

## **A Literature Review: Factors Affecting Parental Behaviour in Early Detection of Children with Retinoblastoma**

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### **Abstract**

*In Indonesia, retinoblastoma is a type of cancer with a high incidence and is the most common cause of death after leukaemia. A delay in early detection contributes to the high prevalence of disease metastases and negative consequences. Further research is required to investigate the factors that affect early warning signs and parental responses to symptoms of retinoblastoma. This literature review aims to look at the factors affecting parental behaviour in early detection of children with retinoblastoma. This literature review searched three databases, including Web of Science, PubMed, and Google Scholar, for publications published between 2016 and 2020 using the key words "behaviour" OR "health behaviour" AND "risk factor" OR "predisposing factor," along with "parents" OR "caregiver" AND "detection" OR "early diagnosis" OR "screening", AND "children" OR "childhood" OR "child" AND "retinoblastoma". The Population, Intervention, Comparison, Outcome, Study Design (PICOS) framework was employed to establish inclusion criteria consisted of parents or carers of children under 5 years diagnosed with retinoblastoma, as well as internal and external factors affecting these parents in the early detection of the disease within the study design including cross-sectional research, qualitative studies, randomised controlled trials. The Joanna Briggs Institute Critical Appraisal were utilised to assess study quality. The review findings from 14 articles revealed that parental behaviour in early detection of children with retinoblastoma is influenced by internal and external factors. The internal factors include parents' or caregiver' socioeconomic status, level of education, individual beliefs, and the age at which a child receives his or her initial diagnosis. Then, the examples of external factors include distance, the support of a healthcare provider and skills, and the source of health information. Further studies on the effectiveness of health education and prevention interventions are required.*

**Keywords:** Behaviour; child health; early detection; parents; retinoblastoma; risk factor

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### **INTRODUCTION**

Retinoblastoma, an uncommon form of childhood cancer, can have severe consequences if not promptly addressed. This incident transpires frequently in developing countries. Retinoblastoma is a highly prevalent malignancy, with over 90% of children residing in developing countries dying from this potentially curable disease as a result of early detection delays and retinoblastoma metastases (Jain et al., 2019). In Indonesia, retinoblastoma is the second leading cause of death among children after leukemia (Ministry of Health Republic of Indonesia [MoH RI], 2018).

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Babies and children suffering from retinoblastoma account for around three percent of all malignancies (Abbas, 2018) while the majority of them are aged 5 years with the highest incidence at the age of 2-3 years (MoH RI, 2018). Furthermore, there are still many children who are brought to health services in advanced stages and early detection is late (MoH RI, 2018). The delay in early detection of retinoblastoma may be caused by many factors; however, research on factors that influence parental behavior in the early detection of retinoblastoma is still limited. The majority of existing studies explored parental care with retinoblastoma children and interventions to manage psychological problems and improve quality of life for children with retinoblastoma (Abd-Elnnaby Salem et al., 2022; Beddard et al., 2020; Belson et al., 2020; Sherief et al., 2023; Wu et al., 2021). Therefore, a review can reveal unexplored areas, such as factors causing screening delays, highlight effective public health initiatives for awareness campaigns and early screening programs, and encourage funding agencies and researchers to fill these gaps. Reviewing retinoblastoma in children is essential for promoting equitable care, enhancing clinical results, and establishing the research agenda to tackle persistent and emerging challenges, thereby supporting global initiatives like the WHO's Global Initiative for Childhood Cancer, which seeks to improve outcomes, particularly in developing countries.

Retinoblastoma cancer is a type of cancer that can be detected early using a tool called an ophthalmoscope (Khedekar et al., 2019). Early detection for retinoblastoma is called the 'Red See Test'. The Red See test is a test that uses an ophthalmoscope in a dark room with the child's eyes open. If the child's eyes are normal, red will be reflected from the child's eyes. Doctors or paramedics at Community Health Centers used the iPhone-based MDEye Care application to detect leukocoria in children, without anesthesia and pharmacological dilation (Khedekar et al., 2018). Additionally, symptoms that parents should be aware of are the appearance of white on the black part of the child's eyes, the eyes tend to be crossed, the eyes shine like a cat's eyes, red eyes, enlarged corneas, inflammation of the eyeball tissue until the child's vision is blurry (MoH RI, 2017).

