

A Scoping Review of Palliative Care in Scotland

Final Report



UNIVERSITY OF
STIRLING

DEPARTMENT OF
NURSING AND MIDWIFERY

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1. Summary

1.1 Abstract

Objectives: To specify the extent of palliative care research in Scotland, in order to identify gaps in the evidence, thus allowing research priorities to be set in an objective way.

Materials and methods: Six electronic databases were systematically searched from January 1990 to April 2005. Six key journals were hand searched from January 1999 – April 2005. Grey literature searches were also conducted. Authors known to be active in the field were contacted, as were Health boards, R & D teams, regional ethical committees, hospices, hospital palliative care teams and key charities associated with palliative care in Scotland.

Results: 44 studies utilising various methodologies were identified using pre determined inclusion and exclusion criteria. The top four main themes drawn from the selected studies were; models of palliative care/provision, symptom control, religious/spiritual issues and education.

27 studies were deemed suitable for inclusion within the research directory.

Conclusions: A wider evidence base for palliative care in Scotland is required.

1.2 Key words

palliative care, Scotland or Scottish, hospice, terminal care, dying patients, bereavement, advanced disease.

1.3 Funding

The proposal for this project came from the Forth Valley Cancer & Palliative Care Research Group. In order to set the agenda for future research it was deemed important to firstly identify the existing evidence base. Funding was kindly provided by: Forth Valley NHS

Acute and Primary Care Operating Divisions and Forth Valley Palliative Care Managed Clinical Network. This funding allowed a nurse with palliative care experience to have dedicated time to work on this project with support from the research sub-group.

1.4 Length of Project

May 2005-December 2005

2. Background

In the speciality of palliative care there is a firm base of endeavour and clinical achievement upon which to build with exciting possibilities for future development. The success of such developments, however, will be influenced strongly by the excellence of the research base of palliative care. Research activity in palliative care, has in the past been hindered by a lack of; research skills amongst practitioners, the focus on patient care as a priority and the fact that palliative care units tend to be relatively small and isolated from academic research institutions (Field et al 2001).

Ethical issues have also posed particular problems in the production of palliative care research in terms of retention and recruitment of frail and vulnerable patients and randomisation into placebo arms of clinical trials (Seymour & Ingleton 2005, Dean & McClement 2002, Grande & Todd 2000).

Early research into bereavement, hospice care and pain, in particular, was pivotal in establishing the speciality of palliative care and provided powerful data about the needs of dying people (Corner 1996). However, much of the research activity in palliative care has included small scale and locally based studies, with little attention to generalisability and how the findings can be used at a national level.

The specialty of palliative care is rapidly developing and is now recognised as a distinct specialty in Scotland (NHS Quality Improvement Scotland (NHSQIS) 2004). Nevertheless, despite the rapid growth in the number and range of palliative care services and in the management and care of dying patients, the evidence base for palliative care in the UK, and particularly in Scotland is weak, and rigorous evaluation of these developments or well designed intervention studies have not been carried out (Field et al 2001). Although, palliative care provision is central to the care of patients with life limiting conditions, such as cancer (NHS Cancer Plan DoH 2000, Scottish Executive 2001), palliative care clinicians need to establish the evidence that supports their decisions and interventions, so that they can provide evidence-based care. This fits with the current agenda for palliative care in Scotland (NHSQIS 2002). The challenge for palliative care is to continually evaluate what it does, retain effective interventions, and refine

those that require improvement, thereby enhancing practice and patient outcomes. Absence of a clear strategic direction, co-ordination and an inadequate infrastructure has hampered palliative care-related research in Scotland. In order to establishing the palliative care research agenda, there must be a clear understanding of the existing evidence base. Therefore, a time limited, scoping exercise was conducted, to discover the current evidence base in Scotland. Confining the scope to Scotland ensured that a) a Scottish focus of current evidenced palliative care practice was identified b) the task of the scope was achievable in the time span c) the findings would be more applicable, and therefore more likely to be acted upon.

3. Methodology

3.1 Scope of the exercise

A scoping exercise rather than a rather than a systematic review was conducted for the following reasons: The definition and methodology for conducting a systematic review are fairly precise and there is clear guidance on how to conduct such reviews (Hearn et al 1999). Systematic reviews, however, normally try to answer a clearly defined question within strict parameters. They also seek to review high quality research papers that are usually defined by the randomised control trial as the 'gold standard' (Hearn et al 1999).

This study, however, sought to identify all Scottish palliative care research, with the knowledge that both qualitative and quantitative methodologies would be used to conduct such research. If a systematic review in this area had been conducted the full extent of Scottish palliative care research would not have been identified.

At the outset of this study several attempts were made to identify a definition and guide of how a scoping review. Arksey & O'Malley (2005) suggest a methodological framework for conducting such a review and describe the stages for conducting a scoping study:

- Stage 1:** Identifying the research question
- Stage 2:** Identifying relevant studies
- Stage 3:** Study selection
- Stage 4:** Charting the data
- Stage 5:** Collating, summarizing and reporting the results

One of the main differences between that of a 'scope' and a systematic review is that a scope does not aim to synthesis or appraise the quality of the data. The framework discussed above was used. However, in this study it was decide to analyse the quality of the data and grade it, in order to have a more comprehensive appraisal of the literature. In addition, we chose to identify current research practice in Scotland. The

following stages were, therefore, also undertaken:

- Stage 6:** Analysing, grading and appraising the literature
- Stage 7:** Identifying key people, charities, hospices and others undertaking research and asking them to participate in the study/nominate other researchers
- Stage 8:** Complete research questionnaire, detailing their research
- Stage 9:** Compilation of research directory
- Stage 10:** Dissemination of results

A research protocol was written for the purposes of this study. Whilst this may not be a pre-requisite for a scoping review it was felt that this would be in line with good research practice and provided a firm base from which to conduct the review. (Appendix 1)

3.2. Aims

The aims of this review were:

- To review the palliative care literature including published and unpublished evidence around aspects of delivery, development and evaluation of palliative care provision.
- To compile a research directory profiling planned, current, and recently completed palliative care research in Scotland.

3.3. Key questions

1. What is the current evidence base for palliative care research in Scotland?
2. What key themes emerge from this data, if any?
3. What are the gaps in the evidence base?
4. What recommendations can be made for future research?

3.4 Search strategy for identification of articles

The research sub-group had previously identified key words for the search strategy. The Key words were: *palliative care, hospice, terminal care, dying patients, bereavement, and advanced disease*. Each key word was combined with Scotland or Scottish and then entered into the six databases previously described. After entering these terms limits of English language and date restrictions were applied.

The results were then reviewed by title, abstract and then full text to determine their suitability for inclusion (Lloyd Jones 2004). The following inclusion and exclusion criteria were applied:

3.5 Inclusion Criteria

- Literature from Peer reviewed journals from January 1990 to April 2005.
- Grey literature such as unpublished thesis MPhil, PhD and MD from January 1990 to April 2005.
- Papers in English language only.
-
- Only Scottish studies were included (the criteria were; patients living in Scotland, or research conducted in a Scottish centre (NHS board, NHS division, care home, and voluntary or private health care institution). If the research involved a multi-centre study, one or more sites were in Scotland.
- Adults aged 16 or above (Studies were included if children were included in a sample with adults).
- Studies were included if patients were described as having palliative care involvement or needs. This included malignant and non-malignant disease. The WHO definition of palliative care was used as a guide in determining the inclusion of palliative care research (WHO 2004)
- Studies were also included if the subject related to palliative care and included relatives, carers, professionals.

3.6 Exclusion Criteria

- Audit, narrative, expert opinions or anecdotal work.
- Research at the planning stage (although this was included in the research directory), Pilot studies, Bachelor, and taught MSc dissertations.

3.7 Electronic databases searched

Medline, Embase, Psycinfo, CINAHL, Web of Science, AMED (Allied and complementary medicine database) and Google Scholar were searched for primary research articles from January 1990 to April 2005. A Cochrane database search was conducted to identify systematic reviews conducted by Scottish authors. In addition a search of the Chief Scientist's Office (CSO) website was also conducted. Eight key authors known to be active in the field were also identified and an author search via Web of Science database was performed.

3.8 Hand searching

Journal hand searching remains an essential component of conducting systematic searches (Droogan 1996, Hearn et al 1999), in order to supplement database searches. International Journal of Palliative Nursing, British Medical Journal, Palliative Medicine, Journal of Advanced Nursing, Cancer Nursing and Journal of Pain and Symptom Management were hand searched for the years January 1999 to April 2005. This time frame was chosen as to conduct a hand search for the years 1990-2005 would have been too time consuming.

3.9 Grey literature searches

It was the intention to search the System for Information on Grey Literature (SIGLE) database to assist in identifying grey literature pertaining to palliative care research, but after some unsuccessful attempts to access the site the company responsible for the database were contacted and they explained that SIGLE was no longer in use. A Google Scholar search was, therefore, performed in attempt to unearth grey literature.

University librarians of all the academic institutions in Scotland (n=23) were contacted

via e-mail to request advice on seeking unpublished thesis (Appendix 2). If they failed to reply a further e-mail was sent. 39% replied (n= 9) after two attempts at contact. This strategy was not successful in revealing further evidence.

In a trade off with validity, versus workload, and competing priorities with the project it became apparent that further grey literature searches would have to be abandoned. A study conducted by Cook et al (2001) explored the value in conducting a grey literature search in palliative care as part of a systematic review. They spent ten months contacting key individuals (over 100), charitable organisations and palliative care teams as well as searching SIGLE. Only one study fulfilling their research criteria was identified. In conclusion the authors suggest that spending excessive time searching the grey literature for palliative care research may not be well invested, particularly for time limited, financially constrained studies.

3.10 Data extraction

A data extraction sheet was adapted from one used previously by the research team at the Cancer Care Research Centre at Stirling University (Hubbard et al 2005). A small pilot was conducted to test the data extraction sheet; following this some slight amendments were made (Appendix 3). One reviewer extracted data from all the selected studies and two other reviewers data extracted from a sample of papers in order to cross validate the results. In order to investigate the heterogeneity of the studies, details such as research setting, participants, and diagnosis, methodology and main themes were included in the data extraction sheet.

3.11 Synthesising evidence/quality appraisal

It was anticipated that the papers identified would use various methodological approaches and it was, therefore, decided not to use a Cochrane study design criteria to weight the studies. This did pose a significant challenge for the authors to identify an appropriate tool to grade both quantitative and qualitative data effectively. Qualitative research is often criticised for lacking technical rigour. This can also be argued for quantitative research, in that the research methodologies can be fundamentally flawed in both approaches (Dixon-Woods et al 2001).

Nevertheless, we wished to grade the quality of our extracted papers, not with the intention of excluding the 'poorer' studies, but to gauge the overall quality. After a thorough exploration of existing grading tools, it was decided to use the same criteria used by Hubbard et al (2005) in their study (devised by Dixon-Woods 2005). These criteria allowed both quantitative and qualitative papers collectively to be graded. The following questions were asked of all retrieved papers:

1. Are the aims and objectives of the research clearly stated?
2. Is the research design clearly specified and appropriate for the aims and objectives of the research
3. Do the researchers provide a clear account of the process by which their findings were produced?
4. Do the researchers display enough data to support their interpretation and conclusions?
5. Is the method of analysis appropriate and adequately explained?

The documents were given a five star grading if they met all of the above criteria, four stars if they met four and so on.

It was decided not only to grade the literature, but also to explore methodological typology and types of evidence. Glasby et al (2004) used criteria previously outlined in the National Service Framework for Older people (Department of Health 2001). These criteria were adopted for our study (table 1) Type A, B or C evidence would be deemed fit for inclusion in our study, as our main focus was published and unpublished research.

Table 1 Criteria for assessing evidence

Type A evidence	Type B evidence	Type C evidence	Other
(A1) Systematic reviews which include at least one Randomised Control Trial (RCT).	(B1) Individual RCT's.	(C1) Descriptive and other research or evaluation not in B	(D) Summary review articles and discussions of relevant literature and conference proceedings not otherwise classified.
(A2) Other systematic and high quality reviews, which synthesise references.	B2) Individual non-randomised, experimental/ intervention studies.	(C2) Case studies	(P) Professional opinion based on clinical evidence or reports of committees.
			(U) User opinion.
			(C) Carer opinion.

4. Key findings

The initial database searches resulted in 298 hits. After applying the exclusion criteria and eliminating duplicates, 24 studies were included. From these studies the reference section of each article was examined and a further three studies were identified and deemed suitable for inclusion. Journal hand searches produced seven articles that had not been previously identified by the electronic databases searches or by other means. The Google Scholar search did not identify any unpublished research articles, but did however reveal one published article that had not previously been identified. Three other articles were identified during the data collection component of the research directory compilation and a colleague identified the remaining two articles.

In total 44 articles were included in the study. An opinion was sought from a secondary reviewer if there was doubt over inclusion or exclusion of a study. All article titles and abstracts were downloaded to a reference-managing database.

4.1 Methodological quality

The grading results for the papers included in the study are shown in table 2 (n=44).

Table 2 grading results

Type of Evidence	Number of Articles	Grade	Number of Articles
A1	0	5 star	9
A2	0	4 Star	13
B1	2	3 Star	16
B2	7	2 Star	5
B3	12	1 Star	1
C1	23		

Studies were given a C1 rating if they used quantitative data analysis, but were felt not to fit the criteria of B3 evidence. 18 studies used qualitative research methods, 18 used quantitative methods and 8 used mixed methodology.

The sample sizes varied considerably. Studies using quantitative methodology had

sample sizes ranging from n=18-319, qualitative n=6-46 and mixed n=10-194 (with one sample size unknown). Within the qualitative studies five used a sample size of six. One of the reasons for this could be that these studies were conducted to form part of a master's qualification. It must be mentioned however that although these studies make a valuable contribution to palliative care literature, they may not be able to influence policy change or practice.

