

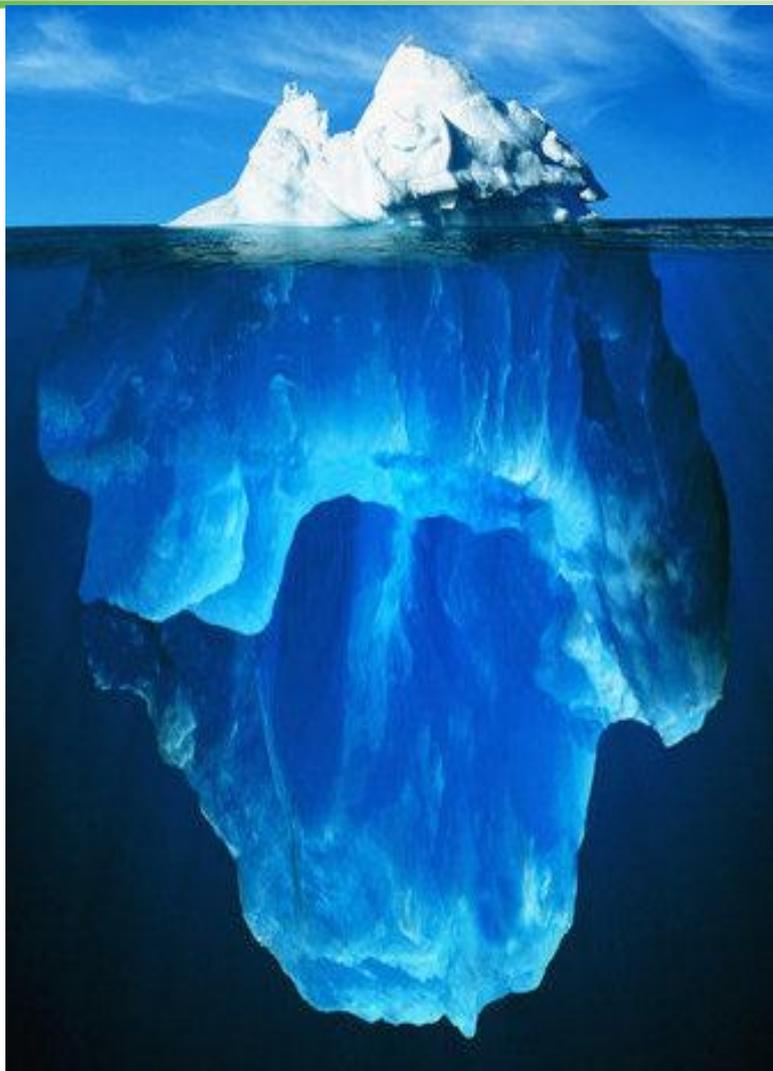
Exploring Public Awareness of Palliative Care

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- Changing demographics & increased demand for palliative care;
- Studies showed international variability; lack of knowledge and confusion (Wallace, 2003; McCarthy et al, 2011; Seymour 2010; Hirai et al., 2011)
- Increasing recognition of palliative care as a public health issue
- Media Attention LCP





(Kellehear, 1999)

Aim: To explore public perceptions towards palliative care.

Objectives

- To identify the public's understanding and perceptions of palliative care
- To explore factors that contribute to the public's knowledge and expectations of palliative care services
- To identify what actions and strategies, if any, might enhance public awareness and understanding of palliative care

Phase 1: Quantitative

- Postal/on-line survey
- Sample: Database (n=4000)
- Inclusion criteria: 18 yrs
- Questionnaire: 3 sections
- Respondents: n=600
- Analysis: SPSS Frequencies & descriptive



Phase 2: Qualitative

- Telephone interviews
- Volunteer Sampling
- Interview Schedule: strategies to increase public awareness
- Respondents: n=60
- Analysis: Content analysed

Demographics:

- 68.8% (n=413) female & 25.2% (n=151) male
- Nearly 70% aged 50 years or over
- Over half were married 54% (n=324)
- Almost a third (30%) were in full time employment
- 42% (n=252) were retired
- Majority of respondents (91.5%) described their ethnic origin as white: 41.5% Protestant & 32.5% as Catholic.



