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Caregivers' Aspirations, Realities, and Expectations: The CARE Tool

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Caregivers to family and friends are increasingly recognized as essential players in the continued shift of care of dependent populations to the community. Currently, Canadian provincial home care programs have neither a comprehensive policy nor an assessment regarding caregivers' needs. This article describes an assessment tool that takes into account caregivers' reality and conditions and that situates them as essential partners with the formal system and reports on the validation and reliability testing of this tool. Seven sites in Quebec and Nova Scotia involving 40 assessors tested the tool with 168 caregivers. Results suggest that this comprehensive tool enables practitioners to understand caregivers' needs and situations. Focus groups with assessors and interviews with home care administrators revealed that the tool increased worker understanding and awareness of what it means to be a caregiver, ascertained the key caregiver concerns, and identified these needs in rapid succession.

Keywords: *caregiver needs; assessment; home care practitioners; home care policy*

Caregivers are increasingly identified by health and social service practitioners as having specific and often unmet needs (Beeson, 2003; Soothill et al.,

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2001). Interventions designed specifically to address caregivers' needs might include support, respite, information, referral, and advocacy. However, caregivers themselves are not generally identified as individual clients of health and social service agencies; case files are typically opened on behalf of the care recipients, and services are offered according to the type and severity of the care recipients' conditions (Soothill et al., 2001). Previous research suggests that caregivers can be approached by policy makers and practitioners in different lights, sometimes as co-clients with the care recipient, sometimes as resources requiring mobilization and education to meet the care recipients needs, and occasionally as partners in care (Guberman & Maheu, 2002; Ward-Griffin & McKeever, 2000). Confusion and ambiguity surrounding caregivers' statuses within the health care system have been associated with their needs either being partially or completely overlooked in practitioners' intervention plans (Guberman & Maheu, 2000; Sharpe, Butow, Smith, McConnell, & Clarke, 2005; Soothill et al., 2001).

Several researchers have documented the links between caregivers' unmet needs and negative outcomes in terms of physical and mental health, finances, employment, and family and social responsibilities (Guberman, Maheu, & Maillé, 1993; Keefe & Medjuck, 1997). Though psychological burden is the most frequently documented and often the most severe consequence for caregivers (Atienza, Stephens, & Townsend, 2002; Zarit & Leitsch, 2001), many report experiencing physical and financial strains as well (Canuscio et al., 2002; Keating, Fast, Frederick, Cranswick, & Perrier, 1999; Kiecolt-Glaser & Glaser, 2003; Lee, Colditz, Berkman, & Kawachi, 2003; Yee & Schulz, 2000; Zarit & Edwards, 1996). Recent shifts in health care policies that move away from hospitalization to day surgery, and that emphasize deinstitutionalization in favor of home-based and community-care options, continue to put pressure on family members and friends to take on caregiving roles, despite the risk of negative consequences (Grunfeld & Glossop, 1997).

Caregiver Assessment

In response to the growing concern for caregivers' well-being, development and implementation of routine caregiver assessments has been offered as a means of bringing caregivers out of the shadows of policy and practice. In 2005, delegates from the National Consensus Development Conference for Caregiver Assessment, including 50 policy, practice, and research leaders from across the United States, unanimously called for the need for routine caregiver assessment (Family Caregiver Alliance, 2006; Feinberg, Newman, Gray, & Kolb, 2004). Indeed, the Carers Act of 1995 gave caregivers in the United Kingdom the statutory right to receive assessments (Seddon & Robinson,

2001). There are several benefits to caregiver assessment that substantiate such movements. For instance, insight into caregivers' circumstances helps practitioners to identify areas of need and/or risk, and provides information with which to tailor appropriate interventions aimed at reducing potentially harmful outcomes (Beeson, 2003; Farcnik & Persyko, 2002; Gaugler, Kane, & Langlois, 2000; Pickard, 2004). The assessment process can also have therapeutic benefits for caregivers in that it provides an opportunity for them to express themselves, to be heard, and to feel understood and validated for their loyalty, strength, hard work, and dedication (Feinberg, 2004; Lundh & Nolan, 2003; Maddock, Kilner, & Isam, 1998). Finally, assessment can identify low- or no-cost ways of helping caregivers, such as providing information, referral, advice, or a sympathetic ear.

Assessment instruments provide practitioners with a standardized format with which to guide the interview process and orient dialogue with caregivers. Assessment also leads to practitioner recognition that caregivers' needs differ from those of care receivers, thus allowing practitioners to implement support services oriented toward the unique needs of caregivers. Assessment will also serve to improve the quality of care provided to care recipients (Feinberg, 2004; Lundh & Nolan, 2003). Several authors point to the significant impact caregiver assessments, and subsequent interventions, can have on quality of care (Feinberg, 2004; Maddock et al., 1998; Zarit & Leitsch, 2001).