On further examination of the articles it became apparent that sampling methods had not been discussed and in fact the majority of the articles (n=30) did not specifically discuss the sampling strategy for their studies. One of the reasons for this could be word restrictions imposed by the publishing companies.

Only two RCT's were identified within the literature search. This is despite the fact that Randomised placebo-controlled double-blind clinical trials are the gold standard in clinical research, particularly when testing the efficacy of a drug (Jones at al 1996) and should be used more in palliative care, (Hardy 2001). While authors have argued that controlled trials using placebos are not always appropriate in palliative care (Kirkham and Abel 2001) they do not argue that RCT's are not a useful method of testing interventions, and the efficacy of therapy.

The methodology used, sample size, aims and objectives for all the studies are detailed in table 3.

Table 3. Studies used in review by title, methodology, sample size and aims and objectives

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Adam, 2000	Discharge planning of terminally ill patients home from an acute hospital	Mixed	12	To explore carers perceptions of the preparation given on adopting the caring role, with particular reference to the information and practical support they received from the hospital staff
Andrew & Whyte, 2004	The experiences of district nurses caring for people receiving palliative chemotherapy	Qualitative	46	To explore the experiences of district nurses caring for people receiving palliative chemotherapy; how they viewed their role, factors that influenced their role and their attitudes to palliative chemotherapy
Bagg et al., 2003	High prevalence of non-albicans yeasts and detection of anti—fungal resistance in the oral flora of patients with advanced cancer	Quantitative	207	To examine in detail the oral mycological flora in a large series of patients with advanced cancer receiving care in three separate hospices
Ball et al., 1998	Fluconazole sensitivities of Candida species isolated from the mouths of terminally ill cancer patients	Quantitative	30	To determine the prevalence of oral candidal carriage among a group of terminally ill cancer patients, to speciate the yeasts present, and to determine their sensitivity to fluconazole
Boyd et al., 2004	Living with advanced heart failure: a prospective, community based study of patients and their carers	Qualitative	20	To describe how patients and carers view health and social care in the last year of life
Brown, 2002 MD Thesis	An investigation of weakness, fatigue, strength, function and quality of life in patients with advanced cancer	Quantitative	68	To investigate the importance of weight loss, altered body composition, the inflammatory response, haematological and biochemical parameters in the experience of weakness and fatigue in patients with advanced cancer. To examine the relationships between objective tests of strength and function and measures of weakness and fatigue and patient-related quality of life in patients with advanced cancer

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Cornbleet et al., 2002	Patient-held records in cancer and palliative care: a randomized, prospective trial	Quantitative	244	To evaluate prospectively the introduction of a patient-held record in the management of patients with advance cancer and palliative care needs
Donnelly, 1999	Traditions associated with dying in the west of Scotland	Qualitative	20	To demonstrate how dying and death in the west of Scotland were perceived by the individual and the community Identifying customs that can inform modern palliative care
Fallon & Hanks, 1999	Morphine, constipation and performance status in advanced cancer patients	Quantitative	50	To examine constipation associated with morphine in an observational study of patients with pain due to advanced cancer
Farrer K et al., 2004 (Unpublished)	An evaluation of a multidisciplinary hospital based palliative care team	Mixed	194	To evaluate the effectiveness of a HPCT in improving 1.Pain and symptom control, effective communication and discharge planning in patient with advanced cancer 2.The knowledge skills and attitudes of medical and nursing staff in relation to cancer pain management
Grady & Travers, 2003	Hospice at home 2: evaluating a crisis intervention service	Mixed	62	To evaluate a rapid-response crisis intervention service, for patients with advanced cancer
Grant et al., 2004	Spiritual issues and needs: Perspectives from patients with advanced cancer and non-malignant disease: A qualitative study	Qualitative	20	To describe the range and context of spiritual issues and needs that patients with advanced cancers and non-malignant illnesses experience, and the extent to which such needs may impact on their well-being
Hamilton & McDowell, 2004	Identifying the palliative care role of the nurse working in community hospitals: an exploratory study	Qualitative	6	To ascertain nurse's and GP's perceptions of and influences on the nurse's role in providing palliative care in community hospitals

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Hjorleifsdottir & Carter, 2000	Communicating with terminally ill cancer patients and their families	Qualitative	12	To investigate whether 4th year undergraduate nursing students raise concerns about communication with terminally ill and dying cancer patients and their families
Hockley et al., 2005	Promoting end-of-life care in nursing homes using an 'integrated care pathway for the last days of life'	Qualitative	16	To evaluate the implementation of an integrated care pathway for the last few days of life using action research methodology
Huby G, 1997	Interpreting silence, documenting experience: An anthropological approach to the study of health service users' experience with HIV/AIDS care in Lothian, Scotland	Qualitative	16	To document people's experience of services they used, so that people's views could inform evaluation of provision
Johnston B, 2002 PhD Thesis	Perceptions of Palliative Nursing	Qualitative	44	To explore the concept of a good nurse in palliative care To discover how nurses perceive good and bad palliative care To discover how dying patients perceive good and bad palliative care
King et al., 2000	Dying at home: evaluation of a hospice rapid-response service	Mixed	U/K	To assess the effectiveness of a hospice rapid response service and its contribution to meeting the needs of palliative care patients at home
Levack et al., 2004	Listen to the patient: quality of life of patients with recently diagnosed malignant spinal cord compression	Quantitative	319	To report quality of life of patients shortly after the diagnosis of malignant spinal cord compression, its relation to physical ability and to emotional well being using SEIQoL-Dw and HAD

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Llewelyn et al., 1999	Group therapy for metastatic cancer patients: report of an intervention	Mixed	11	To examine the viability and acceptability of a breast cancer support group within a specific social context, namely women living in a mixed rural and urban area of north east Scotland, and second, the process and outcome of a group which included both emotion-focused and problem-focused coping
Lockhart-Wood, 2001	Nurse-doctor collaboration in cancer pain management	Qualitative	6	To explore and describe the characteristics of collaborative practice in cancer pain management To uncover any oppressive influences that block nurses' and doctors' ability to collaborate
Loftus, 1998	Student nurses' lived experience of the sudden death of their patients	Qualitative	6	To understand in greater depth the lived experience of third year student nurses caring for dying patients in acute medical, surgical and care of the elderly units
Loftus & Thompson, 2002	An evaluation of a palliative care course for generic nurses	Quantitative	18	To evaluate strengths and deficits in knowledge before and after completion of a palliative care course for generic nurses
Lovell et al., 1993	Bereavement reactions of female Scots and Swazis: A preliminary comparison	Quantitative	40	To investigate whether bereavement reactions in female school pupils and teachers from Scotland and Swaziland differ in intensity
Milligan, 2004	Perceptions of spiritual care among nurses undertaking post registration education	Quantitative	59	To explore the perceptions of qualified nurses undertaking a palliative care module as part of a post registration degree course. To what extent do nurses regard care giving as part of their role? How difficult or easy do nurses find recognizing patients with spiritual care needs and subsequently meeting those needs? What factors do nurses regard as affecting their ability to provide spiritual care?

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Milligan et al., 2001	Oral care for people with advanced cancer: an evidence-based protocol	Quantitative	25	To evaluate a protocol for oral care on patients with advanced cancer. Aims were to record the prevalence of different oral problems among admissions to the hospice, and to monitor changes in oral health and comfort between admission and after 7 days of oral care according to the protocol
Mills et al., 1994	Care of dying patients in hospital	Qualitative	50	To study the nursing care of patients during the final six days in hospital and to identify factors that might influence that care in general hospitals
Mitchell & Sneddon, 1999	Informing the debate: chaplaincy and spiritual care in Scotland	Mixed	10	To explore how healthcare chaplains in Scotland understand and practice spiritual care
Murray et al., 2003	Dying from cancer in developed and developing countries: lessons from two qualitative interview studies of patients and their carers	Qualitative	44	To describe the experiences of illness and needs and use of services in two groups of patients with incurable cancer, one in a developed country and the other in a developing country
Murray et al., 2002	Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community	Qualitative	40	To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease
Murray et al., 2004	Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers	Qualitative	40	To explore whether patients with life threatening illnesses and their informal carers consider they experience significant spiritual needs, in the context of their overall needs, how spiritual concerns might vary by illness group and over the course of the illness, and how patients and their carers think they might be supported in addressing spiritual issues

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Murray et al., 2003	General practitioners and their possible role in providing spiritual care: a qualitative study	Qualitative	40	To explore whether GP's perceive that they have a role in spiritual care What do GP's perceive as helping and hindering them in assessing spiritual needs and providing spiritual care?
Murray et al., 2004 (Unpublished)	Improving out of hours palliative care in the community: The views of patients and their informal and professional carers	Mixed	101	To gain the perspectives of patients with advanced cancer and their informal and professional carers concerning the needs and experiences of out of hours care in the community To collate patients, carer and professional views to recommend service improvements
Oxenham & Cornbleet, 1998	Accuracy of prediction of survival by different professional groups in a hospice	Quantitative	41	To examine the accuracy of prediction of survival by different professional groups in a hospice, both on admission and in the week before death
Potter, 2004	Fatigue experience in advanced cancer: a phenomenological approach	Qualitative	6	Through exploration and examination capture a detailed description of the meaning and experience of fatigue in patients with advanced cancer
Ross & Cornbleet, 2003	Attitudes of patients and staff to research in a specialist palliative unit	Mixed	48	To determine the willingness of patients receiving specialist palliative care to take part in clinical trials, and to elucidate reasons for acceptance or rejection of study entry. A secondary aim was to compare the views of patients with those nurses directly involved in their care
Scott et al., 2003	A prospective study of the impact of weight loss and the systemic inflammatory response on quality of life in patients with inoperable non-small cell lung cancer	Quantitative	106	To examine the relationships between weight loss, the systemic inflammatory response and quality of life in patients with inoperable non-small cell lung cancer

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Scott et al., 2002	The systemic inflammatory response, weight loss, performance status and survival in patients with inoperable non-small cell lung cancer	Quantitative	106	To examine the relationship between magnitude of the systemic inflammatory response and weight loss, performance status and survival in patients with non-small cell lung cancer
Sweeney et al., 1997	Clinical trial of a mucin-containing oral spray treatment of xerostomia in hospice patients	Quantitative	35	To examine the therapeutic effect of a mucin spray in comparison with a mucin-free placebo spray with respect to oral symptoms, pathology and microbiology
Sweeney et al., 1998	Oral disease in terminally ill cancer patients with xerostomia	Quantitative	70	To determine the prevalence of oral signs and symptoms among a group of terminally ill cancer patients
Sweeney et al., 1996	Provision of mouth care by nursing staff for cancer patients in Scotland: Current status and role of training	Quantitative	179	To determine the level of mouth care provided for patients with advanced cancer receiving care in the community and in hospices throughout Scotland. To devise a mouth care training pack and assess its value
Thomas, 2001	Patients' perceptions of visiting: a phenomenological study in a specialist palliative care unit	Qualitative	6	To investigate patients perceptions of visiting in a hospice

Author	Title of Research	Research Methodology	Total Number in Sample	Aims / Objectives
Thompson & Reilly, 2002	The homeopathic approach to symptom control in the cancer patient: a prospective observational study	Quantitative	100	<p>To collect demographic data relating to age of the patients, diagnosis, presence of metastatic disease, source of referral and the new use of CAM since diagnosis</p> <p>To identify up to three problem symptoms and to evaluate the impact of the homeopathic approach on these symptoms</p> <p>To assess any changes in mood disturbance and quality of life at the end of the study period</p> <p>To record how helpful women found homeopathy for their symptoms and satisfaction with the homeopathic approach</p>
Wells et al., 2001	The knowledge and attitudes of surgical staff towards the use of opioids in cancer pain management: can the hospital palliative care team make a difference?	Quantitative	135	To assess the knowledge and attitudes of nursing and medical staff to cancer pain, before and after they worked with the Hospital Palliative Care Team

4.2 Themes arising from included papers

The majority of the studies discussed various issues within the context of the research. In an attempt to group together the studies for the purpose of this scoping exercise one main theme was identified from each article.

The project team predetermined 15 themes and this list was incorporated within the data extraction sheet (appendix 2). All of the themes that were identified came up within the literature, although not necessarily as a main theme, with the exception of 'palliative treatment' (i.e. palliative surgery/radiotherapy). Table 4 outlines the main themes that arose from the literature.

Table 4. Theme by number of articles

Main Theme	No. of Articles
Models of palliative care/provision	12
Pain and/or Symptom control	10
Religious/spiritual issues	6
Education	4
Role of health care professional	4
Quality of life	3
Bereavement	1
Communication	1
Complementary therapies	1
Social support	1
User involvement/ Patient experience	1
TOTAL	44

4.3 Models of palliative care/provision

This topic was the most popular of all. Within this section various aspects of palliative care/provision were examined across a variety of health care settings. The topics researched covered the areas of: care of the terminally ill in hospital, role of a hospital specialist palliative care team, discharge planning, perceptions of visiting, relationships between doctors and nurses managing pain in a hospice, medical and support services

at home, patient held records and integrated care pathways in nursing homes.

Within secondary care the topics ranged from care of terminally ill patients in hospital (Mills et al 1994), discharge planning of terminally ill patients (Adam 2000) and the role of a hospital multi-disciplinary team (Farrer et al 2004). It is acknowledged that the data in Mills study was old. Yet, the findings revealed care of many dying patients in acute hospitals was poor, particularly regarding comfort measures and symptom control. Adam identified the problems inherent in discharging terminally ill patients to home from acute hospitals as far as carers are concerned. She recommends that discharge planning should involve facilitating the carer to make his/her own decisions from a range of available options, to enable them to cope more effectively. Farrer et al carried out a 4 year study to evaluate the effectiveness of a hospital palliative care team using a pre and post test non-equivalent group design. The control group were drawn from two hospitals that did not have HPCTs. The study suggests that HPCTs have a vital role in hospitals to improve unrelieved pain and symptoms in patients with cancer.

