

Palliative care in children and adolescents

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Exploring Invitation and Recruitment Practices in Research with Children and Young People with Life Limiting Conditions (LLC) or Life Threatening Illnesses (LTI) and their Families - A Systematic Review

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Background: Children and young people with LLCs or LTIs are a vulnerable, difficult to treat population. Research is needed to understand how the care, treatment and management of these patients and their families can be improved. Barriers to research include difficulties with securing the support of ethics committees, limited access to children of all ages and their families and the perceived potential burden on all participants. Recruitment to studies in this population is generally slow and delayed.

Aims: To provide an overview of current invitation and recruitment practices and influencing factors in recently published research with children and young people with life limiting conditions and life threatening illnesses and their families. We focus on how practices impact recruitment and retention rates.

Methods: MEDLINE, PsychINFO, Social Sciences Citation index, Web of Science and SCOPUS were searched to identify original research articles recruiting in this population, published within the last 5 years. Forward and backward citation searches of included studies will be conducted. Studies will be critiqued, assessed for quality, and data extracted on key aspects of recruitment, including how potential participants are approached and what barriers were identified by authors. All key processes will be completed by two reviewers. A meta-analysis exploring the effectiveness of different invitation and recruitment strategies will be conducted and, if data permit, regression analysis will explore factors associated with higher levels of recruitment.

Results: The search identified 6,024 articles. We shall present and analyse the type and scope of research in this population and the completeness of the reporting of invitation and recruitment practices.

Discussion: Uneven invitation and recruitment practices may lead to sample bias and limit the meaningfulness of findings. Our results will inform the design and reporting of future research in this population.