

# Screening for Abuse and Neglect of People with Dementia

Aileen Wiglesworth, PhD,\* Laura Mosqueda, MD,\* Ruth Mulnard, RN, DNSc, FAAN,†  
Solomon Liao, MD,\* Lisa Gibbs, MD,\* and William Fitzgerald, PhD‡

**OBJECTIVE:** To investigate characteristics of people with dementia and their caregivers (CGs) that are associated with mistreatment in order to inform clinicians about screening for mistreatment.

**DESIGN:** A convenience sample of CG–care recipient (CR) dyads were assessed for literature-supported factors associated with mistreatment, and evidence of mistreatment for the prior year was collected. An expert panel considered the evidence and decided on occurrences of psychological abuse, physical abuse, and neglect based on criteria adopted before data collection.

**SETTING:** Participants' homes.

**PARTICIPANTS:** One hundred twenty-nine persons with dementia and their CGs.

**MEASUREMENTS:** CG and CR characteristics (demographic, health, and psychosocial variables), relationship characteristics, and three elder abuse and neglect detection instruments.

**RESULTS:** Mistreatment was detected in 47.3%. Variables associated with different kinds and combinations of mistreatment types included the CG's anxiety, depressive symptoms, social contacts, perceived burden, emotional status, and role limitations due to emotional problems and the CR's psychological aggression and physical assault behaviors. The combination of CR's physical assault and psychological aggression provided the best sensitivity (75.4%) and specificity (70.6%) for elder mistreatment as defined by the expert panel. This finding has potential to be useful as a clinical screen for detecting mistreatment.

**CONCLUSIONS:** The findings suggest important characteristics of older adults with dementia and their CGs that have potential for use in a clinical screening tool for elder mistreatment. Potential screening questions to be asked of CGs of people with dementia are suggested. *J Am Geriatr Soc* 58:493–500, 2010.

**Key words:** dementia; elder mistreatment; elder abuse; neglect; caregiver

As Americans grow older, the realization that the presence of dementia is linked to the risk of mistreatment compounds concerns about the rapidly growing population of people with dementia,<sup>1</sup> but how can clinicians identify which patients with dementia are at risk for mistreatment?

Some researchers have addressed this question through the development of CG questionnaires<sup>2</sup> or observational checklists,<sup>3,4</sup> but there is little evidence that they have been adopted for routine use.<sup>5,6</sup> This may, in part, be due to time constraints.<sup>7</sup> A brief screening tool with demonstrated validity is needed.<sup>8</sup>

Elder abuse screening tools have been developed for patients who are cognitively intact and thus able to answer directly about abusive or neglectful experiences as well as about risk factors.<sup>9–11</sup> A published review of the available tools concluded that no single instrument was adequate to identify patients at risk.<sup>8</sup> Currently available screening tools are inappropriate for people with dementia. Indeed, people with dementia have been specifically excluded from studies of screening methods.<sup>11,12</sup> By asking CGs about known and hypothetical risk factors and determining which responses are associated with mistreatment, this study begins to rectify that problem.

Although it is clear that dementia increases the risk of mistreatment,<sup>1</sup> studies of prevalence of abuse and neglect of people with dementia show highly variable results. The prevalence of psychological aggression by CGs has been reported to be from a low of 30% to a high of 60%.<sup>13–15</sup> Reports of the prevalence of physical abuse in people with dementia range from 5.4% to 23.1%.<sup>16,17</sup> This variation is in part because of nonstandard definitions of mistreatment coupled with the methodologies used to identify it, none of which are validated against a rigorous standard for identifying occurrences of mistreatment. Exclusion of individuals with moderate or severe dementia also limits many studies of elder mistreatment, thus limiting the generalizability of the results.<sup>13,18,19</sup>

From the \*Program in Geriatrics, School of Medicine, †Program in Nursing Science and Institute for Memory Impairments and Neurological Disorders, and ‡California Institute for Telecommunications and Information Technology, University of California at Irvine, Irvine, California.

Address correspondence to Aileen Wiglesworth, PhD, Program in Geriatrics, 101 The City Drive South, Orange, CA 928683298. E-mail: awiglesw@uci.edu

DOI: 10.1111/j.1532-5415.2010.02737.x

Mistreatment occurs when CGs cause harm to persons with dementia (referred to hereafter as care recipients (CRs)) through their actions or failure to act. Risk factors can be characteristics of the CR, the CG, their relationship, and the environment. These formed the design of the current study. Some CG factors associated with mistreatment of CR include poor health,<sup>20</sup> social isolation,<sup>14</sup> and mental health problems such as depressive symptoms<sup>13,17,21,22</sup> and anxiety.<sup>23</sup> The CG's perception of caregiving burden has been associated with multiple types of abuse.<sup>13,15,20,23,24</sup> Similarly, being a spouse CG,<sup>15,25</sup> duration of caregiving,<sup>14,21</sup> and a shared living arrangement have been associated with mistreatment.<sup>15,17,20</sup> A poor premorbid relationship<sup>14,23</sup> was associated with CG physical aggression, whereas a good premorbid relationship<sup>22,23</sup> and the use of formal services<sup>24</sup> were associated with lower likelihood of mistreatment. CR factors significantly related to elder abuse included poor functional status<sup>15,21</sup> and more-severe cognitive impairment.<sup>13,15,24,26,27</sup> Several studies have associated CR behavioral problems with mistreatment,<sup>16,23,28,29</sup> and CR physical aggression specifically with physical abuse.<sup>17,21,25</sup>

A more-accurate assessment of mistreatment in a population with dementia can be drawn by examining the entire spectrum of dementia from mild to severe and using the latest consensus-recommended methodology, an expert panel called LEAD (Longitudinal, Experts, All Data), to determine whether people with dementia have been mistreated.<sup>30</sup> Because older adults frequently experience more than one type of mistreatment,<sup>28,31</sup> the current study sought to determine which factors could be used to screen for different mistreatment outcomes in a population of individuals with dementia and their CGs.

