprocal associations between the sense of coherence and experience of physical activity, as well as attitude to physical education were found in a study in Sweden. This study involved 301 adolescents who were assessed using the SOC-13 questionnaire (Sollerhed, Ejlertsson, & Apitzsch, 2005). Moreover, there is some evidence that a health-related physical education program that, congruently with a salutogenic approach, encourages adolescents to pursue self-determined and individualized physical activity objectives, may significantly impact levels of physical health and sense of coherence (Bronikowski & Bronikowska, 2009). Likewise, in patients with psychiatric disabilities and simultaneous somatic conditions, repeated lifestyle interventions that took place over a significant time-period were found to improve both physical health and the sense of coherence (Forsberg, Björkman, Sandman, & Sandlund, 2010).

Finally, we looked for evidence regarding sense of coherence and medication use. Inappropriate use of medicines in adolescents is probably an under-investigated issue which, as suggested by Andersen et al. could be regarded as part of a cluster of risk behaviors among adolescents (Andersen, Holstein, & Hansen, 2006). There is some evidence from a study in Denmark that lower sense of coherence scores in adolescents with frequent headaches are associated with more medication use by adolescents, suggesting that adolescents may use pain relief-medication as an inappropriate coping mechanism (Koushede & Holstein, 2009). This raises a double concern: Chronically ill patients may experience higher levels of potentially psychosomatic symptoms on the one hand, and have more readily access to medication as a way of coping with such symptoms on the other hand.

Sense of Coherence in Relation to Perceived Health, Quality of Life, and Well-Being

Most findings on how sense of coherence relates to perceived health, quality of life and well-being in adolescents with chronic conditions originate in studies conducted by a Belgian research team at Catholic University of Leuven (<http://www.kuleuven.be/switch2/i-DETACH.html>). This team initiated a comprehensive research project aimed at understanding and supporting the transition process of adolescents and young adults with congenital heart disease (CHD). Using the SOC-13 questionnaire, they assessed the sense of coherence in 429 young people with CHD (14–18 years), and found that higher sense of coherence scores and better physical health explained better quality of life in patients, compared to healthy controls (Apers, Moons, et al., 2013); and that sense of coherence at time 1, in a longitudinal study over a 9-month period predicted several domains of general and disease-specific perceived health at time 2 (Apers, Luyckx, et al., 2013). Positive associations between the sense of coherence scores and quality of life measures were evidenced also in other samples of adolescents with CHD, for instance in Japan, in a sample of 172 adolescents aged 12–18 (Nio, 2010); in Australia, in a sample of 114 patients aged 12–20 (Wang, Hay, Clarke, & Menahem, 2014); or in Germany, in a sample of 770 adolescents aged 14–17 (Neuner et al., 2011). The SOC-13 questionnaire was used in all of these studies, except for Neuner et al.'s study, where the sense of coherence was measured with a shortened version, the SOC-L9 questionnaire (Schumacher, Wilz, Gunzelmann, & Braehler, 2000). Moreover, positive associations between the sense of coherence and quality of life measures were found also in a sample of long-term survivors of Hodgkin's lymphoma (Wettergren, Björkholm, Axedorph, & Langius-Eklöf, 2004).

A strong correlation between the sense of coherence measures and emotional health outcomes, such as state anxiety and state depression measures, was evidenced in a survey which included 1183 school children aged 13–19 in Norway (Moksnes, Espnes, & Lillefjell, 2012). A study involving a clinical sample of adolescent female psychiatric patients and a non-clinical sample found similar results, with adolescents scoring high on the sense of coherence having also less anxiety or depressive symptoms (Henje Blom, Serlachius, Larsson, Theorell, & Ingvar, 2010). This led the authors to question whether the sense of coherence mirrors anxiety and depressive symptoms, rather than measuring a distinct construct.

Sense of Coherence in Relation to Self and Identity Issues

In a pioneering work involving 194 young adults with type 1 diabetes, Luyckx et al. demonstrated that scoring high on the sense of coherence was associated with processes of identity development (Luyckx et al., 2008) and that a sense of adulthood, i.e., perceiving oneself as an adult, was associated with better glycemic control and better coping with illness demands (Luyckx, Moons, & Weets, 2011). In another study involving 48 diabetic patients aged 12–18 (Ho, Lee, Kaminsky, & Wirrell, 2008), scoring higher on self-concept as assessed by the Piers-Harris Children's self-concept (Piers & Harris, 1984), correlated with patients' more positive attitudes toward their condition, independently of the severity of their condition.

