



The Unseen Burden: A Scoping Review of Quality of Life in Retinoblastoma-Affected Lives

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Abstract

The primary objective of this Scoping review was to evaluate and consolidate data about the quality of life (QoL) experienced by individuals who have survived retinoblastoma, a very rare form of eye cancer that primarily affects children. The study encompassed a total of 107 articles, comprising a variety of article types such as original research articles, review articles, randomized controlled studies, and experimental studies from different data bases such as google scholar, pubmed and scopus. The majority of the studies encompassed either children or parents, with two studies conducted in India incorporating both parents and children. The most frequently utilized questionnaires for assessing the quality of life (QoL) in this study included the Peds QoL 4.0 (n = 5), the Short form 36 (SF-36) life questionnaire (n = 2), the Kids screen self-report (n = 1) 5%, the Child and Family follow-up (CFFS) survey (n = 1) 5%, the Child Health Questionnaire (CHQ) 5%, the Cancer therapy general FACT-g qnr 5%, medical charts, and thematic analysis (n = 1) 5%, the National eye institute visual field questionnaire (NEIFQ) 5%, treatment-based interventions, and review studies (n = 3) 17.6%. The predominant body of research has primarily concentrated on examining the physical well-being of survivors, their psychological functioning, as well as their educational and employment outcomes. However, comparatively less attention has been given to investigating the impact on family dynamics and the economic circumstances of survivors. Cases of enucleation and visual acuity below 6/18 in the better eye were found to have a detrimental effect on Health-Related Quality of Life (HRQoL).

Keywords: Retinoblastoma (Rb), Survivors, Families, Quality Of Life (QoL), Health Outcomes, Psychosocial Functioning, Review.

Key Messages

The scoping review emphasizes the necessity of conducting comprehensive investigations on the quality of life among retinoblastoma survivors. These studies should specifically address the physical, psychological, and social well-being of individuals with visual impairments, encompassing both children and parents affected by Retinoblastoma.

Introduction

Retinoblastoma is an uncommon form of cancer that affects the retina, the component of the eye responsible for vibrant color vision and light perception [1]. If the illness is not recognized and treated promptly, it may lead to a reduction in vision or even total blindness in either one or both eyes [2]. A person is said to be a cancer survivor if they have finished all of their treatments for the ill-

ness and are either still living with it or have overcome it [3]. In the context of retinoblastoma, survivability entails continuing surveillance of the eyes and consideration of the possibility of treatment-related late sequelae [4]. The primary goal of this proposed study is to explore the studies done on the QoL of Rb survivors and also to determine the variables which contribute to their contentment. A prospective research objective is - How would retinoblastoma affect long-term health, and also what variables contribute to survivors' quality of life? Which other factors influence their daily lives?

Understanding the quality of life in retinoblastoma survivors is important because it can help healthcare professionals identify the physical, emotional, and social needs of survivors and provide appropriate support. Survivors could experience an array of significant consequences as a result of treatment, such as vision loss, hearing loss, cognitive impairment, and increased risk of second-

ary cancers. Such repercussions could influence their standard of living which may require ongoing management and support. Retinoblastoma survivors' quality of life ratings were poorer than those of the normal community.

Methodology

The scoping review methodology was incorporated to identify and summarize the existing literature on the quality of life in retinoblastoma survivors. This methodology allowed for a comprehensive examination of the available research to identify key themes and research gaps. The review was conducted in compliance with guidelines for scoping reviews provided by the Joanna Briggs Institute [5]. Necessary ethical approval has been sought and approved from UOH/IEC/2022/146 dated 26/08/2021 and renewed on 29/08/2022, for carrying on research work.

