Ageing & Society (2019), **39**, 2443–2464
doi:10.1017/S0144686X18000557

ARTICLE

The assessment experience of spousal dementia care-givers: 'It's made me realise that I am a person also'

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(Accepted 18 April 2018; first published online 5 July 2018)

Abstract
This article is based on a study that used a validated care-giver assessment instrument known as 'The C.A.R.E. (Caregivers' Aspirations, Realities, and Expectations) Tool' to understand its usefulness in working with older adults caring for a spouse with cognitive impairment. It draws on data collected as part of a larger, quasi-experimental pre- and post-test study examining the impact of a care-giver assessment on older spousal care-givers of a partner with cognitive impairment. One hundred community-living individuals (average age of 74) participated in the study. Participants met with a third-year nursing student who administered The C.A.R.E. Tool. Within three to seven days following this, a research team member conducted a semi-structured interview by telephone. This interview provided participants with the opportunity to comment on their experience and the usefulness of The C.A.R.E. Tool. Transcriptions of the interviews were analysed using a thematic analysis. Results indicate that the assessment experience was evaluated positively by most participants. Two broad themes emerged: assessment encourages care-givers to take stock of their situation, and it provides a relationship with a caring professional. In particular, the assessment experience gave these care-givers to have the opportunity to reflect, while expressing emotions and developing awareness, and provided them with an appreciated relationship with a caring professional who helped to validate and normalise their situation. For care-givers, the results suggest that assessment may serve as a catalyst for taking action in their care-giving situation or turning to services for help. For practitioners, assessment may increase awareness of the experience of spousal care-givers, potentially leading to interventions to support them. This study found that the attitudes and knowledge of practitioners play a role in care-givers' experience of the assessment as positive. However, the goal of assessment must be clarified, as outcomes of other tools will differ depending on the aims.

Keywords: carer; care-giver; spouse; assessment; benefits; cognitive impairment; practice

Introduction

Care-giving is an ever-growing social phenomenon. Recent statistics continue to confirm this fact. In Canada, for example, between 2007 and 2012, the number of care-givers aged 45 and over increased by 760,000 to 4.5 million care-givers, representing a 20 per cent increase in the number of care-givers over the five years (Sinha 2012). According to Carers UK (2014*b*), every day 6,000 people in the United Kingdom (UK) become care-givers. The estimated prevalence of caring for an adult in the United States of America (USA) is 16.6 per cent, or 39.8 million Americans (AARP 2015). The toll that care-giving can have on the individuals who assume this work, ranging from serious physical and mental health problems, to financial burden, social isolation and constraints on or loss of employment, has been amply documented (Chappell and Funk 2011; Colombo *et al.* 2011; Fast *et al.* 2013; Keefe 2011; Schulz *et al.* 1995; Sinha 2012). However, particularly in North America, care-givers are only beginning to be recognised in public policy, and this policy has rarely been translated into concrete practice (Chappell and Funk 2011; Lavoie 2014; Levine, Reinhard and Feinberg 2004). While many non-profit organisations offer some support to care-givers, notably psycho-educational support groups and some respite programmes, within public health systems in Canada, the USA and in many Organisation for Economic Co-operation and Development (OECD) countries there exist few services directed specifically at care-givers (Colombo *et al.* 2011). Few models of intervention have been developed aimed expressly at care-givers and not many intervention tools have been developed to support practitioners in their work with care-givers (Feinberg 2004; Guberman and Maheu 2002; Keefe *et al.* 2008; Kim *et al.* 2012; Savundranayagam 2014). Notably, in Canada and the USA, there is no legal obligation to identify care-givers' needs through formal assessment nor to address these needs, given that the focus still tends to be on the care recipient (Canadian Caregiver Coaltion 2015; Feinberg, Wolkwitz and Goldstein 2006).

Work done in Canada, the USA and the UK (Feinberg 2004; Guberman *et al.* 2007; Montgomery and Kwak 2008; Nolan and Philp 1999; Silverman 2009) has pointed to the importance of assessment as a first step in recognising care-givers as potential clients of the health and social service system, in understanding their specific circumstances and identifying needs that can be addressed in intervention. Care-giver assessment can enable health-care professionals to obtain the information needed to build individual and collective supports for care-givers (Carers UK 2014*a*; Chappell and Funk 2011; Guberman *et al.* 2007; Pillemer, Suitor and Wethington 2003).

This article is based on a study that used an established care-giver assessment instrument known as 'The C.A.R.E. (Caregivers' Aspirations, Realities, and Expectations) Tool' (Keefe *et al.* 2008), to understand its usefulness in working with older adults caring for a spouse with dementia. The C.A.R.E. Tool is a multi-dimensional psycho-social assessment instrument designed initially for use by home care practitioners but used in other settings such as geriatric hospital departments and community organisations. The authors of The C.A.R.E. Tool have used it in a variety of projects and have trained many practitioners on how to use it. Research suggests that an assessment using an instrument such as The C.A.R.E.

Tool can be important to maintaining the health and wellbeing of care-givers (Guberman *et al.* 2007). The specific objectives of this paper are (a) to examine the impact of using The C.A.R.E. Tool on community-dwelling older spousal care-givers (aged 65 and older) of persons with cognitive impairment, and (b) to discuss implications of these results for health-care professionals.

