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A phenomenological approach to childhood cataract treatment using semi-structured interviews: How might we improve provision of care?

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Author Contributions

LH, JB, SD and BT designed the study. LH and SD recruited the participants. LH conducted the interviews and transcibed the data. KB and LH independently coded and analysed the transcribed data, and then interpreted the data in an iterative manner. LH wrote the first draft the manuscript, and all authors assisted with revisions. All authors were involved in the final proofing process and agreed to be accountable for the content of the manuscript.

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Keywords

Paediatric cataract, parental stress, semi-structured interviews, adherence

Data Statement

Full transcripts of interviews are not available to protect participants' anonymity

Abstract

Purpose: To understand how we might improve the provision of medical care for children with cataracts.

Design: A phenomenological design was employed. Semi-structured interviews were conducted to capture rich descriptions of the phenomena. Our goal in the interview and the analysis was to understand the sources of distress associated with treatment for cataract and deprivation amblyopia which 1) could be addressed by the medical community and 2) related to treatment adherence.

Setting: Interviews were conducted by a non-clinician researcher in New Zealand (NZ) in a location chosen by informants. In NZ the red eye reflex screening test is performed shortly after birth, and surgery to remove paediatric cataracts is publicly funded.

Participants: Families of children who had a history of cataract in Auckland, NZ were posted an invitation to participate. Twenty families were interviewed.

Results: Our analysis illustrated that informants described a wide range of experiences, from declined cataract surgery to full adherence to medical advice including years of patching for more than four hours a day. Across these experiences, we identified three relevant themes; delays in diagnosis, communication between the parent and clinician, and parental social support networks.

Conclusion: The medical community may be better placed to support families dealing with childhood cataract by improving detection of childhood cataract, building appropriate communication pathways, and promoting social support, with an emphasis on empathetic, individualised care.

Article Summary

Strengths and limitations of this study

Strengths:

- Informants had a broad range of experiences, from very positive to very negative, likely to reflect the diversity of the cohort of interest.
- Data from interviews were rich and themes converged across diverse experiences.

Limitations:

- The impact of culture was not a specific focus of the interviews. Our iterative analysis indicated that cultural factors may enhance understanding of families' experiences. This is recommended as an area of further research.
- The authors are generally invested in adherence with ophthalmological recommendations. This bias is clearly stated in our purpose.

Introduction

Elimination of visual impairment from childhood cataract is one of the key objectives of the VISION2020 initiatives[1]. The diagnosis and removal of a childhood cataract requires specialised expertise and surgical facilities, and significant funding has been allocated internationally to meet these needs. However, the vision loss associated with bilateral or unilateral paediatric cataract is not fully resolved with surgical removal of the opaque lens (for overview see[2 3]). A replacement lens needs to be implanted, or compensatory contact lens or spectacle correction prescribed. Children often require follow up surgeries and ongoing assessment of appropriate refraction. Furthermore, the risk of deprivation amblyopia increases sharply if the cataract is not removed shortly after onset[4 5]. Amblyopia is caused by abnormal visual cortex development due to disrupted visual experience and impairs vision in the affected eye(s)[6]. Amblyopia due to congenital cataract is a rare, but its effects on vision are severe due to pronounced visual deprivation at an early age[4 5]. The treatment for amblyopia involves occlusion (patching) or penalization (atropine cycloplegia) of the stronger eye to promote use of the weaker eye. These are home-based therapies which can be difficult for families to implement[7]. Therefore, the efficacy of childhood cataract treatment is affected by a range of factors including early detection, prompt uptake of surgical intervention, and dedicated commitment to follow up care by the family and medical community (for discussion see[8]).

Each step in the treatment pathway for childhood cataract has been investigated, including screening[9-13], factors contributing to delayed utilization of surgical services[14], parental stress associated with childhood cataract treatment[15 16] and compliance with amblyopia treatment[17-21]. Across this predominantly quantitative international body of work, the services that are available, affordable, and accepted by the community being studied vary considerably. In this study, we were interested in the experience of childhood cataract in a setting where advanced ophthalmological services are well established and publicly funded. A qualitative study in the USA found that 'treatment' was one of 6 key themes decreasing quality of life for children with a history of cataracts[22]. Our project compliments this by focusing on families' lived experience (phenomenology) through the treatment pathway. Our aim was to identify sources of distress which 1) could be addressed by the medical community and 2) related to adherence with recommendations from their ophthalmologist.

Methodology

Study context

The study was conducted in Auckland, New Zealand (NZ), where comprehensive childhood vision screening systems are in place (red eye reflex exam at birth and at the 6 week check, pre and in school acuity checks www.wellchild.org.nz/health-info-resources/health-topic/vision), specialised paediatric cataract surgery is publically funded and prioritised, and subsidies are available for refractive correction and occlusion therapy for families who require financial assistance or have particularly high visual needs. The study cohort was culturally diverse and approximately a third had lived and received medical advice outside of NZ. The first author carried out the semi-structured interviews. This author is a non-clinical researcher (not involved in any of the participant's care), and it was made clear to all informants that participation in the study would not impact the care they received.

Patient and Public Involvement

This project was a first step towards understanding how the medical community could improve provision of treatment for childhood cataract; as such the project was to understand their experiences and needs. The project was part of a larger study about the consequences of[23], and potential for rehabilitation after[24] visual deprivation due to childhood cataract, with this step focused on understanding patient experience of the treatment pathway. A lay summary of results are available to all participants, and information will also be disseminated at a community follow up meeting or 'hui'.

Participant recruitment

In phenomenological studies a purposive sampling strategy is supported in order to recruit participants who have experienced the phenomenon under study[25]. Accordingly, research participants were intentionally contacted following a medical records search. Inclusion criteria included history of a visually significant paediatric cataract (congenital, developmental and traumatic cases) and a current age of at least four. Exclusion criteria included severe developmental disorders or severe ocular disease unrelated to paediatric cataract, noted on ophthalmological records. Invitation letters were posted to thirty-nine parents resulting in seventeen positive responses, each of whom were invited to participate in the study, including one parent of a non-verbal child with autism (autism was not noted on the ophthalmological record). One additional family made contact independently; their son had not had surgery to remove his cataract. Two additional families were made aware of the project through their specialist. A total of twenty semi-structured interviews were carried out. The study complied with the tenets of the declaration of Helsinki and was approved by ethics committees from the University of Auckland and the Auckland District Health Board. Participants provided informed consent, and children who were able provided assent.

Semi-Structured interviews

Interviewing is the primary data collection strategy in phenomenological studies[25]. As such, semi-structured interviews were employed focussing on the lived experiences and personal perceptions of the treatment process for childhood cataract and secondary deprivation amblyopia. Interviews were conducted in a private location of the participant's choice and audio recorded (except in one case due to excessive background noise). We requested that both caregivers and the affected child were present, and we encouraged all attendees to contribute to the conversation. Interviews were approximately one hour in length for each family, but varied in an attempt to obtain rich data. Semi-structured interviews were transcribed by the first author. Potentially identifiable information was removed or anonymized, and pseudonyms were assigned (pseudonyms reflect most common NZ names for birth year). The approximate timing of key treatment events were derived from each interview (narrative summary) and used to provide context for understanding phenomenology (lived experience).

Phenomenology

In line with a descriptive phenomenological approach[26-28] our primary goal was to develop an in-depth appreciation of each family's experience of childhood cataract treatment. Our specific research interest was to understand sources of distress which 1) could be addressed by the medical community and 2) related to adherence to medical recommendations.