## DESIGN AND METHODS

The data collected for the study fell in two categories: outcomes (direct evidence of mistreatment used to determine whether abuse or neglect had occurred) and independent variables (measures of factors that hypothetically indicate that mistreatment is likely to be occurring (potential risk factors)). CRs and their CGs (dyads) were recruited for the study, and a home visit was scheduled over the telephone. Data were collected during home visits. Later, an expert (LEAD) panel made a determination about mistreatment of the CR after considering all of the evidence that the research team presented.

To guide the selection of independent variables, the project adopted features of a sociocultural context risk model of elder mistreatment<sup>30</sup> by taking into account individual and interpersonal variables related to the older adult and someone in a position of trust to the older adult, such as a CG. Selection of variables was informed by prior studies and augmented by further interpretation of the model based on the experience of the project's clinicians. Figure 1 shows the theoretical model.

### Overview

The institutional review board of the University of California, Irvine (UCI) approved the study. Inclusion criteria were aged 50 and older, community-living, English-speaking, diagnosed with Alzheimer's disease or a related dementia, and

having an adult CG willing to participate in the research. A convenience sample of CR/CG dyads was recruited from patients of UCI physicians (21%), participants engaged in dementia research at UCI (32%), CGs contacting the local Alzheimer's Association chapter (19%), or clients attending an adult day care center (9%). The remaining participants were recruited through flyers and print media advertisements (14%) or through mass email distribution to UCI employees (5%). Dementia diagnoses were confirmed through medical record review. The research team complied with mandatory reporting laws in California; suspected physical abuse or neglect was reported to Adult Protective Services within 24 hours.

The field research team consisted of a clinician experienced in working with older adults (nurse practitioner or physical therapist) and a research assistant. Dyads were informed before formal consenting that the researchers would report suspected elder mistreatment. Only one dyad refused to participate based on the mandated reporting requirement. The clinician assessed the CR's decision-making capacity (with a tool modeled after the MacArthur Competence Assessment Tool for Clinical Research),<sup>32</sup> obtaining consent from a qualified surrogate as needed. The 90-minute assessment included a brief interview with the dyad, separation of the dyad for data collection, mostly from the CG, using a battery of instruments, and a brief home tour.

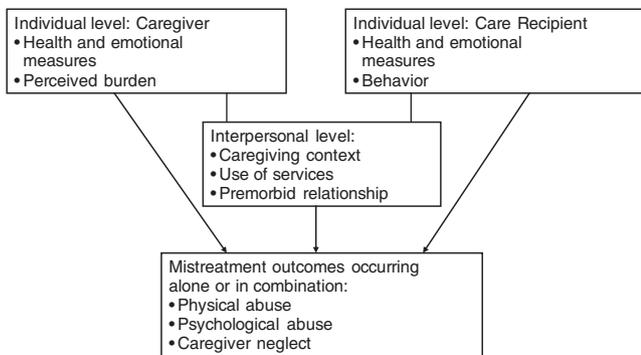
The LEAD panel members included three board-certified geriatricians, with a combined total of 31 years practicing geriatrics and 28 years working in the field of elder abuse (LM, SL, LG). All three were members of a medical response team<sup>33</sup> for an elder abuse forensic center.<sup>34</sup> Other LEAD panel members included a dementia researcher with a doctorate in nursing (RM) and a gerontologist specializing in elder abuse research (AW).

### Outcome Measures

At monthly meetings, the research team presented all available evidence of mistreatment to the LEAD panel to assess presence or absence of CG physical abuse, psychological abuse and neglect in the past year, or inability to assess because of insufficient evidence. Definitions of these types of mistreatment were adopted by the panel a priori as criteria for their decisions (definitions available at <http://www.centeronelderabuse.org/>). The measures of CG, CR, and interpersonal characteristics (Figure 1) were withheld from the LEAD panel so that tests of association would not be compromised. The data presented to the panel consisted of medical records, home visit observations, and data from modified versions of three instruments:

- (1) the CG's self-report on the Physical Assault and Psychological Aggression Scales from the Revised Conflict Tactics Scales (CTS2)<sup>35</sup> and the clinician's responses to
- (2) the Elder Abuse Instrument<sup>3</sup> and
- (3) the Safety of the Environment section of the Self-Neglect Assessment Scale (SotE).<sup>36</sup>

The latter two instruments are elder abuse screening tools with Likert scale scoring (from no evidence to definite evidence of abuse or neglect). After presenting findings from



**Figure 1.** Theoretical model for risk of elder mistreatment by dementia caregivers.

home visits, the research team responded to the panel's questions regarding their observations and assessments. Panel members were polled in round robin fashion, rotating the order of polling so that each member had an opportunity to go first, second, etc. If the poll did not yield a unanimous decision, the panel members stated the reasoning behind their decisions, discussion followed, and the panel was polled again. Most LEAD panel outcome determinations were unanimous, with one dissenting member in fewer than five of 129 decisions.

