Research in Developmental Disabilities 83 (2018) 120–131

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

Review article

Quality of life among parents of children with visual impairment: A literature review

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ARTICLE INFO

Keywords:
Visual impairment
Children
Adolescents
Parents
Caregivers
Quality of life

ABSTRACT

Aims: To describe the experience of parents caregiving children with visual impairment (VI), to determine how their quality of life (QoL) is assessed, and to summarize QoL indicators through a review of the literature.
Methods: A thematic search through PubMed, PsycINFO, ProQuest and ERIC databases was performed of articles published in English in peer-reviewed journals between 1996 and 2016. Publications were included if they referred to both children or adolescents with VI and their parents, or the family context. The complete selection process disclosed 37 papers suitable for review.
Results: Researchers mainly used *ad hoc* interviews and questionnaires to investigate this topic. Two specific tools, the *CarCGQoL* (congenital glaucoma) and the *OTI* (congenital cataract), were identified. Most of the information collected referred to the parents' opinion concerning professional services, their needs and worries, the impact of VI on their emotional well-being and the strategies to assist parents to cope and adjust to the situation.
Conclusions: The experience of caring for a child with VI is mainly influenced by psychosocial factors. Information and guidance to understand the child's visual condition are insufficient, and the available resources reinforce concerns of caregivers regarding the child's opportunities, expressed as negative emotional reactions.

What this paper adds?

The approach to childhood visual impairment should take into consideration the whole family system, particularly from the perspective of parents as main caregivers of a visually impaired child. This paper reviews and analyses the findings of relevant publications on quality of life of parents of children with visual impairment. Key issues for healthcare and educational practices and policies are discussed aiming at improving the quality of life of these parents.

1. Introduction

Visual impairment (VI) in childhood is a low prevalence condition, ranging from 3 per 10.000 in socioeconomically developed

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https://doi.org/10.1016/j.ridd.2018.08.013
Received 28 July 2017; Received in revised form 31 January 2018; Accepted 28 August 2018
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countries, to 15 per 10.000 in poorer countries (Rahi ö Cable, 2003; Resnikoff et al., 2004). It often coexists with other impairments or disabilities (Flanagan, Jackson, ö Hill, 2003; Rahi ö Cable, 2003; Salt ö Sargent, 2014).

The presence of a VI affects children's global development (motor, cognitive and psychosocial aspects), restrains their participation in social activities, and generally worsens their quality of life (Rainey, Elsman, van Nispen, van Leeuwen, ö van Rens, 2016). Vision is an important factor in the learning process that also serves as a non-verbal communication channel governing social interaction. In older children, vision is especially related not only to academic achievements but also to other aspects of life, such as sports practice, autonomy, relationships, etc. (Checa et al., 2003). The limitations and participation restrictions of children with VI may further increase if they suffer from co-existing disabilities. In such a case, it is critical to detect visual function or visual system anomalies in order to strengthen the ratio ability *vs.* disability. However, this strategy is not always a priority for healthcare providers or even for families (Woodhouse, Davies, McAvinchey, ö Ryan, 2014).

As well as affecting the child, the VI condition will presumably affect the whole family environment, especially the parents' quality of life (QoL). Caring for someone who suffers from a permanent disease or disability has an effect on the caregiver's QoL to a greater or a lesser extent. Quality of life is described as a multidimensional concept that reflects global welfare (Brown, Bowling, ö Flynn, 2004). An extensive body of literature exists exploring the relevant QoL domains and the corresponding measurement of their indicators (Adelman, Tmanova, Delgado, Dion, ö Lachs, 2014; Golics, Basra, Salek, ö Finlay, 2013). Accepting a caregiving responsibility may lead to increased stress levels, and result in a negative impact on the individual's physical (fatigue, sleep deprivation, etc.), psychological (suffering, anxiety, depression, etc.) and social (economic environment, workplace, relationship bonds, etc.) areas. Child-rearing may become a particularly exacting task when children suffer from some kind of disease, disability and/or impairment. These findings have been amply documented in research focusing on parents of children with special needs (Barlow ö Ellard, 2006; Gerhardt et al., 2003; Murphy, Christian, Caplin, ö Young, 2007).

The aim of this review is to examine the existing literature to determine how VI in children affects parents' QoL. Two research questions were posed to address this aim: (1) How is parents' QoL assessed? (2) Which are the factors associated with parents' QoL? By presenting a novel global approach to the management of this situation within the framework of family care, we may provide assistance to both children and parents, thus enhancing the children's life participation and satisfaction by means of guiding and assisting their parents.

2. Method

2.1. Search and selection strategy

A thematic search was performed on the PubMed, ProQuest, ERIC and PsycINFO, databases. MeSH terms were used in PubMed and ProQuest, whereas in ERIC and PsycINFO databases search was guided by the terms suggested in their Thesaurus tool. The following equations defined the search of articles regarding caregivers of children/adolescents with visual impairment:

a PubMed and ProQuest: *(parents[MeSH Terms] OR caregivers[MeSH Terms] OR family[MeSH Terms]) AND (vision, low[MeSH Terms] OR vision disorders[MeSH Terms] OR visually impaired persons[MeSH Terms] OR blindness[MeSH Terms])*
b ERIC: *(parents OR child caregivers OR family life) AND (visual impairments OR blindness OR partial vision)*
c PsycINFO: *(Abstract: "parents" OR Abstract: "caregivers" OR Abstract: "family") AND (IndexTerms: "vision disorders" OR IndexTerms: "blind" OR Index Terms: "partially sighted")*

In addition, a secondary literature search was conducted considering the most prevalent visual conditions leading to visual disability in children: retinopathy of prematurity, cortical visual impairment, optic nerve hypoplasia, Leber's congenital amaurosis, retinitis pigmentosa, albinism, cataracts, and glaucoma (Hatton, Ivy, ö Boyer, 2013; Rahi ö Cable, 2003). To continue with the selection process, the following inclusion/ exclusion criteria were stated:

a Inclusion criteria: publications had to be related to children/adolescents with VI, and simultaneously had to refer to the parents experience or to the family context. Papers related to young adults were also included, provided they were under the care of their parents.
b Exclusion criteria: papers related exclusively to the functioning of children or focusing on the assessment of children's QoL, articles regarding visually impaired adults or the elderly population, and those not on topic were excluded.

First, the search was directed at journal articles published in English between 1996 and 2016 in peer-reviewed journals, containing the aforementioned combinations of search terms in the title or the abstract. This preliminary search disclosed 1451 eligible journal articles (406 in PubMed, 439 in ProQuest, 158 in ERIC, and 448 in PsycINFO databases). Secondly, a title selection was conducted. Titles non relevant to or not related to the topic, titles mentioning children but not their parents, those alluding to teachers or to the school context, titles referring to adult/old people, and those describing medical, genetic, etc, aspects were discarded. Thirdly, all remaining abstracts were independently reviewed by the three authors for inclusion in this review. When in disagreement regarding the inclusion of a particular abstract, the full article was retrieved and its contents were carefully examined and discussed until a consensus was reached. Next, duplicated titles were removed. Finally, the reference lists of the included publications were scanned to find additional relevant articles.

In order to gain a wider view of how the existing research has addressed the topic, and a full understanding of the implications of

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