

## Clinicians' perspectives of health-related quality of life (HRQoL) implications of amblyopia: a qualitative study

JILL CARLTON MMedSci (Orthoptics) BMedSci (Orthoptics)

*Health Economics and Decision Science (HEDS), School of Health and Related Research (SchARR), University of Sheffield, Sheffield*

### Abstract

**Aim:** The health-related quality of life (HRQoL) implications of amblyopia and/or its treatment have been reported. However, the clinician's perspective has not previously been explored. The purpose of this study was to explore the HRQoL implications of amblyopia and/or its treatment from a clinician's perspective.

**Methods:** Three focus group sessions were conducted with practising orthoptists. Thematic content analysis was undertaken, to identify HRQoL themes associated with amblyopia and/or its treatment.

**Results:** Nine HRQoL themes associated with amblyopia and/or its treatment were identified. These were adult quality of life issues, hospital appointments, appearance, glasses-wear, patching treatment, atropine treatment, limitation of activities, relationships within the family, and treatment compliance.

**Conclusions:** The HRQoL implications of amblyopia and/or its treatment were similar to those identified in the literature. Participants acknowledged a change in societal attitudes towards glasses and patching, with glasses becoming more socially acceptable. Further research is needed to explore the exact impact of amblyopia and/or its treatment from both the child's and the parental perspective.

**Key words:** Amblyopia, Health-related quality of life (HRQoL), Orthoptist, Qualitative

### Introduction

Amblyopia is an important visual condition which occurs in childhood that can affect up to 5% of the general population.<sup>1–7</sup> Screening programmes currently exist within the United Kingdom (UK) and world-wide to identify children who have, or are at risk of developing, amblyopia. Once amblyopia is diagnosed, treatment is prescribed. This is typically undertaken before the age of 8 years – an important period for a child's physical and emotional development. A number of treatment options exist for amblyopia, which can include glasses-wear, occlusion (patching), atropine, or a

combination of two or all of these. Amblyopia treatment within the UK is typically managed by ophthalmologists and orthoptists.

The evidence relating to the impact of amblyopia on health-related quality of life (HRQoL) has recently been examined.<sup>8</sup> Literature suggests that the condition and (its treatment) do affect the individual and family members.<sup>9–16</sup> However, the way in which amblyopia treatment is administered has changed and some of the literature reporting HRQoL implications of amblyopia is dated. It is necessary to re-evaluate whether the impact of amblyopia upon HRQoL has altered as a result of changes within clinical practice.

Children diagnosed with amblyopia are treated primarily by orthoptists. Often the orthoptist is able to develop a relationship with the child and their carer, and gain insight into the issues surrounding amblyopia treatment. The purpose of this study was to explore the clinician's perceptions of the impact of amblyopia upon HRQoL; and to evaluate whether these correlate with existing evidence published in the literature.

### Methods

Previous research has reported the HRQoL implications of amblyopia and/or its treatment.<sup>8</sup> The purpose of the systematic literature review was to inform the topic guide used to facilitate focus group discussions with practising orthoptists (see Appendix). Diversity within focus groups is noted to aid discussion,<sup>17</sup> and therefore each session consisted of orthoptists with differing educational backgrounds (diploma versus degree), length of time spent working as a clinician and variation in areas of previous employment as a clinician. The format of the focus group sessions was a semi-structured discussion using the topic guide as a prompt where necessary. Three focus group sessions were held in November 2007. Two of the focus group sessions had four participants, and one had five participants; they lasted between approximately 1 hour 10 minutes and 2 hours.

Prior to the start of each focus group, participants were given an information sheet describing the purpose of the study. They were given the opportunity to ask further questions about the study and their potential involvement before the session took place. Written consent was obtained for each participant. The focus group sessions were recorded and transcribed verbatim. The transcripts were imported into QSR (QSR International, Doncaster, Australia) NVivo 8 (a computer-assisted, qualitative data

analysis software package), to manage the data and to facilitate analysis. Transcripts were then coded and thematic content analysis (analysis of the content of the focus group transcripts and a search for themes) was undertaken using Framework (an approach developed by the National Centre for Social Research).<sup>18</sup> The primary aim was to identify HRQoL themes of amblyopia and/or its treatment.

