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# BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024869
Article Type:	Research
Date Submitted by the Author:	29-Jun-2018
Complete List of Authors:	Hamm, Lisa; University of Auckland, School of Optometry and Vision Science Boluk, Karla; University of Waterloo, Recreation and Leisure Studies Black, Joanna; University of Auckland, Optometry and Vision Science Dai, Shuan; University of Auckland School of Medicine, Ophthalmology; Auckland District Health Board, Ophthalmology Thompson, Benjamin; University of Waterloo, Optometry and Vision Science
Keywords:	Paediatric cataract, parental stress, semi-structured interviews, adherence

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Manuscripts

Peer Review Only

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

**Running head:** Family experience of childhood cataract treatment

**Word count:** 4328

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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 transcribed 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.

**Acknowledgements**

We would like to thank all the families who took the time to talk to us about thier experiences, as well as David Welch for his early contributions to the project.

**Financial support:** Lisa Hamm was supported by Education New Zealand. Education New Zealand had no role in data collection, interpretation or reporting.

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2  
3 31 **Conflict of interest:** None of the above authors have any proprietary interests or  
4 32 conflicts of interest related to this submission.  
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10 34 **Keywords**

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11 35 Paediatric cataract, parental stress, semi-structured interviews, adherence  
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16 37 **Data Statement**

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18 38 Full transcripts of interviews are not available to protect participants' anonymity  
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1  
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3 40 **Abstract**

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

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

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

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

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

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

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3 63 **Article Summary**

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5 64 **Strengths and limitations of this study**  
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7 65 *Strengths:*

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10 66 • Informants had a broad range of experiences, from very positive to very negative,  
11 likely to reflect the diversity of the cohort of interest.  
12  
13 68 • Data from interviews were rich and themes converged across diverse experiences.  
14

15  
16 69 *Limitations:*

- 17  
18 70 • The impact of culture was not a specific focus of the interviews. Our iterative  
19 analysis indicated that cultural factors may enhance understanding of families'  
20 71 experiences. This is recommended as an area of further research.  
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22 72  
23 73 • The authors are generally invested in adherence with ophthalmological  
24 74 recommendations. This bias is clearly stated in our purpose.  
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## 76 Introduction

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

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

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## 107 **Methodology**

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### 108 **Study context**

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

### 119 **Patient and Public Involvement**

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

### 128 **Participant recruitment**

129 In phenomenological studies a purposive sampling strategy is supported in order to recruit  
130 participants who have experienced the phenomenon under study<sup>25</sup>. Accordingly, research  
131 participants were intentionally contacted following a medical records search. Inclusion  
132 criteria included history of a visually significant paediatric cataract (congenital,  
133 developmental and traumatic cases) and a current age of at least four. Exclusion criteria  
134 included severe developmental disorders or severe ocular disease unrelated to paediatric  
135 cataract, noted on ophthalmological records. Invitation letters were posted to thirty-nine  
136 parents resulting in seventeen positive responses, each of whom were invited to participate



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3 137 in the study, including one parent of a non-verbal child with autism (autism was not noted  
4 138 on the ophthalmological record). One additional family made contact independently; their  
5 139 son had not had surgery to remove his cataract. Two additional families were made aware of  
6 140 the project through their specialist. A total of twenty semi-structured interviews were  
7 141 carried out. The study complied with the tenets of the declaration of Helsinki and was  
8 142 approved by ethics committees from the University of Auckland and the Auckland District  
9 143 Health Board. Participants provided informed consent, and children who were able provided  
10 144 assent.

### 145 **Semi-Structured interviews**

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

### 159 **Phenomenology**

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

164 Husserl's<sup>26</sup> approach to phenomenology, as made explicit by Giorgi<sup>27</sup>, and summarised by  
165 Wertz<sup>28</sup> includes four steps, which we carried out as follows. 1) *Open reading*; we set aside

166 theoretical and personal biases and attempted to understand each experience as a whole.  
167 2) *Meaning units*; we divided each transcript into units of meaning or 'themes'. 3)  
168 *Psychological reflection*; we reflected on the relevance of the themes to our research  
169 interest, and how they related to each other. This was an iterative process including re-  
170 reading, summarising, grouping together, and redefining meaning units to better reflect  
171 informant experience. 4) *Structural understanding and description*; we consolidated relevant  
172 emergent ideas, which we present as three themes and six sub themes. The first and second  
173 author mutually carried out an analysis of the transcripts and then compared notes which  
174 resulted in the final presentation of themes. We used SRQR reporting guidelines for  
175 qualitative research<sup>29</sup>.

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

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## 190 **Results**

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### 191 **Narrative summary**

192 Informants had a wide range of experiences. Key treatment events are summarised as  
193 cataract diagnosis, cataract removal, refractive correction and amblyopia treatment.  
194 Timelines for each participant are presented in Figure 1, based on estimates from interview  
195 data. Some participants had congenital cataracts which were present at birth, others had

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3 196 cataracts which were detected or developed during early childhood (developmental), and  
4 197 others had traumatic cataracts resulting from an eye injury. It is of note that some parents  
5 198 were unsure whether their child had congenital or developmental cataracts.

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9 199 There were no cases in which access to surgery after diagnosis limited care, however  
10 200 perception of delayed detection of cataract was an important issue raised. We have  
11 201 expanded on this in the first theme. Unlike most families who prioritized prompt cataract  
12 202 removal, Emily and Benjamin's families both declined surgery initially. Both later took up the  
13 203 services, expressing a mixture of frustration and regret. We explore these cases more within  
14 204 the second and third themes.

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20 205 The experience with home implementation of follow up treatment was also diverse.  
21 206 Although no families noted cost of glasses, contacts or patches to be prohibitive, parents  
22 207 expressed concern that acquiring these items and navigating subsidies was complicated and  
23 208 could be stressful. Only children with very early surgery used contact lenses instead of an  
24 209 intraocular lens (IOL). Of the six surgeries done before six months of age, half (Olivia, James  
25 210 and Jack) remained aphakic and used a contact lenses rather than IOLs. Each of these  
26 211 families described the use of the contact lenses as the most stressful part of their  
27 212 experience, with two of the three families describing traumatic events related to inserting,  
28 213 removing and/or losing contact lenses. These two families advocated for further support or  
29 214 re-structuring of contact lens use.

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38 215 Patching experience ranged from none (including children with bilateral cataracts who had  
39 216 equal visual acuity loss in both eyes, and children with unilateral cataract who were given a  
40 217 very poor prognosis), to four hours per day over several years (Olivia, Oliver, Grace and  
41 218 Hannah). The most challenging aspect of care was described as patching, only superseded by  
42 219 use of contact lenses in infancy in the small subset of children for whom it was required. For  
43 220 those who used glasses, feedback was very positive, except for the one participant  
44 221 prescribed glasses in her teenage years (Georgia), who felt uneasy with the aesthetic aspects  
45 222 of wear.

