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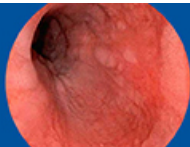
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Julia Ruth, BA Candidate, Lauren Latella, PhD Candidate, Nicholas Talisman,
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Communicative Coping Behavior Checklist: Observation of Persons With Dementia in the Home Environment

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Abstract

Purpose of the Study: Communication contributes to increased stress, mortality, and decreased quality of life (QOL) for persons with dementia (PWD) and caregivers. PWD use communicative coping behaviors (CCBs) to manage the demands of the disease. However, most assessments neither look for nor give credit to communication behaviors. This is the first study to examine CCBs in the home environment as measured by the Communicative Coping Behavior Checklist (CCBC).

Design and Methods: This cross-sectional quantitative study included 26 dementia and 18 cognitively normal control dyads. Raters observed their partners' CCBs at home, over several weeks and completed the CCBC. We analyzed the endorsement rates (how often behaviors were observed by a rater) of emotion and activity-focused CCBs in dementia and control dyads.

Results: The primary outcome was rate of CCB endorsement. Secondary outcomes included dementia diagnosis, cognitive status, depressive mood, life satisfaction (SWL) and QOL. Dementia dyads endorsed 11 of 23 CCBs significantly more than control dyads. Action-focused CCBs ($p < .001$) were more frequent than emotion-focused CCBs ($p = .004$) in dementia dyads. Specific CCBs such as humor correlated with higher caregiver QOL ($p = .019$) and PWD's SWL ($p = .003$). Another CCB, general humor, correlated with lower PWD's SWL ($p = .024$).

Implications: This was the first study to examine CCBs in the home environment comparing dementia and control dyads. Higher endorsement rates of action-focused than emotion-focused CCBs were seen in dementia dyads. We conclude that attention to CCBs during treatment and care will improve QOL and SWL of PWD and caregivers.

Keywords: Language, Communication, Coping, Dementia, Assessment, Alzheimers

Purpose

Some of the most challenging obstacles faced by persons with dementia (PWD) or Alzheimer's Disease (AD) and their caregivers are those posed by difficulties in the communication process (Garcia-Alberca et al., 2012; Orange & Colton-Hudson, 1998; Savundranayam, Montgomery, & Hummert, 2005).

Extensive research has focused on how caregivers cope with the stress and burden of providing care for PWD.

Numerous studies have demonstrated that caregivers for people with dementia are at greater risk for depressive symptoms and anxiety (Joling et al., 2015), burden (Brodaty et al., 2014) and poor health (Schulz & Sherwood, 2008). However, only a handful of studies have examined the coping behaviors used by people with dementia (Oyebode, Motala, Hardy, & Oliver, 2009; Pearce, Clare, & Pistrang, 2002). Even fewer studies focus on communication behaviors as coping mechanisms (Harris & Durkin, 2002).

Discourse Studies of PWD

The study of discourse provides a framework to examine the language that people use to cope with issues of self-identity. Communicative Coping Behaviors (CCBs) are an example of this phenomenon. For example, in a clinical setting, when asked who is the president of the United States, a PWD might say, "Oh, he was forgettable." This statement could be interpreted in a variety of ways. Rather than viewing this behavior as evidence of a deficit, it can be viewed as a coping behavior—an attempt to present oneself as a humorous person who has certain political views (Saunders, 1998a).

Saunders, de Medeiros, and Bartell (2011) examined the explanations of memory loss and humor used by PWD to construct identity in clinical situations. In a longitudinal study, Hamilton (1994) described how one individual maintained the ability to ask and answer questions into advanced stages of AD. Ramanathan (1997) examined the coherence of AD subjects' speech noting that interlocutors frequently take over the conversation, reducing opportunities for subjects to contribute to the conversation. More recently, Mok and Müller (2014) found that even though PWD are willing and able to be conversationalists, the extent of communication breakdown plays a role in the development of positive interpersonal relationships. Basting (2003) contradicted the notion that AD leads to decreased sense of self through autobiographical narrative analysis, and found that the pronoun "I" is pivotal in communication and coping for patients with AD. These studies provide examples of socially contextualized research that delve more deeply into the actual linguistic interaction of the PWD.

