

The Rest of the Story: A Qualitative Study of Complementing Standardized Assessment Data with Informal Interviews with Older Patients and Families

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Abstract

Background While standardized health assessments capture valuable information on patients' demographic and diagnostic characteristics, health conditions, and physical and mental functioning, they may not capture information of most relevance to individual patients and their families. Given that patients and their informal caregivers are the experts on that patient's unique context, it is important to ensure they are able to convey all relevant personal information to formal healthcare providers so that high-quality, patient-centered care may be delivered. This study aims to identify information that older patients and families consider important but that might not be included in standardized assessments.

Methods Transcripts were analyzed from 29 interviews relating to eight patients with hip fractures from three sites

(large urban, smaller urban, rural) in two provinces in Canada. These interviews were conducted as part of a larger ethnographic study. Each transcript was analyzed by two researchers using content analysis. Results were reviewed in two focus group interviews with older adults and family caregivers. Identified themes were compared with items from two standardized assessments used in healthcare settings.

Results Three broad themes emerged from the qualitative analysis that were not covered in the standardized assessments: informal caregiver and family considerations, insider healthcare knowledge, and patients' healthcare attitudes and experiences. The importance of these themes was confirmed through focus group interviews. Focus group participants also emphasized the importance of conducting assessments in a patient-centered way and the importance of open-ended questions.

Conclusions A less structured interview approach may yield information that would otherwise be missed in standardized assessments. Combining both sources could yield better-informed healthcare planning and quality-improvement efforts.

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Key Points for Decision Makers

This study supports complementing a standardized assessment with a conversation that would give patients and caregivers an opportunity to ask questions and build a relationship with the provider.

Informal caregivers and family members serve as a patient's social support network and play a crucial role in patient recovery.

1 Background

Older adults often have multiple chronic illnesses and complex health problems [1] requiring multiple medications and treatments [2]. Comprehensive geriatric assessments (CGAs) are used to collect information on psychosocial, biological, and environmental factors related to the needs of older adults [1] for use in care planning and have shown potential for reducing disability [3]. CGAs may be supported by standardized assessment tools; these have evolved from first-generation tools that combine individually validated single-domain instruments to third-generation instruments that encompass all the geriatric domains with a common set of standardized items [4].

It has been suggested that the critical contribution of CGA lies in its ability to shape post-assessment interventions [5]. With older adults constituting a highly heterogeneous population [6], it is important to tailor care plans to unique individual contexts in keeping with a patient-centered care approach [7]. According to the Institute for Healthcare Improvement [8], patient-centered care is defined as care that “honors the whole person and family, respects individual values and choices, and ensures continuity of care.” Patients and caregivers are the experts on their own circumstances; including them as members of the care team gives access to valuable information that could influence their treatment and health status.

With the increasing focus on providing patient-centered care in mind, we sought to determine whether health information that patients believed was integral to their care was well represented by commonly used standardized assessment tools. We conducted interviews with patients and their informal caregivers to answer the question “What, if any, relevant patient health information was learned during interviews that patients considered important to their health but that might not be included in standardized assessment data?” For comparison with information learned during the interviews, we used two assessment systems mandated for use in two healthcare settings in Ontario, Canada (and other jurisdictions). These included the Functional Independence Measure (FIMTM), used with rehabilitation patients, and the international Resident Assessment instrument—home care (interRAI-HC) assessment, used with home care clients.

1.1 Functional Independence Measure (FIMTM)

The FIMTM is an 18-item assessment of cognitive (five items) and motor (13 items) function [9]. Functional items include self-care, sphincter control, transfers, and locomotion; cognitive items include communication and social cognition. The instrument is scored based on the degree of

assistance needed to complete each of the items, with lower scores indicating a higher level of dependence [10, 11]. The FIMTM is widely used in physical rehabilitation [1, 12] and has undergone extensive psychometric testing of its reliability and validity [9, 10, 12–15].

1.2 International Resident Assessment Instrument—Home Care (interRAI-HC)

The interRAI-HC (or minimum data set [MDS]-HC) [16] is one of a suite of instruments developed by the interRAI consortium for use in a variety of healthcare settings [17–19]. The interRAI-HC includes demographic information, cognition, communication and vision, mood and behavior, psychosocial well-being, functional status, continence, disease diagnoses, health conditions, oral and nutritional status, medications and procedures, social supports, environmental assessment, and other information. It is intended for use with individuals who are currently or who will be receiving home care, which is a predominantly older clientele [17, 20]. The tool is administered by a trained assessor who gathers information from the patient, their caregivers, and, when possible, a review of their clinical record and a discussion with staff. The interRAI-HC has been found to be reliable in an international study [17].