On the other hand, Thomas (2001) examined patients' perceptions of visiting in a specialist palliative care unit and found that coping and lack of control were commonly identified in the small sample of patients they interviewed. They found that visiting had both a negative and positive impact on patients. Some enjoyed visiting but found too many visitors and the length of time they stayed to be tiring. Patients who were not mobile could not 'escape' the visitors if they wished to. In conclusion it was suggested that staff could facilitate patient-managed visiting by perhaps setting boundaries prior to visiting.

Managing difficult symptoms such as cancer pain has also been studied. Lockart-Wood (2001) examined the factors that enhance or impinge on the relationship between nurses and doctors when managing cancer pain in a hospice and she concluded that forums, which are both supportive and informative, should be developed to discuss pain management.

Several of the papers addressed medical and support services at home from a patient/carer/professional perspective (King et al 2000, Murray et al 2004, Grady & Travers 2003, Boyd et al 2004, Murray et al 2002). For instance, Murray et al (2004) examined

the perspectives of patients and carers about their needs and available services. This study looked at two groups with heart failure and the lung cancer; they found that care is prioritised by diagnosis rather than need. They recommend that strategic planning across primary and secondary care, involving health and social services working in partnership with specialist palliative care providers, is needed for people with advanced cardiac disease and other progressive illnesses. Moreover, Boyd et al (2004)'s study regarding living with advanced heart failure draws similar comparisons. The conclusions are that services for heart failure patients are under developed and the role for specialist palliative care services should be evaluated.

Out of hours services (Murray et al 2002) and 'hospice at home' (Grady & Travers 2003, Travers et al 2000) studies were identified. The out of hours study discusses the need for more information for patients and carers when they are at home. They identified that information such as; who to contact and when, and what type of response they should expect. Likewise, professionals should be alerted when such patients are discharged home, to ensure the best possible service is provided. It was recognised that all areas in Scotland do not always have the sufficient nursing and support services to provide a good service. On the other hand, Grady and Travers project relating to hospice at home had two aims: to prevent an admission to hospital/hospice and to facilitate early discharge home. In addition, King et al evaluated a hospice rapid response service. Both studies had similar conclusions in that the services were fairly well evaluated, but would need larger sample sizes to allow a more detailed comparison.

Two studies evaluated documentation in palliative care, specifically, patient held records (Cornbleet et al 2002), and the use of integrated care pathways to promote end of life care in nursing homes (Hockley et al 2004, 2005). Patient held records (PHR) and their benefits have been widely debated. Cornbleet et al (2002) conducted a randomised control trial on behalf of the Scottish partnership for palliative and cancer care and the National council for hospice and specialist palliative care services. They found there was no significant improvement in communication from health professionals or patient satisfaction with the introduction of this document. The findings of this study were similar to that of the study conducted by Lecouturier et al (1999). Hockley et al report an action research project which aimed to promote quality end of life care in eight independent nursing homes using an integrated care pathway for the last days

of life documentation. The improvement in care was characterised by an overarching pattern of dying being more central to care in the nursing homes. The way the ICP documentation was facilitated encouraged a greater openness around death and dying, with nurses and care assistants being more prepared to take responsibility for recognising dying and marking the dying process. The processes also encouraged a greater sense of teamwork.

4.4 Symptom Control

Ten studies were identified which related to symptom control. This is somewhat surprising given that other reviews of palliative care research (NCRI, http://www.ncri.org.uk/documents/activities/strategic/NCRI_Supportive_and_Palliative_Report_web.pdf <http://www.nice.org.uk/pdf/csgsresearchevidence.pdf> have identified symptom control as the most popular area of palliative care research and the area with the most robust evidence base.

Out of the ten studies identified five of these related to oral care. Within this sub-heading prevalence of oral disease was the focus of three papers (Sweeney et al 1998, Bagg et al 2003, Ball et al 1998). The three studies explored the anti-fungal resistance for patients with advanced cancer who had oral candidosis, as well as determining oral disease in patients with a diagnosis of xerostomia.

The treatment of xerostomia (Sweeney et al 1997) and evaluation of an evidence-based protocol (Milligan et al 2001) was the focus of the remaining two studies. Sweeney et al conducted a double blind single phase placebo-controlled trial of a mucin-containing oral spray for the treatment of xerostomia with 35 patients. 26 patients were still in the trial after 14 days. The data revealed that there were no statistical significance between placebo and treatment groups. Neither spray has any major impact on oral microflora. However, patients in both groups wished to continue using the sprays at the end of the trial stating that they had some symptomatic relief. Milligan et al evaluated a protocol for oral care developed by Accord Hospice in Paisley. The evaluation determined that using a clearly defined protocol led to significant and consistent improvements in oral health and comfort. A survey of mouth care practice in other Scottish Hospices found that although there was consensus in some practice, some

hospices were carrying out oral care that was unsupported by research evidence.

One of the other main symptoms to be discussed was fatigue and performance status in patients with advanced cancer (Brown 1996, Scott et al 2002, Potter 2004). The three studies used methodology ranging from experimental, RCT to interpretive qualitative research, and added to the evidence that fatigue is a widespread symptom in people with advanced disease.

Fallon & Hanks (1999) also looked at performance status but in relationship to constipation associated with morphine in a sample of patients with advanced cancer. They found that there was no correlation between morphine dose and laxative dose and persistent constipation in seriously ill patients was more closely related to how ill and disabled the patients were.

The final paper examined the accuracy of prediction of survival by different professional groups in a hospice (Oxenham & Cornbleet 1998). Predictions on 30 patients admitted to one hospice in Scotland were analysed using descriptive statistics. Predictions were most accurate at the end of life. In addition, when different disciplines were compared it was the nursing auxiliary who was the most accurate.

4.5 Religious/Spiritual issues

Religious and spiritual issues are considered to be a significant part of palliative care practice (<http://www.who.int/cancer/palliative/definition/en/>) yet only six studies addressed the spiritual issues and needs of patients with advanced disease (Murray et al 2004, Grant et al 2004, Milligan 2004, Murray et al 2003, Mitchell & Sneddon 1999, Donnelly 1999).

The evidence base suggests that spiritual issues were significant for many patients and their carers in the last year of their life (Murray et al 2003). Patients' spiritual needs centred around their loss of roles and self identify and their fear of dying. Many sought to make sense of life in relation to an invisible and sacred world. They equated anxiety and sleeplessness with their spiritual despair and were best able to engage their own coping strategies when affirmed and valued by health professionals (Grant et al

2004).

Furthermore, exploring the role of health care chaplains in Scotland (Mitchell & Sneddon 1999), found that they are experienced in providing spiritual care in its widest sense, but need to take the initiative to engage in the spiritual care debate, and increase their input to education and training. Moreover, although GPs's stated that they had a role in providing spiritual care to patients with life-threatening illnesses, most hesitated to raise spiritual issues with patients (Murray et al 2003). Concurring with this evidence Milligan (2004) found that nurses working in palliative care in Scotland also felt that providing spiritual care was part of their role. However, they identified, in a survey, several interventions where they had provided spiritual care. Areas of lack of knowledge were, however, also discovered. In a different approach Donnelly (1999) explored traditions associated with dying in the west of Scotland.

4.6 Education

Four studies were found that related to education and palliative care. Education and dissemination of palliative care knowledge are considered an integral part of specialist palliative care in Scotland <http://www.clinicalstandards.org/pdf/finalstand/SPC.pdf>).

Training in the provision of mouth care and lack of formal protocols was identified in Sweeney et al's study (1996). Training packs for oral care were devised after an initial survey sent to hospices, Macmillan nurses and district nurses, highlighted significant deficiencies in training and lack of formal protocols for oral care. A follow up survey found that packs had been well received and resulted in significant changes to oral care.

Student nurses experience of the sudden death of their patients was examined by Loftus (1998). A phenomenological interpretive method was used to explore students' experiences of caring for dying patients. The students recounted how they were affected by sudden death and their perceived vulnerability. They also identified the need for personal support.

On the other hand, Wells et al (2001) investigated whether the hospital palliative care

team could make a difference in the knowledge of surgical staff towards opioids in cancer pain management, using a pre and post education survey. They found that knowledge of doctors and nurses improved after working with the team, and that this mainly occurred through informal teaching including good working relationships and case discussions.

Evaluation has also taken place regarding a palliative care course for generic nurses (Loftus & Thompson 2002). Data were gathered using a validated palliative care quiz and a survey which provided a subjective evaluation of the nurses' practice. They acknowledge that educators still need to explore ways of determining the transferability of education to practice, and to explore ways of measuring the effectiveness of education and training on clinical skills, knowledge and attitudes.

4.7 Role of Health Care Professional

Four studies focused on the role of the health care professional and specialist nurses in relation to delivering palliative care. All of the studies examined the role of the nurse looking after patients with palliative care needs.

Johnston's study (2002) more specifically identified the concept of an expert nurse in palliative care and how dying patients and palliative nurses perceive good and bad palliative care and the expert nurse in palliative care, using an interpretive phenomenological method. Data were collected using methodological triangulation via in-depth interviews and the repertory grid technique. The lived experience of dying patients was characterised by the desire to maintain independence and remain in control. Palliative care nurses experienced both effective and ineffective interpersonal communication, the building of therapeutic relationships with dying patients and attempting to control patients' pain and distressing symptoms. Patients and nurses agreed that the two most important characteristics of an expert palliative nurse were interpersonal skills and personal/humane qualities such as kindness, warmth, compassion and genuineness.

Attitudes of patients and staff to research in a specialist palliative care unit were investigated by (Ross & Cornbleet 2003). The results indicated that staff were favourable

towards research being conducted, but this was under the proviso that the appropriate trial design was utilised.

In a small scale study Hamilton and McDowell's (2004) aimed to identify the perceptions of and influences on the nurse's role in providing palliative care in the community as perceived by nurses and GP's. They identified the nurses' role as multidimensional and made up of communication, teamwork and relationships, holistic care, resources, culture and professional role. The final article also explored the role of district nurses. Particularly, the experiences of district nurses caring for patients receiving palliative chemotherapy and how they viewed their role (Andrew & Whyte 2004). District nurses perceived that they had a significant role in caring for patients at all stages of their cancer journey. Difficulties were, however, perceived at the interface between hospital and primary care.

4.8 Quality of Life

Three studies focussed on quality of life a notably difficult area to research and define (Higginson and Carr 2001).

The impact of weight loss of patients with inoperable non-small cell lung cancer was investigated in Scott et al's study (2003). Quality of life in this study was measured using a standard tool (EORTC). They found that weight loss together with a systemic inflammatory response and fatigue impact on different aspects of quality of life. On the other hand, Levack et al's study (2004) measured the quality of life in relation to disability in patients with spinal cord compression in Levack et al's study (2004). They used the tool (SEIQoL). Their findings however contribute to the debate as to whether quality of life should be measured. They found that QOL determined by the patient may not coincide with the health professionals' opinions.

Moreover, Murray et al's work (2003) compared experiences, needs and available services of Scottish and Kenyan patients with advanced cancer and their carers. Rather than use a standardised measure they explored the experiences of patients and carers using longitudinal qualitative interviews. They found differences in the lived experience of illness between patients with advanced cancer in developed and

developing countries.

4.9 Communication, Complementary therapies, Bereavement, Social Support, User involvement

All of the above categories had one study each relating to that subject matter.

Communication usually has a direct bearing on most palliative care articles, but only one study seemed to explore this as the main focus. The views of student nurses were sought on factors that could influence their feelings of insecurity/security when communicating with terminally ill cancer patients and their families (Hjorleifsdottir & Carter 2000). The findings revealed that communicating with terminally ill and dying cancer patients in the acute setting is difficult for student nurses and issues about death and dying tended to be ignored.

On the other hand, Thompson & Reilly's study (2002) explored the homeopathic approach to symptom control and its impact on mood disturbance and quality of life with 52 patients. Symptom scores for fatigue and hot flushes improved with homeopathic remedies but not pain, some patients reported a transient worsening of symptoms. Satisfaction was high, with most patients reporting the approach as helpful or very helpful.

Moreover, a comparison was made between the bereavement reactions of Scottish and Swazi girls and women after the death of a close relative (Lovell 1993). Interviews were carried out with 40 matched Scottish and Swazi girls and women aged 12-40. Differences in nationalities were found in early grief reactions only. Both groups of women talked about how helpful and unhelpful interactions with others characterised their grief one year after the death of a close relative.

One study investigated the implications of group therapy for patients with advanced cancer (Llewelyn et al 1999) and its perceived helpfulness. They found that although the group was helpful to some women, its effect on mental health was limited. Process analysis showed its relevance, however, to individual women's concerns.

Furthermore, one study sought the views of users to influence health services

evaluation and development in HIV/AIDS care (Huby 1997). The study focused on the participants' views and empowerment and involved an action research project to coordinate services for people with HIV in Lothian.

5. Discussion

5.1 The current evidence base for palliative care research in Scotland

Considering that the time frame was 15 years, and that both published and unpublished research was included, it was somewhat surprising that only 44 articles were included in the review. Indeed had we used a Cochrane style criteria to review the literature the number would be somewhat smaller. Interestingly, the majority of research was related to palliative care provision and only 10 articles to symptom control.

5.2 The key themes to emerge from the data

The themes to emerge from the data are in the areas of Models of palliative care provision and Symptom Control. These two areas are also the most popular as far as the published as well as planned and currently underway research is concerned.

