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The CARES® Observational Tool: A Valid and Reliable Instrument to Assess Person-Centered Dementia Care*

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Abstract

The goal of the current study was to develop a valid and reliable tool to measure whether person-centered care is delivered by direct care workers to persons with dementia. Face validity was initially established through multiple revisions of the CARES® Observational Tool (COT™) by members of the study team. Afterwards, content validity of the COT was established by piloting the tool on 12 observations across 4 nursing homes and review by an interdisciplinary panel of nine scientific experts. The final 16-item version of the COT was then tested for inter-rater reliability by 5 reviewers across 5 standardized dementia care videos. An intra-class coefficient of all possible Kappa coefficients resulted in an ICC of .77. The brief and easy-to-use COT has potential to assess person-centered care interactions between direct care workers and persons with dementia.

Introduction

The principal objective of this study was to develop and test an observational assessment tool (the CARES® Observational Tool, or COT) to ascertain whether person-centered care was present in the day-to-day care interactions between direct care workers and persons with dementia. The concept of person-centered care (“supporting the rights, values, and beliefs of the individual; involving them and providing unconditional positive regard; entering their world and assuming that there is meaning in all behaviour, even if it is difficult to interpret; maximising each person’s potential; and sharing decision making”)¹ has been hailed as a transformative approach in dementia care. However, there remain few valid measures to ascertain whether person-centered elements are present in residential dementia care.

As recent and prior qualitative investigations in nursing homes have emphasized, the personal relationships direct care workers forge with individual residents appear central to quality of care or quality of life outcomes on the part of residents.^{2,3} As most analyses of the staff-resident dynamic focus on ratios rather than relationships, assessing the presence of person-centered dementia care in nursing homes or other residential care settings may help to advance clinical understanding of essential quality of care. Bowers, Esmond, and

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Jacobson (2000) found that direct care providers considered personal relationships with residents integral to providing individualized care.³ Therefore, the current study aimed to develop and test an observational measure of direct care worker-person with dementia interactions to determine if elements of person-centered care are present.

Observational Rating Tools

A review of Alzheimer's disease rating scales found that although 68 measures of Alzheimer's disease exist, most consider major dysfunction in specific domains and are not easy-to-use tools that can assess individuals' responses to specific therapies.⁴ While routine staff reporting of the behavior exhibited by persons with Alzheimer's disease or related dementias (sometimes referred to as "problem behavior" or "inappropriate behavior") is easier to administer and less time-consuming than observational rating protocols, concordance between staff ratings of resident behavior and direct observational measures is moderate at best.⁵ Several observational protocols assess quality of dementia care in residential or other settings.^{6,7} In a review of 34 studies of Dementia Care Mapping (where an observer tracks 5 people with dementia continuously over a period of time and codes whether certain behavior occurs as well as direct care worker interactions with persons with dementia), it was concluded that such approaches effectively measure quality of dementia care and demonstrate concurrent validity with other established measures of quality of life.⁸ A behavioral observational protocol, the Communication Skills Checklist, can help investigators determine whether trained communication skills are applied for persons with dementia.⁹ Other strategies have also been utilized, including a computer-assisted observational tool to examine activity, behavior, and emotional affect of residents every 10 minutes over a 12-hour period (which summarily found that residents were not engaged with their environment).¹⁰

Research Focus

An effective and easy-to-administer instrument to assess person-centered care in dementia remains a gap in the clinical and scientific literature.¹ The goal of the current study was to develop a valid and reliable tool to easily determine the presence of person-centered care elements in direct care worker-person with dementia interactions. While direct care workers' perceptions of their relationships with residents appear key to ensuring person-centered care in nursing homes,^{2,3} direct care worker-reports are not as reliable as behavioral observations. Although various observational protocols exist, these tools are time-intensive to administer and do not necessarily track the direct care worker-resident interaction domains that reflect person-centered care. The present study summarizes the development, testing of face and content validity, and inter-rater reliability analysis of the COT, an observational protocol that is designed to measure the presence of person-centered care elements for individuals with dementia.

