

LIVING AND COPING WITH STRABISMUS AS AN ADULT

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ABSTRACT

Aim/Background: Despite much research on the psychosocial impact of adult strabismus, some employing standardised measures, coping seems poorly delineated. This study aimed to: 1. document problems and their related coping strategies; 2. examine the relevance of a quality of life standardised measure (WHOQOL-BREF).

Methods: A content analysis on structured interview data from 75 individuals was undertaken using the questionnaire items in the four domains of the WHOQOL-BREF as an explicit coding structure. Coping strategies were categorised into three types: 1. adjustment, 2. avoidance, 3. deflection.

Results: Participant data coded reasonably well in all but the social relationships domain. Only women with an exotropic strabismus recorded problems in the psychological domain. Individuals with cosmesis had significantly more items in the social domain, including bullying and name-calling; while individuals with diplopia reported significantly more physical difficulties ($p < .001$). Individuals with cosmesis used deflection significantly more than those with diplopia ($p < .038$). Patterns of deflection and adjustment significantly varied within WHOQOL-BREF domains ($p < .037$).

Conclusions: If the aim is to understand and support adult strabismus, then these data indicate a need for strabismus-specific measures of psychosocial impact and adjustment, and more specifically a move away from the current adaptive/maladaptive taxonomy of coping strategies.

Keywords: Strabismus, adults, psychosocial, coping, qualitative.

INTRODUCTION

In recent years, there has been a move towards trying to understand the psychosocial impact of adult strabismus. In the process, it has been described as a disfigurement and a disability.¹⁻³ Examples of psychosocial sequelae include individuals avoiding mirrors and refusing to be photographed.^{4,5} Burden⁶ implied the condition can affect relationships and occupational roles, a point supported by Nelson and Wagner⁷ who extended the problems to include difficulties related to self-image. However, research in this area is limited. At least two studies have attempted to investigate the possible stigma attached to having an uncorrected strabismus as

an adult by means of researching the impact on the observer. Both Coats et al.⁸ and Olitsky et al.⁹ used a digitally-altered photograph of an individual in extreme esotropic and exotropic conditions as a stimulus to record the responses of adults without strabismus. Results indicated a greater negative bias against women with strabismus, and those with an esotropic strabismus.

Hatt et al.,¹⁰ in an interview study with 30 participants, concluded that adult strabismus results in a wide range of quality of life concerns including negative feelings, problems in relation to daily living activities, and lowered self-esteem. However, the literature seems totally silent on how adults with strabismus

PARTICIPANT INTERVIEW SCHEDULE

Section A: Coping

A1. What have been the most difficult things to cope with as a result of your strabismus?

- (1) _____
(2) _____
(3) _____

A2. How have you dealt with the above?

- (1) _____
(2) _____
(3) _____

A3. In relation to (1), (2) and (3) above, how successful do you feel these coping strategies have been? *(Please mark the line with a slash through it, as before.)*

- (1) Not at all _____ Very much
(2) Not at all _____ Very much
(3) Not at all _____ Very much

Figure 1. Structured interview schedule and data recording form.

manage the problems they face. Certainly, the review of the psychosocial effects of adult strabismus by Durnian et al.¹¹ makes no mention of any research exploring how adults with strabismus cope with their condition. While there is now a psychometrically robust tool for measuring the psychosocial impact of strabismus (the AS-20 developed by Hatt et al.¹²⁻¹⁴), there seems to be a lack of attention directed towards exploring and measuring the effectiveness of the coping strategies employed by adults with strabismus.

Research in adult strabismus has been purely quantitative or qualitative. Quantitative methods (i.e. questionnaires) are used on the assumption that their items are of relevance to the studied population. Qualitative methods allow for an exploration of issues identified as relevant by the study population.¹⁵ The use of mixed methodologies is a way of gaining greater understanding of a particular issue by collecting data that potentially allows the consideration of different perspectives.¹⁶

Jackson et al.¹⁷ highlighted the limitations of reliance on standardised measures in adult strabismus. So, while this study set out to explore and document the issues faced by adults with strabismus with particular reference to the coping strategies employed, it also innovatively explored the relevance of the WHOQOL-BREF, a standardised measure of quality of life.¹⁸

METHODS

Design

Part of a larger mixed-methods repeated-measures study, this report focuses on the qualitative data (the quantitative data is reported elsewhere).^{17,19}

Measures

A structured interview was carried out with each participant lasting, on average, 15 minutes. The interview was similar to the kind of short focused discussion described by Carr,²⁰ where the aim is to look in greater depth and detail at a relatively small

Table 1a. Demographic features of surgical group participants pre-operatively (n=47).

