The effect of strabismus on the quality of life in adult strabismus patients in Egypt

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Purpose
The study aims at identifying the main concerns affecting quality of life (QOL) in adult strabismus patients in Egypt.
Patients and methods
Seventy adults with strabismus, 20 with diplopia and 50 without the disease were recruited. Individual interviews, using 11 open-ended questions, were audiotaped, transcribed, and transcripts reviewed. Phrases regarding how strabismus affected everyday life were grouped into topic areas and the frequency of each topic analyzed for patients with and without diplopia.
Results
With self-esteem, interpersonal relationships, and social anxiety was not surprising based on previous studies of the psychosocial effects of strabismus in adults. Nevertheless, some concerns identified in this study were more unexpected, for example appearance in photos, education, marriage, and no treatment for squint. Other concerns in this study were unexpected as most of the patients did not express these problems, for example, in-depth perception, driving, and sports.
Conclusion
Multiple individual interviews have shown many topics which negatively affect the QOL in strabismic adults. The frequency and type of concerns confirm the importance of health-related QOL assessment as an important aspect of strabismus management.
Cultural difference resulted in a different pattern of patient responses and health-related QOL concerns.

Keywords:
diplopia, strabismus, squint

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Introduction

Strabismus is one of the common eye disorders that are addressed as a result of its effect on quality of life (QOL). Clinical assessment of the impact of squint on QOL has typically been deficient and former studies covering the precise nature of the QOL, effects have targeted psychosocial functioning [1–3], temperament traits, and employment capability.

There are many strabismus-specific health-related quality of life (HRQOL) instruments that have been derived [4–6]. These were based on interviews conducted in their relevant countries and hence affected by cultural and socioeconomic factors in these countries [7,8]. No such interviews were conducted in Middle Eastern countries. We believe the cultural difference will result in a different pattern of patient responses and HRQOL concerns.

Aiming to develop a patient-derived HRQOL instrument in Egypt, we interviewed adult strabismus patients in order to elicit specific issues affecting their QOL in Egypt. This research reported the results of the interviews, describing the patient's most common concerns in Egypt.

Patients

This study included 70 adult patients aged older than 18 years, with different types of strabismus started at least 6 months before the study, excluding patients who are not cooperative, with known history of any psychiatric disease and any patient with any other health-related issues affecting one's QOL.

Methods

This is a prospective cross-sectional study that was performed after obtaining an informed consent from

patients and approval of the study by Alexandria University Ethics Committee.

For the 20 patients with diplopia, diagnoses were: fourth nerve palsy (five), sixth nerve palsy (five), third nerve palsy (two), residual esotropia (four), orbital fracture entrapped muscle (one), consecutive esotropia (one), consecutive exotropia (one), and lost muscle during last surgery (two); four (20%) of the 20 were of childhood-onset strabismus.

For the 50 patients without diplopia, diagnoses were: sensory exotropia, partial accommodative esotropia, congenital esotropia, and accommodative esotropia. Forty-five (90%) of the 50 patients without diplopia had childhood-onset strabismus. To be included in the study, the patients were required to be comfortably conversant in Arabic.

Visual acuity of the 70 cases is mentioned in Table 1.

Individual patient interviews, using a series of 11 open-ended questions (Table 2) were conducted and recorded. The open-ended questions will be derived from previous studies reporting the psychosocial impact of strabismus in adults and from clinical experience [9–13]. All interviews were conducted by the researcher and each is expected to take from ~10 to 35 min depending on the individual [14].

Open discussion will be encouraged for each question. Patients will be interviewed until informational redundancy was reached (no new issues are being raised). Interviews will be transcribed and the transcripts reviewed to extract data for statistics.

For each patient, full history taking will be done, and it will include socioeconomic data as indicators for education and income. Full ophthalmological examination will be conducted to report the degree and type of strabismus as well as any other eye conditions.