Background

While many aspects of being a care-giver are valuable and rewarding (Peacock *et al.* 2010; Rascick and Ingersoll-Dayton 2004; Savundranayagam 2014; Yap *et al.* 2010), care-giving can also have many negative consequences for the care-giver. Guberman summarises these as:

> work overload; role conflict and overload due to multiple caregiver responsibilities; permanent state of worry given the unpredictable situation; serious restrictions imposed by the demands of caregiving, which can lead to a feeling of entrapment; financial worries from medical expenses, indirect expenses and loss of income; and legal problems around mental incompetence, living wills and inheritance issues. (Guberman 2006: 39)

Care-givers whose needs are unmet and who may be experiencing these situations are more likely to have a higher risk of depression, a lower quality of life and may not have the ability to participate fully in society.

Spousal care-givers may be at higher risk for many of these negative consequences. In a meta-analysis of differences between spouse, child and child-in-law care-givers, Pinquart and Sörenson (2011) found that spouses had worse physical health than the other groups, lower levels of instrumental and affective coping, higher levels of depressive symptoms and lower levels of positive psychological wellbeing, partially explained by the fact that they provide more care. The study suggests that spouse care-givers have distinctive needs and may struggle with specific issues linked to their status.

Spouses also tend to be older than other populations of care-givers. Research indicates that older adults in care-giver roles may be particularly vulnerable because care-giving demands may tax their health and physical abilities and compromise their immune response systems, and the stress associated with care-giving can exacerbate existing chronic health conditions (Navaie-Waliser *et al.* 2002; Vitaliano, Zhang and Scanlan 2003). Older care-givers may also be at increased risk for unintentional injuries such as falls, cuts, scrapes and bruises that can range from minor to serious (Hartke *et al.* 2006) and other negative outcomes (Chappell and Funk 2011).

Another group of care-givers who are at greater risk for negative outcomes are those caring for persons with dementia (Bottiggi Dassel, Carr and Vitaliano 2017; Chappell and Funk 2011; Snyder *et al.* 2015), and may experience increased negative health effects such as burnout, anxiety and chronic depressive symptoms (Snyder *et al.* 2015). This is even more so in the case of spousal care-givers for individuals with dementia, as they may feel loneliness, aggravation or resentment at the fact that their partner is unable to correspond to expectations and interact as they were able to in the past (Vitaliano *et al.* 2011). Adams (2008) found that spousal care-givers for individuals with dementia showed significantly more depressive symptoms (*i.e.* less hope for the future, less happiness and enjoyment in life, higher degrees of sadness, being bothered and loneliness), than non-care-giving married adults.

Despite the greater risks to their health and safety, care-givers of persons with dementia often have difficulty in obtaining help. Many attribute this problem to the perceived lack of knowledge on the part of primary care providers with regard to available services and resources (Prorok, Horgan and Seitz 2013). According to these same authors, providers' knowledge is also a 'significant factor in the perceived effectiveness of disease management'.

This portrait of the situation of older spousal care-givers of persons with dementia who are at the cross-roads of the various risk factors points to the need that particular attention be paid to this group to prevent or alleviate many of the negative outcomes they risk experiencing. Professional intervention to improve outcomes for these care-givers requires a thorough understanding of each older spousal care-giver's situation, needs, expectations and experiences at all stages of the course of care. This would ensure a grounded rationale for the choice of intervention strategies to be implemented.

To gain this contextualised appreciation of each care-giver's situation, care-giver assessment uses tools, such as The C.A.R.E. Tool, as a systematic procedure to identify and understand aspects of a care-giver's situation, including problems, strengths and needs (Feinberg, Wolkwitz and Goldstein 2006). Successful care-giver assessment appears to have many benefits for both the care-giver and the care receiver (Feinberg, Wolkwitz and Goldstein 2006; Guberman *et al.* 2007) that include: maintaining the health and wellbeing of care-givers; increasing the care-giver's ability to provide care; preventing or postponing nursing home placement; and an increase in positive emotional and health outcomes for the care recipient (Feinberg, Wolkwitz and Goldstein 2006; Gaugler, Kane and Langlois 2000; Lundh and Nolan 2003; Pickard 2004). But many of these conclusions are not based on systematic evaluations of the assessment experience and its impacts. Advocates for care-giver assessment attest that an opportunity to participate in a formal assessment about their own situation provides care-givers with feelings of acknowledgement and of being valued by the health-care team (Family Caregiver Alliance 2006; Feinberg 2004; Lundh and Nolan 2003). Other literature suggests positive outcomes for care-givers are related to: role recognition; having an opportunity to talk and consider their own needs; self-understanding of their situation; an outlet to express their emotions; space to talk about difficult subjects; increased awareness of services; confirmation of the value of their role; and positive response to the challenges of their role (Ducharme *et al.* 2011; Ewing and Grande 2013; Greene *et al.* 2011; Moore 2008; Snyder *et al.* 2015). One of these studies specifically examined the impact of routine assessments for care-givers and found that care-givers who were assessed over time showed improvement in care-giver fatigue, sufficient support from others, decreased resentment in the role, greater confidence in asking for assistance and were better able to find resources and support (Greene *et al.* 2011). Although care-givers in the UK have a legal right to be assessed when they appear to have needs for support (National Health Service 2014), there are few studies that have evaluated the impact of assessment *per se*. Those that do exist are relatively modest in scope. For example, one local National Health Service trust (Torbay and South Devon NHS Foundation Trust 2017) interviewed 58 care-givers who had been assessed, the large majority of whom felt 'the assessment covered everything that was important'. Half of the assessments led to action plans that were considered useful by the care-givers. However, the evaluation did not address specifically the assessment experience and its impact on the care-givers. Grande *et al.* (2017) tested the impact on family carers of a Carer Support Needs Assessment Tool intervention in end-of-life care and found modest but positive outcomes for those carers who were assessed.

