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African American Dementia Caregiver Problem Inventory: Descriptive Analysis and Initial Psychometric Evaluation

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Objectives: The primary objectives of the present study were: (a) to develop the African American Dementia Caregiver Problem Inventory (DCPI-A) that assesses the types and frequency of problems reported by African American dementia caregivers seeking cognitive–behavioral intervention, (b) to evaluate the intercoder reliability of the DCPI-A, and (c) to measure the perceived severity of common problems reported by this caregiver population. ***Method:*** The development of the DCPI-A was divided into 3 major steps: (a) creating an initial sample pool of caregiver problems derived from 2 parent randomized clinical trials, (b) formulating a preliminary version of the DCPI-A, and (c) finalizing the development of the DCPI-A that includes 20 problem categories with explicit coding rules, definitions, and illustrative examples. ***Results:*** The most commonly reported caregiver problems fell into 5 major categories: (a) communication problems with care recipients, family members, and/or significant others, (b) problems with socialization, recreation, and personal enhancement time; (c) problems with physical health and health maintenance, (d) problems in managing care recipients' activities of daily living; and (e) problems with care recipients' difficult behaviors. Intercoder reliability was moderately high for both percent agreement and Cronbach's kappa. A similar positive pattern of results was obtained for the analysis of coder drift. ***Conclusions:*** The descriptive analysis of the types and frequency of problems of African American dementia caregivers coupled with the outcomes of the psychometric evaluation bode well for the adoption of the DCPI-A in clinical settings.

Impact and Implications

Limited knowledge exists about the specific problems confronted by distressed African American dementia family caregivers. The development of the African American Dementia Caregiver Problem Inventory (DCPI-A) represents an important first step in identifying the specific types and frequency of problems reported by African American dementia caregivers seeking cognitive–behavioral intervention. The most common problems reported by African American dementia caregivers in cognitive–behavioral treatment were as follows: (a) difficulties in communicating with family members, dementia care recipients, and health professionals, (b) limited socialization, (c) challenges with health maintenance, (d) limited self-care opportunities, (e) conflict in negotiating care recipients' activities of daily living, and (f) management of difficult behaviors of the care recipient. The DCPI-A holds considerable promise as a clinical tool for guiding formal assessment and in turn, the development of problem-specific, culturally concordant interventions for this underserved population.

Keywords: African American, Alzheimer's disease, burden, caregiving, problem inventory

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Introduction

Recent epidemiological studies have estimated 5.2 million adults in the United States have Alzheimer's disease or other closely related forms of progressive dementia. The number of individuals over age 65 with dementia is expected to more than double over the next three decades, reaching 13.8 million by 2050 (Alzheimer's Association, 2015).

Although dementia affects all sectors of the U.S. population, the distribution of this syndrome of disorders is spread unevenly across racial and ethnic groups. The prevalence, incidence, and cumulative risk rates of Alzheimer's and related dementias are substantially higher in African Americans than in non-Hispanic Whites. The clinical etiologies of progressive dementia differ between African Americans and non-Hispanic Whites, with vascular dementia accounting for a significantly larger proportion of cases among African Americans (Alzheimer's Association, 2010; Froehlich, Bogardus, & Inouye, 2001).

Most (80%) adults with dementia receive ongoing care in the home from family caregivers (CGs) and significant others. In 2014, approximately 15 million family members and other unpaid CGs provided an estimated 17.9 billion hours of care to people with dementia, a contribution valued at more than $226 billion (Alzheimer's Association, 2015). CGs perform a variety of tasks for family members with dementia, such as dressing and bathing, as well as providing transportation and managing difficult behaviors.

Although caregiving demands are high across all races and ethnicities, African American CGs provide a greater number of hours of care, engage in more demanding caregiving tasks, such as bathing and lifting, and are more likely to report inadequate access to support services (Froehlich, Bogardus, & Inouye, 2001; Sörensen & Pinquart, 2005). Furthermore, African American CGs spend a disproportionately higher percentage of their monthly income on dementia care recipients' (CRs) needs than non-Hispanic White CGs (National Alliance for Caregiving & American Association of Retired Persons, 2009).

As a consequence of multiple demands, caring for a person with dementia is often very difficult, and many family CGs experience high levels of emotional distress and depression. Previous studies have reported prevalence rates of clinically significant depression in dementia CGs ranging from 27% to 50% (Ory, Yee, Tennstedt, & Schulz, 2000). Caregiving also may exert a negative effect on physical health. For example, CGs of spouses with dementia are more likely than married noncaregivers to have lower immune functioning, new hypertension, and new coronary heart disease (Alzheimer's Association, 2015).

Although several studies have found African American CGs endorsed higher levels of reward from their caregiving experiences and concomitantly lower levels of depression than non-Hispanic White CGs, heightened positive appraisals of the CG experience and lower perceptions of depression do not imply the absence of other significant problems, such as compromised physical health (Knight & Sayegh, 2010; Pinquart & Sörensen, 2005; Roff et al., 2004; Sörensen & Pinquart, 2005). Previous research has shown African American CGs reported poorer perceived health and higher numbers of physical symptoms than their non-Hispanic White counterparts (Haley et al., 2004; Pinquart & Sorenson, 2005; Sörensen & Pinquart, 2005). In addition, African American CGs are more likely to engage in unhealthy behaviors, such as poor eating habits, alcohol consumption, and lack of exercise than their non-Hispanic White counterparts, which may contribute to increased risks of cardiovascular disorders and hypertension in African American dementia CGs (Haley et al., 2004; Hargrave, 2006).

