

Conclusion and Recommendations

- Given that the majority of cancer patients would prefer to die at home and although there has been a recent increase in the proportion of cancer patients achieving this, approximately half of patients with home as preferred place of death (PPD) still die in an institutional setting.
- While achieving PPD can be considered an important end in itself, we have no evidence from this study to suggest that home death is associated with better or worse Quality of Life or Palliative Outcomes in last week of life or better grief outcomes for relatives.

The findings have highlighted:

- High levels of service usage including Ambulance and Accident and Emergency by cancer patients in the last three months of life.
- The importance of good communication and information giving in end of life care, in particular, relating to awareness of likelihood of death and discussions around PPD between the patient, their family and healthcare professionals.
- The critical role that key healthcare professionals play in communication and co-ordinating access to services.
- That achieving PPD was not associated with cancer diagnosis, stage of disease or days from diagnosis, suggesting that patient's demographic characteristics and social circumstances may be more important factors associated with achieving PPD at home.
- That while achieving PPD can be considered an important end in itself; the current study provides no evidence to suggest that home death is associated with better or worse Quality of Life or Palliative Outcomes in the last week of life.
- An undocumented burden on informal carers looking after cancer patients before they die exists.

From the findings of the current study the following recommendations have been made:

Recommendation 1:

HCPs caring for patients with end-of life care needs should have additional training in effective communication particularly in initiating discussions about likelihood of death and PPD in order to put an appropriate care plan in place and to enable patients to receive end of life care in PPD wherever possible. It is also recommended that HCPs responsible for delivering end of life care in all settings should be encouraged to complete an evidence based training programme, for example the European Certificate in Essential Palliative Care.

Recommendation 2:

Models such as the 'Delivering Choices' program and Rapid Response Teams should be explored and piloted for N. Ireland to reduce inappropriate ambulance use and admission to hospital.

Recommendation 3:

All patients nearing end of life should have a knowledgeable key health care worker to provide practical and emotional support for the family and to co-ordinate end of life care according to needs of patient and family.

Recommendation 4:

Further work is recommended to explore the burden that providing informal care at home puts on family and friends and to establish how best to support them in this role both practically and financially.

The full report 'Dying with Cancer: Perspectives of Bereaved Relatives/Friends' is available at www.qub.ac.uk/nicr

Further Information

Further data from the N. Ireland Cancer Registry (NICR) is available from the Registry web site: www.qub.ac.uk/nicr, and

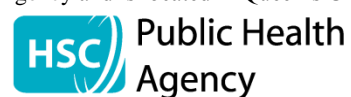
NI Cancer Registry
Centre for Public Health
Mulhouse Building
Grosvenor Road
Belfast, BT12 6DP

Phone: +44 (0)28 9063 2573
e-mail: nicr@qub.ac.uk



Acknowledgements

This audit was funded by Cancer Focus. NICR is funded by the Public Health Agency and is located in Queen's University, Belfast.



DYING WITH CANCER: PERSPECTIVES OF BEREAVED RELATIVES/FRIENDS

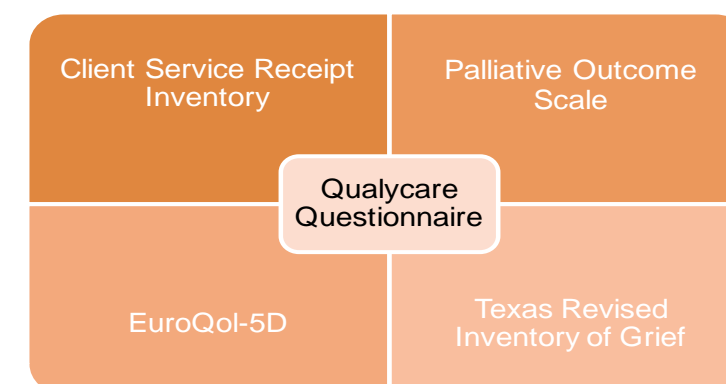
V Cairnduff, D Fitzpatrick, C Donnelly, J Blaney and A Gavin

Background

This summary is from a report which follows on from 'Why cancer patients die in acute hospitals' which described characteristics of those who died within an acute hospital setting and identified late diagnosis as a major factor in hospital death from cancer. This study aimed to establish key factors that influence place of death and specifically those that enable cancer patients to die at home.