2 Methods

The data used in this project were collected as part of a larger ethnographic study entitled InfoRehab Transitions (IRT) that investigated care transitions for older adults with hip fractures. This study was a pan-Canadian study consisting of one large urban site, a mid-size urban site, and a rural site. The methods have been described elsewhere [21–24] and are briefly summarized here. Semi-structured interviews (typically 45–60 min long) were conducted with older adults, their informal caregivers, and their formal care providers at each point of transition (e.g., discharge from acute care to a rehabilitation hospital, or discharge from home care to a long-term care home). These interviews were conducted between December 2009 and December 2010 (see the Electronic Supplementary Material [ESM] 1 for a copy of the interview guide). To participate, patients had to be aged >65 years; have been diagnosed with a hip fracture; and be able to speak, read, and write in English [21, 23]. Family members were included if they spoke English and were caregivers to the patients, and formal care providers were included if they spoke English and were involved in the patient’s circle of care with the ability to comment on pertinent aspects of the healthcare setting [23]. Patients and caregivers were

interviewed separately to gather information about each perspective independent of the caregiver–patient relationship. Multiple interviews were conducted with each participant at each transition point (patients typically had two or three transitions). This allowed the researchers to examine the care transitions from multiple perspectives with a focus on the use and understanding of health information throughout each patient’s care trajectory. Patients were interviewed in their rooms within the healthcare setting after each care transition [21]. Healthcare providers were also interviewed within the healthcare setting, within a staff office, lounge, or cafeteria [21]. Informal caregivers chose their interview locations, which included coffee shops, their homes, and the cafeteria of their loved one’s healthcare setting [21]. The interviews were audio-recorded and transcribed verbatim. Informed consent was obtained from all participants prior to the start of the study. Consent for patient participation involved an initial contact by a healthcare provider who served as a study ‘gatekeeper’ and assessed the cognitive capacity of the patient to participate; this was followed by an informed consent process undertaken with the researcher. The research team had backgrounds in health sciences, epidemiology, and rehabilitation. The interviewers were graduate students or postdoctoral fellows with training in health services research and gerontology. Prior to the start of participant interviews, the research team had explicit discussions about sensitizing concepts that might guide data collection and analysis; these included concepts such as frailty and complex health conditions, gender roles, and the important role of informal caregivers. Self-reflexivity was supported through field notes. Researchers were not known to participants in advance.

We analyzed 29 interviews ($n = 21$ patient interviews; $n = 8$ informal caregiver interviews) that had been previously conducted with eight individual patients and their respective informal caregivers as part of IRT, including data collected from each of the three sites (the full IRT study contained 171 interviews conducted with 134 participants). For the purposes of this secondary analysis, an equal number of male and female patients were chosen so that perspectives of both sexes could be reflected in the analysis. The authors attempted to capture the diversity of individual experiences by analyzing interviews from patients who were ultimately discharged to a variety of care settings (see Table 1 for patient characteristics). We employed a conventional content-analysis approach [25] that involved line-by-line review of the transcribed text to assign codes to individual groups of text or meaning units [26] related to any information brought up by the patient or caregiver during the interview that would be important for the formal care provider to be aware of about the patient’s health condition, circumstances, or goals. These codes

were then grouped into broader themes surrounding the type of health information discussed. Each interview was analyzed separately by two independent coders (two of CL, JE, or MYE) to improve the reliability of findings [27]. Data were analyzed using NVivo 9 software. All three of the coders periodically discussed the themes as they emerged to ensure a unified approach to the theming of the data; discrepancies or alternative explanations were discussed until consensus was reached.

Once a comprehensive list of codes was finalized, three researchers (CL, JE, and MYE) matched the themes to items on the FIMTM and the interRAI-HC assessment tools. These two assessment tools were chosen because they are commonly employed in the older population [28], and they are the data sources for two major mandated reporting systems in Canada: the Home Care Reporting System [29] and the National Rehabilitation Reporting System [30]. Additionally, these two assessments represent a first- and a third-generation assessment tool that previous research has recommended combining to strengthen the information gathered from patients [31]. Together, the multi-dimensional information gathered by the interRAI-HC tool and the information on functional independence gathered by the FIMTM yield a fairly comprehensive picture of the type of information routinely gathered in standardized assessments of older adults. It should be noted that the older RAI-HC assessment is currently being updated to the newer interRAI-HC. To maximize the sustained relevance of our findings, we chose to use the newest version of the tool for this study. The comparison between our codes from the interview data and the items on the FIMTM and the interRAI-HC followed the format used by Berg et al. [32]. Three researchers independently matched the codes to the items on the instruments; any codes that did not match any instrument items were labeled “not covered”. The results of the matching were kept anonymous and presented to each of the researchers. A meeting was held to discuss discrepancies until consensus was reached regarding where the interview codes were matched by or not covered in assessment items.

