

# Vision-Related Quality of Life and Mental Health Outcomes of Children and Young People with Visual Impairment and Their Carers

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## 1. BACKGROUND

- Visual impairment starting in childhood impacts all aspects of the affected individual's life.
- Family-related factors are known to be important to psychosocial adjustment outcomes of children and young people with many chronic health conditions.
- There is currently very limited knowledge in this area in relation to children and young people with visual impairment (CYP-VI).

This study presents quantitative findings of a larger mixed-methods research study which aims

- (1) to identify risk and protective factors that shape positive psychosocial adjustment of CYP-VI, and
- (2) to explore the critical timepoints when these factors employ the greatest influence

in order to inform a development of family-centred interventions informed by patient's priorities.

## A FAMILY SAID ...

*"Children are great because they're so much more resilient than we are. And they also teach us how it's okay because 'Mom, look at me, I do all those things, and I'm independent and I'm happy' And that's wonderful."*

– Mom of a 13 year old boy with an early onset visual impairment

## 2. OBJECTIVES

To investigate the associations between vision-related quality of life (VQoL) and mental health outcomes of CYP-VI and their carers, as a first step towards development of family-centred intervention.

## 2. METHODS

**Design:** Cross-sectional (part of a mixed-method research study)

**Recruitment:** Through the UK's two largest Paediatric Ophthalmology Departments, and relevant vision loss charities.

**Participants:** (1) CYP-VI

- Aged 8–18 years
- With visual acuity of LogMAR  $\geq$  0.5 (defined as moderate, severe visual impairment, and blindness in ICD-11)

(2) Their parents or carers

**Measures:**

*CYP-VI outcomes*

- ❖ Vision-Related Quality of Life Questionnaire for Children and Young People (VQoL\_CYP; self-report)<sup>1</sup>
- ❖ Strengths and Difficulties Questionnaire (SDQ; parent-report)<sup>2</sup>
- ❖ Self-esteem scale of Student Resilience Survey (SRS; self-report)<sup>3</sup>

*Carers' / familial outcomes* (all carer-reports)

- ❖ Satisfaction With Life Scale (SWLS)<sup>4</sup>
- ❖ Patient Health Questionnaire (PHQ-9)<sup>5</sup>
- ❖ General Anxiety Disorder Assessment (GAD-7)<sup>6</sup>
- ❖ Parental Stress Scale (PSS)<sup>7</sup>
- ❖ Me as a Parent (Maap)<sup>8</sup>
- ❖ Family Attachment and Changeability Index 8 (FACI8)<sup>9</sup>
- ❖ Study-specific Family context questionnaire (study-specific FCQ)
- ❖ Hospital's electronic patient records (EPR)

**Procedure:** Study invitation letter and other study materials were sent by post. Participants could choose between printed and online versions of the consent forms and the questionnaires.

**Analysis:** Associations and group differences between the outcomes and other variables were analysed using Spearman's  $\rho$  correlation coefficient, Kruskal-Wallis, and Wilcoxon rank-sum tests.

## 4. RESULTS

VQoL\_CYP: higher VQoL scores indicate *better* VQoL.

- ❖ Better VQoL is associated with fewer internalising ( $r = -0.503, p < 0.001$ ) and externalising problems ( $r = -0.279, p = 0.019$ ).

**SDQ:** higher **internalising and externalising problems** scores indicate *more* behavioural or emotional difficulties.

- ❖ Fewer internalising problems are associated with fewer externalising problems ( $r = 0.469, p < 0.001$ ).

TABLE 1. Sample characteristics

Variable		N	%
Total (overall)		73	
Gender	Female	34	46.58
	Male	39	53.42
Ethnicity	White	50	68.49
	Asian	12	16.44
	Black	8	10.96
	Other	3	4.11
Variable	Median	IQR	min - max
Age (years)	12	6	8-18
VQoL	54.2	11	33.2-78.5
Internalising problems (SDQ)	7	6	0-18
Externalising problems (SDQ)	5	5	0-13

TABLE 2. Factors (non)-significantly associated with better vision-related quality of life and lower behavioural and emotional difficulties ( $p < 0.05$ )

Child's characteristics	Measure	↑ Better VQoL	↓ Fewer internalising problems (SDQ)	↓ Fewer externalising problems (SDQ)
↑ <b>Higher self-esteem</b>	SRS	0.509 (<0.001)	-0.392 (0.001)	-0.310 (0.009)
Gender	EPR	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>
Ethnicity	FCQ	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>
↓ <b>Younger age</b>	FCQ	-0.261 (0.026)	<i>Not sig.</i>	<i>Not sig.</i>
Severity of visual impairment	EPR	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>
<b>Absence of an additional impairment *</b>	FCQ	0.604 (0.024)	0.866 (<0.001)	<i>Not sig.</i>
Carer's characteristics	Measure	↑ Better VQoL	↓ Fewer internalising problems	↓ Fewer externalising problems
↑ <b>Higher carer's satisfaction with life</b>	SWLS	0.443 (<0.001)	-0.270 (0.026)	<i>Not sig.</i>
↓ <b>Fewer carer's anxiety symptoms</b>	GAD7	-0.301 (0.01)	0.434 (<0.001)	0.261 (0.029)
↓ <b>Fewer carer's depression symptoms</b>	PHQ-9	-0.344 (0.003)	0.429 (<0.001)	<i>Not sig.</i>
↓ <b>Lower carer's stress level</b>	PSS	-0.255 (0.033)	0.393 (0.001)	<i>Not sig.</i>
↑ <b>Better carer's parenting self-regulation</b>	MaaP	0.308 (0.009)	-0.269 (0.024)	-0.276 (0.021)
Education level	FCQ	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>
Occupation level	FCQ	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>
Family's characteristics	Measure	↑ Better VQoL	↓ Fewer internalising problems	↓ Fewer externalising problems
↑ <b>Better family functioning</b>	FACI8	0.287 (0.014)	<i>Not sig.</i>	<i>Not sig.</i>
Size of the family	FCQ	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>
Indices of multiple deprivation	EPR	<i>Not sig.</i>	<i>Not sig.</i>	<i>Not sig.</i>

\* Absence of additional impairment reports Cohen's  $d$  statistic. Other significant associations report Spearman's  $\rho$ . Out of 73 CYP-VI, 28 had an additional chronic health condition or impairment.

## 5. CONCLUSIONS

- **Correlations exist between the mental health of children and young people with visual impairment (CYP-VI) and their carers**, indicating both should be considered when assessing VQoL outcomes in this population.
- **Findings are aligned with the 'disability paradox'**, demonstrating that poorer psychosocial outcomes cannot be predicted by clinical characteristics or metrics of relative deprivation that are conventionally considered in clinical practice.
- **Multi-modal psychosocial interventions aimed at improving the mental health of the whole family may facilitate better VQoL of CYP-VI.**

## A FAMILY SAID ...

*"You go through a very long phase of pretending that it doesn't still affect you. I think because it does change your life so much. /.../ But I think there is a huge sense of almost satisfaction when you're out on the other end, and know what works for you, what you need, and where the gaps are."*

– Female, 17 years, with late onset visual impairment; on coming to terms with being visually impaired and the impact on her mental health

## 6. FUTURE WORK

The next stages of the study analysis will:

- Identify additional potential inter- and intrapersonal determinants of psychosocial adjustment in CYP-VI (*quantitative survey data*).
- Inform the sensitive timepoints and characterising the key events that may elicit adaptive responses from families with CYP-VI (*qualitative interview data*).

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