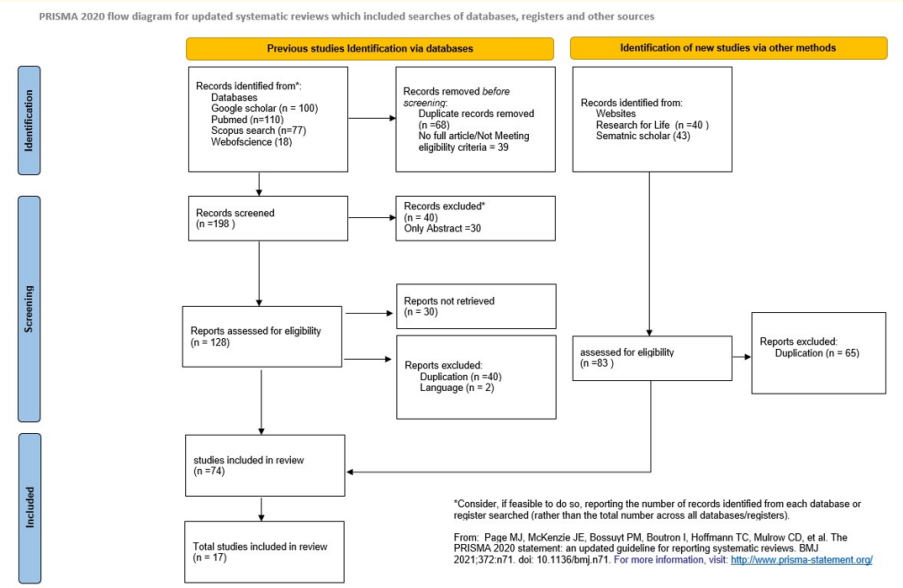
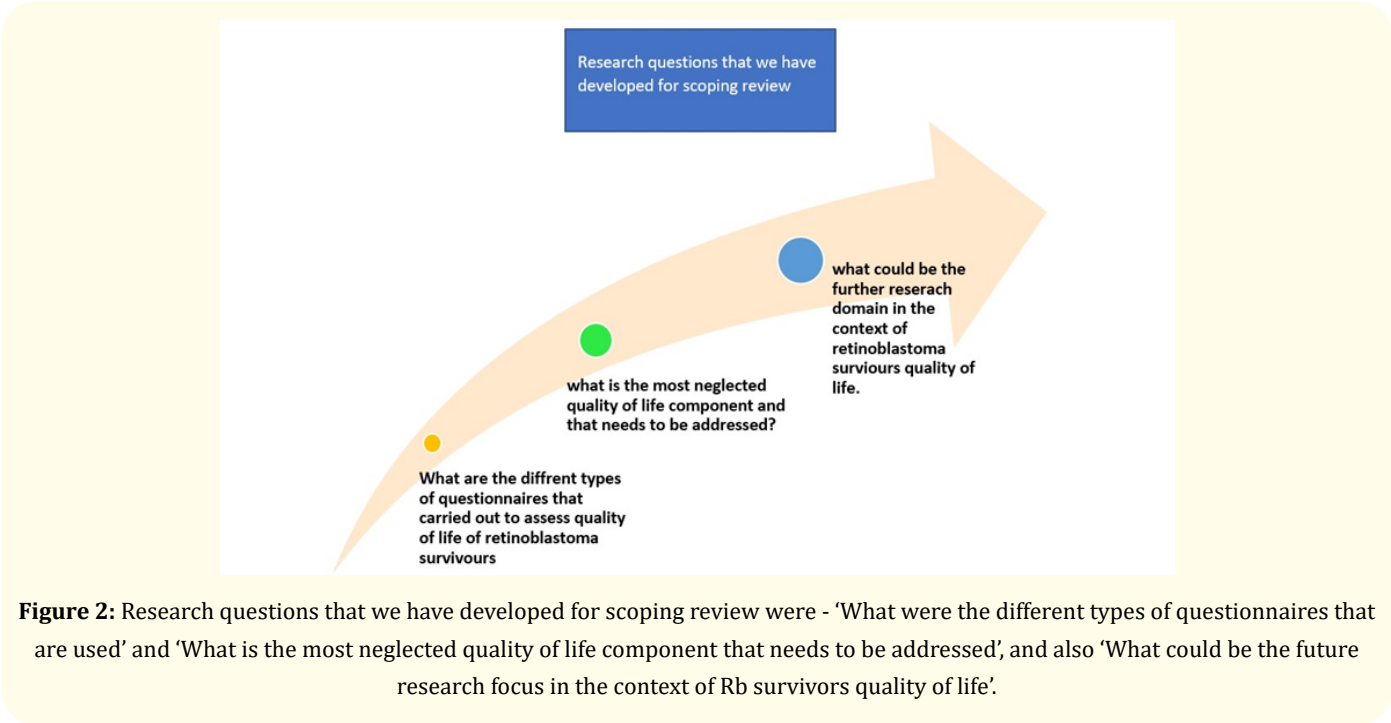


Figure 1: The methodology included a screening process that is identifying suitable articles using search words such as QOL, Retinoblastoma survivors, pediatric QOL, and parent perception. Followed by extracting the eligible articles and removing the duplicates as relevant to the study. Analysis of the study tools implemented, QOL domains that were assessed, study designs used, and results were explored.



