

## 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;50:445–452. © 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 care<sup>1–3</sup> and can suffer many health problems, such as poor psychological morbidity,<sup>4–6</sup> impaired

immune function,<sup>7</sup> and deterioration in overall health.<sup>8</sup> In addition, caregiving itself is an independent risk factor for mortality in caregivers older than 65 years<sup>9</sup> and increased coronary heart disease risk.<sup>10</sup>

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,

Address correspondence to: Richard Harding, PhD, Department of Palliative Care, Policy and Rehabilitation, Cicely Saunders Institute, King's College London, Bessemer Road, London

SE5 9PJ, United Kingdom. E-mail: [richard.harding@kcl.ac.uk](mailto:richard.harding@kcl.ac.uk)

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significant others, and friends).<sup>11</sup> 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,<sup>12</sup> unplanned patient admissions/transfer to institutional care more likely, and higher levels of costly professional input in the home required.<sup>13</sup> 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<sup>14,15</sup> and older patients in general.<sup>16,17</sup> Evidence is also growing in cancer,<sup>18,19</sup> acquired brain injury (ABI),<sup>20,21</sup> and palliative care.<sup>22,23</sup>

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.<sup>24–26</sup> In caregivers of these and other life-limiting conditions, burden has been shown to predict lower quality of life,<sup>27</sup> anxiety, depression, and collapse (carer breakdown).<sup>12</sup> 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).<sup>28,29</sup> 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)<sup>30</sup> is one of the most widely used<sup>31</sup> and has shown reliability in assessing burden of caregivers of patients with dementia, physical illness, and mental illnesses.<sup>32</sup> Two subscales have been derived from the ZBI using factor analysis: personal strain and role strain,<sup>33,34</sup> which are used to group certain caregiver burden questions together, reflecting psychological aspects and the general impact on the caregiver's life, respectively.<sup>35</sup> These two subscales have been examined in dementia caregivers<sup>36</sup> and evaluated in ABI caregivers.<sup>35</sup> 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.<sup>37</sup>

Some differences in caregiver burden between diagnostic groups have been identified using the ZBI (total burden score), specifically between types of dementia,<sup>38</sup> dementia and nondementia patients,<sup>39,40</sup> and between Parkinson's disease and dementia caregivers in Tanzania.<sup>41</sup> 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;<sup>42,43</sup>
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;<sup>44</sup>
3. A national postal questionnaire survey of caregiver experiences of ABI, including those with head injuries, strokes, and brain infections (e.g., encephalitis);<sup>40</sup>
4. Baseline data from a prospective longitudinal cohort study of caregiver burden in dementia involving participants from South East London.<sup>3,25</sup>

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

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