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The effects of strabismus on quality of life in adults

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Abstract

Purpose: As a first step in the development of a health related quality of life instrument, we conducted in-depth interviews to identify the specific concerns of adults with strabismus.

Design: Prospective cross-sectional study

Methods: Thirty adults with strabismus, 17 with diplopia and 13 without were recruited. Individual interviews, using 11 open-ended questions, were audiotaped, transcribed and transcripts reviewed independently by 3 investigators. Phrases regarding how strabismus affected everyday life were grouped into topic areas and the frequency of each topic analyzed for subjects with and without diplopia.

Results: A total of 1508 phrases were extracted: 207 (14%) of 1508 were excluded as they did not pertain to health related quality of life (HRQOL). From the remaining 1301 phrases, 48 topic areas were apparent. For patients with diplopia, the most frequently occurring topics were *Non-specific Negative Feeling* (15/17; 88%) e.g. ‘really hard’; *General Disability* (15/17; 88%) e.g. ‘affects everything’ and *Driving* (14/17; 82%). In those without diplopia, the most frequently mentioned topics were *Appearance to others* (12/13; 92%) e.g. ‘people notice my eyes’ followed by problems with *Eye Contact* (10/13; 77%) and *Interpersonal Relationships* (10/13; 77%). Of the topics that were common to both groups (n=42), 2 of the most frequent were *Driving* and *Non-specific Negative Feeling*.

Conclusions: Multiple individual interviews revealed many topics which negatively affect quality of life in strabismic adults. The frequency and type of concerns confirm the importance of HRQOL assessment as an important aspect of strabismus management.

Introduction

Strabismus is one of many ophthalmological conditions that is addressed because it affects quality of life. Clinical assessment of the impact of strabismus on quality of life has generally been informal and previous studies reporting the precise nature of the quality of life effects have focussed on psychosocial functioning,^{1–8} personality traits⁵ and employment capability.^{4,5} Adults with strabismus have also been reported to suffer low self-esteem and have problems with inter-personal relationships and social anxiety.^{1,2,9} While important, these psychosocial effects are only a part of overall health related quality of life (HRQOL). Measuring HRQOL

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is an important adjunct to clinical examination as it enables comprehensive understanding of the condition itself and proper evaluation of treatment effectiveness.¹⁰ Nevertheless, there are few strabismus specific HRQOL instruments that have been derived based on multiple patient interviews or multiple patient focus groups. Deriving HRQOL items on the basis of direct patient input is preferred to using purely the clinician's or researcher's perspective.¹¹⁻¹³ With a view to developing a patient-derived HRQOL instrument, we interviewed adult strabismus patients in order to elicit specific issues affecting quality of life. This paper reports the results of the interviews, describing patient's most common concerns.

Methods

In this prospective cross-sectional study, thirty adult patients (median age 39.5; range 18 to 74 years) were recruited from outpatient clinics. All types of strabismus were eligible for inclusion. Seventeen (57%) of the 30 patients had diplopia and 13 (43%) did not. Twenty (67%) were female and all patients self-reported their race as 'White.' For the 17 patients with diplopia, diagnoses were: 4th nerve palsy (3), 6th nerve palsy (2), 3rd nerve palsy (2), residual esotropia (2), post retinal detachment surgery (2), and one each with decompensating exodeviation, decompensating esodeviation, consecutive esotropia, Graves' eye disease, post-cataract extraction and Brown syndrome. Seven (41%) of the 17 were childhood onset strabismus. Median corrected visual acuity was 20/20 (range 20/20 to 20/30) for the right eye and 20/25 (range 20/20 to 20/160) for the left eye. For the 13 patients without diplopia, diagnoses were: consecutive exotropia (5), decompensating exodeviation (4), residual esotropia (3) and 3rd nerve palsy (1). Twelve (92%) of the 13 patients without diplopia had childhood onset strabismus. Median visual acuity was 20/20 (range 20/15 to 20/40) for the right eye and 20/25 (range 20/20 to 20/160) for the left eye. We included patients who had undergone surgery (23/30; 77%), but for the majority (18/23; 78%), surgery was performed during a separate episode of care (range from 48 weeks to 51 years previously) and symptomatic strabismus was still present at the time of assessment. The remaining 5/23 (22%) were interviewed within 2 to 25 weeks following surgery and were specifically asked how the strabismus had affected them prior to surgery. To be included in the study, patients were required to be comfortably conversant in English.

