

Adaptation and Feasibility of the interRAI Family Carer Needs Assessment in a Pediatric Setting

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ABSTRACT: Family carers of children with serious illness contribute many hours of medical care in addition to usual daily care. Assessing the needs and supports of family carers is not routine practice. This study is the first to utilize the interRAI Family Carer Needs Assessment in carers of children, seeking to evaluate and improve its ability to capture their needs. This is a prospective pilot study of family carers of children with serious illness receiving care at a pediatric hospice. Thirty carers completed the self-assessment form. Additional feedback was sought inquiring about the appropriateness of questions and missing information relevant to the pediatric setting. All participants reported the assessment captured important information across multiple domains. Additional questions surrounding extra costs, home and school supports, as well as direct impacts of caregiving activities on pain and relationships were identified as important adaptations. The most common unmet needs in carers and care recipients were episodic relief from caregiving (n=17) and housing adaptation (n=17), respectively. Overall, a comprehensive assessment form is feasible in identifying the diverse needs of family carers of children. Future research should focus on using pediatric specific interRAI tools to guide improvements in policy and practice that can address unmet needs.

KEYWORDS: Child, family caregivers, informal caregivers, pediatric, needs assessment, surveys and questionnaires, self report

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Background

The number of children with serious illness requiring extensive caregiving and medical supports has increased substantially in Canada and worldwide.¹ Despite available services, family carers provide the majority of daily care for children with serious illness, and the health and well-being of carers is crucial to achieving optimal outcomes for children.² Routine assessments of the needs and supports of family carers is not common practice. The literature surrounding carers of children with serious illness has focused on identifying the relationship between caregiving responsibilities and carer health outcomes.³ However, there is a paucity of research focusing directly on carer needs, and more specifically the areas of unmet needs.

The Family Carer Needs Assessment is a tool being piloted as part of a larger suite of instruments developed by interRAI, an international collaborative of clinicians and researchers, to support comprehensive assessment and patient-centred care planning for vulnerable persons. interRAI tools have proven reliability and allow clinicians to gather standardized and routine assessments as well as seamlessly connect patient data across multiple healthcare settings.⁴ The use of interRAI assessments have provided benefits in improving policy and practice for vulnerable adult populations within long term care facilities, home care and mental health sectors.^{5–8} The costs of performing these assessments is relatively minimal and has the ability to improve the use of public health resources.⁹

The Family Carer Needs Assessment was created to help identify the unmet needs of family carers of adults requiring significant medical supports. Because family carers of

children with serious illness face similar, if not more intensive challenges,¹⁰ it is hypothesized that the Family Carer Needs Assessment form can be utilized to collect information in this population. This study is the first to implement this instrument in a pediatric setting, with the intent to evaluate its applicability to family carers of children and identify potential pediatric specific adaptations. Additionally, the unmet needs, supports and experience of family carers of children with serious illness were collected.

Methods

Study setting and population

This was a prospective pilot study of a convenience sample of family carers bringing children for symptom management, respite, or summer camp activities at a pediatric hospice in Ottawa, Ontario. The hospice is specialized in addressing the medical needs and providing a safe childcare environment for children with serious illness. Nursing staff, allied healthcare workers, volunteers and a physician experienced in providing pediatric palliative care are available to attend to the child's needs at all times. Profiles of the medical needs of the children were not collected as part of this study. We defined family carers as those who were related to the child (care recipient) and provide a large majority of the home care required. Carers who were non-English speaking, caring for children in foster care or who did not consent to be approached about research were excluded. Study recruitment occurred over an eight-week period, in a sequential manner and mainly during regular working hours. Written informed consent was obtained by a research assistant



Table 1. Components of the interRAI family carer needs assessment.

SECTION	DOMAINS	NUMBER OF QUESTIONS
Identifying information	Demographic characteristics	10
Health and wellbeing	Physical, social, functional, and mood	27
Carer needs assessment	Needs, supports, challenges, and experience	50

who explained the purpose of the study and was available to answer questions throughout. A total of 39 family carers were asked and agreed to participate in the study, of which 30 carers completed the assessment.