Gender	Male 25 (53%); female 22 (47%)
Ethnicity	White 46; Black-Caribbean 1
Age	16 to 61 years
Cause of strabismus	From birth 38 (80.9%); accident 4 (8.5%); unknown cause 3 (6.4%); illness 2 (4.3%)
Previous treatment	Operation 27 (57.4%); other treatment 5 (10.6%); no treatment 15 (31.9%)
Presence/absence of diplopia	Diplopia present 20 (43%); no diplopia 27 (57%)
Direction of strabismus	Esotropia 15 (31.9%); exotropia 32 (68.1%)

Table 1b. Demographic features of comparative group participants (n=28).

Gender	Male 12 (43%); female 16 (57%)
Ethnicity	White 27; Black-Caribbean 1
Age	24 to 79 years
Cause of strabismus	From birth 23 (82%); accident 2 (7%); unknown cause 2 (7%); illness 1 (4%)
Previous treatment	Operation as a child 16 (57%); other treatment 4 (14%); no treatment 8 (29%)
Presence/absence of diplopia	Diplopia present 10 (36%); no diplopia 18 (64%)
Direction of strabismus	Esotropia 11 (39%); exotropia 17 (61%)

subject area; in this case, the problems adults with strabismus face on a day-to-day basis and their related coping strategies. Elicited statements were recorded on the interview schedule as they occurred so participants could both see and confirm the accuracy of reporting (Figure 1). Visual Analogue Scales (VAS), considered easy for respondents to complete and often used in clinical assessments,²⁰ were employed to record the relative success of reported coping strategies (see Figure 1, A3).

Procedure

Ethical approval

Ethical approval was obtained from both the United Bristol Health Care Trust Ethics Committee and the University of the West of England Ethics Committee.

Recruitment

Two participant groups were recruited: patients over the age of 16 with a strabismus suitable for surgical correction, attending Bristol Eye Hospital or Great Western Hospital, Swindon (surgical group); and people who contacted the researcher as a result of newspaper editorials concerning the study (comparative group).

Surgical group participants were seen at their 6-week pre-surgery hospital appointment. Comparative group participants contacted the researcher by phone to discuss the study and were given the choice of either a phone or a face-to-face interview. Additionally, all participants completed a questionnaire pack including three standardised questionnaires:

1. Derriford Appearance Scale (DAS-24)²¹
2. WHOQOL-BREF¹⁸
3. Hospital Anxiety and Depression Scale²²

Data on the nature and severity of strabismus were obtained from the surgical group's medical records and were self-reported by the comparative group.

Participants

The surgical group comprised of an opportunity sample of 98 patients, of which 47 completed both the questionnaires and interview elements of the study - a response rate of 48%. The comparative group comprised of a self-selecting opportunity sample of 28 people, 78% of the 36 who contacted the researcher. See Table 1 for demographic data.

Table 2: Qualitative responses coded by WHOQOL-BREF domains for both the surgical group (n=47) and the comparative group (n=28).

	WHOQOL-BREF domains				Chi-Square results
	Physical	Psychological	Social	Environment	
<i>Surgical group (n=47)</i>					
Gender (M/F)	14/17	0/8	20/17	4/6	$\chi^2=7.877, p<.049$
Cosmesis/Diplopia	7/24	5/3	27/10	0/10	$\chi^2=27.12, p<.001$
Esotropic/Exotropic	15/16	1/7	7/30	5/5	$\chi^2=9.523, p<.023$
Total (% of total items)	31 (36%)	8 (9%)	37 (43%)	10 (12%)	
<i>Comparative group (n=28)</i>					
Gender (M/F)	7/15	1/5	8/9	2/6	Non-significant
Cosmesis/Diplopia	12/10	4/2	13/4	5/3	Non-significant
Esotropic/Exotropic	11/11	4/2	7/10	5/3	Non-significant
Total (% of total items)	22 (42%)	6 (11%)	17 (32%)	8 (15%)	

Data Analysis

Statistical analysis of the quantitative data (reported in Jackson et al.¹⁷) suggested that the WHOQOL-BREF was not focused on the relevant issues for this patient population. Therefore, a content analysis was carried out where the four domains of the WHOQOL-BREF and their related items were used as an explicit coding structure within which to analyse the interview data (Table 3).²³ Participant statements were coded to a domain if they related to the questionnaire item but were not necessarily worded the same way (e.g. “confidence” was coded as “satisfaction with self” in the psychological domain). The use of this predetermined structure highlighted difficulties in coding certain statements, for example, driving could code as “activity of daily living” in the physical domain, but could also be coded as “satisfaction with transport”, an environment domain issue. Where these ambiguities occurred, the data were coded as appearing in both domains, indicated as it occurs in the results. A count was then made of the number of items appearing in each domain.²⁴

RESULTS

All but one of the surgical group participants identified at least one aspect of living with strabismus that was difficult for them; some identified more. All data were included, resulting in 74 statements,

and duplication of 12 between domains resulted in 86 statements in total (Table 2). The comparative group generated 46 statements, and duplication of 7 between domains resulted in a total of 53 statements.

