

## **Quality of life among parents of children with visual impairment: a literature review**

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### **Conflict of interest**

None.

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### **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.

*Keywords:* Visual impairment, Children, Adolescents, Parents, Caregivers, Quality of life

## **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 countries, to 15 per 10.000 in poorer countries (Rahi & Cable, 2003; Resnikoff et al., 2004). It often coexists with other impairments or disabilities (Flanagan, Jackson, & Hill, 2003; Rahi & Cable, 2003; Salt & 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, Elsmann, van Nispen, van Leeuwen, & 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, Díaz, & Pallero 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, & 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, & Flynn, 2004). An extensive body of literature exists exploring the relevant QoL domains and the corresponding measurement of their indicators (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Golics, Basra, Salek, & 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 & Ellard, 2006; Gerhardt et al., 2003; Murphy, Christian, Caplin, & 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, & Boyer, 2013; Rahi & Cable, 2003).

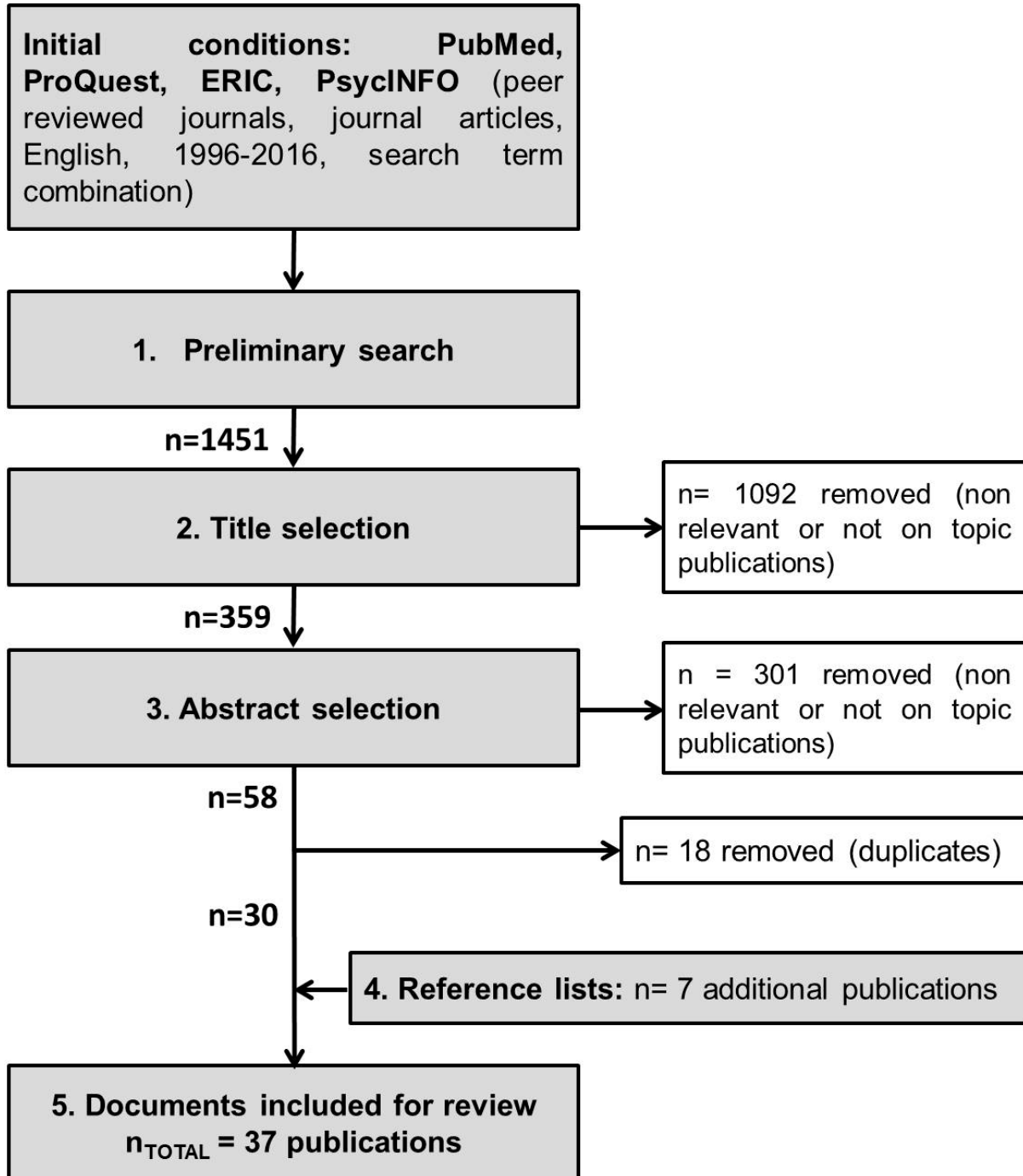
To continue with the selection process, the following inclusion/ exclusion criteria were stated:

- 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 bringing up a child with VI, publications were included irrespective of the study design or data analysis employed by their authors. Following the resulting selection according to these criteria, full copies of all papers were obtained for review. Figure 1 shows the flow diagram of the studies selection process.