Inclusion and exclusion criteria used for selecting the studies:

The assessment comprised research that was published between the years 2000 and 2022. The relevant criteria for inclusion were employed: The investigation was (1) mostly on the quality

of life of retinoblastoma survivors, (2) providing primary data, (3) having published in English, and (4) having peer-reviewed. The assessment excluded research that didn't meet these criteria (Table 1).

Table 1: Criteria for selecting the studies for a scoping review.

Criteria Used for Study Selection	Explanation
Period	Studies published between 2000 and 2022 were included in the review [6].
Inclusion Criteria	The study fixated on the QoL of Rb survivors [7].
	The studies report primary data, randomly controlled trials, and scoping and systematic reviews [8].
	English Literature only [9].
	The study was peer-reviewed [10,11].
Exclusion Criteria	The review did not include any studies that did not meet the aforementioned criteria [6].

Results

This review identified 74 QoL studies of which only 17 fulfilled the inclusion criteria. Geographic distribution these studies were India, China, the US, Brazil, Egypt, and South Africa, The summary of the 2 reviews and 15 are cross-sectional, and Case-Control studies- they included either children or parents, except in the Indian study by Himani Dhingra., *et al.* 2021 and Atul Batral., *et al.* 2016 included both parents and children.

Additionally, the investigations have demonstrated the necessity of additional long-term investigations and studies concentrating on the effect of psychosocial factors on the well-being of retinoblastoma people who survived, along with other gaps in the current research. The originality of this review resides in its exhaustive approach to finding and summarizing the available literature on quality of life in retinoblastoma survivors, as well as noting the research gaps that must be addressed in future studies. The records identified, screened, assessed, included, and retrieved for the current study are depicted in a tabular format (Figure 3).

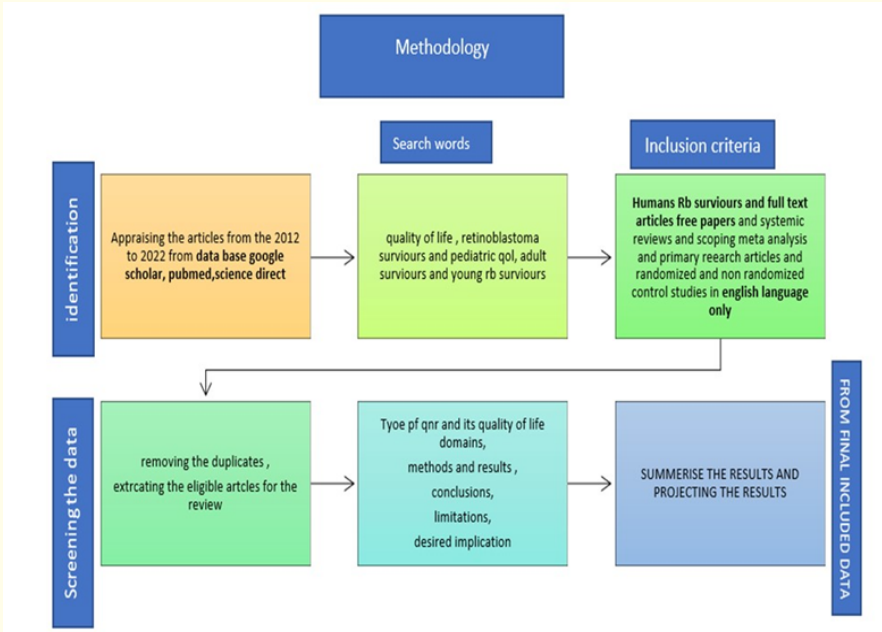


Figure 3: Scoping review data extraction flow diagram.

Also, when examining survivorship from 2000 to 2022, the present literature indicates that there are still gaps in empirical research measuring the variables that impact QoL for this survivor group and how these factors vary over time. For instance, there is a need for a better knowledge of psychosocial functioning among retinoblastoma survivors, as well as a deeper investigation into how financial results and access to treatment may affect their quality of life. Addressing these research gaps might contribute to a better understanding, allowing treatments to be focused on the areas of highest need for survivors, therefore improving their Quality of Life [26].