The aim of this paper is to advance work aimed at supporting family and friend care-givers through a better understanding of the impacts of care-giver assessment. There is still little empirical research on the benefits of the assessment process itself from the care-giver perspective and, specifically, the benefits for older spouses caring for someone with cognitive impairment, a growing group of care-givers. This article draws on interviews with spousal care-givers following their participation in a care-giver assessment. Results from the study may help to address gaps in knowledge as well as provide evidence about the value of care-giver assessments for both care-givers and health-care professionals.

Methods

Study design

This paper draws on data collected as part of a larger, quasi-experimental pre- and post-test study examining the impact of a care-giver assessment on older spousal care-givers of someone with cognitive impairment. The overall study was looking at whether receiving an assessment earlier or later in the care-giving journey affects the impacts of the assessment experience. A sub-objective was to understand the assessment experience from the care-givers' point of view and is the objective of this paper. The study had a second objective which was to examine the impact of the assessment process using The C.A.R.E. Tool on nurse trainees' (who did the assessments) knowledge and attitudes towards dementia spousal care-giving and is the subject of a paper in progress. From October 2010 to January 2012, individuals from two Canadian provinces (Nova Scotia and Prince Edward Island) were recruited from a range of community-based programmes and service points across the continuum, including Alzheimer societies, Caregivers Nova Scotia, home and continuing care agencies, geriatric day hospitals and adult day programmes. Individuals were included if they were 65 years of age or older and supporting a partner/spouse with memory problems, cognitive impairment or dementia in the community.

Description of sample

In all, 100 community-living individuals participated in the study. Just over three-quarters were women (77 per cent) caring for their husband with memory problems, cognitive impairment or dementia. Conversely, 23 per cent were men caring for their wives. Participants' average age was 74 years, with 16 per cent over the age of 80. Participants' spouses/partners (*i.e.* care recipients) ranged in age from 63 to

96 years (average 78) and were experiencing varying levels of cognitive impairment. Thirty were classified as having mild cognitive impairment, 51 were classified as having moderate cognitive impairment, and 19 with severe cognitive impairment.[1] The average length of the relationship was 48 years, with more than half (52%) of the sample being in the current relationship for 50 years or more. While the point at which 'care-giving' begins is difficult to ascertain in a marital relationship, participants indicated that they had been caring for their partner for 6–32 years (not necessarily related to the cognitive decline as it was noted that partners could have other health limitations as well). Varying levels of cognitive impairment were determined from the care-giver perspective by the degree of support needed because of memory or thinking problems (*e.g.* mild: assistance with instrumental activities of daily living (IADLs); moderate: prompting/cueing with basic ADLs; severe: a lot assistance with basic ADLs).

Third-year undergraduate nursing students carried out the assessments. They were recruited from two Canadian post-secondary institutions – Dalhousie University and the University of Prince Edward Island – to participate in the study as assessors. Before going into the field, they took part in a two-day, researcher-led training session which covered the following: content on care-givers and the realities of care-giving, justifications for assessing care-givers, mastering the administration of The C.A.R.E. Tool, an introduction to cognitive impairment, dementias, symptoms and stages, and an orientation to the nature of their participation. Of the ten students, nine were female and one was male. Eight were aged between 19 and 28 and two were in their thirties.

Data collection

Participants met with a nursing student, at a time and place convenient to them. While most assessments took place in the care-giver's home, others were held in churches, in a relative's home and in a restaurant. All participants signed a consent form indicating the goal of the study – to understand the impacts of receiving a care-giver assessment for older people who are supporting their spouse/partner with memory problems – and what their participation entailed. The nursing student also clarified orally at the time of the meeting that the assessment would have no impact on the services that they or the person cared for were currently receiving (if any), or on provision of additional services. The nursing student first began with a structured questionnaire to capture base-line information on such elements as: ability to express emotions, ability to discuss sensitive issues, awareness of services, thoughts about the future and more (*i.e.* pre-test). Following this, the nursing student completed an assessment of the care-giver's situation using The C.A.R.E. Tool (Keefe *et al.* 2008).

The C.A.R.E. Tool was developed and tested by the researchers in previous studies (Barylak *et al.* 2006; Keefe *et al.* 2008). The C.A.R.E. Tool contains ten main sections (*e.g.* 'Juggling Responsibilities', 'Financial Costs', 'Physical and Mental Health', 'Relationship with CR [Care Recipient]'). These sections were purposely ordered to establish rapport and increase comfort for practitioners and care-givers, beginning with less-sensitive task-oriented questions, moving towards more-sensitive and personal questions, and ending with discussion on more concrete issues such as future planning and formal service needs. The C.A.R.E. Tool helps the assessor undertake a guided conversation with the care-giver, and includes both open-ended and closed questions. The assessor is at liberty to follow the direction that the care-giver gives to the conversation and can thus discuss the different themes in the order chosen by the care-giver. Information collected in The C.A.R.E. Tool is used to pinpoint the key areas of difficulty being experienced and these are then matched with supports that would best assist the care-giver, although in the context of this study no services were actually offered or put into place. For the purposes of this study, the assessment is the key intervention whose impacts for care-givers are being measured.

