

Young Caregivers in the End-of-Life Setting: A Population-Based Profile of an Emerging Group

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Abstract

Purpose: Little is known about young caregivers of people with advanced life-limiting illness. Better understanding of the needs and characteristics of these young caregivers can inform development of palliative care and other support services.

Methods: A population-based analysis of caregivers was performed from piloted questions included in the 2001–2007 face-to-face annual health surveys of 23,706 South Australians on the death of a loved one, caregiving provided, and characteristics of the deceased individual and caregiver. The survey was representative of the population by age, gender, and region of residence.

Findings: Most active care was provided by older, close family members, but large numbers of young people (ages 15–29) also provided assistance to individuals with advanced life-limiting illness. They comprised 14.4% of those undertaking “hands-on” care on a daily or intermittent basis, whom we grouped together as active caregivers. Almost as many young males as females participate in active caregiving (men represent 46%); most provide care while being employed, including 38% who work full-time. Over half of those engaged in hands-on care indicated the experience to be worse or much worse than expected, with young people more frequently reporting dissatisfaction thereof. Young caregivers also exhibited an increased perception of the need for assistance with grief.

Conclusion: Young people can be integral to end-of-life care, and represent a significant cohort of active caregivers with unique needs and experiences. They may have a more negative experience as caregivers, and increased needs for grief counseling services compared to other age cohorts of caregivers.

Introduction

CLINICAL STUDIES from the last 15 years confirm that family is the primary source of community caregiving. Upwards of 50% to 80% of caregivers are spouses, 11% to 25% are daughters/daughters-in-law, and a smaller number consist of aging parents, female relatives, or friends.^{1–6} While these groups have been previously described in detail, little is known about how a caregiver’s age impacts their experience and expectations. This article focuses on younger caregivers, a poorly understood and less-studied group.

Reports from the United Kingdom, Europe, Australia, and recently the United States have helped us identify this significant but mostly hidden group of caregivers, commonly defined as young people between the ages of 15 and 25 (although some were found to be as young as 8 years of age).^{7–14} The reports focus on young caregivers of individuals with various forms of chronic illness, such as mental health problems and dementia. Tasks ranged from shopping and cooking

to medical care, showering, and toileting. Caregiving at the end of life lays claim to the physical, emotional, financial, existential, and social resources of those providing care.^{1,3,4,15,16} Unfortunately, our understanding of the needs of patients and their families remains limited, especially when their life-limiting illness is not cancer.^{17–20} Even less is known about particular subsets of caregivers, because of the lack of large, accessible datasets about caregivers of terminally ill patients.

We have previously demonstrated that the South Australian population-based Omnibus health survey can be used to define a cohort of people with terminal illness, as well as their caregivers.²¹ Our article seeks to remedy a gap in the literature using data from this large, annual health survey. The purpose of this current paper is to:

- Compare the sociodemographic features of the total population with those who reported they were active caregivers for the deceased individual;

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Definition of palliative care used in all surveys:

“A palliative care service aims to comfort, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief.”

2001 Survey

1. In the past five years, has anyone close to you died of a terminal illness like cancer, motor neurone disease [amyotrophic lateral sclerosis] or emphysema? If yes, could you please say what that illness was?
2. How long ago did this person die?
3. What was your relationship to this person?
4. What was your most involved level of care for this person?*
5. Think back to when they were first diagnosed. Was the period after their diagnosis through to and including their death better or worse than you would have expected?*
6. Did this person who died of a terminal illness use a palliative care service?

2003 Survey

New questions after question 4 (2001)

- For how long did you provide that care?
- Did you experience any financial burden as a result of this person’s illness and death?*

Card for Question 3

What was your relationship to this person? (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.) (2001-2007)
Spouse/partner Parent Child Sibling Other relative Friend Other (specify)

Card for question 4

What was your most involved level of care for this person? (2001-07) <i>[Put responses on show card]</i>
Day-to-day hands on care Intermittent hands on care Rare hands on care Didn’t provide any care but they were still close to me

FIG. 1. Survey questions.

