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The midwife said “It’s okay” – a qualitative study on the causes of delayed retinoblastoma treatment

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Abstract

Purpose: Retinoblastoma is the most common primary intraocular tumour in children. Its prognosis varies depending on the stage of diagnosis. However, in developing countries such as Indonesia, retinoblastoma still has a poor prognosis as most patients present at advanced stages. This research aims to explore the factors influencing the delay in patients with retinoblastoma reaching referral health facilities from the perspective of their families. **Methods:** A qualitative study using a phenomenological approach was conducted to gather family perspectives through in-depth interviews via WhatsApp calls. Each interview lasted 20-25 minutes and included families of retinoblastoma patients who had visited the eye clinic at Sardjito General Hospital at a late hour. “Late” was defined as tumour spread beyond the eyeball (intraorbital, spread to the optic nerve, or intracranial spread) or involvement of more than one eye. Audio was transcribed verbatim using a mobile phone voice recorder, and open coding was performed using Open Code 4.02 software to identify meaning units, codes, and categories. Triangulation and peer debriefing were used to ensure validity and trustworthiness. **Results:** Several categories emerged, including reasons for seeking help, trust in medical professionals, family compassion, and challenges in health facilities. Challenges in health facilities, particularly diagnostic capabilities, communication, and education about eye tumor, along with negative emotions like denial from families, contributed to delays in seeking treatment for retinoblastoma patients. **Conclusion:** Family compassion plays a positive role in encouraging families to seek medical help. However, challenges in health facilities, particularly in diagnosis, communication, and education about eye tumors, as well as family denial, contribute to the delays in retinoblastoma patients reaching referral health facilities.

Keywords: delayed; denial; family compassion; health facility challenges; retinoblastoma

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INTRODUCTION

Retinoblastoma is the most common primary intraocular tumor in children, with an incidence ranging from 3.4 to 42.6 cases per 1 million live births worldwide [1]. As a malignant solid tumor, retinoblastoma has a widely varying prognosis depending on the stage at which parents first notice the tumor and bring the patient to seek medical care, as well as the availability of treatment modalities at the healthcare facility. Globally, retinoblastoma prognosis varies greatly. In developed countries, retinoblastoma has a favorable prognosis, with survival rates reaching up to 95% [2]. However, in developing countries with lower national income levels, the prognosis for retinoblastoma remains poor [3].

Indonesia, as a developing country, has not yet achieved favourable prognosis rates. Retinoblastoma patients in Indonesia are often brought to medical professionals at advanced stages, which limits treatment options, reduces survival rates, and worsens prognosis. This is reflected in the differing goals of treatment in developed and developing countries: in developed countries, the primary goal of retinoblastoma treatment is eye preservation, and in some cases, even vision preservation. In contrast, in developing countries, such as Indonesia, the focus remains on saving the patient’s life.

Until now, the factors contributing to delays in bringing retinoblastoma patients to healthcare providers have not been thoroughly explored. This qualitative study represents a significant step toward understanding the factors influencing delays in retinoblastoma treatment from the parents' perspective in Indonesia. By examining the experiences of parents of children with retinoblastoma, this study aims to provide a more comprehensive understanding of the key factors that hinder early intervention. The findings of this study are not only expected but also crucial in contributing to the formulation of policies and strategies that effectively support early detection and accelerate access to treatment for retinoblastoma cases in Indonesia. This study aims to explore the perceptions of families of retinoblastoma patients regarding the causes of delays in seeking initial treatment for their child.

METHODS

A qualitative phenomenological approach was used to explore family perspectives on the factors contributing to delays in seeking treatment. Researchers asked families: What are the causes of delays in seeking initial therapy for patients with retinoblastoma? The principal investigator (ITD) is an ophthalmologist with a subspeciality in ocular oncology, assisted by a public health lecturer who is an expert in qualitative research.

The sample was selected using purposive sampling and consisted of families of retinoblastoma patients who visited the eye clinic at Sardjito General Hospital in the advanced stages of the disease. An advanced-stage or delayed retinoblastoma treatment patient was defined as a tumor that had spread beyond the eyeball (intraorbital, spread to the optic nerve, or intracranial spread) or when the tumor involved more than one eye. This criterion was selected because patients in these conditions have a poorer prognosis. Families of the patients who met these criteria were given a detailed explanation about the study. They were asked for their consent to participate while their children were undergoing examinations at the eye clinic.