Measures

Each participant completed the original interRAI Family Carer Needs Assessment, a self-report form gathering information across multiple domains of well-being (physical, social, functional, psychological) with a focus on needs and supports. interRAI instruments are assessed through multiple clinical trials to ensure their reliability and validity prior to publication. This form is currently in the testing phase and is unavailable for publication at this time. An overview of the structure of this assessment form is displayed in Table 1, showing that majority of the questions focus on identifying the current needs of the carer.

Although not formally assessed in a pediatric setting, the reliability of the items and measures included within other interRAI instruments have been tested extensively with proven transferability across many settings, languages and countries.⁴ An additional feedback questionnaire was provided, inquiring about how well the form captured important information, whether the questions were appropriate in caring for children and whether pertinent information was missing. Participants were given the opportunity to provide written feedback on the attached questionnaire or verbal feedback to the research assistant (see Figure 1).

Analysis strategy

The primary objective was to assess the feasibility and applicability of the interRAI Family Carer Needs Assessment in a pediatric carer population using a mixed methods approach. This design was chosen as the qualitative data collection was designed to best inform adaptations of the assessment form which collects quantitative data. Content analysis research methodology as described by Wilson¹¹ was used for the qualitative feedback data. Participant feedback was first transcribed and grouped according to whether it pertained to the specific sections of the form, overall survey structure, or missing information. Key emerging themes were then identified in each grouping by the first author of this paper based on common topics that emerged within the responses, and the frequency of responses referring to each theme was determined. The themes

were reviewed and agreed upon by both authors. Frequencies of quantitative responses were analyzed to determine the extent of needs and supports for both the carer and care recipient (as perceived by the carer), to determine the highest areas of unmet needs. These items were assessed with carers indicating one of the following responses: not received/not needed, not received/supports needed, received/no additional supports needed, received/additional supports needed. An unmet need was defined as an area where carers indicated new or additional supports were needed, regardless if they had been previously received or not.

Ethics

Ethics approval was received from the Children's Hospital of Eastern Ontario Research Ethics Board. Given the sensitivity of information gathered in this study, participants were provided space to express acute concerns and each comment was screened in a timely manner to identify urgent needs in the family carer. There were 2 instances where carer comments were followed up with a social worker.

Results

Thirty family carers participated with a mean age of 41.8 years. The 1 carer was providing care for 2 siblings with serious illness. Care recipient ages ranged from 10 months to 17 years with of mean of 9.8 years. Most carers were the parent or guardian of the child, except for 1 who was the grandmother. Full demographic characteristics are shown in Table 2.

Primary analysis – Participant feedback

The assessment form took an average of 21 minutes to complete. Of the 30 carers, 27 completed the additional feedback questionnaire. All participants who provided feedback reported the assessment form collected important information. Most carers identified items unsuitable for carers of children (n = 20), however stated the form was not missing any pertinent information (n = 18). The verbal and written responses provided (see Tables 3 and 4), were utilized to make informed changes to the assessment form in adapting it to the pediatric carer population. In addition, these suggestions will be passed on to the authors of the original form to determine if they warrant incorporation in the assessment used by carers of adults with high medical needs.

Questions unsuitable to carers of children. The most commonly flagged items on the assessment form were independent activities of daily living (IADL) of the family carers themselves, as some participants felt carers of children are often younger than those caring for adults and are otherwise able to function independently (see Table 3). Analysis of the responses in this section showed 77% of carers (n=23) reported difficulty with at least 1 IADL. Another set of items flagged on the assessment

were supports for the care recipients involving personal care of the child and household work.

Feedback relating to the survey structure itself pointed to a preference for assessment items containing 5-point scales compared to 1 section (carer challenges) utilizing dichotomous (yes/no) answers. Several responses also found the “last 3 days” time period cumbersome and not encompassing of the fluctuating periods of positive and negative carer experiences.

Table 2. Carer and care recipient demographics.