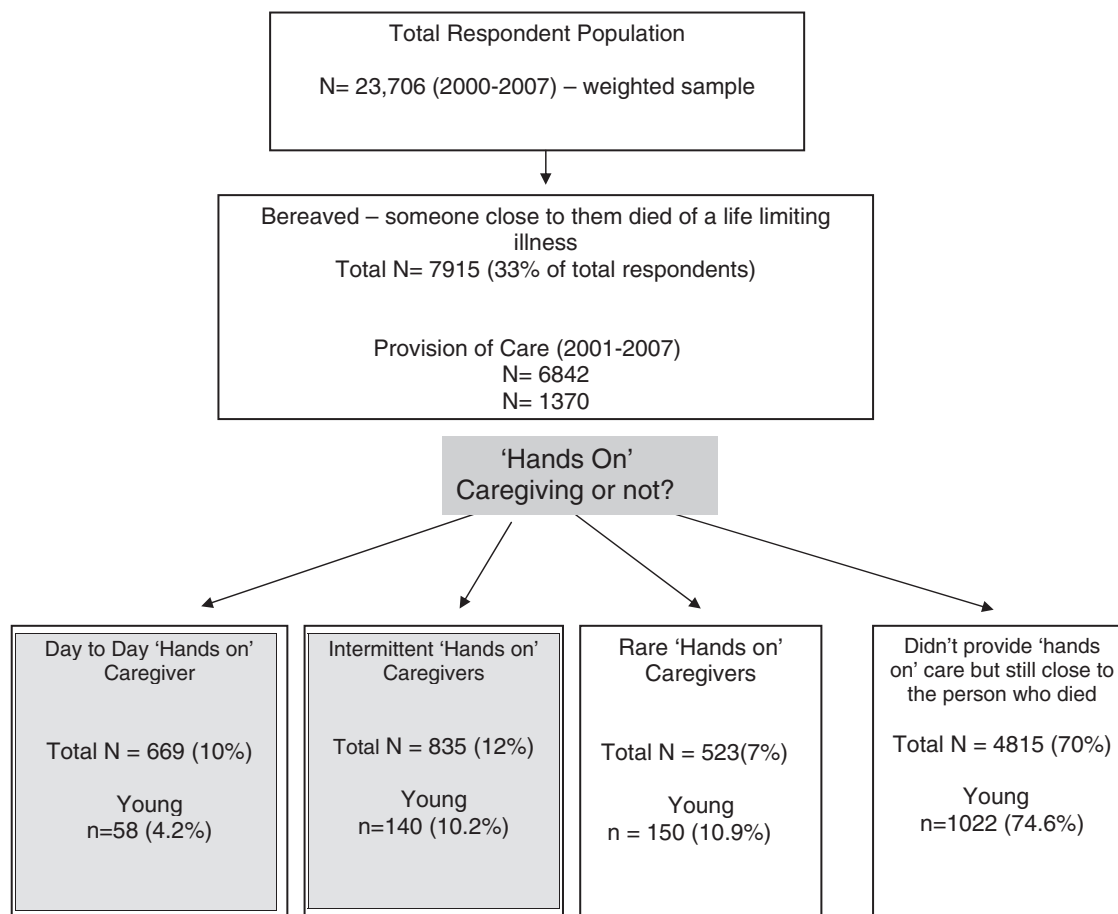


FIG. 2. Distribution of respondent population, bereaved and caregivers. Caregivers are subdivided into three caregiving categories, versus noncaregivers.

- Examine the sociodemographics and the role activities undertaken in caring for the deceased, dividing caregivers into three key age cohorts;
- Explore the caregiving experience among caregivers aged 15–29, with particular attention to examining their unique features.

Methods

The data for this survey were collected in the South Australian Health Omnibus Survey, a state government associated health survey conducted annually since 1991 with approximately 3000 residents each year. The full survey methodology has been detailed elsewhere.²²

Setting and subjects

A total of 23,300 households across 7 years were selected for the survey, which was conducted annually during September to November in 2001 to 2007 using a randomized household selection procedure.

Survey methodology

A set of test questions was developed and reviewed annually by palliative care service volunteers and cognitively intact patients in the inpatient hospice. Palliative care questions were similar to those previously validated.²¹ Survey

questions pertinent for the analyses presented here are in Figure 1.

Data collection. One face-to-face interview, by trained interviewers, was conducted per household with the person aged 15 or older who most recently had a birthday. Demographic information derived from the survey referred to the respondent and not the deceased.