Husserl's[26] approach to phenomenology, as made explicit by Giorgi[27], and summarised by Wertz[28] includes four steps, which we carried out as follows. 1) *Open reading*; we set aside theoretical and personal biases and attempted to understand each experience as a whole. 2) *Meaning units*; we divided each transcript into units of meaning or 'themes'. 3) *Psychological reflection;* we reflected on the relevance of the themes to our research interest, and how they related to each other. This was an iterative process including re-reading, summarising, grouping together, and redefining meaning units to better reflect informant experience. 4) *Structural understanding and description*; we consolidated relevant emergent ideas, which we present as three themes and six sub themes. The first and second author mutually carried out an analysis of the transcripts and then compared notes which resulted in the final presentation of themes. We used SRQR reporting guidelines for qualitative research[29].

Research questions are approached from the frame of our own experiences. Our framing included that 1) a critique of family's responses to a challenging life event was outside our scope and 2) we trusted the evidence suggesting that prompt removal of cataracts and adherence with secondary treatments (such as patching) are in the best interest of the child. We structured our research question to highlight our perspective rather than bracketing our experience from our interpretation; we focused on what the *medical community* could do to alleviate distress, particularly in ways that could promote *adherence*. In the process of seeking to find meaning across the experiences of our informants, we tended towards a constructivist epistemology; fundamentally believing that meaning is constructed rather than discovered. Through iteration, we understood our constructed meaning to be best exemplified in terms of negative and positive experiences of the emergent themes. Therefore the themes presented reflect encouragement to families at their best, and exasperated distress at their worst.

Results

Narrative summary

Informants had a wide range of experiences. Key treatment events are summarised as cataract diagnosis, cataract removal, refractive correction and amblyopia treatment. Timelines for each participant are presented in Figure 1, based on estimates from interview data. Some participants had congenital cataracts which were present at birth, others had cataracts which were detected or developed during early childhood (developmental), and others had traumatic cataracts resulting from an eye injury. It is of note that some parents were unsure whether their child had congenital or developmental cataracts.

There were no cases in which access to surgery after diagnosis limited care, however perception of delayed detection of cataract was an important issue raised. We have expanded on this in the first theme. Unlike most families who prioritized prompt cataract removal, Emily and Benjamin's families both declined surgery initially. Both later took up the services, expressing a mixture of frustration and regret. We explore these cases more within the second and third themes.

The experience with home implementation of follow up treatment was also diverse. Although no families noted cost of glasses, contacts or patches to be prohibitive, parents expressed concern that acquiring these items and navigating subsidies was complicated and could be stressful. Only children with very early surgery used contact lenses instead of an intraocular lens (IOL). Of the six surgeries done before six months of age, half (Olivia, James and Jack) remained aphakic and used a contact lenses rather than IOLs. Each of these families described the use of the contact lenses as the most stressful part of their experience, with two of the three families describing traumatic events related to inserting, removing and/or losing contact lenses. These two families advocated for further support or re-structuring of contact lens use.

Patching experience ranged from none (including children with bilateral cataracts who had equal visual acuity loss in both eyes, and children with unilateral cataract who were given a very poor prognosis), to four hours per day over several years (Olivia, Oliver, Grace and Hannah). The most challenging aspect of care was described as patching, only superseded by use of contact lenses in infancy in the small subset of children for whom it was required. For those who used glasses, feedback was very positive, except for the one participant prescribed glasses in her teenage years (Georgia), who felt uneasy with the aesthetic aspects of wear.

***Figure 1** Timeline of treatment pathway*

Phenomenological summary

Three themes and several sub-themes emerged from the phenomenological analysis related to how the medical system might better mitigate parental distress and encourage adherence. These are summarized in Table 1.

Table 1. Summary of themes and sub-themes

1. Improved detection and diagnosis
a) Red eye reflex exam at birth
b) Referrals and process
2. Communicating with medical community
a) Building rapport
b) Provision of information about cataract and deprivation amblyopia
c) Foresight about treatment pathway
3. Social support
a) Advice from social networks
b) Availability of emotional and practical support

Improved detection and diagnosis

The detection and diagnosis of a cataract was a complex experience for families. It elicited predictable emotions such as disbelief, fear and uncertainty, but also varied experiences related to the family's understanding of timing. If parents understood the timing of diagnosis to be linked to their child's visual outcome, emotions related to perceived efficiency of the screening test and processes surrounding referral were heightened. For those parents who were informed about the cataract promptly, the negative emotions related to an unexpected diagnosis were balanced by a sentiment of more solemn appreciation. By contrast, anger arose for parents if the medical community was perceived to be responsible for a delay. In Table 2 we highlight 2 subcategories which were the targets of the frustration or appreciation. Table 2A highlights cases in which a person perceived to be responsible for the red eye reflex screening test (most commonly the midwife) was directly targeted for appreciation or anger. Table 2B highlights the importance of the process whereby the concern was communicated between professionals, culminating in a diagnosis.

Table 2. Improved detection and diagnosis. *Examples of positive (left column) and negative (right column) experiences relating to timing of diagnosis.*

A – Red eye reflex screening test	
She's been a midwife for ages, and because of that experience, she picked up it. (Lily’s mother)	*We were pretty angry at our midwife because we felt that she should have picked that up.* (Jack’s mother)
B – Referrals and process	
We got sent to a follow up…to test the red eye reflex in the left eye and basically look in detail because they were expecting the possibility of a cataract. So it was diagnosed pretty much right from the start, she would have been about two days old when it was found and diagnosed. (Olivia’s mother)	*She* [Allied medical worker] *put him on a wait list and it took until about 15 months, it was a long time, so I was thinking I guess it’s not a big deal. …when we saw* [ophthalmologist] *he basically outlined right from the beginning that there was no hope. I found it … sorry … there is still a bit of anger there.* (Riley’s mother)

In the left column of Table 2 we can see examples of effective screening, referrals and following up on red flags. By contrast, the right column highlights cases where an opportunity existed for a cataract to be detected earlier, and was missed. These experiences suggest that any strategy to improve medical provision for childhood cataracts needs to start with improved training for screeners, both in terms of administering the test and procedures for prompt referral. Anger with a representative of the medical community, exemplified by Jack and Riley's mother's comments, but shared by many informants, had a lasting impact. A parent's perception of a delay in diagnosis compromised trust in the medical community, which hindered ongoing communication. This was particularly the case if the specialist managing the child's ongoing care was seen to be associated with this initial perceived error. Although experience with detection and diagnosis was an important part of ongoing communication with the medical community, many other factors also contributed to communication, these expanded on within the next theme.

Communicating with the medical community

Once diagnosed, the relationship a family had with the specialist, and to a lesser degree, the allied medical staff, was an important part of their experience, permeating across treatment events. While some families lit up while describing the kindness and competence displayed by the medical professionals they had come to know well, for others anger and frustration expanded when reflecting on their interactions with the medical community.

Rapport between the parents and the specialist appeared to be particularly important, as it formed the foundation of the ongoing relationship with the medical team. Example quotes are presented in Table 3A, with the left panel containing an example of a positive impression, and the right showing an example of a negative impression.

Parental knowledge about childhood cataract ranged widely between participant families. Some families had a scientific background, and could understand and appreciate a detailed explanation. Others had limited background knowledge, but effective communication allowed sufficient understanding for the family to feel comfortable with recommendations. Other parents did not feel as though their questions were addressed sufficiently. In Table 3B, we provide examples of two informants for whom understanding of the condition had an influence on the uptake of surgery. Additionally, some families experienced significant distress over misunderstandings, or gaps of communication. For example, Sophie and Lily's mothers were distraught at the time of the interview about perceived connections between behaviours during pregnancy and the cause of the cataract. Accordingly, it appeared important for the specialist to understand what the relevant information was for each family, and to communicate it at an appropriate level.

