The PROMOTE study: Patient reported outcome measures online to enhance communication and quality of life after childhood brain tumour – systematic review

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Introduction

Quality of life in children treated for brain tumours is at risk of significant impairment into adulthood including cognitive, emotional, behavioural, and social issues but typically there is no systematic screening for such problems. Referral to appropriate services is often reactive rather than proactive. In the PROMOTE study we are developing and testing the feasibility of individualised application of patient-reported outcome measures (PROMs) in paediatric neuro-oncology outpatient clinics.

Aim

To identify and appraise PROMs suitable for use with children who had received treatment for brain tumours. The purpose of the review was to inform subsequent stages in the PROMOTE study in which PROMs will be used individually with children in follow-up clinics to improve communication and treatment plans.

Article selection criteria

The criteria for selection of studies were as follows:

1. **Population:** Children 5 to 18 years old treated for brain tumours or acquired brain injury.
2. **Instruments:** Child and/or parent-reported PROMs of health and well-being psychometrically tested using English language versions.
3. **Evidence:** Indication of some testing/reporting of measurement properties, such as aspects of reliability (test-retest and internal consistency), validity, responsiveness, precision, interpretability, acceptability and feasibility
4. **Date:** Article publication date (not PROM publication date) of 1992 onwards
5. **Language:** English language publication in peer-reviewed journal

Methods – Procedure

We conducted a systematic search of MEDLINE, EMBASE, and PsycINFO to identify evidence of studies that had evaluated the measurement properties of English language versions of PROMs suitable for use with children treated for brain tumours. Two reviewers independently screened all titles and abstracts from the search to select those articles that were likely to yield relevant results. Full texts were then extracted from this list and independently read by the same two reviewers to confirm their relevance and ascertain their contribution to the evidence base.

Results – screening

1. 748 records identified through database searching
2. 472 records after duplicates removed
3. 374 records excluded after screening titles and abstracts
4. 98 full-text articles assessed for eligibility
5. 90 full-text articles excluded, with reasons
6. 8 studies included in qualitative synthesis

Results – PROMs

- Health Utilities Index (HUI)
- Pediatric Quality of Life Inventory – core module (PedsQL-core)
- Pediatric Quality of Life Inventory – brain tumor module (PedsQL-brain tumor)
- Child and Family Follow-up Survey (CFFS)

Results – References

- **HUI: Glaser, A.** et al. Influence of proxy respondents and mode of administration on health status assessment following central nervous system tumours in childhood. *Qual Life Res.* 1997; 6: 43–53; **Barr, R.D.** et al. Health-related Quality of Life in Survivors of Tumours of the Central Nervous System in Childhood - Preference-based Approach to Measurement in a Cross-sectional Study. *Eur J Cancer.* 1999; 35: 248-55; **Glaser, A.** et al. Applicability of the Health Utilities Index to a Population of Childhood Survivors of Central Nervous System Tumours in the U.K. *Eur J Cancer.* 1999; 35: 256-61
- **PedsQL-core: Eiser, C.** et al. The value of the PedsQL™ in assessing quality of life in survivors of childhood cancer. *Child Care, Health Dev.* 2003; 29: 95–102; **Bhat, S.R.** et al. Profile of Daily Life in Children With Brain Tumors: An Assessment of Health-Related Quality of Life. *J Clin Oncol.* 2005; 23: 5493–500
- **PedsQL-brain tumor: Palmer, S.N.** et al. The PedsQL™ Brain Tumor Module: Initial Reliability and Validity. *Pediatr Blood Cancer*. 2007; 49:287–93
- **CFFS: Bedell, G.** Developing a follow-up survey focused on participation of children and youth with acquired brain injuries after discharge from inpatient rehabilitation. *NeuroRehabil*. 2005; 19: 191–205; **Bedell, G.** Further validation of the Child and Adolescent Scale of Participation (CASP) *Dev Neurorehabil*. 2009; 12: 342-51

Conclusion

Although psychometrically valid and reliable, not all these PROMs are suitable for systematic use in an outpatient paediatric neuro-oncology health care setting. Other considerations need to be taken into account relating to the constraints of health care systems including time and resources. PROMs with costly licencing fees are not feasible to use in public health care systems where finances are limited. Also PROMs which are lengthy to discuss will not be adopted due to clinical time constraints. PROMs also need to be relevant and suitable for follow-up consultations after treatment has ended. For these reasons the most suitable PROM identified to date is the PedsQL core module.