Despite mounting evidence of racial and ethnic differences in emotional functioning and health status among dementia CGs, a significant gap exists in our knowledge about the specific problems confronted by African American CGs. Several inventories have been developed to assess CG depression and burden (Fredman, Daly, & Lazur, 1995; Hébert, Bravo, & Préville, 2000; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991), as well as dementia CRs' problems with memory, difficult behaviors, and depression (Alexopoulos, Abrams, Young, & Shamoian, 1988; Cummings et al., 1994; Teri et al., 1992). However, these instruments do not provide specific information about the identified problems of dementia CGs. This is especially important because African American CGs have reported more unmet needs related to support and access to services compared with non-Hispanic Whites (Hinrichsen & Ramirez, 1992). This shortcoming, coupled with the absence of a systematic method for identifying and evaluating the specific concerns of African American CGs, has thwarted efforts in developing effective assessment methods and, in turn problem-specific, culturally concordant interventions for this population. Given the important role of sociocultural factors in the assessment of African American dementia CGs' daily functioning, it is imperative to develop problem-specific assessment methods to address this underserved population's emotional and physical health care needs.

The primary objectives of this Florida State University IRB-approved study were: (a) to develop an inventory (i.e., African American Dementia Caregiver Problem Inventory; DCPI-A) assessing the types and frequency of problems reported by African American CGs seeking cognitive–behavioral intervention, (b) to evaluate the reliability of the DCPI-A across coders and over time, and (c) to assess the perceived severity of common problems reported by this CG population.

Method

Data Sources of African American Dementia CG Problems

The sample pool of dementia CG problems used in developing the DCPI-A was derived from two parent randomized clinical trials, the African American Alzheimer's Caregiver Training and Support project (ACTS; Forducey, Glueckauf, Bergquist, Maheu, & Yutsis, 2012; Glueckauf et al., 2012; Kazmer, Glueckauf, Ma, & Burnett, 2013) and Alzheimer's Rural Care Healthline (ARCH) (Glueckauf et al., 2005, 2007). ACTS project participants were African American dementia CGs from Tallahassee and Jacksonville Florida and their surrounding areas. ACTS participants were recruited from the outpatient rosters of the Tallahassee Memorial Healthcare and Mayo Clinic Florida Memory Disorder Clinics, African American churches, and senior centers, as well as through local and regional media and self-referral. ARCH participants were recruited using outreach strategies identical to those of ACTS. However, ARCH CGs included both African Americans and Whites residing in rural Northern and Central Florida. Note that only the identified problems of African American ARCH participants receiving telephone-based CBT were used in the current study.

ACTS Project: Research design and intervention protocol. One hundred nine African American ACTS participants were randomly assigned to telephone-based cognitive–behavioral therapy (CBT; *n* = 56) or in-person CBT (*n* = 53) and completed all phases of the randomized trial. One hundred CGs were women and 9 were men. CGs' mean age, years of education, and months of caregiving were 58.97 (*SD* = 9.80), 14.64 (*SD* = 2.20), and 43.83 (*SD* = 31.51), respectively. Their relationships to the CRs were as follows: wives (*n* = 23), husband (*n* = 2), daughters (*n* = 66), sons (*n* = 2), other relatives (*n* = 15), and friends (*n* = 1). Seventy-three CRs were women and 36 were men. CRs' mean age and years of education were 80.82 (*SD* = 8.77) and 11.42 (*SD* = 4.01). The dementia diagnoses of CRs were: (a) probable Alzheimer's disease (*n* = 60), (b) dementia with Lewy bodies (*n* = 5), vascular dementia (*n* = 9), other dementias (*n* = 4), dementia of unknown etiology (*n* = 16), and combinations of dementia types (e.g., possible Alzheimer's and vascular dementia (*n* = 15).

The overall structure and content of the CBT program was the same for both the telephone and in-person conditions. However, telephone-based CBT took place at CGs' homes mediated by a remote teleconferencing system, whereas in-person CBT was performed at university-based conference rooms or in private, soundproof rooms at public libraries.

The ACTS CBT intervention consisted of 12 one-hour weekly sessions. Seven sessions were delivered in a small group format (i.e., 3 CGs and 1 counselor) and five sessions were individual CG goal-setting and implementation sessions. A detailed description of the ACTS project's intervention protocol can be found in Glueckauf et al. (2012).

ARCH Project: Research design and intervention protocol. A total of 56 rural dementia CGs were assigned randomly to telephone-based CBT (*n* = 37) or an education and support control condition (*n* = 19) and completed all phases of the ARCH randomized trial. Twenty-four CGs were African Americans and 32 CGs were non-Hispanic Whites.

Of the 24 African American CGs, 18 received telephone-based CBT and 6 were in the control condition. As mentioned above, only the identified problems of the 18 African American CBT participants were used in the development of the DCPI-A. Fourteen African American CBT participants were women and 4 were men. CGs' mean age, years of education, and months of caregiving were 56.82 (*SD* = 11.12), 13.65 (*SD* = 3.02), and 11.35 (*SD* = 11.80), respectively. Their relationships to the CRs with dementia were as follows: daughters (*n* = 10), husbands (*n* = 3), sons (*n* = 1), other relatives (*n* = 3), and friends (*n* = 1). Sixteen CRs were women and 2 were men. CRs' mean age and years of education were 81.38 (*SD* = 8.63) and 10.69 (*SD* = 5.36). The dementia diagnoses of CRs were: (a) probable Alzheimer's disease (*n* = 10), vascular dementia (*n* = 5), (b) dementia with Lewy bodies (*n* = 1), and dementia of unknown etiology (*n* = 2).

The ARCH CBT intervention protocol was identical to that of the ACTS project (see Glueckauf et al., 2007 for a description of the ARCH CBT program). Education and support control participants received written educational materials and were encouraged to contact ARCH staff using a toll-free telephone number if they had questions related to dementia care. Additionally, all control participants were given the option of taking the telephoned-based CBT intervention after the second administration of the dependent measures.

CG inclusion and exclusion criteria. African American CGs enrolled in the ACTS project: (a) were the primary caregiver of a relative or significant other with diagnosed dementia 60 years of age or older, (b) spent a minimum of 6 hours per week providing direct care to the person with progressive dementia, (c) reported specific caregiving problems amenable to short-term CBT, (d) reported no difficulties in hearing over the telephone, (e) did not have a terminal illness, and (f) scored 10 or higher on the Patient Health Questionaire-9 depression module (PHQ-9; Kroenke, Spitzer, & Williams, 2001).