5.3 The gaps in the evidence base

The gaps in the evidence base are in the following areas: User involvement/ Patient Experience, Psychosocial care, Bereavement, Communication and Social support, Complementary therapies. These themes concur with the NICE (2004) and NCRI(2004) research priorities evidence.

It is recognised that there is an increasingly accepted need to create a patient-focused culture of involvement, listening and feedback, where the patient's experience is the catalyst for improving services (DoH 2003), yet few studies used patients as participants. Palliative care prides itself on being patient centred yet a minority of studies in the scope used patients as participants in the research. The evidence base thus far is not based on patient views and patient experience.

Moreover, only one study from the published research and one study from the planned and currently underway research focused on patient experience or involvement. This has been endorsed by the CCRC systematic literature review on patient experience of cancer care (Hubbard et al 2005). Hubbard et al found only five studies related

to patient experience and palliative care and none of these were Scottish. In fact all five studies were conducted outside the UK. Although, the authors acknowledge the ethical dilemmas that face researchers in palliative care, we strongly recommend that if palliative care is to grow as a discipline that more research is done with, and, for patients.

Although, three studies related to psychosocial issues are in the planned, currently underway section (Appendix 6 Research Directory) the scope of published research revealed no studies related to psychosocial care. This is somewhat surprising given that psychosocial services are fundamental to both specialist and generalist palliative care (NHS QIS 2004, NICE 2005, NCRI 2005).

Evidence (Payne and Relf 1994) has demonstrated that bereavement follow up is recognised as being part of palliative care, yet the lack of studies related to bereavement care concurs with a previous systematic review conducted for the NICE guidance (2004) on the first systematic review of bereavement support in the UK. They identified 11 studies, six of which were from the USA.

It is recognised that although complementary therapies have been used in palliative care for several years, their evidence base is weak (Ernst et al 2003). Previous evidence informs us of the use and prevalence of complementary therapies, rather than their safety or efficacy. Little research has been undertaken on complementary therapies in palliative or supportive care (NICE 2004).

The lack of communication and psychological and social support research does not concur with previous systematic reviews (NICE 2004). The evidence of the importance of face to face communication in palliative care is strong, although the majority of this evidence relates to communication skills training for health care professionals (Stewart 1996, Fellowes et al 2003, NICE 2004).

5.4 Recommendations for future research?

This scope identifies the priority areas for future palliative care research in Scotland as: user involvement/patient experience; psychosocial care and support, bereavement

care and support and complementary therapies.

In order to improve the evidence base in palliative care we recommend more collaboration and networking across disciplines and with clinicians and academics, particularly with service (NHS and hospices) and academic institutions. To this end we recommend that clinicians in palliative care are encouraged to access research training.

Funding continues to be an issue in palliative care research. This has been recognised in the UK as a whole, with the introduction of the NCRI SuPac collaboratives (<http://www.mariecurie.org.uk/healthcare/ncri-supportive-and-palliative-care-research-collaboratives.html>). This will redress this to a certain degree. Indeed, both Stirling University and Edinburgh University are involved in the COMPASS collaborative. However, palliative care research in Scotland is still under funded. To this end, we recommend more research is submitted to the CSO as mini and major grant proposals. Methodologically we recommend more RCT's, particularly when testing symptom measures and efficacy of treatment. In addition, more palliative care research is needed in the area of non-malignant disease, to reflect the changing nature of palliative care and the care of people with progressive illness (Murray et al 2002, 2005, www.show.scot.nhs.uk/sehd/nationalframework/Documents/chronicdisease/lcmreport_final.pdf).

5.5 Limitations

Journal hand searching identified seven articles not previously retrieved via electronic searching. The search strategy could have also been to blame. The scope was constrained by time restrictions, Arksey & O'Malley (2005) employed three assistants to complete their scoping study, in a similar time frame. Grey literature searches were not very successful, for instance obtaining PhD's proved to be a problem, the solution may have been to visit University libraries which would have been time consuming.

5.6 Clinical nursing development

This project provided a unique opportunity for five nurses to develop professionally

and personally. The PI (BMJ) led a funded project for the first time and was supported by an experienced Professor of Cancer Care (NK) and Research and Development Manager (MF). The research assistant was seconded from a palliative care support nurse post at Stirling Royal infirmary. One of the Strathcarron home care sisters (JC) backfilled the support nurse post. One of the Strathcarron staff nurses (PC) backfilled the home care post and Strathcarron bank nurse (GS) backfilled the staff nurse post. This secondment allowed the nurses to improve their understanding of each role and setting and share this experience with others. In addition, the bank staff nurse is now a permanent member of staff and the staff nurse who rotated to home care now has a substantive post in home care.

6. Conclusions

There is a lack of Scottish palliative care research currently underway, more research is therefore needed. Few projects are currently being submitted to the Chief Scientist Office. The majority of current palliative care research is funded by UK charities- we recommend that there is more NHS and hospice funding of palliative care research. Moreover, there is little or no ongoing research in the areas of patient experience/ user involvement; non malignant/chronic illness; religious/spiritual issues; education, bereavement, social support, role of health care professional, psychosocial care, quality of life, communication, complementary therapies and ethical issues. We particularly recommend that researchers consider research in the area of non-malignant/ chronic issues and patient experience, as they fit with the philosophy of palliative care and the current political agenda.

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Appendices

Appendix 1

PROTOCOL

TITLE

Palliative Care Research in Scotland – A Scoping Exercise

GROUP

Cancer and Palliative Care Research Sub-Group
NHS Forth Valley

Dr Bridget Johnston - Chief Investigator	Lecturer in Palliative Care, Strathcarron Hospice
Dr Paul Baughan	Macmillan Lead Cancer GP, NHS Forth Valley
Lorna Roe	Macmillan Lead Cancer Nurse, NHS Forth Valley
Suzanne Nimmo	Research Assistant, Strathcarron Hospice

BACKGROUND

In the speciality of palliative care there is a firm base of endeavour and clinical achievement upon which to build and exciting possibilities for future development. The success of such developments, however, will be influenced strongly by the excellence of the research base of palliative care. Research activity in palliative care, has in the past been hindered by a lack of research skills amongst practitioners, the focus on patient care as a priority (although this point is also a positive one) and the fact that palliative care units tend to be relatively small and isolated from academic research institutions (Field et al 2001).

Early research into bereavement, hospice care and pain, in particular, was pivotal in establishing the speciality of palliative care and provided powerful data about the needs of dying people (Corner 1996). However, much of the research activity in palliative care has included small scale and locally based studies, with little attention to generalisability and how the findings can be used at a national level.

The specialty of palliative care is rapidly developing and is now recognised as a distinct specialty in Scotland (NHS Quality Improvement Scotland (NHSQIS) 2004). Nevertheless despite the rapid growth in the number and range of palliative care services and in the management and care of dying patients, the evidence base for palliative care in the UK, and particularly in Scotland is weak and rigorous evaluation of these developments or well designed intervention studies have not been carried out (Field et al 2001). Although, palliative care provision is central to the care of patients with life limiting conditions, such as cancer (NHS Cancer Plan DoH 2000, Scottish Executive 2001), palliative care clinicians need to establish the evidence that supports their decisions and interventions, so that they can provide evidence-based care. This fits with the current agenda for palliative care in Scotland (NHSQIS 2002). The challenge for

palliative care is to continually evaluate what it does, retain effective interventions, and refine those that require improvement, thereby enhancing practice and patient outcomes. A lack of strategic planning, co-ordination and an inadequate infrastructure have hampered palliative care-related research in Scotland. We wish to constructively redress this. Establishing the palliative care research agenda (Hunt 2001) is the focus of this application. In order to do this; however, there must be a clear understanding of the existing evidence base. Therefore we propose that it is essential to conduct a time limited, scoping exercise, to discover the current evidence base in Scotland Confining the scope to Scotland will ensure that a) a Scottish focus of current evidenced palliative care practice will be identified b) the task of the scope will be achievable in the time span.

AIMS OF THE EXERCISE

To establish the palliative care research agenda in Scotland by conducting a search of the existing evidence base.

- 1 A review of palliative care literature including published and unpublished evidence, around aspects of delivery, development and evaluation of palliative care provision.
- 2 The compilation of a research directory profiling recently completed, currently underway and planned palliative care research in Scotland.

KEY QUESTIONS

What is the current evidence base for palliative care research in Scotland?

What key themes, if any, can be identified?

What are the gaps in the evidence base?

What recommendations can be made for future research?

SEARCH STRATEGY INCLUDING SEARCH TERMS AND RESOURCES TO BE SEARCHED

- Key words – palliative care, Scotland or Scottish, terminal care, advanced disease, dying patients, bereavement, hospice
- Databases – EMBASE, Medline, CINAHL, psycINFO, Web of Science, AMED will be searched from 1990-2004
- Key peer reviewed journals will be hand searched from the last 5 years (1999-2004). These include:- International Journal of Palliative Nursing, Palliative Medicine, Cancer Nursing, Journal of Pain and Symptom Management, Journal of Advanced Nursing, British Medical Journal

- The System of Information on Grey Literature in Europe (SIGLE), will be searched
- Authors known to be active in the field will be contacted and asked if they would be willing to participate in the study and complete a questionnaire detailing any planned, published or currently underway research. They will also be asked to nominate or suggest other researchers who may not have been previously identified.
- The key palliative and cancer charities and other organisations (Cancer Relief Macmillan Fund, Cancer Research UK, British Heart Foundation, Chest, Heart and Stroke Association, MS Society, Motor Neurone Disease Association, Scottish Partnership for Palliative Care, Help the Hospices, The National Council for Palliative Care) will also be contacted to ask they have active research in the field and if they would be willing to participate by completing the above mentioned questionnaire
- All NHS Divisions and Academic Institutions will be contacted via the R&D manager, or equivalent, to access unpublished research reports as well as using the NHS E-library & also NHS Division and Health Board libraries
- 3 databases will be used. One will contain names and contact details of the people who have been asked to participate in the study. This database will also be used to track the progress of the data collection in terms of response to questionnaires etc. The other will be used to catalogue the literature identified from the searches. The final database will keep track of all reference material obtained and allow easy identification and retrieval of articles
- Web of Science Cited reference Search, books and bibliographies will also be reviewed, along with citations in these books and articles and references provided by colleagues
- The reference section of each retrieved article will also be checked for research that has not already been identified by the means described previously
- The regional Ethics committees will be contacted via their administrator to identify titles and authors of palliative care research. This approach should help to validate the other search strategies previously discussed

STUDY SELECTION CRITERIA

Inclusion Criteria –

- Literature will be searched for the years 1990-2004.
- Studies selected will be in English Language only.
- Studies must be Scottish studies (the criteria will be; patients living in Scotland, or research conducted in a Scottish centre (NHS board, NHS division, care home, and voluntary or private health care institution). If the research involves a multi-centre study, one or more sites must be in Scotland.
- The studies must be about adults only (16+)
- Studies will be included with patients with any palliative care diagnosis e.g. cancer, neurological disease, respiratory disease, cardiovascular disease or liver disease The WHO definition of palliative care will be used as a guide in determining the inclusion of palliative research (WHO 2004)

- Studies will also be included if patients are not included, but the subject matter must relate to palliative care
- Critical commentary in peer reviews journals of the studies accessed
- Peer reviewed journals only will be accessed.
- Grey literature such as unpublished thesis MPhil, PhD, MD will also be accessed

Exclusion Criteria –

- Audit, narrative, expert opinions or anecdotal work will be excluded.
- Research at the planning stage (although this will be included in the research directory), Pilot studies and Bachelor dissertations will also be excluded.

STUDY QUALITY ASSESSMENT

- Articles deemed to fit the inclusion criteria will be evaluated using a combined validity checklist/data extraction sheet. (appendix 1)
- Initial quality assurance checks will be made, to test the data extraction sheet in the form of a small pilot.
- A comprehensive synthesis and critical evaluation of the literature will be included in the report and dissemination.
- Members of the Group will be asked to evaluate a random selection of articles to test the data extraction/grading criteria that has been applied by the research assistant

STRATEGY FOR EVALUATION OF EVIDENCE

- A grading system described by Droogan & Cullum (1998) will be applied to the qualitative data identified in order to classify the standard of the research. Scottish Intercollegiate Guidelines Network (SIGN 2001) grading criteria will be applied to any quantitative research. (appendix 2)
The current grading criteria may be subject to change following discussion with experts at the Cancer Care Research Centre at Stirling University

SYNTHESIS OF THE EXTRACTED EVIDENCE

- All identified articles will be presented in an evidence table as recommended by NHS Plus – Health at work (www.nhsplus)
- It is hoped that the emerging evidence could be categorised into broad themes, where similarities and differences can be discussed within these themes

- At the moment it is unknown what these themes will be, but contained in the data extraction sheet will be main headings that the articles will be grouped under. Some of these headings include:-

TASK	TIMESCALE
Design questionnaire/covering letter to accompany questionnaire	COMPLETE BY THURS 9TH JUNE 2005
Plan & document dialogue for initial contact with researchers/institutions/charities etc.	COMPLETE BY THURS 9TH JUNE 2005
Identify contacts & formulate list of names & contact details	COMPLETE BY WED 15TH JUNE 2005
Make contact with key people and if active in the field gain consent to participate. If not active exclude from study, but enquire if they are aware of others active in the field	COMMENCE BY WED 15TH JUNE 2005 – COMPLETE BY MONDAY 1ST AUG 2005
Enter all prospective candidates into database	ONGOING
Send out questionnaire & covering letter With stamped addressed envelope (log in database)	POST ALL W/C 15TH AUG 2005 DATABASE INPUT ONGOING
Chase up non-responders after 3 weeks, by e-mail/telephone	CHASE-UP ALL W/C 5TH SEP 2005
Analyse each response as soon after it is returned (this will allow time for further correspondence if the research assistant has any queries)	ONGOING UNTIL 31ST OCT 2005

- Quality
- Communication
- Ethical Issues
- Education
- Decision Making
- Symptom Control

References

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The Cochrane Collaboration <http://www.cochrane.org/>

Richardson A., Miller M., Potter H (2001) Developing, Delivering And Evaluating Cancer Nursing Services: Building The Evidence Base NTResearch **6** (4) pp.726-735

Scottish Intercollegiate Guidelines Network (SIGN) 2001
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Khan S K, Popay J, Kleijnen J (2001) Undertaking Systematic Reviews of Research on Effectiveness:- Phase 2 Development of a review protocol Centre for reviews and dissemination University of York

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www.who.int/cancer/palliative/definition/en/print.html

Appendix 2



Visitor to the Hospice - H.R.H. The Princess Royal

Re: Palliative Care Research in Scotland – A Scoping Exercise

A sub-group of the Forth Valley Cancer & Palliative Care Research Forum is commencing work on a scoping exercise to review the extent of palliative care research in Scotland. This research is funded by 3 separate NHS Forth Valley project grants.