Data analysis. The survey respondents were standardized against all South Australia for gender, 10-year age group, socioeconomic status, and region of residence in line with the 2001 Australian Census²³ using direct standardization²⁴ macros appropriate for combining multiple survey years obtained from the South Australian Department of Human Services.^{21,22} Each respondent was assigned a standardized weight and only weighted data were analyzed. There were no statistically significant differences between the years in response rate, demographics, recency of death, deaths due to cancer, the relationship between the respondent and deceased, or the care provided. We used three major age categories for analytical purposes in this paper. Our young cohort was therefore defined as those aged less than 30 years, extending by 5 years the more common international cohort (ages 15–25 years). This was considered a suitable cutoff point when viewed across the life continuum as most of those in their late teens and twenties are still approaching the high points of social and family responsibility (30–59 years).

TABLE 1. SOCIODEMOGRAPHIC CHARACTERISTICS: TOTAL POPULATION, BEREAVED WHO IDENTIFIED AS INVOLVED IN A CARING ROLE AND THOSE WHO DID NOT

Characteristics	Total population N = 23,706	Bereaved population (n = 7915)	
		Self-identified caring N = 6842	Self-identified noncaring N = 1073
Gender			
Female	50.8	52.9	53.1
Age			
15–29	24.3	20.0	21.9
30–44	27.0	26.7	25.8
45–59	24.5	28.7	28.0
60–75	15.7	16.8	16.5
≥75	8.4	7.8	7.8 ^a
Marital			
Married/ <i>de facto</i>	62.2	66.2 ^b	61.0
Separated/divorced	8.2	8.5	9.5
Widowed	6.0	6.4	9.0 ^b
Never married	23.6	18.9	20.5
Area			
Metropolitan	70.9	67.8	69.1
Rural	29.1	32.3	30.9
Country of birth			
Australia	78.6	78.6	78.3
Outside Australia	21.4	21.4	21.7
Aboriginal & Torres Strait Islander			
Yes	1.6	1.6	1.1 ^a
Education			
Still at school	5.5	3.5	3.0
Left school at <+15 yrs	14.0	13.8	18.8 ^b
Left school at >15 yrs	30.7	30.2	29.8
Trade qualifications/apprenticeship	13.7	15.0	14.7
Certificate/diploma	21.5	23.5	21.0
Bachelor degree	14.6	14.1	12.7 ^a
Employment§			
Employed full-time	37.4	38.5	37.0
Employed part-time or student	25.3	24.6	22.3
Not employed/home duties/other	37.3	36.9	40.7 ^b
Incomes			
Up to \$20,000	18.5	18.6	24.6 ^b
\$20,001–40,000	18.8	18.3	18.6
\$40,001–\$60,000	17.2	17.8	19.2
\$60,001 or more	30.4	32.4	24.4
Not stated	15.2	12.9	13.2
Relationship to the person who died N = 5274			
Spouse/partner	3.3	3.3	33.3
Parent/child	14.4	14.4	0.0
Sibling	5.2	5.2	0.0
Other relative	42.7	42.7	66.7
Friend	30.6	30.6	0.0
Other	3.9	3.9	0.0
Relationship to the person who died			
Close family (includes sibling)	22.9	22.9	33.3
Other family	42.7	42.7	66.7
Friend/other	34.5	34.5	0.0

^a $p < 0.01$.^bAdjusted residual > 2.0.

Descriptive statistics were used to summarize respondent characteristics and responses. Relationships between categorical variables were tested using the χ^2 test and χ^2 test for trend. Two-tailed p values were reported; statistical significance was assumed if $p < 0.0500$. The SAS statistical package (SAS, Cary, NC) was used for analysis.²⁵

Results

Sociodemographic characteristics of all respondents and the bereaved

Detailed reports of the characteristics from the study have been published previously.^{21,26,27} In summary, 35% of the population ($N = 6842$) indicated that someone “close to them

TABLE 2. SOCIODEMOGRAPHIC CHARACTERISTICS OF TOTAL YOUNG BEREAVED AND ACTIVE CAREGIVERS BY AGE GROUP (NUMBERS ARE PERCENTAGES UNLESS OTHERWISE INDICATED)

