Uncovering an invisible network of direct caregivers at the end of life: A population study
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What is This?
Uncovering an invisible network of direct caregivers at the end of life: A population study

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Abstract
Background: Most palliative care research about caregivers relies on reports from spouses or adult children. Some recent clinical reports have noted the assistance provided by other family members and friends.
Aim: This population study aims to define the people who actually provide care at the end of life.
Setting/participants: A South Australian study conducted an annual randomized health population survey (n=23,706) over a 7 year period. A sample was obtained of self-identifying people who had someone close to them die and ‘expected’ death in the last 5 years (n=7915). Data were standardised to population norms for gender, 10-year age group, socioeconomic status, and region of residence.
Results: People of all ages indicated they provided ‘hands on’ care at the end of life. Extended family members (not first degree relatives) and friends accounted for more than half (n=1133/2028; 55.9%) of identified hands-on caregivers. These people came from the entire age range of the adult community. The period of time for which care was provided was shorter for this group of caregivers. People with extended family or friends providing care, were much more likely to be supported to die at home compared to having a spousal carer.
Conclusion: This substantial network of caregivers who are mainly invisible to the health team provide the majority of care. Hospice and palliative care services need to create specific ways of identifying and engaging this cohort in order to ensure they are receiving adequate support in the role. Relying on ‘next-of-kin’ status in research will not identify them.

Keywords
Palliative care, caregivers, community networks

Introduction
It is known that support provided by family and friends is a major determinant of whether seriously ill patients can remain at home.1–3 When in good health, most people state they would prefer to die at home.4–6 Supportive care networks for the aged have been well mapped: day to day, close friends and relatives other than their adult children are more likely to provide emotional and instrumental support.7 Community connections, including friends, neighbours and siblings account for almost half of these supportive relationships8,9 with gender influencing their composition.10 Interestingly, the widowed or never married generally had larger helping networks, while childless people maintain close kin relationships.11 Sociological
research confirms intergenerational solidarity is being maintained with earlier conflict in parent–child relationships seldom interfering in contemporary exchanges of help and support.

Recent findings from two qualitative studies suggest that the focus of service providers needs to shift from the primary caregiver to family/community networks in palliative care. Waldrop suggests the concept of the caregiver shift to thereby incorporate various family members who are not identified on the medical record but are involved in end-of-life care. She also identifies secondary caregivers who provide respite care or additional support, including emotional support for primary caregivers. Horsfall et al., while exploring the quality and effect of networks established or strengthened as a result of caring for a person who had chosen to die at home, found that people’s friendships and community connections increased. At the same time, if admission to an inpatient unit is required, this can present an opportunity for families to complete aspects of their lifelong relationship with the person who is dying.

Over the last 12 years, a programme of work has been undertaken to gain an insight into the care of people at the end of life using whole-of-population representative face-to-face interviews, identifying respondents who have experienced the expected death of someone close. An important profile has emerged: one in three people have had someone close to them die in the last 5 years of an expected illness. Caregiving for these people at the end of life is a frequent activity: 1 in 10 respondents will have provided care and 1 in 30 will have done so intensively, undertaking day-to-day hands-on care. The aim of this study is to clarify the relationship of caregivers to care recipients at the end of life. Using a clinimetric approach, the level of caring was identified with four categories offered: daily ‘hands-on’ care, intermittent ‘hands-on’ care, rare ‘hands-on’ care and ‘no care involvement but still close’ (Figure 1). ‘Care’ was defined to include the contribution to any of the needs of the deceased person from physical care such as bathing to shopping, transport to appointments to collection of medications. What emerges is a frequently ‘invisible’ network of caregivers who are providing support and care for people in the end-of-life setting.

Methods

Setting

South Australia, sparsely settled, comprises 8% of the national population, with most people living in and around the capital city, Adelaide. Australia’s mostly urban population is young with 13.3% aged above 65 years (15.4% in South Australia), with 22% born overseas (20% in South Australia).