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

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227 **Phenomenological summary**

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

231

232 **Table 1. Summary of themes and sub-themes**

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

233

234 **Improved detection and diagnosis**

235 The detection and diagnosis of a cataract was a complex experience for families. It elicited  
 236 predictable emotions such as disbelief, fear and uncertainty, but also varied experiences  
 237 related to the family's understanding of timing. If parents understood the timing of  
 238 diagnosis to be linked to their child's visual outcome, emotions related to perceived  
 239 efficiency of the screening test and processes surrounding referral were heightened. For  
 240 those parents who were informed about the cataract promptly, the negative emotions

241 related to an unexpected diagnosis were balanced by a sentiment of more solemn  
 242 appreciation. By contrast, anger arose for parents if the medical community was perceived  
 243 to be responsible for a delay. In Table 2 we highlight 2 subcategories which were the targets  
 244 of the frustration or appreciation. Table 2A highlights cases in which a person perceived to  
 245 be responsible for the red eye reflex screening test (most commonly the midwife) was  
 246 directly targeted for appreciation or anger. Table 2B highlights the importance of the  
 247 process whereby the concern was communicated between professionals, culminating in a  
 248 diagnosis.

249 **Table 2. Improved detection and diagnosis.** Examples of positive (left column) and negative  
 250 (right column) experiences relating to timing of diagnosis.  
 251

#### 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)*

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253 In the left column of Table 2 we can see examples of effective screening, referrals and  
 254 following up on red flags. By contrast, the right column highlights cases where an  
 255 opportunity existed for a cataract to be detected earlier, and was missed. These experiences  
 256 suggest that any strategy to improve medical provision for childhood cataracts needs to  
 257 start with improved training for screeners, both in terms of administering the test and

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3 258 procedures for prompt referral. Anger with a representative of the medical community,  
4 259 exemplified by Jack and Riley's mother's comments, but shared by many informants, had a  
5 260 lasting impact. A parent's perception of a delay in diagnosis compromised trust in the  
6 261 medical community, which hindered ongoing communication. This was particularly the case  
7 262 if the specialist managing the child's ongoing care was seen to be associated with this initial  
8 263 perceived error. Although experience with detection and diagnosis was an important part of  
9 264 ongoing communication with the medical community, many other factors also contributed  
10 265 to communication, these expanded on within the next theme.

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20 267 ***Communicating with the medical community***

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22 268 Once diagnosed, the relationship a family had with the specialist, and to a lesser degree, the  
23 269 allied medical staff, was an important part of their experience, permeating across treatment  
24 270 events. While some families lit up while describing the kindness and competence displayed  
25 271 by the medical professionals they had come to know well, for others anger and frustration  
26 272 expanded when reflecting on their interactions with the medical community.

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28 273 Rapport between the parents and the specialist appeared to be particularly important, as it  
29 274 formed the foundation of the ongoing relationship with the medical team. Example quotes  
30 275 are presented in Table 3A, with the left panel containing an example of a positive  
31 276 impression, and the right showing an example of a negative impression.

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33 277 Parental knowledge about childhood cataract ranged widely between participant families.  
34 278 Some families had a scientific background, and could understand and appreciate a detailed  
35 279 explanation. Others had limited background knowledge, but effective communication  
36 280 allowed sufficient understanding for the family to feel comfortable with recommendations.  
37 281 Other parents did not feel as though their questions were addressed sufficiently. In Table  
38 282 3B, we provide examples of two informants for whom understanding of the condition had  
39 283 an influence on the uptake of surgery. Additionally, some families experienced significant  
40 284 distress over misunderstandings, or gaps of communication. For example, Sophie and Lily's  
41 285 mothers were distraught at the time of the interview about perceived connections between  
42 286 behaviours during pregnancy and the cause of the cataract. Accordingly, it appeared

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3 287 important for the specialist to understand what the relevant information was for each  
4 288 family, and to communicate it at an appropriate level.  
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7 289 This was particularly poignant for communication about potential future events. Childhood  
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9 290 cataract has a long treatment pathway, much of which is dependent on parents to  
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11 291 implement. When families became exasperated with home based aspects of treatment,  
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13 292 those who were prepared in advance were not as discouraged by these setbacks, whereas  
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15 293 families who had not anticipated the challenges appeared to be quite distressed by them.  
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17 294 Furthermore, the lack of foresight fostered a distrust of the specialist if parents perceived  
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19 295 that information was withheld. Table 3C provides one example from a family who was  
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21 296 warned of the difficulties from the outset (and appreciated the foresight), compared to a  
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23 297 family who felt their specialist had not communicated information which would have been  
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25 298 useful.  
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27 299 Whether the communication between the medical community and the parent was  
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29 300 perceived as positive was individualized and nuanced, but across participants it included  
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31 301 aspects of rapport, clear communication about the condition and of upcoming potential  
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33 302 challenges.  
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304 **Table 3. Communicating with medical community.** Examples of positive (left column) and  
 305 negative (right column) experiences relating to communication.  
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<b>A - Building rapport</b>	
<i>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>	<i>I don't want to go to [...] anymore. He's quite 'nothing can be done, nothing can be done' (Riley's mother)</i>
<b>B – Provision of information about cataract and deprivation amblyopia</b>	
<i>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>	<i>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)</i>
<b>C - Foresight about the treatment pathway</b>	
<i>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)</i>	<i>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)</i>

307

### 308 **Social support**

309 Throughout the interviews, it became apparent that the provision of care was improved if  
 310 there was an awareness of how recommendations fit within the family's social context. This  
 311 includes perspectives or values held by an individual family and the resources available to  
 312 them. It was common for families to include anecdotes about how friends or family  
 313 members reinforced ideas, provided advice, helped pay for travel, supervised a child who  
 314 was patching, looked after other children, or helped remove a contact out of an infant's eye.  
 315 In many cases, such a support person happened to have a related occupation (for example,  
 316 an optometrist, nurse, or physician) which provided extra comfort as parents navigated the



