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Resistiveness to Care during Assistance with Activities of Daily Living in Non-institutionalized Persons with Dementia: Associations with Informal Caregivers' Stress and Well-being

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Abstract

Objectives—Behavior problems that co-occur during assistance with Activities of Daily Living (Resistiveness to Care; RTC) are considered challenging, but are mostly studied in institutions with implications for patients and formal caregivers. RTC is related to, but independent from agitation, and detection of RTC may be left out of common assessments of persons with dementia in studies of informal caregiving (e.g. global assessments of dementia behavioral symptoms, standard assessments of ADL function). This study examines how RTC (frequency and caregivers' stress appraisals of RTC) are related to caregivers' well-being.

Method—234 caregivers of people with dementia reported care receivers' ADL impairment (eating, bathing, dressing), RTC frequency (of eating, bathing dressing), and their stress appraisals of these behaviors (RTC appraisals). Caregivers also self-reported their role overload, role captivity, and depressive symptoms. Hierarchical linear regression models included independent variables (demographics, ADL impairment, RTC frequency, RTC appraisals) with three separate dependent variables (overload, captivity, depressive symptoms).

Results—Two-thirds of informal caregivers reported RTC. Care recipients' ADL impairment was associated with caregiver outcomes, but only before RTC was entered into the models. RTC frequency significantly predicted caregivers' overload, captivity, and depression. RTC appraisals predicted overload and captivity.

Conclusion—RTC is common in persons with dementia residing at home, and RTC has more negative association with informal caregivers' well-being than assistance with ADL. Adding RTC frequency and appraisal items to standard ADL measures may better estimate caregiver needs and risk, and identify modifiable environmental features by assessing behavioral symptoms in context.

Introduction

In addition to the hallmark symptom of memory loss, Alzheimer's disease and related dementias are characterized by difficulties performing activities of daily living (ADL) as

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well as the presence of many behavioral and psychological symptoms of dementia (BPSD). In formal care settings, the construct of Resistiveness to Care (RTC) is becoming more recognized, as research has identified that BPSD (e.g. agitation) is common *within the specific context* of assistance with activities of daily living. In other words, staff's assistance with care needs (e.g. eating, bathing, and dressing the person with dementia) is often accompanied by resistive behaviors. In studies of informal caregiving at home, it is common to assess ADL impairment and/or general BPSD, but researchers usually view these as separate and independent (although related) constructs. In the current study we first review the associations of ADL impairment and BPSD with stress and well-being in informal caregivers. We then consider BPSD within the context of ADL care, or Resistiveness to Care. The purpose of this paper is to address RTC in *informal* care settings, and to examine associations between RTC and the stress and well-being of informal caregivers.

Activities of Daily Living (ADL)

Ability to perform ADL is commonly assessed in persons with dementia by determining the amount of assistance that they need on specific daily tasks. Personal (sometimes called Basic) Activities of Daily Living (PADL, BADL, or ADL; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963) include the need for assistance with self-care activities such as bathing, eating, and dressing. Researchers of dementia often include these measures of ADL for descriptive purposes, for example, to characterize the general level of functioning in the sample, or they include ADL as a measure of objective burden or a kind of primary objective stressor for caregivers (see Stress Process Model, Pearlin, Mullan, Semple, & Skaff, 1990). Caregivers of people with little need for assistance with ADL, for example, may be viewed as having less objective burden or less exposure to primary objective stressors than those caregivers who need to assist a patient with more daily activities.

Behavioral and Psychological Symptoms of Dementia (BPSD)

Behavioral and Psychological Symptoms of Dementia (BPSD), which are also commonly assessed in dementia research, include behaviors such as wandering, agitation, aggression, restlessness, and disturbed mood. BPSD research concludes that these behaviors are caused by both neurological and contextual factors (Moniz-Cook, Stokes, & Agar, 2003; Stokes, 2000; Volicer & Hurley, 2003). Aggression, for example, may increase in people with dementia due to their reduction in acetylcholine in the brain (Wynn & Cummings, 2003) -- a neurological factor -- while aggressive episodes have been said to increase in confusing or frustrating social environments -- a contextual factor (Kitwood, 1998). Behavioral symptoms are viewed as stressful to both familial caregivers and to staff in care facilities, and multiple measures of global BPSD are associated with outcomes such as burden and depressive symptoms in family caregivers (Jackson, Fauth, & Geiser, 2014). A review of the most "problematic" BPSD for caregivers suggested that the most frequently occurring BPSD are not the same behaviors that are identified by caregivers as being the most stressful, nor are they the most strongly associated with global caregiver well-being (Fauth & Gibbons, 2014). Therefore, a targeted approach of determining specific BPSD that are more highly associated with caregiver burden and depressive symptoms is warranted, as is determining the frequency and caregiver appraisals of the stressfulness of these behaviors.