Methods

The study took the form of a mortality follow back study completed by relatives and carers identified as informants on the patient's death certificate on behalf of cancer patients who died during the study period of January to May 2012. It received ethical approval from the Office for Research Ethics Committees Northern Ireland (Ref: ORECNI12/NI/0051). The study design was based on that of the QUALYCARE study (developed by Cicely Saunders Institute, King's College London) and used a questionnaire adapted from that developed by Ann Cartwright in the 1960s which incorporated four validated outcomes measurement tools to collect information on:



- care received in the last three months of life (Client service receipt inventory)
- circumstances of the patient's death, personal preferences for place of death and socio-demographic characteristics
- quality of life in last three months and last week of life, palliative outcomes in last week of life (EuroQol-5D and Palliative Outcomes Scale)
- respondent's grief response (Texas Revised Inventory of Grief).

Results

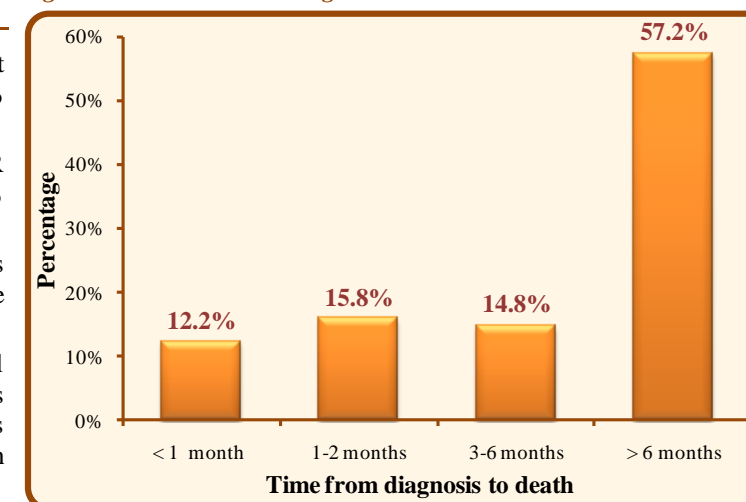
Respondent Characteristics

- A total of 1,495 informants were invited to take part with 467 responding (response rate of 31.2%).
- Over half (52.7%) of respondents were a son/daughter of the patient, while 25.1% were the spouse/partner, 60.4% were female and 65.1% were aged under 60 years.
- The median time from the patient's death until respondents completed and returned the questionnaire was 207 days (IQR 68; Range 135-276).

Patient Characteristics

- In the sample over a third (38.2%) of patients died at home, 41.1% in hospital, 12.0% in a hospice and 8.8% in a care home.
- The median age of cancer patients was 75 years (IQR 18) (mean 73.3 years), 53.7% were males and 54.6% were married or with partner.
- Over half of patients had been diagnosed with cancers of either the digestive organs (26.3%) or the respiratory and intrathoracic organs (23.6%).
- The median time from diagnosis to death for the total sample was 9 months (IQR 25) with 42.8% of patients dying within 6 months of diagnosis, 12.2% of patients died within a month of cancer diagnosis, 15.8% within 1-2 months of diagnosis and 14.8% within 3-6 months.