This was particularly poignant for communication about potential future events. Childhood cataract has a long treatment pathway, much of which is dependent on parents to implement. When families became exasperated with home based aspects of treatment, those who were prepared in advance were not as discouraged by these setbacks, whereas families who had not anticipated the challenges appeared to be quite distressed by them. Furthermore, the lack of foresight fostered a distrust of the specialist if parents perceived that information was withheld. Table 3C provides one example from a family who was warned of the difficulties from the outset (and appreciated the foresight), compared to a family who felt their specialist had not communicated information which would have been useful.

Whether the communication between the medical community and the parent was perceived as positive was individualized and nuanced, but across participants it included aspects of rapport, clear communication about the condition and of upcoming potential challenges.

Table 3. Communicating with medical community. *Examples of positive (left column) and negative (right column) experiences relating to communication.*

A - Building rapport	
We went in and met the paediatric ophthalmologist, and he was just a lovely, lovely man. Yeah, it was just great (Aiden's mother)	*I don't want to go to [...] anymore. He's quite 'nothing can be done, nothing can be done' (Riley's mother)*
B – Provision of information about cataract and deprivation amblyopia	
Asked whether specialist's description of the condition made sense to her: Yes, it did. Otherwise we could never have agreed to the surgery (Lily's mother)	*I was avoiding the surgery from when she was three months onwards […] they were not answering questions that I was asking to my satisfaction (Emily's mother)*
C - Foresight about the treatment pathway	
When she was first diagnosed, the specialist sat us down with this one week old baby and said this is going to be a long, hard road (Olivia's mother)	*Why hadn't (paediatric ophthalmologist) told us about this? We'd been going for three months! […] It's not smooth, it's not transparent, and that's what's hard (Oliver's mother)*

Social support

Throughout the interviews, it became apparent that the provision of care was improved if there was an awareness of how recommendations fit within the family's social context. This includes perspectives or values held by an individual family and the resources available to them. It was common for families to include anecdotes about how friends or family members reinforced ideas, provided advice, helped pay for travel, supervised a child who was patching, looked after other children, or helped remove a contact out of an infant's eye. In many cases, such a support person happened to have a related occupation (for example, an optometrist, nurse, or physician) which provided extra comfort as parents navigated the treatment pathway. When this was not available, it appeared to impact on parental experience and capacity to comply with treatment.

Advice that parents received from friends or family was an important part of their experience. When families were confronted by something new or unfamiliar, for example, when the vision problem was first detected or surgery was offered, families who had others encouraging them to engage with the medical system were likely to move forward with recommendations (example in Table 4A - left). On the other hand, some social networks were sceptical of the medical community, making it difficult or distressing for parents to seek, or act on, medical advice. Families who felt tension between the advice from the medical community and the advice from friends and family experienced an increased burden during an already challenging time (Table 4A - right). Additionally, if this tension existed, and the family member who was given the information did not have the decision making power within the family (as was the case for Benjamin's family – further expanded on in Table 4B right), communication from the medical community was less effective.

Beyond social networks overtly advising with or against medical advice, there was an important emotional and practical role for this extended group. It was not specifically stated that a phone call from a friend, or a ride from a family member directly mitigated distress or delays along the treatment pathway, but the absence of this support appeared to be associated with both. Emily's mother provided a particularly impactful example of this; she was overwhelmed when surgery was recommended, and she declined it, but four years later when she joined a community group allowing social support, she decided to comply with recommendations (Table 4B - left). Like Emily's mother, several families simply felt overwhelmed at diagnosis or during amblyopia treatment, and did not have the emotional or practical support they needed to overcome this feeling. The example we provide in Table 4B – right, is from Benjamin's family, and it also highlights the inter-relationship with practical support, advice, and communication. It is of particular note that contact lens use required additional practical support; Olivia and Jack's families described requiring 2 or more adults to extract the contact from their infant's eye.

As discussed within ‘communication’, the family’s social context also varied widely across informants. It was further complicated with changes over time; a school or job change, for example, impacted the balance of needs and resources a family had.

Table 4. Social Support. *Examples of positive (left column) and negative (right column) experiences relating to social support*

A – Advice from social networks	
Her grandfather, who is a GP, saw that she was looking at things close and her eye was turning in. We took her to an optometrist and they picked up that there was something there, and they referred us to the ophthalmologist who said ‘yes that looks like a cataract to me, we’ll send you to [city]’. And that all happened really quickly (Grace’s mother)	*The doctor is trying to give us good advice […] the sooner we get it done the better. And my mum and dad are pretty much saying ‘No’. So that was another kinda difficulty […] Yeah, an emotional, mental thing as well with the family’s input – what they think about it (Lily’s mother)*
B – Availability of emotional and practical support	
When describing decision to go through with the surgery four years after it was recommended: It was just talking about it I guess with the [Community worker] that I was having the get-togethers with […] she was lovely. I would talk with her and we would talk with [child] and she would even offer to drive us out there and stuff like that. Because that was another issue, just the transport (Emily’s mother)	*We took him to the hospital and they were saying right then and there to do a little surgery [...] I was carrying [another child], and my husband didn’t want him to have the surgery (Benjamin’s mother)*

The parent's perspective on the role they had within their child's care was an important influencer of adherence. This perceived role was related to parenting strategies and belief systems; factors less likely to be directly addressed by the medical community, and therefore not a focus of our analysis. We note simply that parents who perceived the condition as severe from the outset, and had the resources to both advocate for their child within the medical community and be creative in their implementation of home based treatments, tended to experience less distress and be more compliant with recommendations. Several families expressed interest in some form of network which would allow families to share these experiences and strategies directly.

Discussion

The goal of our descriptive phenomenological approach[26-28] was to develop an in-depth appreciation of the individual experience of childhood cataract treatment; with a specific interest in understanding sources of distress which 1) could be addressed by the medical community and 2) related to adherence to medical recommendations.

Strengths and Limitations

We were able to recruit a wide variety of participants, with a diverse range of experiences despite childhood cataract being relatively rare. We were able to conduct rich interviews in which we found some informants were very appreciative of the medical community's role in their experience of medical treatment for childhood cataract, while others felt as though they were let down by the medical community. This diversity, and out theoretical framework allowed us to identify themes and construct meaningful summaries which could be presented in positive and negative terms. In other words, for each potential factor we could consider whether the lack impaired a family's experience, and the presence enhanced it. In some cases this directly linked to whether a family adhered to medical recommendations. In this way, the diversity of informant experience is likely to aid in quality and the generalisability of our analysis.

However, there were some limitations in our design and analysis. During the interviews we did not focus specifically on cultural frameworks for health. However, upon iterative reflection it was our impression that a deep understanding of culture may have facilitated our understanding of informant's experiences. Further expanding on this, perhaps a symbolic interactionism theoretical perspective, would be a valuable direction for future research in order to understand underlying cultural reasons for choices, particularly related to declining available surgery. Furthermore, we started with the belief that adherence with ophthalmological recommendations is the best for children. Therefore discussion around whether a parent's decision to decline surgery or cease patching was in fact best for the child was outside the scope of this project. Similarly, parental motivation was not a focus of our analysis, but is part of the theoretical framework related to adherence[30]. Following up with participants on these points as part of our dissemination step will be a good opportunity to enhance future research.

Summary and Implications of findings

The varied experiences of the diverse informants we interviewed revealed opportunities for systemic improvement in childhood cataract treatment. Early detection and prompt medical treatment are critical for good visual outcomes[4 5]. Delayed detection was a perceived issue for many of our informants. More effective implementation of the red eye reflex exam may improve this situation[12 31]. Survey data from practitioners in New Zealand reflected this opportunity for improvement, specifically highlighting the value of better training for those administering early eye exams[13]. Our work supports the value of such an initiative.

