



Caregiver Assessment: An Essential Component of Continuing Care Policy

About this Brief

This Policy Brief is based on research conducted by Janice Keefe, Nancy Guberman, Pamela Fancey and Lucy Barylak.

For further information on these studies or use of the *C.A.R.E. Tool* visit:

www.msvu.ca/nsca/caregiverassessment

or email: caretool@msvu.ca

This Policy Brief was prepared by J. Keefe, N. Guberman, P. Fancey and T. Krawchenko with support from Research Assistants, A. Bourdon and S. Nadeau.



Target Audience

- Policy Analysts
- Decision Makers
- Health Care Practitioners

Summary

Family and friend caregivers are the backbone of Canada's health and social care systems. The support they provide is indispensable in enabling individuals with long-term health issues to remain in their communities. Caregivers take on a challenging role—one that can impact their physical and mental health, social activities, personal finances, employment and relationships (Health Council of Canada, 2012; Keefe, 2011). Caregivers' health and wellbeing has repercussions for the care recipient, their family, their communities and the health care system. To support this critical role, caregivers need to be understood as partners in care, but also as potential individual clients of health and social care systems in and of themselves.

Caregiver assessments are a key tool to identify and provide such understanding. Such assessments are used by health care practitioners to evaluate the degree and urgency of risk to the health and wellbeing of caregivers or to the deterioration of the caregiving situation. Through assessments, practitioners can more efficiently and appropriately target interventions and supports such as psycho-social counseling and prepare for changes in care. This Policy Brief makes the case for the integration of caregiver assessment in home and long term care services and provides research-based evidence from the literature and studies using the *Caregivers' Aspirations, Realities, and Expectations Tool (C.A.R.E. Tool)*. Home and long term care policy can no longer afford to remain solely focused on persons needing care. Recognizing caregivers as partners and clients is crucial to supporting the care situation. In this, assessment tools have a critical role to play.

Key Findings

- Caregiver assessment provides positive benefits to caregivers such as knowledge about services; increased confidence to take up services; validation and recognition of their role; opportunity to tell their story; and permission to express feelings.
- Caregiver assessment increases practitioner awareness of caregiver contexts and needs and thus can better help direct timely supports, leading to improved service accessibility and appropriateness.
- The *C.A.R.E. Tool* is a validated instrument designed to complete a comprehensive psycho-social assessment that identifies caregiver needs and key areas of concern.
- Caregiver assessment, using the *C.A.R.E. Tool* identifies key areas of difficulty such as physical health, emotional health, future planning, crisis preparation and providing supervision/emotional support for which appropriate and timely care plans can be developed.
- The development of timely care plans helps to address issues upfront and prevent deterioration of a caregiver's situation. This reduces the likelihood of costly interventions such as hospital admissions or emergency placement and improves the efficiency of the health care system.
- Successful implementation of the *C.A.R.E. Tool* requires: clarification of caregiver status within policy and practice; an explicit philosophy within the agency about the role and responsibilities of families in care to clarify the intent of caregiver assessment; and agency buy-in at all levels.



Background

Review of the limited research on caregiver assessment indicates such assessments have positive outcomes for caregivers, care receivers, and practitioners thereby improving efficiencies in the system. By participating in these assessments, caregivers experience: greater acceptance of support; increased confidence to take up services; knowledge on how to make contact in the future; information and referral to appropriate resources; a sense of shared responsibility; recognition and validation of their role; a chance to talk through their issues and reflect on their own needs; self-understanding of their situation; new insights into why they are caring and what they have achieved; expression of bottled-up emotions; permission to talk about difficult subjects; validation of their feelings; and confirmation as people of value (Barylak, Guberman, Fancey & Keefe, 2006; CarersUK, 2002).

Studies of caregiver assessments further find that they provide vital information to practitioners—enabling them to better understand caregiving situations, individual contexts, change over time and thus modify care plans to more appropriately meet the care dyad's needs (Guberman et al., 2003; Levesque et al., 2009; Lundh & Nolan, 2003). Caregiver assessments form a critical component of health promotion by identifying caregivers who are particularly vulnerable to burnout in order to design and implement interventions to address their needs (Fancey, Keefe, Guberman & Barylak, 2008; Kwak, Montgomery, Kosloski & Lang, 2011; Talley & Crews, 2007).

Unfortunately, there is presently very little research on the impact of caregiver assessments on care receivers. Forthcoming work from the American Association of Retired Persons (AARP) Public Policy Institute aims to address this gap by identifying the evidence that supports the link between caregiver assessment/consultation and care recipient outcomes. In the interim, subjective practitioner responses indicate that the enhancement of caregiver wellbeing has positive outcomes for care receivers (Guberman, 2005; Guberman, Keefe, Fancey & Barylak, 2007).

There are also very few studies of the economic costs and benefits of caregiver assessments for the broader health care and social system. Assuming that assessment will prevent a further deterioration of the caregiving situation and delay institutionalization, system savings are implied. For example, the cost of providing modest additional respite services (4 hours per week) is three times less expensive than the cost of having the care recipient enter a long term care facility three months earlier (Légaré, Keefe & Carrière, 2010). The effective use of respite can be appropriately planned through a comprehensive assessment (Seniors Health Strategy Unit, 2012).