Data were collected through structured interviews, which lasted approximately 20-25 minutes, and were conducted via WhatsApp calls. The structured interview guide was developed after reviewing possible causes of delays identified in previous quantitative studies. Families were asked questions regarding the initial symptoms, the time at which the symptoms first appeared, the first healthcare facility visited, the distance to the nearest healthcare facility, and the medical costs incurred.

Before conducting the interviews, researchers provided a detailed explanation of the study's purpose, interview process, and participant rights, including the right to refuse or withdraw participation at any time. Written informed consent was obtained, and participant confidentiality was maintained using pseudonyms in the research report. Audio recordings were transcribed verbatim using a mobile phone voice recording application. To ensure data validity, this study used data triangulation, which involved comparing information obtained from multiple interviews to identify consistency and variations in experiences. Open coding was then conducted using Open Code 4.02 software by all researchers to identify meaning units. The collected meaning units were coded and synthesized to identify relevant categories.

The coding process was conducted after the researchers had fully understood the participants' experiences. Data trustworthiness was ensured through peer debriefing with all researchers, assisted by an experienced qualitative researcher specializing in health behaviour (SS). Data analysis was conducted using Open Code 4.02 software for coding and analysis. The coding process was interactive, where researchers categorized data based on emerging concepts, compared concepts or categories, and linked interrelated concepts and categories. Data from qualitative interviews were analyzed using thematic analysis.

RESULTS

Two participants were interviewed for this study, and an analysis of the audio transcripts was conducted. Both participants were women, aged 30 and 42 years, and were biological mothers of retinoblastoma patients. Both mothers were housewives with a middle-income economic background. The two participants lived at a considerable distance from primary healthcare facilities; one participant resided in Central Java, while the other lived in East Java. Based on the interview analysis (Table 1), four major categories of causes for delays in seeking initial retinoblastoma treatment were identified: 1) reasons for seeking treatment; 2) barriers at initial healthcare facilities; 3) health beliefs; and 4) family affection.

Table 1. Summary of themes

Category	Sub-category	Codes
Reasons for seeking treatment	Lack of family knowledge	"Cat's eye" appearance Tumour increasingly enlarged Symptoms worsening "What kind of disease is this?" At 18 months of age At 1.5 years of age
	Negative emotions	Disbelief Denial Shocked Lost hope Could not think clearly Pessimistic Felt pain
Healthcare facility barriers	Communication barriers with doctors	Doctors did not explain the disease Referred immediately Checked at 3 hospitals
	Distance to healthcare	Far Five hours 23 kilometers 1-1.5 hours travel rented vehicle
	Initial screening issues	Pupils were still okay The midwife said it was fine
Health beliefs	Trust in medical treatment	Did not go to alternative treatment Checked by an ophthalmologist Went to a hospital
	Decision-making for therapy	Agreed immediately Consulted family
Family affection	Cost was not an obstacle	BPJS worked without issue No problem with general costs "Money can be earned, life cannot"
	Distance does not matter	"For the child's health" No matter how far

Lack of knowledge

The family's level of knowledge about the disease, including its symptoms and the importance of early diagnosis, can influence their decision to seek treatment. Families who lack information may not realize the urgency of seeking medical help. Data obtained from the participants show that the community still has minimal knowledge in identifying early symptoms of tumours. This ignorance leads to delays in seeking healthcare, as most perceive the symptoms as ordinary (ignoring them) until unusual signs emerge, as reflected in the following quotes:

> *"Oh yes, I thought this was nothing, like some ordinary illness, doctor. But over time, it got bigger, so I took them to the local eye doctor, and they referred us to Jogja." (P2)*

One participant stated that although they noticed unusual symptoms, they did not take immediate action. Despite limited knowledge, the participant did not attempt alternative treatments before seeking medical care:

> *"Uhm… When they were one and a half years old, their eyes looked like a cat's eye. But as the child grew older, it kept getting bigger. At first, it was only about the size of a soybean." (P2)*

Family's emotional reflection on the diagnosis

Receiving information from a doctor regarding a severe diagnosis like retinoblastoma can be an unpleasant experience for families. Coping mechanisms determine how families react adaptively and make the right decisions. The various emotions experienced by families upon hearing the diagnosis include sadness, pessimism, and disbelief. These feelings also influence the patient's family in seeking medical help. Denial of the bad news often leads families to seek second or third opinions before eventually accepting the patient's condition. This delay contributes to prolonged diagnosis timelines. For example, the second participant required 10 months from the onset of symptoms to diagnosis.