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research. Full ethics approval and research governance was obtained prior to commencement of the study (REC Ref: 07/Q1201/5, Keighley Research Ethics Committee).

## Results

Nine HRQoL themes associated with amblyopia and/or its treatment were identified. These were adult quality of life issues, hospital appointments, appearance, glasses-wear, patching treatment, atropine treatment, limitation of activities, relationships within the family, and treatment compliance. A sample of some direct quotations from the focus group participants are shown in Table 1.

### *Adult quality of life issues*

A number of HRQoL issues were raised in the focus group sessions which related to either adult activities or adult-related concepts. Issues around the impact that amblyopia may have in later life were raised. These included the impact of amblyopia upon work or profession choice; the ability to drive; and the consequences of loss of vision to the good eye (Quote 1).

### *Appointments at the hospital*

One HRQoL implication identified was the need to attend numerous hospital appointments. Issues such as parents having to take time off work, or children missing school, were highlighted (Quote 2). Some participants noted that the hospital appointments may be a positive or negative experience for both parent and child (Quotes 3 and 4).

### *Appearance*

The impact of treatment upon a child's physical appearance was also raised. This may be in the form of wearing glasses or a patch, using atropine, or a combination of these. The implications may be positive or negative in nature (Quote 5). The implications may be felt by the child directly (i.e. through teasing or bullying) or indirectly (through altered relationships with parents or guardians) (Quote 6).

### *Glasses-wear*

Participants identified that glasses-wear may be a HRQoL issue. Some believed that the permanent nature of the glasses could prompt a negative response, particularly from parents (Quote 7). Others felt that societal attitudes towards glasses had changed over recent years and that glasses themselves are much more accepted. This has been reflected in the wide range of

styles available for children, and how glasses are portrayed in the media (Quotes 8 and 9). The issue of comfort and correctly fitting glasses was also raised; some participants felt that this may affect whether a child likes to wear their glasses (Quote 10).

### *Patching treatment*

A number of HRQoL implications were identified related to patching treatment. These included the appearance of the patch, limitation of daily activities due to the visual handicap experienced when the patch is worn, the sensation of the patch on the face, and the impact of patching on relationships within the family (Quotes 11–13). These issues may be positive or negative in nature. For example, some children may enjoy the patching experience in that they get rewards from their parent or guardian for complying with treatment; or they may like the increased time they spend with their parent or guardian to be supervised during the occlusion period (Quote 14).

### *Atropine treatment*

Participants identified a number of issues relating to the implications of atropine. These were largely considering the parental perspective, in that it could be easier to administer this form of treatment in comparison with getting a child to wear their patch (Quote 15). However, other factors were raised, which may be appreciated by the child themselves. These included the non-obvious appearance of this form of treatment (compared with patching), the instillation of the atropine drops, and the effect of bright sunlight on the atropinised eye (Quotes 16 and 17).

### *Limitation of activities*

Participants stated that a child undergoing amblyopia treatment may experience difficulty in undertaking their usual activities. This may be a result of the level of vision in their amblyopic eye, or due to the nature of the treatment modality (e.g. a patch will limit the field of vision whereas atropine does not). The activities could be related to their ability to perform at school, or may include social activities and hobbies (e.g. riding a bike) (Quotes 18 and 19).

### *Relationships within the family*

Participants identified that the administering of treatment can cause negative changes to parent–child relationships and also relationships between siblings (Quote 20). Parents may find the treatment time-consuming and stressful (particularly if compliance is poor); and relationships may become more difficult in some cases (Quote 21).

However, it is possible that the instigation of treatment may improve a parent–child relationship. They get to spend more time engaging with each other (interactive play), and the child may experience praise and rewards if compliance with treatment has been good (Quote 22).

**Treatment compliance**

The issue of treatment compliance and the parental approach to treatment compliance was identified. Participants noted that the information given to parents by the clinician about amblyopia treatment does have an impact on treatment choice, and visual outcome. One participant noted that whilst the 'clinical need' may be for large amounts of daily occlusion, it was recognised that often this is not achievable (Quote 23).

The information given to parents by clinicians is

adapted to encourage treatment adherence. This can centre on techniques to encourage patch- or glasses-wear, such as star charts or other rewards. A number of the focus group participants acknowledged that in prescribing treatment, and giving advice on ways to administer patching (for example), they believed they were giving advice on 'parenting techniques'. One focus group participant stated that when treatment adherence is poor '[parents] ... feel that they're a complete failure'.

