
CONFERENCE ABSTRACT

Integrating Patient Reported Outcomes with digital solutions to empower children and families to self-manage complex health conditions

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Natalie Bradford¹, Christine Cashion², Alison Bowers¹, Rick Walker², Anthony Herbert², Raymond Chan¹, Patsy Yates¹

1: Queensland University Of Technology, Brisbane, QLD, Australia;

2: Children's Health Queensland, South Brisbane, Queensland, Australia;

Introduction: Children with cancer experience distressing and severe symptoms, yet routine monitoring in young people is rare. As a result, symptoms are often undertreated. High symptom burden is associated with increased hospitalisation, lower quality-of-life, poor treatment adherence and long term problems including post-traumatic stress disorder. As part of a larger project that aims to empower and engage children using digital health solutions, the objective of this study was to explore the congruence of symptom burden identified by healthcare providers with child self-report.

Methods: This exploratory study had two phases. A clinical advisory group agreed upon relevance and importance of 15 symptoms; 10 from the Symptoms Screening in Pediatrics tool and an additional five commonly occurring symptoms in children's cancer. In phase one medical records for the first 12 weeks of cancer treatment were reviewed from newly diagnosed children (8-18 years). Data were extracted regarding healthcare provider assessment of symptom occurrence. In phase two, a convenience sample of children undergoing active cancer treatment were recruited during scheduled appointments for chemotherapy. Child and parent proxy completed a survey about the 15 symptoms. The types and severity of symptoms were compared between healthcare provider assessment, parent proxy and child self-report.

Results: There were 3,909 documented assessments by medical (54%), nursing (32%) and allied health clinicians (14%) regarding 25 children. The most commonly assessed symptoms were changes in appetite, nausea, pain and constipation. These clinical assessments identified 1399 occurrences of the 15 symptoms. Most common were nausea, pain, appetite and rash. Least common were changes in taste, feeling cranky, cognition changes and mouth sores. Sixty-eight children were recruited to Phase 2. Child report of symptoms causing the most distress were fatigue, sleep and changes in taste. The symptom causing the least distress were diarrhoea, feeling scared and headache. Parent proxy for total symptom burden (13.80) was similar to child-report (13.43), although parents frequently over and underestimated many symptoms and interrater reliability was weak (0.37, 95%CI -0.36 to 0.70, $p=0.12$).

Discussion: Child report of distress from symptoms differs to parent and healthcare provider assessment and perception of symptoms. This incongruence is likely to limit effective symptom management. The symptoms causing distress to children are amendable to intervention, but only if there is awareness of the prevalence of symptoms.

Conclusion: New strategies are needed to help healthcare providers to support and encourage children and their parents to communicate about distress from symptoms. Harnessing the capabilities of digital technology to provide a child-centric, integrated and systematic mechanism to monitor, report and communicate about symptoms is a promising solution.

Lessons Learned: This study highlighted the importance of asking children themselves about their symptoms. Use of patient reported outcomes with children is feasible and acceptable.

Limitations: These results are not conclusive; the small sample size may have biased findings.

Suggestions for future research: Research is required to integrate digital health solutions into clinical practice across the care trajectory. Such solutions may empower children and families to communicate about symptoms and promote decision making between specialist and community healthcare teams.