Quality of life in children with acute lymphoblastic leukaemia: a systematic review
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CRD summary
The authors of this review concluded that there were discrepancies between children’s and parents’ accounts of quality of life, which led to varied findings across physical, psychological, psychosocial, and cognitive domains, and disease and treatment symptoms. These conclusions reflected the evidence presented, but might need to be treated with caution due to the possibility of missing studies.

Authors' objectives
To review studies on the quality of life in children receiving treatment for acute lymphoblastic leukaemia.

Searching
The authors searched PubMed, EMBASE, CINAHL, BIOSIS Previews, Faculty of 1000 Medicine, Psychology and Behavioural Sciences Collection, Social Sciences Index, and CANCERLIT for articles between 1st May 2001 and 30th June 2007. The search terms were reported and selected paediatric and general oncology journals, and some general paediatric journals known to publish papers on quality of life, were also searched. Full details were reported in the review. Reference lists of all full papers retrieved from databases, electronic journals, and individual author searches, were also checked for further studies. There was no search for unpublished studies.

Study selection
To be eligible, studies needed to be published in English and provide empirical data, evidenced by the children, their parents, or both, on the quality of life in children, who were aged up to 12 years and receiving treatment for acute lymphoblastic leukaemia. All research designs were eligible, including both qualitative and quantitative studies. Those with generic or disease-specific outcome measures were eligible, but those that examined quality of life in relation to specific drug therapies or procedures were excluded. Studies investigating the quality of life across a range of childhood cancers were excluded if the data specific to children undergoing treatment for acute lymphoblastic leukaemia were not reported.

In the included studies, parents, clinicians, and children were sampled. Quality of life dimensions and measures varied, but disease-specific quality of life measures were used in more than half of the included studies. Outcomes were physical, psychological, psychosocial, cognitive, and disease and treatment symptoms.

Two reviewers selected studies for the review and disagreements were resolved through discussion and recourse to a third reviewer.

Assessment of study quality
The quality of the quantitative studies was rated using published criteria relating to study design, participants and recruitment, comparison group, number of participants, and quality of life instruments; the total score available was 15. The criteria for assessing the qualitative studies were based on standards proposed by Popay, et al. 1998 (see Other Publications of Related Interest), that addressed study aims, context sensitivity, sampling strategy, data quality, theoretical or conceptual adequacy and generalisability.

It appears that more than one reviewer was involved in the quality assessment of studies.

Data extraction
One reviewer extracted data on study methods and a second extracted the quality of life findings. These were then checked by a third reviewer.

Methods of synthesis
Studies were combined in a narrative synthesis.
Results of the review

The review included six studies (n=1,043 participants, including 355 parents, 207 children, and 481 healthy controls). Four studies were quantitative with a cross-sectional design. Two of these received a quality rating of 11 and two received nine out of a possible 15. The main weaknesses appeared to be in the cross-sectional design and small sample size. Two studies were qualitative. One of these had a longitudinal design to assess changes over time and was considered to meet certain standards of theoretical or conceptual adequacy, but it relied on the proxy accounts of parents. The other used children's perspectives, but the authors acknowledged the lack of generalisability of their data. All studies except one used a convenience sample.

Children's reported quality of life was assessed in three studies. There were discrepancies between children's and parents' reports of quality of life. These different perspectives on quality of life led to varied findings across physical, psychological, psychosocial, and cognitive domains and disease and treatment symptoms. One study highlighted that parents might underestimate their children's quality of life in relation to their physical health, but overestimate their quality of life in relation to their social and psychological health.

Specific issues highlighted by children or parents included tiredness and depleted energy on treatment, fears associated with medication and treatment effects, mood changes, sleep problems and nightmares, social interaction with peers, and concerns about appearance.

Authors' conclusions

There were discrepancies between children's and parents' accounts of quality of life. These differences led to varied findings across physical, psychological, psychosocial, and cognitive domains, and disease and treatment symptoms.

CRD commentary

This review had defined inclusion criteria for participants and outcomes and broadly defined criteria for interventions and study designs. Searching encompassed a range of databases and other sources. The review was limited to articles published in English, which opens up the possibility of language and publication bias. Studies were quality assessed and the results were used to make recommendations for better research designs. The heterogeneity of the studies made a narrative synthesis the appropriate choice. The authors attempted to reduce the possibility of bias and errors in the review process by the involvement of more than one reviewer.

The authors' conclusions reflected the evidence presented, but the results may need to be interpreted with caution due to the possibility of missed studies through language and publication restrictions.

Implications of the review for practice and research

Practice: The authors did not state any implications for practice.

Research: The authors stated that there was a need to directly measure children's quality of life because parent proxy reports might not be consistent with children's reports. The contribution of qualitative data to the exploration of quality of life in children with acute lymphoblastic leukaemia needed further consideration. There was a need to develop theory driven models of quality of life in childhood cancers to clarify the concept of quality of life. Future research should address the limitations of the current research in terms of study designs and sample sizes and European and international collaboration may be required to recruit sufficiently large samples.

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Other publications of related interest
Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. Qualitative Health Research 1998; 8(3): 341-351.

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