

MÀSTER de PSICOLOGIA, SALUT i QUALITAT DE VIDA



TREBALL FINAL DE MÀSTER

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Does visual impairment in a child or an adolescent affect their parents' quality of life?
A literature review.

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El propòsit d'aquest treball de recerca ha estat escriure un article científic de revisió de literatura sobre de quina forma afecta en la qualitat de vida dels pares el fet de tenir un fill amb un dèficit visual.

Poder aconseguir el meu propòsit comportava documentar-me sobre com s'ha orientat la recerca sobre el paper del cuidador del malalt crònic en general, per després centrar-me en la literatura existent relacionada amb l'impacte que té, sobre els pares i la família, el fet que un infant tingui un dèficit visual, entenent-lo com un cas particular de condició crònica.

Vaig enfocar el Pràcticum I a fer una cerca exhaustiva en diferents bases de dades, i vaig obrir un compte a Mendeley per organitzar la informació. En aquesta primera fase vaig poder recopilar bastants articles relacionats amb l'adaptació, la intervenció, o l'ajust familiar a les condicions cròniques en general, però força menys relacionats amb els cuidadors de persones amb dèficit visual, cosa que denotava que aquest tema s'ha tractat relativament poc fins ara. Per aquesta primera selecció em guiava pels abstracts dels articles. Vaig reunir un total de 110 documents (100 articles publicats en revistes científiques, 5 tesis doctorals, i 5 informes tècnics/líbres).

El Pràcticum II i el Treball Final de Màster (TFM) els he cursat simultàniament durant el primer semestre del curs 2014/15. Fer una segona volta afinant més en els paràmetres de cerca i seguir algunes referències dels articles trobats m'ha permès, finalment, seleccionar-ne 24 dedicats als cuidadors de nens amb dèficit visual, com a material d'anàlisi per a desenvolupar el TFM.

Les tasques que he fet durant el semestre següent les indicacions i els consells pràctics del tutor per concentrar el meu esforç han estat les següents:

- Preparar-me per escriure un article científic a partir de material que ens va proporcionar el tutor, consultant llocs web de revistes científiques on en ocasions s'hi troba informació molt interessant al respecte, i cercant articles de revisió de literatura publicats, que em poguessin orientar sobre com plantejar i desenvolupar el que hauria d'escriure jo.
- Confeccionar un mapa conceptual de la meua proposta d'article, anotant idees a desenvolupar en cadascun dels apartats, tenint en compte a quin públic li pot interessar, (p.e. psicòlegs, optometristes, rehabilitadors visuals), i què el pot diferenciar d'altres articles ja publicats. Reconec que fer això com a pas previ m'ha estat molt útil, després.
- Llegir els 24 articles seleccionats, i per cadascun d'ells, confeccionar una fitxa on he sintetitzat la informació que he trobat interessant per tenir en compte.
- Llegir i resumir alguns dels articles guardats a Mendeley (fora de la selecció dels 24 esmentats més amunt) per confeccionar els apartats d'introducció i de discussió.
- Escriure una temptativa d'abstract en un termini acotat pel tutor, i després, fer una cerca de possibles revistes on podria enviar el meu article (emprant unes eines de cerca que ens va proporcionar el mateix tutor). Tenint en compte factors com l'objectiu i l'abast de la revista, la periodicitat de publicació, i si s'hi poden trobar articles relacionats amb el meu tema de treball, entre altres, tinc quatre opcions per valorar, dues relacionades amb la recerca en optometria o baixa visió/ceguesa, i dues més, relacionades amb la recerca sobre qualitat de vida en general.
- Escriure l'article, revisar-lo, i traduir-lo a l'anglès.

Agraeixo al meu tutor l'orientació, els bons consells, i el suport que m'ha proporcionat.

Does visual impairment in a child or an adolescent affect their parents' quality of life? A review of literature.

Marta Lupón i Bas

ABSTRACT

The comprehensive care of people with visual impairment includes the coordinated action of ophthalmology, optometry, rehabilitation and, often, psychology professionals. When the visually impaired subject is a child or an adolescent, the parents and the school are also involved. There is an important body of research to guide the school framework; however, it seems that there are gaps in the support and the guidance offered to parents. **Aim:** to determine whether the existing research shows that having a child with a visual impairment affects their parents' quality of life and, if it is the case, in what way it does. **Methods:** a thematic search of articles published in English in peer-reviewed journals, from 1995 to 2014, in the ERIC, Proquest, PsycINFO and PubMed databases has been conducted. **Results:** from the selection of 24 papers, it has been possible to identify the common and non-common aspects on the assessment of parents on professional services or the care they receive, the impact of the children's visual impairment on an individual or a family level, the expressed needs and concerns, and the coping strategies and factors that facilitate adjustment. Major coincidences have been found in the parents' satisfaction regarding the care provided by the professionals, in the need of a more extensive information and guidance, and in the fact that the issues that generate a greater concern are the children's future, the school, and psychosocial aspects. Some of the papers reported higher levels of anxiety and perceived stress than those in parents of children without visual impairment, but the results are not always regular. It has also been found that in many cases multiple coping strategies are used, which allow the success of the adjustment (individual and family) and by contrast, negative attitudes from parents often denote gaps in expectations of self-efficacy and empowerment. **Conclusions:** having a child with a visual impairment can affect the parents' quality of life in several ways. To cope with the children's condition and its consequences, it seems reasonable that, from a psychological perspective, the design of a psychoeducational program (in the conventional or in the eHealth ways) can be conceived, based on providing information, training in problem-solving and cognitions control, reinforcing strengths, and reducing anxiety and stress, in order to cover the need for information and guidance, and to improve the perception of self-efficacy and the empowerment of parents.

Keywords: visual impairment, low vision, blindness, children, adolescents, parents, caregivers, family adjustment, quality of life.

La deficiència visual de l'infant o l'adolescent, afecta la qualitat de vida dels seus pares? Una revisió de la literatura.

RESUM

L'atenció integral envers les persones amb deficiència visual comprèn l'acció coordinada de professionals de l'oftalmologia, l'optometria, la rehabilitació, i sovint, de la psicologia. Quan es tracta d'infants i adolescents, hi participen també els pares, i l'escola. El cos d'investigació ha permès orientar el marc escolar, en canvi, sembla que hi ha mancances en el suport i l'orientació dels pares. **Objectiu:** esbrinar si la investigació existent constata que el fet de tenir un fill amb un dèficit visual afecta la qualitat de vida dels seus pares i, en cas afirmatiu, de quina manera. **Mètode:** s'ha fet una cerca temàtica d'articles publicats en anglès en revistes *peer reviewed* entre els anys 1995 i 2014 en les bases de dades ERIC, Proquest, PsycINFO i PubMed. **Resultats:** a partir de la selecció de 24 articles s'ha pogut identificar aspectes comuns i no comuns sobre la valoració que fan els pares dels serveis professionals o l'atenció rebuda, les repercussions del dèficit visual del fill en el pla individual i familiar, les preocupacions i necessitats expressades, i les estratègies d'afrontament i factors que faciliten l'ajust. En el que s'ha trobat més coincidència és en la satisfacció dels pares respecte l'atenció rebuda per part dels professionals, en les necessitats de major informació i orientació, i en què els temes que generen major preocupació són el futur dels fills, l'escola, i els aspectes psicosocials. En alguns dels treballs es documenten nivells d'ansietat i estrès percebut més elevats que en pares de nens sense dèficits, però els resultats no són sempre uniformes. S'ha trobat també que en molts casos s'assoleix l'ajust a la situació emprant múltiples estratègies d'afrontament, i que les actituds negatives dels pares solen denotar mancances en les expectatives d'autoeficàcia i l'empoderament. **Conclusions:** tenir un fill amb un dèficit visual pot afectar de forma molt diversa la qualitat de vida dels seus pares. Per fer front a la condició dels fills i el que en deriva, és raonable que des de la psicologia es pensi en el disseny d'un programa psicoeducatiu, presencial o a través dels formats de la eHealth, basat en la informació, l'entrenament en solució de problemes i el control de cognicions, el reforç de fortaleces, i la reducció de l'ansietat i l'estrès, de manera que quedin cobertes les necessitats d'informació i orientació, i millori la percepció d'autoeficàcia i l'empoderament dels pares.

