interRAI Pediatric Home Care (PEDS-HC) **Assessment Tool: Evaluating Ontario Healthcare** Workers' Experience

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ABSTRACT: High quality pediatric homecare requires comprehensive assessment of the needs, supports, and health care challenges of children with special healthcare needs and their families. There is no standardized homecare assessment system to evaluate children's clinical needs in the home (support services, equipment, etc.) in Ontario, Canada, which contributes to inequitable homecare service allocation. In 2017, the interRAI Pediatric Home Care assessment tool (PEDS-HC) was implemented on a pilot basis in several regions of Ontario. This gualitative descriptive study explores the experiences of homecare coordinators using the PEDS-HC, seeking to understand the utility and feasibility of this tool through focus group discussion. Four major themes were identified including: the benefits of the tool; areas for modification; challenges to use; and Clinical Assessment Protocols to develop. These themes can guide modifications to the tool to improve utility and improve pediatric home care services. The PEDS-HC is an effective tool to assess children needing homecare in a standardized and comprehensive manner. Use of the tool can improve the quality of homecare services by ensuring equity in service provision and facilitate early identification of clinical issues to prevent unexpected health deteriorations.

KEYWORDS: Home care services, pediatrics, needs assessment, focus groups

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Background

The interRAI Home Care assessment system has successfully been used in Canada and globally to comprehensively evaluate long term at-home needs and support service needs for adults.¹ The assessment system provides a comprehensive and standardized approach which facilitates equitable distribution of services.² An interRAI assessment tool was developed in Texas, USA for children with special healthcare needs: the Pediatric Home Care (PEDS-HC) Assessment Form.³ For children with special healthcare needs receiving in-home services in Canada, no standardized assessment tool is currently used. This has led to variability in assessments leading to inequity in resource allocation. The PEDS-HC was provided as a pilot to clinical care coordinators in Ontario. Focus groups were conducted to receive feedback about utility and feasibility of adoption of the tool.

All 14 Local Health Integration Networks (LHINs) in Ontario were invited to participate in the project which took place between February 2017 and March 2019. Nine LHIN agencies participated in 1 of 2 in person or virtual training sessions, and 3 agencies participated in the project. At each location, between 2 and 10 clinical care coordinators were recruited, and each of them used the instrument to assess between 2 and 5 patients in the home. Nine months into the trial period, 2-h focus groups were run at each site. Team members (MD and CV) served as session moderators to encourage discussion

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amongst the participants, they were not involved in development of the instrument and thus could serve as unbiased facilitators. Session transcripts were recorded and then transcribed verbatim. Iterative thematic analysis was performed using NVivo software (released March 2020) to identify emerging themes in the discussion.⁴

Themes

Four themes were identified through analysis of the focus group transcripts: (1) benefits of the tool, (2) areas for modification, (3) challenges to use, and (4) Clinical Assessment Protocols (CAPs) to develop. See Figure 1 for complete details.

Theme: Benefits of the tool

Overall participants agreed that the instrument was helpful to identify the care needs of children in the home and avoid acute care utilization, such as hospitalization. Two participants stated "I find it does give a good picture of a client in the present, sort of in that one moment of time" (P1) and "overall, I do like it, I like the detail of it" (P2). Having a standardized list of items to assess was frequently noted to be useful. Participants also appreciated having both the option to complete the tool on paper or to input directly into the online system on their laptop. The ability to capture an accurate snapshot of the patient led many participants to identify the PEDS-HC as particularly effective for

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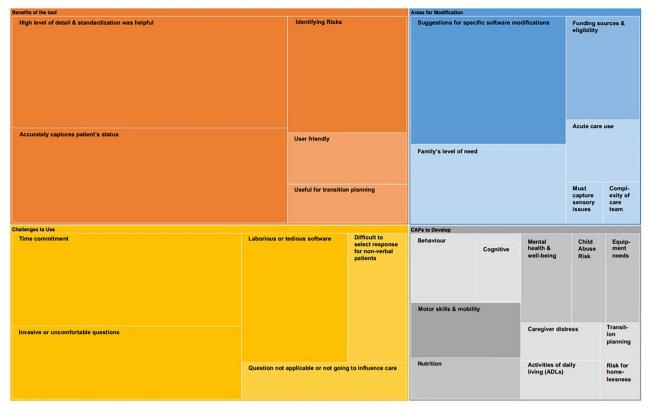


Figure 1. Hierarchy chart of themes and subthemes compared by number of coding references. Larger boxes indicate themes that were discussed more frequently, while darker color indicates the theme frequency across the 3 focus groups (ie, deepest shade shows all 3 focus groups brought up this theme).

identifying risks and longitudinal changes between assessments. One participant noted how the tool helped with risk identification, stating: "Sometimes parents get a little oblivious to that because they're so focused on the physical aspect of their child getting better, that they kind of miss the fact that their child is getting really depressed. And so, when you start asking questions about that, I had this example, I ran into this, and the parent – I could see that she was starting to think about what was happening to their child. So, I think it's good, it helps to highlight an issue for even the parents." (P3).