Summary of the Table-2

Moll Ac (2017) identified a lacuna in research of the limited sample size employed in their study, and the imperative to evaluate the psychosocial and coping proficiencies of individuals diagnosed with retinoblastoma. The authors proposed that forthcoming investigations ought to encompass a more extensive cohort and evaluate the enduring impact of retinoblastoma on health-related quality of life (HRQOL).

S. No	Author	Sample size/Type	Methods	Research gaps/Limitations	Future Research Implications
1	Moll Ac 2007 [12].	The sample size of the study was 65 retinoblastoma survivors aged 8-18 years and their parents.	"The tools used in this paper were the KIDSCREEN self-report questionnaire and the proxy-report version to assess the health-related quality of life (HRQoL) of retinoblastoma survivors".	Small sample size and did not assess the psychosocial and coping skills. And relied on self-reported data and did not assess the long-term effects of RB on HRQOL	Larger sample size and suggested to include the long-term effects of RB on QOL
2	Paula J Belson 2020 [9].	A total of 59 articles were reviewed, and 15 were identified as eligible for inclusion in the review.	Systematic review -gathered info from public domains using keywords focused	Period of the studies included didn't focus on the outcomes-related studies, limited to only United States which could be generalizable	Early interventions to develop and diagnose the disease and to identify the other influencing factors such as age, gender, and treatment modalities need to be focused on in the future research
3	Atul Batra., <i>et al.</i> 2016 [13].	122 parents of Rb	Peds Qol 4.0 among parents and self-reported	The smaller sample did not assess the socioeconomic and cultural factors, did not include the control group and relied on parent proxy, and also dint focuses on the long-term effects of RB on Qol	Need to focus on Vision-related Qol, potential risk factors to be identified, and also include the different participants such as patients, caregivers, and health care providers.
4	Naomi, wein-trub., <i>et al.</i> 2011 [14]	The total sample size of this study was 46 survivors of childhood Rb between the ages of 2-18 years old and their parents.	Child and Family Follow-up Survey (CFFS) to assess participation in daily activities in three environments: home, school, and the community. - Child Health Questionnaire (CHQ) and Pediatric Quality of Life Inventory (PedsQL) to assess health-related quality of life (HRQOL) of survivors of childhood RB. - Parents of survivors completed the CFFS, CHQ, and PedsQL questionnaires, while children completed the PedsQL questionnaire.	Sample selection bias and study is cross-sectional as Qol responses may vary with time. Lack of info on the severity of Rb.	Future research needs to focus on the school quality of life of children who survived cancer and specifically Rb treatment modality and laterality of the disease.
5	Smita C et 2020 [15].	404 survivors from New York with a mean age of 44 years	Cross-sectional survey and qualitative analysis of open-ended responses. Analyzed using thematic analysis	Did not include the other treatment strategies which cause bias and relied on self-reports	Developing the testing interventions to avoid stress and vision-related bullying and also using 3d printing to develop the prosthetic eyes to be more realistic and comfortable which investing the social support and peer role. Focus on longitudinal studies.
6	Atul Batra., <i>et al.</i> 2016 [16].	122 survivors	"The study assessed various factors predicting the QOL, including age at diagnosis, age at assessment, sex, IRSS stage, and previous surgery and radio-therapy. Peds Qol 4.0"	Dint assess the treatment modality, diagnosis age, disease severity, and parents Qol	The paper suggests that future studies should assess the impact of the severity of the disease, treatment modality, socioeconomic status, and parents' QOL on the QOL of retinoblastoma survivors. Longitudinal studies to study the perception of siblings and parents of Rb survivors

