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Social Disruption and Physical Limitation Related to Quality of Life of Adolescents with Asthma

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I am a senior graduating Magna Cum Laude with a B.S. in Nursing. I am an Honors Student and a member of Sigma Theta Tau International Honor Society for Nursing and The National Society of Collegiate Scholars. During my undergraduate education, I received the University of Kentucky's Presidential Scholarship, the Pamela Riggs Peter Scholarship, and the Gorman Foundation Scholarship. In addition, I have been on the Dean's list for five semesters. After

graduation, I plan to work as a pediatric or neonatal intensive care nurse. I intend to pursue further graduate education in the fall of 2009.

As an undergraduate student, I became involved in the College of Nursing Research Intern Program. It was through this opportunity that I joined Dr. Patricia Burkhart's child asthma research team. Over the past five semesters, I have worked with Dr. Burkhart on many aspects of the research process and learned valuable information. During my internship, I developed a research poster, entitled *Factors Related to Quality of Life for U.S. and Icelandic Adolescents with Asthma*, that I presented at multiple conferences. Recently, I gave my first podium presentations on this literature review at the College of Nursing's Student Scholarship Showcase and at the University of Kentucky's Showcase of Undergraduate Scholars. This literature review is the culmination of my work as a research intern.

Social Disruption and Physical Limitation Related to Quality of Life of Adolescents with Asthma

Abstract

During adolescence, teenagers experience many physical, emotional, and social changes. Teenagers with chronic conditions, however, may face challenges in normal adolescent development because their illness can impact body image, independence, and peer socialization. Little is known about the effect of asthma on adolescent quality of life (QOL). In this paper, I review the existing literature on social disruption and physical limitations related to asthma and the subsequent impact on adolescent asthma QOL. In addition, adolescent issues leading to poor control of asthma symptoms and interventions to improve asthma QOL for adolescents are addressed.



Faculty Mentor:

**Dr. Patricia Burkhart, Director of the Undergraduate Nursing Program and Associate Professor
College of Nursing, University of Kentucky**

One aspect of my program of research focuses on how asthma affects quality of life for adolescents living with this chronic condition. Jennifer Baumgardner joined my child asthma research team five semesters ago as an undergraduate research intern. She has been actively involved in the development and implementation of our research projects, including an exploratory study entitled "Factors Related to Quality of Life for U.S. and Icelandic Adolescents with Asthma." Results of that study suggested that adolescents with a diagnosis of asthma experience social disruption, physical limitation, and depressive symptoms. Ms. Baumgardner wrote the current paper to summarize the literature regarding social and physical aspects of asthma quality of life supporting our research findings. I feel that this paper is quality work for an undergraduate student, and it is my pleasure to endorse its publication in *Kaleidoscope*.

Introduction

Currently in the United States, asthma is the leading chronic childhood disease and a major cause of childhood disability (Akinbami, 2006). Children and adults with asthma suffer from wheezing, breathlessness, chest tightness, and nighttime or early morning coughing. Approximately nine million U.S. children under the age of 18 (14%) have been diagnosed with asthma (CDC, 2007). Review of the current prevalence data shows that asthma occurrence increases with age, yet health care use for this chronic disease is the highest among the youngest children (Akinbami, 2006). This disparity might stem from issues with emerging autonomy as children move into adolescence. Mortality rates have risen in the adolescent asthma population, a number much higher than the declining rate of asthma deaths in young children (Akinbami, 2006).

With chronic diseases such as asthma that not only impact a person's livelihood but threaten it, quality of life must be taken into account. Quality of life (QOL) is defined as a multidimensional assessment of an individual's current life circumstances encompassing physical, psychological, social, and spiritual dimensions (Haas, 1999). Nursing, a holistic based profession, must become more aware of issues facing those with chronic illness and the impact the illness has on QOL, especially in adolescents. Implications for the nursing profession include examining not only the medical consequences of the disease, but also the psychosocial disruption and physical limitations and the underlying cause of these factors. CINAHL and Medline were used to search for asthma QOL literature between 2003 – 2008, with keywords including: quality of life, social disruption, physical limitation, adolescence, teen, and asthma. The purpose of this paper is to examine the current literature of the physical and social dimensions of adolescent asthma QOL and to apply these findings to nursing care through the implementation of appropriate interventions.

