Original Article

Comparative Analysis of Informal Caregiver Burden in Advanced Cancer, Dementia, and Acquired Brain Injury

Richard Harding, PhD, Wei Gao, PhD, Diana Jackson, PhD, Clare Pearson, MSc, Joanna Murray, BA, and Irene J. Higginson, PhD, FFPM, FRCP

Department of Palliative Care, Policy and Rehabilitation, Cicely Saunders Institute (R.H., W.G., D.J., C.P., I.J.H.), and Health Service & Population Research, Institute of Psychiatry (J.M.), King’s College London, London, United Kingdom

Abstract

Context. Measurement and improvement of informal caregiver burden are central aims of policy and intervention. Burden itself is a complex construct, and total burden can differ by patient diagnosis, although how diagnosis affects different aspects of caregiver subjective burden is unclear.

Objectives. To compare the subjective burden of caregivers across three diagnostic groups using the 22-item Zarit Burden Inventory.

Methods. We performed a secondary analysis of pooled cross-sectional data from four U.K. studies of informal caregivers of patients with advanced cancer (n = 105), dementia (n = 131), and acquired brain injury (ABI) (n = 215). Zarit Burden Inventory totals, subscales (personal and role strain), and individual mean scores were compared between diagnostic groups using the general linear model, adjusting for caregiver characteristics.

Results. Caregiver age (mean years [SD]: cancer 66.1 [12.0]; dementia 61.9 [13.4]; and ABI 53.8 [10.9]) differed significantly across diagnostic groups (P < 0.001); 81.9%, 36.6%, and 59.1% of caregivers were spouse/partners, respectively (P < 0.001). Total burden was highest in ABI caregivers and lowest in cancer (mean total score [SD]: cancer 23.3 [13.4]; dementia 27.9 [16.4]; and ABI 39.1 [17.3]) (P < 0.001). Subscale scores showed similar patterns (mean personal and role subscale scores [SD]: cancer 11.8 [6.9], 5.8 [4.8]; dementia 14.4 [8.8], 7.3 [5.7]; and ABI 18.7 [9.1], 11.8 [6.0]) (P < 0.001 for both subscales). Most (17 of 22) individual item scores differed by diagnosis group (P < 0.05), except concepts of duty, responsibility, and perception of financial situation.

Conclusion. Our data show that total, subscale, and most individual elements of caregiver subjective burden differ between cancer, dementia, and ABI caregivers. This should be considered when designing future intervention strategies to reduce caregiver burden in these groups. J Pain Symptom Manage 2015; - e-211. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words
Burden, caregiver, cancer, acquired brain injury, dementia, Zarit Burden Inventory

Introduction

The caregiver (or informal carer) holds a unique position of both providing and needing support. Caregivers can bear personal financial costs, which are comparable to or more expensive than those of inpatient care1-5 and can suffer many health problems, such as poor psychological morbidity,4-6 impaired immune function,7 and deterioration in overall health.8 In addition, caregiving itself is an independent risk factor for mortality in caregivers older than 65 years9 and increased coronary heart disease risk.10

Health and social policy have given increasing responsibility to caregivers of patients with acute or chronic illness. As populations age, the burden of care will fall increasingly on caregivers (families,
significant others, and friends. Without caregivers who themselves have adequate health and well-being (both physical and psychological), patient home discharge from acute care may be delayed, domestic informal care arrangements more likely to break down, unplanned patient admissions/transfer to institutional care more likely, and higher levels of costly professional input in the home required. As institutional care more likely, and higher levels of costly professional input in the home required, the Zarit Burden Inventory (ZBI) is one of the most widely referred to as caregiver burden, the 22-item Zarit subjective burden among caregivers (hereafter conceptual domains of need. As increasing number of people become informal caregivers, the provision of support and health care to caregivers to both enable them to care and reduce their morbidity and mortality is becoming a pressing public health issue. An established body of evaluative research exists examining the efficacy of interventions for informal caregivers in dementia and older patients in general. Evidence is also growing in cancer, acquired brain injury (ABI), and palliative care.

