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Quality of Informal Care Is Multidimensional

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Abstract

Purpose—To demonstrate that assessing quality of informal care involves more than merely determining whether care recipient needs for assistance with activities of daily living (ADLs) are satisfied on a routine basis. Potentially harmful behavior (PHB), adequate care, and exemplary care (EC) are conceptually distinct dimensions of quality of care. We investigated the extent to which these three dimensions also are empirically distinguishable.

Design—237 care recipients completed the quality of care measures, and their caregivers completed psychosocial measures of depressed affect, life events, cognitive status, and perceived pre-illness relationship quality.

Results—Confirmatory factor analyses indicated that PHB, adequate care, and EC are empirically distinct factors. Although PHB was moderately related to EC, adequate care was not associated with PHB and was only slightly related to EC. Psychosocial variables were not related to adequate care but were differentially associated with PHB and EC, providing further evidence for the distinction between the measures of quality of care used in this study.

Conclusions—Assessing quality of informal care is a complex endeavor. ADL assistance can be adequate in the presence of PHB and/or the absence of EC. Declines in EC may signal increases in PHB, independent of adequacy of care. These findings produce a brief, portable, and more comprehensive instrument for assessing quality of informal care.

Keywords

caregiving; elder abuse and neglect; quality of informal care

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Quality of informal care traditionally has been conceptualized as the extent to which care recipient needs for assistance are routinely satisfied in terms of basic (e.g., bathing, dressing) and instrumental (e.g., handling personal finances) activities of daily living (e.g., Morrow-Howell, Proctor & Dore, 1998; Morrow-Howell, Proctor, & Rozario, 2001; Skinner et al., 1999). When viewed this way, care ranges from inadequate (care recipient never receives help) to adequate (care recipient always receives help). Adequacy of care assessments are useful for identifying specific areas of deficiency where additional help might be provided. However, we believe that these measures ignore dimensions of quality of care that are critical to care recipient well-being.

One such dimension is potentially harmful caregiver behavior -- actions by caregivers (e.g., screaming and yelling, threatening with nursing home placement, hitting, slapping, handling roughly) that may be detrimental to care recipient welfare without being severe enough to warrant social services or legal intervention. Potentially harmful behavior (PHB) does not necessarily preclude adequate care. For example, a caregiver may scream and yell, threaten with nursing home placement, or even hit or slap the care recipient but still provide adequate assistance with activities of daily living.

Another dimension is "exemplary" care -- the extent to which caregivers consistently demonstrate sensitivity to psychological needs for respect and pleasurable activities (Dooley, Shaffer, Lance, & Williamson, 2007). For example, how frequently are care recipients included family gatherings and provided with the activities they particularly enjoy? Care can be adequate without being exemplary. That is, caregivers may meet care recipient basic needs but make no special efforts to consider care recipient feelings and wishes.

These observations suggest that adequate care should be only modestly (if at all) related to either PHB or exemplary care. On the other hand, there should be some association between PHB and exemplary care such that caregivers who display high levels of exemplary care are unlikely to frequently behave in potentially harmful ways toward their care recipients. However, this association may not be a strong one. For example, frustrated and overburdened caregivers may display some aspects of PHB (e.g., screaming and yelling) while still affording aspects of exemplary care (e.g., including the care recipient in family gatherings, providing favorite foods). Moreover, caregivers who never exhibit PHB are likely to vary widely in the extent to which they make extra efforts to provide exemplary care. In sum, there are reasons to expect that PHB and exemplary care are related, but there also are reasons to suspect that the relation is substantially less than perfect.

Thus, PHB, adequacy, and exemplary care are conceptually distinguishable. This idea is not totally theoretical. Rather, previous research (Dooley et al., 2007) has suggested that quality of informal care is multidimensional. Going a step further, the purpose of these analyses was to demonstrate that PHB, adequacy and exemplary care are empirically as well as conceptually distinguishable.

Care recipients reported on the quality of care they received, and these data were used in our primary analyses. A secondary, but important, step toward showing that quality of informal care is multidimensional involves demonstrating that PHB, adequacy, and exemplary care are differentially related to caregiver psychosocial variables. For the purposes of nomological validation and additional tests of discriminant validity, we used data provided by caregivers relative to their own depression, cognitive status, recent stressful life events, and quality of their pre-illness relationship with the care recipient. We selected these four psychosocial variables because they have been shown in prior research to be related to PHB, exemplary care, or both. Depressed caregivers more frequently display PHB (Williamson, Shaffer, and FRILL, 2001) and less frequently provide exemplary care (Dooley et al., 2007). In addition, it appears

that cognitively impaired caregivers engage in more PHB (e.g., Miller et al., 2006), but associations between caregiver cognitive status and exemplary care have yet to be determined. From the elder abuse and neglect literature, there is evidence that when caregivers experience more stressful life events, they are more likely to abuse and neglect care recipients (e.g., Godkin, Wolf, & Pillemer, 1989; Steinmetz, 1988; Wolf, 1988), but how life events are related to exemplary care is, as yet, unknown. Finally, caregivers with better pre-illness relationships with their care recipients display less PHB and more exemplary care (e.g., Beach et al., 2005; Dooley et al., 2007; Williamson et al., 2001). Notably scarce are data on how caregiver depression, cognitive status, recent stressful life events, and pre-illness relationship quality are related to adequacy of care.