Another noted the need to ask the child themselves about their treatment, and by doing so get information as

**Table 1.** Health-related quality of life themes

HRQoL theme	Quotes
Adult quality of life issues	<i>Quote 1:</i> 'I think it is only really apparent when they get older, if they have amblyopia, that they realise that it stops them doing things later down the line: driving licences, being eligible to do certain jobs, or being able to use a microscope or a slit lamp'.
Appointments at the hospital	<i>Quote 2:</i> 'I think [for] a parent of a child that needs to bring them frequently, it must be really difficult if you work. <i>Time-consuming</i> '. <i>Quote 3:</i> 'Very few children react badly every time they come. Some of them are frightened the first time, for whatever reasons. But generally you can win them over'.
Appearance	<i>Quote 4:</i> 'You get lots of children who are perfectly happy, and skip in, look forward to coming ... But we all know the ones that scream the second you go out to bring them in'. <i>Quote 5:</i> 'I think the coloured patches do help. I think they're a massive, massive help and I think they're so much nicer. And I think the child can choose what colour they want, and they can look a little bit trendier and not just have a big sticky patch that they're really bothered about'. <i>Quote 6:</i> 'The only thing that they do say is "I don't like wearing it when people see me". That would be, I think, the only thing that they would ever say; they tend to just say "I don't like it". "I can't see", is about as far as it goes. They don't say "It stops me playing on computer games", but they do say "I don't like people seeing me with it on'.
Glasses-wear	<i>Quote 7:</i> 'When you first suggest that there may be even a possibility that the child may need glasses a lot of parents still have that [ <i>sharp intake of breath</i> ] "I don't want my child to wear glasses".' <i>Quote 8:</i> 'I think since they started updating glasses, and children's glasses, and they got rid of those NHS plastic frames and things, I think there's been a huge difference ... It's been more acceptable for children to wear glasses'. <i>Quote 9:</i> 'I think glasses are trendier. More people in the media wear glasses, and glasses are almost cooler now. You can choose lots of different frames, especially the kids; they like the Barbie ones and the Harry Potter ones and you've got Action Man glasses. So I think there are lots more options than there used to be, and parents who had glasses who had the old "Oh it's not the National Health ones is it?" are quite pleased to realise there are more options out there'. <i>Quote 10:</i> 'I think with children glasses do become an issue when they're ill-fitting and when they're sliding down their nose and they're always having to poke them up and when they just fall off, and I think then they seem to get a little bit more frustrated with them'.
Patching treatment	<i>Quote 11:</i> 'So wearing a patch and standing out, they are definitely more aware, so you do find a lot of them they don't wear it at school, they stop. They are refusing to wear it at school and then have to wear it at home, because they are more image conscious'. <i>Quote 12:</i> 'Well some children can be severely visually handicapped by having to wear a patch'. <i>Quote 13:</i> 'Putting something on their face is something that they can feel, as well, and the eyes are very sensitive. So that alone I think. When you put a patch on me, it is something you feel, it's something that you notice: there is a change in how you perceive the world. So for a child that's not able to comprehend what's happening, I think it could be a scary thing'. <i>Quote 14:</i> 'I think it becomes a discipline issue. Because it's the parent saying "You're going to do this" and it's the child saying "No I'm not". And they take it off and they don't like it, and there's no reasoning, there's no bargaining. The parents can bribe, but there's no kind of halfway. You can't meet in the middle with having the patch on or not. It either goes on or it doesn't. So I think it becomes the parent trying to stand their ground and say "You've got to wear it" and then all of a sudden it's a big issue. Whether it's about the patching or not, it's a case of the parent fighting the child'.
Atropine treatment	<i>Quote 15:</i> 'Sometimes it can be difficult getting the drops in ... because they physically just don't like having them in'. <i>Quote 16:</i> 'I think you've not got a physical patch, you've got nothing to see'. <i>Quote 17:</i> 'The only problem I think it sometimes causes in the summer months [is] if it's very sunny and very bright, and I've had a few kids that get kind of headaches, and once we've stopped the atropine that's kind of gone away'.
Limitation of activities	<i>Quote 18:</i> 'all your peripheral vision, you know, it's just frustrating. And if your vision is low anyway in that eye, you can't see TV programmes and things like that, which is then affecting maybe their quality of life as a child. In that they can't do what they want to do at that time'. <i>Quote 19:</i> 'They're going to need help navigating around the house so that they don't walk into the doorframes; they're going to need much more help and support from a parent or from teachers or from nursery ... They're probably still going to be able to get about and do what they normally do; they are just not going to be able to do it as well'.
Relationships within the family	<i>Quote 20:</i> 'I've had one or two families where the sibling's been the bully ... Not very often, just once or twice. Big brother or big sister that picks on them and makes fun of them, having to wear the patch'. <i>Quote 21:</i> 'I think if it is a true battle with the child, if there are other children in the house it must have a detrimental effect at some time. In that it's obviously a disruptive influence ... at some point. And it may be that other children feel left out if the parents are constantly [saying] "Here you must wear your patch" and the attention is on that child the whole time ... so it may have a disruptive influence'. <i>Quote 22:</i> 'Rather than a lot of discipline and telling them off or shouting at them, you actually got those parents that are supportive and encouraging and just say how proud they are of their kids when they've achieved something'.
Treatment compliance	<i>Quote 23:</i> '... where you think you want to do something like 6 to 8 hours [patching] but you know that if you're going to tell [the parents] that they're just going to fall flat on the floor, and you're going to have to pick them up off the floor, and you'll never see them again'. <i>Quote 24:</i> 'I think if [the parents] have had a bad experience it can sometimes lead to difficulties trying to coax them to accept the treatment for their child. And they're expecting [bad experiences], they pre-empt bad experiences for their child as well'.