Paraules clau: deficiència visual, baixa visió, ceguesa, nens, adolescents, pares, cuidadors, ajust familiar, qualitat de vida.

La deficiencia visual del niño o el adolescente ¿afecta a la calidad de vida de sus padres? Una revisión de la literatura.

RESUMEN

La atención integral hacia las personas con deficiencia visual comprende la acción coordinada de profesionales de la oftalmología, la optometría, la rehabilitación, y, a menudo, de la psicología. Cuando se trata de niños y adolescentes, también participan los padres, y la escuela. El cuerpo de investigación ha permitido orientar el marco escolar, sin embargo, parece que existen carencias en el apoyo y la orientación de los padres. **Objetivo:** averiguar si la investigación existente constata que tener un hijo con un déficit visual afecta a la calidad de vida de sus padres y, en caso afirmativo, de qué modo. **Método:** se ha realizado una búsqueda temática de artículos publicados en inglés en revistas *peer reviewed* entre los años 1995 y 2014 en las bases de datos ERIC, Proquest, PsycINFO y PubMed. **Resultados:** a partir de la selección de 24 artículos se han podido identificar aspectos comunes y no comunes sobre la valoración de los padres hacia los servicios profesionales o la atención recibida, las repercusiones del déficit visual del hijo en el plano individual y familiar, las preocupaciones y necesidades expresadas, y las estrategias de afrontamiento y factores que facilitan el ajuste. Donde se ha hallado mayor coincidencia es en la satisfacción de los padres respecto a la atención recibida por parte de los profesionales, en las necesidades de mayor información y orientación, y en que los temas que generan mayor preocupación son el futuro de los hijos, la escuela, y los aspectos psicosociales. En algunos de los trabajos se documentan niveles de ansiedad y estrés percibido más elevados que en padres de niños sin déficits, pero los resultados no son siempre uniformes. Se ha hallado también que en muchos casos se logra el ajuste a la situación empleando múltiples estrategias de afrontamiento, y que las actitudes negativas de los padres suelen denotar carencias en las expectativas de autoeficacia y el empoderamiento. **Conclusiones:** tener un hijo con un déficit visual puede afectar la calidad de vida de sus padres de formas muy diversas. Para afrontar la condición de los hijos y lo que deriva de ello, es razonable que desde la psicología se piense en el diseño de un programa psicoeducativo, presencial o a través de los formatos de la eHealth, basado en la información, el entrenamiento en solución de problemas y el control de cogniciones, el refuerzo de fortalezas, y la reducción de la ansiedad y el estrés, de modo que queden cubiertas las necesidades de información y orientación, y mejore la percepción de autoeficacia y el empoderamiento de los padres.

Palabras clave: deficiencia visual, baja visión, ceguera, niños, adolescentes, padres, cuidadores, ajuste familiar, calidad de vida.

INTRODUCTION

Visual impairment, low vision, and blindness, in children and adolescents

Visual impairment (VI) is a functional limitation of the eyes and/or the visual system that can appear in the form of visual acuity (VA) loss, visual field (VF) loss, contrast sensibility loss, photophobia, image distortion, diplopia, etc. It can cause different disability levels when it cannot be corrected, improved or recovered by any medical or surgical treatment, nor glasses or contact lenses. The classification of severity of visual impairment is based on the maximum visual acuity and/or the maximum central visual field attained in the best corrected eye. According to the 10th revision of the *International Statistical Classification of Diseases and Related Health Problems*, ICD-10 (“H-54 Visual impairment including blindness”, 2015), the visual impairment degree is considered moderate when $0.3 > VA^1 \geq 0.1$, severe when $0.1 > VA \geq 0.05$, and it is considered blindness when $VA < 0.05$ and/or $VF < 10^\circ$. It is common to use the expression low vision (LV) for moderate and severe impairments.

Visual impairment in childhood is a low prevalence condition, with an average value of 6 or 7 per 10.000, with a range from 3 per 10.000 in socioeconomically developed countries, to 15 in 10.000 in poor countries (Rahi & Cable, 2003; Resnikoff et al., 2004), and often coexists with other impairments or disabilities (Flanagan, Jackson, & Hill, 2003; Hatton, Ivy, & Boyer, 2013; Mervis, Boyle, & Yeargin-Allsopp, 2002; Rahi & Cable, 2003; Salt & Sargent, 2014).

Vision is an extremely important factor in our learning process and it is a non-verbal communication channel that regularises the interaction between people. The presence of a VI can affect the child's global development (motor, cognitive and psychosocial). Children's learnings are highly influenced by observation and modeling, and eye contact plays an important role in the forging of affective bonds and in expressivity. Vision is also key in motor development because children's curiosity for their surroundings usually motivates them to move around, to use their hands, etc. In older children, vision is especially related not only to academic learning but also to other aspects like sports practice, autonomy, relationships, etc. (Checa, Díaz, & Pallero 2003; Shute, 1991). Using the terminology found in World Health Organization (WHO) *International Classification of Functioning, Disability and Health*, VI can cause activity limitation and participation restriction of children, which is aggravated if they suffer from additional disabilities and/or impairments. In this last case, it is very important to detect anomalies in the visual system or visual function in order to strengthen ability vs. disability which, unfortunately, is not always taken into account. We can find an example of it in a recent study carried out in Welsh special education schools (Woodhouse, Davies, McAvinchey, & Ryan, 2013), where it was found that a significant proportion of children (42% of 173) had never had a previous eye test and, from the 100 who had previously undergone an eye test, 46 of them had been prescribed spectacles but only half of them were wearing them (23).

Therefore, it is reasonable to think that the presence of a moderate or severe VI, or blindness, besides affecting the children, somehow it will also have an impact on those who take care of them: parents and, by extension, the whole family.

Quality of life

Quality of life (QoL) is a multidimensional concept that reflects the global welfare. WHO defines it as the “individuals' perception of their position in life in the context of the culture and value systems in

¹ Different visual acuity (VA) notations are accepted. In this paper it is expressed in decimal notation, but it can also be expressed in fractions, in metres (e.g. $0.3 = 6/18$) or in feet (e.g. $0.3 = 20/70$), and in a logarithmic scale (logMAR).

which they live and in relation to their goals, expectations, standards and concerns” (WHOQOL: “Measuring Quality of Life”, n.d.). Shalock (2004) analysed the literature on the QoL, from which it has been possible to identify that *interpersonal relations, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and rights* are the core QoL domains, and invites us to look at it within Bronfenbrenner’s ecological model framework. Apart from this core domains, he also speaks about QoL core indicators that express more specific aspects of each core domain, which are typically used when assessing QoL (i.e. autonomy, lack of stress, or financial status).

This approach is very useful when trying to answer the suggested research question, that provides the title of this article, and that will guide this project’s development.