Current literature emphasizes frameworks, guiding principles, and suggestions for content to guide the design of caregiver assessment instruments (Corradetti & Hills, 1998; Dunkin & Anderson-Hanley, 1998; Guberman, 2005; Hughes, 1993). Although a concrete set of guidelines for formulating caregiver assessment instruments has not yet been created (Feinberg, 2004), a review of relevant literature emphasizes several common suggestions for content. Caregiver assessment tools must be versatile enough to identify the needs of caregivers from a variety of situations and diverse backgrounds, as well as to capture various complexities in the caregiving experience. Most assessments record demographic details and personal characteristics of both the caregiver and care receiver (Feinberg, 2004). A comprehensive caregiver assessment may also include information related to caregivers' physical and emotional health, additional responsibilities, financial costs associated with caregiving, the caregiving environment (e.g., household structure, geographic locality, and transportation), family and social supports, need for formal support services, and information needs (e.g., legal, financial, and household) (Baxter, 2000; Feinberg, 2004; Guberman, 2005; Melillo & Futrell, 1995).

A description of the types and frequencies of caregiving tasks is another essential component of an assessment instrument, focusing on caregivers'

abilities to assist care receivers with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Corradetti & Hills, 1998; Feinberg, 2004; Melillo & Futrell, 1995). However, Levine, Reinhard, Feinberg, Albert, and Hart (2004) argue that caregiver assessments must go beyond ADL and IADL measurement to address additional issues related to the caregiving experience, such as behavioral supervision, coordination of formal services, the purchase and use of home care equipment, and arranging for medical care. Other researchers call for the inclusion of specific sections to deal with the impact of societal and cultural expectations on the caregiving experience, values and preferences of individual caregivers and care receivers, positive aspects of caregiving, the history and quality of the care receiver/caregiver relationship, relationships with other family members, crisis and future planning, and relationships with formal providers (Feinberg, 2004; Guberman, 2005; Lundh & Nolan, 2003). Taken together, all of these elements can provide practitioners with a detailed portrait of the caregiving situation with which to tailor appropriate intervention plans (Corradetti & Hills, 1998).

The CARE Tool

Given the absence of validated and comprehensive caregiver assessment tools in North America, the goal of the present research was to evaluate the reliability and validity of the Caregivers' Aspirations, Realities, and Expectations Tool (CARE Tool), a multidimensional psychosocial instrument for assessing caregivers. The CARE Tool was designed specifically for use by practitioners in publicly funded home care agencies for the purpose of gathering information on the caregiving experience from the caregivers' perspectives. The Tool also allows caregivers and practitioners to mutually seek solutions to unmet needs or areas of risk, to pinpoint areas of difficulty being experienced, and to help shape intervention plans that would best address caregivers' unmet needs.¹

The impetus for its development emerged from the fact that caregivers' lack of formal status within the health care system can translate into difficulties for health care providers to respond to their needs (Guberman & Maheu, 2000; Sharpe et al., 2005; Soothill et al., 2001). The assessment process is intended to be a cooperative process whereby firsthand information from the caregivers' perspectives is collected, followed by an opportunity for practitioners to contribute their perspectives when summarizing identified areas of concern related to the caregiving situation. This is in line with suggestions from other research teams investigating caregiver assessment (Maddock et al., 1998; Nolan, Grant, Keady, & Lundh, 2003), identifying the need for a blend of practitioner input

as well as self-assessment by the caregiver in a caregiver-directed assessment tool. The Tool was carefully constructed based on an extensive review of validated and nonvalidated instruments designed to measure caregiving experiences, along with nine focus groups involving family caregivers and home care practitioners and one focus group with administrators.

The CARE Tool contains 10 main sections (see the appendix). These sections were intentionally sequenced to establish rapport and increase comfort for practitioners and caregivers, beginning with less sensitive task-oriented questions, moving toward more sensitive, personal, and introspective questions, and ending with discussion on more concrete issues such as planning and formal-service needs. Each section of the CARE Tool enables caregivers to express their feelings related to caregiving and contextualize the caregiving experience in their own words. Specific definitions and guidelines accompany each section of the tool to guide practitioners' interpretation of the information received and to ensure that the tool accurately identifies caregivers' needs. In the summary section of the tool, practitioners are instructed to indicate levels of caregiver difficulty in 15 identified areas related to the caregiving situation, rated on a scale of 1 (*little or no difficulty*) to 4 (*extreme difficulty*).² From the information provided by caregivers, in addition to their own perspectives, practitioners identify key areas of difficulty and are invited to consider and record the types of services that would best help the situation. It is in this section that the practitioners are able to incorporate their perspectives to provide a rationale for the services recommended. The development of the CARE Tool was a first step in the recognition of caregivers' needs. A critical second step, and the focus of this article, was to evaluate the validity and reliability of the CARE Tool. This step is recognized as necessary prior to recommending that the CARE Tool be used in the public home care system.

