The Practical Matters of Including Patient Reported Outcomes in Pediatric Oncology Clinical Care

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Emily L Mueller, MD, MSc 705 Riley Hospital Dr, ROC 4340 Indianapolis, IN 46202 Cell: 312-399-0245 Fax: 317-944-3107 elmuelle@iu.edu Abstract word count: 0 Main text word count: 6654 Number of tables: 0 Number of figures: 0 Short Title: Practicalities of PRO in Clinical Care

Abbreviations:

mHealth PRO SPARK Mobile Health Patient-reported outcomes Supportive care Prioritization, Assessment, and Recomm

A clear call to action exists to include the patient's voice in oncology care.^{1,2} The translation of this imperative is less clear when it comes to implementing patient-reported outcomes (PRO) into clinical care specifically for children with cancer. Many validated PRO measurement tools for both the pediatric patient's and their caregivers, or proxy users, are available. However, in comparison to adult oncology, there are fewer clinical trials among children with cancer that meaningfully include PRO.

Translating clinical research into practical patient care is even more problematic. The decision whether to focus on only the patients' voices versus the input of their caregivers (serving as proxies) remain a delicate

issue. Mack et al found that when using the PROMIS measurement tool, caregivers tended to overestimate their child's symptoms and underestimate their mobility.³ While the patient perspective is key, there are times or situations when the caregiver could or should serve as their voice through proxy reporting, as has been accomplished through the Ped-PRO-CTCAE.⁴

In this issue of *Pediatric Blood & Cancer*, Meryk et al. from the Medical University of Innsbruck, Austria describe their efforts to implement and act clinically on a daily patient-reported outcome measurement tool among children with cancer. The research team created a web-based child-friendly patient portal (ePROtect) to track daily patient reported outcomes. Among the twelve patients enrolled on their study they obtained 891 daily reports with a median completion rate of 85.3% for inpatient stays and 55.9% for outpatient stays. Importantly, the time to complete these measurements was less than one minute. Most participants, including both the patient and their proxy, provided a positive rating for usability measures including "ease of use and satisfaction," "system informational arrangement," and "usefulness." The team responded to any reports of severe symptoms which occurred in 14.7% of time points. Interventions that were performed included extension of supportive care management and admission to the hospital. Meryk, et al were able to successfully implement a web-based PRO tool and enact clinical interventions to outpatient stays to admission for unexpected outcomes.

The platform to collect the PRO is critically important. Mobile health (mHealth) technology tools appear to be a promising method in which to capture PRO. As seen in the Meryk study, mobile platforms are a feasible and acceptable manner in which to approach the collection of PRO by children with cancer. In a longitudinal study, Vettese et al had high utilization and positive usability for the Supportive care Prioritization, Assessment, and Recommendation for Kids (SPARK) web application to improve symptom control among children with cancer or pediatric hematopoietic stem cell transplant recipients.⁵ Others have utilized text messaging features where the responses from patients and family members are emailed to the clinical team.⁶

Despite these successes, there will continue to be barriers to translating PRO into clinical care in the world of pediatric oncology. These barriers tend to be organizational and less frequently due to user or intervention issues.⁷ As most clinicians would attest, available time and insufficient staff remain important factors to help navigate the gathering and converting of PRO into clinical care.⁸

In summary, the challenge to include patient-reported outcomes into clinical care remains complex. Incorporation of the patient's voice will bring depth to our understanding of the journey our patients endure. This will require a balance of information gathering and evaluation. It is important that the tracking of PRO occur without overloading the patient or their caregiver with tasks. Also, it is imperative that we not providing too much information to the clinician who then may not focus on the symptom most concerning to the patient. Infrastructure changes and resource allocation will be required to merge our clinical duties with PRO measurements in order to truly achieve the Institute for Healthcare Improvement's goal of understanding "What matters to you?". This study by Meryk et al is an important step in the right direction of utilizing mHealth to capture, evaluate, and initiate clinical interventions to improve symptom management for children with cancer through their cancer experience.