Other authors have tackled indirectly the relation between the sense of coherence and a sense of self and identity, through constructs of self-esteem or stigmatization. In a sample of young people with uncomplicated epilepsy (Gauffin, Landtblom, & Rätty, 2010), sense of coherence declined in some young adults who were still experiencing epilepsy seizures, as compared with young adults who were free of seizures. Moreover, seizures impacted on self-esteem as well, an important attribute of a sense of self and identity. These findings echo some previous findings in a sample of 200 people with current and past mental health problems, where perceptions of sense of coherence and self-esteem were negatively impacted by experiences of feeling rejected (Lundberg, Hansson, Wentz, & Bjorkman, 2009).

Summary of Main Findings, Research Gaps, and Implications for Practice

Moons and Norekval hypothesized that a strong sense of coherence may be a “pathway for improving the quality of life in children who grow up with chronic diseases” (Moons

& Norekval, 2006). According to these authors, a strong sense of coherence may be shaped as children successfully develop mechanisms to cope with their disease and the stressful situations that are inevitably encountered when growing up with a chronic condition. Unfortunately, our literature search revealed a paucity of research specifically looking at how the sense of coherence relates to major challenges that are faced by adolescents transitioning to adulthood while having to cope with the demands of a chronic condition.

One of these challenges is that of developing autonomous self-care behaviors while adhering to prescribed regimens, and developing a continuous and valuable sense of self, shaped through meaningful personal and social experiences. Although identity development is a prominent developmental task during adolescence and young adulthood (Arnett, 2000), the impact of chronic illness on identity development, and how this shapes the development of the sense of coherence or how the sense of coherence is influenced by potentially impaired or enhanced processes of identity development, remains an under-investigated issue. The pathways between SOC, identity work, and coping with illness demands are important issues which deserve further attention, in order to help clinicians elaborate developmentally appropriate health promotion and patient education interventions for young people who face the challenge of growing up with chronic conditions.

Our main recommendation is that adolescents need to be helped to cope with the concomitant and interrelated developmental and self-management challenges. In order to do so, professional and family caregivers need to develop practices that are sufficiently autonomy-supportive. Such practices must acknowledge the adolescents' need to be addressed not only about disease and treatment-related issues (i.e., self-management issues), but also about general health issues (including communication about protective as well as risky health behaviors) and psychosocial issues (including awareness of their illness experience and the development of psychosocial competences).

Moreover, such practices need to acknowledge the adolescents' self-determination need, by encouraging participation and providing choice whenever it is possible (Aujoulat, Janssen, Pire, Mansveld, & Reding, 2013). Last but not least, adolescents need to be trained to develop self-regulation skills, which include the capacity to define specific health objectives, and identify relevant implementation and feedback strategies on the one hand (Maes & Karoly, 2005), and to develop sufficient stress regulation competency on the other hand (Hampel, Rudolph, Stachow, & Petermann, 2003).

Although there is some evidence that the sense of coherence correlates positively with emotion awareness and negatively with somatic complaints in school children

(Jellesma, Rieffe, Terwogt, & Kneepkens, 2006; Jellesma, Rieffe, Terwogt, & Westenberg, 2011), how the sense of coherence relates to emotion regulation in young people who grew up with a chronic condition and transition to adulthood is yet an under-investigated issue. Following increasing evidence that emotional competence plays an important role in the development and maintenance of health (Brown, Ryan, & Creswell, 2007), it has been recommended that mindfulness interventions be implemented in healthcare settings (McCabe Ruff & Mackenzie, 2009).

To adopt a salutogenic perspective of health, i.e., focusing on strengthening health assets rather than risk factors, as was recommended by Antonovsky (Antonovsky, 1996), is congruent with evidence from evaluations of positive psychology interventions (Sin & Lyubomirsky, 2009), as well as recommendations from youth development models (Blum, 1998; Kia-Keating, Dowdy, Morgan, & Noam, 2011). Moreover, recommendations on how to put salutogenesis into practice for patients with chronic conditions in hospital settings have been issued in relation with the development of the concept of Health-Promoting Hospitals (Pelikan, Krajic, & Dietscher, 2001). A synthesis of the evidence regarding salutogenesis in hospitals is presented in Chap. 27 of this book (Dietscher, Winter, Pelikan. Salutogenesis in hospitals), as well as a synthesis on the sense of coherence in adolescents by Brown-Lewensohn et al. in Chap. 14

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