Method

Evaluation of the CARE Tool relied on two methods. First, analysis of interrater reliability of the tool was conducted by having two assessors (Assessor A and Assessor B) interview caregivers on two different occasions (A1 and A2). Second, focus groups were held with participating practitioners to measure content and construct validity of the instrument and the realism of its implementation in Canadian home care agencies.

Seven home care agencies, four in Quebec and three in Nova Scotia, were chosen as research sites. The participation of home care agencies was integral to this research because the CARE Tool was intended for implementation at the community level as a practice and not a research tool.

In all, 40 home care practitioners participated, including social workers, nurses, and rehabilitation professionals. The participating practitioners were experienced assessors within their given fields, but many of them had little experience in conducting comprehensive psychosocial assessments. Therefore, to ensure consistent administration of the CARE Tool across all practitioners and research sites, the project team developed and conducted extensive 2-day training sessions using a comprehensive training guide and a CARE Tool user guide. A portion of the training included interpretation of information and summary sheet scoring.

Measuring Interrater Reliability and Internal Congruency

Participating practitioners selected clients from their home care program caseloads who were known to have a caregiver and invited the latter to participate. An important goal of the project was to include caregivers in both rural and urban settings, caregivers whose primary language was French or English, a mix of caregiver/care receiver relationships (e.g., spouse, child, sibling, parent) and a variety of illness types (e.g., physical, mental, and cognitive). The recruitment resulted in a purposive convenience sample of 168 caregivers of home care clients, reflecting the desired diversity. Practitioners obtained written consent from the caregivers to participate in the research. Consent forms carefully explained the purpose of the assessment, emphasizing that participation would not directly impact withdrawal or receipt of additional home care services.

Variables

Assessment areas. On the summary page of the CARE Tool, practitioners were asked to rate—on a scale of 0 (*little/no difficulty*) to 3 (*extreme difficulty*)—the caregiver's level of difficulty in 15 preestablished assessment areas (see the appendix).

Key areas of concern. After rating caregivers' perceived level of difficulty in each assessment area, practitioners were asked to prioritize up to three key areas of concern. To ensure the use of common wording among assessors, a list of 37 areas, covering a comprehensive range of topics commonly addressed in home care assessments, was provided. For the purpose of analysis, the 37 areas were then collapsed into 17 groups based on common underlying themes. For example, the mental health variable included issues such as poor mental health, grief or recent loss, and isolation. An "other" category was also added to include assessors' concerns that were distinct from the topics

captured in the list. Because the intent of this analysis was to determine if both Assessor A and Assessor B would identify the same key areas of concern based on information obtained, each of these 17 variables was dichotomized as 1 = *yes* (an area of concern identified by an assessor) or 2 = *no* (not an area of concern identified by an assessor).

Contextual variables. Because assessments were carried out in the home care field, and because home care agencies were chosen according to their access to a diverse sample of caregivers, several contextual issues surfaced during the data collection phase that may have affected the assessments and subsequent Kappa analyses. Therefore, a series of 10 variables measuring assessment conditions, caregiving context, and implementation issues were examined to understand their effect on the level of agreement between Assessor A and Assessor B. Within assessment conditions, we measured practitioners' prior knowledge of caregiver (yes, no), practitioners' experience conducting assessments (number of years), practitioners' professional background (nurse, social worker, or other), presence of others during assessment (yes, no), type of care receiver (spouse, daughter, etc.), geographic region (rural, urban agency), location of research site (Quebec City, Montreal, Halifax), time between A1 and A2 (number of business days), practitioners' familiarity with the tool (number of previous times administered) and caregivers' language (French, English).

Measuring Validity—Practitioners' Perspectives

Following the testing stage, seven focus groups (one at each agency) were held with participating practitioners to validate the assessment tool. Focus group questions were designed to capture feedback on the content of the tool, its usefulness and appropriateness, and possible reasons for discrepancies in the interrater reliability, as well as to discuss whether the Tool had met its objectives. Focus groups were facilitated by the researchers, audio-taped, and transcribed verbatim.

Analysis

Interrater reliability was measured by the examining the strength of agreement between A1 and A2 on each of the 15 assessment areas through cross-tabulations and interpreting Kappa statistics. The Kappa statistic is recognized as an appropriate measure to understand the strength of agreement between two observers or assessors (Landis & Koch, 1977). However, the number of assessors involved and the lack of response distribution

posed interpretation problems for Kappa analyses. To redress the disproportionate distribution of responses across the categories, weights were assigned to the diagonal (see Altman, 1991). This same procedure was used to examine interrater reliability on the 17 key areas of concern. In other words, we sought to examine whether the assessment process would lead two practitioners to comparable conclusions when summarizing the most salient issues in the caregiving situation. In addition to interrater reliability described above, internal congruence between areas of difficulty and key areas of concern was measured. Specifically, the mean score on each assessment area was examined in relation to each key summary area using *t*-test analyses for A1 cases and A2 cases independently to understand the congruency between ratings of assessment areas and key areas of concern.