Characteristics	Young bereaved N = 1606	"Hands-on" Caregiving population ^a N = 2027		
		Ages 15–29 N = 349	Ages 30–59 N = 1208	Ages ≥60 N = 471
Gender				^b
Female	53.7	54.2	59.1	64.5
Marital				^b
Married/ <i>de facto</i>	31.4	31.8	76.0	5.16
Separated/divorced	1.8	1.1	11.1	5.3
Widowed	0.2	0.0	3.7	41.6
Never married	66.6	67.0	9.2	1.5
Area				
Metropolitan	69.6	65.4	68.8	67.8
Rural	30.4	34.6	31.2	32.2
Country of birth				^b
Australia	71.2	94.6	77.1	64.9
Outside Australia	28.8	5.4	22.9	35.1
Aboriginal & Torres Strait Islander				
Yes	1.3	1.4	2.1	1.9
Education				^b
Still at school	17.0	16.1	0.0	00.0
Left school at <+15 yrs	2.9	3.0	6.6	37.7
Left school at >15 yrs	36.4	30.5	31.6	23.7
Trade qualifications/apprenticeship	12.1	16.1	14.5	11.4
Certificate/diploma	19.4	20.1	29.7	19.7
Bachelor degree	12.2	14.4	17.7	7.4
Employment ^c				^b
Employed full time	41.5	38.1	47.4	04.2
Employed part-time or student	43.9	46.5	29.8	8.4
Not employed/home duties/other	14.6	15.4	22.8	87.4
Incomes				
Up to \$20,000	8.5	08.3	10.3	48.8 ^b
\$20,001–40,000	13.7	12.4	18.8	21.7
\$40,001–\$60,000	20.8	22.1	18.7	9.8
\$60,001 or more	32.9	29.9	40.6	7.4
Not stated	24.1	27.3	10.5	12.3
Relationship to the person who died N = 5274				^b
Spouse/partner	0.0	0.0	3.4	34.3
Parent/child	4.8	12.4	40.0	16.5
Sibling	0.6	1.7	3.6	8.5
Other relative	65.2	64.7	31.1	16.9
Friend	23.8	14.1	18.3	22.0
Other	5.5	7.2	3.6	1.7
Relationship to the person who died				^b
Close family (includes sibling)	5.4	14.1	47.0	59.3
Other family	65.2	64.7	31.1	16.9
Friend/Other	29.4	21.3	21.9	23.7

^aCaregiving includes hands-on care provided daily, intermittent, or rarely.

^b $p < 0.01$.

^cNo figures for 2005.

had died of a terminal illness like cancer, motor neurone disease (a.k.a., amyotrophic lateral sclerosis or ALS), or emphysema" in the proceeding 5 years (Fig. 2). Among bereaved respondents, the sociodemographic profiles confirmed slightly more bereaved individuals were women, married, living in rural areas, and more highly educated (all $p < 0.01$), when compared to respondents who did not report a death of one close to them. A slightly smaller proportion (29%) identified they had some kind of care involvement. Of those who self-identified as not engaged at all in a caregiving role ($n = 1073$), most had a close relationship with the deceased

being either a spouse/partner or an extended family member and were from across the age spectrum. They were significantly less likely to be married, have left school early, not be employed (although may be engaged in home duties) and on a very low income (Table 1). Overall, young active caregivers varied little in their sociodemographic composition when compared with young bereaved (Table 2).

Caregivers

The distinct caregiver subpopulations at the end of life comprised 502 (10%) who provided daily care (5–7 days per

TABLE 3. PROFILE OF THE DECEASED VERSUS ACTIVE AND NONACTIVE CAREGIVERS AND A COHORT OF THOSE WHO PROVIDED THEIR ACTIVE CARE^a BY AGE OF CAREGIVERS