Figure 1. Questions asked about palliative and end-of-life care in the South Australian Health Omnibus 2000–2007. Highlights in gray indicate data used in these analyses.

Subjects

The data for this survey were collected in the South Australian Health Omnibus Survey (HOS), a state government–associated health survey administered annually since 1991 to approximately 3000 residents per year, aged 15 years and above. Between 2001 and 2007, a total of 33,300 households were selected for the survey, which was conducted annually during September to November.

Survey methodology

The full survey methodology is detailed elsewhere. Previously, the content and construct validity supporting the use of this survey tool in palliative care service planning and in assessing the impact of palliative care services on caregiver needs have been verified. Palliative care questions have formed a section of the survey since 2000 (Figure 1). The HOS is a multistage, systematic, clustered area sample of households conducted by face-to-face interview. Test
questions were piloted with 50 members of the general public annually.23,25

Data collection. One interview by a trained interviewer was conducted per household with the person aged 15 years or above who most recently had a birthday.

Data analysis. Each year, the survey data were weighted to the most recent Australian Bureau of Statistics Census by sex, 10-year age groups, socio-economic status, rurality and probability of selection within the household to provide population estimates, allowing analysis over several years.22,25,26 Descriptive statistics were used to summarize respondent characteristics and responses. Relationships between categorical variables were tested using the chi-squared test, and chi-squared test for trend with \( p \) values were assumed if \( p < 0.05 \). Logistic regression was used to determine the relationship between selected variables of interest (of caregivers and deceased) and the deceased dying at home when the respondent was an active caregiver. All variables that had a \( p < 0.25 \) at the univariate level were entered into the logistic regression model.27 The SPSS statistical package, 19, was used for analysis.28

Respondents were split into three distinct cohorts for analysis. Clinical and socio-demographic characteristics were determined for the following categories:

- The deceased,
- Caregiver characteristics likely to remain stable, independent of the death of someone close and
- Caregivers characteristics that are more likely to change as a result of caregiving or the death of the care recipient.

Our prior work has demonstrated stability of the first and second sub-categories.23 Due to potentially changing attributes, analyses related to the third should be interpreted with caution even when statistically significant.

The survey is approved annually by the Human Research Ethics Committee, Department of Health, South Australia. Verbal consent and continued participation is accepted given the face-to-face nature of the interview with members of the public in their own homes.

Results

When asked to indicate whether someone ‘close to them had died of a terminal illness like cancer, motor neurone disease or emphysema’ in the proceeding 5 years, this was true for 33% (\( n = 7914 \)) of respondents from the total sample population (\( N = 23,588 \)).23

Invisible network of care

Using definitions presented, bereaved respondents were asked whether they had provided care for the deceased individual. As expected, one cohort of caregivers was those usually identified in the medical records – first-degree relatives, including spouses/partners, parents, adult children or siblings. In addition, we identified a large cohort of ‘invisible’ contributors to end-of-life care – extended family members, including grandparents, aunts, uncles, nieces and nephews, friends, neighbours and community members. The ‘invisible network’ of caregivers comprised the majority (56%) of ‘hands-on’ caregivers and first-degree relatives comprised the minority (\( p<0.001 \)) (Table 1).

<table>
<thead>
<tr>
<th>Role intensity</th>
<th>Caregivers (first-degree relatives; ( n = 895 ))</th>
<th>Sub-total 'Invisible network of caregivers' (( n = 1133 ))</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Hands-on' care (( n \approx 2028 ))</td>
<td>Spouse/partner Parent/adult child Siblings</td>
<td>Extended family Friends Others</td>
</tr>
<tr>
<td>Daily</td>
<td>172 239 34</td>
<td>145 64 14</td>
</tr>
<tr>
<td>Intermittent</td>
<td>20 283 36</td>
<td>268 197 31</td>
</tr>
<tr>
<td>Rare</td>
<td>11 81 19</td>
<td>269 114 31</td>
</tr>
<tr>
<td>Sub-total</td>
<td>203 603 89</td>
<td>682 375 76</td>
</tr>
<tr>
<td>No care, but still close</td>
<td>21 381 268 670</td>
<td>2236 1719 189 4148 4818</td>
</tr>
<tr>
<td>Total</td>
<td>224 984 357 1565</td>
<td>2918 2094 265 5281 6846</td>
</tr>
</tbody>
</table>