- **Knowledge and Perceptions of Palliative Care**
- **Expectations of Palliative Care Services**
- **Enhancing public awareness & understanding of palliative care**

Knowledge & Perceptions of Palliative Care

- 83.3% heard of the term palliative care prior to receiving the questionnaire
- Half of respondents (56%) said they had low knowledge; 19% no knowledge at all
- Qualitative responses stated that some did not know what the term meant or associated it with care of the elderly.
- *“To be quite honest I knew nothing about it. It’s a thing I never even thought about. I think it’s something you don’t think about until you need it” (52)*

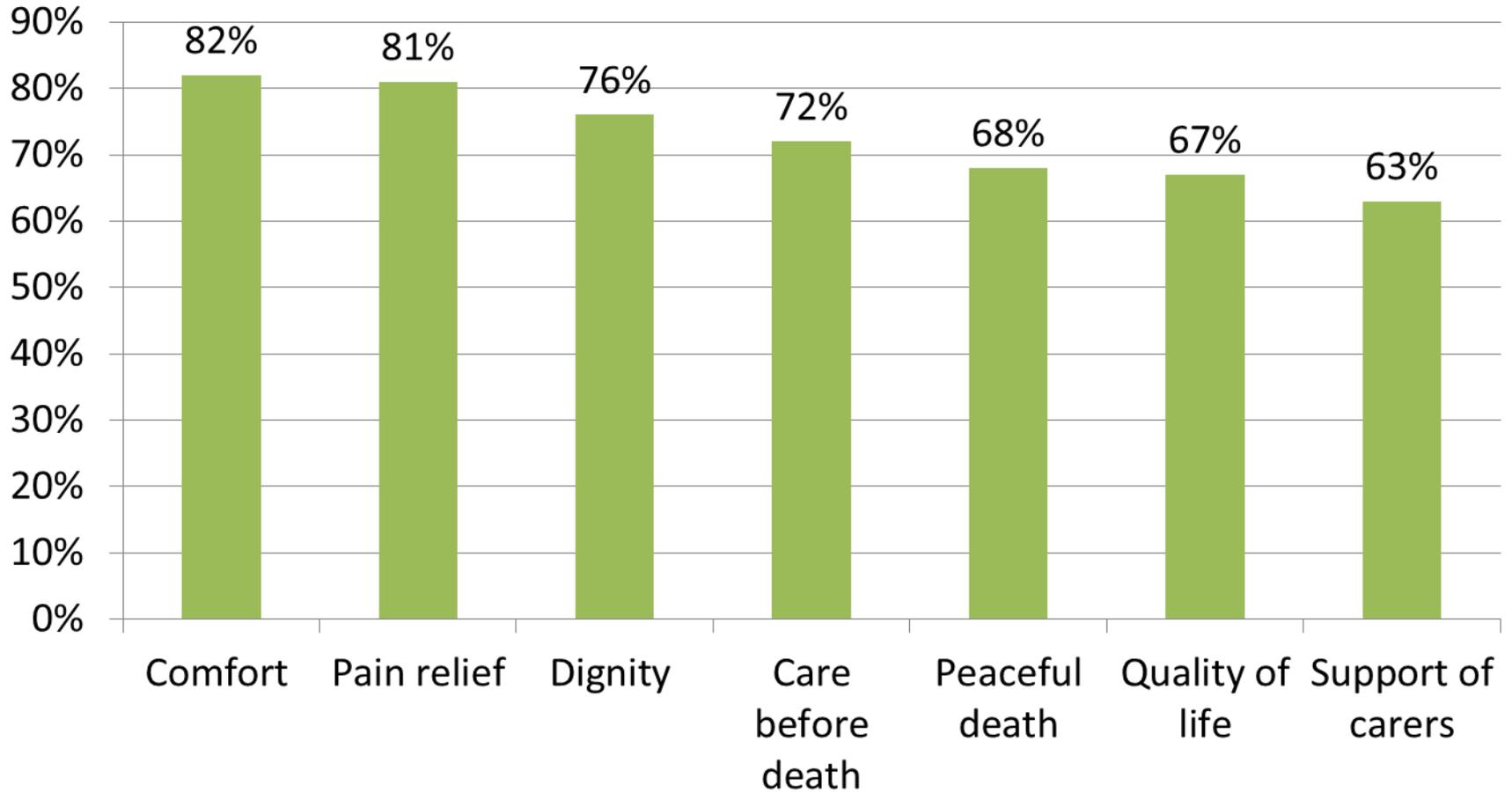
'It is making a person who has terminal cancer as comfortable and as pain-free as possible as end of life approaches' (Res 16)