Table 1 Distribution of the studied cases according to visual acuity

Visual acuity	Without diplopia (*N*=50) [*n* (%)]	With diplopia (*N*=20) [*n* (%)]	Total (*N*=70) [*n* (%)]
Right eye			
1 M	1 (2.0)	0 (0.0)	1 (1.4)
20/20	21 (42.0)	2 (10.0)	23 (32.9)
20/25	2 (4.0)	4 (20.0)	6 (8.6)
20/30	7 (14.0)	0 (0.0)	7 (10.0)
20/50	1 (2.0)	8 (40.0)	9 (12.9)
20/60	2 (4.0)	4 (20.0)	6 (8.6)
20/70	1 (2.0)	0 (0.0)	1 (1.4)
20/80	1 (2.0)	2 (10.0)	3 (4.3)
20/100	11 (22.0)	0 (0.0)	11 (15.7)
20/200	2 (4.0)	0 (0.0)	2 (2.9)
20/500	1 (2.0)	0 (0.0)	1 (1.4)
Left eye			
PL	1 (2.0)	0 (0.0)	1 (1.4)
Hand motion	1 (2.0)	0 (0.0)	1 (1.4)
No PL	1 (2.0)	0 (0.0)	1 (1.4)
20/20	11 (22.0)	6 (30.0)	17 (24.3)
20/25	8 (16.0)	4 (20.0)	12 (17.1)
20/30	3 (6.0)	0 (0.0)	3 (4.3)
20/40	1 (2.0)	0 (0.0)	1 (1.4)
20/50	6 (12.0)	4 (20.0)	10 (14.3)
20/60	0 (0.0)	1 (5.0)	1 (1.4)
20/70	2 (4.0)	0 (0.0)	2 (2.9)
20/80	0 (0.0)	5 (25.0)	5 (7.1)
20/100	6 (12.0)	0 (0.0)	6 (8.6)
20/200	4 (8.0)	0 (0.0)	4 (5.7)
20/16	1 (2.0)	0 (0.0)	1 (1.4)
20/150	1 (2.0)	0 (0.0)	1 (1.4)
20/300	2 (4.0)	0 (0.0)	2 (2.9)
20/400	1 (2.0)	0 (0.0)	1 (1.4)
20/800	1 (2.0)	0 (0.0)	1 (1.4)

M, meter; PL, perception of light.

Table 2 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?

Results

Seventy adult patients (median age, 35.0; range, 19.0–65.0 years) were recruited from the outpatient clinics. All types of strabismus were eligible for inclusion. Twenty of the 70 patients had diplopia and 50 did not; 29 (41.4%) patients were women and 41 patients 58.6% were men.

The number of topics mentioned by each patient were calculated. 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 (Table 3).

With diplopia

Nineteen (95%) of the 20 patients expressed concerns regarding the appearance to self, 18 (90%) of the 20 expressed concerns regarding self-esteem, for example, 'feel inferior' and 'don't feel normal.' Eighteen (90%) of the 20 expressed concerns regarding work, for example, 'I can't do my work' and 'can't go to work.' Sixteen (80%) of the 20 patients expressed concerns regarding financial, for example, 'I can't afford to do the investigations' and 'I can't afford to do the operation.' Sixteen (80%) of the 20 patients reported nonspecific negative feelings such as 'really hard,' 'emotionally draining,' and 'miserable' and 15 (75%) of the 20 reported problems with general disability, for example, '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 three (15%) of the 20 patients.

Without diplopia

Fifty (100%) of the 50 patients mentioned concerns regarding problems with eye contact, for example, 'struggle to look people in the eye,' 'look away from people.' Forty-five (90%) reported problems with appearance to others using phrases such as 'people notice my eyes,' 'people look at me funny,' and 'people think it looks terrible' and 45 (90%) reported problems with interpersonal relationships, for example, 'hard to talk to people,' 'makes people uncomfortable,' and 'problems dating.'

Similarities and differences between patients with and without diplopia

The 17 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'), social, appearance to others, appearance to self (e.g. 'hate appearance, keep one eye covered,' 'my looks freak me out'), financial (e.g. 'appearance decreased my income,' 'lost jobs because of lack of eye contact'); frustrating, general disability, general visual function (e.g. 'almost like being blind,' 'miss things that are going on'), anxiety, nonspecific negative feelings, resignation (e.g. 'learning to live with it'), annoying, 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'), work (e.g. 'takes me longer to do things at work and efforts to reduce symptoms).

Seven topics were mentioned only by the patients with diplopia; these were, back/neck pain (five of 20; 25%), walking (eight of 20; 40%), bump into things (six of 20; 30%), compensatory body posture (13 of 20; 65%), depth perception (two of 20; 10%), lighting (six of 20; 30%), and monocular eye closure (13 of 20; 65%).