A central methodological challenge to the science of intervention valuation studies among caregivers is the lack of appropriate ways to measure caregiver outcomes. The goals of many caregiver interventions are linked with perceived caregiver burden, which itself is associated with negative health outcomes in caregivers of those with common conditions, such as dementia, stroke, and cancer. In caregivers of these and other life-limiting conditions, burden has been shown to predict lower quality of life, anxiety, depression, and collapse (carer breakdown). The concept of burden is commonly applied in health care studies of caregivers and can be defined as both objective burden (the social impact on daily life) and subjective burden (the perception of emotional, social, and relationship strains, anxiety, and depression). Interventions must respond to the needs of specific caregiver populations (and also be individually tailored within diagnostic groups) and not assume that caregivers of different patient diagnostic groups experience similar levels of subjective burden, or that their subjective burden is constituted by identical domains of need.

Among the existing tools that measure the level of subjective burden among caregivers (hereafter referred to as caregiver burden), the 22-item Zarit Burden Inventory (ZBI) is one of the most widely used and has shown reliability in assessing burden of caregivers of patients with dementia, physical illness, and mental illnesses. Two subscales have been derived from the ZBI using factor analysis: personal strain and role strain, which are used to group certain caregiver burden questions together, reflecting psychological aspects and the general impact on the caregiver’s life, respectively. These two subscales have been examined in dementia caregivers and evaluated in ABI caregivers. Additionally, a cut-off score of 24 (within the ZBI total range of 0–88) has been statistically derived for medical practitioners to identify and assess caregivers at risk of depression and encourage them to seek support.

Some differences in caregiver burden between diagnostic groups have been identified using the ZBI (total burden score), specifically between types of dementia, dementia and nondementia patients, and between Parkinson’s disease and dementia caregivers in Tanzania. Caregivers of patients with advanced cancer, dementia, and ABI may face not only some common challenges but also some differences in burden. To our knowledge, no previous study has provided a detailed comparison of subjective burden between these groups, using ZBI subscales and individual question comparisons to further investigate differences in burden by these diagnostic groups. These groups were selected as three quite different patient groups; dementia caregivers usually provide long-term care to elderly people; ABI patients are generally younger; and advanced cancer has a shorter disease trajectory.

The aim of this analysis was to compare caregiver burden scores (total, subscale, and individual questions) among relatively large samples of caregivers of three diverse groups of patients; advanced cancer, dementia, and ABI.

**Methods**

**Design and Data Sources**

This secondary analysis used data pooled from four studies of caregivers (n = 451) of patients with advanced cancer (n = 105), dementia (n = 131), and ABI (n = 215):

1. Baseline data from a multicenter evaluation of palliative day care for advanced cancer patients, involving six centers across the south of England;
2. Baseline data from a two-center evaluation of the “90 Minute Group,” a supportive intervention for the caregivers of palliative care patients with advanced cancer;
3. A national postal questionnaire survey of caregiver experiences of ABI, including those with head injuries, strokes, and brain infections (e.g., encephalitis);
4. Baseline data from a prospective longitudinal cohort study of caregiver burden in dementia involving participants from South East London.

Each study collected data from caregivers using the self-report 22-item ZBI (ZBI-22), with interviewers present in the advanced cancer and dementia studies to collect the questionnaire data and provide support
to respondents if needed. In the ABI study, the postal questionnaire was followed up by telephone interviews with caregivers, enabling missing or ambiguous scores to be clarified.

Responses to each of the 22 items in the ZBI were made on five-point Likert scales from 0 (never) to 4 (nearly always). Overall burden was assessed by the total score of all items, with a higher score representing a greater caregiving burden. In addition to the ZBI, the pooled data set contained basic demographic data: caregiver age, gender, relationship to patient, and patient diagnosis. All analyses used anonymous records with no personal identifiable information; therefore, ethical approval was not required for this secondary analysis. Full ethical approval was separately granted for each of the original studies.