Informal Caregiver Stress and Well-being: The Stress Process Model

Caregivers of people with dementia are faced with the dual challenge of having to assist with ADL, and having to manage BPSD. There is extensive literature describing the daily and cumulative stress, physical strain, and mental burden that caregivers face because of these challenges. Pearlin and colleagues' Stress Process model (Pearlin, et al., 1990; see Figure 1), proposes that objective stressors (such as having to assist with ADL, managing BPSD) are related to subjective caregiver stressors (such as feelings of role overload), and that these stressors can lead to intrapsychic strain (such as feelings of role captivity) and eventually poorer caregiver well-being.

A comprehensive description of subjective stressors, intrapsychic strain, and caregiver outcomes is described by Aneshensal, Pearlin, Mullan, Zarit, and Whitlatch (1995). Specific to the current analyses are *overload*, which involves feeling exhausted by the demands of caregiving, feeling like there are too many things to do in the role, and not having enough time for oneself, and *captivity*, which involves feeling trapped by the caregiving role, and feeling as though caregiving prevents the pursuit of one's own life. Overload and captivity are caregiver-specific outcomes (distress and strain attributed directly to the caregiving role), whereas outcomes such as depressive symptoms represents a more global indicator of reduced well-being, which may be attributed to caregiving stress, as well as other non-caregiving factors.

In longitudinal analyses, both BPSD and ADL in care receivers are linked to increased caregiver overload and captivity (Aneshensal et al, 1995). Although both assistance with ADL and managing BPSD have been found to be stressful for caregivers, studies indicate that BPSD is considered to be *more* stressful than, or more highly associated with caregiver stress and depressive symptoms, than the need to assist with daily functioning (Haley, Brown, & Levine, 1987; Kinney & Stephens, 1989; Piercy, et al., 2013). In growth curve analyses, Gaugler, Davey, Pearlin, and Zarit (2000) found that increases over time in care receiver ADL impairment and in BPSD predicted increased role overload in caregivers (albeit, not captivity), but only when ADL and BPSD were modeled separately as independent variables. When ADL and BPSD were included in the same model, only increased BPSD remained a significant predictor of increased overload, again emphasizing that BPSD may be more "problematic" for caregivers than needing to assist with daily care.

Demographic characteristics of caregivers (gender, education, kin relationship to care receiver) are also associated with greater distress and poorer well-being. In a meta-analysis, Pinquart and Sörensen (2006) reviewed effect sizes from 229 studies and found that female caregivers reported more stress and poorer well-being (burden, depressive symptoms) as compared to male caregivers, although effect sizes were small. Higher levels of education are associated with lower levels of depressive symptoms (Piercy et al., 2013). In a review article, Schulz, O'Brien, Bookwala, and Fleissner (1995) reported multiple studies where spousal caregivers reported greater levels of distress than non-spousal family caregivers (e.g. adult offspring). Because kin relationship (being a spouse) is highly correlated with other variables that are, themselves, related to distress and poorer well-being in caregivers (advanced age, living with the care recipient, employment status, marital status), we follow the rationale of Gaugler et al., 2000 and include kin relationship as a covariate in our

analyses, recognizing it also serves as a partial proxy for these other demographic characteristics.

Research on the Relationships between BPSD and ADL—To date, most research that has considered both ADL-needs and BPSD has viewed them as separate domains, although research has studied associations between the constructs. Norton, Malloy, and Salloway (2001) found a significant relationship between higher BPSD and poorer functioning in ADL. Nagatomo and colleagues (2001) reported that only some ADL tasks were associated with overall levels of BPSD (e.g. toileting), while others were not (e.g. bathing). The nature of this relationship depends largely on the severity of dementia. In the early-to-moderate stages, the need for ADL assistance increases, as does BPSD frequency (Haley & Pardo, 1989). This would indicate a positive correlation between ADL impairment and BPSD. As people move from moderate dementia into advanced stages, however, their cognitive and physical impairment often leads to loss of speech and mobility, thus BPSD tends to decline in later stages of disease, while ADL impairment still increases (Haley & Pardo, 1989). In late-stage dementia, correlations between ADL impairment and BPSD may become negative, thus the overall relationship between BPSD and ADL impairment likely takes an inverted U-shape over the course of early to advanced dementia.