The caregiver’s role

Caregiving someone who suffers from a permanent disease or disability affects the caregiver’s quality of life to a greater or a lesser degree. The research on this topic has generated a vast literature on establishing the dimensions of the quality of life to be taken into account (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Gibbons, Ross, & Bevans, 2014; Glozman, 2004; Golics, Basra, Salek, & Finlay, 2013), as well as measuring its indicators (Lehan, Arango-Lasprilla, Macias, Aguayo, & Villaseñor, 2012; Roth, Haley, Owen, Clay, & Goode, 2001; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999; White, Poissant, Côté-LeBlanc, & Wood-Dauphinee, 2006; Sautter, et al., 2014). Accepting the responsibility of being a caregiver can increase stress levels, and affect the individual’s physical (fatigue, sleep deprivation, etc.), psychological (suffering, anxiety, depression, etc.) and social (economic environment, workplace, relationship bonds, etc.) areas. When speaking about children with impairments, this role usually falls on the parents. In fact, parents are assigned with the role of caregivers from the moment they become parents because they are constantly looking after their children’s physical, intellectual, social and emotional development, and they prepare them for the future. To play this part means to deal with a wide range of time-changing factors like nutrition, security, academic progress, physical activity, autonomy, etc., which can be understood as a challenge in itself and its requirements increase when their children suffer from some kind of disease, disability and/or impairment; this statement is confirmed by the results obtained in researches focused on parents whose children need special care, whether it is generic or related to specific conditions/diseases (Barlow & Ellard, 2006; Everhart, Fiese, & Smyth, 2008; Gerhardt et al., 2003; Lindvall, et al., 2014; Murphy, Christian, Caplin, Young, 2007; Raina et al. 2005; Van Cleave, Heisler, Devries, Joiner, & Davis, 2007; Wallander, Pitt, & Mellins, 1990).

The aim of this project has been to review the literature in order to find if the visual impairment in a child affects their parents’ or caregivers’ quality of life, and how. We are also interested in knowing if parents whose children are healthy and don’t suffer from any impairment have a different perception of their QoL than those who have children with a visual impairment, chronic diseases or other disabilities. This project’s ultimate aim is to establish a framework that allows us to deal with visual impairments on children and adolescents from a global perspective on family care, in order to help them adjust to the situation and lead a life as normal as possible.

METHODS

A thematic search was conducted between April and December 2014. I looked for articles related to caregivers of children with visual impairment in the ERIC, Proquest, PsycINFO and PubMed databases using the following key words, or a combination of them: “parents OR family OR carers OR caregivers”, “visual* impair*”, “visual* impair* child*”, “quality of life” “blind children”, “children with low vision”, “paediatric population”, “coping strategies”, “family adjustment”.

Inclusion and exclusion criteria

The search was directed to find articles published in English in peer reviewed international journals between 1st of January 1995 and 31st December 2014, comprising the key words mentioned above, in the title or the abstract.

Only the publications where the population with visual impairment referred were children and adolescents, and simultaneously made reference to the parents or the family context, were selected. Because the number was not very profuse, we decided to include two references more, where the visually impaired people were young adults (up to 25 years) who were in charge of their parents. Therefore, the papers where the visually impaired population were adults or elderly, or related to the functioning at school or scholar strategies (not including home environments) were discarded.

Additional publications, identified by reviewing the reference list of the articles initially selected which met the inclusion criteria, were also included.

Because of the type of design or data analysis employed, no publication has been excluded.

After taking into account these criteria, 24 publications were selected. The next step of the process has been to read full articles, in order to make a synthesis of the results and to discuss them, as shown in the following sections.

RESULTS

According to the searching parameters, 24 articles that report on what it means for parents to have a child with visual impairment, have been selected

Half of those articles have been published in the last 5 years, from 2010 to 2014 (Correa-Torres & Zebehazy, 2014; Decarlo, McGwin, Bixler, Wallander, & Owsley, 2012; De Klerk & Greeff, 2011; Fathizadeh et al., 2012; Hamblion, Moore, & Rahi, 2011; Jackel, Wilson, & Hartmann, 2010; Lakshmi & Jabeen, 2012; Lee, Tsang, & Chui, 2014; Neofotistou et al., 2014; Pintanel, Gomes, & Xavier, 2013; Shihab, 2012; Smyth, Spicer, & Morgese, 2014). From the other half, eleven of them were published between 2000 and 2009 (Dote-Kwan, Chen, & Hughes, 2009; Ek, 2000; Lappin, 2006; Lennon, Harper, Lloyd, & Biswas, 2008; Leyser & Heinze, 2001; McKillop et al., 2006; Rahi, Manaras, Tuomainen, & Lewando-Hundt, 2004; Rahi, Manaras, Tuomainen, & Lewando-Hundt, 2005; Speedwell, Stanton, & Nischal, 2003; Tröster, 2001; Ulster & Antle, 2005), and the last one between 1995 and 1999 (Leyser, Heinze, & Kapperman, 1996).

Many of these studies have been carried out based on the United States population (Correa-Torres & Zebehazy, 2014; Decarlo et al., 2012; Dote-Kwan et al., 2009; Jackel et al., 2010; Lappin, 2006; Leyser et al., 1996; Leyser & Heinze, 2001; Smyth et al., 2014) and United Kingdom's population (Hamblion et al., 2011; Lennon et al., 2008; McKillop et al., 2006; Rahi et al., 2004; Rahi et al., 2005; Speedwell et al., 2003) but there are some that refer to other European countries (Ek, 2000; Neofotistou et al., 2014; Tröster, 2001), Canada (Ulster & Antle, 2005), South America (Pintanel et al., 2013), Africa (De Klerk & Greeff, 2011), and Asian and Oriental countries (Fathizadeh et al., 2012; Lakshmi & Jabeen, 2012; Lee et al., 2014; Shihab, 2012). Therefore, even though it is scarce, these 24 articles gather a certain degree of sociocultural diversity (Table 1).

Table 1. List of articles according to the country where the study was carried out.

USA	United Kingdom	Germany	Sweden	Greece	Brazil	Canada	Iran	Jordan	India	China	South Africa
8	6	1	1	1	1	1	1	1	1	1	1

In a global sense, they study the aspects related to the needs for information, communication, assistance and support, expressed by the caregivers of children with VI (usually, parents), and the emotional reactions, its impact on family bonds and dynamics, personal experiences, and coping strategies to adjust to their life's situation.

Table 2 is a synthetic list of the articles that contains the following sections: authors and publication dates, aim(s), number of participating parents, children and/or adolescents' age range, VI degree, tools used to assess how parents are affected by their child's visual impairment, methods employed by authors in the data analysis, and a summary of the main results.

