

## Is there a North–South divide in quality of life for children undergoing amblyopia treatment?

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### Abstract

**Aim:** Variation in health care provision between and within countries can lead to differences in clinical outcome. Amblyopia treatment success is widely reported; however, consideration is not always given to whether similar results can be expected in other areas of the world. The impact of treatment upon an individual is poorly documented. This study aimed to investigate whether regional differences in self-reported quality of life (QoL) exist in the treatment of amblyopia.

**Methods:** Data were collected from three Trusts within the United Kingdom (UK) to form North (one Trust) and South cohorts (two Trusts). QoL data were collected from the child's perspective using the Child Amblyopia Treatment Questionnaire (CAT-QoL) instrument. Socio-demographic and clinical data were collected by the clinician. Overall mean scores obtained from the CAT-QoL were compared between a number of clinical and socio-demographic factors (type of amblyopia treatment, patient age, socio-demographic status, ethnicity, amblyopia severity). Two-way ANOVA was calculated for each variable.

**Results:** The South cohort was found to have a higher CAT-QoL score (South 4.28; North 3.62); this was not statistically significantly different ( $p = 0.182$ ). Statistically significant main effects for current treatment type ( $p = 0.04$ ) and age were found ( $p = 0.04$ ). No statistically significant interactions were found between location and age, treatment type, socio-demographic status, ethnicity or amblyopia severity.

**Conclusions:** This study could find no statistically significant evidence to suggest that regional differences exist in the self-reported QoL of children undergoing amblyopia treatment. Age and type of amblyopia treatment were factors associated with worse QoL scores.

**Key words:** Amblyopia, Child, Paediatric, Quality of Life (QoL), Treatment

### Introduction

Inequalities in health care provision across developed and developing countries are widely documented. Differences between countries are to be expected due to differing populations, demands and health care systems. In recent years there has been increasing evidence to suggest that a North–South divide exists within the United Kingdom (UK). Trends in mortality,<sup>1</sup> wages,<sup>2</sup> house prices<sup>3</sup> and unemployment<sup>4</sup> would suggest that living in the South could lead to a longer and more financially secure life. Individual social class inequalities in self-rated general health have also been explored, with large inequalities found depending on where subjects lived.<sup>5</sup>

Evidence-based practice has led us to evaluate the impact a medical condition and/or its treatment has upon an individual. There is increasing interest in capturing the impact of treatment from a patient's perspective, as reflected by the Patient Reported Outcome Measures (PROMs) Programme initiated by the Department of Health (DH).<sup>6</sup> Recent studies have explored the impact of amblyopia and/or its treatment.<sup>7,8</sup> However, there has been little research exploring factors associated with quality of life (QoL) in amblyopia treatment and whether these are influenced by geographical location. This study aimed to investigate whether regional differences in self-reported QoL exist in the treatment of amblyopia, and whether these are influenced by any clinical or socio-demographic factors.

### Methods

Data for this study were collected as part of the development phase of the Child Amblyopia Treatment Questionnaire (CAT-QoL) instrument. The CAT-QoL is a short questionnaire that was designed for children aged 4–7 years to measure the impact of amblyopia from the child's perspective. The instrument was developed through a series of methodological processes including: a systematic literature review; focus groups with clinicians; semi-structured interviews with children with amblyopia; cognitive de-briefing and ranking exercises; and Rasch analysis.<sup>9–14</sup> Data for the development study were collected from nine sites across England; however, the results reported here were from three sites: Doncaster and Bassetlaw NHS Foundation Trust formed the North cohort; Maidstone and Tunbridge Wells NHS Trust and Medway NHS Foundation Trust formed the South cohort. The inclusion criteria were that the child was

at least 4 years of age and had a clinical diagnosis of amblyopia for which they were currently undergoing treatment. Written parent/guardian consent was obtained prior to data collection. Participants were asked to complete a version of the CAT-QoL questionnaire, issued by the clinician. Socio-demographic and clinical data were collected by the clinician.