Social Dimension of Asthma QOL

The social dimension of QOL in adolescents with asthma is extremely important. The influential psychoanalyst, Eric Erikson, describes the achievement of identity as one of the main psychosocial tasks of the adolescent years. Erikson (1968) states that adolescent interactions with others allow for the creation of their adult identity. Striving to fit in during puberty, a time when significant changes in both body and mind are occurring, can be quite challenging. Teenagers with chronic conditions, such as asthma, may face challenges to normal adolescent development because their illness can impact body image, independence, and peer socialization.

Perceptions of the physical and social impact of various chronic illnesses were assessed in adolescents (Wirrell et al., 2006). Of the adolescents ($N = 149$) surveyed in this study, 63% ($n = 24$) of the 38 adolescents with asthma and 58% ($n = 64$) of the 111 adolescents without asthma rated their peers with asthma as experiencing restriction of activities, yet they did not feel that this affected their social functioning. In addition, asthma was not correlated with other areas of social impact of chronic disease including popularity. Adolescents report that "chronic diseases that are 'purely physical' appear to have less impact on social functioning than those associated with mental and/or emotional handicaps" (p.158). Because asthma affects the lungs of the adolescent and not necessarily the appearance, adolescents are able to feel a part of the peer group — a common theme of 'fitting in.'

Ayala et al. (2006) conducted interviews with adolescents diagnosed with asthma ($N = 28$) in the school setting, identifying their feelings about asthma in relation to intrapersonal, interpersonal, and societal factors. The findings of this study suggested that asthma does affect adolescents socially, in relation to their personal control and severity of their asthma. Those with better asthma symptom control (or not severely affected) were thought of more positively by their peers. A section of the interview allowed for the adolescent participants to describe, from their own experiences and the perception of others' experiences, what it meant to have either good or poor asthma symptom control. Words used to describe individuals with poor symptom control included: not happy, freaky, not smart, cannot participate, teased by friends, and loner. Words that were used to describe adolescents with good symptom control included: happy, normal, regular kid, popular, and has cool friends. These labels clearly demonstrate the connection between adolescents severely affected by asthma and the associated social isolation.

Physical Dimension of Asthma QOL

The physical dimension of QOL in adolescents with asthma is also very important. Because asthma affects the lungs of those diagnosed with the condition, physical limitations are likely. Asthma is perceived by adolescents, both with and without asthma, to cause significant physical disability ($p < .001$) and restrict activities ($p < .0005$) (Wirrell et al., 2006). This disability can impact the adolescents negatively because they may struggle with participation in activities that they enjoy, isolating them from their peers. Adolescent athletes with asthma ($N = 32$) who became *dyspnic* during exercise reported a lower QOL ($p < .02$) in relation to general well being and lower physical functioning ($p = .02$) (Hallstrand et al., 2003). These results suggest that adolescents

engaging in activities that required a higher amount of physical activity had a lower QOL when they became short of breath.

Impact on Quality of Life

One key question that arises when asthma QOL is discussed is the level of control adolescents have over their disease. Control over the severity of symptoms can be intertwined with many factors related to asthma quality of life. For example, those with mild cases of asthma or those who have good control of their asthma symptoms are not affected by the breathlessness and other manifestations of asthma. Those with severe asthma or a poorer control of symptoms are more affected physically by asthma and, thus, the condition will have a greater impact on their everyday lives.

As previously mentioned, when adolescents are exhibiting asthma symptoms they often become socially isolated. It is during times of wheezing and breathlessness that these individuals are being characterized as a “loner” or “freaky” (Ayala et al., 2006, p. 211). In addition, when physical limitations are discussed, adolescents with asthma who experienced dyspnea were found to have a decrease in physical functioning, impacting their QOL (Hallstrand et al., 2003). It seems that the main problem surfacing is the underlying theme of control. If adolescents have better control of their asthma, would they suffer a decrease in their quality of life? What can health care professionals do to increase patients’ asthma QOL?

Implications for Nursing Practice and Research

Before nursing interventions can be developed, the reason for poor control of asthma symptoms must be identified. Many times, adolescents with poor control fall into one of two categories: non-adherence to a recommended asthma treatment plan or ineffective treatment. If the adolescent is struggling with poor control of asthmatic symptoms while maintaining adherence to the treatment plan and all medications, the health care provider should be notified and the treatment plan re-evaluated. In this paper, however, non-adherence to recommended asthma treatment plans will be the focus of the nursing implications.