We recognise that the speciality of palliative care is rapidly developing, nevertheless the evidence base in this field remains weak. In order to establish the existing evidence base, and use it as a platform for further research, our group felt it would be helpful to conduct a review of published and unpublished evidence, using strict inclusion and exclusion criteria.

A research directory profiling completed, currently underway and planned research in Scotland will be compiled on completion of the study and will be widely distributed.

In an attempt to unearth the grey literature within academic institutions we are contacting librarians to enlist their help with this project and we are seeking to include research such as unpublished thesis, MPhil, PhD and MD.

We would be grateful if your department could provide our group with a list of the palliative care research (including abstracts if possible) that has been undertaken in the last 5 years within your institution.

If this is not possible, can you make any alternative suggestions as to how we can retrieve such information?

Thank you in anticipation of your help and I look forward to your response.

Yours sincerely

Suzanne Nimmo
Research Assistant
Suzanne.Nimmo@gp25614.forth-hb.scot.nhs.uk

Appendix 3

DATA EXTRACTION/QUALITY ANALYSIS

1. Unique number e.g UI	
2. Name of reviewer	
3. Date of review	
4. How was this document found?	1. Electronic database Name of database 2. References in another document 3. Personal contact 4. Other Please specify
5. Authors of document (surname, initial) and where based	
6. Title of document	
7. Date of publication of document	
8. What type of document is it?	1. Journal Name of journal Volume Issue number Page numbers 2. Book Place of publication

	Place of publication Name of publisher 3. Chapter in book Place of publication Name of publisher Editor(s) of book 4. Other Please specify		
9. What is the document?	1. Reporting the original research		
	Is it qualitative?	YES	NO
	Is it quantitative?	YES	NO
	Is it mixed?	YES	NO
	2. Literature review		
	Is it a systematic review?	YES	NO
	Is it a Cochrane review?	YES	NO
	Years reviewed		
	3. Other Please Specify		
	10. What was the research setting?	Primary Care	YES
Secondary Care		YES	NO
Tertiary		YES	NO

	Social Care			YES	NO		
	Hospice			YES	NO		
	Multi-centre			YES	NO		
	Please state other areas if multi-centre						
Other Please specify							
11. What were the aims and objectives of the research?							
12. Is the purpose of the research adequately described and justified?							
JUSTIFIED			UNCLEAR				
13. Who funded the study?							
NOT KNOWN							
14. When did the study start and finish?							
NOT KNOWN							
15. Total number in the sample							
16. Do the authors claim it was a representative sample? If yes, please describe and specify the response rate							
17. What was the sampling strategy? And was it appropriate to the research question?							
UNKNOWN							
18. Who was included in the sample?		AGE					
		Include age range					
		GENDER		Fem	Yes	No	Unk
				Male	Yes	No	Unk
		ETHNIC GROUP		YES		NO	
SOCIAL CLASS		YES		NO			

	PHYSICAL IMP.	YES	NO
	MENTAL IMP.	YES	NO
	RELATIVES/FRIENDS/ CARERS	YES	NO
	RESEARCHERS	YES	NO
	PROFESSIONALS	YES	NO
	OTHER		
19. What method(s) did the researchers use?	1. INTERVENTION 2. INTERVIEW 3. QUESTIONNAIRE 4. FOCUS GROUP 5. OBSERVATION 6. OTHER		
20. How were the data analysed? Briefly describe	UNKNOWN		
21. Is the procedure reliable/dependable?	RELIABLE	UNCLEAR	POTENTIAL BIAS
22. Are the findings valid/internally coherent/trustworthy	VALID	UNCLEAR	INVALID POTENTIAL BIAS
23. Is there adequate discussion	ADEQUATE	UNCLEAR	INADEQUATE

of the study limitations?			
24. Was consent obtained?	YES	NO	UNKNOWN
25. Was the project ethically approved?	YES	NO	UNKNOWN
26. Please document diagnosis of people included in study (please indicate by a tick if one or more diagnosis is documented).	DIAGNOSIS		TICK IF INCLUDED
	Lung		
	Breast		
	Brain		
	Colorectal		
	Upper G.I.		
	Head & Neck		
	Prostate		
	Ovarian		
	Haematological		
	Cervical		
	Melanoma		
	Bladder		
	Heart Failure		
	COPD		
	Neurological		
Other – Please state			
27. Please document the main theme(s) of the study	THEME		TICK IF INCLUDED
	Communication		
	Quality		
	Models of Palliative Care		
	Ethics		
	Culture		
	Symptom Control		
	Education		
	Economic		
	Learning Disabilities		
	Mental Health		
	Religion		
	Spirituality		
	Assessment		

	Surgery	
	Decision Making	
	Experience	
	Support	
	Other	

QUALITY CRITERIA FOR REVIEW ARTICLES

	GOOD	FAIR	POOR	N/A
1. Does the review answer a well defined question?				
2. Was a substantial effort to search for all the relevant literature made?				
3. Are the inclusion/exclusion criteria reported and appropriate?				
4. Is the validity of the studies adequately assessed?				
5. Is sufficient detail of the individual studies presented?				
6. Have the primary studies been combined or summarised appropriately?				

Quality criteria for inclusion on NHS Centre for Reviews and Dissemination (DARE)

(Song, 1996) Cited in:-

Droogan J, Cullum N. 1998. Systematic reviews in nursing. *International Journal of Nursing Studies* 35, 13-22

SIGN grading system

<i>Levels of evidence</i>	
1++	High quality meta analyses, systematic reviews of RCTs (randomised controlled trials), or RCTs with a very low risk of bias
1+	Well conducted meta analyses, systematic reviews of RCTs, or RCTs with a low risk of bias
1 -	Meta analyses, systematic reviews of RCTs, or RCTs with a high risk of bias
2++	High quality systematic reviews of case-control or cohort or studies High quality case-control or cohort studies with a very low risk of confounding, bias, or chance and a high probability that the relationship is causal
2+	Well conducted case control or cohort studies with a low risk of confounding, bias, or chance and a moderate probability that the relationship is causal
2 -	Case control or cohort studies with a high risk of confounding, bias, or chance and a significant risk that the relationship is not causal
3	Non-analytic studies, e.g. case reports, case series
4	Expert opinion

<i>Grades of recommendation</i>	
A	At least one meta analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or A systematic review of RCTs or a body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results
B	A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 1++ or 1+
C	A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or Extrapolated evidence from studies rated as 2++
D	Evidence level 3 or 4; or Extrapolated evidence from studies rated as 2+

Appendix 4



Visitor to the Hospice - H.R.H. The Princess Royal

Dear Sir/Madam

Re: Palliative Care Research in Scotland – A Scoping Exercise

A sub-group of the Forth Valley Cancer & Palliative Care Research Forum is commencing work on a scoping exercise to review the extent of palliative care research in Scotland.

This research is funded by 3 separate NHS Forth Valley project grants.

We recognise that the speciality of palliative care is rapidly developing, nevertheless the evidence base in this field remains weak. In order to establish the existing evidence base, and use it as a platform for further research, our group felt it would be helpful to conduct a review of published and unpublished evidence, using strict inclusion and exclusion criteria.

A research directory profiling completed, currently underway and planned research in Scotland will be compiled on completion of the study and will be widely distributed.

We are seeking to include research such as unpublished thesis, MPhil, PhD and MD.

If you are currently conducting or planning any research with a palliative care focus and are interested in having your research included in this exciting study could you please complete the attached form.

A proforma (including a consent form) will then be posted to you requesting further details about your research. If you or your organisation are not involved in research at the moment but know of others who we should contact, please complete the attached form.

Yours sincerely

Suzanne Nimmo
Research Assistant

Contact Details

Palliative Care Research in Scotland – A Scoping Exercise

Completed forms can be returned by:

- E-mail: Suzanne.Nimmo@gp25614.forth-hb.scot.nhs.uk
- Post: Education Department. Strathcarron Hospice, Randolph Hill, Denny, Stirlingshire. FK6 5HJ
- Fax: 01324 824576

In order to have time to collate the information provided could the completed forms be returned if possible please no later than **Monday 15th August 2005** thank you

Please tick whichever box applies:

☐

We are currently involved or planning research in palliative care and would like to nominate the person below to provide details to Suzanne Nimmo at Strathcarron Hospice.

☐

We are not currently involved or planning research in palliative care but recommend you contact the following person about their work

☐

We are not currently involved or planning research in this area and are not aware of other work taking place

Name:.....

Position:.....

Organisation:.....

Contact Address:.....

.....

Phone:.....Fax:.....Email:.....

Title of Research (if appropriate):.....

Any other comments please:.....

.....

Thank you for taking the time to complete this form and make a valuable contribution towards this study

Appendix 5

Forth Valley Cancer and Palliative Care Research Forum Palliative Care Research in Scotland - A Scoping Exercise

Introduction	
<p>Please complete this form as fully as possible.</p> <p>Please use black ink and BLOCK CAPITALS as this form may be photocopied.</p> <p>Please return this form to Suzanne Nimmo, Research Assistant, Strathcarron Hospice, Randolph Hill, Denny, Stirlingshire FK6 5HJ.</p> <p>Thank you.</p> <p>If you would prefer to complete this form electronically; contact suzanne.nimmo@gp25614.forth-hb.scot.nhs.uk</p>	
Section 1 – About you	
<p>Your contact details:</p> <p>Name: Please give your full name, including title</p> <p>Position: Job title or position</p> <p>Unit : Name of Unit or Department</p> <p>Institution: Name of your Institution</p> <p>Address: Address for correspondence</p> <p>Postcode: Please give your postcode</p> <p>Telephone: Phone number including code</p> <p>Fax: Fax number including code</p> <p>Email: Email address</p> <p>Internet: Home page or web address</p>	<p>Please write here:</p> <p>Name: _____</p> <p>Position: _____</p> <p>Unit: _____</p> <p>Institution: _____</p> <p>Address: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Postcode: _____</p> <p>Telephone: _____</p> <p>Fax: _____</p> <p>Email: _____</p> <p>Internet: _____</p>
Section 2 – About your project	
<p>Project Title: Please give the full title of your project</p> <p>Start Date: Please give the start date as dd/mm/yyyy</p>	<p>Project Title: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Start Date: ____/____/____</p>

<p>End Date: Please give the end date as dd/mm/yyyy</p> <p>Completion: Please tick the box which best describes your project.</p>	<p>End Date: ____/____/____</p> <p>Completion:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Proposed <input type="checkbox"/> Not yet started <input type="checkbox"/> Work in progress <input type="checkbox"/> Completed <input type="checkbox"/> Written up <input type="checkbox"/> Published
<p>Section 3 – Qualification</p>	
<p>If the project is connected with your obtaining a qualification (e.g. PhD thesis, MD) please give the name of the qualification here:</p>	<p>Qualifications:</p> <p>_____</p> <p>_____</p>
<p>Section 4 - NHS Region</p>	
<p>Please give the name of the NHS region (if known) in which the project work is based:</p>	<p>NHS Region:</p> <p>_____</p>

Section 5 – The aims of your project

Please supply a 250-word description of the aims of your project. **The text you supply here will be used as an abstract for your work in the directory.**

Notes

If you would prefer, please print or type your aims statement/abstract on a separate sheet of paper and securely attach it to this form.

Alternatively you can submit your aims statement/abstract to the project team by plain-text email. Send your email to suzanne.nimmo@gp25614.forth-hb.scot.nhs.uk

Section 6 – Funding

If the cost of your work is being funded by sponsors (including your own institution) please give a brief breakdown here.
An example breakdown might be 'Own NHS Trust 50%, XYZ Foundation 50%'.

Section 7 – References for work already published

If your work, or part of it has already been published, please give a 'Harvard style' reference to the publication:

Section 8 – Data Protection Act 1998 statement
<p>The information you supply to us when you return this form will be stored and manipulated on computer by the research team at Strathecarron Hospice under the Data Protection Act 1998. By signing and returning this form you explicitly give your consent to the data you supply being stored and processed in this way.</p>

Section 9 – What will happen to the information you give us

The information you give us on this form will be used by the research team to assess the suitability of your project for inclusion in the Research Directory. We can only include work relevant to Palliative Care Research in the Directory.

If your work is selected for inclusion in the Research Directory, we will notify you by email or post. The information you have supplied may then be passed on to enquirers, and will be made available in electronic form and be accessed via the Cancer Care Research Centre Website at the University of Stirling.

At the conclusion of the work at Strathcarron Hospice, the information will be passed to NHS Forth Valley.

