

A Novel Instrument for Caregivers in Managing Neuropsychiatric Symptoms of Dementia: Baycrest Quick-Response Caregiver Tool™ *



Robert Madan, MD^{1,2}, Marsha Natadiria, MEd², Anna Berall, RN², Anna Theresa Santiago, MPH, MSc³, Kenneth Schwartz, MD^{1,2}

¹Division of Geriatric Psychiatry, Department of Psychiatry, University of Toronto, Toronto; ²Baycrest Health Sciences, Toronto; ³Biostatistics Department, Princess Margaret Cancer Centre, University Health Network, Toronto, ON

<https://doi.org/10.5770/cgj.25.603>

ABSTRACT

Background

Family caregivers can experience significant stress related to behaviour changes in persons with dementia (PWD). Approaches to support caregivers with stress management when responding to changes in behaviours are needed. The Baycrest Quick-Response Caregiver Tool™ (BQRCT) was developed to provide caregivers with an online tool that can be used in real time to recognize and manage their emotions when managing neuropsychiatric symptoms of dementia.

Methods

A mixed-methods approach was used to evaluate the feasibility of this new tool. Family caregivers of persons with dementia received education about managing neuropsychiatric symptoms of dementia through the online tool. Caregiver demographic information and feedback about the tool was obtained through telephone and online surveys. Health-care providers accessed the tool and also provided feedback.

Results

The 21 caregivers who completed the study found the tool helpful and reported high feasibility that included being able to access, complete, and implement the strategies presented in the tool. The 18 health-care providers found the tool useful and most would recommend it to peers and clients. Participants also provided specific suggestions for improvement, such as including more examples of complex behaviours.

*Some findings from this work were presented at the International Psychogeriatric Association annual conference and the abstract was published along with all the other abstracts for the conference: *Int Psychogeriatr*. Volume 32, Issue S1, October 2020, pp. 123 DOI: <https://doi.org/10.1017/S1041610220002604>

Conclusions

This tool adds to and complements existing strategies for managing neuropsychiatric symptoms of dementia. Its accessibility through the online platform is especially useful for caregivers who are unable to seek help in person, and for health-care providers and caregivers seeking additional resources.

Key words: caregiver support, neuropsychiatric symptoms, dementia, online educational tool, behavioural symptoms, self-management

INTRODUCTION

The rate of Alzheimer's disease and related dementias is increasing globally with a prediction that 74.7 million people worldwide will have dementia by 2030.⁽¹⁾ Neuropsychiatric symptoms are prevalent in dementia.^(2,3) The Cache County study reported a 56% point prevalence of neuropsychiatric symptoms and a cumulative five-year period prevalence of 97% of participants developing at least one neuropsychiatric symptom.⁽⁴⁾ Neuropsychiatric symptoms are associated with poor quality of life for the person with dementia (PWD) and caregiver, caregiver burden and depression, increased health-care costs, and institutionalization.^(5–10) There are concerns regarding limited efficacy, adverse side effects, and risk of death with psychotropics for neuropsychiatric symptoms of dementia.^(11–14) Behavioural interventions for caregivers have been found to be modestly effective. Recent meta-analyses have found that non-pharmacological interventions for caregivers have small but significant effects on reducing neuropsychiatric symptoms and improving caregivers' ability, knowledge, subjective well-being, burden, depression, and anxiety.^(15,16) As a result, behavioural interventions are often recommended to be the first-line treatment for neuropsychiatric symptoms.⁽¹⁷⁾

Behavioural symptoms and mood changes in the PWD pose additional challenges and distress for caregivers. Although caregiver stress can present itself in their interaction with the PWD unintentionally, the emotional state and stress level of the caregiver can be an external contributing factor to the development and worsening of neuropsychiatric symptoms. Caregiver burden can worsen neuropsychiatric symptoms of dementia, which can in turn increase caregiver burden.⁽¹⁸⁾ Reducing either one can positively influence the other. In addition, neuropsychiatric symptoms are related to caregiver burden and institutionalization of the PWD.^(19,20) Caregivers require training in effective techniques that can be used to manage their stress and help reduce behaviours in the PWD.