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3 317 treatment pathway. When this was not available, it appeared to impact on parental  
4 318 experience and capacity to comply with treatment.  
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7 319 Advice that parents received from friends or family was an important part of their  
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9 320 experience. When families were confronted by something new or unfamiliar, for example,  
10 321 when the vision problem was first detected or surgery was offered, families who had others  
11 322 encouraging them to engage with the medical system were likely to move forward with  
12 323 recommendations (example in Table 4A - left). On the other hand, some social networks  
13 324 were sceptical of the medical community, making it difficult or distressing for parents to  
14 325 seek, or act on, medical advice. Families who felt tension between the advice from the  
15 326 medical community and the advice from friends and family experienced an increased burden  
16 327 during an already challenging time (Table 4A - right). Additionally, if this tension existed, and  
17 328 the family member who was given the information did not have the decision making power  
18 329 within the family (as was the case for Benjamin's family – further expanded on in Table 4B  
19 330 right), communication from the medical community was less effective.  
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22 331 Beyond social networks overtly advising with or against medical advice, there was an  
23 332 important emotional and practical role for this extended group. It was not specifically stated  
24 333 that a phone call from a friend, or a ride from a family member directly mitigated distress or  
25 334 delays along the treatment pathway, but the absence of this support appeared to be  
26 335 associated with both. Emily's mother provided a particularly impactful example of this; she  
27 336 was overwhelmed when surgery was recommended, and she declined it, but four years later  
28 337 when she joined a community group allowing social support, she decided to comply with  
29 338 recommendations (Table 4B - left). Like Emily's mother, several families simply felt  
30 339 overwhelmed at diagnosis or during amblyopia treatment, and did not have the emotional  
31 340 or practical support they needed to overcome this feeling. The example we provide in Table  
32 341 4B – right, is from Benjamin's family, and it also highlights the inter-relationship with  
33 342 practical support, advice, and communication. It is of particular note that contact lens use  
34 343 required additional practical support; Olivia and Jack's families described requiring 2 or more  
35 344 adults to extract the contact from their infant's eye.  
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345 As discussed within 'communication', the family's social context also varied widely across  
 346 informants. It was further complicated with changes over time; a school or job change, for  
 347 example, impacted the balance of needs and resources a family had.

348 **Table 4. Social Support.** Examples of positive (left column) and negative (right column)  
 349 experiences relating to social support  
 350

#### 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)*

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

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### 363 Discussion

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

### 368 Strengths and Limitations

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

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3 380 However, there were some limitations in our design and analysis. During the interviews we  
4 381 did not focus specifically on cultural frameworks for health. However, upon iterative  
5 382 reflection it was our impression that a deep understanding of culture may have facilitated  
6 383 our understanding of informant's experiences. Further expanding on this, perhaps a  
7 384 symbolic interactionism theoretical perspective, would be a valuable direction for future  
8 385 research in order to understand underlying cultural reasons for choices, particularly related  
9 386 to declining available surgery. Furthermore, we started with the belief that adherence with  
10 387 ophthalmological recommendations is the best for children. Therefore discussion around  
11 388 whether a parent's decision to decline surgery or cease patching was in fact best for the  
12 389 child was outside the scope of this project. Similarly, parental motivation was not a focus of  
13 390 our analysis, but is part of the theoretical framework related to adherence<sup>30</sup>. Following up  
14 391 with participants on these points as part of our dissemination step will be a good  
15 392 opportunity to enhance future research.

### 26 393 **Summary and Implications of findings**

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28 394 The varied experiences of the diverse informants we interviewed revealed opportunities for  
29 395 systemic improvement in childhood cataract treatment. Early detection and prompt medical  
30 396 treatment are critical for good visual outcomes<sup>4 5</sup>. Delayed detection was a perceived issue  
31 397 for many of our informants. More effective implementation of the red eye reflex exam may  
32 398 improve this situation<sup>12 31</sup>. Survey data from practitioners in New Zealand reflected this  
33 399 opportunity for improvement, specifically highlighting the value of better training for those  
34 400 administering early eye exams<sup>13</sup>. Our work supports the value of such an initiative.

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37 401 Addressing issues that are social rather than organizational is perhaps more complex. The  
38 402 experiences expressed by our informants suggests that improved communication between  
39 403 the patient and the health care community, and promoting strong social support networks  
40 404 are particularly important.

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43 405 These are not new ideas. For example, Shudy et al.<sup>32</sup> thoughtfully use the term 'sense of  
44 406 partnership with the staff' in their review of the impact of paediatric illness on a family,  
45 407 which mirrors the first emergent theme in our analysis. Jackson et al.<sup>33</sup> discuss how close  
46 408 social support networks improve coping in families of children with brain tumours, with  
47 409 ideas closely related to our second theme of social support. Jackson et al. provide a

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3 410 framework for conceptualizing social support, breaking it down into formal (medical) and  
4 411 informal (friends/family), and use informational, emotional, and practical support as  
5 412 qualifiers. Information is typically the domain of formal support, whereas the emotional  
6 413 support most effectively comes from informal connections<sup>33</sup>.

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10 414 In our cohort, the impact of these factors was most dramatic in relation to uptake of surgical  
11 415 services. Both families who declined surgery struggled to establish good communication with  
12 416 a specialist, and did not have strong informal social support networks in place. The specific  
13 417 concerns these families raised are also not new. Insufficient funds for travel or other indirect  
14 418 costs, lack of information, and/or the parent targeted for education not having decisional  
15 419 power are reasons presented in similar work in lower resource areas for delayed  
16 420 presentation for available surgery<sup>14</sup> or follow up<sup>34</sup>.

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23 421 In addition to these poignant cases, additional families in our cohort felt overwhelmed at  
24 422 various stages of the treatment pathway, particularly when attempting patching and contact  
25 423 lens wear. Contact lens use in infants (and to a lesser degree patching) has been associated  
26 424 with higher levels of parental stress<sup>16</sup>. Parental stress is known to contribute to decreased  
27 425 adherence with amblyopia treatment in cases of strabismic and anisometropic amblyopia<sup>20</sup>.  
28 426 These ideas appeared to be consistent with accounts from our informants. Again, good  
29 427 communication and strong social support appeared to mitigate these factors. Although care  
30 428 must be taken when generalizing, we suggest that perhaps communication and practical  
31 429 support may have been factors which account for the difference between the results of  
32 430 Drews et al<sup>16</sup> which revealed an association between the use of contact lenses following  
33 431 paediatric cataract surgery and parental stress and those of Celano et al<sup>15</sup> which did not.  
34 432 Notably, the data reported by Celano et al<sup>15</sup> were collected in the context of a clinical trial, in  
35 433 which extensive information and practical support were provided.

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46 434 The participant families in this study had diverse backgrounds and needs, highlighting the  
47 435 importance of empathetic and individualized care. Although there were many professionals  
48 436 involved in patient care (for example nurses, orthoptists and low vision organizations),  
49 437 paediatric ophthalmologists were generally seen as the primary providers of information.  
50 438 The demand on a single specialist of providing sensitive, individualised support to a diverse  
51 439 community may be significant.