Early detection of retinoblastoma in children is a health behavior related to early identification or screening for signs and symptoms of retinoblastoma to prevent complications. To that end, the Indonesian government has made efforts to prevent the prevalence of metastases by providing information about retinoblastoma through telemedicine or counselling at health facilities. For example, the Indonesian government, through the Indonesian Ministry of Health, often carries out outreach and dissemination of information about childhood cancer and early detection of retinoblastoma in collaboration with the Health Service through the "White Pupil Campaign" (MoH RI, 2017). The "White Pupil Campaign" is presumably an initiative designed to enhance awareness regarding leukocoria, a condition in which the pupil of the eye looks white rather than black under specific lighting conditions or in photographs. The campaign may focus on the early diagnosis of these severe ocular diseases to enhance treatment outcomes. Timely diagnosis is essential as numerous disorders may result in blindness or pose life-threatening risks, exemplified by retinoblastoma. However, delays in early detection and early treatment of retinoblastoma in children are still often found. This could refer to parental awareness and health education, as well as counselling on early diagnosis of malignant diseases in children, particularly retinoblastoma, which is currently underrepresented in the community. Additionally, health-seeking behaviour in Indonesia may vary from that of other regions. Cultural views, stigma associated with cancer, and economic limitations may postpone the pursuit of medical care, hence requiring customised awareness initiatives. This literature review aims to look at the factors affecting parental behaviour in early detection of children with retinoblastoma.

## METHOD

This study employed a literature review that involved iterative process: defining the topic, developing systematic search strategy, locating specific article, analyzing and synthesizing the finding (Belson et al., 2020; Torraco, 2005; Whittemore & Knafl, 2005). Following the review of the research question, this study employed a search strategy utilising three databases: Web of Science, PubMed, and Google Scholar. The keywords “behaviour” OR “health behaviour” AND “risk factor” OR “predisposing factor,” along with “parents” OR “caregiver” AND “detection” OR “early diagnosis” OR “screening”, AND “children” OR “childhood” OR “child” AND “retinoblastoma”, were applied to the queries. The search was restricted to full-text articles published in English and was limited to the years 2016 to 2021. The search yielded 19,284 items, which were then reviewed, 342 were recognised as duplicates, 19,021 were deemed to be excluded, and 263 remained, and 74 papers were screened based on their abstracts. Then, 14 articles were chosen for inclusion in the literature review. The Joanna Briggs Institute (JBI) protocol was used to assess the quality of the included papers. Appraisal of various forms of cross-sectional studies, randomised controlled trials, and qualitative investigations are presented in Table 1.

**Table 1.** Appraisal Results Based on JBI Appraisal Tools

| No                    | Author (Years)               | Criteria |   |   |   |   |   |   |   |   |    |    |    |    | Results       |
|-----------------------|------------------------------|----------|---|---|---|---|---|---|---|---|----|----|----|----|---------------|
|                       |                              | 1        | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 |               |
| Cross-sectional Study |                              |          |   |   |   |   |   |   |   |   |    |    |    |    |               |
| 1                     | Naimatuningsih et al. (2019) | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| 2                     | Hassan et al. (2019)         | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| 3                     | Essuman et al. (2018)        | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| 4                     | Xiao et al. (2020)           | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| 5                     | Fabian et al., (2020)        | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| 6                     | Dominggo et al. (2016)       | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| 7                     | Mattosinho et al. (2017)     | √        | √ | √ | √ | X | X | √ | √ |   |    |    |    |    | 6/8<br>75%    |
| Qualitative Study     |                              |          |   |   |   |   |   |   |   |   |    |    |    |    |               |
| 8                     | Moses et al. (2020)          | √        | √ | √ | √ | √ | √ | √ | √ | √ | √  |    |    |    | 10/10<br>100% |
| 9                     | Gedleh et al. (2018)         | √        | √ | √ | √ | √ | √ | √ | √ | √ | √  |    |    |    | 10/10<br>100% |

**Table 1.** Appraisal Results Based on JBI Appraisal Tools (continue)

| No                                  | Author (Years)        | Criteria |   |   |   |   |   |   |   |   |    |    |    |    | Results       |
|-------------------------------------|-----------------------|----------|---|---|---|---|---|---|---|---|----|----|----|----|---------------|
|                                     |                       | 1        | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 |               |
| 10                                  | Renner et al. (2016)  | √        | √ | √ | √ | √ | √ | √ | √ | √ | √  |    |    |    | 10/10<br>100% |
| 11                                  | Hill et al. (2019)    | √        | √ | √ | √ | √ | X | √ | √ | √ | √  |    |    |    | 9/10<br>90%   |
| 12                                  | Soliman et al. (2016) | √        | √ | √ | √ | √ | √ | √ | √ | √ | √  |    |    |    | 10/10<br>100% |
| 13                                  | Beddart et al. (2020) | √        | √ | √ | √ | √ | √ | √ | √ | X | √  |    |    |    | 9/10<br>90%   |
| <b>Randomized Controlled Trials</b> |                       |          |   |   |   |   |   |   |   |   |    |    |    |    |               |
| 14                                  | Staffieri (2019)      | √        | √ | √ | X | √ | √ | √ | √ | √ | √  | √  | √  | √  | 12/13<br>90%  |

Then, theme analysis was applied to all of the included articles, in accordance with Braun and Clarke (Braun & Clarke, 2006).

