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Quality of Life of the Blind: Looking through a Wider "Lens" Beyond the Medical "Eye"

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ABSTRACT

Over one-fourth of the global population experience Visual Impairment and Blindness (VI&B) where they often experience significant challenges than those who can 'see'. Despite the subject of Quality of Life (QoL) being extensively researched, there is little or no focus on explaining this concept as applicable to persons with VI&B. Furthermore, there is no unified characterization of QoL as a construct although diverse views have been presented in general. This paper seeks to explore the concept of QoL in the specific domain of persons with VI&B. In the process, a comprehensive literature search was carried out using multiple electronic databases where 239 publications were consulted. Selected papers were subjected to a content analysis to identify conceptual and measurement principles pertaining to their QoL. The existing vision-specific QoL instruments are mostly domain specific and focus on the medical aspect of a life of quality, disregarding the influence of environmental and personal factors that contribute to their well-being. Results of the analysis pointed to the fact that QoL of persons with VI&B should draw attention to their specific needs, expectations, and values, where a comprehensive characterization that encompasses physical, psychological, social, material, and environmental aspects, along with an evaluation of the individual's participation, autonomy, personal development, and the impact of vision requires to be explored. This multi-dimensional conceptual model could be used as the basis for the development of a new measure for the assessment of overall quality of life for persons with VI&B.

Keywords: Blindness, Quality of Life, Visual Impairment.

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I. INTRODUCTION

According to the World Health Organization's most recent data (WHO, 2021), 2.2 billion people worldwide suffer from visual impairment and blindness (VI&B), with at least 1 billion of these instances still unaddressed. As per Burton *et al.* (2021), low- and middle-income countries have a prevalence of visual impairment that is thought to be four times greater than that of developed nations. People with VI&B in developing nations are hence frequently excluded from daily activities (WHO, 2019).

Many international organizations have made improving the Quality of Life (QoL) of these communities a top focus, which was furthered with the adoption of the Millennium Development Goals in the mid-1990s and the Sustainable Development Goals in 2015 (Burton *et al.*, 2021; Muhammed & Abubakar, 2019; Porio, 2015; Siu *et al.*, 2021; Sirgy *et al.*, 2006). The WHO designates QoL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1998, p. 2).

According to past research, visual impairment and blindness have a negative influence on one's QoL, (Adigun *et al.*, 2014; Amedo *et al.*, 2016; Burton *et al.*, 2021; Gyawali *et al.*, 2012; Habsyiyah *et al.*, 2015; Klein *et al.*, 1998; Langelaan *et al.*, 2007; Murthy *et al.*, 2018; Panigrahi *et al.*, 2021; West *et al.*, 1997; Yibekal *et al.*, 2020) with blind people scoring worse on the QoL scale than people with mild, moderate, or severe vision impairment (Adigun *et al.*, 2014; Amedo *et al.*, 2016; Asroruddin *et al.*, 2017; Murthy *et al.*, 2018; Vuletić *et al.*, 2016). Additionally, it was shown that QoL ratings decrease as visual impairment becomes more severe, indicating a negative correlation between QoL and the level of visual impairment (Adigun *et al.*, 2014; Amedo *et al.*, 2016; Murthy *et al.*, 2018). Also, it has been stressed that even mild visual impairment could negatively impact one's quality of life by diminishing life satisfaction and mental well-being (Brown & Barrett, 2011; Cumberland & Rahi, 2016). As it is understood that persons with VI&B

regularly encounter more significant challenges than those who can 'see', a study on their quality of life would be of special significance. Although earlier studies have identified a few tools to test this construct specifically for people with VI&B, they have only focused on the medical side of leading a life of quality. This viewpoint is expressed in terms of the medical model of disability, which dates back to the mid-1800s which places the primary focus on a person's physical impairment as the root of their disability (Olkin, 1999). However, researchers may claim that there is a considerable gap in QoL measurement, which is a much wider and more complex construct when it comes to persons with visual impairment and blindness. This is because the social model of disability (Oliver, 1981) and ICF model (WHO, 2002) perceive the concept of disability as a blend of physical, social, and psychological aspects of the people involved.

This paper attempts to bridge this knowledge gap by demystifying the concept of QoL as applicable to persons with VI&B, to derive a valid and reliable instrument to assess this noteworthy construct. The paper is based on a comprehensive literature review of articles drawn from reputed research journals published since 1980. The paper comprises four main sections : the introduction, methodology, results and discussion, and conclusion.

II. Methodology

Since the empirical evidence derived for comprehending the knowledge gap and realizing the objectives of this research is solely the research articles, the process adopted for the literature review is detailed in this section. Research papers for this study have been drawn from three commonly accepted electronic databases including 'PubMed', 'Embase', and 'PsycINFO' which were accessed during the month of August 2022.

