Parents with Asthmatic Children, Quality of Life

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Synonyms

Caregivers' health-related quality of life with asthmatic children; Caregivers' quality of life with asthmatic children; Parents' health-related quality of life with asthmatic children; Parental quality of life with asthmatic children.

Definition

Asthma is the most prevalent chronic health condition in childhood. The quality of life (QoL) of asthmatic children and their parents/caregivers has been increasingly acknowledged as an important outcome in pediatric asthma health care. Although children's QoL has been the main focus of research, scholars and clinicians in the field of pediatric chronic conditions have also started to take an interest in how parents perceive their own QoL. In this relatively new area of inquiry, research has conceptualized and assessed parents' QoL in diverse ways. Consequently, scientific literature on parents' QoL is heterogeneous, and a clear or consensual definition for this construct is still elusive.

Two main approaches have been developed to study the QoL of parents with children who have chronic conditions, including asthma. A generic approach has examined parents' QoL according to the universal definition provided by the World Health Organization, which is that QoL is a multidimensional construct covering the physical health, level of independence, psychological state, social relationships and interactions with the environment, as subjectively perceived by the individual embedded in a cultural context (The WHOQOL Group, 1998). A specific approach, which is applied in the majority of studies, has looked at the perceived impact of a child's disease and treatments on

Reference:
Crespo, C., & Silva, N. (2014). Parents with asthmatic children, Quality of life. In A. C. Michalos (Ed.), *Encyclopedia of Quality of Life and Well-Being Research* (pp. 4611-4618). Dordrecht, The Netherlands: Springer.

parents' lives. Within this approach, two lines of research can be distinguished. The first considers that all parents who have a child with a chronic condition, regardless of the specific diagnosis, face common circumstances, stress factors and reorganization needs. Within this line, Goldbeck coined the term "parental quality of life" as "a uniquely personal perception, denoting the way individual parents feel about the health status of their child and/or non-medical aspects of their lives" (p.1122, 2006). The second line focuses on the impact of having a child with a specific diagnosis such as asthma by examining how the characteristics related to a particular condition can impair parents' QoL. Across studies, authors have referred to this construct using the terms "parents' QoL" and "parents' health-related QoL", and these terms have sometimes been used interchangeably. A theory-driven conceptual clarification of these constructs and a consistent use of these terms would be advantageous for advancing this field of study. In addition to parents' QoL, a number of studies have referred to caregivers' QoL, which includes other family members who assume the primary role of providing informal health care to a child in the home context.

Description

Parents' QoL in the context of pediatric health conditions

The scientific study of the QoL of parents with asthmatic children emerged less than two decades ago and has received increasing attention in recent years due to the confluence of several factors. One of the most influential factors is the paradigm shift in the criteria used to evaluate medical outcomes. In addition to symptom control and other clinical indicators, typical evaluation endpoints, there has been an increase in the inclusion of patient-rated outcomes, such as generic QoL and specific health-related QoL, which are multidimensional constructs that include several areas of well-being and function, as reported by patients and observers (Bullinger, Schmidt, Petersen, & Ravens-Sieberer, 2006). In pediatric health conditions, including asthma, parents have long been considered privileged observers and important sources for reporting their children's QoL. Recently, there has been recognition of the importance of addressing the QoL of the parents/caregivers themselves, which is supported by the idea that the whole family is affected when a child has a

chronic health condition. Goldbeck (2006) found that parents of children with a chronic health condition, compared with parents of healthy children, reported a persistent impairment in most dimensions of perceived parental QoL. A study by Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag, and Grootenhuis (2008) reported that, when compared to parents of healthy children, parents of chronically ill children had lower health-related QoL, with 45% of parents at risk for health-related QoL impairments, including difficulties in sleep, vitality, social functioning, daily activities, and emotions.

One way to understand the negative impact of children's chronic conditions on parents' lives is through the concept of the burden of caregiving, which is defined as a caregiver's perceived responsibilities and limitations that are inflicted upon the self and the family (Canning, Harris, & Kelleher, 1996). For parents of chronically ill children, the tasks of parenting and caregiving go hand in hand as these parents are also the main informal health caregivers. Providing daily care to children is part of every parent's role, yet the high level of care required by a child with a chronic condition can become burdensome and interfere negatively with both the physical and psychological health of a caregiver, which contributes to a decreased QoL. In addition to the consequences related to the individual lives of parents, the burden of caregiving can have direct and indirect impacts on children's health and well-being. Parents are primarily responsible for managing their children's diseases. If parents experience high levels of distress and reduced QoL, they may face more difficulties when carrying out their informal caregiver roles, such as establishing links with health care providers, making decisions about treatments, and following medical prescriptions.