In addition, dementia CRs of the ACTS project were required to have two dependencies in instrumental activities of daily living (IADLs; Lawton, Moss, Fulcomer, & Kleban, 1982). CGs in the ACTS project were excluded if they (a) met criteria for psychotic disorder on the M.I.N.I. 5.0.0 (Sheehan & Lecrubier, 2006), (b) met criteria for moderate or high suicide risk on the M.I.N.I 5.0.0, or (c) had a terminal medical diagnosis. Inclusion and exclusion criteria for CGs in the ARCH project were the same except the inclusion criterion of a PHQ-9 score of 10 or higher was not used in ARCH. However, ARCH participants were required to report significant problems with emotional distress related to caregiving or self-care management to be eligible for the study.

Development of the DCPI-A

The development of the DCPI-A was divided into three major steps. First, a large item pool was created using caregiver problems identified by African American participants from the ACTS and ARCH projects. Second, a preliminary version of the DCPI-A was developed using pilot data from the ACTS project. Third, the DCPI-A underwent major modifications, expanding the number of problem categories, refining category definitions and providing multiple examples of each problem category, and included problem data from both the ACTS and ARCH projects.

Step 1: Creation of item pool. A total of 457 caregiver-identified problems across the ACTS (*n* = 420) and ARCH (*n* = 37) projects formed the original item pool. These problems included a wide variety of caregiving, self-care and personal CG concerns (e.g., CG socialization, recreational and work-related problems). Following problem identification, CGs and their counselors collaboratively developed intervention goals and specific treatment strategies to ameliorate each identified problem. Counselors also recorded progress notes on a weekly basis describing the status of problem resolution, factors that hampered or facilitated goal attainment, and any modifications in treatment strategies. All progress notes and documentation on CGs' goals and strategies were transferred to an Excel spreadsheet for subsequent review and analysis.

Step 2: Adoption of a preliminary coding scheme. Content analysis of pilot data from the ACTS project was performed to guide the initial development of the DCPI-A. Two research assistants sorted 30 CG problem statements into problem categories and were instructed subsequently to achieve consensus on the number and wording of category labels. Five major problem categories emerged from the sorting process and formed the initial version of the DCPI-A. The five categories included: (a) problems dealing with dementia CR's activities of daily living (ADLs/IADLs), (b) problems dealing with CR's difficult behaviors and emotional functioning, (c) CG's anxiety, stress, and depression, (d) CG's self-care needs, and (e) CG's communication problems with the CR, family members and others in the community. Three additional categories were created to ensure the DCPI-A was exhaustive and to provide a vehicle for further development of the instrument: (f) CG's other concerns, (g) unable to code in a single problem category, and (h) unable to code because of ambiguity of the problem statement.

Following the creation of the eight-category version of the DCPI-A, the second author and two research assistants formulated an initial set of coding instructions and category definitions, and listed specific examples of problem categories a-e.

Step 3: Further development and evaluation of the DCPI-A. A new team of three coders was formed to obtain feedback on problem category descriptions and coding rules and subsequently provided data on the reliability of the final version of the DCPI-A. The first phase of this developmental process focused on expanding the number of categories to accommodate a wide range of caregiving problems, eliminating definitional ambiguities, and identifying representative examples of the types of problems associated with specific categories. Ten major iterations to the DCPI-A were made over 14 months. The number of problem categories expanded from 8 in the preliminary version (see Step 2 above) to 20 in the final DCPI-A. The second phase concentrated on the evaluation of intercoder agreement and coder drift using the final version of the DCPI-A.

Three key procedural components were embedded in Step 3 of the development and psychometric evaluation of the DCPI-A: (a) coder training, (b) item screening, and (c) problem coding procedures.

Coder training. The new team of coders included two undergraduate students and one postbaccalaureate research assistant. After reviewing pertinent literature on dementia characteristics and caregiving challenges, coders received an overview of the initial development of the DCPI-A and specific instructions in the use of the Qualtrics-based coding system (Qualtrics, 2016). Four 3-hr coder training sessions were conducted over a period of three months. During each training session team members were asked to code individually a small set of CG problems (i.e., 8 to 10 problems) to evaluate their understanding of the following dimensions of the DCPI-A: category definitions, category examples, and specific category coding rules (e.g., inclusion and exclusionary criteria for each category).

After coding a test set of CG problems, coders compared their category selections, followed by discussion of the specifics elements of each problem that led to the assignment of specific problem categories. Furthermore, coders were asked to address the sources of both agreement and disagreement in category endorsements and to develop consensus on coding instructions for subsequent iterations.

Problem screening. Following the final session of coder training, a screening process was implemented to review the problem statements for subsequent coding into DCPI-A categories. This procedure was initiated as a result of coders' reports noting intermittent difficulties in comprehending problem statements written by ACTS and ARCH project counselors. The screening team consisted of two additional members, the second and third authors, who were responsible for reviewing each set of problem items before a scheduled problem coding session. The screening process included selecting the next set of 8 to 10 CG problems and independently rating the clarity of problem statements. Only those problems with moderately low wording ambiguity were included in subsequent coding process. If consensus between screeners was not achieved on a particular problem statement, it was excluded from the category coding process.

Problem coding. Coders participated in a total of 12 problem coding sessions after completion of their initial training program. The first seven of these sessions were devoted to the development of the DCPI-A. The primary goal of the remaining five sessions was to evaluate the reliability (i.e., intercoder agreement and coder drift) of the final version of the DCPI-A. The primary differences between the first set of seven and the second set of five coding sessions was the former involved coder analysis and justification of areas of agreement and disagreement on the selection of problem categories, whereas the latter contained very limited discussion among coders to ensure the integrity of the reliability (i.e., intercoder agreement) measurement process.