The first step of assembling the relevant articles was the keyword search where 'Quality of life of visually impaired and blind' was used as the main search phrase, which retrieved 239 online scholarly articles in English. Forty-seven of these publications were disregarded due to the presence of duplicates (n=19) and irrelevance (n=28), as their focus was on Health-related QoL which merely assesses the medical aspect of a life of quality, in contradiction to WHO's QoL definition. The remaining publications (n=192) were screened based on title and abstract, to omit papers that focused on societal, family or workplace QoL (n=33). This brought down the number of articles to 159 which were further screened to exclude any empirical research including psychometric analyses of existing QoL instruments (n=44).

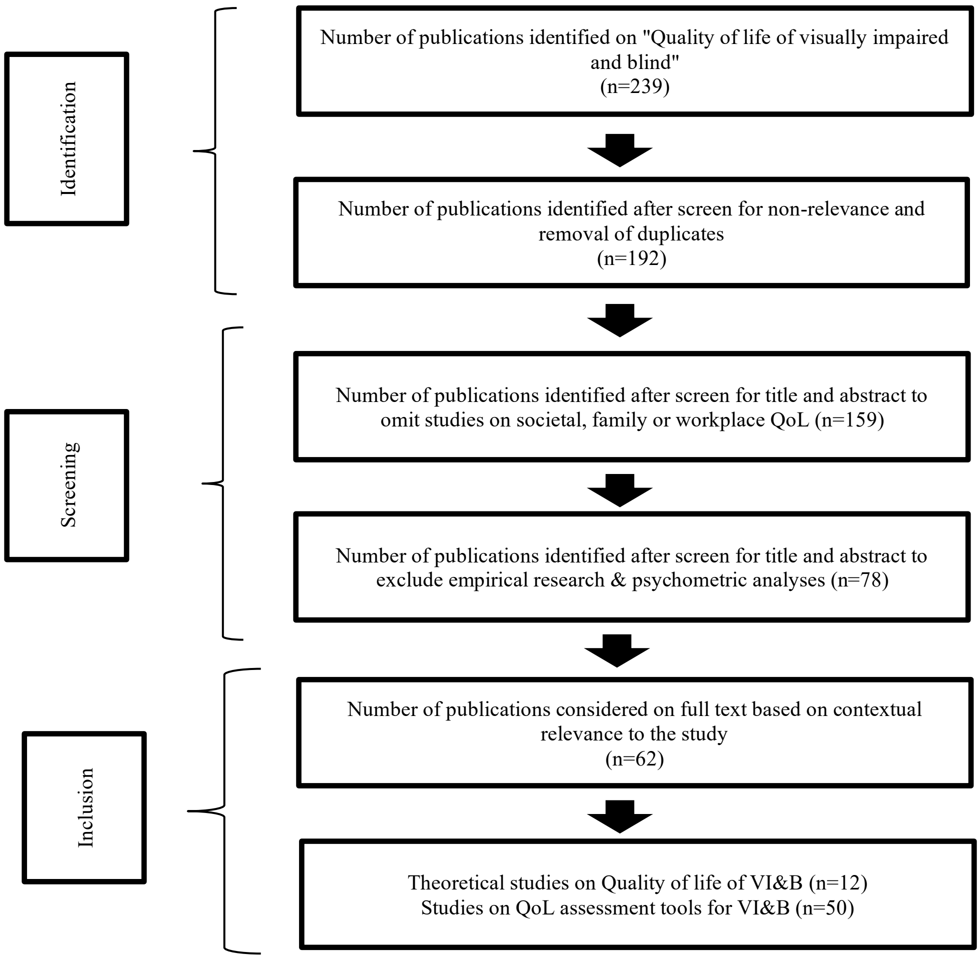

Fig. 1. Search strategy and classification of publications.

Articles that explored the impact of rehabilitation services on QoL and the impact of vision loss on QoL were also excluded at this stage (n=37). This brought down the number of articles to 78, which were screened on the availability of full text. Finally, 62 relevant publications with strong contextual relevance were taken into consideration in the study. These publications were categorized into two broad sub-topics, namely, theoretical studies on QoL of VI&B (n=12) and studies on QoL assessment tools for VI&B (n=50). All four authors extensively engaged in the article screening and selection process, where the selected papers were read and examined collaboratively to obtain insights on QoL measurement of persons with VI&B. Outcomes of this qualitative exercise is presented in the next section, with evidence from respective research papers. The first section is devoted to understanding the nature of the QoL construct, aimed at persons with visual impairment and blindness while the next section highlights the gap in the literature related to their QoL. Fig. 1 summarizes the search strategy applied.