The Elder Abuse Instrument involves a brief medical interview for detecting conditions associated with physical abuse, restraint, and neglect of the CR (e.g., bruising, pressure ulcers). The SotE assesses household safety with ratings for clutter, odor, and other conditions. The CTS2 is widely used in studies of domestic partner violence to measure conflict by direct questioning of victims and perpetrators. The items were adapted for CGs, as in other studies.<sup>26,37</sup> Examples include "I insulted or swore at the patient," and "I kicked the patient." The LEAD panel acknowledged that caregiving is emotional and things may be said in anger or frustration. Endorsement of items on the CTS2 did not indicate abuse had occurred unless the acts were severe or chronic. Therefore, the LEAD panel set a priori guidelines for considering these data by reaching consensus for number of occurrences per year (threshold) that would indicate abuse for seven psychological aggression items and 10 physical assault items. For example, kicking a patient was considered physical abuse if done once, but given no other evidence of psychological abuse, insulting and swearing at a patient must occur six to 10 times over a year to be considered abuse.

### Independent Variable Measures

Independent variables consistent with the model adopted for the study (Figure 1) were operationalized using standardized, validated instruments, most with Likert scales summed over multiple items, as described below.

#### *CG Characteristics*

- Self-rated physical and emotional health: the Medical Outcomes Study 12-Item Short Form Survey (SF-12)<sup>38</sup> consists of one or two items for each of four (of eight) subscales (health status, physical functioning, emotional

status, and role limitations due to emotional problems). Two to six discrete choices for each item are valued proportionately from 0 to 100, with higher scores indicating better health (range 0–100).

- CG depressive symptoms: the Center for Epidemiological Studies Depression Scale (CES-D) Iowa Short Form<sup>39,40</sup> consists of 11 items, with higher scores indicating more symptoms (range 0–22).
- CG state anxiety: the State-Trait Anxiety Inventory (STAI)<sup>41</sup> consists of 20 "state" items, with greater anxiety coinciding with higher scores (range 20–80).
- CG's perceived burden due to the CR's behavioral changes: the Neuropsychiatric Inventory (NPI)<sup>42</sup> Caregiver Distress Scale<sup>43</sup> rates the CG's reactions to each of 13 possible behavior changes from 0 to 5 (not distressing to extremely distressing), with higher scores reflecting greater distress (range 0–65).
- CG social contacts: the Lubben Social Network Scale (LSNS)<sup>44</sup> consists of 10 items about contacts with relatives and friends, with a lower score indicating a smaller social network (range 5–50).

#### *CR Characteristics Assessed by the CG*

- CR's functional capacity: the Bristol Activities of Daily Living scale<sup>45</sup> assesses activities of daily living and instrumental activities of daily living using 20 items, with higher scores indicating poorer functional status (range 0–60).
- CR's disease stage and dementia severity: the Dementia Severity Rating Scale<sup>46</sup> evaluates 11 abilities (e.g., memory, judgment, speech), with higher scores indicating more-advanced disease staging (range 1–51).
- CR depressive symptoms: the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders depression scale<sup>47</sup> evaluates the presence of nine symptoms during the preceding 2 weeks (range 0–9).
- CR's social contacts: the LSNS uses six of 10-items from the standard instrument to assess contacts with relatives and friends (range 6–30).
- CR aggressive behaviors: the CTS2<sup>35</sup> uses two subscales (the 7-item psychological aggression subscale and the 12-item physical assault subscale) on which the questions are assessed in parallel with the CG's self report for the outcome measure of abuse. For example: item (a) I kicked the patient (outcome) is coupled with item (b) The patient kicked me (independent variable). Responses are numbers of occurrences over the last year (0 = none and 1 = once to 6 = >20 times) (range 0–42 and 0–72, respectively).
- CR neuropsychiatric behaviors: the NPI<sup>42</sup> provides frequency and severity ratings for 13 symptom sets, which are multiplied and added, with higher values indicating greater behavioral changes since the onset of dementia (range 0–156).

#### *Interpersonal Characteristics Assessed by the CG*

- The dyad's premorbid relationship: the Mutual Communal Behaviors Scale<sup>48</sup> consists of 10 items describing

relationship interactions, with higher scores indicating more-positive relationships (range 10–40).

- Number of services used: a checklist of 10 services (e.g., adult day care, CG support groups) was adopted from a checklist used by the Institute for Memory Impairments and Neurological Disorders at UCI (range 0–10).

### The Study Sample

Table 1 contains demographic and interpersonal measures. The sample included CRs with all levels of dementia, 79 (61%) diagnosed with Alzheimer's disease. All but 10 CGs (7.8%; 8 paid and 2 neighbors) were family members, most of them spouses ( $n = 88$ , 68%) or daughters ( $n = 21$ , 16%). On average, the predominantly non-Hispanic white sample had 2 to 3 years of college education and a median household income of \$41,000 to \$60,000 per year.

### Analysis

Statistical analyses for normality and group differences were performed using SPSS version 17.0 (SPSS, Inc., Chicago, IL), including one-way analysis of variance (ANOVA) and the Kruskal-Wallis (variables with nonnormal distribution) and Pearson chi-square (categorical variables) tests of appropriate independent variables across four naturally occurring outcome groups. Post hoc tests of significant ANOVA findings were conducted. To discover variables eligible for use in a mistreatment screening instrument for CGs of older adults with dementia, independent-sample *T*-tests and Mann-Whitney tests were conducted for comparison of "mistreatment" and "no mistreatment" groups. Receiver operating characteristic curve (ROC) analyses of 10 independent variables were conducted, as well as further ROC tests of combinations of variables.