Across all 12 coding sessions, coders were instructed to perform independently online CG problem categorizations using Qualtrics survey software and to follow the same procedure across all coding sessions. First, they were asked to read each CG's problem statement and review pertinent DCPI-A categories and coding rules. Second, they were encouraged to identify the DCPI-A category in which the CG problem best fit. If difficulties emerged in coding the problem into a single category, coders were instructed to use supplemental resources (i.e., CG's written goals and the counselor's progress notes) to facilitate the decision-making process. CGs' goal statements included information about the actions, situational factors and/or resources they felt were needed to resolve their presenting problems. Counselor progress notes documented the specific intervention strategies CGs performed to ameliorate their identified problems.

The final version of the DCPI-A contained 20 categories with associated problem definitions, illustrative problem examples, and coding rules (see list of problem categories in Table 1). The first 17 categories represented the primary content domains of caregiv-

Table 1
DCPI-A Coding Categories

1. CG Emotional and Mental Health Problems
2. CG Problems with Socialization, Recreation, Community Participation, and Personal Enhancement Time
3. CG Spiritual/Religious Concerns or Problems
4. CG Health Care and Health Maintenance Problems
5. CG Communication Problems with their CR, Family Members and/or Significant Others in the Community
6. Problems Dealing with CR's ADLs and IADLs
7. CG Problems with CR Difficult Behaviors
8. CR Problems with Socialization, Recreation, and Community Involvement
9. CR Spiritual/Religious Concerns or Problems
10. CR Medical, Health, and Emotional Problems
11. CG Problems with Identifying Resources and/or Obtaining Information for CRs' Physical and Psychosocial Needs
12. Problems with CR Assisted Care (Paid or Volunteer)
13. Problems with Finances for CR's Physical and Psychosocial Needs
14. Problems with CR's Physical Environment (Home or Care Facilities)
15. CG Work-Related Problems (Not Caregiving Related)
16. CG Financial Problems (Not Caregiving Related)
17. CG Problems with General Life Skills (Not Caregiving Related)
18. The "CG's Other Concerns" Subcategory Includes the Problems that Do Not Fit into the First 17 Categories
19. Unable to Code in a Single Problem Category
20. Unable to Code Because of Ambiguity of the Problem

Note. CG = caregiver; CR = care recipient; ADLs = activities of daily living; IADLs = instrumental activities of daily living. "Unable to code" category reflects that the last three DCPI-A categories 18, 19, and 20 were collapsed into one category for analysis in the present study.

ing, self-care and other problems (e.g., work-related difficulties) identified by African American dementia caregivers. Three additional categories were employed to code problems that did not fit within the 17 DCPI-A content categories. The latter 3 categories included: Category 18 – CG's Other Concerns, Category 19 – Unable to Code in a Single Problem Category, and Category 20 – Unable to Code Because of Ambiguity of the Problem. For the purposes of the present study, Categories 18–20 were collapsed into one overarching category of uncoded problems.

Problem severity. The Problem Severity Scale (Glueckauf, 2000; Glueckauf et al., 1992), a single-item 6-point rating scale, with 1 = *no problem* and 6 = *a severe problem*, was used to assess caregivers' appraisals of the severity of their identified problems. CGs' mean problem severity scores were calculated for DCPI-A categories with four or more observations (see Table 2) to ensure a reasonable estimate of the mean.

The Problem Severity Scale was administered to CGs after each of the five ACTS and ARCH individual sessions and the last group session, beginning at Session 7 and ending one week after the last session of the program (i.e., group Session 12). Note that only baseline severity ratings collected during individual Session 7 were used to assess problem difficulty, thus controlling for the effects of the goal implementation process. In previous family caregiving studies, Glueckauf et al. (1992) reported moderately high levels of interrater reliability and concurrent validity for the Problem Severity Scale.

Data Analytic Strategy

Two major approaches were used in analyzing the findings of the present study: (a) descriptive statistics were calculated to assess the frequency of problem category endorsements, proportion of total problem endorsements, and the mean problem severity of commonly endorsed problem categories (see Table 2) and (b) the reliability of the DCPI-A was assessed in two ways: (a) overall intercoder agreement and (b) coder drift (i.e., intercoder agreement across time).

Descriptive analytic approach. A total of 109 problems was used to calculate the frequency and proportion of problem category endorsements. The procedural path followed to obtain this final sample of 109 problems is shown in Figure 1. First, the initial CG problem sample pool consisted of 457 problems. Thirty problems were used in creating the initial version of the DCPI-A. Seventy-four problems were used across the four sessions of coder training and 68 problems were excluded during the screening process. Next, 154 problems were used across coding Sessions 1 to 7 in developing formative versions of the DCPI-A, leaving 131 problems to perform the reliability analysis across coding Sessions 8 to 12 using the final version of the DCPI-A.

To further bolster the integrity of the descriptive analytic approach, two inclusion criteria were instituted. First, for the frequency and proportion of category endorsements, only those problems on which 2 of 3 coders made the same categorical judgment were entered into the descriptive analysis. Second, for the analysis of problem severity, problem categories with fewer than four observations were excluded from the problem severity analysis. Thus, a final sample size of 109 was used to calculate the frequency and proportion of problem DCPI-A category endorsements and 104 items were used to calculate mean severity of problem categories (see Table 2).