Table 2. Summary of the selected articles.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment severity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Correa-Torres, S.M., & Zebehazy, K.T. (2014).</i>	Study the perception of families with Hispanic backgrounds on the interaction between them and those who take care of children who suffer from a VI, and the assistance they received.	11 mothers.	≤ 3 years old (5) ≤ 7 years old (4) 18 years old (1) N/A (1)	Parents report whether their children are "visual learners or not" 6 are, 4 are not, and 1 is/is not.	- Semi structured interview (authors).	- Content analysis.	- 4 themes: <i>assistance received, communication issues, need for information and resources orientation, and understanding cultural differences.</i>
<i>De Klerk, H., & Greeff, A. P. (2011).</i>	Research in processes and features that help parents of visually impaired children to adjust to the circumstances.	5 families.	22 years old (1) 23 years old (3) 25 years old (1)	Parents report VA: between 0.1 and 0.15.	- Semi structured interview (authors).	- Glaser & Strauss' grounded theory principles.	- 4 categories: <i>the role of family values, the process of inclusion, the development of a sense of accomplishment, core category is continuing with life.</i>
<i>Decarlo, D.K., McGwin, G. Jr., Bixler, M.L., Wallander, J., & Owsley, C. (2012).</i>	Identify through focus groups, relevant information in order to create a vision-targeted Health-Related Quality of Life (HRQoL) questionnaire designed for children aged 6 to 12 years old.	19 mothers + 4 fathers.	6 to 12 years old: ≤ 7 years old (3) ≤ 10 years old (13) ≤ 13 years old (8)	Medical records: better VA between 20/40 and 20/800.	- Focus groups: 6 focus groups for children + 6 focus groups for parents.	- Positive (p), negative (n) and neutral (ns) comments counting. - Content analysis.	- Children's group: 36,7% p and 51,55% n; topical areas: <i>glasses and adaptive equipment, psychosocial aspects, school, mobility, symptoms, and participation</i> (social activities, leisure, sports...). - Parents' group: 37,6% p and 45,9% n; topical areas: <i>school-related comments, expectations and frustrations, psychosocial aspects, glasses and adaptive equipment, and symptoms.</i>
<i>Dote-Kwan, J., Chen, D., & Hughes, M. (2009).</i>	Examine the influence of home environment, socioeconomic status and visual functioning on the perception of Latino and Anglo background family needs, in their child's development.	19 mothers + 15 fathers.	11 to 24 months at selection: ≤ 18 months (13) ≤ 24 months (6)	Not stated who reports it. VA from <i>lack of perception of light</i> until 20/200.	- <i>Home Observation Measurement of the Environment Inventory for Children with Severe Handicaps</i> , HOME, 0-3 years old, (Badley et al.). - <i>Family Needs Survey</i> (Bailey & Simeonsson).	- ANOVA and χ^2	- In general, their needs diminished with time but those regarding information of the services provided didn't change (present and future). - Significant differences were found in the most valued needs depending on ethnicity.

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Ek, U. (2000).</i>	Study the emotional reactions, from the children and the family's point of view, when retinoblastoma was diagnosed.	21 families.	1 month to 7 and a half years (22)	Clinical diagnosis. Unilateral enucleation and, in 50% of the cases, treatment of the other eye.	- Interview guide covering the following themes: diagnosis and treatment, emotional reactions, information and support (authors).	- Content analysis.	- 62% of the families were satisfied with the care offered; complaints: some people complained about the delay on the diagnosis or the treatment. - The assessment on hospital care was positive but, it was not the case of the return back home; some families considered essential the psychological support that was provided. - 16 families described symptoms of acute crisis before going back to normal; in 2 of the 4 cases there was not this original reaction, it occurred when the worst had passed. - During the first period, finding other families in the same situation was considered the most therapeutic aspect. - In less than one year, most families did not need assistance.
<i>Fathizadeh, N., et al. (2012).</i>	Study the experiences of blind children caregivers, at home or at education centres.	4 mothers + 4 education centres' caregivers.	Average age: 8 years old (the n° of children is not given)	It is only stated that the children are blind.	- Non structured deep interview (authors).	- Colaizzi's method.	- 2 main topics: the <i>challenge</i> , and the <i>role of society</i> .
<i>Hamblion, E.L., Moore, A.T., & Rahi, J.S. (2011).</i>	Research on the HRQoL of children who suffer from hereditary retinal disorders, and assess its impact on the children's families.	44 parents.	0-16 years old (44) 0-4: there are no self-report (6)	Clinical diagnosis. VA logMar: <0.5 (8) 1≥AV≥0.5 (11) ≥1.01 (19) n/a (6)	- <i>Pediatric Quality of Life Inventory, PedsQL</i> (Varni), children and parents versions. - <i>PedsQL Family Impact Module</i> (Varni).	- T test - Bland and Altman's method.	- Parents assessed their child's HRQoL to be worse than that self-reported by the child - The parent scores in family impact and functioning decreased along with the VA (worse).

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Jackel, B., Wilson, M., & Hartmann, E. (2010).</i>	Find out how parents accepted their children's diagnosis for cerebral visual impairment (CVI), the parents' support given, the educational aids for children, and what the parents' perceptions of the supports that they and their children receive.	80 parents.	≤ 1 year old (2) ≤ 3 years old (35) ≤ 7 years old (24) ≤ 12 years old (12) ≤ 18 years old (7)	They informed the parents. VA≥20/70 (8) VA between 20/70 and 20/160 (11) VA=20/200 (12) n/a (49) 74% of the parents suspect of VF loss.	- Questionnaire (authors).	- Answer frequency.	- Most of the parents had been given information at the time of diagnosis; 51% had not been informed afterwards or had found out by their own means (69%). - 42% of the parents had received the necessary services, and 35% had not been given any kind of service for their child. - 35% of the parents found it difficult to get appropriate accommodations or modifications for their children.
<i>Lakshmi, N., & Jabeen, Z. (2012).</i>	Find out and compare the parental anxiety among the visually and not visually impaired children	120 parents.	12 to 17 years old. (120= 60 with VI and 60 without VI)	It is only stated that the children are visually impaired	- <i>IPAT Anxiety Scale</i> (Catell).	- T test.	- Parents whose children have a VI: there were not significant differences depending on gender (neither child nor parent); the anxiety levels were higher than those from parents with healthy children.
<i>Lappin, G. (2006).</i>	Study the dynamics between a blind child and his caregiver, and have a better knowledge of the dyadic interaction when a children's massage is performed on a regular basis.	1 mother.	11 months (1)	It is only stated that the child suffered a severe VI since birth.	- First interview with the caregiver (author). - Observation of the behaviours and the interactions.	- Positive and negative interactions counting.	- Interactions went from being 100% negative to being 79% positive.. - The mother's communication was more sensitive and self-effective; the child's response was reciprocal.
<i>Lee, F.M.Y., Tsang, J.F.K., & Chui, M.M.I. (2014).</i>	Identify the specific needs of parents with visually impaired children (VI group) studying in mainstream schools, and compare them to those of parents whose children do not have special needs (N group), and to those of parents whose children have learning and behavioural problems (LB group).	26 mothers/ fathers in the VI group. 200 mothers/ fathers in the N group. 43 mothers/ fathers in the LB group.	Average age: between 8 and 11 years old (26).	Optometric examination. Mild LV: VA between 6/18 and 6/60 (18); Moderate and severe LV: VA between 6/60 and 6/120, and VA 6/120 or worse (8).	- <i>Service Needs Questionnaire, SNQ</i> (Child Assessment Service of the Health Department in Hong Kong).	- T test, ANOVA, and Kruskal-Wallis.	- In the VI group, there was no significant difference in SNQ total score between those with or without co-morbid conditions nor according to LV levels were found. - VI group service needs were similar to those in LB group, and were higher than the N group ones. - Stress was higher in VI group than in N group. - 77% of the parents didn't go to any self-help group.