**Fig. 1.** Flow diagram on the inclusion process for the review of literature.



## 2.2. Review process

Firstly, the objectives or research questions posed by the authors were listed to determine the scope of the researchers' interests. Secondly, all data gathering and data analysis methods were identified. Next, relevant QoL indicators were retrieved from the results and discussion sections of each paper. Finally papers were grouped to allow for a better approach to our research questions.

## 3. Results and Discussion

A total of 37 articles were found to be relevant to the predefined search terms and inclusion criteria. Nineteen of them (51%) were published in the last five years (2012-2016), fourteen papers were published between 2002 and 2011 (38%), and four papers were published prior to 2002.

More than two thirds of the reported studies focussed on populations from western countries (Europe, United States, and Canada). The remaining publications were based on populations from the Middle-East and Asian countries, Russia, South America, and Africa, thus offering validity to the review in terms of sociocultural variety.

Major topics of interest were the needs and concerns expressed by parents, as well as the impact of VI on family dynamics and relationships, the opinion of parents on the information, care and support provided by professionals, their attitudes towards VI, their emotional reactions, and the factors and coping mechanisms that ease the adjustment to the situation of caring for a child with VI.

To assess parents' QoL indicators most researchers (68%) designed *ad hoc* questionnaires or interview models, although in some occasions they employed them in combination with



one or more validated generic instruments (22%). In almost one third of the studies only generic instruments were used, and focus groups were created in three cases.

Table 1 presents the complete list of the publications included in the review, with summarized information regarding the following items: aim, number of participating parents, children/adolescents' age range, tools used to gather QoL indicators, procedures for data analysis, and main results according to the authors.

### **Table 1**

Summary of relevant articles regarding parents or caregivers of children with visual impairment

Health professionals and researchers in the field of VI in children have directed their interest mainly to the medical and functional characteristics of it, ignoring other aspects that may also affect children's development. For instance, the QoL of parents and caregivers of children with VI has received relatively scarce research attention until recent years. The results of the present review show that this situation may be currently reversing, although there remains a lack of tools to specifically assess it. Two exceptions are the *Ocular Treatment Index*, OTI (Celano, Hartman, & Drews-Botsch, 2013; Drews, Celano, Plager, D. & Lambert, 2003), which was designed to assess the stress of caregivers of children with congenital cataract, and the *Caregiver's Congenital Glaucoma Quality of Life Questionnaire*, CarCGQoL (Gothwal, Seelam, & Mandal, 2015; Gothwal et al., 2016), which measures the QoL of caregivers of children with primary congenital glaucoma. Given this lack of specific instruments, researchers working on this field have designed *ad hoc* tools (questionnaires or interviews), and have also relied on validated generic instruments. In terms of study design, purposive non-probability sampling is generally used, and some criteria such as age of

children, severity of VI, or concurrent presence of other disabilities were inhomogeneous, probably due to the fact that VI in childhood is a rare condition. There is also heterogeneity in methodology and data analysis. Therefore, comparing the results of the various studies is a complex task, and conclusions of this analysis must be interpreted with caution.

In order to approach the discussion of the present findings, four different areas shall be addressed: 1) the view of parents with regards to professional services or care; 2) their concerns and needs; 3) the impact of the child's VI on their daily life, as well as on that of the whole family; 4) and the coping strategies developed by parents and other factors that may assist them to adjust to the situation.

### *3.1. View of parents regarding services, care, and provided information*

Nineteen articles (51%) document the opinion of parents regarding the professional services, and the received assistance and information. Parents are usually satisfied with the provided health services and care. A counterpoint to that is found in the studies of Jackel, Wilson, & Hartmann (2010), Ek (2000), and Facio et al. (2016) relating to parents of children with retinoblastoma, cerebral visual impairment (CVI) and retinopathy of prematurity (ROP), respectively. The authors of the first two papers note that parents complained about the lack of knowledge about the disease evidenced by the health care providers, associating it with a delay in diagnosis and management of the condition. In the last study, a general attitude of indifference towards parents and children is reported, which caused a negative impact on the perception of quality, satisfaction and parental trust related to professional care.

Five articles report that parents value very positively the possibility to access certain specific services. Thus, Ek (2000) describes how parents are allowed to contact the team's psychologist at any time. In this regards, some families described psychological support as a

*life saver*, particularly during the first few months following diagnosis. The contact with professionals and key workers providing emotional relief is a valuable source of support for parents of children with cancer (Mitchell, Clarke, & Sloper, 2006). Lennon, Harper, Lloyd, and Biswas (2008) assessed the usefulness of providing written reports containing relevant and practical information to parents and teachers, who conveyed a high level of satisfaction with them. Similarly, Neofostitou et al. (2014) assessed the satisfaction of parents with an early care service, documenting the program as an important support for the families. Finally, in the study of Rahi, Manaras, Tuomainen, and Lewando-Hunt (2004) both parents and health professionals agreed that a community link team (CLT) was useful in providing emotional, informational and social support, and Speedwell, Stanton, and Nischal (2003) found that written information was valued as useful, but it was supplied too late to positively impact stress levels.