Specific issues for parents of children with asthma

Asthma is a disease characterized by the alternation of asymptomatic periods and exacerbation episodes marked by shortness of breath, coughing, wheezing, or chest tightness or by a combination of these symptoms. One distinctive characteristic of this condition is its unpredictable nature, which requires constant attention and vigilance from caregivers. Parents of asthmatic children face uncertainty because attacks interfere with the ability to breathe and can occur without warning (Dalheim-Englund, Rydström, Rasmussen, Möller, & Sandman, 2004). Another concern is related to

the long-term effects of this chronic condition, with parents worrying about their child's ability to live a normal life. Research exploring the burden experience described by parents of children with asthma identified the following major areas of distress: interference with activities (e.g., family- and work-related activities and other daily activities), emotional impact (e.g., worries and fears about the long-term effects of a child's medicine and feelings of helplessness), concerns over finances, social relationships, and medical and school support (Schulz, Dye, Jolicoeur, Cafferty, & Watson, 1994). The primary caregiver of a child with asthma needs to juggle a complex set of demands, including taking their child to medical appointments, implementing treatment protocols, buying and administering medications, being attentive to medications' side effects, monitoring symptoms on a daily basis and dealing with the child's asthma attacks, which can involve assessing the severity of the attack and deciding whether to use emergency medication or to make an emergency visit to the hospital. Consequently, it is desirable that parents establish clear communication with health care providers and educators to guarantee that their child's specific needs are met while the child is in school or day-care. Another responsibility that parents face is to protect their child from environmental triggers that elicit asthma attacks, which involves paying special attention to vacuuming and dusting the house and avoiding contact with pets and other allergen stimuli. Moreover, parents must conciliate these demands regarding the child's condition with their daily work and family life demands. With regard to work demands, literature has suggested that parents of asthmatic children are more likely to miss days at work than parents of healthy children (Dean, Calimlim, Kindermann, Khandker, Tinkelman, 2009) and to compromise their work capacity due to sleepless nights. With regard to family life demands, Crespo, Carona, Silva, Canavarro, and Dattilio (2011) argued that the experience of caregiver burden in at least one parent is easily spread to the whole family environment, as the stress and negative emotional reactions associated with this burden are likely to affect family dynamics.

Comparative research examining the QoL of parents of children with asthma, parents of healthy children and parents of children with other chronic conditions has yet to provide clear results. For example, Gau and collaborators (2010) in Taiwan found that mothers of children with asthma reported lower QoL in the physical domain than a group of women from the general population and

that no differences were found in the psychological, social relations, and environmental domains. Another study in the Netherlands (Hatzmann et al., 2008) showed that parents of children with asthma, together with parents of children with sickle cell disease and metabolic diseases, reported lower QoL in a sample that was comprised of ten different conditions and a healthy comparison group. Differences in QoL among these parental groups may be difficult to explain due to the distinctive characteristics of the conditions and the heterogeneity of the samples in terms of disease severity and control. The majority of research in pediatric asthma has taken another route, which is to understand parents' QoL within the specific context of asthma, with the aim of identifying influencing factors and consequences for both parents and children.

Measures and measurement topics

Researchers assessing parents' QoL have endorsed different approaches and, consequently, have used different measures to examine this construct in quantitative empirical studies (see Definition section). Studies adopting a generic approach to parents' QoL have used assessment instruments that are validated for the general population and do not account for the fact that the respondent has a particular condition, such as being the parent of a child with a chronic condition. One example is the use of the World Health Organization Quality of Life (WHOQOL) assessment questionnaire (The WHOQOL Group, 1998) which, in its long version, covers the following six domains: physical, psychological, level of independence, social relationships, environment, and spirituality. This questionnaire has been used in studies aimed at explaining factors linked to QoL (e.g., Crespo et al., 2011) and comparing the QoL of parents with asthmatic children with the general population's QoL (e.g., Gau et al., 2010). The majority of studies, however, have adopted a disease-specific approach, i.e., measuring the impairment associated with being the parent of a child with a chronic condition. For instance, the Ulm Quality of Life Inventory for Parents (Goldbeck, 2006) assesses how having a child with a chronic condition affects different aspects of parents' lives. With regard to asthma-specific measures, the most widely used instrument is the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) developed by Juniper and colleagues in 1996 (Juniper et al., 1996). This 13-item questionnaire assesses how a child's asthma has affected the

caregiver's QoL on a scale from 1 to 7, in which 1 represents severe impairment. In addition to an overall score, this questionnaire provides scores for two dimensions: emotion and activity limitations. One example of the emotion dimension, which consists of 9 items, is the following: "During the past week, how worried or concerned were you about your child's performance during normal daily activities?". The activity limitations dimension includes 4 items, with one example being the following: "During the past week, how often did your child's asthma interfere with your job or work around the house?". Authors of this questionnaire reported its ability to detect changes over time in the QoL of parents of children with asthma and its reliability to detect different degrees of QoL impairment among caregivers. Therefore, it is considered a good evaluative instrument for clinical trials and a discriminative instrument for use in cross-sectional surveys.