Method

Procedure

Analyses were based on data from the first wave of interviews in the second Family Relationships in Late Life (FRILL2) Project, a multi-site, longitudinal study of informal care provided to cognitively or physically impaired community-dwelling adults age 60 or over. The sample was recruited from Athens, GA, Pittsburgh, PA, Tuscaloosa, AL, and surrounding areas. To be eligible for the study, caregivers had to live in the same household as the care recipient and be primarily responsible for providing unpaid help with at least one basic activity of daily living (e.g., bathing, toileting) or two instrumental activities of daily living (e.g., paying bills).

A primary goal of FRILL2 was to oversample African American caregiving dyads in order to obtain data sufficient to address issues (e.g., longitudinal comparisons between White and African American caregivers) conspicuously missing in previous research on the quality of informal elder care. Within these constraints, we attempted to obtain as representative a sample as possible, using the services of the Survey Research Center at the University of Georgia. Initial sampling to locate participants in the areas including and surrounding the data collection sites was based on a combination of targeted random digit dialing (RDD) and list-assisted techniques known to dramatically increase the probability of finding qualified participants. Targeted RDD sampling relied on ethnic density in the geographic areas under study; we sampled from census tracts with higher proportions of African American households. Age-targeted, list-assisted sampling relied on secondary sources to increase the incidence rate of our specified age group. Secondary sources were white pages telephone directories, supplemented by voter registration data and driver's license information. The resulting sample should be more representative than samples attained through traditional convenience sampling methods and also more productive in terms of effort required to locate potential participants. Combining these techniques greatly increases the incidence rate of reaching households with the desired characteristics and the likelihood of locating households in the defined population universe with the required characteristics. During the RDD recruitment phase, a total of 32,753 phone numbers were dialed which resulted, through initial screening, in 877 potential dyads.¹ Of these, 35% refused to be interviewed, 5.6% could not later be reached because of technical phone problems, and 18% were subsequently determined to be ineligible on the basis of additional screening for study criteria. RDD methods produced more eligible White than African American dyads. To increase the number of African American participants, we used community-based snowball referral methods at the Georgia site, in which enrolled African American dyads were re-contacted and asked to provide the names and telephone numbers of

¹Most of the dialed numbers resulted in no contact (e.g., nonworking, disconnected) or produced no eligible respondents. Exact data on the results of numbers dialed are available from Gail M. Williamson.

other potentially eligible dyads. Project staff then called and screened these individuals. Snowballing methods produced 95 potential dyads, of which 14.7% refused participation.

In sum, our recruitment efforts resulted in 771 eligible dyads, 321 (42%) of which declined participation, leaving a sample of 450 dyads (58% participation rate). We do not propose that these dyads represent the entire U.S. population but, rather, that this combination of recruitment methods produced a sample consistent with the purposes of this study.

Face-to-face structured interviews, lasting between 1.5 and 2 hours, were conducted in respondents' homes by pairs of carefully trained interviewers. Each participant (whether caregiver or care recipient) was paid \$25. To prevent data contamination, caregivers and care recipients were interviewed separately and simultaneously. The study was approved by the Institutional Review Boards of the Universities of Alabama, Georgia, and Pittsburgh. The consent form advised participants that suspected cases of abuse or neglect would be reported to the proper authorities. For reporting purposes, cases of suspected abuse or neglect were indicated if: (a) the care recipient reported being physically or psychologically abused or neglected, (b) such treatment was reported and not perceived as a threat but the interviewer suspected that the disclaimer was given under duress (e.g., fear of caregiver retaliation), and/or (c) signs of abuse or neglect sufficient to indicate immediate likelihood of danger to the care recipient were observed by the interviewer. No reportable cases were observed, and no participants refused to be interviewed after being informed of our obligation to report suspected cases of abuse or neglect.