Table 1. Profile of the ‘hands-on’ caregivers × role intensity and relationship with deceased in a survey of caregivers after being in the role in South Australia 2001–2007.
third stating that they earned more than AUD$60,000 per annum while a small number (14%) earned less than AUD$20,000.

Table 2. Socio-demographic profile of the ‘invisible network’ of caregivers – people who provided active care and were not first-degree relatives in a population survey in South Australia 2001–2007.

<table>
<thead>
<tr>
<th>Characteristics of population</th>
<th>n = 1133 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>42</td>
</tr>
<tr>
<td>Female</td>
<td>58</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>&lt;35</td>
<td>36.0</td>
</tr>
<tr>
<td>35–44</td>
<td>19.2</td>
</tr>
<tr>
<td>45–54</td>
<td>19.9</td>
</tr>
<tr>
<td>55–64</td>
<td>12.7</td>
</tr>
<tr>
<td>65–74</td>
<td>8.8</td>
</tr>
<tr>
<td>75+</td>
<td>3.4</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>65.3</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>8.3</td>
</tr>
<tr>
<td>Widowed</td>
<td>2.6</td>
</tr>
<tr>
<td>Never married</td>
<td>8.7</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
</tr>
<tr>
<td>Australia</td>
<td>81.0</td>
</tr>
<tr>
<td>United Kingdom and Ireland</td>
<td>9.4</td>
</tr>
<tr>
<td>Other European countries</td>
<td>5.0</td>
</tr>
<tr>
<td>Asia</td>
<td>1.1</td>
</tr>
<tr>
<td>New Zealand</td>
<td>0.4</td>
</tr>
<tr>
<td>Other</td>
<td>3.1</td>
</tr>
<tr>
<td>Aboriginal or Torres Strait Islander</td>
<td>2.5</td>
</tr>
<tr>
<td>Educational attainment</td>
<td></td>
</tr>
<tr>
<td>Still at school</td>
<td>4.2</td>
</tr>
<tr>
<td>Left before 15 years</td>
<td>8.9</td>
</tr>
<tr>
<td>Left after 15 years</td>
<td>29.0</td>
</tr>
<tr>
<td>Trade qualifications</td>
<td>15.5</td>
</tr>
<tr>
<td>Certificate/diploma</td>
<td>26.9</td>
</tr>
<tr>
<td>Bachelor degree</td>
<td>15.5</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>38.5</td>
</tr>
<tr>
<td>Part time</td>
<td>24.7</td>
</tr>
<tr>
<td>Home duties</td>
<td>12.0</td>
</tr>
<tr>
<td>Retired</td>
<td>13.3</td>
</tr>
<tr>
<td>Student</td>
<td>7.0</td>
</tr>
<tr>
<td>Other, unemployed or injured worker</td>
<td>4.5</td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>Up to AUD$20,000</td>
<td>14.1</td>
</tr>
<tr>
<td>AUD$20,000–AUD$40,000</td>
<td>17.8</td>
</tr>
<tr>
<td>AUD$40,001–AUD$60,000</td>
<td>18.6</td>
</tr>
<tr>
<td>&gt; AUD$60,000</td>
<td>33.7</td>
</tr>
<tr>
<td>Not stated</td>
<td>15.7</td>
</tr>
<tr>
<td>Residence</td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>67.3</td>
</tr>
<tr>
<td>Rural</td>
<td>32.7</td>
</tr>
</tbody>
</table>

Role activity defines caregiving of bereaved respondents

The investigators previously described distinct caregiver sub-populations at the end of life.20 Among all bereaved, 668 (10%) provided daily care, 837 (12%) provided intermittent care and 519 (8%) provided rare care. While spouses, as expected, tended to undertake daily ‘hands-on’ care, equal proportions of either parents or adult children and siblings provided daily or intermittent care. Among the ‘invisible network’, a surprising number (almost a third of the total) engaged in daily ‘hands-on’ care.