Within three to seven days following the pre-test and the assessment a member of the research team (either the professional researcher or the research co-ordinator, a PhD student) conducted a semi-structured interview by telephone which included both open and closed questions (*i.e.* post-test). The post-test provided opportunity for the care-givers to comment on their experience and on why/how the assessment may have been useful or not. The average length of the post-test interview was 48 minutes, with a range of 20–104 minutes. Interviews were recorded, transcribed and entered in MAXQDA Qualitative Data Analysis Software to support analysis. MAXQDA is software designed to facilitate and support qualitative, quantitative and mixed-methods research projects (http://www.maxqda.com/).

The study received ethical approval from the university of the principal investigator. All persons involved signed a standard consent form and were informed of their right to withdraw at any time from the study without prejudice.

This paper is based on care-givers' responses to the open-ended questions of the post-test telephone interview and more specifically on an analysis of their comments to the following questions: 'First, can you tell me about your experience of being assessed? What did you like/not like about this experience?' Based on the developing analysis, responses to two additional open-ended questions were reviewed: (a) 'How helpful was being able to express your emotion or feelings related to care-giving?' and (b) 'How helpful was being able to discuss sensitive issues related to care-giving?' Although there was some probing in the conversation around these questions, we were not able to explore in depth all aspects of respondents' answers due to the constraints of the telephone interview methodology.

Data analysis

Transcripts of the post-test interviews were analysed using a thematic analysis (Braun and Clarke 2006) carried out by the first author of this paper and a doctoral student who joined the research team. As care-giver responses were being read through, codes were assigned to the various units of meaning and organised into thematic categories (*e.g.* 'possibility to talk to someone', 'expression of feelings', 'aired things openly'). These were then merged to produce more conceptually dense categories and efforts were made to ensure that they were exhaustive, unique, homogeneous and relevant (Mayer *et al.* 2000) (*e.g.* the above categories were merged into the overall category 'encourages care-givers to take stock'). The categories were viewed and discussed with other members of the team (inter-rater agreement) who, when in disagreement, discussed their differences until coming to a common understanding. We then did an inter-case analysis that involved rereading all of the material that had been placed in a category to deepen the analysis and develop analytic sub-categories in line with our research questions. The research team constantly revised the analysis until we felt we had a complete understanding of our material in line with our objectives.

Results

For many of our participants, the assessment process was a unique opportunity that left them feeling good about themselves, validated in their work and relieved at having this opportunity to confide in someone. Their comments regarding the benefits of the assessment, understood through the three specific questions in the post-assessment interview, are represented by two broad themes: *encourages care-givers to take stock of their situation* and *provides a relationship with a caring professional.* Each of these themes is composed of sub-categories that we will now present.

Encourages care-givers to take stock

Opportunity to talk about care-giving

> I can't talk to anybody 'cause nobody understands. (Participant 101, woman, 77)

Many of the care-givers interviewed indicated that they do not have the opportunity to really discuss their situation with others. Some have no one they feel they can confide in or that understands what they are experiencing. Others prefer not to divulge what they are going through to family and friends.

Many respondents felt that the people in their circle were not appropriate confidents with whom to discuss the care-giving situation as they were often too emotionally involved, judgemental or caught up in their own lives.

> It [the assessment] was helpful because as I say, speaking to family or friends one feels almost as though maybe they're judging, or they're liable to become upset and concerned, more concerned than is necessary. Whereas, in that kind of an interview there are no strings attached. (Participant 116, woman, 74)

> I don't have the opportunity to talk about these things at home, but when I had someone who wanted to talk about it with me, then I found it an awful lot easier. I daren't hardly mention dementia in my own house. (Participant 261, man, 79)

Given these situations, for many, the assessment was their first opportunity to tell their story. Several respondents explained that another obstacle to talking about their situation is the fear that expressing their difficulties could be mistaken for complaining or could be interpreted as a betrayal of their spouse, as indicated in the following quotes:

> I found that quite helpful for me. That I could speak freely without offending anyone or … just be frank as opposed to speaking freely to someone else and at the same time feeling like I was complaining. (Participant 116, woman, 74)

> I normally try not to say anything – it's like being disloyal. I felt safe talking with the assessor. (Participant 233, man, 71)

The assessment process was also particularly conducive to encouraging care-givers to share their stories as the assessor was totally focused on the care-giver, in opposition to their experience in other interviews related to the care.

> Many times I did not know how to answer because it has always been about him, and I have never thought about me. I have never been interviewed like that before. (Participant 129, woman, 76)

Not only were care-givers enabled to talk about themselves, but also many felt that getting things out in the open impacted them positively, reducing feelings of stress and bringing a feeling of relief.

Expression of emotions

Beyond telling their story to an active listener, respondents explained how in their day-to-day lives they rarely have the time or the opportunities to express their feelings related to their care situation. The assessment experience offered a supportive environment and permission to express even negative sentiments, many of which had not previously been openly shared:

> I think what happened was that I became aware of emotions and thoughts that I hadn't really sat and analysed a whole lot until the assessor brought them forward and the recognition and the analysing of my emotions was very emotional to me. (Participant 252, woman, 65)

> I am not usually able to express my emotions, because I don't normally meet people I can do this with and secondly is the British stiff upper lip, with which I was brought up. Emotions are seen as weaknesses. It was very beneficial despite my upbringing. (Participant 242, man, 82)

This chance to be in touch with these emotions was seen as cathartic or therapeutic by many. Participants spoke about feeling relieved, cleansed, and having less anxiety and stress at the end of the assessment.