> *"It felt painful, eh." (P1)*

> *"I was shocked and couldn't think… I already lost hope… or maybe I just didn't believe it yet." (P2)*

> *"I didn't believe it, doctor. Even though I went to that eye clinic, I still didn't believe it." (P2)*

Barriers related to healthcare Professionals/facilities

Healthcare services play a crucial role in diagnosing and managing diseases such as retinoblastoma. An accurate understanding of diagnosis and treatment, adequate facilities, and integrated services are essential for improving outcomes, especially for aggressive tumors like retinoblastoma. High-quality healthcare ensures early diagnosis and effective treatment, ultimately improving prognosis and patient quality of life. Unfortunately, this level of care is not yet evenly distributed across all healthcare facilities, especially in rural areas. One participant mentioned that the initial examination conducted by a local midwife was insufficient and that the condition was not considered serious:

> *"I thought it wasn't normal, so I checked with the local midwife first. The midwife said it was fine. As long as the vision was still clear, it was fine. But I wasn't sure, so I took them to a doctor." (P1)*

While misdiagnosis was not observed in medical-based facilities, challenges regarding ineffective doctor-patient communication were identified. Healthcare professionals were able to detect the urgency for referrals but lacked clarity in explaining the diagnosis, disease progression, and the importance of immediate action. This caused uncertainty for families in following referral instructions. Both participants shared similar experiences of unclear explanations during their initial visits. Proper diagnosis and explanations were obtained only after examinations at Dr. Sardjito General Hospital.

> *"The doctor said they couldn't explain the illness and just referred me to the hospital in Jogja." (P2)*
>
> *"For the ultrasound… they just told me to go to the hospital in Jogja without any explanation." (P2)*
>
> *"The doctor didn't say anything, just that this needs a referral to the hospital." (P1)*

Healthcare accessibility

Barriers to accessing healthcare include long distances to facilities, lengthy travel times, and limited transportation options. Both families shared that they rented cars to travel to RSUP Sardjito, which imposed significant financial burdens.

> *"The journey took 1 to 1.5 hours." (P1)*
>
> *"Then how long did it take to reach Sardjito?" (I)*
>
> *"Five hours, doctor." (P1)*
>
> *"We rented a car." (P1)*
>
> *"I don't know, doctor. It's far, about a four-hour car ride to Sardjito." (P2)*
>
> *"Did you use your own car?" (I)*
>
> *"No… we rented one." (P2)*

Health belief

Both participants demonstrated a high level of trust in medical treatment. Despite uncertainty or dissatisfaction with previous healthcare services, they did not seek alternative medicine. Healthcare visits ranged from midwives and general practitioners to district hospitals and specialists in eye care. Even when faced with referrals to distant tertiary hospitals (over four hours away), both families followed the recommendations rather than seeking alternative therapies closer to home.

Upon arriving at the tertiary hospital, both participants were offered enucleation (surgery to remove the eye). Although this was a significant and challenging decision with life-changing implications, both families ultimately agreed to the procedure, with one family requiring additional discussions with relatives.

> *"Uhm… I discussed it with my family first, then I agreed." (P1)*
>
> *"No, doctor. I immediately agreed to the eye removal procedure." (P2)*

Parental love and dedication

Both participants, as mothers of the patients, demonstrated immense love and dedication to their children's well-being. This dedication was evident through their willingness to endure long journeys and significant financial burdens to seek treatment. The first participant relied on BPJS insurance, while the second participant covered the medical expenses independently. These examples reflect strong social support, particularly from family members.

> *"No, doctor. No matter how far it is, I'll do it for my child to get better." (P2)*
>
> *"It's not about the cost, doctor. Money can be earned, but life cannot be replaced. I'm not worried about the expenses." (P2)*
>
> *"Yes, for the sake of my child, I'll go however far it takes." (P1)*

DISCUSSION

The delay in seeking early treatment for retinoblastoma patients by their families has a broad impact. This delay can increase morbidity and mortality rates among patients [4]. The causes of this delay vary depending on the type of illness. Commonly, delays in diagnosis arise from coordination issues between patients and doctors, as well as a lack of understanding of the patient's condition [5].

This study reports several factors that may contribute to the delay in seeking treatment for retinoblastoma. These include a lack of family knowledge about the early symptoms of retinoblastoma, negative feelings experienced by the family after receiving a retinoblastoma diagnosis, communication barriers with healthcare providers at initial healthcare facilities, insufficient knowledge of healthcare professionals at these facilities, and the distance from healthcare facilities.