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Lennon, J., Harper, R., Lloyd, C., & Biswas, S. (2008).</i>	Evaluate how helpful parents and those working in the educational setting found written low vision assessment reports.	20 mothers/ fathers + 14 teachers.	9±3 years old (25).	It is only stated that the children are visually impaired.	- Self-administered questionnaire survey with two versions: one for the parents and one for the teachers (authors).	- Answer frequency.	- The report was considered to be easy to understand (but 30% of parents thought it contained too many technical terms).
<i>Leyser, Y., Heinze, A., & Kapperman, G. (1996).</i>	Examine stress, coping strategies, and the needs of a group of families who have a child with VI, and comparing them to a group of families whose children are not visually impaired.	130 families with visually impaired children + 78 families whose children are not visually impaired.	10.6 ± 4,7 years old in the VI group (130). 9,32 ± 3,12 years old in the group without VI (78).	Not stated who reports (parents?): Mild (26) Moderate (47) Severe (57)	- Parent questionnaire (authors). - <i>Family Environment Scale, FES</i> (Moos & Moos).	- Answer frequency. - T test.	- Worrying issues: the <i>future</i> and the <i>children's needs</i> , <i>financial concerns</i> , <i>finding services</i> , <i>time available for themselves or their spouse</i> , <i>impact on siblings</i> , and the <i>lack of understanding or socialising</i> . - More than 50% of the parents hadn't been offered any kind of family counselling. - Personal support sources: family, friends and other parents of visually impaired children. - FES: significant differences were found between groups in <i>personal growth</i> , and <i>system maintenance</i> , but not in <i>relationship</i> .
<i>Leyser, Y., & Heinze, T. (2001).</i>	Examine stresses, coping strategies, education, and changes in family dynamics over time, in families having a child with VI. (This article is a continuation of the previous one; the authors focus on the open-ended comments and statements parents made in the questionnaire).	130 families.	0-6 years old (28) 7-13 years old (66) 14-25 years old (36)	Reported by the children's teachers: Mild (26) Moderate (47) Severe (57)	- Parent questionnaire (authors).	- Parents' comments analysis.	- A common concern is the future, but also mocking, provision of medical services, and information about assistance; many parents are worried about the mainstreaming programs and the teachers. - There were positive comments on the VI impact (<i>e.g. more understanding</i>) as well as negative (<i>e.g. stress, deterioration, frustration</i>). - Formal and informal support was positively valued.

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
McKillop, E., et al. (2006).	Compile information on how families deal with the difficulties that children with CVI have and cope with the situation, working with focus groups of caregivers.	40 caregivers (mothers, fathers, grandparents, etc.)	Not reported (17 children).	Paediatric ophthalmology clinic's patients who show symptoms of poor visual information processing (17).	- 4 focus groups.	- Parents' comments analysis.	- The need for a better access to information and resources was suggested (CVI entails many social problems). - Communication between those who were with the children in a regular basis was considered essential in order to share coping strategies (including teachers). - Parents found family support groups very useful.
Neofotistou, K., et al. (2014).	Estimate families' perceptions concerning the effectiveness of early intervention services and determine whether specific characteristics of the families are associated with parents' satisfaction.	15 mothers.	0-5 years old (15)	Mothers are the ones reporting: - Partial VI (7) - Perception of the light (6) - Total VI (2)	- Modified version of the <i>Dakota Project</i> (Kjerland et al.). - Questionnaire including personal characteristics of each family (authors).	- Frequency and average scores. - Kruskal-Wallis.	- High scores were obtained in all parental satisfaction aspects. - The children and the parents' traits were not related to parental satisfactions.
Pintanel, A.C., Gomes, G.C., & Xavier, D.M. (2013).	Identify the difficult and easy aspects faced by mothers of visually impaired children, in order to guide professionals on how to prepare families.	10 mothers.	Not reported (10).	It is only stated that the children are visually impaired.	- Semi structured interview (authors).	- Content analysis.	- 2 themes: <i>difficult</i> and <i>easy</i> aspects to face. - Unawareness regarding the pathology, lack of access to health services; the information received was considered to be poor. - Overburden caused by the child's need of permanent care and the father's lack of support. - Over-protection and infantilism. - It is hard to find easy aspects: mothers take the role of caregivers thinking about their children's future benefits. - For some mothers, a factor that made it easier was the acquisition of knowledge regarding VI.

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Rahi, J.S., Manaras, I., Tuomainen, H., & Lewando-Hundt, G. (2004).</i>	Find the impact on the experiences of parents and the practices of health care professionals of a novel, hospital-based, key worker service (Community Link Team, CLT).	79 families pre-CLT (1 year earlier) + 68 families post- CLT (from 4 months on) In the interviews, 29 pre and 19 post.	2.48 ± 1.78 years old ("pre" group). 2.11 ± 1.67 years old ("post" group).	Medical records: "Pre" group Mild (25) Moderate (32) Severe (22) "Post" group Mild (27) Moderate (25) Severe (16)	- <i>Measures of Processes of Care, MPOC</i> (King, et al.). - <i>Client Satisfaction Questionnaire, CSQ</i> (Larsen et al.). - Semi structured interview (authors).	- F or T test. - Content analysis.	- MPOC and CQS scores were slightly higher in the "post" group; statistically significant differences were only found in <i>providing general information</i> and <i>providing specific information</i> . - Parents and professionals agreed that CLT provided emotional and social support, information, and helped accessing to specific services.
<i>Rahi, J. S., Manaras, I., Tuomainen, H., & Lewando-Hundt, G. (2005).</i>	Investigate the parents' needs and their experiences with health services, during the 12-18 months after their children were diagnosed with ophthalmic / VI disorders.	147 families (135 mothers +76 fathers). In the interviews, 23 mothers and 2 fathers.	2.21±1.7 years old (147).	Medical records: Mild (53) Moderate (56) Severe (38)	- <i>Measures of Processes of Care, MPOC</i> (King, et al.). - <i>Client Satisfaction Questionnaire, CSQ</i> (Larsen et al.). - Semi structured interview (authors).	- Pearson's correlation coefficient. - T or F test. - Content analysis.	- In MPOC, scores were worse in <i>general information</i> , and the VI's gravity did not set a clear tendency. - Significantly positive correlations were found between MPOC and CSQ scores; <i>general</i> and <i>specific information</i> were the aspects less correlated with satisfaction. - Parents especially voiced the need for information (as well as the need to speak with other parents or more support from professionals).
<i>Shihab, I.A. (2012).</i>	Investigate the parents' attitudes towards their visually impaired children, and the effect of gender, income levels and academic levels on their attitudes.	54 mothers and 45 fathers.	Not reported.	It is only stated that the children are visually impaired.	- Questionnaire (author).	- T test.	- In general, parents showed negative attitudes towards the VI. - Being the father, having a lower income level, and non-university studies were significantly related to a more negative evaluation of the VI.

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Smyth, C. A., Spicer, C. L., & Morgese, Z. L. (2014).</i>	Assess the interaction between the visually impaired child and the adult at meal time and find out if these children have more difficulties to gain the skills needed to eat without help.	30 families.	From 3 months to 3 years old (30).	Clinical diagnosis, functional vision examination. "Visual learners", VA 20/70 to 20/180 (14); "Tactile learners", VA≤20/200 (16).	- Observation and semi structured interview (authors).	- Content analysis.	- Parents' confidence and expectations appeared to be affected by the level of vision impairment. - Parents showed a lack of knowledge and confidence during the children's progress and they felt anxious when it came to let them be more independent; they usually did not give the children enough time to explore objects (more often with tactile children).
<i>Speedwell, L., Stanton, F., & Nischal, K.K. (2003).</i>	Investigate the written information's impact on stress levels of parents of visually impaired children, and the question of who parents thought should provide information and when. There is an experimental group (VI group) and a control group (C group).	34 mothers/ fathers of visually impaired child. 43 mothers/ fathers with visually healthy children. 2nd part → 23 mothers/ fathers whose children suffer from VI.	5.1 ± 3.4 years old Preschool, < 5 years old (11) Primary school, > 5 years old (12) ≤ 1 year old, children without VI (C group).	Clinical diagnosis. Preschool: the use of assistance was deemed as necessary. Primary school: VA≤ 6/18 far sight and N8 in near sight.	- Questionnaire (authors). - <i>Perceived Stress Scale</i> (Cohen et al.).	- Answer frequency depending on information sources. T test and Pearson's correlation coefficient (stress scale).	- Stress: No significant differences between groups. - VI group: positive correlation between <i>children's age</i> and <i>parents' stress</i> before and after receiving the information leaflet; afterwards it was not statistically significant. - VI group: information was deemed useful but it had been given too late. - Most of the parents did not know who to address to get information and orientation on their children's education.
<i>Tröster, H. (2001).</i>	Compare the stress of mothers of visually impaired children (VI group) with that of mothers whose children do not have a VI (group C), to examine stress domains and which factors contributed to their stress	47 mothers, VI group. 47 mothers, C group.	8 months to 7 years old. VI group (47). C group, paired by gender and age with the VI group (47).	Mothers are the ones who report (5 item scale): Complete blindness in both eyes/ perception of light (21) Discern objects in front of their eyes/ 2m away/ better VA (26).	- Questionnaire that includes an adaptation of Abidin's <i>Parenting Stress Index</i> (authors).	- ANOVA (two or three factors).	- Stress: VI group > C group; stress was higher when there were coexisting impairments and with the higher VI levels. - On one hand, mothers whose children suffered from multiple disabilities marked significantly higher in daily stressor agents; on the other hand, there were not significant differences in C group and mothers whose children only suffered from VI. - Perception of support: VI group (all impairment levels)< C group.