Reliability analysis: Overall intercoder agreement and coder drift. As noted above, 131 problems were used to assess overall intercoder agreement and coder drift. In performing the reliability analyses, coders were divided into three pairs: Coder 1/Coder 2,

Table 2
DCPI-A Categories Frequency of Endorsements, Proportion of Total Responses, Problem Severity Scores, and Standard Deviations

Category	Number of endorsements	% of endorsements	Problem severity score	Standard deviation
1. CG Emotional and Mental Health Problems	8	7.3	4.29	1.67
2. CG Problems with Socialization, Recreation, Community Participation, and Personal Enhancement Time	18	16.5	4.75	1.63
3. CG Spiritual/Religious Concerns or Problems	4	3.7	5.00	2.50
4. CG Health Care and Health Maintenance Problems	15	13.8	5.00	1.40
5. CG Communication Problems with their CR, Family Members and/or Significant Others in the Community	22	20.2	4.48	1.24
6. Problems Dealing with CR's ADLs and IADLs	13	11.9	5.08	1.60
7. CG Problems with CR Difficult Behaviors	12	11.0	4.25	.75
8. CR problems with Socialization, Recreation, and Community Involvement	2	1.8	—	—
9. CR Spiritual/Religious Concerns or Problems	0	0	—	—
10. CR Medical, Health, and Emotional Problems	6	5.5	4.60	1.94
11. CG Problems with Identifying Resources and/or Obtaining Information for CRs' Physical and Psychosocial Needs	6	5.5	5.20	2.25
12. Problems with CR Assisted Care (Paid or Volunteer)	0	0	—[b]	—
13. Problems with Finances for CR's Physical and Psychosocial Needs	0	0	—	—
14. Problems with CR's Physical Environment (Home or Care Facilities)	1	.9	—	—
15. CG Work-Related Problems (Not Caregiving Related)	1	.9	—	—
16. CG Financial Problems (Not Caregiving Related)	0	0	—	—
17. CG Problems with General Life Skills (Not Caregiving Related)	1	.9	—	—
18. Unable to Code[a]	0	0	—	—
Total	109	100	—	—

Note. CG = caregiver; CR = care recipient; ADLs = activities of daily living; IADLs = instrumental activities of daily living.
[a] "Unable to code" category reflects that the last three DCPI-A categories 18, 19, and 20 were collapsed into one category for analysis in the present study;
[b] Only mean problem severity scores with 4 or more observations were tabulated to enhance the reliability of mean estimates.

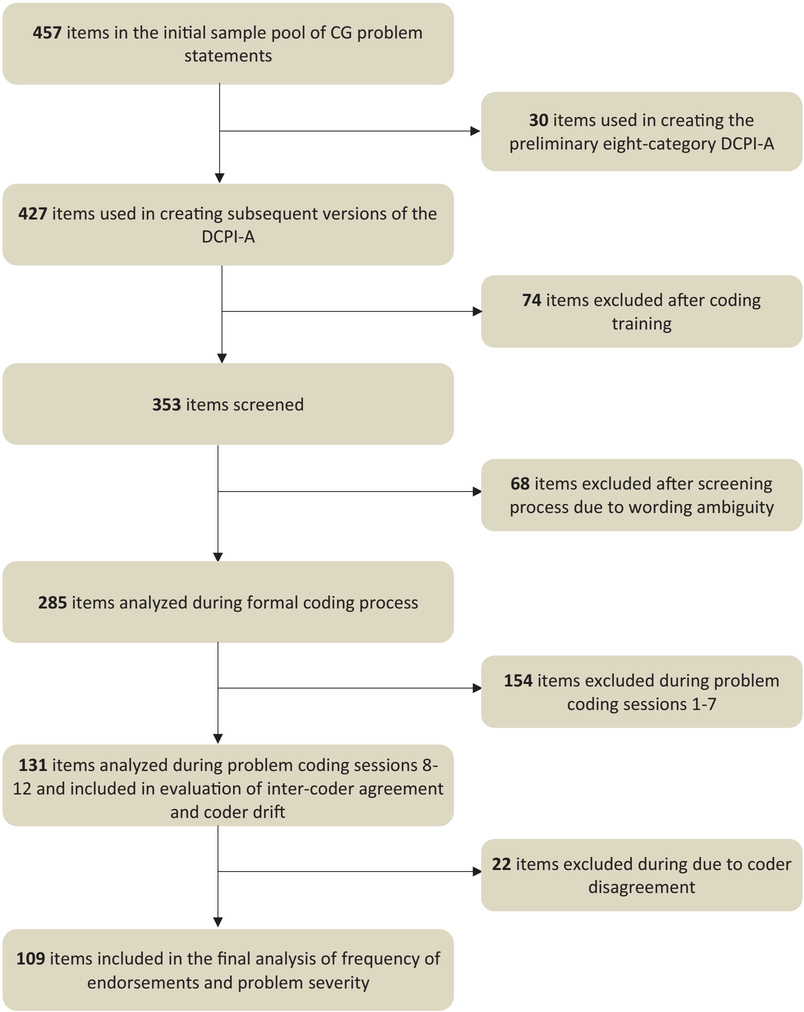

Figure 1. Flowchart outlining the selection process for CG problems included in the DCPI-A descriptive and reliability analyses. See the online article for the color version of this figure.

Coder 1/Coder 3 and Coder 2/Coder 3. If coders agreed in categorizing a specific problem, a numerical value of “1” was assigned to that comparison; if they disagreed on their categorization, “0” was assigned. The reliability analyses were performed on coder data obtained from Sessions 8 to 12. These data were collected over a period of five months with approximately 30 days separating each assessment interval.

Both overall percentage of agreement and percentage of agreement for each of five time periods were calculated by dividing the total number of agreements by the total number of agreements and disagreements and multiplying by 100. An overall kappa and kappa for each of five time periods were also calculated to provide a more conservative reliability estimate.

Results

Descriptive statistics on the frequency and proportion of problem category endorsements, as well as perceived severity of problem categories, will be presented first, followed by the findings of overall intercoder agreement and coder drift analyses. Illustrative examples are provided for problem categories with the highest frequency of endorsements.

