

## Caregiving networks at the end of life findings from the South Australian population study

Catherine M Burns, B Soc Admin, PhD<sup>1,2</sup>  
Amy P. Abernethy, MD<sup>3</sup>  
David C. Currow, MPH, FRACP<sup>1</sup>

<sup>1</sup> School of Medicine, Flinders University, South Australia,  
<sup>2</sup> Social Work Program, Newcastle University,  
New South Wales  
<sup>3</sup> Duke University Medical Centre, Durham, North Carolina,  
USA

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## Background

- Locating a moral stance and practice toward dying
  - Modern dilemma of clinical medicine (Kaufman)
- Health technologies embedded in complex health care systems
  - Offer relief from pain and effect symptom disease management
- Quest to understand a 'Good Death'
  - Emphasises social, emotional and spiritual dimensions (Kelleaher, Steinhauser)
- Special difficulty in distinguishing normal ageing and decline from disease (Goodwin 91)
  - Old age offers greatest challenge in attaining the ideal of death with dignity (Kaufman)

## Community Care

## Background

- Remaining at home when seriously ill
  - Relies upon the support of family and friends (Ramirez A 98, Coristine M 03)
- Most people (80%) wish to die at home (Townsend J, '90, Tang ST 03)
  - Numbers dying in hospital and nursing homes continue to rise (Hunt RW 01, AIHW 09)
- Complicated network of factors influence place of death (Karlsen S 98, Grand GE 98, Cantwell P 2000, Gomes B 06, Gruneir A 07)
  - Availability and quantity of home care, informal and formal are crucial determinants (Higginson 07)

## Community Care

## Background

- Positive reports on caring for frail aged and seriously ill
  - **Intergenerational research** highlights caring for aged parent provides an opportunity to 'give back' to loved ones (Merz em 09)
  - Australian research confirmed caregivers viewed with pride their accomplishments in looking after loved ones (Gribish 06)
  - Greater personal strength and opening of new possibilities (Kim Y 09)
- Importance of extended family relationships
  - Changes in structure and size of kin networks
  - prevalence of 3, 4 generations.
  - Bengston (01) suggests increased opportunity to 'share lives'
- Importance of role of siblings (Avioli 89)
  - Ideally situated to provide social support as their relationships are lifelong, rooted in equality and normatively supported

## Clinical Setting

## Background

- In clinical setting perceptions of family support remain narrow
  - Parent/child and spousal relationships are the perceived norm
- Concept of the 'Caregivers shift' suggested in a recent qualitative study (Waldrop 06)
  - Incorporates various family members not on the medical record involved in end of life care
- Waldrop's identification of the role of secondary caregivers
  - Become reinforcements for primary caregivers
- They provide respite care or additional support including emotional support for the primary caregiver

## Caregiver Research in end of life

## Background

- Large-scale community studies in the aged sector
- Cancer clinical studies of caregivers of terminally ill patients, show substantial variability in the composition
  - Studies are small and non-representative.
- Lack of systematic population based sampling (George L 02)

## Bereaved

### South Australian Health Omnibus Study

- 23,588 households were selected 2000 – 2007 years using published methods (Wilson 91)
- Palliative care questions included from 2001-2007
  - Content and construct validity of this tool previously verified (Currow 04, Abernethy 07)
  - *“In the past five years, has anyone close to you died of a terminal illness like cancer, motor neuron disease or emphysema?”*

## South Australian Health Omnibus Study

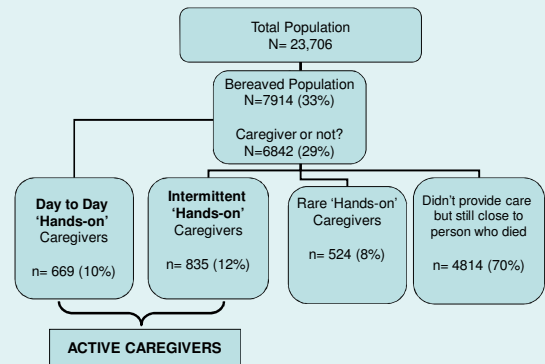
- If **YES**, additional questions asked about:
  - Relationships
  - **Level of care**
  - **Type of illness & age of the deceased**
- Financial burden
- Extra supports needed
- Experience meet expectations
- Use of Specialist Palliative Care Services
- Ability to move on

## South Australian Health Omnibus Survey

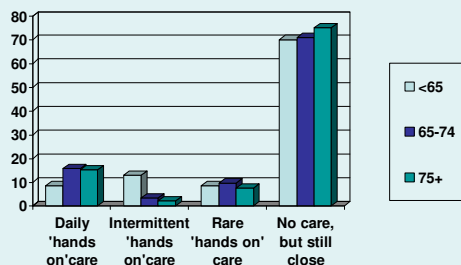
### Caregiving at the End of Life (Abernethy et al 09)

- Population study > understanding of bereaved caregiver features.
- Caregivers best defined by **role activity** rather than using the term interchangeably with family.
- Two distinct groups provide **active care**
  - Daily 'hands on'
  - Intermittent 'hands on'.
- A third, larger provides 'hands on' care either rarely or not at all but perceives themselves as close to the person who was seriously ill.