'I think is basically making things as easy as possible for someone who is terminally ill' (12)

"Its looking after people who are dying and making their death as easy and comfortable as possible" (7)

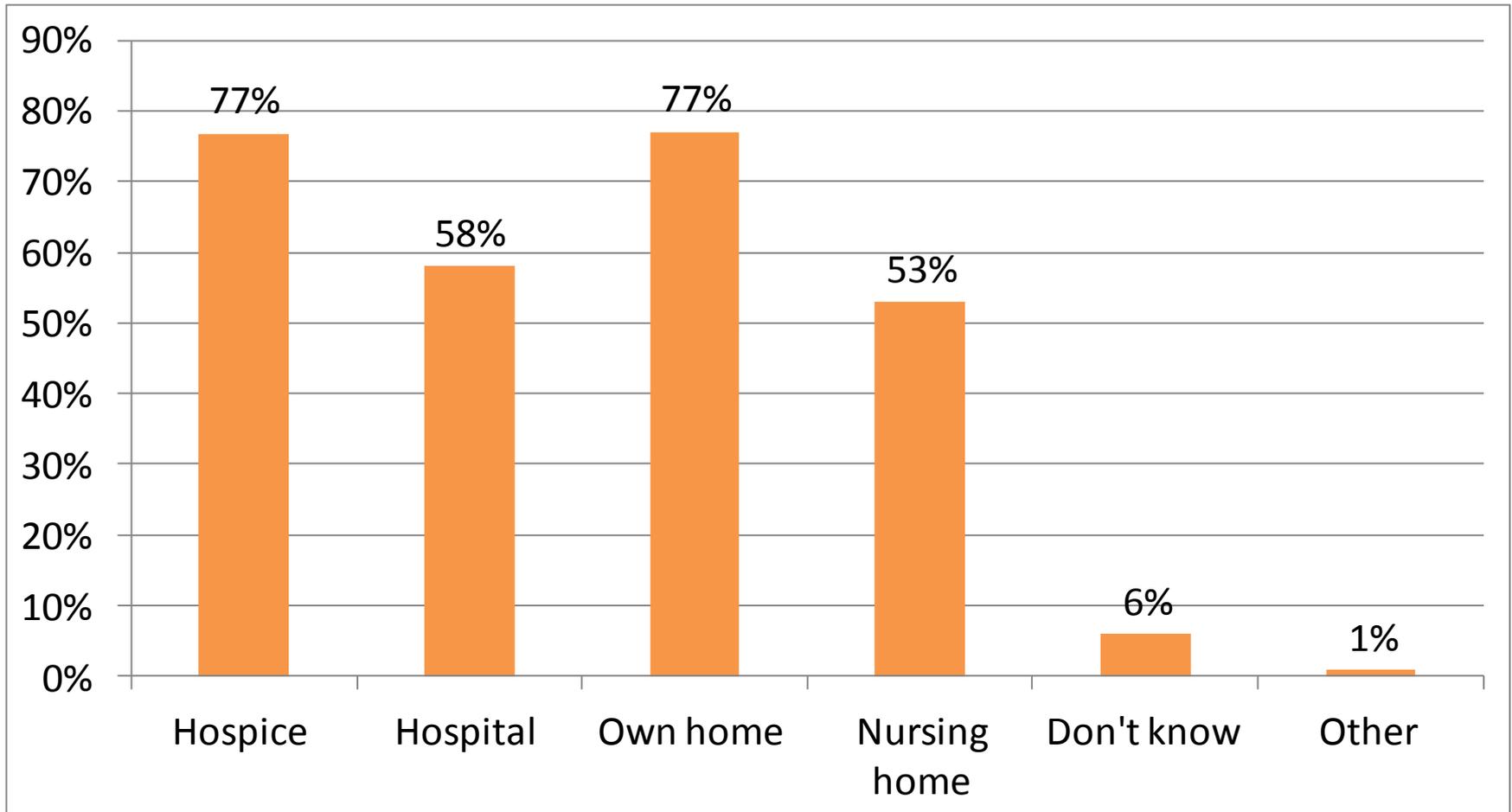
'Caring for cancer patient nearing death, with pain relief and support for caring family member of fatal illness' (Res 62)

