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Quality of life of children with chronic illness

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Abstract

Any physical, emotional, or mental condition that prevented a person from regularly attending school, carrying out regular schoolwork, or engaging in typical childhood activities as well as those that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment are considered chronic health conditions. A child's chronic disease affects every sphere of their life and the illness is a central event for the family. The most commonly observed that children with chronic illness has suffering a lot and leads to increase the stress level, affecting the growth and development, unpleasant feelings, rejection from the peer groups, loneliness leads to psychological distress such as suicidal thoughts, fear of death and hopelessness and that's affecting the quality of life in children. The healthcare providers should pay attention to family management, create a family promotion, and optimize the administration regarding its quality, Comprehensibility, and specificity for each type of chronic disease so that children suffering from diverse chronic conditions have access to a quality life.

Keywords: chronic illness, quality of life, long term illness, chronic disease

Introduction

Conditions that persist more than a year and are severe enough to impede some regular activities are referred to as chronic health conditions, including both chronic illnesses and chronic physical disabilities ^[1]. The number of children with chronic diseases has been increasing annually over the past few decades due to improved medical care increasing survival rates and protecting children with chronic illnesses' lives from life-threatening risks more successfully than in the past ^[2]. Any physical, emotional, or mental condition that prevented a person from regularly attending school, carrying out regular schoolwork, or engaging in typical childhood activities as well as those that required frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment are considered chronic health conditions ^[3]. Chronic illnesses may have hereditary, environmental, or a combination of both causes. Asthma, cystic fibrosis, diabetes, epilepsy, cancer and developmental disabilities like ADHD, cerebral palsy, and autism spectrum disorders are among the common chronic diseases in children ^[4]. In several affluent countries, the prevalence of chronic health issues has surpassed that of acute illnesses. Asthma is one of the most prevalent chronic illnesses in children, and its prevalence is on the rise. Up to one in four children may have a chronic illness, according to previous epidemiological studies, with prevalence estimates ranging from 10% to 30% ^[5]. A child's chronic disease affects every sphere of their life and the illness is a central event for the family.

Materials and Methods

A structured literature search was done using various electronic data bases.

Source of data: PubMed, Cinhal, Science direct, Cochrane, Scholar

Study design: Literature review

Inclusion criteria: Only English articles

Exclusion criteria: Articles of other languages

To identify relevant studies database like PubMed, Medline were searched, and only English articles were considered for the study. This study was done to review the literature on chronic illness which is among children and that affects the quality of life.

Literature and review

Literature related to children with chronic illness

A concurrent cohort study was conducted to assess the overall physical, mental, and social health and life satisfaction in the context of chronic illness among 1253 children between the ages of 5 and 9. The caregivers were examined by using Patient-Reported Outcomes Measurement Information System to evaluate children's overall life satisfaction on a 5-point Likert scale ranging from not at all to very much. The results showed that children with chronic illness had worse general health compared with children without illness ($\beta = -1.20$, $p=0.009$). Children with high stress level and moderate stress levels also had worse health than those with low stress levels. It concluded that children with chronic illnesses are nevertheless capable of living happy and fulfilling lives [6].

A cross-sectional study was conducted in the health area of Valladolid from April to July 2019 to assess the impact of type 1 diabetes mellitus in pediatric patients and its impact on relationships in the family environment. A total of 101 children were selected for the study by using non-random consecutive sampling. The self-care capacity and quality of life in pediatric patients was assessed by using Modified Diabetes Quality of Life and Questionnaire was used to assess the psychological impact in parents/guardians of diabetic children. Paired *t*-test and Wilcoxon rank test were used to test the significance and ANOVA or the Kruskal-Wallis test was used for three or more group comparison of continuous variables. Statistical significance was considered when P value <0.05 for all statistical test. Results showed that majority of the children (70.3%) suffered unpleasant feelings related to diabetes mellitus and (98%) impacted the family environment [7].