### CAT-QoL

Seven treatment-specific versions of the CAT-QoL exist, with each version worded slightly differently to reflect the type of treatment the child is undertaking. The instrument contains eight items which are scored on a 3-level response scale. The instrument scores range from 0 to 16, where a greater score indicates a worse quality of life. Further details on the CAT-QoL instrument are available ([www.cat-qol.org](http://www.cat-qol.org)). Children were asked to complete the CAT-QoL instrument after their routine orthoptic examination.

### Participants

Subjects were categorised in terms of the interocular severity difference between the two eyes at the time of the questionnaire. These were: mild amblyopia  $0 \leq 0.3$  logMAR, moderate amblyopia  $0.31 \leq 0.60$  logMAR, and severe amblyopia  $>0.61$  logMAR. Postcode data of each participant was used to categorise participants into socio-demographic classes.

### Statistical analysis

Overall mean scores obtained from the CAT-QoL instrument were compared between a number of clinical and socio-demographic factors. These included type of amblyopia treatment, patient age, socio-demographic status, ethnicity and amblyopia severity. Two-way ANOVA was calculated for each variable. All analyses were conducted using IBM SPSS Statistics version 19.0.

### Results

Data were collected from 29 June 2011 to 31 October 2011. Summary statistics of the cohorts are shown in Table 1. Descriptive statistics for mean health-related QoL (HRQoL) scores obtained from the CAT-QoL instrument are shown in Table 2. Some participants did not fully complete the CAT-QoL questionnaire, and were therefore excluded from analysis. The South cohort was found to have a higher CAT-QoL score (indicating a worse level of HRQoL). An independent-samples *t*-test was conducted to compare HRQoL using the CAT-QoL instrument for the North and South groups. There was no statistically significant difference in HRQoL scores ( $t(120) = -1.34, p = 0.182$ ). Descriptive statistics for the CAT-QoL instrument scores and cohort are shown in Table 3.

#### HRQoL and current treatment type

Table 3 shows only small numbers of participants undergoing particular treatment (*patch*, *glasses* and *drops*). The majority of participants were prescribed *glasses only* treatment, or *patch and glasses* treatment. It

**Table 1.** Summary statistics for the two cohorts

	North	South
<b>Total</b>	79	68
<b>Gender</b>		
Male	43	37
Female	36	31
<b>Age (years)</b>		
4	5	0
5	40	36
6	24	24
7	9	8
8	1	0
Average age (SD)	5.51 (0.83)	5.59 (0.70)
<b>Ethnicity</b>		
White	76	48
All other	3	20
<b>Socio-demographic status</b>		
1 (worst deprived)	31	1
2	23	13
3	10	11
4	14	21
5 (least deprived)	1	22
<b>Presence of any co-morbidities</b>		
Yes	2	8
No	77	60
<b>Current treatment type</b>		
Patch	1	1
Glasses	46	15
Patch and glasses	32	51
Glasses and drops	0	1
<b>Level of amblyopia</b>		
0 <sup>a</sup>	12	2
Mild	58	47
Moderate	8	17
Severe	1	1
Missing data	0	1

<sup>a</sup>Undergoing maintenance occlusion.

can be seen that the North and South cohorts are not equally distributed, with more of the participants in the South cohort prescribed *patch and glasses* ( $n = 49$  vs.  $n = 31$ ). In both cohorts the mean CAT-QoL score of the *patch and glasses* group was greater than that of the *glasses only* group (North 4.12 cf. 3.17; South 4.62 cf. 3.16). The interaction effect between location and current treatment type was not statistically significant ( $F(2, 125) = 0.512, p = 0.60$ ). There was a statistically significant main effect for current treatment type ( $F(2, 125) = 2.82, p = 0.04$ ); the effect size was medium (partial eta squared = 0.063).