VARIABLE	CARERS (N=30)	CARE RECIPIENTS (N=24)
Age, mean years (range)	41.8 (23-71)	9.78 (10M-17Y10M)
Gender, N (%)		
Female	22 (73.3)	13 (54.1)
Male	8 (26.7)	11 (45.8)
Marital status, N (%)		
Married/partner	25 (83.3)	
Single	5 (16.7)	
Relationship, N (%)		
Parent/guardian	29 (96.7)	
Other relative	1 (3.3)	
Language, N (%)		
English	23 (76.7)	
Other	7 (23.3)	

Additional feedback. Carers indicated several responses that were not related to the assessment but reflected their experience as carers. Stating their satisfaction with the services received, 1 carer wrote “___ condition is very complicated, if we as a family had not received so much support from so many different angles, life would be very very difficult.” Another carer reported “our time for ourselves is hard to find, we are physically and mentally worn out.” Overall, beyond collecting information about carer needs and supports, the experience of filling out this assessment was beneficial for carers to consider their own needs, as well as express both gratitude and frustration with their experience.

Secondary analysis – Needs and supports

We found the highest areas of unmet needs for carers and care recipients were episodic relief from caregiving (n=17) and housing adaptations (n=17) respectively (see Figures 2 and 3). Overall, 63% (n=19) of carers reported at least 1 area where new or additional supports were needed for themselves and 80% (n=24) for the care recipient. Only 37% reported no unmet carer needs and 20% reported no unmet care recipient

Table 3. Feedback questionnaire responses regarding items unsuitable for child carers.

THEME (N)	EXAMPLE FEEDBACK
Function/endorance/ stamina (n=10)	IADL items flagged: managing medications, shopping, transportation, and bathing Child caregivers are usually younger, they would not have issues carrying things/driving/bathing, only when they have to do this with the child and all of their equipment
Supports for care recipient (n=7)	“There were some questions I didn’t feel applied to ___, but I can see how they’d potentially apply to other children (age/ability)” Supports most commonly flagged: personal care (bathing and hygiene) and assistance with household tasks (cleaning and laundry)
Survey structure (n=5)	Dichotomous questions (Y/N response) • “I found some of the questions hard to answer yes or no. I would have answered sometimes to a few questions” Last 3 days time frame • “The ‘last 3 days’ does not accurately provide a picture of reality in the sense that it isn’t enough time. Some periods are longer (or ups and downs) or shorter” Social Needs: changes in last 90 days • “A 90 day period isn’t relevant if one’s caregiver responsibilities have endured for years”

Table 4. Feedback questionnaire responses regarding missing information.

MISSING INFORMATION	SUGGESTION FOR IMPROVEMENTS
Home and school supports	<i>“Adding a question about the quality of at-home support (e.g. PSWs) would have been good”</i>
Direct impact of caregiving activities on health	<i>“Do you feel worn out directly from providing care?”</i>
	Sleep
	<ul style="list-style-type: none"> <i>“How much sleep do you lose from stress and taking over care when stuff cancels?”</i>
	Pain
	<ul style="list-style-type: none"> <i>“Would be good to ask if there is a link between the pain and role as caregiver; e.g. if pain was caused by or is made worse by caregiver activities (such as sore back irritated by lifting child)”</i>
	Relationships
	<ul style="list-style-type: none"> <i>“Ask if taking care of the child had consequence on romantic relationship or marriage. I know couples who separated in that context”</i>
Financial impacts	<i>“Question around need to work to survive despite being exhausted and/or wanting to be more present to care for your child”</i>
	<i>“Extra costs/expenses”</i>
	<i>“Do you have any unpaid help?”</i>
	Current supports paid for directly by caregiver
	<i>“Ask specifically if number of work hours have been reduced since caring for child. Ex: part time, occasional, etc”</i>

needs. Carers faced many challenges, with the most prominent being caring as a major source of stress (see Figure 4).

Discussion

Adaptations for carers of children

Based on feedback and experience administering this assessment form, several modifications are proposed. This includes the addition of “grandparent” as a role describing the relationship to the care recipient, as this was not captured in the original assessment. Furthermore, direct questioning for “education support, including job training AND/OR school support” will make this item more inclusive for children.