Practitioner focus groups. Transcripts were analyzed by the researchers using traditional content and thematic analyses techniques. Analyses took into account comparisons both within and between data sources and asked questions of the data to search for similarities and differences. Conceptual themes, ideas, and assumptions located in the data were identified. These were then defined and refined until we achieved an interjudge consensus on categories that were thorough, exclusive, and relevant to the research question.

Results

Sample description. The sample was derived from caregiving situations where the care receiver was receiving provincial home care services. Consequently, many of the caregivers were providing care at a high level of intensity. More than three quarters of the caregivers and care receivers co-resided (78%), and almost half of the caregivers had been caregiving for longer than 5 years ($M = 7.6$ years, $SD = 7.4$). Most caregivers sampled were women (82%), caring for a spouse (40%) or caring for a parent (41%). There were six cases where parents cared for their disabled children, but the majority of care receivers were older persons ($M = 78$ years, $SD = 14.35$) with one or several health problems. One third of the sample was composed of persons caring for an individual with Alzheimer's disease or a related dementia.

Figure 1 demonstrates that caregivers in this study were experiencing difficulty in all 15 assessment areas, but at varying levels. For example, these caregivers were having the least amount of difficulty in the areas of housing, relations to formal service providers, and financial costs. On the other hand, areas that caregivers were experiencing more difficulty with included the

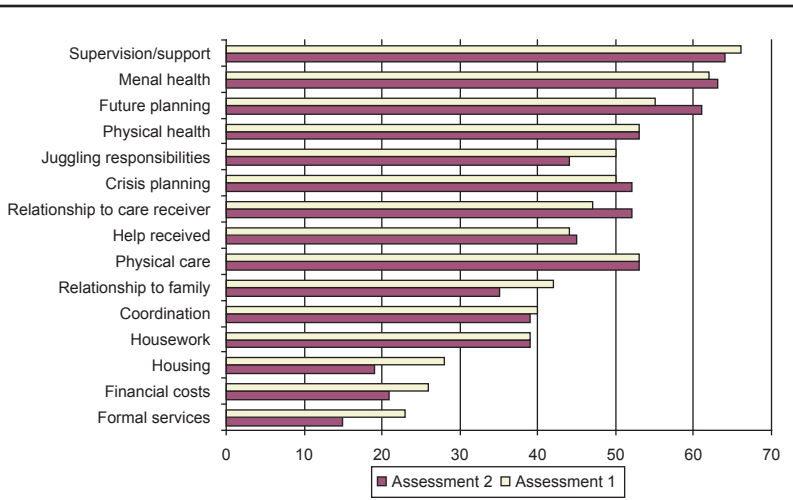


Figure 1. Percentage of Assessors (1 and 2) Who Rated at Least Some Difficulty on 15 Assessment Areas (N = 168)

caregiving activity of supervision for and support to the care receiver, caring for their own physical and mental health, and planning for the future.

As part of the assessment summation, practitioners were instructed to identify two or three key areas of concern for each caregiver assessed. The most common areas were need for respite and caregiver’s mental health, including grief and isolation (see Figure 2). Relations with the care receiver and relations with other family members were also frequently identified as key concerns, as were emergency and future planning. There were only six cases where no areas were identified in A1.

Interrater Reliability Analysis

Table 1 presents the results of the bivariate analysis conducted to measure agreement between A1 and A2. The extent of agreement between the two assessments across the 15 areas ranged from 45% to 79% with 13 areas achieving 50% agreement or higher. In all but 3 areas, the Kappas were considered significant. Although the amount of agreement was favorable, the strength of the agreement for all assessment areas is below the moderate range (for interpretation guidelines, see Altman, 1991).

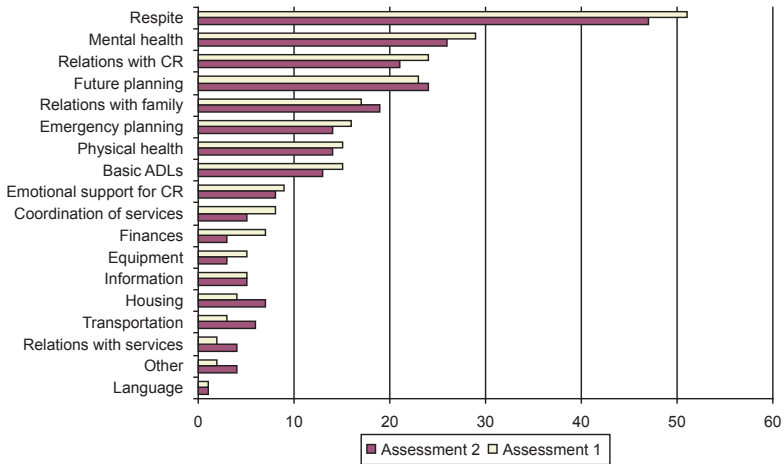


Figure 2. Percentage of Assessors (1 and 2) Who Identified Key Areas of Concern (in descending order)

NOTE: CR = care receiver; ADLs = activities of daily living.