7	Jennifer Ford 2015 [17]	470 adult Rb survivors who were treated at three "Academic medical centers in New York between 1932 and 1994."	"25-item National Eye Institute Visual Field Questionnaire "	The retrospective study design didn't include the control group, only included the population from 3 centers treated in only New York not from other populations	Concentrate on creating therapies to enhance the "vision-focused HRQoL of retinoblastoma survivors, especially those with bilateral illness." To investigate the associations involving socioeconomic factors, therapeutic interventions, and quality of life
8	Paula J. Belson [18]	"71 adolescent and young adult retinoblastoma survivors who were between 14 and 39 years of age."	"Crossectional design, Short form 36 life survey qnr and SF-36, Functional assessment of cancer therapy general FACT-g, also associated socio-demographic profiles"	A cross-sectional design with, a small sample size, did not assess the psychosocial elements	Need to focus on diverse samples to develop a psychosocial intervention for better QoL
9	Hayley Wright 2020 [19]	24 Rb survivors aged 5-18 years and diagnosed Rb before age 5	Used a mixed methods approach to collect data on disability and QoL, including surveys, semi-structured interviews, and medical chart reviews.	No comparison group, small sample size, did not assess the psychosocial elements	The long-term impact of retinoblastoma survivorship on disability and QoL, diverse sample to develop a psychosocial intervention for better QoL
10	Al Qahtani, <i>et al.</i> 2022 [20]	To evaluate the health-related quality of life (HRQOL) of patients who have undergone bilateral enucleation for retinoblastoma.	Crossectional design, Short form 36 life survey qnr and SF-36, and socio-demographic details	Limited by its small sample size and lack of a comparison group. And did not assess age or gender socio-demo elements	"Focus on developing interventions to improve the vision-targeted HRQoL* of retinoblastoma survivors, particularly those with bilateral disease. To study the relationship between age gender treatment modality socio-economic status with QoL"
11	Himani dhingra, <i>et al.</i> 2021 [11].	53 retinoblastoma survivors aged 18-40 years	"Cross-sectional study using the Pediatric Quality of Life Inventory (PedsQL)" questionnaire.	Small sample size, limited to a specific geographic region, cross-sectional design.	Explore the impact of cultural and socioeconomic factors on HRQoL in retinoblastoma survivors in India.
12	Zhang, <i>et al.</i> 2018 [7].	single center, 78 children undergone enucleation	Peds* QoL among parents and children	With a smaller sample size did not assess other treatment-related QoL and single-center recruitment.	Should focus on treatment-related QoL and interventions to improve QoL
13	Bisht, S., Chawla, B. 2019 [21]	"the study included 40 parents (28 mothers and 12 fathers) of children with retinoblastoma, who were randomly assigned to either the yoga group (n = 20) or the control group (n = 20)".	RCT, at a tertiary eye care hospital, 12-week yoga-based training for cases and controls routine care measured the psychosocial stress on QoL	Small sample, the study didn't follow up for further sustainability of yoga-based training	To investigate the long-term effects of practicing yoga to check the sustainability of it
14	Friedman, D. N., <i>et al.</i> 2018 [22].	120 adult survivors of Rb "who were treated at Memorial Sloan Kettering Cancer Centre between 1950 and 2015".	"NEI VFQ (National Eye Institute Visual Functioning Questionnaire) questionnaire to assess vision-related QoL"	Smaller sample and comorbidities and other treatment-related effects didn't study	Longitudinal studies and in diverse samples and effect of time on QoL.

15	Janic, A., <i>et al.</i> 2020 [23]	18 studies, scoping review	Psych info, Embase, and PubMed databases were used to identify the studies that used proms to assess the QoL in Rb pts. And identified the psychometric properties of the studies based on pre-determined inclusion and exclusion criteria.	Did not assess the unpublished literature and other languages and did not focus on the relevant areas that may affect Rb survivors	To explore the use of alternative PROMs that may be more relevant or sensitive to the specific needs of individuals with retinoblastoma. And longitudinal studies
16	Soliman., <i>et al.</i> 2015 [24].	125 children with unilateral Rb	"Cross-sectional study, unilateral RB who were treated at the Children's Cancer Hospital Egypt (CCHE) between 2007 and 2012. Parents/guardians completed the qnr"	Cross-sectional design, collected data from a single center, and did not evaluate the long-term outcome's effects of QoL	Treatment modalities on patient outcomes. And long-term effects of treatment in unilateral Rb*pts
17	Dio-mandé, G., <i>et al.</i> 2022 [25]	35 Pts* with extra-ocular Rb	A cross-sectional study of 35 patients with extra-ocular retinoblastoma who were treated at the ophthalmology department of the University Hospital of Treichville, Abidjan. Participants completed questionnaires that assessed their QoL.	Sample size and cross-sectional design did not evaluate the impact of specific treatment modalities on QoL*.	Future research could evaluate the impression of specific treatment modes on QoL in Pts with extra-ocular retinoblastoma in Abidjan.

Table 2: Retinoblastoma survivors' quality of life from 2000 to 2022 (period): relevant research (N = 17).