**Table 1. Participant Characteristics**

Characteristic	Care Recipient	Caregiver
<b>Demographic</b>		
Female, n (%)	59 (45.7)	90 (69.8)
Age, mean $\pm$ SD	77.1 $\pm$ 8.0	66.5 $\pm$ 12.3
Married, n (%)	94 (72.8)	104 (81)
Income, \$1,000/year, median	41–60 K	41–60 K
Education, years, mean $\pm$ SD	14.2 $\pm$ 3.3	15.0 $\pm$ 2.5
Hispanic, n (%)	11 (8.5)	11 (8.5)
Caucasian, n (%)	121 (93.8)	114 (88.4)
<b>Disease stage, n (%)<sup>*</sup></b>		
Mild	60 (46.5)	
Moderate	55 (42.6)	
Severe	14 (10.9)	
<b>Interpersonal and contextual measures</b>		
Relationship, spouse, n (%)	88 (68.2)	
Caregiving duration > 2 years, n (%)	74 (57.4)	
Co-residence, n (%)	119 (92.2)	
Number of services used, mean $\pm$ SD	5.1 $\pm$ 2.1	
Premorbid relationship, mean $\pm$ SD	33.2 $\pm$ 4.8 <sup>†</sup>	

<sup>\*</sup> Based on a standard segmentation of Dementia Severity Rating Scale scores.

<sup>†</sup> As measured with the Mutual Communal Behaviors Scale.

SD = standard deviation.

## RESULTS

### Prevalence and Outcome Groups

The LEAD panel determined that 61 CRs (47.3%) had been mistreated. Of them, 54 (88.5%) experienced psychological abuse, 13 (19.7%) physical abuse, and 18 (29.5%) neglect. The CG self-reported CTS2 psychological aggression and physical abuse scales were consistent with their LEAD-determined psychological and physical abuse outcomes (each with Pearson chi-square  $P < .001$ ). Evidence of abuse indicated on the neglect scale of the Elder Abuse Instrument was significantly associated with LEAD decisions for neglectful caregiving (Pearson's Chi Square,  $P = .001$ ), as was any indication that the CR was unsafe on the SotE (Pearson chi-square  $P = .004$ ). Because these data were presented to the LEAD as input to their decisions, the strong associations were expected.

Four distinct outcome categories emerged: physical abuse with other mistreatment ( $n = 12$ ; all CRs who were physically abused also experienced psychological abuse, neglect, or both); neglect without physical abuse ( $n = 13$ ; some were psychologically abused as well); psychological abuse only ( $n = 36$ ); and no mistreatment ( $n = 68$ ). These are the four mistreatment outcome groups represented in the columns of Table 2. Of mistreated older adults, 31.0% experienced multiple mistreatment types.

### Characteristics Associated with Mistreatment Groups

Table 2 gives results of statistical comparisons of these and other variables across the four outcome groups. Significant findings indicate that CGs in the physical abuse with other mistreatment group had worse scores than the no mistreatment (same as no abuse or neglect) CGs on the SF12 emotional health scales: role limitations due to emotional problems (the CG's self-assessment of the degree to which emotional problems have interfered with activities) and poorer mean emotional status (the CG's self-assessment of mood states). The two CTS2 scales of the CR's physical assault and psychological aggression behavior were also worse for physically mistreated CRs, and they also had lower income. Neglect without physical abuse differed from the no mistreatment group in that CGs had higher mean perceived burden and fewer social contacts, and both CR behavior scores were worse. CRs who were neglected also had lower income and less education. Those who were psychologically abused only differed from the no mistreatment group by having higher CG mean perceived burden and the same poor CR behavior markers as the other mistreatment groups. There were also some significant differences between mistreatment groups (Table 2). None of the interpersonal measures differed significantly between groups, and of the demographic measures, only income and education differed.

Tests comparing mistreatment and no mistreatment groups were conducted to discover which variables were the best candidates for a screening tool for mistreatment of people with dementia by their CGs (Table 3). The following characteristics differed between the two groups. CG's who mistreated CRs had significantly lower mean education level and worse general emotional health and were more likely to have more depressive symptoms, greater state anxiety, and higher perceived burden. CRs who were mis-