Caregiver assessment is an emerging and promising practice that offers many benefits to improve home and long term care (Family Caregiver Alliance, 2006; Feinberg, 2008; Kelly, Wolff, Gibson & Feinberg, 2013; Kwak et al., 2011; Levesque et al., 2009). Our own research, using the *C.A.R.E. Tool*, contributes to the growing evidence of the advantages of integrating caregiver assessment into current practice.

Key Findings of Studies Using the C.A.R.E. Tool

The *C.A.R.E. Tool* is a validated psychosocial assessment tool for use by health care practitioners to help understand caregivers' aspirations, realities, and expectations (Keefe, Fancey, Guberman, Barylak & Nahmiash, 2008). The *Tool* is used to gather information related to caregivers' needs and helps to identify key areas of concern for which services and support may be considered. The *Tool* also provides summary of the caregiving situation; identifies areas of difficulty experienced by the caregiver; and key areas of concern to be addressed in the future. Data collected using the *Tool* is used to support individual cases, but can also be aggregated to provide an overall picture of caregiver health and wellbeing. In doing so, it can help direct and structure supports at the organization and system level. Since its inception, the *C.A.R.E. Tool* has been used by practitioners across Canada - in Québec, Nova Scotia, Prince Edward Island, New Brunswick, Ontario and Alberta. It has also been culturally adapted for use in France, Israel, Bermuda and the United States (New Jersey) and translated into French, Portuguese, Italian and Hebrew.

The *C.A.R.E. Tool* has been the subject of several studies demonstrating its usefulness in contextualizing and supporting care situations. It has also been used in a demonstration project led by Alberta Health Services on caregiver support and enhanced respite. The key findings from these studies are summarized in Table 1.

Table 1. Characteristics of Studies Using The C.A.R.E. Tool

	Study 1 1999-2000	Study 2 2003-2007	Study 3 2009-2013	Study 4 2011-2013
	Guberman et al., 2001	Keefe et al., 2003-2006	Keefe et al., 2009-2013	Seniors Health Strategy Unit, 2012
Description	Evaluations of the reliability of the <i>Tool</i> when used by different practitioners and focus groups with practitioners to measure content and construct instrument	Assessing the impact of <i>C.A.R.E. Tool</i> on caregivers of persons with and without Alzheimer's Disease and related dementia and determining the conditions of successful implementation within publicly-funded home care agencies.	Determining optimal timing of assessment for older spousal caregivers of a partner with cognitive impairment.	Evaluation of enhanced respite services for caregivers using the <i>C.A.R.E. Tool</i> to identify their respite and support needs.
Outcome	<i>C.A.R.E. Tool</i> was found to be a valid and reliable instrument for assessing caregivers' needs and difficulties.	Caregivers reported greater recognition of their role as a caregiver and perceived practitioners to have better understanding of their situation. Practitioners reported a more comprehensive understanding of caregivers' realities.	The assessment enabled caregivers to express repressed emotions and focus on their own needs.	Benefits of assessment alone, apart from respite, were significant and included validation of caregivers' experience, self-recognition as a caregiver and empathy from a health care professional.
Study Scope	N=168 caregivers, Nova Scotia and Quebec	N=349 caregivers, Prince Edward Island, Quebec and Veterans Affairs Canada	N=100 caregivers, Nova Scotia and Prince Edward Island	N=79 caregivers, Alberta



Across three of the studies, it was found that, on average, caregiver assessment provided the first opportunity for nearly three quarters of caregivers to speak about their caregiving situation to a professional. This finding is an indication that without time for a separate assessment, only limited information about the caregiver’s situation may be obtained through an assessment of the care recipient, or that practitioners may focus solely on the care recipient’s situation to the detriment of the caregiver’s wellbeing. Each of the previously-mentioned studies has a slightly different focus, however, across the different care groups of the first three studies, there are similar findings with regards to the areas of difficulty identified by the assessment. These include physical health, emotional health, future and crisis planning and the work of providing supervision/support to the care receiver (see Figure 1). The studies’ findings indicate that these are key intervention areas that should be addressed by policy.