## Results: Bereaved Population



## Levels of Care of Total Bereaved Population



## Objectives of this report

- To describe naturally occurring networks of family and friends engaged in care at the end of life on a **Daily, Intermittent basis**.
  - Profile socio-demographic features of 65 +
  - Their relationship to the deceased
  - Interrelationship of age of deceased with age of caregiver
  - their experience of end of life care
  - identify needs
  - target caregiver support.

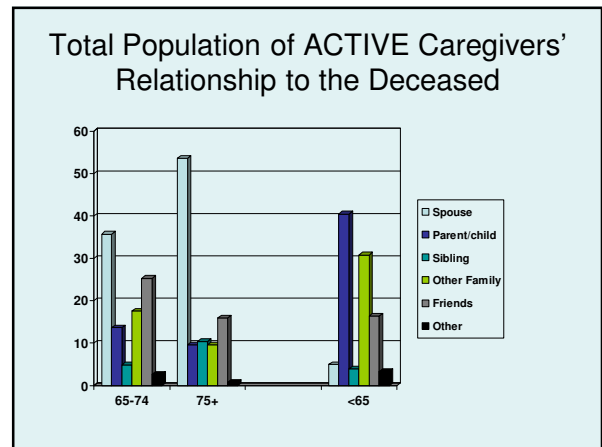
South Australian Health Omnibus Survey		Socio-demographics of Older Bereaved		
Characteristic	65-74 yrs (n= 817) %	75-84 yrs (n=534 %)	85+ yrs (n=86) %	
<b>Gender - female</b>	54.0	57.5	59.3	
<b>Marital</b>				<b>P&lt;0.001</b>
• Married	72.4	56.9	37.2	
• Separated/divorced	7.0	3.7	2.3	
• Widowed	<b>18.8</b>	<b>37.3</b>	<b>57.0</b>	
• Never married	1.8	2.1	3.5	
<b>Education</b>				<b>P&lt;0.001</b>
• Left school <+15 yrs	<b>33.7</b>	<b>50.1 AR (5.6)</b>	<b>49.4</b>	
• Left school >15 yrs	22.2	19.2	23.0	
• Trade qualifications	18.3 AR(3.1)	12.2	9.2	
• Certificate/diploma	19.4 AR(3.0)	13.5	13.8	
• Bachelors degree	6.4	5.0	4.6	

South Australian Health Omnibus Survey		Socio-economics of older Bereaved		
Characteristics (n=1437)	65-74 yrs (n= 817) %	75-84 yrs (n=534) %	85+ yrs (n=86) %	
<b>Country of Birth</b>				<b>P&lt;0.001</b>
Australia	64.5	75.0	76.7	
United Kingdom/Ireland	<b>20.6</b>	<b>13.3</b>	<b>12.8</b>	
Other	<b>15.0</b>	<b>11.6</b>	<b>10.5</b>	
<b>Income</b>				<b>P&lt;0.001</b>
<\$20,000	45.2	<b>61.5</b>	<b>62.8</b>	
\$20,001- \$40,000	28.2	<b>20.1</b>	<b>16.3</b>	
\$40,001- \$60,000	9.1	3.4	4.7	
\$>60,000	6.0	2.4	1.2	
Not stated	11.5	12.6	15.1	

SA Health Omnibus Survey		What was the Relationship of older bereaved to Deceased		
Characteristics (n=1437)	65-74 yrs (n= 817) %	75-84 yrs (n=534) %	85+ yrs (n=86) %	p value
Spouse/partner	10.5	13.1	<b>19.7</b>	<b>.004</b>
Parent/child	5.4	4.5	5.6	
Sibling	13.6	17.2	<b>22.5</b>	
Other family relative	<b>25.5</b>	<b>25.4</b>	<b>25.4</b>	
Friend	<b>41.9</b>	<b>38.6</b>	<b>22.5</b>	
Other	3.3	1.1	4.2	

SA Health Omnibus Survey		Key socio-demographics of older ACTIVE caregivers (n=306)	
	65-74 yrs (n=182) %	75+yrs (n=125) %	
<b>Gender - female</b>	66.3	66.4	
<b>Marital</b>			
Married/defaulto	54.4	24.2	
Separated/divorced	5.5	4.1	
Widowed	<b>39.0</b>	<b>71.0</b>	
Never married	1.1	.8	
<b>Employment</b>			
Working full or part-time	<b>6.5</b>	.9	
Not working	93.5	99.1	