**Table 2. Group Comparisons**

Characteristic	Mean ± Standard Deviation				P-Value*
	Physical Abuse with Other Mistreatment n = 12	Neglect without Physical Abuse n = 13	Psychological Abuse Only n = 36	No Abuse or Neglect n = 68	
<b>Demographic measures</b>					
Caregiver income <sup>†</sup>	4.1 ± 2.1	4.2 ± 2.5	4.6 ± 2.2	4.4 ± 2.3	.89
Caregiver education, years	14.3 ± 2.5	14.2 ± 2.1	14.6 ± 2.4	15.5 ± 2.4	.08
Care recipient income <sup>†</sup>	3.2 ± 1.8 <sup>a</sup>	3.1 ± 2.6 <sup>b</sup>	4.1 ± 2.3	4.8 ± 2.7 <sup>ab</sup>	.047
Care recipient education, years	14.35 ± 2.8	11.7 ± 2.9 <sup>ab</sup>	14.4 ± 3.2 <sup>a</sup>	14.6 ± 3.4 <sup>b</sup>	.03
<b>Caregiver health and emotional measures</b>					
Health status	62.5 ± 29.2	67.3 ± 23.7	70.0 ± 24.8	70.6 ± 23.2	.65
Physical functioning	75.0 ± 32.0	88.5 ± 19.4	76.4 ± 29.8	84.2 ± 26.6	.34
Role limitations due to emotional problems	29.2 ± 39.6 <sup>ab1</sup>	57.7 ± 44.9	69.4 ± 41.9 <sup>a</sup>	77.9 ± 37.0 <sup>b</sup>	.001
Emotional status	63.3 ± 12.3	62.3 ± 27.4	64.4 ± 20.8	72.7 ± 17.1	.07
Depressive symptoms	6.5 ± 3.0	5.4 ± 5.2	5.2 ± 3.8	4.0 ± 3.6	.10
State anxiety	36.6 ± 10.0	38.5 ± 16.5	36.9 ± 12.0	31.5 ± 10.2	.049 <sup>§</sup>
Perceived burden	7.5 ± 5.7	11.1 ± 6.3 <sup>a</sup>	9.0 ± 7.3 <sup>b</sup>	6.0 ± 6.2 <sup>ab</sup>	.03
Social contacts	34 ± 5.5	28.8 ± 9.2 <sup>ab</sup>	35.7 ± 7.0 <sup>a</sup>	35.5 ± 7.1 <sup>b</sup>	.02
<b>Care recipient health, emotional, and behavior measures</b>					
Functional capacity	21.8 ± 14.4	23.5 ± 13.5	19.3 ± 11.7	21.0 ± 14.0	.79
Disease stage	24.9 ± 11.7	24.4 ± 10.3	21.0 ± 9.2	22.7 ± 10.5	.59
Depressive symptoms	2.9 ± 1.6	3.5 ± 2.8	3.1 ± 2.1	2.6 ± 1.7	.27
Social contacts	12.3 ± 4.1	12.7 ± 4.9	16.3 ± 6.0	15.4 ± 5.8	.08
Physical assault	8.4 ± 16.6 <sup>a</sup>	11.8 ± 29.0	5.2 ± 23.4 <sup>b</sup>	1.3 ± 5.4 <sup>ab</sup>	.001 <sup>  </sup>
Psychological aggression	28.6 ± 31.1 <sup>a</sup>	22.9 ± 22.3 <sup>b</sup>	23.9 ± 27.5 <sup>c</sup>	6.2 ± 11.9 <sup>a</sup>	<.001
Neuropsychiatric behaviors	14.6 ± 16.8	18.1 ± 9.4	16.0 ± 16.4	13.1 ± 15.4	.65

\* One-way analysis of variance unless otherwise specified.

<sup>†</sup> Based on 6-point Likert scale from 1 = <\$15,000/year to 6 = >\$81,000/year; 4 = \$41,000–60,000/year.

<sup>‡</sup> Significant post hoc test differences between groups are indicated with matching alpha characters ( $P < .05$ ).

<sup>§</sup> Although significant, the post hoc tests were not significant.

<sup>||</sup> Kruskal-Wallis nonparametric test for comparison of means for “k” independent samples, and Mann-Whitney  $U$  post hoc tests for differences between groups.

treated had lower mean income and were more likely to engage in physical assault and psychological aggression behaviors toward their CGs.

Optimal sensitivity and specificity in relation to the LEAD outcomes were derived from ROC analyses of significant independent variables (Table 3). Combining the variables with the best specificity (occurrence of any CR physical assault incidents in the previous year) and best balance between sensitivity and specificity (occurrence of more than 4 CR psychological aggression incidents in the previous year) gave the best screening option (sensitivity = 75.4%, specificity = 70.6%). If the CR had assaulted the CG (e.g., hitting, slapping) or was repeatedly aggressive psychologically (e.g., shouting, insulting), the CG had probably committed one or a combination of the three kinds of mistreatment.

### Potential Screening Questions

The CTS2 physical assault scale converted for this study to assess CR behavior consists of 12 items. Nearly all CGs who mistreated (18/19, 94.7%) stated that one of three of these items had occurred at least once in the previous year.

- The patient threw something at me that could hurt.
- The patient pushed or shoved me.

- The patient grabbed me.

The CTS2 psychological aggression scale for the CR is seven items. Most CGs who mistreated (45/51, 88.0%) indicated that one of three of these items had occurred at least three times in the past year.

- The patient insulted or swore at me.
- The patient shouted or yelled at me.
- The patient stomped out of the room, house, or yard during a disagreement.