Caregiving across the life course

Care for people with life-limiting conditions occurs across the life course (Figure 2). Young people (<35 years) provided care across all ages up to and including those above 85 years. Older people (>75 years) cared mostly for other older people, or for those a decade younger. On rare occasions, they cared for the very young. Those in early or late middle age provided care to all, across the life course.

General perception of support

The ‘invisible network’ of caregivers (70%) was significantly (p ≤ 0.001) more likely to undertake their role for less than 1 year, in contrast to first-degree relatives (58%) (Table 3). One quarter of the latter caregivers provided ‘hands-on’ care for more than 2 years in contrast to 14% of the invisible network. Palliative care services differed in use with 64% of the invisible network drawing upon this resource compared to 59% (p = 0.026) of caregivers.

Just on one half of the ‘invisible network’ showed equanimity around their expectations of their experience: with 35% indicating it was ‘as expected’, and 17% that it was ‘much better’ than they anticipated. Nonetheless, 42% said it was ‘worse, or much worse than expected’. Among close family caregivers, there was a significant difference (p ≤ 0.001) with 44% reporting it was as expected or better and the same proportion reporting it was worse or much worse than they had anticipated, while 12% did not know what to expect (Table 3). These differences in expectations were reflected in significant differences (p ≤ 0.001) in their grief response, with 22% of the invisible network in comparison to 38% of other caregivers seeking help for their grief.

Both the invisible network (56%) and family caregivers (60%) indicated that they could have had more support. However, for specified areas, figures were comparatively low: physical (17% and 21%) and nursing care (7% for both groups). Information needs for both groups ranged from 12% to 17%, with unmet spiritual and financial support accounting for a very low proportion. Reports of emotional support differed, with 9% of the
invisible network in contrast to 16% of the alternate caregivers indicating more help was needed. A total of 13% of the invisible network and 16% of the family caregivers perceived the deceased person could also have had more emotional support. Finally, when tested with the question would you assist with care again in this situation, 79% and 72% said yes, they would assist with care again if needed.

Place of death

The role the invisible network of caregivers might play in the possibility of staying home to die was explored via logistic regression (Table 4). The ‘invisible network’ was crucial to dying at home. ‘Invisible’ caregivers doubled the likelihood of home death (Table 4). When broken down into specific groups, this included friends (p = 0.013), where the odds ratio (OR) was more than doubled (OR = 2.57, confidence interval (CI): 1.22–5.41); others in the community (p = 0.0027), where the OR was almost trebled (OR = 2.90, CI: 1.13–7.47) and the extended family, where, while the p value was not significant, the OR was elevated (OR = 1.33, CI: 0.62–2.87). Among the family group, while the p value was not significant, siblings providing ‘hands-on’ care increased the likelihood of home death (OR = 1.75, CI: 0.64–4.80) (Table 4). Other factors predicting the likelihood of dying at home included the deceased having cancer (OR = 1.67, CI: 1.06–2.64); being a young caregiver, p = 0.033 (OR = 2.14, CI: 1.06–4.29) and the caregiver being on a low income, p = 0.024 (OR = 0.49, CI: 0.26–0.91).

Discussion

A network of extended family members, friends and others in the community are an important and frequently invisible resource within the circle of ‘hands-on’ caregiving at the end of life, accounting for more than half (n = 1133) of the 2028 respondents. Siblings, part of first-degree relatives, are also frequently invisible to the health team, but important to the caregiving circle.