## RESULTS

### The Characteristic of Included Articles Review

Table 2 showed that the majority of included articles were obtained from PubMed (n=6, 43 percent), Google Scholar (n=6; 50%), and Web of Science (n=1; 7%). Half of the included articles used cross-sectional research designs (n=7; 50%) (Essuman et al., 2018; Naimatuningsih et al., 2019; Hassan et al., 2019; Xiao et al., 2020; Fabian et al., 2020; Domingo et al., 2020; and Mattosinho et al., 2017), followed by qualitative studies (n=6; 42%) (Beddart et al., 2020; Gedleh et al., 2018; Hill et al., 2018; Moses et al., 2020; Renner & McGill, 2016; Soliman et al., 2017; Staffieri et al., 2019). Meanwhile, one paper employed a randomized controlled trials study design (Staffieri et al., 2019). The majority of the included articles are from developing countries including Brazil, Ghana, Kenya, Nigeria, China, the Philippines, and Indonesia, as well as developed countries like England, Canada, and Australia.

**Table 2.** Characteristic of Included Articles (n=14)

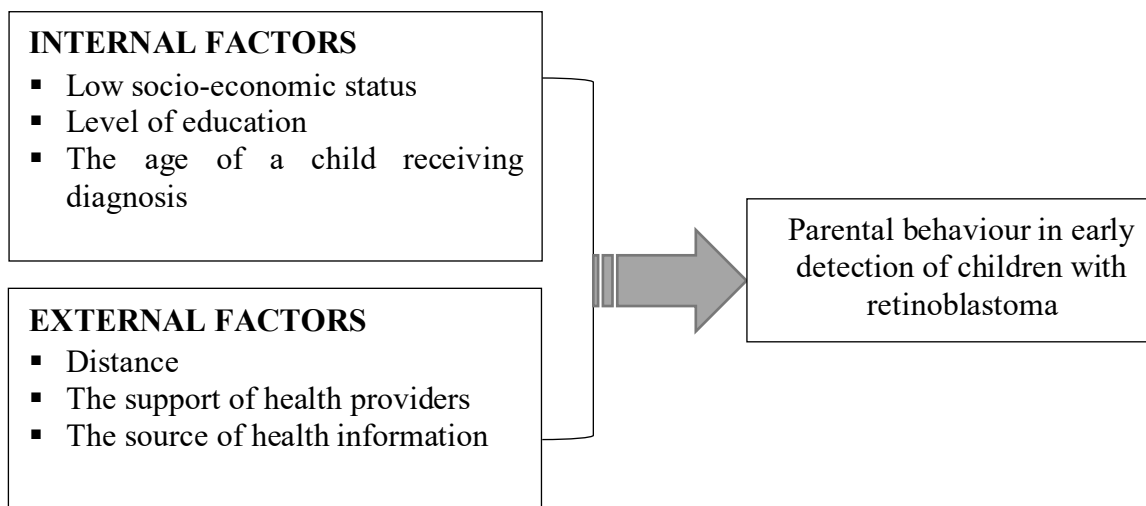
| Category            | n | (%) |
|---------------------|---|-----|
| Databases           |   |     |
| Web of Science      | 1 | 7   |
| PubMed              | 6 | 43  |
| Google Scholar      | 7 | 50  |
| Year of publication |   |     |
| 2016                | 3 | 21  |
| 2017                | 2 | 14  |
| 2018                | 1 | 7   |
| 2019                | 4 | 29  |
| 2020                | 4 | 29  |

**Table 2.** Characteristic of Included Articles (n=14) (continue)

| Category              | n | (%)  |
|-----------------------|---|------|
| Research Design       |   |      |
| Cross-sectional       | 7 | 50   |
| Qualitative study     | 6 | 43   |
| RCT                   | 1 | 7    |
| The Origin of Country |   |      |
| Brazil                | 1 | 7.1  |
| Canada                | 3 | 21.4 |
| Ghana                 | 2 | 14.3 |
| England               | 3 | 21.4 |
| Kenya                 | 1 | 7.1  |
| Nigeria               | 1 | 7.1  |
| China                 | 1 | 7.1  |
| Philippine            | 1 | 7.1  |
| Indonesia             | 1 | 7.1  |
| Australia             | 1 | 7.1  |

### Factors Influencing Parental Behaviour in Early Detection of Children with Retinoblastoma

The findings of the review constructed a theme associated with two themes, illustrated in Figure 1. The finding describes that parental behaviour in early detection of children with retinoblastoma is caused by internal and external factors. Internal factors consist of parents' or caregiver' socioeconomic status, level of education, and the age at which a child receives his or her initial diagnosis are examples of internal factors. External factors include distance, the support of a health provider, and the source of health information.