Figure 1: Time between diagnosis to death

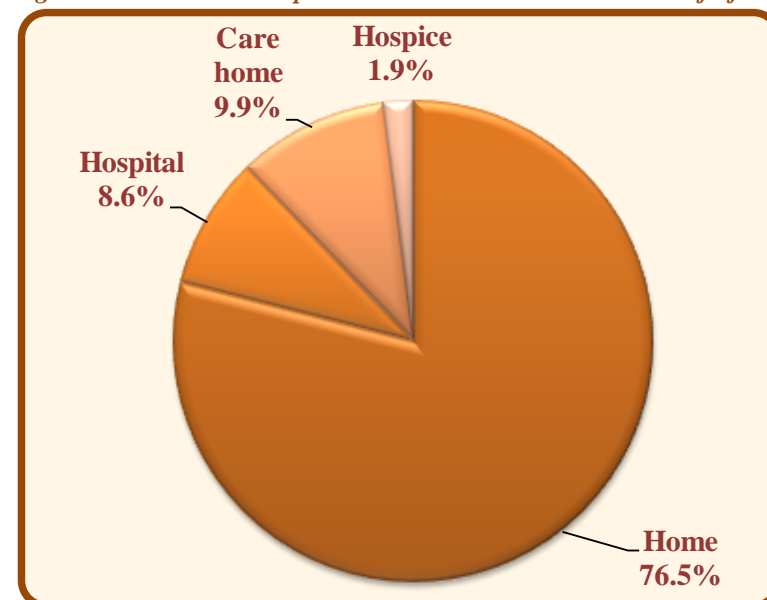


- Compared to the rest of the patients, those who died within 1 month of diagnosis were significantly older (78 years, IQR 17) than the remaining sample (74 years, IQR; IQR; p=0.04) and were mostly made up of patients with cancers of the digestive (40.4%) and intrathoracic organs (29.8%) (p=0.01).
- There were however no differences in terms of deprivation, place of death, marital status or gender (all p>0.05).

Care in last 3 months of life

- Overall, 89.7% (n=419) of patients spent some time at home and 76.5% spent most of their time at home in the last 3 months of life with the average time spent there being 68 days (± 24.8 , range 2-92).
- However 8.6% spent most time (n=40) in hospital, 9.9% (n=46) in a care home and 1.9% (n=9) in a hospice.
- Over three quarters (78.6%) of patients had at least an overnight stay in hospital (median length of stay 14 days (IQ range 21)). 16.6% of patients had at least an overnight stay in a hospice and 14.2% in a care home.
- Over half of patients attended Accident and Emergency (52.5%) while (57.8%) used ambulance services.
- The majority of patients who spent some time at home received care (88.9%) from GP, 55.5% received specialist palliative care at home and 64.2% received other nursing care from district and community nurses at home.
- Over half of patients had four or more members of their family/friends help care for them and 91.5% (n=421) had on-call help from family and friends.
- For respondents who were working (n=266), over two thirds (68.4%) reduced their hours or stopped work as a result of the patient's illness.

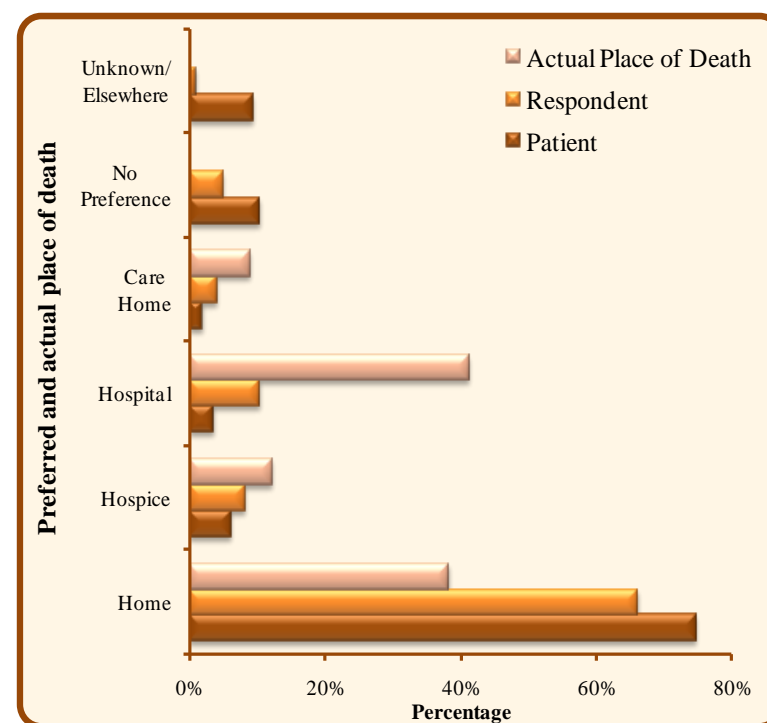
Figure 2: Place Patients spent most time in last three months of life



Place of Death

- Overall, preferred place of patient's death (PPD) was recorded for 426 (91.2%) patients and responders.
- Almost three quarters (74.7%) expressed a preference to die at home, 6% in a hospice, 3.4% in hospital, 1.7% in a care home. 4.9% of patients did not have a preference whilst the preference was either unknown or recorded as elsewhere for 9.2% of patients.
- There was good agreement between PPD of the patient and that expressed by the respondent with 66.1% of respondents preferring the patient to die at home, 10.3% in a hospital, 8.6% in a hospice, 3.9% in a care home. 10.3% of respondents did not have a preference and 0.8% were recorded as unknown or elsewhere. Of the patients and respondents whose PPD was known and those who had a preference, patient's PPD was achieved for 54.1% of patients and 59.3% of respondents.