Friends as caregivers, who were more likely to be women, increased involvement in specialist palliative care services. They offer a unique form of care when a loved one is seriously ill. The altruistic impulse is strengthened by the emotional bonds of family and friendship and thereby ensures that those who are suffering, especially from terminal conditions, are likely to find that there will be those who share their suffering. This compassion, a sympathetic consciousness of others’ distress along with a desire to alleviate it, is the underlying tie that sustains caregivers.

Intergenerational family solidarity

While the American sociologist Talcott Parsons in 1955 had argued after the Second World War that the modern nuclear family was isolated and that intergenerational connectedness had been broken, other sociologists suggested this was a myth and that instead a ‘modified extended family’ had emerged characterized by frequent intergenerational contacts and strong mutual support. Over the following decades, sociologists tackled the theory of intergenerational solidarity stimulated by the remarkable increase in age expectancy and the high fertility immediately post–Second World War in the countries (not ravaged by war) like the United States, Canada, Australia and New Zealand. It had been Durkheim at the end of the 19th century who had introduced the concept of solidarity, which he viewed as a moral phenomenon contributing to the integration and cohesion of society. Our findings dramatically illustrate that caregiving occurs across the life course – from young grandchildren contributing care for their grandparents to siblings caring for young and old brothers and sisters and aunts, uncles, nieces and nephews are likewise engaged in a widespread cloak of solidarity.

While the survival curves differ between cancer and other key degenerative conditions, such as cardiovascular disease, the comparatively long, slow change from a chronic illness to a terminal stage and the inevitable awareness of dying is helping create a modern dying role. Researchers have offered a fresh perspective from psychological theory drawing upon both psychodynamic and role theories. They emphasize a more dynamic view incorporating a life course dimension as originally presented by Eric Erikson. We note that young caregivers of the deceased who did not have cancer were much more likely to undertake longer periods of care and less likely to use palliative care services. There appears to be no research to date on the dying role and young caregivers’ experience in that setting – is it possible to have too much responsibility...
too early? What is the nature of the support that health professionals could offer?

Research into intergenerational relations has highlighted the opportunities caregiving for an ageing parent offers adult children to ‘give back’ to loved ones. This more positive view of caregiving has also been confirmed in an Australian study where caregivers viewed with pride their accomplishments in looking after loved ones. A recent US cancer survey reported greater personal strength and opening of new possibilities for those providing care for someone with a life-threatening illness.

To date, there has been no research on the positive aspects of young people contributing to the care of older family members. The fact that half of the invisible network perceived the experience to be as expected or even better begs the question, why? The recent positive caregiving research will hopefully continue to shed insight into the dying role, relationships within families and the impact on the wider community of a compassionate response. Dying at home may yet be restored as a genuine option as the nascent community hospice movement gathers pace.

Table 3. Experience of those undertaking ‘hands-on’ caregiving (daily, intermittent or rare basis) for someone at the end of life contacted through a population survey in South Australia 2001–2007.