Study findings were presented at two focus group interviews ($n = 5$ and $n = 9$) with English-speaking older adults who had not experienced hip fractures to assess the generalizability of the findings [27]. Convenience sampling was used to recruit participants from the Seniors Helping as Research Partners (SHARP) group, a group that was created by researchers at the University of Waterloo and consists of older adults who wish to voluntarily engage in research activities (<https://uwaterloo.ca/ghs/sharp>). Focus groups were selected in lieu of one-on-one interviews because they provided an opportunity for participants to collaborate with each other when brainstorming topics that were not covered by the research codes or the assessment

Table 1 Participant characteristics by site

Patient	Sex	Age (years)	Caregiver interviews?	Living situation prior to fracture	Care transitions
Small urban					
Patient 1	Female	87	Yes (daughter)—Caregiver 1	Home	Acute care → inpatient rehab → retirement home → home with home care
Patient 2	Male	87	Yes (daughter-in-law)—Caregiver 2	Home	Acute care → inpatient rehab → home with home care
Patient 3	Male	71	Yes (wife)—Caregiver 3	Home	Acute care → home with home care
Rural					
Patient 4	Male	71	No	Home	Rural hospital → respite in retirement home → home (no home care)
Patient 5	Female	92	Yes (daughter)—Caregiver 5	Retirement home	Rural hospital 1 → Rural hospital 2 → long-term care → rural hospital 1 → long-term care
Patient 6	Female	92	Yes (daughter-in-law)—Caregiver 6	Home	Rural hospital → long-term care
Large urban					
Patient 7	Male	91	Yes (wife)—Caregiver 7	Home	Acute care → home with home care
Patient 8	Female	83	No	Home	Acute care → inpatient rehab → assisted living → home with home care

tools. See ESM 2 for the focus group interview guide. Feedback from both of these focus groups was audio recorded and transcribed verbatim with all identifying participant information removed to ensure participant confidentiality. No new information was captured in the second focus group interview; therefore, we concluded data collection. The results of these focus groups were compared with the codes generated by the previous qualitative analysis.

Ethics clearance for the IRT data collection was obtained from the Research Ethics Boards at the Universities of Waterloo, Western Ontario, and British Columbia (see [21–24]). The University of Waterloo Office of Research Ethics provided ethics clearance for the focus group interviews conducted for this project (ORE #19094). Signed and verbal informed consent was obtained for the older adults participating in the focus group interviews after the researchers had thoroughly explained the project and answered all participant questions. Participants were also given a written explanation of the project as well as contact information should they have any questions for the researchers at a later date.

3 Results

Initial coding produced 112 codes. After these codes were compared with the items on the FIMTM and the interRAI-HC, and codes already covered by these instruments were removed, three overarching themes were identified:

informal caregiver and family considerations, insider healthcare knowledge, and patients' healthcare attitudes and experiences. See Table 2 for examples of mapping coding themes onto items from the standardized assessments. Quotes were included to illustrate these findings and were chosen based on relevance to their theme.

3.1 Theme 1: Informal Caregiver and Family Considerations

Patients and their informal caregivers described a variety of living situations and family dynamics that did not map onto items of either assessment. While each patient had a unique position in terms of their home environment and the types of support they received from family and friends, general themes emerged with regards to important family and informal caregiver information that could have an impact on the patient's health. One aspect of this theme pertained to the propensity of the family members to pursue healthcare providers to share information or concerns. Some family members felt they had not been included in important care conversations and made efforts to have their voices heard. One caregiver explains how she became involved with their loved one's treatment after concerns about lack of exercise after the hip fracture repair:

“So I had just said to her and I did give her, I voiced some concerns because I was a little concerned that she was in a wheelchair and not a walker, ok that was a concern of mine. And I had voiced it a couple of

Table 2 Examples of mapping coding themes onto items from assessment tools

Theme	Covered on FIM TM ?	Covered on interRAI-HC?	Quote
Assistance with ADLs	Yes, under 'Motor' domain (eating, toileting, bathing, locomotion, etc.)	Yes, under 'Functional status' items 2 and 3 ask about ADLs; under 'Continence' items 1–4 ask about ADLs; under 'Health conditions' item 3 includes questions about locomotion; under 'Treatments and procedures' under 'Programs' subheading, items ask about receiving scheduled toileting program	"All I cared about it was done and then so then I just helped my mom get into her pajamas, I got her into bed, there's nobody around to help with any of that stuff"—Caregiver 1, Small Urban Site
Marital status	Not covered	Yes, under 'Identification information', item 4 asks about marital status (never married/married/widowed/separated/divorced/partner or significant other)	"Since December 2008 we brought him from Kenya because my mother in-law passed away and he was all alone in Kenya so we brought him up to live with us." – Caregiver 2, Small Urban Site
Insider healthcare knowledge	Not covered	Not covered	"And my family never felt well informed either like before we came over – I've never felt extremely well informed. And I guess this is frustrating because, with the medical background that I have, it's not that great but you think 'I got to know', but how are you going to find out?"—Patient 1, Small Urban Site