Regarding the content of the received information, parents tend to report as insufficient the information on their children's visual conditions and their consequences, on the services or resources they may seek assistance from, and on their children's upbringing. Killebrew & Corn (2002) document 9 cases, leading the authors to recommend an improvement in the effectiveness of communication between ophthalmologists and parents, given that the knowledge and understanding of parents of their children's visual condition and treatment was found to be worse than the corresponding doctors' perceptions.

Some authors investigated possible gender and ethnicity related differences in the demand of information, also taking into consideration the presence of coexisting impairments (Correa-Torres & Zebehazy, 2014; Dote-Kwan, Chen, & Hughes, 2009; Rahi et al., 2005). These authors observed that additional information was mainly requested by women (as compared to men), people belonging to minority ethnic groups (for whom communication is already a challenge), and parents of children with additional disabilities.

The issue of Internet access to information is briefly mentioned (Facio et al. 2016; Jackel et al., 2010; Lennon et al., 2008). The Internet is found to be a preferred source of information of patients suffering from chronic conditions (Bundorf, Wagner, Singer, & Baker, 2006), thus leading Rahi, Manaras, and Barr (2003) to suggest that health professionals ought to consider the Internet as a valid means to provide patients with easily accessed, useful, reliable, frequently updated and easy to understand information.

### 3.2. *Expressed concerns and needs*

Parents are mainly worried about their children's future and their school performance, also expressing concern about psychosocial issues, family organization aspects (siblings, the couple relationship, leisure time, etc.), and communication with doctors and teachers. Concerns about the future are commonly expressed as uncertainty (*e.g.*, will their child be able to be independent and have school or job opportunities?). The attitude of parents may range from overprotection or hiding the child, to being overly impressed and proud of their children's achievements. This bipolarity is also present in the school context: while some parents prefer special schools, others defend mainstreaming as a way to better reflect the conditions the child shall encounter later in life. Overall, school is not only a concern for the families but also is considered an important source of support to assist in the child's development. Psychosocial concerns of parents reflect fear of their children being mocked by peers, their exclusion in leisure activities, the lack of understanding, sensitivity or compassion of others (children and adults), as well as the inadequacy of the politics on accessibility and inclusion (Fathizadeh et al., 2012; McKillop et al., 2006). DeCarlo, McGwin, Bixler, Wallander, and Owsley (2012) collected the opinions of children and parents by means of two focus groups. The three main topics explored in the parents' group

were expectations, frustrations, and psychosocial aspects. In the children's group, discussion about psychosocial aspects evidenced a predominance of negative over positive comments (*e.g.*, verbal mocking, impotence, physical aggression), leading the authors to conclude that the emotional burden associated with VI may impact children to a higher degree than the parents are led to believe. Castañeda et al. (2016) obtained similar findings in their work relating to children with cataracts and their parents. In contrast, Hamblion, Moore, and Rahi (2011), and Sheppard, Eiser, and Kingston (2005) found that parents had worse perceptions of their children's QoL than the children themselves.

The main need most parents express refers to obtaining more information about their children's visual condition and about the life-spanning repercussions of this condition, as well as receiving a better guidance in terms of the services and resources which may assist them to adapt to the situation, and to normalise it. The need for a better communication and understanding between parents and teachers and for more free time for themselves and the whole family are also frequently mentioned by parents. These findings are in agreement with those of Murphy et al. (2007) in a qualitative study with focus groups of parents of children with several disabilities. The identification of the parents' needs, concerns and demands may facilitate the introduction of modifications into the children-caregivers relationship or in the strategic planning of interventions, as it is amply documented in studies on families of children with special needs (Caicedo, 2014; Jackson et al., 2008). These findings are in partial disagreement with those of Lee, Tsang, and Chui (2014) when comparing the needs for services of three different groups of parents (VI, behavioural problems and control group); Indeed, the authors observed that although the number of needs expressed by the VI group was higher than those of the control group, 8 out of the 10 major needs were common for all groups, leading the authors to suggest that these needs were more related to the general condition of "being parents" than to "being parents of children with special needs".