I confirm that the information I have given about the project detailed on this form is accurate to the best of my knowledge. I consent to the information being processed on computer by the research team at Strathcarron Hospice, and to the information being passed on to others as specified above.

Signed _____

Date ____/____/____

Thank you

Please return this form as soon as possible to: Suzanne Nimmo

Research Assistant
Strathcarron Hospice
Randolph Hill
Denny
Stirlingshire FK6 5HJ

Information about our Scoping Exercise

Project Objectives

This project aims to begin to establish the evidence base for palliative care research activity in Scotland.

There are two distinct yet complementary elements:

- A review of palliative care literature including published and unpublished evidence, around aspects of delivery, development and evaluation of palliative care provision
- The compilation of a research directory profiling recently completed, currently underway and planned palliative care research in Scotland

The Team

The project is funded by 3 separate grants from NHS Forth Valley Acute Operating Division, NHS Forth Valley Primary Care Operating Division and the Forth Valley Managed Clinical Network for Palliative Care. The project team is a sub-group from the Forth Valley Cancer & Palliative Care Research Forum and the members of this sub-group are:-

Dr Bridget Johnston - Chief Investigator	Lecturer in Palliative Care, Strathcarron Hospice
Dr Paul Baughan	Macmillan Lead Cancer GP, NHS Forth Valley
Lorna Roe	Macmillan Lead Cancer Nurse, NHS Forth Valley
Suzanne Nimmo	Research Assistant, Strathcarron Hospice

Methods

A thorough search of several databases will be performed to identify palliative care research in the last 15 years. In addition various peer reviewed journals will be hand searched from the previous 5 years. The literature identified will be subject to a structured review process and graded using a validated tool.

Researchers known to be active in the field will be contacted and asked to participate in the study by completing a questionnaire detailing any planned, published or currently underway research. They will also be asked to nominate or suggest other researchers who may not have been previously identified.

Key palliative care and cancer charities and other organisations will be contacted.

All Scottish NHS Divisions, Academic Institutions, Hospices, Palliative Care Teams and Regional Ethics Committees will be contacted in an attempt to identify authors of palliative care research.

Anticipated Results

The dissemination of the study findings should help to promote the current, ongoing and planned work in the field and allow a wider audience to have access to palliative care research and network with researchers active in palliative care research in Scotland.

The study will be published in peer-reviewed journals and presented at palliative care research

conferences.

The research directory will be available electronically via the University of Stirling Cancer Care Research Centre website.

A Scoping Review of Palliative Care in Scotland

Research Directory

Suzanne Nimmo^{1,2}

Dr Bridget Johnston^{1,3}

Dr Paul Baughan²

Professor Nora Kearney³

¹Strathcarron Hospice, Denny Stirlingshire

²NHS Forth Valley

³Cancer Care Research Centre, University of Stirling



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STIRLING**

DEPARTMENT OF
NURSING AND MIDWIFERY



Research Directory

The objective of the second part of the scoping exercise was to compile a research directory (Appendix 6) that would provide information on planned, currently underway and recently completed palliative care research in Scotland. The aim, to improve communication networks between researchers throughout Scotland, and share research practice.

Methodology

The compilation of this research directory was undertaken during the period May 2005- Dec 2005. Data for the directory were collected using a two-stage process. The methods employed to collate the information that would go into the directory were similar to that of Richardson et al (2001) in their scoping review of the aspects of developing, delivering and evaluating cancer nursing research activity.

First stage

Trust Research & Development teams, Ethics Committees, Hospices, and Palliative Care Teams throughout Scotland were contacted, as were cancer charities, Multiples Sclerosis society, Motor Neurone Disease Association and the British Heart Foundation. An e-mail containing a standard letter was sent inviting people to participate in the study (appendix 4). If e-mail addresses were unobtainable or if they returned undelivered a stamped addressed envelope was posted out first class.

A form was also included (appendix 4) which the respondents were asked to complete one of three statements:

1. We are currently involved or planning research in palliative care and would like to nominate the person below to provide details
2. We are not currently involved or planning research in palliative care but recommend you contact the following person about their work
3. We are not currently involved or planning research in this area and are not aware of other work taking place

They were then asked to complete a section with their contact details.

The snowballing effect of respondents nominating others involved in research was effective in identifying others active in research that had not been previously identified to our research team. The research team also identified a list of eight key researchers in palliative care in Scotland who were approached individually. One further e-mail or letter was sent to non-respondents. In total 134 recipients for mailing were identified (including those nominated by others) with a response rate of 58% (n=78).

Second stage

A questionnaire was adapted from a previous study (Richardson et al 2001) and posted in a stamped addressed envelope to those who agreed to participate and were actively involved in research (appendix 5). It was decided that we would not ask participants to complete the questionnaire by e-mail, as the format of the questionnaire may have varied on different computers, but they were given the option if they so wished. 27 participants agreed to complete the questionnaire and the response rate was 88% (n= 23). Some of the participants submitted more than one project and in total 27 projects were included in the directory.

The number of respondents is not exclusive and there were other respondents who had initially replied and stated they were active in the field but did not reply before the deadline despite reminders. All of the information pertaining to the research directory was stored on an access database.

Research Directory Entries

	Author	Project	Theme
1.	Adam Joan	The impact of open visiting on patients and staff in a hospice	Models of palliative care/provision
2.	Biswas Papiya	Comparison of cancer pain management between community and hospice settings: time to pain control	Pain and/or Symptom control
3.	Biswas Papiya	To Establish Concurrent Validity of a Cancer Pain Management Audit System	Pain and/or Symptom control
4.	Chaplin Jackie	Hope and the Lung Cancer Journey : A longitudinal qualitative study	Psychosocial issues
5.	Fallon Marie	Characterisation of the physical properties of the pain caused by bone malignancy and comparison with the physical properties of neuropathic pain	Pain and/or Symptom control
6.	Fallon Marie	Characterisation of the physical properties of the pain caused by bone malignancy and comparison with the physical properties of neuropathic pain by using quantitative sensory testing	Pain and/or Symptom control
7.	Gray David	Oropharyngeal candidosis in cancer patients: An In vivo and in vitro study of single C albicans and mixed C albicans – candida special population	Pain and/or Symptom control
8.	Haraldsdottir Erna	The Constraints of the Ordinary: Caring for Dying Patient in a Hospice in Scotland	Psychosocial issues
9.	Hill Hazel	An ethnographic exploration of psychosocial nursing in an in-patient specialist palliative care unit	Psychosocial issues
10.	Hockley Jo	Developing knowledge about end-of-life care in two independent care homes (nursing) through action research	Models of palliative care/provision
11.	Hubscher Katharine	Longitudinal Study Into The Evolution Of Total Distress In Patients With Advanced Cancer From Referral To Palliative Care Services To Death	Pain and/or Symptom control
12.	Kearney Nora/	Patient & Carer Experiences of Cancer & Cancer Care	Patient experience/ User involvement
13.	Keeley Paul	Recognising Dying in Hospital Inpatients With Advanced Cancer	Pain and/or Symptom control
14.	Kerr Linda	An Exploratory Study of the Need for Bereavement Support Services in one Area of Scotland	Bereavement
15.	Lawton Sally	Dignity in Palliative Care	Psychosocial issues
16.	Macpherson Catriona	Evaluation of Children & Families Service	Models of palliative care/provision

17.	Murray Scott	Working with patients and their carers to develop an effective approach to the delivery of cancer palliative care in primary care	Models of palliative care/provision
18.	Murray Scott	Patients, carers and professionals experiences of diagnosis, treatment and end-of-life care in heart failure: a prospective qualitative interview study	Non malignant/ Chronic illness
19.	Murray Scott/Sra Eldridge	To explore the needs of patients with malignant brain tumours and to propose patient-centred models of care	Patient experience/ User involvement
20.	Nicol Jackie/Fergus Cameron	Triaging For Specialist Inpatient Palliative Care – Is it Possible?	Models of palliative care/provision
21.	Oxenham David	Satisfaction of carers with end-of-life cancer care in Lothian	Models of palliative care/provision
22.	Oxenham David	Estimation of survival in an inpatient specialist palliative care unit: a comparison of different methods	Models of palliative care/provision
23.	Preston Clive	Prospective Study of the Emergency Admission of Patients with Known Lung Cancer in SE Scotland	Models of palliative care/provision
24.	Richardson Heather	Development of a research strategy for Help the Hospices to facilitate research regarding hospice care in the UK	Models of palliative care/provision
25.	Shiekh Aziz	Developing Services to meet the end of life care needs of South Asian Sikh and Muslim patients and their families in Scotland	Models of palliative care/provision
26.	Smith Stephen	An Action Research Study of Palliative Dementia Care	

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Project Title: The Impact of Open Visiting of Patients and Staff in a Hospice
Status: Work in progress
Completion Date: 13/06/2006
Qualification: -
Funding Source: -

Abstract:

Visiting is an integral part of every patient's experience in all health care settings. Over recent decades the visiting has evolved to the current day situation where visiting is more open and patient-centred. At the end of life the family is viewed as integral to the holistic care of a patient and open visiting has become a natural extension of this philosophical stance in many hospices. Thomas (2001) studied patients' perceptions of visiting and identified that patients need time without visitors. It was suggested that there may be a link between the exacerbation of symptoms and visiting times. However, the Care Commission (2003) emphasises the importance of 'keeping in touch' with people who are important and promotes open visiting. There is a need for more research and it is hoped that an exploratory study of the patients' and staffs' perception of open visiting will ensure any policy is to the benefit of terminally ill patients, their families and carers.

Study Aims:

1. Evaluate the impact open visiting has on patients, the multidisciplinary team and staff within a hospice setting.
2. Empower the research group to instigate and participate in 'real world research' which they perceive as relevant to clinical practice.

This secondary objective is pivotal to promoting research awareness among nursing staff who have knowledge but no experience of research.

References:

Care Commission (2003) National Care Standards – Hospice Care Scottish Executive

Thomas R (2001) Patients' Perceptions of Visiting: a phenomenological study in a hospice. Palliative Medicine 15 499-504

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Project Title: Comparison of cancer pain management between community and hospice settings: time to pain control
Status: Completed
Completion Date: 07/2005
Qualification: -
Funding Source: Pharmaceutical Company/UK non profit making charitable organisation

Abstract:

Introduction

Data from an audit of cancer pain management in a community setting was compared to similar data collected in a hospice. Significant differences were found in several measures of pain control, particularly time to pain control. Reasons for this difference are explored.

Method

Pain level and analgesic prescription data were prospectively collected at each patient assessment. A computer program was developed to measure adherence to key recommendations of a cancer pain management guideline (SIGN 44). Success in achieving pain control was defined as achieving a consistent level of mild or no pain. Time to pain control and adherence to guidelines was compared between the two settings. Data was collected on 712 patients and (3,646 assessments) in the community and compared to that from 152 hospice inpatients (1,222 assessments).

Results

At first assessment there was no difference in pain scores between the groups. Hospice patients were visited more frequently than the community patients: median interval between visits was 1.3 vs. 3.8 days respectively ($p=0.001$, wilcoxon test). The Hospice patients on average achieved pain control much faster than the GP group ($p<0.001$ log rank test) but much of this difference disappeared if time to pain control was measured in assessments rather than days. Cox regression was used to examine whether guideline adherence explained the remaining difference between settings can be explained by differences in adherence to guidelines. Adherence to guidelines did explain most of the remaining difference ($P=0.005$) However, even having taken this into account, there remained some difference between the settings ($P=0.06$).

Conclusion

The most important association with time to pain control in this study was frequency of assessments. The next most significant factor was adherence to guidelines. This data supports clinical dictum that frequent reassessment is important in achieving early pain control in patients with cancer.

References:

Above study presented as a poster at British Pain Society meeting March 2005

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Project Title: To Establish Concurrent Validity of a Cancer Pain Management Audit System
Status: Completed
Completion Date: 07/2005
Qualification: -
Funding Source: Pharmaceutical company/UK non profit making charitable organisation

Abstract:

Objectives

To establish Concurrent Validity of a Cancer Pain Management Audit System(CPMAS)

Design

A comparison of data collected prospectively on two groups of patients with cancer in two different settings, using CPMAS, a computer database designed to audit adherence to the SIGN 44 cancer pain guideline (SIGN 44). CPMAS can be said to have concurrent validity if it identifies expected differences in adherence to guidelines between the two settings.

Participants and setting Inclusion criteria were patients over 18 years old with cancer in any site and cancer related pain who were either admitted to Marie Curie Hospice, Edinburgh (152 patients), or managed in the community (712 patients).

Main Outcome Measures

Patient rated POS scores for pain and analgesic prescription data were recorded at each visit. CPMAS calculated adherence to 17 key recommendations of SIGN 44.

Results

The mean pass rate for all guidelines was higher for the Hospice (66.3%, 95% confidence interval (65.3%, 67.3%)) than the Community group (61.8%, 95% confidence interval (61.1%, 62.3%)) ($p < 0.001$). CPMAS detected an expected significant difference between the groups in 10 out of 17 aspects, (greater adherence in hospice group). There was no difference between the groups for 2 of the 17 aspects, and an unexpected difference in a further 5 aspects

Conclusions

The study has demonstrated concurrent validity of CPMAS for key recommendations of SIGN 44 and identified areas where the database requires improvement. CPMAS can be used as a cancer pain management audit tool.

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Project Title: Hope and the Lung Cancer Journey : A longitudinal qualitative study
Status: Work in progress
Completion Date: 2006
Qualification: PhD
Funding Source: Self Funding/NHS

Abstract:

The study aims are to:

1. Explore and illuminate the experience, nature and meaning of hope at different stages of the cancer journey as perceived by adults with lung cancer
2. Utilise the insights gained to identify attributes, attitudes and activities of health care professionals that influence hope at different stages of the cancer journey.

