

Exploring the Reasons for Parental Non-Attendance at the Retinopathy of Prematurity Clinic: A Qualitative Study at a Referral Center in Northeast Iran

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Abstract

Background: Missing scheduled appointments can have serious consequences for infants with retinopathy of prematurity (ROP), such as retinal detachment, glaucoma, myopia, and amblyopia, leading to permanent vision loss and impacting the child's future. Additionally, non-attendance can result in clinician dissatisfaction, inefficient use of healthcare resources, and reduced quality of care. Therefore, it is crucial to evaluate non-attendance rates for initial and follow-up appointments, understand contributing factors and develop interventions to improve adherence. Furthermore, exploring the reasons behind parents' non-attendance for premature infants with ROP and gathering their opinions on appointment reminder systems is essential.

Method: This qualitative study utilized a content analysis approach at the ROP clinic of the Khatam Eye Hospital in Mashhad from 2021 to 2022. The study focused on parents of premature infants with ROP who had missed at least one appointment. Participants were selected through purposive sampling and were interviewed using semi-structured interviews. Thematic content analysis was conducted to identify the reasons for missed appointments.

Results: Out of the 36 participants, 24 (66%) were female, with a mean age of 37 years old. Reasons for non-attendance were categorized into seven main groups, including cultural, economic, geographical, parental indifference to receiving services, infrastructure and management issues, preference for private over government physicians, and other reasons, with 28 subcategories.

Conclusion: Various key factors were identified that contributed to parents not attending the ROP clinic. These factors encompass cultural, economic, and geographic considerations, lack of interest in receiving services, infrastructure challenges, and a preference for private-sector physicians over those in the public sector.

Key Words: Adherence to Treatment, Eye, Parent, Infant, Reasons for Non-Attendance, Retinopathy of Prematurity.

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1- INTRODUCTION

Non-adherence to treatment is a significant global challenge (1-4). Despite considerable advancements in interventions to improve patient adherence over the past decade, adherence levels have shown minimal improvement (2). Non-adherence to treatment is defined as the "degree of non-compliance of individuals with health or treatment recommendations," and is a complex behavioral process influenced by factors such as patient characteristics, the physician-patient relationship, and the healthcare system (5, 6). Healthcare professionals are deeply concerned about the number of patients who avoid seeking medical attention and fail to undergo necessary treatment, leading to suboptimal treatment outcomes, diminished quality of life, and higher healthcare costs (7, 8). Non-adherence to treatment can significantly impact patients, potentially exacerbating the progression and chronicity of their illness (9-11). For instance, timely follow-up and treatment are imperative for conditions such as retinopathy of prematurity (ROP).

ROP is the leading preventable cause of blindness in children (12, 13). As neonatal mortality rates decline globally, ROP is increasingly prevalent not only in advanced countries but also in developing nations due to higher rates of premature birth, limited access to specialized infant care services, and inadequate awareness and training among healthcare professionals. This phenomenon has been labeled the "third epidemic" (14, 15). Timely screening and appropriate interventions can avert blindness in many of these children. Therefore, screening and follow-up for these patients are crucial (16). It is essential to conduct follow-up examinations in infants diagnosed with any degree of ROP. The eyes affected by ROP may initially appear healthy, but abnormal blood vessel proliferation

(neovascularization) may develop in the following weeks, necessitating treatment with laser or intravitreal anti-vascular endothelial growth factor (VEGF) injections. Failure to follow up on screening and treatment increases the risk of retinal tearing and detachment. Individuals with a history of ROP are at risk of retinal detachment during the first and second decades of life. Additionally, myopia, strabismus, amblyopia, cataracts, and glaucoma are considered complications of the disease. Therefore, timely diagnosis, periodic examinations, and treatment are vital in preserving infant vision. Follow-up and further examination of these patients can prevent late complications (17). However, it has been shown that parents of these infants may forget to attend appointments or delay their visits, which can affect the treatment outcome and prolong the recovery process of patients (18).