Table 2. Continued.

Authors (year)	Aim	Participants	Children's age (n° of children)	Impairment gravity (n° of children)	Measuring tools (authorship)	Data analysis	Main results
<i>Ulster, A.A., Antle, B.J. (2005)</i>	<p>Investigate the children and families' adaptation when there is a case of late appearance blindness (not congenital).</p> <p>From a case study (a child who suffered from retinoblastoma), the acceptance of the children's coping skills and the main notions on the quality of life are assessed.</p>	1 family.	The study focuses on the child when he was 6.	Total blindness (bilateral enucleation).	- In-depth interviews, focused on the child when he was 6 years old, and on the parents' retrospective thoughts.	- Descriptive analysis of the case's history.	<p>- Cyclically, the child and the family went through the phases of adjustment and the self-esteem evolution process Tuttle described; the child was faster in the transition.</p> <p>- Several stressor agents/concerns were identified in the parents: medical visits and interventions, the future, disagreements between spouses, or the child's psychological trauma.</p> <p>- The factors that helped with the adjustment were the medical staff support as well as the support given by other families who lived similar experiences; they insisted on the constant need for the latter kind of support.</p>

In the studies presented, children/adolescents' collectives are quite heterogeneous regarding age, impairment's level and other coexisting disabilities. In some of the articles, the children's age range is narrow (e.g. 0 to 3 years old) whereas in others, the age range is wider (e.g. 0 to 18 years old). In a couple of articles, the population coincides because they belong to long studies with several research questions and the yielded results have been published separately (Leyser et al., 1996; Leyser & Heinze, 2001; Rahi et al., 2004; Rahi et al., 2005).

Regarding the impairment's level, in 9 out of 24 articles VA values are expressed in decimal scales, fractions or LogMar, 8 of them use a descriptive classification of the impairment (e.g. mild - moderate - severe, or non-tactile - tactile), and in 7 of them (29%) no additional information is given apart from stating that the children suffer from visual impairment. In 1/3 of the studies the visual impairment's gravity is not determined, in 42% of them it is shown in medical records, and in the rest of the cases parents or teachers are the ones who inform of it.

Although in some of the articles the presence of other disabilities that could affect the children's development was an exclusion criterion, it has not been a common requirement, and within the selected articles, there are 7 of them (29%) in which the children suffer concurrent disabilities (Correa-Torres & Zebehazy, 2014; Jackel et al., 2010; Lee et al., 2014; Neofotistou et al., 2014; Rahi et al., 2004; Rahi et al., 2005; Tröster, 2001).

Regarding the method, a feature that all of the studies share is that they can be classified as descriptive or selective mixed designs (qualitative – quantitative) and, in general, their samples are not too broad. There are 2 case study and in five of the publications (21%) there is a control group formed by parents whose children are not visually impaired (Lakshmi & Jabeen, 2012; Lee et al., 2014; Leyser et al., 1996; Speedwell et al., 2003; Troster, 2001).

Apart from 2 cases where the authors opted for focus groups, in the rest of the studies the data collection tools were interviews and questionnaires in diverse formats, most of which were specifically designed by the authors. In 8 studies, they decided to use questionnaires or scales from other authors that had been already validated (as a single tool or together with an interview), and in two cases, apart from an interview, there was a process of observation through interaction or participation (Table 3).

Taula 3. *Measuring tools frequency of use.*

<i>Interview/Questionnaire (authors)</i>	<i>Interview/Questionnaire (other authors)</i>	<i>Interview/Questionnaire (authors + other authors)</i>	<i>Interview/Questionnaire (authors) + Observation</i>	<i>Focus group</i>
12	3	5	2	2

Regarding data analysis procedures, 12 studies carried out a qualitative analysis from the interview's recording, transcription and coding (content analysis, Grounded Theory, Colaizzi's Method), and 15 articles opted for a data quantitative analysis (frequency, T test, F test, Kruskal-Wallis test, Bland-Altman methods, Pearson's correlation coefficient, and ANOVA). In three articles, both qualitative and quantitative analyses were carried out.

I will summarise the general results obtained, following four main lines of interest: the *parents' assessment on professional services or care*, the *impact that the child's VI caused in an individual level (physical, psychological) as well as the family's*, the *parents' concerns and needs*, and the

parents' *coping strategies and factors that help adjusting*. For a more detailed explanation, see *Discussion*. From the reported results it follows that:

- in general, parents are satisfied with the professional support and care that their children and themselves received.
- when describing personal experiences, it was seen that parents developed a kind of grief after they were informed of the diagnosis. To achieve a higher or lesser degree of adjustment is determined by the progress and the overcoming of said grief which leads to accepting their children's visual impairment. Some of the reactions that came up were incredulity, denial, anger, pain, guilt or sadness.
- many experiences are overcoming challenges: even though some parents show negative attitudes, have low expectations, live as if the situation is a burden or an impediment to their own personal growth or to the family's control and harmony, other parents believe that the family bonds have strengthened or that the feelings of power and understanding have increased, and many are capable to share useful strategies to help them deal with the situation.
- in an individual level, manifestations of severe symptoms (extreme emotions, panic attacks, insomnia, eating problems...) were described in only two articles in which the children's visual impairment derived from a carcinogenic tumour and the treatment chosen was enucleation.
- some comments that indicated parents' negative attitude were the lack of expectations towards their child's future, the stigma that poses having a disabled child, the frustration for not reaching their goals, the feeling that other people do not understand them, or the lack of confidence on their abilities to help their child or on their child's abilities.
- some of the concerns are universal: the future (worsening of the visual condition, work opportunities, living on their own, lack of activity or participation in society...) and the education (monitoring of school activities, providing of adjustments or modifications, teachers' collaboration...). Psychosocial issues (sensitivity and understanding from the other children, integration opportunities, mocking...) are also a concern, as well as family related aspects (siblings, the couple's relationship, leisure...).
- the main need for most parents is getting more information about the children's visual condition and the repercussions it may cause through life-span, as well as being better guided to what services and resources they can resort to in order to adapt to the children and the family's situation and to normalise it. The need for a bigger joint work between parents and teachers is also prevalent.
- the range of coping strategies and factors that help parental and family adjustment to the children's visual impairment is wide. We can deem as extremely important all sources of support (family, friends, health and education professionals, other parents whose children also suffer from visual impairment) as well as having an accepting attitude, developing skills and gaining knowledge in order to have a better understanding of the impairment and to be able to help the child develop his abilities, improving the communication and the interaction, saving some time for oneself and for the couple, develop certain spirituality, etc.