Frequency and Proportion of Problem Category Endorsements

The problem categories with the highest percentage of endorsements were: (a) Category 5 - CG Communication Problems with their CR, Family Members and/or Significant Others in the Community; (b) Category 2 – CG problems with Socialization, Recreation, Community Participation, and Personal Enhancement Time; (c) Category 4 – CG Physical Health and Health Maintenance Problems; (d) Category 6 – Problems Dealing with CR’s ADLs and IADLs; and (e) Category 7 – CG Problems with CR Difficult Behaviors (see Table 2). These five categories accounted for 73.4% of total problem endorsements. Of the remaining 13 problem categories, Categories 1, 3, 8, 10, and 11 comprised 23.8% of problem endorsements and Categories 14, 15, and 17 accounted for the remaining 2.8% of problem endorsements. Categories 9, 12, 13, 16, and 18 had no endorsements.

Category 5 – CG communication problems with their CR, family members and/or significant others in the community. Twenty-two of 109 CG problems (20.2%) were coded in Category 5. Problems in this category ranged from CGs' difficulties in verbal transactions with CRs during daily activities to challenges in communicating with family members, health care providers and colleagues at work. The majority of CGs' problems in this category were related to difficulties in communicating effectively with siblings about their caregiving demands and problems associated with self-initiated, aggressive responding with CRs. For example, one CG reported, "I am passive in seeking help from my siblings." A second CG stated, "I am impatient and critical when my dad [CR] is not ready on time."

Category 2 – CG problems with socialization, recreation, community participation, and personal enhancement time. Category 2 was endorsed 18 times and accounted for 16.5% of total items. This category included CG problems related to personal time, such as limited opportunities for socialization and recreation with family, friends, and others, as well as self-care activities (e.g., going to the hairdresser or getting a manicure). All problem statements in this category focused on difficulties participating in social activities outside the home, including volunteer activities and community service opportunities, and CGs' lack of time for engaging in self-care activities. For example, one CG stated, "I need more time to socialize with my friends." Another CG noted, "I don't have enough time to go to the beauty salon."

Category 4 – CG physical health and health maintenance problems. Category 4 was endorsed 15 times, comprising 13.8% of the total number of problems. This category primarily consisted of CGs' problems attending to their own health care needs and engaging in health-promoting activities. A large proportion of these problems focused on missing doctors' appointments, difficulty managing pain, increased fatigue, and poor physical health. CGs noted habit-related difficulties, such as smoking, lack of exercise, and overeating. CGs also reported specific health problems, such as migraine headaches, elevated blood pressure, difficulty sleeping, and noticeable weight gain. For example, one CG stated, "I haven't been exercising or taking care of my health." Another CG reported, "I have difficulty relaxing, which makes my blood pressure high and gives me migraines."

Category 6 – CG problems dealing with CR's ADLs and IADLs. Thirteen of 109 CG problems (11.9%) were coded in Category 6. Problems in this category centered on CGs' difficulties in assisting their CRs with ADLs and IADLs, such as problems managing CRs' incontinence, challenges with CRs' bathing and hygiene, and difficulties helping CRs to perform household chores and to take medications. One CG noted, "Mother gets up without her walker and falls down." A second CG stated, "I feel sad when my husband has trouble dressing himself." Another CG asserted, "My mom doesn't do her household chores that she is capable of doing."

Category 7 – CG problems with CR difficult behaviors. Category 7 was endorsed 12 times and accounted for 11.0% of the total number of problems. CGs reported difficulties in responding effectively to CRs' repetitive statements, aggressive communication, and paranoia. For example, one CG stated, "My husband gets easily frustrated, speaks loudly and orders me to give him attention." A second CG reported, "My mother constantly asks me where I am going." Another CG indicated, "Mom accuses me of taking her stuff or knowing where it is without telling her."

Of the less commonly endorsed categories, Category 1 – CG Emotional and Mental Health Problems, was endorsed 8 times, accounting for 7.3% of total problem endorsements. This category referred to CG problems with their emotional functioning (e.g., anxiety, frustration, sadness, and depression). Category 10 – CR Medical, Health, and Emotional Problems. Category 10 included CG problems about their CR's specific health concerns (e.g., diet, exercise, and bathroom activities) and had 6 endorsements (5.5% of total problems). Category 11 – CG Problems with Identifying Resources and/or Obtaining Information for CR's Physical and Psychosocial Needs had 6 endorsements, comprising 5.5% of all problem endorsements. Category 11 referred to problems, such as difficulties identifying respite care resources and having limited information about the progression and treatment of Alzheimer's disease.

Category 3 – CG Spiritual/Religious Concerns or Problems, had 4 endorsements (3.7% of problem endorsements) included difficulties related to CGs' inability to find time for religious and spiritual activities, as well as the quality of their religious/spiritual life (e.g., concerns about loss of faith and diminished quality of prayer). Category 8 – CR Problems with Socialization, Recreation, and Community Involvement was endorsed twice (1.8% of total problems). This category referred to CR problems with social isolation, lack of recreational outlets, and limited participation in community activities.

The following categories had one endorsement each: Category 14 – Problems with CR's Physical Environment (Home or Care Facilities), Category 15 – CG Work-Related Problems (Not Caregiving Related), and Category 17 – CG Problems with General Life Skills (Not Caregiving Related). The remaining Categories 9, 12, 13, 16, and 18 had no endorsements. Categories 18–20 were collapsed into in Category 18 as an all-inclusive category for problems that were unable to be coded.

Problem severity. Mean problem severity ratings were calculated for all 18 problem content categories. As noted in the Data Analytic section above, only those problem categories with 4 or more endorsements were included in the problem severity analysis (see Table 2). CGs' mean scores ranged from moderate severity to moderately high severity ($M = 4.25$ to 5.2) among Categories 1 through 7, 10, and 11. Categories 11, 6, 3, and 4 had the highest mean problem severity scores (5.20, 5.08, 5.0, and 5.0, respectively), indicating a moderately high appraisal of problem severity. Mean problem severity scores for Categories 1, 2, 5, 7, 8, and 10 fell within a similar range (i.e., 4.29 to 4.75), but were slightly lower in magnitude. Contrary to expectation, a high degree of consistency in mean problem severity ratings was found across categories with 4 or more endorsements.