To date, only a limited number of studies have explored why patients do not seek medical attention for follow-up treatment. Most of these studies have focused on psychological factors (19-23), while others have highlighted issues such as distrust of the treating physician, psychological challenges like shyness, excessive worry and anxiety, and negative past experiences (20, 24-26). Several studies have found telephone services to be the most effective and cost-efficient method for reminders and follow-ups (27). Phone follow-up can reduce unnecessary visits, and patients can be referred to the most suitable care provider (28). Additionally, short message service (SMS) is a mobile phone feature that can be utilized as a supportive tool to encourage patients to take a more proactive role in their health planning (27, 29, 30). Overall, identifying the reasons for parents' failure to seek medical attention and recognizing existing barriers can be a crucial step in formulating policies and interventions to enhance

treatment compliance and improve health management in premature infants with retinopathy of prematurity. Therefore, this study aimed to investigate the reasons for parents' failure to bring their premature infants with retinopathy of prematurity for examination to the ROP clinic and to examine parents' attitudes towards appointment reminder systems.

2- MATERIALS AND METHODS

This study utilized qualitative methods and a content analysis approach at the ROP clinic for premature infants at Khatam Eye Hospital in Mashhad, the only ROP center in northeastern Iran, which serves approximately 30 patients daily. The aim was to identify and clarify the reasons why parents were not bringing their infants with ROP for examination and to explore parents' perspectives on appointment reminder systems for medical visits in 2021-2022. The research focused on parents of premature infants diagnosed with ROP who were in the stages of disease follow-up but had not visited the clinic for their scheduled appointments. Purposeful sampling was used to select informed individuals for interviews, and parents who agreed to participate in direct individual interviews were approached. The number of interviews continued until no new information was obtained. During the interviews, efforts were made not to overly emphasize the risks of not visiting the clinic. Data was collected through semi-structured interviews, where parents were asked to explain the most important reasons for not bringing their infants to the ROP clinic promptly and to share their views on the appointment reminder system to improve visit attendance and follow-up plans. Semi-structured interview guides were created using secondary and exploratory questions from open-ended interviews with two experts and text reviews.

The interviews were meticulously scheduled in advance, ensuring the

participants' time and commitments were respected. Each interview took place in a comfortable setting chosen by the interviewee and typically lasted 25 to 35 minutes. The interviews were meticulously recorded using two devices, and the interviewer also made detailed notes on key points. Throughout the process, the researchers sought the explicit consent of the interviewees. They adhered to ethical considerations, such as honoring requests not to record certain parts of the interviews or omitting specific aspects from the final results. The researchers were actively engaged in the research process to bolster the study's credibility and maintained open and transparent communication with the participants. All relevant ethical considerations were meticulously observed, and participants were fully informed of the research objectives, implicitly consenting to participate. Furthermore, participants were provided with assurances regarding the confidentiality of their information and the reporting of study results without divulging their identities.

For content examination, the thematic content analysis method was employed, comprising the following sequential stages:

1. Acquaintance with the data,
2. Generation of initial codes,
3. Identification of themes,
4. Review of themes,
5. Definition and labeling of themes,
6. Reporting (31).

The analysis of conceptual codes and themes was carried out manually by R.F with no conflicts of interest, and double checked by F.S. The researchers utilized MAXQDA 2018 software when necessary. After each interview, the resulting text was thoroughly studied multiple times to extract relevant information, meaningful units, and conceptual codes. These conceptual codes were then systematically combined to extract sub-themes, which

were further combined to derive main themes.

Participants' demographic data was analyzed alongside an assessment of parental attitudes toward reminder systems using descriptive statistics. Frequency and mean values were then presented in Excel version 2016.

3- RESULTS

The demographic characteristics of the interview participants are outlined in Table 1. The study included 36 parents of infants with ROP who not visited the clinic for their scheduled appointments. Their responses were divided into seven main topics and 28 subcategories. These categories encompass cultural, economic, and geographical factors, parents' apathy towards receiving services, infrastructural

and management issues, a preference for private sector physicians over government ones, and other reasons. The specifics of these topics, subcategories, and key participant comments can be found in Table 2.

Regarding reminder systems, the results showed that 94.5% of parents (34 people) have access to at least one means of communication, such as a landline, cell phone, or email. Among the 5 reminder systems presented, 20 people (55%) selected text messages, 9 people (25%) chose mobile phones, 4 people (11%) selected landline, 2 people (5%) chose email, and 1 person (2.5%) selected a written reminder (appointment card). The details of parents' views regarding reminder systems are presented in Table 3.

Table-1:.Demographic characteristics of interview participants.