Addressing issues that are social rather than organizational is perhaps more complex. The experiences expressed by our informants suggests that improved communication between the patient and the health care community, and promoting strong social support networks are particularly important.

These are not new ideas. For example, Shudy at al.[32] thoughtfully use the term 'sense of partnership with the staff' in their review of the impact of paediatric illness on a family, which mirrors the first emergent theme in our analysis. Jackson et al.[33] discuss how close social support networks improve coping in families of children with brain tumours, with ideas closely related to our second theme of social support. Jackson et al. provide a framework for conceptualizing social support, breaking it down into formal (medical) and informal (friends/family), and use informational, emotional, and practical support as qualifiers. Information is typically the domain of formal support, whereas the emotional support most effectively comes from informal connections[33].

In our cohort, the impact of these factors was most dramatic in relation to uptake of surgical services. Both families who declined surgery struggled to establish good communication with a specialist, and did not have strong informal social support networks in place. The specific concerns these families raised are also not new. Insufficient funds for travel or other indirect costs, lack of information, and/or the parent targeted for education not having decisional power are reasons presented in similar work in lower resource areas for delayed presentation for available surgery[14] or follow up[34].

In addition to these poignant cases, additional families in our cohort felt overwhelmed at various stages of the treatment pathway, particularly when attempting patching and contact lens wear. Contact lens use in infants (and to a lesser degree patching) has been associated with higher levels of parental stress[16]. Parental stress is known to contribute to decreased adherence with amblyopia treatment in cases of strabismic and anisometropic amblyopia[20]. These ideas appeared to be consistent with accounts from our informants. Again, good communication and strong social support appeared to mitigate these factors. Although care must be taken when generalizing, we suggest that perhaps communication and practical support may have been factors which account for the difference between the results of Drews et al[16] which revealed an association between the use of contact lenses following paediatric cataract surgery and parental stress and those of Celano et al[15] which did not. Notably, the data reported by Celano et al[15] were collected in the context of a clinical trial, in which extensive information and practical support were provided.

The participant families in this study had diverse backgrounds and needs, highlighting the importance of empathetic and individualized care. Although there were many professionals involved in patient care (for example nurses, orthoptists and low vision organizations), paediatric ophthalmologists were generally seen as the primary providers of information. The demand on a single specialist of providing sensitive, individualised support to a diverse community may be significant.

In some cases print materials can help supplement communication of important information and encourage treatment compliance[19], however information alone is often insufficient to promote action[35]. Patient care may benefit from the provision of accurate information and practical support from different professionals. Some research has described the role of a ‘childhood blindness coordinator’ to be particularly beneficial to fill this gap[34 36]. This role can involve helping parents understand the condition, providing foresight about the treatment pathway, as well as providing practical support such as text message reminders and travel planning[34]. In terms of emotional support, formal networks tend to be less effective than informal support networks[33]. However, Ireys et al. showed the benefit of peer support groups for mothers of children with chronic illness[37], and Emily’s family provides a good example of how a caring community volunteer can provide effective support. These are all avenues which could be further explored to help families dealing with childhood cataract.

Conclusion

The message from the literature about childhood cataract is that without a team of supportive professionals working with affected families, the pathway from detection to rehabilitation will be difficult, and outcomes will be compromised[2 3 8]. Our work supports this, and emphasises that to achieve the best visual outcomes for these children, we need to improve screening practices, communicate effectively and consider creative ways to support families with surgical uptake and post-surgical follow up.

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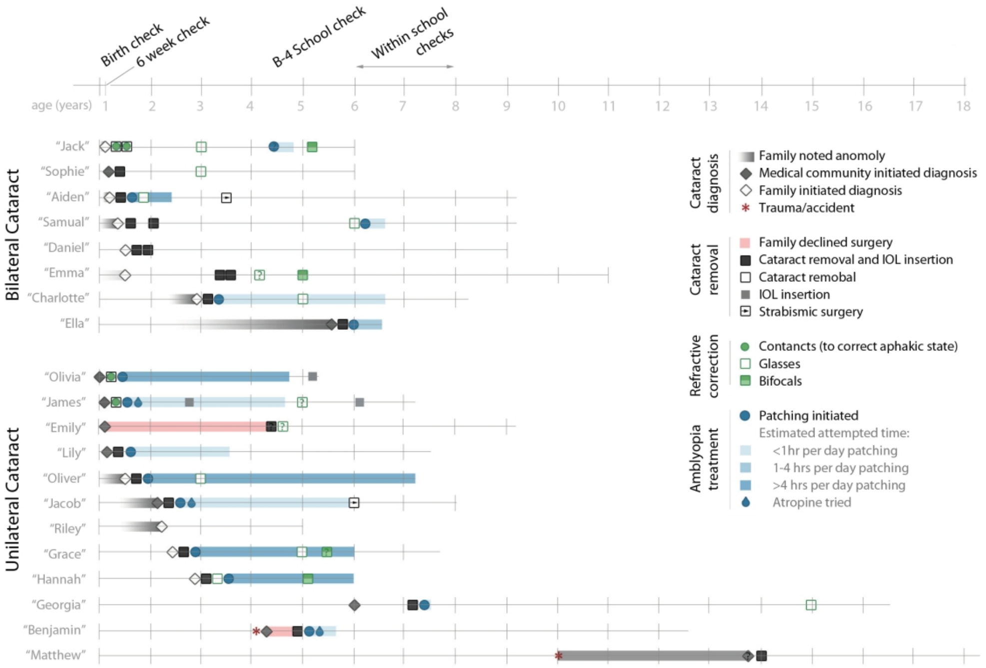

Figure 1 Timeline of treatment pathway

Participants are categorised into cases of unilateral or bilateral cataract. An asterisk by a patient pseudonym indicates a family history of paediatric cataract. Cataract diagnosis is depicted with a diamond. If a medical professional, or a community screen initiated the appointment in which a diagnosis occurred, the diamond is grey, whereas the diamond is white if the family initiated the appointment at which the diagnosis was made. A grey bar preceding a diamond indicates that abnormal behaviour or ocular appearance was noticed by the family prior to diagnosis. Treatment is represented by a square; black represents a surgical intervention, and green optical. Red bars between diagnosis and treatment indicate treatment was recommended during this time, but the family declined. IOL = intraocular lens

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Reporting checklist for qualitative study.

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		Reporting Item	Page Number
Title	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	3
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	#4	Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and	7-8

		guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	#7	Setting / site and salient contextual factors; rationale	6
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of	6-7 and 8-9

		participation (could be reported in results)	(also Figure 1)
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6-7
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Table 1
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Tables 2-4
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	17-20
Limitations	#19	Trustworthiness and limitations of findings	17-18
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	8 and 18
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	1

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BMJ Open

A phenomenological approach to childhood cataract treatment in New Zealand using semi-structured interviews: How might we improve provision of care?

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Author Contributions

LH, JB, SD and BT designed the study. LH and SD recruited the participants. LH conducted the interviews and transcibed the data. KB and LH independently coded and analysed the transcribed data, and then interpreted the data in an iterative manner. LH wrote the first draft the manuscript, and all authors assisted with revisions. All authors were involved in the final proofing process and agreed to be accountable for the content of the manuscript.

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Keywords

Paediatric cataract, parental stress, semi-structured interviews, adherence

Data Statement

Full transcripts of interviews are not available to protect participants' anonymity

Abstract

Purpose: To understand how we might improve the provision of medical care for children with cataracts.

Design: A phenomenological design was employed. Semi-structured interviews were conducted to capture rich descriptions of the phenomena. Our goal in the interview and the analysis was to understand the sources of distress associated with treatment for cataract and deprivation amblyopia which 1) could be addressed by the medical community and 2) related to treatment adherence.

