



Review article

Health and quality of life among the caregivers of children with disabilities: A review of literature



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ABSTRACT

Families caring for children with disabilities face particular challenges and demands compared to those caring for children without disabilities. Evidence suggests that there is considerable variation in how caregivers of children with disabilities adapt to their caregiving demands and stressors. The different adaptations to the children with disabilities may cause different impacts on the health and well-being of caregivers. This paper provides a brief overview of the literature on the impact of caring for children with disabilities on the health and quality of life of caregivers and the factors related to the health outcomes and quality of life. A literature search was conducted by using various electronic databases, including PsychINFO, ScienceDirect, ProQuest, and MEDLINE using specific key terms. Thirty-one articles published in peer-review journals from the last six years (2009–2014) were reviewed. Most of the studies were quantitative studies. Factors discussed that impact on caregivers' health and quality of life include the caregivers' sociodemographic background and child's disability-related factors. Several mediators and moderators including coping strategies, social support, parental stress, self-esteem and self-efficacy are described in this paper. This review highlighted the importance of these factors to better understand the complex nature of stress processes and the caregivers' adaptations to their children's disabilities.

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1. Introduction

Children with disabilities, commonly known as *anak kurang upaya (OKU)* or *anak istimewa* in the Malaysian context is a complex term referring to any children (below the age of 18) who have long-term physical, mental, intellectual and (or) sensory impairments which in interaction with various barriers may prevent them from full and effective participation in the society (Law of Malaysia, 2008). Children with disabilities can also be defined as children being described as having impairments, activity limitations and participation restrictions, or disadvantages, as classified under the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation (WHO), 2007). Children with disabilities require health and other related services beyond that required by normal children in order for them to be individually planned or coordinated. A caregiver is defined as the parent (either mother or father) or other family members (grandmother or grandfather, siblings, aunt or uncle and adoptive parent) of the disabled child who is responsible of parenting or caring for the disabled child. A caregiver provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living (Savage and Bailey, 2004).

The issue of caregiver burden is well-documented for the last several decades and has received considerable emphasis in the literature on the social experience of parenting children with disabilities. Parenting a child with disability goes beyond 'ordinary' parenting as the parents have to cope with many changing demands related to the specific needs of their child. In the beginning of birth of a child with an abnormality, the immediate stressor that the parents encountered was facing a child who was totally different from their expectation. An interesting and comprehensive understanding of reactions from parents when their child was being diagnosed as having a disability has been noted by Sen and Yurtsever (2007). Sen and Yurtsever (2007) divided the general reactions of parents into three main categories; primary reactions, secondary reactions, and tertiary reactions. The reactions of parents commonly start with shock, denial, suffering and depression. Following the primary reactions, the parents will display feelings of guilt, indecision, anger, and shame. The final reactions for the parents are bargaining, acceptance and adaptation to the condition.

The implications of caring for a child with disability are considerable and can have profound effects on the entire family who are parents, siblings, and extended family members. Changes in the healthcare systems and social services have resulted in almost all children staying at home in the care of their families, rather than in an institutional care. Although a nurturing home environment can improve a child's capabilities and independence, providing the high-quality care that is required by a child with long-term functional limitations may impact the health and quality of life (QOL) of the caregivers (Davis et al., 2009).

This paper presents a brief overview of the literature on the impact of caring for a child with disability on health and QOL of the caregivers, and summarizes the factors that affect the health outcomes and QOL. While a few studies have provided evidence on the positive aspects of parenting children with disabilities (Davis

et al., 2009; Myers et al., 2009), this paper only focuses on the negative impact of the caregiving experience.

2. Method

The present review was not intended to be systematic and comprehensive. The review only included both quantitative and qualitative studies that were published in peer-review journals. The literature search was carried out using PsychINFO, ScienceDirect, ProQuest, and MEDLINE electronic databases accessed through the library system of The National University of Malaysia. The search was limited to the original articles published in English from 2009 to 2014. A spectrum of keywords included in the search with different combinations was: "predictors"; "associated factors"; "family impact"; "family quality of life"; "health-related quality of life"; "parental stress"; "caregivers well-being"; and "children with disabilities". Related studies in the Malaysian setting are also included in this review where possible.

The initial search yielded 5, 016 articles. The titles and/or abstracts of the articles were screened. The full texts of 75 articles considered relevant were obtained and reviewed. We included 31 articles in this review that had met the following criteria: (1) focused primarily on parents or caregivers of children/adolescents (18 years and below); (2) the children experiencing developmental disabilities; (3) had the objectives to describe or explain the impact on the health and/or quality of life outcomes of the caregivers and/or to examine the factors or predictors of the health and/or quality of life outcomes. Twenty-six studies were quantitative studies and five studies used the qualitative approach. The journal articles focusing on the validation of the instruments and the studies that included an intervention for children and/or families were excluded from the review.

3. Health and quality of life of caregivers

Quality of life and health outcomes measures used in research and clinical settings vary. Studies included in this review used the measures of general QOL, health-related quality of life (HRQOL), family quality of life (FQOL), and specific health outcomes (e.g., depression, anxiety, parenting stress, sleep quality). WHO defined health as not only being the absence of disease or infirmity, but the presence of complete physical, mental and social well-being (WHO, 1948). QOL is variously defined; however, the most commonly applied definition stated that QOL is 'the individual's perception of their position in life in the context of their culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad concept incorporating an individual's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to the salient features of the environment (WHO, 1997).

HRQOL and FQOL are the component of the overall quality of life. HRQOL is determined primarily by health status and conceived as dynamic, subjective, and multidimensional. The dimensions often include physical, social, psychological, cognitive and spiritual factors (Bakas et al., 2012). The unique characteristic of FQOL definition emphasised on examining the perceptions and

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