Sample

Of the 450 eligible dyads, 53 care recipients had enough missing data (e.g., refused or were unable to answer certain questions due to memory or physical impairment) to remove them from further analyses. The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS; Randolph, 1998) was used to eliminate care recipients who could not, due to cognitive impairment, be relied on to provide valid data. (As noted below, the RBANS also was administered to assess caregiver cognitive status). The RBANS is a comprehensive evaluation of functioning in major areas of cognitive ability (or impairment) specifically designed to detect and characterize abnormal cognitive decline in older adults (Randolph, Tierney, Mohr, & Chase, 1998). It includes five subtests (Attention, Immediate Memory, Delayed Memory, Language, and Visuospatial/Constructional abilities). This instrument has demonstrated good internal and test-retest reliability (Randolph, 1998) as well as a high level of sensitivity (Gold, Queern, Iannone, & Buchanan, 1999; Hobart, Goldberg, Bartko, & Gold, 1999; Moser & Schatz, 2002; Randolph, 1997; Randolph, Tierney, Mohr, & Chase, 1998). Age-adjusted subtest scores were averaged to produce an indicator of cognitive impairment. Scores two standard deviations below the mean were used to identify invalid reports, resulting in 94 care recipients being eliminated from our analyses. An additional 65 care recipients were unable to complete our assessment due to physical disabilities (e.g., arthritic problems prevented writing, recent cataract surgery impaired vision). One caregiver did not complete the T1 interview. Thus, data from 237 dyads were available for our analyses.

On average, care recipients were 75.2 years old ($SD = 8.6$, range = 60 – 102), and 71.5% were at least high school graduates (range = < 7 years – graduate degree). Care recipients in this sample were 56.1% women, and the majority of respondents were either White (70.3%) or African American (28.9%). Care recipients reported suffering from a variety of health conditions, most frequently arthritis (69.3%), hypertension (59.2%), vision or hearing problems (49.3%), heart disease (46.2%), and diabetes (32.8%). Of care recipients included in these analyses, 12.7% had been diagnosed with Alzheimer's disease or another form of dementia, but their data were retained because RBANS results indicated that they were capable of providing valid information.

Average caregiver age was 61.2 years ($SD = 14.7$, range = 18 – 87). Most had at least a high school education (82.8%, range = < 7 years – graduate degree). Median household income was \$20,000 to \$30,000 ($SD = \$10,000$, range = < \$5,000 – > \$100,000). Over one half (65.1%) of caregivers were women; 69.3% were White, and 28.6% were African American. On average, caregivers had been providing care for 6.6 years ($SD = 7.4$, range = < 1 year – 40 years). A requirement for participating in this study was that caregivers and care recipients reside in the same household. Therefore, the vast majority (98.7%) of caregivers were family members (57.1% spouses, 31.9% adult children, 9.7% other relatives such as siblings and grandchildren). Only ten caregivers in this sample were less than 35 years of age; of these, 3 were adult children (range = 23 – 33 years), and the remaining 7 were grandchildren (range = 18 – 32 years) of the care recipient. For these analyses, caregivers were classified as spouse (1) or child/other (2).

Quality of Care Measures – Reported by Care Recipients (Full Text Shown in Appendix)

Potentially harmful behavior (PHB)—Due to the voluntary nature of our sample, we did not expect to identify dyads in which caregivers were guilty of severe forms of abuse and neglect. Rather, we assessed potentially harmful behavior (PHB; e.g., Beach et al., 2005; Dooley et al., 2007; Miller et al., 2006; Shaffer, Dooley, & Williamson, 2007; Williamson et al., 2001) – that is, care that is less than optimal but not so severe that social or legal intervention is required. PHB was measured using a 10-item instrument developed from the Conflict Tactics Scale (Straus, 1979), work by Steinmetz (1988) and Pillemer and Sutor (1992), and our own analyses of the elder abuse and neglect literature. The resulting instrument has adequate psychometric properties (e.g., Williamson et al., 2001), and is comprised of five indicators of psychological mistreatment (e.g., caregiver screams and yells at care recipient) and five indicators of physical mistreatment (e.g., caregiver hits, slaps, or handles care recipient roughly).

Because of their sensitive nature, these questions were placed near the end of the structured interviews, with instructions carefully worded to decrease reactance. Specifically, care recipients responded to items introduced as “methods that people use to get others to do what they want them to do.” Care recipients were asked how often (0 = *never*, 4 = *all the time*) each caregiver behavior occurred. Responses were summed to create a measure with higher scores representing more frequent PHB. Similar to other studies using care-recipient reports (Miller et al., 2006), coefficient α for the 10-item scale was .66.

PHB was, on average, infrequent in this sample ($M = 1.2$) but with considerable variability ($SD = 2.2$, range = 0 – 21). Care recipients most frequently reported psychological indicators of PHB – that is, at least on occasion, caregivers screamed and yelled at them (40.1%) or used a harsh tone of voice, insulted them, called them names, or swore at them (20.9%). However, 2.5% of our care recipients reported that caregivers had hit or slapped them, shaken them, or handled them roughly in other ways. These findings are consistent with those of population-based studies (Cooper et al., 2009; Laumann, Leitsch, & Waite, 2008).