Setting: Interviews were conducted by a non-clinician researcher in New Zealand (NZ) in a location chosen by informants. In NZ the red reflex screening test is performed shortly after birth, and surgery to remove paediatric cataracts is publicly funded.

Participants: Families of children who had a history of cataract in Auckland, NZ were posted an invitation to participate. Twenty families were interviewed.

Results: Our analysis illustrated that informants described a wide range of experiences, from declined cataract surgery to full adherence to medical advice including years of patching for more than four hours a day. Across these experiences, we identified three relevant themes; timing of diagnosis, communication between the parent and clinician, and parental social support networks.

Conclusion: The medical community may be better placed to support families dealing with childhood cataract by improving detection of childhood cataract, building appropriate communication pathways, and promoting social support, with an emphasis on empathetic, individualised care.

Article Summary

Strengths and limitations of this study

Strengths:

- Informants had a broad range of experiences, from very positive to very negative, likely to reflect the diversity of the cohort of interest.
- Data from interviews were rich and themes converged across diverse experiences.

Limitations:

- The impact of culture was not a specific focus of the interviews. Our iterative analysis indicated that cultural factors may enhance understanding of families' experiences. This is recommended as an area of further research.
- The authors are generally invested in adherence with ophthalmological recommendations. This bias is clearly stated in our purpose.

Introduction

Elimination of visual impairment from childhood cataract is one of the key objectives of the VISION2020 initiatives[1 2]. The removal of the opaque lenses preventing a child from seeing requires specialised expertise, surgical facilities and various consumables, at an estimated base cost of approximately $300 USD[3-5] in the developing countries to an estimated $5000 USD in developed countries such as New Zealand. Although childhood cataracts are rare (impacting approximately 2.5 in 10 000 children[6]), the investment in treatment is advocated for globally due to the improvements in quality of life[7] and long term economic benefits[4]. Given the impact, removal of childhood cataracts is prioritized, with many non-governmental organizations (NGOs) supporting communities unable to make this investment[8-10]. Despite NGO support, disparities exist, with childhood cataract accounting for approximately 20-30% of childhood blindness in lower income areas[11 12], and closer to 5%[13] in higher income countries[14].

However, the vision loss associated with bilateral or unilateral paediatric cataract is not fully resolved with merely surgical removal of the opaque lens (for overviews see[15-17]). The cataract needs to be identified and appropriate referrals made[18 19]. A replacement lens needs to be implanted, or compensatory contact lens or spectacle correction prescribed[15]. Children often require follow up surgeries and ongoing assessment of appropriate refraction[15]. Furthermore, there is a risk of secondary conditions, such as glaucoma[20] and the risk of deprivation amblyopia increases sharply if the cataract is not removed shortly after onset[21 22]. Deprivation amblyopia is abnormal visual cortex development caused by visual deprivation, typically by a cataract, in one or both eyes early in life[23]. Deprivation amblyopia leads to long-lasting visual impairment that persists after cataract removal[23]. The impact of deprivation amblyopia on the more basic aspects of vision (contrast sensitivity and visual acuity) of the affected eye(s) is more pronounced following unilateral[22] than bilateral[21] cataract, although the symptoms are varied and dependent on the duration of visual deprivation[24]. The treatment for amblyopia involves occlusion (patching) or penalization (atropine cycloplegia) of the stronger eye to promote use of the weaker eye[23]. These are home-based therapies which can be difficult for families to implement[25]. Taken together, the efficacy of childhood cataract surgery is affected by a range of factors including early detection, prompt uptake of surgical intervention, and dedicated commitment to follow up care by the family and medical community (for discussion see[15 26]).

Each step in the treatment pathway for childhood cataract has been investigated, including screening[19 27-30], factors contributing to delayed utilization of surgical services[31], parental stress associated with childhood cataract treatment[32 33], compliance with amblyopia treatment[34-38] and the impact of cataract removal on quality of life[7 39]. Across this international body of work, the services that are available, affordable, and accepted by the community being studied vary considerably. Studies of social barriers to accessing care, delayed cataract removal and poor follow up tend to be done in lower income countries[7 19 31 40], whereas research into issues such as increasing adherence with amblyopia treatment, tend to cluster in higher income countries[25 34-37]. The research generally reflects the predominant hierarchical needs within communities[41]. However, socio-economic disparities exist within even high-income countries and there is growing recognition that wider research is needed to allow the best visual outcomes for all children[38 41].

In this study, we were interested in the experience of childhood cataract in Auckland, New Zealand (NZ), where ethnicity is diverse (67% European, 15% Maori, 11% other, 9% Asian, 7% pacific peoples, 1% Middle Eastern/Latin American/Africa - from 2006 census data), and advanced ophthalmological services are now well established and publicly funded. In the early 1970s cataract accounted for 22.5% of the children registered as blind in NZ [42], whereas a more recent report indicates substantial improvements in the treatment of childhood cataract, with only approximately 4% of children experiencing blindness or low vision attributed to childhood cataract[43]. There is likely further room for improvement, with a recent report suggesting detection of childhood cataract is suboptimal[30]. There is no published research in NZ about adherence with follow up or the extent of secondary amblyopia following childhood cataract surgery. In the current study we aimed to understand how childhood cataract and its treatment impacted NZ families, as a starting point to address potential gaps in the system. A qualitative study in the USA found that ‘treatment’ itself was one of 6 key themes decreasing quality of life for children with a history of cataracts[39]. Our project probes this idea by focusing on families’ lived experience (phenomenology) throughout the treatment pathway. Our aim was to identify sources of distress which 1) could be addressed by the medical community and 2) related to adherence with recommendations from their ophthalmologist.

Methodology

Study context

The study was conducted in Auckland, New Zealand (NZ), where comprehensive childhood vision screening systems are in place (red reflex exam at birth and at the 6 week check, pre and in school acuity checks) specialised paediatric cataract surgery is publically funded and prioritised, and subsidies are available for refractive correction, occlusion therapy and transportation costs for families who require financial assistance and/or have particularly high visual needs. The study cohort was culturally diverse (reflecting national averages) and approximately a third had lived and received medical advice outside of NZ. The first author carried out the semi-structured interviews. This author is a non-clinical researcher (not involved in any of the participant's care), and it was made clear to all informants that participation in the study would not impact the care they received.

Patient and Public Involvement

This project was a first step towards understanding how the medical community could improve provision of treatment for childhood cataract; as such the project was to understand their experiences and needs. The project was part of a larger study about the consequences of[44], and potential for rehabilitation after[45] visual deprivation due to childhood cataract, with this step focused on understanding patient experience of the treatment pathway. A lay summary of results will be available to all participants, and information will also be disseminated at a community follow up meeting or 'hui'.

Participant recruitment

In phenomenological studies a purposive sampling strategy is supported in order to recruit participants who have experienced the phenomenon under study[46]. Accordingly, research participants were intentionally contacted following a medical records search. Inclusion criteria included history of a visually significant paediatric cataract (congenital, developmental and traumatic cases) and a current age of at least four. Exclusion criteria included severe developmental disorders or severe ocular disease unrelated to paediatric cataract, noted on ophthalmological records. Invitation letters were posted to thirty-nine parents resulting in seventeen positive responses, each of whom were invited to participate in the study, including one parent of a non-verbal child with autism (autism was not diagnosed around the time of cataract surgery). One additional family made contact independently; their son had not had surgery to remove his cataract. Two additional families were made aware of the project through their specialist. A total of twenty semi-structured interviews were carried out. The study complied with the tenets of the declaration of Helsinki and was approved by ethics committees from the University of Auckland and the Auckland District Health Board. Participants provided informed consent, and children who were able provided assent.