Both formal and informal caregivers can benefit from a variety of tools to assist in managing neuropsychiatric symptoms. Frameworks, such as P.I.E.C.E.STM, DICE, and ABC Learning Theory, provide approaches to assess neuropsychiatric symptoms and plan interventions. P.I.E.C.E.S directs care teams to consider the following factors in trying to understand why the neuropsychiatric symptoms are present, which helps inform the creation of a care plan: physical, intellectual, emotional, capabilities, environmental, and social.⁽²¹⁾ DICE directs care teams to describe and investigate caregiver, environmental, and PWD factors to ultimately create a plan and evaluate the outcome.⁽²²⁾ ABC is based on learning theory and assists care teams in analyzing the antecedent to the symptoms, the behaviours, and the consequences of the symptoms or interventions.⁽²³⁾ This can uncover patterns of triggers and reinforcements that sustain the symptoms, and inform the generation of behavioural interventions. DICE has been found to improve family and professional caregiver levels of confidence in dementia care, and P.I.E.C.E.S has been shown to promote interdisciplinary collaboration.^(21,24) These approaches are used by trained health-care professionals in collaboration with caregivers. With the limited availability of health-care professionals to provide training for caregivers, new tools are needed in order to further support and educate caregivers.

The Baycrest Quick-Response Caregiver ToolTM (BQRCT) was developed based on affect education used in group therapy⁽²⁵⁾ to assist formal and family caregivers in real time as they manage neuropsychiatric disorders. Affect management involves the ability to recognize and moderate emotions in response to stressful situations. The BQRCT provides the caregiver with a self-reflective tool to better understand themselves and their feelings, thus contributing to a more effective interpersonal interaction and intervention with the PWD. The BQRCT is quite different from the aforementioned approaches as it is heavily focused on the caregiver, whereas P.I.E.C.E.S and ABC approaches do not focus on caregiver factors. Although DICE considers caregiver level of stress, communication style, and level of education about dementia, similar to P.I.E.C.E.S and ABC, it is used for symptom assessment and planning behavioural interventions. By contrast, the BQRCT is used right in the moment

by the caregiver when the behaviours begin to escalate. The tool is a reflective exercise that asks the caregiver to stop and consider the process of the interaction, reflect on their emotional responses, consider empathically what the other person wants and, finally, to develop a response to the PWD after the reflective process.

Other behavioural interventions do not address the emotional state of the caregiver while the symptoms are occurring, nor do they provide a tool to use in the moment to immediately de-escalate the situation. Caregivers' understanding of their self-perceived stress may enhance their coping and ability to apply learned approaches when responding to changes in mood and behaviours of the PWD. The BQRCT fills in a significant gap that is not addressed by other behavioural interventions and frameworks, and can work complementarily with other interventions to complete the toolbox for the caregiver. Given the bidirectional relationship between neuropsychiatric symptoms of dementia and caregiver burden, effective interventions for caregivers are needed.

The BQRCT was created as a series of educational videos to be used as a stand-alone training tool. The tool involves caregivers viewing a series of four videos and referencing the instruction manual and pocket guide for guidance in the theoretical approach of managing neuropsychiatric symptoms. The goal is to assist caregivers in providing the most helpful response to the PWD and to avoid unintentional escalation of the behaviour.

The purpose of the current pilot study was to assess the feasibility of—and satisfaction with—the BQRCT in caregivers of PWD and health-care providers. Specifically, the study aimed to understand if caregivers could apply the approaches presented in the tool, and whether the approaches were helpful and useful for their needs.

METHODS

Design and Setting

This was a feasibility pilot study involving a cohort of caregivers and health-care providers using a mixed-methods approach. The study was conducted at Baycrest Health Sciences, an academic centre of geriatric care in Toronto, Ontario, Canada. Ethics approval was obtained by the Baycrest Research Ethics Board, approval number 19-11.

Participants

Family caregivers of PWD were recruited for the study through emails, referrals, and advertisements from within hospital clinics/programs and from outside of the organization. Inclusion criteria included: English-speaking, spousal or adult children caregivers, must be managing neuropsychiatric symptoms of dementia, and having a minimum of at least one in-person visit per week with the PWD. The PWD could be either living in the community or in institutional settings. Caregivers were excluded if the PWD had a terminal illness with life expectancy of less than six months, was undergoing active treatments for cancer, or had a diagnosis of

schizophrenia or bipolar disorder. Health-care providers were included if they worked with caregivers of PWD.