Adequacy of care—Care recipients reported whether (0 = *no*, 1 = *yes*) they needed assistance with 18 activities of daily living (ADLs; e.g., bathing, dressing, handling personal finances) during the past week. If help was needed, the frequency to which each need was met was rated on a 4-point scale (1 = *I never had help with this*, 4 = *I always had someone to help me*). Responses were summed and then divided by the number of ADLs for which help was needed to produce an average adequacy of care score that could range from 1 to 4. For the entire sample, the mean was 3.3 ($SD = 0.7$, range = 1 – 4).

Exemplary care—The 11-item Exemplary Care Scale (ECS; Dooley et al., 2007) assessed the provision of personalized care that attends to care recipient psychological well-being (e.g.,

“[Caregiver] makes sure I am included in special gatherings such as family and friends getting together for religious or national holidays [such as Thanksgiving] when at all possible,” “[Caregiver] makes sure that where I live is bright and cheery”). Additionally, the ECS reflects care recipient perceptions of the degree to which caregivers consider their opinions, wishes, viewpoints, self-esteem, and desire for independence or autonomy (e.g., “[Caregiver] does everything he/she can to avoid making me feel that I am a burden to him/her,” “[Caregiver] actively avoids treating me like a child”). Frequency was assessed on a 4-point scale (1 = *never*, 4 = *always*). In this sample, coefficient α was .82 with a mean of 38.8 ($SD = 5.0$, range = 18 – 44).

Nomological Variables – Reported by Caregivers

Caregiver depression—The 20-item Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), a self-report instrument with high internal consistency, test-retest reliability, and validity (e.g., Herzog et al., 1990; Radloff, 1977), assessed caregiver depressed affect. Caregivers indicated how frequently each symptom had occurred in the past week (0 = *rarely or none of the time [less than 1 day]*, 3 = *most or almost all the time [5 – 7 days]*). Mean score was 10.8 ($SD = 9.5$, range = 0 – 47). Coefficient α was .89.

Caregiver cognitive status—To assess caregiver cognitive status, we used the same measure employed for care recipients described previously (RBANS; Randolph, 1998). As with care recipient assessments, scores for caregivers were age-adjusted based on norms of demographically representative samples (ages ranging from 20 to 90). Lower scores indicated lower cognitive functioning (i.e., more cognitive impairment). No caregivers in this sample met criteria for exclusion due to inability to provide accurate data.

Stressful life events—Caregivers were asked to indicate whether (0 = *no*, 1 = *yes*) 18 life events (e.g., death or illness of someone close) had occurred in the past six months. The average number of life events in this sample was 2.5 ($SD = 2.3$, range = 0 – 14).

Pre-illness relationship history—The 10-item Mutual Communal Behavior Scale (MCBS; e.g., Williamson & Schulz, 1995; Williamson et al., 2001; Williamson, Shaffer, & Schulz, 1998) measures perceptions of quality of the interpersonal relationship between caregiver and care recipient prior to illness or disability onset in terms of the frequency of behavioral expressions of communal feelings between caregiver and care recipient before the caregiving relationship existed. Caregivers reported how often (1 = *never*, 4 = *always*) communal behavior was exhibited in their relationships (e.g., “If she/he was feeling bad, I tried to cheer her/him up,” “She/he did things just to please me”). The MCBS has demonstrated good psychometric properties and is stable over time (e.g., Williamson & Schulz, 1995). In this sample of caregivers, mean MCBS was 33.2 ($SD = 5.6$, range = 10 – 40), and Cronbach’s α was .89. MCBS scores were not correlated with length of time in the caregiving role ($r = .11$, *ns*).

Results

Analyses proceeded in stages. Bivariate correlations evaluated associations between care recipient and caregiver demographic factors and the quality of care variables to determine whether demographic variables should be included subsequent analyses. Focal analyses were then conducted in three steps: (a) an initial test of discriminant validity of the three quality of care measures, (b) nomological validation of the quality of care measures, and (c) a second, more stringent test of discriminant validity of the quality of care measures, where the fit of the nomological validation model produced in step (b) was compared to an alternate model that imposed equal associations among the quality of care and caregiver psychosocial variables.

Bivariate Analyses

Correlations between care recipient and caregiver demographic variables and quality of care variables are shown in Table 1. These analyses indicated that care recipients who were younger, male, or more educated reported more PHB. Younger care recipients also reported less adequate and less exemplary care. In addition, care recipients indicated that more exemplary care was provided by female caregivers. Non-spousal caregivers were viewed as providing both more adequate and more exemplary care. Length of time in the caregiving role was related to less exemplary care but not to either PHB or adequacy of care. We found no associations between quality of care variables and caregiver age, gender, ethnicity, education, or household income.