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3 440 In some cases print materials can help supplement communication of important information  
4 441 and encourage treatment compliance<sup>19</sup>, however information alone is often insufficient to  
5 442 promote action<sup>35</sup>. Patient care may benefit from the provision of accurate information and  
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7 443 practical support from different professionals. Some research has described the role of a  
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9 444 'childhood blindness coordinator' to be particularly beneficial to fill this gap<sup>34 36</sup>. This role can  
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11 445 involve helping parents understand the condition, providing foresight about the treatment  
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13 446 pathway, as well as providing practical support such as text message reminders and travel  
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15 447 planning<sup>34</sup>. In terms of emotional support, formal networks tend to be less effective than  
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17 448 informal support networks<sup>33</sup>. However, Ireys et al. showed the benefit of peer support  
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19 449 groups for mothers of children with chronic illness<sup>37</sup>, and Emily's family provides a good  
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21 450 example of how a caring community volunteer can provide effective support. These are all  
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23 451 avenues which could be further explored to help families dealing with childhood cataract.

## 24 452 **Conclusion**

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27 453 The message from the literature about childhood cataract is that without a team of  
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29 454 supportive professionals working with affected families, the pathway from detection to  
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31 455 rehabilitation will be difficult, and outcomes will be compromised<sup>2 3 8</sup>. Our work supports  
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33 456 this, and emphasises that to achieve the best visual outcomes for these children, we need to  
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35 457 improve screening practices, communicate effectively and consider creative ways to support  
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37 458 families with surgical uptake and post-surgical follow up.

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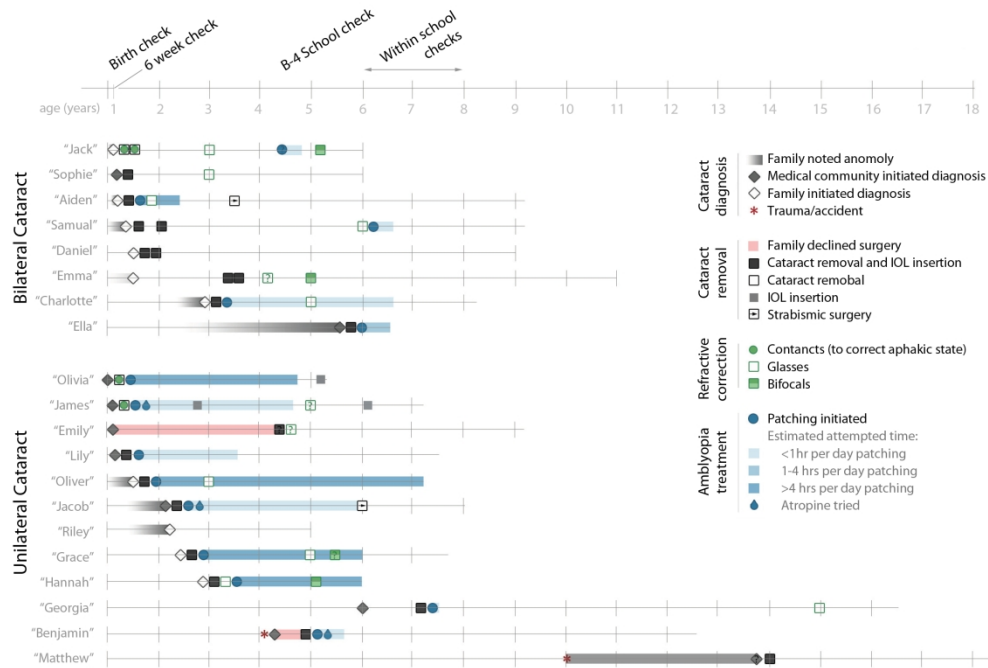


Figure 1 Timeline of treatment pathway

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 the 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

939x647mm (72 x 72 DPI)

# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title	<a href="#">#1</a>	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
	<a href="#">#2</a>	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	<a href="#">#3</a>	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	<a href="#">#4</a>	Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	<a href="#">#5</a>	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, 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.

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14	Researcher	<a href="#">#6</a>	8
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17		Researchers' characteristics that may influence the	
18		research, including personal attributes, qualifications /	
19		experience, relationship with participants, assumptions	
20		and / or presuppositions; potential or actual interaction	
21		between researchers' characteristics and the research	
22		questions, approach, methods, results and / or	
23		transferability	
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25	Context	<a href="#">#7</a>	6
26		Setting / site and salient contextual factors; rationale	
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28	Sampling strategy	<a href="#">#8</a>	6
29		How and why research participants, documents, or	
30		events were selected; criteria for deciding when no	
31		further sampling was necessary (e.g. sampling	
32		saturation); rationale	
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35	Ethical issues pertaining	<a href="#">#9</a>	7
36	to human subjects		
37		Documentation of approval by an appropriate ethics	
38		review board and participant consent, or explanation for	
39		lack thereof; other confidentiality and data security issues	
40	Data collection methods	<a href="#">#10</a>	7
41		Types of data collected; details of data collection	
42		procedures including (as appropriate) start and stop	
43		dates of data collection and analysis, iterative process,	
44		triangulation of sources / methods, and modification of	
45		procedures in response to evolving study findings;	
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50	Data collection	<a href="#">#11</a>	7
51	instruments and		
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53		Description of instruments (e.g. interview guides,	
54		questionnaires) and devices (e.g. audio recorders) used	
55		for data collection; if / how the instruments(s) changed	
56		over the course of the study	
57	Units of study	<a href="#">#12</a>	6-7 and
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participation (could be reported in results)

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Figure 1)

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4	Data processing	<a href="#">#13</a> 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
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11	Data analysis	<a href="#">#14</a> 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
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18	Techniques to enhance trustworthiness	<a href="#">#15</a> Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8
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23	Syntheses and interpretation	<a href="#">#16</a> 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
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28	Links to empirical data	<a href="#">#17</a> Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Tables 2-4
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32	Intergration with prior work, implications, transferability and contribution(s) to the field	<a href="#">#18</a> 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
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42	Limitations	<a href="#">#19</a> Trustworthiness and limitations of findings	17-18
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44	Conflicts of interest	<a href="#">#20</a> Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	8 and 18
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50	Funding	<a href="#">#21</a> 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?