Statistical Analysis

Sample Characteristics. Demographic characteristics among the three groups were compared using the Kruskal-Wallis test for age and the Chi-squared or Fisher’s exact tests (as appropriate) for gender and relationship to patients.

ZBI: Overall, Subscale, and Individual Question Scores. The total score, personal strain score, and role strain score of the ZBI were summarized by boxplots in the three diagnostic groups. Subsequently, the mean score of each of the 22 individual items was plotted and connected with nonsmoothed lines to provide a visual profile comparison by diagnostic groups. The group differences in mean individual question scores and summary subscale scores were examined using the general linear model. The model was adjusted for caregiver age, gender, and relationship to patient. Variables for inclusion in the model were selected based on both \( P \)-values \( (P \leq 0.05) \) in the univariate test and the previous literature, that is, a variable would also be included into the model if prior evidence showed it is an important predictor for caregiving burden but did not show significance in the univariate testing. We used this variable selection strategy because the conventional significance-alone method often leads to the deletion of important confounders, thus increasing vulnerability to bias. Holm-modified Bonferroni procedure was used to control the Type I error for multiple testing. The previously derived cutoff total ZBI score of 24 was used to classify those at risk of depression. A two-tailed 0.05 level of significance was used for all statistical tests. All analyses were carried out using the SAS 9.1 package (SAS Institute, Inc., Cary, NC).

Results

Sample Characteristics

The demographic characteristics of three caregiving populations are presented in Table 1. There were statistically significant differences for both age and kin relationship distribution across the three groups. Caregivers of patients with advanced cancer were older than those of ABI \((P < 0.0001)\) and dementia \((P < 0.0001)\) patients, and the caregivers for ABI were among the youngest (dementia vs. ABI: \(P = 0.014\)). There was no difference in gender distribution across the three groups \((\chi^2_{(df=2)} = 5.50, P = 0.06)\). Most of the caregivers (76.5%) were females. Spouses or partners were taking a major or substantial caring role, whereas the other caregivers’ involvement in caring activities, to a certain degree, mirrored the age pattern of the patient’s diagnosis. For example, patients with advanced cancer were generally older, and 81.9% of caregivers were their spouse/partner; but for ABI patients, as the youngest among the three groups, 57.9% of their carers were their spouse/partner, with 36.7% of ABI carers being parents, whereas only 3.8% of the advanced cancer caregivers were parents (Table 1). The differences of frequency distribution for kin relationship were statistically significant between ABI and advanced cancer \((P < 0.001)\) and ABI and dementia \((P < 0.001)\), but

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total</th>
<th>Cancer</th>
<th>Dementia</th>
<th>ABI</th>
<th>(P)Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>451</td>
<td>105</td>
<td>131</td>
<td>215</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>59.0 (13.0)</td>
<td>66.1 (12.0)</td>
<td>61.9 (13.4)</td>
<td>53.8 (10.9)</td>
<td>0.06</td>
</tr>
<tr>
<td>Median (minimum, maximum)</td>
<td>59 (18, 89)</td>
<td>70 (26, 88)</td>
<td>63 (21, 85)</td>
<td>55 (18, 89)</td>
<td>0.06</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>106 (23.5)</td>
<td>29 (27.6)</td>
<td>37 (28.2)</td>
<td>40 (18.6)</td>
<td>0.06</td>
</tr>
<tr>
<td>Female (%)</td>
<td>345 (76.5)</td>
<td>76 (72.4)</td>
<td>94 (71.8)</td>
<td>175 (81.4)</td>
<td>0.06</td>
</tr>
<tr>
<td>Relationship</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/partner (%)</td>
<td>261 (57.9)</td>
<td>86 (81.9)</td>
<td>48 (36.6)</td>
<td>127 (59.1)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Son/daughter (%)</td>
<td>69 (15.3)</td>
<td>11 (10.5)</td>
<td>58 (44.3)</td>
<td>0 (0.0)</td>
<td>0.06</td>
</tr>
<tr>
<td>Parent (%)</td>
<td>83 (18.4)</td>
<td>4 (3.8)</td>
<td>0 (0.0)</td>
<td>79 (36.7)</td>
<td>0.06</td>
</tr>
<tr>
<td>Others (%)</td>
<td>38 (8.4)</td>
<td>4 (3.8)</td>
<td>25 (19.1)</td>
<td>9 (4.2)</td>
<td>0.06</td>
</tr>
</tbody>
</table>

ABI = acquired brain injury.
there was no difference between advanced cancer and dementia ($P = 0.27$).

