

QUALITY OF LIFE IN RETINOBLASTOMA SURVIVORS IN INDIA: QoLRB INDIA STUDY

A thesis submitted during 2023 to the University of Hyderabad in partial fulfilment of the award of a Ph.D. degree in the Health Sciences (Optometry and Vision Science), School of Medical Sciences

By

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CERTIFICATE

This is to certify that the thesis entitled ***Quality of Life in Retinoblastoma Survivors in India: QoLRB India Study*** submitted by **Padamandala Krishnasri** bearing Reg. No: **18MOPH03**, in partial fulfilment of the requirements for the award of **Doctor of Philosophy** in the **School of Medical Sciences**, is a bonafide work carried out by her under my supervision and guidance. **This thesis is free from Plagiarism and has not been submitted previously in part or in full to this or any other University or Institution for the award of any degree or diploma.** Further, the student has the following publication before submission of the thesis for adjudication and has produced evidence for the same in the form of reprint in the relevant area of her research:

1. Padamandala, K., G Honavar, S., Bansal, R., Prasad M, S. D., Gadiraju, P., & K Vemuganti, G. (2023). Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. *Journal of Cancer Science and Clinical Therapeutics*, 07(02). <https://doi.org/10.26502/jcsct.5079202>

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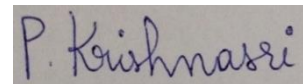
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DECLARATION

I **Padamandala Krishnasri** (18MOPH03) hereby declare that this thesis entitled “*Quality of Life in Retinoblastoma Survivors in India: QoLRB India Study*,” submitted by me under the guidance and supervision of **Prof. Geeta K Vemuganti**, School of Medical Sciences, University of Hyderabad, is a bonafide research work.

I also declare that it has not been submitted previously in part or in full to this University or any other University or Institution for the award of any degree or diploma.

29th December 2023
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To my Amma Nanna Chelli and my dearest Husband&Family, for their patience and limitless
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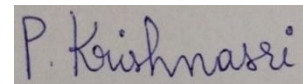
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ABBREVIATIONS

QoL	Quality of Life
HRQoL	Health-Related Quality of Life
WHO	World Health Organization
Rb	Retinoblastoma
NCD	Non-Communicable Diseases
CNS	Central Nervous System
UN	United Nation
OD	Ocular Dexter
OS	Ocular Sinister
OU	Ocular Uterque
GBD	Global Burden Diseases
SDOH	Social Determinants of Health
EBRT	External Beam Radiation Therapy
PBCR	Population-Based Cancer Registry
CT	Computed Tomography
B-Scan	Brightness Scan
NCRP	National Cancer Registry Programme
ASIRs	Adaptive Statistical Iterative Reconstructions
OC	Orbital Cellulities
IAC	Intra Arterial Chemotherapy
IcamC	Intra cameral Chemotherapy
IVC	Intra Venous Chemotherapy
IvitC	Intra Vitreal Chemotherapy
PR	Plaque Radiotherapy
OP	Ocular Prosthesis

Vn	Vision
VA	Visual Acuity
BCVA	Best Corrected Visual Acuity
FFL	Fixing and Following to Light
CF	Counting Finger
HM	Hand Movement
CFS	Centre for Sight
PH	Physical Health
EM	Emotional Health
SoH	Social Health
ScH	School Health
IEC/IRB	Institutional Ethics Committee/ Institutional Review Board
UOH	University of Hyderabad
KSSR	Kids Screen Self-Report
PedsQoL	Pediatric Quality of Life
CFFS	Child and Family Followup Survey
CHQ	Child Health Questionnaire
QnrSF-36	Short Form 36 Life Questionnaire
NEIFQ	National Eye Institute Visual Field Questionnaire
TBI	Treatment-Based Intervention
FACT-G	Functional Assessment of Cancer Therapy-General
CR	Cancer Registry
SSInW	Semi Structure Interview
TTT	Transpupillary Thermo Therapy
AC	Adjuvant Chemotherapy
AAA	Alkylating Antineoplastic Agent
En	Enucleation

PROMIS	Patient Reported Outcomes Measurement Information System
SD	Standard Deviation
PRO	Patient Reported Outcome
SPR	Self-Proxy Report
IQR	Inter Quartile Range
OR	Odds Ratio
LBR	Logistic Binary Regression
UL	Uni Lateral
BL	Bi-Lateral
SES	Socio Economy Status
ULC	Upper Lower Class
LMC	Lower Middle Class
UC	Upper Class
LC	Lower Class
UMC	Upper Middle Class
ICF	Informed Consent Form
IAF	Informed Assent Form
Qnr	Questionnaire
P-Value	Probability-Value(Level of Significance)
AMC	Age Matched Control
OPD	Out Patient Department
TECH	Tertiary Eye Care Hospital
RbS	Retinoblastoma Survivors
UG	Under Graduation
PG	Post Graduation
WNL	Within Normal Limits
VI	Visual Impairment

SR	Stable Regression
CM/PM-RF	Chief Minister/ Prime Minister-Relief Fund
NGO	Non-Government Organization
PN	Patient Narratives
ICRB	International classification of Retinoblastoma

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CHAPTER 1

The initial chapter of this dissertation delves into the background and introduction about survivors of Retinoblastoma and their quality of life. Additionally, it outlines the study's overarching aim, specific objectives and underscores the significance of the research.

1.1 INTRODUCTION

Among the health issues that affect the world today, Cancer holds a unique distinction of being a leading cause of death worldwide. The word "Cancer" is derived from the Greek word "Carciones," which translates to "crab" in reference to the crab-like projections that characterise the spreading nature of Cancer. Cancer science and universal healthcare are advancing rapidly in the current era due to new medical procedures, advances in surgical equipment, and the development of new medications. Biomedical and statistical research aims to effectively identify, cure, and prevent Cancer (*Epocrates Web*, 2022). The study dwells into the quality of life (QoL) in retinoblastoma survivors in India, where retinoblastoma is a paediatric juvenile eye cancer that develops in the retina and is widespread among children under the age of five, regardless of their demographics (Villegas et al., 2013).

The concept of quality of life is multifaceted and often lacks a precise focus, varying significantly from person to person. Its dimensions encompass a broad spectrum, including the physical, emotional, cognitive, functional, social, educational, and other aspects of daily life. Happiness and health are strongly correlated. A healthy person may appreciate life's quality more. People hold diverse attitudes and perspectives on life, and it is a universal desire for each individual on Earth to seek a life filled with fulfilment and joy. The experience of pleasure and

anticipation varies uniquely for each person. Importantly, there is a strong correlation between happiness and health, with good health often enabling a deeper appreciation of life's quality.

Human life expectancy has increased thanks to medical science, but some chronic diseases make it extremely painful and make life pitiful. Due to their diversity, these indicators are challenging to quantify and detect. Subjective by definition. As a result, it can be challenging to define and explain the idea of "quality of life."

QoL has various health related angles like psychological, social, physical, and spiritual. When someone is diagnosed with Cancer, they typically view it as a death sentence and, as a result, they are unable to enjoy life because of their anxiety. Researchers discovered that patients who were better at avoiding a situation than accepting it had more difficulty adjusting to its repercussions.

1.2 QUALITY OF LIFE CONCEPTUALISATION

According to the World Health Organization, quality of life is "an individual's perception of their position in life concerning their values and culture, as well as their goals, expectations, and standards" ("WHO QOL," 1995). D. Felce et al proposed a mixed model of quality of life involving subjective and objective factors coupled with a range of groups and individual values, emphasizing the role of external norms and individual differences in the development of quality of life (Felce & Perry, 1995).

Many different patient groups and research designs are involved in QoL research in medical and health research. Based on the current evaluation of the methodological and conceptual clarity of QoL research, the majority of QoL studies in health and medicine have conceptual and methodological challenges (Haraldstad et al., 2019). A multitude of factors influence quality of life, and these can vary based on individual preferences. Financial security, job satisfaction, family life, health, and safety stand out as some of the most commonly acknowledged elements impacting one's quality of life (*QoL Indicators*, 2022).

Health-related quality of life (HrQoL) surveys frequently assess self-perceived health status, leading to a potential misinterpretation of the term QoL. The current understanding of HrQoL is deemed

unclear, prompting the suggestion to define HrQoL as the statistical assessment of how health impacts QoL or to exclusively use the term to represent the benefits associated with a medical condition (Karimi & Brazier, 2016).

1.2.1 The Quality of Life's Historical Context

After World War II 1945, when socioeconomic inequities were becoming more and more apparent, academic interest in quality of life increased. This catalysed the study of social indicators, which further led to studies on subjective well-being and quality of life. Although the patient's perception of their health has long played a part in medical consultation, researchers did not start systematically collecting and publishing such data in the healthcare literature until the 1960s (*Britannica*, 2022).

The World Health Organization defines "quality of life" as "an individual's perception 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 QOL," 1995). This concept highlights the subjective character of QOL and its relationship to culture and personal values. In their theory of QOL, Ed Diener, a notable positive psychology researcher, and his son Robert Biswas-Diener emphasize subjective well-being. They say that QOL is defined by the presence of pleasant emotions, life satisfaction, and fulfilment, as well as the lack of negative experiences. (Diener & Biswas-Diener, 2002).

Carol E. Ferrans and Merle H. Mishel proposed a model that identifies health-related quality of life (HRQOL) as a subset of overall QOL. Their model includes physical health, psychological well-being, and social relationships as key domains influencing HRQOL. (Ferrans & Powers, 1985).

Robert Cummins developed the Comprehensive Quality of Life Scale, which includes subjective well-being, health, productivity, intimacy, safety, and community as core domains of QOL. Cummins argues that the assessment of QOL should take into account a broad range of life domains (Cummins, 2022)

Giovanni Saracci, a public health researcher, emphasizes the importance of social and environmental factors in shaping an individual's quality of life. His model incorporates not only personal factors but also the broader social and cultural context. (Saracci, 1997). Amartya Sen, a

Nobel laureate in economics, introduced the capability approach to QOL. He argues that well-being should be measured not only in terms of resources but also in terms of individuals' capabilities to function in areas such as health, education, and social participation.(Nussbaum & Sen, 1993).

Martha Nussbaum, a philosopher, extends Sen's capability approach by emphasizing a list of *central human capabilities* that contribute to good life. Her capabilities approach includes elements such as life, physiological health, integrity, and affiliation (*Nussbaum_women_capabilityapproach 2000*). Lawton's model of QOL for older adults focuses on environmental press, competence, and the individual's adaptation to the environment. It particularly addresses how older adults' well-being is influenced by their ability to adapt to their physical and social surroundings. Lawton's model of QOL for older adults focuses on environmental press, competence, and the individual's adaptation to the environment. It particularly addresses how older adults' well-being is influenced by their ability to adapt to their physical and social surroundings. (Byrnes et al., 2006).

These conceptualizations highlight the multidimensional nature of QOL and the importance of considering subjective, objective, and cultural factors when assessing and promoting well-being. Researchers continue to refine and expand these models to better capture the complexity of individuals' experiences and perceptions of quality of life.

1.2.2 Paradigm Shift of QoL Periodically:

1980s-1990s: Broader Dimensions Recognizing the limitations of economic indicators, the 1980s and 1990s saw a paradigm shift towards a broader conceptualization of QOL. This included the incorporation of psychological, social, and health-related dimensions (Nussbaum & Sen, 1993). **Late 1990s-2000s: Subjective Well-Being** In the late 1990s and 2000s, there was an increasing emphasis on subjective well-being and life satisfaction (Cummins, 1999.). This shift led to the development of scales and surveys to capture individuals' own assessments of their lives (Diener & Biswas-Diener, 2002). **2010s-Present: Holistic Approaches** In recent years, there has been a move towards holistic approaches to QOL. Comprehensive models, such as the World Health Organization's multidimensional model, now integrate physical

health, mental well-being, social relationships, and environmental factors (*Measuring the QoL*, 2023). Current Trends (2020s Onward) Ongoing trends include a focus on inclusivity, considering diverse perspectives and cultural variations. The impact of technology on well-being is under exploration, and attention is given to sustainability and environmental factors affecting QOL. Ongoing Challenges and Future Directions Challenges include the need for culturally sensitive QOL measures, longitudinal studies to capture changes over time, and increased interdisciplinary collaboration.

1.2.3 Quality-of-Life Indicators

Quality of life (QoL) is categorized into several major groups. These encompass generic measures, crafted to evaluate health-related quality of life across diverse patient groups and sample populations. Additionally, there are disease-specific measures designed to assess individualized aspects of health-related quality of life within specific illness groups. This approach allows for the inclusion of all facets of life that individual patients deem important. (*Britannica*, 2022; *QoL Indicators*, 2022).

1.3 QUALITY OF LIFE APPLICATIONS IN RESEARCH:

Quality-of-life data finds a myriad of applications, with the most prevalent being the assessment of therapeutic interventions through clinical testing and questionnaires. Beyond this, there are broader implications that extend to demographic and patient monitoring, as well as the enhancement of communication between healthcare providers and patients. Furthermore, an interpersonal application of such data lies in the economic assessment of healthcare, involving indicators specifically designed for cost estimation. This involves evaluating efforts to determine the advantages of treatment, considering both the life span attained and the standard of living. (*Jenickson*, 2020).

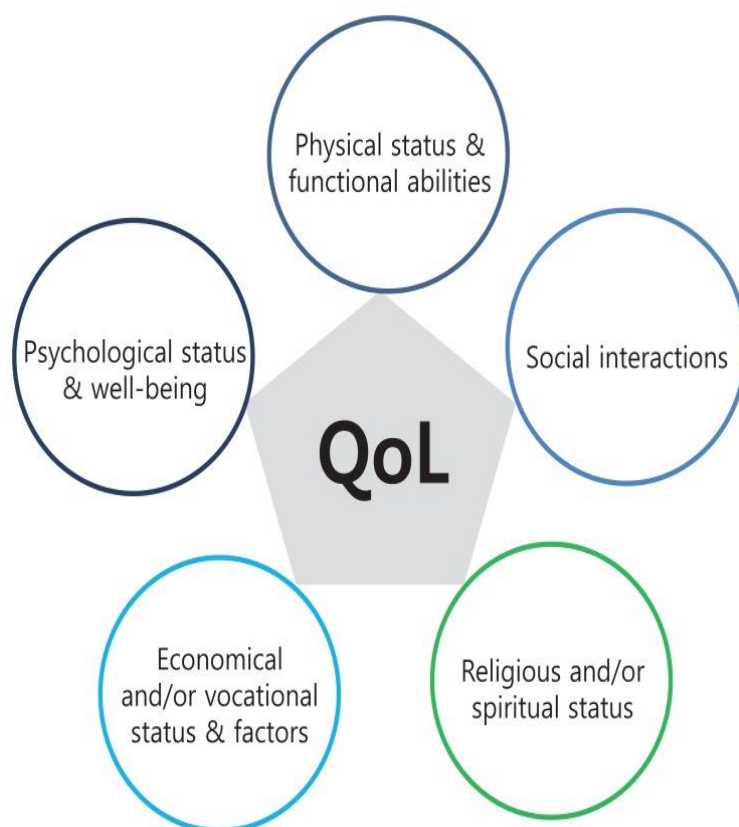


Figure 0.1 Clinical approach to quality of life in children with end-stage renal disease

(Source: ResearchGate, https://www.researchgate.net/figure/Five-domains-in-a-conceptual-definition-of-quality-of-life-QoL4-5_fig1_256481690 [accessed 3 Apr, 2021])

With advancements in clinical and public health that have brought forth effective treatments and drugs, it is only logical that those quantifying health outcomes would now turn their attention to assessing community wellness. This evaluation extends beyond merely saving lives and delves into enhancing the overall quality of daily life (*HrQoL Concepts*, 2018).

1.4 PHYSICAL HEALTH.

The terms "physical activity," "exercise," and "physical fitness" encompass a range of ideas, often used interchangeably and prone to confusion. To clarify, any activity involving energy consumption by an individual—essentially, any regular bodily movement driven by skeletal muscles—is termed physical activity (Caspersen et al., 1985). Specifically, any skeletal muscle-driven movement that expends energy is labelled as physical exercise, with kilocalories

serving as the unit of measurement for energy expenditure. This broad definition includes various professional, sporting, training, domestic, or otherwise activities that individuals regularly engage in.

Exercising is a type of regular physical activity, structured and continuous, with the enhancement or balance of the body as its ultimate or intermediate goal. A group of qualities called physical fitness may be categorised as either skill- or health-related. With the use of particular tests, one may gauge how much a person possesses these qualities (Caspersen et al., 1985). Teenage physical exercise may assist in adolescence to establish healthy adult lifestyles and lower the prevalence of chronic diseases. The effects of adolescent physical activity on adult health are undeniable, hence physical activity promotion must begin in infancy. However, the "how much" is yet uncertain and requires further study. (Hallal et al., 2006).

As Per Can Stock's Visual Representation (Figure 0.2), Physical Health also involves adequate sleep, some physical activity, and nutrition. Braam KI et AL's study stated the effects of combined physical exercise and psychosocial intervention on body composition, psychosocial function, cardiorespiratory fitness, and quality of life in terms of health. Children who are receiving cancer therapy or soon after it frequently have decreased levels of both physical activity and psychological function. Braam also stated that a 12-week program integrating physical activity and psychosocial support for kids with cancer was successful and demonstrated acceptable compliance. Besides a substantial increase in lower body muscular strength over time in the intervention group compared to the control group, did not find any significant effects between-group differences. It shows how physical activity plays a role in cancer therapy.(Braam et al., 2018).

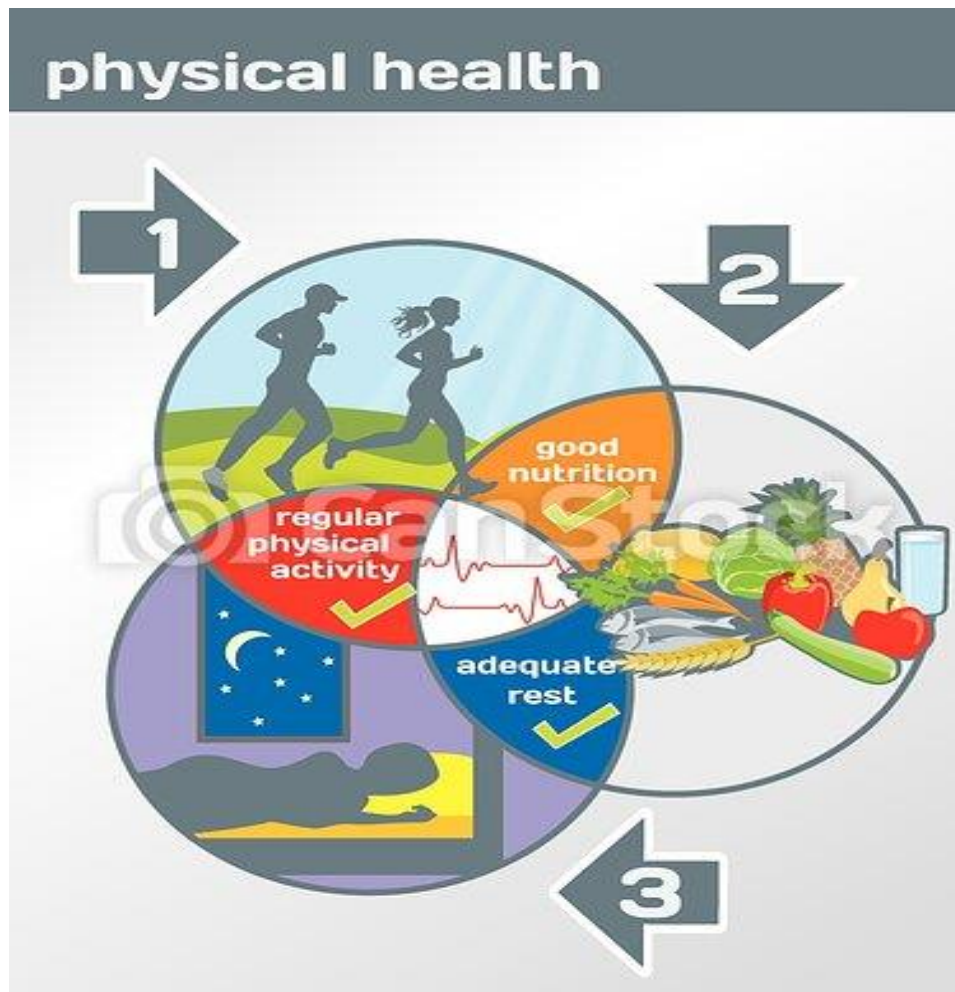


Figure 0.2 Physical Health

(Source: https://cdn.w600.comps.canstockphoto.com/physical-health-diagram-eps-vector_csp16447547.jpg)

Wendy Demark-Wahnefried 2006, proposed that survivors of cancer are more likely to get additional malignancies, cardiovascular disease, diabetes, osteoporosis, and functional decline. They are also more likely to have progressive and recurring illnesses. This susceptible population's general health and quality of life may be improved by lifestyle treatments that enhance food and physical activity habits and smoking cessation.

According to Wendy Demark-Wahnefried et al., the cancer care healthcare practitioner can “significantly influence the long-term wellbeing of people with cancer by: (1) Identifying

possibilities for promoting healthy behaviours such as: quitting smoking, managing weight, and increasing their physical activity; (2) conscientiously monitoring long-term effects among cancer survivors and determining whether they are amenable to intervention; (3) keeping up with the most recent health behaviour recommendations for cancer survivors and available resources for support” (Demark-Wahnefried et al., 2006).

As per the World Health Organisation (WHO) It has been demonstrated that “regular exercise can aid in the prevention and management of non-communicable diseases (NCDs), including heart disease, stroke, diabetes, and several malignancies. Additionally, it lowers blood pressure, maintains a healthy weight, and enhances mental clarity, well-being, and quality of life” (*Physical Activity*, 2022).

In accordance with existing literature and the WHO-established definitions and research, physical inactivity has a detrimental influence on healthcare systems, the ecosystem, economic growth, social well-being, and overall quality of life.

1.5 EMOTIONAL HEALTH

In recent years, the WHO has increasingly acknowledged the crucial role that the mental health plays in achieving global development goals, as evidenced in the study “inclusion of mental health in the Sustainable Development Goals”. It emphasized that the depression remains as one of the primary reasons of disability (*Mental Health*, n.d.).

“*Centre for Disease Control and Prevention*” defines that “Our emotional, psychological, and social well-being all contribute to our mental health. It has an impact on how we think, feel, and act”. It also influences how we deal with stress, interact with people, and make good decisions. Mental health is essential at all stages of life, from infancy and adolescence through maturity(*About Mental Health*, 2021).

A person's emotional health is related to how well they accept and manage their feelings through challenge and change. The ability to digest emotions is one of the characteristics of an emotionally healthy individual(CAPP, 2020).

As per (“Importance of Emotional Health,” 2022) Compromised Emotional health affects Productivity and Financial stability, and it affects health in both positive and negative way, and also potentially affects the individual family’s health and influence the longevity of life.

Isabelle Long Rollen et al 2018 say that Psycho-oncology, a reasonably young multidisciplinary profession, has emerged to address these concerns and offer support for patients facing various problems all across the disease's varying phases.

Waterman A S et al perceived that it is normal for people in good mental health to feel sad, unwell, angry, or unhappy, and these emotions are part of living a fully fulfilled life. It is still often believed that mental health pertains to feelings of happiness and mastery over the environment, even though this is not entirely true(Sm et al., 2011; Waterman, 1993).

If one is struggling with compromised emotional health then the symptoms will be isolating from friends the family, Low energy level, feeling sad or blue, sleeping excessively or insufficient, Fast Passed views, Consuming Matters, Eating too often or too less, Compromised performance at work, Increasing number of personal and social disputes, Irritability, remorse, despondency, or feelings of worthlessness ignoring basic hygiene and grooming(Dan Brennan, 2022). Individual treatment of physical and psychological problems is as crucial as social support and professional counselling for preventing depression and anxiety in long-term cancer survivors. Since younger cancer survivors of working age and female survivors tend to be more impacted by sadness and anxiety, it is important to thoroughly

examine cognitive impairments in long-term cancer survivors after treatment(Götze et al., 2020).

As per Inhestern L et al the majority of survivors (about 40%) reported feeling anxious and around 20% felt depressed. The survivors of adult cancer had higher levels of anxiety but lower levels of depression than the overall population ($p < .001$). There was no difference in anxiety or sadness across subgroups based on how long it had been since their diagnosis. Several factors were linked to increased rates of anxiety and depression among cancer survivors. Anxiety and sadness were shown to be reduced in those who had better social support, family functioning, and physical health(Inhestern et al., 2017).

Cancer survivors of working age reported much greater anxiety levels than the general population. Many people who have overcome cancer often struggle with moderate to severe levels of anxiety and despair. According to the (Inhestern et al., 2017)findings, survivors of cancer who are of working age require access to psychosocial screening and psycho-oncological assistance, such as that offered via survivorship programs. A possible way to determine whether survivors are at a greater risk of experiencing mental distress is to evaluate their current health, the strength of their social networks, and their family histories.

According to Friend AJ et al 2018 systematic Review of 67 papers described sadness, anxiety, behavioural issues, and drug abuse. High-dose anthracyclines, cranial irradiation, sarcoma or CNS tumours, and continuing physical illness increase the risk of mental health issues. The studies they investigated had several limitations, including using siblings of survivors as a control group, self-reporting, and absence of prescription indications when prescribing data was included(Friend et al., 2018).

The literature found several mental health disorders in pediatric cancer survivors, but their incidence, prevalence, and risk factors are unknown. Identifying young cancer patients at

risk for mental health morbidity is critical(Friend et al., 2018). Most survivors of childhood eye cancers are young and therefore entirely reliant on their caretakers and parents, and there is substantial evidence to suggest that emotional health, including mental and physical health, will be compromised after cancer treatment due to extensive intervention and subsequent therapies.

1.6 SOCIAL HEALTH

The World Health Organization (WHO) recognises the importance of the social aspect of health and incorporates it into its constitutional definition of health. A person can respond appropriately to various social circumstances and behave accordingly (“WHO QOL,” 1995). Relationships and interactions with other people are at the heart of what we call "social well-being." When circumstances are challenging, the people we care about may help us get through them. Maintaining social health requires actively seeking out and cultivating meaningful connections with others. The ability to maintain a healthy social life, academic career, and professional career requires deliberate effort. Maintaining social health entails attending to not just the general but also the specific requirements of love partnerships (*Social Wellness*, 2022).

Therefore, regardless of sex, age, level of education, or socioeconomic status, maintaining good social health is necessary for every human being. Children trained to have positive relationships with others maintain such traits into adulthood (*Health & Physical Education*, 2023)

As outlined in the Global Burden Disease (GBD) Report, Cancer and other non-communicable diseases (NCDs) pose a significant threat to global development. This concern was reiterated in the recent UN high-level summit on NCDs, which underscored the limited progress in fulfilling the 2011 political declaration and the third Sustainable Development Goal (SDG). Critical obstacles include the absence of situational evaluations, challenges in priority setting,

and insufficient funding. Local cancer epidemiology information is essential to address these issues, and the GBD report can provide valuable statistics in this regard.

The national statistical profiles of cancer incidence provided by the GBD study exhibit considerable variabilities, reflecting various risk factor exposures, economic circumstances, lifestyles, and the availability of treatment and screening. Policymakers and stakeholders may utilise the GBD study to enhance national and regional cancer control, meet global objectives, and increase cancer care equality(Global Burden of Disease Cancer Collaboration et al., 2019).

Recent national public health goals have emphasized the significance of social determinants of health (SDOH) in cancer detection. But there's still a need to elaborate on these connections to find and execute effective treatments that aim and tackle SDOH to lessen cancer screening disparities. Ariella R. Korn's systematic review of the literature on SDOH and cancer screening stresses where further research is needed to fully include SDOH and suggests ways in which SDOH may be used to improve equality in cancer screening in the future(Korn et al., 2022).

1.7 SCHOOL HEALTH

According to the World Health Organization (WHO), For children to build a strong foundation for their futures, they must have access to educational opportunities that allow them to get the information they need and teach them social and emotional skills, such as self-regulation and resilience. The ability to attend a school of one's choice and to feel secure and supported there has been related to improved health outcomes. In turn, better health is associated with higher levels of school completion, academic achievement, employment, and production(*WHO Guidelines*, 2022). Student-led Health Education Programs Enhancement of positive lifestyles and illness prevention via age-appropriate, progressive learning. Distributed by trained faculty members serving as "Health and Wellness Ambassadors" in each school(*Govt*

India -Vikaspedia, 2022). The term "school health" refers to the coordinated efforts made to ensure that all students have access to the school and community-based services they need to succeed in a healthy setting(*School Health, ASHA*, 2022).

1.8 RETINOBLASTOMA:

Retinoblastoma is a childhood intraocular malignancy that may spread outside the eye if not addressed. Sadly, this is the most frequent kind in developing and underdeveloped nations. The tumor can break through the eyeball's protective layer and become apparent there or in the surrounding area. The optic nerve is another potential route to the brain, and the bloodstream is another way it might spread which may be metastatic(*Classification and Staging of Retinoblastoma - PMC*, 2022.).

In general, oncology refers to the study of cancer. Since ancient times, humans have known about cancer. As a result of the uncontrolled growth of cells, cancer develops in a part of the body which may affect a variety of different body parts(says, 2009). Among children under the age of 5 who develop retinal tumours, retinoblastoma is the most prevalent. Taking a qualitative approach may offer a more subjective approach to improving one's quality of life after cancer survivorship.

1.8.1 Definition of Retinoblastoma:

As per the “National Cancer Institute”, retinoblastoma is defined as “Cancer that forms in the tissues of the retina (the light-sensitive layers of nerve tissue at the back of the eye). Retinoblastoma usually occurs in children younger than 5 years. It may be hereditary or nonhereditary (sporadic)”(*NCI RB Defn.*, 2011a).

Rare but devastating, retinoblastoma is the most frequent primary tumour of the eye in infants and young children, and it may even be present at birth. Most tumours arise without apparent cause, and the disease may be passed on as an autosomal dominant feature(Vm et al., 2013). A 2020 review states that the current standard of care for retinoblastoma is to employ an algorithm in pediatric cancer therapy, which categorizes tumours from tiny to extensive lesions (A to E) based on their size(Shields & Shields, 2004).

1.8.2 Prevalence of Retinoblastoma:

Around 8,000 children are globally diagnosed with retinal cancer known as retinoblastoma each year. In high-income nations, patient survival is >95%, while internationally, it is just 30%. The use of new recommendations, increasing illness awareness for earlier diagnosis, and the exchange of knowledge are all contributing to better results(*Nature Review of RB*, 2022). One instance of retinoblastoma is diagnosed for every 15,000–20,000 live births, which equates to around 9000 new diagnoses each year. This incidence rate is consistent throughout the globe(Dimaras et al., 2012).

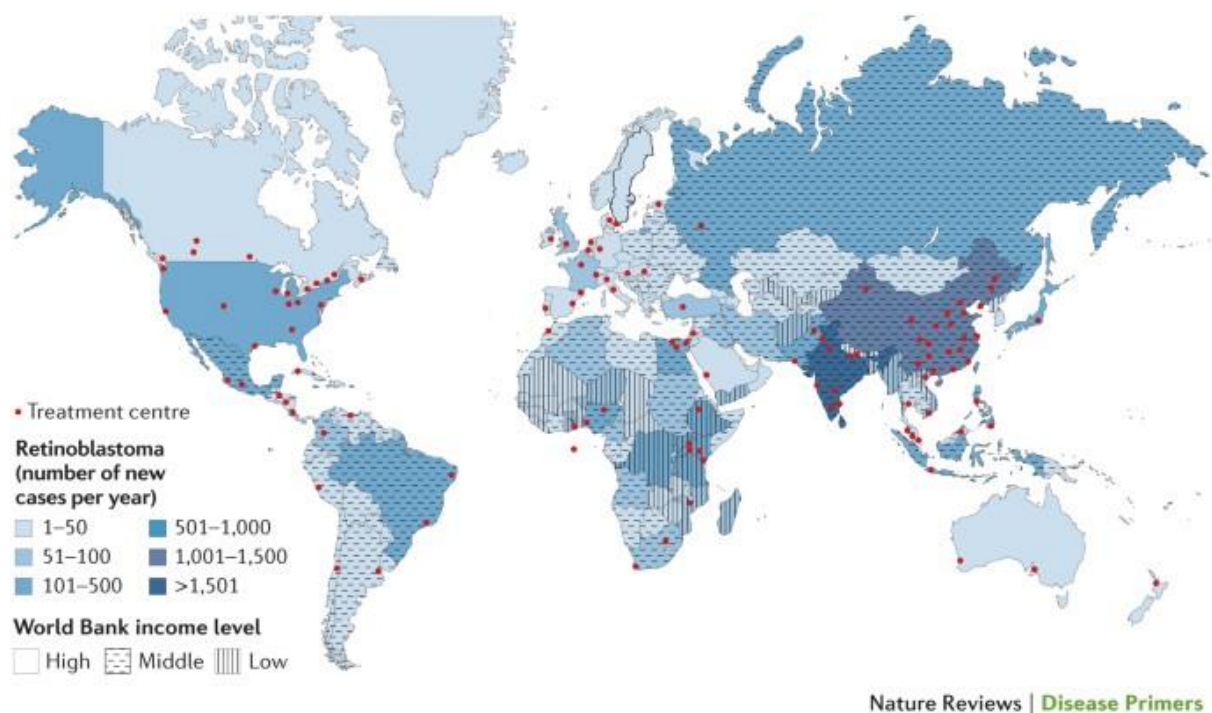


Figure 0.3 World Map

(Source:https://media.springernature.com/lw685/springerstatic/image/art%3A10.1038%2Fnr-dp.2015.21/MediaObjects/41572_2015_Article_BFnrdp201521_Fig2_HTML.jpg)

This report analyses the epidemiology and family history of 1601 British children with retinoblastoma diagnosed 1963–2002 and summarizes the practical ramifications of molecular genetics for diagnosis and counselling. The year of diagnosis and tumour laterality affected incidence rates(MacCarthy et al., 2009).

Laterality and family history were used to determine heritability. 998 instances were unilateral, 581 bilateral, and 22 unknowns. Bilateral instances were detected earlier than unilateral. 35% of bilateral instances are heritable, and all are bilateral. 7 percent of unilateral instances are heritable. 41% of our instances are heritable. Incomplete family history data cause this underestimation. For unilateral patients under 1 year, the incidence rate jumped by 2.5% each year ($p > .0001$); for ages 1-4, the average rise was 0.5% per year (not significant)(MacCarthy et al., 2009).

According to the data derived from the “Population based cancer registries” (PBCR) of Bangalore, Mumbai, Chennai, Delhi and Kolkata it was recorded that incident rates of RB by gender and age variables. It was analysed using standard errors, 95% confidence intervals of ASIR using Poisson distribution. Besides, the “Pooled crude incidence” was also taken between the age group of below 14 years and it was 3.5 per million and ASIR was 4.4 per million. PBCR’s in male children of Chennai (0-4 years) was found to be higher (21.7 per million) and in girl children in Kolkata it was 18.9 per million (Rangamani et al., 2015).

1.9 INTERNATIONAL CLASSIFICATION OF RETINOBLASTOMA:

Table 0.1 The ICRB classification of Retinoblastoma and categorisation of Rb from Group A-E.

International Classification for Intraocular Retinoblastoma (ICRB)	
Group A	<i>Small intraretinal tumors away from foveola and disc</i> * All tumors are 3 mm or smaller in greatest dimension, confined to the retina and * All tumors are located further than 3 mm from the foveola and 1.5 mm from the optic disc
Group B	<i>All remaining discrete tumors confined to the retina</i> * All other tumors confined to the retina not in Group A * Tumor-associated subretinal fluid less than 3 mm from the tumor with no subretinal seeding
Group C	<i>Discrete Local disease with minimal subretinal or vitreous seeding</i> * Tumor(s) are discrete * Subretinal fluid, present or past, without seeding involving up to ¼ retina * Local fine vitreous seeding may be present close to discrete tumor * Local subretinal seeding less than 3 mm (2DD) from the tumor
Group D	<i>Diffuse disease with significant vitreous or subretinal seeding</i> * Tumor(s) may be massive or diffuse * Subretinal fluid, present or past without seeding, involving up to total retinal detachment * Diffuse or massive vitreous disease may include "greasy" seeds or avascular tumor masses * Diffuse subretinal seeding may include subretinal plaques or tumor nodules
Group E	<i>Presence of any one or more of these poor prognosis features</i> * Tumor touching the lens * Tumor anterior to anterior vitreous face involving ciliary body or anterior segment * Diffuse infiltrating retinoblastoma * Neovascular glaucoma * Opaque media from hemorrhage * Tumor necrosis with aseptic orbital cellulites * Phthisis bulbi

doi:10.1371/journal.pone.0034120.t002

Source:

<https://www.researchgate.net/publication/224868686/figure/fig1/AS:340797061910569@1458263760209/International-Classification-for-Retinoblastoma-ICRB-Scheme.png>

1.10 CLINICAL FEATURES OF RETINOBLASTOMA:

Table 0.2 Common presenting features of Retinoblastoma and its percentage

Presenting feature	Percentage
Leucocoria	56
Strabismus	20
Red painful eye	7
Poor vision	5
Asymptomatic	3
Orbital Cellulitis	3
Unilateral Mydriasis	2
Heterochromia Iridis	1
Hyphema	1

(Retinoblastoma: A Comprehensive Review - Scientific Figure on ResearchGate. Available from: https://www.researchgate.net/figure/Common-Presenting-Features-of-Retinoblastoma_tbl1_316624641 [Accessed 1 Dec 2022], n.d.)

1.11 SYMPTOMS OF RETINOBLASTOMA:

As per the American Cancer Society, symptoms of Retinoblastoma include "white pupillary reflex, Lazy eye, and other possible signs and symptoms that include blurred vision, eye pain, redness and bleeding (sometimes) and bulging of the eye, pupil stillness (that does not get constricted when torch light examination or light appears), and also abnormal color of the iris" (*Retinoblastoma: A Comprehensive Review, 2022*). If the stage of Cancer become metastatic, then based on the "location of the cancer symptoms may vary which includes, loss of appetite and weight loss, headache, vomiting, lumps under the skin"(*RB Signs and Symptoms, 2022*).



Figure 0.4 Retinoblastoma Pictorial representation

(Source: <https://www.who.int/news-room/fact-sheets/detail/cancer-in-children>)

1.12 DIAGNOSTIC PROCEDURES AND TESTS FOR RETINOBLASTOMA:

Scheduling an appointment with an ophthalmologist or physician is crucial if there is a suspicion that a child may have Retinoblastoma, especially if there is a family history of the disease. Early diagnosis and therapy may help avoid vision loss and halt the development of Cancer if Retinoblastoma is detected in a child. As Per Figure 0.7 following are the tests are performed in an ophthalmology clinic as part of the examination or retinoblastoma workup.

Biopsies are a standard method for diagnosing most cancers, involving the collection of a tumour sample for microscopic examination by a pathologist or physician. However, biopsies are seldom used to diagnose Retinoblastoma for two reasons. Firstly, they are used to prevent cancer cells from spreading. Secondly, specialists in the field of pediatric oncology seldom need to perform a biopsy to diagnose Retinoblastoma, and the condition is rarely mistaken for other eye disorders in infants (*Tests for Retinoblastoma* | *National Eye Institute*, n.d.).

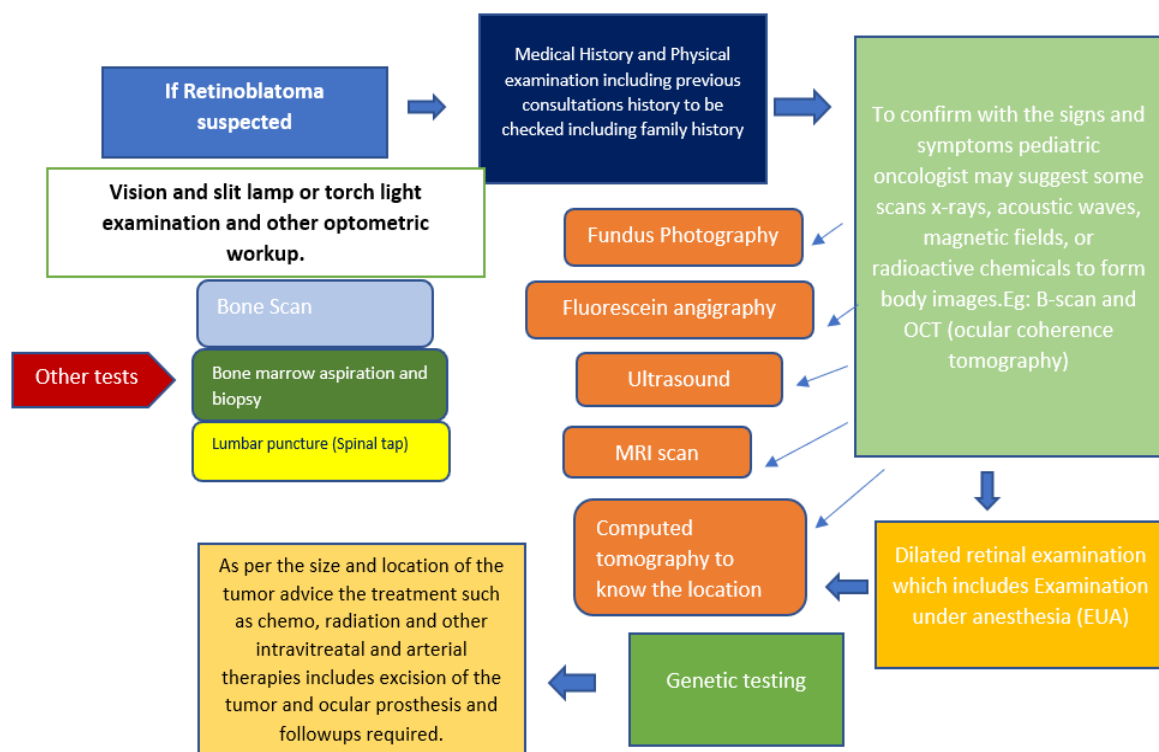


Figure 0.5 Ophthalmic and Optometric Management of Retinoblastoma and Diagnostics

Source: *Tests for Retinoblastoma*

1.13 TREATMENTS OF RETINOBLASTOMA:

Table 0.3 conservative treatment Modalities of Retinoblastoma

Group	Treatment options
A	Focal therapy (TTT/Cryotherapy/Laser Photocoagulation)
B	1) Systemic chemotherapy (VEC)* 2) Focal therapy along with chemotherapy cycles 3) Plaque radiotherapy
C	1) Systemic chemotherapy (VEC)* 2) Focal therapy 3) Sub-tenon Carboplatin
D	1) Systemic chemotherapy (VEC)* 2) Focal therapy 3) Sub-tenon Carboplatin 4) External beam radiotherapy

*VEC: Vincristine, Etoposide, Carboplatin, 6 cycles, given every 28 days

Source: (Chawla et al., 2013).

The 2022 retinoblastoma (RB) review's algorithm encompasses various treatment modalities, including surgical excision, External Beam Radiotherapy (EBRT), Intra-Arterial Chemotherapy (IAC), Intra-Cameral Chemotherapy (IcamC), Intravenous Chemotherapy (IVC), Intra-Vitreous Chemotherapy (IvitC), and radiation-based therapies such as EBRT and plaque radiotherapy (Ancona-Lezama et al., 2020).

1.14 EXEMPLARY CASE PRESENTATION;



Diagnosis and Surgical Management of Retinoblastoma

Autor: Ivonne Jocelyn Rivera Alvarado MD
Co-autores: Luis Alberto Rodríguez Gutiérrez MD, Luis Ignacio Larrazabal Aguerreverde MD, Alejandro Rodríguez García MD

CLINICAL HISTORY

2 YO, male, assisted to our clinic with a history of an **abnormal red réflex** observed by his parents since he was one year old. He was seen by a pediatrician and an ophthalmologist, none of them made a diagnosis. One year later, his parents noted **poor vision** of his left eye.

Family and personal clinical history was unremarkable.

OPHTHALMOLOGIC EXAMINATION

- VA OD 9.6 (TELLER) OS LP
- Left **White reflex**
- OD unremarkable
- OS: midriatic pupil, clear cornea, Deep and quiet chamber, fundus with a **endofitic, elevated lesion** that extends **more than 50 percent** of the retina.

IMAGE

- **Ultrasound** showed an endofitic lesion that occupied the most of the retina, with calcification, no escleral extension. It presented **vitreous seeds**.
- Optic nerve was respected at the CAT-scan



MANAGEMENT

- An **enucleation with an autologous dermis-fat graft** was performed on the left eye.
- The eye was send to pathology.
- The patient and his parents were fully evaluated by the genetic departement, wich made the diagnosis of a **sporadic retinoblastoma**.
- 60 days after the surgery, the patient recived an excelent **prosthesis** with a good motility.

PEARLS

- Always made a differential diagnosis.
- Have an excellent doctor-patient relationship.
- Be clear about the prognosis.
- Do not underestimated the parents observations and complains.
- Prefer the less invasive choice.

PATHOLOGY

- Retinoblastoma showed as an endofitic lesión that do not invade the sclera or the optic nerve, with vitreous seeds.
- It showed Flexner Wintersteiner rosettes and Homer-Wright rosettes.

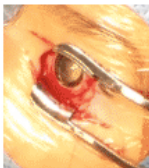
CLASIFICATION

- **Group V** of the Reese-Ellsworth Classification
- Group E of the International Classification of Retinoblastoma



MONITORING

- The patient has been followed by trimestral appointments with a full ophthalmologic examination, included dilation.
- The anophthalmic cavity with the dermis-fat graft has been excaminated directly and by ultrasound.
- The patient is on remission.



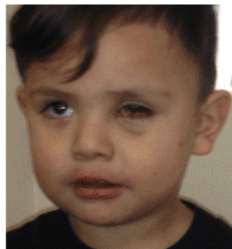




Figure 0.6 Clinic-based retinoblastoma management Example

(Source: https://www.researchgate.net/publication/326892862_Diagnosis_and_Management_of_Retinoblastoma)

1.15 PREVENTION OF CANCER:

Cancer prevention is a crucial strategy to decrease the likelihood of developing Cancer. Victims, their families, and the general public bear the financial burden of cancer treatment on top of the disease's physical and emotional effects. The incidence of Cancer can be reduced through preventative measures, thereby alleviating the suffering of the affected population and lowering cancer-related fatalities. Cancer is not a solitary illness but a set of connected disorders. Individuals' susceptibility to developing Cancer may be affected by various factors, including genetics, lifestyle choices, and environmental factors(*Cancer Prevention Overview (PDQ®)–Patient Version - NCI, 2009*).

1.16 SIGNIFICANCE OF THE STUDY:

The treatment approach for childhood intraocular malignancy focuses on preserving life, saving the eye, and maintaining vision. The duration of treatment, spanning two years with systematic follow-up, involves multiple examinations under general anaesthesia, diagnostic investigations such as X-rays and CT scans, and advanced treatment options like local therapy, enucleation, and chemotherapy. This extensive treatment regimen has implications for the overall well-being of individuals, impacting their physical, mental, and social health, as well as their cosmetic appearance due to potential late sequelae. All these impact the subjects' QoL as they have a long life ahead, cosmetic deformities due to late sequelae of treatment, and healthy functioning (physically, mentally, socially) under their quality of life. Hence, they can expect a better quality of life after the treatment and be prepared for life. In this context, it is important to study the quality of life in retinoblastoma survivors, where most of the subjects are children who need more support to cope with day-to-day activities.

1.17 THE NOVELTY OF THE STUDY:

The novelty of the current study includes individual subject perceptions towards the disease and its treatment consequences from the child and parent level. The study will make use of the

self-report of children to address pediatric childhood cancer needs individually. Notably, the study will focus on the children's coping skills and address the remedial measures as part of their rehabilitation.

1.18 RATIONALE OF THE STUDY:

The examination of the impact of Retinoblastoma (RB) on the health status of survivors, specifically in relation to disabilities and concerns, as well as their potential limitations in engaging in daily activities, lacks comprehensive evaluation. Available longitudinal studies are scarce, and there is a notable absence of an age-matched control group for comparative analysis.

Either depending on parental or self-proxy reports and limited research utilising both methods of data collection. Rb presents a triple challenge due to its manifestation as a childhood tumour, the occurrence of bilateral tumours, and the resulting visual impairments. Additionally, potential complications or sequelae are associated with these tumours, such as the development of secondary malignancies or complications arising from treatment. Therefore, conducting a comprehensive assessment of survivors' and parents' quality of life (QoL) over an extended period would yield more valuable insights.

OBJECTIVE OF THE STUDY:

The primary objective of the study is to assess and investigate the quality of life in retinoblastoma survivors in India following the treatment.

The secondary objectives of the study are:

1. To conduct a scoping review of the literature on the quality of life and influencing factors in Retinoblastoma survivors globally.
2. To investigate the quality of life among retinoblastoma survivors at tertiary care hospitals, in Hyderabad from all over India.

3. To explore the available supporting schemes Using counsellors' interviews and also patients/caregivers' narratives at the institute (CFS) and address them.

1.19 HYPOTHESIS:

The study includes a scoping review to critically evaluate all the studies in this area, followed by interviewing the survivors and their parents independently for a detailed PedsQoL4.0 generic core scale questionnaire which includes 4 major areas e.g. Physical health, Emotional health, social health, School health. As a secondary outcome we also observed the awareness of the parents on the existing supporting schemes available for the affected children. There is a compromised quality of life difference among Retinoblastoma survivors' post-treatment than the control group due to treatment.

CHAPTER -2

THE QUALITY OF LIFE AND INFLUENCING FACTORS IN RETINOBLASTOMA SURVIVORS

The current chapter evaluates and synthesises of information about the Quality of Life and Influencing factors in Retinoblastoma survivors globally from 2000 to 2022 using a scoping review approach.

2.1 INTRODUCTION

Retinoblastoma is an uncommon form of cancer that affects the retina, the component of the eye responsible for vibrant colour vision and light perception (*RB Symptoms & Causes*, 2023). If the illness is not recognised and treated promptly, it may lead to a reduction in vision or even total blindness in either one or both eyes (National Academies of Sciences et al., 2016). A cancer survivor is an individual who has completed all treatments and is either still living with it or has successfully overcome it (*Surviving Cancer*, 2023). In the context of retinoblastoma, survivability entails continuing surveillance of the eyes and consideration of the possibility of treatment-related late sequelae (Dimaras et al., 2015). The primary goal of this proposed study is to examine existing research on the QoL of Rb survivors and determine the variables contributing to their contentment. A prospective research objective is - How would retinoblastoma affect long-term health, and what variables contribute to survivors' Quality of life? Which other factors influence their daily lives?