Table 3 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

	Without diplopia (*N*=50) [*n* (%)]	With diplopia (*N*=20) [*n* (%)]	Total (*N*=70) [*n* (%)]
Adaptation	37 (74.0)	14 (70.0)	51 (72.9)
Annoying	40 (80.0)	16 (80.0)	56 (80.0)
Anxiety	43 (86.0)	18 (90.0)	61 (87.1)
Appearance to others	42 (84.0)	14 (70.0)	56 (80.0)
Appearance to self	45 (90.0)	19 (95.0)	64 (91.4)
Appearance in photos	26 (52.0)	0 (0.0)	26 (37.1)
Behavior	20 (40.0)	11 (55.0)	31 (44.3)
Back neck pain	0 (0.0)	5 (25.0)	5 (7.1)
Bump into things	0 (0.0)	6 (30.0)	6 (8.6)
Busy strange environments	27 (54.0)	8 (40.0)	35 (50.0)
Compensatory body posture	0 (0.0)	13 (65.0)	13 (18.6)
Computer	9 (18.0)	3 (15.0)	12 (17.1)
Concentration	20 (40.0)	8 (40.0)	28 (40.0)
Confidence of others	38 (76.0)	3 (15.0)	41 (58.6)
Cooking	10 (20.0)	2 (10.0)	12 (17.1)
Depression	10 (20.0)	5 (25.0)	15 (21.4)
Depth perception	0 (0.0)	2 (10.0)	2 (2.9)
Driving	10 (20.0)	3 (15.0)	13 (18.6)
Education	25 (50.0)	0 (0.0)	25 (35.7)
Effect of fatigue	25 (50.0)	5 (25.0)	30 (42.9)
Efforts to reduce symptoms	25 (50.0)	10 (50.0)	35 (50.0)
Eye contact	50 (100.0)	3 (15.0)	53 (75.7)
Eye contact from others	50 (100.0)	4 (20.0)	54 (77.1)
Eye fatigue	32 (64.0)	3 (15.0)	35 (50.0)
Financial	40 (80.0)	16 (80.0)	56 (80.0)
Frustrating	45 (90.0)	12 (60.0)	57 (81.4)
General disability	37 (74.0)	15 (75.0)	52 (74.3)
General visual function	40 (80.0)	15 (75.0)	55 (78.6)
Headache	9 (18.0)	5 (25.0)	14 (20.0)
Hobbies	22 (44.0)	3 (15.0)	25 (35.7)
Interpersonal relationships	45 (90.0)	6 (30.0)	51 (72.9)
Jealousy	0 (0.0)	0 (0.0)	0 (0.0)
Lack of support	0 (0.0)	0 (0.0)	0 (0.0)
Lighting	0 (0.0)	6 (30.0)	6 (8.6)
Marriage	40 (80.0)	0 (0.0)	40 (57.1)
Meeting people	45 (90.0)	1 (5.0)	46 (65.7)
Monocular eye closure	0 (0.0)	13 (65.0)	13 (18.6)
No treatment for squint	27 (54.0)	0 (0.0)	27 (38.6)
Nonspecific negative feeling	45 (90.0)	16 (80.0)	61 (87.1)
Physical discomfort	32 (64.0)	6 (30.0)	38 (54.3)
Prisms	2 (4.0)	13 (65.0)	15 (21.4)
Reading	20 (40.0)	3 (15.0)	23 (32.9)
Resignation	32 (64.0)	18 (90.0)	50.0 (71.4)
Self-confidence	45 (90.0)	18 (90.0)	63 (90.0)
Self-conscious	45 (90.0)	18 (90.0)	63 (90.0)
Self-esteem	45 (90.0)	18 (90.0)	63 (90.0)
Sewing	0 (0.0)	0 (0.0)	0 (0.0)
Social	47 (94.0)	18 (90.0)	65 (92.9)
Specific disability	17 (34.0)	7 (35.0)	24 (34.3)
Steps	0 (0.0)	0 (0.0)	0 (0.0)
Sports	3 (6.0)	2 (10.0)	5 (7.1)
Teasing	43 (86.0)	9 (45.0)	52 (74.3)
Walking	0 (0.0)	8 (40.0)	8 (11.4)
Work	30 (60.0)	18 (90.0)	48 (68.6)

(*Continued*)

Four topics were mentioned only by the patients without diplopia appearance in photos (26 of 50; 52%), education (25 of 50; 50%), marriage (40 of 50; 80%), and no treatment for squint (27 of 50; 54%).

The biggest differences in topic frequencies between diplopic and nondiplopic patients were in the areas of eye contact and eye contact from others, with diplopic patients mentioning these concerns much less frequently.