III. Results and Discussion

A. *Analysis of Vision-Specific QoL Measures*

Post (2014) asserts that studies looking into QoL should be clear about how it is conceptualized and operationalized. Therefore, as the first step, it is important to explore to what degree the QoL of people with VI&B has been understood, and how it has been measured. This could be easily achieved by analyzing the existing models and measures that have been used to evaluate this construct.

Twenty-nine (29) vision-specific QoL instruments identified through the literature search were investigated to provide a thorough overview of the QoL measures that are currently available for people with VI&B.

The study made clear that nearly every vision-specific QoL tool found in the literature focused on a multidimensional evaluation of several life domains that constitute a life of quality for an individual. Most of the vision-specific QoL instruments (Barry *et al.*, 2017; Béchetoille *et al.*, 2008; Erickson *et al.*, 2004; Hays *et al.*, 2002; Juniper & Guyatt, 1991; Juniper *et al.*, 1998; Lee *et al.*, 2005; Mitchell *et al.*, 2008; Pesudovs *et al.*, 2006; Sukhawarn *et al.*, 2011; Terwee *et al.*, 1998; Uenishi *et al.*, 2003; Woodcock *et al.*, 2004) were disease-specific and only focused on aspects like visual functionality, independent living, and the effect of visual infirmity, which alone is insufficient for assessing one's QoL.

Despite being acknowledged by the WHO as key drivers of QoL, more than 50% of the vision-specific QoL instruments found in the literature did not consider physical, social, and psychological factors into account when making their evaluation. However, little attention was paid to environmental variables in the few instruments (Du Toit *et al.*, 2008; Hatt *et al.*, 2009; Khadka *et al.*, 2010; Mangione *et al.*, 2001; Misajon *et al.*, 2005; Paudel *et al.*, 2015; Richardson *et al.*, 2009; Sukhawarn *et al.*, 2011; Terwee *et al.*, 1998; Uenishi *et al.*, 2003) that did include physical, social, and psychological factors, together with the dimensions of visual functioning, independent living, and the effect of visual infirmity. Three tools (Brady *et al.*, 2010; Frost *et al.*, 1998; Woodcock *et al.*, 2004) took into account how environmental variables affect the quality of life of an individual with VI&B, but neglected to pay attention to other aspects that affect their well-being. It is clear from this that vision-specific QoL tools were primarily permitted to evaluate the medical element of a life of quality in light of the functional constraints while ignoring the impact of social, psychological, and environmental aspects on QoL.

B. *Quality of Life of Persons with Visual Impairment and Blindness*

Despite being widely used in research, practice, and policy creation, the idea of QoL is highly unclear, as indicated in the paper's introduction. The authors feel that highlighting the knowledge gap regarding the evaluation of QoL for people with VI&B is the first step towards creating an instrument to measure this important construct.

It was discovered that QoL is a well-known but complicated notion that is made up of an endless number of components that are always prone to change and are impacted by societal norms and cultures. The survey of literature makes it clear that QoL measurement should be multidimensional, focused on satisfaction, and emphasize the significance of different life domains.

Further research indicated the need for global QoL evaluation methods and the availability of subjective and objective metrics that are responsive to cultural differences (Anderson *et al.*, 2020; Felce & Perry, 1995; Schalock *et al.*, 2016; Schalock & Verdugo, 2002). According to Salvador-Carulla *et al.* (2014), modern research on quality of life has turned away from general QoL instruments towards a more comprehensive and integrated view of a person's well-being that takes happiness, functionality, and disability into account. Post (2014) expounded on this further, stating that the selection of a QoL measure should be based on the research's emphasis and an analysis of its contents. As a result, the following list of topics on QoL of people with VI&B needs more investigation.

The WHO's International Classification of Functioning, Disability and Health (ICF), emphasizes the biopsychosocial components of disability and views a person's level of functioning as the result of an active interplay between their health conditions, environmental influences, and personal factors (WHO, 2002). The ICF model analyzes how a person experiences disability by looking at their bodily functions, impairments, constraints on activities and participation, as well as the consequences of their physical and social environments, which either hinder or facilitate their functioning. According to McDougall *et al.* (2010), the ICF framework takes into account every aspect of a quality life by enclosing environmental and human aspects. Thus, in order to get an inclusive picture of the person's life, any researcher looking into the quality of life for people with disabilities must use the ICF framework. The ICF framework's components align with the QoL domains and indicators provided by the WHO, making them suitable for inclusion in the QoL construct for individuals with VI&B.

Similar to this, Van Hecke *et al.* (2018) found that QoL is dynamic in nature and wider than health-related QoL in their review of 75 research publications on QoL. Further evidence of the necessity for a disease, target-group or age-specific QoL tool that covers life dimensions valued differently by various groups was also specified in their findings. According to Van Hecke *et al.* (2018), the target group should preferably be included in the creation of the QoL instrument since they can best express what they understand to be a life of quality.

