



St Margaret of Scotland Hospice
Open to All in Need of Care

Audit of Living and Dying Well based on Patient Experience of Non-specialist Palliative Care

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Introduction:

Living and Dying Well: Living and Dying Well – A National Action Plan for Palliative and End of Life Care in Scotland¹ was introduced by the Scottish Government in October 2008. Its aim is to provide fair access to good quality palliative care to all who require it across Scotland.

Aim of the audit: To assess whether Action Points (2, 4, 10 and 16) taken from Living and Dying Well are implemented consistently for patients with palliative care needs.

Method:

A retrospective audit using patient questionnaires.

Subjects: Patients attending the Edwina Bradley Day Hospice or receiving a service from the Community Specialist Palliative Care Team who met the eligibility criteria for this audit.

Measures: A questionnaire enquiring about patient experience of their care **before** referral to St Margaret of Scotland Hospice. Questionnaires were based on themes from patient focus groups and were tested for construct validity, test-retest reliability (% agreement: 85%), and appropriateness of level of language.

Statistical analysis: Statistical analysis was performed using the SPSS (PASW Statistics, version 18.0) for descriptive statistics and frequencies of patients' answers to each question. Further analysis was conducted using cross-tabulations for the sample split into groups based on gender, diagnosis and age.

Results:

Description of the sample: 30 patients (mean age 73.9 years \pm 10.9, range 49-95), 50% male, 50% female. Diagnosis: 67% Cancer, 20% COPD, and 13% CHF.

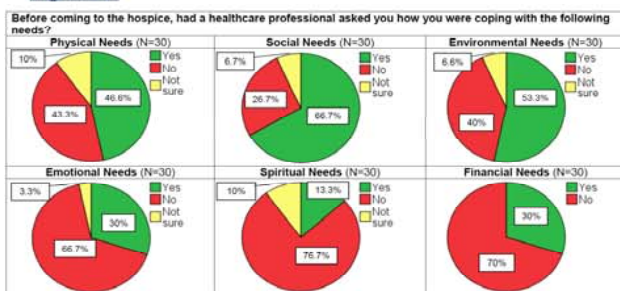
Action Point 2:

This Action Point recommends: Patients with palliative and end of life care needs should be identified and their needs assessed and reviewed regularly.

Audit findings:

➤ Most patients had been asked how they were coping with their physical, social and environmental needs. In contrast, the majority had not been asked about their emotional, spiritual or financial needs. (Figure 1)

Figure 1:



Action Point 4:

This Action Point recommends: Palliative care should be timely, holistic, effective and person-centred.

Audit findings:

➤ Regarding the provision of person-centred care:

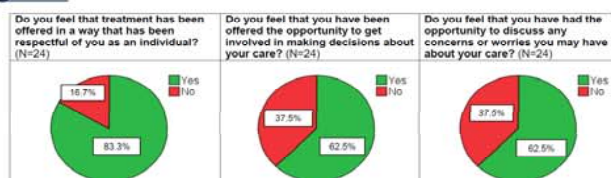
❖ 65.2% of patients said their illness was fully explained to them by their GP or a Hospital doctor in a way they could understand.

❖ 77.8% of patients remembered being told about their hospice referral.

❖ The majority of patients felt that treatment was offered to them in a way that was respectful (83.3%), were offered the opportunity to get involved in making decisions about their care (62.5%) and said they had the opportunity to discuss any concerns or worries they may have had about their care (62.5%). (Figure 2)

➤ More patients with a diagnosis of cancer (75%) felt they had the opportunity to discuss any concerns or worries they may have had about their care compared to those with a diagnosis of COPD or CHF (37.5%).

Figure 2:



➤ Regarding the provision of timely, holistic and effective care:

❖ Between 63% and 75% of patients felt they had received sufficient help or advice to meet their holistic needs (i.e. physical, emotional, social, environmental, spiritual and financial).

✓ More patients in the 73-95 year group felt they had received enough help with their holistic needs compared to those in the 49-72 year group.

✓ More patients with a diagnosis of cancer (87.5%) felt they had received sufficient help with their spiritual and financial needs compared to those with a diagnosis of COPD or CHF (37.5 and 50% respectively).

Action Point 10:

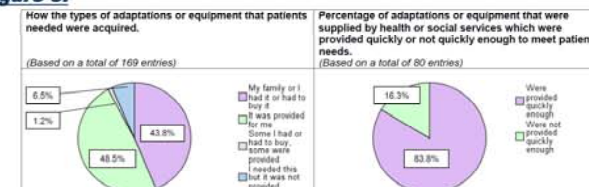
This Action Point recommends: Those wishing to be cared for or die at home should have rapid access to appropriate equipment.

Audit findings:

➤ The percentage of adaptations or equipment provided for patients by health or social services was similar to the percentage of adaptations or equipment patients already had or had to buy. (Figure 3)

➤ The majority of equipment or adaptations provided by health or social services were provided quickly enough to meet patient needs. (Figure 3)

Figure 3:



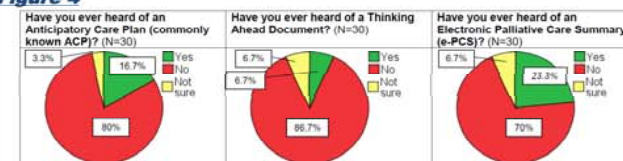
Action Point 16:

This Action Point recommends: Safe and effective processes should be available to facilitate patient information transfer between professionals and organizations.

Audit findings:

➤ The majority of patients had never heard of the Anticipatory Care Plan, the 'Thinking Ahead' document or the Electronic Palliative Care Summary (ePCS) and of those who had heard of one of these documents, less than 50% had started making one. (Figure 4)

Figure 4



Discussion:

• Assessment of more sensitive issues relating to emotional, spiritual and financial needs appears *inadequate*. The reasons for this could be that healthcare professionals do not understand the importance of these concepts or do not feel confident when broaching or exploring such sensitive issues.

• Delivery of person-centred care appears *adequate* for the majority of patients. Attention is warranted to the percentage of patients for whom this is not the case.

• These findings indicate that more resources might be available for patients with a diagnosis of cancer and are comparable to the findings of a study undertaken by Murray et al² in 2002.

• Timely provision of adaptations and equipment was an encouraging finding as it promotes patient independence and choice of place of care. Appropriateness and safety remain a concern for the majority of patients that had to buy the equipment they needed. This demonstrates a lack of adequate risk assessment.

• Regarding ACP, Thinking Ahead and e-PCS documents, it is disconcerting that patients were not informed of their existence. Steps should be taken to ensure all healthcare professionals are aware of these documents and that patients and families are appropriately informed of their usefulness when 'thinking ahead'.

Conclusion:

The finding of this audit demonstrate that patient experience of the delivery and quality of non-specialist palliative care remains variable. This suggests that Living and Dying Well has not yet achieved its aim of improving palliative care for all who require it. Further work, with a larger sample size, is necessary to improve the holistic assessment of patients, the communication between healthcare professionals across all care settings and the involvement of patients in decision making and planning of care.

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References:

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