Methods

Sample

Twelve interactions between nursing home residents and direct care workers were included to establish content validity of the COT. These residents were identified from 4 nursing homes in the Minneapolis/St. Paul region. One nursing home was randomly selected from the Center of Medicare and Medicaid Services list of nursing homes in Minnesota; a convenience sample approach was used to select the other 3 facility sites based on the recommendations of the research assistant and a doctor of nursing science. Facilities were not matched according to any specific criteria in order to facilitate the COT testing process. All 4 facilities were nursing homes; 2 were located in a suburban area, 1 was located in an exurban area, and 1 was located in a rural area over 100 miles from an upper-Midwestern

metropolitan area. Direct care worker-person with dementia care interactions were selected randomly by the rater in each facility; observations were not equally conducted in one area or among certain types of residents. The observer focused on different direct care workers and persons with dementia in recording data for the COT.

After the content validity process was completed, inter-rater reliability was established with videos of care interactions recorded between 5 actual nursing home residents with dementia and direct care staff (see below). Sample descriptive information of five trial care scenario videos, including topic, duration, and sociodemographics of the direct care worker and person with dementia are included in Table 1.

Measure: The CARES® Observational Tool

The Principal Investigator (PI) of the National Institute on Aging-funded grant supporting this project initially created a 16-item observational checklist that included a dichotomous scoring system for each item (1 = observed; 0 = not observed). The items reflected direct care worker care behaviors that were expected to reflect person-centered care according to the following dimensions: *connecting with the person*, *assessing behavior*; *responding appropriately*; *evaluating what works*; and *sharing with others*. The items of the initial observational tool were then summed.

Procedure

Face validity—Face validity refers to whether a measure effectively assesses a construct of interest based on the appearance of items (i.e., the “face” of the measure). Following the initial creation of items, the PI along with input from scientific advisors reviewed the original COT for its content and format. Several validated tools in the literature were considered, specifically the Apparent Emotion Rating instrument developed by Snyder and colleagues¹¹ which itself is based on a comprehensive observational assessment protocol developed by Lawton et al.¹² The Apparent Emotion Rating instrument is a brief observational instrument that assesses the presence or absence of 6 emotions in long-term care residents (3 positive, 3 negative) and demonstrated substantial inter-rater reliability as well as construct validity.¹¹ Utilizing the general formatting, structure, and protocol development of the Apparent Emotion Rating instrument, the COT was developed and further revised.

Content validity—Content validity ensures that the measure under consideration includes items that reflect the entire domain of a construct; or, whether the included items of the COT sufficiently captured the person-centered care. To establish the content validity of the COT, the initial version of the COT was pilot tested in 4 nursing homes. A clinically-trained research assistant, a doctorate of nursing science, and the Associate Director of Education and Outreach of the local Alzheimer’s Association regional office completed a total of 12 observations and their impressions were incorporated into iterative versions of the COT. Further feedback was then solicited from a panel of 9 scientific, interdisciplinary experts to strengthen the content validity of the tool. The primary objective behind the selection of the nine experts was that they reflected various disciplines related to dementia care, including advance practice nursing, occupational therapy, social work, and psychology. Experts were also identified that had national recognition in their discipline, one of whom has extensive experience developing observational forms. These nine experts had prior experience collaborating with the research team to develop online educational and training modules.

Inter-rater reliability protocol—An inter-rater reliability procedure then took place to establish the consistency of the final version of the COT. Five practice videos of actual direct care worker care interactions with nursing home residents living with dementia were

developed and utilized (see Table 1 for descriptions of these five trial scenarios). Five interdisciplinary reviewers completed COT observations for 5 new direct care worker-person with dementia videos without repeat viewings or discussion. A subset of two other interdisciplinary reviewers were chosen from the group of nine experts that provided feedback on content and face validity of the COT. Two interdisciplinary reviewers were invited because of their professional background in social work and occupational therapy, respectively. The last member of the review team was the Principal Investigator of the National Institute on Aging-funded grant supporting this project.

Analysis Plan

Face validity—Establishing face validity of the COT included incorporation of verbal and written feedback on the earlier versions of the tool to refine and revise the COT.

Content validity—Establishing content validity included the incorporation of open-ended feedback from the 12 direct care worker-resident care interactions as well as the open-ended feedback on items provided by the nine interdisciplinary scientific experts in order to revise, rephrase, delete, or add items to better reflect person-centered dementia care on the COT.

Inter-rater reliability—Inter-rater reliability was then determined using a Kappa coefficient for multiple ratings.¹³ Agreement was assessed for the total scores across the five videos and five reviewers using an intraclass correlation coefficient determining the consistency of kappa coefficients across all reviewers.

