ORIGINAL ARTICLE

Why is compliance with occlusion therapy for amblyopia so hard? A qualitative study

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Objective: To explore parents' perceptions and experiences of occlusion (patching) therapy for treatment of amblyopia in children.
Methods: Qualitative study involving semistructured interviews with 25 families of a child with amblyopia being treated at a specialist clinic. Interviews were tape recorded and transcribed verbatim. Data analysis was based on the constant comparative method, assisted by qualitative analysis software.
Results: Parents of children prescribed patching treatment found themselves obliged to manage the treatment. This involved dilemmas and tensions, with many parents describing children's distress, particularly in the early stages of patching treatment. Parents were highly sensitive to the credibility of the treatment, but were sometimes confused by information given in the clinic or did not see clinic staff as authoritative. There was evidence that parents were likely to abandon or modify treatment if no improvement could be detected or if the child continued to suffer socially or educationally. Parents described a range of strategies for facilitating patching, including explanation; normalisation; rewards; customising the patch; establishing a routine; and enlisting the help of others. Whatever their practices in relation to patching, parents were keen to defend their behaviour as that of a ''good parent''.
Conclusions: Interventions that aim to improve compliance should take account of the difficulties and tensions experienced by parents, rather than simply treating non-compliance as resulting from information deficits. Practical support that builds on strategies described by parents is likely to be of benefit.

T he visual system has a vulnerable period during which disturbances of visual experience can cause amblyopia.[1] Amblyopia involves reduced visual acuity (VA) in the absence of organic disease and is caused by deficient visual stimulation, often resulting from strabismus or refractive error in childhood. It is the most common disease affecting VA in childhood, involving up to 4% of the general population.[2] It is a frequent cause of persistent unilateral vision loss between 60 and 80 years of age.[3] The lifetime risk of serious vision loss for the individual with amblyopia is substantial, being at least 1.2–3.3%.[4] Amblyopia is considered treatable up to about 8 years of age, and possibly beyond. It is usually treated with occlusion (patching) of the dominant eye, forcing the amblyopic eye to view and reversing the amblyopia because of the plasticity of the visual cortex in children.

There is a strong clinical belief that patching is successful, with thousands of children treated every year in the United Kingdom. However, the evidence base for patching remains equivocal, and the benefits of early detection and treatment of amblyopia have been questioned.[5] There are uncertainties over which treatment regimens are most effective, and outcome is often suboptimal.[6–9] One explanation for the continuing uncertainty over patching treatment is that many studies fail to address the issue of compliance, which is likely to influence outcomes of treatment.[10–13] Recent work has begun to show evidence of a link between compliance, effective hours patching, and outcome,[14–17] but the reasons for non-compliance remain poorly understood. We aimed to use qualitative methods to explore families' experiences of attempting to patch children who had been diagnosed with amblyopia.

METHODS

This study was approved by Leicestershire research ethics committee. Families where a child was prescribed patching at

a specialist clinic in the East Midlands were selected to represent a range of children's ages, ethnicity, and social class.

Informed consent was obtained from participants after explanation of the study. Semistructured interviews were conducted either in families' homes or at the clinic (according to parental preference), with one or more parents. Interviews explored parents' perceptions of amblyopia and its treatment, and their experiences of patching, using a prompt guide that had been developed following a review of published reports, pilot interviews, and discussions within the study team. The prompt guide was used flexibly in response to the directions in which participants wished to take the interview. All interviews were tape recorded and transcribed verbatim.

Data analysis was based on the constant comparative method.[18] Analysis began with open codes describing each unit of meaning within the transcripts, and included the use of in vivo codes based on the terms used by participants themselves, as well as more conceptual codes. Through careful comparison across transcripts, the open codes were developed and refined into organising themes or categories, which provided the coding frame for analysis. Assignment of data to codes was undertaken by MA using QSR N5 software,[19] and was independently validated by MDW.

RESULTS

In all, 28 families were approached for study participation and 25 agreed. Of the families interviewed, 10 children prescribed patching were male and 15 female, with a mean age of 5.72 years (range 2 to 8 years). Nineteen interviews were conducted with mothers, one interview with a father, and five interviews with both parents. Five families were single parent and in 20 families two adults were living together. Fifteen parents were of white British ethnicity and the remainder were of varying ethnicities. The mean duration

of patching at the time of interview was 18.7 months (range 3 months to 5 years). Outcome of patching therapy was variable.