A second set of bivariate correlations assessed associations between quality of care variables and caregiver-reported psychosocial factors (see Table 2). Care recipients reported more PHB when their caregivers reported more depression, more life events in the past six months, and less communal pre-illness relationships. More exemplary care was related to more communal past relationships but not to either caregiver depression or life events. Caregiver cognitive status was not correlated with any of the quality of care variables nor was adequacy of care related to any caregiver psychosocial factors.

Partial correlations were calculated to determine whether the demographic factors that were associated with quality of care variables (see Table 1) made a difference in associations between quality of care and caregiver psychosocial variables shown in Table 2. These analyses revealed no meaningful changes (M change in $r = .03$, range = $.01 - .06$). Consequently, demographic variables were not included in our focal analyses.

Confirmatory Factor Analyses

If the overall quality of care construct is indeed multidimensional, it should be comprised of scales that measure distinct factors. Primary analyses involved tests of discriminant validity to determine whether PHB, adequate care, and exemplary care were statistically distinct. In addition to tests of discriminant validity, we estimated associations between quality of care factors and relevant caregiver-reported psychosocial variables. Theoretically, these psychosocial variables should be related to quality of care factors in a broader nomological network (Cronbach & Meehl, 1955). As such, the purpose of nomological validation was to establish that the anticipated dimensions of quality of care relate in theoretically meaningful ways to relevant caregiver-reported psychosocial variables. In a second confirmatory factor analysis, we assessed associations among care recipient reports of: (a) PHB, (b) adequate care, and (c) exemplary care and caregiver reports of: (a) caregiver depressed affect, (b) caregiver cognitive impairment, (c) caregiver stressful life events, and (d) caregiver-care recipient pre-illness relationship quality.

Initial test of discriminant validity—We first sought to develop multiple manifest indicators of the three quality of care factors (PHB, adequacy of care, and exemplary care) for input to confirmatory factor analysis (CFA) using LISREL-VII with care recipient data (Jöreskog & Sörbom, 1993). Bagozzi and Edwards (1998) discussed a number of options for doing so: (a) a “total aggregation” approach in which composite scores are used to generate a single manifest indicator for each of the underlying factors, (b) a “total disaggregation” model in which individual items are used as indicators for each factor, and (c) a “partial disaggregation” model in which item parcels are used as indicators. We opted for model (c), the partial disaggregation approach, because using item parcels permits the modeling of factors at the level of latent variables (Coffman & MacCallum, 2005) while minimizing threats of model nonconvergence and ill-fitting models that are often posed by using total disaggregation models (Bandalos, 2002; Landis, Beal, & Tesluk, 2000). For each quality of care measure, we

randomly allocated scale items to three parcels that contained (approximately) equal numbers of items. For example, we randomly assigned the 11 exemplary care items to two 4-item parcels and one 3-item parcel.

The target CFA model that we fit to correlations among item parcels was a 3-correlated factor model corresponding to the three quality of care measures. We also fit a 1-factor model to test for discriminant validity under the rationale that if the three quality of care factors are empirically distinct, then the 1-factor model ought to provide a significantly worse fit to the data.

The target 3-factor CFA model provided a very good fit to the data according to prevailing standards (see Table 3; Hu & Bentler, 1998,1999). Moreover, results in Table 4 indicated that item parcels' loadings on their respective factors were all large and statistically significant. As is shown in Table 3, the 1-factor model fit the data significantly worse than did the target 3-factor model, providing strong support for the discriminant validity of the three quality of care measures. Estimated correlations among the focal quality of care factors further confirmed that they are empirically distinct. Specifically, the correlation between (a) PHB and adequate care was $-.11$ (*ns*), (b) PHB and exemplary care was $-.38$ ($p < .001$), and (c) adequate care and exemplary care was $.17$ ($p < .05$). Thus, consistent with our predictions: (a) more PHB was moderately related to less exemplary care, (b) more adequate care was only modestly associated with more exemplary care, and (c) adequate care was not related to PHB.

Nomological validation—Next, in order to test relations between quality of care factors and caregiver psychosocial measures, we augmented the basic CFA model from the previous step with single-item composite indicators of the variables described earlier. We used single-item composites (a total aggregation approach) for these measures because: (a) each of these measures has been demonstrated to be psychometrically sound, (b) each is sufficiently reliable so as to not seriously attenuate estimated relations with focal quality of care factors, and (c) test statistics are identical for attenuated and disattenuated correlations.

The nomological validation model also provided a reasonably good fit to the data (see Table 3). Estimated relations between the focal quality of care factors and the caregiver psychosocial variables essentially replicated those shown in Table 2.