### 3.3. *Child's visual impairment repercussions on parents and family*

Some publications (19%) describe the grieving process that activates upon receiving news of the child's diagnosis. Non-acceptance, denial or ignorance of the situation result in families not becoming aware of it and, as a consequence, not seeking the information or health services assistance they may require to better care for the child (Pintanel, Gomes, & Xabier, 2013). Some parents express feelings of helplessness, frustration, lack of attachment, or guilt for not understanding their children's behaviour, not accepting their needs or not interpreting their communicative cues. For instance, Lappin (2006) documented 13 types of mother-child interactions, all negative in nature, although only one mother was included in this study. In addition, some parents create overly negative expectations, which may be considered signs of mistrust on their own abilities and those of their child, and low self-esteem (Castañeda et al., 2016; Shibab, 2012; Smyth, Spicer, & Morgese, 2014). In contrast, other parents express family satisfaction (De Klerk & Greeff, 2011; Neofostitou, et al., 2014), stronger family bonds (Leyser & Heinze, 2001), and high self-esteem. For instance, Sola-Carmona, López-Liria, Padilla-Góngora, Daza, and Sánchez-Alcoba (2013) documented higher scores in self-esteem in a group of parents with blind children than in those of a normative sample.

Physical symptoms (extreme emotions, insomnia, etc.) are mentioned in three papers (the latter reporting a single case) in which VI was caused by a carcinogenic tumour giving rise to eye enucleation (Ek, 2000; Sheppard et al., 2005; Ulster & Antle, 2005). However, physical tiredness and burden are commonly reported in descriptive terms. Gothwal et al. (2015) take into account these aspects in their questionnaire to assess the QoL of caregivers of children with congenital glaucoma. The same authors (2016) used this instrument to assess QoL pre

and post glaucoma surgery, reporting that, whereas before surgery 71% caregivers described their QoL to be poor or very poor, with feelings of depression, anxiety, tiredness, anger and irritability, following the intervention this percentage dropped to 20%.

In several of the reviewed publications parents describe the anxiety associated with their child's visual condition. For instance, anxiety is reported using a generic tool and a control group in Lakshmi & Jabeen (2012), and Sola-Carmona et al. (2013). In both studies anxiety scores are higher in the VI group, although statistically significant differences between the VI and control groups are only found in the former study. More recent research by Sola Carmona et al. (2016a) found negative correlations between anxiety and family satisfaction, job satisfaction, and material well-being, also evidencing significant differences in anxiety scores depending on aspects such as the level of knowledge about the child's disability or the perception that parenting a blind child does not affect leisure or job opportunities (Sola-Carmona, 2016b).

Stress is also a QoL indicator frequently reported. For instance, albeit examining a limited number of cases, Fathizadeh et al. (2012) observed that some mothers described stress at feeling the pity or even contempt of others towards them or their children. Similarly, Facio et al. (2016) interviews with 9 parents revealed stress caused by the unreceptiveness of health professionals; on the other hand Speedwell et al. (2003) and Drews et al. (2003) failed to discover significant differences in stress levels between parents of VI children and those of a control group, whereas Lee et al. (2014) and Tröster (2001) encountered these differences, although in the latter no differences were found when parents of children with comorbid impairments were excluded from the VI group. Moreover, Tröster (2001) observed that mothers of children with low vision were more stressed than those of blind children suggesting that the former are more demanding regarding their children's abilities, and underestimate their limitations, or that low vision is a less defined condition than blindness.

This finding may be in agreement with that of Sola-Carmona et al. (2016b) in which better self-esteem scores were found in parents of totally blind children than in those whose children had some visual residue.

The authors of the review realise that, although in most narrative data stress is present, when it is objectively assessed, no significant differences among parents of children with VI and a control/normative group are often found, so, maybe the discrepancy is due to a vital risk absence, unlike e.g. congenital heart diseases (Kaugars, Shields, & Brosig, 2017). Leyser, Heinze and Kapperman (1996) concluded that even if stress and burden are present, families often find mechanisms to cope with them satisfactorily, which is in accordance with the findings of Gerhardt et al. (2003) regarding parents of children with juvenile rheumatoid arthritis.

Regarding the assessment of burden and depression, Dada et al. (2013) found that more than 70% of caregivers showed moderate levels of aggregate burden, with burden reaching severe levels in 5% of cases. The same authors also noted a high prevalence of depression. These findings are in agreement with research conducted on adults with VI and on children with other or coexisting disabilities (Bambara et al., 2009a; Bambara et al., 2009b; Braich, Lal, Hollands, & Almeida, 2012). Likewise, Posokhova et al. (2016) found that parents of children with visual disorders showed a more negative point of view on the children and family situation not only compared to a control group but also compared to those rearing children with hearing disorders.

The relationship between the severity of VI or the presence of comorbid conditions and its impact on the family remains controversial, with inconsistent results amongst the published literature. Some authors conclude that both factors have a negative effect, while others highlight the comorbidity rather than the actual severity of the VI (Sola-Carmona et al., 2016b; Tröster, 2001).