ADL activities of daily living, *FIM* functional independence measure, *interRAI-HC* international Resident Assessment instrument-home care

times because I said you know like I understand she's in a lot of pain but you know like we want to get her up and mobile as soon as possible and whatever"—Caregiver 2, Small Urban Site

Another aspect of the theme regarding family and informal caregiver information was their geographical location in relation to the patient and how it affected the support provided. Some family members lived close by, yet did not offer much informal support, whereas others who were located far away consistently checked in with their loved one and the formal healthcare providers, lending support where possible. While the *interRAI-HC* contains items that ask about hours of care for activities of daily living received from informal supports and whether the patient lives with their informal caregiver, there is no mention of whether the informal caregiver is located nearby. This proved especially relevant when relatives were expected to help coordinate care services for their loved one after hospital discharge. One out-of-town caregiver described the difficulty when her relative asked her to help locate an appropriate nursing home:

"No, she's asked, she said to me on Sunday when I was there, now [caregiver name] you've got to help me find a nursing home or whatever and to be honest with you I don't know how to go about it. Like it's in a different community, I have no idea which nursing homes, you know, are good nursing homes. ... That's a problem for us too, we don't know where to go for

the information because we're not local people, you know."—Caregiver 1, Small Urban Site

Concerns about long travel distances and times were expressed by a caregiver in the large urban centre:

"I think it's the driving here two—twice a day maybe, sometimes only once a day. How I feel I'm so tired when I go home. Meals are all disrupted. The household's disrupted. Your whole life is turned inside out ... It's very taxing, I mean, running—coming home here and then going all the way back and then coming back here, it's a long way and you get tired."—Caregiver 8, Large Urban Site

Information regarding informal caregiver employment often surfaced during the interviews. Some caregivers were limited in the support they could provide because of work schedules or a high number of work hours:

"My daughter works all day in [another city], and then comes to see me and phones me and does what she can to care for me."—Patient 4, Rural Site

Others with a lighter work load had greater flexibility in terms of being able to visit their family member at the hospital and preparing the home for the post-discharge transition. Interviews also yielded information about which caregivers had vehicles they could use to help transport their loved one and whether the vehicle was able to accommodate mobility devices such as wheelchairs and scooters.

3.2 Theme 2: Insider Healthcare Knowledge

Another theme not covered by either assessment tool concerned patients with previous work experience in healthcare (e.g., worked as a nurse) or who had family members with healthcare work experience. This pre-existing knowledge of the healthcare system allowed for a smoother overall care experience since the patients and their family members already had an understanding of what the care pathway could look like and what additional resources would be needed. One informal caregiver explains the benefits of caring for an older adult who previously worked as a nurse:

Caregiver 3, Small Urban Site So when I come down the steps she's ahead of me and when I go up she's behind me. Just as a precaution on things.

Interviewer So did you guys know that or were you told you should try that?

Caregiver 3, Small Urban Site No, she knows that, now she's a retired nurse so she has some experience with this.

Interviewer Well that's good. So do you think that the fact that [patient] was a retired nurse has helped you with this process?

Caregiver 3, Small Urban Site Yeah, she can anticipate what's needed and what procedures, how to do them well. I think that has been a positive.

Informal caregivers with healthcare experience expressed confidence when dealing with the older adult because of their previous exposure to the system. One caregiver explains:

"I deal with this stuff all the time with families and people that are having surgery, going to convalescent care and then going home. So I'm pretty familiar sort of the whole run."—Caregiver 1, Small Urban Site

Having this added confidence allowed some of the informal caregivers to better serve as advocates for their loved ones. One caregiver described how her work as a nurse enabled her to be more assertive when requesting the services required by the older adult she looked after:

"Yeah, like for a lot of people they wouldn't notice these things but you know I know when the nursing care was good nursing care. So you know as I say we pushed but I fear for those who don't have a medical background to just take knowing that, as I say I was a nurse and that we have a daughter who's a physio-therapist."—Caregiver 2, Small Urban Site

3.3 Theme 3: Patient Healthcare Attitudes and Experiences

Another theme relates to patient attitudes towards healthcare resulting from their previous healthcare experiences. Patients with extremely negative experiences often expressed their reluctance to seek care in the future. One patient elaborated:

"I said I don't want to go to [Hospital name]. I had a bad experience at [Hospital name] and I don't want to go. It's over-crowded and the time I was there the bed was like this and the next guy's bed was like this. And the doctors couldn't even get into look at you. It was ridiculous. And they sent me home with a blood sugar count of 32. And that is extremely high."—Patient 8, Large Urban Site

Another patient's previous hospitalization experience had given him a negative predisposition to the care he was receiving:

"So there was a miscommunication with them down here (in the hospital) ... but it doesn't surprise me ... what's going on ... that hospital is going downhill from a year ago. I'll tell you that!"—Patient 4, Rural Site