In this study, the lack of family knowledge regarding abnormalities in a child, which could be early signs of retinoblastoma, is one of the reasons for the delay in receiving treatment at healthcare facilities. Symptoms like the "cat's eye" reflex (leukocoria), changes in vision, or asymmetrical eyes may be overlooked or trivialized. In many cases, parents may not realize that these signs indicate a serious issue. Delays in seeking medical care are often caused by a lack of understanding about the importance of early detection or even a fear of a cancer diagnosis [6]. Uncertainty about the illness initially delays action because parents fail to recognize that early symptoms are severe and require immediate medical attention. This delay also reflects a knowledge gap that could be addressed through increased public education about the symptoms of retinoblastoma.

The emotional responses of the two participants reveal negative feelings upon receiving the bad news (diagnosis of an eye tumor). These feelings were dominated by denial, sadness, shock, and pessimism. These reactions can influence the speed of decision-making and prompt seeking further help for retinoblastoma. Denial has been reported in varying severity of illness and significantly impacts health decision-making, whether it's not accepting the diagnosis, not realizing the diagnosis, delaying seeking help, or low adherence [7].

In the case of the second participant, denial lasted a considerable amount of time. It manifested in actions like visiting three different healthcare facilities to seek clarity before finally accepting the possible diagnosis and the radical management plan (eye removal surgery).

Healthcare providers at the primary care level are the front line for detecting this disease. One participant mentioned that their child's eye was initially declared normal, despite having reported unusual symptoms. This shows the need for improved education for primary healthcare providers (doctors, nurses, midwives, etc.) in detecting retinoblastoma. Misdiagnosis can delay treatment and lead to worse survival outcomes. The use of electronic tools to assist in screening for retinoblastoma could be an effective solution for early detection [8].

At healthcare facilities where medical specialists (doctors and ophthalmologists) were involved, all diagnoses were consistent with eye tumours. However, communication barriers led to a gap in the information received by the family. Participants reported that the minimal information provided by healthcare providers during the referral process was confusing and unclear. This highlights that even with a referral, clear and informative communication from medical staff is essential to ensure that patients and their families understand the next steps. This finding underscores the importance of effective communication in pediatric healthcare, where parents must feel confident in the diagnosis to avoid delays in treatment [9].

Both participants in this study mentioned that the healthcare facilities they visited were at least 17 km away from their homes. This finding is consistent with research from the Bannu Ophthalmology department in India, which reported that factors such as living in remote areas and transportation difficulties affected the delay in retinoblastoma treatment [10]. This emphasizes the need for health policies that support the equitable distribution of healthcare services, such as the development of healthcare facilities in remote areas and better transportation options. Improving transportation infrastructure and accessibility to healthcare, particularly in rural areas, is crucial for helping parents seek necessary care for their children [11].

High trust in medical care was a vital modulator for both participants. This was evidenced by their choice to seek medical help from healthcare facilities, despite the long distance and additional costs involved. Even when families were unsure about the diagnosis given by the previous healthcare facility, both participants chose not to pursue non-medical treatments. This aligns with prior studies showing that early detection and medical intervention are key to managing childhood cancers [12].In both cases, despite coming from middle socio-economic backgrounds and one lacking insurance, neither mentioned financial difficulties as a barrier to seeking medical help. This finding contrasts with previous research, which identified financial hardship as a factor contributing to delays in retinoblastoma treatment [6,10]. The difference may be influenced by the strong family support, driven by affection, which leads them to make sacrifices for the best possible treatment for the patient. This finding aligns with a systematic review that highlights the benefits of social support for childhood cancer survivors [12].

The interaction of several categories influencing the arrival of retinoblastoma patients to referral healthcare facilities is summarized in the fishbone diagram shown in Figure 1. Four main categories influence the arrival of retinoblastoma patients to healthcare facilities: family knowledge about retinoblastoma, healthcare facility constraints, health beliefs, and family affection. The delay in bringing retinoblastoma patients to receive early treatment is primarily due to the lack of family knowledge about early symptoms, coupled with negative emotional responses upon receiving the diagnosis, and barriers in healthcare facilities, such as distance, insufficient healthcare provider competence, and ineffective medical communication. Health beliefs and family affection play a crucial role in motivating families to seek care, even among those from middle socio-economic backgrounds or lacking insurance.