Our research examined the discourse of PWD with the goals of understanding how PWD manage and cope with the experience of AD, how they revealed intact communicative functions, and how they make their desires and needs known.

Coping With Dementia

The literature regarding coping behaviors by PWD describes multiple models, methods, and specific coping behaviors. Cohen and colleagues (Cohen, 1991; Cohen, Kennedy, & Eisdorfer, 1985; Robinson, Giorgio, & Ekman, 2012) reported that people in the early stages of AD learn to cope with the stresses of living with AD. Studies suggest that people can face adversity, learn coping behaviors, and build resilience when being open and receptive to being diagnosed with early stages of AD (McMillen, 1999; Robinson et al., 2012). Werezak and Stewart (2009) developed a model of how PWD cope with their illness; this model consists of five core stages: antecedents, anticipation, appearance, assimilation, and acceptance. Clare (2002) also suggested there is a response process in the use of coping behaviors including registering, reacting, explaining, experiencing, and adjusting. Van Dijkhuizen, Clare, and Pearce (2006) proposed a Level of Connectedness Model for the investigation of coping strategies utilized by patients with

early-stage AD. This model allows coping strategies to be interpersonal rather than individual actions.

Other research examined the themes found in coping behavior. MacQuarrie (2005) found that the various themes of acknowledgment of AD demonstrated independent forms of engagement and withdrawal as coping mechanisms. Studies indicated both positive (Harris & Sterin, 1999) and negative coping strategies are used by PWD (Bahro, Silber, & Sunderland, 1995) and their caregivers (Zucchella, Bartolo, Pasotti, Chiapella, & Sinforiani, 2012). Harris and Durkin (2002) identified 12 unique coping strategies that characterize the experience of individuals with AD. Comparatively, Oyeboode and colleagues (2009) discovered that PWD predominantly used "problem-focused" rather than "emotion-focused" coping strategies reinforcing that PWD are able to actively take independent control over their lives. CCBs as observed in the Communicative Coping Behavior Checklist (CCBC) tend to be emotion-focused coping behaviors (e.g., denial, expressing thankfulness) as opposed to problem- or activity-focused coping behaviors. All of these thematic approaches described here (Bahro et al., 1995; Garcia-Alberca et al., 2012; Harris & Durkin, 2002; Harris & Sterin, 1999; Oyeboode et al., 2009) endeavor to explain how PWD cope with their cognitive impairment.

In order to further explore the kinds of CCBs that PWD use, we developed the CCBC. The CCBC is an instrument completed by caregivers to observe and record the frequency and effectiveness of 22 CCBs.

The proposed instrument, the CCBC, is a discourse/communication-focused approach for examining coping behaviors. By examining CCBs from the perspective of a caregiver, the CCBC offers entry into the perspective on daily life in the home environment of a PWD. Most of the behaviors we examined fall into the realm of emotion-focused in that they deal with the individual's management of the social and emotional dynamics of an interpersonal interaction. We also looked at problem-activity-based coping behaviors that related to persons' changing their activities and daily routines. Examples of these activity-focused behaviors include limiting social activities, avoiding interactions, and changing routines.

Design and Methods

Participants

There were 44 dyads composed of rater and a person being observed: 26 PWD dyads and 18 control dyads. In the PWD dyads, the caregiver was the rater and the PWD was the observed. In the control dyads, one person was designated the rater and the other, the observed.

PWD were women and men, 60 years of age or older who were diagnosed as having AD based on standards set by the NINCDS-ADRDA (McKhann et al., 1984).

The caregiver/rater met the following criteria were friends and/or family members of the care receiver; had no history of cognitive impairment or psychiatric disturbance; and had a minimum daily contact of 6 hr per day with the

participant. The caregiver/rater tended to be the spouse or family member of an older subject who was involved in a clinical research study at the memory clinic. In the control dyad, neither members had a history of cognitive impairment or psychiatric disturbance; and had a minimum daily contact of 6 hr. We recruited study participants from an academic medical center in the mid-Atlantic region of the United States.