Overall Intercoder Agreement and Coder Drift

As shown in Figure 2, average coder agreement was moderately high (83%, $\kappa = .81$). Furthermore, considerable stability was shown across the five reliability assessment intervals ranging from 75.00% agreement ($\kappa = .70$) to 94.12% agreement ($\kappa = .93$). In examining the pattern of coder agreement over time, the transition between Sessions 8 and 9 showed the highest decline (i.e., reduc-

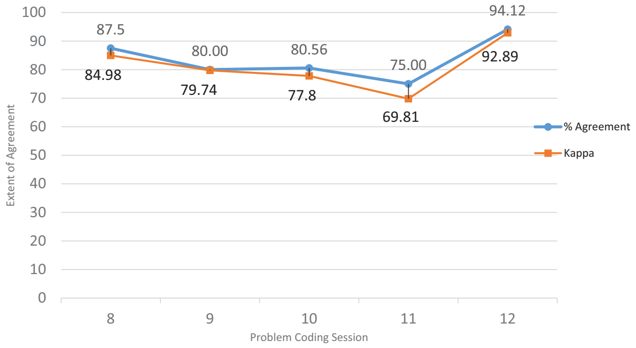

Figure 2. Percentage of agreement and kappa coefficients for problem coding Sessions 8 to 12. See the online article for the color version of this figure.

tion of 8 percentage points). No substantial variation occurred between Sessions 9 and 10, followed by a five-point decline in Session 11. In contrast, a substantial increase in coder agreement was found between Sessions 11 and 12 (i.e., 19 percentage points).

Discussion

The specific objectives of the present study were to assess the types, frequency, and severity of problems endorsed by distressed African American dementia CGs seeking cognitive-behavioral intervention and to conduct a preliminary assessment of the reliability of the DCPI-A across coders and over time. The findings of the descriptive analysis of the types, frequency, and severity of problems will be discussed first, followed by the results of the initial psychometric evaluation of the reliability of the DCPI-A. Last, we will address the limitations of the study and future directions for research on the DCPI-A.

Descriptive Analysis of Dementia CG Problems: Types, Frequency, and Severity

Although previous research (Belle et al., 2006; Burgio et al., 2003; Dang et al., 2008; Gitlin et al., 2003; Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Hilgeman et al., 2009; Sistler & Washington, 1999) has reported positive global psychosocial outcomes (e.g., decreased burden, better anger control, and greater self-efficacy in providing assistance with IADLs) across a wide range of cognitive–behavioral interventions in African American samples, none of these studies has identified the specific types of problems African American dementia CGs sought to ameliorate. The paucity of such information has limited the development and evaluation of tailored, cognitive–behavioral interventions for this underserved population, particularly evaluating the effects of matching specific treatment interventions to specific types of African American CG problems.

As noted previously, the most commonly reported problems fell into five major categories: (a) communication difficulties with CRs, family members, and significant others, (b) limitations in time available for socialization and recreation, (c) CG health and health maintenance problems, (d) CG challenges in managing CR's ADLs and IADLs, and (e) CG problems in responding effectively to CR difficult behaviors. These five categories accounted for 73.4% of total problem endorsements.

Turning to the most frequently endorsed category (i.e., Category 5 – CG Communication Problems with their CR, Family Members and/or Significant Others in the Community), most problem statements in this category focused on communication difficulties in obtaining caregiving assistance for the CR from other family members, specifically the CG's siblings. This finding underscores the importance of identifying the specific communication problems of African American CGs. Previous research (e.g., Lehman, n.d.; Napoles, Chadiha, Eversley, & Moreno-John, 2010) reported communication barriers between African American CGs and CRs and between African American CGs and their health providers. However, none of these studies specified what appears to be the predominant concern of such CGs, namely, not being able to communicate effectively with siblings about the need for assistance in providing care for their parents with dementia. Buttressing the reliability of this finding, several studies have found African American CGs reported a significantly higher need for dementia support services and concomitant receipt of fewer services from family members compared with their non-Hispanic White counterparts (Fox, Hinton, & Levkoff, 1999; Hargrave, 2006; Sörensen & Pinquart, 2005). Furthermore, African American CGs reported significantly more family disagreements than non-Hispanic White CGs (Dilworth-Anderson, Williams, & Gibson, 2002).

The four categories that composed the remaining 53.2% of frequently endorsed problems were divided among CGs' self-care problems, CGs' health problems, CGs' challenges in managing their CRs' ADLs/IADLs and CRs' difficult behaviors (see Table 2). The moderately high percentage of endorsements among these four problem categories merits attention. In previous comparison studies, African American CGs reported significantly lower levels of social isolation and caregiving challenges associated with ADLs/IADLs than those of non-Hispanic White CGs (Fredman, Daly, & Lazur, 1995; Gonzalez, 1997; Hinrichsen & Ramirez, 1992; National Alliance for Caregiving & American Association of Retired Persons, 2009). This commonly reported pattern of findings brings into question the generalizability of previous caregiving research to the clinical context. Unlike participants in general health survey studies and those in intervention studies without inclusionary criteria for marked psychological distress (e.g., Belle et al., 2006; National Alliance for Caregiving & American Association of Retired Persons, 2009; Schulz et al., 2003), African American CGs seeking depression-reduction interventions may be more likely to report problems associated with restrictions of social outlets, health problems, and management of their CRs' ADL/IADLs and difficult behaviors.