Several reasons for poor adherence to asthma management by adolescents have been identified. One explanation is the misconception that as adolescents age, they outgrow their disease. During interviews conducted by Ayala et al. (2006), 59% of the adolescents with asthma ($N = 28$) reported that management behaviors were not needed because they had outgrown their asthma or it was not severe enough to warrant attention. One adolescent said “You only think about it when it you are having problems” (Ayala et al., 2006, p. 212). All

adolescents in this study felt that “managing asthma was time consuming and annoying” (p. 210). A burdensome treatment regimen that interferes with the adolescent’s daily activities can also lead to decreased adherence.

Poor symptom control can result when adolescents have a misunderstanding of the role of their asthma medications. Boulet (1998) found that adolescents and adults with asthma have an increased fear of inhaled corticosteroids believing that these drugs “could cause weight gain, build huge muscles, cause infections, make bones susceptible to fractures, or affect growth” (p. 589). Of the participants included in this study ($N = 600$), 59% ($n = 354$) indicated they were very or somewhat concerned about using inhaled corticosteroids because of the perceived negative side effects.

Health care providers can impact adolescent QOL and increase awareness of the illness with reinforcement of appropriate management skills that often wane in patients who have faced chronic illness. Patients with a chronic condition who are undergoing normal physiological changes (i.e., puberty) become aware of the changing impact of their illness. It is the responsibility of the nursing community, especially nurses who commonly encounter adolescents with asthma, to review and reinforce asthma education at each health care visit. Critical asthma information includes asthma medication administration, asthma triggers, and what to do during an exacerbation of symptoms. The school nurse is in an ideal position to intervene. In a study of 1094 middle school students, 374 received a case management intervention by a school nurse during year one and 720 did not. Of those who received the intervention, 60.7% ($n = 227$) were more likely to bring their medications to school and monitor their asthma symptoms the following year compared to the 34.3% ($n = 247$) who did not receive the intervention (Taras et al., 2004). This finding suggests that interventions by school nurses may be a plausible solution to increasing awareness of self-management of asthma.

In addition, nurses working with primary care providers should also facilitate conversations about asthma issues and asthma self-management. The literature suggests that nurses need to avoid making value judgments and an authoritative approach that can cause a breakdown in trust with the adolescent (Benedictis and Bush, 2007). Open communication among the health care provider, parents, and adolescent will increase future asthma self-management adherence by the adolescent (Benedictis and Bush, 2007).

Making interventions appealing to youth and presenting asthma management in a positive light emerged from adolescent interviews (Ayala et al., 2006). This is important feedback for nurses who work with adolescents with asthma. Many of the adolescents interviewed

mentioned the importance of personalization of interventions. Tailoring materials based on images representing diverse groups of people, as well as featuring celebrities coping with asthma were viewed as effective in encouraging adolescents to continue with daily asthma self-management. The importance of creating strategies to remind the adolescents to take their medication and cue other management behaviors was also identified. These methods included the use of traditional alarm clocks and cell phones. Finally, adolescents reported that rewards for successful management were crucial in achieving change. Examples of rewards included positive feedback from clinicians, helpful asthma devices, as well as candy and prizes (Ayala et al., 2006).

Future Goals

Unfortunately, not much progress has been made in the advancement of knowledge of the affects of asthma quality of life in adolescents. One of the recommendations for future nursing research is testing specific asthma self-management strategies for adolescents that increase symptom control resulting in an improved asthma QOL. An asthma action plan detailing solutions to address issues causing the adolescent's poor control of asthma symptoms should be created.

The effectiveness of peer support groups for adolescents with asthma should be explored. Creating opportunities for open communication between peers with the same chronic illness can help address feelings of isolation while generating additional social networks.

Finally, those individuals who are close to these adolescents, such as parents and teachers, should be informed of the potential complications that the individual with asthma can face during their teenage years. Increased awareness and knowledge of effective symptom control by supportive adults will assist the adolescent with asthma self-management.

Asthma is a serious chronic illness affecting age groups differently. Adolescence is a time of transition from childhood to adulthood and chronic illness will begin to impact teens differently. Adolescents can be affected both socially and physically if their asthma is not managed appropriately. Nurses and other health care professionals have the opportunity to impact patients' lives through open communication and teaching to improve symptom control that may improve QOL, allowing these individuals to lead healthier and happier lives.

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