Semi-Structured interviews

Interviewing is the primary data collection strategy in phenomenological studies[46]. As such, semi-structured interviews were employed focussing on the lived experiences and personal perceptions of the treatment process for childhood cataract and secondary deprivation amblyopia. Interviews were conducted in a private location of the participant's choice and audio recorded (except in one case due to excessive background noise). We requested that both caregivers and the affected child were present, and we encouraged all attendees to contribute to the conversation. Interviews were approximately one hour in length for each family, but varied in an attempt to obtain rich data. Semi-structured interviews were transcribed by the first author. Potentially identifiable information was removed or anonymized, and pseudonyms were assigned (pseudonyms reflect most common NZ names for birth year). The approximate timing of key treatment events were derived from each interview (narrative summary) and used to provide context for understanding phenomenology (lived experience).

Phenomenology

Phenomenology is a qualitative data analysis strategy used in various fields as a tool to delve into personal lived experience[47-49]. This approach is particularly important for childhood medical research, in which parental choices impact childhood health outcomes and these choices exist within a complex context. Our primary goal was to develop an in-depth appreciation of each family's experience of childhood cataract treatment. We felt this goal was best addressed by a descriptive phenomenological approach.

Husserl's[47] approach to phenomenology, as made explicit by Giorgi[48], and summarised by Wertz[49] includes four steps, which we carried out as follows. 1) *Open reading*; we attempted to understand each experience as a whole. 2) *Meaning units*; we divided each transcript into units of meaning or 'themes'. 3) *Psychological reflection;* we reflected on the relevance of the themes to our research interest, and how they related to each other. This was an iterative process including re-reading, summarising, grouping together, and redefining meaning units to better reflect informant experience. 4) *Structural understanding and description*; we consolidated relevant emergent ideas, which we present as three themes and seven sub themes. The first and second author mutually carried out an analysis of the transcripts and then compared notes which resulted in the final presentation of themes. We used SRQR reporting guidelines for qualitative research[50].

Research questions are approached from the frame of our own experiences. Our framing included that 1) we trusted the evidence suggesting that prompt removal of cataracts and adherence with amblyopia treatments (such as patching) are in the best interest of the child, and 2) a critique of family's responses to a challenging life event was outside our scope. We structured our research question to highlight our perspective rather than bracketing our experience from our interpretation; we focused on what the *medical community* could do to alleviate distress, particularly in ways that could promote *adherence*. In the process of seeking to find meaning across the experiences of our informants, we tended towards a constructivist epistemology; fundamentally believing that meaning is constructed rather than discovered. Through iteration, we understood our constructed meaning to be best exemplified in terms of negative and positive experiences of the emergent themes. Therefore the themes presented reflect encouragement to families at their best, and exasperated distress at their worst.

Results

Narrative summary

Informants had a wide range of experiences. Key treatment events are summarised as cataract diagnosis, cataract removal, refractive correction and amblyopia treatment. Timelines for each participant are presented in Figure 1, based on estimates from interview data. Some participants had congenital cataracts which were present at birth, others had cataracts which were detected or developed during early childhood (developmental), and others had traumatic cataracts resulting from an eye injury. It is of note that some parents were unsure whether their child had congenital or developmental cataracts.

There were no cases in which access to surgery after diagnosis limited care, however perception of delayed detection of cataract was an important issue raised. For one child (Riley), parents were told cataract removal would have too poor a prognosis to justify surgery, given the delay in detection. We have expanded on delays in diagnosis in the first theme. Unlike most families who prioritized prompt cataract removal, Emily and Benjamin's families both declined surgery initially. Both later took up the services, phenomena we further explore within the second and third themes.

The experience with home implementation of follow up treatment was diverse. Although no families noted cost of glasses, contacts or patches to be prohibitive, parents expressed concern that acquiring these items and navigating subsidies was complicated and could be stressful. For those who used glasses, feedback was very positive, except for the one participant prescribed glasses in her teenage years (Georgia), who felt uneasy with the aesthetic aspects of wear. Only children with very early surgery used contact lenses instead of an intraocular lens (IOL). Of the six surgeries done before six months of age, half (Olivia, James and Jack) remained aphakic and used a contact lenses rather than IOLs. Each of these families described the use of the contact lenses as the most distressing part of their experience, with two of the three families describing traumatic events related to inserting, removing and/or losing contact lenses. These two families advocated for further support or re-structuring of contact lens use. Patching experience ranged from none (including children with bilateral cataracts who had equal visual acuity loss in both eyes, and children with unilateral cataract who were given a very poor prognosis), to four hours per day over several years (Olivia, Oliver, Grace and Hannah). The most challenging aspect of care was described as patching, only superseded by use of contact lenses in infancy in the small subset of children for whom it was required.

Figure 1 *Timeline of treatment pathway*

Phenomenological summary

Three themes and several sub-themes emerged from the phenomenological analysis related to how the medical system might better mitigate parental distress and encourage adherence. These are summarized in Table 1.

Table 1. Summary of themes and sub-themes

1. Detection and diagnosis
a) Red reflex exam at birth
b) Referrals and process
2. Communication with medical community
a) Rapport
b) Provision of information about cataract and deprivation amblyopia
c) Foresight about treatment pathway
3. Social support
a) Advice from social networks
b) Availability of emotional and practical

support	

Improved detection and diagnosis

The detection and diagnosis of a cataract was a complex experience for families. If parents understood the timing of diagnosis to be linked to their child's visual outcome, emotions related to perceived efficiency of the screening and processes surrounding referral were heightened. Specifically, for those parents who were informed about the cataract promptly, the negative emotions related to an unexpected diagnosis were balanced by deep appreciation. By contrast, delays associated with perceived error elicited anger and distrust in the medical community.

Table 2A highlights the important role of midwives in early screening with the red reflex test; while Lily's mother expresses appreciation from prompt detection (left), Jack's mother express anger about a perceived missed detection (right). Table 2B highlights the importance of the process from detection to diagnosis. Olivia's mother was impressed with the prompt referral pathway and communication between medical staff (left), whereas Riley's mother expressed anger that the medical community had not appropriately referred her son to a specialist.

These experiences suggest that any strategy to improve medical provision for childhood cataracts in NZ needs to start with improved training for midwives, general practitioners and pediatricians, both in terms of administering the red reflex test and procedures for prompt referral. Anger with a representative of the medical community, exemplified by Jack and Riley's mother's comments, but shared by many informants, had a lasting impact. A parent's perception of a delay in diagnosis compromised trust in the medical community, which hindered ongoing communication.

Table 2. Improved detection and diagnosis. *Examples of positive (left column) and negative (right column) experiences relating to timing of diagnosis.*

A – Red reflex screening test	
She's been a midwife for ages, and because of that experience, she picked up it. (Lily's mother)	*We were pretty angry at our midwife because we felt that she should have picked that up.* (Jack's mother)
B – Referrals and process	
We got sent to a follow up…to test the red eye reflex in the left eye and basically look in detail because they were expecting the possibility of a cataract. So it was diagnosed pretty much right from the start, she would have been about two days old when it was found and diagnosed. (Olivia's mother)	*She* [Allied medical worker] *put him on a wait list and it took until about 15 months, it was a long time, so I was thinking I guess it's not a big deal. …when we saw* [ophthalmologist] *he basically outlined right from the beginning that there was no hope. I found it … sorry … there is still a bit of anger there.* (Riley's mother)

Communication with the medical community

Once diagnosed, the relationship a family had with the specialist, and to a lesser degree, the allied medical staff, was an important part of their experience, permeating across treatment events. While some families lit up while describing the kindness and competence displayed by the medical professionals they had come to know well, others relived the anger and frustration when reflecting on their interactions with the medical community. Rapport between the parents and the specialist appeared to be particularly important, as it formed the foundation of the ongoing relationship with the medical team. If there was a connection made and trust established (Table 3A) discourse was positive, whereas if a family was put off by the specialist (Table 3B) the treatment pathway was impaired if not halted.