Several problem categories (3, 8, 9, and 10–17) had relatively low or zero endorsements (see Table 2). Previous research has identified cultural justifications for caregiving, including perceptions of "duty" embedded in the religious or spiritual beliefs of African American CGs (Brodaty & Donkin, 2009; Dilworth-Anderson et al., 2005). Low endorsements among Categories 8, 12, 13, and 14 may have been attributable to family expectations and perceptions of obligation to take care of loved ones as a form of "reciprocity" (Nkongho & Archbold, 1995; Sterritt & Pokorny, 1998; Young & Kahana, 1995). Consistent with this notion, facilitating the CR's socialization, recreational time, and community involvement may be viewed as standard and integral parts of

African American CGs' daily routines and not as distinct events adding to a preexisting array of caregiving stressors. Low endorsements of problems with CR's physical environment and finances for CR's physical and psychosocial needs also may be ascribed to African American CGs' normative perceptions of the need for structural accommodations and increased financial obligation in caring for a loved one with dementia in the home setting (Kosloski, Montgomery, & Karner, 1999; Morycz, Malloy, Bozich, & Martz, 1987). In addition, low endorsements of CG and CR religious concerns (e.g., loss of faith or difficulties attending religious services) may reflect African American religious values, such as acceptance of trials and tribulations as God's will and/or as God's way of strengthening their faith (Dilworth-Anderson et al., 2002; Miltiades & Pruchno, 2002; Napoles, Chadiha, Eversley, & Moreno-John, 2010; Picot, Debanne, Namazi, & Wykle, 1997). Moreover, only a few CGs reported substantial difficulties in obtaining clergy support in bringing their CRs' to religious services or in finding time to attend religious events.

Last, CG work-related problems (Category 15) and CG problems with general life skills (Category 17) also received a limited number of endorsements. This finding may have been attributable to the coding rules associated with these two categories. The coding rules for both these problem categories stipulated CGs' problems at work and with general life skills could not be linked to caregiving-related stressors, thus limiting the number of potential endorsements. Problems with CR assisted care (paid or volunteer) were not reported in the DCPI-A analysis. Similar to Categories 15 and 17, this finding may have been related to the coding specifications of this problem category. Communication problems with staff at nursing homes, adult daycare, and/or family members providing attendant care in the home were coded in Category 5 (i.e., CG Communication Problems with their CR, Family Members and/or Significant Others in the Community). Significant others in the community included both formal and informal health care providers. Thus, zero endorsement of problems with CR's assisted care may have been a function of the DCPI-A decision rules favoring coding of core interpersonal process difficulties (i.e., communication problems) above generic content of the problem (i.e., assisted care).

Turning to the analysis of problem severity, an unanticipated homogeneous pattern of mean severity ratings of problem categories was found. Two possible explanations for this pattern of results are proposed. First, CGs in the ACTS and ARCH cognitive–behavioral interventions (i.e., sample pools for the present study) were asked to prioritize their caregiving and self-care problems and to select the top two or three on which they chose to work. This procedure may have led to the selection of the most demanding and stressful problems in the goal-setting component of the cognitive–behavioral intervention and thus, may have accounted for negative skew in the variation of baseline severity ratings (i.e., moderately high mean severity ratings across all problems).

Second, a one-item problem severity scale was used to assess baseline severity of CGs' identified concerns. Although this scale has shown good test–retest reliability and concurrent validity in previous studies (e.g., Glueckauf, 2000), it may have been less sensitive in detecting variations in problem severity than a multiple-item, behaviorally anchored questionnaire, particularly at the moderate to high end of the rating continuum.

Initial Evaluation of the Reliability of the DCPI-A

The results of the overall intercoder agreement and coder drift analyses were promising. Overall intercoder agreement of the DCPI-A was in the highly acceptable range for both percent agreement and Cronbach's kappa. A similar positive pattern of results was obtained for the analysis of coder drift. Although variations in intercoder agreement occurred across the five assessment intervals, these perturbations were relatively small, particularly in light of the complexity of the category coding task. Note, however, the outcomes of the intercoder agreement and coder drift analyses may have been enhanced by the incorporation of a screening procedure used to eliminate a priori problem statements with ambiguous wording. Nonetheless, the positive findings of these initial psychometric analyses bode well for the use of the DCPI-A in categorizing African American CGs in the clinical context.

Limitations and Future Directions for Research

The primary limitations of the present study were small sample size of CG-identified problems and reliance on African American participants seeking cognitive–behavioral intervention. The number of problems used to calculate the frequency and percentage of DCPI-A category endorsements was 109; a subset of 104 problems was used to generate the mean severity of problem categories. Such sample size restrictions may have reduced the reliability of percentages of problems reported across DCPI-A categories and the mean ratings of problem severity.

Next, the decision to focus on African American dementia CGs seeking intervention for moderate depression and caring for CRs with a minimum two IADL dependences may have constrained the pattern of problem endorsements to the sector of the population in distress. As a consequence, this sampling approach may have reduced the generalizability of the DCPI-A. Thus, this instrument should not be used in assessing the concerns of new or prospective CGs seeking information about future caregiving needs or for those CGs reporting only limited caregiving challenges.

The primary strength of the DCPI-A is in guiding clinical assessment of distressed African American CGs of older adults with dementia. This inventory provides a quick and easy-to-use framework for identifying the specific concerns of CGs prior to the onset of cognitive–behavioral intervention, particularly caregiving and self-care difficulties characterized by ineffective, repetitive behavioral patterns and conflicts about the importance of self-care.

Two major directions for future research on the DCPI-A are offered. First, we plan to replicate the current study with larger samples of African American dementia CGs undergoing cognitive–behavioral intervention to validate the findings. These investigations will provide important data on the comparability between the original and follow-up estimates of DCPI-A problem category percentages and problem severity ratings. They also will provide an evaluation of the stability of the overall coder agreement and coder drift reliability coefficients obtained in the present study. Further research is also needed to assess the generalizability of the current findings across different racial groups and ethnicities.

Second, we plan to develop a dementia caregiver strategies inventory, a companion to the DCPI-A, that categorizes the types of strategies used in cognitive–behavioral intervention to ameliorate the problems of African American dementia CGs. Having such an inventory will facilitate much needed research assessing the outcomes of matching specific categories of CG problems to specific cognitive–behavioral intervention strategies.

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