Figure 3: Patient's and Respondent's preferred place of death at three months prior to death and place of death



Factors associated with achieving a home death

This section reports on patients whose PPD was home (n=372) and examined those who achieved this in terms of patient demographics, disease factors, health and social care input, patient's social circumstances, responders/family/friends input and information giving/communication.

(i) Patient Factors

- A higher proportion of males (61.4%) did not achieve their preference to die at home when compared to females (38.6%; p=0.028).
- No significant association between achieving a home death and deprivation levels were found and although not significant (p=0.059) a higher proportion of patients achieving a home death were partnered (64.0%) compared to those who died elsewhere (51.7%)

(ii) Disease Factors

- No significant associations between cancer diagnosis, Stage of cancer and days from diagnosis to death were observed between patients who achieved and those who did not achieve a home death were observed.

(iii) Health and Social Care factors

- Those who achieved a home death had help from HSC services (94.3%) and GP (97.1%) and Specialist Palliative Care (SPC) visits (87.4%) at home.
- A higher proportion of respondents where a home death was achieved felt that GPs were knowledgeable about the patient and their care (81.7% vs 64.9%; p<0.001), did enough to relieve symptoms (82.8% vs 65.6%; p<0.001), provided as much help as was needed (78.9% vs 59.6%; p<0.001) and rated GP care as 'excellent' or 'very good' (75.5% vs 53.0%; p<0.001) when compared to respondents for patients who did not achieve a home death.

(iv) Social Circumstances

- Patients who achieved PPD at home were likely to live with the respondent or others (83.3% vs 68.9%; p=0.009) in the three months prior to death with patients dying in an institutional setting being more likely to have lived alone prior to death (28.4% vs 15.4%; p=0.009).
- Those who achieved a home death were more likely than others to receive informal care at home from 4 or more members of their family or friends (69.1% vs 41.8%; p<0.001) and had respondents who reduced hours or stopped working during their illness (82.2% vs 64.0%; p=0.01).
- No differences in terms of travel time from where the patients lived to closest relative were observed between patients who achieved PPD at home and those who did not.

(v) Information and Communication

- A higher proportion of patients who achieved PPD at home (75.4%) felt they had received full info in the last week when compared to those who did not (59.6%; p=0.02).
- Higher proportions of patients who died at home discussed their preference with family/friends (82.8%) and or HCP (61.1%) when compared to those who died elsewhere (55.0% and 26.5%; p<0.001).
- Agreement between patient and respondent on PPD at home was more likely to result in a home death with 95.4% of patients who achieved PPD at home agreeing with respondents compared with 64.5% of patients who did not achieve PPD at home.

(vi) Palliative Outcomes in last week of life (POS)

- The palliative outcome scale (POS) was used to assess patient's physical and psychological symptoms, practical considerations, emotional concerns and psychological needs in the last week. The full POS was completed for 333 patients.
- The mean POS score was 14.2 ± 6.1 . Maximum POS score is 40 with a higher score representing a poorer palliative outcome. No significant differences in mean POS scores were observed between patients who achieved PPD at home (n=153), PPD in an institution (n=35) or those who did not achieve PPD at home (n=144). This lack of difference also applied to individual items within the POS scale i.e. management of pain or other symptoms, confusion and being unconscious in last week of life, patient feeling good about themselves, depression in patient, family and friends feeling anxious or worried and whether practical matters were up to date in last week of life (all p> 0.05).

(vii) Quality-of-life in last three months and last week of life (EuroQol-5D)

- The EuroQol-5D scale was used to assess patient's quality of life in the last 3 months and last week of life by assessing five main areas: mobility, self-care, usual activities, pain and discomfort and anxiety and depression.
- There was no significant difference in EuroQol-5D scores in last 3 months or last week of life observed between those who achieved PPD at home or institution and those who did not.

(viii) Respondents Grief: Texas Revised Inventory of Grief (TRIG)

- No significant differences in grief scores were observed between those patients who achieved PPD at home and those who did not.