What do you think palliative care tries to achieve?



- *‘Sometimes we want our loved ones to live forever, but sometimes it is kinder to let them go, but controlling their symptoms to keep people comfortable is an important part of palliative care’ (20)*
- *“easing of the burden, a helping hand, comfort for the patient and relatives..... It’s difficult to quantify the softer aspects but they are still worthy to have”. (30)*
- *“Palliative care to me primarily is to do with relief of pain but it’s also keeping people comfortable..... it’s not only with the physical but it’s also with the psychological.” (57)*

Where do you think people receive palliative care?

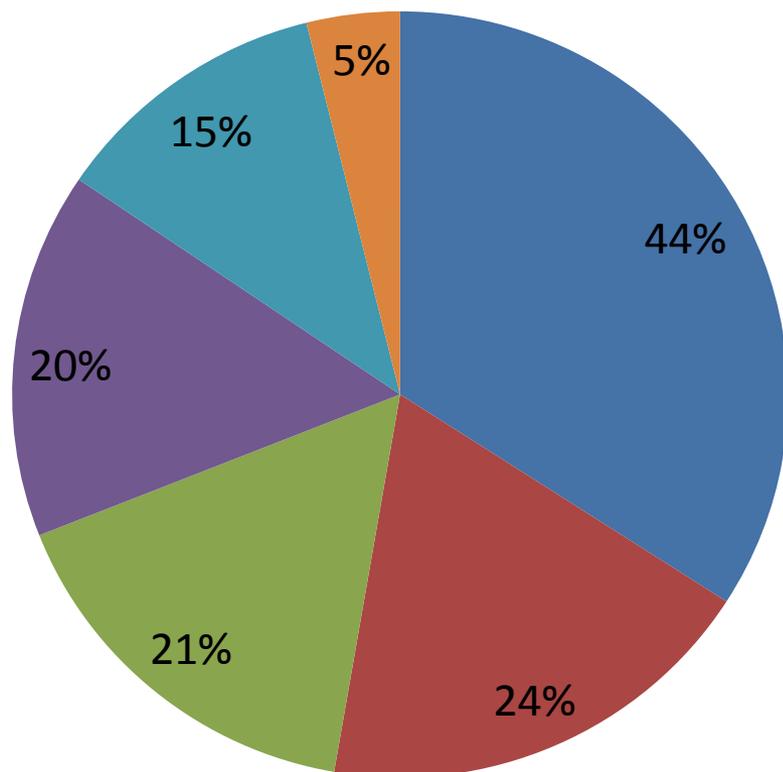


Place of care	% (n)
Home	61% (n=366)
Hospital	2.3% (n=14)
Hospice	6.8% (n=41)
Nursing home	0.8% (n=5)
Don't mind	6.2% (n=37)
Combination of home, hospital, hospice	17.5% (n=105)
Non-responses	5.3% (n=32)