Research on BPSD within the Context of ADL (Resistiveness to Care, or RTC)

—Whereas prior research finds associations between BPSD and poorer overload, captivity, and depressive symptoms (Aneshensal et al., 1995; Gaugler et al., 2000), these studies rely on broad measures of BPSD. In the current study, BPSD is observed specifically within the context of ADL assistance, which in formal care settings is termed RTC. Research on institutional care supports that persons with dementia often struggle, resist, or engage in other uncooperative behavior *during* the staff's efforts to assist with ADL (Mahoney, 1999), and these RTC behaviors are the most common type of BPSD in institutional settings (Fisher, Fink, & Loomis, 1994). Volicer and colleagues propose that RTC is related to, but independent of the more global term, agitation. Contrary to agitation, which operates independent of interactions with others, RTC is a defensive response to staff and caregivers (Volicer, Bass, & Luther, 2007), and includes a range of behaviors, such as aggression, avoidance, and other forms of non-compliance (Kable, Guest, & McLeod, 2013). Aggressive behaviors are reported while residents are being assisted with bathing, dressing, toiling, or feeding (Farrell Miller, 1997; Hope, Keene, Fariburn, McShane, & Jacoby, 1997b; Keene, et al., 1999; Palmstierna & Wistedt, 1987; Schreiner, 2001; Teresi et al., 1997; Ware, et al., 1990).

In some RTC or related research, there is a tendency for studies to focus on one particular care task. Sloane and colleagues (1995) posited that more so than for other activities, people with dementia feel particularly confused, threatened, dominated, insulted and/or physically uncomfortable during bathing, contributing to the increased rate of agitation and aggression during bathing assistance (Sloane, et al., 1995; Sloane, et al., 2004). For a recent comprehensive review of bathing disability, including BPSD occurring during bathing and best practices in reducing bathing-related BPSD, see Wolf and Czekanski (2015). Aselage (2010) describes that eating problems in persons with dementia include physical impairment

with the task (such as difficulty chewing and swallowing), memory-related impairments (eating non-foods, not recognizing foods, or forgetting eating processes), and disturbances during feeding (agitation, resistance, and refusal; akin to RTC). Of the three ADL targeted in this study (bathing, eating, dressing), literature on behavior problems during dressing was the scarcest. Research on dementia-related dressing problems include agitation, aggression, and/or refusal during dressing, or these behaviors are included in constructs such as “inappropriate social behaviors” (O’Leary, Haley, & Paul, 1993), or “asocial behaviors” (Teresi et al., 1997). Research has also focused on specific difficulties and errors that persons with dementia make during dressing (DeAjuriaguerra, Rego, Richard, & Tissot, 1967; Feyeresien, Gendron, & Seron, 1999), although the mechanical difficulties of dressing (inability to button) are not included in constructs of RTC.

Hypotheses and Purpose of the Study—In sum, ADL assistance for persons with dementia and the presence of behavioral symptoms are typically studied as separate (but related) constructs, and both are known stressors for family caregivers. This study builds upon prior literature by studying RTC in informal, at-home caregivers, as the vast majority of RTC research is conducted in institutional settings with implications for the person with dementia and/or the nursing staff. For the current analyses, care receivers’ level of ADL impairment, frequency of RTC, and caregivers’ level of stress associated with RTC are used to predict caregivers’ role-specific and global well-being. We hypothesize that RTC (frequency and appraisals) are significantly associated with poorer caregiver outcomes, even more so than levels of care receivers’ ADL functioning.

In addition to expanding the RTC literature to informal caregivers, the research contributes to the literature in several other ways. First, research on role captivity, overload, and depressive symptoms has linked these outcomes with BPSD, but relies on global measures of behavioral disturbances, not BPSD specific to any particular situations or settings. The current analyses offer a more detailed understanding of BPSD within a specific context, which then highlights more targeted opportunities for intervention. Second, much of the RTC research studies resistance during one task (e.g. disruptive behaviors during assistance with dressing, *or* bathing, *or* eating). Less commonly are these studied collectively, even though standard measures of ADL assistance group these care needs together. Finally, findings from the current analyses may inform assessment approaches. The standard and commonly used measurement of ADL in persons with dementia (in both clinical and research settings) informs us on the functional abilities and care needs of the person with dementia, however with additional items on RTC assessing struggling or resisting during these tasks, similar to those included here, we may also be able to identify caregivers at risk for increased care-related distress and poorer global well-being within a single assessment.

Design and Methods

Design

The study utilized a cross-sectional design. Data were taken from the baseline visit of a larger quasi-experimental, longitudinal study observing effects of Adult Day Services on

persons with dementia and their caregivers. Baseline visits were obtained prior to initiating Adult Day Services.