DISCUSSION

Up until now, it seems that research on the QoL of parents and caregivers of visually impaired children has not been abundant, but it gives the impression that in recent years has increased. Health professionals and researchers specialised in this field have guided their interest into VI's medical and functional aspects. There are several validated tools to assess visually impaired people's QoL such as the *Nottingham Adjustment Scale (NAS)* (Dodds, Flannigan, & Ng, 1993), the *Low Vision Quality-of-Life Questionnaire (LVQOL)* (Wolffsohn & Cochrane, 2000) or the *Impact of Vision Impairment Questionnaire (IVI)* (Weih, Hassell, & Keeffe, 2002); however, there are no tools to specifically assess the caregiver's QoL of the visually impaired.

Because of the lack of specific tools, the authors who have taken an interest on the topic have used either validated generic tools to measure QoL indicators or they have designed "tailored" tools in order to achieve their goals (questionnaires or interviews). However, this fact complicates the task of comparing the studies' results and coming to accurate conclusions.

Sampling and research designs

The studies use purposive non-probability sampling. Using this kind of sampling also implies being cautious when interpreting the studies' results. Another aspect that complicated the comparison was that there is no homogeneity in the selected articles regarding parameters such as the children/adolescents' age, the impairment's gravity level, or the presence of other disabilities.

Most of studies are cross-sectional design, which allows us to get a general picture on the impact that having a visually impaired child causes in the parents' QoL and, from the identification of the parents' needs, concerns and demands, a good idea could be to introduce some changes into child and family care or to plan some kind of intervention, which is already common in studies about families of children with special needs (Caicedo, 2014; Jackson et al., 2008). However, this kind of designs do not allow to accurately detect if there are changes in the parents' QoL when the VI is progressive, when there is any kind of family intervention planned, or when changes are caused by the normal development of the children.

Changes through time are only described in 5 of the selected articles. In Ek (2000) it is reported that even though the impact of the diagnosis and treatment of retinoblastoma is enormous and has a negative effect on all of the parents' QoL dimensions, during the 6 year monitoring period it is observed the family has returned to certain normality. Speedwell et al. (2003) found that giving an information leaflet on VI (in this case, after the diagnosis) does not affect the parents' stress levels and all the parents think that the information was given to them too late. Rahi et al. (2004) assessed the impact of a Community Link Team (CLT) on a paediatric ophthalmology department and they found that both parents and professionals agreed that a CLT provided emotional and social support, information, and helped accessing to specific services. Dote-Kwan et al. (2009) compared Anglo and Latino families and found that, regardless of the family's roots, the home environment was always favourable, there were no differences in the children's development, and that the need for information and services decreased as time passed. Finally, Smyth et al. (2014) found that implementing personalised strategies at mealtime improved the caregiver's confidence and their communication with the child, and the difficulties to set up good eating habits and to encourage more independence when eating, diminished.

Regarding data analysis, parametric and non-parametric tests are used in quantitative studies, according to the constraints of the investigation; when qualitative analysis were carried out the authors made an effort to describe in more or less detail the steps taken, trying to gather certain validity guarantees.

Assessment on services, care, and the information received at the time of diagnosis

In 15 out of the 24 selected articles (62,5%) the parents' assessment on the professional services, the assistance and the information received is reported. Despite some nuances, parents are usually satisfied with the provided health services and care. In only two of the articles, in which the children suffered from retinoblastoma (Ek, 2000) and CVI (Jackel et al., 2010), parents report not to be completely satisfied and mention that the doctors did not seem to have an extensive knowledge about the disease and they connected it to the lateness of the diagnosis and treatment. Regarding the information that they were given, in general, parents believe that they need more information on their children's visual conditions and its consequences, on what services or resources they can turn to, and on their children's upbringing. Dote-Kwan et al. (2009) and Rahi et al. (2005) grasp the differences between mothers and fathers' needs as well as the differences between the needs of different ethnic groups. They found out that those who have more informational needs are mothers (due to the role they play rather than to be an issue of gender), people who belong to minority ethnic groups (for whom communication is already a challenge), and parents of children with additional disabilities. The access to information through the Internet is not addressed but it is sometimes mentioned (Jackel et al., 2010; Rahi et al., 2005). This particular source of information is especially used by people who suffer from chronic conditions (Bundorf, Wagner, Singer, & Baker, 2006); therefore, as Rahi, Manaras, & Barr (2003) suggest, the Internet needs to be taken into account in order to motivate health professionals give patients useful, reliable, updated and easy to understand information.

Five articles report that parents positively assess the access to specific services. Ek (2000) explains that parents whose children have been diagnosed with a retinoblastoma addressed to the team's psychologist, and that they could contact them at any time, at hospital or through the phone. Some families described the project's psychological support as a saviour; the demand for it increased during the first few months, and then decreased after 8 – 12 months. Lennon et al. (2008) assessed the usefulness of providing written reports to parents and teachers, and they obtained a high level of satisfaction with said reports because both groups believed that it provided relevant and practical information. Neofostitou et al. (2014) assessed the satisfaction of parents whose children suffered from VI using an early care service, and the results suggest that the program was an important support for the families. In Rahi et al. (2004) both parents and health professionals agreed that a CLT provided emotional and social support, information and helped accessing to specific services, and Speedwell et al. (2003) found that the provided written information was assessed as useful, even though it did not have an effect on the stress levels because it was given too late.

Visual impairment repercussions on parents and family

Leyser et al. (1996), Ek (2000), Ulster & Antle (2005), De Klerk & Greeff (2011), Fathizadeh et al. (2012), and Pintanel et al. (2013) make references, directly or indirectly, to the grieving process that activates when the child's VI diagnosis is received. They mention the initial impact, the incredulity, the denial, the anger, the pain, the sadness, the depression, the emptiness... and, finally, the reassessment and the acceptance. It is also pointed out that the non-acceptance, denial

or ignoring the situation cause that the families do not become aware of the situation and, in consequence, do not resort to the information or the health services they can be provided of in order to support the child's treatment and cure. In the case study of retinoblastoma, Ulster & Antle (2005) explain that the transition between stages was faster for the child than for the parents, which is a common observation when dealing with children.

Some parents expressed that they feel helpless, frustrated, or guilty for not understanding the behaviour of children, not recognizing their needs or interpret their communicative cues or not feel an outpouring of affection. For example, Lappin (2004) documented 13 types of mother-child interactions, all negative in nature. There are also parents who have created false expectations, and leave the son aside. These are signs of mistrust about their own abilities and the abilities of the child.

The presence of physical symptoms, burden, anxiety and stress has also been reported in some of the studies. The appearance of severe physical symptoms (extreme emotions, panic attacks, insomnia, eating problems...) is only mentioned in two of the articles in which the visual impairment was caused by a carcinogenic tumour and it was treated with enucleation (Ek, 2000; Ulster & Antle, 2005). On the other hand, the physical tiredness and the burden resulting from the child's constant care demands are often mentioned in a descriptive way. In a study on the burden and the depression of blind adults' caregivers (Braich, Lal, Hollands, & Almeida, 2012), the heaviest burden was related to the VI's level, the number of close supervision hours and the caregiving intensity. Another aspect that reflects the burden on carers which has also been observed in this study review is that the mothers are who show higher levels of burden, because usually are main caregivers. Anxiety is been reported quantitatively in Lakshmi & Jabeen (2012) who found that, regardless of the children's or the parents' gender, the anxiety levels were significantly higher in parents' whose children were visually impaired than in parents whose children were not visually impaired. In parents' experiences signs of anxiety were also detected because of the lack of information, or letting the child develop some independence. Stress is also a highly present QoL indicator in the qualitative researches; while Speedwell et al. (2003) did not found significant differences in stress levels between parents of visually impaired children and parents of not visually impaired children, Tröster (2001) and Lee et al. (2014) did find some. In Tröster (2001) it is also found that mothers of children with low vision are more stressed than those who have blind children and, according to the author, it could be because they are more demanding regarding their children's abilities and underestimate their limitations, or because it is not a condition as defined as blindness.