“Well it takes place everywhere but I think its given best either in the hospice or in the home depending on the support. I don’t think it is particularly good in hospitals” (57)

”the best place for palliative care to take place is in the home, that is the best place if it is at all possible. (3)

Primary sources of information



- Close friend/ relative received palliative care
- respondent works in a health care setting
- Newspaper/ magazine
- Television
- Distant friend/ relative received palliative care
- Not sure/ can't recall

- **Reluctance by general public to talk about death and dying: cultural and societal influences**

“People are scared. It’s not discussed. It’s the final taboo. I have no problem in discussing it but I know that’s not the norm. So I think it’s the taboo thing.”(57)

- **Lack of knowledge/information – ‘term itself’**

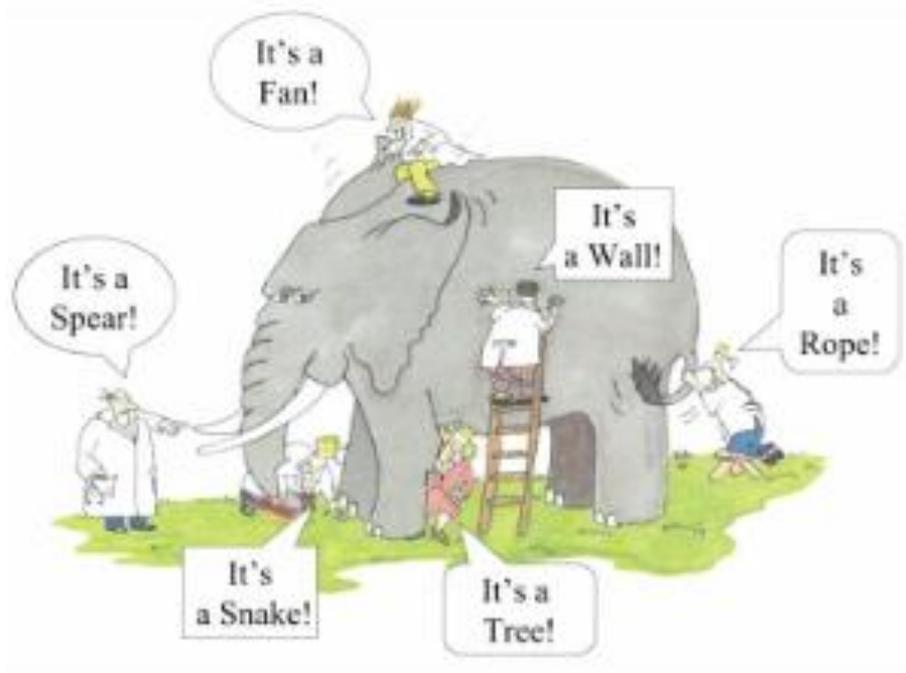
“ if the word palliative care was used more widely in hospitals and surgeries then people would maybe have a better understanding of what it’s all about-(40)

- **Lack of resources & funding to promote palliative care**

Strategies to increase awareness

- **Publicity Campaigns: with sensitivity**
- **Education:**
 - Broad: Use of media
 - Targeted: different groups
 - Community focused
 - Led by 'right' people: people with direct experience

- Findings indicated that whilst public have heard term – wide variability and confusion in understanding
- Palliative Care: associated with cancer; terminal care and care of the elderly
- Expectations for palliative care: care provided at home
- Enhancing awareness:
 - Addressing key barriers: societal influences and taboo
 - Increased understanding and use of the term
 - Importance of education & health promotion approach
 - Community engagement and development
 - Working *with* and not *on* communities



- “Palliative care still befuddles many people.... Even after seeing it people may feel like the many blind scientists touching different parts of an elephant”. (CAPC, 2011)
- Need to be aware of public opinion and understanding.

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