Participants

The sample consisted of 234 persons with dementia and their caregiver (care dyads). All caregivers were required to be the primary caregiver, sharing the same household as the care recipient. Because the purpose of the larger study involved Adult Day Service use in the treatment group, dyads from that group were required to be initiating Adult Day Service use for the first time, with a minimum of four hours a week of services. Both the treatment and control groups were enrolled from 1999 through 2003 via referrals from Adult Day Service staff, respite care agency staff, physicians, and newspaper advertisements (in Pennsylvania and New Jersey). Data for current analyses were taken from baseline, pre-enrollment in Adult Day Services, thus the day service and control groups are combined for the current analyses. An additional 145 caregivers were ineligible for the study for the following reasons: The person with dementia was enrolled in Adult Day Services previously (n=19; 13.1%), or the person with dementia was planning use of Adult Day Services < 4 hours/week (n=3; 2.1%), thus for these reasons they were not eligible to be included in the treatment or control group for the larger study. Other exclusion reasons included the caregiver being not interested in the study (n=26; 17.9%), the caregiver not being available for scheduling or unable to be contacted (n=26; 17.9%), the care receiver not having a dementia diagnosis (n=13; 9.0%), the caregiver and care receiver not co-residing (n=12; 8.3%), the caregiver expressing interest but reporting 'not enough time' (n=12; 8.3%), the person in contact with the study not being the primary caregiver (n=8; 5.5%), the care receiver living in an institution (n=4; 2.8%), and other reasons (n=22; 15.1%).

Procedure

All caregivers included in the study completed informed consent documents, including obtaining consent from the person with dementia or their legal proxy. Persons with dementia were directly assessed only for cognitive status, using the Mini-Mental State Exam (MMSE (Folstein, Folstein & McHugh, 1975). The study was approved by the Institutional Review Board overseeing ethical conduct of research for Pennsylvania State University. Primary caregivers of people with dementia were interviewed in their homes by trained research assistants, and caregivers were asked to report about their care recipient's functioning, including their behavior problems and their need for ADL assistance. Persons with dementia were not specifically excluded from being present during (some or all of) the interview with the caregiver. Care receivers were present during 40.9% of caregiver interviews.

Measures

Assistance with Activities of Daily Living (ADL): Caregivers reported the amount of assistance their care recipient needed to perform personal or basic activities of daily living (ADL; Katz, et al., 1963), including the ability to eat, dress, groom themselves, bathe and shower, use the toilet, and get in and out of bed. The Katz ADL is a widely accepted assessment tool, used continuously in clinical and research applications for over 50 years, with established construct validity and test-retest reliability (for a recent article, see

Hartigan, 2007). Although caregivers reported on six ADL activities, for the current analysis only three activities, eating, bathing and dressing, were used to create the “ADL Impairment” score. This was done because *behavior problems* related to ADL (RTC) were not assessed specifically for grooming, toileting, and transferring in/out of bed, and we wanted consistency between the ADL assistance and RTC contexts. Responses ranged from 0 (the care receiver could do the activity by him/herself and needed no help) to 3 (the care receiver was unable to do the activity by him/herself and needed help all the time). Scores were summed, with higher scores indicating more impairment (total score possible range 0 – 9). All 234 caregivers provided ADL information (no missing data on this variable).

Behavior Problems Occurring during Activities of Daily Living (Resistiveness to Care, or RTC): To assess dementia-related behavioral problems occurring during eating, bathing, and dressing (RTC), caregivers completed the Weekly Record of Behavior (Son, et al., 2007). The full version of this measure asks about the occurrence during the past week of 40 negative and 4 positive behaviors. Caregivers indicate whether or not a particular behavior occurred in the past week, and if so, how frequently (1-2 times, 3-6 times, once or twice a day, or many times a day). Caregivers were also asked how long the behavior lasted (duration in minutes) and on a scale of 1 (not at all) to 5 (very), how upsetting the occurrence of this behavior was to them. For the current study, only the information on behaviors’ frequency and the levels of caregiver distress (appraisals) were used. Six items from this scale assessed behavioral problems occurring during ADL activities of eating, dressing and bathing (see Figure 2), which comprised the RTC scale. Average scores were computed for the frequency of these six behaviors (RTC Frequency) as well as across the caregivers’ stress appraisals of these six behaviors (RTC Appraisals). All 234 caregivers in the sample provided information on RTC frequency. Caregivers who had reported zeros for frequency of RTC (N = 79) were not asked to report on their stress appraisals of those behaviors, therefore only 155 caregivers reported on RTC Appraisals.

Past research on the Weekly Record of Behavior, as a whole, has found it reliable and valid (Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Zarit, et al., 2011). For the current analyses, the subset of six items related to behavior problems during eating, bathing, and dressing (RTC) yielded an internal consistency (Cronbach’s alpha) coefficient of .53. Although this value indicates only moderate inter-item correlations, the subscale measures cumulative exposure to events, and one would not expect that care receivers who display problems in one context necessarily display those problems in multiple contexts. That is, people who resist bathing may do so because of the embarrassment or confusion involved with bathing, and they would not necessarily be more likely to resist eating. For these reason’s moderate inter-item correlation for the RTC scale was considered acceptable.