Beyond rapport, provision of understandable information about the condition was critical. What level of information was understandable varied between informants. Some families had a scientific background, and could appreciate a detailed technical explanation while others had limited background knowledge. Across this spectrum of varied backgrounds, effective communication allowed sufficient understanding for the family to feel comfortable with recommendations. In Table 3B, we provide examples of two informants for whom understanding of the condition directly influenced uptake of surgery.

Appropriate, understandable communication was also important for parents to prepare for potential future events. When families became exasperated with home based aspects of treatment, those who were prepared in advance (Table 3C - left) were more resilient to the setbacks. On the other hand, families who had not anticipated the challenges, or were not provided useful information to face these challenges in advance (Table 3C – right) became increasingly distressed by them, and lost trust in the system.

Whether the communication between the medical community and the parent was perceived as positive was individualized and nuanced, but across participants it included aspects of rapport, clear communication about the condition and of upcoming potential challenges.

Table 3. Communicating with medical community. *Examples of positive (left column) and negative (right column) experiences relating to communication.*

A - Building rapport	
We went in and met the paediatric ophthalmologist, and he was just a lovely, lovely man. Yeah, it was just great (Aiden's mother)	*I don't want to go to [...] anymore. He's quite 'nothing can be done, nothing can be done' (Riley's mother)*
B – Provision of information about cataract and deprivation amblyopia	
Asked whether specialist's description of the condition made sense to her: Yes, it did. Otherwise we could never have agreed to the surgery (Lily's mother)	*I was avoiding the surgery from when she was three months onwards […] they were not answering questions that I was asking to my satisfaction (Emily's mother)*
C - Foresight about the treatment pathway	
When she was first diagnosed, the specialist sat us down with this one week old baby and said this is going to be a long, hard road (Olivia's mother)	*Why hadn't (paediatric ophthalmologist) told us about this? We'd been going for three months! […] It's not smooth, it's not transparent, and that's what's hard (Oliver's mother)*

Social support

Throughout the interviews, it became apparent that provision of care improved if the medical community understood the family's social context. This includes perspectives or values held by an individual family and the resources available to them. Advice that parents received from friends or family was an important part of their social context. Families whose social networks encouraged them to engage with the medical system were likely to move forward with recommendations (example in Table 4A - left). On the other hand, some social networks were sceptical of the medical community, making it difficult or distressing for parents to seek, or act on, medical advice. Families who felt tension between the advice from the medical community and the advice from friends and family experienced an increased burden during an already challenging time (Table 4A - right).

Beyond social networks overtly advising with or against medical advice, there was an important emotional and practical role for this extended group. It was not specifically stated that a phone call from a friend, or an offer to baby-sit other children directly mitigated distress or delays along the treatment pathway, but the absence of this type of support appeared to be associated with both. For example, Benjamin's mother wanted to go through with cataract removal surgery initially, however, she was pregnant and did not have support from her family network (Table 4B – right). Like Benjamin's mother, Emily's mother initially declined surgery. However she was able to revisit this decision when she had more emotional and practical support (Table 4B - left). Families were almost ubiquitously overwhelmed at some point during diagnosis or during amblyopia treatment, and only some had the emotional and practical support they needed to follow through with recommendations. It is of particular note that contact lens use required additional practical support; Olivia and Jack's families described requiring 2 or more adults to extract the contact from their infant's eye. Both families had excellent adherence at all stages of the treatment pathway, and substantial support networks.

As discussed within 'communication', the family's social context also varied widely across informants. It was further complicated with changes over time; a school or job change, for example, impacted the balance of needs and resources a family had. To fully comply with recommendations, parents needed to have the resources to cope with new challenges, advocate for their child, and be creative in their implementation of home based treatments. Supportive social networks appeared critical to meet this high bar.

Table 4. Social Support. *Examples of positive (left column) and negative (right column) experiences relating to social support*

A – Advice from social networks	
Her grandfather, who is a GP, saw that she was looking at things close and her eye was turning in. We took her to an optometrist and they picked up that there was something there, and they referred us to the ophthalmologist who said 'yes that looks like a cataract to me, we'll send you to [city]'. And that all happened really quickly (Grace's mother)	*The doctor is trying to give us good advice […] the sooner we get it done the better. And my mum and dad are pretty much saying 'No'. So that was another kinda difficulty […] Yeah, an emotional, mental thing as well with the family's input – what they think about it (Lily's mother)*
B – Availability of emotional and practical support	
When describing decision to go through with the surgery four years after it was recommended: It was just talking about it I guess with the [Community worker] that I was having the get-togethers with […] she was lovely. I would talk with her and we would talk with [child] and she would even offer to drive us out there and stuff like that. Because that was another issue, just the transport (Emily's mother)	*We took him to the hospital and they were saying right then and there to do a little surgery [...] I was carrying [another child], and my husband didn't want him to have the surgery (Benjamin's mother)*

Discussion

The goal of our descriptive phenomenological approach[47-49] was to develop an in-depth appreciation of the individual experience of childhood cataract treatment; with a specific interest in understanding sources of distress which 1) could be addressed by the medical community and 2) related to adherence to medical recommendations.

Strengths and Limitations

We were able to recruit a wide variety of participants, with a diverse range of experiences despite childhood cataract being relatively rare. We were able to conduct rich interviews in which we found some informants were very appreciative of the medical community's role in their experience of medical treatment for childhood cataract, while others felt as though they were let down by the medical community. This diversity, and our theoretical framework allowed us to identify themes and construct meaningful summaries which could be presented in positive and negative terms. In other words, for each potential factor we could consider whether the lack impaired a family's experience, and the presence enhanced it. In some cases this directly linked to whether a family adhered to medical recommendations. In this way, the diversity of informant experience is likely to aid in quality and the generalisability of our analysis.

However, there were some limitations in our design and analysis. The phenomenological approach does not prioritise counting the frequency with which certain experiences occur. However, it is of interest to know for example, how often parents decline available cataract surgery, or how many families were able to comply with occlusion therapy. We addressed this briefly by including such details in our 'narrative summary'. However, such quantitative questions are best answered with a different methodology. Conversely, a limitation could be that we did not go deep enough into respondents' experiences. For example, during the interviews we did not focus specifically on cultural frameworks for health. Upon iterative reflection it was our impression that a deep understanding of culture may have facilitated our understanding of informant's experiences. Further expanding on this, perhaps a symbolic interactionism theoretical perspective would be a valuable direction for future research in order to understand underlying cultural reasons for choices. Furthermore, we started with the belief that adherence with ophthalmological recommendations is the best for children. Therefore discussion around whether a parent's decision to decline surgery or cease patching was in fact best for the child was outside the scope of this project. Similarly, parental motivation was not a focus of our analysis, but is part of the theoretical framework related to adherence[51]. Following up with participants on these points as part of our dissemination step will be a good opportunity to enhance future research.

Summary and Implications of findings

The varied experiences of the diverse informants we interviewed revealed opportunities for systemic improvement in childhood cataract treatment. Early detection and prompt medical treatment are critical for good visual outcomes[21 22]. Delayed detection was a perceived issue for many of our informants. More effective implementation of the red reflex exam may improve this situation[18 29]. Survey data from practitioners in New Zealand reflected this opportunity for improvement, specifically highlighting the value of better training for those administering early eye exams[30]. Our work supports the value of such an initiative.