According to (Haraldstad et al., 2019) anthropometric research is conducted worldwide and encompasses a broad range of intended audiences, research designs, and Quality-of-life indicators. As per Gill and Feinstein's standards, only 13% defined the concept of QoL, whereas 6% classified QoL over HrQoL. The most often matched criteria indicated the areas of QOL to asses, explained why the measures were selected, and combined the data from numerous

components. The study on QoL uses a range of patient populations and analytical approaches and is a crucial endpoint in the medical and health fields. Most QOL studies in medical and health sciences have conceptual and methodology limitations.

Engaging in physical activities, such as exercise, running, walking, and sports, can actively enhance the QoL (Pucci et al., 2012). In 2017, (Wu et al., 2017) synthesised 31 reports that met the inclusion criteria. Among the included studies, 21 utilised a cross-sectional design, and researchers conducted six longitudinal studies and three school-based physical activity intervention trials. One study employed both cross-sectional and longitudinal approaches. Improved physical activity levels were associated with higher health-related Quality of life. In contrast, increased sedentary behaviour was associated with declining health-related Quality of life in children and adolescents.

Understanding the QoL in retinoblastoma survivors is important because it can help healthcare professionals identify survivors' physical, emotional, and social needs to 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 secondary cancers. Such repercussions could influence their standard of living, which may require ongoing management and support. The QoL of Retinoblastoma survivors' ratings were poorer than others.

2.2 METHODOLOGY:

The scoping review method was incorporated to identify and summarise the existing literature on the Quality of life in retinoblastoma survivors. This method allowed for a comprehensive examination of the available research to identify key themes and research gaps. The review complied with guidelines for scoping reviews provided by the Joanna Briggs Institute (Gottlieb

et al., 2021). The Institutional Ethics Committee approved the research work under reference UOH/IEC/2022/146, dated 26/08/2021, and subsequently renewed it on 29/08/2022.

Table 0.4 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 (Gu et al., 2021).
Inclusion Criteria	The study fixated on the QoL of the Rb survivors (Zhang et al., 2018).
	The studies report primary data collection, randomly controlled trials, and scoping and systematic reviews (Panesar et al., 2006).
	English Literature only (P. J. Belson et al., 2020).
	The study was peer-reviewed (P. Belson, 2021; Dhingra et al., 2021)
Exclusion Criteria	The review did not include any studies that did not meet the aforementioned criteria (Gu et al., 2021).

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.

Figure 1: Scoping Review Methodology

The methodology included a screening process that identified 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 assessed, study designs used, and results were explored.

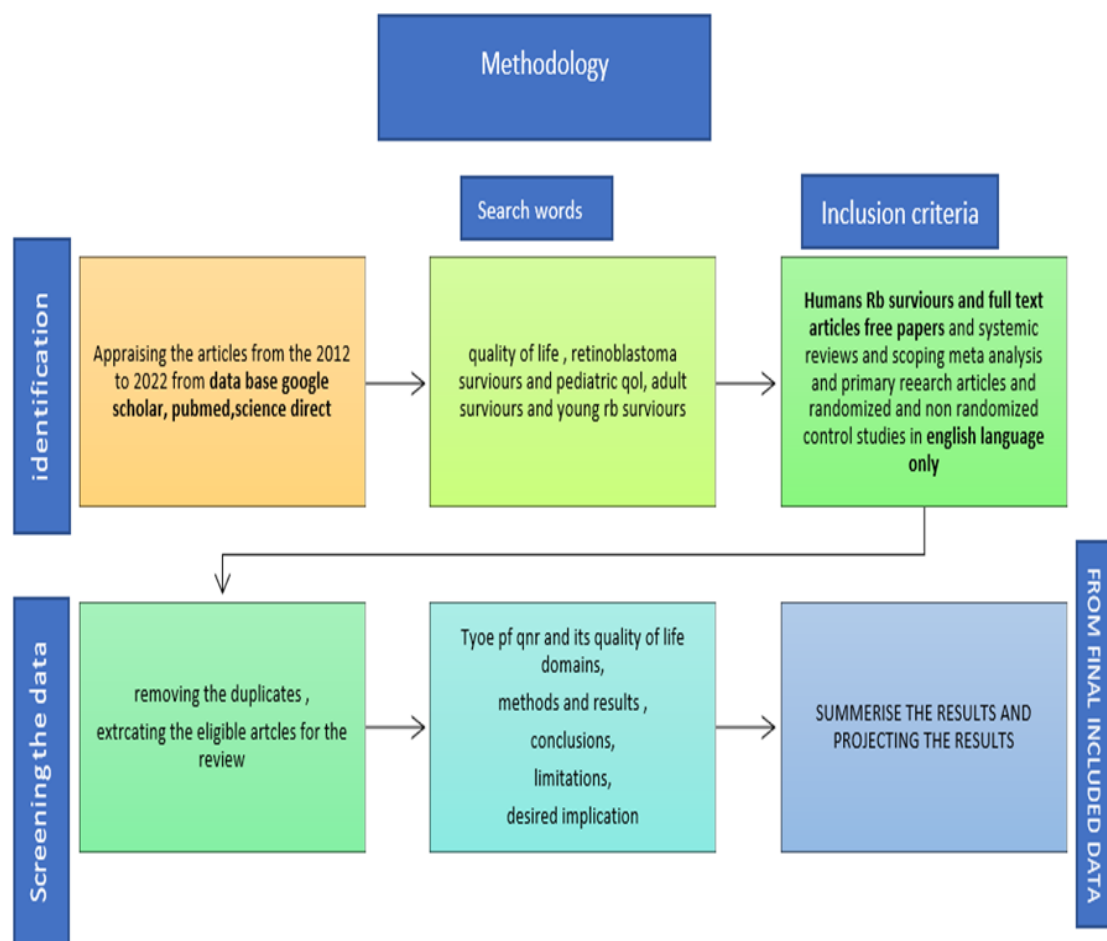


Figure 0.7 Research Objectives Analysed

Research questions developed for scoping review were - ‘What were the different types of questionnaires used?’ ‘What is the most neglected quality of life component that needs to be

addressed?’, and also ‘What could be the future research focus in the context of Rb survivor's quality of life?’.

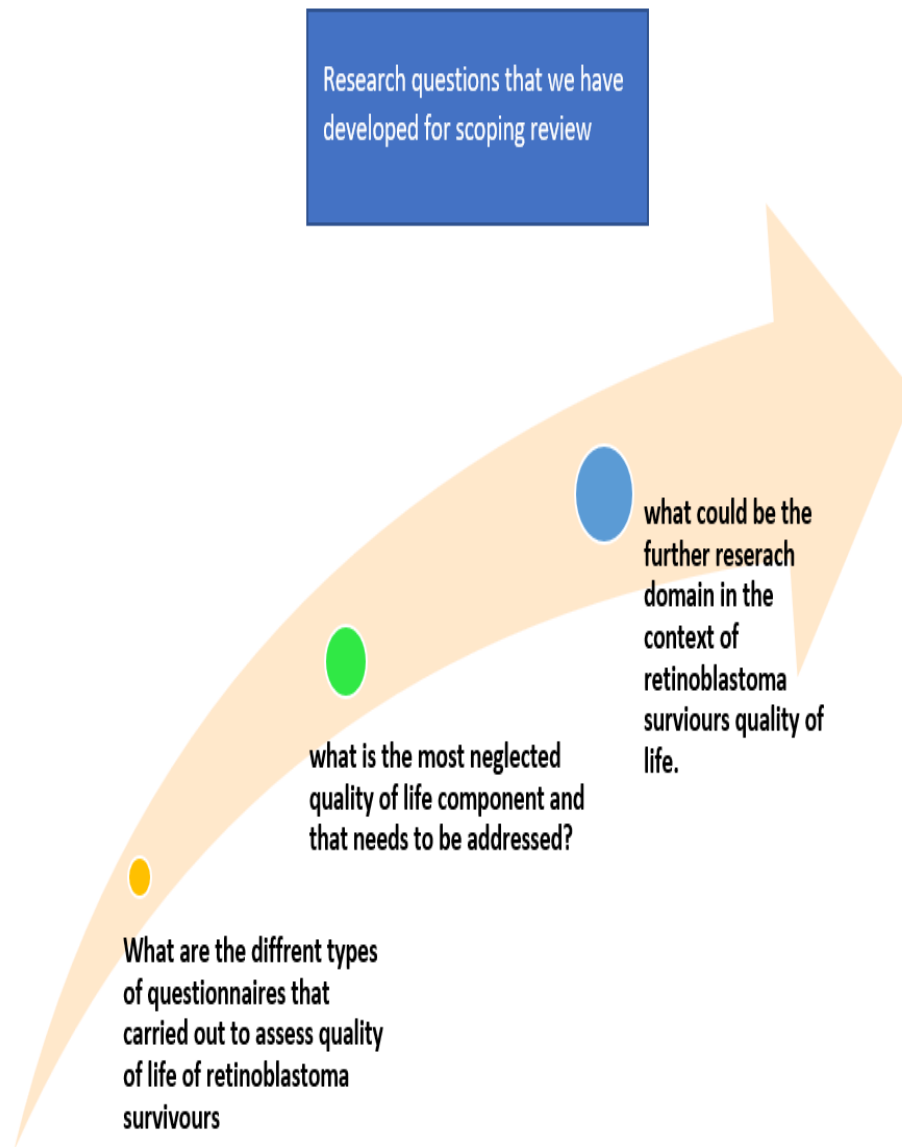


Figure 0.8 Research Questions

Figure 2.9 Research Questions

Inclusion and exclusion criteria used for selecting the studies:

The assessment comprised research published between the years 2000 and 2022. The relevant criteria for inclusion were employed: The investigation was (1) mainly on the Quality of life of retinoblastoma survivors, (2) providing primary data, (3) included articles already published in English and (4) having peer-reviewed. The assessment excluded research that did not meet these criteria (Table 2.3).

2.3 RESULTS:

The review identified 74 QoL studies, of which only 17 fulfilled the inclusion criteria. The geographic distribution of these studies was India, China, the US, Brazil, Egypt, and South Africa. The summary of the two reviews and 15 are cross-sectional and case-control studies, consisting of either children or parents. An exception was the study on India by Himani Dhingra et al. 2021 and Atul Batral et 2016 with parents and children (Batra, Kumari, et al., 2016; Dhingra et al., 2021).

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 people who survived retinoblastoma, along with other gaps in the current research. The originality of this review resides in its exhaustive approach to finding and summarising 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 Figure 2.10 depicts the records identified, screened, assessed, included, and retrieved for the current study. (Fig-2.3)

Analysing survivorship from 2000 to 2022, the current literature suggests that there are still gaps in empirical research regarding measuring the variables influencing QoL for this group of survivors and understanding how these factors evolve. 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 (*Prevalence vs Impact*, 2023).

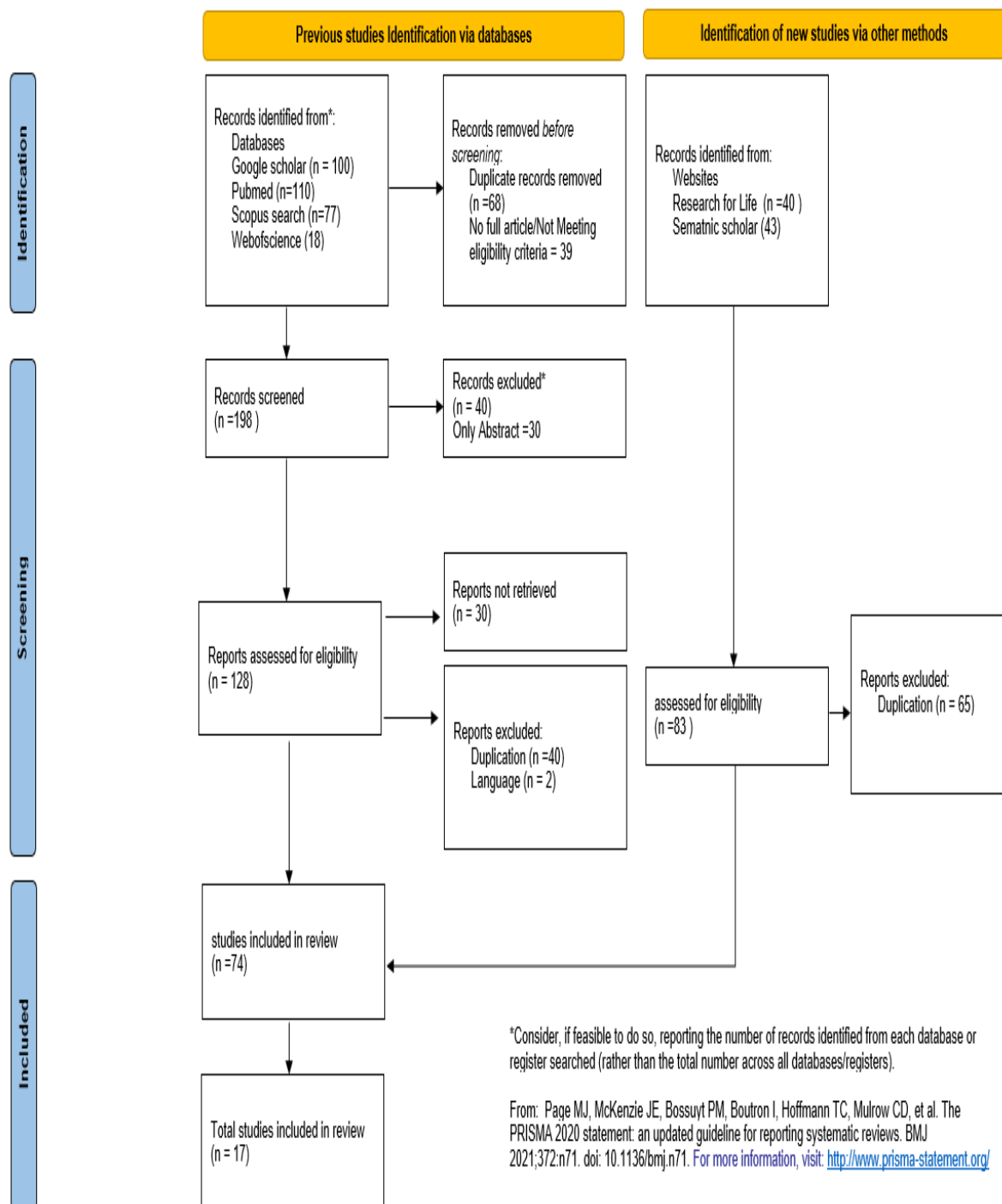


Figure 0.9 Scoping review data flow diagram.

Table 0.5 Retinoblastoma survivors' Quality of life from 2000 to 2022 (period): relevant research (N=17).

S. No	Author	Sample size/Type	Methods	Research gaps/Limitations	Future Research Implications
1	Moll Ac 2007 (van Dijk et al., 2007)	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”.	The sample size was small, and the psychosocial and coping skills were not assessed. And relied on self-reported data and did not assess the long-term effects of RB on HRQOL	A larger sample size and suggested to include the long-term effects of RB on QOL
2	Paula Belson, 2020 (P. J. Belson et al., 2020).	Examined fifty-nine articles and identified fifteen eligible for inclusion in the review.	Systematic review - gathered info from public domains using keywords focused	Period of the studies included did not focus on the outcomes-related studies, limited to only the United States, which could be generalisable	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 future research
3	Atul Batra et al 2016 (Batra, Kain, et al., 2016)	122 parents of Rb	Peds Qol 4.0 among parents and self-reported	The smaller sample did not assess the socio-economic and cultural factors, did not include the control group and relied on parent proxy, and also did not focus on the long-term	need to focus on vision-related QOL and potential risk factors to be identified, including participants such as patients, caregivers, and health

			effects of RB on Qol	care providers.
4	Naomi, Weintraub et al 2011 (Weintraub et al., 2019)	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 are cross-sectional as Qol responses may vary with time—there is a 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 al 2020 (Banerjee et al., 2020)	404 survivors from New York with a mean age of 44 years	cross-sectional survey and qualitative analysis of open-ended responses. Analysed using thematic analysis	did not include the other treatment strategies, which caused 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 invests in social support and peer role. Focus on longitudinal studies.
6	Atul Batra et al 2016 (Batra, Kumari, et al., 2016)	122 survivors	“The study assessed various factors predicting the QOL, including age at diagnosis, age at assessment, sex, IRSS stage, and previous surgery and radiotherapy. Peds Qol 4.0”	did not 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, socio-economic status, and parents' QOL on the QOL of retinoblastom a survivors. Longitudinal studies to study the perception of siblings and parents of Rb survivors
7	Jennifer Ford 2015 (Ford et al., 2015)	470 adult Rb survivors who were treated at three “Academic medical centres in New York between 1932 and 1994.”	“25-item National Eye Institute Visual Field Questionnaire “	the retrospective study design did not include the control group; it only included the population from 3 centres treated in New York, not from other populations	Concentrate on creating therapies to enhance the "vision-focused HrQoL of retinoblastom a survivors, especially those with bilateral illness." To investigate the associations

					involving socio-economic factors, therapeutic interventions, and Quality of life
8	Paula J. Belson (P. J. Belson et al., 2022)	“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 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 (Wright, 2020)	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 a survivorship on disability and QOL, diverse sample to develop a psychosocial intervention for better QoL
10	Al Qahtani et al. 2022 (Al Qahtani et al., 2022)	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	are limited by its small sample size and lack of a comparison group. Moreover, it 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 et al 2021(Dhingra et al., 2021)	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 socio-economic factors on HrQoL in retinoblastoma survivors in India.
12	Zhang et al. 2018 (Zhang et al., 2018)	single centre, 78 children undergone Enucleation	Peds* Qol among parents and children	with a smaller sample size did not assess other treatment-related QoL and single-centre recruitment.	Should focus on treatment-related QoL and interventions to improve QoL
13	Bisht, S., Chawla, B. 2019 (Banerjee et al., 2020)	“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	In a small sample, the study did not follow up for further sustainability of yoga-based training	to investigate the long-term effects of practising yoga to check the sustainability of it
14	Friedman, D. N. et al 2018 (Friedman et al., 2016)	120 adult survivors of Rb “who were treated at Memorial Sloan Kettering Cancer	"NEI VFQ (National Eye Institute Visual Functioning Questionnaire) questionnaire to assess vision-related QoL."	smaller sample and comorbidities and other treatment-related effects did not study	Longitudinal studies in diverse samples and the effect of time on QoL.

Centre
between 1950
and 2015”.

15	Janic, A., et al 2020 (Janic et al., 2020)	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. The psychometric properties of the studies were identified based on pre-determined inclusion and exclusion criteria.	It 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 et al 2015 (Soliman et al., 2015)	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.”	a cross-sectional design collected data from a single centre 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	Diomandé, G. et al 2022 (Selistre et al., 2016)	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.

*Peds: Pediatric, Rb: Retinoblastoma, Pt: Patient, HRQOL: “Health-related quality of life”,
QoL: “Quality of Life”.

Summary of Table 2.2

Moll Ac (2017) identified a lacuna in research due to 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 should encompass a more extensive cohort and evaluate the enduring impact of retinoblastoma on health-related Quality of life (HRQOL) (van Dijk et al., 2010).

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 prioritise early interventions for diagnosing and treating retinoblastoma and identify other variables that may impact outcomes, such as age, gender, and treatment modalities (P. J. Belson et al., 2020, 2022; Janic et al., 2020) .

Atul Batra (2016). H Dhingra (2021), Zhang (2018), and Dimonde (2022) have identified a gap in the existing research about the influence of particular treatment modalities on the QoL of patients diagnosed with extra-ocular retinoblastoma. The authors also observed a dearth of control data matched for age. The authors have proposed that forthcoming studies should assess the influence of particular treatment modalities on the QoL of patients diagnosed with extra-ocular retinoblastoma. This study has also recommended that such research 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 prioritise the assessment of the enduring consequences of therapy on patient outcomes, specifically in individuals afflicted with unilateral retinoblastoma.

Smita C (2020) identified a research gap in omitting 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 prioritise the development of testing interventions aimed at mitigating stress and vision-related bullying, using 3D printing technology to create prosthetic eyes that are more realistic and comfortable, and implementing 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 should prioritise the implementation of longitudinal studies in a broader range of populations and scrutinise the impact of time on the Quality of life.

Belson (2020) and Quahtani (2022) have identified a gap in the 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 socio-economic and demographic factors that could potentially impact the Quality of life (QoL) of the subjects. The scholars proposed that forthcoming investigations should prioritise the evaluation of the QoL of vision, encompassing factors such as socio-economic and demographic characteristics.

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 prioritise examining the enduring effects of retinoblastoma survivorship on disability and QoL alongside developing 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 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 Table 2.2, a total of 17 studies were analysed, of which five acknowledged the existence of a research gap or a limitation in their respective research endeavours. 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 centre, 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 prioritise 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 four remaining studies out of 17 did not explicitly define gaps or limitations in research or future research directions.

Table- 2.6 The literature findings highlight Age, Gender, Treatment, Region, and Vision as influencing factors. The majority of research focused on the survivors' physical health, psychological functioning, and educational and employment results. However, there is a paucity of research examining the impact on family functioning and the financial costs associated with caregiving.

Table 0.6 The influencing factors as per the recent literature

Influencing Factors	Author and Year
Age, Gender, Treatment, Region, Vision	Friedman DN et al. (2016) (Friedman et al., 2016); Chawla et al. (2019) (Bisht et al., 2019a); Garza-Garza LA, et al. (2020) (Garza-Garza et al., 2020),

Paula J. B. et al.'s (2021) meta-analysis and literature review identified age, gender, and treatment methods as future-relevant influencing variables. (P. Belson, 2021). 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 (Korn et al., 2022; Salibasic & Delibegovic, 2018).

2.4 DISCUSSION:

This study highlights the review of studies undertaken on 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 various tools to evaluate the patient's QoL, including the general core scale, follow-up surveys, thematic analysis, and self-report and proxy reports.

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 specific 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.

2.5 PARENTS' PERCEPTIONS OF CHILDREN'S QUALITY OF LIFE WERE LOWER THAN THOSE OF CHILDREN.

(Dhingra et al., 2021) experimented with Retinoblastoma survivors in the northern part of Delhi, India, using health-related QoL of qnr. The study employed a cross-sectional and observational design, including 92 survivors, with a healthy individual from the same family serving as a control group. Results showed that 39% had unilateral and 47% had undergone Enucleation. Where $P < 0.01$ and also found that QoL was compromised in the given data set, and suggested that increased awareness and timely diagnosis play an important role in Rb survivors as part of their rehabilitative care.

2.6 IMPACT OF VISUAL IMPAIRMENT ON VISUAL-RELATED FUNCTIONAL HEALTH AND QOL:

Using the National Eye Institute Visual Field Questionnaire, Danielle Novetsky investigated the impact of retinoblastoma on adult survivors' Quality of life regarding their eyesight. In this retrospective cohort research, hospital patients at three New York City academic medical centres between 1934 and 1994 were asked to complete the questionnaire, with higher scores indicating a better quality of life. Visual impairment was connected with the functional well-being of adult bilateral Retinoblastoma survivors, as determined by analysing data using standard deviation and means score and confidence interval of 95% with a P value of 0.06. (Friedman et al., 2018).

2.7 ADULT SURVIVORS AND QUALITY OF LIFE:

Vision impairment, facial abnormalities, and the fear of recurrence or secondary malignancy affect health-related Quality of life (HrQoL). Nonetheless, few studies have found factors linked with HRQOL in RB patients. Comparing HRQOL of adolescents and young adults

(AYAs) with RB to those of comparison groups and identifying determinants of HRQOL in RB survivors are the objectives of this study. One hundred ninety-eight adolescents and young adults (101 RBs and 97 controls) participated in this cross-sectional study by filling out HRQOL (PROMIS®-29 profile) and psychosocial questionnaires. The patient's medical records provided information on age at diagnosis, visual acuity, lateralisation, heredity, treatment regimen, and anaesthetic history. Linear regression models were used to assess HRQOL correlates. Human resource quality of life (HRQOL) was not significantly different between RB survivors and controls. The RB cohort exhibited a decrease in physical function ($p = .001$), social support ($p = .013$), and self-esteem ($p = .028$) compared to the control group. Overall scores on the PROMIS measure of health and functioning found that differences in visual acuity and self-esteem accounted for 52% of the variation.

In comparison, differences in self-esteem accounted for 38% of the variance. HRQOL in RB survivors was similar to that of their healthy peers despite impairments in physical function and self-esteem. However, most RB survivors in this analysis reported no visual impairments. Therapists should consider measures to boost RB patients' confidence (Belson et al., 2022).

According to (Feng et al., 2020) assessing the Quality of life (QoL) and long-term psychosocial effects of unilateral retinoblastoma treatment in adult survivors (RB) is important. The research method used here is known as a cross-sectional analysis. Participating adults were those who had Enucleation for unilateral RB and were monitored at the Ninth People's Hospital of Shanghai Jiao Tong University School of Medicine; a comparison group of healthy individuals without cancer served as the study's control. Each person answered a series of questions assessing their Quality of life and mental health. The psychological and social impacts included worries, depression, fear of cancer, and a desire to improve one's appearance. Sixty-six RB survivors (43.0% male) and sixty-six healthy people (33.3% male) were compared, with the RB group having a mean age of 27.94 (SD 7.63) and the healthy group a

mean age of 29.18 (SD 8.37). Compared to a control group, adult RB survivors did not show substantially higher rates of depression and anxiety, and they reported having a satisfactory quality of life. Compared to the general population, those who have survived a unilateral RB tend to worry more about their looks (median 1.59 [interquartile range (IQR) 1.27 to 2.16] vs median 0.36 [IQR 0.09 to 1.04]; p 0.001). The Quality of life (QoL) for the vast majority of survivors with unilateral RB is excellent, and they do not have worse psychosocial functioning than a noncancer group. Some forms of psychological and social aid may be more appropriate for females (Feng et al., 2020).

Other studies 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 found in these studies can direct future research in this area. Overall, the studies 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.

While some studies presented their findings and limitations without explicitly addressing research gaps or identifying areas for future exploration, the collective results contribute to our understanding of how retinoblastoma impacts patients' Quality of life. The identified limitations in these studies can serve as valuable pointers for future research endeavours in this domain. In essence, the studies in the table 2.2 underscore the importance of assessing the Quality of life in retinoblastoma patients and offer insights into potential future research to improve patient outcomes.

2.8 THE IMPACT OF POTENTIAL THREATS ON QOL:

Several studies have examined the impact of age on the QoL of retinoblastoma survivors. Kleinerman et al.'s (2019) study revealed that older age at diagnosis was associated with poorer health-related QoL in adult survivors (Shields & Shields, 2004). However, another study found that age at diagnosis did not significantly impact QoL in paediatric survivors (P. J. Belson et al., 2022). Gender has also been examined as a risk factor for QoL in retinoblastoma survivors. Shields et al. (2004) found that female survivors reported poorer overall QoL than male survivors, while another study found no significant gender differences in QoL (Nicolussi et al., 2014; Shields & Shields, 2004).

According to Dunkel et al. (2010), Abramson et al. (2015), and Wiley JF et al. (2013) have collectively demonstrated that treatment significantly influences 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 (Weintraub et al., 2019). The region has also been examined as a risk factor for QoL in retinoblastoma survivors (Rajeshuni et al., 2019; Truong et al., 2015). A study by Chawla et al. (2019) found that survivors from low-income countries reported lower QoL than those from high-income countries (Chawla et al., 2013). Lastly, vision is an important element influencing QoL in retinoblastoma survivors. According to Garza-Garza LA et al. (2020), Carol L Shields (2010), Dunkel et al. (2010), Abramson et al. (2015), Wiley JF et al. (2013), 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. Global RB Outcome study 2022. For example, few studies have examined the impact of socio-economic status on QoL in this population. Additional research is often required to examine the emotional effects of

retinoblastoma treatment and survival (Seth et al., 2017). Finally, there are few studies on therapies that can improve retinoblastoma survivors' Quality of life.

Figure -4 Depicts the key indicators that connected with retinoblastoma survivors' Quality of life utilising 2000–2022 published literature/ journals (Abramson et al., 2015; Bisht et al., 2019b; Chawla et al., 2013; KHORRAMI-NEJAD et al., 2016; Seth et al., 2017; Shields & Shields, 2004):

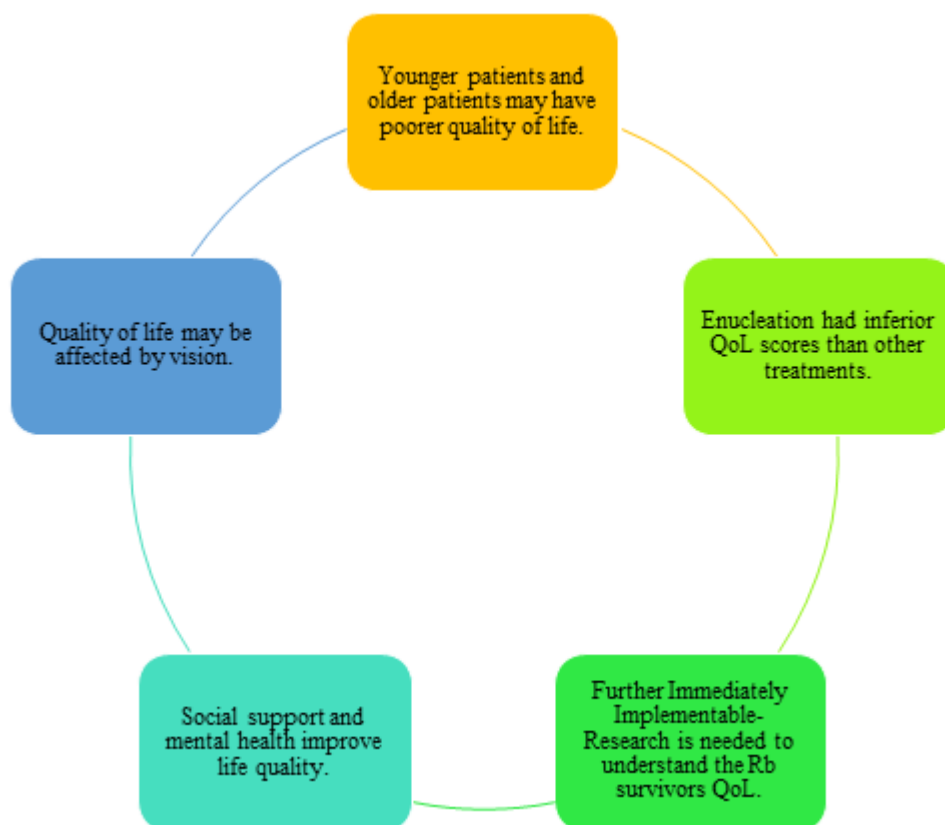


Figure 0.10 Key indicators connected with QoL of retinoblastoma survivors.

- 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 (Wiley et al., 2013).
- The impact of vision status, with some studies suggesting that patients with poor vision or unilateral blindness had poorer Quality of life scores associated with those with normal vision or bilateral vision (KHORRAMI-NEJAD et al., 2016).

- There is an 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 (Shrestha et al., 2019).
- 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 (Harandi et al., 2017).
- 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 socio-economic status, and the effects of long-term survival. (Dhingra et al., 2021a).
- 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 (Dhingra et al., 2021a).
-

2.9 LIMITATIONS & FUTURE SCOPE:

As with any research, the scoping review on the QoL in Rb sufferers has some limitations. One of the study's significant drawbacks was that it was limited to publications in English. The researchers may have overlooked relevant studies published in other languages. Additionally, the study overlooked relevant papers not found in the databases analysed. 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.

2.10 CONCLUSION:

This scoping review, which was narrowed 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 the perspective of parents and children is essential and that age, gender, treatment, region, and vision are significant influencing factors when evaluating QoL. Another forthcoming aspect is that such studies must include psychological performance and educational and occupational outcomes. Subsequent research endeavours ought to investigate the broader dimensions of Quality of life, encompassing familial dynamics and economic effects, to comprehensively comprehend the obstacles that RB survivors and their families encounter.

CHAPTER 3

QUALITY OF LIFE OF RETINOBLASTOMA SURVIVORS: AN INITIAL EXPLORATION

3.1 PILOT STUDY

This chapter deals with Investigating the Quality of life of retinoblastoma survivors: an initial exploration. In which we evaluate the feasibility of implementing the Paediatric quality of life questionnaire, PEDS QL 4.0 generic score, before embarking on a more extensive study.

3.1.1 Introduction:

RB is the most common intraocular malignancy in children globally, with a prevalence of 1 in every 15000-20000 live births across the population, which correlates with 9000 new cases every year globally (*NCI RB Defn.*, 2011b; Dhingra et al., 2021). Rapid progress has been made in diagnosing and treating the disease to save lives and vision in order of priority (Dimaras et al., 2012b; Kivelä, 2009). Together, 43% of the global burden of RB lives in these countries: 1486 children in India, 1103 children in China, 277 children in Indonesia, 260 children in Pakistan, 184 children in Bangladesh, and 142 children in the Philippines (8). Recently, retinoblastoma has exceeded uveal melanoma to become the most common ocular malignancy globally (Dhingra et al., 2021b).

It is important to study the Quality of life in retinoblastoma as it is potentially fatal but has a good prognosis and survival rates with early diagnosis and treatment. It is one of the most easily detectable cancers, constituting 3% of paediatric cancers (*Retinoblastoma* , 2012). However, Quality of life is the most neglected and important aspect of survivorship. It is necessary to create awareness of the affected Quality of life domains and allow timely advocacy of initiatives for addressing the issues at an individual level (Dhingra et al., 2021b).

Few studies have evaluated the QoL in children affected with RB. In one study, the pediatric Quality of life inventory 4.0 generic core scales (PedsQLTM 4.0) among enucleated subjects revealed that the social and academic dimensions were statistically insignificant compared to healthier children and influenced by the laterality of the illness, age, and satisfaction with the ocular prosthesis (Abramson et al., 2003).

Because there is a dearth of scientific research and disparities in a wide range of technological and socio-economic elements that could potentially affect clinical diagnosis and life expectancy, the researchers contend that knowing the impact of retinoblastoma in the Asia Pacific is crucial (7).

Unlike in other paediatric tumours, visual disability, physical appearance, multiple extensive treatments, and challenges in counselling on prognosis and consequences could affect the Quality of life and well-being. The observations in the clinical practice of the researcher also indicate that there appears to be a difference between children's and parents' perceptions of children with RB compared to other children with non-RB eye pathology.

With this rationale, the researcher aimed to evaluate the feasibility of implementing the Paediatric quality of life questionnaire, PEDS QL 4.0 generic score, before embarking on a more extensive study. Through the pilot process, the researcher administered the questionnaire, observed challenges, and gathered preliminary data at a tertiary eye care hospital in South India. The hypothesis posited that there would be a discernible difference in the Quality of life between retinoblastoma (RB) survivors and their parents, compared to a control group of non-retinoblastomas (non-RB) children and their parents.

To evaluate the hypothesis, the researcher aimed to assess the Quality of life of RB and non-RB survivors and their parents' perceptions concerning the QoL of their children in both

groups. A comparison of the differences in Quality of life (QoL) between retinoblastoma (RB) survivors and non-RB survivors, as well as the perceptions of their parents, was attempted.

3.1.2 Methodology:

Study Sampling technique: The researcher utilised a "convenience sampling" technique to access the data already present in the study setting, a tertiary care hospital, to facilitate data collection, considering the rarity of retinoblastoma.

Study population: The study considered two groups of participants. The group of children with RB, as per the information and details provided by the hospital, comprises the treatment group children. Their parents were also considered for administering the questionnaire and the interview. On the other hand, the non-RB children were considered a control group; their parents were also considered to administer the questionnaire and interview, as shown below in 3.1.

The sample was collected from the Centre for Sight (CFS) eye hospital during the pandemic phase in September-October 2021. The cooperating institutes conducted an ethical evaluation of subjects who underwent retinoblastoma treatment, including unilateral or bilateral enucleation, chemotherapy, plaque irradiation, freezing, laser eye coagulation, and usage of supporting and intensive services and ocular prostheses. The subject or the subject's legal representative provided their informed written consent and approval. As per the ethical procedures, informed consent was obtained from the parents of the treatment and control groups and assent from the children of both groups.

Parameters collected for Population Clinical features/parent's data: Demographics such as Age, Gender, Geographical region, Type of treatment, Laterality of the disease, Disease-free survival, BCVA, Parents' income, Parent education level, and Occupation of the parent, time taken to complete the questionnaire, comprehensibility of the questionnaire were included.

QoL Questionnaire details/ content: The Standardised PEDS QL 4.0 Generic core score (Telugu, Hindi, English) versions were used to assess the QoL, which contains the Physical domain (8 items), Social health domain (5 items), School domain (5 items), and Emotional (5 Items) were analysed to check the feasibility of implementing questionnaire time and, documenting the problems faced while collecting the same. Additionally, the researcher administered a questionnaire that included detailed treatment history, electronic gadget usage, nearest blind school presence, financial expenditure of the survivors, and whether the child required special attention.

3.1.3 Study process:

This pilot study was conducted from September 2021 to October 2021 and included 60 patients, of which 15 were RB survivors, 15 were controls, 15 RB case primary caregivers, and 15 were (non-RB) control primary caregivers who are parents. Following institutional Ethics Committee approval, the researcher started recruiting the subjects. As depicted in Fig. 3.1, the study process commenced with applying eligibility criteria, which included individuals aged 2-18 years who had completed two years of treatment at the Centre for Sight Super Specialty Eye Hospital.

The researcher considered a minimum of 1-2 years of disease-free survival to avoid the treatment-related co-morbidities that might influence the questionnaire response. Age-matched controls were utilised, and in cases where individuals in the 2-4-year age group could not consent to or comprehend the questionnaires, parents were allowed to participate. Additionally, parents' perspectives were studied independently. The study followed the WHO definition of Quality of life (QoL), which states the personal understanding and perspective towards their life physically, mentally, emotionally, and socially. Participants who were unwilling to participate and outside the defined age group were excluded from the study.

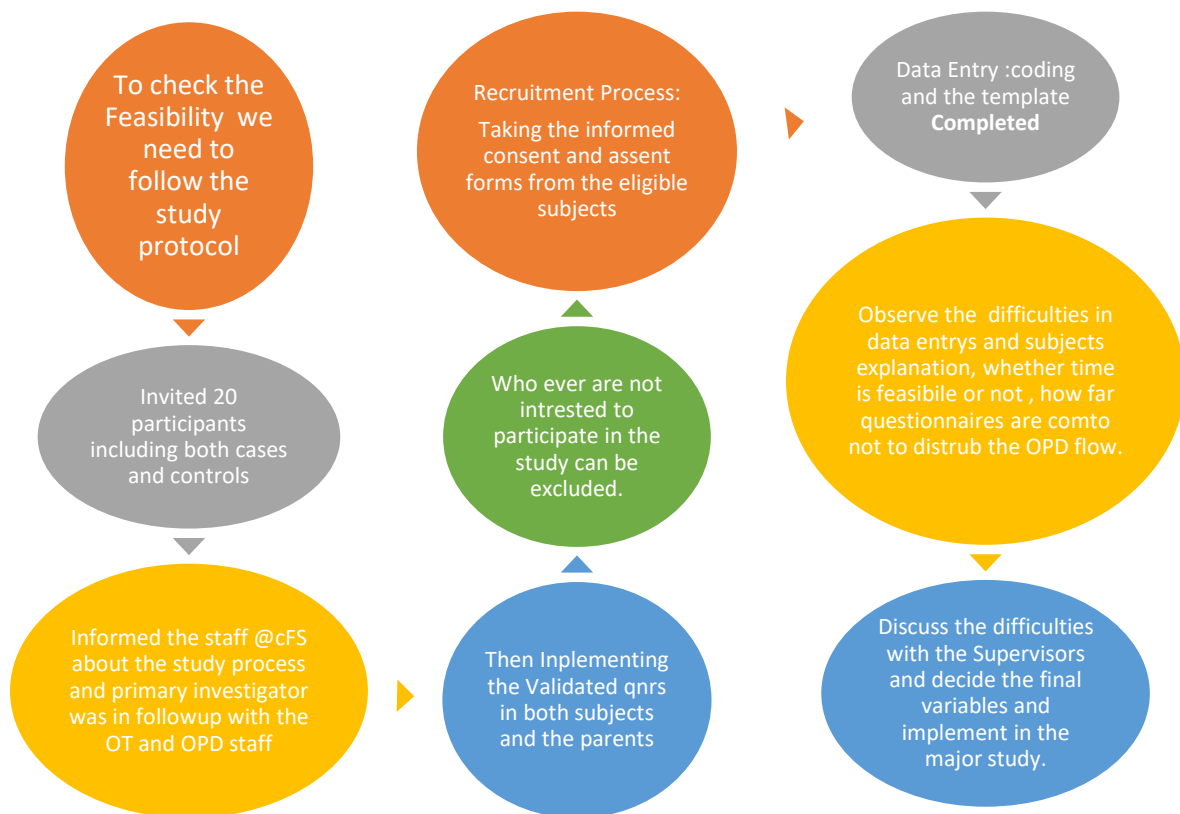


Figure 0.11 The Pilot Process of the Study

Figure-3.1: The Pilot process demonstrates the entire feasibility study procedure where the study invited 60 participants from both the cases and control groups following informed consent. Those who did not consent continued to avail of the regular services at the hospital. The study involved implementing the validated Peds QoL 4.0 Generic Core scale (Figure 3.2) without modification and structured interviews (Figure 3.3) with the recruited subjects. The time it took to complete the questionnaire during their hospital visit and the difficulties children or parents encountered during data collection were recorded. It was made certain that their participation did not interfere with any of the procedures or protocols for which their visit was scheduled.

ID# _____
Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0 - English (India)

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling:

0 if it is never a problem
 1 if it is almost never a problem
 2 if it is sometimes a problem
 3 if it is often a problem
 4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PedsQL 4.0 Parent (2-4)
01/00

PedsQL-4.0-Core-PYC - India/English - Version of 20 Feb - Map Institute
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PedsQL 2

In the past ONE month, how much of a problem has this been for you...

ABOUT My HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult for me to walk more than 100 metres	0	1	2	3	4
2. It is difficult for me to run	0	1	2	3	4
3. It is difficult for me to do sports activity or exercise	0	1	2	3	4
4. It is difficult for me to lift something heavy	0	1	2	3	4
5. It is difficult for me to take a bath or shower by myself	0	1	2	3	4
6. It is difficult for me to do chores around the house	0	1	2	3	4
7. I feel pain	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT My FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens of my age can do	0	1	2	3	4
5. It is difficult to keep up with the teens of my age	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

PedsQL 4.0 - (13-18) Not to be reproduced without permission Copyright © 1998 J.W. Varni, Ph.D. All rights reserved

PedsQL-4.0-Core-PYC - India/English - Version of 08 Apr 2019 - Map
©2007 PedsQL Development Group, Inc.

Figure 0.12 PedsQL-4.0-Core-PYC - India/English - Version of 08 Apr 2019

Ethical clearance: was obtained from the Institution of Ethics (IEC) Committee, University of Hyderabad. IEC Number: UH/IEC/2021/146 Approved on 26-08-2021.

3.1.4 Statistical Analysis:

This pilot study assessed the feasibility of the tools and compared the QoL among cases and control groups. The questionnaire responses were measured on a 5-point (i.e., 0-4) Likert scale. The analyses were conducted using the Microsoft- Excel 2010 version. Descriptive statistics such as mean and standard deviation and the time to complete the implemented questionnaires, interviews and socio-demographic profiles were analysed using Microsoft Excel. Additionally, the researcher investigated how far the questionnaires and the interview variables were understandable and at which part of the questionnaire subjects felt uncomfortable and sought help was also noted. The Quality-of-life variables among self-reported and parent proxy

responses were observed, and the p-values were compared by performing a two-tailed t-test in addition to the descriptive statistics.

Lifestyle:	
12. Age of the subject:	
13. Disease laterality: (OD/O S/OU)	
14. Disease free survival (years)	
15. Treatment modality: (type of surgery)	
16. Duration since the diagnosis : (years)	
17. Visual outcomes:	
18. Address:	
19. Difficulty in answering the qnr/Time	
20. Any other suggestions/needs	

3.1.5 Results:

Of the 60 RB survivors and controls (N=15 cases, N=15 controls, N=15 case parents, and N=15 control parents), the female-to-male ratio was 6:9 and controls (N=7) 8:7, respectively. The mean age of the RB survivors was 5.9 ± 2.4 years, and the controls were 5.9 ± 2.4 years. The disease was unilateral in 9 cases and bilateral RB in 6 cases. (Table 3.1 to 2). The treatments received in the 15 RB survivors were chemotherapy =7, External beam radiation (EXBRT)=2, Brachytherapy=1, and Enucleation=5. The mean time cases took to complete the questionnaire was 15.1 ± 0.4 min, and controls were 12.5 ± 0.5 min. All 15 RB survivors and three controls opted for parents' help while filling up the questions of emotional and social health groups

irrespective of age and gender. All the parents were able to understand the questionnaire and structured interview. The time taken by the parents to fill out the questionnaire was 11.4 ± 1.3 min, and for the controlling parent, 10.5 ± 0.5 min. Vision in bilateral RB cases was having one seeing eye where the Best corrected visual acuity in the better eye (BCVA) was (FFL) Fixing and following the light 6, and 6/12 and better 4, 6/18, and worse five as per the clinical documentation (Table 4).

Table 0.7 Comparison of structured interview study variables among cases and controls.

Variable			Cases (RB Survivors) (n=15)	Control group (n=15)	
Age in years (Mean $\pm$ SD)			5.9 $\pm$ 2.4	5.9 $\pm$ 2.4	
Disease-free survival in years Mean $\pm$ SD			2.6years $\pm$ 1.3	Not applicable	
Gender	Males		9 (60 %)	8 (53.4%)	
	Females		6 (40%)	7 (46.6%)	
Disease laterality	Unilateral		9 (60 %)	Not applicable	
	Bilateral		6 (40%)	Not applicable	
Type of treatment availed	Enucleation		5 (33.3%)	Emmetropia	5 (33.4%)
	Chemotherapy		7 (46.6%)	Myopia	9 (60 %)
	Brachytherapy		1 (6.6%)	Hyperopia	0
	EXBRT		2 (13.3%)	Amblyopia	1 (6 %)
BCVA in the better eye	Fixed and Following light		6 (40%)	6 / 6 in Both eyes	14 (93.4%)
	6/12 to 6/6		4 (26.6%)	< 6 / 9 in one eye	1 (6.6 %)
	6/60 to 6/18		5 (33.3%)	0	
Parents Education Level	Father	High-school 5th to 9th	1 (6.6%)	0	

		SSC	4 (26.6%)	0
		Intermediate	4 (26.6%)	0
		UG	2 (13.3%)	5 (33.4%)
		PG	2 (13.3%)	10 (66.6%)
	Mother	High-class 5th to 9th	1 (6.6%)	0
		SSC	3 (20%)	0
		Intermediate	3 (20%)	0
		UG	4 (26.6%)	5 (33.4%)
		PG	2 (13.3%)	10 (66.6%)
Socio-economic status	Upper lower class		6 (40 %)	0
	Lower middle class		6 (40%)	0
	Upper class		1 (6.6%)	5 (33.3%)
	Upper middle class			
	Lower class		1 (6.6%)	10 (66.4%)
			1 (6.6%)	0
Diagnosis age	In months		18.5 months + 16.9	Not applicable
Average time to complete the questionnaire	Mean± SD		15.1 ± 0.4 min	12.2± 0.6 min
Average time is taken by the cases parent group	Mean± SD		11.4+1.3 min	10.5 ± 0.5 min
Electronic gadgets usage (yes, no)	Yes		13 (86.6%)	15 (100 %)
	No		2 (13.3%)	0
Internet Access availability (yes=1, no=2)	Yes		13 (86.6%)	15 (100%)
	No		2 (13.3%)	0
	Yes		4 (26.6%)	0

Nearest Blind school presence (yes or no)	No		
	Not aware	7 (46.6%)	2 (13.3%)
		4 (26.6%)	13 (86.6%)
Special attention required or not (yes or no)	Yes	7 (46.6%)	0
	No	8 (53.3%)	15 (100%)
Using ocular prosthesis (yes or no)	Yes	5 (100%)	0
	No	0	0

QoL questionnaire analysis: was done using the SPSS version 25; all the domains, including subgroups such as walking, running, sports activity, helping in household chores, lifting heavy objects, taking a shower, feeling pain, having low energy, feeling afraid, sad, or angry and trouble in sleeping, worrying about future, and getting along with other children, other children not wanting to be their friends, teasing by others, keeping up with other children while playing, not able to do the thing that other children can do, and also paying attention in the class, trouble keeping up with the school work, unable to visit the school due to doctor/ hospital visit, unable to go to the school due to unwell were analysed using descriptive statics- mean and standard deviation and significance (*P value*) also calculated.

Table 0.8 Influencing Factors of Quality of Life in Rb Survivors

Factors		N	(N %)
Disease laterality	Unilateral	9	60%
	Bilateral	6	40%
Socio-economic status	Upper lower class	6	40%
	Lower middle class	6	40%
	Upper class	1	6.6%

	Upper middle class	1	6.6%
	Lower class	1	6.6%
Gender	Male	9	60%
	Female	6	40%
Type of treatment availed	Enucleation	5	33.3%
	Chemotherapy	7	46.6%
	ExBRT	2	13.3 %
	Brachytherapy	1	6.6%
Diagnosis age of Rb survivors in Months (Mean $\pm$ SD)		18.5 + 16.9	

In Addition, QoL components were analysed table 3.8 where RB survivor's mean of Physical health was 0.3 SD $\pm$ 0.96, Social health 0.32 SD $\pm$ 1.0, and Emotional health 0.56 SD $\pm$ 1.06, School health 1.6 SD $\pm$ 2.1, where controls mean health score recorded as Physical health 0.3 SD $\pm$ 0.7, Social health 0.06 SD $\pm$ 0.1 and Emotional health 0.2 SD $\pm$ 0.5, School health 0.2 SD $\pm$ 0.4. The *P-value* for the two-tailed t-test shows $P=0.03$ with a 95% confidence interval, which is less than $\alpha=0.05$ in all the domains of Quality of life.

Table 0.9 Quality of life scores among cases and controls (children).