### *3.4. Coping strategies and factors helping adjustment*

Almost half of the studies report coping strategies and other factors that ease the adjustment. Formal and informal support (i.e., health and education professionals, family, friends or groups of parents) are considered crucial for parents and family to adjust to the situation. The support from family and friends is usually mentioned as a major asset for the caregivers of children with chronic illness (Kelso, French, & Fernández, 2005; Nabors, Kichler, Brassell, & Thakkar, 2013). Moreover, communication with other parents is described as an opportunity to share experiences and coping strategies, to become aware of similar concerns and challenges, to improve knowledge of both VI and of the available resources, or to realize that, despite their children's VI, life may be satisfactory.

Some examples of coping strategies parents commonly use and define as empowering are: a conscious attitude of acceptance, an active search for help, a feeling of responsibility towards the child, gaining knowledge about the VI, mutual respect and support within the family, talking about the situation, gaining a positive perspective of the situation, finding time for leisure or respite, helping children developing their skills and to encourage the child's independence, amongst others. In addition, within the family context, better results and better adjustment of all members of the family (including the person with VI) are possible if the family is flexible, adaptable, cohesive, supportive, and well-functioning (Bambara et al., 2009a). Understanding the VI of the child or adolescent as a circumstance that affects the entire family system requires acknowledging the perception of all members of the family, thus allowing the identification and, if necessary, modification of all factors that prevent adaptation and proper functioning, leading to an enhancement of the overall perception of self-efficacy.

### 3.5. *Strengths and limitations of the review*

The study of the experience of caregiving for a child with VI and the impact on the QoL of parents is gaining interest, although published literature has been scarce until recent years. This review highlights some aspects that may assist in planning healthcare and educational practices and policies to improve the QoL of parents. The decision to include in this review papers regardless of study design, methodology or data analysis, even if it may be considered a limitation of the work, responds to an ecological rather than a general approach. In addition, although a rigorous search and selection strategy was conducted, some elements of subjectivity might be present.

## **4. Conclusion**

There is a growing research interest in the field of QoL of parents of children with VI, although the present review revealed that current research efforts remain very eclectic. Specific tools to assess the QoL of parents of children with VI are scarce, albeit a recent developed questionnaire to assess the QoL of caregivers of children with congenital glaucoma may spearhead a hopeful trend for future research in this field. Several QoL indicators were identified in this review, mainly related to the domain of psychosocial well-being and role functioning. Overall, it was found that parents require better and more extensive information and guidance to understand the diagnosis of their children's condition, become aware of the available resources and services, and receive support on how to manage and adjust to the situation; besides, it is underlined that the presence of a social network has a positive impact on empowerment. Professional assistance should focus on these aspects.

**Conflict of interest**

None.

**Ethical approval**

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**Table 1**

Summary of relevant articles regarding parents or caregivers of children with visual impairment

Authors & Country	Study aim	Sample	Children's age range	Data gathering (authorship)	Data analysis	Main results
Castañeda et al., (2016) USA	Determine specific Health-Related Quality of Life (HRQL) and functional concerns affecting both children with cataracts and their parents.	25 mothers + 6 fathers.	0 to 17 years.	- Semi-structured interview (authors).	- Content analysis.	- 5 themes emerged (parents): <i>worry, compensate for condition, treatment, emotions, and affects family.</i>
Celano et al., (2013) USA	Evaluate the caregivers' stress in congenital cataract, and to determine the influence of both treatment and time since diagnosis.	57 mothers + 51 fathers.	11 to 20.5 months.	- <i>PSI</i> (Abidin). - <i>OTI</i> (Drews et al.)	- T test, ANOVA, $\chi^2$ test, ANCOVA.	- Higher levels of stress 3 months after surgery when treatment is intraocular lens vs contact lens, but no group differences at age 12 months (surgery is before 8 months).
Correa-Torres et al., (2014) USA	Study the perception of families with Hispanic backgrounds regarding their interaction with health professionals.	11 mothers.	19 months to 18 years.	- Semi structured interview (authors).	- Content analysis.	- 4 themes emerged: <i>assistance received, need for information or orientation resources, communication, understanding cultural differences.</i>
Dada et al., (2013) INDIA	Assess the magnitude of caregiver burden and depression in parents of children with primary congenital glaucoma (PCG).	53 mothers + 2 fathers.	1 month to 3 years.	- <i>Caregiver Burden Questionnaire</i> (Rudnick). - <i>PHQ-9</i> (Spitzer et al.).	- Mean $\pm$ SD, Median, ANOVA, Bonferroni & Kruskal-Wallis tests.	- Most parents suffered some degree of burden (71% moderate; 5% severe) and depression (36% mild; 22% moderate; 11% severe).
De Klerk et al., (2011) S. AFRICA	Determine the processes and features that help parents to adjust to the circumstances.	5 families.	22 to 25 years.	- Semi structured interview (authors).	- Grounded theory.	- 3 categories: <i>the role of family values, the process of inclusion, the development of a sense of accomplishment;</i> core category: <i>continuing with life.</i>