Informed Consent

This study was reviewed and approved by the [Blinded for Review] University Medical Center Institutional Review Board. Informed consent was obtained from all participants prior to study procedures. Dual consent was obtained from all PWD and their caregivers or legally authorized representatives to protect the rights of these individuals who might recall the details of the study.

Description of the CCBC

The CCBC is an observational checklist of 22 behaviors completed by the caregiver/rater to rate frequency and effectiveness of CCBs. The items on the checklist include management of memory loss (e.g., acceptance and ownership, disclosure, positive attitude and self-acceptance, role relinquishment and replacement, connection with the past, taking a proactive stance, anticipatory adaptation, and spirituality) (McHaffie, 1992; Saunders, 1998a, 1998b; Harris & Durkin, 2002). Seventeen of the CCBs fell into the emotion-focused category (Oyebode et al., 2009), while five were categorized as activity-focused (e.g., avoiding interactions, changing routines, and relinquishing roles).

Using the checklist, the caregiver/rater observed the frequency of behaviors of the PWD/control participant over the course of 2 weeks directly following the study visit. The caregiver/informant rated behaviors on a five-point Likert-type scale between 0 (*never*) and 5 (*very*). While we collected information on effectiveness of each CCB, this paper only focuses on the results of the frequency ratings.

To address issue of face validity, we convened an expert panel, which included an experienced clinician, a neuropsychologist, a statistician, and a geriatrics nurse practitioner who reviewed and finalized item selection and item reduction; question-answer format; question and Likert-type scale response format; and layout of the CCBC prior to administration of the instrument.

In addition, we conducted a focus group with caregivers to review the CCBC before its administration. Each member of the focus group reviewed the CCBC and provided comments on form and content. The session was audiotaped and transcribed. The transcripts were analyzed using a qualitative analysis methodology called "content analysis" (Neuendorf, 2002) to examine the suggestions made by the participants. Those individuals who participated in the focus groups were not enrolled as study participants.

Other Instruments

In addition, we collected data on quality of life, life satisfaction, depressive symptoms, and cognition. The Mini Mental State Examination (MMSE) is a screening instrument frequently used for AD (Folstein, Folstein, & McHugh, 1975). It evaluates orientation, memory, attention, concentration, naming, repetition, comprehension, and the ability to create a sentence and copy two intersecting pentagons. Scores range from 0 to 30. The Alzheimer's Disease Assessment Scale (ADAS-Cog) (Mohs et al., 1997; Rosen, Mohs, & Davis, 1984) is a psychometric instrument that evaluates memory, attention, reasoning, language, orientation, and praxis. A higher score indicates more impairment; the range is 0–70. This was administered to PWD and the observed participant in the control dyads. Quality of Life-AD (QOL) (Logsdon, Gibbons, McCurry, & Teri, 2002) provides a 13-item appraisal of QOL in physical, emotional, interpersonal, and environmental domains. The interviewer collected ratings for the participant, whereas informant ratings of participant QOL were self-administered. This was administered to PWD and their caregiver. The Geriatric Depression Scale (GDS; Yesavage et al., 1982) is a scale designed to identify symptoms of depression in the elderly. The scale consists of 15 printed questions that the participant is asked to answer on the basis of how he/she felt over the past week. One point is given for each appropriate answer indicative of a symptom of depression, for a possible total of 15 points. The Satisfaction with Life Scale (SWL; Diener, Emmons, Larsen, & Griffin, 1985) is a five-item scale designed to measure global cognitive judgments of one's life satisfaction (not a measure of either positive or negative affect). Participants indicate their level of agreement with each of the five items using a seven-point scale that ranges from 7 (*strongly agree*) to 1 (*strongly disagree*). All participants completed the GDS, SWL, and the MMSE.

Training of Caregiver

During the first study visit, we trained the caregivers/rater to identify CCBs. This training included review and discussion of a video and written examples of each CCB followed by a discussion of the items on the checklist and examples of those behaviors.

