

Decision making at the end of life for terminally ill people who live alone

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Background

- Community and home-based palliative care services are facing increasing challenges in service provision due to:
 - an ageing population
 - an increase in the number of people living alone requiring care
 - a decrease in the availability of family caregivers
 - transition from hospital to home as place of care
 - a preference to be cared for and die at home

Background and Significance

- Questions from the field
- Scoping study
- Home Alone Models of Care
- No previous study regarding decision making in this population of clients
- Provide understanding of who or what influences decision making at the end of life

Previous studies

Aoun et al (2007, 2008, 2012, 2013)

Terminally ill people who live alone:

- Had more hospital admissions
- Were less likely to die at home than those with a carer
- Were at a disadvantage in their place of care and place of death

Objectives

- To explore factors that may influence decision making at the end of life from the client and service provider perspective
- To determine how decision making may influence informal and formal service utilisation for palliative care clients who live alone

Design / Methodology

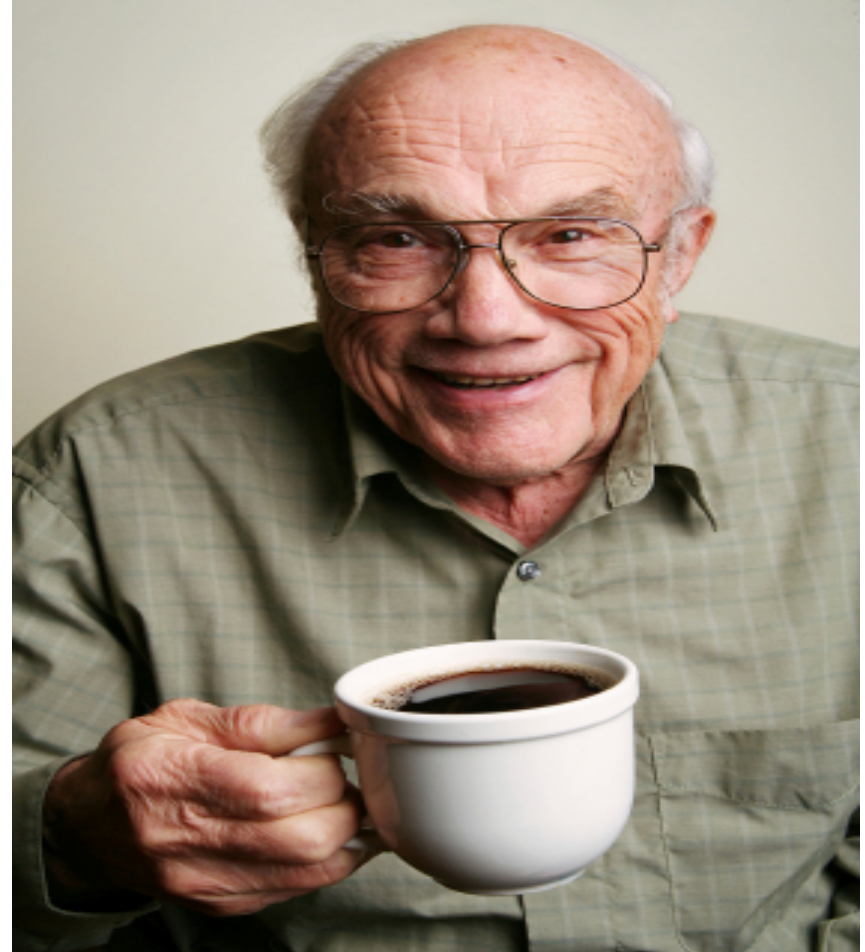
- Collective case study
- Questionnaires (Clients): Demographics, HADS, Australian- Modified Karnofsky Performance Status Scale, Graham and Longman Quality of Life
- Client clinical record: RUGIII, Phase of care, Length of time receiving services, narrative relating to decision making.
- Questionnaire (service providers)
- Conceptual framework: Ongoing change and adaptation model of decision making (King et al 2009)

Setting and Populations

- Silver Chain Hospice Care Service
- Two target groups:
 - Clients who have a cancer diagnosis and who live alone (n=7)
 - Service providers: Clinical Nurse Consultant Managers, Case Co-ordinators, Registered Nurses (n=50)

Scenario: Len

- 73 year old man
- Lived in own home
- Wife died 8 years ago
- Little contact with previous social groups
- Classified as low priority for domestic assistance
- Wanted to remain at home
- Died in private hospital



Themes from clients

- Maintaining independence
- Burden to extended family and friends
- Acceptance of assistance when ready
- Relationships



Questionnaires

Participant	HADS depression subscale	HADS anxiety subscale	Australian-modified Karnofky	QOL rating	QOL satisfaction	Time to death (in weeks)
Lucy	6	7	60%	5	5	46 wks
Ann	3	4	60%	6	6	39 wks
Mary	7	4	60%	8	10	40 wks
Jack	5	6	80%	10	10	41 wks
Len	7	5	60%	7	7	3 wks
Jane	10	10	60%	7	3	19 wks
Dianne	12	9	70%	3	0	12 wks

Information from client record

Participant	Initial Australian-modified Karnofsky	Final Australian-modified Karnofsky	Initial phase of care	Final phase of care	Place of death	Length of stay with SCHCS (in weeks)
Lucy		10		T	Home	106 wks
Ann		30		T	Hospice	109 wks
Mary		50	D	D	Hospice	60 wks
Jack	70	10	D	T	Home	73 wks
Len	70	30	D	D	Hospital	5 wks
Jane		10		T	Home	42 wks
Dianne	70	50	D	D	Hospice	21 wks

RN perspective when things went well

- Wanted to die at home
- Allowed nurses to visit but at prearranged time
- BD visits
- Accepted equipment
- Remained in bedroom
- Independence was important
- Died at home



RN perspective: when things went not so well

- No family / friends
- Fiercely independent
- Refused to accept assistance
- No support services
- Allowed one RN visit per day
- Found deceased on floor at home



Main themes from RNs

- Provision of evidence based information
- Clients understanding of options
- Acceptance of help
- Relationships

Anticipated Outcomes

Findings will ascertain key areas that need to be addressed by service providers to:

- assist people who live alone to maintain optimum quality of life and
- receive palliative symptom management and terminal care in their place of choice.



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Thank you



“People are usually the happiest at home”.

William Shakespeare (playwright)

Decision making at the end of life

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