Overall, participants reported that the tool supported their efforts to implement and allocate home-based care resources equitably and appropriately based on the child and family's needs. There was also consensus that the PEDS-HC instrument was easier to use than other homecare assessment tools available. P4 stated "It's a pretty good tool, I find it user friendly, it was easier to use than another [assessment tool] that we were trying out."

Theme: Areas for modification

Participants identified areas where the PEDS-HC did not adequately capture the relevant information they needed. Aside from specific changes to the software to improve functionality, participants recommended adding the following items: (1) utilization of acute care (emergency room visits and hospitalizations), (2) other financial and funding supports the child is receiving or has applied for, (3) list of all specialists and care teams involved in the child's care, (4) sensory issues for children with autism and related disorders, and (5) a global rating of the child and family's level of need. One participant remarked: "Each child's file needs to capture the other ones [in the same family or household], that somebody else requires care" (P5). Another stated "I think about some families where there is grandparents that live in the home that also need caregiving, that's an additional burden and it doesn't really capture that" (P6).

Theme: Challenges to use

Participants consistently indicated that completing the assessment was time consuming and that some questions seemed overly intrusive, which made them feel uncomfortable. Participants reported that a complete assessment and documentation required between 1 and 3 h, depending on the child's level of medical complexity. Participants reported that this led them to use the PEDS-HC with less complex children (eg, children without at-home devices or equipment) to reduce the time required. The assessment could be tedious because the online software required manual input of responses for every question, even for sections that did not apply to a particular child (eg, money management). One participant said: "*I found it very long. That actually deterred me from doing it, the amount I was supposed to do as fast as I was supposed to do it.* . . So I think the time is something new for us."(P7). Some questions also felt too personal, making the assessor and family uncomfortable, particularly when these questions did not seem relevant to determining the services required. A participant explained: "So there's a lot in here that what would I do with that information, the detail of it is not going to drive my intervention. Particularly around behaviour, because our focus is so much on physical health and intellectual abilities." (P8) For these questions, participants noted that they would preface the question with an explanation, rephrase the question, or offer less specific response options (eg, age range brackets). One participant noted, "I know that a couple of the parents have questioned why I have to ask their age, and how I approach it is that parents are aging and that could potentially impact on their stress level, increased physical, that sort of thing. When I explain that to them, they sort of understand, but if you don't preface it with that, they think you're being nosy." (P9)

Theme: Clinical Assessment Protocols (CAPs) to develop

Some participants were aware of the suite of instruments available in other interRAI assessment instruments, including Clinical Assessment Protocols which provide suggestions related to clinical management based on the results of the assessment tools. Participants were keen to provide suggestions for the development of CAPs, identifying the clinical problems where CAPs would be most relevant and useful to assist with pediatric homecare provision in their settings. The specific CAPs which were suggested included those related to activities of daily living (ADL) performance, behavior (cognitive/mood), mental health and well-being, equipment needs/deficits, mobility and motor skills, nutrition, risk for child abuse, and caregiver distress.

Discussion and Conclusions

We describe the experiences of homecare coordinators during a pilot implementation of the interRAI PEDS-HC, a standardized pediatric homecare tool, to assess the care needs of children and their families. Coordinators reported that the tool was an appropriate and effective assessment for these children. Assessors noted that the tool helped them to identify clinical issues and risk factors which could lead to additional unexpected or urgent healthcare needs, such as emergency room visits or hospitalizations.

Based on these findings, we believe that development of the interRAI PEDS-HC tool is worth pursuing for eventual use in

Ontario, Canada. Although there was a significant time commitment and high level of detail required, assessors acknowledged that it may just take some getting used to and still valued the detailed level of assessment and its importance for ensuring equitable access to care. Many participants even requested to continue using the interRAI PEDS-HC tool well after the conclusion of the study trial period, further indicating efficacy of the tool and satisfaction among end-users. Going forward, the development of CAPs for pediatric home care should be prioritized, since previous studies have shown that CAPs support the implementation of clinical interventions to help individuals maintain and improve health.^{1,2} The results of this study confirm the PEDS-HC as an appropriate assessment for children receiving home care, which can help to ensure that children and their families have access to the best in-home care possible.

Author Contributions

Conception and design of the work: MD, CV. Data acquisition, analysis and interpretation: MD, CV, ALG. Drafting/ Revision of Manuscript: ALG, MD, CV. All authors read and approved the final manuscript.

Ethics Approval and Consent

This study approved by Children's Hospital of Eastern Ontario's ethics board, approval number of 17/172X. Written informed consent was obtained from all study participants.

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