In a review of literature on the function and adjustment process of family members of persons with adult-onset vision loss, Bambara et al. (2009) corroborate that the reactions to the VI can be diverse, and depending on the care to be offered the caregiver may experience burden, and Bambara et al. (2009b) identified that 35.4% of family caregivers of adults with VI were at risk of depression.

The relationship between the family impact and the VI's gravity or the presence of comorbid conditions is not clear, inconsistent results are reported. In Jackel et al. (2010), it was found that many children with CVI suffered from other disabilities and that the VI had been disregarded or that it was not considered the primary disability, and Tröster (2001) reported that mothers of children with multiple disabilities scored significantly higher on daily stressors than those of children with only VI, while between those mothers and the control group the differences were not significant.

The impact of having a visually impaired sibling is not conclusive either. Hamblion et al. (2011) did not find worse QoL scores in visually impaired children's siblings in relation to healthy children's siblings, results that surprised the authors, whereas in Pintanel et al. (2013) a mother said that the siblings were ashamed of the blind sister and that they did not help in taking care of her nor they let her go with them.

Expressed concerns and needs

What parents are most worried about is their children's future and school, but they also express concerns on psychosocial issues, family organization aspects, and communication (with doctors and teachers). Apart from information, other major needs are: having more free time for themselves and the rest of the family, going out with friends, leisure, disconnecting or to keeping the family united; this coincides with what Murphy et al. (2007) found from the data obtained in a qualitative study with focus groups of parents whose children had several disabilities. Amongst the selected articles, it is worth remarking Lee et al. (2014)'s contribution because, after comparing the needs for services of three different groups of parents (VI, LB and control), they found out that 8 out of the 10 major needs were common in all the groups and, therefore, maybe those needs were more related to the fact of being just "parents" rather than to the fact of being "parents of children with special needs".

Concerns about the future are usually expressed through doubt: they fear that their children will not be able to be independent, that they will not have school or job opportunities, etc. That is why some parents think that it is necessary to encourage support and adjustments at home and at school. But there are also testimonies from some parents who state that they are impressed and proud of their children's achievements. In some cases, it is reported that the family overprotects, infantilises or hides the child and, as a consequence, they complicate his future development (Fathizadeh et al., 2012; Pintanel et al., 2013; Smyth et al., 2014).

Regarding the school context, there is a variety of opinions on mainstreaming: there are parents who defend it because it is an example of what will the child encounter later in life, and there are parents who prefer special schools because they believe that there are better prepared professionals and that the child will be better taken care of, and that they will be able to speak with parents who are in the same situation as them. In short, school is considered to be an important source of support. Parents are satisfied with the job carried out by special education and itinerant teachers, unlike that of classroom teachers, arguing that they lack of knowledge and understanding on VI as well as good will to help the child adapt to the classroom.

As optometrist, it has caught my attention that in DeCarlo et al. (2012) it is brought up the fact that when assessing QoL the physical symptoms that come from doing school tasks (visual fatigue, headaches or forced positions due to the really short work distances and to the magnification) are not taken into account; this arises complaints and rejection, so, these conditions are harmful to the child's QoL, and increase the parents' concerns.

Psychosocial concerns are related to the mocking, the exclusion in leisure activities, the incomprehension, the lack of sensitivity or the other's compassion (children and adults), as well as the insufficient politics on accessibility and inclusion. In DeCarlo et al. (2012), the children reported a double amount of negative comments in comparison to the positives (verbal mocking, impotence, fear, physical aggression) in the psychosocial aspects. The authors venture that the VI's emotional burden may impact children to a higher degree than parents believe.

Coping strategies and factors that help with adjustment

Almost half of the studies report coping strategies. Formal support (health, education and rehabilitation professionals) and informal support (extended family, friends, group of parents) are considered to be extremely important sources of support for the parents and family's adjustment to the visually impaired child condition.

Some of the coping strategies parents have used and that have been considered as empowering are: a conscious attitude on acceptance, an active search for help, accepting external help, a feeling of responsibility towards the child, mutual respect and support within the family trying to stay united, developing a feeling of achievement, searching a positive sense from the situation, religious faith, talking about it (with the spouse, professionals, friends), children's massage, helping the children develop their skills and succeed, gathering information about the problem, finding time for leisure or for taking a break, being patient and loving, persist when confronting difficulties, changing or adding routines or environments that encourages the child's independence, etc.

As for the factors that have helped adjusting, the most mentioned is the support from relatives and friends, as well as the support that comes from school and teams of professionals. It is also mentioned the exchange of experiences with other parents at formal support groups or because they met at the hospital, the school, etc. For parents, speaking with other parents represents an opportunity to share experiences, to realise that other families have or had the same concerns and that they also have had to face similar challenges, to share coping strategies, to broaden their knowledge on VI and the available resources, or to "know" that, despite their children's VI, they can live a satisfactory life.

Other factors that make the adjustment easier are: observing the children's progress, being able to choose the school their children are going to attend (whether inclusive or a special education school), or the perception of self-efficiency.

Bambara et al. (2009) explain that from a family-systems perspective when a family is flexible, adaptable, cohesive, supportive, and well functioning, the adjustment of all members of the family (including the person with DV) to the situation is easier. Understanding the VI of the child or adolescent as a circumstance that affects the entire family system means taking into account the perception of all members of the family and, therefore, identify the factors that hinder fit and proper functioning, to modify them.

Proposal of the author

I find it interesting to consider the design of an online psychoeducational program aimed at parents of children with VI where to find professional, reliable, and understandable information, and suitable resources that will enable the parents to continue it according to the personal availability and timing. Some of its advantages would be: no requirement for parents to shift or adapt their work schedules, sharing the caregiving role between the mother and the father, or contents always available to be consulted, and therefore avoiding confusion or forgetfulness effects.

CONCLUSIONS

Having a child with visual impairment can affect the parents' quality of life in many several ways, and it depends on many factors and the relationships between them.

In recent years, some research studies that take an interest in the quality of life of parents with visually impaired children have been developed, understanding the parents' influence and responsibility in the child's care.

There are no specific tools to assess the quality of life of parents of visually impaired children so, therefore, it should be considered to design them in the future. In this project we have gathered a lot of factors to consider.

The child's visual impairment implies, in a greater or lesser extent, the presence of physical symptoms, burden, stress and anxiety. The factors that contribute to it are the lack of information or knowledge about the impairment, the difficulties of establishing affective bonds with the child, the constant care demands, the uncertainty about the future, and the lack of confidence in their own abilities or into the child's ones. The influence of the visual impairment's gravity or presence of comorbid conditions is not clear enough.

What parents are most concerned about are their children's future (at short or long term), school and the psychosocial aspects. Knowing what services the administration offers, guiding parents and facilitating the contact with other parents who live similar situations are some of the ways to help them soothe their concerns and empower themselves.

As health and education professionals, we need to be able to provide the necessary information to parents, adapt ourselves to the family traits and needs, without forgetting that children grow up and, therefore, those needs will change through time. One of the decisive moments when we should devote ourselves more to the family is during the time of diagnosis.

The ways we use to provide information and/or to be in touch with the families must adapt to recent times. If, nowadays, people look up information on the Internet and they stay in contact through social networks, professionals should provide assistance and services through these channels, which have a clear benefit: parents can use them without the complications that pose in-person consultations such as time and necessary trips to the hospital.

Coping strategies, changes in the family system and resorting to formal and informal sources of support help with acceptance and adjusting to the situation. Moreover, parents must interact with their children and encourage them to gain more autonomy. Professional assistance should provide the necessary help the family need to make this happen.

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