Caregiver Outcomes: Based on Pearlin and colleagues’ Stress Process model (1990), caregiver outcomes included measures of depressive symptoms, overload, and captivity. Depressive symptoms were assessed using the CES-D (Radloff, 1977), a 20-item scale measuring the frequency of depressive symptoms over the past week. A summary score was created where a higher score indicated more depressive symptoms ($\alpha=.89$).

The Stress Process model (Figure 1) considers overload to be a “Primary Subjective Stressor” and captivity as a “Secondary Intrapsychic Strain”. For both scales, caregivers report the frequency of thoughts and feelings during the past month, and they could respond to these items (reverse coded when needed) using: 0 “never”, 1 “some of the time”, 2 “most of the time”, and 3 “all of the time”. Overload (4-items; $\alpha=.74$) consisted of two items adapted from Pearlin et al., (1990) regarding feeling exhausted and having time for self, and two reverse-coded items created for the current study (being able to relax and having a block of time). For captivity (7-item scale, $\alpha=.89$), three items came from Pearlin et al. (1990) regarding leading a life of one’s own, feeling trapped, and wishing to run away, and four items were created for the current study (regarding feeling prevented from doing things, putting life on hold, having little in life outside of caregiving, and wishing for someone to take over).

Analysis

To determine the extent to which ADL impairment and RTC were present and co-occurred in the current study, the percentages of the caregivers reporting these was determined via cross-tabulations. To test the main hypotheses three separate hierarchical linear regression models were run with the separate dependent variables (overload, captivity, depressive symptoms). Independent variables for each model were entered as follows: demographic characteristics of the caregivers were entered first as control variables, followed by ADL impairment, RTC frequency, and finally, RTC appraisals. This hierarchical design yielded a test of whether RTC frequency and associated stress appraisals were associated with caregivers’ overload, captivity, and depressive symptoms, even after accounting for demographic variables and levels of ADL impairment in the people with dementia.

Results

Sample characteristics are displayed in Table 1. Just over half of the care recipients were women, with a mean age of 80.1 years. On average, these individuals had a diagnosis of dementia for 31.4 months, or just over 2.5 years. The caregivers were mostly women (79.5%) and had an average age of 62.7 years. Scores on the MMSE can range from 0 to 30, with a score of 24 or lower representing significant cognitive impairment, and care receivers in this sample had an average MMSE score of 14.1 (sd = 6.6). Means of the continuous variables, as well as the bivariate correlations of all variables included in the analyses are included in Table 2.

The Percentage of Care Receivers Demonstrating RTC

Table 3 describes the frequencies with which ADL impairment and RTC were co-reported. The majority of caregivers (59.8%) reported that care recipients had both ADL impairment (in eating, bathing *and/or* dressing), as well as RTC (in eating, bathing *and/or* dressing). Another 6.4% of the sample reported RTC even though their care receiver needed no assistance with eating, bathing, or dressing tasks. Just over a quarter of caregivers (26.1%) reported that need for assistance in eating, bathing and/or dressing, but did not report behavior problems in these contexts. Finally, 7.7% of caregivers reported neither ADL impairment nor RTC.

ADL Impairment, RTC Frequency, and RTC Appraisals: Associations with Caregiver Outcomes

Three separate hierarchical regression models were run with caregiver overload, captivity, and depression used as the dependent variables (see Table 4). Demographic characteristics entered in the first block included caregiver's gender [1=female, 0 = male], education, and whether the caregiver was a spouse [1= spouse; 0 = non-spouse] to the care receiver. Gender was a significant predictor in all three models, with women reporting more overload, captivity, and depressive symptoms. In block two, the level of ADL impairment was entered, and was statistically significant in all three models (higher impairment in eating, bathing, and dressing was associated with greater overload, captivity, and depressive symptoms). In block three, RTC frequency was entered; higher RTC frequency was related to greater feelings of caregiver overload, captivity, and depressive symptoms, and ADL impairment became non-significant. In the final block, RTC appraisal was added. For overload, RTC appraisal was a significant predictor, and RTC frequency became non-significant in these models. For captivity, RTC appraisal was a significant predictor, and RTC frequency remained significant. For depressive symptoms, RTC appraisals was not significant ($p=.08$).

Discussion

Past research on RTC or behavior problems that occur during personal activities of daily living has generally been conducted in nursing homes, and has reported that rates of disturbances occurring during staffs' assistance with clients' personal care are frequent and stressful (Fisher, Fink, & Loomis, 1994; Schreiner, 2001). The current research demonstrates similar results for at-home, family caregivers. Eighty six percent of caregivers in this sample reported having to assist their relative with eating, bathing, or dressing, and two-thirds of the caregivers reported behavioral disruptions (RTC) during these same activities. Therefore, in addition to providing physical assistance with ADL, it was relatively common for caregivers to also be confronted with concurrent RTC.