Second test of discriminant validity—The rationale for our second, more stringent test of discriminant validity of the quality of care factors was based on the following logic. If these three measures represent (qualitatively) different aspects of quality of care, then they ought to exhibit different patterns of relations with caregiver-reported psychosocial variables. Using care recipient responses on the quality of care measures and caregiver responses on caregiver psychosocial variables, we tested this idea by comparing the fits of two models. In the first model, estimated relations between the quality of care factors and caregiver variables were free to vary, that is, caregiver variables could be differentially related to the three quality of care measures in expected directions. In the second, alternative model, correlations between each quality of care factor and caregiver variable were constrained to be equal, such that each relation was the same. The logic of this comparison was that, if the three focal quality of care factors are distinct from one another, then a significant worsening in model fit should occur when fitting the latter model.

Returning to Table 3, the fit of the more constrained model was significantly worse than that of the unconstrained nomological validation model, supporting the idea that the focal quality of care factors exhibit differential relations with caregiver psychosocial variables, thus lending further support to the discriminant validity of our quality of care measures.

Discussion

Our data clearly indicate that, as we expected, assessing quality of informal care involves more than determining whether ADL needs are routinely met. In fact, our measure of adequacy of care was not related to potentially harmful caregiver behavior and shared less than 3% variance with exemplary care. These results (or, rather, the lack thereof) imply that care can be adequate while still involving such behavior as screaming, yelling, and threatening. They further imply that caregivers can meet basic needs without going out of their way to make life especially pleasant. Therefore, if the goal is to obtain a comprehensive evaluation of quality of care, focusing solely on whether care recipient ADL needs are routinely met is likely to miss the mark. Our quality of care dimensions were not, however, entirely independent. That is, PHB was moderately related to exemplary care such that caregivers who more frequently treated their care recipients in potentially harmful ways also were less likely to pay particular attention to their psychological needs.

A similar pattern of results was observed for associations between care recipient-reported quality of care variables and caregiver-reported psychosocial variables. That is, adequacy of care did not appear to be a function of caregiver depression, recent life events, cognitive status, or pre-illness relationship quality. On the other hand, we did find that when caregivers reported more depressive symptoms and life events, their care recipients reported more frequently being subjected to PHB. In addition, consistent with earlier research, caregivers with historically more mutually communal relationships with their care recipients were less likely to display PHB and more likely to provide exemplary care. Taken together, these findings imply that adequacy of care is, at best, a crude estimation of quality of care – one that is prone to underestimate both PHB and exemplary care. We believe our results have several important implications that largely revolve around their predictive utility. To give just one example, the association between PHB and exemplary care suggests that when caregivers become less invested in behaving in ways that demonstrate to their care recipients that their needs for feeling respected and valued as an individual are important, screaming, yelling, and threatening behavior may follow. Thus, a decline in exemplary care could signal that intervention is warranted in order to forestall an escalation in PHB. As our data indicate, this is an early warning sign that would not be detected by adequacy of ADL assistance assessments.

Still, our data have limitations. For example, we did not replicate the finding that cognitively impaired caregivers are more likely to perpetrate PHB (Miller et al., 2006). We suspect that this inconsistency in results is attributable to methodological differences between studies. Different measures of cognitive status (i.e., the Neurobehavioral Cognitive Status Examination [NCSE; Kiernan, Mueller, Langston, & VanDyke, 1987] in Miller et al. versus the RBANS in this study), perhaps varying in sensitivity and/or specificity, may be responsible. Another possibility is that the caregivers in FRILL2 were less impaired than those in the first FRILL project (i.e., the data set used in Miller et al.), resulting in a floor effect for our present analyses. In fact, 39% of FRILL1 caregivers were categorized as cognitively impaired according to NCSE criteria, whereas only 17% of FRILL2 caregivers met similar RBANS criteria. Exactly why this was the case will be explored in depth with further analyses of the data from both FRILL projects.

Other aspects of this study limit the interpretation of our results. First, these data were cross-sectional, precluding causal inferences about relations among PHB, adequate care, and exemplary care as well as the influence of caregiver psychosocial variables. We expect that the longitudinal nature of the FRILL projects will shed light on these questions. Second, because we deliberately oversampled African Americans in proportion to Whites and excluded other ethnic groups, our sample is not representative of the entire population. Additional research is needed to determine if our results apply more broadly. Recall, however, that

ethnicity did not emerge as a meaningful correlate of quality of care. We also note that although some other demographic variables (kinship, length of time in the caregiving role, caregiver gender, and care recipient age, gender, and education) were modestly related to some quality of care factors, additional analyses revealed that controlling for these demographics did not change *associations* between our variables of interest. To give just one example, younger care recipients reported slightly more PHB, slightly less adequate care, and slightly less exemplary care relative to their older counterparts, but controlling for care recipient age did not change results indicating that less communal pre-illness relationships are related to more PHB and less exemplary care. Indeed, there are no theoretical (or, as yet, empirical) reasons to suspect that any demographic factors make a difference in the underlying processes that are the focus of this research program.

