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Title

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

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ABSTRACT

Aims or Purpose

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. The transcripts were analysed using "Framework" analysis 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 included adult quality of life issues; hospital appointments; appearance; glasses-wear; patching treatment; atropine treatment; limited activities; relationships within the family; and treatment compliance.

Conclusions

The HRQoL implications identified were of amblyopia and/or its treatment was 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 and the parental perspective.

INTRODUCTION

The evidence of the impact of amblyopia upon health-related quality of life (HRQoL) has recently been examined¹. Literature suggests that the condition and (its treatment) do impact upon the individual and family members. 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 is to explore the orthoptists' perceptions of the impact of amblyopia upon HRQoL; and to evaluate whether these correlate to existing evidence published in the literature.

MATERIALS AND METHODS

Previous research has reported the HRQoL implications of amblyopia and/or its treatment¹. The purpose of the systematic literature review was to inform the topic guide used to facilitate focus group discussions with practising orthoptists (Appendix 1). Diversity within focus groups is noted to aid discussion², 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 groups sessions were a semi-structured discussion using the topic guide as a prompt where necessary. Three focus

groups sessions were held in November 2007. Two of the focus group sessions had four participants, and one had five participants; and 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 taken for each participant. The focus groups sessions were recorded and transcribed verbatim. Transcripts were then analysed and coded with the primary aim to identify HRQoL themes of amblyopia and/or its treatment. Framework analysis was undertaken using QSR NVivo 8[®]

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research. Full ethical 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 included adult quality of life issues; hospital appointments; appearance; glasses-wear; patching treatment; atropine treatment; limited activities; relationships within the family; and treatment compliance.

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 of 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.

“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.”

Focus Group 2 – Participant 4

Appointments to 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.

“I think a parent of a child that needs to bring them frequently it must be really difficult if you work. Time-consuming.”

Focus Group 1 – Participant 2

Some participants noted that the hospital appointments may be a positive or negative experience for both parent and child. Participants noted:

“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.”

Focus Group 1 –Participant 1

“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.....”

Focus Group 1 – Participant 4

Appearance

The impact of treatment upon a child’s physical appearance was also raised. This may be in the form of wearing glasses; a patch; using atropine; or a combination of these. The implications may be positive or negative in nature.

“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”.

Focus Group 2 – Participant 4

The implications may be felt by the child directly (i.e. through teasing or bullying) or indirectly (through altered relationships with parents/guardians).

“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, 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”.

Focus Group 2 – Participant 4

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.

“..when you first suggest that there may be even a possibility that the child may need glasses a lot of parents still have that (*sharp intake of breath*) “I don’t want my child to wear glasses””.

Focus Group 1 – Participant 1

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.

“I think since they, they started updating glasses and you know, children’s glasses and they got rid of those, erm, NHS, you know plastic frames and things.

I think there's been a huge difference.... It's been more acceptable for children to wear glasses..."

Focus Group 2 – Participant 1

"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, you know, they like the Barbie ones and the Harry Potter ones and you know, 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".

Focus Group 2 – Participant 4

The issue of comfort and correctly fitting glasses was also raised; some participants felt that this may impact upon whether a child likes to wear their glasses.

"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 you know, when they just fall off and I think then it, it sort, they seem to get a little bit more frustrated with them".

Focus Group 2 –Participant 1

Patching treatment

A number of HRQoL implications were identified related to patching treatment. These included the appearance of the patch; limitations to daily activities due to the visual handicap experienced when the patch is worn; the sensation of the patch upon the face; and the impact of patching upon relationships within the family.

“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”.

Focus Group 1 –Participant 3

“Well some children can be severely visually handicapped by having to wear a patch”

Focus Group 1 – Participant 1

“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 sort of how you perceive the world. So for a child that’s not able to comprehend what’s happening, I think it, it could be a scary thing”.

Focus Group 1 – Participant 3

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/guardian for

complying with treatment; or the increased time they spend with their parent/guardian to be supervised during the occlusion period.

“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, there’s no reasoning, there’s no bargaining, you know. 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”.

Focus Group2 – Participant 4

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 to getting a child to wear their patch.

“Sometimes it can be difficult getting the drops in.....Because they physically just don’t like having them in”.

Focus Group 3 – Participant 5

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 to

patching); the instillation of the atropine drops; and the effect of bright sunlight to the atropinised eye.

“I think you’ve not got a physical patch, you’ve got nothing to see...”

Focus Group 1 – Participant 2

“The only problem I think, it sometimes causes in the summer months, 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”.

Focus Group 2 – Participant 4

Limited 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 a person’s 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).

“..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”.

Focus Group 2 – Participant 2

“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”.