The reverse was true for patients with overwhelmingly positive healthcare experiences; they continued to seek help from providers with whom they were comfortable and openly sought follow-up treatments. One caregiver explains her mother's positive care experience with some home care workers:

"She had them once before when she needed some services she said she was going to go with them because she had a good experience with them the last time."—Caregiver 1, Small Urban Site

Informal caregivers often emphasized the patient's attitude towards the healthcare system when discussing care pathways. Some informal caregivers described attitudes of appreciation and compliance with treatment plans. Others depicted the more negative attitudes of older adults with respect to their care. One informal caregiver expressed frustration at her mother's refusal to participate in treatment:

"And my mother is very, very like she's not about to take anybody's advice basically is what you need to say there."—Caregiver 1, Small Urban Site

While the interRAI-HC does include information on whether treatments were ordered and/or implemented, no items on either the interRAI-HC or the FIMTM document patient healthcare attitudes.

3.4 Focus Group Feedback

Focus group interviews were held with older adults who had not experienced hip fracture to assess the generalizability of the above findings to a heterogeneous population of older adults. All participants from both focus groups agreed on the importance and relevance of the list of codes generated through qualitative analysis that had not been addressed by the FIMTM or the interRAI-HC. For example, one older adult commented on the importance of adding questions to assessments that ask about previous experience with the healthcare system:

“For that last point there, it just kind of asks have you had experience with the health care system which means have you been in a hospital before—and I think that could be extended a little bit because that is such valuable information that you actually know where you could go, who do you contact, and oh even if you think there’s something wrong with you but you don’t want to hit 9-1-1 but you’d really like to talk to somebody—where do you go?”—Participant 2, Focus Group 1

No new information came to light during the focus group interviews in terms of additional patient information that should be included in assessments. The main recommendation from these focus groups concerned the delivery of standardized assessments in a patient-centered manner. One aspect of this was the importance of being culturally sensitive while performing these assessments. One participant explained:

“The cultural conditions is very important and I think you guys realized that because in some families if the parent doesn’t speak English very well it’s got to be the child that does the interpreting and some people are very uncomfortable about—to share.”—Participant 5, Focus Group 1

Other aspects of assessment delivery included a discussion on how to balance collecting the required information with allowing patients to openly explain what they believe to be important information for their healthcare providers. While participants agreed a long list of important domains needed to be covered by the assessment questions, they expressed concern at the length of such assessments being delivered to older adults. Despite consensus that the codes developed through qualitative analysis were important areas of patient information, both groups were hesitant to add to an assessment such as the interRAI-HC, which is already very long. A key recommendation that emerged through these focus groups was the idea of using more open-ended questions to gather

assessment information. One participant elaborated on this idea:

“I would wonder about I guess even an open-ended beginning with when you talk to a person ‘what are your concerns about going home? What bothers you?’ So for upfront, by the time I got through all these questions I would be run out of steam to say what you really [wanted to say].”—Participant 1, Focus Group 1

4 Discussion

This study identified information gleaned from interviews with patients aged >65 years and their informal caregivers that was relevant to the patient’s health conditions, circumstances, or goals, but that would not have been asked about in a commonly employed standardized assessment tool.

The first theme uncovered from the qualitative data was informal caregiver and family considerations. Subthemes related to informal caregiver geographic location, propensity to pursue healthcare providers to share information or concerns, employment, and access to a vehicle. Consistent with current literature, the findings of this study show that caregiving from a distance complicates the informal caregiver’s ability to provide support and maintain communication regarding patient needs [33]. Demiris et al. [34] found that informal caregivers who used videophone technology were able to reduce feelings of isolation for their loved one and achieve a greater sense of connectedness. Such applications of technology may be helpful in overcoming barriers created by long-distance caregiving. However, providers must document the location of caregivers and appreciate the challenges of supporting family members from afar.

Another subtheme was the importance of informal caregiver access to a vehicle. According to Statistics Canada [35], providing transportation is the most common caregiving task, which highlights both the need for additional transportation resources for older adults and the importance of caregivers having access to a vehicle. Informal caregiver vehicle access would be especially critical information for patients living in rural areas where a lack of public transportation often complicates access to healthcare services for older adults [36]. Informal caregivers and family members serve as a patient’s social support network and play a crucial role in patient recovery. Here again, lack of access to transportation should be documented because it reveals information on the resources available to the patient.

The second theme described how patients and informal caregivers who had work experience in the healthcare field were more confident advocates and better able to navigate the system, consistent with findings we have reported elsewhere [37]. Engaging patients in their care by recognizing the skills and knowledge they have can lead to more informed patient decision making and improved healthcare effectiveness [38, 39]. With knowledge of a patient's previous healthcare work experience, providers could tailor their language and recommendations to that patient's level of healthcare understanding and potentially recommend the services of a system navigator.