Addressing issues that are social rather than organizational is perhaps more complex. The experiences expressed by our informants suggest that improved communication between the patient and the health care community, and promoting strong social support networks are particularly important. These are not new ideas. Literature concerned with chronic pediatric conditions have described similar phenomena. For example, Shudy at al.[52] highlighted the importance of a 'sense of partnership with the staff' mirroring the second emergent theme in our analysis. Similarly, Jackson et al.[53] discuss how close social support networks improve coping in families of children with brain tumours, with ideas closely related to our third theme of social support. Within our cohort, the impact of these factors was most dramatic in relation to uptake of surgical services. Within the themes of communication and social support, the specific concerns these families raised reflect barriers experienced in lower resources areas. These include indirect costs such as travel[31 41], lack of appropriate information[11 31], beliefs about health[31] and/or the parent targeted for education not having decisional power[31].

In addition to these poignant cases in which surgery was declined, additional families in our cohort felt overwhelmed at various stages of the treatment pathway, particularly when attempting patching and contact lens wear (struggles more consistent with the literature from higher resourced countries). Contact lens use in infants (and to a lesser degree patching) has been associated with higher levels of parental stress[33]. Parental stress is known to contribute to decreased adherence with amblyopia treatment in cases of strabismic and anisometropic amblyopia[37]. These ideas appeared to be consistent with accounts from our informants. Again, good communication and strong social support appeared to mitigate these factors. Although care must be taken when generalizing, we suggest that perhaps communication and practical support may have been factors which account for the difference between the results of Drews et al[33] which revealed an association between the use of contact lenses following paediatric cataract surgery and parental stress and those of Celano et al[32] which did not. Notably, the data reported by Celano et al[32] were collected in the context of a clinical trial, in which extensive information and practical support were provided.

Although all families found parts of the treatment pathway challenging at times, cultural socio economic factors appeared to exasperate the challenges. Some work suggests that if a family does not feel connected with the dominant society (or the person representing the society as the medical professional) their child is less likely to adhere to treatment for amblyopia[38]. In our diverse cohort the concept appeared to extend beyond patching to cataract removal, which has more substantial consequences. Although there were many professionals involved in patient care, paediatric ophthalmologists were generally seen as the primary providers of information. This means the demand on a single specialist of providing sensitive, individualised support to a diverse community may be significant.

In some cases print materials can help supplement communication of important information and encourage treatment compliance[36], however information alone is often insufficient to promote action[54]. Patient care may benefit from the provision of accurate information and practical support from different professionals. Some research has described the role of a 'childhood blindness coordinator' to be particularly beneficial to fill this gap[40 55]. This role can involve helping parents understand the condition, providing foresight about the treatment pathway, as well as providing practical support such as text message reminders and travel planning[55]. In terms of emotional support, formal networks tend to be less effective than informal support networks[53]. However, Ireys et al. showed the benefit of peer support groups for mothers of children with chronic illness[56], and Emily's family provides a good example of how a caring community volunteer can provide effective support. Research within the childhood disability service in New Zealand has suggested the role of a 'cultural case worker' may facilitate both improved communication and supplement social support for families with culturally or linguistically diverse backgrounds[57], working as 'patient advocates' rather than expert medical staff. These are all avenues that could be further explored to help families dealing with childhood cataract.

Although the system for childhood cataract treatment in NZ is technically robust, it does not appear to have sufficient support for families who are unable to effectively advocate for themselves. The current study suggests strategies from research in lower income countries may help some NZ families. Examples are the community roles of 'key informants' and 'childhood blindness coordinators', which facilitate education, detection process, and communication. New Zealand has organisations that could fill these roles, such as the Blind and Low Vision Network New Zealand (BLENNZ, which provides comprehensive support for children, from infancy to 17 years of age, with moderate to severe visual impairment) and social workers or caseworkers. However, their services are not well utilized by families due to the lack of awareness among general population and medical practitioners. Better training for midwives, pediatricians and general practitioners for early detection and referral as well as better awareness of existing support services are likely to be important steps towards improving provision of care for childhood cataract.

Conclusion

Childhood cataract is a rare and challenging condition[15 16 26], its treatment requires much from families during what is already an overwhelming phase of life. Our work suggests that availability of surgery and funding for secondary costs for those who need it is insufficient to achieve the best visual outcomes for NZ children with cataracts. We need to improve screening practices, including streamlining referral pathways to specialised paediatric ophthalmologists. We need to find ways to communicate effectively with diverse families, ensuring the condition and its treatment is understood and family's questions are answered. Finally, we need to consider creative ways to support families with surgical uptake and post-surgical follow up. This requires awareness family context, including available emotional and practical support.

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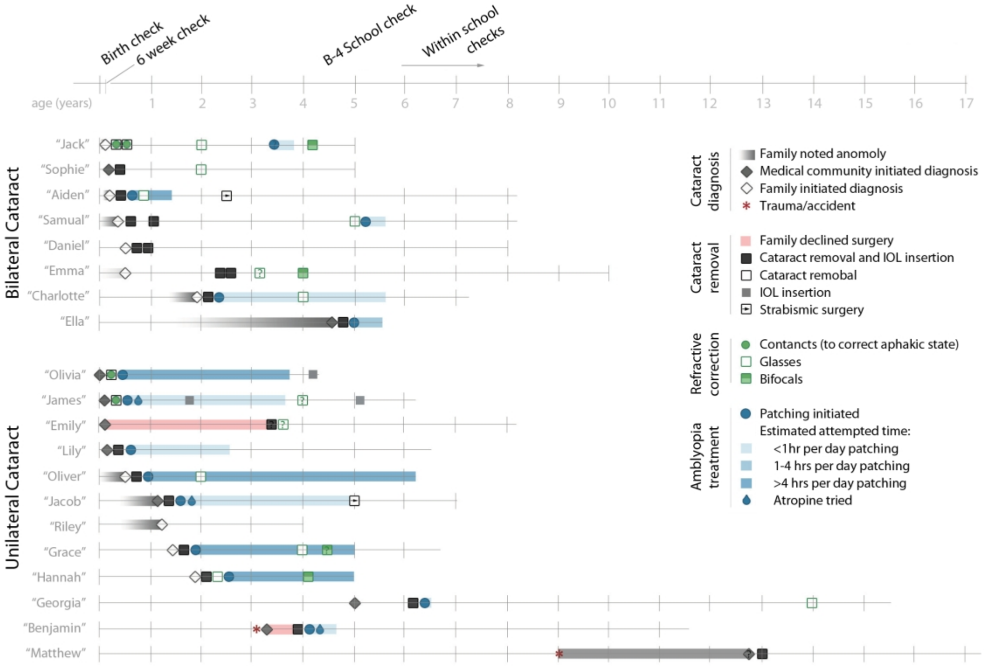

Figure 1. Timeline of treatment pathway. Participants are categorized into cases of unilateral or bilateral cataract. An asterisk by a patient pseudonym indicates a family history of paediatric cataract. Cataract diagnosis is depicted with a diamond. If a medical professional, or a community screen initiated the appointment in which a diagnosis occurred, the diamond is grey, whereas the diamond is white if the family initiated the appointment at which the diagnosis was made. A grey bar preceding a diamond indicates that abnormal behaviour or ocular appearance was noticed by the family prior to diagnosis. Treatment is represented by a square; black represents a surgical intervention, and green optical. Red bars between diagnosis and treatment indicate treatment was recommended during this time, but the family declined. IOL = intraocular lens

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		Reporting Item	Page Number
Title	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	3
Problem formulation	#3	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	#4	Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and	7-8

		guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	8
Context	#7	Setting / site and salient contextual factors; rationale	6
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	6
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	7
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	7
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of	6-7 and 8-9

		participation (could be reported in results)	(also Figure 1)
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	6-7
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	7
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Table 1
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Tables 2-4
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	17-20
Limitations	#19	Trustworthiness and limitations of findings	17-18
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	8 and 18
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	1

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