In the sample, a positive response to any of these six questions would result in 18.6% (24/129) false-positive rate. One way to reduce false positives is with follow-on questions asking the CG about doing these same six actions toward the patient. This and other studies have found this to be a successful strategy for getting those who mistreat to admit to their own abusive actions.<sup>49</sup>

### DISCUSSION

This study shows that people with dementia have high rates of mistreatment despite access to good medical care. Whereas prior studies have failed to validate actual presence of elder mistreatment against a diagnostic standard, this study uses the best standard available, namely the

**Table 3. Comparisons: Mistreatment and No Mistreatment Groups**

Characteristic	Mean (SD)		P-Value*	Sensitivity/Specificity, % <sup>†</sup>
	Abuse, Neglect, or Both n = 61	No Abuse or Neglect n = 68		
<b>Demographic measures</b>				
Caregiver income <sup>‡</sup>	4.4 ± 2.2	4.4 ± 2.3	.90	
Caregiver education, years	14.4 ± 2.3	15.5 ± 2.4	.01	57.4/60.1
Care recipient income <sup>‡</sup>	3.7 ± 2.3	4.8 ± 2.7	.01	60.3/57.4
Care recipient education, years	13.8 ± 3.2	14.6 ± 3.4	.15	
<b>Caregiver health and emotional measures</b>				
Health status	65.6 ± 25.1	70.6 ± 23.2	.24	
Physical functioning	78.7 ± 28.4	84.2 ± 26.6	.26	
Role limitations due to emotional problems	59.0 ± 44.3	77.9 ± 37	.01	70.6/50.8
Emotional status	63.8 ± 20.8	72.7 ± 17.1	.009	52.9/67.2
Depressive symptoms	5.6 ± 4.0	4.0 ± 3.6	.02	57.4/66.2
State anxiety	37.2 ± 12.6	31.5 ± 10.2	.006	57.4/63.2
Perceived burden	9.2 ± 6.8	6.0 ± 6.2	.007	73.8/52.9
Social contacts	33.9 ± 7.7	35.5 ± 7.1	.21	
<b>Care recipient health, emotional, and behavior measures</b>				
Functional capacity	20.7 ± 12.6	20.1 ± 14.0	.89	
Disease stage	22.5 ± 9.9	22.7 ± 10.5	.90	
Depressive symptoms	3.2 ± 2.2	2.6 ± 1.7	.08	
Social contacts	14.7 ± 5.7	15.4 ± 5.8	.51	
Physical assault	7.2 ± 23.3	1.3 ± 5.4	.002 <sup>§</sup>	31.1/91.2
Psychological aggression	24.6 ± 26.9	6.2 ± 11.9	<.001	72.1/72.1
Neuropsychiatric behaviors	16.2 ± 15.1	13.1 ± 15.4	.25	

\* T-test of two independent samples, except as noted.

<sup>†</sup> For detecting mistreatment as defined by a LEAD (Longitudinal, Experts, All Data) panel.

<sup>‡</sup> Based on 6-point Likert scale from 1 = <\$15,000/year to 6 = >\$81,000/year; 4 = \$41,000–60,000/year.

<sup>§</sup> Mann-Whitney nonparametric test of two independent samples.

LEAD panel, to determine presence or absence of mistreatment. The study also demonstrates that, when asked, CGs of patients with dementia will admit to mistreatment. This finding is consistent with a recently published paper from England.<sup>49</sup> The current study confirms a high percentage of simultaneous occurrence of multiple types of mistreatment.<sup>28,31</sup>

Clinicians should be alert to CGs who show signs of anxiety or depression or who mention difficult behaviors of the CR, because the current study suggests that these CGs are more likely to be mistreating their CRs. CGs with low education or few or poor social connections or whose emotional problems affect their activities deserve screening for intervention and prevention of elder mistreatment. Physicians should be particularly concerned about aggressive CRs with dementia because of the likelihood that they suffer physical or psychological mistreatment.

These preliminary findings from a convenience sample indicate that several questions of the CG about the behavior of a patient with dementia may be an effective screen for predicting whether the CG is mistreating the patient. Because the study data are cross-sectional, the CR may have been behaving badly in response to mistreatment, the CG may have been reacting to the CR's behavior, or both. Not only were these CR behaviors a good indicator of mistreatment, but clinicians can be comfortable with incorporating

them into a screening tool, because directly questioning a CG about the behavior of a patient with dementia is a clinical issue as well. It seems that elder mistreatment goes on for months or years before it rises to a level that is detected, if it ever is. There is an opportunity to minimize suffering for the CR and CG through early detection.

## LIMITATIONS AND FUTURE RESEARCH

This study was cross-sectional, and the study sample is biased in being better educated and better off financially than most people with dementia and their CGs. Longitudinal studies are needed to investigate causal relationships and change in abuse patterns and types of abuse over time. For example a hypothesis of a life cycle of CG mistreatment, beginning with psychological abuse, escalating to physical abuse, and culminating in isolation and neglect, could be tested.

Because all CGs were informed that suspected mistreatment would be reported, it is possible that this affected their candor in responding to the questions about abuse and neglect. The self-selecting convenience sample of English-speaking CGs and people with dementia, recruited largely through physicians and service providers, invited researchers into their homes. It is possible that those who are more isolated and wary of participation in research are even more

vulnerable to abuse and neglect, experiencing even higher mistreatment rates than this study reports. Also, characteristics associated with mistreatment may differ in the dementia population not available for this project. Future research should expand the subsamples of people with dementia experiencing one or more categories of mistreatment so that statistically based predictive models can be developed for each subsample.

The suggested screening questions have not been tested in a clinical environment. Skilled elder mistreatment researchers conducting home assessments obtained the data. A follow-on study is needed to test the validity of these questions when used by clinicians in a clinical setting. Screening results must be compared with mistreatment outcomes obtained through validated research methods, such as those used in this study.