**Figure 1.** Factors Influencing Parental Behaviour in Early Detection of Children with Retinoblastoma

## **Internal Factors**

Internal factors, such as parents' or caregivers' lack of education of retinoblastoma, influence treatment decision-making. For example, parents' limited education of identifying diseases in their children or their ability to recognise retinal signs and symptoms, particularly in the early stages (Hassan et al., 2019), and not understanding risk factors, time to diagnosis, and complications (Essuman et al., 2018), all of which cause delays in seeking interventions. Lack of knowledge and perception of the disease before diagnosis, health-seeking behaviour are influenced by the interaction of individual and environmental factors (Renner & McGill, 2016). Parents living in urban areas are more knowledgeable than those living in rural areas ( $p=0.008$ ) (Xiao et al., 2020).

Low levels of education are associated with limited knowledge of retinoblastoma genetics and uptake of genetic counselling (Gedleh et al., 2018). Similar to the research of Hill et al. (2019) there is a misunderstanding of knowledge about genetic disease diagnostics in hereditary retinoblastoma paediatric clients regarding the risk of cancer. Limited information received by parents is because most first-contact doctors do not have sufficient knowledge about retinoblastoma (Xiao et al., 2020). Parents look for information from the internet or groups, but the information obtained from the mass media or online support groups may be incomplete or even wrong, causing misunderstandings about retinoblastoma and creating confusion among parents (Xiao et al., 2020). A low level of education can cause a lack of knowledge about retinoblastoma, the mother's education level correlates with the advanced stage at diagnosis (Essuman et al., 2018). Similarly, the child's dread of disability and the limited education that retinoblastoma is not dangerous lead to resistance to enucleation at the onset of the disease and to the pursuit of traditional treatment (Domingo et al., 2017). Moreover, Domingo et al. (2017) explained that there was one respondent who refused enucleation and five out of 10 respondents stated that they did not agree and had to think about deciding to enucleate at their first consultation. Meanwhile, four respondents agreed to enucleation as an early intervention for the treatment of retinoblastoma.

Socioeconomic status related to family income level influences parents in seeking medical assistance for their children. Low family income levels cause parents to delay carrying out early examinations. Naimatuningsih et al. (2019) show that retinoblastoma children who presented with a poor prognosis mostly occurred at low levels of father's education and employment, low levels of mother's education, mothers who did not work, and low levels of family income. Meanwhile, retinoblastoma children who presented with a good prognosis were most often found at middle levels of father's education and father's employment, low levels of mother's education, mothers who did not work and middle levels of family income. According to Fabian et al. (2020), in a logistic regression analysis, a lower level of national income was significantly correlated with the disease stage category.

The age of diagnosis is the age at which the client initially seeks therapy. A later stage and a bad prognosis are associated with older age at diagnosis (Fabian et al., 2020). In a study of 126 people conducted by Xiao et al. (2020) at the Zhongshan Ophthalmic Centre in China, discovers that unilateral children had an average age much older than at the time of diagnosis and survey (at diagnosis:  $32.4 \pm 20.3$  months vs.  $15.3 \pm 13.0$  months,  $p < 0.001$ ; time of survey:  $33.9 \pm 20.6$  months vs  $24.8 \pm 22.3$  months,  $p < 0.05$ ). Similarly, Fabian et al. (2020) explain that the average age for diagnosis at a retinoblastoma facility is 22-24 months for European kid clients compared to 30-32 months for African child consumers.

## **External Factors**

The distance and burden of travel to referral health services related to transportation and accommodation costs negatively cause parents to not immediately take their children for treatment or carry out repeated consultations. For example, Fabian et al. (2020) explained that European child clients travelled 421.8 km to a retinoblastoma referral centre and African child clients travelled 185.7 km playing a role in late diagnosis of the disease. Furthermore, psychosocial support from peer groups affects parents' insight into immediately screening their child's vision function. Hill et al. (2018) support that psychosocial and peer-to-peer support are important for parents of children with retinoblastoma to have access and initial knowledge in diagnosis. In line with Gedleh et al. (2018) that state that psychosocial support for clients and parents was identified as important for overcoming the diagnosis and moving towards treatment.