Quality of life Variable	Cases Mean $\pm$ SD	Controls Mean $\pm$ SD	P-Value
Physical health	0.3 $\pm$ 0.96	0.3 $\pm$ 0.7	<0.05
Social Health	0.32 $\pm$ 1.0	0.06 $\pm$ 0.1	<0.05
Emotional Health	0.56 $\pm$ 1.06	0.2 $\pm$ 0.5	<0.05
School Health	1.6 $\pm$ 2.1	0.2 $\pm$ 0.4	<0.05

In Table 3.9 where RB and non-RB- parents (control group) show, the mean of Physical Health was 1.9 SD ± 0.6 , Social Health 2.1 SD ± 0.6 , and Emotional Health 1.2 SD ± 1.1 , School Health 1.5 SD ± 1.2 , where control parents mean health score recorded as Physical Health 0.2 SD ± 0.5 , Social Health 0.2 SD ± 0.6 and Emotional Health 1.2 SD ± 1.1 , School Health 0.1 SD ± 0.4 . The P-value for the two-tailed t-test shows $P=0.03$ with a 95% confidence interval, which is less than $\alpha = 0.05$ in all the domains of Quality of life.

Five RB survivors and their parents reported compromised Quality of life due to enucleation. The mean age of the disease diagnosis was 18.5 months SD ± 16.9 (Table 3.6). Notably, the disease laterality, socio-economic status, gender, type of treatment, and diagnosis age of survivors warranted the variation in the Quality of life in the current feasibility study.

Table 0.10 Quality of life scores among parents of cases and controls

Quality of life Variable	Cases Mean $\pm$ SD	Controls Mean $\pm$ SD	P-Value
Physical health	1.9 $\pm$ 0.6	0.2 $\pm$ 0.5	<0.05
Social Health	2.1 $\pm$ 0.4	0.2 $\pm$ 0.6	<0.05
Emotional Health	1.2 $\pm$ 1.1	0.3 $\pm$ 0.6	<0.05
School Health	1.5 $\pm$ 1.2	0.1 $\pm$ 0.4	<0.05

Structural Interviews consisted of age, disease-free survival, type of treatment, use of ocular prosthesis need for special attention, ability to use electronic gadgets, and access to the internet (Table 3.6) Additional features noted were level of education, rural or urban background, parents' education, access to and availability of blind schools in their area, and time taken to complete the survey.

3.1.6 Discussion:

Health-related Quality of life in paediatric practice has a multi-dimensional role where the subject and the parent's perception of disease and the treatment side effects can be addressed individually. It is important to study the Quality of life in retinoblastoma as it is potentially fatal but has a good prognosis and survival rates with early diagnosis and treatment. It is one of the most easily detectable cancers, constituting 3% of paediatric cancers (*Retinoblastoma* 2012) The results demonstrated that the QoL of RB survivors (M 0.6 SD $\pm$ 1.2) was slightly lower than the control group (M 0.2 SD $\pm$ 0.4), and the *P-value* =0.03 was significant. Similarly, the perceptions of parents of QoL of RB survivors (M 1.6 SD $\pm$ 0.8) were lower than that of the parent of the control group (M 0.2 SD $\pm$ 0.5), and the difference was significant *P-value* =0.03.

However, Quality of life is the most neglected and important aspect of survivorship. Unlike in other paediatric tumours, visual disability, physical appearance, multiple extensive treatments, and challenges in counselling on prognosis and consequences could affect the Quality of life and well-being. The observations in the clinical practice of the researcher also indicate that there appears to be a difference between children's and parents' perceptions of children with RB compared to other children with non-RB eye pathology. With this rationale, before embarking on a more extensive study, the authors aimed to evaluate the feasibility of implementing the Pediatric quality of life questionnaire, PEDS QL 4.0 generic score. Previous cross-sectional studies have not identified the feasibility of the Peds Ql-4.0 Generic core scale (Paediatric Quality of Life Inventory Questionnaire) and supplemental interviews like structured interviews to assess the Quality of life among RB survivors. Literature has stipulated that childhood cancer survivors may experience poor Quality of life in adulthood (P. J. Belson et al., 2020). In a recent study, Belson et al.2020 reported that less than six studies out of fifteen eligible studies that were reviewed

had reported a compromised quality of life.

This research shows that the QoL, as mentioned above, and structured interview questionnaires may be used with no adverse outcomes. Time spent filling out the questionnaires was much less than required for the Retinoquest, with the average time for cases being 15.1 ± 0.4 minutes and the average time for controls being 12.5 ± 0.5 minutes (McNeill et al., 2017). However, Himani Dhingra et al. found that it took 13-15 minutes for participants to complete the Peds QL independently, which is quite close to the current findings. In addition, the researchers have found fewer variations in RB survivors' abilities to walk, run, take showers, assist their parents with everyday chores, and carry anything heavy (Table 3.6).

The researchers made specific, interesting observations while evaluating the instrument's feasibility for QoL. Comprehension was seen among the research participants as they walked through the study concerning the questionnaire and interview using the PEDS QL 4.0 generic core scale within the target age range (Krieger et al., 2021; McNeill et al., 2017). While parents were concerned about their children's well-being, few were asked about their treatment options or expected length of stay in the hospital, and the information needs were evident. Therefore, the present study points to educating patients, caregivers, and parents on retinoblastoma and its post-treatment care. There was a significant difference in the Quality of life of those who survived enucleation versus controls, as well as reports from parents acting as proxies for their children.

The present study's findings are superior, lending credence to the idea that, for RB survivors, the therapy is crucial in preserving a Normal Quality of life after treatment, mainly because a delay in diagnosis may affect QoL. However, illness laterality and disease diagnostic time play a critical role in sustaining Quality of life. Early disease identification might save the visual prognosis post-treatment owing to recency bias. These factors have not been seen to alter

significantly among (Batra et al., 2016; Dhingra et al., 2021) RB survivors. The present research found that utilising age-matched controls as subjects to compare the RB survivor's Quality of life as supported by previous research is preferable (Dhingra et al., 2021). Because of scheduling constraints, locating the age-matched control is challenging. Himani et al. recommend using age-matched controls to adjust for socio-economic differences affecting research results. However, the same study revealed that factors including SES, gender, and illness diagnosis had no bearing on the QoL of RB survivors (Dhingra et al., 2021)

The approach was modified by contacting age-matched controls via phone or e-mail to address the research's limitations and augment participant numbers in the primary trial. Patient-reported outcomes from parents and cases in a tertiary eye care setting were analysed. The researcher believes this study may be the first to manually demonstrate the feasibility of the Peds QoL 4.0 generic core scale. This could shed light on the QoL questionnaire admitting problems and how to modify and proceed further.

Challenges faced during the Pilot study need to be addressed.

- Finding age-matched controls- The time-taking process must wait until the age-matched subject gets into the OPD.
- The subjects and the parents of RB survivors are distressed and not able to answer the questions - cases>controls. Still, it can be improved with supportive prior counselling sessions.
- Misguided information in the demographic sheets, like the wrong phone numbers, addresses, and e-mails.
- Addressing the patients when the questionnaire was implemented through phone calls

- Require two to three times mock rounds to make patients/ subjects understand the questionnaire answering process.

3.1.7 Limitation and future scope:

They are recruiting fewer controls due to time constraints and the prevailing pandemic; finding the participants and age-matched young children as controls were complex in an active comprehensive outpatient department. The subjects do not represent varied socio-economic status as the sample is small. This may influence the perspective differences towards the questionnaire. This study supports a larger sample to gain some deeper insights into the Quality of life of RB survivors, which includes Focused group discussions and in-depth interviews, which leads to giving an understanding of the Quality of life of RB survivors in developing countries on a large magnitude.

3.1.8 Implications for Policy and Practise:

- The pilot study results indicated a lower quality of life among the survivors than the control group children.
- The perception of the parents of the survivors about the Quality of life of the survivors was lower compared to the parents of a control group.
- The primary research should be modified to obtain accurate information when the questionnaire is given to children, in addition to the researcher's support and assistance from their parents. Participants who cannot answer the questions quickly require more time to complete the survey.
- Counselling and helping parents and caregivers understand the changes in survivors' Quality of life before and after treatment and answering their questions concerning financial incentives are recommended.

3.1.9 Conclusion:

The pilot study findings indicate that the instrument of Quality-of-life measurement (Peds QL 4.0) was accepted and understood by the participants, especially the parents, thus making it a feasible tool for a more extensive study. As anticipated in this age group, the children required the assistance of parents and researchers. Though more extensive studies are warranted for interpretation, the trend suggests a lower quality of life among the survivors, as well as the perception of parents, thus emphasising the need for pertinent psycho-education and counselling of the cases as well as parents before and after the treatment.

3.2 MAIN STUDY

THE QUALITY OF LIFE IN RETINOBLASTOMA SURVIVORS IN TERTIARY CARE EYE HOSPITAL IN SOUTH INDIA: QOL-RB-INDIA STUDY

3.2.1 Introduction:

Retinoblastoma is an intraocular malignant tumour. It is a prevalent form of ocular malignancy observed primarily in children, exhibiting a high survival rate of over 95% in developed nations (Künkele et al., 2015a). Nevertheless, the long-term consequences of retinoblastoma and its therapeutic interventions pose a significant apprehension for individuals who have overcome the disease. Roughly 50% of retinoblastoma instances exhibit heritability, wherein the child possesses an oncogenic variant of the RB1 tumour suppressor gene in their germline. According to (Künkele et al., 2015a), it is common for these individuals to exhibit the development of multiple retinoblastoma foci during the initial five years of their lives.

Treatments for retinoblastoma include laser treatment, freezing, brachytherapy, local and systemic chemotherapy, external beam radiation, and enucleation (Batra, Kumari, et al., 2016; Künkele et al., 2015; *Retinoblastoma Treatment (PDQ®)–Patient Version - NCI*, 2022). Indeed, the QOL of retinoblastoma patients might be significantly impacted by these treatments despite their proven effectiveness in improving the chances of survival for individuals with retinoblastoma (*Challenges of RB*, 2022).

Multiple studies have evaluated the QOL among people who have survived retinoblastoma. A study conducted in the Netherlands found that retinoblastoma survivors reported a high quality of life (QOL), with certain aspects such as "mood and emotions" and "autonomy" being reported as superior to the general Dutch population (Batra, Kumari, et al., 2016). Nevertheless, a separate investigation conducted by Batra et al. (2016) revealed that retinoblastoma survivors exhibited a lower level of performance in the school health domain

when compared to their counterparts. Batra et al. (2015) revealed that individuals who have survived retinoblastoma exhibit elevated levels of emotional disabilities and experience limitations in their daily activities. The mental health domain exhibited similar outcomes in a study conducted by Friedman et al. (2018) among adult survivors of retinoblastoma (Friedman et al., 2016).

As per the Research by Friedman et al. (2018), an essential factor to consider in retinoblastoma survivors is vision-targeted health-related Quality of life (HrQoL). There is a scarcity of data about the long-term health-related Quality of life (HrQoL) specifically related to vision in adult survivors of retinoblastoma (Friedman et al., 2018). Nevertheless, it has been established that visual impairment can substantially impact the health-related Quality of life (HrQoL) specifically related to vision in individuals who have survived for an extended period (Friedman et al., 2016).

The removal of the eye, known as an enucleation, is occasionally required when treating retinoblastoma. According to qualitative research, enucleation negatively affected adult retinoblastoma survivors' Quality of life (Banerjee et al., 2020b). These patients reported increased worry, sadness, and a sense of helplessness after the procedure.

Few studies have examined RB survivors' Quality of life and ability to engage in everyday activities (Al Qahtani et al., 2022; van Dijk, Huisman, et al., 2007). The availability of data from emerging nations is limited. HrQoL may vary in its impact across different regions with low and middle income, influenced by factors such as terminal illnesses at diagnosis, reduced eye salvage prospects, and poor acceptability of enucleation (Alessi et al., 2007).

According to the research conducted by Banerjee et al. (2020), Retinoblastoma survivors have reported experiencing social and relational difficulties in addition to the physical and psychological consequences associated with the disease and its treatment. For

many of these survivors, bullying and teasing are serious problems that may impair their Quality of life. Increasing public awareness about retinoblastoma and facial variations may reduce the suffering of survivors and guarantee they are not exposed to discriminatory treatment or personal inquiries (Banerjee et al., 2020a).

HrQoL is a multi-dimensional notion that sums up how a patient feels about the impact of their illness and treatment on their body, mind, and relationships. (Langeveld et al., 2002; Varni et al., 2005) It is growing in popularity as a method for gauging cancer patients' Quality of life after treatment. With high childhood RB cure rates and many variables that might affect HrQoL, it is crucial to study young children. This may help us zero in on the areas where adjustments may improve HrQoL the most. Belson et al. (2020) conducted a recent systematic analysis. They found that only 5 of 15 research suitable for inclusion revealed a worse HrQoL in RB survivors compared to controls or the general population. They also stressed the need for more studies to determine what variables influence the long-term results of these survivors and how to treat them best.

Even though the overall survival rates for retinoblastoma have increased, the late effects and impact on survivors' Quality of life continue to be significant concerns. Additional investigation is warranted to enhance comprehension and tackle the physical, psychological, and social dimensions of the Quality of life experienced by individuals who have survived retinoblastoma.

3.2.2 Materials and Methods:

The present study was a one-year cross-sectional observational investigation conducted from September 2021 to 2022 at a tertiary care hospital in South India. Children and adolescents who have completed treatment for retinoblastoma and are between the ages of 2 and 18 years, with a minimum of 2 years since treatment completion, were considered eligible for

participation in this research study. The interval of 2 years following the completion of treatment was chosen to minimise the potential impact of treatment-related complications on the participant's responses to the questionnaire. The control group consisted of age-matched individuals who visited the comprehensive outpatient department. The study obtained informed consent from parents and assent from children, with the parents being informed and the children providing their assent. Neither parent was invited to participate in the study. Participants who fell outside the predetermined age range, those who lacked the cognitive ability to comprehend the study questionnaire, and those whose parents did not consent to study participation were excluded from the research. The study obtained approval from the Institutional Ethics Committee of the University of Hyderabad (UoH). The researcher utilised the standardised PedsQL (version 17) 4.0 Generic Core Scale to measure and evaluate the QoL. The parental assessments for toddlers aged 2-4 years comprised 21 items.

In contrast, the assessments for children and parents in the age range of 5-18 years included 23 items, encompassing four fundamental dimensions: Physical (8 items), Emotional (5 items), Social (5 items), and School functioning (3 items for toddlers and five items for older children). The items were assessed using a 5-point Likert scale ranging from 0 (Never) to 4 (Almost always). The self-report of young children, specifically those aged 5-7 years, was assessed using a 3-point Likert scale. The scale ranged from 0 (indicating "Not at all") to 2 (indicating "Sometimes") and 4 (indicating "A lot"). The scores were initially converted to a numerical range of 0 to 100. Subsequently, the items were reversed and then transformed linearly to a scale ranging from 0 to 100, with the values of 0, 1, 2, 3, and 4 corresponding to 100, 75, 50, 25, and 0, respectively.

Higher scores were indicative of improved Health-Related Quality of Life (HrQoL). The mean scores were computed for each dimension in the case and control groups. Respondents needed to provide answers for at least 50% of the items in each dimension to

calculate the mean score. Failure to meet this requirement resulted in excluding participants from the study. The questionnaires were prepared in Hindi, English, and Telugu languages for the convenience of the patients and their parents. Interviews were conducted separately with children and their parents to mitigate potential bias in individual responses. The study ensured the preservation of privacy and confidentiality.

The data was analysed using SPSS version 25.0. The mean scores and standard deviations (SD) for physical, social, emotional, and school functioning dimensions were computed. The statistical analysis involved comparing data between the survivors and control groups using the student's t-test. The study evaluated the impact of demographic characteristics, socio-economic status (SES), disease laterality, duration since diagnosis, treatment modality, and final visual outcomes on the prediction of QoL using statistical tests such as Chi-square and Student's t-test. In this case-control study, the odds ratio was also analysed.

3.2.3 Results:

The demographic (table 3.10) details of retinoblastoma (RB) survivors and controls (Non-RB) were studied using structured interviews. The study sample comprised 86 cases of RB and an equal number of controls, resulting in 172 participants. The average age of the RB cases was 2.82 years, with a standard deviation of 2.82. The control group exhibited a comparable average age and standard deviation. The gender distribution in both groups was evenly distributed, with 49 cases (57.0%) and 49 controls (57.0%) representing males, while 37 cases (43.0%) and 37 controls (43.0%) representing females.

About the variable "Removal of the eye," a statistically significant difference was observed ($\chi^2 = 50.43$, $df = 3$, $p < 0.01$). Out of the cases involving RB, 47 individuals (54.7%) had undergone the surgical procedure of eye removal, known as enucleation. In contrast, all

individuals in the control group (100%) maintained their eyes without this procedure. Among the cases of RB examined, it was found that 25 cases (29.1%) involved the enucleation of the right eye, 13 cases (15.1%) involved the enucleation of the left eye, and 1 case (1.2%) involved the enucleation of both eyes.

There was a significant difference observed in the variable "Type of treatment" between the cases and controls ($\chi^2 = 102.7$, $df = 4$, $p < 0.01$). Out of the cases involving RB, a total of 16 cases (18.6%) were treated using a combination of therapeutic interventions, while 30 cases (34.9%) were subjected to chemotherapy, and only 1 case (1.2%) received radiation therapy. In contrast, the entirety of the control group (100%) was either provided with spectacle correction (41 cases, 47.7%) or exhibited normal vision (45 cases, 52.3%).

The variable "Zone" about geographic distribution exhibited a statistically significant disparity ($\chi^2 = 107.9$, $df = 5$, $p < 0.01$). The distribution of RB cases across the zones exhibited an uneven pattern, with the South zone having the highest number of cases (17 cases, accounting for 19.8% of the total). The remaining zones exhibited comparatively lower incidences, with 11 cases (12.8%) recorded in the Central zone, 11 cases (12.8%) in the North zone, 15 cases (17.4%) in the East zone, and 29 cases (33.7%) in the West zone. Furthermore, three cases, accounting for 3.5% of the reported cases, were documented within the international zone.

The analysis revealed a statistically significant relationship between family income of cases and controls of RB ($\chi^2 = 51.69$, $df = 5$, $p < 0.01$). Out of the cases analysed in the study about RB, it was found that 15 cases (17.4%) had a family income below 10000, 46 cases (53.5%) had an income ranging from 10000 to 50000, 5 cases (5.8%) had an income between 50001 and 100000, and 5 cases (5.8%) had an income exceeding 100000.

Additionally, it is worth noting that out of the total number of cases, 2 cases (2.3%) were identified as belonging to a dependent family. In comparison, 13 cases (15.1%) did not provide information regarding their family income. All of the controls included in the study had an income exceeding 10000 INR. Specifically, 23 controls (26.7%) fell within the income range of 10000 to 50000, 36 controls (41.9%) had incomes between 50001 and 100000 INR, and 13 controls (15.1%) reported earnings above 100000 INR. Furthermore, 14 controls, accounting for 16.3% of the sample, opted not to provide information regarding their family income.

A notable disparity was observed concerning the variable "Type of school," with a chi-square value of 71.31, a degree of freedom of 13, and a p-value less than 0.01. The cases of RB demonstrated a range of school affiliations, with one case (1.2%) enrolled in a Day Care facility, fifteen cases (17.4%) attending Government schools, thirty-five cases (40.7%) enrolled in Private schools, and another thirty-five cases (40.7%) not currently enrolled in any educational institution. Within the control group, it was observed that 11 individuals (12.8%) received care at Day Care facilities, three individuals (3.5%) were enrolled in Government schools, 68 individuals (79.1%) attended Private schools, and four controls (4.7%) were not enrolled in any educational institution.

A statistically significant difference was observed for the variable "Community setting" ($\chi^2 = 32.83$, $df = 2$, $p < 0.01$). The incidence of RB cases was significantly higher in rural settings, accounting for 37 cases (43.0%), whereas the control group consisted predominantly of individuals from urban areas (80 cases, 93.0%). One control participant, representing 1.2% of the total sample, was categorised as residing in an unspecified community setting called "Others." A statistically significant difference was observed between RB cases and controls concerning the variable "Internet access" ($\chi^2 = 24.78$, $df = 2$, $p < 0.01$).

Table 0.11 Demographic characteristics of RB cases and Controls

Demographic Characteristics	Frequency	Percentage	Frequency	Percentage	χ^2	df	P
	Cases		Control				
Age (Mean and SD)	5.6 $\pm$ 3.4		7 $\pm$ 3.7		2.82	170	<0.05
Gender					0	1	>0.05
Male	49	57.0	49	57.0			
Female	37	43.0	37	43.0			
Removal of the eye					50.43	3	<0.01
Not removal	47	54.7	86	100			
Right Eye	25	29.1	0	0			
Left Eye	13	15.1	0	0			
Both Eyes	1	1.2	0	0			
Type of treatment					102.7	4	<0.01
Combination	16	18.6	0	0			
Chemotherapy	30	34.9	0	0			
Radiation	1	1.2	0	0			
Spectacle Correction	0	0	41	47.7			
Emmetrope	0	0	45	52.3			
Enucleation	39	45.3	0	0			
Zone					107.9	5	<0.01
Central	11	12.8	0	0.0			
North	11	12.8	0	0.0			
South	17	19.8	84	97.7			
East	15	17.4	0	0.0			
West	29	33.7	2	2.3			
International	3	3.5	0	0.0			

Family Income					51.69	5	<0.0 1
<10000	15	17.4	0	0			
10000 to 50000	46	53.5	23	26.7			
50001 to 100000	5	5.8	36	41.9			
> 100000	5	5.8	13	15.1			
Dependent	2	2.3	0	0			
Not Disclosed	13	15.1	14	16.3			
Type of school					71.31	1 3	<0.0 1
Day Car	1	1.2	11	12.8			
Government	15	17.4	3	3.5			
Private	35	40.7	68	79.1			
Not Joined	35	40.7	4	4.7			
Community setting					32.83	2	<0.0 1
Rural	37	43	5	5.8			
Urban	0	0	80	93.0			
Others	49	57	1	1.2			
Internet access					24.78	2	<0.0 1
Yes	62	72.1	85	98.8			
No	20	23.3	1	1.2			
Not Disclosed	4	4.7	0	0.0			
Electronic gadgets usage					32.02	2	<0.0 1
Yes	59	68.6	86	100.0			
No	23	26.7	0	0			
Not Disclose	4	4.7	0	0			
No of siblings					1.33	2	>0.0 5
Not disclose	16	18.6	11	12.8			
Yes	52	60.5	53	61.6			
No	18	20.9	22	25.6			

Special attention required					44.35	2	<0.0 1
Yes	31	36	8	9.3			
No	38	44.2	78	90.7			
May be	17	19.8	0	0			
Mother education level					32.19	5	<0.0 1
Not Disclosed	7	8.1	8	9.3			
Below 10th	24	27.9	1	1.2			
Intermediate	7	8.1	2	2.3			
UG	32	37.2	45	52.3			
PG	15	17.4	30	34.9			
More Than PG	1	1.2	0	0.0			
Father education level					32.72	4	<0.0 1
Not Disclosed	6	7	8	9.3			
Below 10th	23	26.7	1	1.2			
Intermediate	8	9.3	2	2.3			
UG	33	38.4	38	44.2			
PG	16	18.6	37	43.0			
Disease laterality					23.78	2	<0.0 1
Within Normal Limits	0	0	48	55.8			
Unilateral	18	20.9	1	1.2			
Bilateral	68	79.1	37	43.0			
Type of Refractive Error/Disease					168.04	3	<0.0 1
RB	86	100	0	0.0			
hypermetropia	0	0	1	1.2			
Myopia	0	0	41	47.7			
Emmetrope	0	0	42	48.8			
Others	0	0	2	2.3			
Disease-free survival in years					172	3	<0.0 1

< 1 Year	19	22.1	0	0			
>1 Year	67	77.9	0	0			
Not Applicable	0	0	86	100			
Duration since the diagnosis					172	2	<0.01
< 1 Year	9	10.5	0	0			
>1 Year	77	89.5	0	0			
Not Applicable			86	100			
BCVA of Right eye					50.31	4	<0.01
FFL	11	12.8	4	4.7			
MildVI_Worsethan 6/12-6/18	5	5.8	2	2.3			
ModerateVI_Worsethan_6/18-6/60	5	5.8	2	2.3			
Blindness_<3/60	29	33.7	0	0			
WNL (6/6-6/9)	36	41.9	78	90.7			
BCVA of Left eye					26.98	4	<0.01
FFL	17	19.8	4	4.7			
MildVI_Worsethan 6/12-6/18	3	3.5	2	2.3			
ModerateVI_Worsethan_6/18-6/60	3	3.5	3	3.5			
Blindness_<3/60	13	15.1	0	0.0			
WNL (6/6-6/9)	50	58.1	77	89.5			
Status of the tumour					172	2	<0.01
ALL Regressed	43	50	0	0			
Stable Regressed	43	50	0	0			
Not Applicable	0	0	86	100			
Any other significant problem that the patient faces in daily life due to vision loss					22.93	1	>0.05
Yes	7	8.1	2	2.3			

No	79	91.9	84	97.7			
Any other significant problem that the patient faces in daily life due to treatment					1.34	1	> 0.05
Yes	5	5.8	2	2.3			
No	81	94.2	84	97.7			
Nearest blind school					14.3	2	< 0.01
Yes	2	2.3	0	0.0			
No	34	39.5	14	16.3			
Not aware	50	58.1	72	83.7			

Rb Survivor's perception of Quality of life (5-18 Years age group only):

The graph below Figure 3.11 represents the Quality-of-life mean scores perceived by RB survivors and the control group as reported by self, the QoL of physical health (N=86), (Mean, Standard deviation average) were represented.

Figure 1: Quality of life among Rb Survivors and control group

The domain of walking evaluates individuals' capacity to ambulate. The "Case" group exhibited an average score of 75 ± 26.58 , whereas the "Control" group had a higher mean score of 98.41 ± 7.61 . The running variables are the "Case" group, with a mean score of 72.87 ± 23.79 , and the "Control" group, with a higher mean score of 97.62 ± 9.75 . The evaluation of the ability to lift heavy objects in the "Case" group achieved a score of 68.62 ± 24.71 , while the "Control" group achieved a score of 95.24 ± 24.71 . Self-bathing measures an individual's capacity to engage in bathing activities without assistance. On average, the case group obtained a mean score of 67.02 ± 23.37 , while the control group achieved a mean score of 98.41 ± 7.61 .

The domain of home duties encompasses the assessment of an individual's capacity to carry out various tasks related to maintaining a household. The group referred to as "Case" exhibited a mean score of 65.96 ± 27.3 , whereas the group designated "Control" scored 94.84 ± 14.31 . The assessment evaluates the existence of pain or discomfort. The group labelled "Case" scored 67.55 ± 23.4 , but the group labelled "Control" scored 93.25 ± 16.32 . The domain of low energy assesses the degree of energy present. The group referred to as "Case" achieved a score of 66.49 ± 22.89 , whereas the group referred to as "Control" achieved a score of 98.41 ± 7.61 .

Sports Activity or Exercise: This metric assesses an individual's capacity to participate in sports or exercise. The cases obtained a score of 62.23 ± 22.65 , but the group labelled "Control" scored 96.43 ± 11.76 .

Emotional well-being encompasses many domains that are evaluated to gauge an individual's emotional state. These domains include but are not limited to feelings of fear or apprehension, sadness or melancholy, and anger. The group labelled "Case" had comparatively lower scores in these categories than the group labelled "Control." Cases and Control Mean and SD in emotional domain are Afraid or Scared 76.06 ± 24.43 : 94.84 ± 13.59 , Sad or Blue 65.96 ± 22.98 : 96.83 ± 11.44 ; Angry 62.23 ± 25.47 : 88.49 ± 19.99 ; Sleep issues 63.83 ± 23.78 : 97.22 ± 10.15 ; Worrying about future 65.43 ± 24.2 : 99.21 ± 4.42 where P value for the above domain was $P < 0.01$

Domains about social and school life include several aspects such as "Trouble getting along with friends 76.6 ± 26.79 ; 98.81 ± 5.37 ," "Unwillingness of other kids for Friendships 69.98 ± 22.68 ; 99.21 ± 4.42 ," "Teasing by others 69.15 ± 22.85 ; 97.62 ± 8.65 ," "Ability to do things as peers 68.62 ± 22.68 ; 99.21 ± 4.42 ," and "Keeping up with other kids while playing 66.49 ± 22.29 ; 99.21 ± 4.42 ." The "Case" group exhibited lower mean scores in most of these

categories than the "Control" group, indicating possible issues. Cognitive functioning as part of school health is evaluated by domains such as "attentiveness 72.78 ± 26.01 ; 95.34 ± 11.81 ," "forgetfulness 68.89 ± 25.65 ; 97.03 ± 8.15 ," and "difficulty in keeping up with homework 68.89 ± 25.65 ; 97.03 ± 8.15 ." The group labelled "Case" had comparatively lower mean scores in these categories than the group referred to as "Control."

The evaluation of school attendance encompasses two domains, namely "Absence from School due to illness 56.11 ± 19.33 ; 95.76 ± 11.52 " and "Absence from School due to Doctor visits 57.22 ± 18.93 ; 95.76 ± 14.7 ." The group labelled as "Case" had statistically significant $P < 0.01$ lower mean scores in both categories when compared to the group labelled as "Control."

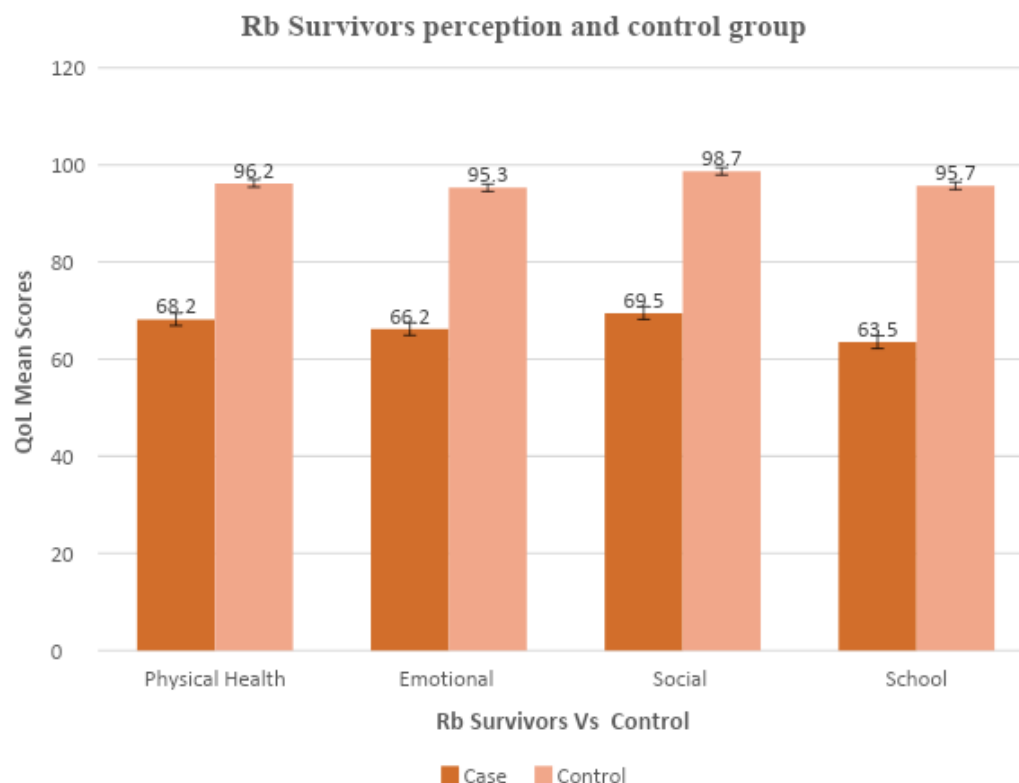


Figure 0.14 Survivors' perception and control group

Figure 4.11 Overall RB survivor's QoL Physical health is 68.2 ± 27.8 SD; 96.2 ± 13 SD. Emotional health 66.2 ± 28.4 SD; 95.3 ± 12.5 SD, Social health 69.5 ± 24.9 SD; 98.7 ± 6.2 SD, School health 63.5 ± 26.5 SD; 95.1 ± 12.2 SD.

Parents' perception of the Quality of life of Rb Survivors:

The quality-of-life scale has four domains: Physical health, Emotional health, social health, and School health. Mean and standard deviation were calculated and compared among cases and control groups. Data is shown in the following bar graph Figure 3.12

Overall, under physical health domain cases and the control group, parents scored walking 74.71 ± 25 and 98.55 ± 9.67 . Running 72.67 ± 25.04 ; 96.51 ± 13.37 ; Lifting heavy objects 70.64 ± 25.78 ; 94.48 ± 16 ; Bathing by self- 73.84 ± 25.7 ; 97.97 ± 10.3 ; House Hold chores 52.33 ± 39.41 ; 93.6 ± 16.35 ; Hurt or ache 73.84 ± 26.26 ; 92.73 ± 18.73 ; Low energy 72.09 ± 28.09 ; 98.5 ± 8 ; Sports activity or Exercise 70.06 ± 27.7 ; 96.8 ± 12 .

Under Emotional domain Afraid or Scared 74.71 ± 25 ; 95.06 ± 13.73 ; Sad or Blue 75.87 ± 24.69 ; 95.06 ± 13.73 ; Angry 50.58 ± 29.45 ; 87.21 ± 21.61 ; Sleep issues 78.2 ± 27.86 ; 98.26 ± 8.39 ; Worrying about future 81.4 ± 29.5 ; 99.13 ± 6 .

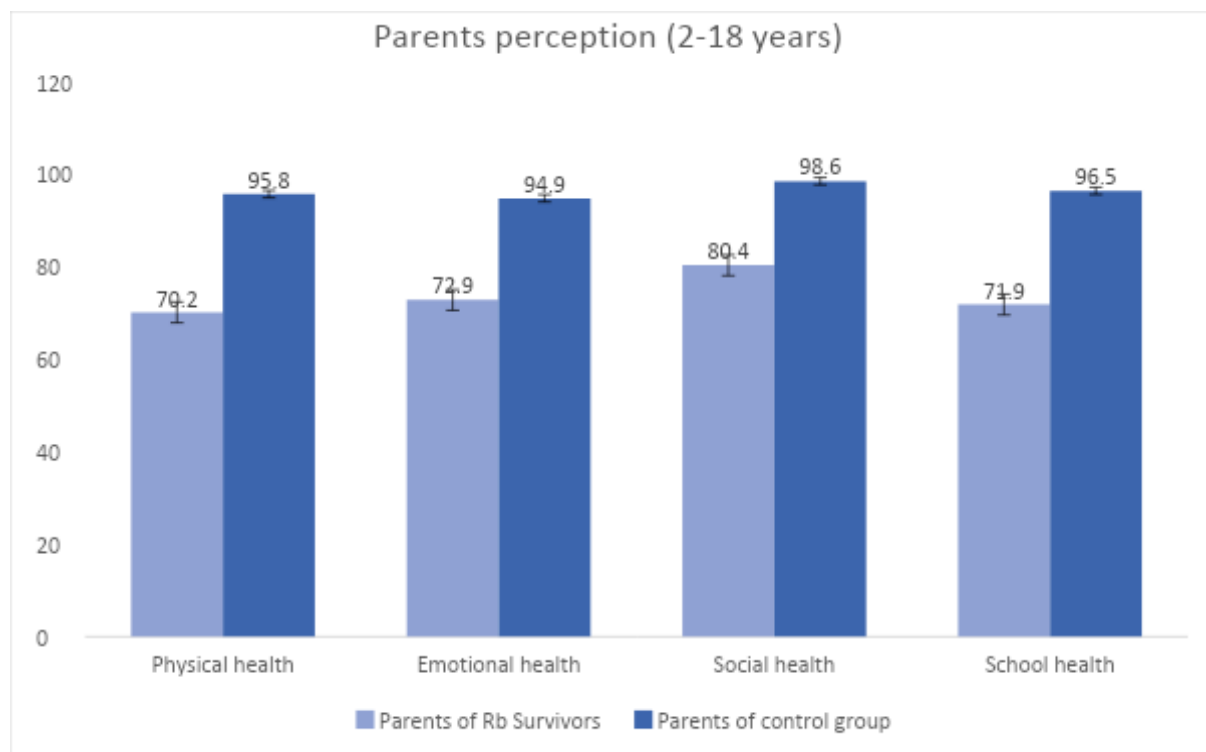


Figure 0.15 Distribution of Quality-of-life perception among parents of RB survivors and control group

Under social health domain: Trouble getting along with other kids 81.4 ± 29.5 ; 99.13 ± 6 ; Unwillingness of other kids for friendship 81.1 ± 23.93 ; 99.42 ± 3.79 ; Teasing by others 79.94 ± 24.5 ; 98.26 ± 7.47 ; Ability to do things as peers 83.14 ± 24.39 ; 99.13 ± 4.16 ; Keeping up with other kids 78.49 ± 23.93 ; 99.42 ± 3.79 where parents perceived compromised QoL in Rb Survivors than control group parents.

Comparatively school health variables such as Attentiveness 77.45 ± 27.04 ; 96.65 ± 12.27 ; Forget fullness scored 80.88 ± 26.26 ; 97.56 ± 8.43 ; Trouble keeping up with homework 69.12 ± 27.2 ; 95.12 ± 14.93 ; Missing School due to unwell 65.69 ± 27.82 ; 96.34 ± 11.2 ; Missing school due to doctor visit 66.67 ± 24.32 ; 95.12 ± 17.32 which are significantly compromised where $p < 0.01$. Over Parents of RB, survivors perceived a reduced quality of life than control group parents. Among RB survivors, there was an increase in school absences, primarily attributed to hospital visits. There was a difference in the number of school days missed due to illness between the two categories. The survivors reported increased forgetfulness and difficulty keeping up with schoolwork.

Section 3 Parents vs. RB survivors self-report:

The Quality-of-life scale has four domains: Physical health, emotional health, social health, and school health. Mean and standard deviations were calculated and compared by parents and self-reports of RB survivors. Data is shown in the following Bar graph Figure 3.13

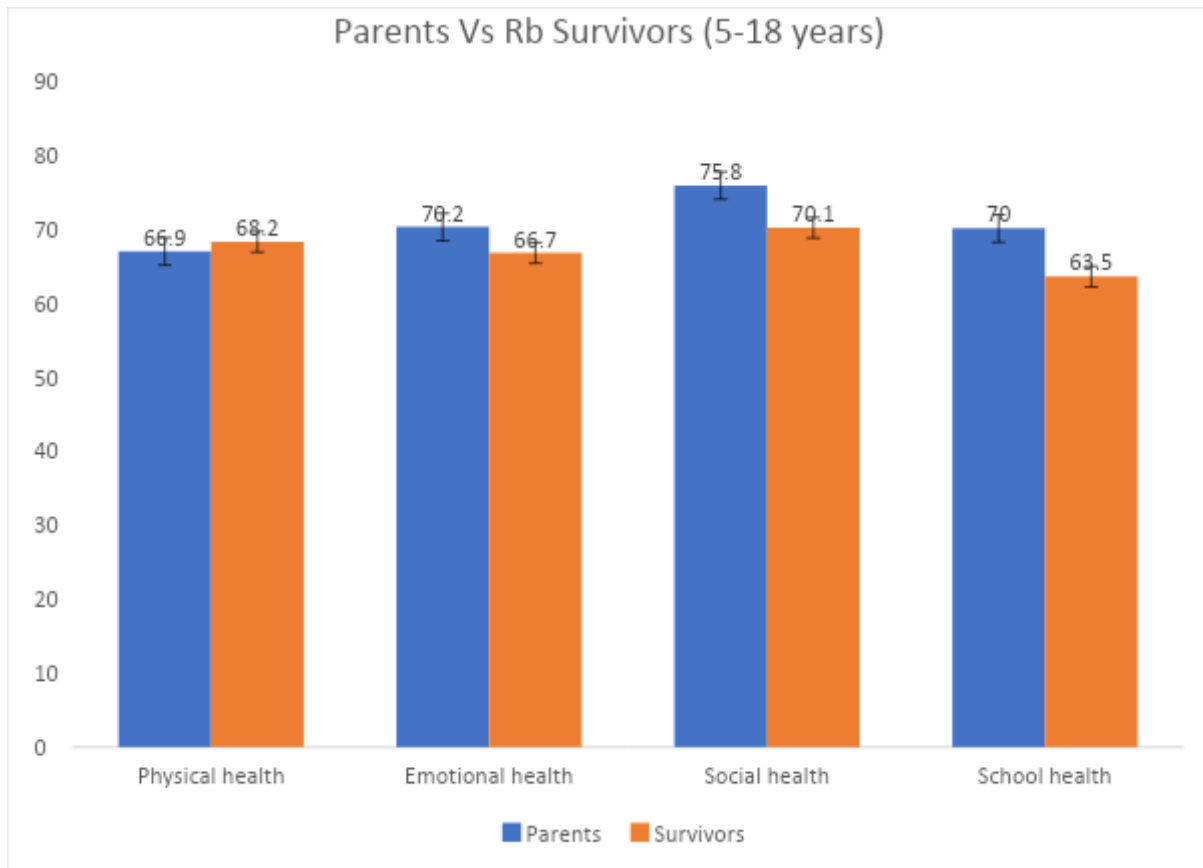


Figure 0.16 Parents vs RB survivors Self-report

Overall mean scores and standard deviation among parents and RB survivor self-reports are showcased above in Figure 3.13 As reported by Parents, the QoL of physical health of RB survivors was 70.2 ± 27.8 ; $96.15 \pm 13SD$, emotional health $72.1 \pm 27.4SD$; $94.4 \pm 12.5 SD$, social health $80.4 \pm 24.9 SD$; $98.6 \pm 6.2 SD$; and school health $71.9 \pm 26.5 SD$; $96.1 \pm 12.2 SD$. As per the Self-report perception, the QoL of Physical health is $68.2 \pm 27.8SD$; $96.2 \pm 13SD$. Emotional health $66.2 \pm 28.4SD$; $95.3 \pm 12.5 SD$, Social health $69.5 \pm 24.9 SD$; $98.7 \pm 6.2 SD$, School health $63.5 \pm 26.5 SD$; $95.1 \pm 12.2 SD$.

Additionally, there were some items where the means for one or both groups fell below the expected average score of 50. Perhaps both parents and children reported relatively low scores for "Ability to do things" (parent mean=79.26, child mean=68.62) and "Sleep issues" (parent mean=77.13, child mean=63.83). For most items, there were no significant differences between the self-reports of children and their parents. However, there were some items where

the means differed between the two groups. Parents reported significantly lower scores than children for "Angry" ($t=-1.92$, $p=0.06$), while children reported significantly lower scores than parents for "Household chores" ($t=1.59$, $p=0.11$). Notably, physical health is compromised in both groups more than the other Quality of life variables.

By performing Logistic binary regression to analyse the odds ratio (OR), it revealed that Age, Type of Treatment, Zone, Family Income, Type of School, Community, Internet, Gadgets, Education of Mother, Education of Father, Literacy, BCVA RE, and QoL Domains (Physical, Emotional, Social, and School). As in where OR Value <1 , on the 0.05 significance level.

Table 0.12 correlation coefficients (Spearman's rho) between four variables

Spearman Correlations among parent perception of Rb Survivors (2-18 years)						
Quality of Life domains			Physical	Emotional	Social	School
Spearman's rho	Physical	Correlation Coefficient	1.000	.375**	.410**	.528**
		Sig. (2-tailed)		0.000	0.000	0.000
		N	86	86	86	51
	Emotional	Correlation Coefficient	.375**	1.000	.381**	.451**
		Sig. (2-tailed)	0.000		0.000	0.001
		N	86	86	86	51
	Social	Correlation Coefficient	.410**	.381**	1.000	.507**
		Sig. (2-tailed)	0.000	0.000		0.000
		N	86	86	86	51

	school	Correlation Coefficient	.528**	.451**	.507**	1.000
		Sig. (2-tailed)	0.000	0.001	0.000	
		N	51	51	51	51
**. Correlation **Correlation is significant at the 0.01 level (2-tailed). n is significant at the 0.01 level (2-tailed).						

Table 3.14 shows a correlation among 2-18 years Rb survivor's parent's responses correlated using Spearman correlation, Physical and emotional: the correlation coefficient is .375**, indicating a moderate positive correlation between physical and emotional functioning. Physical and social: The correlation coefficient is .410**, indicating a moderate positive correlation between physical and social functioning. Emotional and social: The correlation coefficient is .381**, indicating a moderate positive correlation between emotional and social functioning. School functioning: The correlation coefficient is .528**, indicating a strong positive correlation between school functioning and the other three variables: physical, emotional, and social functioning. Notably, RB survivors had a higher no of school absenteeism than the control group.

3.2.4 Discussion:

Health-related Quality of life (HrQoL) refers to a multidomain concept that encompasses the survivor's overall perception of how disease and treatment impact various aspects of their life, including physical, psychological, and social domains (Langeveld et al., 2002; Wengenroth et al., 2015). The use of this tool to assess outcomes in cancer survivors is becoming more widely accepted. It is crucial to assess the impact of HrQoL on survivors of RB, considering the high cure rates in children and various factors that may influence it (Dhingra et al., 2021a; Padamandala et al., 2023). This could aid in identifying areas where remedial measures may be necessary to optimise the HrQoL.

Data are scarce, and findings regarding the HrQoL in this particular cohort are conflicting (Dhingra et al., 2021a). The variation in assessment tools, differing perspectives between parents and children regarding Quality of life, and the diverse demographic profile of the study population may contribute to these findings. In a recent literature review conducted by Belson et al. (2020), it was found that only 5 out of 15 eligible studies reported a compromised HrQoL in RB survivors when compared to controls or the general population. They also stressed the importance of conducting additional research in this field to understand better the factors that influence it.

The study revealed that RB survivors reported lower scores in all psychosocial and physical health summaries than their controls, albeit the difference was slightly less than the scores reported by parents. This finding aligns with a study by Zhang et al. (2018) in China that assessed the Quality of life in children who underwent enucleation for RB. However, Batra et al. (2016) have documented the preservation of physical functioning in survivors of RB, comparable to individuals without the condition. On the contrary, a study conducted by Dijk et al. (2007) in the Netherlands reported a higher HrQoL among RB survivors compared to a reference group of Dutch individuals. Notably, this study revealed that children and adolescents who had survived RB exhibited improved "moods and emotions" and perceived themselves as more autonomous than their healthy counterparts (van Dijk, Imhof, et al., 2007). The conflicting outcomes may be attributed to several factors, such as the early detection of the disease, which necessitates fewer disfiguring treatments, the maintenance of positive body image, greater cultural acceptance, and a multidisciplinary approach to management involving counsellors and psychologists, thereby enhancing the coping mechanisms of cancer patients within the Dutch cohort.

In our investigation, the physical and school components were most significantly impacted. Most daily activities were challenging for the survivors to do, according to their reports, which

eventually led to absenteeism in school due to ill health. This could be connected to the disease's visual impairment. Besides sleep troubles and anxieties about the future, RB survivors reported a lower emotional dimension. This was consistent with the results of an Italian population-based study (Zhang et al., 2018a) that also revealed emotional problems among paediatric cancer survivors. In addition to bullying by others, RB survivors had trouble playing with other children, finding friends, and getting along with their classmates. One of the causes of more significant bullying and disappointment among survivors may be perceived as low self-esteem and a poor body image.

(Batra et al., 2016) revealed a considerably hindered social domain in RB survivors, consistent with other studies. Except for heightened mental issues, including anxiety, loss of control, and depression, which have been linked to childhood bullying and an increased feeling of subjective impairment in the past, Dijk et al.'s (van Dijk et al., 2010) analysis of the QoL of adult RB survivors revealed a generally positive QoL. Therefore, treating these difficulties quickly is crucial so survivors may acquire effective coping mechanisms. The significant findings of the study are as follows.

- Significant reduction in QoL is noticed among children with RB as per the parent perception compared to age-matched control group parents, independent *t-test P value* <0.005 .
- A positive correlation exists between physical, emotional, social and school functioning. This implies that improvements in one domain may lead to improvements in the other domains, as per case parent observation. The Spearman correlation test shows that the correlations are significant at the 0.01 level (2-tailed).
- There is limited research on the perception of Quality of life (QoL) among survivors of RB in a school setting. It was observed that survivors of RB had increased school

absenteeism as a result of doctor visits, impaired memory, and difficulty in keeping up with school work. The study results support the findings of Dhingra et al. (2021a) and Weintraub et al. (2019). Studies found that survivors of RB have a comparable overall HrQoL to a control group of individuals of the same age.

- The results of the study identified that the QoL of parents of Rb survivors and self-proxy reports were negatively affected in many ways, including physical, social, emotional, and school-related dimensions. Despite the minor differences, self-proxy reports indicate a lower quality of life than the parents' group. The study findings indicate notable correlations between enucleation, visual acuity less than 6/18, and socio-economic status, with various aspects of quality-of-life domains among individuals who have survived retinoblastoma.
- A significant observation in our study was that 40% (N=86) of the survivors discontinued their education. In contrast to Western countries, resource-limited countries face unique challenges, such as lack of social and family financial support, vision impairment, inadequate healthcare, low socio-economic status, and limited access to specialised schools. The findings from the study conducted by Dhingra et al. (2021) are more recent than those of previous studies.
- Age, Treatment Type, Zone (region), Family Income, School Type, Community, Internet and Gadgets Usage, Parents Education, Vision (< 6/18), and QoL Domains (Physical, Emotional, Social, and School). like where the Odds ratio (OR) value is < 1. This contradicts a recent study by Dhingra et al. (2021a).

Batra et al. (2016) found no significant difference in HrQoL between metastatic, localised, bilateral, unilateral, or enucleated survivors (Batra, Kain, et al., 2016; Batra, Kumari, et al., 2016). Our research found that visual impairment and enucleation severely impacted survivors'

HrQoL. Possible causes include psychological suffering from eyesight loss, aesthetic defects, and functional impairments (Dhingra et al., 2021a). Facial deformity following enucleation may result from the limited availability of specialised prosthetic implants, the anxiety of recurring procedures, and difficulty maintaining the prosthesis. The rehabilitation of such individuals requires a multidisciplinary team approach to achieve the best cosmetic results.

The impact of disease and treatment on survivors' HrQoL must be adequately communicated to the caregiving staff. Educating instructors and colleagues about the obstacles encountered by survivors may facilitate a more positive school environment adjustment. Remedial measures, such as aids and instructional materials for the visually impaired, could enhance the patient's HrQoL. Lastly, it should be a treatment objective to assess HrQoL on an ongoing basis as these survivors age and to identify and guide them through the challenges they face in education, pursuing suitable employment, and negotiating relationships.

