Exploring Public Awareness of Palliative Care

Dr Sonja McIlfatrick
Reader/Head of Research
Institute of Nursing & Health Research
All Ireland Institute of Hospice & Palliative Care
Background

- WHO: Palliative Care: Public health issue, Fundamental Human right

- Changing demographics & increased demand

- Studies showed international variability; lack of knowledge and confusion (Wallace, 2003; McCarthy et al, 2011; Seymour 2010; Hirai et al., 2011)

- Policy: Living Matters: Dying Matters’ (DHSSPS, 2010)

- Comprehensive knowledge needed to target education and policy campaigns
Aims & Objectives

Aim:
To explore public perceptions towards palliative care among members of PCC Membership Scheme.

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
- To identify what actions and strategies might enhance public awareness and understanding of palliative care
Mixed Methods Design

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=50
- Analysis: Content analysed
Key Findings

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.
83.3% heard of the term palliative care prior to receiving the questionnaire.

But most (75%) had either little or no understanding of the term.

Women and older people reported higher levels of knowledge.

Participants’ knowledge: influenced by personal experience.

Qualitative responses: care of the elderly; terminal care and cancer.
What do you think palliative care tries to achieve?

- 82% Comfort
- 81% Pain relief
- 76% Dignity
- 72% Care before death
- 68% Peaceful death
- 67% Quality of life
- 63% Support of carers
Where do you think people receive palliative care?

- Hospice: 77%
- Hospital: 58%
- Own home: 77%
- Nursing home: 53%
- Don't know: 6%
- Other: 1%
### Preference for place of care

<table>
<thead>
<tr>
<th>Place of care</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>61% (n=366)</td>
</tr>
<tr>
<td>Hospital</td>
<td>2.3% (n=14)</td>
</tr>
<tr>
<td>Hospice</td>
<td>6.8% (n=41)</td>
</tr>
<tr>
<td>Nursing home</td>
<td>0.8% (n=5)</td>
</tr>
<tr>
<td>Don’t mind</td>
<td>6.2% (n=37)</td>
</tr>
<tr>
<td>Combination of home, hospital, hospice</td>
<td>17.5% (n=105)</td>
</tr>
<tr>
<td>Non-responses</td>
<td>5.3% (n=32)</td>
</tr>
</tbody>
</table>

“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)
Sources of information

- Close friend/relative received palliative care (44%)
- Respondent works in a health care setting (24%)
- Newspaper/magazine (21%)
- Television (15%)
- Distant friend/relative received palliative care (5%)
- Not sure/can't recall (5%)

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Barriers to improving awareness

- 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
  - Posters
  - Talks
  - Open days

- **Develop understanding and use of the term**

- **Education:**
  - Broad: Use of media
  - Targeted: different groups
  - Community focused
  - Led by ‘right’ people: people with direct experience
Conclusions

- Current public understanding about palliative care is limited
- Public recognise there is a reluctance to talk about death and dying
- Public believe education should be focused around public media interventions and broader widespread use of the term ‘palliative care’
- This approach fits with WHO definition – palliative care as a public health concern and concept of Health Promoting Palliative Care (Kellehear, 1999).
Research Team

- Dr Sonja McIlfatrick (Principal Investigator)
- Dr Felicity Hasson, Senior Lecturer, University of Ulster
- Dr Dorry McLaughlin, Lecturer in Palliative Care, QUB
- Dr Gail Johnston, Programme Manager Personal and Public Involvement (PPI), PHA
- Audrey Roulston, Lecturer in Social Work, QUB
- Lesley Rutherford, Palliative Care Nurse Consultant, Marie Curie Hospice, Belfast
- Dr Helen Noble, Lecturer in Health Services Research, QUB
- Dr Noleen McCrory, Research Facilitator, Marie Curie Belfast
- Professor George Kernohan, Professor of Health Research, University of Ulster
- Dr Sheila Kelly, Board Member, Patient and Client Council, Northern Ireland
- Dr Avril Craig, Research Officer, Patient and Client Council, Northern Ireland
Center to Advance Palliative Care (2011). 2011 Public Opinion Research on Palliative Care A Report Based on Research by Public Opinion Strategies. Research Commissioned by the Center to Advance Palliative Care Support Provided by the American Cancer Society and the American Cancer Society Cancer Action Network, America.