#### HRQoL and age

The groups were divided into *pre-school* (aged  $<5$  years) and *school-aged* ( $>6$  years). Table 3 shows the two cohorts to be different, with the majority of the South cohort of pre-school age ( $n = 58$ ). A more equal distribution is seen in the North cohort. In both cohorts the mean CAT-QoL score was greater in the *school-aged* group. The interaction effect between location and age was not statistically significant ( $F(2, 128) = 0.337, p = 0.56$ ). There was a statistically significant main effect for age ( $F(2, 128) = 4.30, p = 0.04$ ); the effect size was small (partial eta squared = 0.003).

#### HRQoL and socio-demographic status

Table 3 shows the distribution of the sample across socio-demographic groups. The North cohort has more

**Table 2.** Descriptive statistics for the CAT-QoL instrument

	Instrument	<i>n</i>	Range	Minimum	Maximum	Mean	Standard deviation
North	CAT-QoL	66	8.7	0	8.7	3.62	2.40
South	CAT-QoL	66	12.6	0	12.6	4.28	3.20

**Table 3.** Descriptive statistics for the CAT-QoL instrument scores and cohort

	North				South			
	Sample	CAT-QoL			Sample	CAT-QoL		
		<i>n</i>	Mean	SD		<i>n</i>	Mean	SD
<b>Overall</b>	79	66	3.62	2.40	68	66	4.28	3.20
<b>Ethnicity</b>								
White	76	64	3.70	2.39	48	47	4.39	3.26
All other	3	2	1.05	1.48	20	19	4.03	3.13
<b>Socio-demographic status</b>								
1 (worst deprived)	31	25	4.26	2.32	1	1	3.70	0
2	23	19	3.58	2.78	13	13	4.76	2.25
3	10	8	3.11	1.92	11	10	3.86	2.95
4	14	13	2.75	2.22	21	20	4.53	3.45
5 (least deprived)	1	1	3.70	0	22	22	4.00	3.74
<b>Age</b>								
Pre-school (4–5 years)	45	39	3.09	2.11	36	58	3.95	2.63
School (6 years plus)	34	27	4.40	2.62	32	8	4.69	3.79
<b>Current treatment</b>								
Patch	1	1	3.70	0	1	1	7.60	0
Glasses	46	34	3.17	2.14	15	14	3.16	3.36
Patch and glasses	32	31	4.12	2.65	51	49	4.62	3.09
Glasses and drops	0	0	0	0	1	1	0.00	0
<b>Amblyopia severity</b>								
0 <sup>a</sup>	12	11	2.28	2.43	2	2	1.85	2.62
Mild	58	47	3.70	2.29	47	45	4.13	3.35
Moderate	8	8	5.01	2.38	17	17	5.05	2.97
Severe	1	0	0	0	1	1	3.70	0

<sup>a</sup>Undergoing maintenance occlusion.

participants from *worst deprived* areas, compared with the South cohort (North  $n=25$ , South  $n=1$ ). In the North cohort there is some suggestion that mean CAT-QoL scores are greater in the more deprived areas (with the exception of the one participant in group 5, the least deprived area). This pattern is not seen in the South cohort. The interaction effect between location and socio-demographic status was not statistically significant ( $F(9, 122) = 0.220$ ,  $p = 0.93$ ). There was no statistically significant main effect for socio-demographic status ( $p = 0.93$ ) or location ( $p = 0.49$ ).

#### HRQoL and ethnicity

Table 3 shows the two cohorts are not matched in terms of ethnicity, with the vast majority of participants in the North cohort being *White*. The interaction effect between location and ethnicity was not statistically significant ( $F(3, 128) = 1.11$ ,  $p = 0.29$ ). There was no statistically significant main effect for ethnicity ( $p = 0.17$ ) or location ( $p = 0.10$ ).

#### HRQoL and amblyopia severity

Table 3 shows that the two cohorts are similar in the distribution of amblyopia severity groups. The majority of participants from both cohorts were categorised as having mild amblyopia. There is some suggestion that greater mean CAT-QoL scores are associated with

increased amblyopia severity. The interaction effect between location and amblyopia severity was not statistically significant ( $F(2, 124) = 0.104$ ,  $p = 0.90$ ). There was no statistically significant main effect for amblyopia severity ( $p = 0.10$ ) or location ( $p = 0.99$ ).