The third theme related to patient healthcare attitudes and experiences and the effect they had on compliance with treatment plans. A review conducted by Jin et al. [40] found a link between negative attitudes toward treatment plans and reduced levels of patient compliance. If patients did not agree with the treatment or believe that it would work, they were less likely to adhere to the recommended course of action [40]. Since patient healthcare attitudes, and the experiences that shape these attitudes, are such strong predictors of treatment adherence, it is important they are reflected in the questions asked during comprehensive standardized assessments. Providers should be sensitive to the possibility that patients have had negative experiences, and that these experiences may be coloring their perceptions of current care and recommendations. Frank discussion of these experiences may be helpful in reassuring patients that providers are committed to ensuring negative experiences are not repeated. Establishment of trust may improve adherence.

The recommendations proposed by participants in the focus group interviews centered on delivering standardized assessments in a culturally sensitive way that permits patients to contribute important information about their personal context, thus allowing them to be more engaged partners in care [41]. We note that while both the interRAI-HC and the FIMTM have been widely used internationally, it has been recognized that adaptation of these instruments to local cultures and settings is necessary [42–44]. The participants' suggestions to include broad, open-ended questions to ascertain patients' deepest concerns may also help guard against a serious potential problem introduced with the use of standardized assessments. That is, there may be a tendency for patients to limit the information they share to items of the assessment, seeing that as the provider's focus [45]. Patient-reported outcomes capture information that observation and technology alone cannot yield and are especially important in populations for whom the ultimate goal is quality of life over cure of disease [46]. Incorporating these outcomes through patient interviews could yield additional patient information that might

otherwise be missed and lead to improved patient adherence and health outcomes [46].

While general themes emerged regarding relevant patient information that is not currently included in assessments such as the FIMTM and the interRAI-HC, it would be highly impractical to add additional questions that captured every item of potential interest to these assessments. Within a standardized approach, an open-ended question could capture additional information relevant for a particular patient. More generally, we believe this study supports complementing a standardized assessment with an interview that would give patients and families opportunities to raise points of particular relevance to them, and for a relationship to develop with the patient and family. Further research may be needed to identify the most effective and feasible approaches to integrating these conversations into a busy clinical setting or time-constrained visit and whether they should occur prior to or after a standardized assessment. In keeping with a patient-centered approach, this research should include consultation and collaboration with older adults and their informal caregivers to ensure the findings consider their needs and interests. The comment from the focus group participant noted above suggests merit in an open-ended discussion prior to the standardized assessment. This could ensure that matters important to the patient were identified first, before the patient was fatigued, and would also help build the rapport and relationship key to their effective engagement in decision making [38, 39].

4.1 Limitations

This study has two key limitations. One is that the use of secondary data from hip fracture patients may not have been representative of older patients as a whole. The researchers worked to address this limitation through focus group interviews with older adults who had not experienced a hip fracture; however, consultation with a wider range of patient groups could have identified additional themes. Another limitation to this project was that although our focus group interview participants identified the need for cultural sensitivity in an assessment process, our data collection was limited to English-speaking participants. Consultation with more diverse groups of participants in multiple regions could yield additional insights but was not possible within the resources available for this study.

5 Conclusions

Despite the limitations of this study, we believe it has shown the benefits of supplementing a standardized assessment approach with a more informal interview.

Standardized assessment tools collect valuable patient information for healthcare providers and serve as an important component of geriatric care. However, a less-structured interview approach can yield information that would otherwise be missed. This study identified key areas of information that patients and their informal caregivers felt were relevant to their care but that are not addressed by the FIM™ or the interRAI-HC. While it may not be practical to add additional items to an assessment tool as lengthy as the interRAI-HC, this study highlights the importance of collecting information on each patient's individual concerns and context. These findings are not an exhaustive presentation of assessment areas important for patients and caregivers, but the findings illustrate the value of conversational interactions as a supplement to standardized assessment and for relationship building. Combining this additional information with data collected through standardized assessment tools could yield better-informed healthcare planning and quality-improvement efforts. Additional work needs to be done on how to optimally obtain these types of patient information and how to integrate these changes into existing assessment processes.

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Compliance with Ethical Standards

Conflict of interest CL, JE, ME, and PS have no competing interests. Ethics clearance was obtained through the University of Waterloo Office of Research Ethics (ORE #19094). Informed consent was obtained from all individual participants included in the study.

