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Asthma and Health Related Quality of Life in Childhood and Adolescence

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1. Introduction

Asthma is the most frequent chronic disorder in childhood. Asthma puts a serious burden on children's health related quality of life, despite the availability of effective and safe treatment (Dalheim-Englund et al., 2004; Global Initiative for Asthma, 2010; Masoli et al., 2004; Mohangoo et al., 2005). The overall goal of asthma management is to achieve optimal disease control and health related quality of life improvements (Bateman et al., 2007; Pedersen et al., 2011). The World Health Organization has defined the term health related quality of life as the individual's perception of their position of life in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns (World Health Organization, 1993). The own perception is important because it emphasises that these are the impairments that patients themselves consider important. As in most medical conditions, the correlation between asthma control and health related quality of life is modest. Therefore, the impact that asthma has on a patient's health related quality of life cannot be inferred from the conventional clinical measures of asthma (e.g. spirometry); it must be measured directly (Juniper et al., 1999a, 1999b).
During the past decade, the use of health related quality of life as an essential outcome measure of childhood asthma treatment and management has increased (Merikallio et al., 2005). This review summarises recent literature on: 1) health related quality of life instruments for childhood asthma, 2) the impact of childhood asthma on children's health related quality of life, 3) the impact of children's asthma on caregiver's health related quality of life and 5) factors associated with health related quality of life in childhood asthma.

2. Health related quality of life instruments and childhood asthma

Several feasible, reliable and validated pediatric health related quality of life questionnaires are standardised and available to measure health related quality of life in asthmatic children (Fiese et al., 2005; Raat et al., 2006). Both generic and asthma-specific questionnaires are used to measure health related quality of life in school aged children. Generic health related quality of life questionnaires intend to measure all dimensions of health-related quality of life (Raat et al., 2006). Frequently applied generic health related quality of life questionnaires are: the Child Health Questionnaire (CHQ) (Gorelick et al., 2003), the Pediatric Quality of Life Inventory (PedsQL) (Varni et al., 2005), the TNO-AZL (Preschool) Children's Quality of Life questionnaire (TAPQoL/TACQoL) (Bunge et al., 2005), the Infant-Toddler Quality of

Life (ITQOL) questionnaire (Spuijbroek et al., 2011) and the KIDSCREEN/DISABKIDS questionnaires (Petersen et al., 2005). Asthma-specific health related quality of life questionnaires focus on those dimensions that are likely to be affected by asthma disease or treatment. The most prominent asthma-specific health related quality of life questionnaires are the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) (Juniper et al., 1996; Raat et al. 2005), the How Are You (HAY) (Le Coq et al., 2000) instrument and the Childhood Asthma Questionnaire (CAQ) (Christie et al., 1993).

If children are unable to report about their own experience reliably, parents are appropriate sources of information about health related quality of life (Petsios et al., 2011). One study suggests that fathers may be better proxy reporters than mothers (Petsios et al., 2011). The correlation between child and parent reported quality of life improves with increasing age of the child (Annett et al., 2003). Although the agreement between child self-report and parent proxy report on health related quality of life has been showed as satisfactory, according to Petsios *et al*. (2011), parents may overestimate health related quality of life of their children with asthma. This has to be taken into account when interpreting results from parent reported health related quality of life questionnaires, in comparison with child self-reports.

The PAQLQ is the most frequently used disease-specific health related quality of life instrument with regard to childhood asthma. Therefore, using this instrument has the benefit for researchers that results can more easily be compared with previous findings. However, using the existing health related quality of life instruments may have some limitations. A recent study has investigated whether asthma-specific health related quality of life questionnaires actually include all relevant aspects of asthma-specific health related quality of life for children with asthma (Annett et al., 2003). They have found disagreement between distinct health related quality of life questionnaires on components of asthma-specific health related quality of life: only some components of the asthma symptoms domain and of the activity limitations domain are part of all questionnaires. Furthermore, according to Van den Bemt *et al.* (2010), not all essential components of asthma-specific health related quality of life, according to childhood asthma, are part of existing asthma-specific health related quality of life questionnaires.