Demographic characteristics	Frequency (%)
Infant Gender	
Male	12 (33%)
Female	24 (66%)
Age (year)	37±2
Education	
Illiterate	3 (8%)
Primary School	0 (0)
Secondary School	8 (22%)
Diploma	12 (33%)
B.Sc.	11 (30%)
M.Sc. and above	2 (5%)
Insurance Status	
Health Insurance Services	18 (50%)
Social Security insurance	8 (22%)
Other	3 (8%)
Without insurance	7 (19%)
Place of Residence	
Urban	28 (78%)
Rural	8 (22%)
Number of infants	
Single	32 (89%)
Twin	3 (8%)
triplet	1 (3%)

Table-2: Parents' reasons for missing scheduled ROP clinic appointments.

Main Topic (Theme)	Subsets	
Cultural	<ul style="list-style-type: none"> • Lack of trust in the treating physician • Inappropriate view of parents towards the skills and expertise of hospital staff • Inappropriate attitude towards the staffs working in governmental hospitals • Family problems and husband's disapproval of pursuing treatment 	<p><i>"During my research, I decided to change my child's physician"</i></p> <p><i>"In governmental hospitals, services are often provided by medical students"</i></p> <p><i>"I went to private medical centers because they take better care of the patient"</i></p> <p><i>"My husband is working from morning to late at night and we could not visit"</i></p>
Economic	<ul style="list-style-type: none"> • Low- income • Not having insurance and worrying about costs • Receive free services in medical centers affiliated with social security insurance 	<p><i>"The cost of treatment have become very high"</i></p> <p><i>"Our insurance is social security and we receive similar services also free of charge in hospitals affiliated to social security insurance"</i></p>
Geographical	<ul style="list-style-type: none"> • Distance of residential area to reach to the hospital • Unsuitability of the road and path leading to the hospital • Lack of suitable means of transportation 	<p><i>"I have to walk a long distance every time and we have a long way to the hospital"</i></p> <p><i>"My place of residence is mountainous and does not have a proper road, and it is difficult to travel in winter"</i></p> <p><i>"I live in the village and there is no means of transportation for us"</i></p>
Parents' indifference to receiving services	<ul style="list-style-type: none"> • Low health literacy of parents • Underestimating the Importance of the Disease • Lack of awareness of the possible complications of the disease 	<p><i>"I don't know what my child's illness is and that it needs to be followed up"</i></p> <p><i>"I didn't think it was a big deal"</i></p> <p><i>"I was unaware of the complications of my baby's illness"</i></p>
Infrastructural and management	<ul style="list-style-type: none"> • Improper service delivery time • Insufficient number of visits compared to the number of patients • Appointment Scheduling Problem • Overcrowding in the hospital and waste of time • Spending a lot of time to provide services in the hospital 	<p><i>"The service is provided in the morning shift, which overlaps with my working hours."</i></p> <p><i>"The days of the physician's presence and the number of patients visited in each shift are very limited"</i></p> <p><i>"I came to the hospital several times and failed to get an appointment"</i></p> <p><i>"I spend several hours at the hospital for each visit"</i></p> <p><i>"The care period was very long and I only came the first few times"</i></p> <p><i>"The hospital staff did not behave properly"</i></p> <p><i>"I was not given the right guidance from the staff to continue the"</i></p>

	<ul style="list-style-type: none"> • Long duration of care • Inadequate attention or inappropriate behavior of hospital staff with parents • Lack of order and non-acceptance in some references • Lack of proper guidance from the hospital staff for the next visit 	<i>treatment and I was confused "</i>
Preferring visits by private sector physicians over government ones	<ul style="list-style-type: none"> • High quality of services in the private sector • Overcrowding in the government sector • Lack of sufficient facilities in the service provider center 	<i>" I went to private medical centers because I feel more relaxed about the treatment"</i> <i>" Service provision in government centers is limited and the hospital is overcrowded"</i> <i>"Private medical centers offer more and better facilities"</i>
Other causes	<ul style="list-style-type: none"> • Forgetting the appointment time • Change of the place of residence • Infant death 	<i>" I have forgotten due to the intervals between the last visit and the appointment for the next visit"</i> <i>" I settled in another city because of my husband's job"</i> <i>"My baby has died"</i>

Table-3: Parents' point of view regarding reminder systems.