<table>
<thead>
<tr>
<th>Caregiver experiences</th>
<th>Invisible network (n = 1133)</th>
<th>Caregivers (first-degree relatives; n = 895)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Length of care (n = 1359)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1–12 months</td>
<td>70.1</td>
<td>58.4</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>1–2 years</td>
<td>15.5</td>
<td>16.7</td>
<td></td>
</tr>
<tr>
<td>2–4 years</td>
<td>6.5</td>
<td>12.5</td>
<td></td>
</tr>
<tr>
<td>&gt;4 years</td>
<td>7.8</td>
<td>12.4</td>
<td></td>
</tr>
<tr>
<td>Used palliative care services (n = 1913)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>64.2</td>
<td>59.1</td>
<td>0.026</td>
</tr>
<tr>
<td>No</td>
<td>35.8</td>
<td>40.9</td>
<td></td>
</tr>
<tr>
<td>Expectations (n = 1008)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Much better than expected</td>
<td>16.6</td>
<td>15.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>As expected</td>
<td>35.2</td>
<td>28.4</td>
<td></td>
</tr>
<tr>
<td>Worse or much worse than expected</td>
<td>41.7</td>
<td>44.0</td>
<td></td>
</tr>
<tr>
<td>Didn’t know what to expect</td>
<td>6.5</td>
<td>12.3</td>
<td></td>
</tr>
<tr>
<td>Grief response (n = 844)</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Help with grief sought</td>
<td>22.4</td>
<td>38.5</td>
<td></td>
</tr>
<tr>
<td>No help sought with grief</td>
<td>77.6</td>
<td>61.5</td>
<td></td>
</tr>
<tr>
<td>Further support needed for (n = 808)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical care</td>
<td>15.6</td>
<td>20.8</td>
<td>0.011</td>
</tr>
<tr>
<td>Medications</td>
<td>6.6</td>
<td>6.7</td>
<td>0.916</td>
</tr>
<tr>
<td>Symptom control</td>
<td>11.1</td>
<td>12.4</td>
<td>0.462</td>
</tr>
<tr>
<td>Information on what to expect</td>
<td>15.6</td>
<td>17.2</td>
<td>0.434</td>
</tr>
<tr>
<td>Information about services</td>
<td>12.4</td>
<td>13.9</td>
<td>0.391</td>
</tr>
<tr>
<td>Emotional support for themselves</td>
<td>9.3</td>
<td>16.1</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Emotional support for the person who died</td>
<td>16.3</td>
<td>13.0</td>
<td>0.089</td>
</tr>
<tr>
<td>Other emotional support</td>
<td>5.9</td>
<td>5.7</td>
<td>0.911</td>
</tr>
<tr>
<td>Spiritual support</td>
<td>5.0</td>
<td>3.8</td>
<td>0.311</td>
</tr>
<tr>
<td>Financial support</td>
<td>6.2</td>
<td>8.1</td>
<td>0.181</td>
</tr>
<tr>
<td>Overall perception of support (n = 1463)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, needed more</td>
<td>56.3</td>
<td>59.7</td>
<td>0.258</td>
</tr>
<tr>
<td>No further support needed</td>
<td>5.8</td>
<td>7.2</td>
<td></td>
</tr>
<tr>
<td>Sufficient support was provided</td>
<td>35.0</td>
<td>30.7</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td>2.4</td>
<td>2.8</td>
<td></td>
</tr>
<tr>
<td>Care again? (n = 255)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>79.2</td>
<td>72.5</td>
<td>0.138</td>
</tr>
<tr>
<td>Maybe</td>
<td>15.3</td>
<td>17.9</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>5.5</td>
<td>9.5</td>
<td></td>
</tr>
</tbody>
</table>

Bold type indicates tests that are statistically significant.
Researchers in sociology, social demography and social epidemiology have much to offer to the lens of the bio-psychosocial model of care at the end of life. The link between the tertiary health sector, the primary health-care system and family and friends within the community will need to be strengthened as the ‘baby boomer’ generation moves into the older life phase. It also offers many people throughout Western society an opportunity to think afresh about the role of the civic society as our understanding about this new, complex phenomenon of dying of chronic disease unfolds. Our data indicate that people with varied family ties, many of them young, are prepared to engage in ‘hands-on’ care and that men in particular appear to be shifting their role.

As a research approach, we have demonstrated that it is feasible to interview this population directly for their feedback. A known challenge in end-of-life research is obtaining representative population samples. Most palliative care studies currently exploring family provision of palliative care rely on follow-up of people who had had contact with their health service, and overwhelmingly rely on reports from the spouse or identified next-of-kin. This has limited the ability to identify the broader social networks of support.

This article reports on a population-based approach to identify the ‘invisible network’ of caregivers (irrespective of whether they were touched by a palliative care service). Large population studies assist in the identification of important sub-groups. Young caregivers, who are to date almost invisible in the cancer research literature, can be integral to end-of-life care. Designing clinical studies of sufficient size to capture these differing experiences will improve the quality of our insights into end-of-life caregiving.