BQRCT Structure

Four training videos of approximately 4 to 6 minutes each were developed to provide education about managing neuropsychiatric symptoms of dementia. The first video provides information about neuropsychiatric symptoms of dementia and a general overview of the tool. The three other videos demonstrate how to use the tool and involve actors portraying different scenarios of PWD and their caregivers, as they use self-reflection to monitor their responses and prevent an escalation of neuropsychiatric symptoms. In addition to the videos, a short instruction manual and pocket guide are included in the tool. The instruction manual describes how caregivers can use the tool. The pocket guide is an acronym of the word ‘CARER’ and contains the steps that guide a caregiver’s response to the PWD (Figure 1). A webpage was created on the hospital website for the instruction manual, pocket guide, and videos, and is available to anyone who accesses the webpage at the following permalink: <https://www.baycrest.org/Baycrest/Education-Training/Educational-Resources/Baycrest-Quick-Response-Caregiver-Tool>. Caregivers are able to download and print out the pocket guide so they can use it whenever they need to.

Measures

Family caregivers completed a secure online pre-survey which included demographic questions, current overall health status (RAND Health Self-Rating Question), and the number of neuropsychiatric symptoms experienced by the PWD (Neuropsychiatric Inventory–Questionnaire). Within two weeks of reviewing the tool, the research assistant contacted caregivers by phone to ensure that caregivers were able to access the BQRCT and to complete the feasibility survey. Four weeks after the telephone survey, caregivers completed the online post-survey to further assess feasibility and usefulness of the intervention. Health-care providers provided feedback through an online survey after viewing the tool. The surveys were managed and administered using Qualtrics software version April 2019 (Qualtrics, Provo, UT).

Data Analysis

Participant demographics and survey responses were summarized through descriptive statistics, which were generated using SAS/STAT software version 14.2 and the SAS System for Windows version 9.4 (Copyright 2013 SAS Institute Inc., Cary, NC). Responses to the open-ended questions were transcribed into Microsoft Excel and coded into prevalent themes by two coders for agreement and inter-rater reliability. The open-ended questions asked caregivers and health-care providers what they found helpful about the tool, what they would change about the tool, and also asked whether they had any additional feedback or comments.

RESULTS

Caregivers

A total of 33 family caregivers were recruited, and 21 caregivers completed the study. The 21 caregivers had a mean age of 66 years, 17 were female, 16 completed post-secondary education, and 11 were spouses or partners of the PWD. The 12 caregivers who did not complete the online post-survey either declined or could not be contacted. Based on the RAND Health Self-Rating Scale, 17 of the caregivers who completed the study reported being in ‘good’ to ‘excellent’ health. Caregivers had been taking care of their PWD for an average of 5.2 years and the vast majority were receiving some informal or formal support. Prior to the intervention, caregivers were managing an average of seven neuropsychiatric symptoms out of a possible 12, according to the Neuropsychiatric Inventory–Questionnaire (Table 1).

Overall, the BQRCT received positive feedback at the two-week telephone survey check-in. On average, caregivers rated their ability to navigate, complete, and understand the concepts taught in the training videos as being ‘very good’. All the caregivers accessed the videos, instruction manual, and pocket guide. Due to audio issues, one caregiver was not able to watch the videos. At the post-intervention online survey, caregivers reported that the tool positively impacted their compassion towards the PWD. On average, they reported a ‘good’ ability to implement the tool, found the tool ‘moderately helpful’ for self-reflection, and were ‘somewhat’ able

- C** - (Step 1) **Calm down**: Slow down, take deep breaths, use some positive self-talk
- A** - (Step 2) **Attend** to the interaction without immediately reacting: Remind yourself that this person is unwell, distressed, and can’t explain why
- R** - (Step 3) **Reflect** on your own feelings: What am I feeling (e.g., angry, frustrated, worried, sad)? Why do I feel this way?
- E** - (Step 4) **Empathize** with the other person’s feelings: What is the other person feeling? Why is the other person feeling this way?
- R** - (Step 5) **Respond**: Now I can respond