3.2.5 Limitations of the study:

One limitation of the study is the potential for selection bias. The participants who were unable to answer the questionnaire were rejected. Another drawback of this study is that age-matched controls may not fully account for potential differences in socio-economic and cultural environments between the survivors and controls. Additionally, including an equal number of controls may have introduced some variability. The downside of the study is that it primarily focused on younger patients, which means that we were unable to explore specific adolescent issues that may extend beyond the scope of the questionnaire. A disadvantage of this study is the limited sample size due to time constraints and COVID-19 protocols. The Quality of life associated with eyesight may lead to different conclusions; hence, we have solely utilised paediatric Quality of life data, which could be a future scope of the study.

3.2.6 Future scope:

The study findings have revealed that the emotional QoL is likely to be affected after experiencing school and physical challenges. This highlights the need for continuous monitoring of physical and psychological well-being and the importance of financial planning for the future. In the future, optometrists and ophthalmologists will approach this case with a greater emphasis on clinical analysis rather than psychological interpretation. This opens up opportunities for extensive research and the development of psychological interventions to be explored within this field of study. At some point, caregivers of RB survivors will face additional challenges beyond financial support. The burdens of accommodation, food, and language, which are crucial for every aspect of life, will significantly impact their Quality of life. In the future, there will be a need for comprehensive studies on vision-related QoL improvements. These studies will focus on enhancing the overall well-being and satisfaction of individuals with vision impairments. Additionally, there will be a growing emphasis on understanding the impact of these improvements on the broader concept of health-related Quality of life.

3.2.7 Conclusion:

The study results show that the Quality of life (QoL) of parents of retinoblastoma (RB) survivors and self-proxy reports were negatively affected in many ways, including physical, social, emotional, and school-related dimensions. Despite the minor differences, self-proxy reports indicate a lower quality of life than the parents' group. The study findings indicate notable correlations between enucleation, visual acuity less than 6/18, and socio-economic status, with various aspects of quality-of-life domains among individuals who have survived retinoblastoma.

CHAPTER 4

THE AWARENESS OF SUPPORTING SCHEMES AVAILABLE IN HOSPITAL AND ELSEWHERE

4.1 INTRODUCTION

This chapter investigates the awareness of support programs among patients and their families by analysing narratives from patients and caregivers regarding the various funding schemes offered in the hospital and elsewhere, as well as interviews with counsellors. Furthermore, a number of them indicated that they needed financial support and were not aware of the hospital's or other organizations' funding schemes. According to the primary objective of this thesis, the data demonstrated that the sample consisted of survivors from a variety of socioeconomic backgrounds. Of these, 15 patients had monthly family incomes of more than 10,000 INR, 46 had incomes between 10,000 and 50,000 INR, five families had incomes between 50,000 and 1,00,000 INR, and five families had incomes exceeding 1,00,000 INR. Two patients identified themselves as dependant families whereas 13 patients did not reveal their economic status. Notably, due to eligibility criteria restrictions, only 17 out of the 86 participants in the current study sample had the opportunity to select the hospital's available programme, i.e., *Cankids*.

The investigator also observed that majority of the caregivers expressed the need for financial assistance, and many were unaware of the existing schemes available. The objective was to recognize the present schemes in the Institute and elsewhere, the process of disseminating that information and awareness amongst patients regarding the available schemes. In addition to shedding light on existing funding schemes, the chapter might explore potential gaps or challenges inside the existing support framework and propose recommendations for improvement, which leads to equipping patients and their families with

the knowledge required to navigate the funding options, enabling them to make informed decisions that best suit their exclusive circumstances.

This involves an in-depth review of government-sponsored initiatives, non-profit organizations, and private foundations that provide essential financial aid, grants, and scholarships to patients and their families. The chapter also discusses the eligibility criteria, application processes, and the range of financial support offered by these schemes through the verbatim reports of counselors and patients/caregivers.

By providing detailed information on these funding schemes, the chapter attempts to empower individuals, guiding them in accessing the financial resources essential for managing the complex aspects of retinoblastoma care.

4.2 MATERIALS AND METHODS:

DATA COLLECTION:

Information was collected from counsellors/ caregivers at the hospital.

Parameters Investigated: Identification of available supporting schemes. Assess narratives of caregivers/counsellors about the benefits these schemes provide to the patients. Criteria for eligibility on financial and socio-economic status to access these supporting schemes. Analyze how many patients availed these schemes within the study pool. Exploration of the impact on the QoL at tertiary care level.

- 1. Sampling procedure:** Convenient sampling.
- 2. Supportive schemes data collection:**

Approach: The data was collected through counsellors' verbal reports. The format of information dissemination about supporting schemes during patient counselling at the hospital was not disclosed due to confidentiality and ethical concerns; Only a verbal report was provided by the counsellors.

Content: Availability of supporting schemes. Benefits derived from these schemes. Eligibility criteria of the same and Utilization statistics within the study pool.

3. Parent/caregiver Narratives:

Approach: Patient narratives were collected verbatim from the patients/caregivers, respecting their willingness to share their concerns.

Content: Patients' or caregivers' awareness and experiences with supporting schemes. Concerns expressed by patients/ parents or caregivers.

4. IEC Approvals and Informed Consent:

Ethical Considerations: Institutional Ethics Committee (IEC) approvals were obtained. Informed consent from parents ensured compliance with ethical standards.

5. Structured Interviews:

Content: Financial history of the subjects. Educational background of the parents. The purpose is to Understand the socio-economic status of the subjects. Relating the educational and financial backgrounds to the benefits derived from supporting schemes.

6. Data Synthesis and Analysis:

Integration: Combine quantitative data on scheme utilization with qualitative insights from patient/caregiver narratives.

Analysis: Explore patterns, correlations, and content analysis.

4.3 STUDY PROCESS:

4.3.1 Counsellors' interviews

The format of information dissemination about supporting schemes during patient counselling at the hospital was not disclosed due to confidentiality and ethical concerns; Only a verbal report was given by the counsellors. These counsellors are information providers trained and qualified at the concerned hospital.

Following are the counsellor's Insights on Retinoblastoma Patients' counselling:(*Counselor Interview*, personal communication, 2022)

1. **Emotional Impact:** The counsellor sheds light on the emotional toll Rb diagnosis can have on patients and their families. This includes the initial shock, fear, and anxiety associated with a cancer diagnosis, especially one affecting a child's vision. The interview delves into the counsellor's observations on how families cope with the emotional aspects.

2. **Necessity for Psychosocial Support:** Aside from financial assistance, the counsellor emphasizes the need for psychological support. The counsellor interview report discussed the coping methods and how counselling programs might help the families navigate the emotional difficulties of the illness. It highlights the implication of psychological health assistance as a vital constituent of complete care.

3. **Communication Approaches:** Based on the counsellor's verbatim report, suitable interaction tactics for dealing with retinoblastoma families, such as addressing concerns, sharing information, and reassuring open communication, contribute to building a friendly atmosphere. It explored how to modify communication to different age groups within the patient's family.

4. **RB-related Educational Provision:** The counsellors' interview report mentions the counsellor's role in providing educational support to patients and their families. This may include discussing the medical components of retinoblastoma, treatment options, and likely outcomes clearly and understandably so families can make informed decisions.

5. **Association with Financial Support Schemes:** The counsellor discussed their experiences working with financial assistance programs. This involves inspecting each family's requirements and linking them with applicable financing schemes. The counsellor's verbatim

report inquiries into how the counsellor bridges the emotional and financial aspects of the patient's treatment process.

6. Psychological Impact in the Long Run: The verbatim report of the counsellors explored the possible psychological impact of Rb on patients and their families in the long run, drawing into factors such as survivability, ongoing therapies, and the possibility of vision impairment.

7. Recommendations for Holistic Support: Based on their experience, the counsellor recommends a holistic support system that integrates emotional, psychological, and financial assistance. This could include suggestions for improving existing support programs and promoting a more comprehensive approach to care. Incorporating the counsellor's interview report enhances the chapter by offering a more comprehensive understanding of the challenges Rb patients face and the multifaceted support they require for a holistic and resilient journey.

Patients /Caregivers Awareness of the Schemes (Counselor Interview, personal communication, 2022):

Regarding parents' awareness of supporting schemes, the data was collected through counsellors' verbatim reports, and interactions with the parents/caregivers' narratives were analyzed. There is no structured format /survey followed to obtain the following data; it is entirely based on the resources mentioned above.

1. Information Dissemination: The counsellors' report explored the various channels through which information about funding schemes available to the patients and their caregivers. This includes healthcare institutions, support groups, online platforms, and informational materials distributed during medical consultations. Discuss the importance of ensuring that information reaches individuals at various stages since their Rb.

2. Tailoring Information to Patient Needs: Addressing the demand and providing information to individual patients and their families. Instructional materials in several

languages, considering cultural barriers, and delivering information accessible to people with varying degrees of health literacy were necessary.

3. **Knowledge-based Empowerment:** Demonstrated how understanding financial systems empowers patients and caregivers to be involved actively in decision-making about treatment options. The counsellors discussed how this information had helped families in making informative treatment choices, resulting in better QoL for patients.

4. **Financial application process guidance:** Depending on the counsellors' reports, the data of patients and caregivers was broadly analyzed to determine the need for financial help based on their socio-economic situation. This included discussions with people who have effectively availed benefits, which offered insight into the actions they took and the challenges they overcame.

5. **Role of Peer Networks and Community Care:** Discussed the impact of peer networks and community support in circulating information about financing programs depending on the counsellors' verbatim report. One-on-one communication among peers has been highlighted as a vital method for reaching out to needy families. The current objective will benefit from counsellor reports and narratives of the patient families who have benefited from these schemes.

6. **Feedback Mechanisms:** Identified the existing feedback mechanisms through counsellors and noted its importance in improving the awareness for accessibility of funding schemes. Patient and caregiver feedback has been instrumental in refining communication strategies and addressing gaps or challenges in this process.

7. **Addressing Stigma and Cultural Barriers:** Explored how past awareness efforts addressed the stigma of seeking financial help for Rb in counsellor's report. The report explored strategies to overcome cultural barriers that might have prevented individuals from accessing

the schemes. It emphasized creating a supportive, non-judgmental environment, encouraging individuals to access the needed financial assistance

8. **Promoting Long-Term Financial Health:** Counselors verbatim report emphasized considering the lasting financial impacts of Rb. They pointed out how families financially benefited and planned for life after treatment, emphasizing the impact of awareness of funding programs on decisions for families dealing with Rb (*Counselor Interview*, personal communication, 2022).

4.4 RESULTS:

As per the information gathered from the counsellors, the study highlighted the following insights: **(Fig 4.1)** A hospital councillor reported that "patient will be first sent to us following the clinical and diagnostic procedures after diagnosing the Rb, and we will be explaining to the patient about the treatments dos and don'ts following its protocol. If patients ask for financial assistance and or if we find out a patient in need of financial help, we will report to the in-charge ophthalmologist for approval or referral to avail the financial scheme that is available in our hospital, i.e., *Cankids*." (*Counselor Interview*, personal communication, 2022)

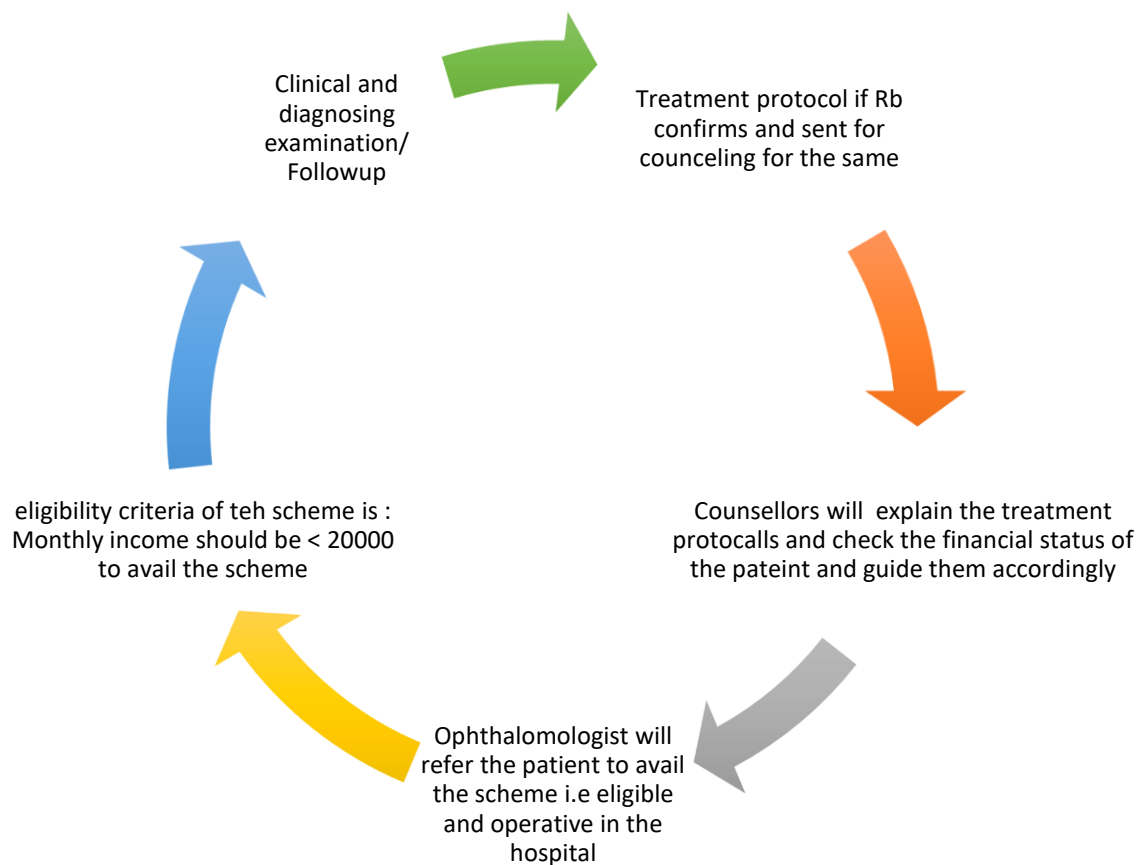


Figure 0.17 Process of referring the patients to avail the supporting schemes in the hospital

“Following the counsellor reference, the Cankids in charge will contact the patient, and they will explain the procedures and the incentives they get through the supporting scheme. Also, the Cankids team will explain the procedures and ways to get them done to some extent if any other schemes¹ are available”- (*Cankids Counsellor Interview*, personal communication, n.d.) Cankids *in charge from the Hospital*.

The esteemed *Cankids* team provides diverse array of services encompassing social support, facilitation of relief funds, harmonious coordination with other non-governmental organizations, seamless railway connections, issuance of blind certificates, provision of ration

¹ Provided by a Govt. Non-Govt. or other supporting NGO team from the hospital.

support, facilitation of pension schemes, promotion of education, enhancement of nutrition, and the provision of family therapy counselling as illustrated in **Fig 4.2.**

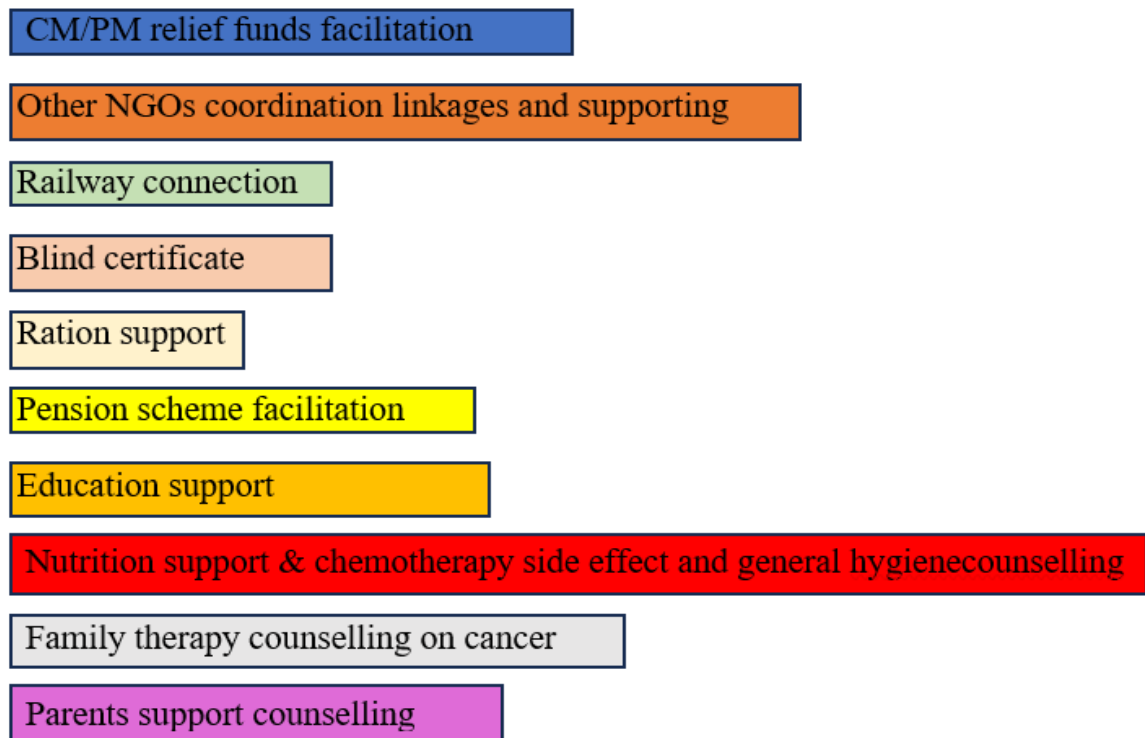


Figure 0.18 Services provided by the Cankids team in the hospital

As directed by ophthalmology clinical staff referral the CFS counselling unit and *Cankids* team will enrol children whose family income is less than 20,000 INR in the *Cankids* program. However, everyone diagnosed with Rb is not eligible for this program. Remarkably, not every Rb patient became aware of this incentive unless the patient specifically inquired or the counsellor assessed the patient's financial status. To qualify for the aforementioned benefit, one must pass a stringent examination. Additional incentives comprise central and state CM/PM relief funds, NGOs like IKSHA, and government cancer programs that offer monthly food supplements to registered Rb patients.

1.1.1 Structured interview:

Based on the structured interview, it was worth noting that out of the 86 patients, only 17 (Table-4.3) availed the Cankids supporting scheme 2 cases (2.3%) were identified as belonging to a dependent family, while 13 cases (15.1%) did not provide information regarding their family income. All of the controls included in the study had an income exceeding 10000 INR.

Income level	N	Cankids avail	No can kids
Unemployed	0	-	-
< 10,000	15	-	-
10,000-50,000	46	17	29
50,000-1,00,000	5	-	5
>1,00,000	5	-	5
Dependent	2	-	2
Not disclosed	13	-	

Figure 0.19 Income Levels of RB Survivors and Utilization of Cankids Support Scheme

1.1.2 Narratives of the patients:

Apart from the counsellor and Cankids team, there are the narratives reported by the parents/caregivers of Rb survivors that provides insight into their emotional states such as sadness, sleeplessness, cognitive dysfunctions, lack of concentration, anxiety episodes, anger, financial distress, etc. that hampers their lifestyle. The verbatim reports were probed to emerge specific themes of the collected narratives from the parents of Rb survivors.

Narrative 1:

Patient age: 9 years now

Age of diagnosis: 2 years.

Gender: Female

Diagnosis: OU- Rb OS-Orbital Rb

Eye: Both eyes

Enucleated eye: Right eye

Type of treatment availed: OU-Chemo, OD-Enucleated,

Methodology: While collecting the Questionnaire data, the patient attendees' narratives were collected through semi-structured interviews.

Psychological implications for the caregiver:

The mother of a 9-year-old female RB survivor who underwent right eye Enucleation narrated that he was forced to leave her job in order to care for her child at home because she needs to adhere to a timely schedule for her child's follow-up treatments, which requires consistent travel. The family is now dependent on a single-parent income. She expressed concerns about the safety of items and furniture around the home, ensuring everything has blunt finishing to avoid any harm to the child (*Investigator Insights, 2022; Parent Narrative, 2022*)

She emphasized the need for special attention for Rb survivors, suggesting that schools should play a role in supporting families with children who have undergone eye removal. She advocated for government or regulatory bodies to provide assistance at the grassroots level. Additionally, she expressed the importance of having special schools tailored to the needs of Rb survivors rather than integrating them into physically challenged schools (Ibid).

The mother highlighted that her child performs exceptionally well academically, surpassing her peers in the class, and suggested the importance of motivating such children. She stressed the need for parent counseling regarding the after-effects of Rb in the daily lives of the Children as they are dependent. Additionally, she expressed expectations for the hospital

and relevant governing bodies to provide families with sufficient information about aspects of children's lives, including education (Ibid).

Narrative 2:

Patient age: 4 years now

Age of diagnosis: 2 years.

Gender: Male

Diagnosis: OU- Rb

Eye: Both eyes

Enucleated eye: Right eye

Methodology: While collecting the Questionnaire data, the patient attendees' Narratives were also collected through semi-structured interviews.

Type of treatment availed: OU-Chemo, OD-Enucleated,

Parents narrative:

The grandfather, serving as the caretaker for a 2-year-old male who underwent right eye Enucleation and subsequent treatments, provided details in the questionnaire. He highlighted their impoverished background, underscoring that the patient is now parentless and has been raised by the grandparents. Engaged in farming, the grandparents rely on daily wages and assistance from relatives (*Parent Narrative*, 2022)

Financial constraints sometimes prevent them from reaching the hospital for the patient's follow-up. Expressing concerns about the child's survival and their own aging, the grandfather earnestly requested financial assistance from the hospital management (*Investigator Insights*, 2022)

Narrative 3:

Patient age: 1.5 years now

Age of diagnosis: 3 years.

Gender: Male

Diagnosis: OU- Rb OS-Orbital Rb

Eye: Both eyes

The type of treatment available: OU-Chemo and other combination therapies.

Parent Narrative:

The father of a 3-year-old Rb survivor shared that the child is energetically keeping up with peers but occasionally displays aggression and anger during follow-up visits. Being a temple priest with limited income, he faces challenges in affording the necessary treatment. The family has experienced difficulties attending follow-ups, particularly during the Covid pandemic, with travel restrictions and financial constraints making it burdensome (*Parent Narrative, 2022*).

The father expressed concerns about settling in Hyderabad due to financial constraints and the lack of job opportunities during frequent follow-up visits for the child. Additionally, they encounter challenges with daily meals, accommodation, and language issues as non-locals (*Investigator Insights, 2022*)

Narrative 4:

Patient age: 9 years currently

Age of diagnosis: 2 years.

Gender: Female

Diagnosis: OD - RB

Eye: Right eye

Type of treatment availed: OU-Chemo and Other Combination therapies (Enucleated)

Parent Narrative:

Her experiences were shared by her mother, who initially pondered stated: “she was the elder one, and we thought how she would survive at this age. Fortunately, treatment saved her from potential challenges. As the days passed, we contemplated enrolling her in a special school to align with her needs. She is a very active child, and now she has to cope with all her friends like before. She remains a vibrant and active child, engaging in various school activities, including sports, and we are training her accordingly. She uses an ocular prosthesis for cosmetic purposes, which helps her to some extent. As of now, we are coming for follow-ups, and this entire journey has been a roller coaster for us. It is not easy to overcome, and we are sometimes still struggling. Thanks to doctors and God for keeping us motivated throughout the treatment process” (*Parent Narrative*, 2022)

Narrative 5

Patient age: 4 years currently

Age of diagnosis: 2 years.

Gender: Female

Diagnosis: OU - RB

Eye: Both eyes

Type of treatment availed: Chemotherapy

Parent Narrative:

The father detailed the circumstances arising from marital and family challenges, resulting in single parenting for the children. He emphasized the impact of financial and relationship difficulties on his child's QoL (*Parent Narrative*, 2022). The complexities of single parenting have created uncertainties about the child's well-being, occasionally leading to confusion about decision-making responsibilities between the parents.

1.1.3 Content analysis of the Narratives

Furthermore, using frequency and percentage, content analysis identified a hierarchical depiction of the primary challenges experienced by caregivers. Notably, emotional distress was assessed, including global sorrow (5/5) at 100%, insomnia (60%/3/5), cognitive impairment (20%/1/5), difficulties focusing (20%/1/5), anxiety attacks (20%/1/5), and parental observations of rage issues in children (20%/1/5).

Additionally, parents or caregivers expressed financial troubles as their top concern, with a noteworthy frequency of 80% (4/5). Alongside this were obstacles like quitting work to take care of the kids at 40% (2/5), giving the kids extra attention at 40% (2/5), skipping doctor's appointments at 40% (2/5), having trouble finding housing while undergoing treatment at 20% (1/5), non-locals having trouble finding a job at 20% (1/5), and the challenging procedure of putting on and taking off an ocular prosthesis at 20% (1/5). Additionally, it was noted that 20% (1/5) of parents said that marriage and family problems prevented them from being able to provide for their children. Moreover, 20% (1/5) of the participants reported being a single parent or depending on their income Table 4.4

Themes	Frequency	%
Sadness	5	100
Financial hardship	4	80

Sleeplessness	3	60
leaving Job to take care of children	2	40
Giving Special attention to the child	2	40
Missing follow-ups	2	40
Single parent income	2	40
Cognitive impairment (forgetting things, confusion)	1	20
Difficulty in concentrating	1	20
Anxiety attacks	1	20
Anger	1	20
Accommodation during the treatment	1	20
Non-locality problems (in getting jobs during the treatment phase)	1	20
Inserting Ocular prosthesis (sometimes we struggle)	1	20
due to marital and family issues unable	1	20
Single parenting	1	20

Figure 0.20 Themes of patient narratives explored

For visual clarity, these findings have been visually portrayed in Figure 4.5, which offers a thorough summary of the difficulties that parents and caregivers encounters while dealing with paediatric oncology, particularly in the case of Rb.

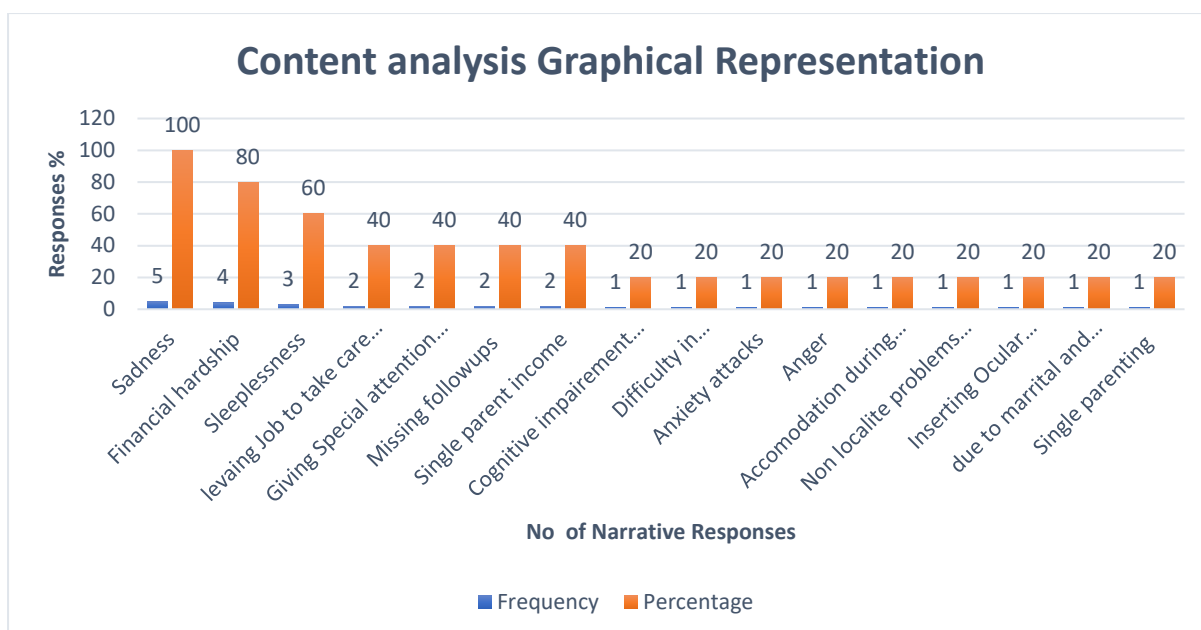


Figure 0.21 Themes of patient narratives explored

The analysis of structured interviews where the demographic and financial status of the subjects revealed that out of 86 Rb survivors, only 17 availed of the Cankids support scheme due to meeting the financial eligibility criteria, while the remaining 69 subjects did not qualify due to their financial criteria $\geq 20,000$ INR. Notably, the counsellor's study explored that if a subject wanted to avail the Cankids scheme, their income should be below 10000 INR. The patients highlighted the following concerns: 17.40 % required Financial, educational, and accommodation support during the treatment and travel allowances support; 53.4% required both financial and educational, and some psychological counselling support and 5.8% required special school support along with financial support; the remaining required other possible needs due to lack of awareness and language barrier as patients partially highlighting as per the investigator's observation from the patient narratives as illustrated in Figure 4.5.

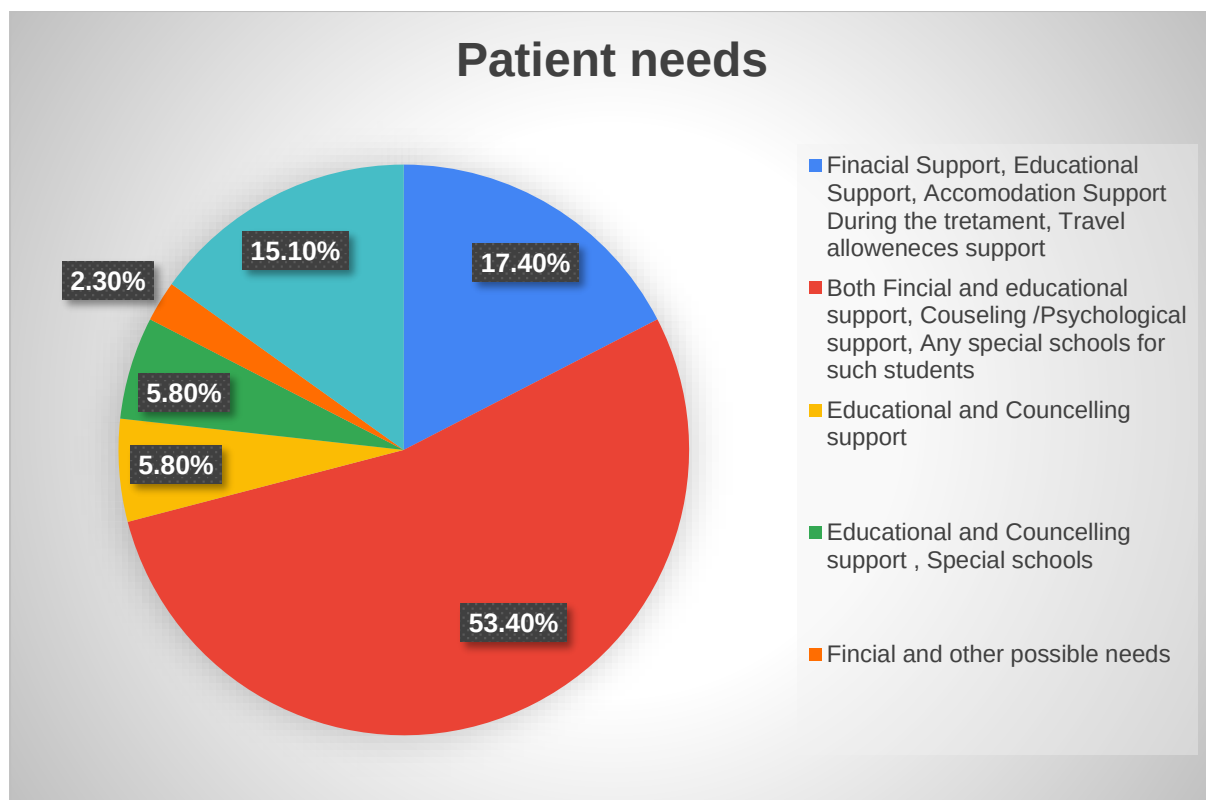


Figure 0.22 Parents account of the Rb patients' needs

4.5 DISCUSSION

In India and other low- and middle-income nations, Rb prevails, with an estimated 1,500 new cases diagnosed annually. India bears the highest burden of the disease globally (Dimaras, 2015; Dimaras et al., 2015; Jain et al., 2019). Rb, the predominant form of primary eye cancer in children, shows no gender or racial preference. Unfortunately, in low- and middle-income countries, the prognosis for children with Rb is often grim, and many succumb to the disease (*Global Disparities*, 2020).

4.5.1 Cancer-Related Schemes and their eligibility criteria in India:

Health Minister's Discretionary Grant (HMDG): Under the HMDG, financial support ranging from Rs 75,000 to Rs 1,25,000 is offered to patients with household annual incomes of up to Rs.1,25,000/- and lower to cover a portion of the cost of cancer treatment at government hospitals” (*State & Central Govt Schemes*, 2023).

Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana (AB-PMJAY): ‘PM-JAY’ is designed for individuals with low-income, including impoverished, deprived rural families and urban workers' families in specific vocations. The benefit cover for secondary and tertiary care hospitalization is up to Rs 5 lakh per family per year (*State & Central Govt Schemes, 2023*).

Cancer Patients Concession for Travel by Air: This service is offered by Air India exclusively for Indian residents undergoing cancer treatment or medical check-ups. A 50% discount is applicable to economy fares for eligible individuals. (*State & Central Govt Schemes, 2023*).

Central Government Health Scheme (CGHS): Serving and retired Central Government personnel and families are eligible for CGHS. Cancer treatment can be obtained at permitted rates from hospitals other than those established under the CGHS (*State & Central Govt Schemes, 2023*).

Health Minister's Cancer Patient Fund (HMCPU) of Rastriya Arogya Nidhi (RAN): Patients living below the poverty line who are receiving cancer treatment at one of the country's 27 Regional Cancer Centres (RCCs) would be eligible for up to Rs 2 lakhs in assistance (*State & Central Govt Schemes, 2023*).

Railways: Facilities for Passengers who are Cancer Patients: Indian Railways provides concessionary tickets for cancer patients upon presentation of a certificate from the director of the cancer hospital or institute where the patient is being treated. The concession is proportionate to their class of seating (*State & Central Govt Schemes, 2023*).

Free Cancer Treatment Under Arogya Sri Scheme of A.P. Govt: Patients with cancer in Andhra Pradesh will receive free treatment if their yearly household income is less than Rs 5 lakh. Arogya Sri cards are provided to anyone earning less than this amount. The government of Andhra Pradesh has partnered with approximately 150 super-speciality hospitals in AP,

Hyderabad, Chennai, and Bangalore to provide treatments under the Arogya Sri plan. The expenses are reimbursed by the government. Post-surgery treatment costs Rs 225 per day (*State & Central Govt Schemes, 2023*).

Mediclaim Scheme of Directorate of Health Services: Permanent residents of Goa are eligible for this plan. The policy provides Mediclaim coverage for radiotherapy and chemotherapy up to Rs 5 lakhs. Treatment will be provided in hospitals registered with the government in Goa and elsewhere (*State & Central Govt Schemes, 2023*).

CTMFFP Scheme (Cancer Treatment & Management Fund for Poor): Patients in UT of J&K whose household income does not exceed Rs.20,000 per month are eligible for financial assistance under the fund. Treatment and management of cancer include surgery, chemotherapy, radiation, or a combination of both (*State & Central Govt Schemes, 2023*).

Karnataka Chief Minister's Relief Fund: The scheme provides financial assistance for individuals from Karnataka who fall under the Below Poverty Line suffering from fatal illnesses (*State & Central Govt Schemes, 2023*).

Cancer Suraksha Scheme by Kerala Social Security Mission: This program is for children under the age of 18 who have cancer and are from low-income households. Those who qualify will get a Patient Card. The hospitals would bear the cost of treatment using money granted by the Mission, up to a limit of Rs 50,000 per case. Additional expenses may be incurred by the hospital as approved by the Mission (*State & Central Govt Schemes, 2023*).

Madhya Pradesh State Illness Assistance Fund: Individuals in Madhya Pradesh who are "below the poverty line" and diagnosed with cancer are eligible to apply for assistance. The financial aid provided ranges from Rs 25,000 to Rs 200,000, and the approved amount will be directly disbursed to the hospital. Interested individuals can complete the application form, available at various offices including the District Collector's, District Chief Medical and Health

Officer's, District Civil Surgeon's, and District Hospital's offices. (*State & Central Govt Schemes, 2023*).

Maharashtra- Chief Minister's Relief Fund (CMRF): Under CMRF Chemotherapy and dialysis costs up to Rs 50,000, transplant-related procedures are covered up to Rs 2 lakhs, and other major surgeries are eligible for up to Rs 1 lakh in assistance. To be eligible, individuals must have a yearly income of less than Rs 1.6 lakhs and should not be covered by any other state-sponsored health program (*State & Central Govt Schemes, 2023*).

Maharashtra-Mahatma Jyotiba Phule Jan Arogya Yojana: According to recommendations that will be implemented, the programme would cover all hospitalization charges up to Rs 5 lakh per family per year on a floater basis in Maharashtra. Patients can get treatment at empanelled hospitals by presenting their ration cards or AAY cards. Medical oncology, radiation oncology, and surgical oncology are all represented (*State & Central Govt Schemes, 2023*).

Free Chemotherapy Programme of Odisha Govt.: “All poor cancer patients in Odisha are eligible for free chemotherapy treatment. District headquarters hospitals in all 30 districts, the capital hospital, and ISPAT General Hospital (IGH) in Rourkela will offer treatment. Free consultations are also provided in district headquarters hospitals as part of the program”. (*State & Central Govt Schemes, 2023*).

Mukh Mantri Punjab Cancer Raahat Kosh Scheme: This plan aims to give financial aid to cancer patients in Punjab. Except for government employees, ESI employees and their dependents, and patients who have health insurance or receive medical reimbursement, each cancer patient receives financial help of up to Rs 1.50 lakhs for treatment (*State & Central Govt Schemes, 2023*).

Free Cancer Medicines Scheme of Rajasthan Government: Cancer treatments of 36 distinct varieties of drugs are on the essential drug list for free distribution from Drug Distribution Counters (DDCs) established in government-run chosen hospitals in Rajasthan (*State & Central Govt Schemes*, 2023).

Aarogya Sri Scheme- Telangana: Below Poverty Line (BPL) households of Telangana state are entitled to free treatment up to Rs 5 Lacs for hospitalization and surgery and up to Rs 10 Lacs for high-end operations under this initiative. Surgery, chemotherapy, and radiotherapy are all covered under this scheme (*State & Central Govt Schemes*, 2023).

Free Cancer Treatment in Govt Hospitals-West Bengal: The West Bengal State Government has made cancer treatment in state-run hospitals and medical institutes entirely free of cost. Free medicine, radiation, chemotherapy, surgical procedures, and beds are all part of the program (*State & Central Govt Schemes*, 2023).

4.5.2 Current active Program at the Hospital is Cankids and its services:

Following referral from the ophthalmologist *Cankids* is actively supporting the patients who are in need of financial and treatment assistance. Hospital Counsellors and the Cankids team provides information about social support to patients, state and central government relief funds facilitation, other NGOs coordination linkages and supporting, Railway connection, blind certificate, ration support, pension scheme facilitation, education support, nutrition support & chemotherapy side effect and general hygiene counselling, family therapy counselling on cancer, Parents support counselling. There are initiatives aimed at enhancing the treatment of Rb in low- and middle-income nations, such as India(Rodriguez-Galindo et al., 2008). A 2008 study published in Paediatrics, for instance, describes twinning initiatives aimed at developing paediatric cancer centres and facilitating government and private sector partnerships(Rodriguez-Galindo et al., 2008).

The notably structured interview reveals that 53.4% needed both financial, educational, and some psychological counselling support and the remaining half are in other needs such as accommodation, special schools' information, and other children's settings in day-to-day living. These results support that existing study of global disparities of childhood cancer, a comprehensive survey conducted across 153 countries, encompassing close to 300 Rb treatment institutions, revealed a notable disparity in the provision of adequate therapy for Rb between children residing in low and middle-income nations compared to their counterparts in high-income nations(*Global Disparities*, 2020). Recent research published in the National Centre for Biotechnology Information (NCBI) revealed that residing in low-income nations was associated with worse survival outcomes among individuals diagnosed with Rb. This implies that those living in socioeconomically disadvantaged regions may qualify for governmental assistance(*Global Disparities*, 2020; "The Global Rb Outcome Study," 2022).

Cankids is a regional non-governmental organization that collaborates with medical institutions in India to provide lodging and assistance to families of pediatric cancer patients(Ahuja et al., 2021). The study also observes that "despite *Cankids* providing the above-mentioned different sources information that helps Rb survivor and her caretaker to acquire the help to hustle free treatment and stay for the same, but due to language and the lack of information and communication few survivors' parents and or caretakers were unable to acquire the maximum help from the local govt and or NGO body's" as per the narratives and *Cankids* in charge experience. To bridge this gap, The Indian government has recently broadened the scope of comprehensive primary care, which may have implications for Rb treatment as part of the Vision 2020 goals(Gupta et al., 2020).

Healthcare professionals must be well informed on how illness and therapy affect survivors' QoL. Educating teachers and classmates about the problems survivors face could

help them adjust better to the school setting. The implementation of remedial measures, such as the provision of aids and teaching material tailored to the needs of individuals with visual impairments, holds significant potential in facilitating the enhancement of patients' Health-Related Quality of Life(Dhingra et al., 2021; Padamandala et al., 2023). Notably, Himani Dhingra *et al.*'s 2021 study also supports the idea that when it comes to school settings, it is essential to educate school teachers and peers to help the survivors(Dhingra et al., 2021). There is a potential existence of additional organizations or support groups in India that cater to the needs of parents with Rb patients. However, the available search results do not provide complete information.

From the narratives and the based on the counsellors and Cankids, the study observes that expressed concerns about the potential long-term effects of treatment on their child's health. These insights support research published in the Journal Pediatric in 2022; parents of individuals who have survived Rb in India have shown a recognition of the significance of early detection and intervention(*Values of Rb Survivors and Parents Regarding Treatment Outcomes: A Qualitative Study | JCO Oncology Practice*, n.d.). Furthermore, these parents have indicated apprehensions about the possible enduring consequences of the therapy on their child's well-being(*Values of Rb Survivors and Parents Regarding Treatment Outcomes: A Qualitative Study | JCO Oncology Practice*, n.d.).

Additionally, anecdotes of parents' narrative study explored that the parents of the patients tried to provide themselves with motivational, moral support through a better lifestyle. While serving the patient, the caregiver encountered several psychological problems like stress and anxiety. It necessitates the need for extended psychological support to improve the psychological health of caregivers. Based on the patient's financial status, their needs are observed to be varying as per the semi-structured interview employed in this study.

4.6 Research gap Analysis:

Despite the contrary narratives, the caregiver has reported that due to Financial and language problems, the caregiver of the Rb patient faces problems and feels distressed and unable to show up for his grandson's treatment sometimes. Similarly, in common, parents expressed extreme feelings of sadness; they were distressed and sleepless for the above reasons, and sometimes, the parents were observed being emotionally frozen or cold. Additionally, from the other narrative, the grandparents themselves are getting older, and they are constantly worried about the future care of their grandchild, which is taking a toll on their emotional status and affecting their mental health.

In the current study population, as per the Hospital and other Canids norms, only <20,000 INR family income patients can avail of the incentive. Available schemes were 4, including govt and NGO. 17/86 study population were availed the *Cankids* as per the secondary data; Patient needs as per their financial needs N=86 as per the secondary data and patient needs, we speculate that Cankids eligibility bar needs to improve above 20,000 INR.

4.7 Advocacy and Recommendations:

The study emphasizes after the investigation provides following recommendations:

- Counselling at diagnosis, pre & post-treatment on all aspects, including finances.
- Revise the eligibility criteria of Cankids and other schemes compared to the existing bar may improve the reliability of financial assistance schemes.
- Increasing self-awareness about the disease.
- Additional schemes with the support of government, NGOs, philanthropy, or third-party insurance could address some of financial aspects.

- Financial needs of later life are to be planned by parents.
- Develop teaching or training material for the parents to cope with their kids' schooling and daily routines.
- As in future direction this education intervention how many approached these agencies to opt the financial help and increased utilization analysis to make better health policies accordingly.

4.8 Limitations of the study:

In the current study, as narratives are very brief and open-ended, there is a lack of continuation and detailed view of the information. Due to time constraints and COVID protocol, only a minimal sample could be studied. Including parent and survivors' narratives is minimal as young adult survivors may have different narratives than the parents' narratives, which may lead to future research scope. Similarly, the inclusion of counsellors and the *Cankids* team and their contribution to the present study were minimal. Future prospective research studies may consider conducting more structured interviews with parents or caregivers to assess their awareness of available supporting schemes during the treatment. Other confounding factors, such as patients' prior knowledge of registering for supporting schemes and parents or caregivers' awareness of available incentives, might have been overlooked in this study. The format of questions asked by the counsellors at the hospital was not disclosed; due to confidentiality and ethical concerns, the counsellors only gave a verbal account. These factors could introduce bias and limit the study's results, given that it was conducted in a single hospital setting.

4.9 CONCLUSION

The study exploring the awareness on schemes of the Rb care in hospital through counsellors' interviews and parents/caregivers' narratives revealed that a limited number of parents/caregivers were aware of the available schemes and supporting incentives. The Cankids program is an opportunity for patients with Rb from families with monthly income below 20,000 INR. Though, majority of the patients are eligible for this incentive, they often discover their eligibility for this incentive when they inquire about the scheme or when the counsellor identifies their financial status. There are also some remarkable incentives, such as the CM/PM relief fund, NGOs like IKSHA, and government and non-government cancer schemes. The hospital also provides awareness programs to the patients about the schemes/facilities available outside the hospital that notably offer a wide range of valuable resources, including disease diagnosis, information on social support, CM/PM relief funds, railway connections, blind certificates, ration support, pension scheme facilitation, education support, nutrition support, family therapy counselling, and parent support counselling. Some positive recommendations include seeking counselling at diagnosis, embracing self-awareness, patients' recovery process, and proactively planning for financial needs in later life.

CHAPTER 5

SUMMARY & CONCLUSION

5.1 SUMMARY:

Health-related quality of life (HrQoL) refers to a multidomain concept that encompasses the survivor's overall perception of how disease and treatment impact various aspects of their life, including physical, psychological, and social domains (Langeveld et al., 2002; Wengenroth et al., 2015). The use of this tool to assess outcomes in cancer survivors is becoming more widely accepted. It is crucial to assess the impact of HrQoL on survivors of Rb, considering the high cure rates in children and various factors that may influence it (Dhingra et al., 2021; Padamandala et al., 2023). This could aid in identifying areas where remedial measures may be necessary to optimize the HrQoL. Data are scarce, and findings regarding the HrQoL in this particular cohort are conflicting (Dhingra et al., 2021a). The variation in assessment tools, differing perspectives between parents and children regarding quality of life, and the diverse demographic profile of the study population may contribute to these findings.

A recent literature review by Belson et al. (2020) examining QoL studies in Rb survivors revealed prominent research gaps, particularly in the comprehensive exploration of both parent and child perspectives. Existing studies disproportionately focus on parental or child perspectives, precluding a holistic understanding of the collective impact on familial dynamics and individual well-being. Moreover, the scarcity of research that systematically scrutinizes the psychological, educational, and occupational outcomes stemming from Rb within the context of QoL represents a significant gap.

The current state of research on Rb survivors' QoL falls short in thoroughly investigating how the experiences of both parents and children connect with various aspects of

life. This limitation hampers our ability to fully understand comprehensive patterns and the interconnections between different domains of life. There is a need for more in-depth studies that encompass the perspectives of parents and children to provide a more complete picture of the impact of Rb on their overall well-being and daily life. Additionally, the need for region-specific QoL investigations in the realm of Rb signifies a gap in understanding how cultural, socio-economic, and geographical factors may uniquely influence the subjective experiences of both parents and children. This void undermines the capacity to tailor interventions and support mechanisms to the specific needs of diverse populations grappling with the aftermath of Rb.

Currently, there is not enough information on the challenges both children and parents face, and this hinders our ability to provide the best support for families dealing with Rb.

Research on QoL in Rb survivors reveals notable gaps such as Limited Rigorous Studies: there is a scarcity of comprehensive and rigorous studies specifically exploring the QoL of Rb survivors, hindering a nuanced understanding of their well-being. Parental and Child Perspectives: the existing research often focuses on parents or children, creating a gap in understanding how both perspectives intersect and contribute to the overall QoL dynamics within families affected by Rb. Impact of Visual Disabilities: there is a lack of in-depth exploration into the QoL challenges specific to survivors with visual disabilities, such as those resulting from enucleation and varying levels of visual acuity.

Region-Specific Studies: the need for region-specific QoL studies is apparent, as cultural, socio-economic, and geographical factors are not adequately addressed in the current research landscape. Longitudinal Studies and Sample Size: insufficient longitudinal studies with larger participant samples limit our understanding of how QoL evolves for Rb survivors,

impeding the development of targeted interventions that enhance the overall well-being of Rb survivors and their families.

The study includes a scoping review to critically evaluate all the studies in this area, followed by interviewing the survivors and their parents independently for a detailed PedsQoL4.0 generic core scale questionnaire, which includes four major areas, e.g. Physical health, Emotional health, social health, School health. As a secondary outcome, we also observed the parents' awareness of the available support schemes for the affected children.

We have framed three objectives to critically evaluate the QoL in Rb survivors:

- To conduct a scoping review of the literature on the QoL and influencing factors in Rb survivors globally.
- To investigate the QoL among Rb survivors from all over India at tertiary care hospitals in Hyderabad.
- To Explore the available supporting schemes at the institute (CFS) and address them.

The first objective – scoping review, followed the JBI guidelines to review the studies in this area critically used the keywords "Retinoblastoma", "survivors", and "Quality of Life" in search for articles on QoL. The study included original and review articles, randomized controlled studies, and experimental studies over 22 years (2000-2022). Search sites included Google Scholar, PubMed, Scopus Research, and Web of Science. The articles that did not meet the inclusion criteria and timeline were excluded.