These analyses also found that gender, ADL impairment, and RTC are associated with caregivers' well-being (overload, captivity, depressive symptoms) but the need for ADL assistance became non-significant when RTC was included in models. Additionally, for overload, the frequency of RTC was a significant predictor only before caregivers' stress appraisals of RTC were entered into regression models, whereas for captivity both frequency and appraisals were significant, and for depressive symptoms, only RTC frequency was significant. Together these findings suggest that *both* RTC frequency *and* appraisals of these behaviors should be considered as playing a role in the diverse aspects of caregivers' stress and well-being. This conclusion is supported by prior reports of global/general Behavioral and Psychological Symptoms of Dementia (BPSD; e.g., Teri et al., 1991), as well as the Transactional model of stress and coping, which finds that both the event of the stressor, and the appraisals of events are important in stress processes (e.g., Lazarus & Folkman, 1984). We also note that R-squared for these models were fairly small, ranging from .15-.17, indicating that overload, captivity, and depressive symptoms have variance explained by variables other than what was included here. The Stress Process model (Pearlin et al., 1990)

also supports that there are additional multicontextual, psychosocial predictors of caregiver outcomes, in and above ADL and RTC.

In sum, our models suggest that RTC are a relatively common experience for at-home, informal caregivers, and exposure to RTC as well as caregivers' perceptions of RTC have a more negative association with caregivers' well-being than the need for caregivers' to assist their relative with personal care in these same domains.

Implications

Current findings have implications for caregiver and care receiver intervention strategies and assessment methods. First, the relatively high frequency of RTC in the current sample emphasizes that care assistance with eating, bathing, and dressing poses specific contexts in which behavior problems are likely to occur at home. While many caregiver interventions currently include caregiver training in how to deal with *general* behavioral and psychological symptoms of dementia (BPSD), a specific focus on the problems that arise during assistance with personal care may be needed (see for example, an intervention approach proposed by Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001; Gitlin, Kales, & Lyketsos, 2012). Educational resources that address managing RTC are currently available in multiple media formats (see for example, Alzheimer's Association, 2014; Andresen, 1995; Center for Telehealth and Healthcare Communications, University of Florida, 2003; Lifeview Resources, 2004). Intervention research has identified that targeting specific approaches in the delivery of ADL assistance in nursing homes can reduce RTC, such as practicing dressing routines with care recipients and using products that were utilized by the person with dementia prior to their dementia onset (Cohen-Mansfield, & Jensen, 2006). It could be beneficial to integrate these types of resources or hands-on training to both at-home caregivers and staff at institutions

Of note in the current study, we asked caregivers to report if the care receiver struggled, resisted, or refused assistance during eating, bathing, and dressing. Although the disruptive behavior across these contexts may look similar to those observing and reporting, the RTC behavior, itself, may have very different etiologies for each task (Moniz-Cook, et al., 2003). Resisting eating, for example, may be caused by dental pain, whereas resisting bathing may be caused by anxiety or embarrassment about undressing. We want to emphasize that interventions addressing RTC, like those addressing general BPSD, should consider a careful screening of the behavior, identification of triggers within the environment, and should manage the behavior in a way that is adaptive to the specific environmental condition and needs of the person (see, for example, Gitlin, Kales, & Lyketsos, 2012).

The current findings also have implications for the assessment of ADL and BPSD. In both clinical and research assessment, ADL and BPSD are treated as two separate domains. Standard evaluation of ADL typically indicates the extent to which the targeted person needs assistance with activities. Assessment of BPSD includes measuring the frequency with which general problem behaviors are observed. By assessing these conditions separately, we essentially treat them as measures of independent (although related) constructs. However, measuring ADL impairment (or need for care assistance from the caregiver) without consideration of the added difficulty of struggling or resisting such help underestimates the

caregiver's needs as well as the skills required in that situation. Likewise, by assessing behavior problems without consideration of the environmental triggers or context in which they occur, we are more likely to adopt reductionist explanations, for example that the problems are due to neurochemical deficiencies, rather than to potentially modifiable features of the environment or interactions with the caregiver. By assessing behavior within context, we are better able to effectively reduce behavior problems through changes in the environment or through changes in care management. More research is needed using measures of BPSD that include the context and potential source of the behavior problems (including, but not limited to RTC), so that we may gain better insight into management of problem behaviors, the needs and skills of the caregiver, and therefore also reduce the behavior's negative impact on caregivers.