There are advantages and drawbacks when using either a generic or disease-specific approach to measure parents' QoL. On one hand, disease-specific instruments focus on areas of functioning that are relevant for asthma; therefore, they can be more sensitive to small but relevant changes, namely in health status, symptom control and functional impairments associated with the disease (Juniper et al., 1996; Vila et al., 2003). Generic QoL instruments, on the other hand, may be more sensitive regarding the psychological state of the parents, which can be influenced by the interaction of different types of factors. Deciding which instruments to use is dependent upon a study's theoretical framework and objectives. Adopting measures assessing generic QoL or parents' impairments that are associated with chronic conditions in general may be useful within a non-categorical approach, which privileges common shared experiences across parents of children with different chronic health conditions. Endorsing a disease-specific strategy may answer specific asthma-related questions within a categorical approach, which examines the idiosyncratic impairments associated with a specific disease. These approaches are not mutually exclusive, and can complement each other to provide a deeper understanding of asthma in the wider context of chronic conditions.

Factors influencing QoL of parents of children with asthma

One factor that can affect parent's QoL is asthma's severity and control. Currently, links between asthma severity and parents' QoL have not been clearly identified, with some studies finding

that higher severity is associated with lower QoL and others finding no significant association (e.g., Everhart, Fiese, & Smyth, 2008). This inconsistency in results may be due to the different methods used to measure both asthma severity (e.g., parent's perception, clinician's assessment, diary ratings of symptoms, and examination of pulmonary function) and parents' QoL, as well as to the heterogeneity of the samples in terms of participants' variability across the spectrum of asthma severity. With regard to asthma's specific QoL impairments, the majority of studies using the PACQLQ measure have found a link between lower parental QoL and asthma severity according to asthma symptoms diaries (e.g., Stelmach et al., 2011), parents' reports of symptoms (e.g., Everhart et al., 2008; Walker et al., 2008) and symptom changes (e.g., Juniper et al., 1996). When clinical parameters such as pulmonary function are considered, the results are less clear, with some studies reporting weak correlations and others reporting no association with parents' QoL. More research is needed to clarify these results, although it has been suggested that variability in disease symptoms, rather than static indicators such as pulmonary function, is more likely to influence parents' QoL in the context of a condition characterized by unpredictability (Erickson et al., 2002).

Furthermore, studies report that parents show more impaired QoL when their children's asthma is uncontrolled, (e.g., Dean et al. 2009; Stelmach et al., 2011). One mechanism through which uncontrolled asthma may affect parents' QoL is via its negative influence on the parental work domain, with research showing that parents with children with uncontrolled asthma missed more days at work than parents with children with controlled asthma (Dean et al., 2009). Additionally, parents' QoL scores were negatively linked to the number of missed days at work (e.g., Walker et al., 2008). Given that parents are responsible for their children's informal health care and symptom monitoring, when children's asthma severity is high and/or uncontrolled, parents will need to take action to reduce the symptoms and avoid environmental triggers. In these situations, the degree of care required may confine parents' regular activities and may heighten their emotional worries about their children's present condition and future lives, which are indicators of a decreased QoL.

Low socio-economic status (SES) is considered a risk factor for children and parents with regard to poor outcomes in pediatric asthma. Specifically, studies have found links between the factors of low income (Erickson et al., 2002) and low SES (e.g., Everhart et al., 2008), and decreased

QoL for parents. Among other factors, a lack of financial resources to meet health care demands and increased worries about being in jeopardy of losing jobs due to frequent absences can explain less affluent parents' QoL impairment. Additionally, compared to other caregivers, single parent caregivers reported having lower QoL (e.g., Everhart et al., 2008). These caregivers may have an increased burden due to taking on the responsibility and chores of managing their child's asthma on their own, and they may be at risk for lower perceived social support (Everhart et al., 2008).