Several components of the form will be kept as originally intended. A majority of carers (77%) reported difficulty with at least 1 IADL. Items that are truly unsuitable for carers of children would not be expected to produce this response. Supports for personal care and household work were understandably less applicable for carers of young children, however, were important for older children and especially for those transitioning to adult care. While some preferred 5-point scales to assess carer challenges, this would make the data more difficult to analyze, as practically we would categorize carers reporting “sometimes” or “most of the time” as still having experienced that challenge. In this study, carers only completed the assessment form once, however the aim of these instruments is to provide routine assessments at every point of care contact. Thus, short time frames may be more useful when comparing across different

time points to identify declines or acute changes, as well as to help discern any recall bias.

Four additional questions are proposed that capture new information not previously found in the original assessment form. (1) To make the assessment form more relatable to children in the Canadian context, the addition of “home supports (i.e. personal support worker)” to the supports for care recipient section. (2) Under carer challenges: “Caring for ___ has put strain on my relationships (e.g. romantic, family, friendships).” (3) Following questions regarding presence and intensity of pain: “Do you think your pain is directly related to or a result of caregiving activities?” (4) To capture out of pocket costs for services that may be region specific, the addition of an open-ended question: “Of the supports you receive, which if any are paid for directly by you?”

Findings

This study suggests the use of a comprehensive interRAI Family Carer Needs Assessment form is feasible and collects important information in family carers of children with serious illness. Minor modifications are suggested to adapt this assessment to the pediatric context and consideration could be given to adding these to the assessment for carers of adults as well. Carers reported a greater extent of unmet needs in care recipients rather than themselves, suggesting carers may not be recognizing their own needs. Furthermore, despite conducting this study in a population that is actively receiving services at a

Study Question Sheet

1. How long did it take you to complete the form?

_____ minutes

2. Did the form collect important information?

Yes No

3. Were there items that do not apply to children?

Yes No

4. Please write out questions you thought did not apply to children:

5. Were there questions you would have liked to be asked that were not there?

Yes No

6. Please write out questions you thought were missing:

Figure 1. Feedback questionnaire.

pediatric hospice, the highest unmet need among carers was overwhelmingly episodic relief from caregiving. Common challenges experienced by family carers may point to potential sources of these unmet needs. Data such as this, collected routinely, on larger scales and within other populations, can inform allocation of resources in order to identify where services are most needed.

Children with serious illness are a highly vulnerable population that require significant medical and home care support, and their outcomes are intimately linked with those of the

family carer. In pediatrics, the care of a child involves the care of the entire family.¹² As a child's medical complexity increases, the needs of family carers become more pronounced and multifactorial.¹³ This stresses the importance of establishing integrated systems of care with the ability to coordinate services across multiple healthcare settings. Standardized assessment tools are an essential part of the success of this integration.¹⁴ Thus, there is potential for benefit from supporting the use of interRAI instruments to improve the quality and equity of pediatric care.

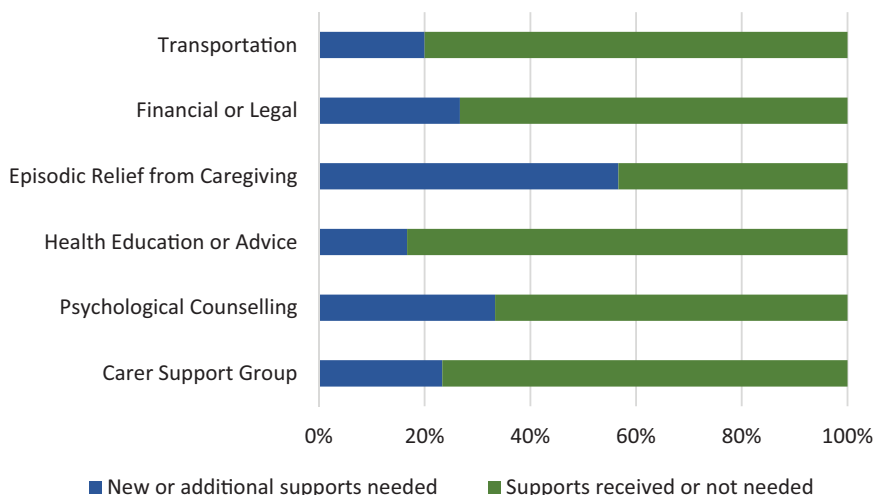


Figure 2. Needs and supports of carer.