A qualitative study with a phenomenological approach was done to explore the meaning of living experience with HIV positive adolescent during September 2019 – January 2020 in Tamale teaching hospital, Ghanaian. 12 HIV infected adolescents were recruited by using purposive sampling technique. The data was collected by in-depth interview method. A semi structured interview with open ended question was delivered for about 30 – 60 minutes. The data was analyzed on Van Manen data analysis with six steps by writing the verbatim transcript, then identify each phrases, then formulate the meanings, arranging the meanings into sub themes, from these sub themes, themes were obtained then formulation of complete description of the phenomena, researcher validates the description of the analysis of results. The study results indicated the adolescent living with HIV is a stressful event, rejection and psychological distress such as suicidal thoughts, fear of death and hopelessness [8].

Literature related to quality of life of children with chronic illness

A cross-sectional study was conducted in Saudi Arabia with an aim to investigate that the Down syndrome children impact the different domains of the quality of life of their caregivers. 261 caregivers of children with down syndrome participated through non-probability convenience sampling

technique. The data were collected using self-administered questionnaire on five points Likert scale, World Health Organization Quality of Life (WHOQOL-BREF) scale were used. The result showed that WHOQOL-BREF domains were 84 (± 15), 88 (± 15), 41 (± 10), and 105 (± 24), including the physical, psychological, social relations, and environmental domains, respectively. There was a significant difference between all of the scores that have been reported for these domains (P -value <0.001). The study concluded that there is an urgent need to use appropriate interventions because the quality of life of caregivers with down syndrome children is greatly damaged in the many dimensions [9].

A cross sectional study was conducted by healthcare facilities in Nigeria with an aim to assess the health related quality of life among HIV infected children. A total of 137 children of HIV positive children participated. The instruments used were Paediatrics Quality of Life Inventory (PedsQL). Linear regression analysis was used to measure the predictors of HRQoL. The result showed that for HIV-positive children, being from upper social class ($p = 0.01$, $R^2 = 0.098$), male gender ($p = 0.005$, $R^2 = 0.063$), higher scores in the caregiver burden scale ($p = 0.009$, $R^2 = 0.150$) and more disease severity ($p < 0.001$, $R^2 = 0.321$) were significant predictors of lower health-related quality of life. The study concluded that HIV-positive children will have better outcomes not only in mortality but in psychosocial variables such as quality of life [10].

A cross-sectional study was conducted in Singapore with an aim to explore the health related quality of life in paediatric patients with Leukemia. The sample consisted of 60 paediatric patients participated through convenience sampling technique. The data were collected using demographical data, adapted pictorial version of the Pediatric Quality of Life Inventory (PedsQL) 4.0. Mann-Whitney U test and Kruskal-wallis test were used to test the significance. The results showed that pediatric patients total score on the PedsQL, $r(60) = 0.29$, $p < 0.05$. Age and Physical Functioning showed a positive correlation that was statistically significant ($r(60) = 0.28$, $p = 0.05$), while Treatment Duration and School Functioning had a positive relationship that was statistically significant ($r(60) = 0.28$, $p = 0.05$). The study concluded that children with cancer had poor HRQOL [11].

Discussion

Chronic illness is an emerging issue in the child's life. The aim of this research was to conduct an overview, a review of reviews, of chronic illness in the children. The most commonly observed that children with chronic illness has suffering a lot and leads to increase the stress level, affecting the growth and development, unpleasant feelings, rejection from the peer groups, loneliness leads to psychological distress such as suicidal thoughts, fear of death and hopelessness and that's affecting the quality of life in children. Children with better control over their symptoms reported higher quality of life scores compared with those who had a progressive disease with a continuous decline [12].

Conclusion

Childhood chronic illnesses are common that have an adverse effect on health related quality of life. Children with chronic conditions that appear in infancy will respond

differently than children who develop conditions during adolescence. Parents should encourage the self-reliance within the children and to avoid the overprotection. Therefore, the healthcare providers should pay attention to family management, create a family promotion, and optimize the administration regarding its quality, comprehensibility, and specificity for each type of chronic disease so that children suffering from diverse chronic conditions have access to a quality life.

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