Problems with patching

For both children and their carers, patching was reported to be generally a difficult experience, particularly at the beginning of treatment. Attempts to make children wear the patch were reported to result in often extreme emotional reactions from the children. A prominent problem was the visual impact of wearing the patch, which caused children to struggle with everyday life, routine activities, and school-work. Wearing the patch was also perceived to have significant social impact, including an increased risk of teasing.

> She used to cry every morning because she wouldn't wear it. [...] was very upset, she didn't want it done at all (participant 13).
> She's in school. When she is doing a lesson, when she is playing with her friends, she's not normal. We can see by her face... she thinks that she's disabled, so she can't do everything that she wants to do (participant 12).

In order to comply with the treatment, parents had to tolerate their child experiencing some degree of distress in the present in return for a possible improvement in vision in the future. Many parents reported that insistence on the patch resulted in significant strain in their relationships with their child.

> Took us weeks to get him used to keeping the patch on, it wasn't a good experience to me seeing my child disturbed (participant 15).

Participants found supporting their child through the initial stages of patching time consuming, especially because children often required additional supervision and attention while patching. The problems associated with compliance meant that it was important to parents that the treatment plan appeared credible. Some had difficulty in understanding or accepting the rationale behind patching, and were baffled or confused by explanations given in the clinic. These parents had trouble in understanding the role of different professionals in the clinic, and sometimes did not recognise or accept that either the diagnosis or the treatment was being given by an authoritative individual. Evidence that their efforts were being rewarded with demonstrable improvements in the child's vision at clinic visits encouraged parents to persevere. However, if no improvements were evident, parents were at risk of becoming alienated.

> When we first went, she did the eye chart and she could barely read the eye chart [....] to me a very important part was the fact that I know there was something happening and something being done. [...] every single time the eye test was done on her, her eyesight [...] had improved (participant 3)
> All the time I am going [to the clinic], and you know alphabet chart and so M is sitting in the chair, and I am say, 'One line, two line, three line, four line.' And it is in the same position. So, why take, why do I go all the time because not improved it is always in the same position, and at the hospital and sitting near the chart and that's it, the alphabet, and uh, ten, fifteen minutes, they say, 'Not improved.' (participant 7)

Some parents who were unable to see improvements in their child's vision decided to abandon patching altogether and focus on other more obviously present priorities. Importantly, parents' accounts emphasised that whether or not they complied with the prescribed treatment, they felt they were doing their best for their child.

> Because he didn't seem to have like a childhood, he couldn't play with other children outside because he kept falling over. [...] So, basically it's just a decision because on our back, because I don't want his schoolwork to slip. [...] I think patching for him has not worked. Doesn't matter how long you patched him for, just him. It's just his eyes not responded to that. And we've lost hope (participant 14)

Similarly, emphasising their status as ''good'' parents some participants modified the prescribed treatment in order to find a balance between their child's current and future needs.

> I wouldn't take him to school in it. [...] He probably would [go to school with patch on] but I myself wouldn't want him to.[...] 'Cause you can get some kids who are really spiteful, and I don't want him to go through that when he doesn't really need to (participant 11).
> She gets everything. So, she starts crying and we stop, stop patching. Sometimes it is our fault (participant 12).

Strategies to support patching

Accounts suggested that participants made often strenuous efforts to get their child to adhere to the patching regime prescribed. Analysis suggested that six main types of strategy could be distinguished: explanation; normalisation; rewards; customising the patch; establishing a routine, and enlisting the help of others.

Explanation

Many parents attempted to provide explanations to their children (especially older children) about why patching was necessary, and to tell them about improvements in vision.

> We just told her it was for her own good and she'd benefit from it and that's it really [important]. Because they want to know why they've got to wear it, don't they? (participant 9)

Rewards

Gifts and treats or reward charts were popular methods of encouraging children to wear the patch. Some parents encouraged their child with attention and praise, and some made the wearing of a patch into a game, though others preferred not to make a ''big deal'' out of the patch.

> at the moment because he's wearing all day for school, he is having a reward system, we're putting money in his box so as he can buy himself an engine for his train (participant 4)

Normalisation strategies

Parents reported attempting to normalise the patch by wearing a patch themselves, or getting siblings, friends and toys to wear a patch. However, what appeared to make

wearing the patch most acceptable to the children was being with other children who were wearing a patch.

> we got the other girls wearing them…(laughs) the other day all the others girls were wearing one for a bit. (Participant 1)

Customising the patch

Many children and parents disliked the appearance of the standard patch, which was pinky-beige in colour and resembled a sticking plaster. Allowing children to choose a different type of patch or a sticker to put on the patch was found to be very helpful in giving children a measure of control and ownership.