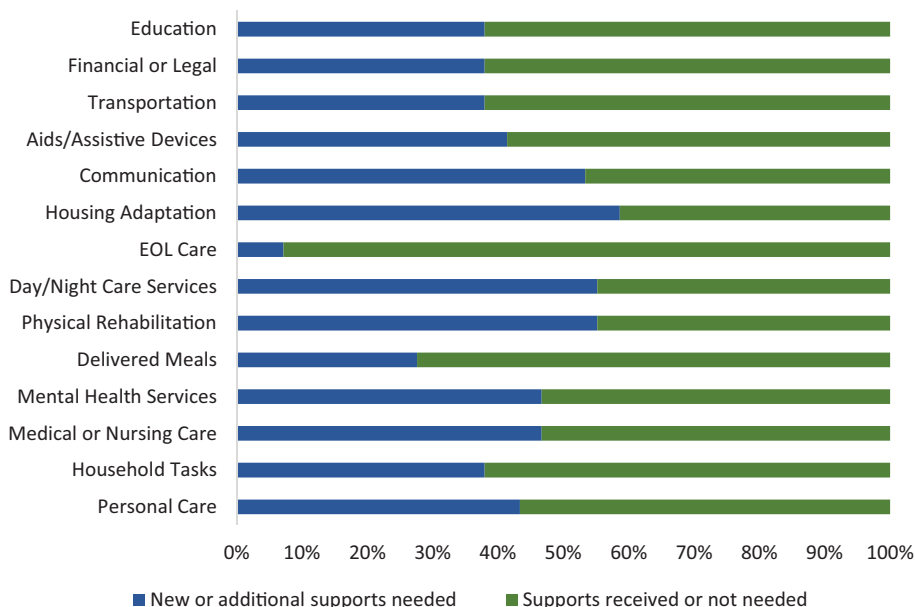


Figure 3. Needs and supports of care recipient (reported by carer).

Illustrative (fictional) example of implementing interRAI assessments into pediatric practice

Ada Fischer is a 45-year-old woman who is a full-time family carer of her 12-year-old son with cerebral palsy, and recently became the carer of her 80-year-old father who suffered a debilitating stroke. Her husband is supportive and often works excessive hours to cover living expenses and out of pocket costs for their sons’ medical care. With increasing care responsibilities, Ada often turns down opportunities to see other friends and family, as she feels guilty being away from home. While numerous healthcare professionals recognize her challenges, time constraints make it difficult to appreciate Ada’s specific unmet needs as well as the needs of those she cares for. If Ada were to complete a needs assessment, early recognition of her need for respite services could occur. Additionally, if her needs were integrated with comprehensive home care assessments for

both her sick child and father, this would allow providers to tailor specific sets of resources to best support the whole family. In this case, the assessment could identify a need for transportation support for her child as his condition progresses, and nursing care for her father while her husband is at work. Using these assessments routinely, providers can identify evolving needs, make informed care plans and monitor progress. If resources are deficient or absent on a population level, policy makers and governments would have standardized tools to collect data and make evidence-based decisions to fund new services and programs that support family carers.

Future directions

While used extensively and even mandated in some Canadian provinces within the mental health, community health and home care adult population¹⁴ interRAI assessments are only