The search turned up 107 publications, of which 74 were QoL studies. Of these, only 17 (n=17) met the inclusion requirements; of these, 15 were original and 2 were reviews. The geographic distribution of these studies was India (n=5), China (n=1), USA(n=4), Brazil (n=1), Egypt (n=1), and Ivory Coast (n=1), Israel (n=1), Europe (n=2), Saudi Arabia (n=1). The

studies (2 review studies and 15 cross-sectional and Case-Control studies) included either children or parents, except two Indian studies, which included both parents and children.

The most commonly used QoL questionnaires were: Peds Qol 4.0 (n=5) 29.4%, Short form 36(SF-36) life questionnaire (n=2) 11%, Kids screen self-report (n=1) 5%, Child and Family follow-up (CFFS) survey (n=1) 5%, Child Health Questionnaire (CHQ)(n=1) 5%, Cancer therapy general FACT-g qnr(n=1) 5%, Medical charts and thematic analysis(n=1) 5%, National eye institute visual field questionnaire (NEIFQ) (n=1)) 5%, treatment-based interventions, review studies (n=3) 17.6% and other QoL questionnaires that measures psychological status and daily activities (n=1) 5%. All these studies recorded low, health-related QoL, vision-related QoL, psychosocial factors, daily activity participation, and disability. In contrast, the studies have evaluated the QoL regarding age, gender, socio-economic status, age at diagnosis, and culture of parents, caregivers, health care professionals, and long-term studies. The limitations of the study include smaller sample numbers, absence of a control group, cross-sectional design, self-reported data, inability to evaluate psychosocial factors, long-term implications, geographic constraints, and lack of diversity, limiting the its usefulness.

The literature further found Age, Gender, Treatment modality, Region, and Vision as the influencing factors. The majority of research focused on the survivors' physical health, psychological functioning, and educational and employment results, and less focused on family functioning and economic status. Notably, parents perceived a reduced QoL for their children compared to the self-reports, as per the literature found in this study. The negative impact on HrQoL was observed in cases of enucleation and visual acuity of less than 6/18 in the better eye.

The second objective, divided into two phases, consists of a pilot phase and the major project phase. The pilot study assessed the feasibility and issues faced, if any, using the QoL

questionnaire and structured interview in South Indian tertiary eye care hospital survivors, age-matched controls, and their parents. Among the 60 subjects, including 15 survivors, 15 age-matched controls, and 30 primary caregivers, the PedsQL 4.0 generic core scale and structured interview were administered and evaluated for physical, social, emotional, and school health. The time taken by survivors was slightly more than 15.1 ± 0.4 minutes vs 12.2 ± 0.6 minutes, while all children needed parental help to complete the questionnaire. The pilot research showed that participants, especially parents, understood and accepted the QoL measuring instrument (PedsQL 4.0), making it suitable for a more extensive study. This age group needed parents and researchers. The tendency suggests a reduction in survivors' QoL, emphasizing the necessity for psychoeducation and counselling before and after treatment.

The pilot study was followed by the main study to evaluate the QoL of Rb survivors as perceived by parents and the self-reported by patients through a Pediatric QoL (PedsQL). The methodology included a cohort of 86 RB survivors, 86 age-matched controls, and their primary carers. Peds QL 4.0 generic core scale and structured interview was administered. QoL on Physical, social, emotional, and school health was evaluated and correlated with clinical and sociodemographic parameters.

Results of this objective include the mean age of the Rb survivors, which is 5.7 years, with an M: F ratio of 1.1: 1. Disease was bilateral in 79% of cases. About 45% (39/86) underwent enucleation while others received Combination therapy 16(18%), Chemotherapy 30 (34%), or radiation, i.e., at least 1 (1%). Disease-free survival at < 2 years at 22.1 % and > 2 years at 77.9%; vision in 6/18 in the best eye was 47 (54.7%). As reported by Parents, the QoL of physical health of Rb survivors was 70.2 ± 27.8 ; $96.15 \pm 13SD$, emotional health $72.1 \pm 27.4SD$; $94.4 \pm 12.5 SD$, social health $80.4 \pm 24.9 SD$; $98.6 \pm 6.2 SD$; and school health $71.9 \pm 26.5 SD$; $96.1 \pm 12.2 SD$.

As per the Self-report perception, the QoL of Physical health is 68.2 ± 27.8 SD; 96.2 ± 13 SD. Emotional health 66.2 ± 28.4 SD; 95.3 ± 12.5 SD, Social health 69.5 ± 24.9 SD; 98.7 ± 6.2 SD, School health 63.5 ± 26.5 SD; 95.1 ± 12.2 SD. There was a significant relationship between the enucleation and QoL domains where $\chi^2 = 67.75$, degree of freedom $df = 36$, and $p < 0.01$. There was a significant association between a vision in the better eye (6/18 or better = 8, 6/18-6/60 = 8, 3/60 or worse 42 and QoL scores were ($\chi^2 = 95.36$, $df = 62$, $p < 0.01$). There was a significant relationship between socio-economic status and QoL domains, where $\chi^2 = 88.5$ $df = 56$, $p < 0.01$.

By performing Logistic binary regression to analyse the odds ratio (OR), it revealed that age, type of treatment, zone, family income, type of school, community, internet, gadgets, education of mother, education of father, literacy, BCVA RE, and QOL domains (physical, emotional, social, and school). As in where OR Value < 1 , on the 0.05 significance level. A significant QoL reduction was noticed among Rb affected children as per the parent perception compared to age-matched control group's parents, with an independent t-test P value < 0.005 . Additionally, a positive correlation exists between physical, emotional, and social functioning and school functioning. As per case parent observation, it implies that improvements in one domain may lead to improvements in the other domains.

Overall, individuals who had survived Rb reported lower scores in all psychosocial and physical health summaries compared to their controls and also their parents. However, the difference is minimal compared to parent-reported scores. This finding aligns with a study conducted in China (Zhang et al., 2018a) that assessed the QoL in children who underwent enucleation for Rb. However, Batra et al. (2016) documented the preservation of physical functioning in survivors of Rb, comparable to individuals without the condition. On the contrary, a study conducted by Dijk et al. (2007) in the Netherlands has reported HRQoL among RB survivors when compared to a reference group of Dutch individuals.

The purpose of the third objective is to gather and evaluate the available supporting schemes at the institute (CFS) and address them; based on the Semi-structured interview, as per the patient narratives, we have gathered the secondary data that are availing by the CFS Patient counsellors and the supporting scheme community, currently highlighting a few themes and unmet needs. Results based on the patient's financial status must vary per our semi-structured interview. The significant findings revealed that the study population, as per the Hospital and other Cankids norms, the study population with <20,000 INR family income can avail the incentive. There are four schemes available, including Government and NGO. As per the secondary data provided by the Cankids counsellor 17/86 of the study population availed the schemes, along with financial support, other subsequent burdens such as accommodation, food, and language, which are essential in every aspect of life, are taking a toll on caregivers of Rb patients' QoL(*Cankids Counsellor Interview*, personal communication, 2022).

Additionally, this objective intended to find repeating elements in the verbatim narratives offered by the parents of Rb survivors. Furthermore, using frequency and percentage, content analysis identified a hierarchical depiction of the primary challenges experienced by caregivers. Notably, emotional distress assessed includes global sorrow (5/5) at 100%, insomnia (60%/3/5), cognitive impairment (20%/1/5), difficulties focusing (20%/1/5), anxiety attacks (20%/1/5), and parental observations of rage issues in children (20%/1/5).

Alongside, parents or caregivers expressed financial troubles as their top concern, with a noteworthy frequency of 80% (4/5). Alongside this were obstacles like quitting work to take care of the kids at 40% (2/5), giving the kids extra attention at 40% (2/5), skipping doctor's appointments at 40% (2/5), having trouble finding housing while undergoing treatment at 20% (1/5), non-locals having trouble finding a job at 20% (1/5), and the challenging procedure of putting on and taking off an ocular prosthesis at 20% (1/5). Additionally, 20% (1/5) of parents

said that marriage and family problems prevented them from being able to provide for their children. Moreover, 20% (1/5) of the participants reported being a single parent or depending on patient / caregiver income.

The inference is that the three aforementioned objectives exhibit a correlation and interdependence, manifesting a complementary nature. The study aims to comprehensively elucidate the QoL experienced by Rb survivors residing in Hyderabad. Furthermore, it endeavours to contribute to developing interventions that can effectively enhance their QoL.

5.2 CONCLUSION:

The scoping review narrowed to 17 studies that met the inclusion criteria, indicating that most studies are rigorous and confirm that QoL is lower in Rb survivors. It also highlighted that the perspective of parents and children is important and that age, gender, treatment, region, and vision are significant factors influencing the evaluation of QoL. Another forthcoming aspect is that such studies must include psychological performance and educational and occupational outcomes. Subsequent research endeavours ought to investigate the broader dimensions of QoL, encompassing familial dynamics and economic effects, to comprehensively comprehend the obstacles that RB survivors and their families encounter. The findings of the pilot study indicated that the instrument of QoL measurement (Peds QL 4.0) was accepted and understood by the participants, especially the parents, thus making it a feasible tool for a more extensive study. As anticipated in this age group, the children required the assistance of parents and researchers. While a more comprehensive study is needed for interpretation, the trend indicates a lower QoL among the survivors and the perception of parents. This underscores the importance of providing relevant psychoeducation and counselling to both cases and parents before and after treatment.

The findings of the major study show that the QoL of parents of Rb survivors and self-proxy reports were negatively affected in many ways, including physical, social, emotional, and school-related dimensions. Despite the minor differences, self-proxy reports indicate a lower QoL than the parents' group. The study findings indicate notable correlations between enucleation, visual acuity less than 6/18, and socio-economic status, with various aspects of QoL domains among individuals who have survived Rb.

The study exploring the awareness on schemes of the Rb care in hospital through counsellors' interviews and parents/caregivers' narratives revealed that a limited number of parents/ caregivers were aware of the available schemes and supporting incentives. The Cankids program is an opportunity for patients with Rb from families with monthly income below 20,000 INR. Though, majority of the patients are eligible for this incentive, they often discover their eligibility for this incentive when they inquire about the scheme or when the counsellor identifies their financial status. There are also some remarkable incentives, such as the CM/PM relief fund, NGOs like IKSHA, and government and non-government cancer schemes. The hospital also provides awareness programs to the patients about the schemes/facilities available outside the hospital that notably offer a wide range of valuable resources, including disease diagnosis, information on social support, CM/PM relief funds, railway connections, blind certificates, ration support, pension scheme facilitation, education support, nutrition support, family therapy counselling, and parent support counselling. Some positive recommendations include seeking counselling at diagnosis, embracing self-awareness, patients' recovery process, and proactively planning for financial needs in later life.

Overall, the study provides vital insights into the field of paediatric oncology, particularly in patients with Rb with visual impairments. The study emphasizes the importance of conducting region-specific thorough examinations of QoL, recognizing the numerous obstacles survivors and their families encounter. The validation of the Peds QL 4.0 instrument

and a more nuanced understanding of its impact on survivors and parents lays the framework for future treatments. Furthermore, while the admirable Cankids program is essential, it requires increased awareness and accessibility. The study promotes an integrated strategy, highlighting the need for early counselling, self-awareness promotion, and ongoing psychological support for caregivers, ultimately enhancing holistic care in the paediatric cancer landscape.

CHAPTER 6

STUDY LIMITATION AND FUTURE SCOPE

6.1 FUTURE SCOPE:

The study findings have revealed that the emotional QoL (QoL) is likely to be affected after experiencing school and physical challenges. It highlights the need for continuous monitoring of physical and psychological well-being and the importance of financial planning for the future. In the future, optometrists and ophthalmologists will approach this case with a greater emphasis on clinical analysis rather than psychological interpretation. It opens up opportunities for exploring extensive research and developing psychological interventions within this field. At some point, caregivers of RB survivors will face additional challenges beyond financial support. The burdens of accommodation, food, and language, which are crucial for every aspect of life, will significantly impact their QoL. In the future, there will be a need for comprehensive studies on vision-related QoL (QoL) improvements. These studies will focus on enhancing the well-being and satisfaction of individuals with vision impairments.

Additionally, there will be a growing emphasis on understanding the impact of these improvements on the broader concept of health-related QoL. The Cankids program is an excellent opportunity for patients with Rb (RB) from families with an income below 20,000 INR. However, many patients become aware of this incentive when they inquire or when the counsellor identifies their financial status.

There are also helpful important incentives, such as the CM/PM relief fund, NGOs like IKSHA, and government cancer schemes! The program offers valuable resources and support, including information on social support, CM/PM relief funds, railway connections, blind certificates, ration support, pension scheme facilitation, education support, nutrition support,

family therapy counselling, and parent support counselling. As in future direction this education intervention how many approached these agencies to opt the financial help and increased utilization analysis to make better health policies accordingly. Some positive recommendations include seeking counselling at diagnosis, embracing self-awareness, and proactively planning for financial needs in later life.

6.2 STUDY LIMITATIONS:

One limitation of our study is the potential for selection bias, as we excluded participants who could not answer the questionnaire. Another drawback of this study is the use of age-matched controls, which may not fully account for potential differences in socio-economic and cultural environments between the survivors and controls. Additionally, including an equal number of controls may have introduced some variability. The downside of our study is that it primarily focused on younger patients, which means that we did not explore specific adolescent issues that may extend beyond the scope of the questionnaire. A disadvantage of this study is the limited sample size due to time constraints and COVID-19 protocols. The QoL associated with eyesight may lead to different conclusions; hence, we have solely utilized paediatric QoL data, which could be a future scope of the study.

BIBLIOGRAPHY

- 4 Reasons Why Your Emotional Health Is Equally Important To Physical Health.* (n.d.). Wake Counseling & Mediation. Retrieved November 26, 2022, from <https://www.wakecounseling.com/therapy-blog/emotional-health-is-equally-important-to-physical-health>
- About Mental Health.* (2021, November 23). <https://www.cdc.gov/mentalhealth/learn/index.htm>
- Abramson, D. H., Beaverson, K., Sangani, P., Vora, R. A., Lee, T. C., Hochberg, H. M., Kirsztrot, J., & Ranjithan, M. (2003). Screening for retinoblastoma: Presenting signs as prognosticators of patient and ocular survival. *Pediatrics*, 112(6 Pt 1), 1248–1255. <https://doi.org/10.1542/peds.112.6.1248>
- Abramson, D. H., Fabius, A. W. M., Issa, R., Francis, J. H., Marr, B. P., Dunkel, I. J., & Gobin, Y. P. (2015). Advanced Unilateral Retinoblastoma: The Impact of Ophthalmic Artery Chemosurgery on Enucleation Rate and Patient Survival at MSKCC. *PLoS ONE*, 10(12), e0145436. <https://doi.org/10.1371/journal.pone.0145436>
- Ahuja, S., Sharma, J., Gupta, S., Bakhshi, S., Seth, R., Singh, A., Bagai, P., & Arora, R. (2021). Patient tracking during treatment of children with cancer in India – An exploratory study. *Cancer Reports*, 5(6), e1359. <https://doi.org/10.1002/cnr2.1359>
- Al Qahtani, M., AlMasfer, S., & Khandekar, R. (2022). Health related quality of life of patients treated with bilateral enucleation for retinoblastoma. *European Journal of Ophthalmology*, 32(4), 1960–1965. <https://doi.org/10.1177/11206721211035637>
- Alessi, D., Dama, E., Barr, R., Mosso, M. L., Maule, M., Magnani, C., Pastore, G., & Merletti, F. (2007). Health-related quality of life of long-term childhood cancer survivors: A population-based study from the Childhood Cancer Registry of Piedmont, Italy. *European Journal of Cancer (Oxford, England: 1990)*, 43(17), 2545–2552. <https://doi.org/10.1016/j.ejca.2007.07.026>

- Ancona-Lezama, D., Dalvin, L. A., & Shields, C. L. (2020). Modern treatment of retinoblastoma: A 2020 review. *Indian Journal of Ophthalmology*, 68(11), 2356–2365. https://doi.org/10.4103/ijo.IJO_721_20
- Banerjee, S. C., Pottenger, E., Petriccione, M., Chou, J. F., Ford, J. S., Sklar, C. A., Robison, L. L., Kleinerman, R. A., Oeffinger, K. C., Francis, J. H., Abramson, D. H., Dunkel, I. J., & Friedman, D. N. (2020a). Impact of enucleation on adult retinoblastoma survivors' quality of life: A qualitative study of survivors' perspectives. *Palliative & Supportive Care*, 18(3), 322–331. <https://doi.org/10.1017/S1478951519000920>
- Banerjee, S. C., Pottenger, E., Petriccione, M., Chou, J. F., Ford, J. S., Sklar, C. A., Robison, L. L., Kleinerman, R. A., Oeffinger, K. C., Francis, J. H., Abramson, D. H., Dunkel, I. J., & Friedman, D. N. (2020b). Impact of enucleation on adult retinoblastoma survivors' quality of life: A qualitative study of survivors' perspectives. *Palliative & Supportive Care*, 18(3), 322–331. <https://doi.org/10.1017/S1478951519000920>
- Batra, A., Kain, R., Kumari, M., Paul, R., Dhawan, D., & Bakhshi, S. (2016). Parents' Perspective of Quality of Life of Retinoblastoma Survivors. *Pediatric Blood & Cancer*, 63(7), 1287–1289. <https://doi.org/10.1002/pbc.25982>
- Batra, A., Kumari, M., Paul, R., Patekar, M., Dhawan, D., & Bakhshi, S. (2016). Quality of Life Assessment in Retinoblastoma: A Cross-Sectional Study of 122 Survivors from India. *Pediatric Blood & Cancer*, 63(2), 313–317. <https://doi.org/10.1002/pbc.25781>
- Beddard, N., McGeechan, G. J., Taylor, J., & Swainston, K. (2020). Childhood eye cancer from a parental perspective: The lived experience of parents with children who have had retinoblastoma. *European Journal of Cancer Care*, 29(2), e13209. <https://doi.org/10.1111/ecc.13209>
- Belson, P. (2021). *Health-Related Quality of Life in Adolescent and Young Adult Retinoblastoma Survivors* [UCLA]. <https://escholarship.org/uc/item/84s1g03x>
- Belson, P. J., Eastwood, J.-A., Brecht, M.-L., Hays, R. D., & Pike, N. A. (2020). A Review of Literature on Health-Related Quality of Life of Retinoblastoma Survivors. *Journal of Pediatric Oncology Nursing*, 37(2), 116–127. <https://doi.org/10.1177/1043454219888805>

- Belson, P. J., Eastwood, J.-A., Brecht, M.-L., Kim, J. W., Hays, R. D., & Pike, N. A. (2022). Health-Related Quality of Life in Adolescent and Young Adult Retinoblastoma Survivors. *Journal of Pediatric Hematology/Oncology Nursing*, 27527530221073766. <https://doi.org/10.1177/27527530221073766>
- Bisht, S., Chawla, B., Tolahunase, M., Mishra, R., & Dada, R. (2019a). Impact of yoga based lifestyle intervention on psychological stress and quality of life in the parents of children with retinoblastoma. *Annals of Neurosciences*, 26(2), 66–74. <https://doi.org/10.5214/ans.0972.7531.260206>
- Bisht, S., Chawla, B., Tolahunase, M., Mishra, R., & Dada, R. (2019b). Impact of yoga based lifestyle intervention on psychological stress and quality of life in the parents of children with retinoblastoma. *Annals of Neurosciences*, 26(2), 66–74. <https://doi.org/10.5214/ans.0972.7531.260206>
- Braam, K. I., van Dijk-Lokkart, E. M., Kaspers, G. J. L., Takken, T., Huisman, J., Buffart, L. M., Bierings, M. B., Merks, J. H. M., van den Heuvel-Eibrink, M. M., Veening, M. A., & van Dulmen-den Broeder, E. (2018). Effects of a combined physical and psychosocial training for children with cancer: A randomized controlled trial. *BMC Cancer*, 18(1), 1289. <https://doi.org/10.1186/s12885-018-5181-0>
- Byrnes, M., Lichtenberg, P. A., & Lysack, C. (2006). Environmental Press, Aging in Place, and Residential Satisfaction of Urban Older Adults. *Journal of Applied Sociology*, 23(2), 50–76. <https://www.jstor.org/stable/43736134>
- Cancer Prevention Overview (PDQ®)–Patient Version—NCI (nciglobal,ncienterprise)*. (2009, June 22). [pdqCancerInfoSummary]. <https://www.cancer.gov/about-cancer/causes-prevention/patient-prevention-overview-pdq>
- CAPP, K. M., BA. (2020, March 6). *What Is Emotional Health? (+ 11 Activities & Examples)*. PositivePsychology.Com. <https://positivepsychology.com/emotional-health-activities/>
- Caspersen, C. J., Powell, K. E., & Christenson, G. M. (1985). Physical activity, exercise, and physical fitness: Definitions and distinctions for health-related research. *Public Health Reports (Washington, D.C.: 1974)*, 100(2), 126–131.

- Challenges of Retinoblastoma management at a Nigerian tertiary eyecare facility.* (n.d.). Retrieved January 19, 2023, from <https://ir.unilag.edu.ng/items/464f2bc8-4d73-4dba-b985-35e5c27c1dfc>
- Chawla, B., Jain, A., & Azad, R. (2013). Conservative treatment modalities in retinoblastoma. *Indian Journal of Ophthalmology*, 61(9), 479. <https://doi.org/10.4103/0301-4738.119424>
- Classification and staging of retinoblastoma—PMC.* (n.d.). Retrieved November 30, 2022, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5998397/>
- Contributors, W. E. (n.d.). *What to Know About Emotional Health.* WebMD. Retrieved November 27, 2022, from <https://www.webmd.com/balance/what-to-know-about-emotional-health>
- Cummins, R. (n.d.). *Beyond Rural Health to Well- Being: An Appraisal of the Comprehensive Quality of Life Scale—Fifth Edition.*
- Cummins—Beyond Rural Health to Well- Being An Appraisal o.pdf.* (n.d.). Retrieved December 16, 2023, from https://www.ruralhealth.org.au/PAPERS/5_fifth.pdf
- Definition, Measures, Applications, & Facts | Britannica.* (2022). <https://www.britannica.com/topic/quality-of-life>
- Definition of retinoblastoma—NCI Dictionary of Cancer Terms—NCI* (nciglobal,ncienterprise). (2011, February 2). [nciAppModulePage]. <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/retinoblastoma>
- Demark-Wahnefried, W., Pinto, B. M., & Gritz, E. R. (2006). Promoting health and physical function among cancer survivors: Potential for prevention and questions that remain. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, 24(32), 5125–5131. <https://doi.org/10.1200/JCO.2006.06.6175>
- Dhingra, H., Arya, D., Taluja, A., Das, S., & Mahajan, A. (2021a). A study analyzing the health-related quality of life of retinoblastoma survivors in India. *Indian Journal of Ophthalmology*, 69(6), 1482–1486. https://doi.org/10.4103/ijo.IJO_2428_20

- Dhingra, H., Arya, D., Taluja, A., Das, S., & Mahajan, A. (2021b). A study analyzing the health-related quality of life of retinoblastoma survivors in India. *Indian Journal of Ophthalmology*, 69(6), 1482–1486. https://doi.org/10.4103/ijo.IJO_2428_20
- Diener, E., & Biswas-Diener, R. (2002). Will Money Increase Subjective Well-Being? *Social Indicators Research*, 57(2), 119–169. <https://doi.org/10.1023/A:1014411319119>
- Dimaras, H. (2015). Retinoblastoma genetics in India: From research to implementation. *Indian Journal of Ophthalmology*, 63(3), 219–226. <https://doi.org/10.4103/0301-4738.156917>
- Dimaras, H., Corson, T. W., Cobrinik, D., White, A., Zhao, J., Munier, F. L., Abramson, D. H., Shields, C. L., Chantada, G. L., Njuguna, F., & Gallie, B. L. (2015). Retinoblastoma. *Nature Reviews. Disease Primers*, 1, 15021. <https://doi.org/10.1038/nrdp.2015.21>
- Dimaras, H., Kimani, K., Dimba, E. A., Gronsdahl, P., White, A., Chan, H. S., & Gallie, B. L. (2012a). Retinoblastoma. *The Lancet*, 379(9824), 1436–1446. [https://doi.org/10.1016/S0140-6736\(11\)61137-9](https://doi.org/10.1016/S0140-6736(11)61137-9)
- Dimaras, H., Kimani, K., Dimba, E. A. O., Gronsdahl, P., White, A., Chan, H. S. L., & Gallie, B. L. (2012b). Retinoblastoma. *Lancet (London, England)*, 379(9824), 1436–1446. [https://doi.org/10.1016/S0140-6736\(11\)61137-9](https://doi.org/10.1016/S0140-6736(11)61137-9)
- Epocrates Web. (n.d.). Retrieved October 9, 2022, from <https://online.epocrates.com/u/29111055/Retinoblastoma/Summary/Highlights>
- Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, 16(1), 51–74. [https://doi.org/10.1016/0891-4222\(94\)00028-8](https://doi.org/10.1016/0891-4222(94)00028-8)
- Ferrans, C. E., & Powers, M. J. (1985). Quality of life index: Development and psychometric properties. *ANS. Advances in Nursing Science*, 8(1), 15–24. <https://doi.org/10.1097/00012272-198510000-00005>
- Ford, J. S., Chou, J. F., Sklar, C. A., Oeffinger, K. C., Novetsky Friedman, D., McCabe, M., Robison, L. L., Kleinerman, R. A., Li, Y., Marr, B. P., Abramson, D. H., & Dunkel, I. J. (2015). Psychosocial Outcomes in Adult Survivors of Retinoblastoma. *Journal of*

Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 33(31), 3608–3614. <https://doi.org/10.1200/JCO.2014.60.5733>

Friedman, D. N., Chou, J. F., Francis, J. H., Sklar, C. A., Li, Y., McCabe, M., Robison, L. L., Kleinerman, R. A., Oeffinger, K. C., Abramson, D. H., Dunkel, I. J., & Ford, J. S. (2018). Vision-Targeted Health-Related Quality of Life in Adult Survivors of Retinoblastoma. *JAMA Ophthalmology*, 136(6), 637–641. <https://doi.org/10.1001/jamaophthalmol.2018.1082>

Friedman, D. N., Chou, J. F., Oeffinger, K. C., Kleinerman, R. A., Ford, J. S., Sklar, C. A., Li, Y., McCabe, M. S., Robison, L. L., Marr, B. P., Abramson, D. H., & Dunkel, I. J. (2016). Chronic medical conditions in adult survivors of retinoblastoma: Results of the Retinoblastoma Survivor Study. *Cancer*, 122(5), 773–781. <https://doi.org/10.1002/cncr.29704>

Friend, A. J., Feltbower, R. G., Hughes, E. J., Dye, K. P., & Glaser, A. W. (2018). Mental health of long-term survivors of childhood and young adult cancer: A systematic review. *International Journal of Cancer*, 143(6), 1279–1286. <https://doi.org/10.1002/ijc.31337>

Garza-Garza, L. A., Ruiz-Lozano, R. E., Rebolledo-Méndez, G., Ibarra-Nava, I., Morales-Garza, H. J., & Ancona-Lezama, D. (2020). Challenge of Retinoblastoma in Mexico in 2020: Perspectives and Solutions. *Journal of Ophthalmology*, 2020, 1953602. <https://doi.org/10.1155/2020/1953602>

Global Burden of Disease Cancer Collaboration, Fitzmaurice, C., Abate, D., Abbasi, N., Abbastabar, H., Abd-Allah, F., Abdel-Rahman, O., Abdelalim, A., Abdoli, A., Abdollahpour, I., Abdulle, A. S. M., Abebe, N. D., Abraha, H. N., Abu-Raddad, L. J., Abualhasan, A., Adedeji, I. A., Advani, S. M., Afarideh, M., Afshari, M., ... Murray, C. J. L. (2019). Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2017: A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncology*, 5(12), 1749–1768. <https://doi.org/10.1001/jamaoncol.2019.2996>

Global Disparities in Childhood Retinoblastoma—NCI (nciglobal,ncienterprise). (2020, March 12). [cgvBlogPost]. <https://www.cancer.gov/news-events/cancer-currents-blog/2020/retinoblastoma-global-disparities-low-middle-income-countries>

- Gottlieb, M., Haas, M. R. C., Daniel, M., & Chan, T. M. (2021). The scoping review: A flexible, inclusive, and iterative approach to knowledge synthesis. *AEM Education and Training*, 5(3), e10609. <https://doi.org/10.1002/aet2.10609>
- Götze, H., Friedrich, M., Taubenheim, S., Dietz, A., Lordick, F., & Mehnert, A. (2020). Depression and anxiety in long-term survivors 5 and 10 years after cancer diagnosis. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 28(1), 211–220. <https://doi.org/10.1007/s00520-019-04805-1>
- Gu, X., Xie, M., Jia, R., & Ge, S. (2021). Publication Trends of Research on Retinoblastoma During 2001–2021: A 20-Year Bibliometric Analysis. *Frontiers in Medicine*, 8, 675703. <https://doi.org/10.3389/fmed.2021.675703>
- Gupta, N., Pandey, A., Dimri, K., & Prinja, S. (2020). Epidemiological profile of retinoblastoma in North India: Implications for primary care and family physicians. *Journal of Family Medicine and Primary Care*, 9(6), 2843–2848. https://doi.org/10.4103/jfmmpc.jfmmpc_265_20
- Hallal, P. C., Victora, C. G., Azevedo, M. R., & Wells, J. C. K. (2006). Adolescent physical activity and health: A systematic review. *Sports Medicine (Auckland, N.Z.)*, 36(12), 1019–1030. <https://doi.org/10.2165/00007256-200636120-00003>
- Haraldstad, K., Wahl, A., Andenæs, R., Andersen, J. R., Andersen, M. H., Beisland, E., Borge, C. R., Engebretsen, E., Eisemann, M., Halvorsrud, L., Hanssen, T. A., Haugstvedt, A., Haugland, T., Johansen, V. A., Larsen, M. H., Løvereide, L., Løyland, B., Kvarme, L. G., Moons, P., ... LIVSFORSK network. (2019). A systematic review of quality of life research in medicine and health sciences. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, 28(10), 2641–2650. <https://doi.org/10.1007/s11136-019-02214-9>
- Harandi, T. F., Taghinasab, M. M., & Nayeri, T. D. (2017). The correlation of social support with mental health: A meta-analysis. *Electronic Physician*, 9(9), 5212–5222. <https://doi.org/10.19082/5212>

Hardavella, G., Aamli-Gagnat, A., Frille, A., Saad, N., Niculescu, A., & Powell, P. (2017). Top tips to deal with challenging situations: Doctor–patient interactions. *Breathe*, 13(2), 129–135. <https://doi.org/10.1183/20734735.006616>

<https://www.cdc.gov/hrqol/concept.htm>. (n.d.).

Inhestern, L., Beierlein, V., Bultmann, J. C., Möller, B., Romer, G., Koch, U., & Bergelt, C. (2017). Anxiety and depression in working-age cancer survivors: A register-based study. *BMC Cancer*, 17(1), 347. <https://doi.org/10.1186/s12885-017-3347-9>

Jain, M., Rojanaporn, D., Chawla, B., Sundar, G., Gopal, L., & Khetan, V. (2019). Retinoblastoma in Asia. *Eye*, 33(1), 87–96. <https://doi.org/10.1038/s41433-018-0244-7>

Janic, A., Bowden, S., Levy, S., Stinson, J., & Dimaras, H. (2020). Patient-reported outcome measures for retinoblastoma: A scoping review. *Journal of Patient-Reported Outcomes*, 4, 66. <https://doi.org/10.1186/s41687-020-00232-7>

Janic, A., Vincent, A., Stinson, J., & Dimaras, H. (2022). Values of Retinoblastoma Survivors and Parents Regarding Treatment Outcomes: A Qualitative Study. *JCO Oncology Practice*, 18(6), e1000–e1015. <https://doi.org/10.1200/OP.21.00474>

Jehp112.pdf. (n.d.). Retrieved November 30, 2022, from <https://ncert.nic.in/textbook/pdf/jehp112.pdf>

Jenkinson, C. (2020, May 6). *Quality of life*. *Encyclopedia Britannica*. <https://www.britannica.com/topic/quality-of-life>. (2020).

Jocelyn Rivera-Alvarado, I., Rodriguez-Garcia, A., Rodriguez Gutierrez, L., & Larrazabal, L. (2018). *Diagnosis and Management of Retinoblastoma*. <https://doi.org/10.13140/RG.2.2.30827.23849>

Karimi, M., & Brazier, J. (2016). Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *PharmacoEconomics*, 34(7), 645–649. <https://doi.org/10.1007/s40273-016-0389-9>

KHORRAMI-NEJAD, M., SARABANDI, A., AKBARI, M.-R., & ASKARIZADEH, F. (2016). The Impact of Visual Impairment on Quality of Life. *Medical Hypothesis*,

Discovery and Innovation in Ophthalmology, 5(3), 96–103.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5347211/>

- Kivelä, T. (2009). The epidemiological challenge of the most frequent eye cancer: Retinoblastoma, an issue of birth and death. *The British Journal of Ophthalmology*, 93(9), 1129–1131. <https://doi.org/10.1136/bjo.2008.150292>
- Korn, A. R., Walsh-Bailey, C., Pilar, M., Sandler, B., Bhattacharjee, P., Moore, W. T., Brownson, R. C., Emmons, K. M., & Oh, A. Y. (2022). Social determinants of health and cancer screening implementation and outcomes in the USA: A systematic review protocol. *Systematic Reviews*, 11(1), 117. <https://doi.org/10.1186/s13643-022-01995-4>
- Künkele, A., Wilm, J., Holdt, M., Lohmann, D., Bornfeld, N., Eggert, A., Temming, P., & Schulte, J. H. (2015a). Neoadjuvant/adjuvant treatment of high-risk retinoblastoma: A report from the German Retinoblastoma Referral Centre. *British Journal of Ophthalmology*, 99(7), 949–953. <https://doi.org/10.1136/bjophthalmol-2014-306222>
- Künkele, A., Wilm, J., Holdt, M., Lohmann, D., Bornfeld, N., Eggert, A., Temming, P., & Schulte, J. H. (2015b). Neoadjuvant/adjuvant treatment of high-risk retinoblastoma: A report from the German Retinoblastoma Referral Centre. *British Journal of Ophthalmology*, 99(7), 949–953. <https://doi.org/10.1136/bjophthalmol-2014-306222>
- Langeveld, N. E., Stam, H., Grootenhuys, M. A., & Last, B. F. (2002). Quality of life in young adult survivors of childhood cancer. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 10(8), 579–600. <https://doi.org/10.1007/s00520-002-0388-6>
- MacCarthy, A., Birch, J. M., Draper, G. J., Hungerford, J. L., Kingston, J. E., Kroll, M. E., Onadim, Z., Stiller, C. A., Vincent, T. J., & Murphy, M. F. G. (2009). Retinoblastoma in Great Britain 1963-2002. *The British Journal of Ophthalmology*, 93(1), 33–37. <https://doi.org/10.1136/bjo.2008.139618>
- Mental health*. (n.d.). Retrieved November 26, 2022, from <https://www.who.int/health-topics/mental-health>
- Mental health equity and creating an accessible system | Deloitte Insights*. (n.d.). Retrieved September 29, 2023, from <https://www.deloitte.com/global/en/our->

thinking/insights/industry/government-public-services/mental-health-equity-and-creating-an-accessible-system.html

- Moayed, M. S., Heidarani, E., & Parandeh, A. (2021). Care needs and preferences from the perspective of COVID-19 patients: A qualitative study. *Medical Journal of the Islamic Republic of Iran*, 35, 64. <https://doi.org/10.47176/mjiri.35.64>
- National Academies of Sciences, E., Division, H. and M., Practice, B. on P. H. and P. H., Health, C. on P. H. A. to R. V. I. and P. E., Welp, A., Woodbury, R. B., McCoy, M. A., & Teutsch, S. M. (2016). The Impact of Vision Loss. In *Making Eye Health a Population Health Imperative: Vision for Tomorrow*. National Academies Press (US). <https://www.ncbi.nlm.nih.gov/books/NBK402367/>
- Nicolussi, A. C., Sawada, N. O., Cardozo, F. M. C., Andrade, V., & Paula, J. M. de. (2014). Health-related quality of life of cancer patients undergoing chemotherapy. *Revista Da Rede de Enfermagem Do Nordeste*, 15(1). <https://doi.org/10.15253/2175-6783.2014000100017>
- Nussbaum, M. C., & Sen, A. (1993). *The Quality of Life*. Oxford University Press.
- Nussbaum_women_capabilityapproach2000.pdf*. (n.d.). Retrieved December 16, 2023, from https://genderbudgeting.files.wordpress.com/2012/12/nussbaum_women_capabilityapproach2000.pdf
- Padamandala, K., G Honavar, S., Bansal, R., Prasad M, S. D., Gadiraju, P., & K Vemuganti, G. (2023). Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. *Journal of Cancer Science and Clinical Therapeutics*, 07(02). <https://doi.org/10.26502/jcsct.5079202>
- Panesar, S. S., Thakrar, R., Athanasiou, T., & Sheikh, A. (2006). Comparison of reports of randomized controlled trials and systematic reviews in surgical journals: Literature review. *Journal of the Royal Society of Medicine*, 99(9), 470–472. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1557878/>
- Physical activity*. (n.d.). Retrieved November 26, 2022, from <https://www.who.int/health-topics/physical-activity>

Prevalence vs impact: A mixed methods study of survivorship issues in colorectal cancer | SpringerLink. (n.d.). Retrieved April 5, 2023, from <https://link.springer.com/article/10.1007/s11136-021-02975-2>

Pucci, G. C. M. F., Rech, C. R., Fermino, R. C., & Reis, R. S. (2012). Association between physical activity and quality of life in adults. *Revista De Saude Publica*, 46(1), 166–179. <https://doi.org/10.1590/s0034-89102012000100021>

Quality of life indicators—Measuring quality of life—Statistics Explained. (2022). https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Quality_of_life_indicators_-_measuring_quality_of_life

Rajeshuni, N., Whittemore, A. S., Ludwig, C. A., Mruthyunjaya, P., & Moshfeghi, D. M. (2019). Racial, Ethnic, and Socioeconomic Disparities in Retinoblastoma Enucleation: A Population-Based Study, SEER 18 2000-2014. *American Journal of Ophthalmology*, 207, 215–223. <https://doi.org/10.1016/j.ajo.2019.04.015>

Rangamani, S., SathishKumar, K., Manoharan, N., Julka, P. K., Rath, G. K., Shanta, V., Swaminathan, R., Rama, R., Datta, K., Mandal, S., Koyande, S., Deshmane, V., Ganesh, B., Banavali, S. D., Badwe, R. A., Ramesh, C., Appaji, L., & Nandakumar, A. (2015). Paediatric retinoblastoma in India: Evidence from the National Cancer Registry Programme. *Asian Pacific Journal of Cancer Prevention: APJCP*, 16(10), 4193–4198. <https://doi.org/10.7314/apjcp.2015.16.10.4193>

Retinoblastoma | *Nature Reviews Disease Primers*. (n.d.). Retrieved December 2, 2022, from <https://www.nature.com/articles/nrdp201521>

Retinoblastoma: A comprehensive review—Scientific Figure on ResearchGate. Available from: https://www.researchgate.net/figure/Common-presenting-features-of-retinoblastoma_tbl1_316624641 [accessed 1 Dec, 2022]. (n.d.).

Retinoblastoma: Overview and More. (n.d.). Verywell Health. Retrieved December 1, 2022, from <https://www.verywellhealth.com/retinoblastoma-5210489>

Retinoblastoma Treatment (PDQ®)—Patient Version—NCI (nciglobal,ncienterprise). (2022, December 2). [pdqCancerInfoSummary]. <https://www.cancer.gov/types/retinoblastoma/patient/retinoblastoma-treatment-pdq>

retinoblastoma—Definition | *OpenMD.com*. (n.d.). Retrieved December 3, 2021, from <https://openmd.com/define/retinoblastoma>

Retinoblastoma—PubMed. (n.d.). Retrieved December 3, 2021, from <https://pubmed.ncbi.nlm.nih.gov/28620731/>

Retinoblastoma—Symptoms and causes. (n.d.). Mayo Clinic. Retrieved April 5, 2023, from <https://www.mayoclinic.org/diseases-conditions/retinoblastoma/symptoms-causes/syc-20351008>

Rodriguez-Galindo, C., Wilson, M. W., Chantada, G., Fu, L., Qaddoumi, I., Antoneli, C., Leal-Leal, C., Sharma, T., Barnoya, M., Epelman, S., Pizzarello, L., Kane, J. R., Barfield, R., Merchant, T. E., Robison, L. L., Murphree, A. L., Chevez-Barrios, P., Dyer, M. A., O'Brien, J., ... Wilimas, J. (2008). Retinoblastoma: One World, One Vision. *Pediatrics*, 122(3), e763–e770. <https://doi.org/10.1542/peds.2008-0518>

Salibasic, M., & Delibegovic, S. (2018). The Quality of Life and Degree of Depression of Patients Suffering from Breast Cancer. *Medical Archives*, 72(3), 202. <https://doi.org/10.5455/medarh.2018.72.202-205>

Saracci, R. (1997). The World Health Organisation needs to reconsider its definition of health. *BMJ (Clinical Research Ed.)*, 314(7091), 1409–1410. <https://doi.org/10.1136/bmj.314.7091.1409>

says, V. S. (2009, December 2). *Cancer History*. News-Medical.Net. <https://www.news-medical.net/health/Cancer-History.aspx>

Selistre, S. G. A., Maestri, M. K., Santos-Silva, P., Schöler-Faccini, L., Guimarães, L. S. P., Giacomazzi, J., Evangelista Júnior, M. C., & Ashton-Prolla, P. (2016). Retinoblastoma in a pediatric oncology reference center in Southern Brazil. *BMC Pediatrics*, 16(1), 48. <https://doi.org/10.1186/s12887-016-0579-9>

Seth, R., Singh, A., Guru, V., Chawla, B., Pathy, S., & Sapra, S. (2017). Long-term follow-up of retinoblastoma survivors: Experience from India. *South Asian Journal of Cancer*, 6(4), 176–179. https://doi.org/10.4103/sajc.sajc_179_16

- Shields, C. L., & Shields, J. A. (2004). Diagnosis and management of retinoblastoma. *Cancer Control: Journal of the Moffitt Cancer Center*, 11(5), 317–327. <https://doi.org/10.1177/107327480401100506>
- Shields, C. L., & Shields, J. A. (2010). Retinoblastoma management: Advances in enucleation, intravenous chemoreduction, and intra-arterial chemotherapy. *Current Opinion in Ophthalmology*, 21(3), 203–212. <https://doi.org/10.1097/ICU.0b013e328338676a>
- Shrestha, A., Martin, C., Burton, M., Walters, S., Collins, K., & Wyld, L. (2019). Quality of life versus length of life considerations in cancer patients: A systematic literature review. *Psycho-Oncology*, 28(7), 1367–1380. <https://doi.org/10.1002/pon.5054>
- Signs and Symptoms of Retinoblastoma*. (n.d.). Retrieved December 1, 2022, from <https://www.cancer.org/cancer/retinoblastoma/detection-diagnosis-staging/signs-and-symptoms.html>
- Sm, L., Gj, W., Et, B., Pm, ten K., & Cl, K. (2011). Evaluating the psychometric properties of the Mental Health Continuum-Short Form (MHC-SF). *Journal of Clinical Psychology*, 67(1). <https://doi.org/10.1002/jclp.20741>
- Soliman, S. E., Dimaras, H., Souka, A. A., Ashry, M. H., & Gallie, B. L. (2015). Socioeconomic and psychological impact of treatment for unilateral intraocular retinoblastoma. *Journal Francais D'ophthalmologie*, 38(6), 550–558. <https://doi.org/10.1016/j.jfo.2015.03.003>
- Tests for Retinoblastoma*. (n.d.). Retrieved December 1, 2022, from <https://www.cancer.org/cancer/retinoblastoma/detection-diagnosis-staging/how-diagnosed.html>
- Tests for Retinoblastoma | National Eye Institute*. (n.d.). Retrieved December 1, 2022, from <https://www.nei.nih.gov/learn-about-eye-health/eye-conditions-and-diseases/retinoblastoma/tests-retinoblastoma>
- The Global Retinoblastoma Outcome Study: A prospective, cluster-based analysis of 4064 patients from 149 countries. (2022a). *The Lancet. Global Health*, 10(8), e1128–e1140. [https://doi.org/10.1016/S2214-109X\(22\)00250-9](https://doi.org/10.1016/S2214-109X(22)00250-9)

- The Global Retinoblastoma Outcome Study: A prospective, cluster-based analysis of 4064 patients from 149 countries. (2022b). *The Lancet. Global Health*, 10(8), e1128–e1140. [https://doi.org/10.1016/S2214-109X\(22\)00250-9](https://doi.org/10.1016/S2214-109X(22)00250-9)
- The Will to Live | Surviving Cancer | Stanford Medicine*. (n.d.). Retrieved April 5, 2023, from <https://med.stanford.edu/survivingcancer/cancers-existential-questions/cancer-will-to-live.html>
- The World Health Organization Quality of Life assessment (WHOQOL): Position paper from the World Health Organization. (1995). *Social Science & Medicine* (1982), 41(10), 1403–1409. [https://doi.org/10.1016/0277-9536\(95\)00112-k](https://doi.org/10.1016/0277-9536(95)00112-k)
- Truong, B., Green, A. L., Friedrich, P., Ribeiro, K. B., & Rodriguez-Galindo, C. (2015). Ethnic, Racial, and Socioeconomic Disparities in Retinoblastoma. *JAMA Pediatrics*, 169(12), 1096–1104. <https://doi.org/10.1001/jamapediatrics.2015.2360>
- Values of Retinoblastoma Survivors and Parents Regarding Treatment Outcomes: A Qualitative Study | JCO Oncology Practice*. (n.d.). Retrieved October 4, 2023, from <https://ascopubs.org/doi/full/10.1200/OP.21.00474>
- van Dijk, J., Huisman, J., Moll, A. C., Schouten-van Meeteren, A. Y., Bezemer, P. D., Ringens, P. J., Cohen-Kettenis, P. T., & Imhof, S. M. (2007). Health-related quality of life of child and adolescent retinoblastoma survivors in the Netherlands. *Health and Quality of Life Outcomes*, 5(1), 65. <https://doi.org/10.1186/1477-7525-5-65>
- van Dijk, J., Imhof, S. M., Moll, A. C., Ringens, P. J., Cohen-Kettenis, P. T., Rijmen, F., & Huisman, J. (2007). Quality of life of adult retinoblastoma survivors in the Netherlands. *Health and Quality of Life Outcomes*, 5, 30. <https://doi.org/10.1186/1477-7525-5-30>
- van Dijk, J., Oostrom, K. J., Huisman, J., Moll, A. C., Cohen-Kettenis, P. T., Ringens, P. J., & Imhof, S. M. (2010). Restrictions in daily life after retinoblastoma from the perspective of the survivors. *Pediatric Blood & Cancer*, 54(1), 110–115. <https://doi.org/10.1002/pbc.22230>
- Varni, J. W., Burwinkle, T. M., & Lane, M. M. (2005). Health-related quality of life measurement in pediatric clinical practice: An appraisal and precept for future research

- and application. *Health and Quality of Life Outcomes*, 3, 34. <https://doi.org/10.1186/1477-7525-3-34>
- Vikaspedia Domains*. (n.d.). Retrieved November 30, 2022, from <https://vikaspedia.in/education/policies-and-schemes/operational-guidelines-on-school-health-programme>
- Villegas, V. M., Hess, D. J., Wildner, A., Gold, A. S., & Murray, T. G. (2013). Retinoblastoma. *Current Opinion in Ophthalmology*, 24(6), 581–588. <https://doi.org/10.1097/ICU.0000000000000002>
- Vm, V., Dj, H., A, W., As, G., & Tg, M. (2013). Retinoblastoma. *Current Opinion in Ophthalmology*, 24(6). <https://doi.org/10.1097/ICU.0000000000000002>
- Waterman, A. S. (1993). Two conceptions of happiness: Contrasts of personal expressiveness (eudaimonia) and hedonic enjoyment. *Journal of Personality and Social Psychology*, 64, 678–691. <https://doi.org/10.1037/0022-3514.64.4.678>
- Weintraub, N., Reshef, N., Pe'er, J., Frenkel, S., Rot, I., Shoshani, N., & Weintraub, M. (2019). The impact of monocular vision on motor function and quality of life in survivors of retinoblastoma. *Pediatric Blood & Cancer*, 66(5), e27623. <https://doi.org/10.1002/pbc.27623>
- Wengenroth, L., Gianinazzi, M. E., Rueegg, C. S., Lüer, S., Bergstraesser, E., Kuehni, C. E., & Michel, G. (2015). Health-related quality of life in young survivors of childhood cancer. *Quality of Life Research*, 24(9), 2151–2161. <https://doi.org/10.1007/s11136-015-0961-3>
- What Is Quality of Life? Why It's Important and How to Improve It*. (2022). Investopedia. <https://www.investopedia.com/terms/q/quality-of-life.asp>
- What is School Health – ASHA*. (n.d.). Retrieved December 2, 2022, from <https://www.ashaweb.org/what-is-school-health/>
- WHO guideline on school health services*. (n.d.). Retrieved November 30, 2022, from <https://www.who.int/publications-detail-redirect/9789240029392>

WHOQOL - Measuring Quality of Life | *The World Health Organization*. (2023).
<https://www.who.int/tools/whoqol>

Why is Social Wellness Important? | Student Life | University of Nebraska Omaha. (n.d.).
Retrieved November 29, 2022, from <https://www.unomaha.edu/student-life/presidents-wellness-committee/social-wellness.php>

Wiley, J. F., Laird, K., Beran, T., McCannel, T. A., & Stanton, A. L. (2013). Quality of Life and Cancer-Related Needs in Patients with Choroidal Melanoma. *The British Journal of Ophthalmology*, 97(11), 10.1136/bjophthalmol-2013-303635.
<https://doi.org/10.1136/bjophthalmol-2013-303635>

Wright, H. (n.d.). *A Thesis Presented to the Faculty of California State University, Stanislaus*.