> I haven't had a chance to let my emotions out at all with anybody, if you know what I mean. It was very relieving to be able to talk to somebody and be open with them. Yeah, emotionally, afterwards it just felt like something had come off of my chest, if you know what I mean, because you don't talk about it with anybody else. (Participant 206, man, 69)

Promotes reflection and awareness

Beyond the possibility of expressing emotions and the relief this brought, many participants indicated that the assessment process helped to increase self-awareness about the care they were providing and the impact this had on their lives, as well as giving them time to step back and reflect on their situation.

Several used words like ‘enlightening’, ‘thought-provoking’ and ‘stimulating’ (Participant 210, woman, 79).

> I honestly don’t feel that I’m doing that much care-giving for my husband at the moment but when talking to her I realised I was (laughing). The things I do, I don’t necessarily think of them as care-giving, they’re just things I have to do. So, it was enlightening, you know, ‘Oh my heavens, I am doing this, or that.’ It’s just a way of life, you don’t think about it. (Participant 219, woman, 66)

Through the assessment process, several participants came to a better understanding of their situation. Many had never had an opportunity to think about the care work in a global and comprehensive way nor reflect on the effect that this work was having on their lives:

> It asked me things I didn’t realise were there. You just do things and you don’t realise sometimes what you are doing but through this, I thought, well I do that but I didn’t think anything of it. It was just an everyday occurrence. (Participant 212, woman, 85)

> I found it [the assessment] quite stimulating and very informative. Only when you sort of go through that type of experience it sort of brings a lot of things under the one umbrella. Where you deal with them individually as time passes by on a given day or week. During the interview I found myself thinking in a more comprehensive way about the care-giving. (Participant 227, man, 71)

> It made me think of things that I had sort of pushed out of my mind, to the back-burner. (Participant 108, woman, 70)

Indeed, through the discussions around the assessment, some became conscious of the fact that they were indeed care-givers:

> I think the interview helped to clarify things. The kind of questions asked made you really see what you were doing and I recognised myself as a care-giver. (Participant 131, woman, 70)

In addition to raising awareness around their role as a care-giver and the consequences this was having on their lives, through the assessment experience, many care-givers were able to use the occasion to take a step back and reflect on many issues that they had been avoiding.

> If the question hadn’t been asked, I would probably have never given it any thought. It was a bit of an eye opener for me. There are various parts to one’s life that have pretty much been put on the backburner. I found the assessment to be very refreshing. (Participant 124, man, 67)

Action

> It prodded me to move a little faster. (Participant 104, woman, 79)

Beyond sharing, reflecting and receiving information, some care-givers indicated how the assessment process itself pushed them to take actions they had been avoiding or now realised were essential to the care situation. For some, this involved accepting the need to turn to services for support despite current reluctance.

> I am going to have to check out the services that are available that I have been told about by the home-care people that come and by friends, but that I have never gotten around to doing it, and as a result of my chat with the assessor, it is going to be in the interests of my own health if I do something about it. (Participant 124, man, 67)

> Since the interview, I have been thinking of ways of finding out from the doctors what options we have. I think I will start pursuing answers in a more proactive way. (Participant 264, woman, 72)

Others became aware of the need to put into place concrete measures in the case of emergencies or to start preparing for the future around issues such as power of attorney, wills and options for caring. Others became motivated to address concerns with their spouse:

> He asked questions that I have avoided thinking about, and they were in there. Then I have acted on them. I had the confidence to confront my husband the other day, which was really difficult but I thought if I put this off any longer he is not going to be able to respond. (Participant 244, woman, 77)

Participants also explained that the aforementioned benefits were directly linked to the actual assessment process, the opportunity of being asked to reflect on specific areas of their experience.

> There were things that I never realised, that I never realised I had difficulties with, but then when she asked me the questions I thought, 'Oh, yeah that bothers me sometimes'. (Participant 110, woman, 84)

> Just, well the questions that were asked and just knowing that some of the thoughts that I've had about being a care-giver and about the method of carrying it out, some of the questions sort of answered the questions of mine, if I was doing a proper job or if I could do better. (Participant 215, woman, 85)

> It was very useful, because it covered a lot of questions that, to some extent, I had answered myself, but clarified my view of my role as a care-giver … Also, it gave me the opportunity to reflect on my experiences because I knew I was going to be sharing them with someone else. I have been living this situation for a while, but it gave me the opportunity to articulate these points. (Participant 242, man, 82)

> I felt that the people who put the assessment together were very aware of the situation that care-givers find themselves and the detail in it showed that the people were knowledgeable of the situation. It was very well constructed and

> it was well ordered. It was a very good assessment. The assessment gave me an opportunity … to air those concerns, share those feelings, to share those problems. (Participant 122, man, 65)

> I have never been interviewed like that before. I was very comfortable with the assessor. They were great questions. It was very beneficial to me. (Participant 129, woman, 76)

> Being asked some of the questions meant the world to me. It made it more real. (Participant 272, woman, 67)

In short, the assessment process was extremely beneficial for the majority in terms of offering a safe space in which to share their experiences and the accompanying emotions. At the same time, it made them more aware of certain issues they are confronted with and enabled them to step back and reflect on their global situation. It also gave them encouragement to seek help and take action. A second important aspect of the impact of the assessment for spousal care-givers was their appreciation of the assessors.