FIGURE 1. “CARER” acronym

TABLE 1.
Caregiver demographics (n=21)

	<i>Completed Pre- and Post-Surveys</i>
Age in years, mean (SD)	66 (13.8)
Sex: Female, n (%)	17 (81.0)
Marital Status: Married or in a domestic partnership, n (%) ^a	19 (90.5)
Relationship to the person with dementia (PWD), n (%)	
Adult child or child-in-law	10 (47.6)
Spouse/partner	11 (52.4)
Education, n (%)	
Completed at least college/university	16 (76.2)
Some college or university or less	5 (23.8)
Employment Status, n (%)	
Unemployed or retired	14 (66.7)
Employed (full or part time)	7 (33.3)
RAND Health Self-Rating Question: Good, very good, or excellent, n (%)	17 (81.0)
Years caring for PWD, mean (SD)	5.2 (3.9)
Lives with PWD: No, n (%)	10 (47.6)
Hours caring for PWD in a week, median (range)	28 (3-168)
Respite care received in the past 4 weeks: Yes, n (%)	10 (47.6)
Level of confidence in managing care for the PWD, mean (SD) <i>1=very low to 5=very high</i>	3.4 (0.9)
Number of symptoms in the PWD (Neuropsychiatric Inventory Questionnaire), mean (SD)	6.6 (2.3)

^aOthers were single, never married, or divorced.

to learn effective approaches to managing neuropsychiatric symptoms. The instruction manual and pocket guide were rated as ‘moderately useful’, and the training videos were rated as ‘helpful’ (Table 2).

Four prevalent themes emerged from the open-ended questions. 1) Caregivers found the tool practical and easy to use: “The mnemonic/acronym helps me to remember what to do.” 2) Caregivers found the tool helpful in managing neuropsychiatric symptoms of dementia: “It is a good reminder to calm down before reacting,” and “Helpful ... to give pause and think about what the other person is feeling.” 3) The tool also allowed caregivers to feel that they are not alone in their situation: “I liked the fact that they seemed to understand the problems that caregivers face with their own emotions in handling the various situations dealing with someone with dementia.” 4) Caregivers provided suggestions for improvement, such as requesting more complex behaviours be portrayed in the videos: “Would’ve liked more videos on different situations, because there are so many. For example, if the person gets really upset and totally abusive ...”

Health-care Providers

A total of 18 health-care providers completed the feedback survey, half of whom were social workers. Health-care providers had a median of 10 years in practice, ranging from 2 to

36 years, with two-thirds practicing in the community and the remainder practicing in a clinical setting. On a five-point scale, where 1 indicates ‘strongly disagree’ and 5 indicates ‘strongly agree’, all health-care providers rated ‘strongly agree’ that the tool was comprehensive, useful, easy to understand, and easy to access and navigate. There were 16 health-care providers who reported that they would recommend the tool to other health-care providers and to caregivers of PWD.

Health-care providers had similar qualitative feedback to caregivers in terms of ease of use and the benefit of reflection before responding: “I liked that it was simple, and allowed the caregiver time to recognize and manage their own feelings.” They commented on the tool’s potential to be helpful in their practice, for example, as a method of facilitating discussions with their clients.

“I feel it would be helpful for health-care providers as it is a way to acknowledge caregivers’ feelings of frustration associated with the caregiving role and to normalize these. It will assist health-care practitioners to open a discussion that allows caregivers an opportunity to discuss their experiences.”