References

1. Wells J, Seabrook J, Stolee P, Borrie M, Knoefel F. State of the art in geriatric rehabilitation. Part I: review of frailty and comprehensive geriatric assessment. *Arch Phys Med Rehabil.* 2003;84:890–7.
2. Hjar E, Cafiero A, Hanlon J. Polypharmacy in elderly patients. *Am J Geriatr Pharmacother.* 2007;5:345–51.
3. Stuck A, Aronow H, Steiner A, Alessi C, Bula C, Gold M, et al. A trial of annual in-home comprehensive geriatric assessments for elderly people living in the community. *New Engl J Med.* 1995;333:1184–9.
4. Gray L, Berg K, Fries BE, Henrard JC, Hirdes JP, Steel K, et al. Sharing clinical information across care settings: the birth of an integrated assessment system. *BMC Health Serv Res.* 2009;. doi:10.1186/1472-6963-9-71.
5. Stuck A, Siu A, Wieland G, Adams J, Rubenstein L. Comprehensive geriatric assessment: a meta-analysis of controlled trials. *Lancet.* 1993;342:1032–6.
6. Filipovych R, Resnick S, Davatzikos C. Understanding heterogeneity in normal older adult populations via clustering of longitudinal data. In: *Proc IEEE Int Symp Biomed Imaging*; 2011. pp. 1101–4.
7. Lauver DR, Gross J, Ruff C, Wells TJ. Patient-centered interventions: implications for incontinence. *Nurs Res.* 2004;53(6):S30–5.
8. Institute for Healthcare Improvement. Innovation series 2004: transforming care at the bedside. Boston, MA: Institute for Healthcare Improvement. 2004. <http://www.ihf.org/resources/Pages/IHIWhitePapers/TransformingCareattheBedsideWhitePaper.aspx>. Accessed 1 June 2015.
9. Kidd D, Stewart G, Baldry J, Johnson J, Rossiter D, Petrukevitch A, et al. The functional independence measure: a comparative validity and reliability study. *Disabil Rehabil.* 1995;17:10–4.
10. Ottenbacher KJ, Hsu Y, Granger CV, Fiedler RC. The reliability of the functional independence measure: a quantitative review. *Arch Phys Med Rehabil.* 1996;77:1226–32.
11. Granger CV, Hamilton BB, Linacre JM, Heinemann AW, Wright BD. Performance profiles of the functional independence measure. *Am J Phys Med Rehabil.* 1993;72:84–9.
12. Paolinelli C, Gonzalez P, Doniez ME, Donoso T, Salinas V. Instrument for the functional evaluation of disability rehabilitation: study on the reliability and clinical experience with the use of functional independence measure. *Rev Med Chil.* 2001;129:23–31.
13. Corrigan JD, Smith-Knapp K, Granger CV. Validity of the functional independence measure for persons with traumatic brain injury. *Arch Phys Med Rehabil.* 1997;78:828–34.
14. Hamilton BB, Laughlin JA, Fielder RC, Granger CV. Inter-rater reliability of the 7-level functional independence measure (FIM). *Scand J Rehabil Med.* 1994;26:115–9.
15. Heinemann AW, Linacre JM, Wright BD, Hamilton BB, Granger CV. Relationships between impairment and physical disability as measured by the functional independence measure. *Arch Phys Med Rehabil.* 1993;74:566–73.
16. Morris JN, Fries BE, Steel K, Ikegami N, Bernabei R, Carpenter GI, et al. Comprehensive clinical assessment in community setting: applicability of the MDS-HC. *J Am Geriatr Soc.* 1997;45(8):1017–24.
17. Hirdes J, Ljunggren G, Morris J, Frijters D, Soveri HF, Gray L, et al. Reliability of the interRAI suite of assessment instruments: a 12-country study of an integrated health information system. *BMC Health Serv Res.* 2008;8:277.
18. Hirdes JP, Fries BE, Morris J, Steel K, Mor V, Frijters DH, et al. Integrated health information systems based on the RAI/MDS series of instruments. *Healthc Manage Forum.* 1999;12:30–40.
19. Morris JN, Fries BE, Bernabei R, Steel RK, Ikegami N, Carpenter GI, et al. RAI—Home Care (RAI-HC) assessment manual for version 2.0. Boston, MA: interRAI; 1999.
20. Hoover M, Rotermann M. Statistics Canada. Seniors' use of and unmet needs for home care, 2009. In: *Health Reports, Volume 23.* Statistics Canada. 2009. <http://www.statcan.gc.ca/pub/82-003-x/2012004/article/11760-eng.htm>. Accessed 1 June 2015.
21. Toscan J, Mairs K, Hinton S, Stolee P. Integrated transitional care: patient, informal caregiver and health care provider