When classifying health related quality of life questionnaires into standardised and individualised health related quality of life instruments, another limitation is revealed. In standardised health related quality of life instruments the questions and range of answers are predetermined and the same for all patients. As opposed to standardised health related quality of life instruments, individualised health related quality of life instruments allow patients to define their quality of life in relation to their goals and expectations. Carr & Higginson (2001) conclude that standardised health related quality of life questionnaires have limited ability to capture the health related quality of life of individual asthma patients.

The most appropriate approach to measure health related quality of life in asthmatic children would be to use a combination of parental and self-reports of both generic and asthma-specific health related quality of life by validated questionnaires (Raat et al., 2006). Whether such health related quality of life measures are truly patient centred and to what extent they actually represent the quality of life of individual or groups of asthmatic children should always be taken into account when one interprets study results (Carr & Higginson, 2001).

3. Impact of asthma on children's health related quality of life

Asthma might have physical, emotional and psychosocial impact on children's lives (Grootenhuis et al., 2007; Juniper, 1997; Merikallio et al., 2005; Sawyer et al., 2004). Important components of health related quality of life are the effects on, and consequences of asthma on peer relationships (e.g., being bullied), the dependence on medication, shortness of breath, cough, limitations in activities and limitations due to the response on cigarette smoke exposure (Van den Bemt et al., 2010). Compared to preschool children without asthma symptoms, preschool children with asthma symptoms have significantly lower health related quality of life scores for lung problems, sleeping, appetite, communication and positive mood health related quality of life scales (Mohangoo et al., 2005).

Most studies have focused on severity of symptoms to examine the impact of asthma symptoms on children's health related quality life; the results are conflicting (Everhart & Fiese, 2009). For example, disease severity is not consistently associated with children's health related quality of life in some studies (Erickson et al., 2002; Vila et al., 2003), whereas others report that children with moderate or severe asthma have a worse level of functioning in several domains of their health related quality of life compared to children with mild asthma (Annett et al., 2001; Merikallio et al., 2005; Mohangoo et al., 2007, 2011; Sawyer et al., 2000) suggesting there may be a 'dose-response' relationship between the frequency and intensity of children's asthma symptoms and their health related quality of life. Mohangoo *et al*. (2007, 2011) evaluated health related quality of life in infants and adolescents with asthma-like symptoms, such as attacks of wheezing and shortness of breath (Mohangoo et al., 2007, 2011). Asthma-like symptoms during the first year of life are associated with impaired health related quality of life at the age of 12 months. Also, the presence of at least four wheezing attacks during the past year was associated with impaired adolescents' health related quality of life. Frequent wheezing attacks mostly affect adolescents' general health, bodily pain, self esteem and mental health (Mohangoo et al., 2007). Previous studies have also found that wheezing attacks more often have a physical impact than a psychosocial impact (Merikallio et al., 2005).

As described earlier, one of the main goals of asthma management is to achieve good asthma control. Asthma control has been defined as the minimisation of night time and daytime symptoms, activity limitation, rescue bronchodilator use and airway narrowing (Global Initiative for Asthma, 2010). Poorly controlled asthma symptoms impair health related quality of life in children (Guilbert et al., 2011). An important issue is whether proper asthma management improves quality of life in asthma patients, and whether poor health related quality of life makes disease management harder. Studies have found that poor health related quality of life is predictive of subsequent asthma-related emergency department visits, which implicates poor asthma control (Magid et al, 2004). Pont *et al*. (2004) show that proper asthma management improves health related quality of life.

In short, children experience asthma as an interruption in daily life that influences them physically, emotionally and socially.

4. Impact of children's asthma on caregiver's health related quality of life

With childhood asthma, the family and particularly the primary caregiver may face a considerable burden. While there are several questionnaires for assessing parental/caregiver's health related quality of life not directly related to asthma (Osman &

Silverman, 1996), there is only one instrument to examine the specific impact of childhood asthma on parental/caregiver functioning: The Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) (Juniper et al., 1996).

Whereas some studies find no association between caregiver's health related quality of life and children's asthma symptoms (Annett et al., 2003), duration of asthma illness and asthma pre-treatment severity (Vila et al., 2003), other studies report that caregiver's and child's health related quality of life are significantly associated with each other (Dean et al., 2009, 2010; Garro, 2011; Halterman et al., 2004). Halterman *et al.* (2004) find that higher symptom levels with regard to childhood asthma are associated with lower parental health related quality of life. Further, when children's symptoms improve, parents show higher health related quality of life.