Table 1. Percentage of Agreement Between Assessor 1 and 2 for 15 Assessment Areas ($N = 168$)

<i>Assessment Area—Difficulties</i>	<i>% of Agreement A1-A2</i>	<i>Kappa</i>
Caregiving tasks—physical/nursing care	59	.260***
Caregiving tasks—household work	54	.142*
Caregiving tasks—supervision/support	45	.170**
Caregiving tasks—coordination	53	.154*
Caregiving tasks—help received from others	50	.129*
Relationship with formal services	70	.116
Housing	67	.120*
Juggling responsibilities	52	.166*
Financial costs	70	.277***
Personal health—physical health	54	.274***
Personal health—mental health	45	.154**
Relationships—with care receiver	58	.312***
Relationships—with family	61	.261***
Planning—crises	79	.141
Planning—future	71	.074

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 2. Percentage of Agreement Between Assessor 1 and 2 for Key Areas of Concern (N = 168)

<i>Key Area of Concern</i>	<i>% of Agreement</i>	
	<i>A1-A2</i>	<i>Kappa</i>
No concern	96	.342***
Relations with CR	75	.286***
Finances	92	.087
Emergency planning	79	.191*
Emotional support for CR	87	.207**
Equipment	95	.281***
Relations with family	83	.432***
Future planning	65	.005
Mental health	67	.181*
Physical Health	79	.124
Housing	93	.300***
Information	90	—
Language	99	—
Respite	69	.389***
Coordination of services	90	.226**
Relations with services	95	.156*
Basic ADLs	79	.134
Transportation	96	.514***
Other	95	.179*

NOTE: A dash indicates that Kappa is missing due to asymmetrical table. CR = care receiver; ADLs = activities of daily living.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Agreement was evident in areas more practical/instrumental in nature, such as physical/nursing care, financial costs, and relationships with the care receiver and the family (see Table 1). Other areas that demonstrated a high frequency of agreement include relationship with formal services, housing, planning for crises, and planning for the future; however, these areas did not achieve a moderate Kappa value or statistically significant differences. Agreement between A1 and A2 differed most in the areas of the caregiving activity of supervision for and support to the care receiver and caregiver's mental health. These two assessment areas were further assessed to investigate the extent to which any contextual variables were at play, but these results do not yield any consistent pattern for improving interrater reliability. Years of experience conducting assessments generally appears to be more important than experience with this particular tool.

Next, the results of interrater reliability for the key areas of concern are presented. Table 2 demonstrates the amount and strength of agreement between A1 and A2 when making conclusions about the caregiving situation. The

Table 3. Internal Congruency of Assessment Area With Related Key Areas of Concern for Assessor A ($R = 0-4$)

<i>Assessment Area</i>	<i>Key Area of Concern and Mean Difficulty Score</i>	
Physical care	Physical health 2.0***	Basic ADLs 1.76**
Housework	Respite 1.15*	Physical health 1.36*
Supervision/support	Respite 2.08**	Service coord. 0.93**
Crisis planning	Emergency planning 2.44***	
Future planning	Future planning 1.84*	Emergency planning 2.26***

NOTE: The Mean represents scores of difficulty from each Assessment Area in the tool (Range 0-3), and are presented in cells with corresponding Key Areas of Concern. Significance levels represent T-test analysis of difficulty scores within Key Areas of Concern. Two Assessment Areas, Coordination and Juggling multiple roles, did not have corresponding Key Areas of Concerns. ADLs = activities of daily living. * $p < .05$. ** $p < .01$. *** $p < .001$.

amount of agreement ranged from 65% to 99% with several Kappa values reaching the moderate range. Future planning, mental health, and respite exemplify the lowest agreement. This finding is consistent with that of the previous section in that mental health and the caregiving activity of supervision and support were two assessment areas with lowest agreement and greatest fluctuation when controlled by contextual variables.

The key areas of concern that yielded least favorable performance, including mental health, respite, and future planning, were further examined by taking into consideration the 10 contextual variables to examine whether agreement would increase, decrease, or remain the same under these specific conditions or contexts. The contextual variables were broken down into three categories: assessment conditions, caregiving context, and project implementation factors.