- perspectives on care transitions for older persons with hip fracture. *Int J Integr Care*. 2012;12:e13.
22. Toscan J, Manderson B, Santi S, Stolee P. "Just another fish in the pond": the transitional care experience of a hip fracture patient. *Int J Integr Care*. 2013;13:e023.
 23. Johnson H, Forbes D, Egan M, Elliott J, Stolee P, Chesworth BM, the InfoRehab Team. Hip fracture care in rural Southwestern Ontario: an ethnographic study of patient transitions and physiotherapy handoffs. *Physiother Can*. 2013;65:266–75.
 24. Sims-Gould J, Byrne K, Hicks E, Khan K, Stolee P. Examining, "success" in post-hip fracture care transitions: a strengths based approach. *J Interprof Care*. 2012;26:205–11.
 25. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15:1277–88.
 26. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;65:105–12.
 27. Harris M. Evaluating public and community health programs. San Francisco: Jossey-Bass; 2010.
 28. Glenny C, Stolee P. Comparing the Functional Independence Measure and the interRAI/MDS for use in the functional assessment of older adults: a review of the literature. *BMC Geriatr*. 2009;9:52.
 29. Canadian Institute of Health Information. Types of Care: Home Care. 2014. http://www.cihi.ca/CIHI-ext-portal/internet/EN/TabbedContent/types+of+care/community+care/home+care/cihi021338#_Databases_and_Data. Accessed 17 June 2015.
 30. Canadian Institute of Health Information. Types of Care: Rehabilitation. 2014. http://www.cihi.ca/CIHI-ext-portal/internet/EN/TabbedContent/types+of+care/hospital+care/rehabilitation/cihi010638#_Databases_and_Data. Accessed 17 June 2015.
 31. Wellens NS, Deschodt M, Flamaing J, Moons P, Boonen S, Boman X, et al. First-generation versus third-generation comprehensive geriatric assessment instruments in the acute hospital setting a comparison of the Minimum Geriatric Screening Tools (MGST) and the interRAI Acute Care (interRAI AC). *J Nutr Health Aging*. 2011;15:638–44.
 32. Berg K, Finne-Soveri H, Teare G, Gray L, Henrard JC, Hirdes J, et al. Relationship between interRAI HC and the ICF: opportunity for operationalizing the ICF. *BMC Health Serv Res*. 2009;9:47.
 33. Cagle JG, Munn JC. Long-distance caregiving: a systematic review of the literature. *J Gerontol Soc Work*. 2012;55:682–707.
 34. Demiris G, Oliver DR, Hensel B, Dickey G, Rantz M, Skubic M. Use of videophones for distant caregiving: an enriching experience for families and residents in long-term care. *J Gerontol Nurs*. 2008;34:50–5.
 35. Sinha M. Portraits of caregiving, 2012. Statistics Canada. 2012. <http://www.statcan.gc.ca/pub/89-652-x/89-652-x2013001-eng.htm>. Accessed 1 Aug 2015.
 36. Lafortune C, Huson K, Santi S, Stolee P. Community-based primary health care for older adults: a qualitative study of the perceptions of clients, caregivers and health care providers. *BMC Geriatr*. 2015;15:57. doi:10.1186/s12877-015-0052-x.
 37. Elliott J, Forbes D, Chesworth BM, Ceci D, Stolee P. Information sharing with rural family caregivers during care transitions of hip fracture patients. *Int J Integr Care*. 2014;14:16.
 38. McNeil H, Elliott J, Stolee P, Heckman G, Boscart V. Integration through engagement: a movement towards older adults' involvement in health care research, planning and decision making. *Int J Integr Care*. 2014; Annual Conf Suppl: URN:NBN:NL:UI:10-1-116167.
 39. Elliott J, McNeil H, Stolee P. Engaging older adults in health care decision-making: key findings and recommendations from the CHOICE knowledge synthesis project. *Int J Integr Care*. 2014; WCIC Conf Suppl: URN:NBN:NL:UI:10-1-116616.
 40. Jin J, Skylar GE, Min Sen Oh V, Chuen Li S. Factors affecting therapeutic compliance: a review from the patient's perspective. *Ther Clin Risk Manag*. 2008;4:269–86.
 41. Epstein RM, Street RL Jr. The values and value of patient-centered care. *Ann Fam Med*. 2011;9:100–3.
 42. Wellens NIH, Flamaing J, Moons P, Deschodt M, Boonen S, Milisen K. Translation and adaptation of the interRAI suite to local requirements in Belgian hospitals. *BMC Geriatr*. 2012;12:53.
 43. Lundgren-Nilsson Å, Grimby G, Ring H, Tesio L, Lawton G, Slade A, et al. Cross-cultural validity of functional independence measure items in stroke: a study using Rasch analysis. *J Rehabil Med*. 2005;37:23–31.
 44. Lawton G, Lundgren-Nilsson Å, Biering-Sørensen Tesio L, Slade A, Penta M, et al. Cross-cultural validity of FIM in spinal cord injury. *Spinal Cord*. 2015;44:746–52.
 45. Ceci C. 'What she says she needs doesn't make a lot of sense': seeing and knowing in a field study of home-care case management. *Nurs Philos*. 2006;7(2):90–9.
 46. Deshpande P, Rajan S, Sudeepthi BL, Abdul Nazir CP. Patient reported outcomes: a new era in clinical medicine. *Perspect. Clin Res*. 2011;2:137–44.