Finally, we note several potential limitations of the current study. First, the reports of RTC and ADL impairments were provided by the caregiver, introducing a potential reporter-bias in measurement. Some prior studies have found a significant association between caregivers' stress and their reports of their relative's functioning. Conde-Sala and colleagues (2013) reported that more burdened and depressed caregivers reported more negative BPSD. Likewise, Arguelles and colleagues (2001) found that caregivers who were more distressed reported greater functional decline in their care receivers. Other studies, however, offer evidence that caregivers are accurate reporters of their care receivers' functional ability (Cotter, Burgio, Stevens, Roth, & Gitlin, 2001). A second possible source of caregiver bias involved the care recipient being present during some (or all) of the interview for 41% of caregivers. Caregivers were interviewed in their homes, and for ethical and safety reasons, the interviewer could not prevent the care recipient from being in the room with the caregiver during the interview. We recognize that some caregivers may have biased their responses if they felt that the care receiver was listening and understanding their responses. Immediately after the interview was completed, interviewers privately rated caregivers on how frank they thought the caregivers were during the interview. One caregiver (.5%) was rated as "probably not too frank". Eighty-eight (41%) were rated as "mostly frank", and the remaining majority of caregivers (n=125; 58%) were rated as "entirely frank". Based on the possible sources of biases, we cannot rule out that caregivers in the present study may be over- or under-estimating ADL and RTC levels. Future studies may want to consider including additional sources of information, for example including third-party observational assessments of functional ability and/or RTC, or determining if having someone watch the person with dementia in another room increases the degree to which caregivers are more frank in their responses.

A second limitation is that the current study used a cross-sectional design. It may be that concurrent rates of RTC, overload, captivity, and depressive symptoms have a relationship that is different from relationships between these constructs over time. A longitudinal study could examine the impact of RTC on long-term caregiver outcomes. Third, only three domains (eating, bathing, dressing) were included in the ADL scale, although traditional ADL measurement includes other tasks, such as grooming, transferring from bed to chair, and toileting. We stated earlier that the purpose of limiting the ADL tasks was so that the ADL and RTC scales used the same tasks, and eating, bathing, and dressing were the three tasks in common on both scales. However individuals who wish to compare our results to

studies using standard ADL assessment should be cautioned about the reduced items included in our ADL measure.

In conclusion, at-home caregivers commonly experience behavioral disturbances while assisting the care recipient in personal care. While ADL assistance is demanding and stressful, RTC in these tasks have a more negative association with informal caregivers' overall role stress and well-being. Future research should move beyond viewing assistance with ADL as involving only physical demands of the caregiver, and should recognize that ADL care is an important context for the occurrence of disruptive behavior. In general, research which seeks to reduce behavior problems of dementia and associated stress in caregivers should consider the environment in which behavior problems were evoked, and incorporate the assessment of context in future interventions.

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Figure 1. Pearlin and Colleagues' (1990) Stress Process Model

Note: Figure adapted from Pearlin, et al., 1990. Gray boxes represent and bolded font represent variables used in the current study

	Behavior	Did the behavior occur in the past week?	If Yes, How many times did it occur?				On average, how long did the behavior last?	To what extent was this behavior upsetting to you?
		YES NO	1-2 times	3-6 times	Once or twice a day	Many times a day	Minutes	Not at all→Somewhat→Very
Eating	Struggled, refused, or resisted to eat	1 0	1	2	3	4		1 2 3 4 5
	Had trouble sitting at a meal	1 0	1	2	3	4		1 2 3 4 5
Bathing	Struggled, resisted, or refused to bathe or shower	1 0	1	2	3	4		1 2 3 4 5
Dressing	Struggled/resisted dressing	1 0	1	2	3	4		1 2 3 4 5
	Wore inappropriate clothes	1 0	1	2	3	4		1 2 3 4 5
	Took off clothes at inappropriate times	1 0	1	2	3	4		1 2 3 4 5

Figure 2.
The Weekly Record of Behavior: Items related to BP-ADL

Table 1

Demographic Characteristics of the Sample

	Caregiver N = 234	Person with dementia N = 234
Average age in years (SD)	62.7 (12.9)	80.1 (8.0)
% Women	79.5%	56.4%
Relationship of caregiver to person with dementia		
Wife	33.3%	
Husband	12.8%	
Daughter/Daughter-in-law	44.0%	
Son/Son-in-law	6.8%	
Other	3.0%	
Ethnicity: White/Caucasian	86.3%	85.9%
Ethnicity: Asian, Black, Latino, Other	13.7%	14.1%
Mean income range	\$40,000 – \$49,999	\$10,000 – \$19,999 ^a
Mean education in years (SD)	13.5 (2.2)	11.2 (3.2)
Mean time (months) since memory problem onset (SD)	n/a	53.2 (40.8)
Mean time (months) since dementia diagnosis (SD)	n/a	31.4 (26.9)
Mean MMSE Score (SD)	n/a	14.1 (6.6)