## CONCLUSION

Because this and other studies show that close to half of people with dementia being cared for by a family member at home experience some form of mistreatment,<sup>13,14,28</sup> routine screening of these individuals is essential. The current study results show that CR aggressive behaviors indicate that the CR is being mistreated. If asked in an empathetic and supportive manner, CGs will admit to abusive behaviors. Clinicians who care for people with dementia have medical, ethical, and legal responsibilities to evaluate the caregiving situation for indicators of mistreatment.

## ACKNOWLEDGMENTS

The Institute for Memory Impairments and Neurological Disorders provided access to research participants recruited for the following grants: P50 AG16573, Alzheimer's Disease Research Center at UCI and State of California; H&W 06-55313, Alzheimer's Disease Research Center of California at UCI. We are grateful to the Alzheimer's Association of Orange County for recruiting their clients as participants. Thanks also to the Alzheimer's Family Services Center and Director, Cordula Dick-Muehlke, PhD, and to UCI clinicians who conducted direct mailings to their clients: Claudia Kawas, MD, Bonnie Olsen, PhD, and Simin Torabzadeh, MD. The professionalism and compassion of the researchers as they collected data from caregiving dyads ensured the success of the project: Pamela Berkson, RN, NP, Sandhya Rao, MS, PT, and Maureen Barnett, BA. Also, thanks to Szu-Yun Leu, PhD, of the General Clinical Research Center, UCI, for consultation on the statistical analyses; Maria Corona, MS, for conducting preliminary analyses; and Dara Sorkin, PhD, Dana Mukamel, PhD, and Janel Alberts, PhD, for reviewing and commenting on a draft version of this article. Western Psychological Services approved use of the CTS2 modified for self-assessment of CGs of older adults.

**Conflict of Interest:** The editor in chief has reviewed the conflict of interest checklist provided by the authors and has determined that the authors have no financial or any other kind of personal conflicts with this paper.

**Author Contributions:** Dr. Mosqueda is responsible for the study concept and served as principal investigator and project director. Dr. Wiglesworth completed and implemented the study design and served as project manager.

Dr. Mulnard was liaison with the Institute for Memory Impairments and Neurological Disorders and served on the LEAD panel, as did Drs. Mosqueda, Gibbs, Liao, and Wiglesworth. Drs. Wiglesworth and Fitzgerald collaborated in designing the study analyses. Dr. Wiglesworth conducted the analyses and prepared the draft manuscript; all other authors reviewed it, and their contributions were incorporated.

**Sponsor's Role:** The project was supported through a research grant from the California Department of Health Services: State of California H&W 04-35515: Abuse of Elders with Dementia: Toward a Model of Prediction. Statistical analyses conducted under the auspices of the UCI General Clinical Research Center were funded by National Institutes of Health Grant GCRC:MO1 RR0082.

## REFERENCES

- Hansberry MR, Chen E, Gorbien MJ. Dementia and elder abuse. *Clin Geriatr Med* 2005;21:315–332.
- Reis M. Validation of the Caregiver Abuse Screen (CASE). *Can J Aging* 1995;14(Suppl 2):45–61.
- Fulmer T, Street S, Carr K. Abuse of the elderly: Screening and detection. *J Emerg Nurs* 1984;10:131–140.
- Reis M, Nahmiash D. Validation of the Indicators of Abuse (IOA) screen. *Gerontologist* 1998;38:471–480.
- Taylor DK, Bachuwa G, Evans J et al. Assessing barriers to the identification of elder abuse and neglect: A communitywide survey of primary care physicians. *J Natl Med Assoc* 2006;98:403.
- Kennedy RD. Elder abuse and neglect: The experience, knowledge, and attitudes of primary care physicians. *Fam Med* 2005;37:481.
- Jones JS, Veenstra TR, Seamon JP et al. Elder mistreatment: National survey of emergency physicians. *Ann Emerg Med* 1997;30:473.
- Fulmer T, Guadagno L, Dyer CB et al. Progress in elder abuse screening and assessment instruments. *J Am Geriatr Soc* 2004;52:297.
- American Medical Association Diagnostic and Treatment Guidelines on Elder Abuse and Neglect. Chicago: American Medical Association, 1992.
- Neale AN, Hwalek MA, Scott RO et al. Validation of the Hwalek-Sengstock elder abuse screening test. *J Appl Gerontol* 1991;10:406–418.
- Yaffe MJ, Wolfson C, Lithwick M et al. Development and validation of a tool to improve physician identification of elder abuse: The Elder Abuse Suspicion Index (EASI). *J Elder Abuse Negl* 2008;20:276–300.
- Cohen M, Halevi-Levin S, Gaglin R et al. Development of a screening tool for identifying elderly people at risk of abuse by their caregivers. *J Aging Health* 2006;18:660–685.
- VandeWeerd C, Paveza GJ. Verbal mistreatment in older adults: A look at persons with Alzheimer's disease and their caregivers in the state of Florida. *J Elder Abuse Negl* 2005;17:11–30.
- Cooney C, Mortimer A. Elder abuse and dementia—a pilot study. *Int J Soc Psychiatry* 1995;41:276–283.
- Pot AM, van Dyck R, Jonker C et al. Verbal and physical aggression against demented elderly by informal caregivers in the Netherlands. *Soc Psychiatry Psychiatr Epidemiol* 1996;31:156–162.
- Cooney C, Wrigley M. Abuse of the elderly with dementia. *Ir J Psychol Med* 1996;13:94–93.
- Paveza GJ, Cohen D, Eisdorfer C et al. Severe family violence and Alzheimer's disease: Prevalence and risk factors. *Gerontologist* 1992;32:493–497.
- Cohen M, Levin SH, Gaglin R et al. Elder abuse: Disparities between older people's disclosure of abuse, evident signs of abuse, and high risk of abuse. *J Am Geriatr Soc* 2007;55:1224–1230.
- Miller LS, Lewis MS, Williamson GM et al. Caregiver cognitive status and potentially harmful caregiver behavior. *J Aging Mental Health* 2006;10:125–133.
- Grafstrom M, Nordberg A, Winblad B. Abuse is in the eye of the beholder. *Scand J Soc Med* 1993;21:247–255.
- Coyne AC, Reichman WE, Berbig LJ. The relationship between dementia and elder abuse. *Am J Psychiatry* 1993;150:643–646.
- Williamson GM, Shaffer DR. Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychol Aging* 2001;16:217–226.
- Compton SA, Flanagan P, Gregg W. Elder abuse in people with dementia in Northern Ireland: Prevalence and predictors in cases referred to a psychiatry of old age service. *Int J Geriatr Psychiatry* 1997;12:632–635.