**ZBI: Overall, Subscale, and Individual Question Scores**

Fig. 1 presents boxplots showing score distributions of total ZBI and the two subscales, personal strain and role strain, in informal caregivers of advanced cancer, dementia, and ABI patients. Caregivers of patients with advanced cancer had the lowest score on the total and two subscales, and those caring for ABI had the highest score on the same three subjective burden scales.

Most observed differences in raw scores of global burden were significant ($P_{	ext{ABI vs. Cancer}} < 0.0001$, $P_{	ext{ABI vs. Dementia}} = 0.029$), personal strain ($P_{	ext{ABI vs. Cancer}} < 0.0001$, $P_{	ext{ABI vs. Dementia}} = 0.06$, $P_{	ext{Cancer vs. Dementia}} = 0.039$), and role strain ($P_{	ext{ABI vs. Cancer}} < 0.0001$, $P_{	ext{ABI vs. Dementia}} = 0.012$, $P_{	ext{Cancer vs. Dementia}} = 0.027$). These differences remained significant even after the difference in caregivers’ age, gender, and relationship to the patient among the three groups were taken into account. Here, caregiver age and relationship were selected into the model on the basis of their statistical significance in the univariate testing and gender on the prior evidence as an important predictor of subjective caregiving burden.

The raw mean and SD were calculated for individual items of the inventory and are displayed in Table 2. A profile chart plotted with the adjusted means is also presented (Fig. 2). Item-specific score showed a similar pattern with that of the global and two subscale scores: the ABI group of caregivers had the highest, whereas the advanced cancer group had the lowest mean score on most of the ZBI items. Most of the differences between ABI and advanced cancer (17 of 22) reached significance level. The differences of half of the ZBI items (q4–q6, q9, q11, q12, q18, and q20–q22) were statistically significant between advanced cancer and dementia, but only six (q1–q3, q17, q20, and q21) of 22 items were significant between ABI and dementia. There was no significant difference observed on five items (q7, q8, q14, q15, and q19) across three diagnostic groups.

With a total score of 24 as the cutoff point, 49%, 56%, and 79% of caregivers for patients with advanced cancer, dementia, and ABI, respectively, were deemed as at risk for depression ($\geq 24$). The proportion of those at risk for depression using this cutoff was significantly different across three groups ($P < 0.001$, $\chi^2_{df=2} = 35.5$).

**Discussion**

In this first comparison of these particular caregiver groups, there are several key findings from our data that may inform future research methods and intervention strategies to support the high needs of informal caregivers of these diagnosis groups, who are often a neglected population.

In our samples, the age of caregivers and their relationship to patients differed significantly between the three diagnostic groups. Caregivers of advanced cancer patients were older, whereas ABI caregivers were significantly younger, meaning that their needs are likely to vary, for example, physical morbidity, opportunity cost in terms of lost employment, and relationship issues (e.g., managing loss of aspects of their relationship). The nature of the relationship between caregiver and patient also varied; with a larger number of ABI caregivers being parents of the patient, cancer caregivers being partners, and dementia caregivers...
Table 2
Mean (SD) for Individual ZBI-22 Items and Mean Comparisons Across Diagnoses