Theoretical models of adaptation in pediatric chronic health conditions, which are supported by empirical findings and clinical evidence, suggest that a warm, positive, cohesive family system is a protective factor for both parents and children. Research has found that a more positive family environment was associated with parents' reporting higher QoL scores (Annett, Turner, Brody, Sedillo, & Dalen, 2010; Crespo et al., 2011). In addition, other studies demonstrated that the impact of the child's condition in the whole family functioning negatively affected parents' QoL (e.g., Everhart et al., 2008; Juniper et al., 1996). Schulz and collaborators (1994) proposed that parents' QoL may be best understood by how they manage their children's asthma over time. A study specifically examining the way that families managed asthma routines (e.g., house cleaning, medication times, etc.) found that when caregivers perceived these routines as burdensome, they reported having lower QoL. This finding suggests that the negative effect associated with the daily management of a health condition is an important factor explaining parents' QoL (Fiese, Wamboldt, & Anbar, 2005). Moreover, Crespo and colleagues' findings (2011) contributed to this idea by showing a negative link between parents' perceived burden and their QoL, which was mediated by family environment such that, when parents experienced more caregiving burdens, they perceived their family environment as less positive, which, in turn, was linked to an impaired QoL.

In addition to the way that parents perceive the impact of pediatric asthma on family functioning and their own experiences of the burdens associated with this condition, another important factor may be how they evaluate their children's well-being and QoL. A number of studies have found that the higher parents rated their children's psychological functioning, the better QoL they reported for themselves (Annett et al., 2010; Vila et al., 2003). Parents of children with asthma worry about the well-being and health of their children; thus, it is likely that perceiving their children

as being well-adjusted eases possible fears about the impact of the condition on their children's lives.

Finally, although not yet conclusive, there is growing evidence that parents' QoL and children's QoL are positively related (e.g., Crespo et al., 2011; Stelmach et al., 2011). It is possible that the transactional nature of the parent-child relationship, in that both family members influence each other over time, is enhanced in dyads in which the child has a chronic health condition. The underlying rationale for this hypothesis is that asthmatic children depend more on their parents than healthy children, especially at a young age, for example, by relying on them during matters related to health care. Moreover, parents of asthmatic children face additional worries about the impact of the disease on their children's lives compared to parents of healthy children. Thus, although there are no longitudinal studies that disentangle the patterns of influence, it is likely that the causal links between parents' QoL and children's QoL are bidirectional.

Conclusion

There is an increasing consensus that pediatric asthma is best understood and treated within a family-based approach. Parents' QoL is currently considered a relevant outcome due to the impairment that caring for a child with asthma can cause in parents' own lives and in parents' ongoing ability to provide care for the child. Despite growing interest in this topic, several gaps in knowledge have yet to be addressed. There is preliminary evidence that parents' QoL might be different for fathers and mothers, yet the majority of studies examining pediatric asthma aggregate both parents' data, with samples primarily composed of mothers. Future studies comparing the levels of reported QoL for mothers and fathers and whether there are different factors influencing the QoL for each parent would be advantageous. Another area of interest is understanding parents' specific needs and the challenges that they face throughout their asthmatic child's development. It is unknown whether parents' QoL differs, and whether their QoL is accounted for by the same factors during their child's infancy, childhood and adolescence. Finally, future directions should include a closer examination of how risk and protective factors for parents' QoL operate. The majority of studies to date have investigated the unique effect of risk factors on QoL; however, parents of children with asthma are often exposed to more than one risk factor. An examination of their combined effects, with a specific

focus on how risk factors interact with each other, is warranted for a more accurate picture of the matrix of influences regarding parents' QoL (Everhart et al., 2008). Research addressing these issues has important implications for health care in pediatric asthma; for example, identifying parents at risk for lower QoL would allow for closer monitoring of these parents and their children starting at the beginning of asthma treatment. In addition to risk factors, which have received most of the attention, there is the need to identify protective factors regarding parents' QoL. This call is supported by a growing recognition that successful asthma management is best achieved by building on parents' and families' resources and strengths. Empirically based family interventions in pediatric asthma have been considered promising avenues for promoting adaptation to the disease, reducing parents' burden and improving both parents and children's QoL.

References

Annett, R. D., Turner, C., Brody, J. L., Sedillo, D., & Dalen, J. (2010).Using structural equation modeling to understand child and parent perceptions of asthma quality of life. *Journal of Pediatric Psychology*, *35*, 870-882. DOI: 10.1093/jpepsy/jsp121

Bullinger, M., Schmidt, S., Petersen, C., & Ravens-Sieberer, U. (2006). Quality of life – evaluation criteria for children with chronic conditions in medical care. *Journal of Public Health*, *14*, 343-355. DOI 10.1007/s10389-006-0066-0

Canning, R. D., Harris, E. S., & Kelleher, K. J. (1996). Factors predicting distress among caregivers to children with chronic medical conditions. *Journal of Pediatric Psychology*, *21*(5), 735-749.