#### Discussion

The assessment of QoL in children undergoing amblyopia treatment is gaining increasing attention both within the UK and internationally. There is a need to investigate whether we should expect differences in QoL scores from one country to another, and even within countries. The results of this study would suggest that there are no differences in self-reported QoL in children undergoing amblyopia treatment according to their geographical location. Overall the North cohort did report better levels of QoL; however, this was not statistically significant. This would appear to contradict the suggestion of other reports that northern areas of the UK are associated with worse indicators of health and wealth. This poses the question as to whether we should expect regional differences in self-reported QoL from children. It is not known at what age a child begins to appreciate the world around them, and how this may (or may not) play a role in other aspects of their life and well-being.

This study did identify some factors which appear to influence QoL scores as measured by the CAT-QoL

instrument. Factors that did appear to influence QoL scores were type of current treatment and age. Older children, and children who had a patch as part of their amblyopia treatment, had worse self-reported QoL. This confirms anecdotal data from parents, who report that treatment can be more difficult after the child starts school.

The evaluation of the impact of a condition and/or its treatment through QoL assessment is challenging, particularly when considering the paediatric population. A number of factors are to be considered, including the age of the child and the task burden. Children do seem to have the capacity to reliably report upon their health between the ages of 4 and 6 years.<sup>15–17</sup> This was also confirmed during the development phase of the CAT-QoL instrument.<sup>11</sup> Children with amblyopia were interviewed in order to identify their thoughts and opinions of their own health; and to find out what impact amblyopia treatment was having upon their daily lives. The participants were able to understand and articulate what it is they feel and experience due to their eye condition.<sup>11</sup> The methodological issues of obtaining QoL data from children are complex. The way in which instruments, such as the CAT-QoL and other PROMs, are administered may influence the quality of data they produce. There are no universally accepted recommendations for mode of administration of PROMs; this is becoming an area of research in its own right. In the present study, the CAT-QoL instrument was given to the child after their routine orthoptic examination. It is unknown whether the CAT-QoL was completed in front of the clinician, or to what extent it was completed independently. It could be argued that if completed in front of the clinician the child may feel unable to respond honestly due to the perceived notion that the questionnaire has some link or association with their treatment.<sup>11</sup> However, if completed in front of the clinician there is some 'check' that the responses obtained are those of the child (and not the parent). Similarly, the child may feel unable to respond honestly if the questionnaire is completed in front of their parent/guardian, for fear of upsetting them. It is acknowledged that the degree to which a child can self-complete a questionnaire is dependent upon their ability; younger children may require assistance with reading the questionnaire and the administration procedures.

The study is not without its limitations. Firstly, it should be acknowledged that the size of the participant sample is small. The data used were collected as part of the multi-centre validation study used to further develop and refine the CAT-QoL instrument. Data collection for the validation study was limited to a finite time period due to funding constraints. Further research is required to explore whether such findings are replicated in a larger, independent dataset. Secondly, it could be argued that the North cohort is not really that North. Additional research is required to determine whether other areas, such as Newcastle or Carlisle, produce similar results.

Furthermore, the measurement of QoL was taken as a 'one-off' measurement. It was not possible to determine whether adaptation to treatment and duration of treatment has an impact upon QoL scores, and indeed whether these are influenced by geographical location.

## Conclusion

This study could find no statistically significant evidence to suggest that regional differences exist in the self-reported QoL of children undergoing amblyopia treatment. However, it must be acknowledged that participant numbers were low, and the geographical locations of the North and South cohorts could be challenged. It did, however, identify that both age and type of amblyopia treatment were factors associated with worse QoL scores, as assessed by the CAT-QoL instrument. The type of treatment and the timing of when it is administered are often determined by clinical need, and negotiated between parent, child and clinician. Further research is required to explore how different aspects of amblyopia treatment may affect a child's QoL, such as timing of treatment within their day. This may influence the advice orthoptists provide when prescribing treatment, to minimise any negative effects that treatment may have.