Decarlo et al., (2012) <i>USA</i>	Identify relevant information to create a vision-targeted HRQL questionnaire for children.	19 mothers + 4 fathers.	6 to 12 years.	- Focus groups: children and parents.	- Frequency of comments, Content analysis.	- 3 main topical areas: <i>glasses and adaptive equipment, psychosocial aspects, school (children); school, expectations and frustrations, psychosocial aspects</i> (parents).
Dote-Kwan et al., (2009) <i>USA</i>	Examine the parents' needs considering ethnicity, home environment, socioeconomic status, and visual functioning in the child's development.	19 mothers + 15 fathers.	11 to 24 months.	- <i>HOME</i> , 0-3 years old, (Badley et al.). - <i>Family Needs Survey</i> (Bailey & Simeonsson).	- ANOVA, $\chi^2$ test.	- Needs diminish with passing time, except those regarding information on provision of services; Significant differences depending on ethnicity.
Drews et al., (2003) <i>USA</i>	Assess caregiver parenting stress in congenital cataract considering diagnosis and treatment, and to develop and validate a specific instrument to assess stress (OTI).	23 mothers + 18 fathers.	2.08 years $\pm$ 9 weeks.	- <i>PSI</i> (Abidin). - <i>OTI</i> (Drews et al.)	- T test, ANOVA.	- Evidence of reliability and validity of OTI is provided; stress levels similar to a normative sample; higher stress levels when unilateral cataract vs bilateral (not significant), and aphakic vs pseudophakic (significant).
Ek, (2000) <i>SWEDEN</i>	Study the emotional reactions in the case of retinoblastoma.	21 families.	1 month to 7 ½ years.	- Interview guide (authors).	- Content analysis.	- Positive aspects: care received, meeting other families; Negative aspects: delay on the diagnosis/ treatment, returning back home, symptoms of acute crisis.
Facio et al., (2016) <i>BRAZIL</i>	Analyse the influence of health professionals' receptiveness on parental care of children with retinopathy of prematurity (ROP).	6 mothers + 3 fathers.	Not reported.	- In-depth interview.	- Narrative analysis.	- 3 themes emerged: <i>informational (un)receptiveness, emotional (un)receptiveness, and (un)receptiveness of their rights.</i>
Fathizadeh et al., (2012) <i>IRAN</i>	Study the experiences of caregivers of blind children, at home or at school.	4 mothers + 4 educators.	Mean age 8 years.	- Non structured deep interview (authors).	- Colaizzi's method.	- 2 main topics emerged: <i>the challenge, and the role of society.</i>

Gothwal et al., (2015) <i>INDIA</i>	Develop and validate an instrument to measure the QoL of caregivers of children with PCG (the <i>CarCGQoL</i> ).	111 caregivers	5,7±8,4 months.	- Focus group. - Semi-structured interview (authors).	- Content analysis.	- Four topics: <i>health and functioning, psychological-spiritual, social and economic, family.</i>
Gothwal et al., (2016) <i>INDIA</i>	Investigate the changes in the QoL of caregivers of children with PCG after glaucoma surgery.	111 caregivers.	5,7±8,4 months.	- <i>CarCGQoL</i> questionnaire (Gothwal et al.).	- Effect size	- Significant improvement after surgery (moderate to large effect size).
Hamblion et al., (2011) <i>UK</i>	Determine the HRQL of children with hereditary retinal disorders and assess its impact on family.	44 parents.	0-16 years.	- <i>PedsQL + Family Impact Module</i> (Varni).	- T test, Bland & Altman method.	- Parents perceive child's HRQL worse than the children themselves; Negative impact on family and functioning as VA worsens.
Jackel et al., (2010) <i>USA</i>	Assess parents' acceptance towards cerebral VI diagnosis (CVI), the support received and their perceptions regarding it.	80 parents.	0-18 years.	- Questionnaire (authors).	- Frequency of answers.	- Negative aspects: little information after diagnosis, not receiving any kind of service, difficulty in receiving proper adjustment or modifications for their children.
Killebrew et al., (2002) <i>USA</i>	Explore communication between parents and ophthalmologists.	7 mothers + 2 fathers.	3 months to 15 years.	- Guided interview (authors).	- Frequency of comments.	- The parents' understanding is worse than the doctors perceive; doctors should be more aware of sources of support for families.
Lakshmi et al., (2012) <i>INDIA</i>	Determine and compare the anxiety levels among parents of children with and without VI.	120 parents.	12 to 17 years.	- <i>IPAT Anxiety Scale</i> (Catell).	- T test.	- Anxiety level higher in VI group; No significant gender differences in VI group.
Lappin, (2006) <i>USA</i>	Study the change in the interaction child-caregiver due to regular child's massage performing.	1 mother.	11 months.	- Interview (author). - Observation.	- Frequency of interactions.	- Interactions turn from 100% negative to 79% positive.
Lee, (2014) <i>CHINA</i>	Identify and compare specific needs among parents of children with VI, with learning/behavioural problems (LB), and no special needs (C).	26 parents VI + 43 LB + 200 C.	8 ½ to 10 ½ years.	- <i>Service Needs Questionnaire, SNQ</i> (Health Department in Hong Kong).	- T test, ANOVA - Kruskal-Wallis test.	- VI group: no significant differences when co-morbid conditions or increased VI severity; Similar needs in VI and LB group (≥ C group); Higher stress levels in VI group than C group.