Individual patient interviews, using a series of 11 open-ended questions, (Table 1) were conducted and audiotaped. The open-ended questions were derived from previous studies reporting the psychosocial impact of strabismus in adults^{1-6, 8, 9} and from clinical experience. All interviews were conducted by a research orthoptist (SRH), each taking from approximately 10 to 35 minutes depending on the individual. Open discussion was encouraged for each question. Further patients were interviewed until informational redundancy was reached (no new issues were being raised by subsequent patients). Interviews were transcribed and the transcripts reviewed independently by 1 clinician (JMH) and 2 non-clinicians (DAL and PAK). Each investigator recorded every phrase or statement pertaining to an aspect of the patient's quality of life or strabismus experience. For each patient, the 3 lists of phrases and statements were combined into a single list, and duplicates removed. This combined list was then reviewed and topic areas identified according to the nature of the extracted responses. Two investigators reviewed a combined list of phrases and topics for all patients to reach agreement on the assignment of each phrase to a topic.

The results were analyzed to determine the frequency with which specific topics were mentioned by patients with and without diplopia.

Results

A total of 1508 phrases were extracted. 143 of the 1508 phrases were excluded as they did not pertain to HRQOL or referred specifically to distant, historical experiences as a child or the experience of undergoing surgery (e.g. 'hard on little kids', 'everyone should have surgery'). An additional 64 phrases were excluded because they were statements of symptoms of diplopia and blurred vision (e.g. 'I see two') without reference to any effects these symptoms had on quality of life. The remaining 1301 phrases yielded 48 topics (Table 2). We calculated the number of topics mentioned by each patient. Patients were considered to have mentioned the topic whether it occurred once or multiple times during the interview. Therefore subsequent analyses of frequency of topics were by patient. We analyzed results for patients with and without diplopia.

Patients with diplopia

All 48 topics were mentioned in the 17 patients with diplopia. The number of topics mentioned by individual patients ranged from 10 to 30 with a median of 22. Nineteen (40%) of the 48 topics were mentioned by at least 50% of the patients (Table 2). Fifteen (88%) of the 17 patients reported *Non-specific Negative Feelings* such as 'really hard,' 'emotionally draining' and 'miserable' and 15 (88%) of 17 reported problems with *General Disability* e.g. 'affects everything,' 'feel handicapped' and 'problem getting through the day.' Difficulties with *Driving* such as 'driving is terrible,' 'extra caution when driving' and 'afraid of hitting something on the side of the road' were mentioned by 14 (82%) of 17 patients. Thirteen (76%) of 17 expressed concerns regarding *Self-esteem* e.g. 'feel inferior' and 'don't feel normal.'

Patients without diplopia

Forty-two of the 48 topics were mentioned in the 13 patients without diplopia. The number of topics mentioned by individual patients ranged from 9 to 27 with a median of 22. Nineteen (45%) of the 42 topics were mentioned by at least 50% of the patients (Table 2). Twelve (92%) of the 13 patients mentioned concerns regarding their *Appearance to Others* using phrases such as 'people notice my eyes,' 'people look at me funny' and 'people think it looks terrible.' Problems with *Eye Contact* were expressed by 10 (77%) of the 13 e.g. 'struggle to look people in the eye,' 'look away from people' and 10 (77%) reported problems with *Interpersonal Relationships* e.g. 'hard to talk to people,' 'makes people uncomfortable' and 'problems dating'.

Similarities and differences between patients with and without diplopia

Of the 48 topic areas, the majority (42/48; 88%) were common to both patients with and without diplopia: 26 of these 42 topics were mentioned by more than 50% of either group (Table 2, shown in bold type). The 12 topics mentioned by more than 50% of the patients both with and without diplopia were: *Adaptation* (adjustments made to cope with strabismus such as 'try to handle with humor' and 'say someone's name so they know I'm talking to them'); *Appearance to Self* (e.g. 'hate appearance, keep one eye covered,' 'my looks freak me out'); *Driving; Efforts to Reduce Symptoms* (e.g. 'try to focus eye so people dont notice,' 'try to straighten eye'); *Financial* (e.g. 'appearance decreased my income,' 'lost jobs because of lack of eye contact'); *General Visual Function* (e.g. 'almost like being blind,' 'miss things that are going on'); *Non-specific Negative Feelings; Resignation* (e.g. 'learning to live with it'); *Self-confidence* (e.g. 'absolutely affects my confidence'); *Self-conscious* (e.g. 'self conscious talking to people,' 'feel embarrassed'); *Self-esteem* (e.g. 'self esteem is about an inch high,' 'feel inadequate') and *Work* (e.g. 'takes me longer to do things at work,') (Table 2). Six topics were mentioned only by the patients with diplopia; these were: *Lack of support* (8 of 17; 47%), *Sewing* (5 of 17; 29%), *Back / Neck Pain* (4 of 17; 24%), *Walking* (4 of 17; 24%) *Bump into Things* (3 of 17; 18%) and *Jealousy* (2 of 17; 12%) (Table 2). The biggest differences in topic frequencies

between diplopic and non-diplopic patients were in the areas of *Eye Contact and Eye Contact from Others*, with diplopic patients mentioning these concerns much less frequently (Table 2).