Data for this study were collected at the following sites: Doncaster and Bassetlaw NHS Foundation Trust; Maidstone and Tunbridge Wells NHS Trust; Medway NHS Foundation Trust. The author gratefully acknowledges the support of orthoptists and clinicians at each of the collaborating sites.

This work is produced by Jill Carlton under the terms of a Personal Development Award research training fellowship issued by the NIHR. The views expressed in this publication are those of the author and not necessarily those of the NHS, The National Institute for Health Research or the Department of Health.

The author has no competing interests.

Ethics approval: The study was approved by the National Health Service Research Ethics Committee for Airedale, UK (REC Ref: 07/Q1201/5), and followed the tenets of the Declaration of Helsinki.

## References

- Hacking JM, Muller S, Buchan IE. Trends in mortality from 1965 to 2008 across the English north-south divide: comparative observational study. *Br Med J* 2011; **342**: d.508.
- Duranton G, Monastiriotis V. Mind the gaps: the evolution of regional earnings inequalities in the UK, 1982–1997. *J Reg Sci* 2002; **42**: 219–256.
- BBC. North-South divide in house prices, says Nationwide. 2013. <http://www.bbc.co.uk/news/business-24290055> [accessed 14 November 2013].
- Express. Jobless toll reveals North-South divide. 2013. <http://www.express.co.uk/news/uk/427020/Jobless-toll-reveals-North-South-divide> [accessed 14 November 2013].
- Doran T, Drever F, Whitehead M. Is there a north-south divide in social class inequalities in health in Great Britain? Cross sectional study using data from the 2001 census. *Br Med J* 2004; **328**: 1043–1045.
- Health and Social Care Information Centre. Patient reported outcome measures. 2013. <http://www.hscic.gov.uk/proms> [accessed 29 January 2014].
- Holmes JM, Strauber S, Quinn GE, *et al.* Further validation of the amblyopia treatment index parental questionnaire. *J AAPOS* 2008; **12**: 581–584.
- Felius J, Chandler DL, Holmes JM, *et al.* Evaluating the burden of amblyopia treatment from the parent and child's perspective. *J AAPOS* 2010; **14**: 389–395.
- Carlton J, Kaltenthaler E. Amblyopia and quality of life: a systematic review. *Eye* 2011; **25**: 403–413.
- Carlton J. Clinicians' perspectives of health-related quality of life (HRQoL) implications of amblyopia: a qualitative study. *Br Ir Orthopt J* 2011; **8**: 18–23.
- Carlton J. Identifying potential themes for the Child Amblyopia Treatment Questionnaire. *Optom Vis Sci* 2013; **90**: 867–873.
- Carlton J. Developing the draft descriptive system for the Child Amblyopia Treatment Questionnaire (CAT-QoL): a mixed methods study. *Health Qual Life Outcomes* 2013; **11**: 174.
- Carlton J. Refinement of the Child Amblyopia Treatment Questionnaire (CAT-QoL) using Rasch analysis. 2013. <http://>

- www.shef.ac.uk/scharr/sections/heds/discussion-papers/1313-1.321879
14. Carlton J. Validation of the Child Amblyopia Treatment Questionnaire (CAT-QoL). 2013. <http://www.shef.ac.uk/scharr/sections/heds/discussion-papers/1314-1.322028>
  15. Connolly MA, Johnson JA. Measuring quality of life in paediatric patients. *Pharmacoeconomics* 1999; **16**: 605–625.
  16. Juniper EF. Health-related quality of life in asthma. *Curr Opin Pulm Med* 1999; **5**: 105–110.
  17. Annett RD. Assessment of health status and quality of life outcomes for children with asthma. *J Allergy Clin Immunol* 2001; **107**: S473–481.