Lennon et al., (2008) <i>UK</i>	Evaluate the helpfulness of low vision assessment reports.	20 parents + 14 teachers.	9±3 years.	- Questionnaire survey (authors).	- Frequency of answers.	- The reports are useful and easy to understand, although 30% of parents find them too technical.
Leyser et al., (1996) <i>USA</i>	Examine and compare stress, coping strategies, and needs of families who have a child with VI vs families whose children have not VI (C).	130 families VI + 78 C.	10,6±4,7 years (VI); 9,32±3,12 years (C).	- Questionnaire (authors). - <i>FES</i> (Moos & Moos).	- Frequency of answers, T test.	- Significant differences between groups in personal growth and system maintenance; VI families endure stress and burden but it is not always considered as overwhelming; many families turn to social support and proper coping strategies.
Leyser et al., (2001) <i>USA</i>	Examine stresses, coping strategies, education, and changes in family dynamics over time.	130 families.	0-25 years.	- Questionnaire (authors).	- Parents' comments analysis.	- Main concerns: children's needs and future, financial issues, finding services, socialisation; Change to positive attitudes and stronger family ties; Usefulness of social support
McKillop et al., (2006) <i>UK</i>	Compile information on how families deal with the difficulties and cope with the situation.	40 parents/ relatives	Not reported.	- 4 focus groups.	- Parents' comments analysis.	- Betterment of access to information and resources, communication, and school functioning is needed; Family support groups are positively valued.
Neofotistou et al., (2014) <i>GREECE</i>	Estimate families' perceptions on early intervention services and determine if some family specific features are associated with parents' satisfaction.	15 mothers.	0-5 years.	- Modified <i>Dakota Project</i> (Kjerland). - Questionnaire (authors).	- Frequency and average scores, Kruskal-Wallis test.	- High scores in parental overall satisfaction; Neither the children's nor the parents' traits are related to satisfaction.
Pintanel et al., (2013) <i>BRAZIL</i>	Identify the challenging and easy aspects faced by mothers, in order to guide professionals on how to prepare families.	10 mothers.	Not reported.	- Semi structured interview (authors).	- Content analysis.	- Negative aspects: pathology unawareness, health services access, poor information, overburden, over-protection; Facilitators: knowledge regarding VI, thinking of future benefits for the child.

Posokhova et al., (2016) <i>RUSSIA</i>	Identify the system of attitudes in parents of young people having hearing (HD), visual disorders (VD), or no sensory disorders (C),	50 parents VD + 46 HD + 40 C.	≥ 17 years.	- Coping questionnaire. (Didenko) - <i>Semantic differential</i> - <i>Parents' attitude</i> questionnaire (Varga&Stolin).	- T test, Pearson's correlation coefficient.	- Almost all VD parents experience anxiety. They show more negative self-esteem, and more feelings of dissatisfaction and tiredness regarding permanent problems; Few parents estimate the future of their children and their success as high.
Rahi et al., (2004) <i>UK</i>	Explore the impact on parents' experiences and the practices of health carers of a novel community link team (CLT).	79 families pre-CLT + 68 families post- CLT.	2,2±1,7 years.	- <i>MPOC</i> (King). - <i>CSQ</i> (Larsen). - Semi structured interview (authors).	- F and T tests, Content analysis.	- Scores slightly higher in "post" group; statistically significant differences in providing both <i>general</i> and <i>specific information</i> .
Rahi et al., (2005) <i>UK</i>	Investigate parents' needs and experiences with health services, after diagnosis of ophthalmic or VI disorders.	135 mothers +76 fathers.	2,2±1,7 years.	- <i>MPOC</i> - <i>CSQ</i> - Semi structured interview (authors).	- Pearson's correlation coefficient, T and F tests, Content analysis.	- Needs: more information, find other parents, higher professional support; Worse scores in <i>general information</i> ; Positive correlation between MPOC and CSQ scores; <i>general</i> and <i>specific information</i> are the aspects less correlated with <i>satisfaction</i> .
Sheppard et al., (2005) <i>UK</i>	Assess the QoL of retinoblastoma survivors and their mothers.	50 families.	8 to 16 years.	- <i>PedsQL TM 4.0</i> (Varni et al.) - <i>SF-36</i> - Guided interview (authors).	- T test, content analysis.	- Compared with population norms: mothers report lower levels of QoL for their child, and similar or higher levels of their own QoL except in energy/vitality; main concerns: school assistance, and the child's future.
Shihab, (2012) <i>JORDAN</i>	Investigate parents' attitudes towards their children, and the effect of gender, income, and academic levels.	54 mothers and 45 fathers.	Not reported.	- Questionnaire (author).	- T test.	- Being the father, lower income and non-university studies are related to negative attitudes towards VI.

