

Assessment: A Powerful Tool for Caregivers and Practitioners

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Why assess caregivers?

- Absence of a real status for caregivers within health and social service systems
- Difficulty in responding to their well-documented needs
- Few intervention models and tools appropriate for understanding the situation, the needs and the perspective of caregivers
- Limits of existing tick-box scales and measures



Why assess caregivers?

- Prevent and alleviate many of the negative consequences of caregiving
- Ensure better quality and more appropriate services
- Prevent caregiving crises
- Sensitize and inform practitioners with regard to the global care situation
- Help practitioners recognition that caregiver needs may differ from those of person needing care
- Provides a rationale for targeting services to caregivers

What assessment?

- **Tools reflect a philosophy and a vision of caregiving and caregivers**
 - CG well-being important to maintain role and quality of care
 - CG assessment reflects resource availability rather than need
 - CG as partners who need to be incorporated into the assessment and care planning process

Current Assessment Practices

Model	Role of Assessor	Services
Questioning (Maintaining care)	Expert	Imparted
Procedural (Resource availability)	Gatekeeper	Allocated
Exchange (CG as partner)	Co-expert/facilitator	Negotiated
(Smale et al 1993)		(Nolan et al 2003)

Standardized comprehensive person-centered assessment tool

- Focuses on the global caregiving situation including cultural diversity, beliefs and values
- Caregiver-led and focus on caregiver perceptions
- Assessment as an intervention

Impact of assessment on caregivers

□ Opportunity to tell one's story

It [the assessment] was very helpful. I normally keep a lot to myself, because I have no one to discuss things with. I don't think, other than a trained professional, other people understand. They think they do, but they don't if they are not in the situation. By being able to say things out loud and not have someone say that it is my imagination, I think it was good to get it off my plate.

It was good so I could tell my side of the story. Nobody ever asked me all those questions.

Impact of assessment on caregivers

Enabled to express (repressed) emotions

It was like a relief. I felt free to say anything that I wanted. It was good therapy. I could bring everything out into the open.

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.

Impact of assessment on caregivers

Promotes self-awareness

Yeah there were things that I never realized, that I never realized I had difficulties with, but then when she asked me the questions I thought, “Oh, yeah that bothers me sometimes.”

It made me think more about my role and how it is affecting me and will affect me.

It was enlightening. I had never thought about it too much, you just take each day as it comes., I guess I never put things in words before. You think about it, but you wait for it to happen. It made me more aware.

Impact of assessment on caregivers

Enables reflexive thinking

You don't get the time as a caregiver to do very much reflection and questions often will prompt your thinking in a certain area that you hadn't considered and that's always helpful. And can broaden your looking at caregiving and whatever aspect is under discussion at the time. So that's been probably for me one of the most valuable aspects of that...

Impact of assessment on caregivers

Provides validation and normalization

It was comforting to me to know that some of the things that I was doing, or maybe not doing were quite normal. [...] of realizing that I was doing okay and what had occurred at times with my husband was quite normal.

It validates you a little bit more – that you have legitimate feelings.

It was very helpful and gave me a little bit more personal strength. To be assured that I was going about things the right way. I had reached a point where I needed to speak to somebody.

Impact of assessment on caregivers

Provides validation and normalization

I think it is nice that you are considered valuable and what you are doing is valued and this is finally coming around and being looked at. I feel caregivers are taken for granted, but they are an integral part of our health system and if caregivers gave up, our health care system would collapse. So I was pleased for me and others and that it [the assessment] was being done.

After the interview I was thinking about how our doctor would not listen to me at the beginning when I was asking for a referral. The assessment reminded me of all those years that the health professionals would not listen to anything that we had to say.