Discussion

Strabismus in adults causes a wide range of quality of life concerns; for patients with diplopia the most common issues identified in this study were *Non-specific Negative Feelings*, *General Disability* and *Driving*, whereas for patients without diplopia the most common concerns were *Appearance to Others*, *Eye Contact* and *Interpersonal Relationships*. Patients with and without diplopia both frequently identified problems with *Non-specific Negative Feelings*, *Driving* and *Self-esteem*. There were some areas that appeared to only affect patients with diplopia, for example *Lack of Support*, *Back/Neck Pain*.

The nature of quality of life concerns was different for non-diplopic and diplopic patients: non-diplopic patients primarily expressed problems with interpersonal relationships and non-verbal communication, whereas for patients with diplopia, problems were predominantly related to everyday physical functioning. It is possible that patients with diplopia are preoccupied with problems performing everyday tasks and that they are therefore less aware of more interpersonal concerns.

Our finding that many patients expressed problems with self-esteem, interpersonal relationships and social anxiety was not surprising based on previous studies of the psychosocial effects of strabismus in adults.^{1, 2, 9} Nevertheless, some concerns identified in this study were more unexpected, for example physical discomfort of the eyes, back and neck pain, problems with different lighting conditions and strong negative emotions, such as resignation and jealousy. These topics will be further evaluated in our next stage of HRQOL instrument development.

The differences between patients in the number of topic areas mentioned, suggests individual HRQOL concerns vary considerably. It is likely that factors such as personality and occupation account for many of the differences between patients and not just severity of disease: there were cases in our study where large angle strabismus was associated with remarkably few concerns and small angle strabismus was associated with significant problems. Previous studies have reported that strabismus affects personality traits^{1, 2, 9} and employment opportunities,^{4, 5} but it remains unknown how different personalities and occupations affect how an individual deals with strabismus.

We investigated the impact of strabismus on HRQOL in adults using multiple in-depth interviews. A study by van de Graaf et al⁸ collected 'an inventory of all problems' from outpatients with strabismus or amblyopia. van de Graaf et al categorized complaints into 3 themes (loss of depth perception; diplopia; visual disorientation and appearance) by means of a focus group and then further divided into domains in order to develop an Amblyopia and Strabismus HRQOL questionnaire.⁸ This previous study describes the results obtained by delivering the questionnaire itself, whereas our present study reports the identification of specific concerns from the patients themselves and therefore we cannot directly compare the studies.

Our finding that strabismus impacts quality of life in adults reaffirms the relevance of measuring HRQOL in patient populations. Patient-derived instruments have been used as a model for the development of vision-related HRQOL questionnaires by other groups,¹¹ but in the past, most studies examining the effects of strabismus on quality of life in adults have used either non-patient-derived questionnaires^{1-3, 6, 8, 9, 14, 15} or generic quality of life instruments.^{2, 3, 9} Basing the content of a HRQOL instrument on patient-defined issues is thought to be more appropriate than basing the content purely on the clinician's or researcher's

perspective.¹¹⁻¹³ The Amblyopia and Strabismus questionnaire described above⁸ appears to have been developed with limited patient input. In addition, the impact of strabismus on quality of life would seem to justify an instrument dedicated to strabismus alone. We plan to use the results of the interviews in our present study to develop a patient-derived, condition-specific, HRQOL instrument. Future studies should compare a patient-derived generic HRQOL instrument to a patient-derived condition-specific instrument, such as the one we are developing.

Our approach of using multiple patient interviews in order to capture quality of life issues has the advantage of being able to cover the spectrum of concerns for a given patient in considerable depth. One weakness of our study is that the patient population was racially homogeneous: it would have been preferable to interview individuals from other racial groups. Nevertheless, our study cohort did represent a variety of social backgrounds and professions. Another potential disadvantage of using in-depth interviews is that the concerns raised may be specific to the individuals interviewed due to either personality, occupation and / or diagnosis, and may not be generalisable to the entire population of adult patients with strabismus. For example some of the concerns expressed by patients with 4th nerve palsy may not be recognized by patients with Graves' eye disease and vice versa. Nevertheless, our goal was to identify a broad range of concerns to develop a HRQOL instrument that will be widely applicable to the majority of adult patients with strabismus, rather than requiring individual instruments for each type of strabismus.

