

# **Exploring public awareness of palliative care**

## **EXECUTIVE SUMMARY**



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## **1 INTRODUCTION**

The World Health Organisation (2004) advocated palliative care as being a public health issue and access to such care is acknowledged by United Nations conventions as a human right (International Federation of Health and Human Rights Organisations, 2011). Although many governments generally adhere to this claim, placing palliative care within public health strategies, how that translates into practice varies widely.

There is evidence of a variable awareness of palliative care reported in international research reported over the last decade. Modification of public perceptions of palliative care is central to improving knowledge of and access to services, empowering individuals, involving communities in palliative and end of life care, and in achieving the objectives of these national strategies. However, it is also recognised that public attitudes to palliative and end of life care are complex and equivocal (Cox et al., 2010) and that efforts to improve public awareness need to facilitate regional and cultural characteristics (Baker 2002; Enguidanos 2011; Conner 2012; Gysels et al., 2012), demographics (Conner 2012, Catt et al., 2005; Cox et al., 2010), ethnicity (Cox et al., 2010) and social structure, including religious affiliation (Burdette et al., 2005; Conner, 2012).

By 2017, 16% of the NI population will be aged sixty five years or over. Given that the prevalence of chronic conditions increases with age, the demand for palliative and end of life services is likely to increase - a pattern that is also reflected internationally (Davis et al., 2004; Seymour et al., 2008). The Palliative and End of Life Care Strategy for Northern Ireland recognises that it is necessary to address people's expectations of options and choice in how and where care is delivered, and promotes open discussion around these issues through the media, education and awareness programmes. To date there has been no published survey of attitudes towards palliative care amongst the population of Northern Ireland. Detailed and comprehensive knowledge of public views within Northern Ireland is needed to target education and policy campaigns, and to manage future needs, expectations and resourcing of end of life care. Raising the awareness of palliative care and exploring the public's perception and views of such services is key to ensuring that people are well empowered to make informed choices.

### **1.2 STUDY AIM AND OBJECTIVES**

The aim of this study was to explore public perceptions towards palliative care among members of the Patient and Client Council Membership Scheme in Northern Ireland.

In order to guide this study four objectives were developed relating to the aim:

1. To undertake a review of the literature over the last ten years to establish the key trends relating to the public's current knowledge, opinions and perceptions of palliative care.
2. To identify the public's views and perceptions of palliative care and possible demographic correlates.
3. To explore the personal views and factors that contribute to the public's knowledge and perception of palliative care.
4. To identify what actions, if any, might enhance awareness and understanding of palliative care or change public perceptions to improve future uptake of services.

## **2. METHODOLOGY**

The study used a combination of qualitative and quantitative methods and comprised two stages, to incorporate:

- Stage 1: A survey distributed to a cohort of the public via the regional database of the Patient and Client Council Membership Scheme
- Stage 2: Telephone interviews with a volunteer sample of 50 participants from stage 1 to explore the issues identified through the literature and survey.

## **3. FINDINGS**

Completed questionnaires were received from 600 respondents, who were predominantly female (69%), Christian (78%), White (91%) and between 40 – 70 years of age (80.3%).

### ***Knowledge of palliative care***

- Whilst the majority of respondents reported that they had heard the term palliative care most people revealed they had little or no knowledge of its meaning. Despite this lack of knowledge, when asked to reflect on the aims of palliative care, the majority cited delivery of comfort (82%), pain relief (81.3%) and dignity (76.3%) as key.
- Participant's knowledge and perceptions of palliative care was largely influenced by their personal experience

- Expectations for palliative care services included providing holistic support, effective symptom management; good communication; and practical support to enable choice and carer support.
- Although the family home was most often identified as the preferred place of care for a patient with palliative care needs, the majority believed that palliative care was delivered in hospice and at home followed by hospital.
- The majority believed that a member of the generalist practice team (general practitioner or district nurse) or a specialist hospice nurse (n=367, 61.2%) would be best placed to discuss palliative care needs.

### **Source of Information**

- The top three key sources of information on palliative care that were declared were:
  - (1) through a close friend or relative who had received care;
  - (2) via a health care setting;
  - (3) newspapers and magazines.

When asked which source they considered the most important, respondents identified the media (television, radio, newspapers) as key in delivering messages to the general public. Interestingly, however this was only recorded as the third source actually used.

### **Barriers to improving awareness**

- Overall the key barrier cited was reluctance among the general public to talk about death and dying. This was attributed to fear and a taboo within society to openly address such issues.
- The second barrier was the lack of knowledge or information held about palliative care, leading to the general public making assumptions which was reinforced by a lack of continuity and coordination between health care services.
- The third barrier was attributed to a lack of funding and resources to promote palliative care.

## Strategies to improve awareness and access

- Respondents were asked to openly record strategies they felt could enhance awareness, access and community involvement in palliative care. Findings revealed a range of approaches such as publicity campaigns, posters, talks, open days and clear signposting from health professionals could enhance awareness.
- A key aspect identified for promoting palliative care was developing increased understanding and use of the term itself. This was associated with dispelling the myth that the term was focused only on care of the dying but to develop wider understanding of the concept.
- Education was identified as an important strategy for improving public awareness of palliative care. It was suggested that the approach toward education should be broad and targeted towards different groups using different approaches. For example, this included targeting secondary schools as well as different discussion groups and publicity campaigns.

## 5. CONCLUSIONS & RECOMMENDATIONS

Current public understanding within Northern Ireland about palliative care is limited and is most often gained through personal experience. Various strategies for improving public awareness were identified, including the need for education and publicity. The public recognise that there is reluctance to talk about death and dying but believe that education should be focused around public media interventions and a broader and more widespread use of the term 'palliative care'. This approach fits with the WHO definition of palliative care as a public health concern and the concept of Health Promoting Palliative Care originated by Kellehear (1999). Health promotion efforts should strive to change public knowledge, attitudes and behaviour around palliative care through educational strategies and policy making involving families and communities

It is recommended that:

- A widespread Public Education programme using a broad approach and targeted at different groups is required to enhance public awareness of palliative care in Northern Ireland



- Public Education should begin in secondary schools to increase children's awareness of end of life issues
- Public education in adults should be delivered in community settings where the public congregate e.g. churches and community centres
- Education should be delivered by professionals or service users with experience of delivering or receiving palliative care using a range of methods to suit different target audiences
- The public should be educated about the wider definition of palliative care, not just focusing on end of life care
- A multi-media approach should be used to increase public awareness of palliative care including magazines and newspaper, posters, TV and radio adverts
- Health professionals should use the word 'palliative' care when talking to patients and their families and avoid euphemisms
- Palliative care services should be mainstreamed and integrated with other care services to avoid public and professional confusion
- Cultural change is required to remove taboos of talking about death and dying in Northern Ireland

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