Health provider's support influences parents in recognizing the early symptoms of retinoblastoma. Gedleh et al. (2018) explain that limited information about retinoblastoma was caused by limited communication within the health team. Furthermore, the same study explained that parents reported having little experience with genetic counselling and testing. Beddard et al. (2020) state that the lack of information received by parents resulted in uncertainty and misdiagnosis. Similarly, Hill et al. (2018) find that parents do not understand if retinoblastoma is a genetic disease and they often misunderstand the implications of genetics on phenotype and cancer risk causing their confusion. Additionally, the length of diagnostic examination by health workers contributes to delays in diagnosis. Mattosinho et al. (2017) find that the medical interval was longer ( $\pm 5-6$  months) than the family interval ( $\pm 1-2$  months), this was due to a lack of knowledge and awareness about retinoblastoma among first-contact doctors in the Brazilian health system. Similarly, Beddard et al. (2020) in their qualitative study in the UK, state that the lack of information provided by primary health workers to parents caused further delays in early detection of retinoblastoma.

Sources of accurate health information regarding retinoblastoma influence parents to immediately seek health assistance. Xiao et al., (2020) find that 36 out of 37 parents obtained information regarding retinoblastoma from doctors including general practitioners, ophthalmologists and eye oncologists. The second source of information is the internet, and the next source of information comes from friends. Gedleh et al. (2018) state that study participants looked for information about retinoblastoma by using the internet to learn on their own because they were not satisfied with the explanation they had received. Increasing knowledge and awareness of parents by providing eye health information pamphlets containing information about eye development and normal vision in babies and children, explanations about strabismus, when it can be observed and should be considered abnormal as well as illustrations about leukocoria which can be observed with the naked eye or with photos, is very effective in encouraging parents to be alert to their child's eyes and seek immediate medical attention (Staffieri et al., 2019).

## **DISCUSSION**

Better early detection of retinoblastoma depends on multiple aspects, including parents' education, as well as collaborative support. However, the finding of the review found that limited education associated with a combined low level of parental education and environment negatively influences the level of acceptance of information about retinoblastoma. Additionally, family income level influences parents in detecting retinoblastoma early and seeking treatment assistance for their children. Low family income levels cause parents to delay early examination and treatment (Naimatuningsih et al., 2019). Income level is related to medical costs and travel costs to tertiary

health care facilities. The distance and burden of travel cost to referral health services discourage parents from seeking treatment or consultation for their children immediately. In line with findings from prior research conducted in Indonesia, a low socioeconomic status, distance and cost, and inadequate access to social support services were identified as significant determinants in the provision of substandard care for children, which ultimately resulted in poor health outcomes (Qur'aniati et al., 2022b; Qur'aniati et al., 2023). Furthermore, the lack of information provided by primary health providers to parents causes further delays in the early detection of retinoblastoma (Beddard et al., 2020; Gedleh et al., 2018). In addition, in delivering inadequate health education to parents, health providers show restricted counselling abilities, which led to parental confusion (Hill et al., 2019). Therefore, support from health providers influences parents' decision to recognize early symptoms and deal with them further. For example, health providers play an important role in providing accurate information about retinoblastoma. Health providers must improve their capabilities in order to establish performance standards or practises that are suitable for delivering screening and detection care for retinoblastoma. This can be achieved through participation in relevant courses or trainings (Qur'aniati et al., 2022a). Moreover, sharing experience amongst parents of children with retinoblastoma or the availability of peer-to-peer support are essential for parents to enhance their coping on carrying out effective screening and coping with diagnosis and treatment (Gedleh et al., 2028; Hill et. al., 2017). Taken together, support from health providers, peers and or communities can strengthen parental behaviour in early detection for retinoblastoma, lowering severe consequences.

The review findings found that children with retinoblastoma experienced late diagnosis. In addition to age of onset and diagnosis, the diagnosis of retinoblastoma in children was delayed. Several studies have suggested that predictive factors for childhood malignancies include sex, disease subtype, location, histology, grade, stage, and other clinical characteristics (Erdmann et al., 2021; Rodriguez-Galindo et al., 2015; Tierens et al., 2016). Cancers with a poor prognosis are prevalent in infants younger than one year and older children older than ten years (Bonaventure et al., 2017; Erdmann et al., 2021; Gatta et al., 2014). Furthermore, low socioeconomic position, and access to healthcare services are evidence to cause lower survival for European and the US children connected with clinical factors that are similar to the findings of this review (Erdmann et al., 2021; Gupta et al., 2014; Mogensen et al., 2018; Siegel et al., 2019; Tolkkinen et al., 2018).