Zhang, L., Gao, T., & Shen, Y. (2018a). Quality of life in children with retinoblastoma after enucleation in China. *Pediatric Blood & Cancer*, 65(7), e27024.
<https://doi.org/10.1002/pbc.27024>

Zhang, L., Gao, T., & Shen, Y. (2018b). Quality of life in children with retinoblastoma after enucleation in China. *Pediatric Blood & Cancer*, 65(7), e27024.
<https://doi.org/10.1002/pbc.27024>

APPENDIX I IEC APPROVAL



UNIVERSITY OF HYDERABAD INSTITUTIONAL ETHICS COMMITTEE DECISION LETTER



IEC No.			
Application No:	UH/IEC/2021/146	Date of review	26-08-2021
Project Title:	Quality of life in Retinoblastoma Survivors in India: QL-RB-India study		
Principal Investigator/ Co-PI:	PI: Padamandala Krishnasri CI: Prof. Geeta K. Vemuganti, Dr. Santosh G Honavar and Dr. M. Surya Durga Prasad		
Participating Institutes if any	----	Approval from Participating Institute	----
Documents received and reviewed	Protocol & ICF		
In case of renewal submission of update	----		
Decision of the IEC:	Approved Duration: One year from date of approval		
Any other Comments Requirements for conditional Approval	----		
Members Present	Dr. A.S. Sreedhar, Dr. P. Uday Kumar, Prof. B. R. Shamanna, Dr. M. Varalakshmi, Sri. A. Madhava Rao, Dr. Stalin Choudary, Prof. Pingali Sailaja, Dr. M. K. Aruansree, Dr. Deepa Srinivas and Ms. A. D. Shobhavathi		

Please note:

- Any amendments in the protocol must be informed to the Ethics committee and fresh approval taken.
- Any serious adverse event must be reported to the Ethics Committee within 48 hours in writing (mentioning the protocol No. or the study ID)
- Any advertisement placed in the newspapers, magazines must be submitted for approval.
- If the conduct of the study is to be continued beyond the approved period, an application for the same must be forwarded to the Ethics Committee.
- It is hereby confirmed that neither you nor any of the members of the study team participated in the decision making/voting procedures and declared conflict of interest.

A S Sreedhar
26/08/2021

Chairman

(Dr. A S Sreedhar)

B. R. Shamanna
26/8/2021

Member Secretary

(Prof. B.R. Shamanna)

M. Varalakshmi
26/8/2021

Convenor

(Dr. M. Varalakshmi)

Address: School of Medical Sciences, University of Hyderabad, C. R. Rao Road, Gachibowli, Hyderabad-5000046
Tel (O): +91-040-23135470/23135471 Email: iec_uoh@uohyd.ernet.in, deanmd@uohyd.ernet.in

APPENDIX II PERMISSION LETTERES



July 12, 2021

TO WHOMSOEVER IT MAY CONCERN

This is to certify that Ms. Krishnasri Padamandala, UoH Reg No. 18MOPH03, pursuing her PhD at the School of Medical Sciences, University of Hyderabad, is undertaking the study "Quality of Life in Retinoblastoma Survivors in India (QL-RB INDIA)" under the supervision of Dr Santosh G Honavar, Director, Ophthalmic Plastic Surgery and Ocular Oncology, Centre for Sight, Banjara Hills, Hyderabad. The management of the hospital has no objection to the scholar enrolling the patients of Centre for Sight Eye Hospital (with due informed consent and under information to Dr Honavar) for the survey mentioned in her project proposal. Centre for Sight expects the scholar to get ethics approval from the University of Hyderabad Institutional Ethics Committee (IEC). If the project is published and/or is presented, Centre for Sight expects the scholar to inform Dr Honavar, duly acknowledge the hospital and also ensure that patient confidentiality is protected.

Santosh G Honavar



Dr. Santosh G Honavar, MD, FACS, FRCOphth
Director, Medical Services, CFS Group
Director, Ophthalmic and Facial Plastic Surgery, Orbit and Ocular Oncology

Santosh G. Honavar
MD FACS
Oculoplasty and Ocular Oncology
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GUJARAT | HARYANA | MADHYA PRADESH | MAHARASHTRA | RAJASTHAN | TELANGANA | UTTAR PRADESH | WEST BENGAL | BIHAR | ANDHRA PRADESH

APPENDIX III: QUESTIONNAIRE TOOLS

ID#	_____
Date:	_____

PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 - English (India)

TEEN REPORT (ages 13-18)

DIRECTIONS

On the following pages is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult for me to walk more than 100 metres	0	1	2	3	4
2. It is difficult for me to run	0	1	2	3	4
3. It is difficult for me to do sports activity or exercise	0	1	2	3	4
4. It is difficult for me to lift something heavy	0	1	2	3	4
5. It is difficult for me to take a bath or shower by myself	0	1	2	3	4
6. It is difficult for me to do chores around the house	0	1	2	3	4
7. I feel pain	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens of my age can do	0	1	2	3	4
5. It is difficult to keep up with the teens of my age	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

ID#	_____
Date:	_____

PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 - English (India)

PARENT REPORT for TEENS (ages 13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for **your teen**. Please tell us **how much of a problem** each one has been for **your teen** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your teen had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking more than 100 metres	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Getting along with other teens	0	1	2	3	4
2. Other teens not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other teens	0	1	2	3	4
4. Not able to do things that other teens of his or her age can do	0	1	2	3	4
5. Keeping up with other teens	0	1	2	3	4

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school work	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

ID#	_____
Date:	_____

PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 - English (India)

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has this been for you...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult for me to walk more than 100 metres	0	1	2	3	4
2. It is difficult for me to run	0	1	2	3	4
3. It is difficult for me to do sports activity or exercise	0	1	2	3	4
4. It is difficult for me to lift something heavy	0	1	2	3	4
5. It is difficult for me to take a bath or shower by myself	0	1	2	3	4
6. It is difficult for me to do help in the house	0	1	2	3	4
7. I feel pain	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids of my age can do	0	1	2	3	4
5. It is difficult to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. It is difficult to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

ID#	_____
Date:	_____

PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 - English (India)

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking more than 100 metres	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children of his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school work	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

ID#
Date:

PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 - English (India)

YOUNG CHILD REPORT (ages 5-7)

Instructions for the interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.

Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the unhappy face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	Not at all	Sometimes	A lot
Is it difficult for you to click your fingers			

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

PHYSICAL FUNCTIONING (problems with...)	Not at all	Sometimes	A lot
1. Is it difficult for you to walk	0	2	4
2. Is it difficult for you to run	0	2	4
3. Is it difficult for you to play sports or exercise	0	2	4
4. Is it difficult for you to pick up big things	0	2	4
5. Is it difficult for you to take a bath or shower	0	2	4
6. Is it difficult for you to help in the house (like pick up your toys)	0	2	4
7. Do you have hurts or aches (Where? _____)	0	2	4
8. Do you ever feel too tired to play	0	2	4

Remember, tell me how much of a problem this has been for you for the last few weeks.

EMOTIONAL FUNCTIONING (problems with...)	Not at all	Sometimes	A lot
1. Do you feel scared	0	2	4
2. Do you feel sad	0	2	4
3. Do you feel angry	0	2	4
4. Do you have trouble sleeping	0	2	4
5. Do you worry about what will happen to you	0	2	4

SOCIAL FUNCTIONING (problems with...)	Not at all	Sometimes	A lot
1. Is it difficult for you to get along with other kids	0	2	4
2. Do other kids say they do not want to play with you	0	2	4
3. Do other kids tease you	0	2	4
4. Can other kids do things that you cannot do	0	2	4
5. Is it difficult for you to keep up when you play with other kids	0	2	4

SCHOOL FUNCTIONING (problems with...)	Not at all	Sometimes	A lot
1. Is it difficult for you to pay attention in school	0	2	4
2. Do you forget things	0	2	4
3. Is it difficult to keep up with schoolwork	0	2	4
4. Do you miss school because of not feeling good	0	2	4
5. Do you miss school because you have to go to the doctor's or hospital	0	2	4

How much of a problem is this for you?

Not at all



Sometimes



A lot



ID#:	_____
Date:	_____

PedsQL™

Paediatric Quality of Life Inventory

Version 4.0 - English (India)

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking more than 100 metres	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing small work, like picking up his or her toys	0	1	2	3	4
7. Feeling pain	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL HEALTH (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children of his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

SCHOOL ACTIVITIES (problems with...)	Never	Almost Never	Some- times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school activities	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

ID#	_____
Date:	_____

PedsQLTM

Pediatric Quality of Life Inventory

Version 4.0 - English (India)

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL HEALTH AND ACTIVITIES (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in active play or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Bathing	0	1	2	3	4
6. Helping to pick up his or her toys	0	1	2	3	4
7. Feeling pain	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL HEALTH (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying	0	1	2	3	4

SOCIAL ACTIVITIES (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Playing with other children	0	1	2	3	4
2. Other kids not wanting to play with him or her	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

***Please complete this section if your child attends school or daycare**

SCHOOL ACTIVITIES (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Doing the same school activities as other children	0	1	2	3	4
2. Missing school/daycare because of not feeling well	0	1	2	3	4
3. Missing school/daycare to go to the doctor or hospital	0	1	2	3	4

ID#	_____
Date:	_____

PedsQL™

Young Adult Quality of Life

Inventory

Version 4.0

युवा के द्वारा दी गयी सूचना (आयु १८-२५ वर्ष)
YOUNG ADULT REPORT (ages 18-25)

निर्देश

निम्न पेज पर एक प्रश्नावली दी गयी है, जो आपके जीवन में विभिन्न क्षेत्रों में आने वाली समस्याओं के बारे में पुछती है। कृपया धेरा लगा कर बतायें कि पिछले महीने में इनमें से प्रत्येक क्षेत्र में आपके के लिये यह किस हद तक समस्या रही है।

- 0 यदि ये बिलकुल समस्या ना रही हो.
- 1 यदि ये थोड़ी समस्या रही हो
- 2 यदि ये कभी-कभी समस्या रही हो
- 3 यदि ये अक्सर समस्या रही हो
- 4 यदि ये लगभग हमेशा समस्या रही हो

यहाँ कोई भी उत्तर सही या गलत नहीं है
 यदि आप किसी प्रश्न को समझने में असमर्थ हैं तो मदद मांगें.
 कृपया सभी प्रश्नों के उत्तर दें.

PedsQL 4.0 - (18-25)
2/07

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PedsQL-4.0-Core_Yad-AU4.0_hin-IN_Academic-Translation

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बीते एक महीने में, आपके के लिये यह किस हद तक समस्या रही है ...

मेरे स्वास्थ्य और गतिविधियों के बारे में (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. १०० मीटर से ज्यादा चलने में मुश्किल होना	0	1	2	3	4
2. दौड़ने में मुश्किल होना	0	1	2	3	4
3. खेलकूद अथवा व्यायाम कि गतिविधियों में भाग लेने में मुश्किल होना	0	1	2	3	4
4. कोई भारी वस्तु उठाने में मुश्किल होना	0	1	2	3	4
5. अपने आप नहाने में मुश्किल होना	0	1	2	3	4
6. घर के रोजमर्रा के काम करने में मुश्किल होना	0	1	2	3	4
7. पीड़ा या दर्द होने में	0	1	2	3	4
8. कम शक्ति स्तर होना	0	1	2	3	4

मेरे भावनाओं के बारे में (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. डरा या सहमा महसूस करना	0	1	2	3	4
2. दुखी या उदास महसूस करना	0	1	2	3	4
3. क्रोधित महसूस करना	0	1	2	3	4
4. सोने में कठिनाई होना या मुश्किल होना	0	1	2	3	4
5. चिंता करना कि क्या होगा	0	1	2	3	4

मेरी दूसरों के साथ कैसी बनती है (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. दूसरे युवाओं के साथ बनाये रखना	0	1	2	3	4
2. दूसरे युवा उसका मित्र ना बनना चाहे	0	1	2	3	4
3. दूसरे युवा द्वारा तंग किया जाना या चिढ़ाये जाना	0	1	2	3	4
4. वो चीज़ें नहीं कर पाना जो उसके उम्र के युवा करते हैं	0	1	2	3	4
5. दूसरे युवाओं के साथ बराबरी करना	0	1	2	3	4

मेरे कार्य अथवा पढ़ाई (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा या कार्य पर ध्यान देना	0	1	2	3	4
2. चीज़ें भूलना	0	1	2	3	4
3. पढ़ाई या कार्य का स्तर बनाये	0	1	2	3	4
4. ठीक ना होने के कारण काम या स्कूल ना जा पाना	0	1	2	3	4
5. चिकित्सक या अस्पताल जाने के कारण काम या स्कूल ना जा	0	1	2	3	4

ID#	_____
Date:	_____

PedsQLTM

Pediatric Quality of Life Inventory

Version 4.0

युवा के लिये पालक / माता-पिता द्वारा दी गयी सूचना (आयु १८-२५ वर्ष)
PARENT REPORT for YOUNG ADULTS (ages 18-25)

निम्न पेज पर एक प्रश्नावली दी गयी है. जो आपके बच्चे के जीवन में विभिन्न क्षेत्रों में आने वाली समस्याओं के बारे में पुछती है. कृपया घेरा लगा कर बतायें कि पिछले महीने में इनमें से प्रत्येक क्षेत्र में आपके बच्चे के लिये यह किस हद तक समस्या रही है .

- 0 यदि ये बिलकुल समस्या ना रही हो
- 1 यदि ये थोड़ी समस्या रही हो
- 2 यदि ये कभी-कभी समस्या रही हो
- 3 यदि ये अक्सर समस्या रही हो
- 4 यदि ये लगभग हमेशा समस्या रही हो

यहाँ कोड़ भी उत्तर सही या गलत नहीं है
 यदि आप किसी प्रश्न को समझने में असमर्थ हैं तो मदद मांगें.
 कृपया सभी प्रश्नों के उत्तर दें.

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 01/00

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बीते एक महीने में, आपके बच्चे के लिये यह किस हद तक समस्या रही है ...

शारीरिक कार्य प्रणाली (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. १०० मीटर से ज्यादा चलने में	0	1	2	3	4
2. दौड़ने में	0	1	2	3	4
3. खेलकूद अथवा व्यायाम कि गतिविधियों में भाग लेने में	0	1	2	3	4
4. कोई भारी वस्तु उठाने में	0	1	2	3	4
5. अपने आप नहाने में	0	1	2	3	4
6. घर के रोजमराह के काम करने में	0	1	2	3	4
7. पीड़ा या दर्द होने में	0	1	2	3	4
8. कम शक्ति स्तर होना	0	1	2	3	4

भावनात्मक कार्य प्रणाली (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. डरा या सहमा महसूस करना	0	1	2	3	4
2. दुखी या उदास महसूस करना	0	1	2	3	4
3. क्रोधित महसूस करना	0	1	2	3	4
4. सोने में कठिनाई होना या मुश्किल होना	0	1	2	3	4
5. चिंता करना कि उसका क्या होगा	0	1	2	3	4

सामाजिक कार्य प्रणाली (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. दूसरे युवाओं के साथ बनाये रखना	0	1	2	3	4
2. दूसरे युवा उसका मित्र ना बनना चाहे	0	1	2	3	4
3. दूसरे युवा द्वारा तंग किया जाना या चिढ़ाये जाना	0	1	2	3	4
4. वो चीज़ें नहीं कर पाना जो उसके उम्र के युवा करते हैं	0	1	2	3	4
5. दूसरे युवाओं के साथ बराबरी करना	0	1	2	3	4

विद्यालय कार्य प्रणाली (के साथ समस्याएँ)	बिल्कुल नहीं	थोड़ी	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा या कार्य पर ध्यान देना	0	1	2	3	4
2. चीज़ें भूलना	0	1	2	3	4
3. पढ़ाई या कार्य का स्तर बनाये रखना	0	1	2	3	4
4. ठीक ना होने के कारण काम या स्कूल ना जा पाना	0	1	2	3	4
5. चिकित्सक या अस्पताल जाने के कारण काम या स्कूल ना जा	0	1	2	3	4

पहचान संख्या _____
तिथि: _____

PedsQL™

बालक और किशोर जीवन गुणवत्ता प्रश्नावली

Version 4.0 - Hindi

किशोर रिपोर्ट (आयु 13-18)

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके लिए परेशानी हो सकती हैं।
कृपया गोला लगाकर हमें बताएँ कि **पिछले एक महीने** में, इनमें से हरेक आपके लिए **कितनी परेशानी** रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी **कभी नहीं** रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी **लगभग कभी नहीं** रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी **कभी-कभी** रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी **अक्सर** रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी **लगभग हमेशा** रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले एक महीने में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी सेहत और कामकाज के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. मेरे लिए 100 मीटर से ज़्यादा चलना मुश्किल होता है	0	1	2	3	4
2. मेरे लिए दौड़ना मुश्किल होता है	0	1	2	3	4
3. मेरे लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. मेरे लिए कोई भारी चीज़ उठाना मुश्किल होता है	0	1	2	3	4
5. मेरे लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. मेरे लिए रोज़ाना के घर के काम करना मुश्किल होता है	0	1	2	3	4
7. मुझे दर्द होता है	0	1	2	3	4
8. मुझे थकान महसूस होती है	0	1	2	3	4

मेरी भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. मुझे डर महसूस होता है	0	1	2	3	4
2. मुझे दुख या उदासी महसूस होती है	0	1	2	3	4
3. मुझे गुस्सा महसूस होता है	0	1	2	3	4
4. मुझे सोने में परेशानी होती है	0	1	2	3	4
5. मुझे इस बारे में चिन्ता होती है कि मेरा क्या होगा	0	1	2	3	4

मेरी दूसरों के साथ कैसी बनती है (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. मुझे दूसरे किशोरों के साथ बनाए रखने में मुश्किल होती है	0	1	2	3	4
2. दूसरे किशोर मेरा दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे किशोर मुझे चिढ़ाते हैं	0	1	2	3	4
4. मैं वे चीज़ें नहीं कर सकता/सकती जो मेरी उम्र के दूसरे किशोर कर सकते हैं	0	1	2	3	4
5. मुझे अपने साथियों की बराबरी करने में मुश्किल होती है	0	1	2	3	4

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. कक्षा में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. मैं चीज़ें भूल जाता/जाती हूँ	0	1	2	3	4
3. मुझे अपना स्कूल का सारा काम और सारा होमवर्क करने में मुश्किल होती है	0	1	2	3	4
4. मैं ठीक न होने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. मैं डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4

पहचान संख्या _____
तिथि: _____

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बाल जीवन गुणवत्ता इन्वेंटरी

Version 4.0 - Hindi (India)

किशोरों (आयु 13-18) के लिए माता-पिता की रिपोर्ट

निर्देश

अगले पेज पर उन चीज़ों की लिस्ट दी गई है जो आपके किशोर के लिए परेशानी हो सकती हैं।
कृपया गोला लगाकर हमें बताएँ कि पिछले एक महीने में, इनमें से हरेक आपके किशोर के लिए
कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

PedsQL 4.0 Parent (13-18)
01/00

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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पिछले एक महीने में, ये बातें आपके किशोर के लिए कितनी परेशानी रही हैं...

शारीरिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. 100 मीटर से ज्यादा चलना	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. खेलकूद या कसरत में भाग लेना	0	1	2	3	4
4. कोई भारी चीज़ उठाना	0	1	2	3	4
5. अपने आप नहाना	0	1	2	3	4
6. घर के रोज़ाना के काम करना	0	1	2	3	4
7. दर्द होना	0	1	2	3	4
8. थकान महसूस होना	0	1	2	3	4

भावनात्मक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. डर महसूस करना	0	1	2	3	4
2. दुखी या उदास महसूस करना	0	1	2	3	4
3. गुस्सा महसूस करना	0	1	2	3	4
4. सोने में परेशानी होना	0	1	2	3	4
5. चिन्ता करना कि उसका क्या होगा	0	1	2	3	4

सामाजिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. दूसरे किशोरों के साथ बनाए रखना	0	1	2	3	4
2. दूसरे किशोर उसका दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे किशोरों द्वारा चिढ़ाना	0	1	2	3	4
4. वे चीज़ें न कर पाना जो उसकी उम्र के दूसरे किशोर कर सकते हैं	0	1	2	3	4
5. दूसरे किशोरों के बराबर आना	0	1	2	3	4

स्कूल की कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा में ध्यान देना	0	1	2	3	4
2. चीज़ें भूलना	0	1	2	3	4
3. स्कूल का सारा काम और सारा होमवर्क करना	0	1	2	3	4
4. ठीक महसूस न होने के कारण स्कूल न जा पाना	0	1	2	3	4
5. डॉक्टर के पास या अस्पताल जाने के कारण स्कूल न जा पाना	0	1	2	3	4

पहचान संख्या _____
तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली

Version 4.0 – Hindi

बाल रिपोर्ट (आयु 8-12)

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके लिए परेशानी हो सकती हैं।
कृपया गोला लगाकर हमें बताएँ कि पिछले एक महीने में, इनमें से हरेक आपके लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

PedsQL 4.0 - (8-12)

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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पिछले एक महीने में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी सेहत और कामकाज के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. मेरे लिए 100 मीटर से ज़्यादा चलना मुश्किल होता है	0	1	2	3	4
2. मेरे लिए दौड़ना मुश्किल होता है	0	1	2	3	4
3. मेरे लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. मेरे लिए कोई भारी चीज़ उठाना मुश्किल होता है	0	1	2	3	4
5. मेरे लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. मेरे लिए रोज़ाना के घर के काम करना मुश्किल होता है	0	1	2	3	4
7. मुझे दर्द होता है	0	1	2	3	4
8. मुझे थकान महसूस होती है	0	1	2	3	4

मेरी भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. मुझे डर महसूस होता है	0	1	2	3	4
2. मुझे दुख या उदासी महसूस होती है	0	1	2	3	4
3. मुझे गुस्सा महसूस होता है	0	1	2	3	4
4. मुझे सोने में परेशानी होती है	0	1	2	3	4
5. मुझे इस बारे में चिन्ता होती है कि मेरा क्या होगा	0	1	2	3	4

मेरी दूसरों के साथ कैसी बनती है (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. मुझे दूसरे बच्चों के साथ बनाए रखने में मुश्किल होती है	0	1	2	3	4
2. दूसरे बच्चे मेरा दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे बच्चे मुझे चिढ़ाते हैं	0	1	2	3	4
4. मैं वे चीज़ें नहीं कर सकता/सकती जो मेरी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. खेलते समय मुझे दूसरे बच्चों की बराबरी करने में मुश्किल होती है	0	1	2	3	4

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. कक्षा में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. मैं चीज़ें भूल जाता/जाती हूँ	0	1	2	3	4
3. मुझे अपना स्कूल का सारा काम और सारा होमवर्क करने में मुश्किल होती है	0	1	2	3	4
4. मैं ठीक न होने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. मैं डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4

PedsQL 4.0 - (8-12)

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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पहचान संख्या _____
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Version 4.0 - Hindi (India)

बच्चों (आयु 8-12) के लिए माता-पिता की रिपोर्ट

निर्देश

अगले पेज पर उन चीज़ों की लिस्ट दी गई है जो आपके बच्चे के लिए परेशानी हो सकती हैं।
कृपया गोला लगाकर हमें बताएँ कि पिछले एक महीने में इनमें से हरेक आपके बच्चे के लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

PedsQL 4.0 - Parent (8-12) बिना अनुमति के पुनः प्रस्तुत न किया जाए
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पिछले एक महीने में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

शारीरिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. 100 मीटर से ज्यादा चलना	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. खेलकूद या कसरत में भाग लेना	0	1	2	3	4
4. कोई भारी चीज़ उठाना	0	1	2	3	4
5. अपने आप नहाना	0	1	2	3	4
6. घर के रोज़ाना के काम करना	0	1	2	3	4
7. दर्द होना	0	1	2	3	4
8. थकान महसूस होना	0	1	2	3	4

भावनात्मक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. डर महसूस करना	0	1	2	3	4
2. दुखी या उदास महसूस करना	0	1	2	3	4
3. गुस्सा महसूस करना	0	1	2	3	4
4. सोने में परेशानी होना	0	1	2	3	4
5. चिन्ता करना कि उसका क्या होगा	0	1	2	3	4

सामाजिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. दूसरे बच्चों के साथ बनाए रखना	0	1	2	3	4
2. दूसरे बच्चे उसका दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे बच्चों द्वारा चिढ़ाना	0	1	2	3	4
4. वे चीज़ें न कर पाना जो उसकी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. खेलते समय दूसरे बच्चों के बराबर आना	0	1	2	3	4

स्कूल की कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. कक्षा में ध्यान देना	0	1	2	3	4
2. चीज़ें भूलना	0	1	2	3	4
3. स्कूल का सारा काम और सारा होमवर्क करना	0	1	2	3	4
4. ठीक महसूस न होने के कारण स्कूल न जा पाना	0	1	2	3	4
5. डॉक्टर के पास या अस्पताल जाने के कारण स्कूल न जा पाना	0	1	2	3	4

पहचान संख्या _____ तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली

Version 4.0 - Hindi (India)

छोटे बच्चों की रिपोर्ट (आयु 5-7)

साक्षात्कारकर्ता के लिए निर्देश:

मैं आपसे ऐसी बातों के बारे में कुछ सवाल पूछने वाला हूँ जो कुछ बच्चों के लिए परेशानी हो सकती हैं। मैं जानना चाहता हूँ कि इनमें से कोई भी बात आपके लिए कितनी परेशानी हो सकती है।

बच्चे को नमूना दिखाएं और उन जवाबों की ओर इशारा करें जिन्हें आप पढ़ रहे हैं।

अगर इससे आपको परेशानी बिल्कुल नहीं है, तो मुस्कुराते चेहरे की ओर इशारा करिये

अगर इससे आपको कभी-कभी परेशानी होती हो, तो बीच वाले चेहरे की ओर इशारा करिये

अगर यह आपके लिए काफी परेशानी हो, तो भाँ सिकोड़े हुए चेहरे की ओर इशारा करिये

मैं हरेक सवाल को पूछूंगा। तस्वीरों की ओर इशारा करके मुझे दिखाइये कि ये बातें आपके लिए कितनी परेशानी रही हैं। आइये पहले अभ्यास के लिए एक सवाल करके देखते हैं।

	बिल्कुल नहीं	कभी-कभी	काफी
क्या आपको उंगलियाँ चिटकाने में परेशानी होती है	😊	😐	😞

बच्चे से अपनी उंगलियाँ चिटका कर दिखाने के लिए कहें ताकि पता चल सके कि सवाल का जवाब सही तरीके से दिया गया या नहीं। अगर बच्चा ऐसा जवाब प्रदर्शित करता है जो उसकी क्रिया से अलग है तो सवाल को दोहराएं।

PedsQL 4.0 - (5-7)

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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इस बारे में सोचिये कि पिछले कुछ हफ्तों में आपका हाल कैसा रहा है। कृपया हर वाक्य को ध्यान से सुनिये और मुझे बताइये कि ये बातें आपके लिए कितनी परेशानी रही हैं।

आइडम को पढ़ने के बाद, नमूने की ओर इशारा करें। अगर बच्चा हिचकिचाता है या लगता है कि वह समझ नहीं पा रहा कि जवाब कैसे दें, तो चेहरों की ओर इशारा करते हुए जवाब के विकल्पों को पढ़ें।

शरीर के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आपके लिए पैदल चलना मुश्किल होता है	0	2	4
2. क्या आपके लिए दौड़ना मुश्किल होता है	0	2	4
3. क्या आपके लिए खेलकूद या कसरत करना मुश्किल होता है	0	2	4
4. क्या आपके लिए बड़ी चीज़ें उठाना मुश्किल होता है	0	2	4
5. क्या आपके लिए अपने आप नहाना मुश्किल होता है	0	2	4
6. क्या आपके लिए रोज़ाना के काम करना मुश्किल होता है (जैसे अपने खिलौनों को उठाना और उन्हें सही जगह पर रखना)	0	2	4
7. क्या आपको दर्द है (कहाँ? _____)	0	2	4
8. क्या आपका कभी थकान के कारण खेलने का मन नहीं करता	0	2	4

याद रखिये, मुझे बताइये कि पिछले कुछ हफ्तों में ये बात आपके लिए कितनी परेशानी रही है।

भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आप डरा हुआ महसूस करते हैं	0	2	4
2. क्या आपको दुख महसूस होता है	0	2	4
3. क्या आप पागल महसूस करते हैं	0	2	4
4. क्या आपको नींद आने में परेशानी होती है	0	2	4
5. क्या आपको इस बारे में चिन्ता होती है कि आपका क्या होगा	0	2	4

सामाजिकता के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आपके लिए दूसरे बच्चों के साथ निभाने में मुश्किल होती है	0	2	4
2. क्या दूसरे बच्चे कहते हैं कि वे आपके साथ नहीं खेलना चाहते	0	2	4
3. क्या दूसरे बच्चे आपको चिढ़ाते हैं	0	2	4
4. क्या दूसरे बच्चे ऐसी चीज़ें कर सकते हैं जो आप नहीं कर सकते	0	2	4
5. क्या आपको खेलते समय दूसरे बच्चों के बराबर आने में मुश्किल होती है	0	2	4

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आपके लिए स्कूल में ध्यान देना मुश्किल होता है	0	2	4
2. क्या आप चीज़ें भूल जाते हैं	0	2	4
3. क्या स्कूल का काम पूरा करने में मुश्किल होती है	0	2	4
4. क्या आप ठीक न होने के कारण स्कूल नहीं जा पाते	0	2	4
5. क्या आप डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाते	0	2	4

ये बातें आपके लिए कितनी परेशानी रही हैं?

बिल्कुल नहीं



कभी-कभी



काफी



पहचान संख्या _____
तिथि : _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली

Version 4.0 – Hindi

छोटे बच्चों (आयु 5-7) के लिए माता या पिता की रिपोर्ट

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके बच्चे के लिए परेशानी हो सकती हैं।

कृपया गोला लगाकर हमें बताएँ कि पिछले एक महीने में, इनमें से हरेक आपके बच्चे के लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या गलत जवाब नहीं हैं।

अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले एक महीने में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

शरीर के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसके लिए 100 मीटर से ज्यादा चलना मुश्किल होता है	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. उसके लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. कोई भारी सामान उठाना	0	1	2	3	4
5. उसके लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. घर में छोटे-मोटे काम करना, जैसे अपने खिलौनों को उठाना और उन्हें सही जगह पर रखना मुश्किल होता है	0	1	2	3	4
7. दर्द होना	0	1	2	3	4
8. उसे थकान महसूस होती है	0	1	2	3	4

भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसे डर महसूस होता है	0	1	2	3	4
2. उसे दुख या उदासी महसूस होती है	0	1	2	3	4
3. उसे गुस्सा महसूस होता है	0	1	2	3	4
4. उसे सोने में परेशानी होती है	0	1	2	3	4
5. उसे इस बारे में चिन्ता होती है कि उसका क्या होगा	0	1	2	3	4

सामाजिकता के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसे दूसरे बच्चों के साथ निभाने में मुश्किल होती है	0	1	2	3	4
2. दूसरे बच्चे उसका दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे बच्चे उसे चिढ़ाते हैं	0	1	2	3	4
4. वे चीज़ें नहीं कर सकता/सकती जो उसकी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. दूसरे बच्चों के साथ खेलते समय उनकी बराबरी करने में मुश्किल होती है	0	1	2	3	4

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. वह चीज़ें भूल जाता/जाती है	0	1	2	3	4
3. उसे अपना स्कूल का सारा काम और सारा होमवर्क करने में मुश्किल होती है	0	1	2	3	4
4. वह ठीक न होने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. वह डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4

पहचान संख्या _____
तिथि: _____

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बालक और किशोर

जीवन गुणवत्ता प्रश्नावली

Version 4.0 – Hindi

नन्हे बच्चों (आयु 2-4) के लिए माता या पिता की रिपोर्ट

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके बच्चे के लिए परेशानी हो सकती हैं। कृपया गोला लगाकर हमें बताएँ कि पिछले एक महीने में, इनमें से हरेक आपके बच्चे के लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
 - 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
 - 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
 - 3 पर गोला लगाएँ अगर यह परेशानी अकसर रही हो
 - 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या गलत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले एक महीने में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

शरीर के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. पैदल चलना	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. सक्रिय खेल या कसरत में हिस्सा लेना	0	1	2	3	4
4. कोई भारी सामान उठाना	0	1	2	3	4
5. नहाना	0	1	2	3	4
6. उसके खिलौने उठाने में मदद करना	0	1	2	3	4
7. दर्द या तकलीफ होना	0	1	2	3	4
8. उसे थकान महसूस होती है	0	1	2	3	4

भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसे डर महसूस होता है	0	1	2	3	4
2. उसे दुख या उदासी महसूस होती है	0	1	2	3	4
3. उसे गुस्सा महसूस होता है	0	1	2	3	4
4. उसे सोने में परेशानी होती है	0	1	2	3	4
5. उसे चिंता होती है	0	1	2	3	4

सामाजिकता के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. दूसरे बच्चों के साथ खेलना	0	1	2	3	4
2. दूसरे बच्चे उसके साथ खेलना नहीं चाहते	0	1	2	3	4
3. दूसरे बच्चों उसे चिढ़ाते हैं	0	1	2	3	4
4. वे चीज़ें नहीं कर सकता/सकती जो उसकी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. वह दूसरे बच्चों के साथ खेलते समय उनका साथ नहीं दे पाता	0	1	2	3	4

*अगर आपका बच्चा स्कूल या डेकेयर में जाता है तो इस भाग को पूरा करें

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. वह स्कूल की उन्हीं गतिविधियों को नहीं कर पाता/पाती जिन्हें उसके समकक्ष बच्चे कर लेते हैं	0	1	2	3	4
2. वह ठीक महसूस न करने के कारण स्कूल/डेकेयर नहीं जा पाता/पाती	0	1	2	3	4
3. वह डॉक्टर के पास या अस्पताल जाने के कारण स्कूल/डेकेयर नहीं जा पाता/पाती	0	1	2	3	4

पहचान संख्या _____

तिथि: _____

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वयस्क जीवन गुणवत्ता प्रश्नावली

Version 4.0 - Hindi (India)

वयस्क रिपोर्ट 7 दिनों का संस्करण

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके लिए परेशानी हो सकती हैं। कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी सेहत और कामकाज के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मेरे लिए 100 मीटर से ज्यादा चलना मुश्किल होता है	0	1	2	3	4
2. मेरे लिए दौड़ना मुश्किल होता है	0	1	2	3	4
3. मेरे लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. मेरे लिए कोई भारी चीज़ उठाना मुश्किल होता है	0	1	2	3	4
5. मेरे लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. मेरे लिए रोज़ाना के घर के काम करना मुश्किल होता है	0	1	2	3	4
7. मुझे दर्द होता है	0	1	2	3	4
8. मुझे थकान महसूस होती है	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मुझे डर महसूस होता है	0	1	2	3	4
2. मुझे दुख या उदासी महसूस होती है	0	1	2	3	4
3. मुझे गुस्सा महसूस होता है	0	1	2	3	4
4. मुझे सोने में परेशानी होती है	0	1	2	3	4
5. मुझे इस बारे में चिन्ता होती है कि मेरा क्या होगा	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी दूसरों के साथ कैसी बनती है (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मुझे दूसरे वयस्क लोगों के साथ बनाए रखने में मुश्किल होती है	0	1	2	3	4
2. दूसरे वयस्क मेरा दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे वयस्क मुझे चिढ़ाते हैं	0	1	2	3	4
4. मैं वे चीज़ें नहीं कर सकता/सकती जो मेरी उम्र के दूसरे वयस्क कर सकते हैं	0	1	2	3	4
5. मुझे अपने साथियों के बराबर आने में मुश्किल होती है	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरे काम/पढ़ाई के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. काम पर या स्कूल में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. मैं चीज़ें भूल जाता/जाती हूँ	0	1	2	3	4
3. मुझे अपना सारा काम या पढ़ाई करने में मुश्किल होती है	0	1	2	3	4
4. मैं ठीक न होने के कारण काम पर या स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. मैं डॉक्टर के पास या अस्पताल जाने के कारण काम पर या स्कूल नहीं जा पाता/पाती	0	1	2	3	4

पहचान संख्या _____

तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली

Version 4.0 - Hindi (India)

किशोर रिपोर्ट (आयु 13-18)

7 दिनों का संस्करण

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके लिए परेशानी हो सकती हैं। कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी सेहत और कामकाज के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मेरे लिए 100 मीटर से ज्यादा चलना मुश्किल होता है	0	1	2	3	4
2. मेरे लिए दौड़ना मुश्किल होता है	0	1	2	3	4
3. मेरे लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. मेरे लिए कोई भारी चीज़ उठाना मुश्किल होता है	0	1	2	3	4
5. मेरे लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. मेरे लिए रोज़ाना के घर के काम करना मुश्किल होता है	0	1	2	3	4
7. मुझे दर्द होता है	0	1	2	3	4
8. मुझे थकान महसूस होती है	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मुझे डर महसूस होता है	0	1	2	3	4
2. मुझे दुख या उदासी महसूस होती है	0	1	2	3	4
3. मुझे गुस्सा महसूस होता है	0	1	2	3	4
4. मुझे सोने में परेशानी होती है	0	1	2	3	4
5. मुझे इस बारे में चिन्ता होती है कि मेरा क्या होगा	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी दूसरों के साथ कैसी बनती है (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मुझे दूसरे किशोरों के साथ बनाए रखने में मुश्किल होती है	0	1	2	3	4
2. दूसरे किशोर मेरा दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे किशोर मुझे चिढ़ाते हैं	0	1	2	3	4
4. मैं वे चीज़ें नहीं कर सकता/सकती जो मेरी उम्र के दूसरे किशोर कर सकते हैं	0	1	2	3	4
5. मुझे अपने साथियों के बराबर आने में मुश्किल होती है	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. मैं चीज़ें भूल जाता/जाती हूँ	0	1	2	3	4
3. मुझे अपना स्कूल का सारा काम और सारा होमवर्क करने में मुश्किल होती है	0	1	2	3	4
4. मैं ठीक न होने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. मैं डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4

पहचान संख्या _____

तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली 7 दिनों का संस्करण

Version 4.0 - Hindi (India)

किशोरों (आयु **13-18**) के लिए माता-पिता की रिपोर्ट

निर्देश

अगले पेज पर उन चीजों की लिस्ट दी गई है जो आपके किशोर के लिए परेशानी हो सकती हैं। कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके किशोर के लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या गलत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले 7 दिनों में, ये बातें आपके किशोर के लिए कितनी परेशानी रही हैं...

शारीरिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. 100 मीटर से ज्यादा चलना	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. खेलकूद या कसरत में भाग लेना	0	1	2	3	4
4. कोई भारी चीज़ उठाना	0	1	2	3	4
5. अपने आप नहाना	0	1	2	3	4
6. घर के रोज़ाना के काम करना	0	1	2	3	4
7. दर्द होना	0	1	2	3	4
8. थकान महसूस होना	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके किशोर के लिए कितनी परेशानी रही हैं...

भावनात्मक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. डर महसूस करना	0	1	2	3	4
2. दुखी या उदास महसूस करना	0	1	2	3	4
3. गुस्सा महसूस करना	0	1	2	3	4
4. सोने में परेशानी होना	0	1	2	3	4
5. चिन्ता करना कि उसका क्या होगा	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके किशोर के लिए कितनी परेशानी रही हैं...

सामाजिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. दूसरे किशोरों के साथ बनाव रखना	0	1	2	3	4
2. दूसरे किशोर उसका दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे किशोरों द्वारा चिढ़ाना	0	1	2	3	4
4. वे चीज़ें न कर पाना जो उसकी उम्र के दूसरे किशोर कर सकते हैं	0	1	2	3	4
5. दूसरे किशोरों के बराबर आना	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके किशोर के लिए कितनी परेशानी रही हैं...

स्कूल की कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. कक्षा में ध्यान देना	0	1	2	3	4
2. चीज़ें भूलना	0	1	2	3	4
3. स्कूल का सारा काम और सारा होमवर्क करना	0	1	2	3	4
4. ठीक महसूस न होने के कारण स्कूल न जा पाना	0	1	2	3	4
5. डॉक्टर के पास या अस्पताल जाने के कारण स्कूल न जा पाना	0	1	2	3	4

पहचान संख्या _____

तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली

Version 4.0 - Hindi (India)

बाल रिपोर्ट (आयु 8-12)

7 दिनों का संस्करण

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके लिए परेशानी हो सकती हैं। कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या ग़लत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी सेहत और कामकाज के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मेरे लिए 100 मीटर से ज्यादा चलना मुश्किल होता है	0	1	2	3	4
2. मेरे लिए दौड़ना मुश्किल होता है	0	1	2	3	4
3. मेरे लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. मेरे लिए कोई भारी चीज़ उठाना मुश्किल होता है	0	1	2	3	4
5. मेरे लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. मेरे लिए रोज़ाना के घर के काम करना मुश्किल होता है	0	1	2	3	4
7. मुझे दर्द होता है	0	1	2	3	4
8. मुझे थकान महसूस होती है	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मुझे डर महसूस होता है	0	1	2	3	4
2. मुझे दुख या उदासी महसूस होती है	0	1	2	3	4
3. मुझे गुस्सा महसूस होता है	0	1	2	3	4
4. मुझे सोने में परेशानी होती है	0	1	2	3	4
5. मुझे इस बारे में चिन्ता होती है कि मेरा क्या होगा	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

मेरी दूसरों के साथ कैसी बनती है (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. मुझे दूसरे बच्चों के साथ बनाए रखने में मुश्किल होती है	0	1	2	3	4
2. दूसरे बच्चे मेरा दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे बच्चे मुझे चिढ़ाते हैं	0	1	2	3	4
4. मैं वे चीज़ें नहीं कर सकता/सकती जो मेरी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. खेलते समय मुझे दूसरे बच्चों के बराबर आने में मुश्किल होती है	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके लिए कितनी परेशानी रही हैं...

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. मैं चीज़ें भूल जाता/जाती हूँ	0	1	2	3	4
3. मुझे अपना स्कूल का सारा काम और सारा होमवर्क करने में मुश्किल होती है	0	1	2	3	4
4. मैं ठीक न होने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. मैं डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4

पहचान संख्या _____

तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली 7 दिनों का संस्करण

Version 4.0 - Hindi (India)

बच्चों (आयु 8-12) के लिए माता-पिता की रिपोर्ट

निर्देश

अगले पेज पर उन चीजों की लिस्ट दी गई है जो आपके बच्चे के लिए परेशानी हो सकती हैं। कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके बच्चे के लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या गलत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

पिछले 7 दिनों में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

शारीरिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. 100 मीटर से ज्यादा चलना	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. खेलकूद या कसरत में भाग लेना	0	1	2	3	4
4. कोई भारी चीज़ उठाना	0	1	2	3	4
5. अपने आप नहाना	0	1	2	3	4
6. घर के रोज़ाना के काम करना	0	1	2	3	4
7. दर्द होना	0	1	2	3	4
8. थकान महसूस होना	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

भावनात्मक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. डर महसूस करना	0	1	2	3	4
2. दुखी या उदास महसूस करना	0	1	2	3	4
3. गुस्सा महसूस करना	0	1	2	3	4
4. सोने में परेशानी होना	0	1	2	3	4
5. चिन्ता करना कि उसका क्या होगा	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

सामाजिक कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. दूसरे बच्चों के साथ बनाए रखना	0	1	2	3	4
2. दूसरे बच्चे उसका दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे बच्चों द्वारा चिढ़ाना	0	1	2	3	4
4. वे चीज़ें न कर पाना जो उसकी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. खेलते समय दूसरे बच्चों के बराबर आना	0	1	2	3	4

पिछले 7 दिनों में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

स्कूल की कार्यप्रणाली (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अकसर	लगभग हमेशा
1. कक्षा में ध्यान देना	0	1	2	3	4
2. चीज़ें भूलना	0	1	2	3	4
3. स्कूल का सारा काम और सारा होमवर्क करना	0	1	2	3	4
4. ठीक महसूस न होने के कारण स्कूल न जा पाना	0	1	2	3	4
5. डॉक्टर के पास या अस्पताल जाने के कारण स्कूल न जा पाना	0	1	2	3	4

पहचान संख्या _____
तिथि: _____

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बाल जीवन गुणवत्ता प्रश्नावली लघु अवधि संस्करण

Version 4.0 - Hindi (India)

छोटे बच्चों की रिपोर्ट (आयु 5-7)

साक्षात्कारकर्ता के लिए निर्देश:

मैं आपसे ऐसी बातों के बारे में कुछ सवाल पूछने वाला हूँ जो कुछ बच्चों के लिए परेशानी हो सकती हैं। मैं जानना चाहता हूँ कि इनमें से कोई भी बात आपके लिए कितनी परेशानी हो सकती है।

बच्चे को नमूना दिखाएं और उन जवाबों की ओर इशारा करें जिन्हें आप पढ़ रहे हैं।

अगर इससे आपको परेशानी बिल्कुल नहीं है, तो मुस्कुराते चेहरे की ओर इशारा करें

अगर इससे आपको कभी-कभी परेशानी होती हो, तो बीच वाले चेहरे की ओर इशारा करें

अगर यह आपके लिए काफी परेशानी हो, तो भाँ सिकोड़े हुए चेहरे की ओर इशारा करें

मैं हरेक सवाल को पढ़ूँगा। तस्वीरों की ओर इशारा करके मुझे दिखाइये कि ये बातें आपके लिए कितनी परेशानी रही हैं। आइए पहले अभ्यास के लिए एक सवाल करके देखते हैं।

	बिल्कुल नहीं	कभी-कभी	काफी
क्या आपको भारी सामान उठाने में परेशानी होती है			

बच्चे से कोई भारी सामान उठाकर दिखाने के लिए कहें ताकि पता चल सके कि सवाल का जवाब सही तरीके से दिया गया या नहीं। अगर बच्चा ऐसा जवाब प्रदर्शित करता है जो उसकी क्रिया से अलग है तो सवाल को दोहराएं।

PedsQL 4.0 - (5-7) Acute बिना अनुमति के पुनः प्रस्तुत न किया जाए
03/00
PedsQL-4.0-Core-Acute-YC - India/Hindi - Version of 27 Jan 17 - Mapi.
ID043653 / PedsQL-4.0-Core-Acute-YC_AU4.0_hin-IN.doc

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इस बारे में सोचिए कि पिछले 7 दिनों में आपका हाल कैसा रहा है। कृपया हर वाक्य को ध्यान से सुनिए और मुझे बताइए कि ये बातें आपके लिए कितनी परेशानी रही हैं।

आइटम को पढ़ने के बाद, नमूने की ओर इशारा करें। अगर बच्चा हिचकिचाता है या लगता है कि वह समझ नहीं पा रहा कि जवाब कैसे दें, तो चेहरों की ओर इशारा करते हुए जवाब के विकल्पों को पढ़ें।

शरीर के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आपके लिए पैदल चलना मुश्किल होता है	0	2	4
2. क्या आपके लिए दौड़ना मुश्किल होता है	0	2	4
3. क्या आपके लिए खेलकूद या कसरत करना मुश्किल होता है	0	2	4
4. क्या आपके लिए बड़ी चीज़ें उठाना मुश्किल होता है	0	2	4
5. क्या आपके लिए अपने आप नहाना मुश्किल होता है	0	2	4
6. क्या आपके लिए रोज़ाना के काम करना मुश्किल होता है (जैसे अपने खिलौनों को उठाना)	0	2	4
7. क्या आपको तकलीफ़ या दर्द है (कहाँ? _____)	0	2	4
8. क्या आपका कभी थकान के कारण खेलने का मन नहीं करता	0	2	4

याद रखिए, मुझे बताइए कि पिछले 7 दिनों में ये बात आपके लिए कितनी परेशानी रही है।

भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आप डरा हुआ महसूस करते हैं	0	2	4
2. क्या आपको दुख महसूस होता है	0	2	4
3. क्या आप पागल महसूस करते हैं	0	2	4
4. क्या आपको नींद आने में परेशानी होती है	0	2	4
5. क्या आपको इस बारे में चिन्ता होती है कि आपका क्या होगा	0	2	4

सामाजिकता के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आपके लिए दूसरे बच्चों के साथ निभाने में मुश्किल होती है	0	2	4
2. क्या दूसरे बच्चे कहते हैं कि वे आपके साथ नहीं खेलना चाहते	0	2	4
3. क्या दूसरे बच्चे आपको चिढ़ाते हैं	0	2	4
4. क्या दूसरे बच्चे ऐसी चीज़ें कर सकते हैं जो आप नहीं कर सकते	0	2	4
5. क्या आपको खेलते समय दूसरे बच्चों के बराबर आने में मुश्किल होती है	0	2	4

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	बिल्कुल नहीं	कभी-कभी	काफी
1. क्या आपके लिए स्कूल में ध्यान देना मुश्किल होता है	0	2	4
2. क्या आप चीज़ें भूल जाते हैं	0	2	4
3. क्या स्कूल का काम पूरा करने में मुश्किल होती है	0	2	4
4. क्या आप ठीक न होने के कारण स्कूल नहीं जा पाते	0	2	4
5. क्या आप डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाते	0	2	4

पहचान संख्या _____
तिथि: _____

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बालक और किशोर जीवन गुणवत्ता प्रश्नावली लघु अवधि संस्करण

Version 4.0 – Hindi (India)

छोटे बच्चों (आयु 5-7) के लिए माता या पिता की रिपोर्ट

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके बच्चे के लिए परेशानी हो सकती हैं।
कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके बच्चे के लिए कितनी
परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या गलत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

PedsQL 4.0 Parent (5-7) Acute
03/00

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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सर्वाधिकार सुरक्षित

PedsQL-4.0-Core-Acute-PYC - India/Hindi - Version of 27 Jan 17 - Mapi.
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पिछले 7 दिनों में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

शरीर के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसके लिए 100 मीटर से ज्यादा चलना मुश्किल होता है	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. उसके लिए खेलकूद या कसरत करना मुश्किल होता है	0	1	2	3	4
4. कोई भारी सामान उठाना	0	1	2	3	4
5. उसके लिए अपने आप नहाना मुश्किल होता है	0	1	2	3	4
6. घर में छोटे-मोटे काम करना, जैसे अपने खिलौनों को उठाना मुश्किल होता है	0	1	2	3	4
7. दर्द या तकलीफ होना	0	1	2	3	4
8. उसे थकान महसूस होती है	0	1	2	3	4

भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसे डर महसूस होता है	0	1	2	3	4
2. उसे दुख या उदासी महसूस होती है	0	1	2	3	4
3. उसे गुस्सा महसूस होता है	0	1	2	3	4
4. उसे सोने में परेशानी होती है	0	1	2	3	4
5. उसे इस बारे में चिन्ता होती है कि उसका क्या होगा	0	1	2	3	4

सामाजिकता के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसे दूसरे बच्चों के साथ निभाने में मुश्किल होती है	0	1	2	3	4
2. दूसरे बच्चे उसके दोस्त नहीं बनना चाहते	0	1	2	3	4
3. दूसरे बच्चे उसे चिढ़ाते हैं	0	1	2	3	4
4. वे चीज़ें नहीं कर सकता/सकती जो उसकी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. वह दूसरे बच्चों के साथ खेलते समय उनका साथ नहीं दे पाता	0	1	2	3	4

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. कक्षा में ध्यान देना मुश्किल होता है	0	1	2	3	4
2. वह चीज़ें भूल जाता/जाती है	0	1	2	3	4
3. उसे अपना स्कूल का सारा काम और सारा होमवर्क करने में मुश्किल होती है	0	1	2	3	4
4. वह ठीक न होने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4
5. वह डॉक्टर के पास या अस्पताल जाने के कारण स्कूल नहीं जा पाता/पाती	0	1	2	3	4

PedsQL 4.0 Parent (5-7) Acute
03/00

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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पहचान संख्या _____
तिथि: _____

PedsQL™

बालक और किशोर जीवन गुणवत्ता प्रश्नावली लघु अवधि संस्करण

Version 4.0 – Hindi (India)

नन्हे बच्चों (आयु 2-4) के लिए माता या पिता की रिपोर्ट

निर्देश

अगले पेज पर कुछ बातों की लिस्ट दी गई है जो आपके बच्चे के लिए परेशानी हो सकती हैं।
कृपया गोला लगाकर हमें बताएँ कि पिछले 7 दिनों में, इनमें से हरेक आपके बच्चे के लिए कितनी परेशानी रही है:

- 0 पर गोला लगाएँ अगर यह परेशानी कभी नहीं रही हो
- 1 पर गोला लगाएँ अगर यह परेशानी लगभग कभी नहीं रही हो
- 2 पर गोला लगाएँ अगर यह परेशानी कभी-कभी रही हो
- 3 पर गोला लगाएँ अगर यह परेशानी अक्सर रही हो
- 4 पर गोला लगाएँ अगर यह परेशानी लगभग हमेशा रही हो

इन सवालों के कोई सही या गलत जवाब नहीं हैं।
अगर आप कोई सवाल समझ नहीं पाते, तो कृपया मदद माँगें।

PedsQL 4.0 Parent (2-4) Acute
03/00

PedsQL-4.0-Core-Acute-PT - India/Hindi - Version of 27 Jan 17 - Mapi.
ID043653 / PedsQL-4.0-Core-Acute-PT_AU4.0_hin-IN.doc

बिना अनुमति के पुनः प्रस्तुत न किया जाए

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सर्वाधिकार सुरक्षित

पिछले 7 दिनों में, ये बातें आपके बच्चे के लिए कितनी परेशानी रही हैं...