Discussion

Strabismus in adults causes a wide range of QOL concerns; for patients with diplopia the most common issues identified in this study were nonspecific negative feelings and general disability, whereas for patients without diplopia the most common concerns were appearance to others, eye contact, and interpersonal relationships. Patients with and without diplopia frequently identified problems with nonspecific negative feelings and self-esteem.

The nature of QOL concerns was different for nondiplopic and diplopic patients: nondiplopic patients primarily expressed problems with interpersonal relationships and nonverbal 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 [14].

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 [13,14]. Nevertheless, some concerns identified in this study were more unexpected, for example, appearance in photos, education, marriage, and no treatment for squint. Other concerns in this study were unexpected as most of the patients did not express these problems, for example, in-depth perception, driving, and sports.

The differences between patients in the number of topic areas mentioned suggest that 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 [13] and employment opportunities[12], but it remains unknown how different personalities and occupations affect and how an individual deals with strabismus [14].

We investigated the impact of strabismus on HRQOL in adults using multiple in-depth interviews [14].

There are many strabismus-specific HRQOL instruments that have been derived. These were based on interviews conducted in their relevant countries and hence affected by cultural and socioeconomic factors in these countries [14]. No such interviews were conducted in Middle Eastern countries. We believe the cultural difference will result in a different pattern of patient responses and HRQOL concerns.

Aiming to develop a patient-derived HRQOL instrument in Egypt, we interviewed adult strabismus patients in order to elicit specific issues affecting QOL in Egypt. This research reported the results of the interviews, describing patient's most common concerns in Egypt.

Our approach of using multiple patient interviews in order to capture QOL 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 our study cohort did not 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 generalizable to the entire population of adult patients with strabismus. For example, some of the concerns expressed by patients with fourth nerve palsy may not be recognized by patients with sensory esotropia and vice versa. Nevertheless, our goal was to identify a broad range of concerns to develop an 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 in Egypt [14].

A study by Van de Graaf *et al.* [10] collected 'an inventory of all problems' from outpatients with strabismus or amblyopia. Van de Graaf *et al.* [10] categorized complaints into three themes (loss of depth perception, diplopia, visual disorientation, and appearance) by means of a focus group and were then further divided into domains in order to develop an amblyopia and strabismus HRQOL questionnaire. 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 [14].

In Hatt *et al.* [14] study 30 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 three investigators. Phrases

regarding how strabismus affected everyday life were grouped into topic areas and the frequency of each topic analyzed for patients with and without diplopia.

Concerning visual acuity, we found that a large number were severely amblyopic. The visual acuity ranged from no perception of light and hand motion to 20/20, unlike the previous study which ranged from 20/160 to 20/20.

Without diplopia

Our patient mentioned these concerns that were not mentioned in the other study: appearance in photos, behavior, depression, education, and marriage. Some patients believed that there was no treatment for squint and they have to live with it. Marriage was one of the main concerns that affected a lot of people, as squint affected their relationship with others and their self-confidence. Also a lot of proposals were refused because they had squint. Most patients who did not undergo the squint surgery were single for a long period. Some patients refuse to take photos of themselves to the extent that one case refuses to take photos in her daughter's wedding. Other patients left the education because their colleges were annoying them.

But in our study we found that our patients did not express these concerns a lot as in other studies: Compensatory body posture, depth perception, driving, lighting monocular eye closure, and sports. Some did not know that there is a treatment for the strabismus; a lot of people see squint as a stigma for life.

With diplopia

In our study we found that our patients did not express these concerns a lot as in other studies: depth perception, driving, hobbies, reading, sports, computer, and lack of support.

Depth perception was not mentioned by our patients mainly because most of them did not understand the expression or cannot express their feelings about it. Reading, hobbies, and sports are considered by a lot of people in Egypt as a luxury that they do not experience; that is why they were not one of their concerns as in the previous study.

Our patients mentioned these concerns that were not mentioned in the other study: behavior and depression. Some patients lost hope, did not want to do anything, and others became more aggressive

Depression affected 25% of our patients; however, it was not mentioned in the previous study. Depression led a lot of patients to lose hope and become less social that some of them cried during the interview.

Multiple individual interviews conducted as part of this study identified many ways in which strabismus affects QOL in adults in Egypt with and without diplopia. The frequency and type of concerns found in this study confirm the importance of HRQOL assessment as an important aspect of strabismus management and provide a basis for developing an AS20 questionnaire in Egypt and proved that cultural difference resulted in a different pattern of patient responses and HRQOL concerns.

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Conflicts of interest

There are no conflicts of interest.

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