Table 2 represents QoL questionnaires, Kids screen self-report, Peds, Child and Family follow-up survey (CFFS), Child Health Questionnaire (CHQ), Short form 36 life qnrSF-36, Cancer therapy general FACT-g qnr, Medical charts and thematic analysis, National eye institute visual field questionnaire (NEIFQ), treatment-based interventions along with sample size, research gaps, and future implications.

*Peds: Pediatric, Rb: Retinoblastoma, Pt: Patient, HRQOL: "Health-related quality of life".

QoL: "Quality of Life".

Belson (2021) and Janic (2020) have posited that the systematic review of prior research lacked a focus on outcome-related studies and was confined to the geographical boundaries of the United States, thereby limiting its generalizability. The authors suggested that forthcoming investigations should prioritize early interventions for the diagnosis and treatment of retinoblastoma, in addition to identifying other variables that may impact outcomes, such as age, gender, and treatment modalities.

The authors Atul Batra in 2016, H Dhingra in 2021, Zhang in 2018, and Dimonde in 2022 have identified a gap in the existing research about the influence of particular treatment modalities on the quality of life (QoL) of patients diagnosed with extra-ocular retinoblastoma. The authors also observed a dearth of control data

that is matched for age. The authors have proposed that forthcoming studies should assess the influence of particular treatment modalities on the quality of life (QoL) of patients diagnosed with extra-ocular retinoblastoma. Additionally, this study has recommended that such research should incorporate age-matched control data.

Weintraub (2011) and Soliman (2015) have identified a research gap in the cross-sectional design of their studies and the absence of long-term follow-up data concerning the impact of treatment modalities on patient outcomes. The authors proposed that forthcoming investigations should prioritize the assessment of the enduring consequences of therapy on patient outcomes, specifically in individuals afflicted with unilateral retinoblastoma.

In their study, Smita C (2020) identified a research gap in the omission of alternative treatment approaches, which could potentially result in biased outcomes. The authors also observed a dependence on self-reported information. The authors proposed that forthcoming investigations should prioritize the development of testing interventions aimed at mitigating stress and vision-related bullying, the utilization of 3D printing technology to create prosthetic eyes that are more realistic and comfortable, and the implementation of longitudinal studies.

In 2018, Daniele Novetsky identified a gap in the existing research about the limited sample size and the necessity to examine the impact of comorbidities and other treatment-related factors. The authors proposed that forthcoming investigations ought to prioritize the implementation of longitudinal studies in a broader range of populations and scrutinize the impact of time on the quality of life.

Belson (2020) and Quahtani (2022) have both identified a gap in the existing research literature of small sample sizes and the absence of a comparison group. The authors of the study acknowledged that their research did not incorporate an evaluation of variables such as age, gender, or other socioeconomic and demographic factors that could potentially impact the quality of life (QoL) of the subjects. The scholars proposed that forthcoming investigations ought to prioritize the evaluation of the QoL of vision, encompassing factors such as socioeconomic and demographic characteristics.

In their study, Hannah Wright (2020) identified a research gap in the absence of a comparison group and the limited sample size. The authors also acknowledged that their investigation did not evaluate the psychosocial components of quality of life. The author proposed that forthcoming research should prioritize the examination of the enduring effects of retinoblastoma survivorship on disability and quality of life (QoL), alongside the development of psychosocial interventions aimed at enhancing QoL.

Bhawna S Chawla and Ford JS 2015 have identified a research gap in the small sample size in their study and the necessity for the subsequent follow-up to ensure the sustainability of yoga-based training. The authors recommended that forthcoming studies should examine the enduring impacts of engaging in yoga to assess its viability.

According to the table provided, a total of 9 studies were analyzed, of which 5 studies acknowledged the existence of a research gap or a limitation in their respective research endeavors. The aforementioned studies have identified several concerns, including but not limited to inadequate sample size, absence of a control group, employment of cross-sectional design, data collection from a single center, insufficient assessment of psychosocial and coping abilities, and inadequate examination of the impact of treatment modalities on quality of life. The aforementioned studies suggest that forthcoming research should prioritize longitudinal studies, incorporate larger sample sizes, encompass diverse samples, examine the impact of specific treatment modalities on quality of life, and investigate the enduring effects of retinoblastoma survivorship on disability and quality of life. The 4 remaining studies out of 17 studies did not explicitly define any gaps or limitations in research or future research directions.