24. Lee M, Kolomer S. Caregiver burden, dementia, and elder abuse in South Korea. *J Elder Abuse Negl* 2005;17:61–74.
25. Pillemer K, Suitor JJ. Violence and violent feelings: What causes them among family caregivers? *J Gerontol* 1992;47:S165–S172.
26. Beach SR, Schulz R, Williamson GM et al. Risk factors for potentially harmful informal caregiver behavior. *J Am Geriatr Soc* 2005;53:255–261.
27. Cooper C, Katona C, Finne-Soveri H et al. Indicators of elder abuse: A cross-national comparison of psychiatric morbidity and other determinants in the Ad-HOC Study. *Am J Geriatr Psychiatry* 2006;14:489–497.
28. Cooney C, Howard R, Lawlor B. Abuse of vulnerable people with dementia by their carers: Can we identify those most at risk? *Int J Geriatr Psychiatry* 2006;21:564–571.
29. Hamel M, Gold DP, Andres D et al. Predictors and consequences of aggressive behavior by community-based dementia patients. *Gerontologist* 1990;30:206–211.
30. Bonnie RJ, Wallace RB, editors. *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: The National Academies Press, 2003.
31. National Center on Elder Abuse. *The National Elder Abuse Incidence Study: Final Report*; 1998.
32. Applebaum PS, Grisso T, Eds *MacCAT-CR: MacArthur Competence Assessment Tool for Clinical Research*. Sarasota, FL: Professional Resource Press, 2001.
33. Mosqueda L, Burnight K, Liao S et al. Advancing the field of elder mistreatment: A new model for integration of social and medical services. *Gerontologist* 2004;44:703–708.
34. Wiglesworth A, Mosqueda L, Burnight K et al. Findings from an elder abuse forensic center. *Gerontologist* 2006;46:277–283.
35. Straus MA, Hamby SL, Boney-McCoy S et al. The revised Conflict Tactics Scales (CTS2): Developmental and preliminary psychometric data. *J Fam Issues* 1996;17:283–316.
36. Dyer CB, Kelly PA, Pavlik VN et al. The making of a self-neglect severity scale. *J Elder Abuse Negl* 2006;18:13–23.
37. Pillemer K, Finkelhor D. The prevalence of elder abuse: A random sample survey. *Gerontologist* 1988;28:51–57.
38. Ware JJ, Kosinski M, Keller SD. A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34:220–233.
39. Kohout FJ, Berkman LF, Evans LF et al. Two shorter forms of the CES-D Depression Symptoms Index. *J Aging Health* 1993;5:179–193.
40. Radloff LS. The CES-D: A self-report depression scale for research in the general population. *Appl Psych Meas* 1977;1:385–401.
41. Spielberger CD. Assessment of state and trait anxiety: Conceptual and methodological issues. *Southern Psychol* 1985;2:6–16.
42. Cummings JL, Mega M, Gray K et al. The neuropsychiatric inventory: Comprehensive assessment of psychopathology in dementia. *Neurology* 1994;44:2308–2314.
43. Kaufer DI, Cummings JL, Christine D et al. Assessing the impact of neuropsychiatric symptoms in Alzheimer's disease: The neuropsychiatric inventory caregiver distress scale. *J Am Geriatr Soc* 1998;46:210–215.
44. Lubben JE. Assessing social networks among elderly populations. *Fam Commun Health* 1988;11:42–52.
45. Bucks RS, Ashworth DL, Wilcock GK et al. Assessment of activities of daily living in dementia: Development of the Bristol activities of daily living scale. *Age Ageing* 1996;25:113–120.
46. Clark CM, Ewbank DC. Performance of the dementia severity rating scale: A caregiver questionnaire for rating severity in Alzheimer disease. *Alzheimer Dis Assoc Disord* 1996;10:31–39.
47. Segal DL, Hersen M, Van Hasselt VB. Reliability of the structured clinical interview for DSM-III-R: An evaluative review. *Comp Psychiatry* 1994;35:316–327.
48. Williamson GM, Schulz J. Caring for a family member with cancer: Past communal behavior and affective reactions. *J Appl Soc Psychol* 1995;25:93–116.
49. Cooper C, Selwood A, Blanchard M et al. Abuse of people with dementia by family carers: Representative cross sectional survey. *BMJ* 2009;338:b155.