Results

Face validity

The COT was revised to include the following: a) a narrative description of the direct care worker-person with dementia interaction event; b) 7 items assessing whether the direct care worker connected with the person with dementia; c) 2 items to ascertain whether the direct care worker assessed the behavior of the person with dementia; d) 4 items to determine whether the direct care worker responded appropriately to the person with dementia's behavior; e) 2 items to assess whether the direct care worker evaluated what worked during the interaction; and f) 3 items to determine whether the direct care worker shared the content of the person with dementia's interaction with other members of the care team, which includes family members.

Content validity

The initial pilot procedure resulted in the creation of a much briefer, 12-item COT that guided raters with example direct care worker-person with dementia interactions. This was done to avoid a “not enough information” response that occurred on earlier versions of the COT and allowed for more complete scoring of the tool.

Expert feedback on the tool helped to limit redundancy in the items and also to offer wording suggestions to improve COT raters' ability to identify direct care worker-person with dementia interactions. For example, an original item to assess whether a direct care worker mentions something about the person with dementia's life was expanded to include examples such as “direct care worker mentions something specific about the person's life and/or direct care worker mentions something meaningful in the person's life, personal life story, or history.” This process resulted in the final version of the COT tested: a 16-dichotomous item observational assessment (see Figure 1).

Inter-rater reliability of the COT

The final version of the COT (see Figure 1) was tested across 5 multiple raters (see above) with a second set of 5 instructional care videos. An intra-class coefficient (ICC) of all possible Kappa coefficients resulted in an ICC of .77, which is also considered substantial agreement.¹³

Discussion

The findings pertaining to the development, establishment of face and content validity, and inter-rater reliability of the COT suggests its utility in assessing important direct care worker-person with dementia interactions in long-term care. Based on several other rigorous tools,^{6,11} the COT pinpoints critical domains of person-centered dementia care interactions including evidence of interpersonal connection between the direct care worker and the person with dementia, ongoing assessment of behavior on the part of the direct care worker, appropriate responses to the person with dementia's behavior, evaluation of what works by the direct care worker, and the sharing of direct care worker-person with dementia care interactions with other staff members. In addition to having general usefulness as an easy-to-use observational assessment, the COT serves as a more powerful test of the presence of person-centered care routines than previous self-report assessments of direct care worker satisfaction or knowledge about dementia.^{14,15}

A number of valid assessment protocols exist to measure and rate dementia behavior in various contexts^{6,7} and the quality of direct care worker-person with dementia interactions. As noted by prominent scholars such as Kitwood,^{16, see also 1} a principal objective of person-centered care in the dementia context is the validation, maintenance, celebration, and understanding of *who* the person with dementia is and the incorporation of this knowledge into day-to-day care. Another key component of establishing and maintaining person-centered care in dementia is the ability to assess whether such standards are being met, particularly in residential care settings where persons with dementia are: 1) more likely to have moderate-to-severe cognitive impairment that adversely influences verbal communication; and 2) at-risk to receive care that is based on administrative, business-oriented routines to maximize efficient use of staff time rather than care that is oriented around personhood, person-directed preferences, and individualized care based on the connections made with the person with dementia. The COT is based squarely on the principles of quality person-centered care (i.e., entering the person with dementia's world and acknowledging the meaning of their behavior, even if it appears to the direct care worker as negative or aggressive)¹. For these reasons, the COT is a tool that can be applied to determine whether direct care workers are providing appropriate care to persons with dementia. Perhaps just as important, the COT can also identify gaps in care that can be addressed with further training to ensure delivery of person-centered care. Finally, the COT can serve as a checklist for staff training, person-centered care concept reinforcement, ongoing staff assessment, and even informal peer-to-peer observations to further reinforce person-centered concepts. Based on the promising results here, the COT is another assessment tool that clinicians, researchers, trainers, supervisors, and others can use to determine whether education is translated into practice and whether effective dementia care is delivered to the person with dementia in a person-centered manner.