<table>
<thead>
<tr>
<th>Item</th>
<th>Question</th>
<th>Cancer N = 105</th>
<th>Dementia N = 131</th>
<th>ABI N = 215</th>
<th>P-Value (F-Value, df)</th>
<th>Multiple Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q1</td>
<td>Relative asks for more help (p)</td>
<td>0.65 (0.90)</td>
<td>0.66 (0.97)</td>
<td>1.35 (1.09)</td>
<td>&lt;0.001 (10.25, 2)</td>
<td>b**, c**</td>
</tr>
<tr>
<td>Q2</td>
<td>Have enough time for self (r)</td>
<td>1.42 (1.34)</td>
<td>1.34 (1.42)</td>
<td>2.43 (1.16)</td>
<td>&lt;0.001 (8.79, 2)</td>
<td>b**, c**</td>
</tr>
<tr>
<td>Q3</td>
<td>Feel stressed between caring &amp; meeting other responsibilities (r)</td>
<td>1.59 (1.29)</td>
<td>1.65 (1.40)</td>
<td>2.52 (1.27)</td>
<td>0.015 (4.42, 2)</td>
<td>b**, c**</td>
</tr>
<tr>
<td>Q4</td>
<td>Embarrassed over behaviors (p)</td>
<td>0.40 (0.82)</td>
<td>0.76 (1.01)</td>
<td>1.33 (1.12)</td>
<td>&lt;0.001 (13.69, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q5</td>
<td>Angry when around your relative (p)</td>
<td>0.71 (0.88)</td>
<td>1.12 (1.08)</td>
<td>1.14 (1.05)</td>
<td>0.004 (5.74, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q6</td>
<td>Affects your relationship with others (r)</td>
<td>0.44 (0.84)</td>
<td>0.88 (1.16)</td>
<td>1.50 (1.27)</td>
<td>&lt;0.001 (10.27, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q7</td>
<td>Afraid of what the future holds for relative</td>
<td>2.38 (1.27)</td>
<td>2.22 (1.47)</td>
<td>2.90 (1.05)</td>
<td>0.50 (0.72, 2)</td>
<td>NA</td>
</tr>
<tr>
<td>Q8</td>
<td>Dependent on you (p)</td>
<td>2.81 (1.18)</td>
<td>2.72 (1.53)</td>
<td>3.14 (1.07)</td>
<td>0.23 (1.48, 2)</td>
<td>NA</td>
</tr>
<tr>
<td>Q9</td>
<td>Strained when around your relative (p)</td>
<td>0.92 (0.93)</td>
<td>1.63 (1.26)</td>
<td>1.65 (1.19)</td>
<td>&lt;0.001 (10.60, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q10</td>
<td>Your health suffered</td>
<td>1.03 (1.16)</td>
<td>1.27 (1.31)</td>
<td>2.03 (1.30)</td>
<td>&lt;0.001 (8.95, 2)</td>
<td>b**</td>
</tr>
<tr>
<td>Q11</td>
<td>Enough privacy (r)</td>
<td>0.55 (0.11)</td>
<td>0.98 (1.37)</td>
<td>1.81 (1.33)</td>
<td>&lt;0.001 (11.04, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q12</td>
<td>Social life has suffered (r)</td>
<td>1.48 (1.45)</td>
<td>1.76 (1.53)</td>
<td>2.44 (1.27)</td>
<td>&lt;0.001 (9.14, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q13</td>
<td>Uncomfortable about having friends over (r)</td>
<td>0.34 (0.96)</td>
<td>0.50 (0.93)</td>
<td>1.07 (1.29)</td>
<td>&lt;0.001 (7.52, 2)</td>
<td>b**</td>
</tr>
<tr>
<td>Q14</td>
<td>Expects you to take care/dependent on you (p)</td>
<td>1.62 (1.65)</td>
<td>1.68 (1.70)</td>
<td>1.74 (1.46)</td>
<td>0.62 (0.48, 2)</td>
<td>NA</td>
</tr>
<tr>
<td>Q15</td>
<td>Do not have enough money</td>
<td>1.14 (1.44)</td>
<td>0.88 (1.31)</td>
<td>1.67 (1.44)</td>
<td>0.25 (1.40, 2)</td>
<td>NA</td>
</tr>
<tr>
<td>Q16</td>
<td>Unable to take care for much longer (p)</td>
<td>0.50 (0.91)</td>
<td>0.76 (1.07)</td>
<td>1.04 (1.20)</td>
<td>0.026 (3.69, 2)</td>
<td>b**</td>
</tr>
<tr>
<td>Q17</td>
<td>Have lost control of life (p)</td>
<td>0.96 (1.22)</td>
<td>1.19 (1.34)</td>
<td>2.14 (1.38)</td>
<td>&lt;0.001 (10.70, 2)</td>
<td>b**, c**</td>
</tr>
<tr>
<td>Q18</td>
<td>Leave the care to someone else (p)</td>
<td>0.34 (0.79)</td>
<td>0.86 (1.21)</td>
<td>1.09 (1.20)</td>
<td>&lt;0.001 (8.59, 2)</td>
<td>a**, b**</td>
</tr>
<tr>
<td>Q19</td>
<td>Uncertain what to do about relative (p)</td>
<td>0.89 (1.09)</td>
<td>1.27 (1.24)</td>
<td>1.26 (1.21)</td>
<td>0.29 (1.23, 2)</td>
<td>NA</td>
</tr>
<tr>
<td>Q20</td>
<td>Should be doing more (p)</td>
<td>1.05 (1.24)</td>
<td>1.02 (1.19)</td>
<td>1.49 (1.21)</td>
<td>0.007 (4.99, 2)</td>
<td>a**, c**</td>
</tr>
<tr>
<td>Q21</td>
<td>Could do a better job (p)</td>
<td>0.99 (1.12)</td>
<td>0.76 (1.04)</td>
<td>1.34 (1.17)</td>
<td>0.001 (6.78, 2)</td>
<td>a**, c**</td>
</tr>
<tr>
<td>Q22</td>
<td>Overall how burdened</td>
<td>1.05 (1.18)</td>
<td>1.75 (1.27)</td>
<td>2.06 (1.30)</td>
<td>&lt;0.001 (16.74, 2)</td>
<td>a**, b**</td>
</tr>
</tbody>
</table>