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024869.R1
Article Type:	Research
Date Submitted by the Author:	24-Oct-2018
Complete List of Authors:	Hamm, Lisa; University of Auckland, School of Optometry and Vision Science Boluk, Karla; University of Waterloo, Recreation and Leisure Studies Black, Joanna; University of Auckland, Optometry and Vision Science Dai, Shuan; University of Auckland School of Medicine, Ophthalmology; Auckland District Health Board, Ophthalmology Thompson, Benjamin; University of Waterloo, Optometry and Vision Science
<b>Primary Subject Heading</b>:	Ophthalmology
Secondary Subject Heading:	Paediatrics, Patient-centred medicine, Qualitative research
Keywords:	Paediatric cataract, parental stress, semi-structured interviews, adherence

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3 1 **Title:** A phenomenological approach to childhood cataract treatment in  
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5 2 New Zealand using semi-structured interviews: How might we  
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7 3 improve provision of care?  
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10 4 **Running head:** Family experience of childhood cataract treatment  
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12 5 **Word count:** 4328  
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15 6 **Authors:**  
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17 7 Lisa Hamm<sup>1</sup>, Karla Boluk<sup>2</sup>, Joanna Black<sup>1</sup>, Shuan Dai<sup>3</sup>, Benjamin Thompson<sup>1,4</sup>  
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31  
32 17 **Author Contributions**  
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34 18 LH, JB, SD and BT designed the study. LH and SD recruited the participants. LH conducted the  
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36 19 interviews and transcribed the data. KB and LH independently coded and analysed the  
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38 20 transcribed data, and then interpreted the data in an iterative manner. LH wrote the first draft  
39  
40 21 the manuscript, and all authors assisted with revisions. All authors were involved in the final  
41  
42 22 proofing process and agreed to be accountable for the content of the manuscript.  
43

44 23 **Acknowledgements**  
45

46 24 We would like to thank all the families who took the time to talk to us about their experiences,  
47  
48 25 as well as David Welch for his early contributions to the project.  
49

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2  
3 28 **Financial support:** Lisa Hamm was supported by Education New Zealand. Education  
4  
5 29 New Zealand had no role in data collection, interpretation or  
6  
7 30 reporting.

8  
9 31 **Conflict of interest:** None of the above authors have any proprietary interests or  
10  
11 32 conflicts of interest related to this submission.  
12  
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17 34 **Keywords**

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19 35 Paediatric cataract, parental stress, semi-structured interviews, adherence  
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24 37 **Data Statement**

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25  
26 38 Full transcripts of interviews are not available to protect participants' anonymity  
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## 40 Abstract

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

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

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

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

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

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

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3 63 **Article Summary**  
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5 64 **Strengths and limitations of this study**  
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7 65 *Strengths:*  
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- 9  
10 66 • Informants had a broad range of experiences, from very positive to very negative, likely  
11 to reflect the diversity of the cohort of interest.  
12 67  
13 68 • Data from interviews were rich and themes converged across diverse experiences.  
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16  
17 69 *Limitations:*  
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- 19 70 • The impact of culture was not a specific focus of the interviews. Our iterative analysis  
20 indicated that cultural factors may enhance understanding of families' experiences. This  
21 71 is recommended as an area of further research.  
22 72  
23 73 • The authors are generally invested in adherence with ophthalmological  
24 recommendations. This bias is clearly stated in our purpose.  
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## 76 Introduction

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

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

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3 104 factors including early detection, prompt uptake of surgical intervention, and dedicated  
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5 105 commitment to follow up care by the family and medical community (for discussion see<sup>15 26</sup>).

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8 106 Each step in the treatment pathway for childhood cataract has been investigated, including  
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10 107 screening<sup>19 27-30</sup>, factors contributing to delayed utilization of surgical services<sup>31</sup>, parental stress  
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12 108 associated with childhood cataract treatment<sup>32 33</sup>, compliance with amblyopia treatment<sup>34-38</sup>  
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14 109 and the impact of cataract removal on quality of life<sup>7 39</sup>. Across this international body of work,  
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16 110 the services that are available, affordable, and accepted by the community being studied vary  
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18 111 considerably. Studies of social barriers to accessing care, delayed cataract removal and poor  
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20 112 follow up tend to be done in lower income countries<sup>7 19 31 40</sup>, whereas research into issues such  
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22 113 as increasing adherence with amblyopia treatment, tend to cluster in higher income countries<sup>25</sup>  
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24 114 <sup>34-37</sup>. The research generally reflects the predominant hierarchical needs within communities<sup>41</sup>.  
25  
26 115 However, socio-economic disparities exist within even high-income countries and there is  
27  
28 116 growing recognition that wider research is needed to allow the best visual outcomes for all  
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30 117 children<sup>38 41</sup>.

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32 118 In this study, we were interested in the experience of childhood cataract in Auckland, New  
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34 119 Zealand (NZ), where ethnicity is diverse (67% European, 15% Maori, 11% other, 9% Asian, 7%  
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36 120 pacific peoples, 1% Middle Eastern/Latin American/Africa - from 2006 census data), and  
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38 121 advanced ophthalmological services are now well established and publicly funded. In the early  
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40 122 1970s cataract accounted for 22.5% of the children registered as blind in NZ<sup>42</sup>, whereas a more  
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42 123 recent report indicates substantial improvements in the treatment of childhood cataract, with  
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44 124 only approximately 4% of children experiencing blindness or low vision attributed to childhood  
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46 125 cataract<sup>43</sup>. There is likely further room for improvement, with a recent report suggesting  
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48 126 detection of childhood cataract is suboptimal<sup>30</sup>. There is no published research in NZ about  
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50 127 adherence with follow up or the extent of secondary amblyopia following childhood cataract  
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52 128 surgery. In the current study we aimed to understand how childhood cataract and its treatment  
53  
54 129 impacted NZ families, as a starting point to address potential gaps in the system. A qualitative  
55  
56 130 study in the USA found that 'treatment' itself was one of 6 key themes decreasing quality of life  
57  
58 131 for children with a history of cataracts<sup>39</sup>. Our project probes this idea by focusing on families'

132 lived experience (phenomenology) throughout the treatment pathway. Our aim was to identify  
133 sources of distress which 1) could be addressed by the medical community and 2) related to  
134 adherence with recommendations from their ophthalmologist.

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## 136 **Methodology**

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### 137 **Study context**

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

### 148 **Patient and Public Involvement**

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

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### 157 **Participant recruitment**

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3 158 In phenomenological studies a purposive sampling strategy is supported in order to recruit  
4  
5 159 participants who have experienced the phenomenon under study<sup>46</sup>. Accordingly, research  
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7 160 participants were intentionally contacted following a medical records search. Inclusion criteria  
8  
9 161 included history of a visually significant paediatric cataract (congenital, developmental and  
10  
11 162 traumatic cases) and a current age of at least four. Exclusion criteria included severe  
12  
13 163 developmental disorders or severe ocular disease unrelated to paediatric cataract, noted on  
14  
15 164 ophthalmological records. Invitation letters were posted to thirty-nine parents resulting in  
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17 165 seventeen positive responses, each of whom were invited to participate in the study, including  
18  
19 166 one parent of a non-verbal child with autism (autism was not diagnosed around the time of  
20  
21 167 cataract surgery). One additional family made contact independently; their son had not had  
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23 168 surgery to remove his cataract. Two additional families were made aware of the project  
24  
25 169 through their specialist. A total of twenty semi-structured interviews were carried out. The  
26  
27 170 study complied with the tenets of the declaration of Helsinki and was approved by ethics  
28  
29 171 committees from the University of Auckland and the Auckland District Health Board.  
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31 172 Participants provided informed consent, and children who were able provided assent.