There was non-significant variation (Chi-Square test) between the total responses from the two groups. In the comparative group, the physical domain had the most responses followed by the social relationships domain, a trend reversed in the surgical group. For both groups the psychological domain contained the least entries. Also for both groups, the environment domain was effectively a subset of the physical domain.

Chi-Square tests on the surgical group data revealed significant differences between the responses by domain in relation to gender, with only female participants recording items in the psychological domain (Table 2). Similarly, only individuals with diplopia recorded items in the environment domain, and significantly more problems in the physical domain, while participants with cosmesis contributed significantly more items to the social relationships domain. Finally, those with an exotropic strabismus recorded significantly more items in the psychological and social domains. No significant results were observed for the comparative group data.

Table 3: Participant responses to the subjects covered by each domain of the WHOQOL-BREF questionnaire (The WHOQoL Group, 1998) used in the content analysis of the interview data for both the surgical group (n=47) and comparative group (n=28).

	Surgical group (n=47)	Comparative group (n=28)
Physical domain		
Pain	5	2
Medical treatment	0	3
Energy	0	0
Ability to get around	8	6
Sleep	0	0
Daily living activities	13	10
Capacity for work	0	0
<i>Extra participant items coded into the physical domain</i>		
Can't see properly	2	1
Everything!	1	0
Environment domain		
Safety in daily life	1	0
Health of physical environment	0	0
Money	0	0
Availability of information	0	0
Leisure activities	0	2
Conditions of living place	0	0
Access to health services	0	0
Satisfied with transport	8	6
<i>Extra participant items coded into the environment domain</i>		
Everything!	1	0
Social relationships domain		
Personal relationships	8	3
Sex	0	0
Support from others	0	0
<i>Extra participant items coded into the social relationships domain</i>		
Others not sure of gaze	7	0
Lack of confidence in meeting others	6	5
Lecturing	1	0
Meeting stranger's gaze	8	3
People staring	2	0
Other people's reactions	4	4
Other's focusing on squint	0	1
People's comments on opaque lens	0	1
Everything!	1	0
Psychological domain		
Ability to enjoy life	0	0
The extent to which life is meaningful	0	0
Ability to concentrate	0	0
Satisfaction with bodily appearance	4	5
Satisfaction with self	3	1
Negative feelings	0	0
<i>Extra participant items coded into the psychological domain</i>		
Everything!	1	0

Table 4: Coping types for both the surgical group (n=47) and the comparative group (n=28).

Coping type	Used (Y/N)	Total	Gender (M/F)	Cosmesis/Diplopia	Esotropia/Exotropia	WHOQOL-BREF domains			
						Physical	Psych	Social	Env
<i>Surgical group (n=47)</i>									
Deflect	Yes	21	8/13	16/5**	7/14	0**	4**	17**	0**
	No	65	30/35	23/42**	21/44	31**	4**	20**	10**
Adjust	Yes	52	25/27	22/30	19/33	25*	3*	18*	6*
	No	34	13/21	17/17	9/25	6*	5*	19*	4*
Avoid	Yes	26*	10/16	9/17	9/17	10	2	8	6
	No	60*	28/32	30/30	19/41	21	6	29	4
<i>Comparative group (n=28)</i>									
Deflect	Yes	11	5/6	10/1*	4/7	1*	2*	8*	0*
	No	42	13/29	24/18*	23/19	21*	4*	9*	8*
Adjust	Yes	38	11/27	20/18*	19/19	19*	4*	8*	7*
	No	15	7/8	14/1*	8/7	3*	2*	9*	1*
Avoid	Yes	8*	2/6	6/2	6/2	3	1	2	2
	No	45*	16/29	28/17	21/24	19	5	15	6

Key: *=significant p<.05; **=significant p<.001

Coding Data Using the WHOQOL-BREF

The participant responses seemed to code reasonably well with the WHOQOL-BREF items for the physical domain (Table 3). There were only two statements that could not be coded; the participant who said that “everything” was a problem, and the individual who reported difficulty in seeing properly. Similarly, all but one statement could be coded in the environment domain, but this domain contained five questionnaire items where no participant statements were coded.