Data Analysis

All statistical analyses were performed using the statistical software package SPSS Version 22 (IBM Corporation, 2013). Descriptive analyses were first performed on demographic measures and covariate instruments. Next, frequencies were run to determine rates of endorsement of CCBs in both dyads. In order to investigate group differences in total and specific CCBs, two-sample *t*-tests and chi-square tests of independence were conducted. Finally, in order to examine associations between CCBC scores and variables of age, sex, education, and depressive symptoms, Pearson's

correlation coefficients were computed within each group. Group comparisons were conducted across different stratifications of dyad types and participant types (PWD dyads vs. control dyads, caregiver vs. Rater, PWD vs. observed).

Results

To compare the rate of endorsement of CCBs across dyad types (PWD vs. control), independent-samples *t*-tests showed significant differences in the use of the following CCBs: using humor to tell jokes ($t = -1.19, p = .054$), avoiding interactions with friends ($t = 3.55, p < .001$), avoiding conversations ($t = 2.31, p < .001$), describing how the brain works ($t = 1.31, p = .007$), word finding ($t = 2.36, p = .004$), repeating things ($t = 5.1, p < .001$), expressing difficulties with memory ($t = 1.38, p = .007$) expressing thankfulness for family support ($t = 1.83, p = .004$), set answer ($t = 2.3, p < .001$), making harsh comments ($t = 1.22, p = .024$), giving up tasks ($t = 2.3, p < .001$), changing routines ($t = 1.29, p = .006$), and using nonverbal cues ($t = 1.83, p < .001$). In all of these analyses, PWD dyads reported more frequent use of CCBs.

Further, independent-samples *t*-tests showed significant differences in the use of both total problem/activity-focused coping behaviors ($t = 4.570, p < .001$) and total emotion-focused coping behaviors ($t = 3.092, p = .004$) endorsed by dyad type. In both cases, the PWD dyads endorsed

significantly more coping behaviors. A chi-square test of independence further showed that the PWD dyads were significantly more likely to endorse any action-focused coping behaviors ($\chi^2 = 14.491, p < .001$) than the control dyad (see Table 1).

Chi-square tests on coping behaviors revealed significant differences between groups for six emotion-focused coping behaviors across dyads, including expressing emotions ($\chi^2 = 9.402, p = .002$), general humor ($\chi^2 = 4.38, p = .036$), giving a set answer ($\chi^2 = 4.156, p = .041$), repetition of phrases ($\chi^2 = 17.052, p < .001$), searching for the right word ($\chi^2 = 6.246, p = .012$), and telling stories ($\chi^2 = 5.115, p = .024$). The other 11 emotion-focused coping behaviors did not display significant differences, though two others approached significance (expressing thankfulness, using nonverbal cues). Significant differences were also found for all but one (changing routines) action-focused behaviors, including avoiding interaction ($\chi^2 = 10.154, p = .001$), avoiding conversation ($\chi^2 = 4.973, p = .026$), limiting social activity ($\chi^2 = 12.774, p < .001$), and relinquishing roles ($\chi^2 = 5.115, p = .024$).

In terms of individual scores on the cognitive test, the PWD had significantly lower MMSE scores than the observed participant in the control dyads ($f = 21.15, p < .001$). There were no significant differences in age, education, SWL, QOL, or MMSE scores ($f = 1.29, p = 2.6$) between the rater and the observed in the control dyads.