### 31 173 **Semi-Structured interviews**

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34 174 Interviewing is the primary data collection strategy in phenomenological studies<sup>46</sup>. As such,  
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36 175 semi-structured interviews were employed focussing on the lived experiences and personal  
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38 176 perceptions of the treatment process for childhood cataract and secondary deprivation  
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40 177 amblyopia. Interviews were conducted in a private location of the participant's choice and audio  
41  
42 178 recorded (except in one case due to excessive background noise). We requested that both  
43  
44 179 caregivers and the affected child were present, and we encouraged all attendees to contribute  
45  
46 180 to the conversation. Interviews were approximately one hour in length for each family, but  
47  
48 181 varied in an attempt to obtain rich data. Semi-structured interviews were transcribed by the  
49  
50 182 first author. Potentially identifiable information was removed or anonymized, and pseudonyms  
51  
52 183 were assigned (pseudonyms reflect most common NZ names for birth year). The approximate  
53  
54 184 timing of key treatment events were derived from each interview (narrative summary) and used  
55  
56 185 to provide context for understanding phenomenology (lived experience).

## 186 Phenomenology

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

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

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

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3 214 negative and positive experiences of the emergent themes. Therefore the themes presented  
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5 215 reflect encouragement to families at their best, and exasperated distress at their worst.  
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For peer review only



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## 218 Results

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### 219 Narrative summary

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

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

234 The experience with home implementation of follow up treatment was diverse. Although no  
235 families noted cost of glasses, contacts or patches to be prohibitive, parents expressed concern  
236 that acquiring these items and navigating subsidies was complicated and could be stressful. For  
237 those who used glasses, feedback was very positive, except for the one participant prescribed  
238 glasses in her teenage years (Georgia), who felt uneasy with the aesthetic aspects of wear. Only  
239 children with very early surgery used contact lenses instead of an intraocular lens (IOL). Of the  
240 six surgeries done before six months of age, half (Olivia, James and Jack) remained aphakic and  
241 used a contact lenses rather than IOLs. Each of these families described the use of the contact  
242 lenses as the most distressing part of their experience, with two of the three families describing  
243 traumatic events related to inserting, removing and/or losing contact lenses. These two families  
244 advocated for further support or re-structuring of contact lens use. Patching experience ranged  
245 from none (including children with bilateral cataracts who had equal visual acuity loss in both

246 eyes, and children with unilateral cataract who were given a very poor prognosis), to four hours  
 247 per day over several years (Olivia, Oliver, Grace and Hannah). The most challenging aspect of  
 248 care was described as patching, only superseded by use of contact lenses in infancy in the small  
 249 subset of children for whom it was required.

250

251

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

253

### 254 **Phenomenological summary**

255 Three themes and several sub-themes emerged from the phenomenological analysis related to  
 256 how the medical system might better mitigate parental distress and encourage adherence.

257 These are summarized in Table 1.

258

259 **Table 1. Summary of themes and sub-themes**

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

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For peer review only

### 262 ***Improved detection and diagnosis***

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

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

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

283

284

285 **Table 2. Improved detection and diagnosis.** Examples of positive (left column) and negative  
 286 (right column) experiences relating to timing of diagnosis.  
 287

A – Red reflex screening test	
<i>She's been a midwife for ages, and because of that experience, she picked up it. (Lily's mother)</i>	<i>We were pretty angry at our midwife because we felt that she should have picked that up. (Jack's mother)</i>
B – Referrals and process	
<i>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)</i>	<i>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)</i>

288

289

### 290 **Communication with the medical community**

291 Once diagnosed, the relationship a family had with the specialist, and to a lesser degree, the  
 292 allied medical staff, was an important part of their experience, permeating across treatment  
 293 events. While some families lit up while describing the kindness and competence displayed by  
 294 the medical professionals they had come to know well, others relived the anger and frustration  
 295 when reflecting on their interactions with the medical community. Rapport between the  
 296 parents and the specialist appeared to be particularly important, as it formed the foundation of  
 297 the ongoing relationship with the medical team. If there was a connection made and trust

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3 298 established (Table 3A) discourse was positive, whereas if a family was put off by the specialist  
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5 299 (Table 3B) the treatment pathway was impaired if not halted.  
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8 300 Beyond rapport, provision of understandable information about the condition was critical.

9  
10 301 What level of information was understandable varied between informants. Some families had a  
11  
12 302 scientific background, and could appreciate a detailed technical explanation while others had  
13  
14 303 limited background knowledge. Across this spectrum of varied backgrounds, effective  
15  
16 304 communication allowed sufficient understanding for the family to feel comfortable with  
17  
18 305 recommendations. In Table 3B, we provide examples of two informants for whom  
19  
20 306 understanding of the condition directly influenced uptake of surgery.

21  
22 307 Appropriate, understandable communication was also important for parents to prepare for  
23  
24 308 potential future events. When families became exasperated with home based aspects of  
25  
26 309 treatment, those who were prepared in advance (Table 3C - left) were more resilient to the  
27  
28 310 setbacks. On the other hand, families who had not anticipated the challenges, or were not  
29  
30 311 provided useful information to face these challenges in advance (Table 3C – right) became  
31  
32 312 increasingly distressed by them, and lost trust in the system.

33  
34 313 Whether the communication between the medical community and the parent was perceived as  
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36 314 positive was individualized and nuanced, but across participants it included aspects of rapport,  
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38 315 clear communication about the condition and of upcoming potential challenges.

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318 **Table 3. Communicating with medical community.** Examples of positive (left column) and  
 319 negative (right column) experiences relating to communication.  
 320

A - Building rapport	
<i>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>	<i>I don't want to go to [...] anymore. He's quite 'nothing can be done, nothing can be done' (Riley's mother)</i>
B – Provision of information about cataract and deprivation amblyopia	
<i>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>	<i>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)</i>
C - Foresight about the treatment pathway	
<i>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)</i>	<i>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)</i>

321  
 322 **Social support**  
 323 Throughout the interviews, it became apparent that provision of care improved if the medical  
 324 community understood the family's social context. This includes perspectives or values held by  
 325 an individual family and the resources available to them. Advice that parents received from  
 326 friends or family was an important part of their social context. Families whose social networks  
 327 encouraged them to engage with the medical system were likely to move forward with

328 recommendations (example in Table 4A - left). On the other hand, some social networks were  
329 sceptical of the medical community, making it difficult or distressing for parents to seek, or act  
330 on, medical advice. Families who felt tension between the advice from the medical community  
331 and the advice from friends and family experienced an increased burden during an already  
332 challenging time (Table 4A - right).