Parents' point of view regarding reminder systems	Very much	Much	Netural	little	Very little
How familiar are you with reminder systems? (For example, have bank reminder messages been sent to you yet?)	2(5%)	13(36%)	10(27%)	8(22%)	3(8%)
How often do you feel the need for a reminder?	8(22%)	12(33%)	7(19%)	7(19%)	2(5%)
How likely are you to read messages sent by other service providers via text messages?	12(33%)	18(50%)	2(5%)	3(8%)	1(2%)
From your point of view, can the use of reminder systems be effective in following up your child's treatment on time?	7(19%)	17(47%)	4(11%)	6(16%)	2(5%)

4- DISCUSSION

Many parents do not utilize the ROP clinic for their infants' medical visits due to various factors, including cultural, economic, and geographical challenges. In addition, some parents lack interest in utilizing available services, favor private-sector physicians over government practitioners, and encounter infrastructural difficulties. Furthermore, 33% of parents have indicated a desire for a reminder system, while 47% have reported that the current reminder system is effective in facilitating timely follow-up on their child's treatment.

The rate of patient non-attendance at medical appointments varies across countries, healthcare systems, and clinical centers. However, it remains a common and significant issue worldwide, imposing considerable costs on healthcare systems (32, 33). Additionally, patients not attending follow-up appointments can delay diagnosing disease and providing appropriate treatment and may indicate non-compliance (34, 35). Ahmadi et al.'s study revealed a non-attendance rate of 9.9% for otolaryngology and head and neck clinics, while Paget et al. found that 12% of patients with cerebral palsy did not attend their appointments. Both studies indicated that non-attendance was associated with factors such as age, sex, socioeconomic status, a history of missing appointments, and rescheduling or canceling appointments (36, 37). Additional studies reported non-attendance rates of 7.7% and 10% in tertiary general pediatric outpatient clinics (38, 39), 11.4% in specialized pediatric centers (40), and 20-30% in pediatric tertiary outpatient dermatology and pulmonology specialist centers (41, 42).

Cultural factors were identified as contributing to patients missing scheduled appointments. These factors included a lack of trust in the treating physician, a shortage of specialized staff in state-run

hospitals, and a lack of spousal consent for receiving treatment. In their 2019 study, Rezaii et al. identified a lack of trust in the medical team as a key reason for diabetic patients to avoid treatment and exhibit poor adherence (26). Furthermore, patients' lack of understanding of their physician's treatment plan can lead to fear and distrust of the physician (43).

Murdock et al. discuss the fear of visits by young physicians as a form of distrust (25). In a study by Kelly et al., 7% of parents found their physician and their recommendations unhelpful, while 42% believed their child was healthy and did not need treatment, indicating a lack of trust in physicians (24). According to Keesara et al., pregnant women avoided receiving services at government centers due to long waits and a lack of respect from service providers. However, they expressed more trust in receiving services at these centers because they emphasize health and quality of care instead of private clinics, which emphasize profits and benefits (44). Contrary to the reasons given by parents, a study by Kruse et al. stated that government hospitals are at least as efficient as private hospitals (45), which contradicts the reasons given by parents in our study. Therefore, it is recommended that physicians establish appropriate and understandable communication with their patients. This improved communication can enhance trust and treatment adherence, offering a hopeful solution to the issue of distrust in healthcare settings.

Economic factors such as low income, financial struggles, lack of insurance, and the potential to receive free services through social security at other centers were cited as reasons for not seeking care at the ROP clinic. Financial constraints, including care costs, parental unemployment, and conflicting work schedules, were also mentioned as barriers to seeking medical care (43, 46). Some

studies have also highlighted travel expenses as a deterrent (24, 47). It is recommended that parents be connected with insurance experts and social support services to receive financial assistance and information on managing expenses.

Geographical barriers and poor accessibility, such as the distance of the hospital from people's homes, inadequate roads and routes to the hospital, and a lack of reliable transportation, were cited as reasons for not seeking medical care. In some instances, transportation challenges, traffic, and limited parking spaces made it difficult for patients to keep their scheduled appointments (43, 46). Our study found that the hospital's location in a congested area with insufficient parking and narrow streets posed a challenge, particularly for parents traveling from a distance. Tasi et al. discovered that weather conditions, especially heavy rain, led to a 50% increase in missed appointments (48). In Kelly's study, 21% of parents interviewed mentioned the long distance to the clinic as a barrier to seeking medical care (24). It is recommended to consider telemedicine options, such as remote consultations, and to improve parking facilities for families unfamiliar with the hospital's location and surroundings.