Table 1. Endorsement of Communicative Coping Behaviors by Dyads Type

Communicative Coping Behavior	PWD (N = 26)	Control (N = 18)	Cramer's V (X^2 p-value)
Emotion-focused CCB	100	88.9	ns
Denial	23.1	16.7	ns
Discussing how the brain works	34.6	16.7	ns
Discussing memory loss	57.7	33.3	ns
Discussing past memory	26.9	22.2	ns
Expressing difficulty with memory	42.3	22.2	ns
Expressing emotions	69.2	22.2	.462 ($p = .002$)
Expressing thankfulness	80.8	55.6	ns
General humor	65.4	33.3	.315 ($p = .036$)
Giving excuses	50.0	44.4	Ns
Having a set answer	30.8	5.6	.307 ($p = .041$)
Making harsh comments	46.2	27.8	Ns
Repetition of phrases	92.3	33.3	.623 ($p < .001$)
Searching for the right word	80.8	44.4	.377 ($p = .012$)
Self deprecating humor	26.9	44.4	ns
Solidarity building humor	53.8	66.7	ns
Telling stories	34.6	5.6	.341 ($p = .024$)
Using nonverbal cues	26.9	5.6	ns
Activity-focused CCB	69.2	11.1	.574 ($p < .001$)
Avoiding conversations	42.3	11.1	.336 ($p = .026$)
Avoiding interactions	42.3	0	.480 ($p = .001$)
Changing routines	19.2	5.6	ns
Limiting social activity	50	0	.539 ($p < .001$)
Relinquishing roles	34.6	5.6	.341 ($p = .024$)

Note: CCB = communicative coping behavior; PWD = persons with dementia; ns = nonsignificant.

However, there was a significant difference in the GDS scores of the caregiver and the rater ($f = 6.17, p = .017$). There were no differences in age, education, GDS, SWL, or QOL scores for when compared across participants (see Table 2).

Further, we examined the relationship between QOL and life satisfaction with specific coping behaviors. There was a positive correlation ($r = .458, p = .019$) between the caregiver self-reported QOL and the endorsement of the use of solidarity building humor (i.e., humor to make people laugh), as well as between the PWD's SWL and the endorsement of solidarity building humor by PWD ($r = .567, p = .003$). There was a negative correlation between the PWD's self-reported SWL and the endorsement of the use of humor by PWD in the face of memory loss ($r = .440, N = 26, p = .024$). In terms of activity-based CCBs, there was a positive correlation between the PWD QOL and the endorsement, the relinquishment, or change in taking on new tasks due to memory ($r = .488, N = 26, p = .011$).

Discussion

The CCBC is a new tool for conceptualizing and observing communication and coping behaviors of PWD. We found that the CCBC allows for meaningful observation of how PWD use communicative behaviors to cope in the home environment. Furthermore, by conducting the research in the home environment for both the caregiver and the patient, we learned a great deal about how PWD reveal coping behaviors naturally.

We achieved several goals in conducting this study. First, we aimed to understand how communication and language functioned as part of the coping process. Second, we wanted to know if communicative coping manifested differently in PWD than in cognitively intact older adults. Third, we wondered if CCBs only occurred in the clinic or if they occurred at home too. Finally, we tried to ascertain if caregivers could serve as raters of their loved ones' behavior outside the clinical environment.

Our study supports research on coping in that most CCBs are endorsed more frequently by caregivers of PWD than by informants of normal participants (Bahro et al, 1995; Harris & Sterin, 1999; MacQuarrie, 2005). Of the 22 CCBs observed in this study, 11 were observed in PWD dyads significantly more often than in control dyads including, expressing emotions, general humor, giving a set answer, repetition of phrases, searching for the right word, and telling stories. In addition, two others behaviors approached significance (i.e., expressing thankfulness and using nonverbal cues).

Using certain CCBs, such as humor, improves both quality of life and life satisfaction. The PWD's self-reported SWL increased when they used more humor about their memory loss. Likewise, caregivers had better reported quality of life indicators when their loved ones with dementia used more humor to build relationships (i.e., solidarity building humor). Further, when the PWD uses solidarity building humor, their self-reported SWL improves. Perhaps the PWD use these different kinds of humor as a defense mechanism to cope with memory loss and to make personal connections, which in turn contributes to better life satisfaction and quality of life for both PWD and their caregivers.

On the other hand, there was a negative correlation between the PWD's self-reported SWL and the endorsement of the use of humor by PWD in the face of memory loss. So what does this mean? Perhaps PWD who tell jokes about losing their memory might have a heightened awareness of their memory problems and hence a lower rating on the SWL. Finally, our results show a significant positive relationship between giving up new and/or old tasks and the perception of QOL for PWD. This may imply that those individuals who gave up tasks felt less pressure and thus may report a higher quality of life.