	Deceased total N = 7915 %	Active caregiver N = 1496	Nonactive caregiver N = 5295	Age of active caregiver n = 1505			p value
				15-29 N = 199%	30-59 N = 886%	60+ N = 420%	
Cancer	79.1	78.6	78.5	78.9	79.7	79.3	.964
Noncancer	20.9	21.4	21.5	21.1	20.3	20.7	
Cause of death							
Motor neurone disease	2.9	2.5	3.1	4.0	2.2	2.1	0.304
Emphysema/other lung disease	9.9	9.7	9.3	6.6	10.0	10.3	0.288
End-stage heart failure	4.7	5.6	4.6	1.5	6.0	6.7	0.24
End-stage liver failure	0.8	0.5	0.8	0.0	0.7	0.5	0.488 ^b
End-stage kidney failure	1.0	1.1	0.8	.5	0.8	1.9	0.133 ^b
HIV/AIDS	0.4	0.3	0.4	0.0	0.5	0.0	0.274 ^b
Other	4.6	5.3	4.2	8.5	5.3	3.6	0.035
Don't know	0.8	0.7	0.8	1.0	0.7	0.5	0.747 ^b
Time From death							^c
0-6 months	23.3	18.3	24.8	17.1	19.6	16.3	< 0.001
7-12 months	17.3	15.7	17.7	20.7	15.4	14.1	
13-18 months	5.7	6.8	5.4	5.7	7.2	6.2	
19-24 months	15.9	16.2	15.8	29.0	14.4	14.1	
25-36 months	16.9	18.7	16.4	14.0	17.9	22.2	
37-48 months	12.1	14.6	11.4	11.4	14.4	16.5	
49-60 months	8.8	9.8	8.5	2.1	11.2	10.5	
Age of deceased (n = 622)							^c
< 40 (n = 31)	5.5	5.0	5.7	10.3	4.9	2.5	
40-49 (n = 50)	10.0	8.1	10.6	23.1	6.7	3.8	< 0.001
50-59 (n = 87)	18.1	14.0	11.4	14.2	14.7	12.1	
60-59 (n = 107)	21.1	17.3	22.2	11.5	17.3	19.7	
70-79(n = 205)	26.5	32.9	24.6	24.4	36.2	29.3	
80+ (n = 142)	18.7	22.7	17.6	16.7	20.2	32.5	
Place of death (n = 414)							^c
Home (n = 90)	19.4	21.1	18.9	29.5	19.6	20.6	0.307
Hospital (n = 221)	59.5	53.1	61.3	44.9	56.3	49.7	
Hospice (n = 65)	13.4	15.3	12.9	15.4	14.7	16.1	
RACF (n = 38)	7.7	10.6	6.9	10.3	9.3	13.5	
SPCS Use (n = 1431)							^c
Yes	57.4	62.7	56.9	58.5	62.6	64.7	0.372
No	42.6	37.3	44.0	41.5	37.4	35.3	

^aActive care = hands-on daily and intermittent caregiver.

^binsufficient cells to test for significance.

^cp = < 0.001.

HIV/AIDS, human immunodeficiency virus/acquired immune deficiency syndrome; RACF, Residential Aged Care Facility; SPCS, Specialist Palliative Care Service as integrated tertiary and primary care services.

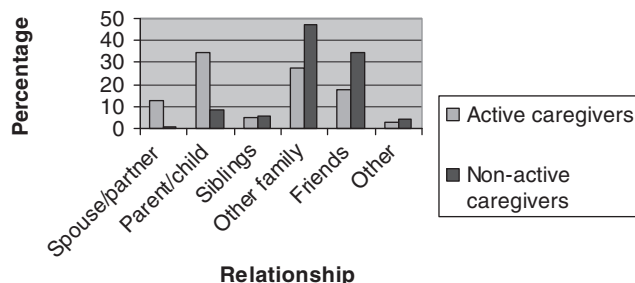


FIG. 3. Relationship of the deceased by caregiving role.

week], 619 (12%) provided intermittent care (2-4 days per week], 425 (8%) provided rare care, and a large group were non-caregiving bereaved individuals 3756 (70%). Among the young cohort, however, these proportions differed with young people less likely to be engaged in daily hands-on care, more likely to undertake caregiving activities on a rarer basis and slightly higher levels reporting they had no active caregiving involvement (Fig. 2).

The sociodemographic features of these active caregivers aged 15-29 years identified some important differences when compared to the other age cohorts (Table 2). Forty-six percent were males, most were not married (69%), almost all were Australia-born (95%), and 16% were still at school. Improved Australian educational standards are reflected in the higher levels of qualifications of those under 60. Most young people

TABLE 4. PROFILE OF EXPERIENCES OF ACTIVE CAREGIVING^a BY AGE OF THE CAREGIVER

Characteristics	Total N = 1504	Day to day N = 669			p value	Intermittent N = 835			p value
		15-29 n = 54	30-60 n = 360	60+ n = 241		15-29 n = 140	30-60 n = 521	N = 174	
Length of care provided (n = 1360)									
0-3 months	27.0	35.7	34.2	21.8		26.9	24.7	26.2	0.08
4-6 months	19.7	21.4	20.3	11.2	0.001	33.3	19.1	20.5	
7-12 months	16.6	3.6	13.5	18.8		15.1	18.5	18	
>12 months	36.7	39.3	32.1	48.2		24.7	37.6	35.2	
SPCS use (n = 6640)									
Yes	62.7	55.6	61.9	64.3	0.477	60.2	63.0	65.2	0.689
No	37.3	44.4	38.1	35.7		39.8	37.0	34.8	
Expectations of death(n = 5928)									
Much better than expected	15.1	8.8	20.1	9.4	0.003	19.2	13.0	17.3	0.06
As expected	31.0	26.3	21.7	29.1		26.2	38.0	38.7	
Worse or much worse than expected	45.0	54.4	50.6	47.3		42.3	41.9	37.3	
Didn't know what to expect	8.9	10.5	7.5	14.1		12.3	7.1	6.7	
Sought help to deal with grief (n = 2745)									
Yes	38.2	50.0	43.2	42.4	0.850	51.6	33.1	22.2	0.002
No, not needed with	61.8	50.0	56.8	57.6		48.4	66.9	77.8	