333 Beyond social networks overtly advising with or against medical advice, there was an important  
334 emotional and practical role for this extended group. It was not specifically stated that a phone  
335 call from a friend, or an offer to baby-sit other children directly mitigated distress or delays  
336 along the treatment pathway, but the absence of this type of support appeared to be associated  
337 with both. For example, Benjamin's mother wanted to go through with cataract removal surgery  
338 initially, however, she was pregnant and did not have support from her family network (Table  
339 4B – right). Like Benjamin's mother, Emily's mother initially declined surgery. However she was  
340 able to revisit this decision when she had more emotional and practical support (Table 4B - left).  
341 Families were almost ubiquitously overwhelmed at some point during diagnosis or during  
342 amblyopia treatment, and only some had the emotional and practical support they needed to  
343 follow through with recommendations. It is of particular note that contact lens use required  
344 additional practical support; Olivia and Jack's families described requiring 2 or more adults to  
345 extract the contact from their infant's eye. Both families had excellent adherence at all stages of  
346 the treatment pathway, and substantial support networks.

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

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354



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

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#### 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)

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## 360 Discussion

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

## 365 Strengths and Limitations

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

376 However, there were some limitations in our design and analysis. The phenomenological  
377 approach does not prioritise counting the frequency with which certain experiences occur.  
378 However, it is of interest to know for example, how often parents decline available cataract  
379 surgery, or how many families were able to comply with occlusion therapy. We addressed this  
380 briefly by including such details in our 'narrative summary'. However, such quantitative  
381 questions are best answered with a different methodology. Conversely, a limitation could be  
382 that we did not go deep enough into respondents' experiences. For example, during the  
383 interviews we did not focus specifically on cultural frameworks for health. Upon iterative  
384 reflection it was our impression that a deep understanding of culture may have facilitated our  
385 understanding of informant's experiences. Further expanding on this, perhaps a symbolic  
386 interactionism theoretical perspective would be a valuable direction for future research in order  
387 to understand underlying cultural reasons for choices. Furthermore, we started with the belief

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2  
3 388 that adherence with ophthalmological recommendations is the best for children. Therefore  
4  
5 389 discussion around whether a parent's decision to decline surgery or cease patching was in fact  
6  
7 390 best for the child was outside the scope of this project. Similarly, parental motivation was not a  
8  
9 391 focus of our analysis, but is part of the theoretical framework related to adherence<sup>51</sup>. Following  
10  
11 392 up with participants on these points as part of our dissemination step will be a good opportunity  
12  
13 393 to enhance future research.

#### 14 15 394 **Summary and Implications of findings**

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17  
18 395 The varied experiences of the diverse informants we interviewed revealed opportunities for  
19  
20 396 systemic improvement in childhood cataract treatment. Early detection and prompt medical  
21  
22 397 treatment are critical for good visual outcomes<sup>21 22</sup>. Delayed detection was a perceived issue for  
23  
24 398 many of our informants. More effective implementation of the red reflex exam may improve  
25  
26 399 this situation<sup>18 29</sup>. Survey data from practitioners in New Zealand reflected this opportunity for  
27  
28 400 improvement, specifically highlighting the value of better training for those administering early  
29  
30 401 eye exams<sup>30</sup>. Our work supports the value of such an initiative.

31  
32 402 Addressing issues that are social rather than organizational is perhaps more complex. The  
33  
34 403 experiences expressed by our informants suggest that improved communication between the  
35  
36 404 patient and the health care community, and promoting strong social support networks are  
37  
38 405 particularly important. These are not new ideas. Literature concerned with chronic pediatric  
39  
40 406 conditions have described similar phenomena. For example, Shudy et al.<sup>52</sup> highlighted the  
41  
42 407 importance of a 'sense of partnership with the staff' mirroring the second emergent theme in  
43  
44 408 our analysis. Similarly, Jackson et al.<sup>53</sup> discuss how close social support networks improve coping  
45  
46 409 in families of children with brain tumours, with ideas closely related to our third theme of social  
47  
48 410 support. Within our cohort, the impact of these factors was most dramatic in relation to uptake  
49  
50 411 of surgical services. Within the themes of communication and social support, the specific  
51  
52 412 concerns these families raised reflect barriers experienced in lower resources areas. These  
53  
54 413 include indirect costs such as travel<sup>31 41</sup>, lack of appropriate information<sup>11 31</sup>, beliefs about  
55  
56 414 health<sup>31</sup> and/or the parent targeted for education not having decisional power<sup>31</sup>.

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2  
3 415 In addition to these poignant cases in which surgery was declined, additional families in our  
4  
5 416 cohort felt overwhelmed at various stages of the treatment pathway, particularly when  
6  
7 417 attempting patching and contact lens wear (struggles more consistent with the literature from  
8  
9 418 higher resourced countries). Contact lens use in infants (and to a lesser degree patching) has  
10  
11 419 been associated with higher levels of parental stress<sup>33</sup>. Parental stress is known to contribute to  
12  
13 420 decreased adherence with amblyopia treatment in cases of strabismic and anisometric  
14  
15 421 amblyopia<sup>37</sup>. These ideas appeared to be consistent with accounts from our informants. Again,  
16  
17 422 good communication and strong social support appeared to mitigate these factors. Although  
18  
19 423 care must be taken when generalizing, we suggest that perhaps communication and practical  
20  
21 424 support may have been factors which account for the difference between the results of Drews  
22  
23 425 et al<sup>33</sup> which revealed an association between the use of contact lenses following paediatric  
24  
25 426 cataract surgery and parental stress and those of Celano et al<sup>32</sup> which did not. Notably, the data  
26  
27 427 reported by Celano et al<sup>32</sup> were collected in the context of a clinical trial, in which extensive  
28  
29 428 information and practical support were provided.

30 429 Although all families found parts of the treatment pathway challenging at times, cultural socio  
31  
32 430 economic factors appeared to exasperate the challenges. Some work suggests that if a family  
33  
34 431 does not feel connected with the dominant society (or the person representing the society as  
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36 432 the medical professional) their child is less likely to adhere to treatment for amblyopia<sup>38</sup>. In our  
37  
38 433 diverse cohort the concept appeared to extend beyond patching to cataract removal, which has  
39  
40 434 more substantial consequences. Although there were many professionals involved in patient  
41  
42 435 care, paediatric ophthalmologists were generally seen as the primary providers of information.  
43  
44 436 This means the demand on a single specialist of providing sensitive, individualised support to a  
45  
46 437 diverse community may be significant.