Provides a relationship with a caring professional

> It is a relief to be able to talk to someone who understands what you may be going through. (Participant 220, man, 77)

Assessors' skills and personality

Many care-givers spoke at length about the attributes of the assessor as an essential component of the assessment process. In many cases, participants indicated that they were more able to express their emotions and talk about their situations because of the level of comfort their assessor inspired. For instance, a participant stated:

> During the assessment, I felt emotional a few times, but I was not uncomfortable, because the assessor was very kind and considerate. I knew I could have had a good cry and the assessor would not have been upset. (Participant 223, woman, 82)

Perceptions of assessor's positive personality traits (*i.e.* being warm, caring, nice, empathetic) were important for many participants to feel that they could speak openly and honestly without feeling judged. For example, one participant said, 'I was very comfortable with her, just because of her personality I guess, she came across very friendly and understanding' (Participant 206, man, 69). Several respondents also commented on the assessors' interview skills as important in the smooth flow and their level of comfort with the assessment.

As well, the fact that the assessor was understanding of their situation but not directly involved in it, as are family and friends, was key to the development of the relationship:

> Well, I found it a bit therapeutic, actually. To talk to somebody about the situation that was totally objective and um, I found that quite helpful for me. That I could

> speak freely without offending anyone or… (Participant 116, woman, 74)
>
> I think it was the chance to speak to somebody who was 'objective', but who was sympathetic about my situation, because one of the problems that you have as a care-giver is the isolation. (Participant 242, man, 82)

Assessors were perceived as objective and knowledgeable and as having practical experience with individuals with cognitive impairments, which enhanced the experience:

> Found talking to someone knowledgeable was helpful – made me feel better. (Participant 225, woman, 74)
>
> I found it very good, I found that the assessor was very personable and knowledgeable … I felt pretty good about being able to talk to someone about these things that most people don't understand. (Participant 125, woman, 75)

Validation: normalisation

> It made me feel like I was doing a really good job of care-giving. (Participant 218, woman, 78)

Another positive impact of the assessment for some participants was that the comments and attitudes of the assessor helped to normalise their situation and helped them to realise that their own experiences were not too different from others. But perhaps, more importantly, for many, the assessment and the assessor gave them positive reinforcement that they were doing a good job:

> The assessor told me that I was very well organised, and my daughter who was with me for some of the questions told me that too. Sometimes you don't realise that you are, you just do it – it made me feel that I was doing a pretty good job. (Participant 232, woman, 73)

A few care-givers were relieved to have decisions they had made validated through the assessment conversation. Others commented on the fact that the assessment served as a form of social recognition of care-givers' experiences and their importance to the health system:

> I think it is nice that you are valuable and what you are doing is valued and this is finally coming around and being looked at. I feel care-givers are taken for granted, but they are an integral part of our health system and if care-givers gave up, our health-care system would collapse. So I was pleased for me and others and that it was being done. (Participant 247, woman, 66)

While most care-givers spoke about the positive impacts of the assessment as related above, some did not perceive the same benefits from this process, although none spoke of their experience as mainly negative. In answer to the question: 'To what extent did the assessment enable you to express your emotions or feelings related to care-giving?', a few care-givers who indicated that they had a good support network in place and people to confide in felt the assessment had not had much impact in this area:

> I didn't learn anything new, but that is my situation. My support system provides me with an outlet. I know that it is important to look after myself and keep myself healthy. (Participant 127, woman, 67)

This was also the case for a couple of respondents in answer to the question: 'To what extent did the assessment enable you to discuss sensitive issues as a care-giver?' Again, those who had other people with whom to discuss their situation, and some caring for a spouse with early stage dementia, derived less benefit in this area than the majority of participants.

Discussion

The purpose of this study was to examine the impact of assessing older spouse care-givers of persons with cognitive impairment, using The C.A.R.E. Tool. Our findings support and strengthen emerging knowledge about the overall benefits of care-giver assessment (Carers UK 2002; Ducharme *et al.* 2011; Ewing and Grande 2013; Feinberg 2004; Greene *et al.* 2011; Moore 2008). Thus, we found that, in line with the few studies on the impact of care-giver assessment (Carradice, Shankland and Beail 2002; Lundh and Nolan 2003; Salmon *et al.* 2005), it provides time, space and an opportunity for care-givers to focus on themselves and their own needs, and openly discuss feelings and emotions related to care-giving. Further, it gives care-givers a sense that there are professionals who understand what they are going through, value their work and with whom they can safely discuss their situation (Byrne 2016; Nankervis *et al.* 1997). The findings suggest that a comprehensive care-giver assessment enables the care-givers to reflect on and understand their care-giving situation in ways that they had not been able to previously and encourages care-givers to take action or consider turning to services for help. More specifically, this study has shown that these benefits exist for a particular population of care-givers who are at high risk for negative impacts on their health and wellbeing, namely older spousal care-givers (Adams 2008; Hartke *et al.* 2006; Navaie-Waliser *et al.* 2002).

Spouses are the least likely of care-givers to self-identify as such because of the marital tie, and personal and social expectations linked to this role (Rousseau *et al.* 2008). This is problematic given that older persons who provide care and experience care-giver strain have been found to have mortality risks 63 per cent higher than non-care-givers (Schulz and Beach 1999). Overwhelmed by the daily routine of caring for a spouse and not identifying the extra demands and worry of care-giving as going beyond their spousal role, many of these care-givers do not realise the extent of the work they are doing nor its impacts on their lives. These care-givers may therefore especially benefit from a guided reflection of their situation, such as that offered by The C.A.R.E. Tool. By accompanying care-givers through such a structured conversation, assessments can provide an opportunity for spousal care-givers to appreciate that the care they are providing might exceed what can be considered as the 'normal' expectations of spousal duty, as well as give them permission to accept support. In the long run, this can act as a preventive measure to breakdown in the care-giving situation or to harmful impacts of care-giving.