It should be considered how childhood asthma affects caregiver's health related quality of life. Caregivers of asthmatic children appear to be more compromised in their resistance to stress, mood, emotional stability, amount of spare time and leisure activities (Garro, 2011). Caregivers of children with uncontrolled asthma report significantly higher absenteeism than their controlled counterparts (Dean et al., 2009, 2010).

Both caregiver's health related quality of life, caregiver's perception of the child's asthma symptoms, and the child's health related quality of life may be important in diagnosis and control of established asthma in childhood (Skoner, 2002). While giving attention to the caregiver's health related quality of life, it should be taken into account that the profile of health related quality of life impairment is different in asthmatic children and in their parents (Farnik et al., 2010). Where activity limitation seems to be the most impaired domain in children, asthma symptom perception and emotional health appear to be the most affected health related quality of life domains in parents.

In addition to evaluation of the asthmatic child, the integral assessment of asthma requires the evaluation of caregiver's health related quality of life. Giving attention to caregiver's health related quality of life is needed in clinical practice in order to avoid possible interferences of the caregiver's distress in the optimization of child's asthma treatment outcomes (Majani et al., 2005).

5. Factors associated with health related quality of life in asthmatic children

As we described earlier, the frequency and severity of asthma attacks and effects of asthma management or treatment are associated with children's health related quality of life. Researchers have also investigated other variables in association to health related quality of life in childhood asthma (Annett et al., 2003; Erickson et al., 2002; Mrazek, 1992; Sawyer et al., 2000, 2001). Hospital admissions, absences from school, limitations of sport and other activities, sleeping problems (and fatigue) are associated with health related quality of life in asthmatic children (Mrazek, 1992). Erickson *et al.* (2002) show that both asthma morbidity and health related quality of life are related to socioeconomic status. Also, household income is most consistently associated with the health related quality of life of asthmatic children and their caregivers. Sawyer *et al.* (2001) report the impact of family functioning on health related quality of life in children with asthma. They have found that the degree to which children are upset by their asthma is related to general functioning of their families, and their symptom levels are associated with several dimensions of family functioning (Sawyer et al., 2000, 2001). Children living in families with more clearly defined roles, greater interest and concern for the well-being of each other and clearer rules have been

found to be less bothered by their asthma symptoms (Sawyer et al., 2000). A study by Annett *et al.* (2003) didn't find an association between health related quality of life of asthmatic children and family functioning, measured by the degree of cohesion among family members.

Results suggest that several factors may impact health related quality of life of asthmatic children. Important predictors of the health related quality of life of asthmatic children are socioeconomic status and family functioning. These findings implicate the need of specific attention to health related quality of life in asthmatic children from families with low socioeconomic status and poor family functioning.

6. Conclusion

Health care workers should be aware of the impact of asthma on children's life, their families and the factors associated with the health related quality of life of these children. Routine use of an health related quality of life questionnaire to evaluate health related quality of life in children with asthma symptoms and their caregivers should be recommended in health care. Specific application, for example, can be found in preventive child health care and in primary health care to prevent impairment of health related quality of life due to asthma symptoms and to realise adequate management of asthma symptoms. Attention should be given to health related quality of life in asthmatic children from families with low socioeconomic status and poor family functioning. Generally, a combination of parental and self-reports of both general and asthma-specific patient centred health related quality of life questionnaires should be applied. Further research should focus on which factors are responsible for the greatest burden on asthmatic children's health related quality of life and their caregivers' health related quality of life and how such risk factors should be prevented and managed.

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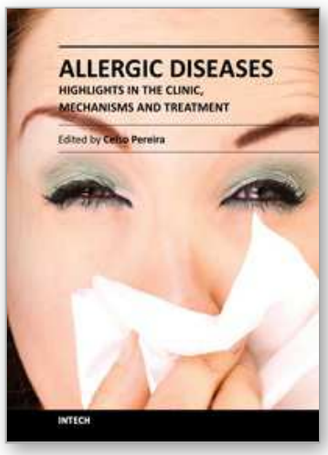

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