शरीर के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. पैदल चलना	0	1	2	3	4
2. दौड़ना	0	1	2	3	4
3. सक्रिय खेल या कसरत में हिस्सा लेना	0	1	2	3	4
4. कोई भारी सामान उठाना	0	1	2	3	4
5. नहाना	0	1	2	3	4
6. अपने खिलौने उठाने में मदद करना	0	1	2	3	4
7. दर्द या तकलीफ होना	0	1	2	3	4
8. उसे थकान महसूस होती है	0	1	2	3	4

भावनाओं के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. उसे डर महसूस होता है	0	1	2	3	4
2. उसे दुख या उदासी महसूस होती है	0	1	2	3	4
3. उसे गुस्सा महसूस होता है	0	1	2	3	4
4. उसे सोने में परेशानी होती है	0	1	2	3	4
5. उसे चिंता होती है	0	1	2	3	4

सामाजिकता के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. दूसरे बच्चों के साथ खेलना	0	1	2	3	4
2. दूसरे बच्चे उसके साथ खेलना नहीं चाहते	0	1	2	3	4
3. दूसरे बच्चों उसे चिढ़ाते हैं	0	1	2	3	4
4. वे चीजें नहीं कर सकता/सकती जो उसकी उम्र के दूसरे बच्चे कर सकते हैं	0	1	2	3	4
5. वह दूसरे बच्चों के साथ खेलते समय उनका साथ नहीं दे पाता	0	1	2	3	4

*अगर आपका बच्चा स्कूल या डेकेयर में जाता है तो इस भाग को पूरा करें

स्कूल के बारे में (इन बातों के साथ परेशानियाँ...)	कभी नहीं	लगभग कभी नहीं	कभी-कभी	अक्सर	लगभग हमेशा
1. वह स्कूल की उन गतिविधियों को नहीं कर पाता/पाती जिन्हें उसके समकक्ष बच्चे कर लेते हैं	0	1	2	3	4
2. वह ठीक महसूस न करने के कारण स्कूल/डेकेयर नहीं जा पाता/पाती	0	1	2	3	4
3. वह डॉक्टर के पास या अस्पताल जाने के कारण स्कूल/डेकेयर नहीं जा पाता/पाती	0	1	2	3	4

గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

Version 4.0 - Telugu (India)

కౌమారుల నివేదిక (వయస్సులు 13-18)

నిర్దేశాలు

మీకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.
గత నెల రోజులలో ప్రతి ఒక్కటి మీకు ఎంత సమస్యగా ఉందో సున్నా చుట్టడం ద్వారా దయచేసి
మాకు తెలపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

గత నెల రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా ఆరోగ్యం మరియు కార్యకలాపాల గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కన్నా ఎక్కువ నడవడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. పరిగెత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఏదైనా బరువైన దాన్ని ఎత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
5. నాకై నేనుగా స్నానం చేయడం నాకు కష్టంగా ఉంది	0	1	2	3	4
6. ఇంటి పనులలో సహాయం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
7. నాకు నొప్పి కలుగుతుంది	0	1	2	3	4
8. నేను అలసటగా ఉన్నాను	0	1	2	3	4

నా అనుభూతుల గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నాకు భయంగా అనిపిస్తుంది	0	1	2	3	4
2. నాకు విచారంగా అనిపిస్తుంది	0	1	2	3	4
3. నాకు కోపంగా అనిపిస్తుంది	0	1	2	3	4
4. నాకు నిద్ర పోవడంలో ఇబ్బంది ఉంది	0	1	2	3	4
5. నాకు ఏమి జరుగుతుందో అని ఆందోళన చెందుతాను	0	1	2	3	4

నేను ఇతరులతో ఎలా కలిసిమెలిసి ఉంటాను (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర కొమారులతో కలిసిమెలిసి ఉండటంలో నాకు ఇబ్బంది ఉంది	0	1	2	3	4
2. ఇతర కొమారులు నా స్నేహితులుగా ఉండాలనుకోరు	0	1	2	3	4
3. ఇతర కొమారులు నన్ను సతాయిస్తారు	0	1	2	3	4
4. నా వయసులో ఉన్న ఇతర కొమారులు చెయ్యగల పనులు నేను చెయ్యలేను	0	1	2	3	4
5. నా తోటివారితో సమానంగా ఉండడం కష్టం	0	1	2	3	4

గత నెల రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

స్కూలు గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. క్లాసులో శ్రద్ధ చూపడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. నేను విషయాలు మర్చిపోతాను	0	1	2	3	4
3. నా స్కూలు పని మొత్తం పూర్తిచెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల నేను స్కూల్ తప్పిపోతాను	0	1	2	3	4
5. వైద్యుని దగ్గరకు లేదా ఆసుపత్రికి వెళ్లడానికి నేను స్కూలు తప్పిపోతాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీ కొమార బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కంటే ఎక్కువ నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామంలో పాల్గొనడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. అతనికి అతనుగా లేదా ఆమెకు ఆమెగా స్నానం చెయ్యడం	0	1	2	3	4
6. ఇంటిపనిలో సహాయం చెయ్యడం	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పులు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4

భావోద్వేగపరమైన కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. అతనికి లేదా ఆమెకి ఏమవుతుందోనని ఆందోళన చెందడం	0	1	2	3	4

సామాజిక విధుల నిర్వహణ (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర కొమారులతో కలిసిమెలిసి ఉండటంలో	0	1	2	3	4
2. ఇతర కొమారులు అతని లేదా ఆమె స్నేహితులుగా ఉండాలనుకోవడం	0	1	2	3	4
3. ఇతర కొమారులచేత సత్కారంపొందటం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర కొమారులు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర కొమారులతో సమానంగా ఉండడం	0	1	2	3	4

PedsQL 4.0 Parent (13-18) అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు కాపీరైట్ © 1998 జెడెల్స్ట్రూ వార్ని, పీహెచ్.డి. అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి 01/00

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గత 7 రోజులలో, ఇది మీ కొమార బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

స్కూలు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. క్లాసులో శ్రద్ధకనబరచడం	0	1	2	3	4
2. విషయాలు మర్చిపోవడం	0	1	2	3	4
3. స్కూలు పని పూర్తి చెయ్యడం	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల స్కూల్ మానెయ్యడం	0	1	2	3	4
5. వైద్యుడి దగ్గరకు లేదా ఆస్పత్రికి వెళ్ళడంకోసం స్కూల్ మానెయ్యడం	0	1	2	3	4

PedsQL 4.0 Parent (13-18) అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు కాపీరైట్ © 1998 జెడెల్క్యూ వార్ని, పీహెచ్ డి. అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి 01/00

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గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

Version 4.0 - Telugu (India)

పిల్లల నివేదిక (వయస్సులు 8-12)

నిర్దేశాలు

మీకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.
గత నెల రోజులలో ప్రతి ఒక్కటి మీకు ఎంత సమస్యగా ఉందో సున్నా చుట్టడం ద్వారా దయచేసి
మాకు తెలపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.
మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

గత నెల రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా ఆరోగ్యం మరియు కార్యకలాపాల గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కన్నా ఎక్కువ నడవడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. పరిగెత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఏదైనా బరువైన దాన్ని ఎత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
5. నాకై నేనుగా స్నానం చేయడం నాకు కష్టంగా ఉంది	0	1	2	3	4
6. ఇంటి పనులలో సహాయం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
7. నాకు నొప్పి కలుగుతుంది	0	1	2	3	4
8. నేను అలసటగా ఉన్నాను	0	1	2	3	4

నా అనుభూతుల గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నాకు భయంగా అనిపిస్తుంది	0	1	2	3	4
2. నాకు విచారంగా అనిపిస్తుంది	0	1	2	3	4
3. నాకు కోపంగా అనిపిస్తుంది	0	1	2	3	4
4. నాకు నిద్ర పోవడంలో ఇబ్బంది ఉంది	0	1	2	3	4
5. నాకు ఏమి జరుగుతుందో అని ఆందోళన చెందుతాను	0	1	2	3	4

నేను ఇతరులతో ఎలా కలిసిమెలిసి ఉంటాను (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండటంలో నాకు ఇబ్బంది ఉంది	0	1	2	3	4
2. ఇతర పిల్లలు నాకు స్నేహితులుగా ఉండటానికి ఇష్టపడటం లేదు	0	1	2	3	4
3. ఇతర పిల్లలు నన్ను సతాయిస్తారు	0	1	2	3	4
4. నా వయసులోని ఇతర పిల్లలు చేయగల పనులు నేను చెయ్యలేను	0	1	2	3	4
5. నేను ఇతర పిల్లలతో ఆడుకుంటున్నప్పుడు వారితో సమానంగా ఆడుకోవడం కష్టంగా ఉంది	0	1	2	3	4

గత నెల రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా ఆరోగ్యం మరియు కార్యకలాపాల గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కన్నా ఎక్కువ నడవడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. పరిగెత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఏదైనా బరువైన దాన్ని ఎత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
5. నాకై నేనుగా స్నానం చేయడం నాకు కష్టంగా ఉంది	0	1	2	3	4
6. ఇంటి పనులలో సహాయం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
7. నాకు నొప్పి కలుగుతుంది	0	1	2	3	4
8. నేను అలసటగా ఉన్నాను	0	1	2	3	4

నా అనుభూతుల గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నాకు భయంగా అనిపిస్తుంది	0	1	2	3	4
2. నాకు విచారంగా అనిపిస్తుంది	0	1	2	3	4
3. నాకు కోపంగా అనిపిస్తుంది	0	1	2	3	4
4. నాకు నిద్ర పోవడంలో ఇబ్బంది ఉంది	0	1	2	3	4
5. నాకు ఏమి జరుగుతుందో అని ఆందోళన చెందుతాను	0	1	2	3	4

నేను ఇతరులతో ఎలా కలిసిమెలిసి ఉంటాను (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండటంలో నాకు ఇబ్బంది ఉంది	0	1	2	3	4
2. ఇతర పిల్లలు నాకు స్నేహితులుగా ఉండటానికి ఇష్టపడటం లేదు	0	1	2	3	4
3. ఇతర పిల్లలు నన్ను సతాయిస్తారు	0	1	2	3	4
4. నా వయసులోని ఇతర పిల్లలు చేయగల పనులు నేను చెయ్యలేను	0	1	2	3	4
5. నేను ఇతర పిల్లలతో ఆడుకుంటున్నప్పుడు వారితో సమానంగా ఆడుకోవడం కష్టంగా ఉంది	0	1	2	3	4

గత నెల రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

స్కూలు గురించి (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. క్లాసులో శ్రద్ధ చూపడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. నేను విషయాలు మర్చిపోతాను	0	1	2	3	4
3. నా స్కూలు పని మొత్తం పూర్తిచెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల నేను స్కూల్ తప్పిపోతాను	0	1	2	3	4
5. వైద్యుని దగ్గరకు లేదా ఆసుపత్రికి వెళ్లడానికి నేను స్కూలు తప్పిపోతాను	0	1	2	3	4

గుర్తింపు సంఖ్య _____

తేది: _____

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పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

Version 4.0 - Telugu (India)

పిల్లల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 8-12)

నిర్దేశాలు

మీ బిడ్డకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది. గత నెల రోజులలో ప్రతి ఒక్కటి మీ బిడ్డకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - Parent (8-12) అనుమతి లేనిదే పునరుత్పత్తి చేయకూడదు కాపీరైట్ © 1998 జెడల్క్యూ వార్ని, పిహెచ్.డి. అన్ని హక్కులు సురక్షితం చేయబడ్డాయి 01/00

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గత నెల రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కంటే ఎక్కువ నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామంలో పాల్గొనడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. అతనికి అతనుగా లేదా ఆమెకు ఆమెగా స్నానం చెయ్యడం	0	1	2	3	4
6. ఇంటిపనిలో సహాయం చెయ్యడం	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పులు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4
భావోద్వేగపరమైన కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. అతనికి లేదా ఆమెకి ఏమవుతుందోనని ఆందోళన చెందడం	0	1	2	3	4
సామాజిక విధుల నిర్వహణ (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండడంలో	0	1	2	3	4
2. ఇతర పిల్లలు అతని లేదా ఆమె స్నేహితులుగా ఉండాలనుకోవడం	0	1	2	3	4
3. ఇతర పిల్లలచేత సతాయింపబడడం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర పిల్లలు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర పిల్లలతో ఆడుకుంటున్నప్పుడు వారితో సమానంగా ఆడుకోవడం	0	1	2	3	4

PedsQL 4.0 - Parent (8-12) అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు కాపీరైట్ © 1998 జెడల్క్యూ వార్ని, పిహెచ్.డి. అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి 01/00

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గత నెల రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

స్కూలు కార్యకలాపాలు (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. క్లాసులో శ్రద్ధకనబరచడం	0	1	2	3	4
2. విషయాలు మర్చిపోవడం	0	1	2	3	4
3. స్కూలు పని పూర్తి చెయ్యడం	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల స్కూల్ మానెయ్యడం	0	1	2	3	4
5. వైద్యుడి దగ్గరకు లేదా ఆస్పత్రికి వెళ్ళడంకోసం స్కూల్ మానెయ్యడం	0	1	2	3	4

PedsQL 4.0 - Parent (8-12) అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు కాపీరైట్ © 1998 జెడల్క్యూ వార్ని, పిహెచ్.డి. అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి 01/00

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గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

చిన్నపిల్లల జీవననాణ్యత ప్రశ్నావళి

Version 4.0 - Telugu (India)

చిన్నవయసు పిల్లల నివేదిక (వయస్సులు 5-7)

ఇంటర్వ్యూ చేసేవారి కోసం సూచనలు:

కొంతమంది పిల్లలకు సమస్యకాగల విషయాల గురించి నేను మిమ్మల్ని కొన్ని ప్రశ్నలు అడగబోతున్నాను. వీటిలో ఏ విషయాలు మీకు ఎంత సమస్యగా ఉన్నాయో నేను తెలుసుకోవాలనుకుంటున్నాను.

బిడ్డకు టెంప్టిటును చూపించండి మరియు మీరు చదివే జవాబులవైపుకి వేలు చూపించండి.

అది మీకు అస్సలు సమస్య కాకపోతే, నవ్వుతూ ఉండే ముఖంవైపుకి వేలు చూపించండి

అది మీకు కొన్నిసార్లు సమస్య అయితే, మధ్యలోని ముఖంవైపుకి వేలు చూపించండి

అది మీకు చాలా సమస్య అయితే, దుఖంతో ఉండే ముఖంవైపుకి వేలు చూపించండి

నేను ప్రతి ప్రశ్న చదువుతాను. అది మీకు ఎంత సమస్యగా ఉందో నాకు చూపించడానికి చిత్రాలవైపుకి వేలు చూపించండి. మనం మొదట ఒక అభ్యాసాన్ని చేద్దాము.

	ఎంత మాత్రం లేదు	కొన్నిసార్లు	చాలా ఎక్కువ
మీ వేళ్ళతో చిటికె వెయ్యడం మీకు కష్టంగా ఉందా	☺	☹	☹

ప్రశ్నకు జవాబు సరిగా చెప్పారో లేదో నిర్ధారించడానికి బిడ్డను అతని లేదా ఆమె వేళ్ళతో చిటికె వెయ్యమని అడగండి.

బిడ్డ అతని లేదా ఆమె చర్మకు భిన్నంగా ఉన్న జవాబుని చూపిస్తే ప్రశ్నను మళ్ళీ అడగండి.

PedsQL 4.0 - (5-7) అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు Copyright © 1998 JW Varni, Ph.D. అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి
01/00
PedsQL-4.0-Core-YC - India/Telugu - Version of 08 Apr 2019 - Mapi.
ID4375-TR-0044 / PedsQL-4.0-Core-YC_tel-IN.doc

గత కొన్ని వారాలుగా మీరు ఎలా ఉన్నారు అనే దాని గురించి ఆలోచించండి. దయచేసి ప్రతిఒక్క ప్రశ్నను జాగ్రత్తగా వినండి మరియు ఇది మీకు ఎంత సమస్యగా ఉందో నాకు చెప్పండి.

ఒక్క అంశం చదివిన తర్వాత, టెంప్లట్ వైపు పైగ చెయ్యండి. బిడ్డ సమాధానం చెప్పడానికి ముహూమాటపడ్డా లేక ఎలా చెప్పాలో అర్థం కానట్లుగా కనిపించినా, ముఖాలవైపుకి చూపుతూ జవాబు ఎంపికలను చదవండి.

శారీరక పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	దాలా ఎక్కువ
1. మీకు నడవడం కష్టంగా ఉందా	0	2	4
2. మీకు పరిగెత్తడం కష్టంగా ఉందా	0	2	4
3. మీకు ఆటలాడడం లేదా వ్యాయామం చెయ్యడం కష్టంగా ఉందా	0	2	4
4. మీకు పెద్ద వస్తువులు పైకెత్తడం కష్టంగా ఉందా	0	2	4
5. మీకు స్నానం చెయ్యడం కష్టంగా ఉందా	0	2	4
6. మీకు ఇంట్లో పనులు చెయ్యడం కష్టంగా ఉందా (మీ బొమ్మలు పైకెత్తడం వంటిది)	0	2	4
7. మీకు దెబ్బలు లేదా నొప్పలు ఉన్నాయా (ఎక్కడ? _____)	0	2	4
8. మీకెప్పుడైనా ఆడుకోలేనంతగా అలసిపోయినట్లు అనిపిస్తుందా	0	2	4

గుర్తుచేసుకోండి, గత కొన్ని వారాల నుండి ఇది మీకు ఎంత సమస్యగా ఉండిందో నాకు చెప్పండి.

భావోద్వేగపరమైన పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	దాలా ఎక్కువ
1. మీకు భయంగా అనిపిస్తుందా	0	2	4
2. మీకు దుఃఖంగా అనిపిస్తుందా	0	2	4
3. మీకు పిచ్చిగా అనిపిస్తుందా	0	2	4
4. మీకు నిద్రపోవడంలో ఇబ్బంది ఉందా	0	2	4
5. మీకేమి జరుగుతుందో అనే దానిగురించి మీరు చింతిస్తారా	0	2	4

సామాజిక పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	దాలా ఎక్కువ
1. ఇతర పిల్లలతో కలవటం మీకు కష్టంగా ఉందా	0	2	4
2. ఇతర పిల్లలు మీతో ఆటలాడడం వారికిష్టంలేదని అంటారా	0	2	4
3. ఇతర పిల్లలు మిమ్మల్ని ఆటపట్టిస్తారా	0	2	4
4. మీరు చెయ్యలేని పనులు ఇతర పిల్లలు చేస్తారా	0	2	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఉండడం కష్టంగా ఉందా	0	2	4

స్కాలు పనితీరు (...లో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	దాదాపు ఎక్కువ
1. మీకు స్కాలులో శ్రద్ధచూపడం కష్టంగా ఉందా	0	2	4
2. మీరు విషయాలు మర్చిపోతారా	0	2	4
3. స్కాలులో ఇచ్చేపని మీరు చెయ్యడం కష్టంగా ఉందా	0	2	4
4. బాగాలేకపోవడం వల్ల మీరు స్కాలుకు వెళ్ళలేకపోతున్నారా	0	2	4
5. మీరు వైద్యుని వద్దకు లేదా ఆస్పత్రికి వెళ్ళాలి కాబట్టి మీరు స్కాలుకు వెళ్ళలేకపోతున్నారా	0	2	4

ఇది మీకు ఎంత సమస్యగా ఉంది?

ఎంత మాత్రం లేదు



కొన్నిసార్లు



చాలా ఎక్కువ



గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత ప్రశ్నావళి

Version 4.0 - Telugu (India)

పిన్న వయసు పిల్లల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 5-7)

నిర్దేశాలు

మీ బిడ్డకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.
గత నెల రోజులలో ప్రతి ఒక్కటి మీ బిడ్డకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా
దయచేసి మాకు తెలుపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.
మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - Parent (5-7) అనుమతి లేనిది పునరుత్పత్తి చెయ్యకూడదు
01/00

PedsQL-4.0-Core-PYC - India/Telugu - Version of 08 Apr 2019 -Mapi.
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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

గత నెల రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కంటే ఎక్కువ నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామంలో పాల్గొనడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. అతనికి అతనుగా లేదా ఆమెకు ఆమెగా స్నానం చెయ్యడం	0	1	2	3	4
6. చిన్నచిన్న పనులు చెయ్యడం, అతను లేదా ఆమె తన ఆటబొమ్మలను తీసుకోవడం వంటివి	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పలు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4

భావోద్వేగపరమైన కార్యకలాపాలు (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. అతనికి లేదా ఆమెకి ఏమవుతుందోనని ఆందోళన చెందడం	0	1	2	3	4

సామాజిక విధుల నిర్వహణ (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండడంలో	0	1	2	3	4
2. ఇతర పిల్లలు అతని లేదా ఆమె స్నేహితులుగా ఉండాలనుకోకపోవడం	0	1	2	3	4
3. ఇతర పిల్లలచేత సత్కారంపడడం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర పిల్లలు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఆడడం	0	1	2	3	4

PedsQL 4.0 - Parent (5-7) అనుమతి లేనిది పునరుత్పత్తి చెయ్యకూడదు
01/00

PedsQL-4.0-Core-PYC - India/Telugu - Version of 08 Apr 2019 -Mapi.
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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

స్కూలు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. క్లాసులో శ్రద్ధకనబరచడం	0	1	2	3	4
2. విషయాలు మర్చిపోవడం	0	1	2	3	4
3. స్కూలు కార్యకలాపాలు చెయ్యడం	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల స్కూల్ మానెయ్యడం	0	1	2	3	4
5. వైద్యుడి దగ్గరకు లేదా ఆస్పత్రికి వెళ్ళడంకోసం స్కూల్ మానెయ్యడం	0	1	2	3	4

గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

వెర్షన్ 4.0 Telugu (India)

చంటిపిల్లల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 2-4)

నిర్దేశాలు

మీ బిడ్డకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.
గత నెల రోజులలో ప్రతి ఒక్కటి మీ బిడ్డకు ఎంత సమస్యగా ఉందో సున్నా చుట్టడం ద్వారా దయచేసి
మాకు తెలపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

దీనిలో ఒప్పు లేదా తప్పు జవాబులు లేవు.
మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - Parent (2-4)

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL-4.0-Core-PT - India/Telugu - Version of 16 dec 16 - Mapi.
ID043653 / PedsQL-4.0-Core-PT_AU4.0_tel-IN.doc

గత నెల రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. చురుకుగా ఆడుకోవడం లేదా వ్యాయామం చెయ్యడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. స్నానం చెయ్యడం	0	1	2	3	4
6. అతని లేదా ఆమె ఆటవస్తువులను అందుకోవడంలో సహకరించడం	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పులు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4

భావోద్వేగపరమైన కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. ఆందోళన చెందడం	0	1	2	3	4

సామాజిక విధుల నిర్వహణ (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో ఆడుకోవడం	0	1	2	3	4
2. ఇతర పిల్లలు అతనితో లేదా ఆమెతో ఆడుకోవాలని అనుకోకపోవడం	0	1	2	3	4
3. ఇతర పిల్లలచేత సతాయించబడడం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర పిల్లలు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఉండడం	0	1	2	3	4

PedsQL 4.0 - Parent (2-4)

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

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01/00

అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL-4.0-Core-PT - India/Telugu - Version of 16 dec 16 - Mapi.
ID043653 / PedsQL-4.0-Core-PT_AU4.0_tel-IN.doc

***మీ బిడ్డను స్కూలుకు లేదా సంరక్షణ కేంద్రానికి పంపుతున్నట్లయితే దయచేసి ఈ విభాగాన్ని పూరించండి**

స్కూలు కార్యకలాపాలు (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. తోటివారి వలె అవే స్కూలు కార్యకలాపాలను చెయ్యడం	0	1	2	3	4
2. ఒంట్లో బాగాలేకపోవడం వల్ల స్కూలు/సంరక్షణ కేంద్రం మానెయ్యడం	0	1	2	3	4
3. వైద్యుడి దగ్గరకు లేదా ఆస్పత్రికి వెళ్ళడంకోసం స్కూలు/సంరక్షణ కేంద్రం మానెయ్యడం	0	1	2	3	4

PedsQL 4.0 - Parent (2-4)

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

01/00

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL-4.0-Core-PT - India/Telugu - Version of 16 dec 16 - Mapi.
ID043653 / PedsQL-4.0-Core-PT_AU4.0_tel-IN.doc

గుర్తింపు సంఖ్య _____

తేది: _____

PedsQL™

వయోజనుల జీవన నాణ్యత

ప్రశ్నావళి

Version 4.0 – Telugu (India)

వయోజనుల నివేదిక

గత 7 రోజుల వెర్షన్

నిర్దేశాలు

మీకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో ప్రతి ఒక్కటి మీకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

- 0 ఇది ఎప్పడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - (Adult) Acute

అనుమతి లేనిదే పునరుత్పత్తి చేయకూడదు

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అన్ని హక్కులు సురక్షితం చేయబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale - Adult - India/Telugu - 20 Aug 09 - Mapi Research Institute.
ID5020 / PedsQL-4.0-Acute-Core-Ad_AU4.0_tel-IN

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా ఆరోగ్యం మరియు కార్యకలాపాల గురించి(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కన్నా ఎక్కువ నడవడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. పరిగెత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఏదైనా బరువైన దాన్ని ఎత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
5. నాకై నేనుగా స్నానం చేయడం నాకు కష్టంగా ఉంది	0	1	2	3	4
6. ఇంటి పనులలో సహాయం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
7. నాకు నొప్పి కలుగుతుంది	0	1	2	3	4
8. నేను అలసటగా ఉన్నాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా అనుభూతుల గురించి(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నాకు భయంగా అనిపిస్తుంది	0	1	2	3	4
2. నాకు విచారంగా అనిపిస్తుంది	0	1	2	3	4
3. నాకు కోపంగా అనిపిస్తుంది	0	1	2	3	4
4. నాకు నిద్ర పోవడంలో ఇబ్బంది ఉంది	0	1	2	3	4
5. నాకు ఏమి జరుగుతుందో అని ఆందోళన చెందుతాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నేను ఇతరులతో ఎలా కలిసిమెలిసి ఉంటాను(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర వయోజనులతో కలిసిమెలిసి ఉండటంలో నాకు ఇబ్బందులు కలుగుతాయి	0	1	2	3	4
2. ఇతర వయోజనులు నా స్నేహితులుగా ఉండాలనుకోరు	0	1	2	3	4
3. ఇతర వయోజనులు నన్ను సతాయిస్తారు	0	1	2	3	4
4. నా వయసులో ఉన్న ఇతరులు చెయ్యగల పనులు నేను చెయ్యలేను	0	1	2	3	4
5. నా తోటివారితో సమానంగా ఉండడం కష్టం	0	1	2	3	4

PedsQL 4.0 - (Adult) Acute

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale - Adult - India/Telugu - 20 Aug 09 - Mapi Research Institute.

ID5020 / PedsQL-4.0-Acute-Core-Ad_AU4.0_tel-IN

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా పని/చదువు గురించి(...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. పనిలో లేదా స్కూలులో శ్రద్ధ కనబరచడం కష్టం	0	1	2	3	4
2. నేను విషయాలు మర్చిపోతాను	0	1	2	3	4
3. నా పని లేదా చదువు పూర్తి చెయ్యడంలో నాకు ఇబ్బంది ఉంది	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల నేను పని లేదా స్కూల్ మానేస్తాను	0	1	2	3	4
5. వైద్యుడి దగ్గరకు లేదా ఆస్పత్రికి వెళ్ళడంకోసం నేను పని లేదా స్కూల్ మానేస్తాను	0	1	2	3	4

PedsQL 4.0 - (Adult) Acute

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale - Adult - India/Telugu - 20 Aug 09 - Mapi Research Institute.
ID5020 / PedsQL-4.0-Acute-Core-Ad_AU4.0_tel-IN

గుర్తింపు సంఖ్య _____

తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

Version 4.0 – Telugu (India)

కొమారుల నివేదిక (వయస్సులు 13-18)

గత 7 రోజుల వెర్షన్

నిర్దేశాలు

మీకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో ప్రతి ఒక్కటి మీకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే

1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే

2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే

3 ఇది తరచుగా ఒక సమస్య అయితే

4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - (13-18) Acute

అనుమతి లేనిది పునరుత్పత్తి చేయకూడదు

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అన్ని హక్కులు సురక్షితం చేయబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale - Child (13 - 18) - India/Telugu - 20 Aug 09 - Mapi Research Institute.
ID5020 / PedsQL-4.0-Acute-Core-A_AU4.0_tel-IN

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా ఆరోగ్యం మరియు కార్యకలాపాల గురించి(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కన్నా ఎక్కువ నడవడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. పరిగెత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఏదైనా బరువైన దాన్ని ఎత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
5. నాకై నేనుగా స్నానం చేయడం నాకు కష్టంగా ఉంది	0	1	2	3	4
6. ఇంటి పనులలో సహాయం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
7. నాకు నొప్పి కలుగుతుంది	0	1	2	3	4
8. నేను అలసటగా ఉన్నాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా అనుభూతుల గురించి(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నాకు భయంగా అనిపిస్తుంది	0	1	2	3	4
2. నాకు విచారంగా అనిపిస్తుంది	0	1	2	3	4
3. నాకు కోపంగా అనిపిస్తుంది	0	1	2	3	4
4. నాకు నిద్ర పోవడంలో ఇబ్బంది ఉంది	0	1	2	3	4
5. నాకు ఏమి జరుగుతుందో అని ఆందోళన చెందుతాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నేను ఇతరులతో ఎలా కలిసిమెలిసి ఉంటాను(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర క్రీడారులతో కలిసిమెలిసి ఉండటంలో నాకు ఇబ్బంది ఉంది	0	1	2	3	4
2. ఇతర క్రీడారులు నా స్నేహితులుగా ఉండాలనుకోరు	0	1	2	3	4
3. ఇతర క్రీడారులు నన్ను సతాయిస్తారు	0	1	2	3	4
4. నా వయసులో ఉన్న ఇతర క్రీడారులు చెయ్యగల పనులు నేను చెయ్యలేను	0	1	2	3	4
5. నా తోటివారితో సమానంగా ఉండడం కష్టం	0	1	2	3	4

PedsQL 4.0 - (13-18) Acute

అనుమతి లేనిది పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale -Child (13 - 18) - India/Telugu - 20 Aug 09 - Mapi Research Institute.
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గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

స్కాలు గురించి(. . .తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. క్లాసులో శ్రద్ధ చూపడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. నేను విషయాలు మర్చిపోతాను	0	1	2	3	4
3. నా స్కాలు పని మొత్తం పూర్తిచెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఒంట్లో బాగాలేకపోవడం వల్ల నేను స్కూల్ తప్పిపోతాను	0	1	2	3	4
5. వైద్యుని దగ్గరకు లేదా ఆసుపత్రికి వెళ్లటానికి నేను స్కాలు తప్పిపోతాను	0	1	2	3	4

PedsQL 4.0 - (13-18) Acute

అనుమతి లేనిది పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

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గుర్తింపు సంఖ్య _____

తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

గత 7 రోజుల వెర్షన్

Version 4.0 – Telugu (India)

కొమారుల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 13-18)

నిర్దేశాలు

మీ కొమార బిడ్డకు సమస్య అయ్యే విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో మీ కొమార బిడ్డకు ప్రతి ఒక్కటి ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - Parent (13-18) Acute

అనుమతి లేనిదే పునరుత్పత్తి చేయకూడదు

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అన్ని హక్కులు సురక్షితం చేయబడ్డాయి

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గత 7 రోజులలో, ఇది మీ కొమార బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కంటే ఎక్కువ నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామంలో పాల్గొనడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. అతనికి అతనుగా లేదా ఆమెకు ఆమెగా స్నానం చెయ్యడం	0	1	2	3	4
6. ఇంటిపనిలో సహాయం చెయ్యడం	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పులు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4

గత 7 రోజులలో, ఇది మీ కొమార బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

భావోద్వేగపరమైన కార్యకలాపాలు(...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. అతనికి లేదా ఆమెకి ఏమవుతుందోనని ఆందోళన చెందడం	0	1	2	3	4

గత 7 రోజులలో, ఇది మీ కొమార బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

సామాజిక విధుల నిర్వహణ(...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర కొమారులతో కలిసిమెలిసి ఉండటంలో	0	1	2	3	4
2. ఇతర కొమారులు అతని లేదా ఆమె స్నేహితులుగా ఉండాలనుకోవడం	0	1	2	3	4
3. ఇతర కొమారులచేత సత్కారంపొందటం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర కొమారులు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర కొమారులతో సమానంగా ఉండడం	0	1	2	3	4

PedsQL 4.0 - Parent (13-18)

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

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గుర్తింపు సంఖ్య _____

తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

Version 4.0 – Telugu (India)

పిల్లల నివేదిక (వయస్సులు 8-12)

గత 7 రోజుల వైర్సన్

నిర్దేశాలు

మీకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో ప్రతి ఒక్కటి మీకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే

1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే

2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే

3 ఇది తరచుగా ఒక సమస్య అయితే

4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - (8-12) Acute

అనుమతి లేనిది పునరుత్పత్తి చేయకూడదు

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అన్ని హక్కులు సురక్షితం చేయబడ్డాయి

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గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా ఆరోగ్యం మరియు కార్యకలాపాల గురించి(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కన్నా ఎక్కువ నడవడం నాకు కష్టంగా ఉంది	0	1	2	3	4
2. పరిగెత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
4. ఏదైనా బరువైన దాన్ని ఎత్తడం నాకు కష్టంగా ఉంది	0	1	2	3	4
5. నాకై నేనుగా స్నానం చేయడం నాకు కష్టంగా ఉంది	0	1	2	3	4
6. ఇంటి పనులలో సహాయం చెయ్యడం నాకు కష్టంగా ఉంది	0	1	2	3	4
7. నాకు నొప్పి కలుగుతుంది	0	1	2	3	4
8. నేను అలసటగా ఉన్నాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నా అనుభూతుల గురించి(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నాకు భయంగా అనిపిస్తుంది	0	1	2	3	4
2. నాకు విచారంగా అనిపిస్తుంది	0	1	2	3	4
3. నాకు కోపంగా అనిపిస్తుంది	0	1	2	3	4
4. నాకు నిద్ర పోవడంలో ఇబ్బంది ఉంది	0	1	2	3	4
5. నాకు ఏమి జరుగుతుందో అని ఆందోళన చెందుతాను	0	1	2	3	4

గత 7 రోజులలో, ఇది మీకు ఎంతగా ఒక సమస్య అయింది ...

నేను ఇతరులతో ఎలా కలిసిమెలిసి ఉంటాను(... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండటంలో నాకు ఇబ్బంది ఉంది	0	1	2	3	4
2. ఇతర పిల్లలు నాకు స్నేహితులుగా ఉండటానికి ఇష్టపడటం లేదు	0	1	2	3	4
3. ఇతర పిల్లలు నన్ను సతాయిస్తారు	0	1	2	3	4
4. నా వయసులోని ఇతర పిల్లలు చేయగల పనులు నేను చెయ్యలేను	0	1	2	3	4
5. నేను ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఉండడం కష్టంగా ఉంది	0	1	2	3	4

PedsQL 4.0 - (8-12) Acute

అనుమతి లేనిది పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

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గుర్తింపు సంఖ్య _____

తేదీ: _____

PedsQL™

పిల్లల జీవన నాణ్యత

ప్రశ్నావళి

గత 7 రోజుల వెర్షన్

Version 4.0 – Telugu (India)

పిల్లల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 8-12)

నిర్దేశాలు

మీ బిడ్డకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో ప్రతి ఒక్కటి మీ బిడ్డకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 - Parent (8-12) Acute

అనుమతి లేనిదే పునరుత్పత్తి చేయకూడదు

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అన్ని హక్కులు సురక్షితం చేయబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale - Parent (8 - 12) - India/Telugu - 20 Aug 09 - Mapi Research Institute.
ID5020 / PedsQL-4.0-Acute-Core-PC_AJ4.0_tel-IN

గత 7 రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కంటే ఎక్కువ నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామంలో పాల్గొనడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. అతనికి అతనుగా లేదా ఆమెకు ఆమెగా స్నానం చెయ్యడం	0	1	2	3	4
6. ఇంటిపనిలో సహాయం చెయ్యడం	0	1	2	3	4
7. నొప్పిలు కలగడం	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4

గత 7 రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

భావోద్వేగపరమైన కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా అనిపించటం	0	1	2	3	4
2. విచారంగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. అతనికి లేదా ఆమెకి ఏమవుతుందోనని ఆందోళన చెందడం	0	1	2	3	4

గత 7 రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

సామాజిక విధుల నిర్వహణ (... తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండడంలో	0	1	2	3	4
2. ఇతర పిల్లలు అతని లేదా ఆమె స్నేహితులుగా ఉండాలనుకోకపోవడం	0	1	2	3	4
3. ఇతర పిల్లలచేత సతాయించబడడం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర పిల్లలు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఉండడం	0	1	2	3	4

PedsQL 4.0 - Parent (8-12)

అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

PedsQL™ Pediatric Quality of Life Inventory Version 4.0 - Generic Core Scale - Parent (8 - 12) - India/Telugu - 20 Aug 09 - Mapi Research Institute.
ID5020 / PedsQL-4.0-Acute-Core-PC_AU4.0_tel-IN

గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

చిన్నపిల్లల జీవననాణ్యత ప్రశ్నావళి

గత 7 రోజుల వెర్షన్

Version 4.0 - Telugu (India)

చిన్నవయసు పిల్లల నివేదిక (వయస్సులు 5-7)

ఇటర్వ్యూ చేసేవారికోసం సూచనలు:

కొంతమంది పిల్లలకు సమస్యకాగల విషయాల గురించి నేను మిమ్మల్ని కొన్ని ప్రశ్నలు అడగబోతున్నాను. వీటిలో ఏ విషయాలు మీకు ఎంత సమస్యగా ఉన్నాయో నేను తెలుసుకోవాలనుకుంటున్నాను.

బిడ్డకు మార్గదర్శిని చూపించండి మరియు మీరు చదివే జవాబులవైపుకి వేలు చూపించండి.

అది మీకు అస్సలు సమస్య కాకపోతే, నవ్వుతూ ఉండే ముఖంవైపుకి వేలు చూపించండి

అది మీకు కొన్నిసార్లు సమస్య అయితే, మధ్యలోని ముఖంవైపుకి వేలు చూపించండి

అది మీకు చాలా సమస్య అయితే, దుఖంతో ఉండే ముఖంవైపుకి వేలు చూపించండి

నేను ప్రతి ప్రశ్న చదువుతాను. అది మీకు ఎంత సమస్యగా ఉందో నాకు చూపించడానికి చిత్రాలవైపుకి వేలు చూపించండి. మనం మొదట ఒక అభ్యాసాన్ని చేద్దాము.

	ఎంత మాత్రం లేదు	కొన్నిసార్లు	చాలా ఎక్కువ
మీ వేళ్ళతో చిటికె వెయ్యడం మీకు కష్టంగా ఉందా	😊	😐	😞

ప్రశ్నకు జవాబు సరిగా చెప్పారో లేదో నిర్ధారించడానికి బిడ్డను అతని లేదా ఆమె వేళ్ళతో చిటికె వెయ్యమని అడగండి. బిడ్డ అతని లేదా ఆమె చర్యకు భిన్నంగా ఉన్న జవాబుని చూపిస్తే ప్రశ్న మళ్ళీ అడగండి.

PedsQL 4.0 - (5-7) Acute అనుమతి లేనిదే పునరుత్పత్తి చేయకూడదు
03/00

PedsQL-4.0-Core-Acute-YC - India/Telugu - Version of 27 Jan 17 - Mapi.
ID043653 / PedsQL-4.0-Core-Acute-YC_tel-IN.doc

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అన్ని హక్కులు సురక్షితం చేయబడ్డాయి

గత 7 రోజులుగా మీరు ఎలా ఉన్నారు అనే దాని గురించి ఆలోచించండి. దయచేసి ప్రతిఒక్క ప్రశ్నను జాగ్రత్తగా వినండి మరియు ఇది మీకు ఎంత సమస్యగా ఉందో నాకు చెప్పండి.

ఒక్క అంశం చదివిన తర్వాత, టెంప్లేట్ వైపు పైగ చెయ్యండి. బిడ్డ సమాధానం చెప్పడానికి మొహమాటపడ్డా లేక ఎలా చెప్పాలో అర్థం కానట్లుగా కనిపించినా, ముఖాలపైపుకి చూపుతూ జవాబు ఎంపికలను చదవండి.

శారీరక పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	చాలా ఎక్కువ
1. మీకు నడవడం కష్టంగా ఉందా	0	2	4
2. మీకు పరిగెత్తడం కష్టంగా ఉందా	0	2	4
3. మీకు ఆటలాడడం లేదా వ్యాయామం చెయ్యడం కష్టంగా ఉందా	0	2	4
4. మీకు పెద్ద వస్తువులు పైకెత్తడం కష్టంగా ఉందా	0	2	4
5. మీకు స్నానం చెయ్యడం కష్టంగా ఉందా	0	2	4
6. మీకు ఇంట్లో పనులు చెయ్యడం కష్టంగా ఉందా (మీ బొమ్మలు పైకెత్తడం వంటిది)	0	2	4
7. మీకు దెబ్బలు లేదా నొప్పులు ఉన్నాయా (ఎక్కడ?_____)	0	2	4
8. మీకెప్పుడైనా ఆడుకోలేనంతగా అలసిపోయినట్లు అనిపిస్తుందా	0	2	4

గుర్తుచేసుకోండి, గత 7 రోజులనుండి ఇది మీకు ఎంత సమస్యగా ఉండిందో నాకు చెప్పండి.

భావోద్వేగపరమైన పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	చాలా ఎక్కువ
1. మీకు భయంగా అనిపిస్తుందా	0	2	4
2. మీకు దుఖంగా అనిపిస్తుందా	0	2	4
3. మీకు పిచ్చిగా అనిపిస్తుందా	0	2	4
4. మీకు నిద్రపోవడంలో ఇబ్బంది ఉందా	0	2	4
5. మీకేమి జరుగుతుందో అనే దానిగురించి మీరు చింతిస్తారా	0	2	4

సామాజిక పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	చాలా ఎక్కువ
1. ఇతర పిల్లలతో సమానంగా ఆడుకోవడానికి మీకు కష్టంగా ఉందా	0	2	4
2. ఇతర పిల్లలు మీతో ఆటలాడడం వారికిష్టంలేదని అంటారా	0	2	4
3. ఇతర పిల్లలు మిమ్మల్ని ఆటపట్టిస్తారా	0	2	4
4. మీరు చెయ్యలేని పనులు ఇతర పిల్లలు చేస్తారా	0	2	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఉండడం కష్టంగా ఉందా	0	2	4

స్కూలు పనితీరు (...తో సమస్యలు)	ఎంత మాత్రం లేదు	కొన్నిసార్లు	చాలా ఎక్కువ
1. మీకు స్కూలులో శ్రద్ధచూపడం కష్టంగా ఉందా	0	2	4
2. మీరు విషయాలు మర్చిపోతారా	0	2	4
3. స్కూలులో ఇచ్చేపని మీరు చెయ్యడం కష్టంగా ఉందా	0	2	4
4. బాగాలేకపోవడం వల్ల మీరు స్కూలుకు వెళ్ళలేకపోతున్నారా	0	2	4
5. మీరు వైద్యుని వద్దకు లేదా ఆస్పత్రికి వెళ్ళాలి కాబట్టి మీరు స్కూలుకు వెళ్ళలేకపోతున్నారా	0	2	4

ఇది మీకు ఎంత సమస్యగా ఉంది?

ఎంత మాత్రం లేదు



కొన్నిసార్లు



చాలా ఎక్కువ



గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత ప్రశ్నావళి

గత 7 రోజుల వెర్షన్

Version 4.0 - Telugu (India)

పిన్న వయసు పిల్లల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 5-7)

నిర్దేశాలు

మీ బిడ్డకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో ప్రతి ఒక్కటి మీ బిడ్డకు ఎంత సమస్యగా ఉండినదో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలుపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

సరియైన లేదా తప్పు సమాధానాలు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

గత 7 రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. 100 మీటర్ల కంటే ఎక్కువ నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. క్రీడా కార్యకలాపం లేదా వ్యాయామంలో పాల్గొనడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. అతనికి అతనుగా లేదా ఆమెకు ఆమెగా స్నానం చెయ్యడం	0	1	2	3	4
6. చిన్నచిన్న పనులు చెయ్యడం, అతను లేదా ఆమె తన ఆటబొమ్మలను తీసుకోవడం వంటివి	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పులు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4
భావోద్వేగపరమైన కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. అతనికి లేదా ఆమెకి ఏమవుతుందోనని ఆందోళన చెందడం	0	1	2	3	4
సామాజిక విధుల నిర్వహణ (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో కలిసిమెలిసి ఉండడంలో	0	1	2	3	4
2. ఇతర పిల్లలు అతని లేదా ఆమె స్నేహితులుగా ఉండాలనుకోవడం	0	1	2	3	4
3. ఇతర పిల్లలచేత సతాయింపబడడం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర పిల్లలు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఆడడం	0	1	2	3	4

గుర్తింపు సంఖ్య _____
తేది: _____

PedsQL™

పిల్లల జీవన నాణ్యత ప్రశ్నావళి

గత 7 రోజుల వెర్షన్

Version 4.0 - Telugu (India)

చంటిపిల్లల కోసం తల్లిదండ్రుల నివేదిక (వయస్సులు 2-4)

నిర్దేశాలు

మీ బిడ్డకు సమస్య కాగల విషయాల జాబితా తర్వాతి పేజీలలో ఇవ్వబడింది.

గత 7 రోజులలో ప్రతి ఒక్కటి మీ బిడ్డకు ఎంత సమస్యగా ఉందో సున్నా చుట్టడం ద్వారా దయచేసి మాకు తెలపండి:

- 0 ఇది ఎప్పుడూ ఒక సమస్య కాకపోతే
- 1 ఇది దాదాపు ఎప్పుడూ ఒక సమస్య కాకపోతే
- 2 ఇది కొన్నిసార్లు ఒక సమస్య అయితే
- 3 ఇది తరచుగా ఒక సమస్య అయితే
- 4 ఇది దాదాపు ఎల్లప్పుడూ ఒక సమస్య అయితే

దీనిలో ఒప్పు లేదా తప్పు జవాబులు లేవు.

మీకు ఒక ప్రశ్న అర్థం కాకపోతే, దయచేసి సహాయం కోసం అడగండి.

PedsQL 4.0 Parent (2-4) అనుమతి లేనిది పునరుత్పత్తి చెయ్యకూడదు
Acute
03/00

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

గత 7 రోజులలో, ఇది మీ బిడ్డకు ఎంతగా ఒక సమస్య అయింది ...