## **CONCLUSION AND RECOMMENDATIONS**

Internal and external factors influence parental behaviour in the early detection of children with retinoblastoma. These internal factors include low parental education, low socioeconomic level, and the child's first diagnosis with retinoblastoma. Aside from internal factors, external factors influencing parents' early discovery of children with retinoblastoma include distance and travel, support from health providers, and access to health information. This study recommends that health providers, particularly physicians, nurses, and midwives, should enhance their knowledge and skills of retinoblastoma in order to furnish precise information to the public, with a particular emphasis on parents. Therefore, parents can conduct efficient individual screenings of their children's visual function for early signals of retinoblastoma and may immediately transport their children to health services if they observe worrisome symptoms. Additionally, it may be necessary to conduct additional research on the effectiveness of health education and prevention interventions in promoting early detection and screening for retinoblastoma within the community.



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## **AUTHOR CONTRIBUTIONS**

NZ contributed in conceptualization, methodology, validation, formal analysis, investigation, resources, data curation, writing original draft, supervision, writing-review and editing, and visualization. S contributed in conceptualization, methodology, validation, formal analysis, investigation, resources, data duration, project administration, and writing original draft. IDK contributed in conceptualization, methodology, validation, formal analysis, investigation, resources, data curation, supervision, and writing original draft. PDR contributed in conceptualization, validation, formal analysis, resources, data curation, visualization, and writing original draft. M contributed in conceptualization, resources, data curation, visualization, writing original draft, writing review and Editing.

## **CONFLICT OF INTEREST**

All authors declare that there are no conflicts of interest in this article.

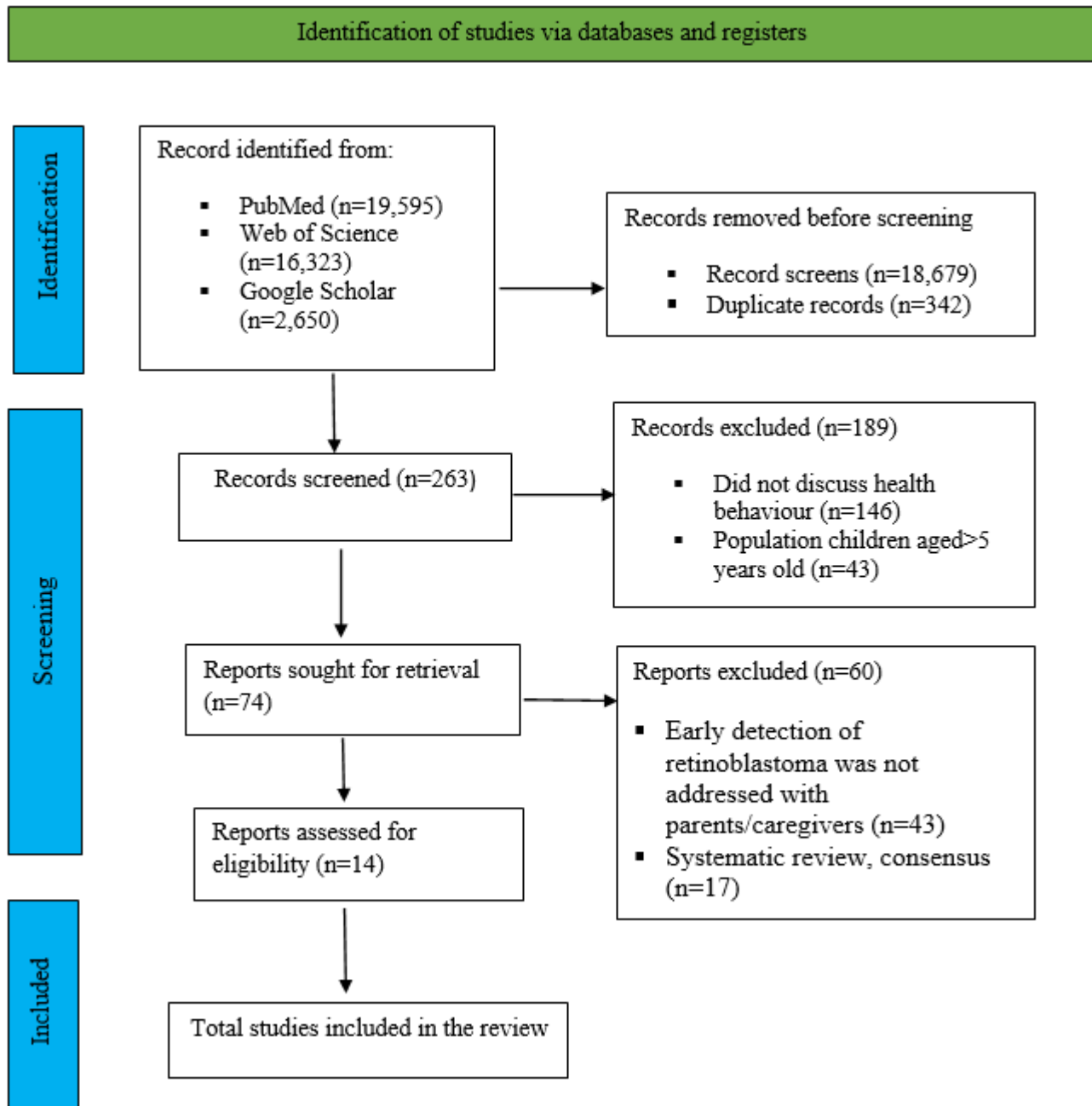
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**Figure 2.** Flow Diagram of Literature Review based on PRISMA 2020 (Page *et al*, 2021)