to how to adapt treatment in response to the problems the child is facing. One of the issues relating to treatment adherence is when to 'admit defeat'. The participants felt that this had to be a parental decision. Sometimes this decision can be influenced by other factors, such as the presence of co-morbidities. In this case, one of the focus group participants stated 'I think parents seem to prioritise treatments a lot more'.

However, treatment compliance may also be influenced by experiences of the parent if they underwent amblyopia therapy during their childhood (Quote 24).

## Discussion

### *Principal findings*

It is clear that the HRQoL themes identified cannot be considered in isolation; some are intrinsically linked (e.g. appearance and patching treatment). The way in which such themes interact can have an impact on treatment decisions made by both clinicians and parents. Focus group participants acknowledged the shift in the way amblyopia treatment has altered over the years. Published studies have shown that atropine is as effective as patching in treating amblyopia,<sup>19–21</sup> and some of the focus groups participants acknowledged that they will now offer this as a first approach when managing cases. They reasoned that as successful visual outcome has been proven to be achievable with atropine treatment, they are more likely to consider this as a treatment option, particularly in light of the (perceived) lower HRQoL implications of this in comparison with patching.

One of the key components identified by the participants was that of the parenting approach to treatment itself. Previous studies have explored the issue of parental understanding and compliance,<sup>22–26</sup> and whilst there is a degree of overlap between these concepts, parental understanding of the condition or treatment cannot solely account for poor treatment compliance. Focus group participants acknowledged that parents and children are given more information in decision-making choices; and that they ultimately decide which treatment option to take, or whether to treat at all. It was noted that the traditional 'will do it because they are told to' approach no longer exists within current NHS practice:

I think the NHS has really changed from what it used to be. You know the patriarchal doctor just tells you what the treatment is and you just go away and do it. It's a much more informed choice now. ... all we're really doing now is suggesting a treatment, and different ways of doing it, but it's up to the parents now, and the child, as to whether they want to go ahead with that. And I think that's a sign of the times that that's definitely changed.

Another finding was the change in the way glasses, patching and education of eye conditions are seen across society as a whole. Clinicians stated that glasses and patch-wear are much more acceptable nowadays, and that the involvement of school or nursery in a child's amblyopia treatment is increasingly common.

### *Comparison with other research*

The HRQoL themes of amblyopia and/or its treatment identified through the focus group sessions are similar to those identified in the literature (the impact on family life, social interactions, undertaking daily activities, and feelings and behaviour).<sup>8</sup> This is not surprising as much of the literature exploring the implications of amblyopia and/or its treatment is taken primarily from a clinical standpoint. The focus group sessions confirmed the importance of issues such as relationships within the family and the difficulties of treatment adherence.

