Prospective, longitudinal data on preference for place of care at the time of death

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Background

- Palliative care developed in response to the increasing medicalisation of death[1]
- Emphasis on the place of death, often used as a proxy outcome measure
- Decision about place of death dynamic

[1] Bowling A. *J Med Ethics* 1983,9:158-161

Background

- The role of caregivers is absolutely crucial to community-based palliative care
- Without a caregiver, community-based care (including death at home) is unlikely

Grande et.al. *Soc Sci Med* 1998
Alhner-Elmqvist et. Al. *Pall Med* 2004
Maida *Pall Med* 2001

Background

- At times caregivers and patients may differ in preferred place of death[1]
- The place of care changes across time, with home not always being the place of choice[2]

[1] Hinton J. *Pall Med* 1994, 8:197-210

[2] Currow DC, et.al. *Irish Med J 2003*

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Ask the right people at the right time

[1] Hinton J. *Pall Med* 1994, 8:197-210

[2] Currow DC, et.al. *Irish Med J 2003*

Aim

1. To determine changes in preferred place of death separately for patients and caregivers
2. To examine the outcomes and characteristics of any discrepancy.

Setting

- Southern Adelaide Palliative Services:
  - Multi-disciplinary SPCS
  - Support local GPs
  - GPs provide majority of primary care
  - SPCS interfaces with other support services such as home nursing, PT/OT
  - Community, hospital, hospice, nursing home
- 1200 referrals per year

Setting

- Median time from referral to death of 50 days (mean 120 days)
- 85% cancer
- 66% of all ‘expected’ deaths

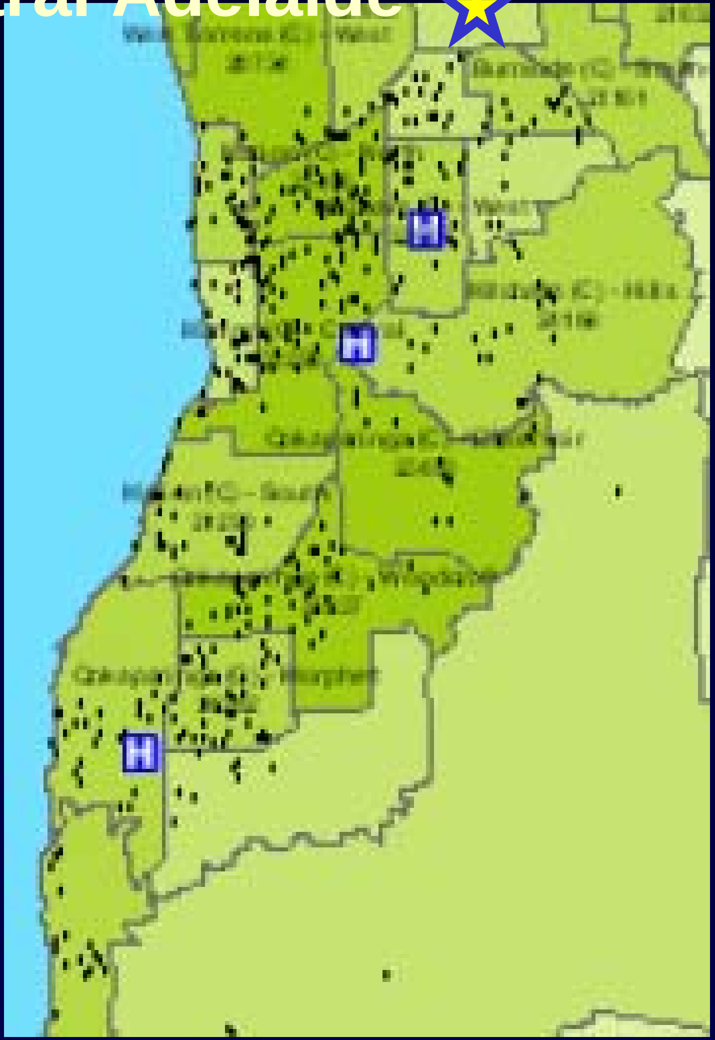
Participants

- Eligibility Criteria
  - Adults referred to SPCS with pain in last 3 months
  - Life expectancy > 48 hours

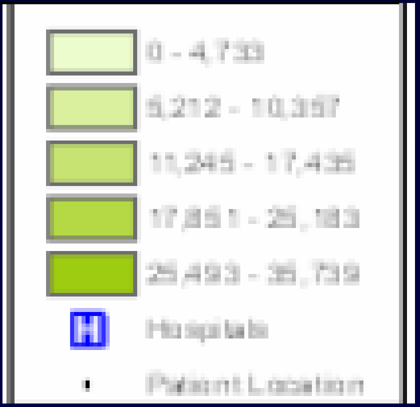
Participant Demographics

Central Adelaide ☆

Distribution of participant locations is consistent with distribution of population density in Southern Adelaide



Population density legend



Design

- Cluster randomized trial
- 2 x 2 x 2 factorial design
  - Case conferencing (CC)
  - Educational outreach visiting for GPs (EOV)
  - Structured educational visiting for patients (SEV)

Methods

- Longitudinal data collection by palliative care nurses
- Caregiver and patient preferred place of death asked at each visit
- Not compulsory data item
- Asked separately if possible
- Visits were fortnightly for 1 month then monthly

Results

- 461 participants recruited over 26 months
- Excluded from the analysis:
  - 49 still alive
  - 70 withdrew
  - Patients without caregivers
  - Participants with less than 2 responses

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69 Patient/Caregiver dyads

Results

Participant demographics

	All	Pt/Caregiver dyad
N	461	69
Age	71 years	73 years
Male	50%	50%
Married	63%	70%
Widowed	24%	20%
Lives alone	24%	14%
Caregiver	94%	100%
Cancer	94%	100%
LOS	145 days	185 days

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Preference for place of death met

- 41/69 patient/caregiver dyads had preference met
- Preference most often met for hospital death
- Only 38% of patients had preference for home death met.

Results

Actual place of death	Preferred place of death			
	Home	Aged care facility	Inpatient facility	**Totals**
Home	9	0	3	**12**
Aged care facility	0	7	1	**8**
Inpatient facility	15	3	31	**49**
Totals (% preference met)	**24** (38%)	**10** (70%)	**35** (89%)	**69**

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Changing preference

- 1/3 people changed their mind during the course of the illness about the best place of care
- Commonly hospice→home→hospice
- 10% resulted in conflict

Results

Conflict between patient and caregiver

- Most conflict transient
- Where conflict unresolved (n=4), the patient had wished to die at home
- No conflict if the patient wished to die in an aged care facility

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Conflict = patient did not die at the place of their choice

Conclusions

- Evolution in patient and caregiver thinking as death approaches
- Home may be the “ideal” but as disease progresses reality sets in
- Conflict between patient and carer usually transient
- Conflict can restricts patients chance of getting preference met

Implications for Practice

1. People are willing to share their views
2. If we are to support caregivers, we need to know preference for place of death early
3. We need to develop good mechanisms for dealing with discrepancies between patients and caregivers, or when people change their minds

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