^aActive caregivers comprise those providing daily or intermittent hands-on care. SPCS, Specialist Palliative Care Service as integrated tertiary and primary care services. For bold values, *p* < 0.05.

involved in active caregiving were also working (85%), including 38% employed full-time. It is likely that income was underreported as one quarter would not declare it and as a group they were receiving high incomes with 33% receiving \$A60,000 or more per annum (Table 2).

Caregivers and family

Young active caregivers were more likely to be a close family member compared to younger bereaved. However, compared to middle-aged and older caregivers, younger caregivers were much more likely to be related to the deceased in more distant ways (Table 2). Interestingly, young people were almost also as likely to care for friends and others as did those over 30. Over half of young caregivers indicated that the deceased had been aged over 60 and 17% said they were 80 and older (Table 3). While the proportions of the deceased with cancer were the same across the age distribution of the caregivers, two other diseases showed significant differences. Young people were significantly less likely to be involved in the active care of a person with end stage heart failure and significantly more likely to have been involved with persons who had a cluster of "other" diseases (Table 3).

Significantly high numbers of these young people (80%) recorded it was less than 2 years since the death of the deceased compared with those people over 30 (50%–57%). No major differences by age were reported in access to palliative care services (Table 3).

How much did the active caregiver profile differ from the inactive?

There were no significant statistical difference for causes of death (Table 3). However, time from death, age of deceased, and place of death did show significant differences: in particular those not engaged in active care reported higher numbers died in hospital (61.3% *p* ≤ 0.001) compared to those who were active caregivers who reported that only 53% died there (Table 3). There were also significant differences in the use of palliative care services with active caregivers much more likely to use this resource (63%) compared to nonactive caregivers (57%; Table 3). Predictably, the relationship to the deceased was a major difference, with significantly higher proportions of active caregivers related to the deceased as spouse, parent or child while nonactive caregivers were much more likely to be extended family members or friends (Fig. 3).

Caregiver experience

In general, more than half of younger caregivers were significantly more likely to be engaged in hands-on care for less than 6 months in contrast to those aged 60 who most provided care for longer than 6 months (Table 4). A substantial proportion (39%) provided this intensive care, that is, on a daily hands-on basis, for more than 12 months.

Overall, 63% of those undertaking active caregiving indicated Specialist Palliative Care Services were available to them and this proportion was not significantly different among the three aged cohorts.

Respondents were asked to indicate in what way the actual experience of death matched their expectations. Among the

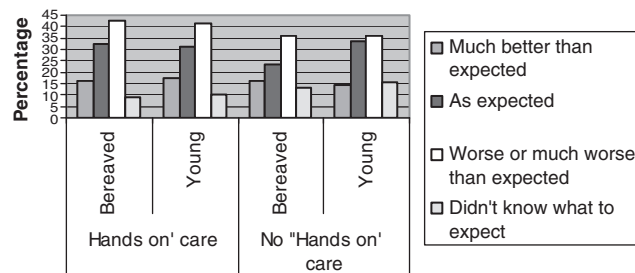


FIG. 4. Bereaved perception of illness experience of caregivers and noncaregivers.

TABLE 5. PERCEPTION OF CAREGIVING BY TIME FROM DEATH OF DECEASED FOR THOSE AGED UNDER THIRTY AND THOSE OVER SIXTY

Time from death	Expectations									
	Much better than expected		As expected		Worse or much worse than expected		Didn't know what to expect		Total	
	< 30	> 60	< 30	> 60	< 30	> 60	< 30	> 60	< 30	> 60
0-12 months	45.1 ^a	46.3	33.1	42.6	42.3 ^a	39.8	31.7	32.8	38.2	40.8
13-24 months	20.7	18.2	27.9	20.5	21.9	23.8	32.9 ^a	26.6	25.1	22.3
25-36 months	16.8	16.4	18.3	18.1	16.1	16.8	17.1	16.9	17.1	17.2
37-60 months	17.4	19.2	20.7	18.8	19.9	19.6	18.3	23.7	19.5	19.8
Total 100.0										

^aAdjusted residual > 2.0.

p = 0.026 for those aged < 30 years.