The social relationships domain is measured by only three items, and coding to these proved challenging. 13 statements from the surgical group related to social interactions, from a general lack of confidence in meeting others, to problems in talking to other people. This domain contained the most items that could not be coded directly to WHOQOL-BREF items, although problems such as bullying, name-calling and staring could be examples indicating a lack of support from others.

In the psychological domain, participant statements were coded to items that might be described as being related to appearance and self-esteem; it also contained a number of empty questionnaire items.

Coping with Strabismus

An innovative superordinate three-category coding system was applied to the participants’ reported coping strategies based on an interpretation of these data as follows: 1. avoid - not doing the activity; 2. adjust - doing the activity in a different way (e.g. taking regular breaks); 3. deflect - doing the activity employing a method meant to distract attention from the strabismus (e.g. joking about it). To take account of participants who reported more than one coping strategy per problem, coping types were entered into SPSS as dichotomous yes/no variables (Table 4).

There was significant between-groups variation (Chi-Square test) in relation to coping types (Table 4, ‘Total’ column), with more avoidant coping recorded in the surgical group ($\chi^2=4.067$, $p<.044$). There were no significant within-group differences in coping type in relation to gender, or squint direction. In both groups, individuals with cosmesis used deflection significantly more than those with diplopia (surgical group $\chi^2=10.664$, $p<.001$; comparative group $\chi^2=4.322$, $p<.038$). In the comparative group, the pattern of use of adjustment was also significant ($\chi^2=7.747$, $p<.005$). For both groups, significant patterns of responses were observed in relation to the use of both deflection and adjustment within the WHOQOL-BREF domains (deflection: surgical group

$\chi^2=25.373$, $p<.001$, comparative group $\chi^2=13.339$, $p<.004$; adjustment: surgical group $\chi^2=9.208$, $p<.027$; comparative group $\chi^2=8.477$, $p<.037$).

Table 5 (not shown here, available online <http://independent.academia.edu/SueJackson/Papers>) contains a detailed list of the issues and coping strategies coded to the WHOQOL-BREF domains. A variety of coping strategies were reported, however, judging the relative success (VAS scores) was difficult as there were multiple instances of individuals reporting at least two or three different coping strategies for one problem, with a combined VAS. Regression analysis was non-significant indicating none of the study variables explained the variance of the VAS.

While a coping strategy might be used by many participants, the reported success varied between individuals. For example, in the social domain, "using specific poses" had scores ranging from 3 to 6.8. The use of multiple coping strategies did not necessarily result in high VAS. For example, in the physical domain, one of the surgical group participants had a three-part coping strategy with a VAS of 4.7.

DISCUSSION

As in previous research, these data suggest a perceived or actual negative social bias towards those with strabismus,^{6,25} associated with problems in self-image, interpersonal relationships, and employment.⁷

As in Satterfield's study,²⁶ some participants reported bullying and name-calling. In particular, women with an exotropic strabismus reported issues related to appearance and self-esteem, while individuals with diplopia reported more physical difficulties.

Moss,²⁷ in a counter-intuitive challenge to the importance of objective severity, provided evidence that poor adjustment is key in understanding the psychosocial impact of conditions affecting appearance. However, research on coping strategies tends to employ a limited adaptive/maladaptive taxonomy.²⁸ The innovative categorisation employed here (i.e. avoidance, distraction and adjustment) has revealed a more nuanced picture of coping strategies as they relate to interactions between factors such as the nature of the situation (physical or social), gender, and the diplopic status of the individual.

It is arguable how effective or acceptable surgery is in tackling a condition associated with social distress. Certainly previous research indicates that many of those affected with adult strabismus delay seeking surgical treatment, in some cases for decades.^{29,30} Social solutions such as interpersonal skills training may be more acceptable, however, despite increased awareness and recognition of the psychosocial impact of appearance-related conditions, it has been suggested that healthcare professionals can find it difficult to offer psychosocial support to help patients cope due to a lack of confidence, resources and skills.³¹

In illustrating the discrepancies between the WHOQOL-BREF questionnaire items and participant issues, these data offer an explanation for the non-significant effects of surgery reported by Jackson et al.¹⁷ in relation to the social and environment domains. Further, they make the case for properly researched, condition-specific measures, but suggest a need to move away from a reliance on standard methods of interpretation involving means, standard deviations and clinical cut-offs if we are to effectively identify and understand where individuals require help and support.

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