In addition, the care-givers in our study spoke frequently of the therapeutic value of having an opportunity to share their experiences and express emotions, a finding that is corroborated by Lundh and Nolan (2003) and Gwyther, Ballard and Hinman-Smith (1990). Indeed, participants' comments point to the importance that care-givers be given the opportunity to tell their story and to have their feelings and experiences recognised and validated. For older adults caring for a spouse with dementia, there are specific factors related to intimacy and identity that may emerge (Adams 2008; Beeson 2003; Hayes, Boylstein and Zimmerman 2009). There are many studies that highlight the benefits of expressing emotions, particularly when the emotions are related to a stressor (Campbell-Sills *et al.* 2006; Graham *et al.* 2008; Stanton and Low 2012). Stanton and Low (2012) emphasise the psychological and physiological benefits of emotional expression. They note that emotional expression can increase individuals' understanding and re-examination of a worrying or traumatic situation and it can allow people to identify significant goals and barriers and 'generate pathways for accomplishing goals' (Stanton and Low 2012: 127); all of these benefits in turn reduce psycho-social and physiological strains associated with a taxing situation. While our study did not measure post-assessment levels of strain, indications from the post-assessment interviews are that a considerable number of participants experienced relief after expressing emotions not previously shared related to the care they provided. Other studies point to the benefits that the normalisation of negative emotions has for those caring for persons with dementia (Adams 2008; Prorok, Hogan and Seitz 2013) and the assessment process provided this normalisation through the assessors' interventions.

These findings help elucidate the specific benefits of a global psycho-social care-giver assessment, such as The C.A.R.E. Tool, and demonstrate how it should be considered as an intervention in and of itself. Not all forms of care-giver assessment lend themselves to this approach. As indicated by Guberman (2006) in a paper prepared for the US Caregiver Assessment Consensus Meeting organised by the Family Caregiver Alliance in 2005, there are many approaches to assessments, including a process to determine eligibility for services; a process of information gathering; and an interactive, personalised, contextually determined helping relationship aimed at the provision of effective support of care-givers (*see also* Byrne 2016; Grande *et al.* 2017; Nolan, Bauer and Nay 2009; Robinson and Williams 2002). Thus, the goal of assessment must be clarified. If the aim is simply to judge whether the care-giver meets criteria for access to services, it is unlikely the practitioner will be open to a global discussion of the care-givers' needs, especially those that cannot be met by the services being offered. The outcomes of such assessments risk being quite different from those indicated here.

It is thus imperative to consider the type of instrument chosen for care-giver assessment. It is questionable whether a standardised tick-box tool or a closed questionnaire would have the same benefits. Dill (1993) advances that it is futile to attempt to develop instruments that adopt the criteria used in the evaluating of scientific instrumentation, and that there is no metric equivalency between levels of need and the amount of services to be given. She suggests that because of the uniqueness of each assessor and each individual to be assessed, the assessment process will vary from case to case regardless of the degree of standardisation of the instrument being used. Indeed, most standardised objective questionnaires serve more as a way of screening for risk to care-giver wellbeing (depression, burden, stress) than as a tool aimed at arriving at a global understanding of the care-givers' situation and as a means of informing an intervention plan (Byrne 2016). According to Solomon *et al.* (2011), unstructured methods are more flexible than standardised measures and enable assessors to probe for more detail and develop a more global impression of a person's situation. These methods thus permit a better understanding of the complete care-giving situation in all its complexity and all its facets. Geron (1997: 7) concurs with the idea that to serve a clinical function, an assessment must provide sufficient information 'to understand the problems, needs, resources, and strengths of a client's situation, and to guide the assessor and the client in making decisions about a care plan' and thus must be able to address multiple dimensions, balancing psychometric precision with practicality.

In addition to the question of the type of assessment that results in the benefits demonstrated by this study, we must consider the general approach that health-care professionals tend to use with care-givers. Numerous studies have shown that care-givers continue to remain 'invisible' to the majority of professionals they encounter in seeking help for the person requiring care (Coleman and Roman 2015; Ewing and Grande 2013; Feinberg 2004; Levine 2008, 2016). Many practitioners promote their own value systems with regard to their expectations of care-givers, particularly spousal care-givers, based on their strong belief in family responsibility for the care of older people (Guberman *et al.* 2006; Rousseau *et al.* 2008), and thus fail to take into account the care-givers' own perspectives and the negative impacts that the care may be having on them. This becomes even more the case in a context where system imperatives push professionals to transfer as much care as possible to family members (Guberman and Maheu 2002; Guberman *et al.* 2006; Ward-Griffin and McKeever 2000) or what has been called 'the care-giver as resource approach' (Guberman and Maheu 2002; Twigg 1988; Ward-Griffith and McKeever 2000). This stance maintains that formal services must not substitute for informal care, the preferred choice. Services are thus meted out in small doses so as not to encourage families to do less. Consequently, while efforts are usually made to ensure that the care-giver is knowledgeable and competent, concern for the care-giver's wellbeing is either marginal or non-existent.

The integration of care-giver assessment into the health system could incite professionals to question this dominant approach by encouraging them to focus specifically on care-givers as persons in their own right and raising their awareness of the multiple negative impacts this approach has on care-givers. This in turn might lead to more realistic expectations of care-givers and possibly to specific interventions and supports for them.