This study adopts a longitudinal qualitative design in order to explore the phenomenon of hope over time. Participants have been recruited at the point at which they have received a diagnosis of lung cancer and were followed for a period of one year or until the terminal phase of their illness. Using a hermeneutic phenomenological approach informed by Gadamer in depth investigation of the experience and meaning of hope from the participants' perspective is taking place (Gadamer 1975).

Data management and analysis is being supported by the use the data analysis software package NVIVO. In-depth analysis of individual interviews to identify the key themes inherent in the meaning of hope for the participants will be guided by the work of Van Manen (1990) which supports the in-depth analysis of qualitative data through the critical examination of the use of language. This is being followed by longitudinal analysis examining and interpreting the data over time and taking account of the influence of the participants' previous experience, the context of their life and their illness and the influence of health care professionals.

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Project Title: Characterisation of the physical properties of the pain caused by bone malignancy and comparison with the physical properties of neuropathic pain by using quantitative sensory testing
Status: Work in progress
Completion Date: 31/08/2006
Qualification: -
Funding Source: CRUK

Abstract:

The aims of the study are to investigate how people experience their pain and how this is affected by treatment.

We will use both questionnaires and quantitative sensory testing to assess patients. Those with malignant bone pain are of special interest and we will look for signs of central sensitisation in these patients. 4-6 weeks following palliative radiotherapy treatments of their bone metastases we will use these techniques to reassess the patients' pain state.

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Status: Work in progress
Completion Date: 31/08/2006
Qualification: -
Funding Source: British Journal of Anaesthesia

Abstract:

The aims of the study are to investigate how people experience their pain and how this is affected by treatment. We are especial interested in people with malignant bone pain.

We plan to do this by asking questions regarding their pain and by carrying out quantitative sensory testing of both affected and unaffected (control) areas of skin. We will carry out functional MRI scanning to determine how these pain messages are handled and then repeat the whole assessment 4-6 weeks later to ascertain how the situation has changed following radiotherapy treatment of the affected area.

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Project Title: Oropharyngeal candidosis in cancer patients: An In vivo and in vitro study of single C albicans and mixed C albicans – candida special population
Status: Not yet started
Completion Date: -
Qualification: -
Funding Source: -

Abstract:

Oral candidosis ('thrush') affects many seriously ill individuals whose defence systems are not fully functional, for example cancer patients undergoing treatment. The main microorganism associated with this disease is yeast called *Candida Albicans*. Recent studies indicate that other types of *Candida* species, such as *Candida glabrata*, are also implicated in the overall disease state. These different *Candida* species adhere to the surfaces of the mouth in the form of complex structures known as biofilms. This is problematic, however, because biofilms are notoriously resistant to antifungal drugs, limiting therapy, treatment options and impeding the resolution of infection. Furthermore, intrinsic resistance to antifungal drugs is exhibited by some *Candida* species. There is now evidence that mixed infections may be more pathogenic than single *C. albicans* infections.

This study will examine the detailed microbiology of the mouths of oral candidosis patients as a means of understanding the complexity of interactions between different yeast species. We will examine the biological attributes (including genetic factors) of individual and combined *Candida* species grown as both free-floating cells and biofilms. These studies will demonstrate the impact that mixed species have on oral candidosis. In addition, these investigations will also highlight the general role that mixed microbial populations have in human infections, thus promoting further research initiatives.

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Project Title: The Constraints of the Ordinary: Caring for Dying Patient in a Hospice in Scotland
Status: Completed
Completion Date: 28/02/2006
Qualification: PhD
Funding Source: Melville Trust/Self funded

Abstract:

The phenomenon "being with" that relates to what the patient is experiencing when close to death is an important aspect underlying specialist palliative care. The aim of this observational study was to generate adequate description of how nurses and nursing care assistants do "being with" in day-to-day nursing practice within a hospice setting. Observational data was collected over an 8-month period in an inpatient hospice in Scotland in 2002.

Drawing on the philosophy of Charles Taylor, I reflect and interpret the way that nurses and nursing care assistants constructed their care for dying patients. I came to understand that the nurses and the nursing care assistants perception of "being with" was in relation to providing 'comfort' rather than facilitating the opportunity of facing death. The consequence of this was that the patients where 'comforted' but they were not encouraged to face death in the way that Saunders suggests. Through revisiting Saunders's theory in the light of my data, it became clear that there is a tension between the 'theory' and the 'practice' of "being with" in relation to its practical outworking.

In conclusion I compare the phenomenon of death as discussed by Saunders with that of Heidegger. By discussing my data in light of Heidegger's theory and how human beings can face death, provides an understanding of how the nurses and nursing care assistants in this hospice cared for dying patients. They constructed "being with" in terms of providing comfort in order to manage their own feelings around death and dying. The research offers some important insights around the tension between the hospice ideology of a 'good death' as provided by Saunders, and how in reality the day-to-day care of dying patients in this hospice was being managed.

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Project Title: An ethnographic exploration of psychosocial nursing in an in-patient specialist palliative care unit
Status: Work in progress
Completion Date: 31/12/2006
Qualification: PhD
Funding Source: Strathcarron Hospice

Abstract:

Psychosocial care is considered to be an integral and essential component of both nursing and palliative care; however, there is a lack of empirical evidence concerning whether, and especially how, nurses provide support for palliative patients' psychosocial needs and whether patients value the support that is offered. This study will help to develop an understanding of those aspects of psychosocial nursing that can realistically be provided within the constraints of a healthcare setting. By focussing on one area of practice, a hospice ward, this study aims to explore:

- Whether nurses provide psychosocial care, and if so, in what conditions, and subject to what constraints;
- Exactly how nurses respond to patients' psychosocial needs, and how they operationalise the concept of 'psychosocial palliative care' (when operationalising includes providing, reporting on, and recording care to allow continuity in care); and
- How patients feel about the psychosocial support which they receive from nurses

By combining data collection methods (observation, interviewing and documentation collection) and triangulating these throughout analyses, the researcher will be able to see how nurses really respond when patients have a psychosocial need and whether the response is appropriate to the patient's need.

This project has been undertaken in collaboration with the staff at the participating hospice and the results will be used directly to advance the psychosocial nursing provided there. Although the results of this study will not be directly generalisable to other healthcare settings, they will be of value to all nurses and all palliative care providers as a means against which to question their own practice.

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Project Title: Developing knowledge about end-of-life care in two independent care homes (nursing) through action research
Status: Completed
Completion Date: 2006
Qualification: PhD
Funding Source: UK non profit making charitable organisation

Abstract:

One in five of the UK population over the age of 65 years will end their life in a care home (Teno 2003). Research around palliative and end-of-life care in care homes is limited. Although educational initiatives with staff into death and dying in care homes have been undertaken there has been difficulty translating this knowledge into practice (Froggatt 2000). In this study an action research approach was adopted to develop staffs' knowledge around end of life care. Two independent care homes (nursing) volunteered to take part.

An initial period of exploration in both nursing homes using focus groups, interviews, participant observation, and a documentary analysis, highlighted organisational and clinical issues around end of life care. High turnover of both trained and untrained staff, lack of a learning culture, and closed communication around death and dying were major barriers to development of end of life care and highlighted the fact that dying was peripheral to nursing home care culture. Two initiatives inductively derived from discussion with staff enabled a greater openness towards death and dying.

The first initiative was the development of 'collaborative learning groups' (CLG's) held following a death in the nursing homes in order that staff could reflect together in care given. In the second nursing home a core group of staff adapted the Liverpool Care Pathway for the Dying. The relevance of these actions to the nursing homes context is developed further by drawing Habermas's Theory of Communicative Action. Two important aspects of Habermas's theory about the social world: the equal importance of the of the 'lifeworld' and the 'system' are developed in order to discuss how the CLG's were able to act as a way of sustaining the lifeworld of those caring for dying residents. The ICP is then discussed as a tool to enhance quality end-of-life care within a system where end-of-life care is rarely openly acknowledged a part of nursing home care.

References:

Hockley J, Dewar B & Watson J (2005) Promoting end-of-life care in nursing homes using An 'integrated care pathway for the last days of life'. *Journal of Research in Nursing*, 10(2): 135-152 care pathway. Report available from: www.stcolumbashospice.org.uk/professional
 Hockley J, Dewar B & Watson J (2004) Developing quality end of life care in eight independent nursing homes through the implementation of an integrated

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Status: Work in progress
Completion Date: 08/2006
Qualification: MD
Funding Source: UK non profit making charitable organisation/Pharmaceutical company

Abstract:

Introduction

The experience of distress is derived from the interaction of physical, psychological, social and spiritual domains. The dynamics of these interactions have not yet been studied over time.

Aims

- To explore the natural course of distress in the terminal phase (last 6 months) of advanced, incurable cancer:
- To examine the relationship between distress and time
- To evaluate the contribution of each individual domain of distress to global distress over this time
- To define the risk factors for initial distress and persistent distress
- To establish the current management of distress.
- To review the potential for the development of formal guidelines for distress management in palliative care.

Methods

The study is longitudinal in design combining qualitative and quantitative research methodology: Patients with cancer who are newly referred to the hospice community team are recruited consecutively. 100 patients in total will be assessed monthly until death or for a maximum of 6 months.

Each monthly assessment involves the documentation of socio-demographic factors, medication, admissions and Karnofsky Performance Status together with the completion of the following validated assessment tools: The Memorial Symptom Assessment Scale (physical distress), the Edinburgh Postnatal Depression Scale (psychological distress), the FACIT-Sp-12 (spiritual distress) and the NCCN Global Distress Thermometer (global distress). For a sub sample of 20 purposively selected patients in the qualitative study, each assessment includes an in-depth interview.

Intention

Quantitative data analysis illustrated by patients' perspectives will provide insight into the experience of total distress in the terminal phases of cancer.

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Project Title: Patient & Carer Experiences of Cancer & Cancer Care
Status: Work in progress
Completion Date: 30/06/2007
Qualification: -
Funding Source: Scottish Executive Health Department SEHD

Abstract:

The Patient and Carer Experiences of Cancer and Cancer Care Programme is a comprehensive research programme encompassing a range of activities. The element of the work relevant to palliative care is the Patient and Carer Advisory Groups aspect. This aims:

- To gather a comprehensive body of knowledge of the needs of people affected by cancer across Scotland
- To establish a system of involving people affected by cancer in determining and prioritising the research agenda of the CCRC
- To develop innovative methods of involving 'hard to reach' groups (i.e., any who do not typically get involved) in the research process
- To create a research programme driven by the needs of people affected by cancer which will influence cancer services
- To work with clinical staff, voluntary organisations and policy makers to use this research to inform cancer service development based on the experiences of people affected by cancer
-

Palliative care patients and their families can be viewed as 'hard to reach' in that they are often perceived as too ill to participate in research. We aim to establish methods of involving end of life patients and carers in research, with patients and carers as co-researchers rather than subjects. Methods will include groups in day hospices, interviews with in-patients and groups in community settings. We are currently discussing methods with staff at various hospices across Scotland and precise methods will be locally negotiated.

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Project Title: Recognising Dying in Hospital Inpatients With Advanced Cancer
Status: Work in progress
Completion Date: 01/04/2008
Qualification: MD Thesis
Funding Source: UK non profit making charitable organisation

Abstract:

There is a dearth of evidence giving reliable means of identifying imminently dying patients. The aim of this project is to delineate clinical, non-invasive features which can reliably identify the dying patient at the bedside. The project aims to test the thesis that the clinical trajectory of the dying patient is in essence that of the acutely unwell patient, the difference being that in advanced cancer, the patient has reached the point at which it is unethical or futile (or both) to intervene to prevent death. Hence, it may be possible to develop a scoring system similar to those used to identify acutely unwell patients from bedside clinical signs which can reliably predict the imminence of death. The project will also assess the reliability in terms of sensitivity, specificity and positive predictive value of signs used conventionally to assess whether a patient has entered the phase of active dying. Finally, the project will assess whether end-of-the-bed signs, ancient in their provenance, are in any way relevant in predicting the imminence of death.

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Project Title: An Exploratory Study of the Need for Bereavement Support Services in one Area of Scotland
Status: Work in progress
Completion Date: 21/12/2007
Qualification: Doctor of Nursing
Funding Source: NHS Hospital Trust

Abstract:

The purpose of this study is to develop an understanding, from the perspectives of bereaved people and professionals, of the need for bereavement support. The study aims to identify:

- what support is currently available for bereaved people
- what type of support bereaved people feel they need
- where, when and by whom should it be provided
- their experience of bereavement support
- the experiences and views of professionals of the need for bereavement support.

Based on the findings of the study, recommendations for education and practice in developing bereavement support will be made.

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Project Title: Dignity in Palliative Care
Status: Work in progress
Completion Date: 01/08/2005
Qualification: -
Funding Source: Self Funding

Abstract:

The principal aim of the study is to gain an understanding of the meanings of the terms dignity when used in palliative care settings by paid staff and volunteers.

Ethical approval has been given for the study. All staff and volunteers have been invited to participate in a short, written questionnaire (n-185). Responses will be anonymous and the only demographic data that will be collected will be to know which staff group the person belongs to.

Data will be coded, themed and categorised using Miles & Huberman's approach to qualitative data analysis.

The findings will show whether individuals share a definition of dignity, or whether the use of the term should be replaced by more explicit terms.

References:

Miles M & Huberman A (1994) Qualitative Data Analysis, Sage Thousand Oaks

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Project Title: Evaluation of Children & Families Service
Status: Not yet started
Completion Date: 31/08/07
Qualification: -
Funding Source: UK non profit making charitable organisation

Abstract:

Macmillan Cancer relief is working with NHS Fife Palliative Care Service to develop a support and counselling service for families with children and young people up to the age of twenty, affected by parental terminal illness and bereavement due to cancer. Further development of the pre-existing counselling service was recommended by a Needs assessment. The service will be externally evaluated and it is anticipated that it may provide a blueprint for similar services to be devolved throughout the UK.