Table 4. Logistic regression of the likelihood of a person dying at home whose caregivers were aged 15 years and above in South Australia, 2004–2006.

<table>
<thead>
<tr>
<th>Relationship of caregiver to the deceased</th>
<th>n</th>
<th>%</th>
<th>OR</th>
<th>95% CI</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>64/371</td>
<td>17.2</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invisible</td>
<td>134/470</td>
<td>28.6</td>
<td>1.92</td>
<td>1.37–2.69</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>13/83</td>
<td>16.1</td>
<td>1.00</td>
<td></td>
<td>0.002</td>
</tr>
<tr>
<td>Parent/child</td>
<td>42/252</td>
<td>16.6</td>
<td>1.08</td>
<td>0.50–2.32</td>
<td>0.850</td>
</tr>
<tr>
<td>Sibling</td>
<td>9/36</td>
<td>24.0</td>
<td>1.75</td>
<td>0.64–4.80</td>
<td>0.279</td>
</tr>
<tr>
<td>Extended family</td>
<td>67/276</td>
<td>24.1</td>
<td>1.33</td>
<td>0.62–2.87</td>
<td>0.459</td>
</tr>
<tr>
<td>Friends</td>
<td>50/151</td>
<td>33.2</td>
<td>2.57</td>
<td>1.22–5.41</td>
<td>0.013</td>
</tr>
<tr>
<td>Other</td>
<td>17/42</td>
<td>40.8</td>
<td>2.90</td>
<td>1.13–7.47</td>
<td>0.027</td>
</tr>
</tbody>
</table>

OR: odds ratio; CI: confidence interval.
Caregivers are defined as providing ‘hands-on’ care on a daily, intermittent or rare basis.

**Implications for research**

Researchers in sociology, social demography and social epidemiology have much to offer to the lens of the bio-psychosocial model of care at the end of life. The link between the tertiary health sector, the primary health-care system and family and friends within the community will need to be strengthened as the ‘baby boomer’ generation moves into the older life phase. It also offers many people throughout Western society an opportunity to think afresh about the role of the civic society as our understanding about this new, complex phenomenon of dying of chronic disease unfolds. Our data indicate that people with varied family ties, many of them young, are prepared to engage in ‘hands-on’ care and that men in particular appear to be shifting their role.

As a research approach, we have demonstrated that it is feasible to interview this population directly for their feedback. A known challenge in end-of-life research is obtaining representative population samples. Most palliative care studies currently exploring family provision of palliative care rely on follow-up of people who had had contact with their health service, and overwhelmingly rely on reports from the spouse or identified next-of-kin. This has limited the ability to identify the broader social networks of support. This article reports on a population-based approach to identify the ‘invisible network’ of caregivers (irrespective of whether they were touched by a palliative care service).

Large population studies assist in the identification of important sub-groups. Young caregivers, who are to date almost invisible in the cancer research literature, can be integral to end-of-life care. Designing clinical studies of sufficient size to capture these differing experiences will improve the quality of our insights into end-of-life caregiving.

**Practice**

The invisibility to the health team of the largest group of day-to-day care providers is a great concern. Changes to the medical record to identify the extent of potential social support would help teams reposition the focus of their psychosocial care.

The HOS findings offer all clinicians caring for the seriously ill either as medical practitioners, nurses or allied health team members the opportunity to reconsider practice. Multidisciplinary teams conducting at least one extensive caregiver (not just family) meeting should become normative practice in end-of-life care. This would enable clarity to be achieved early about the nature of patient needs and the constructive role that a large family network has to play in sustaining high quality of life in the dying process. It offers an opportunity to redress the marginalization of the aged dying experience as already noted by researchers.

**Declaration of conflicting interests**

The authors declare that there is no conflict of interest.

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**References**