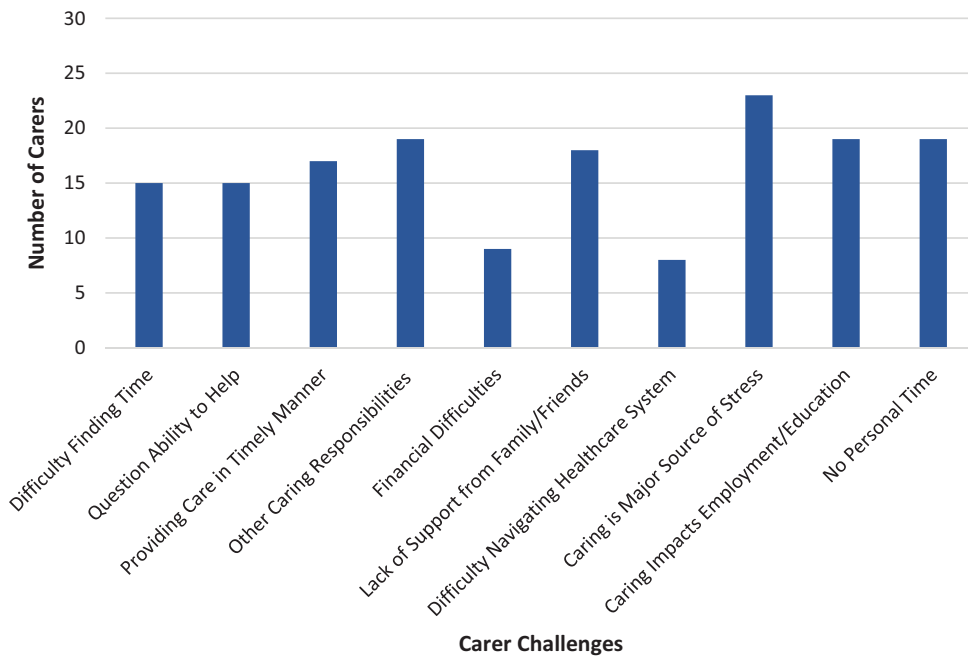


Figure 4. Challenges faced by carers.

beginning to appear for children. The pediatric home care (PEDS-HC) assessment has been developed for children with complex care needs receiving long term support.¹⁵ This tool has been implemented in pilot projects across 3 Ontario regions. A Family Carer Needs Assessment would complement the PEDS-HC, allowing a holistic evaluation of the entire family. Linking carer assessments with care recipient health and complexity of medical needs (the “caregiving dyad”) will be critical for achieving optimal outcomes for vulnerable children and their families.

Finally, the implementation of interRAI assessments require supportive structures to facilitate patient centered care planning that directly address the unmet needs of family carers. One method available for well-established interRAI instruments includes Clinical Assessment Protocols (CAPs), which are clinical algorithms that aim to systemically incorporate all of the information gathered and highlight key areas requiring intervention. This allows healthcare professionals and facilities who implement the interRAI assessment to understand and coordinate the necessary resources for their clients. interRAI data has also been able to identify gaps in care resources and has been utilized as a basis for changing health policy in Canada and abroad.¹⁶ The interRAI Family Carer Needs Assessment does not currently have CAPs developed, and this would require a large focused research effort in the future.

Limitations

This is a pilot study with a small sample size ($n = 30$) implemented in 1 very specialized care setting and may not represent other settings where children with high medical needs

are cared for. Because the corresponding pediatric home care assessment was not utilized in this population, there was no ability to connect the medical care needs of a child with the corresponding care needs of the family carer. Furthermore, the assessment form is only available in English, limiting participation of non-English speaking immigrant, refugee, and indigenous carers. Finally, while interRAI instruments have been widely utilized in adults, more research and experience is needed to establish their efficacy in pediatric populations. Similar to other interRAI instruments, the use of the Family Carer Needs Assessment in different settings will allow for further investigations and improvements in its reliability and validity.

The assessment form does not capture the extent to which a family carer may share caring responsibilities with others. Some family carers may have more established support networks with multiple carers able to assume the primary caregiving role, while others may be single parents providing the entirety of the care required at home. This could be an important element for future research to address, in understanding the difference in carer needs depending on the degree of involvement in the caregiving role.


Conclusion

Comprehensive individualized assessments can be used to capture the varied and multifactorial needs of family carers of children with serious illness. Positive feedback supports integration of interRAI instruments into a pediatric setting. Future research administering a newly adapted pediatric version is needed to determine its use as a clinical tool in evidence-based care planning that can address unmet needs.

Author contributions

C.V. conceived the main purpose and designed the methods of this study. I.S. carried out the implementation of the methods including participant recruitment and data collection. Both authors contributed extensively to reviewing and analyzing the data. I.S. wrote the manuscript incorporating critical feedback and supervision from C.V.

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