Agreement on mental health as a key concern improved when both assessors had experience in home care assessment (73%, $K = .28$, $p < .01$), both assessors were nurses (86%, $K = .46$, $p < .01$), someone else was present at both assessments (74%, $K = .46$, $p < .05$), the care recipient was older than 85 with a non-dementia-related illness (76%, $K = .44$, $p < .01$), the agency was rural (75%, $K = .29$, $p < .01$) and in Nova Scotia (75%, $K = .29$, $p < .01$), both assessors had experience with the CARE Tool (74%,

$K = .29, p < .01$), and the caregivers spoke English at home (71%, $K = .23, p < .05$). Agreement on respite as a key concern improved when practitioners had unmatched years in home care assessment experience (72%, $K = .40, p < .001$), assessors were both social workers (71%, $K = .41, p < .01$), someone else was present at both assessments (74%, $K = .47, p < .05$), the care recipient had some form of dementia (72%, $K = .43, p < .001$), the agency site was in Montreal (74%, $K = .49, p < .001$), at least 13 days lapsed between the first and second assessment (79%, $K = .56, p < .01$), either assessor was inexperienced with the tool (76%, $K = .53, p < .01$) or both were experienced with the tool (71%, $K = .43, p < .001$), and the caregivers spoke English at home (72%, $K = .44, p < .001$). Some contextual differences that emerged could be influenced, in part, by practitioner backgrounds. For example, nurses may be more comfortable with diagnosing mental health as an area of concern, whereas social workers using more service-oriented approaches may be more likely to identify service needs such as respite. Interestingly, future planning did not consistently increase or decrease under any conditions.

Internal congruency. Internal congruency was measured separately by a series of *t* tests to compare key areas of concern with mean scores on each assessment area, in both A1 and A2 assessments (only A1 data are reported). Table 3 illustrates that the areas where assessors attributed a high level of difficulty were consistent with the key areas of concern identified. For example, among cases where supervision and support to the care receiver had high mean scores on areas of difficulty, the corresponding areas of respite and service coordination were indicated as key areas of concern. In other words, there appears to be a high degree of internal congruency between the information obtained from the main body of the tool and subsequent key areas of concern identified as directions for future care planning.

Practitioner Focus Groups

In conjunction with the interrater reliability analysis of the CARE Tool, the qualitative component examined supplemental aspects of its use that speak to its reliability and validity and point to the positive impacts that using such an assessment tool can have for practitioners and caregivers alike. Themes that emerged from analysis of focus group data include increasing the practitioners understanding of caregivers and the caregiving situation, reliable identification of key areas of concern, the tool's ability to adapt and account for diversity, and the changes in practitioners' attitudes and practice.

Increased understanding of caregivers and the caregiving situation. Focus group participants agreed that the CARE Tool increases their understanding of what it means to be a caregiver by enhancing their awareness of, and sensitivity to, the complete caregiving situation. In the words of one practitioner, "I think I see caregivers' lives in a whole new light now. . . . I see more clearly how it is 24 hours a day." Most workers found the tool to be a comprehensive way to gather new information about caregiver concerns and gain an in-depth understanding of their situations. In this sense, practitioners gained access to the meanings and everyday realities of caregiving.

Practitioners discussed how their increased awareness allowed them to understand the cumulative impact of caregiving in the context of everyday life and to move beyond seeing only the symptoms to consider factors that contribute to the complexity of the caregiving experience. Factors that one practitioner noted were "the relationship with the family, the kids, and the system. And you found out there were more issues with other family members, maybe not related to the care receiver, but to the caregiver themselves, which added responsibilities." As such, workers were prompted to go beyond their understanding of caregivers as "burdened" to identify the contributing factors and the impacts of the subjective and objective realities of caregiving, which is essential if an appropriate service plan is to be put into place.

One practitioner described the usefulness of the CARE Tool and its focus on caregiver issues in this way, "In some of the situations . . . you didn't realize the other half of what was going on with the caregiver. Things that they told you that never would normally come up with just your client assessment." Another concurred, indicating how the tool enables assessors to achieve a more reliable and complete portrait of the caregiving situation.

Using this tool, I think I got a very, very good understanding of the caregiver. I found it was a way to dig much deeper, and people have time to dig. I discussed it with some other people, I've done somebody else's [assessed caregiver of another worker's client], not my own, and I brought up things that they didn't even know about, because of the questions being so to the point and really digging deep, that I was able to find out things that their own practitioner wasn't able to find because the person doesn't really disclose it unless they've actually directly been asked that question. It's like avoiding the topic, and then here you are, trying to probe this out of them. And I found I got a lot of stuff from the caregivers.

Thus, workers indicated that the CARE Tool gave them a comprehensive portrait of the caregiver's situation that they found to be more reflective of their lived experience.