It is important to determine if these CCBs are more representative of PWD than of older adults in general. Our findings suggest this is indeed the case (Bahro et al, 1995; Harris & Sterin, 1999; MacQuarrie, 2005). We believe that

Table 2. Demographic Characteristics of Study Participants

Characteristics	PWD dyads (N = 26)		Control dyads (N = 18)	
	PWD Mean (SD)	Caregiver Mean (SD)	Observed Mean (SD)	Informant Mean (SD)
Age	76 (9.23)	66 (11.29)	74 (10.34)	69 (13.85)
Education	16 (3.94)	16 (3.45)	16 (5.80)	16 (2.28)
MMSE	20.73 (5.94)	29.44 (0.87)	28.56 (1.50)	29.0 (1.08)
GDS	1.38 (2.97)	2.54 (2.39)	1.61 (2.12)	0.78 (1.17)
ADAS-Cog	21.6 (8.16)	n/a	8.50 (4.20)	n/a
SWL	15.88 (3.19)	14.15 (2.75)	15.22 (2.65)	16.06 (2.41)
QOL	41.81 (5.02)	36.04 (6.10)	42.17 (6.01)	41.22 (7.24)

Note: ADAS-Cog = Alzheimer's Disease Assessment Scale; GDS = Alzheimer's Disease Assessment Scale; MMSE = Mini Mental State Examination; PWD = persons with dementia; QOL = Quality of Life-AD; SWL = Satisfaction with Life Scale.

people use CCBs to cope with the demands of the disease (e.g., short term memory, executive function) and that these communicative behaviors are integral to coping with social factors of everyday interaction. This study demonstrates individuals suffering from dementia retain these skills as seen in the use of CCBs. We propose that using communication as a coping device is central to the social construction of identity. Furthermore, when clinicians and caregivers recognize and bolster these behaviors, it may have a positive influence on the quality of life for these individuals.

Specifically looking at communication, Aggarwal et al. (2003) revealed disparities between satisfaction of patients with AD with their surroundings and their satisfaction as perceived by caretakers. Reasons for this gap in knowledge included caretakers' feeling they could no longer communicate effectively with their loved ones with AD (Aggarwal et al., 2003). A clinical team could use the CCBC to identify CCBs and to educate the caregiver in how their loved one is using these coping behaviors.

Since the need for coping strategies increases as the disease progresses for the PWD (Bahro et al., 1995), it is important to identify the CCBs used by these individuals in the course of everyday life and in the clinical setting. If clinicians and caregivers were more cognizant of CCBs as preserved skills instead of as symptoms of decline, perhaps the communication between PWD and their caregivers could be improved.

Limitations

The CCBC relies on the observations of caregivers who may not be reliable raters given their lack of training in behavioral research. Although we did train the raters for this study, rater reliability might be an issue for application of this instrument. This analysis does not include longitudinal data since it was difficult to get study participants to complete multiple iterations of the CCBC. Additionally, the CCBC was completed by a small sample of raters.

The CCBC would help the clinician create an individualized communication prescription (Acton, Yauk, Hopkins, & Mayhew, 2007). First, using the CCBC may create a heightened awareness to inform clinicians about how PWD use communication behaviors to cope with real-life situations. Second, the CCBC may aid the clinician in tailoring his or her clinical evaluations, assessments, and conversations to support the physical health, mental health, and identity of PWD. This awareness could lead to a better understanding of communication patterns of PWD and thus a better dynamic of cooperation between person with dementia and caregivers (Jootun & McGhee, 2011). Finally, the clinical team can educate the caregiver about how his or her loved one uses CCBs to cope.

Finding ways to help individuals cope communicatively is a critical part of surviving manifestations of selfhood (Sabat, 2006). The CCBC may be used in the clinical setting to promote person-centered care (Savundranayagam,

2014) by recognizing and supporting PWD to create and maintain their identity in the communication that they use. Future studies might examine how CCBs change over the progression of the disease and how they might differ across other types of dementia. In addition, future interventions should train clinicians to observe and practice these CCBs to improve quality of life and life satisfaction and for both PWDs and their caregivers.

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