### *Strengths and limitations of the study*

It is believed that this study is the first of its kind to raise the issue of HRQoL components of amblyopia between clinicians. This is an under-researched topic, and the use of expert informants to identify HRQoL implications of treatment increases our understanding of the difficulties surrounding the successful management of amblyopia.

In this study, participants were recruited from a small geographical area. It is possible that local adopted treatment or investigation policies may have influenced some of the responses given. Further research is required in order to determine whether the HRQoL themes identified exist on a national scale. Furthermore, it could be stated that conducting focus group sessions with colleagues may narrow, rather than broaden, the range of opinions and experiences shared within the group setting.

It should also be noted that many of the HRQoL implications of amblyopia and/or its treatment are experienced by the child; however, how important these implications are may differ depending upon whether the child or parental perspective is taken. For example, a child may not want to wear a patch during school hours as they are concerned about their appearance, whereas the parent may not want their child to wear the patch during school hours as they are concerned that having the patch on will interfere with the child's schoolwork and education. The parent may rate ability to perform tasks as being more important than appearance; whereas the child may feel the opposite. Parental opinions and perspectives of treatment are likely to inform a child's beliefs either directly or indirectly.

## Conclusion

This study has identified the range of ways in which amblyopia affects QoL (as perceived by clinicians), and is consistent with the literature. These can be experienced by the child or the parent/guardian. The extent to which these affect the individual or the family may account for poor treatment adherence, and ultimately a poor visual outcome. The study also highlighted that there may be a shift in societal views regarding glasses-wear and patching treatment. It is possible that literature describing the implications of amblyopia and/or its treatment is outdated; further research is necessary in this area to determine whether the introduction of different style patches or increased used of atropine occlusion has altered QoL from the child's perspective. In addition, continued education and health promotion of

amblyopia and its treatment will serve to increase awareness, and may contribute to better treatment adherence. Informed treatment choice may be facilitated by the use of decision aids, such as information leaflets,<sup>27</sup> and these may need to be altered to reflect both changes in clinical practice and changes in public opinion. Further research is needed to explore the exact impact of amblyopia and/or its treatment from both the child's and the parental perspective.

## Appendix. Topic guide

### Introduction

- Purpose of study
- Confidentiality
- Recording
- Stress importance of work, encouragement and gratitude for taking part

### Background information

- Names and identification of participants
- Training/educational background
- Years practising orthoptics
- Personal experience of amblyopia and/or treatment
- How much involvement they have with children
- Training and quality of life (QoL)?

### Setting the scene

- Stress want opinions/feelings/recollections of occasions when children and/or parents discuss the following
- Try to ignore literature, focus on own opinions
- No right/wrong answers

### Quality of life

- What do you understand by QoL?
- What are the parents' views?
- What are the children's views?
- Ever record QoL experiences in notes?

### Quality of life implications of amblyopia

- What implications can you think of/believe to be affected by amblyopia?
- Do you feel these are likely to be short term or long term? Why?

### Quality of life implications of amblyopia treatment

- What are they?
- Are these getting more prevalent over time? Have patterns changed?
- Are these worse for child or parent? Why?
- Tease out differences between glasses/patch
- Tease out differences between patch/atropine
- What are the changes over time?
- Are there any sex differences/ethnic differences
- What if co-morbidities are present?
- Any differences with amblyopia classification?
- Give examples

### Do QoL implications affect your decisions/treatment plan from a clinician's perspective?

- Yes/no. Why?

- Are these from a clinician's perspective or do you think your opinion has changed having been a parent?
- Examples of good/bad behaviour
- What do you mean by 'react badly', etc.?

### Summarise

- Summarise key points raised by participants
- Ask if this is a correct representation of what was discussed

### Identified topics from literature

To use as a probe/discussion point if previous provides no information.

#### Family life:

- Carer-child relationships
- Strained relationships within the family

#### Social interactions:

- Feelings of isolation/differing from others
- Bullying
- Interaction with peers

#### Activities:

- Limitation of activities and its impact
- Impact on education (immediate and long-term)

#### Feelings and behaviour:

- Self-esteem and self-image
- Depression, frustration, embarrassment
- Understanding of amblyopia and/or its implications
- Sensation of patch/drops

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