

A mixed-methods study investigating multi-level factors associated with psychosocial adjustment outcomes of children and young people with visual impairment

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1. BACKGROUND

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

Aims of the study:

- (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 a complex interventions model 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 years old boy with an early onset VI

2. METHODS

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

Recruitment: Dec 2021-Dec 2022, through the UK's two largest Paediatric Ophthalmology Departments, and three relevant vision loss charities.

Participants: (1) CYP-VI



- Aged 8-18 years
- With visual acuity of LogMAR ≥ 0.5

(2) their parents or carers

Main measures:

CYP-VI outcomes

- ❖ Vision-Related Quality of Life Questionnaire for Children and Young People (VQoL_CYP; self-report)¹
- ❖ Strengths and Difficulties Questionnaire (SDQ; parent-report)²

Carers' outcomes (all carer-reports)

- ❖ Satisfaction With Life Scale (SWLS)³
- ❖ Patient Health Questionnaire (PHQ-9)⁴
- ❖ General Anxiety Disorder Assessment (GAD-7)⁵

Procedure: study invitation letter and other study materials were sent by post for both the postal survey and the interviews.

Postal survey: participants could choose between printed and online versions of the consent forms and the questionnaires.

Interviews: were conducted online, at home, or at the university.

Analysis:

Postal survey: linear regression modelling

Interviews: thematic analysis

4. RESULTS

VQoL_CYP: higher VQoL scores indicate *better* VQoL.

SDQ: higher **internalising** (emotional symptoms and peer relationship problems) / **externalising** (conduct problems and hyperactivity/inattention) **problems** scores indicate *more* emotional or behaviour difficulties.

31% of CYP-VI (compared to 10% in the general UK population) received an abnormal total behavioural difficulties score (SDQ).

21% of carers reported at least moderate depressive and/or anxiety symptoms.

None of the sociodemographic characteristics nor the severity of visual impairment predicted ($p \geq .05$) any of the three CYP-VI outcomes.

Table. Final standardised linear regression model of *better* vision-related quality of life

Predictor	β	SE	df	95% CIs	p-value
Better peer support	0.28	0.09	66.6	[0.10, 0.47]	.003
More self-reported functional vision difficulties	-0.33	0.08	66.9	[-0.49, -0.17]	<.001
Higher carer's satisfaction with life	0.30	0.08	66.7	[0.14, 0.46]	<.001
Better connection in school	0.25	0.09	66.9	[0.08, 0.43]	.005
	R^2	.600	Adjusted R^2	.574	

Table. Final standardised linear regression model of *more* internalising problems

Predictor	β	SE	df	95% CIs	p-value
More carer's anxiety symptoms	0.27	0.09	68	[0.10, 0.44]	.002
Better peer support	-0.55	0.08	68	[-0.71, -0.38]	<.001
Another chronic health condition	0.53	0.17	68	[0.18, 0.87]	.004
	R^2	.532	Adjusted R^2	.511	

Table. Final standardised linear regression model of *more* externalising problems

Predictor	β	SE	df	95% CIs	p-value
Better peer support	-0.27	0.10	68	[-0.47, -0.06]	.01
Late onset of visual impairment	-0.41	0.21	68	[-0.82, -0.003]	.048
More prosocial behaviour	-0.40	0.10	68	[-0.60, -0.19]	<.001
	R^2	.328	Adjusted R^2	.298	

Important contexts and events in the lives of CYP-VI:

- Healthcare experience (diagnosis, operations, healthcare prof. relationships)
- Educational experience (starting/changing school, teacher relationships, bullying)
- Social life (making friends, sports and hobbies)
- Family life (health of family members, separation, moving homes)

Table. Characteristics of the postal survey (N_{PS}) and the semi-structured interviews (N_I) participants

Variable	Category	N_{PS}	% $_{PS}$	N_I
Total (overall)		78		18
Gender	Female	35	44.9	9
	Male	43	55.1	9
Ethnicity	White	52	67.5	14
	Asian	11	14.3	2
	Black	9	11.7	2
	Other	5	6.5	0
Severity of visual impairment	VI	59	75.6	13
Missing information: 4	SVI/BL	14	17.9	5
Variable	Mean	SD	min-max	
Age (years)	12.3	3.2	8-18	
Vision-related QoL (VQoL_CYP)	53.4	8.5	33.2-78.5	
Internalising problems (SDQ)	7.5	4.4	0-18	
Externalising problems (SDQ)	5.1	3.9	0-13	

Thematic analysis further underscored the importance of:

- support for CYP-VI and their parents in the early years after the diagnosis,
- positive educational experience,
- family and peer support

in the psychosocial adjustment of CYP-VI.

A FAMILY SAID ...

"Quite a lot of conversation is made up of eye contact, and your body language, and all those kinds of things. ... I don't want to say it's difficult socializing with visual impairment, because that's not true. But there's extra things that you need to consider."

– Girl, 14 years, with an early onset VI; on barriers in social interactions

5. CONCLUSIONS

- Our findings highlight significant associations between individual, family, and school characteristics and mental health and VQoL in CYP-VI, **offering potential targets for family-centred and school-based psychosocial interventions.**
- 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 social skills of CYP-VI and the mental health of the whole family may facilitate better psychosocial adjustment outcomes of CYP-VI.

6. CLINICAL RELEVANCE

- Collaborative efforts across services, uniting formal and non-formal means of support, are necessary to improve outcomes for CYP-VI and their families.
- Empowering CYP-VI as well as parents is imperative, especially as most CYP-VI are diagnosed in the first two years after they are born.
- The mental health of both CYP-VI and their carers should be (routinely) considered when assessing psychosocial adjustment outcomes in this population.

References

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Scan the QR code to access the VQoL_CYP Questionnaire

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