SA Health Omnibus Survey		Key socio-demographics of older ACTIVE caregivers (n=306)	
Relationship to the deceased	65-74 yrs (n=182) %	75+yrs (n=125) %	
Spouse	<b>35.7</b>	<b>53.6</b>	<b>P=.004</b>
Parent/child	13.7	9.6	
Sibling	4.9	<b>10.4</b>	
Other family	<b>17.6</b>	9.6	
Friends	<b>25.3</b>	16.0	
Other	2.7	.8	

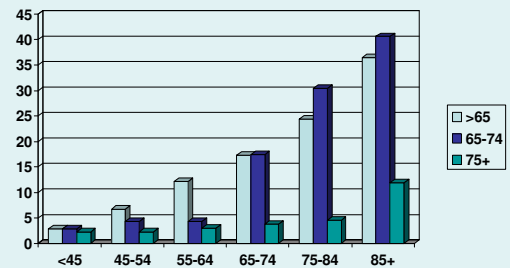


**South Australian Health Omnibus Survey**

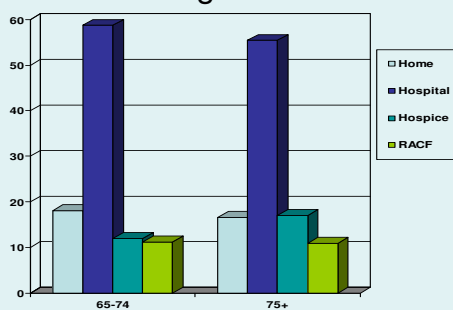
**Profile of the Deceased As reported by Aged**

Cause of Death of Deceased	65 - 74 yrs n=817 %	75+ n=619 %	P value
Cancer	78.0	76.4	.485
Motor Neuron Disease	2.8	2.4	.741
Emphysema	10.3	11.0	.729
Heart Failure	6.1	5.5	.651
Renal failure	2.1	.8	.054
Others	.7	3.7	.423

**Age of Deceased reported by Active Caregivers (aged >65, 65-74, 75+)**



**Place of Death reported by older caregivers**



**Role of Friends contributing end of life care**  
(Burns CM, Abernethy AP et al 2010)

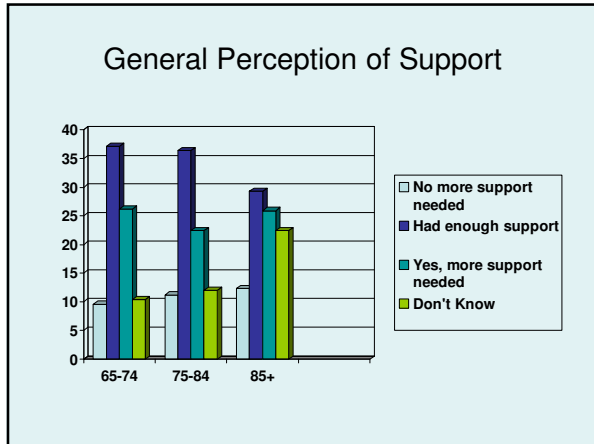
- 55% of friends of deceased providing active care were >65
- They frequently did so for more than 12 months
- The rate of palliative care was higher when they were involved
- Friends as caregivers was a predictor of a home death (OR 1.73 CI 1.15-2.87)

**Role of siblings**

- One quarter of bereaved siblings undertake active 'hands on' caregiving of whom one third were aged over 65
- They were frequently still employed (40%)
- Almost half (42%) of deceased siblings were aged >65
- Palliative care services were much more likely to be used
- The odds ratio of a home death was 1.75

**The extended family: Young Caregivers**  
(Burns CM, LeBlanc TW, Abernethy A, Currow D 2010)

- 14.4% of active 'hands on' caregivers were aged 15-29
  - Almost as many males (46%) as females undertook this role
- They did so while engaged in employment
  - 38% in full time work,
  - had high incomes
- Over half (52%) deceased were aged over 60
  - (11% 60-69, 24% 70-79, 17% 80+)
- Home deaths were more likely (29%)
- Over half found the experience worse than expected and many had a need for assistance with their grief



<b>Australian Health Omnibus</b>	Summary
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**Survey**

- A randomised population survey identified the bereaved in any 5 yr period comprises one third of the total population.
- We have some figures on the prevalence of active, 'hands on' care of the seriously ill, being undertaken in the community – 5.5%
- This figure increases to 8.5% if those undertaking 'hands on' care on a rare basis are included.
- Importantly, confirms there is a network of care ranging across all age groups
- Increasingly it would seem men might be contributing in an active caregiving role beyond that of their spouse

<b>SA Health Omnibus Survey</b>	Discussion
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There is an opportunity for the multidisciplinary aged care team to consider 'health promoting' palliative care

Earlier identification of the prognosis of those with life limiting diseases offers an opportunity for improved communication with the extended family and friends.

Importantly, this could enable a wider network of support to be created to foster dying with dignity at home amongst friends and family.