Data Extraction Table

| No | Author & Year                | Article Title                                                                                                                                    | Method                                                                                                                                                                                                                                                                 | Research Finding                                                                                                                                                                                                                                                                                                                                                                                                                   |
|----|------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. | Essuman et al. (2018)        | Presentation of Children with Advanced Retinoblastoma for Treatment in Ghana: The Caretakers' Perspective                                        | <ul style="list-style-type: none"> <li>▪ Design: Cross-sectional study</li> <li>▪ Sample: 40 caregivers of retinoblastoma patients.</li> <li>▪ Variables: Knowledge of retinoblastoma, initial symptoms, and treatment</li> <li>▪ Instrument: Questionnaire</li> </ul> | <ul style="list-style-type: none"> <li>a. 32 respondents (80%) had basic education.</li> <li>b. 6 caregivers (15.4%) knew their child had cancer.</li> <li>c. 32 caregivers did not know their child had cancer.</li> <li>d. 12 caregivers delayed treatment because they didn't realize the seriousness of the issue.</li> <li>e. No correlation was found between education level and knowledge about retinoblastoma.</li> </ul> |
| 2. | Naimatuningsih et al. (2019) | The Correlation Between Family Socioeconomic Status and the Delayed Treatment of Retinoblastoma Patient of Dr. Soetomo General Hospital Surabaya | <ul style="list-style-type: none"> <li>▪ Design: Cross-sectional study</li> <li>▪ Sample: 33 respondents</li> </ul>                                                                                                                                                    | <ul style="list-style-type: none"> <li>a. 16 fathers had low education and 16 had medium education; p-value = 0.322, showing no correlation.</li> <li>b. 19 mothers had low education and 11 had medium education; p-value = 0.129, showing no correlation.</li> </ul>                                                                                                                                                             |
| 3. | Hassan et al. (2019)         | Assessment of Awareness of Retinoblastoma Among Mothers of Under-Five Children in Kaduna State, Nigeria                                          | Design: Descriptive survey                                                                                                                                                                                                                                             | The mean awareness score of respondents about retinoblastoma was 3.08, indicating significant awareness.                                                                                                                                                                                                                                                                                                                           |
| 4. | Wei Xiao et al. (2020)       | Parent Knowledge of Screening and Genetic Testing in Retinoblastoma                                                                              | Design: Cross-sectional study<br>Sample: 126 parents<br>Variables: Patient and respondent characteristics                                                                                                                                                              | <ul style="list-style-type: none"> <li>a. 68 respondents had education below high school.</li> <li>b. 60 respondents had low income.</li> <li>c. 37 respondents answered all 7 questions correctly.</li> <li>d. Parents with higher education had better</li> </ul>                                                                                                                                                                |

| No | Author & Year          | Article Title                                                                                                           | Method                                                                                                              | Research Finding                                                                                                                                                                                                |
|----|------------------------|-------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|    |                        |                                                                                                                         |                                                                                                                     | knowledge<br>e. 36 of 37 parents received information from doctors; 29 from the internet.<br>f. Information from mass media or online groups was sometimes incomplete or incorrect                              |
| 5. | Shrestha et al. (2021) | Knowledge, Attitude, and Practice of Retinoblastoma Among Caregivers in Nepal                                           | Design: Cross-sectional study<br>Sample: 50 caregivers                                                              | a. 49 respondents (98%) had low awareness about retinoblastoma.<br>b. Only 1 caregiver had prior knowledge about retinoblastoma<br>c. The majority were unaware of risk factors and symptoms of retinoblastoma. |
| 6. | Essuman et al. (2020)  | Sociodemographic Characteristics of Parents and Caregivers of Children Presenting with Advanced Retinoblastoma in Ghana | <ul style="list-style-type: none"> <li>▪ Design: Cross-sectional study</li> <li>▪ Sample: 58 respondents</li> </ul> | a. 86% of respondents had low income and 90% had no health insurance.<br>b. 79% of caregivers were unemployed.<br>c. Significant delays occurred in seeking treatment due to financial constraints.             |
| 7. | Mousa et al. (2020)    | Barriers to Early Presentation of Retinoblastoma in Developing Countries: A Literature Review                           | <ul style="list-style-type: none"> <li>▪ Method: Literature review</li> <li>▪ Sources: 15 studies</li> </ul>        | a. Key barriers: Lack of awareness, poverty, and cultural beliefs about health.<br>b. Cultural stigmas prevented some parents from seeking medical attention.                                                   |
| 8. | Chinta et al. (2021)   | Factors Contributing to Delayed Presentation of Retinoblastoma Patients in India                                        | <ul style="list-style-type: none"> <li>▪ Design: Mixed methods study</li> <li>▪ Sample: 100 families</li> </ul>     | a. Delays in treatment were associated with low socioeconomic status and limited access to specialized care.                                                                                                    |



