Study of predictors of home deaths in terminally ill cancer patients in [the former] CSAHS
"The home deaths project"

Final Report

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Executive Summary

PROJECT MANAGEMENT

This project was unusual within the caring community program because it was essentially a research study. Research has been underdeveloped in palliative care as it has become established and while many palliative care textbooks and conferences focus on "getting started" in research the type of projects such authors have in mind are usually in house, single centre, low-budget audits. Large scale projects such as the one we carried out, competitively unded by an external granting body, are still relatively uncommon within palliative care and there are still many lessons to be learnt regarding fulfilling the requirements of project management. To be sustainable infrastructure is required, and a project officer is indispensable and needs to be supported. The increase in research capacity created by completing this type of project will not be maintained without ongoing support.

Specific lessons that have been learnt from this project that may be less generalisable include:

1. Obtaining ethics clearance from multiple agencies – our own institutional ethics committee was not the problem, but external committees were.
2. Negotiating the process with the CCR was time-consuming given that the CCR's prime role is to collect and report on the data rather than functioning as a research database to be accessed by external scientists
3. Understanding the processes of financial reporting within the institutional constraints and competing with numerous other priorities for business reporting

EVALUATION OUTCOMES

RESULTS OF THE STUDY

A population-based sample of 37 bereaved carers of deceased cancer patients was recruited, and face-to-face interviews conducted. Interviews were tape-recorded, transcribed verbatim, and thematic content analysis conducted.

Participants in this study were informal carers, all next-of-kin comprising 15 spouses, 14 children, three parents, three siblings, one grandchild and one cousin, of patients who had died from cancer. Over a thirteen month period, twenty-seven females and ten males with a median age of 53 years (range 33-81) gave written, informed consent to participate in the study, and were interviewed for approximately one hour each.

No followups of patient records were conducted and therefore all responses were carers' recollections. Deceased patients, 24 males and 13 females, were aged from 37 to 96 years (median 72); most died during 2001 or 2002 and were resident in Sydney's Inner West (the former CSAHS) or in adjacent areas within metropolitan Sydney. One patient/carer resided in rural NSW, one patient died in 1996, and four patients in 2003.

Country of birth for carers and patients is shown in Table 1, with nine patients recorded as not speaking English at home, consistent with the population (see Project Profile p.10). All carers were English speaking, being a recruitment criterion.

Table 1: Country of birth of participants and deceased patients

	Carers	Patients
Australia, NZ, UK	29	25
Europe (Italy, Greece, Austria, Croatia)	5	9
Asia (Vietnam, Sri Lanka)	2	2
Middle East	1	1

Carers reported patients' primary cancer diagnoses as being haematological (7), bowel (6), lung (5), breast (4), brain (3), pancreas (3), prostate (3), renal (2), one each for ovarian, stomach and melanoma, and one unknown primary. While the absolute number are small this pattern of primary sties is quite representative of pattern of primary sties in NSW, with the exception of haematological malignancies, which is an interesting observation.

Place of Death

Data on place of death and involvement of palliative care services is shown in Table 2.
Nine (24%) patients died at home, which compares with 19% for all cancer patients in NSW and 29% of patients referred to palliative care services across Australia. Twenty five patients died in hospital and three in a nursing home. Overall, 28 (76%) patients had contact with some kind of palliative care service, but due to either problems with perceptions or deficits in recall of the carers, it was not possible to categorise this any further e.g. generalist versus specialist; setting/place of contact, however 16 (64%) of the 25 hospital deaths did take place in a designated palliative care ward.

Table 2: Summary of place of death and involvement of palliative care services as recalled by carers

Place of death	**Number of deaths**	**Home PC service involved**	**Inpatient PC service**	**Both**	**Nil**
Home	9	7	2	2	2
Hospital: Inpatient PC	16	8	16	8	0
Acute/other	9	4	0	0	5
Nursing Home	3	0	1	0	2
TOTAL	**37**	**19**	**19**	**10**	**9**

Other data

The questionnaires provided data on demographics of the patient and carer, the carers' perceptions of the patients' diagnoses, symptoms, other health problems, and cause of death, as well as information on the care needs of the patient and the competing responsibilities of the carer (see appendices for questionnaire). Time has not permitted analysis of this quantitative data, but this will be part of our dissemination strategy. Our primary aim will be to evaluate factors of systematic reviews that are relevant to place of death data. Because of the small sample size, it is anticipated that few if any differences will reach statistical significance, but trends would be reportable and meaningful on the context of the previous systematic reviews of Gomes and Lake.

Qualitative Research

Some ten major themes emerged from our interviews. Given that this project aimed to identify factors influencing the place of death, arguably the most important lesson was the finding that the actual place of death is less important to the carer than them being there, especially at the death. There are many other areas that can be improved and they are incorporated in the recommendations below.

Based on these results, we make the following recommendations to improve the experience of patients and their families during the terminal phase.

With regard to sustainability, resources (human, financial, time and information) will be required to fulfil these recommendations, the details of which can be found in section 6. It would be a worthwhile exercise in the interest of sustainability to consider what one might do with one-off projects worth $5K (e.g. produce pamphlet); $20 K (e.g. education video) and $100K (e.g. project officer).

Recommendations

As a result of conducting our project, we have made ten recommendations with regard to the place of death. While many are to increase the support of carers, it is important to realise that others are directed at health care professionals, policy makers, and the broader community both within the inner west of Sydney and Australian society in general. At the time of writing this report we have not completed our analysis of the importance of the factors that influence the place of death that have been previously reported in the health care literature, and we hope to do these soon along with identification of those that may be positively influenced through increased resources and/or policy change. In the subsequent sections of this report we also make a number of recommendations to improve the conduct of future studies on place of death, including the study design, the process for identifying participants, and the tools and study measures.

Despite the limitations of our study results we believe that the population-based sample was broadly representative, and that the results are broadly applicable to Australian urban populations.

Recommendations Summarised

INFORMATION NEEDS

I Recommendation 1,4,: Information needs regarding dying, including how to talk with patients, what to expect, and what to do if someone dies at home

II Recommendation 2,3: Information needs regarding caring: Pain management education, available resources

SERVICE NEEDS

III Recommendation 3,10: Information should be available early in the disease trajectory, and as a "one-stop shop," to make it easier to access all resources, including for people from a non-English speaking background

IV Recommendation 5: Carers should be included in patient management in the hospital

V Recommendation 6: Strategies to link services and communicate a continuum of care to patients and their carers. Also, emphasise after hours support and strategies

VI Recommendation 7: Earlier referral to palliative care services, and increased home visits by palliative care services

VII Recommendation 8: Bereavement services should be offered to all bereaved families

SUPPORT NEEDS

VIII Recommendation 5,9: Carers need to be supported, including in the hospital, given moral support and encouragement, especially at patient death

IX Recommendation 8: Bereavement services offered to all bereaved families, regardless of involvement with palliative care services