No significant difference for those aged < 60 years.

bereaved who provided no hands-on care, both in general and the young in particular, reported remarkably similar profiles (Fig. 4). Approximately 15% thought the experience better than expected, just over a third each thought it was "as expected" or "worse or much worse than expected" and approximately 14% did not know what to expect.

However, for those who did provide hands-on care, the profile was very different for age cohorts. Very few of both the young and the old who provided hands-on care reported it was better than expected (9%), although 20% of those aged 30-59 found it to be so. Instead, half of all those undertaking hands-on care reported it was worse or much worse than expected. This negative perception was lower among all those providing care on an intermittent basis. Further among this young cohort undertaking intermittent care, one fifth reported the experience was "much better than expected" and a quarter that it was "as expected" (Table 4). Did time from death influence perception? We explored the younger and older cohorts (Table 5) and found that both populations report intense impressions in the first year. Among the younger cohort, they were equally as likely to report the experience was better than expected as they were to report it was worse or much worse.

Did length of care impact on perceptions? Young caregivers who provided care for less than 12 months were twice as likely to indicate the experience was negative as those who undertook long-term care (Fig. 5). Interestingly, among those who undertook longer care, a substantially higher number (44%) reported it was better than expected. It was not possible to test for significance as numbers were too small.

Much higher proportions of all three age groups providing daily hands-on care indicated they needed help with their

grief. Among the young, high numbers (52%) still reported a need for help (Table 4).

Caregivers experience when deceased had noncancer

When the deceased had a noncancer condition, levels of care did not differ significantly from those with a cancer condition. But young caregivers were significantly more likely to undertake a longer period of caregiving when the deceased had a noncancer condition, with over half (53%) indicating they provided care for more than 12 months in comparison with 40% who indicated they assisted for 3 months or less when the deceased had died from cancer (Table 6). Furthermore, the use of palliative care services differed significantly with 56% of the young reporting such services were not used when the deceased had a noncancer condition.

Discussion

This study, using a population-based sample and a caregiver concept based on role activity rather than family relationship, identified a surprisingly high proportion of young people (ages 15-29) contributing hands-on care (14.4%) to patients at the end of life. Almost as many young males as females participate in active caregiving (men represent 46%); most provide care while also being employed, including 38% who work full-time. Young caregivers frequently report that the experience was worse than expected (42% of intermittent and 54% of day-to-day caregivers), and recognized a need for assistance with grief during the bereavement period.

Families provided the backbone of caregiving with 80% of active care being undertaken by them, confirming as Eli²⁸ has stressed, that the family connection is the most important aspect when serious illness is involved. A U.S. study of a small sample of children and grandchildren providing the major source of support to an older relative indicated they did so because of both filial duty and a general willingness to help the primary caregiver.²⁹

Our data identified almost as many young males were actively caring as females; this is different from past generations when caregiving responsibilities were predominantly the purview of women. Secondary analysis of U.K. data from the 1990's confirmed the trend of increasing numbers of men

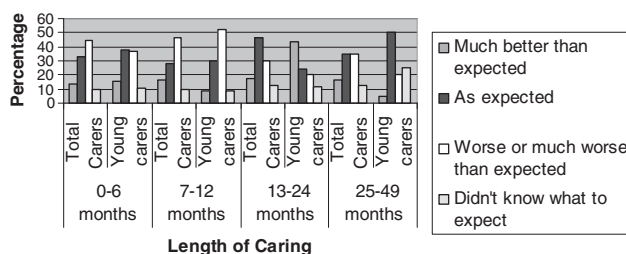


FIG. 5. Comparison of all caregivers and young caregivers perception of illness experience by length of care undertaken.