Crespo, C., Carona, C., Silva, N., Canavarro, M. C., & Dattilio, F. (2011). Understanding the quality of life for parents and their children who have asthma: Family resources and challenges. *Contemporary Family Therapy*, *33*, 179-196. DOI: 10.1007/s10591-011-9155-5

Dalheim-Englund, A.-C., Rydström, I., Rasmussen, B. H., Möller, C., & Sandman, P.-O. (2004). Having a child with asthma – quality of life for Swedish parents. *Journal of Clinical Nursing*, *13*(3), 386-395.

Dean, B. D., Calimlim, B. M., Kindermann, S. L., Khandker, R. K., Tinkelman, D. (2009). The

impact of uncontrolled asthma on absenteeism and health-related quality of life. *Journal of Asthma*, *46*, 861-866. DOI: 10.3109/02770900903184237

Erickson, S. R., Munzenberger, P. J., Plante, M. J., Kirking, D. M., Hurwitz, M. E., & Vanuya, R. Z. (2002). Influence of sociodemographics on the health-related quality of life of pediatric patients with asthma and their caregivers. *Journal of Asthma*, *39*(2), 107-117.

Fiese, B. H., Wamboldt, F. S., & Anbar, R. D. (2005). Family asthma management routines: Connections to medical adherence and quality of life. *The Journal of Pediatrics*, *146*, 171-176. DOI: 10.1016/j.jpeds.2004.08.083

Everhart, R. S., Fiese, B. H., & Smyth, J. M. (2008). A cumulative risk model predicting caregiver quality of life in pediatric asthma. *Journal of Pediatric Psychology*, *33*, 809-818. DOI: 10.1093/jpepsy/jsn028

Gau, B.-S., Chen, Y.-C., Lo, L.-H., Chang, M., Chao, Y.-M., Chiang, B.-L., & Yao, G. (2010). Clinical applicability of the World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF) to mothers of children with asthma in Taiwan. *Journal of Clinical Nursing*, *19*, 811-819. DOI: 10.1111/j.1365-2702.2009.02934.x

Goldbeck, L. (2006). The impact of newly diagnosed chronic paediatric conditions on parental quality of life. *Quality of Life Research*, *15*, 1121-1131. DOI: 10.1007/s11136-006-0068-y

Hatzmann, J., Heymans, H. S. A., Ferrer-i-Carbonell, A., van Praag, B. M. S., & Grootenhuis, M. A. (2008). Hidden consequences of success in pediatrics: Parental health-related quality of life – results from the care project. *Pediatrics*, *122*, e1030-e1038. DOI: 10.1542/peds.2008-0582

Juniper, E. F., Guyatt, G. H., Feeny, D. H., Ferrie, P. J., Griffith, L. E., & Townsend, M. (1996). Measuring quality of life in the parents of children with asthma. *Quality of Life Research*, *5*(1), 27-34.

Schulz, R. M., Dye, J., Jolicoeur, L., Cafferty, T., & Watson, J. (1994). Quality-of-life factors for parents of children with asthma. *Journal of Asthma*, *31*(3), 209-219.

Stelmach, I., Podlecka, D., Smejda, K., Majak, P., Jerzyńska, J., Stelmach, R., …, Stelmach, W. (2011). Pediatric Asthma Caregiver’s Quality of Life Questionnaire is a useful tool for monitoring asthma in children. *Quality of Life Research*. DOI 10.1007/s11136-011-0070-x

The WHOQOL Group (1998). The World Health Organization Quality of Life Assessment (WHOQOL): Development and general psychometric properties. *Social Science & Medicine*, *46*(12), 1569-1585.

Vila, G., Hayder, R., Bertrand, C., Falissard, B., de Blic, J., Mouren-Simeoni, M.-C., & Scheinmann, P. (2003). Psychopathology and quality of life for adolescents with asthma and their parents. *Psychosomatics*, *44*, 319-328. DOI: 10.1176/appi.psy.44.4.319

Walker, J., Winkelstein, M., Land, C., Lewis-Boyer, L., Quartey, R., Pham, L., & Butz, A. (2008). Factors that influence quality of life in rural children with asthma and their parents. *Journal of Pediatric Health Care*, *22*, 343-350. DOI: 10.1016/j.pedhc.2007.07.007.