They also suggested expanding the audience of the tool to include various cohorts such as staff, personal support workers, and individuals who care for persons with mild cognitive

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TABLE 2.
Caregiver feedback about the Baycrest Quick-Response Caregiver Tool (n=21)

	<i>Mean (SD)</i>
<i>Telephone Feasibility Survey: Two Weeks Post-Intervention^a</i>	
Ability to navigate and complete the training videos 1=very poor to 5=very good	4.9 (0.5)
Ability to understand the concepts taught in the training videos 1=very poor to 5=very good	4.8 (0.4)
Length of time it took to complete the training videos 1=much too long to 5=much too short	3.0 (0.2)
Impact on knowledge about managing neuropsychiatric symptoms of dementia 1=not at all to 5=a great deal	3.0 (1.2)
<i>Online Post-Survey: Six Weeks Post-Intervention</i>	
Impact caregiver compassion towards the PWD 1=very negatively to 5=very positively	3.9 (0.7)
Change caregiver interactions with the PWD 1=gotten much worse to 5=improved a lot	3.9 (0.8)
Implement concepts taught in the training videos 1=very poor to 5=very good	3.6 (0.7)
Reflect on and understand their own feelings as related to the PWD's neuropsychiatric symptoms of dementia 1=not at all helpful to 5=extremely helpful	3.2 (1.1)
Learn effective approaches to respond to the PWD's neuropsychiatric symptoms of dementia 1=not at all to 5=very much	3.4 (1.1)
Helpfulness of training videos 1=very unhelpful to 5=very helpful	3.9 (0.9)
Usefulness of instruction manual 1=not at all useful to 5=extremely useful	3.1 (0.8)
Usefulness of pocket guide 1=not at all useful to 5=extremely useful	3.1 (1.1)

^aMissing data for one participant.

impairment. Lastly, they suggested expanding the number of videos to include more scenarios and different response options in the tool, and to elaborate on the guidance in crafting the response to the PWD.

DISCUSSION

This pilot study determined the feasibility of the BQRCT involving a limited sample of self-selected and experienced caregivers and health-care providers. Overall, the tool was well-received and described as practical, easy to use, and helpful. Caregivers reported that the tool positively impacted their compassion towards the PWD, and they were able to reflect on and understand their own feelings as related to the PWD's neuropsychiatric symptoms of dementia. The BQRCT provides caregivers with a tool that can be used in the moment as the symptoms occur, making it distinct yet complementary to other existing frameworks. Caregivers are tasked with managing their own stress in addition to helping manage the PWD's behaviours.⁽²⁶⁾ The BQRCT was found to

provide caregivers with assistance as the PWD's symptoms are occurring in situations where the response of the caregiver may either escalate or de-escalate the situation. This study suggests that caregivers were able to apply the concepts outlined in the BQRCT.

Caregivers who are new to the role may benefit significantly from this tool, in combination with psychoeducation about dementia. Of interest, the caregivers in this study were not new to the role, and have been caring for the PWD for about five years on average. This suggests that the tool could be helpful to caregivers who already have experience in the role. This study did not stratify the results based on type or severity of neuropsychiatric symptom and it is thought that this tool could be helpful at various stages and severity of the disease, allowing the caregiver to stop and reflect in challenging situations.

There is limited literature on the use of reflection and caregiver management of affect when responding to behavioural symptoms of the PWD.^(26,27) The current study expands the scope of self-management support resources for family

caregivers by describing a new online educational tool that assists caregivers to calm down, pause, and reflect empathically before responding to the PWD. Future studies could include both informal and formal caregivers in the community and in institutional settings. Furthermore, outcomes to determine changes in the frequency and severity of the neuropsychiatric symptoms and caregiver distress with the use of the BQRCT should be investigated.

CONCLUSIONS

As the number of PWD increase in coming years, caregivers of PWD will need a range of tools to manage neuropsychiatric symptoms of dementia. The BQRCT's online platform allows caregivers and health-care providers to access the tool at their convenience. It could add to and complement existing tools, and has the potential to be a useful resource for caregivers and health-care providers.

ACKNOWLEDGEMENTS

Not applicable.

CONFLICT OF INTEREST DISCLOSURES

We have read and understood the *Canadian Geriatrics Journal's* policy on conflicts of interest disclosure and declare there are none.

FUNDING

This work was supported by the Ontario Ministry of Health and Long-Term Care: Academic Health Science Centre—Alternative Funding Plan under grant number BMS-17-005. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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Correspondence to: Robert Madan, MD, FRCPC, Baycrest Health Sciences, 3560 Bathurst St., North York, ON M6A 2E1 Canada

Email: rmadan@baycrest.org