Various factors, such as low health literacy among parents, lack of motivation, forgetfulness, and limited knowledge about potential complications, can influence the lack of interest in seeking medical services. Kardas et al.'s study identified lack of motivation and forgetfulness as significant factors contributing to poor medication adherence (49). Additionally, psychological factors like hostility, depression, hopelessness, and stress can also play a role in patient absence (43). Feeling useless for the visit was cited as a reason for not seeking medical care (47). Ballantyne's study also highlighted the importance of attending

appointments as a key factor for attendance (46). To address these issues, it is recommended that educational classes be provided for parents during clinic waiting times to explain the importance of timely visits and the potential consequences for infants. Emphasizing the importance of timely visits will make the audience feel the urgency of the matter.

The decision not to refer patients to hospitals can be attributed to managerial and infrastructural issues, including inappropriate timing and service hours, insufficient allocated visits, challenges in scheduling appointments, high hospital congestion, and lack of staff guidance. Patients often experience long waiting times before receiving services, reducing satisfaction and diminished interest in attending future appointments (43). Research indicates that long waiting times for new patient referrals to hospitals are a key factor in missed appointments (50, 51). Due to work commitments, hours, and associated stress, the hospital's inconvenient timing and service hours make it difficult for employed individuals to attend (43, 47). In a study conducted by Tsai et al. (2019), it was discovered that intervals of less than seven days between current and previous visits resulted in a 34.6% failure-to-attend rate, indicating that the patient had improved and did not require another visit in such a short timeframe. The study also revealed that intervals of more than 57 days between the current visit and the scheduled appointment led to a 22.1% failure-to-attend rate (48). Other factors contributing to non-attendance included errors in service delivery, such as failure to inform or remind the patient of their appointment, scheduling appointments at inappropriate times, and patient frustration with the care delivery structure, including long waiting times and disorderliness in the clinic (47, 52).

Conversely, the Ballantyne study found that mothers reported receiving information about infant growth and developmental expectations could increase attendance at follow-up appointments. Additionally, advanced and convenient scheduling processes, as well as reminders for visit appointments, were identified as facilitators of clinic attendance (46). It was also suggested that increasing the availability of neonatal eye examination centers, a crucial aspect of patient care could help prevent excessive crowding and parental dissatisfaction, highlighting the urgency of addressing this issue.

Other reasons for missing appointments include a preference for private healthcare services, forgetting appointment times, infant mortality, and changing residential locations. A long time between visits can lead to frequent cancellations due to a high workload (43). Murphy et al. identified forgetting the appointment as a common reason for missing appointments (47). Pregnant women were found to prefer private clinics over public ones due to convenience and timely services (44). Karne's study indicated that despite the high cost, private healthcare centers offer better quality services and equipment, qualified physicians and personnel, and cleanliness compared to government centers (53). Kelly et al. found that 18.4% of parents missed psychiatric clinic appointments due to forgetting (24). On the other hand, mothers identified access to resources such as respiratory care, hematology, infant nutrition, and specialists as reasons for attending appointments (46). Implementing a regular appointment reminder program in clinics, utilizing phone calls, text messages, and emails, is recommended.

Our study demonstrated significant strengths, such as the staff's proactive engagement with parents, the clinic's consistent schedule, the quality of facilities, and the parents' active

participation during interviews. These strengths underscore the credibility of our research. However, we also encountered limitations, including some parents' reluctance to participate in interviews due to long waiting times, their infants' restlessness, and incomplete questionnaire answers due to staff being called away by urgent tasks. Furthermore, the absence of explicit discussions on psychological or mental issues suggests that our questions may not have fully addressed these concerns.

5- CONCLUSION

From the parents' perspective, several factors contribute to the decision not to attend ROP follow-up clinics. These include cultural, economic, and geographical barriers, parental indifference towards available services, infrastructure, and management challenges, as well as preference for private clinics over public options. Targeted interventions, such as assessing non-attendance rates and identifying underlying factors, can help improve adherence to scheduled visits. Implementing measures like offering flexible clinic hours and ensuring staff availability during afternoon shifts may enhance service accessibility. These insights are instrumental in shaping neonatal eye health policies, optimizing ROP clinic planning, and facilitating the timely identification of infants at risk for retinopathy of prematurity.

6- DECLARATIONS

6-1. Ethical Considerations

This study was approved by the Research Ethics Committee of Mashhad University of Medical Sciences Research Council (IR.MUMS.MEDICAL.REC.1400.349) and conducted following the guidelines of the Declaration of Helsinki. In accordance with the opinion of the Ethics Committee mentioned above, and considering that no information about participants is provided in this paper,

participants who took part in this study gave informed verbal consent to participate in this research.

6-2. CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

6-3. Availability of Data and Material

The datasets used in this study are available from the corresponding author upon reasonable request.

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