Although the clinical utility of our findings has yet to be determined, they nevertheless provide both researchers and clinicians with a psychometrically sound, comprehensive, and easily-administered measure of quality of informal care. Typically, the three scales together take only 5–10 minutes to complete, making them highly practical and portable (see Appendix for the full text of all scales). In combination, these instruments are expected to be useful in identifying declines in quality of care over time.

These data indicate that understanding the quality of care provided by informal caregivers is a complex endeavor and strongly support the need to evaluate more than whether ADL needs are routinely satisfied. Indeed, it appears that adequacy of care, in terms of meeting ADL needs, is largely unrelated to either PHB or exemplary care. Our analyses represent an important first step toward more sophisticated conceptualization and measurement of quality of informal care.

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Appendix

Adequacy of Care

I am going to ask you some questions about the specific kinds of problems you might have been having this **past week**. For each area, I will ask whether you have needed any kind of help and, if so, how much help you actually received. “Help” means supervision, direction, or personal assistance. When help was needed, please indicate how often you had help using these one of these responses:

1. I never had help with this
 2. Sometimes, I had some help
 3. I usually had someone to help me
 4. I always had someone to help me
1. During the past week, have you needed any help with bathing or showering? [____]
 0. No 1. Yes
 - 1a. [If ‘Yes’] How much help did you receive with this? [____]
 2. During the past week, have you needed any help with dressing? [____]
 0. No 1. Yes
 - 2a. [If ‘Yes’] How much help did you receive with this? [____]
 3. During the past week, have you needed any help with eating? [____]
 0. No 1. Yes
 - 3a. [If ‘Yes’] How much help did you receive with this? [____]
 4. During the past week, have you needed any help getting in and out of bed or chairs? [____]
 0. No 1. Yes
 - 4a. [If ‘Yes’] How much help did you receive with this? [____]
 5. During the past week, have you needed any help walking or using a wheelchair? [____]
 0. No 1. Yes
 - 5a. [If ‘Yes’] How much help did you receive with this? [____]

6. During the past week, have you needed any help getting outside? [____]
0. No 1. Yes
6a. [If 'Yes'] How much help did you receive with this? [____]
7. During the past week, have you needed any help using the toilet, including getting to the bathroom on time? [____]
0. No 1. Yes
7a. [If 'Yes'] How much help did you receive with this? [____]
8. During the past week, have you needed any help with transportation to places out of walking distance? [____]
0. No 1. Yes
8a. [If 'Yes'] How much help did you receive with this? [____]
9. During the past week, have you needed any help with personal grooming (washing face, shaving, combing hair, brushing teeth)? [____]
0. No 1. Yes
9a. [If 'Yes'] How much help did you receive with this? [____]
10. During the past week, have you needed any help taking medications? [____]
0. No 1. Yes
10a. [If 'Yes'] How much help did you receive with this? [____]
11. During the past week, have you needed any help with laundry? [____]
0. No 1. Yes
11a. [If 'Yes'] How much help did you receive with this? [____]
12. During the past week, have you needed any help preparing meals? [____]
0. No 1. Yes
12a. [If 'Yes'] How much help did you receive with this? [____]
13. During the past week, have you needed any help with shopping for items that people usually shop for themselves (clothes, toiletries, etc.)? [____]
0. No 1. Yes
13a. [If 'Yes'] How much help did you receive with this? [____]
14. During the past week, have you needed any help managing money (keeping track of expenses, paying bills)? [____]
0. No 1. Yes
14a. [If 'Yes'] How much help did you receive with this? [____]
15. During the past week, have you needed any help taking care of personal business (insurance claims, taxes, etc.)? [____]
0. No 1. Yes
15a. [If 'Yes'] How much help did you receive with this? [____]
16. During the past week, have you needed any help using the telephone? [____]

0. No 1. Yes

16a. [If 'Yes'] How much help did you receive with this? [____]

17. During the past week, have you needed any help doing heavy work (such as scrubbing floors or mowing the lawn)? [____]

0. No 1. Yes

17a. [If 'Yes'] How much help did you receive with this? [____]

18. During the past week, have you needed any help doing light work (such as dishes or straightening up)? [____]

0. No 1. Yes

18a. [If 'Yes'] How much help did you receive with this? [____]

PHB

Now, I'm going to read a list of methods that people use to get others to do what they want them to do. Please tell me if (caregiver) uses any of these methods to get you to do what he/she wants. Give me the number that best describes how often he/she does any of these things.