The WHOQOL disability module (WHOQOL-DIS) is a QoL measure that is created expressly to evaluate the QoL of people with physical or mental disabilities (Power *et al.*, 2010). Along with physical, psychological, and social components, WHOQOL-DIS includes unique characteristics in QoL measurement encompassing discrimination, autonomy, and inclusion. However, it doesn't place enough emphasis on elements such as financial security, independence, and personal growth that could be important for determining the quality of life for a person with VI&B.

Furthermore, there is no published research on how people with VI&B manage their overall QoL. Even in the studies that have considered people with disabilities, there is no any systematic study to ascertain the QoL of people with VI&B in relation to various socioeconomic standards and cultural aspects, Therefore, there is a major requirement to bridge this knowledge gap.

In addition, the majority of research on the quality of life for people with vision impairment and blindness focuses on how rehabilitation therapies and visual loss affect the quality of life. Hence, it is clear that little to no attention has been paid to explaining "how" or "what" to measure with regard to the general well-being and quality of life of the blind and visually impaired.

Although few instruments have been identified to examine this construct, such as the Quality of Life & Vision Function Questionnaire - QOLVFQ (Carta *et al.*, 1998), the Low Vision Quality of Life Questionnaire - LVQOL (Wolffsohn & Cochrane, 2000), the Visual Symptoms and Quality of Life - VSQ (Donovan *et al.*, 2003), and the Vision & Quality of Life Index - VisQoL (Misajon *et al.*, 2005)), their emphasis was constrained to the medical aspect of a life of quality, which alone is insufficient to assess an the overall quality of life of an individual.

With the development of the disability discipline, the social model (Oliver, 1981) and ICF model (WHO, 2002), which views the concept of disability as a blend of physical, social, and psychological aspects of the people involved, instruments like the Vision Function & Quality of Life Questionnaire - VFQOL (Fletcher, 1997), AQoL-7D (Richardson *et al.*, 2009) and the Papua New Guinea Vision-specific Questionnaire - PNG-VS-QoL (Paudel *et al.*, 2015) were created. These tools evaluated an individual's quality of life in relation to the effects of impairment on their physical, psychological, and social functioning. These instruments, however, do not take into account the environmental factors, such as access to disability-inclusive infrastructure, that might affect the overall quality of life of a person with VI&B.

The remaining instruments for measuring QoL related to persons with VI&B were discovered to be disease-specific, such as the Rhinoconjunctivitis QoL Questionnaire (Juniper *et al.*, 1999), Refractive Error QoL Instrument (Hays *et al.*, 2003), QoL Scale for Myopia (Erickson *et al.*, 2004), Retinopathy Dependent Quality of Life measure (Woodcock *et al.*, 2004), Macular Disease-Dependent Quality of Life measure (Mitchell *et al.*, 2004), Glaucoma QoL Questionnaire (Béchetoille *et al.*, 2008) and Quality of Life Impact of Colour Blindness (Barry *et al.*, 2017) that merely examined the impact of that condition on QoL.

As per Campbell and Converse (1972) “Quality of life must be in the eye of the beholder”. It is apparent that a person with vision loss or blindness may have a very different lifestyle than someone who can see with their own eyes. Thus, research on the quality of life of people with visual impairment and blindness is very important. The thorough analysis of the vision-specific QoL measures and the paucity of literature on the overall QoL of people with VI&B highlight the need for a comprehensive characterization of the QoL construct that takes into account physical, psychological, social, material, and environmental aspects that affect their well-being, along with an assessment of their participation, autonomy, personal development, and the impact of vision on life. This will help to strengthen the assessment of QoL for people with VI&B. Furthermore, the lack of a suitable measure to assess their overall QoL emphasizes the need for a novel QoL instrument that concentrates on all facets of a quality life for people with visual impairment and blindness.

IV. CONCLUSION

This paper was provoked by the realization that QoL relates to the overall well-being of an individual that needs to be examined with respect to his/her needs, expectations, and values, along with an evaluation of their overall perception of life. Thus, the assessment of QoL for persons with VI&B should incorporate a multi-dimensional evaluation of their needs and wants, and their satisfaction on overall well-being, together with the impact of internal and external life conditions, measured through indicators that are perceived as important by them. Limitations of this paper include considering articles that were merely published in English and having more literature prior to 2010, as the authors wanted to exhibit a comprehensive presentation of existing vision-specific QoL constructs. Moreover, the number of electronic databases reviewed for the study were limited to three, as having an unmanageable number of papers would make the analysis more tedious, compromising the quality of the study. As future research, the authors aim to develop an instrument to assess this noteworthy construct, incorporating the substantial insights identified through the review.

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CONFLICT OF INTEREST

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