Note:

^aIncome for this column was only assessed from people with dementia who were not married to their primary caregiver (N = 126)

Table 2

Means and Bivariate Correlations

		CG Gender	CG Education	CG Spouse	ADL Impairment	RTC Frequency	CG RTC Appraisal	CG Depressive Symptoms	CG Captivity	CG Overload
Mean (SD)					3.62 (2.74)	0.41 (0.49)	3.12 (1.26)	15.04 (10.31)	1.38 (0.83)	2.12 (0.62)
CG Gender (1=female)	<i>r</i> (<i>p</i> -value)	1.000	-.037 (.592)	-.188* (.006)	-.134* (.050)	-.082 (.231)	.267* (.001)	.213* (.002)	.271* ($<.001$)	.306* ($<.001$)
CG Education (years)	<i>r</i> (<i>p</i> -value)		1.000	-.197* (.004)	-.092 (.181)	.037 (.594)	.002 (.979)	-.079 (.249)	-.027 (.698)	-.102 (.137)
CG Spouse (1 = spouse)	<i>r</i> (<i>p</i> -value)			1.000	.026 (.710)	-.019 (.781)	-.069 (.420)	.013 (.855)	-.127 (.063)	-.145* (.034)
ADL Impairment	<i>r</i> (<i>p</i> -value)				1.000	.270* ($<.001$)	-.093 (.271)	.140* (.041)	.101 (.143)	.104 (.131)
RTC Frequency	<i>r</i> (<i>p</i> -value)					1.000	.263* (.002)	.232* (.001)	.227* (.001)	.187* (.006)
CG RTC Appraisal	<i>r</i> (<i>p</i> -value)						1.000	.241* (.004)	.319* ($<.001$)	.303* ($<.001$)
CG Depressive Symptoms	<i>r</i> (<i>p</i> -value)							1.000	.596* ($<.001$)	.503* ($<.001$)
CG Captivity	<i>r</i> (<i>p</i> -value)								1.000	.627* ($<.001$)
CG Overload	<i>r</i> (<i>p</i> -value)									1.000

* indicates a Pearson correlation significant at $p < .05$

Table 3

Categorizations of ADL Impairment and Resistiveness to Care

	Have ADL Impairment	Do not have ADL Impairment
Have RTC	140 (59.8 %)	15 (6.4 %)
Do not have RTC	61 (26.1 %)	18 (7.7 %)

Table 4

Hierarchical Regression Analysis for ADL Impairment, RTC Frequency, and Associated RTC Caregiver Stress Appraisals Predicting Three Caregiver Outcomes

	Model 1: Overload			Model 2: Captivity			Model 3: Depressive Symptoms		
	β	SE	R ²	β	SE	R ²	β	SE	R ²
1 Caregiver Gender	0.28 *	0.10		0.25 *	0.14		0.22 *	1.74	
Caregiver Education	-0.12	0.02		-0.04	0.03		-0.06	0.32	
Caregiver Spouse	-0.12	0.08	.12	-0.09	0.12	.08	0.04	1.45	.05
2 Caregiver Gender	0.30 *	0.10		0.27 *	0.14		0.24 *	1.73	
Caregiver Education	-0.10	0.02		-0.02	0.03		-0.05	0.32	
Caregiver Spouse	-0.12	0.08		-0.09	0.11		0.04	1.43	
ADL Impairment	0.13 *	0.02	.13	0.14 *	0.02	.10	0.16 *	0.25	.08
3 Caregiver Gender	0.31 *	0.10		0.28 *	0.13		0.25 *	1.69	
Caregiver Education	-0.11	0.02		-0.03	0.02		-0.06	0.31	
Caregiver Spouse	-0.12	0.08		-0.08	0.11		0.05	1.40	
ADL Impairment	0.08	0.02		0.07	0.02		0.10	0.26	
RTC Frequency	0.19 *	0.08	.17	0.23 *	0.11	.15	0.23 *	1.41	.13
4 Caregiver Gender	0.20 *	0.11		0.18 *	0.16		0.21 *	2.17	
Caregiver Education	-0.10	0.02		-0.05	0.03		-0.08	0.39	
Caregiver Spouse	-0.14	0.10		-0.07	0.14		0.07	1.86	
ADL Impairment	-0.04	0.02		-0.02	0.03		0.09	0.35	
RTC Frequency	0.09	0.10		0.19 *	0.14		0.18 *	1.95	
RTC Appraisals	0.22 *	0.04	.17	0.22 *	0.05	.16	0.15	0.73	.15

* indicates a Beta weight significant at $p \leq .05$