0. Never

1. Almost

2. Sometimes

3. Most of the time

4. All of the time

1. How often has (caregiver) screamed or yelled at you? [____]
2. How often has (caregiver) withheld food from you? [____]
3. How often has (caregiver) threatened to send you to a nursing home? [____]
4. How often has (caregiver) threatened to use physical force? [____]
5. How often has (caregiver) hit or slapped you? [____]
6. How often has (caregiver) shaken you? [____]
7. How often has (caregiver) handled you roughly in other ways (pushed, shoved, grabbed, kicked, pinched)? [____]
8. How often has (caregiver) threatened to stop taking care of or abandon you? [____]
9. How often has (caregiver) used a harsh tone of voice, insulted, called names, or swore at you? [____]
10. How often have you been afraid that (caregiver) might hit or try to hurt you? [____]

ECS

The following statements have to do with the interactions you have with (caregiver). For each statement, please tell me which answer you feel is most accurate.

1. Never

2. Sometimes

3. Often
4. Always
1. (Caregiver) makes sure I am included in special gatherings such as family and friends getting together for religious or national holidays (such as Thanksgiving) when at all possible. [____]
2. (Caregiver) actively avoids treating me like a child. [____]
3. To make me feel refreshed and good about myself, (caregiver) does things like being sure that I am dressed nicely or that my hair is clean and styled. [____]
4. (Caregiver) makes sure that where I live is bright and cheery. [____]
5. (Caregiver) takes the time to sit and talk with me. [____]
6. (Caregiver) does everything he/she can to avoid making me feel that I am a burden to him/her. [____]
7. (Caregiver) really tries to avoid interrupting me when I am talking. [____]
8. When at all possible, (caregiver) makes sure that I get to do some of the things I enjoy (e.g., visiting friends, going for a walk, listening to music). [____]
9. (Caregiver) tries to maintain a relaxed, unhurried atmosphere. [____]
10. (Caregiver) makes sure the food I like is available for meals and snacks. [____]
11. (Caregiver) avoids being too critical of me. [____]

Table 1

Correlations Between Demographic and Quality of Care Variables (N = 237 Dyads)

Variables	Care Recipient-Reported Quality of Care		
	Potentially Harmful	Adequate ^a	Exemplary
1. CR Age	-.23***	.22***	.23***
2. CR Gender ^b	.18**	-.08	-.02
3. CR Education	.18**	-.04	-.08
4. CG Age	-.03	-.04	-.05
5. CG Gender ^b	-.07	-.05	-.19**
6. CG Ethnicity ^c	.05	-.09	.02
7. CG Education	.00	.07	.00
8. CG-CR Kinship ^d	-.12	.13*	.18**
9. CG-CR Income	.02	-.04	-.08
10. Length of Time as CG	.07	-.02	-.15*

Note. CG = Caregiver, CR = Care Recipient.

^a Higher scores = more adequate care.

^b 1 = female, 2 = male.

^c 1 = White, 2 = Non-white.

^d 1 = spouse or equivalent, 2 = child or other.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

Table 2

Correlations Between Caregiver Psychosocial Factors and Quality of Care Variables (N = 237 Dyads)

Caregiver-Reported	Care Recipient-Reported Quality of Care		
	Potentially Harmful	Adequate ^a	Exemplary
Depression	.18*	.01	.06
Cognitive Status ^b	-.01	.01	.02
Life Events	.21**	-.01	-.02
MCBS	-.21**	.02	.18*

Note. MCBS = Mutual Communal Behavior Scale.

^a Higher scores = more adequate care.

^b Higher scores = less cognitive impairment.

*
 $p < .01$.

**
 $p < .001$.

Table 3

Model Goodness-of-Fit Indices

Model	χ^2	df	SRMSR	RMSEA	TLI	CFI
1. Target 3-factor model	36.86*	24	.06	.05	.98	.99
1 vs. 2	453.03***	3				
2. 1-factor model	489.89***	27	.23	.29	.31	.48
3. Nomological validation	85.46***	48	.05	.06	.94	.96
3 vs. 4	24.45**	8				
4. Constrained model	108.43***	56	.08	.06	.93	.95

Note. df = model degrees of freedom. SRMSR = standardized root mean squared residual, RMSEA = root mean squared error of approximation, TLI = Tucker-Lewis index, CFI = comparative fit index.

* $p < .05$.

** $p < .01$.

*** $p < .001$.

Table 4

Model Parameter Estimates

Variable	1	2	3
1. PHB:			
Parcel 1	.51 [*]	--- ^a	---
Parcel 2	.65 [*]	---	---
Parcel 3	.98 [*]	---	---
2. Adequate Care:			
Parcel 1	---	.82 [*]	---
Parcel 2	---	.88 [*]	---
Parcel 3	---	.76 [*]	---
3. Exemplary Care:			
Parcel 1	---	---	.75 [*]
Parcel 2	---	---	.77 [*]
Parcel 3	---	---	.80 [*]

^a These values were fixed equal to zero on an a priori basis.

^{*}
 $p < .001$.