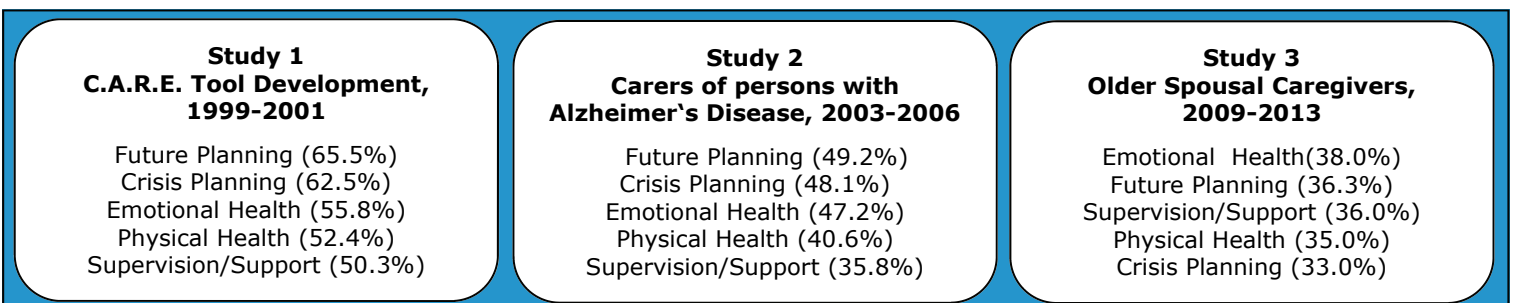
It is significant that **physical health and emotional health** emerge as key areas of concern for many caregivers as numerous studies have documented how these issues are regularly invoked as motives for ending care and institutionalizing the person needing care (Buhr, Kuchibhatla & Clipp, 2006). Caregivers often hide their distress from clinicians making prevention difficult (Wen & Gustafson, 2004). By directly questioning caregivers about potential difficulties in these areas through an assessment tool, clinicians obtain essential information for intervention (Charlesworth, Tzimoula & Newman, 2007). The *C.A.R.E. Tool* brings such contextual understanding to the forefront and in doing so, presents a more complete picture of health and emotional wellbeing enabling practitioners to develop appropriate intervention plans. Further, it has been demonstrated that the use of assessments that addresses these areas led caregivers to feel affirmed, valued and reassured (Nankervis, Schofield, Herman & Bloch, 1997) —findings that have been duplicated by caregivers who have completed an assessment using the *C.A.R.E. Tool*.

Caregivers have identified the work of offering **supervision and support** to the care receiver as an area of concern, given the nature of the illnesses of many of the persons to whom they provide assistance. Persons with dementia, mental health problems or suicidal thoughts require enormous amounts of attention and presence; others with mobility limitations are susceptible to falls. In short, many caregivers are on 24-hour alert. The necessity to provide reassurance, manage difficult behavior, and ensure constant supervision can take an emotional toll on caregivers (Ballard, Lowery, Powell, O’Brien & James, 2000; Black & Almeida, 2004). By identifying these often-invisible activities, and their impact on caregivers through assessment, practitioners can better target psycho-social and education supports (Samia, Hepburn & Nichols, 2012).

Future and crisis planning are also major issues for caregivers. It is important for practitioners and the health and social service system to be aware of the difficulties that caregivers face in preparing for emergencies and the future, even if caregivers are not always conscious of these difficulties themselves. Raising issues such as financial and legal affairs (e.g., advanced directives, power of attorney) and future care arrangements are areas that are often not addressed due to their sensitive nature or family dynamics. When these conversations are initiated through the assessment interview and caregivers are helped to work through their reluctance to address these often delicate and complex subjects, crisis situations may be better mitigated (Nankervis et al., 1997; Samia et al., 2012).

Understanding these top areas of difficulty, as well as others that are raised by specific groups of caregivers (e.g., family relationships, financial costs), helps practitioners develop appropriate and timely care plans. By preemptively addressing these issues before they result in negative health consequences for the caregiver or become crises necessitating costly interventions such as hospital admissions or emergency placement, the efficiency of the health care system may be improved.

Figure 1: Ranking of assessment area by percentage respondents indicating “Some, Significant or Extreme” difficulty—Top five response areas from three studies using the *C.A.R.E. Tool*





Policy Implications

Home care programs often provide services to caregivers such as respite, caregiver support groups and information referrals. These services are not typically informed by an assessment of the individual realities of caregivers. Instead, home care programs focus on person-centered assessment of the person with the chronic health condition or disability to the exclusion of a more family-centered approach which would include the family/friend caregiver and his/her needs. As a consequence, there is a failure to recognize the essential role of caregivers in care.

Policy that embraces a family-centered approach recognizes caregivers as partners and potential clients; and implements practice to assess and address their needs.

Home and long term care policy can no longer afford to remain solely focused on persons needing care. Family/friend support is essential to keeping people in their homes; recognizing caregivers as partners and clients is crucial to realizing this goal.

Implementation Considerations

Studies of the *C.A.R.E. Tool* point to key preconditions for the Tool's successful implementation: clarification of caregiver status within policy and practice; an explicit agency philosophy with regard to the role and responsibilities of families in care to clarify the intent of caregiver assessment; and agency buy-in at all levels. Areas to be addressed in the implementation process involve: integration of the *C.A.R.E. Tool* with existing tools; ensuring training and ongoing supervision of practitioners doing the assessment; defining work organization and ensuring sufficient resources.

Overall, it is found that the *C.A.R.E. Tool* enhances the assessment skills of practitioners and their understanding of the needs of caregivers while improving their capacity to support caregivers and care recipients. This enables an integrated intervention approach, and provides greater recognition of the role played by caregivers in the health system. Despite demonstrations of the positive impact of caregiver assessment on caregivers' health and wellbeing, to date there has been little concerted effort to implement a comprehensive caregiver assessment into health care practice throughout Canada.

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