Table 3 represents Age, Gender, Treatment, Region, and Vision are the influencing factors as per the literature found. The majority of research focused on the survivors' physical health, psychological functioning, and educational and employment results. Less research has investigated the effect on family functioning and the financial cost of caring.

Future-relevant influencing variables were identified as age, gender, and treatment methods in a meta-analysis and literature review done in 2021 by Paula J. B., *et al.* [10]. In a 2022 cross-sectional study, researchers found that retinoblastoma survivors in India scored lower than healthy individuals on psychological functioning and quality of life characteristics. The authors suggest that interventions to improve the psychosocial well-being of retinoblastoma survivors may be beneficial [33,34].

Discussion

This study highlights the review of studies undertaken on the subject of retinoblastoma and how it affects patients' quality of life over 22 years. The overall results suggest that there is a reduction of QoL in Rb survivors however, due to some variation in inclusion criteria, tools used, etc, there are differences reported in these studies. The studies used a variety of tools to evaluate patients' quality of life, including the general core scale, follow-up surveys, thematic analysis, and self-report and proxy reports.

Table 3: Shows the Influencing factors as per the recent literature.

Influencing Factors	Author and Year
Age, Gender, Treatment	Friedman DN., <i>et al.</i> (2016) [27];
Region, Vision	Chawla., <i>et al.</i> (2019) [28];
	Garza-Garza LA., <i>et al.</i> (2020) [29],
	Carol L Shields (2010) [30]; Dunkel., <i>et al.</i> (2010) [31],
	Wiley JF., <i>et al.</i> 2013 [32]

The results of this scoping review demonstrated that all 17 studies found gaps or restrictions in their studies. These studies highlighted problems such as a small sample size, no control group, cross-sectional design, data collection from a single site, inadequate assessment of psychosocial and coping abilities, and the effect of treatment methods on the quality of life. Future research should concentrate on longitudinal studies, higher sample sizes, varied populations, the effects of certain treatment modalities on quality of life, and the long-term impacts of retinoblastoma survivability on disability and quality of life, according to the studies' recommendations.

Other studies simply reported their results and limitations without mentioning any research gaps or areas that should be the focus of future studies. Nevertheless, the results of all studies help us understand how retinoblastoma affects patients' quality of life, and the limitations that were found in these studies can direct future research in this area. Overall, the studies included in the table illustrate the significance of evaluating retinoblastoma patients' quality of life and guide how future research might fill in gaps in the existing body of knowledge to enhance patient outcomes.

The impact of potential threats on QoL

Several studies have examined the impact of age on the QoL of retinoblastoma survivors. Kleinerman., *et al.* 2019 study revealed that older age at diagnosis was associated with poorer health-related QoL in adult survivors [35]. However, another study found that age at diagnosis did not significantly impact QoL in pediatric survivors [18]. Gender has also been examined as a risk factor for QoL in retinoblastoma survivors. Shields., *et al.* the study found that female survivors reported poorer overall QoL than male survivors while another study found no significant gender differences in QoL [35,36].

According to Dunkel., *et al.* (2010) [31], Wiley JF., *et al.* 2013 [32] study treatment has been shown to significantly impact the QoL of retinoblastoma survivors. Survivors who underwent enucleation (removal of the eye) reported significantly poorer QoL than those who received other treatments, such as chemotherapy or radiation [14]. The region has also been examined as a risk factor for QoL in retinoblastoma survivors [37,38]. Chawla., *et al.* 2019 study found that survivors from low-income countries reported lower QoL than those from high-income countries [39]. Lastly, vision has been found as an important element influencing QoL in retinoblastoma survivors. According to Garza-Garza LA, *et al.* (2020) [29], Carol L Shields (2010) [30]; Dunkel., *et al.* (2010) [31], Wiley JF., *et al.* 2013 [32] survivors with visual impairment had lower QoL than those without impairment.

While several studies have examined the impact of various risk factors on QoL in retinoblastoma survivors, there are still gaps in the current research [40]. For example, few studies have examined the impact of socioeconomic status on QoL in this population. Additional research is often required to examine the emotional effects of retinoblastoma treatment and survival [41]. Finally, studies on therapies that can improve retinoblastoma survivors' quality of life are few.

Figure 4 the key indicators that are connected with retinoblastoma survivors' quality of life.