TABLE 6. PROFILE OF CAREGIVING×AGE×CANCER VERSUS NONCANCER LIFE-LIMITING ILLNESS

Characteristics of caregiving	Total young aged N = 5772	15–29 Age		p value
		Cancer N = 6180	Noncancer N = 1701	
Any care				
Yes (n = 1,362)	25.4	24.9	27.7	0.340
Level of care provided (n = 1,362)				
Day-to-day hands on (n = 58)	4.3	4.2	4.7	
Intermittent hands-on care (n = 139)	10.2	9.9	11.3	0.818
Rare hands-on care (n = 149)	10.9	10.8	11.7	
Didn't provide care but still close (n = 1016)	74.6	75.1	72.3	
Length of care (n = 226)				0.022
< 1 year	62.4	65.9	46.3	
> 1 year	37.6	34.1	53.7	
Length of care provided (n = 226)				
0–3 months	39.8	44.6	19.0	
4–6 months	24.8	25.5	21.4	< 0.0001
7–12 months	11.9	13.0	7.1	
> 12 months	23.5	16.8	52.4	
SPCS ^a use (n = 1,319)				
Yes (n = 991)	54.6	57.3	43.7	< 0.000
No (n = 328)	45.4	42.7	56.3	

^aSPCS, Specialist Palliative Care Services provided as integrated tertiary and primary care services.

providing informal care to their spouse or partner.³⁰ Our data lead us to pose the question, will this trend continue as the young cohort move to middle age? Men are participating more in many caring activities including raising children, teaching, and nursing. As caregiving takes on new positive meaning for men^{31,32} it is possible that we will see greater numbers of male caregivers across the whole age spectrum.

Small-scale studies have identified financial hardship as a major problem for young caregivers.^{33,34} Our study confirmed that most were employed, half of them were receiving high incomes and less than 10% earned under \$20,000 per annum. This profile suggests there may be two distinctive groups of young caregivers in the community: those providing long-term care to parents with chronic illness and those we have identified, who may be assisting the family in caring, for a shorter time, for an older or elderly relative with a terminal illness.

Evaluating the impact of serious illness we were able to explore, in a preliminary way, perceptions around the dying experience for the bereaved, some of whom were active caregivers. One third of bereaved, of all ages, found the experience worse than expected. We could not identify from this data, for how many this was their first death experience of a lingering disease. However, another third also reported it was “as they expected.” We note that between 13% and 15% had no idea what to expect. These figures offer a further line of research.

Of some concern was the fact that so many of those involved in hands-on care found it to be worse or much worse than expected and this included the young. While acknowledging that many were closely related to the deceased and reported high grief levels, nonetheless the clinical question could be asked, were they given adequate preparation and support by health professionals? It might be that those engaged in longer caring, 1 to 2 years, were more likely to meet with and obtain information and support and thus indicate that it was much better than expected.

Half of the young caregivers in this study requested help with their grief during the bereavement period. Whether “active caring” was the precipitous factor or whether the loss of a close family member was the proximate cause of this increased need for assistance is not clear.

U.K. qualitative researchers have attempted to ascertain the far-reaching consequences for young caregivers of caring for the seriously ill.^{7,8,12} We know that young caregivers continue to remain invisible to health professionals and teachers.^{7,8,33–37} A chart review of 3479 patients who died in a hospice and home health care program noted that the psychosocial assessment form providing space to identify the primary caregiver, did not enumerate children in the genogram of the family system.³⁸ A recent Australian report identified a range of family, service and system issues that impede young caregivers’ access to services.³⁹ A whole of family approach that acknowledges the complexity of social and economic forces is recommended.

Limitations to the study: Sample

People who live in remote, as distinct from rural, South Australia, those without caregivers, and some people with culturally and linguistically diverse backgrounds were not represented in the data. All results were based upon the recall of the respondent, which is a validated approach.⁴⁰ Respondents may not reliably know whether the deceased used a palliative care service or the place of death, especially when the respondent was not providing frequent care.

Concentration of analyses on those who knew the answers to both questions improved reliability of results. Other limitations were outlined previously.²¹ The other challenge in understanding characteristics of caregivers’ demographics is that respondents are providing current status in responses. For example, marital status is current status not the respondent’s status when providing care so that widowed people may (or may not) have been spousal caregivers.

Conclusion

Young caregivers, who are to date almost invisible in the cancer research literature, can be integral to end-of-life care. Large population-based studies are sufficiently powered to facilitate the identification of important sub-groups of caregivers. Our data raise concern that the cohort of young caregivers may have more negative experiences with caregiving, and more difficulty with grief thereafter, or at least a heightened willingness to ask for help. Designing further clinical studies of sufficient size to capture these differing experiences will improve the quality of our insights into end-of-life caregiving, allowing us to better tailor interventions to subsets of the caregiver population and target the special concerns of young caregivers.

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Author Disclosure Statement

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