| No  | Author & Year             | Article Title                                                                | Method                                                                                                                      | Research Finding                                                                                                                                                                                                                                                                                                                                     |
|-----|---------------------------|------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|     |                           |                                                                              |                                                                                                                             | b. Mothers often blamed themselves, citing cultural and personal guilt as a factor in delayed treatment.                                                                                                                                                                                                                                             |
| 9.  | Diana et al. (2022)       | Awareness Level of Retinoblastoma Among Parents in Malaysia                  | <ul style="list-style-type: none"> <li>▪ Design: Descriptive survey</li> <li>▪ Sample: 200 parents</li> </ul>               | <ul style="list-style-type: none"> <li>a. Respondents with higher education were more likely to know about retinoblastoma.</li> <li>b. Television and healthcare workers were the primary sources of information.</li> </ul>                                                                                                                         |
| 10. | Sitorus et al. (2009)     | Clinical Manifestations and Outcome of Retinoblastoma in Indonesian Patients | <ul style="list-style-type: none"> <li>▪ Design: Retrospective study</li> <li>▪ Sample: 160 patients</li> </ul>             | <ul style="list-style-type: none"> <li>a. Out of 160 patients, 72.5% presented with advanced-stage retinoblastoma.</li> <li>b. A significant number of patients delayed treatment for over 6 months due to financial and logistical constraints.</li> <li>c. Survival rates were much lower in patients who delayed seeking medical care.</li> </ul> |
| 11. | Lestari et al. (2020)     | Challenges in the Management of Retinoblastoma in Indonesia                  | <ul style="list-style-type: none"> <li>▪ Design: Qualitative study</li> <li>▪ Sample: Interviews with 20 parents</li> </ul> | <ul style="list-style-type: none"> <li>a. Limited access to trained healthcare professionals and treatment facilities were significant barriers.</li> <li>b. Lack of knowledge and awareness among parents contributed to delayed diagnosis and treatment.</li> </ul>                                                                                |
| 12. | Rahmatullah et al. (2021) | Analysis of Retinoblastoma Awareness Among Healthcare Providers in Indonesia | <ul style="list-style-type: none"> <li>▪ Design: Cross-sectional study</li> <li>▪ Sample: 150 healthcare workers</li> </ul> | <ul style="list-style-type: none"> <li>a. 75% of healthcare workers were unable to recognize early symptoms of retinoblastoma.</li> <li>b. Training and education on retinoblastoma were identified as critical</li> </ul>                                                                                                                           |



| No  | Author & Year            | Article Title                                                                                              | Method                                                                                                       | Research Finding                                                                                                                                                                                                                                               |
|-----|--------------------------|------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 13. | Nurhasanah et al. (2021) | The Relationship between Family Income and Retinoblastoma Treatment Outcomes at RSUP Hasan Sadikin Bandung | <ul style="list-style-type: none"> <li>▪ Design: Correlation study</li> <li>▪ Sample: 50 patients</li> </ul> | <p>needs.</p> <ul style="list-style-type: none"> <li>a. Families with low income faced significant challenges in accessing timely treatment; p-value &lt; 0.05.</li> <li>b. Poor treatment outcomes were often linked to delayed initial diagnosis.</li> </ul> |
| 14. | Handayani et al., (2022) | Parental Perceptions of Childhood Eye Diseases in Rural Indonesia                                          | <ul style="list-style-type: none"> <li>▪ Design: Qualitative study</li> <li>▪ Sample: 30 parents</li> </ul>  | <ul style="list-style-type: none"> <li>a. Many parents attributed eye diseases to superstitions or traditional beliefs rather than medical causes.</li> <li>b. Misconceptions about eye diseases delayed medical consultation and proper treatment.</li> </ul> |