> […] she's a lively little girl, she don't really care, and when she started school she didn't really care, she jumped on the bus and went, ''Look I'm a pirate'' an' the stickers, you know, the stickers they get for the chart, she always put one on, on her patch, and so everybody wanted a sticker … (participant 5)

Establishing a routine

Parents who reported being able to patch successfully had been able to integrate the wearing of the patch into well structured routines, perhaps particularly those outside the home.

> So what we did was we introduced the patching to coincide with her starting date at the nursery. […] Just to have it integrated as part of her daily routine and to be in a situation where she had a lot going on, once she'd got the patch on (participant 16).

Enlisting support of others

Integration of patching into a routine outside the home required that parents enlist the support of others, particularly teachers and daycare workers. These individuals were important in various aspects of patching including: establishing the routine for the child; applying and removing patches; educating the child's peers; preventing teasing; rewarding patching; and minimising the effects of the visual problems caused by the patch, for example by allowing the child to sit at the front of the class or providing one to one help.

> he's been picked on by a year five girl and called him 'one eye' and names as well…[…] And then what I've done is I've gone straight down to the teacher and then we dealt it that day […] then that was it. Never picked on again. (Participant 15).

However, some teachers and day care workers were better prepared than others to help with patching, and some required support from parents.

Two accounts included counterproductive strategies deployed by children for dealing with the patch. One child was allowed to peep round the patch and another accepted the patch but slept for much of the prescribed time.

DISCUSSION

Patching as a means of treating amblyopia has often shown disappointingly modest improvements, and it is likely that at least some failures of patching are because of non-compliance with prescribed treatment. Our qualitative study provides insights into the reasons why parents find patching difficult. Parents of children prescribed patching treatment found themselves obliged to facilitate the strategic management of the treatment. This role involved dilemmas and tensions, with many parents forced to endure causing distress and other possible negative outcomes, including relationship strain, if they insisted on persisting with patching treatment. Parents were highly sensitive to the credibility of the treatment, and there was evidence that they were likely to abandon treatment if no improvement could be detected or the child continued to suffer socially or educationally. Credibility seemed particularly contingent on demonstrations of improved vision. These findings provide some possible indications that compliance may in part be a marker for amblyopia that is treatable.

Previous work has not produced a consensus on the psychosocial impact of amblyopia,[20][21] but our study suggests that a focus on psychological wellbeing and distress may not capture all dimensions of the experience of caring for a child with amblyopia. Parents' accounts in our study showed that they were concerned to ensure that their child ''passed as normal'' and sought to avoid the stigma[22] associated with wearing a patch, particularly where it might result in teasing by other children. Parents found themselves positioned as ''alert assistants,''[23] acting to protect their child's identity as ''ordinary.''[24] This tension between ensuring their child's welfare in the present and their role as the guardians of their child's future[25] was fraught with difficulty and resulted in some parents abandoning or modifying the regimen. It is important to note that whatever their practices in relation to patching, parents were keen to defend their behaviour as those of a ''good parent'' and their accounts may in part be seen as demonstrations of adequate parenthood.[26] These findings suggest that efforts to improve compliance must take account of the difficulties and tensions experienced by parents rather than simply treating non-compliance as resulting from information deficits.

Our study does have some limitations, including its location in a single clinic. It relies on accounts of behaviour rather than direct observation, and we were unable to test directly whether parents' accounts of successful strategies did reflect their actual practice or result in improved visual outcomes. However, our findings do point to some of the ways in which compliance might be facilitated, by indicating some of the strategies that parents themselves have found useful. These include explanation, normalisation, rewards, customising the patch, establishing a routine, and enlisting the help of others. For all of these strategies, there are practical forms of support that can be provided by professionals who treat amblyopia. For example, it may be very useful for parents to be enabled to offer ways of making the patch more attractive and personal to children, and professionals can help with this by ensuring that alternatives to the standard patch are provided. It is also clear that written information and other support is required for teachers or daycare workers who may be involved in looking after children who are patching. A simple intervention—such as a booklet—that would help parents explain patching to their children and offer some guidance on strategies for engaging their child's cooperation might also be very helpful.

What is already known on this topic

- Amblyopia is the most common problem affecting visual acuity in childhood, and occlusion (patching) therapy is commonly prescribed, but has often shown disappointing results
- Some poor outcomes of patching treatment may be caused by non-compliance, but the reasons for non-compliance are not well understood

What this study adds

- Parents find it difficult to comply with patching treatment for a wide range of reasons, and not simply because of information deficits
- Future interventions should focus on strategies that parents themselves find useful, including explanation, normalisation, rewards, customising the patch, establishing a routine, and enlisting the help of others

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Competing interests: none declared

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