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Patient-reported outcome monitoring in a routine paediatric oncology setting: challenges and opportunities

Cancer affects one in every 500 children younger than 15 years in the UK, and around 1800 new cases are diagnosed in this population every year.¹ Despite advances in treatments and improved overall survival, children with cancer have a high symptom burden, related both to the underlying cancer and associated treatments that can substantially affect their physical, mental, social, and emotional wellbeing, and cognitive function.² Moreover, there are major psychosocial and financial implications for families of children with cancer, and substantial societal health-care costs.

Effective symptom management is the cornerstone of high-quality oncology care. Lack of recognition of the child's symptoms is likely to cause or worsen complications, delay alleviation of their symptoms, limit the ability to safely and effectively deliver treatments, increase hospital and emergency visits, and have a negative effect on clinical outcomes.³

Studies have shown that clinicians' and parents' perceptions of a child's symptoms do not accurately reflect the child's perspective, particularly for subjective attributes such as emotion, pain, cognition, and confidence for the future.⁴ This incongruence is especially important for common, unobservable symptoms such as nausea, which can only be detected through self-reporting. Eliciting the patient's voice through self-reporting of symptoms is crucial to optimising symptom management.

The importance of patient-centred care in improving the quality and effectiveness of health care is well recognised. One way to assess the effect of disease and treatment on symptoms is with the use of patient-reported outcome measures. As stated by the US Food and Drug Administration, patient-reported outcome measures show "the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else".⁵ A 2018 systematic review⁶ identified 38 patient-reported

outcome measures used in paediatric oncology research, measuring a total of 81 symptoms. Self-reporting of symptoms is feasible in the paediatric population because most patient-reported outcome instruments are specifically designed for ages ranging from 8 years to 18 years, with varying recall periods ranging from immediate recall, to up to 1 year. The feasibility of collecting symptom data at multiple timepoints in longitudinal studies supports the potential use of these instruments as clinical tools to monitor symptoms. Electronic reporting platforms have shown promising results for children with cancer, highlighting the need for further development.⁷ Communication of symptom data to clinical teams leads to improved parental understanding of the child's symptoms, better communication with clinicians, and improvement of the children's emotional health-related quality of life.⁸ There is also evidence from an adult oncology setting that symptom reporting with automated clinician alerts results in better health-related quality of life, fewer emergency room visits, fewer hospital admissions, longer duration of palliative chemotherapy, and improved survival compared with usual care.³

However, despite the availability of specific patient-reported outcome symptom tools in paediatric oncology and evidence of clinical effectiveness when used in adult patient populations, their use in routine clinical paediatric oncology practice is minimal. An international survey⁹ revealed that 94% of health-care professionals working in paediatric oncology practices across 52 countries valued routine collection and use of patient-reported outcomes. However, several logistical issues, such as time constraints, insufficient staff, and financial limitations, were identified as potential barriers. Other key barriers were technological, which included a lack of standardised patient-reported outcome platforms that can interface with electronic health records, an absence of financial incentives to develop such platforms, as well as a shortage of standardised processes for integrating patient-reported outcomes in routine clinical workflow.¹⁰

There is a need to develop the infrastructure for systematic collection of symptom data that are communicated, in real time, to clinical teams to enable better identification and timely, efficient clinical management. Patient-reported outcome systems that assess quality of life, adverse effects, resource needs, and practical issues associated with treatment (such as compliance to treatment) should be based on the needs of children, young people, and their families, be age appropriate, and easy for patients to use. They should also be clinically meaningful, actionable, and logistically practical from the clinical team's perspective.

The International Society for Quality of Life Research (ISOQoL) developed a user's guide for implementing patient-reported outcome assessment in routine clinical practice, describing methodological and practical considerations. Successful implementation of such systems in routine clinical practice would require the engagement of everyone involved, including the patients and their families, treating clinical teams, hospital management, and funders, and would also require formal evaluation to assess the effectiveness of the system. Designing and co-producing standardised systems for symptom self-reporting in partnership with key stakeholders could improve the quality and safety of care, outcomes, and quality of life of children with cancer.

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