Our results also indicate the importance of an assessor with specific attributes to support the multi-dimensional approach of this assessment. Many of the care-givers interviewed indicated that they would not have been as open to revealing their situation if the assessor had not possessed certain qualities such as warmth, empathy and professionalism. For health-care professionals, this points to the requirement that their stance not be one of information gathering to make a judgement about the situation, but rather one of support and curiosity aimed at encouraging the care-givers to tell their stories. Care-givers, especially older spouses, may resist the notion of an assessment because they see themselves as family members not care-givers, and also may view assessment as a passing of judgement on their ability and competency to care, which it unfortunately may indeed be (Guberman 2006). Thus, professionals' attitudes and stances are of utmost importance in creating the appropriate safe space for care-givers to feel comfortable enough to share their experience.

Finally, our findings reveal that many of our participants assume that the assessor has knowledge and experience with regard to care-giving issues. To what extent is this the case? The assessors in this study participated in a comprehensive training programme which included understanding care-givers' issues, maintaining attitudes such as non-judgement, and developing competencies such as valorisation and normalisation, as well as receiving information on available resources and supports. Most college and university programmes for health-care workers and professionals, at least in Canada, have limited curricula related to care-giver issues, as reported in interviews by representatives from education and health sectors across Canada in interviews related to other objectives of the larger study. Also, where the question of care-givers are addressed, it is often within the paradigm of care-givers as resources. Care-givers are rarely presented as potential beneficiaries of services nor are students trained on how to intervene with this group. Health-care workers' practice will not change unless the paradigm is changed at the point of training.

Limitations

This study examined potential benefits of care-giver assessment for a specific population, spouses of persons with dementia living in two small Canadian provinces. Because of these jurisdictional constraints and the small sample size, its findings cannot be generalised to other care-giver populations nor to all spousal care-giver groups. Notably, our sample was ethnically homogeneous given the general population of the two provinces it was drawn from at the time of study (between 3 and 5 per cent of their populations are comprised of visible minorities; Statistics Canada 2011). More research is needed to understand the impacts of care-giver assessment in general and for specific groups of care-givers. Further studies could include greater ethnic and sex/gender diversity. As well, the assessment took place as part of a research project and was not linked to outcomes such as increased support or continued support, so that we were not able to evaluate how the assessment process links to service outcomes. Nor were we able to document whether the impacts described in this paper were long-lasting as there was no further follow-up with participants after the post-assessment interview. Again, further research could address these aspects so that we have a better grasp of the role of assessment for care-givers.

Conclusion

There is an increasing awareness of the importance of family and friend care-giving largely due to the concern associated with the demands of an ageing population. Many aspects of being a care-giver can be valuable and rewarding, however, physical, emotional, social and financial implications are also extensively documented. Despite the growing recognition of the pivotal role care-givers play in the health-care system, in OECD countries there are few examples of practice in which the needs of care-givers are identified through a global and comprehensive assessment process focused solely on the care-giver; and yet, structured and systematic approaches to assessment appear to have great potential for improving the quality of services to carers, and indirectly, to care recipients. Having a clear rationale, including an accurate and holistic understanding of the carer's view of their situation and desired outcomes, is fundamental to delivering effective support to carers and enables limited resources to be targeted appropriately. On the other hand, not assessing the needs of care-givers has implications for the care-giver as well as the health system. Jurisdictions touting 'ageing in place' strategies should consider the results of this study, as well as others that offer insights into the value of care-giver assessment.

Note

1 A process to classify the level of cognitive impairment that care recipients were experiencing was conducted by a member of the research team and participants' spouses were assigned into one of three groups: mild, moderate or severe. The classification was based on a review of existing cognitive classification tools and consultation with a geriatrician researcher. The resultant classification differentiates by care-giving responsibilities associated with various stages of cognitive decline. Mild impairment was based on whether the spouse needed assistance with instrumental activities of daily life such as cooking, house or yard work, using the telephone, driving, managing finances or managing his/her medications due to thinking or memory problems; moderate impairment was based on whether the spouse needed prompting or cueing with basic activities of daily living such as bathing, toileting (going to the bathroom), getting dressed, or feeding themselves due to thinking or memory problems; severe impairment was based on whether the spouse needed a lot of assistance with the basic activities of daily life identified above due to thinking or memory problems.

Acknowledgements. The authors acknowledge Felicia Newall for her work on an original draft of the manuscript supported through a Health Professional Student Award (2012–2013).

Declaration of contribution of authors. The authors alone are responsible for the research and writing of this paper. All authors contributed to the design of the study, analysis and interpretation of the findings. All authors reviewed and contributed to the writing of the manuscript and approved the final version.

Funding. This research was funded by the Canadian Institutes of Health Research (FRN-102347).

Conflict of interest. The authors do not have any conflicts of interest.

Ethical approval. Ethical approval for this research was granted by the following: Mount Saint Vincent University Research Ethics Board (file number 2010–006), Capital District Health Authority Research Ethics Board (file number CDHA-RS/2011-104), Colchester East Hants Research Ethics Board (file number CEHHA1110), Northwood Research Advisory Council (no file number), University of Prince Edward Island Research Ethics Board (file number 6003772), PEI Research Ethics Board (no file number) and VON Canada Research Ethics Committee (file number 170511-01).

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Cite this article: Guberman N, Keefe J, Fancey P (2019). The assessment experience of spousal dementia care-givers: 'It's made me realise that I am a person also'. *Ageing & Society* **39**, 2443–2464. https://doi.org/10.1017/S0144686X18000557