47 438 In some cases print materials can help supplement communication of important information  
48  
49 439 and encourage treatment compliance<sup>36</sup>, however information alone is often insufficient to  
50  
51 440 promote action<sup>54</sup>. Patient care may benefit from the provision of accurate information and  
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53 441 practical support from different professionals. Some research has described the role of a  
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55 442 'childhood blindness coordinator' to be particularly beneficial to fill this gap<sup>40 55</sup>. This role can

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2  
3 443 involve helping parents understand the condition, providing foresight about the treatment  
4 444 pathway, as well as providing practical support such as text message reminders and travel  
5 445 planning<sup>55</sup>. In terms of emotional support, formal networks tend to be less effective than  
6 446 informal support networks<sup>53</sup>. However, Ireys et al. showed the benefit of peer support groups  
7 447 for mothers of children with chronic illness<sup>56</sup>, and Emily's family provides a good example of  
8 448 how a caring community volunteer can provide effective support. Research within the childhood  
9 449 disability service in New Zealand has suggested the role of a 'cultural case worker' may facilitate  
10 450 both improved communication and supplement social support for families with culturally or  
11 451 linguistically diverse backgrounds<sup>57</sup>, working as 'patient advocates' rather than expert medical  
12 452 staff. These are all avenues that could be further explored to help families dealing with  
13 453 childhood cataract.

14 454 Although the system for childhood cataract treatment in NZ is technically robust, it does not  
15 455 appear to have sufficient support for families who are unable to effectively advocate for  
16 456 themselves. The current study suggests strategies from research in lower income countries may  
17 457 help some NZ families. Examples are the community roles of 'key informants' and 'childhood  
18 458 blindness coordinators', which facilitate education, detection process, and communication. New  
19 459 Zealand has organisations that could fill these roles, such as the Blind and Low Vision Network  
20 460 New Zealand (BLENNZ, which provides comprehensive support for children, from infancy to 17  
21 461 years of age, with moderate to severe visual impairment) and social workers or caseworkers.  
22 462 However, their services are not well utilized by families due to the lack of awareness among  
23 463 general population and medical practitioners. Better training for midwives, pediatricians and  
24 464 general practitioners for early detection and referral as well as better awareness of existing  
25 465 support services are likely to be important steps towards improving provision of care for  
26 466 childhood cataract.

## 27 467 **Conclusion**

28 468 Childhood cataract is a rare and challenging condition<sup>15 16 26</sup>, its treatment requires much from  
29 469 families during what is already an overwhelming phase of life. Our work suggests that  
30 470 availability of surgery and funding for secondary costs for those who need it is insufficient to

1  
2  
3 471 achieve the best visual outcomes for NZ children with cataracts. We need to improve screening  
4  
5 472 practices, including streamlining referral pathways to specialised paediatric ophthalmologists.  
6  
7 473 We need to find ways to communicate effectively with diverse families, ensuring the condition  
8  
9 474 and its treatment is understood and family's questions are answered. Finally, we need to  
10  
11 475 consider creative ways to support families with surgical uptake and post-surgical follow up. This  
12  
13 476 requires awareness family context, including available emotional and practical support.  
14

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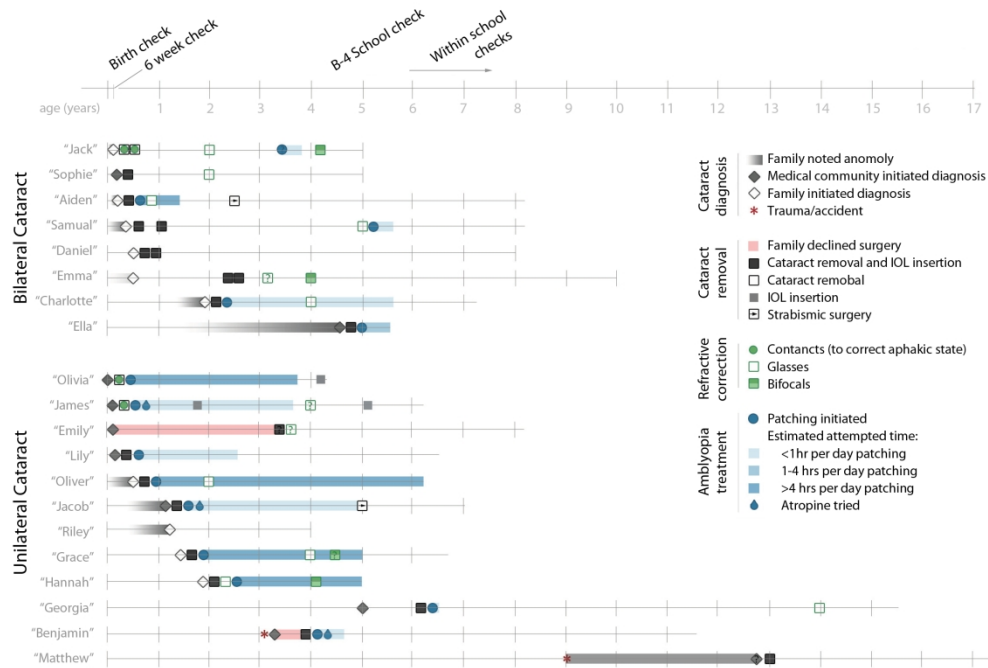


Figure 1. Timeline of treatment pathway. Participants are categorized into cases of unilateral or bilateral cataract. An asterisk by a patient pseudonym indicates a family history of paediatric cataract. Cataract diagnosis is depicted with a diamond. If a medical professional, or a community screen initiated 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

# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

## Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med.* 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title	<a href="#">#1</a>	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
	<a href="#">#2</a>	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	<a href="#">#3</a>	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5
Purpose or research question	<a href="#">#4</a>	Purpose of the study and specific objectives or questions	5
Qualitative approach and research paradigm	<a href="#">#5</a>	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, 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.

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25	Context	<a href="#">#7</a>	6
26		Setting / site and salient contextual factors; rationale	
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28	Sampling strategy	<a href="#">#8</a>	6
29		How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	
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35	Ethical issues pertaining	<a href="#">#9</a>	7
36	to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	
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40	Data collection methods	<a href="#">#10</a>	7
41		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	
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50	Data collection	<a href="#">#11</a>	7
51	instruments and	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	
52	technologies		
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57	Units of study	<a href="#">#12</a>	6-7 and
58		Number and relevant characteristics of participants, documents, or events included in the study; level of	8-9
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participation (could be reported in results)

(also  
Figure 1)

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4	Data processing	<a href="#">#13</a> 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
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11	Data analysis	<a href="#">#14</a> 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
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18	Techniques to enhance trustworthiness	<a href="#">#15</a> Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	8
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23	Syntheses and interpretation	<a href="#">#16</a> 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
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28	Links to empirical data	<a href="#">#17</a> Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Tables 2-4
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32	Intergration with prior work, implications, transferability and contribution(s) to the field	<a href="#">#18</a> 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
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42	Limitations	<a href="#">#19</a> Trustworthiness and limitations of findings	17-18
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44	Conflicts of interest	<a href="#">#20</a> Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	8 and 18
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50	Funding	<a href="#">#21</a> Sources of funding and other support; role of funders in data collection, interpretation and reporting	1
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