The evaluation will:

- Describe the role of the Macmillan children and family support worker incorporating the views of all key stakeholders
- Report on the views of families and key stakeholders of the perceived benefits of the post and its impact
- Identify perceived barriers
- Identify any need to proceed beyond the initial funding period
- Identify further research questions

Methods will be reviewed and negotiated with participants and stakeholders as the project evolves and depending on how the worker's interactions with the families develop. Parents, young people and children's advisory groups have been set up, as has a Steering group of advanced practitioners from around the UK. As the overall aim is to provide an in-depth account, a range of qualitative methods including semi-structured interviews and observation will explore the perceptions and experiences of families and key stakeholders.

The evaluation will be conducted collaboratively by Catriona Kennedy (Napier University), Rhona Hogg (University of Edinburgh) and Alison Worth (University of Stirling).

References:

MacPherson C & Cooke C; 2003; Pilot of a Workbook for Children Visiting a Loved One in a Hospice; International Journal of Palliative Nursing; 9(9), 397 – 403

MacPherson C; 2005; Telling Children Their Ill Parent is Dying; A Study of the Factors Influencing the Well Parent; Mortality; 10(2) 113-126 Needs assessment on 2nd Draft for IJPN

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Project Title: Working with patients and their carers to develop an effective approach to the delivery of cancer palliative care in primary care
Status: Work in progress
Completion Date: 2006
Qualification: -
Funding Source: Chief Scientist Office/Scottish Higher Education Funding Council

Abstract:

Major barriers to effective palliative care in primary care are the lack of proactive care, and the fragmentary nature of care provision. Macmillan Cancer Relief and SE Scotland Cancer Network are about to undertake an important project to improve coordination of care at practice level; the development of computerised cancer registers in each general practice. The regional cancer advisory groups plan to extend this project throughout Scotland, and to increase its scope by using the register to help plan proactive symptom control and problem management at practice level, by introducing a cancer framework of care.

Patient and carer perspectives and concerns have not been formally incorporated in the design of this proposed service initiative. We plan to do this to ensure that services are acceptable and accessible to users. In collaboration with SCAN and Macmillan Cancer Relief, we will formally involve patients and carers throughout the process of the cancer register development and also implementation. We will also evaluate this intervention by interviewing patients and carers in a number of practices where we will pilot the patient informed intervention.

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Project Title: Patients, carers and professionals experiences of diagnosis, treatment and end-of-life care in heart failure: a prospective qualitative interview study
Status: Work in progress
Completion Date: 2006
Qualification: PhD
Funding Source: Department of Health/British Heart Failure Research Initiative

Abstract:

An estimated 1 million people in the UK have heart failure, and the prevalence is set to increase by 70% by 2010. The National Service Framework for Coronary Heart Disease has identified the need to improve services for people with heart failure so they can achieve a better quality of life and receive appropriate palliative care. Policy documents call for more user-centred services, raised standards and reduction of unjustified variations in health services. Services such as heart failure specialist nurses and community-based heart failure clinics are being introduced widely. In order to ensure that services are acceptable and accessible to patients and carers, their perspectives and experiences must be fully integrated in the planning and implementation of such developments.

This qualitative study will gather comprehensive data on patient and carer needs and perceptions of the services available to them in hospital and the community at key points on the heart failure pathway. It will also gather professional perspectives of needs and services. The study will therefore inform the development of needs-led, holistic services with improved access and quality of service provision. Models of care encompassing active treatment and palliative care, as recommended in the national service framework, will then be developed. In particular the study will identify the most appropriate skill mix and location for services, how to reduce avoidable hospital admissions and re-admissions, and how to increase access to palliative care.

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Project Title: To explore the needs of patients with malignant brain tumours and to propose patient-centred models of care
Status: Work in progress
Completion Date: 2008
Qualification: PhD
Funding Source: Bequest – Wiseman Fellowship

Abstract:

1. Construct a patient and carer centred account of their experiences and changing physical, social, emotional and spiritual concerns from diagnosis to death and bereavement.
2. Gain a perspective from professionals case-linked with these patients about the patients' and family needs, and also the main issues they, as professionals, have in providing care.
3. Identify the current availability, access and uptake of information, services and support for the participating patients and their informal and professional carers.
4. Propose patient-centered models of care and intervention studies for this patient group.

Methodologies involved:

1. Conduct an in depth literature review of the subject, including qualitative and quantitative studies, in order to determine the finer details of the study design. A final protocol will be written and ethical permission obtained.
2. The planned study will utilise a qualitative in-depth phenomenological approach to best capture patients' experience of having a brain tumour, and also carer' experiences. Prospective I interviews will be carried out with patients, and their family and professional carers. Routine descriptive clinical data will be collected to help contextualise the findings.
3. A qualitative analysis will be conducted in parallel to the interviews until sufficient data to answer the research questions is obtained, and no new themes are emerging 4. Based upon the evaluation of the quantitative and qualitative analysis, areas of unmet need and specific interventions will be identified for testing in the next phase.

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Project Title: Triaging For Specialist Inpatient Palliative Care – Is it Possible?
 (Joint project with Dr Cameron Fergus)
Status: Completed
Completion Date: 01/07/05
Qualification: -
Funding Source: UK private non-profit making organisation

Abstract:

Background

Many tools exist which can be used to assess the symptoms and needs of palliative care patients. To date no such tool has been validated for use as a triage tool, allowing prioritisation of patients referred for inpatient specialist palliative care. NHS Quality Improvement Scotland suggests that the use of such a tool is desirable for all inpatient specialist palliative care units. This study attempted to produce and validate such a tool.

Aims

A pilot study, using a STAS based tool (the Admission Assessment Tool [AAT]) compared the existing system of triage at the Marie Curie Hospice Edinburgh with the AAT and tested the tool for inter-rater reliability. Validity of the tool was not confirmed. The tool was modified based on the findings of the pilot study and re-evaluated.

Methods

An AAT score for 127 patients based on information received at the time of referral was compared to the admission AAT scores (produced by the admitting doctor and the admitting nurse). These scores were then compared to an assessment of urgency produced for each patient by the hospice's Multi Disciplinary Team.

Results

The overall correct classification rate was approximately two thirds and false positive rates were high. There was poor correlation between the scores produced by the admitting doctor and the admitting nurse.

Conclusion

It is concluded the AAT has not been validated and that there is no quick, easy to use validated system available for the purpose of prioritising patients referred to a specialist inpatient palliative care unit.

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Project Title: Satisfaction of carers with end-of-life cancer care in Lothian
Status: Work in progress
Completion Date: 04/2006
Qualification: -
Funding Source: UK non profit making charitable organisation/NHS

Abstract:

Background

There is evidence that some patients dying of cancer are receiving inadequate or sub-optimal care. This highlights the importance of evaluating existing local services with a view to identifying areas for improvement. Researching user views on the care they receive is a way of highlighting problems which are important to patients. Interviewing terminally ill patients is physically and ethically problematic, and many studies have concentrated on the views of patients' relatives or carers.

The VOICES questionnaire is a validated questionnaire for obtaining retrospective information from carers about the care and services received by patients who have died. It consists of 158 questions asking about care received by the patient in the last year of life. It has been shown to be acceptable to bereaved relatives when sent as a postal questionnaire.

Aims

To assess the quality of care received by patients who die of cancer in Lothian by obtaining information from bereaved relatives and carers.

Methods

Patients who lived in Lothian and who died at least six months previously during a period of six months will be identified from the death register of the General Registry Office (GRO). The patient must have died of cancer and be over 18 years of age. Using an anonymised system, the VOICES questionnaire will be sent to the person who registered the death.

Qualitative data will be content analysed and categorised into common themes. Quantitative and qualitative data will be analysed using multidimensional scaling techniques.

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Project Title: Estimation of survival in an inpatient specialist palliative care unit: a comparison of different methods
Status: Work in progress
Completion Date: 07/2005
Qualification: -
Funding Source: None

Abstract:

Aims

- To compare the predictive accuracy of the Palliative Prognostic Score (PaP) and Clinical Observation in the prediction of 4-week survival.
- To identify the situations best suited to the use of each of these tools.

Methods

A prediction of survival by Clinical Observation was collected for each patient at a weekly Multi-disciplinary team meeting. Calculation of the Palliative Prognostic Score was based on the following data: Symptoms (Anorexia and dyspnoea), Clinical Prediction of survival (admitting doctor), Karnofsky Performance Status, Biological Parameters (WCC, % Lymphocytes).

Results

There is a significant difference between the two methods. While the Clinical Observation method is more specific, with a greater Positive Predictive value for less than 4-week survival. PaP score is considerably more sensitive, with a greater Negative Predictive Value.

Conclusion

This study confirms that Clinical prediction of survival method is more accurate closer to the time of death. It also highlighted weaknesses, leading to overestimation of survival time in many cases. The PaP Score may be employed in cases where overestimation of survival may lead to a patient being inappropriately moved to long term care.

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Project Title: Prospective Study of the Emergency Admission of Patients with Known Lung Cancer in SE Scotland
Status: Proposed
Completion Date: -
Qualification: -
Funding Source: Application made to government organisation

Abstract:

More than 80% of lung cancer patients are incurable at diagnosis and few survive 12 months. Emergency admission to hospital is disruptive for patients and carers and such events can have an adverse impact on quality of life. The majority of emergency admissions are not due to oncological emergencies. Psychosocial stresses have been identified.

Approximately 300 cases of lung cancer are diagnosed per year in Fife. We retrospectively studied 75 emergency admissions of 55 lung cancer patients over 12 months. The commonest reason for admission was "struggling to cope" by either patient, carer or both. It was a concern that medical descriptors were used where there were more complex psychosocial issues perhaps to facilitate admission.

The aim of this prospective study is to examine the reasons for emergency admission for patients with lung cancer, identifying qualitative and quantitative data on the medical, social and psychological reasoning for the admission, as close in time to the point of decision making as possible. It is hoped that clarification of the reasons for admission will provide an opportunity to identify deficiencies in service provision. It will expand our understanding of the experiences and perspectives of lung cancer patients and carers about hospital admission and integrate these with professional views. It will provide information relevant to palliative care and support needs of cancer patients and carers in the community as they move through palliative and terminal care. It will provide an analysis to inform the development and likely success of strategies to avoid emergency admissions for a group of patients who would more appropriately be cared for at home.

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Project Title: Development of a research strategy for Help the Hospices to facilitate research regarding hospice care in the UK
Status: Proposed
Completion Date: -
Qualification: -
Funding Source: UK private non-profit making organisation

Abstract:

Help the Hospices is working on a strategy to guide its research-related activities. This strategy is in the early stages of development and will consider:

- Research activities which consider the role and value of hospice in end of life care
- Evaluation of projects undertaken within or funded by Help the Hospices
- Training events to support the development of research activities - within the organisation and the Hospice Movement generally
- Partnerships with other organisations involved in research regarding hospice/end of life care
- Other activities which promote research in hospice/end of life care

The strategy is likely to begin to be implemented in 2006.

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Project Title: Developing Services to meet the end of life care needs of South Asian Sikh and Muslim patients and their families in Scotland
Status: Work in progress
Completion Date: 2007
Qualification: -
Funding Source: Chief Scientist Office

Abstract:

Background

The NHS in Scotland seeks to develop services that meet the needs of all sections of society fairly. Understanding the end of life needs of patients and their families from the South Asian Sikh and Muslim communities in Scotland is an important first step to develop appropriate, equitable and accessible palliative care service for all.

Aims

From the perspectives of the patient, their family and key health professional, we aim:

- To understand the palliative care needs of South Asian Sikh and Muslim patients
- To integrate and formulate suggestions from patients, their families and professionals that will inform, challenge and enhance provision of primary, hospital and hospice based palliative care services.

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Project Title: An Action Research Study of Palliative Dementia Care
Status: Work in progress
Completion Date: 31/03/2007
Qualification: PhD
Funding Source: Lottery 98%, NHS Trust 2%

Abstract:

Research Objectives

1. Using the WHO definition of Palliative Care as a framework, identify the palliative care needs of people with dementia and their carers in West Lothian.
2. Describe and analyse five dementia care services in West Lothian working collaboratively to enhance palliative dementia care.
3. Determine any impact on practice, when services participating in the research utilise a combination of dementia and palliative care approaches.
4. Analyse the learning that occurs between dementia care practitioners and a facilitator experienced in palliative care during this action research.
5. In relation to palliation for people with dementia, determine potential future implications for practice development and service delivery.

References:

Smith SDM (2005) Dementia Palliative Care Assessment: A Focus on Spiritual Care. Scottish Journal of Healthcare Chaplaincy. 8 1 13-19

Reader Information

Document Purpose	A review (scoping exercise) was undertaken of published and unpublished palliative care research in Scotland in order to identify gaps in the evidence, thus allowing research priorities to be set in an objective way. We also wanted to compile a research directory profiling planned, current, and recently completed palliative care research in Scotland in order to improve communication networks between researchers throughout Scotland, and share research practice.
Authors	Dr Bridget Johnston, Suzanne Nimmo, Dr Paul Baughan, Professor Nora Kearney
Publisher	Cancer Care Research Centre, University of Stirling
Publication Date	May 2006
Target Audience	Palliative care researchers, service providers, palliative care health professionals, health service managers, patients and carers
Further Copies From	cancercare@stir.ac.uk
Copyright	This publication is copyright CCRC and may be reproduced (excluding the CCRC logo) free of charge in any format or medium. Any material used must be acknowledged, and the title of the publication specified
Internet Address	http://www.cancercare.stir.ac.uk
Price	Free