Multiple individual interviews conducted as part of this study identified many ways in which strabismus affects quality of life in adults with and without diplopia. The frequency and type of concerns found in this study confirms the importance of HRQOL assessment as an important aspect of strabismus management and provide a basis for developing a patient-derived HRQOL instrument.

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Institutional Review Board/Ethics Committee approval was obtained. All experiments and data collection were conducted in a manner compliant with the Health Insurance Portability and Accountability Act.

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Table 1

Questions used in individual interviews to elicit health related quality of life concerns of adults with strabismus.

	Questions
1	What bothers you most about your eyes?
2	What bothers you most about having double vision/misaligned eyes?
3	How does having double vision/misaligned eyes affect the things you do every day? What types of things give you problems? What have you started/stopped doing because of your strabismus? How do you feel about any problems/difficulties you have?
4	How does having double vision/misaligned eyes affect your work?
5	How does having double vision/misaligned eyes affect your social life / hobbies?
6	How does strabismus affect your relationships with other people? How does it affect the way you relate to people? How does it affect the way people relate to you?
7	How does having double vision/misaligned eyes affect your self esteem/confidence?
8	Can you describe any financial effects of having misaligned eyes/double vision? Have there been costs associated with your care? Has it affected your ability to earn?
9	Can you describe any coping strategies to help you live with misaligned eyes/double vision? Is there something that you do that helps your symptoms?
10	What are your expectations regarding your visual function in the future?
11	Can you describe any other ways in which having misaligned eyes/double vision affects your life that we haven't covered?

Frequency of health related quality of life topics identified from individual interviews of adults with strabismus with and without diplopia: topics mentioned by more than 50% of patients in either group are shown in bold type.

Table 2

Topics - alphabetical order	Patients with diplopia (n=17)	Patients without diplopia (n=13)	Topics - alphabetical order	Patients with diplopia (n=17)	Patients without diplopia (n=13)
Adaptation	11 (65%)	9 (69%)	Headache	4 (24%)	3 (23%)
Annoying	7 (41%)	2 (15%)	Hobbies	6 (35%)	2 (15%)
Anxiety	10 (59%)	6 (46%)	Interpersonal relationships	7 (41%)	10 (77%)
Appearance to others	8 (47%)	12 (92%)	Jealousy	2 (12%)	-
Appearance to self	10 (59%)	9 (69%)	Lack of support	8 (47%)	-
Back / neck pain	4 (24%)	-	Lighting	6 (35%)	3 (23%)
Bump into things	3 (18%)	-	Meeting people	2 (12%)	7 (54%)
Busy / strange environments	5 (29%)	3 (23%)	Monocular eye closure	11 (65%)	5 (38%)
Compensatory body posture	9 (53%)	3 (23%)	Non-specific negative feeling	15 (88%)	9 (69%)
Computer	4 (24%)	3 (23%)	Physical discomfort	5 (29%)	4 (31%)
Concentration	8 (47%)	6 (46%)	Prisms	8 (47%)	2 (15%)
Confidence of others	3 (18%)	7 (54%)	Reading	12 (71%)	5 (38%)
Cooking	4 (24%)	1 (8%)	Resignation	9 (53%)	8 (62%)
Depth perception	8 (47%)	8 (62%)	Self confidence	12 (71%)	8 (62%)
Driving	14 (82%)	9 (69%)	Self conscious	12 (71%)	7 (54%)
Effect of fatigue	5 (29%)	5 (38%)	Self esteem	13 (76%)	9 (69%)
Efforts to reduce symptoms	9 (53%)	9 (69%)	Sewing	5 (29%)	-
Eye contact	5 (29%)	10 (77%)	Social	11 (65%)	6 (46%)
Eye contact from others	3 (18%)	9 (69%)	Specific disability	8 (47%)	4 (31%)
Eye fatigue	4 (24%)	3 (23%)	Sports	5 (29%)	6 (46%)
Financial	10 (59%)	8 (62%)	Steps	4 (24%)	1 (8%)
Frustrating	10 (59%)	4 (31%)	Teasing	6 (35%)	6 (46%)
General disability	15 (88%)	6 (46%)	Walking	4 (24%)	-
General visual function	11 (65%)	7 (54%)	Work	11 (65%)	7 (54%)

“-” = not mentioned