Impact of assessment on caregivers

- Opportunity to tell one's story**
- Enabled to express(repressed) emotions**
- Promotes self-awareness**
- Enables reflexive thinking**
- Provides validation and normalization**



Impact of assessment on practitioners

- Increases understanding/awareness of what it means to be a caregiver**

I think I already knew, but doing the assessments reinforced my understanding of the sacrifice that caregivers make. Their social life or sacrificing time with their grandchildren to be with their spouse and a lot of times it seems to go unnoticed, because it is expected of them by the care receiver and family members.

Impact of assessment on practitioners

As an assessor walking into their home, you see much more than just the physical nursing care that they do. You see the family management, the finances, how they see the future and their health. For me, it was having a better appreciation and a better knowledge of what caregiving is. The many dimensions

Impact of assessment on practitioners

□ Questions previous assumptions

I guess before [doing the assessments], I would have thought that there was no other way than to take care of your spouse. That it would be my duty. But I think my mind would be a lot more open to the different options to caregiving-maybe using home care a lot more, or putting them into a nursing home earlier.

Some [caregivers] found it rewarding and some didn't. Some wanted to do it for as long as they could, but some realized that it wasn't what they wanted to do.

Impact of assessment on practitioners

- **Shifts focus from symptoms to understanding underlying factors**

The tool can help us identify things which we weren't seeing before but it also changes our perceptions and our way of intervening. In any case that's what I found that it did. By giving us time with the caregiver I really started understanding things. That's what I didn't have before. I had the facts, but I didn't have the explanation. I didn't have the context. And I feel that that greatly influences our way of intervening.

Impact of assessment on practitioners

□ Helps modify practices

Because my focus is always on the client, if there's a caregiver, I've taken that person for granted : “ good, you've got caregiving, I don't have to give you as much this or as much that ”. I mean, I have a relationship with the caregiver, but no focus on that caregiver. It's given me tremendous insight and now, if I have a client who has a caregiver, I would have a different approach. I would definitely do an interview with the caregiver, apart from the client, and go in-depth into this and just look at it in a very different way.

Impact of assessment on practitioners

- **Improves accessibility and appropriateness of services**

I think that maybe a lot of supports and programs for caregivers may be approached in a one size fits all fashion, and there is not holistic support available. Although I realize there may be barriers to this, I think that creating some sort of program where caregivers are matched to one professional to help provide information to the caregivers would create successful situations.

Impact of assessment on practitioners

- **Modifies the notion of “client” and gives a rationale for services to caregivers**

What I think this tool affords us as care coordinators to do and be is hold a space for someone who has never had their space held before.

If we have a tool like this, then we're better able to lay out why they need this service or care or referral to that agency and it's you know, a justification.

Impact of assessment on practitioners

- Increases understanding/awareness of what it means to be a caregiver**
- Questions previous assumptions**
- Shifts focus from symptoms to understanding underlying factors**
- Helps modify practices**
- Improves accessibility and appropriateness of services**
- Modifies the notion of “client” and gives a rationale for services to caregivers**

Two Canadian Tools

- Caregiver Risk Screen
- C.A.R.E. Tool (to understand Caregivers' Aspirations, Realities and Expectations)

What does the screening tool look like?

➤ Caregiver profile

- age, sex, living arrangements, frequency of care, current services

➤ Scale - multidimensional

- 12 statements (impact on physical and mental health, social support, family relations, etc)
- Caller agrees or disagrees (ex. I feel I am losing control over my life because of my present situation)
(4 pt. Scale)
- Total score = level of risk to the caregiver and the caregiving situation

What does the C.A.R.E. Tool look like?

10 sections with open and closed questions

- the caregiving work
- support – formal and informal
- living arrangements and transportation
- other responsibilities and the juggling work
- financial impacts of care
- physical and emotional health
- caregiver/care receiver and family relations
- crisis and long-term planning
- service/support needs
- summary section

To access Risk Screen and C.A.R.E.
Tool:

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http://www.msvu.ca/en/home/community/Centres_Institutes/centreonaging/projects/caregiverassessment/instruments.aspx