ZBI-22 = 22-item Zarit Burden Inventory; ABI = acquired brain injury; df = degrees of freedom.
Score range: 0 = never to 4 = nearly always.
*P < 0.05, **P < 0.01, and NA: no significant differences across the three diagnosis groups.
(p) — included in the personal strain subscale and (r) — included in the role strain subscale.
*The mean comparisons have been adjusted for the differences in carer’s gender and the relationship to patient.

being patients’ children. These differences emphasize the need to understand the nature of the relationship and its contribution to burden within different diagnostic groups when designing and delivering supportive interventions.

Although all caregivers were burdened in the samples, the ABI caregivers consistently self-reported higher subjective burden (total, both subscales, and individual questions) than the caregivers of the other two diagnostic groups. This may be because ABI caregivers spend more time on daily caring activities in the longer term compared with carers of patients with dementia or advanced cancer. Moreover, behavioral problems that many people with ABI present with, such as aggression, are known to be strong predictors of caregiver burden, and ABI patients attract fewer accessible and specific services than the other groups.40 These reasons also may be contributory factors to differences between the ABI and advanced cancer caregivers on most individual items of the ZBI. Although the advanced cancer caregiving population reported lower comparative burden than the ABI and dementia caregivers, we urge caution when interpreting these particular findings. First, it is important to note that the advanced cancer caregivers were sampled from specialist palliative care services, and the aim of palliative care is to support the family caring unit alongside the patient.47 Therefore, we would expect the caregiving burden of similar patients in the absence of palliative care to be higher.48,49 And palliative care is still only received by a fraction of those who may benefit from it.50 Second, as the ZBI was originally developed to assess burden in dementia caregivers, it might not catch all important aspects of caregiving for advanced cancer patients. Usually, a shorter but more intense period of informal caregiving occurs for advanced cancer patients compared with dementia or ABI patients.23,51

It is interesting to note the behavior of the individual Zarit items between the groups where no differences between groups were detected (five of the 22 items). The populations sampled scored similarly for items describing caregiver feeling afraid of the future, feeling the patient is dependent on them, feeling that the patient expects their caregiver to take care of them, having money concerns, and feeling unsure what to do. These items are indicative of a combination of two main themes: a sense of dependency and responsibility, and practical concerns. The first two of these five particular questions (dependency on
carer and feeling afraid for the future) have the highest of individual mean scores in each of the diagnosis groups, suggesting these are common concerns among all caregivers. The other three are fairly consistently low scoring. Our data suggest that these constituent items of caregiver burden do not vary in their severity between caregiving populations.