In addition to drawing a dependable portrait of the situation, practitioners described the tool as useful in quickly identifying needs. For example,

I do short-term counseling with caregivers, and with this tool, I could get all the information that I usually get through the counseling sessions, but it was like all in one booklet. What usually can take me two sessions or three sessions, and I only get bits and pieces of the information, the assessment tool was asking in a systematic way.

Reliable identification of key areas of concern. By giving workers a more global perspective of caregivers' situations, and by helping them to hear the voice and perspective of the caregiver, the tool is perceived as being able to identify key areas of concern in a manner that better supports practice. Knowledge of key issues and concerns moves workers one step closer to responding to needs. Indeed, the CARE Tool actually moved beyond the research objectives by influencing the practitioners and their daily practice.

Adaptable and accounts for diversity. The majority of agency practitioners agree that the CARE Tool is useful in diverse settings and situations and gives valid information when used with caregivers from different sociodemographic groups, such as diverse ethnocultural groups and urban and rural populations. For example, rural Nova Scotian practitioners discussed the tool's adaptability in relation to the rural/urban contrast. They felt that the tool was not only appropriate and adaptable for a rural population, but it also reflected distinct rural concerns such as distance and transportation.

Changing attitudes and practice. Workers reflected on the ways the project influenced their relationship with caregivers and how they had become more empathetic and sensitive. They also proposed several ways that they would intervene differently in the future, such as having the caregiver become involved in determining the care receiver plan, not taking the caregiver for granted, conducting separate interviews, and creating a stronger relationship with the caregiver.

Discussion

This research presents a rationale for why an instrument to assess caregivers is needed and reports on a multimethod approach to evaluating the validity and reliability of the CARE Tool in everyday practice. Based on

our analyses, we can advance that we have developed an instrument that increases practitioner understanding of many aspects of caregiving and enables practitioners to identify and address key areas of concern efficiently. Functional aims were achieved by providing an effective instrument with which to assess caregivers and identify key areas of concern in the caregiving situation, while at the same time actually exerting a positive impact on the assessors and caregivers. In particular, using the tool changed assessors' attitudes toward the caregiving experience, opened their eyes to previously unrecognized issues, and occasionally influenced their practice with caregivers. Assessors also noted that caregivers often reported feeling that the assessment process legitimized their role, gave them recognition for their efforts, and validated their concerns.

The results of the interrater reliability and internal congruency tests suggest that further work is required if the goal is to develop a traditional psychometric assessment tool using scientific benchmarks. We can attest to the challenges of achieving this goal when working within a practice setting. Our research was conducted in a naturalistic setting within which not all conditions can be controlled for, despite protocols being developed for the study. Consequently, given the high levels of variation in data collection (e.g., heterogeneity of the sample, the number of different practitioners involved from a variety of disciplines, the range of practitioners' backgrounds, and the constant flux associated with caregiving situations over time), we find a minimal to moderate level of agreement between A1 and A2 on the 15 assessment areas. Beyond that, the high level of agreement on key areas of concern, which is essentially what shapes decisions around supports and services, is noteworthy. Assessors had a high degree of reliability in identifying the same major areas of concern, which demonstrates that, in the majority of cases, the CARE Tool allows two assessors to come to the same general conclusions about the most pressing concerns in a caregiving situation. It is important to note that this congruence should not be overshadowed by challenges with the agreement scores among the 15 assessment areas. To clarify, whether on a particular visit one assessor scores a 2 as the level of difficulty in a particular assessment area and a week later another assessor scores a 3 on that same area is less critical than whether or not they agree on their summation as to the key areas of concern that will guide subsequent allocation of services. In addition, the data indicate that the summary sheet appears to have a high degree of internal congruency with assessment areas covered in the tool. In other words, difficulties identified in the assessment and key areas of concern on which a service plan should be based were consistent.

This study also demonstrates the power of caregiver assessment in reframing practitioners' understandings of the caregiving situation, their appreciation of caregivers in general, and in informing and modifying their practice. It also suggests that the CARE Tool is an appropriate instrument for assessing caregivers of persons eligible for home care services. It should be noted, however, that assessment is, by definition, a constructed process during which a number of elements can intervene that are difficult to control, and that are beyond what can be captured by statistical tests. In particular, the nature of the developing relationship between an assessor and a caregiver can affect perceptions of difficulty, especially when testing a tool that allows for a certain amount of narrative. What and how certain issues are discussed can differ depending on the interactions between assessor and caregiver. Indeed, when examining the stories caregivers told from A1 to A2, we noted a number of differences and/or discrepancies in the importance and the intensity of certain responses. Beyond the nature of interactions during the assessment, the impact of the emotional charge of caregiving can vary from day to day, thus affecting caregivers' perceptions of their situation at any particular moment. Finally, having been assessed a week earlier may have influenced caregivers' responses to A2 questions. Self-reflection between the two assessments may have led to revision of caregivers' answers, or they may have felt less compelled to repeat their story with the same intensity at the second assessment.