Smyth et al., (2014) <i>USA</i>	Assess the interaction between the child and the adult at meal time and determine if children are less skilful to eat without help.	30 families.	3 months to 3 years.	- Observation, and semi structured interview (authors).	- Content analysis.	- Parents show lack of knowledge and confidence, and anxiety to let children be more independent; the severity of VI affects parents' confidence and expectations.
Sola-Carmona et al., (2013) <i>SPAIN</i>	Describe and analyse the relationship between anxiety, self-esteem, and subjective psychological well-being in families with blind children, and to compare them with normative scores.	33 mothers + 28 fathers.	9,16±4,9 years.	- Questionnaire based on <i>STAI</i> (Spielberger et al.), <i>EBP</i> (Sánchez-Cánovas), and <i>RSES</i> (Rosenberg).	- Mean ± SD, Pearson's correlation coefficient, T test.	- Correlations: psychological well-being and self-esteem (positive), anxiety and psychological well-being, and self-esteem (negative); Compared to normative scores: higher in anxiety and self-esteem, lower in psychological well-being (no significance).
Sola-Carmona et al., (2016) <i>SPAIN</i>	Measure family well-being in parents of blind children.	33 mothers + 28 fathers.	9,16±4,9 years.	- Questionnaire based on subscales of <i>STAI</i> , <i>EBP</i> , and <i>ESFA</i> (Barraca et al.).	- T test, Pearson's correlation coefficient, ANOVA.	- Positive correlations: material well-being and job satisfaction, and family satisfaction; Negative correlations: anxiety and material well-being, and family and job satisfaction.
Sola-Carmona et al., (2016) <i>SPAIN</i>	Investigate the relationship between several personal variables, the family context and the levels of anxiety, subjective psychological well-being and self-esteem in parents of blind children.	33 mothers + 28 fathers.	9.16±4.9 years.	- Questionnaire based on subscales of <i>STAI</i> , <i>EBP</i> , and <i>RSES</i> .	- Mann-Whitney and Kruskal-Wallis tests.	- Less anxiety: rising 1 child, technical qualification, perceiving a salary, non-progressive vision loss, knowledge about the VI, perceiving the child's VI as not affecting leisure/ job opportunities; Better psychological well-being: being married in first nuptials, perceiving the child's condition as not affecting leisure, perceiving one's health as good; Better self-esteem: perceiving the child's condition as not affecting job opportunities.



Speedwell et al., (2003) <i>UK</i>	Investigate the impact of written information on stress levels of parents (VI and control group, C), and determine who should provide information to the parents, and when.	34 parents VI + 43 C.	Up to Primary school.	- Questionnaire (authors). - <i>PSS</i> (Cohen et al.).	- Frequency of answers, T test, Pearson's correlation coefficient.	- No significant differences in stress between groups; positive correlation between children's age and parents' stress in VI group; Information is given too late; most parents don't know who to address.
Tröster, (2001) <i>GERMANY</i>	Compare the stress of mothers of children with and without VI, examine stress domains, and determine which factors contribute to it.	47 mothers VI + 47 control group (C).	8 months to 7 years.	- Questionnaire based on Abidin's <i>PSI</i> (authors).	- ANOVA.	- Stress: VI group > C group; higher stress with comorbid impairments and higher VI severity; no significant differences between groups when the children "only" have VI; VI group perceive less support than C group (regardless of VI severity).
Ulster et al., (2005) <i>CANADA</i>	Present a case study regarding the adaptation of children and families to late onset blindness (retinoblastoma).	1 family.	6 years.	- In-depth interviews.	- Descriptive analysis.	- The process of adjustment is cyclic and eased by social support (staff/parents); Main stressors: medical issues, the future, disagreements between spouses, child's trauma.

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*PHQ-9* = Patient Health Questionnaire; *HOME* = Home Observation Measurement of the Environment Inventory for Children with Severe Handicaps; *CarCGQoL* = Caregiver's Congenital Glaucoma Quality of Life Questionnaire; *PedsQL* = Pediatric Quality of Life Inventory; *IPAT* = Institute for Personality & Ability Testing; *FES* = Family Environment Scale; *MPOC* = Measure of Processes of Care; *CSQ* = Client Satisfaction Questionnaire; *STAI* = State-Trait Anxiety Inventory; *EBP* = Escala de bienestar Psicológico (Psychological Well-being Scale); *RSES* = Rosenberg Self-Esteem Scale; *ESFA* = Escala de Satisfacción Familiar por Adjetivos (Family Satisfaction Scale by Adjectives); *PSS* = Perceived Stress Scale; *PSI* = Parenting Stress index; *OTI* = Ocular Treatment Index.