This study is the first comparison of large groups of caregivers of those with advanced cancer, dementia, and ABI, which are conditions that are all increasingly relevant with an aging population and rising incidence of cancer and dementia. The larger sample size of the ABI study was perhaps reflective of it being a nationwide (U.K.) study, whereas the other diagnostic group participants were drawn from South London. Nevertheless, the number of participants in each group is relatively large compared with previous comparisons of caregiver burden between diagnostic groups.

We recognize several limitations of this study. First, methodological differences between the original data sets (data collection, sampling strategies, and instrument bias) could explain some of the differences in caregiver burden between the diagnosis groups, as could the differences in caregiving characteristics for each diagnosis group, although caregiver characteristics were controlled for in this analysis. Second, our analyses were restricted to the limited number of common demographic variables in the pooled data set and did not include information about whether the caregiver was the primary carer and if they lived with the patient; therefore, we could not identify any further associations beyond the common covariates. However, key variables previously identified in the literature are included (caregiver age, gender, and relationship to patient), and caregiver (rather than patient) characteristics were more strongly associated with high burden in a previous comparison. Third, the performance comparisons were evaluated with cross-sectional data; therefore, we can neither take into account the changing nature of caregiver burden over time as a disease progresses nor address causality. Finally, the cutoff point for depression risk using the ZBI has not been validated or reliably tested. Additionally, the sensitivity (true positive) and specificity (true negative) for all caregivers were 72% and 63%, respectively, meaning that 28% of those above the cutoff score will not be at risk for depression and 37% of those scoring below 24 will be at higher risk. Caution, therefore, should be applied to the interpretation of the results of the depression risk in each diagnosis groups and differences between groups.

These results offer new data to support responsive interventions to the needs of different caregiving populations and to differentiate between diagnosis groups for the support needed, particularly for mental health care. Further work exploring the use of the ZBI as a tool for caregiver burden in different diagnosis groups (i.e., revalidation), either the 22 item or previously validated short forms, would expand the evidence base to detect differences between these caregiving populations. We also would recommend further prospective research into caregiver burden using longitudinal methods to investigate the changing nature of caregiving during different disease trajectories.
Disclosures and Acknowledgments

The original studies were supported by the National Health Service Executive (London and South East), which funded Projects 1 and 2; the Department of Health (R&D grant 030/0066) funded Project 3; and the Department of Health Policy Research Programme funded Project 4. The views expressed in this publication are those of the authors and not necessarily those of the Department of Health. Further financial support for article preparation was provided by the Luff Foundation and the Dunhill Medical Trust. Dr. Gao is 50% supported by the National Cancer Research Institute, U.K., a part of the “COMplex interventions: Assessment, trials and implementation of Services in Supportive and Palliative Care (COMPASS)” collaborative.

The authors thank the patients, carers, staff, and volunteers who participated in the original studies including: 1) six-day and home hospice and palliative care services who recruited and interviewed patients and carers, Danielle Goodwin, and other interviewers in the study; 2) two home palliative care services in London, Celia Leam, and Liz Taylor who worked with us to recruit patients, and Alison Pearce, research assistant; 3) research assistants Shehla Kazim, Amanda Tadrous, and Joel Sheridan and representatives of Headway, the Encephalitis Society and the Meningitis Trust, who helped to disseminate information about the ABI study to carer participants; 4) Community Mental Health Teams for older adults in the South London and Maudsley Mental Health Trust, and the research workers, Beth Foley and Louise Atkins.

References


50. Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, and Palliative Care Section of the Royal Society of Medicine, London, UK. Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives. Southampton: Association for Palliative Medicine of Great Britain and Ireland, 2012.