The uniqueness of this study is that it describes the challenges involved in scientifically measuring interrater reliability of a caregiver assessment tool using traditional quantitative statistical approaches between Time 1 and Time 2 assessments within a naturalistic practice setting. A study with this type of design has the advantage of reflecting the real-life conditions in home care agency practice. This naturalistic approach is valuable because it allows us to better understand the challenges of introducing an assessment of caregiver needs within the structure of publicly funded home care programs.

Practitioners continue to use the tool and speak about its appropriateness. However, broader implementation of the tool is stymied by resource constraints, increased workload pressure within home care agencies, and the push to have a simple checklist to assess the needs of caregivers. To accommodate some of these pressures, the CARE Tool was revised and shortened significantly, reducing the number of questions on which each area of difficulty is based. This abbreviated instrument is currently in the testing phase, with a series of nongovernmental agencies having received training on the tool and how the shortened version can be used as an effective instrument to facilitate a better understanding of caregiver situations.

Caregiver assessment is part of a larger policy issue of how to support the care of dependent adults in the community. Much attention is given to community-care policies, creating increased expectation on family and friend caregivers to provide care, along with an increased demand for home care services. Considering current and projected decreases in the availability of family caregivers because of increased participation by women in the paid labor force, fewer children per family, patterns of migration, and so on (Keefe, Légaré, & Carrière, 2007), practitioners in home care agencies will need to become more actively engaged in their role to support family and friend caregivers. Continued efforts are needed to find and/or develop appropriate instruments to support practitioners in their efforts to recognize caregivers as valuable partners in the system and, more broadly, to maintain caregiver issues on the public policy agenda.

Notes

1. The CARE Tool was developed using a multifaceted data collection and review process, including a review of the scientific and grey literature, contact with frontline North American agencies, and focus groups with key stakeholders. Feedback on the content, design, and implementation of the early drafts of the tool was received from a research advisory committee comprising administrators and government officials in the field and a group of caregivers. The final draft of the CARE Tool was formally pretested in English and French by members of the research team, using the same methods that would be used during testing for interjudge reliability. Thus, two different researchers assessed, separately, each caregiver who participated in the pretests. Following the pretests, final modifications were made to the CARE Tool.

2. Since this study, we have modified this for a scale of 0 to 4 to differentiate between no difficulty and little difficulty. These two levels were merged in the tool that was tested.

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Appendix

Example of Summary Sheet Coding for Assessment Areas (A) and 15 Assessment Areas From Summary Sheet With Their Corresponding Sections and Sample Questions in the Care Tool (B)

(A) Sample Assessment Area (1 of 15) from summary page: Caregiving task-household work	How much difficulty is experienced? None/Little Some Significant Extreme	Potential for deterioration? y/n	Why did you rate it this way? Open-ended response
(B) Assessment Areas on Summary Sheet	Reference Section in the CARE Tool (# of questions) Caregiver/Care Receiver Profiles [20 questions]	Selected sample questions asked in the CARE Tool Age, Marital Status, Length of Time Caregiving, Relationship Living Arrangements, etc.	
Physical/nursing Care Household work Support/supervision Coordination	Description of Caregiving Work and Support [29 specific tasks identified each with sub-questions]	“Do you help or remind (CR) to do any of the following tasks?” “Does anyone else provide help with this task?” “Are you having difficulties with any of these tasks?”	
Help Received Formal Services	Caregiver's Relationship to Formal Services [5 main questions]	“Do you feel comfortable asking the medical personnel, that is hospital staff or (CR's) personal doctor, for information, or for more information?”	
Housing	Housing [5 main questions]	“What difficulties, if any, do you have concerning the condition of your house as it relates to caregiving?”	

(continued)

Appendix (continued)

Juggling Responsibilities	Juggling Responsibilities [12 main questions]	<p>"How do you manage to juggle your responsibilities, commitments, and caring for (CR)?"</p> <p>"How have [these] adjustments affected you personally?"</p>
Financial Costs	Financial Costs of Caregiving [6 main questions]	"We would like to look at the financial cost of care and whether this causes any problems for you."
Physical Health Mental Health	Personal Health [5 main questions]	<p>"Do you have any specific medical or mental health conditions?"</p> <p>"In the past three months, how often have you had the following feelings?"</p>
Relationships with CR Relationships with Family	Caregiver-Care Receiver Family Relationships [10 main questions]	<p>"Are there areas of tension between you and (CR) regarding the care you provide?"</p> <p>"Do you feel appreciated for the work you do?"</p>
Planning-Crisis Planning-Future	Planning Issues, Crisis, and the Future [6 main questions] Service and Support Needs [6 main questions]	<p>"Do you have any plans in place for the future care of (CR)?"</p> <p>"Given all the issues we have discussed, and given what you have just said, what kind of help or resources do you think you need?"</p>

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