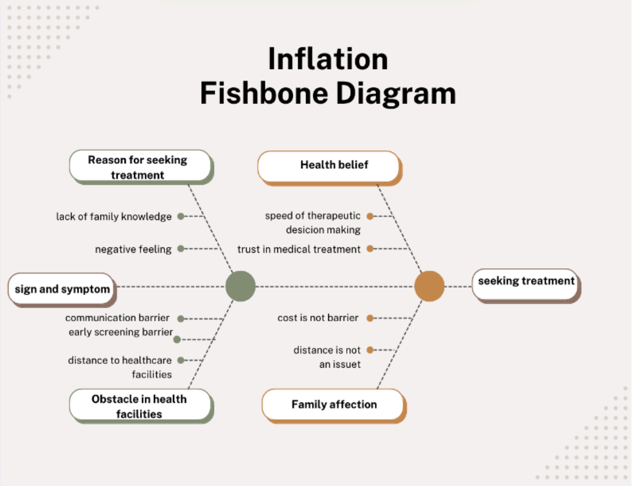

Figure 1. Inflation fishbone diagram

Figure 1. Fishbone diagram illustrating factors influencing the arrival of retinoblastoma patients to referral healthcare facilities. The red lines indicate categories with adverse effects. Due to time constraints and the infrequent incidence of retinoblastoma, the information gathered in this study is not yet saturated, and further in-depth exploration is needed, along with an increase in the number of participants.

CONCLUSION

The challenges identified in this study include the lack of family knowledge about the early symptoms of retinoblastoma, including the negative emotional response of the family when receiving the bad news of a potential eye tumor diagnosis. Additionally, there are healthcare facility-related barriers such as the distance to healthcare facilities, inadequate competence of healthcare staff, and ineffective medical communication. However, the trust families have in medical care and their affection for the patient can be powerful motivators for seeking medical help. Further research is needed to enhance the quality of information gathering and data validation. The implications of this research suggest that there is a need to increase public awareness about the early symptoms of retinoblastoma, improve healthcare providers' competence in early detection and counseling for retinoblastoma cases, and provide psychological support for families of retinoblastoma patients.

REFERENCES

1. Vempuluru VS, Kaliki S. Screening for retinoblastoma: a systematic review of current strategies. Asia-Pacific Journal Ophthalmology (Philadelphia, Pa.). 2021;10(2):192–199.
2. Lu JE, Francis JH, Dunkel IJ, Shields CL, Yu MD, Berry JL, et al. Metastases and death rates after primary enucleation of unilateral retinoblastoma in the USA 2007-2017. The British Journal of Ophthalmology. 2019;103(9):1272–1277.
3. Global Retinoblastoma Study Group; Fabian ID, Abdallah E, Abdullahi SU, Abdulqader RA, Adamou Boubacar S, Bowman R, et al. Global retinoblastoma presentation and analysis by national income level. JAMA Oncology. 2020;6(5):685–695.
4. Swerdlow RH, Burns JM, Khan SM. The Alzheimer's disease mitochondrial cascade hypothesis: progress and perspectives. Biochimica et Biophysica Acta. 2014;1842(8):1219–1231.
5. Bakry MH, Rahmadhany R. Retinoblastoma: Masalah dan hambatan dalam mendiagnosis. Jurnal Biomedika dan Kesehatan. 2019;2(4):162–168.
6. Patierno C, Fava GA, Carrozzino D. Illness denial in medical disorders: a systematic review. Psychotherapy and Psychosomatics. 2023;92(4):211–226.
7. Xiao W, Ji X, Ye H, Zeng H, Gao Y, Yang H, et al. Parent knowledge of screening and genetic testing in retinoblastoma. Journal of Ophthalmology. 2020; 2020:3839792

8. Firoozi M, Besharat MA, Rahimian Boogar E. Emotional regulation and adjustment to childhood cancer: role of the biological, psychological, and social regulators on pediatric oncology adjustment. Iranian Journal of Cancer Prevention. 2013;6(2): 65–72.
9. Wazir MI, Karim S. Causes of delayed presentation of retinoblastoma: a single centre study. International Journal of Health Sciences. 2023;7(S1): 3207–3213.
10. Rezky MK, Dewi C, Djamaluddin M. Evaluasi kebutuhan jalur pedestrian ramah anak di kawasan MIN 6 Banda Aceh. Jurnal Ilmiah Mahasiswa Arsitektur dan Perencanaan. 2022;6(4):56–61.
11. Wollney EN, Bylund CL, Kastrinos AL, Salome G, Sae-Hau M, Fisher CL. et al. Understanding parents uncertainty sources and management strategies while caring for a child diagnosed with a hematologic cancer. PEC Innovation. 2023;3:100198.
12. Deegan A, Brennan C, Gallagher P, Lambert V, Dunne S. Social support and childhood cancer survivors: A systematic review (2006–2022). Psychooncology. 2023;32(6):819–833.