శారీరక ఆరోగ్యం మరియు కార్యకలాపాలు (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. నడవడం	0	1	2	3	4
2. పరిగెత్తడం	0	1	2	3	4
3. చురుకుగా ఆడుకోవడం లేదా వ్యాయామం చెయ్యడం	0	1	2	3	4
4. ఏదైనా బరువైనదానిని ఎత్తడం	0	1	2	3	4
5. స్నానం చెయ్యడం	0	1	2	3	4
6. అతని లేదా ఆమె ఆటవస్తువులను అందుకోవడంలో సహకరించడం	0	1	2	3	4
7. దెబ్బలు తగిలించుకోవడం లేదా నొప్పులు	0	1	2	3	4
8. అలసటగా ఉండడం	0	1	2	3	4

భావోద్వేగపరమైన కార్యకలాపాలు (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. భయంగా లేదా భయపెట్టబడినట్లు అనిపించటం	0	1	2	3	4
2. విచారంగా లేదా నిరాశగా అనిపించటం	0	1	2	3	4
3. కోపంగా అనిపించడం	0	1	2	3	4
4. నిద్ర పోవడంలో ఇబ్బంది	0	1	2	3	4
5. ఆందోళన చెందడం	0	1	2	3	4

సామాజిక విధుల నిర్వహణ (...లో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. ఇతర పిల్లలతో ఆడుకోవడం	0	1	2	3	4
2. ఇతర పిల్లలు అతనితో లేదా ఆమెతో ఆడుకోవాలని అనుకోకపోవడం	0	1	2	3	4
3. ఇతర పిల్లలచేత సతాయింపబడడం	0	1	2	3	4
4. అతని లేదా ఆమె వయసులో ఉన్న ఇతర పిల్లలు చెయ్యగల పనులు చెయ్యలేకపోవడం	0	1	2	3	4
5. ఇతర పిల్లలతో ఆడుతున్నప్పుడు వారితో సమానంగా ఉండడం	0	1	2	3	4

PedsQL 4.0 Parent (2-4) అనుమతి లేనిదే పునరుత్పత్తి చెయ్యకూడదు
Acute
03/00

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అన్ని హక్కులు సురక్షితం చెయ్యబడ్డాయి

*మీ బిడ్డను స్కూలుకు లేదా సంరక్షణ కేంద్రానికి పంపుతున్నట్లయితే దయచేసి ఈ విభాగాన్ని పూరించండి

స్కూలు కార్యకలాపాలు (...తో సమస్యలు)	ఎప్పుడూ లేదు	దాదాపు ఎప్పుడూ లేదు	కొన్నిసార్లు	తరచుగా	దాదాపు ఎల్లప్పుడూ
1. తోటివారి వలె అవే స్కూలు కార్యకలాపాలను చెయ్యడం	0	1	2	3	4
2. ఒంట్లో బాగాలేకపోవడం వల్ల స్కూలు/సంరక్షణ కేంద్రం మానెయ్యడం	0	1	2	3	4
3. వైద్యుడి దగ్గరకు లేదా ఆస్పత్రికి వెళ్ళడంకోసం స్కూలు/సంరక్షణ కేంద్రం మానెయ్యడం	0	1	2	3	4

APPENDIX IV

PARTICIPANT INFORMATION WITH INFORMED CONSENT FORM

<i>Informed Consent Form</i>

Name of the Principal Investigator: Ms. Krishnasri Padamandala

Name of the Organization: University of Hyderabad, Hyderabad

Centre for sight Superspeciality eye hospital, Banjara hills,
Hyderabad.

Name of the Project and version: Quality of life(QL) in Retinoblastoma(RB) survivors in India: QL-RB-India study, Version1

This Informed Assent Form has two parts:

- **Information Sheet (gives you information about the study)**
- **Certificate of Assent (this is where you sign if you agree to participate)**

You will be given a copy of the full Informed Assent Form

Part I: Information Sheet

Introduction:

My Name is Miss Krishnasri Padamandala, my job is to research and investigate the “**Quality of life in Retinoblastoma(RB) survivors in India**”. We would like to know as a result of effective treatment how far the health-related quality of life would impact an RB survivor's life physically, mentally, and psychologically and all other possible dimensions of quality of life.

I am going to give you information and invite you to be part of a research study. You can choose whether or not you want to participate. We have discussed this research with your parent(s)/guardian and they know that we are also asking you for your agreement. If you are going to participate in the research, your parent(s)/guardian also have to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed.

You may discuss anything in this form with your parents or friends or anyone else you feel comfortable talking to. You can decide whether to participate or not after you have talked it over. You do not have to decide immediately.

There may be some words you don't understand or things that you want me to explain more about because you are interested or concerned. Please ask me to stop at any time and I will take time to explain

Purpose:

Why are we doing this research?

We would like to find out the influencing factors of the quality of life in Retinoblastoma (RB) survivors in India, from the childhood cancer survivors' perspective and to study the long-term impact of different treatment options available for RB. And also to provide additional data to understand the needs of RB survivors to identify those who are at greatest risk for the adverse effects of the disease and treatment.

Choice of participants:

Why are you asking me?

We are doing this research in children, adolescents and also Young adults who are a survivor of retinoblastoma. retinoblastoma is more prevalent cancer in children. Quality of life assessment is often neglected but an important aspect of survivorship to be addressed.

Participation is voluntary:

Do I have to do this?

You don't have to be in this research if you don't want to be. It's up to you. If you decide not to be in the research, it's okay and nothing changes. This is still your clinic, everything stays the same as before. Even if you say "yes" now, you can change your mind later, and it's still okay.

If applicable: If anything changes and we want you to stay in the research study even if you want to stop, we will talk to you first.

Procedures:

We are asking you to help us learn more about the quality of life in the RB community. We are inviting you to take part in this research project. If you accept, you will be asked to fill out a questionnaire and participate in the structured interview.

A survey questionnaire and the structured interview will be provided by Miss Krishnasri Padamandala and collected by Miss Krishnasri Padamandala OR You may answer the questionnaire yourself, or it can be read to you and you can say out loud the answer you want me to write down.

If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. The information recorded is confidential, your name is not being included on the forms, only a number will identify you, and no one else except the primary investigator miss Krishnasri Padamandala, and the co-investigator will have access to your survey.

You can ask me to stop and explain again at any time and I will explain more about the process.

Duration:

The research takes place over 1 (one) day in total. During that time, we will visit you for collecting the survey questionnaire and to perform the structured interview at your visit to the hospital (whenever it is scheduled and or possible during the project stipulated time) which will last for about half an hour to an hour (based on the subject response) to collect the responses from you for both survey and interview.

Risks:

We are asking you to share with us some very personal and confidential information for example sensitive and personal issues, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion/interview/survey if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

Benefits:

There will be no direct benefit to you, but your participation is likely to help us find out more about how to assess the quality of life and take the necessary steps to address each issue individually as part of rehabilitation.

You can tell me if you have understood correctly the benefits that you will have if you take part in the study? or you can ask me again if you have any questions.

Reimbursement:

You will not be provided any incentive to take part in the research.

Confidentiality:

The research being done in the RB community may draw attention and if you participate you may be asked questions by other people in the RB community who visits the Centre for sight hospital. We will not be sharing information about you with anyone outside of the research team. The information that we collect from this research project will be kept private. Any

information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key or in an electronic device with an authenticated password. It will not be shared with or given to anyone except Miss Krishnasri Padamandala and the collaborated institutes such as your clinician from the centre for sight super specialty eye hospital and the University of Hyderabad.

Sharing the Results:

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you within the RB community before it is made widely available to the public as a publication and conference. Each participant will receive a summary of the results.

Right to Refuse or Withdraw:

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your job or job-related evaluations in any way. You may stop participating in the [Survey /interview] at any time that you wish without your job being affected. I will allow you at the end of the Survey /interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my remarks or if I did not understand you correctly.

Whom to Contact:

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Name: Miss Krishnasri Padamandala

Address: School of Medical Sciences, University of Hyderabad, Gachibowli, Hyderabad, Telangana-50046, India.

Telephone number: +91 8330939107

e-mail: krishnasri.p6931@gmail.com

This proposal has been reviewed and approved by [the University of Hyderabad, local IEC], which is a committee whose task is to make sure that research participants are protected from harm. If you wish to find about more about the IEC, contact: iec_uoh@uohyd.ernet.in

You can ask me any more questions about any part of the research study if you wish to. Do you have any questions?

Part II: Certificate of Consent.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

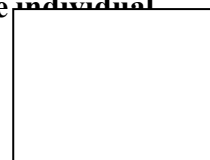
Signature of Participant _____

Date _____

Day/month/year

If illiterate²

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.



² A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb print as well).

Print name of witness _____

Thumb print of participant

Signature of witness _____

Date _____

(Day/month/year)

Statement by the researcher/person taking consent:

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Structured Interview

2. Questionnaire survey

I confirm that the participant was allowed to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent: Miss Krishnasri Padamandala

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

APPENDIX V ASSENT FORM FOR CHILDREN/MINORS

Informed assent

<i>Informed Assent Form for Children/Minors</i>

Name of the Principal Investigator: Ms. Krishnasri Padamandala

Name of the Organization: University of Hyderabad, Hyderabad

Centre for sight Superspecility eye hospital, Banjarahills,
Hyderabad.

Name of the Project and version: Quality of life(QL) in Retinoblastoma(RB) survivors in
India: QL-RB-India study, Version1

This Informed Assent Form has two parts:

- **Information Sheet (gives you information about the study)**
- **Certificate of Assent (this is where you sign if you agree to participate)**

You will be given a copy of the full Informed Assent Form

Part I: Information Sheet

Introduction:

My Name is Miss Krishnasri Padamandala, my job is to research and investigate the “**Quality of life in Retinoblastoma(RB) survivors in India**”. We would like to know as a result of

effective treatment how far the health-related quality of life would impact an RB survivor's life physically, mentally, and psychologically and all other possible dimensions of quality of life.

I am going to give you information and invite you to be part of a research study. You can choose whether or not you want to participate. We have discussed this research with your parent(s)/guardian and they know that we are also asking you for your agreement. If you are going to participate in the research, your parent(s)/guardian also have to agree. But if you do not wish to take part in the research, you do not have to, even if your parents have agreed.

You may discuss anything in this form with your parents or friends or anyone else you feel comfortable talking to. You can decide whether to participate or not after you have talked it over. You do not have to decide immediately.

There may be some words you don't understand or things that you want me to explain more about because you are interested or concerned. Please ask me to stop at any time and I will take time to explain

Purpose:

Why are we doing this research?

We would like to find out the influencing factors of the quality of life in Retinoblastoma(RB) survivors in India, from the childhood cancer survivors' perspective and to study the long-term impact of different treatment options available for RB. And also to provide additional data to understand the needs of RB survivors to identify those who are at greatest risk for the adverse effects of the disease and treatment.

Choice of participants:

Why are you asking me?

We are doing this research in children and also adolescents who are a survivor of retinoblastoma, as retinoblastoma is more prevalent cancer in children.

Participation is voluntary:

Do I have to do this?

You don't have to be in this research if you don't want to be. It's up to you. If you decide not to be in the research, it's okay and nothing changes. This is still your clinic, everything stays the same as before. Even if you say "yes" now, you can change your mind later, and it's still okay.

If applicable: If anything changes and we want you to stay in the research study even if you want to stop, we will talk to you first.

Procedures:

We are asking you to help us learn more about the quality of life in the RB community. We are inviting you to take part in this research project. If you accept, you will be asked to fill out a questionnaire and participate in the structured interview.

A survey questionnaire and the structured interview will be provided by Miss Krishnasri Padamandala and collected by Miss Krishnasri Padamandala OR You may answer the questionnaire yourself, or it can be read to you and you can say out loud the answer you want me to write down.

If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. The information recorded is confidential, your name is not being included on the forms, only a number will identify you, and no one else except the primary investigator miss Krishnasri Padamandala, and the co-investigator will have access to your survey.

You can ask me to stop and explain again at any time and I will explain more about the process.

Duration:

The research takes place over 1 (one) day in total. During that time, we will visit you for collecting the survey questionnaire and to perform the structured interview at your visit to the hospital (whenever it is scheduled and or possible during the project stipulated time) which will last for about half an hour to an hour (based on the subject response) to collect the responses from you for both survey and interview.

I have checked with the child and they understand the procedures _____(initial)

Risks:

Is this bad or dangerous for me?

If anything unusual happens to you, however, we need to know and you should feel free to call us anytime with your concerns or questions.

Will, It hurt?

We are asking you to share with us some very personal and confidential information for example sensitive and personal issues, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the discussion/interview/survey if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

I have checked with the child and they understand the risks and discomforts ____ (initial).

Benefits:

There will be no direct benefit to you, but your participation is likely to help us find out more about how to assess the quality of life and take the necessary steps to address each issue individually as part of rehabilitation.

You can tell me if you have understood correctly the benefits that you will have if you take part in the study? or you can ask me again if you have any questions.

I have checked with the child and they understand the benefits_____ (initial)

Reimbursement:

You will not be provided any incentive to take part in the research.

Confidentiality:

The research being done in the RB community may draw attention and if you participate you may be asked questions by other people in the RB community who visits the Centre for sight hospital. We will not be sharing information about you with anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key or in an electronic device with an authenticated password. It will not be shared with or given to anyone except Miss Krishnasri Padamandala and the collaborated institutes such as your clinician from the center for sight super specialty eye hospital and the University of Hyderabad.

Sharing the Results:

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you within the RB community before it is made widely available to the public as a publication and conference. Each participant will receive a summary of the results.

Right to Refuse or Withdraw:

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your job or job-related evaluations in any way. You may stop

participating in the [Survey /interview] at any time that you wish without your job being affected. I will allow you at the end of the Survey /interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my remarks or if I did not understand you correctly.

Whom to Contact:

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

Name: Miss Krishnasri Padamandala

Address: School of Medical Sciences, University of Hyderabad, Gachibowli, Hyderabad, Telangana-50046, India.

Telephone number: +91 8330939107

e-mail: krishnasri.p6931@gmail.com

This proposal has been reviewed and approved by [the University of Hyderabad, local IEC], which is a committee whose task is to make sure that research participants are protected from harm. If you wish to find about more about the IEC, contact: iec_uoh@uohyd.ernet.in

You can ask me any more questions about any part of the research study if you wish to. Do you have any questions?

Part II: Certificate of Consent.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant _____

Signature of Participant _____

Date _____

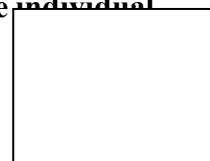
Day/month/year

*If illiterate*³

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness _____

Thumb print of participant



Signature of witness _____

Date _____

(Day/month/year)

Statement by the researcher/person taking consent:

³ A literate witness must sign (if possible, this person should be selected by the participant and should have no connection to the research team). Participants who are illiterate should include their thumb print as well).

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Structured Interview

2. Questionnaire survey

I confirm that the participant was allowed to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent: Miss Krishnasri Padamandala

Signature of Researcher /person taking the consent_____

Date _____ **Day/month/year**

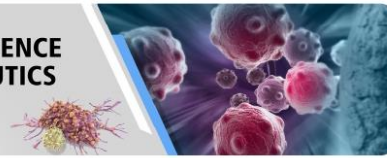
APPENDIX-VI: LIST OF PUBLICATIONS AND PIPELINES

Papers published:

1. Padamandala, K., G Honavar, S., Bansal, R., Prasad M, S. D., Gadiraju, P., & K Vemuganti, G. (2023). Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. *Journal of Cancer Science and Clinical Therapeutics*, 07(02).
<https://doi.org/10.26502/jcsct.5079202>

Papers in communication with Journal:

1. Scoping Review Unveils the Effect of Retinoblastoma on Survivors' Well-being and Standard of Living: Implications for Enhanced Research and Care Beyond Survival- Indian Journal of Cancer- **Under Review**
2. Quality of Life in Retinoblastoma Survivors Tertiary Care Hospital in India: QoL-Rb- India study to Cureus Journal of Medical Sciences. **Submitted, Under Review.**



Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration

Krishnasri Padamandala¹, Santosh G Honavar², Rolika Bansal², Surya Durga Prasad M¹, Padmaja Gadiraju³, Geeta K Vemuganti^{1*}

Abstract

Background: The purpose of this study was to assess the viability of using the quality-of-life questionnaire and structured interview in South Indian tertiary eye care hospital survivors, age-matched controls, and their parents.

Procedure: 15 RB survivors, 15 age-matched controls, and 30 primary carers were included. Peds QL 4.0 generic core scale and structured interview were administered. Physical, social, emotional, and school health were also examined.

Results: Cases and controls had a mean age of 5.9 years, SD + 2.4, based on 60 samples. The questionnaire was completed by children in 15.1 + 0.4 minutes, whereas it took controls in 12.2 + 0.6 minutes. RB survivors (15/15) and controls (3/15) of all ages and genders need parental help to complete the questionnaire. The physical health of RB survivors was 0.3 SD +0.96, the social health was 0.32 SD +1.0, the emotional health was 0.56 SD +1.06, and the school health was 1.6 SD +2.1. Physical health was 0.3 SD +0.7, social health 0.06 SD +0.1, emotional health 0.2 SD +0.5, and school health 0.2 SD +0.4. The P-value for the two-tailed t-test is 95% CI, P0.05.

Conclusion: The pilot research showed that participants, especially parents, understood and accepted the quality of life measuring instrument (Peds QL 4.0), making it suitable for a larger study. This age group needed parents and researchers. The tendency suggests a reduction in survivors' quality of life, emphasizing the necessity for psychoeducation and counseling before and after treatment.

Keywords: Feasibility; Quality of Life Questionnaire; Retinoblastoma; Tertiary Eye Care Center; Pediatric Eye Cancer

Introduction

RB is the most common intraocular malignancy in childhood globally, with a prevalence of 1 in every 15000-20000 live births across the population correlates with 9000 new cases every year globally [1, 2]. Rapid progress has been made in diagnosing and treating the disease by considering saving life and vision in order of priority [3, 4]. Together 43% of the global burden of RB lives in these countries 1486 children in India, 1103 children in China and 277 children in Indonesia, 260 children in Pakistan, 184 children in Bangladesh, and 142 children in the Philippines [5]. Recently retinoblastoma has exceeded uveal melanoma to become the most ocular malignancy globally [2]. It is important to study the quality of life in retinoblastoma as it is potentially

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Corresponding author:

Geeta K Vemuganti, School of Medical Sciences, University of Hyderabad, Prof CR Rao Road, Hyderabad, Telangana 500046, India.

Citation: Krishnasri Padamandala, Santosh G Honavar, Rolika Bansal, Surya Durga Prasad M, Padmaja Gadiraju, Geeta K Vemuganti. Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. Journal of Cancer Science and Clinical Therapeutics. 7 (2023): 118-126.

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Published: May 19, 2023

fatal but has a good prognosis and survival rates with early diagnosis and treatment. It is one of the most easily detectable cancers constituting 3% of pediatric cancers [6]. However, Quality of life is the most neglected and important aspect of survivorship. It is necessary to create awareness of the affected quality of life domains and allow timely advocacy of initiatives for addressing the issues at an individual level [2].

Few studies have evaluated the QoL in children affected with RB. In one study, the pediatric quality of life inventory 4.0 generic core scales (PedsQLTM 4.0) among enucleated subjects revealed that the social and academic dimensions were statistically insignificant compared to healthier children and influenced by the laterality of the illness, age, and satisfaction with the ocular prosthesis [7]. Because there is a dearth of scientific research and disparities in a wide range of technological and socioeconomic elements that could potentially affect clinical diagnosis and life expectancy, the researchers contend that knowing the impact of retinoblastoma in the Asia Pacific area is crucial [8]. Unlike in other pediatric tumors, visual disability, physical appearance, multiple extensive treatments, and challenges in counseling on prognosis and consequences could affect the quality of life and well-being. The observations in the clinical practice of the researcher also indicate that there appears to be a difference between children and the perceptions of parents of children with RB as compared to other children with non-RB eye pathology. With this as rationale before embarking on a larger study, the authors aimed to evaluate the feasibility of implementing the Paediatric quality of life questionnaire, PEDS QL 4.0 generic score.

The researchers administered and observed the difficulties faced during the pilot process. It would also generate preliminary data at the tertiary eye care hospital in south India. We hypothesized that there will be a difference in the quality of life in children who are RB survivors and parents, in comparison with control group children (non-RB) and the perception of their parents.

To evaluate our hypothesis we aimed to assess the quality of life of RB and non-RB survivors, as well as their parent's perceptions with regard to the QoL of their children in both the groups. We also attempted to compare the differences in QoL between RB survivors and non-RB survivors, as well as the perceptions of their parents.

Methodology

Study sampling technique

The authors of this study utilized a "convenience sampling" technique to access the data already there in the study setting (a tertiary care hospital) to make data collecting easier, as retinoblastoma is a rare condition.

Study population

Two groups of participants were considered for the study. The group of children with RB as per the information and details provided by the hospital comprises the treatment group children. Their parents were also considered for the administration of the questionnaire and the interview.

On the other hand, the children who were non-RB were considered as a control group, their parents were also considered to administer the questionnaire and interview as shown below in supplementary table 1.

The sample was collected during the pandemic phase from the Center for Sight (CFS) eye hospital. The cooperating institutes conducted an ethical evaluation of subjects who underwent retinoblastoma treatment, including unilateral or bilateral enucleation, chemotherapy, plaque irradiation, freezing, laser eye coagulation, and usage of supporting and intensive services and ocular prostheses. The subject or the subject's legal representative provided their informed written consent and approval. As per the ethical procedures, informed consent was obtained from the parents of the treatment group & control group as well as assent from the children of both groups.

Parameters collected for Population Clinical features /parents data

Demographics such as Age, Gender, Geographical region, Type of treatment, Laterality of the disease, Disease-free survival, BCVA, Parents' income, Parent education level, and Occupation of the parent, time is taken to complete the questionnaire, comprehensibility of the questionnaire were included.

QoL Questionnaire details/ content

The Standardised PEDS QL 4.0 Generic core score (Telugu, Hindi, English) versions were used to assess the Quality of Life, which contains the Physical domain (8 items), Social health domain (5 items), School domain (5 items), and Emotional (5 Items) were analysed to check the feasibility

Supplementary Table 1: This table shows the distribution of questionnaires between cases and controls as well as the care givers (parents) of these subjects.

	Sample Size	Cases	Controls	Study tools implemented
Total sample size N=60	Children Sample size (A1+A2) N=30	A1 (N=15)	A2 (N=15)	Quality of life questionnaire only
	Parent groups sample size (B1+B2) N=30	B1 (N=15)	B2 (N=15)	Perceptions of QoL of their children questionnaire + structured interview

Citation: Krishnasri Padamandala, Santosh G Honavar, Rolika Bansal, Surya Durga Prasad M, Padmaja Gadiraju, Geeta K Vemuganti. Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. Journal of Cancer Science and Clinical Therapeutics. 7 (2023): 118-126.

of implementing questionnaire time and, documenting the problems faced while collecting the same. Additionally, the researcher administered a questionnaire also implemented includes detailed treatment history, electronic gadgets usage, nearest blind school presence, financial expenditure of the survivors, and whether the child required special attention are not.

Study process

This pilot study was conducted from September 2021 to October 2021 and could include 60 patients, of which 15 were RB survivors, 15 were controls and 15 were RB case primary caregivers, and 15 were (non-RB) control primary caregivers who are parents. Following Institutional Ethics approval, the authors started recruiting the subjects. As shown in (Figure 1) the study process began with the study's eligibility criteria of 2-18 years, having completed two years of treatment at the Centre for Sight Super Specialty Eye Hospital.

The authors have considered a minimum of 1-2 years of disease-free survival to avoid the treatment-related comorbidities that might influence the questionnaire response. Age-matched subjects acted as controls, and whoever could not consent and comprehend the questionnaires, parents were offered the participation (for the 2-4 years age group) and alone to study parents' perspectives also included. The current study followed the WHO definition of quality of life which states the personal understanding and perspective towards their life physically, mentally, emotionally, and socially. Participants who were not willing to participate and were outside the defined age group were excluded from the study.

Figure-1: The Pilot process demonstrates the entire feasibility study procedure where the study invited 60 participants from both the cases and controls group following informed consent. Those who did not consent continued to avail of the regular services at the hospital. The study involved implementing the validated Peds QoL 4.0 Generic Core scale (Figure 2) without modification and structured interviews (Figure 3) with the recruited subjects. The time it took to complete the questionnaire during their hospital visit and the difficulties children or parents encountered during data collection were recorded. It was made certain that their participation did not interfere with any of the procedures or protocols for which their visit was scheduled.

Statistical Analysis

This pilot study checked the feasibility of the tools and compared the QoL among cases and control groups. The questionnaire responses were measured on a 5 (i.e. 0-4) point Likert scale. And the analyses were conducted using Microsoft- Excel 2010 version. Descriptive statistics such as mean and standard deviation and the time taken to complete the implemented questionnaires and interviews; socio-demographic profiles were analysed using excel. Additionally, the authors analysed how far the questionnaires and the interview variables were understandable and at which part of the questionnaire subjects felt uncomfortable and sought help also noted. The quality of life variables among self-reported and parent proxy responses was observed, and compared the p-values were by performing a two-tailed t-test in addition to the descriptive statistics.

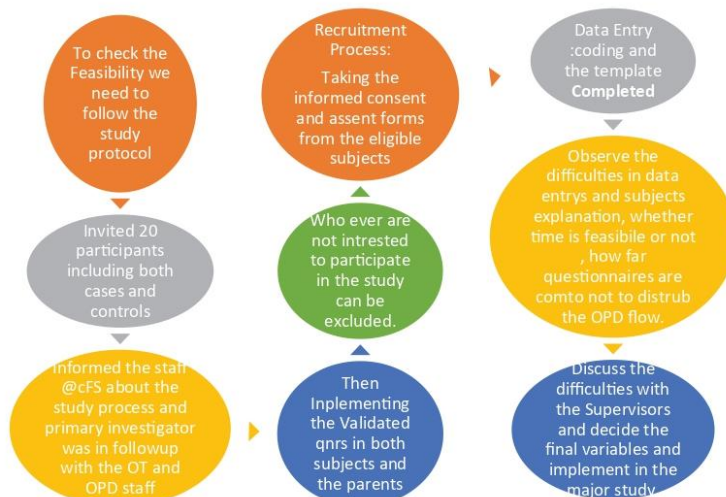


Figure 1: The Pilot process of the study.

Citation: Krishnasri Padamandala, Santosh G Honavar, Rolika Bansal, Surya Durga Prasad M, Padmaja Gadiraju, Geeta K Vemuganti. Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. Journal of Cancer Science and Clinical Therapeutics. 7 (2023): 118-126.

PedsQL™
Pediatric Quality of Life
Inventory
Version 4.0 - English (child)

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the past ONE month by circling.

If it is never a problem
 If it is almost never a problem
 If it is sometimes a problem
 If it is often a problem
 If it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PedsQL 2

In the past ONE month, how much of a problem has this been for you ...

ABOUT MY HEALTH AND ACTIVITIES (problems with...)	Never	Almost never	Sometimes	Often	Almost always
1. It is difficult for me to walk more than 100 meters	0	1	2	3	4
2. It is difficult for me to run	0	1	2	3	4
3. It is difficult for me to do sports activity or exercise	0	1	2	3	4
4. It is difficult for me to lift something heavy	0	1	2	3	4
5. It is difficult for me to take a bath or shower by myself	0	1	2	3	4
6. It is difficult for me to do chores around the house	0	1	2	3	4
7. I feel pain	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with...)	Never	Almost never	Sometimes	Often	Almost always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with...)	Never	Almost never	Sometimes	Often	Almost always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that other teens of my age can do	0	1	2	3	4
5. It is difficult to keep up with the teens of my age	0	1	2	3	4

ABOUT SCHOOL (problems with...)	Never	Almost never	Sometimes	Often	Almost always
1. It is difficult to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

Figure 2: PedsQL-4.0-Core-PYC - India/English - Version of 08 Apr 2019 - Mapi.I
Copyright © 1998 JW Varni, Ph.D.(2-4 age format).

Proforma-5 Structured interview for all the children and adolescents and the parent as follows:

Subject name: _____ DOB: _____
 Age: _____ Mr. Number: _____
 Residence: _____ Gender: _____
 Phone: _____ State: _____
 Socio-economic status: Low/ middle/high
 income

Measure/ variable	Child Mention N/A where ever it is required and or variable is not applicable.	Father Mention N/A where ever it is required and or variable is not applicable.	Mother Mention N/A where ever it is required and or variable is not applicable.
1. Income			
2. Type of school			
3. Belongs to which area of living (Rural or urban)	Rural	Urban	
4. Internet access	Yes	No	
5. Electronic gadgets usage			
6. How many Siblings			
7. Expenditure			
8. Nearest Blind school distance			
9. Special attention is required	Yes	No	
10. Parent Education Level	Father:	Mother:	
11. Type of Lifestyle:			
12. Age of the subject:			
13. Disease laterality: (OD/OS/OU)			
14. Disease free survival (years)			
15. Treatment modality: (type of surgery)			
16. Duration since the diagnosis : (years)			
17. Visual outcomes:			
18. Address:			

Figure 3: Investigator-focused Structured Interview format.

Citation: Krishnasri Padamandala, Santosh G Honavar, Rolika Bansal, Surya Durga Prasad M, Padmaja Gadiraju, Geeta K Vemuganti.
Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. Journal of Cancer Science and Clinical Therapeutics.
7 (2023): 118-126.

Results

Study population demographics

Of the 60 RB survivors and controls (N= 15 cases, N=15 controls, N=15 case parents, and N=15 control parents), the female-to-male ratio was 6:9 and controls (N=7) 8:7, respectively. The mean age of the RB survivors was 5.9 ± 2.4 years and the controls were 5.9 ± 2.4 years. The disease was unilateral in 9 and bilateral RB cases in 6 cases (Table 1-2). The treatments received in the 15 RB survivors were chemotherapy =7, External beam radiation (EXBRT)=2, Brachytherapy=1, and Enucleation=5. The mean time taken by cases to complete the questionnaire was 15.1 ± 0.4 min, and controls were 12.5 ± 0.5 min. All 15 RB survivors and three controls opted for parents' help while filling up the questions of emotional and social health groups irrespective of age and gender. All the parents were able to understand the questionnaire and structured interview. The time taken by the parents to fill out the questionnaire was 11.4 ± 1.3 min, and for the controlling parent, 10.5 ± 0.5 min. Vision in bilateral RB cases was having one seeing eye where the Best corrected visual acuity in the better eye (BCVA) was (FFL) fixing and following the light 6, and 6/12 and better 4, 6/18, and worse five as per the clinical documentation (Table 4).

QoL questionnaire analysis

was done using the SPSS version 25; all the domains,

including subgroups such as walking, running, sports activity, helping in household chores, lifting heavy objects, taking a shower, feeling pain, having low energy, feeling afraid, sad, or angry and trouble in sleeping, worrying about future, and getting along with other children, other children not wanting to be their friends, teasing by others, keeping up with other children while playing, not able to do the thing that other children can do, and also paying attention in the class, trouble keeping up with the school work, unable to visit the School due to doctor/ hospital visit, unable to go to the School due to unwell were analyzed using descriptive statistics- mean and standard deviation and significance (*P value*) also calculated.

In Addition, QoL components were analyzed (Table-2) where RB survivor's mean of Physical health was 0.3 SD ± 0.96 , Social health 0.32 SD ± 1.0 , and Emotional health 0.56 SD ± 1.06 , School health 1.6 SD ± 2.1 , where controls mean health score recorded as Physical health 0.3 SD ± 0.7 , Social health 0.06 SD ± 0.1 and Emotional health 0.2 SD ± 0.5 , School health 0.2 SD ± 0.4 . The *P-value* for the two-tailed t-test shows $P=0.03$ with 95% confidence interval, which is less than $\alpha=0.05$ in all the domains of quality of life.

In (Table-3) where RB and non RB- parents (control group) show the mean of Physical Health was 1.9 SD ± 0.6 , Social Health 2.1 SD ± 0.6 , and Emotional Health 1.2 SD ± 1.1 , School Health 1.5 SD ± 1.2 , where control parents mean health score recorded as Physical Health 0.2 SD ± 0.5 , Social

Table 1: Comparison of structured interview study variables among cases and controls.

Variable		Cases (RB Survivors) (n=15)	Control group (n=15)	
Age in yrs (Mean $\pm$ SD)		5.9 $\pm$ 2.4	5.9 $\pm$ 2.4	
Disease-free survival in yrs Mean $\pm$ SD		2.6years $\pm$ 1.3	Not applicable	
Gender	Males	9 (60 %)	8 (53.4%)	
	Females	6 (40%)	7 (46.6%)	
Disease laterality	Unilateral	9 (60 %)	Not applicable	
	Bilateral	6 (40%)	Not applicable	
Type of treatment availed	Enucleation	5 (33.3%)	Emmetropia	5 (33.4%)
	Chemotherapy	7 (46.6%)	Myopia	9 (60 %)
	Brachytherapy	1 (6.6%)	Hyperopia	0
	EXBRT	2 (13.3%)	Amblyopia	1 (6 %)
BCVA in the better eye	Fixed and Following light	6 (40%)	6 / 6 in Both eyes	14 (93.4%)
	6/12 to 6/6	4 (26.6%)	< 6 / 9 in one eye	1 (6.6 %)
	6/60 to 6/18	5 (33.3%)	0	
Parents Education Level	Father	High-school 5th to 9th	0	
		SSC	0	
		Intermediate	0	
		UG	5 (33.4%)	
		PG	10 (66.6%)	

Citation: Krishnasri Padamandala, Santosh G Honavar, Rolika Bansal, Surya Durga Prasad M, Padmaja Gadiraju, Geeta K Vemuganti. Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. Journal of Cancer Science and Clinical Therapeutics. 7 (2023): 118-126.

Table 4: Influencing factors of Quality of Life in Rb Survivors.

Factors		N	(N %)
Disease laterality	Unilateral	9	60%
	Bilateral	6	40%
Socioeconomic status	Upper lower class	6	40%
	Lower middle class	6	40%
	Upper class	1	6.6%
	Upper middle class	1	6.6%
	Lower class	1	6.6%
Gender	Male	9	60%
	Female	6	40%
Type of treatment availed	Enucleation	5	33.3%
	Chemotherapy	7	46.6%
	ExBRT	2	13.3%
	Brachytherapy	1	6.6%
Diagnosis age of Rb survivors in Months (Mean± SD)		18.5 + 16.9	

Discussion

Health-related quality of life in pediatric practice has a multidimensional role where the subject and the parent's perception of disease and the treatment side effects can be addressed at the individual level. It is important to study the quality of life in retinoblastoma as it is potentially fatal but has a good prognosis and survival rates with early diagnosis and treatment. It is one of the most easily detectable cancers constituting 3% of pediatric cancers [6]. The results demonstrated that the QoL of RB survivors (M 0.6 SD ± 1.2) was slightly lower than the control group (M 0.2 SD ± 0.4), and the *P-value* = 0.03 was significant. Similarly, the perceptions of parents of QoL of RB survivors (M 1.6 SD ± 0.8) were lower than the perception of the parent of the control group (M 0.2 SD ± 0.5) and the difference was significant *P-value* = 0.03.

However, Quality of life is the most neglected and important aspect of survivorship. Unlike in other pediatric tumors, visual disability, physical appearance, multiple extensive treatments, and challenges in counseling on prognosis and consequences could affect the quality of life and well-being. The observations in the clinical practice of the researcher also indicate that there appears to be a difference between children and the perceptions of parents of children with RB as compared to other children with non-RB eye pathology. With this as rationale before embarking on a larger study, the authors aimed to evaluate the feasibility of implementing the Pediatric quality of life questionnaire, PEDS QL 4.0 generic score. Previous cross-sectional studies have not identified the feasibility of the Peds QL-4.0 Generic core scale (Paediatric Quality of Life Inventory Questionnaire) and the supplement interviews like structured interviews to assess the quality of life among RB survivors.

Literature has stipulated that childhood cancer survivors may experience poor quality of life in adulthood [5]. In a recent study, Belson et al. 2020 reported that less than six studies had reported a compromised quality of life out of fifteen eligible studies that were reviewed.

Our research shows that the QoL, as mentioned above and structured interview questionnaires may be used with no adverse outcomes. Time spent filling out the questionnaires was much less than required for the Retinoquest, with the average time for cases being 15.1 + 0.4 minutes and the average time for controls being 12.5 + 0.5 minutes [9]. However, Himani Dhingra et al. found that it took 13-15 minutes for participants to complete the Peds QL independently, which is quite close to our findings. In addition, we have found fewer variations in RB survivors' abilities to walk, run, take showers, assist their parents with everyday chores, and carry anything heavy (Table 4).

The researchers had certain interesting observations while checking the feasibility of the instrument for QoL. Comprehension was seen among the research participants as they walked through the study, with reference to the questionnaire and interview using the PEDS QL 4.0 generic core scale within the target age range [9, 10]. While parents were concerned about their children's well-being, few were asked about their treatment options or expected length of stay in the hospital, and the information needs were evident. Therefore, the present study points to the need to educate patients, caregivers, and parents on retinoblastoma and its post-treatment care. There was a significant difference in the quality of life of those who survived enucleation versus controls, as well as reports from parents acting as proxies for their children.

The present study's findings are superior, lending credence to the idea that, for RB survivors, the kind of therapy is crucial in preserving a Normal Quality of life after treatment, mainly because a delay in diagnosis may affect QoL. However, illness laterality and disease diagnostic time play a critical role in sustaining quality of life. Early disease identification might save the visual prognosis post-treatment owing to recency bias. These factors have not been seen to alter significantly among [2, 11] RB survivors. The present research found that utilizing age-matched controls as subjects to compare the RB survivor's quality of life as supported by previous research is preferable [2]. Because of scheduling constraints, locating the age-matched control is challenging. Himani et al. recommend using age-matched controls to adjust for any socioeconomic differences that could affect research results. However, the same study revealed that factors including SES, gender, and illness diagnosis had no bearing on the QoL of RB survivors [2].

We adjusted the approach by contacting the Age-matched controls by phone or e-mail to compensate for the research's

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shortcomings and increase the number of participants in the primary trial. Patient-reported outcomes from parents and cases in a tertiary eye care setting were analyzed. The author believes this study may be the first to manually demonstrate the feasibility of the Peds QoL 4.0 generic core scale. This could shed light on the QoL questionnaire admitting problems and how to modify and proceed further.

Problems were faced during the QoL questionnaire implementation, which will be modified and addressed with adequate counseling

- Finding age-matched controls- The time-taking process must wait until the age-matched subject gets into the OPD
- The subjects and the parents of RB survivors are distressed and not able to answer the questions - cases>controls. Still, it can be improved with supportive prior counseling sessions
- Misguided information in the demographic sheets, like the wrong phone no and addresses and e-mails
- Addressing the patients when the questionnaire was implemented through phone calls
- Require two to three times mock rounds to make patients/ subjects understand the questionnaire answering process

Limitation and Future Scope

Recruiting fewer controls due to time constraints and the prevailing pandemic, finding the Participants as well as age-matched young children as controls were difficult in an active comprehensive Opd. The subjects do not represent varied socioeconomic status as the sample is not large. This may influence the perspective differences towards the questionnaire. And this study supports a larger sample to gain some deeper insights into the quality of life of RB survivors, which includes Focused group discussions and in-depth interviews, which leads to giving an understanding of the quality of life of RB survivors in developing countries on a large magnitude.

Implications for Policy and Practise

- The results of the pilot study indicated a lower quality of life among the survivors compared to the control group children
- The perception of the parents of the survivors with regard to the quality of life of the survivors was lower compared to the parents of a control group
- We believe that primary research should be modified so that when the questionnaire is given to children in addition to the researcher's support, assistance from their parents is sought, accurate information is obtained, and participants who are unable to answer the questions easily required more time given more time to complete the survey

- Counseling and helping parents and caregivers understand the changes in survivors' quality of life before and after treatment and answering their questions concerning financial incentives are recommended

Conclusion

The pilot study findings indicate that the instrument of quality of life measurement (Peds QL 4.0) was accepted and understood by the participants, specially the parents, thus making it a feasibility tool for a larger study. As anticipated in this age group, the children required assistance of parents and researchers. Though the larger studies are warranted for interpretation, the trend suggests lower quality of life among the survivors, as well as the perception of parents, thus emphasizing the need for pertinent psychoeducation and counseling of the cases as well as parents before and after the treatment.

Statements

Acknowledgment

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Ethics Approval

IEC Number: UH/IEC/2021/146 Approved on 26-08-2021.

Conflict of Interest Statement

"The authors have no conflicts of interest to declare."

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Author Contributions

Krishnasri Padamandala (KSP): Study Designing, Analyzing, and interpreting data, and wrote the first draft of the manuscript.

Dr Santosh G Honavar (SH): Provided all clinical resources and supported and guided throughout the study.

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Dr. Padmaja Gadiraju (PG): Revised and Reviewed the Manuscript.

Dr Rolika Bansal (RB): Supervision and Guidance throughout the study period.

Dr Surya Durga Prasad (SDP): Revised the proposed work and manuscript content critically, data analysis.

Prof Geeta K Vemuganti (GKV): Supervision and final approval of the study and revised the clinically drafted content critically for important intellectual content.

References

1. Retinoblastoma - Definiti | OpenMD.com [Internet] (2021).
2. Dhingra H, Arya D, Taluja A, et al. A study analysing the health-related quality of life of retinoblastoma survivors in India. *Indian J Ophthalmol* 69 (2021): 1482-1486.
3. Kivelä T. The epidemiological challenge of the most frequent eye cancer: retinoblastoma, an issue of birth and death. *Br J Ophthalmol* 93 (2009): 1129-1131.
4. Dimaras H, Kimani K, Dimba EAO, et al. retinoblastoma. *Lancet Lond Engl* 379 (2012): 1436-1446.
5. Belson PJ, Eastwood JA, Brecht ML, et al. A Review of Literature on Health-Related Quality of Life of Retinoblastoma Survivors. *J Pediatr Oncol Nurs* 37 (2020): 116-127.
6. Retinoblastoma - PubMed [Internet] (2021).
7. Abramson DH, Beaverson K, Sangani P, et al. Screening for retinoblastoma: presenting signs as prognosticators of patient and ocular survival. *Pediatrics* 112 (2003): 1248-1255.
8. Zhang L, Gao T, Shen Y. Quality of life in children with retinoblastoma after enucleation in China. *Pediatr Blood Cancer* 65 (2018): e27024.
9. McNeill NA, Kors WA, Bosscha MI, et al. Feasibility of RetinoQuest: e-health application to facilitate and improve additional care for retinoblastoma survivors. *J Cancer Surviv Res Pract* 11 (2017): 683-690.
10. Krieger JL, Neil JM, Duke KA, et al. A Pilot Study Examining the Efficacy of Delivering Colorectal Cancer Screening Messages via Virtual Health Assistants. *Am J Prev Med* 61 (2021): 251-255.
11. Batra A, Kumari M, Paul R, et al. Quality of Life Assessment in Retinoblastoma: A Cross-Sectional Study of 122 Survivors from India. *Pediatr Blood Cancer* 63 (2016): 313-317.

Citation: Krishnasri Padamandala, Santosh G Honavar, Rolika Bansal, Surya Durga Prasad M, Padmaja Gadiraju, Geeta K Vemuganti. Investigating the Quality of Life of Retinoblastoma Survivors: An Initial Exploration. *Journal of Cancer Science and Clinical Therapeutics*. 7 (2023): 118-126.

APPENDIX VII: LIST OF CONFERENCE/PRESENTATIONS

1. We Presented a pilot paper on the Feasibility of a quality-of-life questionnaire in retinoblastoma survivors in India: a qualitative pilot study On December 6th & 7 at the First International Conference on Health and Pharmaceuticals @FTCCI
2. Oral Presentation at Centre for Sight on “Retinoblastoma and Treatment-related care”
3. Quality of life perception among parents of Rb survivors in tertiary eye care clinic in Hyderabad: A pilot study- Presented at Telangana Ophthalmological Society TOS July 2022.
4. Exploring the Emotional Aspects of Parents of Retinoblastoma (Rb) Survivors: Narrative Approach. November 11th, 2022, @ UOH Psychology conference.

Poster presentation

5. Screening the quality-of-life perception among the parents of Rb survivors among 2-5 years of age group in tertiary eye care clinic in Hyderabad: A Cross-sectional study presented a poster at ICFAST September 2022.
6. Quality of life of Rb survivors at tertiary eye care hospital in India: August 21-23,2023, ISOO Africa.



Certificate

awarded to

Dr Krishnasri Padamandala

in recognition of presenting a scientific paper entitled

Quality of life perception among parents

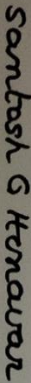
of retinoblastoma (RB) survivors in India: A pilot study

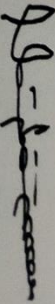
at the Seventh Annual Meeting of the

Telangana Ophthalmological Society at

Warangal, July 22-24, 2022


Dr A Ravindra
President, TOS


Dr Santosh G Honavar
Chairman, Scientific Committee, TOS


Dr V Rajalingam
Secretary, TOS

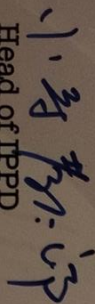


12th India-Japan Science and Technology Conclave
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SCIENCE AND TECHNOLOGY
(ICFAST-2022)**

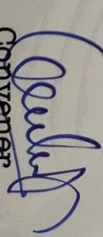


CERTIFICATE OF PARTICIPATION

This is to certify that Krishnasri Padamandala from University of Hyderabad participated/presented in 12th India-Japan Science and Technology Conclave : **International Conference on Frontier Areas of Science and Technology (ICFAST - 2022)** held at University of Hyderabad, Hyderabad 500 046, INDIA during September 09-10, 2022

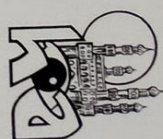

Head of IPPD
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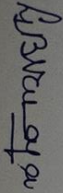
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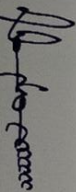
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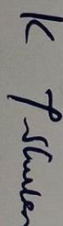
Quality of Life in Rb at Tertiary Eye Care Hospital in India

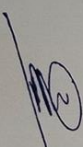
at the 8th Telangana Ophthalmological State Annual Conference 2023

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Dr. V. Rajalingam
Chairman, TSMC & Gen. Sec TOS


Dr. Madhukar Reddy
Org Chairman, LOC


Dr. Raman
Org, Secretary, LOC


Dr. Rishi Swarup
Chairman Scientific Committee, TOS



International Conference on Innovations in Health Interventions: Traditional, Complementary and Alternative Methods (TCAM) in Holistic Healthcare

Under IOE Project 'Health care needs and practices in
Indian men and women with Reproductive System cancer'

(UoH/IOE/RC1-20-030)
University of Hyderabad
10th & 11th, November 2022

Certificate

This is to certify that Dr./Mr./Ms. Krishnasri Padamandala presented a

Approach.

paper titled Exploring the emotional Aspects of Paraneoplastic Syndrome (Ps) Survivors: A Narrative
in International conference on Innovations in Health Interventions: Traditional,
Complementary and Alternative Methods (TCAM) in holistic healthcare, conducted by
UoH/IOE/RC1-20-030, Centre for Health Psychology, School of Medical Sciences and School of
Management Studies, University of Hyderabad.

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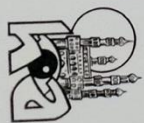




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Certificate of Participation

This is to certify that

DR. KRISHNASRI PADAMANDALA

has participated as a *Delegate / Faculty* at **The 8th Telangana Ophthalmological State Annual Conference** organised by Telangana ophthalmological society under the aegis of HOA's Bhagyanagar TOSCON

held on 7th, 8th & 9th July 2023 at Citadel Hotels & Conventions, Shamshabad, Hyderabad
Telangana State Medical Council has awarded 5 CPD Credit Hours for Delegates and Faculty

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Dr. Ch. Hanmantha Rao
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POSTER PRESENTATION CERTIFICATE

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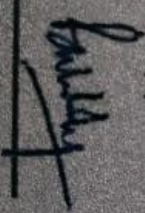


Ido Didi Fabian, M.D.
Conference President

**FIRST INTERNATIONAL CONFERENCE
ON HEALTH & PHARMACEUTICAL - 2021**

CERTIFICATE OF PARTICIPATION

This is to certify that Mr./Ms./Mrs./Dr.Krishnasri Padamandala from University of Hyderabad has attended and presented the paper entitled A Study to Analyze the Feasibility of the Quality of Life Questionnaire in Retinoblastoma Survivors at a Tertiary Eye Care set up in south India: Prospective Pilot study on the occasion of 1st INTERNATIONAL CONFERENCE ON HEALTH & PHARMACEUTICAL-2021 held on 11th & 12th December, 2021 at Hyderabad organised by Multipurpose Awareness Society Hyderabad supported by Ministry of Micro, Small and Medium Enterprises, Govt of India.


DR.RANIGA REDDY BURRI
PRESIDENT
INFECTION CONTROL ACADEMY OF INDIA

Date: 11th & 12th December 2021


M.BODA NAGESWARA RAO
CONFERENCE CONVENOR & PRESIDENT
MULTIPURPOSE AWARENESS SOCIETY

APPENDIX VIII: RETINOBLASTOMA TREATMENT SCHEMES.

1. Health Minister's Discretionary Grant (HMDG)
2. Ayushman Bharat - Pradhan Mantri Jan Arogya Yojana.
3. Cancer Patients Concession for Travel by Air
4. Central Government Health Scheme (CGHS)
5. Health Minister's Cancer Patient Fund (HMCPF) of Rastriya Arogya Nidhi (RAN)
6. Railways: Facilities for Passengers who are Cancer Patients
7. Free Cancer Treatment Under Arogya Sri Scheme of A.P. Govt
8. Mediclaim Scheme of Directorate of Health Services
9. Cancer Treatment & Management Fund for Poor
10. Karnataka Chief Minister's Relief Fund
11. Cancer Suraksha Scheme by Kerala Social Security Mission
12. Madhya Pradesh State Illness Assistance Fund
13. Maharashtra- Chief Minister's Relief Fund (CMRF)
14. Maharashtra-Mahatma Jyotiba Phule Jan Arogya Yojana
15. Free Chemotherapy Programme of Odisha Govt
16. Mukh Mantri Punjab Cancer Raahat Kosh Scheme

Shining Brighter: The Resources and Support for Families Affected by Retinoblastoma

This Brochure briefs about the available state and central government and other NGO support schemes and its eligibility criteria. Retinoblastoma treatment support provided by following NGOs in the hospital and elsewhere

Cankids:

<https://www.cankidsindia.org/>

IKSHA:

<https://www.ikshafoundation.org/>

15. Free Cancer Medicines Scheme of Rajasthan Government
16. Arogya Sri Scheme- Telangana
17. Free Cancer Treatment in Govt Hospitals- West Bengal.



For more details, please consult your Treatment care providers in the respective hospital.

Reference: <https://www.cancerassist.in/govt-schemes-for-cancer-treatment>

**APPENDIX IX:
SIMILARITY REPORT**

**QUALITY OF LIFE IN
RETINOBLASTOMA SURVIVORS
IN INDIA: QoLRB INDIA STUDY**

by Krishnasri Padamandala



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QUALITY OF LIFE IN RETINOBLASTOMA SURVIVORS IN INDIA: QoLRB INDIA STUDY

ORIGINALITY REPORT

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