Focus Group 2 – Participant 5

Relationships within the family

Participants identified that the administering of treatment can cause negative changes to parent-child relationships and also relationships between siblings.

“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”.

Focus Group 3 – Participant 1

Parents may find the treatment time-consuming and stressful (particularly if compliance is poor); and relationships may become more difficult in cases.

“I think if it is a true battle with the child, whether it’s, 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 “here you must wear your

patch” and the attention is on that child the whole time... so it may have a disruptive influence”.

Focus Group 1 – Participant 1

However, it is possible that the instigation of treatment may improve parent-child relationships. They get to spend more time engaging with each other (interactive play); or the child may experience praise/rewards if compliance to treatment has been good.

“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 you know, and kind of, again just say how proud they are of their kids when they’ve achieved something”.

Focus Group 1 – Participant 2

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 upon 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.

“... where you think you want to do something like six to eight hours but you know that if you’re going to tell them that they’re just going to fall flat on the floor, and you know, you’re going to have to pick them up off the floor, and you’ll never see them again”.

Focus Group 3 – Participant 1

The information given to parents by orthoptists is adapted to encourage treatment adherence. This can centre amongst 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”

Focus Group 3 – Participant 3

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

Focus Group 3 – Participant 3

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

“I think if they’ve had a bad experience it can sometimes lead to difficulties trying to coax them to accept the treatment for their child. And their expecting, they pre-empt bad experiences for their child as well”.

Focus Group 3 – Participant 1

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 impact upon 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 amblyopia³⁻⁵; 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 to 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 compliance⁶⁻¹⁰; 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 really we’re 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”.

Focus Group 3 – Participant 5

Another finding was the change in the way glasses, patching and education of eye conditions exists 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 literature¹. 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 such 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 in the context of amblyopia between orthoptists. This is an under-researched topic, and the use of expert informants to identify HRQoL implications of treatment increases our understanding in 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 impacts upon QoL, and is consistent with the literature. These can be experienced by the child or the parent/guardian. The extreme 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 the changing shift of societal views of 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 use 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 leaflets¹¹, 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 and the parental perspective.

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References

1. Carlton J, Kaltenthaler E. Amblyopia and quality of life: a systematic review. http://eprints.whiterose.ac.uk/11040/1/HEDS_DP_10-05.pdf (Paper submitted to Eye – currently under review).
2. Finch H, Lewis J. Focus Groups. In: Ritchie J, Lewis J, editors. *Qualitative Research Practice: A guide for social science students and researchers*. 1 ed. London: SAGE Publications Ltd; 2003. 170-198.
3. PEDIG. A randomized trial of atropine vs. patching for treatment of moderate amblyopia in children. *Arch Ophthalmol* 2002;120:268-278
4. Pediatric Eye Disease Investigator Group, Repka MX, Kraker RT, Beck RW, Holmes JM, Cotter SA, Birch EE, Astle WF, Chandler DL, Felius J, Arnold RW, Tien DR, Glaser SR. A randomized trial of atropine vs patching for treatment of moderate amblyopia: follow-up at age 10 years. *Arch Ophthalmol*. 2008;126(8):1039-44.
5. Scheiman MM, Hertle RW, Kraker RT, Beck RW, Birch EE, Felius J, Holmes JM, Kundart J, Morrison DG, Repka MX, Tamkins SM; Pediatric Eye Disease Investigator Group. Patching vs atropine to treat amblyopia in children aged 7 to 12 years: a randomized trial. *Arch Ophthalmol*. 2008;126(12):1634-42.
6. Newsham D. Parental non-concordance with occlusion therapy. *Br J Ophthalmol* 2000;84:957-62.
7. Newsham D. A randomised controlled trial of written information: The effect on parental non-concordance with occlusion therapy. *Br J Ophthalmol* 2002;86(7):787-91.

8. Searle A, Vedhara K, Norman P, et al. Compliance with eye patching in children and its psychosocial effects: A qualitative application of protection motivation theory. *Psychol Health Med* 2000;5(1):43-54.
9. Searle A, Norman P, Harrad R, et al. Psychosocial and clinical determinants of compliance with occlusion therapy for amblyopic children. *Eye* 2002;16(2):150-5.
10. Norman P, Searle A, Harrad R, et al. Predicting adherence to eye patching in children with amblyopia: An application of protection motivation theory. *Br J Health Psychol* 2003;8(1):67-82.
11. O'Connor AM, Bennett CL, Stacey D, Barry M, Col NF, Eden KB, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2009, Issue 3. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub2

Appendix 1

Topic Guide for Focus Groups

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 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 about if co-morbidities are present?
- Any differences with amblyopia classification?
- Give examples

Is there a difference between the two?

- Why?

Do quality of life 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 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