References:

- Riedl D, Rothmund M, Darlington AS, Sodergren S, Crazzolara R, de Rojas T; EORTC Quality of Life Group. Rare use of patient-reported outcomes in childhood cancer clinical trials - a systematic review of clinical trial registries. Eur J Cancer. 2021 Jul;152:90-99. doi: 10.1016/j.ejca.2021.04.023. Epub 2021 Jun 2. PMID: 34090144.
- Leahy AB, Steineck A. Patient-Reported Outcomes in Pediatric Oncology: The Patient Voice as a Gold Standard. JAMA Pediatr. 2020 Nov 1;174(11):e202868. doi: 10.1001/jamapediatrics.2020.2868. Epub 2020 Nov 2. PMID: 32832974; PMCID: PMC8103813.
- 3. Mack JW, McFatrich M, Withycombe JS, Maurer SH, Jacobs SS, Lin L, Lucas NR, Baker JN, Mann

CM, Sung L, Tomlinson D, Hinds PS, Reeve BB. Agreement Between Child Self-report and Caregiver-Proxy Report for Symptoms and Functioning of Children Undergoing Cancer Treatment. JAMA Pediatr. 2020 Nov 1;174(11):e202861. doi: 10.1001/jamapediatrics.2020.2861. Epub 2020 Nov 2. PMID: 32832975; PMCID: PMC7445628.

- Reeve BB, McFatrich M, Lin L, Lucas NR, Mack JW, Jacobs SS, Withycombe JS, Baker JN, Freyer DR, Hinds PS. Validation of the caregiver Pediatric Patient-Reported Outcomes Version of the Common Terminology Criteria for Adverse Events measure. Cancer. 2021 May 1;127(9):1483-1494. doi: 10.1002/cncr.33389. Epub 2020 Dec 17. PMID: 33332590.
- Vettese E, Cook S, Soman D, Kuczynski S, Spiegler B, Davis H, Duong N, Schechter T, Dupuis LL, Sung L. Longitudinal evaluation of Supportive care Prioritization, Assessment and Recommendations for Kids (SPARK), a symptom screening and management application. BMC Cancer. 2019 May 16;19(1):458. doi: 10.1186/s12885-019-5662-9. PMID: 31096957; PMCID: PMC6521508.
- Leahy AB, Schwartz LA, Li Y, Reeve BB, Bekelman JE, Aplenc R, Basch EM. Electronic symptom monitoring in pediatric patients hospitalized for chemotherapy. Cancer. 2021 Aug 15;127(16):2980-2989. doi: 10.1002/cncr.33617. Epub 2021 May 4. PMID: 33945640.
- Schepers SA, Sint Nicolaas SM, Haverman L, Wensing M, Schouten van Meeteren AYN, Veening MA, Caron HN, Hoogerbrugge PM, Kaspers GJL, Verhaak CM, Grootenhuis MA. Real-world implementation of electronic patient-reported outcomes in outpatient pediatric cancer care. Psychooncology. 2017 Jul;26(7):951-959. doi: 10.1002/pon.4242. Epub 2016 Sep 4. PMID: 27502744.
- Schepers SA, Haverman L, Zadeh S, Grootenhuis MA, Wiener L. Healthcare Professionals' Preferences and Perceived Barriers for Routine Assessment of Patient-Reported Outcomes in Pediatric Oncology Practice: Moving Toward International Processes of Change. Pediatr Blood Cancer. 2016 Dec;63(12):2181-2188. doi: 10.1002/pbc.26135. Epub 2016 Aug 11. PMID: 27511830; PMCID: PMC6347376.
- The Power of Four Words: "What Matters to You?". Institute for Healthcare Improvement. Accessed August 23, 2021. http://www.ihi.org/Topics/WhatMatters/Pages/default.aspx