

## Original Article

# Caregiver Expectations: Predictors of a Worse Than Expected Caregiving Experience at the End of Life

Emma J. Burns, BMed, BA(Hons Soc Ant), FRACGP, FACHPM, Stephen J. Quinn, BMath, MMath, PhD, Amy P. Abernethy, MD, PhD, and David C. Currow, BMed, MPH, PhD, FRACP

Central Adelaide Palliative Care Services (E.J.B.), The Queen Elizabeth Hospital, Adelaide; School of Medicine (S.J.Q.) and Discipline of Palliative and Supportive Services (A.P.A., D.C.C.), Flinders University, Adelaide, South Australia, Australia; and Division of Medical Oncology (A.P.A.), Department of Medicine, Duke University Medical Center, Durham, North Carolina, USA

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## Abstract

**Context.** The gap between informal caregivers' expectations of caregiving at the end of life and their actual caregiving experience has important affective and behavioral consequences.

**Objectives.** This study analyzes for the first time the characteristics of those caregivers who report a worse or much worse than expected caregiving experience, providing a potential for future targeted intervention into the caregiving experience.

**Methods.** The South Australian Health Omnibus is an annual, random, face-to-face, and cross-sectional survey. From 2000 to 2007, respondents were asked a range of questions about end-of-life care, including in several years a question about how the caregiving experience compared with caregivers' expectation(s). Family members and friends who reported a worse or much worse than expected caregiving experience were the focus of this analysis. Univariable and multivariable logistic regression models were created to better define this group.

**Results.** Of the 1628 active caregivers for people at the end of life, almost half (48.3%) reported a worse or much worse than expected caregiving experience. A worse or much worse than expected caregiving experience was significantly associated with gender and with level of care provided. Women who provided daily hands-on care were significantly more likely to have a worse than expected experience compared with women who provided intermittent care (odds ratio [OR] 0.65; 95% CI 0.48–0.88;  $P = 0.005$ ) or rare care (OR 0.39; 95% CI 0.27–0.56;  $P < 0.001$ ). Of all those providing rare care, women were significantly less likely than men to report a worse than expected caregiving experience (OR 0.61; 95% CI 0.41–0.93;  $P = 0.020$ ).

**Conclusion.** Caregiver expectations represent a novel and important focus for investigation into the caregiver experience. Explicitly eliciting expectations may in future lead to ways of better supporting caregivers. *J Pain Symptom Manage* 2015;50:453–461. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Palliative care, caregivers, population survey, expectations, lived experience

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## Introduction

Informal caregivers for people at the end of life are a crucial resource in the community. Factors such as increasing life expectancy and population aging mean that demand for informal caregivers is likely to increase over time.<sup>1,2</sup> For reliance on this unpaid workforce to be sustainable, informal caregivers need to be both

available and willing to take on this role,<sup>1,3–5</sup> often more than once in a lifetime.<sup>1</sup> Understanding and optimizing the caregiving experience is essential to retention of the informal caregiving workforce and to the continuous improvement of outcomes for all stakeholders.

An extensive body of both quantitative and qualitative literature has documented the many burdens

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Address correspondence to: David C. Currow, BMed, MPH, PhD, FRACP, Discipline of Palliative and Supportive Services, Flinders University, Adelaide, South Australia, Australia. E-mail: [David.currow@health.sa.gov.au](mailto:David.currow@health.sa.gov.au)

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associated with informal caregiving at the end of life.<sup>3,4,6,7</sup> There is consensus that this role is associated with significant personal costs, including health, economic, and social costs, as well as a range of potential benefits. However, research into the caregiver burden has been limited by the absence of a guiding theoretical or conceptual framework, by a lack of definitional consensus and clarity, and by the use of small nonrepresentative study samples.<sup>4,6</sup> Other challenges include the heterogeneous nature of the caregiver group and the changing caregiving experience across different disease states over time.<sup>2,7-10</sup> As a result, existing analyses have found it difficult to identify effective and transferable interventions into the caregiver burden.<sup>4,6</sup>

Caregiver expectations represent an important and novel focus in the analysis of the caregiver experience and of caregiver satisfaction in the end-of-life setting. Outside the field of hospice/palliative care, there is an established body of literature focusing on the relationship between people's expectations and their satisfaction with outcomes.<sup>11-21</sup> In short, it is seen that individual satisfaction is increased when expectations are confirmed (or exceeded) by actual experience.<sup>14-16,20-22</sup> Conversely, when expectations are disappointed, individuals experience a range of affective and behavioral consequences including reduced satisfaction.<sup>11,13,17,18</sup> Such negative experiences may have a range of implications, including impacts on caregiver well-being and retention, and flow-on effects for the patient for whom care is being provided.

The aim of this study is to identify and characterize those people who reported a worse or much worse than expected caregiving experience while caring for someone at the end of life. A guiding theoretical and conceptual framework is offered, providing a context for the interpretation of these results and enabling the suggestion of targeted interventions into the caregiving experience. The null hypothesis is that there will be neither sociodemographic factors of the caregiver or the deceased nor service factors to help us identify those people who report a worse or much worse than expected caregiving experience.

## Methods

### Setting

South Australia has 8% of Australia's population, with most people living in the capital city, Adelaide. Other communities spread across the state are relatively small. Two key demographic features are different from the rest of the country. South Australia has a slightly older population than the rest of the country, with 15.4% of people older than 65 years compared with 13.3%

nationally. Twenty percent of people from South Australia were born outside Australia compared with 22% across the nation.

### Survey Methodology and Subjects

Data were collected in the South Australian Health Omnibus Survey (HOS), a state-wide, face-to-face, and cross-sectional health survey administered annually since 1991 to approximately 3000 different respondents annually, aged 15 years and older.<sup>23,24</sup> The methodology has not changed in that time and is a multistage, self-weighting, systematic, and clustered-area sample of households. Seventy-five percent of the sample is drawn from greater Adelaide and outside Adelaide, and the likelihood of a community being selected was proportional to its size. Communities with a population of less than 1000 inhabitants were neither included nor were residents of residential aged-care facilities. HOS used the Australian Bureau of Statistics' Collectors Districts (CDs). There are approximately 200 dwellings per CD, and 340 CDs (from 2041 metropolitan and 1010 nonmetropolitan CDs) were randomly selected annually. A starting point within each CD was then also randomly selected, with a standard skip pattern being used to define the properties that would ultimately be approached. The survey continues to sample until 3000 responses are generated annually.

After pilot testing with 50 members of the general public, the HOS is conducted each Spring. Other than standard sociodemographic data, it is open to any researchers to purchase the space to insert questions of interest. A broad range of health and social topics are canvassed in the face-to-face interview that lasts approximately 90 minutes.

### Data Collection

One interview by a trained interviewer was conducted in each responding household. The person who most recently had a birthday older than 15 years was the selected respondent. If the selected respondent was unavailable, they were not replaced by another household member.

For respondents who identified that someone close to them had died from a terminal illness in the last five years, further information was gathered including whether care was provided. Care was defined for the respondent as including "attention to any of the needs of the person, including hands-on care, overnight care, respite, shopping, collection of medications, taking to appointments, emotional support, bathing, etc." The respondents also were asked to categorize the intensity of care provided: day-to-day hands-on care (care five to seven days per week), intermittent hands-on care (care two to four days per week), or rare hands-on care (care one or less days per week).

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