While the COT holds promise as an observational tool of direct care worker-person with dementia care interactions, there are several limitations that are important to note. The current study only demonstrated face validity, content validity, and inter-rater reliability; higher levels of measurement validity such as criterion or construct were not established. Construct validity in particular is crucial to demonstrate, as it allows the researcher to have confidence that a given measure is operating theoretically as expected (e.g., see <http://>

www.socialresearchmethods.net/kb/constval.php). A controlled evaluation that is currently in progress by the authors includes the COT as an outcome measure; it is hoped that these scientific efforts will further establish the construct validity of the COT. This will also allow for more extensive testing of the COT in the field; as summarized above, inter-rater reliability of the COT was established via video ratings of care scenarios. The authors encourage other researchers and clinical providers to conduct future evaluations of the COT in diverse care settings in order to further develop the acceptability, utility, and validity of this measurement approach.

One of the strengths of the COT is its ease-of-use. Unlike other observational protocols which tend to be time-intensive and require considerable training to administer properly, the COT relies on a fairly simple scoring system to track whether the objectives of providing effective, person-centered care to persons with dementia living in long-term care settings are met. For these reasons, we envision the utility of the COT to extend to a variety of environments that have an interest in ascertaining how well their direct care workers are offering person-centered care to individuals with dementia.

We anticipate that the COT is feasible as an outcome measure for a range of clinical interventions designed to enhance the quality of care for persons with dementia. Such evaluations can range from quality improvement efforts in various types of residential settings (e.g., assisted living memory care units) to more novel research efforts that examine quality of dementia care in families (e.g., family caregiver training approaches designed to enhance how families provide care to their relatives). The established reliability of the tool and its ease of use would allow its administration across scientific studies and practice environments. For these reasons, the COT can serve as an effective assessment tool for research and clinicians who strive to ensure person-centered care for persons with dementia.

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CARES[®] Observational Tool[™]

Today's Date: _____ Start Time: _____ End Time: _____ Total: _____
 Person Being Observed: _____ Person Being Cared For: _____ Person Observing: _____
 Describe the care being done: _____

Score 1 if <u>any</u> bulleted item is observed.		Score 0 if <u>no</u> bulleted item is observed.
1. _____	Greet	• CNA uses a greeting (hello, good morning, etc.)
2. _____	Introduce	• CNA introduces himself/herself
3. _____	Use Name	• CNA uses resident's name
4. _____	Smile/Eye	• CNA smiles and makes eye contact for at least 2 seconds
5. _____	Physical Contact	• CNA makes physical contact (shake hands, rub on back, hug, etc.)
6. _____	Approach	• CNA approaches the resident from the front
7. _____	Eye Level	• CNA crouches down or sits next to resident to be at eye level or below
8. _____	Calm	• CNA is calm and not rushed in approach
9. _____	Ask/Discuss/ Assess	• CNA asks/discusses how resident is feeling or doing
10. _____	15 Seconds	• CNA speaks to resident at least a total of 15 seconds during care interaction
11. _____	Explain	• CNA explains an activity/care (e.g., "I'm here to pick up your laundry.") and/or • CNA proposes an activity (e.g., "Let's go for a walk.")
12. _____	Involve in Care/ Activity	• CNA involves resident in care appropriately (according to their abilities) and/or • CNA tries to involve resident in a care (instead of CNA doing the care for the resident)
13. _____	Resident's Life	• CNA mentions something specific about resident's life and/or • CNA mentions something meaningful in resident's life, personal life story, or history
14. _____	Comfort	• CNA gets resident into a more comfortable position (i.e., repositions resident) and/or • CNA asks if there is anything he/she can bring them or do for them
15. _____	Share	• CNA shares something verbally about the resident with another team member
16. _____	Write	• CNA documents/writes something about resident (chart, Post-it [®] Note, communication book)
_____ Total Score		

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Figure 1.
 The CARES[®] Observational Tool (COT[™])

Table 1

Descriptive characteristics of five trial direct care worker-person with dementia interaction videos.

Care Scenario	Video Duration	Direct Care Worker Characteristics	Person with Dementia Characteristics
Video 1: Staff member helps resident brush teeth	2 minutes	White, female, 50 years of age	White, female, 85 years of age
Video 2: Staff member asks resident if she would like to take a shower	46 seconds	Hispanic, female, 50 years of age	White, female, 78 years of age
Video 3: Staff member helps the resident brush teeth	2 minutes	White, female, 30 years of age	White, female, 75 years of age
Video 4: Staff member asks resident if she would like to take a bath	4 minutes	Hispanic, female, 50 years of age	White, female, 78 years of age
Video 5: Staff member asks resident to get up	41 seconds	Hispanic, male, 40 years of age	Filmed from perspective of dementia