- The impact of treatment modality, with some studies indicating that patients who underwent enucleation had poorer quality of life scores linked to those who underwent other treatments [32].
- The impact of vision status, with some studies suggesting that

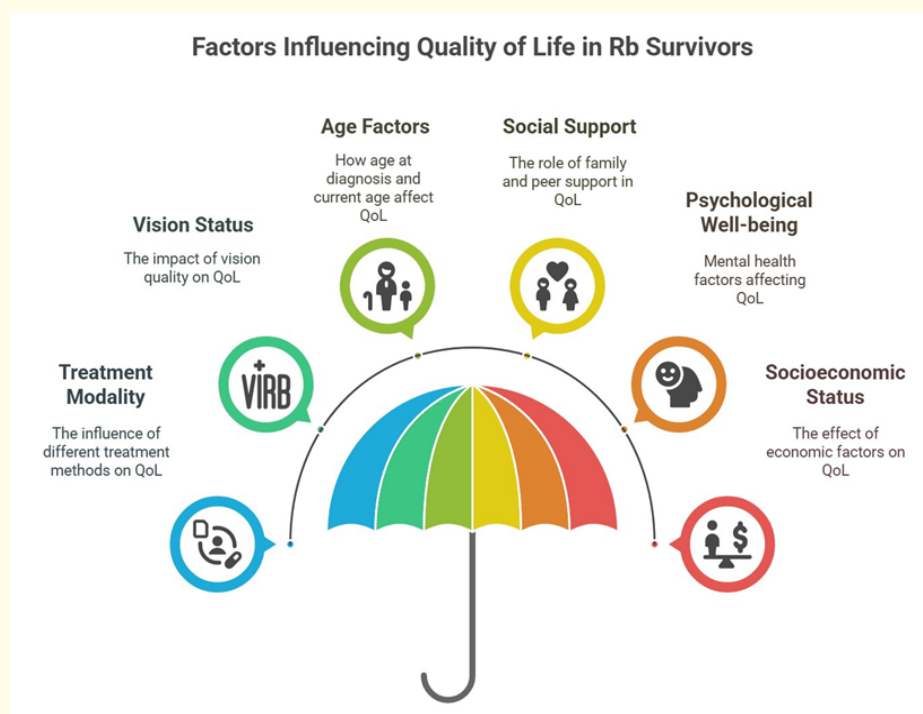


Figure 4: Depicts the key indicators that are connected with retinoblastoma survivors' quality of life utilizing 2000–2022 published literature/journals [31,35,39,41–43].

patients with poor vision or unilateral blindness had poorer quality of life scores associated with those with normal vision or bilateral vision [43].

- The impact of age at diagnosis and current age, with some studies indicating that younger patients and those who are older at the time of assessment may have lower QoL measures [44].
- The value of having close companions, and psychological well-being, with studies highlighting the role of family and peer support, as well as mental health factors such as depression and anxiety, in affecting the quality of life outcomes [45].
- There is a pressing need for more investigation into various aspects of Rb survivors' well-being, including the effects of advanced disease, the roles played by socioeconomic status, and the effects of long-term survival [11].
- These critical aspects demonstrate the complexity and multidimensional QoL in Rb survivors and the necessity for a holistic approach to their distinct requirements and concerns [11].

Limitations and Future Scope

The scoping review on the QoL in Rb sufferers has some limitations, as does any research. One of the study's major drawbacks was that it only included papers published in English. As a result, relevant studies published in other languages may have been overlooked. Additionally, the study might have overlooked relevant papers that were not found in the databases analyzed. Besides these limitations, the scoping review provides crucial insights regarding retinoblastoma survivors' standard of living. The review stresses the effect of several risk factors on life quality, identifies research gaps in the literature, and proposes future research methodologies on this subject.

Conclusion

This scoping review which narrowed down to 17 studies that met the inclusion criteria, indicated that most studies are rigorous and confirm that QoL is lower in Rb survivors. It also highlighted that perspective of both parents and children is important and that

age, gender, treatment, region, and vision are significant influencing factors when evaluating QoL. Another forthcoming aspect is that psychological performance, and educational and occupational outcomes, need to be included in such studies. Subsequent research endeavors ought to investigate the broader dimensions of quality of life, encompassing familial dynamics and economic effects, to furnish a more comprehensive comprehension of the obstacles encountered by rb survivors and their families.

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